

Integrating Palliative Care in Hematopoietic Stem Cell Transplantation: A Qualitative Study Exploring Patient, Caregiver, and Clinician Perspectives

Reanne Booker, MN, NP, Andrew I.G. McLennan, BA (Hons), Sara Beattie, PhD, RPsych, Kelli I. Stajduhar, RN, PhD, FCAHS, FCAN, and Richard Sawatzky, PhD, RN

PURPOSE: To explore patient, caregiver, and clinician perspectives on palliative care for patients undergoing hematopoietic stem cell transplantation (HSCT).

PARTICIPANTS & SETTING: 8 patients who had undergone or would undergo HSCT, 4 caregivers, and 16 HSCT clinicians.

METHODOLOGIC APPROACH: This qualitative, interpretive descriptive study used semistructured interviews conducted via telephone or videoconference.

FINDINGS: Responses were categorized into the following two themes: concerns and challenges during and after HSCT, and tensions with integrating palliative care into HSCT.

IMPLICATIONS FOR NURSING: The findings from this study highlight the unique and varied needs of patients and their caregivers during and after HSCT. More research is required to determine how to best integrate palliative care in this setting.

KEYWORDS quality of life; hematopoietic stem cell transplantation; palliative care; caregivers

ONF, 50(3), 313–323.

DOI 10.1188/23.ONF.313-323

There is a growing body of literature demonstrating that integrating early palliative care (PC) for patients with advanced cancer is associated with several favorable outcomes. Some commonly cited outcomes include improved symptom management, better prognostic understanding, improved quality of life (QOL) for patients and caregivers, and even improved survival in some contexts (Bakitas et al., 2015; Ferrell et al., 2017; Greer et al., 2013; Temel et al., 2010, 2017). In 2016, the American Society of Clinical Oncology published guidelines concerning integrating PC in oncology, and advocated integrating PC for patients with advanced cancer and patients facing high symptom burden (Ferrell et al., 2017). However, despite the proven benefits of integrating PC in oncology, coupled with the known propensity for patients with hematologic malignancies (HMs) to experience high symptom burden (Boucher et al., 2018; Hochman et al., 2018; Manitta et al., 2011), it has been well documented that patients with HMs and patients undergoing hematopoietic stem cell transplantation (HSCT) do not routinely receive PC (Button et al., 2014; Johnston et al., 2018; Leblanc & El-Jawahri, 2018; Roeland & Ku, 2015; Selvaggi et al., 2014). To date, only one published clinical trial has compared early PC to standard care for patients undergoing HSCT (El-Jawahri et al., 2018). According to Shaulov et al. (2022), there are several ongoing or forthcoming clinical trials on early PC for patients with HMs, and one clinical trial on early PC for patients undergoing HSCT.

HSCT is a treatment approach, used with curative intent, for patients with HMs (Bazinet & Popradi,

2019) and other conditions, including nonmalignant autoimmune conditions (Duarte et al., 2019). In the context of advanced and high-risk HMs, HSCT offers an opportunity for cure with significant potential for severe complications such as graft-versus-host disease (GVHD), organ toxicities, and infections (Bazinet & Popradi, 2019). These complications can be life-threatening and may adversely affect a patient's QOL and their ability to function for many months or even years post-transplantation. Symptom burden, manifesting physically and psychosocially, has been reported to be extremely high in patients with HMs and patients undergoing HSCT (El-Jawahri et al., 2020; Manitta et al., 2011). To date, much of the research on integrating PC in oncology has included patients with solid tumors, with few studies including or focusing on patients undergoing HSCT for HMs (El-Jawahri et al., 2020; Ferrell et al., 2017).

Purpose

The palliative and supportive care needs of patients undergoing HSCT for HMs have been well described (Cheng & Lam, 2021; El-Jawahri et al., 2020), as have the potential barriers to and challenges with integrating PC for patients undergoing HSCT (Lewis, 2020; Ruiz et al., 2018; Sánchez et al., 2020; Suthumpong et al., 2021; Wedding, 2021). However, there are few studies that have examined perspectives on PC in HSCT (El-Jawahri et al., 2021; Gemmell et al., 2022). Because the current authors were planning an interventional trial comparing early PC to standard care for patients undergoing HSCT for HMs, they wanted to ensure that the trial development was informed by patient, caregiver, and clinician input. The purpose of this study was to better understand patient, caregiver, and clinician perspectives on integrating PC into the care of patients undergoing HSCT.

Methodologic Approach

Design

This study was part of a multiphase project on integrating PC for patients undergoing HSCT. Interpretive description (ID), a qualitative methodology that aligns with an interpretivist orientation and acknowledges multiple constructed and contextualized realities, was the methodologic approach used (Thorne, 2016). ID is particularly relevant for clinical practice research where the intent is to capture participants' perspectives and move beyond description to interpret responses and apply them to ongoing research, as well as to inform clinical practice and patient care (Thompson Burdine et al., 2021). As

Thorne (2016) articulates, ID develops knowledge pertaining to the subjective and experiential aspects of health experiences. ID intends not to generate theory, but rather to generate knowledge that can be applied to real-world settings.

