

PATIENTS' EXPERIENCE BEFORE, DURING AND AFTER STEM CELL
TRANSPLANTATION-PHENOMENOLOGICAL STUDY

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DEDICATION

To the sixty participants who so generously shared their experience while receiving SCT and to all SCT patients for their courage, strength and resilience in facing the fear. They have inspired us in healthcare to do our best, push the limits of science, and care with our heads and our hearts.

To my family – my spouse, my children, their spouses, my grandchildren, and to my friends and colleagues, for their love, patience, and understanding so I could make this long journey.

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ABSTRACT

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PATIENTS' EXPERIENCES BEFORE, DURING, AND AFTER STEM CELL TRANSPLANTATION: A PHENOMENOLOGICAL STUDY

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Patients with refractory hematological malignancies are frequently candidates for life saving but potentially life threatening treatment such as stem cell transplantation (SCT). The purpose of this study was to develop our understanding of the meaning SCT has for African-American, Latino, and Caucasian patients before, during, and after stem cell treatment.

An extensive review of the literature was conducted to establish a board understanding of the topic. In the study a hermeneutic phenomenological method with the philosophical underpinnings of Ricoeur was used to complete analysis of data from interviews that were conducted before treatment began, at the time of blood count recovery, and day 30, 60, and 100 after stem cell transplantation.

Three major overlapping themes emerged, based in the experiences of the participants; Facing the Fear occurred before SCT treatment began, Getting Through during active treatment, and Going Beyond, Forward primarily during the time period after SCT (30 to 100 days after treatment). Like a Bridge I Never Crossed Before influenced the meaning experiences had for participants across the 3 themes. Contextual

factors of life threatening disease and treatment, lack of experience or knowledge, emotional/coping, culture, symptom burden, and financial burden influenced the transition between the phases of SCT. Additional subthemes which enhanced their experience were identified as Hope for Chances, Choices, and Control; In God's Hands; I Couldn't Have Done This Without Them; Wanting to Know, Not Wanting to Know; and They Went the Extra Mile.

These findings provide guidance for caring for SCT patients and their families and they provide direction of ongoing research. Of the implications for care, most convincing is the need for patient-centered care based in an understanding of the contextual factors that affect patient and family coping. Of the implications for research, perhaps most compelling is the need for research related to education to ensure informed consent and preparation for treatment related experiences, in accord with patient needs.

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CHAPTER I

INTRODUCTION

Focus of Inquiry

Despite improvement in treatment modalities and survival rates for most types of cancer, over the past three decades cancer has remained the second leading cause of death among adults in the United States (ACS, 2014). Cancer impacts people in all ethnic groups, and accounts for 21% of deaths in African Americans, 23% in Whites and 20% in Hispanics (American Cancer Society, 2014). While many types of cancer are now considered curable when discovered at an early stage, others tend to be more aggressive and refractory to standard treatment making them more of an immediate life threatening risk. Patients with hematological malignancies are frequently considered candidates for more aggressive treatment, such as Stem Cell Transplantation (SCT), because of the refractory nature of their disease and the lack of efficacious treatment for cure or substantial control of their disease (Rizzo et al., 2006).

There are approximately forty thousand SCTs performed annually in centers throughout the world with half in United States of America (Rizzo et al., 2006). SCT tends to be most effective in cancers of the hematopoietic system (i.e. leukemias, myeloma, Hodgkin's and non-Hodgkin's lymphoma) and few solid organ cancers (i.e. breast, germ cell). Typically, autologous (stem cell harvested from patients

themselves for infusion after further treatment) transplantation may be performed for patients with myeloma, lymphoma, breast, and renal cell cancers. In addition to the types of cancer previously listed, allogeneic (stem cell from another person) transplantation is used for treatment of all types of leukemia (Ezzone, 2013).

Patients who are offered the treatment option of SCT are in an extremely vulnerable position due to the risks related to their disease and its treatment (Serna et al., 2003; Pentz, et al., 2014). By the time many patients are offered SCT, their disease is incurable or uncontrollable and most will die in a short (months to a year) period of time if SCT treatment is not started. The treatment related risks could also be life threatening or have high morbidity, related to infection, graft versus host disease, or organ toxicity (Pène et al., 2006). Healthcare providers may assume the patients have acquired knowledge and understanding of the risks and uncertain outcomes before the treatment begins. This assumption is not confirmed by the limited research or evidence available (Little et al., 2008). In a study by Lee, Fairclough, Antin and Weeks (2001) patients and their SCT physicians were asked to estimate treatment-related mortality, chance of cure with, and without, SCT and disease free survival. The study demonstrated a discrepancy between SCT patients and physicians estimates of treatment success, specifically when treatment related mortality was above 30% with patients reporting increase chance of success. The study also identified that patients with advanced disease failed to recognize their higher risks. In most SCT centers, patients receive standardized education developed by members of the SCT program and national programs, like the National

Marrow Donor Program. The informed consent process is one way knowledge is ascertained, although again it may be difficult to determine what the patient really knows and understands at this vulnerable time in their illness trajectory (Jacoby et al., 1999; Little et al., 2008).

Changes in the nation's population and their healthcare needs are important to consider in planning research which targets differing ethnic groups (Cohen, Phillips, & Palos, 2001). Cancer incidence and mortality rates are generally higher for African Americans and Hispanics than for whites (ACS, 2014). Distressingly little is known about the experiences of ethnic minority patients who undergo SCT. Research studies have included too few patients of ethnic minority background to accurately describe their experiences (Andrykowski, Henslee, & Barnett, 1989; Belec, 1992; Grassi, Rosti, Albertazzi, & Marangolo, 1996; Bush, Haberman, Donaldson, & Sullivan, 1995; McQuellon, et al., 1996, 1997; Molassiotis, van den Akker, Milligan, Goldman, & Boughton, 1996). Specific treatment related factors effecting emotional distress remain elusive (Bevans, Mitchell, & Mardell, 2008) for all groups of SCT patients. Enhancing healthcare providers' understanding may guide program development strategies that will provide psychosocial support that enhances coping, communication, and education to better meet SCT patient needs.

Statement of Purpose

The purpose of this study was to develop our understanding of the meaning SCT has for African-American, Latino, and Caucasian SCT patients before, during, and after

stem cell treatment. The study used a hermeneutic phenomenological method to complete analysis of data from interviews that were conducted before treatment began, at the time of blood count recovery, and day 30, 60, and 100 after stem cell transplantation. The aims for the parent study are provided in Appendix A (with qualitative study aims 1, 5, and 6). Research question for this study is:

What were the informant's expressions of their experience undergoing treatment (before, during, or after) with stem cell transplantation? Specifically, what were their feelings or concerns about uncertain outcomes or risks (or certainty or confidence and lack of risk) going forward with SCT?

Rationale for the Study

Significance to Nursing

There is a need for studies that assist clinicians/healthcare providers to better understand the patient experience of undergoing potentially life-threatening treatment for life threatening diagnosis in order to design strategies that will educate and support patients receiving treatment. A major emotional response of SCT patients is uncertainty (Baker, Zabora, Polland & Windgard, 1999; Bywater & Atkins, 2001; Coolbrandt & Grypdonck, 2010; Cooper & Powell, 1999; Farsi, Nayen, Negarandeh, 2012; Fife, Huster, Cornetta, et al., 2000; Hacker & Ferrans, 2003; Steeves, 1992; Thain & Gibbon, 1996) however this has not been well explored in SCT patients. The uncertainties of indeterminate prognosis, side effects, persistent symptoms and the possibility of relapse and death can greatly affects SCT patients (Baker, Marcellus, Zabora, Polland, & Jodrey,

1997; Haberman, 1988; Fife, Huster, Cornetta, Kennedy, Akord, & Braun, 2000). Patients and their families are extremely vulnerable and may be facing a difficult, desperate, situation because of the do or die nature of cancer treatment. Anxiety and uncertainty influence how patients make their decisions for treatment (Goodman & Houck, 2001; Bywater & Atkins, 2001). In addition, the response to such decisional burdens may vary depending on the patient and caregiver ethnicity (Braun, Beyth, Ford, & McCullough, 2008). The overall 1-year survival for patients who undergo SCT is approximately 40% (Joffe, Mello, Cook, & Lee, 2007). In the parent study, of the 163 participants 13% died in the first 100 days and 50% within five years (Cohen, Rozmus, & Neumann, 2010). The Center for International Blood and Marrow Transplant Research (Pasquini & Wang, 2012) reports that the day 100 mortality rate is between 12-40% dependent upon the type of SCT, underlying disease, and status (remission or relapse) of disease at the time of treatment. Uncertainty has been studied in nursing and oncology (Mishel, 1984; Mishel 1990; Mishel & Sorenson, 1991; Mishel & Germino, 2010). Further studies that explore the SCT patients' experience with uncertainty could provide the basis for developing intervention strategies to assist patients with managing their illness experience.

There is a need to consider whether and how ethnicity and culture influence patients' responses to SCT. Only a few studies reviewed addressed the role of ethnicity. Bevans and Marden (2006) examined the health-related quality of life (QOL) and symptom distress of Hispanic patients living in the US and outside the US. They found

that their study participants had less of a sense of emotional well-being as indicated by scores 2 points ($M=55.3$, $SD=7.0$) lower than U.S. patients with cancer. In a recent study by Cohen, Rozmus, Mendoza, et al., (2012) ethnicity did not play a significant role in the symptomology or QOL as measured by the M.D. Anderson Symptom Inventory or the Functional Assessment of Cancer Treatment. Findings from the international literature (Bywater & Atkins, 2001; Heinonen, 2004; Farsi, Nayeri, & Negarandeh, 2012; Xuereb & Dunlop, 2003) provide a glimpse into the experiences of SCT patient in different cultures and suggest there are similarities; however there is no study across cultures to establish that with certainty. The tri-ethnic focus of this study contributes to identifying if culture influences patient experiences.

Implicit in the education process is the assurance that the patient has the information needed to make an autonomous informed decision to undergo this treatment. The expression of many SCT patients about lack of choices and their vulnerability leave questions about autonomous decision-making. Bywater and Atkins (2001) raise concern about the methods trusted healthcare providers use to frame conversation about risks, with and without treatment, during the consent process. The authors suggest the nurse or social worker explore the patient's contextual influences during their (initially) assessment by questionnaire or discussion (including cultural and spiritual beliefs) to assist them with the decision making process. Likewise there is concern when patients minimize risks of treatment and are reluctant to discuss the negative aspects. These concerns may be mitigated through advance care planning discussions, the healthcare

team, including the nurse, can assist patients and families to explore factors involved in the decision to have SCT and potential treatment outcomes, preparing them for all possibilities (Neumann, 2013; Haberman, 1995). This study provides evidence to modify current practices for supporting and educating patients and their families as they prepare for, and progress through, SCT.

Improved screening and better tools for measuring emotional difficulties early in the SCT treatment course are indicated (Molassiotis, 1999; Cooke, Gemmill, Kravits, & Grant, 2009). Providing a plan of treatment before SCT therapy begins will assist with identification of psychological issues (depression, high anxiety, and avoidance) and promote successful physical and emotional treatment outcomes (Bryant, Heiney, Henslee-Downey, & Cornwell, 1997; Gaston-Johansson, Fall-Dickson, Nanda, Ohly, Stillman, et al., 2000). Continued societal mental health stigmas make this especially challenging for the patient but it is exceptionally important during this vulnerable time. Greater understanding of the disease and treatment uncertainties will help develop realistic strategies to assist SCT patients to manage the emotional impact during treatment (Germino, et al., 2013; Bryant, Heiney, Henslee-Downey, & Cornwell, 1997; Gaston-Johansson et al., 2000). Most of the patients in the studies presented here were hospitalized for their SCT treatment but with more recent trends in performing outpatient SCT the burden and stress on patients and caregivers may increase the need for outpatient resources.

The research that has been published provides a beginning understanding of uncertainty and the psychosocial factors experienced by SCT patients but there are several implications for future research to develop our understanding of uncertainty and its management. Such knowledge will help guide SCT practice, enhancing our ability to assist SCT patients in making treatment decisions, coping with psychosocial responses, and establishing expectations that are more congruent with life after transplantation. This research contributes to understanding of the influence of these factors on the patient's decision-making process, QOL, and ultimate treatment outcomes.

Researcher's Relationship to the Topic

The principal investigator (PI) has worked with stem cell transplantation patients as an advanced practice nurse for the past 25 years, with 22 years at the institution where this study was conducted and was a collaborator on the parent study. As a member of the institutional ethics committee over that last 10 years the PI has also noted that many SCT patients express that they are unprepared for death or dying as an outcome of treatment. Many of the ethics consults involving SCT patients involved the issue of end-of-life decision making. These observations lead the PI to wonder how patients view their situation of starting treatment for their life threatening cancer diagnosis with very aggressive treatment and if there are ways healthcare professionals can assist patient manage the uncertainties they may be experiencing.

Assumptions

1. Patients were open and forthcoming about their thoughts and feelings about the SCT and associated risks.
2. Patients are experts about the phenomenon of receiving SCT treatment for life threatening diagnosis and are able to interpret their experiences, making meaning over time.
3. The SCT experience represents a potentially life-threatening as well as life-saving treatment option.

Philosophical Underpinnings

The philosophical underpinnings of this study are derived from Ricoeur's phenomenological interpretive approach. Phenomenology is a philosophy and qualitative method of inquiry that encompasses the disciplines of philosophy, sociology, and psychology, in which the purpose is to describe a phenomenon as a lived experience (Heidegger, 1953/1996). Phenomenology was initially described by Husserl and further developed specifically into an interpretive or existential school by Heidegger and Gadamer (Cohen, Kahn, & Steeves, 2000). Hermeneutic inquiry attempts to discover meanings in life experiences and practices that may be unknown to the participant and exceeds merely describing the main concepts and essences (Lopez & Willis, 2004). The purpose of hermeneutics is "reconstruct the internal dynamic of the text, and to restore to the work its ability to project itself outside itself in the representation of a world that (one) I could inhabit" (Ricoeur 1983/2007, p.18).

Although the experience of others is not directly accessible to an outside interpreter, informants' interpretations of their experiences are accessible. The object of analysis for the researcher, in the approach identified by Paul Ricoeur and used here, is the interpretations or meanings of the experience for the informants to gain an understanding about a phenomenon from the participant's point of view and not from the view of an outside observer (Ricoeur, 1983/2007). Ricoeur recognized interpretation (versus simple description) as an essence component to accomplish a profound understanding of the life experiences of human existence (Missel & Birkelund, 2011). Hermeneutic methodology suggests meaning and significance have individual interpretation based on personal variables and cultural influence. The analytic process, according to Ricoeur, describes naïve to explicit understanding that comes from explanation of data interpretation (Ricoeur, 1974/2013). Understanding experience is placed within the paradox of the hermeneutic circle and is only possible when the parts are understood in relationship to the whole; this circular reasoning process represents the interpretative process of understanding (Cohen, Kahn, & Steeves, 2000). As an individual becomes more involved with one component (i.e. part) of the experience understanding on the whole deepens.

