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Sasha Morgan Skendzel  
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IMPLEMENTING A SATISFYING APP-LED BMT SURVIVORSHIP CLINIC:  
OUTCOME ANALYSIS AND LEADERSHIP THEORY INTERVENTION

DNP Project  
Submitted in Partial Fulfillment  
of the Requirements for the Degree of  
Doctor of Nursing Practice

St. Catherine University  
St. Paul, Minnesota

Sasha Morgan Skendzel

May 2019

ST. CATHERINE UNIVERSITY  
ST. PAUL, MINNESOTA

This is to certify that I have examined this  
Doctor of Nursing Practice DNP project  
written by

*Sasha Morgan Skendzel*

and have found that it is complete and satisfactory in all respects,  
and that any and all revisions required by  
the final examining committee have been made.

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Date

DEPARTMENT OF NURSING

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### Executive Summary

With a projected half a million blood and marrow transplant (BMT) survivors in the United States by 2030 (Battiwalla, Tichelli, & Majhail, 2017) transplant centers are challenged with increased demands for improved patient access to high quality long-term follow-up care (Skendzel, 2016). This unique group of survivors has a distinct risk profile for post-treatment complications from exposure to highly toxic levels of chemotherapy and radiation (Sun et al., 2010). Additionally, lack of access to survivorship care increases the risk of poor outcomes for marginalized, high risk, and underserved groups (Bevans et al., 2017; Smith & Hall, 2015).

To expand access, mitigate health disparities, and reduce morbidity (Majhail et al., 2012) amongst adult BMT recipients at the University of Minnesota, an advanced practice provider (APP)-led survivorship clinic was created and implemented. Leadership in the initiative included a nurse practitioner on the team, BMT physician, and a nurse researcher with a background in interprofessional teamwork. The purpose of this quality improvement (QI) initiative was to implement an APP-led survivorship clinic, evaluate implementation goals, and improve patient and provider outcomes following a theory-guided approach.

The implementation process included 4 plan-do-study-act (PDSA; Langley et al., 2009) cycles, with outcomes evaluated in cycles 3 and 4. The project included collecting electronic survey data from both survivors ( $n = 22$  responses) and APPs ( $n = 14$  responses) following an interrupted QI design. Satisfaction was determined using a modified version of the validated (Sansoni, et al., 2011) Short Assessment of Patient Satisfaction (SAPS, University of Melbourne, 2011) with scores  $> 19$  considered satisfying. A modified version of the validated (Peres, Pham, & Phillips, 2013) Systems Usability Scale (SUS; Brooke, 1996) was used to measure provider perceived usability of the electronic care plan templates. Additionally, 10-point Likert scales,

binary, and open-ended questions were used to assess satisfaction, patient self-management, and survivorship care plan (SCP) utility. Data analysis was conducted using descriptive statistics, reporting median scores and percentages for the most common results. For open-ended questions, qualitative analysis was used to identify themes (Skendzel, Holtan, & Finch-Guthrie, 2019).

Implementation outcomes were met in all areas except APP satisfaction ( $n = 7$ , median 13, range 6-19). Patients were overall satisfied with the visit ( $n = 11$ , median SAPS 25, range 19-28). Additionally, 100% of patients were very satisfied with the effect of their care, found the SCP useful, and reported improved post-visit self-efficacy.

Unfortunately, provider dissatisfaction has been associated with poor patient perceived quality of care (McHugh & Stimpfel, 2012) and adverse outcomes (Laschinger & Leiter, 2006; McHugh, Aiken, Eckenhoff, & Burns, 2016) in the literature. To improve this critical outcome, Path-Goal Theory (PGT; House, 1996) and Transformational Leadership (TFL; Bass & Reggio, 2006) were applied in a leadership intervention with the APP team. Following the intervention, APP satisfaction dramatically increased with a median SAPS of 21 ( $n = 7$ , range 14-22).

Additionally, only 15% of APPs reported there was an opportunity to enhance their satisfaction and 71% were satisfied with the care they provided, compared to 68% and 29% respectively.

Patient satisfaction scores remained high with a median SAPS of 22 ( $n = 11$ , range 15-28).

Using theoretical frameworks to guide practice, and a multidisciplinary approach, nurse leaders can implement survivorship care that is satisfying for patients and providers. Currently, there is a gap in the literature that examines the use of theoretical frameworks for developing BMT survivorship models. Our findings provide support for future research regarding the use of PGT and TFL to guide leadership interventions during the implementation process.

Implementing a Satisfying APP-Led BMT Survivorship Clinic:  
Outcome Analysis and Leadership Theory Intervention

**Chapter 1: Background and Objectives**

Medical advancements in cancer treatment have led to a growing number of patients living well beyond the cure. The fight, however, doesn't end when treatment is over. Chemotherapy, radiation, and surgery put survivors at risk for chronic, sometimes fatal, health problems. Unfortunately, care fragmentation and lack of access to high-quality follow-up care significantly increase the risk for morbidity and mortality, with populations suffering from known social determinants of poor health disproportionately suffering from adverse outcomes. For this reason the Institute of Medicine (IOM, 2006) warned in their famous publication *From Cancer Patient to Cancer Survivor: Lost in Transition* of the growing national need for high-quality survivorship care delivered by knowledgeable professionals (Skendzel, 2019).

Patients with high-risk hematologic malignancies and diseases of the blood who receive a potentially curative treatment known as a blood or marrow transplant (BMT), also referred to as a hematopoietic stem cell transplant, make up a subsection of the rapidly growing cancer survivor population (Majhail et al., 2012). In response to national efforts to improve follow-up care for cancer survivors, BMT clinical practice guidelines were published in 2012 (Majhail et al., 2012). Unfortunately, many centers have failed to actualize these guidelines today. At large, this has been due to significant challenges in implementing change in healthcare systems (Hashmi, Carpenter, Khera, Tichelli, & Savani, 2015).

To improve health equity and address the needs of adult BMT survivors at the University of Minnesota, a nurse practitioner (NP) and doctor of nursing practice student (DNP) led a quality improvement initiative (QI) to create and implement an advanced practice provider

(APP) led survivorship clinic. Core project leadership also included a BMT physician and academic mentor in the field of nursing. Together, the team overcame nationally recognized barriers to survivorship implementation using a multidisciplinary approach, theory to guide practice, and literary evidence from diverse disciplines.

Presented here is an overview of the project in its entirety. Content in Chapter 1 includes rationale for the initiative including background and significance, purpose, and project objectives. In Chapter 2, findings from appraised articles identified in the literature review, synthesis of the evidence, and selected theoretical frameworks are presented. In Chapter 3, the implementation plan including design and methods are discussed. Preliminary findings and results of a leadership intervention to improve outcomes are presented in Chapter 4. Likewise, a discussion of these findings, recommendations for future practice, project limitations, and potential areas for future scholarship are presented in Chapter 5. Finally, closing paragraphs discuss the scholarly purpose of this project, demonstrating the important role of DNPs in the expansion of nursing scope of practice to improve population health outcomes in congruence with the American Association of Colleges of Nursing essentials for DNP practice (2006).

### **Background and Significance**

Considered lethal half a century ago, many disorders of the blood and marrow, including high-risk hematologic malignancies, are now curable through autologous and allogeneic BMT. Following fifty years of research, improved conditioning regimens, and significant medical advancements, patient survival and outcomes have dramatically improved (Battiwalla, Tichelli, & Majhail, 2017; Gifford, Sim, Horne, & Ma, 2014). Additionally, expanded treatment indications and alternative stem cell sources have substantially increased the number of patients eligible for transplant (Bevans et al., 2016). As a result, there are over 100,000 transplant

survivors today, a number expected to increase five-fold in the next 15 years (Majhail, et al., 2013). With this growing number of survivors and a mounting body of evidence detailing chronic and potentially life-threatening treatment related post-BMT complications, the fulcrum of care has shifted from simply curing cancer towards improving the health and wellbeing of survivors (Majhail, et al., 2012).

**Health risks.** Stem cell transplant can impact nearly every facet of a recipients' life. Unfortunately, many aspects of treatment place patients at risk for a wide range of complications including exposure to chemotherapy, radiation, drugs, infections, transfusions, donor stem cells, social isolation, painful procedures, and prolonged periods of unemployment. Combined, these well-documented treatment-related complications, occurring after the first 100-days of treatment, are commonly referred to as transplant late-effects (TLE). While an extensive list is beyond the scope of this paper, common physical risks include graft-versus-host disease (GVHD) for allogeneic recipients, cardiomyopathy, impaired organ function, osteopenia, sarcopenia, chronic malnutrition, reproductive organ failure, secondary cancers, and infections (Inamoto & Lee, 2017; Majhail, et al., 2012; Majhail et al., 2013). Furthermore, BMT survivors also experiences higher rates of pain (Paice & Ferrell, 2011; Syrjala, Langer, Abrams, Storer, & Martin, 2005), financial hardship (Hamilton et al., 2013; Khera, et al, 2014), fatigue (Gielissen, 2007), emotional distress (Siegel, 2008; Sun et al., 2011), post-traumatic stress-disorder (El-Jawahri, et al., 2016), sleep disturbances (Jim, et al., 2014), medication non-adherence (Gresch, et al., 2016), unhealthy lifestyle behaviors (Gresch, et al., 2016; Bishop, et al., 2009), and sexual health disorders (Dyer et al., 2016; Yi & Syrjala, 2009) than the general population (Bevans, et al., 2017).

## Survivorship and Social Justice

**Health disparities.** Unfortunately, gaps in care during transitions, lack of access to knowledgeable providers, and known social determinants of poor health all remain substantial barriers to essential screening and prevention in the survivorship period today (Smith & Hall, 2015). Those disproportionately affected include patients of lower socioeconomic status, women, the under or uninsured, those with mental health conditions, and rural BMT recipients (Bevans et al., 2017; Smith & Hall, 2015). These findings are likely true in other at-risk populations, however, very little is known about BMT specific outcome disparities amongst groups such as ethnic minorities (Bevans, et al., 2017). For instance, in the general cancer survivor population, minority status has been associated with poorer outcomes following treatment, particularly for low-income African-Americans (Haynes-Maslow, Allicock, & Johnson, 2015; Healthypeople.gov, 2019).

## National Initiatives

**National support for change.** To address these disparities and improve health equity amongst this growing population in the United States, in 2006 the IOM made several recommendations for the creation and implementation of survivorship care models. Essentially, these recommendations included use of the existing Chronic Care Model (CCM; Wagner, 2010) to structure and develop dedicated survivorship clinics, implementation of guideline-based interventions, and application of health promotion strategies designed to support patient chronic-disease self-management (CDSM). In addition, the IOM along with other leading oncology organizations such as the American Society of Clinical Oncology (ASCO, 2017), American Cancer Society (ACS, 2019), National Cancer Institute (NCI, 2017) and American College of Surgeons Commission on Cancer (ACSCC, 2014), also recommended all patients treated for

cancer receive detailed survivorship care plans (SCP) and dedicated follow-up visits conducted by knowledgeable experts in each sub-specialty of oncology. Further evidence of this national movement included the Healthy People 2020 objectives aimed at reducing health disparities amongst survivors, increasing quality of life, and improving overall 5-year survival rates (Healthypeople.gov, 2019; Smith & Hall, 2015).

**Clinical practice guidelines.** Unfortunately, research and formal clinical practice guidelines (CPG) for TLE screening and preventative practices for adult BMT recipients lagged considerably behind national cancer survivorship recommendations. The first adult BMT-specific CPG emerged in 2012 (Majhail, et al.), a full half of a decade after the initial IOM report. What materialized, albeit untimely, was a comprehensive and detailed set of over 50 assessment points spanning 13 organ systems with variable clinical decision pathways based on age, gender, transplant graft source, history of GVHD, and treatment related exposures.

### **Survivorship Barriers and Support.**

**National barriers.** The establishment of clinical practice standards alone is often not enough to bring practice guidelines to the bedside in healthcare, a phenomenon known as the research-practice gap (Kristensen, Nymann, & Konradsen, 2016). This has remained the case for transplant centers throughout the nation today. At large, challenges to the implementation of change in healthcare systems have been common barriers to adoption of survivorship CPG in BMT (Hashmi, et al., 2015).

A substantial challenge for all centers remains the resounding lack of literature regarding successful survivorship models in BMT. Additional barriers include capacity to add additional clinical visits, time constraints, budget restrictions, inadequate staffing, limited access to non-clinical support services, and lack of electronic medical record (EMR) resources for orders and



standardized care plans (Hashmi, et al., 2015). From a logistical standpoint, reported challenges have included inability to accommodate longer visits, time spent reviewing and preparing survivorship care plans (SCP) to prepare for the visits (Dulko et al., 2013), complexity of the guidelines, and lack of provider knowledge (Majhail & Rizzo, 2013).

**Systems barriers.** At the University of Minnesota (UMN), our challenges were consistent with those seen at the national level. Lack of time and resources for dedicated survivorship visits placed a considerable amount of onus largely on individual BMT physicians to implement the guidelines and communicate findings with patients and their care teams. Furthermore, limited economic and environmental resources to accommodate extra physician full time-equivalent (FTE) hours in our clinic made implementing a physician survivorship clinic nearly an impossible venture despite the growing number clinicians in support of change. Therefore, without additional time, leadership support, or resources, physicians were unable to meet these demands.

**Climate for change.** Fortunately, national support and acceptance regarding the importance of survivorship and long-term follow-up care has improved dramatically since 2016. The tipping point, in part, was likely due to changes in the Foundation for Accreditation of Cellular Therapy (FACT) credentialing requirements and a move towards outcome-based reimbursement models by many large third-party payers (LeMaistre & Farina, 2015). At the University of Minnesota, objective support for change was apparent from the findings of a systemic chart review conducted by a team of academic oncologists in the department (Thaw, et al., 2018). Researchers compared physician practices within our group to the 2012 consensus guidelines and found providers routinely and systemically missed recommended assessments and

diagnostic tests. Upon further analysis, the findings remained true even when physicians with an identified interest in survivorship conducted the visits.

