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Jill Randall
University of Louisville

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CONCEPTUALIZING THE PSYCHOSOCIAL ELEMENTS THAT SHOULD BE ASSESSED IN CANDIDATES FOR HEMATOPOIETIC CELL TRANSPLANTATION: SOCIAL WORKERS' AND PSYCHOLOGISTS' PERSPECTIVES

By

Jill Randall
B.A., St. Olaf College, 2004
M.S.W., University of St. Thomas, 2009

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Jill Randall
B.A., St. Olaf College, 2004
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A Dissertation approved on

April 7th, 2021

By the following Dissertation Committee:

Karen Kayser

Tom R. Lawson

J. Jay Miller

Emma Sterrett-Hong

Lesley Harris

DEDICATION

I dedicate this dissertation to mi Bobo. Without you, I would not have traveled the path of a Ph.D. You loved me and inspired me. And your threat ("If you do not get a Ph.D., I will haunt you from the grave.") provided the final nudge I needed to go for it. Words cannot express my gratitude for you.

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ABSTRACT

CONCEPTUALIZING THE PSYCHOSOCIAL ELEMENTS THAT SHOULD BE ASSESSED IN CANDIDATES FOR HEMATOPOIETIC CELL TRANSPLANTATION: SOCIAL WORKERS' AND PSYCHOLOGISTS' PERSPECTIVES

Jill Randall

April 7, 2021

Background: In the United States, approximately 23,000 hematopoietic cell transplantations (HCT), also known as a bone marrow transplant, are performed annually. Patients who undergo HCT are among the most acutely ill and medically vulnerable oncology populations. Given the arduous nature of HCT, patients undergo an extensive pre-transplant evaluation that typically includes psychosocial assessment. The literature lacks a well-defined conceptual framework of the psychosocial elements that should be assessed in HCT candidates. This has led to practice variation, which has in turn inhibited high quality psychosocial research.

Method: Social workers and psychologists in HCT were recruited to participate in a concept mapping study to elucidate the conceptual domain of psychosocial elements that should be assessed in candidates pre-HCT. Concept mapping is a mixed methodology that uses quantitative methods (multidimensional scaling and hierarchical cluster analysis) to analyze qualitative data. It results in a series of maps that depict the group's composite thinking about the conceptual domain.

Results: Participants brainstormed 114 distinct psychosocial elements and conceptualized the elements into 12 distinct clusters: Transplant Mindset, Support System, Caregiver, Lodging and Transportation, Financial and Legal, Work, Demographic Characteristics, Mental Health, Communication, Education and Resource Needs, Physical Functioning, and Cognition. Analyses of importance ratings showed that that participants who use standardized psychosocial risk rating scales in their practice did not prioritize these clusters differently than those who do not use risk rating scales in their practice.

Conclusion: Findings show that the domain of psychosocial elements is broad and multi-dimensional. The conceptualization converges with the literature in many respects but also contains noteworthy divergences from the current literature. Divergences are of particular interest since the perspectives of these psychosocial professionals have been largely absent from the literature. The maps and findings may be used to inform the development of a pre-HCT psychosocial assessment protocol that would constitute a high quality practice standard and produce consistent data for psychosocial research.

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CHAPTER I: INTRODUCTION

Social workers have played a role in health care settings since the early 1900s (National Association of Social Workers, 2016). They are the primary providers of psychosocial interventions that aim to “optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health” (Institute of Medicine, 2008, p. 9). To provide effective interventions, social workers must first collect and assess data to help them understand the patient and their situation. This is typically done by interviewing the patient and reviewing collateral information such as the electronic health record. According to Sheafor and Horejsi (2003), “When the assessment is complete, the social worker should be able to describe the problem accurately and identify what needs to be changed to improve the client’s situation.” (p. 244).

In short, social workers in health care provide psychosocial assessment and intervention. The term, psychosocial, has only recently been defined by the National Cancer Institute. The same report that touted the importance of psychosocial services in cancer care also noted that no definition of psychosocial was found in the 2007 version of the National Cancer Institute’s dictionary. Today, the National Cancer Institute’s Dictionary provides the following definition for psychosocial:

> In medicine, having to do with the mental, emotional, social, and spiritual effects of a disease, such as cancer. Some of the psychosocial effects of cancer are changes in how a patient thinks, their feelings, moods, beliefs, ways of coping,

> and relationships with family, friends, and co-workers. (National Cancer Institute, 2021).

In light of this broad definition, it is not surprising that, as Dew et al. (2000) state, “The term [psychosocial] has been used to encompass virtually every nonsurgical or nonmedical parameter of patients and their experiences.” (p. 240).

The literature lacks a well-defined conceptual framework of the psychosocial elements that should be assessed in candidates for hematopoietic cell transplantation (HCT), a subspeciality within oncology. This research uses concept mapping methods to address this gap in the literature. This chapter will describe HCT and the patient’s and caregiver’s experience. The role of the pre-HCT psychosocial assessment will be presented along with a discussion of ethical considerations. The chapter will conclude with a discussion of the significance of the problem and opportunities that may arise when the problem is addressed.

Hematopoietic Cell Transplantation

HCT is a highly specialized field that started in the late 1960s. It is relatively young, having transitioned only about 15 years ago from an experimental and final treatment for advanced leukemia to a standard and even initial therapy for some diseases (LeMaistre & Loberiza, 2005). HCT is now used to treat numerous types of blood cancers that are broadly characterized as leukemia, lymphoma, and multiple myeloma (National Marrow Donor Program, 2021). It is also used to treat other blood disorders, immune system disorders, and solid tumors such as severe aplastic anemia, sickle cell disease, testicular cancer, Fanconi anemia, myelofibrosis, thalassemia, and polycythemia vera (National Marrow Donor Program, 2021). Patients who undergo HCT are among the most acutely ill and medically vulnerable oncology populations (Bevans et al., 2008). In the United States, approximately 23,000 transplants are performed annually (D'Souza et al., 2020). Approximately 14,000 of these are autologous transplants and 9,000 are allogeneic transplants (D'Souza et al., 2020). By 2030, it is projected that there will be more than 500,000 HCT survivors in the United States (Majhail, 2017).

Hematopoietic stem cells reside in the bone marrow and produce the red blood cells, white blood cells, and platelets that circulate in the peripheral blood. Each of these blood cells perform a specific function. Red blood cells carry oxygen to organs and tissues; white blood cells constitute the immune system; and platelets control bleeding by clotting the blood. HCT, also known as a bone marrow transplant, works by replacing cancerous (or diseased) hematopoietic stem cells with healthy ones (National Marrow Donor Program, 2019).

There are two types of HCTs: autologous and allogeneic. Some diseases are only treated with allogeneic transplant, while others may be treated with autologous and/or allogeneic transplant. Autologous transplants use the patient’s own hematopoietic cells. Allogeneic transplants use hematopoietic cells donated by someone else such as a family member, an unrelated donor, or stored umbilical cord blood (National Marrow Donor Program, 2019).

Transplant activity has changed significantly over the past 20 years with new technology making transplant less toxic for older adults (Artz, 2017). Twenty years ago, allogeneic transplant was rarely performed on patients over 50. Now patients 60 and over account for over one-third of allogeneic transplants. The number of both allogeneic and autologous transplants among older adults with cancer continues to increase. In 2018, 39% of allogeneic transplant recipients were 60 and older. Patients who were 70 years and older represented 9% of transplants for cancer. Also in 2018, the majority of autologous transplant recipients (55%) were 60 years and over and diagnosed with multiple myeloma or lymphoma. Those 70 years and older represented 15% of autologous transplant activity for those diseases (D'Souza et al., 2020).

Multiple myeloma and lymphoma (Hodgkin and non-Hodgkin) account for 60% of all HCTs, the vast majority of which are autologous transplants. Acute leukemias and myelodysplastic syndromes/myeloproliferative neoplasms (MDS/MPN) account for the majority of allogeneic transplants (75%). Transplant activity for MDS/MPN has been increasing since Medicare approved coverage for evidence development studies (D'Souza et al., 2020).

In 2017, 67% of all transplant recipients were White. Patients identified as African American or Black accounted for 12% of recipients followed by Hispanic at 11% and Asian at 4%. Patients identified as Multiple Race accounted for 1% of all transplant recipients (Center for International Blood and Marrow Transplant - a contractor for the C. W. Bill Young Cell Transplantation Program operated through the U.S. Department of Health and Human Services, 2018a). Both American Indian/Alaska Native and Native Hawaiian/Other Pacific Islander accounted for 1%. Males account for 58% of transplant recipients, and females account for 40% (Center for International Blood and Marrow Transplant - a contractor for the C. W. Bill Young Cell Transplantation Program operated through the U.S. Department of Health and Human Services, 2018b).

HCT Process

The process of HCT starts with a preparatory regimen that uses high-dose chemotherapy to destroy the patient's hematopoietic cells and bone marrow. Some patients also undergo high doses of total body radiation. The purpose of the preparatory regimen is to kill any diseased cells and weaken the immune system so that it will not reject the transplanted cells. Chemotherapy and radiation may last from a few days up to a week and often result in side effects such as vomiting, diarrhea, mouth sores, hair loss, skin rash, nausea, and fatigue (National Marrow Donor Program, 2021). To extend the use of HCT to older adults and those with comorbidities, a less toxic regimen may be used.

After the preparatory regimen, healthy hematopoietic stem cells are administered through an intravenous line (no surgery is required). These cells find their way to the bone marrow where, if the transplant works, they grow and start to produce healthy blood cells. While the transplant itself only takes a couple hours, the treatment process takes several weeks to many months, depending on the type of transplant. After transplant, the patient is monitored carefully for engraftment: the growth and production of new blood cells. Engraftment can take 30 days or longer. During this time, the patient is at the highest risk of developing an infection that their new immune system is not yet strong enough to handle (National Marrow Donor Program, 2021).

Some transplants occur inpatient, and others are performed on an outpatient basis. When inpatient, patients are isolated in their rooms to avoid infection. For allogeneic transplants, inpatient admissions last an average of 36 days for patients who undergo high intensity preparatory regimens versus 27 days for patients who undergo lower intensity preparatory regimens (Broder et al., 2017). For autologous transplants, the average length of the hospital stay is 22 days (Broder et al., 2017). After hospital discharge, patients have clinic appointments multiple times per week (Applebaum et al., 2016). When performed on an outpatient basis, the patient typically needs to visit the clinic daily for labs and monitoring (Applebaum et al., 2016). HCT clinics typically operate 7 days per week, so patients are able to have labs drawn, see a provider, and receive intravenous antibiotics and blood transfusions any day they need. Given the frequency of clinic appointments and need to get to the clinic quickly when signs of infection arise, transplant centers require patients to reside nearby the transplant center, which means some have to relocate for weeks to months.

Caregiver Role

HCT is not to be undergone alone. Patients are required to have a 24/7 caregiver from their own support system after their hospital discharge. Allogeneic recipients are typically required to have a 24/7 caregiver for a minimum of 100 days post-transplant, and autologous recipients are typically required to have one for a minimum of 30 days. The role of the caregiver is vital to the transplant process. Some centers will not perform a transplant without one, and some formalize the importance of the role by asking caregivers to sign non-legally binding contracts to affirm their availability, understanding of, and commitment to the role.

Caregivers are responsible for providing post-transplant care at home. Because waiting to address symptoms can result in serious complications, one of the most important caregiver roles is to monitor the patient for new problems, especially signs of infection, and report them to the HCT team immediately (National Marrow Donor Program, 2021). Caregivers also help with medication management, changing the dressing on the central intravenous line, transportation to the clinic, communicating with the medical team, cleaning surfaces and doing laundry to minimize bacteria and viruses, taking care of children and pets, running errands, and safe food preparation (Langer et al., 2020; National Marrow Donor Program, 2021). Caregivers often take care of finances and also provide emotional support to the patient (National Marrow Donor Program, 2021).

Post-Transplant

It takes 6-12 months for the immune system to "adequately" reconstitute after autologous HCT. After allogeneic HCT, it can take 2 years or more (Majhail, 2017). Until then, patients need to avoid people, places, and things that contain bacteria, viruses, fungi, and molds that could cause a life-threatening infection. Some of these precautions include staying away from large gatherings and crowded places i.e. malls. Food safety for transplant patients includes avoiding foods that are more likely to contain bacteria: soft cheeses, bulk foods/items from self-service bins, deli and lunch meats, raw fish, refrigerated smoked fish, and unwashed fruits and vegetables. Safe food preparation guidelines include washing all fruits and vegetables, not touching raw meat and fish, using separate cutting boards for raw and cooked foods, cleaning can tops with soap and water before opening them, and heating lunch meat until it steams. Patients are encouraged to not eat away from home until the HCT physician deems it is safe. Even then, patients are advised to avoid delis, potlucks, buffets, street vendors, and crowded restaurants (National Marrow Donor Program, 2021).

Late complications. Late complications are medical issues that occur months to years after HCT. Since late complications can result in "significant long-term morbidity and mortality," transplant survivors' relative mortality rates remain higher than their peers in the general population (Majhail, 2017, p. 220). The preparatory regimen, with its high dose chemotherapy and radiation exposures, contributes to the development of many late complications. Chemotherapy and radiation prior to the transplant process also contribute. Some late complications include cataracts, severely dry eyes, eye irritation, mouth pain and dryness, skin rashes, sun sensitivity, scleroderma (hard, tight skin), avascular necrosis (bone breaks down in the joint), and osteopenia (weak bones) (National Marrow Donor Program, 2021).

Secondary cancers are the cause of 5-10% of deaths among transplant patients who survive 2 years or longer (Majhail, 2017). Therefore lifelong cancer screening post-transplant is recommended. Transplant-related exposures may impact any organ, and "the risk for most organ specific late complications continues to increase with time" (Majhail, 2017, p. 221). Ongoing surveillance for these problems is recommended for all HCT recipients. Given the time it takes for the immune system to adequately reconstitute, infections are a common cause of late morbidity and mortality. Also, pre-transplant immunity is lost, so HCT patients need to start getting vaccinations anywhere from 6-12 months post-transplant (Majhail, 2017).

Since allogeneic transplant uses donated cells, the patient becomes a chimera: their blood contains the donor's genetics, while the genetics in the rest of their body remain their own. The transplanted white blood cells (graft), which constitute the immune system, may recognize any part of the body (host) as foreign and attack it. This common complication is called graft-versus-host disease (GVHD). GVHD is characterized as acute and chronic. Acute GVHD develops within weeks to months after transplant, and chronic GVHD typically develops within one year (National Marrow Donor Program, 2021).

Patients with chronic GVHD typically have at least 3 involved areas. The most commonly involved areas include the skin, mouth, liver, and eyes. The gastrointestinal tract, lungs, joints, and genital tract also tend to be involved. Examples of GVHD symptoms include severe eye itching, dryness, and irritation that does not subside; trouble opening the mouth, mouth sores, and mouth irritation that does not subside; itchy skin and rashes, nail changes, and thickening of the skin; trouble breathing and persistent cough; muscle pain and cramps; pain and stiffness in joints; nausea, vomiting, diarrhea, and stomach pain (National Marrow Donor Program, 2021).

For cancer patients, mild GVHD is desirable. It signals a "graft vs. malignancy" effect in which the new immune cells are detecting and eliminating any remaining cancer cells (Costanzo et al., 2013). Severe graft vs. host disease can be fatal. GVHD and its treatment (immunosuppressive agents) are associated with worse quality of life and impaired physical functioning (Khera, Storer, et al., 2012). Chronic GVHD that requires years of immunosuppression is a major cause of long-term morbidity and late mortality (Majhail, 2017; Wingard et al., 2011).

Medical Outcomes Statistics

According to Majhail (2017), "Disease relapse is the main cause of treatment failure in the first 2-4 years after transplantation." (p. 220). An estimated 80 – 90% of patients whose disease remains in remission for 2-5 years after transplant will live another 10 years (Majhail, 2017). For adult patients, three-year probabilities of survival post-HCT range from 27% - 87% depending on many factors including transplant type, disease type, disease status, and donor type (D'Souza et al., 2020). For example, among patients who received an autologous transplant for diffuse large B-cell lymphoma, the 3-year probabilities of survival were 67% and 47%, for patients with chemosensitive and chemoresistant disease, respectively (D'Souza et al., 2020).

Allogeneic transplant entails a higher risk of morbidity and mortality than autologous transplant (D'Souza et al., 2020). The 3-year probabilities of survival among a cohort of patients with acute myelogenous leukemia (AML) who received an allogeneic transplant with an unrelated donor were 53%, 50%, and 27% for patients with early, intermediate, and advanced disease, respectively. Survival for chronic lymphocytic leukemia is slightly better than AML with the 3-year probabilities of survival being 60% and 54% for patients who received a transplant from a fully-matched sibling and unrelated donor, respectively (D'Souza et al., 2020).

Cost

Given the increasing emphasis placed on cost-effectiveness and cost containment in health care, it is important to consider the economic burden of HCT. The Agency for Healthcare Research and Quality has noted that among all procedures, HCT has had one of the most rapid increases in hospital costs (Stranges et al., 2007). Due to its complexity, allogeneic transplant is more expensive than autologous transplant (Broder et al., 2017). A study that used an administrative claims database found that the average cost of health care resource utilization in the 2-year period after allogeneic transplant was $600,000, with 59% of this occurring in the first 90 days and 88% occurring in the first year. For autologous transplant, the total cost was $344,000, with 45% of the cost occurring in the first 90 days and 72% occurring in the first year (Bonafede et al., 2017). While the exact figures vary among studies (Khera, Zeliadt, et al., 2012; Majhail et al., 2009; Majhail et al., 2013; Saito et al., 2008; Saito et al., 2007), it remains clear that HCT is a costly procedure.

The Patient Experience

Emotions

Protective isolation is inherent to the HCT process. Isolation "aims to prevent infection by diminishing the likelihood of contact between the patient and the external world, through the use of structural equipment and strict behavioural rules for healthcare providers, patients, and visitors" (Biagioli, 2017, p. 2). Substantial variability in isolation guidelines exists among transplant centers, and in recent years, guidelines have relaxed some in light of evidence that most infections arise from normal bacteria that live and grow on the patient's skin, nose, and mouth (Biagioli et al., 2017). Qualitative studies have explored patients' experiences with protective isolation. Patients have reported feeling abandoned, lonely, bored, and confined (Cohen et al., 2001). They have also voiced wanting to protect their family members from seeing them in a debilitated state (Cohen et al., 2001). Feeling lonely and isolated is not only related to the absence of others but to the unique experience that is understood by so few people in their support system (Stephens, 2005).

It is well documented that patients experience heightened anxiety and distress in the days leading up to transplant (Hermioni L. Amonoo et al., 2019; Bevans et al., 2008; Corman et al., 2021; Syrjala et al., 2004). Insomnia is also heightened during this time, with one study finding that 50% of patients reported pre-transplant insomnia compared to 27% of matched, non-cancer controls (Lee et al., 2017). Approximately 15% of patients endorse depressive symptoms pre-transplant, and 37% endorse them in the week after transplant (El-Jawahri et al., 2015). One study of recipients of autologous (n = 30) and allogeneic transplant (n = 60) found that 43% had “clinically significant depression” at 6 months post-HCT (El-Jawahri et al., 2016).

A scoping review of studies that included autologous and/or allogeneic recipients who are at least one-year post-transplant found a prevalence of depression ranging from 12-30% (Bevans et al., 2017). Risk factors were younger age, female gender, poor social support, disease relapse, chronic pain, chronic GVHD (Bevans et al., 2017), and lower self-reported physical functioning (Barata et al., 2020). Autologous and allogeneic recipients with documented depression who take antidepressant medications have reported better physical functioning than patients with undertreated and untreated depression (Barata et al., 2020). Those with treated depression still reported worse physical functioning than controls (Barata et al., 2020).

A seminal study by Syrjala et al. (2004) prospectively examined recovery over 5 years in recipients of autologous and allogeneic transplant. A total of 317 patients with leukemia or lymphoma enrolled; 120 were still alive at the 5-year follow-up, of which 21 had recurrent malignancy. Outcomes including physical limitations, return to work, depression, and distress related to treatment/disease were measured prior to HCT, at 90 days, and at 1, 3, and 5 years. At 1 year, only 19% had recovered on all outcomes, and by 5 years, 63% reported no major limitations. Among patients without recurrent malignancy, 84% returned to full-time work by 5 years. Women, patients with physical complications post-HCT, and those with lower social support pre-HCT were more depressed post-HCT. Those with lower social support pre-HCT were slower to recover in terms of distress. Physical recovery occurred earlier than psychological or work recovery. The authors concluded that “full recovery” occurs gradually over 3-5 years (Syrjala et al., 2004).

Studies have reported the prevalence of “emotional distress” as ranging from 22%-43% in recipients who were at least one-year post-transplant (Bevans et al., 2017). Risk factors for heightened distress have included lower income, higher education, lower social support, physical limitations, chronic GVHD, more aggressive disease or treatment, neurocognitive problems, and greater perceived impact of treatment (Bevans et al., 2017).

Study findings on the prevalence of post-traumatic stress disorder (PTSD) symptoms after transplant have been mixed. In their study of 691 transplant recipients, Liang et al. (2019) found that rates of PTSD symptomology were relatively low (3.3%) in HCT recipients at least 6 months post-transplant. Shorter time since transplant, but no other demographic or transplant-related variables, were associated with a greater likelihood of reporting PTSD symptoms in this sample. El-Jawahri et al. (2016) found that among 67 patients, 28% met criteria for PTSD at 6 months post-transplant. In this study, a decline in quality of life and increase in depressive symptoms during HCT hospitalization were significant predictors of PTSD. Time since transplant may help explain the difference in reported rates. The median time since transplant was 10.1 years in Liang et al.’s (2019) sample. In El-Jawahri et al.’s (2016) sample, PTSD was measured at 6 months.

Cognition

Studies on cognitive outcomes have had small sample sizes (Burns et al., 2018) and results have been inconsistent secondary to differences in methods and definitions of constructs (Scherwath et al., 2013). When measured with neuropsychological testing, anywhere from 10%-40% of patients experience cognitive dysfunction a year or more after transplant (Bevans et al., 2017). When measured by patient self-report, the rate is higher: 40% - 60% (Bevans et al., 2017). Recipients of allogeneic transplant with a high-intensity preparatory regimen have been found to exhibit significant cognitive decline compared to healthy controls, while those with a lower intensity preparatory regimens have been found to have cognitive decline later but not immediately post-transplant (Sharafeldin et al., 2018). Cognitive function does not seem to be impacted in recipients of autologous transplant (Sharafeldin et al., 2018).

Sexual Health and Fertility

Sexual dysfunction may be one of the most prevalent and persistent late effects after HCT (Tierney, 2004). Both women and men report a decline in sexual function after transplant, with women reporting worse decline than men (Noerskov et al., 2016). Rates of sexual dysfunction in survivors more than one-year post-HCT vary across studies with anywhere from 6%-46% of men and 33%-80% of women reporting problems (Bevans et al., 2017). Examples of sexual concerns include decreased libido, erectile and ejaculatory dysfunction, ovarian failure leading to premature menopause, vaginal dryness, and painful intercourse (Humphreys et al., 2007; Tierney, 2004). For men, sexual function declines after total body radiation (Wong et al., 2013). Chronic GVHD in both men and women contribute to sexual dysfunction and dissatisfaction (Wong et al., 2013). Infertility is common among HCT survivors due to the toxicity of the preparatory regimen (Joshi et al., 2014). A study comparing 10-year survivors with case-matched controls found that the prevalence of infertility and the reporting of fertility-related concerns was higher among the recipients than the controls (Hammond et al., 2007).

Finances and Work

Relative to other outcomes, the financial consequences of HCT is a newer area of inquiry. One of the first studies was a survey that had 268 respondents from a single institution (16% were < 1 year post-transplant, 53% were 1-3 years post-transplant, and 31% were > 3 years post-HCT) (Khera et al., 2014). All patients were insured. Even so, patients reported cutting back on or not getting prescription medication (19%), not having a medical test or not seeing a provider (21%), and deferring a medical service i.e. physical therapy (28%) related to cost burden. For 38% of patients, out-of-pocket costs for 3 months were greater than $2000.00, and for 12%, costs were above $5000.00. A total of 73% reported that undergoing HCT had hurt them financially, and 3% had declared bankruptcy (Khera et al., 2014).

In their study of 190 recipients with chronic GVHD from 10 different transplant centers, Khera et al. (2019) found that 24% reported difficulty paying medical bills, 28% reported running out of money at the end of the month, 49% reduced spending on utilities and in other areas, 31% used retirement savings, and 16% borrowed money or sold assets. Patients who reported financial burden were more likely to report feelings of anxiety and depression and have trouble sleeping. A total of 34% of the sample had experienced delayed/denied insurance coverage for GVHD treatment. Notably, 73% of respondents had a graduate degree, and nonrespondents had lower pre-HCT income and lower education (Khera et al., 2019). Thus, financial consequences may be more severe than captured by the study. Regarding return to work, studies have found that anywhere from 15%-40% of patients do not return to their previous employment (Bevans et al., 2017). Risk factors for not returning to work include lower income, female gender, chronic GVHD, physical impairment, and more hospitalizations (Bevans et al., 2017).

Regret

Cusatis et al. (2020) examined decisional regret among patients who underwent allogeneic transplant. Regret was measured at 100 days, 6 months, and 1 year post-transplant. Of 184 patients, 28 unique patients (15%) reported feeling some amount of regret at any time point. At each time point, 6-8% expressed regret. Patients who expressed regret also reported having worsening quality of life at each time point. Lastly, the risk of decisional regret was 18% higher for those with disease recurrence (Cusatis et al., 2020). These results are congruent with findings from a qualitative study where some patients expressed that if they had known what their quality of life would be post-transplant, they would not have had one (Jim, Quinn, Gwede, et al., 2014).

Adjustment and Coping

Many patients find adaptive ways to cope with the process of HCT. A qualitative study of survivors found that optimism, or having the "right" frame of mind, about survival was important (Beeken et al., 2011). Some balanced this emphasis on optimism by highlighting the importance of acceptance and not being unrealistic. Patients also expressed that they thought they had little control over their outcome and engaged in activities to distract them from thinking about disease recurrence (Beeken et al., 2011). Recipients also identified that changing their expectations about their physical functioning helped them cope (Beeken et al., 2011).

The Caregiver Experience

The HCT process takes a toll on caregivers' well-being. They have "extensive responsibility for the recipient's well-being and safety" (Cooke et al., 2011, p. 502) and have to juggle other responsibilities including parenting, work, and sometimes caregiving for parents/in-laws (Langer et al., 2020). This toll, before, during, and after transplant, is well-documented.

Similar to patients, caregivers report high levels of anxiety and distress pre-HCT (Simoneau et al., 2013). They also report intrusive thoughts, avoidant behavior, and sleep problems that exceed population norms (Simoneau et al., 2013). In the first 100 days post- transplant, the patient's symptom management needs are a particular source of distress for caregivers (Applebaum et al., 2016). Some caregivers have reported being well-informed about how to care for the patient and what symptoms to anticipate (Jim, Quinn, Barata, et al., 2014), but others feel unprepared (Gemmill et al., 2011). Caregivers have reported feeling less prepared for helping the patient with emotional and cognitive changes (Jim, Quinn, Barata, et al., 2014) and that supporting the patient emotionally was the hardest caregiving activity (Cooke et al., 2011). Not surprisingly, when patients have greater needs, caregivers report more distress and less ability to maintain paid employment and relationships (Akgul & Ozdemir, 2014).

