QUALITY OF LIFE PERCEPTION VARIATIONS IN ALLOGENEIC HEMATOPOIETIC CELL TRANSPLANT RECIPIENTS WITH CHRONIC GRAFT VERSUS HOST DISEASE AND THEIR CARE PROVIDERS

By

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DNP Project Approval Form

This is to certify that

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successfully defended their project entitled:

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Abstract

**Problem** Patient reported outcome (PROs) and quality of life (QoL) perceptions vary between Hematopoietic Cell Transplant (HCT) recipients with chronic graft-versus-host disease (cGVHD), care providers, and clinicians, which may interfere with symptom management and QoL outcomes.

**Objectives** Describe variations in perceptions of QoL between adult HCT patients with cGVHD and their care provider and clinician.

**Background** Studies examining variations in patient-physician HCT QoL demonstrate only moderate agreement with potential underestimation of cGVHD symptom management and outcomes.

**Methods** A descriptive, qualitative design was implemented. The FACT-BMT questionnaire was utilized in this project to create a semi-structured interview questionnaire used to explore and compare QoL perceptions among allogeneic HCT patients and their care provider and clinician.

**Results** Results demonstrate the need to support PROs and QOL assessment in patients with cGVHD to facilitate interventions that improve overall QoL.

**Potential Significance** This project enhances the existing evidence base of knowledge supporting the effectiveness and importance of utilizing PROs to increase QoL in HCT patients living with cGVHD.

**Implications** Routine use of assessing PROs during outpatient HCT clinic visits can allow patients to take an active role in guiding complex treatment decisions and symptom management needs directed at improving life quality.

**Keywords:** allogeneic, chronic graft versus host disease, health related quality of life, hematopoietic stem cell transplant, patient-reported outcomes
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Patient reported outcomes (PROs) represent a promising opportunity to incorporate the individual’s perspective into formal tools for both risk stratification and treatment planning. The value of quantifying PROs is increasingly being recognized, but the routine collection of patient reported information is uncommon. A patient-reported outcome is any report on the status of a patient’s health condition that comes directly from the patient. Clear and meaningful interpretation of PRO scores are fundamental to their use. PRO scores can be valuable in designing studies, evaluating interventions, educating consumers, and informing health policy makers involved with regulatory, reimbursement, and advisory agencies (Cappelleri & Bushmakin, 2014). On the individual level, PROs can be used clinically to screen for conditions, monitor patient progress over time, and to aid in decision making (Snyder, Jensen, Segal, & Wu, 2013). When implemented, PROs have the potential to improve the quality and patient-centeredness of medical care.

Shaw et al. (2016) reported that allogeneic hematopoietic cell transplantation (HCT) cures many patients, but often with the risk of late effects and impaired quality of life (QoL). Additional work is needed to support the integration of PROs into HCT clinical practice and quality reporting. The process of HCT describes a variety of procedures where hematopoietic stem cells of any donor type and any source are given to a recipient in order to repopulate or replace the hematopoietic system in part or whole. Stem cells can be derived from bone marrow, peripheral blood, or umbilical cord blood (Sureda et al., 2015). Donor type is categorized as autologous (self), syngeneic (identical twin), HLA-identical sibling donor, other family donor, or unrelated donor. Based on HLA high-resolution typing, a well-matched unrelated donor (MUD) is defined as a 10/10 and an identical donor is defined as an 8/8. A mismatched unrelated donor (MMUD) refers to an adult unrelated donor mismatched in at least one gene or
genetic sequence (Sureda et al., 2015). A haploidentical donor is defined as a family member where only one HLA haplotype is genetically identical with the patient. Graft versus host disease (GVHD) arises when donor T cells recognize the host as foreign, triggering an immune reaction that causes the clinical manifestations of GVHD (Cloutier, Wall, Paulsen, & Bernstein, 2017). Acute clinical manifestations most commonly affect the skin, liver, and gastrointestinal tract (Cloutier et al., 2017). The clinical diagnosis of acute GVHD is often made when a patient presents with a typical rash, diarrhea, and rising serum bilirubin within the first 100 days after stem cell transplantation (SCT) (Cloutier et al., 2017). Chronic GVHD is a single or multi-organ, alloimmune and autoimmune disorder characterized by immune dysregulation, immune deficiency, impaired end-organ function, and decreased overall survival which occurs after day 100 post-allogeneic HCT (Linhares, Pavletic & Gale, 2013). Therapeutic intervention of cGVHD, typically consists of prolonged immune suppression, which may further aggravate the immune suppression which is already commonly associated with cGVHD, making recipients more vulnerable to a variety of common illnesses (Linhares et al., 2013).

**Background and Significance**

Chronic graft versus host disease (cGVHD) is a common complication of allogeneic HCT, affecting an estimated 30% to 70% of patients (Jagasia et al., 2015). Chronic GVHD is a condition comprised of multiple clinical features similar to other autoimmune and immunologic disorders, varies in severity. The pathophysiology of the cGVHD syndrome could involve inflammation, cell-mediated immunity, humoral immunity, and fibrosis (Jagasia et al., 2015). Clinical signs usually present within the first year after transplantation, but can develop many years after HCT. Clinical indicators of cGVHD may be limited to a single organ or site or may be widespread, significantly impacting patient QoL. Additionally, numerous physical and
psychological threats associated with HCT that can impact a patient’s QoL including prolonged hospitalization, isolation, frequent changes in medical status, invasive procedures, and increased risk of mortality (McQuellon et al., 1997).

Among both patient and healthcare providers, there has been increased interest regarding the importance and need for assessing QoL in post-HCT patient care. Despite this common interest, Barata et al. (2017) found that patient-physician QoL scored indicated only moderate agreement, noting that physicians considerably underestimated patient perceived QoL. This underestimation in a clinical HCT setting could severely impact a patient’s QoL with regard to cGVHD symptom management and health-related outcomes. Three primary reasons for assessing QoL in HCT populations include use of the information to inform complex treatment decisions, to identify rehabilitation needs, and to predict future treatment response (McQuellon et al., 1997). Even with increased attention and interest to assessing and evaluating QoL among HCT patients in clinical settings, no standard for routine assessment and evaluation of PROs currently exists. Assessing PROs in clinical settings is a well-accepted practice and is associated with better detection and monitoring of unmet patient needs pertaining to QoL, emotional support, and daily activities (Barata et al., 2017). The introduction of PROs in clinical HCT settings could help overcome QoL patient-physician inconsistencies and barriers.

The Functional Assessment of Chronic Illness Therapy (FACIT) measurement system consists of numerous questionnaires that assess health-related QoL among patients living with mild and severe chronic illness including cancer patients and cancer survivors (Lee et al., 2015). The FACIT measurement system, widely used across various oncology settings, has well-established psychometric properties with reported population norms for cancer patients and cancer survivors (Lee et al., 2015). Measures found within the FACIT system assessing QoL are
placed into the following seven categories: General Measures (4 instruments), Cancer Specific Measures (21 instruments), Cancer Specific Symptom Indexes (28 instruments), Treatment Specific Measures (12 instruments), Symptom Specific Measures (20 instruments), Non-Cancer Specific Measures (13 instruments), and Pediatric Measures (4 instruments) (FACIT.org, 2010). One treatment specific FACIT scale, the Functional Assessment of Cancer Therapy – Bone Marrow Transplant (FACT-BMT) Scale has been utilized to assess and evaluate QoL among patients undergoing bone marrow transplant. Though not widely implemented, using a validated tool like the FACT-BMT has shown to be an effective way to determine patient QoL status when implemented as routine practice in outpatient HCT clinics (Barata et al., 2017). Care providers need to be aware of differing patient perceptions in order to facilitate change in communication and interventions to improve overall QoL. Since many adult outpatient allogeneic HCT patients develop cGVHD with symptoms significantly impacting their QoL, exploring QoL as it is perceived among adult outpatient allogeneic HCT patients and their care providers (patient caregivers and healthcare professionals) based on the FACT-BMT, is needed to determine how to improve QoL outcomes through early identification and implementation symptom management strategies.

**Purpose**

The purpose of this Doctor of Nursing Practice (DNP) project is to justify the need for and importance of implementing routine assessment and evaluation of QoL among adult allogeneic HCT outpatients in a Comprehensive Cancer Center Clinic setting. This project was implemented to explore variations in QoL perceptions among adult allogeneic HCT outpatients and their caregivers to better understand and enhance approaches to care based on PROs. This project may add to the existing evidence base of knowledge supporting the effectiveness and
importance of utilizing PROs in HCT patient care practice among patients living with cGVHD. Routine use of assessing PROs at outpatient HCT clinic visits can allow patients to take an active role in guiding complex treatment decisions; aid in identification of medical, rehabilitative, and symptom management needs; and to predict individualized response to future treatment.

Incorporating QoL care as a standard measure in the routine care of cGVHD patients is long overdue. Advanced practice providers (APPs), including DNP prepared practitioners, should be held accountable and responsible for including evidence based (EVB) QoL standards of care in the treatment and symptom management of cGVHD among adult allogeneic HCT outpatients. Utilizing evidence-based practice (EBP) to influence change in provided routine care is crucial to the role of a DNP prepared nurse. As a means to influence change in provided routine care, this project addresses Essential V of the American Association of Colleges of Nursing (AACN, 2006) DNP essentials, Health Care Policy.

One key project objective is to discuss recommendations for the utilization of patient-reported questionnaire that evaluates symptoms of cGVHD and QoL ratings. The project question is: Among adult allogeneic HCT outpatients aged 18 and older diagnosed with cGVHD in a Comprehensive Cancer Center, how does the outpatient’s perception of their QoL needs compare to their care provider’s (family or friend and clinician) perception of their QoL needs and how do these perceptions influence QoL outcomes? Ultimately, this project aims to evaluate and describe variations in QoL perceptions between HCT recipients with cGVHD and their care providers.
Literature Review

A systematic literature review was conducted. Databases searched include PubMed, CINAHL, ERIC, and Google Scholar. Key words utilized in the search included allogeneic, chronic graft versus host disease, health related quality of life, healthcare provider, hematopoietic stem cell transplant, and patient-reported outcomes. The literature review included research studies and articles from 2014 through 2018 and was limited to only adult patients and not children. This literature review was limited to free full-text English-language articles only. Articles were excluded if they were not related to allogeneic HCT and QoL outcomes. Articles that focused on specific interventions, caregiver QoL, instrument validation, sickle cell disease, or chemotherapy toxicities were excluded. After applying all search criteria and reading abstracts, 14 articles were found to be appropriate for inclusion in the literature review. The following themes organized the literature review: financial hardship, physical functioning and symptom distress, role functioning, social functioning and depression, spiritual growth and resilience, and multi-item measures to assess PROs.

