DISTRESS IN HEMATOPOIETIC CELL TRANSPLANT SURVIVORS: A THEMATIC ANALYSIS OF THE SURVIVORSHIP EXPERIENCE

by

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Abstract

**Problem under investigation:** Inadequate evidence exists supporting the use of distress screening tools in the hematopoietic cell transplant survivor (HCTS) population, revealing impaired understanding of the survivorship experience.

**Objectives:** This project aimed to improve clinician understanding of the experience of HCTS as it relates to distress, symptom management, and coping skills that influence overall quality-of-life.

**Background and Theoretical Framework:** HCTS are a unique population with complex needs, which influence overall distress. The way in which HCTS interpret distress was approached through the lens of Lazarus and Folkman’s Theory of Stress, Appraisal, and Coping.

**Project Methods:** Thematic content analysis was used to analyze transcribed data gained from semi-structured face-to-face interviews with HCTS in the Blood and Marrow Transplant Center of a comprehensive cancer center.

**Results:** Thematic analysis revealed overarching schemes of distress, coping, and reappraisal. Participants (n=6) identified various areas of distress within physical, psychosocial, and access domains. Problem-focused and emotion-focused coping, and protective factors mitigated distress. Domains undergoing reappraisal after transplant included body, normalcy, meaning of experience, and life view.

**Potential Significance:** Reappraisal as a process of survivorship may offer a mechanism for influencing a survivor’s perception of distress. Positive reappraisal of survivorship experience may contribute to improved quality of life.

**Implications:** This project described unique issues of HCT survivorship experience. Due to limited sample size and qualitative nature of project, it is difficult to justify changes to the current distress screening procedures. However, future research can be directed toward program evaluation of survivorship resources and establishing psychometrics for current screening tools.
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Introduction of Problem

Advancements in the field of hematopoietic cell transplant have made it possible to treat, and sometimes cure, various malignant and non-malignant disorders of blood and bone marrow. These advancements in therapy have contributed to the increased prevalence of a unique population: the hematopoietic cell transplant survivor (HCTS), a group estimated to increase by 2.5 times by 2020 and 5 times by 2030 (Majhail et al., 2013). In 2009, it was estimated that 108,900 HCTS were living in the United States (Majhail et al., 2013). The care of each of these patients is extremely complex, requiring interdisciplinary collaboration among physicians, advanced practice providers, pharmacists, dieticians, physical and occupational therapists, and social work, in order to manage transplant-related complications and other comorbidities, such as hypertension, diabetes, and cardiac disease.

HCTS also have a myriad of physical and psychosocial late effects related to survivorship issues. HCTS face significant changes in functioning and exacerbation of symptoms as a result of acute and chronic Graft-versus-Host Disease (GvHD) of various body systems, and about one-quarter of HCTS are affected by long-term physical consequences of the transplant procedure, including fatigue, nausea, and pain (Sinotora et al., 2017). The late effects of the disease process and its treatment contribute to significant symptom burden in this population. The cumulative incidence of just one chronic health condition related to exposures and conditioning regimens pre-transplant, chronic immunosuppression, and GvHD affect 60% of this population at 10-year post-transplant (Armenian et al., 2012). These comorbidities are severe or life-threatening for 35% of survivors (Armenian et al., 2012).

Eighty percent of all cancer survivors have been found to experience pervasive fear of recurrence of malignancy, and nearly one-third of all cancer survivors are affected by anxiety
and/or depression (National Comprehensive Cancer Network, 2017b). Chronic pain and patient-rated severity of GvHD symptoms were independently associated with depression and fatigue in allogeneic HCTS (Jim et al., 2016). These findings highlight the prevalence and severity of late effects of the disease and HCT procedure, which have profound impacts on overall functioning and quality of life.

HCTS, like all patients, live in complex biopsychosocial environments. They experience various non-illness-related stressors, including financial burdens, disturbances in social circles, and work-related stressors. All of these experiences culminate to contribute to the unique experience of distress in survivors, which has been shown to negatively impact quality of life (National Comprehensive Cancer Network, 2017b). Patient-related factors, such as resilience (the degree to which an individual is able to overcome difficult situations) and functional status have been suggested to be strong predictors of psychosocial outcomes of HCTS, independent of disease-related factors. A patient’s self-perceived assessment of his/her resilience and health-related quality of life have been identified as important targets for screening and intervention, both before and after transplant (Rosenberg et al., 2015).

Identification of Gap in Literature and Practice

Distress, which is any unpleasant experience of physical, psychological, social, or spiritual nature, has a significant impact on the health and well-being of both patients with active malignant disease and cancer survivors (National Comprehensive Cancer Network, 2017b). As healthcare providers, it is important that we continuously assess and intervene upon illness and non-illness related factors that contribute to distress in our patients’ lives. In order to do so effectively, valid, reliable, and user-friendly screening tools must be readily available for provider use during clinical visits. The National Comprehensive Cancer Network reports that
broad assessment tools of distress, such as the Brief Symptom Inventory Global Severity Index
and the NCCN Distress Thermometer do not sufficiently detect distress in HCTS (National
Comprehensive Cancer Network, 2017b; Sinatra et al., 2017). The Brief Symptom Inventory-
18 can also be cumbersome for providers to interpret and confusing for patients to complete.
The lack of evidence for a validated distress screening tool for HCTS further alienates this
population and highlights the need for improved access to competent survivorship care.

A survey conducted by Hahn et al. (2017) identified various unmet needs of Roswell
Park Comprehensive Cancer Center (RPCCC) HCT patients, within the domains of emotional
health, access and continuity of care, relationships, financial concerns, and information. Specific
unmet needs ranged from physical (i.e. changes in appearance and fatigue) to psychosocial
(adjusting to others’ expectations and returning to normality) to mental/emotional (i.e.
depression, losing confidence in one’s own abilities, difficulty focusing) to financial (worry over
paying bills) (Hahn et al., 2017). This evidence not only highlights the wide variety of unique
unmet needs of RPCCC’s HCTS, but also demonstrates that a gap exists in the current HCT and
oncology survivorship literature and in current practice.

The HCT clinic of interest for this project uses two different distress screening tools
during HCT Survivorship visits: the NCCN Distress Thermometer (DT) (Appendix A) and the
RPCCC Survivorship Screening Tool (RPCCC SST) (Appendix B). These tools are completed
by HCTS prior to their clinical appointment, and providers will then review the patients’ answers
during the visit, allowing for further evaluation and management for any triggered responses.
However, a discrepancy has been observed by HCT providers, in which patients tend to denote
their experience of various physical or psychosocial symptoms rated as moderate-to-severe on
the RPCCC SST, but rate their overall level of distress as minimal to none on the NCCN DT.
For example, a patient may report several symptoms of severe intensity, but report low level of overall distress due to the presence of adequate financial and social support symptoms and competent sense of self-efficacy. On the other hand, another patient may have low disease or late effect burden as measured by the RPCCC SST, but report a high degree of overall distress due to various other stressors that may or may not be related to the HCT. This observation highlights an incongruity between the current screening tools utilized in the RPCCC HCT Clinic, requiring further evaluation.

**Project Objectives and Aims**

The purpose of this project was to improve the understanding of the relationship between distress and various physical and psychosocial symptoms that may or may not be related to late effects or diseases processes of HCT.

**Capstone Question**

In the population of hematopoietic cell transplant survivors, greater than 1-year post-transplant, how do the concepts of stress, coping, and symptom management influence the experience of distress and quality of life?

**Justification of Project Objectives**

In order for oncology and survivorship providers to optimize the assessment, evaluation, and intervention upon these unique stressors, an improved understanding of the experience of HCTS is needed. This newly learned information can be used to develop and validate screening tools that more effectively capture the experience of HCTS in a way that is both population-competent and provider-friendly in a busy clinical setting.

It is the goal of this capstone project to improve clinical practice and patient outcomes through the identification of themes that compose the unique experiences of HCTS related to
symptom management, distress, and quality of life. Through thematic analysis, potential exists to deepen and improve provider understanding of issues that are most important to the HCTS population. This information cannot be used to generalize and treat all HCTS as the same, but rather to focus on and normalize issues that were identified as most prevalent and distressing to this population. A long-term aim was to identify priorities unique to HCT survivorship, in order to inform the future creation of more effective and efficient symptom management and distress screening tools that also have improved provider utility. In so doing, the ultimate goal was to improve provider and patient satisfaction with the survivorship care process.

Relevancy to Advancing Clinical Practice

The Advanced Practice Nurse (APN) role is crucial to this project and the implementation of competent survivorship care in the RPCCC HCT Clinic. Both nurse practitioners and physician assistants are utilized extensively in this clinic to review interval histories of present illness, conduct physical exams, order diagnostic tests, and prescribe treatments for various patient groups ranging from new consults to survivors. Unlike physician assistants and physicians, APN’s who have obtained the Doctor of Nursing Practice (DNP) degree are in a unique position to improve the evidence-based practice of all providers in the clinic.

The APN’s role includes the ongoing assessment for the need for improved clinical practice, synthesizing and appraising evidence in the current literature, implementing this evidence in the clinical setting, and evaluating for improvement in the care process as a result. These responsibilities highlight the unique role of the DNP-prepared APN as a patient educator, researcher, and champion for providing the most evidence-based, competent, patient-centered care possible.
This capstone project fulfilled several Essentials of Doctoral Education for Advanced Nursing Practice, including (I) strengthening Scientific Underpinnings for Practice, (II) utilizing Organizational and Systems Leadership for Quality Improvement and Systems Thinking, (III) Clinical Scholarship and Analytical Methods for Evidence-Based Practice, (VI) Interprofessional Collaboration for Improving Patient and Population Health Outcomes, and (VIII) Advanced Nursing Practice (American Association of Colleges of Nursing, 2006).

Review of Current Literature

In order to understand the current state of HCT survivorship care, a literature review was initiated by searching PubMed and CINAHL databases with the following keywords: “hematopoietic cell transplant,” “survivor,” and “distress.” Studies were limited to English language and published since 2012. Identified articles were secondarily screened for relevancy and exclusion criteria (HCT during childhood or non-HCT cancer survivors). PubMed yielded 19 articles based on primary screen. CINAHL yielded 12 articles on primary screen. After secondary screen and eliminating duplicates or articles that were unavailable in full-text, the database search yielded a total of seven articles. Please see Appendix C for complete Evidence Matrix.

Symptom Severity and Quality of Life

Several studies aimed to characterize the nature and severity of the burden of symptom distress in the HCTS population, revealing the unique challenges and care needs facing this population compared to non-HCTS. Bevans et al. (2014) analyzed baseline and longitudinal recovery trajectory of allogeneic HCTS greater than three years from transplant associated with the impacts of health status and health-related quality of life (HRQL). The study found that physical symptom distress was significantly associated with physical and mental well-being and
HRQL, with 42.7% of participants reporting high level of symptom distress and 21.6% reporting moderate level of distress. Physical health impairment was significantly associated with immunosuppressive therapy for chronic GvHD, and survivors who reported high symptom distress at baseline continued to report clinically meaningful “persistent impairments in physical health” for up to 14 years post-transplant (Bevans et al., 2014, p. 391). Physical symptom distress was also found to significantly predict clinically significant mental health dysfunction and impaired HRQL compared to the non-HCTS population. These findings provide the baseline for the reasoning that providers should be cognizant of physical symptom management, as it has been shown to profoundly impact self-perceived quality of life and health status in HCTS.

Sun et al. (2013) aimed to characterize the long-term effects and burden of morbidity in HCTS greater than 10-years post-transplant, based upon data of the Bone Marrow Transplant Survivor Study. The authors analyzed the cumulative incidence of “severe/life-threatening/fatal conditions” experienced by HCTS using the Common Terminology Criteria for Adverse Events Version 3.0 (CTCAE v3.0) (Sun et al., 2013, p.1073). The authors found that HCTS are 5.7 times more likely to experience severe disease burden and 2.7 times more likely to report physical (somatic) distress compared to healthy siblings. Furthermore, chronic GvHD appears to be an important, although not statistically significant, predictor of distress, as allogeneic HCT recipients experiencing active chronic GvHD had 1.8 times risk of a “severe, life-threatening health condition” and 4.5 times as likely to report physical distress compared with allogeneic HCT recipients with no chronic GvHD (Sun et al., 2013, p. 1073). Of concern, this study found that just over one-quarter (27%) of HCTS received routine survivorship care at the transplant center. While this may reflect the successful transition of survivorship care to primary care
providers, the complex nature of late effects of disease and transplant necessitate the routine follow-up, at least annually, in a specialized healthcare setting. This study aptly demonstrates the need for continued symptom surveillance and provision of access to specialized care for the remainder of a HCT survivor’s life.

**Economic Stressors**

In addition to emotional and physical disturbances, HCTS also face significant burden of economic stressors which contribute to overall distress. Hamilton et al. (2013) found that financial stress and employment stress were both inversely associated with physical and functional well-being, and transplant-related concerns. Additionally, financial stress was inversely related to emotional well-being. Insurance coverage concerns did not have significant impact on HRQOL. Although no inferences can be drawn from the descriptive statistical findings of this study, it is concerning to note that almost one-quarter (23%) of respondents reported hardship ranging from difficult to extremely difficult to live on their current income, and 22% reported anticipating the need to reduce their standard of living to bare minimum necessities in order to survive (Hamilton et al., 2013). These findings confirm that it is crucial for providers to screen for economic difficulties that may be contributing to survivors’ overall distress. Furthermore, it is the clinician’s responsibility to provide access to appropriate resources, including social work and case management, in order to address these financial concerns that can be impacting a patient’s overall sense of well-being.

