End-of-Life Decisions: Research Findings and Implications

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When death is near, then, it seems that many in our society struggle with two sides of this existential dilemma, that is, whether to fight on strenuously...or to attempt to bow out gracefully with the acknowledgment that meaningful life is essentially over.

—*Kleespies, 2004 (p. 11)*

END-OF-LIFE DECISIONS

End of life decisions are those that are made for the individual's last period of life, and such decisions may apply to all aspects of an individual's living and dying during that period.

Over the past two decades, well over a thousand empirical and conceptual articles have been published concerning end-of-life decisions and advance directives, in addition to numerous books. Clearly, a thorough review of this material is beyond the scope of this chapter; the reader is referred to reviews by Cicirelli (2001) and Kleespies (2004),

and to George's (2002) methodological critique. The approach here is to give the reader some appreciation of existing research on the various types of end-of-life decisions and the use of advance directives. Also, end-of-life decisions, as influenced by religious, spiritual, and existential beliefs, will be considered as a general coping strategy for dealing with death anxiety, preparing oneself for death, and attaining a good death.

Who Makes End-of-Life Decisions?

The emphasis on individual autonomy in recent years has led to the view that dying individuals should be the ones to make end-of-life decisions for themselves in a way that is authentic and consistent with their beliefs and lifestyles. Yet, whether this is realistic or desirable is open to question, particularly if the dying person's decisions commit all others to carry them out without question. Some dying individuals prefer to leave end-of-life decisions up to family members or physicians. In other cases, paternalistic family members may feel that they know best and should make decisions for the dying family member. This is an area where conflict in the decision making process can occur. Callahan (2002) has cautioned that the needs of terminal patients must be considered in relation to the needs of their family and friends, of their physicians and caregivers, and to the needs and operating habits of institutions concerned with their care. Only by taking all of these influences into consideration can the most appropriate end-of-life care be achieved for all concerned. In any event, many dying patients may be incapable of communicating or making decisions, so that responsibility for end-of-life decisions falls on close family members and physicians.

How Are End-of-Life Decisions Made?

Relatively little is known about the process by which end-of-life decisions are made. It may involve a rational-analytic procedure to compare the possible outcomes of various decision alternatives and choose the course that will be most effective. It may involve some kind of heuristic procedure that combines some reasoning with emotions, values, and cultural norms to make decisions in a practical way. Or, decisions may be based on habit, simple conformance with religious or cultural norms, imitation of others, impulse, random choice, or total ignorance. Decisions may be effective regardless of how they are made, depending on the motivation of the individual involved and the context of the situation.

What Kinds of End-of-Life Decisions Are Made?

End-of-life decisions are those decisions about what happens to an individual before death and after death. Decisions about the period before death include what kinds of medical treatments will be undertaken (aggressive treatment to prolong life or palliative care), how, and perhaps when one will die (hastening death through suicide or assisted suicide), where one will die (home, hospital, nursing home, etc.), and who will make decisions in one's behalf should the individual become decisionally incompetent. Decisions about the period after death include possible autopsy and organ donation, the manner of disposition of the body after death (burial, cremation, giving the body to science, etc.), the nature of any funeral services, and disposition of possessions. One might also classify the content of decisions into formal decisions (those involving a contractual or legal arrangement of some sort, such as an advance directive, an arrangement to enter a nursing home or hospice, a will to distribute possessions, etc.), informal decisions (between family members and/or friends without any binding contract), and personal decisions (to change views in order to cope with dying). Some decisions can be made well in advance, while the individual is relatively healthy, whereas other decisions can be made or revised up to the end of life.

According to Drought and Koenig (2002), the essential end-of-life decision in regard to medical treatment in actual practice involves a choice between doing something in order to continue living and simply giving up and dying, that is, a choice between a wish to die and a wish to prolong life. Kleespies (2004) similarly categorizes end-of-life decisions into a wish to prolong life and a wish to die, but distinguishes between decisions that bring about quick death (assisted suicide and euthanasia) and decisions that do not prolong or may hasten the dying process (e.g., withholding or withdrawing treatment). Once these central decisions are made, other secondary decisions fall into place. Making end-of-life decisions is one means by which the individual is able to gain some measure of perceived control over an otherwise inevitable fate. Primary control is achieved through decisions made directly by the individual or secondary control is achieved by allowing someone (a more powerful other) to decide in one's behalf (Shroepfer, 1999).

