

# Early Intervention With Transplantation Recipients to Improve Access to and Knowledge of Palliative Care

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**Background:** The literature continues to support that patients undergoing hematopoietic stem cell transplantation (HSCT) receive early consultation with palliative care specialists. Nurses can be leaders in this initiative.

**Objectives:** This quality improvement project was conducted to determine whether patients undergoing HSCT, who were provided an early consultation with palliative care, would report increased knowledge and increased ability to access palliative services.

**Methods:** Patients completed a postintervention questionnaire in which the majority of patients reported that they had increased knowledge about palliative care and learned how to access their services.

**Findings:** Patient comments were positive about the successful intervention of early palliative care. The palliative care team, however, revealed a different view of the situation, showing that patients were often overwhelmed, anxious, and sometimes did not remember the content of their meetings.

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Palliative care improves the quality of life of patients and families facing chronic life-threatening illnesses. This is accomplished by using assessment and early identification to prevent suffering and provide relief for physical, psychosocial, and spiritual issues (Bruera & Hui, 2010). Noteworthy benefits of palliative care include symptom management, coping strategies, education for patients about their illness, and increased understanding of the prognosis (Yoong et al., 2013).

Patients, families, and the healthcare team benefit from knowledge of palliative care services. Temel et al. (2010) reported that significant improvements were noted in quality of life and mood when palliative care was initiated early in a population of patients with lung cancer. Patients with lung cancer who were in a palliative care setting tended to have less aggressive care at the end of life. In addition, they had significantly longer survival. A better understanding of palliative care and what it can provide may make patients and families more receptive.

Therefore, the purpose of this quality improvement project was to initiate early palliative care services (prior to initial

admission) for patients undergoing hematopoietic stem cell transplantation (HSCT) and to improve access to and knowledge of palliative care from the initial admission throughout the cancer care journey. The intervention occurred in the form of two meetings between a patient (family members were included if present) and a palliative care nurse practitioner. Following the palliative care intervention, patients reported a significant improvement in their knowledge about palliative care. In addition, 92% of patients felt that they had the information needed to access palliative care in the future.

## Background

The American College of Surgeons Commission on Cancer (CoC) included palliative care recommendations in the *Cancer Program Standards 2012: Ensuring Patient-Centered Care*. The new recommendations stated that “the availability of palliative care services is an essential component of cancer care, beginning at the time of diagnosis and being continuously available throughout treatment, surveillance, and, when applicable, during bereavement” (CoC, 2012, p. 70). A 2011

public opinion research poll conducted by the Center to Advance Palliative Care (CAPC) showed that more than 70% of patients were not at all knowledgeable about palliative care. However, once informed, 95% of patients stated that education on palliative care is important, and 92% said that palliative care should be accessible to patients and families dealing with serious illness (CAPC, 2011).

Palliative care is being increasingly supported in the literature to include care starting at diagnosis and continuing throughout the course of treatment. The Oncology Nursing Society ([ONS], 2014) and the American Society of Clinical Oncology ([ASCO], 2013) both support this practice. ASCO has taken the clinical position that oncologists should offer palliative care alongside treatment for patients with metastatic cancer. ASCO (2013) stated that the goal of palliative care is to support a patient's "physical, emotional, spiritual, and social needs from diagnosis through treatment and beyond" (p. 1). ONS (2014) stated that "all patients with cancer benefit from palliative care and palliative care should begin at the time of diagnosis and continue throughout bereavement" (p. 1).

The National Comprehensive Cancer Network ([NCCN], 2014) published practice guidelines for palliative care, which state that patients who have limited treatment options meet the criteria for early consultation with palliative care specialists. NCCN (2014) also identified patient characteristics to meet the criteria for early consultation, including patients with the potential for frequent readmissions or multiple complications that may require intensive care, higher distress scores, and negative social circumstances (e.g., financial, spiritual, social support issues)—issues that are all common in the HSCT population.