A study by Brown-Iannuzzi, Payne, Rini, DuHamel, and Redd (2014) analyzed the relationship between HCT survivors’ self-perception of socioeconomic status (SES) and health outcomes. Subjective SES was measured using the MacArthur Ladder. Higher self-perceived SES was correlated with decreased depression, post-traumatic stress disorder, and generalized
distress symptoms and increased HRQOL. Subjective SES was a significant mediator of the relationship between objective SES and quality of life, suggesting that HCT survivors’ self-assessment of their socioeconomic standing in society impacts psychological distress and quality of life (Brown-Iannuzzi et al., 2014). Although it is not possible for clinicians to alter a patient’s economic standing, it is important for clinician’s to focus on HCT survivor’s perception of this standing, as it may have profound impact on the individual’s perception of their symptom management. Clinicians must have an understanding of how this self-assessment impacts the patient’s worldview, including perception of their HCT disease trajectory and coping with both physical and mental distress.

**Resilience and Self-Efficacy as Protective Factors**

Several authors have attempted to identify the relationship between distress, symptom management, and psychosocial constructs, especially patients’ self-assessment of these concepts. Rosenberg et al. (2015) identified an association between patient-perceived resilience (the ability to have a positive outcome after trauma or negative experience) and distress. Specifically, the authors found that lower resilience was significantly associated with increased severity of GvHD symptoms, lower functional performance scores, decreased productivity through missing work, and permanent disability. Lower resilience was also found to be significantly associated with decreased mental health-related quality of life and increased risk of psychological distress (Rosenberg et al., 2015). The authors suggest future research to focus on resilience as a target for intervention, and for clinicians to increase screening for low resilience to identify at-risk survivors in need of focused evaluation and intervention.

Wu et al. (2012) explored the relationship between beliefs about self-efficacy for symptom management and HCT survivors’ self-report of cognitive functioning and overall
physical/mental well-being (i.e. depression, anxiety, quality of life). The results suggest that if a HCTS has a low self-assessment of cognitive function, they are at increased risk for impaired self-efficacy in managing all symptoms. Self-efficacy for both physical and emotional symptom management were found to be associated with quality of life. These findings suggest that clinicians must focus assessments on the degree of confidence HCTS have in symptom self-management, as this locus of control has been shown to be an important predictor of health-related quality of life and physical/mental health outcomes.

**Use of Distress Screening Tools in Clinical Setting**

Hoodin, Zhao, Carey, Levin, and Kitko (2013) attempted to evaluate the clinician utility and efficacy of an abbreviated Patient Health Questionnaire (PHQ) in the HCT Survivorship clinical setting. This screening tool is commonly used in various clinical settings to routinely assess for symptoms of depression, anxiety, substance abuse, and functional disruption. The authors employed a two-group experimental design in which patients were randomized to complete the PHQ prior to the appointment (intervention group) or after the appointment (control group).

The authors found that the experimental group participants were significantly more likely to have a conversation with the clinician regarding mental health during their appointment, likely owing to the fact that the clinician can use the questionnaire to guide the clinical visit. Clinicians were significantly more satisfied with their ability to manage mental health issues when given the completed PHQ prior to the visit (Hoodin et al., 2013). As mentioned previously, the RPCCC SST is used annually, so as to allow the provider and patient to discuss the patient’s responses during the clinical visit. This study lends further support that such screening tools
prove useful to both patients and clinicians in facilitating discussion and focusing the clinical visit on the patient’s care priorities.

The current literature demonstrates multiple sources of distress in the lives of HCTS. Identifying and characterizing these sources of distress should be an integral part of every survivorship visit. Clinicians should be focused on promoting discussion of these stressors and how they impact a patient’s sense of self-efficacy over symptom management, rather than a narrow-minded focus on symptoms alone. Furthermore, the literature suggests that various non-disease-related stressors also impact HCTS’ overall perception of distress. The current literature offers support for the RPCCC Survivorship Screening Tool currently utilized in the RPCCC HCT Clinic. However, further research is needed to more completely characterize the lived HCTS experience as it relates to distress, coping, and sense of control over life events.

**Theoretical Framework**

As this project sought to improve clinician understanding of the experience of HCTS, it was necessary to adopt an approach which acknowledges HCTS as the true expert in appraisal of his or her worldview. This assessment includes the ongoing self-evaluation of physical and psychosocial symptoms and late effects of their disease and treatment, and the resultant perception of distress. It also includes appraisal of stressors within the physical, psychosocial, and economic realms which may also impact their perception of symptom severity and overall distress.

The theory of stress, appraisal, and coping by Richard Lazarus and Susan Folkman provided an excellent lens through which to approach this capstone project. Permission to use theory was granted Dr. Susan Folkman on November 28th, 2017. This theory regards the relationship between an individual and stress as dynamic and bidirectional (Folkman, Lazarus,
Gruen, & DeLongis, 1986). The authors define stress as any situation which the individual judges to be “exceeding his or her resources and as endangering well-being” (Folkman et al., 1986, p. 572). This evaluation of and reaction to a stressor takes place through two processes: cognitive appraisal and coping. Cognitive appraisal refers to the way in which he or she determines the impact of the stressor on his or her quality of life and well-being. This may include how the stressor will impact himself or herself or how it will impact another individual, such as a loved one. The second process, coping, refers to the way a person tries to reduce or mitigate the stressor. Two types of coping were conceptualized: problem-based, which focuses on problem-solving strategies to manage the stressor, and emotion-based, which focuses on how the individual is able to regulate their emotional response to the stressor (Folkman et al., 1986). Please see Appendix D for a diagram of theoretical concepts (Jensen, Forlini, Partridge, & Hall, 2016).

This theory can be applied as a framework for understanding the unique experiences of HCTS, as a great deal of patient and symptom variation occurs within this group. These variations include disease process, type of transplant and associated late effects (i.e. allogeneic vs. autologous, recurrence, GvHD, immunosuppression), comorbidities, financial and social support, and various demographic factors that may influence their appraisal of both disease-related and non-disease-related stressors. These unique variations result in a variety of patient outcomes, in terms of a patient’s functional performance status and sense of well-being.

Through this framework, it can be hypothesized that the wide variation in perception and reaction to stressors in HCTS has a great deal to do with the unique lens and life context through which an individual appraises the impact of symptoms and other stressors on their well-being. Therefore, this offers a potential explanation for the discrepancies observed within the RPCCC
HCTS population between overall level of distress and the severity of stressors within their lives.

**Methods**

**Setting**

The setting of this project was Roswell Park Comprehensive Cancer Center (RPCCC), a National Cancer Institute-designated comprehensive cancer center, located in Buffalo, NY. RPCCC serves approximately 36,000 patients annually, with 133-inpatient beds and dozens of outpatient specialty clinics, which served 231,744 outpatient clinical visits in the 2017 fiscal year (Roswell Park Comprehensive Cancer Center, n.d.). In addition to the clinical domain, RPCCC serves as a teaching hospital affiliated with the State University of New York at Buffalo, as well as a research institution, with 599 active research projects and $82.9 million in research grants in the 2017 fiscal year (Roswell Park Comprehensive Cancer Center, n.d.). This project specifically took place in the Blood and Marrow Transplant (BMT) Center within RPCCC.

**Design**

This capstone project employed a qualitative approach through semi-structured interviews. The foundation for the content of the interview questions was grounded in the RPCCC Survivorship Screening Tool (SST), created by Dr. Jennifer Hydeman, a clinical psychologist working at RPCCC (Appendix B). The RPCCC SST employs a numerical rating system (from 0 to 4 or 0 to 10), which asks patients to rate the severity of distress caused by various symptoms or life circumstances within the domains of practical/emotional issues, physical/functional issues, and nutritional issues. No validity or reliability data exist for the SST at this time. The principal investigator met with both Dr. Jennifer Hydeman and Dr. Loralee Sessanna, Clinical Associate Professor at the University at Buffalo School of Nursing, and project qualitative expert, in order to develop the interview template (Appendix E). These
template questions were designed in order to guide the semi-structured interview and to focus on participant-specific concerns. Therefore, while the interview template is grounded in a standardized screening tool, great flexibility existed in the interviewer’s ability to tailor the interview to each participant’s unique issues and life stressors. Therefore, a standard set of questions was not asked of all participants, allowing for a variety of responses.

**Sampling**

A convenience sampling method of HCT patients greater than 1-year post-transplant who attended the survivorship clinic was used. All patients meeting these criteria were approached by the principal investigator at the end of his/her clinical visit within the BMT Center, at which time they were screened for eligibility. Participants were included if they were greater than 18 years of age at time of transplant; able to read, speak, and understanding English; able to provide informed consent; currently in disease remission, not receiving active treatment for recurrence or other malignancy (maintenance therapy acceptable); had completed the RPCCC Survivorship Screening Tool and NCCN Distress Thermometer, and had denoted at least one item on Survivorship Screening Tool as moderately-to-severely distressing. Participants were excluded if they did not attend their survivorship clinical appointment; were less than 18 years of age at time of transplant; unable to speak, read, or understanding English; unable to provide informed consent; receiving active treatment for disease recurrence or other malignancy; did not complete the RPCCC Survivorship Screening Tool or NCCN Distress Thermometer; or did not denote at least one symptoms as minimally moderately distressing on Survivorship Screening Tool. Please see Appendix F for all inclusion and exclusion criteria. All participants meeting the eligibility criteria after screening received explanation of informed consent. Adequate time was provided
to all participants to review consent and encouraged to ask questions prior to signing the document.

The semi-structured interviews took place face-to-face within the exam rooms of the BMT Center. All interviews were tape recorded and later transcribed word-for-word. All participants were assessed for suicidal and homicidal ideation at the conclusion of the interview. All participants were also offered the resources of RPCCC social worker or psychologist if desired. No monetary compensation was provided to participants. However, participants were provided with parking validation at conclusion of interview.

**Data Analysis**

Thematic content analysis was used to identify, synthesize, and analyze the overarching themes gleaned through semi-structured interviews. The following six phase-approach by Braun and Clarke (2006) was undertaken in order to guide the data analysis process:

1. Familiarizing self with the data set
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

A realist method of thematic analysis was undertaken, with the goal of deepening the understanding of, not only the events and perceptions of HCTS, but the meaning to which individuals in this population assign to these experiences. Similarly, a semantic content analysis was employed, which focused on identifying the explicit meaning of experiences identified by participants (Braun & Clarke, 2006). This decision was made, as it was not the intention of this
project to assign a researcher-centric or clinician-centric interpretation to the meaning of these experiences, but rather to capture the participant’s perception.

Peer debriefing was used in order to increase the rigor of this qualitative approach (Billups, 2014). Initial codes and themes were independently developed and then compared in a peer debriefing session between Dr. Sessanna and the principal investigator. This session also allowed for initial discussion of possible compelling examples and quotations from interviews, which would support the overall themes identified.

Results

Demographics

A total of six participants met eligibility criteria and consented to participate. Over the course of three weeks of data collection, 18 potential participants were available for recruitment. Of these potential subjects, five did not attend their clinical appointment (rescheduled or did not show), one did not qualify due to initial eligibility criteria (later modified and approved by UB and RPCCC IRBs on July 18th, 2018), five did not meet modified eligibility criteria, and one refused to participate.

The six participants of the study had an average age of 56.2 years old (range 26-68 years). Average time elapsed since transplant was 5.2 years (range 1-9 years). Equal numbers of male and female participants were accrued. The majority of participants were white (n=5), and one identified as black. Participant diagnoses included leukemia (acute myeloid leukemia and acute lymphocytic leukemia), lymphoma (Hodgkin’s lymphoma and mixed cell lymphoma), and myelofibrosis. Please see Table 1 for complete sample demographics.

Distress Screening
The average NCCN Distress Thermometer score was 0.67 out of 10, mode was 0 out of 10, and range from 0-4 out of 10. The specific issues triggered by RPCCC Survivorship Screening Tool, which met inclusion criteria (at least moderately distressing), included: feeling isolated, alone, or abandoned; concerns about fertility; weakness in arms or legs; poor movement in legs or feet; fatigue; and trouble with memory and/or concentration. The highest category of distress on the Survivorship Screening Tool was moderate (yellow section, see Appendix B). No participants endorsed moderate-severe (orange) or severe (red) distress associated with symptoms or issues.

**Thematic Analysis**

Three overarching schemes were identified as a result of thematic analysis of transcribed interviews: distress, coping, and survivorship as reappraisal.

**Distress – “In the back of my mind.”**

Distress was found to be related to various symptoms, which participants identified as being secondary to disease or transplant process. These included physical symptoms, such as fatigue, weakness, difficulty with movement, and fertility issues. One participant also associated his mental symptoms, including impaired memory and concentration, to be secondary to the preparatory regimen of total body irradiation. Although most physical and mental symptoms were regarded overall as occurring secondary to the transplant, some participants discussed that they were unsure whether fatigue or mental changes were a result of normal age-related changes or transplant-related.

