Ethics, end-of-life decisions and grief*

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Abstract
Ethical 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 may 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 wishes, or simply seeming to survivors to be the right thing to do. This article explores the ways that end-of-life decisions influence grief, offering suggestions on factors that might mitigate problematic outcomes.

Keywords: End-of-life ethics, ethics, ethics and grief

Introduction
The following letter, sent to me anonymously many years ago, illustrates a crucial point. 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 may 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 wishes, or simply seeming to survivors to be the right thing to do.

Dear Ken,
I attended the workshop on grief that you presented in St. Paul on May 14 and was particularly interested, and moved, by the concept of disenfranchised grief. I have attended other workshops on this subject, but until now had not understood how important this concept is to fully understanding grief. You might remember that at the end of that workshop a man came up to you and said that he would like to write to you and that you might get an unsigned letter from some guy in Minnesota. I’m that guy. I drafted


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this letter in my mind several times over the last 6 months and finally decided to share it with you. It will become apparent why I feel that I must remain anonymous.

"Two years ago, my mother passed away. Over the days and weeks that followed, there was the usual grief and sadness to work through, but what my sibs and I couldn’t tell anyone was that mom ended her own life—and that we helped.

In 1994, Mom was diagnosed with a virulent form of breast cancer. The doctors were encouraging about treatment but candid about prognosis. Unless there was an advance in oncology research, she would not survive the cancer. She could expect 18 months to 2 years. I only saw her cry one time in the first few months. That was when she said that she hoped that her family would support her when she made the decision to give up the fight. And then she fought.

She toughed it out through surgery, weekly chemotherapy, radiation, and experimental treatments at the U of M. After 3 years and multiple hospitalizations, the disease and the brutal but time-giving treatments finally consumed her. The cancer had spread throughout her body—to her bones, major organs, around her neck, and across her chest and back. Only in the late stages did she need morphine for the pain. About the same time that the cancer began to erupt through her skin, it shut down one lung and left her with 25 percent capacity in the other. She told me that she hoped it wasn’t God’s plan for her to suffocate to death.

A few weeks, dependent on oxygen, when suffocation appeared to be His plan, she asked us how much morphine she would have to take to not awake in the morning. We didn’t know, and because assisted suicide is illegal, we couldn’t get answers from the medical community. Left to books, the Internet, and shadowy phone calls, we pursued the information. It took us 3 more days to know whether she had enough morphine to free her soul.

My sibs agreed that we would not proceed until each of us could personally come to terms with what Mom was asking of us, and only after we all were sure that this was what she wanted. Each day, Mom reaffirmed her decision. During this time she also asked to see her lifelong minister. Her intentions caused him some professional anguish; she wanted his blessing.

Mom was very spiritual and was a member of her church for 50 years. The whole congregation had been there for her. After some discussion, the minister replied that he had admired her courage throughout the course of the disease and that he was at peace with her decision. He added that it was not his place to give her permission, but he could give her his prayers. On her last day on Earth, they prayed together. I never wanted to believe in Heaven more in my life.

I was next to Mom when she took her last breath, along with my sibs and three of her grandchildren. Suicide wasn’t the cause of her death. It would be an inaccurate and unfair description. She didn’t want to die; she had to die. Cancer tried to dictate the terms of her death. But in the end, Mom finally beat the cancer. She died on her own terms—at home, surrounded by her loved ones.

Our extended family came to know and affirm how Mom died. We had to let most everyone else believe that it was just an extraordinary coincidence that her entire family was at her side. There’s enormous dissonance when you feel that you have to mislead friends about the truth—when you don’t think you did anything wrong—when there is no shame or guilt.

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 this case, John admits to assisting the suicide of his mother. 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 legal ambiguity of Minnesota’s laws.

Positively or negatively, the end-of-life decisions that survivors make influence subsequent grief. This article explores that role. It begins with three central assumptions.

The first is that the end-of-life decisions, like so many of the factors that influence grief responses, can be either facilitating or complicating, perhaps both at the same time. The paper explores both aspects of end-of-life decisions.

A second assumption is that professional caregivers as well as families, medical and nursing staff 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, both groups may influence the others’ decisions. For both family and staff, the aftermath of these actions or subsequent behaviors may generate doubt on the efficiency of these decisions.

A third assumption is that these decisions cannot be understood apart from their context. Prolonged illnesses or sudden deaths create complications to grief in and of themselves. Moreover, these contexts are not mutually exclusive. As Rando (1993) notes, persons even...
within the context of a lengthy illness, can die “suddenly”—that is at unexpected time and manner. The person slowly dying of cancer is not immune from a sudden deterioration or even a heart attack or a stroke. In short then, end-of-life decisions cannot be seen 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 article then considers these strategies.

