A substantial body of literature highlights the challenges that exist providing palliative and end-of-life care for people with a hematological malignancy. This group of patients commonly: 1) receive aggressive care close to the end of life (such as chemotherapy administration, emergency admissions, intensive care unit admissions), 2) die in hospital; and 3) have palliative care integrated later and less often compared to their solid tumor counterparts. Amongst other issues, a significant problem is reported to be difficulties in accurately predicting mortality at the end of life for these patients due to a fluctuating and unpredictable illness trajectory. There can often be potential for cure in the face of critical illness or advanced disease. People with a hematological malignancy who are nearing the end of their life can experience a swift change in the goals of care from curative or life-prolonging, to palliative.

We recently conducted a literature review to identify mortality prediction tools and tools to identify risk of dying for people with a hematological malignancy in their final three months of life. We were interested in how these tools informed the provision of palliative and end-of-life care in this unique population. After a rigorous search, we found only two studies that examined the use of palliative prognostic tools for people with a hematological malignancy [1, 2]. Chou et al. retrospectively tested the Palliative Prognostic Index (PPI), Charlson Comorbidity Index and Glasgow Prognostic Score in a cohort of patients known to a specialist palliative care service.
Ohno et al. [1] sampled from a hospital population and retrospectively examined the PPI and prognostic factors identified in a previous study by Kripp et al. (conducted in a palliative care unit) [3]. No studies were found regarding identifying risk of dying for this population. In contrast, we found an abundance of studies exploring the use of mortality prediction tools in cohorts of patients in the intensive care unit including the Acute Physiology and Chronic Health Evaluation II, the Sequential Organ Failure Assessment, and the Simplified Acute Physiology Score. We stopped gathering such articles when we had in excess of thirty as we realized that this body of literature would not address the aim of our literature review. Identifying risk of mortality once a patient is ventilated in the intensive care unit is not the ideal situation for providing gold-standard palliative and end-of-life care for patients and their families. The phrase ‘too little, too late’ comes to mind.

A wide range of palliative prognostic tools and tools to identify risk of dying have been developed and tested for people with solid tumor cancer, chronic illness and the elderly. However, people with a hematological malignancy are a distinct and unique group of patients due to their underlying disease, treatments received (which affect the bone marrow) and complications experienced (which can be severe but reversible). Aggressive treatment often holds dual potential for cure and death. With the exception of Chou et al. and Ohno et al. studies [1, 2], it is not clear if current tools are applicable for people with a hematological malignancy at the end of life. Several prognostic tools exist for people with a hematological malignancy at earlier stages in their illness trajectory (i.e. upon diagnosis and prior to stem cell transplantation). Prognostic factors associated with mortality earlier in the illness trajectory are likely to differ from those at the end of life.
Why does such a gap in the literature exist regarding prognosticating for the purposes of palliative and end-of-life care provision for a cohort of patients who have well documented challenges in this area? Particularly when hematologists report difficulties knowing when to transition people to a so-called palliative phase and have identified a need for prognostic tools at the end of life. Previous work has indicated that a focus on curative treatment hinders palliative care integration for people with a hematological malignancy [4]. The growing body of literature that exists, highlighting the issues of palliative and end-of-life care provision in the hematology setting, indicates that there is strong interest in addressing this issue, creating momentum for change. Chou et al. and Ohno et al. should be applauded for their work, even so, this does not constitute a broad evidence base for this area of inquiry.

More research is desperately needed to address the gap in the literature regarding prognosticating at the end of life, both promptly and rigorously. As people with a hematological malignancy often have an unpredictable illness trajectory and deteriorate rapidly to a terminal event, we suggest that the focus should be placed on identifying risk of dying, rather than predicting time frames of survival. Predicting survival at the end of life is difficult. Clinicians are often overly optimistic and inaccurate, particularly in the case of lengthy patient-physician relationships, which is common in the hematology setting.

Identifying risk of deteriorating and dying enables patients, families and the health care team to plan for potential palliative care needs. This is termed ‘rainy day thinking’, where patients hope for the best, but prepare for the rest. This will allow
patients and their families more autonomy by giving them the opportunity to have meaningful discussions around end-of-life issues, reassess their goals of care, timely access to specialist palliative care services, and time to prepare for the patient’s death. This can occur whilst continuing current appropriate treatment of curative or life-prolonging intent. We suggest that clinical tools to identify risk of dying be developed, tested, validated, and most importantly, translated into practice, to give people with a hematological malignancy more control over the time that they have left and ultimately, the best death possible.

No conflict of interest to declare.

References