### **APP-Led Survivorship Model**

**Advanced Practice Provider Model.** A culmination of these supporting influences provided the critical mass necessary to move forward with change to our clinical practice standards for follow-up care. Capitalizing on the timely opportunity, a NP on the BMT clinical team and DNP student at St. Catherine University proposed an APP-led survivorship model to expand access, mitigate health disparities, and reduce morbidity for adult BMT recipients (Majhail et al., 2012). Superimposed on the outpatient clinic framework, the proposed model would efficiently use existing resources, overcoming many of the aforementioned barriers. With significant propensity to increase patient access to high-quality care using minimal financial and environmental resources, the APP-led model was considered more feasible than a physician-centered approach.

Nurse practitioners, also known as advanced practice registered nurses (APRN), have a unique educational foundation in leadership and are established purveyors of cost-effective care in oncology. Furthermore, their unique combination of clinical expertise and comprehensive understanding of the health systems in which they operate, make them excellent champions for survivorship reform efforts (Economou & Corcoran, 2016; Sun et al., 2015). Therefore, the APRN project lead was in the perfect position to move forward with this department-wide practice change at the University of Minnesota.

Equipped with objective evidence and the appropriate climate for change, support for the proposed model was garnered from key stakeholders including the division director and existing APP leadership. In addition to the APRN project lead, core team members included a BMT

physician with expertise in transplant late-effects and a nurse researcher with a background in inter-professional teamwork. Together, leadership built partnerships with stakeholders from other disciplines in the department including health information technology (HIT) specialists, administrators, schedulers, nurses, nurse managers, and medical office assistants (MA) to create a multidisciplinary team.

### **Project Purpose and Objectives**

**Purpose and objectives.** The purpose of this quality improvement (QI) initiative was to create an APP-led survivorship model, evaluate primary implementation markers, and improve outcomes through application of leadership interventions founded in theory. To date, BMT survivorship models implemented following theoretical frameworks to promote both patient and provider outcomes have not been documented in the literature. Therefore, project leadership used evidence and theories from other disciplines and sub-specialties of oncology to determine implementation objectives and an implementation plan. Based on these findings, presented in the next chapter, project objectives included the creation of a satisfying clinic model, development of useful and useable electronic care plan templates, determination of appropriate visit length, and promotion of patient self-efficacy to manage their care in accordance with the CCM (Wagner, 2010).

### **Chapter 1 Overview**

With a rapidly growing number of BMT survivors, now more than ever, sustainable survivorship models are needed to meet the complex needs of BMT survivors. To improve health equity amongst our population of adult BMT recipients at the University of Minnesota, an NP on the team developed and implemented an APP-led survivorship clinic. Evidence to support

project objectives and a summary of theories used to guide implementation interventions are presented in the next chapter.

## Chapter 2: Synthesis of the Literature and Theoretical Framework

An in-depth synthesis of the appraised literature was conducted prior to project implementation. The project lead used review findings to determine potential project barriers, identify successful APP-led survivorship models, and establish implementation outcomes. The review process, strategy, synthesis of the findings, and selected theoretical frameworks used to guide these interventions are presented here.

### Literature Review

**Inclusion criteria.** Our preliminary searches limited to the BMT population yielded fewer than 10 articles. Therefore, the NP project lead broadened the search to encompass survivorship implementation studies in all adult cancer specialties. Additionally, leadership determined several types of evidence would be appropriate for inclusion in the review process since, by and large, most of the existing studies were qualitative designs. Other types of scholarly articles included were systemic reviews, protocols, guidelines, meta-analysis, cohort studies, multicenter-studies, quality-improvement, and clinical trials. Further inclusion criteria limited articles to those published on or after 2007, scholarly journals, and those that involved research conducted with the adult (age > 18 years) cancer survivor population.

**Key terms.** Given the multiplicity of phenomena under review, several key terms and medical subject headings (MeSH) were included. These terms included cancer survivor or survivorship, self-efficacy, chronic disease, self-management or self-care, survivorship care plan or patient care plan, stem cell transplant or hematopoietic stem cell, behavior change, systems implementation, systems change, usability or user experience, systems usability scale, PDSA cycle, quality improvement, implementation drivers, patient satisfaction, survivorship program or survivorship model, provider satisfaction, physician satisfaction, APRN satisfaction, and nurse

practitioner satisfaction. To ensure high-yield results, terms were modified to the appropriate and corresponding MeSH or CINAHL headings depending on the database.

**Databases.** With the compulsory amalgam of study designs, disciplines, and phenomenon under evaluation, leadership carefully considered appropriate databases to include in the search process. The selected databases had to allow for diversity in disciplinary contributions to survivorship care and EBP implementation models utilized in healthcare. Thus, chosen databases encompassed evidence from the fields of nursing, medicine, psychology, and rehabilitation. Included databases were CINAHL, PsychInfo, PubMed, and Cochran Review (Skendzel, 2017).

**Appraisal of evidence.** Of the total 606 citations that were identified in the initial search, 88 were considered relevant based on abstract review, and 13 were used to form the evidentiary base for the QI initiative. Leadership further evaluated the studies for their contribution to the body of evidence regarding survivorship implementation models, theoretical frameworks, patient and provider satisfaction, outcome metrics, types of SCP's, and types of interventions used to promote patient self-management (SM). A summary of the findings can be found in Appendices A-B.

To appraise these studies, the project lead used the Johns Hopkins Nursing Evidence-Based Practice guidelines (The John Hopkins University, 2017). This appraisal tool ranks evidence quality into three categories, including high, good, or low with a corresponding letter grade of A-C. Research with adequate controls and generalizable findings constitute high quality (A) studies. In addition, the tool ranks level of evidence based on the study design, with the highest level assigned I, and the lowest assigned III. Randomized control trials (RCT) and experimental designs are regarded as the highest level, or level I. Therefore, non-experimental or

qualitative designs are assigned the lowest level of evidence, or level III. Our team considered levels of evidence I-III appropriate for our QI project since there are a limited number of RCTs and experimental studies evaluating outcomes of newly implemented survivorship models in the existing literature.

### **Synthesis of Evidence**

**Implementation models.** The lead initially reviewed articles for successful implementation models to guide the project. Therefore, studies were evaluated for type of implementation strategies, instruments used to assess outcomes, metrics, length of visit, barriers to practice, and types of theoretical frameworks used to guide interventions. Of the APP-led models, further analysis was conducted regarding degree of clinician involvement and tools used to create the care plans. All studies were descriptive qualitative designs; evidence level III, with a quality rating of A or B.

Predominantly, the newly implemented clinics included in the review were APP-led with some degree of nursing or oncologist involvement. An APP, either a nurse practitioner (NP) or physician's assistant (PA), was responsible for providing verbal follow-up instructions, creating the care plan, and educating patients about survivorship. Length of time for the actual visit and delivery of the care plan ranged from 45 to 90 minutes (Curcio, Lambe, Schneider, & Khan, 2012; Dulko et al., 2013; Mayer, et al., 2014; Sprague et al., 2013).

Unfortunately the initial search revealed significant variability in implementation plans, providing very little evidence for a single model that would best fit our project. Further, specific models and theoretical frameworks to guide the implementation process could not be identified.

A single study used a plan-do-study-act (PDSA; Langley et al., 2009) model to create and

implement the use of EMR based SCPs (Mayer et al., 2015). This model appeared appropriate for moving forward with change in our system given the short timeline for each change cycle.

**Length of visit.** On average, our literature review revealed an appropriate visit length of 45-90 minutes (Curcio, et al., 2012; Dulko et al., 2012). Despite notable barriers, APPs were able to complete the entire visit within this period of time without disruption in workflow in all of the studies (Curcio, et al., 2012; Dulko et al., 2012; Mayer et al., 2014). Please refer to Appendix A, Table A1 for more details.

**Implementation barriers.** Leadership further appraised the literature for potential implementation barriers to identify and address these challenges during the project-planning phase. A frequently reported barrier was the amount of time APPs spent creating the SCP document due to the medical record review process and documentation of the patients' treatment history (Dulko, et al., 2012; Mayer, et al., 2014). In most of the studies, an APP or nurse completed the chart review process prior to the visit to ensure enough allotted clinical time for teaching and assessments. For this reason, multiple researchers recommended completing a portion of the treatment summary prior to the visit (Curcio, et al., 2012; Mayer, et al., 2014).

**Satisfaction.** Satisfaction is a measurable marker of perceived care quality and has been recognized by the Institute for Healthcare Improvement (IHI) as an integral facet of the Triple Aim initiative to reform healthcare (2019). Therefore, the project lead searched the literature to determine both patient and provider satisfaction with APP-led models and potential implementation interventions to target this phenomenon. Overall, patient and provider satisfaction was high (Brennan, Gormally, Boyl, & Spillane, 2014; Curcio, et al., 2012; Mayer, et al., 2014; Sprague et al., 2013). This conclusion was established from studies with sufficiently high evidence, levels ranging from II-III, and of good quality. However, our literature review did



not yield any evidence regarding type of leadership model or specific interventions to promote the satisfaction phenomenon for patients or providers during the implementation process. Please refer to Appendix B, Tables B1-B2, for a summary of these findings.

**Care plan utility.** Since many different electronic templates exist for the creation of survivorship care plans, leadership also appraised the literature to determine the best tool to create the notes. Survivorship care plans are an essential component of the clinical visit and are required by most program credentialing bodies. Individualized SCPs are designed to guide and educate patients about their treatment history and provide a roadmap for early identification and prevention of treatment related risks (ACSCC, 2014; NCI, 2017). However, significant variability exists in the commercially prepared care plans available online. Therefore, leadership reviewed existing evidence to determine an appropriate template for our clinic model, evaluate technical usability of these tools, and assess patient perceptions of the notes created from the templates.

Based on our findings, patient perceived utility of care plans (Table B2, Appendix B) created using existing commercially available electronic templates was overall high (Brennan, Gormally, Boyl, & Spillane, 2014; Curcio, Lambe, Schneider, & Khan, 2012; Mayer, et al., 2014; Sprague et al., 2013). The tool used most frequently was the online Journey Forward (2017) care plan builder. However, literature regarding provider perceived usability of this resource was very limited (Table B1, Appendix B).

The literature search did yield a potential alternative to the commercially prepared tools that involved building the notes within individual EMR systems. A single study conducted by Mayer and colleagues (2015) found high provider perceived usability of SCPs built by the project team within the EMR system Epic. Researchers were able to customize the care plans far

beyond the capacity of commercially prepared tools in order to meet the needs of different cancer sub-specialties in their system. Additionally, they found time to create the note decreased by 15 minutes using auto-populated data fields to fill-in portions of the SCP. For these reasons, provider feedback for the EMR based SCP templates was positive. Therefore, this EMR approach had significant appeal to our project team.

**Patient self-management.** Another phenomenon evaluated in the review process was patient self-management (SM). A single study demonstrated a statistically significant increase in SM amongst cancer survivors after an 8-week exercise program (Lawn, et al., 2014). This type of follow up model, however, was not considered practical for our single episode survivorship visits which would be separated at minimum by 6-month intervals. Therefore, our project team was unable to determine appropriate interventions to target SM behavior during the survivorship visits in accordance with CCM (Wagner, 2010) based on the limited number of studies that evaluated this outcome (Kenzik, et al., 2016; Lawn, et al., 2014; Wiljer, et al., 2009). Please refer to Appendix B, table B3 for more details.

**Measuring outcomes.** The project team further appraised the literature for specific tools to measure these implementation outcomes. Care plan usability was measured using a modified version of the validated (Peres, Pham, & Philips, 2013) Systems Usability Scale (SUS; Brook, 1996) in the study conducted by Mayer and colleagues (2014). In addition, SM was frequently measured using the validated (Ritter & Lorig, 2014) Self-Efficacy to Manage Chronic Disease 6-item scale (SEMCD-6; Lorig, Ritter, Ory, & Whitlaw, 2013). However, types of satisfaction surveys varied significantly between, across, and within studies.

**Potential harm.** It is important to note that none of the reviewed studies reported patient harm or significant adverse events related to the APP-led survivorship care or the use of

electronic SCPs. While benefits beyond satisfaction and usability could not be drawn, theoretical benefits are important to consider. At this time, nearly every leading oncology organization currently recommends the establishment of survivorship care services based on the potential to improve patient care coordination, enhance screening for relapse or secondary malignancy, detect potential complications early to minimize morbidity, and promote survivor well-being (IOM, 2006, Majhail et al., 2012).

### **Summary of Literature Findings**

Conclusions drawn from the literature were used as the evidentiary framework for the implementation model and plan. Foremost, our team determined that the APP-led model was feasible, safe, and satisfaction for both patients and providers was high. In addition, 60-minute visits were deemed appropriate. Further, we determined the SCP template would need to be created specifically for our BMT population, in accordance with the 2012 CPG, and built into our EMR system. Finally, the tools selected to measure usability and self-management outcomes included the SUS and SEMCD-6. Given the variability in satisfaction tools, the project lead elected to use a generic scale known as the Short Assessment of Patient Satisfaction (SAPS; University of Melbourne, 2011), which had been both applied and validated (Sansoni, et al., 2011) in similar practice settings.

Unfortunately, our literature review provided insufficient evidence regarding a specific theory to guide interventions. Therefore the lead determined further research regarding theories to promote CDSM and leadership interventions was necessary. An overview of the selected theories is presented below.

