OPTIMIZING COLLABORATION: A QUALITATIVE ANALYSIS OF BONE MARROW TRANSPLANT PROVIDER PERCEPTIONS OF PALLIATIVE CARE ROLES

by

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ABSTRACT

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Bone marrow transplantation (BMT), also referred to as hematopoietic stem cell transplantation (HPSCT), is a medical procedure utilized to treat a range of malignant and non-malignant diseases including leukemias, lymphomas, aplastic anemia, immune deficiency disorders, solid tumor cancers, and more (Champlin, 1990; *Bone Marrow Transplantation,* 2021; Franjul Sanchez et al., 2020). BMT patients typically experience symptoms associated with induction or condition regiments that are especially burdensome, including but not limited to pain, mucositosis, nausea and vomiting, diarrhea, psychological, spiritual, and emotional concerns that may not be thoroughly addressed through their primary oncology and BMT teams alone (Ruiz et al., 2017). Palliative care integration has been observed to optimize care and quality of life for chronically ill patients due to factors such as consistent inclusion of families in decision-making, successful facilitation of difficult prognostic conversations, and earlier recognition of terminal prognoses, thus leading to increased palliative care and curative treatments (Bogetz et al., 2021; Boyden et al., 2018; Schwantes & O'Brien, 2014). Nevertheless, numerous studies indicate low rates of palliative care integration among patients undergoing hematopoietic stem cell transplantation (HSCT) (Booker et al., 2023; Button et al., 2014; Johnston et al., 2018; LeBlanc & El-Jawahri, 2018; Roeland & Ku, 2015; Selvaggi et al., 2014). Virtual qualitative interviews of BMT providers at Children's Wisconsin were conducted with the goal of characterizing BMT provider perceptions and understanding of palliative care roles and services. Such analyses may identify opportunities for better coordination of services and better treatment experiences for these vulnerable families.

Keywords: palliative care, bone marrow transplant, role theory

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Bone Marrow Transplantation (BMT) Population

Bone marrow transplantation (BMT), also referred to as hematopoietic stem cell transplantation (HPSCT), is a medical procedure utilized to treat a range of malignant and non-malignant diseases including leukemias, lymphomas, aplastic anemia, immune deficiency disorders, solid tumor cancers, and more (Champlin, 1990; *Bone Marrow Transplantation,* 2021; Franjul Sanchez et al., 2020). These malignancies are composed of cancers that form in blood-forming tissues, such as bone marrow, or in cells of the immune system (Franjul Sanchez et al., 2020). Approximately 2,600 children receive BMT treatments in the U.S. each year, with a total median cost of roughly $302,822 per patient (Majhail et al., 2013; Mangurian et al., 2018). Initially developed in 1968, BMT involves administering healthy stem cells normally found in the bone marrow to patients with unhealthy or dysfunctional stem cells due to their condition. Depending on the diagnosis, BMT may serve to augment bone marrow function, it may generate functional cells to replace dysfunctional ones, or it may lead to destruction of malignant or abnormal tumor cells in the bone marrow (Khaddour et al., 1990).

While the populations of patients receiving BMT therapy are heterogeneous in nature, curative intent of treatment is the norm (Ruiz et al., 2018). Patients typically undergo an aggressive and emotionally challenging course of treatment out of efforts to restore and maintain health. Symptoms that are most frequently reported are primarily associated with induction or condition regimens, including chemotherapy, which often result in pain, mucositis, nausea, vomiting, and diarrhea (Ruiz et al., 2018). Other commonly occurring symptoms in this population include confusion, fatigue, breathlessness, insomnia, constipation, and anorexia

(Franjul Sanchez et al., 2020). One study of BMT patients revealed that 68% experienced pain, with 23% reporting severe pain, 78% reporting nausea, and 89% reporting insomnia (Taber et al., 2019; Franjul Sanchez et al., 2020). Several other studies indicate that BMT patients experience, on average, the most intense and aggressive treatments in their final 30 days of life (Ruiz et al., 2018; Franjul Sanchez et al., 2020). Furthermore, while prognostic factors contributing to mortality in adult populations are well-documented, little is documented about pediatric populations despite their higher rates of morbidity and mortality (Kim et al., 2021).

Within general populations, BMT patients face a great deal of uncertainty and stress related to their illness trajectory in addition to financial, social, emotional, and psychological factors related to their illness (NCCN, 2017). Psychological disorders associated with BMT in both adults and children include depression, anxiety, and post-traumatic stress disorder (PTSD) among other subclinical presentations, such as higher overall stress levels and reports of demoralization from the illness experience (Pentz et al., 2014; Ruiz et al., 2018; Franjul Sanchez et al., 2020). Namely, several studies observed increased anxiety in children during the weeks leading up to transplantation as they undergo multiple procedures (Packman et al., 2010; Meyers et al., 1994). Pot-Mees and colleagues (1989) similarly found that 40% of children experienced notable increases in anxiety, depression, peer isolation, and behavioral problems for 6 months following HSCT, compared to only 15% prior to HSCT. This constellation of psychological and behavioral symptoms closely resembled those of PTSD and continued to persist in roughly 35% of patients at 12 months post-HSCT (Pot-Mees et al., 1989). A similar study found that nearly 80% of children experienced moderate symptoms of PTSD up to three months post-HSCT (Stuber et al., 1991).

In addition to difficult medical procedures and psychological outcomes associated with physical functioning, a number of lifestyle changes similarly affect psychological outcomes. For instance, pediatric BMT patients may spend anywhere from 1-3 months in isolation to avoid infection due to treatment-related immune suppression. As a result, children often experience increased depression from isolation as well as declines in social skills and self-esteem due to diminished school attendance and involvement in other essential developmental activities (Phipps et al., 1995; Phipps & Mulhern, 1995; Packman et al., 2010). In younger children, loss of communication skills and adaptive functioning is observed in addition to severe withdrawal behaviors (e.g., social disengagement, decreased play or participation in enjoyed activities, etc.) (Ruthruff, 2006; Pot-Mees et al., 1989). Collectively, BMT patients experience various distressing physical and psychological symptoms throughout the illness trajectory, many of which fluctuate in frequency and severity, thus warranting a great deal of resources and support. Nearly all these symptoms may be modifiable through intensive supportive care measures like palliative care, though resources such as these are scarcely utilized (Nelson et al., 2021; El-Jawahri et al., 2014; Pidala et al., 2010).

Poor psychological functioning is also observed in families of pediatric BMT patients as parents and primary caregivers commonly assume the role of managing resources and support to help mitigate negative treatment effects. Siblings, regardless of involvement in the donation processes, are at increased risk of developing PTSD, anxiety, and low self-esteem (Pentz et al., 2014). Other studies have similarly observed elevated reports of loneliness, limited comprehension of BMT, and negative feelings associated with decreased parental attention (Packman et al., 1998). For parents, emotional concerns such as worry, guilt, fear of losing a child or of relapse are common, in addition to increased occurrence of clinical depression and

anxiety both prior to and following transplantation (Packman et al., 2010). This burden is only further compounded by financial challenges, work-related changes, and various logistical concerns (e.g., childcare, transportation, relocation, etc.) (e.g., Barrera et al., 2012; Lindahl Norberg et al., 2014; Heinze et al., 2015; Manne et al., 2016; Kaziunas et al., 2015). It is clear that distress associated with these factors produces significant impairment not only at the individual level but within the family system as patients and families adjust to numerous physical and lifestyle changes. Helping families adjust to these changes puts a considerable burden on the BMT treatment team.

Pediatric Palliative Care

Palliative care constitutes a specialized form of medical care that is provided to enhance quality of life for patients living with chronic or life-limiting medical conditions (Franjul Sanchez et al., 2020). Having been officially deemed a medical specialty in 2006, regular integration of palliative care practices into various subspecialties is increasingly becoming the standard of care, with greater recognition due in part to medical advancements that allow patients with chronic health conditions to live longer (Franjul Sanchez et al., 2020). Following its inception, estimates predicting a near 87% increase in individuals dying from chronic conditions led the World Health Organization (WHO) to proclaim palliative care a public health necessity requiring earlier integration into healthcare systems for improved access to and delivery of care (WHO, 2011). The American Academy of Pediatrics recommends pediatric palliative care "should be consulted for advanced clinical treatments and complicated decision making and for social and spiritual needs beyond what the primary care team can provide" (Linebarger et al., 2022).

Pediatric palliative care primarily centers around preparing for and managing physical, psychological, social, and spiritual suffering related to one's illness with the goal of improving patient and family quality of life, regardless of prognosis (Center to Advance Palliative Care, 2022; National Coalition for Hospice and Palliative Care, 2018). This differs from hospice or end-of-life care in that it does not require a terminal diagnosis to obtain a referral (Franjul Sanchez et al., 2020; LeBlanc & El-Jawahri, 2015). Instead, palliative care primarily attends to the physical, psychological, educational, social, and spiritual goals of patients and families as they navigate ongoing medical treatment (Foster et al., 2010). They are often multidisciplinary, with teams typically made up of physicians, nurses, social workers, pharmacists, chaplains, dieticians, physical therapists, and paralegals (Franjul Sanchez et al., 2020).

Youth living with serious illnesses often face unique physical, psychological, and developmental challenges that warrant palliative care integration, such as social skill deficits associated with increased isolation, nonadherence to medication and treatment regimens, and decreased decision-making capacity due to poor parent-child dynamics among other challenges (Newman et al., 2023). Early integration of palliative care encourages developmentally appropriate relationship building that allows the team to provide patient-centered, value-based care to children and families facing uncertain futures (Linebarger et al., 2022). Additionally, palliative care aids in facilitating smooth transitions of care between different specialists while addressing communication needs specific to children and families (e.g., acknowledging the child as an individual separate from family; respecting caregivers' knowledge of their children; family dynamics and relationships, etc.) (Franjul Sanchez et al., 2020; Linebarger et al., 2022). Consultation with palliative care has been observed to optimize care and quality of life for chronically ill patients due to factors such as consistent inclusion of families in decision-making,

successful facilitation of difficult prognostic conversations, and earlier recognition of terminal prognoses, thus leading to increased palliative care and curative treatments (Bogetz et al., 2021; Boyden et al., 2018; Schwantes & O'Brien, 2014; Linebarger et al., 2022).

Structural Models of Pediatric Palliative Care

A variety of interdisciplinary pediatric palliative care models presently exist, all of which benefit the care of children living with chronic and life-threatening medical conditions. Foster and colleagues (2010) outline several working pediatric palliative care models, each constituting slightly different treatment modalities and structural limitations. One such model is referred to as the Pediatric Palliative Care Consultative Service model, which directs the pediatric palliative care team to provide consultative services to the primary medical team as they maintain care of the child. With this model there is no dedicated unit, rather palliative care provides treatment through a combination of inpatient and outpatient services. This model is advantageous as it allows the primary treatment team to maintain responsibility for the patient, thus reinforcing trust and continuity of care. However, the model requires primary care providers to reach out for services—a process that is occasionally neglected due to misconceptions surrounding palliative care or perceived misalignment with palliative care treatment goals.