Qualitative studies have found that caregivers talk much more frequently about the negative psychological impacts than positive ones (Langer et al., 2020) and that caregivers voice more negative life changes related to transplant than patients do (Jim, Quinn, Barata, et al., 2014). Caregivers have voiced anxiety, fear, worry, being overwhelmed/overloaded, frustration, anger, irritation, devastation, loneliness, guilt, resentment, unhappiness, helplessness, fear about cancer recurrence, and high anxiety before follow-up appointments (Jim, Quinn, Barata, et al., 2014; Langer et al., 2020). One caregiver described the transplant process as “horrific” (Langer et al., 2020). Another spoke about the experience of fear, “You hear one story after another of who doesn’t get to go home when they are supposed to. And one story after another of whose cancer has returned. And whose graft fails…And it really gets to you. So you just live in fear.” (Langer et al., 2020).

Many caregivers have “described constant vigilance about disinfecting their surroundings to prevent infection, sometimes far longer than required by the transplant team” (Jim et al., 2014, p. 1234). Caregivers have also reported feeling overlooked, since family members’ and friends’ concerns centered exclusively on the patient (Jim, Quinn, Barata, et al., 2014). Caregivers have reported that their relationship with the recipient was significantly changed due to the HCT process. For some, transplant brought them closer, while for others, it brought significant strain to the relationship (Jim, Quinn, Barata, et al., 2014). Some have also described losing their identity (Jim, Quinn, Barata, et al., 2014).

Recent survey research from a single institution assessed caregivers’ quality of life (Jamani et al., 2018). The 849 respondents were a median of 6 years post-HCT (IQR 2-15 years); 67% were female, and 68% reported they were still providing care to the recipient. While mean and median quality of life measures were at or above general population norms, 20% still reported poor quality of life compared to general population norms. Also, the prevalence of depression and sleep disorders were higher than in the general population. Lower caregiver quality of life was associated with female gender, younger age, lower educational attainment, and lower recipient quality of life (Jamani et al., 2018). In the HCT caregiver literature in general, most caregiver participants are female, White, partnered, and employed full time, which limits the generalizability of conclusions and implications (Applebaum et al., 2016).

Spousal Caregivers

The impact of HCT specifically on spousal caregivers has been studied. Years after transplant, the risk of depression among spousal caregivers has been found to be 3.5 times greater than their matched peers (Bishop et al., 2007). One study of patients (n = 691) and caregivers (n = 333) who were a median 10 years post-HCT found that significantly more caregivers than patients reported PTSD symptoms (6.6% vs. 3.3%; p = 0.02) post-transplant (Liang et al., 2019). Patients' report of PTSD symptoms was associated with shorter time since transplant, but caregivers' was not. Those who endorsed PTSD reported significantly higher levels of distress related to uncertainty, family strain, medical demands, finances, identity, and health burden (Liang et al., 2019).

Langer et al. (2010) studied marital adjustment and satisfaction in patients and their spouses in a 5-year longitudinal study. They found that female spouses of male patients had higher rates of relationship maladjustment. Pre-HCT, 9% of female spouses scored in the relationship-maladjusted range; this rose to 24% at 6 months and remained elevated during the study timeframe. While couples were mostly satisfied and divorce was uncommon, female spouses of male patients again were more likely to not be satisfied. They reported decrements in satisfaction at each time point relative to their baseline. For the first 2 years, their male spouses (patients) did not report dissatisfaction, but from 3-5 years, they did report reduced satisfaction (Langer et al., 2010).

Taken together, evidence on the caregiver's experience suggests significant, negative short-term impacts. Many recover over a period of months to years but some do not. Accordingly, it seems that HCT takes as much of a toll, if not more, on the caregiver.

Psychosocial Assessment of HCT Candidates

Given the arduous nature of HCT, patients undergo an extensive pre-transplant evaluation to ensure they are medically eligible and adequately informed. The evaluation includes medical tests and educational sessions. At most centers, it also includes an in-depth psychosocial assessment, typically conducted by a clinical social worker. The psychosocial assessment serves many purposes. It identifies psychosocial factors that require intervention before or close monitoring throughout the transplant process to ensure the best possible outcomes (Austin & Rini, 2013). It also captures baseline functioning to which post-transplant outcomes may be compared. The assessment also provides an opportunity for the social worker to establish rapport with the patient and family and begin addressing their psychosocial needs. Finally, the assessment informs clinical decisions such as referrals to allied health professionals. (Austin & Rini, 2013).

One clinical decision the assessment may inform is whether or not to proceed with transplant. Some psychosocial factors are thought to contribute to risk and poor outcomes. The presence of these is considered in the overall risk assessment and evaluation. In rare cases, patients who would otherwise be medically eligible for HCT are excluded based on psychosocial factors (Foster, McLellan, Rybicki, Tyler, et al., 2009; Richardson, Devine, et al., 2018). Patients facing transplant often have few alternative treatment options. Their diseases are life-limiting and/or life-threatening; non-HCT options may provide them some time but not a potential cure. Therefore, when a patient is otherwise medically eligible, not offering transplant due to psychosocial factors, is a difficult judgment call and an ethical dilemma.

There is a paucity of literature about this ethical issue. A survey of HCT social workers, nurses, physicians, and hospital ethics committee chairpersons examined which psychosocial factors they thought posed the most risk. Participants were asked to respond to 16 case vignettes, each presenting a challenging psychosocial situation, with whether they would recommend proceeding with HCT or not. The situation most frequently identified by respondents as "do not proceed" was "suicidal ideation" (87%), followed by "uses addictive illicit drugs" (82%), "history of non-compliance" (81%), "lives far away and has no caregiver" (69%), "alcoholic" (65%), "mild dementia/Alzheimer's disease" (64%), "significant financial problems" (48%), "morbidly obese" (27%), "caregiver has mental problems" (24%), "daily use of marijuana" (18%), "cognitively impaired" (18%), "borderline personality disorder" (17%), "controlled schizophrenia" (16%), "two suicide attempts" (16%), "treated for major depression" (16%), "current tobacco smoker" (16%), and convicted of a felony (12%). (Foster, McLellan, Rybicki, Tyler, et al., 2009).

Some centers have policies around psychosocial eligibility, but others do not (Randall et al., 2021). Clinical practice guidelines for psychosocial eligibility have not yet been published. Therefore, the extent to which psychosocial factors impact eligibility varies from center to center, and even from physician to physician within the same center (Richardson, Devine, et al., 2018). Tay et al. (2018) assert that the decision whether to proceed should be interdisciplinary and that psychosocial factors should be considered as "tie-breakers" when the potential benefit of HCT is unclear.

The potential for psychosocial assessment results to be used to exclude patients from HCT is a weighty matter. The psychosocial factors identified as “high risk” are those that also tend to be stigmatized by society and used to label patients as “difficult.” These patients are already marginalized and at risk of not accessing the health care they need. They are also the people that the social work profession has a particular call to serve and advocate for (National Association of Social Workers, 2021).

Conceptualizing Psychosocial Elements

Despite the various roles of the pre-HCT psychosocial assessment, the psychosocial elements that should be assessed in HCT candidates have not been rigorously conceptualized. Furthermore, there are no formal consensus guidelines on what should be assessed or on how to adequately measure psychosocial factors. This has led to practice variation (Hong et al., 2016; Trask et al., 2002). Some centers use an interview only and others use one of several standardized tools to summarize psychosocial risk based on the interview (Richardson, Devine, & Nash, 2018). Some centers also incorporate psychometric measures into their assessment protocol (Randall et al., 2021)

Practice variation has inhibited high quality psychosocial research (Muffly & Artz, 2018). Centers produce different quality psychosocial data, which may or may not be useful for research. They also produce different types of data, which limit studies to single center designs with small sample sizes and limited power to detect differences. Single center designs are a particular limitation for research with more psychosocially vulnerable patients, since they constitute a minority of the patients who undergo HCT at any given center (Foster et al., 2009; Sanghee Hong et al., 2019; Richardson, Huang, et al., 2018).

There is a need to conceptualize the psychosocial elements that should be assessed in HCT candidates. A rigorous conceptualization would fill a gap in the literature and produce an underlying framework. The framework could inform the creation of an assessment protocol. If implemented broadly, the protocol would constitute a high and consistent standard for evaluating patients. It would also help ensure that uniform psychosocial data were consistently gathered, thus promoting psychosocial research.

Concept mapping is a mixed-methods, participatory methodology that produces a conceptual framework (Kane & Rosas, 2018) that may be used to develop tools for evaluation (Rosas & Camphausen, 2007). This research uses concept mapping methodology to conceptualize the psychosocial elements that should be assessed in HCT candidates.

Research questions include:

1. How do psychosocial professionals conceptualize the elements they assess in candidates for hematopoietic cell transplantation?

2. Is there a difference in the conceptualization based on the use of standardized risk rating scales in clinical practice?

CHAPTER II: LITERATURE REVIEW

This chapter will review the literature that conceptualizes psychosocial elements that are assessed in different medical specialty areas. The empirical literature investigating the relationship between pre-HCT psychosocial factors and post-transplant outcomes will then be summarized and critiqued. Key theoretical models that underpin this literature will be presented. Lastly, the philosophical underpinnings of this study's methodology will be presented.

Conceptualization of Psychosocial Elements in Specialty Care Contexts

Psychosocial factors have been conceptualized in literature on experimental spinal cord injury treatment (Fronek, 2004), living organ donation (Ismail et al., 2015), solid organ transplantation (Dew et al., 2000; Maldonado et al., 2012; Olbrisch et al., 1989; Twillman et al., 1993), oncology (Schnipper & Varner, 2015a) and HCT (Futterman et al., 1991; Garcia Jr et al., 2005; Kennedy, 1993). These conceptualizations vary based on the primary purpose of the assessment and unique characteristics of the patient population and treatment. Some conceptualizations have been used to develop assessment tools.

Experimental Treatment for Spinal Cord Injury

Based on a literature review and clinical experience, Fronek (2004) conceptualized psychosocial elements in the context of assessing candidates for experimental spinal cord injury treatment. The purpose of assessing candidates is "to ensure emotional, social, and psychological stability of the participant; identify the individual's capacity to deal with negative or positive consequences of participation in the project; assess informed consent and to ensure the principles of nonmaleficence and beneficence are upheld" (p. 6). The conceptualization is organized into 4 equally-weighted domains: person, current environment, disability, and informed consent. The domains are not independent but represent "a complex and dynamic interrelation of influences, which together create a picture of that individual's current functioning." (Fronek, 2004, p. 10).

Unlike HCT patients, individuals with spinal cord injury are not sick. They do not have a life-threatening illness; they experienced a trauma that caused a permanent disability. Assessing aspects of the disability is pertinent for this patient population and comprises one-quarter of the conceptual model. Similarly, the domain of informed consent for the treatment is deemed so important that it comprises one-quarter of the conceptual model. The treatment is experimental, so one of the primary purposes of the assessment is to evaluate factors (i.e. understanding of the treatment and its risks, coercion, and motivation) that bear on informed consent. (Fronek, 2004).

Living Organ Donation

Ismail et al. (2015) conceptualized psychosocial elements in the context of evaluating potential living kidney and liver donors. They conducted a systematic review of published guidelines and used group concept mapping methods to create a visual representation of the psychosocial elements and their interrelationships. They also analyzed the elements' relative importance and how commonly each was assessed in practice. This resulted in 6 domains listed in order of importance: 1) motivation and decision making, 2) personal resources, 3) psychopathology, 4) social resources, 5) ethical and legal factors, and 6) information and risk processing.

That "motivation and decision making" was found to be the most important domain reflects the unique context of living organ donation. Living donors are healthy individuals who elect to undergo a medical procedure that entails some risks and that provides them no direct medical benefit. Ensuring appropriate motivation and sound decision-making is therefore paramount (Massey et al., 2018). Elements in other domains are also unique to the donor population: financial benefit for undergoing the procedure, expectations of the effect on the relationship with the recipient, and health outcome expectations for the recipient.

Solid Organ Transplantation

Dew et al. (2000) specified "the elements that are encompassed by the term *psychosocial"* as it applies to solid organ transplantation (SOT) candidates (p. 240). In this context, the purpose of psychosocial assessment is to inform clinical decisions such as whether the patient is eligible to be put on the waiting list and what supports they may need throughout the transplant process. Also, improved psychosocial status from pre- to post-transplant signals the relative success of the transplant.

Their conceptualization contains 7 core domains: 1) psychiatric history and current status, 2) compliance history and current status, 3) substance use history and current status, 4) mental status, 5) social history and availability of support, 6) family social and mental health history, 7) perceived health, coping style, and quality of life. Within each domain, additional details are provided. For example, social history and availability of support includes the following areas: "employment status, marital status and relationship stability, living arrangements, financial status; contact, availability, and emotional supportiveness of family, friends, and community or religious organizations; religious beliefs and orientation; concurrent stressors (work related, home related, other)" (Dew et al., 2000, p. 240).

In addition to Dew et al.'s (2000) conceptualization, Olbrisch et al. (1989), Twillman et al. (1993), and Maldonado et al. (2012) conceptualized "psychosocial risk factors" in the context of SOT and created scales for psychosocial professionals to rate candidates' risk: Psychosocial Assessment of Candidates for Transplantation (PACT), Transplant Evaluation Rating Scale (TERS), and Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT), respectively. The elements rated in each scale are presented in Table 1. All of the scales have been applied to HCT patients and will be discussed in turn.

Table 1. Psychosocial risk factors identified by the PACT, TERS, and SIPAT

Psychosocial Element	**PACT**	**TERS**	**SIPAT**
Quality of affect		X	
Compliance with treatment	X	X	X
Coping with disease and treatment		X	
Prior history of coping		X	
Drug and alcohol use	X	X	
Alcohol use/abuse/dependence			X
Alcohol use/abuse/dependence – Risk for recidivism			X
Substance use/abuse/dependence (including prescribed and illicit substances)			X
Substance use/abuse/dependence (including prescribed and illicit substances) – Risk for recidivism			X

Nicotine use/abuse/dependence			X
Effect of truthfulness vs. deceptive behavior in presentation			X
Family or support system availability	X		X
Family or support system stability/functionality	X		X
Quality of family/social support		X	
Healthy lifestyle, ability to sustain change in lifestyle	X		X
Health behaviors		X	
Appropriateness of living space and environment			X
Prior psychiatric history (DSM-III-R Axis I)		X	
Prior psychiatric history (DSM-III-R Axis II)		X	
Psychopathology, stable personality factors	X		
Risk for psychopathology	X		X
Presence of psychopathology (other than personality disorders and organic psychopathology)			X
History of organic psychopathology or neurocognitive impairment			X
Influence of personality traits vs. disorder			X
Mental status (past and present)		X	
Relevant knowledge and receptiveness to education	X		
Knowledge and understanding of the transplant process			X
Knowledge and understanding of medical illness process			X
Willingness/desire for transplant			X

*Shading is used to demarcate groups of similar elements.

Psychosocial Assessment of Candidates for Transplantation (PACT). The PACT was developed in the late 1980s based on a literature review and the clinical experience of researchers at one transplant center. It was created to address ethical concerns about unjust exclusion from SOT based on inconsistently applied psychosocial criteria (Olbrisch et al., 1989). Accordingly, the purpose of the scale was to study the clinical judgment of raters. The psychosocial professional completes the PACT after their clinical interview to rate a patient's psychosocial risk in 8 domains as well as provide initial and final overall risk ratings (Olbrisch et al., 1989).

Transplant Evaluation Rating Scale (TERS). The TERS is a 10-item rating scale that is completed post-interview to classify a patient's psychosocial risk in 10 domains. The TERS was designed to "foster further research into the relative impact of psychosocial factors on organ transplant outcome and posttransplant quality of life" (Twillman et al., 1993, p. 145). It was revised from the Psychosocial Levels System (PLS), a tool for assessing HCT candidates, to increase specificity and relevance to the SOT setting (Twillman et al., 1993). Weighted scores for each variable were developed by the authors, but subsequent research found that the weighting system provides no more predictive utility of outcomes than simply summing unweighted item scores (Hoodin & Kalbfleisch, 2001).

Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT). The SIPAT was created to address the problem of unclear psychosocial listing criteria and unclear methods for assessing psychosocial risk (Maldonado et al., 2012). It was developed based on a literature review of psychosocial variables that may influence adherence, quality of life, and organ rejection. It "intends to assess the psychosocial factors that appear to better predict patients' adherence and graft survival." (Maldonado et al., 2012, p. 126). The SIPAT includes 18 factors that are organized into 4 domains: patient's readiness level, social support system, psychological stability and psychopathology, and lifestyle and effect of substance use. The evaluator rates the factors based on their interview with the patient and collateral information (Maldonado et al., 2012).

The authors applied weights to each item because the evidence suggested to them that some psychosocial factors are more predictive of outcomes than others. They tested the scale retrospectively on a sample of 102 liver, heart, and lung transplant patients and found high inter-rater reliability among the 5 raters (Pearson's correlation coefficient = 0.853) as well as predictive utility for dichotomous psychosocial outcomes of "positive" and "negative" (Maldonado et al., 2012). The SIPAT is more detailed than the PACT and TERS. Also, unlike the PACT and TERS, the SIPAT provides direction on how depression, anxiety, and cognitive functioning should be measured. It suggests using the Patient Health Questionnaire-9 or Beck Depression Inventory, the Generalized Anxiety Disorder-7 questionnaire or Beck Anxiety Inventory, and the Mini Mental Status Exam if available. If the instruments are not available, the evaluator is directed to use their clinical judgment.

Oncology

Practice standards for psychosocial assessment published by the Association of Oncology Social Work include 9 areas: 1) age and stage of human development; 2) knowledge about cancer and its treatment, including level of understanding, expectations, and goals for treatment, 3) characteristics of the support system; 4) patient and family psychosocial functioning including strengths, limitations, and coping skills; 5) race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sexual orientation, and gender identity; 6) barriers to care; 7) availability and adequacy of community resources; 8) patient and family's interest in participating in care and medical decision-making; 9) development of a case plan (Schnipper & Varner, 2015b).

Hematopoietic Cell Transplantation

An early article on the role of the social worker in HCT recommended that four broad areas should be assessed pre-transplant: 1) the patient's and family's psychosocial history, 2) family structure and family roles, 3) family's communication and decision-making patterns, preexisting psychological and social problems, and coping skills, and 4) the patient's, family's, and donor's expectations and perceptions of the illness and HCT (Kennedy, 1993).

Psychosocial Levels System (PLS). Two years prior to Kennedy's (1993) article, Futterman et al. (1991) proposed a psychosocial rating scale based on a review of the literature. The PLS contains 7 items that the psychosocial professional rates post-interview to classify a patient's risk: prior psychiatric history, quality of family/social support, prior history of coping, coping with disease and treatment, quality of affect, mental status (past and present), and proneness to anticipatory anxiety (Futterman et al., 1991). The purpose of the PLS is to identify patients at risk for developing emotional challenges during HCT as well as provide a common language of psychosocial variables for the interdisciplinary transplant team (Futterman et al., 1991, p. 177). In contrast to other psychosocial rating scales, compliance and substance use are not listed.

The researchers agreed, based on their clinical experience, that the psychosocial domains varied in importance and amount of contribution to the overall level of risk. Thus, through multiple discussions, three raters (2 licensed clinical psychologists and 1 doctoral-level clinical psychology graduate student) ordered the items according to their theoretical beliefs about the relative contribution of each to overall risk and then assigned a priori weights (Futterman et al., 1991). The domain “prior psychiatric history” carries double the weight of the second heaviest domains, “quality of family/social support’ and “prior history of coping.” The researchers tested the tool in a retrospective chart review of 42 HCT patients at one center. Testing showed strong concordance between raters (Futterman et al., 1991). It is unclear if the tool underwent further testing, as it does not appear in the literature again.

Psychosocial Assessment Interview of Candidates for Hematopoietic Stem Cell Transplantation (PAIC-HSCT). The PAIC-HSCT (147 items) is a structured interview with open-ended and multiple choice questions and also includes the Brief Psychiatric Rating Scale (Garcia Jr et al., 2005). It was developed based on the PACT, TERS, and questions from a structured interview for kidney transplant candidates. It contains 11 domains: social and demographic data, comprehension of the illness, comprehension of the transplantation, medical compliance, lifestyle, coping strategies, mental status exam, psychiatric history, family history, social and family support, and expectations of the transplant. The researchers submitted their initial tool to 13 HCT professionals for review and made changes based on their feedback. Then one researcher pilot-tested the tool on 30 HCT candidates, concluding, based on patients’ feedback, that it was feasible (Garcia Jr et al., 2005).

The PAIC-HSCT is unique from the PLS, TERS, PACT, and SIPAT in that it structures the clinical interview via open-ended and multiple choice questions and does not include a risk rating scale. Like the PLS, after its initial publication, it does not appear in the literature again. Based on a national survey of HCT centers, it seems likely that neither the PLS nor the PAIC-HSCT are currently used in clinical practice (Randall et al., 2021).

Summary of the Conceptual Literature

In summary, the conceptual literature shows that broad psychosocial domains are relatively similar across the medical settings. Even so, there are some subtler differences in the conceptualizations related to the patient population and nature of the medical intervention (i.e. the importance of informed consent for experimental surgery and for organ donors). SOT has produced the most literature. This literature focuses specifically on psychosocial risk factors, which may be a subset of all the elements that should be assessed. This focus is likely due to the responsibility to fairly allocate scare organ resources among many patients in need. Thus, they are seeking to maximize the outcomes from each organ. Accordingly, much of that work has focused on psychosocial elements that are thought to bear on medical and quality of life outcomes, which in turn affect eligibility to be placed on the organ waiting list. In contrast, one patient receiving donated hematopoietic stem cells does not mean that another patient in need will not receive them. Psychosocial factors in HCT then, are considered relative to the risk for each patient, irrespective of other patients.

The item weightings of the PLS, TERS, and SIPAT conceptualize the relative priority of the scale items. In the PLS, prior psychiatric history was given the heaviest weighting (4.0), followed by quality of family/social support (2.0), prior history of coping (2.0), coping with disease and treatment (1.5), quality of affect (1.5), mental status (1.0), and proneness to anticipatory anxiety (0.5) (Futterman et al., 1991). The weightings of the TERS are similar: prior psychiatric history Axis I (4.0), prior psychiatric history Axis II (4.0), substance use/abuse (3.0), compliance (3.0), health behaviors (2.5), quality of family/social support (2.5), prior history of coping (2.5), coping with disease and treatment (2.5), quality of affect (1.5), and mental status (1.0) (Twillman et al., 1993). Subsequent testing of the TERS found that the weighting system provided no additional predictive utility (Hoodin & Kalbfleisch, 2001). The PLS and TERS weightings demonstrate that psychiatric history was conceptualized as the most important contributor to risk for emotional difficulties and worse transplant outcomes. Weightings for the SIPAT could not be found.

Within the limited body of literature, the methods used to conceptualize psychosocial elements vary in their level of rigor from clinical experience and unsystematic literature review to concept mapping. They also vary in their level of participation from the psychosocial professionals who actually conduct assessments, with most being developed with minimal participation. For example, only 1 of 7 authors of the SIPAT was a social worker; the majority were physicians. The concept mapping study with professionals in living organ donation (Ismail et al., 2015) generated the most participation. Of 26 participants, 9 were psychologists. Other disciplines represented included physician, lawyer, philosopher, sociologist, transplant nurse/coordinator, transplant surgeon, and ethicist. At most HCT centers, social workers are responsible for performing the pre-HCT psychosocial assessment, yet their firsthand knowledge and their voices are absent from this literature.

Relationships Between Pre-HCT Psychosocial Factors and Outcomes

The relationship between psychosocial factors and HCT outcomes is an active area of inquiry. If adverse psychosocial factors can be proactively identified, then interventions may be employed to improve clinical outcomes. Evidence of this relationship pertaining to survival and other outcomes will be reviewed.

Survival

An early systematic review evaluated 12 studies that investigated the effect of psychosocial factors on post-transplant mortality in adult patients (Hoodin & Weber, 2003). Categories of variables included social support, depressed mood, psychopathology, coping style, quality of life, and "other" (compliance, family support, individual maturity, marital adjustment, smoking history, and substance use). The authors concluded that the literature was insufficiently developed to determine a relationship between pre-HCT psychosocial factors and survival (Hoodin & Weber, 2003). This conclusion stemmed from methodological shortcomings such as small sample sizes, retrospective designs, and psychosocial measures lacking sensitivity to adequately measure constructs (Hoodin & Weber, 2003).

Three years later, Hoodin et al. (2006) conducted a "mini review" that integrated new data with the data previously reviewed by Hoodin and Weber (2003). The mini review sought to answer the question of whether negative or positive emotions differentially impact post-HCT mortality. The authors noted improvement in methodological quality owing to multivariate analysis to control for confounding factors and longer follow-up periods to handle high attrition related to morbidity and mortality. The "negative emotions" investigated included major and minor depression as assessed by the DSM-IV criteria and other depressive symptomatology measured by scales. The 15 studies varied according to the measures used, which included 7 standardized scales that had psychometric data and brief, researcher-developed self-report questionnaires. In light of the new evidence, the authors concluded that negative emotion pre-HCT was an independent risk factor for worse long-term survival (Hoodin et al., 2006). The effect of positive emotions, such as optimism and hopefulness, improved survival in the short-term (Hoodin et al., 2006).

Since Hoodin et al.'s (2006) review, many studies have examined the relationship between psychosocial variables and post-HCT survival. Variables that have been investigated include overall psychosocial risk, health-related quality of life, depression, anxiety, psychopathology, distress, coping style, social support, substance use, knowledge of treatment, lifestyle factors, compliance, marital status, race/ethnicity, and socioeconomic status (SES).

Psychosocial risk. Four studies that tested the relationship between overall psychosocial risk as measured by the TERS (Richardson, Huang, et al., 2018) and the PACT (Foster, McLellan, Rybicki, Dabney, et al., 2009; Harashima et al., 2019; Hong et al., 2019) found that scores did not predict survival. Solh et al. (2020) found that intermediate-to-high psychosocial risk as measured by the TERS was associated with lower overall survival and higher non-relapse mortality among patients (n=457) with low-to-intermediate disease risk. Among patients (n=90) with high risk disease, though, the TERS score was not associated with outcomes. This finding suggests that psychosocial factors may not significantly impact mortality in patients who are already at high risk of it due to their disease (Solh et al., 2020).

Health-related quality of life. One study assessed the effect of pre-HCT health-related quality of life (HRQoL) on survival. HRQoL was not defined, but the literature generally considers it a subjective, multidimensional concept that includes a person's functioning and ability to experience a fulfilling life in psychological, social, and physical domains (Bevans et al., 2017; International Society of Quality of Life, 2021). HRQoL was measured with the Short Form-36, and findings showed that it was not predictive of survival in recipients of autologous transplant (Wood et al., 2015). In recipients of allogeneic transplant, however, the physical health component of quality of life, but not the mental health component, was strongly predictive of survival (Wood et al., 2015).