In this research methodology the researcher has to trust that important features of the participant's lived experience will be brought up if they are given the opportunity to describe them (Steeves, Parker, & Laughon, 2009). Initially, the researcher's attention will be focused on understanding and interpreting small pieces of data and comparing this

with the meaning of the entire text. Subsequently, the circle will expand as the researcher compares the understanding of one participant's interview to another. Deeper analysis proceeds as the global understanding of the findings is enhanced and causes the researcher to consider richer levels of meaning (Ricoeur, 1974/2013). The cycle of the hermeneutic circle continues as the interpretations of the researcher take the form of narrative text and are subsequently reviewed and rewritten. A unique feature of Ricoeur's tenet is the concept of distanciation which he describes as the linguistic discussion related to the idea of belonging within a historical tradition which we are separated from by distance (Ricoeur, 1983/2007). He describes the process of interpretation is to "render near what is far (temporally, geographically, culturally, spiritually)" (Ricoeur, 1983/2007, p. 35). The findings, which become known in the analytic process, represent the researcher's efforts to present the data in a manner that reflects the meaning of the texts, the cultural context, and describes the essence of the participants' experiences (Cohen, Kahn, & Steeves, 2000). Within the context of this study, it was essential that the relational and contextual features be discerned in order to gain insight into the impact of what life may be like for patients before, during and after treatment with SCT.

Summary

Improvements in the cancer treatments in the last decades have decreased treatment related mortality but patients who are offered SCT are frequently in desperate situations, choosing survival at the risk of uncertain outcomes. The sample for this study

represented a population that is poorly understood and that has not been previously studied. A qualitative approach based on the tenants of Ricoeur was chosen to uncover the experience of SCT patients before, during, and after treatment. The findings provide an understanding of informants' experiences and provide guidance for improved interventions for those preparing for and undergoing SCT.

CHAPTER II
REVIEW OF THE LITERATURE

Problem Identification

Patients with hematological malignancies are frequently candidates for aggressive treatment such as SCT (Rizzo et al., 2006). The transplant trajectory is often defined as occurring in three stages: the pre-transplantation work-up period, which can take 3-6 months or longer depending on type of transplantation, complications, and rate of recovery from previous treatments; the period of active transplantation, which includes conditioning chemotherapy, infusion of stem cells and recovery of neutrophil counts; and the immediate post-transplantation monitoring period, typically defined as occurring up to 100 days post-transplantation, but may range from 1-3 months following discharge from the transplant hospitalization. During this time the patient and caregiver stay close to the transplant center, which for most means living away from home, taking on new roles, altering employment status, and having financial burden. SCT 15-year survivor mortality rates are twice as high as those of the general population (Bhatia et al., 2005). Patients are vulnerable because of risks and complications from their disease and treatment (Bevans, Mitchell, & Marden, 2008; Serna et al., 2003). This sense of vulnerability impacts quality of life, ability to understand information and make treatment decisions, and can cause profound distress.

After SCT there is a high risk for disease relapse, and treatment-related complications can be life-threatening or associated with high morbidity (Copelan, 2006; Pène et al., 2006). Specific treatment-related factors affecting emotional distress remain elusive (Bevans, Mitchell, & Marden, 2008). SCT procedures, duration and long-term sequelae may contribute to profound psychosocial experiences. Understanding SCT patients' psychological experiences across the transplant trajectory will allow nurses to develop interventions for psychosocial support that enhance patient coping and communication, and that provide individualized patient education. The purpose of this literature review is to describe what is known about psychosocial experiences among adult patients receiving SCT.

Literature Search

This review of published literature followed the process described by Whittemore and Knafl (2005). Findings of experimental and non-experimental research designs were included, resulting in a broader understanding of the topic. The relevant literature was summarized and analyzed to derive conclusions about psychosocial experiences of patients who undergo SCT.

Studies were reviewed if they addressed psychosocial factors in patients undergoing SCT and were published in English between January 1988 and December 2012. This time frame allowed for the inclusion of classic studies on this topic (Andrykowski, 1994; Haberman, 1988; Molassiotis, VanDen Akker, Milligan, Goldman, and Boughton, 1996). These findings are still relevant because, although regimen-related

mortality has decreased over the last 2 decades, other risk factors have increased (treating older patients, high-risk diagnosis), resulting in continued high treatment-related risk with related psychosocial issues for patients (Rizzo et al., 2006). Studies were excluded if they focused on non-malignant disease; survivors 6 months or more after treatment; caregivers of patients, children receiving treatment, or nursing staff caring for patients; or used quality of life (QOL) as a proxy for survival or did not examine social or emotional well-being separately from overall QOL.

Data Search and Evaluation

Searches were carried out using several online databases: Cumulative Index to Nursing and Allied Health Literature, Psychology Information, and PubMed. Keywords were psychosocial, uncertainty, cancer, neoplasm, transplantation, stem cell transplantation, and risk. SCT is synonymous with bone marrow transplantation, blood and marrow transplantation, peripheral blood stem transplantation, and hematopoietic stem cell transplantation—terms also used in the search. Reference lists of relevant articles were reviewed for additional sources.

Of the 200 articles retrieved, 26 (Appendix B) met the inclusion criteria. Qualitative research methods were used in 15 studies, quantitative methods in 9 studies, and mixed methods in 2 study. Nine studies were retrospective (about past SCT treatment). Eighteen studies were conducted during treatment and 10 of these were longitudinal. Nurse researchers conducted 17 of the studies. The nine international

studies were conducted in the United Kingdom, Finland, Australia, Belgium, Spain, and Iran. The remaining studies were conducted in the United States.

Some authors have identified separate phases of SCT treatment in which psychological and physical stressors differ and result in varying behavioral and psychological responses (Haberman, 1988; Andrykowski, 1994). Because treatment related patient stressors may differ during the period before treatment initiation, during the hospital course, and during the outpatient treatment period (3 to 6 months after transplant) this paper is organized according to these chronological phases.

Findings

Before Treatment Begins

In prospective studies Bywater and Atkins (2001) and Cooper and Powell (1998) found that informants felt that they had no choice about having SCT treatment because of the aggressive nature of their disease. Participants described fighting for survival and fearing death. Findings were similar in retrospective studies. Fear of death is magnified not knowing if treatments will work (Cohen & Ley, 2000). Patients undergoing SCT often assume the stance of fighting the illness (Cohen & Ley, 2000; Ersek, 1992; Hacker & Ferrans, 2003; Farsi, Nayeri & Negarandeh, 2012). Cooper and Powell (1998) found that patients acknowledged the lethal nature of SCT and felt that the care team was there to bring them back from near death. The main psychosocial responses reported during this phase are uncertainty, anxiety and depression, and the need for information and increased knowledge.

Uncertainty. SCT recipients experience many features of uncertainty (Saleh & Brockopp, 2001). Haberman (1988) described uncertainty as a factor that patients needed to cope with when making the decision to undergo SCT. Upon committing to treatment, there are uncertainties related to survival, complications of SCT, achieving a disease-free state, and QOL. Haberman (1995) found that many patients expressed ambiguity and uncertainty, and some thought SCT would be similar to their previous experience with chemotherapy, only more intense. Patients viewed knowledge of survival odds or risks as a means to impose order and meaning to their suffering. Some redefined grim survival statistics to gain a sense that their personal survival chances were greater (Haberman, 1995; Kahn & Steeves, 1995). Lee, Fairclough, Antin, and Weeks (2001) examined physician-patient dyads' estimates of related mortality, cure with SCT, and cure without SCT vs. actual treatment-related mortality and disease-free survival among patients at least 1 year after SCT. Findings indicate that when treatment-related mortality is low, there is concordance between the patients and their physician's estimates. Among low-risk patients, 80% estimated cure with SCT vs. 62% of physicians; the actual outcome was 52% cured. But when treatment-related mortality risk is high because of type of transplantation and status of disease, patients are more optimistic in their estimates (80% of high-risk patients expected cure with SCT vs. 31% of physicians, with 10% being the actual percentage cured).

Depression, anxiety and related responses. In a study of more than 400 SCT candidates, **depression** was identified in one-third of subjects. Those with higher levels

of mastery and optimism experienced lower distress (Baker, Marcellus, Zabora, Polland, & Jodrey, 1997). Among 76 patients 68% experienced a high level of worry before SCT, the most prevalent and distressing symptom reported. Symptoms included **fatigue**, appearance change, and worry (Bevans, Mitchell, & Marden, 2008). Fatigue is an almost-universal symptom experienced by patients with cancer, and occurs throughout the SCT experience. The psychosocial impact (distress) of fatigue can be quite profound, in part because it serves as a constant reminder of the patient's vulnerability, other unpleasant symptoms, and an uncertain future (Mast, 1998).

The high level of anxiety most patients undergoing SCT experience before treatment begins is detrimental to their learning about treatment (Andrykowski et al., 1995). Molassiotis, VanDen Akker, Milligan, Goldman, and Boughton (1996) reported that patients experienced low self-esteem before transplant and self-esteem remained low through the transplant process, before transplant, and at discharge. Of 50 SCT candidates in Trask et al. (2002) study 50% reported psychological distress and exceeded the threshold level for significant levels of anxiety and 20% experienced clinically significant depression (Trask et al., 2002). Prieto et al. (2005) also reported an increase in anxiety before SCT when compared longitudinally. Farsi, Nayeri, and Nagarandeh (2012) found that at diagnosis, participants perceived their disease and SCT treatment as threats and experienced more fear of death than later in their treatment course. Before diagnosis, they disregarded or misconstrued disease signs and symptoms, but after diagnosis their symptoms became a source of anxiety.

Need for information/knowledge. Some patients believe knowledge helps them stay in control and reduces anxiety (Cohen & Ley, 2000; Cooper & Powell, 1998). Seven participants interviewed 1 month before SCT initiation indicated a high level of uncertainty about preparing for future treatment, and, despite information provided, still felt unprepared for the unfamiliar experience (Bywater & Atkins, 2001). Patients felt the amount of information they had received was not comprehensive enough to relieve their anxiety (Shuster, Steeves, Onega, & Richardson, 1996). Patients want to receive varying amounts of information. Participants in Cohen and Ley's (2000) study expressed extreme fear after reading the informed consent. Some researchers have found that patients feel they receive too much information, which creates fear (Hacker & Ferrans, 2003; Tarzian, Iwata, & Cohen, 1999) and conversely, that lack of information leads to stress (Heinonen et al., 2004). To manage their stress, patients may be reluctant to fully acknowledge the risks or possible negative aspects of SCT (Bywater & Atkins, 2001) (Appendix C).

During Treatment

After admission for SCT treatment, patients must cope with severe physical symptoms and the emotional implications of loss of control, increased dependency on others, isolation, fear, anxiety, and distress. They experience high levels of anxiety related to unpredictable progression of SCT treatment (Shuster, 1996). Patients respond to the challenge of the situation in their own ways. Steeves (1992) reported that patients found meaning in the SCT experience by finding a place for themselves in the social order of the inpatient environment. They may normalize or minimize the experience

(Steeves, 1992). Some change their attitude and mentally escape from their situation (Shuster, Steeves, Onega, & Richardson, 1996).

Vulnerability. Fife et al. (2000) measured coping, depression, anger, uncertainty, anxiety, and vulnerability in patients undergoing SCT. They found that the time during treatment but before stem cells are infused patients experience the highest levels of emotional distress (anxiety, depression, uncertainty) and vulnerability. Prieto et al. (2005) reported anxiety decreased over the first 14 days after SCT and depression peaked on day 7 after SCT and remained higher than before SCT at the time of discharge. Participants reported managing by using cognitive coping (positive reframing), avoiding (strategies to evade problems), using spiritual resources (prayer, trust in God, reading spiritual literature), and being active (making a plan to deal with problems, seeking more information) (Fife et al., 2000). Cognitive coping was associated with decreases in depression, anger, and uncertainty, and avoidance coping was associated with increased anxiety. Coolbrandt and Grypdonck (2010) found that patients feel most vulnerable when their blood counts are at the lowest point (1-3 weeks after chemotherapy), correlating with a loss of physical and mental strength. Cooper and Powell (1998) reported that patients experience pervasive vulnerability. Patients may feel vulnerable about future illness and death, with some likening their experience to being on death row (Baker, Zabora, Polland, & Wingard, 1999). Feelings of vulnerability may also be linked to a sense of personal exposure and shame (Cohen & Ley, 2000).

Isolation. The physical and emotional isolation patients experience is a major psychological factor during hospitalization for SCT. Although some patients (Cohen, Ley, & Tarzian, 2001) feel a profound sense of disconnectedness (likened to prison) during this period of isolation, others perceive isolation as a way to prevent their family members from seeing them at their worst (Cohen, Ley, & Tarzian, 2001; Thain & Gibbon, 1996). Patients may also fear that infection and treatment-related fatigue will create social isolation (Stephans, 2005). It is difficult to ascertain if distress originates as the result of isolation or from dealing with life-threatening treatment for a life-threatening diagnosis (Molassiotis et al., 1996).

Positive attitude, hope, optimism, and courage. Hope, optimism, and courage have been described throughout the entire transplantation process, but especially during the time when treatment side effects are most intense (Molassiotis et al., 1996). Patients may view SCT as their final hope for cure and know that it may hasten death (Cooper & Powell, 1998; Haberman, 1995), leading to a struggle between embracing hope and acknowledging treatment-related risks (Ersek, 1992). Patients may willingly relinquish control to professionals and minimize their focus on perceived treatment-related risks to improve treatment-related outcomes (Haberman, 1995). Patients who feel connected to God may experience increased hope (Saleh & Brockopp, 2001). Coolbrandt and Grypdonck (2010) used the metaphor of writing a positive story to describe the strategies patients use to maintain their belief in a happy ending to their SCT treatment. Participants in their study recognized their nurses' quiet, reassuring manner in carrying them through

the worst times when their blood counts were lowest and they did not have the physical or mental strength to maintain a positive attitude. Saleh & Brockopp (2001) also found that staying positive allows hope to visualize survival and potential cure. The informants in the Thain & Gibbon (1996) study reported taking a positive approach and feeling lucky to be given a chance for cure. The authors speculated that patients who have a strong motivation to beat their illness may experience a sense of failure if they admit to fearing death. Other researchers have found that patients place importance on keeping a positive attitude, working through the negative feelings, and turning control over to God (Stephans, 2005; Ersek, 1992; Hacker & Ferran, 2003).

Concerns about family. Patients acknowledge the importance of family support, but also have concerns about the stress and financial burden their illness and treatment places on their families (Stephans, 2005; Hacker & Ferrans, 2003). Patients may experience an additional burden in having to teach family, friends and acquaintances about their condition (Tarzian, Iwata, & Cohen, 1999). In a more positive light, some patients may experience SCT treatment as a time at which to affirm their relationship with their family (Saleh & Brockopp, 2001) (Appendix D).

After Discharge

Patients in the after-discharge period have questions about their continued recovery and getting back to a normal state, and they may experience grief over the loss of life as it was (Cohen & Ley, 2000). Patients may experience residual side effects of the chemotherapy (fatigue, nausea, weakness, and altered taste and appetite). Many still

need assistance with physical care, medication administration, transportation for clinic visits, and monitoring for side effects. At hospital discharge there is still considerable uncertainty about the success of the treatment in curing or controlling their disease. Restaging with bone marrow biopsies, scans, and laboratory studies is performed at 30 days (and again at 60 and 100 days) after the day of stem cell infusion.

Expectations. Despite feeling positive about their decision to have SCT, patients with higher expectations about functioning may feel distress and be dissatisfied with their recovery (Hacker & Ferrans, 2003; Andrykowski et al., 1995; Heinonen et al., 2004). Andrykowski and coauthors (1995) suggest that the amount of information given to patients before SCT needs to take into consideration both the risk for increased anxiety and the possibility of future disillusionment. Molassiotis, Van Den Akker, Milligan, Goldman, and Boughton, (1996) found that worried patients were angry-hostile and anxious before and at the time of SCT and in the first 2 to 3 weeks after transplant. They suggest that patients with high levels of worry would benefit from professional psychological support to overcome their mood disturbance.

