

**Report to the Board of Directors**

of the

The American Psychological Association (APA)

from

**THE APA WORKING GROUP ON  
ASSISTED SUICIDE AND END-OF-LIFE DECISIONS**

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## INTRODUCTION

### Formation of APA Working Group on Assisted Suicide and End-of-Life Decisions

In June of 1997, the Supreme Court held that assisted suicide is not a constitutionally protected right and that its legality is left up to the states (Vacco v. Quill and Washington v. Glucksberg). In anticipation of the rulings, in April of 1997, the American Psychological Association (APA) Public Communications Office, in collaboration with the Public Interest Directorate, established a working group to create a briefing paper on mental health issues involved in physician-assisted suicide and other end-of-life decisions. This paper was intended to inform news media coverage about assisted suicide anticipated in conjunction with the Court's decision. The briefing paper was subsequently converted into a public information brochure entitled *Terminal Illness and Hastened Death Requests: The Important Role of the Mental Health Professional* and then later published as a journal article in *Professional Psychology: Research and Practice* (Farberman, 1997).

In August of 1997, the APA Board of Directors distributed the information brochure to governance boards and committees of APA and asked them to make recommendations about whether APA should take further action in the area of assisted suicide and end-of-life decisions. In February of 1998, after reviewing recommendations from governance boards and committees, the APA Board of Directors authorized the formation of the Working Group on Assisted Suicide and End-of-Life Decisions (Working Group). The Working Group was charged with the following tasks:

1. Examine the role of psychology in end-of-life decisions and quality of care issues;
2. Address the invisibility of psychology around the issue of end-of-life decisions and recommend methods to increase the visibility of psychology and the role of psychologists in this arena;
3. Consider and make recommendations on whether it might be appropriate for APA to take a position on the issue of assisted suicide and end-of-life decisions.

In April of 1998, a selection subcommittee composed of three members of the APA Board for the Advancement of Psychology in the Public Interest (BAPPI), invited the following individuals to serve as members of the Working Group: Silvia Sara Canetto, Ph.D.; David Clark, Ph.D.; Dolores Gallagher-Thompson, Ph.D.; Judith R. Gordon, Ph.D. (Chair); Therese Rando, Ph.D.; Judith Stillion, Ph.D.; and James L. Werth, Jr., Ph.D. Dr. Clark attended the first meeting of the Working Group and then was no longer able to participate.

### Activities and Process of the APA Working Group

The Working Group met in Washington DC on July 25-26, 1998, October 24-25, 1998, and December 10-12, 1999. Members of the Working Group decided to work on two companion documents in response to the three charges articulated by the APA Board of Directors. This document, *The Report to the Board of Directors of the American Psychological Association from the Working Group on Assisted Suicide and End-of-Life Decisions* (the *Report to the Board*), responds directly to the charges and provides a brief overview of end-of-life issues

as they pertain to the field of psychology. The *Report to the Board* also contains recommendations for immediate consideration by the APA Board of Directors. A second document, *The Resource Guide on End-of-Life Issues* (the *Resource Guide*), is intended to provide more detailed coverage of many of the issues discussed in the *Report to the Board*. The *Resource Guide* is envisioned as a general background reference for psychologists interested in end-of-life issues as they pertain to practice, education, research, and policy. The *Resource Guide* is also conceptualized as a core resource from which a variety of educational publications for psychologists and the public could be produced in the future. Both the *Report to the Board* and the *Resource Guide* were drafted by members of the Working Group and the APA staff liaison, John Anderson, Ph.D. The *Resource Guide* is currently in the middle phase of development (see Appendix A for a detailed, annotated outline).

A large, multidisciplinary Advisory Committee to the Working Group was created to review and comment on preliminary drafts of both documents. The Advisory Committee is comprised of 43 experts in the field of end-of-life decisions and assisted suicide (see Appendix B). A variety of disciplines and a diversity of views are represented on the Advisory Committee. Particular attention was paid to involving experts who advanced the views of communities with special concerns about the topics under discussion (e.g., women, people with disabilities, older persons, and members of ethnic and other minority communities). Drafts of both the *Report to the Board* and the *Resource Guide* were sent to the entire Advisory Committee, and 24 of the 43 members provided comments and/or recommendations for modification. Feedback from the Advisory Committee was incorporated into subsequent drafts of the *Report to the Board* and feedback will be incorporated into the final draft of the *Resource Guide*.

During the Spring 2000 Consolidated Meeting, APA governance boards and committees were asked to review the *Draft Report to the Board* and provide suggestions for modification. Suggestions from boards and committees were incorporated into this final version of the *Report to the Board*. The *Report to the Board* was submitted to the APA Board of Directors at its June 2000 meeting.

### Organization of the *Report to the Board*

The *Report to the Board* is organized into four main sections. Section One provides a general orientation to end-of-life decision-making. This orientation includes a review of historical changes in end-of-life care, an overview of common end-of-life challenges, a discussion of controversies associated with different terms and definitions, and a presentation of critical contextual factors that affect end-of-life care. In Section Two, the relative invisibility of psychology in the arena of end-of-life care is addressed. Section Three discusses current and potential roles for psychologists who are interested in working with end-of-life issues. Section Four addresses the question of whether APA should adopt a position with respect to end-of-life issues and assisted suicide.

### Scope of the *Report to the Board*

For the purposes of this report, the period designated as “end of life” is considered to begin when a person who has been diagnosed with a terminal illness that is incurable and

irreversible has reached the point where appropriate parties such as the physician, the dying person, or significant others have concluded that further treatment is futile or unwarranted. The scope of this report is limited to discussion of end-of-life decisions and assisted suicide for adults. It does not cover end-of-life issues as they relate to minors because to do so would require a thorough and thoughtful consideration of child and adolescent cognitive development, family structure and dynamics, and the rights of parents versus the rights of children. The importance and complexity of end-of-life care for children and adolescents suggest the need for addressing these issues in a separate report by psychologists with specialized expertise in the areas cited above. In addition, this report does not cover end-of-life decision-making in situations where individuals have been determined to be clearly incompetent to make informed health care decisions, such as when they are experiencing advanced dementia or are in a coma. To cover those types of situations would require examination of a wide variety of medical and legal issues related to competency and guardianship. Again, the importance and complexity of these issues suggest the need for a separate report by psychologists with specialized expertise in the areas cited above.

It should be noted that the definition of "end of life" is open to interpretation. For example, in hospice care a terminal diagnosis is currently given when life expectancy is six months or less. However, this time frame was chosen because it was necessary to determine when someone would qualify for Medicare reimbursement for such care. The six-month period has been challenged as arbitrary and based on economic, not scientific, reasons. The determination of futility of care is also subject to debate and open to serious disagreements among family members and/or between family and the medical team. The determination of incompetence is also considered by some to be based on sociocultural constructs and subject to bias.

## **SECTION ONE:**

### **ORIENTATION TO END-OF-LIFE DECISION-MAKING**

#### **Historical Changes Affecting End-of-Life Care**

In 1900, the average lifespan was 47.3 years; by 1997 it had increased to 76.5 years, a gain of 29.2 years in less than a century (Kramarow, Lentzner, Rooks, Weeks, & Saydah, 1999). This overall gain in length of life obscures important differences in longevity across demographic groups. For example, women currently live seven years longer than men do. Among those 85 and older, there are five women for every two men (Bureau of the Census, 1996). An African American woman can expect to live 74 years, compared to 80 years for a European American woman. The estimated life expectancy at birth for African American men is 65 years, as compared to 73 for European Americans (Field & Cassel, 1997). Social class factors, including income and education levels, also affect longevity.

The age distribution of the population in the United States has changed substantially in this century. The number of persons under age 65 has tripled in this period of time while the number of persons 65 or over has jumped by a factor of 11 (Bureau of the Census, 1996). It is particularly noteworthy that the rate of aging of the population is expected to accelerate for the

next half century. In 1994, one in every eight persons in the United States was over 65. By the year 2050, the older adult population is expected to more than double, resulting in a ratio of one older adult to five younger persons. The "old-old," those 85 and over, are the most rapidly growing sector of the aged. By the year 2050, people over 85 are expected to make up 24% of older persons and 5% of the entire population in the United States, numbering over 19 million. Today, three-fourths of those who die annually are older adults. Assuming continued increases in longevity, the proportion of those who die past age 75 will also increase (Field & Cassel, 1997).

