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When Illness is Prolonged: Implications for Grief

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When Illness Is Prolonged: Implications for Grief

Kenneth J. Doka, Ph.D.

Introduction

When Lisa was caring for her mother, who was in the late stages of cancer, the demands of constant caregiving began to take a toll. Even though hospice services provided a health aide for much of the day, Lisa provided care at night. For six weeks, her sleep was interrupted at least three times each evening. Toward the last week of her mother's life, Lisa began to wish that her mother's agony—and hers—would end. Now, after her mother's death, she feels guilty about her feelings.

Tom, too, is troubled by his reaction to his brother's death. When Mark was dying of AIDS Tom visited often, but at the end of Mark's life the physical toll of the disease disturbed Tom. His brother became emaciated by the disease, and his neck and arms were covered with lesions. Tom hated to even touch him; only his deep love and sense of duty compelled him to visit.

"Easy for him, hard for survivors," states the conventional wisdom about sudden loss. Most acknowledge that the suddenness of loss complicates the grief of survivors. There is no time to say goodbye and death is traumatic. Conversely, death after prolonged illness is often considered a blessing or relief. Survivors are seen as having had ample opportunity to grieve the anticipated loss. There is little expectation that grief will be profound, prolonged, or complicated.
Yet the realities of loss are far more complex. While it is clear that sudden losses create complications for survivors (Doka, 1995), prolonged illness can also engender factors that exacerbate grief. Rando (1983) and Sanders (1983) found that both sudden losses and losses after extended illnesses intensified grief. While issues of trauma, preventability, or inability to prepare for the loss certainly trouble survivors of sudden loss, other issues such as disfigurement, suffering, the experience of the illness and the stresses of caregiving, complicate the grief of survivors of the prolonged loss.

The key issue in grief is not to assess what types of losses are easier or harder, but rather to review factors that complicate or facilitate loss in each different circumstance. This chapter attempts to do that in two ways. First, it explores factors that can trouble survivors as they cope with a loss after prolonged illness. Second, it offers suggestions for therapeutic activities that caregivers can use during the illness, as well as at the moment of death and after, to assist grievers, whether those grievers are others or oneself. Prior to this it is critical to understand the process of a prolonged life-threatening illness. For often, issues at any point in the illness may have subsequent effects on grief.

The Process of Life-Threatening Illness

A prolonged life-threatening illness is best viewed as a series of phases (Doka, 1993). The first phase may be described as the prediagnostic phase. This is the period of time between when a person first suspects a problem and when that person seeks medical advice. Few people immediately run to a physician at the first sign of a symptom. It is important to explore this phase for a number of reasons.

This process can reveal much about the ways that a person will cope with life-threatening illness. John, a 56-year-old man, was experiencing frequent and severe headaches. For a long time he simply tried to ignore the problem and self-medicated. As the headaches continued, he began to become anxious, eventually seeking medical help. He never shared his fears, or even the fact that he was undergoing testing, with his wife until he needed to be hospitalized when
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diagnosed with a brain tumor. Throughout his illness, John tended
to exhibit much of the same behavior; he continued to deny the
seriousness of the illness, delayed treatments and coped alone.

Decisions made at this time by either the ill individual or the
caretakers can reverberate for survivors throughout the grieving pe-
riod. When John eventually died, his wife was tormented by her
belief that she should have recognized his discomfort and made him
seek medical help earlier.

The second phase, the acute phase, is characterized as the crisis of
diagnosis. Many families describe this crisis as a major one, second
only to the death itself. This phase actually may extend over a period
of weeks as the individual undergoes a series of medical tests that
gradually narrow the diagnosis. In this process, both patients and
their families may begin to experience anticipatory grief. Such grief
is not only an anticipation of a future possible loss, but also a reac-
tion to the losses being experienced, such as losses of health, mobil-
ity, and future plans.

In a prolonged illness, the chronic phase tends to have significant
implications for the subsequent grief of survivors. This phase is the
period when the goal of medical treatment is still to seek a cure or
extend life. It can be a very difficult time both for patients and their
families. Friends and family who were so present during the crisis
around the diagnosis tend to return to their own lives. The patient
needs to cope with the symptoms of the disease, the side effects of
treatment, and, in many cases, the ongoing demands of life, such as
home, family, and work. If the illness creates significant disability,
family members may be called upon to assume significant caregiving
tasks in addition to their ongoing roles. They must cope together
with the stress, feelings and anxieties that the illness generates. Often
their own plans are contingent on the patient's illness.

