

Bridging the gap: a palliative care consultation service in a hematological malignancy–bone marrow transplant unit

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Background There is often a lack of collaboration between hematological malignancy–bone marrow transplantation (HM-BMT) units and palliative care (PC) services. In this paper, we describe a quality improvement project that sought to close this gap at a tertiary care hospital in Pittsburgh, Pennsylvania, from August 2006 to May 2010.

Design and methods Through a needs assessment, didactic lectures, clinical consultation, and the informal presence of PC clinicians, the team created a palliative care service in HM-BMT unit of the Western Pennsylvania Hospital in Pittsburgh. The following data were collected for each consult: referral reason, daily pain assessments, whether or not a “goals of care” conversation took place, and hospice enrollment. Lastly, satisfaction surveys were administered.

Results During the program, 392 PC consultations were provided to 256 unique patients. Of these 256 patients, the PC clinicians documented the first goals of care conversations in 67% of patients (n = 172). Of the 278 consults referred for pain, 70% (n = 194) involved reports of unacceptable or very unacceptable pain at baseline. Sixty-six percent (n = 129) of these 194 consults involved reports of pain that was acceptable or very acceptable within 48 hours of consultation. In addition, the hospice referral rate grew from a preimplementation rate of 5% to 41% (n = 67) of 165 patients who died during the period of program implementation. Lastly, hematological oncologists reported high levels of satisfaction with the program.

Limitations The main limitation of this project is that it was a single institution study.

Conclusion The successful integration of a PC team into a hematological malignancy unit suggests great potential for positive interdisciplinary collaboration between these two fields.

Treatments of hematological malignancies have advanced greatly in recent years, but the risk of morbidity and mortality from these diseases and their treatments remains high. Palliative care (PC) practitioners therefore have much to offer these patients and their families. There is often a lack of collaboration, however, between the practitioners of palliative care and those who care for patients with hematological malignancies or who do bone marrow transplantation.^{1,2} In this article, we report on a successful quality improvement program that sought to close this gap by creating a PC service and embedding PC providers into a hematological malignancy unit. We discuss our approach, project design, and assessment of the program, along with future implications for collaboration between hematological oncology and palliative care.

There is a recognized paucity of literature exploring the intersections of palliative care and hematological oncology, but patients with hematological malignancies have many needs that can be ameliorated by PC experts.^{1,3} Symptoms of hematological cancer may include pain, dyspnea, nausea, vomiting, fatigue, mucositis, diarrhea, anorexia, and delirium,³ and these problems may be exacerbated or even initiated by treatments for the diseases.⁴ Repeated bone marrow biopsies and aspirations are an additional stressor for patients with hematological malignancies.⁵ Evidence suggests that disease progression and the continued use of antineoplastic therapies (with their associated side effects) in patients who are often weak and malnourished may enhance the likelihood that these patients will die in a hospital.³

Accepted for publication July 18, 2013. Correspondence: Kathy Selvaggi MD, MS; Kathy_Selvaggi@dfci.harvard.edu. Disclosures: The authors have no disclosures. *Dr. Selvaggi was at the Division of Palliative Medicine for the West Penn Allegheny Health System, Pittsburgh, Pennsylvania, at the time that this project was completed. JCSO 2014;12:50-55. ©2014 Frontline Medical Communications. DOI 10.12788/jcso.0015.

Patients who undergo allogeneic bone marrow transplantation are at increased risk because of the potential complication of graft-versus-host disease, which typically causes symptoms such as nausea, anorexia, watery and/or bloody diarrhea, and severe abdominal pain.⁶ In addition, patients with cancer have high rates of psychological complications, including depression marked by hopelessness, guilt, decreased satisfaction with life, and/or loss of self esteem.⁷⁻⁹ Additional layers of social and spiritual distress in transplant patients may arise from periods of isolation related to their immunocompromised states.¹⁰⁻¹²