The causes of death have also changed dramatically. In 1900, the ten leading causes of death were pneumonia, tuberculosis, diarrhea and enteritis, heart disease, stroke, liver disease, injuries, cancer, senility, and diphtheria (Centers for Disease Control and Prevention, 1999). Most people died from infectious illnesses that caused death with certainty and relative rapidity. By 1998, the ten leading causes were heart disease, cancer, stroke, chronic lung disease, pneumonia and influenza, accidents, diabetes, suicide, kidney disease, and chronic liver disease (Martin, Smith, Mathews, & Ventura, 1999). Thus, the contemporary list includes only two causes of death (accidents and suicide) that lead to a quick death. It has been estimated that 70-80% of people in advanced industrial nations now face death later in life from chronic or degenerative diseases characterized by late, slow onset and extended decline (Battin, 1996).

The location where death typically occurs has also changed, moving from the home to technologically sophisticated and often impersonal settings. It has been estimated that in the United States nearly 60 percent of all deaths occur in hospitals or medical centers. Another 16 percent occur in other institutions, such as nursing homes or hospices (Benoliel & Degner, 1995). Only a minority of people die in the care of formal hospice programs, and the majority of these hospice deaths involve cancer diagnoses. More recently, the proportion of those who die at home has begun to increase because changes in Medicare benefits have led to increased availability of home hospice services (Field & Cassel, 1997).

The timing of an individual's death has also changed. As the dying process and death have moved from taking place at home to medical settings, professionals have exerted more control over the timing of dying. Technology now permits life to be greatly extended. It appears that in a growing number of terminal cases medical decisions are made to withhold or withdraw treatment (Field & Cassel, 1997). In 1992, it was estimated that 70 percent of the 6,000 deaths that occur daily in the United States are somehow timed or negotiated with family, doctors, and the dying person when competent, quietly agreeing to not use death-delaying technology (In re L.W., 1992).

Scientific advances in medicine have produced an expanded array of interventions that present individuals, families, and health care professionals with an increased number of very difficult decisions about the timing and course of the dying process. This change has resulted in an expanded role for bioethical review teams in many clinical settings. In 1983, one percent of all medical facilities in the United States had ethics committees and/or multidisciplinary teams that served to oversee difficult medical decisions. By 1993, the American Hospital Association estimated that 60-85% of hospitals had ethics committees (Webb, 1997).

The life-extending potential of medical interventions has also led to the development of a whole new body of end-of-life laws. All 50 states have addressed end-of-life issues either by legalizing some form of advance directive or by enacting alternative provisions for end-of-life decisions in the form of family consent, surrogacy, or succession laws that do not require a document to be signed prior to loss of competence. Although it is beyond the scope of this report to detail all of the changes in end-of-life legislation, three recent legal developments are worth noting because they have widespread significance for end-of-life care and they continue to be the focus of high-profile debates in both politics and the press. One is The Oregon Death with Dignity Act, which was first implemented in 1997 and permits physician-assisted suicide under limited, carefully specified conditions. The second one are the rulings of the U.S. Supreme Court, in June of 1997, that there is no constitutional right to physician-assisted suicide and that states are free to decide whether they wish to legalize this practice (Vacco v. Quill, 1997; Washington v. Glucksberg, 1997). The last one is The Pain Relief Promotion Act, introduced in the United States Congress in 1999. If enacted, funding for training in palliative care would be provided but physicians would be in violation of the Federal Controlled Substances Act if they prescribed or administered opioids, barbiturates, or other controlled medications with the purpose of helping a person to die. Thus, passage of The Pain Relief Promotion Act would functionally negate the Oregon law and prohibit other states from enacting similar laws.

Changes in public attitudes about participation in medical decision-making and about seeking help from mental health professionals are likely to produce corresponding changes in expectations about end-of-life care. In the past two decades, there has been an increased demand by individuals and families for active participation in medical decision-making, especially among well-educated and middle class populations. With the coming of age of the baby boom generation, larger numbers of people in the United States have come to accept mental health services as an important resource for dealing with difficult decisions and emotionally challenging situations. These shifts in attitude, combined with the fact that the baby boom generation is increasingly dealing with end-of-life care for their parents and the prospect of their own mortality, suggest the likelihood of an increasingly sophisticated demand for psychosocial services in dealing with end-of-life decisions.

### Conclusion

*Sweeping advances in public health, biomedical sciences, and clinical medicine over the course of the twentieth century have dramatically altered the ways in which people die in the United States. During the last 100 years there have been changes in longevity as well as in patterns, causes, and places of death. In some respects these changes "have made living easier and dying harder" (Field & Cassel, 1997, p. 14). More effective treatments may significantly extend life but may also confront dying individuals, their families, and health care providers with a prolonged period of dying that involves complex choices about end-of-life care. These changes have resulted in the need to address end-of-life decision-making from many perspectives including medical, legal, ethical, moral, spiritual, economic, and psychosocial dimensions. There is likely to be an increasingly sophisticated demand for psychosocial services in dealing with end-of-life decisions. Furthermore, the specific issue of assisted suicide promises to become one of the most contentious and difficult social issues of our time.*

## Common Challenges at the End of Life

### End-of-Life Tasks and Decisions

As people approach the end of their lives, they and their families commonly face tasks and decisions that include a broad array of choices ranging from simple to extremely complex. They may be practical, psychosocial, spiritual, legal, existential, or medical in nature. For example, dying persons and their families are faced with choices about what kind of caregiver help they want or need and whether to receive care at home or in an institutional treatment setting. Dying persons may have to make choices about the desired degree of family involvement in caregiving and decision-making. They frequently make legal decisions about wills, advanced directives, and durable powers of attorney. They may make choices about how to expend their limited time and energy. Some may want to reflect on the meaning of life, and some may decide to do a final life review or to deal with psychologically unfinished business. Some may want to participate in planning rituals before or after death. In some religious traditions, confession of sins, preparation to “meet one’s maker,” or asking forgiveness from those who may have been wronged can be part of end-of-life concerns. In other cultural traditions, planning or even discussing death is considered inappropriate, uncaring, and even dangerous, as it is viewed as inviting death (Carrese & Rhodes, 1995).

All end-of-life choices and medical decisions have complex psychosocial components, ramifications, and consequences that have a significant impact on suffering and the quality of living and dying. However, the medical end-of-life decisions are often the most challenging for terminally ill people and those who care about them. Each of these decisions should ideally be considered in terms of the relief of suffering and the values and beliefs of the dying individual and his or her family. In addition, any system of medical care has its own primary values that may or may not coincide with the values of the person. For example, in most Western medical systems the principles of individual autonomy (though not to the exclusion of family members and intimates) and informed consent are primary. In contrast, many cultures eschew the principle of autonomy and the principle of interactive, community decision-making is thought to be the ideal. Therefore, well-intentioned presentations of treatment or care possibilities by health care providers may overlook a particular person’s wish not to discuss death.

## Futility

Perhaps the most difficult decisions confronting people at the end of life are those about discontinuing life-extending treatment. Frequently, in the course of caring for a critically ill person, it may become apparent that further intervention will only prolong the dying process and not improve quality of life. Decisions to withhold or discontinue treatment are determined by a variety of factors, including judgments of medical futility and the emotional status and coping styles of the family members and the dying person. At that point, additional treatment is often described as futile. The concept of medical futility takes shape in sociocultural and interpersonal contexts, and conflicts about whether a situation is futile may arise for several reasons. Family members may disagree about future treatment or may oppose the physician's recommendation to discontinue life support. The physician may want to continue treatment and be opposed by either the family or other medical professionals. Legal or ethical issues may also play a role in the decision to stop or maintain life supports. Issues of resource allocation can also influence judgments of futility and life-extending care. Some argue that discontinuation of futile care is good for individuals, families, and society. Others have countered that costs may be a primary motive behind assessments of futility, which disproportionately discriminates against dying persons with limited resources.

## Advance Care Directives

Because decisions concerning futility often involve people who lack the capacity to understand their medical situation or communicate their wishes, there has been a movement to encourage everyone to create advance directives about their medical care while they are still competent. The intention is that by getting a person's desires about end-of-care in writing or by designating a health care proxy, the complexities of making decisions when the dying person's judgment is impaired by the physical and emotional effects of the illness would be reduced. Examples of advance care directives include descriptions of circumstances in which treatment should be received or refused, what extraordinary measures (if any) should be taken to preserve life, and what kind of pain management is wanted. Some of these decisions may impact the time of death but they generally call for widely accepted, legal components of end-of-life care, such as withholding or withdrawing life-sustaining treatments.

