

Exploring Palliative Care Provision for Recipients of Allogeneic Hematopoietic Stem Cell Transplantation Who Relapsed

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Prior to the 1970s, a diagnosis of a hematologic malignancy was a death sentence. However, advances in modern medicine have seen hematopoietic stem cell transplantation (HSCT) develop to be the only potentially curative therapy available for many patients facing an otherwise fatal disease (Kasberg, Brister, & Barnard, 2011). Allogeneic hematopoietic stem cell transplantation (alloHSCT) is the use of a human donor's hematopoietic progenitor cells to repopulate bone marrow following a conditioning regime of high-dose chemotherapy and often radiation (Wingard, 2007). The therapy is used to treat a range of malignant and nonmalignant hematologic disorders, including leukemia, lymphoma, myeloma, aplastic anemia, and myelodysplasia (Center of International Blood and Marrow Transplant Research [CIBMTR], 2011). About 25,000 alloHSCTs are performed globally each year, with about 500 of them in Australia and New Zealand (Australasian Bone Marrow Transplant Recipient Registry [ABMTRR], 2010; National Marrow Donor Program, 2011). Those figures continue to rise as developments are made in tissue typing, supportive care, condition regimes, and complication control (Wingard, 2007). Data from Australia report survival rates of 11%–71% 10 years post-alloHSCT (ABMTRR, 2010).

Despite significant advances, relapse remains the most common cause of treatment failure and death following alloHSCT (Barrett & Battiwalla, 2010; CIBMTR, 2011; Maziarz & Slater, 2011; Pavletic et al., 2010). International rates of relapse-associated mortality range from 33%–47% following alloHSCT (CIBMTR, 2011). Post-relapse treatment is complicated by the patient's decreased ability to withstand additional cytotoxic or immune therapy because of previous damage from chemotherapy, the transplantation conditioning regime, complications, or graft-versus-host disease (Barrett & Battiwalla, 2010). Treatment post-relapse is individualized, depending on various patient characteristics, time

Purpose/Objectives: To quantify the characteristics of patients who die in the hospital from relapse after allogeneic hematopoietic stem cell transplantation (alloHSCT), explore palliative care integration and end-of-life (EOL) care, and benchmark standards of care.

Design: Retrospective chart review cohort study; a cross-sectional survey design guided a national survey.

Setting: A chart review was conducted in a large tertiary hospital in Australia. The survey was distributed to leading alloHSCT centers in Australia and New Zealand.

Sample: The chart review sample group was patients in the hematology department who had received an alloHSCT, relapsed, and died in the hospital (N = 40). The survey sample group was the most advanced nurse involved in patient care at each facility (N = 14).

Methods: A quantitative data collection tool created for chart review, as well as patient notes written by the physician, were examined. The quantitative data collection tool was created for the survey, which was conducted via email or telephone.

Main Research Variables: The chart review measured patient demographics, palliative care integration, EOL care, and symptoms. Survey topics included services available, referrals to palliative care services, EOL discussions, and symptom management.

Findings: About half of the patients were seen by the palliative care service. Many patients experienced severe symptoms in the terminal phase. Survey participants felt EOL discussions were left until the terminal phase. Participants believed early palliative care integration was beneficial for patients and their family.

Conclusions: The chart review demonstrated late integration of palliative care and poor standards of EOL care. Survey results reiterated this and reflected that nurses are supportive of earlier integration of palliative care and improving EOL care.

Implications for Nursing: Palliative care should be integrated earlier, and nursing roles have the potential to address unmet needs for these patients.

Key Words: allogeneic hematopoietic stem cell transplantation; relapse; recurrence; palliative care; end-of-life; advance practice nurses

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between alloHSCT and relapse, and type of relapse (Barrett & Battiwalla, 2010). Only a small minority of patients is able to progress to another alloHSCT following relapse (Mielcarek et al., 2007). Some beneficial therapeutic options are available, such as donor lymphocyte infusion, stem cell re-infusion, conventional chemotherapy, cytokine therapy, and withdrawal of immunosuppression (Barrett & Battiwalla, 2010). Treatment post-relapse is often termed “salvage” and holds very little chance of long-term, disease-free survival (Barrett & Battiwalla, 2010; Mielcarek et al., 2007).

The World Health Organization ([WHO], 2002) recommended that palliative care be integrated in all cancer settings to improve quality of life for patients and families facing the physical, psychosocial, and spiritual problems brought on by serious illness. The focus of palliative care is to prevent or reduce suffering caused by life-threatening illness by means of thorough assessment, early identification, and ongoing management of any holistic problems (WHO, 2012). Although palliative care can be provided regardless of the disease stage or the need for other therapies (National Consensus Project, 2012), end-of-life (EOL) care is provided in the terminal phase when death is imminently approaching (DeSpelder & Strickland, 2009). Referral to specialist palliative care services (SPCSs) is increasingly occurring early in the disease trajectory, particularly for patients with complex issues, such as those found in the relapsed alloHSCT population (National Health and Medical Research Council, 2005; National Institute for Clinical Excellence, 2003).

