



# Improving quantity and quality of life: supportive and palliative care for patients with advanced hematologic malignancies

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Immense progress has been made in the understanding of, and treatment for, hematologic malignancies (HMs). Since the Food and Drug Administration approval of imatinib for the treatment of chronic myelogenous leukemia in early 2001 (1), the field has seen tremendous growth. More recent advances include engineered T-cell treatments, such as chimeric antigen receptor T-cells, and immunotherapies such as checkpoint inhibitors targeting programmed cell death ligand 1 (PD-L1) (2,3). While such developments have been found to lead to durable responses and improved survival, the integration of palliative and supportive care (SC) for patients with HMs has not kept pace. Symptom burden and treatment-related toxicities are known to be high in patients with HMs (4-8). Morbidity and mortality associated with HMs and their treatment continue to be high (9).

In their article on SC and symptom management in patients with advanced HMs, Chan *et al.* (10) provide a comprehensive review of the SC needs of patients with HMs for palliative care (PC) and hematology-oncology providers. As has been well-described in the literature elsewhere, patients with HMs face significant physical and psychosocial symptom burden, which are at least comparable to patients with solid tumors (5-7). Such symptoms include, but are not limited to, pain, nausea and vomiting, anorexia, fatigue,

drowsiness, dyspnea, delirium, depression, and anxiety (5-7). Tsatsou *et al.* (11) conducted a systematic review to examine the unmet SC needs of patients with HMs. The authors found that patients with HMs experienced an array of unmet needs including physical, emotional, practical, informational, and relational needs.

Chan *et al.* (10) offer suggestions for management of disease and treatment-related symptoms, including: transfusion of blood products, prevention and management of infectious complications, and in-depth pain and symptom management. Elements of PC support, such as end-of-life (EOL) care and adopting a palliative approach to care, are mentioned and importantly, the authors conclude that further studies regarding the PC management for patients with advanced HMs are needed. It has been well documented that the terms “supportive care” and “palliative care” are often used interchangeably in the literature as well as clinically (12,13) and yet there are important distinctions that differentiate each term. The roots of PC can be traced back to the work of Canadian surgical oncologist Dr. Balfour Mount who has been credited with coining the term “palliative care” in the 1970s (14). In the ensuing years, the definition of PC has evolved and as per the World Health Organization, PC is now considered ‘applicable early in the

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course of illness, in conjunction with other therapies that are intended to prolong life...' (15). In 2017, the American Society of Clinical Oncology (ASCO) published guidelines on the integration of PC in oncology and emphasized that PC is important for patients with advanced disease as well as those facing high symptom burden (16). There is growing consensus that PC should be offered to patients based on need rather than on prognosis, allowing for PC to be provided even in curative-intent contexts (14,17).

The term 'supportive care' originated in the 1980s as a descriptor of the measures provided to patients undergoing treatment for cancer (14,18). SC involves the prevention and management of treatment-related effects such as chemotherapy induced nausea and vomiting, cytopenias, infections, as well as cancer-related symptoms such as fatigue and pain (14,18). SC spans the trajectory from time of diagnosis through to EOL care (18). There is definite overlap between SC and PC and in the context of HMs, there is a place for both SC and PC.

Given the high symptom burden and risks of morbidity and mortality for patients with advanced HMs, it would seem that patients might benefit from early integration of PC. Indeed, research has demonstrated that early PC, in the context of advanced solid tumor malignancies, is associated with a number of favourable outcomes, including: improved symptom management, better prognostic understanding, improved quality of life for patients and family caregivers, and even improved patient survival in some contexts (14,16). Lack of PC involvement is associated with a number of adverse EOL outcomes, such as: overuse of life-sustaining therapies, aggressive treatment (including chemotherapy) in the weeks preceding death, intensive care unit admissions, more emergency department visits and hospitalizations and underuse of hospice, comprehensive pain and symptom management, psychosocial and spiritual care support (16).

