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Self-efficacy for Symptom Management in Adult Hematopoietic Stem Cell Transplant Patients

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SELF-EFFICACY FOR SYMPTOM MANAGEMENT IN ADULT
HEMATOPOIETIC STEM CELL TRANSPLANT PATIENTS

by

Lynn White

A DISSERTATION

Presented to the Faculty of

the Graduate College in the University of Nebraska Medical Center

in Partial Fulfillment of the Requirements

for the Degree of Doctor of Philosophy

Nursing Graduate Program

Under the Supervision of Professor Marlene Z. Cohen

University of Nebraska Medical Center

Omaha, Nebraska

August 2017

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DEDICATION

I would like to dedicate this body of work to my husband Jeff and daughter Shayla. You have given me unwavering support and encouragement throughout this journey. To Kelly, Linda, LeeAnn, Lori and Elisabeth: Your positive words and encouragement mean more than you know. I love you all.

Jeremiah 29:11 says “For I know the plans I have for you” declares the Lord, “plans to prosper you and not to harm you, plans to give you hope and a future.”

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ABSTRACT

Self-efficacy for Symptom Management in Adult Hematopoietic Stem Cell Transplant Patients

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University of Nebraska Medical Center, 2017

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Hematopoietic stem cell transplant (HSCT) is a treatment for hematologic cancers and other hematologic conditions that causes severe treatment-related symptoms. The first 30 days after HSCT, or the acute phase, is when symptoms are most intense. During this time, the ability of patients to manage their symptoms, in collaboration with their health care providers, is crucial to reduce the distress caused by the symptoms. Self-efficacy is the person's confidence in their ability to perform a behavior, such as symptom management. This body of work describes the concept of self-efficacy for symptom management (SESM), presents an integrated literature review on self-efficacy for symptom management in cancer patients, and presents results from research on SESM during the acute phase of HSCT. The purpose of the longitudinal, descriptive study was to determine changes over time and examine the relationships between SESM, symptom distress and physical function. The meaning of SESM from the patient's perspective pre- and post-HSCT also was explored. The study established that significant changes occur over time in these variables and that a relationship is present between SESM, symptom distress and physical functional status during the acute phase of transplant. Higher SESM was associated with less symptom distress and increased physical function. When symptom distress was highest, patients felt their worst and their self-efficacy was low, which influences how symptoms are managed, and affects outcomes such as functional status, hospital length of stay and overall quality of life. Assessment of SESM early in the treatment process, followed by patient-centered interventions to enhance SESM, will allow patients to manage their symptoms effectively and improve patient outcomes. The information presented here provides a foundation for future

research and development of nursing interventions to enhance a person's SESM during the acute phase of HSCT.

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CHAPTER 1: INTRODUCTION

Background

Hematopoietic stem cell transplant (HSCT), also known as bone marrow or stem cell transplant, is an intensive treatment for hematological cancers such as multiple myeloma, lymphoma, and leukemia and other hematological conditions such as sickle cell disease or aplastic anemia. This treatment offers the potential for disease remission, or for some patients, a cure. A person can receive donor stem cells from themselves (autologous) or donor stem cells from a sibling or unrelated donor (allogeneic). The donor type chosen is dictated by diagnosis, stage, and donor availability. The numbers of HSCT in the United States is increasing as more umbilical cord blood and haploidentical, or half-matched, donors are used (D'Souza, Pasquini, & X., 2016). Researchers are striving to increase survival, reduce complications, and treat persons who previously would not have been candidates for this aggressive treatment due to their age or other chronic illnesses or comorbidities (D'Souza et al., 2016).

The HSCT process consists of several steps including evaluation of the recipient, donor testing and selection, conditioning chemotherapy and for some, radiation, followed by the infusion of stem cells (National Marrow Donor Program, 2017). Before the transplant, the recipient undergoes an evaluation that includes, but is not limited to, a physical exam, lung and cardiac function studies, laboratory testing, and a psychological exam. The patient is admitted to the hospital before starting the preparatory or conditioning regimen. The conditioning regimen consists of high dose chemotherapy, and potential total body irradiation, depending on the type of disease. The conditioning regimen lasts from a few hours to seven days, based on the type of transplant and conditioning regimen. After the conditioning regimen is complete, the stem cells are infused to the patient via an intravenous line. The nadir, or time when the blood counts are at the lowest, occurs at 7-14 days after the conditioning regimen (Anderson et al., 2007).

Engraftment follows, which is when the stem cells begin to produce red cells, white cells, and

platelets, and recovery of the immune system. The risk for complications is especially high during the nadir and prior to engraftment, and symptoms tend to peak in severity and cause the most distress (Anderson 2007; Bevans 2008). Patients are discharged from the acute setting after blood counts have recovered and post-HSCT complications have resolved (Bevans 2008).

The phase up to 30 days after transplant is when the greatest risk for complications exists and physical functioning and overall quality of life (QOL) are at their lowest levels (Bevans, 2010; Pidala, Anasetti, & Jim, 2009). This time is also when treatment-related symptoms are at their peak, causing distress and impacting functional status and outcomes. Symptoms occur in clusters, which adds to the severity and distress. Management of symptoms during this time is of vital importance. However, this time is also when patients are feeling their worst and may not have the ability to manage their symptoms or treatment regimen. Some patients are discharged from the acute care setting before this point and are required to self-manage their symptoms and post-treatment regimens along with their non-professional caregiver (Oguz, Akin, & Durna, 2014).

Conceptual definition of key concepts

Symptom distress

Symptoms are an indication of a condition that is different from normal and are important cues that bring problems to the attention of the caregiver (Rhodes & Watson, 1987). Because of the subjective nature of symptoms, they become known when the patient reports their presence. Distress is a global term that represents an extensive range of emotional concerns that patients experience and may be less stigmatizing or embarrassing to patients than using words like emotional or psychiatric (Holland et al., 2013; Rhodes & Watson, 1987).

Rhodes and Watson (1987) described the meaning of symptom distress as "physical or mental anguish or suffering that results from the experience of symptom occurrence and/or perception of feeling states" (p. 243). Lenz, Pugh, Milligan, Gift, and Suppe (1997) discuss symptom distress within the Theory of Unpleasant Symptoms context as the degree to which the

symptoms bother the person. Another definition provided by Holland et al. (2013) in the National Comprehensive Cancer Network (NCCN) guidelines is that distress is the psychological, emotional, social, or spiritual concern caused by symptoms that may "interfere with the ability to cope effectively with cancer" (p. 192). Terms that are related to distress but different include bother, burden, occurrence, experience, awareness, and perception (Goodell & Nail, 2005; Hsiao, Loescher, & Moore, 2007). Symptom distress can be related to the person's disease or treatment (Goodell & Nail, 2005).

A combination of intensity, frequency, and QOL are components of the symptom experience that may lead to distress (Armstrong, 2003; Goodell & Nail, 2005). The most intense or frequently occurring symptoms are not always the most distressing to the patient (McClement, Woodgate, & Degner, 1997). Examples of distressing symptoms in oncology and transplant patients are prevalent in the literature and include fatigue, worry (anxiety), depression, lack of appetite, pain, sleep disturbances, diarrhea or bowel changes, dry mouth, weakness, and others (Anderson et al., 2007; Badger, Segrin, & Meek, 2011; Bevans, Mitchell, & Marden, 2008; Hefner et al., 2014; Larsen, Nordström, Björkstrand, Ljungman, & Gardule, 2003). Anxiety or depression can influence the amount of distress a person feels from their symptoms (Lenz et al., 1997). Other concerns such as prognosis, disease treatment, and side effects, social or financial concerns or other issues impacts levels of symptom distress (Holland et al., 2013). The most distressing symptoms may not be the most meaningful, and meanings associated with symptoms may impact physical and psychological health (Armstrong, 2003). The perception of the intensity of the symptom may be influenced by the perceived ominous meaning of the symptom (Dodd et al., 2001). For example, a headache may have a different meaning in the healthy individual as opposed to an individual who has just completed intensive treatment for brain cancer.

Management of Symptoms and Symptom distress

The relationship that symptom distress has to patient outcomes in the HSCT population has been well-documented and includes higher anxiety and depression, decreased physical

functional status, and QOL (Bevans et al., 2014; Ransom, Jacobsen, & Booth-Jones, 2006). The presence of symptom distress has been shown to be a predictor of survival in those with cancer and as a prognostic variable of long-term survival in HSCT (Bevans et al., 2014; McClement et al., 1997). HSCT survivors with high symptom distress had impairments in physical health, significantly lower mental health ($p < .001$) and lower health-related QOL (Bevans et al., 2014). Allogeneic and autologous HSCT patients have been found to have similar rates and quality of psychological distress (Hefner et al., 2014). HSCT patients with symptom distress are more likely to be non-adherent to treatment, have sleep disturbances, and anxiety and depression, which can lead to increased hospitalizations (Bevans et al., 2011; Rischer, Scherwath, Zander, Koch, & Schulz-Kindermann, 2009). Management of symptoms impacts treatment-related costs of health, hospitalizations and use of the health care system (Gapstur, 2007; Ryan & Sawin, 2009). Self-management of symptoms has been shown to optimize outcomes and influence QOL and survival in patients with cancer (Hoffman, 2013; McCorkle et al., 2011). Management of symptoms is vital to the symptom experience, both for cancer patients and those who receive HSCT.

Self-efficacy

Self-efficacy is a person's belief or confidence in their ability to implement behaviors to achieve an outcome, such as management of symptoms (Hoffman, 2013). Unless people believe they can have an influence on results, they are not motivated to act (Bandura, 2001). Knowledge and skills of disease care are needed for self-efficacy along with cognitive and affective processes, motivation, confidence, competence, and awareness (Hoffman, 2013; Ryan & Sawin, 2009; White et al., *in press*). Self-efficacy affects self-management of symptoms as the person's perception of their ability to implement interventions will have an impact on the desired outcomes (Hoffman, 2013). As the person's level of performance of self-management behaviors increases, the person's perceived self-efficacy increases and patients are empowered to change behaviors (Hoffman, 2013).

Self-efficacy for symptom management

Self-efficacy for symptom management (SESM) is the ability to implement behaviors to prevent, recognize, and relieve symptoms in patients with cancer or undergoing HSCT (White et al., *in press*). High self-efficacy leads to effective self-management behaviors, and have been shown to improve symptom management in chronic illness, which reduces health care expenditures and utilization of health care services (Novak, Costantini, Schneider, & Beanlands, 2013). High self-efficacy in HSCT patients may lead to more effective symptom management, which in turn would decrease symptom distress and improve outcomes (Bevans et al., 2014).

Theoretical Foundations

The theoretical foundation for this body of work was drawn from a combination of theories by Bandura (1997), Hoffman (2013), and Lenz et al. (1997) (Figure 1). These three theories are based on the concepts of self-efficacy, symptom distress, and self-management of symptoms. Bandura's Self-efficacy theory states that self-efficacy is what people believe they can do under various circumstances and that people act when they believe they can influence results (Bandura, 1986, 2001). Self-efficacy is the ability to perform a desired behavior and must be domain specific, such as symptom management. If persons perceive they are ineffective, they approach intimidating situations with more anxiety (Bandura, 1986). Components that may influence symptom distress are situational, psychological, and physiologic factors (Lenz et al., 1997). A relationship between self-efficacy and the ability to manage symptoms has been shown (Hoffman, 2013). Self-efficacy impacts functional status and quality of life and reduced symptoms impact outcomes such as health status, quality of life and cost of health (Hoffman, 2013; Lenz et al., 1997).

Symptoms are a sign that there is a change in health, and are a critical component of health care, especially for cancer and HSCT patients. The Theory of Unpleasant Symptoms (Lenz et al., 1997) conceptualizes symptoms as a multidimensional experience, where symptoms occur alone or in clusters and can potentiate each other. Symptom distress includes physical and mental

suffering or discomfort, awareness of symptom importance, the need to change actions, frequency, intensity, quality, and duration of symptoms (Hsiao et al., 2007; Lenz et al., 1997). Adverse outcomes from symptom distress include readmission to the hospital after discharge, decreased physical functional status and decreased QOL (Bevans et al., 2014; Novak et al., 2013).

The Theory of Symptom Self-management blends the concept of self-efficacy with symptom management to provide a framework for efficacy-enhancing interventions for patients with cancer (Hoffman, 2013). The outcomes of this theory are performance based, both functional and cognitive, from a person's symptom self-management behaviors (Hoffman, 2013). These three theories provide a conceptual framework that includes self-efficacy, the symptom experience, and self-efficacy for symptom management.

Significance

Self-efficacy plays a critical role in the self-management of symptoms. Memory and concentration impairments are adverse effects of high-dose chemotherapy received during HSCT and have the potential to impact self-efficacy (Wu et al., 2012). Wu et al. (2012) found that better cognitive functioning was associated with improved self-efficacy for symptom management, which was then associated with less depressed mood, reduced anxiety, and better QOL. Self-efficacy is associated with decreased symptoms and is a significant predictor of emotional and physical well-being and QOL after transplant (Bergkvist et al., 2015; Hochhausen et al., 2007; Wu et al., 2012). These studies, while different in their objectives, show that self-efficacy is important in the symptom management for HSCT patients. None of the studies described here, however, evaluated self-efficacy and its relationship to management of symptom distress during the acute phase of HSCT when symptom distress is at its highest levels. Liang et al. (2016) found that SESM impacted the relationship between symptom distress and QOL in breast cancer patients. While no studies were found linking self-efficacy specifically with symptom distress in HSCT patients, it follows that the decrease in symptom occurrence, depression, and anxiety, and the increase in QOL found with greater self-efficacy would be associated with decreased

symptom distress. Despite findings that symptom distress affects patient outcomes, the literature shows that targeted interventions are still lacking (Braamse et al., 2014).

Symptom management is a critical area for clinical research outcomes as identified by the Oncology Nursing Society and by the National Institute for Nursing Research (Knobf et al., 2015; National Institute of Nursing Research, 2016). These priority areas include studies of factors that influence the management of symptoms and contribute to the design of personalized interventions.

Research Question

While there is research published about symptom distress and outcomes in HSCT, very little research has examined self-efficacy and no research is available regarding interventions to facilitate self-efficacy in this population. The relationship between self-efficacy and symptom distress in HSCT patients is not known. Research to identify needs of the HSCT patient regarding self-efficacy to improve symptom management during the acute phase of HSCT has the potential for development of patient-centered interventions. Facilitation of self-efficacy may enable patients to increase engagement in managing their symptoms and lead to improved outcomes.

Purpose and Aims

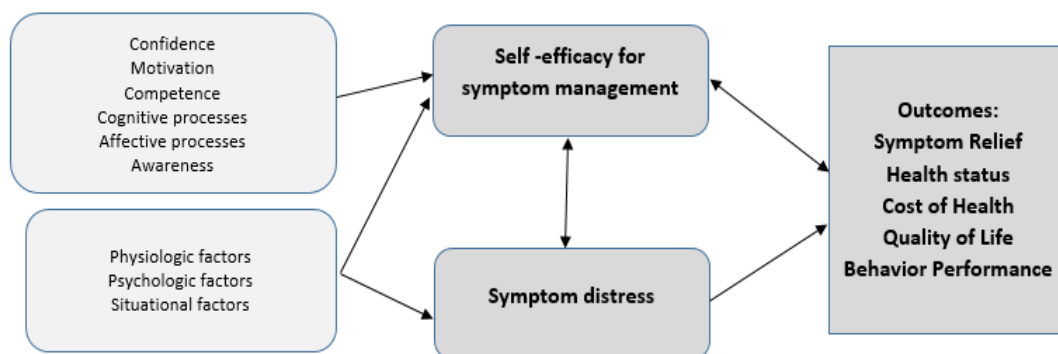
The purpose of this study was to describe the changes over time and relationships between SESM, symptom distress and the outcomes of physical function and length of stay during the acute phase, or 30 days, post-HSCT. The specific aims were:

1. Explore the concept of SESM from the patient's perspective at baseline and 30 days.
2. Determine the changes over time in SESM, symptom distress, and physical function.
3. Examine the relationships among SESM, symptom distress, and physical function.
4. Determine if the relationships among SESM and length of stay, readmission rates, and functional status varies depending on the level of symptom distress.

Summary

Four chapters are presented here to contribute to the understanding of SESM in adult patients with cancer and HSCT recipients. Chapter II analyzes the concept of SESM in cancer patients. Because of the scarcity of literature on SESM in HSCT patients, the concept analysis focused on adult patients with cancer. Chapter III provides an integrative review on SESM. Again, due to the scarcity of literature on SESM in HSCT patients, the review was broadened to include adult patients with cancer. Chapter IV reports on the relationships of SESM, symptom distress and outcomes in the acute phase following HSCT. Chapter V describes the meaning of SESM from the patient's perspective during their HSCT experience. Chapter VI provides a synthesis of the previous content to inform nursing practice on SESM in adult HSCT patients and addresses future steps for nursing practice and research opportunities to enhance SESM in this patient population.

Figure 1: Conceptual Model of Self-efficacy for Symptom Management in the Stem Cell Transplant Patient



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Perceived Self-Efficacy for Symptom Management in Cancer Patients: A Concept Analysis. *Clinical Journal of Oncology Nursing*.

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CHAPTER II: Manuscript 1

Perceived Self-efficacy for Symptom Management in Cancer Patients:

A Concept Analysis

Abstract

Background: Perceived self-efficacy (PSE) for symptom management plays a key role in outcomes for cancer patients such as quality of life, functional status, symptom distress and health care utilization. Greater PSE for symptom management predicts improved performance outcomes including functional health status, cognitive functioning, and disease status. Definition of the concept is necessary for use in research and to guide development of interventions to facilitate PSE for symptom management in cancer patients.

Objective: This analysis will describe the concept of PSE for symptom management in cancer patients.

Methods: A database search was performed for related publications from 2006-2016. Publications considered to be landmark works that informed the analysis published prior to 2006 were included.

Findings: Defining attributes of PSE for symptom management are: cognitive processes, affective processes, motivation, confidence, competence, and awareness. Antecedents identified were presence of symptoms, performance accomplishment, verbal persuasion and presence of threat or fear. Consequences of the concept include symptom relief, health status, cost of care, quality of life and behavior performance. Clarification of concept of PSE for symptom management will accelerate the progress of self-management research and allow for comparison of research data and intervention development.

Implications for Practice

- The concept of perceived self-efficacy (PSE) for symptom management in cancer patients is important as persons with cancer are expected to self-manage symptoms but few have the ability to do so.
- The concept of perceived self-efficacy for symptom management in cancer patients has not been analyzed in nursing literature.
- Patients with high perceived self-efficacy for symptom management have the potential for improved outcomes such as quality of life, functional status, and symptom distress.
- Nurses are positioned to help patients to increase self-efficacy for symptom management by teaching patient's behaviors for managing symptoms.

Background

The purpose of a concept analysis is to clarify concepts by examining their structure and function and to expand the body of nursing knowledge (Walker & Avant, 2011). The concept of perceived self-efficacy (PSE) for symptom management in cancer patients is important as persons with cancer are expected to self-manage symptoms but few can do so (Hoffman, 2013). The concept of PSE for symptom management includes both PSE and symptom management.

Self-efficacy is a key component of self-management of symptoms and is vital for implementation of the behaviors needed for self-management of symptoms. People are motivated to act only when they believe they can influence results (Bandura, 2001). Studies have shown that self-efficacy positively influences self-management behavior and is linked to higher quality of life (QOL) and improvements in health status including decreased physical and psychological symptoms (Lorig & Holman, 2003; Phillips & McAuley, 2013; Porter, Keefe, Garst, McBride, & Baucom, 2008; Torbit, Albiani, Crangle, Latini, & Hart, 2015).

Symptom management is a key component of nursing and cancer care (Armstrong, 2014). Cancer patients' symptoms are frequently occurring, severe, occur in clusters (two or more symptoms co-occurring) and lead to symptom burden and/or distress (Barsevick, 2007; Beck, Towsley, Caserta, Lindau, & Dudley, 2009). As cancer survivors live longer, symptom management becomes important for improving health outcomes, increasing QOL, improving functional status, and decreasing demand for health care services; all decreasing the cost of care (Ryan & Sawin, 2009). Self-management of symptoms optimizes outcomes and influences QOL and survival in patients with cancer (McCorkle et al., 2011). The outcomes of unmanaged symptoms include increased symptom distress and poor prognosis along with decreased QOL, functional status and survival (Gapstur, 2007).

The Oncology Nursing Society Research Agenda identified symptom management and self-management as priorities (Knobf et al., 2015). The National Institute for Nursing Research

also identified symptom science and self-management as priority research areas (National Institute for Nursing Research, 2016). Conceptual clarity will aid in these endeavors.

Purpose

This concept analysis defines and clarifies the concept of PSE for symptom management in cancer patients. Analysis of this concept will allow for conceptual clarity in research and aid in developing interventions to enhance self-efficacy for symptom management.

Data sources

‘Self-efficacy’, ‘perceived self-efficacy’, ‘symptom management’, and ‘cancer’ were used to search several data bases: CINAHL, Google Scholar, PubMed, MEDLINE and PsycINFO. Inclusion criteria were literature that related to PSE, self-efficacy, and symptom management in adult cancer patients, and published in English between 2006-2016. Exclusion criteria were duplicate publications; topics not directly related to self-efficacy and symptom management or adults with cancer. A manual search of references identified additional publications. Landmark publications published prior to 2006 that informed the concept analysis were included. Of the 183 titles and abstracts reviewed, 55 met inclusion criteria or were landmark publications. A concept analysis combining self-efficacy and symptom management has not been published.

