

18. End of Life Issues

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I believe that we should make it a habit to think about death and dying occasionally, I hope before we encounter it in our own life.

–Elizabeth Kübler-Ross¹

It's not that I'm afraid to die. I just don't want to be there when it happens.

–Woody Allen

A Poet at Life's End

The former Poet Laureate of the United States Donald Hall wrote “A carnival of losses: Notes nearing ninety” (Hall, 2018) shortly before his death. Here is an excerpt:

“Suppose I am the 150-year old maple outside my porch. When winter budges toward spring, I push out tiny leaves, which gradually curl yellowish green then enlarge, turning darker green and flourishing through summer. In September flecks of orange seep into the green, and October turns the leaves gorgeously orange and red. Leaves fall, emptying the branches, and in December only a few remain. In January the last survivors flutter down onto snow. These black leaves are the words I write.” (p. 14).

The use of the seasons as a metaphor for the stages of life is a common device, but Hall expresses his feelings beautifully in this short synopsis. He is telling his readers how his life has become circumscribed near the very end (cf., Joan Erikson in Chapter 9 on “very old age”). He had stopped writing poetry a number of years earlier due to his perceived limited ability to continue with his best works behind him. Yet this is still a wonderful piece of prose-poetry. When I read these lines, for me the black leaves, rather than limitation, suggest my favorite *jiu qu hong mei* black tea

gently steeping in my panda-adorned cup. Delicious! Would that we should all fare so well mentally at this stage of life!

Death as the Final Stage of Life

Dying is, of course, the final stage of life as we know it. Confronting death is indeed challenging, not only for the aging or dying person, but also for her or his family, friends, and community. Earlier chapters on Jung and (especially) on Erikson examined some of the psychological issues faced when approaching death in old age, but stopped short of dealing with preparing for death itself and with the process of dying. The present chapter explicitly examines such end of life issues, including psychological states and stages of the dying person, grieving and emotional reactions on the part of others, legal and medical matters, and caring for the terminally ill.

People usually think of dying as the final act in a lifetime drama; a natural end following advanced age. But the tragedy is that some people also die without having lived long lives. Obviously, death can occur in infancy, childhood, or any stage of life prior to old age. Dying “before one’s time” presents its own special problems of coping, adjustment, and, on the part of those close to the dying person, bereavement.

The following section examines the pioneering work of Elizabeth Kübler Ross on the stages of death and dying. The reader should be advised that later research suggests that not all of these stages are always present, and that earlier stages (especially denial and anger) may recur later as well; hence, the ordering of the stages is not always consistent. What is important, however, especially for family members, health caregivers and psychologists, is to be able to recognize each type of reaction when it occurs.

Kübler Ross's Stages of Death and Dying

First Stage: Denial and Isolation

How does a person react upon learning the he or she has a terminal illness? The very first or initial reactions vary considerably from one person to another, ranging from logical rationality and calmness to complete panic. There are too many variables involved to make any kind of simple generalization possible. Reactions depend a great deal on the patient's personality, the manner in which the information is communicated, the certainty with which the diagnosis is presented, and on whether or not the patient already suspected something of the kind. But once the news sinks in the typical reaction is Kübler Ross's first stage of dealing with impending death: denial and isolation.

Denial is that familiar, Freudian form of rationalization in which people simply refuse to face reality. The typical reaction (at least for the unprepared patient) is "No, no, that can't be true." It is as if the shock of realization is just too great to mentally process. It is also very much a normal reaction.

Denial can be an effective defense mechanism when not carried to extremes. It buys one time to marshal one's defenses; to mount a more effective counter-reaction; to more effectively deal with the situation that one faces. In Elizabeth Kübler Ross's words (1969, pp. 39 & 40) "Denial functions as a buffer after unexpected shocking news, allows the patient to collect himself, and with time, mobilize other, less radical defenses Denial is only a temporary defense and will soon be replaced by partial acceptance."

Very rarely will a patient carry their denial to the end of life, but it does happen occasionally. Kübler Ross described one sad example of female patient with terminal cancer who would not listen to any medical information pertaining to her condition, even while hospitalized. She plied her makeup on her face ever thicker as if to disguise her ill condition until it became so grotesque that she resembled a clown. As with most cases of denial, this patient tried to isolate herself from others and wished to be left alone much of the time.

