The Desire for Death in the Setting of Terminal Illness: A Case Discussion

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Have you ever wondered how often patients wish to have their death hastened in the face of terminal illness, and if so, why? Have you wondered whether depression, a loss of dignity, or pain push patients to forego life-extending care? Have you wondered whether faith and a belief in a higher power affect choices at the end of life? If you have, then the following case vignette (of a young man who developed a malignant osteosarcoma) should provide the forum for answers to these and other questions related to care at the end of life.

Caring for the dying patient is among the most challenging clinical tasks a physician faces. Physicians take great pains to alleviate suffering and are trained to prolong life—especially when a satisfactory quality of life can be maintained. Therefore, when a patient with a terminal illness asks to hasten his or her own death, conflict often arises. To a physician, this request can be confusing, anxiety provoking, and infuriating. However, requests to hasten death generally signal the presence of physical, psychological, or social stressors that can frequently be ameliorated. Understanding the nature of such requests allows physicians to ease suffering and reduce the desire for death in such patients.

In this report, we present the case of a patient with terminal illness who expressed a desire to hasten his death. We discuss the meaning of the request and several possible interventions.

CASE VIGNETTE: PART 1

Mr. C, a previously healthy 25-year-old man, noted a painful lump on his left side, which was diagnosed as a highly malignant osteosarcoma. He underwent multiple courses of chemotherapy and radiation therapy as well as 2 surgical resections. Despite these treatments, his tumor continued to grow, leaving Mr. C increasingly short of breath. Eight months after his initial diagnosis, a hemopneumothorax was discovered in his left lung, and he was admitted to the hospital for emergent drainage. During this admission, Mr. C’s oncologist informed him that all curative options had been exhausted and that he had approximately 3 months to live. Mr. C responded by saying, “I have enough pain pills at home to do what I need to do.” Psychiatric consultation was requested regarding the possibility of suicide.

How Common Is the Desire for Hastened Death Expressed in the Setting of a Terminal Illness?

Determining how often patients want the dying process to be sped up is a complicated undertaking, as the experience of being terminally ill differs from patient to patient. On one end of the spectrum is the patient who passively welcomes death. On the other end of the continuum is the actively suicidal individual. One response to a desire for hastened death is exemplified by the practice of euthanasia in The Netherlands, where it
is legal and tightly regulated. (Euthanasia is defined as the administration of a lethal agent by another person to a patient for the purpose of relieving the patient’s intolerable and incurable suffering.) In The Netherlands, euthanasia comprises 2.1% of all deaths annually (the vast majority are among patients with cancer). The primary reason given (in The Netherlands) for choosing euthanasia is “a loss of dignity.” The related practice of physician-assisted suicide (when a physician provides either equipment or medication or informs the patient of the most efficacious use of already available means for the purpose of assisting the patient to end his or her own life) has been legal in the state of Oregon since 1997. From 1998 through 2005, 246 people died in Oregon as a result of physician-assisted suicide, accounting for 32.8 deaths per 10,000 Oregon deaths during that time. Patients who chose physician-assisted suicide tended to be divorced or never married, had higher levels of education, and were likely to be dying of malignant cancer (83% in 2005). According to physicians surveyed, the most frequently mentioned reasons for requesting physician-assisted suicide were a decreasing ability to participate in pleasurable activities, the loss of dignity, and the loss of autonomy.

However, studying euthanasia or physician-assisted suicide allows us to review only the experience of patients who actively seek out a means to hasten their death and leaves out the majority of patients who desire death but who choose not to act on their desire.

To understand the prevalence of the desire for death in the terminally ill, several research groups have conducted controlled clinical studies in inpatient settings (e.g., in tertiary care hospitals or hospices). In an early study, Brown and colleagues examined 331 consecutive palliative care inpatients in a hospital in Winnipeg, Canada. Ultimately, 44 patients were entered into the study (the rest were excluded because of organic mental impairment, an inability to communicate or to consent, or “being too sick to participate.”) The Beck Depression Inventory (a brief clinical screen for depression) and a screen for the desire for a hastened death were used. Eleven patients (25%) were “severely depressed.” Of these, 7 (16%) wished for death and 1 was actively suicidal (2%). None of the other 33 patients suffered from major depression or were suicidal. Although this study was limited by sampling errors, it suggested that, for the dying patient, expression of a desire to die sooner than one normally would may not be equivalent to thoughts of suicide.