Methods

Walker and Avant’s (2011) method was used to determine the antecedents, defining attributes and consequences of this concept. PSE and symptom management have been described previously as individual concepts (see publications in Table 1 and 2) but have not been analyzed together. The attributes, antecedents, and consequences from the individual concept analysis of PSE and symptom management were analyzed and synthesized with data gathered from the literature search to inform this concept analysis.

Results

Definitions and uses of the concept

PSE is a persons' beliefs about their capabilities to produce effects (Bandura, 1986, 1997). Self-efficacy can be further explained as implementing behaviors that are situation or domain specific, with outcome expectancies dependent on the context (Hoffman et al., 2009). The concept of PSE deals with perceived ability, while other similar terms describe the management of behaviors such as self-regulation, self-care, self-monitoring, self-management, and patient directed monitoring (Novak, Costantini, Schneider, & Beanlands, 2013).

For cancer patients, PSE is the person's belief in their ability to implement behaviors to achieve a desired outcome, such as symptom management. Self-efficacy becomes important when a person chooses a plan of action, determines the degree of effort required to achieve the outcome, and the amount of perseverance needed to continue when it is difficult (Hoffman, 2013). Knowledge and skills are required to implement a behavior, but self-efficacy also requires motivation, competence, and perseverance (see Table 1). As PSE increases, persons become empowered to change behaviors (Hoffman, 2013).

Symptom management in cancer is "a dynamic and multidimensional process in which patients intentionally and purposefully act on and interact with the perception (or previous perception) of the symptom(s) to initiate activities or direct others to perform activities to relieve or decrease distress from and prevent the occurrence of a symptom" (Fu, LeMone, & McDaniel, 2004, p. 68). Symptom self-management is application of strategies by an individual to relieve symptoms (Hsiao, Moore, Insel, & Merkle, 2014). Symptom management begins with awareness, presence of discomfort or suffering, identification, and assessment of symptoms from the persons' perspective (Fu et al., 2004). Symptom management includes the presence of one or more symptoms, the symptom experience (intensity, distress, quality, temporality, appraisal), the effectiveness of interventions and the measurement of related outcomes (Brant, 2016). Symptoms

that occur in clusters require different methods of management. For example, pain may exacerbate depression, anxiety, or fatigue, adding to the complexity of care.

PSE for symptom self-management is the “ability to implement situation specific behaviors to attain established goals, expectations, or designated types of outcomes” (Hoffman, 2013, p. E19). Hoffman further defined symptom self-management as “a dynamic, self-directed process of implementing behaviors that recognize, prevent, and relieve or decrease the timing (frequency, duration, occurrence), intensity, distress, concurrence, and unpleasant quality from symptoms to achieve optimal performance outcomes” (p. E19). PSE for symptom management is the ability to implement behaviors to prevent, recognize, and relieve symptoms in cancer patients.

Defining attributes

Attributes must be present if the concept exists (Walker & Avant, 2011). The attributes of PSE for symptom management in cancer patients are cognitive processes, affective processes, motivation, confidence, competence, and awareness (Figure 1).

Cognitive processes. Cognitive processes involve forming ideas, setting goals, and acting to meet them (Zulkosky, 2009). Perception of ability plays a role in learning skills, performing competently and perseverance (Bandura, 1997). How persons perceive and evaluate symptoms (cognitive appraisal) is a catalyst for a response (Hoffman, 2013). PSE for symptom management requires cognitive processes to acquire knowledge, competence and confidence related to both PSE and management of symptoms.

Affective processes. Affective processes such as feelings of anxiety, stress, or depression influence PSE (Bandura, 1997; Mystakidou et al., 2010; Sato & Sumi, 2015). Symptom management is influenced by affective processes as symptom awareness and decisions for management may be altered in conditions of high emotion or distress that are present in cancer patients at points in the disease trajectory. Emotional reactions can change thought processes and actions and have a relationship with cognitive processes (Zulkosky, 2009). Both cognitive processes and affective processes are needed for behavior change (Ryan & Sawin, 2009).

Motivation. Persons' beliefs in their efficacy affects choices they make in management behaviors, including how much effort to expend (Bandura, 1991). Despite having the knowledge or ability to perform behaviors, persons may choose not to act (Zulkosky, 2009). Outcome expectancies are the person's belief that an action will lead to a specific result and, in the case of symptom management, includes prevention or relief of symptoms (Lev, 1997). Motivation must be present for both PSE and symptom management.

Confidence. A characteristic of self-efficacy is confidence, which is the belief in the ability to perform a task or behavior (Robb, 2012). PSE for managing pain, fatigue and other symptoms is key to a person's ability and competence to handle challenging situations. Confidence impacts competence and motivation and is a required attribute for PSE for symptom management.

Competence. Knowledge and skills, including managing medical equipment and communication with providers, are required to be competent in symptom management (Ryan & Sawin, 2009). Competence also includes the physical ability to perform behaviors that could include exercising for fatigue or changing a dressing. The capability of performing actions required to manage symptoms is influenced by motivation, confidence, cognitive and affective processes and is needed for PSE for symptom management.

Awareness. PSE is being aware of the ability to be effective, which includes competence, physical ability and controlling actions (Zulkosky, 2009). Symptom awareness is being cognizant of a sensation, something not known, and interpreted considering the experience (Rhodes & Watson, 1987). Symptoms are subjective and only known when persons report their presence (Rhodes & Watson, 1987). Awareness of symptoms includes recognizing new needs in relation to symptoms and the needed response of actions for management (Fu et al., 2004). PSE for symptom management occurs when persons are aware of changes in their bodies, or the perception of abnormal feelings or symptoms, and then have the confidence, motivation, and competence to respond to the situation.

Constructed cases

Model case. A model case is an example of a how the concept is used that incorporates all of the defining attributes of a concept (Walker & Avant, 2011). A woman diagnosed with leukemia who has undergone several rounds of chemotherapy described her self-efficacy for symptom management prior to her diagnosis, and in subsequent hospitalization and treatment. Her statement: “Since I was diagnosed with cancer, I’m more aware of my body and I pay attention to changes in how I feel” demonstrates cognitive processes and symptom awareness. She demonstrates motivation by stating “I’ll do whatever it takes to stay out of the hospital” and “...the more I do for myself, the more I get to stay out of the hospital, and that means everything to me”. She continued: “I know the symptoms of infections, I was able to monitor that pretty well. I check my central line for signs of infection. I had mucositis so I couldn’t eat or talk, I had to force myself to get pills down. I performed oral care four times a day and ate soft foods. Then my blood counts went up and my mucositis went away and it was better.” These statements show that she is competent and has the cognitive ability to manage a complex regimen. Recognizing changes, being aware of her body and feelings of fear demonstrate affective processes, multidimensionality, dynamics, and awareness. She states, “I’m confident in myself because I know I can’t always rely on others”, further demonstrating that she perceives herself to have self-efficacy for symptom management.

Contrary case. A contrary case is an example of not having self-efficacy for symptom management where none of the attributes are present (Walker & Avant, 2011). Patients may not recognize that self-efficacy is not present, and do not take steps to manage symptoms. This is the situation in this contrary case of a middle-aged woman with lymphoma who did not report developing tingling pain on the right side of her chest and upper arm. During a physical exam, the health care provider identified a rash with small blisters. When asked about the rash, the woman said, “I felt it but didn’t think it mattered, they told me to expect these things.” She said “why didn’t I tell my husband? I don’t know” and “I don’t follow through, I had a problem and I didn’t

tell anybody”. These statements reflect lack of cognitive processes and motivation and lack of awareness that action could be taken to manage these symptoms.

Antecedents

Antecedents must be in place prior to occurrence of a concept (Walker & Avant, 2011). The antecedents of PSE for symptom management in cancer patients are presence of symptoms, performance accomplishments, verbal persuasion and perception of threat or fear.

Presence of symptoms. Symptoms bring awareness of new needs followed by the response of patients to the needs (Fu et al., 2004). Symptoms indicate changes in biopsychosocial functioning, sensations or cognition and provide clinical information (Dodd et al., 2001). In addition to symptom presence, persons also perceive the severity and amount of distress or discomfort (Rhodes & Watson, 1987). How symptoms are perceived can affect the intensity of the symptom experience (Brant, 2016).

Dynamic. Cancer is a dynamic disease, with remissions and recurrences possible (Gapstur, 2007). Symptom management includes evaluating symptoms, determining the meaning and the required behavior, and is affected by types of symptoms, timing (during or after active treatment), environment (home or hospital) and expected outcomes. Each time a symptom occurs, the cycle of evaluation, determining meaning and behavior is repeated (Fu et al., 2004). Changes in management strategies may also occur. PSE is a product of environment, cognition, affective processes, and physical components that are all dynamic (Hoffman, 2013). Presence of stress, anxiety and depression affects PSE (Bandura, 1997).

Multidimensional. Symptom presence and the behaviors required for management are multidimensional, having physical, cognitive, emotional, social, and situational components (Armstrong, 2003; Brant, 2016; Lenz, Pugh, Milligan, Gift, & Suppe, 1997). Symptom management includes perception and cognition, as well as responses to experience, the illness, expected outcomes and environment (Fu et al., 2004). How persons perceive their symptoms and the resulting PSE for symptom management is multidimensional (Armstrong, 2003).

Performance accomplishment. Successful performance of behavior builds PSE (Bandura, 1997). Encouragement of performance accomplishments includes allowing persons to practice a behavior or use return demonstration which, when successful, promotes increased PSE (Zulkosky, 2009). Conversely, failure to perform a behavior may decrease PSE. Distractions, complexity of the task, emotional state, and expertise of the individual modeling the behavior all affect the ability to perform behavior (Richard & Shea, 2011). People take pride in their accomplishments when they believe their success is due to their own efforts and will expend more effort on tasks or behaviors when they believe they are proficient (Zulkosky, 2009).

Verbal persuasion. Verbal persuasion is when someone convinces another that they have the capability for a behavior such as symptom management (Zulkosky, 2009). When persons hear encouragement, they are more likely to use greater effort (Bandura, 1997). Persons can be convinced that they can be successful at task performance. Verbal persuasion can be from health care providers, family and friends, or other patients such as in support groups.

Presence of threat or fear. Symptoms may be perceived as a threat to individual's health (Hoffman, 2013). Evaluation of symptoms involves the intensity, location, frequency and affective impact and the threat posed by the symptom (Dodd et al., 2001). The presence and experience of symptoms may bring a perception of fear and threat, determining whether it is dangerous or potentially disabling, which is the catalyst for initiating management activities (Fu et al., 2004). Interpreting symptoms as recurrence or worsening of the cancer may cause avoidance behavior that will negatively influence PSE (Hoffman, 2013).

Consequences

Consequences are a result of the occurrence of a concept (Walker & Avant, 2011). The consequences of PSE for symptom management in cancer patients include symptom relief, health status, cost of care, quality of life and performance of the management behavior.

Symptom relief. Low PSE for symptom management may result in poorly managed symptom clusters that result in increased distress, increased depression, and anxiety, decreased

functional status and impact relationships and daily life (Kim, McGuire, Tulman, & Barsevick, 2005). Other costs of unmanaged symptoms include increased health care utilization and interference with treatment schedules which can lead to cancer worsening (Kim et al., 2005). Increased PSE for symptom management Effective symptom management leads to symptom relief, decreased distress, and decreased symptom occurrence (Fu et al., 2004).

Health status. Health status includes indicators such as relief or worsening of symptoms, functional status, symptom distress level and survival (Fu et al., 2004). Symptom occurrence is an indicator of health status and patient functioning.

Cost of care. Symptom management impacts cost of health care through use of resources, treatment related services, and hospitalizations (Brant, 2016; Gapstur, 2007). Cost benefit ratio is important in evaluating various symptom management interventions (Brant, Beck, & Miaskowski, 2010). Cost is another component of multidimensionality of symptom management.

Quality of life. Symptom presence and effects have a negative effect on QOL including role performance, functional status, physical performance, cognitive functioning, delay of treatment, and disease status (Brant, 2016; Gapstur, 2007). Self-efficacy has been linked to symptom distress, psychological health, and QOL (Bergkvist et al., 2015; Hochhausen et al., 2007; Kohno et al., 2010; Lee, Robin Cohen, Edgar, Laizner, & Gagnon, 2006; Liang et al., 2016; Liao et al., 2014; Wu et al., 2012). Effective symptom management leads to decreased number or presence of symptoms and directly impacts QOL (Fu et al., 2004). PSE for symptom management can lead to prevention of symptoms and increased QOL.

Behavior Performance. Symptom management in persons with cancer is complex. Persons with low PSE may experience more stress and depression and have lower motivation (Zulkosky, 2009). Performance of symptom management behavior requires problem solving, physical function mastery, and role function (Buffart et al., 2014; Fu et al., 2004). Those with cognitive deficits are challenged in managing complex treatment regimens. Increased number and

severity of symptoms can be related to lower cognitive functioning or ineffectual management behaviors (Fu et al., 2004). PSE for symptom management allows persons to perform the behaviors needed for symptom management.

Empirical referents

Empirical referents are how one recognizes or determines the existence of concepts and are used to develop instruments to measure concepts in research (Walker & Avant, 2011). Self-efficacy can be measured by asking a person if they have confidence in taking an action (Lorig & Holman, 2003). Measurement instruments that have been used in research include the general PSE scale (Jerusalem, Schwarzer, & Schwarzer, 1992), the Arthritis Self-Efficacy Scale (Lorig, Chastain, Ung, Shoor, & Holman, 1989), the Breast Cancer Self-Efficacy Scale (Champion et al., 2013) and the Patient-Reported Outcomes Measurement Information System (PROMIS) self-efficacy scales for managing chronic conditions (American Institute for Research, 2016). Instruments related to PSE for symptom management in cancer patients include the PSE for Fatigue Self-Management tool (Hoffman et al., 2011) and the Symptom-Management Self-Efficacy Scale-Breast Cancer (Liang, Wu, Kuo, & Lu, 2015).

Discussion

Many publications exist in nursing literature regarding the broad concept of self-efficacy. Limited literature is published that combines PSE with symptom management in cancer patients. The concept characteristics described here take prior work by Bandura in the Self-Efficacy Theory (1997) and others and applies it to the situation of PSE for symptom management in cancer patients. This concept analysis also further expands upon the concepts that are in the Theory of Symptom Self-Management by Hoffman (2013). PSE for symptom management is easily influenced, positively or negatively, because of the dynamic state of cancer diagnosis and subsequent treatment. Presence of symptom clusters has the potential to increase the level of symptom distress and complexity of care and is an important when considering how to enhance

PSE for symptom management. Individuals with high PSE for symptom management may have decreased symptom occurrence, symptom distress and higher QOL (Porter et al., 2008).

Implications for Nursing

Recognizing deficits in PSE for symptom management is critical for providing overall care for persons with cancer. Gaps may exist between PSE and ability for symptom management. Persons may have high PSE but may not have the emotional, cognitive, or physical capability to perform needed behaviors. A person with self-efficacy for symptom management may perceive symptoms as less distressing. Nurses are positioned to help patients learn new behaviors for managing symptoms. Interventions to increase self-efficacy, which include partnering, goal setting, education, social support, and internet tools, can aid in making decisions for symptom management (Foster et al., 2016; Goldberg, Hinchey, Feder, & Schulman-Green, 2016; Lee et al., 2006; Myall et al., 2015; Ruland et al., 2013; Schulman-Green & Jeon, 2015; Weber et al., 2007; Zhang et al., 2014; Zhu, Ebert, & Wai-Chi Chan, 2017). Symptom burden may be a barrier for implementation of PSE interventions. PSE for symptom management is an ever-changing concept within a dynamic cancer environment that requires changes of strategies over time.

Conclusion

PSE for symptom management can be learned (Hoffman, 2013). Using individualized plans of care based on the attributes, antecedents and consequences provided here, nurses can partner with cancer patients to reduce symptom burden, facilitate effective symptom management, increase health status and QOL. Conceptual definition and clarity allows for future research initiatives and interventions. This concept should be used in further research regarding symptom management in cancer patients, especially in persons with complex symptomatology such as those with multiple co-morbid conditions, advanced disease or receiving intense treatments. Future research is warranted to find ways to increase self-efficacy for symptom management in cancer care and thus improve patient outcomes.

Figure 1: Perceived Self-efficacy for Symptom Management

Perceived Self-Efficacy for Symptom Management

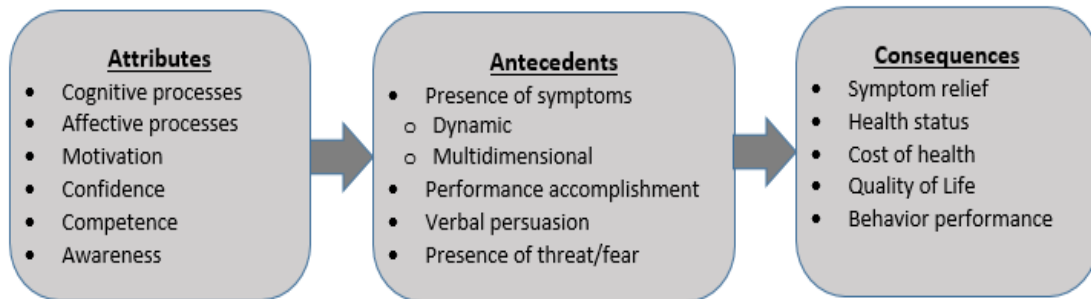


Table 1: Concept Analysis of Perceived Self-efficacy or Self-efficacy

Author	Concept	Attributes	Antecedents	Consequences
Robb, 2012	Self-efficacy in nursing education	Confidence Perceived capability Perseverance	Event occurrence Reaction to event Interpretation of behaviors needed Judgment of capability to perform required behavior	Person decides to perform behavior Person decides not to perform behavior Person performs behavior after verbal persuasion
Townsend & Scanlan, 2011	Self-efficacy related to student nurses in the clinical setting	Confidence Capability Persistence Strength	Mastery experiences Vicarious experiences Social persuasion Physiological and affective state	Approach vs. avoidance Quality of performance Persistence
Zulkosky, 2009	Self-efficacy	Cognitive and affective processes Locus of control	Social experiences Performance accomplishment Verbal persuasion Physiologic cues	Low levels of self-efficacy: Avoid complex responsibilities Lower motivation Giving up Higher stress and depression

Table 2: Concept Analysis of Symptoms in cancer patients

Author	Concept	Attributes	Antecedents	Consequences
Armstrong, 2003	Symptom experience	Symptom occurrence and distress Situational and existential meaning	Demographic characteristics Disease characteristics Individual characteristics	Adjustment to illness QOL Mood Functional status Disease progression Survival
Fu, et al., 2004	Symptom management	Subjective Experiential Intentional Multidimensional Dynamic process Positive and negative outcomes	Not given	Symptom status Quality of life Performance
Gapstur, 2007	Symptom burden	Dynamic Multidimensional Quantifiable Subjective Physiologic	Multiple symptoms related to worsening disease status	Decreased survival Poor prognosis Delay or termination of treatment Increased hospitalizations, medical costs Decreased functional status Lowered self-reported QOL
Kim et al., 2005	Symptom clusters	Relationships of symptoms Relationships of clusters Concurrence Underlying dimensions Stability Common etiology	Presence of 2 or more symptoms	Poorer physical health status Interference with activities of daily living Emotional distress Increased financial burden

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CHAPTER III: Manuscript 2

Self-efficacy for Management of Symptoms and Symptom Distress in

Adult Cancer Patients: An Integrative Review

Abstract

Aims: The purpose of this integrative review is to identify and assess the evidence regarding self-efficacy and management of symptoms and symptom distress in adults with cancer.

Background: Self-efficacy for symptom management plays a key role in outcomes for cancer patients such as quality of life (QOL), functional status, symptom distress and health-care utilization.

Design: Integrative literature review.

Data sources: A database search was performed for publications from 2006-2017. Articles that examined the relationship between self-efficacy and symptom management or self-efficacy and symptom distress in adult cancer patients were selected for inclusion.

Review methods: All publications were critically appraised for methodological quality. Data were extracted and analyzed according to the review aims and key findings.

Results: Twenty publications met the inclusion criteria. The studies reviewed found high self-efficacy to be associated with low symptom occurrence and symptom distress and higher general health and QOL.

High self-efficacy predicted physical and emotional well-being. Low self-efficacy was associated with higher symptom severity, poorer outcomes, and overall functioning. Presence of self-efficacy can be assessed using developed instruments and self-efficacy enhancing interventions are feasible and effective.

Conclusion: This integrative review provided information on the existing literature regarding self-efficacy for symptom management in the cancer population. Presence of a theoretical model and validated instruments to measure self-efficacy for symptom management set a groundwork for needed future research into patient-centered interventions to enhance self-efficacy for symptom management.

Impact Statement

Self-efficacy for symptom management plays a key role in outcomes for cancer patients such as quality of life (QOL), functional status, symptom distress and health-care utilization. This integrative review examined 20 publications to assess current evidence regarding self-efficacy for management of symptoms and symptom distress in adults with cancer. Results showed that high self-efficacy is associated with lower symptom occurrence and distress and better general health and QOL. Nurses are well positioned to implement interventions to enhance self-efficacy for symptom management. Future research needs to develop and test patient-centered interventions to enhance self-efficacy for symptom management.