A growing body of literature indicates palliative care has not been successfully integrated into the hematology setting (Howell et al., 2010; McGrath & Holewa, 2007). Reports in the literature also claim palliative care is poorly understood and integrated in the HSCT setting (Chow & Coyle, 2011; Chung, Lyckholm, & Smith, 2009; Cooke, Gemmill, & Grant, 2011; Kelly, Ross, Gray, & Smith, 2000; Lister, 2001; McDonnell & Morris, 1997). The statistically poor prognosis of recipients of alloHSCT who relapsed, combined with factors such as physical and psychosocial effects of previous treatment, limited therapeutic options available, and potential for high symptom burden increases the likelihood of this group requiring SPCSs.

Literature Review

The issues associated with palliative care integration in the broader hematology setting have been well documented (Howell et al., 2010). Because of the unique nature and specific needs of recipients of alloHSCT who relapsed, a literature search was conducted focusing explicitly on this population. A systematic literature search of the following electronic

databases was conducted: CINAHL® (1993–2012), MEDLINE® (1950–2012), PsycINFO (1872–2012), and the Cochrane Library (1999–2012). The search used the following MeSH terms: *allogeneic hematopoietic stem cell transplantation, relapse/recurrence/disease progression, and palliative care*. The term palliative care was substituted with *holistic care, psychosocial care, emotional care, spiritual care, quality-of-life, total pain, family nursing/centered, EOL care, and terminal care* to enhance search findings. The search returned 309 articles, which were sorted by hand. The inclusion criterion was articles regarding the palliative or holistic care of recipients of alloHSCT who relapsed. This search revealed three relevant articles: a case study, a conceptual framework, and a personal recollection.

Cooke et al. (2011) presented a prospective study of evidence-based palliative care education session for patients who had relapsed following alloHSCT. Two advanced practice nurses (APNs) delivered an education intervention to address the lack of palliative care and EOL education and evaluated the impact of this intervention through observations presented in four case studies. APN is an umbrella term for various types of nurses who work in advanced roles with extended practice, including nurse practitioners and clinical nurse specialists (Schober & Affara, 2006). Cooke et al. (2011) highlighted the valuable role APNs can play in addressing the issue of palliative care integration for recipients of alloHSCT who relapsed. Their study also highlighted the value of patient and family education, the unique nature of patients in fluctuating levels of health, the cure-focused nature of current education interventions, and the benefits associated with palliative care integration. Interestingly, Cooke et al. (2011) alluded to patients' reluctance to accept palliative care integration. Patients in two of the four case studies refused to discuss palliative care or acknowledge they were dying. Three of the case studies reported that patients died in the acute care setting, with two of these patients dying in the intensive care unit—one being ventilated. The study also highlighted the need for advanced care planning for high-risk patients to avoid futile treatment and deaths in inappropriate environments (Cooke et al., 2011). Although these practices conflict with the principles of palliative care, these scenarios may highlight reluctance from patients in integrating palliative care and discussing advance care planning. The article described a practical and evidence-based education intervention, but it has limited value as research because of methodologic weakness; the number of patients who received this intervention is unclear, and outcomes were measured via case study reports.

Yoon, Conway, and McMillan (2006) wrote a retrospective concept analysis of patient education that

aimed to propose a framework for the development of palliative education programs for recipients of alloHSCT who relapsed and their families in Korea. The authors stated the concept analysis was based on an extensive review of the literature, but the search strategy was not discussed. The methodology of the concept analysis was implemented as explained and patient education was analyzed; however, this did not translate to a clear framework on developing education sessions, with no meaningful discussion of palliative care for recipients of alloHSCT who relapsed and their families. Yoon et al. (2006) did, however, discuss the benefits of patient education, the focus on cure, and the existence of under-recognized palliative needs, and called for a multidisciplinary approach to patient education for recipients of alloHSCT who relapsed and their families. The authors articulated that a change in health care from a “traditional hierarchical organization” to a team-oriented approach places the responsibility to educate patients on healthcare professionals from many disciplines (Yoon et al., 2006, p. 134).

Lister (2001), a practicing psychiatrist, presented a retrospective autoethnographic case study that described her personal perspective of her daughter’s experience with acute lymphoblastic leukemia and death following relapse after alloHSCT. The personal recollection expressed the collective family experience and outlined positive and negative aspects of the care the family received (Lister, 2001). In evaluating the usefulness of this article as research, the current authors acknowledge that autoethnography challenges the traditional scientific methodology and validity (Ellis, 2004). Although Lister’s account is personal, subjective, and one-sided, her reflection contributes to the understanding of the family and patient’s social and personal lives through lived experience. Issues revealed in this article included the positives associated with palliative care integration and referral to SPCS, the cure-focused nature of the specialty area, and the unique nature of recipients of alloHSCT in fluctuating levels of health. Lister (2001) said that patients and families truly appreciate clinicians who show they care and tell the truth, noting, “It really matters that physicians be able to face what patients have to face” (Lister, 2001, p. 246). The notion of valuing truth-telling in this account sits in opposition to the case studies described by Yoon et al. (2001) and warrants additional exploration. Although this case study is the story of one family, it provides valuable insight and highlights important messages and themes.