Participants and Setting

Between May 2020 and December 2021, eligible patients, caregivers, and clinicians were invited to participate in an interview. Patients were eligible to participate if they would be undergoing or had undergone HSCT for HM. Caregivers, defined as the patient's family members or close friends, were eligible to participate if they were the primary caregiver for someone who would be undergoing or who had undergone HSCT for HM. Clinicians were eligible to participate if their role involved caring for patients being treated with HSCT for HMs.

Participants were recruited from the outpatient department of a tertiary cancer center in Western Canada. The transplantation program at the cancer center conducts more than 200 transplantations for adults annually, with care being provided by HSCT physicians, nurses, nurse practitioners, pharmacists, and psychosocial clinicians. Although there is no formal survivorship program at the cancer center, there is a clinic for long-term survivors of allogeneic transplantations. Study posters were placed in the outpatient bone marrow transplantation clinic. Individuals who were interested contacted the first author, R.B., directly to learn more about the study and determine eligibility. Because of the COVID-19 pandemic, all study procedures were conducted remotely via email, videoconference, or telephone to minimize participants' risks of exposure to the SARS-CoV-2 virus. Purposive and theoretical sampling were undertaken (Hunt, 2009; Oliver, 2012). Theoretical sampling was used to help identify additional participants who may not have been included otherwise but whose participation might help with maximal variation (Thorne, 2016).

Data Collection

A semistructured interview guide (available upon request) was developed based on Zimmermann et al. (2016) and Ahmed et al. (2022). The interview guide included open-ended questions and prompts. Once participants provided informed consent, the interview was scheduled and then conducted by R.B. via telephone or videoconference, whichever the participant preferred. All interviews were audio recorded and transcribed verbatim. Field notes were kept

during interviews to capture contextual information, such as the participant's location during the interview and demeanor (Phillippi & Lauderdale, 2018). Because all interviews were conducted virtually, field notes were minimal, particularly for interviews conducted via telephone because it was not possible to see the participant, their body language, or their

facial expressions. The average interview duration was 41 minutes (range = 15–71 minutes; median = 39 minutes).

Data Analysis

Data analysis in ID is an inductive, iterative process whereby data collection occurs simultaneously with

TABLE 1. Clinician Demographics (N = 16)

Participant	Age (Years)	Gender	Profession	Education	Years of Practice	Years in Heme/ HSCT
1	26	Female	Nurse	■ BN	4	2
2	28	Female	Hematology nurse practitioner	■ MN	7	7
3	28	Female	Nurse	■ BN ■ In graduate school for MN	5	4
4	28	Female	Nurse	■ BN ■ RN ■ In graduate school for MN	6	5
5	30	Female	Nurse	■ BSN ■ RN ■ In graduate school for MN	8	6
6	32	Female	Nurse	■ BN ■ RN	8	3
7	35	Female	Nurse	■ BSN ■ RN	13	13
8	37	Female	Nurse	■ BN ■ RN	14	14
9	38	Female	Psychologist	■ PhD	5	4
10	42	Female	Hematologist	■ MD	17	12
11	49	Female	Hematologist	■ MD	17	17
12	52	Female	Nurse	■ BSN ■ RN	31	31
13	52	Male	Hematologist	■ MD	20	20
14	53	Female	Nurse	■ BN ■ RN	25	25
15	53	Male	Physician	■ MD	29	26
16	57	Male	Medical oncologist	■ MD	26	26

BN—bachelor of nursing; heme—hematology; HSCT—hematopoietic stem cell transplantation; MD—doctor of medicine; MN—master of nursing

TABLE 2. Patient Demographics (N = 8)

Participant	Gender	Age (Years)		Diagnosis	Type of HSCT	Marital Status ^a	Primary Caregiver	Residence
		At Interview	At HSCT					
1	Female	30	29	MLL	Allo, unrelated	Married	Spouse, mother-in-law	Urban
2	Female	54	47	MDS, smoldering leukemia	Allo, unrelated	Married	Spouse	Rural
3	Female	67	65	AML	Allo, sibling	Divorced	Partner of 2 years, friends	Urban
4	Female	68	53	AML	Allo, unrelated	Married	Spouse	Urban
5	Male	29	27	AML	Allo, unrelated	Married	Spouse	Rural
6	Male	44	-	AML	Allo, unrelated, pre-HSCT	Married	Spouse	Urban
7	Male	47	-	AML	Allo, unrelated, pre-HSCT	Separated	Parents	Rural
8	Male	52	52	Multiple myeloma	Autologous	Married	Spouse	Urban

^a At time of interview
allo—allogeneic; AML—acute myelogenous leukemia; HSCT—hematopoietic stem cell transplantation; MDS—myelodysplastic syndrome; MLL—mixed lineage leukemia

data analysis (Thorne, 2016). Interview transcripts were read repeatedly to get a sense of the broader themes and to develop an iteratively derived coding scheme that was then used to code the data. Once an initial coding scheme was developed by authors A.I.G.M. and R.B., data were then grouped into categories, paying attention to patterns within the data. These initial interpretive understandings were then discussed by the research team to develop a deeper ID analysis. After several category iterations were developed, consensus was achieved on the final categories. NVivo, version 20.4.0, was used to organize and manage data.

Findings

Participants

A total of 28 participants, consisting of 8 patients, 4 caregivers, and 16 clinicians, agreed to be interviewed. Demographic data are presented in Tables 1–3.