In the authors' institution, the University of Michigan Health System, no systematic method was in place for providing palliative care to patients undergoing HSCT. Therefore, a practice gap existed between the current practice for patients undergoing HSCT and the recommended evidenced-based guidelines from NCCN (2014). Based on the authors' observations and experiences with the HSCT population, patients and families often struggle with treatment decisions that develop

throughout their transplantation journey. Early initiation of palliative care and ongoing support about treatment decision making would support the overall quality of care for patients and smooth their passage through the blood and marrow transplantation journey. Perrin and Kazanowski (2015) reported that nurses should be leading the palliative care initiative in educating patients and families.

A retrospective chart review yielded data from adult patients admitted to University of Michigan Health System for allogeneic hematopoietic transplantation (N = 45) during a six-month period (September 2010 to February 2011). Of the 45 patients reviewed, only 5% had a palliative care consultation at any point in time. The disparity between the recommendations found in the current literature and the actual percentage of patients with palliative care consultations prompted a quality improvement project.

## Methods

The multidisciplinary project team was comprised of a staff nurse, chaplain, and clinical nurse specialist, as well as nurse practitioners in the palliative care department who provided the intervention meetings. Institutional review board approval

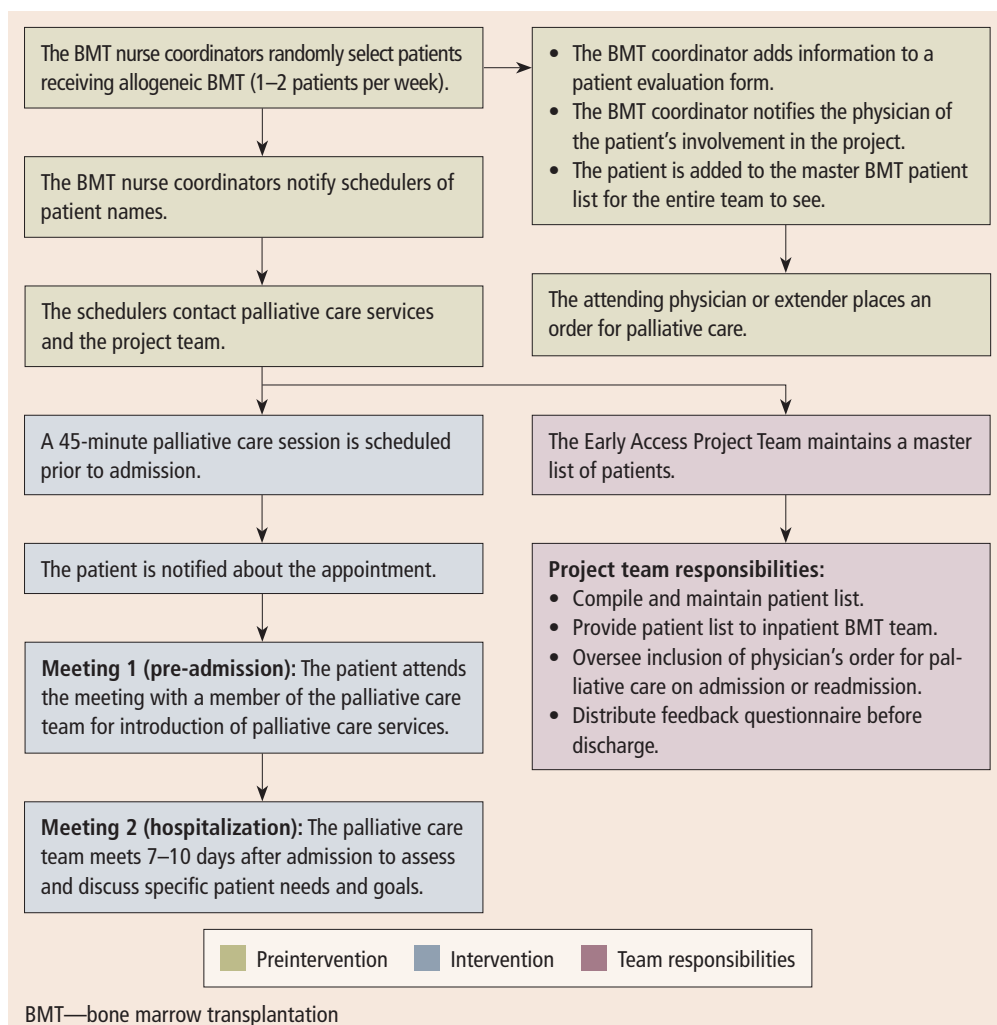
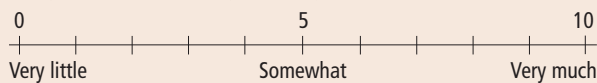