Uncertainty. More than half of patients may experience fear when leaving the inpatient hospital environment (Baker, Zabora, Polland, & Wingard, 1999). They may be uncertain about their ability to resume social and work roles, raising financial concerns (Hacker & Ferrans, 2003; Baker, Zabora, Polland, & Wingard, 1999). Study participants have described feeling suspended between fear and hope, experiencing uncertainty and doubt that linger for months after SCT (Farsi, Najeri, & Negarandeh, 2012).

Unpredictable progress through treatment and an uncertain future prompts high levels of anxiety (Haberman, 1988; Shuster, Steeves, Onega, & Richardson, 1996; Thain & Gibbon, 1996).

Existential questioning. Many researchers reported that patients establish a new sense of what is normal in their life and also a new meaning of the illness and treatment, because of their physical, emotional, and social changes and suffering during SCT (Andrykowski, 1994; Haberman, 1995; Kahn & Steeves, 1995; Coolbrandt & Grypdonck, 2010; Xuereb & Dunlop, 2003). For some patients their SCT was a life changing experience because of long-lasting treatment related side effects or complications such as chronic graft vs. host disease (Heinonen, 2004). After SCT patients may attempt to find or construct a sense of wholeness in response to their situation (Stephans, 2005; Steeves, 1992). They may feel they have another chance at life, (Cooper & Powell, 1998) a new gift, or rebirth (Stephans, 2005; Farsi, Najeri, & Negarandeh, 2012). With this chance comes a responsibility for not wasting it, by exercising caution about how they live after their experience (Stephans, 2005; Coolbrandt & Grypdonck, 2010). Patients may experience a new sense of agency, a regaining of control over aspects of their lives including their health (Xuereb & Dunlop, 2003). For many patients, the SCT experience is a major transition point in their lives, with an importance similar to a birth or marriage (Cohen & Ley, 2000; Stephans, 2005) (Appendix E).

Implications for Nursing Practice and Research

Several of the emotional responses (anxiety, depression, fear, and uncertainty) experienced by patients undergoing SCT are present throughout the treatment phases, although influencing factors may differ. An understanding of these dynamic influencing factors is necessary to develop and implement nursing interventions to address emotional responses.

Implication for nursing practice. The findings suggest that SCT patients will most benefit from educational material and techniques when nurses consider patients' desires about what they want to know, their levels of anxiety, and their emotional responses. Providing education in stages may be helpful. Applying the "ask, tell, then ask again" format at each educational opportunity may be beneficial as nurses and other clinicians ask patients what they understand, then teach, and then ask them what they know. This would allow patients time to absorb the information provided and ensure they have the knowledge they need to prepare for their experiences during and after transplant. It is important to remember that even those who have no questions need some information. Balancing what they need to know to make informed decisions and what they want to know is important and challenging.

Implicit in the education process is the assurance that the patient has the information needed to make an autonomous informed decision. Many patients pointed to a lack of choices and a sense of vulnerability, which raises questions about their autonomous decision-making (Bywater & Atkins, 2001). To support patients' decision making nurses, clergy, or social workers can explore patients' contextual influences

during their decision-making process, including cultural and spiritual beliefs (Bywater & Atkins, 2001), and their perceived choices and vulnerability. Concern emerges when patients minimize risks of treatment and are reluctant to discuss the negative aspects. Establishing what patients' truly understand is important- they may understand the risks and still see the transplant as the “only option” and not want to consider or discuss risks. Concerns about informed decisions might also be mitigated through advance-care planning discussions; the nurse and other healthcare team members can help patients and families explore factors involved in the SCT decision, potential treatment outcomes, and prepare them for all possibilities (Haberman, 1995; Neumann, 2013).

Improved screening instruments to assess emotional difficulties early in the SCT treatment course are indicated (Frick et al., 2006; Jenks Kettmann & Altmaier, 2008; Molassiotis, 1999) to identify psychological issues (depression, high anxiety, and avoidance) and promote an individualized care plan before SCT therapy begins, thereby improving physical and emotional treatment outcomes (Bryant, Heiney, Henslee-Downey, & Cornwell, 1997; Gaston-Johansson et al., 2000; Germino et al., 2013). Most patients represented in these studies were hospitalized for their SCT treatment, but, considering recent trends in performing outpatient SCT, the burden and stress on patients and caregivers (including outpatient or clinic nurses) increase the need for additional outpatient resources.

Implications for research. This review provides a basic understanding of the influence of temporal factors of disease and treatment on the psychosocial responses of

patients undergoing SCT, but further research is needed to better understand the patient experience through the treatment trajectory. Uncertainty emerged as a major influence on emotional responses during the SCT experience (Bywater & Atkins, 2001; Farsi, Nayeri, & Negarandeh, 2012; Cooper & Powell, 1998; Heinonen, 2004; Fife et al., 2000; Coolbrandt & Grypdonck, 2010; Baker, Zabora, Polland, & Wingard, 1999; Thain & Gibbon, 1996; Hacker, 2003); however, uncertainty has not been explored in patients undergoing SCT. Studies of uncertainty in patients with cancer of the prostate, breast, myeloma, gynecological, brain may serve as resources for studying uncertainty in SCT patients (Mishel, 1984; Mishel, 1988; Mishel, 1990; Mishel & Sorensen, 1991; Mishel & Germino, 2010). Studies are needed that further our understanding of whether and how phases of treatment, ethnicity and culture influence patients' responses to SCT. Also missing are studies that evaluate the effect of patient centered education, prior to SCT, on subsequent emotional responses.

Limitations

Findings from international manuscripts included in this review provide a glimpse into the experiences of patients undergoing SCT in different cultures and suggest they are similar; however, there is no study comparing experiences across cultures to establish this with certainty. None of the studies reviewed addressed the role of ethnicity. The following studies, which did not meet the inclusion criteria for this review because of their focus on QOL, have considered ethnicity. Bevans and Marden (2006) examined the health-related QOL and symptom distress among Hispanic SCT patients living within

and outside the United States. They found patients living outside had emotional well-being scores 2 points lower than patients in the United States. In a recent study Cohen et al. (2012) found that ethnicity did not play a significant role in symptoms or QOL as measured by the MD Anderson Symptom Inventory or the Functional Assessment of Cancer Treatment.

Additional limitations of studies included in this review include small sample sizes (Molassiotis, Van Den Akker, Milligan, Goldman, & Boughton, 1996; Hacker, 2003) and lack of attention to issues of rigor, such as achieving saturation (Bywater & Atkins, 2001; Cooper & Powell, 1998; Thain & Gibbon, 1996). Nine of the 26 studies were longitudinal studies, 9 were retrospective, and 18 involved data collected after treatment. However, findings in both retrospective and prospective studies were similar. In quantitative studies similar concepts were measured using different instruments, making comparisons of findings difficult to achieve. However, because of the consistency of results across both quantitative and qualitative studies, the aggregated results reported in this paper provide support for the merit of individual studies.

Summary

The research presented in this review provides the nurse with an initial understanding of the experiences, both positive and more challenging, such as uncertainty and psychosocial distress, experienced by patients undergoing SCT and of changes in those experiences over the course of SCT treatment. Nurses who provide psychological support and care for this population in both inpatient and outpatient settings can build on

the strengths patients bring, such as family support and religious beliefs. Future research that considers the influence of ethnicity is needed, as is longitudinal research that further develops our understanding of patients' uncertainty and its management. Such knowledge will help guide SCT practice, enhance nurses' ability to assist patients in making treatment decisions and cope with psychosocial responses, and establish expectations that are more congruent with life after transplantation. Understanding the influence of these factors on the patients' decision-making processes, QOL, and treatment outcomes will lead to effective nursing interventions for this vulnerable group.

CHAPTER III

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

The purpose of this study was to explore SCT patients' psychosocial experience before, during, and after treatment. The data for this study were collected in semi-structured interviews conducted at a large south central comprehensive cancer center as part of a large mixed method study funded by National Institutes of Health, National Institutes of Nursing Research (grant number R01 NR 05188) that examined QOL and symptoms using quantitative instruments (FACT-BMT and MDASI) and SCT patients' experience qualitatively by conducting semi-structured interviews (Appendix F). Dr. Marlene Cohen was the principal investigator (PI) of the parent study. The aim of the qualitative portion of the parent study was to describe the meaning of experiences of African American, Latino, and non-minority persons having BMT at multiple time points over the course of their treatment and follow-up. There were 164 tri-ethnic SCT patients who participated in the quantitative and qualitative study in 2002 and 2004, after approval was obtained from the Institutional Review Boards of the educational institution. For this study, involving the analysis of the qualitative interviews, approval was obtained again from the cancer center and the educational institution where this principal investigator (also a collaborator on the parent study) is a doctoral student.

Elements within this chapter include a description of the study method. Analysis of transcribed interviews examining informants' experiences used the philosophy and research method of hermeneutic phenomenology. The aims for the parent study are provided in Appendix A. The study setting, participants, data collection, data analysis techniques, study rigor and protection of participants are described below.

Setting

Participants were recruited at a large South Central United States comprehensive cancer center that has the largest stem cell transplantation program in the country. Currently nine-hundred cancer patients per year are treated with stem cell transplantation. During the time of the study a total of 1180 patients (577 in 2002, 603 in 2003) were treated with SCT. There were slightly more (56%) allogeneic transplants performed than autologous. The majority of patients (90%) are from the United States and 10% are international. Data were collected from patients hospitalized at the institution. The Stem Cell Transplantation program has a very active research program with over 30 active treatment protocols. At the time of the parent study the primary SCT unit consisted of a 52-bed unit and employed 136 staff members, which includes 90 registered nurses, 4 licensed vocational nurses, 24 nurse aides, and 18 clerks. In addition, there were 13 Master's prepared nurses, 10 advanced practice nurses, one nurse educator, one Assistant Nurse Manager, and one Nurse Manager. Data were collected while patients were hospitalized or being followed in the outpatient clinic.

Participants

Of the 164 participants in the parent study, 60 participated in semi-structured interviews for the qualitative portion of the study. Purposive sampling of patients was conducted to obtain equal representation from African-American, Hispanic, and Caucasian participants. The following inclusion criteria were applied in the purposeful selection of patients for the parent study: 1) White, Hispanic, or African-American inpatients and outpatients being treated or followed up for SCT at MD Anderson Cancer Center (MDACC), 2) pathological diagnosis of cancer, 3) ≥ 18 years of age, 4) consent to participate, and 5) physically and emotionally capable of completing the research without untoward effects.

Exclusion criteria included: 1) patients who cannot understand the intent of the study (for example, confused patients) and 2) patients whose performance status is too poor (i.e., ECOG or Zubrod greater than 3) to allow them to complete the survey or interview.

Minority Inclusion

As the researchers in the parent study identified, studying populations that are ethnically diverse is very important and is not often achieved in oncology or SCT research studies (Cohen, Phillips, & Palos 2001). The parent study was designed to include an ethnically diverse sample. In the year and state where it was conducted 48% of the population is white, 36% Hispanic, and 12% African-American (U.S. Census Bureau, 2004). This ethnic distribution differs from the total U.S. population only in that a higher

percentage of Hispanic citizens live in that state than in the country as a whole (U.S. is 14% Hispanic, U.S. Census Bureau, 2004). Because the largest racial minority groups in the state and the nation are the African-American and Hispanic populations, the ethnic minority sample selected was African-American and Hispanic. The number of participants in each ethnic group (20 respectively) provided sufficient data to determine if themes vary by race.

Protection of Human Subjects

Internal review board approval was obtained prior to the parent study and for this analysis. All relevant guidelines were followed to protect the rights of study participants. The parent study posed minimal risks to informants. Informants may have experienced some inconvenience due to the time involved in being interviewed and completing the quantitative measures. They may have felt uncomfortable discussing sensitive topics. Informants were assured that their participation was voluntary, and that they could have withdrawn from the study at any time without any consequences. The interviewers were experienced nurses who were familiar with dealing with sensitive topics and were prepared to make psychiatric/mental health referrals, if needed.

Informants' identities were protected. All informants were assigned a study code number. Pseudonyms were given to all informants and the people about whom they talked. Other identifying information was altered. Only the investigators and secretarial staff had access to the tapes. No written material has the informants' names. Transcriptions of tape-recorded interviews were coded with pseudonyms. Data (original taped interviews, hard

copies of transcribed interviews, and computer files on compact disc CD) are stored in a locked filing cabinet.

Patients who participated in the parent study were given a copy of the consent form for their review. The research nurse and GRAs approached patients who meet the study criteria for inclusion in the study, aspects were explained, and patients who were willing to be interviewed were consented.

Possible benefits for informants included the value of reflecting on their experiences. All informants had the opportunity to talk with an interested nurse. Informants may have also experienced some satisfaction from participating in a study that may help determine the most useful way for healthcare providers to care for cancer patients having SCT.

Data Collection

The first interviews were conducted prior to admission for high-dose chemotherapy and after information about SCT, side effects, complications, and prognosis were given by the healthcare team (physician, clinic nurse, physician assistant, and SCT coordinator). Patients were also provided with written information either in a booklet format or compact disc. Informed consent for their disease treatment (either on a research protocol or standard of care) participation in the parent study (ID99-175) was obtained. There were 60 informants in the qualitative study, 20 Caucasian, 20 Hispanic, and 20 African-Americans. Semi-structured interviews were completed before treatment began, at engraftment (the time of blood count recovery), and day 30, 60, and 100 after stem cell transplantation. Transcripts of the interviews were be analyzed in order to

explore SCT patients' psychosocial experience before, during, and after treatment. Seventy-nine per cent of the participants completed all 5 interviews. The informants were identified, informed consent obtained, and interviews conducted over a period of 2 years. Interviews averaged one hour in length and were conducted by ethnically matched research team members. The parent PI reviewed interviewers' techniques and transcripts weekly to ensure interviewers used equivalent techniques. The available data includes the interviewers' field notes.

Data Analysis

In phenomenological research the goal of analysis is a thick description that captures the experience from the perspective of the informant in its fullest and richest complexity (Allen & Jensen, 1990). This analysis provides a detailed description of the meaning of having a SCT. The PI of the parent study, with the help of the research assistants, supervised and verified verbatim transcription of the audiotapes of each interview.

The hermeneutic phenomenological method described by Ricoeur (1992) guided the data analysis. The aim was to make the participant's thick description of the experience as understandable to others as possible. Once an understanding of the overall text was obtained, phrases in the text were highlighted and tentative theme names were identified. . Data were examined line by line and all the important phrases were labeled with tentative theme names. Exemplars were identified that help to describe the theme. They were bits of textual data in the language of the informant that captures essential meanings of themes.

Analysis of data included noting elements within themes. The final label included the range of the identified theme that is inclusive of different elements.

After exemplars were identified, they were clustered, according to observed similarities, into themes for each individual informant. Themes and exemplars were compared for similarities and differences within each informant's transcripts and across all informants' transcripts. Important contextual features, such as ethnicity, and how the experiences vary with these features, were included in the analysis. This analysis identified patterns and relationships among the various informants' data and form a coherent picture of the whole. Descriptive analyses of the demographic data were conducted in order to characterize the sample (Appendix G).

Analysis began with the researcher reading the transcribed interview data. Comments from individual participants were linked with other participants' related comments to establish data points. Mental images began to emerge and possible content themes were considered. During the initial analysis a tentative understanding of the data was obtained as the researcher becomes immersed in readings of the transcripts. Key to this step in the methodology was the identification of essential elements from each interview and about each participant (Cohen et al., 2000).

Central to phenomenological methods is the consideration and understanding of the contextual features that are meaningful to the informants. It is unclear precisely which features will be most meaningful to the informants. Type of cancer, type of SCT, ethnicity, and other sociodemographic differences may be meaningful. The data were compared to

assess if any of these features were revealed. These features were considered in the analysis, in addition to the field notes and the interview data, in order to understand their significance. Moving forward, the data were subject to reduction as the researcher made decisions about the significance of emerging findings in relationship to the overall whole. The purpose of this step was to identify recognizable patterns of meaning to facilitate the development of themes and text exemplars (Cohen, Kahn, & Steeves, 2000; Lopez & Willis, 2004).

