2018

Effect of a nurse-led lymphoma survivorship model of care: A pragmatic phase II pilot randomised controlled trial

Karen Taylor
The University of Notre Dame Australia

Effect of a Nurse-led Lymphoma Survivorship Model of Care: A Pragmatic Phase II Pilot Randomised Controlled Trial

Karen M Taylor

Master of Nursing

Graduate Diploma in Oncology Nursing (Distinction)

Bachelor of Nursing (Post Registration)

Registered Nurse

School of Nursing and Midwifery

University of Notre Dame Australia

Fremantle Campus

This thesis is submitted for the degree of Doctor of Philosophy

2018

Table of Contents

List of Figures

List of Tables

Abstract

Background

Cancer survivorship is recognised as an integral component of the cancer continuum. Robust evidence on how best to deliver tailored survivorship care is limited, particularly for individuals affected by rarer cancers such as lymphoma, a potentially curable haematological cancer. These survivors may face long-term and late effects affecting quality of life due to the aggressiveness of the disease and treatment that may not be adequately addressed in current follow-up models of care.

Aim

To develop and pilot test a nurse-led model of survivorship care intervention that utilises an individualised survivorship care plan and treatment summary (SCPTS), motivational interviewing, tailored support and resources with lymphoma patients who have completed active treatment.

Method

A four-phase prospective study was undertaken: Phase One consisted of integrative/systematic reviews; Phase Two focused on development of the survivorship model of care; Phase Three comprised a pragmatic randomised controlled trial (RCT) to test the intervention; and Phase Four elicited qualitative feedback from intervention participants and their general practitioners' (GP). A published pilot pragmatic RCT protocol was implemented and participants were randomised to a control group (n=30) or intervention group (n=30). Four patient reported outcome measures were administered to both groups at three time points; baseline (Time 1), 3 months (Time 2) and six months (Time 3).

Data Analysis

Descriptive, univariate and multivariate statistical techniques were applied to quantitative data. Content analysis was performed on qualitative interview data and GP evaluations.

Results

Three comprehensive integrative/systematic reviews were undertaken, published (survivorship models of care, SCPTS, survivorship needs assessment measures) and informed the development of a unique and concise evidence-based SCPTS and other model of care (intervention) components. The intervention comprised three face-to-face appointments over six months to deliver the lymphoma survivorship model of care. Intervention participants reported increased self-empowerment and less unmet needs. Test–retest reliability analysis was performed and published for the Short-Form Survivor Unmet Needs Survey (n=40). Ten intervention participants interviewed at completion of the RCT reported a positive experience of the model of care. Feedback from 18/28 (64%) GPs confirmed the SCPTS was a useful tool for patient consultations.

Conclusion

Findings add to a limited body of knowledge in lymphoma survivorship care and nurse-led models of care. They highlight the importance and perceived value of providing individualised, tailored support to lymphoma survivors from treatment completion. The evidence produced from this study provides baseline data to support future rigorous testing of nurse-led models of lymphoma survivorship care with larger samples.

List of Publications

(The complete PDF published versions of these papers are presented in Appendix A)

- Taylor, K., Chan, R.J. & Monterosso, L. (2015). Models of survivorship care provision in adult patients with haematological cancer: An integrative literature review. *Supportive Care in Cancer*, 23(5), 1447–1458
    - This publication was peer-reviewed by two reviewers and underwent revision prior to publication

- Taylor, K., & Monterosso, L. (2015). Survivorship care plans and treatment summaries in adult patients with hematologic cancer: An integrative literature review. *Oncology Nursing Forum*, 42(3), 283–291
    - This publication was peer-reviewed by three reviewers and underwent revision prior to publication

- Taylor, K., & Monterosso, L. (2016). Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors. *The Australian Journal of Cancer Nursing*, 17(1), 6–12
    - This publication was peer-reviewed by two reviewers and underwent revision prior to publication

- Taylor, K., Joske, D., Bulsara, M., Bulsara, C., & Monterosso, L. (2016). Protocol for Care After Lymphoma (CALy) trial: A phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *BMJ Open*, 6(e010817), 1–10
    - This publication was peer-reviewed by three reviewers and underwent revision prior to publication

- Taylor, K., Bulsara, M., & Monterosso, L. (2018). Test–retest of the Short-Form Survivor Unmet Needs Survey. *Asia-Pacific Journal of Oncology Nursing, 5*(2), 165–171
    - This publication was peer-reviewed by two reviewers and underwent revision prior to publication

- Taylor, K., Monterosso, L., & Bulsara, C. (2018). Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *European Journal of Oncology Nursing, 35*, 9–14
    - This publication was peer-reviewed by three reviewers and underwent revision prior to publication

Copyright permission has been obtained from publishers where necessary, and details are included in Appendix A with each paper.

Other Survivorship Research Published Journal Articles

(The complete PDF versions of these papers are presented in Appendix B)

- Monterosso, L., Taylor, K., Platt, V., Lobb, E., Krishnasamy, M., Musiello, T., Bulsara, C., Stratton, K., & Joske, D. (2017). A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma. *European Journal of Oncology Nursing, 28*, 62–68

- Monterosso, L., Taylor, K., Platt, V., Lobb, E., Musiello, T., Bulsara, C., Stratton, K., & Krishnasamy, M. (2017). Living with multiple myeloma: A focus group study of unmet needs and preferences for survivorship care. *Journal of Patient Experience*, 1–10

Copyright permission has been obtained from publishers where necessary, and details are included in Appendix B with each paper.

Invited Non-Peer Reviewed Papers and Presentations

- Taylor, K. "Cancer survivorship" *Health Matters*, Winter Edition Volume 3. Consumers Council of WA, August 2016.
    - Article

- Taylor, K. "Survivorship" *Cancer Matters*, February 2015 Edition. Cancer Council of Australia.
    - Article

- Taylor, K. "Survivorship case studies" Haematology X conference, Crown Towers, Melbourne, 29 July 2017.
    - Oral presentation

- Taylor, K. "After cancer treatment ends" Cancer Council WA/Health Consumers' Council/Carers WA. Perth, 24 August 2016.
    - Oral presentation

- Taylor, K. "Survivorship issues in Western Australia" Genesis Care Perth, 18 May 2016.
    - Oral presentation

- Taylor, K. "Nurse-led survivorship intervention and survivorship issues in Western Australia". Oncology Nurses and Pharmacists Conference, Perth, 30 August 2015.
    - Oral presentation

- Taylor, K. Supervisory/student relationships. InSpire Conference, University of Notre Dame Australia, 30 June 2015.
    - Oral presentation

Conference Presentations

- Taylor, K., & Monterosso, L. "Integrative review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors." HAA2014: Annual Scientific Meetings of the HAA (Haematology Society of Australia and New Zealand, Australian & New Zealand Society of Blood Transfusion and Australasian Society of Thrombosis and Haemostasis). Perth Convention and Exhibition Centre, 19–22 October 2014.
    - Poster presentation

- Taylor, K., & Monterosso, L. "Integrative review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors." 41st Annual Scientific Meeting, Clinical Oncology Society of Australia (COSA), Melbourne Convention Centre, Victoria, 2–4 December 2014.
    - Poster presentation

- Taylor, K., & Monterosso, L. "Integrative review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors" UIC World Cancer Congress, Melbourne Convention Centre, Victoria, 4–6 December 2014.
    - Oral presentation

- Taylor, K., & Monterosso, L. "Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors." Inaugural Science on the Swan research conference, Perth Convention and Exhibition Centre, 21–23 April 2015.
    - Poster presentation

- Taylor, K., & Monterosso, L. "Survivorship care plans and treatment summaries in adult patient with haematological cancer: An integrative review." 18th Winter Congress, Cancer Nursing Society of Australia (CNSA), Perth Convention and Exhibition Centre, 14–16 June 2015.
    - Poster presentation

- Taylor, K. "Effect of a nurse-led lymphoma survivorship clinic: A pilot randomised controlled trial." School of Nursing and Midwifery Research Symposium, University of Notre Dame, Fremantle, 3 June 2016.
    - Oral presentation

- Taylor, K., & Monterosso, L. "Development of a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care: Care After Lymphoma (CALy) Trial." And "Development of a survivorship care plan and treatment summary for lymphoma survivors." Multinational Association of Supportive Care in Cancer (MASCC) International Annual Meeting, Adelaide Convention Centre, South Australia, 23–25 June 2016.
    - 2 Poster presentations

- Taylor, K., & Monterosso, L. "Development of a pilot randomised controlled trial: lymphoma nurse-led model of survivorship care." And "Development of a survivorship care plan and treatment summary for lymphoma survivors." International Conference on Cancer Nursing (ICCN 2016), Hong Kong, 4–7 September 2016.
    - 2 Oral presentations given on my behalf by L. Monterosso

- Taylor, K. "Development of a lymphoma survivorship care plan and treatment summary." 8th International Congress on Innovations in Nursing (ICIN) Conference, Perth, WA, 23–24 November 2016.
    - Oral presentation

- Taylor, K. "Effect of a nurse-led lymphoma survivorship clinic: A pilot randomised controlled trial." Institute of Health Research Symposium, University of Notre Dame, Fremantle, 8 December 2016.
    - Oral presentation

- Taylor, K., Joske, D., Oldham, D., & Monterosso, L. "Development of a survivorship care plan and treatment summary for lymphoma survivors." COSA Survivorship Conference—Adelaide Convention Centre, 2–3 February 2017.
    - Poster presentation

- Taylor, K., & Monterosso, L. "Development of a pilot randomised controlled trial: lymphoma nurse-led model of survivorship care." Nursing and Midwifery Leadership Conference, Perth, 30 November–1 December 2017.
    - Oral Presentation

- Taylor, K., Monterosso, L., & Bulsara, C. "Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care." St John of God Nursing and Midwifery Research Symposium, Perth, 20 August 2018.
    - Oral Presentation

- Taylor, K., Monterosso, L., & Bulsara, C. "Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care." 45th Annual Scientific Meeting, COSA, Perth, 13-15 November 2018.
    - Poster Presentation

Awards and Recognition

- December 2014, I was awarded the IPSEN-COSA Travel grant that enabled me to attend COSA and the World Cancer Congress conferences in Melbourne, Australia. This was only one of two grants awarded and I was the only nurse recipient.

- June 2016, I was awarded: Best Oral Presentation; and Best Presenter, for my PhD proposal presentation at the School of Nursing and Midwifery Research Symposium, University of Notre Dame, Fremantle.

Statement of Contribution by Others

The author of this thesis, under the guidance of the principal supervisor Professor Leanne Monterosso and co-supervisors Associate Professor Caroline Bulsara and Professor Max Bulsara, undertook the planning, research development, literature reviews, data collection, data checking, statistical analysis, interpretation of results, discussions and conclusions included in this thesis. The candidate was 100% responsible for the drafting of this thesis. The candidate is 90% responsible for the published articles associated with the thesis. The articles have been peer-reviewed, and co-authors have contributed to the corrections and recommendations that have made each article relevant and clear.

All supervisors reviewed drafts of this thesis and the manuscripts. All co-authors granted permission to include publications arising from this research in this thesis (Appendix C)

This thesis is the work of Karen Margaret Taylor alone and has not been submitted previously, in whole or in part, in respect of any other academic award at this or any other university.

Signed:

Karen M Taylor

(PhD Candidate)

Professor Leanne Monterosso

(Principal Supervisor)

Acknowledgements

There are many people to thank for helping me on this journey of research. First and foremost, I need to thank my children Braiden and Rachel for listening to all my worries and concerns as the research progressed. This has not been an easy process for me, and their support has been invaluable. As I have gone on my own cancer journey in the final years of this research, I want to thank them for their courage in facing up to this challenge. I want to thank my mum, sister and brother and their families for support.

A huge thank you to Professor Leanne Monterosso who allowed me to move her research grant into a reality. A four-phase study has at times felt well beyond my capabilities; however, the skills I have gained are priceless. In addition, thank you for the personal and professional support you have given every step of the way. Thank you to Associate Professor Caroline Bulsara who has provided advice and reassurance throughout the study. Your input, especially in the qualitative aspects of this thesis has allowed me to capture some incredible insight into my nurse-led model of care. Similarly, thank you to Professor Max Bulsara, without your knowledge, skills and support I would never have been able to negotiate my way through the quantitative analysis of this research.

Thank you to Dr David Joske for your professional and personal support with this research at Sir Charles Gairdner Hospital (SCGH). Thank you to all the other Haematologists at SCGH, for supporting the research and trusting me to transition your patients after they had finished treatment.

Thank you to all the members of the Haematology Survivorship Research Advisory Committee. Professionals and consumers who were committed to

meeting regularly and give of their valuable time. Sandy McKiernan, Pam Adlam, John Erren, Suzie Brans, Kendall Stratton, Leanne Monterosso, Violet Platt, David Joske and David Oldham. Thank you to the WA Cancer and Palliative Care Network (WAPCN) who helped to support the survivorship study financially. Thank you to Kendall Stratton who assisted with the wider aspects of the Collaborative Research Network (CRN) grant. Thank you to Melissa Berg for the interviews.

Thank you to the University of Notre Dame Australia, Fremantle who have supported me as a PhD candidate. I would like to acknowledge the support of the Australian Government's Collaborative Research Networks (CRN) program through the University of Notre Dame Australia (Fremantle) and an Australian Government Research Training Program Scholarship that enabled me to undertake my PhD.

Finally, I particularly want to thank everyone who participated in the research. It is not easy to say yes to a randomised controlled trial.

In January 2017, I was diagnosed with cancer and underwent treatment. My 25 + years of cancer nursing may have given me some insight, however being a cancer patient is something very different. It did strengthen my belief that supporting survivors is important.

Chapter One — Introduction

"When I finished treatment, it was a bit like an anti-climax, it was – okay you have finished treatment, see you later. I felt like I had just been forgotten" Female_NHL

1.0 Introduction

This thesis consists of six related papers that provide a comprehensive account of the development and testing of a pilot nurse-led lymphoma survivorship model of care.

This chapter provides a brief background to lymphoma cancer, the issues survivors face and the need to develop better models of follow-up care for lymphoma patients who finish curative-intent treatment. An overview of the purpose of this study, the research questions that guided all aspects of this study are then presented. The chapter concludes with an overview of the structure of the thesis and a glossary of terms.

The Problem

Lymphoma is a blood cancer originating from B and T cells in the lymphatic system which undergo a malignant change. Although there are around 30 different types, they can be categorised into two main types; non-Hodgkin lymphoma (NHL) or Hodgkin lymphoma (HL) (Cancer Australia, 2018).

In Australia, HL is considered a rarer cancer, accounting for only 0.5% of all cancer diagnosed. It is estimated about 683 cases will be diagnosed, with mortality around 30 cases in 2018 (Australian Institute of Health and Welfare, 2017). Five-year relative survival at diagnosis is 87.5% (Australian Institute of Health and Welfare, 2017). It is the most common cancer of the adolescent and young adult population, with over a third of all incidences in the 15–30-year age group. Unlike other types of lymphoma, HL is diagnosed when the presence of what are termed Reed-Sternberg cells are seen in the biopsy material (Kuppers & Hansmann, 2005).

The majority (80%) of NHL arises from B cells and is the most common type of lymphoma, especially in those over 50 years of age where incidence increase with age (Australian Institute of Health and Welfare, 2017). An estimated 5,720 cases will be diagnosed, and an estimated 1,443 deaths in 2018. Five-year relative survival at diagnosis is approximately 74% (Australian Institute of Health and Welfare, 2017).

Combined, lymphomas represent the sixth most common cancer diagnosis in Australia and worldwide (Cancer Australia, 2018; Howlader et al., 2016) and tend to occur more frequently in men (Australian Institute of Health and Welfare, 2017). Incidence and survival in Australia are increasing. An estimated 6,232 cases were diagnosed in 2017, equating to 4.6% of all cancer cases (Australian Institute of Health and Welfare, 2017). Conversely, an estimated 1,481 people will have died from lymphoma, equating to 3.1% of all cancer deaths in 2017. Improved survival rates have been attributed predominantly to developments in treatment and supportive care options. These include chemotherapy and/or radiotherapy and may involve haematopoietic stem cell transplantation or immunotherapy or targeted therapies (Carey et al., 2012). An estimated 76% of those diagnosed survive at least five years; this is a marked increase from 52% in the mid-1980s.

With increased remission and survival rates, many survivors are living with issues and concerns, called unmet needs, due to the aggressive nature of the cancer and the intensity of treatment (Carey et al., 2012; Sant et al., 2014). These long-term and late effects may have an ongoing impact on health and quality of life (QoL) (Leeuwen & Ng, 2017; Oerlemans, Mols, Nijziel, Lybeert, & van de Poll-Franse, 2011; Sarker et al., 2017). Difficulties faced by lymphoma survivors may relate to: fatigue; poor nutritional intake; decreased exercise capacity; cognition impairment; fear of recurrence;

depression and anxiety; fertility issues; relationship stress; financial concerns; employment issues; and difficulty in obtaining particular types of insurance, for example health and/or travel insurance (Arboe et al., 2017; Bryant et al., 2015; Daniels, Oerlemans, Krol, Creutzberg, & van de Poll-Franse, 2014; Daniels, Oerlemans, Krol, van de Poll-Franse, & Creutzberg, 2013; de Lima et al., 2017; Hall et al., 2016; Jones et al., 2015; Kreissl et al., 2016; Krolak, Collins, Weiss, Harris, & Van der Jagt, 2017; Leeuwen & Ng, 2017; Linendoll et al., 2016; Magyari et al., 2017; Mojs, Warchol-Biedermann, & Samborski, 2017; Oerlemans et al., 2014; van de Wal, van de Poll-Franse, Prins, & Gielissen, 2016; Zimmer et al., 2015). Furthermore, health can be compromised by an increased risk of developing other diseases such as cardiovascular disease and second cancers (Leeuwen & Ng, 2017; Schaapveld et al., 2015). These are often experienced earlier than the general population (Panek-Hudson, 2013), an escalating problem in those diagnosed at a younger age (Grinyer, 2010; Hemminki, Lenner, Sundquist, & Bermejo, 2008), which is further elevated if treatment involves radiotherapy (Ng, LaCasce, & Travis, 2011; Travis et al., 2012). Survivor lifestyle behaviours, such as smoking, can likewise have an effect on secondary disease development (Ng et al., 2011). It is important that health care providers, survivors and their families have an awareness of potential late effects, to ensure timely and appropriate follow-up (Ng et al., 2011).

Regardless of what is currently known about the issues faced by lymphoma survivors, compared with other more common cancers such as breast, prostate and colorectal, this cancer remains understudied in survivorship literature. This gap in the published literature is important to address as inadequate service provision at treatment completion may be leading to unmet needs along the survivorship continuum (De Leeuw & Larsson, 2013). When this research was proposed in 2014, no RCTs were identified that

related to adult lymphoma survivor cohorts. Since that time there has been one published RCT reporting a 12-week exercise intervention in haematological cancer survivors (mainly lymphoma n=33, 89%), assessing cancer-related fatigue (Furzer et al., 2016).

The lack of published evidence-based guidelines for the ongoing management of cancer survivors has previously been acknowledged in the cancer literature (Phillips & Currow, 2010; Rechis, Arvey, & Beckjord, 2013). Current follow-up care for lymphoma patients has traditionally been led by the haematologist (Taylor, Chan, & Monterosso, 2015), with a focus largely on recurrence surveillance (Molassiotis et al., 2017) that overlooks needs-based tailored support and information (Earle & Ganz, 2012; Jefford et al., 2008). Likewise, no consensus exists on whether other health care providers, such as nurses or GPs could deliver holistic care to transition survivors into the survivorship phase upon treatment completion.

Cancer nurses have established expertise in the areas of health promotion, information, support and resource provision (Jackson, Scheid, & Rolnick, 2013). Findings from recent studies have supported nurse-led models of survivorship care that utilised the existing skills of experienced cancer nurses (Beaver et al., 2012; Gates, Seymour, & Krishnasamy, 2015; Howell et al., 2012; Jefford et al., 2016; John & Armes, 2013; Maly, Liang, Liu, Griggs, & Ganz, 2017). An important aspect of these models was the administration of survivor-specific and patient-centred assessment measures to accurately ascertain and address concerns or issues that are important to the survivor. Equally it is proposed these measures may empower survivors to seek out information and support to manage their concerns and ongoing symptoms, and to adopt healthy lifestyle behaviours (Fitch, 2008; Ganz, Casillas, &

Hahn, 2008; McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2010; Stricker et al., 2011).

Patient empowerment or activation (Klemanski, Browning, & Kue, 2016) in this context, indicates the degree to which an individual comprehends that he or she has a role in managing health and health care. It likewise includes the extent to which the individual feels capable of fulfilling that role (Hibbard, Mahoney, Stock, & Tusler, 2007). It could be argued that self-efficacy is an important indicator of a successful transition into survivorship (Rosenberg et al., 2016).

National and international professional cancer organisations have recommended the use of survivorship care plans and treatment summaries (SCPTS) as an important aspect in the facilitation of holistic survivorship follow-up care (Clinical Oncology Society of Australia, 2016; MacMillan Cancer Support & NHS Improvement, 2010; McCabe, Bhatia, et al., 2013). The provision of a written, individualised SCPTS should increase the amount of information that is communicated to the survivor and other health professionals such as the GP who may be responsible for future ongoing care of survivors. A treatment summary succinctly documents an individual's disease and treatment information, along with potential late effects and recommended management. The survivorship care plan is then individualised to each patient and should guide personalised follow-up care with recommendations, screening guidelines, information and healthy lifestyle promotion and support (Alfano, Ganz, Rowland, & Hahn, 2012; Grant & Economou, 2008; Hausman, Ganz, Sellers, & Rosenquist, 2011; Hewitt, Greenfield, & Stovall, 2005; Jabson & Bowen, 2013; Panek-Hudson, 2013; Taylor & Monterosso, 2015).

Aim and Objectives

The purpose of this research was to develop and empirically test an evidence-based nurse-led lymphoma survivorship model of care to transition lymphoma survivors into the survivorship phase, using a pilot pragmatic randomised controlled trial (RCT). This research aimed to facilitate the participant randomised to the intervention group to normal functioning sooner and to produce a reduction in perceived unmet informational, practical and emotional needs or concerns and an increase in participant self-management compared with those randomly assigned to the current standard of care (usual care). This research will furthermore provide baseline data to support hypothesis development, and the calculation of sample sizes for future multisite randomised controlled trials. It thereby fills a gap in lymphoma survivorship care where evidence-based research and outcome evaluation of models of care is lacking (Irwin, Klemp, Glennon, & Frazier, 2011).

Design

The thesis comprised a four-phase prospective study that incorporated quantitative and qualitative research methodology (Figure 1.1). The main focus of this thesis was the phase II pilot pragmatic randomised controlled trial (RCT). Pragmatic RCTs are customarily conducted in the "real-world" setting where patients receive their usual care (Thorpe et al., 2009). In this case, participants were recruited from the haematology department of a large tertiary cancer centre in Perth, Western Australia. As is the case with pragmatic RCTs, recruitment is offered to potentially all eligible patients receiving care in the participating location. Intervention delivery and participant follow-up are closely aligned to usual care to understand the real-world implications of the intervention and to determine the effects of the

intervention in conditions where it would normally be applied (Thorpe et al., 2009). Qualitative research was undertaken to complement the quantitative findings of this study and occurred concurrently with the pragmatic RCT. The qualitative interviews were undertaken with a subset of intervention participants at the completion of all study measures to explore participant perceptions of the nurse-led lymphoma survivorship clinic (NLSC) intervention, assessment measures and SCPTS. Feedback was also sought from intervention participants' GPs to determine the usefulness and utility of the SCPTS to inform practice. As there was no published test–retest reliability data for one of the chosen assessment measures (Short-Form Survivor Unmet Needs Survey), this process was also undertaken as part of this thesis.

Research Questions

A number of questions guided each of the four phases.

Phase One: Systematic/Integrative Literature Reviews

1. Models of survivorship care
    a. What are the common attributes of survivorship models of care developed generally for cancer patients and specifically for haematology cancer patients?
    b. What resources are required to support these models?
    c. What are the potential benefits and shortfalls of these models?
    d. What outcome measures have been used to evaluate these models and what are the findings?

2. Survivorship care plans and treatment summaries (SCPTS)
    a. What are the common attributes of SCPTS developed for haematological cancer patients?
    b. What resources are required to develop SCPTS?
    c. What are the potential benefits and limitations of SCPTS?
    d. What outcome measures have been used to evaluate SCPTS and what are the findings?
3. Needs assessment measures
    a. What reliable and valid measurement tools are currently available to measure the informational and practical needs of lymphoma cancer survivors?
    b. What are the implications of the findings from the review for future research and clinical practice?

Phase Two: Intervention Development

1. What assessment instruments will be chosen to measure: survivor-specific informational, practical and emotional needs; depression, anxiety and stress; mental adjustment; and patient empowerment?
2. What components are required for an SCPTS designed for lymphoma survivors?
    a. How will these be tested for content validity (apparent internal consistency, clarity and reliability)?
3. What information and resources will be required to develop a tailored resource pack, including health promotion strategies?

Phase Three: Pilot Pragmatic Randomised Controlled Trial (RCT)

1. Do participants assigned to the nurse-led lymphoma survivorship clinic intervention demonstrate a reduction in perceived unmet informational,

practical and emotional needs compared with those randomly assigned to usual care?

2. Do participants assigned to the nurse-led lymphoma survivorship clinic demonstrate a reduction in self-reported anxiety, depression and stress and an increase in patient self-management behaviours compared with participants randomly assigned to usual care?
3. Does the SF-SUNS demonstrate test–retest stability and reliability over time?

Phase Four: Qualitative Interviews / General Practitioner Evaluation

1. What questions will best elicit participant perceptions of the assessment measures, the nurse-led survivorship model of care and the SCPTS?
    a. Who should assist with the interview schedule development and who should undertake the interviews to reduce bias?
2. What questions and format will work best to elicit general practitioner (GP) perceptions of the utility and usefulness of the SCPTS.
    a. Who is best suited to provide advice and suggestions regarding the development of an evaluation survey and cover letter that will maximise response rates from GPs?

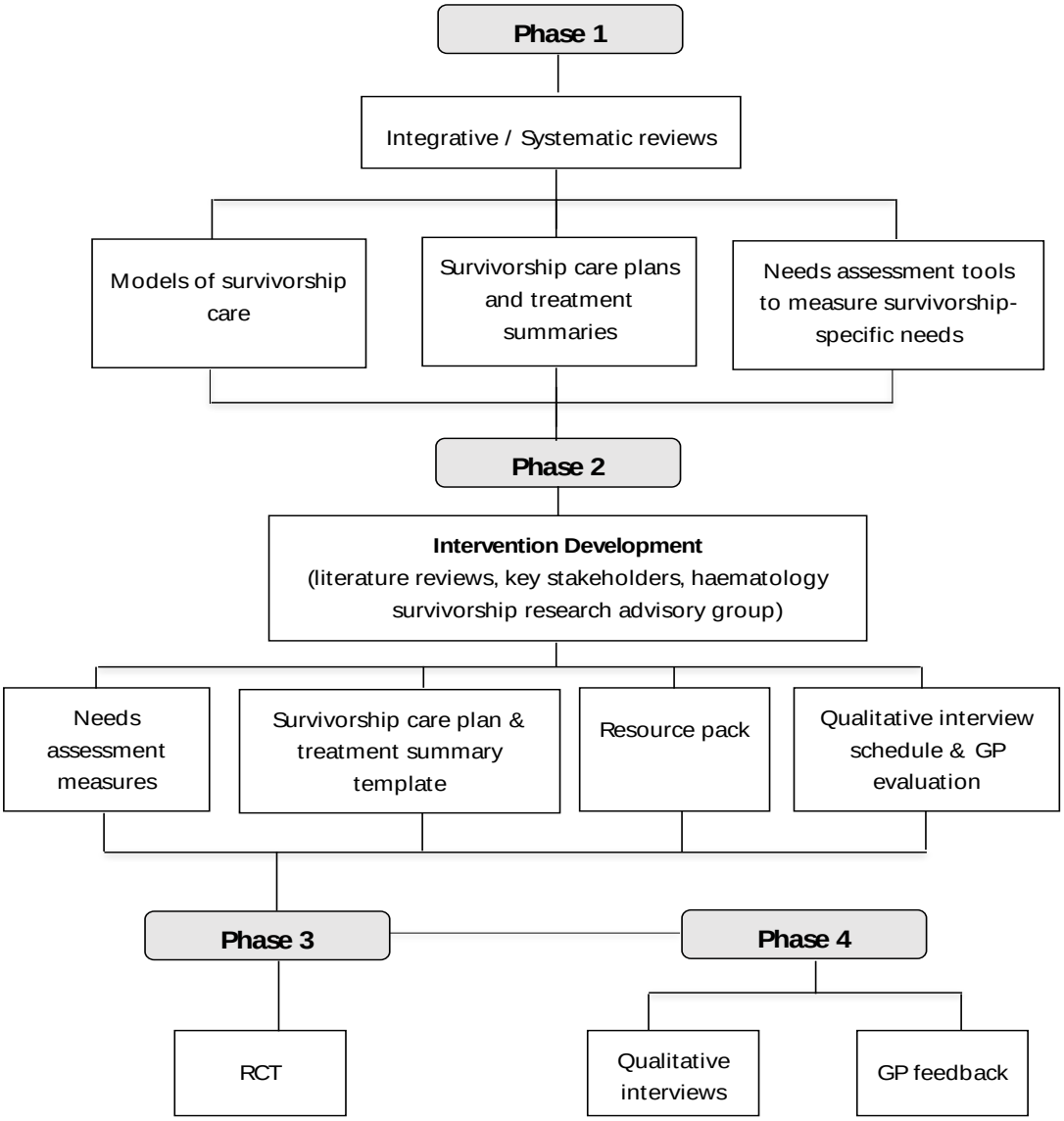


Figure 1.1. Overall study design.

Components of the RCT

The main focus of this thesis has been the pragmatic RCT to test the nurse-led model of lymphoma survivorship care intervention. This intervention comprised three core components:

1. The administration of four self-reporting assessment measures over three time periods
    a. Baseline (Time 1), Three months' post-treatment completion
    b. Three months' post-baseline (Time 2), Six months' post-treatment completion
    c. Six months' post-baseline (Time 3), Nine months' post-treatment completion
2. Provision of an individualised SCPTS consisting of
    a. Diagnosis and treatment information
    b. A tailored list of potential late effects with recommendations for the GP to follow-up
    c. Participant-derived concerns, health goals and proposed actions
    d. General health information, screening recommendations and healthy lifestyle behaviour support
3. Provision of tailored evidence-based education, information and resources to address participant-reported needs, likely post-treatment physical and emotional concerns and maximising participant involvement in healthy lifestyle behaviours.

Overview of the Thesis

The very nature of a thesis by publication will involve some repetition of information, necessary to ensure the readers of the published papers can understand the wider context. As each paper was published from 2015 to 2018, the background and literature have been constantly updated; however, the intent of the research remains unchanged. An introduction and summary of content are given for each chapter.

Chapter Two is the literature review section of the thesis and comprises three published papers. The integrative review of lymphoma models of survivorship care was published in the internationally peer-reviewed journal *Supportive Care in Cancer*. The integrative review of haematological cancer survivorship care plans and treatment summaries was published in the internationally peer-reviewed journal *Oncology Nursing Forum*. The final paper in this chapter is a systematic review of needs assessment measures used with lymphoma survivors and was published in the peer-reviewed journal *The Australian Journal of Cancer Nursing*. Although some papers included other haematology cancers to ensure a wide range of literature was gathered, the primary focus has always been lymphoma. Included after each paper is an updated literature review of current published research on the three topics previously described.

Chapter Three describes the conceptual framework that guided the development of the nurse-led lymphoma survivorship model of care.

Chapter Four describes the development of the essential elements of the nurse-led lymphoma survivorship model of care: the advisory committee; the unique survivorship care plan and treatment summary (SCPTS); the assessment measures; and the resource pack. In addition, it provides further details on the GP evaluations that were used in Phase Four. Where possible, repetitive information contained in the methodology section (Chapter Five) has been reduced in this chapter.

Chapter Five provides an account of the methodology of this thesis. This consists of a protocol paper published in the prestigious and internationally peer-reviewed journal *British Medical Journal Open*. It also includes the ethical considerations of this study.

Chapter Six is the results of the Phase Three pragmatic RCT, GP evaluations and qualitative interviews undertaken in Phase Four and the test–retest reliability analysis of one of the chosen assessment measures; the Short-Form Survivor Unmet Needs Survey (SF-SUNS). This chapter provides a reporting of the results of the pragmatic RCT and GP evaluations and is followed by two published papers. Qualitative interviews were conducted with a subset of intervention participants when they completed all aspects of the study. These results have been published in the internationally peer-reviewed journal *European Journal of Oncology Nursing*. Test–retest reliability of the SF-SUNS was conducted during the pragmatic RCT, results of this analysis have been published in the internationally peer-reviewed journal *Asia-Pacific Journal of Oncology Nursing*.

Chapter Seven presents a discussion of Phase One literature reviews, Phase Three pragmatic RCT and Phase Four GP evaluations and qualitative interviews. Additionally, a summary of the test–retest analysis is presented. This chapter includes the limitations and strengths of this thesis research.

Chapter Eight concludes the thesis and discusses the implications of the study findings and makes recommendations relevant to nursing research and practice, education and future research directions.

References throughout the thesis, including published papers, have been combined into a final reference list. All published papers are included in the appendix in their published form. Several supplementary elements of this thesis are included in the appendix and are listed throughout the thesis.

Glossary of Terms

The following terms have been used in the thesis and are defined here.

Active Treatment: Treatment that is used just after diagnosis until remission of the cancer is achieved.

Assessment Measure: A questionnaire, scale or tool to assist in gathering information to identify and evaluate a range of issues or functional ability of the responder.

Autologous Transplant: A stem cell transplant using the patient's own stem cells that are given back as a "rescue" for high-dose, myeloablative chemotherapy.

Cancer Nurse Coordinator: A registered nurse who is highly experienced and knowledgeable. A specialist in cancer nursing, cancer care and cancer treatments.

Chemotherapy: Chemical drug agents used to treat cancer.

De Novo: New diagnosis of a cancer that is not related to a previous cancer.

GP: General Practitioner.

HL: Hodgkin Lymphoma. One of two main types of lymphoma characterised by the presence of Reed-Sternberg cells. Cancer cells originate in the lymphatic system. Overall term given to several sub-types.

Immunotherapy: Treatment of cancer using drugs that enhance, induce or suppress an immune response in the person to fight cancer. They are thought to work by slowing the growth and spread of cancer cells and by helping the immune system to recognise and kill existing cancer cells.

Informational Needs: Information to assist in decision making and the acquisition of skills to decrease fear, anxiety and misperception.

Late Effects: Absent or subclinical toxicities of treatment that can manifest years later.

Long-Term Effects: Toxicities or issues that appear during treatment and persist.

MOC: Models of Care.

Motivational Interviewing: A directive, patient-centred counselling style for eliciting behaviour change, by assisting patients to explore and resolve ambivalence.

Myeloablative: High-dose chemotherapy that kills cells in the bone marrow spaces, including cancer cells and normal blood-forming cells. This treatment will cause death if untreated by a stem cell transplant.

NHL: Non-Hodgkin Lymphoma. One of two main types of lymphoma, with cancer cells originating in both lymphoid tissue and other organs. Overall term given to several sub-types.

NLSC: Nurse-led Lymphoma Survivorship Clinic.

PET: Positron emission tomography. An imagining scan that detects cancer tumours. Routinely used to assess for disease status. HL patients with a clear mid-treatment PET no longer have routine post-treatment scans.

PCP: Primary Care Provider.

Practical Needs: Direct interventions that support the survivor to complete a task or meet a concern.

QoL: Quality of Life.

RCT: Randomised Controlled Trial.

SCPTS: Survivorship Care Plan and Treatment Summary. The care plan is a personalised document that guides and coordinates follow-up care after treatment has finished. It includes recommendations, information and resources for surveillance of the diagnosed disease, screening for potential long-term and late effects from treatment and health-promoting behaviours. The treatment summary section is a comprehensive summary on the disease and treatment and may include provider contact details.

Self-efficacy: a belief in your ability to achieve a task or succeed in a specific situation.

Self-empowerment: a belief that you know what is best for yourself, and therefore you can take control of your life through strength of mind, goal setting and positive choices.

Survivorship: The experience of living with, through and beyond a diagnosis of cancer. Including the impact on family and friends.

Targeted Therapy: Used to treat cancer by blocking the growth of cancer cells by interfering with specific target molecules.

Unmet Need: Concerns or issues where a lack of support or services is perceived by a person, thereby making it difficult to receive the help they feel they require.

Chapter Two — Phase One

"You are not going to be left to your own devices when you are finished, there will be someone to talk to. I think that would be good yeah" Male_HL

2.0 Literature Reviews

Three manuscripts form this chapter. The literature reviews were an integral aspect of Phase One and guided the design of the intervention to be tested in the pragmatic randomised controlled trial used in this study.

The first integrative review was undertaken to examine the types of survivorship models of care that are currently used in contemporary cancer care in Australia and internationally as well as lymphoma-specific (if any) models of care as reported in the published literature (Taylor, K., Chan, R.J., & Monterosso, L. (2015). Models of survivorship care provision in adult patients with haematological cancer: An integrative literature review, *Supportive Care in Cancer*, *23*(5), 1447–1458). The complete PDF version is in Appendix A.1.

An integrative review was also undertaken to assess the survivorship care plans and treatment summaries (SCPTS) that are being used in lymphoma patient cohorts (Taylor, K. & Monterosso, L. (2015). Survivorship care plans and treatment summaries in adult patients with haematological cancer: An integrative literature review, *Oncology Nursing Forum, 42*(3), 283–291). The review provided an understanding of the types of SCPTS currently used and/or tested including the barriers and facilitators to development and delivery of such tools. This work facilitated the creation of a unique SCPTS for this study. The complete PDF version is in Appendix A.2.

Lastly, a systematic literature review of the needs assessment measures that have been used and tested for the assessment of unmet survivorship unmet needs was undertaken (Taylor, K. & Monterosso, L. (2016). Systematic review of the tools used to assess the informational and practical needs of acute

leukaemia and lymphoma survivors, *The Australian Journal of Cancer Nursing, 17*(1), 6–12). This guided the selection of the Short-Form Survivor Unmet Needs Survey (SF-SUNS) as the key survivorship-specific measure to assess participants in the study. The complete PDF version is in Appendix A.3.

2.1 Models of Survivorship Care

Support Care Cancer
DOI 10.1007/s00520-015-2652-6

REVIEW ARTICLE

Models of survivorship care provision in adult patients with haematological cancer: an integrative literature review

Karen Taylor · Raymond Javan Chan · Leanne Monterosso

Received: 4 September 2014 / Accepted: 8 February 2015

Abstract
Purpose Increasing numbers of haematology cancer survivors warrants identification of the most effective model of survivorship care to survivors from a diverse range of haematological cancers with aggressive treatment regimens. This review aimed to identify models of survivorship care to support the needs of haematology cancer survivors.
Method An integrative literature review method utilised a search of electronic databases (CINAHL, Medline, PsycInfo, PubMed, EMBASE, PsycArticles, and Cochrane Library) for eligible articles (up to July 2014). Articles were included if they proposed or reported the use of a model of care for haematology cancer survivors.
Results Fourteen articles were included in this review. Eight articles proposed and described models of care, and six reported the use of a range of survivorship models of care in haematology cancer survivors. No randomised controlled trials or literature reviews were found to have been undertaken specifically with this cohort of cancer survivors. There was variation in the models described and who provided the survivorship care.
Conclusion Due to the lack of studies evaluating the effectiveness of models of care, it is difficult to determine the best model of care for haematology cancer survivors. Many different models of care are being put into practice before robust research is conducted. Therefore, well-designed high-quality pragmatic randomised controlled trials are required to inform clinical practice.

Keywords Models of care · Survivorship · Haematological cancer · Nurse-led · Shared care · Follow-up care

K. Taylor (✉)
Western Australia Cancer and Palliative Care Network, 189 Royal St., East Perth, WA 6004, Australia
e-mail: kbrtaylor@me.com

K. Taylor
University of Notre Dame Australia, Fremantle, Western Australia

R. J. Chan
NHMRC Health Professional Research Fellow, Queensland University of Technology, Queensland, Australia

R. J. Chan
Cancer Care Services Royal Brisbane and Women's Hospital, Queensland, Australia

L. Monterosso
School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, Western Australia

L. Monterosso
St. John of God Hospital, Murdoch, Western Australia

L. Monterosso
Edith Cowan University, Joondalup, Western Australia

Published online: 19 February 2015

Introduction

Internationally, survivorship care is recognised as a priority in the cancer care continuum. This has been principally guided by the Institute of Medicine (IOM) report in 2005, *From Cancer Patient to Cancer Survivor: Lost in Transition* [1]. By 2008, 16 European countries had defined national cancer plans, but to date, very few have survivorship services operating [2]. The National Coalition for Cancer Survivorship [3] defines survivorship as the experience of living with, through, and beyond a diagnosis of cancer and includes the impact on family, friends, and caregivers. It is recognised throughout the literature, based on the IOM essential components of survivorship care, that survivorship care should include the following components [4, 5]:

Models of Survivorship Care Provision in Adult Patients with Haematological Cancer: An Integrative Literature Review.

Abstract

Purpose: Increasing numbers of haematology cancer survivors warrants identification of the most effective model of survivorship care to survivors from a diverse range of haematological cancers with aggressive treatment regimens. This review aimed to identify models of survivorship care to support the needs of haematology cancer survivors.

Methods: An integrative literature review method utilised a search of electronic databases (CINAHL, Medline, PsycInfo, PubMed, EMBASE, PsycArticles, Cochrane Library) for eligible articles (up to July 2014). Articles were included if they proposed or reported the use of a model of care for haematology cancer survivors.

Results: Fourteen articles were included in this review. Eight articles proposed and described models of care and six reported the use of a range of survivorship models of care in haematology cancer survivors. No randomised controlled trials or literature reviews were found to have been undertaken specifically with this cohort of cancer survivors. There was variation in the models described and who provided the survivorship care.

Conclusion: Due to the lack of studies evaluating the effectiveness of models of care, it is difficult to determine the best model of care for haematology cancer survivors. Many different models of care are being put into practice before robust research is conducted. Therefore, well-designed high-quality

pragmatic randomised controlled trials are required to inform clinical practice.

Introduction

Internationally, survivorship care is recognised as a priority in the cancer care continuum. This has been principally guided by the Institute of Medicine (IOM) report in 2005, *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2005). By 2008, sixteen European countries had defined national cancer plans, but to date very few have survivorship services operating (McCabe, Faithfull, Makin, & Wengstrom, 2013). The National Coalition for Cancer Survivorship (National Coalition for Cancer Survivorship, 2014) defines survivorship as the experience of living with, through and beyond a diagnosis of cancer and includes the impact on family, friends and caregivers. It is recognised throughout the literature, based on the IOM essential components of survivorship care, that survivorship care should include the following components (Grant & Economou, 2008; Landier, 2009):

- Prevention; screening and interventions for recurrence, long-term and late effects; early detection of new cancers;
- Assessment, support, management and information provision of physical, psychological, social and spiritual needs;
- Monitoring, information, and promotion of healthy living behaviours and disease prevention;
- Coordination of care between providers to communicate overall health needs.

Current conventional models of survivorship care, including routine follow-up, predominately focus on surveillance for recurrence and monitoring of

physical side effects, rather than provision of supportive care, health promotion, late effects monitoring and surveillance for new cancers (De Leeuw & Larsson, 2013; Oeffinger & McCabe, 2006). With an increasing awareness that communication between health care professionals and patients is suboptimal and that information provided to patients and primary care providers at treatment completion is often inadequate (Dicicco-Bloom & Cunningham, 2013; McCabe & Jacobs, 2012), there is a growing movement to redesign how survivorship follow-up care is delivered. Furthermore, cancer patients frequently experience multiple health problems earlier than the general population (Panek-Hudson, 2013), suggesting a need for early and ongoing, comprehensive approaches to management designed to promote and support patient participation in maximising recovery.

Haematology cancer patients are underrepresented and understudied in survivorship care (Swash, Hulbert-Williams, & Bramwell, 2014) despite international figures indicating an increase in five year relative survival rates (Sant et al., 2014). The most common haematological cancers are leukaemia, lymphoma and multiple myeloma (MM) (National Cancer Institute, 2006). Each of these has distinctive and complex treatment regimens that commonly involve aggressive high dose chemotherapy agents, and/or targeted therapies, radiotherapy and haematopoietic stem cell transplants (Carey et al., 2012). Unfortunately, the consequence of largely aggressive treatment includes long-term and late physical, practical and psychosocial effects which include: fear of recurrence; fertility; relationship; financial; employment and insurance issues (Allart, Soubeyran, & Cousson-Gélie, 2013; Arden-Close et al., 2011; Hall, Lynagh, Bryant, & Sanson-Fisher, 2013). A qualitative study on specialist-led follow-up with haematology cancer survivors reported a lack of preparation and support in finding information and resources with poor continuity of care as patients transitioned into the

survivorship phase (Parry, Morningstar, Kendall, & Coleman, 2010). These patients therefore may require models of survivorship care with specific components that differ from those designed for the more common cancers (breast, prostate and colorectal).

Two systematic reviews (Howell et al., 2012; Sussman et al., 2012) and a literature review (De Leeuw & Larsson, 2013) on survivorship models of care have been recently published. Sussman et al. (2012) reviewed 12 randomised controlled trials (RCTs) and four systematic reviews. De Leeuw and Larsson (2013) reviewed 21 nurse-led follow-up studies and Howell et al. (2012) evaluated 10 practice guidelines and nine RCTs. All primary outcomes in the reviewed studies were related to recurrence detection and in some cases health-related quality of life and/or patient satisfaction (De Leeuw & Larsson, 2013; Howell et al., 2012; Sussman et al., 2012). Importantly, all studies included cancers with similar trajectories of care (breast, prostate, colon) making generalisations to other complex cancers such as haematological cancers difficult. Therefore, the haematology focus of this integrative literature review will add to the limited body of knowledge currently available in this cohort of survivors.

This integrative literature review undertook an analysis of the literature to examine the following questions:

1. What are the common attributes of survivorship models of care developed generally for cancer patients and specifically for haematology cancer patients?
    a. What resources (human, financial, tools, care plans) are required to support these models of care?
    b. What are the potential benefits and shortfalls of these models of care?

c. What outcome measures have been used to evaluate these models of care and what are the findings?

Method

The integrative literature review method was chosen as the theoretical framework to guide this review. It is structured according to five stages: problem formulation; literature search; data evaluation; data analysis and presentation. This allows for an in-depth evaluation of the issues encompassing the empirical, theoretical and clinical approaches within a structured systematic methodology (Whittemore & Knafl, 2005).

Problem formulation

To date, the term 'Model of Care' (MOC) has not been well defined in published literature. In this review, MOC, as defined by the Robert Wood Johnson Foundation (Robert Wood Johnson Foundation, 2014), is a conceptual outline of how to plan all current and future facility and clinical services to guide and direct a patient's experience within a health care system. Essential elements of any MOC include: a clear identification of health professionals responsible for planning and coordination of care; care delivery setting (Sussman et al., 2012); promotion of health maintenance; effective illness interventions; and establishing and evaluating expected clinical outcomes (Gerber, Stout, Schmitz, & Stricker, 2012).

The medical specialist has traditionally led haematology cancer care follow-up, however other models of cancer survivorship follow-up are now emerging (Weaver, Jessup, & Mayer, 2013). Therefore, the focus of this integrative literature review was to identify models of care used by health care providers to ensure quality survivorship follow-up for haematology cancer survivors.

Literature search

The primary search utilised the following electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL); Medline; PsycInfo; PubMed; EMBASE; PsycArticles and Cochrane Library from earliest records to July 2014. Combinations of the following search terms were used: (model of care or follow-up or nurse-led or shared care or primary care provider-led or General Practitioner-led or oncology-led or end of treatment or post treatment) and (survivorship or cancer survivor or survivorship care) and (cancer or neoplasm or oncology) and (haematology or leukaemia or lymphoma or multiple myeloma). A hand search of the reference lists from full text articles was correspondingly employed. Searches were restricted to the English language, humans and adults. Inclusion criteria used were: clinician experiences of MOC for the post treatment phase of haematological cancer; articles that reported on models of care; and articles that reported on the structure of survivorship services. Exclusion criteria were: studies with less than a 50% haematology cancer patient/haematologist cohort; studies that reported MOC for patients who received curative surgery only (i.e. no chemotherapy and/or radiotherapy treatment); studies reporting MOC from child, adolescent or adult survivors of a childhood cancer; non-cancer MOC studies; MOC studies that lacked provider of survivorship care information; and opinion papers, letters, editorials, commentaries, conference abstracts, conference proceedings or case studies.

Data evaluation stage

Abstract titles were reviewed by one author [KT] to assess eligibility. A summary of the selection process (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) is provided in Figure 2.1.1. The initial search yielded 2907 abstracts. Following removal of duplicate articles and screening using the exclusion and inclusion criteria, 61 full-text articles were retrieved. Of

these, 14 articles met the inclusion criteria and were included in this review. Methodological characteristics documented included: authors; publication year; country; study design; model; provider; disease; years post treatment; sample size and response rate; resources required; potential benefits; potential deficits; outcome measures; results and level of evidence developed by (Melynyk & Fineout-Overholt, 2011) shown in Table 2.1.1. Due to variations in study population and methodologies used, meta-analysis was not possible.

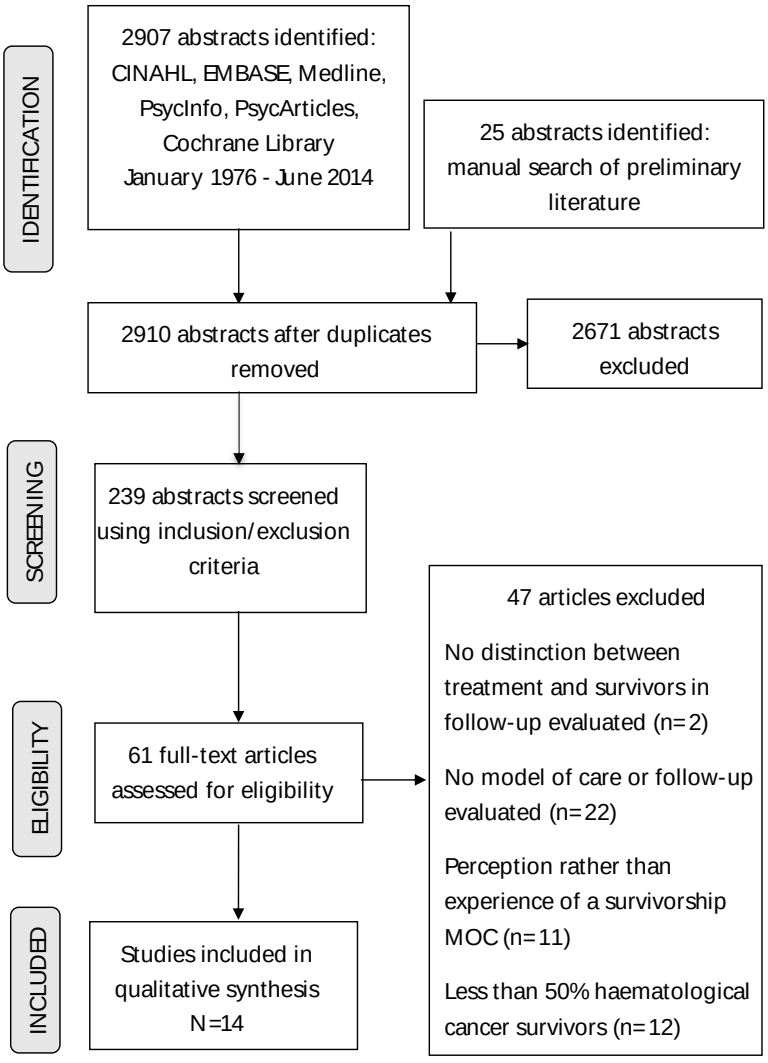


Figure 2.1.1. Flowchart of literature search results.

Table 2.1.1 Levels of Evidence

Level	Evidence
I	Systematic review of all relevant randomised controlled trials
II	At least one well designed randomised controlled trial
III	Well-designed controlled trials without randomisation
IV	Well-designed cohort studies, case control studies, interrupted time series with a control group, historically controlled studies, interrupted time series without a control group or with case-series
V	Systematic reviews of descriptive and qualitative studies
VI	Single descriptive and qualitative studies
VII	Expert opinion from clinicians, authorities and/or reports of expert committees or based on physiology

Results

Study characteristics

No systematic reviews of haematology cancer survivorship models of care were found. In total, 14 articles were included in this review. Eight articles described and proposed different models of survivorship care (Cooper, Loeb, & Smith, 2010; Hahn & Ganz, 2011; Hewitt et al., 2005; Landier, 2009; Leigh, 2008; McCabe, Bhatia, et al., 2013; McCabe & Jacobs, 2012; Oeffinger & McCabe, 2006) (Table 2.1.2). An additional six articles reported the use of a range of models of care for haematology cancer survivors: two reported nurse-led studies (Gates, Seymour, & Krishnasamy, 2012; John & Armes, 2013) and four referred to physician-led studies (Chubak et al., 2012; Dicicco-Bloom & Cunningham, 2013; Frew et al., 2010; Greenfield et al., 2009) (Table 2.1.3). The included articles reported views from Australia (n=1), United States of America (USA) (n=10) and United Kingdom (UK) (n=3), shown in Table 2.1.3. The eight articles that described and proposed various models of survivorship care were categorised into three main settings: hospital-based; primary care-based and shared care and included models, providers, and characteristics. The results are shown in Table 2.1.2.

These included articles used multiple terms to describe clinicians. For clarity, the following terms have been used: primary care provider (PCP) to denote community-based general practitioners (GP) or family physicians; specialist to represent the main hospital consultant oncologist (medical, radiation, surgical) or haematologist; and nurse which includes nurse specialist, nurse practitioner (NP) or nurse coordinator.

Of the six studies that reported the use of specific models of survivorship care, four were quantitative and two were qualitative studies. Studies reflected moderate (IV) to low (VI) levels of evidence.

Table 2.1.2 Existing or Proposed Models of Cancer Survivorship Care

Setting	Model	Provider	Model Characteristics
Hospital	Multi-disciplinary survivorship clinic (Oeffinger & McCabe, 2006)	Oncologist, network of consulting physicians, oncology or haematology nurse practitioner (NP), psychologist, social worker	• Can be consultative or ongoing • Multiple providers seen at same visit • Complex and resource intense • Co-morbid and treatment related conditions can be addressed • Can be extension of care, embedded in treatment team • Disease-specific specialist defines follow-up plan • NP follow-up who communicates with PCP to initiate shared care • Large patient cohort needed

	Consultative clinic (Cooper et al., 2010; Leigh, 2008)	Specialist	• Ongoing (rarely Oncologist takes on primary carer role)
	Consultative clinic (Oeffinger & McCabe, 2006)	Specialist	• One-time comprehensive visit • Treatment summary and survivorship care plan • Review of recommendations – surveillance, screening, health promotion
	Survivorship follow-up clinic (Hewitt et al., 2005; McCabe, Bhatia, et al., 2013)	Specialist	• Separate from routine care • Holistic assessment of survivor • End of treatment or on maintenance therapy • Treatment summary, survivorship care plan and individualised information provision • Can have telephone follow-up
	Late effects clinic [(McCabe & Jacobs, 2012)	Nurse and/or specialist	• Haematology /Oncology treatment centres
	Nurse-led (Cooper et al., 2010; Hewitt et al., 2005)	Oncology nurse or NP	• Comprehensive, long-term follow-up to assess, and provide primary care needs • ASCO surveillance recommendations used • Clinic and/or telephone follow-up
Primary	General	Nurse collaboration	• Referral for services or

Care	survivorship clinic (Hahn & Ganz, 2011; Landier, 2009)	with practice specialist PCP (i.e. breast care PCP)	refers to specialists
	PCP-led (McCabe & Jacobs, 2012)	PCP	• Full transition to PCP after treatment completion • Can have communication from specialist: late effects management and surveillance • Usually low risk for recurrence or late effects
Shared Care	Shared care (Hewitt et al., 2005; Oeffinger & McCabe, 2006)	Specialist & PCP	• Oncologist for oncology related issues • PCP for co-morbidities, other cancer screening and prevention

Note. ASCO American Society of Clinical Oncology; *NP* Nurse practitioner; *PCP* primary care physician

Data Analysis and Presentation

Cancer survivorship MOC

The first component of this integrative literature review was to identify different models of survivorship care (Table 2.1.2). Characteristically, hospital-based follow-up care is commonly specialist-led, with often no end point (Cooper et al., 2010; Leigh, 2008). Survivors may acquire an impression the specialist has become their primary carer, particularly if they have assessed and treated co-morbid conditions during the treatment phase (Oeffinger & McCabe, 2006). Multidisciplinary disease-specific clinics (Landier, 2009; McCabe & Jacobs, 2012; Oeffinger & McCabe, 2006) and survivorship clinics were most often a one-time consultation for an assessment, plan of follow-up care provision and referrals to other health

care providers (Hewitt et al., 2005; McCabe, Bhatia, et al., 2013). Clinics within this framework frequently consulted on one aspect of post treatment care, such as late effects (McCabe & Jacobs, 2012).

Nurse-led survivorship clinics, as described, were mostly hospital based and delivered a number of interventions including: information; symptom management; psychosocial support; allied health referrals and health promotion strategies (Cooper et al., 2010). They can involve longer consultations and more frequent patient contact (Cooper et al., 2010; De Leeuw & Larsson, 2013). PCP-led models involved a complete transition of all care from the hospital specialist to PCP (Hahn & Ganz, 2011; Landier, 2009; McCabe & Jacobs, 2012). This can be challenging for specialists who decide to transition care, as the level of knowledge and experience amongst PCPs can differ (Landier, 2009; McCabe, Bhatia, et al., 2013).

Shared care models involved more than two providers sharing care and responsibility (Hewitt et al., 2005; McCabe & Jacobs, 2012). According to Oeffinger and McCabe (2006) after treatment completion, the PCP assumes responsibility for: maintenance of survivor health; management of any co-morbid conditions; ongoing physical and psychosocial concerns; and health promotion. The medical specialist provides a survivorship care plan and treatment summary and ongoing consultation for recurrence or problematic late effects if required. Both providers are to undertake monitoring, therefore a clear delineation of responsibility for particular screening and surveillance is important (Landier, 2009). Landier (2009) identified shared care as appropriate for low risk and even some moderate risk patients, however intensively treated patients (i.e. haematological cancers) require specialist monitoring.

Nurse-led

The two studies that evaluated nurse-led follow-up in lymphoma survivors predominately targeted late effects and health promotion. Gates et al. (2012) studied a nurse-led component of a haematology late effects survivorship multidisciplinary team, whereas John and Armes (2013) reported on nurses replacing specialist-led follow-up, independently delivering comprehensive survivorship care. Both clinics assessed for supportive care needs and concerns and delivered health promotion and information (Gates et al., 2012; John & Armes, 2013). John and Armes (2013) provided an annual clinic with nurse contact details, whereas Gates et al. (2012) delivered four consultations over a six month period. Both studies measured different outcomes and utilised different comparative groups, thereby making them difficult to compare, especially as Gates et al. (2012) has only published preliminary results. John and Armes (2013) prospective comparative study of 61 patients concluded that patient satisfaction was equivalent in the nurse-led clinic cohort compared with the medical-led clinic cohort and was in some cases preferred. However, the number in each group was not reported and it is possible patient satisfaction was related more to the decrease in wait times. It would likewise be difficult to attribute lifestyle changes to the clinic as patients were seen annually.

Physician-led

The included physician-led studies (n=4) presented comparisons of self-reported practices in survivorship follow-up (Dicicco-Bloom & Cunningham, 2013) and clinician perceptions of survivorship follow-up (Chubak et al., 2012; Frew et al., 2010; Greenfield et al., 2009). A qualitative exploratory study by Chubak et al. (2012) reported the views of clinicians and administrators (n=40) from 10 integrated cancer centres. All respondents reported shared care was being practised. This was based on the assumption

that all survivors have a PCP, and despite respondents reporting a lack of standard approaches to sharing care between clinicians. Support for survivorship-specific care appeared lacking, with 22% (n=9) observing it would not add to current care and may decrease care integration. The authors concluded that interviewing respondents from sites without survivorship care would give an unbiased account. However, there may have been a lack of awareness related to the benefits of survivorship care.

Dicicco-Bloom and Cunningham (2013) qualitatively assessed the feasibility of a shared care survivorship model with 21 primary care clinicians. The overall perception was that primary carers are already involved in survivor follow-up, despite poor information provision from specialists. They perceived electronic medical records are often inaccessible. The authors further concluded survivorship care plan reasearch is limited. PCPs felt excluded once patients entered the hospital system, especially when follow-up extended well past treatment, to healthy patients with no recurrent cancer. This was reflected in the study by Greenfield et al. (2009) who reported the views of clinicians (n=475) regarding long-term follow-up and found only 5% (n=14) of haematology cancer survivors are discharged after two years, and only 42% (n=45 lymphoma) and 32% (n=10 leukaemia) are discharged after five years. This finding may be explained by the complex and ongoing late effect sequelae in haematology patients and their expectation of long-term specialist follow-up. Although respondent numbers were not reported, it was perceived that long-term specialist follow-up gave survivors false reassurance and perpetuated the illness role. Whereas the PCP-led model was perceived as normalising the survivors' experience, with a corresponding increase in co-morbid disease management. The authors concluded by proposing a risk stratification process whereby low risk survivors are transitioned early to PCP and high risk survivors stay within

the hospital model or become part of a shared care model supported by survivorship care plans.

Frew et al. (2010) studied survivor (n=626) and clinican (n=2302) views on different models of care. Respondents could choose from a number of follow-up models, but were not asked if they would reject a particular model. What was evident in the study by Frew et al. (2010) was specialist follow-up was the most experienced by survivors (84% n=528) and clinicians (95% n=2167). However specialists who had experienced non-specialist models of follow up (60% n=819) preferred this model over all others including specialist-led (87%).

Table 2.1.3 Methodological Characteristics of Models of Haematological Cancer Survivorship Care (n=6)

Author **Year** **Country** **Level of Evidence**	**Study Design**	**MOC** **Provider**	**Disease** **Years' Post-Treatment** **Sample Size (Response Rate %)**	**Resources Required**	**Potential Benefits**	**Potential Deficits**	**Outcome Measures**	**Results**
Chubak et al. 2012 USA VI	Exploratory study Semi-structured telephone interviews	Shared care	10 Cancer Research Network sites Cancer types not identified 40/48 (83%) Administrators /clinical leaders/providers in oncology, primary care	SCP—only 5 responders identified the use of Support groups	Time and lack of specialists to follow-up survivors	Clearer evidence to support survivorship care needed 6/10 sites survivor-specific tools not being used	Perspectives on: survivor needs; current survivorship practices; barriers; areas for future research	Only 2/10 sites had formal survivorship programs (1 nurse-led, 1 physician assistant-led) Responses for survivorship care needs: address fear recurrence 35%; information on long-term effects 40%; nutritional and exercise support 27%; psychosocial support 62.5% Overall uncertainty about best models of survivorship care
DiCicco-Bloom	In-depth	Shared care	21 Primary	Electronic	Primary care	No guidelines	Understand	Absence of systematic

& Cunningham 2013 USA VI	interviews on information sharing to/from specialist & patients		care clinicians (PCC) (11 PCP & 10 NP) Unknown patient types or survivorship period	medical records access SCP	perspective Information sharing ensures effective care transitions	or consensus for many cancers on screening, surveillance, late effects (LE)	nature of interactions between primary care, specialist & patient	information sharing among PCP, patient, specialist Some patients continue to see PCC during treatment Reliance on patients to provide clinical information from specialists (not always reliable for complex conditions/treatment) Academic hospital settings were worst in communication to PCC SCP effect on patient outcomes—limited evidence
Frew et al. 2010 UK IV	Comparison survey on models of follow-up	Models presented for perception & experience: hospital-based; telephone; non-specialist; group; patient managed; no	Cancer diagnosis or treatment not disclosed Range to over 10 years 626 (21%) survivors/carer	Nil described	Non-specialist models tend to provide more psychological support	Survey did not ask for survivor diagnosis & treatment which may alter model preference Survey did not	Perceptions of reasons for follow-up; levels of preference for different follow-up models; effect of individual experience on	Reasons for follow-up: monitoring for early complications; detecting recurrence; detecting LE, providing information & support (70%) Preference for model of follow-up experienced:

		follow-up	940 (32%) PCP 804 specialists including haematology 558 nurses/allied health (47%)			ask if any models would be rejected so potential deficits not identified	follow-up model preference	86% survivors preferred hospital-based follow-up, which was experienced most (84%) Clinicians had experience of more models of follow-up Specialists endorsed non-specialist or patient managed follow-up (87%) PCP endorsed hospital-based and patient managed follow-up (83%)
Gates et al. 2012 Australia IV	Quasi-experimental comparison healthy cohort versus Hodgkin lymphoma (HL) survivors	Late effects MDT haematology transplant physician, radiation oncology, cardiology, endocrinology, primary care liaison, psychology,	HL 5 years 30 HL + 30 healthy participants (91%)	Education package Screening tools (Late Effects Supportive Care Needs Screening Tool; The General Health Index; The Health Promoting	Health promotion Psychosocial issues identified & resources and support given Importance of surveillance Survivor sees all relevant	SCP not given until 2nd visit (at 4 months)	Primary outcome: health promotion intervention from nurse to improve HL survivors knowledge and motivation to adopt health promoting	No final published results from this study Anecdotal analysis shows appreciation of: SCP; screening assessment

		LE social worker, LE CNC) Nurse-led clinic for health promotion: 2 visits + 2 phone calls		Lifestyle Profile II) SCP copy to survivor/PCP	providers on same day		behaviours Secondary outcomes: improved perception of health status; reduced LE unmet needs; reduced LE worry	
Greenfield et al. 2009 UK IV	E-survey comparison of clinician views on long-term follow-up	PCP-led	18–45-year-old breast, lymphoma, leukaemia, or germ cell survivors >2 years 421 cancer clinicians (36% haematologist, 33% oncologist, 18% surgeon, 10% nurse, 2% other) 54 PCP	Communication Specialist nurse support (91% most important resource) Risk stratification—low risk to PCPs, high risk hospital follow-up SCP & TS	Specialists can focus on acute care Lower costs PCP: existing relationship with survivor; accessible; convenient; knowledge of local support; expertise in chronic health	Potential loss of outcome data, LE information to specialists PCP: Lack expertise in survivor-ship issues, increases survivor anxiety, time issues No tumour specific follow-up guidelines	Compare long-term follow-up: reasons for follow-up; advantage/disadvantage of PCP-led follow-up; current practice; resources and support required	Specialists rated clinical reasons for follow-up higher Nurses and PCP rated both clinical & supportive reasons higher Reasons for follow-up: PCP rated recurrence (96%) Specialists rated LE (76%) recurrence (71%) Haematologist use of follow-up protocol for leukaemia and lymphoma 19% Discharge to PCP: 5%

								at 2 years 42–32% by 5 years
John & Armes 2013 UK IV	Prospective comparison specialist-led versus nurse-led	Survivorship follow-up clinic Nurse-led (replaces specialist follow-up)	Lymphoma 3 years 50 notes audited (25 per group) 120 survivors (60 per group) assessed wait time 61 (82%) survivors assessed patient satisfaction (unclear split medical-led versus nurse-led)	2 CNS Information prescription	Longer consultations Written information provision Holistic needs assessment Monitoring for late effects Health promotion Post-treatment contact	Annual clinic visit Preferred clinic not assessed	Documentation Wait time Patient satisfaction	Documentation improved—50% of psychological & sexual issues still not recorded Wait times reduced from average 65 mins (specialist) to 10 mins (Nurse) Nurse-led was equal to specialist-led clinic and preferred in some areas Nursing telephone workload increased

Note. CNC Cancer Nurse Consultant; *CNS* Cancer Nurse Specialist; *HL* Hodgkin Lymphoma; *LE* Late effects; *MDT* multi-disciplinary team; *MM* multiple myeloma; *NHL* Non-Hodgkin Lymphoma; *NP* Nurse practitioner; *PCP* primary care provider; *SCP* survivorship care plan; *TS* treatment summary

Discussion

Deciding upon a model of survivorship follow-up care for haematology cancer survivors is difficult due to the considerable variability between the types of haematological cancers, range of treatment regimens and long-term and late effects that impact the survivorship phase of the cancer continuum (Hall, Lynagh, et al., 2013). For haematology cancer survivors, different models have been proposed and utilised. However, we are unable to determine the best or the most appropriate model. This finding is consistent with those of Campbell et al. (2011), reporting that no model was identified as better than any others. The reasons for these findings are that most of the articles were not evaluative in nature, and do not allow comparison. Patients who have only received a single model of care would not be able to comment on potential benefits of other models of care, therefore further research in understanding survivors' perspectives of follow-up care is required.

The transition of survivor care to the PCP requires PCP willingness. A study involving PCP views reported the willingness to accept exclusive care for lymphoma patients was three years after treatment completion (Del Giudice, Grunfeld, Harvey, Piliotis, & Verma, 2009). This may be due to the complex nature and length of the treatment regimens (Allart et al., 2013) and a lack of tumour specific follow-up protocols used by haematologists (Greenfield et al., 2009). With a lack of guidance and comprehensive information communicated from the haematologist (Dicicco-Bloom & Cunningham, 2013; Greenfield et al., 2009), PCPs may be reluctant to accept exclusive care of what they perceive as complex and 'high risk' patients (Del Giudice et al., 2009). Shared care maybe more satisfatory to haematologists, survivors and PCPs as it encompasses the strengths and expertise of providers from more than one discipline. As a study of follow-up care providers has reported, a

high proportion of survivors are followed up by multiple providers (Forsythe et al., 2014). Therefore, it is important that good coordination and communication is in place to reduce the possibility of either incomplete or duplication of services between multiple providers. Cooper et al. (2010) proposed that patients' transition into survivorship phase and out to primary care through specialist nurses so that monitoring for recurrence, psychosocial needs and health promotion are addressed and communicated to survivors and health care providers. This too has implications with John and Armes (2013) demonstrating that increased nurse workload occurred with patients utilising telephone contact between the scheduled clinic visits.

Establishing survivorship care provision will require careful planning and robust prospective evaluations. It is important to note that coordinated survivorship care interventions are complex interventions (Medical Research Council, 2000) and can be resource intensive, requiring robust evaluations using patient and system outcomes. This integrative review identified the three models of care: physician-led, nurse-led and shared care models. Ultimately, high quality pragmatic RCTs are required to test the effectiveness of these models. There is an urgent need for health research funders to understand the need for good survivorship cancer care and fund the development and evaluation of the effects of various models of survivorship care.

To the best of our knowledge, this review is the first that examines the characteristics, resources required and effectiveness of survivorship care models specifically for patients with haematological cancer. A number of limitations of this review are acknowledged. The search revealed only a relatively small number of articles that met the inclusion criteria. Furthermore, the variation of study methodology, range of measures,

populations and follow-up approaches made it difficult to compare models of care and enabled only tentative conclusions (Gates et al., 2012; John & Armes, 2013). Additionally, short-term follow-up or the timing of interventions may have been insufficient to report whether different models have impacted survivorship care. Finally, an inherent bias in interpretation might be due to the evaluator.

Conclusion

There is a paucity of effectiveness research related to haematology cancer survivors and specifically models of survivorship care in this cohort. Shared care models have been suggested as an alternative to exclusive specialist care. For shared care to work effectively ongoing communication channels need to be established and maintained. Nurse-led models have been proposed as another feasible model, where a specialist nurse intervenes directly and acts as the conduit between patient, hospital-based treatment team and PCP. However, more research is needed to define how these models should be best configured and evaluated for their effectiveness. For future development, a haematology-specific survivor-based needs assessment tool, individualised treatment summary and survivorship care plan would be integral. These would assist in guiding survivor-centred screening, health promotion and identification of needs to be monitored and managed. This approach may address many of the barriers that have been postulated.

Future research will need to account for increasing cancer incidence and survival rates, making extensive specialist follow-up care more difficult to maintain for new patients and survivors. To provide quality survivorship care, new and innovative models of haematology survivorship follow-up are

required that address the need for long-term follow-up that accounts for potential late treatment effects, risks of secondary cancers, development of treatment related co-morbid conditions and psychosocial well-being. This review revealed a lack of high quality evidence suggesting the effectiveness of any single model of care. A well-designed pragmatic randomised controlled trial, assessing patient and system outcomes including costs, is required to inform clinical practice.

Literature Review Update

The same search criteria, terms and databases were reviewed to ascertain recent developments or research in lymphoma models of survivorship care in the published literature. The search period was 2014 to January 2018. In this period, no new models of haematology or lymphoma-specific survivorship care were proposed or tested.

Results revealed 10 abstracts worthy of further assessment. Five articles either did not include lymphoma cohorts (Downs-Holmes, Dracon, Svarovsky, & Sustin, 2014; Hebdon, Abrahamson, McComb, & Sands, 2014; Jefford et al., 2016; Ye, Cheung, Goddard, Horvat, & Olson, 2015) or used a lymphoma cohort of less than 50% (Sharp et al., 2014). One article reported the perception of quality care rather than a model of survivorship care (Tzelepis et al., 2015). Of the remaining articles reviewed, three studies were related to follow-up care that was already occurring with survivors (Christen et al., 2016; Franco et al., 2017; Matheson et al., 2016), and the fourth article reported a study of nurses opinions regarding survivorship care (Langbecker, Ekberg, Yates, Chan, & Chan, 2016). Although these articles would not have met the original inclusion criteria, they have been described below as they continue to inform current follow-up practices which may not be meeting the needs of lymphoma survivors.

Two articles reported studies of survivors who had been diagnosed with cancer, including lymphoma, when they were aged between 16–39 years (Christen et al., 2016; Matheson et al., 2016). Christen et al. (2016) reported the preferences for support from survivors who were more than five years' post-diagnosis and showed that 92 (57%) were still receiving follow-up with a medical focus. There was a clear preference for oncology specialist follow-

up. Conceivably this could be due to a lack of exposure to other models of survivorship care and the need for late effects monitoring. A study of HL survivors (n=10), two and seven months' post-treatment (Matheson et al., 2016) described the loss of security when treatment completed. Survivors wanted better preparation and information for the future regarding recovery, such as mitigating the effects of fatigue; body image; fertility; sexuality; employment; socialising; and how to assess for lymphoma recurrence. No model of survivorship care was proposed; however, the authors suggested informal peer support and use of patient navigators as a worthwhile support mechanism when treatment completes.

Two qualitative studies examined specialist-led discussions (Franco et al., 2017) and haematology cancer nurses' opinions on survivorship care (Langbecker et al., 2016). The specialist-led qualitative study recorded 21 discussions led by doctors who were transitioning their lymphoma patients into the survivorship phase (n=40 patient visits recorded) (Franco et al., 2017). The study revealed a lack of consistency in discussion content or format. Data revealed that patients were seeking normalisation of their current health problems and trying to understand their general health in the future. Doctors did not provide reassurance or predictions of long-term outcomes. Patients were encouraged by their doctors to seek routine follow-up with other health care providers once specialist follow-up ceased after five years. Health promotion discussions were haphazard, with few specific recommendations, assistance or referrals. Social issues and emotional health and well-being were not widely discussed. The authors indicated that if discussions on the important areas of health promotion and psychosocial issues had occurred, it might have decreased fear of recurrence, distress and uncertainty. Likewise, the authors suggested these types of discussions may have acknowledged and supported patients who have experienced a major

life event which could have ongoing impacts on personal relationships, finances and employment (Franco et al., 2017). The study of haematology cancer nurses' opinions (n=136) of survivorship care (Langbecker et al., 2016) revealed two main themes; the ongoing focus on active treatment, and which health professional should be responsible for providing survivorship care. The authors indicated nurses were interested in developing models of survivorship care; however, there were many challenges to overcome before this type of survivorship care could be utilised.

These articles support the continuing need to explore survivorship models of care that are patient-centred, structured and address concerns of perceived importance to the survivor when treatment is completed.

2.2 Survivorship Care Plans and Treatment Summaries

Article

Survivorship Care Plans and Treatment Summaries in Adult Patients With Hematologic Cancer: An Integrative Literature Review

Karen Taylor, MNurs, GradDipOnc, BN, RN,
and Leanne Monterosso, PhD, BNurs (Hons1), GCert Teach, FACN

Purpose/Objectives: To identify current survivorship care plans (SCPs) and treatment summaries (TSs), both of which have been recommended by the Institute of Medicine as ways to facilitate the delivery of holistic survivorship care, to meet the needs of survivors of hematologic cancer.

Data Sources: Databases searched for eligible articles were CINAHL®, the Cochrane Library, EMBASE, MEDLINE, PsycARTICLES, PsycINFO®, and PubMed.

Data Synthesis: Four articles that reported on experience, dissemination, or components of SCPs or TSs were included. Hematology-specific literature was limited, and no randomized, controlled trials or literature reviews were found for the cohort of survivors of hematologic cancer. Content analysis was used to summarize the findings.

Conclusion: A lack of high-quality evidence evaluating the effectiveness of SCPs and TSs on hematologic cancer survivorship follow-up care exists. Nurses have established expertise in health promotion, information, support, and resource provision; they can develop and disseminate SCPs and TSs to facilitate communication among the survivor, specialist, and primary care provider.

Implications for Research: Well-designed, randomized, controlled trials on SCPs and TSs are required, particularly for cancers not well represented in the literature.

Key Words: survivorship care plan; treatment summary; survivorship; hematologic cancer

ONF, 42(3), XXX–XXX. doi: 10.1188/15.ONF.XXX-XXX

Survivorship, as defined by the National Coalition for Cancer Survivorship (2014), is the experience of living with, through, and beyond a diagnosis of cancer, including the impact on family, friends, and caregivers. Survivorship care is recognized as a priority in the cancer care continuum and has largely been driven by the Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt, Greenfield, & Stovall, 2005). A key recommendation of this report was the provision of a survivorship care plan (SCP) and treatment summary (TS) for all survivors (Palmer et al., 2014). Following the release of the report, many countries around the world developed and initiated national cancer initiatives (McCabe, Faithfull, Makin, & Wengstrom, 2013). Survivorship care should include the following components (Grant & Economou, 2008; Landier, 2009; Rechis, Arvey, & Beckjord, 2013):

- Coordination of care among providers to communicate overall health needs
- Monitoring, information about, and promotion of healthy living behaviors and disease prevention (e.g., guidelines for diet and exercise, alcohol consumption, tobacco cessation, sun protection, and healthy weight management)
- Prevention, screening, and intervention for recurrence, as well as long-term and late effects; early detection of new cancers or second malignancies by adherence to recommended surveillance guidelines (e.g., colonoscopies, mammograms, pap smears, skin checks); and awareness of comorbidities
- Psychosocial well-being assessment, support, management, and information provision for physical, psychological, social, and spiritual needs.

Routine follow-up care focuses largely on surveillance for recurrence and the monitoring of physical side effects, neglecting supportive care, health promotion, late-effects monitoring, and surveillance for new cancers (de Leeuw & Larsson, 2013). Awareness of the suboptimal communication that occurs between healthcare professionals, including primary care providers (PCPs), and patients is increasing; important information is often not provided at treatment completion (Dicicco-Bloom & Cunningham, 2013; McCabe & Jacobs, 2012). In addition, patients with cancer frequently experience multiple health problems earlier than the general population (Panek-Hudson, 2013). As such, a need exists for comprehensive early and ongoing approaches to management; these should take advantage of teachable moments at the end of active treatment to promote and support patient participation in maximizing recovery by the adoption of healthy lifestyle behaviors (Alfano, Ganz, Rowland, & Hahn,

Survivorship Care Plans and Treatment Summaries in Adult Patients with Hematological Cancer: An Integrative Literature Review.

Abstract

Problem Identification: Survivorship care plans [SCPs] and treatment summaries [TS] have been recommended by the Institute of Medicine as facilitators to deliver holistic survivorship follow-up care. An integrative literature review was undertaken to identify current SCPs and TS to meet haematological cancer survivors needs.

Literature Search: A search of relevant electronic databases for eligible articles was executed. Included articles described SCP and/or TS use with haematological cancer survivors or haematologists.

Data Evaluation: Four articles that reported on experience, dissemination or components of SCPs and/or TS were included. Haematology-specific literature was limited and no randomized control trials or literature reviews were found for the haematological cancer survivor cohort.

Synthesis: Content analysis was used to summarize the findings.

Conclusions: This review revealed a lack of high quality evidence evaluating the effectiveness of SCPs and/or TS on haematological survivorship follow-up care. Nurses have established expertise in health promotion, information, support and resource provision, and therefore can develop and disseminate SCPs and TS to facilitate communication between the survivor, specialist and primary care.

Implications for Practice or Research: Well-designed randomized control trials on SCPs and TS are required, especially for cancers not well represented in the literature.

Introduction

Survivorship, as defined by the National Coalition for Cancer Survivorship (2014), is the experience of living with, through and beyond a diagnosis of cancer including the impact on family, friends and caregivers. Survivorship care is recognized as a priority in the cancer care continuum and, has largely been driven by the Institute of Medicine [IOM] report in 2005, *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2005). A key recommendation of this report was provision of a survivorship care plan and treatment summary (SCPTS) for all survivors (Palmer et al., 2014). Following the report many countries around the world developed and initiated national cancer initiatives (McCabe, Faithfull, et al., 2013). Utilising IOM essential elements, SCPTS, survivorship care should include the following components (Grant & Economou, 2008; Landier, 2009; Rechis et al., 2013):

- Prevention; screening and intervention for recurrence, long-term and late effects; early detection of new cancers or second malignancies (including recommended surveillance guidelines such as colonoscopy, skin checks, mammogram, pap smear); and co-morbidities;
- Psychosocial well-being assessment, support, management and information provision for physical, psychological, social and spiritual needs;
- Monitoring, information, and promotion of healthy living behaviours and disease prevention including: diet and exercise recommendations; tobacco cessation; decreasing alcohol consumption; sun protection; and healthy weight management; and

- Coordination of care between providers to communicate overall health needs.

Currently, routine follow-up focuses largely on surveillance for recurrence and monitoring physical side effects; thus, neglecting supportive care, health promotion, late effects monitoring and surveillance for new cancers (De Leeuw & Larsson, 2013). There is an increasing awareness that communication between health care professionals, including primary care providers [PCPs] and patients is suboptimal, and that important information is often not provided at treatment completion (Dicicco-Bloom & Cunningham, 2013; McCabe & Jacobs, 2012). Furthermore it is reported that cancer patients frequently experience multiple health problems earlier than the general population (Panek-Hudson, 2013). This suggests a need for comprehensive early and ongoing approaches to management that should take advantage of 'teachable moments' at the end of active treatment to promote and support patient participation in maximising recovery by the adoption of healthy lifestyle behaviours (Alfano et al., 2012; Grant & Economou, 2008; Hewitt et al., 2005; Panek-Hudson, 2013).

The provision of SCPTS have been seen as important elements of communication with survivors and the numerous multi-disciplinary health care providers. What appears as an obvious solution to ensuring optimal follow-up and recommendation adherence is hampered by the complexity of cancer types and treatment. Especially evident within haematological cancers which are made up of diverse blood, immune and bone marrow diseases that make standardisation of inclusions very difficult (Rechis et al., 2013). Furthermore, in this survivor cohort there is an absence of clear guidelines for follow-up care (Earle, 2007; Phillips & Currow, 2010; Rechis et al., 2013).

The most common haematological cancers are leukaemia, lymphoma and multiple myeloma [MM] (National Cancer Institute, 2006). Each cancer type has distinctive and complex treatment regimens that commonly involve high dose chemotherapy agents, and/or targeted therapies, radiotherapy and hematopoietic stem cell transplants (Carey et al., 2012), often at different institutions. Unfortunately, the outcome of these largely aggressive treatments is a number of long-term and late physical, practical and psychosocial effects which commonly include: fear of recurrence; fatigue; nutrition; exercise; fertility; relationship; financial; employment; and insurance issues (Allart et al., 2013; Hall, Lynagh, et al., 2013). These patients therefore require SCPTS that reflect disease-specific differences rather than those designed for the more common cancers (breast, prostate and colorectal) who follow similar patterns of survivorship and for whom SCPTS templates are widely available.

Haematological cancer patients are understudied and underrepresented in survivorship care (Swash et al., 2014) despite increasing five-year relative survival rates internationally (Sant et al., 2014). Consequently, the haematology focus of this integrative review will add to the limited body of knowledge currently available in this cohort of survivors.

This integrative review undertook an analysis of the literature to examine the following questions:

1. What are the common attributes of SCPs and TS developed for haematological cancer patients?
    a. What resources (human, templates) are required to develop these SCPs and TS?
    b. What are the potential benefits and limitations of these SCPs and TS?

c. What outcome measures have been used to evaluate these SCPs and TS and what are the findings?

Method

The integrative review method was chosen as the theoretical framework to guide this literature review as it allows for an in-depth evaluation of the issues encompassing the empirical, theoretical and clinical approaches within a structured systematic methodology (Whittemore & Knafl, 2005). The method is structured according to five stages: problem formulation; literature search; data evaluation; data analysis and presentation (Whittemore & Knafl, 2005).

Problem formulation

In this review, a SCP is defined as a personalised document that guides and coordinates follow-up care, including recommended surveillance, screening, and health promoting behaviours, in addition to providing information, education and resources for management of potential long-term and late effects of cancer treatment (Hausman et al., 2011; Salz et al., 2014). Within cancer survivorship, TS specifically refer to comprehensively summarised information on disease, procedures and treatments received for a particular cancer (Hausman et al., 2011; Jabson & Bowen, 2013). The aim of these tools is to provide written communication from the treatment team to survivor, and current and future health care providers with clear delineation of responsibility of care (Earle, 2006; McCabe, Bhatia, et al., 2013). A number of components have been proposed for inclusion in SCPTS based on recommendations from the IOM (Hewitt et al., 2005). An overview of relevant components for haematological cancer survivors have been listed in Box 2.2.1 and have been adapted from the published literature (Ganz et al.,

2008; Hewitt et al., 2005; McCabe, Bhatia, et al., 2013; Palmer et al., 2014; Salz et al., 2014).

There is consensus that responsibility for the creation and dissemination of these tools rests with the treating team (Earle, 2007; Hausman et al., 2011; Hewitt, Bamundo, Day, & Harvey, 2007; McCabe, Faithfull, et al., 2013; Salz et al., 2014; Stricker et al., 2011). However, it has been identified that development of such individualised tools are time consuming, especially if treatment occurs across multiple sites and there is a lack of integration or absence of electronic records (Earle, 2007; McCabe, Bhatia, et al., 2013; Parry, Kent, Forsythe, Alfano, & Rowland, 2013; Rechis et al., 2013; Salz et al., 2014). Accordingly, nurses have been suggested as the logical choice to create and deliver SCPTS, not only to "free up" specialists time but also because of their well-established role in providing information to patients that is holistic and individualised (Jackson et al., 2013; Marbach & Griffie, 2011).

Box 2.2.1 Components for Haematological Survivorship Care Plan and Treatment Summary

Survivorship Care Plan

- Follow-up schedule including all relevant health care providers responsibility
- Recovery timeframes for treatment toxicities
- Health care providers responsible for (including provision of referral/tests):
    - monitoring of long-term effects and onset of potential late effects
    - monitoring and screening for recurrence and second cancers
    - recommended cancer screenings (e.g. mammogram, pap smear, skin checks, colonoscopy)
    - co-morbid conditions
- Monitoring for potential physical, psychological, social issues and referrals for:
    - fear of recurrence
    - anxiety / depression
    - relationship issues (marital, parenting, family and friends)
    - fertility and sexual functioning
    - employment, financial assistance, insurance, legal aid

○ counselling • Promotion of healthy lifestyle behaviours ○ smoking cessation ○ alcohol reduction ○ healthy dietary modifications, weight reduction ○ physical activity • Resource list and where to find information on: ○ support groups ○ other allied health providers ○ specific disease and treatment information
Treatment Summary • Diagnosis, tests performed, results • Disease characteristics, site, stage / classification • Date of treatment initiation and completion • Chemotherapy / targeted therapy drugs and cycles: amount, alterations (reduction / escalation) • Type of Surgery (if applicable) • Radiotherapy: site, dosage, timeframe • Clinical trials • Blood product support • Transplant: Allogeneic / Autologous • Maintenance treatments and impact on health • Adverse reactions or complications • Contact information for each modality • Coordinator of continuing care contact information • Psychosocial, nutritional, and other supportive services used

Templates can reduce the time required to complete SCPTS, providing information is readily accessible. The American Society of Clinical Oncology [ASCO] and NursingCenter Prescription for Living provide three page downloadable templates (McCabe, Partridge, Grunfeld, & Hudson, 2013). Internet-based SCP tools such as the Journey Forward™ Survivorship Care Plan Builder and LIVESTRONG™ Care Plan (Hausman et al., 2011) deliver a comprehensive summary and detailed long-term follow-up plan of care once pertinent information is provided. However their utility is limited by the length (14 pages) of the tool (McCabe, Partridge, et al., 2013). For survivors

and health care professionals outside the USA, educational and supportive care resources may not be applicable. Hill-Kayser et al. (2013) studied use and satisfaction of the LIVESTRONG Care Plan and found responding survivors rated the provision and amount of information as good to excellent (93% n=276). Interestingly it was reported that 65% (n=186) of responding survivors had not been given information contained in the SCP by health care providers after treatment completion. Furthermore, psychosocial concerns or risks were often not addressed, thereby necessitating later delivery after a health care professional had performed a follow-up needs assessment (Belansky & Mahon, 2012). Ganz et al. (2008) and Stricker et al. (2011) proposed a dedicated survivorship visit is ideal to assess needs and deliver SCPTS, however, they did not stipulate when that visit should take place.

The majority of studies on SCPTS are largely descriptive or exploratory and have not established evidence that use of SCPTS improve survivor outcomes (Grant & Economou, 2008; McCabe, Faithfull, et al., 2013). A randomised control trial of breast cancer patients by Grunfeld et al. (2011) compared SCP provision to PCPs with usual care (no SCP), and showed no difference in patient-reported outcomes between the two groups. This study has been criticised (Jefford, Schofield, & Emery, 2012; Stricker, Jacobs, & Palmer, 2012) as control PCPs received a comprehensive discharge letter that may have contained recommendations for follow-up. Since both groups may have received similar information albeit in different formats, results should be viewed with caution due to potential contamination of the control group. Since published literature in haematological cancer survivorship is rare the focus of this integrative review was to identify SCPTS used with haematological cancer survivors to facilitate development of tools that can be used with this unique survivor cohort.

Literature search

The primary search utilised the following electronic databases: Cumulative Index to Nursing and Allied Health Literature [CINAHL]; Medline; PsycInfo; PubMed; EMBASE; PsycArticles and the Cochrane Library from January 2000 to July 2014. Combinations of the following search terms were used: (survivorship care plan or treatment summary or follow-up care plan or post treatment plan or written follow-up instructions) AND (survivorship or cancer survivor) AND (cancer or neoplasm or oncology) AND (haematology or leukaemia or lymphoma or multiple myeloma). A hand search of reference lists from full texts was also employed. Searches were restricted to the English language, humans and adults. Inclusion criteria were: studies that reported on SCP and TS use in post treatment phase of haematological cancer survivorship; and studies that reported usage perceptions of SCPTS experienced by health care providers and/or survivors. Exclusion criteria were: studies with less than a 25% haematological cancer patient cohort or haematologist viewpoint; studies reporting SCPTS from child, adolescent, adult survivors of a childhood cancer or non-cancer populations; and opinion papers, letters, editorials, commentaries, conference abstracts, conference proceedings or case studies.

Data evaluation stage

Abstract titles were reviewed by one author [KT] to assess eligibility. A summary of the selection process (Moher et al., 2009) is provided in Figure 2.2.1. The initial search yielded 697 abstracts. Duplicate articles were removed and abstracts were screened against the inclusion and exclusion criteria. Abstracts that did not provide cancer or provider type were sought for further screening. Twenty full-text articles were retrieved; of these four articles were reviewed. Documented methodological characteristics included: authors and study information; intervention; sample characteristics

including participant details, response rate and years' post treatment; outcome measures; results; limitations and comments and level of evidence as developed by (Melynyk & Fineout-Overholt, 2011). Due to variations in study population and methodologies used, meta-analysis was not possible. Results are shown in Table 2.2.1.

The haematology component in the majority of studies was low. No systematic reviews on studies related to SCPTS were identified. The four included studies were all from the USA. They assessed both survivor and clinician views on the experience of receiving or disseminating SCPTS. Included articles used various terms to describe treating clinicians. For clarity in this integrative review, the term specialist will refer to the following treating consultants: haematologist, medical or radiation oncologist. The research studies all used quantitative approaches and reflected a low level (IV) of quantitative evidence. Reviewed studies were related to the survivorship phase of the cancer trajectory.

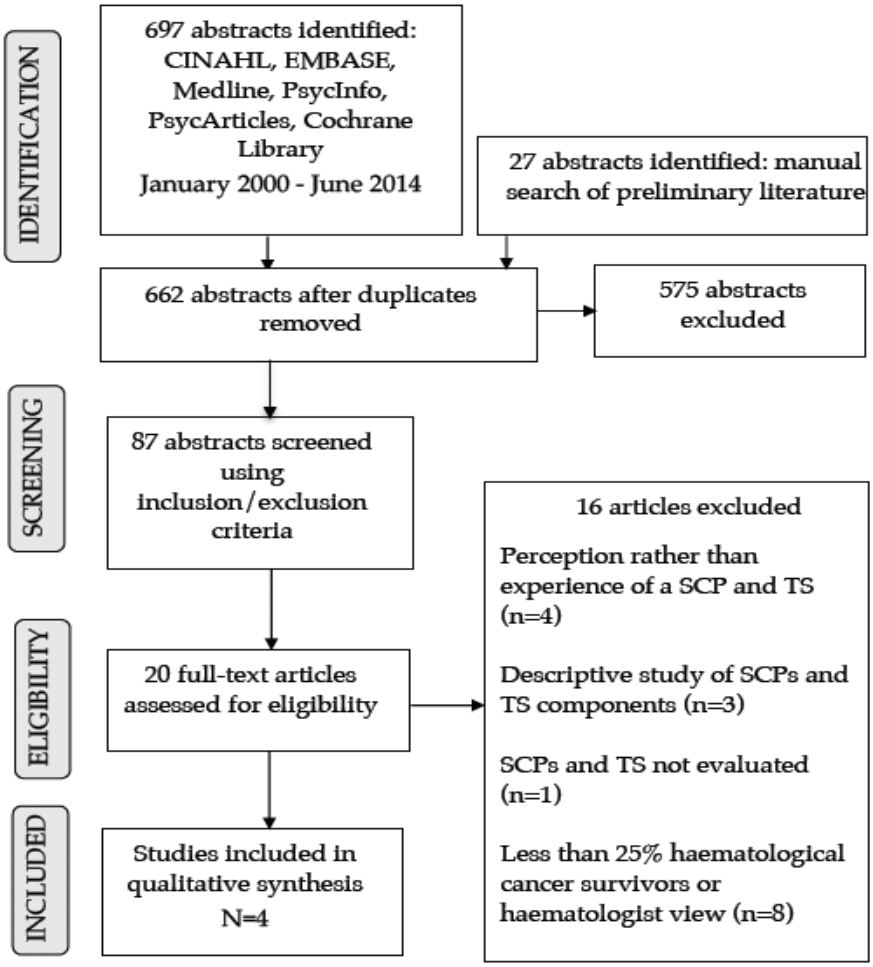


Figure 2.2.1. Flowchart of literature search results.

Table 2.2.1 Levels of Evidence

Level	**Evidence**
I	Systematic review of all relevant randomised control trials
II	At least one well designed randomised control trial
III	Well-designed controlled trials without randomisation
IV	Well-designed cohort studies, case control studies, interrupted time series with a control group, historically controlled studies, interrupted time series without a control group or with case series
V	Systematic reviews of descriptive and qualitative studies
VI	Single descriptive and qualitative studies
VII	Expert opinion from clinicians, authorities and/or reports of expert committees or based on physiology

(Melynyk & Fineout-Overholt, 2011)

Data Analysis and Presentation

Characteristics of reviewed articles are detailed in Table 2.2.2.

Table 2.2.2 Methodological Characteristics of Haematological Cancer Survivorship Care Plans and Treatment Summaries (n=4)

Author	Study Design	Intervention	Sample Characteristics	Outcome Measures	Results	Limitations and Comments	Level of Evidence
Curcio et al 2012 USA	Pre/post-test question-naire	Survivorship protocol with SCPTS developed by specialist and NP (40–75 minutes to complete) Delivered by NP using ASCO-generic template	30 survivors convenience sample included: breast (53%); NHL (26%); lung (10%); gastrointestinal (10%) <2 years' post-treatment 10/24 (41%) PCP 8/10 (80%) staff	Improved disease knowledge Decreased anxiety Satisfaction Fidelity to NCCN follow-up guidelines Cost-benefit analysis	Increased knowledge: disease, treatment, follow-up, signs of recurrence, LE Decreased anxiety High satisfaction in survivors (76%) and staff (100%) PCP satisfied (100%) Consistent fidelity to NCCN guidelines	Low anxiety scores at baseline Small samples No cost-benefit analysis SCPTS to survivor/PCP	IV
Friedman et al 2010 USA	Mailed question-naire	SCP and rating of the most important informational needs	67/164 (41%) NHL survivors 9 months–12.6 years' post-treatment 22/76 (29%) physicians involved in survivorship care	Informational SCP needs of survivors / physicians Congruence between survivors / physicians	Survivor needs: recurrence screening, LE, treatment, overall health monitoring, nutrition, exercise, insurance, finances Physician needs: treatment complications Higher concordance on medical issues compared to psychosocial issues	Small samples Same questions for survivors/physicians Disease specific cohort	IV

Merport et al 2012 USA	Mailed question-naire	SCPTS developed / delivered by specialist TS inclusions reported: diagnosis; stage; treatment; start dates; treatment fields; drugs	108/369 (29%) specialists [Haematologist (32%)] 400/3568 (11%) PCP Cancers reported: breast (44%); prostate (36%); colorectal (35%); lung (31%); haematology (20%)	SCP and TS use and obstacles among specialists SCP and TS receipt and informational preferences among PCPs	Use: 56% prepare TS 14% prepare SCP (sent to PCP/patient) Obstacles: 47% no training; 46% no template; 40% no reimbursement Receipt of TS 54% Information preferences: 95% treatment summary; 89% follow-up schedule; 89% recommendations; 84% potential side effects; 67% treatment-related health risks	Low response rates Self-reported practices Responder bias (potential over estimation of use) Reported lack of routine use of TS/SCP	IV
Sabatino et al 2013 USA	2010 National Health Interview Survey [NHIS] data	Survivor reported receipt of TS or written follow-up plan	1345 (60.8%) survivors including: breast (20%); prostate (14%); cervix/uterus (13%); melanoma (11%); colorectal (8%); other (31%) [including haematology] <4 years and >4 years post treatment	Receipt of TS and/or follow-up instructions Recent surveillance for recurrence, other cancer screening	Survivors <4 years received: 38% TS 58% written follow-up 29.4% both 33.1% neither More treatment modalities—lower TS provision Higher income and clinical trial participation—higher written instruction provision	Haematology sample % not specified Self-reported data may not reflect actual documents received Separate reporting of survivors diagnosed after IOM report (<4 years)	IV

Note. ASCO-American Society of Clinical Oncology; IOM-Institute of Medicine; LE-late effects; NCCN-National Comprehensive Cancer Network; NHL-non-Hodgkin lymphoma; NP-nurse practitioner

The study by Sabatino et al. (2013) reported a subset of survivors (n=407) who were within four years of diagnosis, a timeframe that corresponded to the IOM report calling for all survivors to receive SCPTS. Survivors were asked if they had ever received a SCP and /or TS. The authors found that 38% (n=155) of survivors acknowledged receipt of a treatment summary and 58% (n=236) written follow-up instructions or plan. The authors reported that written follow-up instructions were received more often in those recipients who were part of a clinical trial (85% n=346) and demographically were reported as having a higher income (67% n=274). Hematopoietic stem cell transplant survivors were included, however numbers were not reported.

Curcio, Lambe, Schneider, and Khan (2012) studied both survivors and clinicians. Haematological cancer survivors accounted for 26% (n=8) of the overall survivor cohort studied (n=30). Survivors were highly satisfied with the provision of SCPTS and reported an increase in knowledge. Anxiety levels decreased, although levels were not high at baseline, and may have decreased naturally with time. Equally survivor satisfaction may have been related to the survivorship visit and follow-up telephone call rather than SCP provision. PCPs were reported as being satisfied (100% n=10) with SCPTS. The authors reported PCPs appreciated the content, which aided communication and were useful tools to provide clarification of the survivor's follow-up plan.

Friedman, Coan, Smith, Herndon II, and Abernethy (2010) studied non-Hodgkin lymphoma survivors (n=67) and physicians (n=22) involved in survivorship care. The informational needs on the SCP were reported as being congruent between the PCP and survivor. Interestingly all respondents rated medical content more important than psychosocial issues, perhaps reflecting survivor expectations in the current model of survivorship follow-

up. Furthermore, survivors ranked the plan to monitor overall health the sixth most important element of the SCP compared to physicians who ranked it thirteenth. This led the authors to conclude that survivors' view follow-up as part of general health maintenance, whereas physicians separate cancer survivorship care and non-cancer related care.

Merport, Lemon, Nyambose, and Prout (2012) evaluated clinician (n=108) use and PCP (n=400) receipt of SCPTS. Fifty-four percent (n=216) of PCPs received a TS. However, the study reported that only 42% (n=46) of specialists (including haematologists) prepared a TS. SCP preparation by specialists was low at 14% (n=15), nonetheless the authors reported all SCP were sent to survivors and PCPs. Barriers identified in this study included: no template was provided; no training was given to health care professionals on how to develop SCPTS; and specialists perceived no financial reimbursement was given for their time in developing and delivering SCPTS. Therefore, a lack of support from treating clinicians may mean development and dissemination remains low, with the possibility SCP remains medically focused.

All these studies showed a lack of routine use of SCP TS even though survivors and PCPs valued the tools and the direction for survivorship follow-up they provided.