Another commonly utilized model is the Dedicated Pediatric Palliative Care Service, where palliative care is an admitting service that represents a subspecialty within the hospital similar to other established specialties (e.g., general medicine, oncology, neurology, etc.). While advantages of this model include 24/7 availability of palliative care as well as an abundance of staff proficient in palliative care delivery, there are several disadvantages. Because patients would be switching units, they may experience a sense of abandonment from their primary care team, which may elicit stress related to reorientation with new providers. Additionally, this

model may indirectly perpetuate the stigma of palliative care as a service meant for end of life, rather than a model of care integrated throughout the illness trajectory. Similar challenges include lack of continuity of care for patients discharged from institutions that do not offer home-based palliative care.

Another well-established model of care is referred to as Integrated Pediatric Palliative Care. This model involves an institutional palliative care team that provides oversight, education, and training to leading members of each unit. This model is distinct in that the institutional palliative care team is responsible for creating and enforcing the standards of care that are to be used across specialties, without typically providing direct patient care. Advantages associated with this model include maintenance of patient relationships with their primary care teams, as well as an overall appreciation of palliative care as a standard of care embedded throughout the institution. Another advantage is that it helps transition palliative care practices into institutions where funding or staff is limited. However, despite oversight from an institutional palliative care team, this model runs the risk of smaller silos of palliative care providers differing in their standards of care across clinical contexts. Additionally, if patients can be discharged, continuity of services at home for institutions without home-based palliative care initiatives is difficult.

Several other palliative care models exist, such as integrated home and hospital palliative care programs, or solely home-based hospice and palliative care programs, many of which require significant financial and staffing commitments, resolution of communication challenges across care environments, or specific insurance requirements that those of low socioeconomic status may not meet.

Regardless of the type of palliative care model that is utilized, several domains central to palliative care delivery exist across models. Each of these core domains prioritize patient-

centered communication, symptom management, and efforts to increase quality of life. The National Coalition of Hospice and Palliative Care published the *Clinical Practice Guidelines for Quality Palliative Care, 4th Edition* in 2018, outlining eight primary domains of palliative care as well as guidelines for practice and implementation (National Coalition of Hospice and Palliative Care, 2018). Endorsed by the American Academy of Pediatrics, the eight core domains of palliative care address 1) elements related to the structure and processes of care, 2) physical aspects of care, 3) psychological and psychiatric aspects of care, 4) social aspects of care, 5) spiritual, religious, and existential aspects of care, 6) cultural aspects of care, 7) care of the patient nearing the end of life, and 8) ethical and legal aspects of care (*Clinical Practice Guidelines for Quality Palliative Care,* 2019) (see Table 1).

Benefits of Palliative Care Consultation

Advancements in palliative care have led to improved management of physical, psychological, and emotional symptoms for those with chronic health conditions (Ruiz et al., 2017). Through specialty care provided across domains, early palliative care referral has been observed to improve patient and family quality of life, symptom control, treatment decision-making, advance care planning, and end-of-life care. It has also been observed to reduce costs associated with care due to earlier detection and treatment of symptoms (Brumley et al., 2007). For patients with hematological malignancies, pilot programs have demonstrated several positive outcomes, including but not limited to improved care satisfaction, quality of life, patient agency and participation in care, and promotion of coordinated care (Ruiz et al., 2017). Several other studies examining palliative care integration in this population have documented better prognostic understanding among patients, improved quality of life for patients and caregivers, and improved survival rates (Booker et al., 2023; Bakitas et al., 2015; Ferrell et al., 2017; Greer

et al., 2013; Temel et al., 2010, 2017). Palliative care integration is also associated with greater outcomes related to disease relapse following BMT for all patients (Ruiz et al., 2017). Within pediatric populations, a growing body of literature suggests embedded models of palliative care are associated with improvements in both quality of care and quality of life for patients and families (Salek et al., 2022).

In response to evidence suggesting positive outcomes associated with palliative care, several major professional organizations have endorsed early palliative care intervention, including the American Academy of Pediatrics, the American Society of Clinical Oncology, the Oncology Nursing Society, and the American College of Surgeons' Commission on Cancer among others (American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care, 2000; Loggers et al., 2016). Nevertheless, a multitude of studies indicate low rates of palliative care integration among patients with hematological malignancies and patients undergoing hematopoietic stem cell transplantation (HSCT) (Booker et al., 2023; Button et al., 2014; Johnston et al., 2018; LeBlanc & El-Jawahri, 2018; Roeland & Ku, 2015; Selvaggi et al., 2014).

As previously mentioned, BMT patients experience symptoms associated with induction or condition regiments that are especially burdensome, including but not limited to pain, mucositosis, nausea and vomiting, diarrhea, psychological, spiritual, and emotional concerns that may not be thoroughly addressed through their primary oncology and BMT teams alone (Ruiz et al., 2017). It is not surprising that these symptoms are associated with decreased quality of life, and while advancements in the field of high-dose therapy and stem cell transplantation have led to increased success rates, elevated mortality risk for high-dose therapies within pediatric populations continues to persist. As evidenced, incorporation of specialized palliative care to

address physical and psychological needs into the care of BMT patients and their families is instrumental in optimizing patient health outcomes and adjustment (Chung et al., 2009).

Role of Palliative Care in Pediatric Bone Marrow Transplantation

Within the BMT population, little exploration of palliative care integration exists despite its seemingly complimentary nature. Nevertheless, as BMT has evolved from a last-chance intervention to one increasingly pursued to maintain remission and increase patient and family quality of life, a need for palliative care integration to address physical and psychological factors associated with this subpopulation is apparent. Historically, BMT teams have assumed the role of providing supportive care, with a particular emphasis on managing pain from the procedure, reducing risk of infection, managing nutrition, and engaging in discussions about patient prognosis among other elements of care similar to palliative care (Chung et al., 2009). However, BMT patient diagnoses are often unpredictable in nature, leading to fluctuating illness presentations and unclear prognoses (Franjul Sanchez et al., 2020). As such, it is of primary importance that patients with hematologic malignancies be referred to palliative care early in treatment to help with coping and adjustment to these drastic circumstances.

Although the BMT population is heterogeneous, most BMT patients experience symptoms associated with induction or treatment regimens, including but not limited to nausea and vomiting, pain, mucositis, and diarrhea (Ruiz et al., 2018). Additional psychological, spiritual, and emotional concerns warrant thorough assessment and integration, though are not always sufficiently addressed by primary oncology and BMT teams alone (Ruiz et al., 2018). For example, psychosocial adjustment in pediatric BMT patients has been shown to increase with greater familiar support and cohesiveness (Phipps & Mulhern, 1995), both of which may be evaluated for prior to HSCT for improved patient outcomes. Additionally, early integration of

palliative care for hematopoietic cell therapy recipients has been shown to elucidate goals of care, increase conversations related to advanced care planning, and improve overall quality of care for patients and their families (Ruiz et al., 2018; Tierney et al., 2014; Button & Chan, 2014). Nevertheless, early palliative care interventions are not commonly utilized in bone marrow transplant units despite evidence for enhanced patient agency, greater participation in their care, and greater promotion of coordinated care for patients and their families (Ruiz et al., 2018; Loggers et al., 2016; Button & Chan, 2014). Further, of those who do receive palliative care services, studies within adult populations have suggested a significant gap in palliative care consults between solid tumors and hematologic malignancies, indicating patients with hematologic malignancies are referred to palliative care much less frequently than patients with solid tumors (Franjul Sanchez et al., 2020).

Within pediatric populations, palliative care consults commonly occur late in the course of the disease when the child is nearing death (Szymczak et al., 2018). One study examining palliative care consultations among pediatric patients who died of cancer found that while most were referred to palliative care, the majority occurred after the first (40%) or multiple (18%) relapses (Johnston et al., 2012). Despite these findings, the prevalence of pediatric BMT collaboration with palliative care is overwhelmingly undocumented, and the variability of palliative care models across geographical region, patient demographics, and institutions emphasizes a need to better understand the nature of palliative care collaboration with BMT teams.

Barriers to Consultation

Despite clinical utility and evidence for improved patient outcomes, public knowledge, perceptions, and attitudes toward palliative care remains mixed. Current research suggests

palliative care consultation generally occurs later in the course of an illness, and misconceptions regarding palliative care among providers and community members influences palliative care delivery and patient access to care (Mcllfatrick et al., 2021). Common misperceptions include the belief that palliative care is meant for end-of-life situations. Others may have a vague or unclear understanding of the role of palliative care—a trend observed both nationally and internationally (Mcllfatrick et al., 2021). One study examining public perceptions and understanding of palliative care indicated that more than 55% of participants believed palliative care was primarily used for end-of-life treatment, roughly 42% did not believe palliative care addressed psychological issues brought up by serious illness, and 39% did not believe palliative care served to improve a person's ability to participate in daily activities (Mcllfatrick et al., 2021). Another study suggested that roughly 50-70% of adults in the U.S. and other countries have never heard of palliative care, and of those who did, their knowledge of palliative care needed to be corrected (Franjul Sanchez et al., 2020). Additional misconceptions include beliefs that palliative care encourages patients to discontinue curative treatments for their illness, that those receiving palliative care no longer receive care from their primary doctors, or that palliative care is solely meant for cancer patients (Mcllfatrick et al., 2021).

Misconceptions due to knowledge of palliative care domains have also been documented among medical professionals. Physicians may conflate palliative care with hospice or end-of-life care, leading to a greater reluctance to refer patients or seek consultation (Franjul Sanchez et al., 2020). This misperception may be due to lack of exposure to palliative care practices in training, including during residency and fellowship (Franjul Sanchez et al., 2020). One study in support of this hypothesis found that of those who participated, only 46% of physicians reported attending lectures or obtaining continuing education credits in palliative care, 37% had no exposure or

training in palliative care practices at all, 29% completed a single rotation in residency or fellowship, and only 1% had more than six months of training in palliative care practices (El-Jawahri et al., 2018; Fanjul Sanchez et al., 2020). Another scoping review of oncologists and hematologists views revealed that while many studies documented provider understanding of well-known benefits of palliative care, only a few studies indicated lesser-known benefits of palliative care, such as facilitating goals of care conversations or encouraging shared decision-making (Salins et al., 2020).

Misconceptions of palliative care within the greater medical community also contribute to less optimal collaboration between the two specialties. Nickolich et al. (2016) evaluated perceptions of palliative care providers among hematologist oncologists and solid tumor oncologists, revealing that roughly 61% of hematologic oncologists believed palliative care was to be utilized for end-of-life care and that it is contradictory to cancer treatment, as compared to only 16% of solid tumor oncologists. Similarly, a large majority of hematologic oncologists endorsed beliefs that palliative care was only to be integrated when no more therapeutic options were available, and that palliative care was incongruent with curative treatment (Nickolich et al., 2016; Franjul Sanchez et al., 2020). In some ways, providers may associate palliative care referrals with giving up or losing hope (Sarradon-Eck et al., 2019). It is important to note, however, that most of the literature evaluating provider perceptions have occurred within adults rather than pediatric oncology (Szymczak et al., 2018).