Emotional factors. Many studies have examined the effect of pre-HCT depression on survival. El-Jawahri et al. (2017) found that depression was not associated with survival among autologous patients (n = 3786) but did predict worse survival for allogeneic patients (n = 7433). Sample size was a strength of this study, but measurement was a limitation. Depression was measured via a single-item reported by transplant center staff to a registry database. The item asks, "Is there clinically significant depression requiring treatment?" This wording may be interpreted differently by different staff, which poses a problem for the reliability and validity of this data. Barata et al. (2020) found that depression, as measured by a score of 10 or greater on the PHQ-8, did not have an effect on overall survival in a sample of recipients who had received allogeneic HCT and a sample who had received autologous HCT. As measured by two subscales on the BSI-18, neither depressive nor anxiety symptoms predicted survival. (Pillay, Lee, Katona, Burney, & Avery, 2014). When measured by the Million Behavioral Medicine Diagnostic, depression did not affect 1 year-mortality in allogeneic transplant recipients

(Pereira et al., 2010). The PACT items, “psychopathology/stable personality factors” and “risk for psychopathology” have been found to have no effect on mortality (Foster, McLellan, Rybicki, Dabney, et al., 2009; Harashima et al., 2019; Hong et al., 2019). The mainly null findings of these studies conflict with Hoodin et al.’s (2006) review that found an association between “negative emotions” and survival.

Studies have examined the relationship between pre-HCT distress and survival. Among 4 studies, distress was measured in 5 different ways. Of the two studies that used investigator-constructed ratings, one found that distress was unrelated to survival (Ehrlich et al., 2016), while the other found that patients with distress had a higher 1-year mortality rate compared to those who did not (Park et al., 2010). The latter study categorized patients as having “distress” if a diagnosis of adjustment disorder, anxiety disorder, delirium, dementia, mood disorder, personality disorder, or substance abuse was documented in their medical record. The study that measured distress specifically related to cancer and its treatment using the Cancer and Treatment Distress Scale (CTXD) found no association between distress and survival in autologous or allogeneic patients (Knight et al., 2016). When measured with the Brief Symptom Inventory (BSI-18), patients with higher scores on the somatic symptoms subscale, called “somatic distress” by the authors, had poorer survival (Pillay et al., 2014). Scores on the subscale measuring “global distress” were not associated with mortality (Pillay et al., 2014).

This literature has strengths and limitations. The studies have large enough sample sizes to use multivariate statistics. Statistical analyses are consistent, though there is some variation in the number of demographic and medical covariates analyzed. Measurement is a limitation. Studies varied greatly in their measurement of psychosocial constructs. The retrospective nature of the studies likely contributed to this. Also, samples are not geographically diverse enough to represent the general HCT population. With the exception of a few national samples, the published literature represents specific geographic locales: Illinois, Ohio, Florida, Seoul (South Korea), Melbourne (Australia), and Tokyo (Japan). Therefore, caution should be used in generalizing the results. The age of the data is another limitation. Among the eight studies that reported time periods, the range for data collection was 2000-2017, with only two studies including data collected no earlier than 2010. Changes in HCT practice over time limit the comparability of data collected earlier vs. later.

Coping style and spirituality. Research on coping style and spirituality is limited. In their investigation of a relationship between coping style and survival, Pillay et al. (2014) used the Mental Adjustment to Cancer (MAC) subscales to examine coping styles include fighting spirit, anxiety/preoccupation, helpless/hopeless, fatalism, and avoidance. They found no relationships with survival. A study that investigated the relationship between "spiritual absence" and survival after allogeneic HCT found that individuals with the highest spiritual absence scores were more likely to die within 1 year of transplant (Pereira et al., 2010). The measure in this study assessed "the degree to which patients lack religious or spiritual personal resource to cope with medical stressors." (Pereira et al., 2010, p. 1172).

Social support. Findings on the relationship between social support and post-HCT survival have been mixed. A 2013 systematic review identified 6 studies that investigated this relationship (4 published articles, 1 dissertation, and 1 abstract) (Beattie et al., 2013). Of the articles, the most recently published was in 2005. The dissertation was completed in 2007, and the abstract was published in 2011. Three of the published studies and the abstract found an association between better support and survival (Colón et al., 1991; Foster et al., 2005; McLellan et al., 2011; Rodrigue et al., 1999), but the dissertation, which was the largest study (n = 272) found no association (Artherholt, 2007). In this literature, social support was measured inconsistently with both validated scales (Artherholt, 2007; Frick et al., 2005) and investigator-constructure measures (Colón et al., 1991; Foster et al., 2005; McLellan et al., 2011; Rodrigue et al., 1999). Most of the research examined the presence of social support. Frick et al. (2005) was the only study to examine the quality of support. They found that "positive" social support did not influence survival but that "problematic" social support, as measured by the Illness Specific Scales of Social Support, was associated with poorer survival (Frick et al., 2005).

Literature published since (or not included) in Beattie et al.'s (2013) review has also contained mixed findings. Ehrlich et al. (2016) retrospectively reviewed psychosocial assessment reports that were documented in the medical record of 400 recipients of allogeneic transplant and coded each patient as having "poor support" or "good support." Good emotional support predicted longer survival (Ehrlich et al., 2016). Other studies that have examined social support have used the PACT items of "family or support system stability" and "family or support system availability." Foster, McLellan, Rybicki, Dabney, et al. (2009) found that better scores for family or support system availability predicted decreased risk of mortality, but Harashima et al. (2019) and Hong et al. (2019) found no association.

There is much opportunity for increased rigor in this area of research. Social support is a complex construct, and it has been conceptualized and measured in different ways in this literature. Future research should be guided by theory of how social support influences health (main effect or buffer) and should include conceptual definitions of social support. It should also apply more sophisticated measurement instruments for both perceived and received support.

Substance use. An early, retrospective, single center study identified 17 patients with “lifetime substance abuse” and compared their survival with 17 patients matched on clinical variables (Chang et al., 1997). The patients with “lifetime substance abuse” were found to have worse survival, a difference that persisted after stratifying for transplant type and cigarette smoking (Chang et al., 1997). Another retrospective, single center study reviewed medical records from 2000-2010 to identify “alcohol use disorder” (AUD) among patients who underwent autologous transplant for lymphoma (Graf et al., 2016). Within the sample of 754 patients, 86% were white, median age at transplant was 53 (range 18-78), and 11% (n=81) were identified as having AUD. Findings showed AUD was associated with worse survival. Analysis of AUD, comorbidity index score, and age as 3 risk factors found that non-relapse mortality by day 100 post-transplant (surrogate for treatment-related mortality) increased from 1% in patients with no risk factors, to 3% in patients with 1 risk factor, 6% in patients with 2 risk factors, and then to 27% in patients with all 3 risk factors (Graf et al., 2016). The PACT item, “drug and alcohol use" has been found to not be associated with survival (Foster, McLellan, Rybicki, Dabney, et al., 2009; Harashima et al., 2019; Hong et al., 2019).

The body of literature that examines the relationship between substance use and survival is extremely limited. The age of the data and retrospective nature of the studies is a limitation. Reliability and validity in the measurement of substance use is another limitation. The studies that used older data classified patients as having substance use based on chart review. Given the stigma around substance use, patients may not share this information, or if they do, they may not share it accurately. Also, providers may inconsistently document it in the medical record. Studies using the PACT rely on a single item rated by the psychosocial professional. The item does not distinguish between drug and alcohol use. Patients, knowing they are being evaluated for HCT eligibility, may not fully disclose their substance use. Overall, the amount and rigor of the empirical evidence does not substantiate the conclusion that patients with substance use fare worse with transplant.

Other PACT items. Foster, McLellan, Rybicki, Dabney, et al. (2009) found that better scores on "relevant knowledge and receptiveness to education" as measured by the PACT item predicted decreased risk of mortality, but Harashima et al. (2019) and Hong et al. (2019) found that it did not. The item, "healthy lifestyle, ability to sustain change in lifestyle" has been found to have no relationship with survival (Foster, McLellan, Rybicki, Dabney, et al., 2009; Harashima et al., 2019; Hong et al., 2019). Two of three studies found that "compliance with medications and medical advice" was not associated with survival (Foster, McLellan, Rybicki, Dabney, et al., 2009; Hong et al., 2019), while one found that poorer compliance was associated with worse survival (Harashima et al., 2019).

Marital status. Evidence on relationship between marital status and post-transplant survival conflicts. Some studies have found no relationship (Colón et al., 1991; Frick et al., 2005; Molassiotis et al., 1997; Tschuschke et al., 2001) but some have found that being married is an advantageous prognostic factor (Hoodin et al., 2004; Pillay et al., 2014). A recent, large study used data reported to an observational database to examine the relationship between marital status and survival post-HCT among patients 40 and older who had undergone autologous (n = 5714) or allogeneic (n = 10,226) transplant (Tay et al., 2020). Marital status was defined as being married or living with a partner. Median follow-up was 40 months (range: 1-106 months) in the autologous cohort and 37 months (range: 1-102 months) in the allogeneic cohort. Results showed that marital status was not associated with survival in either of the cohorts (Tay et al., 2020). The age of much of the literature is a limitation. The relationship between marital status and survival may be moderated by gender and dimensions of social support i.e. type and quality (Aizer et al., 2013). Measuring dimensions of social support and conducting analyses that account for potential differences in effect based on gender could help clarify this literature.

Race and ethnicity. A review by Majhail, Nayyar, Burton Santibañez, et al. (2012) included 9 studies that examined differences in outcomes among people of color. Four included only patients undergoing autologous HCT for multiple myeloma (Hari et al., 2010; Khaled et al., 2009; Saraf et al., 2006; Verma, Howard, & Weiss, 2008); four included patients undergoing allogeneic HCT for acute and chronic leukemias (Baker et al., 2009; K. S. Baker et al., 2005; Ballen et al., 2010; Serna et al., 2003); and one included patients undergoing autologous and allogeneic transplants for multiple diagnoses (Mielcarek et al., 2005). For autologous transplant, one study found that black patients had worse survival than white patients (Khaled et al., 2009), and 4 studies (Hari et al., 2010; Mielcarek et al., 2005; Saraf et al., 2006; Verma et al., 2008) found no association between race and survival. For allogeneic transplant, analyses of data from 1985-1999 and 1990-2000 found that patients identified as Hispanic had worse survival than non-Hispanic whites but that blacks and Asians had comparable survival to non-Hispanic whites (Baker et al., 2005; Serna et al., 2003). Analysis of data from a single institution from 1992-2000 and analysis of data reported to a national registry between 1995-2004 found that recipients of allogeneic transplant who were black had worse survival compared to whites, controlling for socioeconomic status (Mielcarek et al., 2005). Taken together, the evidence suggests that patients of color are at risk for worse survival after allogeneic HCT; the evidence is mixed for post-autologous survival (Majhail et al., 2012).

Since Majhail et al.'s (2012) review, two studies (Ailawadhi et al., 2017; Bhatnagar et al., 2015) have found no differences in survival according to race after autologous transplant. A single center, retrospective study conducted with 296 patients (73% NHW and 27% people of color) who underwent allogeneic transplant for leukemia and lymphoma found that survival was comparable between the two groups (Khera et al., 2015). This study also measured medical resource utilization post-transplant (inpatient admissions, length of stay, emergency room visits, and outpatient visits) and found that it was comparable between NHWs and people of color. The researchers posited that the comparable survival in their sample was explained by the uniform post-transplant treatment approach at their center (Khera et al., 2015).

The small body of literature that examines the relationship between race and ethnicity and HCT outcomes is retrospective and uses data from a national registry or from a single center. National registry data tends to lack details about psychosocial variables, and even the single center designs, because they are retrospective, are inherently limited in the types of data they can use. The current literature does not explicitly state the theoretical framework(s) that guides the inquiry. Future research should use prospective designs and incorporate social science theory. This would take inquiries beyond the characteristic of socially-assigned race and inform the selection of instruments to measure structural and other important factors such as perceived everyday racism and neighborhood segregation.

Socioeconomic status. A large, heterogenous sample found no effect of SES on overall survival (Knight, Syrjala, et al., 2016). Other research in HCT that has found low SES, independent of race, has been associated with worse survival (Baker et al., 2009; Silla et al., 2009).

Summary Critique

Overall, the literature that examines the relationship between psychosocial variables and survival lacks specified theoretical frameworks. It also contains varied methodological quality and scattered use of measures. Given this, it is difficult to make conclusions about what psychosocial variables may influence survival after HCT. Moreover, the answer to this question is likely a moving target based on continuing advancements in transplant medicine. For example, the availability of lower intensity preparatory regimens meant HCT could be offered to older adults and individuals with comorbidities. Therefore, in the last 10 years, the transplant population has become an increasingly older population (Burns, March 23, 2021). Also, two drugs recently approved by the U.S. Food and Drug Administration (ruxolitinib and ibrutinib) have the potential to improve outcomes for patients experiencing steroid-refractory acute and chronic GVHD (Burns, March 23, 2021).

Future research could be enhanced with reporting of theoretical frameworks that guide the research, clearly conceptualized psychosocial variables, prospective designs, consistent use of instruments that have good reliability and accumulated evidence of validity in oncology/medical populations, and a standard set of medical and demographic covariates. Finally, it is critical that researchers delineate the variables that are most likely to influence survival and focus rigorous research efforts on them.

Other Outcomes

Medical outcomes other than survival that have been studied include health-related quality of life, readmission, nonadherence, and immune reconstitution.

Health-related quality of life. H. L. Amonoo et al. (2019) conducted a systematic review of literature examining the association between positive psychological constructs and health outcomes in HCT. Positive psychological constructs were defined as constructs that characterize individuals who feel positive about life and function well psychologically. Examples of these include optimism, hope, gratitude, perseverance, vitality, meaning, purpose in life, personal growth, and contentment. The authors found 18 eligible studies with a total N = 4201 and mean age = 47. Optimism was the most frequently studied construct (12 studies) and health-related qualify of life was the most frequently studied outcome (11 studies). The 17 studies with quantitative analyses all found an association between a positive psychological construct and better health outcomes. Of the studies that reported race/ethnicity, 79% of study participants were non-Hispanic white.

Hospital readmissions. Hospital readmissions are an outcome of interest, since studies have found a positive association between readmissions and mortality in HCT patients (Richardson, Huang, et al., 2018). TERS overall psychosocial risk rating was found to be associated with risk of hospital readmission within 90 days but not length of inpatient transplant stay (Richardson, Huang, et al., 2018). In the same study, TERS items for prior psychiatric history and poor coping skills that were scored as at-risk also predicted readmission (Richardson, Huang, et al., 2018). Among patients considered psychosocially high-risk, readmission for infection was more common; readmissions for other causes did not differ significantly between the high-risk and low-risk groups. Only 2% of patients were identified as noncompliant, and these were more likely to be readmitted (Richardson, Huang, et al., 2018).

Nonadherence. Nonadherence to the post-transplant regimen can lead to life-threatening complications. Overall, patients at greater risk for nonadherence are those who are younger, male, and express concerns about medical costs (Bevans et al., 2017). Mumby et al. (2011) studied a cohort of patients undergoing autologous transplant on an outpatient basis. They defined nonadherence as “refusal of oral hygiene, prescribed exercise programs, oral nutrition, and/or prescribed medications” (p. 556). This definition resulted in 80% of patients (n = 121) being labeled as nonadherent. Men and patients with elevated depression scores were more likely to be nonadherent. Stepwise regression models found that gender, depression, global distress, and nausea and vomiting severity predicted noncompliance with the interaction of gender and psychological variables explaining most of the variance (Mumby et al., 2011).

Mishkin et al. (2019) examined whether overall psychosocial risk, as measured by the SIPAT, predicted nonadherence. They defined nonadherence as “at least one life-threatening nonadherence event in the first 6 months post-transplant,” which resulted in 18 (21%) of patients being labelled nonadherent (Mishkin et al. 2019, p. 2223). Results showed an independent association between the SIPAT score and nonadherence after controlling for type of transplant, age, sex, and disease.

Immune reconstitution. Immune reconstitution has been an outcome of interest for biobehavioral research. Faster return of immune system function has been associated with fewer side effects and better survival (Auletta & Lazarus, 2005; Porrata et al., 2008). Psychosocial variables that have been studied as predictor variables include anxiety, depression, distress, socioeconomic status, optimism, compliance, and substance use.

McGregor et al. (2013) studied a cohort of 70 autologous transplant recipients who were 93% non-Hispanic White, 55% male, and an average of 38 years old. They measured cancer and treatment-related distress, anxiety, and depression pre-transplant, and they measured white blood cell count recovery on days 5-22 post-HCT. Using linear mixed model regression analyses that controlled for gender and treatment-related variables, they found that higher anxiety and depression subscale scores as measured by the Symptom Checklist-90-R were associated with slower white blood cell recovery. Scores on the Cancer and Treatment Distress scale were not associated with white blood cell recovery (McGregor et al., 2013).

Knight, Rizzo, et al. (2016) examined the relationship between low socioeconomic status and expression of a gene profile that has been associated with worse survival. SES was measured as patient income estimated by mean household income tied to their residential zip code. While planning to analyze racial and ethnic groups separately, the samples were insufficient, so their analysis is limited to non-Hispanic whites only. Patients of lower SES were found to be more likely to express the adverse gene profile. Even so, the largest and most heterogenous samples (n = 646 autologous and allogeneic recipients) found no effect of SES on neutrophil (type of white blood cell) and platelet engraftment (Knight, Syrjala, et al., 2016). Variables associated with low SES prior to transplant in this study were worse physical functioning, distress, and poor sleep quality.

Knight et al. (2014) examined the effect on pre-transplant optimism and anxiety on the number of days to engraftment. They found that higher optimism and lower anxiety were associated with fewer days to engraftment in recipients of autologous but not allogeneic transplant. This association, however, did not hold when they reduced the sample to only those patients who completed their surveys before engraftment (Knight et al., 2014). Engraftment is a significant and celebrated milestone, so patients' self-reports of optimism and anxiety after this event may be altered and not accurately reflect their pre-engraftment emotional state.

Finally, Foster, McLellan, Rybicki, Dabney, et al. (2009) found that better scores on the PACT item for compliance were associated with faster neutrophil and platelet engraftment and that better scores on the drug/alcohol use item were associated with faster platelet engraftment.

Summary Critique

This literature examines the relationship between psychosocial factors and outcomes that are hypothesized to influence survival. The independent and outcome variables that have been studied are scattered, which has resulted in a lack of accumulated evidence between any one psychosocial factor and non-survival medical outcome. Researchers should delineate the most salient factors and non-survival outcomes and focus their research efforts on those.

Theoretical Models

There is an abundance of theoretical literature elucidating the complex relationships between psychosocial factors and biomedical factors/outcomes. While not explicitly stated, the literature reviewed in the previous section is generally underpinned by these models. This section will review some key theoretical models.

Biopsychosocial Model

In 1977, George L. Engel critiqued the reigning biomedical model, which conceptualized disease in terms of molecular biology. He argued that biological factors alone were insufficient for conceptualizing health and illness. Instead, he proposed that health and illness should be conceptualized in terms of biologic, psychologic, and social factors. Drawing from a general systems theory perspective, the biopsychosocial model proposes that all of these factors interact and influence one another to shape health and illness. Thus this model advances a holistic understanding of the person (Engel, 1977).

McEwen’s Stress Process Model

McEwen’s stress process model offers a framework to understand the widely accepted relationship between stress and the development and progression of disease (McEwen, 1998). The model suggests that people who endure more stress are more likely to have poor health over time. Stress is defined as “a threat, real or implied, to the psychological or physiological integrity of an individual” and may be acute (i.e. a major event or an event that produces a flight or fight response) or chronic (i.e. minor daily stresses) (McEwen, 2000, p. 108). Sources of stress may be physical, social, emotional, and/or environmental (McEwen, 1998).

The model depicts the brain’s perception of stress directly influencing the body’s physiological response to stress (i.e. activating stress hormones and the immune system). The brain’s perception of stress also indirectly influences the physiological response through an individual’s behavioral response (McEwen, 1998). While the physiological response to stress protects the body in the short-term, over time it causes damage, adversely affecting organ systems and accelerating disease processes. This wear and tear over time is referred to as allostatic load. The heavier the load a person carries over their lifetime, the more risk they have for morbidity and mortality (McEwen, 1998).

Andersen’s Biobehavioral Model of Cancer Stress

Andersen et al. (1994) propose a model in response to literature showing that psychological distress and acute and chronic negative life events are linked with impaired immune system functioning. Their model suggests mechanisms by which psychological and behavioral responses influence biomedical processes and outcomes specific to cancer. Specifically, their model depicts the cancer diagnosis and treatment producing stress, which then leads to reduced quality of life. This affects the central nervous system and neuroendocrine system and results in in lower immunity. Lower immunity has direct and reciprocal impacts on both localized cancer and metastatic disease, ultimately affecting the course of the disease. In addition to impacting immunity, stress also directly influences compliance and health behaviors. Compliance and health behaviors have a reciprocal relationship with one another.

Health behaviors impact immunity. For example, distressed individuals may be more likely to engage in unhealthy eating, cigarette smoking, and substance use. They also may have difficulty sleeping and be less likely to exercise. These behaviors negatively impact immune system functioning. Compliance impacts both local and metastatic disease. For example, noncompliance in attending radiation therapy appointments or stopping the prescribed course of radiation early may lead to treatment failure at the local site. Similarly, not taking oral chemotherapy as prescribed and not returning for follow-up monitoring could lead to failure to control metastases.

Compared to McEwen's (1998) model, Andersen et al.'s (2004) model focuses more on proximal contributors and pathways for disease progression and outcomes. Accordingly, it does not include environmental-level factors associated and accumulated stress load over a lifetime. The role of immunity as the link between psychological and behavioral factors and disease course seems particularly salient in the setting of HCT, where treatment involves destroying, in whole or in part, the patient's immune system.

Biobehavioral Model of Recovery Post-HCT

Costanzo et al. (2013) proposes a model by which psychosocial factors influence post-HCT outcomes. Their model highlights "psychosocial/behavioral factors" including mood/affect, psychological stress, protective cognitive and behavioral processes, and social support. Stress from these factors is proposed to activate the neuroendocrine and sympathetic nervous systems and innervate the bone marrow. These processes modulate immune cell recovery and inflammation post-HCT. Immune recovery and inflammation influence engraftment, infections, and graft vs. host disease, which in turn impact clinical outcomes including disease relapse, survival, and quality of life (Costanzo et al., 2013). Like Andersen et al.'s (2004) model, immune system functioning is a key mechanism. Also like Andersen et al.'s (2004) model, intrapersonal and interpersonal factors, but not environmental-level factors, are considered.

Philosophical Underpinnings for this Study

Postmodernism and constructivism form the philosophical base for this study and will be discussed briefly.

Postmodernism

According to Howe (1994), "The most pervasive notion [of postmodernism] is that there are no transcendent, universal criteria of truth, judgement and taste that can be applied to all situations at all times in all places" (p. 520). Truth is localized and dependent on context. Truth is interpreted, and its meaning is embedded in language. As language changes, so do meaning and truth. Truth evolves to serve different purposes and can only be appraised within its own local context where it meets perceived needs and serves specific purposes. (Howe, 1994).

Postmodernism champions pluralism and embraces multiple realities. (Howe, 1994). It de-centers power by having no absolute authorities or privileged perspectives. Instead of having their realities defined by special holders of knowledge and power, individuals who have historically had less power are invited to participate in social discourse, shaping it with the knowledge of their experiences (Howe, 1994).

Application. The psychosocial elements that should be assessed in HCT candidates is specific to HCT. While it is useful to consider what factors are assessed in other contexts, it is imperative that the community of HCT psychosocial professionals speak to assessment in their context. This concept mapping study de-centers power by inviting active participation among psychosocial professionals whose experience is not currently captured in the literature. It invites them to voice their experience, and it values this as a contribution to knowledge.

Constructivism

Constructivism asserts that reality does not exist in an empirical way but is created by the individual as they interact with their environment (Berger & Luckmann, 1966). Thus, reality is determined by the individual's experience. Social constructionism, closely related to constructivism, claims that individuals' knowledge of the world is mediated by their socially shared understandings within a society or culture, and their behavior is influenced by the meaning the make of events, not the events themselves. Individuals are also constrained by the external structures of society, including relational processes through which patterns of norms and expectations are established (Berger & Luckmann, 1966).

Application. This study assumes that psychosocial professionals construct knowledge based on their individual experiences. Their knowledge is influenced by the meaning they make while working with patients and families undergoing HCT. Their knowledge is also influenced by their social work or psychology education, professional socialization, transplant center processes/protocols, and relationships with their team members and social work colleagues. Through their experiences, study participants construct their realities. Concept mapping methods elicits this from them and represents the composite reality of the participants in a conceptual framework.

CHAPTER III: METHODOLOGY

The purpose of this study is to explicate a conceptual framework of psychosocial elements assessed in candidates for hematopoietic cell transplantation (HCT) and to explore differences in the conceptualization based on the use of risk rating scales in clinical practice. As discussed in chapter 2, current conceptualizations do not contain the perspective of those who actually perform this clinical work. Therefore this study uses a participatory methodology that engages the voices of those previously unheard and seeks to capture the diversity of their thoughts regarding a topic in which they have special knowledge. Research questions include:

1. How do psychosocial professionals conceptualize the elements they assess in candidates for hematopoietic cell transplantation?

2. Is there a difference in the conceptualization based on the use of standardized risk rating scales in clinical practice?

Because the study is exploratory, there are no hypotheses.

Concept Mapping

Overview

Concept mapping is a mixed methodology that uses multivariate statistics to analyze qualitative data (Kane & Trochim, 2007). It is a systematic process used to elicit, compile, and organize the ideas of a group of stakeholders (Kane & Trochim, 2007). The process yields a composite framework, or conceptualization, that is visually represented in a series of maps. Concept mapping has many uses: theory building, program and intervention planning, evaluation, and developing scales and measures (Kane & Rosas, 2018).

Since it was introduced 30 years ago, concept mapping methodology has been used in many academic areas including education (Morley et al., 2017; Winseman et al., 2015; Ziring et al., 2018), nutrition (Keita et al., 2016; Reppond et al., 2018; Walker et al., 2010), child welfare (Miller et al., 2017; Miller & Jones, 2015; Ridings et al., 2010), community wellness (Burke et al., 2009; Dulin Keita et al., 2016; Kading et al., 2019), violence prevention (Maddox et al., 2019; Snider et al., 2010; Vives-Cases et al., 2017), and gerontology (Anderson et al., 2014; Bennett et al., 2018; Conrad et al., 2011). Concept mapping has also been used in cancer care. Some examples of study purposes in cancer care include identifying barriers to cancer screening (Lobb et al., 2013; Weinstein et al., 2015), translating research into clinical practice (Graham et al., 2008; Vinson, 2014), and survivorship needs of adolescents and young adults (Hydeman et al., 2019).

In their foundational text on the methodology, Kane and Trochim (2007) describe six steps in the concept mapping process: 1) preparing, 2) generating the ideas, 3) structuring the statements, 4) analyzing the data, 5) interpreting the maps, and 6) using the maps. Each step builds upon the previous and will be reviewed in turn.