Discussion

Published haematology research regarding SCPTS is limited. Currently no randomised control trials or literature reviews exist for this understudied cohort of cancer survivors. This is despite the current belief that SCPTS are beneficial in complex and rare cancer survivor groups such as haematology

(Mor Shalom, Hahn, Casillas, & Ganz, 2011) where health problems may take many years to develop (Sabatino et al., 2013). With the increased risk of psychosocial, physical and economic long-term and late effects from disease and cancer therapy, patients often experience difficulties accessing post treatment follow-up which may potentially lead to poorer overall health outcomes (Friedman et al., 2010).

Within the literature that reported the development and dissemination of the SCPTS (Curcio et al., 2012; Merport et al., 2012) there was a lack of information regarding resources used by the specialist to develop the SCPTS (Merport et al., 2012). Similarly, information on how generic ASCO templates were tailored by the specialist and nurse practitioner for the different cancer survivors was not provided (Curcio et al., 2012). Details on any evidenced-based guidelines for follow-up care used in SCP (Merport et al., 2012), and the clinical expertise of the health professionals creating SCPTS was equally lacking.

Standardised templates linked to electronic health records that would directly populate TS have been proposed to provide health providers with diagnosis and treatment information (Merport et al., 2012; Salz et al., 2014), particularly relevant when survivors have had treatment across a number of sites (Merport et al., 2012). Sabatino et al. (2013) similarly found low TS and SCP delivery when survivors had more than one treatment modality. Furthermore, the long duration of treatment that occurs in some haematological cancer regimens can make it difficult to find and summarise dose modifications and issues that have occurred over the entire treatment phase. It is clear that haematology-specific cancer SCPTS templates and guidelines are necessary as generic cancer templates cannot convey all the appropriate information required, adding to the complexity of this issue

(Friedman et al., 2010). As recommended by Curcio et al. (2012) and Sabatino et al. (2013) provision of SCPTS soon after treatment completion is required to assess the need for information and resources.

Friedman et al. (2010) argued that providing extra information to survivors could overload and dilute the impact of the most important information that needs to be conveyed. This view is supported by Cox and Faithfull (2013) who reported clinicians consider late effects information impacts psychological adjustment and increases the amount of late effects through autosuggestion. However, these authors reflect the perception of clinicians rather than patients and as Hill-Kayser et al. (2013) argue this paternalistic approach is no longer acceptable. Providing tailored SCPTS to cancer survivors, empowers individuals to learn about their disease and treatment and assume responsibility for future surveillance and disease management, facilitating engagement in a future healthy lifestyle (Jackson et al., 2013). This is particularly vital for younger survivors given the expectation of a longer survivorship period (Jabson & Bowen, 2013).

Multidisciplinary collaboration has been suggested (Mor Shalom et al., 2011) as a strategy for developing SCPTS. Interdisciplinary education needs to acknowledge the value of each provider's contribution within the team. Recommendations that clearly detail provider responsibility can ensure survivors are not over or under tested and adhere to recommendations that are evidenced or consensus based (Curcio et al., 2012).

Nurses can be a key component in implementing care plans, and providing comprehensive information, education and resources, especially in preventative health and screening as reported by Curcio et al. (2012). Mor Shalom et al. (2011) revealed nurse practitioner-developed SCP may not be

read by PCPs, and indeed 100% PCPs (n=15) reported they would not act upon expensive testing recommendations. Therefore, specialists need to reinforce the importance of nurses as an essential element in survivorship care planning (Hewitt et al., 2007).

It is important that SCPTS be developed in conjunction with a robust model of haematological survivorship follow-up care that will address the issues and barriers related to implementation. Many professional organisations are calling for SCP development for accreditation, but there is risk that cancer programs that develop SCP to meet professional requirements may be reluctant to make the organisational changes necessary to actually deliver the SCP to survivors and PCPs (Birken, Mayer, & Weiner, 2013). Institutions and/or specialists who perceive a lack of financial reimbursement and support for the additional time required to prepare and deliver SCPTS maybe be disinclined to support widespread implementation (Earle, 2007; McCabe, Partridge, et al., 2013; Salz et al., 2014).

A number of limitations of this review are acknowledged. The search revealed a small number of articles meeting inclusion criteria. All studies reviewed had low sample numbers and/or response rates, especially for those studies which explored PCP experiences of SCPTS. Haematological survivor and haematologist numbers were limited, decreasing the applicability to haematological cancer survivors. The reliance on self-reported practices in all the studies and a lack of comparison groups restricts the conclusions that can be drawn. Study participants may have had more experience with and/or a bias towards or against SCPTS implementation. This lack of standardisation makes it difficult to compare and draw conclusions regarding the benefits for survivors with the dissemination of

these tools. Finally, an inherent bias in interpretation might be due to the evaluator.

Conclusion and Implications for Nursing

This integrative review identified published literature on SCPTS and their applicability to haematological cancer survivors. Treatment advances in haematological cancer means patients are living longer (Sant et al., 2014), however the extended recovery trajectory involves a heavier symptom burden and post treatment complications due to the aggressive nature of both the haematological disease and the treatment required. Therefore, these haematological cancers are unlike the other cancers that are currently used as benchmarks such as breast or prostate (Parry et al., 2010).

Nurses can influence and guide the development of relevant survivorship care recommendations, thereby facilitating a paradigm shift to encompass all aspects of the cancer trajectory. Nurses with advanced research skills (e.g. PhD prepared) would be well placed to take the lead in adopting and translating current follow-up guidelines for haematological cancer patients into evidenced-based and disease-specific templates. Nurses are in a position to provide and disseminate SCPTS comprising individualised and relevant resources, information and education to ensure the needs of haematological cancer survivors are met. Correspondingly nurses need to support and empower survivors to take control of and ultimately self-manage their ongoing needs.

This review revealed a lack of high quality evidence related to haematological cancer survivor care. Addressing specific and ongoing concerns of these patients, along with the dissemination of this information

to survivors and clinicians, especially in primary care is important. As survival rates continue to increase, the successful integration of haematological survivorship care into the cancer continuum is vital.

Future Research

Further research will need to account for the inclusion of each component of the SCP, the survivor's desire for this knowledge and information, as well as the best way to develop and deliver haematological cancer specific SCPTS. Research is required on the types of models of care most suitable for delivering SCPTS to haematological cancer survivors, including their perspectives on follow-up provision. Nurse-led haematology survivorship clinics that facilitate shared care between the treating team and primary care may be the most appropriate model to deliver SCPTS to achieve the best outcomes for patients transitioning into the survivorship period and require further evidence-based research. Methods that will optimise communication and clarity with provider responsibility, thereby decreasing over or under use of surveillance and screening tests are fundamental aspects of this research. Finally, research in how best to decrease the amount of time needed to prepare SCPTS, and the ideal time to effectively deliver SCPTS is necessary. Well-designed pragmatic randomised controlled trials are required to inform clinical practice. As the amount of outcome-based research increases so too will our understanding of providing optimal survivorship care.

Literature Review Update

The same search criteria, terms and databases were reviewed to ascertain recent developments or research in lymphoma survivorship care plans and treatment summaries in the published literature. The search period was 2014 to January 2018. Results found 17 abstracts worthy of further assessment.

Assessment of the articles revealed no new articles that meet the inclusion criteria of the original integrative review (Behrend, 2014; Brennan, Gormally, Butow, Boyle, & Spillane, 2014; Frick et al., 2017; Jabson, 2015, 2015; Klemanski et al., 2016; Kvale et al., 2016; Maly et al., 2017; Mayer, 2014; Mayer, Birken, Check, & Chen, 2015; Mayer, Green, et al., 2015; Palos et al., 2014; Playdon et al., 2016; Rosenberg et al., 2016; van de Poll-Franse, Nicolaije, & Ezendam, 2017). The majority of articles included breast cancer cohorts and, therefore, predominantly female participants, which may not accurately reflect the perceptions and use of SCPTS by lymphoma survivors or men. Two articles of interest that did not meet the inclusion criteria have been described (Brant et al., 2016; Mayer et al., 2016). Both articles relate to SCP use and primary care, a specific area of interest examined in this thesis.

The study by Brant et al. (2016), reporting satisfaction with an SCP, evaluated breast (n=52, 78%) and lymphoma (n=15, 22%) survivors, carers (n=39) and n=23 primary care providers (PCP). Results from the lymphoma cohort revealed higher quality of life (QoL) scores compared with breast cancer survivors, and that PCPs of lymphoma survivors were highly satisfied with the SCP. The authors suggested that an SCP may contribute to improved patient confidence in PCPs who provide survivorship care. Conversely the study of a breast cancer cohort (which may not be applicable to lymphoma survivors) randomised 34 females into two groups; SCP only group, where

an SCP was delivered by an oncology nurse practitioner (NP) and an SCP plus PCP group, where participants received an SCP from the NP and attended a six-week follow-up visit with their PCP. Both groups reported improved confidence in survivorship information; however the SCP only group were identified as having increased worry compared with the group who were able to discuss the SCP with their PCP at the six-week follow-up visit (Mayer et al., 2016).

2.3 Needs Assessment Measures

The Australian Journal of Cancer Nursing

Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors

Karen Taylor* • PhD(c), MNurs, GradDipOnc, BN, RN
Survivorship Cancer Nurse Coordinator, Western Australia Cancer and Palliative Care Network
189 Royal Street, East Perth, WA 6004
School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, WA 6959
Email: Karen.Taylor@health.wa.gov.au Tel: +61 (0)428 411 309

Leanne Monterosso • PhD, BNurs (Hons), GCert Teach, FACN
Chair of Nursing, School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, WA 6959
St John of God Murdoch Hospital, WA; Adjunct Professor of Nursing, School of Nursing, Edith Cowan University
Joondalup, WA 6027

* Corresponding author

Abstract

Purpose: To identify validated measurement tools to assess the informational and practical concerns of leukaemia and lymphoma survivors. Cancer nurses have the potential to lead the way in providing quality post-treatment survivorship care.

Method: This systematic review utilised a search of electronic databases for eligible articles published to March 2014. Included articles described a tool to assess informational and/or practical concerns of leukaemia and/or lymphoma survivors.

Results: Seven full text articles were identified that described cancer-specific tools used to assess informational and/or practical needs of this survivor cohort. There was variation in the use of cancer survivor-specific tools and generic cancer tools.

Conclusions: No haematology-specific needs assessment tools were identified. Therefore only tentative conclusions on the best tool for this cohort can be made. Further research is required to develop reliable and validated tools that will support the selection of the most appropriate tool for leukaemia and lymphoma survivors.

Keywords: Leukaemia and lymphoma cancer; survivorship; instruments; measures; tools; supportive care needs; unmet needs; perceived needs.

Introduction

Leukaemia and lymphoma are the most common blood and bone marrow cancers[1]. Effective treatments are largely aggressive and cause a number of long-term and late physical, practical and psychosocial effects, which significantly impact lifestyle in the survivorship phase[2]. Survivorship is defined as the experience of living with, through and beyond a diagnosis of cancer[3]. As with other cancers, the haematology cancer health professional role has extended to include provision of patient care in the survivorship phase. This important step forward has been driven largely by the 2005 Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition*[4], considered the seminal paper for cancer survivorship. The report recommended survivorship care as a priority in the cancer trajectory with a number of specific issues relevant to the survivorship phase. These issues can be categorised according to the seven domains of Fitch's[5] supportive care framework; physical, informational, emotional, psychological, social, spiritual and practical concerns. The framework can be used across the cancer continuum including haematology survivorship care[6]. Whilst survivorship care is developing for other cancers, haematology cancers remain understudied in survivorship literature[7], despite increasing five-year relative survival rates internationally[8-10].

The purpose of this review was to source tools that could be used to assess two domains from the supportive care framework: informational and practical concerns. These were chosen as a result of our findings from a qualitative study undertaken with leukaemia and lymphoma patients that revealed a number of unmet needs, predominately informational and practical[11], thought to relate in part to the extensive nature of the treatment and the uncertainty around long-term remission and potential late effects.

The terms 'informational needs' and 'practical needs' are rarely considered or defined as separate entities in the literature. For clarity and consistency, Fitch's definitions[5] of needs have been used. Informational needs are defined as information to

Systematic Review of the Tools Used to Assess the Informational and Practical Needs of Acute Leukaemia and Lymphoma Survivors.

Abstract

Purpose: To identify validated measurement tools to assess the informational and practical concerns of leukaemia and lymphoma survivors. Cancer nurses have the potential to lead the way in providing quality post-treatment survivorship care.

Method: This systematic review utilised a search of electronic databases for eligible articles published to March 2014. Included articles described a tool to assess informational and/or practical concerns of leukaemia and/or lymphoma survivors.

Results: Seven full text articles were identified that described cancer-specific tools used to assess informational and/or practical needs of this survivor cohort. There was variation in the use of cancer survivor-specific tools and generic cancer tools.

Conclusions: No haematology-specific needs assessment tools were identified. Therefore, only tentative conclusions on the best tool for this cohort can be made. Further research is required to develop reliable and validated tools that will support the selection of the most appropriate tool for leukaemia and lymphoma survivors.

Introduction

Leukaemia and lymphoma are the most common blood and bone marrow cancers (National Cancer Institute, 2006). Effective treatments are largely aggressive and cause a number of long-term and late physical, practical and psychosocial effects, which significantly impact lifestyle in the survivorship phase (Arden-Close et al., 2011). Survivorship is defined as the experience of living with, through and beyond a diagnosis of cancer (National Coalition for Cancer Survivorship, 2014). As with other cancers the haematology cancer health professional role has extended to include provision of patient care in the survivorship phase. This important step forward has been driven largely by the 2005 Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2005), considered the seminal paper for cancer survivorship. The report recommended survivorship care as a priority in the cancer trajectory with a number of specific issues relevant to the survivorship phase. These issues can be categorised according to the seven domains of Fitch (2008) supportive care framework; physical, informational, emotional, psychological, social, spiritual and practical concerns. The framework can be used across the cancer continuum including haematology survivorship care (Hall, Campbell, et al., 2013). Whilst survivorship care is developing for other cancers, haematology cancers remain understudied in survivorship literature (Swash et al., 2014) despite increasing five-year relative survival rates internationally (Hall, Lynagh, et al., 2013; Rowland & Bellizzi, 2008; Sant et al., 2014).

The purpose of this review was to source tools that could be used to assess two domains from the supportive care framework: informational and practical concerns. These were chosen as a result of our findings from a qualitative study undertaken with leukaemia and lymphoma patients that

revealed a number of unmet needs, predominately informational and practical (Monterosso et al., 2015), thought to relate in part to the extensive nature of the treatment and the uncertainty around long term remission and potential late effects.

The terms 'informational needs' and 'practical needs' are rarely considered or defined as separate entities in the literature. For clarity and consistency Fitch's definitions (Fitch, 2008) of needs have been used. Informational needs are defined as information to assist in decision-making and acquiring of skills to decrease fear, anxiety and misperception (Fitch, 2008). Fear of recurrence is often reported as an informational need for this cohort (Koch, Jansen, Brenner, & Arndt, 2013). Two recent systematic reviews on this topic reported tools used to measure fear of recurrence; tools to measure other informational needs were not reported (Koch et al., 2013; Thewes et al., 2012). Practical needs are defined as direct interventions or help that support the survivor to complete a task or meet a concern (Fitch, 2008). Insurance and employment issues are often cited as unmet needs for leukaemia and lymphoma survivors (Chen et al., 2012). Other common informational and practical needs reported in haematology survivorship literature include late effects, fatigue, nutrition, exercise, fertility and sexual concerns, relationship issues, financial issues, personal care and accessing support services (Allart et al., 2013; Arden-Close et al., 2011; Beckjord, Arora, Bellizzi, Hamilton, & Rowland, 2011; Behringer et al., 2013; Gates et al., 2015; Hall, Lynagh, et al., 2013; Hawkins et al., 2008).

Gates et al. (Gates et al., 2015) argued that haematology cancer nurses have an important role in this changing dynamic, especially in developing sustainable, nurse-led survivorship care. If nurses are to take on a greater role in survivorship care they require accurate, reliable and validated tools to

assess patients entering the post-treatment phase (Muzzatti & Annunziata, 2013). Hawkins et al. (2008) proposed that tools designed for patients to self-identify perceived needs are required to support survivorship care. These tools could then guide the development of appropriate models of care, resources and tailored support that are patient-centred rather than based on the perceptions of health professionals (Fitch, 2008; McDowell et al., 2010). The timing of patient needs assessments is equally important. Research showing interventions and assessments undertaken in the early survivorship phase (up to two years post-diagnosis) can lead to fewer unmet needs moving into the extended survivorship phase (over five years)(Aziz, 2007; McDowell et al., 2010).

There is a dearth of published literature that has critically evaluated tools used to measure the perceived unmet needs of leukaemia and lymphoma survivors (Arden-Close, Pacey, & Eiser, 2010; Muzzatti & Annunziata, 2013). Tools specifically developed for these patients in the treatment phase such as the Functional Assessment of Cancer Therapy: Lymphoma or Leukaemia (FACT-LYM, FACT-Leu) have also been in the survivor population (Cella et al., 2012; Hlubocky, Webster, Cashy, Beaumont, & Cella, 2013). Hence, it is possible survivor-specific needs may not be captured.

Given that each cancer patient's journey is unique it is important to measure individual needs and match practical support to meet these needs. Therefore, the leukaemia and lymphoma-specific focus of this paper will add to the limited body of knowledge currently available in this survivor cohort.

The following questions guided this systematic review:

1. What reliable and valid measurement tools are currently available to measure the informational and practical needs of acute leukaemia and lymphoma cancer survivors?
2. What are the implications of the findings from this review for future research and clinical practice?

Method

A systematic review methodology was chosen to guide this review. To guide literature searches and analysis of articles, a study protocol was devised. As the use of needs assessment tools dictates a quantitative study method, qualitative studies and the qualitative component of quantitative studies were excluded. Mixed methods research was included with only the quantitative element evaluated.

Literature search

The primary search utilised the following electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsychInfo, PubMed, EMBASE, PsychArticles, and the Cochrane Library from earliest records to March 2014. Search terms related to leukaemia and lymphoma cancers, assessment, survivorship and needs. A hand search of the reference lists from full text articles was also employed. Searches were restricted to English and adult acute leukaemia or lymphoma survivors. Inclusion and exclusion criteria are shown in Table 2.3.1. Studies with only multiple myeloma participants were excluded as these patients are living with cancer (Osborne et al., 2012). Likewise, studies with only allogeneic transplant participants were excluded as they have ongoing conditions such as Graft-versus-Host-Disease.

Table 2.3.1 Inclusion and Exclusion Criteria

Inclusion Criteria
• Use of a cancer survivor-specific or generic cancer tool or instrument • Validity and reliability of tool tested with leukaemia and/or lymphoma cancer survivors • Informational and/or practical needs reported • Adult leukaemia and lymphoma cancer survivors only
Exclusion Criteria
• Tools used in the treatment or diagnostic phase • Tools used with relapse or secondary leukaemia or lymphoma cancer survivors only • Studies reporting survivors of a childhood leukaemia or lymphoma cancer • Studies related to caregivers, or comparative studies between caregivers and survivors • Studies with less than 50% leukaemia or lymphoma cancer survivor cohort • Opinion papers, letters, editorials, commentaries, conference proceedings, or case studies

Quality appraisal and data extraction

Abstract titles were reviewed by author (KT) to assess eligibility. The instrument/tool(s) used in eligible full text articles were then appraised (KT and LM) to determine whether they measured informational and/or practical needs of the leukaemia or lymphoma survivor. A summary of the selection process using the PRISMA 2009 Flow Diagram (Moher et al., 2009) is provided in Figure 2.3.1.

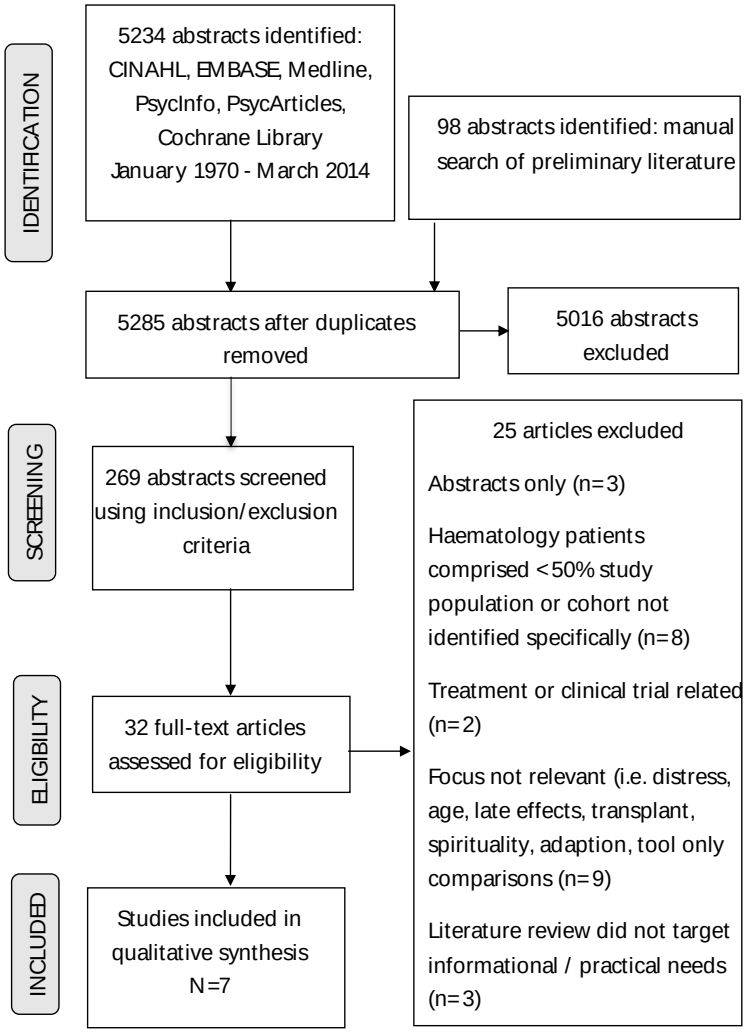


Figure 2.3.1. Flowchart of literature search results.

The methodological characteristics documented included: authors; publication year; study design; comparison group; outcome measures; disease; sample size and response rate; survivorship period; cancer-specific and non-cancer specific tools; reported unmet informational and practical needs; results and study quality (Fowkes & Fulton, 1991) shown in Table 2.3.2. Due to variations in study population, methodologies and tools used, meta-analysis was not possible. Study quality was assessed using Fowkes and Fulton (1991) guidelines and checklist for critically appraising quantitative research. Assessment of the methodological quality of studies

utilised a classification system of poor (under 40% of quality items), good (40–70% of quality items) or very good (over 70% of quality items) as reported by Hall, Lynagh, et al. (2013). In addition, the validity of each tool was assessed according to: how the tool covered the informational and/or practical needs of the participants; correlation with other generic cancer or survivor-specific tools; and whether results confirmed study outcomes. Tool reliability was determined by internal consistency of the items and whether test–retest reliability had been performed. Generalisability of the tool to leukaemia or lymphoma survivors was gauged from the study results, along with the clinical usefulness of the tool for these survivors.

Table 2.3.2 Methodological Characteristics of Selected Articles (n=9)

Authors Year Country	**Study Design Comparison Group Outcomes Measured**	**Disease Sample Size (Response Rate %) Survivorship Period**	**Tools Cancer Survivor-specific Non-cancer Tools/Investigator Questions**	**Unmet Information/Practical Needs Reported**	**Results**	**Study Quality**
Arden-Close et al 2011 UK	Cross sectional Administered questionnaires Gender comparison Health related quality of life, late effects and perceived vulnerability; satisfaction with care; expectations and satisfaction of clinic visit	Lymphoma n=115 (79.9%) >5 yrs	QoL-CS (Quality of Life Cancer Survivors) Yes SF-12v2 (Medical Outcomes Study Health Survey Short Form 12 version 2) Princess Margaret Hospital Satisfaction with Doctor Questionnaire 18 late effects & 10 general issues at consultation	Only questions related to discussion of topics, late effects	No gender difference in late effects or perceived vulnerability Men: more late effects, worse health related quality of life, wanted to discuss more topics (women discussed the topics) Shorter wait time=more topics discussed Health related quality of life dependent on whether survivors' follow-up expectations are met	Good
Friedman et al 2010 USA	Cross sectional Mailed questionnaire Comparison of survivors and	Non-Hodgkin lymphoma n=67 (41%) 9 months–12.6	Investigator questionnaire	Informational needs to be included in survivorship	Survivorship care plan tailored for particular survivors Survivor: survivorship care plan inclusions: screening for	Poor

	physicians Informational survivorship care plan needs of survivors and physicians Congruence between survivors / physicians	years Physicians involved in survivorship care n=22 (29%)		care plan	recurrence/late effects; treatment summary; monitor overall health/nutrition/exercise; insurance Survivor/Physician concordance higher on medical issues compared to psychosocial issues No differences reported between survivorship length	
Hall et al 2013 Australia Canada	Cross sectional Cross cultural Mailed questionnaires Comparison of Australian and Canadian haematology survivors Percentage of survivors reporting unmet needs; domain scores; 10 most prevalent high unmet needs	Leukaemia, lymphoma, multiple myeloma Australia: n=268 (37%) >3 years Canada: n=169 (45%) 1–5 years	SUNS (Survivors' Unmet Needs Survey) Yes	Informational needs: cancer recurrence and spread Work & financial needs	Similar levels of unmet needs Fatigue highest concern across both cohorts Multiple areas of need found in; females, younger age, expense due to cancer, vocational education level, seeing Dr re treatment or concerns Work & financial needs higher for Australian survivors	Good
Hjermstad et al 2003 Norway	Prospective cohort at 4 time points Administered questionnaires Comparison of autologous lymphoma	Leukaemia, lymphoma n=123 (94%) <1 year post-transplant	CARES-SF (CAncer Rehabilitation Evaluation System Short Form) No EORTC QLQ-C30	Financial, insurance, weight gain, transport, fear of recurrence, employment,	Few patients requested help with any items CARES-SF useful for assessing sexual, marital, medical interaction to address specific issues at follow-up	Good

	with allogeneic leukaemia transplant patients Rehabilitation needs and health related quality of life; physical function measures of CARES-SF compared to EORTC QLQ-C30		(European Organization for Research and Treatment Quality of Life Core questionnaire) No	fatigue	High correlation with physical function between the two scales	
Lobb et al 2009 Australia	Cross sectional Mailed questionnaire No comparison group Assessment of unmet informational and emotional needs after treatment	Leukaemia, lymphoma, multiple myeloma n=66 (50%) 6 weeks–1 year post-treatment	CaSUN (Cancer Survivors Unmet Needs Survey) Yes	Concerns: fear of recurrence; care coordination; information on services	Care coordination after treatment important, significant for unmarried or working patients Fear of recurrence, emotional & relationship needs greater in younger patients Top endorsed needs: managing health with medical team; communication between doctors; best medical care	Good
Parry et al 2012 USA	Mixed methods Cross sectional Mailed questionnaire No comparison group Health service and psychosocial needs of adult leukaemia and	Lymphoma, leukaemia n=477 (45%) < 4 years	Houts et al Service Need Inventory, refined by Kornlith et al. 14 items	Practical needs: child care; financial	Unmet need highest in: sexual issues; handling medical and living expenses; emotional difficulties; employment; health insurance Women more likely to report unmet child care needs Relationships were observed	Poor

	lymphoma survivors				among service needs, overlapping areas of unmet need	
Zebrack 2000 USA	Mixed methods Cross sectional Mailed questionnaires / semi structured interviews No comparison group Experience of quality of life in long term survivors at various life stages	Leukaemia, lymphoma n=53 (50%) 10 years	QoL-CS (Quality of Life Cancer Survivors) Yes 27 in depth interviews	Fear of recurrence, fatigue, employment, support, financial, family	Fatigue, pain, fear of recurrence—ongoing issues Family distress and finances continue to impact survivors Financial issues worse in older survivors Relapse not related to quality of life Income rated significantly to quality of life Positive associations with ability to cope after cancer	Good

Data Analysis

The initial search yielded a large number of abstracts (n=5234). Following removal of duplicate articles and abstract screening using exclusion and inclusion criteria, 32 full text articles were sought and further appraised. Of these, seven articles were reviewed and referred to one or more relevant tools (Arden-Close et al., 2011; Friedman et al., 2010; Hall, Campbell, et al., 2013; Hjermstad et al., 2003; Lobb et al., 2009; Parry, Lomax, Morningstar, & Fairclough, 2012; Zebrack, 2000). No tool had been specifically developed for exclusive use with leukaemia or lymphoma survivors. Two studies reported researcher-developed questionnaires (Arden-Close et al., 2011; Friedman et al., 2010).

The seven included articles reporting haematological cancer survivor cohort studies from Australia (n=2), Canada (n=1), the United States of America (USA) (n=3), Norway (n=1) and United Kingdom (UK) (n=1). The periods of survivorship ranged from six weeks post-treatment through to 12 years after diagnosis (Arden-Close et al., 2011; Friedman et al., 2010; Hall, Campbell, et al., 2013; Hjermstad et al., 2003; Lobb et al., 2009; Parry et al., 2012; Zebrack, 2000). Of the reviewed studies, four utilised comparative groups related to unmet needs among different: treatment types (Hjermstad et al., 2003); countries (Hall, Campbell, et al., 2013); gender (Arden-Close et al., 2011); and survivors and physicians (Friedman et al., 2010). Outcome measures varied across all studies, although the majority related to unmet needs after treatment completion (Table 2.3.2). The assessment of methodological quality (Fowkes & Fulton, 1991) revealed most studies (n=5) were 'good'; two were classified as 'poor'. Two studies (Parry et al., 2012; Zebrack, 2000) utilised mixed method designs, six studies (Arden-Close et al., 2011; Friedman et al., 2010; Hall, Campbell, et al., 2013; Lobb et al., 2009; Parry et al., 2012; Zebrack,

2000) were cross sectional and one (Hjermstad et al., 2003) was prospective. Methodological quality varied with sample sizes ranging from 22 to 477 participants and response rates varying from between 29% and 94%.

Results

Five tools were identified and could be dichotomised as either those designed for cancer survivors (survivor-specific) or those developed for cancer patients undergoing treatment and used with a cancer survivor cohort (generic cancer tools). Utilising the definitions of informational and practical needs as previously described ensured consistency with the data extracted from the articles. Comparisons of the five main assessment tools identified in this review are shown in Table 2.3.3.

Table 2.3.3 Comparison of Assessment Tools

Tool	Cancer Survivor-specific	Content	Scale Scoring	Information Needs	Practical Needs
CARES-SF (CAncer Rehabilitation Evaluation System Short Form)	No	59 items—degree problem applies 5 summary scales: physical; psychosocial; sexual; marital; medical interaction	5 point Lower scores = fewer problems	No	Yes
CaSUN (Cancer Survivors Unmet Needs Survey)	Yes	35 supportive care needs items, 6 positive outcome items, 1 open ended item 5 needs domains: existential survivorship; comprehensive cancer care; information; quality of life; relationships	5 point Higher scores = greater needs	Yes	Yes
EORTC QLQ-C30 (European Organization for Research and Treatment Quality of Life Core questionnaire)	No	5 functioning scales: physical; role; emotional; social; cognitive 3 symptom scales: pain; fatigue; nausea & vomiting 6 items: dyspnoea; sleep; appetite; diarrhoea; constipation; financial impact	8 point Function: higher scores = better function Symptom: higher scores = more problems	No	Yes
QoL-CS (Quality of Life Cancer Survivors)	Yes	4 domains: physical well-being (8 items), psychological well-being (18 items), social well-being (8 items), spiritual/existential well-being (7 items)	10 point Higher scores = best QoL	No	Yes
SUNS (Survivors' Unmet Needs Survey)	Yes	5 domains: informational needs (8 items), financial concerns (11 items), access & continuity of care (22 items), relationships (15 items), emotional health (33 items)	5 point Higher scores = greater need	Yes	Yes

The generic cancer tools: CAncer Rehabilitation Evaluation System Short Form (CARES-SF); and European Organization for Research and Treatment Quality of Life Core questionnaire (EORTC QLQ-C30) were not survivor-specific and no data in relation to previous use in any haematology survivor cohorts was described (Hjermstad et al., 2003). Reliability scores and validity information was variable in the detail reported. Similarly, the three cancer survivor-specific tools: Cancer Survivors Unmet Needs Survey (CaSUN); Quality of Life Cancer Survivors (QoL-CS); and Survivors' Unmet Needs Survey (SUNS) provided variable reliability and validity data (Arden-Close et al., 2011; Hall, Campbell, et al., 2013; Lobb et al., 2009; Zebrack, 2000).

All studies documented tool domains and scoring scales. Only two tools addressed both informational and practical needs (CaSUN, SUNS) (Hall, Campbell, et al., 2013; Lobb et al., 2009). The SUNS is the only tool developed using a mixed cohort that included haematological cancer survivors (Hall, Campbell, et al., 2013). All reviewed articles reported the clinical usefulness of the tools to the haematological cohort studied.

The majority of studies (n=5) assessed the informational needs of survivors (Table 2.3.2). Of the survivor-specific tools used to assess informational needs, the CaSUN (Lobb et al., 2009) includes an explicit information domain with response items such as: "I need up to date information"; "I need understandable information". It is assumed that follow-up is required for those patients who score highly for such items. The SUNS tool similarly includes an informational domain with questions targeted to "Finding information …" or "Dealing with fears … or feelings…"(Hall, Campbell, et al., 2013). In general, a high score allows the assessor to identify areas of need. However, neither tool explicitly asks if the survivor would like help with their issue or concern.

Arden-Close et al. (2011) measured gender-related informational needs using the cancer survivor-specific tool QoL-CS. Although this article made gender-specific recommendations, it did not provide insight into what assessment tools best identify gender differences. Friedman et al. (2010) developed a questionnaire that focused on information that should be included in survivorship care plans such as: specific information about cancer recurrence; nutrition and exercise; screening plan; information for family members. This questionnaire both identified needs and enquired whether respondents wanted information. On the other hand, the CARES-SF (Hjermstad et al., 2003) does enquire if patients would like assistance with their concerns. However, it does not explicitly identify survivor informational needs. In contrast, Parry et al. (2012) used a non-validated survey that identified informational and practical needs of haematology survivors examining if participants received the help they required.

The definition of `practical need' differed between authors, making identification of suitable tools somewhat difficult. The QoL-CS tool (Arden-Close et al., 2011; Zebrack, 2000) examined practical concerns including: employment; sexuality; financial burden and fatigue. Unlike the other cancer survivor-specific tools, a higher score indicated a better quality of life outcome. It was unclear if the tool recommended users to follow-up concerns that generated low scores. Similarly, the EORTC QLQ-C30 assessed the practical need of financial concerns but focused on more treatment related concerns that are unlikely in the survivorship phase (Hjermstad et al., 2003). Needs relating to fatigue management, fertility, sexuality, nutrition, exercise, insurance, finances and employment were explored by the majority of tools or investigator-derived questionnaires to varying degrees. The late effects of treatment were reported as both an informational need and a practical area where a plan for screening should occur (Arden-Close et al., 2011; Friedman

et al., 2010). Likewise, fear of recurrence issues were similarly reported (Friedman et al., 2010; Hall, Campbell, et al., 2013; Hjermstad et al., 2003; Lobb et al., 2009; Zebrack, 2000).

Although a variety of tools were used, there was consensus regarding the most prevalent leukaemia and lymphoma survivor informational and practical needs. The commonly reported informational needs were: treatment late effects; cancer recurrence including fear of recurrence; care coordination; and information on available resources (Friedman et al., 2010; Hall, Campbell, et al., 2013; Hjermstad et al., 2003; Lobb et al., 2009; Zebrack, 2000). The most consistently identified practical needs were: fatigue management; employment; financial; insurance; family; and sexuality (Hall, Campbell, et al., 2013; Hjermstad et al., 2003; Lobb et al., 2009; Parry et al., 2012; Zebrack, 2000). Arden-Close et al. (2011) addressed potential differences in gender and found men wanted more information however were often unable to receive this from the medical consultation. Women, on the other hand, were able to discuss the topics they wanted. Other studies found women had higher unmet needs related to family issues (Hall, Campbell, et al., 2013; Lobb et al., 2009; Parry et al., 2012); similarly younger survivors had higher unmet informational and practical needs (Hall, Campbell, et al., 2013; Lobb et al., 2009). Conversely disease and treatment type did not identify those with greater unmet needs.

Discussion

Providing information across the cancer continuum is one of the most important aspects of care, yet it is a frequently reported unmet need especially in the survivorship phase (Husson et al., 2013). Leukaemia and lymphoma patients differ from other cancer patients in the considerable

variability between their cancer types and the range of treatments affecting many aspects of their lives (Hall, Lynagh, et al., 2013). With improving survival rates, those diagnosed younger (18–45 years) can now expect to live longer, raising additional concerns and unmet needs (Arden-Close et al., 2011). Information provision must be individualised and tailored to specific patients' needs (Husson et al., 2013; Parry et al., 2012). As highlighted by Friedman et al. (2010) survivorship care plans need to account for differing informational and practical needs of survivors, primary care providers and haematologists.

Generic cancer tools include items related to diagnosis and treatment issues, which are not necessarily specific to the survivorship phase. This review has shown that survivor-specific tools can be used to assess unmet needs of leukaemia and lymphoma participants in the survivorship phase. Therefore, tools specific to the survivorship phase would be more appropriate to assess for unmet needs and concerns in this cohort.

Arden-Close et al. (2011) and Aziz (2007) have argued that survivors should be afforded the opportunity to obtain support and access resources earlier in the survivorship continuum. They assert survivors need information about immediate and long-term impacts of the cancer, together with practical needs related to fatigue, exercise, nutrition, fertility, sexuality, insurance, finances, employment and late effects. Leukaemia and lymphoma survivors may also want resources to address healthy lifestyle choices (Arden-Close et al., 2011; Boyes, Girgis, D'Este, & Zucca, 2012) or support to deal with the psychosocial aspects such as relationships, anxiety and fear of recurrence, reported in many studies as the highest unmet needs (Hall, Campbell, et al., 2013; Hjermstad et al., 2003; Lobb et al., 2009).

We acknowledge a number of limitations. There was variation in tools used across a wide range of survivors from the early survivorship phases (under two years) (Hall, Campbell, et al., 2013; Hjermstad et al., 2003; Lobb et al., 2009; Parry et al., 2012) through to 12 years post diagnosis (Friedman et al., 2010; Zebrack, 2000). This made comparative generalisations of informational and practical needs difficult and enabled only tentative conclusions. Our findings are limited to comparing those areas surveyed with the assessment tools. As such, the review could not determine a broader range of supportive care needs for all haematological cancer survivors. Further, the relatively low response rate reported for some studies reduces the likelihood of the sample being representative of leukaemia and/or lymphoma survivor populations, and sampling bias could result in distorted conclusions. Extracting the psychometric properties of the tools was hampered by a lack of detailed data to support validity and reliability (Hall, Campbell, et al., 2013; Hjermstad et al., 2003; Lobb et al., 2009). Finally, an inherent bias in interpretation might be considered.

Notwithstanding the limitations, this review identified a consensus on the most prevalent informational and practical needs of leukaemia and lymphoma survivors. This important finding can assist haematology cancer nurses when making decisions regarding the most appropriate tools to use and may assist in the development of haematology cancer survivor-specific tools that measure: perceived informational and practical needs; the extent to which needs are being met; and the survivors' need for support across all supportive care domains. In this way nurses are ideally positioned to provide individualised information and resources to these survivors and further this area of research.

Conclusion

There is a paucity of studies related to leukaemia and lymphoma survivors and specific validated tools that can be used to identify and measure the informational and practical needs of this cohort. While cancer survivor-specific needs assessment tools do exist and have been used with more common cancer groups, further research is required to determine their relevance and applicability to leukaemia and lymphoma survivors to ensure specific concerns are heard and addressed via appropriate support and information. Equally, generating psychometric data will ensure valid and reliable tools are utilised. As the only tool developed that included a haematology cohort, the use of the SUNS tool in further leukaemia and lymphoma survivor populations will allow a greater body of knowledge to be developed.

Literature Review Update

The same search criteria, terms and databases were reviewed to ascertain recent developments and published research on needs assessment measures used with lymphoma survivors. The search period was 2014 to January 2018. Results found 30 abstracts worthy of further assessment, however no articles met the original inclusion criteria.

Of these, six articles did not include lymphoma survivor cohorts (Burg et al., 2015; Czerw, Marek, & Deptała, 2015; de Jong, Tamminga, de Boer, & Frings-Dresen, 2016; Faller et al., 2016; Smith, Klassen, Coa, & Hannum, 2016) or the lymphoma survivor cohort was less than 50% (Klassen et al., 2017).

Seventeen articles did not discuss needs assessment measures and reported health care provider perceptions (Coa et al., 2015; Daniel, Emmons, Fasciano, Fuemmeler, & Demark-Wahnefried, 2015; Karvinen, Bruner, & Truant, 2015; Spector et al., 2015) or measured only one informational or practical need, such as fear of recurrence (van de Wal et al., 2016), distress (Hall et al., 2016; Magyari et al., 2017; Mojs et al., 2017; Oerlemans et al., 2014; Raphael, Frey, & Gott, 2017), fatigue (Daniels et al., 2014; de Lima et al., 2017; Kreissl et al., 2016; Linendoll et al., 2016), cognition impairment (Krolak et al., 2017; Zimmer et al., 2015) or employment (Arboe et al., 2017). Five articles assessed the impact of cancer on the survivor rather than their practical and informational unmet needs (Bryant et al., 2015; Drost et al., 2016; Jones et al., 2015; Sarker et al., 2017; Smith, Samsa, Ganz, & Zimmerman, 2014).

Two articles included information from studies that had been identified and reviewed in the systematic review article of this thesis (Hall, D'Este, Tzelepis, Lynagh, & Sanson-Fisher, 2014; Jiao et al., 2017). Hall, D'Este, et al. (2014)

undertook a sub-analysis of the participants who had indicated high or very high unmet needs in the SUNS. Jiao et al. (2017) undertook a rapid review of needs assessment measures for post-treatment survivors. The authors identified six studies that described five needs assessment measures. Two measures were specific to survivors of a childhood cancer, and the three other measures had been used in studies previously examined in this review.

Chapter Summary

Published literature related to models of post-treatment follow-up cancer care and cancer survivorship care was reviewed and discussed in the published model of cancer survivorship care review and updated review. There was a lack of robust evidence to guide development of evidence-based survivorship models of care including recommendations for the health professional best placed to lead and/or deliver this care. Therefore, as the researcher is a nurse, it was important to develop and test the viability of a nurse-led survivorship model of care.

Similarly, the second integrative literature review revealed a lack of evidence in the published literature regarding the use of SCPTS with lymphoma survivors, and the methods and frameworks that could be used to develop and deliver these tools. Further, there was a lack of personalisation of the SCPTS to the patient. Consequently, this prompted the researcher to develop and test a unique lymphoma-specific SCPTS for this study, the detail of which is outlined in Chapter Four.

There is still a need for strong research that tests the appropriateness of currently validated cancer survivorship-specific measures that will best assess unmet needs in lymphoma survivor cohorts. The final systematic

literature review assessed validated needs assessment measures that had been developed and/or tested with lymphoma survivors. This work resulted in the Short-Form Survivor Unmet Needs Survey (SF-SUNS) being chosen as the most appropriate measure for this study. Further details are outlined in Chapter Four.

In summary, at the completion of these reviews, clear gaps were evident in some areas: the most suitable model of care for lymphoma survivors; the most appropriate SCPTS to use with this cohort; and the best measures to capture lymphoma survivorship-specific unmet needs. The outcomes from these reviews supported the need for high-quality research such as the pragmatic randomised controlled trial used for this thesis. The following chapter outlines the conceptual framework that guided this thesis.

Chapter Three — Conceptual Framework

"Being able to put my thoughts and feelings into words, being able to just say it out loud to someone was quite therapeutic and then discussing some solutions was really really helpful" Female_HL

3.0 Conceptual Framework

The purpose of this chapter is to outline the conceptual framework that guided the development and/or pilot testing of essential elements of the nurse-led lymphoma survivorship model of care. These included the unique survivorship care plan and treatment summary, choice of assessment measures and development of a resource pack. These essential elements will be further detailed in Chapter Four. Included in the discussion of the conceptual framework is a description of motivational interviewing, a technique that was used with participants randomised to the intervention of the pragmatic RCT.

Conceptual Framework

This study is guided by Bandura's theory of self-efficacy; defined as one's ability to succeed in a specific situation or achieve a specified skill, such as making a difficult decision or, within the context of this study, communicating with a health care professional (Bandura, 1977). Within the area of health, self-efficacy is identified as an affirmative personal resource that can contribute to managing one's health generally and how an individual manages a crisis (Schumacher, Sauerland, Silling, Berdel, & Stelljes, 2014). In this instance a lymphoma diagnosis, treatment and life thereafter. An individual's sense of self-efficacy can have a major influence on how challenges, tasks and goals are approached (Bandura, 1977). This is the principal concept underpinning self-management education, which teaches patients to identify their problems and provides skills in decision making and developing an appropriate action plan (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Philip, Merluzzi, Zhang, & Heitzmann, 2013).

Empowering patients to become responsible for the management of their health and well-being can contribute to the influence and control patients (self-efficacy) ultimately have over their health. Positive effects of empowerment in patients who are managing the consequences of a cancer diagnosis and treatment can lead to improved quality of life and survival through improved health outcomes including physical and emotional well-being (Bodenheimer et al., 2002; Foster et al., 2015; Kuijpers, Groen, & Aaronson, 2013). It has been reported that encouraging self-efficacy and assisting patients to become self-empowered may help lymphoma survivors adjust to the challenges of their lives during and after treatment and assist in the resumption of "normal" life activities (Schumacher et al., 2014).

Notwithstanding the positive influences of individual or self-empowerment and self-efficacy, previous life experiences held by the patient can impact upon how he/she will cope and function from diagnosis, throughout treatment and in the post-treatment phase of life (Richardson, 2002). Perceived self-efficacy has a direct influence on the choices that individuals make and how they cope once they have initiated a course of action (Bandura, 1977). Self-efficacy, as mentioned previously, is task-specific and therefore an individual can learn in a specific setting, regardless of previous failure in other contexts. Similarly, motivation can be influenced by self-efficacy. Individuals with high self-efficacy are more likely to actively persist and complete a task. Individuals with low self-efficacy may sometimes be motivated to learn more about a subject or situation they are unfamiliar with. However it may also lead to a state of learned helplessness and lack of motivation (Bandura, 1977). Consequences of inadequate support may include lower levels of self-management, reduced utilisation of appropriate support services and worsening health (Foster et al., 2015; Hoffman, Lent, & Raque-Bogdan, 2013). It is therefore imperative that a patient's life

experiences be explored and considered when developing a model of survivorship care in order to provide an appropriate level of support that is tailored to the individual.

Working with individuals (i.e. cancer survivors in the context of this study) to develop a personalised patient action plan (i.e. survivorship care plan) that includes tailored healthy lifestyle resources will likely result in a reduction in the perceived need for support from the health care system by patients (Bodenheimer et al., 2002; Foster & Fenlon, 2011). Maintaining patients' motivation to enact healthy lifestyle changes and "follow through" is important particularly for those individuals who may have lower levels of empowerment and/or self-efficacy (Foster et al., 2015), since it is known that people who give up a task before completion will retain their self-debilitating and/or limiting expectations (Bandura, 1977).

In keeping with the concepts underpinning self-empowerment and self-efficacy, it was recognised that a nurse-led model of survivorship care developed specifically for this study needed to incorporate self-reported assessment measures to accurately identify an individual survivor's ability to self-manage his/her health and well-being (Philip et al., 2013). Further, it was anticipated there would be variations across domains measured (i.e. survivorship needs; depression, anxiety and stress; mental adjustment to cancer; self-empowerment). Patient self-assessment can facilitate targeted support that will allow lymphoma survivors to improve self-efficacy and management of the effects of a lymphoma diagnosis and treatment (Foster et al., 2015). The conceptual framework guiding this study's nurse-led lymphoma survivorship model of care is outlined in Figure 3.1.1.

Motivational interviewing was explored as a credible technique to use in the nurse-led lymphoma survivorship model of care. This form of interviewing is defined as a directive, patient-centred counselling style for prompting behaviour change by facilitating patients to explore and resolve uncertainty (Litt, 2006). The researcher was guided by the four principles of motivational interviewing when developing the study intervention: resisting the urge to fix participant problems; gaining understanding of the participant's motivations; listening with empathy; and empowering the participant to have hope for the future and be positive they could make changes if desired (Rollnick, Miller, & Butler, 2008).

To assist intervention participants with the process of making changes to unhealthy lifestyle behaviours such as cigarette smoking and excessive alcohol consumption, the researcher customised a motivational chart based on work by Rollnick et al. (2008) to provide to these participants (Appendix J.2). During a motivational interview, questions can be posed to the interviewee as he/she works with the researcher through the process of change to help guide thoughts and motivations. Questions such as: 'why do you want to make a change?'; 'what important benefits do you anticipate will come from the change?'; 'how will you make the change?'; 'what are you already doing towards making the change?

Once a motivational chart has been completed, the role of the interviewer is to summarise the benefits and barriers posed by the interviewee and reflect all the positive change behaviours the interviewee has committed to undertake. Interviewees who are not ready to make changes at the first nurse-led lymphoma survivorship clinic (NLSC) appointment will be encouraged to address these issues at subsequent NLSC appointments. The success of this approach requires interviewees to feel in control of these

changes since permanent behaviour changes can only be made by individuals who are motivated (Rollnick et al., 2008). Bandura's theory of self-efficacy (Bandura, 1977) is also a principal concept in self-management education, which teaches patients to identify their problems and provides skills in decision making and developing an appropriate action plan (Bodenheimer et al., 2002). Empowering patients to become more responsible for the management of their health and well-being can contribute to the influence and control patients have over their health which has the advantage of improving quality of life (Bodenheimer et al., 2002; Kuijpers et al., 2013). It is anticipated that increasing a patient's empowerment and providing healthy lifestyle resources will result in a reduction in the perceived need for support from the health care system by patients (Bodenheimer et al., 2002).

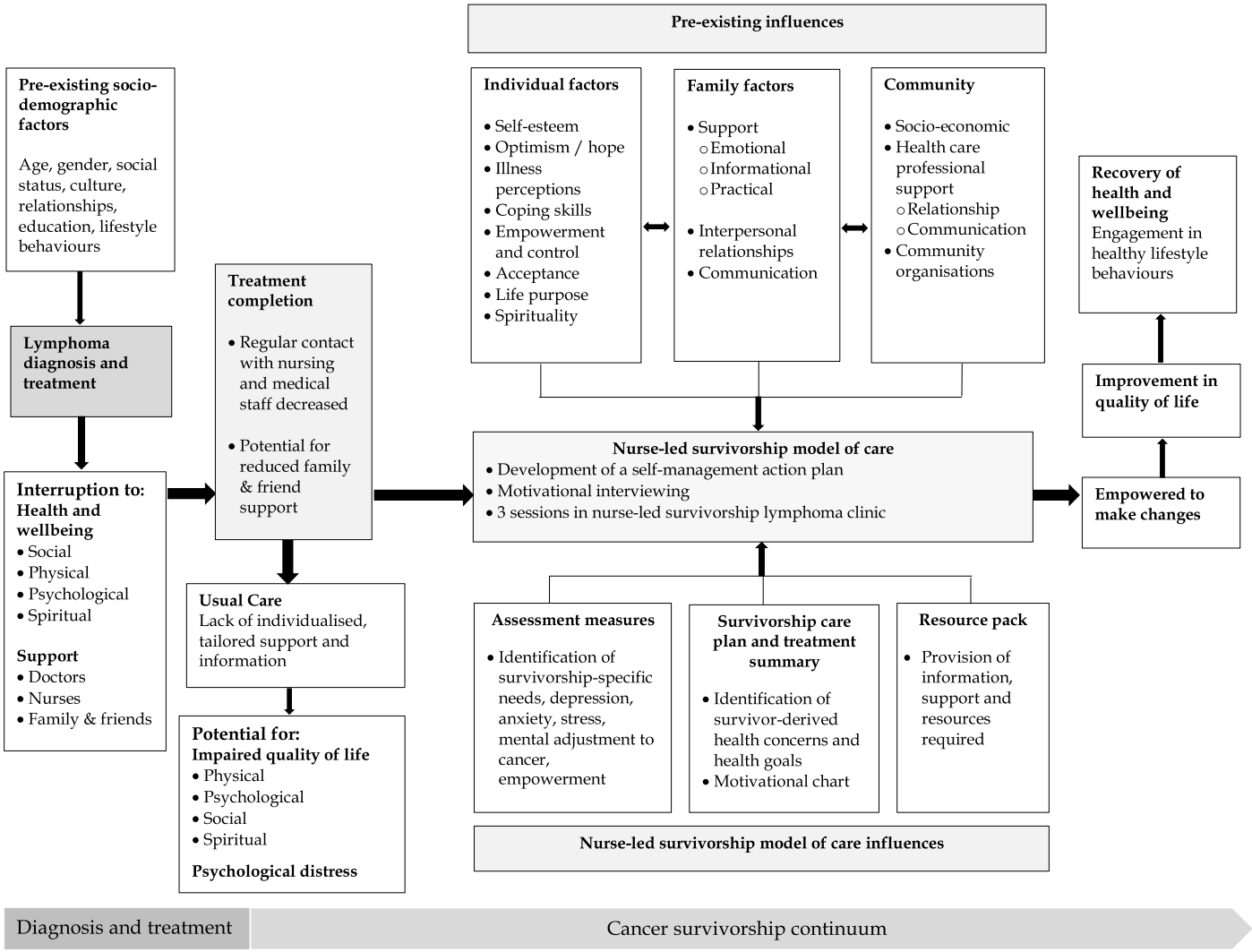


Figure 3.1.1. Conceptual diagram of the nurse-led lymphoma survivorship model of care

Chapter Summary

In summary, the nurse-led model of survivorship care utilised a conceptual model based on self-efficacy and the development of a self-management plan with actions to assist lymphoma survivors to recover their health and well-being and to engage in healthy lifestyle behaviours.

Development of a survivor-centred SCPTS, the identification of assessment measures that would allow survivors to self-report issues and concerns and the assembly of appropriate and targeted resources facilitated lymphoma survivors to transition into the survivorship phase with support. An important element of the conceptual framework of this model of care was to understand the life experiences and factors that were important to the individual before they were diagnosed with lymphoma and how these experiences and factors may have influenced their motivation for self-efficacy and empowerment.

The following chapter of this thesis details the development of the essential elements of the survivorship model of care which were used in the pragmatic RCT.

Chapter Four — Phase Two

"Because you do feel a bit sometimes like you are just treated like a number. Having things individualised helped a lot" Female_NHL

4.0 Intervention Development

The purpose of this chapter is to describe in detail the processes related to the development of a nurse-led lymphoma survivorship model of care. While the following information has been presented using separate headings for clarity, it does not necessarily reflect that development occurred linearly. Development of some components occurred concurrently where necessary. The rationale for concurrent development was to progress the proposed research as expeditiously as possible to meet candidacy and Human Research Ethics Committee (HREC) submission requirements promptly since the estimated time frames required for approval were somewhat lengthy.

This chapter begins with a brief section that describes the haematology survivorship research advisory committee that was initiated to guide the nurse-led lymphoma survivorship model of care. The model of care comprised the following essential components: development of a lymphoma survivorship care plan and treatment summary (SCPTS); assessment measures; and development of a resource pack. These components are described briefly in Chapter Five of this thesis, with more detail given in this chapter to provide clarity on development. Likewise, the final section of the chapter provides detail on the development of the GP evaluation (Phase Four), which is briefly discussed in Chapter Five.

Haematology Survivorship Research Advisory Committee (HSRAC)

This committee was convened in 2014, at the beginning of the research process and comprised academic and clinical health professionals (doctors, nurses and psychologists), a community support group executive and two

consumers who met monthly at the study site for the duration of the study. The committee was guided by Terms of Reference, with the primary aim to provide insight, feedback and guidance on the development of the intervention components for the pragmatic RCT, including inclusion/exclusion criteria, timeframes and recruitment strategies. The opinions of all members were valued, especially those of the consumers who had a unique insight into lymphoma post-treatment follow-up at the study site.

Survivorship Care Plan and Treatment Summary

The unique lymphoma-specific survivorship care plan and treatment summary (SCPTS) developed for this RCT is described in Chapter Five, in the form of a published protocol article (Taylor, Joske, Bulsara, Bulsara, & Monterosso, 2016). However, detail is provided in this chapter regarding how the SCPTS was created.

At the completion of the integrative review on SCPTS, no Australian or international SCPTS were perceived as appropriate for use in the study centre. Therefore, an SCPTS was developed that was more patient-centred and unique to this study cohort. The first full draft comprised two pages of diagnosis and treatment information including chemotherapy drug names and information on administration, dosing, protocol changes and potential long-term and late effects which included recommended follow-up by the GP. This was followed by a page that allowed lymphoma survivors an opportunity to document their health concerns and health goals. Two further pages listed general health screening and healthy lifestyle behaviour information. This draft was presented to the SCGH Haematology Department for review prior to content validation. The draft SCPTS was sent

to health professionals including GPs and consumers to ascertain apparent internal consistency, clarity and reliability. Appendix F.2 contains the validation document that was sent with the SCPTS. All reviewers received the same document to review.

Each item was assessed for:

- Content clarity—whether each item was clearly defined (Yes/No)
- Apparent internal consistency
    - a) whether each item belonged in the SCPTS (Yes/No)
    - b) the general fit with other items (Yes/No)
- Content validity—level of relevance of each item
    - 4-point Likert-type rating scale (1=not relevant to 4=highly relevant).

The content validity index (CVI) (Polit & Beck, 2006) score was generated for each item. "Yes" scores (content, clarity and apparent internal consistency) and scores of 3 or 4 (content validity) were added. The intent of the evaluation was to remove low scoring items and to assess for agreement of greater than 80% per item. A comments section was provided for each item to gain further feedback.

Six consumers completed an evaluation. Results indicated consumers were unsure what late effects meant or what was meant by extra-nodal disease. There was however, overwhelming consensus on the clarity (CVI: .98), the apparent internal consistency (CVI: 100) and relevancy (CVI: .95) of the items. Consumer comments related to the meaning of late effects and made suggestions on the wording of elements of the SCPTS, i.e. 'could it say main aims, not goals?'. Two consumers felt the general lifestyle information should already be known to patients.

Six clinicians completed the evaluation; these included haematology nurses (n=4) and GPs (n=2). Consensus was achieved on clarity (CVI: .99). Apparent internal consistency was slightly lower (CVI: .91), this result was evident from GPs who did not find all the treatment summary information was required, although the result of whether each item generally belonged within the SCPTS was high (CVI of .99). Relevancy of items generated a low result (CVI: .84). This was again attributed to the GPs who indicated all the detailed drug information and disease information was not relevant. Comments reflected that a long treatment summary with information thought more relevant to the haematologist should be removed. One GP commented that it would be inappropriate to ask a patient what their main health concerns would be, this should be specified by the doctor.

One of the evaluated GPs sent the document to other GPs (n=6) for comment. Feedback was emailed to the researcher; however, no evaluation forms were completed. It was unclear what information had been provided on the intent of the SCPTS. All feedback was considered, however not all comments were relevant. Suggestions for inclusion on the SCPTS that were not deemed relevant by the HSRAC were: listing all past medical history; all allergies and adverse reactions not related to treatment; travel immunisation schedules; information on sexually transmitted diseases; contraception advice; stratification of recurrence risk; male and female versions; and doctor-derived concerns not patient-derived. Comments that were relevant included: reducing the treatment summary section and removing the chemotherapy drug lists; giving the general health information to the survivor only (GPs indicated they know this information); and moving the potential late effects section to after the treatment summary section.

A section for haematologists to sign the TS and late effects section was added as research had indicated nurse-led SCPTS might not be valued by GPs (Mor Shalom et al., 2011). Once consensus was reached from HSRAC on changes to the treatment section and the wording of a few items, the final document was a TS (half a page in length) and SCP (one and a half pages in length), with the general health information in a two-page document for survivors (Appendix F.1). The final SCPTS was reviewed and approved by the haematologists at the study site for provision to patients recruited to the trial.

A search of the literature was undertaken for potential late effects that can affect lymphoma survivors. Two documents in chart form were created for NHL and HL late effects, including recommendations for follow-up. These documents were circulated to the SCGH haematologists and radiation oncologists for review and comment. Once approved, they were used when completing potential late effect information on the SCPTS.

Measures

At the completion of the needs assessment systematic review (Taylor & Monterosso, 2016) and in consultation with the HSRAC, four assessment measures were chosen for the pragmatic RCT. These measures were required to ascertain: survivor-specific informational, practical and emotional needs; anxiety, depression and stress; mental adjustment to cancer; and patient empowerment. Copies of the assessment measures are located in Appendix E.2 to E.5.

The needs assessment systematic review (Chapter 2.3) identified the importance of a survivor-specific measure that had been developed with a cohort of survivors including lymphoma survivors. The measure chosen was

the *Short-Form Survivor Unmet Needs Survey (SF-SUNS)*(Campbell et al., 2014). Further information on this measure is found throughout the thesis and particularly in Chapter 6.3.

The prevalence of the symptoms of distress are often overlooked in survivorship research (Holland et al., 2010). Therefore, it was imperative that a measure be found that would allow participants an opportunity to self-report items that encompass distress such as depression, anxiety and stress. Thus, the *Depression Anxiety Stress Scale (DASS21)*(Antony, Bieling, Cox, Enns, & Swinson, 1998; Lovibond & Lovibond, 1995) was chosen for this study. Distress has been defined as a multifactorial disagreeable emotional experience that may interfere with the ability to cope effectively with cancer, and can be psychological, social and/or spiritual in nature (Holland et al., 2010). To improve the identification and management of distress, screening in survivors is essential as many aspects of distress, such as fear of cancer recurrence, uncertainty about the future, loss of health, anger and preoccupation with thoughts around cancer may continue after treatment completion (McCarter et al., 2018). Patient outcomes are improved when distress screening is implemented and interventions provided (Mitchell, 2013), however many research studies that report a lack of benefit with screening are more likely due to a lack of appropriate follow-up for those identified with distress (Meijer et al., 2013). During this study, as items of distress were identified, the appropriate support and resources were offered to the intervention group participants during the study period. For those in the control group, support was offered after they had completed all elements of the study.

Leading on from the selection of the DASS21 to measure components of distress, an assessment measure that has items that are similarly related to

aspects of distress and coping was considered appropriate to gauge a wider view on patient-reported concerns and issues in this area. Therefore the *Mini Mental Adjustment to Cancer Scale (Mini-MAC)* (Watson, Law, & dos Santos, 1994) was selected.

The fourth measure chosen was the *Patient Empowerment Scale (PES)* (Bulsara & Styles, 2013) as it was important to measure the self-reported level of a patient's coping ability and self-efficacy in managing their illness and making decisions about support strategies. Empowerment can be seen as a proactive strategy in acknowledging what an individual feels they can control, and equally importantly, what lies outside of their control (Bulsara & Styles, 2013). This was meaningful for the study as the SCPTS involved participant-derived aspects. Consequently, it was important to assess the level of a participant's empowerment, especially when they would be encouraged to seek out support and information for themselves as required.

Assessment measures would be posted to those randomised to the control group after baseline; therefore, a letter was created to remind them about the study and to encourage them to complete and return the assessment measures. (Appendix G).

Resource Pack

A resource pack was developed after consideration of the evidence (reported haematology survivor unmet needs and concerns) from the integrative reviews undertaken in Phase One. The information assembled for dissemination to the intervention group participants needed to address anticipated participant-identified unmet needs, likely post-treatment physical and emotional concerns, and to encourage optimal participant

involvement in healthy lifestyle behaviours. Information currently in use by established cancer support sources such as the Cancer Council Australia and the various state-based Cancer Council websites were assessed. Standardised Australian Government information (as referenced below) was likewise obtained. Where information was insufficient or not targeted to the lymphoma cohort, the researcher adapted the information using a variety of credible cancer sources including Australian, North American and United Kingdom oncology websites.

All participants were offered the following booklets and information sheets:

- *Living Well After Cancer* (Bell & Fagan, 2015)
- *Exercise for People Living with Cancer* (Bruce, 2016)
- New insurance policies (Cancer Council Western Australia, 2016)
- Australian Guide to Healthy Eating (Australian Government, 2015)
- Coping with fear of recurrence (American Society of Clinical Oncology, 2015)
- Coping with cancer fatigue (Cancer Council Victoria, 2015)
- Coping with memory and concentration impairment (developed by the researcher)
- Cancer survivor exercise program (Edith Cowan University, 2015)
- Cancer Council WA "Life Now" information and dates (Cancer Council Western Australia, 2015–2017)
    - A programme of supportive care activities such as exercise, yoga, meditation for any person who has or had cancer

Targeted information was offered based on responses to the baseline measures or requested from the participant at the first NLSC appointment. This could include the following booklets and/or information sheets:

- "*Cancer and Your Finances*" (Bruce, 2015)

- "*Sexuality, Intimacy and Cancer*" (Bruce, 2016)
- Rekindle study information, University of Sydney, Australia
    - This was a study to test an online resource to promote sexual well-being for patients and partners. Once recruitment closed in 2016 this information was no longer offered.
- Cancer Council Pro Bono programs (legal, financial and workplace advisory) (Cancer Council Australia, 2015)
- Information on insurance and countries with reciprocal health care agreements with Australia (developed by the researcher)
- Quit smoking (Cancer Council, 2016)
- Motivational chart (developed by the researcher)
- Mental Health Plan information (Australian Government, 2015)
- Canteen (CanTeen, 2015)
    - A support group to help young people (12–25 years) cope with cancer in their family, or their own cancer
- Centrelink (Australian Government, 2015)
    - An Australian Government department delivering social and health payments and services.

A checklist was created of resources and information given to the intervention participants throughout the study period (Appendix J.1).

General Practitioner (GP) Evaluation

The completed SCPTS was given to all intervention participants and sent to GPs. Participants were encouraged to share this document with future health professionals and discuss with their GP during the trial. It was important therefore to gain an understanding of the thoughts and perceptions of GPs who received the SCPTS. This was to gauge the use and usefulness of the document.

An evaluation based on the proposed SCPTS was developed. Advice on the document was sought from the GP on the HSRAC to make the evaluation targeted and succinct and to ensure that the cover letters to accompany the evaluation and SCPTS similarly were clear and concise. The final evaluation was one and a half pages in length and was checked by a GP researcher from the University of Melbourne, not involved in the research. His comments indicated the size and content was appropriate to gain the information required.

The evaluation collected a small amount of demographic information: years working as a GP; gender; and if the intervention participant had been seen in the last six months. The first section of the evaluation comprised 'yes/no/not applicable' questions related to the SCPTS, receipt and discussions (7 items). The next section rated elements of the SCPTS and used a Likert-type scale: 1=very poor; 2=poor; 3=adequate; 4=good; 5=very good (4 items). Five open questions followed and ascertained if: further information was required; information did not belong on the SCPTS; any general comments; further haematology education required; and the preferred format for education. The final evaluation form is found in Appendix H.

The GP cover letters were each one page in length. The introductory cover letter was attached to the initial posting of the SCPTS after the intervention participant had completed the first NLSC intervention appointment. The content gave a brief overview of their patient's involvement in the RCT and the intent of the SCPTS. Any urgent clinic concerns were directed to the haematology department at the study site (SCGH). As previously described GP input had indicated a listing of chemotherapy drug names was not required, therefore a link to EviQ (an Australian evidence-based cancer treatment protocols and information website for health professionals) with

username and password were included if GPs wanted to look drug information up for themselves. The subsequent cover letter was attached with the evaluation and a further copy of the SCPTS to remind the GP their patient had participated in an RCT and to ask if they would complete an evaluation. Both cover letters are found in Appendix H.

Chapter Summary

In summary, a number of important elements were developed that guided the thesis and the components that would be tested in the pragmatic RCT. A unique lymphoma-specific SCPTS was developed. However, it was important to ensure the content validity of the SCPTS items prior to use in the pragmatic RCT. Likewise, it was important the haematologists were confident that evidence-based late effects information and recommendations were going to be given to their patients. In addition, this chapter discussed the assessment measures chosen and the resource pack that was developed. Furthermore, the creation of an evaluation of the SCPTS by GPs has been detailed in this chapter as only condensed detail was provided in Chapter Five, methodology and Chapter Six, pragmatic RCT results.

The following methodology chapter of this thesis is in the format of the protocol journal article that was published in the *British Medical Journal Open*, and which provides a complete overview of the pragmatic RCT.

Chapter Five — Methodology

"A bit more confidence to go ahead in the future" Female_HL

5.0 Protocol and Methods

The protocol and methods used to conduct Phase Three and Four of this thesis are represented by the manuscript published in the *British Journal of Medicine Open* access in 2016. This manuscript has been reproduced here, and the complete PDF version is in Appendix A.4. A detailed discussion was limited by the journal word count requirement. Therefore, further details are in Chapter Four.

Open Access Protocol

BMJ Open

Protocol for Care After Lymphoma (CALy) trial: a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care

Karen Taylor,[1,2] David Joske,[3,4] Max Bulsara,[5] Caroline Bulsara,[2] Leanne Monterosso[2,6,7]

To cite: Taylor K, Joske D, Bulsara M, *et al*. Protocol for Care After Lymphoma (CALy) trial: a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *BMJ Open* 2016;**6**:e010817. doi:10.1136/bmjopen-2015-010817

► Prepublication history for this paper is available online. To view these files please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2015-010817).

Received 16 December 2015
Revised 23 March 2016
Accepted 28 April 2016

For numbered affiliations see end of article.

Correspondence to
Karen Taylor;
Karen.Taylor@health.wa.gov.au

ABSTRACT

Introduction: Lymphoma is the sixth most common cancer diagnosed in Australia and internationally. Owing to the aggressive nature of the disease and intensity of treatment, survivors face long-term effects that impact on quality of life. Current models of follow-up post-treatment fail to address these complex issues. Given that 74% of patients with lymphoma cancer now survive 5 years beyond diagnosis and treatment, it is important to address this gap in care.

Aim: To determine self-reported informational and practical needs, anxiety, depression, stress, coping and empowerment at baseline, 3 and 6 months.

Methods and analysis: A pilot randomised controlled trial will test the effect of a nurse-led lymphoma survivorship clinic compared with usual post-treatment care at a large tertiary cancer centre in Western Australia. The intervention will comprise three face-to-face appointments with delivery of tailored resources, a survivorship care plan and treatment summary (SCP TS). The SCP TS will be given to the participant and general practitioner (GP). Intervention participants will be interviewed at completion to explore the perceived value of the intervention components and preferred dose. An evaluation developed for GPs will assess receipt and use of SCP TS. The primary intent of analysis will be to address the feasibility of a larger trial and requisite effect and sample size.

Ethics and dissemination: Ethics approval has been granted by the University of Notre Dame Australia and Sir Charles Gairdner Hospital in Western Australia. Peer-reviewed publications and conference presentations will report the results of this phase II trial.

Trial registration number: ANZCTRN126150005 30527; Pre-results.

Strengths and limitations of this study

- This is the first randomised controlled trial of a nurse-led model of survivorship care for patients completing treatment for lymphoma cancer in Western Australia.
- This trial will test a developed lymphoma-specific survivorship care plan and treatment summary.
- As a pilot study, it is designed to provide preliminary data on the efficacy and feasibility of a nurse-led survivorship intervention for the purposes of planning a phase III study.

INTRODUCTION

Lymphoma is a general term for over 20 blood cancers that originate from T and B cells in the lymphatic system[1] where lymphocytes undergo a malignant change and multiple uncontrollably. Lymphomas, when combined, represent the sixth most commonly diagnosed cancer worldwide,[2] with Hodgkin's lymphoma (HL) and non-Hodgkin's lymphoma (NHL) the two main forms. HL represents 11.5% of all lymphomas and is the third most common cancer in the adolescent and young adult population.[1] With the exception of HL, incidence increases with age; thus, NHL is predominantly a cancer of the older population (over 65 years).[1 3]

The incidence of lymphoma in Australia is increasing, with a projected diagnosis of 5680 cases in 2015. This will equate to 4.5% of all cancer cases.[4] In Australia, the overall survival rate has improved, and ~74% of people diagnosed with lymphoma are reported as being alive at 5 years compared with 49% in the 1980s.[4] Despite these encouraging results,[5] this group of cancers remain understudied and subsequently under-represented in survivorship care.[6]

Lymphoma treatment regimens commonly involve aggressive high-dose chemotherapy and/or targeted therapy agents, radiotherapy

Protocol for Care After Lymphoma (CALy) Trial: A Phase II Pilot Randomised Controlled Trial of a Lymphoma Nurse-led Model of Survivorship Care.

Abstract

Introduction: Lymphoma is the sixth most common cancer diagnosed in Australia and internationally. Due to the aggressive nature of the disease and intensity of treatment, survivors face long-term effects that impact on quality of life. Current models of follow-up post-treatment fail to address these complex issues. Given that 74% of lymphoma cancer patients now survive five years beyond diagnosis and treatment, it is important to address this gap in care.

Aim: To determine self-reported informational and practical needs, anxiety, depression, stress, coping and empowerment at baseline, three and six months.

Methods and Analysis: A pilot randomised controlled trial will test the effect of a nurse-led lymphoma survivorship clinic compared with usual post-treatment care at a large tertiary cancer centre in Western Australia. The intervention will comprise three face-to-face appointments with delivery of tailored resources, a survivorship care plan and treatment summary (SCPTS). The SCPTS will be given to the participant and general practitioner. Intervention participants will be interviewed at completion to explore the perceived value of the intervention components and preferred dose.

An evaluation developed for GPs will assess receipt and use of SCPTS. The primary intent of analysis will be to address the feasibility of a larger trial and requisite effect and sample size.

Ethics and Dissemination: Ethics approval has been granted by the University of Notre Dame Australia and Sir Charles Gairdner Hospital in Western Australia. Peer-reviewed publications and conference presentations will report the results of this phase II trial.

Trial Registration: Australian New Zealand Clinical Trial Registry ANZCTRN12615000530527.

Introduction

Lymphoma is a general term for over 20 blood cancers that originate from T and B cells in the lymphatic system (American Cancer Society, 2014), where lymphocytes undergo a malignant change and multiply uncontrollably. Lymphomas, when combined, represent the sixth most commonly diagnosed cancer worldwide (Surveillance Epidemiology and End Results (SEER), 2014), with Hodgkin (HL) and non-Hodgkin lymphoma (NHL) the two main forms. Hodgkin lymphoma represents 11.5% of all lymphomas and is the third most common cancer in the adolescent and young adult population (American Cancer Society, 2014). With the exception of Hodgkin lymphoma, incidence increases with age, thus non-Hodgkin lymphoma is predominantly a cancer of the older population (over 65 years) (American Cancer Society, 2014; Quaresma, Coleman, & Rachet, 2015).

The incidence of lymphoma in Australia is increasing, with a projected diagnosis of 5680 cases in 2015. This will equate to 4.5% of all cancer cases

(Australian Institute of Health and Welfare, 2014). In Australia, the overall survival rate has improved and approximately 74% of people diagnosed with lymphoma are reported as being alive at 5 years compared with 49% in the 1980s (Australian Institute of Health and Welfare, 2014). Despite these encouraging results (Sant et al., 2014), this group of cancers remain under-studied and subsequently under-represented in survivorship care (Swash et al., 2014).

Lymphoma treatment regimens commonly involve aggressive high dose chemotherapy and/or targeted therapy agents, radiotherapy and haematopoietic stem cell transplants (Carey et al., 2012). Such treatments result in distressing long-term and late physical, practical and psychosocial effects, which can produce ongoing unmet needs. These needs relate to physical and psychosocial impacts such as: fear of recurrence; fatigue; poor nutrition; exercise; fertility; relationship; financial; employment; and insurance issues (Taylor et al., 2015). Furthermore, these patients commonly experience related health problems earlier than the general population (Panek-Hudson, 2013) and are at risk of specific late effects. Cardiovascular disease is particularly pertinent in this cohort due to chemotherapy combinations and cumulative dosing (Aleman et al., 2007; Ng et al., 2011) as well as mediastinal radiotherapy (Travis et al., 2012; van Leeuwen-Segarceanu et al., 2011). Patient health and lifestyle behaviours, for example smoking, likewise have an effect on disease development (Ng et al., 2011). Lymphoma patients have an increased relative risk of second cancers, higher when diagnosed at a younger age (Grinyer, 2010; Hemminki et al., 2008) and further elevated when treatment includes radiotherapy (Ng et al., 2011; Travis et al., 2012). The potential for the development of bone marrow disease is greater in the first decade, however unlike second cancer risk, this decreases and then plateaus in the second decade (Ng et al., 2011). Patients

who require a haematopoietic stem cell transplant have additional transplant related late effects risks (Bishop et al., 2010; Choi et al., 2008). Although patients may be unable to modify some late effect risks, awareness of relevant potential late effects may ensure timely follow-up for symptomology (Ng et al., 2011).

The traditional model of haematological cancer care follow-up has largely been haematologist-led within the acute hospital setting (Taylor et al, 2015). Information at treatment completion is often inadequate (Dicicco-Bloom & Cunningham, 2013; McCabe & Jacobs, 2012), with a lack of clear guidelines for the ongoing management of survivors (Phillips & Currow, 2010). This has led to an emerging focus on redesigning survivorship follow-up care and delivery.

Lobb et al. (2009) demonstrated patient-reported needs amongst Western Australian haematological cancer survivors (n=66) not addressed during routine follow-up post-treatment completion and thereby classified as unmet needs. Almost two thirds of respondents (59%) would have found it helpful to talk with a health professional at treatment completion. A recent qualitative study conducted by the authors with lymphoma and leukaemia cancer survivors (n=19) in Western Australia (Monterosso et al., 2015) found unmet needs relating to information, practical support, coping strategies and transitioning from active treatment into the survivorship phase. Findings suggested that tailored, end of treatment interventions should form a key component of survivorship care. Participants suggested a cancer coordinator nurse as an important element to initiate and transition patients into the survivorship phase.

Nurse-led models of care have demonstrated potentially satisfactory outcomes (Gates et al., 2015; Howell et al., 2012; John & Armes, 2013) and are

proposed as an acceptable pathway to transition into the survivorship phase (Cooper et al., 2010). A dedicated nurse-led survivorship clinic to administer patient-centred survivor-specific needs assessments is an important aspect of survivorship care to address patient concerns and empowering survivors to manage their own health and ongoing symptoms (Fitch, 2008; Ganz et al., 2008; McDowell et al., 2010; Stricker et al., 2011).

Empowering patients enables them to become more responsible for the management of their own health and well-being and can contribute to the influence and control patients have over their own health which has the advantage of improving quality of life (Bodenheimer et al., 2002; Kuijpers et al., 2013). Bandura's theory of self-efficacy (Bandura, 1977), the principal concept in self-management education, teaches patients to identify their problems and provides skills in decision making and developing an appropriate action plan (Bodenheimer et al., 2002). It is anticipated that increasing empowerment and providing healthy lifestyle resources will result in a reduction in the patient perceived need for support from the health care system (Bodenheimer et al., 2002).

Survivorship care plans (SCPs) and treatment summaries (TS) have been recommended as facilitators to deliver holistic survivorship follow-up care by: the Institute of Medicine (Palmer et al., 2014); the American Society of Clinical Oncology (McCabe, Bhatia, et al., 2013); the UK National Cancer Survivorship Initiative (MacMillan Cancer Support & NHS Improvement, 2010); and the proposed Clinical Oncology Society of Australia survivorship guidelines (Clinical Oncology Society of Australia, 2014). A personalised SCP would guide follow-up care by including recommendations, information and resources for surveillance, screening of potential long-term and late effects, and health promoting behaviours (Taylor & Monterosso, 2015). The TS

would comprehensively summarise information on diagnosis and treatments (Hausman et al., 2011; Jabson & Bowen, 2013). Cancer nurses have established expertise in the areas of health promotion, information, support and resource provision (Jackson et al., 2013), and therefore can develop and disseminate SCPs and TS to facilitate communication between the survivor, specialist and primary care.

Aim

The aim of the Care After Lymphoma (CALy) study is to develop and empirically test an evidence-based nurse-led lymphoma survivorship clinic to transition participants into the survivorship phase, using a pilot randomised controlled trial (RCT) design. This phase II trial of an intervention is aimed at reducing the immediate and long-term physical and psychosocial consequences of haematological cancer treatment and to enable the participant to return to normal functioning sooner. The nurse-led lymphoma survivorship clinic has three core components: 1) needs assessments to determine individual informational or practical issues or concerns; 2) provision of a tailored SCPTS to enhance communication between the participant and all other health professionals with whom the patient has contact post-treatment; and 3) provision of individualised evidence-based education, information and resources to address patient-reported needs, likely post-treatment physical and emotional concerns and maximising participant involvement in healthy lifestyle behaviours. The aims are aligned with the Australian national research priority for preventative healthcare to reduce comorbid diseases in cancer survivors.

The Medical Research Council framework for the development and evaluation of complex interventions has guided the development of this trial

(Campbell et al., 2007; Medical Research Council, 2000). The evaluation of a model for nurse-led evidence-based survivorship care will provide level II baseline data to: endorse the suitability of outcome measures; establish acceptability of the intervention and randomisation; provide recruitment and attrition rates; support hypothesis development; and calculate sample sizes for future phase III multisite randomised controlled trials. In addition, it will add psychometric information on the Short-Form Survivor Unmet Needs Survey (SF-SUNS) and will provide data on a test–retest analysis.

Research Questions

The following research questions guide this pilot RCT:

1. Do participants assigned to the nurse-led lymphoma survivorship clinic demonstrate a reduction in perceived unmet informational and practical needs compared with those randomly assigned to usual care?
2. Do participants assigned to the nurse-led lymphoma survivorship clinic demonstrate a reduction in self-reported anxiety, depression and stress and an increase in patient self-management behaviours compared with participants randomly assigned to usual care?
3. What is the perceived efficacy and value of the nurse-led lymphoma survivorship clinic from the perspective of a subset of survivors in the intervention group?
4. To what extent does the provision of a SCPTS to GPs improve the communication between the treating hospital, GP and the participant?
5. Does the Short-Form Survivor Unmet Needs Survey (SF-SUNS) demonstrate stability and reliability over time?

Methods

Design

The evidence to support the development of this phase II CALy trial comprised a qualitative study using a focus group methodology with lymphoma, leukaemia and multiple myeloma survivors (Monterosso et al., 2015). The evidence also encompassed three systematic reviews regarding: models of haematological survivorship care; survivorship care plans and treatment summaries in haematological cancer patients; and tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors (Taylor et al., 2015; Taylor & Monterosso, 2015; Taylor & Monterosso, 2016). Information gained from this preliminary work guided the intervention components to be developed and the operationalisation of the feasibility and acceptability of a nurse-led RCT.

The randomised controlled trial framework has been developed using the Consolidated Standards of Reporting Trials (CONSORT) statement and checklist (Moher et al., 2010; Schulz, Altman, & Moher, 2010). Outcomes will be measured using validated needs assessment instruments. Reporting will include: inclusion and exclusion criteria; missing data; drop out; and early closure of the trial if required (Figure 5.1.1). The survivorship cancer nurse coordinator (CNC) is a specialist cancer nurse with an extensive haematology nursing background and formal counselling qualifications, including motivational interview techniques.

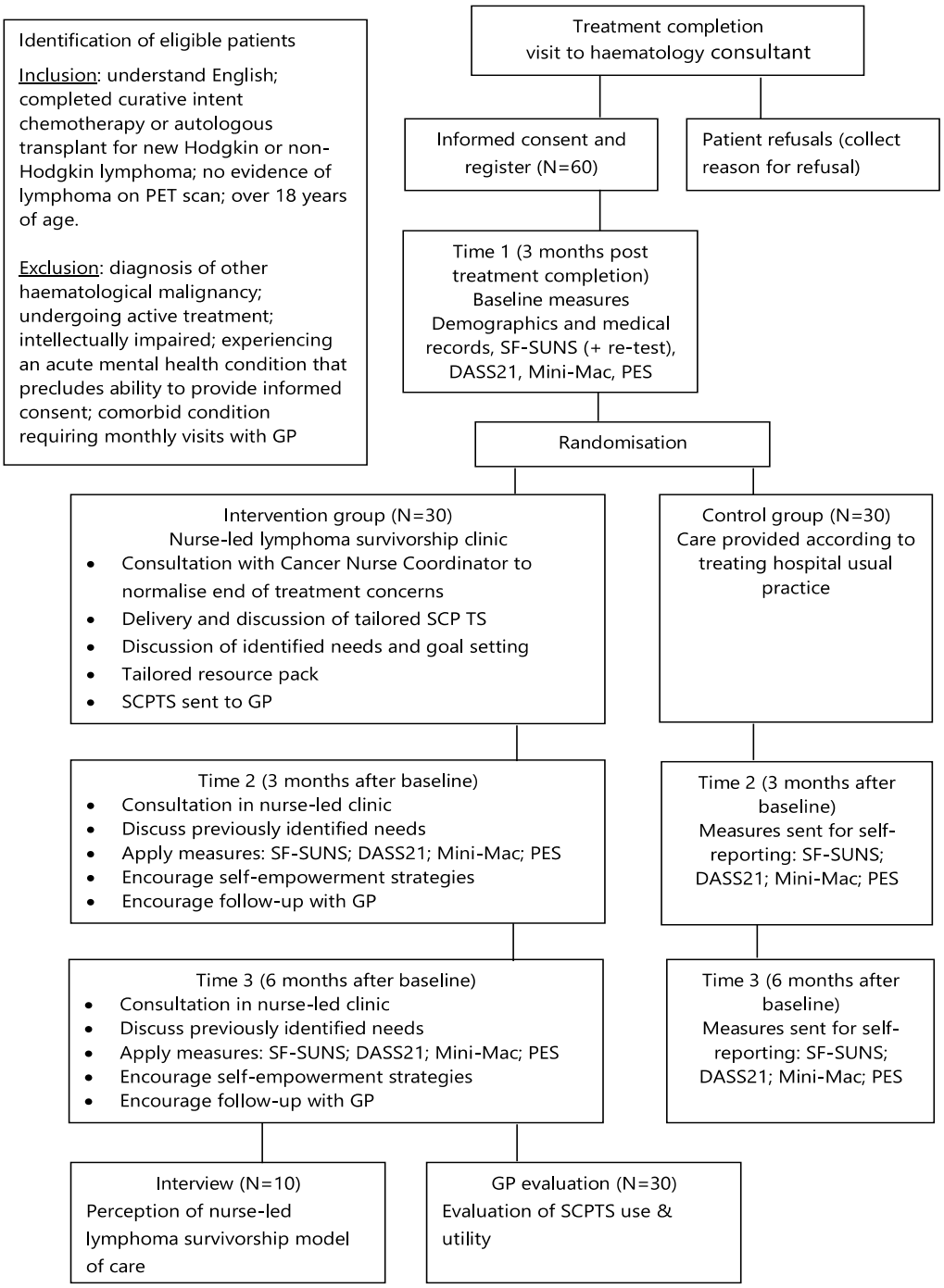


Figure 5.1.1. Trial flow chart.

Population and setting

A convenience sample of lymphoma cancer patients from a specialised haematology department in a comprehensive cancer centre of a large acute tertiary hospital in Perth, Western Australia, will be used. Follow-up by a haematologist occurs every three months for the first 12 months. The nurse-led survivorship clinic intervention will be an additional care activity to the medical haematology follow-up and will involve three appointments over six months. It will commence at three months post-treatment completion and cease at nine months post-treatment.

Inclusion criteria

1. Pathologically confirmed new diagnosis of Hodgkin or non-Hodgkin lymphoma.
2. Completed first-line curative-intent chemotherapy or second-line curative-intent autologous stem cell transplant within the previous three months.
3. No evidence of lymphoma disease on mid-treatment interim PET scan or post-treatment PET scan where these are performed.
4. Able to understand and read English.
5. Over 18 years of age.

Exclusion criteria

1. Diagnosis of other haematological malignancy or an incurable lymphoma.
2. Did not undergo chemotherapy.
3. Further treatment and follow-up at another hospital.
4. Intellectually impaired or experiencing an acute mental health condition that precludes the ability to provide informed consent.
5. Comorbid condition requiring monthly visits with GP.

To measure selection bias, minimal data will be completed on eligible participants who decline to participate. Reasons for refusal will be recorded to gain valuable information for future research.

Recruitment

Identification of eligible participants will be undertaken by haematology clinicians who will provide details to the survivorship cancer nurse coordinator. Ongoing education of clinicians (haematologists and nurses) regarding all aspects of the study, its progress and recruitment will facilitate cooperation and support. Eligible participants will be met after treatment completion by the CNC who will discuss the study and provide a Participant Information and Consent Form (PICF). Consenting participants randomised to the intervention group (n=30) will be offered the opportunity to consent to a qualitative interview at completion of all time points. Approximately one third of participants (n=10) will be required for this phase. Participant's names and contact details will be entered onto a master-coding sheet and assigned a numerical identifier code after randomisation.

Survivorship Care Plan (SCP) and Treatment Summary (TS)

An extensive review of the literature (Taylor & Monterosso, 2015) and available survivorship care plans and treatment summaries was undertaken. Many institutions in Australia are utilising USA based templates that are large (up to 20 pages), not tailored to the individual and provide resources that are not contextualised to the Australian healthcare setting. Therefore, we developed a lymphoma SCPTS in collaboration with a haematology consultant, GP and other multidisciplinary team members (e.g. consumers, psychologist, cancer nurses, and academic cancer researchers). This has been created as a word document template to be filled in by the nurse. The

perspectives of lymphoma survivors (n=6) and clinicians (including GPs) (n=6) were sought to determine the relevance of the proposed SCPTS items. Each item was assessed for content and apparent internal consistency (whether items should be included and the general fit with other items) using either yes or no responses to the items. Content validity utilised a rating scale (1=not relevant to 4=highly relevant). The content validity index (CVI) (Polit & Beck, 2006) was generated for each item by adding the number of "yes" scores (content, clarity and apparent internal consistency) and scores of 3 or 4 (content validity). The mean CVI consumer results were as follows: clarity 0.98; apparent internal consistency 100; content validity 0.95. Consumers demonstrated complete agreement of 1.0 for internal consistency items. The mean CVI clinician results were as follows: clarity 0.99; apparent internal consistency 0.95; content validity 0.84. Feedback in the comments section of the evaluation interestingly indicated GPs did not value or require a large treatment summary document. Consensus of the research team was reached for the TS (half a page in length) and SCP (one and a half pages in length).

The TS is completed using existing medical record information such as: diagnosis; treatment; complications; and use of allied health providers. The first section of the SCP includes a table for the inclusion of individualised potential late effects. This table comprises: the late effect; information for the GP about tests or follow-up required and when; and the symptomology the participant needs to be aware of, with encouragement to follow these up with the GP. Prior to recruitment a comprehensive list of potential late effects and follow-up required was developed for each lymphoma type using available published literature and guidelines (KT). This list was circulated, discussed and amended by the haematologists who were aware these would be used to guide their population of the table. Tailored individualised

potential late effects will be documented based on treatments administered, participant's demographics and health characteristics. Once the TS and this aspect of the SCP are completed it will be emailed to the haematologist for final approval. Once amendments (if any) are made the haematologist signs the TS. The second page of the SCP is patient-centred and populated by the nurse in consultation with the participant. Participants will be asked to identify three main concerns, health goals and proposed actions to achieve these goals.

Sample size

The calculation of a sample size is not required for pilot RCTs as effect size is not yet known. Rather the purpose of the pilot is to determine variability in measures from which effect sizes can be calculated. Approximately 75 patients are seen per year at the study setting; however, this figure is inclusive of new and existing patients. Therefore, a consecutive sample of 60 participants will be recruited and randomised 1:1 to either control or intervention group (30 participants are expected in each group). It is necessary to establish test–retest reliability for the SF-SUNS by demonstrating a minimum intraclass correlation (ICC) of 0.8. Therefore, a sample size of 39 (rounded up to 40 participants) administered on two consecutive occasions no more than five days apart (baseline and 5 days later) is required to achieve 80% power to detect this ICC of 0.8 (Walter, Eliasziw, & Donner, 1998).

Patient-reported outcome measures

A review of the literature (Taylor & Monterosso, 2016) has resulted in four assessment instruments being selected to measure the outcomes proposed: *Short-Form Survivor Unmet Needs Survey (SF-SUNS); Depression Anxiety Stress Scale (DASS21); Mini Mental Adjustment to Cancer Scale (Mini-MAC);* and

Patient Empowerment Scale (PES). These instruments have demonstrated reliability and validity with haematological cancer survivors as shown in Table 5.1.1.

Table 5.1.1 Outcomes Assessment Instruments

Instrument	**Use**	**Items and Factors**	**Internal Consistency**	**Additional Issues**
Short-Form Survivor Unmet Needs Survey (SF-SUNS) (Campbell et al., 2014)	Developed for cancer survivors to assess unmet needs. Assess the gap between patient self-reported concerns and the level of support they require Discriminates between survivors at different stages post-treatment completion	30 items—0 (no unmet need) to 4 (very high unmet need) Four factors: information (3 items); financial concerns (8 items); access and continuity of care (6 items); relationships and emotional health (13 items)	Cronbach's alpha scores for all domains were ≥ 0.85 ICC across all domains high i.e. ≥0.9 indicating SF-SUNS reliably measured the level of unmet need	Test–retest reliability not established Will be undertaken during this study
Depression Anxiety Stress Scale (DASS-21) (Lovibond & Lovibond, 1995)	Measures multiple dimensions of depression, anxiety and stress	Three 7 item scales—0 (did not apply to me at all) to 3 (applied to me very much, or most of the time) 5 severity ratings: normal; mild; moderate; severe; and	Cronbach's alpha subscales scores were: 0.94 depression; 0.87 anxiety; and 0.91 for stress (Antony et al., 1998)	Used to support SUNS psychometric properties in haematology cancer survivors

		extremely severe		
Mini Mental Adjustment to Cancer Scale (Mini-MAC) (Boyes, Girgis, D'Este, & Zucca, 2011)	Measures cancer-specific coping strategies	29-item—5 cancer-specific coping strategies: helplessness-hopelessness (8 items); anxious preoccupation (8 items); fighting spirit (4 items); cognitive avoidance (4 items); and fatalism (5 items). Scale—1 (Definitely does not apply to me) to 4 (definitely applies to me)	Reliability using Cronbach's alpha coefficients for each subscale ranged from 0.62–0.88	Used with small sample of haematology cancer survivors
Patient Empowerment Scale (PES) (Bulsara & Styles, 2013)	Measures level of patient's coping ability and self-efficacy in terms of managing their illness and making decisions about support strategies	15-item 4-point Likert-type scale	A high degree of reliability has been established using the Rasch Extended Model with the Person Separation Index of 0.926	Used in haematology / oncology patients

Note: Cronbach's alpha is considered a measure of scale reliability and a high score indicates good internal consistency reliability of the test.

Baseline data collection

Baseline data collection from consenting participants will occur three months after treatment completion. All participants will self-report demographic information and complete the four assessment instruments. In addition, they will receive a second SF-SUNS instrument to complete no later than five days after the baseline testing. These will be returned via a reply-paid envelope to allow the researchers to undertake test–retest reliability testing. Medical demographic information obtained will include: type of haematological cancer; stage of disease; type of treatment received (chemotherapy, immunotherapy, radiotherapy); date of diagnosis; time since diagnosis; treatment complications or dose modifications; and comorbidities. Personal demographic information collected will include: sex; age; marital status; age of children (if any); postcode; occupation; income level; education level; health behaviours such as smoking, alcohol consumption and weight.

Randomisation

After baseline assessment participants will be randomised to either the current standard of care or intervention group. Computer generated random numbers using a four-digit sequence have been generated and linked to group allocation by an independent statistician. An independent member of the research team, to ensure confidentiality and offset bias in randomisation, has sealed a hard copy of each individual number and group in an opaque envelope. The envelopes are consecutively numbered and will be distributed to consenting participants in this order. Control group participants will be made aware that another researcher will follow-up non-questionnaire return with a telephone call to the participant after two weeks.

Control group

Control group participants will receive follow-up care as per haematologists' usual practice. At three and six months after baseline, the same four assessment instruments will be sent to the participant and they will self-report any issues or unmet supportive care needs. An addressed reply-paid envelope will be provided to return assessments. Participants who score high unmet needs will be encouraged to discuss these with their haematologist at their usual follow-up appointment.

Intervention group

Following baseline data collection, intervention group participants will have an appointment at the nurse-led lymphoma survivorship clinic. The first page of the SCPTS will be populated prior to this appointment. At the first nurse-led lymphoma survivorship clinic, any concerns the participant has regarding the end of treatment will be discussed and normalised. The nurse will discuss the TS and potential late effects. The second page of the SCP will be completed by the nurse using an electronic template in collaboration with the participant. At this time the importance of follow-up recommendations will be emphasised. The SCP will then be printed, signed and dated by the participant and the nurse. The completed SCPTS will then be copied, with the original given to the participant, a copy placed in the participant's medical records, and a copy sent to their GP. Motivational interviewing techniques will be employed for healthy lifestyle behaviours and to assess for readiness to make behavioural change. Participants will be encouraged to identify and explore behaviours they would like to modify using a chart that enables them to list likes and dislikes of specific behaviours and potential impacts of perceived behavioural change. By listening to concerns, highlighting conflicts arising from behaviour and documenting on the chart will potentially enable participants to assume control of decision making

related to behavioural change. Participants will be encouraged to set realistic timeframes and identify habits and beliefs that may possibly be hindering change. Tailored evidenced-based information and advice in a resource pack will then be issued. It is anticipated that a consultation of 60 minutes will be required in a private clinic room.

A further two appointments will be made at three and six months after baseline, where the same four assessment instruments will be completed by the participant and they will self-report any issues or unmet supportive care needs. These will be discussed and the appropriate resources support and information provided. Participants will be encouraged to discuss their health concerns, goals and progress with any action they may have taken. Participants will be asked if they have seen their GP in the last three months and if they took the SCPTS and discussed any of the late effects screening recommendations, their participant-identified concerns or goals. This will aid the transition to GP follow-up where the benefits of shared care will be explained. A checklist for each participant of the resources provided will be kept.

Data Analysis

Quantitative data will be analysed using univariate and multivariate statistical techniques with SPSS data analysis software. Descriptive statistics will be used to analyse the demographic variables collected. Responses to the SF-SUNS, DASS21, Mini-MAC and PES will be scored according to the algorithms in the instrument manuals. Measures from all instruments will be checked for normal variance within the two groups. Within each group, paired t-test comparisons will be made between baseline measurements and at each time point: baseline; three months; six months. Differences between

intervention and control groups will then be assessed at each time point. Test–retest reliability using ICC will be undertaken on the SF-SUNS instrument. The minimum ICC value required for this scale is 0.8. Participants who drop out or are lost to follow up or need to be excluded after commencement will be accounted for by intention to treat analyses. Confidence intervals will reflect the contrast between groups to show treatment effect. Missing data, incomplete answers and non-response will be recorded.

Qualitative interviews

Supplementary in-depth semi-structured interviews will occur with approximately 10 consenting participants when they have completed all intervention components (after six months). This number will allow for saturation of themes (Crouch & McKenzie, 2006; Onwuegbuzie & Leech, 2007; Sandelowski, 1995). Telephone interviews will be digitally recorded and undertaken by an independent researcher to ensure participants are given the opportunity to freely express both positive and negative perceptions of their experience. The use of a qualitative approach will provide depth of information regarding the personal impact of the nurse-led lymphoma survivorship clinic on the participant. The interviews will also highlight any issues or challenges for this group that could be better addressed in the future.

Interviews will be transcribed verbatim and thematic analysis used to determine themes and patterns within the text (Grbich, 1998; Patton, 2014; Smith, 2007). QSR NVivo qualitative analysis data management software will be used to manage interview data.

GP evaluations

A non-validated evaluation will be sent to GPs who have received the SCPTS. This was developed in consultation with a GP and will ascertain if GPs made use of the SCPTS and to elicit perceptions of the value and effectiveness of this document in facilitating communication between the treating hospital and GP, and GP and participant. This will guide future refinement of the SCPTS. Analysis will utilise descriptive statistics and distribution analysis techniques. Open-ended questions will utilise content analysis techniques. GPs will be called by the researcher after two weeks for non-return of the questionnaire to remind them to fill in and return the evaluation in the reply-paid envelope.

Discussion

A significant culture change is required for providers to recognise survivorship care as a standard component of quality cancer care that involves all health professionals, participants and families. The gap in knowledge contributes to a current model of survivorship care that is fragmented, with inadequate service provision at treatment completion, leading to unmet needs along the survivorship continuum (De Leeuw & Larsson, 2013). The cancer specialist is not necessarily required for routine screening and follow-up. However, the involvement of other health professionals, including primary care, necessitates the need for an awareness of the treatment delivered and the long-term and late effect risks (Taylor & Monterosso, 2015).

This study will address the lack of robust empirical evidence in haematology survivorship care. A nurse-led model of care would assist patients transitioning from the end of treatment to the survivorship phase.

Furthermore, the provision of an individualised SCPTS is a means to empower individuals with knowledge about their disease and treatment and to assume responsibility for future surveillance and disease management. It will likewise take advantage of 'teachable moments' at the end of active treatment to support and promote patient participation in healthy lifestyle behaviours (Taylor et al., 2015). This is particularly vital for younger survivors, given the expectation of a longer survivorship period (Jabson & Bowen, 2013).

The intervention has been timed to occur in the early survivorship phase. This has been supported by preliminary focus group work including lymphoma cancer survivors who indicated they often felt abandoned at treatment completion (Monterosso et al., 2015). This timing also concords with McDowell et al. (2010) who found assessments and interventions undertaken in the early survivorship phase (up to two years post diagnosis) led to fewer unmet needs moving into the extended survivorship phase (over five years).

The CALy trial will examine the impact and effectiveness of the nurse-led lymphoma survivorship clinic intervention through an assessment of the important clinical outcomes: unmet informational and practical needs; depression, anxiety and stress; coping; and self-empowerment as measured by the instruments chosen. It is therefore designed to improve the identification of unmet needs. Testing of such an intervention by a randomised controlled trial has not been published in lymphoma survivorship studies to date. Consequently, it will make a significant contribution to the planning and delivery of survivorship care. Likewise, it represents a substantial and original contribution to knowledge and support for haematology survivorship care as few studies aim to improve the

psychosocial and supportive care of this cohort. If the intervention achieves its intended outcomes, it may potentially lead to the development of nurse-led haematology survivorship clinics across the tertiary health sector in Western Australia that could ultimately be expanded to all cancer survivors.