Similar to associations with loss of hope, several studies have cited provider awareness of the stereotyped association of death among patient families, noting provider discomfort with initiating consultation conversations or observation of patient views that discussing death is taboo (Prod'homme et al., 2018, Horlait et al., 2016; Morikawa et al., 2016, LeBlanc et al.,

2015, Cripe et al., 2019; Nyiro et al., 2018; Salins et al., 2020). Several other national and international studies cited oncologist discomfort with the idea that introducing palliative care may elicit fear from patients, while others described provider observations of family distress following mention of palliative care (Sarradon-Eck et al., 2019, Smith et al., 2012; Salins et al., 2020). Other similar studies documented provider experiences with having to carefully explain what constitutes palliative care in order to refute misperceptions or negative connotations associated with the label (Hay et al., 2017, Wright & Forbes, 2017; Salins et al., 2020). Provider discomfort with initiating these conversations results in delayed introductions out of efforts to reduce anticipated patient distress despite a lack of documented associations between introduction and patient distress (Loggers et al., 2016; Franjul Sanchez et al., 2020).

Another barrier to consultation among BMT providers includes an overall sense of ownership of their patients. Due to the intense and unpredictable nature of hematologic malignancies, providers often develop close bonds with patients and their families. As such, providers may feel a sense of ownership or responsibility to maintain the trust and rapport they establish with their patients, thus leading to hesitancy regarding the introduction of new team members (Franjul Sanchez et al., 2020; Salins et al., 2020). Similarly, several studies have cited provider perceptions of self-efficacy to assess and treat palliative care needs as a factor limiting consultation (Cherny & Catane, 2003, Johnson et al., 2008; Ward et al., 2009; Schenker et al., 2014; LeBlanc et al., 2015; Feld et al., 2019; Sarradon-Eck et al., 2019; Salins et al., 2020).

Providers' personal views and attitudes surrounding palliative care, largely shaped by prior exposure, also impact openness to consultation. For example, one study indicated that medical oncologists worldwide felt as though palliative care providers were not sufficiently trained in oncology practices, while another study of American oncologists revealed that they

questioned the expertise of palliative care providers due to their inability to differentiate a sick patient who was recovering from a dying patient (Cherny & Catane, 2003; Gidwani et al., 2017). Various other studies have demonstrated findings consistent with the idea that primary treating providers perceive palliative care providers as lacking appropriate insight into the course of illness and treatment outcomes or poor overall competency, thus contributing to inconsistent communication practices (Rhondali et al., 2013; Schenker et al., 2014; LeBlanc et al., 2015; Gidwani et al., 2017; Salins et al., 2020).

Historically, structural barriers influencing the quality and quantity of palliative care integration within the BMT population have also been identified. For instance, communication issues due to lack of unified medical record system for sharing patient information is among the most frequently cited (McCaughan et al., 2018; Franjul Sanchez et al., 2020). This barrier to communication arises when palliative care specialists are unable to access important patient documentation that may weaken the quality of care discussions. It may also limit the quality of collaboration with primary providers who have previously provided care that is overlapping or inconsistent with the care provided by palliative care specialists (McCaughan et al., 2018; Franjul Sanchez et al., 2020). While communication issues related to electronic medical records have largely resolved due to implementation of revised systems, the impact of such may continue to impact providers who lacked exposure to palliative care integration throughout their training and early careers.

Other studies have highlighted institutional failure to outline clear direction for specialty-specific roles, as well as imposed time restrictions on care and mandates regarding when patients must be discharged as limiting factors (Firn et al., 2018). Unfortunately, the importance of organizational direction in outlining roles among interdisciplinary teams as a means of

facilitating collaboration has been well-documented (Blackmore & Persaud, 2012; Nancarrow et al., 2013, Firn et al., 2018). With these limitations in place, optimization of patient outcomes is compromised as the likelihood of collaboration is diminished.

Role Conceptualization in Healthcare Settings

Provider decisions to seek consultation may be further influenced by confusion regarding the differentiation of care roles in the context of collaboration. This may especially be the case for instances where providers in both specialties have expertise in specific areas of treatment (e.g., pain management, facilitating goals of care discussions, etc.). For instance, one study revealed that oncologists and hematologists felt that managing symptoms, providing psychosocial support, and facilitating open communication with patients represented care practices that were central to the role of oncology, and that they had sufficiently developed these skills in their training (Cherny & Catane, 2003; Johnson et al., 2008; Ward et al., 2009; Salins et al., 2020). Providers have also reported palliative care roles such as facilitating end-of-life care as contradictory to their practice, noting that their role was to cure patients (Prod'homme et al., 2018).

Though not comprehensively examined within the BMT population, challenges related to role confusion and conflict are shaped by a variety of factors previously outlined. For instance, provider level of education, physical proximity to palliative care providers in the work environment, and biases that influence willingness to facilitate communication between specialties are likely all factors contributing to providers knowledge and assessment of roles. In a study of hospital-based generalist palliative care providers' perceptions on facilitators and barriers to collaboration, proactive communication, role negotiation, active problem-solving, and

recognition of generalists' expertise were all identified as factors improving collaboration between specialties (Firn et al., 2016). Another study examining ward social workers' views of collaboration with palliative care social workers identified problems with role negotiation between specialties as an element hindering collaboration. They further identified trust and flexibility as characteristics necessary to successfully navigate negotiation, and that lack of each of these tended to compromise the quality of collaboration (Firn et al., 2017).

Studies evaluating types of palliative care service models have cited role confusion as being especially relevant to models where specialties are more closely integrated (Firn et al., 2016). Specifically, provider concerns regarding who is best equipped to address oncology patients' palliative care needs represented a source of conflict. Similarly, referring providers operating within more integrated models tended to prefer taking on leadership roles, where palliative care providers responded to their lead (Firn et al., 2016). It is likely that variables related to the systems with which multiple specialties operate influence the frequency and presentation of role conflict.

Theoretical Framework

The presence of role confusion or conflict as factors influencing BMT providers' decisions to collaborate with palliative care may be best understood within the context of role theory. Defined by Conway (1988), role theory represents "a collection of concepts and a variety or hypothetical formulations that predict how actors will perform in a given role, or under what circumstances certain types of behaviors can be expected." Previously utilized within nursing and pharmacy research, role theory may be used to relate structural and organizational characteristics to the individual (Schuler et al., 1977). Conceptual frameworks such as this one

allow for exploration of how factors such as attitudes and perceptions of individuals within a given context influence behavior (Brookes et al., 2007). For instance, the context of a non-collaborative or hostile work environment may lead providers of a specific subspecialty to form false or negative preconceived notions or negative attitudes regarding palliative care. This could be due, in part, to fewer opportunities for interactions that would dispel these attitudes.

Regarding the definition of 'role' as it relates to role theory, it can be defined as a description of the behaviors, characteristics, norms, and values of a person or position (Major, 2003; Thomas & Biddle, 1966). Roles may be highly personalized depending on the individual and context, since not everyone is exposed to the same set of expectations, nor does anyone perform their roles in the exact same way (Major, 2003). In the context of the present study, BMT providers may have been shaped by a number of factors including but not limited to institutional policies and regulations, nature of prior coursework, personality features (e.g., openness to collaborate, personal attunement, etc.), and either individual or BMT position-related values that shape understanding of roles.

Through the work of Hardy and Conway (1988), role theory was developed to encompass three primary perspectives: 1) social structuralism, 2) symbolic interactionism, and 3) the dramaturgical perspective. Social structuralism refers to social systems and structures, both of which are known to influence behavior. For instance, lack of institutional efforts to outline expected roles and responsibilities across disciplines may lead to poor collaboration or openness to seek consultation. Symbolic interactionism, then, emphasizes the idea of individuals interacting bidirectionally to influence their environment through a process of self-reflection, which includes consideration of one's own perspectives and the perspectives of the other person within the context of an interaction (Brookes et al., 2007). For instance, how does the quality and

nature of social interactions between two or more individuals impact completion of a shared goal? Finally, the dramaturgical perspective refers to the theory of role taking, where the action of role playing may help one learn how to perform a role most appropriately. For example, a palliative care provider may serve as the 'role occupant' and palliative care services as the 'role set' (Major 2003). Within this dynamic, the 'role occupant' may act out role expectations from the 'role sender' who could be any number of entities, such as a BMT provider, the role set itself, a patient/family, etc. Role senders possess their own expectations of the role occupant's response to their role expectation. For instance, a role sender may believe that palliative care providers are exceptionally skilled at symptom management. How the role occupant ultimately performs these roles is often influenced by social norms (e.g., provider cultural or individual preferences for taking a leading role vs. consultative role, etc.), demands, and rules (e.g., institutional guidelines regarding role responsibilities, insurance barriers, etc.). Others, including BMT providers, may also judge or hold specific beliefs regarding the role occupant's performance based on factors such as personality or perceived efficacy. Together, these 'role episodes' include a set of complex interactions between the role sender, the role occupant, and the role set to influence perceptions and interpretations of a role (Major 2003).

Understanding the various individual, social, and structural dynamics within specific models of care is essential to conceptualizing roles and scope of practice (Davidson & Elliott, 2001). For instance, high mortality rates or increased burden of chronic illness may influence how models of care are actualized and how interdisciplinary care methods are implemented (Chew & Van Der Weyden, 2003), thus leading professionals to be challenged in their roles (Brookes et al., 2007; Wagner, 2001).

The social interactionist and functionalist perspectives both constitute what is referred to as social interaction theory (Conway, 1988). This framework allows for diverse application of what are known as 'role constructs,' which are defined and implemented to form a 'role episode'—a cycle that involves role sending, a subsequent response by the receiver, and the effects of that response on the role senders (Thomas & Biddle, 1966). For example, Taylor and colleagues (2020) conceptualized five role constructs derived from Hardy and Conway (1988) in their qualitative analysis of health profession perceptions of expanding rural community pharmacists' role. They included: 1) Role ambiguity (e.g., disagreement on the role expectation associated with a lack of clarity of those expectations); 2) Role conflict (e.g., the receiver perceives existing role expectations as being contradictory or mutually exclusive); 3) Role overload (e.g., inadequate resources relative to the possibility of excessive demands); 4) Role identity (e.g., the individual's interpretation of role expectations or position-specific norms that include the attitudes, behaviors, and cognitions expected of a role occupant); and 5) Role insufficiency (e.g., differences in fulfilling role expectations, obligations, or goals as perceived by self or significant others). Role constructs such as these may be presented individually or collectively to inform individual behaviors within a given environment.