FIGURE 1. Process Flow Chart for Early Access to Palliative Care Services

1. How much has your knowledge and understanding of palliative care and their services increased since your first meeting? Place an X along the line to indicate your rating from 0–10.



2. Please share what you learned through meeting with palliative care. Check all that apply.

- What palliative care is
- Developing your goals of care
- How to access palliative care
- Advanced care planning
- Shared decision making
- Other

3. Do you feel that you have the information you need to access palliative care easily?

- Yes
- No

4. Please share any additional comments you have about palliative care.

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**FIGURE 2. Early Access to Palliative Care Pilot: Patient Questionnaire**

was obtained for this project. Patients undergoing allogeneic HSCT admitted to the University of Michigan Health System were the only population included in the project. Inclusion criterion was planned admission for an allogeneic HSCT for patients diagnosed with various hematologic malignancies that were characterized as serious, life-threatening conditions. Patients were randomly selected by the HSCT clinic coordinators to participate in this project to gain knowledge about the benefits of palliative care and how to access these services. A descriptive method of analysis was used for the project to share the perspectives and opinions of this patient population.

Prior to admission, the outpatient HSCT scheduling staff contacted eligible patients and caregivers to request the initial meeting with palliative care. This meeting was scheduled along with other meetings that were required prior to transplantation. At this meeting, the palliative care team nurse practitioner assessed the patient's knowledge of palliative care, introduced advanced care planning, and gave the patient written educational materials. The second meeting with the nurse practitioner was scheduled during admission, about eight days after transplantation, and focused on individualization of the plan of care for the patient. Discussions were guided by the nurse practitioner but varied in content depending on the needs of the patient and family. Finally, patients were given information about the support services and palliative care clinic to access after discharge, if desired.

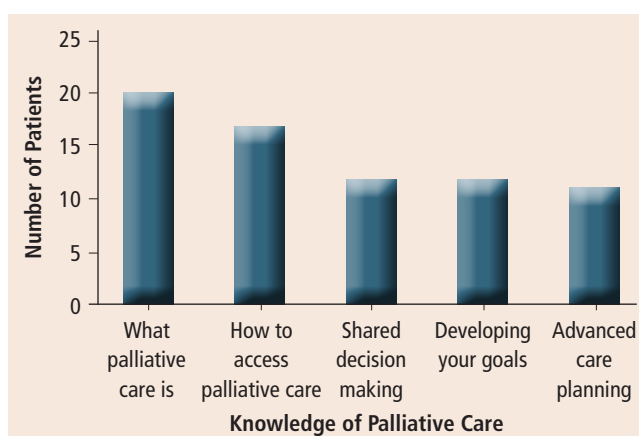
During admission, it was necessary to obtain a physician's order to consult palliative care. This was key for communication with the palliative care team, acknowledging that

the patient was now hospitalized. The staff nurse followed up with the medical bone marrow team to ensure the order was placed. Communication between the ordering team and staff nurse included an ongoing checklist of patients currently enrolled in the project. Under the scope of this initial order, nursing could request additional follow-up visits by palliative care as needed. Additional visits were available on request by the patient or family, social worker, chaplain, or other healthcare providers involved in the patient's care. The project team was organized by a process flow chart (see Figure 1), which identified and explained the roles of all participants. This allowed the multidisciplinary colleagues to understand the overall structure of the project and understand their roles for patient care. Development of scripts to guide phone conversations and supportive materials for the scheduling staff was completed to make the process run efficiently.

