

DEATH AND DYING: ISSUES FOR EDUCATIONAL GERONTOLOGISTS

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Abstract:

Research findings and other information on three topics, death orientations, the dying process, and bereavement, are reviewed with a major focus on the elderly. It is suggested that relevant knowledge and issues in these and other areas in death and dying are important for gerontological practitioners and it is proposed that such death-related content be systematically integrated into academic curricula at the pre-service and in-service levels.

Article:

Educational gerontologists and professionals who deliver services to the elderly can hardly avoid coming into contact with the subject of death, and it is essential that workers in this specialty have some basic knowledge of the field of death and dying, its research literature, current thinking, and unresolved issues. The purpose of this paper is to present some relevant information in a format useful for educational gerontologists. Therefore, its major focus is on reviewing death-related studies that pertain to the elderly. Specifically, three topics are addressed: death orientations, the dying process, and bereavement.

DEATH ORIENTATIONS

Avoiding the Subject

Despite the positive impact of the death awareness movement there still is much ambivalence about the topic and many people find it easier to avoid the subject than to deal with it. Adult children often find it difficult to talk about death with their aging parents arguing that the topic is embarrassing and will upset their elders. The consequences of such avoidance, however, can be tragic. For example, an old parent may become ill and mentally incompetent or comatose. The issues of the right to forego life-prolonging treatment and of informed consent for certain medical procedures remain unresolved. In recent reports on decision-making about life-extending procedures when the patient is incompetent, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983a, 1983b) stresses the importance of the family's involvement. The Commission recommends that patients be enabled to give directions prior to becoming incompetent, such as through a "living will" and that they be enabled to name a surrogate to act on their behalf. Adult children could avoid much anguish, self-blame, and guilt if they openly discussed and settled such matters with their parents. Less essential but still significant is the question of the kind of funeral arrangements an aging parent prefers. Surveys have shown that most elderly persons do indeed have preferences (Wass, Christian, Myers, & Murphey, 1979).

Health care professionals in hospitals and nursing homes often are awkward and uncomfortable around terminally ill patients and avoid not only the subject but the patient as well (Bowers, Jackson, Knight, & LeShan, 1975), sometimes resorting to bizarre behaviors and practices (Glaser & Strauss, 1968; Sudnow, 1967; Taylor, 1977). Yet many elderly persons want to talk about death and do so among themselves (Roberts, Kimsey, Logan, & Shaw, 1970; Matse, 1975) or in group situations (Saul & Saul, 1973). Several authors have reported that old persons not only agreed to talk about death to assist with the research but deeply appreciated the opportunity (Feifel, 1959; Saul & Saul, 1973; Wass, 1977). In addition, one needs to consider the pleas by advocates for better caring and emotional support for the elderly (Butler, 1975, 1980; Roose, 1969; Saunders, 1972). Both institutionalized and noninstitutionalized old persons are likely to talk about death when given the opportunity. It certainly seems to be a strong need in the terminal phase.

Fears and Anxieties

Death fears and anxieties have been a subject of great interest to many researchers. As a result an enormous amount of literature has accumulated and continues to grow. Yet the results are often inconsistent and sometimes raise as many questions as they answer. There exists no theory of death fears, but many different concepts have been formulated.

Death fear or anxiety has been conceptualized as a unidimensional trait (Templer, 1970); as four dimensional including fear of death of self, death of others, the dying of self, and the dying of others (Collett & Lester, 1969); as consisting of eight dimensions (Hoelter, 1979); as a continuum from negative feelings of fear to positive emotions of joy (Ray & Najman, 1974); as having both an affective as well as cognitive component (Dickstein, 1972); as multidimensional, complex, and consisting of different levels of awareness (Feifel & Branscomb, 1973); and as personal constructs of threat (Krieger, Epting, & Leitner, 1974), among others. There are as many or more instruments for measuring death fear as there are conceptualizations. Of the major assessment techniques—clinical observation, self-report techniques, and projective techniques—the latter two have been generally used. Rating scales have been used mostly with young adults; interviews and questionnaires have been commonly used with elderly persons (Wass & Forfar, 1982). A more extensive review of the research literature on death fears and correlates as it relates to the elderly has been published elsewhere (Wass & Myers, 1982). It was found, essentially, that as a group the elderly are less fearful of death than younger age groups. Although such a finding may seem reasonable, it may not be meaningful since the elderly are a highly heterogeneous group. Comparisons *among* elderly populations seem far more helpful. Such studies have been carried out. Elderly women have been found to be more fearful of death than their male counterparts. Urban, educated elderly persons with high incomes seem to be less fearful of death than poorly educated, low-income, rural elderly persons. High levels of death fear seem to be closely linked with poor physical and emotional health (observed and self-reported). Elderly persons living in the community appear to be less fearful of death than those residing in an institution. Being institutionalized also seems to be associated with increased morbidity and mortality. Although one might expect religious belief to be a factor in alleviating death fear among the elderly, studies have produced conflicting findings indicating that religious belief is associated with lowered death fear, with heightened death fear, and that no relationship exists between these variables (Wass & Myers, 1982). One obvious reason for the inconsistencies in the results is that widely divergent methods have been used to measure religious belief, thus making comparisons difficult.