Ethics

Ethics approval has been gained from the relevant hospital (2015-020) and university (015007F) Human Research Ethics Committees (HRECs). The trial is registered at the Australian and New Zealand Clinical Trials Registry (ACTRN 1261500530527) and the Western Australia Cancer Clinical Trials Registry. The trial is open to patient recruitment. It is not expected participants will be exposed to any undue risks or harm by participation. Participant information will remain confidential and de-identified where appropriate. Economic harm will be minimised by providing appointments when the participant is already attending the hospital. Exploring concerns may be distressing and if this occurs, participants will be referred to the appropriate counselling services as per usual clinical practice. Collected data will be securely stored at the university for 15 years after study completion and will only be accessible with written permission from the researcher and relevant university and hospital sites.

Chapter Summary

In summary, this published article outlines the development of the nurse-led lymphoma survivorship model of care and the components that were required to undertake a high-quality phase II pilot pragmatic RCT. These include:

- Development and review of a unique tailored survivorship care plan and treatment summary (SCPTS)
- Selection of four assessment measures
- Motivational interviewing chart
- Development of a resource pack
- Three structured appointments in the nurse-led lymphoma survivorship intervention
- Creation of a General Practitioner (GP) evaluation of the SCPTS
- Development of the interview schedule

Where detail is limited, further information is in Chapter Four of this thesis.

The following chapter of this thesis reports in the first section on the results that were obtained from the pragmatic RCT and the GP evaluations. The following two sections are the results of the qualitative interviews and the test–retest reliability analysis of the SF-SUNS. These are presented in the format of journal articles that were published in the *European Journal of Oncology Nursing* and the *Asia-Pacific Journal of Oncology Nursing* respectively.

Chapter Six — Results

"I got the chance to talk over my concerns and I think that is very important."

Female_HL

6.0 Results of Phase Three and Phase Four

Four sections form this chapter. The first two sections describe the statistical techniques applied to the data followed by results for the pragmatic randomised controlled trial (RCT) and general practitioner (GP) evaluation surveys. The third section of this chapter presents the sixth and final published paper that reports the results from the qualitative semi-structured interviews undertaken with a subset of intervention participants after their completion of the study. Interviews were conducted by an independent researcher to minimise potential bias and allow participants an opportunity to speak freely about their perceptions and experiences. This published manuscript has been reproduced in this chapter (Taylor, K., Monterosso, L., & Bulsara, C. (2018). Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care, *European Journal of Oncology Nursing, 35*, 9–14). The complete PDF version is in Appendix A.5.

The final section comprises the fifth published journal article that reports the test–retest reliability of the SF-SUNS, the survivorship-specific needs assessment measure selected for this research. This testing was undertaken as published test–retest reliability data was not yet available when the study protocol was developed. This manuscript has been reproduced in this chapter (Taylor, K., Bulsara, M., & Monterosso, L. (2018). Test–retest reliability of the Short-Form Survivor Unmet Needs Survey, *Asia-Pacific Journal of Oncology Nursing, 5*(2), 165–171). The complete PDF version is in Appendix A.6.

6.1 Results of the Pragmatic Pilot Randomised Controlled Trial

Statistical Techniques

Quantitative data were analysed using IBM SPSS version 25 (IBM Corp, 2017). Demographic variables were described using mean, standard deviation, median and range where applicable. The degree of sample generalisation between groups (control and intervention) was ascertained and reported using a Pearson Chi-square test, except when cell counts were below five in which case a Fisher's Exact test result was reported. Subjective data such as lifestyle factors was not tested. Responses to the SF-SUNS, DASS21, Mini-MAC and PES used Likert-type scales and were scored according to the algorithms provided in the relevant instrument manuals. Analysis was by intention to treat, unanswered items on questionnaires were recorded. Statistical significance was set at 0.05 (2-tailed) unless otherwise stated.

Non-parametric tests were used where measures were not normally distributed as determined by the Shapiro Wilk test. The Kruskal–Wallis test was used to compare total scale and domain scores of each instrument at each time point across age, gender, and lymphoma type. Within each group, paired t-test (or non-parametric alternative Wilcoxon Paired Rank Sum test) comparisons on the total scale and domain scores of each instrument were made between Time 1 (baseline) and Time 2 (3 months) and Time 1 and Time 3 (6 months). Independent t-tests (or non-parametric Mann–Whitney U test) were used to assess the differences on the total scale and domain scores and each item between the two groups at each time point. The Friedman test was used to measure the intervention participants across the three time points on

the total scale and domain scores of each instrument.

Linear Mixed Modelling (LMM) with Bonferroni post-hoc comparisons were used to examine change over the study timeframe between the control and intervention groups. LMM is suitable for data where: multiple measures are repeatedly taken from the same individuals; data is not necessarily normally distributed; and permits missing data points (missing at random) (West, Welch, & Galecki, 2015). Therefore, LMM provides flexibility of modelling data means along with the variances and covariances (IBM Corp, 2017). Each assessment measure, including the domains within each measure, were treated as a separate dependent variable model. Covariates were treated as fixed effects and included group (control versus intervention), time (1, 2 and 3), with cofounders of age, gender and lymphoma type. Individuals were treated as a random effect. Group x time and gender x time interactions were examined for each model and were included in the final reported model only if statistically significant. Place of residence was not modelled due to the low numbers from regional or rural areas. Final model residuals were assessed for normality to check the assumption for the LMM was met. All models were assessed to meet this assumption with only some slight deviation in the tails for some models.

Spearman's Rho correlation coefficient analysis was used to describe the relationship between the SF-SUNS and each of the other measures; PES, DASS21, Mini-MAC. Combined scores from the two groups were used at each time point to describe the strength and direction of the correlation. The strength of the correlation coefficient was determined using the following values: small r=.10 to .29; medium r=.30 to .49; large r=.50 to 1.0 (Cohen, 1988).

The CONSORT (Consolidated Standards of Reporting Trials) diagram (Moher et al., 2010) depicting the flow of participants through this trial is presented in Figure 6.1.1. Missing data were minimal and estimated not to exceed 1–1.5% of the total data volume. Recruitment commenced in July 2015 and was completed in January 2017. All participants had completed the study by October 2017.

Quantitative analysis tables demonstrating the depth of analysis undertaken in this thesis are found in Appendix L for the following:

- Reliability of assessment measures (Table 1)
- Wilcoxon Singed Rank Sum test (Table 2)
- Linear mixed models, non-significant results of the SF-SUNS (Table 3) and Mini-MAC (Table 4).
- Paired t-tests (Table 5)
- Independent t-tests (Table 5)
- Kruskal–Wallis tests (Tables 6–8)

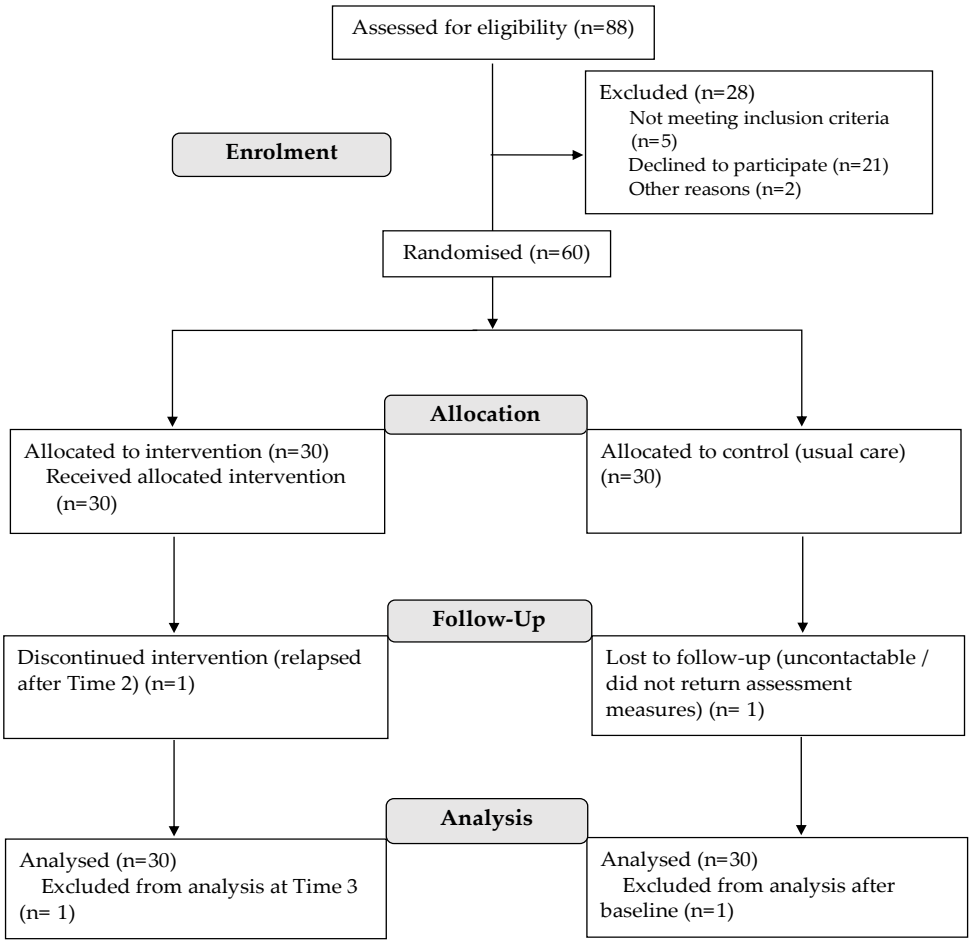


Figure 6.1.1. CONSORT flow diagram for pragmatic RCT.

Results

Demographic data

Of 88 eligible patients (Figure 6.1.1), 60 consented to participate in the trial (68%). The 28 patients who were excluded had comparable demographic characteristics (obtained from their medical records) with those of participants; there were more males (n=16, 58%) than females (n=12, 42%) with a similar age range (24–82 years, *M*=63 years, *SD*=14). Like the participants, the majority of non-participants were in a relationship, had NHL, and were within the first eight months since diagnosis. Reasons for exclusion included:

- Not meeting inclusion criteria due to relapse of disease (n=5)

- Declined to participate (n=21)
    - Extra time required at the hospital (n=8)
    - Travel to the hospital for regional patients (n=2)
    - Feeling overwhelmed by treatment experience or wanting to move on and forget they had lymphoma (n=9)
    - Not interested with no other reason given (n=2)
- Other reasons (n=2)
    - Died after assessment for eligibility

Demographic and disease characteristics of study participants are shown in Table 6.1.1 for both control and intervention groups. More males (73%) than females (27%) were randomised to the intervention group indicating a statistically significant degree of generalisation which was not seen in the control group. Likewise, lymphoma type was disproportionate, with an increased number of HL cases in the intervention group (40%) compared with recognised worldwide trends in lymphoma distribution which were mirrored in the control group; NHL (80%), HL (20%) (Howlader et al., 2016). There were a greater number of participants within the first eight months of diagnosis, an expected result when recruiting participants after treatment completion. A statistically significant degree of sample generalisation in marital status was found; however, this difference was not significant when participants were grouped into 'in a relationship' or 'not in a relationship'. There were more metropolitan residents in the study, although similar representation of residence was found in both groups.

Three age group categories were chosen to reflect the adolescent and young adult age range (18–29 years), those with more likelihood of working and having children living at home (30–59 years) and those less likely to be working or have dependent children (>60 years).

Table 6.1.1 Demographic Characteristics for RCT Participants (n=60)

	Intervention n=30	**Control n=30**	**Group Difference**	
Characteristics	**N (%)**	**N (%)**	**Pearson Chi-Square**	***P* Value**
Gender			6.79	**.018**
Male	22 (73)	12 (40)		
Female	8 (27)	18 (60)		
Age group (years)			0.89	.712
18–29	8 (27)	5 (16)		
30–59	12 (40)	14 (47)		
60–86	10 (33)	11(37)		
Lymphoma diagnosis			2.86	.158
Non-Hodgkin	18 (60)	24 (80)		
Hodgkin	12 (40)	6 (20)		
Time since diagnosis			0.29	**.**789
5–8 months	20 (67)	18 (60)		
>9 months	10 (33)	12 (40)		
Marital status			5.14*	.273
Single	9 (30)	5 (16)		
Married/defacto	17 (57)	20 (67)		
Divorced/separated	4 (13)	2 (7)		
Widowed	0 (0)	3 (10)		
Children^				
<25 (living at home)	12 (40)	9 (30)		
Adult children	9 (30)	13 (43)		
No children	9 (30)	8 (27)		
Highest level of education			1.56	.498
Secondary school or less	7 (23)	11 (37)		
Trade/vocational college	9 (30)	9 (30)		
University	14 (47)	10 (33)		
Employment status#			1.09	.435
Working	15 (50)	12 (40)		
Not working	15 (50)	18 (60)		
retired	7 (23)	9 (30)		
no return to work date	5 (16)	5 (16)		

looking for work	2 (7)	4 (13)		
sick pension	1 (3)	0 (0)		
Income level			4.10*	.586
$0–$30,000	13 (43)	15 (50)		
$30,001–$70,000	7 (23)	6 (20)		
$70,001–100,000	4 (13)	5 (16)		
$100,001–$130,000	2 (7)	1 (3)		
>$130,000	4 (13)	1 (3)		
chose not to answer	0 (0)	2 (7)		
Residence			0.48*	.731
Metropolitan	24 (80)	26 (87)		
Regional	6 (20)	4 (13)		
Lifestyle factors^				
Smoking				
Current smoker	4 (13)	3 (10)		
Quit <12 months	2 (7)	2 (7)		
Quit >12 months	5 (16)	5 (16)		
Never smoked	19 (63)	20 (67)		
Alcohol consumption				
Current	17 (57)	19 (63)		
Occasional <1 drink/week	9 (30)	10 (33)		
2–3 drinks/week	6 (20)	3 (10)		
4–5 drinks/week	1 (3)	0 (0)		
6–7 drinks/week	0 (0)	3 (10)		
Binge drinking weekends	1 (3)	0 (0)		
2–3 drinks/night	0 (0)	3 (10)		
Never	13 (43)	11 (37)		
Weight				
Underweight (<50 kg)	1 (3)	0 (0)		
Overweight (>95 kg)	5 (16)	6 (20)		

Note. **Bolded** *p* value indicates statistical significance $p<.05$; *Fisher's Exact test result reported; #Two main groups examined— 'Working' or 'Not working'; ^Subjective data not analysed

Assessment measures

All participants completed all items on the SF-SUNS, DASS21 and Mini-MAC. The PES gave participants the option of leaving a question blank; however, most participants completed all items across the three time points. The question most frequently left blank was "complementary therapies help me cope with my illness" (n=12, 48%). There were more missing items from the control group (19 vs 6 items). Across both groups, there were five missing items at Time 1, 12 items at Time 2 and eight items at Time 3.

Cronbach's alpha results supported scale reliability in all measures across the three time points. Cronbach's alphas in the present study ranged from:

- SF-SUNS = .70 to .96
- DASS21 = .79 to .94
- Mini-MAC = .58 to .90
- PES = .75 to .79

Unmet needs (as measured by the SF-SUNS) and patient empowerment (as measured by the PES) demonstrated a medium to strong, negative correlation between the two variables at: Time 1, r=–.51, n=60, p=<.001; Time 2, r=–.35, n=59, p=<.001; and Time 3, r=–.56, n=58, p=<.001. High levels of empowerment were associated with lower levels of unmet needs. The relationship between SF-SUNS and psychological distress (as measured by the DASS21) revealed a strong, positive correlation between the two variables at: Time 1, r=.75, n=60, p=<.001; Time 2, r=.80, n=59, p=<.001; and Time 3, r=.77, n=58, p=<.001. Low levels of psychological distress were associated with lower levels of unmet needs. Likewise, the relationship between the SF-SUNS and mental adjustment to cancer (as measured by the Mini-MAC) indicated a strong, positive correlation between the two variables at: Time 1, r=.58, n=60, p=<.001; Time 2, r=.71, n=59, p=<.001; and

Time 3, r=.67, n=58, p=<.001. Lower levels of unmet needs were associated with better mental adjustment to the cancer diagnosis.

Fidelity

Control group

No participant randomised to the control group received the SCPTS or the resource pack during the study. Four participants (13%) required at least one phone call at Time 2 for non-return of measures, resulting in three (75%) returned. At Time 3, 10 participants (33%) required at least one phone call for non-return of measures. Seven participants (70%) posted back the measures within a month and two (20%) brought the completed measures to their haematologist appointment. Twenty-nine participants completed Time 2 and Time 3 measurements.

Intervention group

All intervention participants completed the first NLSC appointment face-to-face. The average time of consultation was 64.28 minutes (range 20–120 minutes) and the average time from baseline was 9.63 days (range 0–56 days). Four participants (13%), prior to the baseline appointment, indicated they would be unable to return to the hospital within the next few weeks if randomised to the intervention. Therefore, the first NLSC appointment was planned for the same day as baseline if required. Two participants (6%) did not present for their scheduled NLSC appointment and were eventually seen 31 and 56 days later. The average time of the second NLSC appointment was 46.13 minutes (range 19–90 minutes) and 44.31 minutes (range 15–70 minutes) for the third NLSC appointment. Four participants (13%) requested a telephone appointment after their haematologist appointments had been cancelled and moved to a future date. Assessment measures were completed over the phone, and any written information requested was emailed or

posted. Thirty participants at Time 1 and Time 2 and 29 participants at Time 3 completed all elements of the study.

Intervention group

Concerns and health goals

Half of the participants identified fear of recurrence, and one-third identified fatigue and/or cognitive impairment as concerns on the SCPTS (Table 6.1.2). Counselling referrals to a clinical psychologist were offered to those who self-reported struggling with a psychosocial issue. Those who accepted a counselling opportunity (n=4, 13%) had issues with fear of recurrence and/or managing stress and anxiety. At study completion, one participant (3%) continued to self-report a high / very high level of fear of recurrence on the SF-SUNS. Fatigue was ongoing and remained a moderate to very high unmet need self-reported on the SF-SUNS in one third of participants (n=10, 34%). Cognition impairment likewise remained an issue with 52% (n=15) self-reporting this as a moderate to high unmet need on the SF-SUNS.

The majority of participants (n=25, 83%) wanted to increase or start physical exercise and over half wanted to make healthy lifestyle changes (Table 6.1.2).

Table 6.1.2 Top Five Concerns and Health Goals Identified from SCPTS

Rank	Participant-identified Concerns	N (%)	Participant-identified Health Goals	N (%)
1	Fear of recurrence or other cancer	15 (50)	Increasing or undertaking physical activity/exercise	25 (83)
2	Fatigue	10 (33)	Healthy lifestyle (including weight loss, healthy diet, reducing alcohol intake)	16 (53)
3	Memory and concentration issues	9 (30)	Work (balancing with life now, taking opportunities)	13 (43)
4	Quit cigarette	4 (13)	Travel	10 (33)

	smoking			
5	Financial and insurance issues	4 (13)	Managing stress, anxiety and mental health	8 (26)

A motivational chart was used as an aid to list participant likes, dislikes and conflicts that might arise while trying to quit a particular behaviour. Four participants (13%) used the chart to assist with smoking cessation. Three participants (10%) were able to quit smoking by the end of the study, and one young person had reduced smoking to social situations only. Two young participants (6%) used the chart to address excessive or binge alcohol intake. At study completion, one participant indicated complete abstinence and felt this achievement had helped control other aspects of his life. The other participant had verbalised at her first NLSC appointment: "I am sick of cancer sucking the joy out of my life" and felt the peer pressure would be difficult to withstand if she made lifestyle changes. At study completion, she had reduced her alcoholic intake and acknowledged that getting healthy and taking back control of her life had included taking herself out situations where she felt pressured.

Assessment of the nurse-led lymphoma survivorship model of care

Survivorship unmet needs (SF-SUNS)

Friedman tests were undertaken to measure total scale and domain scores to compare participants in the intervention group of the nurse-led lymphoma survivorship model of care at Time 1 (pre-intervention), Time 2 (3 months' post-intervention) and Time 3 (6 months' post-intervention). Total scale SF-SUNS scores identified the highest unmet need at Time 2 (*Md*=22), then Time 1 (*Md*=18) with Time 3 (*Md*=16) the lowest (X^2 (2, *N*=29) = 7.60, *p*=.022). Significant results were evident in the financial concerns domain with greater unmet need reported at Time 1 (*Md*=6) and Time 2 (*Md*=6) with Time 3

(*Md*=4) the lowest X^2 (2, *N*=29) = 6.08, *p*=.048. The access and continuity of care domain demonstrated higher unmet need at Time 1 (*Md*=1) with Time 2 (*Md*=0) and Time 3 (*Md*=0) reporting no unmet need X^2 (2, *N*=29) = 6.53, *p*=.038. The relationships and emotional health domain identified the highest unmet need at Time 1 (*Md*=12,) and Time 2 (*Md*=12) with Time 3 (*Md*=8) the lowest X^2 (2, *N*=29) = 6.69, *p*=.035. A significant difference was not reported for the information domain (X^2 (2, *N*=29) = 2.04, *p*=.360).

In the intervention group, scores decreased from Time 1 to Time 3 for total scale (*z*=–2.15, *p*=.031, *r*=.28); and access and continuity of care domain scores (*z*=–2.31, *p*=.021, *r*=.30) both with a small–moderate effect size. All other results had a small effect size and were not statistically significant.

The Kruskal–Wallis test revealed no significant distribution across lymphoma type. The intervention >60 years age group had very low scores for access and continuity of care domain at Time 2 compared with the other two age groups (*Md*=0 vs *Md*=2, 18–29 years and *Md*=2.5, >60 years; *p*=.012). Although there was a disproportionate number of males to females, women had significantly higher scores at Time 1 (*Md*=41 vs *Md* 16; *p*=.046), particularly evident in the relationships and emotional health domain (*Md*=21 vs *Md*=7; *p*=.007). Conversely, at Time 3, men recorded a significantly higher median than women (*Md*=2 vs *Md*=0; *p*=.024) in the information domain. The control group results revealed more unmet needs in the 30–59 years age group at Time 1 (*Md*=25.5 vs *Md*=18, 18–29 years and *Md*=13, >60 years; *p*=.016), and these were significantly higher in the financial concerns (*Md*=9 vs *Md*=3, 18–29 years and *Md*=6, >60 years; *p*=.019) and access and continuity of care domains (*Md*=2.5 vs *Md*=1, 18–29 years and >60 years; *p*=.012). This continued to be an unmet need for this age group at Time 3 for the access and continuity of care domain (*Md*=4 vs *Md*=1, 18–29 years and

Md=0, >60 years; *p*=.023). Women in the control group had significantly higher scores at Time 1 (*Md*=24 vs Md 17; *p*=.034), especially in the relationships and emotional health domain (*Md*=13 vs Md=5.5; *p*=.004).

Intervention group mean scores were highest at Time 1 (*M*=27.33) and continued to decrease over the study period. The domain with the most significant decrease was the access and continuity of care domain. The control group scores were highest at Time 2 (*M*=28.62); nonetheless were not significant.

Independent t-tests, conducted to compare total scale and domain scores across the time points, demonstrated higher mean scores in the control group compared with the intervention group. The relationships and emotional health domain scores for the control group increased over the study period. All scores had a small effect size and no results were significant.

Individual items on the SF-SUNS were also assessed to identify specific aspects of unmet need. Significant differences were found indicating that the intervention group at Time 1 reported a higher level of need for finding information about complementary or alternative therapies (*M*=0.87, *SD*=1.04, *Md*=0) than the control group (*M*=0.27, *SD*=0.52, *Md*=0) [*U* 592, *z* 2.45, *p*=.014, *r* .32]. Time 3 results indicated the control group felt less able to speak to others about their emotions or deal with feeling depressed (Table 6.1.7). Although not significant, six control group participants (21%) continued to record high / very high unmet needs for fear of recurrence at Time 2 and 3. Likewise, the control group reported more unmet cognition impairment (n=20, 34%) at study completion. Both concerns documented by intervention participants on the SCPTS.

LMM analysis, adjusting for gender, lymphoma type and age, reported group (control or intervention), time (1, 2 or 3), and lymphoma type (NHL or HL) were not significantly associated with the SF-SUNS (Appendix L). The LMMs for the domains (Table 6.1.3) reported a significant effect for time in the information domain, showing Time 1 scores were higher (p=.025). The LMM for the financial domain reported those with NHL had higher scores compared to those with HL (p=.010). The access and continuity of care domain LMM reported those with NHL had higher scores compared to those with HL (p=.021) and as age increased, unmet needs in this domain decreased (p=.039). The LMM for the relationships and emotional health domain reported that women had more unmet needs compared to males (p=.010).

Table 6.1.3 Linear Mixed Model Results of SF-SUNS Domains

Variable	Beta Estimate	Std. Error	95% Confidence Interval		*P* Value
			Lower	Upper	
Information Domain					
Intercept	3.23	1.00	1.20	5.22	.002
Group—Control[a]	0.37	0.67	–0.97	1.70	.585
Lymphoma[b] (NHL)	0.50	0.81	–1.12	2.13	.536
Gender[c] (Male)	–0.65	0.66	–1.97	0.68	.332
Time 1[d]	0.76	0.33	0.10	1.42	**.025**
Time 2[d]	0.36	0.33	–0.30	1.02	.287
Age	–0.02	0.02	–0.06	0.02	.276
Financial Concerns Domain					
Intercept	7.70	2.62	2.44	12.94	.005
Group—Control[a]	–1.40	1.76	–4.93	2.14	.434
Lymphoma[b] (NHL)	5.70	2.15	1.40	10.00	**.010**
Gender[c] (Male)	–1.56	1.75	–5.06	1.94	.376
Time 1[d]	0.83	0.66	–0.47	2.13	.209
Time 2[d]	1.00	0.66	–0.31	2.30	.133
Age	–0.80	0.05	–0.18	0.02	.105
Access and Continuity of Care Domain					
Intercept	4.23	1.58	1.12	7.44	.009

Group—Control[a]	–0.81	1.06	–2.93	1.31	.448
Lymphoma[b] (NHL)	3.05	1.29	0.47	5.62	**.021**
Gender[c] (Male)	–0.97	1.05	–3.07	1.13	.360
Time 1[d]	0.94	0.48	–0.01	1.90	.053
Time 2[d]	0.49	0.48	–0.47	1.44	.316
Age	–0.06	0.03	–0.12	–0.00	**.039**
Relationships and Emotional Health Domain					
Intercept	20.54	4.63	11.28	29.81	.000
Group—Control[a]	–1.75	3.11	–7.99	4.49	.577
Lymphoma[b] (NHL)	4.59	3.79	–3.00	12.18	.231
Gender[c] (Male)	–8.20	3.09	–14.39	–2.02	**.010**
Time 1[d]	0.93	1.19	–1.42	3.28	.435
Time 2[d]	1.97	1.19	–0.39	4.33	.100
Age	–0.11	0.09	–0.28	0.06	.211

Note. **Bolded** *p* value indicates statistical significance $p<.05$; [a] Comparison group set to zero (Intervention); [b] Comparison group set to zero (HL); [c] Comparison group set to zero (Female); [d] Comparison group set to zero (Time 3)

Psychological distress (DASS21)

Friedman tests performed on the intervention group did not identify significant differences on the total scale and domain scores between the three time points. Total scale scores revealed the highest levels were at Time 1 (*Md*=10) and Time 2 (*Md*=10) with Time 3 (*Md*=8) the lowest (X^2 (2, *N*=29) = 1.55, *p*=.462). Domain results revealed higher levels of depression at Time 2 (*Md*=3), then Time 1 (*Md*=2), with Time 3 (*Md*=1) the lowest (X^2 (2, *N*=29) = 3.12, *p*=.210). This result was reflected in the stress domain with higher levels identified at Time 2 (*Md*=5) then Time 1 (*Md*=4) and Time 3 (*Md*=4) (X^2 (2, *N*=29) = 4.00, *p*=.135). Greater levels of anxiety were identified at Time 1 (*Md*=3) and Time 2 (*Md*=3) with Time 3 (*Md*=2) lower (X^2 (2, *N*=29) = 0.16, *p*=.923).

A Wilcoxon Signed Rank Sum test revealed no significant differences in the intervention group, and all results had a small effect size. There were no significant differences in the distribution of scores across age groups, gender

or lymphoma type in the intervention group. The control group demonstrated a significant difference in the distribution of total scale scores across gender at Time 2, with women reporting higher scores (*Md*=16 vs *Md* 5; *p*=.022). Domain scores revealed women had higher levels in the depression domain at Time 1 (*Md*=2.5 vs *Md* 1; *p*=.039) and Time 2 (*Md*=6 vs *Md* 0; *p*=.016), and anxiety domain at Time 2 (*Md*=3.5 vs *Md*=1; *p*=.017). No significant results were reported across age group or lymphoma type. No significant results were identified in the control group; however, total scale scores did decrease over the study period.

Independent t-tests revealed no significant results in either the control or intervention groups. Intervention group mean scores were highest at Time 2 (*M*=15.63), and although they had decreased by Time 3 (*M*=13.03), they continued to reflect higher mean scores than at Time 1 (*M*=12.67). Intervention group mean anxiety (*M*=3.53) and stress (*M*=6.80) domain scores were slightly higher at Time 2, with stress mean scores higher at Time 3 (*M*=5.66) than at Time 1 (*M*=5.17). Control group mean scores revealed Time 1 (*M*=15.57) and Time 3 (*M*=15.14) scores were higher compared with the intervention group, with the Time 2 mean anxiety domain score highest (*M*=3.63) when compared with the intervention group.

Individual items on the DASS21 were assessed to detect specific traits of psychological distress. Results did not reveal any significant differences in the items between the two groups at any time point.

LMM examining DASS21 total scale score and domains (Table 6.1.4), adjusting for gender, lymphoma type and age, reported no significant group (control or intervention) or time (1, 2 or 3) effects. However, women reported

higher scores compared with men for all DASS21 models: Total scale (p=.013); depression (p=.032); anxiety (p=.007); and stress (p=.029).

Table 6.1.4 Linear Mixed Model Results of the DASS21

Variable	Beta Estimate	Std. Error	95% Confidence Interval		*P* Value
			Lower	Upper	
Total Scale					
Intercept	17.12	5.12	6.86	27.38	.001
Group—Control[a]	–2.75	3.45	–9.66	4.17	.429
Lymphoma[b] (NHL)	5.77	4.20	–2.64	14.19	.175
Gender[c] (Male)	–8.75	3.42	–15.60	–1.90	**.013**
Time 1[d]	0.16	1.23	–2.28	2.60	.897
Time 2[d]	0.95	1.23	–1.49	3.40	.441
Age	–0.02	0.09	–0.21	0.17	.857
Depression Domain					
Intercept	4.67	1.99	0.68	8.66	0.23
Group—Control[a]	–1.34	1.34	–4.02	1.35	.322
Lymphoma[b] (NHL)	2.05	1.63	–1.21	5.32	.213
Gender[c] (Male)	–2.92	1.33	–5.58	–0.26	**.032**
Time 1[d]	–0.21	0.52	–1.24	0.82	.683
Time 2[d]	0.53	0.52	–0.50	1.56	.309
Age	0.01	0.04	–0.06	0.09	.744
Anxiety Domain					
Intercept	3.91	1.44	1.03	6.79	.009
Group—Control[a]	–0.76	0.96	–2.69	1.12	.433
Lymphoma[b] (NHL)	1.06	1.17	–1.29	3.40	.370
Gender[c] (Male)	–2.70	0.96	–4.61	–0.78	**.007**
Time 1[d]	0.56	0.43	–0.30	1.42	.202
Time 2[d]	0.08	0.44	–0.78	0.94	.852
Age	0.01	0.03	–0.39	0.07	.589
Stress Domain					
Intercept	8.65	2.12	4.40	12.90	.000
Group—Control[a]	–0.74	1.43	–3.59	2.12	.607
Lymphoma[b] (NHL)	2.69	1.73	–0.78	6.17	.126
Gender[c] (Male)	–3.16	1.41	–5.99	–0.33	**.029**
Time 1[d]	–0.28	0.59	–1.44	0.88	.632
Time 2[d]	0.24	0.59	–0.93	1.40	.685
Age	–0.04	0.04	–0.12	0.04	.276

Note. **Bolded** p value indicates statistical significance p<.05; [a] Comparison group set to zero (Intervention); [b] Comparison group set to zero (HL); [c] Comparison group set to zero (Female); [d] Comparison group set to zero (Time 3)

Adjustment to cancer (Mini-MAC)

Friedman tests on the intervention group did not identify significant differences on the total scale scores between the three time points (X^2 (2, N=29) = 3.75, p=.154). However, a significant result in the fighting spirit domain was identified, with the highest level of fighting spirit evident at Time 1 (*Md*=13) then Time 3 (*Md*=12) with Time 2 (*Md*=11) the lowest (X^2 (2, N=29) = 12.00, p=.002). Other domains reported no significant differences: fatalism (X^2 (2, N=29) = 1.35, p=.508); helplessness/hopelessness (X^2 (2, N=29) = 1.12, p=.572); anxious preoccupation (X^2 (2, N=29) = 0.73, p=.695); and cognitive avoidance (X^2 (2, N=29) = 0.08, p=.959).

A Wilcoxon Signed Rank test on the intervention group revealed a decrease in scores from Time 1 to Time 2 (z –2.60, p=.009, r .34) with a small–moderate effect size in the fighting spirit domain for the intervention group. All other results had a small effect size and were not significant.

Those with NHL in the intervention group reported significantly lower median scores at Time 1 on the total scale scores (*Md*=58 vs *Md* 72.5; p=.009), in the anxious preoccupation (*Md*=13 vs *Md* 20.5; p=.010) and cognitive avoidance (*Md*=8 vs *Md* 10; p=.037) domains. Significant results were not identified at other time points or in gender or age groups. Conversely the control group's 30–59 years age group had the highest total scale scores at each time point in comparison with the other two groups (Time 1: *Md*=72.5 vs *Md*=64, 18–29 years and *Md*=63, >60 years; p=.040. Time 2: *Md*=77 vs *Md*=59, 18–29 years and *Md*=63, >60 years; p=.012. Time 3: *Md*=73 vs *Md*=61, 18–29 years and *Md*=57, >60 years; p=.019). Higher scores in this group were notable at Time 2 in the helplessness/hopelessness (*Md*=15 vs *Md*=8, 18–29 years and >60 years; p=.011) and anxious preoccupation (*Md*=21 vs *Md*=15, 18–29 years and *Md*=14, >60 years; p=.011) domain scores. Anxious

preoccupation scores at Time 3 were likewise higher (*Md*=22 vs *Md*=17, 18–29 years and *Md*=15, >60 years; *p*=.023). The cognitive avoidance domain revealed the 30–59 years age group had the highest scores compared with the other two groups at Time 1 (*Md*=12 vs *Md*=10, 18–29 years and *Md*=8, >60 years; *p*=.005) and Time 3 (*Md*=12 vs *Md*=9, 18–29 years and >60 years; *p*=.017). One aberration to this trend was noted at Time 2 in the fatalism domain where scores revealed those >60 years of age had significantly higher scores compared with the other two groups (*Md*=16 vs *Md*=11, 18–29 years and *Md*=14, 30–59 years; *p*=.029). A significant distribution of fatalism scores revealed NHL participants recorded higher scores at Time 1 (*Md*=16 vs *Md*=12; *p*=.013), Time 2 (*Md*=15 vs *Md*=10; *p*=.010) and Time 3 (*Md*=14 vs *Md*=10; *p*=.015) compared with those diagnosed with HL. However, it should be noted there were more NHL participants in this group than HL. The fighting spirit domain at Time 3 showed a significant difference with NHL participants recording a higher median (*Md*=12 vs *Md*=10; *p*=.039). No significant differences in the distribution of gender scores were reported.

The fighting spirit domain in the intervention group identified a significant decrease from Time 1 to Time 2 (*p*=.009). Likewise, the fighting spirit domain (*p*=.002), along with anxious preoccupation (*p*=.037) was significant in the control group at Time 1 to Time 3. Independent t-tests that compared both groups at each of the three time points did not identify significant differences. For the intervention group, total scale and domain mean scores decreased from Time 1 to Time 3, with the exception of cognitive avoidance domain mean score which was highest at Time 2 (*M*=8.80; *p*=.043). Results of the independent t-tests revealed the control group had a decrease in scores across the domains; fatalism, fighting spirit and anxious preoccupation over the study period. Fatalism and fighting spirit scores were lower for the control group when compared with the intervention group. In contrast, the

helplessness/hopelessness (*M*=12.62 vs *M*=12.00) and cognitive avoidance (*M*=10.14 vs *M*=8.52) domain scores continued to increase and were highest in this group when compared with the intervention group at Time 3; however, the results were not significant.

Individual items on the Mini-MAC were evaluated to detect any specific areas where either group had greater concerns. Significant differences were found at Time 2 indicating the control group struggled more with having a cancer diagnosis and trying not to think about it (Table 6.1.7). For the control group, trying not to think about having cancer was still an issue at Time 3 (Table 6.1.7).

LMM analysis of the Mini-MAC and domains fighting spirit and fatalism, adjusting for gender, lymphoma type and age, reported group (control or intervention), gender and lymphoma type were not significant contributors (Table 6.1.5). For all Mini-MAC models, total scale (*p*=.020), fatalism (*p*=.035) and fighting spirit (*p*=.029) domain scores were higher at Time 1 (Table 6.1.5). In addition, for the LMM fatalism domain, scores increased as age increased (*p*=.005). For the fighting spirit domain, a significant interaction between group and time was found, reporting that the control group had a higher fighting spirit domain score at Time 2 (*p*=.049). No significant results were found in the LMM for other domains; helplessness/hopelessness, anxious preoccupation and cognitive avoidance (Appendix L).

Table 6.1.5 Linear Mixed Model Significant Results of Mini-MAC

Variable	Beta Estimate	Std. Error	95% Confidence Interval		*P* Value
			Lower	Upper	
Total scale					
Intercept	67.65	5.49	56.65	78.64	.000
Group—Control[a]	1.38	3.70	–6.04	8.80	.711
Lymphoma[b] (NHL)	0.09	4.51	–8.93	9.12	.983

Gender[c] (Male)	–5.29	3.67	–12.64	2.07	.155
Time 1[d]	2.93	1.25	0.46	5.40	**.020**
Time 2[d]	1.97	1.25	–0.50	4.44	.117
Age	–0.03	0.10	–0.23	0.17	.780
Fatalism Domain					
Intercept	10.87	1.17	8.53	13.21	.000
Group—Control[a]	–0.65	0.79	–2.23	0.92	.411
Lymphoma[b] (NHL)	0.01	0.96	–1.91	1.93	.992
Gender[c] (Male)	–0.40	0.78	–1.96	1.16	.609
Time 1[d]	0.69	0.32	0.05	1.33	**.035**
Time 2[d]	0.57	0.32	–0.07	1.21	.081
Age	0.06	0.02	0.02	0.11	**.005**
Fighting Spirit Domain					
Intercept	11.71	0.95	9.82	13.61	.000
Group—Control[a]	–.031	0.70	–1.70	1.09	.665
Lymphoma[b] (NHL)	1.09	0.76	–0.44	2.62	.159
Gender[c] (Male)	0.36	0.62	–0.89	1.60	.571
Time 1[d]	0.83	0.38	0.08	1.58	**.029**
Time 2[d]	–0.24	0.38	–0.98	0.51	.531
Age	–0.02	0.02	–0.06	0.01	.211
Group—Control[a] * Time 1[d]	0.38	0.53	–0.68	1.43	.480
Group—Control[a] * Time 2[d]	1.06	0.53	0.01	2.12	**.049**

Note. **Bolded** *p* value indicates statistical significance $p<.05$; [a] Comparison group set to zero (Intervention); [b] Comparison group set to zero (HL); [c] Comparison group set to zero (Female); [d] Comparison group set to zero (Time 3)

Patient empowerment (PES)

No significant difference was reported on the Friedman test conducted on the intervention group. Results identified an increase from Time 1 (*Md*=49) to Time 2 (*Md*=51) with Time 3 (*Md*=52) the highest empowerment scores (X^2 (2, *N*=29) = 4.71, *p*=.095). A Wilcoxon Signed Rank test revealed no significant increase in empowerment scores at Time 1 to Time 2 or Time 1 to Time 3 in the intervention group; all results had a small effect size.

The distribution of scores from the intervention group, as measured by the Kruskal–Wallis test, was similar across the age groups, gender and lymphoma types. In the control group, results indicated a significant distribution of higher scores for the >60 years age group at Time 1 (*Md*=54 vs

Md=46, 18–29 years and *Md*=47, 30–59 years; *p*=.010), Time 2 (*Md*=50 vs *Md*=44, 18–29 years and 30–59 years; *p*=.011) and Time 3 (*Md*=51 vs *Md*=44, 18–29 years and *Md*=45, 30–59 years; *p*=.024), demonstrating more empowerment. At Time 2, men had the highest scores (*Md*=48 vs *Md*=44; *p*=.036). Those with NHL had the highest scores at Time 1 (*Md*=50.5 vs *Md*=43.5; *p*=.010) and Time 2 (*Md*=48 vs *Md*=42; *p*=.014).

Paired-sample t-tests indicated the highest level of empowerment in the intervention group was at Time 2 and Time 3; however, these were not significant results. Whereas control group results identified a significant decrease from Time 1 to Time 2 (*p*=.005) in the level of empowerment this group recorded. Although not significant, the lowest scores were recorded at Time 3. The highest empowerment scores were identified in the intervention group compared with the control group at Time 2 (*M*=49.50 vs *M*=45.79; *p*=.016). No further significant results were identified.

Individual items on the PES revealed significant differences for the control group. The results indicated the control group felt less adept at making lifestyle changes at Time 2 and Time 3 and at Time 1 indicated a need for support from family and friends. This was in contrast to the intervention group where results indicated they had all the information they needed to manage their health and adapt to and make lifestyle changes at Time 2 and Time 3 (Table 6.1.7).

The LMM for the PES, adjusting for gender, lymphoma type and age, reported no significant group (control or intervention), lymphoma, gender or time (1, 2 or 3) effects (Table 6.1.6). However, a significant group x time interaction was reported indicating Time 1 scores were higher in the control group (*p*=.013) and then decreased over the study period.

Table 6.1.6 Linear Mixed Model Results of PES

Variable	Beta Estimate	Std. Error	95% Confidence Interval		*P* Value
			Lower	Upper	
Intercept	45.19	2.07	41.05	49.32	.000
Group—Control[a]	–2.71	1.55	–5.79	0.38	.085
Lymphoma[b] (NHL)	0.95	1.65	–2.36	4.26	.569
Gender[c] (Male)	1.70	1.35	–1.00	4.40	.213
Time 1[d]	–1.76	0.90	–3.55	0.04	.055
Time 2[d]	–0.59	0.90	–2.38	1.20	.516
Age	0.06	0.04	–0.01	0.14	.093
Group—Control[a] * Time 1[d]	3.21	1.28	0.68	5.74	**.013**
Group—Control[a] * Time 2[d]	–0.83	1.28	–3.36	1.71	.521

Note. **Bolded** *p* value indicates statistical significance $p<.05$; [a] Comparison group set to zero (Intervention); [b] Comparison group set to zero (HL); [c] Comparison group set to zero (Female); [d] Comparison group set to zero (Time 3)

Table 6.1.7 Assessment Measure Items that Demonstrated a Statistically Significant Difference between Control and Intervention Groups

Measure **Time** **Item**	**Control Group Mean (SD) Median**	**Intervention Group Mean (SD) Median**	**Test Pool Effect***	**Effect Size #**
SF-SUNS				
Time 1				
Finding information about complementary or alternative therapies	0.27 (0.52) 0	0.87 (1.04) 0	*U* 592, *z* 2.45, *p* **.014**	*r* .32
Time 3				
Telling others how I was feeling emotionally	1.10 (1.01) 1	0.21 (0.82) 0	*U* 186.50, *z* –4.25, *p* **.000**	*r* .55
Dealing with feeling depressed	1.24 (1.33) 1	0.62 (0.98) 0	*U* 302.50, *z* –1.99, *p* **.047**	*r* .26
Mini-MAC				
Time 2				
I have difficulty believing this happened to me	2.76 (0.95) 3	2.20 (1.03) 2	*U* 301, *z* –2.11, *p* **.035**	*r* .27
I deliberately push all thoughts of cancer out of my head	2.59 (0.98) 3	2.03 (0.96) 2	*U* 301, *z* –2.12, *p* **.034**	*r* .28
Time 3				
Not thinking about it helps me cope	2.48 (0.98)3	1.97 (0.98) 2	*U* 296, *z* –2.03, *p* **.042**	*r* .27
I deliberately push all thoughts of cancer out of my head	2.48 (0.87) 3	2.03 (1.02) 2	*U* 297, *z* –2.00, *p* **.046**	*r* .26
PES				
Time 1				

I need the support of family and friends	3.77 (0.43) 4	3.43 (0.73) 4	*U* 338, *z* –1.99, *p* **.047**	*r* .26
Time 2				
I have all the information I need to manage my illness	3.03 (0.63) 3	3.47 (0.63) 4	*U* 590, *z* 2.66, *p* **.008**	*r* .35
I can adapt to changes in my lifestyle	3.03 (0.78) 3	3.40 (0.68) 3	*U* 553, *z* –1.98, *p* **.048**	*r* .26
Health professionals are happy to include me in decisions related to my illness	3.28 (0.53) 3	3.53 (0.82) 4	*U* 570, *z* 2.33, *p* **.020**	*r* .30
I accept that I have to change my lifestyle	2.86 (0.74) 3	3.30 (0.65) 3	*U* 568, *z* 2.28, *p* **.023**	*r* .30
Time 3				
I am capable of handling my illness	3.28 (0.59) 3	3.62 (0.49) 4	*U* 547, *z* 2.24, *p* **.025**	*r* .29
I have all the information I need to manage my illness	3.14 (0.64) 3	3.59 (0.57) 4	*U* 577, *z* 2.17, *p* **.007**	*r* .36
I am capable of helping health professionals reach decisions related to my illness	3.31 (0.54) 3	3.62 (0.56) 4	*U* 546, *z* 2.23, *p* **.026**	*r* .29
I accept that I have to change my lifestyle	2.83 (0.89) 3	3.34 (0.67) 3	*U* 556, *z* 2.29, *p* **.022**	*r* .30
I have a lot of confidence in my local GP	3.03 (0.98) 3	3.59 (0.63) 4	*U* 564, *z* 2.45, *p* **.014**	*r* .32

Note. Significance level 0.05 (2-tailed); *Mann–Whitney U test; #Effect size r=z/square root N (total number of cases). Therefore r=z/7.7 (60 cases), 7.68 (59 cases), 7.6 (58 cases). 0.2=small effect, 0.5=moderate effect, 0.8=large effect

6.2 Results of the General Practitioner Evaluation

Statistical Techniques

The data collected from the GP evaluations were analysed using descriptive statistics and content analysis for open-ended items. A Likert-type scale was used to assess four items on the usefulness of the SCPTS content (1=very poor, 2=poor, 3=adequate, 4=good, 5=very good). Cronbach's alpha of 0.93 indicated these items were reliable.

Results

Twenty-eight GPs who had received an SCPTS six months previously for intervention participants were sent the SCPTS evaluation. Although the study randomised 30 participants to the intervention group, two participants did not have a GP during the study. One GP had two participants in the study and chose only to respond once. Five further participants had not seen their GP during the study; however, two GPs sent back an evaluation stating they had not seen the participant. The overall response rate was 64% (18 evaluations returned). A number of strategies were employed to maximise evaluation return such as follow-up phone calls which resulted in one evaluation return. Although five medical practices were faxed another copy of the documents, this did not result in the return of an evaluation. Participants were also encouraged to remind the GP to fill out an evaluation. Three patients requested a copy of the evaluation they could personally hand over at their next GP visit, this resulted in one evaluation returned.

Of the GPs who did not return an evaluation (n=10, 36%), seven were male, eight had metropolitan medical practice addresses and two were regional. No further information was collected.

Of the GPs who did return an evaluation (n=18, 64%), 11 (61%) were male, and the majority were metropolitan based (n=16, 89%). The range of years practicing as a GP were; 6–14 years (n=2, 11%), 15–20 years (n=6, 33%) and 25–30 years (n=10, 56%). Responses to use of the SCPTS are reported in Table 6.2.1.

Table 6.2.1 Responses to Use of SCPTS (n=18)

Item	**Yes** **N (%)**	**No** **N (%)**	**Not Applicable** **N (%)**
Seen patient in last 6 months	16 (89)	2 (11)	
Received SCPTS	16 (89)	2 (11)	
Read on receipt	16 (89)	1 (5.5)	1 (5.5)
GP initiated appointment	6 (33)	11 (61)	1 (5.5)
Participant initiated appointment	7 (39)	10 (55)	1 (5.5)
Participant brought SCPTS	8 (44)	7 (39)	3 (17)
SCPTS discussed with participant	11 (61)	4 (22)	3 (17)
GP Initiated Support	9 (50)	6 (33)	3 (17)

GPs' perception of the usefulness of the SCPTS was evaluated. Sixteen GPs responded to this section and responses are reported in Table 6.2.2. Responses ranged from adequate to very good. As indicated, the majority of GPs (n=13, 81%) perceived the SCPTS was good to very good.

An open-ended section investigated what further information GPs would like on the SCPTS. Ten (56%) GPs provided responses which included:

haematologist contact details or other treatment details (psychological support implemented or planned); frequency of haematology review; what blood tests the GP needed to order; drug names written in full rather than use of acronyms; vaccination schedule post-autologous transplant; peripheral neuropathy management; potential fertility issues; and 'brain training' (? for cognitive impairment).

Table 6.2.2 Description of GP Responses (n=16)

	Raw Scoring (N)	**Mean (SD) [Range]**
Usefulness of treatment information	Adequate (2) Good (8) Very good (6)	4.25 (0.68) [3–5]
Usefulness of survivorship care plan information	Adequate (3) Good (7) Very good (6)	4.19 (0.75) [3–5]
Usefulness of patient-derived health concerns, goals and actions	Adequate (1) Good (12) Very good (3)	4.13 (0.50) [3–5]
Usefulness of SCPTS for patient	Adequate (2) Good (9) Very good (5)	4.19 (0.66) [3–5]
Total combined scores		16.75 (2.38) [12–20]

GPs were queried if any information was not required on the SCPTS; n=6 (34%) responded: four (67%) indicated no information needed to be removed; one GP wrote it was 'all good', and one indicated the information 'was really well presented'.

Over half of GP respondents (n=10, 56%) took up the opportunity to make additional comments. Responses were dichotomised as: positive ("As far as questionnaires go this was excellent. Concise and brief", "Great idea"); neutral ("Rang when I learnt of diagnosis to offer follow-up. I did not ring

again when I got the plan", "Diagnosed the lymphoma and not seen him since", "nothing further to add"); or negative ("Not clear what you expect GP to follow-up [or] what follow-up provided by haematology clinic. I expect a letter with instructions once you discharge from your service", "further comments are pointless").

GPs were solicited if they would like further education on the management of haematology survivors, n=13 (72%) responded (yes=4, 31%, no=9, 69%). Those who responded 'yes', indicated they would like education either in a workshop or online n=1, online or a learning package n=1, online n=2. Three GPs indicated they would like further education on other haematology malignancies, case studies, post-treatment vaccinations.

6.3 Results of Qualitative Interviews

European Journal of Oncology Nursing 35 (2018) 9–14

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care

Karen Taylor[a,b,*], Leanne Monterosso[a,c,d], Caroline Bulsara[a]

[a] School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, Western Australia, Australia
[b] Western Australia Cancer and Palliative Care Network, Perth, Australia
[c] Centre for Nursing and Midwifery Research, St John of God Murdoch Hospital, Western Australia, Australia
[d] School of Nursing, Edith Cowan University Joondalup, Western Australia, Australia

ARTICLE INFO

Keywords:
Lymphoma cancer
Survivorship
Qualitative interviews
Nurse-led clinic intervention
Survivorship care plans and treatment summaries

ABSTRACT

Purpose: To explore and describe lymphoma survivors' thoughts and perceptions of the components of a nurse-led lymphoma survivorship clinic intervention.
Methods: An exploratory, qualitative descriptive study using interviews from 10 participants who had transitioned post-treatment into the survivorship phase via a nurse-led lymphoma survivorship clinic intervention.
Results: Thematic analysis revealed three major themes: Reassurance and individualised care; Information and support; and Empowerment. Participants described the reassurance they gained from having contact with a health professional post-treatment who individualised information and support. A survivorship care plan and treatment summary was developed for this study and was believed to be very patient-centred and helpful. This enabled participants to take back control of their health and well-being and to rebuild confidence.
Conclusions: In this study, participants expressed a need for patient-centred follow-up care that addressed their concerns and supported them in the survivorship phase to get their life back on track. Nurse-led follow-up may offer a viable model of post-treatment survivorship care to lymphoma cancer survivors.

1. Introduction

Lymphomas are haematological cancers that originate from the lymphatic system, and are mainly categorised as either Hodgkin (HL) or non-Hodgkin lymphoma (NHL) (American Cancer Society, 2014). Worldwide, lymphomas represent the sixth most commonly diagnosed cancer (Surveillance Epidemiology and End Results (SEER), 2014). Australian incidence is increasing with an estimated 6323 cases expected in 2017, which will equate to 4.6% of all cancer cases (Cancer Australia, 2017a). However, developments in treatment and supportive care options such as chemotherapy, haematopoietic stem cell transplantation, radiotherapy and targeted therapies have improved five year survival to 76% (Cancer Australia, 2017b). With increased remission and survival rates, many survivors experience issues and concerns, called unmet needs, which can impact quality of life and well-being (Carey et al., 2012; Sant et al., 2014). These can relate to issues such as: fatigue; poor nutrition; exercise capacity; cognition impairment; fear of recurrence; fertility, relationships; finances; employment; and insurance (Taylor et al., 2015; van der Poel et al., 2014). Health can be further compromised by late effects of treatment such as cardiovascular disease and second cancers (Grinyer, 2010; Ng et al., 2011; Travis et al., 2012), often experienced earlier than the general population (Panek-Hudson, 2013).

Haematological survivorship studies mainly report on mixed haematological samples regardless of variations in clinical features, treatment, curability and relative survival (Hall et al., 2013; Lobb et al., 2009; McGrath, 2014). A study of lymphoma (n = 236) and myeloma (n = 178) survivors on anxiety, depression and unmet needs in the early survivorship period (under two years) reported decreasing anxiety and depression rates in the myeloma cohort and increasing rates in the lymphoma cohort (Oberoi et al., 2017). The authors indicated a need for cohort specific studies, especially in the early survivorship period (Oberoi et al., 2017) to ensure targeted support. Lymphoma only studies often reflect a survivorship period beyond 2 yrs at assessment (Ferrer et al., 2011; Friedman et al., 2010; Oerlemans et al., 2014), which may not reflect the unique needs of those who have recently completed treatment, limiting generalisability. A recent study by the authors (Monterosso et al., 2017) reported on focus groups with lymphoma survivors (n = 17), the majority (n = 13, 76%) who were 12–30 months post-treatment completion. Participants recounted unmet needs related to information, coping strategies and support, especially when transitioning into survivorship. Findings suggested cancer nurse

* Corresponding author. Western Australia Cancer and Palliative Care Network, 189 Royal St, East Perth, Western Australia 6004, Australia.
E-mail address: Karen.Taylor@health.wa.gov.au (K. Taylor).

https://doi.org/10.1016/j.ejon.2018.01.011
Received 24 July 2017; Received in revised form 28 January 2018; Accepted 29 January 2018

Qualitative Results from a Phase II Pilot Randomised Controlled Trial of a Lymphoma Nurse-led Model of Survivorship Care.

Abstract

Purpose: To explore and describe lymphoma survivors' thoughts and perceptions of the components of a nurse-led lymphoma survivorship clinic intervention.

Methods: An exploratory, qualitative descriptive study using interviews from 10 participants who had transitioned post-treatment into the survivorship phase via a nurse-led lymphoma survivorship clinic intervention.

Results: Thematic analysis revealed three major themes: Reassurance and individualised care; Information and support; and Empowerment. Participants described the reassurance they gained from having contact with a health professional post-treatment who individualised information and support. A survivorship care plan and treatment summary was developed for this study and was believed to be very patient-centred and helpful. This enabled participants to take back control of their health and well-being and to rebuild confidence.

Conclusions: In this study, participants expressed a need for patient-centred follow-up care that addressed their concerns and supported them in the survivorship phase to get their life back on track. Nurse-led follow-up may offer a viable model of post-treatment survivorship care to lymphoma cancer survivors.

Introduction

Lymphomas are haematological cancers that originate from the lymphatic system, and are mainly categorised as either Hodgkin (HL) or non-Hodgkin lymphoma (NHL) (American Cancer Society, 2014). Worldwide, lymphomas represent the sixth most commonly diagnosed cancer (Surveillance Epidemiology and End Results (SEER), 2014). Australian incidence is increasing with an estimated 6,323 cases expected in 2017, which will equate to 4.6% of all cancer cases (Cancer Australia, 2017). However, developments in treatment and supportive care options such as chemotherapy, haematopoietic stem cell transplantation, radiotherapy and targeted therapies have improved five year survival to 76% (Cancer Australia, 2017). With increased remission and survival rates, many survivors experience issues and concerns, called unmet needs, which can impact quality of life and well-being (Carey et al., 2012; Sant et al., 2014). These can relate to issues such as: fatigue; poor nutrition; exercise capacity; cognition impairment; fear of recurrence; fertility, relationships; finances; employment; and insurance (Taylor et al., 2015; van der Poel et al., 2014). Health can be further compromised by late effects of treatment such as cardiovascular disease and second cancers (Grinyer, 2010; Ng et al., 2011; Travis et al., 2012), often experienced earlier than the general population (Panek-Hudson, 2013).

Haematological survivorship studies mainly report on mixed haematological samples regardless of variations in clinical features, treatment, curability and relative survival (Hall, Campbell, et al., 2013; Lobb et al., 2009; McGrath, 2014). A study of lymphoma (n=236) and myeloma (n=178) survivors on anxiety, depression and unmet needs in the early survivorship period (under two years) reported decreasing anxiety and depression rates in the myeloma cohort and increasing rates in the lymphoma cohort (Oberoi et al., 2017). The

authors indicated a need for cohort specific studies, especially in the early survivorship period (Oberoi et al., 2017) to ensure targeted support. Lymphoma only studies often reflect a survivorship period beyond two years at assessment (Ferrer, Huedo-Medina, Johnson, Ryan, & Pescatello, 2011; Friedman et al., 2010; Oerlemans et al., 2014), which may not reflect the unique needs of those who have recently completed treatment, limiting generalisability. A recent study by the authors (Monterosso et al., 2017) reported on focus groups with lymphoma survivors (n=17), the majority (n=13, 76%) who were 12–30 months post-treatment completion. Participants recounted unmet needs related to information, coping strategies and support, especially when transitioning into survivorship. Findings suggested cancer nurse coordinators could be a feasible approach to delivering structured, individualised support early post-treatment (Monterosso et al., 2017).

Nurse-led models of survivorship care have been proposed to transition patients post-treatment and have demonstrated acceptable outcomes in haematology cohorts (Gates et al., 2015; Howell et al., 2012; John & Armes, 2013). As a minimum, nurse-led models should include: administration of survivor-specific needs assessments to identify patient concerns (McDowell et al., 2010; Stricker et al., 2011); development and delivery of a survivorship care plan and treatment summary (SCPTS), to guide holistic follow-up (Clinical Oncology Society of Australia, 2016; MacMillan Cancer Support & NHS Improvement, 2010; McCabe, Bhatia, et al., 2013); and support to assist survivors to take ownership of their health and well-being (Bodenheimer et al., 2002; Kuijpers et al., 2013). To date, studies that have tested nurse-led models of care have focused on survivors of common cancers (breast, prostate, colon) (Jefford et al., 2016; Maly et al., 2017; Taylor et al., 2015), been based in acute care settings, used long consultations, and involved more

frequent patient contact (Cooper et al., 2010; De Leeuw & Larsson, 2013), which may preclude generalisability to other cancers or limit economic viability.

In order to provide lymphoma survivors with specific and responsive supportive care, the unique issues and unmet concerns of this cohort need to be assessed in the early survivorship period (under one year). The aim of this sub-study was to provide qualitative semi-structured interview data from a sample of participants who had been randomised to the intervention group of the Care After Lymphoma (CALy) phase II randomised controlled trial study (RCT) (Taylor et al., 2016). The RCT aimed to develop and test a nurse-led lymphoma survivorship clinic (NLSC) intervention to assist participants transitioning from treatment completion into the early survivorship phase. This study will add to the limited literature that exists in lymphoma specific early survivorship.

Methods

Methodological framework

A qualitative descriptive methodology was utilised to provide a comprehensive summary of a specific experience by the participants (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000), using a semi-structured interview design. The interview schedule consisted of the same open-ended questions and was developed by the researchers. To ensure participants felt able to express themselves and their perceptions freely, interviews were conducted by an experienced independent researcher.

Sample and setting

A purposive sample of lymphoma patients from a large tertiary hospital cancer centre in Perth, Western Australia were recruited from the intervention group of the RCT. A non-probability purposive sampling provides rich information from participants who have the greatest amount of in-depth knowledge and experience of a particular circumstance or event (Patton, 2014). Only participants who had completed all aspects of the NLSC intervention were approached by the survivorship cancer nurse conducting the clinic intervention. These participants had completed four measures: *Short-Form Survivor Unmet Needs Survey (SF-SUNS); Depression Anxiety Stress Scale (DASS21); Mini Mental Adjustment to Cancer Scale (Mini-MAC);* and *Patient Empowerment Scale* at three time points; baseline (prior to randomisation), 3 months and 6 months. At the first NLSC appointment (approximately one week after baseline), participants completed and received an individualised lymphoma SCPTS, developed for this study (Taylor et al., 2016). Participants' GP were sent a copy. A motivational interview technique was used to provide evidenced-based information, advice and support at the first intervention appointment and reinforced with additional resources and support as required over the next two appointments.

All participants approached agreed to be interviewed. Each participant was nine months' post-treatment completion and the sample reflected an equal gender distribution and range of ages. Data saturation was achieved after ten interviews.

Interviews

The study was approved by the relevant hospital and university human research ethics committees. Informed written consent was obtained by all

participants prior to interview scheduling. Interviews were conducted from February 2016 to May 2017 and occurred after the last NLSC appointment. Telephone interviews were conducted at a time convenient for the participant and were digitally recorded. The following are examples of the interview questions: 'Did you have any concerns or needs not addressed by any of the questions?'; 'What aspects of the clinic would you want to stay the same for future patients?'; 'Would you recommend the clinic to other patients finishing treatment?'; 'How do you feel about having the health concerns, goals and actions individualised to yourself?'; and 'Overall how useful was the SCPTS to you?' Interviews were transcribed verbatim, de-identified and an identifier code applied. Digital recordings and transcribed interviews were saved in a password-protected file on a secure server. After the first three interviews, the question order was slightly altered to enhance the flow of the interview.

Data Analysis

Interview transcripts were imported into NVivo 11 (NVivo 11, 2016) to facilitate management of data and completion of the analysis. Thematic analysis was used to establish patterns and themes within the text (Grbich, 1998; Patton, 2014; Smith, 2007). Thematic analysis allows for participant diversity of ideas and perceptions (Smith, 2007), thus providing a depth of information regarding the personal impact of the NLSC on the participant. Subthemes were developed from the data and allowed for a logical organisation of the themes that emerged. The criteria of credibility, auditability and fittingness were applied to the data analysis process to ensure rigor (Beck, 1993). Credibility was maintained by triangulation with another member of the research team (Beck, 1993) to ensure independent reading and analysis of the transcripts by KT and CB who allocated codes

and themes to the generated data (Braun & Clarke, 2006). The researchers met to discuss the codes and any discrepancies before consensus on emerging themes was reached. The ample use of extracts or quotes from the data demonstrated fittingness to the agreed codes. A comprehensible audit trail maintained auditability, demonstrated by documentation of research planning through to analysis, and through a reflective discourse and debrief process with colleagues.

Results

Participants

Ten semi-structured interviews were conducted with all participants willing to share an opinion for each of the interview guideline areas. Demographic and disease information is shown in Table 6.3.1. There were equal numbers of males and females, with similar age range (24 –74 years) and lymphoma type. The majority of participants resided within the metropolitan area (n=8, 80%), were working (n=6, 60%), were married or defacto (n=6, 60%) and had a university degree or trade qualification (n=8, 80%).

Time elapsed from end of study to interview ranged from 1 to 26 days (mean 6.5 days, SD 7.8 days). The majority of interviews (n=8) were done within 5 days. No time limit was set and interviews ranged from 17 minutes through to 48 minutes (mean 30.5 minutes).

Table 6.3.1 Demographic Characteristics for Interview Participants (n=10)

Characteristics	Males n=5 (50%)	Females n=5 (50%)
Age group at baseline		
24–25	2	2
48	1	1
65–74	2	2
Lymphoma diagnosis		
Non-Hodgkin	2	2
Hodgkin	3	3
Highest level of education		
Secondary school or less	1	1
Trade/vocational college	2	2
University	2	2
Employment status		
Working	4	2
Retired	1	2
No return to work date	–	1
Marital status		
Single	1	2
Married/defacto	4	2
Divorced	–	1
Residence		
Metropolitan	4	4
Regional	1	1

Themes

Three major themes emerged from analysis and coding of data: reassurance and individualised care; information and support; and empowerment. Subthemes have been included to add clarity.

Reassurance and individualised care

Overall, the NLSC was well received and deemed a positive experience for participants, although it would have been reassuring to know about the

clinic intervention during treatment. The assessment questionnaires and the SCPTS were perceived to facilitate individualised care.

Timing of support

Most participants indicated they would have liked knowledge of the clinic intervention during treatment so they could feel reassured that someone was still interested in supporting them and they were 'not going to be abandoned'. This would take the form of a contact person they could trust.

> *"Just knowing that I was still going to get some support" F_25yo_HL*

> *"But to know that look, don't worry, after treatment you are going to see a nurse, that would have been very calming for me" F_64yo_HL*

The use of questionnaires to elicit unmet needs and concerns

Questionnaires were used to elicit unmet needs and areas of concern that could be discussed with participants at the NLSC appointment. Participant responses served as a focus for the follow up appointment. Feedback about the questionnaires indicated some questions were hard to answer.

> *"Sometimes I found that I couldn't say yes or no to the questions, because they didn't apply I suppose, and I had to answer" F_64yo_HL*

Nonetheless, the questionnaires were able to cover aspects thought to be important to participants' overall wellbeing, as one said,

> *"They covered a multitude of the different things like your emotional well-being, mental well-being and physical well-being, all the things that you know you can struggle with" F_24yo_HL*

The supportiveness of the intervention

All participants wanted the intervention structure to remain the same, describing the one-to-one, personalised nature of the intervention a valuable opportunity to talk to someone who was not family, friends or a doctor. They described being listened to and 'feeling safe' to ask questions on a range of topics, especially questions they felt they could not ask their haematologist. Participants indicated support was individualised and felt reassured they could get their life back on track.

> *"The one-on-one was really helpful because then you felt like you could pretty much ask anything, or talk about anything, and you didn't feel like there would be other people around to listen to your private conversations. A safe space, ask questions and get reassurance and the right answers. That was good" F_24yo_HL*

> *"Someone that you can speak to and address the problems that you don't get the time with the doctors to talk about" F_64yo_HL*

Another participant also commented on how he could discuss other aspects of the cancer experience. He said,

> *"What I particularly liked was the opportunity to have a conversation around things other than treatment. Dealing with some of the fears that you may have that you didn't feel like you could ask your specialist about. Or where do I go for complementary therapies. The kind of questions that specialists I don't think are necessarily geared for. Or don't have time really to cover. The ability to have a chat to a nurse that can help you through the next part of the journey" M_48yo_NHL*

A couple of participants indicated that the intervention should have been conducted according to patient preferences. This included a preference for the NLSC to be away from the hospital and closer to their home.

> *"We should be providing services close to home where possible and I think there are some really great opportunities for the survivorship study to get out into the community even though they are still run by the hospital" M_48yo_NHL*

Although two participants found returning to the hospital traumatic, they felt the NLSC experience helped them to overcome their aversion as it was felt to be a safe place they could communicate their fears and receive reassurance.

> *"The torture as a result of the treatment – going back to the hospital made me feel all that. It actually helped me deal with the fact that I can go to the hospital and not feel sick – so there was a positive to" M_48yo_NHL*

Nurse contact and rapport

It was also felt contact should have been more frequent with telephone support between face to face visits, to provide extra support and to 'check-in' with the participant.

> *"I think you need to make them a bit closer together – a bit more frequent. And also make it where patients can choose. Make it more patient-driven - where the patient tells you how often they want to see or talk to someone" F_48yo_NHL*

There was also an indication that many wanted the contact to go beyond the study timeframe. As one participant said,

"I don't feel like I am on my own steam yet. I am thinking 2 years before I have got my confidence and hopefully my health back" F_64yo_HL

All participants described the relationship with the nurse who ran the intervention as comfortable and flexible, and felt they could call or speak to her with any issues if they wanted to. Participants provided comment and perceptions of the nurse as follows:

"And she did explain things so that I understood them more. She was really good at making you feel relaxed" F_48yo_NHL

"You felt like you had enough time to talk about and ask questions you didn't feel rushed and I think that was really good" F_24yo_HL

Survivorship care plan and treatment summary

The written patient-centred SCPTS was described as reassuring when it guided follow-up and for keeping on track with healthy lifestyle behaviours.

"Yes, it was good because it is reassuring, it is a guideline of what to do which I needed and knowing what to look out for and should be doing" F_64yo_HL

Feedback from participants regarding the SCPTS being sent to the GP indicated only two GPs discussed the SCPTS with them. Other participants indicated they either had not seen the GP or the GP acknowledged receipt but did not discuss.

Information and support

Participants appreciated the opportunity to discuss, record and receive written individualised information, support and resources. Although some

information such as late effects was confronting at the time, it was nevertheless appreciated. All felt the information received at the NLSC was relevant and appropriate because it was tailored to their unique needs. Most felt they had not received this information or support from the treating team, however, it was acknowledged that possibly verbal information had been given but not retained.

Individualisation of the SCPTS

Participants liked the individualisation of the health concerns, goals and actions, and the accompanying written information and/or contacts.

> *"When I did have a concern, I was given printed notes about those issues and I think that is really good. Because I do have trouble with my memory now, and I can go back over those notes and sometimes it is like reading it anew, you know" F_64yo_HL*

The treatment summary was well-received with most participants describing it as 'good to have', especially as a tool for communication with other health professionals.

> *"I think it was useful to sit down and have that initial meeting. I think it was really good that it was sent to my GP" F_25yo_HL*

However, one participant was unsure of the value to himself,

> *"But I think this kind of treatment summary is the sort of thing I would give to my GP, or if I am seeing a new Dr, or if I was travelling and I got sick. I almost feel like it's less useful for me, but more useful for other people" M_24yo_HL*

One participant felt the terminology related to the disease location could have been put in simpler language and this helpful recommendation was utilised for subsequent treatment summaries.

> *"Sometimes you don't always understand the medical terms so I think putting it into more simpler language would be a bit more helpful" F_48yo_NHL*

Late effect information

The potential late effect information given on the SCPTS was individualised to each participant. It came as a shock to many that heart disease and other cancers, for example, were possible consequences of the treatment received.

> *"Well that was a bit of a shock to me because they hadn't been mentioned prior to the treatment. … but at the same time, it was probably easier on me not knowing anyway" F_64yo_HL*

Participants appreciated having the information and felt it could help with GP consultations, specifically around planning of health management into the future.

> *"That gave me something to go to my GP with and go okay I think I need to monitor this and this. And it helped me set out a care plan with my Dr as well" F_48yo_NHL*

> *"It is always a bit overwhelming, but I think it is a good way to highlight the possible things that could happen. I think it reduces you're stress because you are not just in the dark about it. I think it is really important for yourself and the GP. If anything does change you know at least you are going to get it early" F_24yo_HL*

One participant indicated they had heard the potential late effect information at diagnosis and another described being told there were some possible late effects after she had completed treatment,

> *"Oh, he just briefly spoke about 'you just need to be careful, you need to look after your skin, you need to do annual breast checks, you need to look after your heart. You know there is a possible risk you could get these problems in the future'. That is sort of how he mentioned it" F_24yo_HL*

Neither participant had received written information and did not feel they knew how to follow-up these risk factors. This was an important consideration when developing the SCPTS to ensure follow-up suggestions for the GP and participant were given.

> *"[GP] just asked me to come in and discussed it with me and then he kind of just saved it and then he linked me in with support services to make sure I was monitoring all of my side-effects, so I think he thought it was good" F_25yo_HL*

Empowerment

Most participants perceived the intent of the NLSC was to assist with transitioning away from a reliance on the treating team, to taking responsibility for monitoring and seeking support.

Nurturing empowerment

All participants described the SCPTS as useful and perceived it as a means to remind them to 'stay on track' with healthy lifestyle behaviours or for encouragement with achieving their goals.

"It just kind of helped remind me of my goals, and every time I had the meeting with [KT], it was like a kind of thing to remember my goals and I thought was a really beneficial thing" M_24yo_HL

Although one participant described the initial discussion and plan as helpful, she felt she should not have had to seek out services and arrange appointments.

"Maybe actually getting linked into the services they talk about. Rather than just getting the information and being left with it, it was kind of like I had to go and seek it out myself. I think it would have been really helpful to have someone contact me" F_25yo_HL

It appeared she did not want to take responsibility for her follow-up care. The remaining participants described understanding and appreciating the need to take back control of their health and well-being. They described the opportunity to discuss and write down their own health concerns, health goals and the actions they planned to take with a health professional as confidence building and assisted in increasing their positivity post-treatment completion.

"There are definitely days where you go thru and you start to question yourself, but being able to talk to someone about it made me feel more confident about being finished" M_25yo_HL

"I started thinking a bit more positive" M_71yo_HL

Participants noted that having the opportunity to record and discuss participant-specific issues had personalised both the appointment and the SCPTS.

"It identified what you personally were worried about and it wasn't just a general thing that everyone can be worried about, but it was specific to you. And then having the specific needs addressed with a certain plan or the actions column that you could put in place. I think that was really helpful because you see how you could be proactive about things" F_24yo_HL

Monitoring progress

Participants felt the follow-up over the next six months in the NLSC allowed them to monitor their progress and see how they were going.

"That was good. It was something to monitor my progress and it feels more personal" M_25yo_HL

"It sort of crystallises your thinking for the future. If you don't do something like that you tend to drift along day to day" F_74yo_NHL

Receiving written and contact information for support allowed participants to engage and take ownership for how and when they dealt with their goals and concerns. Even when issues remained unmet, having the issue normalised was equally important.

"Well the fatigue and the memory [problems] I have still got. It was useful to find that other people suffer the same things, that I am not alone on that!" F_64yo_HL

Usefulness of general health information

Participants received general health and screening information and felt it was helpful. Most read it again at home, then put it aside. They felt the value was in having it to refer to if needed.

"I think that it is really good to get the information and just have it there. I thought that was very handy" F_24yo_HL

This document was not sent to the GP, as GPs involved in evaluating the SCPTS for content clarity, internal consistency and content validity, indicated they knew this information and did not want it. It was noteworthy that two participants had given it to the GP and it had guided follow-up care.

"I basically took all the information into my GP and let him read thru it and he used it to help guide my care plan in the right direction" F_48yo_NHL

Discussion

This study contributes to the growing body of cancer-specific survivorship literature. The current model of specialist follow-up care for cancer survivors is inadequate, with many survivors experiencing unmet needs that can remain poorly addressed throughout the survivorship continuum (De Leeuw & Larsson, 2013). It is essential survivorship care incorporates an awareness of treatment and disease, long-term and late effect risks, as well as healthy lifestyle behaviours (Taylor et al., 2015), and facilitates communication amongst all health professionals and the patient and family. Expertise in the provision of health promotion, support and information has always been the purview of cancer nurses (Jackson et al., 2013), therefore nurse-led models should be considered within any proposed model of survivorship care.

This study involved a cohort of lymphoma participants and specifically targeted those in the early survivorship phase (first nine months' post-treatment). Studies that involve a single subtype of haematological cancer are important in ascertaining the psychosocial and supportive care interventions

that are specific and most appropriate (Oberoi et al., 2017). Assessing and providing an intervention in the early survivorship period has been shown to lead to a reduction in the unmet needs as survivors continue beyond five years (McDowell et al., 2010).

Participants described having time within the NLSC appointment to ask questions and seek individualised support as fundamentally helpful. An important point of difference with medical follow-up where participants perceived the specialist as too busy, or perhaps not interested when they were seeking reassurance and support. Interestingly, some participants would have preferred a follow-up appointment away from the hospital, an important consideration with future planning of nurse-led clinics. Participants had not previously met the nurse who provided the intervention, she is however, a cancer nurse coordinator with extensive haematology/oncology nursing and counselling experience and qualifications. A health professional who can quickly build a strong and positive rapport allows participants a greater opportunity to explore their own unmet needs (Ross, 2013). This may be why participants responded favourably to the intervention and is important when considering nurse-led models of survivorship care.

Empowering participants with an individualised SCPTS that provided disease and treatment knowledge, and allowed them to assume responsibility for their future health and well-being (Taylor & Monterosso, 2015), was described as helpful from all participants. The expectation of younger survivors living longer with potential issues is important (Jabson & Bowen, 2013), nevertheless all participants in this study, regardless of age, appreciated the follow-up guidance they could discuss and implement with their GP. Information on general health and screening allowed participants a

sense of independence of when and how they would seek follow-up. Of particular importance to participants was the opportunity to personalise the SCPTS and concentrate on what was important to them as they moved forward after treatment had completed. Conversely, our study revealed a small subset of participants who were not ready to take back control of their future health and well-being. It is important to acknowledge those patients and provide individualised support that meets their needs at the time, without building further dependency in the survivorship phase.

Survivorship literature highlights the concept of 'teachable moments' (Alfano et al., 2012; Grant & Economou, 2008; Hewitt et al., 2005; Panek-Hudson, 2013) at the end of active treatment to support and promote patient participation in healthy lifestyle behaviours. It was thought that participants in this study would need to be encouraged to engage in healthy lifestyle behaviours. However, it was evident that participants did feel a need to improve their health, and for some, change their lifestyle to adopt healthier lifestyle behaviours they had not been able to do during the stress of treatment. These participants particularly described the opportunity to revisit the SCPTS over the preceding months allowed them to monitor and reflect on their achievements and help them to keep focused on their goals.

Limitations

This study reflects the views of a subset of lymphoma participants who underwent a nurse-led clinic survivorship intervention and therefore could not be generalisable to the wider survivorship population who have experienced a nurse-led clinic. Nonetheless, the use of qualitative interview research allowed an opportunity to gain a deeper understanding of the experiences of this select group. The findings are presented to help build research that is based on patient experience and feedback. The small number

of participants is not a methodological limitation in qualitative research when data saturation is reached.

Conclusion

The interviews were conducted to ascertain the participant's perception of the efficacy and value of the components of the nurse-led intervention and to highlight any issues or challenges for this cohort that could be better addressed in the future. Survivorship care offered by nurses may address the patient-perceived unmet needs at the conclusion of active treatment. Participants indicated the need for security in knowing there would be support when treatment completed and would likewise value the opportunity to have their concerns heard. An individualised SCPTS that empowers survivors to address healthy lifestyle issues and provide a follow-up guide for late effects of the disease and treatment assists in refocusing responsibility back to the patient. Nurse-led survivorship care may offer an acceptable model to deliver patient-centred post-treatment follow-up. This model allows the time required to individualise and tailor supportive survivorship care.

6.4 Results of Test–retest of the SF-SUNS Analysis

Original Article

Test–Retest Reliability of the Short-Form Survivor Unmet Needs Survey

Karen Taylor[1,2], Max Bulsara[3], Leanne Monterosso[1,4,5]

[1]School of Nursing and Midwifery, University of Notre Dame Australia, [2]Western Australia Cancer and Palliative Care Network, Perth, [3]Institute for Health Research, University of Notre Dame Australia, Fremantle, [4]St John of God Murdoch Hospital, Murdoch, [5]School of Nursing, Edith Cowan University Joondalup, Western Australia, Australia

Corresponding author: Karen Taylor RN, BN, GradDipOnc, MN

Western Australia Cancer and Palliative Care Network, Perth, WA, Australia

Tel: 61 08 9222 0202, Fax: 08 9222 2444

E-mail: Karen.Taylor@health.wa.gov.au

Received: December 22, 2017, Accepted: January 22, 2018

ABSTRACT

Objective: Reliable and valid needs assessment measures are important assessment tools in cancer survivorship care. A new 30-item short-form version of the Survivor Unmet Needs Survey (SF-SUNS) was developed and validated with cancer survivors, including hematology cancer survivors; however, test–retest reliability has not been established. The objective of this study was to assess the test–retest reliability of the SF-SUNS with a cohort of lymphoma survivors (n = 40). **Methods:** Test–retest reliability of the SF-SUNS was conducted at two time points: baseline (time 1) and 5 days later (time 2). Test–retest data were collected from lymphoma cancer survivors (n = 40) in a large tertiary cancer center in Western Australia. Intraclass correlation analyses compared data at time 1 (baseline) and time 2 (5 days later). Cronbach's alpha analyses were performed to assess the internal consistency at both time points. **Results:** The majority (23/30, 77%) of items achieved test–retest reliability scores 0.45–0.74 (fair to good). A high degree of overall internal consistency was demonstrated (time 1 = 0.92, time 2 = 0.95), with scores 0.65–0.94 across subscales for both time points. **Conclusions:** Mixed test–retest reliability of the SF-SUNS was established. Our results indicate the SF-SUNS is responsive to the changing needs of lymphoma cancer survivors. Routine use of cancer survivorship specific needs-based assessments is required in oncology care today. Nurses are well placed to administer these assessments and provide tailored information and resources. Further assessment of test–retest reliability in hematology and other cancer cohorts is warranted.

Key words: Cancer survivorship, internal consistency, lymphoma, short-form Survivor Unmet Needs Survey, test–retest reliability

Access this article online

Quick Response Code:

Website: www.apjon.org

DOI: 10.4103/apjon.apjon_4_18

Cite this article as: Taylor K, Bulsara M, Monterosso L. Test–Retest Reliability of the Short-Form Survivor Unmet Needs Survey. Asia Pac J Oncol Nurs 2018;5:165-71.

Test–retest Reliability of the Short-Form Survivor Unmet Needs Survey.

Abstract

Background: Reliable and valid needs assessment measures are important assessment tools in cancer survivorship care. A new 30-item short form version of the Survivor Unmet Needs Survey (SF-SUNS) was developed and validated with cancer survivors, including haematology cancer survivors, however test–retest reliability has not been established.

Aim: To assess test–retest reliability of the SF-SUNS with a cohort of lymphoma survivors (n=40).

Design: Test–retest reliability of the SF-SUNS was conducted at two time points; baseline (time 1) and five days later (time 2).

Methods: Test–retest data was collected from lymphoma cancer survivors (n=40) in a large tertiary cancer centre in Western Australia. Intra-class correlation (ICC) analyses compared data at time 1 (baseline) and time 2 (5 days later). Cronbach's alpha analyses were performed to assess internal consistency at both time points.

Results: The majority (23/30, 77%) of items achieved test–retest reliability scores .429–.757 (fair to good). A high degree of overall internal consistency was demonstrated (time 1=.918, time 2=.945), with scores .646–.942 across subscales for both time points.

Conclusions: Mixed test–retest reliability of the SF-SUNS was established. Our results indicate the SF-SUNS is responsive to the changing needs of lymphoma cancer survivors. Routine use of cancer survivorship specific needs-based assessments are required in oncology care today. Nurses are well placed to administer these assessments and provide tailored information and resources. Further assessment of test–retest reliability in haematology and other cancer cohorts is warranted.

Introduction

Lymphoma blood cancers are malignant T or B cell lymphocytes in the lymphatic system and are categorized under two main types: non-Hodgkin lymphoma (NHL) and Hodgkin Lymphoma (HL). NHL represents approximately 88% of all lymphomas, while HL is predominately diagnosed in the adolescent and young adult population (Howlader et al., 2016). Combined, they represent the sixth most common cancer diagnosis worldwide (Howlader et al., 2016). Consistent with worldwide trends, the incidence of lymphoma in Australia is increasing, and with a projected diagnosis of 6232 cases in 2017, this equates to 4.6% of all cancer cases (Cancer Australia, 2017). An estimated mortality rate of 1481 equates to 3.1% of all deaths from cancer in 2017 (Cancer Australia, 2017). Projected figures for 2017 in the USA have a similar expected incidence of lymphoma of 4.8% and mortality of 3.6%. (Howlader et al., 2016). Treatment for lymphoma generally comprises high-dose chemotherapy and/or targeted immunotherapy agents and may include radiotherapy and hematopoietic stem cell transplants (Carey et al., 2012). These treatments have resulted in an improvement to overall survival of approximately 76% at five years compared with 52% at five years in the 1980s (Cancer Australia, 2017). Notwithstanding the positive impact treatment has had on survival rates

(Sant et al., 2014), the consequences of disease and treatment continue long after treatment completion (Campbell et al., 2014). Long-term and late effects may produce ongoing unmet needs such as fear of recurrence, fatigue, poor nutrition, exercise, fertility, relationship, financial, employment, and insurance issues (Taylor et al., 2015).

To provide optimal supportive cancer care to lymphoma survivors, the identification of patients' perceived concerns and level of support needed is required (Campbell et al., 2014). This is especially important for younger patients (18–45 years of age) where the expectation of long-term remission can raise additional concerns and unmet needs (Arden-Close et al., 2011). Receiving relevant information and practical support soon after treatment ends, especially resources related to healthy lifestyle behaviours (Arden-Close et al., 2011; Boyes et al., 2012; Hall, Campbell, et al., 2013; Hjermstad et al., 2003; Lobb et al., 2009), can help mitigate the impact of disease and treatment and lead to fewer unmet needs further along the survivorship continuum (Aziz, 2007; McDowell et al., 2010). A qualitative study with lymphoma cancer survivors (n=17) undertaken in Western Australia (Monterosso et al., 2017) reported unmet informational and practical needs as participants transitioned from treatment to the survivorship phase. The findings suggested tailored post-treatment support and interventions are fundamental components of excellent survivorship care.

The measures used to assess unmet needs are equally important. Generic cancer measures which comprise items related to diagnosis and treatment are often not specific enough for the survivorship phase (Taylor & Monterosso, 2016). Comprehensive, relevant, reliable, and validated needs assessment measures that are survivor-specific are essential to capture unmet needs that become evident when treatment ends (Taylor & Monterosso,

2016). These measures can guide health professionals in providing individualised information, support, and resources (Campbell et al., 2014; Taylor & Monterosso, 2016). Two recent systematic reviews (Jiao et al., 2017; Taylor & Monterosso, 2016) revealed that needs assessment tools are varied and may not capture all the possible unmet needs patients may have. The reviews likewise found validity and reliability evidence limited. The Survivor Unmet Needs Survey (SUNS) was identified as a measure that had strong psychometric properties and was developed and psychometrically tested with a large cross-sectional sample of cancer survivors (*n*=550) including a small cohort of haematology cancer participants (*n*=31, 5.6%) (Campbell et al., 2010). Campbell et al. (2010) confirmed a high overall internal consistency of items for their study with an overall Cronbach's alpha of 0.99. The authors also reported high test–retest reliability although the results were not published (Campbell et al., 2010). Internal consistency of the SUNS was further tested in two studies of haematological cancer survivor cohorts. A cross-sectional study with 529 haematological cancer survivors (Hall, D'Este, Tzelepis, Sanson-Fisher, & Lynagh, 2014) demonstrated overall Cronbach's alpha values >0.9, and a weighted Kappa coefficient score of >0.6 for test–retest reliability; acceptability was reported for 40/89 (45%) items. Qualitative data from 17 semi-structured interviews indicated that the SUNS was considered relevant by this cohort of haematological cancer survivors (Hall, D'Este, et al., 2014). A cross-sectional study of haematological cancer survivors from Australia and Canada (*n*=437) reported similar levels of unmet needs across the two cohorts using the SUNS, with fatigue (*n*=76, 17%) and financial concerns (*n*=39, 9%) rated as high unmet needs (Hall, Campbell, et al., 2013). Despite the clinical utility of the original SUNS, it was considered potentially burdensome for use in the clinical setting given the large number of items (*n*=89). In 2014, the 30-item short-form-SUNS (SF-SUNS) was developed and validated with a mixed sample of cancer

survivors (*n*=1589), including haematological cancer survivors (*n*=84, 5%) (Campbell et al., 2014). Construct validity and intraclass correlation coefficients (ICCs) of the SF were similar to those of the original SUNS. Cronbach's alpha scores for the final four domains were ≥0.85, and ICCs for the three domains from the original SUNS (financial concerns, information, and access and continuity of care) and the SF-SUNS were high (>0.9). Discriminant validity demonstrated the SF-SUNS ability to discriminate between individuals who had recently received treatment and those who had not. The authors recommended further testing of the SF-SUNS for test–retest reliability (Campbell et al., 2014). The 30-item SF-SUNS was therefore judged to be more practical and likely to be completed by participants in our larger study, particularly as the SF-SUNS was one of four measures to be administered to participants in a pilot randomised trial to measure the effect of a nurse-led survivorship model of care (Taylor et al., 2016).

For researchers and clinicians to develop targeted follow-up support for cancer cohorts underrepresented in survivorship literature, such as lymphoma (Swash et al., 2014), cohort-specific studies in the early survivorship phase are required (Oberoi et al., 2017). Therefore, this study recruited only those with a lymphoma diagnosis who had completed treatment. Discerning the issues and concerns of this group requires survivor-specific measures that are psychometrically sound and fully tested. The SF-SUNS has been used within the clinical setting; however, since test–retest reliability of the SF-SUNS had not been established, the aim of the present study was to establish test–retest reliability of the SF-SUNS to add to the psychometric data available in the published literature on this instrument.

Methods

Design

Test–retest reliability of the SF-SUNS was conducted at two time points: baseline (time 1) and 5 days later (time 2). This time frame was chosen to reduce recall bias and change in the level of unmet needs (Terwee et al., 2007). Ethical approval to conduct the study was obtained from the human research ethics committee of the study site (2015-020) and university (015007F).

Population and setting

A convenience sample of 40 lymphoma cancer patients who were 3 months' post-treatment completion were recruited from the haematology department of a large tertiary hospital in Western Australia. Inclusion criteria were pathologically confirmed new diagnosis of NHL or HL; completed first-line curative-intent chemotherapy or second-line curative-intent autologous stem cell transplant within the previous 3 months; no radiological evidence of lymphoma posttreatment (on positron emission tomography [PET] scan); able to understand and read English; and over 18 years of age. Participants were excluded if they had not been treated with chemotherapy; had received further treatment at another hospital (as experiences or interventions may have introduced bias); or were cognitively impaired or experiencing an acute mental health condition that prohibited the provision of informed consent.

Sample size

The sample size calculation was derived from Walter et al. (1998) and used a fixed alpha of .05 from two observations with reliability values of R0=.6 (acceptable) and R1=.8 (expected), indicating a minimum sample size of n=39.

Short-Form Survivor Unmet Needs Survey

The SF-SUNS assesses unmet needs across four domains: information needs (3 items); work and financial needs (8 items); access and continuity of care needs (6 items); and coping, sharing, and emotional needs (13 items). Patient self-reported concerns and the level of support required are measured using a Likert-type scale: 0—no unmet need, 1—low unmet need, 2—moderate unmet need, 3—high unmet need, and 4—very high unmet need. Domain scores are generated by adding each item score and dividing by the total number of domain items (Filsinger, Burkhalter, & Campbell, 2011).

Procedure

The researcher identified and approached eligible participants after treatment completion to discuss the study and provide them with a participant information and consent form. Following informed consent, demographic and baseline (time 1) SF-SUNS questionnaires were then administered to participants. After completion of the questionnaires, participants were provided with another blank copy of the SF-SUNS accompanied by instructions to complete the questionnaire at home 5 days later and post back using the supplied reply-paid addressed envelope. Participants were advised to record the date of completion if this differed from the specified due date.

Data collection

At the request of the research team's haematologist, baseline demographic and SF-SUNS data were collected from consenting participants 3 months post-treatment completion and PET scan to confirm the absence of disease. Demographic information obtained included lymphoma type, stage of disease, type of treatment received (chemotherapy +/− radiotherapy), date of diagnosis, time since diagnosis, comorbid conditions, gender, age, weight,

marital status, age of children (if any), postcode, occupation, income level, education level, and health behaviours such as smoking and alcohol consumption. Participants then completed the SF-SUNS at time 2 (5 days following time 1 completion) at home.

Data Analysis

All analyses were performed using IBM SPSS Statistics Version 25 data analysis software (IBM Corp, 2017). Descriptive statistics were used to analyse all data. Descriptive analyses were used to analyse and describe demographic data. To assess for absolute consistency of SF-SUNS items for test–retest reliability data, an ICC with a random-effects model was used to compare each item at time 1 and time 2. The ICC measure was chosen for its ability to discriminate between sets of scores ranked in the same order but not necessarily in agreement and adjusts for the degree of test–retest agreement expected by chance (Bujang & Baharum, 2017; Cicchetti, 1994). The closer the value of the ICC to 1.0, the greater the reliability of the item or measure (Weir, 2005). The guidelines developed by Cicchetti and Sparrow (1981) were used to determine the level of clinical significance of the ICC values obtained: <.40 = poor, .40–.59 = fair, .60–.74 = good, and >.75 = excellent. For this study, items classified as achieving "fair to excellent" reliability, ICC >.40 (Rosner, 2016), were reported. Cronbach's alpha, a measure of internal consistency, was used to measure the scale reliability.

To examine the distribution of unmet needs, the five levels of unmet need were collapsed to three levels. A score of 0 (no unmet need) remained the same. Scores of 1 or 2 (low and moderate unmet need) were reclassified as 1 (low–moderate unmet need), and scores of 3 or 4 (high and very high unmet need) were classified as 2 (high–very high unmet need).

Results

Participant characteristics

There were slightly more male (*n*=22, 55%) participants, and a greater number of participants with NHL (*n*=29, 72.5%) compared with HL (*n*=11, 27.5%) (Table 6.4.1). This was in keeping with the current disease statistics which reflect a greater number of NHL than HL diagnoses (Howlader et al., 2016). Almost one-third of participants were aged between 18 and 39 years (32.5%), and a greater proportion had a university qualification (*n*=6, 40%) (Table 6.4.1). Although the majority of participants were currently working (*n*=15, 37.5%) and had been throughout their treatment, 30% (*n*=12) were looking for work or had no return to work date set. Over half the participants had a partner (*n*=25, 62.5%). Forty participants completed both time 1 and time 2 SF-SUNS. The majority of participants (*n*=35, 87.5%) completed time 2 SF-SUNS 5 days after time 1 (range 4–7 days).

Table 6.4.1 Baseline Participant Demographic and Disease Characteristics (n=40)

Characteristics	N (%)
Gender	
Male	22 (55.0)
Female	18 (45.0)
Age group (years)	
18–39	13 (32.5)
40–59	12 (30.0)
60–74	9 (22.5)
75+	6 (15.0)
Marital status	
Single	10 (25.0)
Married/de facto	25 (62.5)
Divorced	3 (7.5)
Widowed	2 (5.0)
Lymphoma diagnosis	
Non-Hodgkin	29 (72.5)

Hodgkin	11 (27.5)
Highest level of education	
Secondary school or less	11 (27.5)
Trade, vocational college	13 (32.5)
University or higher	16 (40.0)
Employment status	
Working	15 (37.5)
Retired	13 (32.5)
Looking for work/no return to work date	12 (30.0)

Test–retest

ICCs, 95% confidence intervals, and clinical significance are shown in Table 6.4.2. One (3%) item met the "excellent" criteria for clinical significance; Finding car parking I can afford at the hospital or clinic. Twelve (40%) items met the "good" criteria (.60–.74) and 11 (37%) items met the "fair" criteria (.40–.59). In summary, test–retest data showed "fair" to "good" reliability for the majority of items (23/30, 77%).

Internal consistency

Overall Cronbach's alphas were .918 at time 1 and .945 at time 2, with subscales (Table 6.4.2) ranging from .744 and .695 for information needs, .646 and .828 for work and financial needs, .891 and .853 for access and continuity of care, and .897 and .942 for coping, sharing, and emotional needs, respectively. These results support strong internal consistency for the overall scale. Item-to-total correlations between .40 and .70 indicate that items are not redundant or measuring needs similar to other items within the instrument (Leong & Austin, 2006). Using this criterion, the SF-SUNS demonstrated item-to-total correlations between .40 and .70 at time 1 for 24 items (80%) and at time 2 for 19 items (63%) (Table 6.4.2). The majority of items were considered relevant and to be measuring unique needs.

Table 6.4.2 Item Test–retest Reliability and Internal Consistency (n=40)

Domain (*n*=4)	Item Description	ICC (95% CI)	Level of Clinical Significance	Cronbach's Alpha		Item-to-total Correlation	
				Time 1	Time 2	Time 1	Time 2
Information needs	Items (*n*=3)			.744	.695		
	Finding information about complementary or alternative therapies	.694 (.490–.825)	Good			.304	.504
	Dealing with fears about cancer spreading	.560 (.304–.740)	Fair			.589	.626
	Dealing with worry about whether treatment has worked	.568 (.316–.746)	Fair			.654	.714
Work and financial needs	Items (*n*=8)			.646	.828		
	Worry about earning money	.631 (.401–.787)	Good			.486	.466
	Having to take a pension or disability allowance	.390 (.093–.623)	Poor			.446	.384
	Paying household bills or other payments	.692 (.488–.825)	Good			.550	.597
	Finding what type of financial assistance is available and how to obtain it	.700 (.499–.829)	Good			.668	.713
	Finding car parking that I can afford at the hospital or clinic	.757 (.586–.864)	Excellent			.018	.455
	Understanding what is covered by my medical insurance or benefits	.314 (.007–.568)	Poor			.203	.060
	Knowing how much time I would need away from work	.736 (.553–.851)	Good			.545	.501
	Doing work around the house (cooking, cleaning, home repairs, etc.)	.366 (.065–.606)	Poor			.122	.701
Access and continuity of care	Items (*n*=6)			.891	.853		
	Having access to cancer services close to my home	.446 (.159–.663)	Fair			.437	.619
	Getting appointments with specialists quickly enough	.377 (.078–.614)	Poor			.701	.436

	(oncologist, surgeon, etc.)						
	Getting test results quickly enough	.662 (.444–.806)	Good			.569	.507
	Having access to care from other health specialists (dietitians, physiotherapists, occupational therapists)	.526 (.260–.718)	Fair			.508	.671
	Making sure I had enough time to ask my doctor or nurse questions	.579 (.329–.753)	Fair			.590	.477
	Getting the health care team to attend promptly to my physical needs	.529 (.264–.720)	Fair			.592	.497
Coping, sharing and emotional needs	Items (*n*=13)			.897	.942		
	Telling others how I was feeling emotionally	.429 (.140–.651)	Fair			.577	.476
	Finding someone to talk to who understands and has been through a similar experience	.329 (.023–.578)	Poor			.449	.573
	Dealing with people who expect me to be "back to normal"	.620 (.386–.780)	Good			.568	.768
	Dealing with people accepting that having cancer has changed me as a person	.509 (.239–.707)	Fair			.681	.812
	Dealing with reduced support from others when treatment has ended	.673 (.406–.813)	Good			.824	.824
	Dealing with feeling depressed	.734 (.550–.850)	Good			.535	.720
	Dealing with feeling tired	.487 (.211–.692)	Fair			.566	.712
	Dealing with feeling stressed	.552 (.294–.735)	Fair			.780	.691
	Dealing with feeling lonely	.715 (.522–.838)	Good			.527	.615
	Dealing with not being able to feel "normal"	.475 (.196–.683)	Fair			.570	.697
	Trying to stay positive	.628 (.397–.785)	Good			.548	.646
	Coping with having a bad memory or lack of focus	.639 (.412–.791)	Good			.496	.864
	Dealing with changes in how my body appears	.275 (–.037–.537)	Poor			.229	.244

Note. ICC: Intraclass correlation; CI: Confidence interval

Discussion

Our study is the first to report test–retest data for the SF-SUNS. The majority of items met absolute consistency for reliability ICC scores of >.40 for test–retest, categorized as "fair" to "good." An "excellent" clinical significance score was achieved for only one item (3%), related to car parking costs which are unlikely to change over time. Needs-based instruments such as the SF-SUNS measure the degree of an individual's perceived unmet need at one point in time. Importantly, Cronbach's alpha scores at time 1 and time 2 demonstrated a high degree of internal consistency and high item-to-total correlations, confirming that items in the tool were reliable.

A criterion for psychometrically sound needs-based tools is the requirement for an instrument to be responsive to changes over time (DeVellis, 2012; McDowell, 2006; Streiner & Norman, 2003). Although our ICC results may reflect the responsiveness of the SF-SUNS to changes in need over the data collection period, further research is required to detect clinically meaningful change for patients (Jiao et al., 2017). All participants completed the time 2 questionnaire at home, well away from the haematology clinic where the time 1 questionnaire was completed. It is possible that participants may have had additional time to more accurately reflect on the level of unmet need. Similarly, time 1 scores may have been impacted by participants' anxiety at the hospital appointment where patients often worry about test results and potential relapse (Thewes et al., 2012). In addition, fatigue is a recognized effect of lymphoma treatment (Arden-Close et al., 2011), and may have potentially affected participant responses at either time point. Finally, most items were similarly balanced for both time points from "no unmet need" to "low unmet need" or "low unmet need" to "no unmet need."

It is important to allow cancer survivors the opportunity to self-identify unmet needs and issues of concern. Survivorship needs-based instruments provide a consistent method for this purpose (Hawkins et al., 2008). Furthermore, it is important that any tool is responsive to change as individuals' issues, concerns, thoughts, and feelings can change from day-to-day (McDowell, 2006; Streiner & Norman, 2003), particularly during survivorship transition as individuals move on with their lives after cancer treatment. Such reliable and valid instruments can facilitate individualized survivorship care and tailored support and resources (Taylor & Monterosso, 2016).