## Theoretical Framework

Theory, by definition, is used to shape and predict reality (Dahnke & Dreher, 2016, p. 205). Therefore, it can be a powerful tool in the creation of survivorship clinical models. In accordance with the IOM's recommendation (2006) to use the CCM (Wagner, 2010) as a platform for survivorship models and interventions, the phenomena of chronic-disease self-management (CDSM), guided the projects teams' initial selection of a theoretical framework.

The phenomenon of satisfaction was identified as an important outcome in several survivorship implementation studies because of its potential impact on perceived care quality. However, literature regarding theoretical models or leadership interventions to address this marker during the initial implementation process could not be found in the existing literature. Therefore, modalities to support satisfaction were not incorporated in our initial implementation plan. Based on preliminary results of the project outcome evaluation, leadership theories were explored and applied in an intervention to improve provider satisfaction in later stages of the project. The leadership intervention is discussed in further detail in Chapter 3.

## Model Theoretical Framework

**Self-management theory.** The survivorship phenomenon encompasses many of the same concepts as CDSM. Numerous models for self-care (Orem, 1991), health promotion (Pender, Mardaugh, & Parsons, 2015), self-efficacy (Bandura & Adams, 1977; Resnick, 2002) and CDSM (Lorig, et al., 1999) exist in nursing and allied health. Project leadership was drawn to the Individual and Family Self Management Theory (IFSMT; Ryan & Sawin, 2009) because it addresses these phenomena collectively, in a single unifying theory. Additionally, the incorporation of family, or caregivers, in the IFSMT aligned with our holistic view of survivors as only a part of patient-caregiver entity. Therefore, our team considered the IFSMT an ideal

theoretical framework to guide project implementation, care plan creation, and visit interventions.

**Self-efficacy and self-management.** A critical assumption of the IFSMT is the ability of healthcare providers to promote change by influencing certain contextual and *process* domains of self-management. In accordance with theoretical propositions, clinicians have the capacity to positively change patient behavior by enhancing patient's self-efficacy. The phenomenon of self-efficacy, in brief, is a person's perceived self-confidence to master an attainable task. Bandura first described the concept of self-efficacy, a critical and influential facet of behavior change, in 1977. Since that time, self-efficacy has been identified as one of the strongest predictors of self-management behavior in both the chronic disease and cancer survivor populations to date (Daniali, Darani, Eslami, & Mazaheri, 2017; Haas, 2011; Lorig, Ritter, Ory, & Whitelaw, 2013; Neupert, Lachman, & Whitbourne, 2009). Therefore, project leadership considered interventions to improve survivor self-efficacy to self-manage a focal point for health promotion interventions incorporated in the survivorship visits.

**IFSMT model.** According to theoretical principles, providers can influence patient self-management outcomes during the *process* stage of behavior development. This can be achieved through acts of social facilitation in which the provider partners with patients to increase self-efficacy by using influence, support techniques, and collaboration to set attainable goals. Additionally, the process of self-management, according to the theory, can also be enhanced through education regarding healthy behaviors and realistic expectations for change. Therefore, we posited that APPs could apply these principles during survivorship visits through risks education and behavioral goal setting to improve CDSM.

### **Intervention Theoretical Framework**

**Leadership theory.** Preliminary project outcomes, detailed in depth in Chapter 4, showed APPs were dissatisfied with the care they were providing during the visits. Considering the growing body of research linking provider dissatisfaction with poor patient perceived quality of care (McHugh & Stimpfel, 2012) and increase adverse outcomes (Laschinger & Leiter, 2006; McHugh, Aiken, Eckenhoff, & Burns, 2017), provider satisfaction was considered a key outcome in this initiative. Through careful appraisal and adoption of leadership theoretical frameworks, survivorship change champions hypothetically have the ability to overcome barriers to satisfaction. Therefore, the project lead evaluated theoretical approaches designed to promote satisfaction to guide leadership interventions and improve outcomes.

**Provider satisfaction phenomenon.** Provider satisfaction is a complex phenomenon, closely related to job satisfaction. It can be defined as an emotional feeling of fulfillment and connectedness with ones work (Spector, 1997), valuing the care provided (Locke & Latham, 1990) and having a positive emotional response to the care process (Schermerhorn, Osborn, & Hunt, 2000). In healthcare, involvement in decisions (Freeborn & Hooker, 1995), intellectual stimulation (Boamah, Read, & Laschinger, 2017), promotion of creativity (Freeborn & Hooker, 1995), and professional empowerment (Boamah, Spene-Laschinger, Wong, & Clarke, 2017) have been associated with satisfaction and motivation to preform shared goals (Maslow, 1970; Skendzel, 2018; Zhu, Avolio, & Walumbwa, 2009). Additionally, leadership behaviors and environmental factors, which can influence satisfaction, include transformational leadership (Boamah, Laschinger, Wong, & Clarke, 2017; Higgins, 2015), positive interpersonal relationships (Cicolini, Comparcini, & Simonetti, 2014), and a supportive environment (Fetter, 2012; Wu, Singh-Carlson, Odell, Reynolds, & Su, 2016).

**Path goal theory.** Path-Goal Theory (PGT; House, 1996) encompasses a complex interplay of environment, context, leader behaviors, and follower dynamics to improve satisfaction and motivation towards group goals. Consequently, the project lead considered this an excellent leadership approach to address the multifaceted phenomena of provider satisfaction. According to House (1996), PGT leaders employ specific behaviors in the process of motivating followers to achieve goals while simultaneously removing barriers and fostering satisfying work environment (Evans, 1970; House, 1996; Northouse, 2019, p. 118). The types of behaviors used are based on followers' degree of group affiliation, locus of control, desire for structure, and perceived abilities (Northouse, 2019; House, 1996). Particularly, group oriented, value based, and supportive behaviors were found to have the greatest potential for impact on provider satisfaction during CPG implementation.

Group oriented behaviors enhance follower empowerment, involvement in decisions, and creativity. As stated above, these factors have been associated with increased job satisfaction in healthcare. Following this process, leaders pose problem questions to their teams, encourage group participation, and identify common emerging solutions from the responses (House, 1996; Skendzel, 2018).

In addition to a shared-leadership approach, PGT highlights the important role of leaders in creating and articulating a care model that aligns with the morals of their team. Ultimately, this behavior results in improved follower self-efficacy and a heightened internal motivation to achieve shared goals (House, 1996). Examples of these activities include displaying confidence and passion about the impact survivorship services can have on improved health equity, frequent positive performance evaluations, praise for meeting goals, and sharing positive feedback.

Change related ambiguity occurs when job roles or standards deviate from traditional norms. This can lead to considerable job-related stress (Porter-O'Grady & Malloch, 2018). Unquestionably, the process of implementing a new survivorship service line, which requires providers' deviate from the traditional standard of practice, can elicit this type of anxiety response. Unfortunately, these change-related stressors can be counterproductive for teams since the resulting anxiety response has been demonstrated to reduce intellectual problem solving, creativity, and satisfaction (Fiedler & Garcia, 1987). To address this, PGT recommends leaders use supportive and attentive behaviors to mitigate change related stressors (House, 1996). Examples of these behaviors include evaluating individual team member's unique needs and instilling confidence in their ability to provide high-quality care.

**Transformational leadership.** Realizing the full breadth of the survivorship long-term follow-up guidelines in clinical practice requires BMT care teams to transcend their traditional practice norms. A leadership approach, which has demonstrated the ability to promote satisfaction and empower teams to reach higher goals in the literature, is Transformational Leadership (TFL; Bass & Riggio, 2006; Boamah, et al., 2017). Key TFL behaviors include idolized influence, inspirational motivation, intellectual stimulation, and individualized consideration (Bass & Avolio, 1990). Transformational leaders act as strong role models, exhibit authentic moral alignment with their mission, encourage group problem solving, and provide positive coaching (Skendzel, 2018).

## Chapter 2 Overview

With insufficient evidence regarding theory grounded survivorship implementation models, project leadership reviewed and synthesized findings from studies conducted in other fields of oncology and used evidence from diverse disciplines. Based on the literature review, the



project team identified several outcomes for the project. Measureable goals included patient and provider satisfaction, care plan utility, and patient self-efficacy to manage their care. To accomplish these goals, theories were selected to guide implementation interventions including IFSMT, PGT, and TFL. A culmination of these scholarly findings was used as the framework to create the project implementation plan, which is discussed further in the next chapter.

### Chapter 3: Project Implementation, Design, Methodology, and Sample

With a foundation for the project carefully constructed from the literary findings, leadership implemented the APP-led survivorship clinic. This chapter discusses the implementation process, with specific examples of how literature findings and theoretical principles were applied in the different phases of model development. Furthermore, the project design, methodology, and sampling techniques used for the outcome analysis are also discussed.

#### Pre-Implementation

In the pre-implementation period, project leadership used evidence from the literature and IFSMT to build the foundation for the APP-led clinic model and overcome identified barriers. Activities during this period included efforts to garner stakeholder support, educate staff, establish a multidisciplinary team, create the implementation plan, and set measurable outcome goals.

**Support and education.** To increase awareness about the need for change and gain support for the survivorship clinic within our department, leadership carried out a series of department-wide presentations. Target populations included key stakeholders such as physicians, APPs, nursing staff, administrative staff, and department leadership. We also conducted numerous educational interventions with the APP team including presentations, mock visits with role-playing, and one-on-one educational sessions.

**Addressing time barriers.** Based on the literature findings, project leadership took several measures to ensure adequate time for the visit. First, the lead sought and was granted approval for 60-minute visits. Second, the lead updated the admission history and physical templates to include a disease treatment history table that could be saved in the chart for later

retrieval during the survivorship visits. These interventions ensured efficient use of the clinical visit time.

In partnership with a department HIT specialist, project leadership also created electronic resources for the visits using the existing EMR system Epic (Mayer, et al., 2015). These included guideline based SCP templates with auto-populated data and drop-down menus for recommended tests. The lead also created an electronic SmartSet for common survivorship orders and referrals was also created to allow APPs to select multiple options and sign them with a single click. Examples of the electronic resources can be found in Appendix C, Figures 1-2.

**Improving equity.** To address access barriers, the project team determined survivorship services would be a standard of care for all patients at day + 100, 1-year, and 2-years post-transplant. Working closely with HIT and the BMT scheduling team, the lead created EMR generated referrals for the survivorship visits. Furthermore, schedulers were taught to use the referrals to set-up future APP survivorship visits on days patients would also have routine disease restating tests. Leadership designed these interventions to improve equity of access and minimize travel burden for the survivorship visits (Bevans et al., 2017; Smith & Hall, 2015).

**Ensuring continuity.** As fundamental pillars in the patient's care-team, project leadership considered physician involvement essential to maintain care continuity. To ensure physician partnership, the lead levied upon the exiting APP-physician Tandem Model (Herrmann, 2005). Accordingly, APPs were asked to conduct the clinical visit, create the SCPs, address self-management goals, and order appropriate diagnostic tests or specialty referrals based on their findings. The physicians, therefore, agreed to follow-up on test results and initiate appropriate therapeutic modalities during their disease-restaging visit with their patients the following week. To further eliminate gaps in care and improve communication with patients

existing care team, the lead trained APPs to use the electronic routing function of the EMR to send patient care plans to primary care providers and referring oncologists.

**Promoting self-management.** By design, SCPs inform patients about their treatment history, risks for complications, and provide recommendations to mitigate those risks. Therefore, our team identified the SCP as the ideal platform to incorporate the elements of IFSMT detailed in Chapter 2 (Ryan & Sawin, 2009). To accomplish this, the project lead educated APPs about their essential role in improving patient knowledge about the domains of chronic disease and facilitating the development of SM goals. Furthermore, the SCP templates were fashioned to include specific line items for the documentation of SM goals.

To help patients and providers identify areas for improved SM, the validated (Ritter & Lorig, 2014) SEMCD-6 (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001) was selected for use in as stated in the literature section above. According to instrument guidelines, patients rank their confidence, or self-efficacy, to manage domains of their chronic disease on a scale from 0-10. To ensure providers would have this data at the beginning of the visits, MAs were trained to administer the survey tool during the rooming process. Additionally, APPs were provided education about how to interpret the scale and supplied with teaching resources to guide the SM enhancing interventions.

**Multidisciplinary team.** Vital to the success and sustainability of new model was the strategic creation of a multidisciplinary team. Prior to project implementation, team members met routinely to address perceived barriers to implementation, align resources, and address timeline objectives. Each member contributed expertise specific to their unique discipline in order to overcome actual or potential barriers to implementation following a collaborative approach (Kinnaman & Bleich, 2004).

**IRB and ethical considerations.** Potential ethical considerations were carefully reviewed prior to obtaining internal review board (IRB) approval. After appraising the literature, an identified theoretical risk of harm was associated with the post-transplant risk-education. This was based on a single study which reported evidence of increased patient anxiety attributed to survivorship visit content which discussed the patients history of cancer, survivorship as a chronic disease, and potential health risks related to their cancer treatment (Jefford et al., 2011). In an effort to further moderate this potential risk, the lead modified the SEMCD-6 (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001) in a way that replaced the language “chronic disease” with “survivor” in the title and line items.

Despite this potential risk, prominent oncology organizations recommend dedicated survivorship visits and individualized care plans (ACS, 2019; ACSCC, 2014; ASCO, 2017; NCI, 2017). Largely, this is due to evidence demonstrating the benefits of providing survivorship services. Furthermore, a study conducted by Blinder et al. (2013) actually found the opposite to be true, concluding survivors had greater peace of mind after receiving survivorship care. Therefore, based on a risk-benefit analysis, it was deemed safe and appropriate to incorporate risk education content in the visits.