Most interviews began with patients and caregivers speaking about their experiences during and following HSCT, and clinicians gave their observations of patient and caregiver symptoms and

experiences during and following HSCT. As the interviews progressed, an exploration of the participants' awareness of and experiences with PC ensued. The discussion of patient and caregiver experiences, coupled with their thoughts on PC, contributed to a preliminary understanding of how PC might be integrated into the care of patients undergoing HSCT.

Perspectives on PC in HSCT

Concerns and Challenges With HSCT

Patients, caregivers, and clinicians spoke about the intense physical and psychosocial symptoms that occur during and after HSCT. Several participants suggested that there was an expectation that some degree of suffering was inevitable with HSCT. One clinician said, "There is a certain amount of physical suffering that is just assumed. It's accepted that there's going to be a high intensity of symptom burden."

Clinician participants expressed that symptom burden in HSCT could be better managed, particularly psychosocial and existential symptoms. Many participants shared that patients did not always seem

TABLE 3. Caregiver Demographics (N = 4)

Participant	Age (years)		Gender	Relation to Patient	Marital Status	Residence
	At Interview	At HSCT ^a				
1	29	28	Female	Spouse	Married	Rural
2	53	47	Male	Spouse	Married	Rural
3	70	70	Female	Spouse	Married	Urban
4	69	69	Male	Family friend	Single	Urban
^a At time of patient's HSCT HSCT—hematopoietic stem cell transplantation						

to understand or even be aware of the potential side effects and complications associated with HSCT. One clinician explained,

It's the unknown going into [HSCT]. They get this laundry list of things that could happen to them, and they could be in [the intensive care unit] or anything like that. And for some people, it's much worse than they could ever expect.

Physical Symptom Concerns

Several participants spoke about the multitude of physical symptoms that can arise post-HSCT. Participants acknowledged that patients experienced intense HSCT side effects such as nausea, vomiting, diarrhea, mucositis, and pain. Participants also shared that physical issues may persist for many months or even years post-HSCT, particularly for patients who develop chronic GVHD. Ongoing fatigue and cognitive dysfunction were acknowledged by participants as being persistent and bothersome longer-term physical issues post-HSCT. Participants acknowledged that physical symptoms and side effects associated with HSCT could be particularly intense. One clinician said, "Doing your daily tasks of living become these insurmountable challenges. I think that's what people don't understand. You know, [chemotherapy] in the past made you feel really lousy and nauseous and tired, but this is like times 10."

Psychosocial and Spiritual Concerns

Psychosocial and existential concerns such as anxiety, depression, the inability to return to work, relationship challenges including sexual health concerns, and worries about disease recurrence or development of complications were frequently reported by participants. Patients and caregivers felt that psychosocial needs were not always well managed, and more support was

needed. Clinicians also expressed the need for better psychosocial and spiritual support for patients and caregivers, as well as improved coordination of care. One patient said, "The mental health side, particularly for young adults, I would say . . . they're just working on getting established in their lives when they're going through this. . . . The mental health side is not something you cure in a hospital with [chemotherapy]." One clinician said, "Sure, we might cure a lot of people, but they come out of it with, you know, debilitating effects. . . . Like, 'Your cancer's gone, so we'll discharge you, but as a person, you're still not intact.'"

Concerns After HSCT

Patients and caregivers reported a lack of availability of support for concerns post-HSCT, particularly following discharge. Many participants shared that they had not expected physical and psychosocial symptoms and side effects to be so persistent. In addition, participants who were from rural regions indicated that they struggled to find support in their hometowns, something that became more problematic once they were no longer being closely followed by the HSCT team. One patient said, "There's by far, in my opinion, not enough being done in order to provide that long-term aftercare support to patients once they check out of the hospital."

Treatment Expectations and Prognostic Understanding

Clinicians expressed concern that some patients and caregivers may not fully appreciate the possible risks and complications associated with HSCT. Participants were unsure if this was because of insufficient information being provided or patients and caregivers having difficulty understanding provided information, or if patients were intentionally choosing to disregard such information as

an avoidance or disassociation tactic. Many participants, including patients, caregivers, and clinicians, felt that patients had a poor understanding of what to expect with HSCT and were unprepared. One clinician said, “Even a patient that we had who was a physician, they said, ‘I didn’t understand what I was really going to go through.’” Some participants felt that patients understood some aspects of HSCT but did not understand other aspects of transplantation, particularly when it came to the complications associated with HSCT and the effects on their QOL. Others acknowledged that some patients and caregivers may have preferred not knowing detailed information about the treatment or prognosis as a way of coping with the situation. One clinician said, “Many of them are told the information about the chances of success, but I think even if it’s a very slim number, they all think that they’re going to be those ones that will make it through.” One caregiver said,

We had the big scary meeting before saying, you know, “These are the statistics, these are your chances.” . . . But to be honest, we kind of just put that to the side because it just put so much fear in our hearts, and if there’s a chance this could work, we clung to that to get us through.

Tensions With Integrating PC in HSCT

Participants’ responses also clustered into another category pertaining to tensions associated with integrating PC in HSCT. Many participants harbored misperceptions about PC, and nearly all participants, including clinicians, felt that PC was associated with end-of-life care. One clinician stated, “I think that [patients] think PC means end of life. And there’s no hope . . . no doctors are coming to see you, no one cares anymore. The very negative connotation that people associated with the word ‘palliative.’” Also within this category was the notion that HSCT is a curative-intent treatment and, therefore, participants found it difficult to see how PC could be integrated into care, particularly if they thought that PC was meant for end-of-life care. Clinicians emphasized that the unique features of HMs and HSCT created challenges for integrating PC.