Decisions to Prolong Life

The desire to survive is strong in most people, and many wish to do everything possible to remain alive, even if the quality of continued

life is low. When the patient's cognitive faculties are adequate, and when both patient and physician agree on treatments to sustain life, there is no problem. Problems arise when there is disagreement. In cases where the physician regards further treatment as medically futile, wasteful of resources, and needlessly prolonging the patient's suffering, but the patient wishes to pursue all possible treatments to prolong life in the hope of some kind of miracle cure, there can be problems in the doctor-patient relationship. More commonly, a patient is in a comatose or vegetative state and family members wish to prolong the patient's life at any cost, either hoping for a cure or feeling that their loved one's life is of value, no matter how low the quality of that life (Rubin, 1998). Hospitals, physicians, and ethicists have struggled to establish guidelines as to when further treatment is futile, and when an institution is justified in declining to treat a patient further, yet there have been no clear-cut decisions (Kleespies, 2004). Rather, decisions are made on a case-by-case basis. Another complication arises when a patient or family might wish to continue treatments to prolong life, but are constrained by financial costs and other burdens on the family to choose other end-of-life alternatives (Emanuel, Fairclough, Slutsman, & Emanuel, 2000).

One national survey estimating the extent to which older adults want aggressive treatments to prolong life (Eleazer et al., 1996) found that 10% of Whites, 19% of Blacks, 4% of Hispanics, and 10% of Asians favored such interventions. Cicirelli (1998), using scenarios depicting terminal illness and low quality of life, found that some 52% of senior-center participants wanted to strive to live for as long as possible, although specific interventions were not examined. In studies of time-trade-offs (the amount of their remaining time seriously ill patients would be willing to exchange for a shorter life in better health), most patients were unwilling to trade much time; those who would trade the least time were more likely to want various measures to extend life (Tsevat et al., 1998).

Decisions to Refuse Life-Sustaining Treatments

Many terminally ill patients have no wish to undergo life-prolonging interventions that do not restore health, that diminish the quality of life, and are futile in the long run. Rather, they prefer that any treatments other than comfort care (e.g., relief of pain, aid in breathing, etc.) be withdrawn or withheld, and they be allowed to die more naturally as the underlying disease takes its course. Such decisions may actually hasten the dying process and thus, in effect, be a form of passive euthanasia (Kleespies, 2004). This may constitute an ethical

problem for the ethicist or health care provider, but not necessarily for the patient. For example, withdrawing treatments already in place may have the effect of ending life more quickly, as when hemodialysis is discontinued. Additionally, the use of increasing doses of analgesics to control pain in an effort to provide comfort care may have the unintended effect of ending life more quickly. The principle of double effect is used to provide justification in the latter case, arguing that the intention is to relieve pain and not to cause death. Such decisions are generally approved by ethicists and religious bodies.

A large body of empirical research has investigated the preferences of patients and their surrogates for various treatment interventions and the factors influencing these preferences. Among the various interventions that are regarded as life-prolonging are respirators, intubation, intravenous feeding, hemodialysis, chemotherapy, radiation, cardiac resuscitation, defibrillation, and use of antibiotics. The degree to which treatment interventions were refused depended on the type of treatment. The more aggressive and intrusive the treatment intervention and the more serious the patient's state of health, the more likely that the treatment would be refused. For example, 92% of elderly adults would refuse a respirator, 89% tube feeding, 75% intravenous fluids, 41% antibiotics, and 21% oxygen (Henderson, 1990). Cohen-Mansfield, Droge, and Billig (1992), among others, reported similar results. With regard to CPR, 34% of elders would refuse treatment under current health conditions, 67% if acutely ill, and 92% if terminally ill (Schonwetter, Walker, Solomon, Indurkhya, & Robinson, 1996). However, stated preferences also depend on the way the questions are asked, the kinds and degree of information available to the patient, expected effectiveness of treatments in influencing likelihood of survival, and so on (e.g., Coppola, Bookwala, Ditto, Lockhart, Danks, & Smucker, 1999; Shonwetter et al., 1996). Such studies have made it clear that many patients have gross misconceptions about the effectiveness of certain treatments. Also, treatment preferences have been shown to be only moderately stable over time, and only moderately correlated with the treatment preferences of surrogate decision makers who would act if the patient became incapable of deciding (Cicirelli, 2001).

Decisions to End Life: Suicide, Assisted Suicide, and Euthanasia

When dying individuals experience a very low quality of life including intractable pain and suffering, psychological distress, loss of function, and/or loss of dignity, some seek to gain control over their situation by

making a decision to end life by active means. Within the context of terminal illness, suicide is an action to end one's own life, assisted suicide is the provision of the means to end one's own life, and voluntary active euthanasia is the ending of an individual's life by another at the individual's request. Suicide, although not illegal, is condemned by many in society; assisted suicide is legal (with many qualifications) only in Oregon and the Netherlands, and voluntary active euthanasia is legal only in some countries, for example, the Netherlands and (briefly) in Australia (Leigh & Kelly, 2001).

