Spiritual, Ethical and Pastoral Aspects of Death and Bereavement



Gerry R. Cox and Ronald J. Fundis Editors



Series Editor: John D. Morgan

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Introduction

Gerry R. Cox and Ronald J. Fundis

As the world continues to age, the technologies improve, and the catastrophic and debilitating diseases persist, ethical dilemmas will most likely multiply for societies in general and for mental, physical and spiritual health providers in particular. While societies struggle encumbered with ethical uncertainties without an apparent sense of urgency, professional practitioners, patients and their family members continue to experience the realities of human suffering, the technological limitations, and almost overwhelming personal and psychological burdens in the absence of societal arrangements and rituals needed to educate, support and comfort them.

This collection of previously unpublished essays addresses a wide range of topics so relevant to the on-going debates regarding dying and death and the subtleties, nuances, and complexities which accompany these phenomena. The authors have attempted to contribute their experiences, insights and research results in such a way as to clarify rather than obfuscate. Topic coverage is broad; however, content depth is not sacrificed. The diversity of authors' backgrounds, both geographical and disciplinary, also serves to make this volume rather unique.

In Part I, David Meagher makes a case for the ethics and necessity of death education. After discussing death education and what it is supposed to do, he describes the research in death education. He then defines ethics and addresses ethical issues. Meagher closes by offering ethical principles relevant to the educational process. The focus of this chapter is limited principly to academic education and does not fully address applications and nonacademic settings.

Ross Gray and Brian Doan begin by discussing the changing attitudes toward cancer and the role of heroes in that change. By developing

heroic role models for those who have cancer, society has placed an added burden upon them. The authors view hope—both the causes and the consequences—in the development of cancer. They close with an examination of ethical and clinical issues.

Lynne Martins examines the charismatic movement and its impact on dying and bereavement. She analyzes the pros and cons of the charismatic movement and its impact on dying and bereavement within congregations and parishes. She discusses the paradox of Romans 8:28: what to do when God is silent and with hope as the key element of faith. While some might argue that introducing elements of one's own faith might be too intrusive, ethnocentric, or even unwelcome, Martin eloquently develops the charismatic viewpoint.

In Part II, Delton Glebe focuses upon the uniqueness of pastoral care for aiding the dying and bereaved. He examines the dying process, grieving, and the role of the pastor. He also discusses expectations of the pastor, dilemmas in pastoring, styles of pastoring, and pastoral resources. Although there is not a consensus among pastoral counselors that discovering a client's history of coping with previous "smaller" problems or traumas, Glebe builds a case that this can be a useful and productive strategy.

Jean Crabtree offers an approach for ministering to people with AIDS. While ministering to the dying is difficult, ministering to those with AIDS is even more challenging. She offers an approach for meeting the needs of those dying with AIDS. Using the experience of Women's College Hospital, she makes a case for facing the problem in the manner presented in the Canadian experience. This chapter is, in fact, an impassioned plea to effectively minister to AIDS patients and their families.

Dorothy Southall presents a practical model for clergy and lay people to work together in the grieving process. She develops a model for communications between clergy and lay people; offers methods of communications; develops a model for viewing lay persons in grief; and closes with a plan for clergy and lay people to work together. Issues regarding the role of the laity and the continuum of care are raised by the author.

Lynne Martins closes Part II with a model for adjustment for the dying and bereaved. She suggests that the church is a model for healing grief—psychologically, physically, and spiritually. She develops the concept of corporate mourning and the role of the church. The strength of community that comes from small groups such as Sunday schools, choirs, etc. are also discussed. In addition she incorporates familiar stages of grief with practical aspects of ministering to the dying and bereaved. Martins also develops the role of networking and support systems to aid the dying and the bereaved. She finishes with resources to aid both the lay person and the helping professional.

Part III opens with Paul Sakalauskas' examination of the role of belief systems for the bereaved in a comparative study of Canada and the United States. The impact of spiritual and cultural beliefs is also presented. Case studies are used to illustrate the process. He also discusses immigrants and refugees plus the cultural influence that they brought with them. As a funeral director, Sakalauskas offers an analysis of the caregiver's role and examines relevant studies.