A process of writing and rewriting, which is crucial to phenomenology (Ricoeur, 2007), was used to move from identification and comparison of themes to forming a coherent picture of the whole. As the researcher gained insight into, and a tentative understanding of, the meaning of the experience of these patients as conveyed through the exemplars and in the themes, this understanding was summarized in writing and shared with the dissertation committee members. This served to document the process and drive the transformation of the field text to a coherent text through a reflective process of writing and rewriting.

The researcher reviewed the interviewers' field notes for additional data that informed the emerging findings. These field notes contain details of the context of the interviews and other details that the tape recordings may fail to capture such as emotions felt and displayed. Field notes include observations concerning all activities and social exchanges that were observed. The interviewers recorded their field notes immediately after each interview and expanded the notes later. The interviewers attempted to keep the time

period between a field experience and writing expanded notes on that experience to less than 24 hours.

Scientific Rigor

The number of patient interviews used for analysis in each ethnic group was 20 (n=60). Most, but not all participants, were interviewed during each of the time periods. The usual way to determining sample size is through saturation, which indicates that researchers conduct interviews until they no longer hear new statements from informants and the data are increasingly redundant (Streubert & Carpenter, 2011). Although saturation was achieved before the conclusion of analysis the decision was made to review all the available data sets. The sample size in the parent study was based on previous research that provided detailed description of other experiences (Cohen et al., 2000). This number exceeds the number of interviews and informants used in other research and enabled the researcher to analysis the data from sufficient numbers of minority group members to accurately understand themes that vary by ethnicity, allowing phenomena to be captured in its complexity and was more than sufficient to obtain thick descriptions of the experiences under study. The PI of this study read all informants' interviews until saturation was achieved and also read the remaining (past the point of saturation) interviews to ensure that all themes and variation in the data were discovered and all participants were represented.

Sampling in phenomenological studies is purposeful, not random, since the issue of the findings is "trustworthiness" rather than generalizability. Demographic

information and data are collected under rigorous conditions so that people in different settings who read the results are able to decide whether the findings will apply to their setting. The informants are the experts in the experience to be studied. The aim is to balance variability and homogeneity (Cohen, Kahn, & Steeves, 2000). Limiting the sample to patients from one SCT unit made it easier to describe the context in detail and the variability of the patients should provide enough heterogeneity to allow a wide exploration of the experience of having a SCT.

The key elements in evaluating trustworthiness of a qualitative study are credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). In the parent study credibility and dependability are demonstrated by the patient's descriptions of the experience of SCT treatment and the way the study was conducted, contributing to the trustworthiness. Patients were interviewed 5 times over a period of 3 months (before treatment began and at set points during and after treatment). Participants were selected after they signed informed consent for treatment. Demographic information (including ethnicity) was collected on informants. Clinicians with considerable experience (over 7 years) were on the parent research team and included this researcher. Investigators, who study the experience of patients undergoing SCT, or other life threatening treatments for life threatening medical diagnoses, will evaluate the transferability of the findings (Missel & Birkelund, 2011). An audit trail was maintained and made available for other investigators interested in evaluating for transferability. Confirmability was assured by having additional researchers participate in the analysis

and confirm the findings of the PI. The initial data gathering process followed a precise method that was continued in the analysis phase of this study.

Summary

Interpretive phenomenology is an appropriate methodology for this study because it supports a holistic approach to describing and understanding patients' experiences on the health-illness continuum. Nurses require this understanding in order to share knowledge about the patient with other healthcare team members and to prescribe interventions that are meaningful in addressing the patients' needs (Cohen, Kahn, & Steeves, 2000).

Hermeneutic phenomenological research provides the means to better understand the patient experience through the interpretive process. Morse (2009) writes the "description pointing out the obvious and the not so obvious (until it is pointed out) but the interpretive analysis is the creative contribution.... identifying the meaning in what we all see, making the trivial profound, and the obvious significant" (p. 579). This method of inquiry contributes to our understanding of SCT patients' experiences across the treatment continuum.

CHAPTER IV

ANALYSIS OF DATA

This chapter contains a discussion of the participants in the study and the study findings. The three overlapping themes that emerged from the analysis, Facing the Fear, Getting Through, and Going Beyond, Forward, are described, as are subthemes that influence the meaning the themes had for the participants. Also described is the influence of Like a Bridge I Never Crossed Before on the three overlapping themes (Figure 1).

Description of the Sample

Of the 164 participants in the parent study, 60 participated in semi-structured interviews. Purposive sampling ensured equal representation of African-American (AA, n=20), Latino (n=20), and Caucasian (n=20) participants. Inclusion criteria were: 1) White, Hispanic, or AAs being treated or followed for SCT at a large south central US comprehensive cancer center, 2) pathological diagnosis of cancer, 3) ≥ 18 years of age, 4) consent to participate, and 5) physically and emotionally capable of completing the interviews without untoward effects. Exclusion criteria were: 1) could not understand the intent of the study and 2) poor performance status (i.e., ≥ 3 ECOG or Zubrod score). The goal of SCT may be either control of disease, as in multiple myeloma, or cure of disease. For 18 of the participants the intent was control rather than cure. Of these 11 were African American, 4 were Latino, and 2 were white. The goal of their SCT may have had an impact the meaning SCT had for informants.

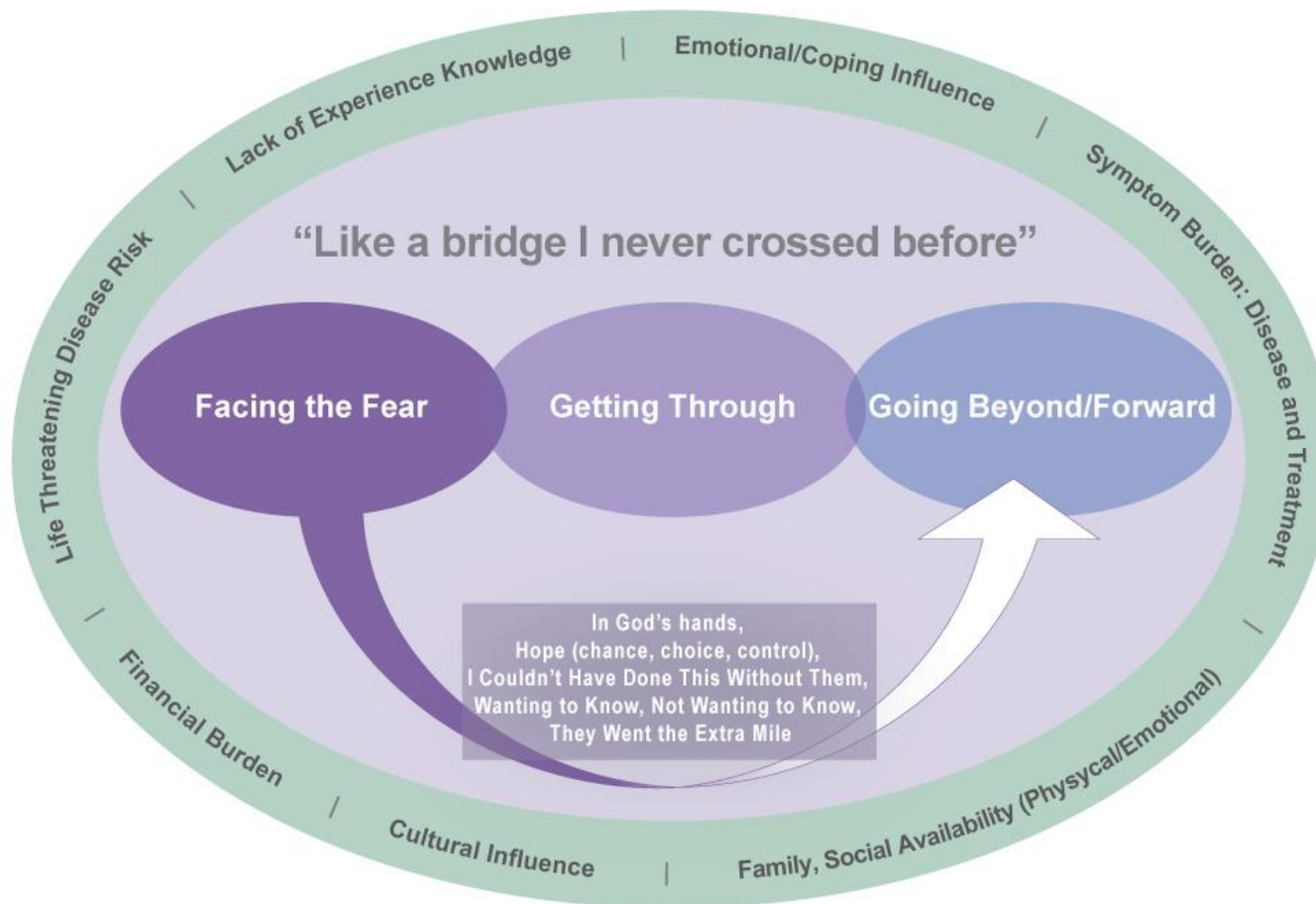


Figure 1: Major themes (3 ovals) and subthemes (in box) related to the SCT experience. Contextual features identified by informants indicated in the outer ring.

Findings

Three major overlapping themes emerged, based in the experiences of the participants within a given time period. Major aspects of Facing the Fear occurred before SCT treatment began, Getting Through during active treatment, and Going Beyond, Forward primarily during the time period after SCT (30 to 100 days after treatment). Like a Bridge I Never Crossed Before influenced the meaning experiences had for participants across the 3 themes. This phrase, spoken by a Latino man, exemplifies the experience of SCT, a life threatening treatment for a life threatening diagnosis. SCT patients may wonder if the metaphorical bridge they chose to cross when they made the decision to have SCT is sound and what they will find on the other side. They live with the knowledge that wondering about the answers to whether the decision was good and the result worth the risk may be preferable to the certainty of knowing the outcome. The tension between the distress of uncertainty, which many informants felt and expressed, and not wanting a known but unwelcome outcome is central to Like a Bridge I Never Crossed Before. The transition through the phases of SCT was not a linear process and was influenced by contextual factors of life threatening disease and treatment, lack of experience or knowledge, emotional/coping, culture, symptom burden, and financial burden. The 3 major themes were influenced by subthemes of Hope for Chances, Choices, and Control; In God's Hands; I Couldn't Have Done This Without Them; Wanting to Know, Not Wanting to Know; and They Went the Extra Mile (Appendix H).

The contextual factors and subthemes may carry different weight within the major themes and within ethnic groups.

Overlapping Themes

Informants provided great detail when discussing the experience of discovering their cancer diagnosis and their previous treatment. Several (5-6 in each ethnic group) described delay in diagnosis, misdiagnosis, or delay in starting treatment due to lack of insurance, disbelief about diagnosis, or resistance to starting treatment.

Facing the fear. As one middle-aged Latina professional woman described it, she was referred for cancer care but only learned the nature of the referral from the phone greeting at the referral site.

“...I had too much protein.... and I had to go see another doctor... dialed the number, and they said Cancer Center, I thought I had the wrong number, so I hung up, and then I dialed it again, and again it was Cancer Center.... told you need to come right away.... probably Multiple Myeloma, but we need to do a bone marrow biopsy; which was completely foreign to me, I had no idea what that meant”.

In relation to the diagnosis of cancer, previous treatment, and the need for SCT, informants in all three ethnic groups described fear, loss of control, urgency to start treatment, along with a sense of guilt, depression, anxiety, nervousness and/or helplessness, and uncertainty about what to expect from SCT. Having fear or being

scared were the most commonly expressed feelings. They felt bad when others lacked empathy about their feelings and anger when told they looked good, like they were not even ill. They described their life as stopping or that life was not the same. Informants identified coping strategies including maintaining a positive or optimistic attitude, remaining tranquil, being hopeful, and finding distractions. A Caucasian middle-aged male informant described efforts to “remain neutral, not positive or negative because his having cancer was God’s will”. Many patients (more frequently expressed by AA informants) described a process of transforming (turning point) or setting aside fear, denial, worry, shock for more positive outlook “getting through”, “anticipate success”, “cease dwelling on the negative”, “an interruption in life got to get through” “dedicate life to getting better”

Getting through. The challenge of going through SCT was discussed by informants during active treatment with SCT and explains their will to sustain hope and motivation in the face of emotional and physical distress. As one Caucasian informant said “it’s scary and hard to comprehend, don’t think about it, just get through it”. Getting Through for participants of all ethnicities with a variety of knowledge of what to expect included expressions of “let go and let it happen, did not know what to expect” vs. “knew what to expect” [and wanting] “to get started and “get it over.” Latino informants said: “[I] had to take this option,” “best choice to conquer cancer,” “always benefit and risks in life,” “had to do or die,” “have to have,” ”put 100% into it,” “every little thing you can

die...anxious about that...once got SCT worst was over,” and “seriousness makes me think.” One middle-aged Caucasian man stated:

some ways you are a little apprehensive about what is happening because you are not sure of the outcome but when you are faced with the situation like I had, it is actually the only alternative for survival,

As at every time period, Like a Bridge I Never Crossed Before was part of Getting Through. Three AA men with multiple myeloma questioned the efficacy of treatment, saying: “cancer might come back because I am getting my own stem cells”; maybe I should “postpone [treatment] until [doctors] will have something better”; and treatment is “just experimenting”. Another middle-aged AA man both questioned the treatment choice and trusted those who provided it:

“I don’t know if it would have been better. It might be better that I used my own (stem cells). It is just something that I am thinking. Just logic, if you have something in your body and you put the same thing back in it, you kind of think that it would still be there, but I trust my doctors and if they felt like it would improve if I would use mine, I was willing to go along with that.”

Another middle-aged professional AA male with multiple myeloma said:

... if I get complete remission, I won’t die tomorrow, it will be the day after tomorrow.... but complete remission is like the Holy Grail of this whole enterprise.... Who knows how long I will be in remission before it comes back....

that seems to be the most certain thing there is about this whole situation... this is a tough disease...a very smart disease, and it will be back, sooner or later...

During this phase of SCT the physical symptoms were difficult and added to informants' stress and challenged their coping skills. One informant described physical symptoms as: "harder than expected, requires 5 months of your life, emotionally, physically and mentally, not I did not know [but] can't know until you are doing it." Another said: "So sick it scared me too.... Family wondering if I was going to make it...."

Particularly troubling for those informants who experienced it were changes in mental status. One said:

The most difficult experience...losing of one's capacity to really be conscious of all of the things, organized, and being able to think clearly. One has a lot of nightmares and lots of crazy like thoughts; with all of that chemo... It is what tormented me....

Going beyond, forward. Participants interviewed at day 30, 60 and 100 were focused on their hopes for the future, going beyond their cancer diagnosis and treatment. However, Like a Bridge I Never Crossed Before remained with them influencing the meaning of Going Beyond, Forward for them. Almost half described the uncertainty of Like a Bridge I Never Crossed Before. They still did not know how they would "come out" or "what to expect." Distressing experiences included being scared ("disease would

return”, “to push self too much for fear of feeling so bad again”), worried (“significance of new symptom”, “not know what to expect”), isolated (“from outside world and people”, “forgotten about them”), frustrated (having the “spirit and mind of a young person but body going with other parts”), and lack of control (“sort of out of the loop” waiting on blood counts and letting others do things). Almost half of the Caucasian informants spoke of the risk of treatment, saying: “told me I could die,” “this was a very serious procedure,” “there were no guarantees,” “anything could happen,” and “live or die by the [stem cell] bag.”