What Do Recent Studies Reveal Regarding the Wish for a Hastened Death?

Several recent studies have brought a more systematic approach to the epidemiology of patients who desire to hasten their own death. Chochinov and co-workers examined the prevalence, stability, and determining factors of the desire for a hastened death. They recruited 200 patients with cancer from 2 inpatient palliative care units in Winnipeg, Canada (and excluded those too cognitively impaired or too ill to participate). They collected data via a semistructured interview that included specific questions about the wish to die, a variety of standardized instruments (i.e., the Beck Depression Inventory, the Memorial Pain Assessment Card, and the Karnofsky Functional Performance Status Scale), and an analog measure of social support for the evaluation of their subjects. After their initial interview, follow-up interviews were conducted with those patients still alive 2 weeks later. Chochinov et al. found that 45% of patients expressed an occasional and fleeting desire to die. This percentage was much greater than was found either by Brown et al. or by studies of The Netherlands euthanasia cohort.

In another study, Breitbart and colleagues studied the relationship among depression, hopelessness, and a desire for hastened death in 92 terminally ill cancer patients in a palliative care hospital in New York, N.Y. All of their subjects had a Mini-Mental State Examination score above 20 (i.e., not significantly cognitively impaired), spoke English, were able to consent to the study, and were thought not to be at risk of psychological harm from participation in the study. This cohort was comprised of severely ill patients (mean time to death was 28 days). As with the Chochinov and colleagues’ study, Breitbart and co-workers used multiple standardized instruments (including the Structured Clinical Interview for DSM-IV-TR, the Schedule of Attitudes Toward Hastened Death, the Hamilton Rating Scale for Depression, the Beck Hopelessness Scale, the Duke-UNC Functional Social Support Questionnaire, the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale, the Memorial Symptom Assessment Scale, the Karnofsky Performance Rating Scale, and the McGill Quality of Life Questionnaire). Unlike Chochinov and colleagues, Breitbart’s group did not distinguish between patients with a fleeting desire to die and those whose desire was sustained. Nevertheless, among these 92 patients, 15 (17%) expressed a sincere and unequivocal desire for death that persisted over time.

Both Chochinov and co-workers and Breitbart and associates studied only the sickest of terminally ill patients. This methodology excluded those patients who suffered from a terminal illness but who did not require an inpatient hospitalization.

In contrast, Kelly and co-workers studied cancer patients seen by the palliative care services (including inpatient, outpatient, and general hospital consult settings)
in a major teaching hospital in Wooloongaba, Australia. This group recruited 256 patients (with a 49% participation rate) who had a Mini-Mental State Examination score greater than 17, spoke English, and were able to give consent and to communicate effectively. Kelly and co-workers used a variety of standardized instruments to measure a desire for hastened death, along with depression, physical symptoms, social support, and the quality of family relations. Among this cohort, 59% of patients had no desire for a hastened death, while 14% had a strong desire to quicken the dying process. Kelly and colleagues found a clinically significant difference between the rates of a desire for hastened death seen in palliative care inpatient settings (23%) and those in the general hospital population (5%).

From these data, the rate of a desire for a hastened death among terminally ill patients ranged from 17% to 45% (when including those with a fleeting desire to die) and depended on the population studied and the way it was evaluated.

Is It Important to Learn Why Some Dying Patients Desire to Hasten Their Death and Others Do Not?

Since the minority of terminally ill patients make consistent requests to hasten their own death, it is important to understand which factors lead patients to make such requests. Such knowledge will go a long way toward understanding the meaning of these requests and how best to approach them. Overall, there is strong evidence that psychological and social factors (e.g., comorbid depression, hopelessness, loss of dignity, and the impact of spiritual beliefs), rather than the physical ones (e.g., functional status and the level of pain control), are the chief determinants of the desire to hasten death.

Is There a Relationship Between Clinical Depression or Mood Symptoms and a Desire for Hastened Death?

