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Palliative Care During and Following Allogeneic Hematopoietic Stem Cell Transplantation (HSCT)

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Abstract

Purpose of Review—The purpose of this review is to synthesize recent literature regarding the provision of palliative care to patients during and following allogeneic HSCT, highlighting factors which mediate impairments in health-related quality of life in this patient population, and the intervention approaches and models of care delivery that clinicians can consider to address unmet needs for palliative care and to strengthen patient and family resiliency.

Recent Findings—Provision of palliative care simultaneous with the delivery of treatment directed at the underlying malignancy has emerged as a recommended practice for patients with advanced cancer and high symptom burden, and a recent randomized trial demonstrates the effectiveness of early palliative care in reducing some of the symptom burden and mood disturbances associated with HSCT. Although more research is needed, there is an expanding body of research-tested interventions to ameliorate the physical and psychological morbidity of HSCT across the transplant trajectory.

Summary—Palliative care interventions delivered by an interdisciplinary team that includes transplant clinicians and palliative care across the HSCT trajectory can alleviate physical and psychological morbidity, thereby improving the patient and family experience of HSCT.

Keywords

Hematopoietic stem cell transplantation; palliative care; patient-reported outcomes

Introduction

Hematopoietic stem cell transplantation (HSCT) is an aggressive and potentially curative therapy for many malignant and non-malignant diseases. It is used with increasing frequency worldwide(1). High dose conditioning regimens and transplant complications such as acute and chronic graft-versus-host disease (GVHD), infection, graft failure, relapse, and late treatment effects, produce significant toxicities, resultant symptom burden and functional

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losses, impairments in health-related quality of life (HRQL), and physical, emotional and spiritual suffering across the transplant continuum. While HSCT holds the potential to cure approximately 50–80% of patients who undergo this procedure, 50% of those who die after HSCT will die within the first 6 months after transplant(2).

With its focus on symptom management, quality of life, patient and family support, and emphasis on facilitating advance care planning, clarifying goals of care, and promoting shared decision-making, palliative care has much to offer to patients undergoing HSCT. Provision of palliative care simultaneous with the delivery of treatment directed at the underlying malignancy has emerged as a recommended practice for patients with advanced cancer and high symptom burden(3).

While this recommendation is supported by evidence from randomized trials that demonstrate the generally beneficial effects of palliative care on both patients with cancer and their caregivers(4), comparatively few studies have examined the effects of palliative care specifically in patients being treated for a hematologic malignancy, including those undergoing HSCT(5). However, a recent randomized trial of simultaneous palliative care in patients undergoing hematopoietic stem cell transplantation demonstrates that delivery of a palliative care intervention (addressing primarily physical and psychological symptoms) concurrent with transplant care resulted in improved outcomes in quality of life, mood, and symptom burden(6). These results provide a strong rationale for the integration of specialized palliative care team members into the interdisciplinary transplant team, comparable to the routine involvement of nutrition, social work, pharmacy and rehabilitation medicine(7, 8).

At the same time, there may be attitudinal and logistical barriers to the routine integration of appropriate components of palliative care in care of HSCT recipients, including the often unpredictable clinical course of HSCT, the absence of a clear transition between the curative and palliative phase of treatment, the limited training and experience members of transplant teams have had comanaging patients with palliative care teams, and the lack of accurate and validated prognosticators of short term results of critical illness in individual patients(9–12).

This review synthesizes recent literature relevant to the provision of palliative care to patients during and following allogeneic HSCT, highlighting factors which mediate impairments in health-related quality of life in this patient population, and the intervention approaches that palliative care and transplant clinicians can consider to address these issues.

Overview of the Physical and Psychological Demands Across the Transplant Continuum

Physical demands of HSCT are many and include symptom burden and associated functional impairments that are attributable to the high-dose conditioning regimen(13), persistent and late treatment effects(14), as well as procedural pain and anxiety from bone marrow biopsies and lumbar punctures(15), and the variable and often severe symptom profile of acute and chronic GVHD and its treatment with immunosuppression(16, 17).