As discussed, the key themes identified in the three articles included the cure-focused nature of the specialty; the importance of patient education; the unique nature of recipients of alloHSCT in their disease trajectory (fluctuating levels of health and potential to deteriorate

rapidly); the benefits of palliative care; and roles of the multidisciplinary team, specifically the value of APN roles in integrating palliative care. These themes shed some light on the issue and highlight areas for future research, such as the role of APNs in integrating palliative care and the reluctance of recipients of alloHSCT who relapsed to accept palliative care integration. The paucity of literature regarding palliative care for recipients of alloHSCT who relapsed presented evidence that was low-level, anecdotal, or qualitative and, although useful in some respects, carries limited value as evidence. As a result of the limited amount of evidence found in the literature review, the broader hematology palliative care literature will be referred to throughout the current article when appropriate and relevant.

The current authors’ study was conducted to generate knowledge regarding palliative and EOL care provision for recipients of alloHSCT who relapsed through a two-armed approach—a retrospective chart review and a national survey.

Methods

This study aimed to quantify numbers and characteristics of recipients of alloHSCT who relapsed and died in the hospital setting, as well as highlight current practices of palliative and EOL care provision via a retrospective chart review. A national survey aimed to benchmark the palliative and EOL care provision of recipients of alloHSCT who relapsed in Australia through the insight of APNs. The research question guiding this study was: What are the current standards of palliative and EOL care provision for recipients of alloHSCT who relapsed at a local and national level?

Design and Sample

A descriptive, exploratory design was used to conduct a retrospective chart review examining the characteristics and integration of palliative care for patients that died in the hospital following a relapse from alloHSCT. A cross-sectional survey design was used to gather information from APNs at alloHSCT centers throughout Australia and New Zealand on standards of palliative and EOL care in their units.

The chart review employed purposive sampling of eligible patients that met the following criteria: (a) had a hematologic malignancy, (b) had undergone an alloHSCT, (c) experienced disease recurrence, (d) died in hospital, and (e) were aged older than 16 years. The study did not include patients who had died at home because their care is not captured in accessible medical records. Patients from the Royal Brisbane and Women’s Hospital, a large metropolitan hospital on the eastern coast of Australia, were included in the study.

Transplantation coordinators from the 16 leading alloHSCT centers in Australia and New Zealand registered with ABMTRR were contacted and asked to participate or nominate an appropriate person, which was explained to be the most senior nurse involved in patient care. This group of nurses was experienced and knowledgeable in the specialty area and, therefore, had valuable insight.

Procedure

A data collection tool was developed based on CIBMTR, the foremost international registry that collects data on alloHSCTs, and the Palliative Care Outcomes Collaboration (PCOC), a national benchmarking organization in Australia measuring palliative care provision and outcomes. The data collection tool covered patient demographics, relapse information, palliative care integration, EOL care, death characteristics, and symptoms experienced during the terminal phase. Demographic data aligned with that collected by CIBMTR. Symptoms experienced by patients in the terminal phase were measured via the **PCOC Symptom Severity Score**, a clinician-rated score of symptoms experienced by the patient. Although this is a validated tool from the PCOC, its use is intended to be prospective. In the absence of a validated tool to measure symptoms experienced retrospectively, the tool was modified for retrospective use.

The authors obtained a list of all recipients of alloHSCT, relapses, and deaths from January 2007 to December 2012. Disease recurrence was confirmed via medical officer documentation, and pathology results were checked for confirmation. The charts of eligible patients were then obtained and reviewed using the data collection tool. Approval was obtained from both the Royal Brisbane and Women's Hospital and Griffith University, Brisbane, ethics committees prior to commencing the chart review.

A survey tool was developed and distributed to the major alloHSCT centers in Australia and New Zealand from March 1 to April 30, 2013. The survey consisted of 14 questions designed to measure the professional experience of the respondents, the services available to recipients of alloHSCT who relapsed, and the current patterns of palliative care referrals and EOL discussions from a hematologist. One open-ended question, "What do you think could be changed/improved at your facility in regards to palliative care provision for relapsed alloHSCT patients and their families?" allowed for free-text responses. Although palliative care is recommended early in the disease trajectory for patients with hematologic malignancies, current patterns of referral to SPCS were considered when creating this tool. The tool was reviewed and piloted by five hematology oncology expert clinicians.

