

Importance of Meaning-Making for Patients Undergoing Hematopoietic Stem Cell Transplantation

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Hematologic malignancies, although comprising a small percentage of all cancers, lead to unique and sometimes magnified treatment challenges. The five-year survival rate for patients with acute myeloid leukemia and acute lymphoblastic leukemia, the most common hematologic malignancies that require stem cell transplantation, ranges from 22%–29% (Pulte, Gondos, & Brenner, 2009); these conditions are treated with aggressive regimens of chemotherapy, radiation, and sometimes hematopoietic stem cell transplantation (HSCT). In addition to the physical side effects of chemotherapy (e.g., pain, nausea, fatigue), treatment of hematologic malignancies often involves other challenges, including extended hospitalization and a high risk of treatment failure or disease recurrence that places these patients at risk for particularly high levels of cancer-related distress (Albrecht & Rosenzweig, 2012).

HSCT is a commonly used treatment for hematologic malignancies. HSCT is a procedure in which stem cells are collected from peripheral blood, bone marrow, or umbilical cord blood and infused into a patient who has undergone an intensive conditioning regimen that typically includes multiagent chemotherapy. Although HSCT is considered a curative treatment for many hematologic malignancies, outcomes after transplantation vary by disease type, remission status at transplantation, donor type, and other factors (Barrett & Battiwalla, 2010). Elimination of cancer often is associated with complications that can be fatal, including traditional chemotherapy-related adverse effects (e.g., nausea and vomiting, fatigue, alopecia, mucositis, major organ toxicity, infertility, hormone-related morbidity, secondary malignancy); infection related to extreme immune suppression, particularly in the immediate post-transplantation period; graft failure; and acute and chronic graft-versus-host disease (GVHD), which can range from mild skin rashes to fatal respiratory and digestive conditions (Potter & Kerridge, 2004). Most deaths occur within the first two

Purpose/Objectives: The purpose of this integrative literature review of hematopoietic stem cell transplantation (HSCT) for hematologic malignancies was to determine whether meaning-making might be helpful to improve coping and psychological adaptation as patients navigate HSCT.

Data Sources: CINAHL®, MEDLINE®, and PsychINFO databases, and ancestry searches. Search terms included *bone marrow transplant, hematopoietic stem cell transplant, hematologic malignancy, quality of life, lived experience, psychosocial, psychological, isolation, and social support*.

Data Synthesis: Twenty-four research articles published from 1989–2012 were included. Five major themes emerged: (a) lived experience, (b) coping style, (c) quality of life, (d) psychological morbidity, and (e) potential for post-traumatic growth. Meaning-making was a thread that ran through each of the key areas of the HSCT experience.

Conclusions: Physical, psychosocial, and spiritual issues arise during HSCT that are unique among patients diagnosed with cancer. Meaning-making is key to adaptive coping and helps to reduce physical, psychosocial, and spiritual challenges, as well as assists patients in experiencing positive personal growth. Interventions focused on meaning-making should be tested in this population.

Implications for Nursing: Nurses are positioned to develop and deliver meaning-making interventions for patients undergoing HSCT and to assess patient-oriented outcomes.

Key Words: coping; post-traumatic stress; quality of life; spirituality/religiousness; stem cell/marrow transplantation
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years after transplantation and are related to disease relapse or complications related to HSCT, including GVHD and HSCT-related toxicities (Wingard et al., 2011). Risk factors for nonrelapse-related death include older age and the presence of chronic GVHD (Wingard et al., 2011). Although the 10-year survival rate of those who survive the first two years post-transplantation is high (80%–92%), the overall life expectancy of those undergoing HSCT for hematologic malignancy remains low (Wingard et al., 2011). Mortality rates are four- to nine-fold higher than those expected in the general

population for at least 30 years following HSCT, which is an estimated 30% lower life expectancy regardless of age (Mohty & Mohty, 2011).

The decision to proceed with HSCT is not one that patients or physicians take lightly, given the potential complications. In addition, HSCT requires substantial financial and time commitments on the part of the patient. The time to recovery is extended because patients stay in the hospital for up to one month for the actual transplantation and then require multiple medical visits for years thereafter, often with at least one readmission to the hospital. In addition to the logistic considerations in choosing HSCT, patients face a multitude of personal considerations, including their psychosocial and spiritual well-being. Therefore, the purpose of this integrative review of the lived experience of patients undergoing HSCT was to determine whether, and in what way, meaning-making might be helpful to these patients in coping and adapting as they navigate the challenges of HSCT.

Background

Much research has been conducted on the lived experience and psychosocial consequences of advanced cancer. Important themes have emerged regarding the components of psychosocial and spiritual well-being for patients suffering from oncologic diseases, including self-awareness, coping and adjustment, relationship changes and role retention, connectedness, sense of faith, feelings of control and confidence, living with meaning and hope, and the possibility for a transformative experience or personal growth after cancer (Andrykowski, Lykins, & Floyd, 2008; Carpenter, Brockopp, & Andrykowski, 1999; Lin & Bauer-Wu, 2003). Patients with a strong sense of psychosocial and spiritual well-being are better equipped to cope with the rigors of treatment, as well as the possibly terminal nature of their disease (Lin & Bauer-Wu, 2003; Whitford & Olver, 2012). Some studies even suggest that effective coping and decreased depression positively influence survival (Loberiza et al., 2002; Volker et al., 2001).