The burden of unmet psychological needs is similarly high among adults undergoing HSCT and in HSCT survivors, and includes anxiety, depression, psychological distress (including worry, uncertainty, and fear of recurrence), post-traumatic stress disorder, treatment-related financial burden, and cognitive impairment(5, 18–22). There is evidence that psychological issues are underrecognized and undertreated(18, 23, 24).

Symptom burden and psychological issues have negative consequences in terms of impairments in quality of life, limitations in physical, social and vocational functioning, non-adherence, and increased length of stay. The transition back to the workplace, school and family roles may be adversely affected by symptom burden and physical limitations associated with persistent and late treatment effects and acute and chronic GVHD. Career goals, life priorities, and spiritual well-being may have been altered, both positively and negatively, by the transplant experience(25–28).

Using PRO Measures to Identify Palliative/Supportive Care Needs During and Following HSCT

HRQL is a global construct that has evolved in response to the need to evaluate a patient's overall sense of well-being and how it relates to disease and treatment. Beliefs, expectations and experiences influence an individual's assessment of their HRQL, and thus the individual should be considered the best source of information about their HRQL. This has been affirmed by the World Health Organization in their definition of quality of life as an individual's perception of their position in life, in the context of the culture and values systems in their life, and in relation to their goals, expectations, standards and concerns(29). Essential to the concept of HRQL is the notion that the meaning of one's current situation is essential; two individuals may have the same objective state of health but they may perceive their HRQL quite differently. Several different models of HRQL applicable to the context of HSCT have been proposed(30, 31). There is a wide array of valid and reliable PRO measures available to screen for or evaluate various aspects of HSCT-relevant aspects of HRQL including symptoms, functional status, emotional distress, financial burden, psychological concerns such as post-traumatic stress disorder, and emotional, social or spiritual well-being.

Considerations in selecting a measure include its psychometric properties, availability in multiple languages, the mode of administration (e.g. in-person interview, self-administered questionnaire), barriers to accessing the measure (cost, permissions), respondent burden, ease of scoring, and interpretability (normed scores, clinically important difference, interpretive cut points for diagnosis).

Many of the available PRO measures have not been well-tested in HSCT recipients. Validated HSCT-specific modules are available for the Functional Assessment of Cancer Treatment-General(32) and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30(33). There are two available inventories to evaluate GVHD-associated symptom burden(34, 35). The Cancer and Treatment Distress (CTXD) is a 22-item measure of the overall level of distress and the factors contributing to distress. It has six subscales, reflecting uncertainty, family strain, health burden, finances, loss of identity, and medical demands. The CTXD has demonstrated strong measurement properties in capturing psychological distress before and after HSCT(36, 37). A recent report provides evidence for the content validity of the Patient-Reported Outcomes Measurement Information (PROMIS) Profile-29 to assess symptoms and function in HSCT survivors(38). Consensus on a core measure set for HSCT is still evolving(39).

Supportive and Palliative Interventions to Improve HRQL, Symptoms and Well-being

Guidelines relevant for managing the common supportive care needs in patients undergoing HSCT are available from organizations such as the Oncology Nursing Society, National Comprehensive Cancer Network (NCCN), Multinational Association of Supportive Care in Cancer, American Psychosocial Oncology Society, and the American Society of Clinical Oncology, although few palliative and supportive care interventions have been specifically tested in HSCT recipients. Several recent reviews synthesize the evidence for the use of exercise and rehabilitation(40–42), yoga(43), and meditation(44), non-pharmacologic management of fatigue(45), management of neurocognitive dysfunction(46), sleep disruption(47), nutritional compromise(48), and mood disturbance and psychological distress(49), and the use of complementary and integrative treatments(50). Evidence-based guidelines for the surveillance and management of late effects and other supportive care concerns in HSCT survivors(51) and in HSCT survivors with cGVHD(52, 53) have been endorsed internationally.

