2005

Ethics, End-of-Life Decisions, and Grief

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Recommended Citation
LIVING WITH GRIEF

ETHICAL DILEMMAS AT THE END OF LIFE

HOSPICE FOUNDATION OF AMERICA

EDITED BY KENNETH J. DOKA, BRUCE JENNINGS & CHARLES A. CORR

Foreword by Jack D. Gordon, Chairman, Hospice Foundation of America
End-of-life decisions do more than prolong or terminate a life. These ethical decisions may haunt survivors long after the death occurs. They may complicate grief, creating family dissension, inhibiting support, and increasing ambivalence over the nature or circumstances of the death. Conversely, end-of-life decisions need not always be negative. In other circumstances, they may facilitate the grief process, allowing survivors a meaningful end to the story of a loved one, providing survivors a modicum of control that ends a person's pain, following the deceased's wishes, or simply seeming to survivors like the right thing to do.

A letter I received a number of years ago illustrates that point. The author of the letter, identified only as John, wrote that he had assisted in the death of his mother. She had been diagnosed with a virulent form of cancer. In great pain, she asked that her children aid her as she ended her life. John and his siblings agreed. What John did not realize was that the ethical dilemma would deeply influence his subsequent grief.
He wrote,

The “normal grief” of losing a parent was further aggravated by a sense that there are some in society that would disapprove of her decision or feel it was improper or even criminal for us to assist. Some prosecutors might have a hard time overlooking it. In Minnesota it’s a felony to assist in suicide, subject to 15 years in prison. I don’t know that what we did fits a legal definition of “assist,” but we supported her in the decision. It seems incongruous that we all might be part of a criminal conspiracy. Even though I don’t think a jury would convict us, we don’t want to have to defend ourselves in a court of law or even to the public.

Perhaps someday, if Congress doesn’t try to protect us from ourselves, we’ll be able to talk about it publicly. My siblings and their spouses are all highly educated, mostly professional people, respected in our fields and not used to being muted by controversy. At this time we don’t want to be poster children for assisted suicide. Unlike Kevorkicide (can I coin a term?), it was a very private, very personal act of love and compassion. And I have come to understand that the resulting grief is disenfranchised.

In this case, John faces an ethical dilemma. On the one hand, his mother is in pain and wishes to end her life. On the other hand, John realizes that assisting his mother places him in legal jeopardy. While he understands the act to be merciful and has the support of his siblings and extended family, his decision still generates ambivalence. He believes the action might arouse investigation and legal prosecution. The letter indicates a need to process his grief, and, in doing so, to explore his role in his mother’s decision to terminate her life. Yet, well aware of the potential limits to confidentiality, he has to do it anonymously in a letter—unable to even seek a reply. Counseling seems precluded by the ambiguity of Minnesota’s laws.

Positively or negatively, the end-of-life decisions that survivors make influence subsequent grief. This chapter explores that influence. It begins with three central assumptions.
The first is that the end-of-life decisions, like so many of the factors that affect grief responses, can be facilitating or complicating, perhaps even at the same time. The chapter explores both aspects of end-of-life decisions.

The second assumption is that professional caregivers—medical and nursing staff—as well as families have a stake in these ethical decisions. They may have opinions as to the best course of action. Staff, especially in long-term care institutions, may develop attachments to the patient. Hence, ethical decisions may influence the course of bereavement in both family and staff. In addition, each group may influence the other’s decisions. For both family and staff, the aftermath of these actions or subsequent behaviors may generate doubt as to the wisdom of these decisions.

The third assumption is that these decisions cannot be understood apart from their context. Prolonged illnesses or sudden deaths in and of themselves each create complications to grief. Moreover, these contexts are not mutually exclusive. As Rando (1993) reminds us, persons even within the context of a lengthy illness can die “suddenly”—that is, at an unexpected time or in an unanticipated manner. The person slowly dying of cancer is not immune to a sudden deterioration or even a heart attack or stroke. In short, then, end-of-life decisions cannot be viewed apart from the context in which they occur. This context will eventually influence the experience of grief.