Misperceptions of PC

Many participants shared that their experiences with and knowledge of PC were limited. Several recounted experiences when a loved one had received PC prior to death and, as such, they associated PC with dying. One participant said, “My mom was in palliative care

and then she died in hospital. . . . That’s immediately what I think of. I hate it.” Of note, all patients initially indicated that they would feel distressed or anxious if PC had been introduced during their HSCT, as one explained:

I think my gut reaction would’ve been, “Ah, OK. Does this mean it’s incurable? Uh, am I dying?” It probably would’ve raised a little bit of anxiety in me had they not explained exactly what they meant. . . . My gut response would’ve been “end-of-life care.”

Another participant stated,

The first thing I’d think is, “This is not the exact conversation I wanna have.” It’d be . . . that whole idea of dying . . . when it comes to the words “palliative care” . . . to me, it seems like we’re giving up hope and you’re just prepping me for the ultimate death.

Once the definition of PC was shared with participants and it was explained that PC can help with symptom management and other aspects of care, all participants agreed that early PC implementation could be beneficial.

Tensions Between Curative and Palliative Intent

Some clinicians indicated that they found it difficult to bring up PC, and worried that patients might lose confidence in their treatment or even lose trust in their care team. Other clinicians suggested that there was an incongruity with introducing PC in a curative-intent context, such as HSCT, particularly given the misperceptions that PC is the same as end-of-life care. One clinician said,

If you agree to do a transplant on somebody but you start to have a discussion to say, “Well, you know, you’re pretty old and if you need to go to the [intensive care unit], you’re going to die, so we recommend against it,” then I’m sure the patient starts to think, “I don’t know how hard these guys are going to work to save my life if I get sick.”

Clinicians also felt that having PC available for difficult conversations and to allow patients to talk about the possible outcomes would be helpful, as expressed by one clinician: “Maybe we don’t discuss the downside of the treatment enough, and so sometimes it helps to know that there’s another team

that's also going to help look after you if the downside comes true."

Tensions Associated With Unique Aspects of HSCT

Clinicians spoke on the unique nature of HMs and HSCT as potential challenges to the integration of PC. For example, many discussed the challenges with prognostic uncertainty and the rapidity of decline for patients with HMs as barriers to knowing when to refer patients to PC. One clinician explained, "You could be doing very, very well and then not, within weeks. You go from full-on cure to end-of-life care within a month. And it's very difficult to switch that mindset." Another clinician said, "Overnight, they can change from curative intent to palliative intent with a very short life expectancy." Other clinicians spoke of the responsiveness of HMs to chemotherapy, even in the context of advanced disease, again making it challenging to know when to refer patients to PC. Clinicians felt that interventions such as blood transfusions or a course of oral chemotherapy were often considered inappropriate by PC clinicians as they considered these interventions to be life-sustaining or life-prolonging rather than being provided with palliative intent. This was seen as a potential barrier to referring patients to PC and an area of misunderstanding between PC and hematology/HSCT clinicians. One clinician said,

The recommendation is to not give noncurative [chemotherapy] close to the end of life, and that gets you black marks . . . if you're slinging [chemotherapy] in the last few weeks of life. The trouble is, often for the hematologic cancers, the [chemotherapy] can be fairly gentle and well tolerated and often control the cancer symptoms the best. A little bit of daily etoposide can actually control the pain from the lymphoma mass better than morphine.

Discussion

The purpose of this study was to explore the perspectives of patients, caregivers, and clinicians regarding the integration of PC in HSCT. Findings suggest there is a potential role for PC in the care of patients undergoing HSCT, but the way PC is integrated into this clinical context requires careful consideration. Participants in this study spoke of the intense physical and psychosocial symptoms as well as associated distress that can arise during and after HSCT. Other studies have also reported that patients with HMs and patients undergoing HSCT experience a high

KNOWLEDGE TRANSLATION

- Patients and caregivers experience an array of physical, psychosocial, spiritual, practical, and informational needs during and following hematopoietic stem cell transplantation (HSCT).
- Unique aspects of HSCT may make it challenging to integrate palliative care for patients undergoing transplantation.
- The findings from this study can inform approaches to integrating palliative care for patients undergoing HSCT.

symptom burden that is at least comparable to, if not more severe than, that of patients with solid tumors (Manitta et al., 2011; Mitchell, 2018; Simon et al., 2021).

Participants in this study also spoke about the persistence of symptom burden, even years post-HSCT, coupled with a perceived lack of long-term support, particularly for participants who reside away from the city where they received their HSCT. An array of late and long-term complications can occur post-HSCT. The incidence of chronic health conditions in patients who have undergone allogeneic HSCT is 64% at 10 years post-HSCT and 71% at 15 years post-HSCT (Bhatia, 2014). Some cancer centers have established survivorship programs or clinics to help address the needs of survivors after HSCT (Battiwala et al., 2017). However, there may still be a role for PC support, particularly for patients who do not have access to survivorship services.