Although there is an intuitive connection between the desire for death and symptoms of clinical depression, several groups have sought to examine this link more systematically. Chochinov and co-workers found a statistically significant association between clinical depression and the desire for hastened death. They found that 59% of the patients who expressed a desire for hastened death had clinical depression, while only 8% of patients without a desire for hastened death were depressed. Furthermore, terminally ill patients with a history of depression had vulnerability for a desire for hastened death even if they did not have active symptoms of mood disorder. Chochinov and colleagues also found a statistically significant association between a history of depression and a desire for a hastened death. Their regression analysis revealed that other factors (e.g., low family support, pain, and poor functional status) were intercorrelated with depression; however, having had a depressive episode was the only factor that predicted a desire for hastened death.

Breitbart and associates also found a significant association between clinical depression and a desire for hastened death. Patients with depression were 4 times as likely to have a desire for hastened death as compared with those who were not depressed (47% vs. 12%). In addition, Breitbart and colleagues examined the role of hopelessness (defined as a pessimistic cognitive style assessed by the Beck Hopelessness Inventory) on the desire for hastened death. Most terminally ill patients remained hopeful about their lives. However, patients who expressed hopelessness were more likely to desire a hastened death independent of whether or not they were depressed. Furthermore, two thirds of the patients with both clinical depression and hopelessness were more likely to desire death.

Jones and colleagues studied a desire for hastened death in 224 inpatients with various stages of cancer (i.e., not just those who were terminally ill) in a cancer hospital in Toronto, Canada. Using psychological instruments and exclusion criteria similar to those in previously mentioned studies, Jones et al. found a desire for hastened death in 2% of their patients; however, the prevalence in those with advanced disease was 6.5%. Their regression analysis found both depression and hopelessness to be independent predictors of a desire for hastened death. In fact, hopelessness was a stronger predictor than clinical depression. Other factors (e.g., the number of physical symptoms, pain, and disease stage) that one might have thought would influence a desire for hastened death were not predictive of such a desire, but Jones et al. postulated that their effects could have been mediated through hopelessness and depression.

The data from these studies indicate that there is a strong correlational relationship between the clinical manifestations of major depressive disorder and patients with life-threatening illness expressing a desire for a hastened death. Furthermore, it would seem that the experience of hopelessness is also associated with the desire for a hastened death in these patients independently of major depressive disorder.

What Is the Impact of Physical Function and Pain on a Desire for Hastened Death?

Most studies on the desire for a hastened death have been performed in palliative care units or in tertiary care hospitals—settings in which pain is likely to be better controlled than in less specialized venues. Therefore, the question of how pain influences desire for a hastened death in a terminally ill patient remains difficult to answer. Nevertheless, Chochinov and colleagues reported that 77% of patients who desired a hastened death had moderate to severe pain. Breitbart and associates, using a
univariate analysis, showed that low levels of physical function, distress from physical symptoms, and a high number of physical symptoms were weakly associated with a desire for hastened death—but the presence or intensity of pain was not. Kelly and co-workers found that an index of physical symptom severity (the Memorial Symptom Assessment Scale) significantly correlated with a desire for hastened death, but it was less potent a factor than either psychological or social symptoms. Lastly, although the research of Jones and associates demonstrated that one third of their patients reported pain in the preceding 24 hours and that an equal number had 9 or more distressing physical symptoms, neither of these factors directly contributed to a desire for hastened death—only the stage of illness was partially correlated.

Another study by Akechi and colleagues sought to determine why some cancer patients with depression desire an early death and others do not. They performed a retrospective analysis on 1721 cancer patients seen by the psychiatric consultation service in a cancer hospital in Hiroshima, Japan. They found that 220 patients (12.8%) were clinically depressed. Of those, 113 (51.4%) expressed a desire to die. A regression analysis demonstrated that the only factors that significantly increased the risk for a desire to die were poor performance status (odds ratio [OR] = 1.29) and severe depression (OR = 1.8). Pain, specifically, did not increase the risk of having a desire to die early. Finally, in their analysis of physician-assisted suicide in Oregon, Sullivan and associates reported that the loss of body functions was a strong reason for a desire for hastened death.