Summary Statement

This integrative review provides information on existing literature regarding self-efficacy for symptom management in the cancer population. High self-efficacy leads to better symptom management behaviors and lower symptom distress, better functioning, and overall quality of life. Groundwork is present in the literature to support further research into patient-centered interventions to enhance self-efficacy for symptom management.

Introduction

Changes in screening, early detection methods, and advances in treatments have resulted in a decrease in overall death rates and an increase in the number of persons living with cancer in the United States (Jemal et al., 2017; Miller et al., 2016). Living with cancer increases the complexity of care as persons often have other chronic illnesses in addition, such as heart disease, diabetes, or chronic lung disease (Hoffman, 2013). Acute and long-term symptoms related to a cancer diagnosis are both physical and psychological and result from not only the disease process but also from the treatments. Symptom management is an important part of the plan of care for cancer patients as uncontrolled symptoms impact quality of life (QOL), functional status, perception of health, cost of health care, and survival (Brant, 2016).

Self-efficacy is a key component of self-management of symptoms and is vital for implementation of the behaviors needed for self-management of symptoms. People are motivated to act only when they believe they can influence results (Bandura, 2001). Studies have shown that self-efficacy positively influences self-management behavior and is linked to higher QOL and improvements in health status including lower physical and psychological symptoms (Lorig & Holman, 2003; Phillips & McAuley, 2013; Porter, Keefe, Garst, McBride, & Baucom, 2008; Torbit, Albiani, Crangle, Latini, & Hart, 2015).

Symptom management is a key component of nursing and cancer care (Armstrong, 2014). Cancer patients' symptoms occur frequently, in clusters (two or more symptoms co-occurring) and lead to symptom burden and/or distress (Fu, McDaniel, & Rhodes, 2007; Gapstur, 2007; Kim & Abraham, 2008). Self-management of symptoms optimizes outcomes and influences QOL and survival in patients with cancer (McCorkle et al., 2011). The outcomes of unmanaged symptoms include higher symptom distress and disease progression along with lowered self-reported QOL, functional status and survival (Gapstur, 2007).

Self-efficacy and symptom management are key concepts that affect outcomes for cancer patients in all stages of treatment. Understanding self-efficacy, symptom distress and the role that symptom management strategies have in controlling symptoms is imperative for maintaining or potentially improving functional status and QOL for cancer patients. The purpose of this integrative review is to examine current experimental and non-experimental research as well as theoretical and empirical literature regarding self-efficacy and the management of symptoms and symptom distress in adults with cancer.

Background

According to Bandura's Social Cognitive Theory (1986), self-efficacy is a person's belief in their ability to implement behaviors to achieve a desired outcome, such as symptom management, and includes not only using the skills required to perform a behavior, but also knowing how and when to use them under diverse circumstances. Self-efficacy can be learned, and therefore self-efficacy for symptom management can be learned (Hoffman, 2013). As self-efficacy increases, persons become empowered to change behaviors that are vital for self-management. Unless people believe they can have an influence on results, they are not motivated to act (Bandura, 2001). Self-efficacy has been associated with future health status and must be considered when teaching symptom management behaviors (Lorig & Holman, 2003).

Symptoms are a subjective experience that reflects a change from the normal state and are important cues that bring problems to the attention of the caregiver (Dodd et al., 2001). The experience of distress from the presence of a symptom or cluster of symptoms is the catalyst for a person to report their presence and seek help (Fu et al., 2007). Symptom management in cancer is "a dynamic and multidimensional process in which patients intentionally and purposefully act on and interact with the perception (or previous perception) of the symptom(s) to initiate activities or direct others to perform activities to relieve or decrease distress from and prevent the occurrence of a symptom" (Fu, LeMone, & McDaniel, 2004, p. 68). Symptom management begins with awareness, presence of discomfort or

suffering, identification, and assessment of symptoms from the persons' perspective (Fu et al., 2004). Symptom management includes the presence of one or more symptoms, the symptom experience (intensity, distress, quality, temporality, appraisal), the effectiveness of interventions and the measurement of related outcomes (Brant, 2016). Symptoms often occur in clusters and require different methods of management, which increases the burden on the patient and their caregiver. For example, pain may exacerbate depression, anxiety, or fatigue, adding to the complexity of care.

Symptom distress is a global term that represents the amount of suffering experienced by patients in relation to the perception of the symptoms that are present (Holland et al., 2013). Symptom distress is measured by self-report and is caused by presence of symptoms along with concerns about illness or prognosis, disease treatment and side effects, psychosocial or spiritual issues or financial concerns (Holland et al., 2013). The most distressing symptoms may not be the most severe, and the inability of patients to manage distressing symptoms is often the reason for seeking care (Badger, Segrin, & Meek, 2011). Symptom distress is a key area of focus for clinical interventions as it has been shown to negatively affect outcomes, including higher anxiety and depression, functional status and QOL (Anderson et al., 2007; Bevans et al., 2014).

Self-efficacy positively influences self-management behavior and is linked to higher QOL and improvements in health status including lower physical and psychological symptoms (Lorig & Holman, 2003; Porter et al., 2008). Self-management of symptoms impacts cost of health through treatment-related services, hospitalizations and use of the health care system (Gapstur, 2007; Ryan & Sawin, 2009). Self-management of symptoms has been shown to optimize outcomes and influence QOL and potentially survival in patients with cancer (Hoffman, 2013; McCorkle et al., 2011).

Self-efficacy for symptom management is a predictor of patient outcomes for chronic disease populations (Kelleher, Somers, Locklear, Crosswell, & Abernethy, 2016). The Oncology Nursing Society Research Agenda identified symptom management and self-management as priorities (Knobf et al.,

2015). The National Institute for Nursing Research also identified symptom science and self-management as priority research areas (National Institute for Nursing Research, 2016).

The aim of this integrative review was to identify, assess and synthesize data from current experimental and non-experimental research as well as theoretical and empirical literature regarding self-efficacy for management of symptoms and symptom distress in the adult cancer population. The concepts of interest are self-efficacy for symptom management in the population of adult patients with cancer and subpopulation pre-or post-hematopoietic stem cell transplant (HSCT). The sampling frame includes research studies and theoretical publications.

Methods

This is an integrative review of publications in the nursing literature focusing on the concepts of self-efficacy for symptom management and symptom distress. The methodological approach used was the five-stage approach from Whitemore and Knafl (2005) of problem identification, literature search, data evaluation, data analysis and presentation. This method was chosen as it allows for inclusion of experimental and non-experimental research studies as well as theoretical publications in the analysis

A search was performed using the databases CINAHL, Cochrane Library, MEDLINE, Biomedical Reference Collection, PsychINFO, NIH Reporter and Google Scholar. A keyword search using MeSH terms included, but was not limited to self-efficacy AND symptom management, self-efficacy, AND symptom distress, and HSCT and cancer. The initial search was limited to HSCT patients only. Due to the limited number of publications found, the search was widened to include the population of cancer patients. The search was limited to January 2006-April 2017 to capture the most recent literature as cancer treatment and symptom management strategies change frequently. Additional articles were identified manually by searching references of retrieved articles. The first author selected journal articles based on the inclusion and exclusion criteria. Decisions were reviewed by the second author. Inclusion criterion were publication dates between 2006-2017, English language, discussion of outcomes

or concepts of self-efficacy for symptom management and symptom distress, and population of adult patients with cancer or undergoing HSCT. Exclusion criteria included pediatric population, caregivers of HSCT or cancer patients, and unpublished manuscripts (dissertations).

Search Outcomes

Figure 1 presents a flowchart of the identification of relevant articles. The initial search yielded 338 articles. After examining titles and abstracts in relation to the inclusion criteria and excluding duplicates, 35 were selected for full text review for relevance. Nine additional articles were retrieved from a manual search of references from full text reviews. Of these 44 articles, 24 were excluded based on exclusion criteria, primarily outcomes or concepts not directly related to the self-efficacy for management of symptoms or symptom distress. Twenty articles were selected for inclusion in this review (Table 1). Eighteen research studies were selected including five intervention studies and 13 descriptive studies. One integrative review and one theory paper were included in the review as the data presented were directly relevant to self-efficacy and symptoms in this population.

Quality Appraisal

The selected publications were published in peer reviewed journals. The research articles were evaluated for quality of methodology using a quality appraisal tool developed by blending components of tools in published reviews from Lines, Hutton, and Grant (2016) and Guo, Whitemore and He (2011) (Table 2). Criteria for quality appraisal included the study design, methodology, sample, instruments, analysis methods and key findings. Studies that were randomized controlled trials were also evaluated using criteria from the Critical Skills Appraisal Programme (CASP, 2017) (Table 3). The integrative review article selected for inclusion was evaluated using review criteria adapted from CASP criteria (Table 4). The theoretical publication was evaluated based criteria from Walker and Avant (2011) (Table 5). No papers were rejected based on methodological quality.

Data Abstraction and Synthesis

Publications were synthesized based on factors that influenced self-efficacy for management of symptoms and symptom distress in persons with cancer. To facilitate the synthesis, data were extracted into an evidence table. This supported comparison of populations, methodologies and analyses relating to similarities in outcomes (Table 1).

Results

The 20 articles reviewed were from 18 studies from the United States, Sweden, Scotland, United Kingdom, Taiwan, Norway, Greece, and China. The participants were patients with breast, lung, prostate, colorectal, gastrointestinal, or hematologic cancer or were undergoing treatment with chemotherapy or HSCT or had advanced cancer. Sample sizes ranged from 74 to 325 for the 17 quantitative studies and eight for the mixed methods study. The mean age across all studies was 57.7 years.

The relationship between self-efficacy and symptoms is established in cancer patient populations. Higher self-efficacy has been associated with higher symptom management and lower symptoms (Bergkvist et al., 2015; Oakley, Johnson, & Ream, 2010; Porter et al., 2008). Higher self-efficacy for coping with symptoms was associated with greater well-being (Shelby et al., 2014). Paterson, Robertson, and Nabi (2015) reported a decrease in self-efficacy when symptoms significantly increased for men with prostate cancer. Patients low in self-efficacy reported higher levels of symptoms and symptom distress including pain, anxiety, fatigue, and functional well-being (Bergkvist et al., 2015; Kelleher et al., 2016; Mystakidou et al., 2010; Papadopoulou et al., 2017; Porter et al., 2008). Reduced symptoms, better performance status, and overall general health also contribute to self-efficacy (Bergkvist et al., 2015; Hoffman, 2013; Mystakidou et al., 2010).

For HSCT patients, higher self-efficacy after transplant results in increased health related QOL, lower depression and better general health (Bergkvist et al., 2015; Hochhausen et al., 2007). Lower self-efficacy after transplant resulted in poor general health and higher symptom occurrence (Bergkvist et al.,

2015). Cognitive function is a factor to consider for self-efficacy for symptom management in these patients as high doses of chemotherapy required for HSCT regimens may lead to impaired cognition. Wu et al. (2012) suggests that interventions to increase self-efficacy will reduce the negative impact of subjective cognitive impairment. There is an association between self-efficacy, general health, the occurrence of symptoms, and ability to manage symptoms (Bergkvist et al., 2015; Hochhausen et al., 2007; Wu et al., 2012).

Self-efficacy impacts QOL through lower symptom occurrence and distress in cancer patients (Hochhausen et al., 2007; Liang et al., 2016; Mystakidou et al., 2010). Liang (2016) found that self-efficacy for symptom management mediated the association between symptom distress and QOL in breast cancer patients. Lower symptom distress led to better QOL through higher self-efficacy. Other publications support the relationship between self-efficacy and QOL in lung, prostate, breast, and colorectal cancer patients (Hoffman, 2013; Mosher et al., 2016; Papadopoulou et al., 2017; Porter et al., 2008; Shelby et al., 2014; Zhang et al., 2014).

Instruments to measure self-efficacy should measure a person's beliefs in their ability to perform the task within the situation of the study, in this case, symptom management (Bandura, 1997). There are validated and reliable instruments available to measure self-efficacy for various behaviors in specific cancer populations (Hoffman et al., 2011; Liang, Wu, Kuo, & Lu, 2015). Liang et al. (2015) developed and tested an instrument that measures self-efficacy in women with breast cancer and included items regarding communication, the severity of symptoms, managing emotional and interpersonal disturbances and acquiring resources while undergoing chemotherapy. Hoffman et al. (2011) developed and validated an instrument to measure self-efficacy for fatigue self-management for patients undergoing chemotherapy. These instruments are self-report measures and have the potential for use to assess self-efficacy in other contexts in cancer populations.

This review included four intervention studies designed to enhance self-efficacy. While the interventions varied in methodology, all resulted in improved self-efficacy (or trends) or lower symptom severity or distress. Zhang et al. (2014) developed a nurse led intervention that included self-efficacy education, management of symptoms, relaxation techniques, and health coaching. Hoffman et al. (2017) used an exercise and balance intervention to impact fatigue severity and found that as behavior performance increased, self-efficacy for the behavior improved when compared to a control group. Ruland et al. (2013) discussed an internet intervention that provided symptom self-management information and support and allowed for communication and a diary. Oakley et al. (2010) used a diary intervention for symptom communication and medication scheduling. These interventions show promise for increasing self-efficacy and symptom management behaviors and decreasing symptom distress. An integrative review conducted by Zhu, Ebert, and Wai-Chi Chan (2017) found that internet based programs moderated by healthcare providers have positive effects on self-efficacy and symptom distress in women with breast cancer during treatment.

Discussion

The publications in this review demonstrate a link between self-efficacy, management of symptoms and symptom distress and QOL. The presence of self-efficacy not only predicted higher physical and emotional well-being but also was associated with lower symptom occurrence and symptom distress. This, in turn, leads to better overall health and improved quality of life. Barriers such as impaired cognitive function must be considered when evaluating self-efficacy. While the study by Wu et al. (2012) described in this review discussed impaired cognitive function in those patients having HSCT, it should be noted that other patients who receive chemotherapy treatment are also at risk for impaired cognitive function (Ahles, Root, & Ryan, 2012; Cohen, Shonka, Armstrong, & Wefel, 2014). Other barriers to developing self-efficacy for symptom management include patients having the belief that nothing can be done to alleviate symptoms or difficulty interpreting the cause of the symptom and whether to report them

to their health care provider. However, a barrier to effective symptom management is low or lack of self-efficacy.

Assessment of patient's self-efficacy for symptom management provides a guide for directing care interventions. Instruments are available that are short and convenient for patients to complete either by paper or electronic means (Kelleher et al., 2016). As demonstrated by the few intervention studies selected for this review, more research is needed into effective self-efficacy enhancing interventions that can be tailored for patients or caregivers to use for problem-solving and managing symptoms. The Theory of Symptom Self-Management can be used as a framework to support the development of self-efficacy enhancing interventions (Hoffman, 2013).

Nurses are well positioned to assess patient's self-efficacy and to impact the development of patient-centered interventions to assist patients to manage their symptoms related to cancer and treatment. Nurse led interventions have been shown to be feasible and effective for increasing self-efficacy and decreasing symptom severity and distress. These interventions include not only education regarding symptom management, but mechanisms for patients to communicate and discuss the presence of symptoms. Patients with low self-efficacy may not feel empowered to communicate the presence of symptoms, especially if the symptoms are related to managing emotions such as anxiety or depression, or seem mild in nature. Providing mechanisms for communication of symptom presence followed by education of how to manage those symptoms has the potential to impact distress and QOL. The few intervention studies available to enhance self-efficacy for symptom management in oncology patients is an indication that more research is needed on this topic. Focusing research on a specific phase of treatment such as during chemotherapy, during intensive treatment such as HSCT, or post-treatment, allows for the development of patient-centered interventions.

A limitation of the research on this topic is that except for the studies from China and Taiwan, the patient population was mostly Caucasian. Lack of diversity is a common finding in studies regarding

HSCT patients. The lack of diversity affects the ability to generalize findings and potential development of interventions to other populations. Another limitation of the review findings is the variability of stages of illness of the participants. Studies presented in this review had participants that included those newly diagnosed, undergoing treatment and 1 year or more post-treatment. The studies for HSCT patients were conducted at one-year or later post-HSCT when the potential for symptom burden is less than during the acute phase of transplant. There are no publications that assess self-efficacy during the acute phase of HSCT when symptoms are the most intense. The cross-sectional methodology of some of the selected studies is also a limitation, as self-efficacy has the potential to change depending on phase of treatment and severity of symptoms. A limitation of this review is that the studies selected for inclusion were English language. There may be relevant studies published in other languages that were omitted in this review. Strengths of this review are the use of a framework to guide the selection of studies and analysis and the use of quality appraisal tools specific to the publication type. The inclusion of articles from a variety of countries is also a strength of the review.

Conclusion

Recognizing deficits and intervening to enhance self-efficacy is critical for providing overall care for those cancer patients with presence of symptoms or symptom distress. Targeted interventions to enhance self-efficacy while promoting symptom management behaviors would assist patients in navigating the treatment experience, decrease symptom occurrence, and improve functional status and QOL. Research into interventions that would achieve these goals is necessary to improve QOL for adult patients with cancer.

Figure 1: Flow Diagram of Article Selection

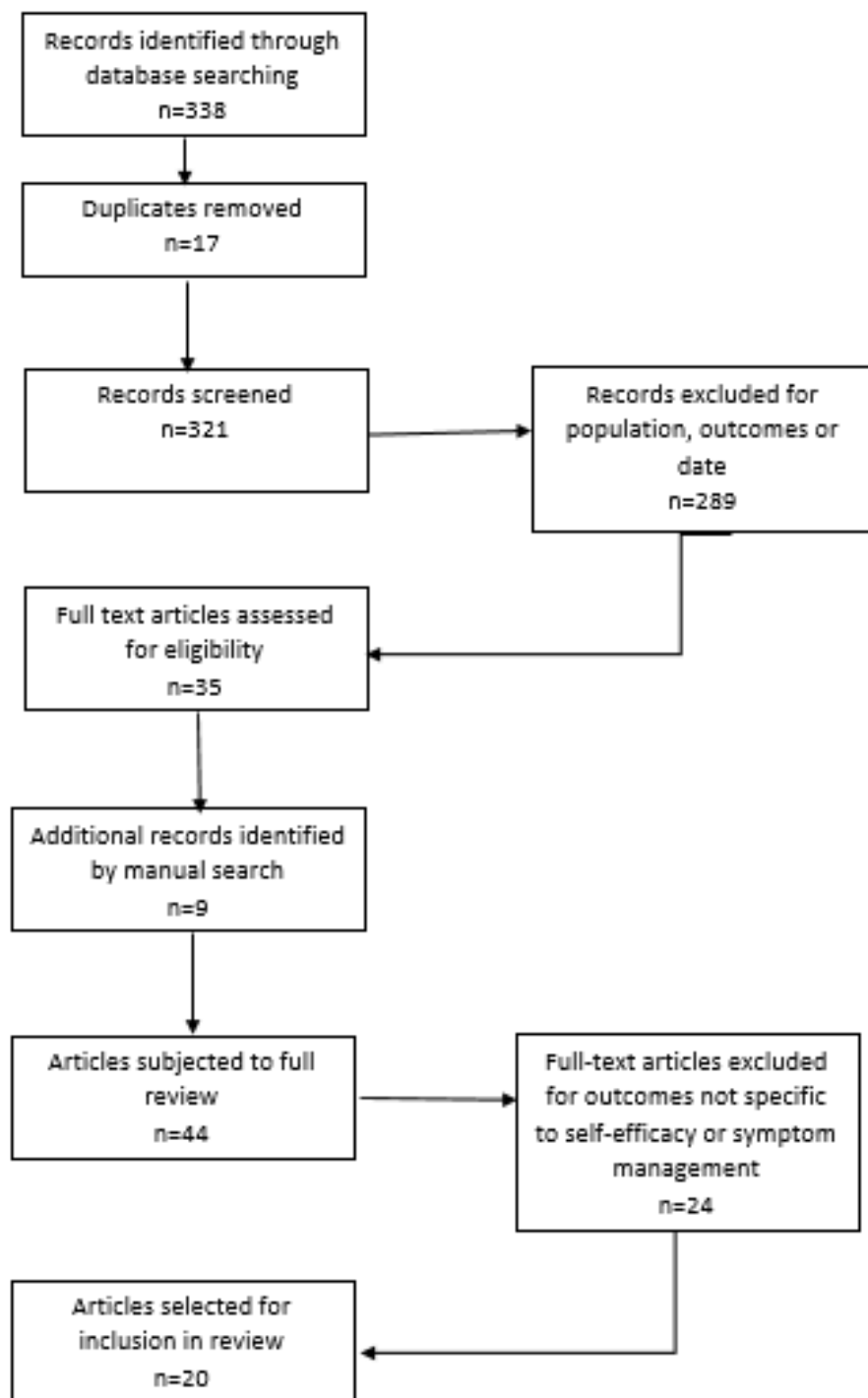


Table 1: Selected Publications

Reference	Setting and sample	Purpose / aim	Methods	Findings
(Bergkvist et al., 2015)	Sweden; Patients who had received an allogeneic HSCT for a hematological disease (median 5 years post-transplant)	Compare general health, symptom occurrence, and self-efficacy long-term survivors of HSCT who had received either home care or hospital care during the early phase after HSCT.	Quantitative; Descriptive Cross-sectional; Survey	No differences in general health, symptom occurrence or self-efficacy between hospital and home care groups High SE was associated with better general health and lower symptom occurrence
(Hochhausen et al., 2007)	United States; Leukemia patients who received an allogeneic HSCT (1-year post-transplant)	Examine effects of pre-HSCT social support, self-efficacy, and optimism in predicting post-HSCT health related QOL	Quantitative; Descriptive Longitudinal; Telephone survey at baseline and post-transplant	Social support, self-efficacy and optimism significantly predicted physical and emotional well-being post HSCT
(Hoffman et al., 2009)	United States; Patients with breast, lung, colon, and other sites of cancer, undergoing chemotherapy and experiencing symptoms of pain or fatigue	Test a theoretical model with the hypothesis that physical functional status is predicted through patient characteristics, cancer-related fatigue, other symptoms, and perceived SE for fatigue self-management	Quantitative; Secondary data analysis; Cross-sectional Survey	Results validated the model; Perceived SE had a positive effect on functional status and served as a mediator between cancer related fatigue and physical functional status
(Hoffman et al., 2011)	United States; Patients with breast, lung, colon, and other sites of cancer, undergoing chemotherapy and experiencing symptoms of pain or fatigue	Describe the development and testing of the Perceived Self-efficacy for Fatigue Management (PSEFSM) instrument	Quantitative; Instrument development	PSEFSM demonstrated reliability and validity and can be used to measure perceived SE for fatigue self-management in the chronic illness population