Along with symptom burden, participants also expressed a need for information and practical support. Many participants felt that treatment expectations did not match reality and that HSCT was much more difficult than anticipated. Participants were unsure if unrealistic treatment expectations were because of insufficient information provided upfront, difficulty comprehending the nature of the potential risks and complications, or a desire to avoid discussing and thinking about the prognosis and complications. Congruent with the literature, clinicians acknowledged the differing degrees that patients want honest disclosure about their prognosis, as well as the varying degrees to which clinicians feel comfortable discussing the prognosis (Bennardi et al., 2020; Derry et al., 2019; Gray et al., 2021; Wedding, 2021). Misperceptions regarding prognosis may be because of inadequate communication and education, inadequate prognostic disclosure, or a patient's individual capacity to process, accept, and discuss their prognosis (Derry et al., 2019; Gray et al., 2021). Treatment expectations and prognostic understanding are essential because they

can influence medical decision-making, including treatment wishes at the end of life (Cartwright et al., 2014; El-Jawahri et al., 2015).

In addition to learning more about the PC needs of patients and caregivers, findings suggested that there are tensions associated with integrating PC in HSCT. Such tensions are related to misperceptions held by patients, caregivers, and clinicians, as well as to the integration of PC in a curative-intent context. In addition, unique challenges associated with HMs and HSCT were also raised by participants. Prognostic uncertainty remains a significant challenge in HSCT. Patients whose underlying malignancy might be cured can experience flares of GVHD or other late or long-term complications that can contribute to morbidity and mortality for years to come after HSCT (Inamoto & Lee, 2017; Majhail, 2017). Given these risks and the challenges of prognostic uncertainty, shifting from a prognosis-based model of PC referral to a needs-based model may be helpful (Leblanc & El-Jawahri, 2018; Suthumpong et al., 2021).

As others have reported, participants, including clinicians, harbored misperceptions about PC (Bennardi et al., 2020; Hui et al., 2018). Many participants indicated that they perceived PC to be the same as end-of-life or hospice care and, as such, found it difficult to envision how PC could be delivered alongside a curative-intent treatment such as HSCT. For patients, it seemed that a lack of exposure to PC contributed to their misperceptions. Once PC was explained, participants agreed that it could benefit patients and caregivers during and after HSCT. Education on PC should be incorporated into patient care early in the disease trajectory. Ideally, PC education and training should be part of healthcare provider programs or curricula, and clinicians should possess core competencies and skills to provide at least primary PC and to adopt a palliative approach to care (Evans et al., 2019; Sawatzky et al., 2017). Harden and Schembri (2016) conducted a quality improvement project where patients were provided a PC consultation prior to and shortly after HSCT to potentially increase their knowledge of PC. The authors found that an early PC consultation increased knowledge of PC and recommended that early PC be implemented for patients undergoing HSCT (Harden & Schembri, 2016).

Limitations

There are several limitations that should be noted. The sample size was small, particularly for caregivers, and as such, the results of this study cannot be generalized. Only one patient had undergone autologous

HSCT. Although it is well known that the side effects and complications can be quite different for allogeneic and autologous transplantations, the experiences of this participant were similar to those of other patients. The majority of patients and caregivers were post-HSCT. The needs of patients and caregivers likely vary significantly, depending on where the patient is in the treatment trajectory. Needs may also vary depending on the type of HM with which the patient has been diagnosed.

There was a lack of dissenting perspectives regarding the integration of PC, particularly among clinicians. Based on the literature and the authors' experiences, not all HSCT clinicians support integrating PC. It is important to include perspectives opposed to integrating PC, particularly when considering how to implement PC into practice. Participants in this study, particularly clinicians, may have an interest in PC being integrated in HSCT and, therefore, may not be representative of the broader population.

As with all research, interpretation of data is influenced by the researchers' experiences and backgrounds. The situatedness of the researcher in ID is important, and the clinical experience of a researcher is considered beneficial in developing research questions that are clinically meaningful. Accordingly, the experience of R.B. as a clinician in HSCT prior to moving to PC affords the unique perspective of having an awareness of these two fields.

Implications for Nursing

Patients and caregivers experience significant physical, psychosocial, and existential symptoms as well as associated distress during and following HSCT. Nurses are ideally suited to assess and assist in managing such distress, including advocating for specialist PC referrals when required. In addition, nurses can play a pivotal role in helping to educate patients, caregivers, and colleagues on the importance of PC in oncology, and help to correct the misperceptions associated with PC. More research is required to gain a comprehensive understanding of the needs of patients and caregivers undergoing HSCT, as well as to determine how to best integrate PC into this care. The current authors are conducting a randomized clinical trial to compare early PC to standard care for patients and caregivers undergoing HSCT (ClinicalTrials.gov, 2023).

Conclusion

The integration of PC in oncology is associated with several positive outcomes for patients and caregivers, yet integrating PC into the care plan for patients

undergoing HSCT has not been widely adopted as part of routine care. This study revealed that patients and caregivers undergoing HSCT have significant physical and psychosocial symptoms, that there are barriers to integrating PC (including misperceptions of PC among clinicians, patients, and caregivers), and that there are unique aspects of HMs and HSCT that require special consideration when integrating PC in HSCT. The optimal model for integrating PC remains to be determined. Incorporating PC earlier in the HSCT trajectory of care may mitigate the difficulties associated with prognostic uncertainty and the rapidity of decline that can occur after HSCT, with the goal of ensuring that the HSCT experience is as good as possible for all involved.