There is one additional assumption. There are strategies both during and after the decision making that can be helpful to families and staff. These strategies can enhance the possibility that this decision-making process can be facilitative of grief while mitigating complicating features. A final section of the chapter considers these strategies.

**COMPLICATING FACTORS**

As stated earlier, end-of-life decisions can both facilitate and complicate grief—sometimes simultaneously. In addition, end-of-life decisions cannot be separated from the context in which they occur. Research has indicated that sudden deaths as well as deaths that follow long-term illness each create their own complications (Rando, 1993).
Sudden deaths often occur from circumstances such as an accident, suicide, or homicide. While each circumstance creates unique issues for bereavement, all share complicating factors, such as a sense that the death was preventable and a lack of forewarning. These factors also can complicate reactions to a sudden death from natural causes such as a heart attack, aneurysm, or stroke. Here, too, there is preventability and lack of forewarning. In such circumstances, ethical decisions such as terminating treatment or stopping heroic measures are often undertaken in both shock and grief, with little forethought.

There are other factors when the illness is prolonged. Family caregivers may be highly stressed as they cope with the incessant physical, financial, social, and psychological demands of life-threatening illness. It may be difficult to witness the slow deterioration and pain of the dying patient. The illness may generate considerable ambivalence as family members simultaneously wish for death and an end of the person’s and family’s suffering and wish that the person would remain alive. There also may be ambivalence as the person’s physical appearance deteriorates to such an extent that family members are repulsed even as they seek to care and to comfort. Ambivalence has long been identified as a factor that complicates grief (Rando, 1993; Worden, 2002).

End-of-life dilemmas themselves can reflect and even generate considerable ambivalence. The individual or family making the decision can be torn between a desire to end suffering and a continued quest to retain hope even in the face of impending death. Individuals or family members may experience conflict between following their own beliefs and choices and honoring the expressed wishes or beliefs of the deceased. The following case, drawn from clinical experience, illustrates this conflict:

My husband had made it clear that he did not want continued treatment when we knew it to be futile. However, it was hard to accept that. I believed that when there is life, there is always hope. He would not want anything more. Yet, I felt I should continue. I followed his wishes and he died shortly afterward. I still wonder if I should have kept on going.
This passage suggests another potential factor in end-of-life decisions. Normally, one person within the family system may hold the health proxy. In the United States, such a proxy authorizes a given person to make medical decisions for an individual incapable (perhaps because of unconsciousness or diminished capacity) of making such decisions. Family members may differ in their abilities to communicate with one another and in their opinions about what should be done. Thus, end-of-life decisions can create or revive family conflicts. These conflicts in turn can render the process of decision making more complex. They may limit subsequent support while generating concurrent crises such as family fights that complicate the grief process. In some cases, family disagreements and subsequent legal actions can generate considerable publicity and debate can even polarize communities, further limiting support and generating increased ambivalence about the decision process. These factors, too, complicate grief (Rando, 1993; Worden, 2002).

I held his [her father’s] health proxy. My sister came in from California. She wanted [artificial] feeding to continue. I had kept it so she could be there when he died. Now I knew it was time to stop. She did not agree. I told her this was Dad’s wish. She knew that but still could not let go. Finally after four days, I said “stop.” Because there was family disagreement, the ethics committee became involved. Dad died a day later. I felt one more painful day. My sister felt she was right since he died naturally—whatever that means—the day before the committee would decide. She left right after the funeral. We have not spoken since the funeral.

Some of the decisions that may be made, such as assisting a suicide, can create additional issues for survivors. They may lead to legal investigations that add to the stress of the loss. The decision may isolate the proxy from other family members. It may, as the opening letter indicated, disenfranchise grief.
Disenfranchised grief refers to a loss that cannot be openly acknowledged, socially sanctioned, or publicly mourned (Doka, 2002). The individual experiences a loss but can neither share the full circumstances of the death nor receive subsequent support. Thus, the end-of-life decisions that individuals make may alienate others within the family system or even risk public censure—disenfranchising their grief.