A young AA woman with many complications expressed regret about her decision to have treatment saying:

“I was walking and now I am not walking. Right now it is like, the best way I can describe it is, I’m in a lake in the middle, either I can go back or I can go forward.... right now I am stuck in the middle. Honestly, if I had to do it over again, I wouldn’t”

In contrast, another AA woman spoke of renewed hope: “hope, they used word, cancer-free, never used that before, revived my spirit for the hope”.

Several informants reported looking at life very differently: “affected life tremendously, turns whole life around, totally different,” “no other choice but to look at life differently,” and “cancer threatens that [which] you know.” An AA male said the process: “made me respect life more, want to live, so many nice people [at cancer center]

changed my attitude [about racially different people], I come from small town where white folks are snotty”.

While the physical effects of treatment had decreased for most informants in this later phase, over half still reported fatigue and weakness. Gastrointestinal symptoms were the second most frequently reported physical symptom, with taste alteration and anorexia described as the “most disturbing” and causing the “greatest agony”. Six informants described difficulty with mental acuity at days 30 and 60 interviews. Eight of the 26 informants who received allogeneic SCT reported symptoms related to graft vs. host disease.

Subthemes

The themes were influenced by subthemes of Hope for Chances, Choices, and Control; In God’s Hands; I Couldn’t Have Done This Without Them; Wanting to Know, Not Wanting to Know; and They Went the Extra Mile (Figure 1). The subthemes may vary in significance within the major themes and within ethnic groups.

Hope for chance, choice, control. Informants across all phases of transplantation and ethnicity identified SCT as their hope for a chance for survival or only choice to control their disease. Several informants said their lives would end if they did not have the SCT and they wanted more time even if SCT was not a cure for their disease “see if I can overcome disease”, “I would have been dead”, “insurance to keep in remission”, and “tired of hearing you have 6 months or 1 year to live”, “going for home run - have 15%

chance”. An AA older (60’s) woman with previous diagnosis of breast cancer and now secondary leukemia conveyed Hope for Chance, Choice, Control:

“Cure, yes. Cure basically. That is the bottom line. Don’t want to have the fear that this could just pop up at any time. I am taking control of my life with this and if I don’t do it, I mean it is an ultimate end, but if I don’t do it, I will always say, I should have done this. I have to have to take the chance. There is no way I could say no to this”.

Hope for Chance, Choice, Control includes an implicit tension. As for the AA woman immediately above, many who had been given a choice to have SCT or not, did not see a choice. This was the “last road” and they had to take it, it was the “final card” and they had to play it. A few Latino and Caucasian informants said that science and medicine might not be advanced enough yet to provide them with a cure for their disease and hoped they would live long enough for science to catch up. Informants identified “getting better” as the outcome verses cure. They spoke of SCT as way to “get better help” and that SCT was their “best option” and in their “best interest.” A few mentioned that SCT “provided treatment if not cure”. Several informants acknowledged they were facing their own mortality, saying that they realized they “might not walk out of the hospital” or “go home again”.

A few informants mentioned their gratitude to live at a time when SCT was available to them and to receive treatment at “a very hope-giving place.” They expressed

their hopes also “gratifying to know [I am] on [the] right track”, and “engraftment [promotes] more positive feelings, with hope for no setbacks” and positive expressions “stop and smell roses,” “not as overwhelmed as I thought,” “happy I am doing well”, “grateful someone out there saved my life, so blessed”, “a bad day is just that, a day, the next will be better”, “have patience”, “stay positive”, and “with faith in God everything will be alright, God is on my side”.

One AA woman whose father had the same type of cancer said she was encouraged because technology had improved since her father’s death. Another Caucasian 50 year old woman informant was hopeful of long remission so that with further “research something even better” will be found. Knowing that someone unknown contributed to the treatment provided a sense of gratitude. A man who traveled from Mexico for treatment said: “the world has opened up to me because someone is giving life. It is very beautiful to know that there are still good people in the world”. An AA professional woman informant share how she maintained hope:

”it is very important that you maintain a certain sense of optimism going through this kind of process...even though you need to be involved in your treatments, you have to have a certain amount of detachment so that you don’t succumb to feelings of hopelessness and all of that”

Informants expressed a desire for the future and returning to a normal life: “putting life back together and focusing on work, family and feeling better”, “getting

their lives back to some degree of normalcy”, “independence back”, “get back to work”, and to have “clean blood and be able to start building new life”, “future of whatever God wants”. Some informants were more specific said: “doing normal things with family”, ”study”, ” back to work”, “swimming without intravenous catheter”, “immune system recovery”, “working on daughter’s wedding”, and “riding motorcycle”.

For some, maintaining hope was difficult in the face of what was happening to them. Informants described: “terror of chemo wiping out immune system”, “not sure of outcome [but] only alternative for survival”, and “different perspective on life, thought I was in ‘death chamber’ [during aggressive chemo and cells infusion] now on way back up“. One participant’s family was fearful she was dying because she was so ill: “3-4 days really bad, scared me”. Others said: “felt alone” and “scared, didn’t know how sick”.

A woman who received a matched unrelated transplant for her leukemia conveyed hope and vulnerability as she expressed at day 100 how she felt about her life after SCT:

If I have to draw a picture...like a broken glass... like sometimes when a glass breaks, like say for instance a vase, you can put it back together like a kaleidoscope, and I feel like I have been through so much like a broken glass, and now I have been put back together like a kaleidoscope, and it can turn out beautiful.

One of the contextual factors which greatly impacted informants’ hope for SCT and continued care was the financial burden. Before treatment started informants had to

work out their financial situation, which was also a source of stress for many. Equivalent numbers (6-8) of informants from each ethnic group reported financial hardship related to SCT. Financial problems resulted from participants having to quit their job, paying for housing near the treatment center, and paying for expensive parking. Some had to take out a loan, take money from family, or apply for disability and social services. Disability and social services were not available to those from out of the state or the country.

Half the Latinos, 4 AA, and 7 Caucasian informants described the financial burden of SCT. They worried because they couldn't work. Savings were depleted and there continued to be costs associated with their treatment, including expensive parking fees. Informants who were outside of the United States were required to pay an estimated charge before treatment began and once that money was close to being exhausted they were required to pay additional funds before further care was given. Three informants experienced a block on their account, which led to cancelled or postponed care. They said: "worse moment of disease - block your appointments", "they simply closed the door to me for treatment", and "getting money is complicated".

In God's hands. An AA woman shared that she felt the choice to have SCT was not hers but God's. Over half of informants described their belief in God and prayer as their major source of support going through the SCT experience. Informants believed that God had a direct or indirect (by providing physicians with knowledge) influence on the

outcome of their treatment. Some found strength through prayer and some thought needing and having SCT was a trial of their belief system.

Informants described: visualizing the “hands of God attacking disease”, believing “here to fight for one’s life which God has given”, and “asking for His blessing on marrow, me, and donor”. AA informants shared similar beliefs in the benefit of putting their focus on God and their lives in His hands and the power of prayer. They also expressed the sense that God is with them and they are not alone. A Caucasian male informant proudly said that he was “on prayer lists in 60 countries” and a Caucasian female informant said she “expected the worst [as she has experience with her illness] been that way every time, this time God said okay you don’t need to hurt any more”.

Another AA professional woman informant in her 60’s stated:

...they [family] pretty much accepted the fact that, I mean, this is just a season in my life, you know, and we will just prepare to deal with whatever. We feel like I am going to be just all right because we know a Man, him name is Jesus...expect to be in good shape, expect to be in total remission and expect to be a voice for that Man.

Prayer was described as a means to help make decision to have SCT and to make it through treatment. It was a source of comfort to know others were praying for them. Some felt God had a direct hand in safely getting them through treatment: “need to know Jesus, let go and let God”, “God in the equation or will not make it”, and “God would

take care of everything”. One informant wanted to know if her physician “knew God” and thought it was important for him to accept God’s guidance before he treats patients.

I couldn’t have done this without them. As in so many aspects of the meaning of SCT for participants, there is a tension in their relationship to family. SCT patients discussed how important their families were in helping them get ready for treatment, going through and recovering from SCT: “took weight off by organizing things at home”, “wife forces me to do things had to”, “family stayed away [to decrease risk of infection]” and “without family hard to endure”. Three informants said they probably would have opted not to have the SCT had their family members not persuaded them to have it.

Informants said this treatment had some positive family changes and for some brought their families together. One Caucasian middle-aged woman informant described how she and her brothers got closer when they “thought they were going to lose her and that she was kind of a bridge for her healing family.” In contrast several informants felt that SCT treatment put stress on family members. Participants worried about family members’ ability to assume caregiver role, effect on dependent children, lost income for family support, and expressed guilt about “wrecking” family member’s holiday or causing caregivers increased burden, “messing up so many peoples’ lives, after 3-4 years [they] need to go on with lives”, “roller coaster for everyone, tough on kids”, and “felt bad putting family through this”. Several informants who were parents of young and

adult children expressed guilt about the effect of their illness on their children's lives.

One middle aged AA male informant spoke of how his illness affected his family.

It has affected them (family) tremendously....brought them to a standstill in their lives...turning around on dimes to facilitate things for me and I guess they are dealing with their own personal feelings...

Several informants shared their attempt to decrease the family stress by protecting family members. Two informants expressed relief that this illness happened to them instead of siblings, because they felt better able to handle the demands of treatment. A young engaged African-American woman questioned continuing in the relationship with her fiancé because of her uncertain future. Others also described attempts to protect their family members from the burden of their care by looking strong in front of them and worrying about them. A few informants said it was sometimes a difficult task to “stay positive, strong, and lighthearted so family members would not be worried, alarmed, or be sad”. Some informants reported that they felt their families were trying to protect them by filtering outside responsibilities, spouses being overprotective, and their children insisting that everything would be fine.

Informants spoke about a disruption in their family and work roles (husband, wife, mother, father, sister, brother, bread winner). A mother spoke of the difficulty her teenage daughter had with her not being able to be there for her.

Several informants discussed how important it was for family members to know and understand what the treatment entailed but one Caucasian young woman shared that she thought too much information was not always good for family members because she believed it focused the family caregiver's attention away from supporting the patient to trying to understand the changes in the patient's medical condition. She felt she had to be a "medical encyclopedia" for her mother caregiver.

Participants said some family members initially denied illness or were initially shocked but then just assumed everything would be all right. Informants also reported words or actions of family members that were disappointing such as a lack of understanding about what the informants were going through and their needs, a "reluctance to share feelings or take on additional responsibility", or "discounting the informant's contribution to the family".

Informants described a sense of responsibility for preparing their families for unexpected/unwanted outcomes. An AA man described how he used this as an opportunity to talk to his children about "death as a part of life" that has to be dealt with. Another Latino man shared that he made a point of speaking with his children every night to keep them informed of what was going on. One young woman described how her family "set down talked about it, even the burial, kids were prepared not like I wanted, did not want to scare them but family don't sugar coat nothing just take each day at a time".

Wanting to know, not wanting to know. Informants, with the exceptions of three individuals, were satisfied with the information they received before SCT. Several patients did not understand their diagnosis or prognosis. For example, thinking that having too much protein was a result of eating too much meat. By the phase of time after transplantation (day 30 – 100) fewer (one third) informants stated they were satisfied with the information provided before and during treatment although several shared that they experienced fear when they did not know what to expect and fear once they learned about side effects and complications that may occur. Three participants who initially were satisfied with the information they received experienced life-threatening complications after which they felt they had been adequately prepared.

Informants described negative aspect of information. Several stated that sometimes it is better not to know all the facts about treatment because knowing would lead to a negative emotional response and affect tranquility. A few stated that providers told them they might die which was a difficult to accept. Some patients thought they were told the worst-case scenarios so they would not be scared or feel like an underachiever when problems occurred. Three informants did not want to know about side effects for fear this would prompt them to experience those problems One Caucasian male informant in his 60's said:

[I] got a couple of books and I opened a couple of pages and looked at one of those and said, oh my God, I sure hope this doesn't happen, I sure hope that

doesn't happen. I just closed the book and said: no I don't want to know about this, I am keeping my positive attitude and if something terrible takes me out, okay, so be it.

Informants varied as to how much and when they wanted information. One Caucasian woman in her 50's said: "I scared myself so badly I have three family members who review and interpret all scientific and purely medical stuff [information] they think I need to know." Another Caucasian man in his 30's said he would sign anything just to start treatment and was not interested in knowing more about treatment. There were a few who, at the time of active treatment, thought they were given too much information and reported it made them nervous or anxious and they would rather "go with the flow" and there was "too much doom and gloom". During the later interviews there were nine informants who said they received more information than they wanted or needed: "don't want details, then [I] have to live with that anticipation, want to trust physician, they made the best decision, leave it up to them and pray".

To the contrary, at the time of active treatment eleven informants said that they felt they did not receive enough information either for themselves or for family, but differed in the type of additional information they wanted, for example more on side effects, how it feels, statistics, scientific information, or more opportunity to ask questions. Another group of eleven informants spoke of being misinformed: "set up for worse", "a lot of reading but not what you want", "read all bad things but not enough

good”, and “they made big deal out of things that were not a big deal”. Two Latino informants who spoke English as a second language reported it was “tough to understand everything”. A participant’s wife reported that she wanted more information but that her husband wanted less, he was a “just do it” kind of person. Finally, at the period after SCT, twelve informants expressed that they did not receive enough information: “after reading all information provided it still was not enough”, “not enough on the bad stuff”, “family was not prepared enough”, and “want hard core stats”. Several wished they had the opportunity to talk to someone who had been through their type of SCT. However one Caucasian woman who did talk to another SCT recipient was frightened by her negative depiction of the SCT process.

They went the extra mile. Overall informants expressed confidence in the physicians and nurses caring for them. During the period before SCT most informants described nursing staff members as “knowledgeable” and exemplifying a “caring attitude”. Informants shared that they thought the “nurses were very good, professional and tried very hard to make them feel comfortable”. Positive comments were also made about the physicians, an advanced practice nurse, nurses’ aide, pharmacist and chaplain. During the inpatient active treatment stage, when informants had the most interaction with the nursing and medical teams, over half (14 AA, 11 Latino, 13 Caucasian) the informants in all groups described positive experiences with healthcare providers.

Informants said the nursing staff was “very good”, “competent”, “professional”, and “helpful”: “went the extra mile” and “treated [me] like a person not number”.

In contrast, a small (3-4) group in each of the ethnic groups reported problems. Some AA informants said: “there was nothing special about staff, one nurse did not know my diagnosis, I could not understand why she was hanging my medications”. Another informant said a “volunteer walked into his room and put a hand on his head and said they were going to pray”. This upset the patient and his wife and he instructed this person to leave. Several Latino informants said that staff was “cold, competent, but not personalized”. A Caucasian female informant said: “if they spent 1 or 2 extra minutes of undivided attention it would make a huge difference so I wouldn’t feel like a commodity instead of a person“. Finally, one 65-year-old Caucasian male advised other patients to “know your own details [illness and treatment] so they [healthcare team] can keep you straight as they have so many patients”. Several were dissatisfied with “long waits in clinics”. A few participants expressed concerns about providers; one Latino informant had “difficulty communicating with a physician because of the physician’s accent”. One Caucasian informant expressed mistrust of information provided by a community physician who was described as: “one who makes their living off disease” A Caucasian woman said she felt “some information was kept from her to maintain secrets between providers, which created fear for her”.