Although pain appears to have a role in the development of a desire for an early death among some terminally ill patients, surprisingly, pain’s role does not appear to be as substantial as one would expect. Regardless of the level of pain control that a particular medical unit or team can achieve, it is often the fear of pain (rather than the pain itself) that looms large for many cancer patients; of note, 10% to 20% of patients experience severe and uncontrolled pain at some time in the last year of their life.

How Do Social Support and Family Factors Affect a Desire for Hastened Death?

Most clinicians assume that patients with better social supports and close family connections are better equipped to confront the stress of their illness and are therefore less likely to develop a desire for hastened death. However, Chochinov and co-workers reported a marginal negative correlation between the degree of satisfaction with one’s social network and the desire for a hastened death. They noted that the quality, not the quantity, of the patient’s social network helped to protect against a desire for hastened death. Breitbart and colleagues found that the perception of the “self as a burden to others” was linked with a desire for hastened death. Kelly and co-workers found that perceiving oneself as a burden to others, having poor family cohesion, and having both a small number and a poor quality of social supports were all correlated with a desire for a hastened death. The data appear to support the perception that better (though not necessarily more) social support and feelings of a connection to others reduce the risk of patients developing a desire for hastened death.

What Clinician Factors Correlate With a Desire for a Hastened Death?

An unexpected area of inquiry has been the role of the clinician in influencing his or her patients to develop a desire for hastened death. Kelly and co-workers examined various characteristics of physicians who referred patients with a strong desire to hasten their deaths. In this study, the referring physicians did not know that their patients went on to express a desire for hastened death. As mentioned previously, in this study, patient factors associated with a desire for hastened death were clinical depression, perceiving oneself as a burden to others, and having poor family cohesion. There were also several clinician factors associated with a patient’s expression of a desire for hastened death. These factors included having little or no training in counseling or psychotherapy, possessing the attitude that the doctor would assist the patient to hasten his or her death were it legal and requested, and perceiving emotional distress when sitting with the patient. These data suggest that a physician’s personal limitations and biases can influence a terminally ill patient’s request for a hastened death.

How Does the Loss of Dignity Affect the Desire for a Hastened Death?

Chochinov and colleagues also studied the role of dignity in a cross-sectional study of 213 patients with cancer who had less than 6 months to live. A 7-point self-report dignity scale (which has not been standardized) was used along with a variety of standardized instruments; only 16 patients (7.5%) saw loss of dignity as a great problem, while 78% of patients felt that their dignity was intact. No difference was found in the survival time of the 2 groups.

However, those with a loss of dignity more frequently reported a desire for hastened death, had increased levels of depression and hopelessness, and required an increased need for help with activities of daily living. A regression analysis found a statistically significant correlation between several factors (including being younger, worrying about one’s physical appearance, needing help with bathing, having pain, being an inpatient, and perceiving themselves as being a burden to others) and sustaining a loss of dignity. Although loss of dignity did not appear to affect mortality, it worsened the quality of life for those patients with terminal illness.
Do Spiritual Beliefs Affect One’s Desire for a Hastened Death?

Spirituality is one of the most universal yet elusive factors thought to have an impact on the desire for a hastened death. Spirituality (defined as the way in which a person understands his or her life in view of its ultimate meaning and value) is for some, encompassed within organized religion. According to Kearny and Mount, “spiritual issues . . . lie at the very center of the existential crisis that is terminal illness.” Therefore, many clinicians expect that spirituality has a significant impact on the development of the desire to hasten death in terminally ill patients. In 1 study, McClain and colleagues studied 160 patients (with a life expectancy of less than 3 months) in a palliative care hospital using the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale, along with other standardized instruments, to assess the role of spirituality on end-of-life despair, which they defined as a combination of hopelessness, the desire to hasten death, and a desire for an early death. They found that spiritual well-being had a strong negative correlation with end-of-life despair. In particular, the ability to find an overarching meaning—even at the end of life—was protective against the development of hopelessness, the desire for a hastened death, or thoughts of suicide.