Ted Creen develops a model visualization process for handling grief. Using the example of visualization of Psalm 23, Creen demonstrates the model of visualization to assist in facing grief.

Greg Mogenson examines three approaches to the mourning process. Using the concept of irreplaceable objects, he develops an imaginal approach which he contrasts with Freud's notion of "reality testing." He then uses Shelly's elegy, "Adonais," to further contrast Freud's materialistic account of the grieving process. He finishes with an application of the imaginal approach to the mourning process. An example of a dialogue between an image-oriented therapist and a bereaved patient is developed.

Michael Bull develops a persuasive case for the importance of balance as individuals attempt to cope with lifetime losses. Anticipatory grieving, "what if" thinking, and denial are examined in the context of crisis—not merely as dangerous but as potential opportunity. Balancing lifetime losses enhances not only the grieving process, but also enriches daily lives and relationships.

In Part IV, Connie Guist offers an African perspective of attitudes toward childhood death. Her research presents a case for awareness of cultural heritage for caregivers responding to childhood death. Her analysis of Kenyan attitudes toward dying and bereavement provides an understanding of the role of culture in attitude development.

Carol Irizarry presents a study of Australian children's responses to the death of a grandparent. While few studies exist, Irizarry offers new insights into the grieving of children. She found that parents were often unaware of their children's reactions and responses: children remembered a great deal about their grandparent's death; they felt pressured to get over the death quickly; and the opportunity to help children develop was often missed.

Craig Seaton offers a practical guide for helping dying children cope with their future utilizing guided autobiography with an extensive, detailed appendix for maximizing its potential.

In Part V, Mary Kachoyeanos and Florence Selder attempt to answer the question of whether parental grieving is as definite and orderly as

traditional grief theorists suggest, or unending as clinicians who work with the grieving suggest. Using a sample of bereaved parents from a Compassionate Friends group, they offer a view of parental survival of sudden death of a child that focuses on the process based upon a Life Transition theory framework. The chapter demonstrates that parental grieving is long-lasting and offer suggestions for aiding the process and Kachoyeanos and Selder support the Compassionate Friends approach.

Kjell Kallenberg systematically develops the concept of "view of life" and its effects on bereavement and loss. The components of "view of life" are empirically tested using in-depth interviewing techniques on a group of subjects who have experienced a sudden and unexpected death. Four distinct patterns of grief emerged from the research that were correlated with aspects of "view of life." The attitudes of trust/mistrust served as major indicators of distinct grief patterns.

Tadini Bacigalupi examines the historical foundations of Americans' health and life perceptions as outgrowths of their views on death. There is considerable literature describing the United States as a death-denying society, a society whose members seem to go to almost any length to postpone death. It is suggested that Americans no longer life, but rather live in fear of death. In this sense, America may indeed be a paranoid society.

Vernon Gunckel offers an analysis of the impact of social change on the role of the funeral director and clergy in the funeral and postfuneral needs of individuals. He also discusses the role of funeral directors and clergy in sponsoring support groups.

Dorothy Ley offers an overview of spirituality and spiritual care in hospice. The role of spirituality and spiritual care is not only a part of the structure of the organization, but it is also a part of the process of managing pain, re-establishing communication, finding oneself, and facing suffering. She also discusses the care of those with AIDS.

In Part VI, Brian Woodrow examines the question of personhood and the biomedical ethical decision of neoeuthanasia. Woodrow suggests the landmark decision of the British Columbia Court of Appeal in July of 1988 was correct in ruling that the human fetus was not a person. Woodrow argues that active euthanasia on newborn infants with severe abnormalities is not killing. He also casts light on using anencephalic neonates for transplantation purposes. He closes with words of caution and challenge.