Table 1. Transplantation Statistics (N = 613)

Variable	n	%
Total HSCT performed between January 1, 2007, and March 12, 2012	613	100
AlloHSCT performed	434	71
Relapsed from alloHSCT	107	25
Deceased post-relapse	75	70
Died at treating hospital	30	40
Died at other healthcare facility	22	29
Died at home	14	19
Place of death missing	9	12

alloHSCT—allogeneic hematopoietic stem cell transplantation; HSCT—hematopoietic stem cell transplantation

Note. Patients who received an alloHSCT following autologous HSCT are included in deceased statistics of the alloHSCT.

Note. Some patients may have received follow-up care at private facilities, and outcomes are inaccessible.

A list of registered transplantation centers and contacts was obtained from ABMTRR. This small group of transplantation centers conducts the majority of alloHSCTs in Australia and, therefore, would reflect routine practices and referral patterns to SPCS. Transplantation coordinators or nominated APNs were contacted by phone to be provided information on the study and give a contact email address. A cover letter, information sheet, and survey were emailed to potential participants, who then could respond via email or telephone. The cover letter explained the purpose and nature of the study, and the information sheet outlined who was conducting the study, ethical clearance, informed consent, and contact details for the researchers, ethics committee, and the university. Ethical approval was obtained from the university ethics committee before commencing the national survey. Informed consent was provided verbally over the phone or implied by the respondent returning the questionnaire, as approved by the university ethics committee and outlined to participants in the information sheet. Participant confidentiality was maintained at all times through de-identification and anonymous coding of data. The views of the APNs were measured regarding integration of palliative care for recipients of alloHSCT who relapsed and the standards of care their facility provided for physical, psychosocial, and spiritual symptoms.

Data Analysis

Quantitative data were analyzed using Predictive Analytics Software, version 20. Descriptive statistics were used to analyze data from the chart review and survey, and bivariate descriptive statistics were used to test relationships between variables depending on distribution of the data. Qualitative data that emerged from the free-text responses in the survey were analyzed through

Table 2. Sample Characteristics (N = 30)

Characteristic	n
Gender	
Male	19
Female	11
Primary disease	
Acute leukemia	21
Chronic leukemia	4
Myeloproliferative/myelodysplasia disorder	2
Multiple myeloma/plasma cell disorder	2
Lymphoma	—
Other	1
Reason for admission	
Investigation	2
Fevers or infection	7
Respiratory distress	2
Pain	2
Planned treatment (radiation therapy or chemotherapy)	3
Graft-versus-host disease	5
End-of-life care	4
Hematopoietic stem cell transplantation	4
Other	1
Age at death (years)	
16–25	5
26–45	6
46–60	13
61–75	6
Place of death	
Hematology/bone marrow transplantation unit	22
Oncology ward	4
Intensive care unit	4
Primary cause of death	
Recurrence of original malignancy	11
Sepsis	7
Graft-versus-host disease	6
Multi-organ failure	2
Respiratory failure	1
Other	3

a process of content analysis to identify common themes. Correlations were tested extensively between variables using the appropriate tests according to distribution of the data; however, no correlations were found.

Results

From January 2007 to December 2012, 681 HSCTs were performed at the chosen hospital, including stem cell re-infusions but excluding donor lymphocyte infusions. All HSCTs performed for nonhematologic disorders (n = 17) or on children (n = 51) were excluded. Table 1 provides a summary of transplantation statistics. Of the 613 transplantations performed on adults with a hematologic disorder in the five-year study period, 71% were alloHSCT (n = 434). Records show that about 25% of these patients relapsed, and 71% of those patients subsequently died. The patients died at the treating hospital, another healthcare facility (e.g., private facility, hospital closer to home), or home; 12%

(n = 9) had missing data regarding place of death. Of the other healthcare facilities mentioned, it was not possible to identify if these had dedicated palliative care beds or were in the acute care setting. The issue of recipients of alloHSCT who relapsed dying in the acute care setting also was reflected in responses from the national survey.

We often have the palliative bone marrow [transplantation] patients on the ward, an acute care facility, because palliation is left too late and the patient is too unwell to be transferred to a palliative care unit.

Of the 75 deceased recipients of alloHSCT who relapsed, 30 died as inpatients in the treating hospital. All 30 patient charts were reviewed. Table 2 displays basic demographics, reason for final admission, and key characteristics of the patient's death. Time from relapse to death ranged from 3–538 days, with a median time of 72 days. The median length of stay for terminal admission was 18 days, ranging from 1–91 days.

Table 3 presents the data on EOL care. Twenty-four medical records had documented EOL discussions with the patient by a member of the healthcare team, and all records had documentation of EOL discussions with the family or next of kin. According to one survey respondent, the lack of nurses documenting engagement in EOL discussions may not reflect a lack of interest or support for palliative care integration.

Nurses, in general, appear to be much more accepting of the need for palliative care input, and they need to be encouraged by senior staff to be more vocal and to advocate for their patients in getting palliative care involved.