Prepare

To prepare for a concept mapping study, the researcher identifies the domain of conceptualization (Trochim, 1989b). For this research, the conceptual domain was identified as psychosocial elements that should be assessed in HCT candidates. The researcher then prepares focus prompts to be used in the brainstorming phase and the rating activity (Kane & Trochim, 2007). A brainstorming focus prompt provides direction to the participants and helps capture their ideas about the conceptual domain. There are two commonly used types of prompts (Kane & Trochim, 2007). One is a statement instruction: "Generate ideas about (the topic)." Another is an incomplete sentence that participants would finish: "A successful outcome means…" This study used a statement instruction: "Generate short phrases that describe elements that should be assessed in an HCT candidate." This prompt type made sense given that participants were provided with an initial statement set. The rating activity focus prompt provides participants instructions on rating the ideas in the statement set. For this study, the rating prompt was, "In your view, how important is this item for the quality assessment of a transplant candidate?"

Sampling and participants. The researcher identifies and selects participants for the concept mapping process (Trochim, 1989b). Participants may represent a broad or narrow range of stakeholders, depending on the purpose of the study and utilization of the maps (Kane & Trochim, 2007). Clinical social workers and psychologists who work in HCT were selected for this study because of their ability to contribute information needed to answer the research questions. Both have knowledge and experience in assessing HCT candidates that has not been represented in the literature. Furthermore, they will use the maps to create an assessment protocol for their clinical practice.

The goal of sampling "is to achieve a broad sampling of *ideas* rather than a representative sampling of persons" (Kane & Trochim, 2007, p. 36). For this study, participants were selected for the brainstorming phase based on their availability to participate in an in-person session at the Association of Oncology Social Work's (AOSW) annual conference. A non-random, purposive sample was recruited via emails sent to AOSW membership. While brainstorming may be done remotely and even asynchronously, the in-person format had the following advantages: face-to-face interaction, no technological difficulties, not having to schedule across time zones, higher and more focused participation due to no distraction from demanding caseloads, and team-building that could promote the study's subsequent tasks.

It is not necessary for participants to participate in all phases of the concept mapping process, though the resulting maps tend to be better understood by those who have (Kane & Trochim, 2007). Participants in the brainstorming phase were offered the opportunity to participate in the sorting and rating phases. To increase the number of participants, additional participants were recruited via email for the sorting and rating phases. This occurred through invitation sampling. The researcher contacted participants who had participated in the brainstorming phase and in previous survey research and who had expressed a desire to be involved with the project. Inclusion criteria for the study were psychosocial professionals (social workers and psychologists) who have experience assessing HCT candidates.

The number of participants in concept mapping may vary. According to Kane and Trochim (2007), having 10-40 participants "seems to provide a good framework" and ensures "a variety of opinions" (Kane and Trochim, 2007, p. 36). For the structuring phase, Jackson and Trochim (2002) recommend a minimum of 15 participants. This study met these standards. A total of 18 individuals, representing 16 different transplant centers, participated in the in-person brainstorming session. Given time constraints at the AOSW conference, the session was continued via two conference calls. A total of 12 participants attended the first conference call, and 8 attended the second. A total of 25 participants participated in the sorting and rating tasks, with 18 providing usable sorting data and 24 providing usable rating data.

Preparing for the study also involved applying to the University of Louisville's Institutional Review Board for approval to conduct research with human subjects. Approval was granted before any study activities with human subjects commenced. Since the additional conference calls were a deviation in the study protocol, an amendment was submitted and approved by the IRB before the calls were conducted. Given the low risk of harm, informed consent was obtained via preamble before the brainstorming phase and the structuring phase.

Generate the Ideas

In this phase, the goal is to develop an exhaustive list of items, called "statements," that capture the diversity of thought around the conceptual domain (Kane & Trochim, 2007). In most concept mapping studies, group brainstorming (Diehl & Stroebe, 1991) is used to generate the exhaustive list, but Kane and Trochim (2007) mention some alternative methods. One method is to use a predetermined statement set, e.g. based on theoretical categories or scale items. Another method is to tap into a "naturally occurring 'text database'" i.e. organizational reports, memos, and other documentation (Kane and Trochim, 2007, p. 62). Groenewoud et al. (2008) used multiple sources of data to generate a statement list: an internet search, semi-structured interviews, and associated documents. Haque and Rosas (2010) used data from a photovoice project (photos with captions) as their statement set. Ismail et al. (2015) developed an initial statement list based on a systematic literature review and then asked participants to build on this list during the brainstorming session.

For this project, the researcher generated an initial list of items from assessment template data that was collected in a nationwide survey of psychosocial professionals in HCT (Randall et al., 2021). The researcher abstracted all but redundant text from the templates until no new ideas appeared. This saturation point occurred after 20 templates. During the in-person session facilitated by the researcher, the purpose of the research was explained, along with the specific purpose of the brainstorming session. Participants introduced themselves and ground rules were established. The researcher provided a paper copy of the list to all participants in the in-person group and asked them to contribute any other ideas based on the focus prompt. The purpose of starting with an initial list was to maximize the limited amount of time available during the in-person session. This method also allowed more voices to be heard. Given their anonymity, it also allowed expression without the potential discomfort of being judged for their practice. Thus, this method may have yielded greater breadth of thought in the statement set.

Idea synthesis. In addition to contributing new ideas to the list, participants engaged in idea synthesis. Idea synthesis is the process used to reduce and edit the statement set in a manner that maintains the overall integrity of the ideas. It yields a final statement set that is considered the conceptual domain and is used in the next concept mapping phase. (Kane & Trochim, 2007). Idea synthesis ensures that there is only one idea per statement, that each statement is relevant to the project, and that statements are worded clearly. Idea synthesis also ensures that the final statement set is a manageable size. The size of the final statement set needs to balance capturing the full breadth of the conceptual domain with minimizing participant burden (Rosas & Kane, 2012).

It is not unusual for idea synthesis to take several hours (Kane & Rosas, 2018). It is also not unusual to eliminate a significant number of statements during this process. For example, Groenewoud et al. (2008) reduced a statement set (generated through literature review) of 750 down to 178. A pooled study analysis of 69 concept mapping studies found that there was an average of 96 statements in the final set per study (SD = 17), range 45 – 132. In this study, the initial brainstormed list contained 153 statements, and the final statement set included 114.

Structure the Statements

The structuring phase includes two conceptual tasks: sorting and rating. The sorting and rating activities may occur in an on-site session or electronically. Given the geographic dispersal of participants, sorting and rating were completed electronically via groupwisdom™, a proprietary online application (The Concept System, 2020).

Sorting refers to grouping statements into sets of like ideas according to theme or meaning. This identifies participants' perceptions of how the ideas relate to one another organizes the complexity within the conceptual domain. Consistent with Kane and Trochim's (2007) recommendations, participants were given instructions on sorting. This was done via a video that the researcher created to introduce the activity. The video was embedded in the groupwisdom™ application (The Concept System, 2020) so that participants viewed it before commencing the task. Instructions asking the participants to 1) read through all of the statements first, 2) sort each statement into a pile according to their view of the theme or meaning, 3) group the statements for how similar they are to one another in theme or meaning, 4) do *not* create groups according to priority or value, 5) do *not* create categories such as ‘other’ or ‘miscellaneous’ to group dissimilar statements, 6) if unrelated to all the other statements, put it alone in its own category, and 7) make sure every statement is sorted somewhere. These rules help ensure that interrelationships between statements are captured in the participant’s determination of where the statement is best located. Participants were also asked to name each pile according to the theme or meaning. In the effort to address the potential concern participants may have about creating the “right” number of piles, participants were informed that people vary in how many categories they create.

After sorting, participants were asked to rate each statement’s importance. The rating focus prompt was used: “In your view, how important is this item for the quality assessment of a transplant candidate?” Response choices were on a 5-point Likert scale, with higher scores reflecting more importance: Very important (5), Important (4), Moderately important (3), Slightly important (2), Relatively unimportant (1).

The researcher included video instructions to participants as an introduction to the rating activity. Instructions addressed the tendency to answer according to a response set or rate the importance of all items highly (Kane & Trochim, 2006). To combat this tendency, participants were instructed to first scan the entire list of statements to get a sense of which ones are of relatively higher and lower importance. They were then asked to make comparative judgments between the statements, using the full range of values, from 1 to 5 (Kane & Trochim, 2006).

Analysis

Concept mapping analysis uses the sorting and rating data to generate conceptual maps and other reports. The maps and reports produced in this study's analysis include: point map, cluster map, point rating map, cluster rating map, pattern match, and go-zone graphs. Each will be explained. The Concept System® groupwisdom™ application was developed specifically for concept mapping analysis and was used in this study (The Concept System, 2019).

Sorting analysis. Three steps, each building on the previous, form the core analysis of the sorting data. First, individual binary similarity matrices were computed for each participant based on how they sorted the statements. These matrices were aggregated to produce a similarity matrix. This matrix is a square symmetric matrix showing the number of participants who sorted each pair of statements together. Higher values indicate greater agreement about the conceptual relationship, while lower values indicate little (or no) conceptual relationship (Trochim, 1989b).

Multidimensional scaling. Second, multidimensional scaling (MDS) was performed on the similarity matrix (Kane & Trochim, 2007). MDS output represents the matrix as distances between the original statements, where each item is located as a separate point on a two-dimensional (X, Y) plot. This plot, referred to as a point map, consists of points representing each statement. On this map, items that are often sorted together appear closer to one another than items not often sorted together (Kane & Trochim, 2007).

The stress value (Kruskal & Wish, 1978) is the primary statistic of interest in MDS. The stress value indicates the degree of discrepancy (or goodness-of-fit) between the MDS solution (distances on the point map) and the values in the original similarity matrix. A lower stress value is desirable because it indicates better concordance. According to Kane and Rosas (2018), typical concept mapping projects have stress values ranging from 0.10 – 0.35, which signals that the map is interpretable. In their pooled study analysis, Rosas and Kane (2012) found that the average stress value for 69 studies was 0.28 with range: 0.17 – 0.34.

Hierarchical cluster analysis. Third, hierarchical cluster analysis (HCA) is performed on the multidimensional scaling coordinates. HCA uses resemblance coefficients to analyze similarities in datasets (Romesburg, 2004). In concept mapping, HCA uses Ward's algorithm and the MDS *x-y* coordinate data to partition the map into clusters (Rosas & Camphausen, 2007). Cluster parameters are defined using analysis of variance as developed by Ward (1963). This analysis divides the coordinates, or statements, on the point map into distinct clusters.

The bridging statistic is essential in cluster analysis. It ranges from 0 – 1 and indicates the frequency with which a statement is sorted into a particular cluster vs. other clusters (Kane & Trochim, 2007). Statements with lower bridging values are sorted more frequently with statements in their immediate vicinity as opposed to statements in other clusters. These statements are considered to reflect the meaning of that part of the map more strongly and are referred to as "anchors." Statements with higher bridging values are sorted more frequently with statements in other areas of the map. These "bridges" "suggest a broader relationship of that statement across the map, providing a 'bridge' from its home location to other cluster or areas" (Kane and Rosas, 2012, p. 63).

Observing anchoring and bridging relationships is helpful to understanding the overall meaning of the map.

Finalizing the cluster solution. There is no formula to determine the final cluster solution, and there is no one "right" number of clusters (Kane & Trochim, 2007). Different cluster solutions are examined and a final solution is selected based on the aforementioned statistics and goals of the project. Some projects involve the participants in this process, others use a small advisory group, and for some, the decision is made solely by the researcher. For this study, the researcher worked with a member of the dissertation committee to select a final cluster solution that fit with the goals of the study. The researcher then labeled the clusters based on the labels that participants used when sorting.

Rating analysis. Analysis of ratings data varies based on the needs of the research. This study generated point rating maps, cluster rating maps, pattern matches and go-zone graphs. Point rating maps show the average ratings of importance for each statement. Cluster rating maps show the average importance ratings for all statements in a cluster.

Pattern match. A pattern match compares average cluster ratings from two groups (Kane & Trochim, 2007). The two groups in this study were participants who use standardized psychosocial risk rating scales in their practice and those who do not. Therefore, the pattern match examined differences in the importance ratings of each cluster for these groups.

Go-zone graphs. Go-zone graphs are bivariate graphs that are produced for each cluster. They are divided into quadrants based on the mean importance rating by participants who do not rate risk (x-axis) and the mean importance rating by participant who do rate risk (y-axis). The upper right quadrant (called the Go-Zone) shows statements in the cluster that are above average in importance for both groups. The lower left quadrant contains statements that were rated below average importance by both groups. The upper left and lower right quadrants, then, show statements that were rated higher than average by one group but not the other. Go-zone displays are particularly helpful for detailing subsequent planning efforts (Kane & Trochim, 2006).

Interpretation

Concept mapping provides many different visual outputs that represent aspects of the group's mental model. The researcher interprets these based on the literature (Kane & Trochim, 2007). This interpretation will be brought to the participants after the conclusion of this dissertation. A session will be held to present the visual displays that result from the concept mapping analysis and have the participants discuss them. The goal is for participants to understand the clusters and ratings. The researcher will also facilitate discussion of the meaning of the results and how they may help inform the development of a pre-HCT psychosocial assessment protocol. Finally, the assessment protocol will be developed, implemented, and tested.

In conclusion, concept mapping methodology was used to formally and systematically identify the psychosocial elements that should be assessed in HCT candidates, how the elements relate to one another in meaning, and how they compare to one another in terms of their importance.

CHAPTER IV: RESULTS

The aim of this study was to engage social workers and psychologists to conceptualize the elements they assess in candidates for hematopoietic cell transplantation (HCT). There were two research questions: 1) How do psychosocial professionals conceptualize the elements they assess in candidates for hematopoietic cell transplantation? and 2) Is there a difference in the conceptualization based on the use of standardized risk rating scales in clinical practice? Findings related to these questions will be discussed in this chapter.

Participants

A questionnaire (available in Appendix A) was administered to participants to gather personal characteristics and information related to their professional practice. Due to constraints of groupwisdom™ only 5 questions could be included in the online application. Participants (n = 27) completed these questions before the sorting and rating activities. Participants (n = 23) completed the remaining questions via Qualtrics after they completed the sorting and rating activities. The sample was overwhelmingly comprised of non-Hispanic white, female social workers with a Master's degree. One respondent identified as Asian; one identified as male; and one identified as a psychologist with a Ph.D.

Regarding their professional practice, participants' years of practice experience in HCT patients ranged from 1 – 30 years (median 5 years), 74% practiced in both inpatient and outpatient settings, and 26% practiced only in the outpatient setting. Almost half of participants assessed more than 3 HCT candidates per week, while the remaining assessed 3 or fewer per week. Regarding use of standardized risk rating scales, one-third reported using a scale while two-thirds reported not using a scale. A majority of the participants (83%) were members of the Association of Oncology Social Work. In terms of practice location, geographic diversity was well-represented: Northeast (17%), Southeast (17%), Midwest (26%), West (17%), Southwest (22%).

Generating the Ideas

The final statement set is presented in Table 2.

Table 2

Final Statement Set (N = 114)

	Statements
1	Quality assessment of an HCT candidate should include their knowledge of community resources.
2	Quality assessment of an HCT candidate should include their social activities.
3	Quality assessment of an HCT candidate should include their interests.
4	Quality assessment of an HCT candidate should include their goal for having a transplant.
5	Quality assessment of an HCT candidate should include concerns their family has about proceeding with transplant.
6	Quality assessment of an HCT candidate should include the presence of sexual abuse.
7	Quality assessment of an HCT candidate should include the presence of emotional abuse.
8	Quality assessment of an HCT candidate should include any impairment in hearing.
9	Quality assessment of an HCT candidate should include ethnicity.
10	Quality assessment of an HCT candidate should include their spirituality.
11	Quality assessment of an HCT candidate should include their communication preferences.
12	Quality assessment of an HCT candidate should include fertility preservation.
13	Quality assessment of an HCT candidate should include the caregiver’s understanding of the transplant process.

14	Quality assessment of an HCT candidate should include the caregiver’s functional limitations.
15	Quality assessment of an HCT candidate should include a family history of non-cancer chronic illness.
16	Quality assessment of an HCT candidate should include their adjustment to illness.
17	Quality assessment of an HCT candidate should include whether or not they have a legal will.
18	Quality assessment of an HCT candidate should include whether or not a power-of-attorney for finances has been appointed.
19	Quality assessment of an HCT candidate should include parking needs.
20	Quality assessment of an HCT candidate should include the quality of their support system.
21	Quality assessment of an HCT candidate should include the quality of their relationship with their spouse or partner.
22	Quality assessment of an HCT candidate should include use of community resources.
23	Quality assessment of an HCT candidate should include legal status if the patient is international.
24	Quality assessment of an HCT candidate should include their birthplace.
25	Quality assessment of an HCT candidate should include use of complementary and alternative medicine.
26	Quality assessment of an HCT candidate should include a trauma history.
27	Quality assessment of an HCT candidate should include sexual health.
28	Quality assessment of an HCT candidate should include their coping strategies.
29	Quality assessment of an HCT candidate should include their coping style.
30	Quality assessment of an HCT candidate should include their physical functioning.
31	Quality assessment of an HCT candidate should include any barriers.
32	Quality assessment of an HCT candidate should include their hobbies.
33	Quality assessment of an HCT candidate should include unmet educational needs related to transplant.
34	Quality assessment of an HCT candidate should include the quality of their relationships with transplant team members.
35	Quality assessment of an HCT candidate should include adherence.
36	Quality assessment of an HCT candidate should include their comfort level with self-advocacy.
37	Quality assessment of an HCT candidate should include health literacy.
38	Quality assessment of an HCT candidate should include their knowledge of supportive care options.
39	Quality assessment of an HCT candidate should include their motivation for having a transplant.
40	Quality assessment of an HCT candidate should include their understanding of the transplant process.

41	Quality assessment of an HCT candidate should include their beliefs that guide medical decision-making.
42	Quality assessment of an HCT candidate should include concerns they have about proceeding with transplant.
43	Quality assessment of an HCT candidate should include the presence of physical abuse.
44	Quality assessment of an HCT candidate should include changes between their previous quality of life and current quality of life.
45	Quality assessment of an HCT candidate should include their health behaviors.
46	Quality assessment of an HCT candidate should include advance directives.
47	Quality assessment of an HCT candidate should include legal issues.
48	Quality assessment of an HCT candidate should include their use of substances.
49	Quality assessment of an HCT candidate should include any impairment in vision.
50	Quality assessment of an HCT candidate should include their cognition.
51	Quality assessment of an HCT candidate should include mental status.
52	Quality assessment of an HCT candidate should include family substance use.
53	Quality assessment of an HCT candidate should include family mental health.
54	Quality assessment of an HCT candidate should include their mental health.
55	Quality assessment of an HCT candidate should include a history of significant losses.
56	Quality assessment of an HCT candidate should include gender identity.
57	Quality assessment of an HCT candidate should include sexual orientation.
58	Quality assessment of an HCT candidate should include race.
59	Quality assessment of an HCT candidate should include their religion.
60	Quality assessment of an HCT candidate should include cultural traditions.
61	Quality assessment of an HCT candidate should include their communication style.
62	Quality assessment of an HCT candidate should include languages they speak.
63	Quality assessment of an HCT candidate should include their learning preferences.
64	Quality assessment of an HCT candidate should include their desired level of information.
65	Quality assessment of an HCT candidate should include pertinent developmental history.
66	Quality assessment of an HCT candidate should include their highest level of formal education.
67	Quality assessment of an HCT candidate should include their plan to cover expenses while off work.
68	Quality assessment of an HCT candidate should include financial concerns.
69	Quality assessment of an HCT candidate should include their source(s) of income.
70	Quality assessment of an HCT candidate should include Veterans Administration (VA) benefits.
71	Quality assessment of an HCT candidate should include a military history.

72	Quality assessment of an HCT candidate should include employment status.
73	Quality assessment of an HCT candidate should include occupation.
74	Quality assessment of an HCT candidate should include use of pharmacy assistance programs.
75	Quality assessment of an HCT candidate should include use of financial assistance programs.
76	Quality assessment of an HCT candidate should include their mode of transportation.
77	Quality assessment of an HCT candidate should include fertility concerns.
78	Quality assessment of an HCT candidate should include their pharmacy benefits.
79	Quality assessment of an HCT candidate should include their insurance coverage.
80	Quality assessment of an HCT candidate should include their relocation plan (if they need to relocate).
81	Quality assessment of an HCT candidate should include the caregiver’s understanding of the caregiver role.
82	Quality assessment of an HCT candidate should include the caregiver’s cognition.
83	Quality assessment of an HCT candidate should include the degree of cooperation among multiple caregivers to manage the schedule.
84	Quality assessment of an HCT candidate should include the availability of caregiver(s).
85	Quality assessment of an HCT candidate should include the caregiver’s ability to perform required tasks.
86	Quality assessment of an HCT candidate should include the strength of the caregiver’s support system.
87	Quality assessment of an HCT candidate should include their post-discharge 24/7 caregiver plan.
88	Quality assessment of an HCT candidate should include the caregiver’s plan to work vs. visit vs. stay with patient during the patient’s admission.
89	Quality assessment of an HCT candidate should include the caregiver’s comfort level with self-advocacy in the medical setting.
90	Quality assessment of an HCT candidate should include the caregiver’s desired level of information.
91	Quality assessment of an HCT candidate should include any problems the caregiver has had with past medical providers.
92	Quality assessment of an HCT candidate should include the caregiver’s mental health.
93	Quality assessment of an HCT candidate should include substance use by the caregiver.
94	Quality assessment of an HCT candidate should include the caregiver’s physical health.
95	Quality assessment of an HCT candidate should include the caregiver’s employment.
96	Quality assessment of an HCT candidate should include the caregiver’s education level.

97	Quality assessment of an HCT candidate should include the caregiver’s coping strategies.
98	Quality assessment of an HCT candidate should include the caregiver’s coping ability.
99	Quality assessment of an HCT candidate should include their perceived level of social support.
100	Quality assessment of an HCT candidate should include support system quantity.
101	Quality assessment of an HCT candidate should include family stressors.
102	Quality assessment of an HCT candidate should include family involvement.
103	Quality assessment of an HCT candidate should include potential health risks in the home environment.
104	Quality assessment of an HCT candidate should include whether they rent vs. own with mortgage vs. own without mortgage.
105	Quality assessment of an HCT candidate should include the presence of plants in the home.
106	Quality assessment of an HCT candidate should include the presence of pets in the home.
107	Quality assessment of an HCT candidate should include their living situation.
108	Quality assessment of an HCT candidate should include their strengths.
109	Quality assessment of an HCT candidate should include a family history of causes of death.
110	Quality assessment of an HCT candidate should include a family history of cancer.
111	Quality assessment of an HCT candidate should include family composition.
112	Quality assessment of an HCT candidate should include their perception of how their support system has adjusted to their illness.
113	Quality assessment of an HCT candidate should include the impact of illness on their significant relationships.
114	Quality assessment of an HCT candidate should include marital status.

Structuring the Statements

Participants sorted the statements into piles that made sense to them and then rated each statement according to the variable *importance*. Specifically, participants were asked, “In your view, how important is this item for the quality assessment of a transplant candidate?” Likert-scale response options included “1 Relatively unimportant, 2 Somewhat important, 3 Moderately important, 4 Important, and 5 Very important.”

Mean importance ratings for the statements ranged from 1.76 to 5.0. Statement 84 *“Quality assessment of an HCT candidate should include the availability of* *caregiver(s).”* was rated most important at 5.00 (SD = 0). Statement 24 *“Quality assessment of an HCT candidate should include their birthplace”* was rated least important at 1.76 (SD = 0.86). Mean importance ratings for each statement are presented in Table 3.