Gerry Cox and Ronald Fundis discuss the ethical problems of practicing euthanasia. After examining the types of euthanasia, they offer an analysis of the medical, legal, and moral issues facing physicians and families. The administration of certain pain-killing drugs is examined as a possible source of a more subtle form of euthanasia. Abbyann Lynch addresses four ethical issues regarding organ transplants. After discussing the need for donors, she asks whether donors should choose to be donors or, as in many European countries, be assumed to be donors unless one says no. Is it more ethical to have individuals opt in or opt out? Secondly, how "dead" ought the organ donor be? Thirdly, she addresses the question of growing human fetuses for organ donors. Fourthly, the issue of government funding for organ transplantation is examined. Her analysis should offer a stimulus for further discussion among professionals and the general public.



PART I

Ethical Issues

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CHAPTER 1

The Ethics of Death Education

David K. Meagher

In giving thought to this chapter on the "Ethics of Death Education," it reminded me of a poem I read many years ago. This poem, *A Learned Man*, by Stephen Crane, seemed to succinctly describe a major concern about death education and the death educator. Crane wrote [1, p. 119]:

A learned man came to me once. He said, "I know the way—Come." And I was overjoyed with this. Together we hastened. Soon, too soon, were we Where my eyes were useless. And I knew not the ways of my feet. I clung to the hand of my friend, But, at last he cried, "I am lost."

Humankind has always concerned itself with death. We have developed rituals, designed institutions, formulated concepts and constructed language to help us cope with our own mortality and ultimate death. In our coping processes, we have created the funeral industry, hospice for the terminally ill, the science of thanatology, and death education.

In the last two years, death education has come under fire by a number of individuals and agencies. A sample of some of the criticisms would include the following statements: "Much of death education is psychological manipulation, it is a form of value modification that is being practiced on subjects (students and participants) by persons who

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presume that attitudes need to be changed" [2, p. 5]. This critic goes on to ask: "Are we solving anything with this? Or are we only creating new problems?"

Another criticism states that: "Death education is not simply a matter of an educator helping a student/client through a crisis. Programmed repetition of death, despair, and personal evaluation of self-worth in these programs may be turning the participants into suicide victims" [3, p. 34].

A third critic asks: "What are the attitudes the death education advocate wants to change? What are the various death practices for which they seek 'wider acceptance'? The answer to these questions may not be easy to accept. Death education allows or encourages the participant to choose as options various death practices: suicide, euthanasia or abortion. These practices are completely acceptable to the death education practitioner" [4, p. 12].

Are these criticisms completely objective and valid? I think not. Is there justification for these criticisms? I believe there is. Does death education suffer from an almost a priori lack of credibility with respect to efficiency? Upon close scrutiny, this may be so.

Death education-what is it? Death education has been defined as that educational process by which the participant confronts the objective data surrounding the phenomena of death and dying, examines personal attitudes, and develops strategies for dealing with these phenomena as the final stages of life. Death education has also been defined as a process whereby each person is helped to develop from childhood through maturity and to senescence with an acceptance of death as a fact of life. Consistent with these two definitions is the concept that death education is a process to help individuals come to terms with his/her own feelings and attitudes towards death and dying. The death education referred to is not an endeavor limited to schools, but is directed to any and all death education programs. In addition to educational institutions at all levels, death education workshops and seminars are being offered by hospitals, residential care facilities. churches, community organizations, the federal government within its own jurisdiction, and by professional associations, not only for their membership but for the society as a whole. Education programs are offered by hospice through their out-reach programs. Organizations such as the American Red Cross, the Girl Scouts of America, and Cancer Care offer classes on coping with loss and dealing with the dying family member. Death education programs have been presented in newspapers, on television and in a variety of self-awareness, selfdevelopment books, such as Personal Death Awareness and The Art of Dying. In a way, one might define grief counseling as a form of death education. Death education does have, after all, three major components: prevention, crisis intervention and survivor postvention.

What is death education supposed to do? The literature provides the following answers.