It is important to note that the original SUNS demonstrated low test–retest reliability acceptability (Hall, D'Este, et al., 2014), with the authors suggesting that the test–retest timeframe was too long at 28 days. Since our study was part of a larger study involving an intervention group, a 5-day later test–retest assessment was deemed an appropriate timeframe to ensure completion of the time 2 SF-SUNS before the implementation of any needs-based interventions associated with the larger study (Taylor et al., 2016). Importantly, this time period was also in keeping with the recommended 2–14-day time period for test–retest procedures (DeVellis, 2012; McDowell, 2006; Streiner & Norman, 2003).

A limitation of this sub-study may have been the sample size of 40 participants, despite sample size calculations indicating that this number would be sufficient to adequately perform test–retest reliability with confidence. Many participants (*n*=16, 40%) attended the baseline appointment, where time 1 SF-SUNS was administered, accompanied by a support person (partner or family member). We acknowledge this may have influenced time 1 responses. Likewise, time 2 responses may have similarly

been influenced as the SF-SUNS was completed at home. We can confirm that participants did not receive any needs-based interventions between time 1 and time 2 completion of the SF-SUNS.

Conclusion

We suggest that needs-based assessments should be used routinely during the survivorship period to facilitate survivorship care that is tailored and responsive to individuals' changing needs. Valid and reliable survivor-specific measures are essential for routine screening and follow-up. Nurses in particular are a valuable resource in the survivorship phase to assess for areas of concern or unmet needs and for the provision of information, support, and resources that are tailored to the individuals' unique needs. Further testing of the SF-SUNS is recommended in haematology and other cancer populations to further understand and demonstrate the responsiveness of this instrument to changes in need over the survivorship period.

Chapter Summary

This chapter has documented the analysis and findings of data collected in Phases Three and Four of this study and reports possibly the first published data from a pilot RCT to test a nurse-led lymphoma survivorship model of care.

Results from the pragmatic RCT showed the proposed conceptual framework could guide a survivorship model of care that empowered survivors to make changes to improve their quality of life and engage in healthy lifestyle behaviours. This model allowed participants the time to individualise and tailor their own supportive survivorship care needs. Randomisation was found to be effective as both groups were well-matched for demographic variables. Univariate and multivariate analyses demonstrated that intervention participants who received the nurse-led lymphoma survivorship model of care had lower levels of unmet informational and practical needs and lower levels of depression, anxiety and stress at study completion compared to the control group participants. Likewise, better adjustment to the cancer diagnosis and self-empowerment was shown in those randomised to the intervention group.

Findings from Phase Four GP evaluations indicated that GPs made use of and were satisfied with the unique lymphoma SCPTS they received for intervention participants.

As previously stated the nurse-led lymphoma survivorship model of care used with this lymphoma cohort had not been previously reported in the published literature and was a new undertaking at the study site. Therefore, it was considered important to understand the experiences and perspectives

of intervention participants from a qualitative perspective. The qualitative study (Phase Four) provided strength to the quantitative data collected during the pragmatic RCT by documenting and analysing the personal experiences and perceptions of a group of intervention participants. Results demonstrated participants needed support when treatment finished. In particular, they valued: the opportunity to discuss and record their concerns on the individualised SCPTS; the record of treatment and guidelines for follow-up with the GP; and promotion of their engagement in healthy lifestyle behaviours. Likewise, participants appreciated the one-to-one nature of the appointments and the additional information and further support provided.

As mentioned, test–retest reliability data for the SF-SUNS measure had not been previously published, and it was considered important to undertake this additional step during the pragmatic RCT. Findings indicated the majority of the SF-SUNS items achieved 'fair' to 'good' for reliability with this cohort. This published manuscript is considered an important contribution to the cancer survivorship literature.

The following chapter provides a discussion of the results from this study including the pragmatic RCT, GP evaluations and qualitative interviews with intervention participants. The chapter will begin with a summary of findings from Phase One and will conclude with a discussion of the limitations and strengths of the thesis research.

Chapter Seven — Discussion

7.0 Discussion

The following discussion will present and explore the relevance of the major findings from this study in relation to theoretical and clinical issues. This will be followed by a discussion on the limitations and strengths of the study. The final chapter will present the conclusions from this study in addition to implications and recommendations for nursing practice, education and future research.

The principal research question developed and tested in this study was that it might be possible to decrease the number and level of unmet informational, practical and emotional needs that may occur when lymphoma patients finish treatment, and promote self-empowerment using a nurse-led lymphoma survivorship model of care. This research was undertaken in four phases, and development of the components of the nurse-led lymphoma survivorship model of care and their implementation are reported in detail in this thesis.

It was intended that this study would build on Australian cancer survivorship research, in particular, lymphoma-specific survivorship. The conceptual framework for this study was based on Bandura's theory of self-efficacy. This was considered the most appropriate framework to guide the development of the nurse-led lymphoma survivorship model of care since it emphasises the importance of individual empowerment to enable the patient to take responsibility for their future health and well-being. In addition, providing support and encouragement may assist with better adjustment to having cancer and resumption of normal activities of daily living. To achieve this aim, a pragmatic RCT to examine a nurse-led model of survivorship care was conceptualised, developed and delivered to a cohort of lymphoma survivors at a large tertiary cancer centre in Perth, Western Australia. The

intervention comprised a patient-centred survivorship care plan and treatment summary (SCPTS), motivational interviewing to empower survivors to make healthy lifestyle changes and individualised support and tailored resources. To date, no RCTs have been published that report a nurse-led survivorship model of care using a lymphoma survivor cohort.

This study utilised and collaborated with a multidisciplinary advisory committee that included lymphoma survivor consumers. It was particularly important that this research engaged with consumers who had undergone previous lymphoma treatment at the study site and were thereby able to have input into the design, delivery and evaluation methods of this research. This research is, therefore, able to address the Australian Commission on Safety and Quality in Health Care, National Safety and Quality Health Service (NSQHS) Standard 2, Partnering with Consumers (Australian Commission on Safety and Quality in Health Care, 2017). Likewise, this research addresses the NSQHS Standard 5, Comprehensive Care, as it ensured the care given to participants was individualised and considered the impact of the disease and treatment on their health, quality of life and well-being (Australian Commission on Safety and Quality in Health Care, 2017).

A diagnosis of cancer is the beginning of a profound and life-changing experience that can have a long-lasting effect on the remainder of a person's life and the lives of their family and friends (Corner & Bailey, 2009). Research is constantly striving to improve the treatment offered and therefore overall survival rates (Hewitt et al., 2005; Wait et al., 2017); however, a valuable opportunity is missed in supporting the quality of survival once treatment is completed (McConnell, White, & Maher, 2017). A cancer-free future may often be characterised by ongoing physical and psychosocial health concerns (Aaronson et al., 2014). Post-treatment, health professionals have an

opportunity to provide support for a range of biopsychosocial issues and have a positive effect on facilitating a change or improvement in healthy lifestyle behaviours. There is increasing evidence that a healthy lifestyle reduces the risk of morbidity and mortality and many interventions, such as exercise, are safe and effective (Aaronson et al., 2014); however, promotion and referral for these interventions is low (Boyes et al., 2012).

The rationale for Phase One (the systematic and integrative reviews) was to examine: how lymphoma survivorship follow-up is occurring and the models of care currently in use; the use of survivorship care plans and/or treatment summaries with this cohort; and the assessment measures that are used to determine survivorship unmet needs. This was followed by Phase Two where components of the intervention were developed for use in Phase Three which comprised the pragmatic RCT. In Phase Four additional evaluation of the model of care and the SCPTS was conducted with GPs and a subset of intervention participants.

A full discussion related to each of the three literature reviews, qualitative interviews with intervention participants and the SF-SUNS test–retest results is in each published article. The first section of this chapter will provide a summary of the three literature reviews. This will be followed by a presentation and exploration of the relevant major findings from the pragmatic RCT and GP evaluations. Furthermore, a summary of the qualitative interviews and the SF-SUNS test–retest is provided in this chapter. This chapter concludes with a consideration of the limitations and strengths of this thesis.

Summary of the Phase One Literature Reviews

Published models of post-treatment cancer follow-up and/or survivorship care was explored in the *models of survivorship care provision in adult patients with haematological cancer: an integrative literature review* (Taylor et al., 2015). This review found a lack of guidance and consensus for follow-up care including determination of the appropriate health professional/s to deliver survivorship care. The review likewise highlighted a lack of consensus regarding the type of care model most appropriate for the early survivorship period. It was also evident that further lymphoma-specific models of survivorship care research are required. This particular cohort of cancer patients has different needs (Parry et al., 2010) than those of the more prevalent cancers such as breast, prostate and colorectal. These cancer types have similar trajectories of treatment and care and generate the most survivorship model of care research. Any model of care proposed for early lymphoma survivors needs to be offered in addition to haematologist follow-up as the risk of lymphoma recurrence in the first two years' post-treatment is very high (Lymphoma Association, 2017).

Haematology follow-up for at least five years appears the norm in the published literature (Franco et al., 2017); and concurs with follow-up provision undertaken by the haematology department in Western Australia where this research was undertaken. In this follow-up period other health professionals, including GPs, may be involved in care provision and therefore open and effective communication is essential (Dicicco-Bloom & Cunningham, 2013). Nurses have been proposed as a conduit to transition survivorship care from the treating team to the GP (Cooper et al., 2010). This will necessitate the communication of potential late effects of disease and treatment and the recommended surveillance and management. Research

has indicated many GPs may not be provided with this vital information (Hall, Lynagh, et al., 2013). Nurses may similarly have an important role in normalising post-treatment effects (Franco et al., 2017) and encouraging survivors to seek information and support on healthy lifestyle behaviours and how to return to "normal functioning" sooner (Cooper et al., 2010). These findings were the basis for conceptualising and developing a nurse-led lymphoma survivorship model of care.

A key recommendation of the Institute of Medicine for survivorship care was the dissemination of SCPTS to all cancer survivors (Hewitt et al., 2005). The *survivorship care plans and treatment summaries in adult patients with hematologic cancer: an integrative literature review* (Taylor & Monterosso, 2015), reported a lack of evidence on their use with lymphoma survivors and furthermore on the most appropriate methods of developing and delivering this document. The reviewed literature (Taylor & Monterosso, 2015) and the researcher's recent search for newly published literature on lymphoma SCPTS usage demonstrated a continued lack of routine use.

Experienced oncology nurses are able to provide holistic and individualised information provision and have therefore been recognised as a practical solution to the creation and delivery of SCPTS (Jackson et al., 2013; Marbach & Griffie, 2011). To provide timely information and resources, two authors (Curcio et al., 2012; Sabatino et al., 2013) proposed that dissemination of SCPTS should occur soon after treatment completion. This recommendation was endorsed by a recent qualitative study with lymphoma patients undertaken at the same treatment centre as this research. These participants indicated a lack of information and support when treatment ended (Monterosso et al., 2017). In the present study, delivery of the SCPTS to participants randomised to the intervention group occurred three months

after treatment completion to facilitate early identification of issues and concerns and provision of appropriate support, information and resources. The SCPTS review likewise reported a lack of detail on how standardised templates were completed and the evidence-based guidelines that were used. This was addressed in the development of a unique lymphoma-specific SCPTS for this thesis. A recent study with breast cancer participants (Mayer et al., 2016), as outlined in the literature review update in Chapter Two, reported a decrease in levels of anxiety in patients when SCPTS provision by a nurse was coupled with GP follow-up to discuss the SCPTS contents. Although this finding had not been available when this thesis was developed, participants in the present study who had received an SCPTS were encouraged to discuss the contents with their GP after the first NLSC appointment and then at each subsequent GP visit. Qualitative results from this thesis reported that participants experienced feelings of shock when potential late effects information was given. However, participants indicated an appreciation of this knowledge to empower them to follow-up in the future (Ng, 2014). This finding confirmed those of previous studies that reported tailored SCPTS could empower survivors to assume responsibility for future surveillance and disease management (Hill-Kayser et al., 2013; Jabson & Bowen, 2013; Jackson et al., 2013).

Nurses and health professionals require reliable, validated and accurate measures to assess survivors for unmet issues and concerns once treatment has completed (Muzzatti & Annunziata, 2013). Early identification is important to ensure management and support is delivered effectively and appropriately (Girgis, Delaney, & Miller, 2015). The *systematic review of the tools used to assess the informational and practical needs of the acute leukaemia and lymphoma survivors* (Taylor & Monterosso, 2016) in this thesis reported a need for survivorship-specific needs assessment measures that had been used in

lymphoma survivor cohorts. Likewise, early assessment to mitigate unmet needs in the future was reported (McDowell et al., 2010) and considered applicable for this research. Therefore, a post-treatment timeframe of three months for baseline assessment was established. As the review found limited published literature on survivorship-specific measures to assess unmet needs in lymphoma survivor cohorts, this is an area that requires further research.

In developing the SCPTS for this study, it was important to seek and act upon the feedback given by clinicians and survivors. GPs indicated a preference for a succinct treatment summary, a finding supported by a recent study delivering an SCP to primary care physicians (Ezendam et al., 2014). Therefore, a concise document was developed that was deliberately patient-centred and only reported possible late effects that were pertinent to each participant. The SCPTS literature review undertaken as part of this thesis reported on large templates which covered all potential late effects and were therefore not tailored to the individual. As reported by Klemanski et al. (2016), the American Society of Clinical Oncology (ASCO) has recently reduced their SCPTS templates to two pages, in line with Commission on Cancer standards which clarified the type of information that an SCPTS was to include (Klemanski et al., 2016). The minimum information required is similar to that included in the SCPTS developed for this study (Deline, 2016); however, the care plan element differs. The new ASCO SCPTS templates provide a list of problem areas encountered by survivors, whereas participants in this study were able to generate their own lists.

Discussion of Phase Three Pragmatic Randomised Controlled Trial

This pilot study contributes evidence-based data to the emerging body of nurse-led survivorship research, and in lymphoma-specific care. In Western Australia, the current model for all haematology cancer survivorship follow-up is haematologist-led, however many survivors experience a range of unmet needs that may be poorly identified and addressed throughout the survivorship period (De Leeuw & Larsson, 2013; Monterosso et al., 2017). Health care providers need to recognise the importance of survivorship care as a standard component of optimal holistic cancer care that involves patients and families, along with other health professionals, including primary care. The objective of the study was to assist participants, randomised to the intervention, to transition from the end of treatment into follow-up care, often referred to as the early survivorship phase, up to two years' post-diagnosis (Aziz, 2007; McDowell et al., 2010). The aim was to assess if the intervention reduced the number and level of self-reported unmet informational, practical, emotional needs, depression, anxiety and stress and increased adjustment to cancer and patient empowerment. Additionally, the study assessed the use of an individualised SCPTS as a resource for participants and their GPs to have a written record of their disease, treatment and future surveillance of potential late effects (Taylor et al., 2015). Notably, the SCPTS was also a tool for participants to record their three most important concerns and three most important health goals, along with the actions required to deal with concerns and achieve health goals. The intervention likewise utilised the 'teachable moment' (Alfano et al., 2012; Panek-Hudson, 2013) that presents at treatment completion, to support and encourage healthy lifestyle behaviours (Taylor & Monterosso, 2015). This

was particularly salient for the younger participants, as there was an expectation of a longer survivorship period (Jabson & Bowen, 2013).

The early survivorship phase was chosen to provide responsive, supportive care for the unique concerns and unmet needs of this cohort. A prospective longitudinal study found 30% (n=353) of survivors had five or more unmet needs at treatment completion that did not improve after six months (Armes et al., 2009). This concurs with research which has suggested less unmet needs were evident in the extended survivorship phase (over five years) if assessments and interventions were undertaken in the early survivorship phase (up to two years' post-diagnosis) (McDowell et al., 2010). It is possible this thesis study may have also decreased the feelings of abandonment survivors often feel at treatment completion (Matheson et al., 2016; Monterosso et al., 2017; Taylor, Monterosso, & Bulsara, 2018).

The present pilot study suggests that survivors do have issues and concerns post-treatment that can remain unresolved over time. This may impact quality of life (QoL) (Hansen et al., 2013). Although statistical significance was not reached in this pilot study, a comparison of the mean results obtained from the two groups indicated a trend towards lower unmet needs in the intervention group at Time 3 with higher levels of empowerment revealed. Overall, those reporting no unmet needs at the completion of the study on the SF-SUNS (n=5, 9%) was very low. In contrast, a study of Canadian and Australian haematological survivors, one to 60 months' post-diagnosis, found 21% (n=71) reported no unmet needs (Hall, Campbell, et al., 2013). As a pilot study in the early survivorship phase, it is difficult to compare findings with larger studies with variable survivorship periods that found low levels of unmet needs in haematological survivor cohorts (Campbell et al., 2014; Hall, D'Este, et al., 2014).

The most endorsed concerns on the SCPTS were fear of recurrence, fatigue and cognition impairment. These findings are consistent with current research. A recent study of leukaemia and lymphoma survivors (n=477) reported the prevalence of fear of recurrence was higher in females and younger participants (Jones et al., 2015). This finding was supported by a study of different cancer types (n=2615) including lymphoma survivors (n=379), that found those in active follow-up and the early survivorship phase (0 to 5 years' post-diagnosis), experienced more fear of recurrence (van de Wal et al., 2016). Nonetheless, this study revealed satisfaction with information provision led to less reported fear of recurrence (van de Wal et al., 2016). This was reflected in the present study, where only one intervention participant recorded a high/very high level of unmet need for fear of recurrence at Time 2 and 3, compared with six control group participants at Time 2 and 3.

A recent study of Dutch HL survivors compared with a normative population revealed higher fatigue prevalence (41–43% vs 23–28%). Those with fatigue also had higher levels of anxiety (23% vs 13%) and depression (18% vs 12%) (Daniels et al., 2014). The authors suggested coping strategies may provide a clinically meaningful reduction in fatigue (Daniels et al., 2014). There may also be an association of fatigue with increasing age that may affect the ability to recover from fatigue (Kreissl et al., 2016). The present study found fatigue was still prevalent at nine months' post-treatment (Time 3), with participants continuing to report a moderate to very high unmet need.

Cognitive impairment is a condition that is not fully understood (Mojs et al., 2017), however, is described as a treatment side-effect (Zimmer et al., 2015). A recent review of psychological outcomes found cognitive decline can range

from mild attention, memory and thinking problems to severe impairment such as dementia (Mojs et al., 2017). A recent study of lymphoma patients (n=262) demonstrated significantly lower cognitive scores (p .018) and greater frequency of impairment when compared with healthy controls (32% vs 7%) (Krolak et al., 2017). This was supported by a smaller study (n=30 vs n=10 controls) which found a significant difference on objective and subjective cognition tests for lymphoma patients who were within 3 months of treatment completion (Zimmer et al., 2015). At the completion of the present study, cognition impairment remained an issue for many participants across both groups, however the control group reported more unmet need at the end of the study. This may indicate that normalisation, information and support may assist lymphoma survivors to cope with this condition.

Survivorship unmet needs

Participants in the intervention group demonstrated an increase in total scale median scores at Time 2, suggesting more unmet needs were evident in this group at this time point. However, all scores were lowest at Time 3 perhaps implying participants needs were met by study completion. Significantly, those participants aged >60 years had the lowest scores, and this may be due to their life stage where some practical issues such as finances, employment, relationship and emotional concerns are less of a concern than for younger age groups. Women in both groups had the highest Time 1 total scale median scores which concur with other Australian research indicating women had higher levels of unmet need (Lobb et al., 2009; Sanson-Fisher et al., 2000). In contrast, men in the intervention group at Time 3 had the highest median scores for the information domain, a finding reflected in a study of gender differences and survivorship follow-up which likewise found men had more unmet informational needs (Arden-Close et al., 2011). Unmet needs decreased across the study period suggesting intervention participants were

able to have their needs, issues and concerns resolved suggesting this may have been attributable to the nurse-led lymphoma survivorship model of care intervention. The control group scores were significantly higher in the 30–59 years age group suggesting this age group may require more support when treatment ends to facilitate return to "normal" functioning and may warrant further exploration in future research. This finding concurs with those of a study that reported follow-up services should account for the distinctive burden of supportive care needs in different age groups (Sharp et al., 2014). The majority of results in the control group (total scale and domain mean scores) decreased by Time 3, however, were higher than intervention group scores at Time 3. Although not statistically significant, likely due to this pilot study being underpowered, the researcher suggests these higher scores may reflect a lack of targeted support when treatment completed. Conversely, the relationships and emotional health domain mean scores increased over the study period. Talking about emotions and depression were endorsed as a moderate to high unmet need by the majority of participants in the control group and the researcher proposes this may be an area that requires support at treatment completion to assist in mitigating escalating or unresolved unmet need. Those with NHL had significantly higher scores in the financial and access and continuity of care domains than those with HL across both groups at all time points suggesting a need for targeted support to this cohort when treatment completes.

Psychological distress

Scores on the three domains of the DASS21 remained similar for both cohorts across the study. The majority of domain scores were below population norm scores outlined in the DASS scoring manual: depression <4.5; anxiety <3.5; and stress <7.0 (Lovibond & Lovibond, 1995) and suggests the lymphoma cohort under study had good psychological coping mechanisms. Participants

in the intervention group showed a decrease in all scores by Time 3. This downward trend suggested psychological distress concerns were no longer evident and likely resolved at study completion. The data revealed an increase in the intervention group mean scores at Time 2, and although they had decreased by Time 3, they were nonetheless higher than Time 1 scores. The researcher proposes this may be due to discussions around these issues in the nurse-led lymphoma survivorship clinic (NLSC) appointment. Anxiety and stress were the highest at Time 2, and stress continued to be elevated at Time 3, an area highlighted as a concern in research with cancer survivors (Marker, 2015).

Women in the control group, when compared with men, had higher total scale and anxiety median scores at Time 2, and higher depression scores at Time 1 and Time 2. This concurs with the findings from the SF-SUNS of unmet needs in the anxiety and depression domain. Although statistical significance was not reached, the direction of change revealed total scale mean scores decreased over the study period and remained higher in comparison with the intervention group mean scores. This was especially evident with anxiety being higher in the control group compared with the intervention group at Time 2. These findings concur with research that indicated depression and anxiety is a common psychological problem in haematology cancer survivors (Hall et al., 2016; Lobb et al., 2009; Mitchell et al., 2011).

Mental adjustment to cancer

Fighting spirit is described as a combination of optimism and confidence that the effects of cancer are controllable and the individual can actively deal with the situation (Wills & O'Carroll Bantum, 2012). Participants in the intervention group revealed significantly lower fighting spirit domain scores

at Time 1 and Time 2. These participants were given an opportunity to debrief about their diagnosis and treatment experiences and, therefore, the researcher suggests these participants may have felt they no longer had to 'fight' or 'beat' their cancer. Helplessness/hopelessness, defined as a sense of incapacity or 'giving into the cancer' (Czerw et al., 2015), showed a decrease from Time 1 to Time 3 in the intervention group and may indicate this group were not incapacitated by having had cancer. The anxious preoccupation domain can be understood to reflect preoccupation with the cancer that cannot be controlled by the individual (Czerw et al., 2015; Watson et al., 1994). The intervention group had a slight increase in median scores by Time 3 revealing this group were thinking about the cancer more. However, these participants were also aware this was their last appointment in the NLSC and may have been experiencing some anxiety about the completion of this individualised support. Participants with NHL in the intervention group had the lowest total scale, and median anxious preoccupation and cognitive avoidance (defined as a tendency to avoid actively thinking about the cancer and its implications (Watson et al., 1994)) domain scores, perhaps reflecting this group's ability to think beyond the cancer after treatment has been completed.

The 30–59 years age group in the control group had the highest median scores across all time points. Helplessness/hopelessness at Time 2, anxious preoccupation at Time 2 and Time 3, and cognitive avoidance at Time 1 and Time 3 had significantly higher median scores. These results may indicate that this age group, who continued with usual care, were not able to find ways to discuss their cancer concerns and were trying to actively avoid thinking about the cancer without success. Those control participants aged >60 years had significantly higher fatalism domain median scores at Time 2. The level of fatalism is said to impact whether an individual can control or

influence their cancer (Park, Edmondson, Fenster, & Blank, 2008), and may indicate the older age group felt they were not able to influence the diagnosis, perhaps due to age. Control participants with NHL had significantly higher median scores, especially in the fighting spirit domain at Time 3 suggesting the cancer was seen as a challenge they were still overcoming.

Fatalism, fighting spirit and anxious preoccupation mean scores decreased and helplessness/hopelessness and cognitive avoidance scores increased in the control group over the study. This may suggest a sense of powerlessness in coping with the cancer diagnosis, regardless of treatment completion and remission status. This is reflected in mean fatalism and fighting spirit scores which were lower than those of the intervention group. In addition, the suggestion of a sense of powerlessness is supported by the majority of the control group participants (compared with the intervention group) at Time 2 who significantly endorsed the items related to difficulty believing cancer had happened to them and trying to push all thoughts of cancer away, and at Time 3 indicating they did not want to think about cancer and were pushing thoughts of cancer away.

Self-empowerment

Participants in the intervention group demonstrated an increase in scores for self-empowerment from Time 1 through to Time 3. This study also found those >60 years of age, regardless of group allocation (intervention or control) were more empowered, especially compared with those in the 30–59 years age group. The researcher suggests this may, in part, be due to the life experiences and previous exposure to adversity older adults may have encountered. At Time 1 and Time 2 those with NHL, characteristically a disease of older age (Cancer Australia, 2017), had higher median scores. The

researcher suggests these participants may have already been more empowered due to age. Conversely, mean scores in the control group were lowest at Time 3. This finding suggests this group of participants felt less able to control aspects of their cancer and move on with their life, although further research is required to explore this trend.

The most endorsed items indicated the intervention group felt they had all the information they needed, were able to adapt and make changes to their lifestyle, felt health professionals included them in discussions and by Time 3 were more confident in their GP. The researcher suggests this may be due to the SCPTS sent to their GPs which outline future follow-up recommendations.

Nurse-led lymphoma survivorship model of care

While this pilot study was not sufficiently powered to demonstrate a significant effect between the two groups, the direction of change in the results suggests the nurse-led lymphoma survivorship model of care may be an effective intervention for targeted cancer cohorts. For some participants in the intervention, one or two appointments in the NLSC would have been sufficient to impart the SCPTS and give individualised and tailored resources as these survivors do not require intensive support (Campbell et al., 2014). However, those with high levels of unmet need after the provision of the SCPTS and resources may need more support. This was evidenced by the increase in needs at Time 2. These needs had diminished in the most part by Time 3 indicating a sustained follow-up may not be warranted.

Participants who utilised the motivational chart to make healthy lifestyle changes reported pressure to cease smoking or reduce alcohol during treatment. However, these participants indicated adequate support was not

provided at such a high-stress time. The participants acknowledged the motivational chart and support as a useful way to explore the unhealthy behaviour and their motivations in continuing. Likewise, these participants felt the motivational interviewing assisted them to be empowered to quit or reduce the unhealthy behaviours. Further study would be required to ascertain sustained change over a longer period than the study timeframe of six months.

Discussion of the Phase Four General Practitioner Evaluations

Data from the GP evaluations indicated the SCPTS had been received, read and in some cases prompted the GP to make an appointment (n=16, 89%) with the patient. However, not all GPs indicated they had discussed the SCPTS with their patient during the trial (n=11, 61%). Discussion of the SCPTS between participants and their GPs was encouraged; however, the participant could choose when and if they discussed the SCPTS during the trial. Five intervention participants indicated at the completion of the study they had not visited or discussed the SCPTS with their GP. As a copy of the SCPTS is held by the participant and his/her GP, it is envisaged the document could potentially be used at future appointments.

Of those GPs who completed the Likert-type scale, the majority (n=13, 81%) found the SCPTS useful and rated it as good to very good. Just over half of GP responders (n=10, 59%) requested further haematology or medically related information be included on the SCPTS, perhaps indicating insufficient information was communicated from the haematology department. As a treatment summary document, it was not the intent of the SCPTS to provide all health-related information. The majority of responders indicated they did not want further education on the SCPTS (n=9, 69%). The

present study did not address the management of other medical conditions, and this may be an area that would need consideration for future inclusion, particularly in older cancer participants who have an increased likelihood of co-morbidities.

Summary of the Phase Four Qualitative Interviews

In quantitative research, participants may not have an opportunity to articulate their perceptions, thoughts and feelings as they complete questionnaires with set responses. The researcher sought to avoid this limitation by including a qualitative sub-study (Phase Four) using a cohort of intervention participants to add depth and further explore some aspects of the quantitative data obtained (Creswell & Clark, 2011). This process of triangulating the data, using multiple methods of data collection, strengthened and supported the study outcomes as a more holistic understanding of the key findings was obtained from different sources (Sarantakos, 2013).

Additional support is particularly valuable when patients are transitioning from active treatment to life without treatment (Knott, Turnbull, Olver, & Winefield, 2012). Reality, however, suggests this period is characterised by the reduction or cessation of cancer care support in the acute setting (Rabin, Simpson, Morrow, & Pinto, 2011). The support conceptualised for the nurse-led lymphoma survivorship model of care and offered by an experienced cancer nurse was appreciated by participants at a time when previous cancer patients have expressed the fear they would be abandoned once treatment had completed (Lobb et al., 2009; Matheson et al., 2016; Monterosso et al., 2017). Participants who were interviewed highlighted both the importance of a safe environment to ask questions and expressed the importance of trust

and rapport developed between themselves and the researcher during the study. The majority of lymphoma survivors wanted to make healthy lifestyle behaviour changes; however, there were limited options that specifically target cancer survivors. Having an opportunity to discuss preferences and decisions with the researcher about individual goals and action plans was seen as very helpful. This can enhance self-efficacy leading to greater psychosocial well-being. This concurs with findings from a recent study which revealed a positive correlation between increased levels of self-efficacy and more emotional and functional well-being, alongside fewer cancer-related issues (Papadopoulou et al., 2017). Participants particularly liked how the SCPTS was personalised to them and they were able to document the issues and concerns most important to them.

Summary of the Test–retest Reliability Analysis

The SF-SUNS test–retest reliability sub-study added psychometric data for this measure in a lymphoma-specific cohort of survivors. The results demonstrated the majority of items achieved fair to good reliability intraclass correlation (ICC) scores. It is essential that survivorship-specific needs assessment measures detect clinically meaningful changes over time in the survivorship phase (DeVellis, 2012; McDowell, 2006; Streiner & Norman, 2003). An important consideration when issues and concerns are rapidly changing as survivors move beyond the diagnosis and treatment phases and begin to move forward with their lives. These results, now available in the published literature will allow other researchers an opportunity to make informed choices when choosing a survivorship-specific needs assessment measure for their cohorts.

Limitations of the Research

Specific limitations are addressed in each published manuscript. Limitations of the pragmatic RCT included the recruitment by chance of more males than females in the intervention group, and a disproportionate number of HL to NHL that did not reflect current lymphoma statistics (Cancer Australia, 2017). However, it is acknowledged this is a possibility when randomisation of groups occurs (Deaton & Cartwright, 2017). As a pilot study, a sample size calculation was not required, and it is acknowledged that 60 participants may not be adequate to see a true effect of the intervention. It must be highlighted the purpose of this pragmatic pilot RCT was to generate data that can be used to power future robust larger RCTs. This aim was achieved.

Fidelity of the intervention was maintained, and no control group participant received the intervention while on the study. It is unknown if survivorship information was imparted to control group participants by haematologists. This is considered unlikely however as needs of this group were higher than those of the intervention group.

The PhD candidate administered the intervention and entered the data from both groups. There is a potential for bias when the researcher evaluates their own service. Due to the constraints of a PhD which related to a lack of funding to employ an independent experienced cancer research nurse, a number of measures were employed to mitigate potential bias. Statisticians reviewed data and assisted with quantitative analysis to decrease the risk of bias in evaluation. Control group participants were only contacted by an independent member of the research team if this was required.

Alterations were made to how the NLSC appointments were conducted when haematologist appointments were altered. This was required to ensure timeframes were maintained. However, a strength of the NLSC intervention was its ability to be flexible to accommodate the requests of participants.

As a pragmatic RCT, there was a usual care group who did not receive the nurse-led lymphoma survivorship model of care. It is important when examining new models that a comparison group is provided, especially as research on the benefits of an SCPTS is limited. Future research to investigate the provision of the intervention to the usual care group after study timeframes are completed may provide valuable data on the benefits of delayed delivery compared with no delivery.

Assessment measures used in this study may not have captured all the concerns and issues that applied to lymphoma survivors. There were limitations to using the DASS21, for example, where a control group participant complained of a dry mouth it was unknown whether this was a sign of anxiety or an ongoing treatment effect. This was comparably true for the question related to lack of initiative which may have been related to fatigue rather than a sign of depression. Some participants expressed difficulty with answering particular questions on the Mini-MAC. Some participants at baseline indicated that some items, for example; 'I take one day at a time', 'I am apprehensive' or 'I have difficulty believing that this happened to me', both "applied" and "did not apply". Intervention participants who indicated similarly at the NLSC appointments were guided to reflect on how they felt at present, as per questionnaire instructions. Many participants at baseline needed to be reminded the assessment questionnaires were related to the present, not how they felt during treatment.

An economic evaluation of the cost of a nurse-led lymphoma survivorship model of care would have enhanced the research and added information on the viability of the model. This would correspondingly have examined the time and cost required for nurses to deliver this model of survivorship care. Likewise, an evaluation of lymphoma survivors' utilisation of the primary healthcare system from Medicare data could have examined if there was an increase in GP visits with the intervention group participants who were encouraged to see the GP compared with control group participants who were not given any post-treatment support. The time constraints of this PhD thesis prevented this lengthy form of evaluation. Further, as the study was only conducted with participants from one haematology department, it would be difficult to generalise the findings of this thesis to the other two public tertiary haematology departments in Perth Western Australia.

The time constraints of a PhD candidacy, as well as the significant size of this thesis, prevented an examination of the experience and needs of carers of RCT study participants. This is an important aspect of care and should be considered a potential future area for research. No data were collected from patients who declined the research. Therefore, it is unknown if these patients had more or diverse issues and unmet needs. Providing a nurse-led follow-up appointment to all lymphoma patients when they complete treatment as standard practice may contribute to supporting patients who would otherwise not seek assistance.

Finally, GP feedback could be improved with an investigation into whether and why some GPs did not receive the SCPTS. All medical centres were contacted if evaluations were not received with faxed copies being sent if medical practices indicated non-receipt. Whether the participant's GP did eventually receive the SCPTS and evaluation remains unknown. Further,

some GPs may have chosen not to return the evaluation. Nevertheless, the response rate for evaluation returns was considered acceptable at 64% (Livingston & Wislar, 2012).

Strengths of the Research

The major strength of this research and a key aspect was the tailored and personalised nature of the nurse-led lymphoma survivorship model of care, delivered by one experienced cancer nurse clinician (the PhD candidate). This ensured consistency and accuracy of all data. Information provision that is tailored to the patient's perceived needs is a significant factor in survivorship care, support and empowerment (Bulsara & Styles, 2013; Hall, D'Este, et al., 2014; Husson et al., 2013). Equally important was the early knowledge of late effects that may assist in timely follow-up with the GP when haematology department surveillance ends (Ng et al., 2011). An additional strength of this research was the lymphoma-specific cohort which allowed the researcher an opportunity to assess needs that were disease-specific (Oberoi et al., 2017). The nurse-led survivorship model of care was developed for lymphoma survivors in the early survivorship period, a time when studies have indicated there is an increase in distress as treatment completes (Girgis & Butow, 2009; Hewitt et al., 2005; Jefford et al., 2008) and survivors may feel abandoned by the treating team (Matheson et al., 2016; Monterosso et al., 2017).

Recent studies have indicated survivors want more detail and more information on healthy lifestyle behaviours, psychological support and resources (Keesing, McNamara, & Rosenwax, 2015; Mayer, Birken, et al., 2015). A strength of the conceptualised model was to develop information that was delivered as part of the general health aspect of the SCPTS and

within the resource pack developed for the study. GP evaluations on the SCPTS indicated a content rating of good to very good from the majority of GP respondents. Therefore, the researcher suggests the nurse-led lymphoma survivorship model of care was able to accommodate the needs of both survivors and GPs.

Assessment measures were utilised to assess and evaluate survivorship, distress, adjustment and coping and empowerment post-treatment at three time points. This assisted with discussion and targeting of resources during the nurse-led lymphoma survivorship clinic appointments for the intervention group. It may have also assisted those in the usual care (control) group to identify areas they may have discussed with their haematologist or GP. The unique lymphoma SCPTS was patient-centred and allowed intervention participants an opportunity to seek support on the issues and health goals that were important to them at their life stage. This has not been a feature of any SCPTS found in the published literature at the time of development. Motivational interviewing techniques require a particular skill set, and fortunately, the researcher was competent in this area. Utilising this skill and assisting the intervention participants to understand the impact of continuing unhealthy lifestyle behaviours, was an important promoter for change that they were empowered to make. This was an important element of the conceptual framework developed when the research was planned to aid recovery of health and well-being and engagement in healthy lifestyle behaviours to improve quality of life.

The research allowed participants an opportunity to debrief after a life-changing and often traumatic experience, such as a cancer diagnosis. This was an aspect that was highlighted in the qualitative interviews and anecdotally to the researcher during the face-to-face appointments. The

nurse-led lymphoma survivorship model of care provided normalisation of some of the long-term effects such as fatigue, fear of recurrence and/or cognitive impairment, with provision of further information. This was likewise perceived by many participants as missing from haematology follow-up care. The researcher suggests debriefing and normalisation, along with information, resources and support may help to mitigate these issues continuing in the longer-term.

Lastly, an important strength was the use of and collaboration with the haematology survivorship research advisory committee which consisted of academic, clinical health and community support group professionals and lymphoma survivor consumers. The input of the consumers provided significant insight into current lymphoma post-treatment follow-up and on gaps they perceived in their own cancer survivorship journey.

Chapter Summary

This chapter summarises the key findings from the four phases of this thesis study. In keeping with a pilot pragmatic RCT design, the small numbers of participants recruited limited the power of this study to potentially demonstrate statistically significant results. Nevertheless, this study provides a valuable contribution for future rigorous testing of nurse-led survivorship models of care to transition patients from treatment into the survivorship phase. The large body of work presented in this PhD thesis by publication exceeds the minimum requirement of four published manuscripts. The final publication, currently undergoing preparation for publication will report the LMM data from the pragmatic pilot RCT and provide evidence to generate sample size calculations to support future RCT studies.

Providing individualised and tailored information, support, resources and a patient-centred survivorship care plan and treatment summary in the early survivorship period may lead to less unmet needs and better recovery of health and well-being in the future.

The final chapter will conclude this thesis and discuss the implications of this type of research. Furthermore, it will provide recommendations for clinical nursing, future research and education in survivorship care for nurses who are a valuable and integral component of high-quality supportive survivorship care.

Chapter Eight — Conclusion

"But to know that look, don't worry, after treatment you are going to see a nurse, that would have been very calming for me" F_64yo_HL

8.0 Implications and Recommendations

Implications

Provision of evidence-based cancer survivorship care must be a common goal throughout the healthcare system, as cancer diagnoses and survival rates continue to increase. The impact of cancer does not end with active treatment as cancer survivors continue to have numerous diverse and varied needs at different time points along the survivorship trajectory. Efficient targeting and provision of clinical services is key to meeting and improving the care of cancer patients at all stages.

This study was based on the assumption that the current model of lymphoma follow-up, which is haematologist-led, has been unable to comprehensively provide the supportive care required to transition patients from the treatment phase into the survivorship phase. Consequently, a nurse-led lymphoma survivorship model of care was conceptualised, successfully developed and tested within this research.

Sixty lymphoma patients from one haematology department in Perth, Western Australia were recruited and randomised. While not the aim of a pilot study, many findings were not statistically significant, likely due to the small number of participants. The intervention participants did demonstrate less unmet informational and practical needs, less depression, anxiety and stress while demonstrating higher levels of coping and empowerment compared with the control (usual care) group. As intended, the study did produce data that can be used to power larger randomised trial studies for future competitive funding applications.

Psychological concerns among patients are often not addressed by clinicians in follow-up due to a number of limitations on their time and the availability of routine screening mechanisms. Clinicians will often assess for signs of depression, which is common following a cancer diagnosis (Mitchell, Ferguson, Gill, Paul, & Symonds, 2013) without addressing the levels of anxiety and stress which can be a major concern for cancer survivors (Marker, 2015; Mitchell et al., 2011). Findings from this study suggest anxiety and stress can remain elevated over time and was notable in the control group where scores were higher in comparison with the intervention group who had an opportunity to discuss concerns and issues. Therefore, future interventions may need to consider anxiety-related issues such as fear of recurrence, thereby normalising the need for psychosocial support when developing cancer survivorship support and resources.

Participants in the 30–59-year-old age group across both the control and intervention groups exhibited higher levels of unmet practical concerns and less empowerment, a finding that corresponds to this life stage where patients are often juggling family, employment and financial issues. This study has confirmed the need that lymphoma patients require support and resources that are targeted to their life stage, and which can support them to re-establish their lives post-treatment. A finding supported by the qualitative interviews which revealed patients appreciated the individualised aspect of the nurse-led lymphoma survivorship model of care, valued the opportunity to discuss their concerns and issues and had a plan for monitoring potential late effects in the future, regardless of their age and life circumstances.

Lack of resources and support for survivors was evident in Phase Two of this study when a resource pack was developed. It would be difficult in the limited time survivors have in their haematologist appointments to provide

and discuss all the information and support an individual lymphoma survivor might need at that time. Therefore nurse-led survivorship models of care may provide the time and space to assist with this issue.

Recommendations

The results of this cancer nursing thesis have provided phase II evidence of the need for future research on nurse-led survivorship models of care in unique and rarer cancer groups such as lymphoma. The research highlighted the need for nurses to consider the whole cancer trajectory, not just the diagnosis and treatment phases of cancer care. The wider implications of the long-term and late effects of diagnosis and treatment for cancer survivors are equally imperative. Delivering cancer survivorship care that is evidence-based, holistic, cost-effective and adaptable to different health care settings is a continual challenge. Regardless of this, the provision of quality care and improvement in overall quality of life should be a greater focus in effective healthcare initiatives than just successful medical treatment. The following recommendations could enhance research in the area of cancer survivorship.

Clinical Nursing

- Experienced and senior cancer nurses should provide training and education on the use of assessment measures in survivorship to all nurses working in cancer care.
- Cancer nurses should be encouraged to identify and refer patients to appropriate health care providers for psychological and emotional support.
- Cancer nurses should be encouraged to undertake research and professional development to address the gaps in information and

resources provided to patients during their treatment and survivorship phases.

- Experienced cancer nurses should be provided with additional time to provide holistic follow-up on survivorship needs post-treatment.
- Cancer nurses should be offering educational forums to survivors to enhance post-treatment coping skills, healthy lifestyle behaviour choices and normalisation of treatment effects.
- Cancer nurses should be encouraged to provide input into the development and delivery of SCPTS for all cancer survivors.
- Cancer nurses should find opportunities to communicate with GPs to ensure survivorship needs will be addressed in the future.

Research

- Further research should be undertaken to promote and support the development, testing and evaluation of survivorship models of care.
- Further research on nurse-led survivorship models of care should be undertaken with survivors of:
    - Other haematological cancers
    - Other cancers.
- Further research should include the recruitment of cancer patients from rural/regional areas and evaluate the provision of localised support.
- Exploring options for providing targeted support to carers during cancer treatment and post-treatment requires further investigation.
- Further examination of debriefing mechanisms during and after treatment for patients is required.
- Research that encourages advocacy and peer support among survivors is required:
    - Investigation of the types of peer support mechanisms currently available

  - Development of peer support for patients of all stages of the cancer trajectory.
- Longitudinal studies are required to determine:
  - If participants follow through recommendations with their GP when haematologist follow-up is completed
    - If this impacts earlier diagnosis and management of late effects
  - If healthy lifestyle choices were maintained and how motivation to continue was sustained.
- Future studies in the primary care arena to deliver nurse-led survivorship models of care would be valuable.
- Larger phase III multi-centre studies are required to explore nurse-led survivorship models of care that deliver patient-centred options for frequency and type of contact, such as face-to-face or telephone support.
- Further studies in the development and examination of psychometrically sound measures that capture the unique needs of survivors of less common cancers, such as lymphoma are essential.

Education

- Findings from this study could be used to increase public awareness of resources that can normalise and provide support for the issues and concerns that occur post-treatment.
- Findings from this study could be used in hospitals to provide greater awareness of community-based support organisations
  - Carer support mechanisms.
- An awareness of and provision of multi-cultural support and information requires further development and testing.

- Further education is necessary to provide relevant information and support resources to regional and rural Australia to enable improved referral pathways and communication between health care providers.
- Further research and education is required to increase support for employees and employers where identified employment concerns may arise
    - Provide access to information on support services and employee entitlements
    - Identify barriers that inhibit employers from implementing supportive policies in the workplace
    - Provide better mechanisms for transitioning back into the workforce or retraining.
- Increased flexibility in accessing financial government funding and effective utilisation.
- Promotion of the re-evaluation of funding allocation for rarer cancers is required by cancer agencies and professional health organisations to ensure equity of research and services.

References

Aaronson, N. K., Mattioli, V., Minton, O., Weis, J., Johansen, C., Dalton, S. O., . . . van de Poll-Franse, L. V. (2014). Beyond treatment – psychosocial and behavioural issues in cancer survivorship research and practice. *European Journal of Cancer Supplements, 12*(1), 54–64. doi:10.1016/j.ejcsup.2014.03.005

Aleman, B. M., van den Belt-Dusebout, A. W., De Bruin, M. L., van 't Veer, M. B., Baaijens, M. H., de Boer, J. P., . . . van Leeuwen, F. E. (2007). Late cardiotoxicity after treatment for Hodgkin lymphoma. *Blood, 109*(5), 1878–1886. doi:10.1182/blood-2006-07-034405

Alfano, C. M., Ganz, P. A., Rowland, J. H., & Hahn, E. E. (2012). Cancer survivorship and cancer rehabilitation: Revitalizing the link. *Journal of Clinical Oncology, 30*(9), 904–906. doi:10.1200/jco.2011.37.1674

Allart, P., Soubeyran, P., & Cousson-Gélie, F. (2013). Are psychosocial factors associated with quality of life in patients with haematological cancer? A critical review of the literature. *Psycho-Oncology, 22*(2), 241–249.

American Cancer Society. (2014). *Cancer facts and figures*. Atlanta, GA: American Cancer Society.

American Society of Clinical Oncology. (2015). Coping with fear of recurrence. Retrieved 1 April 2015

Antony, M. M., Bieling, P. J., Cox, B. J., Enns, M. W., & Swinson, R. P. (1998). Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychological Assessment, 10*(2), 176–181. doi:10.1037/1040-3590.10.2.176

Arboe, B., Olsen, M. H., Goerloev, J. S., Duun-Henriksen, A. K., Johansen, C., Dalton, S. O., & Brown, P. D. N. (2017). Return to work for patients with diffuse large B-cell lymphoma and transformed indolent

lymphoma undergoing autologous stem cell transplantation. *Clinical Epidemiology, 9*, 321–329.

Arden-Close, E., Absolom, K., Greenfield, D., Hancock, B., Coleman, R., & Eiser, C. (2011). Gender differences in self-reported late effects, quality of life and satisfaction with clinic in survivors of lymphoma. *Psycho-Oncology, 20*(11), 1202–1210.

Arden-Close, E., Pacey, A., & Eiser, C. (2010). Health-related quality of life in survivors of lymphoma: A systematic review and methodological critique. *Leukemia and Lymphoma, 51*(4), 628–640.

Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., . . . Richardson, A. (2009). Patients' supportive care needs beyond the end of cancer treatment: A prospective, longitudinal survey. *Journal of Clinical Oncology, 27*(36), 6172–6179. doi:10.1200/JCO.2009.22.5151

Australian Commission on Safety and Quality in Health Care. (2017). *National Safety and Quality Health Service Standards*. Sydney: ACSQHC.

Australian Government. (2015). Australian guide to healthy eating. Department of Health and Ageing. Retrieved 1 April 2015

Australian Government. (2015). Better access to mental health care. Retrieved 1 April 2015

Australian Government. (2015). Centrelink. Retrieved 1 April 2015

Australian Institute of Health and Welfare. (2014). *Cancer in Australia: An overview, 2014. Cancer series no. 78. Cat. No. Can 75.* Canberra: AIHW.

Australian Institute of Health and Welfare. (2017). *Cancer in Australia 2017. Cancer series no.101. Cat. No. Can 100*. Canberra AIHW.

Aziz, N. M. (2007). Cancer survivorship research: State of knowledge, challenges and opportunities. *Acta Oncologica, 46*(4), 417–432.

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191–215. doi:10.1037/0033-295X.84.2.191

Beaver, K., Campbell, M., Williamson, S., Procter, D., Sheridan, J., Heath, J., & Susnerwala, S. (2012). An exploratory randomized controlled trial comparing telephone and hospital follow-up after treatment for colorectal cancer. *Colorectal Disease, 14*(10), 1201–1209. doi:10.1111/j.1463-1318.2012.02936.x

Beck, C. T. (1993). Qualitative research: The evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research, 15*(2), 263–266. doi:10.1177/019394599301500212

Beckjord, E. B., Arora, N. K., Bellizzi, K., Hamilton, A. S., & Rowland, J. H. (2011). Sexual well-being among survivors of non-Hodgkin lymphoma. *Oncology Nursing Forum, 38*(5), E351–359.

Behrend, S. W. (2014). Survivorship care plans. *Oncology Nursing Forum, 41*(4), 447.

Behringer, K., Muller, H., Gorgen, H., Flechtner, H. H., Brillant, C., Halbsguth, T. V., . . . Borchmann, P. (2013). Sexual quality of life in Hodgkin lymphoma: A longitudinal analysis by the German Hodgkin study group. *British Journal of Cancer, 108*(1), 49–57.

Belansky, H., & Mahon, S. M. (2012). Using care plans to enhance care throughout the cancer survivorship trajectory. *Clinical Journal of Oncology Nursing, 16*(1), 90–92. doi:10.1188/12.cjon.90-92

Bell, J., & Fagan, M. (2015). *Living well after cancer*: Cancer Council Australia.

Birken, S. A., Mayer, D. K., & Weiner, B. J. (2013). Survivorship care plans: Prevalence and barriers to use. *Journal of Cancer Education, 28*(2), 290–296. doi:10.1007/s13187-013-0469-x

Bishop, M. M., Lee, S. J., Beaumont, J. L., Andrykowski, M. A., Rizzo, J. D., Sobocinski, K. A., & Wingard, J. R. (2010). The preventive health behaviors of long-term survivors of cancer and hematopoietic stem cell transplantation compared with matched controls. *Biology of Blood*

and Marrow Transplantation, 16(2), 207–214. doi:10.1016/j.bbmt.2009.09.015

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *Journal of the American Medical Association, 288*(19), 2469–2475. doi:10.1001/jama.288.19.2469

Boyes, A., Girgis, A., D'Este, C., & Zucca, A. (2011). Flourishing or floundering? Prevalence and correlates of anxiety and depression among a population-based sample of adult cancer survivors 6 months after diagnosis. *Journal of Affective Disorders, 135*, 184 - 192.

Boyes, A. W., Girgis, A., D'Este, C., & Zucca, A. C. (2012). Prevalence and correlates of cancer survivors' supportive care needs 6 months after diagnosis: A population-based cross-sectional study. *BioMed Central Cancer, 12*(1), 150. doi:10.1186/1471-2407-12-150

Brant, J. M., Dudley, W. N., Gray, E., Oliver, D., Blaseg, K., & Aders, K. (2016). Navigating the transition from cancer care to primary care: Assistance of a survivorship care plan. *Oncology Nursing Forum, 43*(6), 710. doi:10.1188/16.ONF.710-719

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. doi:10.1191/1478088706qp063oa

Brennan, M., Gormally, J., Butow, P., Boyle, F., & Spillane, A. (2014). Survivorship care plans in cancer: A systematic review of care plan outcomes. *British Journal of Cancer, 111*, 1899–1908. doi:10.1038/bjc.2014.505

Bruce, J. (2015). *Cancer and your finances*: Cancer Council Australia.

Bruce, J. (2016). *Exercise for people living with cancer*: Cancer Council Australia.

Bruce, J. (2016). *Sexuality, intimacy and cancer*: Cancer Council Australia.

Bryant, A. L., Smith, S. K., Zimmer, C., Crandell, J., Jenerette, C. M., Bailey, D. E., . . . Mayer, D. K. (2015). An exploratory path model of the

relationships between positive and negative adaptation to cancer on quality of life among non-Hodgkin lymphoma survivors. *Journal of Psychosocial Oncology, 33*(3), 310–331. doi:10.1080/07347332.2015.1020978

Bujang, M. A., & Baharum, N. (2017). A simplified guide to determination of sample size requirements for estimating the value of intraclass correlation coefficient: A review. *Archives of Orofacial Sciences, 12*(1), 1–11.

Bulsara, C., & Styles, I. (2013). Development of a cancer related patient empowerment scale using the polytomous Rasch measurement model. *Cancer and Clinical Oncology, 2*(1), 1–16.

Bulsara, C., Styles, I., Ward, A. M., & Bulsara, M. (2006). The psychometrics of developing the patient empowerment scale. *Journal of Psychosocial Oncology, 24*(2), 1–16. doi:10.1300/J077v24n02_01

Burg, M. A., Adorno, G., Lopez, E. D. S., Loerzel, V., Stein, K., Wallace, C., & Sharma, D. K. B. (2015). Current unmet needs of cancer survivors: Analysis of open-ended responses to the American Cancer Society study of cancer survivors II. *Cancer, 121*(4), 623–630. doi:10.1002/cncr.28951

Campbell, H. S., Hall, A. E., Sanson-Fisher, R. W., Barker, D., Turner, D., & Taylor-Brown, J. (2014). Development and validation of the short-form survivor unmet needs survey (SF-SUNS). *Supportive Care in Cancer, 22*(4), 1071–1079. doi:10.1007/s00520-013-2061-7

Campbell, H. S., Sanson-Fisher, R., Turner, D., Hayward, L., Wang, X. S., & Taylor-Brown, J. (2010). Psychometric properties of cancer survivors' unmet needs survey. *Supportive Care in Cancer, 19*(2), 221–230. doi:10.1007/s00520-009-0806-0

Campbell, M. K., Tessaro, I., Gellin, M., Valle, C. G., Golden, S., Kaye, L., . . . Miller, K. (2011). Adult cancer survivorship care: Experiences from the

Livestrong centers of excellence network. *Journal of Cancer Survivorship, 5*(3), 271–282. doi:10.1007/s11764-011-0180-z

Campbell, N., Murray, E., Darbyshire, J., Emery, J., Farmer, A., Griffiths, F., . . . Kinmonth, K. (2007). Designing and evaluating complex interventions to improve health care. *British Medical Journal, 334*, 455–459.

Cancer Australia. (2017). Lymphoma in Australia. Retrieved from https://lymphoma.canceraustralia.gov.au/statistics 21 November 2017

Cancer Australia. (2017). Non-Hodgkin lymphoma in Australia. Retrieved from https://canceraustralia.gov.au/affected-cancer/cancer-types/lymphoma/non-hodgkin-lymphoma-statistics 4 May 2017

Cancer Australia. (2018). Lymphoma in Australia. Retrieved from https://lymphoma.canceraustralia.gov.au/statistics 2 February 2018

Cancer Council. (2016). Quit smoking: Cancer Council Australia.

Cancer Council Australia. (2015). Cancer council pro bono programs: Cancer Council Australia.

Cancer Council Victoria. (2015). Coping with cancer fatigue: Cancer Council Victoria.

Cancer Council Western Australia. (2015–2017). Life now. Retrieved 2015–2017

Cancer Council Western Australia. (2016). New insurance policies. Retrieved 1 March 2018

CanTeen. (2015). Cancer support for teenagers. Retrieved 1 April 2015

Carey, M., Anderson, A., Sanson-Fisher, R., Lynagh, M., Paul, C., & Tzelepis, F. (2012). How well are we meeting haematological cancer survivors' preferences for involvement in treatment decision making? *Patient Education and Counseling, 88*(1), 87–92. doi:10.1016/j.pec.2011.12.014

Cella, D., Jensen, S. E., Webster, K., Hongyan, D., Lai, J.-S., Rosen, S., . . . Yount, S. (2012). Measuring health-related quality of life in leukemia:

The functional assessment of cancer therapy – leukemia (FACT-Leu) questionnaire. *Value in Health, 15*(8), 1051–1058.

Chen, A. B., Feng, Y., Neuberg, D., Recklitis, C., Diller, L. R., Mauch, P. N., & Ng, A. K. (2012). Employment and insurance in survivors of Hodgkin lymphoma and their siblings: A questionnaire study. *Leukemia and Lymphoma, 53*(8), 1474–1480.

Choi, M., Sun, C. L., Kurian, S., Carter, A., Francisco, L., Forman, S. J., & Bhatia, S. (2008). Incidence and predictors of delayed chronic kidney disease in long-term survivors of hematopoietic cell transplantation. *Cancer, 113*(7), 1580–1587. doi:10.1002/cncr.23773

Christen, S., Vetsch, J., Mader, L., Dehler, S., Korol, D., Kuehni, C., . . . Michel, G. (2016). Preferences for the organization of long-term follow-up in adolescent and young adult cancer survivors. *Supportive Care in Cancer, 24*(8), 3425–3436. doi:10.1007/s00520-016-3157-7

Chubak, J., Tuzzio, L., Hsu, C., Alfano, C. M., Rabin, B. A., Hornbrook, M. C., . . . Nekhlyudov, L. (2012). Providing care for cancer survivors in integrated health care delivery systems: Practices, challenges, and research opportunities. *Journal of Oncology Practice, 8*(3), 184–189. doi:10.1200/jop.2011.000312

Cicchetti, D. V. (1994). Guidelines, criteria, and rules of thumb for evaluating normed and standardized assessment instruments in psychology. *Psychological Assessment, 6*(4), 284–290. doi:10.1037/1040-3590.6.4.284

Cicchetti, D. V., & Sparrow, S. A. (1981). Developing criteria for establishing interrater reliability of specific items: Applications to assessment of adaptive behavior. *American Journal of Mental Deficiency, 86*(2), 127.

Clinical Oncology Society of Australia. (2014). www.Cosa.Org.Au/media/224898/cancer-survivorship-critical-components-model-for-wellness-draft-20150227.pdf. Retrieved 3 November 2015

Clinical Oncology Society of Australia. (2016). *Model of survivorship care: Critical components of cancer survivorship care in Australia position statement.*

Coa, K. I., Smith, K. C., Klassen, A. C., Caulfield, L. E., Helzlsouer, K., Peairs, K., & Shockney, L. (2015). Capitalizing on the "teachable moment" to promote healthy dietary changes among cancer survivors: The perspectives of health care providers. *Supportive Care in Cancer, 23*(3), 679. doi:10.1007/s00520-014-2412-z

Cohen, J. W. (1988). *Statistical power analysis for the behavioural sciences* (2nd ed.). Hillsdale, New Jersey: Lawrence Erlbaum Associates.

Cooper, J. M., Loeb, S. J., & Smith, C. A. (2010). The primary care nurse practitioner and cancer survivorship care. *Journal of the American Academy of Nurse Practitioners, 22*(8), 394–402. doi:10.1111/j.1745-7599.2010.00528.x

Corner, J., & Bailey, D. (2009). *Cancer nursing: Care in context* (2nd ed.). Oxford, UK: Blackwell Publishing Ltd.

Cox, A., & Faithfull, S. (2013). 'They're survivors physically but we want them to survive mentally as well': Health care professionals' views on providing potential late effect information. *Supportive Care in Cancer, 21*(9), 2491–2497. doi:10.1007/s00520-013-1806-7

Creswell, J. W., & Clark, V. L. P. (2011). *Designing and conducting mixed methods research*. Thousand Oaks, California: SAGE Publications.

Crouch, M., & McKenzie, H. (2006). The logic of small samples in interview-based qualitative research. *Social Science Information, 45*(4), 483–499. doi:10.1177/0539018406069584

Curcio, K. R., Lambe, C., Schneider, S., & Khan, K. (2012). Evaluation of a cancer survivorship protocol: Transitioning patients to survivors. *Clinical Journal of Oncology Nursing, 16*(4), 400–406. doi:10.1188/12.CJON.400-406

Czerw, A. I., Marek, E., & Deptała, A. (2015). Use of the Mini-MAC scale in the evaluation of mental adjustment to cancer. *Contemporary Oncology, 19*(5), 414–419. doi:10.5114/wo.2015.54900

Daniel, C. L., Emmons, K. M., Fasciano, K., Fuemmeler, B. F., & Demark-Wahnefried, W. (2015). Needs and lifestyle challenges of adolescents and young adults with cancer: Summary of an Institute of Medicine and Livestrong foundation workshop. *Clinical Journal of Oncology Nursing, 19*(6), 675–681. doi:10.1188/15.CJON.19-06AP

Daniels, L. A., Oerlemans, S., Krol, A. D., Creutzberg, C. L., & van de Poll-Franse, L. V. (2014). Chronic fatigue in Hodgkin lymphoma survivors and associations with anxiety, depression and comorbidity. *British Journal of Cancer, 110*(4), 868–874. doi:10.1038/bjc.2013.779

Daniels, L. A., Oerlemans, S., Krol, A. D., van de Poll-Franse, L. V., & Creutzberg, C. L. (2013). Persisting fatigue in Hodgkin lymphoma survivors: A systematic review. *Annals of Hematology, 92*(8), 1023–1032. doi:10.1007/s00277-013-1793-2

de Jong, M., Tamminga, S. J., de Boer, A. G. E. M., & Frings-Dresen, M. H. W. (2016). The quality of working life questionnaire for cancer survivors (QWLQ-CS): A pre-test study. *BMC Health Services Research, 16*(1), 194. doi:10.1186/s12913-016-1440-4

De Leeuw, J., & Larsson, M. (2013). Nurse-led follow-up care for cancer patients: What is known and what is needed. *Supportive Care in Cancer, 21*(9), 2643–2649. doi:10.1007/s00520-013-1892-6

de Lima, F. D., Bottaro, M., de Oliveria Valeriano, R., Criuz, L., Battaglini, C. L., Vieira, C. A., & de Oliveria, R. J. (2017). Cancer-related fatigue and muscle quality in Hodgkin's lymphoma survivors. *Integrated Cancer Therapy, June 1*. doi:10.1177/1534735417712009

Deaton, A., & Cartwright, N. (2017). Understanding and misunderstanding randomized controlled trials. *Social Science & Medicine*. doi:10.1016/j.socscimed.2017.12.005

Del Giudice, M. E., Grunfeld, E., Harvey, B. J., Piliotis, E., & Verma, S. (2009). Primary care physicians' views of routine follow-up care of cancer survivors. *Journal of Clinical Oncology, 27*(20), 3338–3345. doi:10.1200/jco.2008.20.4883

Deline, M. (2016). The Commission on Cancer (CoC) clarifies the survivorship care plan standard: What you need to know. Retrieved from https://www.advisory.com/research/oncology-roundtable/oncology-rounds/2014/09/the-coc-clarifies-the-survivorship-care-plan-standard-what-you-need-to-know 13 March 2018

DeVellis, R. F. (2012). *Scale development: Theory and applications* (3rd ed.). Thousand Oaks, California: Sage

Dicicco-Bloom, B., & Cunningham, R. S. (2013). The experience of information sharing among primary care clinicians with cancer survivors and their oncologists. *Journal of Cancer Survivorship, 7*(1), 124–130. doi:10.1007/s11764-012-0253-7

Downs-Holmes, C., Dracon, A., Svarovsky, T., & Sustin, M. (2014). Development of a survivorship program. *Clinical Journal of Oncology Nursing, 18*(suppl 5), 53.

Drost, F. M., Mols, F., Kaal, S. E. J., Stevens, W. B. C., Graaf, W. T. A. v. d., Prins, J. B., & Husson, O. (2016). Psychological impact of lymphoma on adolescents and young adults: Not a matter of black or white. *Journal of Cancer Survivorship, 10*(4), 726–735. doi:10.1007/s11764-016-0518-7

Earle, C. C. (2006). Failing to plan is planning to fail: Improving the quality of care with survivorship care plans. *Journal of Clinical Oncology, 24*(32), 5112–5116. doi:10.1200/jco.2006.06.5284

Earle, C. C. (2007). Long term care planning for cancer survivors: A health services research agenda. *Journal of Cancer Survivorship, 1*(1), 64–74. doi:10.1007/s11764-006-0003-9

Earle, C. C., & Ganz, P. A. (2012). Cancer survivorship care: Don't let the perfect be the enemy of the good. *Journal of Clinical Oncology, 30*(30), 3764–3768. doi:10.1200/JCO.2012.41.7667

Edith Cowan University. (2015). Vario wellness clinic. Retrieved 1 April 2015

Ezendam, N. P. M., Nicolaije, K. A. H., Kruitwagen, R. F. P. M., Pijnenborg, J. M. A., Vos, M. C., Boll, D., . . . van de Poll-Franse, L. V. (2014). Survivorship care plans to inform the primary care physician: Results from the ROGY care pragmatic cluster randomized controlled trial. *Journal of Cancer Survivorship, 8*(4), 595–602. doi:10.1007/s11764-014-0368-0

Faller, H., Koch, U., Brähler, E., Härter, M., Keller, M., Schulz, H., . . . Mehnert, A. (2016). Satisfaction with information and unmet information needs in men and women with cancer. *Journal of Cancer Survivorship, 10*(1), 62–70. doi:10.1007/s11764-015-0451-1

Ferrer, R. A., Huedo-Medina, T. B., Johnson, B. T., Ryan, S., & Pescatello, L. S. (2011). Exercise interventions for cancer survivors: A meta-analysis of quality of life outcomes. *Annals of Behavioral Medicine, 41*(1), 32–47. doi:10.1007/s12160-010-9225-1

Filsinger, S., Burkhalter, R., & Campbell, H. S. (2011). *Survivor unmet needs survey: User guide*. Retrieved from Ontario, Canada

Fitch, M. (2008). Supportive care framework. *Canadian Oncology Nursing Journal - Revue Canadienne De Nursing Oncologique, 18*(1), 6–24.

Forsythe, L. P., Arora, N. K., Alfano, C. M., Weaver, K. E., Hamilton, A. S., Aziz, N., & Rowland, J. H. (2014). Role of oncologists and primary care physicians in providing follow-up care to non-Hodgkin lymphoma survivors within 5 years of diagnosis: A population-based study. *Supportive Care in Cancer, 22*(6), 1509–1517. doi:10.1007/s00520-013-2113-z

Foster, C., Breckons, M., Cotterell, P., Barbosa, D., Calman, L., Corner, J., . . . Smith, P. W. (2015). Cancer survivors' self-efficacy to self-manage in the year following primary treatment. *Journal of Cancer Survivorship, 9*(1), 11–19. doi:10.1007/s11764-014-0384-0

Foster, C., & Fenlon, D. (2011). Recovery and self-management support following primary cancer treatment. *British Journal of Cancer, 105*, S21. doi:10.1038/bjc.2011.419

Fowkes, F. G., & Fulton, P. M. (1991). Critical appraisal of published research: Introductory guidelines. *British Medical Journal, 302*(6785), 1136–1140.

Franco, K., Shuk, E., Philip, E., Blanch-Hartigan, D., Parker, P. A., Matasar, M., . . . Bylund, C. L. (2017). Communication between oncologists and lymphoma survivors during follow-up consultations: A qualitative analysis. *Journal of Psychosocial Oncology, 35*(5), 513. doi:10.1080/07347332.2017.1313352

Frew, G., Smith, A., Zutshi, B., Young, N., Aggarwal, A., Jones, P., . . . Maher, E. J. (2010). Results of a quantitative survey to explore both perceptions of the purposes of follow-up and preferences for methods of follow-up delivery among service users, primary care practitioners and specialist clinicians after cancer treatment. *Clinical Oncology, 22*(10), 874–884. doi:10.1016/j.clon.2010.06.008

Frick, M. A., Vachani, C. C., Bach, C., Hampshire, M. K., Arnold-Korzeniowski, K., Metz, J. M., & Hill-Kayser, C. E. (2017). Survivorship and the chronic cancer patient: Patterns in treatment-

related effects, follow-up care, and use of survivorship care plans. *Cancer, 123*(21), 4268–4276. doi:10.1002/cncr.30862

Friedman, D. R., Coan, A. D., Smith, S. K., Herndon II, J. E., & Abernethy, A. P. (2010). Informational needs assessment of non-Hodgkin lymphoma survivors and their physicians. *American Journal of Hematology, 85*(7), 528–532.

Furzer, B. J., Ackland, T. R., Wallman, K. E., Petterson, A. S., Gordon, S. M., Wright, K. E., & Joske, D. J. L. (2016). A randomised controlled trial comparing the effects of a 12-week supervised exercise versus usual care on outcomes in haematological cancer patients. *Supportive Care in Cancer, 24*(4), 1697–1707. doi:10.1007/s00520-015-2955-7

Ganz, P. A., Casillas, J., & Hahn, E. E. (2008). Ensuring quality care for cancer survivors: Implementing the survivorship care plan. *Seminars in Oncology Nursing, 24*(3), 208–217. doi:10.1016/j.soncn.2008.05.009

Gates, P., Seymour, J. F., & Krishnasamy, M. (2012). Insights into the development of a nurse-led survivorship care intervention for long-term survivors of Hodgkin lymphoma. *The Australian Journal of Cancer Nursing, 13*(1), 4–10.

Gates, P., Seymour, J. F., & Krishnasamy, M. (2015). A nurse-led survivorship intervention for survivors of Hodgkin lymphoma: A pilot study. *The Australian Journal of Cancer Nursing, 16*(2), 19–26.

Gerber, L. H., Stout, N. L., Schmitz, K. H., & Stricker, C. T. (2012). Integrating a prospective surveillance model for rehabilitation into breast cancer survivorship care. *Cancer, 118*(Suppl 8), 2201–2206. doi:10.1002/cncr.27472

Girgis, A., & Butow, P. (2009). Cancer survivorship: Research priorities at the national and international levels. *Cancer Forum, 33*(3), 194–197.

Girgis, A., Delaney, G. P., & Miller, A. A. (2015). Utilising ehealth to support survivorship care. *Cancer Forum, 39*(2), 86–89.

Grant, M., & Economou, D. (2008). The evolving paradigm of adult cancer survivor care. *Oncology, 22*(4), 13–22, 27.

Grbich, C. (1998). *Qualitative research in health: An introduction*. Thousand Oaks, California: Sage Publications.

Greenfield, D. M., Absolom, K., Eiser, C., Walters, S. J., Michel, G., Hancock, B. W., . . . Coleman, R. E. (2009). Follow-up care for cancer survivors: The views of clinicians. *British Journal of Cancer, 101*(4), 568–574. doi:10.1038/sj.bjc.6605160

Grinyer, A. (2010). The late effects of mantle field radiotherapy: The information and support needs of women survivors of Hodgkin's disease. *European Journal of Oncology Nursing, 14*(3), 183–189. doi:10.1016/j.ejon.2009.12.006

Grunfeld, E., Julian, J. A., Pond, G., Maunsell, E., Coyle, D., Folkes, A., . . . Levine, M. (2011). Evaluating survivorship care plans: Results of a randomised clinical trial of patients with breast cancer. *Journal of Clinical Oncology, 29*(36), 4755–4762. doi:10.1200/JCO.2011.36.8373

Hahn, E. E., & Ganz, P. A. (2011). Survivorship programs and care plans in practice: Variations on a theme. *Journal of Oncology Practice, 7*(2), 70–75.

Hall, A., Campbell, H. S., Sanson-Fisher, R., Lynagh, M., D'Este, C., Burkhalter, R., & Carey, M. (2013). Unmet needs of Australian and Canadian haematological cancer survivors: A cross-sectional international comparative study. *Psycho-Oncology, 22*(9), 2032–2038.

Hall, A., D'Este, C., Tzelepis, F., Lynagh, M., & Sanson-Fisher, R. (2014). Factors associated with haematological cancer survivors experiencing a high level of unmet need across multiple items of supportive care: A cross-sectional survey study. *Supportive Care in Cancer*. doi:10.1007/s00520-014-2264-6

Hall, A., D'Este, C., Tzelepis, F., Sanson-Fisher, R., & Lynagh, M. (2014). The survivor unmet needs survey (SUNS) for haematological cancer

survivors. A cross-sectional study assessing the relevance and psychometric properties. *BioMed Central, 14*(211), 1–20. doi:10.1186/1472-6963-14-211

Hall, A., Lynagh, M., Bryant, J., & Sanson-Fisher, R. (2013). Supportive care needs of hematological cancer survivors: A critical review of the literature. *Critical Reviews in Oncology/Hematology, 88*(1), 102–116.

Hall, A. E., Sanson-Fisher, R. W., Carey, M. L., Paul, C., Williamson, A., Bradstock, K., & Campbell, H. S. (2016). Prevalence and associates of psychological distress in haematological cancer survivors. *Supportive Care in Cancer, 24*(10), 4413–4422. doi:10.1007/s00520-016-3282-3

Hansen, D. G., Larsen, P. V., Holm, L. V., Rottmann, N., Bergholdt, S. H., & Søndergaard, J. (2013). Association between unmet needs and quality of life of cancer patients: A population-based study. *Acta Oncologica, 52*(2), 391–399. doi:10.3109/0284186X.2012.742204

Hausman, J., Ganz, P. A., Sellers, T. P., & Rosenquist, J. (2011). Journey forward: The new face of cancer survivorship care. *Journal of Oncology Practice, 7*(3 Supplement), e50s–56s.

Hawkins, N. A., Pollack, L. A., Leadbetter, S., Steele, W. R., Carroll, J., Ryan, E. P., . . . Dolan, J. G. (2008). Information needs of patients and perceived adequacy of information available before and after treatment of cancer. *Journal of Psychosocial Oncology, 26*(2), 1–16.

Hebdon, M., Abrahamson, K., McComb, S., & Sands, L. (2014). Transitioning patients to survivorship care: A systematic review. *Oncology Nursing Forum, 41*(6), 615–625. doi:10.1188/14.ONF.615-625

Hemminki, K., Lenner, P., Sundquist, J., & Bermejo, J. L. (2008). Risk of subsequent solid tumors after non-Hodgkin's lymphoma: Effect of diagnostic age and time since diagnosis. *Journal of Clinical Oncology, 26*(11), 1850–1857. doi:10.1200/jco.2007.14.6068

Hewitt, M. E., Bamundo, A., Day, R., & Harvey, C. (2007). Perspectives on post-treatment cancer care: Qualitative research with survivors, nurses, and physicians. *Journal of Clinical Oncology, 25*(16), 2270–2273. doi:10.1200/jco.2006.10.0826

Hewitt, M. E., Greenfield, S., & Stovall, E. (2005). *From cancer patient to cancer survivor: Lost in transition*. Washington DC: The National Academies Press.

Hibbard, J. H., Mahoney, E. R., Stock, R., & Tusler, M. (2007). Do increases in patient activation result in improved self-management behaviors? *Health Services Research, 42*(4), 1443–1463. doi:10.1111/j.1475-6773.2006.00669.x

Hill-Kayser, C. E., Vachani, C. C., Hampshire, M. K., Di Lullo, G., Jacobs, L. A., & Metz, J. M. (2013). Impact of internet-based cancer survivorship care plans on health care and lifestyle behaviors. *Cancer, 119*(21), 3854–3860. doi:10.1002/cncr.28286

Hjermstad, M. J., Evensen, S. A., Kvaloy, S. O., Loge, J. H., Fayers, P. M., & Kaasa, S. (2003). The CARES-SF used for prospective assessment of health-related quality of life after stem cell transplantation. *Psycho-Oncology, 12*(8), 803–813.

Hlubocky, F. J., Webster, K., Cashy, J., Beaumont, J., & Cella, D. (2013). The development and validation of a measure of health-related quality of life for non-Hodgkin's lymphoma: The functional assessment of cancer therapy – lymphoma (FACT-Lym). *Lymphoma, 2013*, 9.

Hoffman, M. A., Lent, R. W., & Raque-Bogdan, T. L. (2013). A social cognitive perspective on coping with cancer: Theory, research, and intervention. *The Counseling Psychologist, 41*(2), 240–267. doi:10.1177/0011000012461378

Holland, J. C., Andersen, B., Breitbart, W. S., Compas, B., Dudley, M. M., Fleishman, S., . . . Zevon, M. A. (2010). Distress management. *Journal of*

the National Comprehensive Cancer Network, 8(4), 448–485. doi:10.6004/jnccn.2010.0034

Howell, D., Hack, T., Oliver, T., Chulak, T., Mayo, S., Aubin, M., . . . Sinclair, S. (2012). Models of care for post-treatment follow-up of adult cancer survivors: A systematic review and quality appraisal of the evidence. *Journal of Cancer Survivorship, 6*(4), 359–371. doi:10.1007/s11764-012-0232-z

Howlader, N., Noone, A. M., Krapcho, M., Miller, D., Bishop, K., Kosary, C., . . . Cronin, K. A. (2016). *SEER (Surveillance, Epidemiology and End Results) cancer statistics review, 1975–2014.* Retrieved from Bethesda, MD: https://seer.cancer.gov/csr/1975_2014/

Husson, O., Thong, M. S., Mols, F., Oerlemans, S., Kaptein, A. A., & van de Poll-Franse, L. V. (2013). Illness perceptions in cancer survivors: What is the role of information provision? *Psycho-Oncology, 22*(3), 490–498.

IBM Corp. (2017). Released 2017. IBM SPSS statistics for Macintosh, version 25.0. Armonk, NY: IBM Corp.

Irwin, M., Klemp, J. R., Glennon, C., & Frazier, L. M. (2011). Oncology nurses' perspectives on the state of cancer survivorship care: Current practice and barriers to implementation. *Oncology Nursing Forum, 38*(1), E11–19. doi:10.1188/11.onf.e11-e19

Jabson, J. M. (2015). Follow-up care instructions, treatment summaries, and cancer survivors' receipt of follow-up health care and late/long term effects. *Supportive Care in Cancer, 23*(7), 1851–1856. doi:10.1007/s00520-014-2532-5

Jabson, J. M. (2015). Treatment summaries, follow-up care instructions, and patient navigation: Could they be combined to improve cancer survivor's receipt of follow-up care? *Journal of Cancer Survivorship, 9*(4), 692. doi:10.1007/s11764-015-0444-0

Jabson, J. M., & Bowen, D. J. (2013). Cancer treatment summaries and follow-up care instructions: Which cancer survivors receive them? *Cancer Causes & Control, 24*(5), 861–871. doi:10.1007/s10552-013-0163-7

Jackson, J. M., Scheid, K., & Rolnick, S. J. (2013). Development of the cancer survivorship care plan: What's next? Life after cancer treatment. *Clinical Journal of Oncology Nursing, 17*(3), 280–284. doi:10.1188/13.cjon.280-284

Jefford, M., Gough, K., Drosdowsky, A., Russell, L., Aranda, S., Butow, P., . . . Schofield, P. (2016). A randomized controlled trial of a nurse-led supportive care package (SurvivorCare) for survivors of colorectal cancer. *Oncologist, 21*(8), 1014–1023. doi:10.1634/theoncologist.2015-0533

Jefford, M., Karahalios, E., Pollard, A., Baravelli, C., Carey, M., Franklin, J., . . . Schofield, P. (2008). Survivorship issues following treatment completion – results from focus groups with Australian cancer survivors and health professionals. *Journal of Cancer Survivorship, 2*, 20–32.

Jefford, M., Schofield, P., & Emery, J. (2012). Improving survivorship care. *Journal of Clinical Oncology, 30*(12), 1391–1392. doi:10.1200/JCO.2011.40.1539

Jiao, M., Hall, A., Nolte, L., Piper, A., Lisy, K., & Jefford, M. (2017). A rapid review of needs assessment tools for post-treatment cancer survivors. *European Journal of Cancer Care, e12764*, 1–10. doi:10.1111/ecc.12764

John, C., & Armes, J. (2013). Developing a nurse-led survivorship service for patients with lymphoma. *European Journal of Oncology Nursing, 17*(5), 521–527. doi:10.1016/j.ejon.2013.03.001

Jones, W. C., Parry, C., Devine, S., Main, D. S., Sasaki, S. O., & Tran, Z. V. (2015). Prevalence and predictors of distress in post-treatment adult

leukemia and lymphoma survivors. *Journal of Psychosocial Oncology, 33*(2), 124–141. doi:10.1080/07347332.2014.992085

Karvinen, K., Bruner, B., & Truant, T. (2015). The teachable moment after cancer diagnosis: Perceptions from oncology nurses. *Oncology Nursing Forum, 42*(6), 602–609. doi:10.1188/15.ONF.602-609

Keesing, S., McNamara, B., & Rosenwax, L. (2015). Cancer survivors' experiences of using survivorship care plans: A systematic review of qualitative studies. *Journal of Cancer Survivorship, 9*, 260–268.

Klassen, A. C., Smith, K. C., Shuster, M., Coa, K. I., Caulfield, L. E., Helzlsouer, K. J., . . . Hannum, S. (2017). "We're just not prepared for eating over our whole life": A mixed methods approach to understanding dietary behaviors among longer term cancer survivors. *Integrative Cancer Therapies*, 1–13. doi:10.1177/1534735417731515

Klemanski, D. L., Browning, K. K., & Kue, J. (2016). Survivorship care plan preferences of cancer survivors and health care providers: A systematic review and quality appraisal of the evidence. *Journal of Cancer Survivorship, 10*, 71–86.

Knott, V., Turnbull, D., Olver, I., & Winefield, A. (2012). A grounded theory approach to understand the cancer-coping process. *British Journal of Health Psychology, 17*(3), 551–564. doi:10.1111/j.2044-8287.2011.02054.x

Koch, L., Jansen, L., Brenner, H., & Arndt, V. (2013). Fear of recurrence and disease progression in long-term (>5 years) cancer survivors–a systematic review of quantitative studies. *Psycho-Oncology, 22*(1), 1–11.

Kreissl, S., Mueller, H., Goergen, H., Mayer, A., Brillant, C., Behringer, K., . . . Borchmann, P. (2016). Cancer-related fatigue in patients with and survivors of Hodgkin's lymphoma: A longitudinal study of the German Hodgkin study group. *Lancet Oncology, 17*(10), 1453–1462. doi:10.1016/s1470-2045(16)30093-6

Krolak, D., Collins, B., Weiss, L., Harris, C., & Van der Jagt, R. (2017). Cognitive function and its relationship to other psychosocial factors in lymphoma survivors. *Supportive Care in Cancer, 25*(3), 905–913. doi:10.1007/s00520-016-3480-z

Kuijpers, W., Groen, W. G., & Aaronson, N. K. (2013). A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: Relevance for cancer survivors. *Journal of Medical Internet Research, 15*(2), e37–e37. doi:10.2196/jmir.2281

Kuppers, R., & Hansmann, M. L. (2005). The Hodgkin and Reed/Sternberg cell. *International Journal of Biochemistry & Cell Biology, 37*(3), 511–517. doi:10.1016/j.biocel.2003.10.025

Kvale, E. A., Huang, C. H. S., Meneses, K. M., Demark-Wahnefried, W., Bae, S., Azuero, C. B., . . . Ritchie, C. S. (2016). Patient-centered support in the survivorship care transition: Outcomes from the patient-owned survivorship care plan intervention. *Cancer, 122*(20), 3232–3242. doi:10.1002/cncr.30136

Landier, W. (2009). Survivorship care: Essential components and models of delivery. *Oncology, 23*(4), 46–53.

Langbecker, D., Ekberg, S., Yates, P., Chan, A., & Chan, R. J. (2016). What are the barriers of quality survivorship care for haematology cancer patients? Qualitative insights from cancer nurses. *Journal of Cancer Survivorship, 10*(1), 122–130. doi:10.1007/s11764-015-0458-7

Leeuwen, F. E., & Ng, A. K. (2017). Late sequelae in Hodgkin lymphoma survivors. *Hematological Oncology, 35*(S1), 60–66. doi:10.1002/hon.2402

Leigh, S. A. (2008). The changing legacy of cancer: Issues of long-term survivorship. *Nursing Clinics of North America, 43*(2), 243–258.

Leong, F. T., & Austin, J. T. (2006). *The psychology research handbook: A guide for graduate students and research assistants* (2nd ed.). Thousand Oaks, CA: Sage.

Linendoll, N., Saunders, T., Burns, R., Nyce, J. D., Wendell, K. B., Evens, A. M., & Parsons, S. K. (2016). Health-related quality of life in Hodgkin lymphoma: A systematic review. *Health and Quality of Life Outcomes, 14*(1), 114. doi:10.1186/s12955-016-0515-6

Litt, J. (2006). *Putting prevention into practice: Guidelines for the implementation of prevention in the general practice setting* (2nd ed.). Melbourne, Victoria, Australia: The Royal Australian College of General Practitioners

Livingston, E. H., & Wislar, J. S. (2012). Minimum response rates for survey research. *Archives of Surgery, 147*(2), 110.

Lobb, E. A., Joske, D., Butow, P., Kristjanson, L. J., Cannell, P., Cull, G., & Augustson, B. (2009). When the safety net of treatment has been removed: Patients' unmet needs at the completion of treatment for haematological malignancies. *Patient Education and Counseling, 77*(1), 103–108.

Lovibond, S. H., & Lovibond, P. F. (1995). *Manual for the Depression Anxiety Stress Scales* (2nd ed.). Sydney: Psychology Foundation University of New South Wales.

Lymphoma Association. (2017). Lymphoma relapse. Retrieved from https://www.lymphomas.org.uk/about-lymphoma/treatment/what-happens-when-lymphoma-relapses-comes-back 9 March 2018

MacMillan Cancer Support & NHS Improvement. (2010). *The national cancer survivorship initiative vision*. UK: Department of Health, London.

Magyari, F., Kosa, K., Berecz, R., Illes, A., Miltenyi, Z., Simon, Z., & Illes, A. (2017). Employment status and health related quality of life among Hodgkin-lymphoma survivors- results based on data from a major treatment center in Hungary. *Health and Quality of Life Outcomes, 15*.

Maly, R. C., Liang, L., Liu, Y., Griggs, J. J., & Ganz, P. A. (2017). Randomized controlled trial of survivorship care plans among low-income,

predominantly latina breast cancer survivors. *Journal of Clinical Oncology, 35*(16), 1814–1825.

Marbach, T. J., & Griffie, J. (2011). Patient preferences concerning treatment plans, survivorship care plans, education, and support services. *Oncology Nursing Forum, 38*(3), 335–342. doi:10.1188/11.ONF.335-342

Marker, J. (2015). Recovering from and surviving cancer: A consumer perspective. *Cancer Forum, 39*(2), 76–79.

Matheson, L., Boulton, M., Lavender, V., Collins, G., Mitchell-Floyd, T., & Watson, E. (2016). The experiences of young adults with Hodgkin lymphoma transitioning to survivorship: A grounded theory study. *Oncology Nursing Forum, 43*(5), E195–204. doi:10.1188/16.ONF.E195-E2014

Mayer, D. K. (2014). Survivorship care plans: Necessary but not sufficient? *Clinical Journal of Oncology Nursing, 18*, 7–8. doi:10.1188/14.CJON.S1.7-8

Mayer, D. K., Birken, S. A., Check, D. K., & Chen, R. C. (2015). Summing it up: An integrative review of studies of cancer survivorship care plans (2006-2013). *Cancer, 121*(7), 978–996. doi:10.1002/cncr.28884

Mayer, D. K., Deal, A. M., Crane, J. M., Chen, R. C., Asher, G. N., Hanson, L. C., . . . Rosenstein, D. L. (2016). Using survivorship care plans to enhance communication and cancer care coordination: Results of a pilot study. *Oncology Nursing Forum, 43*(5), 636–645. doi:10.1188/16.ONF.636-645

Mayer, D. K., Green, M., Check, D. K., Gerstel, A., Chen, R. C., Asher, G., . . . Rosenstein, D. L. (2015). Is there a role for survivorship care plans in advanced cancer? *Supportive Care in Cancer, 23*(8), 2225–2230. doi:10.1007/s00520-014-2586-4

McCabe, M. S., Bhatia, S., Oeffinger, K. C., Reaman, G. H., Tyne, C., Wollins, D. S., & Hudson, M. M. (2013). American Society of Clinical Oncology

statement: Achieving high-quality cancer survivorship care. *Journal of Clinical Oncology, 31*(5), 631–640. doi:10.1200/JCO.2012.46.6854

McCabe, M. S., Faithfull, S., Makin, W., & Wengstrom, Y. (2013). Survivorship programs and care planning. *Cancer, 119*(Suppl 11), 2179–2186. doi:10.1002/cncr.28068

McCabe, M. S., & Jacobs, L. A. (2012). Clinical update: Survivorship care – models and programs. *Seminars in Oncology Nursing, 28*(3), e1–e8. doi:10.1016/j.soncn.2012.05.001

McCabe, M. S., Partridge, A. H., Grunfeld, E., & Hudson, M. M. (2013). Risk-based health care, the cancer survivor, the oncologist, and the primary care physician. *Seminars in Oncology, 40*(6), 804–812. doi:10.1053/j.seminoncol.2013.09.004

McCarter, K., Britton, B., Baker, A. L., Halpin, S. A., Beck, A. K., Carter, G., . . . Wolfenden, L. (2018). Interventions to improve screening and appropriate referral of patients with cancer for psychosocial distress: Systematic review. *BMJ Open, 8*(1). doi:10.1136/bmjopen-2017-017959

McConnell, H., White, R., & Maher, J. (2017). Categorising cancers to enable tailored care planning through a secondary analysis of cancer registration data in the UK. *BMJ Open, 7*(11). doi:10.1136/bmjopen-2017-016797

McDowell, I. (2006). *Measuring health: A guide to rating scales and questionnaires* (3rd ed.). Oxford: Oxford University Press.

McDowell, M. E., Occhipinti, S., Ferguson, M., Dunn, J., & Chambers, S. K. (2010). Predictors of change in unmet supportive care needs in cancer. *Psycho-Oncology, 19*(5), 508–516.

McGrath, P. (2014). Patient perspectives on the usefulness of routine telephone follow-up as psychosocial support for hematologic malignancies: Australian findings. *Oncology Nursing Forum, 41*(1), 40–44.

Medical Research Council. (2000). *A framework for development and evaluation of RCTs for complex interventions to improve health*. UK: MRC Health Services and Public Health Research Board.

Meijer, A., Roseman, M., Delisle, V. C., Milette, K., Levis, B., Syamchana, A., . . . Thombs, B. D. (2013). Effects of screening for psychological distress on patient outcomes in cancer: A systematic review. *Journal of Psychosomatic Research, 75*(1), 1–17. doi:10.1016/j.jpsychores.2013.01.012

Melynyk, B., & Fineout-Overholt, E. (2011). *Evidence-based practice in nursing & healthcare: A guide to best practice* (2nd ed.). Philadelphia: Wolters Kluwer, Lippincott Williams & Wilkins.

Merport, A., Lemon, S. C., Nyambose, J., & Prout, M. N. (2012). The use of cancer treatment summaries and care plans among Massachusetts physicians. *Supportive Care in Cancer, 20*(7), 1579–1583. doi:10.1007/s00520-012-1458-z

Mitchell, A. J. (2013). Screening for cancer-related distress: When is implementation successful and when is it unsuccessful? *Acta Oncologica, 52*(2), 216–224. doi:10.3109/0284186X.2012.745949

Mitchell, A. J. D., Chan, M. M., Bhatti, H. M., Halton, M. M., Grassi, L. P., Johansen, C. P., & Meader, N. P. (2011). Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: A meta-analysis of 94 interview-based studies. *Lancet Oncology, 12*(2), 160–174. doi:10.1016/S1470-2045(11)70002-X

Mitchell, A. J. D., Ferguson, D. W., Gill, J., Paul, J. B., & Symonds, P. P. (2013). Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: A systematic review and meta-analysis. *Lancet Oncology, 14*(8), 721–732. doi:10.1016/S1470-2045(13)70244-4

Moher, D., Hopewell, S., Schulz, K. F., Montori, V., Gøtzsche, P. C., Devereaux, P. J., . . . Altman, D. G. (2010). CONSORT 2010 explanation

and elaboration: Updated guidelines for reporting parallel group randomised trial. *British Medical Journal, 340*, c869.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *British Medical Journal, 339*(b2535).

Mojs, E., Warchol-Biedermann, K., & Samborski, W. (2017). What do we know about psychological outcomes of lymphoma in adults? *European Psychologist, 22*(2), 121–131. doi:10.1027/1016-9040/a000285

Molassiotis, A., Yates, P., Li, Q., So, W. K. W., Pongthavornkamol, K., Pittayapan, P., . . . Chan, R. J. (2017). Mapping unmet supportive care needs, quality-of-life perceptions and current symptoms in cancer survivors across the Asia-Pacific region: Results from the international step study. *Annals of Oncology, 28*(10), 2552–2558.

Monterosso, L., Taylor, K., Platt, V., Krishnasamy, M., Lobb, E. A., Musiello, T., . . . Joske, D. (2015). *Defining concerns, unmet needs and support preferences for haematology cancer survivors: An exploratory study to inform intervention development*. Retrieved from University of Notre Dame Australia, Fremantle

Monterosso, L., Taylor, K., Platt, V., Lobb, E., Krishnasamy, M., Musiello, T., . . . Joske, D. (2017). A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma. *European Journal of Oncology Nursing, 28*, 62–68. doi:10.1016/j.ejon.2017.03.002

Mor Shalom, M., Hahn, E. E., Casillas, J., & Ganz, P. A. (2011). Do survivorship care plans make a difference? A primary care provider perspective. *Journal of Oncology Practice, 7*(5), 314–318.

Muzzatti, B., & Annunziata, M. A. (2013). Assessing quality of life in long-term cancer survivors: A review of available tools. *Supportive Care in Cancer, 21*(11), 3143–3152.

National Cancer Institute. (2006). NCI dictionary of cancer terms http://www.Cancer.Gov/dictionary/?Cdrid=45708. Retrieved 3 April 2014

National Coalition for Cancer Survivorship. (2014). Http://www.Canceradvocacy.Org/. Retrieved 3 April 2014

Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description – the poor cousin of health research? *BMC Medical Research Methodology, 9*(1), 52–52. doi:10.1186/1471-2288-9-52

Ng, A., LaCasce, A., & Travis, L. B. (2011). Long-term complications of lymphoma and its treatment. *Journal of Clinical Oncology, 29*(14), 1885–1892.

Ng, A. K. (2014). Current survivorship recommendations for patients with Hodgkin lymphoma: Focus on late effects. *Blood, 124*(23), 3373.

NVivo 11. (2016). *Qualitative data analysis software; QSR international Pty Ltd. Version 11*.

Oberoi, D., White, V., Seymour, J., Prince, H. M., Harrison, S., Jefford, M., . . . Giles, G. (2017). The course of anxiety, depression and unmet needs in survivors of diffuse large B cell lymphoma and multiple myeloma in the early survivorship period. *Journal of Cancer Survivorship, 11*, 329–338. doi:10.1007/s11764-016-0591-y

Oeffinger, K. C., & McCabe, M. S. (2006). Models for delivering survivorship care. *Journal of Clinical Oncology, 24*(32), 5117–5124. doi:10.1200/jco.2006.07.0474

Oerlemans, S., Mols, F., Nijziel, M. R., Lybeert, M., & van de Poll-Franse, L. V. (2011). The impact of treatment, socio-demographic and clinical characteristics on health-related quality of life among Hodgkin's and non-Hodgkin's lymphoma survivors: A systematic review. *Annals of Hematology, 90*(9), 993–1004. doi:10.1007/s00277-011-1274-4

Oerlemans, S., Mols, F., Nijziel, M. R., Zijlstra, W. P., Coebergh, J. W., & van de Poll-Franse, L. V. (2014). The course of anxiety and depression for patients with Hodgkin's lymphoma or diffuse large B cell lymphoma: A longitudinal study of the PROFILES registry. *Journal of Cancer Survivorship, 8*(4), 555–564. doi:10.1007/s11764-014-0367-1

Onwuegbuzie, A., & Leech, N. (2007). A call for qualitative power analyses. *Quality & Quantity, 41*(1), 105–121. doi:10.1007/s11135-005-1098-1

Osborne, T. R., Ramsenthaler, C., Siegert, R. J., Edmonds, P. M., Schey, S. A., & Higginson, I. J. (2012). What issues matter most to people with multiple myeloma and how well are we measuring them? A systematic review of quality of life tools. *European Journal of Haematology, 89*(6), 437–457.

Palmer, S. C., Jacobs, L. A., Demichele, A., Risendal, B., Jones, A. F., & Stricker, C. T. (2014). Metrics to evaluate treatment summaries and survivorship care plans: A scorecard. *Supportive Care in Cancer, 22*(6), 1475–1483. doi:10.1007/s00520-013-2107-x

Palos, G. R., Zandstra, F., Gilmore, K., Russell, L., Flores, J., & Rodriquez, M. A. (2014). Transforming cancer survivorship care through quality improvement initiatives. *Clinical Journal of Oncology Nursing, 18*(4), 468. doi:10.1188/14.CJON.468-470

Panek-Hudson, Y. (2013). Survivorship care – time for innovation? *The Australian Journal of Cancer Nursing, 14*(1), 7–12.

Papadopoulou, C., Kotronoulas, G., Schneider, A., Miller, M., McBride, J., Polly, Z., . . . Maguire, R. (2017). Patient-reported self-efficacy, anxiety, and health-related quality of life during chemotherapy: Results from a longitudinal study. *Oncology Nursing Forum, 44*(1), 127. doi:10.1188/17.ONF.127-136

Park, C. L., Edmondson, D., Fenster, J. R., & Blank, T. O. (2008). Positive and negative health behavior changes in cancer survivors: A stress and

coping perspective. *Journal of Health Psychology, 13*(8), 1198–1206. doi:10.1177/1359105308095978

Parry, C., Kent, E. E., Forsythe, L. P., Alfano, C. M., & Rowland, J. (2013). Can't see the forest for the care plan: A call to revisit the context of care planning. *Journal of Clinical Oncology, 31*(21), 2651–2653.

Parry, C., Lomax, J. B., Morningstar, E. A., & Fairclough, D. L. (2012). Identification and correlates of unmet service needs in adult leukemia and lymphoma survivors after treatment. *Journal of Oncology Practice, 8*(5), e135–141.

Parry, C., Morningstar, E., Kendall, J., & Coleman, E. A. (2010). Working without a net: Leukemia and lymphoma survivors' perspectives on care delivery at end-of-treatment and beyond. *Journal of Psychosocial Oncology, 29*(2), 175–198. doi:10.1080/07347332.2010.548444

Patton, M. Q. (2014). *Qualitative research & evaluation methods: Integrating theory and practice*. Thousand Oaks, California: SAGE Publications.

Philip, E. J., Merluzzi, T. V., Zhang, Z., & Heitzmann, C. A. (2013). Depression and cancer survivorship: Importance of coping self-efficacy in post-treatment survivors. *Psycho-Oncology, 22*(5), 987–994. doi:10.1002/pon.3088

Phillips, J. L., & Currow, D. C. (2010). Cancer as a chronic disease. *Collegian, 17*(2), 47–50.

Playdon, M., Ferrucci, L. M., McCorkle, R., Stein, K. D., Cannady, R., Sanft, T., & Cartmel, B. (2016). Health information needs and preferences in relation to survivorship care plans of long-term cancer survivors in the American Cancer Society's study of cancer survivors-I. *Journal of Cancer Survivorship, 10*(4), 674. doi:10.1007/s11764-015-0513-4

Polit, D., & Beck, C. (2006). The content validity index: Are you sure you know what's being reported? Critique and recommendations. *Research in Nursing & Health, 29*, 489–497.

Quaresma, M., Coleman, M. P., & Rachet, B. (2015). 40-year trends in an index of survival for all cancers combined and survival adjusted for age and sex for each cancer in England and Wales, 1971–2011: A population-based study. *Lancet, 385*(9974), 1206–1218. doi:10.1016/S0140-6736(14)61396-9

Rabin, C., Simpson, N., Morrow, K., & Pinto, B. (2011). Behavioral and psychosocial program needs of young adult cancer survivors. *Qualitative Health Research, 21*(6), 796–806. doi:10.1177/1049732310380060

Raphael, D., Frey, R., & Gott, M. (2017). Psychosocial distress in haematological cancer survivors: An integrative review. *European Journal of Cancer Care, 26*(6), e12640-n/a. doi:10.1111/ecc.12640

Rechis, R., Arvey, S. R., & Beckjord, E. B. (2013). Perspectives of a lifelong cancer survivor – improving survivorship care. *Nature Reviews Clinical Oncology, 10*(2), 117–120. doi:10.1038/nrclinonc.2012.212

Richardson, G. E. (2002). The metatheory of resilience and resiliency. *Journal of Clinical Psychology, 58*(3), 307–321. doi:10.1002/jclp.10020

Robert Wood Johnson Foundation. (2014). Glossary of health care quality terms. Retrieved from www.rwjf.org/quality/equality/glossary 21 June 2014

Rollnick, S., Miller, W. R., & Butler, C. (2008). *Motivational interviewing in health care: Helping patients change behavior*. New York, NY: Guilford Press.

Rosenberg, C. A., Flanagan, C., Brockstein, B., Obel, J. C., Dragon, L. H., Merkel, D. E., . . . Hensing, T. A. (2016). Promotion of self-management for post treatment cancer survivors: Evaluation of a risk-adapted visit. *Journal of Cancer Survivorship, 10*(1), 206–219. doi:10.1007/s11764-015-0467-6

Rosner, B. (2016). *Fundamentals of Biostatistics* (8th ed.): Cengage Learning US.

Ross, L. (2013). Facilitating rapport through real patient encounters in health care professional education. *Australian Journal of Paramedicine, 10*(4), 1–11.

Rowland, J. H., & Bellizzi, K. M. (2008). Cancer survivors and survivorship research: A reflection on today's successes and tomorrow's challenges. *Hematology/Oncology Clinics of North America, 22*(2), 181–200.

Sabatino, S. A., Thompson, T. D., Smith, J. L., Rowland, J. H., Forsythe, L. P., Pollack, L., & Hawkins, N. A. (2013). Receipt of cancer treatment summaries and follow-up instructions among adult cancer survivors: Results from a national survey. *Journal of Cancer Survivorship, 7*(1), 32–43. doi:10.1007/s11764-012-0242-x

Salz, T., McCabe, M. S., Onstad, E. E., Baxi, S. S., Deming, R. L., Franco, R. A., . . . Oeffinger, K. C. (2014). Survivorship care plans: Is there buy-in from community oncology providers? *Cancer, 120*(5), 722–730. doi:10.1002/cncr.28472

Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health, 18*(2), 179–183. doi:10.1002/nur.4770180211

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*(4), 334–340. doi:10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G

Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000). The unmet supportive care needs of patients with cancer. Supportive care review group. *Cancer, 88*(1), 226–237.