It is likely that several previously identified barriers to consultation may contribute to these role constructs in a way that compromises collaboration between specialties. For instance, lack of extensive medical training in palliative care delivery may lead to role ambiguity among providers due to inadequate understanding of tasks in their regular practice. Similarly, institutional policies that fail to define role expectations may contribute to role conflict and poor attitudes among specialties in the sense that providers may experience disagreement over the domains of palliative care delivery they wish to provide. Unfortunately, scant literature has

examined the role of palliative care in BMT practices or provider perceptions to date. Further consideration of structural, contextual, social, and personal factors and how each interact simultaneously will serve to enhance understanding of how BMT providers make the decision to collaborate with palliative care based on roles and expectations.

The aims of the present study will consequently be two-fold. The researchers hope to first characterize BMT provider perceptions and understanding of palliative care roles and services. Second, they hope to analyze potential overlap or discrepancies between knowledge of palliative care domains and perception of roles. Further examination of the perceived roles of palliative care in BMT practices may elucidate factors influencing the nature of collaboration between specialties, thus informing best practices. Similarly, closer examination of palliative care perceptions within the BMT subspecialty may influence targeted interventions aiming to decrease barriers to collaboration that may be contingent upon factors unique to this specialty or context, thus optimizing patient outcomes.

Methods

Participants

Six Bone Marrow Transplant providers serving the BMT unit at Children's Wisconsin (CW) were recruited to participate in the present study. Participants were made up of a combination of physicians and medical fellows (n = 5), and one advanced practice nurse practitioner. To maintain anonymity of the providers given the small sample size, demographic data was not collected.

The BMT program at CW was developed in 1980, at which point the first bone marrow transplant was performed. Since this time, more than 1,400 successful transplants have been completed. In addition to the palliative care team, BMT providers recruited for the present study interact with a number of specialists who provide care for patients receiving BMT therapy. These specialists include but are not limited to pediatric oncologists and hematologists, gastroenterologists, radiation oncologists, pharmacists, pathologists, otolaryngologists, infectious disease specialists and palliative care providers. They also regularly provide care to patients alongside social workers, child life specialists, child psychologists, and BMT coordinators. Regarding conditions that are treated through the BMT program, those that are seen most include leukemia, lymphoma, hemophagocytic lymphohistiocytosis (HLH), primary immunodeficiencies, severe aplastic anemia, sickle cell anemia, thalassemia, and various metabolic storage diseases.

Most recently, CW implemented an automatic trigger policy for palliative care consultation within the BMT program, such that patients admitted for BMT are automatically referred for palliative care services. It is important to note that at the time of interview completion this policy was newly established. As a result, the effects of such changes are likely not reflected in the data at the time it was collected.

Procedure

The present study was part of a larger study evaluating BMT provider perceptions of palliative care, with topics including perceptions and role of palliative care in the BMT population, concerns and benefits regarding interactions with palliative care, and competency and training in palliative care domains. The study was approved by the University of Wisconsin-

Milwaukee Institutional Review Board in September of 2021, and data collection was completed in June of 2022.

BMT providers that met the inclusion criteria of being a doctor, nurse practitioner, or fellow at CHW were recruited to participate in the present study. That is, two BMT providers and study team members emailed potential participants to assess their interest in completing a 45-minute virtual interview on BMT provider perceptions of the role and use of palliative care. Once participants expressed interest, graduate student team members conducted a brief screening via phone or doxy.me videoconferencing platform to discuss study aims and consent forms. At this time, a date was selected to complete their interview.

All interviews and screening phone calls were completed by graduate students to protect against the risk of real or perceived coercion from colleagues involved in the study. All interviews took place via phone call or the doxy.me videoconferencing platform and audio recorded for study transcription. Doxy.me is an industry-leading, password-protected video telehealth platform that utilizes encryption and HIPAA-compliant security features to ensure optimal caller protection (Mark, 2023). Additionally, no personal health information, video, or audio recordings are stored within the platform. Prior to study participation, participants were emailed a doxy.me link to join the call. No additional downloads or device configuration was required by either the participant or interviewer to enter the platform. Following interview completion, audio recordings were saved to a secure shared drive and all interviews were transcribed and de-identified by trained research assistants to ensure participant confidentiality. All study procedures were supervised by Hobart Davies, PhD, a study investigator and clinical faculty member with expertise in qualitative research at the University of Wisconsin-Milwaukee.

Dr. Davies was on-call during all interviews in case of any participant distress or ethical questions raised by the interviewer.

Measures

Qualitative Interview

Participants completed a 45-minute semi-structured qualitative interview conducted by graduate student team members to protect participant identity and maintain professional boundaries among study personnel also employed at CW. The interview guide was developed by team members with extensive expertise in qualitative research methodology, pediatric health psychology, and the BMT population. Interview items were developed with the goal of evaluating factors related to perceptions of palliative care roles and domains through the lens of BMT providers, with the hope of better understanding the nature of BMT and palliative care interactions. For the purposes of the present study, a subset of interview items was selected pertaining to provider beliefs of palliative care roles and understanding of palliative care domains and areas of clinical expertise (see Table 2).

Data Analytic Plan

Researchers conducted a thematic analysis of interview transcripts consistent with the standard content analysis method of qualitative coding—a method that has long been accepted as a credible tool for understanding and reaching consensus in social sciences and healthcare research (Mohajan, 2018). To start, a team of three graduate students with expertise in qualitative methodology individually evaluated the de-identified transcripts to identify themes and related operational definitions for these themes. Following individual theme development, group members met to discuss individual themes and rationale to reach a consensus on final themes and

operational definitions. After final themes were identified, team members read through the transcripts once more and coded responses according to the agreed-upon themes. After individual coding was complete, group members met a final time to discuss code discrepancies and come to a consensus. To reach consensus, group members offered feedback and information regarding individual-level interpretation with the goal of aligning with a shared interpretation. To reduce subjectivity in reaching consensus, simple descriptive statistics, and agreement percentages were provided. Of note, no universally accepted threshold presently exists for quantifying what is considered reliable or highly reliable, though Miles and Huberman (1994) suggest a standard of 80% agreement on 95% of codes. Additionally, all code discrepancies were debated through open discussion between raters until full consensus was achieved across all participant responses.

Thematic content analysis is not tied with a particular theoretical framework and can therefore be utilized flexibly to account for the presence or absence of a specific theory (Kleinheksel & Rockich-Winston, 2020). The flexibility of this approach was preferable in the current study, as it was the researchers' hope that the concept of role theory would not bias the data analytic process. Rather, theme identification emerged organically, with interpretations unique to the context and experiences of participants. Final analyses either supported or refuted the various components of role theory (e.g., role ambiguity, role conflict, etc.) as factors associated with BMT provider perceptions of palliative care integration.

Results

Defining Palliative Care Roles

The first aim of the study was to evaluate BMT provider perception and understanding of palliative care roles. Responses to interview item *"What do you think are and are not the roles of*

palliative care in BMT?" produced the following themes: *Quality of Life/Coping with Disease, Pain/Medication Management, Beyond End of Life, For End of Life, Collaborative/Aligned with BMT, and Unclear/Not sure.* An additional theme, *Consultants,* contained two subthemes within, titled *Prefers role limitations* and *Prefers Expanding Role* (see Table 3).

Quality of Life/Coping with Disease

The theme *Quality of Life/Coping with Disease* included participant responses that broadly describe palliative care as a source responsible for improving quality of life and facilitating illness coping among patients. Most responses included mention of palliative care being able to address aspects of chronic illness that are difficult to experience, such as increased isolation, difficult symptoms, or coming to terms with illness trajectory among other challenging illness-related circumstances. For example, one participant stated "I think that the rules really are just you know, about, you know, the quality-of-life type of stuff. So, a lot of our patients have issues with pain, a lot of our patients have issues with isolation, have issues with, you know, coping with their disease, or coping with the complications related to their therapy."

Pain/Medication Management

This theme encompassed participant responses detailing palliative care's ability to aid in pain, medication, or symptom management beyond what BMT providers feel they are capable of. Responses coded with this theme commonly mentioned recommendations that palliative care providers may make for management of these aspects. For example, one participant indicated that "palliative care has helped us with a lot of, you know, specifically nausea, pain management, those types of things that we, you know… some ideas or options that we may not think about."

Beyond End of Life

The theme *Beyond End of Life* included a participant response that emphasized palliative care roles and responsibilities spanned beyond those relevant to end-of-life. This comment was made before describing a situation when they aided in end-of-life care for a patient who passed. In stating "another situation that I had, again, you know, not that they're not only helpful for end of life" prior to recounting their story further emphasized participant recognition of roles beyond those surrounding end of life.

For End of Life

In contrast to the prior theme, this theme captured participant responses that specifically emphasized the role that palliative care providers play in providing comfort for and facilitating conversations regarding circumstances relevant to end of life, especially those that are sensitive in nature. Responses coded as such typically included situations of current or imminent death. For instance, one participant stated, "I did also have a patient who unfortunately died on a weekend and was in the hospital on the floor, like on the hot unit…it's really nice for us to know that we have [palliative care] to help support us during those, you know, rare situations, too."

Consultants

Responses coded under this theme included those referring to some mention of palliative care's role in making suggestions/recommendations to the BMT team. For example, one participant stated *"I mean, I think they are like consultants in a way. And so, they… we kind of provide them details about the patient and they provide recommendations based on that kind of full medical assessment from our team."*

Additional contrasting sub-themes centered around perceptions of the degree to which palliative care should be involved in making these suggestions/recommendations.

Prefers Role Limitations. Participant responses coded under this subtheme described feeling content with their current way of practicing, such that palliative care does not write their own patient orders, but instead leaves primary decision-making to the BMT team. Additionally, responses coded under this subtheme may have voiced a preference for palliative care providers to defer to the BMT team for medical decision-making. For instance, one participant said *"I don't think necessarily that palliative care always needs to like, place orders, if that makes sense. They're usually a consulting service. And so there will be some times that they may have recommendations for some sort of management that may have an interaction with what I'm doing. And so, I think, you know, remaining a consulting service…. I mean, obviously, I don't think they should be managing the medical part, because that's what we're focusing on."*

Prefers Role Expansion. In contrast to the prior subtheme, responses categorized under this subtheme detailed BMT provider desires for palliative care to be more active in placing orders and/or making medical decisions for patients. For example, one participant stated *"I would include prescribing. That would be really helpful. The management of the medication… that doesn't necessarily happen but would be really helpful as well. I think a lot of times what happens is we are… we collaborate, but not necessarily, and then we carry out the orders. I think the advantage of having MDs and APNPs would be that they could actually carry out those orders."*

Collaborative/Aligned with BMT

Responses included in this theme emphasized the importance of active collaboration, communication, and alignment between both teams as a necessary component of palliative care. One participant's response highlighted the collaborative process of treating a patient together with palliative care, stating they were comfortable with palliative care taking on several roles

"just as long at as long as you know, we're in agreement, and we're or at least in communication with each other. I don't think that there's necessarily a boundary for the palliative care team. I just want to make sure that we're aligned, and we're working as a team."