To protect the privacy of patients and providers participating in this QI initiative, the project lead designed the patient surveys to maintain anonymity of all participants. Therefore patient demographic data beyond age group, sex, time from transplant, and cell source was omitted. Additionally, the lead sent providers a link to complete the forms through a secure electronic email communication. Finally, all data was stored in a password protected Survey Monkey (2019) account, only accessible to project leadership.

All participants implied informed consent by reviewing the electronic consent form at the beginning of the survey and either clicking okay to continue to the survey, therefore implying consent, or closing the window to exit. In addition, patients were provided verbal information about the voluntary nature of their participation prior to being offered the opportunity to complete the survey. A sample of the consent form can be found in Appendix D, Figure 3.

Approval to carry out the survivorship implementation plan, outcome evaluation, and leadership intervention was sought from the IRB team on three separate occasions, reflecting separate stages of the project. Permission to implement the survivorship model following the PDSA approach and obtain anonymous feedback from participants was initially granted from the University of Minnesota IRB. Prior to assessing implementation outcomes, collecting data, the leadership intervention, and repeat data collection approval was again sought from both the University of Minnesota and St. Catherine University IRB committees. Following each submission, the review committee determined the implementation plan, outcome analysis, and leadership intervention were non-human research.

### **Project Implementation**

**Implementation model.** The implementation process included 4 PDSA (Langley et al., 2009) cycles (C). During C1, pre-implementation, objective project goals were established. In addition, APP education was completed, a multidisciplinary survivorship team was created, and a readiness assessment was conducted. In C2, the pilot implementation period, a total of 5 visits were completed and feedback was obtained from the providers. Based on provider recommendations, changes were made to the electronic templates. Full implementation occurred in C3. Implementation markers were assessed using anonymous, electronic, patient and provider

surveys. In C4, outcomes were re-assessed and findings were shared with the greater BMT community. An example of PDSA C3 can be found in Appendix E, Figure 4, of this document.

**Outcome measures.** Based on findings from the literature review, the project committee deemed several implementation goals critical for the evaluation of both patient and provider outcomes. Preliminary outcomes were measured in PDSA C3 included patient and provider satisfaction, care plan usability and utility, patient perceived self-management, and perceived appropriateness of the clinical visit length. In C4, only satisfaction data and open-ended questions regarding means for further improvement of the clinic model were collected. See Appendix E, Table E1 for a full list of objective outcome measures.

**Timeline.** The project, from C1-4, was carried out over a total of 27 months. Pre-implementation planning and assessment of readiness began in November of 2016. Outcome evaluation in C3 was conducted in October through November of 2018. Based on initial data analysis, a leadership intervention to improve outcomes was carried out in the latter portion of C3. The intervention was conducted over a 60-day period from December of 2018 through January of 2019. In February of 2019, the final stage of the project, leadership conducted a final outcome analysis and disseminated findings through a poster-presentation at the national Transplant and Cellular Therapies meetings of American Society for Blood and Marrow Transplant and Center for International Blood and Marrow Transplant Research (CIBMTR).

**Budget and ROI.** The project lead estimated the overall implementation budget would be \$1,500.00 US dollars (USD) for the first 12 months. Budget items included the cost of a secured iPad for data collection, paper and ink to print SCPs, and patient folders to store the printed materials. Reimbursement for the 60-minute survivorship consultations, billed at the highest level for an office visit, was estimated at \$148.00 USD (Centers for Medicare and

Medicaid Services, 2019). In the first 12 months, the APP's conducted 108 survivorship visits.

Therefore, the total return on investment (ROI) was 965.6% (with  $ROI = \frac{\text{value} (\$15,984.00 \text{ USD}) - \text{cost} (1,500.00 \text{ USD})}{\text{cost} (1,500.00 \text{ USD})} \times 100$ ) the first year alone (Chen, 2019).

While the iPad was calculated into the initial project ROI, it was later purchased using research funds awarded from the University of Minnesota Marrow on the Move research bank (University of Minnesota Department of Medicine, 2019). Of note, the leadership intervention did not add appreciable cost and was therefore not part of the ROI.

Estimated revenue of the fully operational clinic, with a predicted average of 200 visits per year, was \$29,600 USD. Therefore, it was considered not only an economically feasible but also a profitable model considering the low operating costs. Staff salaries and clinic operating expenses were not calculated into our profit analysis since the model did not require any additional FTE or clinic operating time. Further financial analysis of profit generated from additional cash flow into the UM system through referrals and diagnostic tests ordered during the visits was not assessed for purposes of this project.

**Resources.** Minimal physical, economic, and environmental resources were required for project implementation, outcome analysis, and the leadership intervention. Patient educational resources were printed, or ordered, free of charge from the National Marrow Donor Program's (NMDP, 2019) online catalog. Tools to assess patient self-efficacy and implementation markers were either open source materials or used with permission by the authors free of charge. Survey data from both patients and providers was obtained using a commercially available online survey tool. Communication between survivorship leadership, key stakeholders, and the multidisciplinary clinical team was conducted using an existing password protected and secure electronic mail server or in person.



### **Design, Sample, and Methodology**

**Design.** Electronic survey data was collected from both survivors ( $n = 22$  responses) and APPs ( $n = 14$  responses) following an interrupted QI design. Both patient and provider satisfaction was evaluated using a modified version of the validated (Sansoni, et al., 2011) SAPS (University of Melbourne, 2011) 7-item scale both. Scores  $> 19$  were considered satisfying in accordance with the scale-scoring rubric. Permission to both use and alter the scale for the purpose of this project was granted by the authorizing institution prior to data collection. Provider perceived usability of the electronic care plan templates was measured using a modified version of the open-source, validated (Peres, Pham, & Phillips, 2013), SUS (Brooke, 1996). Tabulated scores of greater than or equal to 68 were considered above average as recommended by the creators of the tool.

In addition to survey data, 10-point Likert scales, binary, and open-ended questions were used to assess satisfaction, patient self-management, and survivorship care plan (SCP) utility (Skendzel, Holtan, & Finch-Guthrie, 2018). Qualitative data collected by the lead during the leadership intervention consisted of APP responses to open ended-questions following a Six Sigma 5 Why's format (2017). In the post-intervention period, our team only evaluated satisfaction using the modified SAPS portion of the surveys, which were re-administered to both parties. Additionally, we included open-ended questions to allow participants the option to provide feedback in blank text fields. Included in Appendix F is a blank version of both patient (Figure 5) and provider (Figure 6) SAPS surveys.

**Sample.** A convenience sample of patients was created on a first-come first-serve basis. Surveys were offered to patients at the beginning of their survivorship visits by trained MAs as described in the IRB documents. Furthermore, patients were informed their participation was

voluntary in person by the MAs and in writing through the informed consent process. Please refer to Appendix G, Table G1 for sample characteristics

The project team administered the surveys to patients over two 30-day periods, following an interrupted design in C3 ( $n = 11$ , pre-intervention) and C4 ( $n = 11$ , post-intervention). Patient respondents in the pre-intervention group were predominantly male ( $n = 8$ ), age 56-75 years old ( $n = 7$ ), and had undergone an autologous stem cell transplant ( $n = 8$ ), within 1 year ( $n = 6$ ) or less ( $n = 5$ ) of transplant. Age distribution was similar in the post-intervention group ( $n = 11$ ) with most of the respondent's age 56-75 years old ( $n = 6$ ). However, the second sample was predominantly female ( $n = 7$ ), with a slightly higher number having undergone an allogeneic transplant ( $n = 6$ ). Respondents in the second sample were more evenly distributed in the post-transplant period ( $n = 4 < 6$  months,  $n = 3$  at 1 year, and  $n = 4$  at 2-years).

At the time of data collection, there were 12 members of the APP team besides the project lead. More than half of the total team ( $n = 11$  eligible), excluding the project lead, participated in the pre-intervention survey ( $n = 7$ ) in C3, interventional meeting ( $n = 8$ ), and post-intervention ( $n = 7$ ) evaluation in C4. All APP respondents ( $n = 7$ ) who completed the SAPS survey also completed the SUS portion of the survey. The SUS was administered in the pre-intervention period only.

The small patient and provider sample sizes were deemed appropriate based on the limited number of potential participants during the data collection period and the QI design. The average number of survivorship visits conducted in 30 days, typically 10-15 encounters per month, capped participation at 15 respondents or fewer during the data collection period.

Furthermore, the 30-day period selected for data collection was founded on the PDSA

implementation model in which rapid change cycles typically occur over 4-6 week periods (Taylor et al., 2014).

**Methods.** Project leadership analyzed the data using descriptive statistics. Median scores and percentages were reported for the most common results. For open-ended questions, our team used qualitative analysis to identify themes (Skendzel, Holtan, & Finch-Guthrie, 2019). We conducted the qualitative analysis process following a deductive approach. Therefore, the lead grouped similar responses into categories and themes were confirmed with project team members.

### Chapter 3 Overview

Early in the pre-implementation phase, the project lead incorporated findings from the literature review to overcome potential barriers. Once the implementation plan and resources were created for the new model, the project was carried out over four PDSA cycles. With the model fully implemented and operational, leadership assessed project outcomes using tools identified in the literature search. An analysis of these outcomes is presented in the next chapter.

## Chapter 4: Outcome Analysis and Intervention

In the final stages of the project, leadership evaluated the success of these interventions in achieving implementation outcomes. Therefore, a preliminary analysis was conducted to determine areas for improvement in C3. Based on these findings, an theory-based intervention was conducted to improve outcomes. This chapter discusses the preliminary analysis, provides an overview of the intervention, and presents outcome results.

### Preliminary Outcome Analysis

**Provider results.** Based on our analysis of the survey findings, APPs found the visit length appropriate, with none ( $n = 7$ ) of the respondents reporting the 60-minute visits were too short. In addition, usability of the SCP template was above average, with a median SUS score of 68 ( $n = 7$ , range 40-75). Despite these findings, APPs were overall dissatisfied with the visit, with a median SAPS of 13 ( $n = 7$ , range 6-19). Only 29% were satisfied with the care they provided and 68% felt their satisfaction could be improved. The two areas of greatest dissatisfaction involved shared decision-making and education regarding post-transplant risks with only 29% reporting satisfaction in each of these domains.

**Patient results.** Similar to providers, patients found the visit length appropriate with none of the patients ( $n = 11$ ) reporting the visit was too short. Additionally, 100% of patients were very satisfied with the effect of the visit and found the SCP useful. The majority of respondents, 91% in total, reported improved post-visit self-efficacy to self-manage their survivorship care. Furthermore, patients were overall satisfied with the visit, with a median SAPS of 25 ( $n = 11$ , range 19-28). However, patients had slightly lower satisfaction scores in the same two visit domains as providers, with 27% reporting they were very dissatisfied with education about post-transplant risks and 37% dissatisfied with shared decision making.

**Key preliminary findings.** Implementation outcomes were met in all areas with the exception of APP satisfaction. Both patients and providers had lowest satisfaction scores in the areas of risk education and patient involvement in care planning decisions. Selected provider (Figures 7-9) and patient (Figures 10-12) pre-intervention outcomes can be found in Appendices H-I.

### **Leadership Intervention**

**Combined Leadership Theory Framework.** To improve provider satisfaction, the project lead applied theoretical propositions of PGT (House, 1996) and TFL (Bass & Riggio, 2006), discussed in Chapter 2, in a leadership intervention with APPs. When applied synergistically, these theories have the potential to effectively address the multiple facets and interrelated concepts of the provider satisfaction phenomenon. Therefore, the lead created a leadership framework combining both PGT and TFL to guide interventional activities specifically designed to overcome barriers to satisfaction. An illustrative depiction of the model can be found in Appendix J, Figure 13.

**Leadership intervention.** Over a 60-day period, the lead provided positive feedback to the team, celebrated milestones, met individually with APPs to address their unique needs, and held an interventional meeting to identify satisfaction barriers. During the meeting the lead applied principles of TFL including idolized influence, inspirational motivation, intellectual stimulation, and individualized consideration. Furthermore, following tenants of PGT, a root cause analysis was carried out following a Six Sigma 5 Why's approach (Six Sigma, 2017). Instead of directing the meeting by proposing solutions, the lead acted as a facilitator in the problem solving process helping team members identify themes to identified barriers which were then grouped into mutually exclusive categories. Finally, team members were asked to propose

potential ways to overcome each barrier while the lead simultaneously assisting in the process of synthesizing their individual solutions into shared resolutions.

**Qualitative analysis.** Qualitative analysis of APP responses including the identification, clarification, and confirmation of identified themes was completed with the APP group during the meeting. Barrier categories included preventable time constraints, workflow discontinuity, and need for enhanced knowledge regarding cardiopulmonary TLEs. All APPs present at the meeting verbally participated in the intervention and analysis process.

**Shared goals.** Together the team and project lead created several mutual, measurable, and attainable satisfaction goals were created based on the identified barriers. First, the team determined pre-visit surveys and forms that did not directly relate to the visit should be administered at a future appointment. Unfortunately, time to complete the surveys had led to considerable infringement on the valuable and limited patient-provider interaction during the visits. Second, to improve continuity, APPs requested visits be clustered on one or two schedules each day to allow them to “get into the flow” of conducting their survivorship-focused presentations and assessments. Finally, we found providers needed more education about cardiopulmonary TLEs in order to tailor risk education activities to their individual patients.

**Goal attainment.** Using a multidisciplinary approach, the project lead partnered with administrators, schedulers, nurse managers, MAs, and oncology clinical pharmacists to achieve identified goals. Following a meeting with nursing leadership, the nurses and MAs worked together to change the pre-visit survey workflow. In addition, system administrators and the BMT schedulers created a new scheduling scheme to cluster the visits as requested. Finally, the lead worked with pharmacy faculty to create a cardiopulmonary chemotherapy late-effects pocket card designed for quick reference during the visits.