Sant, M., Minicozzi, P., Mounier, M., Anderson, L. A., Brenner, H., Holleczek, B., . . . De Angelis, R. (2014). Survival for haematological malignancies in Europe between 1997 and 2008 by region and age: Results of EUROCARE-5, a population-based study. *Lancet Oncology, 15*(9), 931–942. doi:10.1016/S1470-2045(14)70282-7

Sarantakos, S. (2013). *Social research* (4th ed.). UK: Palgrave MacMillan

Sarker, S.-J., Smith, S. K., Chowdhury, K., Ganz, P. A., Zimmerman, S., Gribben, J., & Korszun, A. (2017). Comparison of the impact of cancer between British and US long-term non-Hodgkin lymphoma survivors. *Supportive Care in Cancer, 25*(3), 739–748. doi:10.1007/s00520-016-3454-1

Schaapveld, M., Aleman, B. M., Eggermond, A. M. v., Janus, C. P., Krol, A. D., Maazen, R. W. M. v. d., . . . Leeuwen, F. E. v. (2015). Second cancer risk up to 40 years after treatment for Hodgkin's lymphoma. *The New England Journal of Medicine, 373*(26), 2499–2511.

Schulz, K. F., Altman, D. G., & Moher, D. (2010). CONSORT 2010 statement: Updated guidelines for reporting parallel group randomised trials. *British Medical Journal, 340*, c332.

Schumacher, A., Sauerland, C., Silling, G., Berdel, W. E., & Stelljes, M. (2014). Resilience in patients after allogeneic stem cell transplantation. *Supportive Care in Cancer, 22*(2), 487–493. doi:10.1007/s00520-013-2001-6

Sharp, L., Deady, S., Gallagher, P., Molcho, M., Pearce, A., Thomas, A. A., . . . Comber, H. (2014). The magnitude and characteristics of the population of cancer survivors: Using population-based estimates of cancer prevalence to inform service planning for survivorship care. *BMC Cancer, 14*(767), 1–10.

Smith, J. A. (2007). *Qualitative psychology: A practical guide to research methods*. Thousand Oaks, California: SAGE Publications.

Smith, K. C., Klassen, A. C., Coa, K. I., & Hannum, S. M. (2016). The salience of cancer and the "survivor" identity for people who have completed acute cancer treatment: A qualitative study. *Journal of Cancer Survivorship, 10*(3), 457. doi:10.1007/s11764-015-0489-0

Smith, S. K., Samsa, G., Ganz, P. A., & Zimmerman, S. (2014). Is there a relationship between posttraumatic stress and growth after a lymphoma diagnosis?: Posttraumatic stress and growth relationship

after cancer diagnosis? *Psycho-Oncology, 23*(3), 315–321. doi:10.1002/pon.3419

Spector, D. J., Noonan, D., Mayer, D. K., Benecha, H., Zimmerman, S., & Smith, S. K. (2015). Are lifestyle behavioral factors associated with health-related quality of life in long-term survivors of non-Hodgkin lymphoma? *Cancer, 121*(18), 3343–3351. doi:10.1002/cncr.29490

Streiner, D. L., & Norman, G. R. (2003). *Health measurement scales: A practical guide to their development and use* (2nd ed.). Oxford: Oxford University Press.

Stricker, C. T., Jacobs, L. A., & Palmer, S. C. (2012). Survivorship care plans: An argument for evidence over common sense. *Journal of Clinical Oncology, 30*(12), 1392–1393. doi:10.1200/jco.2011.40.7940

Stricker, C. T., Jacobs, L. A., Risendal, B., Jones, A., Panzer, S., Ganz, P. A., . . . Palmer, S. C. (2011). Survivorship care planning after the Institute of Medicine recommendations: How are we faring? *Journal of Cancer Survivorship, 5*(4), 358–370. doi:10.1007/s11764-011-0196-4

Surveillance Epidemiology and End Results (SEER). (2014). *Cancer statistics review, 1975–2011*. Retrieved from National Cancer Institute

Sussman, J., Souter, L. H., Grunfeld, E., Howell, D., Gage, C., Keller-Olaman, S., & Brouwers, M. (2012). *Models of care for cancer survivorship*. Toronto, Ontario: Cancer Care Ontario.

Swash, B., Hulbert-Williams, N., & Bramwell, R. (2014). Unmet psychosocial needs in haematological cancer: A systematic review. *Supportive Care in Cancer, 22*(4), 1131–1141. doi:10.1007/s00520-014-2123-5

Taylor, K., Chan, R. J., & Monterosso, L. (2015). Models of survivorship care provision in adult patients with haematological cancer: An integrative literature review. *Supportive Care in Cancer, 23*(5), 1447–1458. doi:10.1007/s00520-015-2652-6

Taylor, K., Joske, D., Bulsara, M., Bulsara, C., & Monterosso, L. (2016). Protocol for care after lymphoma (CALy) trial: A phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *BMJ Open, 6*(e010817), 1–10. doi:10.1136/bmjopen-2015-010817

Taylor, K., & Monterosso, L. (2015). Survivorship care plans and treatment summaries in adult patients with hematologic cancer: An integrative literature review. *Oncology Nursing Forum, 42*(3), 283–291.

Taylor, K., & Monterosso, L. (2016). Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors. *The Australian Journal of Cancer Nursing, 17*(1), 6–12.

Taylor, K., Monterosso, L., & Bulsara, C. (2018). Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *European Journal of Oncology Nursing, 35*, 9–14. doi:10.1016/j.ejon.2018.01.011

Terwee, C. B., Bot, S. D. M., de Boer, M. R., van der Windt, D. A. W. M., Knol, D. L., Dekker, J., . . . de Vet, H. C. W. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology, 60*(1), 34–42. doi:10.1016/j.jclinepi.2006.03.012

Thewes, B., Butow, P., Zachariae, R., Christensen, S., Simard, S., & Gotay, C. (2012). Fear of cancer recurrence: A systematic literature review of self-report measures. *Psycho-Oncology, 21*(6), 571–587.

Thorpe, K. E., Zwarenstein, M., Oxman, A. D., Treweek, S., Furberg, C. D., Altman, D. G., . . . Chalkidou, K. (2009). A pragmatic–explanatory continuum indicator summary (PRECIS): A tool to help trial designers. *Journal of Clinical Epidemiology, 62*(5), 464–475. doi:10.1016/j.jclinepi.2008.12.011

Travis, L. B., Ng, A., Allan, J., Pui, C. H., Kennedy, A., Xu, X. G., . . . Boice, J. (2012). Second malignant neoplasms and cardiovascular disease following radiotherapy. *Journal of National Cancer Institute, 104*(5), 357–370.

Tzelepis, F., Sanson-Fisher, R. W., Hall, A. E., Carey, M. L., Paul, C. L., & Clinton-McHarg, T. (2015). The quality of patient-centred care: Haematological cancer survivors' perceptions. *Psycho-Oncology, 24*(7), 796–803. doi:10.1002/pon.3728

van de Poll-Franse, L. V., Nicolaije, K. A. H., & Ezendam, N. P. M. (2017). The impact of cancer survivorship care plans on patient and health care provider outcomes: A current perspective. *Acta Oncologica, 56*(2), 134–138. doi:10.1080/0284186X.2016.1266080

van de Wal, M., van de Poll-Franse, L., Prins, J., & Gielissen, M. (2016). Does fear of cancer recurrence differ between cancer types? A study from the population-based profiles registry: PROFILES – fear of cancer recurrence in cancer survivors. *Psycho-Oncology, 25*(7), 772–778. doi:10.1002/pon.4002

van der Poel, M. W., Oerlemans, S., Schouten, H. C., Mols, F., Pruijt, J. F., Maas, H., & van de Poll-Franse, L. V. (2014). Quality of life more impaired in younger than in older diffuse large B cell lymphoma survivors compared to a normative population: A study from the population-based PROFILES registry. *Annals of Hematology, 93*(5), 811–819. doi:10.1007/s00277-013-1980-1

van Leeuwen-Segarceanu, E. M., Bos, W. J., Dorresteijn, L. D., Rensing, B. J., der Heyden, J. A., Vogels, O. J., & Biesma, D. H. (2011). Screening Hodgkin lymphoma survivors for radiotherapy induced cardiovascular disease. *Cancer Treatment Reviews, 37*(5), 391–403. doi:10.1016/j.ctrv.2010.12.004

Wait, S., Han, D., Muthu, V., Oliver, K., Chrostowski, S., Florindi, F., . . . Aapro, M. (2017). Towards sustainable cancer care: Reducing inefficiencies, improving outcomes—a policy report from the All.Can initiative. *Journal of Cancer Policy, 13*, 47–64. doi:10.1016/j.jcpo.2017.05.004

Walter, S. D., Eliasziw, M., & Donner, A. (1998). Sample size and optimal designs for reliability studies. *Statistics in Medicine, 17*(1), 101–110. doi:10.1002/(SICI)1097-0258(19980115)17:1<101::AID-SIM727>3.0.CO;2-E

Watson, M., Law, M., & dos Santos, M. (1994). The Mini-MAC: Further development of the mental adjustment to cancer scale. *Journal of Psychosocial Oncology, 12*, 33–46.

Weaver, L. C., Jessup, A., & Mayer, D. K. (2013). Cancer survivorship care: Implications for primary care advanced practice nurses. *Nurse Practitioner, 38*(11), 1–11. doi:10.1097/01.npr.0000435784.40143.62

Weir, J. P. (2005). Quantifying test–retest reliability using the intraclass correlation coefficient and the SEM. *Journal of Strength and Conditioning Research, 19*(1), 231–240. doi:10.1519/00124278-200502000-00038

West, B. T., Welch, K. B., & Galecki, A. T. (2015). *Linear-mixed models—a practical guide using statistical software* (2nd ed.). Boca Raton, Florida: Taylor and Francis/CRC Press.

Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing, 52*(2), 546–553.

Wills, T. A., & O'Carroll Bantum, E. (2012). Social support, self-regulation, and resilience in two populations: General-population adolescents and adult cancer survivors. *Journal of Social and Clinical Psychology, 31*(6), 568–592.

Ye, A. Y., Cheung, W. Y., Goddard, K. J., Horvat, D., & Olson, R. A. (2015). Follow-up patterns of cancer survivors: A survey of Canadian

radiation oncologists. *Journal of Cancer Survivorship, 9*(3), 388–403. doi:10.1007/s11764-014-0390-2

Zebrack, B. (2000). Quality of life of long-term survivors of leukemia and lymphoma. *Journal of Psychosocial Oncology, 18*(4), 39–59. doi:10.1300/J077v18n04_03

Zimmer, P., Mierau, A., Bloch, W., Struder, H. K., Hulsdunker, T., Schenk, A., . . . Elter, T. (2015). Post-chemotherapy cognitive impairment in patients with B-cell non-Hodgkin lymphoma: A first comprehensive approach to determine cognitive impairments after treatment with rituximab, cyclophosphamide, doxorubicin, vincristine and prednisone or rituximab and bendamustine. *Leukemia and Lymphoma, 56*(2), 347–352. doi:10.3109/10428194.2014.915546

Appendix A

A.1 Models of Survivorship Care Provision in Adult Patients with Haematological Cancer: An Integrative Review

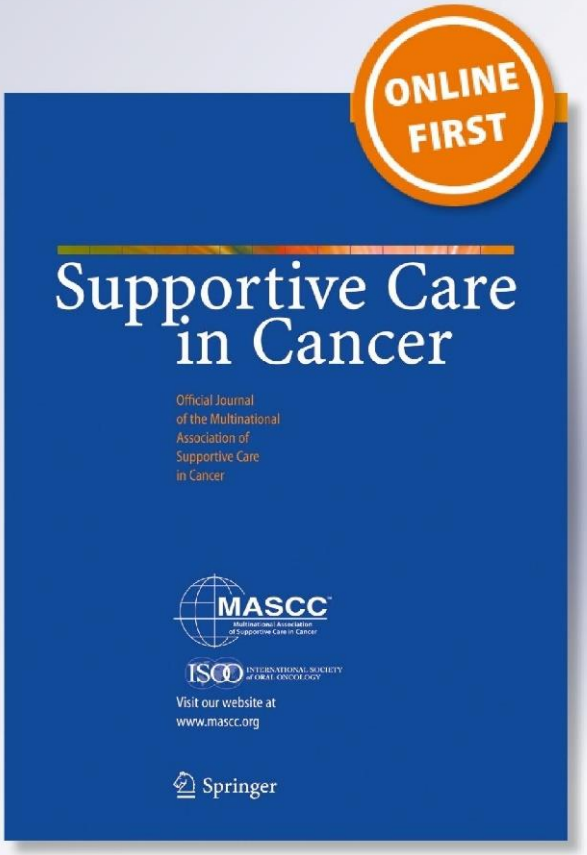
Models of survivorship care provision in adult patients with haematological cancer: an integrative literature review

Karen Taylor, Raymond Javan Chan & Leanne Monterosso

Supportive Care in Cancer

ISSN 0941-4355

Support Care Cancer
DOI 10.1007/s00520-015-2652-6



Springer

Support Care Cancer
DOI 10.1007/s00520-015-2652-6

REVIEW ARTICLE

Models of survivorship care provision in adult patients with haematological cancer: an integrative literature review

Karen Taylor · Raymond Javan Chan · Leanne Monterosso

Received: 4 September 2014 / Accepted: 8 February 2015

Abstract
Purpose Increasing numbers of haematology cancer survivors warrants identification of the most effective model of survivorship care to survivors from a diverse range of haematological cancers with aggressive treatment regimens. This review aimed to identify models of survivorship care to support the needs of haematology cancer survivors.
Method An integrative literature review method utilised a search of electronic databases (CINAHL, Medline, PsycInfo, PubMed, EMBASE, PsycArticles, and Cochrane Library) for eligible articles (up to July 2014). Articles were included if they proposed or reported the use of a model of care for haematology cancer survivors.
Results Fourteen articles were included in this review. Eight articles proposed and described models of care, and six reported the use of a range of survivorship models of care in haematology cancer survivors. No randomised controlled trials or literature reviews were found to have been undertaken specifically with this cohort of cancer survivors. There was variation in the models described and who provided the survivorship care.
Conclusion Due to the lack of studies evaluating the effectiveness of models of care, it is difficult to determine the best model of care for haematology cancer survivors. Many different models of care are being put into practice before robust research is conducted. Therefore, well-designed high-quality pragmatic randomised controlled trials are required to inform clinical practice.

Keywords Models of care · Survivorship · Haematological cancer · Nurse-led · Shared care · Follow-up care

K. Taylor (✉)
Western Australia Cancer and Palliative Care Network, 189 Royal St., East Perth, WA 6004, Australia
e-mail: kbrtaylor@me.com

K. Taylor
University of Notre Dame Australia, Fremantle, Western Australia

R. J. Chan
NHMRC Health Professional Research Fellow, Queensland University of Technology, Queensland, Australia

R. J. Chan
Cancer Care Services Royal Brisbane and Women's Hospital, Queensland, Australia

L. Monterosso
School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, Western Australia

L. Monterosso
St. John of God Hospital, Murdoch, Western Australia

L. Monterosso
Edith Cowan University, Joondalup, Western Australia

Published online: 19 February 2015

Introduction

Internationally, survivorship care is recognised as a priority in the cancer care continuum. This has been principally guided by the Institute of Medicine (IOM) report in 2005, *From Cancer Patient to Cancer Survivor: Lost in Transition* [1]. By 2008, 16 European countries had defined national cancer plans, but to date, very few have survivorship services operating [2]. The National Coalition for Cancer Survivorship [3] defines survivorship as the experience of living with, through, and beyond a diagnosis of cancer and includes the impact on family, friends, and caregivers. It is recognised throughout the literature, based on the IOM essential components of survivorship care, that survivorship care should include the following components [4, 5]:

- Prevention; screening and interventions for recurrence, long-term and late effects; early detection of new cancers;
- Assessment, support, management, and information provision of physical, psychological, social, and spiritual needs;
- Monitoring, information, and promotion of healthy living behaviours and disease prevention; and
- Coordination of care between providers to communicate overall health needs.

Current conventional models of survivorship care, including routine follow-up, predominately focus on surveillance for recurrence and monitoring of physical side effects, rather than provision of supportive care, health promotion, late effects monitoring, and surveillance for new cancers [6, 7]. With an increasing awareness that communication between health care professionals and patients is suboptimal and that information provided to patients and primary care providers at treatment completion is often inadequate [8, 9], there is a growing movement to redesign how survivorship follow-up care is delivered. Furthermore, cancer patients frequently experience multiple health problems earlier than the general population [10], suggesting a need for early and ongoing, comprehensive approaches to management designed to promote and support patient participation in maximising recovery.

Haematology cancer patients are underrepresented and understudied in survivorship care [11] despite international figures indicating an increase in 5-year relative survival rates [12]. The most common haematological cancers are leukaemias, lymphomas, and multiple myelomas (MM) [13]. Each of these has distinctive and complex treatment regimens that commonly involve aggressive high-dose chemotherapy agents, and/or targeted therapies, radiotherapy, and haematopoietic stem cell transplants [14]. Unfortunately, the consequence of largely aggressive treatment includes long-term and late physical, practical, and psychosocial effects which include fear of recurrence, fertility, relationship, financial, employment, and insurance issues [15–17]. A qualitative study on specialist-led follow-up with haematology cancer survivors reported a lack of preparation and support in finding information and resources with poor continuity of care as patients transitioned into the survivorship phase [18]. These patients, therefore, may require models of survivorship care with specific components that differ from those designed for the more common cancers (breast, prostate, and colorectal).

Two systematic reviews [19, 20] and a literature review [6] on survivorship models of care have been recently published. Sussman et al. [20] reviewed 12 randomised controlled trials (RCTs) and four systematic reviews. De Leeuw and Larsson [6] reviewed 21 nurse-led follow-up studies and Howell et al. [19] evaluated ten practice guidelines and nine RCTs. All primary outcomes in the reviewed studies were related to recurrence detection and in some cases health-related quality of life and/or patient satisfaction [6, 19, 20]. Importantly, all studies included cancers with similar trajectories of care (breast, prostate, and colon), making generalisations to other complex cancers such as haematological cancers difficult. Therefore, the haematology focus of this integrative literature review will add to the limited body of knowledge currently available in this cohort of survivors.

This integrative literature review undertook an analysis of the literature to examine the following questions:

(1). What are the common attributes of survivorship models of care developed generally for cancer patients and specifically for haematology cancer patients?
(a). What resources (human, financial, tools, and care plans) are required to support these models of care?
(b). What are the potential benefits and shortfalls of these models of care?
(c). What outcome measures have been used to evaluate these models of care and what are the findings?

Method

The integrative literature review method was chosen as the theoretical framework to guide this review. It is structured according to five stages: problem formulation, literature search, data evaluation, data analysis, and presentation. This allows for an in-depth evaluation of the issues encompassing the empirical, theoretical, and clinical approaches within a structured systematic methodology [21].

Problem formulation

To date, the term 'Model of Care' (MOC) has not been well defined in published literature. In this review, MOC, as defined by the Robert Wood Johnson Foundation [22], is a conceptual outline of how to plan all current and future facility and clinical services to guide and direct a patient's experience within a health care system. Essential elements of any MOC include a clear identification of health professionals responsible for planning and coordination of care, care delivery setting [20], promotion of health maintenance, effective illness interventions, and establishing and evaluating expected clinical outcomes [23]. The medical specialist has traditionally led haematology cancer care follow-up; however, other models of cancer survivorship follow-up are now emerging [24]. Therefore, the focus of this integrative literature review was to identify models of care used by health care providers to ensure quality survivorship follow-up for haematology cancer survivors.

Literature search

The primary search utilised the following electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsycInfo, PubMed, EMBASE, PsycArticles, and Cochrane Library from earliest records to July 2014. Combinations of the following search terms were used: (model of care or follow-up or nurse-led or shared care or primary care provider-led or General Practitioner-led or oncology-led or end of treatment or post-treatment) and (survivorship or cancer survivor or survivorship care) and (cancer or neoplasm or oncology) and (haematology or leukaemia or lymphoma or multiple myeloma). A hand search of the reference lists from full-text articles was correspondingly employed. Searches were restricted to the English language, humans and adults. Inclusion criteria used were: clinician experiences of MOC for the post-treatment phase of haematological cancer; articles that reported on models of care; and articles that reported on the structure of survivorship services. Exclusion criteria were: studies with less than a 50 % haematology cancer patient/haematologist cohort; studies that reported MOC for patients who received curative surgery only (i.e. no chemotherapy and/or radiotherapy treatment); studies reporting MOC from child, adolescent, or adult survivors of a childhood cancer; non-cancer MOC studies; MOC studies that lacked provider of survivorship care information; and opinion papers, letters, editorials, commentaries, conference abstracts, conference proceedings, or case studies.

Data evaluation stage

Abstract titles were reviewed by one author [KT] to assess eligibility. A summary of the selection process [25] is provided in Fig. 1. The initial search yielded 2,907 abstracts. Following removal of duplicate articles and screening using the exclusion and inclusion criteria, 61 full-text articles were retrieved. Of these, 14 articles met the inclusion criteria and were included in this review. The documented methodological characteristics included authors, publication year, country, study design, model, provider, disease, years post-treatment, sample size and response rate, resources required, potential benefits, potential deficits, outcome measures, results, and level of evidence developed by Melynyk and Fineout-Overholt [26] shown in Table 1. Due to variations in study population and methodologies used, meta-analysis was not possible.

Results

Study characteristics

No systematic reviews of haematology cancer survivorship models of care were found. In total, 14 articles were included in this review. Eight articles described and proposed different models of survivorship care [27, 28, 1, 5, 29, 30, 9, 7] (Table 2). An additional six articles reported the use of a range of models of care for haematology cancer survivors: two

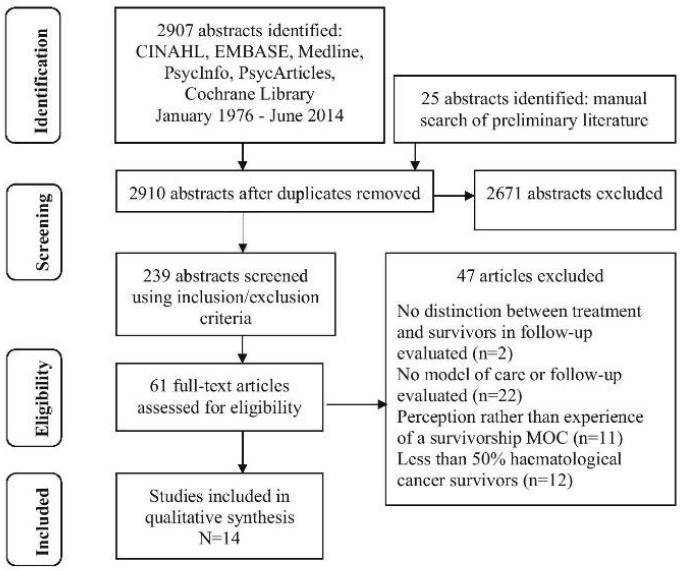


Fig. 1 Flowchart of literature search results

Table 1 Levels of evidence

Level	Evidence
I	Systematic review of all relevant randomised controlled trials
II	At least one well-designed randomised controlled trial
III	Well-designed controlled trials without randomisation
IV	Well-designed cohort studies, case control studies, interrupted time series with a control group, historically controlled studies, interrupted time series without a control group or with case–series
V	Systematic reviews of descriptive and qualitative studies
VI	Single descriptive and qualitative studies
VII	Expert opinion from clinicians, authorities and/or reports of expert committees or based on physiology

reported nurse-led studies [31, 32] and four referred to physician-led studies [33, 8, 34, 35] (Table 3). The included articles reported views from Australia (n=1), the US (n=10), and the UK (n=3) shown in Table 3. The eight articles that described and proposed various models of survivorship care were categorised into three main settings hospital-based, primary care-based, and shared care and included models, providers, and characteristics. The results are shown in Table 2. These included articles used multiple terms to describe clinicians. For clarity, the following terms have been used: primary care provider (PCP) to denote community-based general practitioners (GP) or family physicians; specialist to represent the main hospital consultant oncologist (medical, radiation, and surgical) or haematologist; and nurse which includes nurse specialist, nurse practitioner (NP), or nurse coordinator.

Of the six studies that reported the use of specific models of survivorship care, four were quantitative and two were qualitative studies. Studies reflected moderate (IV) to low (VI) levels of evidence.

Data analysis and presentation

Cancer survivorship MOC

The first component of this integrative literature review was to identify different models of survivorship care (Table 2). Characteristically, hospital-based follow-up care is commonly specialist-led, with often no end point [27, 29]. Survivors may acquire an impression the specialist has become their primary carer, particularly if they have assessed and treated co-morbid conditions during the treatment phase [7]. Multidisciplinary disease-specific clinics [5, 9, 7] and survivorship clinics were most often a one-time consultation for an assessment, plan of follow-up care provision and referrals to other health care providers [1, 30]. Clinics within this framework frequently

Table 2 Existing or proposed models of cancer survivorship care

Setting	Model	Provider	Model characteristics
Hospital	Multidisciplinary survivorship clinic [7]	Oncologist, network of consulting physicians, oncology or haematology nurse practitioner (NP), psychologist, and social worker	Can be consultative or ongoing Multiple providers seen at same visit Complex and resource intense Co-morbid and treatment-related conditions can be addressed Can be extension of care, embedded in treatment team Disease-specific specialist defines follow-up plan NP follow-up who communicates with PCP to initiate shared care Large patient cohort needed
	Consultative clinic [27, 29]	Specialist	Ongoing (rarely Oncologist takes on primary carer role)
	Consultative clinic [7]	Specialist	One-time comprehensive visit Treatment summary and survivorship care plan Review of recommendations — surveillance, screening, andhealth promotion
	Survivorship follow-up clinic [1, 30]	Specialist	Separate from routine care Holistic assessment of survivor End of treatment or on maintenance therapy Treatment summary, survivorship care plan, and individualised information provision Can have telephone follow-up
	Late effects clinic [9]	Nurse and/or specialist	Haematology/ oncology treatment centres
	Nurse-led [1, 27]	Oncology nurse or NP	Comprehensive, long-term follow-up to assess and provide primary care needs ASCO surveillance recommendations used Clinic and/or telephone follow-up

Table 2 (continued)

Setting	Model	Provider	Model characteristics
Primary care	General survivorship clinic [5, 28]	Nurse collaboration with practice specialist PCP (i.e. breast care PCP)	Referral for services or refers to specialists
	PCP-led [9]	PCP	Full transition to PCP after treatment completion
			Can have communication from specialist: late effects management and surveillance
			Usually low risk for recurrence or late effects
Shared care	Shared care [1, 7]	Specialist and PCP	Oncologist for oncology-related issues
			PCP for co-morbidities, other cancer screening, and prevention

ASCO American Society of Clinical Oncology, *NP* Nurse practitioner, *PCP* primary care physician

consulted on one aspect of post-treatment care, such as late effects [9].

Nurse-led survivorship clinics, as described, were mostly hospital-based and delivered a number of interventions including information, symptom management, psychosocial support, allied health referrals, and health promotion strategies [27]. They can involve longer consultations and more frequent patient contact [27, 6]. PCP-led models involved a complete transition of all care from the hospital specialist to PCP [28, 5, 9]. This can be challenging for specialists who decide to transition care, as the level of knowledge and experience amongst PCPs can differ [5, 30].

Shared care models involved more than two providers sharing care and responsibility [1, 9]. According to Oeffinger and McCabe [7], after treatment completion, the PCP assumes responsibility for maintenance of survivor health, management of any co-morbid conditions, ongoing physical and psychosocial concerns, and health promotion. The medical specialist provides a survivorship care plan and treatment summary and ongoing consultation for recurrence or problematic late effects if required. Both providers are to undertake monitoring, therefore, a clear delineation of responsibility for particular screening and surveillance is important [5]. Landier [5] identified shared care as appropriate for low-risk and even some moderate-risk patients; however, intensively treated patients (i.e. haematological cancers) require specialist monitoring.

Nurse-led

The two studies that evaluated nurse-led follow-up in lymphoma survivors predominately targeted late effects and health promotion. Gates et al. [31] studied a nurse-led component of a haematology late effects survivorship multidisciplinary team, whereas John and Armes [32] reported on nurses replacing specialist-led follow-up, independently delivering comprehensive survivorship care. Both clinics assessed for supportive care needs and concerns and delivered health promotion and information [31, 32]. John and Armes [32] provided an annual clinic with nurse contact details, whereas Gates et al. [31] delivered four consultations over a 6-month period. Both studies measured different outcomes and utilised different comparative groups, thereby making them difficult to compare, especially as Gates et al. [31] have only published preliminary results. A prospective comparative study of 61 patients by John and Armes [32] concluded that patient satisfaction was equivalent in the nurse-led clinic cohort compared with the medical-led clinic cohort and was, in some cases, preferred. However, the number in each group was not reported, and it is possible that patient satisfaction was related more to the decrease in wait times. It would likewise be difficult to attribute lifestyle changes to the clinic as patients were seen annually.

Physician-led

The included physician-led studies (n=4) presented comparisons of self-reported practices in survivorship follow-up [8] and clinician perceptions of survivorship follow-up [33–35]. A qualitative exploratory study by Chubak et al. [33] reported the views of clinicians and administrators (n=40) from ten integrated cancer centres. All respondents reported shared care was being practised. This was based on the assumption that all survivors have a PCP and despite respondents reporting a lack of standard approaches to sharing care between clinicians. Support for survivorship-specific care appeared lacking, with 22 % (n=9) observing it would not add to current care and may decrease care integration. The authors concluded that interviewing respondents from sites without survivorship care would give an unbiased account. However, there may have been a lack of awareness related to the benefits of survivorship care.

Dicicco-Bloom and Cunningham [8] qualitatively assessed the feasibility of a shared care survivorship model with 21 primary care clinicians. The overall perception was that primary carers are already involved in survivor follow-up, despite poor information provision from specialists. They perceived electronic medical records are often inaccessible. The authors further concluded survivorship care plan research is limited. PCPs felt excluded once patients entered the hospital system, especially when follow-up extended well past treatment to healthy patients with no recurrent cancer. This was reflected in the study by Greenfield et al. [35] who reported the views of clinicians (n=475) regarding long-term follow-up and found only 5 % (n=14) of haematology cancer survivors are discharged after

Table 3 Methodological characteristics of models of haematological cancer survivorship Care ($n=6$)

Author, year, country	Study design	MOC provider	Disease, years post-treatment, sample size (response rate %)	Resources required	Potential benefits	Potential deficits	Outcome measures	Results	Level of evidence
Chubak et al. [33], 2012, USA	Exploratory study Semi-structured telephone interviews	Shared care	Ten Cancer Research Network sites Cancer types not identified 40/48 (83 %) Administrators /clinical leaders /providers in oncology, primary care	Survivorship care plan (SCP) — only five responders identified use of support groups	Time and lack of specialists to follow up survivors	Clearer evidence to support survivorship care needed 6/10 sites survivor-specific tools not being used	Perspectives on: survivors needs; current survivorship practices; barriers; areas for future research	Only 2/10 sites had formal survivorship programs (1 nurse-led, 1 physician assistant-led) Responses for survivorship care needs: address fear recurrence 35 %; information on long-term effects 40 %; nutritional and exercise support 27 %; psychosocial support 62.5 % Overall uncertainty about best models of survivorship care	VI
DiCicco-Bloom and Cunningham [8], 2013, USA	In-depth interviews on information sharing to/from specialist and patients	Shared care	21 Primary care clinicians (PCC) (11 PCP and 10 NP) Unknown patient types or survivorship period	Electronic medical records access SCP	Primary care perspective Information sharing ensures effective care transitions	No guidelines or consensus for many cancers on screening, surveillance, late effects (LE)	Understand nature of interactions between primary care, specialist, and patient	Absence systematic inflion sharing among PCP, patient, specialist Some patients continue to see PCC during treatment Reliance on patients to provide clinical information from specialist (not always reliable for complex conditions/treatment) Academic hospital settings were worst in communication to PCC SCP effect on patient outcomes — limited evidence	IV

Table 3 (continued)

Author, year, country	Study design	MOC provider	Disease, years post-treatment, sample size (response rate %)	Resources required	Potential benefits	Potential deficits	Outcome measures	Results	Level of evidence
Frew et al. [34], 2010, UK	Comparison survey on models of follow-up	Models presented for perception and experience: hospital-based; telephone; non-specialist; group; patient-managed; no follow-up	Cancer diagnosis or treatment not disclosed	Nil described	Non-specialist models tend to provide more psycho-logical support	Survey did not ask for survivor diagnosis and treatment which may alter model preference	Perceptions of reasons for follow-up; levels of preference for different follow-up models; effect of individual experience on follow-up model preference	Reasons for follow-up: monitoring for early complications; detecting recurrence; detecting LE; providing information and support (70 %) Preference for model of follow-up experienced: 86 % survivors preferred hospital-based follow-up and was experienced most (84 %) Clinicians had experience of more models of follow-up Specialists endorsed non-specialist or patient-managed follow-up (87 %) PCP endorsed hospital-based and patient-managed follow-up (83 %)	IV
			Range to over 10 years			Survey did not ask if any models would be rejected so potential deficits not identified			
			626 (21 %) survivors/ carers 940 (32 %) PCP						
			804 specialists (including haematologists) 558 nurses /allied health (47 %)						
Gates et al. [31], 2012, Australia	Quasi-experimental comparison healthy cohort versus Hodgkin lymphoma (HL) survivors	Late effects MDT (haematologist, transplant physician, radiation oncologist, cardiologist, endocrinologist, primary care liaison, psychologist, LE social worker, LE CNC) Nurse-led clinic for	HL 5 years	Education package Screening tools (Late Effects	Health promotion Health promotion	SCP copy to survivor/PCP SCP not given until	Primary outcome: health promotion intervention from nurse to improve HL survivors knowledge and motivation to adopt health promoting behaviours Primary outcome: health promotion	No final published results from this study No final published results from this study	IV

Table 3 (continued)

Author, year, country	Study design	MOC provider	Disease, years post-treatment, sample size (response rate %)	Resources required	Potential benefits	Potential deficits	Outcome measures	Results	Level of evidence
		health promotion: two visits + two phone calls		Supportive Care Needs Screening Tool; the General Health Index; the Health Promoting Lifestyle Profile II)		second visit (at 4 months)	intervention from nurse to improve HL survivors knowledge and motivation to adopt health promoting behaviours		
			30 HL + 30 healthy participants (91 %)	SCP copy to survivor/PCP	Psychosocial issues identified and resources and support given Importance of surveillance Survivor sees all relevant providers on same day		Secondary outcomes: improved perception of health status; reduced LE unmet needs; reduced LE worry	Anecdotal analysis shows appreciation of: SCP; screening assessment	
Greenfield et al. [35], 2009, UK	E-survey comparison of clinician views on long-term follow-up	PCP-led	18–45 years old breast, lymphoma, leukaemia, or germ cell survivors	Communication	Specialist nurse support (91 % most important resource)	Potential loss of outcome data, LE information to specialists	Compare long-term follow-up: reasons for follow-up; advantage/ disadvantage of PCP-led follow-up; current practice; resources and support required	Specialists rated clinical reasons for follow-up higher	IV
			>2 years	Specialist nurse support (91 % most important resource)	Lower costs	PCP: lack expertise in survivorship issues, increases survivor anxiety, time issues		Nurses and PCP rated both clinical and supportive reasons higher	
			421 cancer clinicians (36 % haematologist, 33 %	Risk stratification — low risk to PCPs, high risk	PCP: existing relationship with survivor; accessible; convenient;	No tumour-specific follow-up guidelines		Reasons for follow-up: PCP-rated recurrence (96 %)	

Table 3 (continued)

Author, year, country	Study design	MOC provider	Disease, years post-treatment, sample size (response rate %)	Resources required	Potential benefits	Potential deficits	Outcome measures	Results	Level of evidence
			oncologist, 18 % surgeon, 10 % nurse, 2 % other) 54 PCP	hospital follow-up SCP and treatment summary (TS)	knowledge of local support; expertise in chronic health			Specialists rated LE (76 %) recurrence (71 %) Haematologist use of follow-up protocol for leukaemia and lymphoma 19 % Discharge to PCP: 5 % at 2 years, 42 32 % by 5 years	
John and Armes [32], 2013, UK	Prospective comparison specialist-led versus nurse-led	Survivorship follow-up clinic Nurse-led (replaces specialist follow-up)	Lymphoma 3 years 50 notes audited (25 per group) 120 survivors (60 per group) assessed wait time 61 (82 %) survivors assessed patient satisfaction (unclear split medical-led versus nurse-led)	2 CNS Information prescription	Longer consultations Written information provision Holistic needs assessment Monitoring for late effects Health promotion Post-treatment contact	Annual clinic visit Preferred clinic not assessed	Documentation Wait time Patient satisfaction	Documentation improved — 50 % of psychological and sexual issues still not recorded Wait times reduced from average 65 min (specialist) to 10 min (nurse) Nurse-led was equal to specialist-led clinic and preferred in some areas Nursing telephone workload increased	IV

CNC cancer nurse consultant, *CNS* cancer nurse specialist, *HL* Hodgkin lymphoma, *LE* late effects, *MDT* multidisciplinary team, *MM* multiple myeloma, *NHL* non-Hodgkin lymphoma, *NP* nurse practitioner, *PCP* primary care provider, *SCP* survivorship care plan, *TS* treatment summary

2 years, and only 42 % (n=45 lymphoma) and 32 % (n=10 leukaemia) are discharged after 5 years. This finding may be explained by the complex and ongoing late effect sequelae in haematology patients and their expectation of long-term specialist follow-up. Although respondent numbers were not reported, it was perceived that long-term specialist follow-up gave survivors false reassurance and perpetuated the illness role. Whereas the PCP-led model was perceived as normalising the survivors' experience, with a corresponding increase in comorbid disease management. The authors concluded by proposing a risk stratification process whereby low-risk survivors are transitioned early to PCP and high-risk survivors stay within the hospital model or become part of a shared care model supported by survivorship care plans.

Frew et al. [34] studied survivor (n=626) and clinican (n=2302) views on different models of care. Respondents could choose from a number of follow-up models but were not asked if they would reject a particular model. What was evident in the study by Frew et al. [34] was specialist follow-up, which was the most experienced by survivors (84 % n=528) and clinicians (95 % n=2167). However, specialists who had experienced non-specialist models of follow-up (60 % n=819) preferred this model over all others including specialist-led (87 %).

Discussion

Deciding upon a model of survivorship follow-up care for haematology cancer survivors is difficult due to the considerable variability between the types of haematological cancers, range of treatment regimens, and long-term and late effects that impact the survivorship phase of the cancer continuum [17]. For haematology cancer survivors, different models have been proposed and utilised. However, we are unable to determine the best or the most appropriate model. This finding is consistent with those of Campbell et al. [36], reporting that no model was identified as better than any others. The reasons for these findings are that most of the articles were not evaluative in nature and do not allow comparison. Patients who have only received a single model of care would not be able to comment on potential benefits of other models of care; therefore, further research in understanding survivors' perspectives of follow-up care is required.

The transition of survivor care to the PCP requires PCP willingness. A study involving PCP views that reported the willingness to accept exclusive care for lymphoma patients was 3 years after treatment completion [37]. This may be due to the complex nature and length of the treatment regimens [15] and a lack of tumour specific follow-up protocols used by haematologists [35]. With a lack of guidance and comprehensive information communicated from the haematologist [8, 35], PCPs may be reluctant to accept exclusive care of what they perceive as complex and 'high risk' patients [37]. Shared care may be more satisfactory to haematologists, survivors, and PCPs as it encompasses the strengths and expertise of providers from more than one discipline. As a study of follow-up care providers has reported, a high proportion of survivors are followed up by multiple providers [38]. Therefore, it is important that good coordination and communication is in place to reduce the possibility of either incomplete or duplication of services between multiple providers. Cooper et al. [27] proposed that patients' transition into survivorship phase and out to primary care through specialist nurses so that monitoring for recurrence, psychosocial needs, and health promotion are addressed and communicated to survivors and health care providers. This too has implications with John and Armes [32] who demonstrated that increased nurse workload occurred with patients utilising telephone contact between the scheduled clinic visits.

Establishing survivorship care provision will require careful planning and robust prospective evaluations. It is important to note that coordinated survivorship care interventions are complex interventions [39] and can be resource intensive, requiring robust evaluations using patient and system outcomes. This integrative review identified the three models of care: physician-led, nurse-led, and shared care models. Ultimately, high-quality pragmatic RCTs are required to test the effectiveness of these models. There is an urgent need for health research funders to understand the need for good survivorship cancer care and fund the development and evaluation of the effects of various models of survivorship care.

To the best of our knowledge, this review is the first that examines the characteristics, resources required, and effectiveness of survivorship care models specifically for patients with haematological cancer. A number of limitations of this review are acknowledged. The search revealed only a relatively small number of articles that met the inclusion criteria. Furthermore, the variation of study methodology, range of measures, populations, and follow-up approaches made it difficult to compare models of care and enabled only tentative conclusions [31, 32]. Additionally, short-term follow-up or the timing of interventions may have been insufficient to report whether different models have impacted survivorship care. Finally, an inherent bias in interpretation might be due to the evaluator.

Conclusion

There is a paucity of effectiveness research related to haematology cancer survivors and specifically models of survivorship care in this cohort. Shared care models have been suggested as an alternative to exclusive specialist care. For shared care to work effectively, ongoing communication channels need to be established and maintained. Nurse-led models have been proposed as another feasible model, where a

specialist nurse intervenes directly and acts as the conduit between patient, hospital-based treatment team, and PCP. However, more research is needed to define how these models should be best configured and evaluated for their effectiveness. For future development, a haematology-specific survivor-based needs assessment tool, individualised treatment summary and survivorship care plan would be integral. These would assist in guiding survivor-centred screening, health promotion, and identification of needs to be monitored and managed. This approach may address many of the barriers that have been postulated.

Future research will need to account for increasing cancer incidence and survival rates, making extensive specialist follow-up care more difficult to maintain for new patients and survivors. To provide quality survivorship care, new and innovative models of haematology survivorship follow-up are required which address the need for long-term follow-up that accounts for potential late treatment effects, risks of secondary cancers, development of treatment-related co-morbid conditions, and psychosocial well-being. This review revealed a lack of high-quality evidence suggesting the effectiveness of any single model of care. A well-designed pragmatic randomised controlled trial, assessing patient and system outcomes including costs, is required to inform clinical practice.

Conflict of interest None

References

1. Hewitt ME, Greenfield S, Stovall E (2006) From cancer patient to cancer survivor: lost in transition. The National Academies Press, Washington DC
2. McCabe MS, Faithfull S, Makin W, Wengstrom Y (2013) Survivorship programs and care planning. Cancer 119(Suppl 11): 2179–2186. doi:10.1002/cncr.28068
3. National Coalition for Cancer Survivorship (2014) http://www.canceradvocacy.org/. Accessed 3 April 2014
4. Grant M, Economou D (2008) The evolving paradigm of adult cancer survivor care. Oncology 22(4):13–22, 27
5. Landier W (2009) Survivorship care: essential components and models of delivery. Oncology 23(4):46–53
6. De Leeuw J, Larsson M (2013) Nurse-led follow-up care for cancer patients: what is known and what is needed. Support Care Cancer 21(9):2643–2649. doi:10.1007/s00520-013-1892-6
7. Oeffinger KC, McCabe MS (2006) Models for delivering survivorship care. J Clin Oncol 24(32):5117–5124
8. Dicicco-Bloom B, Cunningham RS (2013) The experience of information sharing among primary care clinicians with cancer survivors and their oncologists. J Cancer Surviv 7(1):124–130. doi:10.1007/s11764-012-0253-7
9. McCabe MS, Jacobs LA (2012) Clinical update: survivorship care — models and programs. Semin Oncol Nurs 28(3):e1–e8. doi:10.1016/j.soncn.2012.05.001
10. Panek-Hudson Y (2013) Survivorship care — time for innovation? Aust J Cancer Nurs 14(1):7–12
11. Swash B, Hulbert-Williams N, Bramwell R (2014) Unmet psychosocial needs in haematological cancer: a systematic review. Support Care Cancer 22(4):1131–1141. doi:10.1007/s00520-014-2123-5
12. Sant M, Minicozzi P, Mounier M, Anderson LA, Brenner H, Holleczek B, Marcos-Gragera R, Maynadié M, Monnereau A, Osca-Gelis G, Visser O, De Angelis R (2014) Survival for haematological malignancies in Europe between 1997 and 2008 by region and age: results of EUROCARE-5, a population-based study. Lancet Oncol 15(9):931–942. doi:10.1016/S1470-2045(14)70282-7
13. National Cancer Institute (2006) NCI dictionary of cancer terms. http://www.cancer.gov/dictionary/?CdrID=45708. Accessed 3 April 2014
14. Carey M, Anderson A, Sanson-Fisher R, Lynagh M, Paul C, Tzelepis F (2012) How well are we meeting haematological cancer survivors' preferences for involvement in treatment decision making? Patient Educ Couns 88(1):87–92. doi:10.1016/j.pec.2011.12.014
15. Allart P, Soubeyran P, Cousson-Gélie F (2013) Are psychosocial factors associated with quality of life in patients with haematological cancer? A critical review of the literature. Psycho-Oncology 22(2): 241–249
16. Arden-Close E, Absolom K, Greenfield D, Hancock B, Coleman R, Eiser C (2011) Gender differences in self-reported late effects, quality of life and satisfaction with clinic in survivors of lymphoma. Psycho-Oncology 20(11):1202–1210
17. Hall A, Lynagh M, Bryant J, Sanson-Fisher R (2013) Supportive care needs of hematological cancer survivors: a critical review of the literature. Crit Rev Oncol Hematol 88(1):102–116
18. Parry C, Morningstar E, Kendall J, Coleman EA (2010) Working without a net: leukemia and lymphoma survivors' perspectives on care delivery at end-of-treatment and beyond. J Psychosoc Oncol 29(2):175–198. doi:10.1080/07347332.2010.548444
19. Howell D, Hack T, Oliver T, Chulak T, Mayo S, Aubin M, Chasen M, Earle C, Friedman A, Green E, Jones G, Jones J, Parkinson M, Payeur N, Sabiston C, Sinclair S (2012) Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence. J Cancer Surviv 6(4):359–371. doi:10.1007/s11764-012-0232-z
20. Sussman J, Souter LH, Grunfeld E, Howell D, Gage C, Keller-Olaman S, Brouwers M (2012) Models of care for cancer survivorship. Cancer Care Ontario, Toronto
21. Whittemore R, Knafl K (2005) The integrative review: updated methodology. J Adv Nurs 52(2):546–553
22. Robert Wood Johnson Foundation Glossary of Health Care Quality Terms. http://www.rwjf.org/quality/equality/glossary. Accessed 21 June 2014
23. Gerber LH, Stout NL, Schmitz KH, Stricker CT (2012) Integrating a prospective surveillance model for rehabilitation into breast cancer survivorship care. Cancer 118(Suppl 8):2201–2206. doi:10.1002/cncr.27472
24. Weaver LC, Jessup A, Mayer DK (2013) Cancer survivorship care: implications for primary care advanced practice nurses. Nurse Pract 38(11):1–11. doi:10.1097/01.npr.0000435784.40143.62
25. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Br Med J 339:b2535
26. Melynyk B, Fineout-Overholt E (2011) Evidence-based practice in nursing & healthcare: a guide to best practice, 2nd edn. Kluwer, Philadelphia
27. Cooper JM, Loeb SJ, Smith CA (2010) The primary care nurse practitioner and cancer survivorship care. J Am Acad Nurse Pract 22(8): 394–402. doi:10.1111/j.1745-7599.2010.00528.x
28. Hahn EE, Ganz PA (2011) Survivorship programs and care plans in practice: variations on a theme. J Oncol Pract 7(2):70–75
29. Leigh SA (2008) The changing legacy of cancer: issues of long-term survivorship. Nurs Clin N Am 43(2):243–258

30. McCabe MS, Bhatia S, Oeffinger KC, Reaman GH, Tyne C, Wollins DS, Hudson MM (2013) American Society of Clinical Oncology statement: achieving high-quality cancer survivorship care. J Clin Oncol 31(5):631–640. doi:10.1200/JCO.2012.46.6854
31. Gates P, Seymour JF, Krishnasamy M (2012) Insights into the development of a nurse-led survivorship care intervention for long-term survivors of Hodgkin lymphoma. Aust J Cancer Nurs 13(1):4–10
32. John C, Armes J (2013) Developing a nurse-led survivorship service for patients with lymphoma. Eur J Oncol Nurs 17(5):521–527. doi:10.1016/j.ejon.2013.03.001
33. Chubak J, Tuzzio L, Hsu C, Alfano CM, Rabin BA, Hornbrook MC, Spegman A, Von Worley A, Williams A, Nekhlyudov L (2012) Providing care for cancer survivors in integrated health care delivery systems: practices, challenges, and research opportunities. J Oncol Pract 8(3):184–189. doi:10.1200/jop.2011.000312
34. Frew G, Smith A, Zutshi B, Young N, Aggarwal A, Jones P, Kockelbergh R, Richards M, Maher EJ (2010) Results of a quantitative survey to explore both perceptions of the purposes of follow-up and preferences for methods of follow-up delivery among service users, primary care practitioners and specialist clinicians after cancer treatment. Clin Oncol 22(10):874–884. doi:10.1016/j.clon.2010.06.008
35. Greenfield DM, Absolom K, Eiser C, Walters SJ, Michel G, Hancock BW, Snowden JA, Coleman RE (2009) Follow-up care for cancer survivors: the views of clinicians. Br J Cancer 101(4):568–574. doi:10.1038/sj.bjc.6605160
36. Campbell MK, Tessaro I, Gellin M, Valle CG, Golden S, Kaye L, Ganz PA, McCabe MS, Jacobs LA, Syrjala K, Anderson B, Jones AF, Miller K (2011) Adult cancer survivorship care: experiences from the LIVESTRONG centers of excellence network. J Cancer Surviv 5(3):271–282. doi:10.1007/s11764-011-0180-z
37. Del Giudice ME, Grunfeld E, Harvey BJ, Piliotis E, Verma S (2009) Primary care physicians' views of routine follow-up care of cancer survivors. J Clin Oncol 27(20):3338–3345. doi:10.1200/jco.2008.20.4883
38. Forsythe LP, Arora NK, Alfano CM, Weaver KE, Hamilton AS, Aziz N, Rowland JH (2014) Role of oncologists and primary care physicians in providing follow-up care to non-Hodgkin lymphoma survivors within 5 years of diagnosis: a population-based study. Support Care Cancer 22(6):1509–1517. doi:10.1007/s00520-013-2113-z
39. Medical Research Council (2000) A framework for development and evaluation of RCTs for complex interventions to improve health. UK

A.2 Survivorship Care Plans and Treatment Summaries in Adult Patients with Hematologic Cancer: An Integrative Literature Review

Permission to use the article was granted on the 13 March 2018 by the Licensing Manager of the Oncology Nursing Forum and the publisher the Oncology Nursing Society of America.

Article

Survivorship Care Plans and Treatment Summaries in Adult Patients With Hematologic Cancer: An Integrative Literature Review

Karen Taylor, MNurs, GradDipOnc, BN, RN,
and Leanne Monterosso, PhD, BNurs (Hons1), GCert Teach, FACN

Problem Identification: Survivorship care plans (SCPs) and treatment summaries (TSs) have been recommended by the Institute of Medicine as ways to facilitate the delivery of holistic survivorship care. An integrative literature review was undertaken to identify current use of SCPs and TSs to meet the needs of survivors of hematologic cancer.

Literature Search: Databases searched for eligible articles were CINAHL®, the Cochrane Library, EMBASE, MEDLINE®, PsycARTICLES, PsycINFO, and PubMed.

Data Evaluation: Four articles that reported on experience, dissemination, or components of SCPs or TSs were included. Hematology-specific literature was limited, and no randomized, controlled trials or literature reviews were found for the cohort of survivors of hematologic cancer.

Synthesis: Content analysis was used to summarize the findings.

Conclusions: High-quality evidence evaluating the effectiveness of SCPs and TSs on hematologic cancer survivorship follow-up care is lacking. Nurses have established expertise in health promotion, information, support, and resource provision; they can develop and disseminate SCPs and TSs to facilitate communication among the survivor, specialist, and primary care provider.

Implications for Research: Well-designed, randomized, controlled trials on SCPs and TSs are required, particularly for cancers not well represented in the literature.

Key Words: survivorship care plan; treatment summary; survivorship; hematologic cancer

ONF, *42*(3), 283–291. doi: 10.1188/15.ONF.283-291

Survivorship, as defined by the National Coalition for Cancer Survivorship (2014), is the experience of living with, through, and beyond a diagnosis of cancer, including the impact on family, friends, and caregivers. Survivorship care is recognized as a priority in the cancer care continuum and has largely been driven by the Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt, Greenfield, & Stovall, 2005). A key recommendation of this report was the provision of a survivorship care plan (SCP) and treatment summary (TS) for all survivors (Palmer et al., 2014). Following the release of the report, many countries around the world developed and initiated national cancer initiatives (McCabe, Faithfull, Makin, & Wengstrom, 2013). Survivorship care should include the following components (Grant & Economou, 2008; Landier, 2009; Rechis, Arvey, & Beckjord, 2013).

- Coordination of care among providers to communicate overall health needs
- Monitoring, information about, and promotion of healthy living behaviors and disease prevention (e.g., guidelines for diet and exercise, alcohol consumption, tobacco cessation, sun protection, and healthy weight management)
- Prevention, screening, and intervention for recurrence, as well as long-term and late effects; early detection of new cancers or second malignancies by adherence to recommended surveillance guidelines (e.g., colonoscopies, mammograms, Papanicolaou tests, skin checks); and awareness of comorbidities
- Psychosocial well-being assessment, support, management, and information provision for physical, psychological, social, and spiritual needs

Routine follow-up care focuses largely on surveillance for recurrence and the monitoring of physical side effects, neglecting supportive care, health promotion, late-effects monitoring, and surveillance for new cancers (de Leeuw & Larsson, 2013). Awareness of the suboptimal communication that occurs between healthcare professionals, including primary care providers (PCPs), and patients is increasing; important information is often not provided at treatment completion (Dicicco-Bloom & Cunningham, 2013; McCabe & Jacobs, 2012). In addition, patients with cancer frequently experience multiple health problems earlier than the general population (Panek-Hudson, 2013). As such, a need exists for comprehensive early and ongoing approaches to management; these should take advantage of teachable moments at the end of active treatment to promote and support patient participation in maximizing recovery

by the adoption of healthy lifestyle behaviors (Alfano, Ganz, Rowland, & Hahn, 2012; Grant & Economou, 2008; Hewitt et al., 2005; Panek-Hudson, 2013).

The provision of SCPs or TSs has been seen as an important element of communication with survivors and multidisciplinary healthcare providers. What appears to be an obvious solution to ensuring optimal follow-up and recommendation adherence is hampered by the complexity of cancer types and treatment. This problem is particularly evident within hematologic cancers, which are made up of diverse blood, immune, and bone marrow diseases that make standardization of inclusions very difficult (Rechis et al., 2013). This survivor cohort lacks clear guidelines for follow-up care (Earle, 2007; Phillips & Currow, 2010; Rechis et al., 2013).

The three main types of hematologic cancer are leukemia, lymphoma, and myeloma (American Society of Hematology, 2015). Each cancer type has distinctive and complex treatment regimens that commonly involve high-dose chemotherapy agents, as well as targeted therapy, radiation therapy, and hematopoietic stem cell transplantation (Carey et al., 2012); these regimens often take place at different institutions. Unfortunately, a number of long-term and late physical, practical, and psychosocial effects that commonly include fear of recurrence, fatigue, and issues related to nutrition, exercise, fertility, relationships, finances, employment, and insurance can result from these largely aggressive treatments (Allart, Soubeyran, & Cousson-G lie, 2013; Hall, Lynagh, Bryant, & Sanson-Fisher, 2013). Patients with hematologic cancer require SCPs or TSs that reflect disease-specific differences instead of those designed for patients with more common cancers (e.g., breast, prostate, colorectal) that follow similar patterns of survivorship and are widely available.

Patients with hematologic cancer are understudied and underrepresented in survivorship care (Swash, Hulbert-Williams, & Bramwell, 2014), despite internationally increasing five-year relative survival rates (Sant et al., 2014). The hematology focus of this integrative review will add to the limited body of knowledge available regarding this cohort of survivors.

This review undertook an analysis of the literature primarily to examine the common attributes of SCPs and TSs developed for patients with hematologic cancer, including (a) resources (e.g., human, templates) required to develop SCPs and TSs, (b) potential benefits and limitations of SCPs and TSs, and (c) outcome measures that have been used to evaluate SCPs and TSs, as well as the findings of those measures.

Methods

The integrative review method was chosen because it allows for an in-depth evaluation of the issues encompassing the empirical, theoretical, and clinical approaches within a structured systematic methodology (Whittemore & Knafl, 2005). The method is structured according to five stages: problem formulation, literature search, data evaluation, data analysis, and presentation (Whittemore & Knafl, 2005).

Problem Formulation

In the current review, an SCP is defined as a personalized document that guides and coordinates follow-up care (e.g., recommended surveillance, screening, health-promoting behaviors) in addition to providing information, education, and resources for the management of potential long-term and late effects of cancer treatment (Hausman, Ganz, Sellers, & Rosenquist, 2011; Salz et al., 2014). Within cancer survivorship, a TS specifically refers to comprehensively summarized information regarding disease, procedures, and treatments received for a particular cancer (Hausman et al., 2011; Jabson & Bowen, 2013). The aim of these tools is to provide written communication from the treatment team to survivor, as well as clear delineation of responsibility of care to current and future healthcare providers (Earle, 2006; McCabe, Bhatia, et al., 2013). A number of components have been proposed for inclusion in SCPs and TSs based on recommendations from the IOM (Hewitt et al., 2005). An overview of relevant components for survivors of hematologic cancer are listed in Figure 1 and have been adapted from the published literature.

Much of the responsibility for the creation and dissemination of SCPs and TSs rests with the treating team (Earle, 2007; Hausman et al., 2011; Hewitt, Bamundo, Day, & Harvey, 2007; McCabe, Faithfull, et al., 2013; Salz et al., 2014; Stricker et al., 2011). However, the development of such individualized tools is time consuming, particularly if treatment occurs across multiple sites and if a lack of integration or absence of electronic records exists (Earle, 2007; McCabe, Bhatia, et al., 2013; Parry, Kent, Forsythe, Alfano, & Rowland, 2013; Rechis et al., 2013; Salz et al., 2014). Nurses have been suggested as the logical choice to create and deliver SCPs and TSs, not only to free up specialists' time but also because of their well-established role in providing holistic, individualized information to patients (Jackson, Scheid, & Rolnick, 2013; Marbach & Griffie, 2011).

Templates can reduce the time required to complete SCPs and TSs, providing that the required information is readily accessible. The American Society of Clinical Oncology (ASCO) and Lippincott's NursingCenter.com provide three-page downloadable templates (McCabe, Partridge, Grunfeld, & Hudson, 2013). Once the pertinent information is provided, Internet-based SCP tools, such as the Journey Forward Survivorship Care Plan Builder and the LIVESTRONG® Care Plan

(Hausman et al., 2011), deliver a comprehensive summary and a detailed long-term follow-up plan of care. However, their use is limited by the length (14 pages) of the tool (McCabe, Partridge, et al., 2013). For survivors and healthcare professionals outside of the United States, the available educational and supportive care resources may not be applicable. Hill-Kayser et al. (2013) studied use and satisfaction of the LIVESTRONG Care Plan and found that a majority (93%, n = 276) of responding survivors had rated the provision and amount of information as good to excellent. About 65% (n = 186) of responding survivors had not been given information contained in the SCP by healthcare providers after treatment completion. In addition, psychosocial concerns or risks were often not addressed, thereby necessitating later delivery after a healthcare professional had performed a follow-up needs assessment (Belansky & Mahon, 2012). Ganz, Casillas, & Hahn (2008) and Stricker et al. (2011) proposed that a dedicated survivorship visit would be ideal to assess patient needs and to deliver SCPs and TSs; however, they did not stipulate when that visit should take place.

The majority of studies regarding SCPs and TSs are largely descriptive or exploratory and have not established evidence showing that the use of SCPs and TSs improves survivor outcomes (Grant & Economou, 2008; McCabe, Faithfull, et al., 2013). A randomized, controlled trial of patients with breast cancer by Grunfeld et al. (2011) compared SCP provision to PCPs with usual care (no SCP); the study showed no difference in patient-reported outcomes between the two groups. However, this study has been criticized (Jefford, Schofield, & Emery, 2012; Stricker, Jacobs, & Palmer, 2012) because control PCPs received a comprehensive discharge letter that may have contained recommendations for follow-up care. Both groups may have received similar information, albeit in different formats, so results should be viewed with caution because of potential contamination of the control group. Because published literature in hematologic cancer survivorship is rare, the focus of this integrative review was to identify SCPs and TSs used with survivors of hematologic cancer to facilitate the development of tools that can be used with this unique survivor cohort.

Literature Search

The primary search took place from January 2000 to July 2014 and used the CINAHL®, Cochrane Library, EMBASE, MEDLINE®, PsycARTICLES, PsycINFO, and PubMed electronic databases. Combinations of the following search terms were used: *survivorship care plan* OR *treatment summary* OR *follow-up care plan* OR *post-treatment plan* OR *written follow-up instructions* AND *survivorship* OR *cancer survivor* AND *cancer* OR *neoplasm* OR *oncology* AND *hematology* OR *leukemia* OR *lymphoma* OR *multiple myeloma*. A hand search of reference lists from full texts was also employed. Searches were restricted to the English language, humans, and adults. Inclusion criteria were (a) studies that reported on SCP and TS use during the post-treatment phase of hematologic cancer survivorship and (b) studies that reported usage perceptions of SCPs and TSs experienced by healthcare providers and survivors. Exclusion criteria were (a) studies with less than a 25% cohort of patients

Survivorship Care Plan

- Follow-up schedule (includes responsibilities of all relevant healthcare providers)
- Monitoring for potential physical, psychological, and social issues, as well as referrals for
  - Anxiety and depression
  - Counseling
  - Employment, financial assistance, insurance, and legal aid
  - Fear of recurrence
  - Fertility and sexual functioning
  - Relationship issues (e.g., family and friends, marital, parenting)
- Promotion of healthy lifestyle behaviors
  - Alcohol reduction
  - Dietary modifications and weight reduction
  - Physical activity
  - Smoking cessation
- Recovery time frames for treatment toxicities
- Resource list and where to find information regarding
  - Other allied health providers
  - Specific disease and treatment information
  - Support groups
- Responsibilities of healthcare providers (in addition to provision of referrals and tests)
  - Comorbid conditions
  - Monitoring of long-term effects and the onset of potential late effects
  - Monitoring and screening for recurrence and second cancers
  - Recommended cancer screenings (e.g., colonoscopies, mammograms, Papanicolaou tests, skin checks)

Treatment Summary

- Adverse reactions or complications
- Blood product support
- Chemotherapy or targeted therapy (alterations, amount, cycles, and drugs)
- Clinical trials
- Contact information for each modality
- Coordinator of continuing care contact information
- Date of treatment initiation and completion
- Diagnosis, tests performed, and results
- Disease characteristics, site, and stage or classification
- Maintenance treatments and impact on health
- Psychosocial, nutritional, and other supportive services used
- Radiation therapy (dosage, site, and time frame)
- Transplantation (allogeneic or autologous)
- Type of surgery (if applicable)

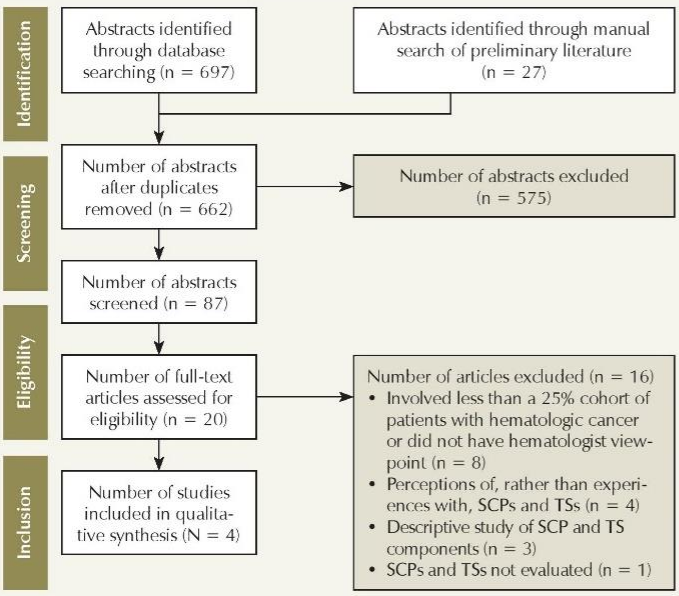
Figure 1. Recommended Components of Hematologic Cancer Survivorship Care Plan and Treatment Summary

Note. Based on information from Ganz et al., 2008; Hewitt et al., 2005; McCabe, Bhatia, et al., 2013; Palmer et al., 2014; Salz et al., 2014.

with hematologic cancer or hematologist viewpoint; (b) studies that reported perceptions of, rather than experiences with, SCP and TS use; (c) studies reporting SCPs and TSs from child, adolescent, adult survivors of a childhood cancer, or non-cancer populations; and (d) opinion papers, letters, editorials, commentaries, conference abstracts, conference proceedings, or case studies.

Data Evaluation Stage

Abstract titles were reviewed to assess eligibility. A summary of the selection process (Moher, Liberati, Tetzlaff, & Altman, 2009) is provided in Figure 2. The initial search yielded 697 abstracts. Duplicate articles were removed, and abstracts were screened against the inclusion and exclusion criteria. Abstracts that did not provide cancer or provider type were sought for further screening. Twenty full-text articles were retrieved; of those, four articles were reviewed. Documented methodologic characteristics included author information, study design and intervention, sample characteristics (e.g., participant details, response rate, years post-treatment), outcome measures, results, limitations and comments, and level of evidence as developed by Melnyk and Fineout-Overholt (2011) (see Table 1). Because of variations in study population and methodologies used, meta-analysis was not possible.



PRISMA—Preferred Reporting Items for Systematic Reviews and Meta-Analyses; SCP—survivorship care plan; TS—treatment summary

Figure 2. PRISMA Flowchart of Literature Search Results

The hematology component in the majority of studies was low. No systematic reviews on studies related to SCPs and TSs were identified. The four included studies were all from the United States. They assessed survivor and clinician views on the experience of receiving or disseminating SCPs and TSs. Included articles used various terms to describe treating clinicians. For clarity in this article, the term "specialist" will refer to the following treating consultants: hematologist and medical or radiation oncologist. The research studies all used quantitative approaches and reflected a low level (IV) of quantitative evidence. Reviewed studies were related to the survivorship phase of the cancer trajectory. Characteristics of reviewed articles are detailed in Table 2.

Data Analysis and Presentation

Sabatino et al. (2013) reported a subset of survivors (n = 407) who were within four years of diagnosis—a time frame corresponding with the IOM report's recommendation that all survivors receive SCPs and TSs. Survivors were asked if they had ever received a SCP or TS. The authors found that 38% (n = 155) of survivors acknowledged receipt of a TS, and that 58% (n = 236) had received written follow-up instructions. Written follow-up instructions were received more often by those patients who were part of a clinical trial (85%, n = 346) and by those who were reported as having a higher income (67%, n = 274). Survivors who had undergone hematopoietic stem cell transplantation were included; however, numbers were not reported.

Curcio, Lambe, Schneider, and Kahn (2012) studied survivors and clinicians. Survivors of hematologic cancer accounted for 26% (n = 8) of the overall survivor cohort studied (n = 30). Survivors were highly satisfied with the provision of SCPs and TSs and reported an increase in knowledge. Anxiety levels decreased, although levels were not high at baseline and may have decreased naturally with time. Survivor satisfaction may have been related to the survivorship visit and follow-up telephone call rather than SCP provision. PCPs were reported as being satisfied (100%, n = 10) with SCPs and TSs. The authors reported that PCPs appreciated the content, which aided communication and was useful in providing clarification of the survivor's follow-up plan.

Friedman, Coan, Smith, Herndon, and Abernethy (2010) studied survivors of non-Hodgkin lymphoma (n = 67) and physicians (n = 22) involved in survivorship care. Informational needs in the SCP were reported as being congruent between the PCP and survivor. All respondents rated medical content as more important than psychosocial issues, perhaps reflecting survivor expectations in the current model of survivorship follow-up. In addition, survivors ranked the plan to monitor overall health the sixth most important element of the SCP as compared to physicians who ranked it 13th. This led the authors to conclude that survivors view follow-up as part of general health maintenance, whereas physicians separate cancer survivorship care and non-cancer–related care.

Merport, Lemon, Nyambose, and Prout (2012) evaluated clinician (n = 108) use and PCP (n = 400) receipt of SCPs and TSs. About 54% (n = 216) of PCPs received a TS. However, the study reported that only 42% (n = 46) of specialists, including hematologists, prepared a TS. SCP preparation by specialists was low at 14% (n = 15); however, the authors reported that all SCPs were sent to survivors and PCPs. Barriers identified in this study included the lack of a template and of training given to healthcare professionals regarding the development of SCPs and TSs, as well as specialists' perceived absence of financial reimbursement for their time spent developing and delivering SCPs and TSs. The absence of support from treating clinicians may mean that development and dissemination remain low, with the possibility that SCPs stay medically focused.

These four studies all showed a lack of routine use of SCPs and TSs, although survivors and PCPs reported that they valued the tools and the direction for survivorship follow-up care that they provided.

Discussion

Published hematology research regarding SCPs and TSs is limited. No randomized, controlled trials or literature reviews exist for this understudied cohort of survivors, despite the belief that SCPs and TSs are beneficial to complex and rare survivor groups (e.g., hematology) (Shalom, Hahn, Casillas, & Ganz, 2011) in which health problems may take many years to develop (Sabatino et al., 2013). With the increased risk of psychosocial, physical, and economic long-term and late effects from disease and cancer therapy, patients often experience difficulties accessing post-treatment follow-up, which may lead to poorer overall health outcomes (Friedman et al., 2010).

Within the literature that reported the development and dissemination of the SCP and TS (Curcio et al., 2012; Merport et al., 2012), a lack of information regarding resources used by the specialist to develop the SCP and TS was observed (Merport et al., 2012). Similarly, information concerning how generic templates were tailored by the specialist and nurse practitioner to different survivors was not provided (Curcio et al., 2012). Details on any evidence-based guidelines for follow-up care used in SCPs (Merport et al., 2012) and the clinical expertise of the health professionals creating SCPs and TSs was equally lacking.

Table 1. Levels of Evidence

Level	Evidence
I	Systematic review of all relevant randomized, controlled trials
II	At least one well-designed, randomized, controlled trial
III	Well-designed, controlled trials without randomization
IV	Well-designed cohort studies, case-control studies, interrupted time series with a control group, historically controlled studies, interrupted time series without a control group or with case series
V	Systematic reviews of descriptive and qualitative studies
VI	Single descriptive and qualitative studies
VII	Expert opinion from clinicians or authorities, reports of expert committees, or based on physiology

Note. Based on information from Melnyk & Fineout-Overholt, 2011.

Standardized templates linked to electronic health records that would directly populate TSs have been proposed to provide health providers with diagnosis and treatment information (Merport et al., 2012; Salz et al., 2014); doing so would be particularly relevant when survivors have had treatment across a number of sites (Merport et al., 2012). Sabatino et al. (2013) found low TS and SCP delivery when survivors had more than one treatment modality. The long duration of treatment that occurs in some hematologic cancer regimens can make difficult the finding and summarizing of modifications and issues that have occurred during the entire treatment phase. Guidelines and templates for SCPs and TSs specific to hematologic cancers are necessary because generic cancer templates cannot convey all of the appropriate information required, adding to the complexity of this issue (Friedman et al., 2010). Curcio et al. (2012) and Sabatino et al. (2013) noted that the provision of SCPs and TSs soon after treatment completion is required to assess the need for information and resources.

Friedman et al. (2010) argued that providing extra information to survivors could overload and dilute the impact of the most important information that

Table 2. Methodologic Characteristics of Hematologic Cancer Survivorship Care Plans and Treatment Summaries

Study	Design and Intervention	Sample Characteristics	Outcome Measures	Results	Limitations and Comments
Curcio et al., 2012	Pre- and post-test questionnaire Survivorship protocol with SCPs and TSs developed by specialist and NP (40–75 minutes to complete); delivered by NP using ASCO generic template	30 survivors (convenience sample included survivors of breast cancer [53%], NHL [26%], lung cancer [10%], and gastrointestinal cancer [10%] less than two years post-treatment); 10 (41% RR) PCPs; 8 (80% RR) staff	Improved disease knowledge; decreased anxiety; satisfaction; fidelity to NCCN follow-up guidelines; cost-benefit analysis	Survivors reported increased knowledge of disease, treatment, follow-up, signs of recurrence, and LEs, as well as decreased anxiety and consistent fidelity to follow-up frequency as per NCCN guidelines. High satisfaction with SCPs and TSs was noted by survivors (76%), PCPs (100%), and staff (100%).	Limitations included low anxiety scores at baseline, small sample sizes, and a lack of cost-benefit analysis.
Friedman et al., 2010	Mailed questionnaire Rating of the most important informational needs in SCPs	67 (41% RR) survivors of NHL (9 months–12.6 years post-treatment); 22 (29% RR) physicians involved in survivorship care	Survivors' and physicians' informational needs in SCPs; congruence in needs between survivors and physicians	Survivors' informational needs include information about recurrence screening, LEs, treatment, overall health monitoring, nutrition, exercise, insurance, and finances. Physicians' informational needs include treatment complications. Survivors and physicians rated medical issues as more important than psychosocial issues.	Limitations included small sample sizes, as well as having the same questions asked of survivors and physicians and a disease-specific cohort.
Merport et al., 2012	Mailed questionnaire SCPs and TSs developed and delivered by specialists; TSs reported diagnosis, stage, treatment, start dates, treatment fields, and drugs.	108 (29% RR) specialists, of which 35 (32%) were hematologists; 400 (11%) PCPs. Reported cancers were breast (44%), prostate (36%), colorectal (35%), lung (31%), and hematologic (20%).	SCP and TS use and obstacles among specialists; SCP and TS receipt and informational preferences among PCPs	Of the specialists, 56% reported preparing TSs, and 14% reported preparing SCPs, both of which were sent to the PCP and patient. About 47% of specialists had no training in doing so, 46% have no template, and 40% receive no reimbursement. Of the PCPs, 54% reported receiving a TS. SCP receipt was not reported. Among the PCPs, informational needs, from highest to lowest, were TS (95%), follow-up schedule (89%), recommendations (89%), potential side effects (84%), and treatment-related health risks (67%).	Limitations included low response rates, self-reported practices, and responder bias (potential overestimation of use). The study showed a reported lack of routine use of SCPs and TSs.
Sabatino et al., 2013	2010 National Health Interview Survey Survivor-reported receipt of TS or written follow-up instructions	1,345 (61% RR) survivors (i.e., breast cancer [20%]; prostate cancer [14%]; cancer of the cervix or uterus [13%]; melanoma [11%]; colorectal cancer [8%], other cancer, including hematologic [31%]) less than and more than four years post-treatment	Receipt of TS or written follow-up instructions; recent surveillance for recurrence or other cancer screening	Of the survivors who were less than four years post-treatment, 38% had received a TS, 58% had received written follow-up instructions, 29% had received both, and 33% had received neither. More treatment modalities meant lower provision of TSs, whereas higher income and clinical trial participation meant higher provision of written follow-up instructions.	Limitations included an unspecified number of respondents who had been diagnosed with hematologic cancer, as well as self-reported data's failure to reflect the actual documents received. The study included separate reporting of survivors diagnosed after the IOM report (less than four years).

Note. All four studies reflected a low level (IV) of quantitative evidence based on information from Melnyk and Fineout-Overholt (2011).

ASCO—American Society of Clinical Oncology; IOM—Institute of Medicine; LE—late effect; NCCN—National Comprehensive Cancer Network; NHL—non-Hodgkin lymphoma; NP—nurse practitioner; PCP—primary care physician; RR—response rate; SCP—survivorship care plan; TS—treatment summary

needs to be conveyed. This view is supported by Cox and Faithfull (2013) who reported that clinicians consider late-effects information to affect psychological adjustment and increase the amount of late effects through autosuggestion. However, these authors reflect the perception of clinicians rather than patients, and, as Hill-Kayser et al. (2013) argued, this paternalistic approach is no longer acceptable. Providing tailored SCPs and TSs to survivors empowers individuals to learn about their disease and treatment and assume responsibility for future surveillance and disease management, facilitating engagement in a future healthy lifestyle (Jackson et al., 2013). This is particularly vital for younger survivors, given the expectation of a longer survivorship period (Jabson & Bowen, 2013).

Multidisciplinary collaboration has been suggested (Shalom et al., 2011) as a strategy for developing SCPs and TSs. Interdisciplinary education must acknowledge the value of each provider's contribution within the team. Recommendations clearly detailing provider responsibility can help to ensure that survivors are not over- or undertested and that they adhere to evidence- or consensus-based recommendations (Curcio et al., 2012). However, caution must be exercised when using consensus-based recommendations.

Nurses can be a key component in implementing care plans and providing comprehensive information, education, and resources, particularly in preventive health and screening (Curcio et al., 2012). Shalom et al. (2011) revealed that nurse practitioner-developed SCPs may not be read by PCPs—100% (n = 15) of PCPs reported that they would not act on expensive testing recommendations. Consequently, specialists must reinforce the importance of nurses as an essential component of survivorship care planning (Hewitt et al., 2007).

SCPs and TSs should be developed in conjunction with a robust model of hematologic cancer survivorship follow-up care that will address the issues and barriers related to implementation. Many professional organizations are calling for SCP development for accreditation. However, cancer programs that develop SCPs solely to meet professional requirements may be reluctant to make the organizational changes necessary to actually deliver the SCPs to survivors and PCPs (Birken, Mayer, & Weiner, 2013). Institutions and specialists perceiving a lack of financial reimbursement and support for the additional time required to prepare and deliver SCPs and TSs may be disinclined to support widespread implementation (Earle, 2007; McCabe, Partridge, et al., 2013; Salz et al., 2014).

The authors acknowledge several limitations of the current review. The search revealed a small number of articles meeting inclusion criteria. All studies reviewed had low sample numbers and response rates, particularly those studies that explored PCP experiences of SCPs and TSs. The numbers of survivors of hematologic cancer were limited, decreasing the applicability of findings to survivors of hematologic cancer. The reliance on self-reported practices in all four of the studies and a lack of comparison groups restrict the conclusions that can be drawn. Study participants may have had more experience with SCPs and TSs, as well as a bias toward or against SCP and TS implementation. This lack of standardization makes comparing studies and drawing conclusions regarding benefits to survivors difficult. In addition, an inherent bias in interpretation may be related to the evaluator.

Knowledge Translation

Structured communication among all health professionals on the history and future needs of survivors of hematologic cancer is required.

Survivorship care plans (SCPs) and treatment summaries (TSs), which provide information and practical assistance for guiding patients with hematologic cancer into the survivorship phase, require further work.

The intent of SCPs and TSs is broader than meeting organizational and accreditation guidelines.

Implications for Nursing

This integrative review identified published literature on SCPs and TSs and their applicability to survivors of hematologic cancer. Treatment advances in hematologic cancer mean that patients are living longer (Sant et al., 2014); however, the extended recovery trajectory involves a heavier symptom burden and post-treatment complications because of the aggressive nature of the hematologic disease and the treatment required. These hematologic cancers are unlike the other cancers that are often used as benchmarks (e.g., breast cancer, prostate cancer) (Parry, Morningstar, Kendall, & Coleman, 2011).

Nurses can influence and guide the development of relevant survivorship care recommendations, thereby facilitating a paradigm shift to encompass all aspects of the cancer trajectory. Nurses with advanced research skills (e.g., PhD prepared) would be well placed to take the lead in adopting and translating follow-up guidelines for patients with hematologic cancer into evidence-based and disease-specific templates. Nurses are in a unique position to provide and disseminate SCPs and TSs comprising individualized and relevant resources, information, and education to ensure that the needs of survivors of hematologic cancer are met. Nurses must also support and empower survivors to take control of and, ultimately, self-manage their ongoing needs.

The current review revealed a lack of high-quality evidence related to the care of survivors of hematologic cancer. Addressing the specific and ongoing concerns of these patients, along with disseminating this information to survivors and clinicians, particularly in primary care, is important. As survival rates continue to increase, the successful integration of hematologic cancer survivorship care into the cancer continuum is vital.

Conclusion

Further research will need to account for the inclusion of each component of the SCP, the survivor's desire for this knowledge and information, and the best way to develop and deliver SCPs and TSs that are specific to hematologic cancer. Research is required regarding the models of care that are most suitable for delivering SCPs and TSs to survivors of hematologic cancer, including their perspectives on follow-up provision. Nurse-led hematology survivorship clinics that facilitate shared care between the treating team and PCPs may be the most appropriate model to deliver SCPs and TSs. This may help to achieve the best outcomes for patients transitioning into the survivorship period but requires further evidence-based research. Methods that will optimize communication and clarity with provider responsibility, decreasing overuse or underuse of surveillance and screening tests, are fundamental aspects of this research. Research in how best to decrease the amount of time needed to prepare SCPs and TSs and the ideal time to effectively deliver SCPs and TSs is necessary. Well-designed, pragmatic, randomized, controlled trials are required to inform clinical practice. As the amount of outcome-based research increases, so too will the understanding of providing optimal survivorship care.

Karen Taylor, MNurs, GradDipOnc, BN, RN, is a survivorship cancer nurse coordinator at the Western Australia Cancer and Palliative Care Network in Perth and a PhD candidate, and Leanne Monterosso, PhD, BNurs (Hons1), GCert Teach, FACN, is a professor, both in the School of Nursing and Midwifery at the University of Notre Dame Australia in Fremantle. No financial relationships to disclose. Taylor can be reached at karen.taylor@health.wa.gov.au, with copy to editor at ONFEditor@ons.org. (Submitted October 2014. Accepted for publication December 12, 2014.)

References

Alfano, C.M., Ganz, P.A., Rowland, J.H., & Hahn, E.E. (2012). Cancer survivorship and cancer rehabilitation: Revitalizing the link. *Journal of Clinical Oncology, 30,* 904–906. doi:10.1200/JCO.2011.37.1674

Allart, P., Soubeyran, P., & Cousson-G lie, F. (2013). Are psychosocial factors associated with quality of life in patients with haematological cancer? A critical review of the literature. *Psycho-Oncology, 22,* 241–249. doi:10.1002/pon.3026

American Society of Hematology. (2015). Blood cancers. Retrieved from http://www.hematology.org/Patients/Cancers

Belansky, H., & Mahon, S.M. (2012). Using care plans to enhance care throughout the cancer survivorship trajectory. *Clinical Journal of Oncology Nursing, 16,* 90–92. doi:10.1188/12.CJON.90-92

Birken, S.A., Mayer, D.K., & Weiner, B.J. (2013). Survivorship care plans: Prevalence and barriers to use. *Journal of Cancer Education, 28,* 290–296. doi:10.1007/s13187-013-0469-x

Carey, M., Anderson, A., Sanson-Fisher, R., Lynagh, M., Paul, C., & Tzelepis, F. (2012). How well are we meeting haematological cancer survivors' preferences for involvement in treatment decision making? *Patient Education and Counseling, 88,* 87–92. doi:10.1016/j.pec.2011.12.014

Cox, A., & Faithfull, S. (2013). 'They're survivors physically but we want them to survive mentally as well': Health care professionals' views on providing potential late effect information. *Supportive Care in Cancer, 21,* 2491–2497. doi:10.1007/s00520-013-1806-7

Curcio, K.R., Lambe, C., Schneider, S., & Khan, K. (2012). Evaluation of a cancer survivorship protocol: Transitioning patients to survivors. *Clinical Journal of Oncology Nursing, 16,* 400–406. doi:10.1188/12.CJON.400-406

de Leeuw, J., & Larsson, M. (2013). Nurse-led follow-up care for cancer patients: What is known and what is needed. *Supportive Care in Cancer, 21,* 2643–2649. doi:10.1007/s00520-013-1892-6

Dicicco-Bloom, B., & Cunningham, R.S. (2013). The experience of information sharing among primary care clinicians with cancer survivors and their oncologists. *Journal of Cancer Survivorship, 7,* 124–130. doi:10.1007/s11764-012-0253-7

Earle, C.C. (2006). Failing to plan is planning to fail: Improving the quality of care with survivorship care plans. *Journal of Clinical Oncology, 24,* 5112–5116. doi:10.1200/JCO.2006.06.5284

Earle, C.C. (2007). Long term care planning for cancer survivors: A health services research agenda. *Journal of Cancer Survivorship, 1,* 64–74. doi:10.1007/s11764-006-0003-9

Friedman, D.R., Coan, A.D., Smith, S.K., Herndon, J.E., II, & Abernethy, A.P. (2010). Informational needs assessment of non-Hodgkin lymphoma survivors and their physicians. *American Journal of Hematology, 85,* 528–532. doi:10.1002/ajh.21725

Ganz, P.A., Casillas, J., & Hahn, E.E. (2008). Ensuring quality care for cancer survivors: Implementing the survivorship care plan. *Seminars in Oncology Nursing, 24,* 208–217. doi:10.1016/j.soncn.2008.05.009

Grant, M., & Economou, D. (2008). The evolving paradigm of adult cancer survivor care. *Oncology, 22,* 13–22, 27.

Grunfeld, E., Julian, J.A., Pond, G., Maunsell, E., Coyle, D., Folkes, A., . . . Levine, M.N. (2011). Evaluating survivorship care plans: Results of a randomized, clinical trial of patients with breast cancer. *Journal of Clinical Oncology, 29,* 4755–4762. doi:10.1200/JCO.2011.36.8373

Hall, A., Lynagh, M., Bryant, J., & Sanson-Fisher, R. (2013). Supportive care needs of hematologic cancer survivors: A critical review of the literature. *Critical Reviews in Oncology/Hematology, 88,* 102–116. doi:10.1016/j.critrevonc.2013.03.008

Hausman, J., Ganz, P.A., Sellers, T.P., & Rosenquist, J. (2011). Journey forward: The new face of cancer survivorship care. *Jounal of Oncology Practice, 7*(Suppl. 3), e50s–e56s. doi:10.1200/JOP.2011.000306

Hewitt, M., Greenfield, S., & Stovall, E. (Eds.). (2005). *From cancer patient to cancer survivor: Lost in transition.* Washington, DC: National Academies Press.

Hewitt, M.E., Bamundo, A., Day, R., & Harvey, C. (2007). Perspectives on post-treatment cancer care: Qualitative research with survivors, nurses, and physicians. *Journal of Clinical Oncology, 25,* 2270–2273. doi:10.1200/JCO.2006.10.0826

Hill-Kayser, C.E., Vachani, C.C., Hampshire, M.K., Di Lullo, G.,

Jacobs, L.A., & Metz, J.M. (2013). Impact of internet-based cancer survivorship care plans on health care and lifestyle behaviors. *Cancer, 119,* 3854–3860. doi:10.1002/cncr.28286

Jabson, J.M., & Bowen, D.J. (2013). Cancer treatment summaries and follow-up care instructions: Which cancer survivors receive them? *Cancer Causes and Control, 24,* 861–871. doi:10.1007/s10552-013-0163-7

Jackson, J.M., Scheid, K., & Rolnick, S.J. (2013). Development of the cancer survivorship care plan: What's next? Life after cancer treatment. *Clinical Journal of Oncology Nursing, 17,* 280–284. doi:10.1188/13.CJON.280-284

Jefford, M., Schofield, P., & Emery, J. (2012). Improving survivorship care. *Journal of Clinical Oncology, 30,* 1391–1392. doi:10.1200/JCO.2011.40.5886

Landier, W. (2009). Survivorship care: Essential components and models of delivery. *Oncology, 23,* 46–53.

Marbach, T.J., & Griffie, J. (2011). Patient preferences concerning treatment plans, survivorship care plans, education, and support services. *Oncology Nursing Forum, 38,* 335–342. doi:10.1188/11.ONF.335-342

McCabe, M.S., Bhatia, S., Oeffinger, K.C., Reaman, G.H., Tyne, C., Wollins, D.S., & Hudson, M.M. (2013). American Society of Clinical Oncology statement: Achieving high-quality cancer survivorship care. *Journal of Clinical Oncology, 31,* 631–640. doi:10.1200/JCO.2012.46.6854

McCabe, M.S., Faithfull, S., Makin, W., & Wengstrom, Y. (2013). Survivorship programs and care planning. *Cancer, 119,* 2179–2186. doi:10.1002/cncr.28068

McCabe, M.S., & Jacobs, L.A. (2012). Clinical update: Survivorship care—Models and programs. *Seminars in Oncology Nursing, 28,* e1–e8. doi:10.1016/j.soncn.2012.05.001

McCabe, M.S., Partridge, A.H., Grunfeld, E., & Hudson, M.M. (2013). Risk-based health care, the cancer survivor, the oncologist, and the primary care physician. *Seminars in Oncology, 40,* 804–812. doi:10.1053/j.seminoncol.2013.09.004

Melnyk, B.M., & Fineout-Overholt, E. (2011). *Evidence-based practice in nursing and healthcare: A guide to best practice* (2nd ed.). Philadelphia, PA: Wolters Kluwer/Lippincott Williams and Wilkins.

Merport, A., Lemon, S.C., Nyambose, J., & Prout, M.N. (2012). The use of cancer treatment summaries and care plans among Massachusetts physicians. *Supportive Care in Cancer, 20,* 1579–1583. doi:10.1007/s00520-012-1458-z

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *BMJ, 339,* b2535. doi:10.1136/bmj.b2535

National Coalition for Cancer Survivorship. (2014). Defining cancer survivorship. Retrieved from http://www.canceradvocacy.org/news/defining-cancer-survivorship

Palmer, S.C., Jacobs, L.A., DeMichele, A., Risendal, B., Jones, A.F., & Stricker, C.T. (2014). Metrics to evaluate treatment summaries and survivorship care plans: A scorecard. *Supportive Care in Cancer, 22,* 1475–1483. doi:10.1007/s00520-013-2107-x

Panek-Hudson, Y. (2013). Survivorship care—Time for innovation? *Australian Journal of Cancer Nursing, 14,* 7–12.

Parry, C., Kent, E.E., Forsythe, L.P., Alfano, C.M., & Rowland, J.H. (2013). Can't see the forest for the care plan: A call to revisit the context of care planning. *Journal of Clinical Oncology, 31,* 2651–2653. doi:10.1200/JCO.2012.48.4618

Parry, C., Morningstar, E., Kendall, J., & Coleman, E.A. (2011). Working without a net: Leukemia and lymphoma survivors' perspectives on care delivery at end-of-treatment and beyond. *Journal of Psychosocial Oncology, 29,* 175–198. doi:10.1080/07347332.2010.548444

Phillips, J.L., & Currow, D.C. (2010). Cancer as a chronic disease. *Collegian, 17,* 47–50. doi:10.1016/j.colegn.2010.04.007

Rechis, R., Arvey, S.R., & Beckjord, E.B. (2013). Perspectives of a lifelong cancer survivor—Improving survivorship care. *Nature Reviews. Clinical Oncology, 10,* 117–120. doi:10.1038/nrclinonc.2012.212

Sabatino, S.A., Thompson, T.D., Smith, J.L., Rowland, J.H., Forsythe, L.P., Pollack, L., & Hawkins, N.A. (2013). Receipt of cancer treatment summaries and follow-up instructions among adult cancer survivors: Results from a national survey. *Journal of Cancer Survivorship, 7,* 32–43. doi:10.1007/s11764-012-0242-x

Salz, T., McCabe, M.S., Onstad, E.E., Baxi, S.S., Deming, R.L., Franco, R.A., . . . Oeffinger, K.C. (2014). Survivorship care plans: Is there buy-in from community oncology providers? *Cancer, 120,* 722–730. doi:10.1002/cncr.28472

Sant, M., Minicozzi, P., Mounier, M., Anderson, L.A., Brenner, H., Holleczek, B., . . . De Angelis, R. (2014). Survival for haematological malignancies in Europe between 1997 and 2008 by region and age: Results of EUROCARE-5, a population-based study. *Lancet Oncology, 15,* 931–942. doi:10.1016/S1470-2045(14)70282-7

Shalom, M.M., Hahn, E.E., Casillas, J., & Ganz, P.A. (2011). Do survivorship care plans make a difference? A primary care provider perspective. *Journal of Oncology Practice, 7,* 314–318. doi:10.1200/JOP.2010.000208

Stricker, C.T., Jacobs, L.A., & Palmer, S. C. (2012). Survivorship care plans: An argument for evidence over common sense. *Journal of Clinical Oncology, 30,* 1392–1393. doi:10.1200/JCO.2011.40.7940

Stricker, C.T., Jacobs, L.A., Risendal, B., Jones, A., Panzer, S., Ganz, P.A., . . . Palmer, S.C. (2011). Survivorship care planning after the Institute of Medicine recommendations: How are we faring? *Journal of Cancer Survivorship, 5,* 358–370. doi:10.1007/s11764-011-0196-4

Swash, B., Hulbert-Williams, N., & Bramwell, R. (2014). Unmet psychosocial needs in haematological cancer: A systematic review. *Supportive Care in Cancer, 22,* 1131–1141. doi:10.1007/s00520-014-2123-5

Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing, 52,* 546–553. doi:10.1111/j.1365-2648.2005.03621.x

A.3 Systematic Review of the Tools Used to Assess the Informational and Practical Needs of Acute Leukaemia and Lymphoma Survivors

Permission to use the article was granted on the 13 March 2018 by Cambridge Publishing and the Editor of The Australian Journal of Cancer Nursing, Cancer Nursing Society of Australia.

The Australian Journal of Cancer Nursing

Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors

Karen Taylor* • PhD(c), MNurs, GradDipOnc, BN, RN
Survivorship Cancer Nurse Coordinator, Western Australia Cancer and Palliative Care Network
189 Royal Street, East Perth, WA 6004
School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, WA 6959
Email: Karen.Taylor@health.wa.gov.au Tel: +61 (0)428 411 309

Leanne Monterosso • PhD, BNurs (Hons), GCert Teach, FACN
Chair of Nursing, School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, WA 6959
St John of God Murdoch Hospital, WA; Adjunct Professor of Nursing, School of Nursing, Edith Cowan University
Joondalup, WA 6027

* Corresponding author

Abstract

Purpose: To identify validated measurement tools to assess the informational and practical concerns of leukaemia and lymphoma survivors. Cancer nurses have the potential to lead the way in providing quality post-treatment survivorship care.

Method: This systematic review utilised a search of electronic databases for eligible articles published to March 2014. Included articles described a tool to assess informational and/or practical concerns of leukaemia and/or lymphoma survivors.

Results: Seven full text articles were identified that described cancer-specific tools used to assess informational and/or practical needs of this survivor cohort. There was variation in the use of cancer survivor-specific tools and generic cancer tools.

Conclusions: No haematology-specific needs assessment tools were identified. Therefore only tentative conclusions on the best tool for this cohort can be made. Further research is required to develop reliable and validated tools that will support the selection of the most appropriate tool for leukaemia and lymphoma survivors.

Keywords: Leukaemia and lymphoma cancer; survivorship; instruments; measures; tools; supportive care needs; unmet needs; perceived needs.

Introduction

Leukaemia and lymphoma are the most common blood and bone marrow cancers[1]. Effective treatments are largely aggressive and cause a number of long-term and late physical, practical and psychosocial effects, which significantly impact lifestyle in the survivorship phase[2]. Survivorship is defined as the experience of living with, through and beyond a diagnosis of cancer[3]. As with other cancers, the haematology cancer health professional role has extended to include provision of patient care in the survivorship phase. This important step forward has been driven largely by the 2005 Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition*[4], considered the seminal paper for cancer survivorship. The report recommended survivorship care as a priority in the cancer trajectory with a number of specific issues relevant to the survivorship phase. These issues can be categorised according to the seven domains of Fitch's[5] supportive care framework; physical, informational, emotional, psychological, social, spiritual and practical concerns. The framework can be used across the cancer continuum including haematology survivorship care[6]. Whilst survivorship care is developing for other cancers, haematology cancers remain understudied in survivorship literature[7], despite increasing five-year relative survival rates internationally[8-10].

The purpose of this review was to source tools that could be used to assess two domains from the supportive care framework: informational and practical concerns. These were chosen as a result of our findings from a qualitative study undertaken with leukaemia and lymphoma patients that revealed a number of unmet needs, predominately informational and practical[11], thought to relate in part to the extensive nature of the treatment and the uncertainty around long-term remission and potential late effects.

The terms 'informational needs' and 'practical needs' are rarely considered or defined as separate entities in the literature. For clarity and consistency, Fitch's definitions[5] of needs have been used. Informational needs are defined as information to

assist in decision-making and acquiring of skills to decrease fear, anxiety and misperception[5]. Fear of recurrence is often reported as an informational need for this cohort[17]. Two recent systematic reviews on this topic reported tools used to measure fear of recurrence; tools to measure other informational needs were not reported[12,13]. Practical needs are defined as direct interventions or help that support the survivor to complete a task or meet a concern[5]. Insurance and employment issues are often cited as unmet needs for leukaemia and lymphoma survivors[14]. Other common informational and practical needs reported in haematology survivorship literature include late effects, fatigue, nutrition, exercise, fertility and sexual concerns, relationship issues, financial issues, personal care and accessing support services[2,8,15-19].

Gates *et al.*[18] argued that haematology cancer nurses have an important role in this changing dynamic, especially in developing sustainable, nurse-led survivorship care. If nurses are to take on a greater role in survivorship care they require accurate, reliable and validated tools to assess patients entering the post-treatment phase[20]. Hawkins *et al.*[19] proposed that tools designed for patients to self-identify perceived needs are required to support survivorship care. These tools could then guide the development of appropriate models of care, resources and tailored support that are patient-centred rather than based on the perceptions of health professionals[5,7]. The timing of patient needs assessments is equally important. Research showing interventions and assessments undertaken in the early survivorship phase (up to two years post-diagnosis) can lead to fewer unmet needs moving into the extended survivorship phase (over five years)[21,22].

There is a dearth of published literature that has critically evaluated tools used to measure the perceived unmet needs of leukaemia and lymphoma survivors[20,23]. Tools specifically developed for these patients in the treatment phase such as the Functional Assessment of Cancer Therapy: Lymphoma or Leukaemia (FACT-LYM, FACT-Leu) have also been used in the survivor population[24,25]. Hence, it is possible that survivor-specific needs may not be captured.

Given that each cancer patient's journey is unique, it is important to measure individual needs and match practical support to meet those needs. Therefore, the leukaemia and lymphoma-specific focus of this paper will add to the limited body of knowledge currently available in this survivor cohort.

The following questions guided this systematic review:

1. What reliable and valid measurement tools are currently available to measure the informational and practical needs of acute leukaemia and lymphoma cancer survivors?
2. What are the implications of the findings from this review for future research and clinical practice?

Method

A systematic review methodology was chosen to guide this review. To guide literature searches and analysis of articles, a study protocol was devised. As the use of needs assessment tools dictates a quantitative study method, qualitative studies and the qualitative component of quantitative studies were excluded. Mixed methods research was included with only the quantitative element evaluated.

Literature search

The primary search utilised the following electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsychInfo, PubMed, EMBASE, PsychArticles, and the Cochrane Library from earliest records to March 2014. Search terms related to leukaemia and lymphoma cancers, assessment, survivorship and needs (see Appendix 1 for the search strategy). A hand search of the reference lists from full text articles was also employed. Searches were restricted to English and adult acute leukaemia or lymphoma survivors. Inclusion and exclusion criteria are shown in Table 1. Studies with only multiple myeloma participants were excluded as these patients have an incurable cancer and could therefore be termed "living with cancer"[1,26]. Likewise, studies with only allogeneic transplant participants were excluded as they have ongoing conditions such as graft-versus-host-disease.

Quality appraisal and data extraction

One author (KT) reviewed abstract titles to assess eligibility. KT and LM then appraised the instrument/tool(s) used in eligible full text articles to determine whether they measured informational and/or practical needs of the leukaemia or lymphoma survivor. A summary of the selection process using the PRISMA 2009 Flow Diagram[27] is provided in Figure 1.

Table 1: Inclusion and exclusion criteria

Inclusion criteria
Use of a cancer survivor-specific or generic cancer tool or instrument
Validity and reliability of tool tested with leukaemia and/or lymphoma cancer survivors
Informational and/or practical needs reported
Adult leukaemia and lymphoma cancer survivors only
Exclusion criteria
Tools used in the treatment or diagnostic phase
Tools used with relapse or secondary leukaemia or lymphoma cancer survivors only
Studies reporting survivors of a childhood leukaemia or lymphoma cancer
Studies related to caregivers, or comparative studies between caregivers and survivors
Studies with less than 50% leukaemia or lymphoma cancer survivor cohort
Opinion papers, letters, editorials, commentaries, conference proceedings, or case studies

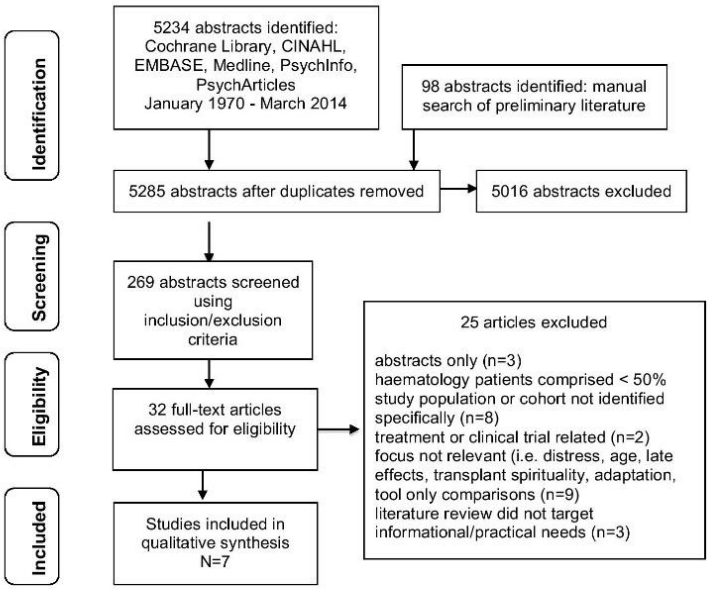


Figure 1: Flow chart of literature search results

The methodological characteristics documented included: authors; publication year; country; study design; comparison group; outcome measures; disease; sample size and response rate; survivorship period; cancer-specific and non-cancer-specific tools; reported unmet informational and practical needs; results and study quality[28], as shown in Table 2. Due to variations in study population, methodologies and tools used, meta-analysis was not possible. Study quality was assessed using Fowkes and Fulton's[28] guidelines and checklist for critically appraising quantitative research. Assessment of the methodological quality of studies utilised a classification system of poor (under 40% of quality items), good (40–70% of quality items) or very good (over 70% of quality items) as reported by Hall *et al.*[8]. In addition, the validity of each tool was assessed according to: how the tool covered the informational and/or practical needs of the participants; correlation with other generic cancer or survivor-specific tools; and whether results confirmed study outcomes. Tool reliability was determined by internal consistency of the items and whether test-retest reliability had been performed. Generalisability of the tool to leukaemia or lymphoma survivors was gauged from the study results, along with the clinical usefulness of the tool for these survivors.