The Role of Health Care Providers In Giving the Patient the News

Kübler Ross believes that it is not a question of *whether* to tell a patient he or she has a terminal illness but rather one of *how* to inform the patient. This requires considerable sensitivity. The physician should examine her or his own attitudes toward death, and must be very sensitive to the patient's defenses and willingness to hear this news. Kübler Ross says "It is an art to share this painful news with any patient. The simpler it is done, the easier it is usually is for a patient who recollects it at a later date, if he can't 'hear it' at the moment. Our patients appreciated it when they were told in the privacy of a little room rather than being told in the hallway of a crowded clinic" (1969, p. 37). It is cruel, she insists, to tell a patient of a terminal condition when she or he is not yet quite ready to hear this.

But Kübler Ross stated that "I think it is the worst possible management of any patient, no matter how strong, to give him a concrete number of months or years. Since such information is wrong in any case, and exceptions in both directions are the rule, I see no reason why we even consider such information" (p. 30). This advice should be tempered, she acknowledges, because the patient may need time to get his or her affairs in order while he or she still has the strength and resolve to do so.

Kübler Ross noted that physicians and nurses received training in how to save and prolong lives, but not in how to help a person come to grips with death. With such an attitude, losing a patient is perceived as a failure. Too often, then, doctors were willing to use any and all means available to keep the patient alive. However, this view seems to be changing – remember that her book was written in 1969. Increasingly today health care professionals are trained to deal more effectively and directly with end of life issues taking into account the patient's needs and best interests.

Second Stage: Anger

For most patients the denial stage cannot last for a very long time. Once this reaction abates, and the reality of the situation sinks in, the patient's reaction changes. Instead of "It can't be true" the reaction becomes "Why *me*?" As with denial, anger is a perfectly natural reaction. Yet this emotion can be very hard for family and friends to comprehend, especially when the anger is displaced onto others, including his or her health care providers, sometimes in the form of temper tantrums. It is therefore very important to understand not only how the ill person feels, but why as well; or as Kübler Ross says, to put oneself in the position of the dying person. One must acknowledge the anger as a legitimate reaction. The sick person needs to be given time to deal with their anger as well as respect and understanding.

The anger stage usually lasts longer than denial. Although most people eventually move beyond this stage, some experience great difficulty in doing so. Complications may also result from unrelated mental health issues, such as unresolved anger from other sources. Kübler Ross described the case of a young nun, Sister I., with Hodgkin's disease, who seemed to carry over childhood resentments, having always been expected to be the "good girl." Her present situation was also compounded by other factors, including the death of her father at about the same time she was diagnosed, family business issues, and other forms of stress. Professional mental health workers or (if the patient is religious) chaplains or spiritual advisers can often help to move the patient through and beyond this stage, as was the case with Sister I.

Third Stage: Bargaining

Some people pass over the anger stage and enter into a period of bargaining, usually with God, in an attempt to extend the time that they do have, or at least to improve the quality of that time. Often they believe that if they are willing to make some sort of personal sacrifice then they will be granted such a favor in return. In some cases such "bargains" can indeed produce genuine good deeds, as when (for example) a dying father forgives a son or daughter for some past transgression – or perhaps asks for

forgiveness himself. In essence the dying person requests an extension, or “time off for good behavior.”

Bargaining in this manner is in some regards like a throwback to childhood, in which the “bad” child pleads with his or her parents – if they just give him another chance then he will be good. But even when bargaining seems childish the family, health care professionals, and mental health professionals, must be able to recognize bargaining behavior and to provide appropriate acknowledgment (if asked for) and support. However, bargaining is often private and secretive.

Fourth Stage: Depression

Eventually the dying person is no longer able to deny the certainty of death. Following the stages of denial, anger, and bargaining, she finally accepts this reality. This is the time when depression sets in. It often occurs when physical symptoms worsen and this deterioration cannot be ignored.

Kübler Ross distinguishes between two kinds of depression. The first she calls *reactive depression*, the second *preparatory depression*. Reactive depression is a response to a loss that has already occurred; loss of physical or mental functioning, or the resulting loss in self-esteem due to the medical condition. In contrast, preparatory depression concerns the future; it anticipates her final stage of acceptance.