In spite of the proven benefits of integration of PC in oncology, it has been well established that patients with HMs do not routinely receive PC (14,16). The barriers to early integration of PC for patients with advanced HMs have been well-described in the literature (4,19). Disease and treatment-related factors such as the heterogeneity of HMs and associated diverse disease trajectories and treatments mean that patients' needs vary considerably (19,20). For example, patients with indolent lymphomas may experience low symptom burden and low risk of mortality while patients with acute leukemias might face high symptom burden and high mortality (19). In addition, some patients may experience moderate symptom burden

and mortality or prolonged periods with low, but not absent, symptom burden (19). Accordingly, patients' SC and PC needs can be quite diverse.

Additional challenges to integrating PC for patients with HMs include the potential for rapidity of decline, the possibility for HMs to remain responsive to treatment even in the setting of advanced or relapsed disease, and prognostic uncertainty, all of which can make it difficult to know when to introduce PC (4,8,19-23). As Cheng & Lam (8) explain, it is not uncommon for patients with HMs to recover after episodes of near-death deterioration.

Patient, family caregivers, and clinicians may harbour misperceptions about PC and may regard PC as being the same as EOL or hospice care. This can make it difficult for patients and clinicians to see how PC might fit into what is often a very cure-focused context (24). As others have described, there is a lack of training and education on PC in healthcare provider curricula and training (19,22). In addition, as Franjul Sánchez *et al.* (22) describe, bidirectional training and collaboration among PC and hemato-oncology clinicians may be helpful. Indeed, Chan *et al.* (10) present their article as a resource/guide for both PC and hemato-oncology clinicians. Further, education on PC for patients and family caregivers may also help to erode some of the misperceptions and stigma associated with PC (25). Finally, as Chan *et al.* (10) describe, hemato-oncology clinicians should possess basic PC competencies and skills to be able to provide primary PC and adopt a palliative approach to care. Along with more education on PC, research on PC for patients with HMs is also needed. As Wedding (4) pointed out, approximately 9.5% of all cancer deaths are caused by HMs in the United States and yet only 0.4% of published studies on PC are in patients with HMs. Research is needed to both determine the unique needs of patients with HMs and to assess the effectiveness and role of PC for patients with HMs (4,25).

Perhaps somewhat unique to advanced HMs, patients with HMs may require and benefit from transfusion support throughout the disease trajectory, even at EOL, as articulated by Chan *et al.* (10). In some jurisdictions, hospice agencies may not permit transfusion support, even if the intent is to relieve symptoms, due to logistics and costs (19); this has been reported to be a potential barrier to referring patients with HMs to PC. Similarly, the use of palliative-intent chemotherapy or anti-microbials may provide significant symptom relief for patients with advanced HMs but may not always be accepted or permitted if the patient is receiving PC or hospice care (19,20). There is a

need for policy that supports PC integration, even in the context of curative-intent treatment, such as for transfusion, chemotherapy, and antimicrobial options for patients with HMs (4,25).

## Conclusions

It is apparent that patients with HMs experience a diverse array of SC and PC needs from the time of diagnosis through treatment, survivorship/follow-up, and EOL phases of the illness trajectory. Challenges such as prognostic uncertainty, rapidity of decline, and risks of morbidity and mortality, mean that patients' needs may oscillate between PC and SC. Patients with HMs and their family caregivers have significant SC and PC needs, including physical, psychosocial, existential, practical, informational, and relational needs. Allowing for more flexible delivery of PC, titrated to patient need rather than being tied to prognosis, and ensuring policy aligns with the unique characteristics of HMs and their treatment, may help better address patient needs and help mitigate challenges such as prognostic uncertainty, rapidity of decline, heterogeneity of diseases and treatments in HMs. Continued progress and advances in tumor biology, immuno-oncology, and disease-directed treatments for patients with HMs will undoubtedly save lives and the integration of PC can help save deaths.

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