Data analysis

The initial search yielded a large number of abstracts (n=5234). Following removal of duplicate articles and abstract screening using exclusion and inclusion criteria, 32 full text articles were sought and further appraised. Of these, seven articles were reviewed and referred to one or more relevant tools[2,6,29-33]. No tool had been specifically developed for exclusive use with leukaemia or lymphoma survivors. Two studies reported researcher-developed questionnaires[2,29].

The seven included articles reporting haematological cancer survivor cohort studies were from Australia (n=2), Canada (n=1), the United States of America (USA) (n=3), Norway (n=1) and United Kingdom (UK) (n=1). The periods of survivorship ranged from six weeks post-treatment through to 12 years after diagnosis[2,3,7,30-33]. Of the reviewed studies, four utilised comparative groups related to unmet needs among different: treatment types[30]; countries[6]; gender[7]; and survivors and physicians[29]. Outcome measures varied across all studies, although the majority related to unmet needs after treatment completion (Table 2). The assessment of methodological quality[28] revealed most studies (n=5) were "good"; two were classified as "poor". Two studies[32,33] utilised mixed method designs, six studies[2,6,29,31-33] were cross-sectional and one[30] was prospective. Methodological quality varied with sample sizes ranging from 22 to 477 participants and response rates varying from between 29% and 94%.

Cancer Nurses Society of Australia

Table 2: Methodological characteristics of selected articles (n=9)

Authors Year Country	Study design Comparison group Outcomes measured	Disease Sample size (response rate %) Survivorship period	Tools Cancer survivor-specific Non-cancer tools/ Investigator questions	Unmet information/ Practical needs reported	Results	Study quality
Arden-Close *et al.*[2] 2011 UK	Cross-sectional Administered questionnaires Gender comparison Health-related quality of life, late effects and perceived vulnerability; satisfaction with care; expectations and satisfaction of clinic visit	Lymphoma n=115 (79.9%) › 5yrs	QoL-CS (Quality of Life Cancer Survivors) Yes SF-12v2 (Medical Outcomes Study Health Survey Short Form 12 version 2) Princess Margaret Hospital Satisfaction with Doctor Questionnaire	Only questions related to discussion of topics, late effects	No gender difference in late effects or perceived vulnerability Men: more late effects, worse health-related quality of life, wanted to discuss more topics (women discussed the topics) Shorter wait time = more topics discussed Health-related quality of life dependent on whether survivors' follow-up expectations are met	Good
Friedman *et al.*[5] 2010 USA	Cross-sectional Mailed questionnaire Comparison of survivors and physicians Informational survivorship care plan needs of survivors and physicians Congruence between survivors/ physicians	Non-Hodgkin lymphoma n=67 (41%) 9 months – 12.6 years Physicians involved in survivorship care n=22 (29%)	Investigator questionnaire	Informational needs to be included in survivorship care plan	Survivorship care plan tailored for particular survivors Survivor: survivorship care plan inclusions: screening for recurrence/late effects; treatment summary; monitor overall health/nutrition/exercise; insurance Survivor/physician concordance higher on medical issues compared to psychosocial issues No differences reported between survivorship length	Poor
Hall *et al.*[4] 2013 Australia Canada	Cross-sectional Cross-cultural Mailed questionnaires Comparison of Australian and Canadian haematology survivors Percentage of survivors reporting unmet needs; domain scores; 10 most prevalent high unmet needs	Leukaemia, lymphoma, multiple myeloma Australia: n=268 (37%) ‹3 years Canada: n=169 (45%) 1–5 years	SUNS (Survivors' Unmet Needs Survey) Yes	Informational needs: cancer recurrence and spread Work and financial needs	Similar levels of unmet needs Fatigue highest concern across both cohorts Multiple areas of need found in: females, younger age, expense due to cancer, vocational education level, seeing doctor about treatment or concerns Work and financial needs higher for Australian survivors	Good
Hjermstad *et al.*[6] 2003 Norway	Prospective cohort at 4 time points Administered questionnaires Comparison of autologous lymphoma with allogeneic leukaemia transplant patients Rehabilitation needs and health-related quality of life; physical function measures of CARES-SF compared to EORTC QLQ-C30	Leukaemia, lymphoma n=123 (94%) ‹1 year post-transplant	CARES-SF (CAncer Rehabilitation Evaluation System Short Form) No EORTC QLQ-C30 (European Organization for Research and Treatment Quality of Life Core questionnaire) No	Financial, insurance, weight gain, transport, fear of recurrence, employment, fatigue	Few patients requested help with any items CARES-SF useful for assessing sexual, marital, medical interaction to address specific issues at follow-up High correlation with physical function between the two scales	Good
Lobb *et al.*[8] 2009 Australia	Cross-sectional Mailed questionnaire No comparison group Assessment of unmet informational and emotional needs after treatment	Leukaemia, lymphoma, multiple myeloma n=66 (50%) 6 weeks – 1 year post-treatment	CaSUN (Cancer Survivors Unmet Needs Survey) Yes	Concerns: fear of recurrence; care coordination; information on services	Care coordination after treatment important, significant for unmarried or working patients Fear of recurrence, emotional and relationship needs greater in younger patients Top endorsed needs: managing health with medical team; communication between doctors; best medical care	Good
Parry *et al.*[9] 2012 USA	Mixed methods Cross sectional Mailed questionnaire No comparison group Health service and psychosocial needs of adult leukaemia and lymphoma survivors	Lymphoma, leukaemia n=477 (45%) ‹4 years	Houts *et al.* Service Need Inventory, refined by Kornlith *et al.* 14 items	Practical needs: child care; financial	Unmet need highest in: sexual issues; handling medical and living expenses; emotional difficulties; employment; health insurance Women more likely to report unmet child care needs Relationships were observed among service needs, overlapping areas of unmet need	Poor
Zebrack[11] 2000 USA	Mixed methods Cross sectional Mailed questionnaires/semi structured interviews No comparison group Experience of quality of life in long term survivors at various life stages	Leukaemia, lymphoma n=53 (50%) 10 years	QoL-CS (Quality of Life Cancer Survivors) Yes 27 In-depth interviews	Fear of recurrence, fatigue, employment, support, financial, family	Fatigue, pain, fear of recurrence – ongoing issues Family distress and finances continue to impact survivors Financial issues worse in older survivors Relapse not related to quality of life Income rated significantly to quality of life Positive associations with ability to cope after cancer	Good

The Australian Journal of Cancer Nursing

Results

Five tools were identified and could be dichotomised as either those designed for cancer survivors (survivor-specific) or those developed for cancer patients undergoing treatment and used with a cancer survivor cohort (generic cancer tools). Utilising the definitions of informational and practical needs as previously described ensured consistency with the data extracted from the articles. Comparisons of the five main assessment tools identified in this review are shown in Table 3.

The generic cancer tools: CAncer Rehabilitation Evaluation System Short Form (CARES-SF); and European Organization for Research and Treatment Quality of Life Core questionnaire (EORTC QLQ-C30) were not survivor-specific and no data in relation to previous use in any haematology survivor cohorts was described[30]. Reliability scores and validity information was variable in the detail reported. Similarly, the three cancer survivor-specific tools: Cancer Survivors Unmet Needs Survey (CaSUN); Quality of Life Cancer Survivors (QoL-CS); and Survivors' Unmet Needs Survey (SUNS) provided variable reliability and validity data[2,6,31,33].

All studies documented tool domains and scoring scales. Only two tools addressed both informational and practical needs (CaSUN, SUNS)[6,31]. The SUNS is the only tool developed using a mixed cohort that included haematological cancer survivors[6]. All reviewed articles reported the clinical usefulness of the tools to the haematological cohort studied.

The majority of studies (n=5) assessed the informational needs of survivors (Table 2). Of the survivor-specific tools used to assess informational needs, the CaSUN[31] includes an explicit information domain with response items such as: "I need up to date information"; "I need understandable information". It is assumed that follow-up is required for those patients who score highly for such items. The SUNS tool similarly includes an informational domain with questions targeted to "Finding information ..." or "Dealing with fears ... or feelings..."[6]. In general, a high score allows the assessor to identify areas of need. However, neither tool explicitly asks if the survivor would like help with their issue or concern.

Arden-Close *et al.*[2] measured gender-related informational needs using the cancer survivor-specific tool QoL-CS. Although this article made gender-specific recommendations, it did not provide insight into what assessment tools best identify gender differences. Friedman *et al.*[29] developed a questionnaire that focused on information that should be included in survivorship care plans such as: specific information about cancer recurrence; nutrition and exercise; screening plan; and information for family members. This questionnaire both identified needs and

Table 3: Comparison of assessment tools

Tool	Cancer survivor-specific	Content	Scale Scoring	Information needs	Practical needs
CARES-SF (CAncer Rehabilitation Evaluation System Short Form)	No	59 items – degree problem applies 5 summary scales: physical; psychosocial; sexual; marital; medical interaction	5 point Lower scores = fewer problems	No	Yes
CaSUN (Cancer Survivors Unmet Needs Survey)	Yes	35 supportive care needs items, 6 positive outcome items, 1 open-ended item 5 needs domains: existential survivorship; comprehensive cancer care; information; quality of life; relationships	5 point Higher scores = greater needs	Yes	Yes
EORTC QLQ-C30 (European Organization for Research and Treatment Quality of Life Core questionnaire)	No	5 functioning scales: physical; role; emotional; social; cognitive 3 symptom scales: pain; fatigue; nausea and vomiting 6 items: dyspnoea; sleep; appetite; diarrhoea; constipation; financial impact	8 point Function: higher scores = better function Symptom: higher scores = more problems	No	Yes
QoL-CS (Quality of Life Cancer Survivors)	Yes	4 domains: physical well-being (8 items) psychological well-being (18 items) social well-being (8 items) spiritual/existential well-being (7 items)	10 point Higher scores = best QoL	No	Yes
SUNS (Survivors' Unmet Needs Survey)	Yes	5 domains: informational needs (8 items) financial concerns (11 items) access and continuity of care (22 items) relationships (15 items) emotional health (33 items)	5 point Higher scores = greater need	Yes	Yes

enquired whether respondents wanted information. On the other hand, the CARES-SF[30] does enquire if patients would like assistance with their concerns. However, it does not explicitly identify survivor informational needs. In contrast, Parry *et al.*[32] used a non-validated survey that identified informational and practical needs of haematology survivors examining if participants received the help they required.

The definition of "practical need" differed between authors, making identification of suitable tools somewhat difficult. The QoL-CS tool[2,33] examined practical concerns including: employment; sexuality; financial burden and fatigue. Unlike the other cancer survivor-specific tools, a higher score indicated a better quality of life outcome. It was unclear if the tool recommended users to follow up concerns that generated low scores. Similarly, the EORTC QLQ-C30 assessed the practical need of financial concerns, but focused on more treatment-related concerns that are unlikely in the survivorship phase[30]. Needs relating to fatigue management, fertility, sexuality, nutrition, exercise, insurance, finances and employment were explored by the majority of tools or investigator-derived questionnaires to varying degrees. The late effects of treatment were reported as both an informational need and a practical area where a plan for screening should occur[2,29]. Likewise, fear of recurrence issues were similarly reported[6,29-31,33].

Although a variety of tools was used, there was consensus regarding the most prevalent leukaemia and lymphoma survivor informational and practical needs. The commonly reported informational needs were: treatment late effects; cancer recurrence including fear of recurrence; care coordination; and information on available resources[6,29,31,33]. The most consistently identified practical needs were: fatigue management; employment; financial; insurance; family; and sexuality[6,30-33]. Arden-Close *et al.*[7] addressed potential differences in gender and found men wanted more information; however, they were often unable to receive this from the medical consultation. Women, on the other hand, were able to discuss the topics they wanted. Other studies found women had higher unmet needs related to family issues[6,31,32]; similarly younger survivors had higher unmet informational and practical needs[6,31]. Conversely, disease and treatment type did not identify those with greater unmet needs.

Discussion

Providing information across the cancer continuum is one of the most important aspects of care, yet it is a frequently reported unmet need, especially in the survivorship phase[34]. Leukaemia and lymphoma patients differ from other cancer patients in the considerable variability between their cancer types and the range of treatments affecting many aspects of their lives[8]. With improving survival rates, those diagnosed younger (18–45 years) can now expect to live longer, raising additional concerns and unmet needs[2]. Information provision must be individualised and tailored to specific patients' needs[32,34]. As highlighted by Friedman *et al.*[29], survivorship care plans need to account for differing informational and practical needs of survivors, primary care providers and haematologists.

Generic cancer tools include items related to diagnosis and treatment issues, which are not necessarily specific to the survivorship phase. This review has shown that survivor-specific tools can be used to assess unmet needs of leukaemia and lymphoma participants in the survivorship phase. Therefore, tools specific to the survivorship phase would be more appropriate to assess for unmet needs and concerns in this cohort.

Arden-Close *et al.*[2] and Aziz[22] have argued that survivors should be afforded the opportunity to obtain support and access resources earlier in the survivorship continuum. They assert survivors need information about immediate and long-term impacts of the cancer, together with practical needs related to fatigue, exercise, nutrition, fertility, sexuality, insurance, finances, employment and late effects. Leukaemia and lymphoma survivors may also want resources to address healthy lifestyle choices[2,35] or support to deal with the psychosocial aspects such as relationships, anxiety and fear of recurrence, reported in many studies as the highest unmet needs[6,30,31].

We acknowledge a number of limitations. There was variation in tools used across a wide range of survivors from the early survivorship phases (under two years)[6,30-32] through to 12 years post-diagnosis[29,33]. This made comparative generalisations of informational and practical needs difficult and enabled only tentative conclusions. Our findings are limited to comparing those areas surveyed with the assessment tools. As such, the review could not determine a broader range of supportive care needs for all haematological cancer survivors. Further, the relatively low response rate reported for some studies reduces the likelihood of the sample being representative of leukaemia and/or lymphoma survivor populations, and sampling bias could result in distorted conclusions. Extracting the psychometric properties of the tools was hampered by a lack of detailed data to support validity and reliability[6,30,31]. Finally, an inherent bias in interpretation might be considered.

Notwithstanding the limitations, this review identified a consensus on the most prevalent informational and practical needs of leukaemia and lymphoma survivors. This important finding can assist haematology cancer nurses when making decisions regarding the most appropriate tools to use and may assist in the development of haematology cancer survivor-specific tools that measure: perceived informational and practical needs; the extent to which needs are being met; and the survivors' need for support across all supportive care domains. In this way nurses are ideally positioned to provide individualised information and resources to these survivors and further this area of research.

Conclusion

There is a paucity of studies related to leukaemia and lymphoma survivors and specific validated tools that can be used to identify and measure the informational and practical needs of this cohort. While cancer survivor-specific needs assessment tools do exist and have been used with more common cancer groups, further research is required to determine their relevance and applicability to leukaemia and lymphoma survivors to ensure specific concerns are heard and addressed via appropriate support and information. Equally, generating psychometric data will ensure valid and reliable tools are utilised. As the only tool developed that included a haematology cohort, the use of the SUNS tool in further leukaemia and lymphoma survivor populations will allow a greater body of knowledge to be developed.

Appendix: Combinations of search terms used

haematology cancer
OR haematology (hematology) malignancy
OR hematologic neoplasm
OR haematological (hematological) cancer
OR blood cancer
OR acute leukemia (leukaemia)
OR myeloid acute
OR lymphocytic acute
OR nonlymphocytic acute
OR lymphoma
OR Hodgkin disease/lymphoma
OR Non (non) Hodgkin's
OR T-Cell OR B-Cell
OR oncology
AND
tool/s
OR screening tool/s
OR instrument/s
OR measurement tool/s
OR measurement scale/s
OR psychological test/s
OR questionnaire/s
AND
survivor
OR survivorship
OR cancer survivor/s
OR after cancer
AND
supportive care need/s
OR unmet need/s
OR need/s
OR needs assessment
OR perceived need
OR information needs
OR practical needs

References

1. National Cancer Institute. NCI dictionary of cancer terms. 2006 [cited 2014 3 April]. Available from: http://www.cancer.gov/dictionary/?CdrID=45708.
2. Arden-Close E, Absolom K, Greenfield D, Hancock B, Coleman R, Eiser C. Gender differences in self-reported late effects, quality of life and satisfaction with clinic in survivors of lymphoma. Psycho-Oncology. 2011;20(11):1202–10.
3. National Coalition for Cancer Survivorship. 2014 [cited 2014 3 April]. Available from: http://www.canceradvocacy.org/.
4. Hewitt ME, Greenfield S, Stovall E. From cancer patient to cancer survivor: Lost in transition. Hewitt M, Greenfield S, Stovall E, editors. Washington DC: The National Academies Press; 2006.
5. Fitch M. Supportive care framework. Canadian Oncology Nursing Journal — Revue Canadienne De Nursing Oncologique. 2008;18(1):6–24.
6. Hall A, Campbell HS, Sanson-Fisher R, Lynagh M, D'Este C, Burkhalter R, Carey M. Unmet needs of Australian and Canadian haematological cancer survivors: A cross-sectional international comparative study. Psycho-Oncology. 2013;22(9):2032–8.
7. Swash B, Hulbert-Williams N, Bramwell R. Unmet psychosocial needs in haematological cancer: A systematic review. Supportive Care in Cancer. 2014;22(4):1131–41.
8. Hall A, Lynagh M, Bryant J, Sanson-Fisher R. Supportive care needs of hematological cancer survivors: A critical review of the literature. Critical Reviews in Oncology/Hematology. 2013;88(1):102–16.
9. Rowland JH, Bellizzi KM. Cancer survivors and survivorship research: A reflection on today's successes and tomorrow's challenges. Hematology/Oncology Clinics of North America. 2008;22(2):181–200.
10. Sant M, Minicozzi P, Mounier M, Anderson LA, Brenner H, Holleczek B, Marcos-Gragera R, Maynadié M, Monnereau A, Osca-Gelis G, Visser O, De Angelis R. Survival for haematological malignancies in Europe between 1997 and 2008 by region and age: Results of EUROCARE-5, a population-based study. Lancet Oncology. 2014;15(9):931–42.
11. Monterosso L, Taylor K, Bulsara C, Platt V, Stratton K, Musiello T, Joske D. Defining concerns, unmet needs and support preferences for haematology survivors: An exploratory study to inform intervention development. Fremantle, Western Australia: University of Notre Dame Australia; 2015.
12. Koch L, Jansen L, Brenner H, Arndt V. Fear of recurrence and disease progression in long-term (>5 years) cancer survivors-a systematic review of quantitative studies. Psycho-Oncology. 2013;22(1):1–11.
13. Thewes B, Butow P, Zachariae R, Christensen S, Simard S, Gotay C. Fear of cancer recurrence: A systematic literature review of self-report measures. Psycho-Oncology. 2012;21(6):571–87.
14. Chen AB, Feng Y, Neuberg D, Recklitis C, Diller LR, Mauch PN, Ng AK. Employment and insurance in survivors of Hodgkin lymphoma and their siblings: A questionnaire study. Leukamia & Lymphoma. 2012;53(8):1474–80.
15. Allart P, Soubeyran P, Cousson-Gélie F. Are psychosocial factors associated with quality of life in patients with haematological cancer? A critical review of the literature. Psycho-Oncology. 2013;22(2):241–9.
16. Beckjord EB, Arora NK, Bellizzi K, Hamilton AS, Rowland JH. Sexual well-being among survivors of non-Hodgkin lymphoma. Oncology Nursing Forum. 2011;38(5):E351–9.
17. Behringer K, Muller H, Gorgen H, Flechtner HH, Brillant C, Halbsguth TV, Thielen I, Eichenauer DA, Schober T, Nisters-Backes H, Fuchs M, Engert A, Borchmann P. Sexual quality of life in Hodgkin lymphoma: A longitudinal analysis by the German Hodgkin study group. British Journal of Cancer. 2013;108(1):49–57.
18. Gates P, Seymour JF, Krishnasamy M. Insights into the development of a nurse-led survivorship care intervention for long-term survivors of Hodgkin lymphoma. Australian Journal of Cancer Nursing. 2012;13(1):4–10.

19. Hawkins NA, Pollack LA, Leadbetter S, Steele WR, Carroll J, Ryan EP, Ryan JL, Morrow GR, Dolan JG. Information needs of patients and perceived adequacy of information available before and after treatment of cancer. Journal of Psychosocial Oncology. 2008;26(2):1–16.
20. Muzzatti B, Annunziata MA. Assessing quality of life in long-term cancer survivors: A review of available tools. Supportive Care in Cancer. 2013;21(11):3143–52.
21. McDowell ME, Occhipinti S, Ferguson M, Dunn J, Chambers SK. Predictors of change in unmet supportive care needs in cancer. Psycho-Oncology. 2010;19(5):508–16.
22. Aziz NM. Cancer survivorship research: State of knowledge, challenges and opportunities. Acta Oncology. 2007;46(4):417–32.
23. Arden-Close E, Pacey A, Eiser C. Health-related quality of life in survivors of lymphoma: A systematic review and methodological critique. Leukaemia & Lymphoma. 2010;51(4):628–40.
24. Cella D, Jensen SE, Webster K, Hongyan D, Lai J-S, Rosen S, Tallman MS, Yount S. Measuring health-related quality of life in leukemia: The functional assessment of cancer therapy — leukemia (FACT-Leu) questionnaire. Value in Health. 2012;15(8):1051–8.
25. Hlubocky FJ, Webster K, Cashy J, Beaumont J, Cella D. The development and validation of a measure of health-related quality of life for non-Hodgkin's lymphoma: The functional assessment of cancer therapy — lymphoma (FACT-LYM). Lymphoma. 2013;2013:9.
'26. Osborne TR, Ramsenthaler C, Siegert RJ, Edmonds PM, Schey SA, Higginson IJ. What issues matter most to people with multiple myeloma and how well are we measuring them? A systematic review of quality of life tools. European Journal of Haematology. 2012;89(6):437–57.
27. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: The prisma statement. British Medical Journal. 2009;339(b2535).
28. Fowkes FG, Fulton PM. Critical appraisal of published research: Introductory guidelines. British Medical Journal. 1991;302(6785):1136–40.
29. Friedman DR, Coan AD, Smith SK, Herndon II JE, Abernethy AP. Informational needs assessment of non-Hodgkin lymphoma survivors and their physicians. American Journal of Hematology. 2010;85(7):528–32.
30. Hjermstad MJ, Evensen SA, Kvaloy SO, Loge JH, Fayers PM, Kaasa S. The CARES-SF used for prospective assessment of health-related quality of life after stem cell transplantation. Psycho-Oncology. 2003;12(8):803–13.
31. Lobb EA, Joske D, Butow P, Kristjanson LJ, Cannell P, Cull G, Augustson B. When the safety net of treatment has been removed: Patients' unmet needs at the completion of treatment for haematological malignancies. Patient Education and Counseling. 2009;77(1):103–8.
32. Parry C, Lomax JB, Morningstar EA, Fairclough DL. Identification and correlates of unmet service needs in adult leukemia and lymphoma survivors after treatment. Journal of Oncology Practice. 2012;8(5):e135–41.
33. Zebrack B. Quality of life of long-term survivors of leukemia and lymphoma. Journal of Psychosocial Oncology. 2000;18(4):39–59.
34. Husson O, Thong MS, Mols F, Oerlemans S, Kaptein AA, van de Poll-Franse LV. Illness perceptions in cancer survivors: What is the role of information provision? Psycho-Oncology. 2013;22(3):490–8.
35. Boyes A, Girgis A, D'Este C, Zucca AC. Prevalence and correlates of cancer survivors' supportive care needs 6 months after diagnosis: A population-based cross-sectional study. BioMed Central Cancer. 2012;12:150.

A.4 Protocol for Care After Lymphoma (CALy) Trial: A Phase II Pilot Randomised Controlled Trial of a Lymphoma Nurse-led Model of Survivorship Care

Open Access Protocol

BMJ Open

Protocol for Care After Lymphoma (CALy) trial: a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care

Karen Taylor,[1,2] David Joske,[3,4] Max Bulsara,[5] Caroline Bulsara,[2] Leanne Monterosso[2,6,7]

To cite: Taylor K, Joske D, Bulsara M, *et al*. Protocol for Care After Lymphoma (CALy) trial: a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *BMJ Open* 2016;**6**:e010817. doi:10.1136/bmjopen-2015-010817

► Prepublication history for this paper is available online. To view these files please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2015-010817).

Received 16 December 2015
Revised 23 March 2016
Accepted 28 April 2016

For numbered affiliations see end of article.

Correspondence to
Karen Taylor;
Karen.Taylor@health.wa.gov.au

ABSTRACT

Introduction: Lymphoma is the sixth most common cancer diagnosed in Australia and internationally. Owing to the aggressive nature of the disease and intensity of treatment, survivors face long-term effects that impact on quality of life. Current models of follow-up post-treatment fail to address these complex issues. Given that 74% of patients with lymphoma cancer now survive 5 years beyond diagnosis and treatment, it is important to address this gap in care.

Aim: To determine self-reported informational and practical needs, anxiety, depression, stress, coping and empowerment at baseline, 3 and 6 months.

Methods and analysis: A pilot randomised controlled trial will test the effect of a nurse-led lymphoma survivorship clinic compared with usual post-treatment care at a large tertiary cancer centre in Western Australia. The intervention will comprise three face-to-face appointments with delivery of tailored resources, a survivorship care plan and treatment summary (SCP TS). The SCP TS will be given to the participant and general practitioner (GP). Intervention participants will be interviewed at completion to explore the perceived value of the intervention components and preferred dose. An evaluation developed for GPs will assess receipt and use of SCP TS. The primary intent of analysis will be to address the feasibility of a larger trial and requisite effect and sample size.

Ethics and dissemination: Ethics approval has been granted by the University of Notre Dame Australia and Sir Charles Gairdner Hospital in Western Australia. Peer-reviewed publications and conference presentations will report the results of this phase II trial.

Trial registration number: ANZCTRN126150005 30527; Pre-results.

Strengths and limitations of this study

- This is the first randomised controlled trial of a nurse-led model of survivorship care for patients completing treatment for lymphoma cancer in Western Australia.
- This trial will test a developed lymphoma-specific survivorship care plan and treatment summary.
- As a pilot study, it is designed to provide preliminary data on the efficacy and feasibility of a nurse-led survivorship intervention for the purposes of planning a phase III study.

INTRODUCTION

Lymphoma is a general term for over 20 blood cancers that originate from T and B cells in the lymphatic system[1] where lymphocytes undergo a malignant change and multiple uncontrollably. Lymphomas, when combined, represent the sixth most commonly diagnosed cancer worldwide,[2] with Hodgkin's lymphoma (HL) and non-Hodgkin's lymphoma (NHL) the two main forms. HL represents 11.5% of all lymphomas and is the third most common cancer in the adolescent and young adult population.[1] With the exception of HL, incidence increases with age; thus, NHL is predominantly a cancer of the older population (over 65 years).[1 3]

The incidence of lymphoma in Australia is increasing, with a projected diagnosis of 5680 cases in 2015. This will equate to 4.5% of all cancer cases.[4] In Australia, the overall survival rate has improved, and ~74% of people diagnosed with lymphoma are reported as being alive at 5 years compared with 49% in the 1980s.[4] Despite these encouraging results,[5] this group of cancers remain understudied and subsequently under-represented in survivorship care.[6]

Lymphoma treatment regimens commonly involve aggressive high-dose chemotherapy and/or targeted therapy agents, radiotherapy

and haematopoietic stem cell transplants.[7] Such treatments result in distressing long-term and late physical, practical and psychosocial effects, which can produce ongoing unmet needs. These needs relate to physical and psychosocial impacts such as fear of recurrence, fatigue, poor nutrition, exercise, fertility, relationship, financial, employment and insurance issues.[8] Furthermore, these patients commonly experience related health problems earlier than the general population[9] and are at risk of specific late effects. Cardiovascular disease is particularly pertinent in this cohort due to chemotherapy combinations and cumulative dosing[10 11] as well as mediastinal radiotherapy.[12 13] Patient health and lifestyle behaviours, for example, smoking, likewise have an effect on disease development.[11] Patients with lymphoma have an increased relative risk of second cancers, higher when diagnosed at a younger age[14 15] and further elevated when treatment includes radiotherapy.[11 12] The potential for the development of bone marrow disease is greater in the first decade; however, unlike second cancer risk, this decreases and then plateaus in the second decade.[11] Patients who require a haematopoietic stem cell transplant have additional transplant-related late-effect risks.[16 17] Although patients may be unable to modify some late-effect risks, awareness of relevant potential late effects may ensure timely follow-up for symptomology.[11]

The traditional model of haematological cancer care follow-up has largely been haematologist led within the acute hospital setting.[8] Information at treatment completion is often inadequate,[18 19] with a lack of clear guidelines for the ongoing management of survivors.[20] This has led to an emerging focus on redesigning survivorship follow-up care and delivery.

Lobb *et al*[21] demonstrated patient-reported needs among Western Australian haematological cancer survivors (n=66) not addressed during routine follow-up post-treatment completion and thereby classified as unmet needs. Almost two-thirds of respondents (59%) would have found it helpful to talk with a health professional at treatment completion. A recent qualitative study conducted by the authors with lymphoma and leukaemia cancer survivors (n=19) in Western Australia[22] found unmet needs relating to information, practical support, coping strategies and transitioning from active treatment into the survivorship phase. Findings suggested that tailored, end-of-treatment interventions should form a key component of survivorship care. Participants suggested a cancer coordinator nurse as an important element to initiate and transition patients into the survivorship phase.

Nurse-led models of care have demonstrated potentially satisfactory outcomes[23–25] and are proposed as an acceptable pathway to transition into the survivorship phase.[26] A dedicated nurse-led survivorship clinic to administer patient-centred survivor-specific needs assessments is an important aspect of survivorship care to address patient concerns and empower survivors to manage their own health and ongoing symptoms.[27–30]

Empowering patients enables them to become more responsible for the management of their own health and well-being, and can contribute to the influence and control patients have over their own health which has the advantage of improving quality of life.[31 32] Bandura's theory of self-efficacy,[33] the principal concept in self-management education, teaches patients to identify their problems and provides skills in decision-making and developing an appropriate action plan.[31] It is anticipated that increasing empowerment and providing healthy lifestyle resources will result in a reduction in the patient-perceived need for support from the healthcare system.[31]

Survivorship care plans (SCPs) and treatment summaries (TS) have been recommended as facilitators to deliver holistic survivorship follow-up care by the Institute of Medicine,[34] the American Society of Clinical Oncology,[35] the UK National Cancer Survivorship Initiative[36] and the proposed Clinical Oncology Society of Australia survivorship guidelines.[37] A personalised SCP would guide follow-up care by including recommendations, information and resources for surveillance, screening of potential long-term and late effects and health-promoting behaviours.[38] The TS would comprehensively summarise information on diagnosis and treatments.[39 40] Cancer nurses have established expertise in the areas of health promotion, information, support and resource provision,[41] and therefore can develop and disseminate SCPs and TS to facilitate communication between the survivor, specialist and primary care.

AIM

The aim of the Care After Lymphoma (CALy) study is to develop and empirically test an evidence-based nurse-led lymphoma survivorship clinic to transition participants into the survivorship phase, using a pilot randomised controlled trial (RCT) design. This phase II trial of an intervention is aimed at reducing the immediate and long-term physical and psychosocial consequences of haematological cancer treatment and to enable the participant to return to normal functioning sooner. The nurse-led lymphoma survivorship clinic has three core components: (1) needs assessments to determine individual informational or practical issues or concerns; (2) provision of a tailored survivorship care plan and treatment summary to enhance communication between the participant and all other health professionals with whom the patient has contact post-treatment; and (3) provision of individualised evidence-based education, information and resources to address patient-reported needs, likely post-treatment physical and emotional concerns and maximising participant involvement in healthy lifestyle behaviours. The aims are aligned with the Australian national research priority for preventative healthcare to reduce comorbid diseases in cancer survivors.

The Medical Research Council framework for the development and evaluation of complex interventions

has guided the development of this trial.[42 43] The evaluation of a model for nurse-led evidence-based survivorship care will provide level II baseline data to endorse the suitability of outcome measures, establish acceptability of the intervention and randomisation, provide recruitment and attrition rates, support hypothesis development and calculate sample sizes for future phase III multisite RCTs. In addition, it will add psychometric information on the Short-Form Survivor Unmet Needs Survey (SF-SUNS) and will provide data on a test–retest analysis.

RESEARCH QUESTIONS

The following research questions guide this pilot RCT:

1. Do participants assigned to the nurse-led lymphoma survivorship clinic demonstrate a reduction in perceived unmet informational and practical needs compared with those randomly assigned to usual care?
2. Do participants assigned to the nurse-led lymphoma survivorship clinic demonstrate a reduction in self-reported anxiety, depression and stress and an increase in patient self-management behaviours compared with participants randomly assigned to usual care?
3. What is the perceived efficacy and value of the nurse-led lymphoma survivorship clinic from the perspective of a subset of survivors in the intervention group?
4. To what extent does the provision of an SCP TS to general practitioners (GPs) improve the communication between the treating hospital, GP and the participant?
5. Does the SF-SUNS demonstrate stability and reliability over time?

METHODS

Design

The evidence to support the development of the phase II CALy trial comprised a qualitative study using a focus group methodology with lymphoma, leukaemia and multiple myeloma survivors.[22] The evidence also encompassed three systematic reviews regarding models of haematological survivorship care; SCPs and TS in patients with haematological cancer; and tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors.[8 38 44] Information gained from this preliminary work guided the development of intervention components and the operationalisation of the feasibility and acceptability of a nurse-led RCT.

The RCT framework has been developed using the Consolidated Standards of Reporting Trials (CONSORT) statement and checklist.[45 46] Outcomes will be measured using validated needs assessment instruments. Reporting will include inclusion and exclusion criteria; missing data; dropout; and early closure of the trial if required (figure 1). The survivorship cancer nurse coordinator (CNC) is a specialist cancer nurse with an extensive haematology nursing background and formal counselling qualifications, including motivational interviewing techniques.

Population and setting

A convenience sample of patients with lymphoma cancer from a specialised haematology department in a comprehensive cancer centre of a large acute tertiary hospital in Perth, Western Australia, will be used. Follow-up by a haematologist occurs every 3 months for the first 12 months. The nurse-led survivorship clinic intervention will be an additional care activity to the medical haematology follow-up and will involve three appointments over 6 months. It will start at 3 months post-treatment completion and cease at 9 months post-treatment.

Inclusion criteria

1. Pathologically confirmed new diagnosis of HL or NHL.
2. Completed first-line curative intent chemotherapy or second-line curative intent autologous stem cell transplant within the previous 3 months.
3. No evidence of lymphoma disease on mid-treatment interim positron emission tomography (PET) scan or post-treatment PET scan where these are performed.
4. Able to understand and read English.
5. Over 18 years.

Exclusion criteria

1. Diagnosis of other haematological malignancy.
2. Did not undergo chemotherapy.
3. Further treatment and follow-up at another hospital.
4. Intellectually impaired or experiencing an acute mental health condition that precludes the ability to provide informed consent.
5. Comorbid condition requiring monthly visits with GP.

To measure selection bias, minimal data will be completed on eligible participants who decline to participate. Reasons for refusal will be recorded to gain valuable information for future research.

Recruitment

Identification of eligible participants will be undertaken by haematology clinicians who will provide details to the survivorship CNC. Ongoing education of clinicians (haematologists and nurses) regarding all aspects of the study, its progress and recruitment will facilitate cooperation and support. Eligible participants will be met after treatment completion by the CNC who will discuss the study and provide a Participant Information and Consent Form (PICF). Consenting participants randomised to the intervention group (n=30) will be offered the opportunity to consent to a qualitative interview at completion of all time points. Approximately one-third of participants (n=10) will be required for this phase. Participants' names and contact details will be entered

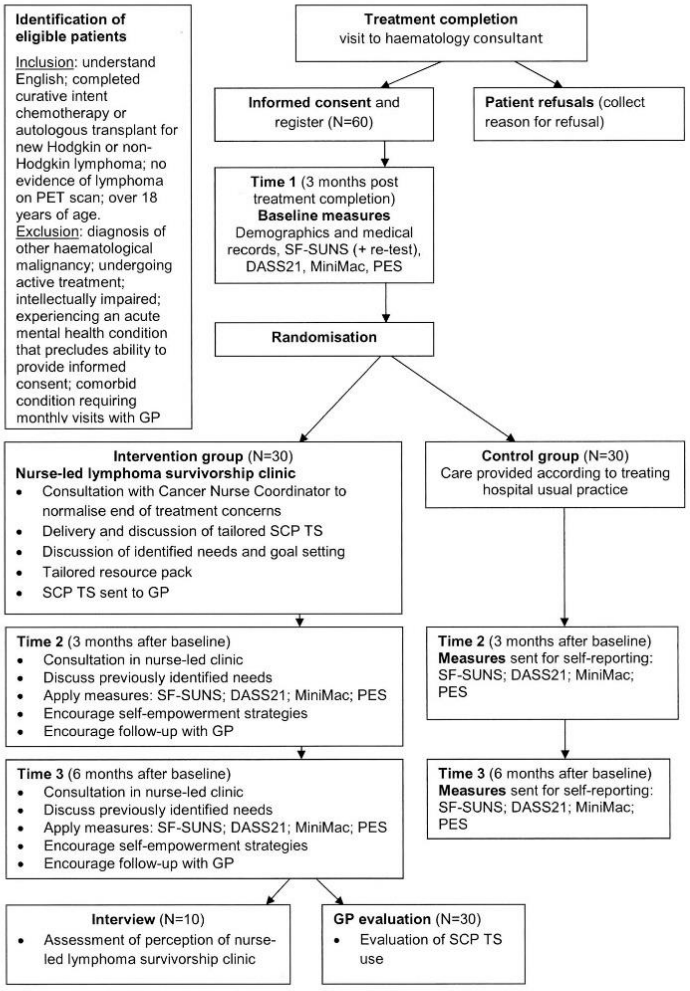


Figure 1 Trial flow chart. DASS-21, Depression Anxiety Stress Scale; GP, general practitioner; Mini-MACM, Mini-Mental Adjustment to Cancer Scale; PES, Patient Empowerment Scale; PET, positron emission tomography; SCP TS, survivorship care plan and treatment summary; SF-SUNS, Short-Form Survivor Unmet Needs Survey.

onto a master coding sheet and assigned a numerical identifier code after randomisation.

SCP and TS

An extensive review of the literature[38] and available SCPs and TS was undertaken. Many institutions in Australia are using US-based templates that are large (up to 20 pages), not tailored to the individual and provide resources that are not contextualised to the Australian healthcare setting. Therefore, we developed a lymphoma SCP TS in collaboration with a haematology consultant, GP and other multidisciplinary team members (eg, consumers, psychologists, cancer nurses and academic cancer researchers). This has been created as a word document template to be filled in by the nurse. The perspectives of lymphoma survivors (n=6) and clinicians (including GPs; n=6) were sought to determine the relevance of the proposed SCP TS items. Each item was assessed for content and apparent internal consistency (whether items should be included and the general fit with other items) using either yes or no responses to the items. Content validity used a rating scale (1=not relevant to 4=highly relevant). The content validity index (CVI)[47] was generated for each item by adding the number of 'yes' scores (content, clarity and apparent internal consistency) and scores of 3 or 4 (content validity). The mean CVI consumer results were as follows: clarity 0.98; apparent internal consistency 100; content validity 0.95. Consumers demonstrated complete agreement of 1.0 for internal consistency items. The mean CVI clinician results were as follows: clarity 0.99; apparent internal consistency 0.95; content validity 0.84. Feedback in the comments section of the evaluation interestingly indicated GPs did not value or

require a large TS document. Consensus of the research team was reached for the TS (half a page in length) and SCP (one and a half pages in length).

The TS is completed using existing medical record information such as diagnosis, treatment, complications and use of allied health providers. The first section of the SCP includes a table for the inclusion of individualised potential late effects. This table comprises the late effect; information for the GP about tests or follow-up required and when; and the symptomology the participant needs to be aware of, with encouragement to follow these up with the GP. Prior to recruitment, a comprehensive list of potential late effects and follow-up required was developed for each lymphoma type using available published literature and guidelines (KT). This list was circulated, discussed and amended by the haematologists who were aware these would be used to guide their population of the table. Tailored individualised potential late effects will be documented based on treatments administered, participants' demographics and health characteristics. Once the TS and this aspect of the SCP are completed, it will be emailed to the haematologist for final approval. Once amendments (if any) are made, the haematologist signs the TS. The second page of the SCP is patient centred and populated by the nurse in consultation with the participant. Participants will be asked to identify three main concerns, health goals and proposed actions to achieve these goals.

Sample size

The calculation of a sample size is not required for pilot RCTs as effect size is not yet known. Rather the purpose of the pilot is to determine variability in measures from which effect sizes can be calculated. Approximately 75 patients are seen per year at the study setting; however, this figure is inclusive of new and existing patients. Therefore, a consecutive sample of 60 participants will be recruited and randomised 1:1 to either control or intervention group (30 participants are expected in each group). It is necessary to establish test–retest reliability for the SF-SUNS by demonstrating a minimum intraclass correlation (ICC) of 0.8. Therefore, a sample size of 39 (rounded up to 40 participants) administered on two consecutive occasions no more than 5 days apart (baseline and 5 days later) is required to achieve 80% power to detect this ICC of 0.8.[48]

Patient-reported outcome measures

A review of the literature[44] has resulted in four assessment instruments being selected to measure the outcomes proposed: SF-SUNS; Depression Anxiety Stress Scale (DASS21); Mini-Mental Adjustment to Cancer Scale (Mini-MAC); and Patient Empowerment Scale (PES). These instruments have demonstrated reliability and validity with haematological cancer survivors as shown in table 1.

Baseline data collection

Baseline data collection from consenting participants will occur 3 months after treatment completion. All participants will self-report demographic information and complete the four assessment instruments. In addition, they will receive a second SF-SUNS instrument to complete no later than 5 days after the baseline testing. These will be returned via a reply-paid envelope to allow the researchers to undertake test–retest reliability testing. Medical demographic information obtained will include type of haematological cancer, stage of disease, type of treatment received (chemotherapy, immunotherapy, radiotherapy), date of diagnosis, time since diagnosis, treatment complications or dose modifications, and comorbidities. Personal demographic information collected will include sex, age, marital status, age of children (if any), postcode, occupation, income level, education level and health behaviours such as smoking, alcohol consumption and weight.

Randomisation

After baseline assessment, participants will be randomised to either the current standard of care or intervention group. Computer-generated random numbers using a four-digit sequence have been generated and linked to group allocation by an independent statistician. An independent member of the research team, to ensure confidentiality and offset bias in randomisation, has sealed a hard copy of each individual number and group in an opaque envelope. The envelopes are consecutively numbered and will be distributed to consenting participants in this order. Control group participants will be made aware that another researcher will follow-up non-questionnaire return with a telephone call to the participant after 2 weeks.

Control group

Control group participants will receive follow-up care as per haematologists' usual practice. At 3 and 6 months after baseline, the same four assessment instruments will be sent to the participant, and they will self-report any issues or unmet supportive care needs. An addressed reply paid envelope will be provided to return assessments. Participants who score high unmet needs will be encouraged to discuss these with their haematologist at their usual follow-up appointment.

Intervention group

Following baseline data collection, intervention group participants will have an appointment at the nurse-led lymphoma survivorship clinic. The first page of the SCP TS will be populated prior to this appointment. At the first nurse-led lymphoma survivorship clinic, any concerns the participant has regarding the end of treatment will be discussed and normalised. The nurse will discuss the TS and potential late effects. The second page of the SCP will be completed by the nurse using an electronic template in collaboration with the participant. At this

Table 1 Outcomes assessment instruments

Instrument	Use	Items and factors	Internal consistency	Additional issues
Short-Form Survivor Unmet Needs Survey (SF-SUNS)[49]	Developed for cancer survivors to assess unmet needs. Assess the gap between patient self-reported concerns and the level of support they require Discriminates between survivors at different stages post-treatment completion	30 items—0 (no unmet need) to 4 (very high unmet need Four factors: information (3 items); financial concerns (8 items); access and continuity of care (6 items); relationships and emotional health (13 items)	Cronbach's α scores for all domains were ≥0.85 intraclass correlation (ICC) across all domains high, ie, ≥0.9 indicating SF-SUNS reliably measured the level of unmet need	Test–retest reliability not established Will be undertaken during this study
Depression Anxiety Stress Scale (DASS-21)[50]	Measures multiple dimensions of depression, anxiety and stress	Three 7-item scales—0 (did not apply to me at all) to 3 (applied to me very much, or most of the time) 5 subscale severity ratings: normal, mild, moderate, severe and extremely severe	Cronbach's α subscale scores were: 0.94 depression; 0.87 anxiety; and 0.91 stress[51]	Used to support SUNS psychometric properties in haematology cancer survivors
Mini-Mental Adjustment to Cancer Scale (Mini-MAC)[52]	Measures cancer-specific coping strategies	29 items—5 cancer-specific coping strategies: helplessness–hopelessness (8 items); anxious preoccupation (8 items); fighting spirit (4 items); cognitive avoidance (4 items); and fatalism (5 items). Scale-1 (definitely does not apply to me) to 4 (definitely applies to me)	Reliability using Cronbach's α coefficients for each subscale ranged from 0.62 to 0.88	Used with small sample of haematology cancer survivors
Patient Empowerment Scale (PES)[53]	Measures level of patient's coping ability and self-efficacy in terms of managing their illness and making decisions about support strategies	15-item 4-point Likert-type scale	A high degree of reliability has been established using the Rasch Extended Model with the Person Separation Index of 0.926	Used in haematology/ oncology patients

Cronbach's α is considered a measure of scale reliability and a high score indicates good internal consistency reliability of the test.

time, the importance of follow-up recommendations will be emphasised. The SCP will then be printed, signed and dated by the participant and the nurse. The completed SCP TS will then be copied, with the original given to the participant, a copy placed in the participant's medical records and a copy sent to their GP. Motivational interviewing techniques will be employed for healthy lifestyle behaviours and to assess for readiness to make behavioural change. Participants will be encouraged to identify and explore behaviours they would like to modify using a chart that enables them to list likes and dislikes of specific behaviours and potential impacts of perceived behavioural change. By listening to concerns, highlighting conflicts arising from behaviour and documenting on the chart will potentially enable participants to assume control of decision-making related to behavioural change. Participants will be encouraged to set realistic time frames and identify habits and beliefs that may possibly be hindering change. Tailored evidenced-based information and advice in a resource pack will then be issued. It is anticipated that a consultation of 60 min will be required in a private clinic room.

A further two appointments will be made at 3 and 6 months after baseline, where the same four assessment instruments will be completed by the participant, and they will self-report any issues or unmet supportive care needs. These will be discussed and the appropriate resources, support and information provided. Participants will be encouraged to discuss their health concerns, goals and progress with any action they may have taken. Participants will be asked if they have seen their GP in the last 3 months and if they took the SCP TS and discussed any of the late-effect screening recommendations, their participant-identified concerns or goals. This will aid the transition to GP follow-up where the benefits of shared care will be explained. A checklist for each participant of the resources provided will be kept.

DATA ANALYSIS

Quantitative data will be analysed using univariate and multivariate statistical techniques with SPSS data analysis software. Descriptive statistics will be used to analyse the demographic variables collected. Responses to the SF-SUNS, DASS21, Mini-MAC and PES will be scored according to the algorithms in the instrument manuals. Measures from all instruments will be checked for normal variance within the two groups. Within each group, paired t test comparisons will be made between baseline measurements and at each time point: baseline, 3 months and 6 months. Differences between intervention and control groups will then be assessed at each time point. Test–retest reliability using ICC will be undertaken on the SF-SUNS instrument. The minimum ICC value required for this scale is 0.8. Participants who drop out or are lost to follow-up or need to be excluded after the start will be accounted for by intention-to-treat analyses. CIs will reflect the contrast between groups to show treatment effect. Missing data, incomplete answers and non-response will be recorded.

Qualitative interviews

Supplementary in-depth, semistructured interviews will occur with ~10 consenting participants when they have completed all intervention components (after 6 months). This number will allow for saturation of themes.[54–56] Telephone interviews will be digitally recorded and undertaken by an independent researcher to ensure participants are given the opportunity to freely express positive and negative perceptions of their experience. The use of a qualitative approach will provide depth of information regarding the personal impact of the nurse-led lymphoma survivorship clinic on the participant. The interviews will also highlight any issues or challenges for this group that could be better addressed in the future.

Interviews will be transcribed verbatim and thematic analysis used to determine themes and patterns within the text.[57–59] QSR NVivo qualitative analysis data management software will be used to manage interview data.

GP evaluations

A non-validated evaluation will be sent to GPs who have received the SCP TS. This was developed in consultation with a GP and will ascertain if GPs made use of the SCP TS and to elicit perceptions of the value and effectiveness of this document in facilitating communication between the treating hospital and GP, and GP and participant. This will guide future refinement of the SCP TS. Analysis will use descriptive statistics and distribution analysis techniques. Open-ended questions will use content analysis techniques. GPs will be called by the researcher after 2 weeks for non-return of the questionnaire to remind them to fill in and return the evaluation in the reply-paid envelope.

DISCUSSION

A significant culture change is required for providers to recognise survivorship care as a standard component of quality cancer care that involves all health professionals, participants and families. The gap in knowledge contributes to a current model of survivorship care that is fragmented, with inadequate service provision at treatment completion, leading to unmet needs along the survivorship continuum.[60] The cancer specialist is not necessarily required for routine screening and follow-up. However, the involvement of other health professionals, including primary care, necessitates the need for an awareness of the treatment delivered and the long-term and late-effect risks.[8]

This study will address the lack of robust empirical evidence in haematology survivorship care. A nurse-led model of care would assist patients transitioning from the end of treatment to the survivorship phase. Furthermore, the provision of an individualised SCP TS

is a means to empower individuals with knowledge about their disease and treatment and to assume responsibility for future surveillance and disease management. It will likewise take advantage of 'teachable moments' at the end of active treatment to support and promote patient participation in healthy lifestyle behaviours.[38] This is particularly vital for younger survivors, given the expectation of a longer survivorship period.[40]

The intervention has been timed to occur in the early survivorship phase. This has been supported by preliminary focus group work including lymphoma cancer survivors who indicated they often felt abandoned at treatment completion.[22] This timing also concords with McDowell *et al*,[29] who found assessments and interventions undertaken in the early survivorship phase (up to 2 years post diagnosis) led to fewer unmet needs moving into the extended survivorship phase (over 5 years).

The CALy trial will examine the impact and effectiveness of the nurse-led lymphoma survivorship clinic intervention through an assessment of the important clinical outcomes: unmet informational and practical needs; depression, anxiety and stress; coping; and self-empowerment as measured by the instruments chosen. It is therefore designed to improve the identification of unmet needs. Testing of such an intervention by an RCT has not been published in lymphoma survivorship studies to date. Consequently, it will make a significant contribution to the planning and delivery of survivorship care. Likewise, it represents a substantial and original contribution to knowledge and support for haematology survivorship care as few studies aim to improve the psychosocial and supportive care of this cohort. If the intervention achieves its intended outcomes, it may potentially lead to the development of nurse-led haematology survivorship clinics across the tertiary health sector in Western Australia that could ultimately be expanded to all cancer survivors.

Ethics

Ethics approval has been gained from the relevant hospital (2015-020) and university (015007F) Human Research Ethics Committees (HRECs). The trial is registered at the Australian and New Zealand Clinical Trials Registry (ACTRN 1261500530527) and the Western Australia Cancer Clinical Trials Registry. The trial is open to patient recruitment. It is not expected participants will be exposed to any undue risks or harm by participation. Participant information will remain confidential and deidentified where appropriate. Economic harm will be minimised by providing appointments when the participant is already attending the hospital. Exploring concerns may be distressing and if this occurs, participants will be referred to the appropriate counselling services as per usual clinical practice. Collected data will be securely stored at the university for 15 years after study completion and will only be accessible with written permission from the researcher and relevant university and hospital sites.

Dissemination

We plan to complete the study by December 2017 and report trial results in 2018. It is anticipated the main trial outcomes will be published in a single paper in a refereed cancer journal. Further publications will explore the qualitative data and the test–retest reliability measures of the SF-SUNS. We will correspondingly present findings at national and international conferences.

Author affiliations
[1]Western Australia Cancer and Palliative Care Network, Perth, Western Australia, Australia
[2]School of Nursing and Midwifery and Centre for Nursing and Midwifery Research, University of Notre Dame Australia, Fremantle, Western Australia, Australia
[3]Sir Charles Gairdner Hospital, Nedlands, Western Australia, Australia
[4]School of Medicine, University of Western Australia, Crawley, Western Australia, Australia
[5]Institute for Health Research, University of Notre Dame Australia, Fremantle, Western Australia, Australia
[6]St John of God Hospital, Murdoch, Western Australia, Australia
[7]School of Nursing, Edith Cowan University, Joondalup, Western Australia, Australia

Contributors KT contributed to the literature reviews and study design, was involved in all aspects of protocol and interventions and the overall preparation and writing of the manuscript. She is undertaking this research as part of her PhD. LM is the principal investigator of the study and the principal PhD supervisor of KT. LM obtained the grant funding to support the study and has led the development and contributed to all aspects of the study, including design; protocol and interventions; manuscript preparation and revision. DJ contributed the original concept for this study and has participated in all aspects of the design, protocol and intervention development, manuscript preparation and revision. MB has contributed to the study's research questions, methodology, data analysis plan, manuscript preparation and revision. CB has contributed to the study's qualitative component, methodology, manuscript preparation and revision. All authors have been involved in drafting and critical evaluation of this manuscript. All authors have read and approved the final version.

Funding This study is supported through the University of Notre Dame Australia (Fremantle) Australian Government's Collaborative Research Networks (CRN) program.

Competing interests None declared.

Ethics approval Sir Charles Gairdner Hospital HREC 2015-020 and University of Notre Dame Australia HREC 015007F.

Provenance and peer review Not commissioned; externally peer reviewed.

REFERENCES

1. American Cancer Society. *Cancer facts & figures 2014*. Atlanta, GA American Cancer Society, 2014.
2. SEER (Surveillance, Epidemiology and End Results). *Cancer statistics review, 1975–2011*. National Cancer Institute, 2014.
3. Quaresma M, Coleman MP, Rachet B. 40-year trends in an index of survival for all cancers combined and survival adjusted for age and sex for each cancer in England and Wales, 1971–2011: a population-based study. *Lancet* 2015;385:1206–18.
4. Australian Institute of Health and Welfare. *Cancer in Australia: an overview, 2014*. Cancer series no. 90. Cat. no. Can 88. Canberra: AIHW, 2014.

5. Sant M, Minicozzi P, Mounier M, *et al*. Survival for haematological malignancies in Europe between 1997 and 2008 by region and age: results of EUROCARE-5, a population-based study. *Lancet Oncol* 2014;15:931–42.
6. Swash B, Hulbert-Williams N, Bramwell R. Unmet psychosocial needs in haematological cancer: a systematic review. *Support Care Cancer* 2014;22:1131–41.
7. Carey M, Anderson A, Sanson-Fisher R, *et al*. How well are we meeting haematological cancer survivors' preferences for involvement in treatment decision making? *Patient Educ Couns* 2012;88:87–92.
8. Taylor K, Chan RJ, Monterosso L. Models of survivorship care provision in adult patients with haematological cancer: an integrative literature review. *Support Care Cancer* 2015;23:1447–58.
9. Panek-Hudson Y. Survivorship care—time for innovation? *Aust J Cancer Nurs* 2013;14:7–12.
10. Aleman BM, van den Belt-Dusebout AW, De Bruin ML, *et al*. Late cardiotoxicity after treatment for Hodgkin's lymphoma. *Blood* 2007;109:1878–86.
11. Ng AK, LaCasce A, Travis LB. Long-term complications of lymphoma and its treatment. *J Clin Oncol* 2011;29:1885–92.
12. Travis LB, Ng AK, Allan JM, *et al*. Second malignant neoplasms and cardiovascular disease following radiotherapy. *J Natl Cancer Inst* 2012;104:357–70.
13. van Leeuwen-Segarceanu EM, Bos WJ, Dorresteijn LD, *et al*. Screening Hodgkin's lymphoma survivors for radiotherapy induced cardiovascular disease. *Cancer Treat Rev* 2011;37:391–403.
14. Grinyer A. The late effects of mantle field radiotherapy: the information and support needs of women survivors of Hodgkin's disease. *Eur J Oncol Nurs* 2010;14:183–9.
15. Hemminki K, Lenner P, Sundquist J, *et al*. Risk of subsequent solid tumors after non-Hodgkin's lymphoma: effect of diagnostic age and time since diagnosis. *J Clin Oncol* 2008;26:1850–7.
16. Bishop MM, Lee SJ, Beaumont JL, *et al*. The preventive health behaviors of long-term survivors of cancer and hematopoietic stem cell transplantation compared with matched controls. *Biol Blood Marrow Transplant* 2010;16:207–14.
17. Choi M, Sun CL, Kurian S, *et al*. Incidence and predictors of delayed chronic kidney disease in long-term survivors of hematopoietic cell transplantation. *Cancer* 2008;113:1580–7.
18. Dicicco-Bloom B, Cunningham RS. The experience of information sharing among primary care clinicians with cancer survivors and their oncologists. *J Cancer Surviv* 2013;7:124–30.
19. McCabe MS, Jacobs LA. Clinical update: survivorship care—models and programs. *Semin Oncol Nurs* 2012;28:e1–8.
20. Phillips JL, Currow DC. Cancer as a chronic disease. *Collegian* 2010;17:47–50.
21. Lobb EA, Joske D, Butow P, *et al*. When the safety net of treatment has been removed: patients' unmet needs at the completion of treatment for haematological malignancies. *Patient Educ Couns* 2009;77:103–8.
22. Monterosso L, Taylor K, Joske D, *et al*. *Defining concerns, unmet needs and support preferences for haematology survivors: an exploratory study to inform intervention development*. Fremantle, Western Australia: University of Notre Dame Australia, 2015.
23. Gates P, Seymour JF, Krishnasamy M. Insights into the development of a nurse-led survivorship care intervention for long-term survivors of Hodgkin's lymphoma. *Aust J Cancer Nurs* 2012;13:4–10.
24. Howell D, Hack TF, Oliver TK, *et al*. Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence. *J Cancer Surviv* 2012;6:359–71.
25. John C, Armes J. Developing a nurse-led survivorship service for patients with lymphoma. *Eur J Oncol Nurs* 2013;17:521–7.
26. Cooper JM, Loeb SJ, Smith CA. The primary care nurse practitioner and cancer survivorship care. *J Am Acad Nurse Pract* 2010;22:394–402.
27. Fitch M. Supportive care framework. *Can Oncol Nurs J* 2008;18:6–14.
28. Ganz PA, Casillas J, Hahn EE. Ensuring quality care for cancer survivors: implementing the survivorship care plan. *Semin Oncol Nurs* 2008;24:208–17.
29. McDowell ME, Occhipinti S, Ferguson M, *et al*. Predictors of change in unmet supportive care needs in cancer. *Psychooncology* 2010;19:508–16.
30. Stricker CT, Jacobs LA, Risendal B, *et al*. Survivorship care planning after the Institute of Medicine recommendations: how are we faring? *J Cancer Surviv* 2011;5:358–70.
31. Bodenheimer T, Lorig K, Holman H, *et al*. Patient self-management of chronic disease in primary care. *JAMA* 2002;288:2469–75.
32. Kuijpers W, Groen WG, Aaronson NK. A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: relevance for cancer survivors. *J Med Internet Res* 2013;15:e37.
33. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. *Psychol Rev* 1977;84:191–215.
34. Palmer SC, Jacobs LA, Demichele A, *et al*. Metrics to evaluate treatment summaries and survivorship care plans: a scorecard. *Support Care Cancer* 2014;22:1475–83.
35. McCabe MS, Bhatia S, Oeffinger KC, *et al*. American Society of Clinical Oncology statement: achieving high-quality cancer survivorship care. *J Clin Oncol* 2013;31:631–40.
36. MacMillan Cancer Support and NHS Improvement. *The National cancer survivorship initiative vision*. London, UK: Department of Health, 2010.
37. COSA. 2014. http://www.cosa.org.au/media/224898/cancer-survivorship-critical-components-model-for-wellness-draft-20150227.pdf
38. Taylor K, Monterosso L. Survivorship care plans and treatment summaries in adult patients with hematologic cancer: an integrative literature review. *Oncol Nurs Forum* 2015;42:283–91.
39. Hausman J, Ganz PA, Sellers TP, *et al*. Journey forward: the new face of cancer survivorship care. *J Oncol Pract* 2011;7(Suppl 3): e50s–6s.
40. Jabson JM, Bowen DJ. Cancer treatment summaries and follow-up care instructions: which cancer survivors receive them? *Cancer Causes Control* 2013;24:861–71.
41. Jackson JM, Scheid K, Rolnick SJ. Development of the cancer survivorship care plan: what's next? Life after cancer treatment. *Clin J Oncol Nurs* 2013;17:280–4.
42. Campbell NC, Murray E, Darbyshire J, *et al*. Designing and evaluating complex interventions to improve health care. *BMJ* 2007;334:455–9.
43. Medical Research Council. A framework for development and evaluation of RCTs for complex interventions to improve health 2000.
44. Taylor K, Monterosso L. Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors. *Aust J Cancer Nurs* 2016;17:6–13.
45. Moher D, Hopewell S, Schulz KF, *et al*. CONSORT 2010 Explanation and Elaboration: updated guidelines for reporting parallel group randomised trial. *BMJ* 2010;340:c869.
46. Schulz KF, Altman DG, Moher D. CONSORT 2010 Statement: updated guidelines for reporting parallel group randomised trials. *BMJ* 2010;340:c332.
47. Polit D, Beck C. The content validity index: are you sure you know what's being reported? Critique and recommendations. *Res Nurs Health* 2006;29:489–97.
48. Walter SD, Eliasziw M, Donner A. Sample size and optimal designs for reliability studies. *Stat Med* 1998;17:101–10.
49. Campbell HS, Hall AE, Sanson-Fisher RW, *et al*. Development and validation of the Short-Form Survivor Unmet Needs Survey (SF-SUNS). *Support Care Cancer* 2014;22:1071–9.
50. Lovibond SH, Lovibond PF. *Manual for the depression anxiety stress scales*, 2nd edn. Sydney: Psychology Foundation University of New South Wales, 1995.
51. Antony MM, Bieling PJ, Cox BJ, *et al*. Psychometric properties of the 42-item and 21-item versions of the depression anxiety stress scales in clinical groups and a community sample. *Psychol Assess* 1998;10:176–81.
52. Boyes AW, Girgis A, D'Este C, *et al*. Flourishing or floundering? Prevalence and correlates of anxiety and depression among a population-based sample of adult cancer survivors 6months after diagnosis. *J Affect Disord* 2011;135:184–92.
53. Bulsara C, Styles I. Development of a cancer related patient empowerment scale using the Polytomous Rasch measurment model. *Cancer Clin Oncol* 2013;2:1–16.
54. Crouch M, McKenzie H. The logic of small samples in interview-based qualitative research. *Soc Sci Inf* 2006;45:483–99.
55. Onwuegbuzie A, Leech N. A call for qualitative power analyses. *Qual Quant* 2007;41:105–21.
56. Sandelowski M. Sample size in qualitative research. *Res Nurs Health* 1995;18:179–83.
57. Grbich C. *Qualitative research in health: an introduction*. CA: Sage Publications, 1998.
58. Patton MQ. *Qualitative research and evaluation methods: integrating theory and practice*. SAGE Publications, 2014.
59. Smith JA. *Qualitative psychology: a practical guide to research methods*. SAGE Publications, 2007.
60. de Leeuw J, Larsson M. Nurse-led follow-up care for cancer patients: what is known and what is needed. *Support Care Cancer* 2013;21:2643–9.

BMJ Open

Protocol for Care After Lymphoma (CALy) trial: a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care

Karen Taylor, David Joske, Max Bulsara, Caroline Bulsara and Leanne Monterosso

BMJ Open 2016 6:
doi: 10.1136/bmjopen-2015-010817

A.5 Qualitative Results from a Phase II Pilot Randomised Controlled Trial of a Lymphoma Nurse-led Model of Survivorship Care

Permission was granted by the publisher Elsevier and the European Journal of Oncology Nursing to include this article as published in this thesis for non-commercial purposes. doi:10.1016/j.ejon.2018.01.011.

European Journal of Oncology Nursing 35 (2018) 9–14

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care

Karen Taylor[a,b,*], Leanne Monterosso[a,c,d], Caroline Bulsara[a]

[a] School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, Western Australia, Australia
[b] Western Australia Cancer and Palliative Care Network, Perth, Australia
[c] Centre for Nursing and Midwifery Research, St John of God Murdoch Hospital, Western Australia, Australia
[d] School of Nursing, Edith Cowan University Joondalup, Western Australia, Australia

ARTICLE INFO

Keywords:
Lymphoma cancer
Survivorship
Qualitative interviews
Nurse-led clinic intervention
Survivorship care plans and treatment summaries

ABSTRACT

Purpose: To explore and describe lymphoma survivors' thoughts and perceptions of the components of a nurse-led lymphoma survivorship clinic intervention.
Methods: An exploratory, qualitative descriptive study using interviews from 10 participants who had transitioned post-treatment into the survivorship phase via a nurse-led lymphoma survivorship clinic intervention.
Results: Thematic analysis revealed three major themes: Reassurance and individualised care; Information and support; and Empowerment. Participants described the reassurance they gained from having contact with a health professional post-treatment who individualised information and support. A survivorship care plan and treatment summary was developed for this study and was believed to be very patient-centred and helpful. This enabled participants to take back control of their health and well-being and to rebuild confidence.
Conclusions: In this study, participants expressed a need for patient-centred follow-up care that addressed their concerns and supported them in the survivorship phase to get their life back on track. Nurse-led follow-up may offer a viable model of post-treatment survivorship care to lymphoma cancer survivors.

1. Introduction

Lymphomas are haematological cancers that originate from the lymphatic system, and are mainly categorised as either Hodgkin (HL) or non-Hodgkin lymphoma (NHL) (American Cancer Society, 2014). Worldwide, lymphomas represent the sixth most commonly diagnosed cancer (Surveillance Epidemiology and End Results (SEER), 2014). Australian incidence is increasing with an estimated 6323 cases expected in 2017, which will equate to 4.6% of all cancer cases (Cancer Australia, 2017a). However, developments in treatment and supportive care options such as chemotherapy, haematopoietic stem cell transplantation, radiotherapy and targeted therapies have improved five year survival to 76% (Cancer Australia, 2017b). With increased remission and survival rates, many survivors experience issues and concerns, called unmet needs, which can impact quality of life and well-being (Carey et al., 2012; Sant et al., 2014). These can relate to issues such as: fatigue; poor nutrition; exercise capacity; cognition impairment; fear of recurrence; fertility, relationships; finances; employment; and insurance (Taylor et al., 2015; van der Poel et al., 2014). Health can be further compromised by late effects of treatment such as cardiovascular disease and second cancers (Grinyer, 2010; Ng et al., 2011; Travis et al., 2012), often experienced earlier than the general population (Panek-Hudson, 2013).

Haematological survivorship studies mainly report on mixed haematological samples regardless of variations in clinical features, treatment, curability and relative survival (Hall et al., 2013; Lobb et al., 2009; McGrath, 2014). A study of lymphoma (n = 236) and myeloma (n = 178) survivors on anxiety, depression and unmet needs in the early survivorship period (under two years) reported decreasing anxiety and depression rates in the myeloma cohort and increasing rates in the lymphoma cohort (Oberoi et al., 2017). The authors indicated a need for cohort specific studies, especially in the early survivorship period (Oberoi et al., 2017) to ensure targeted support. Lymphoma only studies often reflect a survivorship period beyond 2 yrs at assessment (Ferrer et al., 2011; Friedman et al., 2010; Oerlemans et al., 2014), which may not reflect the unique needs of those who have recently completed treatment, limiting generalisability. A recent study by the authors (Monterosso et al., 2017) reported on focus groups with lymphoma survivors (n = 17), the majority (n = 13, 76%) who were 12–30 months post-treatment completion. Participants recounted unmet needs related to information, coping strategies and support, especially when transitioning into survivorship. Findings suggested cancer nurse

* Corresponding author. Western Australia Cancer and Palliative Care Network, 189 Royal St, East Perth, Western Australia 6004, Australia.
E-mail address: Karen.Taylor@health.wa.gov.au (K. Taylor).

https://doi.org/10.1016/j.ejon.2018.01.011
Received 24 July 2017; Received in revised form 28 January 2018; Accepted 29 January 2018

coordinators could be a feasible approach to delivering structured, individualised support early post-treatment (Monterosso et al., 2017).

Nurse-led models of survivorship care have been proposed to transition patients post-treatment and have demonstrated acceptable outcomes in haematology cohorts (Gates et al., 2015; Howell et al., 2012; John and Armes, 2013). As a minimum, nurse-led models should include: administration of survivor-specific needs assessments to identify patient concerns (McDowell et al., 2010; Stricker et al., 2011); development and delivery of a survivorship care plan and treatment summary (SCPTS), to guide holistic follow-up (Clinical Oncology Society of Australia, 2016; MacMillan Cancer Support & NHS Improvement, 2010; McCabe et al., 2013); and support to assist survivors to take ownership of their health and well-being (Bodenheimer et al., 2002; Kuijpers et al., 2013). To date, studies that have tested nurse-led models of care have focused on survivors of common cancers (breast, prostate, colon) (Jefford et al., 2016; Maly et al., 2017; Taylor et al., 2015), been based in acute care settings, used long consultations, and involved more frequent patient contact (Cooper et al., 2010; De Leeuw and Larsson, 2013), which may preclude generalisability to other cancers or limit economic viability.

In order to provide lymphoma survivors with specific and responsive supportive care, the unique issues and unmet concerns of this cohort need to be assessed in the early survivorship period (under one year). The aim of this sub-study was to provide qualitative semi-structured interview data from a sample of participants who had been randomised to the intervention group of the Care After Lymphoma (CALy) phase II randomised controlled trial study (RCT) (Taylor et al., 2016). The RCT aimed to develop and test a nurse-led lymphoma survivorship clinic (NLSC) intervention to assist participants transitioning from treatment completion into the early survivorship phase. This study will add to the limited literature that exists in lymphoma specific early survivorship.

2. Methods

2.1. Methodological framework

A qualitative descriptive methodology was utilised to provide a comprehensive summary of a specific experience by the participants (Neergaard et al., 2009; Sandelowski, 2000), using a semi-structured interview design. The interview schedule consisted of the same open-ended questions and was developed by the researchers. To ensure participants felt able to express themselves and their perceptions freely, interviews were conducted by an experienced independent researcher.

2.2. Sample and setting

A purposive sample of lymphoma patients from a large tertiary hospital cancer centre in Perth, Western Australia were recruited from the intervention group of the RCT. A non-probability purposive sampling provides rich information from participants who have the greatest amount of in-depth knowledge and experience of a particular circumstance or event (Patton, 2014). Only participants who had completed all aspects of the NLSC intervention were approached by the survivorship cancer nurse conducting the clinic intervention. These participants had completed four measures: *Short Form Survivor Unmet Needs Survey (SF-SUNS); Depression Anxiety Stress Scale (DASS21); Mini Mental Adjustment to Cancer Scale (Mini-MAC);* and *Patient Empowerment Scale* at three time points; baseline (prior to randomisation), 3 months and 6 months. At the first NLSC appointment (approximately one week after baseline), participants completed and received an individualised lymphoma SCPTS, developed for this study (Taylor et al., 2016). Participants' GP were sent a copy. A motivational interview technique was used to provide evidenced-based information, advice and support at the first intervention appointment and reinforced with additional resources and support as required over the next two appointments.

All participants approached agreed to be interviewed. Each participant was nine months' post-treatment completion and the sample reflected an equal gender distribution and range of ages. Data saturation was achieved after ten interviews.

2.3. Interviews

The study was approved by the relevant hospital and university human research ethics committees. Informed written consent was obtained by all participants prior to interview scheduling. Interviews were conducted from February 2016 to May 2017 and occurred after the last NLSC appointment. Telephone interviews were conducted at a time convenient for the participant and were digitally recorded. The following are examples of the interview questions: 'Did you have any concerns or needs not addressed by any of the questions?'; 'What aspects of the clinic would you want to stay the same for future patients?'; 'Would you recommend the clinic to other patients finishing treatment?'; 'How do you feel about having the health concerns, goals and actions individualised to yourself?'; and 'Overall how useful was the SCPTS to you? Interviews were transcribed verbatim, de-identified and an identifier code applied. Digital recordings and transcribed interviews were saved in a password-protected file on a secure server. After the first three interviews, the question order was slightly altered to enhance the flow of the interview.

2.4. Data analysis

Interview transcripts were imported into NVivo 11 to facilitate management of data and completion of the analysis. Thematic analysis was used to establish patterns and themes within the text (Grbich, 1998; Patton, 2014; Smith, 2007). Thematic analysis allows for participant diversity of ideas and perceptions (Smith, 2007), thus providing a depth of information regarding the personal impact of the NLSC on the participant. Subthemes were developed from the data, and allowed for a logical organisation of the themes that emerged. The criteria of credibility, auditability and fittingness were applied to the data analysis process to ensure rigor (Beck, 1993). Credibility was maintained by triangulation with another member of the research team (Beck, 1993) to ensure independent reading and analysis of the transcripts by KT and CB who allocated codes and themes to the generated data (Braun and Clarke, 2006). The researchers met to discuss the codes and any discrepancies before consensus on emerging themes was reached. The ample use of extracts or quotes from the data demonstrated fittingness to the agreed codes. A comprehensible audit trail maintained auditability, demonstrated by documentation of research planning through to analysis, and through a reflective discourse and debrief process with colleagues.

3. Results

3.1. Participants

Ten semi-structured interviews were conducted with all participants willing to share an opinion for each of the interview guideline areas. Demographic and disease information is shown in Table 1. There were equal numbers of males and females, with similar age range (24–74 years) and lymphoma type. The majority of participants resided within the metropolitan area (n = 8, 80%), were working (n = 6, 60%), were married or defacto (n = 6, 60%) and had a university degree or trade qualification (n = 8, 80%).

Time elapsed from end of study to interview ranged from 1 to 26 days (mean 6.5 days, SD 7.8 days). The majority of interviews (n = 8) were done within 5 days. No time limit was set and interviews ranged from 17 min through to 48 min (mean 30.5 min).

Table 1
Demographic characteristics for interview participants (n = 10).

Characteristics	Males n = 5 (50%)	Females n = 5 (50%)
Age group at baseline		
24-25	2	2
48	1	1
65-74	2	2
Lymphoma diagnosis		
Non-Hodgkin	2	2
Hodgkin	3	3
Highest level of education		
Secondary school or less	1	1
Trade/vocational college	2	2
University	2	2
Employment status		
Working	4	2
Retired	1	2
No return to work date	–	1
Marital status		
Single	1	2
Married/defacto	4	2
Divorced	–	1
Residence		
Metropolitan	4	4
Regional	1	1

3.2. Themes

Three major themes emerged from analysis and coding of data: Reassurance and individualised care; Information and support; and Empowerment. Subthemes have been included to add clarity.

3.3. Reassurance and individualised care

Overall, the NLSC was well received and deemed a positive experience for participants, although it would have been reassuring to know about the clinic intervention during treatment. The needs assessment questionnaires and the SCPTS were perceived to facilitate individualised care.

3.3.1. Timing of support

Most participants indicated they would have liked knowledge of the clinic intervention during treatment so they could feel reassured that someone was still interested in supporting them and they were 'not going to be abandoned'. This would take the form of a contact person they could trust.

> *"Just knowing that I was still going to get some support" F_25yo_HL*

> *"But to know that look, don't worry, after treatment you are going to see a nurse, that would have been very calming for me" F_64yo_HL*

3.3.2. The use of questionnaires to elicit unmet needs and concerns

Questionnaires were used to elicit unmet needs and areas of concern that could be discussed with participants at the NLSC appointment. Participant responses served as a focus for the follow up appointment. Feedback about the questionnaires indicated some questions were hard to answer.

> *"Sometimes I found that I couldn't say yes or no to the questions, because they didn't apply I suppose, and I had to answer" F_64yo_HL*

Nonetheless, the questionnaires were able to cover aspects thought to be important to participants' overall wellbeing, as one said,

> *"They covered a multitude of the different things like your emotional well-being, mental well-being and physical well-being, all the things that you know you can struggle with" F_24yo_HL*

3.3.3. The supportiveness of the intervention

All participants wanted the intervention structure to remain the same, describing the one-to-one, personalised nature of the intervention a valuable opportunity to talk to someone who was not family, friends or a doctor. They described being listened to and 'feeling safe' to ask questions on a range of topics, especially questions they felt they could not ask their haematologist. Participants indicated support was individualised and felt reassured they could get their life back on track.

> *"The one-on-one was really helpful because then you felt like you could pretty much ask anything, or talk about anything, and you didn't feel like there would be other people around to listen to your private conversations. A safe space, ask questions and get reassurance and the right answers. That was good" F_24yo_HL*

> *"Someone that you can speak to and address the problems that you don't get the time with the doctors to talk about" F_64yo_HL*

Another participant also commented on how he could discuss other aspects of the cancer experience. He said,

> *"What I particularly liked was the opportunity to have a conversation around things other than treatment. Dealing with some of the fears that you may have that you didn't feel like you could ask your specialist about. Or where do I go for complementary therapies. The kind of questions that specialists I don't think are necessarily geared for. Or don't have time really to cover. The ability to have a chat to a nurse that can help you through the next part of the journey" M_48yo_NHL*

A couple of participants indicated that the intervention should have been conducted according to patient preferences. This included a preference for the NLSC to be away from the hospital and closer to their home.

> *"We should be providing services close to home where possible and I think there are some really great opportunities for the survivorship study to get out into the community even though they are still run by the hospital" M_48yo_NHL*

Although two participants found returning to the hospital traumatic, they felt the NLSC experience helped them to overcome their aversion as it was felt to be a safe place they could communicate their fears and receive reassurance.

> *"The torture as a result of the treatment – going back to the hospital made me feel all that. It actually helped me deal with the fact that I can go to the hospital and not feel sick – so there was a positive to" M_48yo_NHL*

3.3.4. Nurse contact and rapport

It was also felt contact should have been more frequent with telephone support between face to face visits, to provide extra support and to 'check-in' with the participant.

> *"I think you need to make them a bit closer together – a bit more frequent. And also make it where patients can choose. Make it more patient-driven - where the patient tells you how often they want to see or talk to someone" F_48yo_NHL*

There was also an indication that many wanted the contact to go beyond the study timeframe. As one participant said,

> *"I don't feel like I am on my own steam yet. I am thinking 2 years before I have got my confidence and hopefully my health back" F_64yo_HL*

All participants described the relationship with the nurse who ran the intervention as comfortable and flexible, and felt they could call or speak to her with any issues if they wanted to. Participants provided comment and perceptions of the nurse as follows:

> *"And she did explain things so that I understood them more. She was really good at making you feel relaxed" F_48yo_NHL*

"You felt like you had enough time to talk about and ask questions you didn't feel rushed and I think that was really good" F_24yo_HL

3.3.5. Survivorship care plan and treatment summary

The written patient-centred SCPTS was described as reassuring when it guided follow-up and for keeping on track with healthy lifestyle behaviours.

"Yes, it was good because it is reassuring, it is a guideline of what to do which I needed and knowing what to look out for and should be doing" F_64yo_HL

Feedback from participants regarding the SCPTS being sent to the GP indicated only two GPs discussed the SCPTS with them. Other participants indicated they either had not seen the GP or the GP acknowledged receipt but did not discuss.

3.4. Information and support

Participants appreciated the opportunity to discuss, record and receive written individualised information, support and resources. Although some information such as late effects was confronting at the time, it was nevertheless appreciated. All felt the information received at the NLSC was relevant and appropriate because it was tailored to their unique needs. Most felt they had not received this information or support from the treating team, however, it was acknowledged that possibly verbal information had been given but not retained.

3.4.1. Individualisation of the SCPTS

Participants liked the individualisation of the health concerns, goals and actions, and the accompanying written information and/or contacts.

"When I did have a concern, I was given printed notes about those issues and I think that is really good. Because I do have trouble with my memory now, and I can go back over those notes and sometimes it is like reading it anew, you know" F_64yo_HL

The treatment summary was well-received with most participants describing it as 'good to have', especially as a tool for communication with other health professionals.

"I think it was useful to sit down and have that initial meeting. I think it was really good that it was sent to my GP" F_25yo_HL

However, one participant was unsure of the value to himself,

"But I think this kind of treatment summary is the sort of thing I would give to my GP, or if I am seeing a new Dr, or if I was travelling and I got sick. I almost feel like it's less useful for me, but more useful for other people" M_24yo_HL

One participant felt the terminology related to the disease location could have been put in simpler language and this helpful recommendation was utilised for subsequent treatment summaries.

"Sometimes you don't always understand the medical terms so I think putting it into more simpler language would be a bit more helpful" F_48yo_NHL

3.4.2. Late effect information

The potential late effect information given on the SCPTS was individualised to each participant. It came as a shock to many that heart disease and other cancers, for example, were possible consequences of the treatment received.

"Well that was a bit of a shock to me, because they hadn't been mentioned prior to the treatment. … but at the same time, it was probably easier on me not knowing anyway" F_64yo_HL

Participants appreciated having the information and felt it could help with GP consultations, specifically around planning of health management into the future.

"That gave me something to go to my GP with and go okay I think I need to monitor this and this. And it helped me set out a care plan with my Dr as well" F_48yo_NHL

"It is always a bit overwhelming, but I think it is a good way to highlight the possible things that could happen. I think it reduces you're stress because you are not just in the dark about it. I think it is really important for yourself and the GP. If anything does change you know at least you are going to get it early" F_24yo_HL.

One participant indicated they had heard the potential late effect information at diagnosis and another described being told there were some possible late effects after she had completed treatment,

"Oh, he just briefly spoke about 'you just need to be careful, you need to look after your skin, you need to do annual breast checks, you need to look after your heart. You know there is a possible risk you could get these problems in the future'. That is sort of how he mentioned it" F_24yo_HL

Neither participant had received written information and did not feel they knew how to follow-up these risk factors. This was an important consideration when developing the SCPTS to ensure follow-up suggestions for the GP and participant were given.

"[GP] just asked me to come in and discussed it with me and then he kind of just saved it and then he linked me in with support services to make sure I was monitoring all of my side-effects, so I think he thought it was good" F_25yo_HL

3.5. Empowerment

Most participants perceived the intent of the NLSC was to assist with transitioning away from a reliance on the treating team, to taking responsibility for monitoring and seeking support.

3.5.1. Nurturing empowerment

All participants described the SCPTS as useful and perceived it as a means to remind them to 'stay on track' with healthy lifestyle behaviours or for encouragement with achieving their goals.

"It just kind of helped remind me of my goals, and every time I had the meeting with [KT], it was like a kind of thing to remember my goals and I thought was a really beneficial thing" M_24yo_HL

Although one participant described the initial discussion and plan as helpful, she felt she should not have had to seek out services and arrange appointments.

"Maybe actually getting linked into the services they talk about. Rather than just getting the information and being left with it, it was kind of like I had to go and seek it out myself. I think it would have been really helpful to have someone contact me" F_25yo_HL

It appeared she did not want to take responsibility for her follow-up care. The remaining participants described understanding and appreciating the need to take back control of their health and well-being. They described the opportunity to discuss and write down their own health concerns, health goals and the actions they planned to take with a health professional as confidence building and assisted in increasing their positivity post-treatment completion.

"There are definitely days where you go thru and you start to question yourself, but being able to talk to someone about it made me feel more confident about being finished" M_25yo_HL

"I started thinking a bit more positive" M_71yo_HL

Participants noted that having the opportunity to record and discuss participant-specific issues had personalised both the appointment and the SCPTS.

> *"It identified what you personally were worried about and it wasn't just a general thing that everyone can be worried about, but it was specific to you. And then having the specific needs addressed with a certain plan or the actions column that you could put in place. I think that was really helpful because you see how you could be proactive about things" F_24yo_HL*

3.5.2. Monitoring progress

Participants felt the follow-up over the next six months in the NLSC allowed them to monitor their progress and see how they were going.

> *"That was good. It was something to monitor my progress and it feels more personal" M_25yo_HL*

> *"It sort of crystallises your thinking for the future. If you don't do something like that you tend to drift along day to day" F_74yo_NHL*

Receiving written and contact information for support allowed participants to engage and take ownership for how and when they dealt with their goals and concerns. Even when issues remained unmet, having the issue normalised was equally important.

> *"Well the fatigue and the memory [problems] I have still got. It was useful to find that other people suffer the same things, that I am not alone on that!" F_64yo_HL*

3.5.3. Usefulness of general health information

Participants received general health and screening information and felt it was helpful. Most read it again at home, then put it aside. They felt the value was in having it to refer to if needed.

> *"I think that it is really good to get the information and just have it there. I thought that was very handy" F_24yo_HL*

This document was not sent to the GP, as GPs involved in evaluating the SCPTS for content clarity, internal consistency and content validity, indicated they knew this information and did not want it. It was noteworthy that two participants had given it to the GP and it had guided follow-up care.

> *"I basically took all the information into my GP and let him read thru it and he used it to help guide my care plan in the right direction" F_48yo_NHL*

4. Discussion

This study contributes to the growing body of cancer-specific survivorship literature. The current model of specialist follow-up care for cancer survivors is inadequate, with many survivors experiencing unmet needs that can remain poorly addressed throughout the survivorship continuum (De Leeuw and Larsson, 2013). It is essential survivorship care incorporates an awareness of treatment and disease, long-term and late effect risks, as well as healthy lifestyle behaviours (Taylor et al., 2015), and facilitates communication amongst all health professionals and the patient and family. Expertise in the provision of health promotion, support and information has always been the purview of cancer nurses (Jackson et al., 2013), therefore nurse-led models should be considered within any proposed model of survivorship care.

This study involved a cohort of lymphoma participants and specifically targeted those in the early survivorship phase (first nine months' post-treatment). Studies that involve a single subtype of haematological cancer are important in ascertaining the psychosocial and supportive care interventions that are specific and most appropriate (Oberoi et al., 2017). Assessing and providing an intervention in the early survivorship period has been shown to lead to a reduction in the unmet needs as survivors continue beyond five years (McDowell et al., 2010).

Participants described having time within the NLSC appointment to ask questions and seek individualised support as fundamentally helpful. An important point of difference with medical follow-up where participants perceived the specialist as too busy, or perhaps not interested when they were seeking reassurance and support. Interestingly, some participants would have preferred a follow-up appointment away from the hospital, an important consideration with future planning of nurse-led clinics. Participants had not previously met the nurse who provided the intervention, she is however, a cancer nurse coordinator with extensive haematology/oncology nursing and counselling experience and qualifications. A health professional who can quickly build a strong and positive rapport allows participants a greater opportunity to explore their own unmet needs (Ross, 2013). This may be why participants responded favourably to the intervention and is important when considering nurse-led models of survivorship care.

Empowering participants with an individualised SCPTS that provided disease and treatment knowledge, and allowed them to assume responsibility for their future health and well-being (Taylor and Monterosso, 2015), was described as helpful from all participants. The expectation of younger survivors living longer with potential issues is important (Jabson and Bowen, 2013), nevertheless all participants in this study, regardless of age, appreciated the follow-up guidance they could discuss and implement with their GP. Information on general health and screening allowed participants a sense of independence of when and how they would seek follow-up. Of particular importance to participants was the opportunity to personalise the SCPTS and concentrate on what was important to them as they moved forward after treatment had completed. Conversely, our study revealed a small subset of participants who were not ready to take back control of their future health and well-being. It is important to acknowledge those patients, and provide individualised support that meets their needs at the time, without building further dependency in the survivorship phase.

Survivorship literature highlights the concept of 'teachable moments' (Alfano et al., 2012; Grant and Economou, 2008; Hewitt et al., 2005; Panek-Hudson, 2013) at the end of active treatment to support and promote patient participation in healthy lifestyle behaviours. It was thought that participants in this study would need to be encouraged to engage in healthy lifestyle behaviours. However, it was evident that participants did feel a need to improve their health, and for some, change their lifestyle to adopt healthier lifestyle behaviours they had not been able to do during the stress of treatment. These participants particularly described the opportunity to revisit the SCPTS over the preceding months allowed them to monitor and reflect on their achievements and help them to keep focused on their goals.

4.1. Limitations

This study reflects the views of a subset of lymphoma participants who underwent a nurse-led clinic survivorship intervention and therefore could not be generalisable to the wider survivorship population who have experienced a nurse-led clinic. Nonetheless, the use of qualitative interview research allowed an opportunity to gain a deeper understanding of the experiences of this select group. The findings are presented to help build research that is based on patient experience and feedback. The small number of participants is not a methodological limitation in qualitative research when data saturation is reached.

5. Conclusion

The interviews were conducted to ascertain the participant's perception of the efficacy and value of the components of the nurse-led intervention and to highlight any issues or challenges for this cohort that could be better addressed in the future. Survivorship care offered by nurses may address the patient-perceived unmet needs at the

conclusion of active treatment. Participants indicated the need for security in knowing there would be support when treatment completed, and would likewise value the opportunity to have their concerns heard. An individualised SCPTS that empowers survivors to address healthy lifestyle issues, and provide a follow-up guide for late effects of the disease and treatment assists in refocusing responsibility back to the patient. Nurse-led survivorship care may offer an acceptable model to deliver patient-centred post-treatment follow-up. This model allows the time required to individualise and tailor supportive survivorship care.

Conflicts of interest

There are no competing interests. No conflict of interest has been declared by the authors in relation to this study.

Funding

This research is supported though an Australian Government Research Training Program Scholarship and the University of Notre Dame Australia (Fremantle), Australian Government's Collaborative Research Networks (CRN) program.

Acknowledgements

Melissa Berg for conducting the interviews and study participants for the generous gift of their time and opinions.

References

Alfano, C.M., Ganz, P.A., Rowland, J.H., Hahn, E.E., 2012. Cancer survivorship and cancer rehabilitation: revitalizing the link. J. Clin. Oncol. 30, 904–906.
American Cancer Society, 2014. Cancer Facts and Figures. American Cancer Society, Atlanta, GA.
Beck, C.T., 1993. Qualitative Research: the evaluation of its credibility, fittingness, and auditability. West. J. Nurs. Res. 15, 263–266.
Bodenheimer, T., Lorig, K., Holman, H., Grumbach, K., 2002. Patient Self-management of chronic disease in primary care. J. Am. Med. Assoc. 288, 2469–2475.
Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qual. Res. Psychol. 3, 77–101.
Cancer Australia, 2017a. Lymphoma in Australia. Australian Government. https://lymphoma.canceraustralia.gov.au/statistics, Accessed date: 20 June 2017.
Cancer Australia, 2017b. Non-hodgkin Lymphoma in Australia. Australian Government. https://canceraustralia.gov.au/affected-cancer/cancer-types/lymphoma/hodgkin-lymphoma-statistics, Accessed date: 20 June 2017.
Carey, M., Anderson, A., Sanson-Fisher, R., Lynagh, M., Paul, C., Tzelepis, F., 2012. How well are we meeting haematological cancer survivors' preferences for involvement in treatment decision making? Patient Educ. Counsel. 88, 87–92.
Clinical Oncology Society of Australia, 2016. Model of Survivorship Care: Critical Componenets of Cancer Survivorship Care in Australia Position Statement. Model of Survivorship Care Working Group.
Cooper, J.M., Loeb, S.J., Smith, C.A., 2010. The primary care nurse practitioner and cancer survivorship care. J. Am. Acad. Nurse Pract. 22, 394–402.
De Leeuw, J., Larsson, M., 2013. Nurse-led follow-up care for cancer patients: what is known and what is needed. Support. Care Cancer 21, 2643–2649.
Ferrer, R.A., Huedo-Medina, T.B., Johnson, B.T., Ryan, S., Pescatello, L.S., 2011. Exercise interventions for cancer survivors: a meta-analysis of quality of life outcomes. Ann. Behav. Med. 41, 32–47.
Friedman, D.R., Coan, A.D., Smith, S.K., Herndon II, J.E., Abernethy, A.P., 2010. Informational needs assessment of non-Hodgkin lymphoma survivors and their physicians. Am. J. Hematol. 85, 528–532.
Gates, P., Seymour, J.F., Krishnasamy, M., 2015. A nurse-led survivorship intervention for survivors of Hodgkin lymphoma: a pilot study. Aust. J. Cancer Nurs. 16, 19–26.
Grant, M., Economou, D., 2008. The evolving paradigm of adult cancer survivor care. Oncology 22, 13–22 27.
Grbich, C., 1998. Qualitative Research in Health: an Introduction. Sage Publications, CA.
Grinyer, A., 2010. The late effects of mantle field radiotherapy: the information and support needs of women survivors of Hodgkin's disease. Eur. J. Oncol. Nurs. 14, 183–189.
Hall, A., Campbell, H.S., Sanson-Fisher, R., Lynagh, M., D'Este, C., Burkhalter, R., Carey, M., 2013. Unmet needs of Australian and Canadian haematological cancer survivors: a cross-sectional international comparative study. Psycho Oncol. 22, 2032–2038.
Hewitt, M.E., Greenfield, S., Stovall, E., 2005. From Cancer Patient to Cancer Survivor: Lost in Transition. The National Academies Press, Washington DC.
Howell, D., Hack, T., Oliver, T., Chulak, T., Mayo, S., Aubin, M., Chasen, M., Earle, C., Friedman, A., Green, E., Jones, G., Jones, J., Parkinson, M., Payeur, N., Sabiston, C., Sinclair, S., 2012. Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence. J. Cancer Sci. 6, 359–371.
Jabson, J., Bowen, D., 2013. Cancer treatment summaries and follow-up care instructions: which cancer survivors receive them? Cancer Causes Contr. 24, 861–871.
Jackson, J.M., Scheid, K., Rolnick, S.J., 2013. Development of the cancer survivorship care plan: what's next? Life after cancer treatment. Clin. J. Oncol. Nurs. 17, 280–284.
Jefford, M., Gough, K., Drosdowsky, A., Russell, L., Aranda, S., Butow, P., Phipps-Nelson, J., Young, J., Krishnasamy, M., Ugalde, A., King, D., Strickland, A., Franco, M., Blum, R., Johnson, C., Ganju, V., Shapiro, J., Chong, G., Charlton, J., Haydon, A., Schofield, P., 2016. A randomized controlled trial of a nurse-led supportive care package (SurvivorCare) for survivors of colorectal cancer. Oncologist 21, 1014–1023.
John, C., Armes, J., 2013. Developing a nurse-led survivorship service for patients with lymphoma. Eur. J. Oncol. Nurs. 17, 521–527.
Kuijpers, W., Groen, W.G., Aaronson, N.K., 2013. A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: relevance for cancer survivors. J. Med. Internet Res. 15 e37–e37.
Lobb, E.A., Joske, D., Butow, P., Kristjanson, L.J., Cannell, P., Cull, G., Augustson, B., 2009. When the safety net of treatment has been removed: patients' unmet needs at the completion of treatment for haematological malignancies. Patient Educ. Counsel. 77, 103–108.
MacMillan Cancer Support & NHS Improvement, 2010. In: The National Cancer Survivorship Initiative Vision. Department of Health, UK, London.
Maly, R.C., Liang, L., Liu, Y., Griggs, J.J., Ganz, P.A., 2017. Randomized controlled trial of survivorship care plans among low-income, predominantly latina breast cancer survivors. J. Clin. Oncol. 35, 1814–1825.
McCabe, M.S., Bhatia, S., Oeffinger, K.C., Reaman, G.H., Tyne, C., Wollins, D.S., Hudson, M.M., 2013. American Society of Clinical Oncology statement: achieving high-quality cancer survivorship care. J. Clin. Oncol. 31, 631–640.
McDowell, M.E., Occhipinti, S., Ferguson, M., Dunn, J., Chambers, S.K., 2010. Predictors of change in unmet supportive care needs in cancer. Psycho Oncol. 19, 508–516.
McGrath, P., 2014. Patient perspectives on the usefulness of routine telephone follow-up as psychosocial support for hematologic malignancies: Australian findings. Oncol. Nurs. Forum 41, 40–44.
Monterosso, L., Taylor, K., Platt, V., Lobb, E., Krishnasamy, M., Musiello, T., Bulsara, C., Stratton, K., Joske, D., 2017. A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma. Eur. J. Oncol. Nurs. 28, 62–68.
Neergaard, M.A., Olesen, F., Andersen, R.S., Sondergaard, J., 2009. Qualitative description - the poor cousin of health research? BMC Med. Res. Meth. 9 52–52.
Ng, A., LaCasce, A., Travis, L.B., 2011. Long-term complications of lymphoma and its treatment. J. Clin. Oncol. 29, 1885–1892.
Oberoi, D., White, V., Seymour, J., Prince, H.M., Harrison, S., Jefford, M., Winship, I., Hill, D., Bolton, D., Kay, A., Millar, J., Doo, N.W., Giles, G., 2017. The course of anxiety, depression and unmet needs in survivors of diffuse large B cell lymphoma and multiple myeloma in the early survivorship period. J. Cancer Sci. 11, 329–338.
Oerlemans, S., Mols, F., Nijziel, M.R., Zijlstra, W.P., Coebergh, J.W., van de Poll-Franse, L.V., 2014. The course of anxiety and depression for patients with Hodgkin's lymphoma or diffuse large B cell lymphoma: a longitudinal study of the PROFILES registry. J. Cancer Sci. 8, 555–564.
Panek-Hudson, Y., 2013. Survivorship care - time for innovation? Aust. J. Cancer Nurs. 14, 7–12.
Patton, M.Q., 2014. Qualitative Research & Evaluation Methods: Integrating Theory and Practice. SAGE Publications.
Ross, L., 2013. Facilitating rapport through real patient encounters in health care professional education. Aust. J. Pharm. 10, 1–11.
Sandelowski, M., 2000. Whatever happened to qualitative description? Res. Nurs. Health 23, 334–340.
Sant, M., Minicozzi, P., Mounier, M., Anderson, L.A., Brenner, H., Holleczek, B., Marcos-Gragera, R., Maynadié, M., Monnereau, A., Osca-Gelis, G., Visser, O., De Angelis, R., 2014. Survival for haematological malignancies in Europe between 1997 and 2008 by region and age: results of EUROCARE-5, a population-based study. Lancet Oncol. 15, 931–942.
Smith, J.A., 2007. Qualitative Psychology: a Practical Guide to Research Methods. SAGE Publications.
Stricker, C.T., Jacobs, L.A., Risendal, B., Jones, A., Panzer, S., Ganz, P.A., Syrjala, K.L., McCabe, M.S., Baker, K., Miller, K., Casillas, J., Rosenstein, D.L., Campbell, M., Palmer, S.C., 2011. Survivorship care planning after the Institute of Medicine recommendations: how are we faring? J. Cancer Sci. 5, 358–370.
Surveillance Epidemiology and End Results (SEER), 2014. Cancer Statistics Review, 1975-2011. National Cancer Institute.
Taylor, K., Monterosso, L., 2015. Survivorship care plans and treatment summaries in adult patients with hematologic cancer: an integrative literature review. Oncol. Nurs. Forum 42, 283–291.
Taylor, K., Chan, R.J., Monterosso, L., 2015. Models of survivorship care provision in adult patients with haematological cancer: an integrative literature review. Support. Care Cancer 23, 1447–1458.
Taylor, K., Joske, D., Bulsara, M., Bulsara, C., Monterosso, L., 2016. Protocol for Care after Lymphoma (CALy) trial: a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. BMJ Open 6, 1–10. http://dx.doi.org/10.1136/bmjopen-2015-010817.
Travis, L.B., Ng, A., Allan, J., Pui, C.H., Kennedy, A., Xu, X.G., Purdy, J., Applegate, K., Yahalom, J., Constine, L.S., Gilbert, E., Boice, J., 2012. Second malignant neoplasms and cardiovascular disease following radiotherapy. J. Natl. Cancer Inst. 104, 357–370.
van der Poel, M.W., Oerlemans, S., Schouten, H.C., Mols, F., Pruijt, J.F., Maas, H., van de Poll-Franse, L.V., 2014. Quality of life more impaired in younger than in older diffuse large B cell lymphoma survivors compared to a normative population: a study from the population-based PROFILES registry. Ann. Hematol. 93, 811–819.