The basic goals of death education have been described as:

- 1. information sharing—including the dissemination of relevant concepts related to thanatology, to the care of the dying and bereaved;
- 2. values clarification—this involves activities which enable individuals to consider a variety of alternatives and then to incorporate these choices into healthful behavior. Included in this outcome is the goal to help the participant consider socioethical issues related to death and to define value judgements that these issues raise;
- 3. the development of effective coping behaviors—including problem-solving skills for self-reliance and helping others to make appropriate adjustments. The goal is to help the participant deal effectively with the idea of his/her personal death and the death of significant others; and
- 4. the adoption of a positive attitude toward death and dying.

However acceptable these might appear to be, these goals contain statements that are grist for the critic's mill and with some justification. Terms such as "appropriate adjustments," "positive attitude," and "effectively dealing with one's death," raise the issue of whose definitions of "appropriateness. "relevancy," "positive," and "effectiveness" will be accepted.

In death education, as in all of education, the concern is with human beings—to do something for them and with them. Is it the intention of death education to change attitudes? Should it be? The response in the literature since the beginnings of death education in the late sixties and early seventies has been an overwhelming **YES**. Simpson wrote in 1979 that the attitudinal objectives in death education are of primary importance [5, pp. 165-174]. In the same year, Hoetler and Epley stated that the prevalent assumption concerning the impact of death education has been the derivation of positive benefits from exposure to death related subject matter [6, pp. 67-76]. There seems to have been a universal agreement that the desired outcome of death education is the influencing or changing of attitudes of the participant. The direction of this change has been defined as toward a more positive or favorable attitude. An assumption underlying the choice of material that is presented in death education is that an adequate and appropriate death education is one that is based upon facing reality and not avoiding it. This is one of the places that lends some credibility to the aforementioned criticisms. What constitutes a positive or favorable attitude toward death and dying? If there is an agreement that a certain attitude is positive and that another attitude is negative, can this agreement be validated by empirical research? But we do not yet fully know which responses to death are healthy and which are pathological.

This brings to mind the question of what constitutes a good death? Is a good death a death that was portrayed in "The Love Story," by Erich Segal, where the wife is dying; her face is made up; the slats of the blinds are angled so the sun shines through from heaven above [7]. In her last moment, she reaches for her husband, touches his hand, and asks him not to worry. Death is shared in a loving, non-fearing way.

When we say "a good death" do we mean "good" for the patient, "good" for the family, "good" for the institution, "good" for the society, or is the term not possible to generically or universally define? Might a "good death" depend on the wishes of the individual? Might not "good" be limited to how the individual wishes to live through his/her own dying?

Increased and heightened personal death awareness is obviously of significance. Whether or not it has fulfilled a role in preventing morbidity or pathological bereavement patterns or produced a better dving process is unclear. Ernest Becker, in The Denial of Death wrote that on a conscious level one may accept the eventuality of one's death, but on an emotional level, one may strongly deny it [8]. A positive death attitude may be seen as one in which this conflict is in the process of being resolved. A negative death attitude, conversely, is usually defined as a tendency to accept totally a denial or rejection of one's own death. Too often, though, a positive attitude toward death and dving has been described as accepting one's own death as inevitable. This presents a potential conflict of some interest. Does death education advocate that the dying patient accept death as inevitable in the light of some research that describes the rejection of the inevitability of death as a variable that seems to increase longevity and the quality of life in terminally ill patients? I refer here to the concept of the "survival quotient" which theorizes that terminally ill patients who are able to accept the severity of their disease, but deny the inevitability of their death, tend to live beyond their prognosis. Do we have valid research which clearly describes the negative consequences of a death denial or avoidance? Is there some inherent ethical wrong in an avoidance of death?

Catherine Sanders, in her book *The Mourning After*, describes four types of bereavement emerging from her study of bereavement [9]. One

type was identified as the "denial group." Sanders writes that individuals in this group are "... needing to employ defence mechanisms in order to deal with crisis" [9, p. 129]. They are what she calls "determined optimists," reluctant to admit common human foibles and keep a "stiff upper lip."