Reanne Booker, MN, NP, is a nurse practitioner in palliative and end-of-life care services in the Foothills Medical Centre at Alberta Health Services and a PhD candidate in the School of Nursing at the University of Victoria in British Columbia; **Andrew I.G. McLennan, BA (Hons)**, is a graduate student in clinical psychology in the Department of Psychology at the University of Regina in Saskatchewan; **Sara Beattie, PhD, RPsych**, is a psychologist in the Department of Psychosocial and Rehabilitation Oncology at the Tom Baker Cancer Centre in Calgary, Alberta; **Kelli I. Stajduhar, RN, PhD, FCAHS, FCAN**, is a professor in the School of Nursing and Institute on Aging and Lifelong Health at the University of Victoria; and **Richard Sawatzky, PhD, RN**, is a professor in the School of Nursing at Trinity Western University in Langley, both in British Columbia. Booker can be reached at reanne.booker@ahs.ca, with copy to ONFEditor@ons.org. (Submitted July 2022. Accepted November 19, 2022.)

The authors gratefully acknowledge all participants for their time and contributions to this study.

Booker is supported by the RK Dixon Family Award from the Alberta Cancer Foundation (grant #27265).

Booker, Beattie, and Stajduhar contributed to the conceptualization and design. Booker completed the data collection. Booker, McLennan, and Stajduhar provided statistical support. Booker, McLennan, and Stajduhar provided the analysis. All authors contributed to the manuscript preparation.

REFERENCES

- Ahmed, S., Naqvi, S.F., Sinnarajah, A., McGhan, G., Simon, J., & Santana, M.J. (2022). Patient and caregiver experiences: Qualitative study comparison before and after implementation of early palliative care for advanced colorectal cancer. *Canadian Journal of Nursing Research*, 55(1), 110–125.
- Bakitas, M.A., Tosteson, T.D., Li, Z., Lyons, K.D., Hull, J.G., Li, Z., . . . Ahles, T.A. (2015). Early versus delayed initiation of concurrent palliative oncology care: Patient outcomes in the ENABLE III randomized controlled trial. *Journal of Clinical Oncology*, 33(13), 1438–1445. <https://doi.org/10.1200/JCO.2014.58.6362>
- Battiwalla, M., Tichelli, A., & Majhail, N.S. (2017). Long-term survivorship after hematopoietic cell transplantation: Roadmap for research and care. *Biology of Blood and Marrow Transplantation*, 23(2), 184–192. <https://doi.org/10.1016/j.bbmt.2016.11.004>
- Bazinnet, A., & Popradi, G. (2019). A general practitioner's guide to hematopoietic stem-cell transplantation. *Current Oncology*, 26(3), 187–191. <https://doi.org/10.3747/co.26.5033>
- Bennardi, M., Diviani, N., Gamondi, C., Stüssi, G., Saletti, P., Cinesi, I., & Rubinelli, S. (2020). Palliative care utilization in oncology and hemato-oncology: A systematic review of cognitive barriers and facilitators from the perspective of healthcare professionals, adult patients, and their families. *BMC Palliative Care*, 19(1), 47. <https://doi.org/10.1186/s12904-020-00556-7>
- Bhatia, S. (2014). Caring for the long-term survivor after allogeneic stem cell transplantation. *Hematology, ASH Education Program*, 2014(1), 495–503. <https://doi.org/10.1182/asheducation-2014.1.495>
- Boucher, N.A., Johnson, K.S., & Leblanc, T.W. (2018). Acute leukemia patients' needs: Qualitative findings and opportunities for early palliative care. *Journal of Pain and Symptom Management*, 55(2), 433–439. <https://doi.org/10.1016/j.jpainsymman.2017.09.014>
- Button, E.B., Gavin, N.C., & Keogh, S.J. (2014). Exploring palliative care provision for recipients of allogeneic hematopoietic stem cell transplantation who relapsed. *Oncology Nursing Forum*, 41(4), 370–381. <https://doi.org/10.1188/14.ONF.370-381>
- Cartwright, L.A., Dumenci, L., Siminoff, L.A., & Matsuyama, R.K. (2014). Cancer patients' understanding of prognostic information. *Journal of Cancer Education*, 29(2), 311–317. <https://doi.org/10.1007/s13187-013-0603-9>
- Cheng, H.W.B., & Lam, K.O. (2021). Supportive and palliative care in hemato-oncology: How best to achieve seamless integration and subspecialty development? *Annals of Hematology*, 100(3), 601–606. <https://doi.org/10.1007/s00277-020-04386-8>
- ClinicalTrials.gov. (2023). *Early integration of palliative and supportive care in cellular therapy (PALS-CT)*. <https://clinicaltrials.gov/ct2/show/NCT05190653>
- Derry, H.M., Reid, M.C., & Prigerson, H.G. (2019). Advanced cancer patients' understanding of prognostic information: Applying insights from psychological research. *Cancer Medicine*, 8(9), 4081–4088. <https://doi.org/10.1002/cam4.2331>
- Duarte, R.F., Labopin, M., Bader, P., Basak, G.W., Bonini, C., Chabannon, C., . . . Mohty, M. (2019). Indications for haematopoietic stem cell transplantation for haematological diseases, solid tumours and immune disorders: Current practice in Europe, 2019. *Bone Marrow Transplantation*, 54(10), 1525–1552. <https://doi.org/10.1038/s41409-019-0516-2>