Unclear/Not Sure

One participant provided commentary suggesting a general lack of ability to comment on specific roles of palliative care. This comment followed general mention of their consultative nature and stated, *"I don't know if I can comment on like, what their role should not be, other than what they would do under their palliative care purview."*

Defining Domains of Care

Following the previous item, participants were asked to "*Please tell me about what your beliefs are regarding palliative care in the following roles?"* at which point they were prompted to comment on the following domains of palliative care: 1) pain and symptom management, 2) physical aspects of care, 3) psychological and psychiatric aspects of care, 4) social aspects of care, 5) spiritual, religious, and existential aspects of care, 6) cultural aspects of care, 7) end of life care, and 8) ethical and legal aspects of care. Participant responses to each domain revealed seven themes outlining the degree to which palliative care providers should be involved in each role and under what set of circumstances. These themes included the following: *Yes/Active Role, Yes/Complimentary, Yes/Limitations, Yes/Family Preference, No/Not Active, Overlapping Roles, and Unsure or Infrequent* (see Table 4). Theme definitions and number of participants depicting each theme across the eight domains of care are discussed (see Table 5).

Domain 1: Pain and Symptom Management

When inquiring about palliative care's role in addressing pain and symptom management, participant responses reflected the following themes: *Yes/Active* and *Yes/Complimentary* (see Table 5).

Yes/Active. All six participant responses included some commentary consistent with the *Yes/Active* theme, which encompasses responses that described palliative providers as playing an active, collaborative, and helpful role in addressing the associated domain of care. For example, one participant indicated *"They definitely have a big role in that. They've helped me a lot with that."*

Yes/Complimentary. One participant provided a partial response consistent with the *Yes/Complimentary* theme, which described palliative care's ability to provide an additional layer of support, expertise, and resources beyond what the BMT team would typically have access to for the associated domain. For example, when asked about pain and symptom management, this participant explained that *"for many of our patients, [palliative care] has provided me with ideas that I hadn't thought of, so I think that's an area of their expertise I value."*

Domain 2: Physical Aspects of Care

Participant responses regarding palliative care's role in addressing physical aspects of care, the following themes emerged: *Yes/Active, Yes/Complimentary, Unsure or Infrequent, Yes/Limitations,* and *No/Not Active* (see Table 5).

Yes/Active. Four participant responses reflected the *Yes/Active* theme. These responses were brief, yet indicated palliative care's involvement in addressing physical aspects of patient is helpful or that they play a strong role in this domain. Sample responses include "*Also strong"* or "*Again, I think they also have been very helpful."*

Yes/Complimentary. Two participants provided responses in line with the *Yes/Complimentary* theme. Together, these responses demonstrated the feeling that palliative care adds an additional layer of support in this domain due to their ability to identify and recommend resources related to physical functioning perhaps beyond what the BMT team may have. For instance, one participant expressed *"I feel like they can help make connections and things like that or identify when we need more help with getting support or physical therapy, etc."*

Yes/Limitations. Two additional partial responses aligned with the *Yes/Limitations* theme. These responses portrayed the sentiment that palliative care can and should be incorporated in some aspects of caring for physical symptoms, with limitations, or that they should aid in collaboration regarding medical decision-making as long as they do not have the final say. For example, one participant said *"There are medical, like direct medical issues that I don't think necessarily…I think that they help weigh in on… I think the only exception would be like when you're trying to decide, like, if they're an intubation candidate, or, you know, something from that medical standpoint, like bigger picture from their perspective. But I don't think the day-to-day, other than if it's related to medications that they recommend, necessarily. If that makes sense."*

No/Not Active. Two participants provided partial responses in line with the *No/Not Active* theme. These responses collectively described feeling as though palliative care should not be involved in medical decision-making or providing care related to physical aspects if it is outside their expertise. Specifically, one participant stated, "*I don't think they should be involved in the medical piece,"* while the other stated *"if it is not in their area of expertise, then they should not be involved."*

Unsure/Infrequent. One participant provided a partial response consistent with the *Unsure/Infrequent* theme, reflecting general confusion regarding the interviewers questioning of palliative care's role in addressing physical aspects of care. This participant stated, "*I don't know if I totally understand what that means."* This participant further proceeded to provide a response in concordance with the *Yes/Limitations* theme.

Domain 3: Psychological and Psychiatric Aspects of Care

Participant responses to the query about palliative care's role in addressing psychological and psychiatric aspects of care aligned with the following themes: *Yes/Active, Yes/Complimentary,* and *Overlapping Roles* (see Table 5).

Yes/Active. All six participants provided either full or partial responses that aligned with the *Yes/Active* them. These responses reflected the feeling that palliative care is helpful and actively involved in addressing psychological or psychiatric aspects of care. For instance, one participant asserted, "*I think they are actively involved in those conversations and decision-making with us,"* while another stated "*Yeah, I think they have a good role for that."*

Yes/Complimentary. Two participant responses aligned with the *Yes/Complimentary* theme. Responses coded as such generally reflected the feeling that palliative care compliments BMT's ability to treat physical aspects of care due to their ability to spend additional time with patients, identify and facilitate connection to helpful resources, and pinpoint when patients may require additional services beyond what the BMT team may have been able to provide. For example, one participant expressed that "*they can make sure that we're not missing something, meaning we need to rope in our psychiatry or psychology staff more."* Similarly, another

participant stated, "*they can at least help identify when they maybe need to reconnect with their psychologist or spend more time with them."*

Overlapping Roles. One participant provided a partial response in consonance with the *Overlapping Roles* theme. This response indicated overlapping roles between palliative care and staff psychologists in this domain, specifying "*We do have a really great psychology team here, too. So, there's definitely some overlap there."*

Domain 4: Social Aspects of Care

Inquiry into palliative care's role in addressing social aspects of care elicited participant responses reflective of the following themes: *Yes/Active, Yes/Complimentary, Overlapping Roles,* and *Unsure or Infrequent* (see Table 5).

Yes/Active. Four participants included partial or full responses in line with the *Yes/Active* theme. These responses generally indicated that palliative care is and should be actively involved and are helpful in addressing social aspects of care. One participant explained that they should be "*part of the conversation, part of our decision-making,"* while another expressed, "*I think we have had them involved in some of that [here]."*

Yes/Complimentary. One participant included a full response consistent with the *Yes/Complimentary* theme. This response indicated some level of appreciation for palliative care's role in addressing social aspects of care due to their exceptional abilities, perhaps beyond what the BMT team alone may have been able to provide. They stated, "*They're exceptional at it. They're much better at it than I am."*

Overlapping Roles. One participant included a partial response in line with the *Overlapping Roles* theme. This response demonstrated role overlap between other healthcare

professionals when it comes to addressing social aspects of care, stating "*Again, there's some overlap there with social work."*

Unsure or Infrequent. Two participants indicated full and partial responses that aligned with the *Unsure or Infrequent* theme. These responses portrayed some confusion regarding what the researchers were referring to when mentioning social aspects of care in addition to some commentary indicating they have relied on palliative care to address these aspects of care less frequently due to social work's ability to provide relevant services. For instance, one participant explained, "*I guess I'm unsure with social... what the term social refers to...like in terms of family interactions or interactions of the child with peers or siblings or so, I don't know."* Another participant expressed, "*I feel like maybe we've relied more on social work for these types of things traditionally...but [palliative care] tends to be more involved too, just not as much as maybe some of the other things."*

Domain 5: Spiritual, Religious, and Existential Aspects of Care

When asked to comment on their beliefs regarding palliative care's role in treating spiritual, religious, and existential aspects of care, the following themes emerged from participant responses: *Yes/Active, Yes/Complimentary, Yes/Family Preference,* and *Unsure or Infrequent* (see Table 5).

Yes/Active. Two participants included brief, yet clear commentary aligning with the belief that palliative care helps address spiritual, religious, and existential aspects of care. They stated, "*Yeah, [palliative care] has been helpful"* while another simply stated, "*helpful."*

Yes/Complimentary. Four participants included full or partial responses indicative of the *Yes/Complimentary* theme. Collectively, these responses described observation of palliative

care's ability to identify specific resources and connect multiple pieces of information or services to address these aspects of care beyond what the BMT team may be able to. For example, one participant expressed, "*I think that in general, the palliative care team is much more open to those kinds of things. And they're definitely good at bringing in not just internal expertise, meaning our chaplain service, but external expertise... people who are going to connect much better with the family."* Another participant stated, "Palliative care has been able to...I've been in situations where they've said, *'Hey, let's get the chaplain involved, or let's, you know'... we've had families that have requested specific, you know, cultural things that have been helpful to them that they've been able to, again, spend the time with families and identify that wish or need. That's been helpful."*

Yes/Family Preference. One participant provided a full response in line with the *Yes/Family Preference* theme, which generally depicted the notion that palliative care's role in addressing spiritual, religious, and existential aspects of care should be left up to the patient and family being treated. They commented, "*Should be involved if the family wants them involved."*

Unsure of Infrequent. Two participants provided partial responses that related most closely to the *Unsure or Infrequent* theme. These responses demonstrated some hesitancy regarding their willingness to involve palliative care in addressing this domain of care or their lack of exposure to palliative care's role in addressing this domain. For instance, one participant tentatively stated, "*I guess I would be fine with them dealing with that"* while another expressed, "*You know, that has not come up as often."*

Domain 6: Cultural Aspects of Care

Participant responses regarding the role of palliative care in addressing cultural aspects of care were consistent with the following themes: *Yes/Active, Yes/Family Preference, Overlapping Roles,* and *Unsure or Infrequent* (see Table 5).

Yes/Active. Three participants provided full or partial responses in line with the *Yes/Active* theme. These responses revealed beliefs that palliative care is both helpful and good at attending to these aspects, and that they should be skilled at addressing them given their roles. For instance, one participant expressed, *"Yeah, certainly. Yes, palliative care needs to be culturally aware and culturally sensitive and meet the family's needs from a cultural… you know, respecting those cultural aspects."* Another participant stated, "*Yeah, I think they're good at it."*

Yes/Family Preference. One participant provided a response concurrent with the *Yes/Family Preference* theme. This response reflected the belief that palliative care should be involved in addressing cultural aspects of care if it is the family's desire. They stated, "*Should be involved if a family wants them involved."*

Overlapping Roles. Two participants gave full or partial responses that corresponded with the *Overlapping Roles* theme. These responses aligned with the notion that either palliative care or the BMT team could address these aspects of care. For example, one participant explained, *"I think it would kind of be the same as the religious like, whatever they would potentially or not potentially feel comfortable with, but we would be fine, having that conversation with them."* Another participant similarly stated, *"I don't know if they're necessarily any better than the rest of us."*

Unsure or Infrequent. One participant response aligned with the *Unsure or Infrequent* theme, thus indicating a degree of uncertainty regarding palliative care's role in addressing cultural aspects of care. They commented, "*I don't know; neutral."*

Domain 7: End of Life Care

Participant comments regarding the role of palliative care in addressing end of life care revealed the following themes: *Yes/Active, Yes/Complimentary,* and *Overlapping Roles* (see Table 5).