Although all of the patients were listed as “do not resuscitate” before their death, the median time for this change was two days prior to death (range = 1–29 days). Some of the patients were still undergoing active treatment at the time of their death (e.g., observations, IV medications, blood tests), and, for those whom active treatment was ceased, the median time for cessation was one day before death (range = 1–9 days). Survey respondents also reported problems transitioning to the terminal phase.

Changing the focus of care is often done in a haphazard or messy way, or done right at the end of life when there is no question that the patient is dying.

Our hematologists (and I am pretty sure this is a universal hematologist trait) are renowned for leaving end-of-life discussions [until] too late. They push and push treatment onto patients, even patients that are voicing a wish to discontinue

Table 3. End-of-Life (EOL) Care Discussions (N = 30)

Variable	n
EOL discussions documented with patient	24
EOL discussions documented with family	30
EOL discussions documented by treating team	27
EOL discussions documented by nursing staff	12
Patient made "do not resuscitate" request	30
Active treatment ceased before death	21
Patient reviewed by specialist palliative care services	17

treatment. I understand their wish to cure and give patients every wish possible, but . . . I see too often patients and families given false hope by their hematologists, pushing them to try every last treatment possible, despite how futile it might be.

Only 17 of the patients who died were seen by an SPCS, with a median time of one day prior to death (range = 1–277 days). The issue of late referral to an SPCS also was found in the national survey, and free-text responses highlighted the need for support from palliative care specialists. One respondent wrote,

In our facility, this is the major problem. Palliation is left too late and it leads to a plethora of problems. One of the biggest problems is staff seem to get confused in the transition. For example, some nurses are reluctant to provide analgesia because they think it will kill the patient, even though the patient is in the terminal phase.

Table 4 presents the results of clinician-rated symptoms experienced by patients in the terminal phase. These scores were based on documentation from healthcare professionals' medical notes, including free-text entries, pain scores on observation sheets, and use of "as required" medications. Documentation reflected that discussions of psychosocial and spiritual issues were mostly absent. The lack of documentation may reflect a lack of priority on these issues. Survey respondents highlighted a lack of focus on psychosocial and spiritual issues and the potential for nursing roles to meet the need. Other respondents felt SPCS involvement could reduce levels of distress.

I feel the nursing staff could be less task orientated and give patients 5–10 minutes of time to chat and ask, "How are you really doing?" Medical reviews are not in-depth regarding feelings, so flagging emotional and mental issues could be a nursing role.

I believe that early referral and early discussions around palliative and end-of-life care would prevent a lot of distress for the patient, their families, and the staff working with them.

Survey Responses

APNs from 16 transplantation centers were identified, with a response rate of about 88% (n = 14). Respondents included APNs in various roles as presented in Table 5. All had a significant amount of experience, ranging from 5–22 years in the specialty area, with a median time of 12 years. None of the survey respondents reported having an alloHSCT nurse practitioner at their center.

Referral patterns and views regarding referrals to SPCSs are presented in Table 6. Some respondents reported that they felt relapsed patients were not appropriately referred to SPCSs: "Hematologists will often refer to palliative care for symptom management, or only involve for terminal care at late stage."

We tend to use the palliative care team more in pain management; they are part of our hospitals chronic pain management team.

Although some APNs reported many positive encounters with SPCSs, others reported issues.

We are very lucky in our institution that we have a very good relationship with our palliative care team.

Our palliative care team will not take referrals if a patient is on active treatment, which includes blood product support or medications that could have treatment possibility. Our palliative care team [is] also not good at shared care.

Table 4. Clinician-Rated Patient Symptom Severity Scores (N = 30)

Variable	n
Pain	
Absent	10
Mild	5
Moderate	7
Severe	8
Other symptoms^a	
Absent	3
Mild	5
Moderate	9
Severe	13
Psychosocial or spiritual issues	
Absent	19
Mild	2
Moderate	5
Severe	4
Family or caregiver distress	
Absent	14
Mild	7
Moderate	9
Severe	—

^a Other symptoms included nausea, vomiting, anorexia, itch or irritation, constipation, diarrhea, wound, incontinence, fatigue, dyspnea, edema, and delirium.

Table 5. Professional Roles of Survey Respondents (N = 14)

Role	n
Clinical nurse consultant or specialist	10
Nurse unit manager	2
Bone marrow transplantation coordinator	1
Nurse educator	1

Respondents reported the majority of relapsed alloHSCt patients received EOL discussions from their hematologists during the terminal phase (n = 10) or when post-relapse treatment was failing (n = 8). Participants were asked to choose one response; however, in most cases, respondents chose two. Most APNs felt that these discussions should occur after relapse (n = 10). The survey responses indicate nursing staff feel they have little influence over timing of palliative care referrals or EOL discussions.

When patients receive end-of-life discussions from their hematologist is dependent on the consultant.

This hospital seems to be very medically driven, nursing staff voice their concerns; however, it is not taken on board until late in the disease trajectory or in the terminal phase.