Significant others can often help to brighten the mood of a person who is depressed for whatever reason. However, Kübler Ross believes that attempting to cheer up a person with anticipatory depression can be self-defeating. Whereas such a person may have a strong need for support, this need might best be met by other means than attempting to talk the person out of their depression: “In preparatory grief there is no or little need for words. It is much more a feeling that can be mutually expressed and is often done better with a touch of a hand, a stroking of the hair, or just sitting silent together. This is the time when the patient may just ask for a prayer, when he begins to occupy himself with things ahead rather than behind. It is a time when too much interference from visitors who try to cheer him up hinders his emotional preparation rather than enhancing it” (1969, pp. 87-88).

Kübler Ross believed that this form of depression is both necessary and beneficial in reaching the final, acceptance stage.

Fifth Stage: Acceptance

Acceptance of one's impending death should not be mistaken for a happy state, but it can be a more peaceful state than the preceding four stages. When this stage is reached the patient has done some mourning and grieving for herself, and she is tired, probably weak, and even resigned. Some of the pain may be gone (at least the emotional pain) and the patient's circle of visitors is usually diminished by her own choice. Perhaps she desires only to see one or two very close family members. Short visits may be best. Nonverbal sharing may be much more important than active talking.

Kübler Ross states that "This is a time when the television is off! . . . The patient may just make a gesture of the hand to invite us to sit down for awhile. He may just hold our hand and ask us to sit in silence" (1969, p. 113). Such private, intimate moments can be the most meaningful for both parties – the patient and the loved one, as both acknowledge silently that the end of the struggle is near.

Evaluating Kübler Ross

Research does not show clear support for Kübler Ross's five stages (Kastenbaum & Moreland, 2018). As stated earlier, any, all, or none of these stages may occur in a given person, and when they do occur they may not happen in her specified order. However, at least *some* of the stages can be observed in *many* people, and *all* of them can be observed in *some* people. In the absence of a more comprehensive theory concerning the final stages of life, Kübler Ross's stage descriptions can be highly useful to families and health care professionals alike. At least they provide some guidelines for signs to look for; and when they are present they also give some guidance as to how to react to them. But it seems fruitful to think of these stages as types of *coping strategies* that people may employ to varying degrees rather than as sequences through which they inevitably travel.

Kübler Ross should be remembered as a pioneer in the study of death and dying whose work helped focus an entire industry of health care professionals on the critical importance of dealing with death and dying in a realistic and dignified manner. Kübler Ross was an activist and advocate for honest communication between caregivers, patients, and families.

How *do* We Want to Die?

People are Living Longer

Today people live longer than ever before. This longevity is due to many factors, including safer environments, healthier diets, better medical care and treatment, and the conquest of numerous infectious diseases with vaccines and antibiotics. Infant mortality – deaths in childbirth and infancy – is no longer the threat it once was, and better medicine and medical care facilities for the elderly have also extended life at the other end of the age spectrum.

The latter can be a mixed blessing for some, when quality of life issues are considered. Doctors and nurses are trained to save lives, sometimes at all costs – including very real expenses to families and insurance companies. Losing a patient in a hospital or rest home may be regarded as losing a battle. In other words, losing a patient is still sometimes considered a failure on the part of the medical professional, even when the patient is elderly and may have little or no hope for a life that is healthy, active, and free of pain.

Palliative Care for the Elderly and the Hospice Model

But a different model has begun to emerge. That model is one of hospice and of palliative care, in which dying is seen (quite naturally, one would think) as a normal part of life, and in which the patient nearing the end of life is understood to have special needs that must be recognized as that time of transition approaches. In *hospice care* both patient and staff understand that death is close at hand – if not in a matter of hours then perhaps in a matter of days or weeks. The patient needs understanding and assistance, and the ability to control her or his pain so that the last

moments are not intolerable. The goal of the staff is not to prevent death, but rather to make the patient comfortable both *in* the process of dying, and *with* the process. Hence *palliative care treatment* refers not to treating the patient's illness; rather it pertains to the provision of comfort to the terminally ill. In some cases this can include pain management through large doses of morphine.

Palliative care also includes provision of the small pleasures that a sense of normalcy requires. This includes (for most) companionship, entertainment, preferred foods; perhaps a holy book by the bedside. Comfort with the process means that the patient, family, and staff deal with the fact of the encroaching death, and do not fight it or ignore its inevitability. This can be painful or uncomfortable for those close to the patient, but facing this reality is necessary for the well-being of the dying person, at least if the person is mentally aware of his/her state and surroundings; for everyone concerned must make their necessary preparations. This means not only taking care of legal matters, such as wills and living wills, but also people need to be prepared psychologically for death. Simple acknowledgment is the all important start of all preparations and is also the most crucial step.