Financial Hardship

Two of the studies (Abel et al., 2016 and Brister, Baer, Lazarus, Weiman & Mazanec, 2017) specifically explored financial hardship as a factor associated with worse QoL. Abel et al. (2016) identified 46% of participants experienced income decline after HCT and 71% reported hardship as a result. Not only was financial hardship prevalent and associated with worse QoL, but was also found to correlate with higher levels of perceived stress. Similarly, Brister et al. (2017) found that financial concerns were the most prevalent concern when exploring the social domain, reported by 64% of participants.
Physical Functioning and Symptom Distress

Physical functioning and symptom distress were discussed in several of the articles reviewed (Alaloul, Brockopp, Andrykowski, Hall, & Al Nusairat, 2015; Bevans et al., 2014; Brister et al., 2017; Kenzik, Huang, Rizzo, Shenkman & Wingard, 2015; & Li et al., 2015). Aaloul et al. (2015) explored physical functioning, role functioning, and social functioning domains, as well as an overall symptom score. While no significant difference was noted in emotional and cognitive domains, higher overall symptom scores were significantly associated with poorer QoL across all identified domains (Aaloul et al., 2015). Bevans et al. (2014) further support these findings with their related findings that physical symptom distress negatively affected all outcomes. The impact of symptom distress on physical health varied based on time since HCT; impairment in physical health was greatest in survivors experiencing high symptom distress and who were within the first decade post transplantation (Bevans et al., 2014). Further, extended treatment with systemic immunosuppressive therapy also predicted inferior physical health (Bevans et al., 2014). Brister et al. (2017) investigated specific concerns in each domain, and found physical concerns of fatigue, body changes, and balance difficulties as the most prevalent reports from respondents. Physical symptoms are most strongly associated with physical HRQoL (Kenzik et al., 2015). Li et al. (2015) added the only study which specifically discussed sexual dysfunction, noting the importance of awareness and early diagnosis of physical problems affecting genitalia related to conditioning regimens, medications, and GVHD as important factors for QoL in long-term survivors of HCT.

Role Functioning, Social Functioning, and Depression

Most of the studies (Artherholt, Hong, Berry & Fann, 2014; Barata et al., 2017; Brister et al., 2017; El-Jawahri et al., 2015; Hoodin, Zhao, Carey, Levine & Kitko, 2013; Jim et al., 2016;
& Kenzik et al., 2015) included measures that assessed depression, either associated with role function, social function, or as an independent factor affecting QoL outcomes. Frequent screening for symptoms of depression including post HCT are needed as post-HCT depression is common (Artherholt et al., 2014). Barata et al. (2017) report suboptimal patient and physician agreement, particularly in the areas of emotional and social well-being, further reinforcing the need for implementation of PROs in the daily care of HCT recipients in order to contribute to improving patient-centered care. Within the emotional domain, Brister et al. (2017) identified more than half of respondents feared their cancer returning or a new cancer developing. These results underscore the importance of clinicians addressing all QoL domains in cancer survivors (Brister et al., 2017). While hospitalized, El-Jawahri et al. (2015) reported that patients’ QoL markedly declines throughout hospitalization. Specifically, the proportion of patients with depression more than doubled from baseline to day plus eight. Patients undergoing HCT reported an abrupt deterioration in QoL and substantially worsening depression during hospitalization (El-Jawahri et al., 2015). Hoodin et al. (2013) further confirm findings of the prevalence of clinically significant depression (21%), anxiety (14%), or suicidal ideation (8%). Further, screening allowed patients to discuss their psychological symptoms and providers were significantly more satisfied with the management of psychological issues for the experimental group (Hoodin et al., 2013).

**Spiritual Growth and Resilience**

Two studies identified spiritual growth (Lynch Kelly, Lyon, Periera, Garvan, & Wingard, 2018) and resilience (Rosenberg et al., 2015) as important factors influencing patient reported QoL. Spiritual growth and total perceived stress were correlated. Activity, nutrition, stress management, and social support evaluation are important to include in QoL assessments, as
related intervention may reduce stress and inflammation (Lynch et al., 2018). Similarly, lower
patient resilience was associated with higher severity cGHVD, lower performance scores,
missing work due to health, and permanent disability (Rosenberg et al., 2015). Patient-reported
resilience is independently associated with health and psychosocial outcomes (Rosenberg et al.,
2015).

Assessment Measures

Shaw et al. (2016) performed a review of the current literature and found there is general
agreement that using PROs to assess HRQoL is the gold standard. Physicians often overestimate
HRQoL compared with patients’ self-reports, therefore incorporation of PROs into HCT follow-
up care results in better patient-physician communication and enhances patient satisfaction
(Shaw et al., 2016). Despite a large body of literature addressing the importance of PROs to
HCT patients, there is a lack of consensus about the best measures to use (Shaw et al., 2016). In
addition, there is insufficient evidence describing how physicians interpret or use PRO results
from research studies in assessing their patients and recommending treatments (Shaw et al.,
2016).

Conceptual Framework

Using the revised Wilson and Cleary model for HRQoL, physical well-being is described
as experienced sensations that are cognitively processed with the background of previous
somatic experiences and with information from the environment. A person’s cognitive
representation of the symptom includes thoughts about its possible identity, cause, consequence,
progression, and cure (Ferrans, Zerwic, Wilbur & Larson, 2005). Ferrans et al. (2005) describe
social environmental characteristics as the interpersonal or social influences on health
outcomes, including the influence of family, friends, and healthcare providers. Emotional
factors include experiences, evaluation, and interpretation of symptoms influenced by complex
interactions with both individual factors, such as knowledge and personality characteristics, as
well as environmental factors (Ferrans et al., 2005). Perceptions of well-being therefore are
dependent on the person’s perception of each of these attributes, as well as internal standards by
which those perceptions are judged. Because of differences in values, an impairment that makes
life not worth living for one person might be considered only an inconvenience for another
(Ferrans et al., 2005).

The Revised Wilson and Cleary model for HRQoL clearly portrays the intended
meaning. Health related QoL is a term that was developed with the purpose to narrow the focus
of life satisfaction to the effects of health, illness, and treatment on QoL, excluding aspects that
are not related to health, such as cultural, political, or societal attributes (Ferrans et al., 2005).

One key aspect of the revised model for HRQoL includes the multiple layers of influence
on health outcomes at both individual and environmental levels. Intrapersonal factors are
individual characteristics, while interpersonal factors (social support systems), institutional
factors (healthcare facilities), community factors (relationships among institutions and informal
social networks in a defined area), and public policy comprise the environmental characteristics
(Ferrans et al., 2005). Individual characteristics in this conceptual model include demographic,
developmental, psychological, and biological factors that influence health outcomes.

Environmental characteristics are categorized as either social or physical.

The primary focus of this model are the five boxes in the center, with the five center
boxes depicting five types of measures of patient outcomes (see Appendix A for more
information on the revised Wilson and Cleary model). Ferrans et al., (2005) describe each of the
five constructs. First, biological function, described as the function of cells, organs, and organ
systems. Second, symptoms, referring to physical, emotional, and cognitive symptoms perceived by a patient. Functional status, the third component, includes physical, psychological, social, and role function. Fourth, general health perceptions, refers to a subjective rating that includes all of the health concepts overall. Fifth, overall QoL, described as subjective well-being. Quality of life in this model is how satisfied someone is with their life as a whole. The model arrows indicate dominant causal associations. While reciprocal relationships might exist, they are not characterized in the model figure (pictured in Appendix A).

In this conceptual model of HRQoL, Ferrans et al. (2005) describe biological function as a continuum of ideal function on one end, and serious life-threatening pathological function at the other end. Any alteration in biological function affects all components of health, including symptoms, functional status, perceptions of health, and overall QoL. Since the experience, evaluation, and interpretation of symptoms are part of the characteristics of the individual and the environment, symptoms play an important role in HRQoL. Likewise, one's ability to perform physical function tasks, as well as, social function, role function, and psychological function, are imperative when assessing HRQoL. When rating their health, patients often consider multiple aspects of their health, with consideration of the importance of each. Finally, overall QoL, how satisfied someone is with life as a whole comprises the final aspect of this model. Life satisfaction can be measured through a single global question, asking how satisfied the person is with life in general, or through a series of questions about satisfaction with various aspects of life.

As depicted by the revised Wilson and Cleary model for HRQoL, each of the vital components for assessing perceptions of QoL in a Comprehensive Cancer Center’s adult outpatient HCT clinic patients diagnosed with cGVHD, can be compared to patient QoL.
perceptions described by their care providers (patient caregiver, nurse, APP) in an attempt to enhance QoL outcomes.

Methodology

Project Design

The FACT-BMT questionnaire was utilized in this qualitative-descriptive project to create a semi-structured interview questionnaire exploring QoL perceptions and experiences among adult allogeneic HCT outpatients through use of recorded individual interview sessions (see Appendix D). To explore if their perception of the patient’s QoL coincided with the patient’s reported QoL, the same semi-structured interview questions were asked of the patient family or friend care providers. Family or friend care providers had the option of completing the interview by telephone. The same semi-structured interview questionnaire was administered as a written pen and paper self-report questionnaire among participating patient healthcare providers (see Appendix E). Tool reliability was established through a trial interview of two non-participant subjects to ensure that the question design appropriately elicited responses. Interview tool validity was established by a practicing expert HCT APP at the Comprehensive Cancer Center, a community expert, as well as a qualitative expert.

Hsieh and Shannon’s (2005), directed content analysis method can be utilized when existing theory or prior and available research surrounding a phenomenon of interest could benefit from further exploration and description (p. 1281). The goal of directed content analysis is to validate or conceptually extend upon preexisting variables and predetermined categories (Hsieh & Shannon, 2005). The FACT-BMT questionnaire consists of the following five QoL dimensions: 1) Physical Well-Being; 2) Social and Family Well-Being; 3) Emotional Well-Being; 4) Functional Well-Being, and 5) Additional Concerns. These five preexisting QoL
dimensions were utilized as predetermined categories to develop the semi-structured
questionnaire created to explore QoL among adult allogeneic HCT patients through individual
interview sessions (Appendix D) and the perceptions of patient QoL among healthcare
providers as a written self-report questionnaire or a recorded telephone interview.

