Editorial

Palliative care for patients with hematological malignancies—beyond specialist care

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In the field of oncology, hematologic malignancies (HM) are unique in their presentation, complications and treatment. As tissue for diagnosis and reevaluation is commonly more easily obtained (i.e., peripheral blood, bone marrow), it has also been easier to develop new and exciting treatments including aggressive chemotherapy, targeted treatment and cellular therapies. In an effort to enable aggressive treatment, good supportive care including: transfusion of blood products, anti-bacterial and anti-fungal therapy as well as better tools for early detection of invasive infections, are an integral part of many of these treatments.

Despite this early and broad interest in supportive care as a tool to assist cancer treatment, the integration of early and effective palliative care (PC) for patients with HM has been slow and many HM patients undergo aggressive interventions at the end-of-life (EOL). Multiple causes for this state of affairs have been suggested including the unpredictable trajectory of these diseases, especially the difficulty in recognizing EOL in HM, as well as attitudinal and policy barriers (1,2). In addition, data proving the benefit of this practice in HM are still sparse. Randomized controlled trials have shown the benefits of early PC provided by PC specialists in inpatient settings such as high-risk acute leukemia (3) as well as hematopoietic stem cell transplantation (4,5), however other HMs have not been adequately studied.

To improve PC for patients with HM, improved access to specialist PC will not be sufficient. While specialist PC may be the gold standard, in most centers, availability is limited. To truly improve access to PC for HM patients, secondary PC provided by hemato-oncology teams will need to improve as well. A few measures will be needed to achieve this lofty goal, including increased awareness, better research, improved PC training and policy changes.

Awareness

Clearly, awareness of a palliative approach to care as a beneficial tool alongside life-prolonging treatments is a critical first step in improving the PC administered by hemato-oncologists. Encouragingly, despite previous reports of hesitancy by hemato-oncologists (6-8), there seems to be a growing understanding that early integration of PC may be beneficial for HM patients. Recent studies have shown improvements in referral to specialist PC for patients with HM across settings although many HM patients continue to experience aggressive care at the EOL (9,10). We are hopeful that as seen in other fields of medicine, we will see

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ever greater numbers of hemato-oncologists with a deep understanding of the importance of PC to the care of HM patients and a willingness to improve their PC expertise.

Research

Both PC specialty and hemato-oncology teams will benefit from a better understanding of the unique physical, psychosocial and spiritual challenges facing HM patients and clinicians and how they may be addressed. A recent study by Chan *et al.* describes the landscape of PC challenges in the setting of HM and review recommendations for the supportive and PC of these patients (11). The review includes issues critical to HM such as transfusions of blood products, infection management and use of growth factors as well as more general issues such as symptom management all of which may serve hemato-oncology teams seeking to improve PC skills. However, in comparison with solid tumors, studies of PC in the hematology literature are far less common, leading to gaps in knowledge (1,12). For example, there is a lack of strong evidence for use of blood products and growth factors for alleviation of symptoms in advanced HM rather than to support aggressive treatment, as reviewed by Chan *et al.* (11). Evidence for effective models of PC provision for HM patients have lagged behind those for solid tumors. These gaps in knowledge should be seen as a call for further research and indeed some progress has been made in recent years. Data as to the impact of targeted and cellular treatments on quality of life and EOL outcomes are beginning to be reported (13). In addition, new prognostic tools which are being developed and validated for use in HM may assist patients and clinicians to reach shared decisions better reflecting patient values and needs (14,15). Future studies should also take into consideration the variety of HM as well as the varying trajectories of these diseases. Patients with aggressive diseases characterized by sudden and extreme changes in clinical status in an otherwise curable disease may have different needs entailing different models of care than those with indolent, prolonged, albeit incurable disease (12).

Training

Adequate PC training should be provided for hemato-oncology trainees and specialists. While beyond the scope of Chan *et al.*'s review, it is imperative that hemato-oncology teams seeking to improve PC skills look beyond the narrow focus of symptom management alone to include all PC competencies (16). In particular, the ability of PC practitioners to elicit patient values and goals of care in the face of clinical uncertainty should be embraced and refined in the setting of HM. Here too, different diseases and trajectories face different challenges to clarifying goals and preserving patient autonomy and dignity. The curriculum of PC training for hemato-oncologists needs to be defined and proliferated with an emphasis on the unique challenges facing HM patients.

Policy

Multiple regulatory barriers have impeded HM patient's access to PC. Advocacy for palliative use of blood products in inpatient and outpatient hospice settings are underway which may improve the ability of clinicians to provide adequate symptom management for patients with HM across settings. A major step forward in this field could come from adopting home transfusion of blood products (17). As quality of life for many HM patients facing recurrent febrile neutropenia may entail broad-spectrum antimicrobial treatment as well as imaging and microbial sampling even in the setting of hospice care (18), policy barriers should not impede such efforts if they lie within the patient's goals of care.

As hemato-oncology teams move forward from PC reluctance to a more open approach, PC providers and hemato-oncology teams will need to collaborate better in advancing research and training as well as changing policy. Primarily, we will need to look beyond specialist PC and create models of care that support secondary PC in addition to designing and implementing effective training programs to ultimately improve quality of life for HM patients.

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