It is difficult to know the actual incidence of these means of actively ending life, because social disapproval or illegality keeps large numbers of such cases from being reported. Suicide rates among older adults have been increasing (e.g., "Suicide rate," 1996), but one doesn't know how many of these suicides take place among the terminally ill. Although some authors (e.g., Jamison, 1996) suggest that most assisted suicides are reported as deaths from natural causes, the experience with legalized assisted suicide in Oregon indicates that relatively few terminal patients (only 91 over a four-year period) actively chose to end their lives in this way (Hedberg, Hopkins, & Southwick, 2002).

In various survey studies reviewed by Cicirelli (2001), support for legalization of assisted suicide ranged from 40% to 67% of adult respondents. However, in studies attempting to ascertain the degree to which respondents would favor assisted suicide for themselves if terminally ill, only 12% to 21% reported that they would do so (Blendon, Szalay, & Knox, 1992; Cicirelli, 1997). Results of several surveys (Cicirelli, 2001) indicated that a clear majority of adults support the legalization of voluntary active euthanasia. In general, support for euthanasia has risen over time, for older as well as younger individuals (Leinbach, 1993). In a study comparing preferences for assisted suicide and voluntary active euthanasia, potential patients preferred that a physician administer a lethal dose whereas physicians preferred that patients take the responsibility for administering lethal medications themselves (MacDonald, 1998).

Advance Directives

Advance directives are means for expressing one's wishes regarding end-of-life treatment and care before such time as one becomes incapable of making decisions for oneself. Now legal in all 50 states, advance directives in the form of a living will or a durable power of attorney for health care presumably guarantee a patient's right to

refuse unwanted medical treatment, thus recognizing the autonomy of the individual to make treatment decisions. The 1990 Patient Self-Determination Act, which required federally funded facilities to ask incoming patients for advance directives, gave further support to their use.

However, both forms of advance directive have their advantages and disadvantages. Although the typical living will allows the individual to specify which of a number of life-prolonging treatments should be refused in the event of a terminal illness, thus allowing a measure of control over the dying process, critics charge that living wills are deficient in many aspects. Living wills may not apply to overall goals for the patient's treatment, may prematurely stop treatments when a patient could be saved, may not apply to the patient's actual situation, and may provide instructions that are not easily interpreted or are too vague to guide treatment in specific instances (Emanuel, 1995; Fagerlin, Ditto, Hawkins, Schneider, & Smucker, 2002). Living wills that contain a statement of the patient's basic values and goals for end-of-life care, rather than specific treatment preferences, may help to remedy some of these objections. Further, some critics question whether a document prepared at an earlier point in time can adequately represent a patient's views at some later point in time, when thinking and feelings (indeed, a person's actual identity) may have changed (Kleespies, 2004).

The second type of advance directive is the durable power of attorney for health care, which empowers a proxy to make treatment decisions in one's behalf, should one become incapacitated. This type of document offers a proxy the flexibility to make decisions in relation to specific treatment situations that might not be foreseen at the time of making a living will. However, the patient must have trust in the wisdom and integrity of the person selected as a proxy decision maker to act in a way consistent with the dying individual's basic values and goals. Existing evidence (Cicirelli, 2001; Fagerlin et al., 2002) indicates substantial lack of agreement between the treatment wishes of individuals and surrogate decision makers, with surrogates' decisions more closely reflecting their own preferences than those of patients. At the very least, effective communication between the patient and the surrogate decision maker is required.

On the positive side, however, the advance directive constitutes a legal document expressing the patient's intentions, which can be invoked when the situation requires it. Even if imperfect, it can provide evidence of the patient's wishes to discontinue life-prolonging treatment. More important, preparation of an advance directive provides

an opportunity for individuals to confront and examine their feelings about the dying process and the end of life in advance of serious illness or catastrophic events. Having full and frank discussions with loved ones about end-of-life care in advance, of the actual need for such care, can result in less stress and greater satisfaction with decisions (Fagerlin et al.; 2002; Haley, Allen, Reynolds, Chen, Burton, & Thompson, 2002).

On the practical level, questions exist about the degree to which advance directives are completed and their usefulness. In their review, Fagerlin et al. (2002) estimate that only about 18% of all adults have drafted any type of advance directive, although the percentage is somewhat higher among those with chronic and terminal illnesses. The comprehensive national Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT) intervention carried out with 4804 patients in acute care hospitals (Teno, Licks, et al., 1997; Teno, Lynn, et al., 1997) found that the intervention following the Patient Self-Determination Act did not influence elders' enactment of advance directives, although it did increase the recording of existing directives in patients' charts. More important, among patients who had advance directives, only 12% had discussed their advance directive with their doctor, only 35% of physicians were aware of the directive by the second week of hospitalization, and fewer than 10% of patients received treatments in accordance with the directive. The clear implication of these findings is that, when a patient is decisionally incapacitated, it is important to have someone to serve as a strong advocate (perhaps a proxy decision maker) to consult with physicians and other hospital staff so that end-of-life treatments are those that the patient desired.