Today not everyone who is elderly dies in a hospital or nursing home. An increasingly number now dies at home or other hospice facility, perhaps even peacefully. In past eras it was much more common to die at home because long-term care facilities were not available and families simply had no other care options for their aging kin. Indeed, this might be the death we all desire, which is not to say that we actually desire death, but that given its inevitability, it is the preferred "model" for most of us.

In this newer model of hospice care terminally ill patients are treated at home, or if that is not possible, in a home-like atmosphere. Dame Cecily Saunders, an English nurse, began the hospice movement, which includes palliative care, in London with the founding of St. Christopher's hospice in 1967. (See: Saunders and others, 1981).

Hospices are not so much places as they are concepts. They are organizations which are funded to some extent (depending on nation, state, or province) on private insurance and donations

and/or public monies, and they are usually connected with hospitals, doctors and nurses, social workers, and chaplains or other representatives from local religious support groups. Hospice care does not include life support machines or intensive care units. Instead hospices stress palliative care and the family, social, and spiritual needs of their clientele. They recognize that their patients are terminally ill, so their purpose is to aid in providing palliative care and a good quality of life for patients, no matter how much time they have remaining.

Living with Style into Old Age

I once visited my friend's elderly mother in an assisted living home in Florida. Vera, who had lived well into her late nineties (and I do mean she had lived *well*) was mentally as sharp as anyone I knew; in fact, her short- and long-term memory capabilities easily exceeded my own. Physically, however, she required a walker to get around and some help with keeping up her daily household chores.

Vera had established a daily ritual in which she and several close friends participated: The cocktail hour. This elderly group of men and women gathered every day at four-thirty in their lounge to have a bit of a tittle – for some a cocktail, for others a simple fruit juice or ginger ale – and to exchange pleasantries. The latter often consisted of sharing the latest joke they caught via the Internet. The content of the jokes were almost always *X-rated*. Indeed, the two themes they seemed to enjoy the most were sex and the problems of aging!

I admit that I really could not keep up with her – dry vodka martinis are just not my forte. But I can say that I thoroughly enjoyed my brief visit. All of these people had become well acquainted with death – it happened to their comrades on a very regular basis. They were realists, yet they knew how to enjoy the moments that they shared together. They tried not to let the fact that they were aging get them down, even making light of it.

Although I usually ignore and delete jokes sent over the

Internet I began to peruse them, looking for the kinds I thought they would enjoy, and then I began forwarding to my friend who in turn collected them for her mother and her friends.

Vera is gone now, having lived a full 98 years, and we miss her! But fortunately, I am told, the cocktail hour she established still remains in place. And the spirit with which she enjoyed her life remains as well.

Decisions, Decisions

A *living will* is a document stating what sort of medical interventions a person would like administered if she or he becomes incapacitated and incapable of expressing her wishes. For example, does one wish to be kept on life support when all reasonable hope of recovery is gone? Or for a very elderly and sickly person, should physicians or paramedics attempt to resuscitate them following a major cardiac event? Reflecting on these choices it might seem that many people would choose the first option, but only those of advanced age who are very ill might choose the latter. But that example illustrates the need to revisit and review one's living will from time to time.

Yet even the first case – not wishing to be kept on life support – can raise concern with some people who fear that their lives might be terminated prematurely by uncaring medical personnel or family members. There are many angles to consider in composing a living will, including different legal interpretations that can occur in different parts of the country or world. Yet composing a living will is something that everyone should consider.

Then there is also the extremely sensitive question of *euthanasia*, or unnaturally inducing death in order to relieve suffering. There are two forms of euthanasia: *passive euthanasia* – in which “extraordinary” treatment (artificial life support) is withheld – and *active euthanasia* (also called *physician assisted suicide*). In some countries and in at least some states in the U. S. physician assisted suicide is legal, but the practice remains quite controversial. There are many obvious moral and ethical considerations; to name just one, whether or not the patient's

mental condition is sound enough to be able to make the decision to die.

Between these two extremes – passive and active euthanasia – there is also a gray area: the patient may be allowed to self-dose on morphine in order to control his pain. At some point when the pain becomes uncontrollable this practice may lead to death by overdose. Some people might find this practice acceptable whereas others might object for moral reasons, including in some cases religious beliefs.

Even people who see some merit in the concept of euthanasia worry (perhaps rightfully) about the possibility of abusive practices.