Despite these potential needs for PC services, patients with hematological cancers are known to have less access to PC specialists than do patients with solid tumors, and when palliative care is available, such patients tend to be seen later in the disease course.^{3,4,13-17} Although the effects of PC consultation among hematological patients has not been studied extensively, some evidence suggests an association between the lack of palliative care and adverse outcomes, including greater patient and family distress^{4,18} and poor bereavement outcomes.⁴ In addition, integrating palliative care may address problems experienced by the partners of patients who have undergone hematopoietic stem cell transplantation, including more fatigue, cognitive dysfunction, depressive symptoms, and sleep and sexual problems, compared with healthy controls.¹² Health care providers, particularly nurses, are at increased risk for high levels of stress and professional burnout when they care for this patient population, and evidence suggests that palliative care may help with their problems as well.¹⁹ In addition, early access to palliative care among patients with other types of malignancies has been shown to improve quality of life and mood, and to increase the length of survival,^{20,21} as well as decrease costs.²² The same certainly may be true for the integration of palliative care into hematological oncology.

There are many explanations for the lack of integration of PC clinicians into hematological malignancy–bone marrow transplant (HM-BMT) teams. First, because these teams generally include social workers and may also include psychiatrists specializing in the needs of these patients, the HM-BMT teams may not want to add “another team” (such as a PC team) to address problems they feel their team already has the expertise to address.¹⁶ In addition, HM-BMT clinicians may mistakenly equate palliative care with hospice care. Some HM-BMT clinicians may not be aware that PC aims to relieve suffering and improve the quality of life for seriously ill patients alongside their curative treatments, whereas enrollment in hospice indicates, generally, that no further attempts at curative or life-prolonging treatment will be made.¹ We aimed to overcome some of these barriers by creating a PC service in an HM-BMT unit in a hospital where no PC program previously existed.

Project design a methods

Location

The HM-BMT unit at the Western Pennsylvania Hospital (part of the West Penn Allegheny Health System) in Pittsburgh is a 20-bed inpatient unit, with over 500 admissions per year. The unit staff includes 6 attending physicians, 12 fellows, 30 nurses, 1 care coordinator, 1 social worker, and 2 transplant coordinators. All patients on the unit have hematological malignancies and some are stem cell transplantation patients. All attending physicians on the unit performed transplants, although some did more than others.

Needs assessment

The PC program was initiated in August 2006. From August through October 2006, we (KJS and SAJ) performed semistructured interviews of the hematological malignancy unit staff to determine their understanding of the role of PC consultation and whether they viewed palliative care as different from hospice. In addition, informal conversations revealed that those managing the care of patients with hematological malignancies equated palliative care with end-of-life care and hospice. One physician, for example, specified that they called for palliative care when felt that “nothing more could be done.”

Didactic education

The PC team gave a series of 10 1-hour palliative care conferences on pain and nonpain symptom management; grief; bereavement; goals of care discussions; end-of-life care; and hospice. These lectures were given multiple times over several months, and were open to physicians, nurses, social workers, care coordinators, and the hospital chaplain. The sessions were offered at varying times of the day, so staff from different shifts would be able to attend. Each session had 2 through 10 participants.

Clinical consultation and education

Once clinicians were aware of the availability of PC services, oncologists began referring patients to the PC clinicians and standard palliative care consults were performed. Frequently, the PC team joined the attending HM-BMT physician and fellows who made rounds on these patients. Each patient who had been referred for conversations regarding goals of care was discussed with the primary hematology physician to understand the trajectory of the patient’s illness, to determine the patient’s understanding of the prognosis, and to know if any goals of care discussions had been initiated in the outpatient setting. Members of the HM-BMT team were invited to participate in discussions with patients and families regarding end-of-life decision making, referrals to hospice, and goals of care. The HM-BMT fellows were responsible for the primary management of these patients and were available 24 hours a day to assist with medication regimens and titrations.