Despite the somewhat pessimistic SUPPORT findings regarding the efficacy of advance directives and the equally pessimistic conclusion of Drought and Koenig (2002) that, on the practical level, no real choice in end-of-life care exists, a few studies offer more positive conclusions. In Oregon, a state which has concern for careful end-of-life planning, advance decision documents had been completed by about two thirds of deceased patients, with 90% of families well satisfied with the end-of-life care received (Wyden, 2000). Other programs, which focused on discussions of values and preferences between patients, their significant others, and clinicians (Hammes & Rooney, 1998; Molloy et al., 2000), found both a high incidence of advance directives and treatment consistent with these preferences. Clearly more extensive exploration and communication about end-of-life issues appears to achieve more satisfying end-of-life care.

RELIGIOSITY, SPIRITUALITY, EXISTENTIALISM, AND END-OF-LIFE DECISIONS

Although religiosity, spirituality, and existentialism are relatively distinct, many modern scholars have used them in combined, overlapping, or integrated form. In any event, they are reviewed here as distinct.

Religiosity

Commonly, it is characterized as a multidimensional concept (Cicirelli, 2002): (a) organizational religiosity (religious affiliation and attendance at religious activities), (b) non-organizational religiosity (practices independent of a particular religion or denomination, such as reading religious books), (c) subjective or intrinsic religiosity (feelings of intensity and commitment to one's religion, (d) religious coping (using religious faith to deal with life's problems), (e) religious beliefs (including specific beliefs about God, prayer, and an afterlife), and (f) ethical standards of right and wrong (as derived from the religion and to be followed in daily living).

The content of the beliefs may vary relative to particular religions (e.g., Christianity, Judaism, Islam, Hinduism, Buddhism, etc.), including the nature of God, the type and purpose of prayer, and the idea of immortality or an afterlife. Religion can be used as a coping mechanism for dealing with death anxieties and preparing for death. However, religious beliefs may have a negative effect for some individuals (Franks, Templer, Cappelletty, & Kauffman, 1990–1991; Fry, 1990; Koenig, 2002; Pargament, Koenig, Tarakeshwar, & Hahn, 2001), with fears of punishment, or eternal damnation by God, creating anxiety which exacerbates the dying process. Whatever the religious beliefs, they are likely to influence the nature of the end-of-life decisions that are made.

Spirituality

A somewhat elusive concept, spirituality can be viewed as an emotional reaction to experiencing a relationship, or identification with someone or something more powerful or superior to oneself, and that can provide a sense of protection and comfort (Cicirelli, 2001). It is a broader concept than religion *per se*. Walsh (1999, 2004) defines spirituality as an overarching construct that refers more generally to transcendent beliefs and practices (experienced either within or outside formal religious structures) and is both broader and more personal. In

the same vein, Sulmasy (2002) defines spirituality as the individual's relationship with the transcendent; it is about the search for some kind of transcendent meaning. Spirituality may be expressed in a particular religious practice, a philosophical belief, in relationships with nature, the arts, and so on.

Koenig (2002) states that religious needs involve making peace in one's relationships with God and others and preparing oneself for a life to come, whereas spiritual needs may include religion but are not restricted to it. Spiritual needs also involve finding purpose and meaning to life, forgiving others and receiving forgiveness, accepting what one has accomplished and become during life, and saying goodbye. Following Koenig, one can view spirituality as a more encompassing term, with religious and non-religious spirituality as subcategories. The religious place their faith in God to satisfy their spiritual needs. The spiritual, but non-religious, for example, atheists, agnostics, and apathists (those indifferent to the existence of a personal God), may satisfy their spiritual needs by identifying with an impersonal God (e.g. one with no interest in individuals), the universe, science, mankind, nature, a philosophical worldview, and so on. For such people, decisions regarding immortality may mean continuation of earthly life through cloning, cryonics, and the like, or through symbolic immortality (leaving a legacy behind). Others may be indifferent to immortality of any kind and have no concern with satisfying spiritual needs. Fulfillment of spiritual needs is important for many dying patients (Fitchett, Burton, & Sivan, 1997; Koenig, 2002); others are content simply to accept death when it comes.

Existentialism

Although existentialism represents a broad domain in philosophy, the social sciences, and the literary world, the focus here will be on certain aspects related to psychology and the end of life. An existential approach to behavior emphasizes conflicts arising from an individual's confrontation with basic issues of existence with which everyone has to deal in some fashion (Cherny, Coyle, & Foley, 1994; Greenberg, Koole, & Pyszczynski, 2004; Yalom, 1980). These given issues, discovered by deep reflection, are four ultimate concerns fundamental to an individual's existence in the world: death, isolation, freedom, and meaninglessness.