It is important to note that advance directives are not without their problems or limitations. Some of the common issues cited in the literature include:

- Few people prepare advance directives, in part because of a generalized reluctance to face death;
- Even if people do have them, their wishes may not be followed;
- The kind of planning for death which is required in advance directives goes against the values of many cultural and religious communities, including the perceived duties of dying persons and their families;

- Individual preferences for life-sustaining medical treatments are only moderately stable within the short term (up to six months) and are even less stable over longer periods;
- Healthy individuals appear to be unable to predict their own preferences under states of impaired health;
- Substantial fluctuations in the will to live have been documented in terminally ill people in palliative care settings;
- Among the factors that appear to play a role in the refusal of life-sustaining treatments are depression and family support;
- Concerns about costs influence the preferences of individuals and family members about life-extending measures.

Health care providers must be sensitive to the limitations of an advance directive for a particular individual over time, the need for ongoing exploration of the desires and needs of dying people and their loved ones, and the likelihood that such directives may be in conflict with some people's values and traditions.

### Terminology, Definitions, and Other Barriers to Communication

Discussions about end-of-life issues can be difficult for many reasons. First, dying and death are not openly discussed in many cultures. Second, the rapid pace of change in medical technology has made it difficult to develop a standard terminology for discussing dying and death. Third, dying and death are so rooted in cultural customs and individual beliefs and behaviors that a universal vocabulary has not evolved. The same words have different meanings to different people. Fourth, issues of life and death are deeply personal, tapping our most basic human values.

Discussion about end-of-life decisions are particularly difficult because of a lack of consensus about descriptive terminology. Different words may be used by different writers for the same concept, or the same terminology may be used but with a variety of meanings. In order to clarify the meaning of key words used in this report, a glossary has been included in Appendix C. Many of the terms in it are straightforward and utilized in a relatively uniform and systematic way in the literature. Other terms are used selectively to frame arguments or positions. Roy and McDonald (1998) have noted that the language used to describe end-of-life decisions that shorten or do not prolong life can “signify opening moves in a moral debate” (p. 123). Two commonly used terms that frequently generate confusion or controversy are “hastened death” and “assisted suicide.”

#### The Term “Hastened Death”

Some authorities believe that the psychosocial, cultural, medical, and ethical issues associated with all end-of-life decisions affecting the time of death are similar. They use the term “hastened death” to refer to a variety of interventions including voluntary cessation of

eating and drinking, withholding and withdrawing life-sustaining treatment, the double effect phenomenon, terminal sedation, assisted suicide, and voluntary (but not involuntary) euthanasia (Cantor & Thomas, in press). Others limit the term to include only double effect, terminal sedation, and assisted suicide (Alpers & Lo, 1999). Still others use the term to include only assisted suicide and euthanasia (Block & Billings, 1998). Others do not use the term at all but prefer to describe the specific intervention under discussion.

Differences in the use of the term “hastened death” arise from disagreements about what types of interventions can rightfully be likened to others. For example, some would argue that withdrawing life-sustaining treatment can be placed on the same continuum as assisted suicide because they both speed up the dying process. Others would argue that to place such terms under the single rubric of hastening death creates an unacceptable perception of permissibility for certain interventions like assisted suicide that should never be allowed. In this view assisted suicide is sharply distinguished from “letting the person die” from the underlying disease process by, for example, withholding or withdrawing treatment. In general, differences in use of the term hastened death represent different views about what types of interventions are permissible under what circumstances as well as different views about the potential for abuse associated with different end-of-life interventions.

#### The Term “Assisted Suicide”

In the United States, the term “assisted suicide” commonly refers to situations in which people with incurable, and ultimately terminal, illnesses, request the help of others in ending their lives. Assisted suicide has been defined by the American Association of Suicidology (1996) as “the deliberate and knowing provision of information, the means, and/or help to another person for an act of suicide” (p. 6). Those who reject the use of the word “suicide” in end-of-life contexts focus on at least two major points. First, they argue that the use of the term may be an inappropriate extension of the model of suicide (Sullivan & Youngner, 1994). According to this view, “the cutting short of a viable life, as generally connoted by the term ‘suicide’, differs from a terminally ill patient’s attempt to exercise some control over their dying process” (Farrenkopf & Bryan, 1999, p. 245). They suggest that the traditional view of suicide as a self-destructive act that is motivated primarily by emotional distress or psychopathology does not apply to all situations in which a terminally ill person wants to exercise control over the timing and manner of death. A second argument of those who do not like the term is that most of the suicidology literature is based on the contention that all people who want to die have significant psychopathology and should be prevented from dying (Society for Health & Human Values, 1995). Those who argue against the use of the term “assisted suicide” point to evidence that indicates that some decisions to die are not motivated by clinical depression or other psychopathology (MacDonald, 1999). Third, in general, those who view helping an incurable, terminally ill person to die as a legitimate issue to be considered along with other end-of-life decisions believe that using the word “suicide” in the end-of-life context may negatively bias discussion and decision-making. For example, The Oregon Death with Dignity Act (1995) states that “under the Act, ending one’s life in accordance with the law does not constitute suicide.” The Act specifically prohibits euthanasia, where a physician or other person directly administers a medication to end another’s life.

Those who prefer the term “assisted suicide” in the context of end-of-life decision-making see the action as qualitatively different from other medical decisions that may affect the time of death. First, they assert that the suicide prevention model is applicable even at the end of life since there is evidence that terminally ill people who want to die are clinically depressed (Chochinov et al., 1995, Canetto & Hollenshead, 1999). They hold that the term “assisted suicide” carries implications for prevention and promotes caution in responding to requests. Second, they argue that incurability and terminal status are hard to diagnose definitively. Third, they argue that requests for assisted suicide can almost always be addressed by exploring and treating unmet needs of dying people (Emanuel, 1998). They point out that there are higher costs associated with decisions leading to death because they are irreversible and subject to abuse and to medical error. Fourth, some equate assisted suicide with killing. Therefore, they believe that using the term assisted suicide or physician-assisted suicide is the most accurate descriptor that does not obscure, embellish, or use euphemisms for what is happening.

This report does not take a stand on any of the views described above. However, the term "assisted suicide" is used in this report because it is widely used in the medical, legal, psychological, and popular literature to describe the voluntary self-administration of medication for the purpose of ending life (Sullivan, Hedberg, & Fleming, 2000b) and thus it is well-understood.

### Conclusion

*End-of-life decision-making subsumes a broad array of medical, psychological, existential, spiritual, legal, family, and economic decisions. Words shape debate, discussion, attitudes, and public policy. Even when well-meaning people try to be neutral in presenting material, word choice can unintentionally bias thinking and debate. The discussion above and the definitions included in the glossary of this report are intended to provide as much clarity as possible in an area that is complex and often emotionally charged and highly politicized.*

### Critical Contextual Issues

A thoughtful discussion of issues at the end of life requires consideration of the social, economic, and cultural contexts in which these issues unfold. In the United States, unique dilemmas in end-of-life decisions are created by a combination of a lack of a national health care system and the social, economic, and cultural diversity of the country’s population.

#### Issues of Access and Variability in Health Care at the End of Life

The national debate about end-of-life care typically focuses on choices about treatment options and about who has the right or expertise to make the choices. This debate assumes that people have options about their care. Although the medical system in the United States offers excellent care choices, the options are largely available only for those who have money or are insured. Individuals who do not have access to private health care insurance often suffer from insufficient and/or poor quality care. Most of the uninsured are older women, children, and ethnic minorities. Access to life-extending medical technology is similarly a function of resources. Higher income individuals are more likely to have a private attending physician,

which is related to maintenance of life-sustaining care (Mishara, 1999). As noted by Field and Cassel (1997), “people may have the theoretical right to make their own medical choices, but many do not have the financial access to minimal care necessary for implementation of those choices” (p. 48). It should be noted that concerns about costs also influence the preferences of individuals and family members about life-extending measures (Covinsky et al., 1996).

Even when dying people have access to medical care, the quality of care is highly variable and less than desirable. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT Principal Investigators, 1995) conducted from 1989 to 1994 is the most massive research effort to date associated with the process of dying in America. The study tracked some nine thousand people with various serious and terminal illnesses during the final stages of their life. It also included a large slice of the medical establishment, involving interviews with some 1600 physicians, 500 nurses, and many other health care professionals at numerous prestigious medical institutions. In Phase I of the study, researchers examined how people were treated when they entered the hospital, how medical decisions were made, and what happened to them and their families during the acute treatment period and for six months afterward. Findings from the study were quite dramatic:

- Half of the people who were still conscious had moderate to severe pain at least half of the time before they died;
- More than half of the doctors in the study did not know about their patients’ preferences for life-sustaining treatment;
- Nearly 40% of the individuals spent at least 10 days in an intensive care unit.