By using a qualitative open-ended interview approach, participating patients were
afforded the opportunity to communicate, in their own words, their individual and unique
perspectives regarding QoL experiences. By using the same questionnaire as a written self-
report questionnaire, clinician providers were afforded the opportunity to communicate, through
written response regarding their individual and unique perspective regarding their perception of
patient QoL experiences and needs. Offering healthcare providers the option to complete the
questionnaire as a written self-report measure in lieu of participating in a recorded interview
session was viewed as a means to increase project participation by reducing participation
burden. It should be noted that although clinician providers were offered the option of
participating in an individual interview session, all clinician providers participating in this
project opted to complete the questionnaire as a paper and pen self-reported measure. Family or
friend care providers were offered the option to participate in a face to face interview session, or
recorded telephone interview session.

**Ethical and Human Subject Considerations**

Prior to implementation, the project protocol was approved by the University at Buffalo
Internal Review Board (UB IRB) as well as the Comprehensive Cancer Center’s IRB. As per
the UB IRB approved protocol, all recorded interviews and transcription records will be
retained for three years in a secured and locked file cabinet drawer located in the Primary
Investigator’s home office. Prior to collecting data, written informed consent was obtained from
all patients and family or friend care providers participating in the interview sessions and from all clinician providers completing the questionnaire as a written self-report. Verbal informed consent was obtained by all family and friend participants completing the questionnaire via the telephone interview option. Participant confidentiality and privacy were maintained through use of recruitment and data collection strategies taking place in a private clinic setting, the de-identification of collected data, and use of de-identified data in any public presentation or publication.

**Recruitment Strategy**

Informational flyers describing the project and project participation were made available to the APPs and physicians working in the Roswell Park Comprehensive Cancer Center (RPCCC) outpatient HCT clinic. The flyers described the project purpose and the eligibility criteria (see Appendix C). The physician or APP referenced the flyer when offering participation in the project opportunity to all eligible presenting patients. Participation screening was achieved through a targeted recruitment process where current patients attending RPCCC outpatient HCT clinic who met the eligibility criteria were invited to participate. Project eligibility criteria included the following: a) being greater than or equal to 18 years of age; b) having a diagnosis of cGVHD; c) being a current RPCCC clinic outpatient; d) having a scheduled appointment with the HCT clinic; e) having the ability to read and speak the English language; and f) having a clinician and a family or friend care provider willing to participate in the project. If participants met all eligibility criteria and voiced interest in project participation, informed consent was signed.
Data Collection

Data collection took place at a Comprehensive Cancer Center located in Buffalo, New York. Using convenience sampling, all adult outpatient HCT patients who have received an allogeneic HCT and who have been diagnosed with cGVHD were eligible to participate. Patients who did not have a care provider but were willing to participate in the project were excluded. Care providers consisted of the APP, nurse, or family or friend caregiver of the patients interviewed, forming a triad. A triad consists of the patient participant, family/friend caregiver, and their clinician (nurse, APP, physician). Demographic data of all patients interviewed and their care providers was collected using a standard demographic form (see Appendix B). The sample size was determined based upon the point of saturation with 15 patient triad interviews conducted.

All interview sessions took place in a private examination or conference room. Only project team members and persons authorized by participants were present during the interview. One on one interviews then took place either in a private exam room, or in a private conference room. Some caregiver participants elected to participate in a telephone interview. Consent was signed and contact information was collected and a time and date were set to complete the recorded interview. Participants were made aware that interviews would be recorded and the digital recorder was turned on for the duration of the open ended question and answer session. The participant may have elected to have the recording paused or stopped at any time. When the interview was complete, the digital recorder was turned off. Recorded interviews were transcribed for analysis. Telephone interviews were also recoded and transcribed verbatim just as the in person interviews. Data storage and analysis took place in the private home office of the Primary Investigator.
Additional probing questions were offered to patient participants as needed to elicit a comprehensive response (see Appendices E and F for interview guide details). Family/friend caregivers who were present at the time of the patient participant’s appointment, but opted to participate in the project were provided an alpha-numeric code for confidential identification and contacted by telephone to complete the interview.

Data Analysis

Hsieh and Shannon’s (2005) directed content analysis method was utilized for qualitative data analysis to explore and clarify if items currently found in the FACT-BMT questionnaire accurately captured reported QoL experiences and perceptions among adult allogeneic HCT outpatients, to determine if items currently found in the FACT-BMT questionnaire can be utilized as assess adult allogeneic HCT outpatient healthcare provider understanding of a patient’s perceived QoL, and to explore similarities and differences among adult allogeneic HCT outpatients and their care providers with regards to QoL perceptions and outcomes. Patient and care provider demographic data were analyzed manually and sample characteristics are reported using descriptive statistics. A table displaying the demographic descriptive statistics is found in Appendix F. All interviews were recorded and transcribed verbatim. Qualitative data analysis consisted of directed content analysis using open coding which entailed reading through participant responses and highlighting passages guided by the five predetermined categories. Data that could not be coded as one of the five predetermined categories were set aside and later analyzed to determine if they represented a new category or a subcategory of an existing code (Hsieh & Shannon, 2005). Each of the five predetermined categories found in the FACT-BMT are described and supplemented with specific examples of direct participant quotes.
in Table F4. A qualitative expert performed a second review of the data analysis process and findings.

**Results**

To explore QoL perception among adult allogeneic HCT outpatients and their care providers, the following five predetermined categories found in the FACT-BMT were explored individually with triads: a) physical well-being; b) social/family well-being; c) emotional well-being; d) functional well-being; and e) additional concerns were explored individually with triads (see Appendix G). This project was comprised of 15 triads. A triad was made up of a patient participant, their care provider, and their healthcare professional or clinician. Patient participants were primarily those aged 61 to 75 years (46.7%) and most often between one and five years post-transplant (73.3%). Patient participants were primarily male (89%) and had undergone an unrelated donor HSCT (66.7%). Care provider participants were predominantly aged between the years 61 to 75. Care providers were primarily female (89%) and were most often identified as a spouse or significant other of the patient participant. Healthcare professional participants (clinicians) were all female (N=7). Furthermore, 51.1% of the healthcare professionals (clinicians) participating in the project were found to be half the age of their patients with ages ranging between 18 to 30 years and an average age of 24 years. It was additionally noted that 42.9% of the healthcare providers (clinicians) participating in this project were aged between 31 to 45 with an average age of 38 years [see appendix G for participant demographic details]. This finding indicated that 94% of the participating clinician providers were younger than the patient participating in the project.

Overall perceptions, as recounted by patients, their family or friend care provider, and their healthcare professional regarding QoL were consistent with minor variances in perception
and articulation as expected with differing perspectives and changes over time. In the category of physical well-being, weakness and limiting fatigue were themes primarily identified by all three participant categories. The category of social/emotional well-being was dominated with overall feelings of support. Emotional well-being was most often reported as frustration throughout all participant categories. In the category of functional well-being, physical limitations and reduced overall QoL were qualified with the resounding feeling of being grateful to be alive. Exploration of additional concerns revealed concerns regarding relapse, late effects of treatment, and an overall desire to return to a previous state of health and sense of normalcy.

**Patient Perceptions**

In addition to weakness and limiting fatigue, common themes in the physical well-being category shared by patients who participated in this project included feeling tired, incapable, and completely different. One patient explained, “If you were looking at me, everything from the hair on my head to the bottoms of my toes, it’s changed everything”. Overall, patient participants reported good support. One participant stated, “All my friends and family are very close. Keeping me going in terms of calling, checking up on me, showing me that they are still there”. Despite feelings of overall support, there is reason for additional management regarding social and family well-being. Across the project, every patient participant reported having no sex life, either related to emotional factors, fatigue, or physical limitations or restrictions affecting their ability to participate in sexual activity. Emotionally, patient participants reported that despite their feelings of frustration surrounding restrictions and uncontrolled symptoms, they were accepting and adapting to their new normal. As stated by one patient participant, “I’m just trying to resume a normal life. I just finally came to the realization that there are some things I can’t do, so I’ll do what I can”. Common ways of coping reported by patient
participants include repression and distraction. In general, patient participants had an underlying feeling of being a burden, affecting their emotional well-being. Functionally, patient participants reported sleeping well, but being bothered by the inability to work and wishing their QoL was improved. Regardless, the overall theme remained feeling grateful to be alive. As stated by one patient participant, “Well it’s never good, but even though it’s ugly, I should be glad that I’m alive”. Additional concerns shared by patient participants were numerous. Primarily financial concerns, lack of symptom resolution, and continued restrictions was troublesome to patient participants. “You have a new normal. I thought I’d have the leukemia and that transplant and I’ll go back to being normal. But nobody goes back to normal”. Physical and emotional factors related to treatment such as cognitive impairment, being emotionally blunted, and an overall feeling of lost identity warrant further work to improve patient perceptions of QoL. Despite these additional concerns, patient participants reported overall improved family relationships.

**Care Provider Perceptions**

Care providers from all triads described patients as being frustrated and completely affected regarding their physical well-being. One care provider commented, “Physically he can’t do a lot of things because he’s weak, he’s tired, and it’s really affecting him… He has to rely on somebody and he hates that”. While patient participants all reported feeling very supported, caregiver participants reported decreased support over time. Once care provider stated, “They feel like he should be better by now. They are just tired of it”. The overwhelming themes of frustration and lack of normalcy presented again regarding emotional well-being described by care provider participants. As voiced by one care provider, “There’s frustration that we can’t put a roadmap on this… Frustration of not knowing what to expect or when to
expect a return to normalcy”. Similar to patient participants who reported detachment as a form of coping, care provider participants acknowledged this detachment and distraction as coping mechanisms as well. Despite these coping mechanisms, care provider participants reported patients being upbeat, and coping well overall using additional tactics such as faith and humor. Functionally, according to the care provider participants, QoL remains a concern. Themes supporting physical limitations, while improving over time, were reported as hindering patient satisfaction with QoL. One participant maintained, “I don’t think he’ll ever be satisfied with the current quality of life because he’s lost so much of the things he used to be able to do”. Similar to patient perceptions of QoL, care provider participants described additional patient concerns as encompassing financial concerns, duration of symptoms, and overall loss of self. One caregiver participant stated, “He thought he was going to have the transplant, maybe if he’s lucky get a little GVH, not too much, then after that he’d go back to being fit as a fiddle if he did everything they said, and the case is, you’re never going to be”.