- El-Jawahri, A., LeBlanc, T.W., Burns, L.J., Denzen, E., Meyer, C., Mau, L.-W., . . . Petersdorf, E. (2018). What do transplant physicians think about palliative care? A national survey study. *Cancer*, 124(23), 4556–4566. <https://doi.org/10.1002/cncr.31709>
- El-Jawahri, A., Meyer, C., Mau, L.-W., Mattila, D., Burns, L.J., Ullrich, C., . . . LeBlanc, T.W. (2021). What do patients think about palliative care? A national survey of hematopoietic stem cell transplant recipients. *Blood*, 138(1, Suppl.), 2968. <https://doi.org/10.1182/blood-2021-149766>
- El-Jawahri, A., Nelson, A.M., Gray, T.F., Lee, S.J., & LeBlanc, T.W. (2020). Palliative and end-of-life care for patients with hematologic malignancies. *Journal of Clinical Oncology*, 38(9), 944–953. <https://doi.org/10.1200/JCO.18.02386>
- El-Jawahri, A., Traeger, L., Kuzmuk, K., Eusebio, J., Vandusen, H., Keenan, T., . . . Temel, J.S. (2015). Prognostic understanding, quality of life and mood in patients undergoing hematopoietic stem cell transplantation. *Bone Marrow Transplantation*, 50(8), 1119–1124. <https://doi.org/10.1038/bmt.2015.113>
- Evans, J.M., Mackinnon, M., Pereira, J., Earle, C.C., Gagnon, B., Arthurs, E., . . . Wright, F.C. (2019). Integrating early palliative care into routine practice for patients with cancer: A mixed methods evaluation of the INTEGRATE Project. *Psycho-Oncology*, 28(6), 1261–1268. <https://doi.org/10.1002/pon.5076>
- Ferrell, B.R., Temel, J.S., Temin, S., Alesi, E.R., Balboni, T.A., Basch, E.M., . . . Smith, T.J. (2017). Integration of palliative care into standard oncology care: American Society of Clinical Oncology clinical practice guideline update. *Journal of Clinical Oncology*, 35(1), 96–112. <https://doi.org/10.1200/JCO.2016.70.1474>
- Gemmell, R., Halley, A., Stevens, A.-M., Allam, A., Perkins, M., Ethell, M., . . . Droney, J. (2022). Palliative care for patients around the time of haematopoietic stem cell transplant: A qualitative study of patients' perceptions and experiences of unmet need and attitudes towards palliative care involvement. *Supportive Care in Cancer*, 30(3), 2253–2261. <https://doi.org/10.1007/s00520-021-06556-4>
- Gray, T.F., Temel, J.S., & El-Jawahri, A. (2021). Illness and prognostic understanding in patients with hematologic malignancies. *Blood Reviews*, 45, 100692. <https://doi.org/10.1016/j.blre.2020.100692>
- Greer, J.A., Jackson, V.A., Meier, D.E., & Temel, J.S. (2013). Early integration of palliative care services with standard oncology care for patients with advanced cancer. *CA: A Cancer Journal for Clinicians*, 63(5), 349–363. <https://doi.org/10.3322/caac.21192>
- Harden, K.L., & Schembri, J.A. (2016). Early intervention with transplantation recipients to improve access to and knowledge of palliative care. *Clinical Journal of Oncology Nursing*, 20(4), E88–E92. <https://doi.org/10.1188/16.CJON.E88-E92>
- Hochman, M.J., Yu, Y., Wolf, S.P., Samsa, G.P., Kamal, A.H., & Leblanc, T.W. (2018). Comparing the palliative care needs of patients with hematologic and solid malignancies. *Journal of Pain and Symptom Management*, 55(1), 82–88.e1. <https://doi.org/10.1016/j.jpainsymman.2017.08.030>
- Hui, D., Hannon, B.L., Zimmermann, C., & Bruera, E. (2018). Improving patient and caregiver outcomes in oncology: Team-based, timely, and targeted palliative care. *CA: A Cancer Journal for Clinicians*, 68(5), 356–376. <https://doi.org/10.3322/caac.21490>
- Hunt, M.R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research*, 19(9), 1284–1292. <https://doi.org/10.1177/1049732309344612>
- Inamoto, Y., & Lee, S.J. (2017). Late effects of blood and marrow transplantation. *Haematologica*, 102(4), 614–625. <https://doi.org/10.3324/haematol.2016.150250>
- Johnston, E.E., Muffy, L., Alvarez, E., Saynina, O., Sanders, L.M., Bhatia, S., & Chamberlain, L.J. (2018). End-of-life care intensity in patients undergoing allogeneic hematopoietic cell transplantation: A population-level analysis. *Journal of Clinical Oncology*, 36(30), 3023–3030. <https://doi.org/10.1200/JCO.2018.78.0957>
- Leblanc, T.W., & El-Jawahri, A. (2018). Hemato-oncology and palliative care teams: Is it time for an integrated approach to patient care? *Current Opinion in Supportive and Palliative Care*, 12(4), 530–537. <https://doi.org/10.1097/spc.0000000000000385>
- Lewis, E.A. (2020). Optimizing the delivery of early palliative care for hematology patients receiving a stem cell transplant: A role for a nurse practitioner. *Canadian Oncology Nursing Journal*, 30(4), 239–245. <https://doi.org/10.5737/23688076304239245>
- Majhail, N.S. (2017). Long-term complications after hematopoietic cell transplantation. *Hematology/Oncology and Stem Cell Therapy*, 10(4), 220–227. <https://doi.org/10.1016/j.hemonc.2017.05.009>
- Manitta, V., Zordan, R., Cole-Sinclair, M., Nandurkar, H., & Philip, J. (2011). The symptom burden of patients with hematological malignancy: A cross-sectional observation study. *Journal of Pain and Symptom Management*, 42(3), 432–442. <https://doi.org/10.1016/j.jpainsymman.2010.12.008>
- Mitchell, S.A. (2018). Palliative care during and following allogeneic hematopoietic stem cell transplantation. *Current Opinion in Supportive and Palliative Care*, 12(1), 58–64. <https://doi.org/10.1097/SPC.0000000000000327>
- Oliver, C. (2012). The relationship between symbolic interactionism and interpretive description. *Qualitative Health Research*, 22(3), 409–415. <https://doi.org/10.1177/1049732311421177>
- Phillippi, J., & Lauderdale, J. (2018). A guide to field notes for qualitative research: Context and conversation. *Qualitative Health Research*, 28(3), 381–388. <https://doi.org/10.1177/1049732317697102>
- Roeland, E., & Ku, G. (2015). Spanning the canyon between stem cell transplantation and palliative care. *Hematology, ASH Education Program*, 2015, 484–489. <https://doi.org/10.1182/asheducation-2015.1.484>
- Ruiz, M., Reynolds, P., Marranzini, R., Khan, A., Ketterer, J., & Brahim, A. (2018). Role of early palliative care interventions