Some informants (one third) described problematic communication, including conflicting messages from different physicians about symptoms for example “one physician stated it was surprising and another said it was normal”. Other informants were frustrated in the inability to get clear answers to their queries about complications they were experiencing: “they don’t have all the answers, everyone is different but they must have some in the ball park” and “some nurses act as if you are a need to know basis, it is your life and body and you have right to know everything, it is not a secret shouldn’t treat us like we are children, it makes it scary and we are vulnerable”. Consistent with earlier time periods several Latino informants described that providers “assisted them greatly in the SCT treatment”, but a few thought that health care providers as formal and impersonal: “they tell you things in a very cold way”.

Summary of the Findings

These findings identified the major overlapping themes, subthemes and contextual features experienced by informants before treatment, during active treatment and after treatment with SCT. Differences occurring during treatment phases and ethnicity were noted. In the following chapter these findings will be compared with literature reviewed and implications for practice and research will be identified.

CHAPTER V

SUMMARY OF THE STUDY

For patients who undergo SCT the phases of treatment present situations that are likely to result in a sense of uncertainty and vulnerability. The physical and emotional challenges of SCT are multi-factorial and multi-faceted and the needs of patients change over time and phases of treatment. Previous studies have provided a glimpse into patients' psychosocial issues with SCT treatment but did not identify them within the context of treatment phases or consider ethnicity. Knowledge of the unique needs of patients across the stages of SCT and across ethnic groups is essential to provide nursing care that is timely, patient-centered and supportive.

The purpose of this study was to develop an understanding of the meaning SCT has for African-American, Latino, and deepen our understanding of SCT for Caucasian patients, before, during, and after stem cell treatment. The use of hermeneutic phenomenology guided by the interpretive philosophical approach of Ricoeur (1983/2007) was most appropriate for analyzing the rich data to develop our understanding of the meaning the SCT experience had for informants. An extensive data set of 273 interviews with 60 informants over 3 time periods, before SCT treatment began, during active treatment phase and after SCT (day 30,60 and 100) was analyzed. Through a process of comparing groups and time periods differences and similarities in their experiences were discovered. The study findings are unique in that they represent

the experiences of 60 African-American, Latino, and Caucasian patients through the 3 month SCT treatment trajectory (Appendix H). Informants provided a rich picture of their cancer journey leading them to the decision to have SCT and facing the fear in their pursuit of this aggressive treatment with uncertain outcomes, which was interpreted into major themes.

Summary of Findings

Three major overlapping themes emerged, based in the experiences of the participants within a given time period. They are: Facing the Fear, Getting Through, and Going Beyond/Forward. Like a Bridge I Never Crossed Before occurred across the themes and influenced the meaning experiences had for the participants. Participants' experiences were also influenced by contextual factors of life threatening disease and treatment, emotional/coping, culture, symptom burden, lack of knowledge of the treatment, family availability, and financial burden. Each of the major themes includes subthemes of Hope for Chances, Choices, and Control, Couldn't Have Done It Without Them, It's In God's Hands, Need to Know versus want to know, and They Went the Extra Mile. The contextual factors and subthemes carried different weight within the major themes and within ethnic groups.

In the first phase before treatment started informants described their cancer journey leading to the realization and decision to have SCT, thereby Facing the Fear of uncertain outcomes and putting them in a situation of increased risk. Although most informants had previous experience with cancer treatment, all but 2 of the informants had

no previous treatment with SCT. There was variation in their need and desire for information about treatment.

During the phase of active treatment with chemotherapy, stem cell infusion and recovery of side effects, informants described Getting Through, sustaining hope and motivation despite physically and emotionally challenging situations. Symptom burden was great as they experienced the physical side effects of high dose chemotherapy, and reliance on healthcare providers was increased. Uncertainties about the meaning of symptoms lead to fear and anxiety.

The theme of Going Beyond, Moving Forward occurred during the period after SCT. Informants were still uncertain about the treatment outcomes yet wanted to regain control of their lives. Most affirmed their decision to have SCT and several expressed frustration they were not able to do more activities due to fatigue and late effects of SCT. Hope for a future beyond their cancer diagnosis and moving forward were expressed by informants.

Informants' methods of coping with the SCT experience were identified as: maintain a positive attitude (hoping for chance to live, a choice for life and control of their life), faith, family, acquiring information and healthcare providers. Differences between informants, ethnic groups of informants and time periods were discovered.

These findings provide guidance for caring for SCT patients and their families and they provide direction of ongoing research. Of the implications for care, most convincing is the need for patient-centered care based in an understanding of the

contextual factors that affect patient and family coping. Of the implications for research, perhaps most compelling is the need for research related to education to ensure informed consent and preparation for treatment related experiences, in accord with patient need

Discussion of the Findings

The study assumptions were met in that informants were open and forthcoming about their thoughts and feelings about SCT as a life-threatening and life-saving treatment with associated risks. Informants demonstrated expertise in coping with life threatening illness and finding meaning in their experience.

Like a Bridge I Never Crossed Before, words used by a middle-aged Latino informant, captured the sense of the unknown and risk or vulnerability experienced by individuals going through SCT treatment in this analysis. This sense of vulnerability and uncertainty has been described in previous literature (Copper & Powell, 1998; Saleh & Brockopp, 2001; Haberman, 1998; Baker, Zabora, Polland, & Wingard, 1999; Bywater & Atkins, 2001; Fife et al. 2000; Coolbrandt & Grypdonck' 2010; Farsi, Najeri, & Negarandeh, 2012; Coolbrandt & Grypdonck 2010; Cohen & Ley, 2000) and helps to explain how informants framed their experience and coped with the burden their illness and SCT treatment placed on them and their family. Likewise the subtheme of hope for chances, choices, and control was consistent with findings from other studies (Cohen & Ley, 2000; Haberman, 1995; Heinonen, Volin, Zevon, Uutela, Barrick & Rutuu, 2004; Cooper & Powell, 1998; Bywater & Atkins, 2001). Among the unique findings in this study was that AA informants were much more likely to express their goal for treatment

as getting better rather than cure. This may be attributable to the fact that there were 11 of the 20 patients in this group (vs 4 Latino and 2 Caucasian) were diagnosed with multiple myeloma and SCT is intended to provide a remission versus cure for that disease.

In this study informants describing their experience when facing aggressive treatment for their life threatening disease and the resultant fear and emotional distress for them and their families; their lack of experience or knowledge with higher dose chemotherapy and stem cell transplantation; the symptom burden, greatest during the inpatient treatment phase; the cost of SCT, which put them in a financially vulnerable situation because work/career goals were postponed, lost, or suspended. Ethnicity influenced the way informants responded to threat (coping styles – faith based, optimism) and communicated when their primary language differed from that of most providers (Latino informants). A few AA informants either questioned or appreciated the equality of treatment they received compared to “white” SCT patients. Possible inequality of treatment, level of respect (identified as a positive experience) and difficulty finding potential minority donor were all mentioned by AA informants.

Life Threatening Diagnosis

After active treatment all informants except 2 affirmed the decision to have SCT, with informants more frequently and openly discussing risk, possible death, and no guarantee that treatment would be successful, supporting findings from Iran (Farsi, Nayen, & Negarandeh, 2012). Interviews at the time of count recovery, during active treatment (T5), more frequently included expressions of thoughts about the future and

regaining control over their lives, identified in previous studies (Cohen & Ley, 2000; Shuster, Steeves, Onega, & Richardson, 1996; Xuereb & Dunlop, 2003; Molassiotis, Van Der Akker, Milligan, Goldman & Boughton, 1996) informants described the return of normalcy to their lives and a sense of relief at having made it through their active aggressive therapy, which some described as like being in a death chamber or feeling locked up again, supporting earlier findings (Baker, Zabora, Polland, & Wingard, 1999; Thain & Gibbon, 1996; Cohen, Ley, & Tarzian, 2001). One Latino informant with multiple myeloma did share during the second interview (getting through) that he thought he was cured. A few Latino and AA informants shared they were doing SCT for their family. Latino and Caucasian informants identified the promise of science/medicine in providing a cure, if not now, at some point in the future. They (Latino and Caucasian) acknowledged that cure may not be possible but wanted to stay alive long enough for science to catch up.

Wanting to Know, Not Wanting to Know

Information was critical to informants' preparation for treatment. Noteworthy is the finding that satisfaction with education varied greatly between and within individuals, some wanting more and some wanting less information and some wanting more or less at different times. The differences were due in part to their individual coping styles (Hacker & Ferrans, 2003; Tarzian, Iwata, & Cohen, 1999) and in part due to symptom experiences. Before SCT informants (with few exceptions) were satisfied and accepted information provided. A few Latino informants expressed their belief that it is better not

to know all the facts because of the impact of that knowledge on their peace of mind and tranquility. Several Latino informants mentioned the mind body connection. For example, if I know about side effects or what happens to another it may happen to me. Some patients shared that they stopped reading about negative aspects of SCT because it made them more fearful. Many patients who accepted that there were negative side effects and outcomes of SCT also said that everyone is different, keeping hope that this would not happen to them, supporting results from earlier studies (Hacker & Ferrans, 2003; Tarzian, Iwata, & Cohen, 1999). Informants' satisfaction with the information they received about SCT varied among groups and over time, with many sharing their struggle with uncertainty and the reality that it was not possible to fully prepare (no script or formula) and advised future patient to "expect the unexpected" and "take one day at a time". Informants who had medical complications after SCT were likely to say that they felt poorly prepared for the complications.

The findings have educational and ethical implications (informed consent) for healthcare providers. They suggest that SCT patients will most benefit from educational material and techniques when nurses consider patients' desires about what they want to know, their levels of anxiety, and their emotional responses. Providing education in stages may be helpful. Applying the "ask, tell, then ask again" format at each educational opportunity may be beneficial as nurses and other clinicians ask patients what they understand, then teach, and then ask them what they know. This would allow patients time to absorb the information provided and ensure they have the knowledge they need to

prepare for their experiences during and after transplant. It is important to remember that even those who have no questions need information. Balancing what they need to know to make informed decisions and what they want to know is important and challenging.

Implicit in the education process is the assurance that the patient has the information needed to make an autonomous informed decision. Many patients in this study identified having a lack of choices, which raises questions about their autonomous decision-making. Bywater and Atkins (2001) raised a similar concern. Our findings support the recommendation to explore patients' contextual influences during their decision-making process, including cultural and spiritual beliefs, and their perceived choices and vulnerability. Ethical concern emerges when patients minimize risks of treatment and are reluctant to discuss the negative aspects of treatment. Establishing what patients' truly understand is important. They may understand the risks and still view the transplant as the only option, and, while understanding the risks, may not want to consider or discuss them (Cooke, Gemmill, Kravits, & Grant, 2009). Concerns about informed treatment decisions might be mitigated through advance-care planning discussions; the nurse and other healthcare team members can help patients and families explore factors involved in the SCT decision, potential treatment outcomes, and prepare them for all possibilities. Education is an ongoing process throughout the SCT treatment and beyond. Informants in this study provided insight into their individual needs for information, which changed over time and circumstances, particularly if they experienced complications. Nurses need to be aware that patients' educational needs will change over

time, based on their situations and their desire for more information. SCT survivorship programs need to focus on education for the future to improve quality of life and allay fears about the future.

Emotional/Coping Influence

Confirming findings from previous research is that the major emotional experience that transcended ethnicity in this study was fear versus hope. These concepts were previously described in this population/patient treatment group (Xuereb & Dunlop, 2003; Hacker & Ferrans, 2003; Tarzian, Iwata, & Cohen, 1999; Shuster, 1996; Stephans, 2005; Farsi, Najeri, & Negarandeh, 2012; Molassiotis et al., 1996; Cooper & Powell, 1998; Haberman, 1995; Ersek, 1992). Several informants describe the struggle they had in trying to maintain a sense of control and psychological balance with competing feelings (being on a roller coaster, the desire (rather than natural state) to remain optimistic, attempt to be tranquil despite panic). Many of the emotions and thoughts expressed by informants related to purpose of treatment, risk acknowledgment, and uncertainty remained the same throughout the phases of SCT experience, with AA and Latino informants expressing more positive emotional responses (hope, gratitude for the opportunity of have SCT).

Implications for nurses include providing support to SCT patients through these struggles in order to maintain hope that is realistic and abating fear that may be excessive. Distress screening is increasingly being recognized as an essential assessment element in cancer care as it greatly impacts health and quality of life through the disease and

treatment process. The American Psychosocial Oncology Society, Association of Oncology Social Work, and Oncology Nursing Society endorses the American College of Surgeons Commission on Cancer requirement that states that by 2015 cancer centers will be required to implement a psychosocial distress screening program (ONF, 2013). Improved screening instruments to assess distress and emotional stress has been recognized in SCT care (Frick, 2006; Jenks Kettmann & Altmaier, 2008; Molassiotis, 1999) to identify psychological issues (depression, high anxiety, and avoidance) and promote an individualized care plan before SCT therapy begins, thereby improving physical and emotional treatment outcomes (Bryant, Heiney, Henslee-Downey, & Cornwell, 1997; Gaston-Johansson et al., 2000; Germino et al., 2013). Depending on the individual's coping style and belief system, social work, psychologist, psychiatrist, chaplain may provide additional needed support.

Symptom Burden

During the interviews conducted immediately after chemotherapy and stem cell infusion informants were understandably more focused on the physical symptoms which was also demonstrated in the quantitative research aspect of the parent study (Cohen, Rozmus, Mendoza, Padhye, Neumann, Gning, Aleman, Giralt, Cleeland, 2012). Fatigue, taste alteration, and anorexia persisted to days 30, 60 and 100. Fatigue has been identified in the literature as symptom impacting patient's quality of life for considerable time after SCT (Andrykowski, Brady, Greiner, et al., 1995; Bevans, Mitchell & Marden, 2008; Stephans, 2005; Cooke, Gemmill, Kravits, & Grant, 2009). Nursing management of side

effects is crucial in patient safety and comfort during this treatment with high risks for serious complications. Helping patients manage their expectations through education about actual and potential side effects is also important.

Resources Identified by Informants

Factors which informants consistently identified as assisting them through the SCT treatment experience were principally their faith (more frequently identified by AA and Latino), family, information/knowledge, their ability to have positive attitude, trust in their healthcare team and the cancer center. Faith and spirituality has been identified in previous studies (Ersek, 1992; Saleh, 2001; Fife, 2000; Hacker & Ferrans, 2003) as a force in helping patients deal with cancer diagnosis and treatment. African-American and Latino's reliance on faith and spirituality was not identified in other SCT studies/literature because of the underrepresentation of minorities. Implications for practice include exploring the significance of religion and spirituality for patients and providing religious support through chaplain service early (even before admission for treatment) may be of great benefit to individuals who identified faith as important.

Also, consistent with earlier findings (Cohen, Ley, & Tarzian, 2001; Hakcer & Ferrans, 2003; Stephans, 2005), all groups identified family as essential for getting through SCT. New is the finding that almost half of Latino informants reported that their SCT experience brought the family closer together. Overtime informants were increasingly likely to report a reciprocal protective relationship with family members. They were attempting to be stronger than they felt for the family in hopes to not

contribute to mental, physical, and emotional fatigue of the caregiver and they felt some family members were being protective (something too protective) of them. Consistent with earlier studies, family could also be a source of additional burden (Saleh & Brockopp, 2001; Tarzian, Iwata, & Cohen, 1999). Caregivers are essential to successfully getting SCT recipients through treatment especially in the outpatient setting. Support (education, counseling, support group, health promotion) is important to sustain their ability as caregivers and also to allay the concern/burden on the patient (Cooke, Gemmill, Kravits & Grant, 2009).