Despite the proliferation of research on the importance of psychosocial and spiritual well-being to the overall quality of life (QOL) of patients with advanced cancer, survivors of HSCT continue to experience challenges. HSCT recipients have mortality rates that can be up to twice as high as that of the general population, even 15 years after a successful transplantation, and they are more likely to have difficulty holding a job and obtaining health insurance than their healthy siblings (Bhatia et al., 2007). Baker, Zabora, Polland, and Wingard (1999) found that in the first year following HSCT, patients continued to struggle with problems in three areas: (a) physical—including fatigue, changes in appearance,

appetite disturbances, and physical restrictions; (b) psychological—including fears about the future, loss of control, anxiety, and depression; and (c) community reintegration—including returning to former roles, separation from home, family and friends, difficulty resuming social relationships, dealing with stigmatization, problems with family and children, and financial and employment difficulties (Baker et al., 1999).

Another study (N = 172) showed that 48% of participants felt that they had “returned to normal” at a mean of 43 months post-transplantation (Andrykowski et al., 1995, p. 576). Reasons included decreased strength and energy, sexual and fertility problems, pulmonary difficulties, anxiety, depression, health-related unemployment, and difficulties in interpersonal relationships. A more recent study found that HSCT survivors ranked difficulty returning to work and the resulting financial problems as their number one concern after physical symptoms, and that these difficulties were associated with feelings of hopelessness, anger, and frustration (Sheldon, Kazmi, Klein, & Berry, 2013).

A large body of research on the lived experience of patients undergoing HSCT has established that these patients experience numerous physical, psychosocial, and spiritual stressors. However, a paucity of research exists regarding specific theory-driven interventions to address the psychosocial and spiritual concerns unique to patients undergoing HSCT. Understanding the role and importance of meaning-making for patients undergoing HSCT can foster the development of interventions to address some of the psychosocial and spiritual concerns facing these patients..

Theoretical Framework

Mishel’s (1988) Uncertainty in Illness Theory suggests that critical illness is accompanied by uncertainty, defined as an absence of meaning. That uncertainty is appraised by the patient as either a danger or an opportunity, and coping and adaptation to illness is dependent on reducing the uncertainty in the situation or accepting it as a sign of hope. Park and Folkman (1997) suggested that finding meaning, both global and situational, is important in stress and coping. In fact, the authors posited that the cognitive process of meaning-making is central to positive psychosocial and psychospiritual outcomes after traumatic or stressful events (Park & Folkman, 1997).

Global meaning is defined as a generalized worldview composed of basic goals and fundamental assumptions about life, beliefs, and understanding of the past and present that shape expectations for the future (Park & Folkman, 1997). Global meaning typically includes the attributes of stability or coherence throughout life’s path, optimistic bias (i.e., exaggerated

sense of personal control), and personal relevance (i.e., belief about the likelihood that bad things will happen).

Situational meaning refers to the individual's initial appraisal of the personal significance of an event. If situational meaning is incongruent with global meaning, the event is determined to be stressful. Coping requires either a change in global meaning or a reappraisal of situational meaning to achieve congruence, thus relieving the stress of the event (Park & Folkman, 1997). If congruence cannot be reached, the individual may begin to suffer from anxiety, depression, and hopelessness.

Literature Search

Electronic databases (CINAHL®, MEDLINE®, and PsychINFO) were searched for articles from 1989–2012 using the following search terms: *bone marrow transplant, hematopoietic stem cell transplant, hematologic malignancy, quality of life, lived experience, psychosocial, psychological, isolation, and social support*. Because of the changes in transplantation procedures over time, articles regarding the experience of transplantation prior to 1989 were determined to be out of date. In addition, an ancestry search was conducted on the research studies obtained from the initial search.

Only English-language articles were reviewed. Research designs included descriptive articles using qualitative methodology as well as primary research and experimental reports. The articles chosen for review were those that focused on description of the lived experience of patients undergoing HSCT and correlation between factors affecting their psychosocial and spiritual well-being. None of the articles tested a meaning-making intervention. Articles were excluded if they addressed exclusively HSCT for diseases other than hematologic malignancy (e.g., breast cancer), focused on children rather than adults, included only patients undergoing autologous stem cell transplantation, related only to physical measures of the HSCT experience, or enrolled only participants who were 10 or more years post-transplantation.

Data Evaluation

A total of 24 research articles met the final criteria for inclusion in the current review (see Table 1). The majority of the articles used qualitative methods ($n = 12$); the others were mixed methods ($n = 6$), quantitative methods ($n = 5$), or experimental ($n = 1$). The research spanned seven countries, including the United Kingdom, Sweden, Belgium, Iran, France, and Australia, although the majority was completed in the United States. The research was conducted across disciplines, including nursing, medicine, and psychology. All studies had clear purpose statements or research questions

and used appropriate methods. In addition, many of the studies using quantitative methods used the same instruments to measure variables, lending credibility and generalizability to the study results.

The majority of the studies used convenience samples, although several used samples from larger projects. General limitations of the studies were related to small sample sizes because of issues of access to patients, although several studies cited high dropout rates from participant morbidity and mortality.

Several themes related to the experience of HSCT patients emerged, including descriptive lived experience, coping style, QOL, psychological morbidity, and post-traumatic growth. The relationship between those factors is presented in Figure 1, and the role of meaning-making in relationship to the factors is shown in Figure 2.

Data Analysis and Findings

Lived experience: Physical symptoms associated with HSCT are a central factor in the lived experience reported by participants. The troublesome physical symptoms most often cited were fever, fatigue, pain, alopecia, cognitive issues, medication side effects, and changes in sexuality. Researchers investigating the variable of isolation found that the physical symptoms were more distressing than the psychological symptoms reported (Collins, Upright, & Aleksich, 1989). However, the majority of the articles with this theme noted that the physical symptoms were secondary to the psychosocial and spiritual challenges posed by HSCT. Feelings of loss of control, facing mortality, and uncertainty were common (de Carvalho, Gonclaves, Bontempo, & Soler, 2000; Gaskill, Henderson, & Fraser, 1997; Persson & Hallberg, 1995; Sherman, Cooke, & Grant, 2005; Thain & Gibbon, 1996).