The manner of death, too, may complicate subsequent grief. Even the decision to terminate life support may not ensure an easy death. Family members may interpret or misinterpret the final actions of the dying person as evidence of pain. Even when the death does not occur with signs of evident distress, families and especially decision makers may still worry about the way the person died. For example, it is generally believed by the medical community that neither artificial feeding nor hydration is always necessarily palliative. Yet, decision makers or other family members may still perceive the patient as suffering from thirst or starvation. These images can haunt subsequent bereavement.

Even decisions to continue treatment may generate issues. Families may feel, in retrospect, that they have let the person suffer needlessly. They may sense the active disapproval and even isolation of medical personnel. In other cases, the pain experienced by the dying individual may cause family decision makers to wish that they had taken a more proactive role to end the suffering. This may be one reason that Swarte, van der Lee, van der Born, van den Bout, and Heintz (2003) found that in the Netherlands, family and friends of individuals who died by euthanasia seem to have less intense grief manifestations than those of individuals who died by natural death from cancer.

**FACILITATING FACTORS**

End-of-life decisions may not always compound bereavement. In some cases, active decision making at the end of life can be a facilitating factor, easing the strains of grief. Parsons and Lidz (1967) have challenged the notion that contemporary Western societies deny death. Instead, the authors suggest that Western societies take an activist orientation toward death—accepting its inevitability but trying to control its timing and nature.
The hospice and palliative care movements, as well as the movement toward physician-assisted suicide, can be seen as extensions of this orientation. While these movements accept that death occurs, they attempt to assert some control over the way the person dies, trying to make that death less painful, and in physician-assisted suicide, timed to the patient's choice.

Individual end-of-life decisions also can provide that sense of control at an otherwise uncontrollable time. This notion of control may mitigate the sense of powerlessness that one often feels in the face of death.

Moreover, these decisions may be the end result of a process that in and of itself is therapeutic. The best end-of-life decisions are made in a reflective process wherein the individual consults with medical personnel as well as other family members. The process can do much to ease subsequent grief. It can allow consensus building that can generate support and ease isolation. It can offer increased information and discussion that acknowledges the inevitability of death and the futility of further medical interventions and so can assist survivors in accepting the reality of death. The decision-making process can provide an opportunity to confront painful emotions and finish unfinished business. In some cases, this process provokes strong spiritual reflection as one assesses not only how one's philosophy or theology addresses the ethical issues involved but also how one's spirituality more directly speaks to the very loss. All of these factors may ease the tasks that one struggles with in grief (Worden, 2002).

Product as well as process may have a role in facilitating grief. Neimeyer (2001) notes that the reconstruction of meaning is a major factor in coping with grief. An individual may define the decision-making process as enabling a loved one to die a good death, perhaps by easing pain or fulfilling that person's wishes and reaffirming the individual's own responsibility. These inferred meanings might offer subsequent comfort.

Even if one cannot find meanings in the nature of death, one might see decisions, for example, to allow an autopsy or donate tissue or organs, as conferring subsequent benefits, incidental to the death. A person may see that these decisions benefited others or allowed medical science to find or to confirm new information. Finding benefits also facilitates the grief process (Frantz, Farrell, & Trolley, 2001).
Family members are not the only ones with a stake in decision making. Professional caregivers also may be in deep distress over ethical decisions.

A number of years ago, there was a case in a local nursing home of a woman in the advanced stages of Alzheimer’s disease who was dying of cancer. The woman thought everyone who worked around her was a son, daughter, or parent. She treated them as such. She endeared herself to the staff. Her husband, old and infirm himself, barely visited. There came a point when he asked that treatment cease. The staff felt considerable distress at her death. The ethics committee reviewed the decision, showing the woman’s advanced directives and reminding staff that artificial feeding and hydration are not always palliative. At the conclusion of the discussion, one of nurses stood up and said, “If it is so damn ethical, why do I feel so bad?” (Doka, 1994).

Staff members had become deeply attached to the woman. They experienced grief at her death. The initial intervention simply served to explain the ethical process that led to a decision to terminate all treatment, including nutrition and hydration. The staff had not been consulted before the decision was made. A review of the decision and a reaffirmation that it had been carefully made in conjunction with an ethics committee did little to mitigate staff grief.