The nature of stresses in the chronic phase will be influenced
strongly by the pattern of the illness. Some illnesses, such as mul-
tiple sclerosis, have a pattern characterized by descents that then
stabilize for a while at a new level of disability. Other diseases—
leukemia and AIDS, for example—have patterns of remission and
relapse. Still others, including degenerative diseases like muscular
dystrophy or some forms of cancer, show long, slow declines in health and functioning.

Each of these patterns creates unique issues for survivors. For example, family members coping with the stress of caring for a patient during a period of slow decline may experience a strong sense of relief along with the grief. These natural feelings of relief at the death may generate significant guilt.

In some cases, patients may temporarily enter a recovery phase, where they and their families believe that the illness has been cured or controlled. John and his physician hoped that the surgery had fully removed the brain tumor. John’s functioning returned to normal levels, and for two years he believed the illness was behind him. Even in this period, John reported three responses typical in recovery. First, he experienced a new sense of appreciation for life and began to reorder his priorities. Second, he realized that the illness had changed his life in a number of ways, some of which were not favorable. Given his insurance risk, he felt locked in his job, and he also believed that he was unlikely to be promoted beyond his present level. Finally, even though John believed he was cured, he constantly struggled with anxiety. Each new headache or pain brought intense fear of cancer.

In the terminal phase the goal of treatment shifts from cure or control to comfort. Here, the patient and family begin to prepare for eventual death. Both may need to make or review decisions on such questions as whether or not to enter a hospice program, whether or when to terminate certain treatments or withdraw life support and who should be empowered to make decisions should the patient no longer be able. The decisions made about these issues may reverberate throughout the grieving process.

**Living with Grief After Prolonged Illness**

Whenever one experiences loss, certain reactions are common. Grief affects at all levels—physically, emotionally, cognitively, behaviorally, and spiritually. Physically, bereaved persons may experience a variety of reactions including physical aches and pains, nausea, or
insomnia. Tiredness is typical too, as the body compensates for long periods of operating under stress.

Emotional reactions are also common. Any feelings—anger, jealousy, anxiety and sadness, to name just a few—may be evident. Two deserve special mention. Sometimes survivors may experience a sense of relief or emancipation. The burdens of caregiving have ceased, as has the deceased’s suffering. As mentioned earlier, these feelings may generate guilt. Survivors may also feel guilty about decisions made during the course of the illness. They may experience ‘moral’ guilt, believing the illness and suffering of the deceased were a punishment for their transgressions. They may experience ‘role’ guilt as well, regretting that they were not a better spouse or child. This type of guilt can be very evident after a prolonged illness where the strains of constant caregiving exacerbate tensions or provoke anger and resentment toward the ill person.

Cognitive reactions can include depersonalization, confusion and disorientation. Survivors may actually behave differently, or find it difficult to concentrate. Some survivors may seek reminders of the deceased; others may avoid such reminders. Some may find it difficult to engage in activity; others may seek diversion in constant activity.

Spiritually, grief has many manifestations. Some persons may search for meaning in the loss. Some may return to their spiritual roots, while others may question their spiritual and religious beliefs. Even the great Christian apologist, C.S. Lewis, reacted with a strong sense of spiritual alienation when his wife died of cancer. “Where is God when you need him? . . . A door slammed in your face. . . .” (Lewis, 1961, p. 4). Later he could realize it was his own frantic need that slammed that door.

All of these reactions are common to any grief. And the experience of grief, as in any loss, is highly individual, dependent on the nature of the relationship and the personality and coping styles of the bereaved, as well as the availability of informal and formal support. Yet when loss follows a prolonged illness, several factors can complicate the grief of survivors.
1. The Experience of Illness

First, there is the meaning of the disease. As Sontag (1978) reminds us, diseases are steeped in meaning. They are not simply perceived as biological processes but carry psychological and social implications as well that vary among individuals. For some individuals a diagnosis of AIDS simply is viewed as a tragic viral infection. Others may view it as a shameful stigma or a punishment from God. The degree to which a disease is defined with negative meanings by survivors or others in their community may affect the willingness or ability of survivors to seek and obtain support. For example, if survivors define AIDS as shameful, they may be reluctant to share their loss with others, effectively disenfranchising their grief. If survivors define it as a punishment from God, their spirituality may give scant comfort; in fact, their spiritual struggle is likely to complicate their grief.

