

## CHAPTER 4.14

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# The Psychology of Death

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In some respects, attempting to summarize the complex area of “the psychology of death” is a daunting task, whose difficulty is revealed by comparing it with writing a hypothetical summary of “the psychology of life.” Clearly, the scope of the latter would be vast, encompassing psychological development from infancy through later life; emotional and motivational considerations; cognitive and decision making processes under favorable and unfavorable circumstances; clinically significant disorders and their assessment and treatment; social and interpersonal processes that call for their own level of analysis; and human coping, resilience, and personal growth, to name just a few topics of relevance. Viewed broadly, the psychology of death is equally variegated as a discipline or field of study, spanning research on the maturation of the concept of death throughout childhood; death anxiety, fear, threat, and avoidance; cognitive impairment at the end-of-life and its implications for decision making regarding life-sustaining treatment options; the refinement of assessment and diagnostic protocols for such disorders as complicated grief; family and caregiver dynamics in anticipation of or in the wake of death and loss; and the emergence of personal hardiness and meaning-making as a function of grappling with mortality. This chapter provides an orientation to many of these topics, concentrating on three major domains of research that have a substantial empirical base: the study of death anxiety and related emotions and motives, the end-of-life arena, and the experience of grief and loss. In each instance we will focus special attention on issues and findings of particular relevance to the readers of this

handbook, namely those that concern older adults and those who care for them.

### DEATH ATTITUDES

Although the capacity of *Homo sapiens* to contemplate their own mortality might be considered a defining characteristic of our species, it is clearly one that has evolved across historical time, yielding a rich spectrum of cosmologies, religions, philosophies, and folk beliefs that attempt to interpret the place of death in human life. Likewise, recent psychological research indicates that conceptions of death evolve across the course of development, perhaps beginning with the young child’s germinal sense of self as distinct from his or her caretaker, and finding expression in predictable forms of separation protest and grief when bonds to the attachment figure are threatened (Bowlby, 1980). By middle childhood most children have begun to master the rudiments of an abstract “adult” death concept – the idea that death involves a cessation of bodily and sensory function, is irreversible (at least at a physical level), and perhaps most threateningly, is universal, in the sense that it inevitably applies to them and those they love (Speece and Brent, 1992). Although cultural variations exist in the specific content of death beliefs (e.g., whether it is envisioned as an entry to an afterlife, to a cycle of death and rebirth, or simply to a state of non-being), children of diverse cultures show parallels in conceiving of death in increasingly abstract and psychologically sophisticated terms as they mature (Tamm and Granqvist, 1995). The acquisition of this basic suite of subcomponents

of a mature death concept permits the contemplation of mortality in adolescence and young adulthood, both as an existential theme encountered across the course of development, and as a specific challenge as people encounter the reality of death in the form of illness, accidents, homicide, and suicide of known and unknown persons.

### Death anxiety

Literally thousands of studies have been performed on the attitudes people report in response to the contemplation of personal death, concentrating mainly on their experience of death anxiety, fear, threat, and avoidance. Although terminological distinctions are sometimes made between these attitudes, in fact most measures used to gauge their intensity in different groups have in common a focus on negative affect, dread, and terror in the face of personal death. As such measures have been refined across a period of nearly 50 years (Neimeyer, 1994, 1998), they have begun to yield a clearer picture of conditions under which the contemplation of or confrontation with death triggers substantial anxiety and often avoidance, and the various facets of fear of death that trigger special concern for some people.

Although contemporary Western society has been widely described as "death denying," segregating death in institutional settings where it becomes the province of specialists, in fact ample evidence suggests that people acknowledge thinking of death commonly, and that they typically do so with some measure of apprehension. Here, too, developmental trends can be observed, such that anxieties about personal death begin to climb in adolescence, reach their peak in middle adulthood, and, at least in some studies, wane in the closing years of life (Wong *et al.*, 1994). Not surprisingly, however, these gross trends disguise a wide variation in the degree to which focusing on one's eventual death triggers despair, paralysis, or defensive avoidance, on the one hand, or some form of acceptance, affirmation, or even meaning on the other. Indeed, more recent multidimensional assessments of death attitudes even suggest that such contradictory states can co-exist within a given person, necessitating a more fine-grained approach to assessment of death concerns than has historically been the case in this broad literature.

### Death concerns in older adults

Quantitative reviews of research on death attitudes among older adults shed light on factors associated with heightened apprehension regarding personal mortality as one ages. Not surprisingly, anxieties about dying are exacerbated by deteriorating physical health, and are especially prominent for seniors struggling with issues of "ego integrity," or a sense of having lived fully and well. More generally, fear of death covaries with other indices of psychological distress, such that a general disposition towards depressive rumination or anxious anticipation of an uncertain future tends to find expression in or reinforce death-related apprehensions, *per se*. Environmental factors also seem to predict greater death anxiety, such as living in an institutional rather than community setting. But perhaps surprisingly, religious belief, which has generally been associated with lower fears of death, seems substantially unrelated to death anxiety in later years, perhaps as a function of range restriction in religiosity in the older population (Fortner *et al.*, 2000).