### Post-Intervention Outcome Analysis

**Provider results.** Following the leadership intervention, the project team re-administered the satisfaction portions of both the patient and provider surveys using a traditional interrupted design format. Provider satisfaction markedly improved, with an increase in median SAPS score by 7 points ( $n = 7$ ) on the 28-point scale. This increase was dramatic and equated to an overall median SAPS of 21 ( $n = 7$ , range 14-22), demonstrating APP's were satisfied with the survivorship visits in the post-intervention period. Furthermore, their potential for improved satisfaction positively decreased, with only 15% reporting their satisfaction could be further enhanced compared to 68% pre-intervention. Additionally, 71% of APPs reported satisfaction with the care they provided compared to 29% prior to the intervention.

Provider satisfaction also improved in the two domains with the lowest pre-intervention satisfaction scores as well. Satisfaction with shared-decision making increased from 29% pre-intervention to 71% post-intervention. Similarly, satisfaction with risk education increased from 29% pre-intervention to 43% post-intervention. Selected provider findings are presented in Figures 14-16 of Appendix K.

**Patient results.** Patients remained overall satisfied, with a median SAPS score of 22 ( $n = 11$ , range 15-28). However, improvement in shared decision-making and risk-education was not found. Accordingly, 64% of patients were satisfied or very satisfied with their degree of involvement in shared-decision making compared to 66% in the pre-intervention group. Similarly, satisfaction with risk education was 72% and further decreased to 54% in the post-intervention group. Slightly less than half the respondents ( $n = 4$ ) provided feedback to the open question regarding means to improve their visit satisfaction. However, most responses were “nothing” more could be done. Please refer to Appendix L, Figures 17-19, for more details.

**Chapter 4 Overview**

Implementation goals were assessed in the advanced stages of the project, after the APP-led clinic model had been fully implemented and operational for several months. Based on these outcomes, the project lead conducted a theory based leadership intervention following principals of PGT and TFL to improve provider satisfaction. Further synthesis of these findings, potential practice applications, and identified areas for future scholarship are discussed in the next chapter.



## Chapter 5: Discussion and Recommendations

While limited conclusions can be drawn directly from the outcomes of this small QI initiative, the project demonstrates the important role of theory and leadership in the creation and implementation of APP-led survivorship models. Presented in this chapter is a discussion of pertinent findings, recommendations for practice, and areas for future scholarship. In addition, we highlight the important role of nurse leaders as change champions in the implementation of survivorship care models to improve health outcomes for BMT survivors.

### Discussion

Using PGT and TFL leadership interventions, and a multidisciplinary collaborative approach, our team was able to implement the APP-led survivorship model and meet project objectives in all areas. Additionally, our model of APP-led survivorship care was satisfying for patients and promoted their self-efficacy to manage their survivorship journey. Analysis of secondary findings also showed the new model was feasible, safe, and profitable. Additionally, the electronic care plans created in the EMR were useful for patients and useable for providers. Finally, the 60-minute visit length was appropriate. These findings were consistent with the limited amount of literature assessing APP-led survivorship models.

Provider satisfaction, however, was lower than we had anticipated in the preliminary outcome analysis. This was in stark contrast to literature findings, which demonstrated high provider satisfaction with APP-led models (Brennen, et al., 2014; Curcio, et al., 2012; Mayer et al., 2014; Sprague et al., 2013). Interestingly, the root-cause of provider dissatisfaction was not related to known, previously reported, barriers. Instead, dissatisfaction was secondary to visit mechanics and need for enhanced knowledge regarding chemotherapy related TLEs.

While APP satisfaction improved following the leadership intervention, patient satisfaction with shared decision-making and TLE risk education did not increase as we had anticipated. We did not further evaluate the underlying cause of their dissatisfaction in these two visit domains because overall satisfaction was above our pre-set threshold for intervention. Additionally, findings from our literature review did not delineate which aspects of the clinical visit patients found satisfying to the same degree we subdivided visit domains. Therefore generators of patient dissatisfaction in these areas remain unknown.

### **Limitations**

As a single center quality improvement initiative (QI) there were several notable limitations. Our sample sizes were appropriate for the PDSA model selected to guide our implementation process, however they were small. This model limited our data collection to two 30-day periods. On average we conduct 15-20 survivorship visits in that period. Accordingly, our target number of patient responses was 10-15 both before and after the intervention. In addition, we had limited existing evidence to base our interventions from. Finally, our surveys evaluated subjective data. Inherently, this type of data is subject to response bias. Therefore, our findings were not intended to be generalizable but instead to guide our implementation interventions and provide support for further research.

### **Recommendations**

The findings of this QI initiative were not intended to be generalizable, however, they do provide support for potential application of established leadership theories and implementation models to promote satisfying survivorship care. Since satisfaction has become increasingly important in the era healthcare reform, the significance of this outcome cannot be further underscored. Therefore, we recommend survivorship change champions consider making

provider satisfaction a priority and adopt leadership interventions founded on PGT and TFL theory early in project development (House, 1996; Bass & Riggio, 2006). By doing so, project leaders could potentially curtail the degree of provider dissatisfaction we found in our preliminary outcome analysis.

### **Future Scholarship**

**Combined Leadership Theory Framework.** At this time, further research is necessary to determine a correlational relationship between the impact of the PGT (House, 1996) and TFL (Bass & Riggio, 2006) leadership framework (Skendzel, Holtan, & Finch-Guthrie, 2018) on the phenomenon of provider satisfaction with survivorship care. While our results are encouraging, this was a small QI initiative with limited patient and provider samples. Therefore, large-scale studies evaluating the use of the model, involving multiple centers, is needed.

**Epicerter of dissatisfaction.** More research is also needed to determine the source of patient dissatisfaction with portions of the clinical visits. While patients were overall satisfied with the visits, individual item analysis of the SAPS surveys revealed patients had lower satisfaction scores in the areas of risk education and shared decision making, than the project team expected. Therefore, more information is needed regarding patient risk-education expectations in order to improve our teaching strategies. To better understand our survivors' unique experiences, a follow up descriptive study using a phenomenological approach is needed.

**Measuring equity.** Reducing health disparities in our patient population was a driving force behind the creation of this model, however, we did not specifically collect data in this area. While the new APP-led clinic serves over 200 patients annually, a comparatively substantial increase in access to care, we do not know if access has improved amongst our high-risk groups. During this implementation project, we did not collect or review retrospective follow-up data to

determine if patients traditionally lost-to-follow-up are being adequately served or the impact of these interventions on specific health equity outcomes. Consequently, more information is needed regarding the influence our preventative care services and self-management interventions have on transplant related morbidity amongst groups at high risk for poorer outcomes.

**Research.** Finally, our data analysis was limited to outcomes directly pertaining to the implementation process. Therefore, we did not evaluate the impact of this new care model on patient morbidity and mortality. This is an important area to focus future research efforts since there are very few published prospective studies evaluating survivorship outcomes in the BMT population. Without question, this newly established APP-led model presents an opportunity for survivorship research at our center. In addition to evaluating site-specific outcomes, collaboration with the Center for International Blood and Marrow Transplant Research (CIBMTR, 2019) to further existing national research initiatives in this area is critical.

### **Nursing Leadership**

**Leading change.** While the primary purpose of this project was to improve the health and wellbeing of BMT recipients, the parallel intention was to demonstrate the important role of DNP prepared APRNs in leading healthcare reform efforts to improve the health of the nation. In 2010 the IOM, in their report on The Future of Nursing, Leading Change, Advancing Health, emphasized the important role of nurse leaders with advanced education in healthcare reform. Today, DNP prepared nurses are particularly equipped with the knowledge and experience to be these change catalysts. This initiative, led and implemented by an APRN in accordance with the AACN (2006) essentials of DNP practice, demonstrates the vital role nurses play in overcoming barriers to implementing clinical practice guidelines in complex (Porter-O'Grady & Malloch2018) health systems today.

By addressing the multifaceted needs of survivors, APRNs function at the top of their educational expertise and are in a key position to improve health equity, care access, and the quality of follow-up care cancer survivors receive in accordance with the IHI Triple Aim (2019), Healthy People 2020 (2019), and National Institute on Health's initiatives (Bevans, et al., 2017). The strategic position of oncology APRNs on healthcare teams, their unique clinical expertise, and their educational foundation make them the perfect change champions for survivorship initiatives. Thus, this project demonstrates that through the creation and implementation of APP-led survivorship clinics, nurse leaders can have a dramatic impact on the overall health and well being of the cancer survivor population.

### **Conclusion**

Significant strides have been made in the treatment of blood and marrow diseases in the last 50 years. However, the battle is far from over at the point of cure. Known disparities in health equity and inadequate access to high-quality follow-up care have resulted in a considerable amount of preventable morbidity and mortality, pushing survivorship to the forefront of national healthcare reform efforts.

Achieving high quality survivorship care requires passionate, supportive, and transformative leaders capable of implementing change in complex health systems. As highly qualified change agents, nurses are in a key position to improve the lives of survivors in accordance with national health initiatives through the implementation of guideline based APP-led survivorship models. Through application of theoretical frameworks, multidisciplinary teamwork, collaborative partnerships, and transformational leadership these highly qualified leaders can create and implement satisfying survivorship models for patients and providers alike.

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Appendix A  
Literature Review: Implementation Models

Table A1

*APP-led Survivorship Implementation Models, Metrics, Visit Length, and Barriers*

Study	Type of Model	Instruments	Visit Length	Care Plan	Barriers and Facilitators
Mayer, et al. (2014)  Level of Evidence IIIB	1. Nurse (RN) created the care plan and a nurse practitioner (NP) conducted the visit and discussed the recommendations	1. Systems Usability Scale (Useability.gov, 2017) 2. Satisfaction 3. AHRQ Consumer Assessment Questionnaire (2017)	90 min	Journey Forward online template (2017)	- Length of time to complete treatment summary was too long + Discussing a pre-completed SCP during a routine visit only added 16 minutes and did not affect workflow
Curcio, Lambe, Schneider, and Khan. (2012)  Level of Evidence IIIA	1. Collaborative NP/Oncologist/RN	1. Generalized anxiety Disorder Seven Item Scale (GAD7) 2. Patient, provider, PCP satisfaction 3. Assessment of knowledge	60 min	American Society of Clinical Oncology (2017)	+ Adherence to practice guidelines - Treatment summary should be completed before survivorship visit + Provider satisfaction + No interruptions in workflow with 60 minute visit
Sprague et al. (2013)  Level of Evidence IIIB	1. APP created the SCP and completed the visit. Document was sent to the patients PCP	1. Patient satisfaction and usability phone survey	45-90 min	Journey Forward online template (2017)	- No data was collected from providers creating and administering the SCP's

<p>Dulko et al. (2012)</p> <p>Level of Evidence IIIB</p>	<p>1. APP created SCP in collaboration with oncologist and completed the visit</p>	<p>1. Telephone interviews with providers involved in care delivery and patients 2. Survey mailed to PCP's to assess barriers to following the SCP</p>	<p>60 min</p>	<p>Journey Forward online template (2017)</p>	<ul style="list-style-type: none"> <li>- APP identified time searching through EHR a barrier to completing the SCP on time</li> <li>- APP's found it time consuming and difficult to request and review outside records</li> <li>+ All staff felt APP's should be responsible for creating and conducting survivorship visits and the care plan</li> <li>+ All care plans and visits could be completed in 60 minutes</li> </ul>
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Appendix B  
Literature Review: Summary of Patient and Provider Outcomes

Table B1

*Provider Care Plan Usability and Visit Satisfaction*

Study	Level of Evidence	Provider Usability	Provider Satisfaction	Provider Behavior Change	PCP Satisfaction & Usability
Taylor and Monterosso. (2015).	IIIB	NA	NA	NA	- 1. Lack of standardized SCP templates 2. Lack of reimbursement
Curcio, Lambe, Schneider, and Khan. (2012)	IIIA	NA	+	NA	+
Mayer, et al. (2014)	IIIB	+	+	NA	- Length of plans impractical
Mayer, et al. (2015)	IIIB	+	NA	NA	+ 1. Providers found the EMR based SCP templates useable 2. Time to complete SCP reduced by 15 minutes due to auto-populated data
Sprague et al. (2013)	IIIB	- Time (60 minutes) to complete care plan impractical	NA	NA	- Lack of knowledge about Survivorship a barrier

Table B2

*Patient Care Plan Usability and Visit Satisfaction*

<b>Study &amp; Level of Evidence</b>	<b>Level of Evidence</b>	<b>Intervention</b>	<b>Patient Usability</b>	<b>Patient Satisfaction</b>	<b>Patient Behavior Change</b>
Kenzik et al. (2016)	IIIA	Outcomes of SCPs provided with or without verbal explanation	NA	NA	+
Wiljer, et al. (2009)	IIIA	Survivorship consult, SCP, & reflective interview	+	NA	NA
Lawn et al. (2014)	IIIB	Assess SM enhancing techniques effect on SESM and patient acceptability, feasibility, physical improvement, and self-efficacy	NA	NA	+
Brennan, Gormally, Boyle, and Spillane. (2014)	IIB	Systemic review of SCP outcomes	NA	+	-
Taylor and Monterosso. (2015)	IIIB	Review of survivorship visit and SCP outcomes amongst SCT survivors	NA	+	NA
Curcio, Lambe, Schneider, and Khan. (2012)	IIIA	Outcomes of survivorship visit and care plan	+	+	NA
Mayer, et al. (2014)	IIIB	Survivorship visit and SCP outcomes	NA	+	NA
Sprague et al. (2013)	IIIB	Outcomes of SCP's	+	+	NA
Dulko et al. (2012)	IIIB	Barriers and facilitators of survivorship visit and SCP	+	NA	NA



Table B3

*Patient Post-Visit Self-efficacy to Manage Chronic Disease*

<b>Study</b>	<b>Level of Evidence</b>	<b>Intervention</b>	<b>SEMCD-6 Scores</b>	<b>Self-Efficacy</b>	<b>Self-Management Behavior</b>
Kenzik et al. (2016)	IIIA	Outcomes of SCPs provided to patients with or without verbal explanation	+ Increased SE scores with verbal explanation of SCP	+	+
Lawn et al. (2014)	IIIB	Flinders Live Well program based on self-management support coaching	NA	NA	+
Wiljer, et al. (2009)	IIIA	Survivorship consult, SCP, & reflective interview	-	-	+ CBI scores

Appendix C  
Electronic Resources: Sample Care Plan and SmartSet

**BMT 1-Year Post-Allogeneic Transplant  
Survivorship Care Plan**

**Date:** @DATE@

**Treatment Team:**  
@PATIENTCARETEAM@

**Date of Transplant:** \*\*\*

\*\*\*Copy & Past Transplant Essential Data & Chemotherapy Treatment Table from Problem List\*\*\*

**Post-Transplant Treatment or Maintenance Therapy: (Delete if not needed)**

<i>Treatment</i>	<i>Number of Cycles</i>	<i>Date Range</i>	<i>Tolerance &amp; Outcomes</i>
***	***	***	***

**Survivorship Self-Management Goals:**

<i>Goal</i>	<i>Activities</i>	<i>Resources</i>
***	***	***
***	***	***
***	***	***

**General Health Maintenance:**

- Call the BMT clinic if you develop a skin rash, oral sores, eye pain or excessive dryness, shortness of breath, new cough, bleeding, diarrhea, nausea, or vomiting. Vaccinations should be given at 1 and 2 years after your transplant, these may be given at your annual anniversary visits in the BMT clinic, by your primary care provider, or your local oncologist. An exception is the influenza vaccine, which can be given after day +60 post-transplant during influenza season. See table below for more information.
- For general health concerns you can be seen by your primary care provider.
- If you have questions about your transplant or follow up tests contact your BMT RN coordinator.