Healthcare Professional (Clinician) Perceptions

All healthcare professional participants opted to complete a written questionnaire as opposed to participating in a recorded interview. Their statements are somewhat abbreviated as an effect of the written response variation in data collection. However, written responses were found to be congruent with patient and caregiver participant responses. In addition to limiting fatigue, healthcare professional participants recognized change in appearance and continuation of symptoms as key physical factors influencing patient perceptions of QoL. One healthcare professional participated stated, “Fatigue which affected his ability to work. Appearance (aged skin) has affected him and his emotional state”. Most often, sexual concerns were not addressed by the healthcare provider, and when noted, were described as negative sexual affects related to
either physical or emotional factors. With regard to the social and family category, the “patient feels supported” was a common theme reported by healthcare professional participants. Emotionally, healthcare professional participants felt that patients were coping well. One healthcare professional stated, “Coping well, but frustrated the he can’t do everything”. Despite feelings of depression and/or anxiety associated with chronic illness and treatment experiences, healthcare professionals noted an overall perception that their patients are happy to be alive. Regarding functional well-being, healthcare professional participants recognized patients’ difficulties with keeping up, limitations and restrictions, and inability to work or participate in many activities that they were previously able to do. However, most healthcare professional participants noted patients’ ability to enjoy some activities and their joy in doing so. As stated by a healthcare professional participant, “Given severity of illness and chronic GVHD, he has less satisfaction with quality of life, but also grateful for the quality of life he has”. Additional concerns perceived by healthcare professional participants included financial concerns, patient feeling of being a burden, frustration, and the related impact on family relationships. Overall healthcare professional participants shared the perception that cGVHD has long term physical effects that hinder the ability to lead a normal life. As stated by one of the healthcare provider participants, “Chronic GVHD and its impact on his relationships and ability to lead a normal life”.

Discussion

Gaps in current literature include the effective implementation of PROs in treatment of HCT patients. There is little evidence that patient and care provider QoL perceptions are routinely assessed despite the 2005 National Institutes of Health (NIH) Chronic Graft-Versus-Host Disease Consensus Response Criteria Working Group’s recommendations. Several
measures to document serial evaluations of cGVHD organ involvement were recommended. The Working Group identified two broad categories of tools for use in the assessment of response. Categories include (1) the “cGVHD-specific” core measures that directly measure organ-specific manifestations of cGVHD, and (2) the “nonspecific” ancillary measures that could reflect overall impact of cGVHD, treatment, comorbidity, or other illness or function related QoL (Lee et al., 2015). Nonspecific measures of function and PROs related to functional status and health-related quality of life (HRQoL) could potentially offer additive objective and subjective data regarding the effects of cGVHD and its therapy (Lee et al., 2015). The effects of cGVHD and its treatment on general physical and emotional HRQoL are other endpoints that may be responsive to change as a result of cGVHD therapy. Lee et al. (2015) noted, that because evidence of sensitivity to change is lacking, instruments are only “strongly encouraged.” Increasing attention is being paid to the importance of implementing PROs in the management of individualized care. Chronic GVHD results in many long term implications affecting HRQoL for patients who have received and allogeneic HCT. Current literature reports the need to evaluate PROs, and describes related benefits to guiding treatment decisions. Unfortunately, this is not a widely described practice in the management of HCT patients today.

Care providers need to be aware of differing patient perceptions in order to facilitate changes in interventions to improve overall QoL. This project correlates with current literature, which describes variations in QoL perceptions between HCT recipients with cGVHD and their caregivers, supporting the need for integration of PROs into HCT clinical practice. While overall themes falling within each of the five categories were similar across participant groups, perception variations were evident between patients, caregivers, and healthcare professionals. Caregiver perceptions of physical well-being were not inclusive of all physical symptoms
affecting patients and symptoms acknowledged were not felt to be as severe as perceived by patient participants and their caregivers. While social support was recognized across the board, sexual function was under-assessed by healthcare professional participants and was not addressed when it was identified. Regarding emotional and functional well-being, clinicians focused solely on coping abilities of HCT recipients and their satisfaction with still being alive. Patient and caregiver participants were primarily focused on the lack of return to normalcy and inability to resume activities previously enjoyed. This disparity indicates the need for more in-depth exploration of emotional and functional well-being by healthcare providers in order to improve QoL perceptions.

These project findings are supported by the revised Wilson and Cleary model, showing that individual characteristics and environmental characteristics influence biological function, symptoms, functional status, and general health perceptions, leading to perceptions of overall QoL. The revised Wilson and Cleary model was a counterpart framework for this project as a graphic depiction of the significant components for assessing QoL perceptions. Key categories of the revised Wilson and Cleary model transposed with these project findings can be used to create a converted model describing individual and environmental characteristics and QoL perceptions in allogeneic HCT recipients (see Appendix H for details).

**Financial Hardship**

Similar to literature review findings, financial hardship was found to be a factor associated with worse QoL. Project participants reported feeling like a burden related to being dependent on family for financial support. One participant revealed, “I’d like to go back to work and be useful, but I don’t know if I can physically.” Even for those participants who were retired and not experiencing financial hardship, financial concerns affecting QoL were reported.
One participant recalls, “What was our travel money turned into our medical. We’d like to be spending it elsewhere”. These project findings support current literature in describing finances as a factor influencing QoL perceptions.

**Physical Functioning and Symptom Distress**

In conjunction with literature review findings, increased symptom distress correlated to negative effects in all five categories. As identified in the current literature, these project findings also support the relationship between poorer health and QoL outcomes associated with prolonged immunosuppressive therapy. Symptoms of fatigue and body changes cited in the literature coincide with these project findings as well as sexual dysfunction. However, these project findings identified emotional and cognitive concerns as factors influencing QoL perceptions.

**Role Functioning, Social Functioning, and Depression**

As shown in the literature review, these project findings support the evidence that HCT recipients are concerned about cancer returning or a new cancer developing. Also in correlation with literature findings, these project findings show poorer QoL perceptions are associated with hospitalization. Nearly all project participants identified symptom exacerbation and hospitalization as the two key components influencing their ability to cope and functional well-being. Depression and anxiety, however are not included on the FACT-BMT and were not directly addressed in this project. Future studies should incorporate depression and anxiety symptoms and their influence on QoL perceptions.

**Spiritual Growth and Resilience**

This project’s findings enhance the literature in regards to spiritual growth and resilience. Literature review findings allude to the importance of evaluation of social support and patient
resiliency as important factors associated with health and psychosocial outcomes. These project findings show that even with poor physical health, participants feel supported, which significantly impacted their QoL perceptions. Social/family support has a substantial impact on coping abilities and patient perceptions of QoL. When asked about QoL, one patient stated, “It means being happy with your situation, your health, and your family. I’ve got good family, but I’ve got lousy health. Sometimes I feel pretty useless, but it’s slowly getting better”.

Furthermore, hope for the future was a pivotal factor in patient QoL perceptions despite poor physical well-being and poor functional well-being. One participant stated, “Things are harder, but they are more rewarding when you do them”. Even with poor physical health, hope for a return to normalcy or return to some previously enjoyed activities improved participant QoL perceptions, even when it is just an idea rather than the reality they are living. One participant stated it clearly, “I have developed mindsets about maintaining strength, endurance, courage, tenacity, bouncing back, and resilience...It’s going to get better”.

**Assessment Measures**

Based on these project findings, a modified FACT-BMT should be created to incorporate disparities identified through in-depth, one-on-one, open ended interviews (see Appendix I for details). Each of the five categories should remain with modifications to the content and wording of questions included to more accurately reflect patient perceptions and to enhance provider understanding of factors influencing overall HRQoL in HCT recipients. Some of the existing questions in the additional concerns category can be removed completely as items that were not identified by patient participants involved in this project. A shorter questionnaire can address patient concerns evidenced by these project findings.
In a modified FACT-BMT, in the physical well-being category, using general terminology such as uncontrolled symptoms rather than identifying specific symptoms as depicted on the current FACT-BMT is recommended. Omitting or changing physical symptoms listed, such as nausea, pain, or feeling ill would improve the tool, allowing for more individualized and more frequently recognized PRO options. Based on these project findings, the most commonly reported uncontrolled symptoms included dry eyes, shortness of breath, diarrhea, weakness, skin problems, mouth sores, and joint pain. These items are not included on the current FACT-BMT and the existing tool could be enhanced by inclusion of these additional symptoms.

Social and family well-being assessment items are well-represented in the current FACT-BMT tool. The inclusion of satisfaction with sex life on the FACT-BMT is an important criterion, easily incorporated into ongoing clinical evaluation in this fashion. These project findings reveal that sexual satisfaction was rarely addressed by clinicians, even though it was found to negatively impact QoL ratings both from patient participant as well as caregiver participant perspectives. Incorporation of the FACT-BMT into ongoing clinical evaluation would ensure that this important patient concern is monitored and incorporated into ongoing treatment decisions.

When assessing emotional well-being, the FACT-BMT tool could be enhanced by adding frustration as a feeling to be evaluated. Feeling sad, satisfied with coping, losing hope, feeling nervous, worry about dying, and worry that the condition will get worse are the Likert-rated items on the current FACT-BMT tool. These project findings identified frustration as the most prevalent emotion when assessing emotional well-being. Based on these project findings, replacing feeling sad, with feeling frustrated on the FACT-BMT would reflect a more accurate
QoL rating. These project findings conclude that hope for the future is the primary factor maintaining patient resiliency and emotional well-being. Changing the Likert item on the current FACT-BMT to read, I have hope for a better future, would better capture HCT recipient mindsets regarding emotional well-being. I am losing hope in the fight against my illness, as currently written in the FACT-BMT is detrimental in itself to patient emotional well-being as stated and would not capture an accurate score in the emotional well-being category.