The first, and perhaps the most ultimate concern, is death, with a basic existential conflict between the inevitability of death and the desire to continue to live. The second concern is existential isolation, with an individual able to share feelings, experiences, and thoughts with others only to a limited degree, never able to completely bridge

the gap. The conflict is between our awareness of absolute isolation from others and our desire to fuse our inner experiences with those of others. The third concern is existential freedom, that is the absence of any external structure or basic rules by which one can organize one's life. The individual has complete autonomy. The conflict is between one's awareness of this freedom and one's desire for some external structure, or design, to channel one's choices in a constructive manner. The fourth concern is existential meaninglessness. As posed by Yalom (1980), if one must die, if one must be alone in the world, if one must live in a void with no external design for living, then what meaning does life or death really have? Is there any real value or purpose to life? The conflict is that humans are creatures who need to seek and create meaning in a universe without meaning. Some regard existentialism as pessimistic in that these basic concerns and needs cannot be met, leading to defense mechanisms to alleviate the resulting anxiety in order to survive in an absurd world. Yet others (e.g., Ryan & Deci, 2004) see existentialism as a more optimistic philosophy of liberation, personal search for meaning, and engagement.

Given the need and abilities to create subjective meanings, one can find ways of transcending this finite existence through some kind of literal or symbolic immortality, or by simply accepting the end of existence at death. People can create their own purpose in living, their own values, beliefs, meaning of death, and means of dealing with dying. Whether one considers religious, spiritual, and existential beliefs as separate, overlapping, or integrated, these beliefs influence end of life decisions in dealing with death anxiety, preparing for death, and attaining a good death.

Influence of Spirituality on Decision Making

Examples of spiritual beliefs influencing end-of-life decisions are limited. An individual may make use of spiritual beliefs and needs as guides to end-of-life decisions. Individuals may also make end-of-life decisions to satisfy spiritual needs as part of a general coping strategy to help deal with death anxiety and preparation for death.

As an example of the influence of spiritual needs on end-of-life decisions, one can mention that decisions to prolong life by aggressive treatment appear to be related to certain values and attitudes related to death. According to Cicirelli (1997), decisions in relation to end-of-life scenarios were related to greater intrinsic religiosity, less value for quality of life, less fear of the dying process, and greater fear of destruction of the body. Underlying such decisions are feelings that life is sacred and should be preserved at all costs.

Refusal of life-prolonging treatments has been related to less fear of the dying process, to greater value placed on quality of life, and to less religiosity (Cicirelli, 1997; Cohen-Mansfield et al., 1992; Mutran, Danis, Bratton, Sudha, & Hanson, 1997). Ethnicity also plays a role, with African Americans less likely to refuse treatment, compared to Caucasians, Hispanics, and Asians (Cicirelli, 2000; Eleazer et al., 1996).

Not surprisingly, existing studies indicate that greater religiousness is associated with less favorable attitudes toward suicide, assisted suicide, and euthanasia (Cicirelli, 1997; Leinbach, 1993). In addition, those who placed greater value on quality of life and less value on the preservation of life, and who had less fear of the destruction of the body, but greater fear of the dying process, were more likely to favor some active means of ending their life if terminally ill (Cicirelli, 1997; Cicirelli, MacLean, & Cox, 2000).

Cross-Cultural Variations

In a multicultural society, such as the United States, considerable variability in views about end-of-life decisions is to be expected. Braun, Pietsch, and Blanchette (2000) have presented a model of end-of-life decision making in which individual values, beliefs, and behaviors regarding end-of-life decisions are influenced by the ethnic, religious culture, regional cultures, all acting within the dominant world view. Thus, one might expect considerable variation regarding end-of-life decisions among adherents to a particular religious denomination, modified further by their ethnic culture. Furthermore, many members of a particular religious group do not accept all the aspects of religious dogma, idiosyncratically shaping the content of their religious faith. For example, some Christians have serious doubts about the existence of an afterlife (Cicirelli, 2002).

The Christian values of the dignity and sanctity of human life, the sovereignty of God over human life, the commitment to care for those who suffer, and an acceptance of suffering as witness to their faith, help shape Protestant views on end-of-life decision making, although there are wide denominational variations (Rowell, 2000). Most Protestant faiths now support the withholding and withdrawal of futile treatment, with palliative care for the terminally ill. Assisted suicide and euthanasia are typically condemned. Yet the notion that God has given humans the capacity to make free choices offers some support for the right to terminate one's own life through suicide. Indeed, many Protestants use the Christian value of compassion for the suffering as an argument for assisted suicide and euthanasia.

On the other hand, typical African American Protestant religious views are that pain and suffering in the dying process is a test of spiritual commitment, and thus adherents are less likely to subscribe to palliative care (Crawley, Payne, Bolden, Payne, Washington, & Williams, 2000). At the same time, they are more likely to want medical treatments to extend life for as long as possible (Cicirelli, 2000, 2001, 2002; Eleazer et al., 1996).