In Phase II of the study, a number of interventions were put in place that a large panel of experts on end-of-life medicine and law thought would change treatment patterns and make the process of dying more comfortable. In the end, those patients who received the interventions were treated the same as those patients for whom no such efforts were made.

### Conclusion

*In the United States there are serious inequities in access to medical care, based on income and paid labor history, so that technological advances in medicine are not uniformly available to all segments of the population. Women, children, and ethnic minorities are over-represented among the poor and uninsured and they have fewer health care options available to them. Even when there is access to care, findings from the SUPPORT study suggest that many people may suffer from under-treated pain and that physicians are often unaware of their patient’s preferences for life-sustaining treatment.*

### Diversity Issues in End-of-Life Decision-Making

In the United States, the dominant discourse about illness, dying and death focuses on autonomy, independence, self-control, and individual choice. The health care system reinforces this individualistic focus through the legal structures of advance directives and informed consent.

This focus on the individual and on planning for death presupposes a particular situation and assumptive world that include the following elements:

- the individual is the primary decision-maker;
- the individual has an interest in being in charge;
- there is a clear communication and understanding between the individual and the medical team about diagnosis, prognosis, and options;
- the individual has equal financial access to the different options offered;
- the individual has the power and sense of entitlement to make whatever choice is desired;
- the individual is competent to make choices;
- the individual values discussing and planning for death;
- the individual has a spiritual orientation that does not emphasize divine interventions, and allows for choice in time and manner of death (Koenig, 1997).

There are many people in the United States for whom at least some of these conditions do not pertain. The model above is particularly inadequate to account for the experiences and values of persons who are in one way or another culturally different or socially disadvantaged. This includes ethnic and religious minorities for whom individual decision-making is not a priority. Persons who are economically disadvantaged also do not fit the conditions of an end-of-life model that assumes equal access to different options. The same may be true of persons with disability. In fact, a social or minority model for conceptualizing disability may be more suitable than the medical model because many of the barriers that confront disabled people are of social origin, involving widespread devaluation of this particular form of diversity.

Social and cultural groups vary with regard to beliefs and opinions regarding end-of-life decision-making. This includes the appropriateness of talking about and planning for death, informing persons that they are dying, and the roles of the individual, family members, and physicians regarding end-of-life decisions. These groups also vary in even more basic dimensions (such as orientation to the future, conceptions of the self and personhood, and beliefs about the rights of the individual) that may have implications for end-of-life decision-making. In addition, individual differences within social groups can be as great as, or greater than, differences between groups because individuals are often exposed to multiple and sometimes contradictory systems of values. Similarly, individuals from the same demographic group do not all think the same way. Another variable is that group experiences and the system of values affecting attitudes and behavior are not fixed. Rather they are constantly evolving within specific social and historical contexts. Finally, diversity factors do not apply to minorities only, and are relevant not only to individuals and their families, but also to professional care providers (Koenig, 1997). Diversity considerations are therefore critical in developing a psychological agenda for end-of-life issues, especially in a demographically diverse and socially stratified

country like the United States.

A diversity perspective shows that the ethical and practical questions that have dominated the national debate on the end of life are not universal concerns. For example, persons of Chinese descent may place a value on protecting the dying person from negative information (Hallenbeck, Goldstein, & Mebane, 1996), and therefore may not discuss impending death with the dying person. Similarly, family dynamics in recent immigrants from Mexico or Korea may tolerate less individual autonomy than is permitted in families of European or African descent that have not recently immigrated (Field & Cassel, 1997). In addition, in many cultural and religious traditions, there may be an expectation that women rely on the authority and advice of male authorities (e.g., family members, professionals, etc.) for decision-making. In some traditions, there may also be an expectation of women's self-sacrifice (Wolf, 1996). Further, planning about dying is contrary to traditional Navajo values, particularly the value of "avoiding thinking or speaking in a negative way ('doo'ajiniidah')" (Carrese & Rhodes, 1995, p. 828). In this tradition, discussion of negative information is harmful in that it may bring about a feared negative outcome. Finally, among some ethnic minorities, longevity may be an intrinsic good, independent of health status.

Studies have found that African Americans and Hispanics are more likely than European Americans to express a preference for life-sustaining treatment, regardless of the state of the disease, and independent of educational level (Caralis, Davis, Wright, & Marcial, 1993; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998). These preferences may be related to negative experiences with the medical system (including inadequate care, as well as difficulties in negotiating their needs), leading to a lack of trust in professional advice (Hallenbeck et al., 1996; Koenig, 1997).

Further examples of diverse positions that are socially based include people in the disability community, who express serious concern about sanctioning assisted suicide. A common attitude among the non-disabled indicates that some would rather be dead than disabled, which, taken in the context of medical-industry emphasis on cost savings, could lead to withholding critical services to people with disabilities. Such concerns regarding the effects of devaluation and cost-saving strategies are also highly relevant to other disenfranchised groups such as people suffering from alcohol and drug abuse or dependence.

Issues of social, economic, and cultural diversity become even more critical in decisions that may affect the timing of death. In the United States, no matter how carefully any safeguards are framed, such decisions are practiced in a context of social inequality, bias, and unequal access to services. In regard to assisted suicide and euthanasia, it has been argued that the persons who are the most vulnerable to coercion or abuse are those "whose autonomy and well-being are already compromised by poverty, lack of access to good medical care, or membership in a stigmatized social group" (New York State Task Force on Life and the Law, 1994, pp. vii-viii). This argument has been extended to include all types of end-of-life decisions (Canetto & Hollenshead, 1999; Orentlicher, 1997). Older persons, women, religious and ethnic minorities, sexual minorities, and persons with disabilities who are seriously ill, may be particularly likely to be perceived as burdensome by the medical system. Furthermore, they may also have a lower sense of entitlement to resources, and may come to see themselves as appropriate candidates for

an accelerated death.

### Conclusion

*In a diverse society with a variety of social and cultural values as well as a history of unequal access to medical care, issues surrounding dying and death become more complicated than in more homogeneous societies. Those working with dying persons and their families must be aware of the enormous inequities in access to and quality of health care and of the influence of profound differences in beliefs, values, and self-concepts of disenfranchised people on end-of-life decision-making.*

### Conclusion to Section One

*This section reviewed the impact of medical technology and biomedical advances that have dramatically altered how people experience the dying process and dying; the impact of terminology on end-of-life discussions; the unequal access to, and degree of responsiveness from, the U. S. health care system; and, the critical impact of the wide range of every kind of diversity in our culture. All these factors will inevitably affect the quality of living and dying for everyone in the United States. Psychologists are particularly well-suited, by virtue of their discipline and their specialized skills to assess and work with the psychosocial aspects of these challenging realities.*

## **SECTION TWO:**

### **CHARGE A: Address the Invisibility of Psychology Around the Issue of End-of-Life Care and Recommend Methods to Increase the Visibility of Psychology and the Role of Psychologists in this Arena**

There are a number of ways people can look at a field to determine whether a particular profession has been active in a given subject area. For example, one could study the curricula in undergraduate and graduate programs; determine if the professional association has developed policies, guidelines, or other initiatives in the area; look at the number of members involved in policy discussions or testifying before legislative committees; count the number of presentations at professional meetings or conventions; count the number of publications in the profession's flagship journals; ascertain how many members of the profession are heavily involved in organizations that produce research, education, or practice on a given topic; and so forth. Using any of these measures, it seems appropriate to conclude that psychology is a latecomer to professional discussions concerning end-of-life issues in general as well as the specific case of assisted suicide. Although some psychologists have made important contributions to the field, there is little evidence that the discipline of psychology as a whole has considered end-of-life issues to be an important area that deserves substantial professional time and attention.

Other organizations have been far more active in the end-of-life arena. For example, the Hospice Foundation of America sponsors an annual national teleconference on issues related to the end of life. The Association for Death Education and Counseling (ADEC), the largest interdisciplinary organization of professionals dealing with education and counseling of dying

and bereaved persons, publishes a newsletter, sponsors journals, holds an annual conference, and provides a certification program for death educators and bereavement therapists.

An extensive, systematic study of psychology's participation in end-of-life matters could not be done within the time and funding parameters of this Working Group. However, some preliminary evidence that substantiates psychology's lack of participation in this area was found. For example, there are only 60 psychologists among the approximately 2000 members of ADEC. There is no mention of dying or death or end-of-life decisions in either the APA accreditation guidelines for psychology programs or the APA Code of Ethics. No psychologists have provided testimony to Federal legislative committees involved with end-of-life issues.