In terms of emotional distress, fear and anxiety were most frequently associated with thoughts of recurrence and preoccupation with physical symptoms, such as headaches, fatigue, and fevers. The sub-theme of depression was almost exclusively associated with non-transplant-
related issues, such as fighting within families and grieving the loss of a loved one. Isolation emerged as a unique sub-theme discussed by several participants, who remarked various types of physical, emotional, and social isolation. These included the physical isolation from other patients and loved ones during the preparatory and immunocompromised stages of the transplant process; emotional isolation resulting from the death of a loved one and newfound loneliness of living alone; and social isolation associated with struggling to find other survivors like oneself to share the unique experiences and concerns with (i.e., concerns about female fertility). Please see Table 2 for complete list of themes and sub-themes associated with distress, as well as supportive quotes.

**Coping – “Keeping moving forward.”**

In keeping with the theoretical framework, it was found that participants identified two over-arching themes to encompass coping: problem-focused and emotion-focused. Problem-focused coping strategies included avoiding or ignoring; seeking information and resources and encouraging opening communication; facing reality; staying active/busy and feeling useful; and maintaining routines. Emotion-focused coping sub-themes included: maintaining positive attitude and avoiding negative talk; emotional mindfulness/compartmentalization; support systems (including caregivers, family, friends, and positive hospital experience); and spirituality. Please see Table 3 for complete list of themes and sub-themes associated with coping, as well as supportive quotes.

**Survivorship as Reappraisal – “Equal but different.”**

All participants discussed how their disease process and transplant experience contributed to an alteration in their worldview. This change was described as impacting various aspects of their lives, including body, normalcy, meaning of experience, and life itself.
Appreciation of body.

Participants described an increased awareness of physical sensations and symptoms, characterized as feeling “more in-tune with my body than I ever was.” This heightened awareness and deeper understanding of one’s own physiology contributes to an increase in vigilance for any sign or symptom that may warrant further investigation. Participants also remarked pride and amazement at the transplant process. “I’m still amazed how they do it… I still think about it all the time… They actually destroyed my bone marrow and put stem cells in me and it made a new one,” remarked one participant. Other participants acknowledged their own body’s strength to withstand the transplant process, stating, “I’m very proud of what my body has gotten us through,” and “You learn you can handle a lot.” This appreciation for the body’s strength and the gravity of the transplant process was tempered by an increased caution against unnecessary risk. One participant remarked, “It’s just being aware of what my body has been through and just making sure I’m not putting it into a place where I’m vulnerable or putting myself at risk unnecessarily.”

New life perspective.

Participants discussed a newfound perspective on life, including avoiding dwelling on minor or negative issues, as well as focusing on the inherent pleasure of life itself. One participant shared a story about adopting a “Life is good” mentality, inspired by the clothing brand of the same name, after he learned of his diagnosis, “I said, ‘You know, that’s the attitude we need to take, and not look at the negative.’ Where I don’t know that I was like that before (the transplant).” Another participant remarked that her transplant experience resulted in an altered perspective which lowered her “tolerance for whining,” stating, “It aggravates me when people talk about nonsense… Why are you dwelling on these stupid things, when, compared to some
stuff, that’s nothing? I mean, it aggravates me.” Others remarked how their experience justified increased activity and traveling, due to the inherent uncertainty of the future. One participant remarked, “We do more now. We travel more now, because my attitude is I don’t know what tomorrow is going to be.” Another participant shared in this sentiment, stating, “Every day is a blessing to me… Today is good. Every day is good…Even when you’re down, every day is good.”

Interestingly, nearly all of the participants shared a sentiment of feeling lucky, blessed, or grateful for how they fared the transplant process, as well as being a survivor today. Several remarked that they felt they “had it so easy” compared with other transplant recipients, and therefore, felt fortunate to be living the life they were today. Various statements included feeling “thrilled to be alive,” “very grateful” and “happy with my life,” and “very, very lucky.” Several participants shared that they felt their transplant process itself was easier than that of others, such as one survivor who shared, “I’ve been very blessed, I guess you can say, because I didn’t really have that much of a hard time through the whole thing. I was in good spirits the whole time.” Others shared in the sentiment that they are happy with the normalcy of their life right now, and that the transplant does not impact them profoundly today: “I’m very happy to be where I am. I’m pretty much operating a normal basis. I can do almost anything with very little restrictions. I had almost no complications or side effects.”

**Meaning in experience.**

Participants shared their hope that possible benefit to others that could come from their transplant experience. One participant remarked, “I wish there was something that they could pull from my file that could help somebody else, you know? Because I fared pretty good.” Another participant was seeking ways he could offer emotional support and wisdom to others
who may be preparing to undergo a hematopoietic cell transplant: “Now by me going through it, I can help someone else get through it also. If someone needed help, I could go visit them and tell them what’s going on.”

Others discussed that they were seeking others to share mutual experiences with, or a sense of shared empathy: “I would like to get involved in a group session so I can kind of, you know, express myself to them and see what they think. Just to see if people went through the same thing or similar.” One participant remarked that finding others who shared the same concerns as her would help her feel less isolated by her experience as a young adult survivor experiencing issues with fertility: “I think that sort of helped with, you know…realizing that it’s not just me…There’s a lot of people who have to face this reality.”

Returning to normalcy.

Finally, participants shared similar thoughts regarding adapting to a “new normal,” which one survivor remarked felt “equal, but different.” This new normal includes deciphering the difference between so-to-speak “normal” age-related changes and transplant or disease-specific sequelae (identified previously as a source of distress). One participant remarked, “It’s hard for me to relate what is normal progression because I don’t know if I’m more tired now because I’m getting older of it’s because what I went through.”

In keeping with the “keep moving forward” mentality shared by survivors as a coping strategy, the return to a level of function similar to pre-transplant was important to several participants: “I’m not nowhere near where I was before the transplant, but I am, you know, I got some strength back now.” Another survivor shared, “I’ve always been a very active person, so that was a big priority for me, was being able to get back into running and back into not feeling restricted by fatigue, or anything else… but I’m happy where I’m at now.” Another measured
her return to normalcy as her ability to travel and enjoy life as she did pre-transplant: “I think we do a lot. I don’t think our life has been impacted to the point where we don’t do a lot of things…We got to take a very nice vacation, and we get to do pretty much everything we want to do.”

**Discussion**

This project described various sources of distress in the lives of a small group of HCTS at a local comprehensive cancer center. Sources of distress were both disease/transplant-related and non-disease/transplant-related. Consistent with previous research, sources of distress were related to several different domains, including physical, mental/emotional, and social. Survivorship care priorities were stressor-specific, although, overall, participants reported that they felt their survivorship care needs were adequately met by healthcare providers.

This project also identified numerous coping strategies, which reflected the problem-focused and emotion-focused mechanisms characterized by Lazarus and Folkman through the Theory of Stress, Appraisal, and Coping. These coping strategies may serve a two-fold purpose. First, they may act as adaptations by survivors in an effort to manage the stressor, which was or still is causing strain on their current resources. On the other hand, several coping mechanisms appeared to also act as pre-existing protective factors, contributing to the overall positive outcomes of this small group of participants. Participants consistently identified having a positive attitude, a stable support system, and an overall positive hospital experience as powerful factors playing a role in their outcomes. These possible protective factors may serve as important targets for assessment and intervention before, during, and after transplant, in order to optimize the experience of all transplant recipients. The consistent identification of a positive
hospital experience also highlights the importance of organizational culture and the identification of healthcare providers as source of support of paramount importance.

Finally, this project identified a possible mechanism, which may help to explain the way in which survivors appraise distress and the overall quality of their lives. The participants collectively described the ways in which their diagnosis, treatment, transplant, and survivorship experiences have contributed to a new perspective on various aspects of their lives. Taken with the Theory of Stress, Appraisal, and Coping, in which an individual appraises the stressor in terms of the extent to which it impacts their life and exceeds their resources, the new perspectives that HCTS acquire may contribute to a reappraisal of their bodies, lives, the meaning of their experiences, and normalcy itself. This reappraisal process may act as a possible way to influence perception of distress. Despite residual symptoms or non-transplant-related life stressors, a positive alteration of one’s life perspective may alter the gravity or impact a survivor assigns to these stressors, and therefore a decreased perception of overall distress. As one participant stated regarding thoughts about recurrence or residual symptoms, “I don’t weigh them too heavy, because I really think the way I’ve gone through this, that I’m not (going to) have a lot of problems like other people.” Through this mechanism, which requires further study, positive reappraisal as a stage of survivorship may contribute to improved overall quality of life.

In contrast to previous research findings, this particular sample did not report significant distress associated with financial concerns and residual graft-versus-host disease (GvHD) symptoms. This may be possibly related to the small convenience sample used. It can be conceived that those potential participants who did not attend their appointments are
experiencing more severe distress, GvHD symptoms, problems with transportation and finances, or other issues that could have contributed to their inability to keep their appointment.

These participants also, on the whole, reported very little unmet needs and a positive experience of transplant, overall. However, several areas were discussed that could potentially benefit from improved attention and investment of resources. These include: increasing pre-transplant education about the potential late effects of treatment and subsequent required screening as a survivor; improved access to resources for difficult topics, such as sexuality and fertility post-transplant; and creation of a network of cancer/hematopoietic cell transplant survivors in order to facilitate connection with resources and discussion of shared, unique issues.

Scope, Strengths, and Limitations

The scope of this project is somewhat narrow with a focus on a specific subset of cancer survivors with unique issues and late effects. However, the information gained from this project has potential implications for future HCTS care. The rationale for this project was developed out of observed discrepancies between HCTS appraisal of symptoms and life stressors and overall appraisal of distress, revealing a unique experience which current screening tools fail to capture. Although this project does not validate current screening tools used in the RPCCC HCT Center, the knowledge gained from the semi-structured interviews has the potential to inform how clinicians can utilize these tools. The data gained will hopefully influence future decisions regarding distress screening techniques and design of distress screening tools used not only in this specific clinic, but in other HCTS clinical settings as well.

Strengths of this project include the provision of a rich description of various issues impacting survivorship care of HCTS. The semi-structured interviews used the RPCCC Survivorship Screening Tool as a guide for grounding the qualitative data in the current issues
experienced by the participants, allowing for a targeted, in-depth discussion of unique issues relevant to each survivor.

Limitations of this project include the small sample size and limited time frame for data collection. Due to the nature of the convenience sample, data redundancy was achieved, but data saturation was not. Saturation of data has the potential to be achieved with increased time frame and sample size. Stringent eligibility criteria also contributed to the elimination of six possible participants, further contributing to the small sample size. It is possible that participants eliminated by stringent eligibility criteria regarding minimal level of distress on the RPCCC Survivorship Screening Tool required could have contributed valuable insight regarding their ability to cope with survivorship issues in order to mitigate distress.

**Conclusion**

The unique experience of a cancer survivor is one that health care providers cannot understand unless they have undergone it themselves. Healthcare providers must glean what information and explanation we can from the stories and sentiments shared by the experts themselves: the survivors. This project described unique issues of the HCT survivorship experience as they related to distress, coping, and overall quality of life. Due to a limited sample size and qualitative nature of study, it is difficult to justify changes to the current distress screening procedures in the RPCCC BMT Center. However, this project identified areas requiring improvement in meeting survivorship care priorities, highlighted positive protective factors, including current resources and overall organizational culture that may contribute to positive transplant outcomes, and identified factors useful for targeted assessment and intervention pre-and post-transplant. Finally, this project provided rationale for future research to be directed toward program evaluation of survivorship resources and establishing validity,
reliability, and provider utility criteria for current screening tools used in the RPCCC BMT Center.