Catholic religious views about the sanctity of human life, the sovereignty of God over life, the meaning of suffering, and the importance of love and mercy lead to the endorsement of compassionate palliative care (such as hospice) during the dying process (Alexander, 2000). Assisted suicide and euthanasia are strongly opposed.

Although great diversity of religious views exists among the various branches of American Judaism (Kavesh, 2000), certain shared beliefs and values underlie typical Jewish end-of-life decisions. Saving life whenever possible is important, yet it is acknowledged that God alone determines how and when death will come. Organ transplants are viewed as consistent with the value placed on saving life. The relief of pain is regarded as a virtue, with the withholding or withdrawal of futile treatment at the end of life sanctioned. Euthanasia is universally condemned, but some branches of Judaism see the principle of autonomy as justification for suicide and assisted suicide.

Muslim beliefs (Hai & Husain, 2000) are similar in many ways to those of Judaism, with God (Allah) as the creator and master who determines when and how illness and death will come. Prolonging life on artificial life supports is discouraged and refusal of treatment is considered to be a valid choice. However, suicide, assisted suicide, and euthanasia are not acceptable. Organ donation for helping another person or saving a life is allowed.

Beliefs among the many branches of Buddhism are diverse. In general, however, because a person passes from the present life into the next, Buddhists see no meaning in treatments to extend life (Nakasone, 2000). They support palliative care to relieve suffering. Because they believe that a person should be buried with all parts of the body in order to make the transition to the next life, organ donations are considered unacceptable. Any needed end-of-life decisions are made by family consensus, not as an autonomous decision of the individual.

Hindu beliefs (Fry, 1999) similarly stress that the body and soul should be intact at the time of death so that the person will be reincarnated whole in the next life. Thus, use of artificial life supports, autopsy, and organ donations are seen as objectionable.

Non-religious individuals, while lacking specific beliefs to inform their end-of-life decisions, nevertheless are guided by their own philosophical and spiritual beliefs. Individual autonomy is important, although the content of decisions must be in accord with overall views.

Age as a Factor in End-of-Life Decisions

One might expect that age of the individual would be a factor influencing end-of-life decisions, if only because normal expectancies for additional years of life vary with the age of the individual. Older adults experience numerous reminders that death is no longer in the remote future, such as the preponderance of their peers in obituary columns, marketing of funeral plans, increase in chronic conditions, mobility limitations, and declining cognitive abilities (Cicirelli, 2003). Various authors have noted that older adults undergo a kind of psychological reorganization to cope with death fears and reach an acceptance of death (McCoy, Pyszczynski, Solomon, & Greenberg, 2000; Wong, 2000). An increasing acceptance of death is particularly noticeable among the very old, and many feel ready to go whenever death comes (Cicirelli, 2002).

In their qualitative study of terminally ill patients, Staton, Shuy, and Byock (2001) noted sharp differences between adults in their forties and those in their seventies and eighties. The older adults were more accepting and resigned to their approaching death, refusing aggressive treatments, whereas younger adults viewed their illness as an enemy to be aggressively treated. Paradoxically, spiritual growth was observed only among the younger group, once it became clear that death was unavoidable. Staton et al. concluded that the older adults had dealt with many spiritual and other death-related concerns over a long period of time.

Although terminally ill children and adolescents do not have a legal right to be involved in end-of-life decisions, Stillion and Papadatou (2002) maintain that decisions regarding treatment should be discussed with them. In most cases, parents opt for aggressive treatment hoping for a cure until the futility of further treatment becomes undeniable. Many parents and cultural groups attempt to protect children and adolescents from learning that they have a terminal condition, but the increasing severity of their symptoms, in spite of the aggressiveness of treatment, leads these young patients to suspect their true condition. Although young children's understanding of death gradually increases with age, children with a terminal illness appear to gain an unusual understanding of death and their own mortality. Adolescents

who are terminally ill typically begin an active search for meaning in
their dying experience.

INFLUENCE OF DYING ON SPIRITUAL GROWTH

An earlier discussion was concerned with the influence of spiritual
beliefs on end-of-life decisions. Influence in the reverse direction is
also a possibility, that is, appropriate end-of-life decisions will allow
for spiritual growth while dying. This is an important consideration,
although the degree of spiritual growth may partially depend on the
extent to which the individual has already been able to satisfy spiri-
tual needs before the end-of-life period begins.

Certainly, one of the stated goals of hospice care for those who
refuse life-extending treatments in favor of palliative care is to deal
with spiritual needs. However, Battin (2001) argues that terminal
patients choosing assisted suicide shorten their lives by an average of
only 3.3 weeks, thus avoiding the agonal phase of dying (a period
when more than 50% of patients report moderate to severe pain).
Unless one feels that some special aspect of spiritual growth depends
on enduring pain and discomfort until the bitter end, it would seem
that any spiritual needs could be met and spiritual growth achieved
before the chosen time for the assisted suicide act is reached.