Based on evidence of the prevalence of symptoms, psychological distress, including post-traumatic stress disorder, financial burden, and impairments in physical functioning during the following HSCT, it is reasonable to recommend that screening and appropriate assessment of these components of physical and psychological health and well-being should occur at regular intervals and at least annually during transplant follow-up(54). There is evidence that routine screening and evaluation using multidimensional measures can detect psychological distress, and can distinguish the domains contributing to distress (anxiety, depression, uncertainty, interactions with the treatment team), that may be amenable to tailored management including referrals to social work, financial specialists, case managers, mental health professionals or spiritual counselors(55–58).

Relatively few interventions to manage symptom burden, impairments in physical function, and psychological distress have been formally tested in HSCT recipients. Effective symptom management together with use of effective coping strategies are essential to improving other long-term outcomes including physical function, emotional well-being and depressed mood(13, 59). There is evidence to suggest that interventions to promote spiritual well-being may also favorably affect quality of life, symptom distress, depression and anxiety(60). Although not tested in HSCT recipients, there is evidence in advanced solid tumors and in cancer survivors that psychotherapy to enhance one's sense of meaning in life may provide benefits across multiple outcome domains(61–64).

Information needs are prominent across the HSCT trajectory, with a recent study suggesting that there are significant unmet needs for information about late effects and post-transplant quality of life(65). Mobile health technologies may offer new approaches to provide HSCT recipients and their families with information and tools for self-management support across the transplant trajectory(66, 67).

Advance care planning is a central feature of palliative care. Advance care planning is a process that includes both provision of medical information about available choices, discussions of the goals of care and the patient's healthcare-related values, preferences and priorities, and shared decision-making and documentation of the patient's priorities for provision of future healthcare(68). Tierney et al. have described the important role of palliative care specialty providers, including advanced practice nurses, in communicating prognostic information to patients and families, participating in routine periodic family meetings, and clarifying the goals of care, particularly when there is a deteriorating clinical picture or transfer to the ICU(69). Guidelines for conducting effective family meetings to provide information, psychological and practical support, and to strengthen shared decision-making have been described, and are applicable to the provision of palliative care to HSCT recipients(70). Enhanced training of the HSCT interdisciplinary team to deliver advance care planning interventions and to integrate them into their clinical workflow would serve to strengthen implementation of advance care planning activities in HSCT settings.

Models for Integration of Palliative Care into HSCT

There is preliminary evidence that the delivery of palliative care alongside the technically complex and aggressive treatment of hematologic diseases with HSCT is feasible, acceptable to patients and clinicians, and likely to favorably affect outcomes. El-Jawahri et al. randomly assigned patients hospitalized for HSCT to usual care or a palliative care consultation with a minimum of twice weekly follow-up visits by a palliative care consultant during the hospital stay(6). The palliative care intervention focused on symptom management and strengthening coping skills. The palliative care intervention lowered anxiety and mitigated the worsening in depression and symptom burden seen in the usual care group. At three-month follow-up, the intervention group had less depression and better quality of life, and their family caregivers had lower depression scores(6). These improvements were sustained at six-month follow-up; transplant recipients who received the palliative care intervention had lower levels of depression and post-traumatic stress disorder (PTSD). Importantly, the improved psychological outcomes were mediated by the lower levels of anxiety and symptom burden that patients in the palliative care intervention arm experienced during the HSCT hospitalization(71). A consultative model of palliative care provision for HSCT recipients has also been shown to be acceptable to transplant clinicians, and to improve pain management outcomes and process outcomes such as hospice referral and documentation of goals of care discussion(72). Models for routine implementation of a pre-transplant palliative care consultation and monthly visits by palliative care have been shown in small single arm studies to be feasible, acceptable, and to improve mode and hope(73), and that embedding palliative care specialists within the transplant team increases the number palliative consultations requested for HSCT recipients(74).