Healthcare providers played an important role in the informants' SCT experience. Most expressed positive sentiments about providers (nurses and doctors), supporting earlier findings (Coolbrandt & Gryndonck, 2010; Bywater & Atkins, 2001; Cohen, Ley, & Tarzian, 2001). Rotations of physicians and nurses received some negative comments. Communication between provider and patient was a major source of satisfaction or lack of satisfaction. The Latino informants expressed that providers demonstrated less emotional involvement or engagement than they were used to in their culture. Implications for nursing include consistency in assignments of nurses to patients. It may be helpful to start every shift by asking patients what their major concerns are, how their family is, and their current expectations for SCT treatment. That is, spend a few minutes of uninterrupted patient-centered time. Assist nurses to understand the significance of SCT for patient and their likely hopes and fears for their future. Many informants described SCT as a life-changing event. Assisting patients to have realistic expectations

is exceedingly important. Educating patients on nursing roles and cultural differences in nurse roles is likely to be helpful in establishing realistic expectations. Staff stress and burnout, noted by one informant, suggests that it may be important to address staff members' compassion fatigue by providing support for nursing staff.

Conclusions and Implications

The findings of this study provided information to increase our understanding of the SCT experience throughout the treatment trajectory. Based on the findings, the nursing practice implications include:

1. Assessing for the meaning SCT has for the patient and family members, and the contextual features that influence their experience of SCT over time.
 - i. Providing patient-centered care based in an understanding of the contextual factors that influence psychosocial responses to SCT and affect patient and family coping.
 - ii. Establishing nurse-patient assignments that are consistent and support care based in that understanding.
 - iii. Facilitate timely referrals to chaplain services, social workers, and support groups for the patient and the caregiver, based in that understanding.
2. Assessing for the meaning SCT education has for patients and their family members.

- i. Modify the information that is provided and the depth and amount of detail based on the understanding developed from the assessment, while providing the information they need to make informed decisions regarding care.
3. Assessing for the meaning physical side effects and symptoms of SCT have for patients.
 - i. Provide symptom care that is responsive to that meaning. For example, if indicated, give the patient control when possible (use of patient control analgesia).
4. Assessing for the meaning that being post SCT has for patients and their family members.
 - i. Providing education that informs patients about what to expect, for example, about restaging and follow-up after active treatment.
 - ii. Providing interventions and referrals to assist patients in reestablishing life roles and new normal such as a Survivorship program.

Providing support to nursing staff caring for SCT patients to mitigate compassion fatigue and stress, both for their own sake and so that they can more effectively engaged in assessing meaning and then establishing effective interventions for SCT patients and their families.

Recommendations for Further Studies

Based on the findings from this study, further studies are needed that evaluate:

1. Whether interventions, based on the meaning SCT has for patients, influences their experience of SCT over time. For example: Does early referral to chaplain services affect the meaning SCT has overtime for individuals for whom religion is important?
2. Whether establishing patient-centered care based in an understanding of the contextual factors influence psychosocial responses to SCT.
3. Whether modifications in SCT education, based in the meaning SCT education has for patients and family members, influences the coping of those individuals and their ability to make informed decisions regarding care.
4. Whether providing information about what care to expect post SCT and providing interventions and referrals to assist patients in establishing life roles and new normal, such as a Survivorship program, influence the meaning being post SCT has for patients.

The data set provides many opportunities for further analysis to more specifically describe and interpret experiences related to age, gender, religiosity, types of transplantation (autologous versus allogeneic), curative versus noncurative therapeutic goal, triangulation with quantitative analysis in same study, coping style and information seeking.

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APPENDIX A

Aims of Parent Study

Aims of parent study (MDACC protocol ID 99-175)

1. Describe the experience of having BMT; analyze, and present these descriptions using phenomenological methods.
2. Identify the meaning of quality of life as described by patients who have BMT.
3. Identify symptom prevalence and severity in BMT patients at multiple time points.
4. Evaluate the relationship of symptoms, functional status, and quality of life.
5. Describe the experiences of African American and Latino persons having BMT.
6. Identify and compare experiences of African American and Latino persons having BMT with non-minorities patients, including the meaning of quality of life and symptom severity and prevalence.

APPENDIX B
Literature Matrix

Literature Matrix

Author/discipline-country of origin - year Number of SCT patients	Research Question or Purpose of Study	Study Design	Major Findings
<p>Andrykowski, Brady, Greiner et al./intra-disciplinary – US - 1995</p> <p>N=172, 1-10 years after SCT</p>	<p>Patients perception of return in normal, examine expectation-outcome congruency and psychological distress.</p>	<p>Retrospective, Descriptive stat to measure QOL after SCT, outcome, expectations and informed consent</p>	<ul style="list-style-type: none"> • Level of anxiety experienced before SCT impacts learning. • Higher patient expectation of functioning after treatment correlated less satisfied with their recovery. • Decision to pursue SCT as positive. • Greater psychological distress with discordance between pre-SCT expectations and post-SCT functional status.
<p>Baker, Marcellus, Zabora, Polland, Jodrey/Intra-disciplinary – US – 1997</p> <p>N= 437</p>	<p>Identify the magnitude and predictors of psychological distress among SCT candidates</p>	<p>Quantitative – correlational stat- 7 instruments prospective, single point before decision about SCT treatment</p>	<ul style="list-style-type: none"> • Depression identified in one-third candidates. • Mastery (control over ones fate) (r -0.25, $p < 0.001$) and optimism(r -0.30, $p < 0.001$) were negatively correlated with distress.
<p>Baker, Zabora, Polland,& Wingard/Intra-disciplinary – US – 1999</p> <p>N=84, before SCT, hospital discharge and 6 month, 1 year</p>	<p>Examines the problems of SCT patients/survivors in returning to “normal” life after SCT.</p>	<p>Qualitative structured interviews and standardized measures . Prospective, longitudinal</p>	<ul style="list-style-type: none"> • Fear of recurrence and death. • Great than 50% expressed fear when leaving the hospital, vulnerability to future illness and death • Loss of control (30%), anxiety and depression, cautious about how one lives, feelings of isolation, guilt feelings, anger, difficulty resuming role social and at work and financial concern.

<p>Bevans, Mitchell & Marden/Nursing – US – 2008</p> <p>N= 76 before SCT to day 100 after SCT</p>	<p>Examine the symptom experience of SCT patients at 4 time points</p>	<p>Quantitative- univariate descriptive. Clusters: Spearman rho correlation coefficient. prospective, longitudinal</p>	<ul style="list-style-type: none"> • High level of worry ($r_s > 0.30$, $p < 0.01$) most prevalent and distressing symptom prior to treatment, 50% in early transplant period. • Before SCT symptom cluster included fatigue, appearance change and worry.
<p>Bywater & Atkins/nursing – UK - 2001</p> <p>N= 7</p>	<p>Examined patients experience how they prepared for SCT</p>	<p>Qualitative, pt interviewed 1 month prior to SCT Saturation not identified. Prospective.</p>	<ul style="list-style-type: none"> • Preparing for unknown journey, did not know what was to happen despite information given- lacked experience • No choice if want to live, fight for survival. Maintain hope. Reluctance to fully acknowledge risk • Trust in healthcare professionals and autonomy in decision making
<p>Cohen & Ley /nursing – US – 2000</p> <p>N= 20 autologous SCT</p>	<p>Experience of having SCT</p>	<p>Qualitative Retrospective one time point post SCT</p>	<ul style="list-style-type: none"> • Fear of unknown and hope for survival, death seemed certain if did not have treatment, magnified by fear of not knowing. • Loss of physical and psychological control related to not knowing also prompted feelings of vulnerability, personal exposure and shame. Uncertainty life altering experience. Liminal passage
<p>Cohen, Ley, & Tarzian/nursing – US- 2001</p> <p>N=20</p>	<p>Explore patient experiences with autologous SCT</p>	<p>Qualitative- hermeneutic phenomenology Retrospective, single point post SCT</p>	<ul style="list-style-type: none"> • Physical isolation (prevent infection and also protect family from seeing them so ill); • Emotional isolation (profound sense of disconnectedness with others) and physical and emotional isolation

			<ul style="list-style-type: none"> • Positive presence of care providers, additional coping strategies, informing others of needed support).
Coolbrandt & Grypdonck/nursing – Belgium - 2010 N= 15	Explore how patients undergoing SCT keep courage and pull through this demanding therapy.	Qualitative grounded theory Retrospective, single point post SCT	<ul style="list-style-type: none"> • Outcome uncertainty: treatment risks and disease relapse. • Writing positive story to maintain courage (hope nor optimism can explain); endure and give meaning to suffering; do best in believing in happy endings; keep faith; count blessing; assaults of negative events use rationalization (not as bad off as someone else) • Most vulnerable: nadir of counts. losing physical and mental strength. Nurse carried through worst time (not with false optimism or encouragement but quite reassurance)
Cooper & Powell/nursing – US - 1998 before SCT, 6 weeks and 12 weeks post SCT N=6	Describes the experience of vulnerability and inherent uncertainty of patients undergoing SCT	Interviews with patients and caregivers, method of analysis not specifically discussed. Prospective, longitudinal.	<ul style="list-style-type: none"> • Patients experience identified uncertainty as a renewal of hope, redefining the meaning of illness and means to move to another chance at life, having BMT was not a choice. • Pervasive vulnerability and uncertainty ...the uncertainty of treatment was outlined and became paramount in the patients’ anxieties. “almost like they kill you and then bring you back”p62.

<p>Ersek /nursing – US – 1992 N= 20</p>	<p>Explore the patients' experiencing hope when confronted with information about negative outcomes.</p>	<p>Qualitative – grounded theory Retrospective, single point post SCT</p>	<ul style="list-style-type: none"> • Dealing with it – confronting negative possibilities by appraising the illness experience as a threat, allowing emotional response, working through it and moving on. • Keeping it in its place- managing impact by controlling response (looking at experience in positive light, not dwelling, turning control over to God, attitude of fighting the illness, managing uncertainty, focus on future, managing view of self).
<p>Farsi, Nayen, Negarandeh / nursing – Iran – 2012 N= 10</p>	<p>Describe the coping process All participants were Muslim</p>	<p>Prospective, longitudinal (before and 2-6 months after) qualitative using grounded theory</p>	<ul style="list-style-type: none"> • Perceived threat (included initially disregarding disease signs and symptoms, as time went on they experienced increased sensitivity, perceived risk and limited time, changes in everyday life) • Suspension between fear and hope with feelings of uncertainty and doubt • Rebirth, finding meaning • Contextual factors : internal, external, and time • Coping strategies: cognitive and behavioral actions to survive, protect health & restore equilibrium. Muslim connection with divine purpose.

<p>Fife, Huster, Cornetta, et al. /intra-disciplinary – US - 2000 N=101</p>	<p>Examine adaptation to stress</p>	<p>Descriptive statistical methods measure coping, depression, anger, uncertainty, and anxiety . Ways of Coping Checklist. Prospective, longitudinal (4 time points) before SCT and post (last one 12 months) after SCT.</p>	<ul style="list-style-type: none"> • Cognitive coping was associated with decreased depression ($r = 0.31, p = 0.01$), anger, ($r = 0.27, p = 0.05$) uncertainty ($r = 0.34, p = 0.01$) and avoidance ($r = -0.29, p = 0.05$) was associated with increased anxiety. • Pre-transplant (during treatment but 1-2 days before cells given) greatest emotional distress (anxiety, $X = 21.07$; depression, $X = 22.4$; uncertainty, $X = 20.57$) and vulnerability.
<p>Haberman/nursing – US – 1995 N=23</p>	<p>Examined patient experience with SCT</p>	<p>Qualitative Prospective, single point before SCT</p>	<ul style="list-style-type: none"> • Did not know what to expect and that SCT was final hope for cure but also treatment could hasten their death. • Relinquish control to healthcare provider and minimize focus on perceived treatment risks to improve outcomes. • Patients redefined grim survival statistics in their favor to increase chance of their survival. • When first diagnosed ambiguity and uncertainty allowed for hope.
<p>Hacker & Ferrans/nursing – US - 2003 N=16 7 patients in qualitative study</p>	<p>Aim to describe the patient's QOL immediately after SCT and to describe the trajectory of changes during the transition from</p>	<p>Quantitative – ANOVA very small sample size Qualitative – no philosophical framework identified Prospective, longitudinal (before SCT, before discharge; 2 weeks post; 6 wks post discharge).</p>	<ul style="list-style-type: none"> • Quantitative results focused on physical symptoms. • Qualitative- Health and functioning of life: Incongruent expectations regarding health care, concern about curing disease, differed on need for information (too much vs. not enough) • Psychological and spiritual aspects:

	hospital to home.		positive attitude, pessimistic and uncertain, boredom, fearful about future, need to fight and persevere; socioeconomic and family aspects, ability to work, support of family, fear of overburdening family.
Heinonen, Volin, Zevon, Uutela, Barrick & Rutuu/Intra-disciplinary – Finland – 2004 N=109	Identify stressors experienced by patients diagnosed with hematological diseases and treated with allogeneic SCT	Quantitative multivariate analysis for concept mapping, multidimensional scaling & hierarchical clustering. Retrospective, single point (minimal 4 months after SCT).	<ul style="list-style-type: none"> • Stress clusters (8): Change of life and impact of long-lasting treatment; • Side-effects; distress related to treatment outcome and physiological status; • Family-related stress; fear of death and depressive thoughts; negative social support; • Stress related to lack of information and medical staff.
Lee, Fairclough, Antin, & Weeks/ intradisciplinary- US – 2001 N=263	Examined patient/physicians estimates of mortality, cure with SCT, and cure without, actual treatment related mortality.	Survey to patients and physicians Prospective, single point prior to SCT.	<ul style="list-style-type: none"> • Treatment related mortality (TRM) was low (<than 30%) there was concordance between physicians and patients but as TRM high patients were more optimistic than physicians. (95% confidence interval [CI], 40-64). • There was no control over style and type of information provided to patient.
Molassiotis, Van Der Akker, Milligan, Goldman & Boughton/intra-disciplinary – UK - 1996 N=26	Measure changes in psychological status, self-esteem, dependence on others, physical symptom distress and coping during	Quantitative Scales: Profile of Mood Scale (POMS); Rosenberg scales of adult self-image; Symptom Distress Scale (SDS); Coping checklist. Prospective, longitudinal (4 times point	<ul style="list-style-type: none"> • Tension-anxiety and depression constant while anger-hostility ($r = 0.46$, $r = 0.58$, $p < 0.05$) and anxiety ($r = 0.64$, $r = 0.58$, $p < 0.05$) increased by time 4. Pre-transplantation patients had low self-esteem ($X = 5.04$, standard deviation [SD] = 2.31) and increased dependence

	isolation for bone marrow transplantation.	from day before SCT to 1 month after discharge).	($X = 5.28$, $SD = 2.7$). <ul style="list-style-type: none"> • Main coping mechanism was hope; maintain control over situation and acceptance. Psychological support assisted patients with mood disturbance. • Difficulty determining if increased stress was from isolation versus stresses from patients “confronting life-threatening disease, an unpredictable treatment and an aggressive therapeutic intervention” p 18.
Prieto, Atala, Blanch, Carreras, Rovira, Cirera, & Gasto /intradisciplinary – Spain – 2005. N= 220 4 time points during hospitalization (before SCT and up to 14 days after SCT infusion)	Objective to provide data on patient-related emotional (depression and anxiety) and physical functioning during hospitalization for autologous or allogeneic SCT	Hospital anxiety and depression scale (HADS); created scales: physical status, energy level, systemic symptom. ANOVA statistics calculate differences of groups over time. Prospective, longitudinal	<ul style="list-style-type: none"> • Increase anxiety ($F = 14.08$, $p \leq 0.001$) before transplantation decreased by 14 day after transplantation and depression ($F = 20.87$, $p \leq 0.001$) peaked day 7 after SCT (correlated with increase physical symptoms) and remained higher than baseline at the time of discharge. • Autologous (58% of sample) had better physical status and energy level than allogeneic patients with no difference in anxiety and depression.
Saleh, & Brockopp/nursing – US – 2001 N= 9	Purpose to further understanding the concept of hope and to describe hope as it relates to patient hospitalized with BMT.	Hermeneutic phenomenologic approach. Prospective single point before BMT	<ul style="list-style-type: none"> • Feeling connected with God, this allowed for hope; • Affirming relationships mainly family members; • Staying positive, personal attitude of hope ; anticipating survival, potential for cure, • receiving positive information, talking w