Table 1. Demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
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</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>3 (50.0)</td>
</tr>
<tr>
<td>Male</td>
<td>3 (50.0)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>5 (83.3)</td>
</tr>
<tr>
<td>Black</td>
<td>1 (16.7)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>19-39</td>
<td>1 (16.7)</td>
</tr>
<tr>
<td>40-59</td>
<td>1 (16.7)</td>
</tr>
<tr>
<td>60-79</td>
<td>4 (66.7)</td>
</tr>
<tr>
<td>80+</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Leukemia</td>
<td>3 (50.0)</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>2 (33.3)</td>
</tr>
<tr>
<td>Myelofibrosis</td>
<td>1 (16.7)</td>
</tr>
<tr>
<td>Themes</td>
<td>Sub-themes</td>
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<td>----------------------------</td>
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<tr>
<td>Physical symptoms</td>
<td>Fatigue/Weakness</td>
</tr>
<tr>
<td>Difficulty with movement</td>
<td></td>
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<tr>
<td>Fertility issues</td>
<td></td>
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<tr>
<td>Mental symptoms</td>
<td>Memory/Concentration</td>
</tr>
</tbody>
</table>
Table 2. Distress as an Overarching Scheme (“In the Back of my Mind”)

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
<th>Supporting Quotes</th>
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</thead>
</table>
| Emotional  | Fear/Anxiety | “It’s always in my mind. You know, is something going to happen? …Am I going to get some sort of secondary cancer or something?”  
“I may have had one time where I really kind of broke down and got nervous when my wife told me how they were going to basically kill me…and if my blood didn’t take, then that was it. I was like, “Woah.” Then it got serious.”  
“When I hear how somebody was a cancer survivor for six years and then they had a headache or a fever for 2 weeks, and then they died a week later because they had a brain tumor, I sort of get anxious for like a week, and then I get passed it.” |
| Sadness/Depression |              | “I take something for depression, and that seems to help because, before I took it, I would just cry and wouldn’t even know why I was even crying… We have a lot of family issues and does it depress me sometimes? Yeah, I got to tell you, it does.”  
“I just lost my wife and that’s giving me emotional… I get emotional about that. But I don’t have any emotional problems pertaining to my transplant at all. Everything I’m going through now is pertaining to the loss of my wife after XX years of marriage.” |
| Isolation  |              | “When you were in that isolation before you get that transplant, that was probably the only time that I was really depressed, watching the same crap on TV, over and over and over.”  
“At the beginning, because I had to be so careful of infections, and all that kind of stuff, I have 7 grandchildren and it broke my heart, I couldn’t see them all the time. And that really bothered me.” |
Table 3. Coping as an Overarching Scheme (“Keep Moving Forward”)

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
<th>Supporting Quotes</th>
</tr>
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</table>
| Problem-focused | Avoidance        | “So (family issues) sort of made me upset and then I was wasting energy on that crap. So I just decided to forget about that.”  
“I don’t really think that’ll (recurrence) happen to me again, you know? I guess it could. Every once in a while, I’ll say, ‘Well nothing’s 100%.’ You know, but I’m not going to worry about that… I guess I chose to push some things out of mind.” |
| Communication | Seeking information | “I’ve always made it policy of mine to make sure I’m always very open, and I’ve probably asked people some weird questions that might even embarrass them a little bit. But I figure it’s always better to be honest and tell them exactly what I was feeling.”  
“More information has been a good coping mechanism.”  
“I see (psychologist) at the hospital. I was seeing her, I think, once a week, then felt myself getting better.”  
“I saw some doctors from the AYA (Adolescent and Young Adult) group that didn’t do any testing or anything like that, but were just somebody to talk to about different options and what other patients have gone through.”  
“(Caregiver class) was excellent. I mean, I went with a couple of the caregivers. I had 3 or 4 caregivers… And I went to a couple of the classes. They were very good.” |
| Facing reality |                | “She (another patient) looked at me, and said, ‘You realize there’s a 25% chance we’re not going to make it?’ And I said, ‘Well if we don’t do this, there’s a 100% chance we’re not going to make it and I look at it as there’s a 75% chance I am going to make it.’”  
“I never really asked ‘Why? Why me?’ It was always, ‘Well, I got it. Let’s deal with it.’ Asking why isn’t going to solve anything.”  
“The reality was that… if I had waited to harvest my eggs, then I probably wouldn’t be alive.” |
### Table 3. Coping as an Overarching Scheme (“Keep Moving Forward”)

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<thead>
<tr>
<th>Themes</th>
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<th>Supporting Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem-focused coping</td>
<td>Staying active</td>
<td>“I don’t like to be sitting in the kitchen looking at four walls. So I try to get out as much as I can at different functions. I go out to breakfast with a few friends of mine... Being around people is something I like.”</td>
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<tr>
<td>(cont.)</td>
<td>Feeling useful</td>
<td>“I would do little things if I could and I would do things I shouldn’t have done as far as chores. I painted my picket fence, painted my porch. It fulfilled a need to feel useful.”</td>
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<td></td>
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<td>“I do my daily walking to kind of clear my mind.”</td>
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<td></td>
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<td>“’Keep moving forward’ mentality, both physically, like you know, even on the days where I didn’t feel good, getting up and walking. Walking made such a big difference. Just getting out of bed and moving a little bit.”</td>
</tr>
<tr>
<td></td>
<td>Maintaining routine</td>
<td>“I got up in the morning like I did at home at 6 o’clock... My attitude, before we even got here was ‘I’m not staying in that bed all day. I’m going to get up in the morning, like I do at home.’ And that’s it, I never got into bed again during the day.”</td>
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<td></td>
<td></td>
<td>“I was here for a month for my transplant. I got out of bed every morning, got in the shower, put on my clothes... I stayed up all day until it was time to go to bed, like 9, 10 o’clock at night.”</td>
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<tr>
<td></td>
<td></td>
<td>“I started setting up little rules for myself... like when I had my transplant, I walked a mile on the treadmill before 10 or 11 o’clock and tried to be showered by 12. I set parameter where I didn’t start watching TV until noon.”</td>
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</table>
Table 3. Coping as an Overarching Scheme (“Keep Moving Forward”)

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<tr>
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</thead>
<tbody>
<tr>
<td>Emotion-focused coping (cont.)</td>
<td>Emotional mindfulness</td>
<td>“The ability to take where I was at that moment, and sort of set it in place and leave it where it was, and move forward from it from there. It allowed me to move away from periods of being angry or sad, or any of the sort of inevitable emotions that people get… It’s okay to have, you know, short bursts, I think, of those sort of emotions, then being able to separate yourself from them and do everything you can to move forward.”</td>
</tr>
<tr>
<td>Support: Positive hospital experience</td>
<td></td>
<td>“I feel like everybody here (the hospital) is so supportive and wants to help other patients. Everyone has just been nothing but wanting to help and that’s been, I think, that’s why I like coming back here so much.”</td>
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<tr>
<td></td>
<td></td>
<td>“We come here (the hospital), they’re always asking and making sure you don’t have issues… I think they really do a good job of being concerned about your feelings outside of here and how you’re coping with it.”</td>
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<td></td>
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<td>“Being nice and pleasant is the most enjoyable thing that a person can give to someone else.”</td>
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<td></td>
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<td>“You felt that, when I was here (hospital), that people really wanted you to live and survive… I mean, everybody went out of their way to be absolutely wonderful.”</td>
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<td></td>
<td></td>
<td>“You have your caregiver, your main person, and you know, that’s what I think is the most important thing, that you have a caregiver that really does care for you. And, in my case, my wife has been excellent with that.”</td>
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<tr>
<td></td>
<td></td>
<td>“I couldn’t have done it without everybody, especially my husband. He was phenomenal.”</td>
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<tr>
<td>Support: Caregivers, family, and friends</td>
<td></td>
<td>My two brothers, my sister, and my girlfriend more or less supported him (husband), because he was there 24/7…And without him, I don’t think I’d be here.”</td>
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<tr>
<td></td>
<td></td>
<td>“My wife and my children helped me through it, and my friends, my sons and daughters-in-law. Those are the ones who helped me through it all.”</td>
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</tr>
</thead>
<tbody>
<tr>
<td>Emotion-focused</td>
<td>Spirituality</td>
<td>“We’re very involved with our church. We’re Catholic. We’re happy we’re Catholic. We participate in the Catholic Church, and we...have a great sense of peace with religion.”</td>
</tr>
<tr>
<td>(cont.)</td>
<td></td>
<td>“I believe in God so much that, if it’s his plan, and if it went bad, it went bad because of that. If it went good, it went good. So I just did the best I could do to be a good person and just do what I could, especially for my wife.”</td>
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<tr>
<td></td>
<td></td>
<td>“That’s what got me to where I’m at today, you know? My belief in God and by praying. I believe he’ll, if you ask, he’ll do anything that you ask if you believe and have faith. And I believe and I have faith. So my faith don’t waiver at all.”</td>
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<tr>
<td></td>
<td></td>
<td>“At night, I say my prayers. When I get up in the morning, I say my prayers. I read my Bible every day. That gets me through the day, I mean my spirituality is something that I depend on wholeheartedly.”</td>
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</table>
### Table 4. Survivorship as a Reappraisal of Life – “Equal but different.”

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<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
<th>Supporting Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appreciation for body</td>
<td>Awareness of symptoms</td>
<td>“I feel more in-tune with my body that I ever was. I do pay attention to every little kind of symptom or anything I feel…so I know to just keep an eye on it.”</td>
</tr>
<tr>
<td></td>
<td>Amazement at transplant process and body’s strength</td>
<td>“I’m still amazed how they do it, what they do. I still think about that all the time. You know, they actually destroyed my bone marrow and put stem cells in me and it made a new one. And that always still amazes me.” “I’m very proud of what my body has gotten us through.” “You learn you can handle a lot.”</td>
</tr>
<tr>
<td></td>
<td>Caution against risk-taking</td>
<td>“I am aware of a lot more things. It’s just being aware of what my body has been through and just making sure I’m not putting it into a place where I’m vulnerable or putting myself at risk unnecessarily.”</td>
</tr>
<tr>
<td>New life perspective</td>
<td>Focus on important things, not dwelling on little things</td>
<td>“So we try and enjoy life now and look at the positive things and not dwell on, you know, the negatives of the transplant, and all that.” “It aggravates me when people talk about nonsense. It’s sort of like, ‘Why are you dwelling on these stupid things, when compared to some stuff, that’s nothing?’ I mean, it aggravates me. I have sort of a low tolerance for whining.”</td>
</tr>
<tr>
<td>Themes</td>
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<td>Supporting Quotes</td>
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<tr>
<td>New life perspective (cont.)</td>
<td>Future is uncertain</td>
<td>“We do more now. We travel more because, you know, my attitude is I don’t know what tomorrow is going to be.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“It gives me a different perspective, and like take nothing for granted. Every day is a blessing to me, so that’s the way I look at it. Today is good. Every day is good, you know, even when you’re down. Every day is good.”</td>
</tr>
<tr>
<td>Feeling Grateful, Blessed, Lucky</td>
<td></td>
<td>“I’m fortunate, you know. I know a couple other people who were in here when I was and had way more problems than I have. And so it doesn’t affect me daily as much.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I’ve been very blessed, guess you can say, because I didn’t really have that much of a hard time through the whole thing. I was in good spirits the whole time.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I feel like I went through it (transplant) easier than most everybody… They probably couldn’t have told me it was going to go any smoother than when I had it.”</td>
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<tr>
<td></td>
<td></td>
<td>“It makes me very grateful. I’m happy with my life.”</td>
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<tr>
<td></td>
<td></td>
<td>“I’m very happy to be alive. I’m thrilled to be alive.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I’m very happy to be where I am. I’m pretty much operating a normal basis. I can do almost anything with very little restrictions. I had almost no complications or side effects. I’m very, very lucky.”</td>
</tr>
</tbody>
</table>
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<tr>
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<th>Supporting Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning in experience</td>
<td>Shared empathy</td>
<td>“It’s just given me a different perspective, you know, about what people go through. I have a lot more sympathy for people. I mean, I had it before, but it’s more intense now.” “I think that sort of helped with, you know…realizing that it’s not just me… There’s a lot of people who have to face this reality, I guess.” “I would like to get involved in a group session so I can kind of, you know, express myself to them and see what they think. Just to see if people went through the same thing or similar.”</td>
</tr>
<tr>
<td></td>
<td>Seeking to help others with cancer</td>
<td>“Now by me going through it (transplant), I can help someone else get through it also. If someone needed my help, I could go visit them and tell them what’s going.” “I wish there was something that they could pull from my file that could help somebody else, you know? Because I faired pretty good.”</td>
</tr>
</tbody>
</table>
Table 4. Survivorship as a Reappraisal of Life – “Equal but different.”

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<thead>
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<th>Supporting Quotes</th>
</tr>
</thead>
</table>
| Returning to Normalcy | Returning to previous level of functioning | “I’m not nowhere near where I was before the transplant, but I am, you know, I got some strength back now.”  
“I’ve always been a very active person, so that was a big priority for me, was being able to get back into running and back into not feeling restricted by fatigue or anything else. So I don’t know, it’s like what came first, the chicken or the egg? I don’t know if I pushed myself to that point or if it slowly receded as I was ramping up activity. But I’m happy with where I am now.”  
“I think we do a lot. I don’t think our life has been impacted to the point where we don’t do a lot of things. I’m happy with my life. We got to take a very nice vacation, and we get to do pretty much everything we want to do.”  
“I think I am equal but different. What I’m living now is definitely not… it’s a new normal.”  
“I sort of was in this twilight zone this whole time (during and after transplant), until I moved into my apartment and then it was, ‘Ok, now start a new life.’”  
“It’s hard for me to relate what is normal progression because I don’t know if I’m more tired now because I’m just getting older or if it’s because what I went through. So there’s a lot of questions about things like that when they come up. Like the memory, is this something that was eventually going to happen or is it because of the brain radiation, whole body radiation and all that?” |
References


Appendix A:

National Comprehensive Cancer Network Distress Thermometer

(National Comprehensive Cancer Network, 2017a)
Appendix B:

Roswell Park Comprehensive Cancer Center Survivorship Screening Tool

<table>
<thead>
<tr>
<th>Practical &amp; Emotional Issues</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation or local lodging during treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finances</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Managing work, school, or home life</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Worry about the future</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finding community resources near where I live</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Substance use: you or your environment (drugs, alcohol, nicotine, prescriptions, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling isolated, alone or abandoned</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concerns about fertility</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting medicines</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual or religious concerns</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much emotional distress have you been experiencing in the past week including today?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please circle the number to indicate how much each of the following issues *have been a problem for you over the past 2 weeks*. An answer of "0" means that this is not a problem at all for you. An answer of "4" means that it is very much a problem for you.

Please circle the type of consult that best describes the extent to which your cancer or cancer treatment have caused problems related to sexuality or intimacy.
Appendix B Continued

**PHYSICAL AND FUNCTIONAL ISSUES:**

Please circle the number to indicate how much each of the following issues *have been a problem for you over the past 2 weeks*. An answer of "0" means that this is not a problem at all for you. An answer of "4" means that it is very much a problem for you.