in hematological malignancies and bone marrow transplant patients: Barriers and potential solutions. *American Journal of Hospice and Palliative Care*, 35(11), 1456–1460. <https://doi.org/10.1177/1049909118772849>

Sánchez, A.F., Fuentes Armesto, A.M., Briones Chávez, C., & Ruiz, M. (2020). Revisiting early palliative care for patients with hematologic malignancies and bone marrow transplant: Why the delay? *Cureus*, 12(9), e10504. <https://doi.org/10.7759/cureus.10504>

Sawatzky, R., Porterfield, P., Roberts, D., Lee, J., Liang, L., Reimer-Kirkham, S., . . . Thorne, S. (2017). Embedding a palliative approach in nursing care delivery: An integrated knowledge synthesis. *Advances in Nursing Science*, 40(3), 261–277. <https://doi.org/10.1097/ANS.000000000000163>

Selvaggi, K.J., Vick, J.B., Jessell, S.A., Lister, J., Abrahm, J.L., & Bernacki, R. (2014). Bridging the gap: A palliative care consultation service in a hematological malignancy-bone marrow transplant unit. *Journal of Community and Supportive Oncology*, 12(2), 50–55. <https://doi.org/10.12788/jcs0.0015>

Shaulov, A., Aviv, A., Alcalde, J., & Zimmermann, C. (2022). Early integration of palliative care for patients with haematological malignancies. *British Journal of Haematology*, 199(1), 14–30. <https://doi.org/10.1111/bjh.18286>

Simon, S.T., Pralong, A., Hallek, M., Scheid, C., Holtick, U., & Herling, M. (2021). What is known about palliative care in adult patients with allogeneic stem cell transplantation (allo-SCT)? *Annals of Hematology*, 100(6), 1377–1389. <https://doi.org/10.1007/s00277-021-04538-4>

Suthumpong, C., Tran, D.B., & Ruiz, M. (2021). Perceptions

and misperceptions of early palliative care interventions for patients with hematologic malignancies undergoing bone marrow transplantation. *Cureus*, 13(3), e13876. <https://doi.org/10.7759/cureus.13876>

Temel, J.S., Greer, J.A., El-Jawahri, A., Pirl, W.F., Park, E.R., Jackson, V.A., . . . Ryan, D.P. (2017). Effects of early integrated palliative care in patients with lung and GI cancer: A randomized clinical trial. *Journal of Clinical Oncology*, 35(8), 834–841. <https://doi.org/10.1200/jco.2016.70.5046>

Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., . . . Lynch, T.J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, 363(8), 733–742. <https://doi.org/10.1056/nejmoa1000678>

Thompson Burdine, J., Thorne, S., & Sandhu, G. (2021). Interpretive description: A flexible qualitative methodology for medical education research. *Medical Education*, 55(3), 336–343. <https://doi.org/10.1111/medu.14380>

Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice* (2nd ed.). Routledge.

Wedding, U. (2021). Palliative care of patients with haematological malignancies: Strategies to caregiver overcome difficulties via integrated care. *Lancet Healthy Longevity*, 2(11), e746–e753. [https://doi.org/10.1016/s2666-7568\(21\)00213-0](https://doi.org/10.1016/s2666-7568(21)00213-0)

Zimmermann, C., Swami, N., Krzyzanowska, M., Leighl, N., Rydall, A., Rodin, G., . . . Hannon, B. (2016). Perceptions of palliative care among patients with advanced cancer and their caregivers. *Canadian Medical Association Journal*, 188(10), E217–E227. <https://doi.org/10.1503/cmaj.151171>