Table 3

Mean Ratings by Statement

	Statement	Mean rating	S.D.
1	Quality assessment of an HCT candidate should include their knowledge of community resources.	3.60	0.98
2	Quality assessment of an HCT candidate should include their social activities.	3.00	1.00
3	Quality assessment of an HCT candidate should include their interests.	3.64	1.02
4	Quality assessment of an HCT candidate should include their goal for having a transplant.	4.44	0.57
5	Quality assessment of an HCT candidate should include concerns their family has about proceeding with transplant.	3.88	0.99
6	Quality assessment of an HCT candidate should include the presence of sexual abuse.	4.12	0.95
7	Quality assessment of an HCT candidate should include the presence of emotional abuse.	4.50	0.58
8	Quality assessment of an HCT candidate should include any impairment in hearing.	3.12	0.99
9	Quality assessment of an HCT candidate should include ethnicity.	2.72	1.18
10	Quality assessment of an HCT candidate should include their spirituality.	3.60	0.85
11	Quality assessment of an HCT candidate should include their communication preferences.	4.04	0.73
12	Quality assessment of an HCT candidate should include fertility preservation.	3.84	1.01
13	Quality assessment of an HCT candidate should include the caregiver’s understanding of the transplant process.	4.56	0.57
14	Quality assessment of an HCT candidate should include the caregiver’s functional limitations.	4.54	0.58
15	Quality assessment of an HCT candidate should include a family history of non-cancer chronic illness.	2.28	1.00

16	Quality assessment of an HCT candidate should include their adjustment to illness.	4.48	0.64
17	Quality assessment of an HCT candidate should include whether or not they have a legal will.	3.16	1.05
18	Quality assessment of an HCT candidate should include whether or not a power-of-attorney for finances has been appointed.	2.8	1.06
19	Quality assessment of an HCT candidate should include parking needs.	2.88	1.21
20	Quality assessment of an HCT candidate should include the quality of their support system.	4.60	0.56
21	Quality assessment of an HCT candidate should include the quality of their relationship with their spouse or partner.	4.20	0.80
22	Quality assessment of an HCT candidate should include use of community resources.	3.38	0.75
23	Quality assessment of an HCT candidate should include legal status if the patient is international.	3.64	1.44
24	Quality assessment of an HCT candidate should include their birthplace.	1.76	0.86
25	Quality assessment of an HCT candidate should include use of complementary and alternative medicine.	3.24	1.14
26	Quality assessment of an HCT candidate should include a trauma history.	3.92	0.63
27	Quality assessment of an HCT candidate should include sexual health.	3.32	0.93
28	Quality assessment of an HCT candidate should include their coping strategies.	4.56	0.50
29	Quality assessment of an HCT candidate should include their coping style.	4.52	0.57
30	Quality assessment of an HCT candidate should include their physical functioning.	3.79	0.82
31	Quality assessment of an HCT candidate should include any barriers.	4.76	0.43
32	Quality assessment of an HCT candidate should include their hobbies.	2.96	1.02
33	Quality assessment of an HCT candidate should include unmet educational needs related to transplant.	4.29	0.93
34	Quality assessment of an HCT candidate should include the quality of their relationships with transplant team members.	4.00	0.63
35	Quality assessment of an HCT candidate should include adherence.	4.76	0.51
36	Quality assessment of an HCT candidate should include their comfort level with self-advocacy.	3.80	0.75
37	Quality assessment of an HCT candidate should include health literacy.	4.29	0.73
38	Quality assessment of an HCT candidate should include their knowledge of supportive care options.	3.68	0.73

39	Quality assessment of an HCT candidate should include their motivation for having a transplant.	4.42	0.57
40	Quality assessment of an HCT candidate should include their understanding of the transplant process.	4.76	0.43
41	Quality assessment of an HCT candidate should include their beliefs that guide medical decision-making.	4.40	0.69
42	Quality assessment of an HCT candidate should include concerns they have about proceeding with transplant.	4.80	0.40
43	Quality assessment of an HCT candidate should include the presence of physical abuse.	4.72	0.53
44	Quality assessment of an HCT candidate should include changes between their previous quality of life and current quality of life.	4.28	0.53
45	Quality assessment of an HCT candidate should include their health behaviors.	4.36	0.62
46	Quality assessment of an HCT candidate should include advance directives.	4.40	0.80
47	Quality assessment of an HCT candidate should include legal issues.	3.56	1.02
48	Quality assessment of an HCT candidate should include their use of substances.	4.72	0.60
49	Quality assessment of an HCT candidate should include any impairment in vision.	3.13	1.17
50	Quality assessment of an HCT candidate should include their cognition.	4.48	0.57
51	Quality assessment of an HCT candidate should include mental status.	4.68	0.47
52	Quality assessment of an HCT candidate should include family substance use.	3.60	0.98
53	Quality assessment of an HCT candidate should include family mental health.	3.24	0.81
54	Quality assessment of an HCT candidate should include their mental health.	4.84	0.37
55	Quality assessment of an HCT candidate should include a history of significant losses.	3.72	0.78
56	Quality assessment of an HCT candidate should include gender identity.	3.48	1.20
57	Quality assessment of an HCT candidate should include sexual orientation.	2.80	1.36
58	Quality assessment of an HCT candidate should include race.	2.88	1.14
59	Quality assessment of an HCT candidate should include their religion.	3.16	0.78
60	Quality assessment of an HCT candidate should include cultural traditions.	3.84	0.78
61	Quality assessment of an HCT candidate should include their communication style.	3.92	0.69

62	Quality assessment of an HCT candidate should include languages they speak.	4.04	0.87
63	Quality assessment of an HCT candidate should include their learning preferences.	4.08	0.80
64	Quality assessment of an HCT candidate should include their desired level of information.	4.04	0.79
65	Quality assessment of an HCT candidate should include pertinent developmental history.	3.56	0.94
66	Quality assessment of an HCT candidate should include their highest level of formal education.	2.58	1.04
67	Quality assessment of an HCT candidate should include their plan to cover expenses while off work.	4.36	0.79
68	Quality assessment of an HCT candidate should include financial concerns.	4.46	0.50
69	Quality assessment of an HCT candidate should include their source(s) of income.	4.13	0.73
70	Quality assessment of an HCT candidate should include Veterans Administration (VA) benefits.	2.88	0.95
71	Quality assessment of an HCT candidate should include a military history.	2.75	1.05
72	Quality assessment of an HCT candidate should include employment status.	3.84	1.05
73	Quality assessment of an HCT candidate should include occupation.	3.28	0.96
74	Quality assessment of an HCT candidate should include use of pharmacy assistance programs.	3.40	1.10
75	Quality assessment of an HCT candidate should include use of financial assistance programs.	3.68	1.01
76	Quality assessment of an HCT candidate should include their mode of transportation.	4.12	0.91
77	Quality assessment of an HCT candidate should include fertility concerns.	3.80	0.94
78	Quality assessment of an HCT candidate should include their pharmacy benefits.	3.88	1.18
79	Quality assessment of an HCT candidate should include their insurance coverage.	4.46	0.82
80	Quality assessment of an HCT candidate should include their relocation plan (if they need to relocate).	4.84	0.37
81	Quality assessment of an HCT candidate should include the caregiver’s understanding of the caregiver role.	4.76	0.43
82	Quality assessment of an HCT candidate should include the caregiver’s cognition.	4.24	0.76
83	Quality assessment of an HCT candidate should include the degree of cooperation among multiple caregivers to manage the schedule.	4.40	0.63

84	Quality assessment of an HCT candidate should include the availability of caregiver(s).	5.00	0
85	Quality assessment of an HCT candidate should include the caregiver’s ability to perform required tasks.	4.88	0.34
86	Quality assessment of an HCT candidate should include the strength of the caregiver’s support system.	4.40	0.80
87	Quality assessment of an HCT candidate should include their post-discharge 24/7 caregiver plan.	4.96	0.20
88	Quality assessment of an HCT candidate should include the caregiver’s plan to work vs. visit vs. stay with patient during the patient’s admission.	3.29	1.17
89	Quality assessment of an HCT candidate should include the caregiver’s comfort level with self-advocacy in the medical setting.	4.00	0.80
90	Quality assessment of an HCT candidate should include the caregiver’s desired level of information.	3.80	0.75
91	Quality assessment of an HCT candidate should include any problems the caregiver has had with past medical providers.	3.72	0.92
92	Quality assessment of an HCT candidate should include the caregiver’s mental health.	4.52	0.57
93	Quality assessment of an HCT candidate should include substance use by the caregiver.	4.58	0.70
94	Quality assessment of an HCT candidate should include the caregiver’s physical health.	4.28	0.72
95	Quality assessment of an HCT candidate should include the caregiver’s employment.	3.84	0.78
96	Quality assessment of an HCT candidate should include the caregiver’s education level.	3.00	0.94
97	Quality assessment of an HCT candidate should include the caregiver’s coping strategies.	4.20	0.69
98	Quality assessment of an HCT candidate should include the caregiver’s coping ability.	4.32	0.73
99	Quality assessment of an HCT candidate should include their perceived level of social support.	4.28	0.72
100	Quality assessment of an HCT candidate should include support system quantity.	3.72	0.83
101	Quality assessment of an HCT candidate should include family stressors.	4.12	0.59
102	Quality assessment of an HCT candidate should include family involvement.	4.04	1.04
103	Quality assessment of an HCT candidate should include potential health risks in the home environment.	4.16	0.97
104	Quality assessment of an HCT candidate should include whether they rent vs. own with mortgage vs. own without mortgage.	2.12	0.91
105	Quality assessment of an HCT candidate should include the presence of plants in the home.	2.32	1.16

106	Quality assessment of an HCT candidate should include the presence of pets in the home.	2.84	1.16
107	Quality assessment of an HCT candidate should include their living situation.	4.52	0.64
108	Quality assessment of an HCT candidate should include their strengths.	4.35	0.56
109	Quality assessment of an HCT candidate should include a family history of causes of death.	2.50	1.08
110	Quality assessment of an HCT candidate should include a family history of cancer.	2.68	1.16
111	Quality assessment of an HCT candidate should include family composition.	3.32	1.05
112	Quality assessment of an HCT candidate should include their perception of how their support system has adjusted to their illness.	3.80	0.80
113	Quality assessment of an HCT candidate should include the impact of illness on their significant relationships.	4.16	0.61
114	Quality assessment of an HCT candidate should include marital status.	2.68	1.29

Concept Mapping Analysis

First, a similarity matrix was calculated based on the sorting data for all participants. The possible matrix values for the statements could range from 0 to 18, where 0 indicates that the statements were never sorted in the same pile together and 18 indicates that every participant (n = 18) sorted the statements into the same pile. A portion of the overall similarity matrix is presented in Table 4 to illustrate this piece of the analysis. The table shows that statements were sorted together at various frequencies. For example, participants never sorted statement 5 *"Quality assessment of an HCT candidate should include concerns their family has about proceeding with transplant"* with statement 7 *"Quality assessment of an HCT candidate should include the presence of emotional abuse."* Therefore, the similarity matrix shows a zero. Participants sorted statement 2 *"Quality assessment of an HCT candidate should include their social* *activities"* with statement 3 *"Quality assessment of an HCT candidate should include their interests"* 15 times. Therefore, the similarity matrix shows a 15.

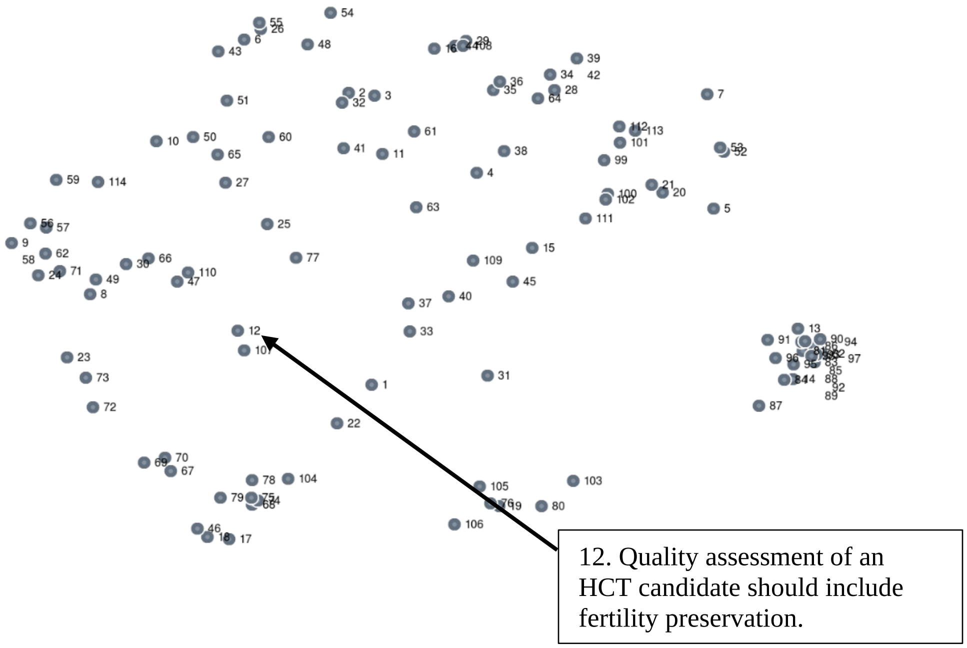
Table 4

Portion of the Overall Similarity Matrix (Illustrative Example)

Statement Index	1	2	3	4	5	6	7	8
1		2	3	2	1	0	0	0
2	2		15	2	1	3	2	1
3	3	15		3	1	3	2	1
4	2	2	3		9	0	0	1
5	1	1	1	9		0	0	0
6	0	3	3	0	0		14	0
7	0	2	2	0	0	14		0
8	0	1	1	1	0	0	0	
9	0	2	1	0	0	0	0	2
10	2	6	6	0	1	1	0	1
11	1	3	2	4	5	0	0	2
12	1	0	0	2	1	1	0	5
13	0	0	0	2	2	0	1	0
14	0	0	0	0	2	0	0	0

Multidimensional scaling (MDS) was used to analyze the similarity matrix. MDS used a two-dimensional solution to produce *x* and *y* coordinates for each statement. A point map was computed based on the coordinates and is presented in Figure 1. This point map emerged after 11 iterations and had an overall stress value of 0.2914. The stress value indicates the degree of discrepancy (or goodness-of-fit) between the MDS solution (distances on the point map) and the values in the original similarity matrix. A lower stress value is desirable because it indicates better concordance. According to Kane and Rosas (2018), typical concept mapping projects have stress values ranging from 0.10 – 0.35, which signals that the map is interpretable. In their pooled study analysis, Rosas and Kane (2012) found that the average stress value for 69 studies was 0.28 with range: 0.17 – 0.34. This study's stress value is therefore considered acceptable. Statement 12 is highlighted in Figure 1 to show how the map is configured.

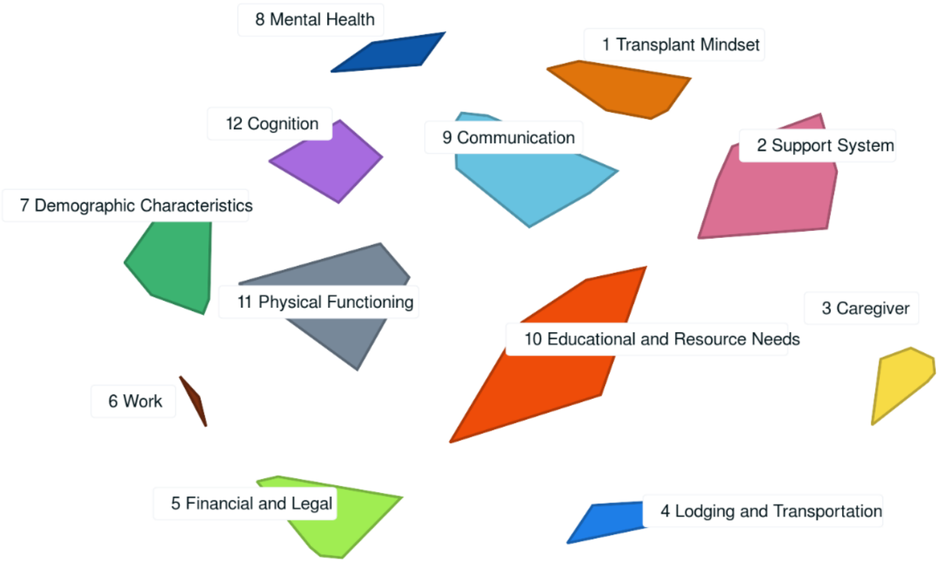
Figure 1. Point Map



12. Quality assessment of an HCT candidate should include fertility preservation.

After the point map was configured, hierarchical cluster analysis (HCA) used resemblance coefficients to analyze similarities among the pairs of data. The coordinates from the MDS were used as input for the HCA, which divided the coordinates on the point map into clusters. The clusters were labeled based on participant labels in the sorting phase and represent the overall theme of the statements in each cluster. The final, 12-cluster solution is presented in Figure 2. The 12 clusters are *Transplant Mindset, Support System, Caregiver, Lodging and Transportation, Financial and Legal, Work, Demographic Characteristics, Mental Health, Communication, Education and Resource Needs, Physical Functioning, and Cognition*.

Figure 2. Final Cluster Map



Mean cluster bridging values for the final 12-cluster solution ranged from 0.06 to 0.77. Lower bridging values indicate that statements in the cluster were sorted together at a higher rate, meaning there is greater cohesiveness among statements within the cluster. The *Caregiver* cluster was the most cohesive, with a bridging value of 0.06. Higher bridging values indicate that statements in the cluster were sorted together less often than statements in the other clusters, meaning there is less cohesiveness among the statements within the cluster. The *Educational and Resource Needs* cluster was the least cohesive, with a bridging value of 0.77. Bridging values and the statements in each cluster are presented in Table 5.

Table 5

Clusters, Statements, and Bridging Values

	Statement	Bridging Value
Cluster 1: Transplant Mindset		
16	Quality assessment of an HCT candidate should include their adjustment to illness.	0.42
28	Quality assessment of an HCT candidate should include their coping strategies.	0.50
29	Quality assessment of an HCT candidate should include their coping style.	0.42
34	Quality assessment of an HCT candidate should include the quality of their relationships with transplant team members.	0.52
35	Quality assessment of an HCT candidate should include adherence.	0.53
36	Quality assessment of an HCT candidate should include their comfort level with self-advocacy.	0.52
39	Quality assessment of an HCT candidate should include their motivation for having a transplant.	0.57
42	Quality assessment of an HCT candidate should include concerns they have about proceeding with transplant.	0.57
44	Quality assessment of an HCT candidate should include changes between their previous quality of life and current quality of life.	0.44

64	Quality assessment of an HCT candidate should include their desired level of information.	0.51
108	Quality assessment of an HCT candidate should include their strengths.	0.42
	Mean Bridging Value	0.49
Cluster 2: Support System		
5	Quality assessment of an HCT candidate should include concerns their family has about proceeding with transplant.	0.67
7	Quality assessment of an HCT candidate should include the presence of emotional abuse.	1.00
20	Quality assessment of an HCT candidate should include the quality of their support system.	0.58
21	Quality assessment of an HCT candidate should include the quality of their relationship with their spouse or partner.	0.55
52	Quality assessment of an HCT candidate should include family substance use.	0.78
53	Quality assessment of an HCT candidate should include family mental health.	0.78
99	Quality assessment of an HCT candidate should include their perceived level of social support.	0.52
100	Quality assessment of an HCT candidate should include support system quantity.	0.58
101	Quality assessment of an HCT candidate should include family stressors.	0.55
102	Quality assessment of an HCT candidate should include family involvement.	0.62
111	Quality assessment of an HCT candidate should include family composition.	0.75
112	Quality assessment of an HCT candidate should include their perception of how their support system has adjusted to their illness.	0.52
113	Quality assessment of an HCT candidate should include the impact of illness on their significant relationships.	0.51
	Mean Bridging Value	0.64
Cluster 3: Caregiver		
13	Quality assessment of an HCT candidate should include the caregiver’s understanding of the transplant process.	0.13
14	Quality assessment of an HCT candidate should include the caregiver’s functional limitations.	0.09
81	Quality assessment of an HCT candidate should include the caregiver’s understanding of the caregiver role.	0.02
82	Quality assessment of an HCT candidate should include the caregiver’s cognition.	0.01
83	Quality assessment of an HCT candidate should include the degree of cooperation among multiple caregivers to manage the schedule.	0.01
84	Quality assessment of an HCT candidate should include the availability of caregiver(s).	0.11

85	Quality assessment of an HCT candidate should include the caregiver's ability to perform required tasks.	0
86	Quality assessment of an HCT candidate should include the strength of the caregiver's support system.	0.03
87	Quality assessment of an HCT candidate should include their post-discharge 24/7 caregiver plan.	0.27
88	Quality assessment of an HCT candidate should include the caregiver's plan to work vs. visit vs. stay with patient during the patient's admission.	0.01
89	Quality assessment of an HCT candidate should include the caregiver's comfort level with self-advocacy in the medical setting.	0.01
90	Quality assessment of an HCT candidate should include the caregiver's desired level of information.	0.06
91	Quality assessment of an HCT candidate should include any problems the caregiver has had with past medical providers.	0.19
92	Quality assessment of an HCT candidate should include the caregiver's mental health.	0.01
93	Quality assessment of an HCT candidate should include substance use by the caregiver.	0.01
94	Quality assessment of an HCT candidate should include the caregiver's physical health.	0.06
95	Quality assessment of an HCT candidate should include the caregiver's employment.	0.06
96	Quality assessment of an HCT candidate should include the caregiver's education level.	0.09
97	Quality assessment of an HCT candidate should include the caregiver's coping strategies.	0.06
98	Quality assessment of an HCT candidate should include the caregiver's coping ability.	0.01
	Mean Bridging Value	0.06
Cluster 4: Lodging and Transportation		
19	Quality assessment of an HCT candidate should include parking needs.	0.57
76	Quality assessment of an HCT candidate should include their mode of transportation.	0.59
80	Quality assessment of an HCT candidate should include their relocation plan (if they need to relocate).	0.58
103	Quality assessment of an HCT candidate should include potential health risks in the home environment.	0.63
105	Quality assessment of an HCT candidate should include the presence of plants in the home.	0.59
106	Quality assessment of an HCT candidate should include the presence of pets in the home.	0.52
	Mean Bridging Value	0.58
Cluster 5: Financial and Legal		

17	Quality assessment of an HCT candidate should include whether or not they have a legal will.	0.71
18	Quality assessment of an HCT candidate should include whether or not a power-of-attorney for finances has been appointed.	0.51
46	Quality assessment of an HCT candidate should include advance directives.	0.77
67	Quality assessment of an HCT candidate should include their plan to cover expenses while off work.	0.30
68	Quality assessment of an HCT candidate should include financial concerns.	0.23
69	Quality assessment of an HCT candidate should include their source(s) of income.	0.34
70	Quality assessment of an HCT candidate should include Veterans Administration (VA) benefits.	0.39
74	Quality assessment of an HCT candidate should include use of pharmacy assistance programs.	0.24
75	Quality assessment of an HCT candidate should include use of financial assistance programs.	0.24
78	Quality assessment of an HCT candidate should include their pharmacy benefits.	0.31
79	Quality assessment of an HCT candidate should include their insurance coverage.	0.24
104	Quality assessment of an HCT candidate should include whether they rent vs. own with mortgage vs. own without mortgage.	0.45
	Mean Bridging Value	0.39
Cluster 6: Work		
23	Quality assessment of an HCT candidate should include legal status if the patient is international.	0.65
72	Quality assessment of an HCT candidate should include employment status.	0.53
73	Quality assessment of an HCT candidate should include occupation.	0.62
	Mean Bridging Value	0.60
Cluster 7: Demographic Characteristics		
8	Quality assessment of an HCT candidate should include any impairment in hearing.	0.56
9	Quality assessment of an HCT candidate should include ethnicity.	0.34
24	Quality assessment of an HCT candidate should include their birthplace.	0.46
49	Quality assessment of an HCT candidate should include any impairment in vision.	0.50
56	Quality assessment of an HCT candidate should include gender identity.	0.37
57	Quality assessment of an HCT candidate should include sexual orientation.	0.40
58	Quality assessment of an HCT candidate should include race.	0.34

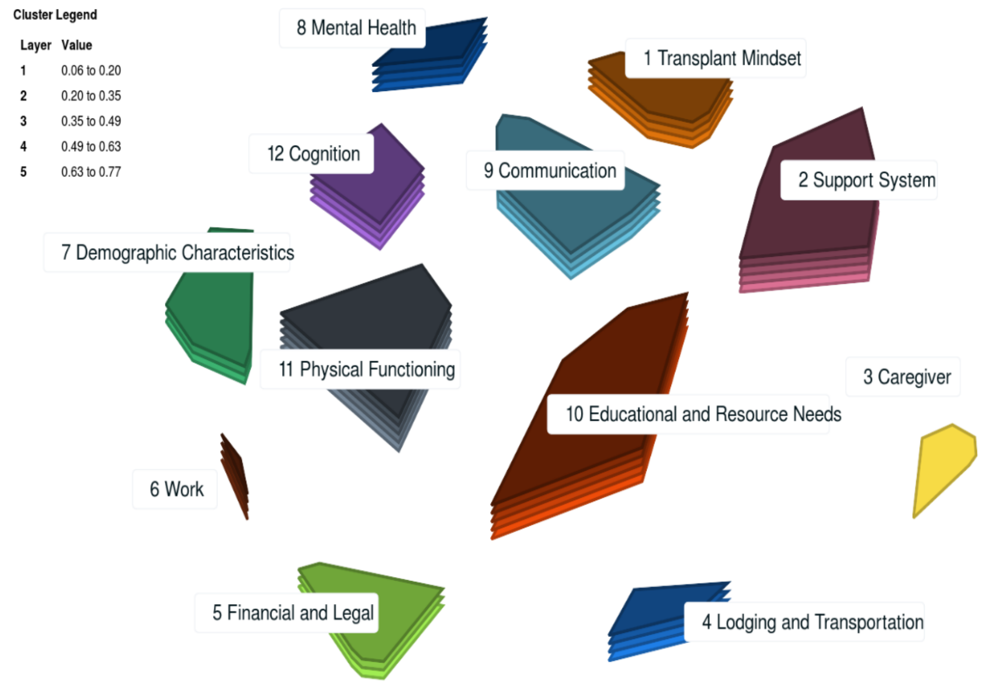
59	Quality assessment of an HCT candidate should include their religion.	0.56
62	Quality assessment of an HCT candidate should include languages they speak.	0.40
71	Quality assessment of an HCT candidate should include a military history.	0.54
114	Quality assessment of an HCT candidate should include marital status.	0.61
	Mean Bridging Value	0.46
Cluster 8: Mental Health		
6	Quality assessment of an HCT candidate should include the presence of sexual abuse.	0.54
26	Quality assessment of an HCT candidate should include a trauma history.	0.53
43	Quality assessment of an HCT candidate should include the presence of physical abuse.	0.59
48	Quality assessment of an HCT candidate should include their use of substances.	0.57
54	Quality assessment of an HCT candidate should include their mental health.	0.51
55	Quality assessment of an HCT candidate should include a history of significant losses.	0.52
	Mean Bridging Value	0.54
Cluster 9: Communication		
2	Quality assessment of an HCT candidate should include their social activities.	0.51
3	Quality assessment of an HCT candidate should include their interests.	0.51
4	Quality assessment of an HCT candidate should include their goal for having a transplant.	0.53
11	Quality assessment of an HCT candidate should include their communication preferences.	0.55
32	Quality assessment of an HCT candidate should include their hobbies.	0.53
38	Quality assessment of an HCT candidate should include their knowledge of supportive care options.	0.64
41	Quality assessment of an HCT candidate should include their beliefs that guide medical decision-making.	0.61
61	Quality assessment of an HCT candidate should include their communication style.	0.50
63	Quality assessment of an HCT candidate should include their learning preferences.	0.54
	Mean Bridging Value	0.55
Cluster 10: Educational and Resource Needs		

1	Quality assessment of an HCT candidate should include their knowledge of community resources.	0.86
15	Quality assessment of an HCT candidate should include a family history of non-cancer chronic illness.	0.72
22	Quality assessment of an HCT candidate should include use of community resources.	0.76
31	Quality assessment of an HCT candidate should include any barriers.	0.96
33	Quality assessment of an HCT candidate should include unmet educational needs related to transplant.	0.77
37	Quality assessment of an HCT candidate should include health literacy.	0.66
40	Quality assessment of an HCT candidate should include their understanding of the transplant process.	0.67
45	Quality assessment of an HCT candidate should include their health behaviors.	0.82
109	Quality assessment of an HCT candidate should include a family history of causes of death.	0.74
	Mean Bridging Value	0.77
Cluster 11: Physical Functioning		
12	Quality assessment of an HCT candidate should include fertility preservation.	0.67
25	Quality assessment of an HCT candidate should include use of complementary and alternative medicine.	0.64
30	Quality assessment of an HCT candidate should include their physical functioning.	0.51
47	Quality assessment of an HCT candidate should include legal issues.	0.83
66	Quality assessment of an HCT candidate should include their highest level of formal education.	0.65
77	Quality assessment of an HCT candidate should include fertility concerns.	0.60
107	Quality assessment of an HCT candidate should include their living situation.	0.90
110	Quality assessment of an HCT candidate should include a family history of cancer.	0.67
	Mean Bridging Value	0.68
Cluster 12: Cognition		
10	Quality assessment of an HCT candidate should include their spirituality.	0.66
27	Quality assessment of an HCT candidate should include sexual health.	0.59
50	Quality assessment of an HCT candidate should include their cognition.	0.61
51	Quality assessment of an HCT candidate should include mental status.	0.58

60	Quality assessment of an HCT candidate should include cultural traditions.	0.63
65	Quality assessment of an HCT candidate should include pertinent developmental history.	0.64
	Mean Bridging Value	0.62

The Cluster Bridging Map is presented in Figure 3. The mean bridging values are displayed in the third dimension; the fewer levels a cluster has, the more cohesive it is relative to the other clusters.

Figure 3. Cluster Bridging Map



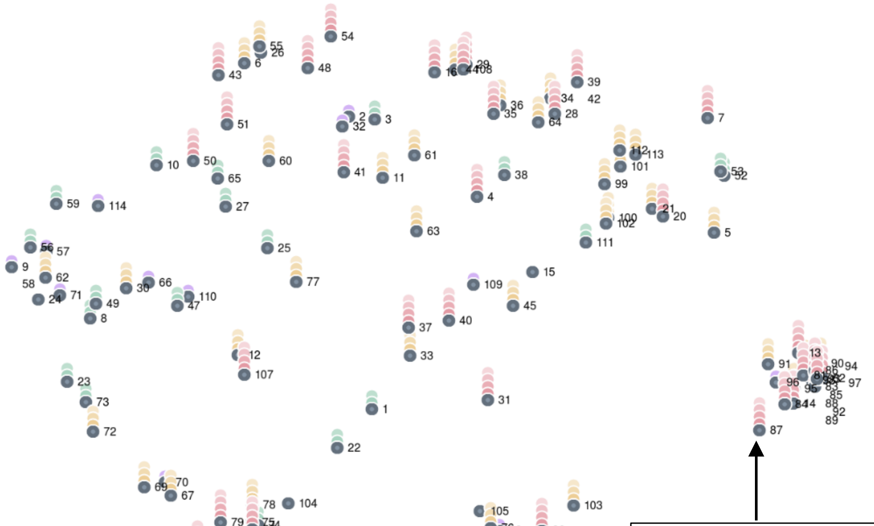
Item and Cluster Ratings Analyses

Ratings data were analyzed from the 24 participants who participated in this phase of the study. Participants rated each statement according to their view of how important it was in the quality assessment of a transplant candidate. Figure 4 is a Point Rating Map that uses the Point Map in Figure 1 to visually depict the ratings data for each statement. The number of layers in the column's height indicates the mean importance. For example, statement 87 has 5 layers, which indicates the highest level of importance. Many statements with 5 layers are located at the top of the map and in the lower right corner.