TABLE 1 Patient characteristics

Characteristic	No. of patients (N = 256)
Sex, n (%)	
Men	127 (50)
Mean age, 60 y (range, 22-85)	–
Women	129 (50)
Mean age, 60 y (range, 20-89)	–
Ethnicity, n	
White	234
African American	17
Middle Eastern	1
Latino	2
Asian American	2

In addition to the process described above, the PC team attended the HM-BMT team's weekly interdisciplinary meetings, at which each patient was discussed; the PC team made treatment recommendations and communicated these to the assigned nurse, hematology fellow, and social worker. One member of the PC team was present on the unit approximately 2 hours every day for informal discussions and face-to-face communication.

Patient assessment

For each patient who had been referred for a PC consultation, the reason(s) for the referral and an assessment of pain level acceptability (very acceptable, acceptable, or not acceptable) was documented. As clinically indicated, daily assessments of pain characteristics were noted in the medical record. In addition, goals of care discussions, hospice enrollment, and confirmation of code status were documented.

Data regarding the acceptability, usefulness, and effectiveness of the program among clinicians were also col-

lected through satisfaction surveys 18 months after program initiation. These surveys asked clinicians to rate, on a Likert scale of 1 to 5, the ease of referral to a PC consult (1 = not easy at all, 5 = extremely easy), the ease of communication between the HM-BMT and PC teams (1 = not easy at all, 5 = extremely easy), the extent to which the PC team provided useful recommendations for pain management (1 = little or none, 5 = all that was needed), and the usefulness of teaching and emotional support for the HM-BMT team (1 = little or none, 5 = all that was needed). Physicians were also asked to rate, on a Likert scale of 1 to 5, the helpfulness of the PC team in addressing the problems of pain management, nausea, constipation, dyspnea, delirium, depression/anxiety, end-of-life decision making, family distress, and home care planning (1 = not helpful at all, 5 = extremely helpful). Lastly, physicians were asked to rate, on a Likert scale of 1 to 5, their overall satisfaction with the PC service (1 = not satisfied at all, 5 = extremely satisfied), and how important they felt it was to have a palliative medicine service team for the bone marrow transplant patients (1 = not important at all, 5 = extremely important).

This pilot project explored the feasibility of embedding a PC team into an HM-BMT unit. No identifying data were collected from patients, and all patients were expected to benefit directly from the knowledge to be gained. There was no funding source for this project.

Results

Between August 2006 and May 2010, 392 consults were performed on 256 unique patients with hematological malignancies. In all, 41% (n = 161) of these consults were for post-stem cell transplantation patients and half of the consults were for leukemia patients (n = 196). Of the 256 unique patients seen in consultation, the median period of follow-up for all 392 consults was 4 days, with a mean of 8 days of follow-up. Some 50% (n = 129) of the unique patients seen were female, and 91.4% (n = 234) were white (Tables 1 and 2).

Reasons for referral

In all, 71% of consult referrals (n = 278) were for pain control, and 44% (n = 172) were for discussion of goals of care. Patients could be referred to the PC team for multiple reasons, leading to summative percentages greater than 100%. A smaller number of consultations addressed one or more of the following: constipation, anxiety, nausea/vomiting, anxiety, depression, and delirium. It was not uncommon that several other symptoms were present in addition to those that prompted the treating physician to refer the patient for a PC consultation.

Pain control

In all, 70% (n = 194) of the 278 consultations done by the PC team for pain control were for patients who had unac-

TABLE 2 Consult characteristics of patients referred for palliative care consultations

Characteristic	No. of consultations (%) ^{a,b}
Disease	
Leukemia	196 (50)
Lymphoma	101 (26)
Multiple myeloma	51 (13)
Myelodysplastic syndrome	20 (5.1)
Treatment status	
Poststem cell transplant	161 (41)
Reason for consult	
Pain	278 (71)
Goals of care	172 (44)

^aN = 392. ^bPatients could be referred to the palliative care team for multiple reasons, leading to summative percentages greater than 100%.

ceptable or very unacceptable pain at baseline. Of these 194 consults, 66% (n = 129) reported pain levels that were acceptable or very acceptable within 48 hours of consultation (Figure 1). Twenty percent (n = 39) of these patients referred for pain control because they initially had unacceptable or very unacceptable pain, later had reports of pain levels that were acceptable within 72 to 96 hours of the initial consultation. Of these, 13% (n = 26) had difficult pain syndromes that were not well controlled within 96 hours.