			<p>other patients; 1</p> <ul style="list-style-type: none"> • Living in the present, keeping busy and working thru each day; • Fostering ongoing accomplishments, achieving personal goals
Shuster/nursing – US – 1996 N=11	Examine the patients experience	Qualitative Prospective, interviewed 1 to 4 times during hospitalization	<ul style="list-style-type: none"> • High level of anxiety unpredictable progression through treatment. • Information was not enough to ameliorate this anxiety. • Changed their attitude about unknown or mentally escape. • Not aware family withholding undesirable information.
Steeves /nursing – US – 1992 N=6 male patients	Examined patient experience with SCT	Qualitative interviews before and 100 days after treatment given Prospective, interviewed pre-BMT to day 100, not reported in longitudinal method	<ul style="list-style-type: none"> • Patient normalized or minimized events or experience to deal with uncertainty of frightening or unusual events.
Stephans/nursing – Australia – 2005 N= 5 autologous (6 months after SCT)	Explore the lived experience of patients who have undergone HSCT” 206 describe the patients’ experiences, concerns and the impact that SCT has had on their lives.	Husserlian phenomenological methodology and Giorgi’s method of analysis. Retrospective, one time at least 6 months after SCT.	<ul style="list-style-type: none"> • Fear – relapse, dying • Isolation (3) few others experienced SCT, dealing with infection and fatigue also isolating- different from others in social world • Concern about others’ well-being and coping skills – families, chose not to share with her partner how ill • Adaptation, adjustment and recovery: recovered self energy level lower level,

			<p>talking with other patients helpful in adjusting and coping, professional literature not patient perspective.</p> <ul style="list-style-type: none"> • New physical self learned to adapt to new normal. • Change in values, outlook, and priorities all reported change in relationships with others-closer relation increase important than just being sociable. Following adjustment closer, more emotional reappraisal and reassessment of life values. • Separate transplant experience from diagnosis and initial treatment. Transplant as a transition point in life experience • New life new gift of life, not wanting to waste, reborn, resurrection new wholeness, • Bereavement: losing life as it was
<p>Tarzian, Iwata, & Cohen/Nursing-US-1999 N=20 autologous</p>	<p>Explore patients' experiences having an autologous SCT</p>	<p>Qualitative – phenomenological Retrospective, one time(patients both pre and post pathway)</p>	<ul style="list-style-type: none"> • Themes included: range of needs for information; everyone is different, balance of giving right amount of information based on patients' desire (fear of knowing too much – post transplant); • Talking to someone who has been there; • Patients' burden of teaching family.

<p>Thain & Gibbon/nursing – UK – 1996</p> <p>N= 6</p>	<p>Examined patient experience with SCT – described 5 stages of SCT</p>	<p>Qualitative study- no philosophical framework identified. Interviews were analyzed categories. Retrospective(no identified time since SCT)</p>	<ul style="list-style-type: none"> • Uncertainty related to survival • Positive approach, lucky to be given chance • Prison in protective isolation, relationships and physical effects. • Genuine uncertainty about the future expressed. Motivated to beat their illness, viewed admitting to fear of dying as sense of failing.
<p>Trask, Paterson, Riba, Brines, Griffith, Parker, et al./intra-disciplinary – US- 2002</p> <p>N= 50 SCT candidates</p>	<p>Examine the relative contributions of anxiety and depression to psychological distress and if this differs between patient and staff.</p>	<p>Quantitative- Result of distress thermometer(DT), (HADS);Coordinator rating compared using ANOVA & Pearson product-moment coefficients. Prospective, pre SCT one interview</p>	<ul style="list-style-type: none"> • Fifty percent of patients significant levels ($t = 0.47, df = 17, p > 0.05$) of emotional distress (≥ 5, scale 0-10; mean 4.17, SD = 2.49) and anxiety (mean 7.65, SD = 2.76). • 20% report levels of depression (mean 4.38, SD = 2.71). • Moderate agreement between patient and coordinators ratings of emotional distress and anxiety (coordinators underestimated high level of emotional distress reported by patients).
<p>Xuereb & Dunlop/Psychology- intra-disciplinary – Australia – 2003</p> <p>N=10</p>	<p>Provide a description of the lived experience of people with leukemia or lymphoma who were treated with SCT.</p>	<p>Qualitative- phenomenological Retrospective, interview single point post SCT (6m-10 years)</p>	<ul style="list-style-type: none"> • Meaning of illness and how their life was affected (physically and psychologically) • Sense of agency (how they maintained or regained control of health and valued aspects of life).

APPENDIX C

Psychosocial Factors SCT Patients Experience Before Treatment from Review of Literature

Psychosocial factors SCT patients experience before treatment from review of literature

Psychosocial factors/major themes	Emotion/feeling experienced	Method of coping identified in the literature	Nursing implications/considerations
<p>Threat to life from disease and treatment</p> <p>Uncertainty (outcomes)</p> <p>Loss of control – no choice but to have SCT</p>	<p>Fear</p> <p>Anxiety</p> <p>Depression</p> <p>Distress/stress</p> <p>Low self-esteem</p>	<p>Fighting –disease, for life</p> <p>Knowledge impose order/take control/mastery</p> <p>Resolution to have SCT – control disease through decision making</p> <p>Redefine statistics of grim prognosis</p> <p>Optimism</p> <p>Avoidance – reluctance to fully appraise oneself</p>	<p>Assess need for information and depth/degree of detail desired by patient to necessary to make informed decision.</p> <p>Acknowledge patient’s cancer experience leading to SCT and emotional experience.</p> <p>Provide support and information to manage the uncertainty and anxiety experience.</p>

APPENDIX D

Psychosocial Factors SCT Patients Experience During Treatment
from Review of Literature

Psychosocial factors SCT patients experience during treatment from review of literature

Psychosocial factors/major themes	Emotion/feeling experienced	Method of coping identified in the literature	Nursing implications/considerations
<p>Increased physical symptoms – symptom distress, loss of strength</p> <p>Uncertainty - meaning of new symptoms</p> <p>New environment – prolonged (weeks to months)</p> <p>Isolation – to prevent infection</p> <p>Dependency on others</p> <p>Concern about this dependency and the affect/burden on others.</p>	<p>Distress</p> <p>Vulnerability</p> <p>Anxiety</p> <p>Fear</p> <p>Shame</p> <p>Despair from physical symptom intensity</p> <p>Disconnectedness</p> <p>Hope</p> <p>Optimism</p> <p>Courage</p>	<p>Finding place in hospital social environment</p> <p>Normalizing/minimizing the event – thinking there is always someone who is worse.</p> <p>Social support</p> <p>Attitude – hope, optimism, courage maintain positive thinking</p> <p>Spirituality – faith in God, faith in positive outcome</p> <p>Mental escape – distraction, TV, sleep</p> <p>Acquire more information/knowledge</p> <p>Reframe isolation – protect family from seeing the worse</p> <p>Relinquish control to professional/others</p>	<p>Manage intense physical symptoms giving patient control when possible (use of patient control analgesia)</p> <p>Assess need for information and depth/degree of detail desired by patient about side effects and complications and treatment interventions.</p> <p>Acknowledge patients’ emotional expression and support measures of coping; provide spiritual, psychological resources (chaplain service, counselor, family presence).</p>

APPENDIX E

Psychosocial Factors SCT Patients Experience After Treatment
from Review of Literature

Psychosocial factors SCT patients experience after treatment from review of literature

Psychosocial factors/major themes	Emotion/feeling experienced	Method of coping identified in the literature	Nursing implications/considerations
<p>Expectations of treatment and recovery. Ability to resume previous roles. Uncertainty of treatment outcomes. Grief over loss of life as it was. Re-exam the meaning of life existential significance.</p>	<p>Distress Anxiety Anger Fear vs. hope Doubt</p>	<p>Reframe expectations focusing on positive aspect of SCT (new norm, rebirth) Support from social relationships and health care providers Establish new life goals: find significance in health, relationships. Acquire new knowledge about late and long terms effects.</p>	<p>Assist in explanation of restaging test results Assist patient establishing life roles and new normal Acknowledge patient's emotional response and provide support for coping Provide information about survivorship.</p>

APPENDIX F
Interview Questions

Interview Questions

The interview questions used for the original Cohen study were as follows:

1. What was it like for you to have your BMT (blood and marrow transplantation)?
2. What did the staff do that was important in regard to your concerns? Although staff members, of course, intend to be helpful, this is not always the case. Please talk about what was important and whether it was helpful or not helpful.
3. Who else was helpful? How were they helpful?
4. What would you tell someone to prepare them for having a BMT? What would have prepared you better? What surprised you or was unexpected? What would have helped your family prepare for this treatment?
5. Please tell me about the symptoms that you are experiencing.
6. How was your experience with this interview? What suggestions do you have for changes?

APPENDIX G

Informants Demographic Information

Informants Demographic Information

Characteristic	Totals (n=60)	African American (n=20)	Latino (n = 20)	Caucasian (white non-Hispanic) (n = 20)
Gender:				
<i>Male</i>	29	7	13	9
<i>Female</i>	31	13	7	11
Mean age years (range years)	47 (22-71)	45 (22-64)	48 (22-65)	49 (32-71)
Marital status:				
<i>Married</i>	36	8	15	13
<i>Single/Widowed/Divorced</i>	24	12	5	7
Survival				
<i>< or = 100 days</i>	50	17	15	18
<i>6 months</i>	41	16	13	14
<i>1 year</i>	38	15	11	12
<i>3 years</i>	30	11	9	10
<i>5 years</i>	26/59	8/19	8	10
<i>10 years</i>	21/57 (37%)	5/19 (26%)	7 /19 (37%)	9/19 (47%)
<i>Lost to follow-up</i>	3	1 > 3 yrs	1 > 5 yrs	1 > 5 yrs
Education:				
<i>Some High School or Less</i>	6	2	4	0
<i>High School Graduate</i>	19	6	4	9
<i>Some College/College Grad</i>	22	9	9	4
<i>Post-baccalaureate</i>	13	3	3	7
Type of Transplant:				
<i>Allogeneic</i>	26	6	10	10
<i>Autologous</i>	34	14	10	10
Intent of Transplant: for disease control/cure	18/43	11/9	4/16	2/18
Interviews completed				
5	47			
4	6			
3	2			
2	3			
1	2			
Total	273			

APPENDIX H

Major Findings, Summary, and Nursing Implications

Major Findings, Summary, and Nursing Implications

Phase of transplant	Major themes – subthemes	Emotional response	Method of coping identified	Nursing implications/considerations
Before treatment	<p>Facing the fear</p> <p>Aspects contributing/influencing to vulnerability</p> <p>Threat to life from disease and treatment</p> <p>Lack of experience/knowledge</p> <p>Cultural influence</p> <p>Financial burden</p> <p>Family/social physical and emotional availability</p> <p>Coping style/emotional influence</p>	<p>All informants:</p> <p>Cancer dx and SCT :</p> <p>Fear/scared – SCT</p> <p>Life stopped – SCT</p> <p>Loss of control – only chance/only choice for control/cure</p> <p>Urgency to start treatment</p> <p>Guilt – delayed trx, effect on family</p> <p>Depression</p> <p>Anxiety</p> <p>Nervousness</p> <p>Helplessness</p> <p>Uncertainty – what to expect</p> <p>Roller coaster</p> <p>Stress – financial</p> <p>Role disruption</p> <p>Unique to ethnic group</p> <p>AA: Race identified as potential disadvantage; get</p>	<p>Maintain positive/optimistic attitude</p> <p>Remain tranquil</p> <p>Hopeful</p> <p>Remain neutral</p> <p>Distractions: work, music,</p> <p>Faith – AA, Latino (more frequent)</p> <p>Family – support</p> <p>Information- satisfied with info provided; few Latino – avoidance: better not know everything;</p> <p>Healthcare provider – knowledgeable, competent.</p>	<p>Assess need for information and depth/degree of detail desired by patient (and lay caregiver) necessary to make informed decision</p> <p>Acknowledge patient’s cancer experience, cultural influence leading to decision to have SCT and emotional experience</p> <p>Assess for emotional distress and coping style</p> <p>provide psychological support and information to manage the uncertainty and anxiety experience</p> <p>Facilitate referral to chaplain services, social work,</p>

		better as treatment goal;		support group for patient and caregiver Discuss advanced care planning
During treatment	<p>Getting through : will to sustain hope and motivation</p> <p>Aspects contributing/influencing to vulnerability</p> <p>Symptom burden</p> <p>Lack of experience/knowledge</p> <p>Uncertainty - meaning of new symptoms</p> <p>Cultural : language barrier with Spanish speaking informants</p>	<p>Hope - desire to get life back</p> <p>Doubt – treatment now (AA)</p> <p>Symptom distress</p> <p>Fear – severity and meaning of symptoms (all)</p> <p>Mental status changes</p> <p>Isolation</p> <p>Gratitude: institution, donor</p> <p>Despair/terror of chemo/loss of immune system (Caucasian)</p> <p>Appreciative of life - AA</p> <p>Distress – for informant and family</p> <p>Guilt – family distress</p>	<p>Attitude – hope, optimism, courage</p> <p>maintain positive thinking</p> <p>Spirituality – faith in God, faith in positive outcome (Latino, AA)</p> <p>Minimizing possible complications – everyone is different</p> <p>Support from familial and social relationships (more than half Latino – brought family closer)</p> <p>Mental escape – distraction, TV, sleep</p> <p>Acquire more information/knowledge vs too much information leading to anxiety and fear.</p>	<p>Manage intense physical symptoms giving patient control when possible (use of patient control analgesia)</p> <p>Assess need for information and depth/ degree of detail desired by patient about side effects and complications and treatment interventions.</p> <p>Acknowledge patients’ emotional expression and support measures of coping; provide spiritual, psychological resources (chaplain service, counselor, family presence).</p>

			Relinquish control to professional/others – do what doctors and nurses say.	
After discharge (to 100 days)	<p>Going Beyond, Forward: life after treatment Aspects contributing/influencing to vulnerability</p> <p>Life threatening disease: uncertainty about success of treatment for cure/remission</p> <p>Familial social role: Ability to resume previous roles.</p> <p>Financial burden: back to work.</p> <p>Re-exam the meaning of life existential significance, change attitude</p>	<p>Hope</p> <p>Uncertainty/Distress/scared - don't know results of SCT</p> <p>Change attitude</p> <p>Fatigue and weakness</p> <p>Anxiety</p> <p>Regaining control/taking back control</p> <p>Frustrated with inability to do more.</p> <p>Fear vs. hope</p> <p>Grateful having SCT</p> <p>Regret about having SCT</p>	<p>Reframe expectations focusing on positive aspect of SCT (new norm, rebirth)</p> <p>Support from social relationships and health care providers</p> <p>Establish new life goals: find significance in health, relationships.</p> <p>Acquire new knowledge about late and long terms effects.</p>	<p>Educate about restaging, follow-up</p> <p>Assist patient establishing life roles and new normal</p> <p>Acknowledge patient's emotional response and provide support for coping</p> <p>Provide information about what to expect in future – Survivorship program</p>