Feelings of social isolation also were common, with the wish to be in touch with family, friends, staff, and the outside world cited throughout the studies (de Carvalho et al., 2000; Gaskill et al., 1997; Sherman et al., 2005; Thain & Gibbon, 1996). Other social concerns reported included the loss of relationships, role changes, and changes in school or work goals (Gaskill et al., 1997; Sherman et al., 2005).

Finding meaning and meaning-making were prevalent themes throughout the literature in this category. Xuereb and Dunlop (2003) examined meaning in the specific context of HSCT and found that participants related the meaning of their illness and treatment back to their previously held beliefs about the world, and that the amount of agency or control participants felt in the situation also was related to values held and worldview at the time of diagnosis (Xuereb & Dunlop, 2003). Another study found that participants highly valued shared meaning-making between themselves and the nursing staff during their hospitalization for HSCT (Gaskill et al., 1997). In addition, those same participants used what the authors

Table 1. Literature Review by Identified Themes

Study	Purpose	Sample	Design and Method	Findings
Theme: Lived Experience				
Collins et al., 1989	To better understand patient perceptions of reverse isolation while undergoing HSCT	6 patients undergoing HSCT and undergoing isolation for 21–25 days	Qualitative; interviews guided by phenomenologic hermeneutics	Physical side effects of treatment brought more distress than the isolation.
de Carvalho et al., 2000	To identify the expression of interpersonal needs by patients during the phases of BMT	23 patients (age range = 13–43 years, with majority 30–40 years) undergoing HSCT for a variety of hematologic malignancies	Qualitative; interviews guided by phenomenologic hermeneutics	Need for control was predominant and fulfilled best during discharge planning. Wished affection was second and met most during planning for discharge phase. Wished inclusion was third and fulfilled most during initial condition phase. Overall needs were not met as well during the transplantation phase.
Gaskill et al., 1997	To explore the phenomenon of isolation from the perspective of patients being cared for in reverse isolation during BMT	7 adults (age range = 19–70 years) undergoing HSCT; 5 were in isolation for the first time, 2 for the second time	Qualitative; interviews guided by phenomenologic hermeneutics	Major themes extracted were striving to take charge, intellectualizing the need for isolation, and being in touch with family and staff. Patients expressed the importance of nurses understanding the meaning and experiences of their illness and how it can be a form of healing.
Persson & Hallberg, 1995	To explore patient experiences, both physical and psychological, during the active phase of the disease and treatment (chemotherapy or BMT) related to leukemia or lymphoma	5 patients undergoing treatment for leukemia or lymphoma in one Swedish hospital	Mixed methods, qualitative and quantitative; interviews guided by phenomenologic hermeneutics; QOL assessed via EORTC QLQ-C30, GQOL, and SOCS	Psychological themes: sense of threat to their lives, loss of control, living with uncertainty Patients minimized physical problems and focused on gaining control of the situation.
Persson & Hallberg, 2004	To uncover the meaning of the lived experience of falling ill with acute leukemia or highly malignant lymphoma, being under treatment (chemotherapy or BMT), and of life following the event	18 patients (mean age = 57.7 years) at a hospital in southern Sweden from January 1989 to September 1993	Qualitative; interviews guided by phenomenologic hermeneutics	Respondents were put into three main groups. 1. Believed in life; fought for it and came through 2. Life goes on; adapted and found a balance in the new life 3. Life was over; felt out of control and lost belief in life Meaning-making is key to QOL, and narrative approach could be useful for nurses to better understand patient experiences and help reframe maladaptive feelings.
Sherman et al., 2005	To describe the various issues discussed by participants in a monthly post-transplantation support group	8 members of a monthly post-HSCT support group, ranging from young to middle-aged adults	Qualitative; observation guided by phenomenologic hermeneutics	Physical themes: coping with long-term physical complications, differing experiences of normality, fatigue, cognitive changes, medication issues or side effects, changes in sexuality Psychosocial themes: uncertainty, meaning and changing of perspectives, entitlement, and depression. Social themes: role/relationship changes, labeling/role expectations, interpersonal communication, and changes in work/school priorities
Thain & Gibson, 1996	To describe the perceptions of a small group of HSCT recipients	6 patients (mean age = 45 years, range = 31–54 years) in remission following HSCT at a United Kingdom hospital	Qualitative; interviews guided by phenomenologic hermeneutics	Five themes emerged, including facing mortality and death, luck, “prison” (protective isolation), relationships, and physical effects. Greater importance was placed on psychosocial than physical concerns.

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Table 1. Literature Review by Identified Themes (Continued)