Goals of care discussions

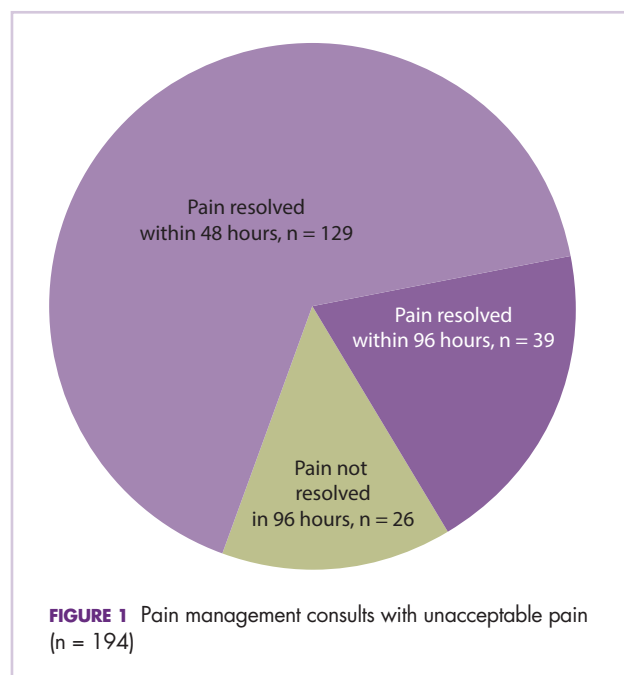
Palliative care consultants documented the first inpatient “goals of care” conversation in 67% (n = 172) of the 256 patients they saw. Of these 172 patients, 60% (n = 104) subsequently had a Do Not Resuscitate/Do Not Intubate (DNR/DNI) order entered during their stay in the hospital (Figure 2). Overall, 41% (n = 104) of the 256 unique patients seen by our program had a DNR/DNI order entered over the course of this initiative. Of the 165 patients who had consults and who died during the period of program implementation, 41% (n = 67) were referred to hospice programs (Figure 3); the decision was always made with both the PC service and the HM-BMT services collaborating, so it is impossible to say who initiated the referral. Prior to the implementation of the program, fewer than 5% of HM-BMT unit patients who died were referred to hospice by the hematology physicians. (At the time, a consultative PC service did not exist.) One of the potential barriers to referring patients with hematological malignancy to hospice is the need for occasional blood transfusion and antibiotics. To overcome this barrier, “carve-outs” for transfusions were available at certain hospices on a one-to-one basis, allowing for the referral of patients that might have otherwise been denied access to hospice.

Satisfaction surveys

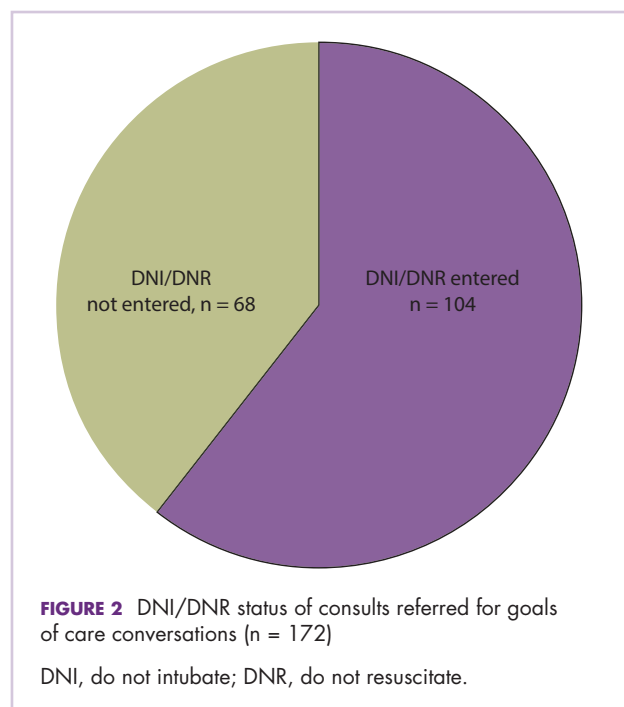
Of the 18 HM-BMT physicians who participated in the program, 78% (n = 14) completed satisfaction surveys. When asked to rate their experiences with the PC service, 100% of the completing physicians said they were “extremely satisfied” with their overall experience with the PC service. In addition, 100% of completing physicians reported that the PC service was “extremely helpful” in both pain management and family distress amelioration. Further details regarding the physician survey can be seen in Table 3. A total of 60% of physicians identified the management of delirium, depression, and anxiety symptoms as needing improvement; these symptoms are frequently manifested in this patient population.¹¹