CASE VIGNETTE: PART 2

Mr. C (who appeared surprisingly robust and alert) was lying in his hospital bed when the psychiatric consultant saw him. Apart from the chest tube draining from his left side and the intravenous line that provided fluids, he did not appear physically ill. He was dressed in hospital pants and a t-shirt. During the interview, the consultant ascertained Mr. C’s pain status, inquired about gastrointestinal symptoms, and screened for depression. However, most of the exchange focused on Mr. C’s suggestive statement that he would take his own life when he returned home. By actively listening to Mr. C, the consultant allowed Mr. C to express his fears and frustrations about his impending death. The pressure he felt to “figure it all out” or to have some profound insight before he died angered Mr. C. He was saddened by the realization that his life would be foreshortened; he would never have a career, never marry, and never have children. Although he had recently graduated from college, most of his friends were scattered across the United States, and he did not have a significant other. His parents were understandably shaken by their son’s illness and were, consequently, unable to provide the emotional support Mr. C wanted. Mr. C did not belong to a spiritual community. However, he had grown up on the seashore, and he was happiest when he was sailing. In fact, he desperately wanted to leave the hospital to go sailing. He wanted to live only as long as he could sail and as long as he was not a burden to his parents. Mr. C’s pain was well controlled, he had no gastrointestinal symptoms, and he was not clinically depressed. His hinting that he would overdose on his pain medications was an expression of his distress about his medical situation and not evidence of a clear plan for suicide.

What Does the Request to Hasten Death Communicate to Others?

Statements about death often communicate an intolerable internal or interpersonal state. For example, while Mr. C did not attempt to harm himself, he did communicate his distress to his caregivers and thereby tacitly requested help. Coyle and Sculco performed a phenomenological inquiry of 7 patients with advanced cancer who expressed a desire to die. They performed 3 to 6 semistructured interviews over the course of days to months. The interview structure was then coded, and 9 significant themes were extracted. Themes included paradoxical manifestations of the will to live, gestures of altruism (e.g., a wish to relieve the family from the burden of caring for the patient), and cries of despair. Although none of their patients intended to commit suicide, Coyle and Sculco concluded that a desire to hasten death is a means of communication between the patient and the world—one that needs to be explored to best help the patient.

When a terminally ill patient expresses a desire to die early or sooner than one could, his or her physicians must strive to understand the underlying problem and address it appropriately. From the outset, the physician should realize that there is always something that can be done. Even when all curative medical and surgical interventions have been exhausted, patients and their families appreciate when their doctors listen to their concerns. Additionally, active listening allows the doctor to provide care that is better tailored to the patient’s needs and worries.

What Can Be Done to Ease the Distress of the Patient Confronting Death?

Many patients are afraid of the process of dying. They worry about what they don’t know, about being in pain, and about being left alone at the end of their life. Doctors can offer comfort by informing the dying patient about what to expect from the dying process and by treating his or her pain. Physicians must promise to do what they can actually accomplish, and they should set reasonable expectations for their patients and themselves. Although physicians often wish to be as available as possible with their dying patients, physicians should not promise to be with their patients throughout the dying process if they cannot actually provide this service.

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Pain and other physical symptoms should be treated aggressively, and manifestations of toxicity, which are common in terminally ill patients, should be watched for.

Even in a patient who is dying, depression (which is common) is, and should be, treated. It can be a primary problem (as in a patient with a history of major depressive disorder), a result of medications (e.g., corticosteroids), or organic (e.g., due to metastases or to a paraneoplastic syndrome). The approach to treating depression in a dying patient is similar to that used in the treatment of non-terminal patients. First-line agents (e.g., selective serotonin reuptake inhibitors and serotonin-norepinephrine reuptake inhibitors [SNRIs]) should be selected on the basis of their side effect profile. For example, recent studies have suggested that SNRIs (e.g., duloxetine) can be helpful for the treatment of neuropathic pain—a symptom common in cancer patients.19,20 Stimulants may also be used to improve both energy and mood. Once depression is treated, many terminally ill patients feel better, improve their quality of life, and relinquish their desire to hasten death.21

How Does Caring for a Terminally Ill Patient Affect Clinicians?

Facing the difficult emotions of patients and families, as well as their own memories and challenges, is challenging for even the most experienced practitioner. Therefore, the work of caring for a dying patient is best performed in the context of a multi-disciplinary team, which helps to distribute the varied aspects of this work and allows staff to support one another through difficult situations. For example, when a patient’s desire to hasten death involves difficulties in relationships or faith at the end of life, a physician should feel comfortable engaging the patient around his or her concerns. However, doctors should be equally comfortable referring their patients to social workers, chaplains, or psychologists. Only by paying attention to one’s own limitations can the physician who cares for a dying patient best serve the patient.