Study	Purpose	Sample	Design and Method	Findings
Theme: Lived Experience				
Xuereb & Dunlop, 2003	To explore the experience of leukemia and BMT, with specific focus on the meaning the experience had for patients	10 patients (age range = 27–54 years) who had been inpatients on the BMT ward in one of three major hospitals in Sydney, Australia	Qualitative; interviews, guided by phenomenologic hermeneutics	Meaning: meaning of leukemia was related to the values of the patient at the time of diagnosis. Exploration of phenomenologic reality could facilitate the focus of therapy for each individual. Agency: how a patient engaged with cancer is part of a life-long pattern of dealing with challenge.
Theme: Coping Style				
Coolbrandt & Grypdonck, 2010	To clarify the main strategy patients use to keep courage during HSCT and to analyze the processes of coping with the HSCT	15 patients (mean age = 47.2 years, range = 23–62 years) undergoing HSCT at two academic and one general hospital in Flanders, Belgium	Qualitative; interviews guided by phenomenologic hermeneutics	During HSCT, patients cope by trying to write a positive story and keep courage to see it through to its happy ending. These efforts involve more active strategies than the passive concept of hope.
Farsi et al., 2012	To elicit the coping process of adults experiencing acute leukemia who underwent HSCT therapy	10 patients (mean age = 29.3 years, range = 18–48 years) with AML or ALL undergoing HSCT at a hospital in Tehran, Iran	Qualitative, longitudinal; interviews guided by phenomenologic hermeneutics	Five themes emerged: perceived threat, suspension between fear and hope, rebirth, contextual factors, and coping strategies. “Finding meaning” was the final outcome that indicated effective coping.
Schoulte et al., 2011	To investigate the influence of coping style on interference caused by a variety of common post-treatment symptoms after HSCT	105 HSCT recipients (mean age = 35.98 years, range = 19–56 years) from 15 sites across the United States	Mixed methods, quantitative, and qualitative; interviews; coping style assessed using the brief COPE scale, symptom distress measured with BBMTM	Emotion-focused and instrumental coping did not predict interference scales ($p > 0.05$). Avoidant coping significantly predicted increased interference from skin, eye, mouth, and gastrointestinal symptoms ($p < 0.05$), as well as from cognitive symptoms (e.g., fear, worry) and cognitive difficulties ($p < 0.05$). A generalized avoidant coping style before treatment increased symptom interference from common cancer symptoms.
Shuster et al., 1996	To describe in depth the patterns of meaning employed by patients in the hospital as they coped with the experience of undergoing HSCT	11 adults (age range = 20–51 years) undergoing their first HSCT	Qualitative; interviews guided by phenomenologic hermeneutics	Five themes emerged representing the coping strategies of the respondents, each interpreted as an area of challenge to the respondent, physiologic functioning, alertness, attitude, social relationships, and spirituality. Some respondents realized they could change the BMT experience by changing their attitudes, including ignoring perceived bad occurrences or thinking about time differently, but many struggled with the meaning of their experience.
Widows et al., 2000	To examine whether trauma appraisals, coping, social support, and social constraint were associated with the severity of PTSD symptoms in patients undergoing BMT	102 patients undergoing their first HSCT at Moffitt Cancer Center	Mixed methods, qualitative and quantitative; interviews, SCID-I/NP, PCL-C, Brief COPE, ISEL, Social Constraint Scale, and the TEQ, which was developed for this study	Increased PTSD symptomatology is associated with more negative appraisals of the BMT experience, greater use of avoidant coping styles, lower levels of social support, and greater social constraint ($p < 0.05$). Each of the variables accounted for significant ($p < 0.05$) variability in PTSD symptomatology beyond relevant demographic and medical variables. This confirms prior research on the PTSD prevalence and symptoms in BMT recipients and also identified a set of theoretically derived psychological characteristics that increase risk of PTSD symptomatology post-BMT.

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Table 1. Literature Review by Identified Themes (Continued)

Study	Purpose	Sample	Design and Method	Findings
Theme: Quality of Life				
Ferrell et al., 1992	To apply the concept of QOL to BMT survivors and to explore the specific impact of BMT on QOL	119 BMT survivors (mean age at transplantation = 29.39 years) selected from the files of the City of Hope National Medical Center	Qualitative; analysis of written answers to six open-ended survey questions	Researchers created a model of influencing factors of BMT on the four dimensions of well-being: physical/symptoms, psychological, social, and spiritual. Although many aspects of QOL are common between BMT recipients and other cancer survivors, some unique issues exist related to the impact of BMT on QOL.
Johnson-Vickberg et al., 2001	To examine global meaning (i.e., the belief that life has purpose and coherence) and psychological adjustment in HSCT survivors	85 survivors of HSCT (mean age = 40 years, range = 17–59 years)	Mixed methods, quantitative and qualitative; interviews, PMI LAP-R, BSI-GSI, PLC-C, MOS SF-36	Global meaning was inversely related to global psychological distress and BMT-related psychological distress (PTSD-like symptoms related to the cancer treatment) and positively related to mental health aspects of QOL (e.g., emotional functioning, social functioning). Global meaning may be an important factor in psychological adjustment of BMT survivors.
Molassiotis & Morris, 1998	To assess post-BMT experiences to determine whether QOL differs between HSCT recipients of autologous or sibling-matched allogeneic HSCT and those receiving unrelated donor marrow transplantations	28 adult survivors (mean age = 31.6 years (range = 17–48 years) of matched unrelated donor allogeneic BMT from a large teaching hospital in London	Qualitative; analysis of written answers to open-ended survey questions	Nine themes related to QOL emerged: normality, enjoyment and fulfillment in life, being psychologically healthy, being physically healthy, being independent, having family and relationships, having work, experiencing happiness, and having material support. The data suggest that matched unrelated donor BMT survivors do not have a different perception of QOL than other transplantation survivors, but they seem to suffer from more adverse side effects, particularly psychological, which could be targeted by pretransplantation interventions and long-term psychosocial services.
Zittoun et al., 1999	To develop instruments to assess QOL during intensive chemotherapy and HSCT; analyze the role of the main variables in patient perception of overall QOL during such treatments; and evaluate the impact of disclosure of the self-assessment on team support and psychotherapeutic interventions and, therefore, on short-term QOL	178 adult (n = 117 completed the study) patients (median age = 44 years, range = 16–83 years) in a Paris hospital for intensive treatment of hematologic malignancies (induction, consolidation, or BMT)	Experimental; EORTC QLQ-30, HADS	The most frequent and distressing symptoms were physical. Anxiety, depression, and sleep disturbances might be induced or enhanced by physical symptoms. The drop-out rate (34%) corresponded to patients with severe or lethal complications, suggesting that physical and psychological symptoms of the total patient population were underestimated. The highest levels of psychological distress were seen at week 2. Self-assessed QOL was not correlated with physical morbidity but was influenced by emotional subscales, mainly depression. Disclosing self-assessment results to staff allowed better allocation of psychotherapeutic interventions according to level of anxiety and depression, but did not influence outcome measurements.
Theme: Psychological Morbidity				
Ho et al., 2002	To investigate the association between pretransplantation psychosocial variables and psycho-physiologic outcomes during the immediate convalescence period	50 patients (mean age = 43 years, range = 24–62 years) undergoing their first BMT at Royal Melbourne Hospital from July 1997 to June 1998	Quantitative; FES-RD, CRI, BSI-GSI, 100 mm visual analog pain scale	Pretransplantation family relationships and coping resources associated moderately with psychological distress during the convalescent period of HSCT. Findings support a family-centered approach to HSCT care and provide evidence for usefulness of pretransplantation psychosocial interventions.