Figure 4. Point Rating Map

Point Legend

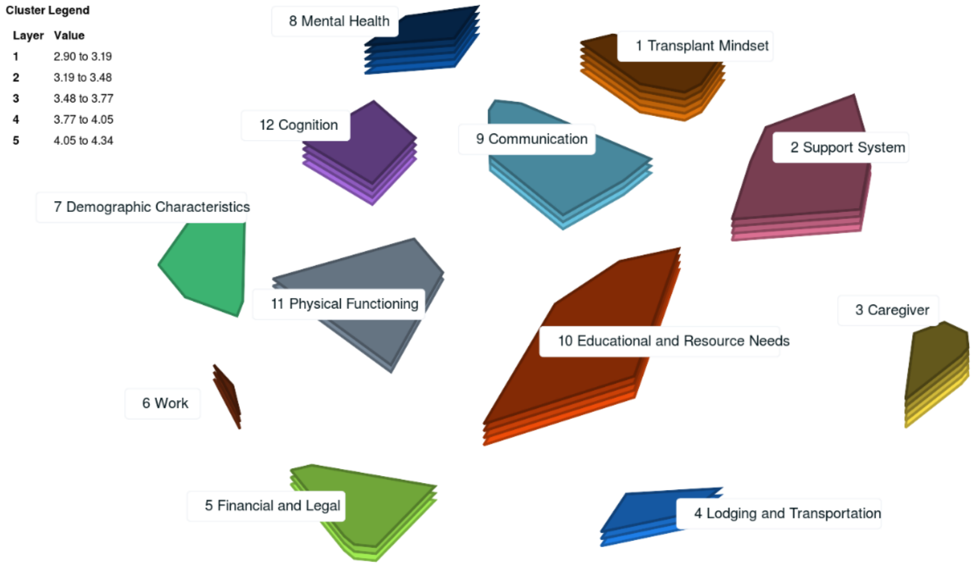
Layer	Value
1	1.61 to 2.29
2	2.29 to 2.97
3	2.97 to 3.64
4	3.64 to 4.32
5	4.32 to 5.0



87. Quality assessment of an HCT candidate should include their post-discharge 24/7 caregiver plan.

The Cluster Rating Map in Figure 5 depicts the mean importance rating of all statements in each cluster. The more layers a cluster has, the higher average importance the statements in that cluster had relative to the other clusters. The *Transplant Mindset,* *Caregiver, and Mental Health* clusters have 5 layers, which indicates the highest level of importance. Conversely, the *Demographic Characteristics* cluster has only 1 layer, which indicates that statements in the cluster were rated the least important.

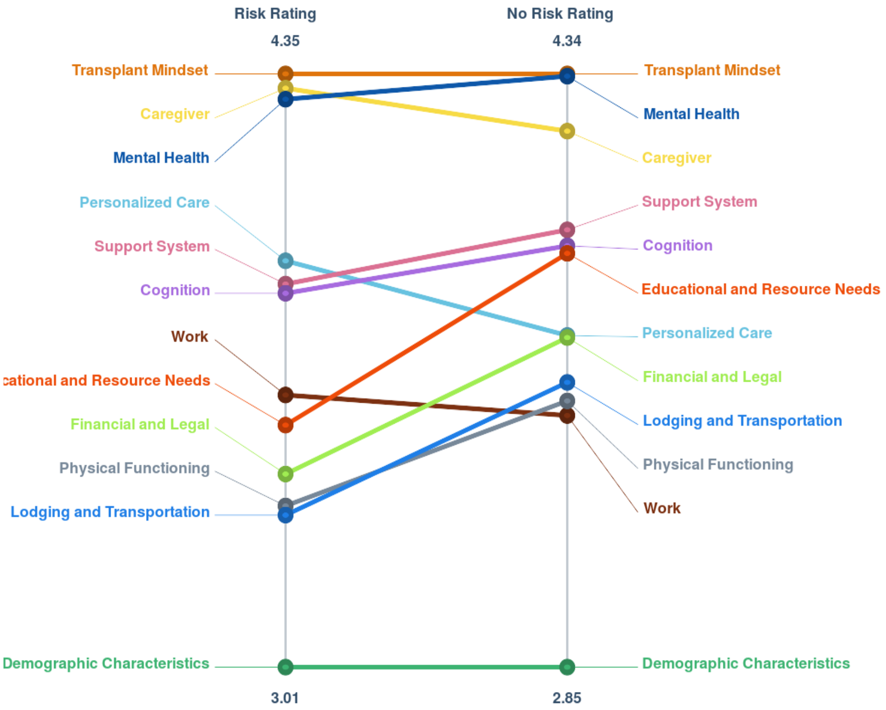
Figure 5. Cluster Rating Map



Group Differences

A pattern match was used to explore differences between participants who use standardized psychosocial risk rating tools in their practice and those who do not. This analysis compared cluster importance ratings between the two groups. Of the 24 participants who provided ratings data, 8 used a standardized psychosocial risk rating tool and 16 did not. The pattern match is presented in Figure 6.

Figure 6. Pattern Match



r = 0.91

The 3 highest rated clusters for both groups were *Transplant Mindset, Caregiver,* and *Mental Health,* while the lowest rated cluster for both groups was *Demographic Characteristics.* The correlation statistic for all cluster ratings was high (r = 0.91).

Welch's *t*-tests were used to examine differences between the two groups in mean ratings for each cluster. For the *Transplant Mindset* cluster, the mean rating among participants who do not rate risk was 4.34 (SD = 0.10), and the mean rating among those who do was 4.35 (SD = 0.11). Results from a t-test showed no significant difference between these mean ratings ($t_{(20)}$ = 0.07, p = 0.94). For the *Support System* cluster, the mean rating among participants who do not rate risk was 3.95 (SD = 0.19), and the mean rating among those who do was 3.88 (SD = 0.16). Results from a t-test showed no significant difference between these mean ratings ($t_{(24)}$ = 0.44, p = 0.67). For the *Caregiver* cluster, the mean rating among participants who do not rate risk was 4.20 (SD = 0.27), and the mean rating among those who do was 4.32 (SD = 0.38). Results from a t-test showed no significant difference between these mean ratings ($t_{(38)}$ = 0.68, p = 0.50).

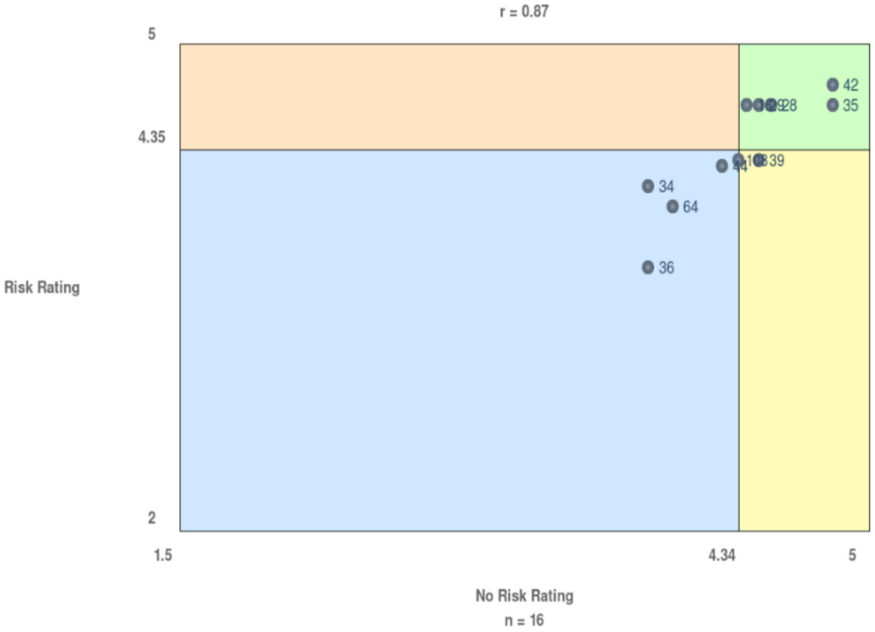
For the *Lodging and Transportation* cluster, the mean rating among participants who do not rate risk was 3.56 (SD = 0.72), and the mean rating among those who do was 3.35 (SD = 1.09). Results from a t-test showed no significant difference between these mean ratings ($t_{(10)}$ = 0.38, p = 0.71). For the *Financial and Legal* cluster, the mean rating among participants who do not rate risk was 3.68 (SD = 0.67), and the mean rating among those who do was 3.56 (SD = 0.83). Results from a t-test showed no significant difference between these mean ratings ($t_{(19)}$ = 0.31, p = 0.76). For the *Work* cluster, the mean rating among participants who do not rate risk was 3.48 (SD = 0.07), and the mean rating among those who do was 3.63 (SD = 0.07). Results from a t-test showed no significant difference between these mean ratings ($t_{(4)}$ = 0.68, p = 0.54).

For the *Demographic Characteristics* cluster, the mean rating among participants who do not rate risk was 2.85 (SD = 0.35), and the mean rating among those who do was 3.01 (SD = 0.23). Results from a t-test showed no significant difference between these mean ratings ($t_{(20)}$ = 0.72, p = 0.48). For the *Mental Health* cluster, the mean rating among participants who do not rate risk was 4.33 (SD = 0.18), and the mean rating among those who do was 4.29 (SD = 0.31). Results from a t-test showed no significant difference between these mean ratings ($t_{(10)}$ = 0.15, p = 0.89). For the *Communication* cluster, the mean rating among participants who do not rate risk was 3.68 (SD = 0.28), and the mean rating among those who do was 3.93 (SD = 0.35). Results from a t-test showed no significant difference between these mean ratings ($t_{(16)}$ = 0.94, p = 0.36).

For the *Educational and Resource Needs* cluster, the mean rating among participants who do not rate risk was 3.89 (SD = 0.81), and the mean rating among those who do was 3.56 (SD = 0.83). Results from a t-test showed no significant difference between these mean ratings ($t_{(16)}$ = 0.77, p = 0.45). For the *Physical Functioning* cluster, the mean rating among participants who do not rate risk was 3.48 (SD = 0.07), and the mean rating among those who do was 3.38 (SD = 0.43). Results from a t-test showed no significant difference between these mean ratings ($t_{(9)}$ = 0.38, p = 0.71). For the *Cognition* cluster, the mean rating among participants who do not rate risk was 3.91 (SD = 0.29), and the mean rating among those who do was 3.85 (SD = 0.23). Results from a t-test showed no significant difference between these mean ratings ($t_{(10)}$ = 0.18, p = 0.86).

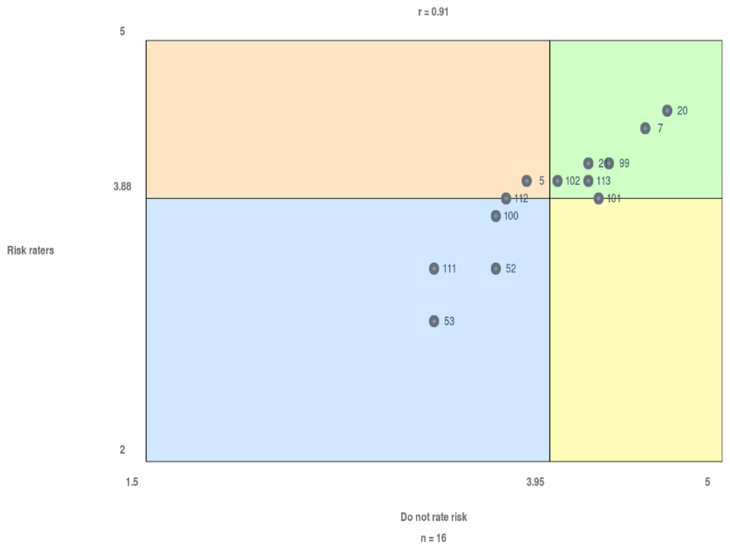
Go-Zone Graphs. Go-zone graphs are bivariate graphs produced for each cluster. They are divided into quadrants according to the mean importance ratings for the two groups: participants who use standardized psychosocial risk rating scales and participants who do not. Statements in the right upper quadrant (referred to as the Go-Zone) rate above the cluster's mean importance rating for both groups, while statements in the lower left quadrant rate below the mean for both groups. Statements in the upper left quadrant were rated above the mean only by participants who use risk ratings, and statements in the lower right quadrant were rated above the mean only by participants who do not use risk ratings. Figures 7 – 18 present the go-zone graphs for the 12 clusters in the final solution.

Figure 7. Transplant Mindset Cluster Go-Zone Graph



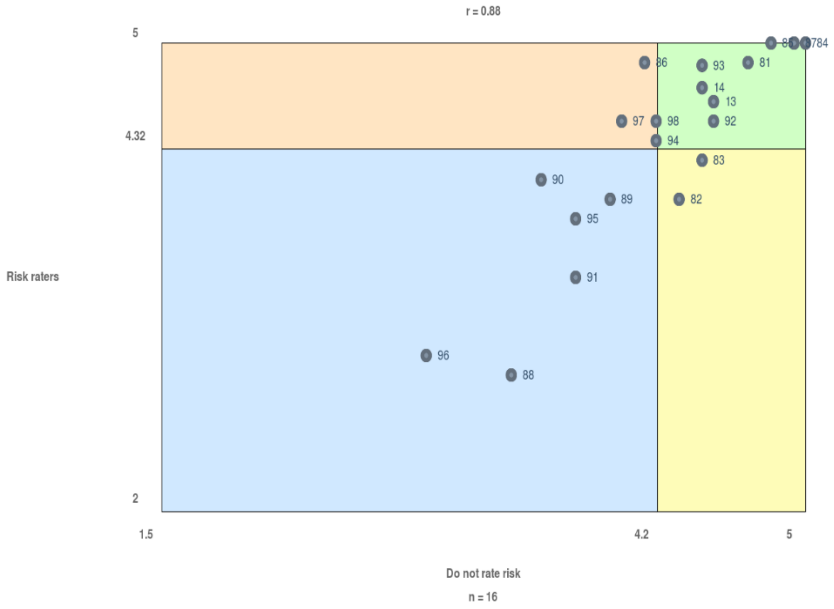
The five statements in the Go-Zone (upper right quadrant) of the *Transplant Mindset* cluster include: 16 Quality assessment of an HCT candidate should include their adjustment to illness, 28 Quality assessment of an HCT candidate should include their coping strategies, 29 Quality assessment of an HCT candidate should include their coping style, 35 Quality assessment of an HCT candidate should include adherence, and 42 Quality assessment of an HCT candidate should include concerns they have about proceeding with transplant. Five statements rated below the mean for both groups and are in the lower left quadrant: 34 Quality assessment of an HCT candidate should include the quality of their relationships with transplant team members, 44 Quality assessment of an HCT candidate should include changes between their previous quality of life and current quality of life, 64 Quality assessment of an HCT candidate should include their desired level of information, and 108 Quality assessment of an HCT candidate should include their strengths.

Figure 8. Support System Cluster Go-Zone Graph



Statements in the Go-Zone of the *Support System Cluster* include: 7 Quality assessment of an HCT candidate should include the presence of emotional abuse, 20 Quality assessment of an HCT candidate should include the quality of their support system, 21 Quality assessment of an HCT candidate should include the quality of their relationship with their spouse or partner, 99 Quality assessment of an HCT candidate should include their perceived level of social support, 102 Quality assessment of an HCT candidate should include family involvement, and 113 Quality assessment of an HCT candidate should include the impact of illness on their significant relationships. Statements that were rated below the mean by both groups include: 52 Quality assessment of an HCT candidate should include family substance use, 53 Quality assessment of an HCT candidate should include family mental health, 100 Quality assessment of an HCT candidate should include support system quantity, 111 Quality assessment of an HCT candidate should include family composition, and 112 Quality assessment of an HCT candidate should include their perception of how their support system has adjusted to their illness.

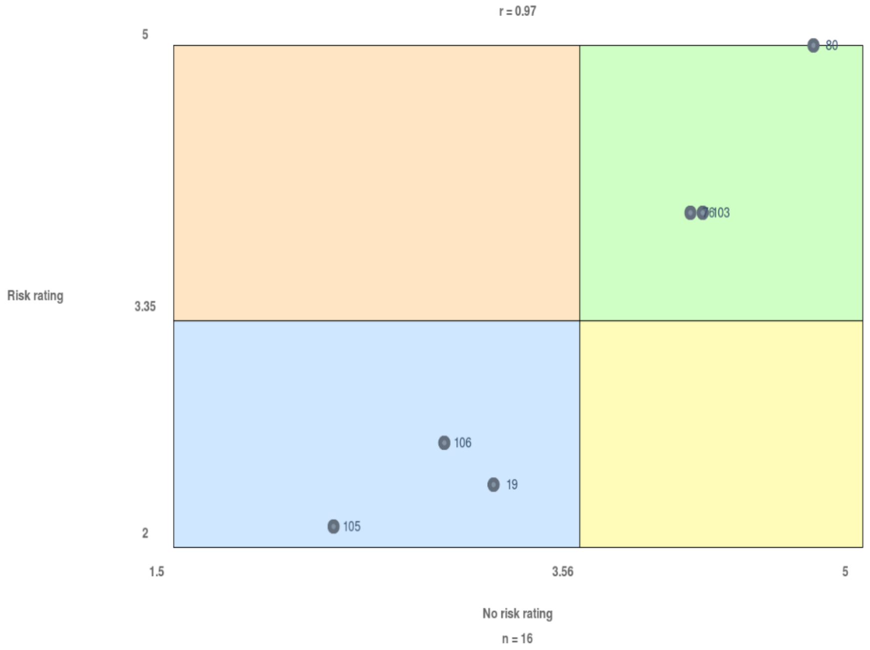
Figure 9. Caregiver Cluster Go-Zone Graph



Statements in the Go-Zone of the *Caregiver* Cluster include: 13 Quality assessment of an HCT candidate should include the caregiver's understanding of the transplant process, 14 Quality assessment of an HCT candidate should include the caregiver's functional limitations, 81 Quality assessment of an HCT candidate should include the caregiver's understanding of the caregiver role, 84 Quality assessment of an HCT candidate should include the availability of caregiver(s), 85 Quality assessment of an HCT candidate should include the caregiver's ability to perform required tasks, 87 Quality assessment of an HCT candidate should include their post-discharge 24/7 caregiver plan, 92 Quality assessment of an HCT candidate should include the caregiver's mental health, and 93 Quality assessment of an HCT candidate should include substance use by the caregiver.

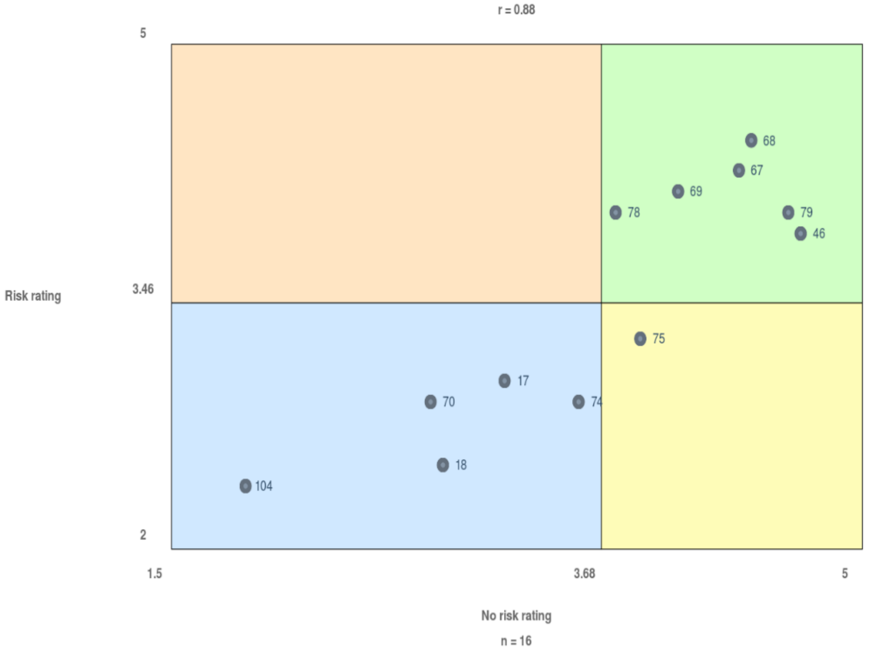
Statements that were rated below the mean by both groups include: 88 Quality assessment of an HCT candidate should include the caregiver's plan to work vs. visit vs. stay with patient during the patient's admission, 89 Quality assessment of an HCT candidate should include the caregiver's comfort level with self-advocacy in the medical setting, 90 Quality assessment of an HCT candidate should include the caregiver's desired level of information, 91 Quality assessment of an HCT candidate should include any problems the caregiver has had with past medical providers, 95 Quality assessment of an HCT candidate should include the caregiver's employment, and 96 Quality assessment of an HCT candidate should include the caregiver's education level.

Figure 10. Lodging and Transportation Cluster Go-Zone Graph



Statements in the *Lodging and Transportation* cluster that were rated above the mean by both groups and therefore fall in the Go-Zone include: 76 Quality assessment of an HCT candidate should include their mode of transportation, 80 Quality assessment of an HCT candidate should include their relocation plan (if they need to relocate), and 103 Quality assessment of an HCT candidate should include potential health risks in the home environment. Statements in the *Lodging and Transportation* cluster that were rated below the mean by both groups include: 19 Quality assessment of an HCT candidate should include parking needs, 105 Quality assessment of an HCT candidate should include the presence of plants in the home, and 106 Quality assessment of an HCT candidate should include the presence of pets in the home.

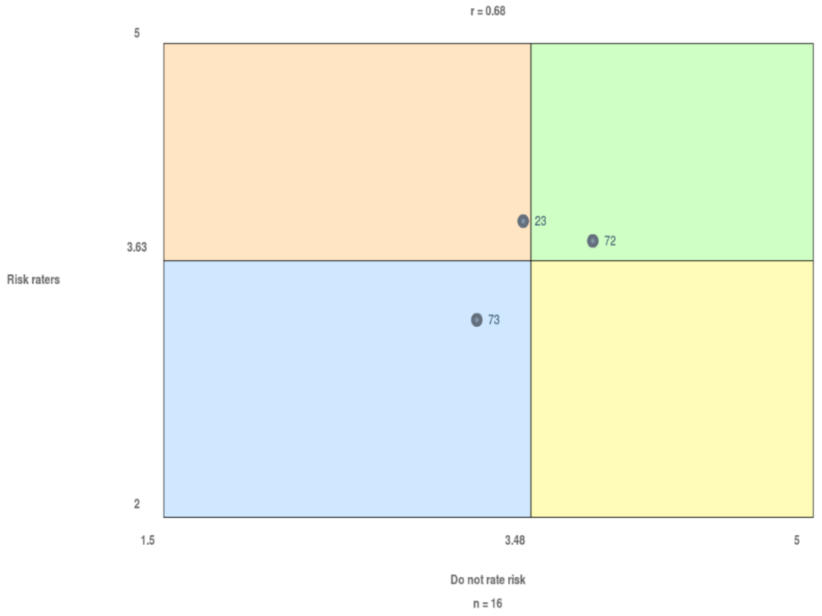
Figure 11. Financial and Legal Cluster Go-Zone Graph



Statements in the *Financial and Legal* cluster are located in the Go-Zone include: 46 Quality assessment of an HCT candidate should include advance directives, 67 Quality assessment of an HCT candidate should include their plan to cover expenses while off work, 68 Quality assessment of an HCT candidate should include financial concerns, 69 Quality assessment of an HCT candidate should include their source(s) of income, 78 Quality assessment of an HCT candidate should include their pharmacy benefits, and 79 Quality assessment of an HCT candidate should include their insurance coverage.

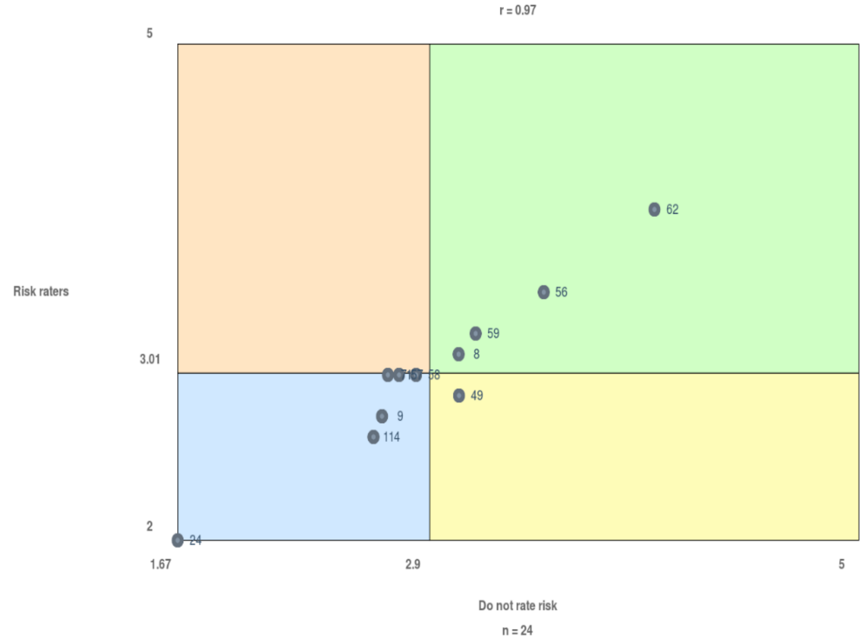
Statements in the *Financial and Legal* cluster that were rated below the mean by both groups include: 17 Quality assessment of an HCT candidate should include whether or not they have a legal will, 18 Quality assessment of an HCT candidate should include whether or not a power-of-attorney for finances has been appointed, 70 Quality assessment of an HCT candidate should include Veterans Administration (VA) benefits, 74 Quality assessment of an HCT candidate should include use of pharmacy assistance programs, and 104 Quality assessment of an HCT candidate should include whether they rent vs. own with mortgage vs. own without mortgage.