In a rating out of 10 with higher scores indicating they agreed and lower scores indicating they disagreed, the respondents indicated that they felt patients and families benefitted from early palliative care referrals (\bar{X} = 8.5, SD = 1.23). However, they did not feel palliative care was effectively integrated for relapsed alloHSCt patients (\bar{X} = 4.5, SD = 2.62). The respondents felt that their center cared well for physical symptoms (\bar{X} = 7.9, SD = 1.69) and psychosocial or spiritual issues (\bar{X} = 7.1, SD = 1.64).

The qualitative data in the free-text responses from the APN were subjected to a process of content analysis by the researcher. The main statements were identified to reflect the core, or what truly represents the respondent's account (Holloway & Wheeler, 2010). The APNs were so passionate about the topic that they responded with a sizeable amount of data. Common themes found in the responses of the APNs included a desire for timely integration of palliative care and EOL discussions, the belief that HSCt is a medically dominated and cure-focused specialty, identification of barriers to accessing SPCs (e.g., stigma, consultant preference), that SPCs often are referred to only for pain management or in the terminal phase, that deaths of relapsed alloHSCt patients are distressing for nurses, and that nurses are more accepting of palliative care and focused on holistic care. They were particularly vocal regarding

the potential for nursing roles to improve integration of palliative care for relapsed alloHSCt patients.

Our center has integrated palliative care earlier when it is nursing driven, in the multidisciplinary team meetings the doctors are listening to the nurses more about when to involve palliative care. Our center allows for a nursing referral to the palliative care nursing team independently of a medical referral.

There is a hospital in Ireland . . . and they have a combined HSCt/palliative care [clinical nurse consultant] who meets patients right at the start of treatment. They have had great patient outcomes from the formation of this role, patients feeling empowered to make decision regarding palliation.

Findings

Data from the chart review define the relapsed alloHSCt population in numbers and characteristics, whereas data from the survey depict a group of highly experienced respondents. Findings of the retrospective chart review correlate with those of the national survey and demonstrate a "too little, too late" approach to palliative care, high symptom burden experienced by patients, and support from nursing staff for improved integration of palliative care for relapsed alloHSCt patients.

Discussion

Demographics

Demographic data from the chart review such as gender, disease, and age were consistent with national and international data (ABMTRR, 2010; CIBMTR, 2011) and are, therefore, representative of the larger population. Demographic data have important implications for care because most patients who relapse from alloHSCt are young to middle-aged and have aggressive, myelosuppressive, potentially refractory disease. These patients have a poor prognosis and are not likely to live for lengthy periods of time post relapse. Not only are these patients complex and require high levels of acute care, but they also are likely to have young to middle-aged families and have not reached retirement age; therefore, serious financial implications exist for families. Families that experience strain at times of change or have a simultaneous pile-up of demands, are at greater risk of stress and inability to cope (Denham & Looman, 2010; Harmon-Hanson & Rowe-Kaakinen, 2005).

Too Little, Too Late

Although the majority of relapsed alloHSCt patients will not survive and have limited time remaining

post-relapse, this study reflects poor integration of palliative care and EOL care provision, as demonstrated in untimely or lack of cessation of active treatment, do not resuscitate orders, SPCS referrals, and EOL discussions. The results of the national survey confirm findings of the chart review. These findings reflect inadequate or lack of advanced care planning, which is increasingly becoming an issue in the current healthcare setting (Thomas & Lobo, 2011). Evidence demonstrates benefits associated with advanced care planning for other vulnerable groups and helps prevent ongoing futile treatment and inappropriate place of death (Thomas & Lobo, 2011). Previous research demonstrates that hematology patients typically die in the acute care setting and have lower referral rates to palliative care services than patients with solid tumors (Ansell et al., 2007; Auret, Bulsara, & Joske, 2003; Maddocks, Bentley, & Sheedy, 1994; Middlewood, Gardner, & Gardner, 2001). Qualitative research demonstrates the acute care setting is not an ideal place for hematology patients to die (McGrath, 2001b, 2002).

The PCOC (2009) recognize late referrals, crisis referral, non-referral, and unnecessary referrals have a potential negative impact on patients and their families. The lack of agreement on when a referral is appropriate has led to the development of the Palliative Care Needs Guidelines. A referral is indicated when the needs of the patient surpass the capacity of the treating team in addressing the basic functions of palliation (PCOC, 2009). Referral to SPCSs often is recommended after diagnosis of a hematologic malignancy because of the high rates of morbidity and mortality found in this population (Smith & Guthrie, 2011). WHO (2002) determined a referral to an SPCS is appropriate at any time in the disease trajectory if a patient with a life-limiting illness (or the patient's significant others) have needs (physical, psychological, social, or spiritual) that are not being met. However, a gap clearly exists between guidelines and actual practice in the care of recipients of alloHSCT who relapsed. SPCSs care holistically for the patient and family, improve symptoms, and aid in the transition to EOL care (Chow & Coyle, 2011). Involvement with an SPCS is associated with enhanced quality of life and mood for patients (Temel et al., 2007, 2010) and improvements in short- and long-term outcomes for caregivers (Abernethy et al., 2008).