Sanders writes that there has been concern that those individuals undergoing grief who do not ventilate their emotions will be a risk for poor outcome. This was not the case in her study, Sanders reports. The coping mechanism of the "denial group" appeared to be facilitative. They did not deny death itself, but rather they denied their overt emotions surrounding the bereavement. Denial, Sanders concludes, is apparently an adaptive defence that serves them well in crises.

Much of the death education research has been studies which attempt to answer the question: Does death education cause any change in the participant? Much research has focused on the impact of the experience on something called "death anxiety" and/or "fear of death"; not the outcome of avoidance or acceptance or the assimilation and utilization of new knowledge. We tend to hypothesize that lowered anxiety or lessening of fear will bring about a greater acceptance of one's own death and the death of others (more the death of others, I suspect, than one's own death). As Ray and Najman wrote [10, p. 311]: "Since death is in fact inevitable, accepting it might be the least we can do. Not only do we thereby avoid anxiety associated with fear, but we would probably be, in such circumstances, best able to provide and prepare for death." Desired outcomes?

There is a great deal to be desired from this type of research and reading any number of these studies will probably create confusion in the reader.

What do these studies reveal? Why is there confusion? A review of some recent studies might provide an answer. Hare and Cunningham found no difference between experimental and control groups in the fear of death [11]. Of course, these researchers permitted their subjects to choose their own treatment groups.

Lockard, in *Death Studies*, reported that the experimental group in this study had significantly lower death anxiety than did the control group at two weeks, four weeks and one year post treatment [12]. It was reported, though, that neither group deviated from some "defined" middle range of anxiety.

Peace and Vincent compared and correlated two variables: hospice care nurses and non-hospice care nurses experience in death education and their death anxiety [13]. Hospice care nurses had significantly more death education than the non-hospice care nurses, but they were not significantly different from the non-hospice care nurses in the level

of death anxiety. Both groups, it was reported, tended to fall within a "defined middle range" of anxiety. Watts reported a "favorable" death attitude change resulting from a relatively brief death education unit [14].

The studies examining the effect of death education tend to employ a death anxiety scale (most often quoted instrument is the Templer Death Anxiety Scale) in a pre/posttest design along with course/ workshop evaluations by participants and self descriptions of attitudes or behaviors by the participants. These instruments are all inadequate means to assess the effectiveness of death education courses. Sanders addresses many issues concerning research in bereavement [9]. She states that stereotypes such as "pathological grief" and "bad grief" are often based on poorly designed research. A major research problem, according to Sanders, is inadequate instrumentation, primarily the lack of reliability and validation testing. The instruments have not been standardized; yet we use them, arrive at conclusions and develop programs of intervention based on these findings. Another major research problem, Sanders believes, is investigator bias. She writes that if one believes that "training will bring about a desired 'better' caregiver or person, one will prove it."

The lack of validity may be the reason why studies employing these instruments tend to produce contradictory results. Fredrich Agatstein, in a 1980 article on attitude change in Death Education, wrote [15, p. 324]:

Using the criterion of death anxiety reduction or such vaguely defined evaluative terms as **Positive** or **Adaptive** as proofs for our effectiveness leaves a great deal to be desired. We may be implying that the nature of death is known or knowable and that there are objective criteria we ought to be feeling and thinking about death.

It seems to me that it is natural, therefore normal, for one to experience some degree of existential or annihilation anxiety. Some difficulty exists in accepting many of the contained on death anxiety, fear of death, death avoidance scales as indicants of an undesired level of death anxiety, fear or attitude toward death. many items seem to be normal death concerns. An examination of these items on the scales used to determine the presence and intensity of death fear and anxiety (agreement indicates the presence of fear/anxiety) will illustrate the concern. The following items were extracted from a variety of scales in current use.

- 1. I fear dying a painful death.
- 2. I am afraid of a long slow death.