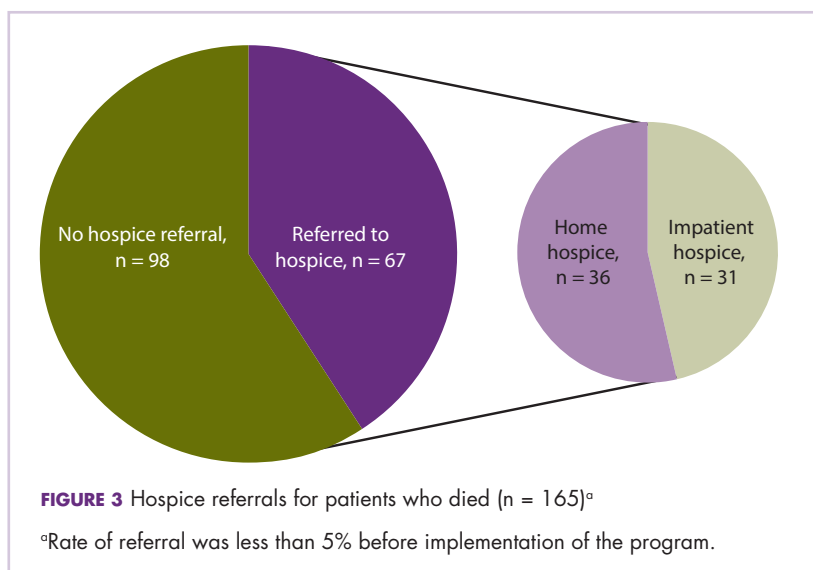
Discussion and future implications

Overall, this quality improvement effort resulted in pain control for many patients, increased the numbers of documented conversations on goals of care, and significantly in-



creased the number of referrals to hospice for HM-BMT patients. In addition, the program was reviewed positively by hematology oncology clinicians, suggesting that other programs and hospitals may succeed in embedding PC physicians into HM-BMT units. The program collected limited data to assess the success of the program; future studies might collect additional data, such as cost effectiveness and the number of rehospitalizations. In a landmark study of the early introduction of palliative care, patients





with advanced lung cancer who had PC access had better outcomes – including better quality of life, fewer symptoms of depression and anxiety, and significantly longer survival – than did patients without PC access.²⁰ There are few data, however, on the utility of PC consultation in patients with hematological malignancies, or on the impact of palliative care in patients receiving stem cell transplantation; these would be fruitful areas for future study.

That 41% (n = 104) of the 256 unique patients seen by our program had a DNR/DNI order entered over the course of this initiative suggests that the consultations may have helped many patients avoid unwanted intensive care unit (ICU) admissions and resuscitation efforts; in other medical centers, the implementation of PC services has led to a reduction in the proportion of inpatient deaths occurring in the ICU²³ and a reduction in emergency department visits and hospitalizations.²⁰ Although we did not collect

financial data, previous evidence suggests that palliative care leads to the more efficient use of resources²⁴ and to savings for patients and families.^{22,25,26} The number of patients who had a DNR/DNI order suggests a potential cost savings as well. A future study or quality improvement initiative might explore this potential cost savings.

