

Palliative Care: Just for Cancer Patients?

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"Why is palliative care available for cancer patients and not for everyone with a terminal illness?" A nurse manager from a general medical unit asked this fairly common question during a hallway conversation the other day. "Why don't you attend to all of the patients who die from end stage renal or liver failure, or COPD, or cardiac disease? They could use your help as well." Once again I was aware of vaguely uncomfortable feelings as I struggled for an answer. As a nurse with over twenty years of experience in oncology, the move into a strictly palliative care practice was a natural one for me. I might never have questioned the nature of our patient population if it had not been for the challenging queries of colleagues. An informal survey of co-workers in palliative care confirmed that the manager's question is a fairly common one and worth a closer look.

One of the fundamental texts on the subject, the Oxford Textbook of Palliative Medicine (Doyle, Hanks, & MacDonald, 1993), cites several reasons for the fact that most palliative programs offer care mainly to cancer patients and their families. The authors note that terminal cancer diagnoses, as well as AIDS and some neurological disorders, "are characterized by constantly changing physical symptoms, increased risk of psychosocial distress, societal misunderstanding, and a relatively short period of final illness" (p.3). If we examine what usually happens to people dying with a non-cancer diagnosis, we will usually see something quite different. Even though the illness may eventually lead to death, people will live, on average, much longer with any medical diagnosis other than cancer. This is one of the reasons why cancer is such a terrifying word.

No one questions the intense needs of patients facing imminent death from cancer. However, while cancer can move with lightning speed, it can also be a chronic illness, advancing and then receding with treatment over the course of many years. How, then, is chronic cancer any different from chronic liver failure, chronic renal disease, or chronic respiratory diseases? How does the lived experience of people with these various diagnoses differ from each other? Each of these illnesses may be characterized by exacerbation's and remissions with an eventual terminal phase requiring support for patients and families. Is the support required by people dying from cancer different from the support needed by someone dying from any other medical condition?

Part of our struggle with this question may relate to the use of the emotionally laden words "terminal" and "dying". It is important to remember that patients and families living through the dying process can have very different interpretations of the unfolding illness than we will, as health care workers. Contrary to most public perceptions, we know that cancer does not always lead to death. We also know that people with chronic medical conditions may well die of their disease. With any illness other than cancer, we have the opportunity to distance ourselves intellectually and emotionally from an inevitable outcome. It may be more difficult for everyone

involved to understand and accept that a non-cancer illness has entered the terminal phase. People with a chronic illness may die, but when do we begin to identify them as "dying"? At what point in their illness are patients ready and willing to accept palliative care?

The growing body of palliative care knowledge on management of physical symptoms such as pain, opioid toxicity, dyspnea, asthenia etc. directly relates to cancer care. Of course, palliative care is more than the management of physical symptoms; nevertheless it is also clearly tied to the rhythms of cancer. Every other medical diagnosis will have its own symptom control challenges. If, however, we restrict our vision by looking only through the lens of medical practice, we may miss an opportunity (indeed, an obligation) to review the current state of palliative care practice. It may be that palliative care physicians, by the nature of their specialized knowledge and responsibilities, will have more difficulties in broadening their scope of practice to include non-cancer populations. While the medical diagnosis of a terminal illness is important for nurses, chaplains, social workers, rehabilitation therapists etc. to be able to plan care, the specific diagnoses is perhaps less crucial than the word "terminal". For example, there are general areas of care that nurses will attend to for all dying patients, such as skin care, mouth care, positioning, elimination, and family support.

It is perhaps in the patient and family support areas of practice that palliative care workers will have the most to share with colleagues. Anyone who is dying will benefit from skilled psychosocial, emotional, and spiritual support, and a connected interdisciplinary team of care providers. Palliative care teams, with representation from all health care disciplines, can be models for practice throughout our various health care systems. We must begin by asking what patients and their families need; what more can and should be done to ensure that sufficient support is available to help people through their dying process, whatever the cause of death. The last thirty or so years have obscured the fundamental understanding and acceptance of the inevitability of death, at least in the areas of the world that have access to intensive care units and the latest in technology. It will take a shift in our current "western" cultural beliefs and education of all health care workers before we can say that people who are dying have adequate access to palliative care.

Is this answer sufficient to satisfy our colleagues and relieve our discomfort when we are asked why we do not provide care for everyone who is dying? Our current incarnation of palliative care has grown out of the overwhelming needs of people dying from cancer. It is clear that my colleague's question does not yet have a very satisfying answer for health care providers working with the general "medical" population of patients. The challenge is theirs to do the research to articulate the unique needs of the patients with whom they work. Non-physicians in particular may continue to struggle with the lack of clarity and easily identified boundaries of care, since their skills may be more easily transferred to other patient groups. If the goal of palliative care is to assist the terminally ill to die well, we must deepen our understanding both of dying and of what it means to care for people with terminal illness.

References

1. Doyle, D., Hanks, G., & MacDonald, N. (1993). *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press.