Reference	Setting and sample	Purpose / aim	Methods	Findings
(Hoffman, 2013)	United States; Cancer patients	Describe how nurses can apply a tested middle-range theory in clinical practice to increase patient's perceived SE	Theoretical model; Exemplars	Nurses can use perceived SE enhancing symptom self-management interventions to improve functional status and QOL of cancer patients
(Hoffman et al., 2017)	United States; Post-surgical patients with non-small cell lung cancer	Investigate effects of an exercise intervention to promote perceived self-efficacy for fatigue self-management	Quantitative; RCT; Surveys in person and telephone pre-surgery, post-surgery, and weeks 1, 3 and 6; weekly diary; functional outcomes pre-surgery, post-surgery, and weeks 3 and 6	Intervention was feasible; intervention group improved in perceived SE for fatigue self-management; fatigability was reduced and mental and physical health components of functional performance in intervention group improved when compared to control group
(Kelleher et al., 2016)	United States; Patients with breast and gastrointestinal cancer	Examine how patient reported outcomes of SE for pain, function and other symptoms were associated with pain, symptom severity and distress, and physical and psychosocial functioning	Quantitative; Descriptive; Cross-sectional; surveys	SE scores for pain and other symptoms correlated positively with pain, symptom severity and distress, and physical and psychosocial functioning Patients with lower levels of SE had poorer outcomes and functioning overall
(Liang et al., 2015)	Taiwan; Women with breast cancer	Develop and evaluate the reliability and validity of the Symptom -Management Self-Efficacy Scale--Breast Cancer (SMSES-BC) in chemotherapy	Quantitative; Instrument development	SMSES-BC has acceptable reliability and validity for measuring symptom-management self-efficacy related to chemotherapy

Reference	Setting and sample	Purpose / aim	Methods	Findings
(Liang et al., 2016)	Taiwan; Outpatients with breast cancer	Examine association between symptom distress and QOL; Propose symptom management SE as a mediator between symptom distress and QOL	Quantitative; Descriptive; Cross-sectional survey	Symptom management self-efficacy mediated the association between symptom distress and global QOL, functional QOL and symptom QOL; Lower symptom distress was indirectly associated with better QOL through higher SE
(Mosher et al., 2016)	United States; Lung cancer patients and their family caregivers	Examine efficacy of a telephone based symptom management intervention	Quantitative; RCT; Survey at baseline, 2 and 6 weeks	No significant differences between groups in symptoms, SE for symptom management or perceived social constraints from the caregiver
(Mystakidou et al., 2010)	Greece; Advanced cancer patients in a palliative care unit	Assess the relationship and influence of demographic and clinical characteristics on SE beliefs	Quantitative; Descriptive Cross-sectional survey	SE significantly correlated with levels of anxiety, physical condition, and demographics; SE is influenced by components of anxiety, age, physical performance, and gender
(Oakley et al., 2010)	United Kingdom; patients treated with oral chemotherapy and health professionals that cared for them	Gain insight into the patient experience; develop understanding of complexities in receiving oral chemotherapy; investigate the use of a diary and the impact on self-medication, symptom management adherence and self-efficacy	Mixed method; Literature review, ethnographic study, feasibility study Participant observation; Informal conversations; Field notes and reflective diary;	Themes of relinquishing control and moderating factors; Trends showed an association between effective symptom management and increased SE

Reference	Setting and sample	Purpose / aim	Methods	Findings
			Formal interviews; Intervention development	
(Papadopoulou et al., 2017)	England, Scotland, Northern Ireland; Patients with breast or colorectal cancer scheduled to receive adjuvant chemotherapy	Explore changes over time in SE and predictive ability of changes in state anxiety and health related QOL during chemotherapy	Quantitative; Descriptive; Longitudinal; Surveys prior to starting chemotherapy and at the start of 6 subsequent chemotherapy cycles	No significant time effects for overall SE; SE significantly associated with decreased anxiety at all time points; Significant relationship between SE and health-related QOL at all time points
(Paterson et al., 2015)	United Kingdom; Men newly diagnosed with prostate cancer	To test social support theoretical model and detail self-management behaviors	Quantitative; Longitudinal; Surveys at baseline and 6 months; Subsample completed diaries	Self-management SE significantly reduced at 6 months; Significant decline in QOL at 6 months post-diagnosis
(Porter et al., 2008)	United States; Patients with early stage lung cancer and their caregivers	Examine SE for managing pain, symptoms, and function; Examine associations between SE and patient and caregiver adjustment	Quantitative; Descriptive; Cross-sectional Telephone survey	Patients low in SE reported significantly higher levels of pain, fatigue, lung cancer symptoms, depression, anxiety, and significantly worse physical and functional well-being; When patients and caregivers both had low SE, the patient had higher anxiety and poorer QOL
(Ruland et al., 2013)	Norway;	Examine effects of an internet-based interactive health communication application on	Quantitative; RCT;	Significant effect on symptom distress;

Reference	Setting and sample	Purpose / aim	Methods	Findings
	Patients with breast or prostate cancer and undergoing treatment	symptom distress, depression, SE, health related QOL and social support	Surveys at 3, 6, 9 12 months	no significant differences in other outcomes
(Shelby et al., 2014)	United States; Women with breast cancer taking adjuvant endocrine therapy	Examine the relationships between physical symptoms, SE for coping with symptoms, and functional, emotional, and social well-being	Quantitative; Descriptive; Cross-sectional; Survey	Higher SE for coping with symptoms was associated with greater functional, emotional, and social well-being after controlling for physical symptoms; SE for coping with symptoms moderated the relationship between physical symptoms and functional and emotional well- being
(Wu et al., 2012)	United States; HSCT survivors with at least moderate distress \bar{x} = 1 year 8 months post-HSCT	Examine whether SE for symptom management mediates relations between subjective cognitive functioning and psychological adjustment and health related QOL	Quantitative; Descriptive; Cross-sectional Survey and telephone interview	Subjective cognitive impairment reduces confidence in ability to manage common post-HSCT symptoms; Better subjective cognitive functioning associated with greater self-efficacy for symptom management, which in turn was associated with less depressed mood. reduced anxiety and better QOL
(Zhang et al., 2014)	China; Colorectal cancer patients diagnosed within the last 6 months	To test effects of a nurse led SE enhancing intervention compared to routine care	Quantitative; RCT; Survey at 3 and 6 months	Intervention group had significant improvement in SE and a reduction in symptom severity, symptom interference, anxiety, and depression.

Reference	Setting and sample	Purpose / aim	Methods	Findings
(Zhu et al., 2017)	Reviewed publications in Chinese and English; Women with breast cancer undergoing treatment	Synthesize studies regarding effectiveness of internet based interactive programs on symptom distress, social support, SE, QOL and psychological well-being	Integrative review	Internet based interactive programs moderated by health care professionals have positive effects on SE, symptom distress, and psychological well-being, but inconclusive effects on social support and QOL

HSCT=Hematopoietic Stem Cell Transplant; RCT = Randomized Control Trial; SE=Self-efficacy; QOL= quality of life

Table 2: Quality Appraisal for Selected Quantitative Studies

Author / date	Did the study address a clearly focused issue	Methodology appropriate	Sample size	Power analysis included	Recruitment strategy appropriate	Response rate %	Instrument reliability / validity reported	Outcome accurately measured to minimize bias	Confounding factors or limitations identified	Data analysis sufficiently rigorous	Clear statement of findings	Can the results be applied to another context
Bergkvist et al., 2015	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Hochhausen et al., 2007	Y	Y	Y	N	Y	Y	Y	Y	y	Y	Y	Y
Hoffman et al., 2009	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Hoffman et al., 2011	Y	Y	Y	N	Y	N	Y	Y	Y	Y	Y	Y
Hoffman et al., 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Kelleher, Somers, Locklear, Crosswell, & Abernethy, 2016	Y	Y	Y	N	Unknown	N	Y	Y	Y	Y	Y	Y
Liang, Wu, Kuo, & Lu, 2015	Y	Y	Y	N	Unknown	N	Y	Y	Y	Y	Y	Y
Liang et al., 2016	Y	Y	Y	N	Unknown	N	Y	Y	Y	Y	Y	Y
Mosher et al., 2016	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y
Mystakidou et al., 2010	Y	Y	Y	N	Unknown	Unknown	Y	Y	Y	Y	Y	Y
Oakley, 2010	Y	Mixed methods	Y	N	Unknown	N/A	N	Y	Y	Y	Y	Y

Author / date	Did the study address a clearly focused issue	Methodology appropriate	Sample size	Power analysis included	Recruitment strategy appropriate	Response rate %	Instrument reliability / validity reported	Outcome accurately measured to minimize bias	Confounding factors or limitations identified	Data analysis sufficiently rigorous	Clear statement of findings	Can the results be applied to another context
Papadopoulou et al., 2017	Y	Y	Y	N	Y	N	Y	Y	Y	Y	Y	Y
Paterson, Robertson, & Nabi, 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Porter, Keefe, Garst, McBride, & Baucom, 2008	Y	Y	Y	N	Y	N/A	Y	Y	Y	Y	Y	Y
Ruland et al., 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Shelby et al., 2014	Y	Y	Y	N	Unknown	N	Y	Y	Y	Y	Y	Y
Wu et al., 2012	Y	Y	Y	N	Y	N	Y	Y	Y	Y	Y	Y
Zhang et al., 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Table 3: Quality Appraisal for Randomized Controlled Trials

Reference	Was the assignment of patients to treatments randomized?	Were all the patients who entered the trial properly accounted for at its conclusion?	Were subjects blind to treatment?	Were the groups similar at the start of the trial? (other factors that might affect outcome)	Aside from the intervention, were the groups treated equally?	How large was the treatment effect? (outcomes measured, primary outcome clearly specified, results for each outcome?)	How precise was the estimate of the treatment effect? (confidence limits)	Can the results be applied?	Were all clinically important outcome considered?	Are the benefits worth the harms and costs?
Hoffman et al., 2017	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
Mosher et al., 2016	Y	Y	N	Y	Y	Y	N	Y	Y	Y
Ruland et al., 2013	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
Zhang et al., 2014	Y	Y	N	Y	Y	Y	N	Y	Y	Y

Table 4: Quality Appraisal for Review Article

Reference	Did the publication address a clearly focused question?	Did the authors review the right type of publications?	Were all important, relevant studies discussed and included?	Did the authors do enough to ensure the quality of the publication?	If the results of the review were combined, was it reasonable to do so?	Were all important outcomes considered?	Clear statement of findings?	Can the results be applied to another context?
Zhu, Ebert, & Wai-Chi Chan, 2017	Y	Y	Y	Y	Y	Y	Y	Y

Table 5: Quality Appraisal for Theoretical Article

Reference	Did origins of the theory refer to its initial development?	Does the meaning relate to the theory's concepts and how they relate to each other?	Does the theory have logical adequacy?	Usefulness: Is the theory practical and helpful to the discipline and provide a sense of understanding or predictable outcome?	Can generalizations be made from the theory?	Parsimony: Can the theory be stated simply while still being complete in the explanation of the phenomenon in question?	Is the theory testable?
Hoffman, 2013	Y	Y	Y	Y	Y	Y	Y

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CHAPTER IV: Manuscript 3

Self-efficacy for Symptom Management in the Acute Phase
of Hematopoietic Stem Cell Transplant

Abstract

Context: Hematopoietic stem cell transplant (HSCT) is an intensive treatment associated with distressing treatment and disease-related symptoms that affect patient outcomes such as functional status and quality of life. Self-efficacy for symptom management (SESM) is a person's belief in their ability to perform behaviors to prevent and relieve symptoms.

Presence of SESM can impact symptom distress and functional status.

Objectives: This study describes the changes over time and relationships among SESM, symptom distress, and physical functional status in adults during the acute phase of HSCT.

Methods: Patients ($n = 40$) completed measures of symptom distress, SESM, and physical function at time points prior to, and at days seven, 15 and 30 post-transplant.

Clinical outcomes were length of stay and number of readmissions.

Results: Symptom distress, physical function, and SESM changed significantly over time.

There was a significant negative relationship between symptom distress and physical function and between symptom distress and SESM at all time points. The lowest levels of SESM and physical function were at day seven when symptom distress was highest.

Symptom distress was a moderator for the relationship between physical function and SESM at day 15.

Conclusion: This is the first study to examine SESM in the acute phase of HSCT. Higher SESM was associated with fewer symptoms and increased physical function. Less symptom distress is associated with higher physical function and confidence to manage symptoms. These findings provide the basis for development of patient-centered

interventions to enhance SESM when symptoms are at their highest immediately after HSCT.

Introduction

Hematopoietic stem cell transplant (HSCT) is an intensive treatment option for some types of cancer. The HSCT process includes conditioning chemotherapy with or without radiation treatments, followed by infusion of stem cells, either from the patient themselves (autologous) or from a sibling or unrelated donor (allogeneic). Disease diagnosis, stage, and donor availability determine transplant type. Regardless of the type of transplant a person receives, treatment-related symptoms are severe and can have significant effects on patient outcomes such as functional status and quality of life (QOL) (Andersson, Ahlberg, Stockelberg, & Persson, 2011; Pidala, Anasetti, & Jim, 2009; Wong et al., 2010). The presence of concurrent symptoms is greater during the first 30 days and along with other factors such as physical, psychosocial, or emotional issues causes symptom distress (Anderson et al., 2007; Bevans, Mitchell, & Marden, 2008; Cohen et al., 2012). Helping patients to manage their symptoms during the intense treatment period immediately after HSCT may improve the symptom experience and influence patient outcomes.

Self-efficacy is the belief of a person in their ability to perform behaviors (Bandura, 1997). Self-efficacy for symptom management (SESM) is the ability to implement behaviors to prevent, recognize, and relieve symptoms in cancer patients (White et al., *in press*). SESM requires not only knowledge and skills, but also cognitive processes, motivation, and confidence (Hoffman, 2013; White et al., *in press*). The relationship between self-efficacy and symptom distress is not known, however, presence of self-efficacy has been linked to better general health, lower symptom occurrence and better physical and emotional well-being after HSCT (Bergkvist et al., 2015; Hochhausen

et al., 2007; Wu et al., 2012). Self-efficacy, measured prior to HSCT, significantly predicted physical and emotional well-being one year after HSCT (Hochhausen et al., 2007). Self-efficacy was associated with decreased symptoms and was a significant predictor of emotional and physical well-being and QOL for those who were one year or more post-transplant (Bergkvist et al., 2015; Hochhausen et al., 2007; Wu et al., 2012).

Patients who undergo HSCT experience high symptom burden and symptom distress (Bevans et al., 2008; Braamse et al., 2014). Symptoms that have been shown to be most distressing are both physical and psychological in nature and include fatigue, weakness, sleep disturbances, worry or anxiety, lack of appetite, bowel problems and pain (Anderson et al., 2007; Bevans et al., 2008; Cohen et al., 2012). Highest symptom intensity occurs between 10 and 14 days after conditioning chemotherapy is initiated and usually return to baseline by day 30 post-transplant (Anderson et al., 2007; Campagnaro et al., 2008). Symptoms usually present in clusters, and have an additive effect, increasing the burden on patients and their caregivers (Cleeland, 2007). Consequences of high symptom burden include decreased survival, depression, delay in treatment, increased hospitalizations, and medical costs (Cleeland, 2007; Gapstur, 2007). HSCT patients with high symptom distress are more likely to be non-adherent with medication regimens, have sleep disturbances, anxiety, and depression, which can lead to increased hospital length of stay (Bevans et al., 2011; Lee et al., 2005; Rischer, Scherwath, Zander, Koch, & Schulz-Kindermann, 2009). Stress from the HSCT process, along with symptom distress has been shown to impact blood count recovery and overall health in the acute phase of transplant (Hobfoll et al., 2015). High symptom distress and inadequate

symptom management has a negative effect on physical and mental health, functional status, and ultimately, QOL (Bevans et al., 2014; Cleeland, 2007; Gapstur, 2007).

Both the Oncology Nursing Society and the National Institute for Nursing Research have identified symptom management as a priority for research (Knobf et al., 2015; National Institute of Nursing Research, 2016). These priority areas include studies of factors that influence the management of symptoms and contribute to the design of personalized interventions. This study of SESM in HSCT patients aligns with these research priorities.

The relationship between SESM and symptom distress in HSCT patients is unknown. The purpose of this study was to describe the changes over time and relationships among SESM, symptom distress, and the outcomes of physical function, readmission, and length of stay during the acute phase (30 days) post-HSCT. The specific aims were:

1. Determine the changes over time in SESM, symptom distress, and physical functional status.
2. Examine the relationships among SESM, symptom distress, and physical function.
3. Determine if the relationships among SESM and length of stay, readmission rates, and functional status varied depending on the level of symptom distress.

Methods

Design and Participants. This was a longitudinal, descriptive, pilot study. After obtaining institutional review board approval (Appendix A and B), participants who were undergoing either autologous or allogeneic HSCT were recruited consecutively from a

single center in the Midwestern U.S. Inclusion criteria were that patients were at least 19 years old and met evaluation criteria for undergoing a stem cell transplant. Exclusion criteria were that the patient did not speak English or could not sign their consent.

Hertzog (2008) suggests a sample size of 20 to 25 for single group pilot studies. The initial enrollment goal was 30 participants to allow for attrition. When enrollment exceeded expectations, IRB approval to increase enrollment was sought and obtained (Appendix C and D). Forty-six patients were eligible for the study. Two were excluded for exclusion criteria and four declined to participate. Reasons for not participating were “not good at answering questions” and “not interested.” The final sample was 40 participants.

After signing consent, participants completed paper/pencil surveys at baseline, which was after admission to the hospital and before beginning the conditioning chemotherapy regimen. Post-transplant time points were at 7, 15 and 30 days after transplant. A brief interview was conducted with the participant at baseline and day 30 to obtain the patient’s perspective on SESM during the transplant process. These results are reported elsewhere (White, Cohen, Berger, Kupzyk, & Bierman, *under review*).

Measures. Variables measured in this study included demographic and clinical data, symptom distress, SESM, physical functional status, length of stay and readmission rates.

Demographic and clinical data. Demographic and clinical data were collected from patients during baseline data collection and from the medical records. Data collected included gender, race, age, employment status, educational level, marital status, the presence of a caregiver, type of disease, type of transplant, comorbidity score, length

of stay for transplant admission, number of readmissions and length of stay for readmission within 30 days after transplant. Comorbidity scores were calculated using the Hematopoietic Cell Transplant-Comorbidity Index (HCT-CI). The HCT-CI score measures health status prior to transplant and considers both comorbidities and age as prognostic factors (Sorrer et al., 2014). The scores were divided into three risk groups; low (0-2), medium (3-4) and high (≥ 5) with a higher score indicating a higher mortality risk (Sorrer et al., 2005).

Symptom distress. Symptom distress was measured using the Symptom Distress Scale (SDS) (McCorkle, 1987) (Appendix F). The tool is a cancer-specific, 13-item self-report questionnaire that uses a one to five scale ranging from no distress to extensive distress to measure the degree of distress from 11 different symptoms that are frequently reported by cancer patients. The symptoms, in order of presentation on the tool, are nausea, appetite, insomnia, pain, fatigue, bowel pattern, concentration, appearance, breathing, outlook, and cough. The remaining two items in the tool assess the frequency of nausea and pain (McCorkle, Cooley, & Shea, 1998). A total score of 25 or greater indicates moderate distress while a score of 33 or greater is considered severe distress (McCorkle et al., 1998). Reliability and validity have been demonstrated previously (McCorkle et al., 1998; Stapleton, Holden, Epstein, & Wilkie, 2015). Cronbach's alpha was .823 at baseline and ranged from .694 - .864 in this study.