- 3. I am disturbed by the physical degeneration in a slow death.
- 4. I am disturbed by the thought that my abilities will be limited while I lie dying.
- 5. Being separated from my loved ones at death makes me anxious.
- 6. The affect of my death on others troubles me.
- 7. It worries me to think of the financial situation of my survivors.
- 8. I dread the helplessness of dying.
- 9. I have misgivings about the fact that I might die before achieving my goals.

In a survey of over 4,000 students, the above statements are frequently identified as personal concerns, yet subjects do not seem to be extremely afraid of or hesitant in discussions of death, dying, and bereavement; or do they report any extreme difficulty in coping with the death of a loved one. Are these issues, concerns, or attitudes that we really wish to change; or are they changeable only by the elimination of death as a human experience?

Is there a need to change the death attitude of the population? Are anxiety levels in the population so high they impede the individual in his/her quest for a satisfying life? Does death education cause a change in the attitude towards death and dying? Does death education reduce anxiety? If there is any change in the attitude or anxiety, does it translate into modified behavior? If there is a change in the attitude, a reduction of fear and/or anxiety, is the effect long-lasting? Do persons who have completed a course(s) in death cope more effectively with their own death and the death of loved ones? Do care givers who have completed a course on death and dying give more considerate care? Before we begin to develop theories and create programs that reflect that theory, we need to answer these and other questions. In order to arrive at these answers, there is a need for more sophisticated instruments designed to measure behavioral changes induced by death education. Although demonstrably effective, in lessening post bereavement morbidity even specific programs directed toward particular groups of bereaved people that have been aimed at lessening their risk status (i.e., widow to widow, parents of a murdered child, SIDS support groups), still require more study before generalizing. Not to involve ourselves in this process of evaluation and accountability appears unethical. The material of death education must be based on a valid data base: the concepts and theories coming from proven hypotheses.

It may be necessary to define the word **ethics**: ethics is "the study of the general nature of morals and of the specific moral choices to be made by the individual in his relationship with others" (*American Heritage Dictionary*). More importantly, ethics is a system of values

that guides behavior in relationships among people. On the other hand, morals are one's personal or private system of values—a conviction about how one "ought" to behave in relation to others. Morals are interpersonal—their force comes from internal feelings that arise when a person has or has not acted in accordance with them (feelings of guilt or pangs of conscience). This definition is very important because a great deal of the content of death education addresses ethics and morals. Some of the ethical issues that are generally included in death education follow:

- 1. the definition of when life begins and when life ends,
- 2. the definition of the term "quality of life" and the criteria that constitute acceptable or unacceptable quality,
- 3. the rights of a person to refuse treatment and if there is a right—who possesses this right; what constitutes an adult and competency,
- 4. the right of a person to die—living will, including the use of drugs to end life,
- 5. legislating DNR codes and the withdrawing of life support including declaring nutritional intervention as medical intervention,
- 6. funeral rituals including a dilemma of personal choice vs. cultural-religious requirements. This is an interesting dilemma, especially for young people who do not see the ritual that their family employed in the past as being satisfactory or relevant at the time of the death of a family member. How do they go about resolving the personal issues or desires and that which their family or religion say must be done,
- 7. organ donation. My surveys of 4,000 students reveal that a majority of these students would decline the opportunity to be an organ donor. Two major reasons for not being a donor are generally offered. Firstly, there is a complete lack of faith/trust in the American medical care system and its practitioners. Secondly, the students stated that if they were to fill out a donor card or form, their family would be greatly disturbed, and
- 8. nuclear issues including the politics and economics of nuclear energy and nuclear weaponry stockpiling. Death education confronts emotions: anger, fear, loneliness, and rejection. Death education asks, at times coerces, the participant to confront undesired situations: the death/loss of a loved one, the death/loss of the self, past losses, current losses, and impending/future losses.

In many instances, death education has gone beyond the examination of personal death attitudes for the purpose of self awareness and has become involved in AIDS non-death related issues, the politics of the holocaust, the issues of personal freedom (including the right to suicide, the financial cost of keeping people alive, etc.).