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Table 1. Literature Review by Identified Themes (Continued)

Study	Purpose	Sample	Design and Method	Findings
Theme: Psychological Morbidity				
Jenks Kettmann & Altmeier, 2008	To examine the role of social support in mitigating depression among bone marrow transplantation recipients	86 patients (mean age = 35 years, range = 18–55 years) undergoing first BMT at one of 15 medical centers in the United States from March 1995 to October 2000	Quantitative; MOS-SSS, CES-D	Moderate levels of depressive symptoms were observed in BMT recipients ($p < 0.05$); 29% and 28% met criteria for clinical depression at pre-BMT and one-year post-BMT, respectively. Women reported more depressive symptoms than men. Social support pre-BMT predicted depression levels post-BMT after controlling for initial levels of depression ($p < 0.001$). Because BMT usually requires a period of prolonged isolation, healthcare providers must work with families prior to BMT to establish plans and expectations for this time. Healthcare providers also need to provide a higher level of social support themselves.
Molassiotis et al., 1996	To evaluate mood states, dependence on others, and self-esteem of patients undergoing HSCT; identify common coping mechanisms of patients during isolation for HSCT; evaluate specific distress symptoms and their association with mood disturbance; compare psychological morbidity of patients treated with different isolation types (LAF versus HEPA filtered rooms) and the effects of professional psychological support on patient mood state	26 patients undergoing HSCT in three HSCT centers in the United Kingdom during a 15-month period	Longitudinal study with quantitative methods; POMS, Rosenberg scales of adults self-image, SDS, Coping Style Checklist	High psychological morbidity was present the day prior to transplantation and remained high throughout hospitalization and up to one month afterward. Anxiety and depression did not decrease over time but anger and hostility did increase, particularly one month after discharge. Self-esteem and dependence on others did not change over time, but participants were found to have low levels at the start. Coping mechanisms included hope, directing attention, maintaining control, and acceptance. Psychological distress had a carry-over effect up to one month postdischarge. Different types of isolation (LAF versus HEPA filtered rooms) were not associated with differences in mood disturbance. Patients who received psychological support during BMT had significantly lower mood disturbance.
Perry, 2000	To test a psychosocial intervention aimed at encouraging patients to be more involved in their transplantation preparation, and to explore the psychosocial impact of BMT	254 HSCT recipients (mean age = 42 years) treated at Sydney Royal North Shore, Royal Melbourne Hospital, Royal Adelaide Hospital, and Royal Brisbane Hospital	Mixed methods, experimental, qualitative and quantitative; interviews, HADS, MACS, PrepTP, PostTP	The intervention group was better prepared, had fewer problems, and was less anxious. Some aspects of the transplantation were common to all HSCT recipients regardless of intervention status, including trying to maintain a sense of humor, feeling slowed down, difficulty maintaining a positive outlook, fear of disease recurrence, and difficulty maintaining a “fighting spirit.” The intervention group had higher scores for “hopelessness and helplessness” and “fatalism.” Many confounding factors are involved, such as disease and BMT type, which may influence patient and staff perception of disease and treatment.
Theme: Post-Traumatic Growth				
Andrykowski et al., 1993	To explore the positive changes that occur with a cancer diagnosis	133 patients undergoing HSCT	Quantitative; POMS, SOCS meaningfulness subscale, SIP, CPBS, PHQ, SER	Although malignant diseases are associated with a multitude of negative sequelae, these are not stressors with uniformly negative consequences; instead, the cancer experience represents more of a psychosocial transition for patients.

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Table 1. Literature Review by Identified Themes (Continued)

Study	Purpose	Sample	Design and Method	Findings
Theme: Post-Traumatic Growth				
Tallman et al., 2010	To study post-traumatic growth and psychological and physical well-being among patients undergoing HSCT	25 adults (mean age = 37.21 years) who received HSCT at one of 15 sites in the United States	Mixed methods, qualitative and quantitative; interviews, LOT-R, MOS-SSS, FACT-G, CES-D, PTGI	Mean PTGI score was 74.2, with a significant effect for gender ($p = 0.04$). Domain of post-traumatic growth included increased personal strength, enhanced personal relationships, appreciation of life, new life perspectives, health, and spirituality, and growth responses increased over time. Post-traumatic growth and well-being after treatment were predicted by dispositional optimism and social support, both assessed prior to treatment. Assisting survivors to articulate growth as part of ongoing care may be valuable.
Widows et al., 2005	To identify psychosocial predictors of individual differences in post-traumatic growth to explore the relationship of post-traumatic growth with post-transplantation levels of psychological distress and PTSD symptomatology, and to explore whether post-traumatic growth was differentially related to actual versus perceived changes in psychological distress over time	72 BMT recipients (mean age = 45 years, range = 21–70 years) from the Moffitt Cancer Center	Quantitative; CRI, ISEL-SF, POMS, PTGI, TEQ, PCL-C, POMS- SV	Greater post-traumatic growth was related to younger age ($p = 0.05$), less education ($p = 0.001$), greater use of positive reinterpretation, problem solving ($p < 0.05$), seeking alternative rewards as coping strategies in the pretransplantation period ($p = 0.05$), more stressful appraisal of aspects of the transplantation experience ($p < 0.05$), and more negatively biased recall of pretransplantation levels of psychological distress ($p = 0.01$). Patients who appraised BMT as producing greater emotional distress and who had more concerns about survival reported greater post-traumatic growth.