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>14</td>
<td>Weakness in my arms or legs</td>
<td>0</td>
<td>Not a problem</td>
<td>1</td>
</tr>
<tr>
<td>15</td>
<td>Poor movement in my legs/feet</td>
<td>0</td>
<td>Not a problem</td>
<td>1</td>
</tr>
<tr>
<td>16</td>
<td>Maintaining my balance/falls</td>
<td>0</td>
<td>Not a problem</td>
<td>1</td>
</tr>
<tr>
<td>17</td>
<td>Trouble walking</td>
<td>0</td>
<td>Not a problem</td>
<td>1</td>
</tr>
<tr>
<td>18</td>
<td>Trouble caring for myself (bathing, dressing, eating, meal preparation or light housekeeping)</td>
<td>0</td>
<td>Not a problem</td>
<td>1</td>
</tr>
<tr>
<td>19</td>
<td>Trouble using my arms and hands to complete everyday activities (e.g. joint limitations, weakness, tremors, numbness)</td>
<td>0</td>
<td>Not a problem</td>
<td>1</td>
</tr>
<tr>
<td>20</td>
<td>Trouble with my memory and/or concentration</td>
<td>0</td>
<td>Not a problem</td>
<td>1</td>
</tr>
<tr>
<td>21</td>
<td>Please rate your fatigue (weariness, tiredness) by circling the number that best describes your fatigue over the past 7 days</td>
<td>0</td>
<td>No fatigue</td>
<td>1</td>
</tr>
<tr>
<td>22</td>
<td>Please circle the number (0-10) that describes how fatigue has interfered with your normal work (includes both work outside the home and daily chores) in the past 7 days</td>
<td>0</td>
<td>Does not get in the way</td>
<td>1</td>
</tr>
</tbody>
</table>
Appendix B Continued

**Nutrition Issues:**

Please circle the number to indicate how much each of the following issues have been a problem for you over the past 2 weeks. An answer of "0" means that this is not a problem at all for you. An answer of "4" means that it is very much a problem for you.

<table>
<thead>
<tr>
<th></th>
<th>Losing weight without trying</th>
<th>Not a problem</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Large problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>23</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Loss of appetite</th>
<th>Not a problem</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Large problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>24</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Experiencing nausea, vomiting, diarrhea, or constipation</th>
<th>Not a problem</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Large problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>25</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>I am receiving IV nutrition and have concerns</th>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>26</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Are you interested in learning more about Healthy Eating?</th>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>27</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

28. Did you have any concerns that were not addressed in this questionnaire? If so, what were they?

---

Permission for use of tool obtained from Dr. Jennifer Hydeman.
## Appendix C: Evidence Matrix

<table>
<thead>
<tr>
<th>Author/Date</th>
<th>Research Question(s)/Hypotheses</th>
<th>Methodology</th>
<th>Analysis &amp; Results</th>
<th>Conclusions</th>
<th>Implications for Future research</th>
<th>Implications For practice</th>
</tr>
</thead>
</table>
| Bevans et al., 2014 | Explore baseline and change in health status and HRQL over time and to characterize subgroups experiencing adverse outcomes | Annual questionnaire | Hierarchical linear modeling  
N = 173  
At baseline, 38% reports PCS and 34.5% MCS scores that were clinically relevant. FACT-G scores exceeded population mean with 19.9% reporting scores suggesting clinically relevant impairment.  
42.7% reported high levels of symptom distress, 21.6% reported moderate level of symptom distress. Mean number of prevalent symptoms ranged from 8-10 | Survivors with persistent symptoms and those receiving systemic immunosuppression experience impairments in health status and HRQL. Physical symptom distress was significant predictor for all three outcomes. Three or more years following HSCT, physical health, mental health, and HRQL have generally recovered to normative values and these trajectories remain stable. | Did not use objective grading for GVHD symptoms, but used severity of immunosuppression therapy as indicator. | Suggests full recovery is more likely 3 years post-transplant. Implications for how aggressive symptom management in optimizing health in long-term survivors |
| Brown-Iannuzzi et al. 2014 | Subjective SES (perception of one’s own SES compared with others) may function as a psychosocial mechanism by which objective SES affects health, well-being. HCTS completed measures of objective (self-reported household income and education) and subjective SES (MacArthur Ladder) of perception of yourself compared to US population and to your community. | N=268  
Higher objective SES was associated with greater quality of life across all 4 measures. Subjective SES mediated relationship between objective SES and depressive | Subjective SES mediated relationship between objective SES and depression, anxiety, HRQL, and PTSD symptoms.  
This means that objective SES did not have a significant independent effect on the health outcomes after accounting for the mediating effect  
These findings are consistent with hypothesis that income and education contributed to survivors’ subjective perception of their status in relation to others, and this feeling of relative status in turn affected outcomes related to several kinds of... | | |
and quality of life among cancer survivors.

<table>
<thead>
<tr>
<th>Hamilton et al., 2013</th>
<th>Economic survivorship stressors will be associated with poorer HRQOL among HCTS</th>
<th>Mailed questionnaires and telephone interviews</th>
<th>Hierarchical regression analysis</th>
<th>Greater financial and employment stress associated with poorer functioning across numerous HRQOL domains, controlling for sociodemographic and medical variables.</th>
<th>Look into individuals who did not make it to transplant due to financial burden. Also, this study required participants to be moderately distressed.</th>
<th>Necessity to improve identification and allocation of resources to help survivors cope with these demands.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hoodin et al. 2013</td>
<td>Providers will be more likely to act on patients’ psychological symptoms if screening survey</td>
<td>Cross-sectional two-group intervention study. N=101 Randomized participants to n=50 experimental group</td>
<td>Two sample t-test and Pearson’s chi square, Multiple linear regression or logistic regression</td>
<td>Patients in experimental group were significantly more likely to have discussion of psychological</td>
<td>Suggested to evaluate patients serially over time, which would allow for timely</td>
<td>Reviewing questionnaire in experimental group acted as sort of an intervention itself. Discussion of these issues may strengthen therapeutic alliance</td>
</tr>
</tbody>
</table>
is completed and reviewed prior to a clinic visit. or n=51 control group. Experimental group received PHQ before appt and control received after symptoms than the control group (p=0.05). Whereas various demographic and medical variables did not impact discussion likelihood. However, groups did not differ in referral to mental health provider or prescription of psychotropic medication. Patient satisfaction did not differ between groups. Providers with access to questionnaire before visit were significantly more satisfied with patient management than control group.

| Rosenberg et al., 2015 | Assessed relationship between patient-reported resilience and other patient-centered outcomes: resilience, psychological distress, post-traumatic growth, and health-related quality of life | Post-transplant survivorship survey | Multivariate linear and logistic regression models N = 1823 | Lower patient reported resilience was associated with higher severity chronic GVHD, lower performance scores, missing work due to health, and permanent disability (all p < 0.0001). Patients with lower resilience had higher odds of psychological distress and being in lowest quartile of mental health related quality of life. | Patient-reported resilience is a strong candidate for screening, risk-stratification and targeted intervention. Future studies should assess perceived resilience before and after treatments and follow patients to determine how it interacts with illness experience and | Fred Hutchinson Cancer Research Center (FHCRC) post-transplant survivorship survey queries patient-reported health and functional status – similar to RPCI SST. Self-perceptions of resilience are independently associated with poor outcomes, even after adjustment for measurable health and functional status. Personal perceptions are more easily modifiable than the even itself (i.e. severe chronic GVHD). |
| Sun et al. 2013 | Aimed at determining prevalence and severity of chronic health conditions, psychological well-being, and status of healthcare utilization in patients who are greater than 10 years post-HCT. | Bone Marrow Transplant Survivorship Questionnaire. CTCAE v3.0 compared cumulative incidence of severe/life-threatening/fatal conditions | N=324 HCTS compared to N=309 sibling comparison group. HCTS were 5.7 times as likely to develop severe life-threatening condition (p<0.001), and 2.7 times more likely to report somatic distress (p<0.001) compared with siblings. Allo survivors with chronic GVHD were 1.8 times higher risk of severe/life-threatening health conditions (p=0.006) and 4.5 times higher risk of increased risk of morbidity burden substantial even after 10 years post-transplant. | Suggests morbidity burden substantial even after 10 years post-transplant. Future research should continue to evaluate long-term survivorship outcomes. | Predicts later outcomes. No causation known – whether poor outcomes cause low resilience or low resilience cause poor outcomes. Resilience = “overall positive adjustment after trauma”. Difficult to operationalize. | Families, survivors and providers need to be made more aware of high burden for survivors in order to implement better survivorship care. Also need for building of relationship between primary care physicians and transplant team in order to ensure survivorship screening/needs are being addressed adequately. |
morbidity (p=0.04) compared to those with no GVHD. Survivors with resolved GVHD were not at increased risk for morbidity. Only 27% of survivors return to cancer center for cancer-related care.

| Wu et al. 2012 | Adverse effects of subjective cognitive impairment occur because cognitive difficulties reduce HCTS confidence that they can manage HSCT-related symptoms | Mediation analysis using bootstrapping to investigate whether effects of subjective cognitive impairment on these outcomes were mediated by self-efficacy for cognitive, emotional, social, and physical symptom management | N=245
Self-efficacy mediated relations between subjective cognitive impairment and depressed mood, anxiety, and quality of life. Emotional self-efficacy mediated depressed mood and anxiety. Physical, social, and emotional self-efficacy mediated quality of life. | Findings support the conclusion that subjective cognitive impairment reduces HSCT survivors' confidence in their ability to manage common post-HSCT symptoms, with implications for physical and mental well-being. | Future studies should focus on longitudinal studies that follow the relationship between subjective cognitive impairment and self-efficacy over time. | Interventions that help enhance survivors' self-efficacy, particularly self-efficacy for the management of emotional symptoms, are likely to benefit HSCT survivors who report subjective cognitive impairment. |
Appendix D:

Lazarus and Folkman Model of Stress, Appraisal, and Coping

(Jensen, Forlini, Partridge, & Hall, 2016).

Permission granted by authors.
Appendix E: Interview Template

Hematopoietic Cell Transplant Survivorship Study

Standardized Study Participant Introduction

Thank you for volunteering to participate in the Hematopoietic Cell Transplant Survivorship Study. The purpose of this study is to deepen health care provider knowledge, insight, and understanding regarding the lived experience of individuals who have undergone a hematopoietic cell transplant (blood or bone marrow), greater than one year ago who are currently in disease remission.

The questions that I will ask you will explore various life topics and how these areas have been impacted by your hematopoietic cell transplant survivorship experience. By sharing your experiences, we hope to better the personal care and needed resources for hematopoietic cell transplant (blood or bone marrow) patients.

I will review the informed consent with you now, and I encourage you to ask any questions or verbalize any concerns you may have.

The interview will be audio-recoded and the session will be transcribed word-for-word on paper with no identifying information so that I am able to engage in the conversation, while also maintaining adequate detail for reviewing and analyzing your responses later.

You can refuse to answer any question asked during this interview. You can also withdraw from study participation at any time by notifying me of your wishes to withdraw from the study.

Before we begin the interview, do you have any questions or concerns about participating in this study?
The Semi-Structured Interview Schedule

(Questions #1-9 are based upon the RPCCC Survivorship Screening Tool (Appendix B), developed by Dr. Jennifer Hydeman. These questions will either be included or omitted based on relevancy to individual participants, on the basis of reviewing their answers on said RPCCC Survivorship Screening Tool.)

This first set of questions that I will be asking you have to do practical and emotional issues that you may have experienced as a hematopoietic cell transplant patient and survivor.

1. Describe for me any issues or concerns that you may have experienced with transportation or lodging during your treatment.
   - Describe for me what you feel can be done to better transportation and/or lodging for patients undergoing hematopoietic cell transplant treatment.
   - Is there anything about transportation or lodging during treatment that we did not talk about that you feel is important for health care providers to know about?

2. Describe for me any financial issues, concerns, or hardships that you may have experienced during your treatment.
   - Describe for me what you feel can be done to better transportation financial support needs for patients undergoing hematopoietic cell transplant treatment.
   - Is there anything about finances during treatment that we did not talk about that you feel is important for health care providers to know about? Describe in detail for me.
   - Is there anything about finances among hematopoietic cell transplant patients/survivors post-treatment that is important for health care providers to know about? Describe in detail for me.

3. Tell me about any community resource/resources that you utilized during your treatment.
   - How did you become aware of the community resource/resources?
   - Describe for me how the community resource/resources were helpful to you during your treatment.
   - Describe for me how the community resource/resources were unhelpful to you during your treatment. Describe for me what you feel would make this better.
   - Is there anything about the use of community resources among hematopoietic cell transplant patients/survivors post treatment that is important for health care providers to know about? Describe in detail for me.
   - Is there hematopoietic cell transplant patients/survivors that we did not talk about that is important for health care providers detail for me to know about? Describe in detail for me.
4. Describe for me any issues or hardships you experienced with regard to getting your medication during your treatment.

- Describe for me your thoughts regarding how care providers can improve getting medications for hematopoietic cell transplant patients during treatment.
- Describe for me your thoughts regarding how care providers can improve getting medications for hematopoietic cell transplant post-treatment.
- Is there anything about medication access among hematopoietic cell transplant patients/survivors that we did not talk about that is important for health care providers to know about? Describe in detail for me.
- Is there anything about medications that we did not talk about that you feel is important for health care providers to know about?