Self-efficacy for Symptom Management. SESM was measured using the *Self-efficacy for Managing Symptoms* (SEMS) (Appendix G) and *Self-efficacy for Managing Medications and Treatment* (SEMMT) (Appendix H) instruments selected from the Patient-Reported Outcomes Measurement Information System (PROMIS) Self-efficacy

for Managing Chronic Conditions measures (American Institute for Research, 2016). The PROMIS tools are a collection of tools developed with funding from the National Institutes of Health that use item response theory to measure patient-reported outcomes (Gruber-Baldini, Velozo, Romero, & Shulman, 2017; Jensen et al., 2015). These are newly developed tools and have limited reporting in the literature. Initial calibrations across chronic conditions show good internal consistency and cross-sectional validity (Gruber-Baldini et al., 2017). Reliability estimates have not been reported for the full item banks.

The SEMS instrument has 28 questions with responses on a scale from one (not at all confident) to five (very confident). The instrument includes items that assess persons' level of confidence to manage their symptoms in different settings including hospital and home and to keep symptoms from interfering with activities of life such as work, sleep, relationships, or recreational activities (Patient-Reported Outcomes Measurement Information System, 2015). Cronbach's alpha reliability for this study was .973 at baseline and ranged from .965 - .987 for other time points. The SEMMT has 26 questions with the same scale from one to five. The items assess the person's confidence in managing medication schedules, managing medications in challenging situations, understanding the difference between medication side effects and symptoms, and ability to follow a treatment plan (Patient-Reported Outcomes Measurement Information System, 2015). Cronbach's alpha reliability for this study was .967 at baseline and ranged from .975 - .988 at other time points.

Physical Function. Physical function was measured using the *PROMIS Physical Function – Short Form 10a* (Appendix I). This 10-question form measures self-reported

capability within the domains of role and physical function. Questions are rated on a 5-point scale from “without any difficulty” to “unable to do.” This instrument has been used in research with persons who have cancer and was found to be valid and reliable across age and race-ethnic groups (Jensen et al., 2015). Jensen et al. (2015) reported the Cronbach’s alpha in cancer patients to be from .92 - .96. The same study also reported high convergent validity and discriminant validity. Cronbach’s alpha reliability for this study was .855 at baseline and ranged from .904 - .914 at other time points.

Length of stay and readmission(s). Length of stay, number of readmissions and readmission length of stay were tracked via the medical record and by self-report of participants. Length of stay data were not reported for patients that died prior to or after 30 days post-transplant.

Data analysis

Descriptive statistics were obtained for all variables (means, standard deviations, frequency distributions and percentages). Normality tests were performed and met the assumptions of the statistical tests used in the data analysis in all but one case. Normality was examined with skew and kurtosis indicating non-normality in the SEMS instrument. These data were log transformed for further analysis.

For the first research aim, repeated measures analysis of variance (RM-ANOVA) and paired t-tests were used to examine how SESM, symptom distress and physical function changed over time. Paired samples t-tests were calculated to assess changes in each of the variables between adjacent time points. The second research aim used correlations to examine the relationship between SESM, symptom distress, and physical function. A general linear model was used to examine if baseline SESM predicted

changes in symptom distress and physical function over time. For the final aim, interaction effects between SESM and symptom distress predicting physical function were examined. Interaction plots, with inputs of ± 1 standard deviation to indicate low and high values of distress and self-efficacy, were used to interpret significant moderation of the effect of symptom distress on functional status, length of stay and readmission rates.

Results

The demographic and clinical data are presented in Table 1 and Figures 1 and 2. Approximately half of the sample was female, mean age of 58.27 years (SD = 8.73) at baseline, and the race/ethnic distribution was almost exclusively white. Mean length of stay was 12.84 days (SD 8.33) for both transplant types. Autologous transplant recipient's average length of stay at 12 days, and allogeneic transplants had an average length of stay of 16 days. One person died before 30 days after transplant. The majority were employed full time with the remaining participants retired, on disability or unemployed. At least 70% had greater than a high school education and were married, with their spouse as their caregiver.

Autologous transplant was the most common transplant type, and the most common primary disease was multiple myeloma. The highest number of participants had a comorbidity score in the medium risk range. Over 70% of the participants were not readmitted to the hospital after discharge. At baseline, the most frequently occurring symptoms were fatigue, pain, and insomnia (Figure 1). At days seven and 15, the most frequently occurring symptoms were lack of appetite, fatigue, and bowel changes. At day 30, fatigue, lack of appetite, pain, and changes in appearance were most frequent. Severe

and moderate distress levels were highest at day 7 and day 15 respectively, while the lowest distress levels were at baseline and day 30 (Figure 2).

The first specific aim was to determine the changes over time in symptom distress, SESM and physical functional status. Descriptive statistic means are presented in Table 2 and Figures 3 and 4. At day seven, the mean score for symptom distress peaked, and the means for self-efficacy and physical function were the lowest. For symptom distress, change over time was significant [$F(1.99, 57.64) = 14.94, p < .001$]. There was a significant linear trend ($p = .001$) and a significant quadratic effect ($p < .001$) indicating the slope changed over time. Dependent samples t-tests indicated a significant increase in symptom distress between baseline and day seven, and significant decreases between day seven and 15, and day 15 and 30 (Figure 3; Table 3).

Results from both the SEMMT and SEMS instruments were used to measure SESM. There was a significant change in SEMMT over time [$F(2.6, 75.4) = 5.318, p = .003$]. There was not a significant linear trend, but the quadratic effect was significant ($p = .012$) indicating the slope changed over time. Paired t-tests indicated a significant decline between baseline and day seven, and an increase between day seven and day 15 (Figure 4; Table 3). There was a significant change in SEMS over time [$F(2.8, 80.89) = 7.418, p < .001$] with a significant linear trend ($p = .023$) and a significant quadratic effect ($p = .001$). Paired t-tests indicated a significant decline between baseline and day seven, and increased between day seven and day 15, and between day 15 and day 30 (Figure 4; Table 3).

There were significant changes in physical function over time [$F(2.8, 76.3) = 4.86, p = .004$]. There was not a significant linear trend, but the quadratic effect was

significant ($p = .009$). Paired t-tests indicated a significant decline between baseline and day seven. No differences were found between other adjacent time points (Figure 4; Table 3).

The second specific aim was to examine the relationships between SESM, symptom distress and physical function. Table 4 presents correlation data. Significant negative relationships were found between symptom distress and physical function and between SESM and symptom distress at all time points. A significant positive relationship was found between SEMMT and SEMS at each time point. There was a positive relationship between SESM and physical function at all time points

The final specific aim was to determine if the relationship between SESM, length of stay, readmission rates, and functional status varied depending on the level of symptom distress. No moderating effects of symptom distress were found at baseline, day 7 or day 30. An interaction was found at day 15 between symptom distress and SESM predicting physical function ($p < .01$). The interaction was marginally significant at day seven ($p = .06$). In participants with low symptom distress, higher SESM was associated with higher physical function. In participants with high symptom distress, higher SESM was associated with lower physical function (Figure 5). The moderating effect of symptom distress on the relationship between SEMMT and physical function mirrors that of SEMS shown in Figure 5.

Discussion

This longitudinal, descriptive study examined relationships and changes over time in SESM, symptom distress and physical function for adult patients receiving HSCT. This is the first known report on SESM and symptom distress during the first 30 days

after HSCT. The findings will now be discussed in relation to clinical data and each specific aim and implications for nursing practice provided. Symptoms that caused distress found in this sample are similar to what has been reported in other studies with lack of appetite, fatigue, insomnia, and bowel changes common at day 15 and lack of appetite, fatigue, and insomnia common at day 30 (Anderson et al., 2007; Andersson et al., 2011; Bevans et al., 2008; Cohen et al., 2012). These studies did not report most common symptoms at day seven. Bevans et al. (2008) reported levels of distress in allogeneic transplant patients with the majority at a low level at baseline and 43% moderate to severe levels at 30 days post-transplant. Levels between baseline and 30 days post-transplant are not reported.

The first aim determined that there were significant changes over time in symptom distress which is similar to other studies where symptom distress peaked at day seven and returned to baseline levels by day 30 (Anderson et al., 2007; Cohen et al., 2012; Hobfoll et al., 2015). Physical function also changed over time, which is consistent with studies that show HSCT patients with higher symptom distress have lower physical and mental health status (Anderson et al., 2007; Andersson et al., 2011; Bevans et al., 2014).

SESM was measured using two instruments: the SEMS and SEMMT. Using each tool contributed to a complete picture of SESM that included not only managing symptoms with medications and a treatment plan (SEMMT), but also judgment regarding symptom management, recognizing and managing new symptoms, and performing daily activities or living a normal life, despite having symptoms (SEMS). SESM was lowest when symptom distress was the highest, a time when management of symptoms is vital

for outcomes. Changes over time in SESM have not previously been studied during the acute phase of HSCT.

The second aim found significant relationships between SESM, symptom distress and physical function during the acute phase of HSCT with higher SESM associated with fewer symptoms and increased physical function. These findings are consistent with results from other studies on HSCT patients, in which high self-efficacy was associated with better general health and lower symptom occurrence and self-efficacy predicted greater physical well-being (Bergkvist et al., 2015; Hochhausen et al., 2007). However, the timing of these studies was between one and five years post-transplant. Wu et al. (2012) reported in patients who were greater than one-year post-transplant, better subjective cognitive functioning was associated with greater self-efficacy for symptom management and led to less depressed mood, reduced anxiety, and higher QOL. Other studies examined self-efficacy and symptoms and found those with lower levels self-efficacy reported higher symptom severity and distress, levels of pain, fatigue and worse physical condition and performance (Kelleher, Somers, Locklear, Crosswell, & Abernethy, 2016; Mystakidou et al., 2010; Porter, Keefe, Garst, McBride, & Baucom, 2008). These studies were in patients with cancer, not receiving HSCT and not during acute treatment or hospitalization. The results of this study are significant in that they confirm that SESM impacts symptom distress during the acute phase of transplant.

For the final aim, there was an interaction present between the moderator variable of symptom distress, SESM and physical function at day 15. In participants with low symptom distress, high SESM was associated with higher physical function. Having less symptom distress has an impact on overall feelings of health and physical function and

may increase confidence to manage symptoms. This interaction was only present at day 15. This may be due to symptom distress being at the highest level at day 7. When patients feel their worst, as they were when their symptom distress was highest at day 7, they may be unable to participate in symptom management activities. By day 15, patient's symptom distress is starting to lessen, and physical function and self-efficacy are improving resulting in the moderation effects seen here. This conclusion is verified by the patient's perspective as patients described feeling too poorly to participate in their care (White et al., *under review*). For example, when talking about his symptoms, one patient stated, "I was sicker than a dog...there was no way I could have pulled myself through or anything I could have done to make myself feel better." Another patient stated, "it didn't matter what I did, I just felt horrible" and "for a long time in this process I was not self-sufficient, and that's tough." As patients improve (day 15), the interaction between symptom distress, SESM and physical function may be more apparent and then return to baseline levels as symptoms lessen by day 30.

Evidence shows that interventions to reduce distress improve patients' ability to follow treatment regimens and improve outcomes of care (Holland & Alici, 2010). Patients are being discharged from the acute care setting earlier and effective symptom management is essential. Patients are expected to manage their symptoms and treatment plans, but not all are able to do so. Having a plan of care that includes assessment of SESM before HSCT will allow for patient-centered interventions to enhance SESM and reduce symptom distress. Using the results from the assessment, multidisciplinary interventions that are patient-specific can be developed. These could include focusing on areas that impact SESM such as symptom awareness, feelings of anxiety, stress, or

depression, setting goals and acting to meet them, in addition to knowledge of how to manage treatment regimens and communication with care providers (White et al., *in press*). The interventions would be targeted toward the patient's need, whether it be coaching, finding resources, or education for the caregiver. Ideally, implantation of these interventions would occur when symptom distress is low, as high physical and psychological symptom distress is a barrier to SESM (Wu et al., 2012).

Limitations

This study was a single-center study with a small sample size. Most of the participants received autologous transplants. Allogeneic HSCT patients tend to have more severe symptoms and a longer recovery time (Wong et al., 2010). Another limitation is the lack of ethnic diversity, which is common in clinical care and HSCT studies (Baker et al., 2009; Schriber et al., 2017). This makes the generalization of study results difficult. White, non-Hispanic, and married persons tend to score self-efficacy at higher levels (Gruber-Baldini et al., 2017).

Strengths

To the author's knowledge, this is the first study that has used the PROMIS self-efficacy tools to measure SESM in the HSCT population. The combination of the SEMS and SEMMT instruments for measuring SESM provided a more comprehensive view of the concept. The participation rate was high with 87% of patients approached consenting to the study. The questionnaire completion rate was 144 out of 160 data points (90%), with most of the missing data due to participants being too ill to complete the surveys. Symptom and SESM data from these patients would have been valuable as their symptom experience was likely more severe.

This is the first study found to examine SESM in HSCT patients and has established the relationship between SESM, symptom distress and functional status in the acute phase of HSCT and provides a foundation for future intervention research. Enhancing SESM during all phases of transplant, but especially when symptoms are at their most distressing, has the potential to improve symptom management and ultimately patient outcomes. For HSCT patients with severe symptoms and complex treatment regimens, nurses can assess and implement patient-centered interventions to enhance SESM. Facilitation of self-efficacy will enable patients to manage their symptoms effectively and lead to improved outcomes including functional status, QOL, and decreased utilization of health care resources.

Table 1: Demographic and Clinical data (N=40)

Demographics (Baseline)		N	%
Gender	Women	18	45
	Men	22	55
Race	White	39	97.5
	Non-white	1	2.5
Employment	Full time	27	67.5
	Disability	4	10
	Retired	8	20
	Unemployed	1	2.5
Education	Upper secondary (10-12)	10	25
	Post-secondary (Vocational)	15	37.5
	Associate's Degree	2	5
	Bachelor's Degree	10	25
	Post graduate Degree	3	7.5
Marital Status	Married	28	70
	Single	6	15
	Divorced	5	12.5
	Widowed	1	2.5
Caregiver	Spouse	28	70
	Family member	6	15
	Friend	4	10
	None	2	5
Primary Disease	Acute Myelocytic Leukemia	9	22.5
	Acute Promyelocytic Leukemia	1	2.5
	Lymphoma	9	22.5
	Myelodysplastic Syndrome	1	2.5
	Multiple Myeloma	20	50
Transplant Type	Autologous	29	72.5
	Allogeneic		
	Related Allogeneic	7	17.5
Unrelated Allogeneic	4	10	
Comorbidity Score	0-2	9	22.5
	3-4	19	47.5
	≥ 5	12	30
Readmissions*	0	29	72.5
	1	6	15
	2	1	2.5

* 3 patients were not discharged at 30 days post-HSCT; 1 patient was deceased.

Table 2: Descriptive Statistics Means (SD) at all time points

Instrument	Baseline	Day 7	Day 15	Day 30
SDS	11.85 (6.83)	17.55 (8.20)	13.64 (7.85)	10.19 (6.17)
Physical Function	42.06 (7.84)	36.61 (7.44)	38.61 (8.93)	40.03 (8.56)
SEMMT	45.81 (8.63)	42.90 (8.66)	45.69 (8.60)	47.57 (10.46)
SEMS	47.29 (6.73)	44.48 (5.21)	46.58 (6.28)	48.75 (7.94)

Abbreviations: SDS = Symptom Distress Scale; SEMMT = Symptom Management for Managing Medications and Treatments; SEMS = Self-efficacy for Managing Symptoms

Table 3: Dependent Samples t-tests (p-values) at all time points

Dependent Samples t-tests (p-values)				
Instrument	Baseline – Day 7	Day 7-15	Day 15-30	Baseline-Day 30
SDS	<.001*	.003*	<.001*	.083
Physical Function	<.001*	.187	.426	.107
SEMMT	.044*	.031*	.157	.430
SEMS	.008*	.027*	.024*	.406

Abbreviations: SDS = Symptom Distress Scale; SEMMT = Symptom Management for Managing Medications and Treatments; SEMS = Self-efficacy for Managing Symptoms

**Table 4: Correlation between symptom distress, physical function, and self-efficacy
Correlation to SEMS scale r(p)**

		Physical Function	SEMMT	SEMS
Symptom Distress	Baseline	-.530** (.001)	-.324* (.044)	-.605** (<.001)
	Day 7	-.499** (.004)	-.320 (.065)	-.469** (.005)
	Day 15	-.677** (<.001)	-.272 (.120)	-.614** (<.001)
	Day 30	-.463** (.007)	-.439* (.011)	-.602** (<.001)
Physical Function	Baseline		.268 (.094)	.367* (.020)
	Day 7		.265 (.150)	.376* (.037)
	Day 15		.136 (.457)	.539** (.001)
	Day 30		.331 (.060)	.526** (.002)
SEMMT	Baseline			.541** (<.001)
	Day 7			.655** (<.001)
	Day 15			.559** (.001)
	Day 30			.757** (<.001)

** Correlation is significant at the .01 level (2-tailed).

* Correlation is significant at the .05 level (2-tailed).

SEMMT = Self-efficacy for Managing Medications and Treatments; SEMS= Self-efficacy for Managing Symptoms Scale