End-of-Life Period in Relation to Spiritual Needs

The end-of-life period is that time period when end-of-life decisions
are made. It is discussed here rather than earlier in the chapter to lend
more focus to the issue of whether end-of-life decisions can be made
to satisfy spiritual needs.

The end-of-life period for an individual can be defined as the
period from the beginning of dying until the actual occurrence of
death. The duration of such a period may vary from just a few min-
utes or hours (as in sudden death) to a few years (as in some illnesses).
Similarly, great variations as well as inaccuracies in the trajectory of
dying exist, depending on the type of illness and characteristics of the
individual (Bradley, Fried, Kasl, & Idler, 2000). In some cases there is
continuous decline in health until death, in other cases there are inter-
mittent acute periods separated by periods of remission of symptoms.

Typically, an illness is considered terminal when it has a predictably
fatal outcome and no known cure exists (Kleespies, 2004). It is exceed-
ingly difficult to determine just when the terminal phase of the end of
life begins and to estimate the amount of time left to live. Operationally,
the onset of the terminal phase is usually considered to be that time

when the physician indicates that the person has only a limited time left to live. Yet physician prognosis of life expectancy is highly inaccurate (Christakis & Lamont, 2000; Drought & Koenig, 2002; George, 2002). Such estimations are rendered more problematic by the fact that Medicare regulations stipulate that payment for hospice care can be made for no more than a six month period. Because estimation of time left to live is so uncertain, most physicians typically wait to pronounce a patient "terminal" until very late in the trajectory of dying, with the result that the majority of patients who enter hospice care do so only a few weeks before death. According to Kaufman (2002), a dying trajectory cannot be identified for more than half of patients at the end of life (e.g., sudden deaths, extreme frailty and dementias, COPD, and congestive heart failure). Certainly much research is needed in this area (George, 2002).

If one had a better idea of the length of time one would live before dying, one could then make end-of-life decisions and plan more effectively for care. Travis, Loving, McClanahan, and Bernard (2001) expanded Pattison's concept of living while dying to include awareness of dying, living-dying interval, dying, and death. Extending this idea still further, one can conceive of living (prior to awareness), living while dying, dying while living, active dying, and death. During living while dying, end-of-life decisions may include decisions about relationships on a job, about relationships with a partner, about further curative attempts (or about palliative care), about maintaining control during the dying process, and so on. During dying while living, decisions may involve dealing with increased pain and other symptoms, anxiety about death, and so on.

Regardless of whether an individual may be considered terminally ill by medical personnel, many patients do not appear to be aware that death is approaching or do not seem to be willing to accept it. Hinton (1999) conducted weekly interviews with hospice cancer patients and found that, in the final eight weeks of life, only 42% were fully certain that they were going to die, although the great majority considered death to be a possibility. Acceptance of death was reported for only 51% of patients. It is of interest that both the degree of awareness and acceptance of death were not constant but appeared to fluctuate over time, with as many as 18% showing falling acceptance as death grew nearer. If lack of awareness and acceptance of approaching death is indeed typical of the majority of patients who are dying on a known slow trajectory, then one might ask whether such patients experience end-of-life spiritual needs or show spiritual growth during the dying process. The search for the spiritual dimension of the dying patient presupposes that persons near death are

"sentient, responsive, expressive, and able to converse" (Kaufman, 2002). One might also wonder whether end-of-life spiritual needs and spiritual growth are at all applicable to the large number of individuals who die unexpectedly and quickly, or who are dementing, comatose, or otherwise incapable of realizing that death is close at hand. Even among those who are cognitively competent and aware of approaching death, one wonders how many have spiritual needs. One recent study (McGrath, 2003) suggests that the majority of hospice patients do not seek comfort in religious or spiritual perspectives. Certainly there appears to be little or no concern for spiritual needs among dying patients receiving substandard nursing home care when merely maintaining existence is a struggle (Kayser-Jones, 2002). However, such questions do not invalidate the importance of end-of-life spiritual concerns for those dying patients who experience them.

In the context of approaching death, individuals have three areas of concern. The first involves dealing with symptoms. The second concerns the practical need for various end-of-life decisions. The third area of concern involves the psychological need for existential and spiritual meaning. Questions about the meaning and purpose of life, about the meaning of one's illness, about the future, and about what happens after death are all part of the search for meaning. Patient's existential distress near the end of life has been viewed (Cherny et al., 1994) as, at least partially, due to such concerns as disrupted or distorted personal integrity (changes in body and intellectual functioning, changes in social and professional functioning), negative retrospection (unfulfilled aspirations, remorse and guilt, questions of the worth of achievements in life), future-related concerns (separation, hopelessness, futility, meaninglessness, death itself), and religious concerns (fear of divine retribution, illness as punishment, fear of a void). According to Wong (2000), individuals are motivated to search for personal meaning, whether religious or secular, that buffers them against personal anomie and offers a sense of predictability and control at the end of life.

