For anyone who has encountered palliative care in their personal or professional lives, the term is inextricably tied to a face and a story. It is worth taking a closer look at the clinical interactions that leave such a deep imprint on the people involved.

The World Health Organization describes palliative care as an approach aiming to relieve suffering and to improve quality of life of patients and families facing life-threatening illness.\(^1\) It was Dame Cicely Saunders who shaped the current concept of palliation in the early twentieth century—she spoke of “total pain”, encompassing the interplay of physical, psychosocial and spiritual stresses.\(^2\) An interdisciplinary team works actively to understand and alleviate every aspect of suffering, considering its impact on the whole experience of terminal disease.

In this year’s section on “Literature, the Arts and Medicine,” the McMaster University Medical Journal (MUMJ) asked for submissions from patients, their loved ones and members of their healthcare team, to explore the thoughts and feelings of people experiencing palliative care. Many choose to reflect in writing, although sculpture, music and painting have also been used by patients as forms of creative expression. One powerful example is Robert Pope’s series of acrylics, depicting his journey undergoing chemotherapy for Hodgkin’s lymphoma.\(^3\) MUMJ also recognizes the untold stories—some find it difficult to find the words, the time or the right listener. As healthcare professionals we are called to tap into these silent reflections, to enable our patients, families and colleagues to share in an environment of support and mutual respect.

A thoughtful tribute to Jim Dillon is offered by his widow Pam and by Reverend John Lougheed. Here we see the important role of a spiritual care provider in developing meaningful connections with families. Pam writes, “Could I dare to write about the joy we found, and would it be believed if I said we laughed every day, and that we talked about his death often and openly and still carried on with hope?” Open communication between healthcare providers and patients can help everyone to find peace with the passing of a loved one.

It is commonly believed that the constant exposure to death and dying would be disheartening for healthcare providers working in this setting. Yet a qualitative study of professionals in palliative and hospice care found that, though their work was punctuated by painful and distressing experiences, it provided them with a positive opportunity to normalize dying and to add meaning to their own lives.\(^4\) Tamara Hoppe shares a similar perspective as a medical student: she describes coming to terms with suffering seen on the wards, and finding a greater self-awareness through her interactions with patients.

A recent article in the New Yorker described a study of terminally-ill patients, where two-thirds of the group reported having had no discussion with their physicians about their goals for end-of-life care, though they carried an average prognosis of four months.\(^5\) Healthcare professionals may feel ill-equipped or uncomfortable eliciting a patient’s personal beliefs, yet broaching the subject is the keystone to effective palliative care. Patients from the study who proceeded to enter hospice care, where these discussions are paramount, were less likely to require intensive-care services, reported less suffering, and their family members were less likely to suffer from depression following their death.\(^5\) As healthcare providers, reflecting on our own values may enable us to overcome our reservations and to engage in an open dialogue about what approaching end-of-life means. Dr. Ahmed Jakda uses poetry as a medium for reflection, beautifully describing the human connection that he finds at the heart of every clinical encounter.

Where our treatment options fail, our ability to auscultate and investigate rendered futile, it exposes the patient-physician encounter as a simple human interaction. We are reminded that the relationships we form are in themselves therapeutic, and that our capacity to cure is only a subset of our capacity to heal.

Palliative care aims to alleviate suffering, and though this is often associated with the end-of-life, it is not reserved
for the terminally ill. Quality of life is threatened for many people experiencing chronic disease or pain. Palliation is often under-used in these settings, where it can be introduced concurrent with other medical treatments. Brigette Rieger, who suffers from severe neuropathic pain secondary to a meningioma, benefitted from a pain management plan developed by an interdisciplinary team. She writes, “I’m unable to work and I’m mostly confined to my home, so this so-called ‘benign’ brain tumour has taken a lot from me.” Her story reminds us to be mindful of the words we use to frame a disease, which is ultimately experienced uniquely by each patient.

Palliative care strives to uphold a patient-centered approach to relieve the patient’s personal experiences of suffering, in physical, psychosocial, and spiritual domains. At its most fundamental, isn’t this goal at the heart of all medicine? Isn’t this the model of what healthcare professionals should provide throughout the patient’s life course? We lament a lack of time, resources, training—but perhaps we need to prioritize this holistic approach in our use of the time and resources that we do have.

Principles of palliative care are broached in the health sciences curricula, yet the art of the interaction is learned at the bedside, and the important aspects of care are defined by those who receive it. For patients and families to impress this philosophy upon the world’s caregivers—what an incredible legacy.

REFERENCES

Author Biographies
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