ALL—acute lymphoblastic leukemia; AML—acute myeloid leukemia; BBMTM—Bull Bone Marrow Transplant Module; BMT—bone marrow transplantation; BSI-GSI—Brief Symptom Inventory Global Severity Index; CES-D—Centers for Epidemiological Studies—Depression scale; COPE—Coping Orientation to Problems Encountered; CPBS—Cancer Patient Behavior Scale; CRI—Coping Responses Inventory; EORTC QLQ-C30—European Organisation for Research and Treatment of Cancer Quality of Life Instrument; FACT-G—Functional Assessment of Cancer Therapy—General; FES-RD—Family Environment Scale: Relationships Dimension; GQOL—Global Quality of Life scale; HADS—Hospital Anxiety and Depression Scale; HEPA—high-efficiency particle absorption; HSCT—hematopoietic stem cell transplantation; ISEL-SF—Interpersonal Support Evaluation List—Short Form; LAF—Laminar Air Flow; LOT-R—Life Orientation Test—Revised; MACS—Mental Adjustment to Cancer Scale; MOS SF-36—Medical Outcomes Study 36-Item Short-Form Health Survey; MOS-SSS—Medical Outcomes Study Social Support Survey; PCL-C—PTSD Checklist: Civilian; PHQ—Perceived Health Questionnaire; PMI LAP-R—Personal Meaning Index of the Life Attitude Profile Revised; POMS—Profile of Mood Scale; POMS-SV—POMS short version; PostTP—Perceptions of Post-Transplant Preparation scale; PrepTP—Perceptions of Pre-Transplant Preparation scale; PTGI—Post-Traumatic Growth Inventory; PTSD—post-traumatic stress disorder; QOL—quality of life; SCID-I/NP—Structured Clinical Interview for DSM-IV Axis 1 Disorders; SDS—Symptom Distress Scale; SER—Symptom Experience Report; SIP—Sickness Impact Profile; SOCS—Sense of Coherence Scales; TEQ—Trauma Experience Questionnaire

termed “intellectualization” (i.e., rationalization or trying to understand intellectually why the disease happened instead of focusing solely on emotions), which may be another form of meaning-making, to cope with extended isolation (Gaskill et al., 1997). Persson and Hallberg (2004) reported that meaning-making was a key factor in the QOL of their participants during HSCT. They suggested that a narrative approach may be useful for nurses to facilitate meaning-making in this patient population.

Coping style: One study defined coping as creating a pattern of meaning and concluded that effective coping was evidenced by participants who were able to reassess negative appraisals of HSCT as positive (Shuster, Steeves, Omega, & Richardson, 1996). Those researchers noted that many patients struggled to find meaning in their experiences. Important factors in appraisal were physiologic functioning (i.e., interference of physical symptoms), attitude, social relationships, spirituality, perceived threat, suspension between fear and hope, and the idea of rebirth (Farsi, Nayeri, & Negarandeh, 2012; Shuster et al., 1996). Coping was defined specifically as meaning-making by Farsi et al. (2012), who determined that “finding meaning” in the experience of HSCT was the final outcome that represented effective coping (Farsi et al., 2012, p. 104). Similarly,

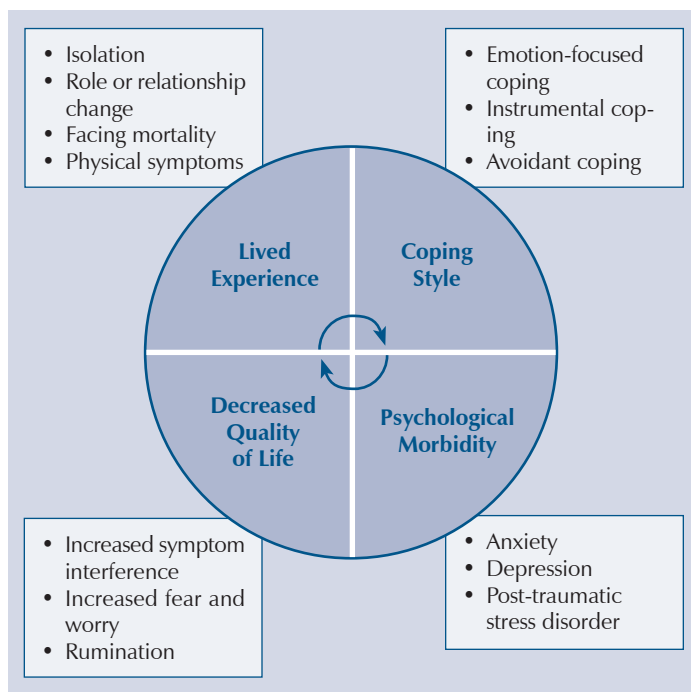


Figure 1. Factors Affecting Quality of Life in Patients Undergoing Hematopoietic Stem Cell Transplantation

Coolbrandt and Grypdonck (2010) determined that “keeping courage” through creating a positive story or a positive appraisal of the situation indicated adequate coping for their participants. However, these authors suggested that coping requires more than passive acceptance of the situation (Coolbrandt & Grypdonck, 2010, p. 220).

Schoulte, Lohnberg, Tallman, and Altmaier (2011) examined the influence of coping style on participant abilities to manage a variety of physical symptoms associated with HSCT. The authors divided coping style into three categories. The first, emotion-focused coping (defined as trying to see the positive side of the situation), and the second, instrumental coping (characterized by information gathering), were considered adaptive coping styles. The third, avoidant coping, in which the patient turns to distractors such as alcohol or denies the existence of the situation, was considered maladaptive. The researchers found that although adaptive coping styles (emotion-focused and instrumental) did not predict symptom interference, an avoidant coping style was significantly associated with increased interference of physical symptoms ($p < 0.05$) (Schoulte et al., 2011). The study also found that an avoidant coping style significantly predicted interference by psychosocial symptoms, including fear, worry, and cognitive problems. The authors concluded that an avoidant coping style is a negative predictor for physical and psychological functioning during HSCT (Schoulte et al., 2011).