Provision of palliative care simultaneous with HSCT using either a consultative model or an embedded model with routine inclusion of a formalized palliative care intervention for all HSCT recipients is feasible and acceptable during and immediately following HSCT, and improves outcomes for patients and their family caregivers. There is also some evidence to suggest that models where the palliative care specialist is integrated into the team could also serve to increase the capacity of non-palliative specialist team members to offer palliative care interventions such as goals of care discussions(75). Additional research is needed to test other models of concurrent palliative care such as co-rounding(76, 77) and standardized triggers for palliative care referral(78) that have been found to be effective in improving clinical and health services outcomes as well as quality indicators in the solid tumor setting.

Following HSCT, fragmentation of care between transplant center and oncology and primary care providers in the home community may contributed to overlooked palliative care needs. Transplant survivors typically experience several transitions in care settings and care providers. These transitions create shifts in the roles of care providers, as well as in the responsibilities of patients and their informal caregivers, and whenever such changes occur, discontinuity in care may develop. Survivorship clinics may help to address the fragmentation of care. Integration of palliative care into HSCT survivorship care has had limited formal study(79), and deserves focused examination.

Triggers for Early Palliative Care Involvement

Given the significant workforce challenges in palliative care, it is unlikely that every patient undergoing HSCT can be seen by a palliative care specialist. LeBlanc et al. have proposed evidence-based triggers for early palliative care interventions in patients undergoing treatment of a hematologic malignancy(10). These triggers include patients with significant and/or refractory symptom burden, complex family and psychosocial needs, patients with an unfavorable prognosis and/or multiple comorbidities which would portend a poor outcome, and patients with significant psychological distress or who demonstrate limited coping skills. Beyond these clinical characteristics, they and others identify hospitalization for HSCT, disease relapse, worsening prognosis as reflected by organ failure, life-threatening complications, or transfer to the intensive care unit, and the development of clinically severe chronic GVHD as sentinel transitional events along the transplant trajectory where inclusion of palliative care has been shown to improve the experience for both patients and their family caregivers(69, 74).

Measuring the Quality of Palliative Care in HSCT

With respect to quality metrics, the Measuring What Matters (MWM) indicators can be used as an audit tool by transplant teams to identify gaps in the provision of palliative care to HSCT recipients. For example, in a recent study, hematology patients were less likely to receive routine screening for physical symptoms and to have their emotional needs discussed(80). MWM indicators can serve to highlight areas for quality improvement, and document the effects of inclusion of specialty palliative care providers in the provision of HSCT care.

Limitations

There has been limited research examining the effects of different models of providing palliative care to patients undergoing HSCT, there is more robust evidence regarding the prominent needs for supportive and palliative care in this patient population(81–85). Continued research is needed to develop and psychometrically validate instruments for screening and evaluation of unmet palliative care needs in HSCT recipients, to comparatively evaluate population-specific models for the delivery of palliative care to this patient population, and to test and tailor for use across the HSCT trajectory those palliative interventions that have demonstrated effectiveness in managing symptoms, reducing psychological distress, and promoting shared decision-making in other cancer treatment contexts.

Conclusions

Palliative care focuses on symptom management, psychological support and strengthening advance care planning and shared decision-making. Approaches drawn from palliative care can be applied across the HSCT treatment trajectory through survivorship and end of life to improve outcomes for both patients and their families. Integration of palliative care specialists into the interdisciplinary transplant team either as consultants or as a routine component of the care pathway for managing HSCT recipients helps to ensure that this patient population has access to services that address their significant needs for palliation, thereby optimizing both disease-control and quality of life outcomes.

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Key Points

- With its focus on reducing physical and emotional suffering and promoting shared decision-making, palliative care has much to offer to patients undergoing HSCT.
- Provision of palliative care simultaneous with HSCT is feasible, acceptable to patients and clinicians, and effective in improving symptom burden and improving mood during and in the 6 months after transplantation
- An expanding body of evidence from randomized trials performed during and following HSCT supports the effectiveness of exercise, rehabilitation, complementary and integrative therapies, meditation, and yoga in managing symptom burden, fatigue, sleep disturbance, neurocognitive dysfunction, nutritional deficits, impairments in functional status, and mood disturbances and psychological distress.