A.6 Test–Retest Reliability of the Short- Form Survivor Unmet Needs Survey

Original Article

Test–Retest Reliability of the Short-Form Survivor Unmet Needs Survey

Karen Taylor[1,2], Max Bulsara[3], Leanne Monterosso[1,4,5]

[1]School of Nursing and Midwifery, University of Notre Dame Australia, [2]Western Australia Cancer and Palliative Care Network, Perth, [3]Institute for Health Research, University of Notre Dame Australia, Fremantle, [4]St John of God Murdoch Hospital, Murdoch, [5]School of Nursing, Edith Cowan University Joondalup, Western Australia, Australia

Corresponding author: Karen Taylor RN, BN, GradDipOnc, MN

Western Australia Cancer and Palliative Care Network, Perth, WA, Australia

Tel: 61 08 9222 0202, Fax: 08 9222 2444

E-mail: Karen.Taylor@health.wa.gov.au

Received: December 22, 2017, Accepted: January 22, 2018

ABSTRACT

Objective: Reliable and valid needs assessment measures are important assessment tools in cancer survivorship care. A new 30-item short-form version of the Survivor Unmet Needs Survey (SF-SUNS) was developed and validated with cancer survivors, including hematology cancer survivors; however, test–retest reliability has not been established. The objective of this study was to assess the test–retest reliability of the SF-SUNS with a cohort of lymphoma survivors (n = 40). **Methods:** Test–retest reliability of the SF-SUNS was conducted at two time points: baseline (time 1) and 5 days later (time 2). Test–retest data were collected from lymphoma cancer survivors (n = 40) in a large tertiary cancer center in Western Australia. Intraclass correlation analyses compared data at time 1 (baseline) and time 2 (5 days later). Cronbach's alpha analyses were performed to assess the internal consistency at both time points. **Results:** The majority (23/30, 77%) of items achieved test–retest reliability scores 0.45–0.74 (fair to good). A high degree of overall internal consistency was demonstrated (time 1 = 0.92, time 2 = 0.95), with scores 0.65–0.94 across subscales for both time points. **Conclusions:** Mixed test–retest reliability of the SF-SUNS was established. Our results indicate the SF-SUNS is responsive to the changing needs of lymphoma cancer survivors. Routine use of cancer survivorship specific needs-based assessments is required in oncology care today. Nurses are well placed to administer these assessments and provide tailored information and resources. Further assessment of test–retest reliability in hematology and other cancer cohorts is warranted.

Key words: Cancer survivorship, internal consistency, lymphoma, short-form Survivor Unmet Needs Survey, test–retest reliability

Access this article online

Quick Response Code:

Website: www.apjon.org

DOI: 10.4103/apjon.apjon_4_18

Cite this article as: Taylor K, Bulsara M, Monterosso L. Test–Retest Reliability of the Short-Form Survivor Unmet Needs Survey. Asia Pac J Oncol Nurs 2018;5:165-71.

Introduction

Lymphoma blood cancers are malignant T or B cell lymphocytes in the lymphatic system and are categorized under two main types: non-Hodgkin lymphoma (NHL) and Hodgkin Lymphoma (HL). NHL represents approximately 88% of all lymphomas, while HL is predominately diagnosed in the adolescent and young adult population.[1] Combined, they represent the sixth most common cancer diagnosis worldwide.[1] Consistent with worldwide trends, the incidence of lymphoma in Australia is increasing, and with a projected diagnosis of 6232 cases in 2017, this equates to 4.6% of all cancer cases.[2] An estimated mortality rate of 1481 equates to 3.1% of all deaths from cancer in 2017.[2] Projected figures for 2017 in the USA have a similar projected incidence of lymphoma of 4.8% and mortality of 3.6%.[1] Treatment for lymphoma generally comprises high-dose chemotherapy and/or targeted immunotherapy agents and may include radiotherapy and hematopoietic stem cell transplants.[3] These treatments have resulted in an improvement to overall survival of approximately 76% at 5 years compared with 52% at 5 years in the 1980s.[2] Notwithstanding the positive impact treatment has had on survival rates,[4] the consequences of disease and treatment continue long after treatment completion.[5] Long-term and late effects may produce ongoing unmet needs such as fear of recurrence, fatigue, poor nutrition, exercise, fertility, relationship, financial, employment, and insurance issues.[6]

To provide optimal supportive cancer care to lymphoma survivors, the identification of patients' perceived concerns and level of support needed is required.[5] This is especially important for younger patients (18–45 years of age) where the expectation of long-term remission can raise additional concerns and unmet needs.[7] Receiving relevant information and practical support soon after treatment ends, especially resources related to healthy lifestyle behaviors,[7-11] can help mitigate the impact of disease and treatment and lead to fewer unmet needs further along the survivorship continuum.[12,13] A qualitative study with lymphoma cancer survivors (n = 17) undertaken in Western Australia[14] reported unmet informational and practical needs as participants transitioned from treatment to the survivorship phase. The findings suggested tailored post-treatment support and interventions are fundamental components of excellent survivorship care.

The measures used to assess unmet needs are equally important. Generic cancer measures which comprise items related to diagnosis and treatment are often not specific enough for the survivorship phase.[15] Comprehensive, relevant, reliable, and validated needs assessment measures that are survivor-specific are essential to capture unmet needs that become evident when treatment ends.[15] These measures can guide health professionals in providing individualized information, support, and resources.[5,15] Two recent systematic reviews[15,16] revealed that needs assessment tools are varied and may not capture all the possible unmet needs patients may have. The reviews likewise found validity and reliability evidence limited. The Survivor Unmet Needs Survey (SUNS) was identified as a measure that had strong psychometric properties and was developed and psychometrically tested with a large cross-sectional sample of cancer survivors (n = 550) including a small cohort of hematology cancer participants (n = 31, 5.6%).[17] Campbell *et al.*[17] confirmed a high overall internal consistency of items for their study with an overall Cronbach's alpha of 0.99. The authors also reported high test–retest reliability although the results were not published.[17] Internal consistency of the SUNS was further tested in two studies of hematological cancer survivor cohorts. A cross-sectional study with 529 hematological cancer survivors[18] demonstrated overall Cronbach's alpha values >0.9, and a weighted Kappa coefficient score of >0.6 for test–retest reliability; acceptability was reported for 40/89 (45%) items. Qualitative data from 17 semi-structured interviews indicated that the SUNS was considered relevant by this cohort of hematological cancer survivors.[18] A cross-sectional study of hematological cancer survivors from Australia and Canada (n = 437) reported similar levels of unmet needs across the two cohorts using the SUNS, with fatigue (n = 76, 17%) and financial concerns (n = 39, 9%) rated as high unmet needs.[9] Despite the clinical utility of the original SUNS, it was considered potentially burdensome for use in the clinical setting given the large number of items (n = 89). In 2014, the 30-item short-form-SUNS (SF-SUNS) was developed and validated with a mixed sample of cancer survivors (n = 1589), including hematological cancer survivors (n = 84, 5%).[5] Construct validity and intraclass correlation coefficients (ICCs) of the SF. were similar to those of the original SUNS. Cronbach's alpha scores for the final four domains were ≥0.85, and ICCs for the three domains from the original SUNS (financial concerns, information, and access and continuity of care) and the SF-SUNS were high (>0.9). Discriminant validity demonstrated the SF-SUNS ability to discriminate between individuals who had recently received treatment and those who had not. The authors recommended further testing of the SF-SUNS for test–retest reliability.[5] The 30-item SF-SUNS was therefore judged to be more practical and likely to be completed by participants in our larger study, particularly as the SF-SUNS was one of four instruments to be administered to participants in a pilot randomized trial to measure the effect of a nurse-led survivorship model of care.[19]

For researchers and clinicians to develop targeted follow-up support for cancer cohorts underrepresented in survivorship literature, such as lymphoma,[20] cohort-specific studies in the early survivorship phase are required.[21] Therefore, this study recruited only those with a lymphoma diagnosis who had completed treatment. Discerning the issues and concerns of this group requires survivor-specific measures that are psychometrically sound and fully tested. The SF-SUNS has been used within the clinical setting; however, since test–retest reliability of the SF-SUNS had not been established, the aim of the present study was to establish test–retest reliability of the SFSUNS to add to the psychometric data available in the published literature on this instrument.

Methods

Design

Test–retest reliability of the SF-SUNS was conducted at two time points: baseline (time 1) and 5 days later (time 2). This time frame was chosen to reduce recall bias and change in the level of unmet needs.[22] Ethical approval to conduct the study was obtained from the human research ethics committee of the study site (2015-020) and university (015007F).

Population and setting

A convenience sample of 40 lymphoma cancer patients who were 3 months' posttreatment completion were recruited from the hematology department of a large tertiary hospital in Western Australia. Inclusion criteria were pathologically confirmed new diagnosis of NHL or HL; completed first-line curative intent chemotherapy or second-line curative intent autologous stem cell transplant within the previous 3 months; no radiological evidence of lymphoma posttreatment (on positron emission tomography [PET] scan); able to understand and read English; and over 18 years of age. Participants were excluded if they had not been treated with chemotherapy; had received further treatment at another hospital (as experiences or interventions may have introduced bias); or were cognitively impaired or experiencing an acute mental health condition that prohibited the provision of informed consent.

Sample size

The sample size calculation was derived from Walter *et al.*[23] and used a fixed alpha of 0.05 from two observations with reliability values of R0 = 0.6 (acceptable) and R1 = 0.8 (expected), indicating a minimum sample size of $n = 39$.

Short-form Survivor Unmet Needs Survey

The SF-SUNS assesses unmet needs across four domains: information needs (3 items); work and financial needs (8 items); access and continuity of care needs (6 items); and coping, sharing, and emotional needs (13 items). Patient self-reported concerns and the level of support required are measured using a Likert-type scale: 0 – no unmet need, 1 – low unmet need, 2 – moderate unmet need, 3 – high unmet need, and 4 – very high unmet need. Domain scores are generated by adding each item score and dividing by the total number of domain items.[24]

Procedure

The researcher identified and approached eligible participants after treatment completion to discuss the study and provide them with a participant information and consent form. Following informed consent, demographic and baseline (time 1) SF-SUNS questionnaires were then administered to participants. After completion of the questionnaires, participants were provided with another blank copy of the SF-SUNS accompanied by instructions to complete the questionnaire at home 5 days later and postback using the supplied reply-paid addressed envelope. Participants were advised to record the date of completion if this differed from the specified due date.

Data collection

At the request of the research team's hematologist, baseline demographic and SF-SUNS data were collected from consenting participants 3 months posttreatment completion and PET scan to confirm the absence of disease. Demographic information obtained included lymphoma type, stage of disease, type of treatment received (chemotherapy +/− radiotherapy), date of diagnosis, time since diagnosis, comorbid conditions, gender, age, weight, marital status, age of children (if any), postcode, occupation, income level, education level, and health behaviors such as smoking and alcohol consumption. Participants then completed the SF-SUNS at time 2 (5 days following time 1 completion) at home.

Data analysis

All analyses were performed using IBM SPSS Statistics Version 25 data analysis software (IBM Corp. Released 2017. IBM SPSS Statistics for Macintosh, Version 25.0. Armonk, NY: IBM Corp). Descriptive statistics were used to analyze all data. Descriptive analyses were used to analyze and describe demographic data. To assess for absolute consistency of SF-SUNS items for test–retest reliability data, an ICC with a random-effects model was used to compare each item at time 1 and time 2. The ICC measure was chosen for its ability to discriminate between sets of scores ranked in the same order but not necessarily in agreement and adjusts for the degree of test–retest agreement expected by chance.[25,26] The closer the value of the ICC

to 1.0, the greater the reliability of the item or measure.[27] The guidelines developed by Cicchetti and Sparrow[28] were used to determine the level of clinical significance of the ICC values obtained: <0.40 = poor, 0.40–0.59 = fair, 0.60–0.74 = good, and >0.75 = excellent. For this study, items classified as achieving "fair to excellent" reliability, ICC >0.40,[29] were reported. Cronbach's alpha, a measure of internal consistency, was used to measure the scale reliability.

To examine the distribution of unmet needs, the five levels of unmet need were collapsed to three levels. A score of 0 (no unmet need) remained the same. Scores of 1 or 2 (low and moderate unmet need) were reclassified as 1 (low–moderate unmet need), and scores of 3 or 4 (high and very high unmet need) were classified as 2 (high–very high unmet need).

Results

Participant characteristic

There were slightly more male ($n = 22$, 55%) participants, and a greater number of participants with NHL ($n = 29$, 72.5%) compared with HL ($n = 11$, 27.5%) [Table 1]. This was in keeping with the current disease statistics which reflect a greater number of NHL than HL diagnoses.[1] Almost one-third of participants were aged between 18 and 39 years (32.5%), and a greater proportion had a university qualification ($n = 16$, 40%) [Table 1]. Although the majority of participants were currently working ($n = 15$, 37.5%) and had been throughout their treatment, 30% ($n = 12$) were looking for work or had no return to work date set. Over half the participants had a partner ($n = 25$, 62.5%). Forty participants completed both time 1 and time 2 SF-SUNS. The majority of participants ($n = 35$, 87.5%) completed time 2 SF-SUNS 5 days after time 1 (range 4–7 days).

Table 1: Baseline participant demographic and disease characteristics ($n = 40$)

Characteristics	*n* (%)
Gender	
Male	22 (55.0)
Female	18 (45.0)
Age group (years)	
18-39	13 (32.5)
40-59	12 (30.0)
60-74	9 (22.5)
75+	6 (15.0)
Marital status	
Single	10 (25.0)
Married/de facto	25 (62.5)
Divorced	3 (7.5)
Widowed	2 (5.0)
Lymphoma diagnosis	
Non-Hodgkin	29 (72.5)
Hodgkin	11 (27.5)
Highest level of education	
Secondary school or less	11 (27.5)
Trade, vocational college	13 (32.5)
University or higher	16 (40.0)
Employment status	
Working	15 (37.5)
Retired	13 (32.5)
Looking for work/no return to work date	12 (30.0)

Test–retest

ICCs, 95% confidence intervals, and clinical significance are shown in Table 2. One (3%) item met the "excellent" criteria for clinical significance; Finding car parking I can afford at the hospital or clinic. Twelve (40%) items met the "good" criteria (0.60–0.74) and 11 (37%) items met the "fair" criteria (0.40–0.59). In summary, test–retest data showed "fair" to "good" reliability for the majority of items (23/30, 77%).

Internal consistency

Overall Cronbach's alphas were 0.92 at time 1 and 0.94 at time 2, with subscales [Table 2] ranging from 0.74 and 0.69 for information needs, 0.65 and 0.83 for work and financial needs, 0.89 and 0.85 for access and continuity of care, and 0.90 and 0.94 for coping, sharing, and emotional needs, respectively. These results support strong internal consistency for the overall scale. Item-to-total correlations between 0.40 and 0.70 indicate that items are not redundant or measuring needs similar to other items within the instrument.[30] Using this criterion, the SF-SUNS demonstrated item-to-total correlations between 0.40 and 0.70 at time 1 for 24 items (80%) and at time 2 for 19 items (63%) [Table 2]. The majority of items were considered relevant and to be measuring unique needs.

Discussion

Our study is the first to report test–retest data for the SF-SUNS. The majority of items met absolute consistency for reliability ICC scores of >0.40 for test–retest, categorized as "fair" to "good." An "excellent" clinical significance score was achieved for only one item (3%), related to car parking costs which are unlikely to change over time. Needs-based instruments such as the SF-SUNS measure the degree of an individual's perceived unmet need at one point in time. Importantly, Cronbach's alpha scores at time 1 and time 2 demonstrated a high degree of internal consistency and high item-to-total correlations, confirming that items in the tool were reliable.

A criterion for psychometrically sound needs-based tools is the requirement for an instrument to be responsive to changes over time.[31-33] Although our ICC results may reflect the responsiveness of the SF-SUNS to changes in need over the data collection period, further research is required

Table 2: Item test-retest reliability and internal consistency (n=40)

Domain (*n*=4)	Item description	ICC (95% CI)	Level of clinical significance	Cronbach's alpha		Item-to-total correlation	
				Time 1	Time 2	Time 1	Time 2
Information needs	Items (*n*=3)			0.74	0.69		
	Finding information about complementary or alternative therapies	0.69 (0.49-0.83)	Good			0.30	0.50
	Dealing with fears about cancer spreading	0.56 (0.30-0.74)	Fair			0.59	0.63
	Dealing with worry about whether treatment has worked	0.57 (0.32-0.75)	Fair			0.65	0.71
Work and financial needs	Items (*n*=8)			0.65	0.83		
	Worry about earning money	0.63 (0.40-0.79)	Good			0.49	0.47
	Having to take a pension or disability allowance	0.39 (0.09-0.62)	Poor			0.45	0.38
	Paying household bills or other payments	0.69 (0.49-0.83)	Good			0.55	0.60
	Finding what type of financial assistance is available and how to obtain it	0.70 (0.50-0.83)	Good			0.67	0.71
	Finding car parking that I can afford at the hospital or clinic	0.76 (0.59-0.86)	Excellent			0.02	0.45
	Understanding what is covered by my medical insurance or benefits	0.31 (0.01-0.57)	Poor			0.20	0.06
	Knowing how much time I would need away from work	0.74 (0.55-0.85)	Good			0.55	0.50
	Doing work around the house (cooking, cleaning, home repairs, etc.)	0.37 (0.07-0.61)	Poor			0.12	0.70
Access and continuity of care	Items (*n*=6)			0.89	0.85		
	Having access to cancer services close to my home	0.45 (0.16-0.66)	Fair			0.44	0.62
	Getting appointments with specialists quickly enough (oncologist, surgeon, etc.)	0.38 (0.08-0.61)	Poor			0.70	0.44
	Getting test results quickly enough	0.66 (0.44-0.81)	Good			0.57	0.51
	Having access to care from other health specialists (dietitians, physiotherapists, occupational therapists)	0.53 (0.26-0.72)	Fair			0.51	0.67
	Making sure I had enough time to ask my doctor or nurse questions	0.58 (0.33-0.75)	Fair			0.59	0.48
	Getting the health care team to attend promptly to my physical needs	0.53 (0.26-0.72)	Fair			0.59	0.50
Coping, sharing and emotional needs	Items (*n*=13)			0.90	0.94		
	Telling others how I was feeling emotionally	0.43 (0.14-0.65)	Fair			0.58	0.48
	Finding someone to talk to who understands and has been through a similar experience	0.33 (0.02 to 0.58)	Poor			0.45	0.57
	Dealing with people who expect me to be "back to normal"	0.62 (0.39-0.78)	Good			0.57	0.77
	Dealing with people accepting that having cancer has changed me as a person	0.51 (0.24-0.71)	Fair			0.68	0.81
	Dealing with reduced support from others when treatment has ended	0.67 (0.46-0.81)	Good			0.82	0.82
	Dealing with feeling depressed	0.73 (0.55-0.85)	Good			0.53	0.72
	Dealing with feeling tired	0.49 (0.21-0.69)	Fair			0.57	0.71
	Dealing with feeling stressed	0.55 (0.29-0.74)	Fair			0.78	0.69
	Dealing with feeling lonely	0.72 (0.52-0.84)	Good			0.53	0.61
	Dealing with not being able to feel "normal"	0.47 (0.20-0.68)	Fair			0.57	0.70
	Trying to stay positive	0.63 (0.40-0.79)	Good			0.55	0.65
	Coping with having a bad memory or lack of focus	0.64 (0.41-0.79)	Good			0.50	0.86
	Dealing with changes in how my body appears	0.28 (−0.04-0.54)	Poor			0.23	0.24

ICC: Intraclass correlation, CI: Confidence interval

to detect clinically meaningful change for patients.[16] All participants completed the time 2 questionnaire at home, well away from the hematology clinic where the time 1 questionnaire was completed. It is possible that participants may have had additional time to more accurately reflect on the level of unmet need. Similarly, time 1 scores may have been impacted by participants' anxiety at the hospital appointment where patients often worry about test results and potential relapse.[34] In addition, fatigue is a recognized effect of lymphoma treatment[7] and may have potentially

affected participant responses at either time point. Finally, most items were similarly balanced for both time points from "no unmet need" to "low unmet need" or "low unmet need" to "no unmet need."

It is important to allow cancer survivors the opportunity to self-identify unmet needs and issues of concern. Survivorship needs-based instruments provide a consistent method for this purpose.[35] Furthermore, it is important that any tool is responsive to change as individuals' issues, concerns, thoughts, and feelings can change from day-to-day,[32,33] particularly during survivorship transition as individuals move on with their lives after cancer treatment. Such reliable and valid instruments can facilitate individualized survivorship care and tailored support and resources.[15]

It is important to note that the original SUNS demonstrated low test–retest reliability acceptability,[18] with the authors suggesting that the test–retest timeframe was too long at 28 days. Since our study was part of a larger study involving an intervention group, a 5-day later test–retest assessment was deemed an appropriate timeframe to ensure completion of the time 2 SF-SUNS before the implementation of any needs-based interventions associated with the larger study.[19] Importantly, this time period was also in keeping with the recommended 2–14-day time period for test–retest procedures.[31-33]

A limitation of this study may have been the sample size of 40 participants, despite sample size calculations indicating that this number would be sufficient to adequately perform test–retest reliability with confidence. Many participants ($n = 16$, 40%) attended the baseline appointment, where time 1 SF-SUNS was administered, accompanied by a support person (partner or family member). We acknowledge that this may have influenced time 1 responses. Likewise, time 2 responses may have similarly been influenced as the SF-SUNS was completed at home. We can confirm that participants did not receive any needs-based interventions between time 1 and time 2 completion of the SF-SUNS.

Conclusion

We suggest that needs-based assessments should be used routinely during the survivorship period to facilitate survivorship care that is tailored and responsive to individuals' changing needs. Valid and reliable survivor-specific measures are essential for routine screening and follow-up. Nurses in particular are a valuable resource in the survivorship phase to assess for areas of concern or unmet needs and for the provision of information, support, and resources that are tailored to the individuals' unique needs. Further testing of the SF-SUNS is recommended in hematology and other cancer populations to further understand and demonstrate the responsiveness of this instrument to changes in need over the survivorship period.

Financial support and sponsorship

This research is supported through the University of Notre Dame Australia's Collaborative Research Network Grant and an Australian Government Research Training Program Scholarship.

Conflicts of interest

There are no conflicts of interest.

References

1. Howlader N, Noone AM, Krapcho M, Miller D, Bishop K, Kosary C, *et al.* SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2014. Bethesda, MD: National Cancer Institute; 2016.
2. Cancer Australia. Lymphoma in Australia: Australian Government; 2017. Available from: https://www.lymphoma.canceraustralia.gov.au/statistics. [Last accessed on 2017 Nov 21].
3. Carey M, Anderson A, Sanson-Fisher R, Lynagh M, Paul C, Tzelepis F, *et al.* How well are we meeting haematological cancer survivors' preferences for involvement in treatment decision making? Patient Educ Couns 2012;88:87-92.
4. Sant M, Minicozzi P, Mounier M, Anderson LA, Brenner H, Holleczek B, *et al.* Survival for haematological malignancies in Europe between 1997 and 2008 by region and age: Results of EUROCARE-5, a population-based study. Lancet Oncol 2014;15:931-42.
5. Campbell HS, Hall AE, Sanson-Fisher RW, Barker D, Turner D, Taylor-Brown J, *et al.* Development and validation of the Short-Form Survivor Unmet Needs Survey (SF-SUNS). Support Care Cancer 2014;22:1071-9.
6. Taylor K, Chan RJ, Monterosso L. Models of survivorship care provision in adult patients with haematological cancer: An integrative literature review. Support Care Cancer 2015;23:1447-58.
7. Arden-Close E, Absolom K, Greenfield DM, Hancock BW, Coleman RE, Eiser C, *et al.* Gender differences in self-reported late effects, quality of life and satisfaction with clinic in survivors of lymphoma. Psychooncology 2011;20:1202-10.
8. Boyes AW, Girgis A, D'Este C, Zucca AC. Prevalence and correlates of cancer survivors' supportive care needs 6 months after diagnosis: A population-based cross-sectional study. BMC Cancer 2012;12:150.
9. Hall A, Campbell HS, Sanson-Fisher R, Lynagh M, D'Este C, Burkhalter R, *et al.* Unmet needs of Australian and Canadian haematological cancer survivors: A cross-sectional international comparative study. Psychooncology 2013;22:2032-8.
10. Hjermstad MJ, Evensen SA, Kvaløy SO, Loge JH, Fayers PM, Kaasa S, *et al.* The CARES-SF used for prospective assessment of health-related quality of life after stem cell transplantation. Psychooncology 2003;12:803-13.
11. Lobb EA, Joske D, Butow P, Kristjanson LJ, Cannell P, Cull G, *et al.* When the safety net of treatment has been removed: Patients' unmet needs at the completion of treatment for haematological malignancies. Patient Educ Couns 2009;77:103-8.

12. Aziz NM. Cancer survivorship research: State of knowledge, challenges and opportunities. Acta Oncol 2007;46:417-32.
13. McDowell ME, Occhipinti S, Ferguson M, Dunn J, Chambers SK. Predictors of change in unmet supportive care needs in cancer. Psychooncology 2010;19:508-16.
14. Monterosso L, Taylor K, Platt V, Lobb E, Krishnasamy M, Musiello T, *et al.* A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma. Eur J Oncol Nurs 2017;28:62-8.
15. Taylor K, Monterosso L. Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors. Aust J Cancer Nurs 2016;17:6-12.
16. Jiao M, Hall A, Nolte L, Piper A, Lisy K, Jefford M. A rapid review of needs assessment tools for post-treatment cancer survivors. Eur J Cancer Care 2017;e12764:1-10.
17. Campbell HS, Sanson-Fisher R, Turner D, Hayward L, Wang XS, Taylor-Brown J, *et al.* Psychometric properties of cancer survivors' unmet needs survey. Support Care Cancer 2010;19:221-30.
18. Hall A, D'Este C, Tzelepis F, Sanson-Fisher R, Lynagh M. The survivor unmet needs survey (SUNS) for haematological cancer survivors: A cross-sectional study assessing the relevance and psychometric properties. BMC Health Serv Res 2014;14:211.
19. Taylor K, Joske D, Bulsara M, Bulsara C, Monterosso L. Protocol for care after lymphoma (CALy) trial: A phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. BMJ Open 2016;6:e010817.
20. Swash B, Hulbert-Williams N, Bramwell R. Unmet psychosocial needs in haematological cancer: A systematic review. Support Care Cancer 2014;22:1131-41.
21. Oberoi D, White V, Seymour J, Prince HM, Harrison S, Jefford M, *et al.* The course of anxiety, depression and unmet needs in survivors of diffuse large B cell lymphoma and multiple myeloma in the early survivorship period. J Cancer Surviv 2017;11:329-38.
22. Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, *et al.* Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol 2007;60:34-42.
23. Walter SD, Eliasziw M, Donner A. Sample size and optimal designs for reliability studies. Stat Med 1998;17:101-10.
24. Filsinger S, Burkhalter R, Campbell HS. Survior Unmet Needs Survey: User Guide. Ontario, Canada: University of Waterloo; 2011. p. 1433-7339.
25. Cicchetti DV. Guidelines, criteria, and rules of thumb for evaluating normed and standardized assessment instruments in psychology. Psychol Assess 1994;6:284-90.
26. Bujang MA, Baharum N. A simplified guide to determination of sample size requirements for estimating the value of intraclass correlation coefficient: A review. Arch Orofac Sci 2017;12:1-11.
27. Weir JP. Quantifying test-retest reliability using the intraclass correlation coefficient and the SEM. J Strength Cond Res 2005;19:231-40.
28. Cicchetti DV, Sparrow SA. Developing criteria for establishing interrater reliability of specific items: Applications to assessment of adaptive behavior. Am J Ment Defic 1981;86:127-37.
29. Rosner B. Fundamentals of Biostatistics. 8th ed. United States: Cengage Learning; 2016.
30. Leong FT, Austin JT. The Psychology Research Handbook: A Guide for Graduate Students and Research Assistants. 2nd ed. Thousand Oaks, CA: Sage; 2006.
31. DeVellis RF. Scale Development: Theory and Applications. 3rd ed. Thousand Oaks, California: Sage; 2012.
32. McDowell I. Measuring Health: A Guide to Rating Scales and Questionnaires. 3rd ed. Oxford: Oxford University Press; 2006.
33. Streiner DL, Norman GR. Health Measurement Scales: A Practical Guide to Their Development and Use. 2nd ed. Oxford: Oxford University Press; 2003.
34. Thewes B, Butow P, Zachariae R, Christensen S, Simard S, Gotay C, *et al.* Fear of cancer recurrence: A systematic literature review of self-report measures. Psychooncology 2012;21:571-87.
35. Hawkins NA, Pollack LA, Leadbetter S, Steele WR, Carroll J, Dolan JG, *et al.* Informational needs of patients and perceived adequacy of information available before and after treatment of cancer. J Psychosoc Oncol 2008;26:1-6.

Appendix B

B.1 A Qualitative Study of the Post-treatment Experiences and Support Needs of Survivors of Lymphoma

 doi:10.1016/j.ejon.2017.03.002

European Journal of Oncology Nursing 28 (2017) 62–68

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma

Leanne Monterosso, PhD, BNurs(Hons), GCert Tert Teach, RN, RM, NNT, FACN [a, b, c, *],
Karen Taylor, PhD(c), MNurs, GDipOnc, BN, RN [a, d],
Violet Platt, MNurs, BSc(Hons), EMBA, GAICD, RN [a, d],
Elizabeth Lobb, PhD, MAppSci, B.Ad.Ed. PGCert Bereave Counsel [e, f, g],
Meinir Krishnasamy, PhD, MSc, BA(Hons) DipN, RGN [h, i],
Toni Musiello, DPhil Health Psych, MSc Health psych, BSc(Hons) [j],
Caroline Bulsara, PhD, GDip Ed Studies, BA(Hons) [a], Kendall Stratton, BN, RN [k, a],
David Joske, MBBS FRACP FCRPA [j, k]

[a] School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, Western Australia, Australia
[b] St John of God Murdoch Hospital, Western Australia, Australia
[c] School of Nursing, Edith Cowan University Joondalup, Western Australia, Australia
[d] Western Australia Cancer and Palliative Care Network, Perth, Australia
[e] Calvary Health Care, Kogarah, New South Wales, Australia
[f] Cunningham Centre for Palliative Care, Darlinghurst, New South Wales, Australia
[g] The University of Notre Dame, Darlinghurst, New South Wales, Australia
[h] Department of Nursing, University of Melbourne, Victoria, Australia
[i] Research and Education Lead-Nursing, The Victorian Comprehensive Cancer Centre, Victoria, Australia
[j] University of Western Australia, Crawley, Western Australia, Australia
[k] Sir Charles Gairdner Hospital, Nedlands, Western Australia, Australia

ARTICLE INFO

Article history:
Received 19 September 2016
Received in revised form
10 February 2017
Accepted 5 March 2017

Keywords:
Lymphoma
Focus groups
Survivorship
Unmet needs

ABSTRACT

Purpose: To explore the post-treatment experiences and preferences for follow-up support of lymphoma survivors.
Methods: Two focus groups were conducted with 17 participants to explore informational, psychological, emotional, social, practical and physical needs, 6–30 months post-treatment for lymphoma. Perceptions regarding a potential model of survivorship care were also elicited.
Results: Thematic content analysis revealed five key themes: Information; Loss and uncertainty; Family, support and post-treatment experience; Transition, connectivity and normalcy, and Person-centred post-treatment care. Participants described a sense of loss as they transitioned away from regular interaction with the hospital at the end of treatment, but also talked about the need to find a "new normal". Establishing post-treatment support structures that can provide individualised information, support, reassurance and referrals to community and peer support were identified as a helpful way to navigate the transition from patient to post-treatment survivor.
Conclusions: Participants in our study articulated a need for a flexible approach to survivorship care, providing opportunities for individuals to access different types of support at different times post-treatment. Specialist post-treatment nurse care coordinators working across acute and community settings may offer one effective model of post-treatment support for survivors of haematological malignancies.

* Corresponding author. University of Notre Dame Australia, 19 Mouat Street, Fremantle, WA 6959, Australia.
E-mail address: leanne.monterosso@nd.edu.au (L. Monterosso).

http://dx.doi.org/10.1016/j.ejon.2017.03.002
1462-3889/

1. Introduction

Lymphomas are complex, potentially life limiting haematological (blood) malignancies that have a marked impact on quality of life and long-term health as a consequence of the aggressive or chronic nature of the treatments required to manage them (Carey et al., 2012). Lymphomas are immune-related cancers, broadly categorised as non-Hodgkin or Hodgkin lymphoma, and can be indolent or aggressive in nature (National Cancer Institute, 2016). Advances in treatment efficacy, including haematopoietic stem cell transplants, bone marrow support with blood component transfusions and white cell stimulation, along with advances in decreasing severity of infection risk, remission rates have improved (Lichtman, 2008).

In Australia, the context for this study, the 2012 estimated age-standardised rates (ASRs) of Hodgkin lymphoma incidence and mortality were 2.7 and 0.3 respectively (Cancer Australia, 2017a). These figures compare favourably with the European Union (EU-27) estimated ASRs of Hodgkin lymphoma incidence (2.3) and mortality (0.4) for the same period (Ferlay et al., 2013). The estimated Australian ASRs of incidence and mortality for Non-Hodgkin lymphoma were 19.1 and 5.4 respectively compared with EU-27 estimated ASRs of 11.6 and 3.8 respectively (Cancer Australia, 2017b; Ferlay et al., 2013).

Late and long-term side effects of treatment for lymphoma are common and can include fatigue; nutritional and physical activity deficits; fertility, sexuality and relationship concerns; and financial, employment and insurance issues (Allart et al., 2013; Arden-Close et al., 2011; Hall et al., 2013b). As advances in remission and cure rates improve, survivors are living longer with the consequences of their disease and treatment (Sant et al., 2014), and many experience unmet needs that impact long-term health and wellbeing (Arden-Close et al., 2011). In a study of 53 long-term survivors of leukaemia and lymphoma (Zebrack, 2000), issues such as fatigue (n = 23, 42%), remained an ongoing problem. The authors indicated fear of recurrence and financial concerns were also predominant factors in long-term survivors (no figures given). In a study of 437 haematology survivors in Australia and Canada, fatigue was identified as the greatest unmet concern (n = 76, 16%), with the Australian cohort only (n = 268, 61%) reporting a higher level of unmet financial concerns (n = 39, 15%) (Hall et al., 2013a). Survivors of haematological malignancies have been show to experience ongoing issues up to a decade or more post-treatment completion (Ferrer et al., 2011). Severe fatigue impacting functional capacity, emotional well-being and ability to return to work (Ferrer et al., 2011; Kangas et al., 2008; Oerlemans et al., 2013), and persistent cognitive impairment have been reported as debilitating long-term effects of treatment (van der Poel et al., 2014).

There is limited evidence available to inform the development of patient-focused haematology survivorship services in Australia. However, some evidence exists to indicate patients' preferences for post-treatment follow-up care. In a study of 66 cancer survivors representing the major haematological diagnostic groups (non-Hodgkin lymphoma 48%, Hodgkin lymphoma 12%, multiple myeloma 26%, leukaemia 14%), help with managing the fear of recurrence (42%) and ongoing case management (33%) were identified as unmet needs in the post-treatment period (Lobb et al., 2009). The opportunity to discuss experiences with a health care professional at treatment completion was identified as potentially helpful by 59% of participants. McGrath (2014) reported findings from a qualitative study of 50 haematology survivors that explored use of routine telephone follow-up as a supportive care strategy. The sample represented the haematologic diagnostic groups of multiple myeloma (n = 15), lymphoma (n = 14) and leukaemia (n = 17). Although telephone follow-up support was perceived by the majority of participants as potentially beneficial, many individuals did not support the idea as they wanted to 'move on' from cancer and would not have welcomed any contact.

Unlike more common malignancies such as breast and prostate cancer, evidence to inform the development of optimal follow-up guidelines for haematological survivorship care is lacking. This study set out to explore the experiences of and preferences for post-treatment support in Australian survivors of lymphoma 6–30 months post-treatment completion. For the purpose of the study, participants were deemed 'lymphoma survivors' if their haematologist had documented ongoing remission at least six months from treatment completion as our intent was to better understand post-treatment support needs.

2. Methods

2.1. Methodological framework

We undertook a qualitative, descriptive study (Neergaard et al., 2009; Sandelowski, 2000) utilising focus groups to explore and better understand the post-treatment experiences and support needs of lymphoma survivors. Focus groups allow for collection of a broad range of information and insight when little is known or understood about a topic (Neergaard et al., 2009; Sandelowski, 2000), while providing peer support and normalisation of experiences that group participants may share. Excellent facilitation is important to ensure all participants have an opportunity to contribute as they wish, avoiding dominance of one or two experiences (Tausch and Menold, 2016). For the purpose of our study, a PhD prepared haematology clinical psychologist experienced in conducting focus groups with vulnerable populations, facilitated the digitally recorded focus groups and was supported by a specialist cancer nurse who acted as scribe to support detail and accuracy of interpretation of the digitally recorded focus group data.

The study was approved and undertaken in accordance with the ethical standards guiding the Human Research Ethics Committees of the relevant study site and university. Informed written consent was obtained from all participants prior to study participation.

2.2. Sample and setting

The study was undertaken at a large tertiary hospital with a comprehensive cancer centre in Western Australia. Between 1 July 2009 and 1 December 2013, 479 patients were referred to the hospital for treatment of lymphoma. Potentially eligible study participants were identified through a manual search of the hospital cancer registry patient records. Eligibility criteria included: i) aged over 25 years (in Australia Youth Cancer Services provide specialist, age-appropriate treatment and support for young cancer patients aged 15–25; ii)) currently residing in Western Australia; iii) fluent in English; iv) completed treatment at least 6 months prior to study; and v) no cognitive impairment (as indicated in the medical record or during recruitment process where participants' ability to understand the study details and provide consent was assessed). Exclusion criteria were patients who: i) had relapsed after first-line therapy; ii) were receiving care or follow-up or had undertaken an allogeneic transplant at another hospital; and iii) were undergoing work-up for autologous transplant. These exclusion criteria ensured experiences from other hospital sites and continuing treatment experiences did not influence the data collected.

2.3. Focus groups

Two digitally recorded focus groups were carried out and data from each group transcribed verbatim. The transcriptions were checked for accuracy by the facilitator and support nurse, drawing on the notes taken during the groups and by listening to the recordings. Digital recordings of interviews and transcribed interviews were saved in password-protected files on a secure server.

A semi-structured interview guide was developed by the research team based on previously reported study data and clinical experience. Interview questions allowed for exploration of informational, psychological, emotional, social, practical, physical and spiritual aspects of post-treatment support need. Participants were also asked to talk about what they thought would have been or could be of help to them in the post-treatment period.

2.4. Data analysis

The focus group transcript data were imported into NVivo to enable the management of data, and the process of data analysis. Thematic content analysis methodology was applied to explore and organise data into codes and themes (Braun and Clarke, 2006). Transcripts were initially coded by CB. Subsequently each transcript was read independently by two other members of the study team (TM, KT). Thematic content analysis is a widely used analytical approach to qualitative data where themes, identified through coding, reflect key patterns within the textual data. This inductive approach was regarded as the most appropriate for our data, allowing themes to emerge from the content of the focus groups rather than considering data in response to questions pre-constructed by the researchers (Sarantakos, 2013). Data saturation point was reached following analysis of the two focus groups.

2.5. Rigour

Researchers (KT, CB and TM) met to discuss outcomes from the independent coding process and agreed on emerging themes. Discrepancies were discussed until consensus was reached. This allowed for development of a coding system that ensured a strategy of reliability throughout the process (Morse, 2015). Rigour of data analysis was ensured by applying the criteria of credibility, auditability and fittingness (Beck, 1993). Credibility was obtained through use of researchers to complete independent coding thereby ensuring categories accurately captured issues being discussed. Decisions related to allocation of discrete data elements to codes and fittingness of the codes, were demonstrated through extensive use of quotes or extracts from the data. Fittingness was further achieved by reflecting on the core concepts of unmet survivorship needs as confirmed by the research team (van Manen, 1997). Documentation of all steps in the analysis process, including opportunities for reflection on the codes and debriefing about the content of the transcription ensured a coherent audit trail and therefore maintained auditability.

3. Results

3.1. Participants

Of the 79 eligible lymphoma participants, 11 returned opt-out forms without providing a reason for this decision. The remaining 68 participants were contacted to further explain the study and provide focus group details. Of these 22 (32%) agreed to participate in a focus group, however five people did not attend on the day. Reasons for non-participation included: migrating overseas/interstate (n = 2); recently relapsed or other cancer (n = 5); family bereavement (n = 1); working fulltime (n = 1); declined to provide a reason when contacted by telephone (n = 20); did not respond to voicemail message (n = 13); severe symptom burden (n = 1); unable to arrange transport (n = 1); family objection (n = 1); deceased (n = 1).

The disease and demographic characteristics of the participants who did not take part in a focus group were comparable with those who participated. The age range of participants was 27–85 years with a mean age of 63.8 years (SD 14.5). The average time since last treatment was 14.6 months (SD 8.2) with a range of 6–30 months (Table 1).

3.2. Themes

Five themes emerged from analysis and coding of data: Information; Loss and uncertainty; Family, support and post-treatment experience; Transition, connectivity and normalcy, and Person-centred post-treatment care.

3.3. Information

Participants described difficulty in obtaining information from some members of the health care team after treatment had finished, feeling that professionals sometimes didn't understand or pre-empt the type of information and support they required post-treatment:

> "My GP doesn't even really know that much about cancer, I think I've been teaching him … but you could phone the Cancer Council and get quite a bit of information if you wanted to …" F_46yo_NHL

Participants indicated that a generic list of services and written information describing what to expect post-treatment would be helpful:

> "An instruction sheet, so basically you've just had your last chemotherapy session one month ago, you've done your test, you're in remission, here's what you need to do for the next 12 months" M_48yo_HL

Table 1
Participant demographic information (N = 17).

Demographic variable	Focus group 1 N = 8	Focus group 2 N = 9
Gender		
Male	5	4
Female	3	5
Age		
25-35	0	1
36-50	2	0
51-64	1	2
65-79	5	5
80+	0	1
Married Status		
Married	5	5
De Facto	2	1
Divorced	0	2
Single	1	1
Diagnosis		
NHL	7	9
HL	1	0
Time since treatment completion		
6–11 months	4	
12–16 months	4	
17–24 months		7
25–29 months		2

Compounding the issue of information support was recognition that retention of information given in preparation for end of treatment was challenging and that being given important information at different times or repeatedly may be helpful:

"I don't think anyone explains it all to us, is there a rule book? 'After 3 months, you should … '" M_ 48yo_HL

"I think about things in between visits … I have questions, so every three months I come back" F_73yo_NHL

3.4. Loss and uncertainty

Post-treatment side effects were spoken about in terms of loss; a loss of strength and physical function, a loss of control around nutrition and sustenance, a loss of energy and interest, and a loss of concentration. Comments around what to expect indicated most would have found it helpful to know how long side effects continue for, and what was normal:

"I just think, for me the chemo's given me this neuropathy and I mean I'm learning to walk again, and stuff like that, I can't feel my legs so it's like I'm on air cushions …" F_46yo_NHL

For some, the changes post-treatment were noticed when trying to get back to exercise and movement. They felt their physical abilities had declined:

"Yeah, I mean I walk the streets but I don't like doing that, I can go one block and then I'm exhausted. But I do feel better when I do something, but I can't do it long enough for it to benefit me." F_75yo_NHL

Many participants spoke about coping with the emotional experience and impact of their cancer treatment through avoidance:

"I can personally say that I did have my down moments … but it's so hard and I thought it's worse being in this state, just get out- just get going, just don't think about it – it's easier to just get on with it rather than get depressed – I know that's easier said than done." F_28yo_NHL

Living with the fear of cancer recurrence was described as a common experience and although one or two participants talked about seeking help and reassurance to address their fear, most described getting on with living alongside the uncertainty and fear:

"I don't think you ever quite get rid of the shadow … I don't think you ever get free of that slightly depressed feeling that's in the back of your head that it could come back." F_46yo_NHL

"I just want to be living well ….if I'm going to live for only 5 more years, I just want to live well for those 5 years and extract as much as I can …" M_48yo_HL

The most commonly mentioned strategies used post-treatment to try and cope with the impact of their diagnosis, its treatment and on-going uncertainty included exercise, having children around, and hope for the future:

"[Weight lifting exercise class] I went twice a week and after 3 months I was really feeling much better and almost back to my energy level and I'm not even back to it now after a year, and that was a twice a week thing which was really good. So then I thought if I can go to weight lifting I can go to badminton, and I did that twice a week and that kept my mind occupied, something to do and being active and I think it is something that's very useful." F_46yo_NHL

"I think having kids around brings you up a bit and makes you realise that life isn't so tough …" F_28yo_NHL

"… but also you need to be busy mentally and do things for the future and I really amazed myself in two months after chemo when I planted my vegetables and I thought 'will I be alive to eat it'." F_46yo_NHL

3.5. Family and significant others, support and post-treatment experience

Family members and significant others were largely seen as helpful but at times participants described experiences where they could be unintentionally dismissive and appeared to lack understanding:

"… people say to me, think positive. What does that mean? You know what I mean? I understand the concept of it …" M_48yo_HL

"… you're back doing the dishes, doing the washing, where as everyone kind of rallied before, yep you're alright now – off you go." F_52yo_NHL

"I've got young children, you know, - so you still are carrying on with your parental duties and all of that sort of stuff, but as soon as you've got your remission … certain people in my life went – oh he's fixed, and suddenly you're not cancer boy any more so people suddenly switch off …" M_48yo_HL

Some participants commented that as they physically and outwardly began to look better, others' expectations of them changed:

"But when your hair grows again and your skin colour comes back and you're not passed out in the chair most of the time, … people tend to quickly move on from that where as you haven't you know what I mean, you haven't'. … whilst you're not having chemo any more it's not finished for you yet …" M_48yo_HL

Some participants had found value in attending peer support groups where others understood what they had gone through and experienced:

"It's just like everybody's been saying, it's nice to come where people understand you – I mean that my family and friends have all been amazing but they don't understand. They just all say yes we know you're going through it and we feel for you, but they just don't understand." F_46yo_NHL

One participant found the support received from belonging to a group of other young people made a big difference to their experience:

"… I couldn't kind of get along with the people I was having treatment with just because our lives were so different. It was so helpful … I just went to those little meetings and there were people my age talking about the same sort of stuff." F_28yo_NHL

But for others a group situation was difficult, at times overwhelming, leaving them feeling uncomfortable:

"You're always identified as the cancer person or with the cancer group … but sometimes it weighs a bit heavy, like the people there you don't necessarily want to broadcast it to the whole world." F_75yo_NHL

3.6. Transition, connectivity and normalcy

The relationships established during treatment and the security that came through knowing they were being treated and monitored closely by an expert or team who genuinely cared for them was greatly valued:

"I just had this feeling of 'wow' I am so privileged to have the treatment and the knowledge of the professional care here, the medical staff, all of them …" F_73yo_NHL

"I was under Dr X and they always said that you know, if you ever have any problems, ring me personally and you can come straight in, don't bat an eyelid. So I was very confident in the team and I knew there was support if I needed it." F_52yo_NHL

But with completion of treatment and the transition to a different relationship with the hospital and treating team, some participants felt that although their medical needs were met, they did not feel connected or understood holistically:

"… my specialist is great, …excellent doctor, but I walk in there and you get nothing other than your um, medical moment for want of a better term- there's no, you know, like [the doctor's] just happy that you've got a remission so [the doctor's] done the job, you know, and it was literally, ok 'so what happens now?' 'I'll see you in 3 months.'" M_48yo_HL

Leaving the support of the hospital was experienced as a loss. Some felt their safety net and reassurance had gone along with the camaraderie of other patients who were undergoing a similar experience. Many were left wondering what their purpose was moving forward:

"I used to be this guy that had a sense of purpose and a reason for going– all of a sudden all of that is taken away and no-one's telling you what to do next, it's just come and see me in 3 months' time … for me, a massive sense of loss. It's a loss of purpose and identity, actually. … You know I used to call them my chemo buddies and yeah you'd sit with the same people every time and the nurses, everybody that you just had a connection with and it's just severed." M_48yo_HL

Participants spoke about being so focused on getting through treatment they had not had time to process what would happen when treatment finished. There was a sense of adjusting to this change post-treatment without adequate preparation. One participant talked about having to take responsibility for herself again:

"… but I felt um hang on, they've spewed me out the door and I thought; now I'm going to have to do something for myself." F_46yo_NHL

Overwhelmingly, participants wanted things to return to normal or a new normal post-treatment. They wanted to get on to with their lives, get back to work and move forward; to put cancer to one side or leave it behind:

"… and I got to a point after treatment where I just told my friends to stop talking about it and stop asking I felt like it was taking over my life and I wanted other things to focus on." F_28yo_NHL

But moving from the structure of treatment and hospital support back into "normal life" was difficult. Some expected to return to their life as it was pre-diagnosis and found it challenging when this did not happen:

"… when your chemo's finished they kept telling me it would take a year to get back to normal and I'm like 'you don't know me, that's not going to happen, I'm going to walk out of here and flip a switch and I'm going to be back to normal' well it's not the case." M_51yo_NHL

The need to find a new meaning or purpose post-treatment and a realisation that one had changed and that what matters in life had changed were strong elements in the data gathered:

"You lose kind of like your purpose in life, you're not the same like you used to be before your cancer." F_46yo_NHL

"You're not so cocky now, …I really have sympathy for others, whereas before – now I really listen to them." M_66yo_NHL

"I never want to be a CEO again, I never want to be in that place, I want to be there for me and my family … it certainly makes you more empathetic- makes you have more empathy for others, it certainly gives you that gene, because I certainly didn't have much at all [before]." M_48yo_HL

Moving away from the "cancer label" and not wanting to be stigmatised was important for many participants as they transitioned into the post-treatment phase:

"When I went to the gym with the cancer group … I would have really benefitted from having an individual membership and being by myself … you get a card and 'oh, are you with the cancer group?!' I don't want to be labelled all the time … even though you're looking for support." F_52yo_NHL

3.7. Person centred post-treatment care

Participants recognised that support needs varied from diagnosis through treatment and on into follow-up, the post-treatment stage. But when discussion was guided during the focus groups to services or support that would have been useful post-treatment, participants talked about the need for this to be individualised, stating it would be difficult to get a "one size fits all" approach to their support needs:

"A group is great. But if you were ringing up asking for help you'd probably want one-on-one." M_70yo_NHL

However, most participants felt that some sort of "check-up" (follow-up) appointment at the hospital around one month post-treatment would be helpful where the focus was on the experience of the individual rather than the disease:

"I think a follow-up would be a good idea because there aren't any follow-ups as such. A formal follow-up, either with a clinical

psychologist or nurse when you come for your cancer follow-ups." F_70_NHL

Some participants suggested this appointment should be mandatory, a logical transition from hospital care to a "new normal":

"I also don't think that if you make someone available it will do any good. You got to send me there. You've got to have an appointment for me to go there otherwise I'll use tomorrow [as an excuse not to go]." M_70yo_NHL

Wanting a personal connection with a qualified professional was a strong theme, a person to seek reassurance from and check worrying symptomology:

"When you can phone somebody who is there for you right then and there specifically for that reason, to say well if you're worried, yes go and see - because you doubt yourself, you think am I being neurotic about every little ache or pain … am I being silly or should I see the doctor, maybe I'm just being silly. It would just be nice to have that support that you know that there's the cancer nurse there for you, somebody in the know that can say 'don't worry about it' or 'yes come in and see your specialist." F_46yo_NHL

Peer support was also described as valuable when the peer had undergone a similar experience and for some people it was important to get away from "the medics":

"… probably the best thing that could happen to those other people is not go and see the specialist, but sit in a room with us." M_48yo_HL

"… I would have appreciated a formal session like this, talking to people who've already been where I was and where I'm going." M_51yo_NHL

4. Discussion

This research contributes to a small but growing body of literature reporting on post-treatment experiences and support needs of survivors of lymphoma. Data from our study identified five key themes of relevance to the post-treatment experience of lymphoma survivors: Information; Loss and uncertainty; Family, support and post-treatment experience; Transition, connectivity and normalcy, and Person-centred post-treatment care.

Information needs varied across participants in our study, reflecting findings from other qualitative studies of haematological cancer survivors (Gansler et al., 2010) and emphasising the importance of flexibility in services developed if they are to successfully address the information needs of post-treatment survivors. Participants in this study described difficulty in accessing the kind of information they needed from tertiary and community health professionals once the acute treatment period was over, a finding commonly reported in studies of non-haematology cancer survivors (Taylor and Monterosso, 2016). Participants described a sense of loss in terms of support, connectivity and reassurance when they transitioned away from active care to the post-treatment phase, indicating that there is opportunity to develop and implement tailored post-treatment preparation interventions to enhance the experience and wellbeing of haematology survivors. Living with fear of cancer recurrence was a common experience for participants in our study, and is widely recognised as one of the most distressing or prevalent concerns of cancer survivors (Butow et al., 2015; Park et al., 2013). Helping people find strategies to live with fear of recurrence is a key issue in the advancement of post-treatment survivorship care.

Dealing with the side effects of treatment was described as one of the most difficult aspects of the post-treatment phase. Participants in our study felt they weren't adequately prepared to manage the issues they faced, and suggested that information on the duration of side effects, what to expect and how to cope with them would have been helpful. This finding offers an important and achievable target for improvement in post-treatment care of survivors of lymphoma.

Some participants described difficulty in adjusting to a "new normal" post-treatment and actively sought a new sense of purpose and identity. A clear sense of moving away from cancer and putting it to one side so that a new norm could be established was evident for some. This finding suggests that working with patients ahead of treatment completion to prepare a "new narrative" for themselves may better support people to transition from their identity as a cancer patient.

Although there was a general recognition of the value of support provided through existing family and friend networks, some participants felt that once they started to look and feel better, family or significant others' expectations of what they were capable of doing exceeded what they felt ready or able to do. The need to develop survivorship services that directly support families or important others so they can be effective partners in the transition to life post-treatment, as well as keep themselves well, is evident.

In response to questions about helpful components of post-treatment care, many participants described the ability to contact a health professional to seek reassurance, check in about concerning symptoms and get advice and information as an important element in enabling confident transition to survivorship. Specialist post-treatment nurse care coordinators working across tertiary and community settings may offer an effective model to address this need for survivors of haematological malignancies.

A follow-up appointment post-treatment focusing on refection of the diagnosis and treatment experience as a way of being able to "move on" to the next phase of life was also recommended as a potentially useful intervention and is worthy of consideration as one component of person-centred post-treatment care.

4.1. Limitations

The limitations in this study include the small sample size and the single site recruitment. However, the findings do offer valuable insight into the post-treatment experiences and support needs of participants in our study, and offer tangible opportunity for the development of post-treatment services and interventions targeted to the needs of survivors of lymphoma, although more works needs to be done to establish the credibility of our findings to other haematological cancer patients' post-treatment. Participants chose to opt-in and therefore it is not possible to assess whether those with greater needs or worse experiences of post-treatment care excluded themselves. However, experiences of those people who gave their time to take part have provided a valuable addition to a small but growing body of research in this area. The use of a clinical psychologist as the facilitator for the focus groups (disclosed to participants at the beginning of the focus group) may have influenced the issues participants chose to share or withhold dependent on previous access to or attitudes toward a psychologist.

5. Conclusion

Survivors of lymphoma experience many and complex post-treatment issues that require tailored intervention as part of a comprehensive package of person-centred post-treatment care. Data from our study suggest that integration of professional, peer and family/important other support strategies may prove to be most effective. Specialist haematology nurse care coordinators working across tertiary and community settings could offer a feasible and efficient way of coordinating tailored programs of support around survivors of haematological malignancies.

Funding

The authors disclose the study was supported by funding from the Cancer and Palliative Care Research and Evaluation Unit, Western Australian Cancer and Palliative Care Network.

Conflict of interest

The authors have no funding or conflicts of interest to disclose.

Acknowledgements

We thank all participants for their willingness to participate in this important study.

References

Allart, P., Soubeyran, P., Cousson-Gélie, F., 2013. Are psychosocial factors associated with quality of life in patients with haematological cancer? A critical review of the literature. Psycho-Oncology 22, 241–249.
Arden-Close, E., Absolom, K., Greenfield, D., Hancock, B., Coleman, R., Eiser, C., 2011. Gender differences in self-reported late effects, quality of life and satisfaction with clinic in survivors of lymphoma. Psycho-Oncology 20, 1202–1210.
Beck, C.T., 1993. Qualitative research: the evaluation of its credibility, fittingness, and auditability. West. J. Nurs. Res. 15, 263–266.
Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qual. Res. Psychol. 3, 77–101.
Butow, P., Fardell, J.E., Smith, A., 2015. Fear of cancer recurrence: an overview and Australian perspective. Cancer Forum 39, 95–100.
Cancer Australia, 2017a. Hodgkin Lymphoma in Australia. Australian Government. https://lymphoma.canceraustralia.gov.au/statistics. Accessed 6 February 2017.
Cancer Australia, 2017b. Lymphoma in Australia. Australian Government. https://canceraustralia.gov.au/affected-cancer/cancer-types/lymphoma/hodgkin-lymphoma-statistics. Accessed 6 February 2017.
Carey, M., Anderson, A., Sanson-Fisher, R., Lynagh, M., Paul, C., Tzelepis, F., 2012. How well are we meeting haematological cancer survivors' preferences for involvement in treatment decision making? Patient Educ. Couns. 88, 87–92.
Ferlay, J., Steliarova-Foucher, E., Lortet-Tieulent, J., Rosso, S., Coebergh, J.W.W., Comber, H., Forman, D., Bray, F., 2013. Cancer incidence and mortality patterns in Europe: estimates for 40 countries in 2012. Eur. J. Cancer 49, 1374–1403.
Ferrer, R.A., Huedo-Medina, T.B., Johnson, B.T., Ryan, S., Pescatello, L.S., 2011. Exercise interventions for cancer survivors: a meta-analysis of quality of life outcomes. Ann. Behav. Med. 41, 32–47.
Gansler, T., Kepner, J., Willacy, E., Soloe, C., Rupert, D., Jarblum, M., Driscoll, D., Orr, A., Fitzgerald, T., Esparza, A., 2010. Evolving information priorities of hematologic cancer survivors, caregivers, and other relatives. J. Cancer Educ. 25, 302–311.
Hall, A., Campbell, H.S., Sanson-Fisher, R., Lynagh, M., D'Este, C., Burkhalter, R., Carey, M., 2013a. Unmet needs of Australian and Canadian haematological cancer survivors: a cross-sectional international comparative study. Psycho-Oncology 22, 2032–2038.
Hall, A., Lynagh, M., Bryant, J., Sanson-Fisher, R., 2013b. Supportive care needs of hematological cancer survivors: a critical review of the literature. Crit. Rev. Oncology/Hematology 88, 102–116.
Kangas, M., Bovbjerg, D.H., Montgomery, G.H., 2008. Cancer-related fatigue: a systematic and meta-analytic review of non-pharmacological therapies for cancer patients. Psychol. Bull. 134, 700–741.
Lichtman, M.A., 2008. Battling the hematological malignancies: the 200 years' war. The Oncologist 13, 126–138.
Lobb, E.A., Joske, D., Butow, P., Kristjanson, L.J., Cannell, P., Cull, G., Augustson, B., 2009. When the safety net of treatment has been removed: patients' unmet needs at the completion of treatment for haematological malignancies. Patient Educ. Couns. 77, 103–108.
McGrath, P., 2014. Patient perspectives on the usefulness of routine telephone follow-up as psychosocial support for hematologic malignancies: Australian findings. Oncol. Nurs. Forum 41, 40–44.
Morse, J.M., 2015. Critical analysis of strategies for determining rigor in qualitative inquiry. Qual. Health Res. 25, 1212.
National Cancer Institute, 2016. NCI Dictionary of Cancer Terms. http://www.cancer.gov/dictionary. Accessed 3 April 2016.
Neergaard, M.A., Olesen, F., Andersen, R.S., Sondergaard, J., 2009. Qualitative description - the poor cousin of health research? BMC Med. Res. Methodol. 9, 52–52.
Oerlemans, S., Mols, F., Issa, D.E., Pruijt, J.H., Peters, W.G., Lybeert, M., Zijlstra, W., Coebergh, J.W., van de Poll-Franse, L.V., 2013. A high level of fatigue among long-term survivors of non-Hodgkin's lymphoma: results from the longitudinal population-based PROFILES registry in the south of The Netherlands. Haematologica 98, 479–486.
Park, C.L., Cho, D., Blank, T.O., Wortmann, J.H., 2013. Cognitive and emotional aspects of fear of recurrence: predictors and relations with adjustment in young to middle-aged cancer survivors. Psycho-Oncology 22, 1630–1638.
Sandelowski, M., 2000. Whatever happened to qualitative description? Res. Nurs. Health 23, 334–340.
Sant, M., Minicozzi, P., Mounier, M., Anderson, L.A., Brenner, H., Holleczek, B., Marcos-Gragera, R., Maynadié, M., Monnereau, A., Osca-Gelis, G., Visser, O., De Angelis, R., 2014. Survival for haematological malignancies in Europe between 1997 and 2008 by region and age: results of EUROCARE-5, a population-based study. Lancet Oncol. 15, 931–942.
Sarantakos, S., 2013. Social Research, fourth ed. Palgrave MacMillan, UK.
Tausch, A.P., Menold, N., 2016. Methodological aspects of focus groups in health research: results of qualitative interviews with focus group moderators. Glob. Qual. Nurs. Res. 3.
Taylor, K., Monterosso, L., 2016. Systematic Review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors. Aust. J. Cancer Nurs. 17, 6–12.
van der Poel, M.W., Oerlemans, S., Schouten, H., Mols, F., Pruijt, J.H., Maas, H., Van De Poll-Franse, L., 2014. Quality of life more impaired in younger than in older diffuse large B cell lymphoma survivors compared to a normative population: a study from the population-based PROFILES registry. Ann. Hematol. 93, 811–819.
van Manen, M., 1997. Researching Lived Experience: Human Science for an Action Sensitive Pedagogy, second ed. Althouse, London Ontario.
Zebrack, B., 2000. Quality of life of long-term survivors of leukemia and lymphoma. J. Psychosoc. Oncol. 18, 39–59.

B.2 Living with Multiple Myeloma: A Focus Group Study of Unmet Needs and Preferences for Survivorship Care

 The full web link to access this article is doi:10.1177/2374373517715011

Research Article

Journal of Patient Experience
2018, Vol. 5(1) 6-15

DOI: 10.1177/2374373517715011
journals.sagepub.com/home/jpx
SAGE

Living With Multiple Myeloma: A Focus Group Study of Unmet Needs and Preferences for Survivorship Care

Leanne Monterosso, PhD, BNurs(Hons), GCert Tert Teach, RN, RM, NNT, FACN[1,2,3], Karen Taylor, PhD(c), MNurs, GDipOnc, BN, RN[1,4], Violet Platt, MNurs, BSc(Hons), EMBA, GAICD, RN[1,4], Elizabeth Lobb, PhD, MAppSci, B.Ad.Ed.[5,6], Toni Musiello, DPhil Health Psych, MSc Health psych, BSc (Hons)[7], Caroline Bulsara, PhD, GDip Ed Studies, BA(Hons)[1], Kendall Stratton, BN, RN[1,8], David Joske, MBBS FRACP FCRPA[9,10], and Meinir Krishnasamy, PhD, MSc, BA(Hons) DipN, RGN[11]

Abstract

Purpose: To describe the unmet informational, psychological, emotional, social, practical, and physical needs and preferences for posttreatment survivorship care of individuals living with multiple myeloma to inform the development of relevant, person-centered, survivorship services. **Methods:** An exploratory, descriptive study using 2 focus groups with 14 participants, 6 to 49 months postdiagnosis. **Results:** Thematic analysis revealed 7 key themes: information needs, experience with health-care professionals, coping with side effects, communicating with family and friends, dealing with emotions, support needs, and living with the chronicity of myeloma. Participants described key characteristics of survivorship care relevant to their needs and indicated they would like a more whole of person approach to follow-up when the main treatment phases had completed. **Conclusion:** Participants in this study described unmet needs across a breadth of domains that varied over time. The development of flexible, person-centered approaches to comprehensive survivorship care is needed to address the considerable quality-of-life issues experienced by people living with multiple myeloma. Nurse-led care may offer 1 viable model to deliver enhanced patient experience—providing the vital "link" that people described as missing from their survivorship care.

Keywords

multiple myeloma, survivorship, focus groups, unmet needs, support

[1] Centre for Nursing and Midwifery Research, School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, Western Australia, Australia
[2] St John of God Murdoch Hospital, Western Australia, Australia
[3] School of Nursing, Edith Cowan University, Joondalup, Western Australia, Australia
[4] Western Australia Cancer and Palliative Care Network, Perth, Australia
[5] Calvary Health Care Kogarah, New South Wales and Cunningham Centre for Palliative Care, Darlinghurst, New South Wales, Australia
[6] School of Medicine, The University of Notre Dame, Darlinghurst, New South Wales, Australia
[7] School of Surgery, University of Western Australia, Crawley, Western Australia, Australia
[8] WA Youth Cancer Service, Sir Charles Gairdner Hospital, Nedlands, Western Australia, Australia
[9] Sir Charles Gairdner Hospital, Nedlands, Western Australia, Australia
[10] School of Medicine, University of Western Australia, Crawley, Western Australia, Australia
[11] Department of Cancer Experiences Research, Peter MacCallum Cancer Centre, University of Melbourne, Victoria, Australia

Corresponding Author:
Karen Taylor, University of Notre Dame Australia, Fremantle, 19 Mouat Street, Fremantle 6959, Australia.
Email: Karen.Taylor@health.wa.gov.au

Introduction

Around 1700 people are diagnosed with multiple myeloma (myeloma) each year in Australia with approximately 840 people dying from the disease annually (1). Myeloma is a malignant incurable plasma cell disorder (2). Treatment depends on disease stage, general health and age, aiming to suppress disease and control symptoms through chemotherapy, radiotherapy, immunotherapy regimens, including autologous transplantation (3,4). Symptoms of myeloma include bone pain, fractures, renal disease, anemia, infection, and fatigue, all of which have considerable impact on lifestyle, role functioning, and quality of life (5,6).

In a qualitative study of 20 people living with myeloma 5 years after diagnosis (7), the considerable impact on emotional, social, role and work-related areas of life, and fears regarding uncertainty of the future was described (7). In a survey of 113 hematological cancer survivors, including myeloma patients in the first 12 months following initial treatment (8), managing fear of recurrence was the most frequently endorsed unmet need (n = 42, 73%). This was followed by the need for care coordination (n = 22, 33%) with two-thirds (n = 39, 59%) reporting the opportunity to discuss diagnosis and treatment experiences with a healthcare professional would have been helpful (8).

We set out to explore the experiences of a cohort of patients living with myeloma. In accordance with the definition of a cancer survivor as articulated by the National Coalition for Cancer Survivorship (9), patients recruited to this study were cancer survivors living with, through, and beyond a diagnosis of myeloma. Despite the recognized profile of chronic, complex symptoms and treatment side effects experienced by people living with myeloma, little is known about their preferences for support and survivorship care. This project aimed to establish the unmet needs and preferences for survivorship support in a cohort of patients 6 to 49 months postdiagnosis of myeloma.

Methods

Design

A descriptive, exploratory study was chosen, as it allowed for in-depth investigation of experiences and survivorship care needs of participants, while maintaining a focus on study aims, through the use of semistructured focus group prompts (10,11). Thematic content analysis was chosen as the approach to focus group data, ensuring issues of importance to participants were revealed (12). The study was undertaken in accordance with the ethical standards of the Human Research Ethics Committees of Sir Charles Gardiner Hospital (Ref. 2012-135) and the University of Notre Dame Australia (Ref. 013030F).

Sample

The local Cancer Registry recorded 248 new cases of myeloma between July 1, 2009 and December 1, 2013 from the study site. A manual search of patient hospital records determined the date of diagnosis and treatments received to ascertain study eligibility. The Death Registry was searched to avoid contacting families of deceased patients. Sixty-three eligible participants were sent a letter of invitation from the study site hematologist; a participant information and consent form and an opt-out form to be returned within 2 weeks. Six opt-out forms were returned, 5 without indicating a reason and 1 objection to recruitment. The research assistant telephoned remaining eligible participants (n = 57) 1 week later to further explain the study and provide focus group location and time details.

Inclusion Criteria

- Aged between 25 and 85 years.
- Fluent in English.
- No cognitive impairment (as indicated by medical record or during recruitment process).
- May be receiving oral chemotherapy considered as disease maintenance.

Exclusion Criteria

- Receiving care or follow-up at another hospital (where experiences could have potentially influenced interview data).
- Undergoing an autologous transplant (exposure to a group setting considered a potential health risk).

Focus Groups

Two 90-min focus groups were conducted at a large tertiary cancer center in Western Australia. All participants provided written informed consent prior to participation. Focus group questions were derived from a comprehensive literature review of key issues and concerns in this cohort and research team clinical experience (Table 1). They prompted participants to discuss informational, psychological, emotional, spiritual, social, practical, and physical needs, along with views about survivorship support and care.

Focus groups were facilitated by a hematology clinical psychologist experienced in facilitating focus groups with vulnerable populations, digitally recorded, and transcribed verbatim. Codes replaced participant names, and clinician identifiers were removed to ensure anonymity of responses prior to analysis. Electronic transcriptions were stored in a password-protected file on a secure server.

Data Analysis

NVivo 11 was used to manage data and undertake analysis. Transcripts were read and analyzed independently by C.B., T.M., and K.T. with content assigned to codes and themes generated from the data (12). These researchers discussed the coding and reached consensus on emerging themes. Rigor of the data analysis process was ensured by applying the criteria of credibility, auditability, and fittingness (13).

Table 1. Guiding Questions for Myeloma Focus Groups.

Theme	Questions
General introduction questions	• What have been your key "moments" since diagnosis and commencing treatment? • What have been the most important things you needed since you began living with myeloma? • What do you think could be put into place to support people who are living with myeloma? • What were your key concerns about finishing your first treatment phase?
Informational	• What have been your biggest informational needs? • How would you like to access this information? • What is the best way you could be supported now that you are living with myeloma? • What advice would you have for another patient who is living with myeloma?
Psychological	• What is most reassuring to you during treatment phases? • What was most distressing to you after treatment phases? • What things, if any, are you worried about now? • What things, if any, do you look forward to when you finish a particular treatment phase? • If you have experienced worry and fear about myeloma returning • How did you need to manage this worry/fear?
Emotional/spiritual	• What have been your biggest emotional needs? – positive impact – negative impact • How did you feel at the end of each treatment phase? – relieved, scared, adrift? – did these feelings change over time? • How do you feel when you don't need to see the hematologist as frequently? • Can you describe any spiritual issues or concerns since you began living with myeloma?
Social	• How has your life changed since you began living with myeloma? • Has your social life changed since you began living with myeloma? • How does/did your treatment affect your relationships with the people closest to you?
Practical	• What have been your biggest practical concerns? • How would you like your care to be handled after you complete a treatment phase? • How would you like your care to be communicated or coordinated when you complete a phase of treatment? • Have you made any plans to change your life? • Has anyone told you where to access help or support after treatment if you need it?
Physical	• What have been your biggest physical concerns? • Do you recall speaking to a member of the health team about the possible effects some treatments can have? • What did/do you need the most to help you with the physical side effects?
Perceptions on a survivorship model of care	• If you could design a model of care to best support myeloma patients, what would it look like? – who would be in the care team? – how would you access this care and how would they communicate with you? – what services would be provided? – how often would you like to contact/access this care model?

Independent coding and researcher checking to ensure categories accurately captured issues being discussed maintained credibility. Extensive use of examples from the data demonstrated fittingness. Auditability was maintained by documenting research planning through to analysis, and through a reflective process of discussion, and debrief with colleagues. The merging of individuals with and without hematology expertise added to the richness of interpreted data and provided a balance to the analytical process.

Results

Participants

Eighteen (31.5%) of 57 eligible individuals agreed to participate. Fourteen participants attended on the scheduled day (Figure 1). On average, 31 months (standard deviation [SD]: 13.8; range: 6-49 months) had elapsed since diagnosis. Thirteen participants had a partner and 5 indicated at least 1 child <20 years of age living at home. Participants in focus group 1 had received 1 line of treatment and an autologous transplant (n = 5). Seven participants in focus group 2 had received at least 2 lines of treatment. Five participants had received 1 autologous transplant, and 1 participant had received a second autologous transplant.

Age range and time since diagnosis were comparable with those who did participate. The majority of nonresponders preferred to not provide a reason (Figure 1).

Main Themes

The following 7 themes emerged and reflect data from both groups: information needs, experience with health-care

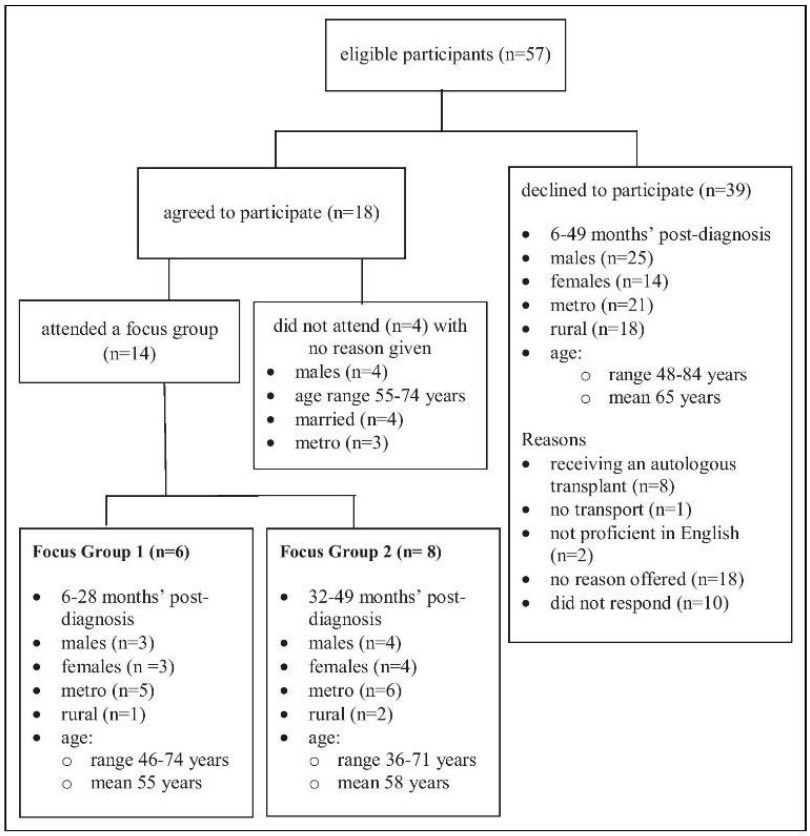


Figure 1. Recruitment and participant characteristics.

professionals, coping with side effects, communicating with family and friends, dealing with emotions, support needs, and living with the chronicity of myeloma.

Information Needs (Box 1)

Participants had differing views about the amount of information they had received at diagnosis and most had never heard of myeloma before. Some were overwhelmed and felt they couldn't absorb the information, others felt they were not given enough. All participants reported using the Internet. Many felt a list of reputable and reliable sites to search would have been helpful and may have made the diagnosis less confronting.

> [I] typed in multiple myeloma and read something about 'it's not curable' and turned the computer off and went 'no!'. . . . the average person out there who goes online doesn't get the full medical details . . . that's the information you want. (MM2-7)

Experiences with Health-Care Professionals (Box 1)

Participants suggest, in the main, their experiences of medical care were positive, but some said it was difficult to obtain "holistic support." Participants discussed ways to maximize the value of their consultation appointments. Some indicated they would have liked to review blood results prior to appointments, to process the information and determine the "right questions to ask," agreeing this would help reduce anxiety.

> . . . but if you're told that [out of remission] at an appointment, you're just in shock, you're useless. So yes [before appointment] it does make a much better consultation. (MM2-2)

Participants spoke positively about general practitioners (GP) when cancer symptoms were recognized and communicated effectively. Negative experiences were described as those where a GP had not recognized symptoms of a serious illness resulting in a delayed diagnosis.

Box 1. Information Needs and Experiences of Health-Care Professionals.

Information needs	"You get a package of books and stuff. There's a limit to how much you can absorb I think, especially initially you know, you're kind of reeling." MM1 -1
	"I think in a way, because [the consultant] didn't say I never got around to asking some things that I would've [liked to]." MM1-4
Experiences of health-care professionals	"I think the nurses are quite knowledgeable . . . but a lot of them don't have the time to sit with you, I mean while they're in the room they'll talk a little bit like that's how the one nurse told me about the plastic knife and fork when I said everything tastes like metal." MM2-7
	"I don't know if the doctors realize how anxious we get waiting for these result . . . I just couldn't wait, I was just a bit of a wreck, because you never know—it's like waiting to find out if you're sick again, so I got them to send the results to my house." MM2-7
	"My GP actually picked mine up . . . and she's very good, I was very fortunate to have that doctor." MM1-4
	"My GP didn't pick anything up! And I'd been having these symptoms for about a year and a half, I've had a broken rib and it don't heal . . ." MM1-5

Box 2. Coping With Side Effects.

Side effects	"I can't just go out and kick a footy, do all those hard sorts of sports that I loved to do, but now I just can't do those sorts of things, too much of a risk." MM2-3
Others expectations	". . . all of a sudden you look good, you look normal, you know. People look at me and think 'you can't possibly be sick'." MM1-6
	"I feel tired a lot . . . My muscles have all gone. Whereas, I was working manually, I would spend a half hour doing office work in the day, then 10 hours of lifting and stuff . . . I'm trying to swim every day and walk and things and people say, "you've got a good life, going to the beach every day." MM1-5
Hair loss	"I'm proud of it, you know, I'd always say "I'll never be bald, I'll never be bald" and, I'd no control over it. And waking up and seeing your pillow covered with hair just absolutely ruined my mind, and I was just really really impacted by that." MM1 -1
	"You are someone who has cancer, from that point [losing hair] onwards. I found it very confrontational." MM2-2
	". . . I'm a hairdresser by trade, so for me to have no hair it's like "I can't possibly have no hair!" M1-2
Peripheral neuropathy	"I couldn't even get toothpaste out of a tube, it affected my strength in my hands and feet. I was driving along I day, and I couldn't feel the controls, the pedals, so, I've given up driving, which, again, is a very frustrating thing to do." MM1-4
	"And with the feet problem, exercising is tough, because I get to the point where I don't trust my feet anymore, you know . . . Even making a run to cross the road, the green man . . . you think "will I go? will I go? will my feet listen to what my brain's telling them to do?" MM1 -1
Fatigue	"I think that's the most frustrating thing, when you've had some sort of treatment, or when your whole system's down, when you're really weary and tired, and you can't do . . . even simple chores are a real hassle. And you're so frustrated that you can't do . . . just the normal things." MM1-4

Coping With Side Effects (Box 2)

Most participants struggled with treatment side effects, described as "the most difficult part of their experience." Participants felt health professional support and guidance in preparing for, coping with, and managing side effects were inadequate.

> I found one of the challenging things is understanding and dealing with the side effects. My issue is about coping . . . so I never quite know if it's an important side effect or not. I don't want to waste the doctor's time on unimportant things. (MM2 -1)

A number of side effects were mentioned; however, hair loss, peripheral neuropathy, and fatigue were most widely experienced and discussed. All participants described hair loss as difficult; besides the emotional impact to self-image and identity, it labeled them as having cancer. Peripheral neuropathy impacted day-to-day functioning and well-being. Fatigue was described as

Box 3. Communicating With Family and Friends and Dealing With Emotions.

Family support	"But it's the after, once you look OK—don't get me wrong, my family's still there and they still know I'm sick . . . but people look at you and go 'you look fantastic' you know, and you do, you look good, you've got your hair back. So people don't assume you're sick, they don't know your journey, and it's a physical thing." MM1-2
Children	"My grandchildren didn't recognize me, they don't think I'm the same person (laughs) . . . we were so close, you know they did everything with me and after I spent 5 weeks in hospital I'm like a stranger and I think like they've just got to get to know me again." MM2-4
	"You know, how many birthdays have I got left? How many things like teaching them how to drive? Basic things like that." MM2-3
Hope and positivity	"So although you always want to have hope and you always try and find some bit of hope, there's this massive expectation of people with cancer to be constantly positive." MM2-5
	"If I don't find something positive out of it . . . it'll come to an end much quicker than I want it to—even though there's maybe an inevitable thing for us. So I try to live on ok, there's a reality, but there's a little bit of hope about having positivity about it." MM2-8
	". . . you've really got to seize the moment all these other people are just dawdling through life and we're able to actually focus more on making sure that it's a good day, and we all have to go about that different ways of managing risks, accepting we've got limitations, but if you can keep that positive focus to try and make every day a really good day, then I think life's brilliant." MM2-1

excessive and long lasting; however, some found physical exercise beneficial.

Participants described a sense of loss, as the disease and treatment had changed their life. They discussed the difficulty of appearing "well on the outside," while dealing with challenging side effects not physically obvious to others. In a sense, the cancer was viewed as "forgotten," and there was an expectation to resume normal duties and roles. Support from loved ones wavered when participants began to improve and look better.

Communicating with Family and Friends (Box 3)

Families were supportive; however, at times the ways in which they tried to help was not useful or even wanted. There was a sense that family and friends were uncomfortable or unable to cope when the participant was "down" or wanted to talk about prognosis. One participant spoke of the difficulty in having to refuse advice perceived as helpful.

> . . . and in the end with all the herbal things and stuff I just had to say, 'I've chosen conventional treatment, I'm happy, it's working for me, just leave me alone' . . . . you're trying to manage yourself but also all those people around you so it's really hard work. (MM2-2)

Participants described talking to their children about myeloma as a key difficulty and "stressful." Regardless of children's ages, participants wanted to talk honestly using age-appropriate language during conversations without frightening them.

> It's very hard, she was only 9 when I was diagnosed, so, to try and tell her what was going to happen to me, we have to sort of tread lightly, because she's known cancer to be deadly . . . both her grandparents [died] . . . to say those words that her mum had it, would've been just traumatic. I had to try and find ways to explain it to her, that I wasn't going to end up in a coffin, you know? (MM1-2)

Dealing With Emotions (Box 3)

Many participants perceived stress was a contributing factor to their diagnosis and response to treatment.

> . . . stress, I think that's a massive part of my diagnosis, I was separated [at] diagnosis . . . I have noticed that when it's stressful . . . that's when my levels go up. (MM2-3)

Similarly, participants talked about their emotional response to diagnosis and how emotions fluctuated with disease status. There was the feeling they should be able to express the good and bad aspects without pressure to be continually positive. Coping strategies were discussed generally and specifically, especially those that helped maintain hope for the future such as better treatment options or having something to look forward to. Exercise, a positive frame of mind, and not "giving in" were identified as helpful strategies.

> Food and exercise. Book a holiday. Always have something to look forward to. (MM2-3)

For many participants, there was a sense that living with myeloma had a positive impact on their well-being, forcing them to "live in the now" and "appreciate the moment."

A reluctance to accept professional psychological support was described and a few felt by the time they had an appointment the need had passed. Participants who had accessed an

Box 4. Support Needs and Living With the Chronicity of the Disease.

Support needs	"It's not that you want to go and see a psychologist out in the suburbs cos maybe they've never dealt with somebody [with cancer] like that." MM2-7
Peer support	"You don't want to upset anybody and that's why I started going to the meetings . . . because you actually got to talk about it! With your family you don't sit like this and have a discussion. I mean initially I found it a bit sort of "oh my god" but then once you start talking it's like here, I mean everybody's in the same boat. I think it's a great opportunity for us to get our story out." MM1-2
	"And you wanted empathy not sympathy . . . But you could only get empathy from someone who was exactly where you are." MM1-6
	"Well maybe if there was a contact register . . . specific to people who did want to help, and you could be told 'this person is more than happy for you to contact them, you know, please do' or 'would you like us to get them to contact you?' Because sometimes . . . if X had've rung me, I would've been perfect with that, but I just couldn't do it myself." MM1-6
	"I know of other people at other hospitals and I've said 'you done that?' and they're saying 'no, haven't done that, what's that all about?' and I'm thinking surely there's got to be a common path that we tread down, with slight branches off depending on individuals, but there's got to be a common path—is that right or not?" MM2-8
Link person	"One thing I have thought about that I would really have liked is one person that I had the phone number of that I knew that I could ring if my appointment was wrong, if I was feeling depressed and wanted to arrange counseling, just one person. That was mine in this hospital somewhere." MM2-2
	"Yeah, just knowing that at any point you can ring up and you know, not get a message press this press that and get through to someone who couldn't help you anyway." MM2-3
Living with myeloma	"I don't think any of us really forget about it, there's not a day that goes by that I don't anyway!"MM1-2
Remission	"I feel fantastic. Everything's back to normal, apart from still having the disease, obviously. But I'm back at work, I'm back with the girls training for netball . . . So that is good, not being on anything." MM1-2

experienced cancer care psychologist at the hospital found it beneficial.

Support Needs (Box 4)

Gaps in service provision were identified during discussions, and participants made suggestions on what they would have found helpful. Participants described changing needs with regard to individual or group support at different stages in their cancer journey. They recognized individual differences existed in the types of support they may choose to access or want provided. Some found support groups useful to share experiences and gain informational, emotional, and social support. Others felt the group environment would be intimidating, or they would be unable to connect with others. Another issue was hearing about different treatment regimens, making them feel insecure about their treatment. However, for most there was a longing to be connected with others of a similar age and life stage.

> I found it really hard to go to the clinic and have my treatment because I didn't want to be sitting next to people who were quite a bit older than me. I couldn't talk to them because I felt like I didn't have anything in common. Obviously I did, because I had the disease . . . MM1-2

The suggestion was made that a contact register in the hospital could be beneficial, where individuals could approach others who had myeloma to talk through their shared experiences. Although, participants felt those overwhelmed by negative experiences would be unhelpful to connect with.

Participants felt a health professional link/support person was required, who had expert knowledge, be able to offer information, advice, and provide reassurance. This person could also act as the contact between participants and the wider support team and help facilitate communication.

Living With the Chronicity of the Disease (Box 4)

Participants discussed the chronicity of myeloma, living with an incurable disease and inevitability of relapse.

> Well, they say 'it's going to come back, it's not curable, it's treatable, but don't kid yourself because we can't cure you', so there's always this 'oh my gosh'. It's tough because you know you've got to go through it all again [treatment]. (MM1-6)

Many participants had experienced a relapse and spoke about dealing with recurrence. For some, the recurrence was as devastating as the initial diagnosis.

I'm not on drugs, I'm on a roll, and then you get symptomatic again and it was confirmed it was bad. It was devastating. (MM2-2)

Death and dying was not discussed in depth during the focus groups. Conversely, participants discussed periods of remission as a time when life returned to a sense of normality. This was expressed as comforting and liberating.

Discussion

Reports of the experiences of people living with myeloma and a description of their unmet needs are limited in published literature (14,15). Our study contributes to an understanding of the experiences of care and treatment for this group of people. Consistent with recent work (16,17), our findings indicate that support is required for people to adjust to living with an incurable disease has an unpredictable trajectory of remission, relapse, and refractory disease (18,19). This is an important area for future intervention. Most of the people in our study had never heard of myeloma before their own diagnosis, and as such, the need to ensure that patients and their support networks are well informed about the disease and what they can do to keep themselves well is an important consideration for enhancing survivorship experience (20,21).

Treatment side effects were described as one of the worst aspects of the experience, with many people reporting feeling unprepared to recognize or cope with them (20,22). Preparation and strategies for self-management of side effects were identified as a priority area where more intervention is required. Fatigue and peripheral neuropathy were reported as particularly challenging, as they impact negatively on daily functioning and the quality of life (16). These present important areas for future multidisciplinary, survivorship research. Developing effective, feasible resources that enable prompt, access to information about the disease, its treatments, and side effects is an important focus for survivorship innovation to minimize or ameliorate these unmet and highly burdensome needs. Survivorship research to minimize the physical and psychological impact of the complex symptoms and side effects of myeloma is urgently needed.

System issues highlighted as opportunities to improve posttreatment experiences included knowing blood results prior to an appointment, as a way of reducing anxiety and maximizing time for discussions at hospital appointments (16), and ensuring a focus on addressing emotional needs as well as medical issues.

Participants spoke about having to manage family's feelings and reactions while they tried to cope with their own. Development of survivorship services or resources targeted at family members/support networks may enhance posttreatment experiences for all affected by this disabling and complex disease.

Given the rarity and incurability of myeloma (23), some patients identified myeloma support groups as an important component of their survivorship care, providing information, emotional support, and a venue for shared understanding of their experience. A health professional "link" person was consistently identified as an important component of supportive survivorship care.

Limitations

This study reflects the views of a specific cohort of myeloma patients who self-selected to participate in our qualitative, exploratory study. The intent was to offer deeper understanding of the experiences of an underresearched group of people about whom we know little about their experiences. Given the intent of the work, the small number of people who took part and the heterogeneity across participants does not present methodological limitations as they would in a quantitative study. The findings are offered as an opportunity to build further research informed by patients' experiences. We acknowledge that disclosure by the focus group facilitator of her role as a psychologist may have influenced the content participants chose to share and issues discussed, but the similarity of our data with that reported from other studies undertaken with this group of patients indicates that this did not influence the information shared.

Conclusion

Participants in this study described unmet needs across a breadth of domains that varied over time. The development of flexible, person-centered approaches to comprehensive survivorship care is needed to address the considerable quality-of-life issues experienced by people living with multiple myeloma. Nurse-led care may offer 1 viable model to deliver enhanced patient experiences—providing the vital "link" that people described as missing from their survivorship care.

Acknowledgments

We thank all participants for their willingness to take part in this important study.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The study was supported by funding from the Cancer and Palliative Care Research and Evaluation Unit, Western Australian Cancer and Palliative Care Network.

References

1. Australian Institute of Health and Welfare. *Cancer in Australia: An Overview, 2014*. Cancer series no. 90. Cat. no. Can 88. Canberra, Australia: AIHW; 2014.

2. National Cancer Institute. NCI dictionary of cancer terms. 2017. https://www.cancer.gov/publications/dictionaries/cancer-terms/. Accessed April 3, 2017.
3. Allart P, Soubeyran P, Cousson-Gélie F. Are psychosocial factors associated with quality of life in patients with haematological cancer? A critical review of the literature. Psychooncology. 2013;22:241-9.
4. Osborne TR, Ramsenthaler C, Siegert RJ, Edmonds PM, Schey SA, Higginson IJ. What issues matter most to people with multiple myeloma and how well are we measuring them? A systematic review of quality of life tools. Eur J Haematol. 2012;89:437-57.
5. Johnsen AT, Tholstrup D, Petersen MA, Pedersen L, Groenvold M. Health related quality of life in a nationally representative sample of haematological patients. Eur J Haematol. 2009;83:139-48.
6. Molassiotis A, Wilson B, Blair S, Howe T, Cavet J. Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners. Psychooncology. 2011;20:88-97.
7. Molassiotis A, Wilson B, Blair S, Howe T, Cavet J. Living with multiple myeloma: experiences of patients and their informal caregivers. Support Care Cancer. 2011;19:101-11.
8. Lobb EA, Joske D, Butow P, Kristjanson LJ, Cannell P, Cull G, et al. When the safety net of treatment has been removed: patients' unmet needs at the completion of treatment for haematological malignancies. Patient Educ Couns. 2009;77:103-8.
9. National Coalition for Cancer Survivorship. 2017. http://www.canceradvocacy.org. Accessed April 3, 2017.
10. Neergaard MA, Olesen F, Andersen RS, Sondergaard J. Qualitative description—the poor cousin of health research? BMC Med Res Methodol. 2009;9:52.
11. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health. 2000;23:334-40.
12. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3:77-101.
13. Beck CT. Qualitative research: the evaluation of its credibility, fittingness, and auditability. West J Nurs Res. 1993;15:263-6.
14. Hauksdottir B, Klinke ME, Gunnarsdottir S, Bjornsdottir K. Patients' experiences with multiple myeloma: a meta-aggregation of qualitative studies. Oncol Nurs Forum. 2017; 44:E64-E81.
15. Osborne TR, Ramsenthaler C, de Wolf-Linder S, et al. Understanding what matters most to people with multiple myeloma: a qualitative study of views on quality of life. BMC Cancer. 2014;14:496.
16. Maher K, De Vries K. An exploration of the lived experiences of individuals with relapsed Multiple Myeloma. Eur J Cancer Care. 2011;20:267-75.
17. Cormican O, Dowling M. Managing relapsed myeloma: the views of patients, nurses and doctors. Eur J Oncol Nurs. 2016;23:51-58.
18. Stephens M, McKenzie H, Jordens CFC. The work of living with a rare cancer: multiple myeloma. J Adv Nurs. 2014;70: 2800-9.
19. Vlossak D, Fitch MI. Multiple myeloma: the patient's perspective. Can Oncol Nurs J. 2008;18:141-51.
20. Bishop MM, Curbow BA, Springer SH, Lee JA, Wingard JR. Comparison of lasting life changes after cancer and BMT: perspectives of long-term survivors and spouses. Psychooncology. 2011;20:926-34.
21. Dahan JF, Auerbach CF. A qualitative study of the trauma and posttraumatic growth of multiple myeloma patients treated with peripheral blood stem cell transplant. Palliat Support Care. 2006;4:365-87.
22. Potrata B, Cavet J, Blair S, Howe T, Molassiotis A. Understanding distress and distressing experiences in patients living with multiple myeloma: an exploratory study. Psychooncology. 2011;20:127-34.
23. Holt S. Multiple Myeloma: Risk Factors, Diagnosis and Treatments. New York, USA: Nova Biomedical; 2014.

Author Biographies

Leanne Monterosso, professor, is the inaugural Chair of Nursing (Clinical Nursing) at the University of Notre Dame Australia (Fremantle) and St John of God Hospital Murdoch. Her research interests include cancer and palliative care. Leanne is particularly interested in understanding the experiences of people living with cancer and undertaking implementation research to test nursing interventions to support these individuals and their families.

Karen Taylor is an experienced Cancer Nurse coordinator with the Western Australian Cancer and Palliative Care Network and a PhD candidate in cancer survivorship research at the University of Notre Dame Australia. Karen has a professional background in haematology, oncology, bone marrow transplant nursing across public and private hospitals in Australia. Karen is interested in research related to nurse-led models of survivorship care and supporting haematological cancer survivors.

Violet Platt is the co-director and director of Nursing of WA Cancer and Palliative Care Network. Violet is responsible for the delivery of all Statewide Cancer and Palliative Care Strategic initiatives and operationally responsible for the Statewide cancer nurse coordination service.

Elizabeth Lobb is the Cunningham Centre for Palliative Care's professor of Palliative Care based at Calvary Health Care Sydney and adjunct professor in the Faculty of Medicine at the University of Notre Dame Australia (Sydney). Elizabeth has established national and international research collaborations.

Toni Musiello is an experienced Clinical and Research psychologist, who holds a Doctorate and Masters degree in Health psychology. Toni has an interest in Psycho-oncology research.

Caroline Bulsara, associate professor, is a research coordinator in the School of Nursing and Midwifery, University of Notre Dame Australia (Fremantle). Caroline works primarily with qualitative research methods and community participatory research and provides leadership to universities, primary health care and non-government organizations to build research capacity.

Kendall Stratton is a Cancer Nurse specialist in the Western Australia Youth Cancer service and project manager of survivorship research at the University of Notre Dame Australia. Kendall has a professional background in paediatric and adolescent

oncology, haematology and bone marrow transplant nursing across hospital and community settings.

David Joske is a Clinical haematologist and Medical co-director at Sir Charles Gairdner Hospital and holds a clinical professor role at the University of Western Australia. David was head of Department from 1994-2013 and has had two NHMRC Fellowships. He has research interests in Supportive Care in cancer, psycho-oncology and lymphoma and is the founder and Chairman of the Solaris Cancer Care Foundation, which offers support to cancer patients and survivors in Western Australia.

Meinir Krishnasamy is chair in Cancer Nursing at the University of Melbourne and Research and Education lead for Cancer Nursing at the Victorian Comprehensive Cancer Centre. Mei is chief investigator on several national and international research grants, and sits on several national expert cancer policy committees.

Appendix C

Joint Authors' Declarations

Statement of Co-Authorship

Survivorship care plans and treatment summaries in adult patients with hematologic cancer: An integrative literature review. *Oncology Nursing Forum*, 2015, 42(3), 283–291

List of Authors: Taylor, K., & Monterosso, L.

PhD candidate: Karen M Taylor

Contribution of the PhD candidate to the paper:

The candidate undertook the search terms lists, literature search, review of journal articles, analysis of the journal articles, writing of the manuscript, revision for reviewers, and editing prior to publication. The co-author contributed search strategy, corrections, clarity with discussion, recommendations, review of revisions.

Karen M Taylor 04/02/2018

Leanne Monterosso 04/05/2018

Statement of Co-Authorship

Publication: Models of survivorship care provision in adult patients with haematological cancer: An integrative literature review. *Supportive Care in Cancer*, 2015, 23(5), 1447–1458

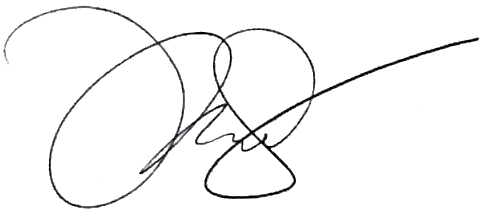
List of Authors: Taylor, K., Chan, R.J., & Monterosso, L.

PhD candidate: Karen M Taylor

Contribution of the PhD candidate to the paper:

The candidate undertook the search terms lists, literature search, review of journal articles, analysis of the journal articles, writing of the manuscript, revision for reviewers, and editing prior to publication. The co-authors contributed search strategy, corrections, clarity with discussion, recommendations, review of revisions.

Karen M Taylor 02/02/2018



Raymond J Chan 06/02/2018

Leanne Monterosso 04/05/2018

Statement of Co-Authorship

Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors. *The Australian Journal of Cancer Nursing*, 2016, 17(1), 6–12

List of Authors: Taylor, K., & Monterosso, L.

PhD candidate: Karen M Taylor

Contribution of the PhD candidate to the paper:

The candidate undertook the search terms lists, literature search, review of journal articles, analysis of the journal articles, writing of the manuscript, revision for reviewers, and editing prior to publication. The co-author contributed search strategy, corrections, clarity with discussion, recommendations, review of revisions.

Karen M Taylor 04/02/2018

Leanne Monterosso 04/05/2018

Statement of Co-Authorship

Protocol for Care After Lymphoma (CALy) trial: A phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *BMJ Open*, 2016, 6(e010817, 1–10

List of Authors: Taylor, K., Joske, D., Bulsara, M., Bulsara, C., & Monterosso, L.

PhD candidate: Karen M Taylor

Contribution of the PhD candidate to the paper:

The candidate undertook writing the manuscript, revision for reviewers, and editing prior to publication. The co-authors contributed corrections, recommendations, review of revisions.

Karen M Taylor 04/02/2018

David Joske 09/02/2018

Max Bulsara 07/05/2018

Caroline Bulsara 09/05/2018

Leanne Monterosso 04/05/2018

Statement of Co-Authorship

Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *European Journal of Oncology Nursing,* 2018, 35, 9–14.

List of Authors: Taylor, K., Monterosso, L., & Bulsara, C.

PhD candidate: Karen M Taylor

Contribution of the PhD candidate to the paper:

The candidate undertook the analysis of results, writing of the manuscript, revision for reviewers, and editing prior to publication. The co-authors contributed analysis support, corrections, recommendations, review of revisions.

Karen M Taylor 04/02/2018

Leanne Monterosso 04/05/2018

Caroline Bulsara 09/05/2018

Statement of Co-Authorship

Test–retest of the Short-Form Survivor Unmet Needs Survey. *Asia-Pacific Journal of Oncology Nursing*, 2018, 5(2), 165–171.

List of Authors: Taylor, K., Bulsara, M., & Monterosso, L.

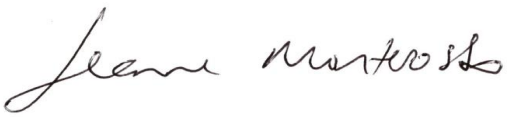
PhD candidate: Karen M Taylor

Contribution of the PhD candidate to the paper:

The candidate undertook the analysis of data, writing of manuscript, revision for reviewers, and editing prior to publication. The co-authors contributed corrections, recommendations, review of revisions.

Karen M Taylor 04/02/2018

Max Bulsara 07/05/2018



Leanne Monterosso 04/05/2018

Appendix D

Patient Information and Consent Form

SIR CHARLES GAIRDNER HOSPITAL

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

Participant Information Sheet/Consent Form

Effect of a Nurse-Led Lymphoma Survivorship Clinic: A Pilot Randomised Controlled Trial

Protocol Number: 2015-020
Project Sponsor: University of Notre Dame Australia
Coordinating Principal Investigator: Professor Leanne Monterosso
Principal Investigator: Karen Taylor
Associate Investigators: Dr David Joske, Violet Platt, Kendall Stratton, Professor Max Bulsara

What does my participation involve?
You are invited to take part in this research project, which is called the effect of a nurse-led lymphoma survivorship clinic. You have been invited because you have received treatment for lymphoma cancer: either Hodgkin's lymphoma or Non-Hodgkin's lymphoma. This research is specifically for patients who have completed treatment and are entering into the post treatment or 'survivorship' phase. Your haematologist has recommended you and has provided your contact details as you are about to, or have already finished treatment.

This Participant Information Sheet/Consent Form explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in this study.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or your treating doctor.

Your participation is **voluntary**. If you don't wish to take part, you don't have to.
If you decide you want to take part, you will be asked to sign the consent section. By signing it you are telling us that you:
• Understand what you have read
• Consent to take part in this research
• Consent to be involved in the research described
• Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

What is the purpose of this research?

"Survivorship" is a term that is commonly used to describe the experience of living with, through and beyond a diagnosis of cancer. People who have completed treatment for a blood (haematological) cancer such as lymphoma can have problems that impact on the practical, physical and emotional quality of their life. This study will test a nurse-led lymphoma survivorship clinic that will provide information, education and practical support to people like yourself who have just finished treatment. This will help in moving (transitioning) on from hospital care. Information will also be passed onto your General Practitioner (GP) about the treatment you have received and what to expect in the future. This will be in the form of a survivorship care plan treatment summary, which has been suggested as a way to help patients and GPs find out about the treatment received and the issues that may require further assessment and support with.

Western Australia has no formal survivorship care and this research aims to identify whether a survivorship clinic would be acceptable to patients like yourself to help reduce the number of problems encountered after treatment ends and to provide information to enable a healthy lifestyle. This pilot research will form the basis for future expansion of survivorship care for all blood cancer survivors across Western Australia.

Who is organising and funding the research?

This research is being conducted by Karen Taylor who is a PhD student at the University of Notre Dame Australia, under the supervision of the coordinating principal investigator Professor Leanne Monterosso. Karen is an experienced haematology cancer nurse. Other members of the research team include Dr David Joske from the SCGH Haematology Department, Violet Platt, Director of Nursing at the WA Cancer and Palliative Care Network, Kendall Stratton from the Youth Cancer Service and Professor Max Bulsara who is a leading biostatistician. This research is funded by the University of Notre Dame Australia.

No member of the research team will receive a personal financial benefit from your involvement in this research project.