Yes/Active. Five participants provided full or partial responses congruent with the *Yes/Active* theme. These responses conveyed a belief that palliative care should play an active role in providing end of life care, and that they are often helpful when doing so. Sample participant responses included, "*Yeah, for sure. Involved and actively," "they have a major role,"* and *"very helpful."*

Yes/Complimentary. Two participants provided responses corresponding with the *Yes/Complimentary* theme. These responses reflected the belief that palliative care can connect patients to resources and facilitate care related to end of life and be exceptionally skilled at it. For example, one participant stated, *"I think in general, they're probably better than I am at it, but that's not because I'm not good at it. Unfortunately, it's because they're just better at it. And I'll be the first to admit it. So, when we use them, it's really for the higher-level expertise that they have, or experiences that they have that are just more ongoing than my own."*

Overlapping Roles. One participant provided a partial response accordant with the *Overlapping Roles* theme, indicating potential shared roles in providing end of life care. This

participant mentioned, "*I think we're all pretty good at it"* in reference to both BMT and palliative care teams.

Domain 8: Ethical and Legal Aspects of Care

When asked about palliative care's role in addressing ethical and legal aspects of care, the following themes emerged: *Yes/Active, Yes/Complimentary, Yes/Limitations, Overlapping Roles,* and *Unsure or Infrequent* (see Table 5).

Yes/Active. Two participants gave full or partial responses representative of the *Yes/Active* theme. These responses were brief yet conveyed the belief that palliative care is helpful when addressing ethical and legal aspects of care. Sample responses include, "*helpful"* and "*that's been helpful"* in reference to an example that aligned with the *Yes/Complimentary* theme.

Yes/Complimentary. Two participants provided responses in line with the *Yes/Complimentary* theme. These responses demonstrated beliefs that palliative care adds an additional layer of support when addressing ethical and legal aspects of care. For example, one participant stated, *"I think they can… that the palliative care teams can really serve as a like, I think of one... So, they can serve as an extra set of eyes, for lack of a better word. And a not fully removed, but an educated third party who can really inform those kinds of discussions."*

Yes/Limitations. Two participants provided full or partial responses consistent with the *Yes/Limitations* theme. These comments reflected beliefs that palliative care may be involved in addressing ethical and legal aspects of care under specific conditions, such as provider comfort level, oversight from primary medical team, or familiarity with family. For instance, one participant stated, "*I think that might fall into like, the spiritual and the cultural piece of things*

that are open to having their thoughts related to those things, but would defer to like, what their comfort level is. But probably, then, under the guidance of like a primary medical team."

Overlapping Roles. One participant provided a response in line with the *Overlapping Roles* theme. This participant indicated they have previously utilized other services to address ethical and legal aspects of care. They stated, *"I have, you know, consulted ethics in certain situations. So that's interesting."*

Unsure or Infrequent. Two participant responses were consistent with the *Unsure or Infrequent* theme. These responses indicated some degree of uncertainty or lack of exposure to palliative care addressing ethical and legal aspects of care. For instance, one participant explained, *"Um, yeah, I mean, I haven't had to work with palliative care on that specifically... I mean, I could see how maybe they would identify a situation that we maybe would need to bring to ethics, but I haven't had any personal experience with palliative care and that, but I could see that being a thing."*

Reliability Assessment

Percentage Agreement

Percentage agreement between coders was assessed to demonstrate rater consistency. Graduate trainees who are proficient in qualitative data and analysis. The coding team was made up of three graduate trainees who are proficient in qualitative data and analysis. Percentage agreement for the dataset was 79.3%, thus suggesting a high level of consistency. As stated, agreement percentages at or above 0.80 are considered highly reliable.

Discrepancy Resolution

While overall agreement was high, discrepancies between coders for individual themes were discussed iteratively through a process of open sharing of thought processes and perspectives. Following thorough discussion, coding frameworks were adjusted accordingly, and coders arrived at full consensus for all responses, thus contributing to a rich and comprehensive interpretation of the data.

Discussion

Summary of Findings and Relation to the Literature

The present study sought to characterize BMT provider perceptions and understanding of palliative care roles. Specifically, providers were asked to provide open-ended commentary on what they believe are and are not the roles of palliative care in BMT. Following this question, they were asked to indicate their beliefs regarding the role of palliative care across each of the eight domains of palliative care. Participant responses to the broader question about roles of palliative care in BMT revealed themes related to their work improving patient coping and quality of life (e.g., *Quality of Life/Coping with Disease*), their role in treating pain and managing medications (e.g., *Pain/Medication Management*), the extent to which they provide end-of-life care (e.g., *Not Just for End of Life* and *Beyond End of Life*), BMT provider perceptions regarding the scope of their role as consultants to the primary treating team (e.g., *Prefers Role Limitations* and *Prefers Expanding Role*), their beliefs regarding the nature of collaboration or degree of alignment between both teams (e.g., *Collaboration/In Alignment with BMT*), as well as some uncertainty regarding the roles of palliative care (e.g., *Unclear/Not Sure*).

Later inquiry of participants' beliefs surrounding the role of palliative care across eight established palliative care domains revealed the themes expressing general support for palliative care involvement and collaboration due to their expertise and degree of helpfulness, with some

occasional limitations (e.g., *Yes/Active Role, Yes/Complimentary, Yes/Limitations,* and *Yes/Family Preference*). Other themes demonstrated participant experiences of overlapping roles between providers within some domains of care (e.g., *Overlapping Roles*), participant uncertainty regarding the role of palliative care in that domain (e.g., *Unsure or Infrequent*), as well as beliefs that palliative care should not or cannot provide care in a specific domain (e.g., *No/Not Active*).

In general, analysis of participant data and emergent themes largely coincided with extant literature regarding oncologist and hematologist perceptions of palliative care roles. Broadly, most themes and associated qualitative commentary reflected generally positive interpretations of the types of services palliative care provides as they pertain to BMT. Responses similarly demonstrated a clear propensity for ongoing collaboration and communication between care teams. For example, the themes *Collaborative/Aligned with BMT, Prefers Expanding Role, Yes/Active, Yes/Complimentary,* and *Yes/Family Preference* all conveyed feeling as though palliative care should be actively involved, that they provide an additional layer of support and expertise beyond would the BMT team may have been able to provide in some domains, and that active collaboration and communication with them is valued.

Findings of this nature align with existing studies demonstrating positive attitudes and desire for collaboration given palliative care roles and perceived benefits. For instance, several studies evaluating perceptions of palliative care among multidisciplinary pediatric oncology teams revealed favorable opinions and provider beliefs that palliative care offers a range of valuable contributions to the care of children, that palliative care providers are exceptionally emotionally skilled, and that early integration, collaboration, and open communication between teams is preferred (Syzmczak et al., 2018; Salek et al., 2022; Supper et al., 2014; Ward et al., 2009). Several similar studies expressed pediatric oncologist or hematologist acknowledgement

that palliative care should be better integrated into the care of pediatric cancer patients (Cuviello et al., 2022), which aligned with the theme *Expanding Role* in the present study, which reflected participant desires to allow palliative care to play a more active role in several care domains and decision-making processes.

Additional themes, such as *Yes/Limitations,* similarly described participant sentiments that palliative care should play a role in the care of pediatric patients undergoing BMT, though under specific circumstances. For instance, several participants expressed feeling as though for some areas of care, the BMT team should take the lead in primary decision-making or should have the final say despite palliative care being involved in the collaborative process. Findings such as these have been replicated in the literature, with evidence suggesting that referring providers operating under a more integrated model of care, similar to that of the present study, preferred to take on more of a more role, where palliative providers followed their lead (Firn et al., 2016). Several participant responses included in this theme also referenced preferences regarding the types of services or duties the primary treatment team should address, as opposed to palliative care. Namely, several lengthier participant responses aligned with the *Yes/Limitations* theme were coded under discussion of physical aspects of care, suggesting that the BMT team should assume most roles related to medical decision-making with the exception of perhaps symptom control or pain management. Despite being indicative of provider role preferences between teams, responses such as these may also reflect BMT providers' sense of ownership over their patients, a trend that is well-documented in the literature regarding palliative care consultation (Franjul Sanchez et al., 2020).

Another related theme was that of *Prefers Role Limitations.* Participant responses coded under this theme reflected similar preferences for the BMT team to take the lead as primary

decision-maker, with palliative care serving to augment care delivery. Additional points made included the beliefs that palliative care should continue to assume a consultative role as opposed to being a primary treating team. One participant supported this notion with the reasoning that palliative care assuming a more consultative role would prevent conflicts in care approaches among providers. They stated, *"There will be some times that [palliative care] may have recommendations for some sort of management that may have an interaction with what I'm doing. And so, I think, you know, remaining a consulting service and that collaborative service is probably the best for all of them."* Other responses provided specific care tasks that palliative care should refrain from, such as placing orders. Examples such as these contradict literature that suggests pediatric oncology providers recognize the need for better and earlier integration of palliative care in treatment, in addition to desires for active collaboration under a concurrent rather than sequential model of care as a means of improving patient outcomes (Cuviello et al., 2020; Supper et al., 2014; Ward et al., 2009). However, BMT provider beliefs regarding roles of palliative care in aspects of care they preferred to assume may be influenced by a number of factors found in previous studies, including but not limited to sense of ownership over patients, perception of self-efficacy in addressing a specific domain of care, or provider perceptions of the responsibilities, duties, and functions of palliative care as shaped by prior education or institutional culture and expectations (Salek et al., 2022; El Jawahri et al., 2018; Franjul Sanchez et al., 2020; Cherny & Catane, 2003; Johnson et al., 2008; Ward et al., 2009).

Factors such as these may similarly contribute to role ambiguity or confusion regarding how roles should be allocated across disciplines. For instance, participant responses aligned with the *Unclear/Not Sure* and *Unsure or Infrequent* themes reflected provider inability to provide straightforward definitions of roles between providers. These responses also suggested some lack

of exposure to palliative care assuming specific roles historically, such as with social, spiritual/religious, or legal and ethical aspects of care. Confusion regarding role delineation is overwhelmingly well-documented in the literature as a factor limiting collaboration with palliative care (Cherny & Catane, 2003; Johnson et al., 2008; Ward et al., 2009; Salins et al., 2020). Other institutional or training factors have similarly been documented as elements influencing role confusion. Namely, several studies have cited lack of exposure to palliative practices among providers both in residency and fellowship, as well as fewer opportunities for exposure and lower rates of pursuing continued education of palliative care competencies in the years following (El Jawahri et al., 2018; Franjul Sanchez et al., 2020). Similarly, institutional failure to outline clear direction for specialty-specific roles further limits the quality and frequency of collaboration (Firn et al., 2018; Blackmore & Persaud, 2012; Nancarrow et al., 2013).