As research on death attitudes has become more sophisticated, investigators have begun to focus attention on more specific foci of death concern, and a wider range of death-related attitudes beyond death anxiety and similar negative emotional responses. The former, more differentiating focus has highlighted particular apprehensions that vary by ethnicity, and that are associated with negative attitudes towards ageing. For example, research suggests that older White Americans express greater concerns about the dying process (dying alone, in uncontrolled pain, etc.), perhaps reflecting their greater likelihood to spend the final weeks and months of their lives in institutional settings that compromise their personal sense of control and isolate them from family. Older African Americans, on the other hand, report greater fear of the state of death, as they struggle more commonly with apprehension regarding the unknown, and an afterlife of punishment or reward. For both groups, however, it is striking that death anxiety is a significant predictor of their negative attitudes towards ageing, as well as the negative stereotypes they hold towards their older peers (DePaola *et al.*, 2003). Essentially the same finding emerges for professional caregivers, such that those with more negative attitudes towards death acknowledge devaluing and

disliking those older adults with whom they work, as well as reporting greater apprehension about their own ageing process. Conversely, many caregivers report substantial death acceptance, and comfort and competence in dealing with the realities of mortality and loss, an orientation that seems to be reinforced by training in hospice and palliative care.

### THE END OF LIFE

The contents of this book demonstrate that significant attention has been given to the process and implications of ageing. Similarly, vast amounts of human and financial resources have been focused on delaying the actual moment of death. However, comparatively little emphasis has been placed on how people actually experience the dying process, and the work that has been done in this area has centered around the physical and medical aspects of dying and death, to the relative exclusion of psychological, spiritual, interpersonal, and cultural/societal (i.e., "psychosocial") aspects of the end of life. Of the non-medical topics associated with the dying process and eventual death, religious/spiritual issues have probably been discussed most often. In this section, we focus on psychosocial issues near the end of life. For more detailed discussions of this topic, see Chochinov and Breitbart (2000), Lawton (2000), and Werth *et al.* (2002).

#### **Need for attention to psychosocial issues near the end of life**

As discussions of the end of life progress from being focused solely on physical aspects of the dying process to a more holistic consideration of the person who is dying and her or his support system, the need for attention to psychosocial issues becomes clear. In fact, recent research on the factors dying individuals believe are primary contributors to their quality of life demonstrates the central nature of issues such as freedom from psychological suffering, ability to interact with loved ones, and connection with one's higher power (Steinhauser *et al.*, 2000).

Both research and clinical experience indicate that, although psychological factors such as mood and anxiety disorders or a sense of hopelessness may be present for some people as they approach death, they should not be considered normal or expected and therefore should not be accepted, because they

are treatable in the vast majority of cases (Block, 2001). Such mental health conditions can severely impair quality of life and affect decision making, both for the dying person and for her or his loved ones. Similarly, tension or "unfinished business" between the dying person and significant others can interfere with achieving a peaceful death of the dying person and can complicate the grieving process of the survivors, especially if there are disagreements over treatment decisions. Another key consideration is the cultural belief system(s) of the dying person and loved ones (Irish *et al.*, 1993), especially if the perspective of these individuals differs from the views of the healthcare team.

#### **Typical Concerns of Patients and Their Loved Ones Near the End of Life**

As death approaches, people naturally may be concerned about whether their own, or their loved one's, suffering will be treated efficiently and effectively. Fortunately, most physical aspects of suffering, such as pain and breathlessness, can be effectively ameliorated for nearly everyone, although a small percentage of people may need to be sedated to unconsciousness in order for them not to suffer physically.

Once physical symptoms are palliated, attention often turns to psychosocial matters (Werth *et al.*, 2002). Some people, depending on their cultural beliefs, may be concerned about losing autonomy, especially if control has been important to them prior to the dying process. Fear of the loss of dignity, a construct that is very individualized, can lead to significant distress. Many people may have existential concerns (e.g. the meaning of one's life) that may or may not be related to spiritual or religious beliefs (e.g. the purpose of suffering).

Some people may be afraid of losing mental acuity (e.g. through dementia or the effects of medication), perhaps because this would mean losing the ability to make their own decisions; in addition, the possibility of losing capacity may be perceived as a loss of self and, further, incapacity would interfere with the ability to interact and communicate meaningfully with loved ones. Another interpersonal concern of individuals nearing the end of life is being a physical, emotional, and financial burden on loved ones; meanwhile, significant others may be worried about

not being able to provide proper care for the dying person.