Additionally, worry about dying was not identified as a concern among any of the project participants. However, fear of relapse was a major concern identified among the majority of project participants. Modification of the current FACT-BMT to indicate worry about relapse in place of worry about dying would more accurately depict HCT patient concerns. Another minor but important distinction when evaluating PROs in the emotional well-being category could be addressed by substitution of the phrase, I worry that my condition will get worse, with I worry that my condition will not get better. While project participants noted an improvement in their condition over time, they were generally dissatisfied with symptom management and overall QoL and voiced concerns regarding fear that “this is as good as it gets”.

Although cited in the literature as key factors influencing role functioning and social functioning and identified by project participants as additional concerns, depression and anxiety symptoms are not included in the current FACT-BMT. Addition of these important elements should be added to the FACT-BMT in order to address all vital aspects of social, emotional, and functional well-being. These items could be included in the emotional well-being category by incorporating the word anxious in place of feeling nervous, and the addition of the statement, I feel depressed.
Functional well-being is well represented in the Likert items identified in the current FACT-BMT. Minor changes such as inclusion of taking care of the home in addition to being able to work would better represent patient participant reflections of functional status. A change in the final Likert item, I am content with the quality of my life right now should be changed to I am satisfied with my quality of life right now. Although this seems like an insignificant word difference, patient participants consistently identified their acceptance (contentment) of the QoL, without actually being satisfied (happy) with their functional status and its impact on their current QoL.

Additional concerns is a broad category, encompassing all remaining items that HCT recipients experiencing cGVHD reported experiencing. Based on these project findings, many of the existing FACT-BMT Likert items in the additional concerns category could be removed. Primary additional concerns captured in the open-ended one-one-one interviews conducted with patient participants include concerns about ever being able to work again and side effects of the treatment being worse than they thought they were going to be. This was stated by the majority of participants and reinforced the importance of future recommendations to improve patient and family education regarding expected implications of undergoing an allogeneic HCT. Additional main concerns for patient participants included lack of enjoying food, affecting their ability to gain weight as well as participation in social activities. Concerns of change in body appearance, ability to drive, unrelenting fatigue, and lack of interest in sex were predominant. Being a burden either by causing personal hardship or financial burden to family members were important additional concerns verbalized. Blurred vision as an additional concern is an important inclusion, but is best included in the physical well-being category.
Strengths and Limitations

Limitations of this project include being a single study, conducted at one comprehensive cancer center in the United States. Based on the demographics of participants, these findings may not be widely generalizable to the greater population. However, this study is generalizable to adult HCT recipients of all ages, across the country. This study was limited to Caucasian and Hispanic participants by availability only. Middle to upper class, educated, retired Caucasians dominated the sample characteristics. All participants did have a strong support system, as HCT recipients who did not have a caregiver who was willing to also participate in the project were excluded. Most of the patient participants were retired, so financial impact could have been altered compared to younger, working adults, or those with young children, undergoing HCT. Project results could have been impacted by length of time since HCT, support systems in place, financial stability, type of HCT, amount of cGVHD, and alternative treatment options available. These project findings indicate the importance of ongoing evaluation of PROs in HCT recipients throughout the treatment trajectory.

Using in-depth one on one interviews in a private setting allowed for a thorough investigation of patient and their caregivers’ QoL perceptions. It is unknown if utilization of a self-reported Likert-scale tool would elicit clear QoL perceptions, limiting the validity of these project findings to similar interview techniques. Specific strategies are needed to develop a clear procedure for implementing a QoL assessment tool into routine care of HCT patients. Future studies should aid in the development of a standard QoL assessment tool.

Future Recommendations

Future lines of research should assess patient and physician agreement on QoL throughout the HCT process, when late effects of cGVHD worsen survivors’ satisfaction with
life (Barata et al., 2017). Utilization of patient-reported questionnaires to evaluate ongoing GVHD symptoms and QoL ratings would help ensure that clinicians caring for HCT recipients are aware of patient perceptions of symptom management and QoL ratings, influencing treatment decisions. A modified FACT-BMT would be beneficial in ongoing evaluation. Future studies should assess the reliability and validity of a modified FACT-BMT.

Enhanced patient and family education regarding the physical, social, emotional, and functional implications of undergoing HCT are imperative to complete disclosure to guide patient decisions. An overwhelming number of patient and caregiver participants reported not knowing the consequences of undergoing HCT. Additional research is needed to evaluate the efficacy of utilization of PROs for ongoing symptom and QoL evaluation to improve outcomes. Perhaps most importantly, additional research is needed to enhance treatment options. While HCT remains effective at prolonging patient survival, improvement is needed on QoL outcomes. Identification of improved treatment options that allow for adequate QoL ratings is imperative to improving patient and caregiver satisfaction. Additional research is needed to evaluate the QoL perceptions of HCT patients compared to the perceptions of their care providers (family/friend/paid caregiver and clinician caregiver).

**Contributions to Practice**

Future implications for advanced nursing practice include the utilization of screening tools, or simply asking the question, “how satisfied are you with your current quality of life?” for long-term follow-up and routine practice in caring for HCT patients. As depicted by the revised Wilson and Cleary model for HRQoL, each of the vital components for assessing perceptions of QoL are addressed using the FACT-BMT. This project data supports the NIH Chronic Graft-versus-Host Disease Consensus Response Criteria Working Group’s
recommendation to document serial evaluations of cGVHD specific and nonspecific manifestations. These PROs related to HRQoL offer additive objective and subjective data regarding the effects of cGVHD and its therapy. Patient reported QoL should be assessed using the FACT-BMT as a part of ongoing evaluation and clinical care in HCT recipients.
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Appendix A

Revised Wilson and Cleary Model

Figure A. Revised Wilson and Cleary Model for Health-Related Quality of Life. Adapted from “Conceptual model of Health-Related quality of life,” by C. E. Ferrans, J. J. Zerwic, J. E. Wilbur, and J. L. Larson. Copyright by JAMA. Used with permission.
Appendix B

Demographic Form

Donor Identification
- Haplo
- Sibling
- Unrelated
- Not applicable

Date of Transplant
- 100 days - 6 months ago
- 7 – 12 months ago
- 1 - 5 years ago
- 5 years ago
- Not applicable

Age
- 18 – 30 years
- 31 – 45 years
- 46 – 60 years
- 61 – 75 years
- 76 – 90 years

Gender
- Male
- Female
- Other: ________________________________

Relationship to patient
- Self (I am the patient)
- Healthcare professional (MD, PA, NP, RN)
- Spouse or Significant Other (please circle)
- Sibling
- Friend
- Other: ________________________________
Appendix C

Informational Flyer

Quality of Life Perception Variations in Allogeneic Hematopoietic Cell Transplant Recipients with Chronic Graft versus Host Disease and their Care Providers

PI: Jennifer Buyea, RN, MSN; Co-Investigator: Pamela Paplham, DNP, AOCNP, FNP-BC, FAANP

Project Aim: To evaluate and describe variations in quality of life (QoL) perceptions between hematopoietic cell transplant (HCT) recipients with chronic graft versus host disease (cGVHD) and their caregivers.

Capstone Question: In Roswell Park Comprehensive Cancer Center’s adult Outpatient HCT clinic patients diagnosed with cGVHD, how do QoL perceptions relayed by patients through open-ended question and answer interviews, compare to patient QoL perceptions described by their care providers (caregiver, nurse, APP) to influence quality of life ratings?

Methods: In this qualitative study design, using an open-ended interview technique, both patients and their care providers are offered the opportunity to communicate their individual and unique perspectives regarding HCT patient QoL. Eight open-ended interview questions, designed using clinical expertise and derived from the Functional Assessment for Cancer Therapy – Blood and Marrow Transplant (FACT-BMT), a validated tool used to assess QoL in HCT recipients will be used. Similar content was formulated into open-ended questions to elicit the “lived experience” to gain an enriched understanding of QOL perceptions. Interview questions will be used to explore perceptions of QoL in the areas of a) physical well-being, b) social/family well-being, c) emotional well-being, and d) additional concerns. The same questions will be used to prompt perceptions from both the patient and their care providers. Interviews will be recorded and then transcribed for analysis.

Screening is achieved through a targeted recruitment process where the people who are invited to participate are present at the Outpatient Blood and Marrow Transplant Clinic at Roswell Park Comprehensive Cancer Center. The physician or advanced practice provider (APP) will refer patients who are interested and meet the eligibility criteria listed below.

Inclusion Criteria:
- ≥ 18 years of age who has undergone an allogeneic HCT
- Diagnosis of chronic Graft Versus Host Disease
- Outpatient at Roswell Park
- Scheduled for an outpatient appointment with the Blood and Marrow Transplant Clinic
- Ability to read/speak English Language
- Have a clinician and family/friend caregiver who is also willing to participate in the project

Exclusion Criteria:
- Patient < 18 years of age and or patients under the care of the pediatric HCT service
- Patients without a diagnosis of chronic Graft Versus Host Disease

All participants will receive a $5 Spot Coffee gift card!
### Appendix D

**Patient Semi-Structured Interview Guide**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Patient Interview Question</th>
<th>Probing Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical Well-Being</strong></td>
<td>Describe some of the side effects of your treatment or other physical symptoms you have and how they affect your ability to function the way you'd like to.</td>
<td>Tell me about your medications and how they change the way you feel.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>How is your physical activity or participation in activities that you used to enjoy different than it used to be?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tell me anything else that you think we should know about your physical well-being that I didn’t ask about.</td>
</tr>
<tr>
<td><strong>Social/Family Well-Being</strong></td>
<td>Tell me about the feelings of acceptance and emotional support you feel you are receiving from your partner, friends, and/or family.</td>
<td>How well does your partner, friends or family support you through your illness?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are there some additional ways they could support you that they may not know, or have trouble doing?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>How comfortable are you telling your partner, friends or family if you don’t like something they are doing, or if you need something more or different from them?</td>
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<tr>
<td></td>
<td></td>
<td>How have physical changes in your body affected your current sex life?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tell me how your relationship with your sex partner has changed because of your illness.</td>
</tr>
<tr>
<td><strong>Emotional Well-Being</strong></td>
<td>How would you describe the feeling you have most often regarding your illness?</td>
<td>Sometimes people think they are expected to act or feel a certain way when they are ill. Tell me about a time when you tried to act or feel a different way because you thought you were supposed to.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What kinds of things do you do to cope with your illness?</td>
</tr>
<tr>
<td></td>
<td>How well do you feel you are coping with your illness and what factors influence your ability to cope?</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>What kinds of things make coping more difficult?</td>
</tr>
</tbody>
</table>
Tell me anything else that you think we should know about your emotional well-being that I didn’t ask about.