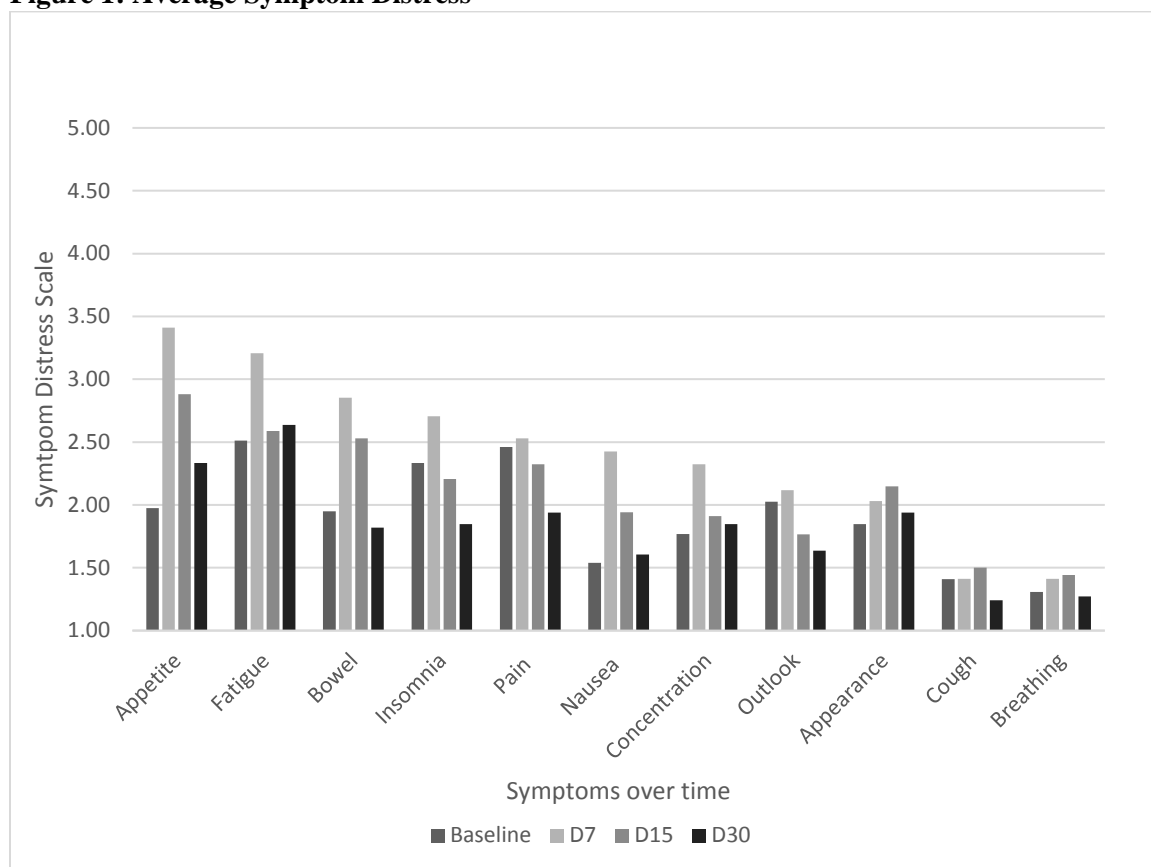
Figure 1: Average Symptom Distress

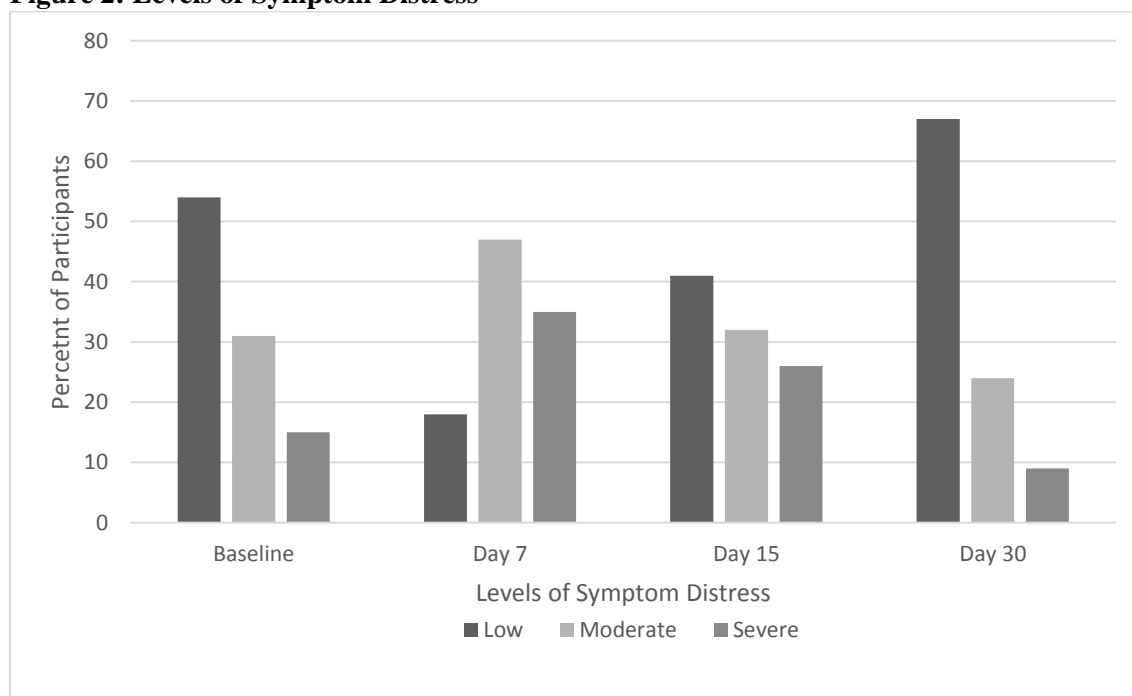
Figure 2: Levels of Symptom Distress

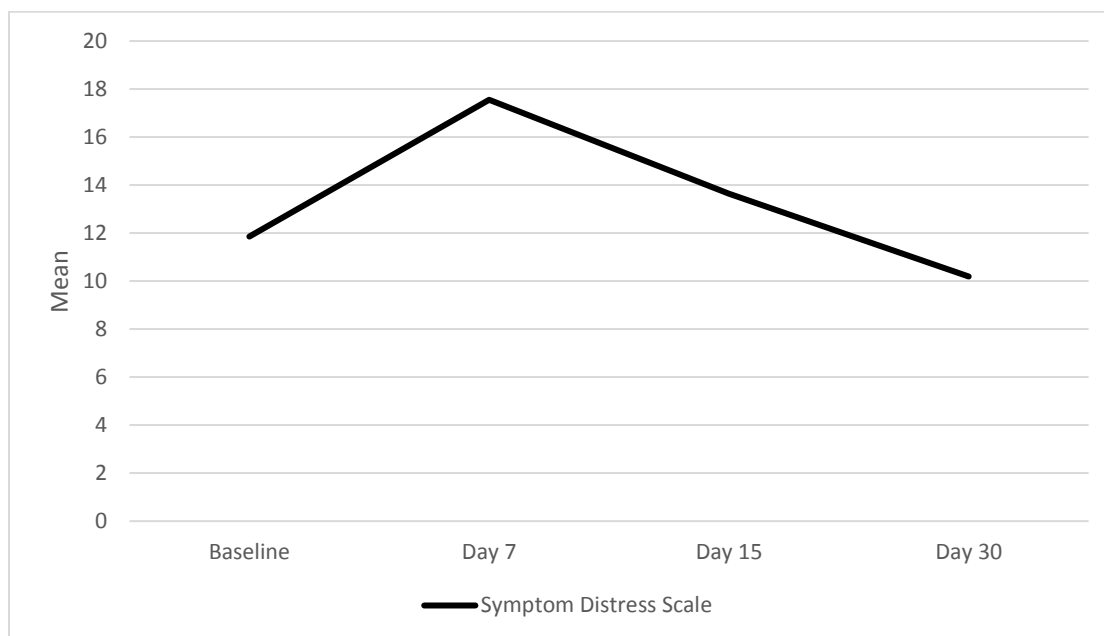
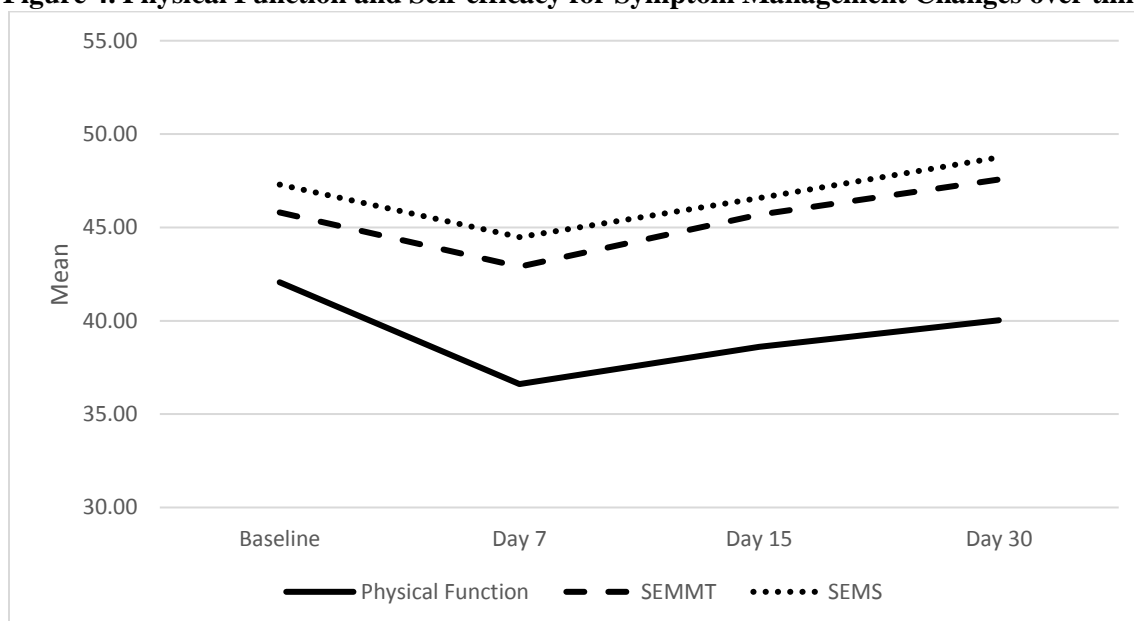
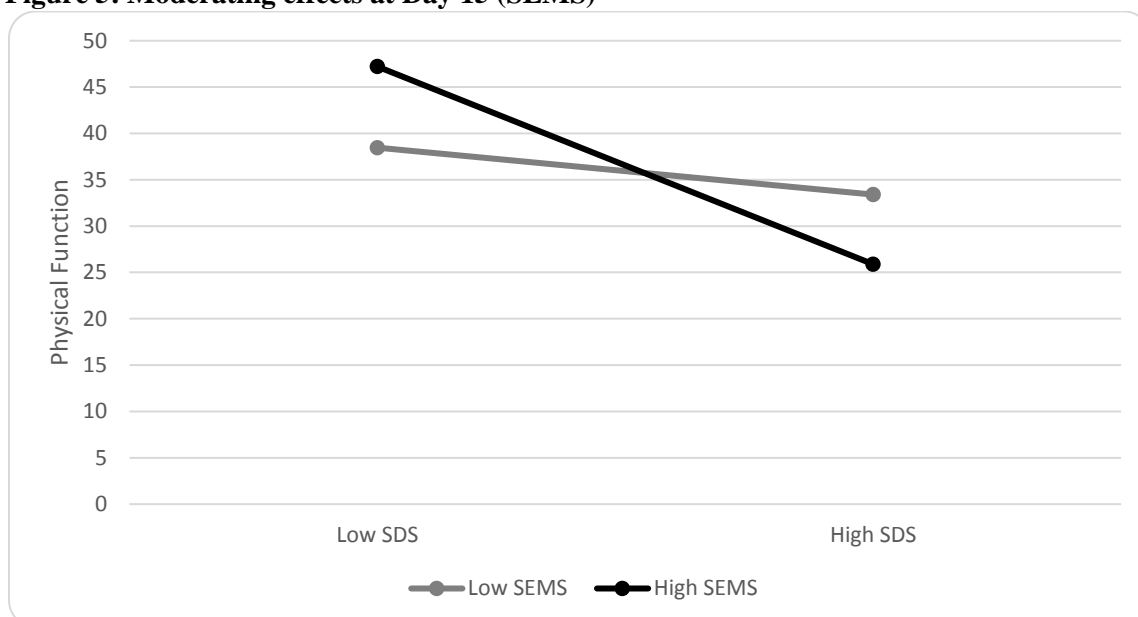
Figure 3: Symptom Distress Changes over time

Figure 4. Physical Function and Self-efficacy for Symptom Management Changes over time



SEMMT = Self-efficacy for Managing Medications and Treatments; SEMS = Self-efficacy for Managing Symptoms

Figure 5: Moderating effects at Day 15 (SEMS)

SEMS = Self-efficacy for Managing Symptoms, SDS = Symptom Distress Scale

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CHAPTER V: Manuscript 4

The Meaning of Self-efficacy for Symptom Management in the Acute Phase of Hematopoietic
Stem Cell Transplant

Abstract

Background: Hematopoietic stem cell transplant (HSCT) is an intensive treatment that offers the potential for longer life or cure for some types of cancer. HSCT is associated with decreased quality of life (QOL), functional status and distressing symptoms. Self-efficacy for symptom management (SESM) is a person's belief in their ability to implement behaviors to manage these symptoms. Presence of SESM can affect symptom distress, health care utilization and post-transplant outcomes.

Objective: The purpose of the study was to explore the meaning of SESM in adults during the acute phase of HSCT.

Methods: Interviews were conducted prior to and at 30 days post-transplant. Descriptive thematic analysis was performed on verbatim interview transcripts.

Results: Themes of confidence, being responsible, and caring for mind, body, spirit were identified with subthemes of self-confidence, confidence in other, confidence and symptom level, vigilance, self-advocacy, and normalcy. Participants reported having high SESM pre-transplant, and having much less or no SESM when symptom distress was the most severe.

Conclusions: This is the first study to examine the patient's perspective of self-efficacy in the acute phase of HSCT. This contributes to existing literature on the concept of symptom management and expands nursing knowledge of SESM in patients undergoing HSCT.

Implications for Practice: Nurses can assess SESM prior to transplant and implement interventions to enhance SESM when symptoms are at their most distressing after HSCT. The findings from this study can provide the basis for creating behavioral interventions to enhance self-efficacy for symptom management in HSCT patients.

Introduction

Hematopoietic stem cell transplant (HSCT), also known as a stem cell or bone marrow transplant, is a treatment that offers the potential for an extended length of life and cure for some types of cancer. HSCT is an intensive treatment that is associated with decreased health-related quality of life (QOL) and functional status along with distressing symptoms (Larsen, Nordstrom, Ljungman, & Gardulf, 2007) Patients can receive donor stem cells either from themselves (autologous) or from a sibling or unrelated donor (allogeneic). The type of disease the person has along with the stage and donor availability dictate the type of transplant. The HSCT process consists of evaluation testing and donor selection, intensive chemotherapy and possibly radiation treatments, the stem cell reinfusion (transplant), and is followed by a recovery period. The acute phase of HSCT, which is the first 30 days after transplant, is when the greatest risk for complications exists and when symptom distress is the most severe. Patients often are discharged from the hospital setting within 30 days after transplant and expected to self-manage symptoms. Self-efficacy for symptom management (SESM) is vital during this time as prevention, recognition and symptom relief during this time can be a complex process.

Background

Self-efficacy is a key component of the management of symptoms. Self-efficacy is a person's belief in their ability to implement behaviors to achieve a desired outcome (Bandura, 1986). Self-efficacy includes not only the confidence, but also the knowledge and skills, motivation, and competence to perform the behavior under diverse circumstances (Hoffman, 2013). Studies have shown that cancer patients and those receiving HSCT who have high self-efficacy experience lower levels of pain, fatigue, and psychological distress and better general health and QOL (Bergkvist et al., 2015; Porter, Keefe, Garst, McBride, & Baucom, 2008). Cancer patients with lower levels of self-efficacy have been shown to have higher levels of pain, fatigue, depression, anxiety and poorer functioning and overall outcomes (Kelleher, Somers, Locklear, Crosswell, & Abernethy, 2016; Porter et al., 2008).

Symptom management is a process that is dynamic and multidimensional (Fu, LeMone, & McDaniel, 2004; White et al., *in press*). Self-efficacy for symptom management (SESM) is the ability to implement behaviors to prevent, recognize, and relieve symptoms in cancer patients (White et al., *in press*). SESM can be changed or influenced, in a positive or negative way, because of the dynamic state of the disease process, and the intensity of the transplant process. SESM plays a key role in outcomes for HSCT patients as symptom management affects symptom distress, QOL, and health care utilization.

Many publications describe self-efficacy in cancer patients, but limited literature has been published on self-efficacy in HSCT patients (Bergkvist et al., 2015; Hochhausen et al., 2007; Wu et al., 2012). This study fills a gap in the literature regarding the meaning of SESM for patients undergoing HSCT. The purpose of this study was to explore the meaning of SESM in adults during the acute phase of HSCT.

Methods

Patients in this study were part of a longitudinal descriptive study that examined the relationship between SESM and symptom distress during the first 30 days after HSCT. After obtaining approval from the Institutional Review Board (Appendix A and B), patients who were receiving autologous or allogeneic transplant were recruited consecutively at a single center. Eligibility requirements for inclusion in the study were those receiving a transplant who are at least 19 years of age. Exclusion criteria included not speaking English and not being admitted to the hospital for the transplant. Forty-six patients were eligible for participation in the study. Two were excluded for exclusion criteria, and four declined to participate. Reasons for not participating were “not good at answering questions” and “not interested.” The final sample was 40 participants. The portion of the study reported here used qualitative descriptive methodology and analysis was guided by thematic analysis (Braun & Clarke, 2006; Sandelowski, 2000; Willis, Sullivan-Bolyai, Knafl, & Cohen, 2016).

After participants had signed consent forms, the principal investigator (PI) conducted interviews using open-ended scripted questions to ensure a standardized approach (Table 1). Interviews were conducted at baseline (prior to transplant) and 30 days after transplant. The baseline interview was conducted in person, in the participant's hospital room shortly after admission, but before initiation of the transplant chemotherapy regimen. If a caregiver was present, they were given the option to stay for the interview. All post-transplant interviews were completed via telephone, except for two interviews that were completed in person. All interviews were digitally recorded and professionally transcribed verbatim. The PI verified the accuracy of the transcription. The PI performed analysis with close consultation and recommendations by the second author and verification by the interdisciplinary team. The researchers used the descriptive analysis process outlined by Braun and Clarke (2006) to identify codes and search for themes within the data. Themes were developed using multiple readings, examining entire transcripts, and underlining and labeling passages with theme labels. Themes were reviewed, defined, and named, and compared across factors such as the type of transplant and time of interview (pre- and post-transplant).

Results

Demographic and clinical data

A total of 70 interviews from 40 patients were analyzed. Missing interviews were due to patient death before 30 days (1), too ill to participate (4) and declined the final interview (5). Demographic and clinical data were obtained from the participants and the electronic medical record. Study participants ranged in age from 29 to 72 years with a mean of 58.27 years (SD 8.73). Eighteen (45%) were women, 22 (55%) men, and 39 (97.5%) were white. While 27 (67.5%) were employed full-time, the remainder were retired (8, 20%), on disability (4, 10%) or unemployed (1, 2.5%). Educational levels were high school (10, 25%), post-secondary/vocational and associate's degree (17, 42.5%), and baccalaureate or post-graduate degree (13, 32.5%). The majority were married (28, 70%) and their spouse was their primary caregiver.

Most participants received an autologous stem cell transplant (n = 29, 72.5%), and 11 received an allogeneic stem cell transplant (related = 7, unrelated = 4). Cancer diagnoses were multiple myeloma (20, 50%), leukemia (10, 25%), lymphoma (9, 22.5%), and myelodysplastic syndrome (1, 2.5%). Comorbidity scores were calculated using the Hematopoietic Cell Transplant Comorbidity Index (HCT-CI), which is a measure of health status that indicates mortality risk after HSCT (Fred Hutchinson Cancer Research Center, 2017; Sorror et al., 2014). The score considers both comorbidities and age with a higher score indicating a higher mortality risk. Twelve (30%) of the participants were considered high risk with a score of 5 or greater, 19 (47.5%) had a score of 3-4, and 9 (22.5%) were in the low-risk group. The average length of stay in the hospital after HSCT was 12.84 days (SD 8.33). Most of the participants were not readmitted to the hospital after discharge (29, 72.5%). Six patients (15%) were readmitted one time, and one patient was readmitted twice.

Themes

The meaning of SESM was described as confidence both in one's self and in others. Confidence included levels pre- and post-transplant as symptom distress varied. Level of confidence was the only aspect that differed from pre-to post-transplant. Responsibility included vigilance and advocacy. Caring for mind, body and spirit was identified as a theme and includes normalcy. Themes were consistent between autologous and allogeneic transplant. Table 2 outlines the themes, subthemes, and further description follows.

Theme: Confidence

Self-confidence. When asked what SESM meant to them, the participants responded in ways that reflected their confidence and perspectives on managing symptoms. Several participants described the meaning of SESM in relation to the amount of confidence they felt, "I'm pretty confident in my ability to care for myself", and "I'm confident in explaining my symptoms maybe, to a nurse, if I have a problem and how I feel about it; if I'm anxious about it." Another participant felt less confident after transplant, explaining, "I'm not real confident on the

symptom side. I can describe what happened. I just don't know why it happened or what I need to do to correct it." The dynamic state of the disease and transplant process was also a factor in confidence, as reflected in the statements of "It's the uneasiness of what is happening, what the hell is happening, you know, uncertainty. That is when I don't say I lose my confidence; it's shaken" and "Anybody who says their confidence isn't tested is not being honest with themselves, I think." A 48-year-old woman who was discharged and then developed an infection in her bowel described her experience as:

My confidence at home was getting pretty drained. There wasn't much left. When my doctor said he wanted to admit me, I was like almost relieved at that point because I knew that I wasn't at that point taking care of myself the way I needed to be taken care of.

Post-transplant participants described their sense of SESM in relation to the environment, whether in the hospital or at home after discharge. While some participants felt that SESM was no different in the hospital than at home, others felt that the hospital was too controlled. One person described being "micromanaged" in the hospital setting. Another described it in this way:

You feel like you don't really have control over your own health because they don't really allow you to in a sense...take this pill when you are scheduled to...and this is hospital policy and we do it at this time and blah blah, but when you get out, you are able to make your own schedule and do it the way you want- still right, still 12 hours apart but maybe not at 7 a.m. and 7 p.m., but now it's 9 a.m. and 9 p.m. because that's better for me.

Another participant, a 61-year-old female autologous recipient, spent 14 days in the hospital post-transplant. She discussed her sense of confidence in her SESM as being limited by the nursing staff, stating:

The nurses...some of them were so over-zealous that I felt like they took away my sense of self-efficacy. They were just so eager to – ‘don’t do this without buzzing. Don’t do this.’ I know that there’s safety issues, understandable, and they didn’t want me to fall, because obviously I was weak and everything, but sometimes I just felt this sense of hovering.

One’s environment and feelings of control have an impact on self-confidence, both pre- and post HSCT. Participants described feeling that they needed to take control of themselves, that they do not have or had lost control, or that they wanted control. Specific statements included “Before this happened, I was an extremely healthy 52-year-old. I’m not anymore, and now all of the sudden you’re in a situation where you’re out of control. Cancer controls it, you don’t” and “It’s very frustrating, when you lose control.”

Confidence in others. Another aspect of confidence is in relation to those who are caring for the HSCT recipients, both professional providers and non-professionals, such as spouses or family members. The need for, and presence of confidence in their health care team was expressed as, “I have a good feeling about it, mainly because of the confidence in my doctor,” and “I felt confident in my care team, that they were on top of it and listened to me and reacted properly and promptly.” Others related their confidence in relation to their support systems stating, “All my family and friends are here...you gotta [sic] have a support team” and “Part of symptom management is also relying on the support of your family.” A 66-year-old man talked about discussing symptoms with his wife. He described how he felt lightheaded one day and said “and so I collaborated with my wife on that, but if I had to think of that myself, I’d have never got there. So, it’s nice to have somebody like that here.”

Confidence and symptom level. When responding to the question about how much SESM they had prior to HSCT, participants expressed either they had a high level or a lot (25), were ambiguous in their response (10), or did not give a direct answer (5). Those with high SESM stated “I have the utmost confidence” and “I have all the confidence in the world.” Others were

not as certain in their response, stating, “I’m hoping I’m good” and “Now it’s getting kind of real, so, I don’t know.” Participants provided examples of how they had managed symptoms prior to transplant. These included examples of symptom recognition such as “I’ve come to a point now going through chemo that I recognize something’s going to happen and then I say here we go.” One 68-year-old female who worked as a housekeeper described that she had high SESM because she could tolerate symptoms stating, “A little pain is not going to bother me. It doesn’t bother me. I’ve been known to – I walked around with a broken arm in two places for six weeks. I just kept working.”