Furthermore, limitations like these may similarly complicate instances where roles overlap between providers, as was observed in the present study. Namely, the *Overlapping Roles* theme documented provider recognition of multiple providers or disciplines being competent to address particular aspects of care. For instance, several providers expressed that they were sufficiently able to address care related to end of life as well as cultural aspects of care. Other responses indicated prior utilization of other healthcare professionals to address various care needs, such as social work for social aspects of care, the ethics board for ethical and legal aspects, or chaplain services for spiritual, religious, and existential aspects of care. As previously cited, provider decisions to seek consultation are often influenced by confusion regarding role differentiation in the context of collaboration, especially in instances where multiple providers hold expertise in specific domains of care (Cherny & Catane, 2003; Johnson et al., 2008; Ward et

al., 2009; Salins et al., 2020). Additionally, several studies have suggested increased overlap in clinical skills and abilities between oncologists and palliative care providers, as well as less appreciation for the unique expertise palliative care teams may provide (Ward et al., 2009). Lack of formal training in professional collaboration combined with inadequate institutional clarification of roles will also threaten the nature of collaboration between care teams, thus influencing role perceptions due to less frequent exposure (Ward et al., 2009). Provider burden regarding role differentiation within the context of overlapping roles may also help to explain provider efforts to distinguish clear limits or boundaries for palliative care roles, as discussed under the *Prefers Role Limitations* theme.

In some instances, participant confusion surrounding role differentiation was presented as a general inability to define palliative care roles. Most notably, the *No/Not Active* and *Unsure or Infrequent* themes demonstrated some lack of knowledge regarding the clinical expertise and skills associated with palliative care. These responses also indicated several preferences regarding the level of involvement palliative care should have in certain domains. While reasoning for lack of knowledge on or preferences regarding degree of involvement were not expanded upon, multiple studies have cited pediatric oncology and hematology provider perceptions of palliative care teams as lacking appropriate insight into the course and treatment outcomes as well as poor overall competency to provide certain aspects of care (Rhondali et al., 2013; Schenker et al., 2014; LeBlanc et al., 2015; Gidwani et al., 2017; Salins et al., 2020). Similar studies specified challenges of definition and awareness of one another's roles and competencies and physician resistance as barriers to interdisciplinary collaboration (Supper et al., 2014; Salek et al., 2022). Participant understanding of palliative care roles and expertise was especially evident in responses detailing the absence of palliative care in addressing physical

aspects of care, and that palliative care should not be involved in physical aspects of care *"if it is not their area of expertise."* Even positive participant responses occasionally demonstrated lack of knowledge regarding palliative care training and expertise. For instance, one participant response coded under the *Yes/Complimentary* theme attributed palliative care provider abilities to the frequency of contact with patient families rather than specific training. They stated, *"I think they have been aware of situations that I wasn't aware of...but I don't necessarily think it's because of their palliative care training. I think they just knew their families better than I did."*

Despite some indications of inaccurate or incomplete role definitions, it is important to note that most participants provided modern and advanced descriptions of palliative care roles as they pertain to pediatric BMT. That is, palliative care is commonly involved in facilitating care related to end of life, aiding in coping and adjustment to chronic illness, as well as pain and symptom management, all of which play a central role in the treatment of children undergoing BMT therapy. These aspects of care were specifically reflected in the themes *Quality of Life/Coping with Disease, Pain/Medication Management,* and *For End of Life. Several* additional participants expanded on these well-known palliative care roles in the theme *Beyond End of Life*, which clarified the roles of palliative care expanding beyond end-of-life planning or treatment. It is important to note, however, that no participants explicitly mentioned palliative care's role in addressing psychological/psychiatric aspects of care, spiritual, religious, and existential aspects of care, cultural aspects of care, ethical and legal aspects of care, or social aspects of care when asked to comment on what they believe are and are not the roles of palliative care broadly. Interestingly, when prompted with each domain of care in the subsequent question, most participants at least partially agreed that palliative care plays a role. Findings of this nature align with previous literature documenting providers' ability to identify well-known benefits of

palliative care, with much smaller samples able to indicate lesser-known benefits of palliative care, such as facilitating goals of care conversations, shared decision-making, etc. (Salins et al., 2020).

Relation to Role Theory

Identification of various behaviors, characteristics, norms, and values of individuals within an institution and under a role theory framework will likely aid in characterizing these role perceptions (Brookes et al., 2008). Adopted from the work of Brookes et al. (2008) and Taylor et al. (2020) in nursing and pharmacy research, a simplified role theory framework based on the work of Hardy and Conway (1988) that outlined five primary role constructs was considered. These constructs included Role Ambiguity, Role Identity, Role Conflict, Role Insufficiency, and Role Overload, most of which aligned with emergent themes from the present study.

Specifically, several themes depicting confusion or lack of clarity surrounding the roles of palliative care in pediatric BMT, such as *Unclear/Not Sure* and *Unsure or Infrequent*, likely fell within the construct of Role Ambiguity. This construct describes some disagreement regarding role expectations often influenced by a lack of ability to define those expectations (Taylor et al., 2020). Participant responses coded under the *Unclear/Not Sure* and *Unsure or Infrequent* presented vague or unclear definitions of palliative care roles and expertise, several of which contributed to their inability to appropriately identify a discipline most appropriate for a care task (e.g., ethics board vs. Palliative care, chaplain services vs. Palliative care, etc.).

Moreover, Role Ambiguity is often related to Role Identity, or the individual's perception of role expectations. Often, role identity encapsulates position-specific norms that influence the

attitudes, behaviors, and cognitions assumed within a role occupant (Brookes et al., 2008). For example, institutions may provide insufficient explanations of roles and responsibilities between care teams, thus contributing to role confusion. Often, role confusion or lack of knowledge regarding another's abilities and expertise may then lead them to assume specific roles themselves, thus contributing to a sense of ownership and competence. In the present study, themes depicting participant beliefs that palliative care should take a primary, leading role, or that they should assume the role of providing care in particular domains likely aligned with this construct. For instance, the themes *Prefers Role Limitations, Yes/Limitations,* and *No/Not Active* included commentary related to the perception that they should assume a leading role with a final say in most medical decision-making, especially as it pertains to physical aspects of care. Role identification in these instances may have been shaped by any number of factors, such as feeling a sense of primary ownership over patients, experiencing a sense of self-competence to address specific aspects of care, attitudes or beliefs regarding the clinical skills and expertise of palliative care providers being substandard to the role required among others.

Role Ambiguity and Identity are also tied to the construct of Role Conflict, which describes instances where the participant views role expectations as being contradictory or mutually exclusive (Brookes et al., 2008). In the present study, themes referring to role overlap between BMT and palliative care providers (e.g., *Overlapping Roles*), those detailing desires for clear boundaries and open communication as necessary for successful collaboration (e.g., *Collaborative/In Alignment with BMT*) are likely associated with this construct. More specifically, if individuals identify closely with a role that other providers may similarly identify with, these individuals may disagree with the care of other providers they feel is contradictory to the care they are able to give, thus contributing to unpleasant or stressful interpersonal reactions

that later influence openness to collaboration. Similarly, participant descriptions of overlapping roles without clear boundaries or limitations may lead to less streamlined provision of care or stressful interactions among colleagues. Overlapping roles between providers may also threaten participants' role identity and subsequent willingness to collaborate with palliative care.

Two additional role constructs, Role Insufficiency and Role Overload, were much less evident in the present study. Role Insufficiency, which refers to perceived disparities in fulfilling role expectations as perceived by self or others (Brookes et al., 2008), may have contributed to participant perceptions of the knowledge and expertise of palliative care as being insufficient. However, participant responses did not adequately expand on reasons for wanting role limitations or less involvement of palliative care, for example. However, themes such as *Yes/Active Role* or *Yes/Complimentary* occasionally included commentary that palliative care providers were able to address certain aspects of care much better than they would be able to, perhaps indicating a deficiency in capabilities as dictated in the Role Insufficiency construct.

The other role construct, Role Overload, refers to inadequate resources necessary to address demands required of one's role (Brookes et al., 2008). Interestingly, participants did not discuss feeling as though roles or responsibilities among providers were influenced by lack of time or resources despite having been cited as barriers to collaboration (Ward et al., 2009; Salek et al., 2022). It is possible that these factors were simply not touched upon in detail, or they may have been subtly related to participant comments about palliative care providers knowing families better in certain scenarios, which may indirectly be a function of time constraints. Similarly, responses coded under the *Prefers Role Expansion* theme may have indicated desires for palliative care to take a more active role in certain care tasks due to feelings of role overload,

or they may have been influenced by other factors, such as beliefs regarding palliative care expertise.

Practical Implications

As previously highlighted, the expansion of palliative care practices over time due to healthcare advancements has led to calls for extended research into factors influencing role performance and collaboration between specialties. Within pediatric cancer literature, the need for earlier and more integrated involvement of palliative care to optimize patient outcomes is well-documented (Salek et al., 2022). In addition to increased survival rates and improved quality of life, psychological functioning, and symptom management, embedded palliative care models have been observed to increase palliative care referral rates and palliative care service delivery, improve workflow efficiency and quality of care, and enhance oncologist satisfaction (Calton et al., 2016; Muir et al., 2010; Salek et al., 2022). Nevertheless, existing literature evaluating the role and outcomes of embedded palliative care models within pediatric oncology is incredibly scarce (Salek et al., 2022). Additionally, varying models of care delivery across institutions have made it difficult to characterize roles and role perceptions, thus contributing to inconsistent or compromised collaboration (Cherny & Catane, 2003; Johnson et al., 2008; Ward et al., 2009; Salins et al., 2020).

It is clear that the dynamics and interactions of individuals operating within the same structure interact concurrently to inform role perceptions and expectations (Brookes et al., 2008). Moreover, a sizeable body of literature suggests factors such as role ambiguity and role conflict contribute to lower overall productivity, tension, anxiety, dissatisfaction, and group withdrawal among treatment teams (Chang & Hancock, 2003; Lambert & Lambert 2001; Majomi et al. 2003, Brookes et al., 2008). It is possible that careful description of responsibilities and scope of

duties while working to improve communication strategies may help to eliminate these problems (Brookes et al., 2008). As such, understanding constructs influencing these perceptions is imperative to the development of revised care models or quality improvement initiatives aimed at optimizing multidisciplinary collaboration.

Most recently, a study conducted by Salek and colleagues (2022) developed and tested an embedded care model within a pediatric cancer center following a hybrid approach to qualitative research. This process involved utilization of focus groups to gather multidisciplinary perspectives on best approaches for palliative care integration followed by short education sessions on the embedded model. Opportunities were presented for providers of multiple disciplines to participate in the co-design of an embedded model within their institution, which entailed open discussion of predicted benefits and challenges related to discipline-specific culture and structural makeup of the institution. Aside from concerns regarding inadequate resources, qualitative analysis of provider feedback indicated physician resistance to embedded care models as a barrier to successful implementation. Additionally, participant discussion often related to expectations regarding responsibilities, with relevant codes including increased patient and family stress and role clarity and confusion among multidisciplinary clinicians. Consequently, design of the new model involved tasking palliative care clinicians with the job of developing and distributing a list of specific services and core competencies unique to their discipline together with identified stakeholders to help clarify roles and responsibilities across providers. Participant perceptions regarding a need for educational interventions aimed at increasing physician buy-in were implemented, which helped to normalize palliative care integration in routine cancer care. In addition to providing evidence of similar benefits to early palliative care integration as in adult populations, studies such as this provide an excellent

example of how centering the voices of multidisciplinary clinicians to include their preferences, beliefs, and hesitations can lead to increased engagement and success of palliative care collaborations within specific institutions.