A broader theoretical context for considering death-related fears has been provided by Erikson, Butler, and Frankl. In Erikson's (1959) postulation of the eighth and final stage in the life cycle the crisis to be resolved is between integrity or despair. Integrity is achieved when an old person near the end of life can look back and conclude that life has had meaning and purpose, that having lived has made a difference, and that one's humanity has been fulfilled. Erikson (1963) states: "in such final consolidation death loses its sting" (p. 140). When such a state of serenity is not reached, an individual experiences a deep fear of death, despair at realizing that it is too late to start another and better life, and a total nonacceptance of death in the face of such unfulfillment (Erikson, 1963). R. N. Butler (1963) advanced a similar notion with his concept of the "life review." According to Butler, the life review is triggered by the realization that one has reached the end of life and that death is near. The life review serves to prepare the individual for dying. Through the process of reminiscing, an old person revives past experiences, reevaluates them, and integrates them into a new understanding. When unrealized ambitions, unresolved conflicts, and other negative life experiences become predominant at this time, then, in Butler's view, the old individual feels anguish, fear, and despair. Viewed from these vantage points, an old person's emotions seem to center not so much around a fear of death but a fear of having lost all chances for living a more acceptable life. We have found no studies that were based on these theoretical formulations.

A third theoretical orientation, Frankl's (1959) existentialistic theory of the purpose and meaning of life, has been used as a basis for developing a measuring instrument, the Purpose of Life Test (Crumbaugh & Maholick, 1969). Another instrument apparently existentialistically oriented has been developed by Thauberger, Cleland,

and Thauberg (1979). These tests seem particularly relevant for old persons (Crumbaugh, 1972) but have rarely been used with them.

The notion that fears of death center around the concern about having to die before one is finished living or with unfinished business has also been advanced (Keele-Ross, 1969; Meyer, 1975). Other death-related fears among the elderly have been found to focus on being helpless and dependent, taking a long time to die, and making loved ones unhappy (Carey, 1976; Stricherz & Cunningham, 1982). Often old patients are unafraid of dying. In fact, they wait for it, welcome it as a release, and plead for it (*see* references in the next section). In one survey Kastenbaum (1971) discovered that 25% of the old, terminally ill patients he interviewed wanted to die.

Terminal Issues

In surveys of elderly persons on the question of whether an individual should be kept alive by artificial means and on whether they would so want to be kept alive, the large majority responded with "No" (Mathiau & Peterson 1970; Preston & Williams, 1971; Wass, 1977). Feifel (1959) has commented that the temporal proximity or distance of death may be a determining factor in one's attitude toward it. This raises the question: Do the views of elderly persons change as death becomes imminent? The question has been answered in general. Many health care givers who work with terminally ill old patients report that these patients do indeed want to die when there is no reasonable hope for recovery, that they frequently plead with the physician or with God to be allowed to die. Systematic clinical observations have produced similar results (e.g., Butler, 1975; Kastenbaum, 1967; Kithler-Ross, 1969; Lasagna, 1970; Saunders, 1972). Many cases upon which the demand for the right to die have been based are found in the vast literature on euthanasia. To ascertain how individual old persons in given situations feel about being allowed to die requires that individuals periodically state their views and wishes verbally and, more importantly, in writing. This may mean that the family generate the courage to initiate dialogue on the subject as indicated earlier. The high suicide rate among the elderly (Wass & Myers, 1982) attests to the fact that many take matters into their own hands.