Attaining a Good Death

The notion of a "good death" has been advanced by various scholars of death and dying as one aspect of preparation for death. Although what constitutes a good death may be unique to the individual, Block (2001) sees six goals to be achieved: optimizing physical comfort, maintaining a sense of continuity with one's self, maintaining and enhancing relationships, making meaning of one's life, achieving a sense of control, and confronting and preparing for death. Wong and

Stiller's (1999) conception of a good death is similar in many respects, "having a sense of control, discussing the practical implications of dying, exploring an afterlife, talking about religious/spiritual issues, reviewing the past, having a sense of humor, not avoiding painful truths, taking an interest in personal appearance, benefiting from the presence of significant others, and participating in physical expressions of caring (p. 81)." In a similar vein, Lester (1996) presented five criteria of an appropriate death: that the individual should have a role in his/her own death and not leave it to chance, that the body should retain its integrity, that the death be consistent with the person's life style, that the time of death should be appropriate, and that the different types of death (physical, psychological, social, & anthropological) coincide in time. To these criteria might be added that an appropriate death should be consistent with the person's spiritual beliefs and values.

It may be argued that individuals' end-of-life decisions are related to their conceptions of what is a good or appropriate death. Reaching end-of-life decisions that promote a good death cannot be achieved independently of spiritual needs especially those under the subcategory of existential needs. Clearly, not everyone can achieve a good death, but making good end-of-life decisions can be viewed as a means of achieving some measure of control over one's dying in a way that allows one to achieve other aspects of a good death.

CONCLUSION

The end-of-life period begins when the person becomes aware that his/her condition is terminal, extends through the duration of the dying process, and ends when death occurs. Various types of end-of-life decisions may be made during this period, with the goal of giving the dying individual greater control over the dying process. These decisions range from the enactment of formal and legal documents to informal and non-binding agreements regarding how, where, and when the person will die.

Unfortunately, advance directives specifying end-of-life treatments have been only partially successful in attaining this goal for various reasons. Only a minority of individuals have prepared advance directive, with others resisting their use. Among those who have used them, stability of preferences for treatment is only moderate, surrogate decision-makers for incompetent patients may not truly represent their views, treatment preferences may not apply to the actual situation, and medical personnel may be unaware of, or simply ignore, the advance directives of patients. Yet, some programs have been quite

successful, not only in fostering completion of advance directives but in implementing end-of-life treatment consistent with the dying patient's wishes.

The role of end-of-life decisions in relation to alleviation of death anxiety and increasing preparation for death is two-fold. On the one hand, one's religious, spiritual, and existential needs or beliefs appear to have an influence on the nature of end-of-life decisions. On the other hand, the kinds of end-of-life decisions that are made can allow for deeper examination of spiritual concerns during the dying period, leading to increased spiritual growth and death acceptance. In this context, end-of-life decisions may be part of a good death. However these ideas are still in the exploratory stage.

The fact that only a minority of people have a trajectory of dying that includes a period where they are aware and accepting of impending death leads to the question of whether spiritual growth during the dying process is likely for many dying patients. At the other end of the spectrum are people whose end-of-life trajectory is very long, so that they may need to be more concerned with decisions to deal with living while dying than with end-of-life spiritual growth. The challenge for researchers and practitioners is to find ways to help both groups of people achieve as good a death as possible. To this end, better communication and cooperation must be developed between those involved in end-of-life decision making and in end-of-life care, that is, between patient and family, patient and medical personnel, and so on.

Thus far, research on how people make effective end-of-life decisions is limited, and has had only partial success. Successful results are not easily generalized, but seem to apply to particular kinds of individuals and circumstances. Further work is needed regarding the process by which these decisions are made, as well as regarding the kinds of decisions, both formal and informal, that are most effective in improving the quality of the end-of-life period.

However, this is too important an area to be ignored, and new approaches must be developed. Braun and Kayashima (1999) have an idea that may be of significance. They suggest that churches and temples can be good places to foster discussions about certain end-of-life issues, preferably including whole families. Topics such as the meanings of life and death, spiritual needs at the end of life, and end-of-life treatment and care could be explored in relation to the content of religious faith. The goal here would be to attain spiritual growth prior to the dying process, or certainly before active dying.

However, it is not clear where non-religious people would fit in or benefit. An additional challenge would be to improve the quality of the dying process for those who are not religious or feel no need to satisfy either spiritual or existential needs.

MAIN POINTS

1. The end-of-life period begins with dying and ends with death.
2. End-of-life decisions are made in last period of life.
3. Religious, spiritual, and existential beliefs influence end-of-life decisions to alleviate death fears and prepare for death.
4. Conversely, end-of-life decisions themselves may influence spiritual growth while dying.
5. A good death may also be a possible outcome of end-of-life decisions.

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