### **Decision Processes Regarding End-of-Life Treatment Options**

Regardless of whether a person knows she or he is dying, there are many end-of-life decisions that need to be made. Different countries and regions within countries have very different laws, rules/regulations, and norms in terms of accepted/acceptable options near the end of life. However, through much of the developed world, the following decisions will need to be made (either explicitly or by default): whether to draft a last will and testament and what it should say; whether to prepare an advance care directive (e.g. a living will or durable power of attorney for healthcare) and the particulars of the document; whether and how to talk to loved ones and healthcare providers about one's pending death; whether to try to die at home, in a care facility, or in hospital; whether to receive hospice care; and whether to try to live as long as possible or consider hastening death in some way (e.g. withholding or withdrawing life-sustaining treatment, asking a physician for medication that could be used to end one's life). The last option – hastening death – will be discussed in the next section.

Communication is an important aspect of many end-of-life decisions; however, open discussion of relevant considerations may not take place for any number of factors related to the dying person, loved ones, healthcare providers, and the intersection of these individuals (Quill, 2000). Cultural beliefs may preclude talking about death by anyone or among certain members of these three groups. In addition, psychological factors such as diagnosable depression or anxiety may interfere with conversation and interpersonal dynamics, while concerns surrounding issues such as perceptions of "being a burden" may prevent open discussion.

As a result of these psychosocial issues, people may not be ready when they or their loved ones are nearing death. Important decisions may not have been made or even considered. This, then, may lead to misunderstandings and misperceptions about what should happen as the person moves through the dying process. In fact, research has demonstrated that neither physicians nor loved ones can accu-

rately predict the dying person's treatment preferences, possibly leading to decisions for care that are consistent with the loved one's or physician's desires and beliefs but not those of the person who is dying. This research indicates that there is a need for culturally respectful dialogue about end-of-life decisions in order to maximize the appropriateness of care.

### **Hastening death**

Probably the most discussed and debated aspects of end-of-life care are when (if ever) a person should be allowed to implement a decision that could affect the manner and timing of death and what actions are acceptable in such situations. Assisted suicide and voluntary active euthanasia have been the most controversial end-of-life decisions in most countries, but in many parts of the world there is also active debate about other interventions such as withholding or withdrawing life-sustaining treatment (e.g. do-not-resuscitate orders, not starting or stopping ventilators), terminal sedation (purposefully sedating a person to unconsciousness and withholding treatment, including nutrition and hydration, until the person dies), and futility policies (where the healthcare team decides not to continue treatment in spite of the requests of the dying person and/or loved ones) (Kleespies, 2003).

Although some have stated that these actions are different for a variety of reasons based on moral, ethical, or legal reasoning, from a psychosocial perspective, the motivating factors for them are often similar. Just as clinical depression and/or hopelessness may affect a decision regarding assisted suicide, it is possible that they may also lead to a request for terminal sedation. Similarly, a person may be coerced to "request" that a ventilator be turned off or "request" active euthanasia. Research on the desire for death (which does not specify the mode of death) demonstrates the importance of these psychosocial issues. In addition, research on why people have requested and received assisted suicide and euthanasia indicates that control and dignity are also important factors.

### **Conclusion**

Although psychosocial issues near the end of life have been receiving attention only relatively

recently, their importance in the quality of life experienced by the person approaching death and her or his loved ones cannot be overstated. Both research and practice demonstrate that psychological, spiritual, interpersonal, and cultural/societal issues can have a profound impact on end-of-life care and decisions. These factors also affect loved ones' experiences of grief and bereavement after the person dies.

## GRIEF AND BEREAVEMENT

In the broad context of end-of-life care, it is important to bear in mind that the ending of the life of the patient marks the beginning of a changed life for bereaved survivors. Although the majority of bereaved persons respond to loss by drawing on characteristic human capacities for coping and resilience, such favorable outcomes are by no means assured. It is therefore important to recognize the biopsychosocial impact of bereavement, to be alert to the signs of complications in the grieving process, and to assist more profoundly distressed survivors in adapting to a world in which their loved one is absent.

### Symptoms of Separation

The impact of bereavement can be observed on even the most basic physiological levels. Existing research documents predictable clusters of symptoms associated with intense grief, including shortness of breath, tachycardia, dry mouth, sweating, frequent urination, digestive disturbance, and choking sensations. Taken together with other symptoms such as restlessness, increased muscular tension, and insomnia, these responses can be understood as part of a broader pattern of sympathetic arousal in response to the stress of separation (Parkes, 1996). At a more psychological level, the acute pangs of grief that peak in the early weeks following loss are associated with heightened anxiety, depression, and keen yearning for the deceased, as well as characteristic behaviors that suggest "searching" for the lost loved one, all of which is consonant with a deeply rooted evolutionary response to threats to primary attachment bonds.