<table>
<thead>
<tr>
<th>Functional Well-Being</th>
<th>Tell me about the work you are doing now.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Describe your current level of functioning regarding your ability to work, sleep, and enjoy life.</td>
<td>Tell me about your sleeping habits.</td>
</tr>
<tr>
<td>Quality of life means something different to everyone. Tell me what it means to you and how satisfied you are with your current quality of life.</td>
<td>Tell me about the things that bring you joy in your life right now?</td>
</tr>
<tr>
<td>Tell me anything else that you think we should know about your social/family well-being that I didn’t ask about.</td>
<td>What kinds of things make quality of life better?</td>
</tr>
<tr>
<td></td>
<td>What kinds of things make quality of life worse?</td>
</tr>
<tr>
<td></td>
<td>Tell me about your satisfaction with your quality of life right now.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Additional Concerns</th>
<th>What concerns you about your physical health?</th>
</tr>
</thead>
<tbody>
<tr>
<td>As you know, many things change after you have a bone marrow transplant.</td>
<td>What concerns you about how your illness has affected your mental or emotional health?</td>
</tr>
<tr>
<td>What are some of the additional concerns you have regarding your physical, mental, or emotional state; future implications; financial concerns; or family relationships?</td>
<td>What are your concerns about the future related to your illness?</td>
</tr>
<tr>
<td></td>
<td>Tell me about your financial concerns related to your illness.</td>
</tr>
<tr>
<td></td>
<td>What concerns you about how your illness has affected your family relationships?</td>
</tr>
<tr>
<td></td>
<td>Tell me anything else that you think we should know about your quality of life that I didn’t ask about.</td>
</tr>
</tbody>
</table>


### Appendix E

**Care Provider Semi-Structured Interview Guide**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Care Provider Interview Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical well-being</td>
<td>• Describe some of (patient name's) side effects of his/her treatment or other physical symptoms he/she has and how they affect his/her ability to function the way he/she would like to.</td>
</tr>
<tr>
<td>Social/Family well-being</td>
<td>• Tell me about the feelings of acceptance and emotional support you feel (patient name) is receiving from (you or their partner, friends, and/or family).</td>
</tr>
<tr>
<td></td>
<td>• What are some factors that are impacting (patient name’s) current sex life?</td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>• How would you describe the feeling (patient name) has most often regarding his/her illness?</td>
</tr>
<tr>
<td></td>
<td>• How well do you feel (patient name) is coping with his/her illness and what factors influence his/her ability to cope?</td>
</tr>
<tr>
<td>Functional well-being</td>
<td>• Describe (patient name’s) current level of functioning regarding his/her ability to work, sleep, and enjoy life.</td>
</tr>
<tr>
<td></td>
<td>• Quality of life means something different to everyone. Tell me what it means to (patient name) and how satisfied he/she with his/her current quality of life.</td>
</tr>
<tr>
<td>Additional concerns</td>
<td>• As you know, many things change after having a bone marrow transplant. What are some of the additional concerns (patient name) has regarding his/her physical, mental, or emotional state; future implications; financial concerns; or family relationships?</td>
</tr>
</tbody>
</table>
## Appendix F

### Participant Demographics

<table>
<thead>
<tr>
<th></th>
<th>Patient Participant n (%)</th>
<th>Caregiver Participant n (%)</th>
<th>Healthcare Professional Participant n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Donor identification</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>5 (33.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unrelated</td>
<td>10 (66.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Date of transplant</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7-12 months ago</td>
<td>2 (13.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5 years ago</td>
<td>11 (73.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;5 years ago</td>
<td>2 (13.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-30 years</td>
<td>3 (20)</td>
<td>0 (0)</td>
<td>4 (57.1)</td>
</tr>
<tr>
<td>31-45 years</td>
<td>3 (20)</td>
<td>2 (13.3)</td>
<td>3 (42.9)</td>
</tr>
<tr>
<td>46-60 years</td>
<td>2 (13.3)</td>
<td>6 (40)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>61-75 years</td>
<td>7 (46.7)</td>
<td>7 (46.7)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>12 (80)</td>
<td>3 (20)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Female</td>
<td>3 (20)</td>
<td>12 (80)</td>
<td>7 (100)</td>
</tr>
<tr>
<td><strong>Relationship to patient</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self</td>
<td>15 (100)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Healthcare professional</td>
<td></td>
<td></td>
<td>7 (100)</td>
</tr>
<tr>
<td>Spouse/Significant Other</td>
<td></td>
<td>11 (73.3)</td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>1 (6.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>3 (20)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G

Content Analysis Findings

<table>
<thead>
<tr>
<th>Category</th>
<th>Key Themes within Category</th>
<th>Supporting Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Perceptions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical well-being</td>
<td>Tired</td>
<td>“If you were looking at me, everything from the hair on my head to the bottoms of my toes, it’s changed everything.”</td>
</tr>
<tr>
<td></td>
<td>Incapable</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Completely different</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Weak</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Limited</td>
<td></td>
</tr>
<tr>
<td>Social/Family well-being</td>
<td>Tremendous support</td>
<td>“All my friends and family are very close. Keeping me going in terms of calling, checking up on me, showing that they are still there.”</td>
</tr>
<tr>
<td></td>
<td>No sex-drive</td>
<td></td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>Repression</td>
<td>“I’m just trying to resume a normal life. I just finally came to the realization that there are some things I can’t do, so I’ll do what I can.”</td>
</tr>
<tr>
<td></td>
<td>Burdensome</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Acceptance</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Distraction</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Adapting</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Restrictions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Symptoms</td>
<td></td>
</tr>
<tr>
<td>Functional well-being</td>
<td>Inability to work</td>
<td>“Well it’s never good, but even though it’s ugly, I should be glad that I’m alive.”</td>
</tr>
<tr>
<td></td>
<td>Sleeping well</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wishing QoL was better</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Grateful to be alive</td>
<td></td>
</tr>
<tr>
<td>Additional concerns</td>
<td>Relapse</td>
<td>“You have a new normal. I thought I’d have the leukemia and that transplant and I’ll go back to being normal. But nobody goes back to normal.”</td>
</tr>
<tr>
<td></td>
<td>Cognitive Impairment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Financial concerns</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of symptom resolution</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Symptom duration</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Improved family relationships</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emotionally blunted</td>
<td>“I don’t want to talk to anybody. I used to be the guy you called when you needed help with anything. Now I’m always the person that needs help.”</td>
</tr>
<tr>
<td></td>
<td>Burden on family</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Restrictions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lost identity</td>
<td></td>
</tr>
<tr>
<td>Caregiver Perceptions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical well-being</td>
<td>Frustrated</td>
<td>“Physically he can’t do a lot of things because he’s weak, he’s tired, and it’s really affecting him...He has to rely on somebody and he hates that.”</td>
</tr>
<tr>
<td></td>
<td>Weak</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Completely affected</td>
<td></td>
</tr>
<tr>
<td>Social/Family well-being</td>
<td>Very supportive</td>
<td>“They feel like he should be better by now. They are just tired of it.”</td>
</tr>
<tr>
<td></td>
<td>Decreased support over time</td>
<td></td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>No sexual relationship</td>
<td>“There’s frustration that we can’t put a roadmap on this...Frustration of not knowing what to expect or when to expect a return to normalcy.”</td>
</tr>
<tr>
<td>------------------------------</td>
<td>-----------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Upbeat</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Frustrated</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Coping well</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Faith</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Humor</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Distraction</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Detachment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Support/Acceptance</td>
<td></td>
</tr>
<tr>
<td>Functional well-being</td>
<td>Limited</td>
<td>“I don’t think he’ll ever be satisfied with the current quality of life because he’s lost so much of the things he used to be able to do.”</td>
</tr>
<tr>
<td></td>
<td>Unsatisfied with QoL</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Improved over time</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Grateful</td>
<td></td>
</tr>
<tr>
<td>Additional concerns</td>
<td>Relapse</td>
<td>“He thought he was going to have his transplant, maybe if he’s lucky get a little GVH, not too much, then after that he’d go back to being fit as a fiddle if he did everything they said, and this is the case, you’re never going to be.”</td>
</tr>
<tr>
<td></td>
<td>Wishing for how it was</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Loss of self</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Financial concerns</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Duration of symptoms</td>
<td></td>
</tr>
<tr>
<td>Healthcare Professional Perceptions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical well-being</td>
<td>Limited</td>
<td>“Fatigue which affected his ability to work. Appearance (aged, skin) has affected him and his emotional state.”</td>
</tr>
<tr>
<td></td>
<td>Fatigue</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Change in appearance</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Continued symptoms</td>
<td></td>
</tr>
<tr>
<td>Social/Family well-being</td>
<td>Feels supported</td>
<td>“Patient feels supported”</td>
</tr>
<tr>
<td></td>
<td>Sexuality not covered</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Negative sexual effects</td>
<td></td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>Frustrated</td>
<td>“Coping well, but frustrated that he can’t do everything.”</td>
</tr>
<tr>
<td></td>
<td>Copes well</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Happy to be alive</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Depressed/Anxious</td>
<td></td>
</tr>
<tr>
<td>Functional well-being</td>
<td>Having trouble keeping up</td>
<td>“Given severity of illness and chronic GVHD, he has less satisfaction with quality of life, but also grateful for the quality of life he has.”</td>
</tr>
<tr>
<td></td>
<td>Enjoys some activities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Limited by fatigue</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Can’t do a lot he did before</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unable to work</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Restricted</td>
<td></td>
</tr>
<tr>
<td>Additional concerns</td>
<td>Financial concerns</td>
<td>“Chronic GVHD and its impact on his relationships and ability to lead a normal life.”</td>
</tr>
<tr>
<td></td>
<td>Being a burden</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Frustrated</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Impact on relationships</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Inability to lead a normal life</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Long term physical effects</td>
<td></td>
</tr>
</tbody>
</table>
Appendix H

Revised Wilson and Cleary Model for Health-Related Quality of Life

Figure H. Application of project findings to the Revised Wilson and Cleary Model for Health-Related Quality of Life. Adapted from “Conceptual model of Health-Related Quality of Life,” by C. E. Ferrans, J. J. Zerwic, J. E. Wilbur, and J. L. Larson. Copyright by JAMA. Used with permission.
Appendix I

Modified FACT-BMT

Below is a list of statements that other people with chronic graft versus host disease have said are important. Please circle the number that indicates your response as it applies to how you have felt over the last 7 days.