Questions concerning life-and-death decisions for terminally ill, about who should be involved in the decision-making process, who should have the ultimate authority, and what should be the criteria for the decisions are unanswered at the present time. They are complex matters involving ethical, moral, and legal as *much as* medical issues, and quick solutions cannot be expected. These questions along with another even more fundamental question, namely how to define death (and life), have been of public concern for at least a quarter of a century. Congressional committees conducted hearings on these questions as early as in the 1960's. The issues have periodically been brought before the public through the mass media since 1976 when the case of Karen Quinlan was widely publicized (although not followed through). Since then a number of other cases bearing on the issues have come before the courts and have received national press attention, such as the case of Barber vs. the Superior Court of the County of Los Angeles (Steinbock, 1983) in which two physicians were charged with murder for removing the intravenous tubes that provided their patient with nourishment and hydration. The case *was* dismissed, but for the first time nourishment was equated with treatment equivalent to the application of a respirator or ventilator for example. For information on progress, current status, and new developments regarding the right to die, one cannot rely on journalists and television reporters. Yet, since these matters may affect us personally at any time or may affect loved ones, or clients, especially if they are of advanced age, it is important to become informed about these issues. Various volumes prepared by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1981, 1982, 1983a, 1983b) provide the least expensive, most readable systematic and comprehensive treatment of the subject and other related subjects of interest to the elderly. These include the status of state laws on natural death, the usefulness of a living will, informed consent, access to health care, and distribution of quality health care, among others. In addition, Concern for Dying, a nonprofit educational council established in 1938, has for many years published regular newsletters, bibliographies, living will forms (at no cost), and other valuable information.

The Dying Process

The question of how the dying cope with their terminality is of interest to health professionals, psychologists, and other helping professionals as well as those who are personally experiencing the impending loss of life. Koller-Ross (1969) developed a theory of five stages of dying: denial, anger, bargaining, depression, and acceptance, through which a patient passes in the terminal phase of life. This theory has been widely accepted especially by nurses. Oversimplified versions of it are found in many textbooks, films, and other training materials. Kubler-Ross herself never promulgated such oversimplification. The theory, however, has been criticized, and alternatives have been proposed. Those working with people professionally recognize that a person's emotional and cognitive make-up is far too complex to suggest that five emotions, one at a time, in a certain sequence, can account for all that goes on within the psyche of a terminally ill person. Weisman (1972) has provided a comprehensive analysis of the denial phenomenon, its processes, and purposes, pointing out that there are degrees of denial and that these vary with the patients' and others' interpersonal interaction patterns, and are closely linked with the patient's value system and self-esteem. Pattison (1977) described phases of dying in terms of the patient's management of anxiety at various points. The most outspoken critic of the five-stages-theory, Shneidman (1980), emphasized the emotional turmoil, the complex clustering of conflicting feelings, and the alternations between hope and despair, rage and resignation, and denial and acceptance. All of these theories must be viewed in the social milieu in which dying commonly occurs, with the dynamics of the interactions between health professionals and patients, among health professionals, between family and patients, etc., considering the roles and statuses and other characteristics these persons hold, and considering also the general organization of the hospital.

None of the theories above have been tested with old, terminally ill patients, as Weisman (1972) recommended. Yet 80% of the persons who die in any one year are age 65 or older (Butler, 1980). What *has* been studied and reported are the social contexts of dying with rich, illustrative case material pertaining specifically to the aged. Health professionals are found to be biased against old, dying patients (unless they enjoy great wealth and high status), that they tend to treat them in a routine manner, withhold information, expect unquestioning, docile behavior, and keep communication to a minimum. All these behaviors indicate low concern, low interest, little empathy, and minimal respect (Glaser & Strauss, 1968; Lasagna, 1970; Sudnow, 1967; Weisman, 1972). The situation is worse in typical nursing homes (Butler, 1975; Taylor, 1977). Such treatment has been termed "psychosocial death" (Weisman, 1972) and may be largely responsible for old, dying patients feeling undignified, lonely, and forsaken at a time when they may be in great need for emotional support and companionship as indicated previously.

The rapidly developing hospice movement may bring about dramatic changes. Davidson (1979) believes that it may have a positive influence on hospital care, and Butler (1980) feels that it may do the same for nursing home care. Hospice also extends its care into the home. There seems to be a general trend toward home health care delivery for the terminally ill. This development requires that members of the family and others taking over the primary care functions become knowledgeable about the psychological, social, and spiritual needs of the patient in addition to learning to provide palliative care.

BEREAVEMENT AND GRIEF

General Studies

Bereavement generally refers to the loss of a loved one through death. Grief refers to the various somatic, emotional, and behavioral responses to that loss (Jackson, 1979; Raphael, 1983). A number of authors prefer the term "mourning" to "grief" (Davidson, 1979, 1984; Furman, 1984). Others distinguish between them, such as Parkes and Weiss (1983). Most authors use them interchangeably.