Although large-scale longitudinal research has documented that the majority of bereaved men and women cope effectively with bereavement, eventu-

ally overcoming the acute symptoms noted above, this is by no means always the case. Indeed, bereavement has been associated with serious neuroendocrine disturbance and sleep disruption, as well as evidence of generalized anxiety or panic syndromes in over 40 percent of spouses some time during the first year of bereavement. Perhaps most worrisome is the accumulating evidence that the stress of bereavement is associated with a 40 to 70 percent increase in mortality among surviving spouses in the first six months following loss. Numerous investigators, for example, have long linked bereavement with cardiovascular disease, including heightened risk of myocardial infarction and congestive heart failure (Osterweis *et al.*, 1984). Evidence is also accumulating that loss undermines the functioning of the immune system, providing an instigating context for the onset of infectious diseases and cancer. Other contributors to mortality risk are clearly behaviorally mediated, such as an increased incidence of alcohol abuse and consequent cirrhosis of the liver, as well as increased risk of suicide. Such statistics argue persuasively that the many stresses associated with profound loss can have a serious, and even lethal, impact on a sizable minority of bereaved persons. It is also likely that these risks are magnified for an older bereaved population, which could be especially susceptible to the effects of social isolation and failing health as they contend with the biopsychosocial impact of loss.

### Complicated Grief

In view of these findings, psychologists have attempted to determine factors that identify persons at risk for negative outcomes associated with protracted and intense grief. Some of these risk factors can be objectively assessed through a review of the circumstances surrounding the death, as more chronic and unremitting grief is typically associated with sudden, unexpected, and traumatic death and closeness of the kinship tie to the decedent. Others, however, call for clinical judgment, such as an evaluation of the level of conflict or ambivalence in the premorbid relationship with the decedent, or assessments of mourner liabilities (such as a history of depression) that impede adaptation to loss (Worden, 1996). Particularly promising have been efforts to conceptualize complications in the

grieving process itself that are distinct from major depression, panic disorder, and posttraumatic stress disorder. For example, investigators have recently garnered empirical support for a set of diagnostic criteria for complicated grief, marked by efforts to avoid reminders of the deceased, purposelessness and futility, a shattered world view, and clinically significant disruption in life functioning (Prigerson and Jacobs, 2001). Moreover, diagnosis of traumatic grief six months following the loss has been associated with deleterious long term outcomes, in terms of a range of both psychological and medical outcomes.

### Grief Counseling and Therapy

In addition to identifying persons at risk, helping professionals can assist the bereaved in coping with both the short term and long term challenges of loss. In the immediate aftermath of the death, for example, the bereaved may benefit from coaching in symptom management techniques, such as relaxation skills and thought-stopping to interrupt distressing intrusive imagery. In the longer run, however, what seems called for are opportunities for emotional self-expression and a deeper processing of the significance of the loss for their ongoing lives. Fortunately, contemporary grief theory and research are expanding to provide guidance in these therapeutic efforts (Stroebe *et al.*, 2001). As a result, the helping professions are developing a subtler appreciation of the ways in which loss, especially of a more traumatic kind, can shake the assumptive foundations of bereaved persons' lives, undermining their sense of security, predictability, and worth. If, as recent research suggests, the attempt to reaffirm or reconstruct a world of meaning that has been challenged by loss is a core process in grieving (Neimeyer, 2001), then it follows that interventions to assist survivors in making sense of the loss and perhaps even eventually finding a "silver lining" in it could be especially helpful to troubled survivors. Indeed, current data suggest that many bereaved people find new and sustaining meanings in their lives and losses, experiencing "post-traumatic growth" (Tedeschi *et al.*, 1998) with or without professional help. Although a small but growing literature has begun to demonstrate that grief therapy can make a positive contribution to these outcomes

(Allumbaugh and Hoyt, 1999), such results are by no means universal, with some evidence suggesting that older adults are served least well by existing forms of treatment (Neimeyer, 2000). Thus, the equivocal outcomes of much of grief counseling and therapy suggest that more research is needed into how and whether various forms of therapy assist grieving persons in integrating the loss experience into their lives and moving forward towards a more hopeful future.

### CONCLUSION

Despite the daunting complexity of comprehending the role of death in human life, researchers have made substantial headway in investigating the psychology of death, concentrating especially on the causes, correlates, and consequences of various death attitudes, the special challenges faced by individuals and families at the end of life, and the subsequent adaptation of survivors to bereavement. Each of these areas has special relevance to the understanding of older adults, for whom such attitudes, (inter)personal decision making, and post-loss adaptation become compellingly important.

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