Palliative Care of Hematopoietic Cell Transplant Recipients and Families

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Objectives: *To provide support for the early integration of palliative care into the care of hematopoietic cell transplant (HCT) recipients and families with the goal of improving care.*

Data Sources: *Journal articles and on-line databases.*

Conclusion: *Early integration of palliative care for HCT recipients at high risk for complex symptom clusters, non-relapse mortality, or relapse offers an opportunity to clarify goals of care, advanced care planning, and improving the quality of care for both recipients and families.*

Implications for Nursing Practice: *The palliative care service can support the HCT nurse in providing complex care to HCT recipients who are faced with significant side effects, toxicities, and complications of transplant.*

Key Words: *Hematopoietic cell transplantation, palliative care, advanced care planning, goals of care*

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Hematopoietic cell transplantation (HCT) is a potentially curative therapy for a number of malignant and non-malignant diseases. In the United States it is estimated that more than 18,000 transplants are performed each year.[1] The number of individuals surviving 5 or more years is estimated at 150,000.[2] The primary indications for autologous HCT are multiple myeloma and non-Hodgkin's lymphoma and for allogeneic HCT acute leukemia and myelodysplastic syndromes.[1] While outcomes have improved significantly since the first successful allogeneic transplant performed in 1968 for a child with an immunodeficiency syndrome,[3] HCT remains a high-risk medical procedure. One-year non-relapse mortality (NRM) in

the autologous setting ranges from 5% to 15%.[1,4] NRM for allogeneic transplant following high-dose conditioning regimens approaches 40% with deaths secondary to infections, graft versus host disease (GVHD), and organ failure.[5,6] In allogeneic transplant, the NRM with reduced-intensity conditioning is lower than that seen following high-dose conditioning regimens, but the benefit appears to be offset by a higher risk of relapse.[7,8]

The journey of survivorship is long and arduous and, even when things go well, there are significant physical and psychosocial challenges for both HCT survivors and their families. The focus of this article is the integration of palliative care into the comprehensive management of adult HCT recipients and families. A detailed review of the principles of HCT, types of grafts, and complications following HCT is beyond the scope of this article. However, the reader is referred to "Hematologic Malignancies in Adults" for a thorough background.[9] The focus of palliative care is on symptom management, improving quality of life, clarifying goals of care, and supporting the patient and family. This article will discuss the commonly observed side effects and toxicities from high-dose conditioning regimens and outcomes of HCT. The opportunities to integrate palliative care into the management of HCT recipients will be highlighted. Lastly, the article will describe one transplant center's experience in maximizing the appropriate use of intensive care for acutely ill HCT recipients.

Palliative Care Models

Palliative care is defined as specialized interdisciplinary care for patients with serious illness that focuses on relief of symptoms and psychological distress.[10] Palliative care has been endorsed as a best practice in oncology by the American Society of Clinical Oncology and is incorporated into the clinical practice guidelines of the European Society for Medical Oncology and the Society for Surgical Oncology.[11] It is recommended that palliative care be delivered within the continuum of comprehensive cancer care, which would include care of individuals undergoing HCT.[11] There is an expanding body of evidence that supports the advantages of early integration of palliative care. Cited benefits include improved quality of life, symptom burden, mood, patient satisfaction, and decreased caregiver burden. Palliative care can lower costs and reduce rates of unnecessary hospitalizations, diagnostic and treatment interventions, and non-beneficial intensive care.[12-15]

Rangachari and Smith[16] describe primary, secondary, and tertiary palliative care delivery models. *Primary palliative care* refers to the basic skills and competency required of all physicians, nurses, and other healthcare providers that is delivered by the primary team, in this case the HCT team. Secondary palliative care is provided by clinicians with specialized expertise in palliative medicine who provide consultation to the primary care team. The tertiary model refers to academic medical centers where palliative care specialists address the most complex cases and engage in research and education.[17] In a quaternary level of care, the palliative care team assumes full responsibility for the patient. The secondary model of palliative care delivery represents the most common use of the palliative care team.

There are several challenges to fully integrating palliative care into the care of HCT recipients and oncology in general. One barrier is the shortage of trained palliative medicine providers.[11] The provision of palliative care exclusively by palliative care specialists is neither sustainable nor desirable.[18] Given the shortage of palliative care specialists, one goal of the palliative care service in the consultant role is to support the HCT team in the provision of primary palliative care. The physicians in the Blood and Marrow Transplant (BMT) Program at Stanford University Medical Center primarily consult the palliative care medicine team for help in managing complex symptom clusters. A second barrier is the lack of financial support and reimbursement infrastructure to support early palliative care interventions.[11] Despite a growing body of evidence to support early palliative care, a third barrier is the perception that palliative care is synonymous with hospice or end-of-life care. The association between palliative care and hospice or end-of-life care is common among physicians, nurses, patients, and families. The concept that palliative care is appropriate for any patient with a serious or chronic illness across the trajectory of illness is difficult for clinicians to embrace.

High-dose Conditioning Therapy Sequelae

Care of HCT recipients and families is delivered by a multidisciplinary HCT team that delivers primary palliative care focused on curing the