Post-transplant level of confidence varied depending on the transplant experience and amount of symptom distress. For some, the experience was not as difficult as expected with comments such as “I thought I got along pretty good, better than I thought” and “I would say it went pretty smooth, things went like I expected they would have.” However, more often, participants described their level of confidence as low when their symptoms were the most distressing. These participants described their experience as: “You know you should be able to do something about it but you can’t”, “I didn’t have as much [SESM] as I thought I would due to the fact it affected me so bad”, “I tell myself I’m going to feel good, and the only time that didn’t work was when...I had an infection, there was no way I could have pulled myself through it”, “I would have liked to have done more for myself, and I was just so weak.” A 59-year-old female explained:

You just don’t feel good and there’s not much you can do about it. Then, toward this last week or so, you feel better because you’re starting to feel better and then you can do things or set little goals for yourself... Again, it’s like as you felt better, then you were more confident in what you could do.

A 63-year-old female who stated she had a high level of SESM prior to transplant stated, “Beginning before I got sick, I had a lot of confidence, but then once I got sick and got all these infections, I was pretty much just at everybody else’s mercy. I had no self-confidence at all.”

Other participants commented in similar ways saying, “I always have self-confidence that I can manage my own symptoms and there was a point in time there where I didn’t feel that way” and “When you don’t feel well, nothing’s well, and that’s kind of a broad statement, but it takes it all in.”

When describing the meaning of SESM from the post-transplant perspective, participants elaborated on their symptom experience. Symptom recognition and presence is key to SESM. The symptoms mentioned varied widely in type and severity. Most commonly discussed, in order of frequency, were fatigue, lack of appetite, diarrhea, having an infection and/or fever, changes in taste and weakness (Table 3). In addition to relating specific symptoms, some participants described general feelings of being unwell. A 59-year-old male who worked in a professional role described his experience as:

You just sit there, and I was unable to read because I couldn’t concentrate from the chemo or from whatever, and they said that was normal, so I couldn’t read a book. I had no interest in watching TV, and I ended up just sitting there for days, what felt like five, six days, and I suppose I would doze off and on. They didn’t want me in bed. They wanted me sitting and up and moving because they thought that would help my recovery, and I’m sure it did, so I tried to stay out of bed, but I just didn’t have any interest in doing anything. I just kind of sat there.

One participant described it as “Bam, and pardon my words, you feel like crap, you literally feel like crap...it doesn’t matter what you do, it’s not going away.” Another verbalized it as:

It was fatigue and just an overall blah feeling. I had no pain. I really wasn’t nauseous. I just have never felt so bad. I can’t explain it. In all the things that I’ve had, I guess I always equate pain with how I feel, and this was not painful, but at the same time, I’ve never felt so rotten in my life, and it just went day after day after day.

One participant described her experience with mucositis after allogeneic transplant as:

The worst thing was the mucositis, it was really bad. I didn't eat, couldn't talk, couldn't do anything besides get some pills down, and that was because I had to force myself. I literally would cry when I took them.

Theme: Responsibility

While confidence is a key component of SESM, responsibility and follow through are also important. Being responsible was identified as a theme as participants discussed how they view responsibility for care, advocacy, and symptom awareness.

Participants described the meaning of SESM as being responsible, which included understanding, communication, and follow through. Participants stated SESM is “to express what I feel and know what my symptoms are” and “to be able to take care of the symptoms myself, recognize them and maybe do treatment for them.” Two other participants noted: “I know I'm ultimately responsible, that I can't expect everybody else to just do it” and “owning my response to the symptoms and the procedures and following through with what needs to be done.” Others viewed SESM looking toward the future saying, “it means to manage what I can, because I do what I need to do knowing that if I don't, then it's going to cause something down the road” and “if we don't manage the symptoms, we're not going to get better. We're going to get worse, and if we get worse, we don't have anybody to blame but ourselves.”

Post-transplant responses were reflective of the HSCT and the responsibility of managing the treatment regimen. Participants gave examples of how they demonstrated SESM after HSCT, both before and after discharge from the hospital. Managing medications was a common response, with one participant stating, “I keep asking to get off some of the drugs, because I'm taking more medication than I want to take.” Another talked about the complexity of the medication regimen:

I've actually got a spreadsheet for my med list, for my nausea meds and this and that, so if I do go on them, I can keep track of what time of the day I took which one and all this and that.

Vigilance. Participants talked about being aware of their bodies, changes, and symptom recognition both pre-and post-transplant. A 50-year-old male participant described the meaning of SESM to him as “I’m watching for any infection or anything, something that might be out of line.” Post-transplant comments included “I’m tired, but I think it’s me learning to be more aware of – and not only being more aware but also acting upon, knowing when I’m fatigued”, “I’ve stayed on top of it in terms of knowing what my body is, I take my temperature and my blood pressure a couple times a day, so I’m pretty comfortable knowing if something goes wrong” and “I ask myself - do I recognize the symptom as being a symptom or is it severe enough to report?” A young woman, age 29, explained, “I’m just aware; I recognize, I kept myself aware of what to look for and I get scared because I guess I not only have to care for myself, but I have to care for my kids too.”

Self-advocacy. Having self-efficacy for a behavior such as symptom management includes being able to advocate for one’s own needs. The theme of self-advocacy was repeated pre-and post-transplant by these participants as “It means to be sure to relate to them [health care team] my symptoms and keep things clarified and that both parties involved understand each other for the best outcome” and “I’m not afraid to ask questions to find out the answers and carry through with it.”

Some participants were very explicit in their belief in their self-advocacy stating, “If I need to speak up for any help that I need, I’m not afraid to do that. I will self-advocate” and “I am my own advocate. How about that? I am my own advocate. Because you have to be able to stand up for yourself.” When describing how he had developed SESM, a 69-year-old man stated, “Now any time my body changes or something changes, I speak up right away. I used to just keep it in and go through it, but now things are a little bit more complicated, so I speak up.”

Theme: Caring for mind, body, and spirit

Several participants described psychological and spiritual aspects of the meaning of SESM in addition to the physical. Descriptions included attitude, seeking to be normal again, taking their mind off their symptoms, and a holistic approach, in addition to acceptance and coping. They described how having a positive attitude affected how they managed symptoms as “My ability to accept what I’ve got to deal with and the way that I approach it with my attitude”, “To me, it’s about having a positive attitude, I can manage my symptoms by telling myself that I’m going to be better”, and “I think you have to have the right attitude, which gives you the confidence to look forward to your journey.” One participant talked about avoiding negative thoughts: “I just don’t dwell on the negative. I do give myself time to grieve about issues, which I think is very important, but try not to go past that five-minute pity party.” Two participants talked about the difficulties of managing their mindset stating, “This is the hard part. The head. Keeping my head straight. I know the physical part is taken care of” and “Because I’ve always been a tough guy and just, you know, and I got real frustrated because I couldn’t take it.” A 58-year-old male stated post-transplant that:

I went in there with a fighter’s attitude and I think that’s a good thing, because a little while there a person would usually want to give up, but I didn’t want to do that. I want to be around for my family. I mean, there was a tough time there for a bit, but I think I tried to use my positive mental attitude to fight through it and it made me a lot more spiritual than I’d ever been before.

One participant described a holistic approach to SESM stating, “You know you can’t just do the medical part. You have to do the mind, the spirit, the body. You have to do it all, and I’ll never forget that.” Another participant stated post-transplant that “It changes you physically and it changes you mentally, as well. Hopefully, it’s mostly for the best.”

Participants described symptoms that affected mind and body. One person described his change in appearance as “I look in the mirror, and I see no hair. That’s what I see. Hey look, a reminder of what you have.” Other responses included “I get moody or angry for no reason...my family notices this and it’s hard”, “The mental is tough, I just want it over” and “This grand finale is the transplant...its awful scary to me.”

Normalcy. Seeking to be normal again is an aspect that includes psychosocial and spiritual in addition to the physical condition. Participants described wanting to be home or to get back to work or other activities that were important to them both pre-and post-transplant. Participants discussed being physically normal again by saying “I wanted my body back” and “There’s a normalcy you have to have, in order to get back to it, but you have to do certain things [physical therapy].” Others talked about wanting to return to activities they could do pre-transplant such as driving: “I’m the kind of person that just wants to keep going, and this stuff’s kinda [sic] cramping my style,” and playing golf “I’m anxious to get going again because I golf a lot and I haven’t golfed in about a month and a half or two months.” Another participant expressed uncertainty as: “Hopefully, by the time my 100 day’s post-transplant comes around, I’ll be living a semi-normal life like I want, but there’s no promises.”

Conclusions

While there are research studies published on self-efficacy in HSCT patients (Bergkvist et al., 2015; Hochhausen et al., 2007; Wu et al., 2012), we were unable to find other qualitative research describing what self-efficacy means to patients in the acute phase of HSCT. Believing that SESM is present will influence the choices they make to manage symptoms, the effort they put forth and how they persist when there are setbacks (Bandura, 1991). Most of the participants felt that they had high SESM before HSCT. Several participants related that as symptom distress increased, self-efficacy lessened. Other studies also have shown that self-efficacy is significantly associated with symptom severity such as pain, anxiety, distress, and symptom severity in cancer patients (Kelleher et al., 2016; Mystakidou et al., 2010; Papadopoulou et al., 2017). This is the

time in the HSCT process when symptom management interventions are most important, and nursing interventions are vital to enhance or reinforce self-efficacy. Nurses should be mindful of and balance patients' personality, their level of SESM, and need for control when providing for patient safety. Understanding individual patients' experience will help guide nurses to provide more interventions when necessary and to explain the rationale for these changes.

Other publications have discussed patients seeking normalcy at 100 days or longer after HSCT (Hacker, 2003; Lyons et al., 2010; Mosher et al., 2011). Mosher et al. (2011) reported patients seeking normal at between one and three years after transplant as they resumed work and social roles and Hacker (2003) discussed normalcy as a concept within QOL. Returning to normal is a part of psychological well-being and a way to measure recovery (Lyons et al., 2010; Whedon & Ferrell, 1994). Results from this study show that patients are seeking to return to normal as early as before HSCT and within 30 days post-transplant.

In prior studies, physical symptoms, distress, and QOL have been determined to be key factors in the experience both pre-and post-transplant (Mosher, Redd, Rini, Burkhalter, & DuHamel, 2009; Pidala, Anasetti, & Jim, 2009; Smith, Hobson, & Haig, 2016). Symptoms frequently reported after HSCT include fatigue, worry, appetite changes, feeling sick, insomnia and bowel changes (Anderson et al., 2007; Bevans, Mitchell, & Marden, 2008; Campagnaro et al., 2008; Stapleton, Holden, Epstein, & Wilkie, 2015). Psychological distress that includes anxiety is also common in HSCT recipients (Baliouisis, Rennoldson, & Snowden, 2015; Mosher et al., 2009). These findings are supported here by participants comments about anxiety, worry and being scared. Assessment pre-transplant to identify patients who may be more psychologically vulnerable or have anxiety or depression is important as they are at risk for poorer outcomes and longer length of hospital stay (Cooke, Gemmill, Kravits, & Grant, 2009). The patients in this sample highlighted the importance of health care providers providing holistic care. Variability in reactions to the HSCT process and symptom burden between patients has been documented and is influenced by chemotherapy regimen, comorbidities, disease state, prior

treatment toxicities and other factors (Bevans et al., 2008; Campagnaro et al., 2008; Dahan & Auerbach, 2006). The themes and interview excerpts presented here confirm the findings from these other studies, add the concept of self-efficacy to the discussion, and give voice to the patient perspective.

Interventions have been developed to enhance self-efficacy in cancer patients (Hoffman et al., 2017; Zhang et al., 2014; Zhu, Ebert, & Wai-Chi Chan, 2017). Hoffman et al. (2017) developed an intervention to increase self-efficacy for the management of fatigue. Other interventions include a telephone based symptom management intervention, use of a diary, an internet-based health communication application, and a nurse intervention that included education, relaxation techniques for symptom management and health-coaching sessions (Mosher et al., 2016; Oakley, Johnson, & Ream, 2010; Ruland et al., 2013; Zhang et al., 2014). SESM enhancing interventions specifically for transplant patients have not been developed but should be holistic and developed mutually with the patient to ensure strategies that are individualized to patient needs and personality traits.

Limitations of this study include that themes were not validated with participants after the analysis was completed, however, an interdisciplinary team verified the themes. A second limitation is missing data from patients who were too ill or in the intensive care unit to complete the final interview at 30 days post-transplant. The perspective of these patients, if they later recovered enough to participate in an interview, would have been valuable as their symptom experience was likely more severe and longer lasting than the other participants. Another limitation is that the sample is from one center, lacks ethnic and education diversity and so results may be different in other locations.

Implications for Practice

Nurses can help patients enhance their SESM. The findings from this study provide the basis for creating and implementing behavioral interventions to enhance SESM. Patients' understanding of SESM as confidence in self and others in addition to the changes in the level of

confidence related to symptom distress are important findings to use when developing interventions. Assessing patient's SESM before HSCT to determine their needs for symptom management will aid in the development and implementation of education or problem-solving strategies to enhance symptom management when it is needed. Being responsible for behaviors, being vigilant of changes, and speaking up when symptoms arise also are important topics to include in interventions. Recognizing when patients are at risk for increased symptom distress and decreased self-efficacy is important for timing of interventions. Patients with low SESM are at risk for higher symptom distress and poorer overall outcomes (Kelleher et al., 2016).⁶ Patients with high SESM that results in more effective symptom management have the potential for improved outcomes such as higher QOL and functional status and lower symptom distress (Bergkvist et al., 2015; Hochhausen et al., 2007; Hoffman, 2013). These findings add the patient's perspective to existing literature on both self-efficacy in HSCT and self-efficacy specifically for symptom management.

Table 1. Scripted Interview Questions

Baseline
1. What does self-efficacy for symptom management mean to you?
2. How much self-efficacy do you feel you have for symptom management?
3. Can you give examples?
30 days Post-transplant
1. How much self-efficacy did you have for managing your symptoms during the last 30 days?
2. Can you give examples?
3. What might have helped you to develop self-efficacy for symptom management?

Table 2. Themes and Subthemes

Confidence
Self-confidence
Confidence in others
Confidence and symptom level
Responsibility
Vigilance
Self-advocacy
Caring for mind, body, spirit
Normalcy

Table 3. Post-transplant Signs and Symptoms (in order of frequency discussed)

Discussed by > 5 participants	Discussed by 3-4 participants	Discussed by 1-2 participants
Fatigue Lack of appetite Diarrhea Infection/fever Changes in taste Weakness	Anxiety Frustrated Pain Nausea/vomiting Scared	Insomnia Change in appearance Weight loss Mucositis Rash/swelling Feeling unwell Difficulty concentrating Trouble breathing Depression Worry Dehydration

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CHAPTER VI: DISCUSSION

Summary

The concept analysis, literature review and research results presented in this dissertation add to existing literature on self-efficacy for symptom management (SESM) in the adult hematopoietic stem cell transplant (HSCT) patient population. This research study establishes the need for assessment of SESM prior to the transplant process and for the development and implementation of patient-centered interventions to enhance SESM. The results of this study showed a significant relationship between symptom distress, SESM and physical function (health status) as was described in the conceptual model in Chapter I.

Chapter II provided an analysis of the concept of perceived SESM in cancer patients using the Walker and Avant (2011) method and included the definition, attributes, antecedents, and consequences of perceived SESM. Perceived SESM is how the patient views their ability to implement behaviors to prevent, recognize, and relieve symptoms (White et al., *in press*). Definition of the concept is necessary for research and guides future intervention development.

The concept analysis described the concepts of self-efficacy and symptom management. These concepts have been analyzed separately in nursing literature; however, this is the first analysis of the concept of SESM. Constructed cases, both a model and a contrary case, demonstrated how the concept is operationalized in patients with cancer. The attributes of SESM are cognitive processes, affective processes, motivation, confidence, competence, and awareness. Antecedents are the presence of symptoms, performance accomplishment, verbal persuasion and presence of threat or fear. Consequences of perceived SESM are symptom relief, health status, the cost of care, quality of life (QOL), and behavior performance.

Chapter III presented an integrative literature review that examined self-efficacy and management of symptoms and symptom distress in patients with cancer. The review included 20 articles, including intervention and descriptive research, one integrative review and one theory paper. Only three of the 20 publications described self-efficacy and symptom management in

HSCT patients; all three were studies conducted with patients who were at one year or longer post-HSCT (Bergkvist et al., 2015; Hochhausen et al., 2007; Wu et al., 2012). Results of the review showed a relationship exists between self-efficacy and symptoms in cancer patients, with high self-efficacy leading to better symptom management and lower symptom distress.

The concept analysis presented in Chapter II and the literature review in Chapter III supported and expanded upon the theoretical foundations and conceptual relationships discussed in Chapter I. Chapters II and III also provided the foundation for the research presented in Chapters IV and V. The concept analysis and literature review results established the conceptual definition and the presence of a relationship between self-efficacy and symptoms in cancer patients and HSCT patients one year or more post-transplant. What remained unknown was the relationship between these concepts in the HSCT population within the first 30 days post-transplant. Chapter IV described the longitudinal, descriptive research study methodology and results and Chapter V describes the patient's perspective of SESM.

The study purpose was to describe the changes over time and relationships among SESM, symptom distress, and the outcomes of physical function and length of stay during the acute phase, or 30 days post-HSCT. The specific aims were:

1. Explore the concept of SESM from the patient's perspective at baseline and 30 days.
2. Determine the changes over time in SESM, symptom distress, and physical function.
3. Examine the relationships among SESM, symptom distress, and physical function.
4. Determine if the relationships among SESM and length of stay, readmission rates, and functional status varies depending on the level of symptom distress.

Demographic and clinical data were similar to what was found in other studies in HSCT patients (Bevans, Mitchell, & Marden, 2008; Cohen et al., 2012; Wu et al., 2012). Symptom experience and timing was also comparable to those reported in other studies (Anderson et al., 2007, Cohen et al., 2012). For the first aim, significant changes over time were found in all variables: SESM, symptom distress and physical function. Significant relationships were found

among symptom distress, SESM, and physical function at all time points for the second aim. For the final aim, physical function and SESM varied depending on the level of symptom distress at day 15. Overall, higher SESM was associated with fewer symptoms and increased physical function while less symptom distress was associated with increased physical function and SESM. This study established a relationship between SESM and symptom distress, specifically during the phase of HSCT when symptom distress is highest.

Chapter V described the meaning of SESM from the perspective of patients both before and after HSCT. Themes of confidence, responsibility and caring for mind, body, and spirit were described by study participants along with subthemes of self-confidence, confidence in others, confidence and symptom level, vigilance, self-advocacy, and normalcy. These themes related to the findings of the concept analysis such as confidence (self and others), cognitive processes (self-advocacy), affective processes and motivation (mind, body, spirit), awareness (vigilance), the presence of symptoms (symptom level), and symptom relief (normalcy). These findings validate the concept analysis and give voice to the patient's experience.

Practice and Research Implications

The presence of SESM in cancer and HSCT patients is vital for optimal patient outcomes. Because a relationship exists between SESM, symptom distress, and physical function, enhancement of SESM has the potential to reduce symptom distress and improve patient outcomes. SESM can be learned, which creates an opportunity for nursing intervention.

SESM should be assessed at the earliest opportunity after treatment for cancer is begun. Instruments have been developed and tested to assess self-efficacy in survivors with breast cancer (Champion et al., 2013), SESM in patients with breast cancer (Liang, Wu, Kuo, & Lu, 2015) and for self-efficacy for fatigue management (Hoffman et al., 2011). For other patient populations or general symptom management, assessment can be done briefly and efficiently with the Patient-Reported Outcomes Measurement Information System (PROMIS) self-efficacy scales for managing chronic conditions using the instrument short forms or computer adaptive testing

(Patient-Reported Outcomes Measurement Information System, 2015). SESM can be assessed using the Self-efficacy for Managing Symptoms Short Form 8a (Figure 1) and Self-efficacy for Managing Medications and Treatments Short Form 8a (Figure 2). Computer adaptive testing delivers questions based on patient's response to a previously administered question.

Educational or problem-solving strategies that are patient specific can be developed using results from the assessment. For example, if patients respond that they are not confident in listing their medication names or schedule, remembering to take medications as prescribed, or finding the information they need to manage symptoms, a patient-centered intervention can be developed. If persons respond that they are not confident in understanding the differences between symptoms and side effects of medication, education can be tailored that contrasts signs and symptoms of potential complications of treatment (i.e. fever, infection, mucositis) with the adverse effects of the persons' medications. The assessment finding would guide the multidisciplinary intervention, which will be targeted toward the patient need, whether it be coaching, education, or finding resources. Multi-disciplinary involvement is critical as needs for SESM include expertise from nurses as well as pharmacists, physical therapists, social workers, case managers, or cognitive behavioral therapists. Administration of these interventions should occur when symptom burden or distress is low, as the presence of high physical and psychological symptom distress is a barrier to SESM (White, Kupzyk, Berger, Cohen, & Bierman, *in process*; Wu et al., 2012).

SESM plays a key role in outcomes for patients in all stages of treatment for cancer, including HSCT. This body of work lays the foundation for assessment and development of patient-centered intervention development. Future research should test the outcomes of these interventions in relation to the presence of symptom distress, physical functional status, use of health care resources, and overall QOL.