Not only the meaning but the nature of the disease may affect the grief of survivors. Each disease has its own unique symptoms, treatment and side effects, and pattern, and each will affect the grief of survivors differently.

Two critical symptoms that have significant effects on grief are disfigurement and mental disorientation and/or personality change. Disfigurement, especially facial, can create strong ambivalent feelings in family members. While they love the person, they may be physically repulsed by them. Such feelings later can generate strong feelings of guilt. One mother, whose adult son died of AIDS, succinctly described these reactions:

In the end he had wasted away to a skeleton. There were red lesions. He was always so handsome. Now I couldn't even bear to look at him, to touch him. One day after I bathed him, I actually had to vomit. I hope he didn't know. I am so ashamed.

Mental deterioration and personality change are not uncommon in prolonged illness. In some illnesses, like Alzheimer's, it is the essence of the disease. In others, such as AIDS or some forms of cancer, it can occur either as a direct result of the disease process or as a side effect of treatment. In some other cases, patients, given the psychological stress of a prolonged illness as well as facing death, may cope in ways uncharacteristic of prior behavior.
Such changes can have many effects on the grieving process. In and of themselves they create an additional loss that survivors must experience. They also can generate strong feelings of ambivalence, anger and resentment. Survivors are now caring for a very different person from the one they once knew. For example, one wife recounted her experiences with her husband as he died of a brain tumor:

In the end, he became so different—he was so angry and hateful. I kept saying ‘This is not the man I married,’ but I wondered where all this hate came from. Was it the tumor, the medication, or was this always a part of him that stayed hidden? Sometimes even now I think, ‘How much of my marriage was real?’

This case illustrates another aspect of mental deterioration and/or personality change. Her husband’s angry outbursts caused conflict between them in the terminal phase, leaving her, at his death, with much guilt and considerable unfinished business.

2. The Extent of a Patient’s Suffering

The perception of how much a patient suffered in a prolonged illness can influence grief in four ways. First, it can contribute to feelings of helplessness among family members. Second, suffering can generate ambivalence about the patient’s continued living. The patient’s intimate network may truly want that person to live, but they may also want the patient’s suffering, as well as their vicarious suffering, to end. Later, survivors may feel guilty about wishing for the patient’s death. They also may feel guilty about their grief, thinking it selfish to grieve a merciful death.

Third, the perception that the patient suffered greatly may diminish the social support available to immediate survivors. Comments such as “It’s better he’s dead, he suffered so much,” serve to effectively disenfranchise grief.

Finally, the question of suffering can deeply trouble survivors’ spirituality. They may find themselves angry with God or find their own spirituality inadequate in providing a framework to understand the suffering. This can rob survivors of the strength their spirituality previously provided.
3. The Issue of Medical Decisions

Throughout the course of a prolonged illness, patients and their families have to make more decisions now than they did in the past. While years ago there may have been few options in treatment, now individuals may need to decide among a variety of options. Should one treat a problem such as cancer surgically, using chemotherapy or radiation therapy? Even within therapies there are options. How radical should the surgery be? What course of chemotherapy should one select? When should care become palliative, not curative? Should one attempt to be on an experimental protocol? In addition to conventional options, patients and their families may have to negotiate a host of nonconventional therapies—some complementary, like imaging, and some true alternative therapies that exist outside of and often preclude conventional medical treatment.

Technology, too, is complex and has created ethical issues. In many ways, struggles with issues of euthanasia and abortion derive from a similar difficulty in defining the beginnings and ends of life. Living wills and advance directives may help clarify a patient’s wishes and assist families with discussions over these issues, but there still are considerable areas of gray. When should treatment stop? What treatments should be terminated? Who is responsible for ultimately making these decisions?

Beyond the complexities of treatment and technology, there is another significant factor that has contributed to the patient’s and family’s increased role in medical decisionmaking. Due to concerns about liability, as well as increased attention to a patient’s autonomy and rights, many physicians are reluctant to offer strong advice and direction. Many physicians instead see their role as presenting an array of options for patients to decide. While this enhances patient autonomy, patients and their families may feel overwhelmed and unprepared as they make medical decisions.

After the patient dies, family members may be inclined to second guess those decisions. This can complicate the grieving process, generating further anger or guilt. In some cases it may even exacerbate conflicts between family members if they blame one another for choices made. Such conflicts may divert energy from grief and limit social support.
Interventions for Grief in Prolonged Illness

While there may be factors that complicate grief when illness is prolonged, the extended time of the illness does offer opportunity for activities and interventions during the illness, and at the time of death, that can mitigate grief. And, as with all losses, there also are activities and interventions helpful to survivors after the loss.