What Happened to Mr. C?

Ultimately, Mr. C was deemed to be safe (i.e., he was judged not to be at imminent risk of harming himself), and he returned home. He declined referrals for outpatient individual psychotherapy, but the notion of a support group appealed to him, and he was given contact information for one near his home. Mr. C also agreed to be followed by the palliative care service so that his physical symptoms could be managed.

CONCLUSIONS

Few requests are more confusing or anxiety provoking for a physician than a dying patient’s request to hasten his or her own death. Physicians should recall that such a request is typically a means for a patient to communicate some form of distress to his or her doctor; rarely is it a declaration of suicide intent. By inquiring about this distress, a physician can begin to address its underlying cause and to improve the quality of life for the terminally ill patient.

REFERENCES


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This thorough and practical review of the approach to a terminally ill patient’s request for a hastened death, the differential diagnosis and a variety of management approaches are discussed (medical, psychiatric, and psychosocial).


This prospective study used semistructured interviews to investigate the prevalence of the desire for death in terminally ill patients. The study also examined the stability of this desire over time and its association with other psychiatric disorders. Two hundred terminally ill patients were recruited from palliative care units in Winnipeg, Canada. Within this population, occasional wishes for an early death were common (45% of patients), but only 8.5% of these patients had a serious and pervasive wish to die. The desire for death correlated most strongly with measures of depression (59% of patients with a desire for death were depressed as opposed to 7% of patients who did not wish to hasten their death).


This study examined the extent to which dying patients perceive they are able to maintain a sense of dignity and attempted to ascertain how multiple variables relate to the issue of dignity in these patients. The authors performed a cross-sectional study of 213 terminally ill patients in palliative care units. They used an analogue 7-point dignity scale as well as a variety of other psychological instruments. In this cohort, 16 patients (7.5%) stated that loss of dignity was a great concern to them. These patients had significantly more psychological distress and physical symptoms as well as the loss of the will to live.


This consensus statement reviews the clinical characteristics of normal grief and clinical depression and explains strategies for differential diagnosis. The article also reviews treatment strategies for terminally ill patients with depression.


This is a prospective study of 92 terminally ill cancer patients at a palliative care hospital in New York, N.Y., which assessed the prevalence of the desire for hastened death among terminally ill cancer patients and identified associated risk factors. The authors used the Structured Clinical Interview for DSM-IV-TR and a battery of psychological instruments to evaluate the patients. They found that 17% of patients desired a hastened death. The desire for hastened death was significantly associated with a diagnosis of major depression, with measures of symptom severity, and with hopelessness.


This is a retrospective study of 1721 patients seen by the psychiatric consultation service at the National Cancer Hospital in Japan, the authors compared background differences among cancer patients with and without major depression. In this population, 220 patients (12.8%) were diagnosed with depression. Of these, 113 (51%) had suicidal ideation. The authors used the Structured Clinical Interview for DSM-IV-TR and a battery of psychological instruments to evaluate the patients. They found that 17% of patients desired a hastened death. The desire for hastened death was significantly associated with the role of clinician-related factors.


This study is a phenomenological exploration of the meanings and uses of expressing the desire for hastened death in 7 patients with advanced cancer. The researchers engaged in a series of in-depth semistructured interviews that were taped, transcribed, coded, and organized into themes. They found that a desire for hastened death communicated many meanings that could be categorized into 9 different themes. The authors concluded that, regardless of its meaning, the desire for a hastened death is a means of communication for patients.


This cross-sectional study examined the clinical factors associated with a wish to hasten death in advanced cancer patients, focusing on the role of clinician-related factors. The authors collected questionnaire data from 256 terminally ill patients and their treating doctors. Kelly and colleagues identified both patient factors (perceiving themselves to be a burden to others, major depression, and lower family cohesion) and physician factors (willing to assist the patient in hastening death were it legal and requested, the doctor perceiving lower levels of optimism and greater emotional distress in the patient, and the doctor having less training in psychotherapy) that were associated with a higher desire for hastened death in these patients.