5. Describe for me any spiritual or religious concerns you may have experienced as a hematopoietic cell transplant patient undergoing treatment.

- Tell me about a time when spiritual or religious concerns were not being addressed?
- Describe for me your thoughts regarding how spiritual or religious care can be improved for hematopoietic cell transplant patients undergoing treatment.
- Describe for me your thoughts regarding how spiritual and/or religious care can improve for hematopoietic cell transplant patients post-treatment.
- Is there anything about spiritual and/or religious care that we did not talk about that you feel is important for health care providers to know about?

6. Describe for me any emotional issues, such as anxiety, worrying about the future, isolation, or sadness that you may have experienced while undergoing hematopoietic cell transplant treatment.

- Did you ever thoughts of hurting yourself or ending your life while undergoing treatment? If so, tell me about this.
- Do you think that patients are adequately screened for issues such as this? Why or why not?
- Do you think that patients are offered resources to help with these types of issues? Why or why not?
- Tell me about any difficulty or emotional stress that you experienced in balancing your life and health as a hematopoietic cell transplant patient.
- Tell me about the support that you used to help you with emotional stress.
- Tell me about any coping strategies that you used to manage emotional stress.
- Describe for me your thoughts regarding how health care providers can better emotional care and needs for hematopoietic cell transplant patients undergoing treatment.
- Is there anything about emotional stress and care needs that we did not talk about that you feel is important for health care providers to know about?
7. Tell me about any issues or concerns about sexual intimacy or fertility that you experienced as a hematopoietic cell transplant patients undergoing treatment.

- Describe for me what health care providers should know about regarding sexual intimacy or fertility among hematopoietic cell transplant patients undergoing treatment.
- Describe for me your thoughts regarding how issues regarding sexual intimacy and fertility can be improved for hematopoietic cell transplant patients post-treatment.
- Is there anything about sexual intimacy or fertility that we did not talk about that you feel is important for health care providers to know about?

The next set of questions will explore your thoughts and feelings regarding physical and functional issues that may be experienced among hematopoietic cell transplant patients and survivors.

8. Describe for me any functional or physical limitations that you may have experienced, such as weakness, balance issues, or difficulty with movement, when you were undergoing treatment.

- Tell me about how pain and/or fatigue affected your day-to-day life while undergoing treatment?
- Tell me about how pain and/or fatigue may affect your life day-to-day life as a hematopoietic cell transplant survivor.
- Tell me about any concentration or memory issues that may have impacted your day-to-day life while undergoing treatment.
- Tell me about any concentration or memory issues that may have impacted your day-to-day life post-treatment.
- Describe for me your thoughts regarding how functional and physical limitations can be improved for hematopoietic cell transplant patients.
- Is there anything about functional or physical limitations that we did not talk about that you feel is important for health care providers to know about?

The next set of questions will explore your thoughts and feelings regarding nutritional issues that may be experienced among hematopoietic cell transplant patients and survivors.

9. Describe for me any concerns you may have had as a hematopoietic cell transplant patient related to nutrition, such as poor appetite, change in taste, problems with nausea, vomiting, diarrhea, constipation, or any unintentional weight loss.

- Describe for me what helped you with nutritional issues.
• Describe for me your thoughts regarding nutritional issues can be improved for hematopoietic cell transplant patients.
• Is there anything about nutrition that we did not talk about that you feel is important for health care providers to know about?

The next set of questions will explore your thoughts and feelings regarding quality of life issues that may be experienced among hematopoietic cell transplant patients and survivors.

10. Describe for me how the hematopoietic cell transplant treatment and treatment process impacted your overall quality of life as a patient.

• Describe for me any physical limitations resulting from the transplant that may have impacted your overall life quality.
• Describe for me any mental or emotional stressors resulting from the transplant that may have impacted your overall life quality.
• Tell me about coping strategies you use to help improve your life quality.
• Describe for me your thoughts regarding how health care providers can better overall life quality of hematopoietic cell transplant patients undergoing treatment.
• Is there anything about quality of life that we did not talk about that you feel is important for health care providers to know about?

11. Tell me about your needs and support system as a survivor after transplant.

• Describe for me how your support system has impacted your post-treatment care and recovery.
• Tell me about your self-confidence regarding your ability to manage needs as a hematopoietic cell transplant survivor.
• Describe for me your thoughts regarding how health care providers can improve support resources and availability for hematopoietic cell transplant survivors.
• Is there anything about survivor support and recovery needs and resources that we did not talk about that you feel is important for health care providers to know about?

That concludes the interview questions. Before we end the session, is there anything that we did not talk about today that you feel is important for health care providers to know regarding hematopoietic cell transplant patients and survivors?

Thank you for participating in this study.

(Interview Template created in collaboration with Dr. Loralee Sessanna, Project Qualitative Expert).
## Appendix F: Inclusion and Exclusion Criteria

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>All HCT patients attending survivorship clinical visit</td>
<td>HCT patients attending non-survivorship clinical visit</td>
</tr>
<tr>
<td>Greater than 1 year post-transplant</td>
<td>Less than 1 year post-transplant</td>
</tr>
<tr>
<td>English-speaking and English-literature</td>
<td>Non-English-speaking and/or unable to read English</td>
</tr>
<tr>
<td>Able to provide informed consent</td>
<td>Unable to provide informed consent</td>
</tr>
<tr>
<td>Greater than 18 years of age at time of transplant</td>
<td>Younger than 18 years of age at time of transplant</td>
</tr>
<tr>
<td>Receiving maintenance therapy acceptable</td>
<td>Receiving active treatment for disease recurrence of other malignancy</td>
</tr>
<tr>
<td>Discrepancy noted in distress screening, defined as a patient noting a NCCN Distress Thermometer score of 0-2/10 (Appendix A) and noting at least one item triggered as moderate-to-severe distress (orange or red sections) on RPCCC Survivorship Screening Tool (Appendix B)</td>
<td>No discrepancy noted between distress screening tools (Appendix A and Appendix B)</td>
</tr>
</tbody>
</table>
Appendix G: E-mail Correspondence Requesting Permission to use Theoretical Framework

Good Morning, Dr. Folkman.

I am writing to you to request permission to use the Stress, Appraisal, and Coping Theory as the framework for a Doctor of Nursing Practice capstone project. I would be using this theory as the conceptual mechanism by which hematopoietic stem cell transplant survivors appraise distress differently and utilize varying coping mechanisms to mitigate stressors. My project seeks to deepen the understanding of the lived experience of hematopoietic stem cell transplant survivors through semi-structured interviews discussing distress and the meaning to which these survivors assign to various stressors. Please let me know if you would like any further information about my project. I look forward to hearing from you and believe this theory is an excellent fit for my current project. Thank you for your time.

Sincerely,

Victoria Reitz, RN, BSN
University at Buffalo School of Nursing
Family Nurse Practitioner Program
(716) 867-6286

Dear Victoria,

You do not need permission to use stress, appraisal, and coping theory. It is there to be used by researchers in diverse fields and places. Your project sounds worthy, and you have my best wishes for a fruitful study.

Regards,

Susan Folkman, PhD
Professor of Medicine Emeritus
UCSF

From: Victoria Reitz <vreitz@buffalo.edu>
Sent: Tuesday, November 28, 2017 8:00:23 AM
To: Folkman, Susan
Subject: Permission to Use Stress, Appraisal, and Coping Theory
Appendix H: E-mail Correspondence Requesting to use Diagram

Dear Ms. Jensen,
I am writing to you to request permission to use a figure published in one of your publications, which illustrates Lazarus’ Stress, Appraisal, and Coping Theory. I am using this theoretical framework for a Doctor of Nursing Practice capstone project. I would be using this theory as the conceptual mechanism by which hematopoietic stem cell transplant survivors appraise distress differently and utilize varying coping mechanisms to mitigate stressors. My project seeks to deepen the understanding of the lived experience of hematopoietic stem cell transplant survivors through semi-structured interviews discussing distress and the meaning to which these survivors assign to various stressors.
I wanted to request your permission to utilize Figure 1 which I found in the following publication:


I enjoyed reading this article and also feel the graphic (Figure 1) detailing the theoretical framework is both concise and easy to read. I would provide citation of your article as the source of this figure in my research proposal. Please feel free to contact me with any other questions/concerns you may have regarding my project.
Thank you for your time.
Sincerely,

Victoria Fitzpatrick (Reitz), RN, BSN
University at Buffalo School of Nursing
Doctor of Nursing Practice, Family Nurse Practitioner Program
*(716) 867-6286*

**Charmaine Jensen <c.jensen2@uq.edu.au> Apr 3**

Hi Victoria,

That’s fine to go ahead and use the requested figure. Do you have the software to cut the figure yourself or do you need me to send you the graphic?
Kind regards,

Charmaine Jensen

From: Victoria Reitz <vlreitz@buffalo.edu>
Sent: Tuesday, 3 April 2018 11:22 PM
To: Charmaine Jensen <c.jensen2@uq.edu.au>
Subject: Re: Permission to Use Figure for Stress, Appraisal, and Coping Theory
June 28, 2018

Dear Victoria Fitzpatrick,

On 6/28/2018, the IRB reviewed the following submission:

<table>
<thead>
<tr>
<th>Type of Review:</th>
<th>Initial Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title of Study:</td>
<td>Distress in Hematopoietic Cell Transplant Survivors: A Thematic Analysis of the Survivorship Experience</td>
</tr>
<tr>
<td>Investigator:</td>
<td>Victoria Fitzpatrick (Reitz)</td>
</tr>
<tr>
<td>IRB ID:</td>
<td>STUDY00002424</td>
</tr>
<tr>
<td>Documents Reviewed:</td>
<td>• Consent Form 6-20-18.pdf, Category: Consent Form; • HCT Survivorship Study HRP-503 Protocol 6-20-18.docx, Category: IRB Protocol; • HCTS Study Interview Template.docx, Category: Surveys/Questionnaires; • Victoria Fitzpatrick_4.6.18 Letter of Support.doc, Category: Site Permission Letter</td>
</tr>
</tbody>
</table>

The IRB approved the study from 6/28/2018 to 6/27/2019 inclusive. The Initial study materials for the project referenced above were reviewed and approved by the SUNY University at Buffalo IRB (UBIRB) by Non-Committee Review. The IRB has determined that the study is no greater than minimal risk. Before 6/27/2019 or within 30 days of study closure, whichever is earlier, you are to submit a continuing review application with required explanations. You can submit a continuing review application by navigating to the active study in Click IRB and selecting ‘Create Modification / CR’. Studies cannot be conducted beyond the expiration date without re-approval by the UBIRB.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system.

The consent form document includes the HIPAA authorization for use/disclosure of personal health information and has met the required elements of the federal regulations of HIPAA.

UBIRB approval is given with the understanding that the most recently approved procedures will be followed and the most recently approved consent documents will be used. If modifications are needed, those changes may not be initiated until such modifications have been submitted to the UBIRB for review and have been granted approval.
As principal investigator for this study involving human participants, you have responsibilities to the SUNY University at Buffalo IRB (UBIRB) as follows:

1. Ensuring that no subjects are enrolled prior to the IRB approval date.

2. Ensuring that the study is not conducted beyond the expiration date without re-approval by the UBIRB.

3. Ensuring that the UBIRB is notified of:
   - All reportable information in accordance with the New Information SOP (HRP-024).
   - Project closure/completion by submitting a Continuing Review/Modification submission.

4. Ensuring that the protocol is followed as approved by UBIRB unless a protocol amendment is prospectively approved.

5. Ensuring that changes in research procedures, recruitment or consent processes are not initiated without prior UBIRB review and approval, except where necessary to eliminate apparent immediate hazards to subjects.

6. Ensuring that the study is conducted in compliance with all UBIRB decisions, conditions, and requirements.

7. Bearing responsibility for all actions of the staff and sub-investigators with regard to the protocol.

8. Bearing responsibility for securing any other required approvals before research begins.

If you have any questions, please contact the UBIRB at 716-888-4888 or ub-irb@buffalo.edu. Please include the project title and number in all correspondence with the UBIRB.
July 10, 2018

Victoria Fitzpatrick, RN

victoria.reitz@roswellpark.org

Dear Ms. Victoria Fitzpatrick:

On 7/10/2018, the IRB Office reviewed the following submission:

<table>
<thead>
<tr>
<th>Type of Review:</th>
<th>Initial Study</th>
</tr>
</thead>
<tbody>
<tr>
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<tr>
<td>IRB ID:</td>
<td>STUDY00000679 / IRB 067918</td>
</tr>
<tr>
<td>Funding:</td>
<td>None</td>
</tr>
<tr>
<td>Grant ID:</td>
<td>None</td>
</tr>
<tr>
<td>IND, IDE, or HDE:</td>
<td>None</td>
</tr>
</tbody>
</table>
| Documents Reviewed: | • HCTS Study Interview Template.docx, Category: Other;  
                      • Consent Form 6-20-18.pdf, Category: Consent Form;  

The external IRB’s approval for this study will expire on 6/27/2019.

Please be advised that only the Roswell Park stamped consent form can be used to enroll subjects.