Figure 1: Self-efficacy for Managing Symptoms – Short Form 8a

PROMIS Item Bank v1.0 – Self-Efficacy for Managing Symptoms – Short Form 8a

Self-Efficacy for Managing Symptoms – Short Form 8a

Please respond to each question or statement by marking one box per row.

	CURRENT level of confidence...	I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
SEMSX010	I can manage my symptoms during my daily activities	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX014	I can keep my symptoms from interfering with relationships with friends and family.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX009	I can manage my symptoms in a public place	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX011	I can work with my doctor to manage my symptoms	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX017	I can keep my symptoms from interfering with my personal care	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX008	I can manage my symptoms when I am at home	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX015	I can keep my symptoms from interfering with the work I need to do.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX027	I can find the information I need to manage my symptoms	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Figure 2: Self-efficacy for Managing Medications and Treatments – Short Form 8a

PROMIS Item Bank v1.0 - Self-Efficacy for Managing Medications and Treatments – Short Form 8a

Self-Efficacy for Managing Medications and Treatments – Short Form 8a

Please respond to each question or statement by marking one box per row.

CURRENT level of confidence...		I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
DEMMT005	I can follow directions when my doctor changes my medications.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
DEMMT019	I can take my medication when I am working or away from home	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
DEMMT023	I can take my medication when there is a change in my usual day (unexpected things happen)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
DEMMT008	I can manage my medication without help.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
DEMMT002	I can remember to take my medication as prescribed	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
DEMMT017	I can use technology to help me manage my medication and treatments (for example: to get information, avoid side-effects, schedule reminders)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
DEMMT010	I can list my medications, including the doses and schedule	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
DEMMT024	I can figure out what treatment I need when my symptoms change	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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APPENDIX A



3900 W. Avera Drive
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605-322-4755
Fax: 605-322-4763

Avera.org

January 20, 2016

Lynn White,
Avera McKennan Hospital and University Health Center
1325 S. Cliff Ave
Sioux Falls SD 57117

Dear Ms. White:

Concerning the following Study:

Our Study # 2016.004

Protocol Title: *Self-efficacy for Symptom Management in Stem Cell Transplant Patients*

This is to inform you that the Avera IRB reviewed your request for expedited approval of the above referenced research study. This study qualified for expedited review under FDA and NIH (OHRP) regulations. This determination was made based on **Appendix D (7)**. This is to confirm that I have approved your application. You are further recognized as the principal Investigator. The study is subject to continuing review on or before 1/19/2017.

The following items were reviewed and approved:

- **IRB application, consent, survey**

Continued approval is conditional upon your compliance with the following requirements:

- An approved, stamped copy of the Informed Consent Document (ICD) as noted above is included. No other consent document should be used. Each subject must sign the approved ICD prior to initiation of any protocol procedures. The original signed informed consent document must be placed in each subject's medical/research chart. In addition, each subject must be given a copy of the signed consent document.
- All protocol amendments and changes to approved research must be submitted to the IRB and not be implemented until approved by the IRB except where necessary to eliminate apparent immediate hazards to the study subjects.
- Significant changes to the study site and significant deviations from the research protocol must be reported.
- All deaths, life-threatening problems or serious or unexpected adverse events, *whether related to the study article or not*, must be reported to the IRB within ten (10) working days of the event (or your knowledge thereof). An Adverse Event Report should be used for reporting all SAEs.

Please note that changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full Committee review. Contact the Department of Human Subjects Protection at (605) 322-4706, if you have any questions or require further information.

Respectfully yours,

Sandra G. Ellenbolt, JD
Director, Department of Human Subjects Protection/IRB Chair

*Sponsored by the Benefactors
and Preservation Society*

APPENDIX B



NEBRASKA'S HEALTH SCIENCE CENTER

Office of Regulatory Affairs (ORA)
Institutional Review Board (IRB)

April 11, 2016

Lynn White, RN, MSN
CON - UNMC

IRB # 158-16-EP

TITLE OF PROPOSAL: Self-efficacy for Symptom Management in Stem Cell Transplant PatientsDATE OF EXPEDITED REVIEW: 03/25/2016DATE OF FINAL APPROVAL AND RELEASE: 04/11/2016 VALID UNTIL: 03/25/2017

CLASSIFICATION OF RISK: Minimal

EXPEDITED CATEGORY OF REVIEW: 45 CFR 46.110, Categories 5 and 7

The IRB has completed its review of the above-titled protocol. The IRB has determined you are in compliance with HHS Regulations (45 CFR 46), applicable FDA Regulations (21 CFR 50, 56) and the Organization's HRPP policies. Furthermore, the IRB is satisfied you have provided adequate safeguards for protecting the rights and welfare of the subjects to be involved in this study. This letter constitutes official notification of final approval and release of your project by the IRB. You are authorized to implement this study as of the above date of final approval.

Please be advised that only the IRB approved and stamped consent form can be used to make copies to enroll subjects. Also, at the time of consent all subjects must be given a copy of *The Rights of Research Subjects* and "What Do I Need to Know" forms.

The IRB wishes to remind you that the PI is ultimately responsible for ensuring that this research is conducted in full compliance with the protocol, applicable Federal Regulations, and Organizational policies.

Finally, under the provisions of this institution's Federal Wide Assurance (FWA00002939), the PI is directly responsible for submitting to the IRB any proposed change in the research or the consent form. In addition, any adverse events, unanticipated problems involving risk to the subject or others, noncompliance, and complaints must be promptly reported to the IRB in accordance with HRPP policies.

This project is subject to periodic review and surveillance by the IRB and, as part of the Board's surveillance, the IRB may request periodic progress reports. For projects which continue beyond one year, it is the responsibility of the PI to initiate a request to the IRB for continuing review and update of the research project.

On behalf of the IRB,

Signed on: 2016-04-11 09:27:00.000

Gail Paulsen, RN, BSN, CIP
IRB Administrator III
Office of Regulatory AffairsAcademic and Research Services Building 3000 / 96750 Nebraska Medical Center / Omaha, NE 68198-7830
402-559-8483 / FAX: 402-559-3300 / Email: lrbone@unmc.edu / http://www.unmc.edu/irb

APPENDIX C



3900 W. Avera Drive
Sioux Falls, SD 57108-9721
605-322-4706
Fax: 605-322-4760

Avera.org

October 6, 2016

Lynn White,
Avera McKennan ICU
800 East 21st Street
Sioux Falls SD 57105

Re IRB Study # 2016.004 Protocol Title: Self-efficacy for Symptom Management in Stem Cell Transplant Patients

Dear Ms. White:

This is to inform you that I have reviewed your request for review and approval of the item(s) listed below associated with the above referenced research study on behalf of the Avera Institutional Review Board. This request qualified for expedited review under FDA and NIH (OHRP) regulations. This is to advise you that I have approved your requested changes.

The following were reviewed and approved:

- Increased enrollment, data collection changes

The study is subject to continuing review on or before 1/19/2017. You are reminded that you are required to report any serious adverse events to the Avera Institutional Review Board within ten (10) business days of its occurrence (or your knowledge thereof).

Please note that changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full Committee review. Contact the Avera Department of Human Subjects Protection, at (605) 322-4706, if you have any questions or require further information regarding this IRB action.

Respectfully yours,

Sandra G. Ellenbolt, CIM, JD
Director, Department of Human Subjects Protection/IRB Chair

*Sponsored by the Menardine
and Presentation Sisters*

APPENDIX D



NEBRASKA'S HEALTH SCIENCE CENTER

Office of Regulatory Affairs (ORA)
Institutional Review Board (IRB)

October 27, 2016

Lynn White, RN, MSN
College of Nursing
UNMCIRB # 158-16-EPTITLE OF PROPOSAL: Self-efficacy for Symptom Management in Stem Cell Transplant Patients

RE: Request for Change, dated 10/07/2016

DATE OF IRB EXPEDITED REVIEW: 10/27/2016

Dear Ms. White:

The UNMC IRB has completed its review of the above mentioned Request for Change involving an increase in target accrual (from 30 to 60 subjects) and changes in the demographic data collection.

This letter constitutes official notification of IRB approval of the revised IRB application. For the record there were no changes in the informed consent form at this time.

You are authorized to implement this change accordingly.

Respectfully Submitted on Behalf of the IRB,

Signed on: 2016-10-27 09:20:00.000

Gail Paulsen, RN, BSN, CIP
IRB Administrator III
Office of Regulatory Affairs

APPENDIX E

Protocol Information

General Info Reviews E-Signatures Emails

Date/Time ▲	Recipients	Subject
1/13/2017	sandra.ellenbolt@avera.org, lynn.white@avera.org	Protocol Approved 1/13/2017

RE: Our Study #2016.004-100057

Protocol Title: Self-Efficacy for Symptom Management in Stem Cell Transplant Patients

Dear Dr. White:

This is to advise you that the Avera Institutional Review Board (IRB) has reviewed and approved the continuation of, "Self-Efficacy for Symptom Management in Stem Cell Transplant Patients". This has been approved until 1/12/2018. The following documents were approved: Informed Consent version 1/13/17

Continued approval is conditional upon your compliance with the following requirements:

- An approved, stamped copy of the Informed Consent Document (ICD) as noted above within Section 15 - IRB Submission documents. No other consent document should be used. Each subject must sign the approved ICD prior to initiation of any protocol procedures. The original signed informed consent document must be placed in each subject's medical/research chart. In addition, each subject must be given a copy of the signed consent document.
- All protocol amendments and changes to approved research must be submitted to the IRB and not be implemented until approved by the IRB except where necessary to eliminate apparent immediate hazards to the study subjects.
- Significant changes to the study site and significant deviations from the research protocol must be reported.
- All deaths, life-threatening problems or serious or unexpected adverse events, whether related to the study article or not, must be reported to the IRB within ten (10) working days of the event (or your knowledge thereof). An Adverse Event/Unanticipated Problem Report should be used for reporting all SAEs or Unanticipated problems.

Please contact the Avera Department of Human Subjects Protection directly at 605.322.4706 if you have any questions about the terms of this approval.

APPENDIX F



NEBRASKA'S HEALTH SCIENCE CENTER

Office of Regulatory Affairs (ORA)
Institutional Review Board (IRB)

March 10, 2017

Lynn White, RN, MSN
UNMC

IRB # 158-16-EP

TITLE OF PROPOSAL: Self-efficacy for Symptom Management in Stem Cell Transplant PatientsDATE OF EXPEDITED REVIEW: 03/10/2017VALID UNTIL: 03/10/2018EXPEDITED CATEGORY OF REVIEW: 45 CFR 46.110, Categories 5 and 7

The UNMC IRB has completed its review of the Application for Continuing Review for the above titled research project including the complete protocol file and has expressed it as their opinion that you have provided adequate safeguards for the rights and welfare of the subjects involved in this study and are in compliance with HHS regulations (45 CFR 46) and FDA regulations (21 CFR 50.56) as applicable.

This letter constitutes official notification of the re-approval of your research project by the IRB for the IRB approval period indicated above. You are therefore authorized to continue this study. **All copies of the outdated consent form(s)/study information sheet(s) must be discarded immediately.** The original IRB stamped form(s) may be archived.

We wish to remind you that, under the provisions of the Federal Wide Assurance (FWA 00002939) from the Institution to HHS, the Principal Investigator is directly responsible for keeping the IRB informed of any proposed changes involved in the procedures or methodology in the protocol and for promptly reporting to the Board any unanticipated problems involving risks to the subjects or others.

In accordance with HRPP policies, this project is subject to periodic review and monitoring by the IRB and, as part of their monitoring, the IRB may request periodic reports of progress and results. For projects which continue, it is also the responsibility of the Principal Investigator to initiate a request to the IRB for Continuing Review of the research project in consideration of the IRB approval period.

On Behalf of the IRB,

Signed on: 2017-03-10 09:45:00.000

Gail Paulsen, RN, BSN, CIP
IRB Administrator III
Office of Regulatory Affairs

APPENDIX G

Self-efficacy for Symptom Management in Stem Cell Transplant Patients

Demographic and Clinical Data Collection Tool

(Collected from Electronic Medical Record)

Subject ID _____

1. Age _____
2. Gender M / F
3. Race _____
4. Ethnicity _____
5. Employment status
 - a. Full time / Part time / Retired / Disability / Unemployed
 - b. If unemployed or disability – prior employment _____
6. Marital status Married / Single / Widowed / Divorced
7. Family Caregiver Y / N
8. Primary Disease _____

Location _____

Stage _____
9. Transplant type (circle one)
 - a. Autologous / Related Allogeneic / Unrelated Allogeneic / Cord Blood
10. Conditioning Regimen _____
11. Comorbid conditions Comorbidity Score _____
 - a. _____
 - b. _____
 - c. _____
12. Length of stay for transplant admission _____

APPENDIX H

SYMPTOM DISTRESS SCALE

Instructions

Below are 5 different numbered statements. Think about what each statement says, then place a circle around the one statement that most closely indicates how you have been feeling lately. The statements are ranked from 1 to 5, where number one indicates no problems and number five indicates the maximum amount of problems. Numbers two through four indicate you feel somewhere in between these two extremes. Please circle one number on each card.

Degrees of Distress**Nausea (1)**

1 I seldom if ever have nausea	2 I have nausea once in a while	3 I have nausea fairly often	4 I have nausea half the time at least	5 I have nausea continually
-----------------------------------	------------------------------------	---------------------------------	---	--------------------------------

Nausea (2)

1 When I do have nausea, it is very mild	2 When I do have nausea, it is mildly distressing	3 When I have nausea, I feel pretty sick	4 When I have nausea, I usually feel very sick	5 When I have nausea, I am as sick as I could possibly be
---	--	---	---	--

Appetite

1 I have my normal appetite and enjoy good food	2 My appetite is usually, but not always, pretty good	3 I don't really enjoy my food	4 I have to force myself to eat my food	5 I cannot stand the thought of food
--	--	-----------------------------------	--	---

Degrees of Distress**Insomnia**

1 I sleep as well as I always have	2 I occasionally have trouble getting to sleep and staying asleep	3 I frequently have trouble getting to sleep	4 I have difficulty getting to sleep and staying asleep almost every night	5 It is almost impossible for me to get a decent night's sleep
---------------------------------------	--	---	---	---

Pain (1)

1 I almost never have pain	2 I have pain once in a while	3 I have pain several times a week	4 I am usually in some degree of pain	5 I am in some degree of pain almost constantly
-------------------------------	----------------------------------	---------------------------------------	--	--

Pain (2)

1 When I do have pain, it is very mild	2 When I do have pain, it is mildly distressing	3 When I do have pain, it is usually fairly intense	4 The pain I have is very intense	5 The pain I have is almost unbearable
---	--	--	--------------------------------------	---

Fatigue

1 I seldom feel tired or fatigued	2 There are periods when I am rather tired or fatigued	3 There are periods when I am quite tired and fatigued	4 I am usually very tired and fatigued	5 Most of the time, I feel exhausted
--------------------------------------	---	---	---	---

Bowel

1 I have my normal bowel pattern	2 My bowel pattern occasionally causes me some discomfort	3 My present bowel pattern occasionally causes me considerable discomfort	4 I am usually in considerable discomfort because of my present bowel pattern	5 I am in almost constant discomfort because of my bowel pattern
-------------------------------------	--	--	--	---

Concentration

1 I have my normal ability to concentrate	2 I occasionally have trouble concentrating	3 I occasionally have considerable trouble concentrating	4 I usually have considerable difficulty concentrating	5 I just can't seem to concentrate at all
--	--	---	---	--

Degrees of Distress

Appearance				
1 My appearance has basically not changed	2 Occasionally I am concerned about the worsening of my physical appearance	3 I am not often concerned that my appearance is worsening	4 Most of the time I am concerned that my physical appearance is worsening	5 The worsening of my physical appearance is a constant, preoccupying concern
Breathing				
1 I usually breathe normally	2 I occasionally have trouble breathing	3 I often have trouble breathing	4 I can hardly ever breathe as easily as I want	5 I almost always have severe trouble with my breathing
Outlook				
1 I am not worried or frightened about the future	2 I am slightly worried but not frightened about things	3 I am worried and frightened about things	4 I am very worried and frightened about things	5 I am terrified by thoughts of the future
Cough				
1 I seldom cough	2 I have an occasional cough	3 I often cough	4 I often cough, and occasionally have severe coughing spells	5 I often have persistent and severe coughing spells

APPENDIX I

PROMIS Item Bank v1.0 - Self-Efficacy for Managing Symptoms

Please rate your **CURRENT** level of confidence in managing your health conditions by filling in one box per row. Consider all of your health conditions and all of your symptoms in your responses to the questions. If a question is not something you have experienced, choose an answer based on similar experiences.

	CURRENT level of confidence...	I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
SEMSX001	I can make a moderate reduction in my symptoms	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX002	I can reduce my symptoms to my satisfaction	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX003	I can control my symptoms by taking my medications	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX004	I can control my symptoms by using methods other than taking medication (for example: relaxation exercises, distraction).	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX005	I can do something to reduce my	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	symptoms when they worsen					
SEMSX006	I can do something to prevent my symptoms from worsening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5
SEMSX007	I can manage unexpected or new symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5
SEMSX008	I can manage my symptoms when I am at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5
SEMSX009	I can manage my symptoms in a public place	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5
SEMSX010	I can manage my symptoms during my daily activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5
SEMSX011	I can work with my doctor to manage my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5
SEMSX012	I can manage my symptoms as well as other people with symptoms like mine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5

SEMSX013	I can keep my symptoms from interfering with my sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5
SEMSX014	I can keep my symptoms from interfering with relationships with friends and family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5

CURRENT level of confidence...

I am not at all confident

I am a little confident

I am somewhat confident

I am quite confident

I am very confident

		I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
SEMSX015	I can keep my symptoms from interfering with the work I need to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5
SEMSX016	I can keep my symptoms from interfering with my recreational activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5
SEMSX017	I can keep my symptoms from interfering with my personal care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5

SEMSX018	I can enjoy things, despite my symptoms	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX019	I can still accomplish most of my goals in life, despite my symptoms	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX020	I can live a normal life, despite my symptoms	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX021	I can be physically active, despite my symptoms	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX022	I can maintain my sense of humor, despite my symptoms	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX023	I can recognize when my symptoms change	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX024	I know what to do when my symptoms worsen	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX025	I can rely on my judgment to manage my	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	symptoms, even when others disagree with me					
SEMSX026	I can manage my symptoms when I am in an unfamiliar place	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX027	I can find the information I need to manage my symptoms	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMSX028	I can manage my symptoms when I am tired	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

APPENDIX J

PROMIS Item Bank v1.0 - Self-Efficacy for Managing Medications and Treatments

Please rate your **CURRENT** level of confidence in managing your medications and other treatments by filling in one box per row. Consider all of your health conditions and all of your symptoms in your responses to the questions. If a question is not something you have experienced, choose an answer based on similar experiences.

	CURRENT level of confidence...	I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
SEMMT001	I can take several medications on different schedules	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT002	I can remember to take my medication as prescribed	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT003	I know when and how to take my medications	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT004	I can fit my medication schedule into my daily routine	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT005	I can follow directions when my doctor changes my medications	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT006	I can manage my medication without	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	help.					
SEMMT007	I can get help when I am not sure how to take my medicine	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT008	I can remember to refill my prescriptions before they run out	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT009	I can remember to take my medications when there is no one to remind me	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT010	I can list my medications, including the doses and schedule	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT011	I can actively participate in decisions about my treatment	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT012	I can find information to learn more about my treatment	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT013	I can use my own judgment regarding treatment	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	alternatives (including not having treatment)					
SEMMT014	I can work with my doctor to choose the treatment that seems right for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5

CURRENT level of confidence...

I am not at all confident I am a little confident I am somewhat confident I am quite confident I am very confident

		I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
SEMMT015	I know what to do when my medication refill looks different than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5
SEMMT016	I know what to do if I forget to take my medication(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5
SEMMT017	I can use technology to help me manage my medication and treatments (for example: to get information, avoid side-effects, schedule reminders)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		1	2	3	4	5

SEMMT018	I can continue my treatment when traveling	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT019	I can take my medication when I am working or away from home	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT020	I can take my medicine even if it causes mild side effects	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT021	I understand the difference between my symptoms and medication side effects	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT022	I can continue my treatment when I am not feeling well	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT023	I can take my medication when there is a change in my usual day (unexpected things happen)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT024	I can figure out what treatment I need when my symptoms	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	change					
SEMMT026	I can follow a full treatment plan (including medication, diet, physical activity)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SEMMT027	I can travel to my local pharmacy to fill my prescriptions	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

APPENDIX K

PROMIS Item Bank v1.0 –Physical Function - Short Form 10a

Physical Function – Short Form 10a

Please respond to each item by marking one box per row.

		Not at all	Very little	Somewhat	Quite a lot	Cannot do
PFA01	Does your health now limit you in doing vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFC06	Does your health now limit you in walking more than a mile?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFC07	Does your health now limit you in climbing one flight of stairs?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFA05	Does your health now limit you in lifting or carrying groceries?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFA02	Does your health now limit you in bending, kneeling, or stooping?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
		Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
PFA11	Are you able to do chores such as vacuuming or yard work?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFA16	Are you able to dress yourself, including tying shoelaces and doing buttons?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFC08	Are you able to shampoo your hair?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFA03	Are you able to wash and dry your body?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFC05	Are you able to get on and off the toilet?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1