A search of the Uncover database, which contains over 8,800,000 articles from well over 18,000 multidisciplinary journals, for articles on the topic of assisted suicide was made for the period between January and May of 1998. This search produced a total of 152 articles. Of those 152 articles, 47 appeared in law journals, 18 were published in medical journals, and 41 appeared in hospital, ethics, dying and death, aging, and nursing journals. During that same period, no APA journals published any articles on assisted suicide. Although psychologists are likely to be found among the authors of some of these articles, it is nonetheless significant that none of these articles were published in APA journals.

In addition, a review of the APA programming at the annual APA Convention during the years of 1994 through 1999 was conducted. Approximately 8800 separate events (e.g., presentations, symposia, poster sessions, workshops, etc.) were offered at APA Conventions during these years. In that period, there were only nine events related to dying and death, 14 events related to assisted or rational suicide, and three events associated with death-related loss. Of those 26 events, nine were symposia, six were films, three were poster sessions, one was a discussion session, one was a conversation hour, and six were continuing education workshops (approximately 360 continuing education workshops were offered from 1994-1999). It is important to note that only one of the six continuing education workshops was devoted entirely to end-of-life issues. It is also worth noting that a continuing education workshop on end-of-life issues and assisted suicide scheduled for presentation in 1999 was canceled because of lack of enrollment.

There is also evidence that other professions do not recognize psychology as an important discipline when discussing end-of-life decision-making. For example, the excellent report by the Institute of Medicine, entitled Approaching Death: Improving Care at the End of Life (Field & Cassel, 1997), discusses psychosocial care for dying persons, but does not include psychologists as members of the interdisciplinary team for palliative home care or as members of a hospital-based palliative care team. The report specifies that members of such a hospital-based team might include "one or more physicians, specialist nurses, social workers, pharmacists, and chaplains" (p. 112). Psychologists and psychiatrists are conspicuous by their absence.

The good news is that there has been more activity on end-of-life issues within the discipline in recent years. APA published a master lecture series book on helping people living with serious illness (Costa & VandenBos, 1990). The appointment of this Working Group is an example of increased interest and involvement. In addition, a section of a recent issue of

*Professional Psychology: Research and Practice* (June, 1999) was devoted to the subject; *Psychology, Public Policy, and Law* will have a special issue on “hastened death” in June, 2000; and *The Counseling Psychologist*’s July, 2000 theme issue is on suicide, and includes a long article on rational/assisted suicide. The APA Office of AIDS has produced training materials on dealing with end-of-life issues when working with persons with HIV/AIDS. Finally, there is one chapter devoted to dying and death in the new *Encyclopedia of Psychology* (Kazdin, 2000). These developments are evidence that the discipline has become aware of the need for more education, research, practice involvement, and policy formation around issues concerning the end-of-life period.

### Conclusion

*Although individual psychologists have been productive in addressing issues related to end-of-life decision-making, there is little evidence that organized psychology has played an important role in discussing quality of care for dying persons, producing a body of research concerning end-of-life decision-making, engaging in the national discourse on end-of-life care and public policy, or in educating its own members regarding this important final stage of life. However, recent developments do indicate that psychology as a discipline has begun to view end-of-life issues as a legitimate and important topic to be included in practice, education, research, and policy.*

### Recommendations

*The following recommendations are made in order to increase the visibility of psychology and the role of psychologists in the arena of end-of-life decision-making.*

- 1. Conduct a survey of all APA divisions and state and provincial psychological associations to determine if they have formed, or are interested in forming, interest groups on end-of-life issues. Encourage interest groups to organize programming at national, state, and regional conventions and meetings. Encourage interest groups to assist in assessing how well palliative care is being addressed in the context of managed care.*
- 2. Develop a mechanism to identify and involve experts from the various divisions in order to implement the various recommendations of the Report (e.g., experts in media psychology).*
- 3. Publish the report of the Working Group in an appropriate APA journal such as Professional Psychology: Research and Practice or the American Psychologist.*
- 4. Publish the final version of the Resource Guide as an APA book.*
- 5. Sponsor a master lecture series on end-of-life care and publish the proceedings as a book.*
- 6. Develop and deliver a continuing education program for practicing psychologists on*

*end-of-life issues and assisted suicide. Offer the program on-line through the APA website and on-site at the national APA Convention and state and provincial psychological association conventions.*

*7. Organize an area on the APA website that provides key end-of-life documents, an end-of-life bibliography, names and contacts of other psychologists interested in end-of-life issues, links to other relevant websites, and a listing of times for chat rooms to operate for psychologists interested in the area.*

*8. Encourage the editors of appropriate APA journals to publish special issues on end-of-life topics.*

*9. In cooperation with organizations such as the National Hospice and Palliative Care Organization, the Hospice Foundation of America, and the Department of Veterans Affairs, co-sponsor teleconferences concerning end-of-life issues with downlinks at various institutions where psychologists and other professionals could facilitate discussion groups.*

*10. Plan and implement a Public Interest MiniConvention on end-of-life decision-making and care.*

*11. Work with the Public Communications Department of APA to produce psychological science-based educational materials targeted to specific audiences (e.g., mental health workers, people living with terminal illnesses, families of people with terminal illnesses, etc.). Educational materials for mental health workers should encourage them to examine the ethical and legal (both criminal and civil) implications of providing services to clients and families considering requests for medical interventions that may affect the timing of death.*

*12. Adopt official APA policy statements on end-of-life decisions and assisted suicide such as those provided in Appendices D and E.*

### **SECTION THREE**

#### **CHARGE B: Examine the Role of Psychology in End-of-Life Decisions and Quality of Care Issues**

Psychologists can make significant contributions to improve the quality of end-of-life decision-making and care by actively engaging these issues in the context of practice, education, research, and public policy.

Since psychology as a discipline does not have a strong history of working in the arena of terminal illness and end-of-life decision-making, attending educational programs offered by other disciplines and participating as members of interdisciplinary treatment teams or research panels are vital strategies for “getting up to speed.” These types of collaborations provide psychologists with partners who have been working in this arena for some time (e.g., medical

doctors, nurses, social workers, ethicists, and chaplains/clergy) while at the same time permitting psychologists to bring their considerable skills and knowledge to the table for the shared mission of improving the quality of care at the end of life. In this way, psychologists can learn from those with experience while demonstrating the value of including mental health professionals as active participants in end-of-life decision-making.

### Clinical Roles

With appropriate training in end-of-life issues, psychologists are particularly suited to carry out clinical roles in assessment, intervention, advocacy, and interdisciplinary service delivery. Assessment at the end of life includes several areas such as evaluation of mood and anxiety disorders, pain, family and caregiver interactions, psychological and cognitive functioning, and existential concerns. Psychologists are also well prepared to plan and implement interventions with individuals, family members, and providers. They can treat clinical depression if and when it arises in end-of-life contexts, as well as other mental health problems. Psychologists can provide end-of-life counseling including facilitating emotional expression, helping caregivers to appreciate the psychological dimensions of the suffering involved, and being effective listeners and sounding boards for people who are dying, their families and caregivers, and even their health care providers. Properly trained psychologists can also work effectively with issues of mourning and loss, traumatic stress, and general objectives for care of dying individuals (Weisman, 1972). They can also serve as advocates for good medical care along with other professionals (i.e., nurses, social workers, and chaplains).

Equally important is participation of psychologists in hospital ethics committees, palliative care, and other multidisciplinary teams. Quill and his colleagues (1998) have observed that "Comprehensive, interdisciplinary palliative care is the standard of care for persons with progressive, advanced disease for whom prognosis is limited and the focus of medical management is quality of life" (p. 555). In addition, Cummings (1998) has stated that

the multitude of issues faced by patients and families dealing with a life-threatening illness exceeds the expertise of any one caregiver. The availability of different team members provides opportunity for support from a number of sources. The interdisciplinary team...is best equipped to provide a nurturing environment for patient and family. (p. 19)

### Assessment Activities

When working with people who are dying, it is essential to assess the overall quality of care they are receiving, to identify sources of suffering and ways of alleviating them, and to determine what decisions need to be made and who needs to be involved in making and implementing them. Aside from formal assessment procedures, the mental health professional working in any clinical role with people at the end of life should keep a number of critical questions in mind. Answering these questions will require regular consultation with others, including family caregivers, primary care physicians, nursing staff, pain specialists, oncologists, psychiatrists, ethicists, gerontologists, hospice workers, clergy, friends, and volunteers. Below are some of the key questions for exploration (please note that a more detailed list of issues to

consider when reviewing end-of-life decision-making can be found in Appendix F):

- Is medical care accessible and adequate?
- Are palliative care and pain management adequate?
- Are the psychosocial needs of the dying person, family, and caregivers being addressed?
- Are cultural issues identified and addressed?
- Are spiritual and existential concerns being addressed?
- Is either the physical disease process or the treatment for it creating emotional distress or cognitive impairment?

