

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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