**Has @NAME@ been diagnosed with chronic GVHD? Yes: (date of cGVHD diagnosis)\*\*\* No\*\*\***

**Current Systemic Immunosuppression: (list)\*\*\***

**Chronic GVHD NIH Score At Today's Visit\*\*\***

**Survivorship Care Plan:**

This individualized care plan is designed to inform you and your healthcare team of the recommended follow-up visits, tests, health maintenance activities, and cancer screening you should receive after transplant.

**Immune System:**

Risks	Preventative Measures	Recommendations
Infections, viral reactivations	<ul style="list-style-type: none"> <li>Continue to take prescribed medications to prevent infection if you are treated for graft-vs-host disease</li> <li>Symptoms of a cold such as fever, cough, congestion, and shortness of breath should be reported to your primary care provider</li> <li>Immunizations will be administered at 1 &amp; 2 years after transplant. See schedule above.</li> </ul>	{BMT Survivorship Immune System:146077}

**Eyes:**

Risks	Preventative Measures	Recommendations
Cataracts, dry eyes, GVH of the eyes, viral infections, and other eye changes	<ul style="list-style-type: none"> <li>Yearly eye exam</li> <li>Screening and treatment for high blood pressure or diabetes</li> <li>Call if you have eye pain, visual changes, or floaters immediately</li> <li>Call If you are experiencing dry eyes and symptoms do not improve with Refresh eye drops</li> </ul>	{BMT Survivorship Eyes:146078}

**Mouth:**

Risks	Preventative Measures	Recommendations
Dry mouth, oral GVH, cavities, and oral cancer	<ul style="list-style-type: none"> <li>Report any new symptoms such as dry mouth or painful sores</li> <li>You can use over the counter Biotene for dry mouth or try sucking on sour candy before meals</li> <li>Get a dental checkup every year and a cleaning every 6 months</li> <li>If you have a prosthetic heart valve, central venous catheter or “port”, or are still taking immunosuppression you may need to take an antibiotic before your dental visits.</li> </ul>	{BMT Survivorship Mouth:146079}

**Lungs**

Risks	Preventative Measures	Recommendations
Changes in function from chemotherapy or radiation; lung infections (pneumonia)	<ul style="list-style-type: none"> <li>Tell your provider about difficulty breathing, a cough, or new shortness of breath</li> <li>Avoid use of tobacco products or smoking</li> <li>Routine lung exams</li> </ul>	{BMT Survivorship Lungs:146080}

**Heart and Blood Vessels**

**Heart Disease Risk Score: @ASCVDRISK@**

Risks	Preventative Measures	Recommendations
Damage from chemotherapy and/or radiation; early	<ul style="list-style-type: none"> <li>Ask your provider if you should receive consultation from a cardiologist (heart doctor) or have special screening</li> <li>Follow a “heart healthy” lifestyle. For more</li> </ul>	{BMT Survivorship Heart and Blood Vessels:146081}



development of heart valve disease	<p>information visit the National Heart, Lung, and Blood Institute website at:  <a href="https://www.nhlbi.nih.gov/health/health-topics/topics/heart-healthy-lifestyle-changes">https://www.nhlbi.nih.gov/health/health-topics/topics/heart-healthy-lifestyle-changes</a></p> <ul style="list-style-type: none"> <li>• Don't smoke. If you currently smoke and are ready to quit, we can help you find ways to quit</li> <li>• Maintain a healthy weight</li> <li>• Exercise regularly</li> <li>• Avoid foods that have high amounts of:                             <ul style="list-style-type: none"> <li>○ Salt/sodium (less than 2,300 mg of sodium per day)</li> <li>○ Saturated and trans fats</li> <li>○ Limit alcohol to less than 1 drink for women and 2 drinks for men per day</li> <li>○ Sugar such as soft drinks or sugary snacks</li> </ul> </li> </ul>	
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**Hormones**

<b>Risks</b>	<b>Preventative Measures</b>	<b>Recommendations</b>
Low thyroid function, low function of other glands (adrenals and others)	<ul style="list-style-type: none"> <li>• Certain endocrine/hormone disorders are more common after transplant. For this reason, talk to your provider about:                             <ul style="list-style-type: none"> <li>○ Fatigue</li> <li>○ Muscle weakness</li> <li>○ Changes in cold tolerance</li> <li>○ Reduced interest in sex</li> <li>○ Erectile dysfunction</li> </ul> </li> <li>• Certain tests may be used to monitor for hormone changes if you are experiencing symptoms. These tests are done at 1 year</li> <li>• If you have been on steroids you will need to slowly taper or decrease the dose as recommended by your provider/pharmacist. Do not stop taking steroids without consulting with your provider.</li> <li>• If you have been on steroids in the past, you may need steroids during periods of illness</li> </ul>	{BMT Survivorship Hormones:146082}

**Liver:**

<b>Risks</b>	<b>Preventative Measures</b>	<b>Recommendations</b>
Damage from chemotherapy or other drugs, buildup of iron from blood transfusions, infections, and GVHD	<ul style="list-style-type: none"> <li>• Certain tests may be ordered at your next survivorship visit to evaluate liver function based on your individual risk factors.</li> <li>• Talk to your provider before taking herbal supplements or over the counter drugs like Tylenol.</li> <li>• Ask your doctor if you should be treated for iron overload</li> <li>• Avoid alcohol in excess</li> </ul>	{BMT Survivorship Liver:146083}

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***Kidneys and Bladder:***

<b>Risks</b>	<b>Preventative Measures</b>	<b>Recommendations</b>
Damage from chemotherapy or other drugs, infections, high blood pressure	<ul style="list-style-type: none"> <li>Monitoring blood tests of kidney function during follow up visits</li> <li>Treating high blood pressure and diabetes</li> <li>Drink adequate amounts of water</li> <li>Report symptoms of infection such as frequent urination, pain with urination, foul odor to urine, or blood in the urine</li> <li>Talk to your provider before taking herbal supplements or over the counter drugs like Ibuprofen</li> </ul>	{BMT Survivorship Kidneys and Bladder:146085}

***Nervous System:***

<b>Risks</b>	<b>Preventative Measures</b>	<b>Recommendations</b>
Neuropathy from chemotherapy, changes in cognitive function	<ul style="list-style-type: none"> <li>Report changes in sensation or discomfort in feet or hands</li> <li>Tell your provider about ongoing changes in memory, ability to concentrate, or inability to make decisions</li> </ul>	{BMT Survivorship Nervous System:146084}

***Muscle & Connective Tissue***

<b>Risks</b>	<b>Preventative Measures</b>	<b>Recommendations</b>
Reduced muscle strength, reduced stamina, GVHD causing hardening of muscle tissues (scleroderma) or inflammation of tissue over muscles (fasciitis)	<p>Let your provider know if:</p> <ul style="list-style-type: none"> <li>You notice changes in your muscle strength</li> <li>Require extra assistance with daily activities</li> <li>Experience pain or difficult bending or moving joints</li> <li>If you have been on steroids and are experiencing weakness particularly when standing up from a chair</li> <li>Need help creating an exercise routine</li> <li>Notice reduced range of motion of the arms, hips, or legs</li> </ul> <p>Follow general guidelines for physical activity as recommended by the Office of Disease Prevention &amp; Health Promotion:</p> <p><b>Avoid Inactivity</b> Some physical activity is better than none — any amount has benefits.</p> <p><b>Do Aerobic Activity</b> Do aerobic physical activity in episodes of at least 10 minutes, as many times as possible per day. This could include going for walks or using the elliptical or</p>	{BMT Survivorship Muscle and Connective Tissue:146086}

	<p>stationary bike. Ask your doctor what aerobic activities would be safe and helpful for you, and set a goal for yourself!</p> <p><b>Strengthen Muscles</b> Do muscle-strengthening activities (such as lifting light weights or using resistance bands and/or going up and down stairs) that are moderate or high intensity and involve all major muscle groups at least 4 days a week.</p>	
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**Screening for Steroid-Induced Myopathy:** 30 Second Chair Stand (*Delete if not needed*)

**Reference Range:** Below Average Scores. **Number of Repetitions:**\*\*\*

Age	Men	Women
< 64	< 14	<12
65-69	< 12	< 11
70-74	< 12	< 10
75-79	< 11	< 10
80-84	< 10	< 9
85-89	< 8	< 8

Center for Disease Control and Prevention. (2017). *Assessment: 30-Second Chair Stand*. Retrieved online [www.cdc.gov/stedi](http://www.cdc.gov/stedi).

**Emotional Health**

Risks	Preventative Measures	Recommendations
Stress, depression, anxiety	<p>Talk to your provider about:</p> <ul style="list-style-type: none"> <li>• Changes in feelings, mood, or emotional wellbeing</li> <li>• Interest in support groups</li> <li>• If you are concerned about your caregivers emotional wellbeing</li> <li>• Desire to speak with a counselor for ongoing support</li> </ul>	{BMT Survivorship Emotional Health:146087}

**Sexual Health**

Risks	Preventative Measures	Recommendations
Reduced libido due to hormonal changes, erectile dysfunction, vaginal dryness, vaginal graft-vs-host disease, vaginal infections, sexually transmitted diseases	<p>Talk to your provider about:</p> <ul style="list-style-type: none"> <li>• Reduced libido or concerns regarding your sexual health</li> <li>• Men: Erectile dysfunction</li> <li>• Women: Vaginal dryness, pain during intercourse, vaginal bleeding after intercourse, changes in vaginal discharge that may indicate infection (green/white/foul odor)</li> <li>• General Recommendations:</li> <li>• It is safe to have sex if your platelet count is &gt; 50,000 and you feel physically and emotionally ready</li> <li>• Women can use water-based lubricants to reduce discomfort from dryness. Prescription topical</li> </ul>	{BMT Survivorship Sexual Health:146088}

	<p>estrogen may help as well.</p> <ul style="list-style-type: none"> <li>• Use barrier protection such as condoms to prevent sexually transmitted diseases, you are at higher risk for infections due to a weakened immune system</li> </ul>	
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**Fertility (delete if N/A)**

Risks	Preventative Measures	Recommendations
Difficulty with sexual intercourse; difficulty having a baby	<ul style="list-style-type: none"> <li>• Women should avoid becoming pregnant for 2 years</li> <li>• Birth control should be used to prevent pregnancy</li> <li>• If you are interested in having a baby, discuss this with your provider</li> </ul>	{BMT Survivorship Fertility:146089}

**Cancer Screening:**

Risks	Preventative Measures	Recommendations
Higher risk for the development of solid tumors, PTLD, and blood cancers	<ul style="list-style-type: none"> <li>• Perform a full self skin exam monthly to assess for any changes in moles or signs of skin cancer</li> <li>• Minimize excessive sun exposure and wear sunscreen</li> <li>• Women should perform breast-self exams and report any changes in such as a new lump, discharge from nipples, and red or dimpled areas of the breast.</li> <li>• Imaging for breast cancer known as mammography is recommended for women starting at age 40 or 8 years after radiation exposure.</li> <li>• Screening for colorectal cancer should begin at age 50.</li> <li>• All women should have a pap smear every 1-3 years beginning at age 21</li> <li>• Men should perform a monthly testicular self-exam if they have been exposed to radiation as part of their cancer treatment.</li> </ul>	{BMT Survivorship Cancer Screening:146090}

**Recommended Tests & Follow-Up:**

<b>Referrals &amp; Tests Ordered Today:</b> Your BMT physician will review these tests and referral results. If you require treatment based on the results, a member of the BMT team will contact you.	<b>Orders placed today:</b> @ORDERSNMENC@ (Note to providers: After signing orders use the refresh tool to display results)
<b>Future Tests/Referrals:</b> All recommendations above should be completed within 2 months either by your primary care provider or local oncologist (cancer doctor).	<b>Recommendations that were not ordered today should be completed by your:</b> {BMT Survivorship Recommendations:146091}
<b>Follow Up Care:</b> Continue to see your care team members routinely after transplant.	<b>BMT Provider: ***</b> <b>Hematologist/Oncologist:***</b> <b>Primary Care Provider: ***</b>

Figure 1. Sample of 1-year post-allogeneic BMT SCP template created by project leadership.