Figure 12. Work Cluster Go-Zone Graph



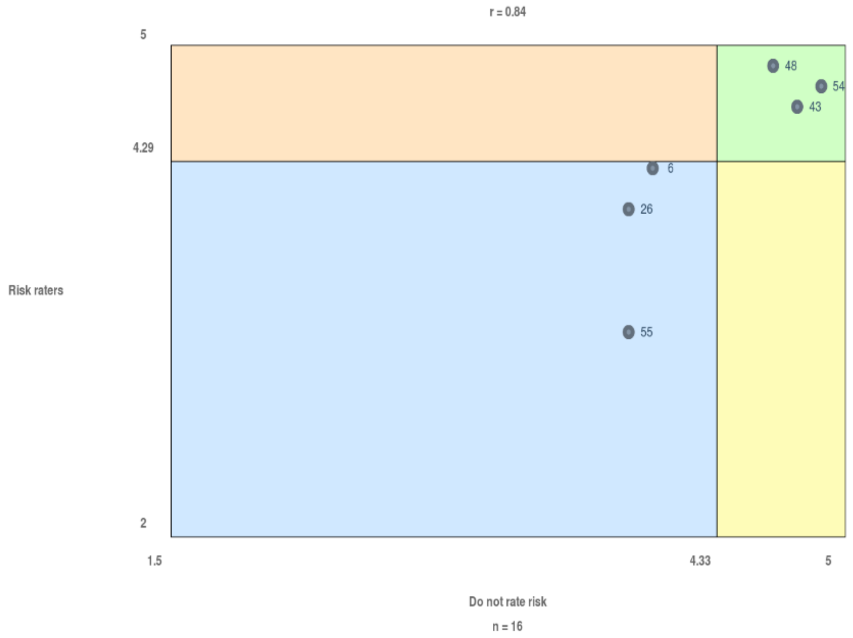
The statement in the *Work* cluster that is located in the Go-Zone is 72 Quality assessment of an HCT candidate should include employment status. The statement that both groups rated below the mean is 73 Quality assessment of an HCT candidate should include occupation.

Figure 13. Demographic Characteristics Cluster Go-Zone Graph



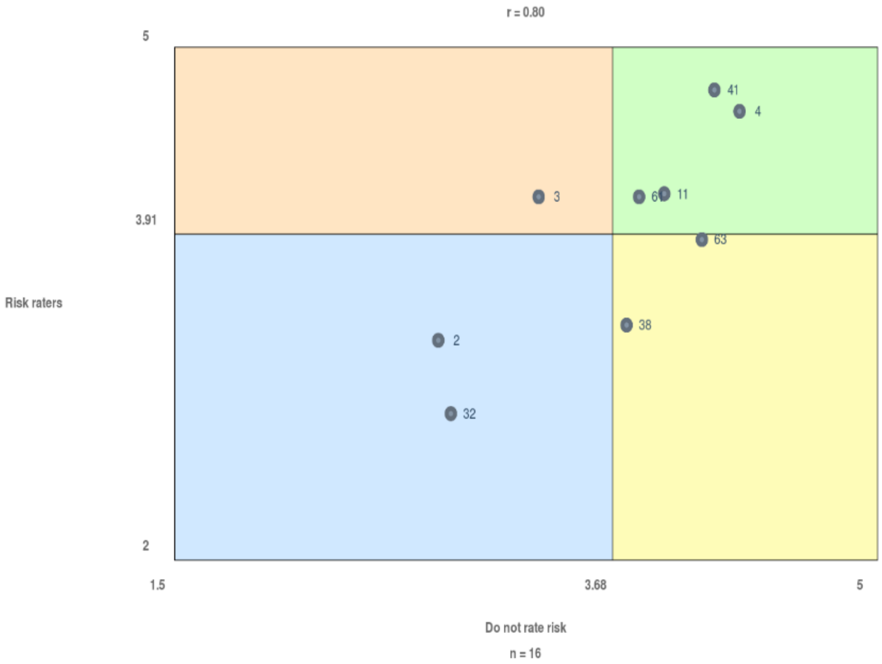
Statements in the *Demographic Characteristics* cluster that are located in the Go-Zone include: 8 Quality assessment of an HCT candidate should include any impairment in hearing, 56 Quality assessment of an HCT candidate should include gender identity, 59 Quality assessment of an HCT candidate should include their religion, and 62 Quality assessment of an HCT candidate should include languages they speak. Statements in the *Demographic Characteristics* cluster that were rated below the mean by both groups include: 9 Quality assessment of an HCT candidate should include ethnicity, 24 Quality assessment of an HCT candidate should include their birthplace, 57 Quality assessment of an HCT candidate should include sexual orientation, 58 Quality assessment of an HCT candidate should include race, 71 Quality assessment of an HCT candidate should include a military history, and 114 Quality assessment of an HCT candidate should include marital status.

Figure 14. Mental Health Cluster Go-Zone Report



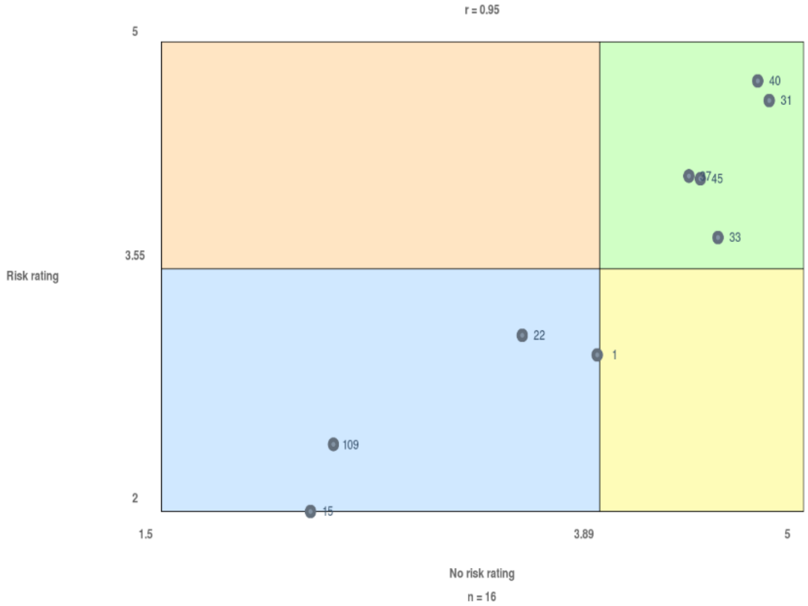
Statements in the *Mental Health* cluster that are located in the Go-Zone include: 43 Quality assessment of an HCT candidate should include the presence of physical abuse, 48 Quality assessment of an HCT candidate should include their use of substances, and 54 Quality assessment of an HCT candidate should include their mental health. Statements that were rated below the mean by both groups include: 6 Quality assessment of an HCT candidate should include the presence of sexual abuse, 26 Quality assessment of an HCT candidate should include a trauma history, and 55 Quality assessment of an HCT candidate should include a history of significant losses.

Figure 15. Communication Cluster Go-Zone Graph



Statements in the *Communication* cluster that were rated above the mean by both groups include: 4 Quality assessment of an HCT candidate should include their goal for having a transplant, 11 Quality assessment of an HCT candidate should include their communication preferences, 41 Quality assessment of an HCT candidate should include their beliefs that guide medical decision-making, and 61 Quality assessment of an HCT candidate should include their communication style. Statements in the *Communication* cluster that were rated below the mean by both groups include: 2 Quality assessment of an HCT candidate should include their social activities, and 32 Quality assessment of an HCT candidate should include their hobbies.

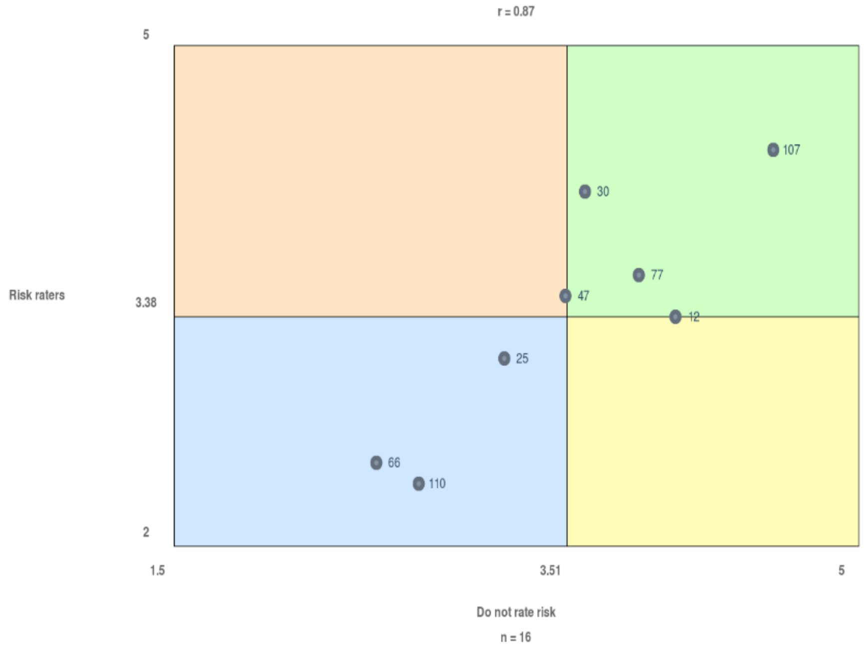
Figure 16: Educational and Resource Needs Cluster Go-Zone Graph



Statements in the *Educational and Resource Needs* cluster that were rated above the mean by both groups include: 31 Quality assessment of an HCT candidate should include any barriers, 33 Quality assessment of an HCT candidate should include unmet educational needs related to transplant, 37 Quality assessment of an HCT candidate should include health literacy, 40 Quality assessment of an HCT candidate should include their understanding of the transplant process, and 45 Quality assessment of an HCT candidate should include their health behaviors.

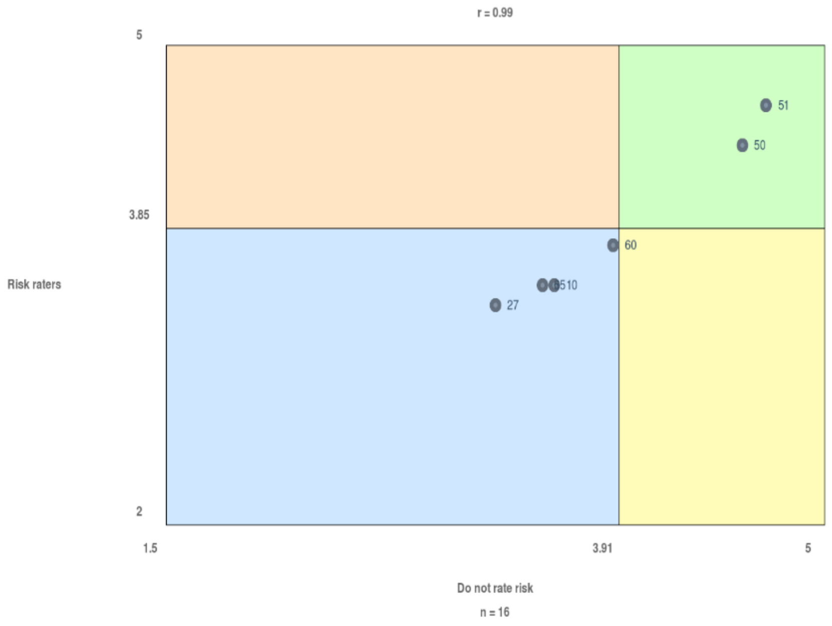
Statements in the *Educational and Resource Needs* cluster that were rated below the mean by both groups include: 1 Quality assessment of an HCT candidate should include their knowledge of community resources, 15 Quality assessment of an HCT candidate should include a family history of non-cancer chronic illness, 22 Quality assessment of an HCT candidate should include use of community resources, and 109 Quality assessment of an HCT candidate should include a family history of causes of death.

Figure 17. Physical Functioning Cluster Go-Zone Graph



Statements in the *Physical Functioning* cluster that fell in the Go-Zone include: 30 Quality assessment of an HCT candidate should include their physical functioning, 77 Quality assessment of an HCT candidate should include fertility concerns, 107 Quality assessment of an HCT candidate should include their living situation. Statements in the *Physical Functioning* cluster that were rated below the mean by both groups include: 25 Quality assessment of an HCT candidate should include use of complementary and alternative medicine, 66 Quality assessment of an HCT candidate should include their highest level of formal education, 110 Quality assessment of an HCT candidate should include a family history of cancer.

Figure 18. Cognition Cluster Go-Zone Graph



Statements in the *Cognition* cluster that fall in the Go-Zone include: 50 Quality assessment of an HCT candidate should include their cognition, and 51 Quality assessment of an HCT candidate should include mental status. Statements in the *Cognition* cluster that were rated by both groups below the mean include: 10 Quality assessment of an HCT candidate should include their spirituality, 27 Quality assessment of an HCT candidate should include sexual health, 60 Quality assessment of an HCT candidate should include cultural traditions, 65 Quality assessment of an HCT candidate should include pertinent developmental history.

CHAPTER V: DISCUSSION AND CONCLUSIONS

This chapter will offer an interpretation of the results presented in the previous chapter. It will also offer implications for practice, policy, workforce training, and research. Since concept mapping is a multi-step process, results from each step will be discussed in turn. Even so, the results can only be fully understood in the context of the overall analyses. The data must be taken together, critically examined, and interpreted as a whole in the context of the study.

Map Interpretations

The final solution contained 12 clusters. Based on the bridging values, the *Caregiver* cluster was the most cohesive. This means that participants sorted the statements in this cluster together at a higher rate than they sorted the statements in any other cluster. In order of most to least cohesive, the *Caregiver* cluster was followed by *Financial and Legal, Demographic Characteristics, Transplant Mindset, Mental Health, Communication, Lodging and Transportation, Work, Cognition, Support System, Physical Functioning, and Educational and Resource Needs.* The *Educational and Resources Needs* cluster was the least cohesive. Its position in the center of the map reflects this, since comparatively, the statements in the cluster were more frequently sorted with statements in clusters around the map.

Statement Interpretations

Convergence with the literature. The statements that were brainstormed in this study capture ideas that are present in the literature. Overall, the statements cover all of the elements listed in the PACT, SIPAT, and TERS. One exception is the SIPAT item "effect of truthfulness vs. deceptive behavior in presentation" that asks the professional to evaluate the degree to which the patient has been "forthcoming with negative information." The profession of social work endorses a strengths-based perspective. Statement *108 Quality assessment of an HCT candidate should include their strengths* captures this idea.

The AOSW standards for psychosocial assessment lists "barriers to care" as one of 8 areas that should be assessed. This idea is captured in statement *31. Quality assessment of an HCT candidate should include any barriers.* This statement was rated 4.76 and had a bridging value of 0.43. Thus, while participants considered this element highly important, they ascribed different meanings to it in relation to the other elements. The AOSW standards also list assessment of physical disability, which is reflected in the following statements: *8. Quality assessment of an HCT candidate should include any impairment in hearing, 30. Quality assessment of an HCT candidate should include their physical functioning,* and *49. Quality assessment of an HCT candidate should include any impairment in vision.*

Furthermore, the AOSW standards include assessment of "race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sexual orientation, and gender identity," which are all represented in the brainstormed statements. Socioeconomic status is generally considered a measure of class standing that can be measured by factors such as income, occupation, and education level. These elements are reflected in the following statements: *69. Quality assessment of an HCT candidate should include their source(s) of income, 72. Quality assessment of an HCT candidate should include employment status, 73. Quality assessment of an HCT candidate should include occupation,* and *66. Quality assessment of an HCT candidate should include their highest level of formal education.*

The substantial and growing body of literature on HCT caregivers acknowledges that they are significantly impacted by the transplant process and in need of assessment and interventions to promote their own well-being. This is strongly emphasized in the brainstormed statements. Of the 114 statements, 20 of them specifically mentioned the caregiver. This reflects more than a brief screening. The 20 items constitute a full assessment of the caregiver. This level of attention is congruent with the substantial body of literature on the role, experience, and variety of outcomes of HCT caregivers.

The psychosocial risk rating tools applied to HCT rate the family or support system in terms of availability, quality, stability, functionality, mental health, and substance use. These ideas are captured in the brainstormed statements: *6. Quality assessment of an HCT candidate should include the presence of sexual abuse, 7. Quality assessment of an HCT candidate should include the presence of emotional abuse, 20. Quality assessment of an HCT candidate should include the quality of their support system, 21. Quality assessment of an HCT candidate should include the quality of their relationship with their spouse or partner, 43. Quality assessment of an HCT candidate should include the presence of physical abuse, 52. Quality assessment of an HCT candidate should include family substance use, 53. Quality assessment of an HCT candidate should include family mental health, 99. Quality assessment of an HCT* *candidate should include their perceived level of social support, 100. Quality assessment of an HCT candidate should include support system quantity, 101. Quality assessment of an HCT candidate should include family stressors, 102. Quality assessment of an HCT candidate should include family involvement, 111. Quality assessment of an HCT candidate should include family composition, 112. Quality assessment of an HCT candidate should include their perception of how their support system has adjusted to their illness,* and *113. Quality assessment of an HCT candidate should include the impact of illness on their significant relationships.*

Another area of convergence between the literature and the statements is fertility and sexual health. Outcomes literature identifies fertility and sexual concerns as common and enduring aspects of post-transplant life. Fertility and sexual concerns do not appear in the literature on psychosocial risk since they are not considered risk factors for poorer survival. Yet, participants identified that these areas should be assessed and addressed pre-transplant as evidenced by the following statements: *12. Quality assessment of an HCT candidate should include fertility preservation, 27. Quality assessment of an HCT candidate should include their sexual health,* and *77. Quality assessment of an HCT candidate should include fertility concerns.*

Assessing the patient's knowledge and understanding of their diagnosis and the proposed treatment is ubiquitous in conceptualizations of psychosocial elements that should be assessed prior to planned, intensive medical interventions. The patient's desire for the medical intervention as well as cognition/mental status are also present in conceptualizations, but to a slightly lesser degree. These ideas relate to the ethical principle of informed consent for medical treatment. Upholding the principle of informed consent requires two preconditions: competence to understand and choose and voluntariness (no coercion) in choosing (Beauchamp & Childress, 2013). It also requires that providers disclose information about the diagnosis, all reasonable treatment options, and the potential risks and benefits of those options. Additionally, providers must check for understanding of this information (Beauchamp & Childress, 2013).

Dew et al. (2000), writing in the context of solid organ transplantation, recommend that "mental (cognitive) status should routinely be included in the psychosocial evaluation, because cognitive status will affect patients' ability to understand the transplant experience and provide informed consent, as well as comprehend what is required of them" (p. 241). Informed consent is strongly emphasized in the conceptualization of psychosocial elements that should be assessed in candidates for experimental spinal cord injury, because the treatment is experimental. Even though HCT is now a standard therapy for many diseases, patients are often offered the opportunity to participate in research studies. According to Raj et al. (2017), patients may be asked to participate in up to 10 studies, each with lengthy consent documents. This can understandably be overwhelming and add stress when patients and their caregivers are already feeling distressed and vulnerable. Accordingly, ensuring understanding, clear communication, and voluntariness is all the more important.

Fifteen statements reflect aspects of informed consent: *4. Quality assessment of an HCT candidate should include their goal for having a transplant, 11. Quality assessment of an HCT candidate should include their communication preferences, 33. Quality assessment of a transplant candidate should include any unmet educational needs, 36. Quality assessment of an HCT candidate should include their comfort level* *with self-advocacy, 37. Quality assessment of an HCT candidate should include health literacy, 38. Quality assessment of an HCT candidate should include their knowledge of supportive care options, 39. Quality assessment of an HCT candidate should include their motivation for having a transplant, 41. Quality assessment of an HCT candidate should include their beliefs that guide medical decision-making, 42. Quality assessment of an HCT candidate should include concerns they have about proceeding with transplant, 50. Quality assessment of an HCT candidate should include their cognition, 51. Quality assessment of an HCT candidate should include mental status, 61. Quality assessment of an HCT candidate should include their communication style, 63. Quality assessment of an HCT candidate should include their learning preferences, 64. Quality assessment of an HCT candidate should include their desired level of information,* and *65. Quality assessment of an HCT candidate should include pertinent developmental history.* These statements clearly demonstrate that participants consider supporting the patient's informed decision-making is one purpose of their assessment. This purpose is less well-recognized than other purposes but should not be overlooked.

Participants' ideas also reflected aspects of informed consent with the caregiver: *13. Quality assessment of an HCT candidate should include the caregiver's understanding of the transplant process, 81. Quality assessment of an HCT candidate should include the caregiver's understanding of the caregiver role, 82. Quality assessment of an HCT candidate should include the caregiver's cognition, 89. Quality assessment of an HCT candidate should include the caregiver's comfort level with self-advocacy in the medical setting,* and *90. Quality assessment of an HCT candidate should include the caregiver's desired level of information.*

Finally, the financial impact of HCT was apparent in the statements and accords with literature regarding the financial consequences of HCT. Participants brainstormed 11 ideas that address financial status, needs, and use of assistance programs. This reflects a comprehensive financial assessment. It also connects with a previous finding in the literature that social workers rated resolving financial barriers for uninsured or underinsured patients as one of their most common challenges (Stickney Ferguson et al., 2018). Examples of statements related to finances include *18. Quality assessment of an HCT candidate should include whether or not a power-of-attorney for finances has been appointed, 68. Quality assessment of an HCT candidate should include financial concerns, 74. Quality assessment of an HCT candidate should include use of pharmacy assistance programs,* and *79. Quality assessment of an HCT candidate should include their insurance coverage.*

Divergence with the literature. One major divergence between the ideas gathered and the empirical literature is regarding the construct of psychosocial distress. Distress is a prominent construct in the literature but does not appear in the statement list. The term distress was selected by a National Comprehensive Cancer Network panel that introduced clinical management guidelines for it in 1997. The term was selected because it was thought to be more acceptable and less stigmatizing than terms such as psychiatric, psychosocial, or emotional (National Comprehensive Cancer Network, 2021). In 2015, the American College of Surgeon’s Commission on Cancer mandated that accredited cancer centers screen all patients for psychosocial distress. This resulted in a boon for research on the prevalence and sources of distress as well as screening and program implementation.

The National Comprehensive Cancer Network's widely used definition of psychosocial distress is "a multifactorial unpleasant experience of a psychological (cognitive, behavioral, emotional), social, spiritual and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment" (National Comprehensive Cancer Network, 2021). The definition also states that distress "extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis" (National Comprehensive Cancer Network, 2021). Clearly, distress is a broad, multidimensional construct. The purpose of screening for distress is to identify patients who need more comprehensive assessment and intervention. It is likely, then, that study participants did not mention distress as an element that should be assessed because they were brainstorming a comprehensive, detailed list of elements that should be assessed.

Depressive symptomatology is notable in the literature but does not specifically appear in the statement set. It appeared in the initial brainstormed list but was synthesized into statement *54. Quality assessment of an HCT candidate should include their mental health* along with other constructs including anxiety, suicidal ideation, obsessive-compulsive disorder, schizophrenia, eating disorder, personality disorder characteristics, panic attacks, post-traumatic stress disorder, attention deficit and hyperactivity disorder, history of psychiatric hospitalization and psychoactive medication. This was done out of concern for participant burden related to the number of statements that would need to be sorted and rated.

Sorting Interpretations

Participants seemed to sort the statements based on the overarching theme of *capacities*. Sorting according to *capacities* aligns the purpose of psychosocial assessment to “identify the individual’s capacity to deal with negative or positive consequences of [transplant] (Fronek, 2004, p. 6). Dictionary definitions of capacity lend richer description to this idea: a person’s ability to do a specific thing, the maximum amount that can be received or contained, the actual or potential ability to withstand or perform, the quality or state of being susceptible to a specific treatment or action (Dictionary.com, 2021). Psychosocial professionals in HCT are assessing the patient’s and caregiver’s ability to withstand the arduous transplant process. Do they have what it takes? What will help them and what will hinder them?

Perhaps the most interesting cluster is the *Caregiver* cluster. The *Caregiver* cluster included the most statements (n = 20) of any cluster and was by far the most cohesive with a bridging value of 0.06. Participants viewed the caregiver as conceptually distinct from the broader support system and elevated its importance with a mean rating of 4.24 compared to 3.92 for the *Support System* cluster. This reinforces the attention that the outcomes literature pays to caregivers. Interestingly, the vast majority of the literature that examines associations between pre-HCT psychosocial factors and post-HCT outcomes measures family/social support but not specifically the caregiver. This is likely due to the research using the PACT, SIPAT, and TERS. These measures ask the psychosocial professional to rate the family/support system but not specifically the caregiver.

HCT is a treatment for life-threatening and life-limiting illness. HCT itself can also be life-threatening and life-limiting. Taken together, the statements in the *Transplant Mindset* cluster speak to a frame of mind or overarching approach around the intensive treatment they are about to undergo. Statements in this cluster related to the patient's capacity for coping and adjustment to illness, adhering to treatment, processing information, self-advocacy, and forming relationships with transplant team members. It also included how their quality of life has changed, their motivation for undergoing HCT, and concerns they have about proceeding with transplant. Statement *108. Quality assessment of a transplant candidate should include their strengths* was also sorted in this cluster, indicating that participants viewed it as relating to the idea of an attitude, approach, or frame of mind that would increase their capacity to handle HCT. Elements within this cluster, such as coping and adherence, have been examined within the literature, but the construct of a mindset towards transplant has not been conceptualized, measured, or studied. Beeken, Eiser, & Dalley's (2011) qualitative study touched on this construct by identifying mechanisms that patients find helpful for adjustment such as optimism balanced with realism; focusing on the short-term; adjusting expectations of physical functioning; positively-interpreted comparisons to other patients, and not thinking about their illness.

Rating Interpretations

The Pattern Match analysis showed the clusters in rank order of importance according to two groups: participants who use standardized psychosocial risk rating scales in their practice and those who do not. Three clusters were ranked highest by both groups: *Transplant Mindset, Caregiver, and Mental Health.* The next 8 clusters ranged from 3.47 to 3.92 in mean importance and varied in their rank order between the two groups. These clusters included *Support System, Cognition, Educational and Resource Needs, Communication, Financial and Legal, Work, Lodging and Transportation, and Physical Functioning.* There was high correlation between the groups' ratings.

The high rating of the *Transplant Mindset* cluster aligns with theories that link stress and adherence to disease outcomes. According to these theories, reducing the impact of stress on the body leads to better outcomes. The elements that participants rated above the mean importance for the cluster demonstrate this connection. Participants rated adjustment to illness, coping strategies, coping style, adherence, and concerns the patient has about proceeding with HCT as the highest priority for assessment in this cluster. These elements may increase or decrease stress, thereby impacting outcomes.

Physical Functioning was rated lower in importance relative to other clusters, suggesting that the patient's capacity in this area is a lower priority for determining readiness for transplant. Indeed, this study showcases that patients need far more than physical capacities to undergo transplant. They need emotional, mental, social, and material capacities. They also need a caregiver with emotional, mental, social, and material capacities. Unfortunately, some centers do not have a psychosocial professional proactively assess every patient (Randall et al., 2021).

There was clear agreement between the two groups that *Demographic Characteristics* ranked the lowest in importance. The relatively low rating of *Demographic Characteristics* is discordant with the priority the empirical literature places on these factors. Of all the brainstormed statements, more is known about demographic characteristics as risk factors for poorer survival and other outcomes than any other variables. One of the first things researchers consider is differences in groups based on these variables. The participants considered these a lower priority in their assessment. This may be due to participants viewing the items as “checkbox” information that is mostly found in the electronic health record rather than gathered through their clinical interview. The low ratings may also be attributed to social workers perceiving that their interventions do not target these aspects.

Rating Differences

T-tests were performed to examine differences between mean ratings for statements in each cluster by two groups: participants who use risk rating tools in their practice and participants who do not use risk rating tools. There were no significant differences in mean ratings for the two groups. This suggests that psychosocial risk rating tools do not significantly influence the way psychosocial professionals prioritize the importance of the elements they assess in a transplant candidate.