Communication regarding death and dying is valued highly by surviving relatives of patients (McGrath, 2001a). Timely, open, and honest communication offers an opportunity for patients to share their thoughts, develop a new kind of hope, discover meaning in death and dying, and make plans for death and EOL care (Chung et al., 2009; Dalgaard, Thorsell, & Delmar, 2010). This sort of autonomy is a key concept in the

Table 6. Specialist Palliative Care Services Referrals (N = 14)

Referral	n
Stage at which most patients receive a referral	
Significant physical symptoms present	8
Significant psychosocial or spiritual issues	1
Relapse or shortly after	1
Post-relapse treatment failing	4
During terminal phase	6
Not at all	2
Stage at which most patients should be referred	
Significant physical symptoms present	7
Significant psychosocial/spiritual issues	1
Upon relapse/shortly after	7
Post-relapse treatment failing	6
During terminal phase	—
Not at all	—

Note. The respondents top two choices were entered, if preferred.

provision of the “good death” (DeSpelder & Strickland, 2009). Anecdotal reports suggest that patients with hematologic malignancies typically prefer to die at home, which—although challenging—is possible with appropriate community services (Boyce, McHugh, & Lyon, 2003; Stockelberg, Lehtola, & Norén, 1997).

Many healthcare professionals may not understand the difference between palliation and EOL care, or have the ability to incorporate cure and palliation simultaneously (Yoon et al., 2006). The practices of one of the SPCSs set in the alloHSCT centers (e.g., did not accept patients receiving blood products, no patients undergoing active treatment) reflect a lack of understanding in this concept or the specific needs of this population.

A study on Australasian hematologist referral patterns to SPCSs demonstrated they overrate their referral patterns but have a reported willingness to refer (Auret et al., 2003). In that study, nursing staff also reported a willingness that was not reflected in their documentation. That suggests other complex issues are impeding palliative care integration and SPCS referrals (e.g., patient readiness), as highlighted in the literature review, or a lack of SPCS tailored to meet the specific needs of recipients of alloHSCT who relapsed, as reported in the national survey.

Symptoms

Documentation in the physician notes demonstrated that pain and other symptoms were not well controlled in the terminal phase of recipients of alloHSCT who relapsed; however, this contrasted with views of the APNs who felt their center cared well for physical symptoms. Previous research on patients with end-stage acute leukemia reported a high incidence of pain in the terminal phase, as well as poor management and documentation

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Knowledge Translation

Despite facing a particularly poor prognosis, patients who relapse following allogeneic hematopoietic stem cell transplantation (alloHSCT) experience inadequate standards of palliative care provision.

Disparity exists between current practices of palliation for patients who relapse following alloHSCT and what advanced practice hematology nurses feel is appropriate.

Advanced practice nurses working in the hematology setting believe they can improve the holistic care of patients who relapse following alloHSCT.

(Stalfelt, Brodin, Pettersson, & Eklof, 2003). Recipients of alloHSCT are at high risk for exhibiting multiple complex symptoms, and poor symptom management has been associated with high levels of distress (Fife, Monahan, Abonour, Wood, & Stump, 2009). Pain can provoke deep emotional, social, and existential suffering for patients and families (Stalfelt et al., 2003).

Timely collaboration with an SPCS with expertise in symptom management would assist hematology specialists in managing symptoms (Chow & Coyle, 2011). "Palliative care involves more than the control of distressing symptoms; it aims to relieve suffering, a subtle concept which extends to the way in which the illness affects that whole individual" (Jeffrey, 1995, p. 123). Pain control and symptom management are the foundation of good palliative care (DeSpelder & Strickland, 2009), along with the concept of total pain, which views pain as not a purely physical experience, but includes the physical, spiritual, psychological, and social aspects of a person's life (Saunders, 1978).

Documentation on psychosocial or spiritual issues was negligible, as were family or caregiver stress in the patient records, and survey data reflected minimal focus on psychosocial and spiritual issues in current practice and in the APNs' opinions. That lack of documentation may indicate that medical and nursing staff do not consider these issues an important aspect of clinical care. The free-text responses indicated APNs placed a strong emphasis on the benefits of palliative care for physical symptom management, particularly pain. However, the current study's authors found it concerning that nursing staff may be undervaluing psychosocial and spiritual care of recipients of alloHSCT who relapsed.