Widows, Jacobsen, and Fields (2000) looked at the relationship between coping style and symptoms of post-traumatic stress disorder (PTSD) in post-HSCT recipients. Again, an avoidant coping style was significantly related to reports of PTSD symptoms ($p < 0.05$) (Widows et al., 2000). In addition, the study confirmed prior research regarding the prevalence of PTSD symptoms in HSCT survivors, and determined that in addition to an avoidant coping style, low levels of social support, increased social constraints, and negative appraisal of the HSCT experience all were characteristics that put patients at an increased risk for PTSD after treatment with HSCT (Widows et al., 2000).

Quality of life: HSCT survivors have described several primary influences to QOL, including physical well-being, psychological well-being, social well-being or good social relationships, spiritual well-being, normality, enjoyment and fulfillment in life, and being able to work (Ferrell et al., 1992; Molassiotis & Morris, 1998). In addition, one study found that although physical symptoms were more distressing than other symptoms, it was psychological factors such as level of anxiety and depression that were highly correlated with self-assessed QOL (Zittoun, Achard, & Ruszniewski, 1999). Research also suggests that although HSCT survivors and other cancer survivors share many common experiences, some aspects of the HSCT experience are unique, such as prolonged hospitalization and isolation, which may place HSCT survivors at a higher risk for psychosocial distress (Molassiotis & Morris, 1998). That finding is supported by a literature review on QOL in HSCT recipients, which concluded that many transplantation survivors have adjustment difficulties, but that additional research needs to be conducted to determine the subgroups of patients undergoing HSCT who are most at risk (Mosher, Redd, Rini, Burkhalter, & DuHamel, 2009).

The importance of meaning was addressed further in relation to QOL by Johnson-Vickburg et al. (2001). The authors found that global meaning (i.e., belief that life has purpose and coherence) was inversely related to global psychological distress and to HSCT-related psychological distress, which they described as PTSD-like symptoms. The presence of global meaning also was correlated positively with aspects of self-assessed QOL, including emotional and social functioning. Johnson-Vickburg et al. (2001) concluded that global meaning was an important factor in the psychological adaptation of HSCT recipients.

Psychological morbidity: Many cancer survivors suffer from depression and anxiety, which qualifies as psychological morbidity. In one study, 29% of respondents met the criteria for clinical depression prior to transplantation, and 27% still met the criteria one

year post-transplantation (Jenks Kettmann & Altmeier, 2008). An earlier study (Molassiotis, Van Den Akker, Milligan, Goldman, & Boughton, 1996) looked at the incidence of depression and anxiety throughout the transplantation process and found that patients experienced high levels of these symptoms the day before transplantation, and that these symptoms remained high for almost one month postdischarge. Molassiotis et al. (1996) also found that anger and hostility increased during the transplantation period and remained high until after discharge, and that the specifics of the transplantation plan did not affect depression and anxiety ratings.

Research findings regarding predisposing factors for depression and anxiety include poor pretransplantation family and social relationships, minimal coping resources, female gender, prolonged isolation, and fear of disease recurrence (Ho, Horne, & Szer, 2002; Jenks Kettmann & Altmeier, 2008; Perry, 2000). Predictors for decreased mood disturbances during transplantation include receiving psychological support during transplantation, a pre-transplantation education intervention that adds a sense of control for the patient, and increased levels of social and family support prior to transplantation (Ho et al., 2002; Jenks Kettmann & Altmeier, 2008; Molassiotis et al., 1996; Perry, 2000). Researchers conclude that psychosocial interventions prior to and during the transplantation period would be useful in decreasing the incidence of anxiety and depression among patients undergoing HSCT.

Post-traumatic growth: Three studies examined the possibility that the HSCT experience could have a positive psychological, psychosocial, or spiritual outcome regardless of the physical consequences. Areas of personal growth after transplantation included increased personal strength, enhanced personal relationships, appreciation of life, new life perspectives, and increased spirituality (Tallman, Shaw, Schultz, & Altmaier, 2010). Predictors of post-traumatic growth were found to be dispositional optimism, social support prior to transplantation, younger age, use of positive reappraisal, problem solving, seeking alternative rewards as a coping strategy prior to transplantation, and, perhaps somewhat unexpectedly, increased levels of negative bias (i.e., negatively biased recall of pretransplantation levels of psychological distress) and recall regarding the transplantation event (Tallman et al., 2010; Widows, Jacobsen, Booth-Jones, & Fields, 2005). Research findings support the idea that HSCT is a stressful and difficult event, but that both PTSD and post-traumatic growth may occur, suggesting that healthcare providers can tell patients that growth experiences throughout the transplantation process are possible (Andrykowski, Brady, & Hunt, 1993; Tallman et al., 2010; Widows et al., 2005).

Implications for Practice

The studies reviewed revealed several important findings regarding the experience of patients undergoing HSCT. Physical, psychosocial, and spiritual challenges occur during the transplantation period, with common physical complaints including nausea, fatigue, pain, alopecia, cognitive difficulties, and medication side effects. Common psychosocial and spiritual challenges include feelings of loss of control or helplessness, living with uncertainty, facing death, social isolation, role and relationship changes, and changes in work or school goals and priorities. The literature is divided on whether physical, psychosocial, or spiritual challenges are the more distressing concerns for patients, although these issues clearly relate to one another.