<table>
<thead>
<tr>
<th>PHYSICAL WELL-BEING</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a lack of energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have diarrhea</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Because if my physical condition, I have trouble meeting the needs of my home and family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am bothered by the side effects of my treatment</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am forced to spend time in bed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have unresolved symptoms</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have dry eyes</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have blurred vision</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have shortness of breath</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have weakness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have skin problems</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have mouth sores</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have joint pain</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SOCIAL/FAMILY WELL-BEING</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel close to my friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I get emotional support from my family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I get support from my friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My family has accepted my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am satisfied with family communication about my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel close to my caregiver</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am satisfied with my sex life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EMOTIONAL WELL-BEING</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel frustrated</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am satisfied with how I am coping with my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have hope for a better future</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel anxious</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel depressed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>A little bit</td>
<td>Somewhat</td>
<td>Quite a bit</td>
<td>Very much</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>------------</td>
<td>--------------</td>
<td>----------</td>
<td>-------------</td>
<td>-----------</td>
</tr>
<tr>
<td>I worry that my condition will not get better</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I worry about relapse</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>FUNCTIONAL WELL-BEING</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am able to work and take care of my home</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My work is fulfilling</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am able to enjoy life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have accepted my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am sleeping well</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am enjoying the things I usually do for fun</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am <strong>satisfied</strong> with my quality of life right now</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>ADDITIONAL CONCERNS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am concerned about ever being able to work again</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel distant from other people</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>The side effects of treatment are worse than I thought they were going to be</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I enjoy food</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I like the appearance of my body</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am able to drive</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I get tired easily</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am interested in sex</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have concerns about my ability to have children</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I would still have had the transplant if I knew it would be like this</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I can think the way I used to</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My eyesight is blurry</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I worry that my illness is a hardship for my family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>The cost of my treatment is a burden</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Revised Wilson and Cleary model for health-related quality of life.

Ferrans, Carol J <cferrans@uic.edu>
To: Jennifer Buyea <jkbuye@buffalo.edu>

Fri, Jun 22, 2018 at 11:00 AM

Dear Ms. Buyea,

Thank you for your email and interest in our work. I am pleased to grant you permission to use our model for your DNP Capstone, as well as your publication of your capstone work. There is no charge for this permission.

I wish you every success with your Capstone project.

Best regards,

Carol Estwing Ferrans, PhD, RN, FAAN
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October 29, 2018

Dear Jennifer BUYEA:

On 10/29/2018, the IRB reviewed the following submission:

<table>
<thead>
<tr>
<th>Type of Review:</th>
<th>Initial Study</th>
</tr>
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<tbody>
<tr>
<td>Title of Study:</td>
<td>Quality of Life Perception Variations in Allogeneic Hematopoietic Cell Transplant Recipients with Chronic Graft versus Host Disease and their Care Providers</td>
</tr>
<tr>
<td>Investigator:</td>
<td>Jennifer BUYEA</td>
</tr>
<tr>
<td>IRB ID:</td>
<td>STUDY00002650</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>
<tr>
<td>Documents Reviewed:</td>
<td>• HRP-502-Buya Consent Document_IRB_provider.pdf, Category: Consent Form;</td>
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<td>• HRP-502-Buya Telephone Consent Document_IRB__caregiver.pdf, Category: Consent Form;</td>
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<td>• Patient Interview Guide_IRB.docx, Category: Surveys/Questionnaires;</td>
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<td>• Family or Friend and Healthcare Professional Care Provider Interview Guide_IRB.docx, Category: Surveys/Questionnaires;</td>
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<td>• Letter of Support, Category: Site Permission Letter;</td>
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<td>• Demographic Form_IRB.docx, Category: Surveys/Questionnaires;</td>
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<tr>
<td></td>
<td>• Informational Flyer_IRB.pdf, Category: Recruitment Materials;</td>
</tr>
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</table>

The IRB approved the study from 10/29/2018 to 10/28/2019 inclusive. Before 10/28/2019 or within 30 days of study closure, whichever is earlier, you are to submit a continuing review with required explanations. You can submit a continuing review by navigating to the active study and clicking Create Modification / CR.
If continuing review approval is not granted before the expiration date of 10/28/2019, approval of this study expires on that date. The Initial Study materials for the project referenced above were reviewed and approved by the SUNY University at Buffalo IRB (UBIRB) by Initial Study Review. Before to 10/28/2019 inclusive. Before 10/28/2019 or within 30 days of study closure, whichever is earlier, you are to submit a continuing review with required explanations. You can submit a continuing review by navigating to the active study and clicking Create Modification / CR.

If continuing review approval is not granted before the expiration date of 10/28/2019, approval of this study expires on that date 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 clicking Create Modification / Continuing Review. 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.

UB IRB approval is given with the understanding that the most recently approved procedures will be followed and the most recently approved consenting 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.

Prior to the expiration of this approval, you will receive notification that it is time for the UBIRB to conduct its periodic review of your study. Studies cannot be conducted beyond expiration date without re-approval by the UBIRB.

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 Reportable New Information Form Smart Form.
   - Project closure/completion by the Continuing Review/Modification/ Study Closure smart form.
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.
QUALITY OF LIFE PERCEPTION VARIATIONS IN ALLOGENIC HEMATOPOIETIC CELL TRANSPLANT RECIPIENTS WITH CHRONIC GRAFT VERSUS HOST DISEASE AND THEIR CARE PROVIDERS
Jennifer Kaye Buyea, RN, MSN, DNP-S

PURPOSE
Justify the need for and importance of implementing routine assessment and evaluation of QoL among adult allogeneic HCT outpatients in a Comprehensive Cancer Center Clinic setting.

Project Objectives
• Clarify variations in quality of life (QoL) perceptions among adult allogeneic hematopoietic stem cell transplant (HCT) outpatients and their caregivers
• Better understand and enhance approaches to care based on patient reported outcomes (PROMs)
• Discuss recommendations for the utilization of patient-reported questionnaire that evaluate symptoms of chronic graft-versus-host disease (cGVHD) and QoL, ratings

Study Question
Among adult allogeneic HCT outpatients age 18 and older diagnosed with cGVHD in a comprehensive cancer center, how does the perception of patient QoL needs compared to their care provider (family or friend) and overall perception of QoL, needs and obstacles change?
BACKGROUND AND SIGNIFICANCE

Chronic graft-versus-host disease (cGVHD)

Chronic Graft Versus Host Disease (cGVHD)

- Common complication of allogeneic HCT, affecting an estimated 30% to 75% of patients (Jagadeeswaran et al., 2010)
- Comprised of multiple clinical features similar to other autoimmune and immunologic disorders
- Varies in severity
- Clinical signs usually present within the first year after transplantation, but may develop many years after HCT
- May be limited to a single organ or site or may be widespread

LITERATURE REVIEW

Systematic Literature Review
Themes
Importance of PROs
Systematic Literature Review

- Databases:
  - PubMed
  - CHIHL
  - ERIC
  - Google Scholar

- Key words:
  - Hemorrhoidectomy
  - Transplant
  - Allergens
  - Health-related quality of life
  - Healthcare provider
  - Patient-reported outcomes
  - Chronic Graft Versus Host Disease

Themes


Themes

- Spiritual growth (Lyons, Myra, Perkins, O’Farrell, & Wingard, 2016)
- Resilience (Rosenberg et al., 2016)
- Multi-item measures to assess PROs (Chow et al., 2015)

Patient Reported Outcomes (PROs)

- Three primary reasons for assessing QoL in HCT populations
  - Use of the information to inform complex treatment decisions
  - Identify rehabilitation needs
  - Predict late treatment outcomes (McGhee et al., 2007)
- No standard for routine assessment and evaluation of PROs currently exists
- Well-accepted practice
- Associated with better detection and monitoring of unmet patient needs, emotional support, and daily activities (Barata et al., 2017)
Patient Reported Outcomes (PROs)

- Introduction of PROs in clinical HCT settings could help overcome QoL patient-physician misconceptions and barriers
- Functional Assessment of Cancer Therapy – Bone Marrow Transplant (FACT-BMT) Scale has been utilized to assess and evaluate QoL among patients undergoing bone marrow transplant
- Effective way to determine patient QoL status when implemented as routine practice in outpatient HCT clinics (Banada et al., 2017)
- Care providers need to be aware of differing patient perceptions in order to facilitate change in communication and interventions to improve overall QoL.

CONCEPTUAL FRAMEWORK

Revised Wilson and Cleary model for Health-Related Quality of Life (HRQoL)

Health-Related Quality of Life (HRQoL)

- Physical well-being
  - Experienced sensations that are cognitively processed with the background of previous similar experiences and with information from the environment
- Cognitive representation of the symptoms
  - Includes thoughts about the probable identity, cause, consequences, progression, and cure (Ferrans, Zerweck, Wilbur & Lach, 1985)
- Social environmental characteristics
  - Interpersonal or social influences on health outcomes

Health-Related Quality of Life (HRQoL)

- A term developed with the purpose to narrow the focus of life satisfaction to the effects of health, illness, and treatment on QoL, excluding aspects that are not related to health, such as cultural, political, or societal attributes (Ferrans et al., 2005)
- Perceptions of well-being are dependent on the person's perception, as well as external standards
- Because of differences in values, an impairment that makes life not worth living for one person might be considered only an inconvenience for another (Ferrans et al., 2005)
QUALITY OF LIFE PERCEPTION VARIATIONS

**Conceptional Framework**

Analyzing Wilson and Lopro's Model for Health-Related Quality of Life. Adapted from "Conceptional models" in Health-Related Quality of Life, edited by C. S. Ferrans, J. J. Zeevi, J. E. Wilcox, and J. L. Linnen. Copyright by ARHA, used with permission.

**METHODOLOGY**

- **Project Design**
  - Ethical and Human Subject Considerations
  - Recruitment Strategy
  - Data Collection
  - Data Analysis

- **Data Collection**
  - A semi-structured interview was utilized to create the interview schedule.
  - Use of an open-ended interview approach.
  - The same semi-structured interview was administered as a written pen and paper self-report questionnaire among participating patient healthcare providers.