Capacity for making health-care decisions may need to be assessed in more detail (Veterans Affairs National Center for Cost Containment, 1997). To evaluate cognitive status, psychologists working with other members of the treatment team can determine if impaired cognitive functioning is temporary (e.g., due to delirium, which is common among older hospitalized persons and may be reversible, once the cause is determined) or if it is due to a more chronic condition such as dementia. It is important to note that individuals may be competent to make decisions in one area but not in another (e.g., persons may be able to make valid decisions about their desire to withdraw from a given treatment regime while not being considered competent to handle their own financial resources) (Grisso, 1986, 1994). Careful attention must also be given to clinical depression, since it can be difficult to assess in dying persons and yet have an enormous impact on quality of life and decision-making.

In addition to assessing cognitive status and depression, requests for interventions that might affect the timing of death should always, independent of legality or the values of the practitioner, be a signal to explore the overall quality of care. They should also prompt psychologists to explore any feelings that patient may have about being undeserving of care or a burden to others. The psychologist should explore the psychological, interpersonal, social, spiritual, economic, gender-related, and cultural reasons behind such requests. Such explorations may reveal areas of unmet needs or feelings about the self that could suggest a variety of interventions to improve the quality of life. For example, data suggest that uncontrollable pain is not the primary motive for people who request assisted suicide. Reasons for requests for both assisted suicide and euthanasia include many nonphysical symptoms such as loss of personhood, discomfort other than pain, loss of dignity, concern about loss of control, loss of meaning in life, being a burden, and dependency (Back, Wallace, Starks, & Pearlman, 1996; Canetto & Hollenshead, 1999; Chin, Hedberg, Higginson, & Fleming, 1999; Cohen, Fihn, Boyko, & Jonsen, 1994; Coombs Lee & Werth, in press; Ganzini et al., 2000; Sullivan et al., 2000a, b; Wilson, Viola, Scott, & Chater, 1998).

Suffering at the end of life and requests for assisted suicide and other interventions that may affect the time of death frequently are associated with clinical depression. It is important to note that older people are less likely to endorse depressive symptoms or suicidal ideation than

younger people with the same level of depression and therefore are less likely to be recognized as depressed by self-report. Additional complexity is caused by the many serious medical problems that older depressed individuals tend to have that can make diagnosis a challenge, even for mental health professionals with special training in this field (Koenig, Meador, Cohen, & Blazer, 1988). The *Resource Guide* will contain a more detailed discussion of assessment issues related to depression, dementia, delirium, and decisional capacity at the end of life. It will identify personal and professional issues that mental health providers should examine before practicing in this area, including personal values and beliefs, quality and extent of professional training in end-of-life issues, and ability to make use of consultation and referral.

### Clinical & Counseling Activities

It is important to understand that clinical work at the end of life differs from traditional psychotherapy in significant ways. It can involve advocacy interventions directed toward assuring quality of care, psychoeducational interventions aimed at improving understanding about dying and death, and systems interventions required to facilitate communication between the dying individual and his or her family and among the individual, the family, and the medical team. In addition, clinical work may occur in non-traditional settings (e.g., the home, the hospital, nursing homes, etc.). Professional boundaries may be more fluid than in traditional psychotherapy cases. For example, it is common for mental health professionals working with the terminally ill to respond to requests for tangible support – a drink of water, a special meal, something from the store, etc. Moreover, the focus of clinical work may be less on insight-oriented psychotherapy (although that can occur), and more on decision-making, emotional coping and support, existential concerns, and bearing witness at the end of life.

Special themes may arise during counseling with terminally ill people. Within some communities, dying persons and those who care about them may need help in completing “unfinished business” (Kubler-Ross, 1969), and achieving an appropriate death (Weisman, 1972). Within these communities, psychologists can help dying persons raise and resolve issues of meaning in their individual lives through values clarification and/or life review or reminiscence therapy. Spiritual issues frequently arise when working with dying persons and the exploration of spiritual themes is an important part of offering support and assisting in the creation of meaning. Because spiritual issues are not often considered to fall within the domain of psychotherapy, many therapists have limited experience and training in this area and thus should be alert to the limits of their expertise and make referrals when appropriate. None of the issues discussed here are universally applicable to all individuals or communities, and the discussion of diversity issues in Section One of this report should be referred to in this regard.

Other themes that may arise in end-of-life clinical work that distinguish it from traditional psychotherapy include a heightened emphasis on grief, mourning, loss, and feelings about dying and death, and coping with sorrow, depression, anger, guilt, and anxiety. Unresolved grief over the earlier deaths of loved ones is likely to arise as some dying people relive past losses in preparation for losing everything. Fears about dependency, the loss of autonomy, control, and dignity are other themes that may arise in counseling dying persons. In addition, being a burden to others emotionally, physically, or economically are common concerns that may need to be addressed.

Misunderstandings among family and caregivers concerning the nature of anticipatory mourning is also a frequent theme. Psychologists may reduce the risk of complicated mourning by promoting healthy anticipatory mourning processes (Rando, 2000) and normalizing anticipatory mourning among family and caregivers. This may include working with people who have had upsetting images of death, traumatic stress reactions, or post-traumatic stress reactions following previous losses (the *Resource Guide* will contain a more extensive discussion of grief, mourning, loss, and trauma).

Terminally ill people face emotionally charged and symbolic milestones of loss during the course of the dying process. For example, accepting a feeding tube, or deciding to have a permanent infusion line implanted through which medications like morphine can be administered on a continuous basis, may represent an important signal to the dying person that death is becoming more imminent, and may symbolize surrender or acceptance. Other symbolic decisions that arise include whether to get hospice care, receive care at home, or be in a medical setting of some kind. Each of these decisions may represent losses that need to be experienced and grieved.

Dying individuals and those close to them may need help with problem solving and decision-making of a more general nature. Clinicians can help clarify, identify, frame, and articulate choices and priorities. For some, this may include making sure a will is in order or completing an advance care directive. Psychologists can clarify the purpose and function of advance directives to help individuals and families discuss advance care planning and also, if necessary, act as advocates to help ensure that these directives are followed. It is important to note that some communities regard advance directives with great suspicion because they are viewed as leading to rationed care.

Attending to such details as identifying and designating a responsible guardian or health-care proxy for the dying person and providing psychological support as the person makes that choice is another task that psychologists can assume. Some dying individuals may wish to consider what kind of legacy they want to leave, and to plan the kind of memorialization they want. Even the smallest end-of-life decisions can have meaning and implications that deserve exploration and emotional support. Ambivalence about many of these decisions is normal, and the clinician can help people identify the mix of feelings they experience so that they can make thoughtful choices. However, psychologists working in this arena must bear in mind that in some communities, planning for death is unacceptable or even considered dangerous.

If the dying person is no longer competent to participate in decision-making because of the effects of the underlying illness or of various pain medications, the proxy decision-makers acting on the individual's behalf can often benefit from skilled psychological assistance. The emotional burden of making life and death decisions for a loved one can be enormous because some decisions are irreversible. There may also be conflict among family members about the best course of action. Psychologists can play a positive role in clarifying the situation, facilitating discussion, providing support for the decision-makers, and helping them deal with any residual feelings of guilt or regret over their decision.

A final cautionary note to clinicians working in end-of-life venues is in order. The intensity of working with people who are dying makes it essential for such professionals to have a strong support system to handle issues of loss, grief, vulnerability, and traumatization from working so closely with dying and death.

### Advocacy Activities

Dying individuals often have difficulty communicating with health providers about symptoms, fears, and needs, and psychologists can act as their advocates. Advocacy for quality care for terminally ill individuals and their families may involve working as part of multidisciplinary teams to ensure that individual needs and quality of life issues are understood and addressed. Physicians often lack training in end-of-life care and palliative services. Physicians have been repeatedly shown to under-recognize and under-treat pain and depression in dying individuals (Peruzzi, Canapary, & Bongar, 1996; Quill et al., 1998). Therefore, psychologists may act as advocates for increased pain control as well as provide special expertise in assessment of depression (Conwell, Pearson, & DeRenzo, 1996).