Coping style appears to be a crucial variable in patient adjustment to HSCT related to the level of distress associated with physical, psychosocial, and spiritual challenges. An avoidant coping style is generally agreed to be maladaptive and was found to be associated with increased PTSD symptoms. Meaning-making was cited by participants as having an important relationship to effective coping, regardless of specific coping style. Those participants who were able to find meaning in their HSCT experience were better able to manage physical symptoms and were less likely to report pathologic depression, anxiety, and PTSD symptoms after transplantation than those who struggled to find meaning. The relationship between

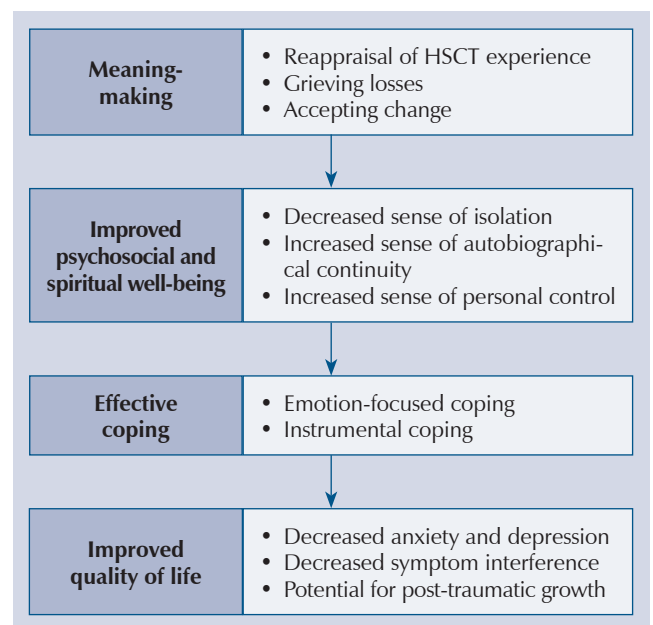


Figure 2. The Role of Meaning-Making in Improving Quality of Life in Patients Undergoing Hematopoietic Stem Cell Transplantation (HSCT)

Knowledge Translation

Coping style is a crucial factor in patient adjustment to hematopoietic cell transplantation.

Meaning-making is a key to effective coping.

Narrative-based interventions may be particularly appropriate to aid in meaning-making for this population.

effective coping and ultimate survival or disease outcome remains unclear.

In the studies reviewed, patients undergoing HSCT defined their QOL more in terms of psychosocial and spiritual symptoms than in terms of physical symptoms. Returning to a normal lifestyle and retaining social and family relationships were paramount among the psychosocial and spiritual concerns affecting QOL. Those patients who were able to reduce the incongruence between their generalized worldview at the time of diagnosis and the experience of HSCT also were much more likely to rate their QOL as high and were much less likely to report symptoms of PTSD.

Ineffective coping may be related to true psychological morbidity, including clinical depression and anxiety, particularly during the immediate transplantation period and up to one month postdischarge. However, research findings suggest that the experience of HSCT does not have to be a uniformly negative experience, and that patients may be assisted in experiencing personal growth following HSCT. Areas of personal growth included increased personal strength, enhanced personal relationships, appreciation of life, new life perspectives, and increased spirituality. For personal growth to occur, patients required, among other factors, good social support prior to and during transplantation and the use of positive reappraisal.

The literature suggests that the lived experience of HSCT includes troublesome physical symptoms, fear and worry, and social isolation, and these may make effective coping difficult. Meaning-making may influence patients toward an adaptive coping style that would improve psychosocial and spiritual well-being and minimize the risk for psychological morbidity. That, in turn, could foster post-traumatic growth and improve overall QOL in patients undergoing HSCT.

If nurses caring for patients undergoing HSCT use a targeted meaning-making intervention to promote adaptive coping, they may be able to help prevent psychological morbidity, increase psychosocial and spiritual well-being, and create the potential for post-traumatic growth in these patients, thereby increasing their overall QOL. The majority of the literature reviewed suggested that psychosocial and spiritual,

or meaning-making, interventions by nurses would be beneficial for patients undergoing HSCT, although no specific recommendations were offered. Two articles suggested that narrative approaches and “writing a positive story” (Coolbrandt & Grypdonck, 2010, p.220) may be an approach to promote meaning making for this population (Persson & Hallberg, 2004). Some authors suggest that storytelling may be an effective meaning-making intervention for patients who are critically ill because it allows for positive reappraisal and regaining a sense of control in an out-of-control situation (Pennebaker, 2000; Polkinghorne, 1996; Sakalys, 2003; Sandelowski, 1994). Some authors suggest, too, that the diagnosis of cancer represents a disruption in a patient’s autobiography, leading to distress caused by uncertainty and role changes, and that oral storytelling is an effective strategy to address this disruption and help alleviate the distress (Hubbard & Forbat, 2012). In addition, oral storytelling from patient to nurse may alleviate some of the stress of isolation by providing human contact and a caring listener (Heiney, 1995; Smith, 2002; Watson, 2007). Nurses are well positioned to implement narrative interventions that aid in the meaning-making process. Asking patients to tell their story is within every nurse’s scope of practice, and listening to a patient’s story is part of the caring nurse-patient relationship. Helping patients to reflect on the meaning of their experience and to reappraise the experience is a natural next step in the nursing process when caring for those undergoing HSCT. Development of a structured narrative intervention designed to promote meaning-making in the HSCT population will improve nursing practice in this area.

Conclusion

Much of the research regarding HSCT has been directed at understanding the patient experience and determining that a psychosocial and spiritual intervention designed to encourage meaning-making would be useful in this population. However, no research has been identified describing the clinical testing of such interventions with patients undergoing HSCT. A nurse-administered meaning-making intervention, such as storytelling, could have a positive impact on QOL in the HSCT population during the immediate transplantation period and afterward.

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