What does participation in this research involve?

Consent

If you decide to participate in this study, please sign the consent form and bring it to your next haematologist appointment at SCGH. Karen will contact you on that day either before or after your appointment. Karen will need to check that you are eligible for the study by asking about your diagnosis and treatment. Your medical records will need to be accessed, but this will not occur without your consent.

Once you have consented, Karen will ask you to fill out four (4) questionnaires. These will be used to assess whether you have any particular needs related to practical, physical, emotional or social issues that are known to possibly affect patients after treatment for cancer such as lymphoma. These questionnaires my take up to an hour to complete.

Study Design

This study is called a randomised controlled trial. This means half the participants will get usual care with their haematologist and the other half will receive usual care and will participate in the nurse-led lymphoma survivorship clinics. This will be decided randomly. Once you have completed the questionnaires you will be asked to open a sealed envelope which will identify the group to which you will be assigned.

Control Group

If you open an envelope that indicates you are part of the control group you will be sent the same set of four (4) questionnaires at 3 months and 6 months. We ask that you complete them at home as soon as possible and send them back in the reply-paid envelope. If we haven't received them in two weeks' time, another research team member will call to check you have received them and that you have filled them in. At 6 months, once you complete the last set of questionnaires, your participation in the study will stop. All questionnaires will be checked by Karen once they are sent back and if at any time you have indicated you are struggling with an issue or concern, contact will be made with your haematologist to let them know so they can follow up with you.

Intervention Group

If you open an envelope that indicates you are part of the intervention group, an appointment will be made with you to come to the first of three (3) nurse-led lymphoma survivorship clinics run by Karen. The first clinic session will take place within a week of the initial questionnaires being completed. You are welcome to bring a partner, friend or family member to all the nurse-led lymphoma survivorship clinics. At the first clinic appointment any issues or concerns that you have highlighted on the questionnaires will be discussed. During this clinic, education on healthy lifestyle behaviours will be provided. You will also receive a resource pack of information designed to meet your individual needs or concerns. A survivorship care plan treatment summary will be completed by yourself and Karen to ensure you agree with the contents. How these documents will help you will be explained. The survivorship care plan treatment summary will also be sent to your GP and you are asked to take this document with you if you see your GP. At three and six months after baseline, you will be asked to return to the nurse-led lymphoma survivorship clinic and the same four questionnaires will be filled in by yourself and any issues or concerns discussed and support and information given.

After the six month clinic appointment, if you have consented to an interview, you may be contacted to give some feedback on the value, function and benefit of the nurse-led lymphoma survivorship clinic. Approximately 10 participants will be asked for this feedback in a telephone interview at a time that is convenient to you. It is not anticipated that this interview will take longer than an hour. This interview will be digitally recorded and typed into a document. All names and identifying information will be removed to protect your identity before analysis takes place.

We ask that you do not share the resources, information, survivorship care plan treatment summary with any other patients in the haematology clinics as this will affect the study results.

Monitoring of the study
This study will be monitored in accordance with the research protocol and the National Statement on Ethical Conduct in Human Research (2007) and the Australian Code for the Responsible Conduct of Research (2007).

Venue and Commitment required
The study will be conducted onsite at Sir Charles Gairdner Hospital (SCGH) and we ask that you complete all aspects of the study including: completing all questionnaires; returning questionnaires promptly and attending all clinic appointments as required. Questionnaires may take up to 30 minutes to complete. The nurse-led lymphoma survivorship clinics including questionnaire completion will be approximately one(1) hour. This study requires a commitment of six months.

Access to Personal Records and Confidentiality
Your medical records will need to be accessed to gain the information required to fill in the treatment summary and partially fill the survivorship care plan prior to the first nurse-led lymphoma survivorship clinic. This includes information such as your name, date of birth, address, gender, marital status, education, diagnosis and treatment.

Bias
This research project has been designed to make sure the researchers interpret the results in a fair and ethical way.

Costs
There are no direct costs associated with participating in this research project, nor will you be paid. If required, you may be asked to give up your time to travel to the first nurse-led lymphoma survivorship clinic and group session, which may incur travel and parking costs. The second and third nurse-led lymphoma survivorship clinic appointments will be scheduled to coincide with your routine three (3) monthly haematologist review appointments.

Do I have to take part in this research project?
Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.
Your decision whether to take part or not, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with Sir Charles Gairdner Hospital.

What are the possible benefits of taking part?
We cannot guarantee or promise that you will receive any benefits from this research. However, possible benefits may include identification of issues and concerns earlier in the post treatment period and referral to services that may assist with these issues.
Participant Information Sheet/Consent Form 22 August 2016 Version 6 It is intended the findings from this research will guide the development of expanded nurse-led survivorship clinics for all haematology patients and an expansion to other cancer patient.

What are the possible risks and disadvantages of taking part?
You may feel that some of the questions we ask are upsetting. If you do not wish to answer a question, you may skip it. If you become upset or distressed as a result of your participation in the study, the research team will arrange for counselling or other appropriate support. This will be provided free of charge by qualified staff who are not members of the research team.

What if I withdraw from this research project?
If you decide to withdraw from the project, please notify Karen. She will not collect additional information from you, although personal information already collected will be retained to ensure that the results can be measured properly and to comply with the law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell Karen when you withdraw from the research project.

What happens when the research project ends?
At the end of the study Karen will send you a summary of the study results. The results may not be available for up to 2 years after the study has finished for you as it depends on the length of time it takes to recruit all the patients required and for Karen to complete her PhD studies.

What will happen to information about me?
By signing the consent form you consent to the collection and use of your personal information for the research project. Your information will only be used for the purpose of this research and will only be disclosed with your permission, except as required by law. All information will remain confidential and will be kept in the locked office of Professor Leanne Monterosso at the University of Notre Dame Fremantle campus during the study. Information will be de-identified and stored in a locked archive for 15 years from the time the study is closed and published. After that time it will be destroyed.

Your health records and any information obtained during the research project are subject to inspection (for the purpose of verifying the procedures and the data) by the relevant authorities and authorised representatives of the Sir Charles Gairdner Hospital Human Research and Ethics Committee, relevant to this Participant Information Sheet, or as required by law. By signing the Consent Form, you authorise release of, or access to, this confidential information to the relevant research personnel and regulatory authorities.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission.

In accordance with relevant Australian and/or Western Australian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

Complaints and compensation
Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome. In the unlikely event that you experience any research-related harm as a result of taking part in this study, you will be provided with medical treatment/care at no cost to you. The term "research-related harm" means both physical and mental injury caused by the study drug, study product or study procedures required by the trial. Your consent to participate in this study does not affect your right to pursue a legal remedy from any party involved with the study, in respect to an injury alleged to have been suffered by you as a result of your participation.

Who has reviewed the research project?
All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of Sir Charles Gairdner Hospital and the University of Notre Dame Australia. This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

Further information and who to contact
The person you may need to contact will depend on the nature of your query. If you want any further information concerning this research or if you have any problems which may be related to your involvement, you can contact the researcher
Karen Taylor Survivorship Cancer Nurse Coordinator, Telephone contact: 0428 411 309, Email: Karen.Taylor@health.wa.gov.au Or Professor Leanne Monterosso (ph) 9433 0103.

Complaints contact person
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact the Executive Officer of the Sir Charles Gairdner and Osborne Park Health Care Group Human Research Ethics Committee on (08) 6457 2999, HREC.SCGH@health.wa.gov.au. Or the Executive Officer of the Human Research Ethics Committee, Research Office, The University of Notre Dame Australia, on (08) 9433 0943, research@nd.edu.au

Consent Form

Effect of a Nurse-Led Lymphoma Survivorship Clinic: A Pilot Randomised Controlled Trial

Protocol Number: 2015-020
Project Sponsor: University of Notre Dame Australia
Coordinating Principal Investigator: Professor Leanne Monterosso
Principal Investigator: Karen Taylor
Associate Investigators: Dr David Joske, Violet Platt, Kendall Stratton, Professor Max Bulsara

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

Signature _____ Date _____

Declaration by Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher (please print) _____

Signature _____ Date _____

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Appendix E

Assessment Measures

E.1 Demographic Questionnaire

Personal and Medical Demographic Questions

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

(Administered by Researcher)

Name:	
Code:	
Date:	

GP	
Contact Details:	

Personal Questions

1. Sex?
   a. Female
   b. Male
2. Age (in years)?
3. Marital Status (please circle)
   a. Single
   b. Married / De facto
   c. Divorced / Separated
   d. Widowed
4. Age (s) of Children (if any)?
   a. Child 1 .....
   b. Child 2 .....
   c. Child 3 .....
   d. Child 4 .....
5. Are you a primary carer?
   a. Yes (who for)
   b. No
6. Occupation?
7. Working Status (please circle)
   a. Currently working
      i. Full
      ii. Part time
   b. Retired
   c. Looking for work
   d. No return to work date set
8. Income level (please circle)
   a. $0 - $30,000
   b. $30,001 - $70,000
   c. $70,001 - $100,000
   d. $100,001 - $130,000
   e. Over $130,001
   f. Prefer not to answer
9. Education level?
   a. Secondary school or less
   b. Trade, vocational, college
   c. University or higher

Page 1

Medical Questions

10. Cancer type?

11. ECOG status:

12. Date of Diagnosis?

13. Time since diagnosis? (in months)

14. Stage of cancer at diagnosis
    a. Stage I
    b. Stage II
    c. Stage III
    d. Stage IV

15. Type of treatment received (please circle)
    a. Chemotherapy
    b. Immunotherapy
    c. Radiotherapy

16. Other chronic conditions (eg diabetes) Please list

Lifestyle related questions

17. Smoking status?
    a. Never smoked
    b. Quit smoking
        i. When (months or years)?
    c. Current smoker
        i. How many per day?

18. Do you drink alcohol?
    a. Yes
    b. No
        i. On average how many units per day?

19. Weight? (in Kg)

20. Postcode?

E.2 Short-Form Survivor Unmet Needs Survey

INSTRUCTIONS

We would like to know what unmet needs you have had IN THE LAST MONTH as a result of having cancer now or in the past. An **unmet need** is a need that you have not been able to satisfy.

For each question, place a circle around the number that best describes your level of unmet need IN THE LAST MONTH. Please answer each question, even if you feel there is no way to solve the problem or you do not have any unmet needs.

0	**No unmet need** – This was not a problem for me as a result of having cancer now or in the past.
1	**Low unmet need** – I needed a small amount of help with this problem but was not able to get it.
2	**Moderate unmet need** – I needed a moderate amount of help with this problem but was not able to get it.
3	**High unmet need** – I needed a high amount of help with this problem but was not able to get it.
4	**Very high unmet need** – I needed a very high amount of help with this problem but was not able to get it.

EXAMPLE

For each statement, circle the choice that best describes your level of unmet need.					
	No Unmet Need	Low Unmet Need	Moderate Unmet Need	High Unmet Need	Very High Unmet Need
Finding information about complementary or alternative therapies	0	1	(2)	3	4
If you circled #2, it means that IN THE LAST MONTH, you had a moderate need to know about complementary or alternative therapies but you were not able to get that information or help with your concerns.					
Circle the choice that best describes your level of unmet need.					
Knowing how much time I would need away from work	(0)	1	2	3	4
If you circled **0**, it means that, IN THE LAST MONTH, knowing how much time you needed away from work was not a problem for you.					

We know that your unmet needs may change over time. In this survey, we want to know only about the unmet needs you have had IN THE LAST MONTH.

Please go to the next page to begin the survey.

A. Unmet Information Needs: *This part of the survey is about unmet needs that relate to finding information IN THE LAST MONTH*

For each statement, circle the choice that best describes your level of unmet need.		*No Unmet Need*	*Low Unmet Need*	*Moderate Unmet Need*	*High Unmet Need*	*Very High Unmet Need*
1.	Finding information about complementary or alternative therapies	0	1	2	3	4
2.	Dealing with fears about cancer spreading	0	1	2	3	4
3.	Dealing with worry about whether the treatment has worked	0	1	2	3	4

B. Unmet Work and Financial Needs: *This part of the survey is about unmet needs you may have had about your job and finances IN THE LAST MONTH*

For each statement, circle the choice that best describes your level of unmet need.		*No Unmet Need*	*Low Unmet Need*	*Moderate Unmet Need*	*High Unmet Need*	*Very High Unmet Need*
4.	Worry about earning money	0	1	2	3	4
5.	Having to take a pension or disability allowance	0	1	2	3	4
6.	Paying household bills or other payments	0	1	2	3	4
7.	Finding what type of financial assistance is available and how to obtain it	0	1	2	3	4
8.	Finding car parking that I can afford at the hospital or clinic	0	1	2	3	4
9.	Understanding what is covered by my medical insurance or benefits	0	1	2	3	4
10.	Knowing how much time I would need away from work	0	1	2	3	4
11.	Doing work around the house (cooking, cleaning, home repairs, etc.)	0	1	2	3	4

C. Unmet Needs for Access and Continuity of Care: ***This part of the survey is about unmet needs that relate to medical care IN THE LAST MONTH***

For each statement, circle the choice that best describes your level of unmet need.		*No Unmet Need*	*Low Unmet Need*	*Moderate Unmet Need*	*High Unmet Need*	*Very High Unmet Need*
12.	Having access to cancer services close to my home	0	1	2	3	4
13.	Getting appointments with specialists quickly enough (oncologist, surgeon, etc.)	0	1	2	3	4
14.	Getting test results quickly enough	0	1	2	3	4
15.	Having access to care from other health specialists (dieticians, physiotherapists, occupational therapists)	0	1	2	3	4
16.	Making sure I had enough time to ask my doctor or nurse questions	0	1	2	3	4
17.	Getting the health care team to attend promptly to my physical needs	0	1	2	3	4

D. Unmet Coping, Sharing and Emotional Needs: ***This part of the survey is about unmet needs that relate to your relationships with others and your emotional health IN THE LAST MONTH***

For each statement, circle the choice that best describes your level of unmet need.		*No Unmet Need*	*Low Unmet Need*	*Moderate Unmet Need*	*High Unmet Need*	*Very High Unmet Need*
18.	Telling others how I was feeling emotionally	0	1	2	3	4
19.	Finding someone to talk to who understands and has been through a similar experience	0	1	2	3	4
20.	Dealing with people who expect me to be "back to normal"	0	1	2	3	4
21.	Dealing with people accepting that having cancer has changed me as a person	0	1	2	3	4

For each statement, circle the choice that best describes your level of unmet need.		*No Unmet Need*	*Low Unmet Need*	*Moderate Unmet Need*	*High Unmet Need*	*Very High Unmet Need*
22.	Dealing with reduced support from others when treatment has ended	0	1	2	3	4
23.	Dealing with feeling depressed	0	1	2	3	4
24.	Dealing with feeling tired	0	1	2	3	4
25.	Dealing with feeling stressed	0	1	2	3	4
26.	Dealing with feeling lonely	0	1	2	3	4
27.	Dealing with not being able to feel 'normal'	0	1	2	3	4
28.	Trying to stay positive	0	1	2	3	4
29.	Coping with having a bad memory or lack of focus	0	1	2	3	4
30.	Dealing with changes in how my body appears	0	1	2	3	4

E.3 Depression Anxiety Stress Scale

DASS21 *Name:* *Date:*

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

E.4 Mini Mental Adjustment to Cancer Scale

MINI-MAC SCALE

Name: _____ Date:

A number of statements are given below which describe people's reactions to having cancer. Please tick the box to the right of each statement, indicating how far it applies to you **at present**.

	Definitely does **not** apply to me	Does **not** apply to me	Applies to me	Definitely applies to me
1. At the moment I take one day at a time	☐	☐	☐	☐
2. I see my illness as a challenge	☐	☐	☐	☐
3. I've put myself in the hands of God	☐	☐	☐	☐
4. I feel like giving up	☐	☐	☐	☐
5. I feel very angry about what has happened to me	☐	☐	☐	☐
6. I feel completely at a loss about what to do	☐	☐	☐	☐
7. It is a devastating feeling	☐	☐	☐	☐
8. I count my blessings	☐	☐	☐	☐
9. I worry about the cancer returning or getting worse	☐	☐	☐	☐
10. I try to fight the illness	☐	☐	☐	☐
11. I distract myself when thoughts about my illness come into my head	☐	☐	☐	☐
12. I can't handle it	☐	☐	☐	☐
13. I am apprehensive	☐	☐	☐	☐
14. I am not very hopeful about the future	☐	☐	☐	☐

	Definitely does **not** apply to me	Does **not** apply to me	Applies to me	**Definitely** applies to me
15. I feel there is nothing I can do to help myself	☐	☐	☐	☐
16. I think it is the end of the world	☐	☐	☐	☐
17. Not thinking about it helps me cope	☐	☐	☐	☐
18. I am very optimistic	☐	☐	☐	☐
19. I've had a good life what's left is a bonus	☐	☐	☐	☐
20. I feel that life is hopeless	☐	☐	☐	☐
21. I can't cope	☐	☐	☐	☐
22. I am upset about having cancer	☐	☐	☐	☐
23. I am determined to beat this disease	☐	☐	☐	☐
24. Since my cancer diagnosis I now realise how precious life is and I'm making the most of it	☐	☐	☐	☐
25. I have difficulty in believing that this happened to me	☐	☐	☐	☐
26. I make a positive effort not to think about my illness	☐	☐	☐	☐
27. I deliberately push all thoughts of cancer out of my mind	☐	☐	☐	☐
28. I suffer great anxiety about it	☐	☐	☐	☐
29. I am a little frightened	☐	☐	☐	☐

E.5 Patient Empowerment Scale

PATIENT SUPPORT STRATEGIES QUESTIONNAIRE

INSTRUCTIONS TO PATIENT

Please indicate by marking with a tick (✓) whether you strongly agree, agree, disagree or strongly disagree with the following statements. Please read the statements carefully and tick your responses to them. **If a question does not apply to you please leave it blank**.

	Strongly agree	Agree	Disagree	Strongly disagree
1. I am capable of handling my illness	☐	☐	☐	☐
2. I have all the information I need to manage my illness.	☐	☐	☐	☐
3. I am capable of helping health professionals reach decisions related to my illness.	☐	☐	☐	☐
4. My family are very supportive.	☐	☐	☐	☐
5. I need the support of my family and friends	☐	☐	☐	☐
6. My family and friends still rely on me.	☐	☐	☐	☐
7. I can adapt to the changes in my lifestyle.	☐	☐	☐	☐
8. Health professionals are happy to include me in decisions related to my illness.	☐	☐	☐	☐
9. I want my family and friends to continue to rely on me.	☐	☐	☐	☐
10. My friends are always supportive.	☐	☐	☐	☐

	Strongly agree	Agree	Disagree	Strongly disagree
11. I still feel useful in my daily life.	☐	☐	☐	☐
12. My spiritual beliefs help me cope with my illness.	☐	☐	☐	☐
13. I accept that I have to change my lifestyle.	☐	☐	☐	☐
14. Complementary therapies help me cope with my illness.	☐	☐	☐	☐
15. I have a lot of confidence in my local GP.	☐	☐	☐	☐

Appendix F

F.1 Lymphoma Survivorship Care Plan and Treatment Summary

THE UNIVERSITY OF NOTRE DAME AUSTRALIA — Sir Charles Gairdner Hospital

LYMPHOMA SURVIVORSHIP CARE PLAN & TREATMENT SUMMARY

Diagnosis: CHOOSE
Subtype:
Stage:

Date:

TREATMENT SUMMARY

Date of **Diagnosis**:Click here to enter a date. Age at Diagnosis: ☒New

Location/s of disease:

Goal of treatment:

Chemotherapy regimen: No. of cycles given: Reason for stopping:

Chemotherapy START date: Click here to enter a date. Chemotherapy END date: Click here to enter a date.

Significant Alterations:

Current Maintenance treatment: Clinical Trial:

Major **side effects** experienced during treatment:

Allergy or **drug reactions** during treatment:

Radiotherapy START date: Radiotherapy END date: Type:

Region treated: Radiation Oncologist:

Haematopoietic Stem Cell Transplant:

Allied Health Providers accessed during treatment: ☐Physio ☐Dietician ☐Social work ☐Psychologist ☐Psychiatrist ☐OT ☐Other (list):

SURVIVORSHIP FOLLOW-UP CARE PLAN

Possible Late Effec of Treatment	Recommended Follow-up	Patient things to watch for
Heart Disease	**GP** to monitor cardiac risk factors: • Regular cholesterol • Blood pressure check If concerned **GP** can arrange • Echocardiogram • ECG • Stress test	• Chest pain • Shortness of breath • Dizziness • Ongoing breathlessness after minor activity
Skin cancer risk	• Avoid sunburn • Annual skin check and discuss spots of concern with **GP**	• Cover up and apply regular sunscreen wher outside • Look at your whole body monthly and encourage your partner to check your back Please discuss any concerns with GP
Bone marrow cancer risk	• Annual full blood picture by **GP** for the next **10 years**	• Excessive tiredness • Unusual areas of bruising or bleeding Please discuss any concerns with GP and haematologist

Haematologist: Signature:

GP contact details:

30/07/2015 Approved Version 1

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

Sir Charles Gairdner Hospital

Patient-identified Main Health Concerns	Patient-identified Health Goals	Patient-identified Actions*
1. 2. 3.	1. 2. 3.	

*Please Note: It is the patient's responsibility to arrange the recommended follow-up discussed today with their GP.

Patient Signature: Date:

Survivorship Coordinator: Karen Taylor: 0428 411 309 Signature:

The Haematology team will continue to assess this patient regarding their haematology cancer.
Urgent clinical advice can be obtained by contacting the relevant haematologist on 6457 3333.

30/07/2015 Approved Version 1

Sir Charles Gairdner Hospital Lymphoma Survivorship Care Plan — THE UNIVERSITY OF NOTRE DAME AUSTRALIA

GENERAL HEALTH INFORMATION for PATIENTS

Please discuss any of the following issues with your GP

Your GP can refer you back to SCGH if they are concerned your lymphoma may be recurring

Important NEW symptoms to watch for:

- Any persistent new or unusual:
  - Shortness of breath, chest pain or palpitations
  - Pain including bones
  - Swelling of arms or legs
  - Bleeding or bruising
  - Skin spots or changes to moles
- Unintentional weight loss
- Persistent loss of energy
- Recurrence of presenting signs and symptoms
- Night sweats
- Generalised itching
- Firm painless swollen lymph nodes

Possible effects of treatment to discuss:

- Excessive tiredness, difficulty sleeping
- Tingling, numbness or pain in fingers and toes
- Distress, anxiety, depression
- Altered interest or impaired sexual intimacy
- Possible impaired fertility
- Possible changes to menstrual cycle
- Memory loss and/or confusion
- Skin changes
- Education, employment and social difficulties

Current General Screening Recommendations:

Aim to follow-up age appropriate screening. Finding cancer early offers the best chance of successful treatment (with more frequent screening if you have other risk factors)

Reason	Tests	Frequency	Coordinating provider
Breast Cancer	Mammogram	2 yearly age 50-75	GP/ Breastscreen
Cervical cancer	Pap Smear	2 yearly from age 18	GP
Colorectal cancer	Faecal Occult Blood Test (FOBT) Colonoscopy	2 yearly from age 50 3-5 yearly if family history	GP (Note: Department of Health arranges 5 yearly FOBT screening)
Skin cancer risk	Full skin examination	Annually	GP / Dermatologist

General Health Recommendations:

Mental and spiritual health	• Treatment completion can affect you and your family emotionally, socially and spiritually • Access counselling and support services ○ GP can arrange private psychologists and counsellors. You may be eligible for subsidised treatment under a Mental Health Care Plan
Infection risk	• Treatment may increase your risk of infection • Annual flu vaccination is recommended. Your GP can arrange this
Dental issues	• Some treatment can cause dental issues • An annual check-up with your dentist is recommended
Contraception	• It is recommended you discuss this with your GP if you have been advised not to plan a pregnancy within 6 months of treatment completion

Sir Charles Gairdner Hospital Lymphoma Survivorship Care Plan

Staying Healthy and Reducing the Risk of Recurrence:

A healthy lifestyle is important in your ongoing recovery from treatment and can reduce the risk of other cancers occurring. The following healthy lifestyle choices can also reduce other illnesses developing such as heart disease and diabetes.

Healthy diet	• Aim for 2 serves of fruit and 5 serves of vegetables every day ○ Include cereals, fibre and dairy products • Aim to reduce the amount of sugar, fat, salt • https://**livelighter**.com.au www.eatforhealth.gov.au

Healthy body weight	• Avoid becoming too underweight, overweight or obese
	  ○ A healthy Body Mass Index (BMI) range is 20 – 25
	• Aim for a waist measurement of < 80 cm women & < 94 cm men
	• If you need to reduce your weight
	  ○ reduce your overall calorie intake
	  ○ limit alcohol – contains a lot of calories
	  ○ increase wholegrain foods
	• Weight gain and maintenance may require dietitian input

Regular exercise	• Aim for 30 minutes 5 times per week
	• Gradually increase your levels of planned exercise
	  ○ i.e. exercise class, swimming, walking group
	• Take opportunities to be physically active
	  ○ i.e. take the stairs rather than lifts, walk instead of driving
	  ○ The amount rather than intensity of exercise is important

Sun smart	• Avoid sunburn ○ increased risk from chemotherapy and /or radiotherapy use • Aim to balance sun exposure for vitamin D and risk of skin cancer • http://www.cancerwa.asn.au/prevention/sunsmart/
Limiting or avoiding alcohol	• Aim for no more than 2 standard drinks per day ○ 1-2 alcohol free days each week • Many diseases and some cancers can be alcohol related

Avoid smoking	• To reduce the risk of recurrence and other cancers
	• Help can be obtained through
	  ○ GP
	  ○ Quitline 13 78 48
	  ○ www.quitnow.gov.au
	  ○ http://makesmokinghistory.org.au/im-ready-to-quit/ways-to-quit/
	  ○ Fresh start 13 11 20 or FreshStart@cancerwa.asn.au

Resources:

- GP
- Cancer Council 13 11 20 http://www.cancerwa.asn.au
- Leukaemia Foundation 1800 620 420
- Lymphoma Association 1800 359 081
- Carers Australia 1800 242 636

F.2 Content Validity Evaluation Form

Validation of the Survivorship Care Plan Treatment Summary (SCP TS) for use with lymphoma cancer survivors

The Survivorship Care Plan Treatment Summary (SCPTS) has been developed by the chief investigator Karen Taylor (Cancer Nurse Coordinator Survivorship, Western Australia Cancer and Palliative Care Network (WACPCN) & PhD candidate, University of Notre Dame Australia (UNDA)). The principal supervisor for this research, Professor Leanne Monterosso PhD, BNurs(Hons) and the associate clinical investigator, Professor David Joske have assisted with the development, content and structure of the SCPTS.

To assist in ensuring this document is clear, consistent and valid for use with lymphoma survivors, I would like to invite you to assist in this process by answering a number of questions that relate to each of the areas this SCP TS covers. This will determine the content clarity, apparent internal consistency and content validity of the Survivorship Care Plan Treatment Summary (SCP TS) that has been developed for use with lymphoma cancer survivors.

If you have any questions before or after you have completed this questionnaire, please contact Karen Taylor 0428 411 309 or Karen.Taylor@health.wa.gov.au

Please read the following directions carefully and fill in all sections of the table.

Your participation in this part of my research project is invaluable and greatly appreciated.

Evaluation of the Survivorship Care Plan Treatment Summary (SCP TS)

The components of this questionnaire will be scored as either a Yes/No answer or on a 4-point Likert-type scoring scale:

1. Clarity - refers to whether each item is clearly defined – Y = yes or N = no

2a. Apparent internal consistency – refers to whether each item belongs in the SCPTS – Y = yes or N = no

2b. Apparent internal consistency – refers to whether each item generally belongs within the SCPTS – Y = yes or N = no

3. Content validity index – refers to the level of relevance each item has when assessing the question inclusion for the SCPTS.

Please score in this column according to the following 4-point Likert-type scoring scale

Not Relevant=1	Somewhat Relevant=2	Quite Relevant=3	Highly Relevant=4

The tables are divided into three sections:

- Table 1 refers to the Survivorship Care Plan section
- Table 2 refers to the Treatment Summary section
- Table 3 refers to the General Health and Screening section

Please look at the section each table refers to and use the following table to assess each item.
Please add any comments/suggestions in the box provided.

Table 1 Survivorship Care Plan

Content	1. Is this heading/information clear? Y/N	2a. Should this information be included in a survivorship care plan? Y/N	2b. Does this information generally fit with the other information Y/N	3. How relevant is this information for a survivorship care plan? Score between 1-4	Please indicate whether you are: Lymphoma Survivor (LS); GP (GP); Haematologist (H) or Nurse (N)	Comments
Possible late effect column						
Follow-up recommended						
Discussion notes						
My main health concerns						
My main health goals						
Haematologist details						
Survivorship coordinator details						
GP details						

Table 2 Treatment Summary

Information	1. Is this information clear? Y/N	2a. Should this information be included in a treatment summary? Y/N	2b. Does this information generally fit with the other information? Y/N	3. How relevant is this information for a treatment summary? Score between 1-4	Please indicate whether you are: Lymphoma Survivor (LS); GP (GP); Haematologist (H) or Nurse (N)	Comments
Date of diagnosis						
Age at diagnosis						
New or relapse						
Subtype						
Location of disease						
Extra-nodal sites						
Major co-morbid conditions						
Goal of treatment						
Chemotherapy regimen						
Clinical trial						
Chemotherapy start date						
Chemotherapy end date						
Number of cycles planned						
Number of cycles given						
Reasons for stopping						
Planned						

maintenance						
Blood product support						
Toxicities						
Major side-effects						
Current side-effects						
Treatment drug summary						
Radiotherapy start date						
Radiotherapy end date						
Region treated						
Dose						
Response						
Contact details						
Stem cell transplant						
Allied health providers						

Table 3 General Health and Screening

Information	1. Is this information clear? Y/N	2a. Should this information be included in general health and screening? Y/N	2b. Does this information generally fit with the other information? Y/N	3. How relevant is this information for general health and screening? Score between 1-4	Please indicate whether you are: Lymphoma Survivor (LS); GP (GP); Haematologist (H) or Nurse (N)	Comments
New symptoms to watch for						
Possible effects of treatment						
Staying healthy table						
Diet						
Exercise						
Sun Smart						
Weight						
Alcohol						
Smoking						
Screening						
Mental health						
Resources						
General screening recommendations						

Thank You for taking the time to fill in this questionnaire
Your contribution will assist in improving patient services/outcome

Appendix G

Control Group Letter

Sir Charles Gairdner Hospital [Date]
Haematology Clinic

Dear [insert name],

Nurse-led Lymphoma Survivorship Trial

You have agreed to be part of a study to test the effect of a nurse-led lymphoma survivorship clinic against the usual standard of follow-up care.

As part of your commitment to this research, we are asking you to fill in the same 4 questionnaires you did 3 months ago and return them in the provided reply-paid envelope. We would ask you to do this as soon as possible after receiving them.

We appreciate your participation as your commitment to this research will assist in the development of survivorship services in Western Australia.

If you have any questions or would like further information then please do not hesitate to contact me on 0428 411 309.

Yours sincerely

Karen Taylor
Survivorship Cancer Nurse Coordinator
PhD Candidate

Appendix H

GP Letters and Evaluation

H.1 GP cover letter for SCPTS

Sir Charles Gairdner Hospital
Haematology Clinic

[Date]

Dear Doctor [insert name]

Lymphoma Survivorship Trial

Your patient, [insert name] s participating in a randomised controlled trial to test the effect of a nurse-led lymphoma survivorship clinic against the usual standard of follow-up care. This clinic is for lymphoma patients who have finished their chemotherapy treatment. As part of this clinic intervention a "Survivorship Care Plan & Treatment Summary" has been developed in conjunction with the Consulting Haematologist, the patient and myself.

Survivorship care plans and treatment summaries have been proposed as a way to improve communication between clinicians and the patient. Cancer patients treated with chemotherapy may be at increased risk of certain health problems. The purpose of this document is to:

- summarise the treatment given;
- list possible current and late effects of treatment and recommended follow-up;
- identify the patient's major health concerns and goals; and
- provide general health information to promote wellness.

The patient may make an appointment to meet with you to discuss their recommended follow-up care.

If you have any urgent clinical concerns these should be directed to the Haematology Department at SCGH who will continue to follow up this patient and send their usual clinic letter documentation.
EviQ can be accessed to provide further up to date, evidence-based cancer treatment information. Free access is available at: www.eviq.org.au. Username: phc. Password: phc.

As part of the assessment of this Survivorship Care Plan & Treatment Summary, an evaluation form will be sent to you in six months to gauge your use of the Survivorship Care Plan & Treatment Summary, and your thoughts on its usefulness.

If you have any questions or would like further information about this survivorship study, please do not hesitate to contact me.

Yours sincerely

Karen Taylor
Survivorship Cancer Nurse Coordinator/PhD Candidate
Karen.Taylor@health.wa.gov.au
0428 411 309

H.2 GP Cover Letter for Evaluation

Sir Charles Gairdner Hospital
Haematology Clinic

[Date]

Dear Doctor [insert name]

Lymphoma Survivorship Trial

Your patient [insert name] has been part of a randomised controlled trial to test the effect of a nurse-led lymphoma survivorship clinic against the usual standard of follow-up care.

We would like your feedback as to whether the information we provided in the Survivorship Care Plan & Treatment Summary has been helpful to you. A plan for this patient should have been posted to you six months ago when the patient commenced in the trial. A copy has been attached with this letter.

Please complete the attached questionnaire and return in the provided reply-paid envelope. Alternatively, it can be faxed back "Attention Karen Taylor Survivorship CNC" to 6457 4432 or scanned to the email address below.

We appreciate all the information that you are able to give as this will assist in the evaluation of survivorship services.

If you have any questions or would like further information then please do not hesitate to contact me.

Yours sincerely

Karen Taylor
Survivorship Cancer Nurse Coordinator
PhD Candidate
Karen.Taylor@health.wa.gov.au
0428 411 309

H.3 GP Evaluation of SCPTS

GP QUESTIONNAIRE OF SURVIVORSHIP CARE PLAN & TREATMENT SUMMARY

THE UNIVERSITY OF NOTRE DAME AUSTRALIA

GP name: Number of years working as a GP: Your Gender: M / F

Have you seen this patient in the last 6 months? YES NO

The following questions all relate to the **Survivorship Care Plan & Treatment Summary** document.

Please circle your answer for the following questions

1. Did you **receive** the Survivorship Care Plan & Treatment Summary for this patient in the mail 6 months ago?	YES	NO	
2. Did you **read** the plan **on receipt**?	YES	NO	
3. Did you or the medical practice **initiate a patient appointment** upon receipt?	YES	NO	
4. If you **did not initiate a patient appointment**, did the patient initiate an appointment to discuss the plan with you?	YES	NO	
5. Did the **patient bring a copy** of their plan to the appointment?	YES	NO	NA
6. Did you **discuss** the plan with the **patient**?	YES	NO	NA
7. Did you initiate any **support or resources** for the patient as a result of discussing their health concerns, health goals and actions?	YES	NO	NA

For each item below, circle the number to the right that best fits your rating on the following questions

Survivorship Care Plan & Treatment Summary	Scale				
	Very Poor	Poor	Adequate	Good	Very Good
1. Overall how useful would you rate the **treatment** information given?	1	2	3	4	5
2. Overall how useful would you rate the **survivorship care plan** information given?	1	2	3	4	5
3. Overall how useful would you rate the patient **health concerns, goals and action** information given?	1	2	3	4	5
4. How would you rate the overall **usefulness** of this document for this patient?	1	2	3	4	5

What further information would you like to receive on this plan?_____

What information **does not** need to be on the plan?_____

Page 1 of 2

Other Comments_____

_____

_____

_____

_____

_____

Would you like further education on the management of haematology "survivors"? YES NO

If yes then what aspects? _____

_____

_____

_____

_____

How would you like that Education? Workshop / Online / learning package / at my practice /other (please specify)_____

Thank you for your participation.

Please return to the researcher in the reply paid envelope or Fax to 6457 4432 or scan Karen.Taylor@health.wa.gov.au.

Appendix I

Interview Questions

Interview guide for patient participants

Thank you for volunteering for this interview and for participating in the survivorship study. I would like to talk to you about your experience of the survivorship clinic and record your thoughts about this and any suggestions you may have to improve the experience for future patients. As you may be aware, the study involves a 'nurse-led cancer survivorship clinic' – something that hasn't been offered to cancer patients before. The study was focusing on the development and testing of this new form of cancer survivorship or follow-up care after treatment has finished.

From your perspective what are your thoughts about the questionnaires you were asked to complete at each clinic visit?

1. Did you have any concerns or needs that weren't addressed by any of the questions?
   - if yes, can you please tell me what these were?

2. The time it took to answer all the questions?

3. Did you think any questions were too intrusive?

We are hoping survivorship care will become routine for all cancer patients when they finish treatment at the hospital. As you know at the moment the survivorship clinic is offered after all treatment is completed.

4. Would you have preferred to know about this clinic after diagnosis or earlier in the treatment phase?
   - would this have helped you think beyond the treatment phase to what comes after treatment finishes?
   - why do you feel this way, can you explain?

5. What aspects of the clinic would you want to stay the same for other cancer patients in the future?

6. Can you please describe the difference (if any) this clinic has made for you after finishing your treatment phase?
   6.1 What do you consider the best part of coming?
   6.2 Were there are any downsides to coming?
   6.3 If you could change anything about the clinic, what would you change?

7. Would you recommend the clinic for other patients who are about to finish treatment?

- why or why not?

Now I would like to ask some questions on your thoughts of the survivorship care plan and treatment summary you received. This is the document Karen gave you.

8. Did you find the treatment summary section a helpful summary of your diagnosis and treatment? (This is page 1)

- would you like to see more information on that part?
- did you feel any information was not explained enough or difficult to understand?

9. What were your thoughts and reactions to the potential late effects information you were given? (These are on the first page under the treatment summary).

- were they as you expected?
- did they add to your worry about the cancer treatment?
- had this information been given to you before by your doctors?

10. How did you feel about having the health concerns, goals and actions individualised to yourself? (This was the second page).

- did you find it useful to explore your needs in this way?
- were you concerned this information would be shared with your medical team?

11. Do you have any thoughts on the general health and screening information? (This was the 2 page sheet).

- did you find it useful?
- were there parts you found more useful than others?

12. Did you discuss the survivorship care plan and treatment summary with your GP?

- did they have any thoughts on this document they shared with you?

13. Overall how useful was the survivorship care plan and treatment summary to you?

Thank you for patience, these few questions relate to finding out about the study.

14. Did your haematology Dr mention the study to you prior to the researcher Karen contacting you?

14.1 Did your haematology Dr discuss the survivorship care plan and treatment summary with you?

Lastly these questions are about Karen's nurse-led clinic – these are not about the treatment clinic or Dr appointments.

From your perspective what are your thoughts about:

15. Its location? Would you have preferred to be away from the hospital?

16. The timing of the visit?

5.1 Do you have any thoughts about when the clinic should commence?

- just before the last treatment?
- immediately after the last treatment?
- later than 3 months after treatment has completed?

17. The length of each clinic visit?

18. The information you were given?

- was it too much or too little?
- was the timing of the information right?
- how relevant was the information to you?

19. Do you have any other thoughts or issues to raise that we haven't discussed today?

I appreciate the time you have given today and your insights and thoughts in relation to your experience. Thank you for agreeing to this interview, and for your participation throughout

Appendix J

J.1 Checklist for Nurse-led Lymphoma Survivorship Clinic Appointment

Patient details

Script for Clinic:

- Go over treatment summary pre filled
- Go over SCP pre filled LE
- Go over Needs assessment questionnaires and highlight concerns they self-reported
- Add in main concerns, goals and actions
    - Motivational chart if needed
- Go over healthy info and screening sheet and highlight applicable to them
    - Other questions that may come up
- Go over resources given
- Encourage take SCPTS when visiting GP

☐ SCPTS / GP letter in hospital record and uploaded to MOSAIQ
☐ SCPTS and cover letter sent to GP

☐ Next appointment DATE:

Received back
☐ SF-SUNS re-test

RESOURCES GIVEN
☐ **SCPTS**
☐ **General health information sheet**

☐ Motivational chart

Booklets:
☐ "Living Well After Cancer"
☐ "When Cancer Changes your financial plans"
☐ "Sexuality, Intimacy and Cancer"
☐ "Cancer Work and You"
☐ "Exercise"

Information Sheets:
☐ Fatigue
☐ Coping with Fear of Recurrence
☐ Legal or financial Service
☐ Canteen postcard
☐ Pro Bono information
☐ Insurance information
☐ Cognition information
☐ Workplace Advisory
☐ Life Now Information and dates
☐ Patient education sessions
☐ CCWA information and support services
☐ CCWA counselling brochure
☐ Solaris brochure
☐ Healthy eating guide
☐ Exercise (ECU)
☐ Mental Health Plan information

Numbers:
☐ Centrelink 13 27 17
☐ Family Assistance office 13 61 50
☐ Financial Counselling Helpline 1800 007 007
☐ Salvation Army 1300 36 3 622
☐ Rekindle 1300 85 44 37

J.2 Motivational Chart

Motivational chart

Behaviour/Problem:	LIKE	DISLIKE
Stay the Same	List what you like about the behaviour	List what you don't like about the behaviour
Change	List what you think will be better	List what you think will be difficult

Appendix K

K.1 SPIRIT Checklist for Protocol

SPIRIT 2013 Checklist: Recommended items to address in a clinical trial protocol and related documents*

Section/item	Item No	Description	Addressed on page number
Administrative information			
Title	1	Descriptive title identifying the study design, population, interventions, and, if applicable, trial acronym	1
Trial registration	2a	Trial identifier and registry name. If not yet registered, name of intended registry	1
	2b	All items from the World Health Organization Trial Registration Data Set	3
Protocol version	3	Date and version identifier	Footnote of protocol
Funding	4	Sources and types of financial, material, and other support	22
Roles and responsibilities	5a	Names, affiliations, and roles of protocol contributors	1-2
	5b	Name and contact information for the trial sponsor	1
	5c	Role of study sponsor and funders, if any, in study design; collection, management, analysis, and interpretation of data; writing of the report; and the decision to submit the report for publication, including whether they will have ultimate authority over any of these activities	No role
	5d	Composition, roles, and responsibilities of the coordinating centre, steering committee, endpoint adjudication committee, data management team, and other individuals or groups overseeing the trial, if applicable (see Item 21a for data monitoring committee)	21

1

Introduction			
Background and rationale	6a	Description of research question and justification for undertaking the trial, including summary of relevant studies (published and unpublished) examining benefits and harms for each intervention	8
	6b	Explanation for choice of comparators	7
Objectives	7	Specific objectives or hypotheses	7
Trial design	8	Description of trial design including type of trial (eg, parallel group, crossover, factorial, single group), allocation ratio, and framework (eg, superiority, equivalence, noninferiority, exploratory)	9-10
Methods: Participants, interventions, and outcomes			
Study setting	9	Description of study settings (eg, community clinic, academic hospital) and list of countries where data will be collected. Reference to where list of study sites can be obtained	10
Eligibility criteria	10	Inclusion and exclusion criteria for participants. If applicable, eligibility criteria for study centres and individuals who will perform the interventions (eg, surgeons, psychotherapists)	10
Interventions	11a	Interventions for each group with sufficient detail to allow replication, including how and when they will be administered	16
	11b	Criteria for discontinuing or modifying allocated interventions for a given trial participant (eg, drug dose change in response to harms, participant request, or improving/worsening disease)	NA
	11c	Strategies to improve adherence to intervention protocols, and any procedures for monitoring adherence (eg, drug tablet return, laboratory tests)	16
	11d	Relevant concomitant care and interventions that are permitted or prohibited during the trial	16
Outcomes	12	Primary, secondary, and other outcomes, including the specific measurement variable (eg, systolic blood pressure), analysis metric (eg, change from baseline, final value, time to event), method of aggregation (eg, median, proportion), and time point for each outcome. Explanation of the clinical relevance of chosen efficacy and harm outcomes is strongly recommended	13
Participant timeline	13	Time schedule of enrolment, interventions (including any run-ins and washouts), assessments, and visits for participants. A schematic diagram is highly recommended (see Figure)	9 &Figure 1

2

Sample size	14	Estimated number of participants needed to achieve study objectives and how it was determined, including clinical and statistical assumptions supporting any sample size calculations	13
Recruitment	15	Strategies for achieving adequate participant enrolment to reach target sample size	11
Methods: Assignment of interventions (for controlled trials)			
Allocation:			
Sequence generation	16a	Method of generating the allocation sequence (eg, computer-generated random numbers), and list of any factors for stratification. To reduce predictability of a random sequence, details of any planned restriction (eg, blocking) should be provided in a separate document that is unavailable to those who enrol participants or assign interventions	15
Allocation concealment mechanism	16b	Mechanism of implementing the allocation sequence (eg, central telephone; sequentially numbered, opaque, sealed envelopes), describing any steps to conceal the sequence until interventions are assigned	15
Implementation	16c	Who will generate the allocation sequence, who will enrol participants, and who will assign participants to interventions	15
Blinding (masking)	17a	Who will be blinded after assignment to interventions (eg, trial participants, care providers, outcome assessors, data analysts), and how	NA
	17b	If blinded, circumstances under which unblinding is permissible, and procedure for revealing a participant's allocated intervention during the trial	NA
Methods: Data collection, management, and analysis			
Data collection methods	18a	Plans for assessment and collection of outcome, baseline, and other trial data, including any related processes to promote data quality (eg, duplicate measurements, training of assessors) and a description of study instruments (eg, questionnaires, laboratory tests) along with their reliability and validity, if known. Reference to where data collection forms can be found, if not in the protocol	15
	18b	Plans to promote participant retention and complete follow-up, including list of any outcome data to be collected for participants who discontinue or deviate from intervention protocols	15

3

Data management	19	Plans for data entry, coding, security, and storage, including any related processes to promote data quality (eg, double data entry; range checks for data values). Reference to where details of data management procedures can be found, if not in the protocol	17
Statistical methods	20a	Statistical methods for analysing primary and secondary outcomes. Reference to where other details of the statistical analysis plan can be found, if not in the protocol	17
	20b	Methods for any additional analyses (eg, subgroup and adjusted analyses)	18
	20c	Definition of analysis population relating to protocol non-adherence (eg, as randomised analysis), and any statistical methods to handle missing data (eg, multiple imputation)	17
Methods: Monitoring			
Data monitoring	21a	Composition of data monitoring committee (DMC); summary of its role and reporting structure; statement of whether it is independent from the sponsor and competing interests; and reference to where further details about its charter can be found, if not in the protocol. Alternatively, an explanation of why a DMC is not needed	NA
	21b	Description of any interim analyses and stopping guidelines, including who will have access to these interim results and make the final decision to terminate the trial	NA
Harms	22	Plans for collecting, assessing, reporting, and managing solicited and spontaneously reported adverse events and other unintended effects of trial interventions or trial conduct	15
Auditing	23	Frequency and procedures for auditing trial conduct, if any, and whether the process will be independent from investigators and the sponsor	NA
Ethics and dissemination			
Research ethics approval	24	Plans for seeking research ethics committee/institutional review board (REC/IRB) approval	21
Protocol amendments	25	Plans for communicating important protocol modifications (eg, changes to eligibility criteria, outcomes, analyses) to relevant parties (eg, investigators, REC/IRBs, trial participants, trial registries, journals, regulators)	21

Consent or assent	26a	Who will obtain informed consent or assent from potential trial participants or authorised surrogates, and how (see Item 32)	11
	26b	Additional consent provisions for collection and use of participant data and biological specimens in ancillary studies, if applicable	NA
Confidentiality	27	How personal information about potential and enrolled participants will be collected, shared, and maintained in order to protect confidentiality before, during, and after the trial	21
Declaration of interests	28	Financial and other competing interests for principal investigators for the overall trial and each study site	22
Access to data	29	Statement of who will have access to the final trial dataset, and disclosure of contractual agreements that limit such access for investigators	21
Ancillary and post-trial care	30	Provisions, if any, for ancillary and post-trial care, and for compensation to those who suffer harm from trial participation	21
Dissemination policy	31a	Plans for investigators and sponsor to communicate trial results to participants, healthcare professionals, the public, and other relevant groups (eg, via publication, reporting in results databases, or other data sharing arrangements), including any publication restrictions	21
	31b	Authorship eligibility guidelines and any intended use of professional writers	NA
	31c	Plans, if any, for granting public access to the full protocol, participant-level dataset, and statistical code	NA
Appendices			
Informed consent materials	32	Model consent form and other related documentation given to participants and authorised surrogates	Ethics approved
Biological specimens	33	Plans for collection, laboratory evaluation, and storage of biological specimens for genetic or molecular analysis in the current trial and for future use in ancillary studies, if applicable	NA

*It is strongly recommended that this checklist be read in conjunction with the SPIRIT 2013 Explanation & Elaboration for important clarification on the items. Amendments to the protocol should be tracked and dated. The SPIRIT checklist is copyrighted by the SPIRIT Group under the Creative Commons "Attribution-NonCommercial-NoDerivs 3.0 Unported" license.

K.2 CONSORT Statement for Pragmatic RCT

CONSORT 2010 checklist of information to include when reporting a randomised trial

Section/Topic	Item No	Checklist Item	Reported on Page No
Title and abstract			
	1a	Identification as a randomised trial in the title	i
	1b	Structured summary of trial design, methods, results, and conclusions	11
Introduction			
Background	2a	Scientific background and explanation of rationale	2-6
and objectives	2b	Specific objectives or hypotheses	7
Methods			
Trial design	3a	Description of trial design (such as parallel, factorial) including allocation ratio	8
	3b	Important changes to methods after trial commencement (such as eligibility criteria), with reasons	NA
Participants	4a	Eligibility criteria for participants	131
	4b	Settings and locations where the data were collected	131
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	137-138
Outcomes	6a	Completely defined pre-specified primary and secondary outcome measures, including how and when they were assessed	127-128
	6b	Any changes to trial outcomes after the trial commenced, with reasons	NA

Sample size	7a	How sample size was determined	133
	7b	When applicable, explanation of any interim analyses and stopping guidelines	NA
Randomisation:			
Sequence generation	8a	Method used to generate the random allocation sequence	136
	8b	Type of randomisation; details of any restriction (such as blocking and block size)	136
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	136
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	136
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	NA
	11b	If relevant, description of the similarity of interventions	
Statistical methods	12a	Statistical methods used to compare groups for primary and secondary outcomes	146-148
	12b	Methods for additional analyses, such as subgroup analyses and adjusted analyses	170
Results			
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were randomly assigned, received intended treatment, and were analysed for the primary outcome	149
	13b	For each group, losses and exclusions after randomisation, together with reasons	149
Recruitment	14a	Dates defining the periods of recruitment and follow-up	148

	14b	Why the trial ended or was stopped	148
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	151-152
Numbers analysed	16	For each group, number of participants (denominator) included in each analysis and whether the analysis was by original assigned groups	154-155
Outcomes and estimation	17a	For each primary and secondary outcome, results for each group, and the estimated effect size and its precision (such as 95% confidence interval)	156-173
	17b	For binary outcomes, presentation of both absolute and relative effect sizes is recommended	156-173
Ancillary analyses	18	Results of any other analyses performed, including subgroup analyses and adjusted analyses, distinguishing pre-specified from exploratory	175-212
Harms	19	All important harms or unintended effects in each group	NA
Discussion			
Limitations	20	Trial limitations, addressing sources of potential bias, imprecision, and, if relevant, multiplicity of analyses	234-237
Generalisability	21	Generalisability (external validity, applicability) of the trial findings	223
Interpretation	22	Interpretation consistent with results, balancing benefits and harms, and considering other relevant evidence	223-232
Other information			
Registration	23	Registration number and name of trial registry	122
Protocol	24	Where the full trial protocol can be accessed, if available	122-143
Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	xxii

Appendix L

Quantitative Analysis Tables

Table 1 Reliability of Assessment Measures

Measure	Domain	Original study Cronbach's alpha	Current study Cronbach's alpha		
			Time 1 N=60	Time 2 N=59	Time 3 N=58
SF-SUNS	Information (3 items)	0.85[a]	0.70	0.80	0.82
	Financial Concerns (8 items)	0.90[a]	0.74	0.90	0.88
	Access and Continuity of Care (6 items)	0.90[a]	0.89	0.85	0.88
	Relationships and emotional health (13 items)	0.95[a]	0.92	0.96	0.96
DASS21	Depression (7 items)	0.94[b]	0.90	0.93	0.92
	Anxiety (7 items)	0.87[b]	0.79	0.79	0.83
	Stress (7 items)	0.91[b]	0.86	0.94	0.92
Mini-MAC	Helplessness/Hopelessness (8 items)	0.87[c]	0.89	0.87	0.90
	Anxious Preoccupation (8 items)	0.88[c]	0.87	0.88	0.92
	Fatalism (5 items)	0.62[c]	0.62	0.61	0.68
	Fighting Spirit (4 items)	0.76[c]	0.61	0.59	0.58
	Cognitive Avoidance (4 items)	0.74[c]	0.82	0.85	0.89
PES	15 items	0.93[d,e]	0.75	0.79	079

[a] Campbell et al. (2014); [b] Antony et al. (1998); [c] Watson et al. (1994); [d] Bulsara, Styles, Ward, and Bulsara (2006); [e] Pearson's Separation Index (Cronbach's alpha equivalent)

Table 2 Intervention Group Wilcoxon Signed Rank Test

Measure	Mean (SD) Median	Wilcoxon Signed Rank	Effect Size
SF-SUNS			
Time 1 – Time 2 Total scale scores	27.33 (20.63) 18.50 26.27 (22.81) 22.00	*z* -0.35 *p* .726	*r* .05
Time 1 – Time 2 Information	2.97 (3.18) 2.50 2.33 (2.00) 2.00	*z* -1.12 *p* .262	*r* .15
Time 1 – Time 2 Financial concerns	6.70 (5.93) 6.50 7.63 (7.58) 6.00	*z* -0.10 *p* .923	*r* .01
Time 1 – Time 2 Access and continuity of care	3.97 (5.88) 1.50 2.24 (3.43) 0	*z* -1.69 *p* .090	*r* .22
Time 1 – Time 2 Relationships and emotional health	13.70 (10.87) 12.50 13.90 (12.75) 11.50	*z* -0.19 *p* .846	*r* .03
Time 1 - Time 3 Total scale scores	27.33 (20.63) 18.50 21.41 (22.95) 16.00	*z* -2.15 *p* **.031**	*r* .28
Time 1 – Time 3 Information	2.97 (3.18) 2.50 1.97 (2.34) 2.00	*z* -1.37 *p* .169	*r* .18
Time 1 – Time 3 Financial Concerns	6.70 (5.93) 6.50 5.76 (6.36) 4.00	*z* -1.71 *p* .088	*r* .22
Time 1 – Time 3 Access and continuity of care	3.97 (5.88) 1.50 2.24 4.75) 0	*z* -2.31 *p* **.021**	*r* .30
Time 1 – Time 3 Relationships and emotional health	13.70 (10.87) 12.50 11.45 (12.28) 8.00	*z* -1.69 *p* .091	*r* .22
DASS21			
Time 1 – Time 2 Total scale scores	12.67 (12.01) 10.00 15.63 (15.61) 9.50	*z* -1.24 *p* .214	*r* .16
Time 1 – Time 2 Depression	4.03 (4.75) 2.00 5.30 (5.78) 2.50	*z* -1.14 *p* .255	*r* .15
Time 1 – Time 2 Anxiety	3.47 (3.36) 3.00 3.53 (3.67) 3.00	*z* -0.08 *p* .940	*r* .01
Time 1 – Time 2 Stress	5.17 (5.05) 4.00 6.80 (6.97) 4.50	*z* -1.62 *p* .106	*r* .21

Time 1- Time 3 Total scale scores	12.67 (12.01) 10.00 15.61 (13.40) 8.00	*z* -0.03 *p* .976	*r* .004
Time 1 – Time 3 Depression	4.03 (4.75) 2.00 4.14 (5.38) 1.00	*z* -0.05 *p* .957	*r* .006
Time 1 – Time 3 Anxiety	3.47 (3.36) 3.00 3.45 (3.93) 2.00	*z* -0.05 *p* .961	*r* .006
Time 1 – Time 3 Stress	5.17 (5.05) 4.00 5.66 (5.75) 4.00	*z* -0.42 *p* .675	*r* .05
Mini-MAC			
Time 1 – Time 2 Total scale scores	65.30 (12.62) 64.50 64.27 (13.44) 63.50	*z* -0.64 *p* .524	*r* .08
Time 1 – Time 2 Fatalism	14.13 (3.03) 14.00 14.30 (2.81) 14.00	*z* -0.35 *p* .732	*r* .05
Time 1 – Time 2 Fighting Spirit	12.40 (2.59) 13.00 11.33 (2.32) 11.00	*z* -2.60 *p* **.009**	*r* .34
Time 1 – Time 2 Helplessness/Hopelessness	12.77 (4.88) 11.50 12.83 (4.79) 12.50	*z* -0.04 *p* .969	*r* .08
Time 1 – Time 2 Anxious preoccupation	17.27 (5.84) 16.00 17 (6.07) 16.50	*z* -0.41 *p* .686	*r* .05
Time 1 – Time 2 Cognitive avoidance	8.73 (3.17) 8.50 8.80 (3.26) 9.00	*z* -0.17 *p* .865	*r* .02
Time 1 - Time 3 Total scale scores	65.30 (12.62) 64.50 62.59 (15.03) 64	*z* -1.17 *p* .241	*r* .15
Time 1 – Time 3 Fatalism	14.13 (3.03) 14.00 13.76 (3.44) 14.00	*z* -1.11 *p* .266	*r* .14
Time 1 – Time 3 Fighting Spirit	12.40 (2.59) 13.00 11.55 (2.43) 12.00	*z* -1.80 *p* .073	*r* .23
Time 1 – Time 3 Helplessness/Hopelessness	12.77 (4.88) 11.50 12 (4.74) 9.00	*z* -1.31 *p* .190	*r* .17
Time 1 – Time 3 Anxious preoccupation	17.27 (5.84) 16.00 16.76 (6.34) 17	*z* -0.50 *p* .616	*r* .07
Time 1 –	8.73 (3.17) 8.50	*z* -0.59 *p* .556	*r* .08

Time 3 Cognitive avoidance	8.52 (3.94) 8.00		
PES			
Time 1 – Time 2	48.33 (5.11) 48.50 49.50 (5.63) 50.50	*z* -1.16 *p* .246	*r* .15
Time 1 – Time 3	48.33 (5.11) 48.50 50.21 (5.63) 52.00	*z* -1.78 *p* .075	*r* .23

Note. Significance level 0.05 (2-tailed); Effect size: 0.2=small effect, 0.5=moderate effect, 0.8=large effect

Table 3 Linear Mixed Model Results of SF-SUNS Total Scale

Variable	Beta Estimate	Std. Error	95% Confidence Interval		*P* Value
			Lower	Upper	
Intercept	35.79	8.93	17.91	53.67	.000
Group—Control[a]	–3.61	6.02	–15.67	8.45	.551
Lymphoma[b] (NHL)	13.82	7.32	–0.85	28.50	.064
Gender[c] (Male)	–11.39	5.97	–23.35	0.56	.061
Time 1[d]	3.46	2.09	–0.68	7.59	.101
Time 2[d]	3.79	2.09	–0.35	7.93	.072
Age	–0.27	0.16	–0.60	0.06	.109

Note. [a] Comparison group set to zero (Intervention); [b] Comparison group set to zero (HL); [c] Comparison group set to zero (Female); [d] Comparison group set to zero (Time 3)

Table 4 Linear Mixed Model Results of Mini-MAC Domains

Variable	Beta Estimate	Std. Error	95% Confidence Interval		*P* Value
			Lower	Upper	
Helplessness/Hopelessness Domain					
Intercept	14.18	1.74	10.70	17.67	.000
Group—Control[a]	–0.67	1.17	–3.00	1.68	.571
Lymphoma[b] (NHL)	0.11	1.42	–2.74	2.96	.938
Gender[c] (Male)	–1.97	1.16	–4.29	0.35	.094
Time 1[d]	0.36	0.49	–0.62	1.34	.465
Time 2[d]	0.43	0.49	–0.55	1.41	.383
Age	–0.01	0.03	–0.07	0.05	.735
Anxious Preoccupation Domain					
Intercept	20.40	2.28	15.84	24.96	.000
Group—Control[a]	1.33	1.54	–1.75	4.42	.389
Lymphoma[b] (NHL)	–0.73	1.87	–4.48	3.02	.698
Gender[c] (Male)	–2.05	1.52	–5.10	1.01	.185
Time 1[d]	0.96	0.49	–0.02	1.93	.055
Time 2[d]	0.38	0.49	–0.60	1.36	.440
Age	–0.04	0.04	–0.12	0.05	.360
Cognitive Avoidance Domain					
Intercept	10.71	1.22	8.28	13.15	.000
Group—Control[a]	1.19	0.81	–0.44	2.82	.150
Lymphoma[b] (NHL)	–0.38	0.99	–2.37	1.60	.700
Gender[c] (Male)	–1.22	0.81	–2.84	0.40	.137
Time 1[d]	–0.09	0.36	–0.81	0.63	.802
Time 2[d]	0.30	0.36	–0.42	1.02	.409
Age	–0.02	0.02	–0.06	0.03	.387

Note. [a] Comparison group set to zero (Intervention); [b] Comparison group set to zero (HL); [c] Comparison group set to zero (Female); [d] Comparison group set to zero (Time 3)

Table 5 Descriptive Data of the Multi-item Measures by Group at Each Time Point and Between Time Points

Measure	Baseline (Time 1)#			3 months (Time 2)#			6 Months (Time 3)#			Time differences^			
										Time 1 – Time 2		Time 1 – Time 3	
	Control Group*	Intervention Group*	*P* value (Cohen's *d*)	Control Group*	Intervention Group*	*P* value (Cohen's *d*)	Control Group*	Intervention Group*	*P* value (Cohen's *d*)	Control	Intervention	Control	Intervention
SF-SUNS[a]	26.53 (21.84)	27.33 (20.63)	.885 (-.04)	28.62 (27.82)	26.27 (22.81)	.723 (.09)	25.72 (25.99)	21.41 (22.95)	.506 (.18)	*t* (28) -0.46 *p* .648	*t* (29) 0.39 *p* .698	*t* (28) 0.32 *p* .753	*t* (28) 1.99 *p* .057
Information	3.30 (2.58)	2.97 (3.18)	.657 (.12)	3.21 (3.29)	2.33 (2.01)	.221 (.27)	2.76 (2.82)	1.97 (2.34)	.249 (.31)	*t* (28) 0.43 *p* 0.673	*t* (29) 1.20 *p* .240	*t* (28) 1.36 *p* .185	*t* (28) 1.52 *p* .139
Financial concerns	7.03 (6.13)	6.70 (5.93)	.831 (.05)	6.38 (8.38)	7.63 (7.58)	.549 (-.16)	6.28 (7.77)	5.76 (6.36)	.782 (.07)	*t* (28) 0.62 *p* .538	*t* (29) -0.89 *p* .383	*t* (28) 0.68 *p* .505	*t* (28) 1.02 *p* .317
Access and continuity of care	2.60 (4.35)	3.97 (5.88)	.310 (.27)	3.28 (4.32)	2.40 (3.43)	.391 (.23)	2.34 (2.87)	2.24 (4.75)	.920 (.03)	*t* (28) -0.98 *p* .338	*t* (29) 1.88 *p* .070	*t* (28) 0.34 *p* .737	*t* (28) 2.47 *p* **.020**
Relationships and emotional health	13.60 (11.51)	13.70 (10.87)	.973 (.01)	15.76 (13.79)	13.90 (12.75)	.593 (.14)	14.34 (14.10)	11.45 (12.28)	.408 (.22)	*t* (28) -0.93 *p* .361	*t* (29) -0.19 *p* .907	*t* (28) -0.22 *p* .826	*t* (28) 1.32 *p* 0.199
DASS21[b]	15.57 (13.91)	12.67 (12.01)	.391 (.22)	14.17 (13.67)	15.63 (15.61)	.704 (-.10)	15.14 (13.76)	13.03 (13.40)	.558 (.16)	*t* (28) 0.75 *p* .462	*t* (29)=-1.53 *p* .136	*t* (28) 0.24 *p* .812	*t* (28) - 0.19 *p* .853
Depression	4.33 (5.37)	4.03 (4.75)	.819 (.06)	4.59 (5.44)	5.30 (5.78)	.627 (-.13)	4.83 (5.56)	4.14 (5.38)	.633 (.13)	*t* (28) -0.28 *p* 0.79	*t* (29)=-1.58 *p* 0.13	*t* (28) -0.58 *p* 0.57	*t* (28) -0.06 *p* 0.95
Anxiety	4.60 (5.05)	3.47 (3.36)	.310 (.27)	3.63 (4.18)	3.53 (3.67)	.932 (.02)	3.55 (3.95)	3.45 (3.93)	.921 (.03)	*t* (28) 1.22 *p* .232	*t* (29) -0.14 *p* .888	*t* (28) 1.38 *p* .179	*t* (28) -0.06 *p* .892
Stress	6.63	5.17	.270	5.97	6.80	.617	6.76	5.66	.471	*t* (28) 0.67	*t* (29) -1.85 *p*	*t* (28) -0.22	*t* (28) -0.65 *p*

	(5.15)	(5.05)	(.29)	(5.69)	(6.97)	(-.13)	(5.82)	(5.75)	(.19)	*p* .510	.074	*p* .825	.522
Mini-MAC[s]	68.47 (12.74)	65.30 (12.62)	.337 (.25)	67.72 (15.22)	64.27 (13.44)	.359 (.24)	65.38 (15.52)	62.59 (15.03)	.489 (.18)	*t* (28) 0.51 *p* .614	*t* (29)=0.61 *p* .547	*t* (28) 1.81 *p* .081	*t* (28) 1.35 *p* .188
Fatalism	14.27 (3.29)	14.13 (3.03)	.871 (.04)	13.79 (3.58)	14.30 (2.81)	.547 (-.16)	13.28 (3.56)	13.76 (3.44)	.603 (-.14)	*t* (28) 0.80 *p* .428	*t* (29) -0.39 *p* .701	*t* (28) 1.94 *p* .062	*t* (28) 1.13 *p* .267
Fighting spirit	12.47 (2.13)	12.40 (2.59)	.914 (.03)	12.07 (2.61)	11.33 (2.32)	.257 (.30)	11.24 (2.91)	11.55 (2.43)	.661 (-.12)	*t* (28) 0.96 *p* .345	*t* (29) 2.80 *p* **.009**	*t* (28) 3.50 *p* **.002**	*t* (28) 2.13 *p* **.042**
Helplessness/hopelessness	12.47 (4.31)	12.77 (4.88)	.802 (-.07)	12.66 (4.76)	12.83 (4.79)	.887 (-.03)	12.62 (4.41)	12.00 (4.74)	.608 (.14)	*t* (28) -0.04 *p* .968	*t* (29) 1.11 *p* .909	*t* (28) 0.00 *p* 1.00	*t* (28) 1.39 *p* .176
Anxious preoccupation	19.47 (5.34)	17.27 (5.84)	.133 (.40)	18.66 (5.68)	17.00 (6.07)	.284 (.28)	18.10 (6.14)	16.76 (6.34)	.415 (.22)	*t* (28) 1.46 *p* .154	*t* (29) 0.33 *p* .742	*t* (28) 2.20 *p* **.037**	*t* (28) 0.65 *p* .521
Cognitive avoidance	9.80 (3.13)	8.73 (3.17)	.195 (.03)	10.55 (3.25)	8.80 (3.26)	**.043** (.54)	10.14 (3.06)	8.52 (3.94)	.086 (.46)	*t* (28) -1.68 *p* .105	*t* (29) -0.14 *p* .888	*t* (28) -0.73 *p* .474	*t* (28) 0.16 *p* .876
PES[d]	48.77 (6.03)	48.33 (5.11)	.765 (.80)	45.79 (5.85)	49.50 (5.63)	**.016** (-.65)	47.21 (6.07)	50.21 (5.63)	.056 (-.50)	*t* (28) 3.06 *p* **.005**	*t* (29) -1.45 *p* .158	*t* (28) 1.41 *p* .170	*t* (28) -1.97 *p* .059

Note. *Data given as mean (SD); **Bolded** *p* value indicates statistical significance $p<.05$; # Independent T-test results; ^ Paired-sample T-test results; [a]Higher scores represent higher levels of need; [b]Higher scores represent higher levels of psychological need; [c]Higher scores represent more endorsement of the domain trait; [d]Higher scores represent more empowerment; SF-SUNS: Short-Form Survivor Unmet Needs Survey; DASS21: Depression, Anxiety Stress Scale; Mini-MAC: Mental Adjustment to Cancer Scale; PES: Patient Empowerment Scale; Cohen's *d*: 0.2=small effect, 0.5=moderate effect, 0.8=large effect

Table 6 Age Differences Across Measures at Each Time Point within the Control and Intervention Groups

Measure	Control Group				Intervention Group			
	Age Group 1 18–29 years N=5	Age Group 2 30–59 years N=14	Age Group 3 >60 years N=11	Group Comparison*	Age Group 1 18–29 years N=8	Age Group 2 30–59 years N=12	Age Group 3 >60 years N=10	Group Comparison*
	Mean(SD) Median	Mean(SD) Median	Mean(SD) Median		Mean(SD) Median	Mean(SD) Median	Mean(SD) Median	
SF-SUNS Time 1								
Total scale scores	17 (9.25) 18	36.36 (25.49) 25.5	18.36 (15.84) 13	X^2 8.31, p **.016**	30.50 (14.37) 34	28.75 (27.11) 15	23.10 (16.75) 18	X^2 1.06, p .587
Information	2 (2.35) 1	4.57 (2.44) 4	2.27 (2.24) 2	X^2 *5.47*, p .065	4.13 (3.40) 4	3.17 (3.71) 1.5	1.80 (1.99) 1.5	X^2 1.94, p .380
Financial concerns	2.60 (2.07) 3	9.93 (7.05) 9	5.36 (4.23) 6	X^2 7.88, p **.019**	6 (3.34) 7	7.42 (8.57) 5	6.40 (3.69) 5	X^2 0.57, p .751
Access and continuity of care	0.80 (0.84) 1	4.57 (5.75) 2.5	0.91 (1.22) 1	X^2 8.89, p **.012**	3.88 (3.14) 3.5	5.42 (8.30) 2	2.30 (3.71) 1	X^2 1.78, p .411
Relationships and emotional health	11.60 (7.83) 12	17.29 (13.02) 13.5	9.82 (10.14) 5	X^2 *5.16*, p .076	16.50 (10.94) 16	12.75 (11.16) 13.5	12.60 (11.23) 9	X^2 0.68, p .713
SF-SUNS Time 2								
Total Scale scores	18.60 (8.26) 17	39.31 (33.92) 28	20.55 (22.08) 12	X^2 *2.81*, p .245	22.50 (12.81) 22	36.17 (30.94) 28	17.40 (12.20) 16	X^2 2.23, p .327
Information	2.20 (1.64) 3	4.15 (3.56) 3	2.55 (3.45) 0	X^2 *2.13*, p .344	2 (1.51) 2	2.75 (2.61) 3	2.10 (2.13) 2	X^2 0.83, p .662
Financial concerns	3.20 (2.59) 3	9.23 (10.16) 5	4.45 (7.10) 2	X^2 *2.18*, p .336	4.75 (2.87) 5.5	12.08 (10.15) 13.5	4.60 (2.99) 6	X^2 2.58, p .275
Access and continuity of care	1 (1.73) 0	4.92 (5.20) 3	2.36 (3.38) 1	X^2 *3.80*, p .149	2.63 (2.97) 2	4.08 (4.19) 2.5	0.20 (0.83) 0	X^2 8.88, p **.012**
Relationships and emotional health	12.20 (8.20) 13	21 (16.03) 16	11.18 (10.47) 10	X^2 *2.43*, p .296	13.13 (8.71) 12	17.25 (16.89) 11	10.50 (9.38) 9	X^2 0.66, p .717
SF-SUNS Time 3								
Total Scale scores	17.60 (9.94) 20	36.69 (31.32) 22	16.45 (19.76) 7	X^2 *4.14*, p .126	14.71 (11.19) 16	26.92 (31.18) 18.5	19.50 (16.95) 14	X^2 0.48, p .787
Information	2 (1.23) 2	3.85 (3.05) 4	1.82 (2.79) 0	X^2 *3.69*, p .158	0.71 (1.25) 0	2.17 (2.92) 1	2.60 (1.96) 3.5	X^2 3.76, p .153

Financial concerns	3.20 (1.92) 4	9.46 (10.30) 5	3.91 (4.4) 3	X^2 *1.84*, *p* .399	2.71 (2.69) 2	8.58 (8.91) 6	4.50 (2.07) 4	X^2 2.04, *p* .361
Access and continuity of care	1 (1.23) 1	3.85 (3.24) 4	1.18 (2.14) 0	X^2 7.54, *p* **.023**	0.71 (1.50) 0	3.83 (6.99) 1	1.40 (1.71) 1	X^2 1.84, *p* .399
Relationships and emotional health	11.40 (9.71) 11	19.54 (16.21) 15	9.55 (11.80) 4	X^2 3.16, *p* .206	10.57 (7.83) 11	12.33 (14.46) 8.5	11 (13.07) 6.5	X^2 0.33, *p* .847
DASS21 Time 1								
Total scale scores	10 (5.79) 9	18.79 (15.72) 13	14 (13.92) 10	X^2 1.87, *p* .392	14.63 (10.03) 12.5	12 (14.14) 8	11.90 (11.74) 7.5	X^2 1.84, *p* .398
Depression	2 (2.35) 1	5.50 (6.19) 2.5)	3.91 (5.19) 1	X^2 1.61, *p* .446	3.75 (3.96) 2	3.67 (5.12) 1.5	4.70 (5.25) 3	X^2 1.26, *p* .533
Anxiety	2 (2.45) 2	5.86 (5.64) 4.5	4.18 (4.94) 3	X^2 2.17, *p* .338	4 (3.42) 3	3.42 (3.73) 2	3.10 (3.14) 2.5	X^2 0.63, *p* .732
Stress	6 (1.58) 6	7.43 (5.60) 6.5	5.91 (5.79) 5	X^2 1.03, *p* .599	6.88 (5.14) 5.5	4.92 (5.81) 4	4.10 (4.04) 3	X^2 2.98, *p* .226
DASS21 Time 2								
Total scale scores	11.80 (7.53) 9	17.15 (15.96) 11	11.73 (13.18) 5	X^2 1.27, *p* .530	11.75 (12.90) 6	19.33 (19.76) 10	14.30 (12.05) 13.5	X^2 0.58, *p* .749
Depression	2.40 (3.78) 1	6.38 (6.50) 5	3.45 (4.28) 1	X^2 2.07, *p* .355	3.50 (3.82) 1.5	6.50 (7.44) 3	5.30 (4.88) 4	X^2 1.002, *p* .606
Anxiety	2.20 (1.79) 2	4 (4.71) 2	3.82 (4.45) 1	X^2 0.24, *p* .885	2.63 (2.93) 2	4.33 (4.72) 3.5	3.30 (2.83) 3.5	X^2 0.72, *p* .698
Stress	7.20 (3.27) 6	6.77 (6.34) 5	4.45 (5.84) 4	X^2 2.70, *p* .259	5.63 (6.74) 3.5	8.50 (8.43) 5.5	5.70 (5.27) 5	X^2 0.37, *p* .831
DASS21 Time 3								
Total scale scores	8.60 (7.67) 6	17.62 (14.97) 12	15.18 (14.44) 12	X^2 1.19, *p* .552	12.57 (8.85) 15	12.75 (16.97) 5.5	13.70 (12.40) 8	X^2 1.14, *p* .566
Depression	1.20 (2.17) 0	6.46 (5.88) 4	4.55 (5.75) 2	X^2 4.67, *p* .097	3.57 (3.91) 3	3.42 (5.81) 1	5.40 (5.99) 4.5	X^2 0.57, *p* .753
Anxiety	2.20 (2.28) 2	3.85 (3.98) 3	3.82 (4.65) 2	X^2 0.38, *p* .826	2.43 (2.51) 2	3.5 (4.52) 1.5	4.10 (4.20) 3.5	X^2 0.27, *p* .874
Stress	5.20 (4.15) 5	7.31 (6.63) 5	6.82 (5.81) 8	X^2 0.35, *p* .841	6.71 (4.96) 8	5.92 (7.19) 2.5	4.60 (4.58) 3.5	X^2 0.64, *p* .728
Mini-MAC Time 1								
Total scale scores	64 (7.28) 64	74.29 (13.30) 72.5	63.09 (11.42) 63	X^2 6.45 *p* **.040**	69.75 (13.42) 72.5	62 (13.67) 64.5	65.70 (10.61) 62	X^2 2.05, *p* .358
Fatalism	11.40 (1.95) 12	14.93 (3.29) 16	14.73 (3.29) 15	X^2 5.28, *p* .071	13.75 (2.32) 14	13.17 (3.04) 13	15.60 (3.20) 15.5	X^2 3.65, *p* .162
Fighting spirit	12.60 (1.52) 13	12.71 (1.98) 13	12.09 (2.63) 13	X^2 0.22, *p* .896	12.50 (2.45) 12.5	12.33 (3.20) 13.5	12.40 (2.12) 12.5	X^2 0.09, *p* .958
Helplessness/hopelessness	11.40 (4.22) 9	13.5 (4.62) 14.5	11.64 (4.01) 10	X^2 1.59, *p* .451	14 (5.76) 12.5	12.33 (5.05) 11.5	12.30 (4.24) 11	X^2 0.41, *p* .814
Anxious preoccupation	19.40 (2.07) 19	21.57 (5.14) 21.5	16.82 (5.71) 18	X^2 4.67, *p* .097	19.75 (6.86) 20.5	16.42 (5.92) 15	16.30 (4.79) 16	X^2 1.46, *p* .481
Cognitive avoidance	9.20 (1.92) 10	11.57 (2.77) 12	7.82 (2.86) 8	X^2 10.52, *p* **.005**	9.75 (2.87) 10	7.75 (2.30) 8	9.10 (4.15) 8.5	X^2 2.71, *p* .258
Mini-MAC Time 2								

Total scale scores	58.4 (8.26) 59	76.69 (12.33) 77	61.36 (15.71) 63	X^2 8.82, p **.012**	67.38 (13.79) 71.5	62.83 (14.22) 61.5	63.50 (13.24) 62.5	X^2 0.84, p .657
Fatalism	10.20 (1.64) 11	14.08 (2.9) 14	15.09 (4.04) 16	X^2 7.07, p **.029**	13.88 (2.85) 14	13.50 (2.36) 13.5	15.60 (3.06) 15	X^2 2.62, p .270
Fighting spirit	12.20 (2.68) 11	13.15 (1.95) 13	10.73 (2.83) 12	X^2 4.67, p .097	11.63 (2.07) 11.50	11/17 (2.66) 11	11.30 (2.31) 11.5	X^2 0.17, p .92
Helplessness/hopelessness	9.60 (2.61) 8	15.46 (4.24) 15	10.73 (4.50) 8	X^2 9.08, p **.011**	13.25 (3.92) 14	13.42 (5.57) 12.5	11.80 (4.73) 9.5	X^2 1.20, p .550
Anxious preoccupation	17 (2.83) 15	22 (4.28) 21	15.45 (6.17) 14	X^2 9.07, p **.011**	19.13 (6.92) 20	16.25 (6.14) 16.5	16.20 (5.47) 14.5	X^2 1.14, p .567
Cognitive avoidance	9.40 (2.30) 9	12 (2.35) 12	9.36 (3.98) 10	X^2 4.21, p .122	9.50 (2.73) 10/5	8.50 (3.37) 8.5	8.60 (3.75) 9	X^2 1.25, p .536
Mini-MAC Time 3								
Total scale scores	55.20 (14.87) 61	73.69 (14.20) 73	60.18 (13.14) 57	X^2 7.97, p **.019**	65.43 (14.97) 71	58.92 (18.41) 54.5	65 (10.41) 65.5	X^2 1.55, p .461
Fatalism	10.20 (3.42) 11	13.85 (3.85) 15	14 (2.79) 14	X^2 4.42, p .110	13.14 (3.29) 13	12.75 (3.67) 14	15.40 (2.91) 15	X^2 2.93, p .231
Fighting spirit	10.20 (4.27) 10	12 (1.87) 12	10.82 (3.28) 11	X^2 1.43, p .489	12.29 (1.70) 13	11 (3.16) 11.5	11.70 (1.83) 11.5	X^2 0.73, p .694
Helplessness/hopelessness	9.80 (2.05) 9	14.46 (3.80) 14	11.73 (5.12) 8	X^2 5.69, p .058	12.29 (5.02) 9	11.50 (5.32) 9	12.40 (4.22) 11	X^2 0.83, p .659
Anxious preoccupation	16.20 (5.81) 17	21.69 (4.96) 22	14.73 (5.61) 15	X^2 7.51, p **.023**	18.29 (7.18) 20	15.33 (7.30) 12	17.40 (4.53) 18	X^2 1.72, p .422
Cognitive avoidance	8.80 (3.11) 9	11.69 (2.75) 12	8.91 (2.74) 9	X^2 8.17, p **.017**	9.43 (3.65) 9	8.33 (4.46) 7.5	8.10 (3.78) 8	X^2 0.53, p .767
PES Time 1	45.80 (3.49) 46	46.71 (5.37) 47	52.73 (5.95) 54	X^2 9.13, p **.010**	47 (4.90) 47	49.42 (4.72) 50	48.10 (5.92) 48.5	X^2 0.99, p .610
PES Time 2	45.40 (4.93) 44	42.54 (5.30) 44	49.82 (4.54) 50	X^2 8.97, p **.011**	49.13 (4.49) 49.5	49.17 (4.91) 49.5	50.20 (7.48) 51.5	X^2 0.50, p .778
PES Time 3	46 (5.66) 44	44.31 (5.19) 45	51.18 (5.4) 51	X^2 7.46, p **.024**	49.86 (5.11) 52	51.08 (4.81) 51.5	49.40 (7.14) 51	X^2 0.33, p .849

Note. *Kruskal–Wallis test results; **Bolded** p value indicates statistical significance $p<.05$

Table 7 Gender Differences Across Measures at Each Time Point within the Control and Intervention Groups

Measure	Control Group			Intervention Group		
	Male N=12	Female N=18	Group Comparison*	Male N=22	Female N=8	Group Comparison*
	Mean(SD) Median	Mean(SD) Median		Mean(SD) Median	Mean(SD) Median	
SF-SUNS Time 1						
Total Scale scores	17.42 (11.07) 17	32.61 (25.24) 24	X^2 4.49, p **.034**	23.64 (20.66) 16	37.50 (17.91) 41	X^2 3.98, p **.046**
Information	2.25 (2.22) 2.5	4 (2.61) 4	X^2 3.24, p .072	2.73 (3.41) 1.5	3.63 (2.50) 4	X^2 1.13, p .288
Financial concerns	6.08 (4.27) 6	7.67 (7.15) 6	X^2 0.05, p .815	6.45 (6.47) 5	7.38 (4.37) 7	X^2 1.03, p .310
Access and continuity of care	1.92 (1.93) 1.5	3.06 (5.42) 1	X^2 0.06, p .811	3.68 (5.80) 1.5	4.75 (6.43) 2	X^2 0.23, p .631
Relationships and emotional health	7.17 (4.63) 5.5	17.89 (12.79) 13	X^2 8.09, p **.004**	10.77 (10.27) 7	21.75 (8.52) 21	X^2 7.18, p **.007**
SF-SUNS Time 2						
Total Scale scores	20.73 (20.42) 16	33.44 (31.05) 24.5	X^2 1.37, p .242	25.27 (24.21) 20.5	29 (19.66) 26	X^2 0.67, p .412
Information	2.27 (2.65) 2	3.78 (3.57) 3.5	X^2 1.26, p .261	2.36 (2.04) 2.5	2.25 (2.05) 2	X^2 0.03, p .867
Financial concerns	5.55 (7.33) 2	6.89 (9.13) 3.5	X^2 0.12, p .733	7.73 (7.75) 6	7.38 (7.60) 6	X^2 0.002, p .962
Access and continuity of care	2.36 (3.26) 2	2.5 (3.28) 1.5	X^2 0.34, p .563	2.55 (3.46) 0.5	2 (3.55) 0	X^2 0.29, p .593
Relationships and emotional health	10.55 (8.14) 10	18.94 (15.68) 13	X^2 1.48, p .224	12.64 (13.93) 9.50	17.38 (8.55) 16.5	X^2 3.02, p .082
SF-SUNS Time 3						
Total Scale scores	17.82 (16.41) 15	30.56 (29.81) 21.5	X^2 1.37, p .242	22.81 (25.90) 17	17.75 (12.99) 14	X^2 0.001, p .981
Information	2.27 (2.15) 2	3.06 (3.19) 2	X^2 0.17, p .678	2.52 (2.40) 2	0.50 (1.41) 0	X^2 5.12, p **.024**
Financial concerns	5.18 (5.76) 3	6.94 (8.88) 4	X^2 0.10, p .750	6.19 (7.11) 4	4.88 (3.98) 4.5	X^2 0.01, p .922
Access and continuity of care	2.09 (2.17) 2	2.5 (3.28) 1.5	X^2 0.002, p .963	2.38 (5.22) 1	1.88 (3.48) 0	X^2 0.20, p .654
Relationships and emotional health	8.27 (7.53) 6	18.06 (15.99) 14	X^2 2.71, p .100	11.81 (13.79) 8	10.50 (7.64) 8.5	X^2 0.22, p .642
DASS21 Time 1						

Total scale scores	9.42 (5.38) 9	19.67 (16.33) 15.5	X^2 1.96, p .161	11.14 (12.67) 7.5	16.88 (9.42) 16	X^2 3.71, p .054
Depression	2.17 (3.54) 1	5.78 (5.97) 2.5	X^2 4.27, p **.039**	3.59 (5.08) 1.5	5.25 (3.69) 4	X^2 3.25, p .072
Anxiety	2.33 (1.67) 2	6.11 (5.97) 5	X^2 2.31, p .128	3.05 (3.30) 2.5	4.63 (3.46) 3.5	X^2 2.10, p .147
Stress	4.92 (2.84) 5	7.78 (6.04) 6.5	X^2 1.53, p .217	4.50 (4.98) 3.5	7 (5.07) 5.5	X^2 3.14, p .077
DASS21 Time 2						
Total scale scores	6.36 (6.20) 5	18.64 (14.89) 16	X^2 5.27, p **.022**	13.95 (16.07) 8.5	20.25 (14.19) 22	X^2 1.61, p .205
Depression	1.64 (2.54) 0	6.39 (5.98) 6	X^2 5.77, p **.016**	4.82 (6.10) 2	6.63 (4.90) 8.5	X^2 1.18, p .277
Anxiety	1.36 (1.50) 1	5 (4.70) 3.5	X^2 5.70, p **.017**	3.23 (3.88) 2	4.38 (3.11) 4	X^2 1.41, p .235
Stress	3.36 (3.01) 4	7.56 (6.40) 6.5	X^2 3.22, p .073	5.91 (6.64) 4	9.25 (7.70) 7	X^2 1.50, p .220
DASS21 Time 3						
Total scale scores	8.82 (7.14) 6	19 (15.50) 17	X^2 2.48, p .115	12.86 (14.53) 8	13.50 (10.69) 16.5	X^2 0.24, p .625
Depression	2.55 (3.08) 2	6.22 (6.32) 4	X^2 1.68, p .195	4.43 (5.69) 2	3.38 (4.72) 0.5	X^2 0.36, p .546
Anxiety	1.64 (1.50) 1	4.72 (4.54) 4	X^2 2.41, p .121	3.10 (3.83) 2	4.37 (4.31) 4	X^2 0.46, p .498
Stress	4.64 (3.41) 4	8.06 (6.66) 9.5	X^2 1.12, p .289	5.52 (6.22) 3	6 (4.63) 5.5	X^2 0.32, p .572
Mini-MAC Time 1						
Total scale scores	65.83 (10.21) 64.5	70.22 (14.19) 69.5	X^2 1.04, p .309	63.41 (13.50) 62	70.50 (8.40) 71.5	X^2 2.26, p .133
Fatalism	14.67 (3.09) 15.5	14 (3.48) 14.5	X^2 0.28, p .594	13.55 (2.96) 13.5	15.75 (2.77) 16	X^2 3.30, p .069
Fighting spirit	12.83 (1.53) 13	12.22 (2.46) 12.5	X^2 0.36, p .549	12.32 (2.64) 13	12.63 (2.62) 13	X^2 0.05, p .832
Helplessness/hopelessness	11.33 (3.68) 10	13.22 (4.62) 15.5	X^2 1.23, p .267	12.18 (4.97) 10.5	14.38 (4.53) 12.5	X^2 2.30, p .130
Anxious preoccupation	18.08 (4.50) 19	20.39 (5.76) 20.5	X^2 1.63, p .201	16.91 (6.14) 16	18.25 (5.15) 18.5	X^2 0.60, p .437
Cognitive avoidance	8.92 (3.0) 9.5	10.39 (3.17) 11	X^2 1.43, p .232	8.45 (3.10) 9	9.50 (3.46) 8	X^2 0.11, p .739
Mini-MAC Time 2						
Total scale scores	64.64 (14.42) 64	69.61 (15.79) 67.5	X^2 0.66, p .418	62.86 (13.65) 61.5	68.13 (12.91) 73	X^2 1.32, p .250
Fatalism	14.36 (4.37) 15	13.44 (3.09) 14	X^2 0.70, p .403	13.82 (2.54) 14	15.63 (3.25) 16.5	X^2 2.49, p .114
Fighting spirit	12.36 (2.58) 12	11.89 (2.68) 12	X^2 0.17, p .683	11.55 (2.15) 11.5	10.75 (2.82) 11	X^2 0.44, p .508
Helplessness/hopelessness	11.36 (4.06) 10	13.44 (5.09) 14	X^2 1.35, p .246	12.64 (4.95) 11.5	13.38 (4.60) 13.5	X^2 0.27, p .602

Anxious preoccupation	17 (4.90) 19	19.67 (6.02) 19.5	X^2 1.17, p .279	16.41 (6.26) 15.5	18.63 (5.55) 21	X^2 1.22, p .270
Cognitive avoidance	9.55 (3.45) 11	11.17 (3.05) 11	X^2 0.99, p .319	8.45 (3.13) 8.5	9.75 (3.66) 10	X^2 0.99, p .320
Mini-MAC Time 3						
Total scale scores	63.73 (12.66) 63	66.39 (17.31) 67.5	X^2 0.55, p .458	60.33 (15.86) 61	68.50 (11.36) 71)	X^2 1.87, p .171
Fatalism	14.45 (3.53) 15	12.56 (3.52) 12.5	X^2 1.90, p .168	13.05 (3.31) 13	15.63 (3.25) 15.5	X^2 2.87, p .090
Fighting spirit	12.27 (2.53) 12	10.61 (3.01) 10.5	X^2 1.61, p .204	11.43 (2.62) 12	11.88 (1.96) 12.5	X^2 0.06, p .806
Helplessness/hopelessness	10.55 (3.14) 9	13.89 (4.66) 13	X^2 3.51, p .061	11.76 (4.80) 9	12.63 (4.84) 10	X^2 0.76, p .383
Anxious preoccupation	16.27 (5.48) 17	19.22 (6.39) 20	X^2 1.23, p .268	16.33 (6.95) 15	17.88 (4.55) 20	X^2 0.96, p .327
Cognitive avoidance	10.18 (3.16) 11	10.11 (3.09) 10.50	X^2 0.19, p .666	7.76 (3.53) 8	10.50 (4.50) 11	X^2 2.65, p .104
PES Time 1	50.92(6.11) 51.5	47.33(5.69) 47	X^2 2.81, p .094	48.86 (5.43) 51	46.87 (4.05) 48	X^2 1.72, p .279
PES Time 2	48.55(5.63) 48	44.11(5.46) 44	X^2 4.40, p **.036**	49.41 (5.37) 49.5	49.75 (6.67) 52.5	X^2 0.43, p .510
PES Time 3	47.73(6.07) 47	46.89(6.23) 46.5	X^2 0.13, p .718	50.29 (4.98) 51	50 (7.46) 52.5	X^2 0.05, p .825

Note. *Kruskal–Wallis test results; **Bolded** p value indicates statistical significance $p<.05$

Table 8 Lymphoma Differences Across Measures at Each Time Point within the Control and Intervention Groups

Measure	Control Group			Intervention Group		
	NHL N=24	HL N=6	Group Comparison*	NHL N=18	HL N=12	Group Comparison*
	Mean(SD) Median	Mean(SD) Median		Mean(SD) Median	Mean(SD) Median	
SF-SUNS Time 1						
Total Scale scores	28.17 (24.14) 23	20 (4.69) 18.5	X^2 0.08, p .775	26.72 (23.56) 17.5	28.25 (16.21) 26	X^2 0.55, p .459
Information	3.38 (2.65) 3.5	3 (2.45) 3	X^2 0.10, p .753	2.33 (3.33) 0	3.92 (2.81) 3	X^2 3.28, p .070
Financial concerns	7.92 (6.49) 7	3.5 (2.26) 4	X^2 3.12, p .077	7.22 (7.08) 5	5.92 (3.75) 7	X^2 0.002, p .966
Access and continuity of care	3 (4.78) 1.5	1 (0.89) 1	X^2 0.92, p .339	4.61 (7.14) 1.5	3 (3.28) 1.5	X^2 0.01, p .914
Relationships and emotional health	13.88 (12.68) 11.5	12.50 (5.21) 11.5	X^2 0.11, p .735	12.56 (11.03) 10	15.42 (10.88) 13.5	X^2 0.49, p .484
SF-SUNS Time 2						
Total Scale scores	30.87 (30.71) 22	20 (8.44) 21	X^2 0.003, p .957	28.72 (28.21) 19.5	22.58 (10.84) 23	X^2 0.02, p .882
Information	3.48 (3.59) 2	2.17 (1.47) 2.5	X^2 0.17, p .680	2.17 (2.15) 2	2.58 (1.83) 2.5	X^2 0.45, p .504
Financial concerns	7.43 (9.12) 4	2.33 (1.63) 2	X^2 1.50, p .220	9 (8.96) 6	5.58 (4.46) 6	X^2 0.33, p .564
Access and continuity of care	3.87 (4.62) 3	1 (1.67) 0	X^2 2.68, p .102	2.39 (3.87) 0	2.42 (2.81) 1	X^2 0.06, p .800
Relationships and emotional health	16.09 (15.16) 11	14.50 (7.15) 14.5	X^2 0.16, p .686	15.17 (15.11) 11	12 (8.33) 11.5	X^2 0.01, p .916
SF-SUNS Time 3						
Total Scale scores	27.17 (28.78) 18	20.17 (9.52) 22	X^2 0.19, p .666	24.11 (27.51) 14.5	17 (12.38) 16	X^2 0.06, p .805
Information	2.78 (3.10) 2	2.67 (1.51) 3	X^2 0.28, p .600	2.28 (2.63) 2	1.45 (1.75) 0	X^2 0.55, p .458
Financial concerns	7.22 (8.45) 4	2.67 (2.16) 3.5	X^2 1.07, p .301	7.28 (7.40) 4.5	3.27 (3.00) 4	X^2 2.04, p .154
Access and continuity of care	2.57 (3.12) 2	1.5 (1.52) 1.5	X^2 0.20, p .654	3.06 (5.84) 1	0.91 (1.45) 0	X^2 1.30, p .254
Relationships and emotional health	14.61 (15.36) 9	13.33 (8.62) 16	X^2 0.14, p .705	11.50 (14.52) 7	11.36 (7.99) 11	X^2 0.81, p .368
DASS21 Time 1						

Total scale scores	16.92 (15.12) 11	10.17 (5.19) 9	X^2 0.69, p .405	12.72 (13.91) 8	12.58 (9.02) 11	X^2 0.52, p .471
Depression	4.92 (5.81) 2	2 (2) 1	X^2 0.12, p .732	4.56 (5.53) 2.5	3.25 (3.31) 2	X^2 0.04, p .847
Anxiety	5.25 (5.34) 3.5	2 (2.53) 1	X^2 1.93, p .164	3.11 (3.64) 1.5	4 (2.95) 3	X^2 1.77, p .184
Stress	6.75 (5.72) 5.5	6.17 (1.72) 6	X^2 0.08, p .774	5.06 (5.32) 4	5.33 (4.83) 5	X^2 0.44, p .509
DASS21 Time 2						
Total scale scores	14.78 (14.95) 8	11.83 (7.39) 10	X^2 0.11, p .746	18.11 (17.61) 10.5	11.92 (11.75) 7	X^2 0.65, p .421
Depression	4.87 (5.83) 2	3.5 (3.73) 3	X^2 0.19, p .661	6.28 (6.52) 3	3.83 (4.30) 1.5	X^2 1.70, p .193
Anxiety	4 (4.57) 2	2.17 (1.60) 2	X^2 0.15, p .703	3.78 (4.22) 3	3.17 (2.79) 2.5	X^2 0.00, p .983
Stress	5.91 (6.15) 4	6.17 (3.87) 5.5	X^2 0.50, p .480	8.06 (7.60) 5.5	4.92 (5.68) 3.5	X^2 0.69, p .406
DASS21 Time 3						
Total scale scores	16.78 (14.69) 12	8.83 (7.14) 9	X^2 1.22, p .269	13.17 (15.57) 7	12.82 (9.53) 15	X^2 0.25, p .620
Depression	5.39 (6.01) 2	2.67 (2.66) 2.5	X^2 0.50, p .479	4.28 (6.21) 1	3.91 (3.91) 4	X^2 0.04, p .835
Anxiety	4 (4.22) 3	1.83 (2.14) 1	X^2 0.91, p .339	3.44 (4.29) 1.5	3.45 (3.47) 3	X^2 0.16, p .694
Stress	7.39 (6.11) 7	4.33 (4.08) 3.5	X^2 1.05, p .304	5.72 (6.34) 3.5	5.55 (4.91) 4	X^2 0.00, p 1.00
Mini-MAC Time 1						
Total scale scores	68.96 (13.85) 69	66.5 (7.26) 68	X^2 0.05, p .815	60.56 (12.65) 58	72.42 (8.98) 72.5	X^2 6.90, p **.009**
Fatalism	15 (3.02) 16	11.33 (2.81) 12	X^2 6.15, p **.013**	13.72 (3.20) 13.5	14.75 (2.77) 14	X^2 0.76, p .383
Fighting spirit	12.79 (2.21) 13	11.17 (1.17) 11	X^2 3.56, p .059	12.06 (2.69) 12	12.92 (2.47) 13.5	X^2 0.76, p .382
Helplessness/hopelessness	12.21 (4.48) 10.5	13.5 (3.67) 15	X^2 0.52, p .472	11.94 (4.88) 10.5	14 (4.82) 12.5	X^2 2.17, p .140
Anxious preoccupation	19.38 (5.90) 19	19.83 (2.14) 19	X^2 0.00, p 1.00	15.17 (5.51) 13	20.42 (4.98) 20.5	X^2 6.61, p **.010**
Cognitive avoidance	9.58 (3.28) 10	10.67 (2.50) 11.5	X^2 1.45, p .229	7.67 (2.70) 8	10.33 (3.26) 10	X^2 4.34, p **.037**
Mini-MAC Time 2						
Total scale scores	68.87 (16.04) 66	63.33 (11.73) 64	X^2 0.57, p .451	62.44 (14.46) 61	67 (11.81) 70	X^2 1.08, p .299
Fatalism	14.65 (3.33) 15	10.5 (2.59) 10	X^2 6.62, p **.010**	14.17 (2.81) 14	14.50 (2.91) 15	X^2 0.16, p .686
Fighting spirit	12.39 (2.76) 13	10.83 (1.47) 10.5	X^2 3.03, p .082	11.44 (2.15) 11	11.17 (2.66) 11.5	X^2 0.029, p .864
Helplessness/hopelessness	12.74 (5.07) 13	12.33 (3.67) 13	X^2 0.003, p .956	12.44 (5.24) 11.5	13.42 (4.19) 14	X^2 1.10, p .294

Anxious preoccupation	18.61 (6.24) 19	18.83 (3.06) 20	X^2 0.06, p .808	16 (6.16) 15	18.50 (5.85) 17.5	X^2 1.36, p .244
Cognitive avoidance	10.48 (3.46) 11	10.83 (2.48) 11.5	X^2 0.03, p .871	8.39 (3.20) 9	9.42 (3.40) 9.5	X^2 0.77, p .381
Mini-MAC Time 3						
Total scale scores	67.30 (15.46) 69	58 (14.64) 62	X^2 1.54, p .215	61.67 (16.08) 62	64.09 (13.73) 70	X^2 0.52, p .471
Fatalism	14.13 (3.09) 14	10 (3.69) 10	X^2 5.92, p **.015**	13.78 (3.57) 14	13.73 (3.38) 13	X^2 0.05, p .821
Fighting spirit	11.78 (2.76) 12	9.17 (2.71) 10	X^2 4.26, p **.039**	11.56 (2.55) 12	11.55 (2.34) 12	X^2 0.01, p .946
Helplessness/hopelessness	13.09 (4.80) 13	10.83 (1.60) 11.5	X^2 0.82, p .367	11.94 (4.82) 9.5	12.09 (4.83) 9	X^2 0.00, p 1.00
Anxious preoccupation	18.13 (6.48) 19	18 (5.10) 19.5	X^2 0.04, p .850	16.06 (6.28) 15.5	17.91 (6.56) 20	X^2 0.74, p .391
Cognitive avoidance	10.17 (3.03) 11	10 (3.46) 11	X^2 0.01, p .935	8.33 (4.10) 8	8.82 (3.84) 9	X^2 0.10, p .751
PES Time 1	50.13 (5.78) 50.5	43.33 (3.56) 43.5	X^2 6.62, p **.010**	48.89 (5.31) 50	47.50 (4.89) 48	X^2 0.43, p .510
PES Time 2	47 (5.84) 47	41.17 (2.99) 41	X^2 6.05, p **.014**	49.33 (4.91) 49.5	49.75 (6.78) 52.5	X^2 0.24, p .625
PES Time 3	48.13 (5.96) 48	43.67 (5.61) 42	X^2 2.80, p .094	50.56 (5.07) 51.5	49.64 (6.67) 52	X^2 0.04, p .839

Note. *Kruskal–Wallis test result; **Bolded** p value indicates statistical significance $p<.05$