### Emerging Models of Service Delivery

There are two emerging models of service delivery through which psychologists can make effective contributions to end-of-life decision-making: functioning as a team member in a hospital or hospice setting and functioning as part of an ethics committee to provide insights into the psychological aspects of cases being reviewed. Although participation in hospital ethics committees and multidisciplinary treatment teams is a relatively new role for most psychologists, it is clear that psychologists can add a unique perspective to health care providers dealing with difficult end-of-life decisions. For example, informed psychologists can participate in case reviews to facilitate better planning and decision-making and help to educate hospital staff about psychological aspects of care of dying individuals. They can also help to coordinate individual and family care. In addition, psychologists can provide expert psychological guidance to ethics committees struggling with issues of competency and depression. Finally, they can also support medical staff more directly by helping them to deal with difficult patients or family members as well as supporting them in dealing with their own feelings around grief, loss, and dying (Block & Billings, 1998; Field & Cassel, 1997).

### Conclusion

*Psychologists have much to offer in working with dying persons and their families and loved ones. They receive excellent training in assessment of cognitive and overall psychological functioning and depression. They have strong intervention skills, the ability to promote decision-making and problem solving, the skills to clarify values and communication, and experience in providing brief therapies. In addition, they can work with issues of anticipatory mourning, cumulative loss, unresolved grief, and stress secondary to illness and loss. They have skills in listening and communicating that permit them to be excellent advocates for dying persons and their families. Finally, psychologists can bring an in-depth understanding of psychological factors to multidisciplinary teams working with dying persons, their families, and caregivers. Specialized training and supervised experience in end-of-life care, however, is a prerequisite to*

*providing any type of service associated with end-of-life care.*

### Recommendations

- 1. Develop a directory of psychologists interested and involved in end-of-life issues, specifying their activities in education, research, practice, and policy; this could be accomplished by adding an end-of-life-issues interest code to the standard APA membership questionnaire. This directory, which can appear on the APA website can be a useful tool in helping psychologists, other professionals, and the public to identify potential consultants in the field.*
- 2. Produce and disseminate a case book with examples of terminally ill people and their families facing difficult end-of-life decisions that illustrate the ethical issues associated with these cases and provide models for working with these situations. This case book could serve as an educational tool for psychologists, helping them to understand the complexities central to working with people at the end of life. It should include cases of individuals and groups who are particularly likely to be perceived and encouraged to perceive themselves as more expendable and less deserving of continued life: e.g., people who are older, people who are poor, women, people of color, gay men, lesbians bisexuals, people with disabilities.*

### Education and Training Roles

#### Education of the Profession

Since psychology does not have a strong history of working in the arena of terminal illness and end-of-life decision-making, the discipline will need to focus on self-education first. As mentioned previously, attending educational programs offered by other professions and participating in interdisciplinary treatment teams or research panels are vital strategies for bringing the profession “up to speed.” The field of thanatology (the study of dying, death, and bereavement) is essentially a multidisciplinary area of study and those wishing to specialize in it should be receptive to learning from a variety of professionals. There are, however, a significant number of psychologists who have attained stature as authorities in this field and they may be in a position to serve as teachers and mentors. It is essential for end-of-life issues to be integrated into existing undergraduate and graduate courses (Abeles & Barlev, 1999; International Work Group on Death, Dying, and Bereavement, 1991). Free-standing courses in the psychology of dying and death can also be added to both undergraduate and graduate curriculum.

Content areas for these courses could include: the demographics of aging and dying; the process of dying; loss, mourning, and grief; attitudes toward dying and death; quality of life issues; needs of the dying, their loved ones, and their caregivers; understanding the culture of the medical setting; ethical issues involved in end-of-life care; quality of care issues; the importance of ritual at the end of life; gender and diversity issues in end-of-life care and decision-making; incidence and effects of depression, dementia, and delirium at the end of life; and clinical training in assessment of people at the end of life. Integration across the curriculum of gender and diversity issues and exposing students to a variety of social and cultural groups in their

practica should occur at every level. Practical experience can be offered to students through supervised practica and internships in hospitals, nursing homes, hospices, and home health care agencies. Supervised practical experience can also be gained through illness-focused agencies, illness and bereavement groups, and mental health agencies serving relevant populations. Extracurricular activities planned through Psi Chi or a Psychology Club can provide additional exposure.

Professional education and training in end-of-life issues is different from training in standard counseling and psychotherapy techniques both in style and in content. As noted above, clinical work with people at the end of life is typically more short-term and interactive and it involves more advocacy than other kinds of counseling. Educational methods should also include values clarification and self-exploration of personal attitudes toward death (Stillion, 1983, 1999).

### Education of the Public

As more psychologists become knowledgeable about working with people making end-of-life decisions, they can make significant contributions to the public dialogue about end-of-life issues. Psychologists, along with other health care providers, can appear on panels dealing with end-of-life decision-making. They can work with the media, prepare publications, videos, and other psychoeducational materials. They can also encourage discussion about dying and death with clients and their family members when culturally appropriate.

People need knowledge in order to communicate effectively with health care providers. Psychologists can help people understand loss, grief, and mourning; explain the concept of traumatic stress in response to difficult deaths and losses; and help understand differences between normal sadness and clinical depression at the end of life. They can teach people to be more aware of unique individual needs and assumptions about dying and death. They can identify common problem areas for families, significant others, or intimates facing death, encourage values clarification around end-of-life issues, provide information about advance care planning and how to implement it, clarify issues involved in difficult end-of-life decisions, and teach coping mechanisms. They can raise awareness of when or how sexism, ageism, ethnocentrism, and ableism influence end-of-life planning and decision-making, and of the social and cultural pressures that may result in some groups and individuals being devalued.

### Conclusion

*Psychology as a discipline has the potential to contribute unique insights and make valuable contributions to care at the end of life. However, the discipline must find ways to incorporate dying, death, grief, and loss into existing courses at the graduate and undergraduate levels. Individual psychologists wishing to work in this arena must find ways to get ongoing professional education in end-of-life issues. Interdisciplinary initiatives are fruitful ways of learning in this field. Psychologists can also make significant contributions to community education.*

### Recommendations

*1. Conduct a survey to assess the amount and type of educational experiences that undergraduate and graduate programs in psychology offer in the area of dying, death, and bereavement.*

*2. Develop a faculty guide for integrating end-of-life issues into psychology curricula at undergraduate and graduate levels. The faculty guide should provide the rationale for including end-of-life issues in psychology courses, emphasize key content in end-of-life care, discuss strategies for integrating information into courses commonly taught, review strategies for developing placements for practicum students, provide examples of interactive exercises, and present discussion topics to be used for building awareness and processing students' affective responses to difficult end-of-life situations.*

### Research on End-of-Life Issues

The third area in which psychologists can play an important and productive role in improving care at the end of life has to do with planning and conducting research. The quality and amount of existing research on end-of-life decision-making is limited. Therefore, there are multiple opportunities for extending behavioral and psychological knowledge about the end of life and about decisions that may affect the timing of death.

### Ethical and Methodological Issues

A word of caution is in order. There are ethical issues involved in research with people at the end of life. Persons who are seriously sick and dying are a psychologically vulnerable population at risk for exploitation. For example, dying persons may experience fluctuating patterns of cognitive impairment, which may require investigators to reexamine informed consent and participation in research. Another ethical issue has to do with the fact that participation in research may interfere with care and add stress to people whose energy level and sense of wellbeing may be fragile. On the other hand, there are possible benefits and rewards derived from participation in research. Potential benefits include a sense of altruism, a value that may be important for persons at the end of life, as well as receiving the attentive care and state-of-the-science monitoring that is often associated with a clinical trial of a new care program.

There are a variety of methodological problems associated with much of the existing research having to do with end-of-life issues (Rosenfeld, in press). For example, many studies have had one or more of the following design limitations: (a) dependent variables of questionable utility (e.g., hypothetical questions about some future possible scenario), (b) sample selection bias (e.g., participants are either not terminally ill or, if they are, they are closely screened so the results are non-generalizable), and (c) study site bias (e.g., palliative care centers provide convenient samples but most people do not go through the dying process in such places). Another methodological difficulty associated with end-of-life research has to do with the fact that symptoms associated with the illness and/or the medications to alleviate those symptoms may interfere with the ill person's ability to actively participate in the study or remember information accurately. One strategy to ameliorate this limitation is to interview significant others in addition to the dying person.