Such matters of life and death may not be easy to deal with but it is important to be aware of them as they may someday affect any of us in a very personal way, either directly when we ourselves near the end of life, or indirectly, as when a loved one is faced with such a decision.

Grief and Mourning

When we lose a loved one, we grieve, each in our own way as this is a path with no clear roadmap for us to follow. How long does grieving last? I think it best to think of grieving as a process rather than as a means of reaching a goal, that goal being something like “closure” or “getting over it” or “complete healing.” Does anyone ever completely recover from the loss of a child, or of a beloved spouse? (I still mourn the loss of some of my favorite pets, never mind my first wife or my parents!)

I composed the following poem based on my own childhood memories:

A Child's Grief²

old pete, a kindly man,
had been a plumber
who, after retiring,
gave my grateful father
most of his tools

the old man i knew was playful
if also a little odd
“eat your beans, mickey”
was something he said to me
as we sat ‘round the table:

his wife (my honorary gram’),
was seated by my mother
with baby brother
balanced on her knee,
next to me ‘n old pete

the next time i saw pete
(i was now five)
his face was waxen-grey
he was laid out in his dark suit and tie
on silky-white coffin lining

i was told that he had died
he would be buried and
we’d be together no more
but how does a child process that?
indeed, how does anyone?

I think I understood all of this intellectually. But emotionally experiencing the loss of someone, no matter what your age, is a time-bound process. The reality that someone has truly gone is not easily grasped. Is this a form of denial, or is it just a function of the way we are put together? I’ve known people who talk to their deceased loved ones after they’ve departed, at least for a limited time; and not only religious people who believe in an afterlife. As long as the ego is strong and the griever is non-delusional defense mechanisms are just that; they exist to protect the ego, and if such behavior helps a person to get through the grieving process I can see no harm in it.

Mourning time has no set limit; it varies from person to person. A mistake that some grievers make is to *foreclose* on the process (cf., Erikson’s teenage foreclosure), by rushing back into

their “normal” mode of living, yet denying their need to mourn, by, for instance, dating a new person before sufficient time has elapsed for them following their loss. Indeed, counselors everywhere warn against making any major life changes before a sufficient time for mourning has passed. Mourning is a painful but necessary process!

What can be done to ease the pain of this process? Having close friends or family who can support is foremost. Seeing a professional counselor or joining a grief support group can also be a lifesaver. But some people seek instead solitude. With such people, or with anyone who suffers a loss, it is still important to be at the ready to support them whenever the need should arise.

But how can a friend and family member help? First of all do not avoid the subject of death when it arises. If a person is not comfortable with this then he or she should probably back away from the situation. Death is the elephant in the room!

Second, be ready to answer the call when needed. Keep in mind that the person in mourning is probably very lonely and in need of other people—but only when they are receptive.

Third, avoid “answers”! Supporting them means mainly listening empathetically, not offering advice. Be especially aware of pressuring the person (e.g., “Hasn’t enough time gone by now? When are you going to get back to real life?”) An exception would be in making positive suggestions, as long as they are *only* suggestions. For example, “I found a great deal of comfort by joining a support group after my husband passed away.” Notice especially the “I” language (“I found...”) as opposed to the “you” reference (“You would find...”). This is support, not advice.

It is said that in life the only sure things are death and taxes. Some scammers can avoid taxes, but death eventually comes to all; we need to accept it as part of the life cycle. In that I offer a final word (poem):

Illogic²

the old-timer confessed
he gave not a gnat's ass
what the future might bring
 once he'd passed on

why then at age ninety
when the old oak tree fell
did he plant a sapling?
 can you say?

perhaps he thought he would
live to see it grow tall,
strong and formidable
 as he'd always been...

go figure.

Questions for thought and discussion:

1. What should a dying person be told about his/her condition? Does it depend on the person?
2. What about the dilemma of life-support and “heroic” measures? Living wills?
3. How can friends and family support a person in the final stages of life?
4. How do other cultures and societies deal with issues of death and dying?
5. How do we handle bereavement and mourning? What if the person dies “before her/his time”?
6. What role does religion and spirituality play in coping with death and dying?

In-class exercise: Using the above questions as a stimulus, write a brief “reflection” on the subject of death and dying. It can be personal (involve someone close to you) or impersonal (abstract). This is *optional* – anyone who has faced death and dying issues recently may be excused if they find this exercise uncomfortable!

Notes

1. Kubler-Ross (1969, p. 29).
2. Fleming (2017).

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