It is imperative that the goal of death education be the process of examining issues and not decisions. Paternalism is not an ethical death education position. The participant has the right to know enough about what is going to occur within the death education experience that he/she is able to make an informed decision about participating. In the case of school death education, the parents of the school child should be involved in the decision making process.

When controversial issues are being presented or discussed, the participant has the right to expect that various views of the issue will be presented and each point of view will be validly presented. Too often participants are made to feel their beliefs, feelings or choices are wrong when they differ from the group.

The creation of ethical principles relevant to the educational process in death and dying must include:

- 1. Autonomy and informed consent the participant must be permitted autonomous decisions. Before the start of any course, workshop, seminar on death and dying begins, the participants should be required to give consent. This consent requires disclosure of adequate and relevant information that must be comprehended by the participant/registrant. The decision must be completely voluntary and informed. Any plans to use the participants as subjects in a research project must be approved by the participants. The participant has to be respected in **their right to experience/think about** his/her **dying in a personal way.**
- 2. Confidentiality participants must not be coerced into revealing experiences, feelings, or thoughts about death and dying. The person has the right to control the dissemination of personal or sensitive information about himself/herself. There must not be any use of coercive techniques or material.
- 3. *Beneficience* the death educator must try to do good, to further the welfare or well being of the other. The criteria of "good" must be what is beneficial to the participant, not to the educator's own death issues.

In order to act ethically, the death educator must be prepared to provide directly or indirectly necessary psychological/emotional support services to the participant. An ethical death educator must also be available between and after all sessions. The death educator is responsible for the creation of an environment or experience that causes the participant to feel or think about issues that he/she may not have felt

outside the death education experience. We must create an environment in which the participant may experience an emotional safety.

4. Nonmaleficience — the death educator must take great care not to harm the person with which he/she is working. Harm is the outcome to improper or unethical death education practices. Greater harm results when no one is there to provide support.

Dr. Jonas Salk, a noted physician, was once asked to define the health of a child. He answered the question by saying, "I define the health of a child as being the quality of the adult around the child." Healthy death education might be defined as the quality of the death educator.

In closing, there is a fable that focuses on what we do and with whom we do it. A Chinese angel visited hell. He saw many people seated around a table covered with delicious food of every description. Beside each person there was a pair of yard-long chopsticks. But everyone there was wasting away with starvation, because no one was able to manipulate the clumsy chopsticks adequately to feed himself.

Then the angel went to visit heaven. There he saw another table piled with all kinds of wholesome delicious food. Each person seated around the table was also provided with yard-long chopsticks. These people were happy and contented. They were feeding each other across the table with their yard-long chopsticks. The moral is—the difference between heaven and hell is the people.

REFERENCES

- S. Crane, A Learned Man, in *The New Pocket Anthology of American Verse*, (O. Williams, ed.), Washington Square Press, New York, 1961.
- C. Chmelynski, Does "Death Education" Belong in the Classroom, School Board News, p. 5, January 1, 1991.
- 3. F. M. Bordewich, Mortal Fears, The Atlantic, February 1988.
- 4. P. Schlafly, Death Education Comes Into Open, The Brooklyn Spectator, April 13, 1988.
- 5. M. A. Simpson, Death Education—Where Is thy Sting?, Death Education, 3, pp. 165-174, 1979.
- 6. J. W. Hoelter and R. J. Epley, Death Education and Death Related Attitudes, *Death Education*, 3, pp. 67-76, 1979.
- 7. E. Segal, Love Story, Harper and Row, New York, 1970.
- 8. E. Becker, The Denial of Death, The Free Press, New York, 1973.
- 9. C. Sanders, *Grief: The Mourning After*, John Wiley and Sons, New York, 1989.
- 10. J. J. Ray and J. Najman, Death Anxiety and Death Acceptance: A Preliminary Approach, *Omega*, 5, pp. 311-315, 1974.