Document content is consistent with international recommendations (Majhail et al., 2012).

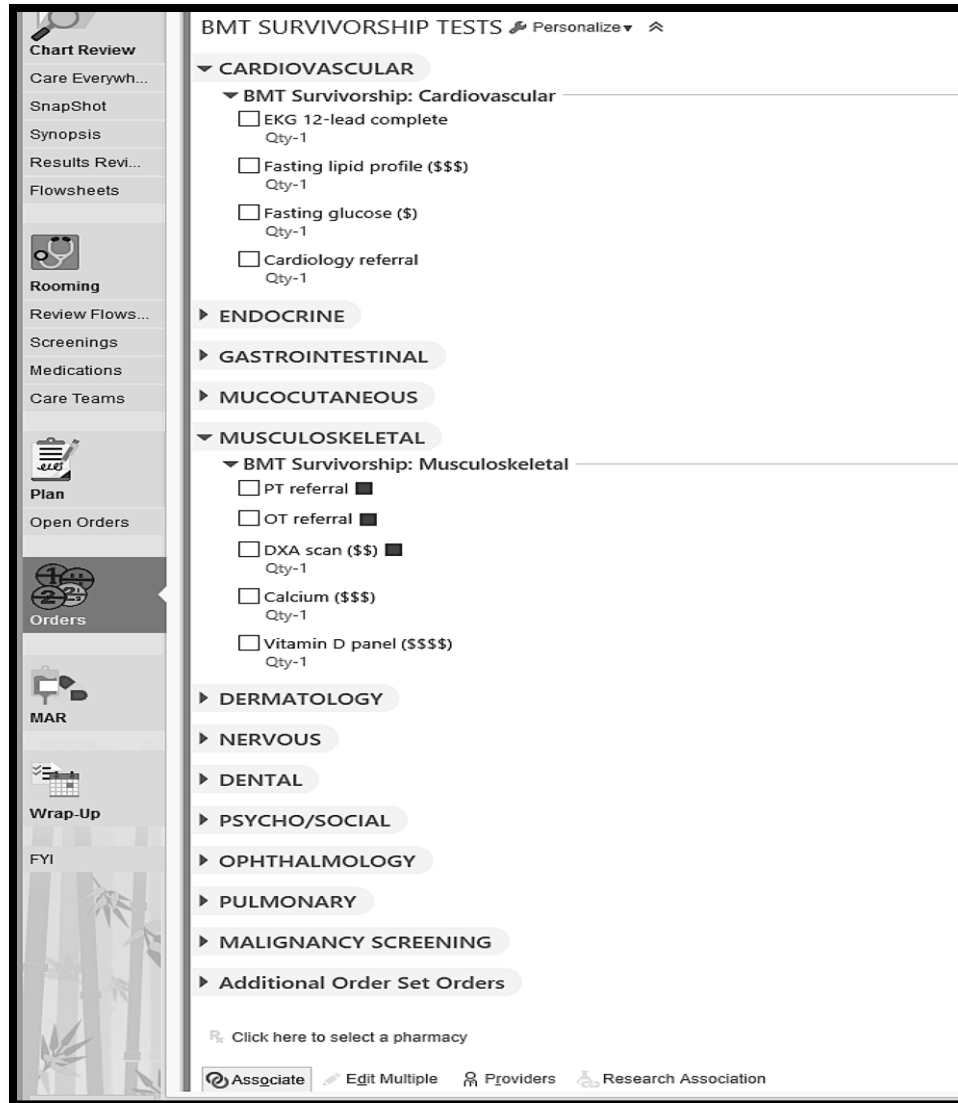


Figure 2. Sample of the survivorship SmartSet created for commonly ordered tests. Each system was designed to be expanded with a mouse click to select relevant tests. Tests could therefore be singled with a single click at the end of the visit to ensure efficient use of provider time in the order entry process.



## Appendix D

### Electronic Consent

#### Electronic Participation Consent

You are invited to participate in this quality improvement project because we are interested in understanding your perception of the visit and care plan. This project is being conducted by Sasha Skendzel, NP through St. Catherine University and the BMT quality improvement team at MHealth. The purpose of this survey is to modify our visits and tools to ensure the care planning process is satisfying and the resources provided are useable. The survey includes items about satisfaction, care plan usability, and patient self-confidence to self-manage their care. The data that we collect from this survey will be used for quality improvement to enhance the way we deliver survivorship care. It will take approximately 10 minutes to complete.

Your responses to this survey will be anonymous and results will be presented in a way that no one will be identifiable. Confidentiality will be maintained to the degree permitted by the Survey Monkey technology used.

Your participation is voluntary and your decision whether or not to participate will not affect your relationships with the clinicians or quality improvement team. If you decided to stop at any time you may do so. You may also skip any item that you do not want to answer.

By clicking "okay" you will indicate consent and begin the survey process. After you have read each question please rank your response. If you do not wish to complete the survey please close the survey window at this time.

*Figure 3.* Example of the electronic consent form used for patient and provider participants.

Elements of this form were modified and adopted from the St. Catherine University IRB website survey consent template (2017). More information about this general template can be retrieved from <https://www.axiommentor.com/pages/irb/info.cfm#IRB%20application>.

Appendix E  
 Implementation Model and Outcome Measurements  
**PDSA Cycle 3: *Implementation and Primary Outcome Evaluation***

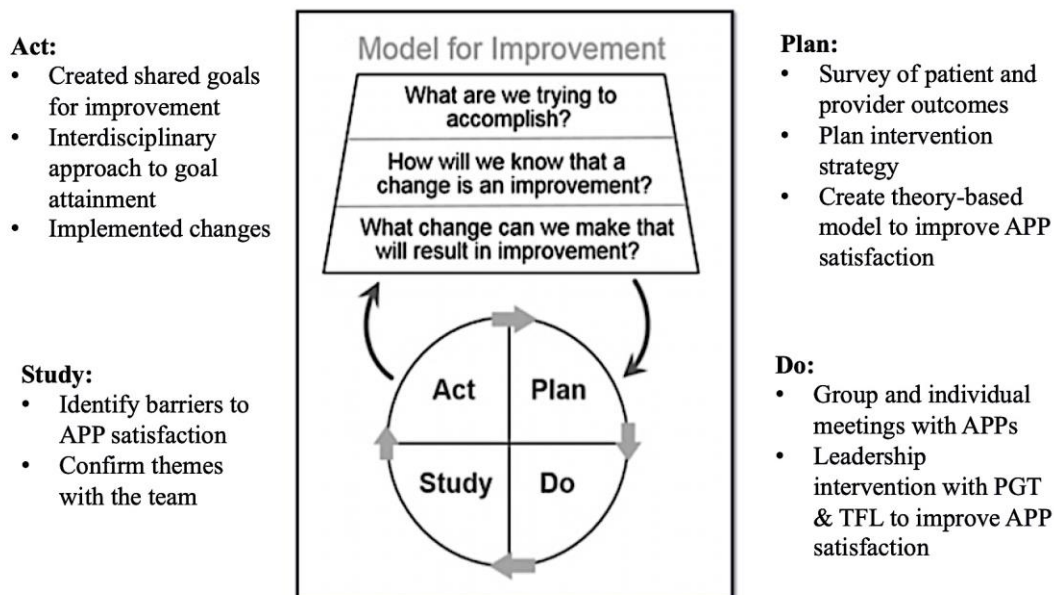


Figure 4. Example of PDSA model and C3 interventions. Reprinted with permission from Langley, et al. (2009). The improvement guide: A practical approach to enhancing organizational performance (2<sup>nd</sup> ed.). San Francisco, CA: Jossey-Bass Publishers.

Table E1

*Implementation Outcomes and Measures*

Implementation Outcome	Outcome Measurements
Appropriate visit length	< 10% of patients and APPs report the visit length was too short
Satisfaction with care provided	Median score > 19 on the validated (Sansoni, et al., 2011) and modified Short Assessment of Patient Satisfaction scale (SAPS; University of Melbourne, 2011)
Care plan perceived as useful and useable	> 80% of patients report the care plan useful. APPs report electronic care plan templates useable with median score > 68 on the validated (Peres, Pham, & Phillips, 2013) Systems Usability Scale (SUS; Brooke, 1996)
Patient improved self-efficacy to manage care	> 80% of patients report improved self-efficacy to manage their survivorship needs

## Appendix F

## Satisfaction Surveys

## Patient Version of the SAPS Survey

The following questions are designed to help the survivorship quality improvement team better understand your satisfaction with the care you received during your survivorship visit encounter. After you have read each question click the answer that best describes how you feel.

1. How satisfied are you with the effect of the care you received during the survivorship visit?

- Very Satisfied 0  
 Satisfied 1  
 Neither 2  
 Dissatisfied 3  
 Very dissatisfied 4

2. How satisfied are you with the explanations the practitioner provided you about your survivorship care and potential post-transplant risks?

- Very dissatisfied 0  
 Dissatisfied 1  
 Neither 2  
 Satisfied 3  
 Very satisfied 4

3. Was the practitioner very careful to ask about everything related to your survivorship needs and care during the visit?

- Strongly agree 0  
 Agree 1  
 Not sure 2  
 Disagree 3  
 Strongly disagree 4

4. How satisfied were you with the choices you had in the decisions affecting your health care during the survivorship visit?

- Very dissatisfied 0  
 Dissatisfied 1  
 Neither 2  
 Satisfied 3  
 Very satisfied 4

5. How much of the time did you feel respected by the practitioner providing your care during the survivorship visit?

- All of the time 0
- Most of the time 1
- Half of the time 2
- Some of the time 3
- None of the time 4

6. The time you had with the practitioner was too short.

- Strongly agree 0
- Agree 1
- Not sure 2
- Disagree 3
- Strongly disagree 4

7. Are you satisfied with the care you received during the survivorship visit?

- Very Satisfied 0
- Satisfied 1
- Neither 2
- Dissatisfied 3
- Very dissatisfied 4

*Figure 5.* Sample of the blank electronic SAPS survey administered to patients to assess satisfaction outcomes. Survey was modified and used for this QI initiative with written permission from the University of Melbourne. A copy of the original survey can be found at [https://www.continence.org.au/data/files/Reports/Short\\_Assessment\\_of\\_Patient\\_Satisfaction\\_SPAS.pdf](https://www.continence.org.au/data/files/Reports/Short_Assessment_of_Patient_Satisfaction_SPAS.pdf).

## Provider Version of the SAPS Survey

1. How satisfied are you with the effect of your care during the survivorship visits?
  - Very Satisfied 0
  - Satisfied 1
  - Neither 2
  - Dissatisfied 3
  - Very dissatisfied 4
  
2. How satisfied are you with the explanations you provided patients about their survivorship care and potential post-transplant risks?
  - Very dissatisfied 0
  - Dissatisfied 1
  - Neither 2
  - Satisfied 3
  - Very satisfied 4
  
3. Did you feel like you were able to thoroughly understand and make a plan for the patients survivorship needs during the visit?
  - Strongly agree 0
  - Agree 1
  - Not sure 2
  - Disagree 3
  - Strongly disagree 4
  
4. How satisfied were you with the choices and resources you had to help patients make informed decisions about their care after transplant in the survivorship period?
  - Very dissatisfied 0
  - Dissatisfied 1
  - Neither 2
  - Satisfied 3
  - Very satisfied 4
  
5. How much of the time did you feel the patient respected your expertise in providing survivorship care?
  - All of the time 0
  - Most of the time 1
  - Half of the time 2
  - Some of the time 3
  - None of the time 4

6. The time you had with the patient was too short.

- Strongly agree 0  
 Agree 1  
 Not sure 2  
 Disagree 3  
 Strongly disagree 4

7. Are you satisfied with the care you provided during the survivorship visit?

- Very Satisfied 0  
 Satisfied 1  
 Neither 2  
 Dissatisfied 3  
 Very dissatisfied 4

8. Has your satisfaction with the survivorship care you provide during the visits improved since you previously completed this survey?

Yes

What was the most helpful? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

No

9. Could your satisfaction with the care you provide during survivorship visits be further enhanced?

Yes

What changes could we make to the survivorship care model to improve your satisfaction with the visits? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

No

*Figure 6.* Sample of the blank electronic SAPS survey administered to patients to assess satisfaction outcomes. Survey was modified and used for this QI initiative with written permission from the University of Melbourne. A copy of the original survey can be found at [https://www.continence.org.au/data/files/Reports/Short\\_Assessment\\_of\\_Patient\\_Satisfaction\\_SPAS.pdf](https://www.continence.org.au/data/files/Reports/Short_Assessment_of_Patient_Satisfaction_SPAS.pdf).

## Appendix G

## Sample Characteristics

Table G1

*Participant Characteristics*

	<b>Respondents Pre-Intervention</b>	<b>Respondents Post-Intervention</b>
<b><i>BMT Survivors</i></b>	<b><i>n = 11 Total</i></b>	<b><i>n = 11 Total</i></b>
<b><i>Age:</i></b>	<b><i>n = 11</i></b>	<b><i>n = 11</i></b>
36-55 years old	4	4
56-75 years old	7	6
76 + years old	0	1
<b><i>Sex:</i></b>	<b><i>n = 9</i></b>	<b><i>n = 11</i></b>
Female	1	7
Male	8	4
<b><i>Cell Source:</i></b>	<b><i>n = 11</i></b>	<b><i>n = 11</i></b>
Autologous	8	5
Allogeneic	3	6
<b><i>Time Post-BMT:</i></b>	<b><i>n = 11</i></b>	<b><i>n = 11</i></b>
< 6 months	5	4
1 year	6	3
2 years	0	4
<b><i>APP Team</i></b>	<b><i>n = 7</i></b>	<b><i>n = 7</i></b>
SAPS Survey	7	7
SUS Survey	7	NA

Appendix H

Provider Preliminary Results

Are you satisfied with the care you provided during the survivorship visit?