Nursing Roles

The APNs reported significant disparity between perceived practices of hematologists and what they felt was appropriate. The survey indicated nurses were supportive of palliative care integration and early EOL discussions; however, the chart review demonstrated

nursing documentation did not substantiate such support. Interestingly, the variation between self-reported support and actual practice has also been reflected in surveys from hematologists (Auret et al., 2003). The discrepancy between perceived and actual practices might suggest a lack of multidisciplinary team decision making in the care of these patients at a national level. McGrath and Holewa (2007) reported that a "medico-centric, paternalistic, hierarchical" environment is one of the issues preventing integration of palliative care into hematology (p. 83). Such a system lacks democratic multidisciplinary team decision making, and hematology specialists act as gatekeepers to SPCS access (McGrath & Holewa, 2007).

The current study indicates APNs' desire to improve the palliative care integration and EOL care provision for recipients of alloHSCT who relapsed, as well as a belief that nurses can play a key role in addressing this issue. Doing so will be challenging in an area of medicine reported to have a strong curative and biomedical focus (Chow & Coyle, 2011). Nursing's unique contribution to health care lies in the multifaceted commitment to holistic caring values and has the potential to deliver integrated care that helps "restore the science of the whole" (Griffith, 1999, p. 20). APNs undoubtedly have the potential to improve the care of recipients of alloHSCT who relapsed if provided with appropriate education and support, particularly if they have a commitment to stay true to the nursing ethos of holistic care.

Limitations

The chart review findings were based on documentation in medical records and are dependent on the quality of the notes. Because the study reported on a single-site, retrospective chart review of palliative care integration and EOL care provision in a single Australian hospital, additional research in other hospital settings may allow confirmation and exploration of the issues identified. Although this study had a small sample group, data were nonetheless insightful and revealing.

Implications for Practice and Research

The findings of the current study have significant implications for practice. First and foremost, the study has identified shortfalls in the palliative and EOL care of recipients of alloHSCT who relapsed in Australia and New Zealand. Although all relevant healthcare professionals have a responsibility to address this issue, the current study has revealed nurses felt they had an important role to play in improving current care for these patients. Reflecting on the literature review and national survey results, nursing staff may be able improve the palliative and EOL care of recipients of alloHSCT who

relapsed through nurse-led education sessions, nurse-led advanced care planning, nurse-initiated referrals to SPCs, specialist palliative care APN roles within the hematology setting, and greater decision-making power for nurses in team discussions of care goals. In particular, two main areas of potential development have been identified through this study: APN roles and nursing communication.

The scope of nursing practice is being redefined in response to increasingly complex healthcare systems, with APNs becoming recognized as valuable and necessary to meet the needs of patients (Lindeke, Fagerlund, Avery, & Zwygart-Stauffacher, 2010). Hematology—particularly alloHSCT—is a rapidly developing discipline where patients have complex healthcare needs (Knopf, 2011). Nurses have an opportunity to improve current standards in palliative and EOL care provision for recipients of alloHSCT who relapsed by becoming partners and leaders in clinical care (Knopf, 2011). Literature on APN roles in hematology and alloHSCT have focused on the provision of medical tasks; however, as nurses expand their roles, additional skills and responsibilities must be incorporated with the core elements of nursing practice (Kelly, Crotty, Perera, & Dowling, 2010). In fact, many of the values of nursing mirror those of palliative care, including caring; compassion; empathy; listening; focus on the family; patient autonomy; and value on psychosocial, spiritual, and physical issues. The development of APN roles that incorporate palliative care and alloHSCT could be invaluable in meeting the needs of this patient population.

Effective and compassionate communication is the foundation of good palliative nursing (Molloy, Virani, Kelly, & Munevar, 2010). However, communication is a skill developed through education and experience, rather than something naturally occurring. Nurses identify communication as a key area of improvement and report the most difficult areas of communication include discussing bad news and spiritual concerns and talking with physicians about palliative care issues (Molloy et al., 2010). Much of the literature regarding palliative care communication has focused on physician-patient communication and breaking bad news, but nurses are the continual presence in the clinical

settings and often spend significant amounts of time with patients and families helping them to interpret bad news and listening to their concerns (Molloy et al., 2010). Nursing communication with patients on both formal and informal levels has the potential to improve the palliative and EOL care provision of patients that relapse following alloHSCT. Molloy et al. (2010) noted that education on communication is needed in graduate nursing education programs and on an ongoing basis for practicing nurses.

Additional research is warranted to evaluate the impact of any newly established APN roles and benefits associated with education interventions and advanced care planning for this population. Because nurses and hematologists overestimate their support of palliative care, research is required to investigate the complexities with transitioning a patient group with such acute needs to palliation. Exploration is needed into patient and family perspectives of relapse post-alloHSCT and their readiness to receive palliative care or referral to SPCs. Value exists in examining whether current SPCs are well suited to the specific needs of recipients of alloHSCT who relapsed. Future prospective studies, and those gathering information from patients or hematology specialists on these topics, would be beneficial.

Conclusion

The issue of poorly integrated palliative and EOL care for relapsed patients will escalate as more alloHSCTs are performed each year. Although advances are continually made, healthcare providers must strive to provide best-practice palliative and EOL care for the many patients that fail to stay in remission following alloHSCT.

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