As a reminder, this research project is subject to approval by the external IRB, but also requires acceptance by the Roswell Park IRB prior to initiation by the investigator. Please promptly notify the local IRB office upon:

1) Any new Unanticipated Problems or any other Reportable New Information

2) Any new or updated information regarding potential Conflict of Interests

3) Any changes in local study team members

4) Notification of renewal by the reviewing IRB. A progress report must be submitted to the ORSP at least ten days prior to the expiration date noted above for continuing review.
5) Any modifications/updates in the research project

6) Closure of the Study

The principal investigator is responsible for ensuring that the research complies with all applicable regulations. The Roswell Park IRB reserves the right to stop the research for violations of regulatory or IRB requirements.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103), including the reporting of Unanticipated Problems and any other Reportable New Information.

Sincerely,
Donald Handley MSc, MBA
July 17, 2018

Dear Victoria Reitz:

On 7/17/2018, the IRB reviewed the following submission:

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<tr>
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<td>IRB ID:</td>
<td>MOD00004525</td>
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<tr>
<td>Documents Reviewed:</td>
<td>• HCT Survivorship Study HRP-503 Protocol 7-17-18 for UB.docx, Category: IRB Protocol;</td>
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The IRB approved this modification on 7/17/2018. The modification materials for the project referenced above were reviewed and approved by the SUNY University at Buffalo IRB (UBIRB) by Non-Committee Review. The expiration date of this study is 6/27/2019. Before 6/27/2019 or within 30 days of study closure, whichever is earlier, you are to submit a continuing review application with required explanations. You can submit a continuing review application by navigating to the active study in Click IRB and selecting ‘Create Modification / CR’. Studies cannot be conducted beyond the expiration date without re-approval by the UBIRB.

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• All reportable information in accordance with the New Information SOP (HRP-024).

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If you have any questions, please contact the UBIRB at 716-888-4888 or ub-irb@buffalo.edu. Please include the project title and number in all correspondence with the UBIRB.
July 18, 2018

Victoria Fitzpatrick

victoria.reitz@roswellpark.org

Dear Ms. Victoria Fitzpatrick:

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<td>IRB ID:</td>
<td>MOD00003205 / IRB 067918</td>
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<tr>
<td>Funding:</td>
<td>None</td>
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<tr>
<td>Grant ID:</td>
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Sincerely,
Donald Handley MSc, MBA
DISTRESS IN ADULT HEMATOPOIETIC CELL TRANSPLANT SURVIVORS

A Capstone Defense

Victoria Fitzpatrick, RN, BSN
August 2018

Purpose

- Identify sources of distress and coping strategies used by hematopoietic cell transplant survivors
- Improve healthcare provider understanding of the unique experience of hematopoietic cell transplant survivors

Specific Aims

- Identify overarching themes composing experience of adult HCTS related to distress and quality of life
- Identify connections between stress and coping mechanisms for adult HCTS
- Identify adult HCTS care priorities (symptoms, psychosocial issues, daily stressors)

HCCN Distress Thermometer for Patients

Instructions: Please circle the number (0-10) that best represents how much distress you have been experiencing in the past week including today.

Extremely distressed: 0
1 2 3 4 5 6 7 8 9 10

No distress

Symptoms
- Fatigue
- Depression
- Vision
- Anxiety
- Headache
- Hearing
- 3. Metabolism

Other Problems
- Sleeping
- Appetite
- Infection
- Heart
- Dizziness
- Skin
- Incontinence
- Nausea
- Swallowing
- Constipation
- Incontinence
- FULL QUESTIONNAIRE

8/19/2018
Roswell Park Comprehensive Cancer Center
Survivorship Screening Tool

- 3 Domains
  - Practical & Emotional Issues
  - Physical & Functional Issues
  - Nutrition Issues

Capstone Question
In the population of hematopoietic cell transplant survivors, greater than one year post-transplant, how do the concepts of stress, coping, and symptom management influence the experience of distress and quality of life?

Background – Hematopoietic Cell Transplant
- Hematopoietic stem cell (transplant)
  - Autologous
  - Allogeneic
  - Syngeneic
- Myeloablative therapy (conditioning regimen)
- Post-transplant care
- Complications
  - Pancytopenia
  - Impaired nutrition
  - Immunosuppression
  - Graft-versus-Host Disease (GvHD)
  - Graft failure and disease recurrence
  - Secondary malignancy
  - Organ toxicity

Background – Survivorship
- 108,900 HCTS living in U.S. in 2009
- Estimated 2.5-fold increase by 2020 and 5-fold increase by 2030 (Majhail et al., 2013)
- Complex disease-related and non-disease-related needs (Hahn et al., 2017)
- Long-term physical consequences of disease and treatment (Armenian et al., 2012; Sinatora et al., 2017)
- Long-term mental consequences (Jim et al., 2016; National Comprehensive Cancer Network, 2017a)
Literature Review – Characterizing Sources and Nature of Distress for Adult HCTS

- Symptom burden (Bevans et al., 2014; Sun et al., 2013)
- Socio-economic stressors (Brown-Iannuzzi et al, 2014; Hamilton et al., 2013)
- Self-appraisal contributing to distress (Rosenberg et al., 2015; Wu et al., 2012)
- Current distress screening tools (Hoodin et al., 2013; National Comprehensive Cancer Network, 2017a)

Justification for Theoretical Framework

- Goal to understand sources of distress and degree of impact of stressors
- Helps to understand variety of stressors and reactions
- Useful lens for understanding discrepancy between symptom severity and overall distress
- Potential explanation for appraisal and coping as determinant for overall perception of distress

Setting

- Roswell Park Comprehensive Cancer Center (Buffalo, NY)
  - National Cancer Institute-designated comprehensive cancer center
  - Clinical, Research, and Educational Departments
  - Inpatient and outpatient units
  - Approximately 36,000 patients (2017)
- Blood and Marrow Transplant (BMT) Center (Roswell Park Cancer Institute, n.d.)
Methods/Design
- Descriptive qualitative approach
- Semi-structured individual interviews (tape recorded and transcribed)
- Interview question template based on RPCCC Survivorship Screening Tool
- Convenience sampling until data redundancy achieved

Sampling
- Convenience sampling of patients attending survivorship appointment in RPCCC BMT Center
- Eligible participants screened by principal investigator at conclusion of clinical appointment

Inclusion Criteria
- Greater than 1 year post-transplant
- English-speaking, English-literate
- Able to provide informed consent
- Greater than 18 years of age at time of transplant
- Receiving maintenance therapy acceptable
- Marked at least one item as moderately distressing on RPCCC Survivorship Screening Tool (yellow, orange, or red regions)

Exclusion Criteria
- Less than 1 year post-transplant
- Unable to read, speak, or understanding English
- Unable to provide informed consent
- Younger than 18 years of age at time of transplant
- Receiving active treatment for malignancy
- Did not complete RPCCC SST
- Did not mark area of at least moderate distress on RPCCC SST (yellow, orange, or red regions)
Data Analysis
- Realist content analysis
- Rich thematic description
- Semantic
- 6 Phases of Thematic Analysis (Braun & Clarke, 2006)
  - Familiarizing self with the data
  - Generating initial codes
  - Searching for themes
  - Reviewing themes
  - Defining and naming themes
  - Producing the report

Methods of Reducing Bias
- Peer debriefing with qualitative expert

Protection of Human Subjects
- Security of informed consents, audio recordings, and transcribed data
- De-identification of data
- Provision of psychosocial resources/debriefing

Results: Demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>3 (50.0)</td>
</tr>
<tr>
<td>Male</td>
<td>3 (50.0)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>5 (83.3)</td>
</tr>
<tr>
<td>Black</td>
<td>1 (16.7)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>19-39</td>
<td>1 (16.7)</td>
</tr>
<tr>
<td>40-59</td>
<td>1 (16.7)</td>
</tr>
<tr>
<td>60-79</td>
<td>4 (66.7)</td>
</tr>
<tr>
<td>80+</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Leukemia</td>
<td>3 (50.0)</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>2 (33.3)</td>
</tr>
<tr>
<td>Myelofibrosis</td>
<td>1 (16.7)</td>
</tr>
</tbody>
</table>

Results: Distress Screening
- Specific Issues Triggered by Survivorship Screening Tool, meeting inclusion criteria
  - Feeling isolated, alone, or abandoned
  - Concerns about fertility
  - Weakness in arms or legs
  - Poor movement in legs or feet
  - Fatigue
  - Trouble with memory and/or concentration
- Average NCCN Distress
  Thermometer score: 0.67/10
- NCCN Distress Thermometer score range: 0-4/10
Results: Schemes

- Distress – “In the back of my mind”
- Coping – “Keep moving forward”
- Reappraisal – “Equal but different”

Results: Distress – Physical Symptoms

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-Themes</th>
<th>Supporting Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical symptoms</td>
<td>Fatigue/Weakness</td>
<td></td>
</tr>
<tr>
<td>“...you almost feel like a baby the way you have to be taken care of, especially at first.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“It’s always tougher, at first, because you’re a lot weaker... You’re more fragile.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty with movement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“There’s limitations that just make it more difficult to do stuff where I need to get down on the ground and get back up.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“It’s difficult to go up and down stairs, and because of balance, I really need to hang onto a handrail or something like that... I don’t have the strength in my upper legs.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fertility issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“I experienced atrophy in both feet and both hands, it’s constantly tingling and stopping... When I walk, if I don’t remember to pick up my foot, I will trip over something.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Immediately after transplant, I started having menopausal symptoms, hot flashes and stuff like that...” (The doctor) basically explained that the type of chem that I got had put me into an infertile state.”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Results: Distress – Mental and Emotional

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-Themes</th>
<th>Supporting Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical symptoms</td>
<td>Memory/Concentration</td>
<td></td>
</tr>
<tr>
<td>“I feel a little more distant. Sometimes my mind says one thing and my body is a different thing, I’m on the computer sometimes I’m thinking about one thing and I type something else differently.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“A lot of that is memory... It’s hard for me to get off of what I’m thinking sometimes and get onto something else.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional</td>
<td>Fear/Sanity</td>
<td></td>
</tr>
<tr>
<td>“It’s all in my mind. You know, is something going to happen? Am I going to get some sort of secondary cancer or something...”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“I may have had one time when I really kind of broke down and got nervous when my wife told me how they were going to basically kill me, and if my blood didn’t take, then that was it. When I was like, ‘What? Then it got serious.’”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“When I hear how somebody was a cancer survivor for six years and then they had a headache or a fever for 2 weeks, and then they died a week later because they had a brain tumor, I sort of get anxious for like a week, and then I get passed it.”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Results: Distress – Emotional

<table>
<thead>
<tr>
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<th>Supporting Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional (cont.)</td>
<td>Sadness/Depression</td>
<td></td>
</tr>
<tr>
<td>“I take something for depression, and that seems to help because, before I took it, I would just cry and wouldn’t even know why I was even crying... We have a lot of family issues and does it depress me sometimes? Yeah, I got to tell you, it does.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“I just lost my wife and that’s giving me something... I get emotional about that, but I don’t have any emotional problems pertaining to my transplant at all...” (I’m) going through now is pertaining to the loss of my wife after it’s years of marriage.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“When we were in that isolation before you get that transplant, that was probably the only time that I was really depressed, watching the same crap on TV, over and over and over.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“At the beginning, because I had to be so careful of infections, and all that kind of stuff, I have 7 grandchildren and it broke my heart, I couldn’t see them all the time. And that really bothered me.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“It’s been hard to find other people who are able to share those experiences, especially other women.”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Results: Coping – Problem-focused

<table>
<thead>
<tr>
<th>Table 1: Coping as an Overarching Scheme (“Keep Moving Forward”)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme</strong></td>
</tr>
<tr>
<td>Problem-focused</td>
</tr>
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</table>

### Results: Coping – Problem-focused (cont.)

<table>
<thead>
<tr>
<th>Table 2: Coping as an Overarching Scheme (“Keep Moving Forward”) (cont.)</th>
</tr>
</thead>
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<td><strong>Theme</strong></td>
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### Results: Coping – Emotion-focused

<table>
<thead>
<tr>
<th>Table 3: Coping as an Overarching Scheme (“Keep Moving Forward”) (cont.)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme</strong></td>
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<tr>
<td>Emotion-focused</td>
</tr>
</tbody>
</table>

### Results: Coping – Emotion-focused (cont.)

<table>
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<tr>
<th>Table 4: Coping as an Overarching Scheme (“Keep Moving Forward”) (cont.)</th>
</tr>
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<tbody>
<tr>
<td><strong>Theme</strong></td>
</tr>
<tr>
<td>Emotional mindfulness</td>
</tr>
</tbody>
</table>
Results: Coping – Emotion-focused (cont.)

Table 3: Coping as an Overarching Scheme ("Keeping Moving Forward") (cont.)

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
<th>Supporting Quotes</th>
</tr>
</thead>
</table>
| Support: Positive hospital experience | "I feel like everybody here at the hospital is so supportive and want to help other patients. Everyone has just been nothing but wanting to help and that’s been, I think, that’s why I like coming back here so much."
|                          | "We come here (the hospital), they’re always asking and making sure you don’t have issues. I think they really do a good job of being concerned about your feelings outside of here and how you’re coping with it."
|                          | "Not to be insensitive and pleasant to people means a lot to a patient. When people see you provide, like you (health care providers) are pleasant and cordial, and that uplifts me. I’m pretty sure it would uplift another patient or another person also. Being nice and pleasant is the most important thing that a person can give to someone else."
|                          | "You feel that, when I was in the hospital, that people really wanted you to live and survive. I mean, everybody went out of their way to be absolutely wonderful."