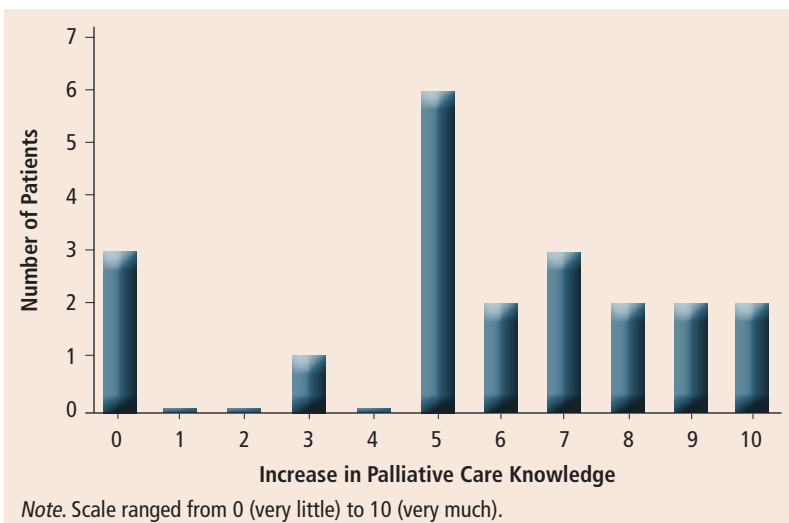
During the palliative care meetings, the team focused on specific interventions about advanced care planning such as maintaining hope, helping the patient to prepare for the unexpected, and reinforcing their advance directives and wishes/goals of care. They also intervened with consistent supportive communication for the patient and caregiver, including discussions about the patient's values and hopes for transplantation, what is meaningful to them, collaboration about goals of care, and anticipatory guidance with provision of resources and referrals. Perceptions of palliative care were measured by a questionnaire given to patients 14 days after transplantation to evaluate their opinions about their knowledge of and access to palliative care (see Figure 2). Exit interviews were conducted with each of the two nurse practitioners within the palliative care team at the University of Michigan Health System to gain insight about the process and outcomes of the project.

## Discussion

Twenty-five patients participated in the project to completion. One additional patient was unable to complete the questionnaire because of mentation changes. Six patients were identified but unable to participate for a variety of reasons, including three patients with relapsed disease, two



**FIGURE 3. Knowledge Gained by Patients Regarding Available Palliative Care Services (N = 25)**



**FIGURE 4. Patient Report of Palliative Care Knowledge (N = 25)**

patients with missed appointments, and one patient who refused to participate.

According to the patient questionnaire data, improvement was seen in the patients' knowledge about palliative care and their ability to access palliative care for themselves. When asked, "How much has your knowledge of palliative care increased," 83% of patients (n = 21) reported that their knowledge of palliative care increased in a range from "somewhat" to "very much." Following the intervention, 92% of patients (n = 23) felt that they had the information needed to access palliative care in the future. As affirmed by the learning and knowledge gained through meeting with palliative care, patients and families reported positively that they gained knowledge about shared decision making, developing goals, and advanced care planning (see Figures 3 and 4). Patients and families were given the opportunity to share comments and most reflected a positive experience with learning about palliative care.

### Reflections From Interviews With the Palliative Care Team

At the project's completion, two Early Access Project Team members (the CNS and RN) met with each nurse practitioner separately to solicit their individual perceptions of the patient meetings (see Figure 5). The nurse practitioners reported that stress and fear were exhibited by many of the patients during the palliative care meetings; therefore, the patients' overall readiness to learn and ability to comprehend the information was uncertain. The palliative care team acknowledged the risks, fears, and level of stress exhibited by patients and families, and offered time to process, share, and express feelings, thoughts, and concerns. Encouragement and support were offered, and they assured patients and families that palliative care would be available—inpatient and outpatient—as needed.

