
FROM THE EDITOR

The Goals of Palliative Care: Beyond Symptom Control

My father died a basically “good death.” He died, comfortably, at home, in his own bed, clean shaven, surrounded and embraced by his family. My father lived with widely metastatic prostate cancer for 5 years. In those 5 years, he had minimal pain and no episodes of infection or hospitalizations. He did extremely well for 4 years and 6 months, even working. The last 6 months were marked by progressive weight loss and weakness, requiring him to slow down. But up until the day before he died, he was ambulatory, showered and dressed himself, argued with my mother, and was pain free. On a Tuesday morning, for the first time in his long illness, he did not get out of bed. He was drowsy and not completely responsive. My mother called to tell me of the change. I left morning rounds at the hospital, collected a few essential medications, and went straight to their home (the home I grew up in). I spent the next and last 24 hours of his life sitting in a chair at the side of his bed, feeding him drops of liquid morphine and haloperidol to keep him comfortable, free of pain, free of confusion and agitation. My mother slept beside him that entire night. When the hospice nursing aide arrived on Wednesday morning it was clear that my father was very near death. We both bathed my father, and I insisted on shaving him. He had about 4 days worth of beard growth, and I knew he would want to die clean shaven. After shaving the left side of his face, he stopped breathing. I kissed him, thanked him for giving me life, and then I completed shaving the right side of his face.

By most standards, my father had good palliative care and died a basically “good death.” He had excellent control of pain and other physical symptoms. He had excellent quality of life right up to the last 24 hours of his life. His preferences for treatment and care were respected. He died where he wanted to die, at home, in his own bed, surrounded by those he loved, free of pain and physical distress. What more can palliative medicine provide? Should palliative care practitioners have goals that extend beyond providing relief from pain and symptom distress? What might those goals be? What should the goals of palliative care be “beyond symptom control”?

Certainly, most palliative care guidelines would stress several issues beyond symptom control. Expanding the focus of care beyond the patient to include the family is a basic and relatively universal practice in palliative care. This would extend to and include grief and bereavement counseling (or at least referral to such services) for family members after the death of the patient. Most palliative care definitions and guidelines would also endorse the concept that palliative care strives to meet physical, psychological, social, and spiritual expectations and needs, while remaining sensitive to personal, cultural, and religious values, beliefs, and practices. In that regard, many hospice and palliative care programs have members of the clergy (pastoral or spiritual counselors) and mental health practitioners (social workers, psychologists, psychiatrists) as part of the “team” in addition to nurses and physicians. The role of the spiritual counselor or clergy often varies from program to program and from culture to culture. I am unaware of widely accepted guidelines for the role of clergy in palliative medicine. Similarly, mental health professionals are only beginning to clarify their roles and develop novel interventions in the palliative care setting. Our journal, *Palliative & Supportive Care*, is one of the instruments of this developing field.

Hence the following question seems pertinent at this time in the evolution of palliative care and palliative medicine as a discipline: Is helping a patient achieve a sense of life completion and acceptance of death an appropriate or achievable goal of palliative medicine? And, if it is, who on the palliative care team should be responsible for achieving such a goal?

I was recently visiting colleagues at the Institut Curie, the main cancer hospital in Paris. I had the honor of conducting a workshop there on “existential aspects of end-of-life care.” The workshop was attended by several prominent and experienced palliative care physicians and nurses, psycho-oncologists, psychiatrists, and psychologists. The discussion was dynamic and, as one might expect in Paris, quite animated and accompanied by incredible pastries! We were discussing end-of-

life care issues such as existential distress, loss of meaning, loss of dignity, and despair. In discussing several of the novel existentially oriented counseling interventions that were being developed by psychiatrists and psychologists in palliative care (e.g., meaning-centered interventions developed by Breitbart and colleagues at Memorial Sloan-Kettering, dignity conserving interventions developed by Chochinov and colleagues in Canada and Australia, and life completion narratives developed by Steinhilber and colleagues at Duke University), I stated that I was beginning to see myself as a “Doctor of Despair.” I was curious to see if others with long careers in palliative medicine had the same vision of themselves. To get a discussion of such issues started, I asked the palliative care clinicians in the room to tell me what they saw as their goals as palliative care clinicians. The response was immediate, simple, clear, and emphatic. Overwhelmingly, the palliative care clinicians saw their main goal and obligation as “assuring that the patients under their care die receiving adequate pain and symptom control.” Nothing more, nothing less.

“What about helping patients achieve some sense of life completion? What about helping provide the opportunity for patients to reconcile with family and friends and achieve meaning, peace, transcendence? What about the goal of helping patients achieve a sense of acceptance of death?” I asked. Again the answer was swift and emphatic. “That’s not our job! That’s the job of the clergy, the priest, the rabbi.”

“The clergy? What of the nonreligious person?” I asked. “Are these religious or spiritual goals exclusively, or are they universal, human goals that are clearly a part of what patients want from their physicians and nurses?” Many surveys of patients near the end of life reveal that they want their existential concerns addressed by their physicians and nurses (Moadel et al., 1999; Singer et al., 1999). Ira Byock (1997), in his book *Dying Well*, points out that patients have a number of important tasks as they approach the end of life: (1) sense of completion with worldly affairs, (2) sense of completion in relationships with community, family friends, (3) sense of meaning about one’s life, (4) experience love of self, of others, (5) acceptance of finality of life and of one’s existence as an individual, and (6) surrender to the unknown—“letting go.” Are these tasks the sole domain of the clergy? Are these tasks not as relevant to the care of the dying as pain control or control of dyspnea? Are these tasks not then also the domain and responsibility of the palliative care physician and the palliative care team?

I have no doubt that there are very divergent views regarding this issue in the palliative care community, and I encourage those of you who have

opinions to address them in letters or essays on this care addressed to me as Editor-in-Chief. I also have no doubt that one of the most powerful influences on opinions regarding the question of whether such goals are the appropriate domain of palliative care clinicians lies with the following reality. We know how to assess and treat pain. We have opioids and other potent analgesics. We have the tools and the medications and anesthetic interventions to treat pain. There are clear, well-established, evidence-based guidelines for managing pain, and other physical symptoms. As a result, we gladly and enthusiastically embrace the assessment and treatment of pain as a “primary goal and responsibility of the palliative care physician and nurse.” We do not yet have the same mastery of the assessment and treatment of “despair” at the end of life. We do not have easily administered interventions to aid clinicians in helping patient restore a sense of meaning and dignity in their lives. We do not have interventions to help facilitate life closure or acceptance of death. As one of the palliative care physicians in Paris said to me “Even if I wanted to help with these existential issues, I would not know how to help . . . not even how to begin.”

But, there is a beginning. More and more clinician researchers in psychiatry, psychology, nursing, and palliative care are beginning to grapple with the issues of existential and spiritual distress or suffering: despair, loss of meaning, dignity, life completion. Interventions are being developed and tested in clinical trials. Many of these interventions are being developed and tested by those of us in psychiatry and psychology at the interface of palliative medicine, but nurse clinician researchers and palliative care clinicians themselves are beginning to develop and test interventions in this domain of palliative care as well. One day we will have the ability to provide palliative care practitioners with the knowledge and skills necessary for the assessment and treatment of existential concerns, and the focus of palliative care will extend beyond symptom control.

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