Results: Reappraisal

Table 4: Survivorship as a Reappraisal of Life ("Equal but different")

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
<th>Supporting Quotes</th>
</tr>
</thead>
</table>
| Appreciation for body   | Awareness of symptoms       | "I feel more in tune with my body that I ever was. I do pay attention to every little kind of symptom or anything I feel, I know to just keep an eye on it."
|                          | Amusement at transplant     | "I’m still amazed at how they do it, what they do. I still think about that all the time. You know, they actually destroyed my knee, and it put them cells in me and it made a new one. And that always amazes me."
|                          | Caution against risk-taking | "I am aware of a lot more things. It’s just being aware of what my body has been through and just making sure I’m not putting it into a place where I’m vulnerable or putting myself at risk unnecessarily."

Results: Reappraisal (cont.)

Table 3: Coping as an Overarching Scheme ("Keeping Moving Forward") (cont.)

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
<th>Supporting Quotes</th>
</tr>
</thead>
</table>
| Spiritual               | Support: Positive hospital experience | "You know, you’re young, you’re in good shape, and you know, that’s always the most important thing, that you’re a young person that really does care for you. And, in my case, my wife has been excellent with that."
|                          | "I don’t know how they do it, they’re wonderful. Especially my husband, he was phenomenal. My two brothers, my sister, my mother, my girlfriend, even or less supported him (patient), because he was there, too. And, without me, I don’t think I’d be here."
|                          | "My wife and my children helped me through it, and my friends, my team and daughter too. These are the ones who helped me through it."
|                          | "I think if it went bad, it went bad because of that, if it went good, it went good. I felt that I could do it with a good person and just do what I could, especially for my wife."
|                          | "That’s what got me through it all today, you know. The bond I had with my Bargaining. I haven’t been able to get over this, you know, I don’t have the same bond as it was."
|                          | "I feel like I’ve been there before and have faith. And believe and I have felt. So, this faith never went at it."
|                          | "At night, I say my prayers. When we get up in the morning, I say my prayers. I pray every day. That gets me through the day, and I read my I never really is something that I chew on an umbrella."

Results: Coping – Emotion-focused (cont.)

Table 3: Coping as an Overarching Scheme ("Keeping Moving Forward") (cont.)

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
<th>Supporting Quotes</th>
</tr>
</thead>
</table>
| Emotional               | Support: Positive hospital experience | "You know, you’re young, you’re in good shape, and you know, that’s always the most important thing, that you’re a young person that really does care for you. And, in my case, my wife has been excellent with that."
|                          | "I don’t know how they do it, they’re wonderful. Especially my husband, he was phenomenal. My two brothers, my sister, my mother, my girlfriend, even or less supported him (patient), because he was there, too. And, without me, I don’t think I’d be here."
|                          | "My wife and my children helped me through it, and my friends, my team and daughter too. These are the ones who helped me through it."
|                          | "I think if it went bad, it went bad because of that, if it went good, it went good. I felt that I could do it with a good person and just do what I could, especially for my wife."
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<th>Sub-themes</th>
<th>Supporting Quotes</th>
</tr>
</thead>
</table>
| New life perspective   | Feeling Grateful, Blessed, Lucky | "I’m fortunate, you know. I know a couple other people who were in here when I was and had way more problems than I have, and so it doesn’t affect me as much."
|                        |            | "I’ve been very blessed, guys you can say, because I didn’t really have that much of a hard time through the whole thing. I was in good spirits the whole time."
|                        |            | "I feel like I went through it (transplant) easier than most everybody... They probably couldn’t have told me it was going to go any smoother than when I had it."
|                        |            | "It makes me very grateful. I’m happy with my life."
|                        |            | "I’m very happy to be alive. I’m not taking life for granted."
|                        |            | "I’m very happy to be where I am. I’m pretty much operating normal basis. I can do almost anything with very little restrictions, that almost no complications or side effects, I’m very, very lucky." |

### Table 4: Surviving as a Reappraisal of Life - "Equal but different" (cont.)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-themes</th>
<th>Supporting Quotes</th>
</tr>
</thead>
</table>
| Meaning in experience  | Shared empathy | "It’s just given me a different perspective, you know, about what people go through. I have a lot more sympathy for people. I mean, I had it before, but it’s never intense now."
|                        |            | "I think that sort of helped with, you know, realizing that it’s not just me... There’s a lot of people who have to face this reality, I guess."
|                        |            | "I would like to get involved in a support group so I can kind of, you know, express myself to them and see what they think. Just to see if people went through the same thing or similar."
|                        |            | "Now by me going through it (transplant), I can help someone else get through it also if someone (transplant)."
|                        |            | "I would like to get involved in a support group so I can kind of, you know, express myself to them and tell them what’s going on."
|                        |            | "I said there was something that they could pull from my life that pretty much somebody else, you know? Because I lived pretty good."
| Seeking to help others with cancer |            | "I think you can understand, you know, like psychology and everything."
|                        |            | "I think you can understand, you know, like psychology and everything."
| Returning to Normalcy  | New normal | "I think I am equal but different. What I’m being now is definitely not, it’s a new normal."
|                        |            | "I lost all of my hair in this transplant. I lost all of my hair in this transplant."
|                        |            | "I lost all of my hair in this transplant. I lost all of my hair in this transplant."
|                        |            | "It’s hard for me to relate what is normal progression because I don’t know if I’m getting older or if it’s because I went through. So there’s not a lot of questions about things like that when they come up."
|                        |            | "I think you can understand, you know, like psychology and everything."

### Table 4: Surviving as a Reappraisal of Life - "Equal but different" (cont.)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-themes</th>
<th>Supporting Quotes</th>
</tr>
</thead>
</table>
| Returning to Normalcy  | Returning to previous level of functioning | "I’m not over here, where I was before the transplant, but I am, you know, I get some strength back now."
|                        |            | "I’ve always been a very active person, so that was a step up for me."
|                        |            | "I’ve always been a very active person, so that was a step up for me."
|                        |            | "I’ve always been a very active person, so that was a step up for me."
|                        |            | "I’ve always been a very active person, so that was a step up for me."
|                        |            | "I think we do a lot. I don’t think our life has been impacted to the point where we don’t do a lot of things. I’m happy with my job. We get to take a very nice vacation, and we get to do pretty much everything we want to do."
Discussion

- Various sources of distress, related and not related to disease or transplant
- Stressor-specific care priorities
- Coping mechanisms as adaptations and/or pre-existing protective factors
- Positive attitude, positive hospital experience, and stable support system were most consistent protective factors discussed by all participants

Discussion

- Survivorship as a reappraisal of:
  - Life
  - Body
  - Normalcy
  - Meaning of experience
- Reappraisal = possible mechanism influencing perception of distress
- Positive reappraisal of survivorship experience may contribute to improved quality of life

Discussion

- Compared with prior research:
  - Minimal GVHD symptoms
  - Generally positive experience overall
  - Few reports of unmet needs
- Area for needed improvement discussed:
  - Pre-transplant education of late effects of treatment and subsequent screening
  - Access to resources for difficult topics (i.e., sexuality, fertility) post-transplant
  - Creation of network for cancer survivors to discuss issues, find support

Discussion

- Strengths
  - Rich description of various issues impacting survivorship care
  - Use of RPCCC Survivorship Screening Tool acting as guide for interview grounded in the patient-specific issues
- Limitations
  - Small sample size
  - Limited time frame for data collection
  - Convenience sample
  - Stringent eligibility criteria
Discussion

• Future Research
  • Thematic analysis of larger sample size with expanded eligibility criteria to reach data saturation
  • Establish validity, reliability, and clinician satisfaction with RPCCC Survivorship Screening Tool
  • Program evaluation of classes, resources for HCT patients and survivors

Conclusions: Contribution to Innovation of Clinical Practice

• Described unique issues of hematopoietic cell transplant survivorship experience from the experts
• Identified areas requiring improvement in meeting survivorship care priorities
• Highlighted positive protective factors, including resources and overall organizational culture
• Identified factors useful for targeted assessment and intervention pre- and post-transplant
• Provided rationale and direction for future research

Conclusion

• Questions?
• Concerns?
The Semi-Structured Interview Schedule (cont.)

3. Tell me about any community resource/organization you utilized during your treatment.
   - How did you become aware of the community resource/organization?
   - Describe for me how the community resource/organization was helpful to you during your treatment.
   - Describe for me how the community resource/organization was unhelpful to you during your treatment. Describe for me what you felt would make it better.
   - Is there anything about the use of community resources among hematopoietic cell transplant patients/survivors that you consider important for health care providers to know about? Describe in detail for me.
   - Is there anything about the use of community resources among hematopoietic cell transplant patients/survivors that you did not talk about that is important for health care providers to know about? Describe in detail for me.

4. Describe for me any issues or hardships you experienced regarding your medication during your treatment.
   - Describe for me any thoughts regarding how care providers can improve getting medications for hematopoietic cell transplant patients during treatment.
   - Describe for me any thoughts regarding how care providers can improve getting medications for hematopoietic cell transplant patients.
   - Is there anything about medication access among hematopoietic cell transplant patients/survivors that you did not talk about that is important for health care providers to know about? Describe in detail for me.
   - Is there anything about medications that you did not talk about that you feel is important for health care providers to know about? Describe in detail for me.

The Semi-Structured Interview Schedule (cont.)

5. Describe for me any spiritual or religious concerns you may have experienced as a hematopoietic cell transplant patient undergoing treatment.
   - Tell me about any spiritual or religious concerns you may have experienced as a hematopoietic cell transplant patient undergoing treatment.
   - Describe for me your thoughts regarding how spiritual or religious concerns can be improved for hematopoietic cell transplant patients.
   - Describe for me your thoughts regarding how spiritual or religious concerns can be improved for hematopoietic cell transplant patients undergoing treatment.
   - Is there anything about spiritual or religious concerns that you did not talk about that you feel is important for health care providers to know about?

6. Describe for me any emotional issues, such as anger, worrying about the future, or isolation, that you may have experienced while undergoing hematopoietic cell transplant treatment.
   - Tell me about any emotional issues that you have experienced while undergoing hematopoietic cell transplant treatment.
   - Describe for me your thoughts regarding how an emotional issues can be improved for hematopoietic cell transplant patients undergoing treatment.
   - Describe for me your thoughts regarding how emotional issues can be improved for hematopoietic cell transplant patients.
   - Is there anything about emotional issues that you did not talk about that you feel is important for health care providers to know about?

7. Tell me about any issues or concerns about sexual intimacy or fertility that you experienced as a hematopoietic cell transplant patient undergoing treatment.
   - Describe for me any thoughts regarding sexual intimacy or fertility that you experienced during hematopoietic cell transplant treatment.
   - Describe for me any thoughts regarding sexual intimacy or fertility that you experienced during hematopoietic cell transplant treatment.
   - Describe for me your thoughts regarding how sexual intimacy or fertility can be improved for hematopoietic cell transplant patients undergoing treatment.
   - Is there anything about sexual intimacy or fertility that you did not talk about that you feel is important for health care providers to know about?
### Table 1

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Title</th>
<th>Journal</th>
<th>Year</th>
</tr>
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<tbody>
<tr>
<td>Smith et al.</td>
<td>Effects of Exercise on Mental Health</td>
<td>Journal of Psychology</td>
<td>2023</td>
</tr>
<tr>
<td>Brown et al.</td>
<td>The Role of Social Support in Mental Health</td>
<td>American Journal of Psychiatry</td>
<td>2023</td>
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<tr>
<td>Johnson</td>
<td>Understanding Mental Health Issues</td>
<td>Canadian Journal of Public Health</td>
<td>2023</td>
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### Table 2

<table>
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<tr>
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<td>8/19/2018</td>
<td>Updates to the mental health practices in schools and community centers</td>
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### Table 3

<table>
<thead>
<tr>
<th>Project Name</th>
<th>Description</th>
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<tr>
<td>Mental Health</td>
<td>Initiative focuses on improving mental health outcomes</td>
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<tr>
<td>Community</td>
<td>Education programs for mental health awareness</td>
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### Table 4

<table>
<thead>
<tr>
<th>Region</th>
<th>Key Initiatives</th>
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<tbody>
<tr>
<td>Urban</td>
<td>Enhanced mental health services for underserved communities</td>
</tr>
<tr>
<td>Rural</td>
<td>Outreach programs to remote communities</td>
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</table>

### Table 5

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Goal</th>
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<tbody>
<tr>
<td>Stress Levels</td>
<td>Decrease by 20% within the next 5 years</td>
</tr>
<tr>
<td>Suicide Rates</td>
<td>Reduce by 15% within the next 5 years</td>
</tr>
<tr>
<td>Depression</td>
<td>Improve by 10% within the next 5 years</td>
</tr>
</tbody>
</table>

### Table 6

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Care</td>
<td>Implement telehealth services for remote communities</td>
</tr>
<tr>
<td>Funding</td>
<td>Secure additional federal and private funding</td>
</tr>
<tr>
<td>Training</td>
<td>Increase mental health provider training for all community workers</td>
</tr>
</tbody>
</table>
Acknowledgements

- Dr. Pamela Paplam, Dr. Loralee Sessanna, and Dr. Tammy Austin-Ketch for project advisement.
- Dr. Philip McCarthy, Mr. Steven Schinnagel, and the physicians, advanced practice providers, and nurses of the Blood and Marrow Transplant Center at Roswell Park Comprehensive Cancer Center for project support.
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References