The nurse practitioners shared with the project team that early exposure to palliative care is a beneficial part of patient care, and that "we are not even scratching the surface." They also sensed that "patients did not fully comprehend the risks

of the upcoming [HSCT]," and they were "not sure if the [HSCT] patient population is ready, or perceive the need to learn at the time of initial meeting." Often, during the initial meeting, the patients exhibited fear, anxiety, and a feeling of being scared to proceed with the transplantation, or a feeling of dread and uncertainty and concern for the procedure. The palliative care team made a recommendation to "pause and settle in before pushing the education, information, and brochures [because] a lot comes out when you wait for it and let the patient lead the way." The nurse practitioners reflected on the overall experience and categorized it as "definitely useful."

### Observations From the Palliative Care Team

The palliative care team observed that patients were experiencing difficulty retaining information in the session prior to admission. There were many contributing factors. These sessions were often coupled with other appointments, and patients were often overwhelmed. Their ability to understand the educational content was compromised because of the effect of their hospitalization and the stress of HSCT. It was the impression of the nurse practitioners that the patients were in survival mode, trying to manage all that was being required of them, including the hospital admission, consents for treatment, learning about what symptoms to expect, and the emotional distress of their diagnosis. Despite these limitations, patients still managed to increase their knowledge about palliative care and understand how to access the service.

### Recommendations From the Palliative Care Team

Based on the time spent with patients undergoing HSCT, the palliative care team recommended that the timing of the first meeting be adjusted. "[The] earlier the better, as early as the initial discussion of bone marrow transplant consultation . . . to capture those high-risk patients that never make it to transplant" but could still benefit from palliative care support. Patients appeared to be under great stress during the second meeting as well. The second meeting took place about eight days after HSCT, and many patients were exhibiting side effects related to their treatment course, fatigue, and weakness. It was recommended that

- What is your assessment of patients' readiness to learn for pre-admission appointment?
- Were patients receptive to learning?
- Who did you engage with more: patient, caregiver, or both?
- Do you think early palliative care exposure is beneficial? How?
- Based on this experience, do you have any suggestions on an appropriate time to have this discussion?
- Do you feel that patients and caregivers gained knowledge about palliative care to help with the treatment course?

**FIGURE 5. Sample Exit Interview Questions for Nurse Practitioners**

## Implications for Practice

- ▶ Introduce palliative care early in the hospitalization process so patients may become knowledgeable about palliative care services.
- ▶ Continue to provide information about palliative care to patients and their family members throughout the course of care.
- ▶ Become educated about the principles and benefits of palliative care.

the second meeting should occur during the chemotherapy conditioning regimen before transplantation, prior to onset of HSCT-related side effects.

### Limitations

Structuring the questionnaire as only a post-test was a limitation of this project. In retrospect, a pretest of the patient's knowledge about palliative care would have better evaluated the effectiveness of the intervention. Budget limitations related to staffing from the palliative care team limited the number of patients enrolled in the project each week to one or two patients; therefore, the small sample size limits the applicability of these findings. Given the availability of additional resources and time, every admitted patient would have participated in this quality improvement project.

## Implications for Nursing Practice

This project brought to light the continued need to provide palliative care information to patients and families throughout the cancer journey and to determine when they are best able to hear this information. Patients, families, and healthcare providers should recognize the value of an early introduction to palliative care in the course of treatment and during life-prolonging treatment (Greer, Jackson, Meier, & Temel, 2013). Bedside nurses have opportunities to assess patients' needs and knowledge. If nursing staff feel empowered to teach palliative care principles, they could play an important role in assessing a patient's readiness to discuss palliative care and then provide patient education about the benefits of palliative care at the appropriate time for patients and families.

## Conclusion

From the literature, the benefit of early palliative care discussions for patients undergoing HSCT is clear. Temel et al. (2010) proved that, when palliative care was initiated early for patients with lung cancer, quality of life and mood improved, and patients experienced longer survival. The authors of the current article believe that the integration of palliative care discussions prior to hospitalization for patients undergoing HSCT is essential. Patients can gain the necessary knowledge and learn how to access palliative

care through early consultation. Nurses can play a key role in assessing patients' emotional and intellectual readiness to learn about palliative care. Perhaps targeting key family caregivers as learners would be a strategy to use in the future. This project suggests a benefit to the palliative care team introducing palliative care early in the course of transplantation care, but that the most effective timing to deliver the information still has yet to be determined.

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