Despite the overall success of our program, there were several challenges for the PC providers in this patient population. Hematological malignancies are a heterogeneous set of diseases with a pace of disease trajectory that is often more rapid than that of solid tumors. The absence of reliable clinical indicators of refractory disease, as well as the unpredictability of their treatment regimens and their associated morbidity and mortality (i.e. sepsis, hemorrhage)

when cure is the goal, make prognostication very different from that of solid tumor oncology.^{3,4} It is important for the PC consultant to understand that palliative transfusions and antibiotics play a prominent role in this patient population, that curative intent may seem more distinct from PC goals than in other malignancies, and that there are long-term relationships between the patient and the oncologist.^{3,4} Palliative care as a field, therefore, must approach collaboration with hematology with these caveats well understood and respected.

In addition to these difficulties, it is important to note that some of our success resulted from particulars of the situation at hand, and this represents a limitation of our program. The leader of this initiative (KJS) is board certified both in oncology and in hospice and palliative medicine. She practiced as a transplantation physician during the early part of her career, giving her significant insight into the

culture of HM-BMT, and she had completed a fellowship in palliative medicine immediately before the period of program implementation. With the current PC shortage,²⁷ it is not feasible to expect that every hematological oncology unit will be able to access this kind of expertise. However, we hope that such individuals may take the lead in implementing these types of programs, and through intensive up-front educational efforts such as ours, they may raise the bar of generalist PC

TABLE 3 Results of physicians' satisfaction survey^{a,b}

Assessment	Mean	Scale
Ease of referral	4.8	1 = not easy at all
Ease of communication	4.9	5 = extremely easy
Useful pain management recommendations	5.0	1 = little or none
Non-pain symptom management clinical recommendations	4.8	5 = all that was needed
Helpfulness of psychosocial support recommendations	4.9	1 = not helpful at all
Helpfulness of end-of-life care discussions	4.9	5 = extremely helpful
Helpfulness addressing family distress	5.0	
Helpfulness addressing home care planning	5.0	
Overall satisfaction with the palliative care service	5.0	1 = not satisfied at all 5 = extremely satisfied
Importance of palliative care for patients with HM-BMT	4.9	1 = not important at all 5 = extremely important

^aPercentage of surveys completed was 78% (14 of 18 HM-BMT physicians). ^bIncluded open-ended question, What areas could be improved? Response: Treatment of delirium, depression, and anxiety.

competency. Indeed, this appears to be what took place during our program; by the end of the period of program implementation, hematological oncologists consulted and trusted the palliative care nurse practitioner (SAJ) – who had no oncology-specific training – just as they did the clinician with highly specific HM-BMT and PC training.

Our program sought to enhance collaboration between our two medical specialties; a similar willingness to refer hematology patients to palliative care has recently been reported elsewhere.²⁸ Recently, a single institution study by Corbett et al. documented that 11.6% of all referrals received during a 4-year period were from hematology, and that such hematology referrals increased each year, as did the proportions of patients referred for symptom control.²⁹ The researchers concluded that close ties between PC and hematology resulted in earlier referrals and more time for clinicians to address complex issues. They also noted an association between PC involvement and death outside the ICU. These findings corroborate our own and are encouraging.

Overall, by creating a PC consultation service in an HM-BMT unit of a tertiary care hospital in Pittsburgh, we increased the number of hospice referrals on the unit, conducted the first discussions of goals of care with a majority of patients seen, and succeeded in controlling the pain of the great majority of patients seen by the PC providers. Our PC program was well received by the HM-BMT physicians, as revealed by the satisfaction surveys, especially in the areas of communication skills, psychosocial support, and end-of-life care discussions. Future studies may confirm our hypotheses that PC involvement leads to improved quality of life for patients, shorter hospital stays, and more efficient use of health care dollars. We hope to see more such programs and research at the intersection of hematological oncology and palliative care in the near future.

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