Engel (1961) defined grief as a sickness, whereas Deutsch (1937) so defined the *absence* of grief. Freud (1917) viewed grief as an internal struggle between conflicting libidinal impulses and the resolution of grief as the withdrawal of libidinal energies from the deceased. His term "grief work" has been widely adopted to characterize the active participation of the bereaved in the process toward recovery. Most contemporary

researchers and clinicians consider grief to be a normal reaction to an overwhelming loss through death and a process of healing as of a deep wound (Parkes and Weiss, 1983).

Descriptions of acute grief reactions in the literature are surprisingly similar. *Somatic* reactions are described as: tightness in throat and chest, shortness of breath, choking, headache, dizziness, gastrointestinal disturbances, loss of appetite, physical exhaustion, and insomnia. *Emotional* reactions include a wide range of feelings, typically of shock, numbness, helplessness, yearning or separation pain, sadness, depression, anger, rage, hostility, guilt and despair. *Distorted perceptions* are also commonly reported, such as seeing the image of the deceased and "sensing" his or her presence (Bornstein, Clayton, Halikas, Maurice, & Robins, 1973; Bowlby, 1973; Clayton, 1979; Horowitz, 1976; Lindemann, 1944; Glick, Weiss, and Parkes, 1974; Parkes, 1970a, 1970b).

Researchers disagree sharply on the *duration* of grief. Lindemann (1944) believed that normal grieving lasts approximately 8 to 10 weeks. Contemporary researchers suggest that it lasts one to two years (Bornstein, et al., 1973; Lynch, 1977; Maddison and Viola, 1968; Glick, Weiss, and Parkes, 1974) and sometimes three to four years (Parkes, 1972). Several writers question whether a significant loss can ever be fully resolved (Worden, 1982; Raphael, 1983).

Various authors have postulated *stages* or phases of grief (e.g., Bowlby, 1977; Gorer, 1967). In general, there seems to be an initial phase of shock and numbness, followed by intense emotional pain, depression, despair, and so on, eventually followed by a period of reorganization and renewal. Some bereavement specialists have found it more functional to identify the *tasks* of grieving. Worden (1982) has described four such tasks for the bereaved individual: to accept the reality of the loss, experience the pain of the grief, to adjust to an environment in which the deceased is missing, and to withdraw emotional energy from the deceased and to reinvest it in other relationships. Similar classification systems have been offered by Furman (1984) and Parkes and Weiss (1983).

Much additional study is needed to clarify the characteristics and kinds of *abnormal* grief, but there is agreement in the literature about the occurrence of at least three types: *chronic*, *inhibited*, and *delayed* grief (Bowlby, 1969; Jacobs and Douglas, 1979; Maddison and Walker, 1970; Wahl, 1970). Abnormal grief is viewed as exaggerations and distortions of normal grief processes, but as Parkes and Weiss (1983) note, individuals vary so greatly in duration, intensity, and form of grief that it is difficult to determine with certainty whether certain symptoms are within the range of normal grief or whether they are pathological. This uncertainty has special significance for the elderly. For a careful and concise discussion of various grief patterns and their manifestations the reader is referred to Worden's recent work (1982).

Raphael (1983) has listed the following conditions as outcomes of pathological grief: General ill health, psychosomatic, psychiatric and psychosocial disorders, depression, altered relationships, vulnerability to loss, anniversary reactions, and mortality.

Concerning mortality, researchers have found that a significantly increased number of widowed persons die within one year of bereavement (Williams & Polak, 1979; Clayton, 1979). Jacobs and Douglas (1979) suggest that grief serves as a bridge or mediating process between the loss of the spouse and the subsequent death.

Old Griefers

It has been suggested that the general patterns and processes of grieving among younger adults do not readily apply to the elderly (Skelskie, 1975). Raphael (1983) suggests that the grief of older persons is more diffuse, and that agitation, irritability, depression, and hallucinatory experiences may be more frequent and more pronounced. Older persons have been found to respond to significant loss not only with greater amounts of stress but also with a greater variety of manifestations of stress (Hamilton, 1982). In one study it was found that older persons often die close to significant

anniversary dates (Barraclough & Shepherd, 1976). A recent study by Gallagher and Thompson (1982) suggests that the death of a spouse requires more readjustment on the part of elderly survivors than any other stressful life event. Gramlich (1968) noted that not only are grief reactions in elderly persons more diffuse, they are often also completely obscured. These findings are supported by Skelskie (1975) and Burnside (1969) who found that irritability and apathy among old persons in convalescent hospitals are often unrecognized as signs of grief and instead are diagnosed as symptoms of organic brain disease.