Summary of Interpretations

The conceptual domain of psychosocial elements that should be assessed in HCT candidates is broad and multidimensional. The elements far exceed those that are found in conceptualizations of psychosocial risk. The ideas were configured into 12 distinct clusters. Psychosocial professionals seemed to organize the elements based on domains of capacity. Ratings data showed no differences in ratings based on whether the psychosocial professional uses a standardized risk rating scale in their practice. Ratings data also showed that *Caregiver*, *Transplant Mindset*, and *Mental Health* clusters were the highest priorities.

Implications

The following implications arise from the study and the existing body of literature.

Social Work Practice

Study findings offer HCT social workers and psychologists a conceptualization of the psychosocial elements that is not limited to "risk factors" and that was created from their own voices and knowledge. Pre-HCT psychosocial assessment should include all domains of capacity as conceptualized by the participants and give highest priority to patients' mental health, mindset about transplant, and the caregiver. The statements and resulting clusters can be considered a comprehensive picture of the pre-HCT psychosocial assessment. Psychosocial professionals can compare their current practice to it and identify opportunities to align their practice.

The conceptualization will inform the creation of a psychosocial assessment protocol. The findings suggest implications for the protocol. First, the clusters may provide an organizational structure for the overarching domains that should be assessed. Second, elements that fell in the go-zones should be given higher priority for assessment. Time can be limited in the dynamic, too-often crisis-oriented setting of HCT. When the ideal amount of time for assessment is not available, psychosocial professionals needs to focus on the most important elements. The go-zone graphs can inform these.

Third, given how challenged the empirical literature is by inconsistent and poor quality measurement, a protocol should specify variables to measure with standardized instruments that have strong psychometric properties. Only 1-2 should be administered in order to minimize burden (Austin & Rini, 2013). Therefore, priority constructs need to be identified. The conceptual framework suggests that variables within mental health, transplant mindset, and the caregiver should be considered. Lastly, the protocol needs to include methods to collect accurate demographic data, because these data are essential for conducting high quality research.

One clear practice implication of the conceptual framework is that assessing the patient includes thoroughly assessing the caregiver. Given their vital importance, the caregiver should be considered as much the social worker's client as the patient. Social workers should offer programs and interventions to promote caregivers' well-being. Many centers already offer support groups and other psychosocial care services to caregivers. Those that do not should prioritize implementing such programs.

The NASW Code of Ethics mandates social workers to "critically examine and keep current with emerging knowledge relevant to social work and fully use…research evidence in their professional practice" (National Association of Social Workers, 2021). This study has several implications for research-informed social work practice. Research findings on the predictive value of psychosocial factors on HCT outcomes are mixed and do not support patients being excluded from HCT based on psychosocial factors. This suggests the need for caution about how psychosocial assessment results are used in determining a patient's eligibility for transplant. It also suggests a need for ongoing conversation about stigma related to psychosocial factors and how bias may underlie eligibility decisions. As Richardson, Devine, et al. (2018) candidly acknowledged, "we are concerned that perhaps providers hesitate to enroll patients with psychosocial risk factors because, consciously or subconsciously, we may simply not like taking care of them" (p. 1427). The role of implicit bias in clinical decision-making has been documented (Garb, 2013), and social workers are not immune to this.

Program Policy

The psychosocial domain is vitally important for the HCT process. Much funding goes towards advancing medical research and technology. Unfortunately, this technology is useless if patients do not have the capacity to endure the treatment. Said another way, optimizing the technology without optimizing the patient is short-sighted. Providing the best care for patients means focusing on *them*, promoting *their capacity*, not just advancing the medical technology they receive. Financial resources need to be allocated so that patients can get to and through HCT. Additionally, all patients should be assessed and provided subsequent care to bolster their capacity. Unfortunately, evidence shows that at some transplant centers, not all patients are assessed (Randall et al., 2021).

The results of this study in conjunction with the literature on caregivers' experience and outcomes suggests that going through HCT is as arduous for them as for the patient. There are well-known risks to their health and well-being. Ethically, this raises the question of whether a more formalized informed consent process should be implemented for the caregiver. If so, what information do they need about the risks? Adding further complexity to the situation, most patients have few caregiver options. Thus, the caregiver is under pressure to assume the role because the patient may not be able to move forward with HCT without them.

The mixed findings of the effect of psychosocial high risk factors on outcomes do not support excluding patients from transplant based on psychosocial factors unless there is a clear indication of imminent harm. Also, psychosocial eligibility policies seem premature and should be revisited by transplant programs that use them.

Workforce Training

Consistent with the concept mapping emphasis on valuing voice, opportunities exist to continue elevating the voices of psychosocial professionals in HCT by presenting the conceptual framework and resulting assessment protocol at professional conferences and to interdisciplinary teams. The conceptual framework may be used to educate social workers and psychologists new to HCT. This would be particularly valuable at smaller centers where turnover may result in no training for the incoming social worker. Finally, education for all members of the HCT team about the state of the evidence linking psychosocial factors to outcomes is warranted. Without education on this, professionals might harbor misunderstandings about this relationship. As Richardson, Devine, et al. (2018) remarked, “practically there remains little doubt among HCT providers that patients who continue to abuse substances do worse with HCT” (p. 1475). This thinking, which is not supported by evidence, influences clinical decision-making and could have serious consequences for the patient’s type and quality of care.

Research

Concept mapping has not been used before in HCT. In recent years, increasing emphasis has been placed on participatory research with funding sources requiring that projects be guided by patients, caregivers, and community stakeholders (Patient Centered Outcomes Research Institute, 2021). Concept mapping methodology would bring this participatory component and could help clarify ambiguous concepts. “Barriers” is one of these concepts. Concept mapping studies have elucidated the meaning of barriers in various contexts (Ahmad et al., 2012; Daoud et al., 2018). Given its high importance and potential for greater conceptual clarity, a concept mapping study to conceptualize barriers in the context of HCT is warranted.

The literature contains factors that researchers and clinicians think are important for undergoing HCT, but the voices of patients and caregivers have largely not been heard. A concept mapping study could help define and conceptualize what patients and caregivers perceive helped them and hindered them during the HCT process. Their ideas and thinking could reveal dimensions that have not been considered by researchers and clinicians.

The literature would benefit from some delineation of the most salient psychosocial factors and outcomes that need to be investigated with prospective, multi-center studies. The statements in the Go-Zones from the highest rated clusters suggest what these might be. From the *Mental Health* cluster, these include mental health and substance use, both of which are present in the literature but could benefit from more rigorous measurement and new investigation. From the *Transplant Mindset* cluster, these include adjustment to illness, coping strategies, coping style, and adherence. From the *Caregiver* cluster, these include the caregiver's understanding of the transplant process, the caregiver's functional limitations, substance use, mental health, and ability to perform required tasks. These variables have not been examined in the literature.

The literature has described caregivers' experience and outcomes from primarily a quantitative perspective. Qualitative research could make significant contributions and should be conducted. Specifically, a phenomenological study could provide a rich description of the lived experience and common meaning of going through HCT as a caregiver. This rich description of the essence of the caregiving experience is a gap in the literature, that if filled, could suggest novel interventions to support this population. Another area for investigation is to understand how patients and caregivers define "success" in HCT. What constitutes a successful experience and outcome for them? Concept mapping methodology could help answer this question.

Study Strengths

This study fills a gap and addresses limitations in the literature. As previously discussed, the literature that conceptualizes the psychosocial elements that should be assessed in HCT candidates is extremely limited. The field of HCT has mostly relied on conceptualizations of psychosocial risk factors produced in the context of solid organ transplantation. This study fills that gap by providing a conceptualization specific to HCT that encompasses all factors, not just those thought to contribute to risk.

Conceptualizations were produced primarily based on literature review and the clinical experience of a few people, most of whose roles do not include performing psychosocial assessments. Concept mapping methodology addresses these limitations. It offers a more rigorous method of conceptualization as outlined in Chapter 3. Its mixed-methods approach elicits the perspectives of many individuals who regularly assess HCT candidates. Previously, their voices had not been heard. Lastly, the data and conceptual framework generated by this study are action-oriented. They may be used to inform practice changes that would move the field forward.

Study Limitations

No study is without limitations. One limitation of this study is the way in which power was conceptualized. While positioned lower in the health care hierarchy relative to other disciplines, social workers still have power related to being members of the health care system. In HCT, they serve a gatekeeping function in that their interpretation of the patient’s psychosocial risk can impact the patient’s access to transplant. In this study, the participants identified primarily as non-Hispanic white, which also positions them as having more power. This may have influenced the elements they choose to assess and the priority they give to those elements. The lack of racial/ethnic diversity in the sample likely accurately reflects the field, as previous study results (Stickney Ferguson et al., 2018) have also shown minimal diversity in this professional population. This lack of diversity reflects a structural problem. Future research can address this limitation by purposively sampling racially and ethnically diverse participants.

There are several limitations related to the reliability and validity of concept mapping methodology. Concept mapping studies are highly contextual; thus the reliability and validity of the data can be difficult to assess (Miller, 2016). In concept mapping, validity refers to “the degree to which a map accurately reflects reality” (Trochim, 1989, p. 106). Validity can be discussed in terms of internal validity and external validity. Internal validity refers to the research process itself, the coherence of the design components and ability to answer the research question (Panke, 2018). In this study, internal validity was strengthened through adherence to the concept mapping process as outlined in foundational texts and by ongoing consultation with a committee member who has expertise in the methodology.

According to Creswell and Poth (2018) the validity of qualitative data is best assessed by the researcher, participants, and readers/reviewers. Validity, or validation, in this sense is a process of evaluating the trustworthiness or authenticity of the data.

(Creswell & Poth, 2018). Several strategies support the validation of the qualitative data. The statement editing process contributed to the trustworthiness of the data by clarifying wording and meaning. The congruence of the qualitative data with topics and themes in the literature is also evidence of trustworthiness. The oral defense of this dissertation will also check validity and the researcher's scientific interpretation before being presented to participants.

In terms of the validity of the statistical processes, multidimensional scaling and hierarchical cluster analysis allow "meaning and relationships to emerge by aggregating the 'biases' or 'constructions' of many" (Jackson & Trochim, 2002, p. 330). Instead of forcing the participants to sort according to a priori categories that could be influenced by the researcher's bias, concept mapping allows them to sort based on the meanings they have based on their social realities (Jackson & Trochim, 2002). Given the researcher's experience assessing HCT candidates, this aspect of the method was helpful for reducing bias. Another strategy for assessing validity is to compare the number of piles individuals created with the final cluster solution. In this study, the mode number of piles was 13, which is very close to the final 12-cluster solution. This suggests that the cluster solution is an adequate representation of group's aggregate mental model.

External validity refers to the generalization of the findings. The number of participants poses a challenge for external validity. It is unknown how many social workers and psychologists work within HCT programs in the U.S., but there are approximately 143 transplant centers and each would have at least one psychosocial professional. The perspectives represented in this study, then, are of a relatively small percentage of the total number of psychosocial professionals and would not be generalizable to the entire population. The lack of diversity in the sample also poses a challenge to external validity. The vast majority of the sample identified as non-Hispanic white, female, social workers. It is possible that professionals of color, males, and psychologists would have different perspectives on what psychosocial elements should be assessed, the relational structure of those elements, and their importance. Therefore, the conceptual framework may not adequately incorporate those perspectives.

In concept mapping, reliability refers to replicability and requires close attention to each stage of the multi-stage research process (Miller, 2016; Trochim, 1989a). As mentioned above, reliability was supported by following the concept mapping process as outlined in foundational texts and by ongoing consultation with a committee member who has expertise in the methodology. One way to test reliability would be to ask the same participants to sort and rate the statements in the future and compare the maps and data (Jackson & Trochim, 2002). Additionally, the brainstorming phase could be repeated and final statement sets compared.

Conclusions

The purpose of this study was to explicate a conceptual framework of the psychosocial elements that should be assessed in HCT candidates and to test if there is a difference in the way psychosocial professionals who use risk rating scales their practice conceptualize the elements compared to psychosocial professionals who do not. The study effectively answered these questions.

The use of concept mapping successfully ensured that the breadth of the topic was explored and revealed different dimensions of the conceptual domain. The resulting conceptual framework provides a strong starting point for practical action. The cluster solution suggests a structure for organizing a comprehensive pre-HCT psychosocial assessment protocol. It also suggests priority areas for assessment. Most importantly, the participants in this study will carry on the work of creating a protocol. This is their work, which the researcher has been privileged to facilitate. If tested and then implemented broadly, the protocol will bring a high quality, consistent standard for social work practice in this area.

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APPENDIX A: PARTICIPANT QUESTIONNAIRE

Please tell us about yourself, your professional perspectives, and your center.

1. What is your professional role?
    a. Social Worker
    b. Psychologist

2. How many years of practice experience do you have with HCT patients?

3. What, if any, standardized risk assessment tool do you use?
    a. SIPAT
    b. PACT
    c. TERS
    d. None of the above

4. What is your age?

5. What is your race/ethnicity?
    a. Non-Hispanic White
    b. African American or Black
    c. Asian
    d. Hispanic/Latino/Latina
    e. American Indian or Alaska Native
    f. Native Hawaiian or Other Pacific Islander
    g. Multiple Race

6. How often do you have the time you need to complete a quality pre-transplant psychosocial assessment? (Likert scale: Always, Most of the time, About half the time, Sometimes, Never)

7. How often do you have the time you need to adequately address needs that are identified in the pre-transplant psychosocial assessment? (Likert scale: Always, Most of the time, About half the time, Sometimes, Never)

8. In your view, how do the following risk factors compare to one another? Please rank all of the factors according to the amount of risk they pose for a poor outcome. Use the drag and drop feature to order them from 1-6 with 1 representing the highest risk and 6 representing the lowest risk.

   a. No caregiver / poor support system
   b. Compliance issues
   c. Illicit drug use
   d. Alcohol misuse
   e. Unsafe, unstable housing
   f. Serious, untreated mental health issues

9. What has helped shape your view about factors that pose a risk for a poor transplant outcome? (Multi-line text entry)

10. At your center, how often are psychosocial risk factors considered when deciding whether a patient is eligible for a transplant? (Likert scale: Always, Most of the time, About half the time, Sometimes, Never)

11. In terms of practice setting, which best describes your experience with transplant patients? (Select one)
    a. Only outpatient
    b. Only inpatient
    c. Both outpatient and inpatient

12. Approximately how many pre-transplant psychosocial assessments do you conduct in a typical week?
    a. Less than 1
    b. 1
    c. 2
    d. 3
    e. More than 3

13. What treatments do the patients that you assess undergo? (Check all that apply)
    a. Autologous transplant
    b. Allogeneic transplant

    c. CAR T-cell therapy

14. What treatments does your center offer? (Check all that apply)
    a. Autologous transplant
    b. Allogeneic transplant
    c. CAR T-cell therapy

15. Which, if any, professional associations are you currently a member of? (Check all that apply)
    a. AOSW
    b. APOS
    c. IPOS
    d. ASTCT
    e. NASW
    f. Other, please specify:______________________________
    g. I am not currently a member of any professional association.

16. What is the highest degree you have earned? Bachelor's degree___ Master's degree___ DSW___ PsyD___ Ph.D.___

17. How would you describe your gender? Female ___ Male ___ Transgender ___

18. What is the geographic region of your center?

    a. Northeast
    b. Southeast
    c. Midwest
    d. West
    e. Southwest

19. Is there anything else you would like to share with the researchers about your experience working in HCT?

CURRICULUM VITAE

Jill M. Randall

Telephone: (612) 599-0909
Email: jill.randall@louisville.edu

EDUCATION

Ph.D. 2021	University of Louisville, KY Kent School of Social Work
M.S.W. 2009	St. Catherine University / University of St. Thomas, St. Paul, MN 4.0 GPA Research project: *Resilience in the Hmong and Somali Communities*
B.A. 2004	St. Olaf College, Northfield, MN *Summa Cum Laude* Phi Beta Kappa Honor Society Major: Social Work Concentration: Women's Studies

RESEARCH INTERESTS

Psychosocial oncology; cancer care delivery; implementation science; hematopoietic cell transplantation; palliative care; older adults; treatment decision-making; end of life

PEER REVIEWED JOURNAL PUBLICATIONS

1. **Randall, J.**, Anderson, G., & Kayser, K. (2021). Pre-transplant psychosocial assessment practices: A national survey of transplant centers [Manuscript in preparation].

2. **Randall, J.** (2019). Supporting treatment decision making for older adults facing allogeneic hematopoietic cell transplantation. *Journal of Psychosocial Oncology (37)*1: 1-4.

3. Gaston, N. R.; **Randall, J.**; and Kiesel, L. (2018). Physician assisted suicide and Midwest social workers: Where do we stand? *Journal of Social Work in End-of-Life and Palliative Care (14)*1: 1-20.

4. Stickney Ferguson, S.; **Randall, J.**; Dabney, J., Kalbacker, M.E.; Boyle, N.; Thao, V.; Denzen, E.; and Murphy, E. A. (2018) Perceived workforce challenges among clinical social workers in hematopoietic cell transplantation programs. *Biology of Blood and Marrow Transplantation, 24,* 1063–1068.

5. **Randall, J.**; Keven, K.; Atli, T.; and Ustun, C. (2015). Process of allogeneic hematopoietic cell transplantation decision making for older adults. *Bone Marrow Transplantation, 51,* 623-628.

BOOK CHAPTER

Datta, S. S., Mukherjee, A., & **Randall, J**. (2020). Psychosocial management of patients undergoing HSCT and donors of stem cells. In M. Chandy, V. S. Radhakrishnon, & R. Sukumaran (Eds.), *Contemporary bone marrow transplantation. Organ and tissue transplantation*. Springer. https://doi.org/10.1007/978-3-319-64938-2_10-1

AWARDS AND SCHOLARSHIPS

John Richard Binford Memorial Award	2021
American Cancer Society Doctoral Training Grant	2019-present
Association of Oncology Social Work Conference Scholarship	2018
University of Louisville Research Assistantship	2017-2019

RESEARCH EXPERIENCE

Dissertation Research 2019-2021
University of Louisville
Conceptualizing the Psychosocial Elements That Should be Assessed in Candidates for Hematopoietic Cell Transplantation: Social Workers' and Psychologists' Perspectives
Dissertation Chair: Dr. Karen Kayser

Qualitative Data Analysis 2020
University of Louisville
Examining the Acceptability, Appropriateness, and Feasibility of Using mHealth for Education of Cervical Cancer Preventative Services with African American Women

Co-Investigator 2019-2020
University of Louisville
Pre-Hematopoietic Cell Transplantation Psychosocial Assessment Practices: A National Survey of Transplant Centers
Survey Research

Research Assistant 2017-2019
University of Louisville
Couples Coping with Impaired Sexual Functioning During and After Treatment for Rectal Cancer
Principal Investigator: Karen Kayser, Ph.D.
CareSTEPS: A Supportive Care Program for the Caregivers of Advanced Lung Cancer Patients
Principal Investigator: Karen Kayser, Ph.D.

Qualitative Researcher 2018-2019
University of Louisville
The Impact of Lived Experience as a Youth in Out-Of-Home Care on Direct Care Staff

Co-Investigator 2018-2020
University of Louisville
Secondary Data Analysis of Individualized Care Plans for Hematopoietic Cell Transplant Survivors

Staff Lead, Working Group on Social, Emotional, Cognitive Outcomes 2016-2017
National Marrow Donor Program®, Be The Match®
Engaging Patients in Setting a Patient-centered Outcomes Research Agenda in Hematopoietic Cell Transplantation. Funded by: Patient-Centered Outcomes Research Institute Eugene Washington Engagement Award (PCORI EAIN-2956)

Staff Lead, Social Work Workforce Group 2013-2017
National Marrow Donor Program®, Be The Match®
System Capacity Initiative
Perceived Workforce Challenges Among Clinical Social Workers in Hematopoietic Cell Transplantation Programs

Co-Investigator 2011-2012
University of Minnesota Blood and Marrow Transplant Program
What Was It Like? The Experience of Related Stem Cell Donors

Survey Researcher 2008-2009
St. Catherine University / University of St. Thomas, St. Paul, Minnesota
M.S.W. Research Project: Resilience in the Hmong and Somali Communities

COURSES TAUGHT

1. Generalist Social Work Practice II (BSW program; Teaching Assistant)
2. Research Methodology and Design (MSSW program)
3. Psychosocial Oncology I: Interpersonal Practice (MSSW program)

PROFESSIONAL EXPERIENCE

Clinical Supervisor for Licensure
National Marrow Donor Program®, Be The Match® 2016-2017
University of Minnesota Medical Center, Fairview 2012-2013
Provided individual and group supervision to social workers seeking licensure

M.S.W. Field Instructor 2015-2017
National Marrow Donor Program®, Be The Match®

Staff Lead, Social Work Workforce Group 2013-2017
National Marrow Donor Program®, Be The Match®
System Capacity Initiative
Co-Author of BMT Clinical Social Worker Role Description

Team Lead, Patient Support Center 2013-2017
National Marrow Donor Program®, Be The Match®

Toastmaster's International
Club President 2016-2017
Member 2013-2017

Program Development and Implementation 2013-2015
National Marrow Donor Program®, Be The Match®
Created and implemented a telephone-based psychosocial distress screening program
Training received through the American Psychosocial Oncology Society/Yale School of Nursing Screening for Psychosocial Distress Program

Support Group Facilitator 2011-2017
For patients and caregivers undergoing hematopoietic cell transplantation

Social Worker 2005-2013
University of Minnesota Medical Center, Fairview
Blood and Marrow Transplant Program
Acute Rehabilitation Unit
Medical/Surgical Unit

PEER REVIEWED CONFERENCE PRESENTATIONS

1. **Randall, J.** & Kayser, K. (2020). *Pre-transplant psychosocial assessment practices: A national survey of transplant centers.* Abstract accepted for poster presentation at the annual meetings of the American Society for Transplantation and Cellular Therapy and the Center for International Blood and Marrow Transplantation. Orlando, FL.

2. LaJoie, A. S., Washington, A. M., Anderson, G., **Randall, J.**, Smith, L. C., & Kayser, K. (2019). *Evaluating the impact of health promotion and health education programs to reduce HPV and cervical cancer burden in rural communities: A systematic review.* Abstract accepted for podium presentation at the American Public Health Association's 2019 Annual Meeting and Expo.

3. Gaston, N. R. & **Randall, J.** (2018). *Palliative sedation: What is it and what is my role as a hospice social worker?* Abstract accepted for podium presentation at the Social Work Hospice & Palliative Care Network General Assembly. Boston, MA.

4. **Randall, J**.; Eusden, O.; Ebert, L.; Harding, L.; and Jacobson, D. (2017). *Compassion is a phone call away: Promoting access to psychosocial support through telephone-administered services.* Podium presentation at the Association of Oncology Social Work 33rd Annual Conference. Denver, CO.

5. Dabney, J.; Stickney Ferguson, S.; Kalbacker, M.E.; **Randall, J.**; Thao, V.; Denzen, E; and Murphy, E. A. (2015). *Leaders in building capacity: Advocating for the role of BMT clinical social workers.* Podium presentation at Association of Oncology Social Work 31st Annual Conference. Seattle, WA.

6. Pederson, K.; **Randall, J.**; Jacobson, D.; Stickney Ferguson, S.; and Foster, J. (2015). *The parent caregiver: A supportive intervention to help parents care for themselves during a child's oncology treatment.* Poster presentation at Association of Oncology Social Work 31st Annual Conference. Seattle, WA.

7. **Randall, J.**; Foster, J; Denzen, E.; Moore, H.; Stickney Ferguson, S.; and Murphy, E. A. (2015). *Psychosocial distress screening: Application of the oncology standard to HCT patient care.* Poster presentation at the Oncology Nursing Society 40th Annual Congress. Orlando, FL.

8. **Randall J.**; Foster, J.; Denzen, E.; Moore, H.; Stickney Ferguson, S.; and Murphy, E. A. (2015). *Psychosocial distress screening: Application of the oncology standard to HCT.* Poster presentation at the 2015 BMT Tandem Meetings. San Diego, CA.

9. Foster, J.; Denzen, E.; Moore, H.; Idossa, L.; **Randall, J.**; Murphy, E.A. (2014). *Patient navigation: A systems-level approach to nursing practice.* Poster presentation at the Oncology Nursing Society 39th Annual Congress. Anaheim, CA.

10. Leary, E.; Schoeppner, K.; Otterlei, L.; **Randall, J.**; Defor, T. (2013). *Creation and implementation of a structured outreach program to address unmet psychosocial, financial and emotional needs of related stem cell donors utilizing data analysis from a quantitative research study.* Poster presentation at the Association of Oncology Social Work 29th Annual Conference. San Diego, CA.

11. Otterlei, L.; **Randall, J.**; Leary, E.; Schoeppner, K. (2012). *What was it like? The experience of related stem cell donors.* Podium presentation at the Association of Oncology Social Work 28th Annual Conference. Boston, MA.

SERVICE ACTIVITIES

ASTCT Social Work SIG Steering Committee	2021 – present
Journal of Psychosocial Oncology Editorial Board	2021 – present
Association of Oncology Social Work Membership Committee	2020 – present
Be The Match Barriers to Transplant Advisory Group	2020 – present
Reviewer for the Journal of Psychosocial Oncology	2017 – present
Be The Match Patient Services Advisory Group	2018 – 2020
BMT InfoNet Support Group Facilitator	2017, 2020
Association of Oncology Social Work Conference Planning Committee	2016 – 2017
Courier of hematopoietic cells from donor to patient	2015 – 2016

PROFESSIONAL SOCIETIES AND LICENSURE

American Psychosocial Oncology Society	2021 – present
Society for Social Work Research	2020 – present
American Society for Transplantation and Cellular Therapy	2018 – present
Association of Oncology Social Work	2012 – present
Licensed Independent Clinical Social Worker, MN Board of Social Work	2012 – present

INVITED PRESENTATIONS

1. **Randall, J**. (2020). *Psychosocial eligibility for hematopoietic cell transplantation.* Podium presentation at the Social Work Special Interest Group meeting held during the Transplantation and Cellular Therapy meetings. Orlando, FL.

2. **Randall, J.** (2017). *Caregivers: Facing Challenges and Forging Resilience.* Podium presentation at the BMT InfoNet annual Survivorship Symposium. Raleigh, NC.

3. Carpenter, P. A. & **Randall, J.** (2016). *Coping with chronic GVHD of the skin and deeper tissues: Resources for health professionals.* Health professional webinar sponsored by the National Marrow Donor Program.

4. Schoeppner, K.; Ave'Lallemant, T.; Lucas, B.; Salazar, L.; Simms, J.; and **Randall, J.** (2015). *Caring for the psychosocial health needs of BMT caregivers.* Podium presentation at the National Marrow Donor Program's annual Council Meeting in Minneapolis, MN.

5. Jourdan, D. and **Randall, J.** (2014). *Psychosocial distress screening: Applications for HCT practice.* Podium presentation at the National Marrow Donor Program/Be the Match’s annual Council Meeting. Minneapolis, MN.

6. **Randall, J.** & Leary, E. (2012). Keynote speakers on the topic of stress management at the Multiple Myeloma Patient and Caregiver Seminar presented by the Leukemia and Lymphoma Society. St. Louis Park, MN.