In addition to increasing provider buy-in, further development of revised care models and quality improvement initiatives aimed at optimizing collaboration between BMT and palliative care teams through role clarification will enhance child and family access to holistic care (Salek et al., 2022). More specifically, efforts to maximize collaboration between palliative care and BMT teams will aid in creating opportunities for more equitable care across populations. Recent pediatric data demonstrate that, like adults, racial and ethnic disparities exist in the end-of-life experiences of children and adolescents, including but not limited to more intense interventions at end of life for children who are Black, Indigenous, or of color as compared to white children (Linebarger et al., 2022). Similarly, research in pediatric oncology and patients with complex chronic medical conditions demonstrate low hospice enrollment rates and high in-hospital death rates for children who are Black, Indigenous, and people of color, and those with fewer resources (Linebarger et al., 2022). Findings indicating a need for further clarification of BMT and palliative provider role perceptions and interactions may inform efforts to adopt implementation-determinant frameworks in healthcare settings to understand why disparities exist (Nilsen, 2015; Woodward et al., 2021).

It is recommended that three health equity domains to existing implementation determinant frameworks be integrated: (1) culturally relevant factors of recipients, (2) clinical encounter or patient-provider interaction, and (3) societal context (e.g., social determinants of health) (Woodward et al., 2021). For example, regular assessment of patient and family experiences within the BMT program may highlight factors related to culture or context-specific

barriers to care that emphasize care gaps linked to role confusion among clinicians. Namely, attention to cultural aspects of care constitutes a core domain of palliative care training and expertise. Primary treating providers with limited knowledge of this role or perceived self-efficacy in addressing cultural factors despite less comprehensive training may further contribute to care disparities.

In addition to revised models of integrated palliative care, efforts to improve role perceptions among providers may include institutional and policy efforts to outline clear distinctions in role expectations and clinical expertise associated with each discipline. Programs may also work with their institution to develop or implement educational interventions, including clinical mentorship models, aimed at increasing knowledge of provider expertise and improving provider interactions.

Limitations and Future Directions

The present study was not without limitations that may impact the interpretation of findings. Thematic content analysis, like other qualitative methodologies, is relatively subjective and limited to researcher interpretation and biases. Similarly, while qualitative analysis may provide a rich, contextually specific and in-depth understanding of participant perceptions and experiences, relatively small sample sizes and lack of standard statistical analyses understandably limit the generalizability of findings. The current study's inclusion of six participants, representing a subsample of BMT team members at CW, may have fallen short of sufficiently capturing the thoughts and experiences of a broader web of clinicians included in the treatment of pediatric BMT patients.

Similarly, efforts to recruit a diverse array of multidisciplinary providers did not achieve expectations, which may have compromised our ability to evaluate variation in role perception and understanding across team members. Given prior evidence of varying perspectives and openness to collaboration between disciplines due to role differences, education/training differences, and culture associated with specific occupations among other factors highlights the need for further research accounting for such diversity (Salek et al., 2022). Among the most fundamental perspectives not captured within the present study, however, were those of palliative care providers. Future research should similarly aim to capture palliative care perspectives regarding the shared and disparate roles of primary and palliative care providers within the BMT framework. Efforts to do so will help to illuminate ways in which working relationships between both specialties may be improved to diminish dissatisfaction, role stress, burden, and burnout associated with ineffective collaboration (Supper et al., 2014).

Moreover, while findings regarding BMT provider perceptions and understanding of palliative care roles were rich in nature, questions aimed at uncovering the specific reasoning, beliefs, or attitudes that inform perceptions were not incorporated. Prior negative interactions, stigma associated with palliative care, lack of training in palliative care service provision, and perceived self-efficacy contributing to devaluation of palliative care expertise represent several of many factors that influence role perceptions (Ward et al., 2009). For example, Szymczak et al. (2018) found that despite possessing highly favorable beliefs about their institution's palliative care team and agreeing that early integration is ideal, pediatric oncology providers found consulting with palliative care to be profoundly difficult and emotionally burdensome due to negative or inaccurate perceptions held by the patient family. Future research should further examine the thought processes associated with difficult emotional experiences to shed light on

appropriate educational and workplace interventions aimed at reducing distress. For instance, exploration of factors related to this distress may reveal information such as BMT providers' lack of confidence in their ability to effectively introduce palliative care to patient families. This lack of confidence may contradict provider identification with the role of delivering effective medical communication and care coordination or maintaining family emotional and psychological well-being among other role expectations. Research highlighting the processes underlying role perceptions and appraisal may inform educational interventions aimed at adjusting perceptions.

Of note, information such as this may be uniquely associated with the structures and policies of specific institutions. Future research should aim to conceptualize factors unique to institutions while simultaneously centering multidisciplinary team voices and concerns. If specific models or interventions are implemented, long-term research assessing outcomes should be enacted. For example, if interventions aimed at decreasing provider dissatisfaction due to ineffective collaboration, utilization of various needs assessment tools, such as the Palliative Care Needs Assessment Guidelines and the associated Progressive Cancer Needs Assessment Tool may help to clarify areas in need of further improvement (Supper et al., 2014). Within the present study, it is important to clarify the exploratory nature of efforts to characterize BMT providers' perceptions of palliative care roles. Specifically, the automatic trigger policy aimed at integrating palliative care upon patient admission to the BMT program was enacted in 2020, which was close to the time study data was collected. Follow-up studies are needed to evaluate long-term outcomes of early integration models within pediatric BMT care, with particular emphasis on the factors influencing role confusion, ambiguity, or conflict.

As is evident from the present study, implementation of a role theory framework is conducive to characterizing expectations and perceptions of palliative care roles within pediatric

BMT care models. Findings regarding positive role perceptions and desire for collaboration combined with evidence of role ambiguity and confusion among other role constructs further underscore the need for initiatives aimed at better coordination of services. In doing so, care teams may work to optimize patient outcomes and enhance treatment experiences for these vulnerable families.

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Appendix:

Tables

Table 1.

Domains of Palliative care

Domain	Definition
Domain 1: Structure and Processes of Care	This domain outlines the interdisciplinary nature of a palliative care team, with attention paid to the professional qualifications, education, training, and support that is required to deliver optimal patient and family-centered care. This domain also describes the elements of a comprehensive palliative care assessment and care plan in addition to system-based processes and structural elements unique to palliative care.
Domain 2: Physical Aspects of Care	This domain outlines the process of palliative care assessment and care planning as it relates to treatment of physical symptoms, with special emphasis on patient and family-centered holistic care.
Domain 3: Psychological and Psychiatric Aspects	This domain highlights the processes of assessing and caring for the psychological and psychiatric aspects of care associated with chronic illness.
Domain 4: Social Aspects of Care	This domain highlights the approach of palliative care in addressing patient and family social support needs.
Domain 5: Religious, Spiritual, and Existential Aspects of Care	This domain focuses on addressing patient and family spiritual, religious, and existential needs related to their care.
Domain 6: Cultural Aspects of Care	This domain outlines ways in which cultural factors bidirectionally influence the delivery of palliative care and how the care is received by the patient and family based on these factors.
Domain 7: Care of the Person Nearing End of Life	This domain centers around addressing symptoms and situations common to the end of life.
Domain 8: Ethical and Legal Aspects of Care	This domain focuses on factors related to advance care planning, surrogate decision-making, legal considerations, and related palliative care issues with a focus on preserving patient autonomy while upholding ethical imperatives.

Table 2.

Qualitative Interview Questions

Topic	**Interview Questions**
Defining Roles	1) What do you think are and are not the roles of palliative care in BMT? 2) Please tell me about what your beliefs are regarding palliative care in the following roles. a. Pain and symptom management? b. Physical aspects of care? c. Psychological and psychiatric aspects of care? d. Social aspects of care? e. Spiritual, religious, and existential aspects of care? f. Cultural aspects of care? g. End of life care? h. Ethical and legal aspects of care?

Table 3.

Operational Definitions—Defining Palliative Care Roles

Theme	**Definition**
Quality of life/coping with disease	Broad mention of PC being a source responsible for improving overall quality of life and facilitating illness coping among patients
Pain/medication management	Mention of some aspect of pain, medication, and/or symptom management beyond what BMT is capable of
Beyond end of life	Mention that roles expand beyond end-of-life planning or treatment
For end of life	Mention of aid in conducting sensitive end-of-life conversations; that it's helpful in providing comfort and conversations regarding the circumstances at end of life
Consultants— Prefers role limitations Or Prefers role expansion	Based on the notion that PC makes suggestions/recommendations to the BMT team— The participant appreciates the current way of practicing (i.e., PC does not write own orders and leaves decision-making to the BMT team) and/or voices a preference for PC to defer to primary team for medical decision-making or The participant wishes the PC providers could be more active in placing orders and/or making medical decisions for patients
Collaborative/aligned with BMT	Stresses importance of active collaboration and communication/alignment between treatment teams
Unclear/not sure	Lack of ability to provide commentary on PC's role

Table 4.

Operational Definitions—Defining Domains of Palliative Care

Theme	**Definition**
Yes/active role	Some mention of being actively involved in conversations, collaboration, and decision-making with the primary providers as part of that domain of care; mention that involvement in this domain of care would be helpful
Yes/complimentary	Mention of palliative care providers adding an additional layer of support, expertise, and access to resources for this domain above and beyond what BMT would normally provide
Yes/limitations	Palliative care should be involved in this domain of care, but with some restrictions (e.g., under guidance of primary medical team, etc.)
Yes/family preference	Palliative care's role in providing care in this domain is dependent on family needs and preferences
No/not active	Palliative care does not or should not provide care in this domain
Overlapping roles	The care provided in this domain overlaps with BMT or another specialty (e.g., social work, chaplain services, etc.) or is a domain of care that BMT is comfortable providing, but palliative care can also provide
Unsure or infrequent	Comments about being unsure of palliative care's role in this domain, or that their involvement is uncommon

Table 5.

Participant Theme Counts Across Palliative Care Domains

Theme	Pain/Symptom Management	Physical Aspects	Psychological/ Psychiatric	Social Aspects	Spiritual, Religious, Existential	Cultural	End of Life	Ethical and Legal	Total
Yes/Active Role	6	3	6	4	2	3	5	2	31
Yes/Complimentary	1	2	2	1	4	0	2	2	14
Yes/Limitations	0	2	0	0	0	0	0	2	4
Yes/Family Preference	0	0	0	0	1	1	0	0	2
No/Not Active	0	1	0	0	0	0	0	0	1
Overlapping Roles	0	0	1	1	0	2	1	1	6
Unsure or Infrequent	0	1	0	2	1	1	0	2	7

Note: Responses describing more than one theme were counted once per theme depicted. The same theme mentioned more than once in a single response was counted once.