Old persons are survivors. The longer they live, the more peers and relatives they will survive. When old persons lose friends and intimate companions, their bereavement is multiple and their grief complicated. It is highly likely that an additional loss will occur before the grieving for a previous one has been completed. To our knowledge, there is no research on the effects of multiple bereavement in old age, but it is reasonable to assume that it intensifies the grief responses. Thus, old persons may be chronic grievers, but in contrast with younger age groups, chronic grief for them is normal rather than pathological.

Old people, however, *can* adjust to loss and grief and, in fact, they usually do (Heyman & Gianturco, 1973). Glick, Weiss, and Parkes (1974) identified high socioeconomic status as positive correlates of successful grief resolution. Studies that indicate increased morbidity and mortality among the elderly widowed, seem to show that a complex of social and psychological variables interact to affect the situation, including characteristic coping styles, concurrent stresses and crises, preexisting relationship with the diseased, religious belief, and responses of the family and social network (Raphael, 1983). The adequacy of an older individual's social-support network is perhaps the most critical factor. In a study of the support systems of old widows, Schiamberg (1982) reports that the most frequent response of the participants to the question of emotional resources available was "no one." This seems to be particularly true for elderly widowers (Rubinstein, 1983; Vinick, 1983). One recent study (Baraki, 1983) indicates that bereaved elderly persons report visitation as more beneficial than telephone contacts especially in the later periods of bereavement. Several longitudinal studies supported by the National Institute on Aging on the effects of supportive networks on bereaved old men and women are currently underway and promise to provide greater insight into the types and quality of supports that assist best with effective coping in specific situations (Dimond & Lund, 1983; Faletti & Berman, 1983; Faletti, 1984).

Meanwhile, a variety of services providing support for bereaved older individuals exist. In fact, more services exist than do studies to prove their efficacy! Many programs of this nature are reviewed in an article by Myers and Salmon (in press). Both peer and other support systems have been developed. Silverman (1969) developed a widow-to-widow support system in Boston that began as a model program and has been adopted in many cities throughout the country. Vachon, Lyell, Rogers, Freedman-Letofsky, and Freeman (1980) have provided empirical support for the efficacy of self-help interventions for widows. The American Association of Retired Persons has developed a widowed persons service and has a guide for widowed persons (undated). This guide includes a variety of information sources that provide bereaved older readers with help in coping with their losses.

Counselors and other helping professionals employed in a variety of settings can be of assistance to bereaved older individuals. It is important that these helping persons be able to cope with their own feelings about death and dying, that they hold positive attitudes toward older people, and that they themselves have support groups available as they help older persons with their grief. This is especially true in hospice settings, but also in senior centers, mental health clinics, and other settings where counseling services are provided.

Some recent studies suggest that *indirect* services, such as encouraging contacts with friends and family members and teaching creative uses of time, are effective for those elderly bereaved who do not wish counseling or therapy (Clark, 1983; Vinick, 1983).

SOME IMPLICATIONS

Implications of the preceding information for educational gerontologists may be discussed in each of three areas: teaching, direct-service consulting, and research. These implications are based on the relevance of issues related to death and dying for older people and hence, by extension, on the importance of these areas for gerontologists.

Teaching is affected in two areas, pre-service and in-service education. Curriculum planners in undergraduate and graduate gerontology programs must be concerned with providing appropriate instruction for future gerontological practitioners. Obviously, some exposure to death and dying is both relevant and necessary. At least one course in this area should be a requirement in any academic program. Some areas, such as counseling and psychological services, may require additional coursework for effective professional preparation. Many persons currently working with older persons in service capacities have not had any opportunity for coursework or workshops in this area. Educational gerontologists can arrange for the provision of such training in their local areas.

Many educational gerontologists already provide in-service training through their consulting work with agencies that provide service to the elderly. It is often the case that educators serve as consultants through their work on advisory boards of community agencies. They can help to improve services to older persons through helpful suggestions to agency administrators and planners regarding appropriate training sessions for service personnel in the area of death and dying. Moreover, they can provide consultative expertise to these agencies for the development of peer support and other direct service programs to help older people explore their feelings, attitudes, and fears concerning death and dying, to help them prepare for their own dying and death, as well as to help them deal with grief associated with the loss of loved ones.

Research needs in the area of dying, death, and bereavement are manifold. Concerning education, specifically, it would be helpful to know the curriculum requirements for the best preparation of gerontological practitioners, both pre-service and in-service. Studies of appropriate educational programs for older individuals and groups to help them prepare for death and to deal with the deaths of others would be useful.

The suggestion that content related to death and dying be introduced into academic gerontology curricula is not new. It is proposed here that a systematic approach to including such content is needed. As we work towards the development of standards for professional preparation in all these areas, there can be no doubt that death and dying will be a critical area of concern in the preparation of persons to work with older persons.

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