Throughout the illness, caregivers can assist families in acknowledging the many responses they may be having. Especially in the terminal phase, family members may be troubled by feelings of ambivalence—hoping that the individual's struggle, and their own, is nearing an end. If the dying person begins to withdraw, family members may feel confused, hurt, and rejected. They may be physically exhausted. Guilt, anger, and sadness are common. They may feel awkward, unsure of what to say or do. Helping families to acknowledge and address these feelings prior to loss may help later grief.

Two actions that can be extremely helpful in this period are remembrance and ritual. Reminiscence can be powerful both for the dying person and for friends and family. For the dying person, reminiscence reinforces the sense that one's life had meaning and purpose. For family and friends, it provides an opportunity to share memories and to finish business. In some cases, it may allow a moment to accept or offer forgiveness or even simply to clarify feelings. Later, family and friends can take comfort in these moments, feeling that they were able to share love.

Rituals, too, can be significant ways to finish business and to say goodbye. For example, the Roman Catholic Ritual of Anointing the Sick can give families and patients a sense of religious comfort. But rituals need not be overtly religious. In one family, a dying father simply hugged each of his children, giving each one a special gift. And rituals, because they involve activity, can also reaffirm a sense of control in an otherwise uncontrollable situation.

Other activities can serve a similar purpose. One of the great values of hospice care is that it keeps the family directly involved in the care of the dying person. To the extent that families are both able and comfortable, this process can mitigate later grief. Family members may be more aware of the suffering, and thus are more prepared
to accept the death. In addition, ongoing involvement provides opportunities for non-verbal acts or feelings. After the death, survivors can remember, and be encouraged to recount, the many ways they demonstrated care. However, a key issue is respecting limits of comfort. Survivors may be troubled at the physical deterioration of the dying person and disturbed by their own feelings of repulsion and perhaps withdrawal.

Many of these activities can be encouraged with comatose patients as well. Often simple acts such as stroking the person or taking part in routine physical care can assuage feelings of uselessness. This period, too, can be a meaningful opportunity for family members to take leave and finish remaining business, saying things to the comatose person that might have otherwise caused discomfort.

The time of death provides other important moments. Survivors need not be rushed out of the room. They may wish to exercise the option to spend time with the deceased, perhaps to say a few closing words or perform a special act such as dressing or washing the body.

After the death, survivors need to struggle with their loss. Like other survivors, they will experience the roller coaster of grief reactions, including physical, emotional, cognitive, behavioral, and spiritual manifestations. Often, it is helpful to review the illness experience with survivors, beginning with their experience even before the diagnosis. This will provide an opportunity to assess any issues from the illness that may affect the grieving process.

While survivors of a loss through prolonged illness struggle with many issues common to anyone experiencing grief, one unique issue is the need for survivors to recapture the image of the person prior to his or her illness. When an illness is prolonged and the dying person slowly fades away, images of the person at the time of the illness can overwhelm earlier, more positive and vibrant images. Many of the interventions mentioned before, such as reminiscence and ritual, as well as reviewing photographs, can reaffirm those previous images. Funeral homes, too, can play a significant role when they prepare the deceased to look more as he or she was prior to the ravages of the illness.
Conclusion

While these actions may help mitigate grief, it is critical to affirm that survivors of someone who has died because of a prolonged illness will still experience grief. That grief must be coped with, in each survivor's own individual style.

One of the myths that often troubles survivors of a death after prolonged illness is the belief that the death itself was a mercy and that they had ample time to adjust to the loss. As this chapter has indicated, each type of death creates its own unique issues for survivors. The fact that a prolonged illness preceded a death does not necessarily mean that the death was either expected or welcomed. Many survivors can have a profound sense that the death was not expected at the time it occurred (Doka, 1984). And even if there are feelings of relief, these feelings are simply part of the mix of feelings that make up the process of grieving.

A key issue with survivors when loss is prolonged is not to disenfranchise their grief. Disenfranchised grief occurs when a loss is negated and the survivors' right to grieve is unsupported (Doka, 1989). The antidote to disenfranchised grief lies in the simple acknowledgment that every circumstance of loss, including loss after prolonged illness, creates its own unique grief.