- 11. J. Hare and B. Cunningham, Effects of a Child Bereavement Training Program for Teachers, *Death Studies*, 4, pp. 345-354, 1988.
- B. E. Lockard, Immediate, Residual, and Long-term Effects of a Death Education Instructional Unit on the Death Anxiety Level of Nursing Students, *Death Studies*, 13, pp. 137-160, 1989.
- 13. H. G. Peace and P. A. Vincent, Death Anxiety: Does Death Education Make a Difference, *Death Studies*, 12, pp. 337-344, 1988.
- 14. P. R. Watts, Evaluation of Death Attitude Change Resulting from a Death Educational Instructional Unit, *Death Education*, 1, pp. 187-194, 1978.
- 15. F. Agatstein, Attitude Change and Death Education: A Consideration of Goals, *Death Education*, 3, pp. 323-332, 1980.



CHAPTER 2

Self-Healing for Persons with Cancer: Issues for Health Professionals

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Despite the uncertain scientific status of psychospiritual influence on cancer etiology and progression, health professionals working with persons who have cancer cannot afford to dismiss patient beliefs in self-healing. The psychological implications of such beliefs are important in their own right.

This chapter explores the potential positive and negative consequences for patients of popular conceptions of self-healing. Clinical and ethical issues related to health professionals' response to patients are discussed, and a rationale is presented for adopting a flexible, personcentered approach.

The issue of whether psychological factors are relevant to cancer etiology and progression has received increasing attention over the last two decades. Popular bestsellers by Simonton, Mathews-Simonton, and Creighton [1], Hay [2], Siegel [3, 4], and others have brought ideas of psychological and spiritual (hereafter psychospiritual) influence on cancer, including the possibility of self-healing, into the mainstream of North American thinking. According to these writers, the path to self-healing lies in becoming more expressive, loving, positive and courageous people. Specific techniques—such as meditation, mental imagery, and positive thinking—have been advocated as having direct and indirect healing effects.

Individual patients, professionals, and members of the public are almost inevitably aware of these ideas about self-healing. Indeed, in a

recent survey of university students and health professionals, the vast majority of respondents indicated a belief that psychological factors contributed to cancer etiology and progression [5]. A majority also indicated that they would use psychospiritual techniques to help battle illness should they ever be diagnosed with cancer.

Despite the popularity of the self-healing notion, numerous studies and reviews from the fields of oncology, psychology, and psychoneuroimmunology have failed to clarify the question of whether, and to what degree, psychospiritual factors may influence cancer [6-10]. A recent randomized controlled study reporting that group psychotherapy prolonged survival for cancer patients is suggestive of benefit for at least some patients under some conditions, but the need for replication and generalization of findings dictates that scientific consensus will be unlikely in the near future [11].

Because this issue of the scientific status of psychospiritual self-healing appears unresolved at present, many health professionals working with cancer patients assume that it need not be taken seriously. We are uncomfortable with such a dismissive stand. Important needs may be met for patients regardless of the question of scientific merit. For example, we think that the aspiration of cancer patients to heal themselves represents, in part, a healthy and natural identification with the age old hero myth [12, 13]. This notion—which we have discussed at length elsewhere—reframes self-healing as the expression of an urge for self-transcendence, i.e., for overcoming our usual human limitations. Without pursuing further this particular example, we wish to stress the point that psychological implications of beliefs in self-healing are important *in their own right*. Such beliefs have important consequences for health-related decisions and behavior.

In the remainder of this chapter we will consider the potential benefits and problems of belief in psychospiritual influence outside of the context of its supposed effect on disease causation and etiology. We will then elaborate a model to guide health professionals on how to be helpful to patients about this issue.

BENEFITS

From our clinical work, we are convinced that many cancer patients experience major benefits from believing that psychospiritual factors influence their illness. In the face of a life situation characterized by loss of control, patients who believe that their health will improve by practicing imagery, by changing their relationships, or by redefining life priorities, typically feel more "in control." This can markedly reduce anxiety and depression. Similarly, many patients find that the