Complicating factors

As stated earlier, end-of-life decisions can both facilitate and complicate grief, sometimes simultaneously. In addition, it was stated that end-of-life decisions could not be separated from the context in which they occur. Research has indicated that sudden death, as well as deaths that follow long-term illness, creates its own complications (see 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 as well as a lack of forewarning. These factors can also complicate a sudden death from natural causes such as a heart attack, aneurysm or stroke. Here, too, there is preventability and lack of forewarning. Ethical decisions such as terminating treatment or stopping heroic measures are often undertaken then in both shock and grief with little forewarning or forethought.

There are other factors when the illness is prolonged. Family caregivers may be highly stressed as they cope with incessant physical, financial, social and psychological demands of life-threatening illness. It may be difficult to witness the slow deterioration and pain expressed by the dying patient. The illness may generate considerable ambivalence as family members simultaneously wish for death and an end to the person’s and family’s suffering while concurrently wishing that the person would remain alive. There may also 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 (Worden, 1991; Rando, 1993).

End-of-life decisions 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 midst of impending death. Individuals or family members may experience conflict between following their own beliefs and choices while honoring the expressed wishes or beliefs of the deceased.

This suggests another potential factor in end-of-life decisions. Normally, one person within the family system may hold the health proxy. Such a proxy in the United States authorizes a given person to make medical decisions for an individual incapable (perhaps because the ill individual is unconscious or has diminished capacity) of making such decisions. Families 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 family conflicts or revive family disputes. These family conflicts then can make 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 consequent 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 (Worden, 1991; Rando, 1993).

Some of the decisions that may be made, such as assisting a suicide, can create additional issues for survivors. They may create legal investigations that add to the stress of the loss. The decision may isolate them 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 may render 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 even 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 that neither artificial feeding nor hydration are necessarily palliative. Yet, decision makers or other family members may still perceive the patient as suffering with thirst or experiencing starvation. These images can haunt subsequent bereavement.

Even decisions to continue treatment may generate issues. Families may feel, on retrospect, that they may have let the person suffer needlessly. They may sense the active disapproval and even isolation of medical personnel. In other cases, the pain and suffering experienced by the dying individual may create a situation where family decision makers wish that they took a more proactive role to end suffering. This may be one reason why Swarte et al. (2003) found that, in the Netherlands, family and friends of individuals who died by euthanasia seem to have less intense grief symptoms than those who died by natural death from cancer.

Facilitating factors

End-of-life decisions may not only 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 the timing and nature of death. The hospice and the palliative care movements, as well as movement toward physician-assisted suicide, can be seen as extensions of this orientation. While all of these movements accept that death occurs, all attempt to assert some control over the way that the person dies, trying to make that death less painful, and, in physician-assisted suicide, timed to the patients’ choice.

Individual end-of-life decisions can also provide that sense of control. These decisions allow a semblance of control at an otherwise uncontrollable time. This notion of choice may mitigate the sense of powerlessness that is often felt 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 where the individual has to consult with medical personnel as well as with other family members. The process can be as much to ease subsequent grief. It can allow a process of 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 complete unfinished business. In some cases, this reflective process provokes strong spiritual reflection as individuals assess not only how their philosophy or theology addresses the ethical issues involved but also how their spirituality more directly speaks to the very loss. All of these factors may ease the tasks that are struggled with in grief (Worden, 1991).

Product as well as process may have a role in facilitating grief. Neimeyer (2001) reminds us that the reconstruction of meaning is a major factor in coping with grief. An individual may define the decision-making process as one that enabled a loved one to die a good death, perhaps by easing pain or fulfilling that person’s wishes and reaffirming one’s own responsibility. In such a case, 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 other persons or allowed medical science to find new, or confirm previous, information. Finding benefits also facilitates the grief process (Frontz et al., 2001).

Professional caregivers: Beyond ethical rounds

Family members are not the only persons with a stake in decision making. Professional caregivers also may be in deep distress over ethical decisions that are made.

A number of years ago, there was a case in a local nursing home where a woman in the advanced stages of Alzheimer’s disease 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 where he asked treatment to 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 decision making that led to a decision to terminate all treatment including nutrition and hydration. The staff had not been consulted before the decision. A review of the decision and a reaffirmation that the decision had been carefully made in conjunction with an ethics committee did little to mitigate staff grief.

The point is that ethical decisions cannot only be dealt with at a cognitive level nor be seen as only the responsibility 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”—that is 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 the 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

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

The grief of family members is facilitated when family members are encouraged to have a deliberative and inclusive process. Decisions to terminate treatment arouse strong feelings of ambivalence (Walwork & Ellisen, 1985; Richmond & Ross, 1994). 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 crucial as it also develops a greater level of consensus and subsequent support. However, such a process does take time. This time allows the family the opportunity to weave their decisions into a consistent narrative of the patient’s illness and death (Gilbert, 2002).

This process cannot be rushed. For families that are engaged in the process, it is important 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. client’s father) 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 with a patient’s death. After the death, patients may need to review the decisions that they made in the course of the illness. Physicians need to understand that this as a crucial 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 progress but also 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 important, then, to recognize the complement of that. 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 their consequence.

References


Biographical Notes

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