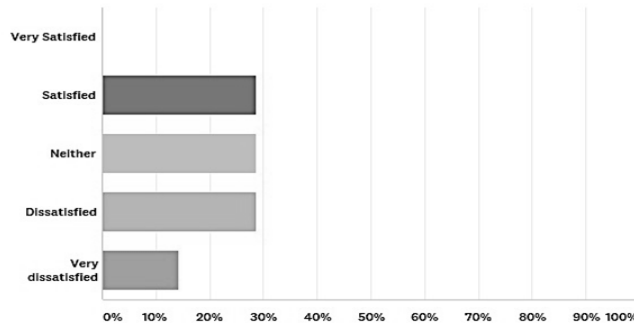


Figure 7. Provider pre-intervention satisfaction with care provided during the visit.

Could your satisfaction with the care you provide during survivorship visits be further enhanced?

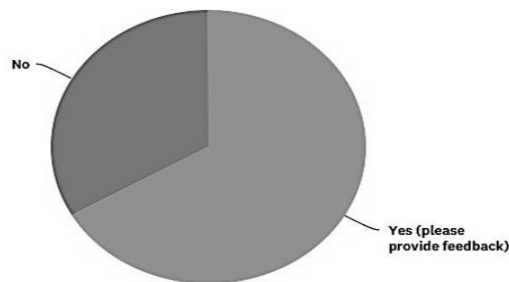


Figure 8. Provider pre-intervention perceived potential for enhanced satisfaction.

How satisfied are you with the explanations you provided patients about their survivorship care and potential post-transplant risks?

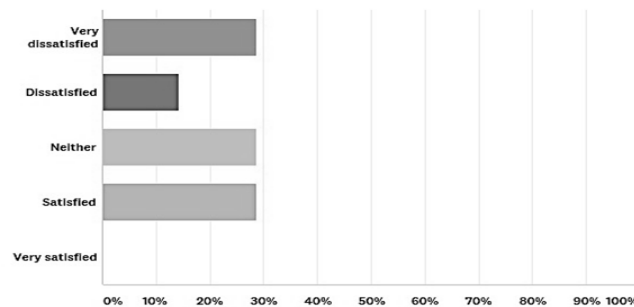


Figure 9. Provider pre-intervention perceived satisfaction with education provided about post-transplant risks.



Appendix I

Patient Preliminary Results

Are you satisfied with the care you received during the survivorship visit?

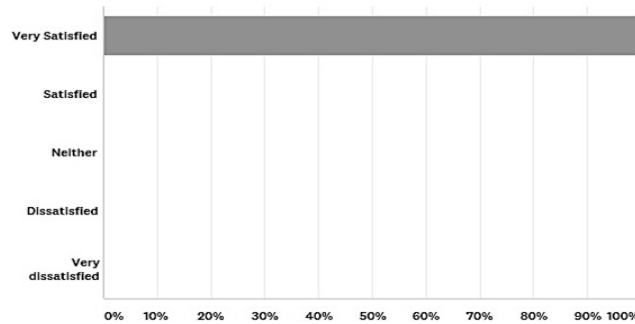


Figure 10. Patient pre-intervention satisfaction with survivorship visit.

Did this visit increase your self-confidence to manage your care?

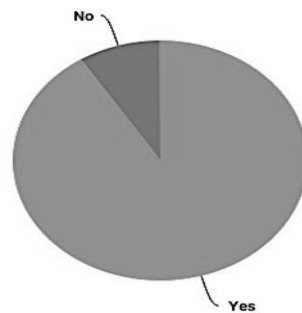


Figure 11. Patient perceived self-efficacy to manage survivorship care after the visit.

How satisfied are you with the explanations the practitioner provided you about your survivorship care and potential post-transplant risks?

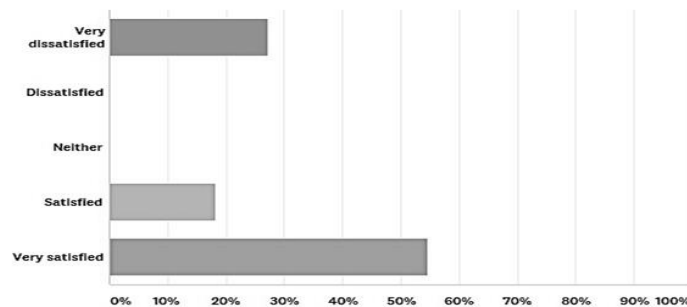


Figure 12. Patient pre-intervention satisfaction with education about post-transplant risks.

Appendix J

Combined Leadership Theory Framework

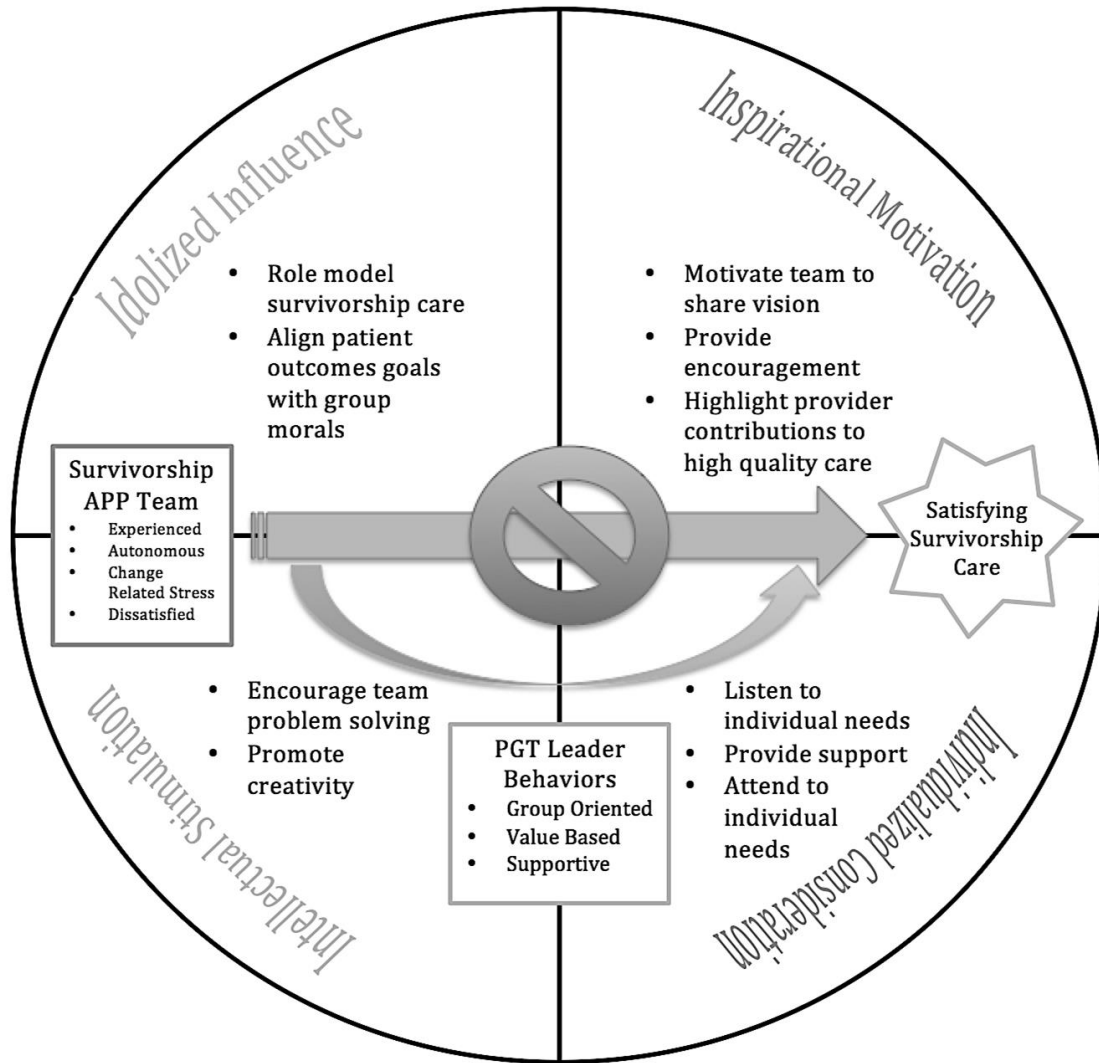


Figure 13. Combined Leadership Theory Framework. Synergistic application of Path-Goal Theory and Transformational Leadership. Adopted and modified with permission from “Path-Goal Leadership Theory” by Clark, D. R., 2013, retrieved from [http://www.nwlink.com/~donclark/leader/lead\\_path\\_goal.html](http://www.nwlink.com/~donclark/leader/lead_path_goal.html).

Appendix K

Provider Post-intervention Satisfaction Outcomes

Are you satisfied with the care you provided during the survivorship visit?

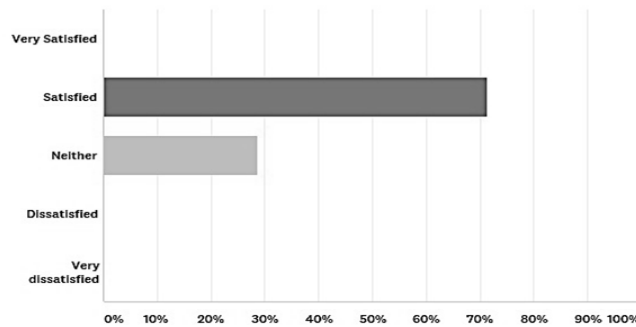


Figure 14. Provider post-intervention satisfaction with care provided during the visit.

Could your satisfaction with the care you provide during survivorship visits be further enhanced?

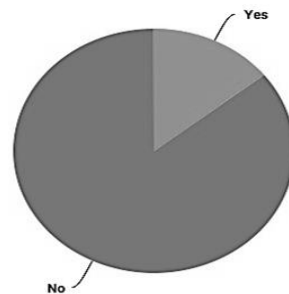


Figure 15. Provider post-intervention perceived potential for enhanced satisfaction.

How satisfied are you with the explanations you provided patients about their survivorship care and potential post-transplant risks?

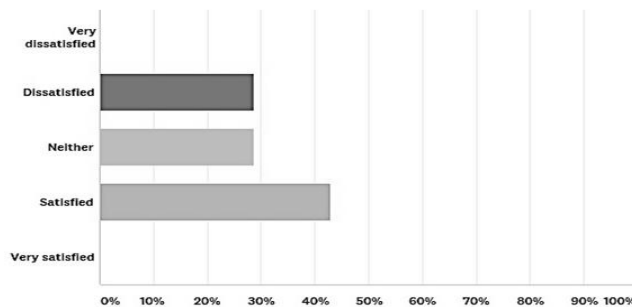


Figure 16. Provider pre-intervention perceived satisfaction with education provided about post-transplant risks.

Appendix L

Patient Post-Intervention Satisfaction Outcomes

How satisfied are you with the effect of the care you received during the survivorship visit?

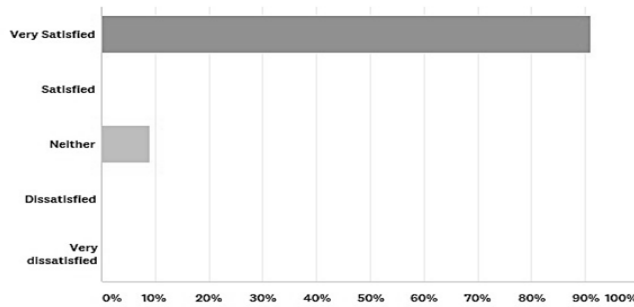


Figure 17. Patient post-intervention satisfaction with survivorship care.

How satisfied are you with the explanations the practitioner provided you about your survivorship care and potential post-transplant risks?

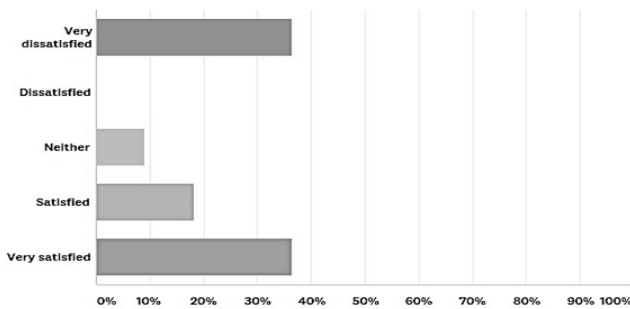


Figure 18. Patient post-intervention satisfaction with education about post-transplant risks.

How satisfied were you with the choices you had in the decisions affecting your health care during the survivorship visit?

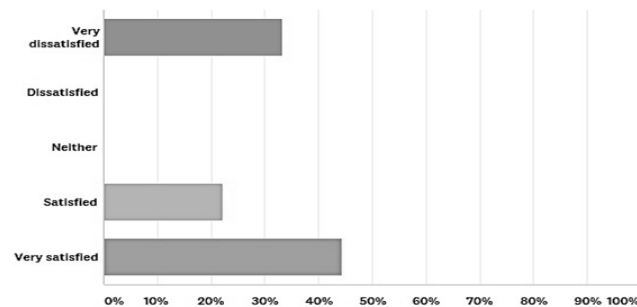


Figure 19. Patient post-intervention satisfaction with shared decision-making.