- **Project Design**
  - The FACT-BMT questionnaire consists of the following five QoL dimensions:
    1) Physical Well-Being
    2) Social and Family Well-Being
    3) Emotional Well-Being
    4) Functional Well-Being
    5) Additional Concerns
  - Dimensions were utilized as predetermined categories.
  - Qualitative open-ended interview approach.
Tool Reliability and Validity

- Tool reliability was established through the interview of two non-participant subjects.
- Interview tool validity was established by a practicing expert HCT/PP of the Comprehensive Cancer Center, a community expert, as well as a qualitative expert.

Ethical and Human-Subject Considerations

- Project protocol was approved by the University at Buffalo Internal Review Board (IRB) as well as the Comprehensive Cancer Center's IRB.
- All recorded interviews and transcription records will be retained for three years in a secured and locked file cabinet drawer.
- Prior to collecting data, written (or verbal) informed consent was obtained.
- Confidentiality and privacy maintained through use of a private clinical setting.
- De-identification of collected data.

Recruitment Strategy

- Informational flyers describing the project purpose and eligibility criteria.
- Targeted recruitment process.
- Project eligibility criteria included the following:
  - Greater than or equal to 18 years of age.
  - Diagnosis of CCMH.
  - Current RPCCC clinic outpatient.
  - Scheduled appointment with the HCT clinic.
  - Ability to read and speak the English language.
  - Having a clinician and a family or friend care provider willing to participate in the project.

Data Collection

- Convenience sampling.
- Demographic data of all patients interviewed and their care providers were collected using a standard demographic form.
- Sample size was determined based upon the point of saturation with 10 patient trial interviews conducted.
- All interviews took place in a private examination or conference room.
- All interviews were recorded and transcribed verbatim.
- Additional probing questions were offered to patient participants as needed to obtain a comprehensive response.
Data Analysis

- Qualitative analysis consisted of directed content analysis using open coding.
- Reading through participant responses and highlighting passages guided by the five predetermined categories.
- Patient and care provider demographic data were analyzed manually and sample characteristics are reported using descriptive statistics.
- A qualitative report performed a second review of the data analytic process and findings.

Patient Participant Demographics

- Predominantly aged 61 to 75 years (46.7%)
- Most often between one and five years post-transplant (73.5%)
- Predominantly male (89%)
- Predominantly underwent an unrelated donor HSCT (66.7%)

Care Provider Participant Demographics

- Predominantly aged between the ages 61 to 75
- Predominantly female (89%)
- Most often identified as a spouse or significant other
Clinicor Participant Demographics

- All female (IV)
- 53.7% were found to be half the age of their patients with ages ranging between 18 to 30 years and an average age of 24 years
- 42.9% were aged between 31 to 45 with an average age of 30 years
- 4.3% of the participating clinician providers were younger than the patients participating in the project.

Overall Perceptions

- Overall perceptions were consistent among participant categories with minor variations in perception and articulation as expected with differing perspectives and changes over time

Physical well-being

- Weakness and limiting fatigue were themes primarily identified by all three participant categories

Social emotional well-being

- Dominated with overall feelings of support
- Emotional well-being was most often reported as fluctuation throughout all participant categories

Overall Perceptions

- Functional well-being
  - Physical limitations and resultant overall CQ
  - Qualified with the reconciling feeling of being grateful to be alive

Additional concerns

- Concerns regarding relapse
- Late effects of treatment
- Overall desire to return to a previous state of health and sense of normalcy

Patient Perceptions

- Physical well-being
  - "Yes"
  - "Insurable"
  - "Completely different"
  - "Worse"
  - "Limited"

If you were looking at me, everything from the hair on my head to the bottom of my toes, it’s changed everything."

Patient Perceptions

Social/Relational well-being
- Tremendous support
- No isolation

"All my friends and family are very close, helping me going in terms of calorie, checking up on me, showing that they are still there."

Emotional well-being
- Depression
- Bullying
- Anxiety
- Hopelessness
- Loss
- Resignation
- Symptoms

"I'm just trying to resume a normal life. I just slowly came in the realization that there are some things I can't do or will do what I can."

"The life of my book would be, The Cost of Surviving. What if I was and what if I stood away?"

Functional well-being
- Ability to work
- Sleeping well
- Working out, was better
- Grateful to be alive

"Well, I am good, but even though it's ugly, I should be glad that I am alive."
Care Provider Perceptions

Physical well-being:
- Frustrated
- Weak
- Completely affected

"Physically he can't do a lot of things because he's weak, he's tired, and it's really affecting him. He looks up to somebody and he forgets that."

Care Provider Perceptions

Social/family well-being:
- Very supportive
- Decreased support over time
- No sexual relationship

"They feel like he owes them better by now. They are jummeled up."

Care Provider Perceptions

Emotional well-being:
- Unhkeit
- Frustrated
- Coping well
- Pain
- Humor
- Distraction
- Detachment
- Support/Acceptance

"There's frustration that we can't find a solution on this... frustration that it's not knowing what to expect when to expect a return to normalcy."

Care Provider Perceptions

Functional well-being:
- Limited
- Unsatisfied with QOL
- Improved over time
- Grateful

"I don't think he'll ever be satisfied with the current quality of life because he's just too much of the things he used to be able to do."

QUALITY OF LIFE PERCEPTION VARIATIONS
Care Provider Perceptions

- Anxiety
- Worrying for the first time
- Loss of self
- Financial concerns
- Duration of symptoms

Clinician Perceptions

Physical wellbeing
- Limited
- Fatigue
- Change in appearance
- Contained symptoms

Clinician Perceptions

Social/Becky wellbeing
- Feels supported
- Sexuality not an issue
- Negative sexual effects

Clinician Perceptions

Emotional wellbeing
- Frustrated
- Depress
- Happy to be alive
- Depressed/Anxious
## Quality of Life Perception Variations

### Contributions to Practice

**Future Implications**

- Utilization of screening tools for long-term follow-up and routine practice in caring for HCT patients.
- Simply asking the question, “how satisfied are you with your current quality of life?”
- As described by the revised Wilson and Cleary model for H-ESOL, each of the vital components for assessing perception of QOL are addressed using the FACT-BMT.
- Supports the NIH Chronic Grief versus Host Disease Consensus Response Criteria Working Group’s recommendation to document initial evaluations of G4-HDV risk and nonrisk manifestations.

### Clinician Perceptions

**Functional well-being**

- Having trouble keeping up
- Enjoys some activities
- Limited by fatigue
- Can’t do as he did before
- Unable to work
- Restricted

“Chronic severity of illness and altered QOL. I am more realistic with quality of life, but also grateful for the quality of life he has.”

**Additional concerns**

- Financial concerns
- Being a burden
- Frustrated
- Impact on relationships
- Inability to lead a normal life
- Long-term physical effects

“Chronic GVHD and its impact on health relationships and ability to deal with normal life.”
QUALITY OF LIFE PERCEPTION VARIATIONS

Future Implications for Advanced Practice Nursing

- PROs related to HRQoL offer additive objective and subjective data on the effects of COVID-19 and its therapy.
- Patient reported HRQL should be assessed using the FACT-SWB as a part of ongoing evaluation and clinical care to HCT interventions.
- A modified FACT-SWB would be beneficial in ongoing evaluation.
- Future studies should assess the reliability and validity of a modified FACT-SWB.
- Enhanced patient and family education regarding the physical, social, emotional, and functional implications of undergoing HCT are imperative to provide comprehensive care.

**Applied Model**

- Pearson and Citranni Model for HRQoL using project findings and categories included in the FACT-SWB.

**Future Implications for Advanced Practice Nursing**

- PROs related to HRQoL offer additive objective and subjective data on the effects of COVID-19 and its therapy.
- Patient reported HRQL should be assessed using the FACT-SWB as a part of ongoing evaluation and clinical care to HCT interventions.
- A modified FACT-SWB would be beneficial in ongoing evaluation.
- Future studies should assess the reliability and validity of a modified FACT-SWB.
- Enhanced patient and family education regarding the physical, social, emotional, and functional implications of undergoing HCT are imperative to provide comprehensive care.

**Table: Physical Well-Being**

<table>
<thead>
<tr>
<th>Item</th>
<th>None at all</th>
<th>A little bit</th>
<th>Some what</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a lack of energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>I have diarrhea</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have swelling</td>
<td>0</td>
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<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>I am bothered by the side effects of my treatment</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am tired to keep going</td>
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<td>2</td>
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<td>4</td>
</tr>
<tr>
<td>I have pain</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have dry eyes</td>
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<tr>
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<td>4</td>
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<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>I have problems</td>
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<td>2</td>
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<tr>
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<td>2</td>
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<tr>
<td>I have pain in my joints</td>
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**Table: Functional Well-Being**

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<tr>
<td>Too tired to do things for my family</td>
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<tr>
<td>I get emotional support from my family</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I get support from my friends</td>
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<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>My family has accepted my disease</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am satisfied with family communication</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am happy with my care</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am satisfied with my life</td>
<td>0</td>
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**Table: Emotional Well-Being**

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<tr>
<td>I feel hopeless</td>
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<tr>
<td>I feel nervous</td>
<td>0</td>
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<td>4</td>
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<tr>
<td>I am depressed</td>
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<td>4</td>
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<td>I worry about things</td>
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</table>

**Table: Social Well-Being**

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<th>Some what</th>
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<th>Very much</th>
</tr>
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<tbody>
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<td>I feel isolated</td>
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<td>3</td>
<td>4</td>
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<tr>
<td>I feel left out</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel accepted</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel supported</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel loved</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
STRENGTHS AND LIMITATIONS

Strengths

- Using in-depth one on one interviews in a private setting allowed for a thorough investigation of patient and their caregivers' QOL perceptions.
- It is unknown if utilization of a self-reported Likert-scale tool would yield similar QOL perceptions. Longitudinal validity of these project findings to similar interview techniques.
- Insight into modifications needed to enhance the effectiveness of the FACT-QM tool as an evaluation tool.
Limitations

- A single study, conducted at one comprehensive cancer center in the United States.
- Based on the demographics of participants, these findings may not be widely generalizable to the greater population.
- Limited to Caucasian and Hispanic participants by availability only.
- Subjects to upper-class, educated, intended Caucasians dominated the sample.
- Relatively weak support system, as HCT recipients who did not have a caregiver willing to also participate in the study were excluded.

Questions?

References