The point is that ethical decisions cannot be dealt with only at a cognitive level nor be seen as the responsibility only of families and ethics committees. Caregiver grief can often be disenfranchised (Doka, 2002). Caregivers can become highly attached to patients. In fact, Fulton (1987) applied the “Stockholm syndrome”—the long-accepted concept that captive can identify with captors—to the care of the dying. To Fulton, the essence of the Stockholm syndrome is that crisis situations intensify the process of bonding. When patients die, caregivers may experience profound grief. This grief may be exacerbated when caregivers feel powerless over the decisions that may govern a person’s death. Both the lack of a formal role in this decision-making process and subsequent inattention to caregiver grief can complicate that bereavement, engendering distress and compassion fatigue (Doka, 1994; Puntillo et al., 2001).
IMPLICATIONS FOR PROFESSIONAL AND FAMILY CAREGIVERS

Though ethical decisions at the end of life can have significant effects on the grief reactions of both family members and professional caregivers (Richmond & Ross, 1994; Swarte & Heintz, 1999; Walwork & Ellison, 1985), there has not been much discussion of how the process by which end-of-life decisions are made and implemented can be made more therapeutic. A few points seem to be central.

The grief of family members is facilitated when they are encouraged to have a deliberative and inclusive process. Decisions to terminate treatment arouse strong feelings of ambivalence (Richmond & Ross, 1994; Walwork & Ellison, 1985). In addition, Foster and McLellan (2002) found that individuals report that they rely on family and friends to help make their end-of-life decisions. Such consulting is critical, as it develops a greater level of consensus and subsequent support. However, such a process does take time. This time allows the family an opportunity to weave their decisions into a consistent narrative of the patient's illness and death (Gilbert, 2002).

This process cannot be rushed. When families are engaged in the process, it is critical that physicians and others do not attempt to apply pressure to quicken that process. Two comments, drawn from clinical experience, illustrate the role of that deliberative process.

His physician [i.e., the client's father’s] kept pushing for us to make decisions to continue treatments long after it was necessary. We continued to ask, "How is this palliative?" He never could answer. Finally he simply said, "It's what I would do for my father." I said, "Fine, but you give us no compelling reason to do it to my Dad." Even now I am still troubled by his intrusion. My mother, though, was fearful—feeling we should listen to the doctor.

While in this case, the doctor's interference with the decision-making process created a note of distress, in the next case, the physician's respect for the family process was clearly appreciated.
The doctor was wonderful. She laid out the facts, all the options, patiently answered all our questions. It seemed clear that Mom would not emerge from her vegetative state. Yet, we still decided to wait a few days before disconnecting life support. We decided as a family that we would rather wonder if we waited too long rather than worry we terminated support quickly. This doctor understood. When Mom died, we were ready and at peace with our decision.

Moreover, the process may not end and with the patient’s death. After the death, decision-makers may need to review the decisions that they made in the course of the illness. Physicians need to understand that this is a critical aspect of care and one that is both necessary and facilitative of the grief process.

This process, however, should not be restricted to family members; staff members, too, have a stake in ethical decisions. They, too, need to be debriefed when patients die, especially when that death follows end-of-life decisions that may be seen as either prolonging suffering or hastening death. These debriefings should not only concentrate on the ethics of the decision-making process but should acknowledge the ways that these decisions may influence caregiver grief (see Doka, 1994; Puntillo et al., 2001).

Ethical decisions never arise in a vacuum. Culture, technology, social and individual values, spiritual and religious traditions, and legal struggles are among the many factors that frame ethics. It is critical, then, to recognize the complement of that fact. Ethical decisions do not proceed in a vacuum either. Decisions that have been made may continue to be reconsidered and reviewed long after the choice and its consequences.
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Dr. Doka was elected President of the Association for Death Education and Counseling in 1993. In 1995, he was elected to the Board of Directors of the International Work Group on Dying, Death and Bereavement and served as chair from 1997-1999. The Association for Death Education and Counseling presented him with an Award for Outstanding Contributions in the Field of Death Education in 1998.

REFERENCES