## Priority Areas for Future Research

1. There is no common lexicon of terms to describe key events and phenomena at the end of life. Therefore, researchers from a variety of disciplines should work toward the development of a consensus on key terms and concepts related to dying and death. Such collaboration could provide a basis for developing theories and advancing knowledge that would be more readily utilized and understood by professionals in all disciplines involved with end-of-life care.
2. There is little documentation about the ways in which the people live the last phase of life and die. Normative research should focus on emotions, cognitions, behaviors, and attitudes of dying persons as well as on interactions between dying persons, family members, and professional caregivers engaged in end-of-life decisions. Research on normative experiences could also examine the role of psychological, social, cognitive, and behavioral factors associated with common problems at the end of life. This could include the study of psychological issues in pain and suffering, studies of the prevalence of neuropsychological symptoms in persons suffering from different diseases, and studies of the prevalence of depression and delirium in persons with advanced medical diseases. It should also include the study of family dilemmas and responses to a dying person.
3. It is important to determine how the dying experience and the meaning of dying differs in relation to diversity factors such as gender, sexual orientation, education, and cultural group membership.
4. Research to develop or refine assessment instruments for older, sick, and/or dying persons is needed. Less taxing measures of depression, decision-making capacity, and quality of life should be developed with sensitivity to diversity issues among sick, older, and dying populations.
5. Research on optimal end-of-life experiences is also needed. It is important to understand how people want to live the last phase of their lives and the conditions that they believe will lead to an appropriate death for them. Researchers should be looking at the variability of views depending on gender, ethnicity, sexual orientation, age, education, income, religious background, living arrangements, and family structure.
6. Research to determine the adequacy of palliative care and the psychological effects of rationing health care on persons of limited means and their families is needed. For example, does such rationing increase the likelihood that such persons will request an intervention that may affect the time of death?
7. We know very little about the availability and quality of psychological services for persons in the last phase of life and their families. Research to discover the extent, timing, type, and delivery modes of psychological services in use by dying persons and their families at the present time is in order.

8. Outcome evaluations concerning existing psychological services are also necessary. This area of research may include surveys of current forms and uses of psychological services as well as the exploration of optimal psychological services that could or should be available. Research is also needed to investigate barriers to quality psychological care (i.e. attitudinal, organizational, legal, cultural, economic, and other factors that impede the application of existing knowledge and principles of psychological care).
9. Research on the relative efficacy of various models of training health and mental health care providers to work successfully with dying patients and their families is needed.
10. Research on the psychosocial interactions of dying persons is also needed. This would include how they interact with caregivers and families regarding decisions for care, and the variability of those interactions depending on sex, ethnicity, age, sexual orientation, education, religious background and practice of the dying person, the primary family caregiver, and the primary professional caregiver.
11. The effect of caregiver burden on end-of-life decisions is another fruitful area for research. At what point, if any, in the dying process are caregivers likely to consider interventions that may shorten life for their loved ones and what variables contribute to these thoughts?
12. The entire area of psychological, interpersonal, medical, social, and existential concerns that underlie requests for interventions that may affect the time of death needs definitive research. In addition, the responses of family and professional caregivers to such requests need examination, as does the effect of their responses on the dying person.
13. Ethical issues in research involving those who are dying and their families need to be examined and articulated in a systematic way.
14. There is currently an opportunity to conduct research on assisted suicide itself. Where assisted suicide is legal, psychological autopsy studies of assisted suicide cases could be carried out. It is also important to study factors that distinguish the following groups of individuals: (a) dying persons who do not request assisted death; (b) dying persons who only express an interest in it; (c) dying persons who request it but do not go through it; and, (d) dying persons who actually carry out assisted suicide.
15. Where assisted suicide is legal or decriminalized, it is important to determine how its availability affects anxiety and comfort levels about the end of life among older people, the terminally ill, and the disabled. Further, does the availability of assisted suicide affect the timing of death (i.e., do people die sooner than they would have if this action was not available or does its availability result in people staying alive longer with the knowledge they can make decisions about the timing of death)? What is the impact of any policy changes on devalued and disadvantaged groups should be monitored.

## Conclusion

*Psychologists' ability to design research, analyze qualitative and quantitative data, publish results, and do meta-analyses as results accumulate are powerful skills for advancing understanding of this complex and difficult stage of life. Designing, conducting, analyzing data, and presenting the results of research are major strengths that psychologists can bring to the study of the end-of-life period. However, carrying out research at the end of life has special ethical concerns that must be addressed. In spite of these, there are multitudes of questions that deserve to be addressed in systematic research programs. Interdisciplinary research in this area would be especially helpful.*

### Recommendation

*1. Develop and publish a research agenda. The American Psychological Association, in collaboration with other behavioral and social science organizations and key staff of relevant federal agencies, should convene a group of research scientists for the purpose of articulating a phased program of research to address key end-of-life issues. APA could publish this research agenda along with potential funding sources in the Monitor, in division newsletters, and on the APA website. In addition, APA could promote the development of federally funded requests for proposals based on the research agenda.*

### Policy Roles

The report of the Institute of Medicine (IOM) Committee on Care at the End of Life (Field & Cassel, 1997) identified five broad areas of deficiencies in current care for people with life-threatening and incurable illnesses. Each of these five areas present numerous opportunities at federal, state, and local levels for psychologists who are interested in playing advocacy or policy roles to advance the quality of care at the end of life.

First, many people suffer needlessly at the end of life. Sometimes suffering arises when caregivers fail to provide palliative and supportive care known to be effective (e.g., appropriate treatment of pain and depression; pharmacological, compensatory, and environmental interventions to address dementia and other forms of cognitive impairment; individual and family counseling to facilitate communication about needs and expectations associated with end-of-life care; etc.). At other times, suffering arises when the aggressive use of ineffectual or intrusive interventions serves to prolong the period of dying unnecessarily or to dishonor the dying person's wishes about care. Too often, dying people and their families are either not aware of these care options, not fully apprised of the probable benefits and burdens of these various options, or are the recipients of care that is inconsistent with their wishes as expressed in written or oral directives. Psychologists can join other health care professionals in advocating for the development of public, institutional, and organizational policies to ensure that individuals and families know what types of interventions and services are available to them; understand what types of outcomes they can reasonably expect from such services and interventions; and receive end-of-life care that is consistent with their values, beliefs, and wishes.

Suffering can also be reduced by advocacy aimed at encouraging health care institutions to adopt mechanisms for monitoring and evaluating end-of-life care from the perspective of

individuals and families. As Field and Cassel (1997) point out, many commonly used physiological and functional indicators of quality of care are not linked to outcomes as experienced by persons and families. Psychologists can play a critical role in encouraging hospitals and other health care institutions to develop and utilize quality of care measurements that are: (1) relevant to the experiences of dying individuals and those close to them; (2) sensitive to the effects of changes in care; and (3) efficient and practical to use.

A second area of deficiency cited by the IOM Report has to do with the numerous legal, organizational, and economic obstacles that interfere with quality care at the end of life. Outdated drug-prescribing laws, burdensome regulations, and problematic medical board policies often intimidate physicians and other professionals who wish to relieve their patients' pain but are unable to do so because of scrutiny from regulatory boards and committees that frequently fail to understand either modern techniques for pain management, or the psychological and behavioral distinctions between drug tolerance and physical dependence on the one hand, and addiction on the other. In addition, fragmented organizational structures often complicate the coordination of care and reduce the likelihood that individuals and families will access various types of support services that are essential elements of quality care. This is especially true with respect to accessing psychological and psychoeducational services that are rarely integrated with primary care. Psychologists can play an important role in advocating for systemic changes in these types of legal and organizational obstacles to quality care.

Because over 70% of those who die every year are covered by Medicare (Field & Cassel, 1997), economic obstacles to quality end-of-life care largely arise from the nature and quality of Medicare benefits. A major concern about Medicare's hospital payment policies is that they encourage premature patient discharge and discourage appropriate inpatient palliative services. Since the 1980s, Medicare has used a prospective payment scheme that pays for most hospital stays on the basis of diagnosis-related category or group (DRG). If hospitals spend less than the prospectively-determined DRG payment, they keep the difference. They are not routinely compensated if they spend more. Thus, there is an incentive to both limit hospital stays and limit inpatient support and palliative services. These incentives may be particularly devastating to dying people who are among the sickest of Medicare beneficiaries with the most complex psychological and psychosocial needs. In this context, it is often difficult to adequately address and coordinate palliative and psychosocial support care prior to discharge. Advocacy is needed to modify payment categories and payment levels to ensure that there are resources to support a coordinated inpatient, interdisciplinary team that includes psychologists and other professionals skilled in addressing psychological and psychosocial needs.

Medicare coverage for hospice services is unfortunately quite limited. To qualify for Medicare hospice benefits, individuals must be certified as having a life expectancy of six months or less if the illness runs its natural course. Thus, the hospice benefit is not applicable to many people with serious illness with an uncertain course. A major limitation of the home health benefit of hospice services has to do with the fact that beneficiaries must either be homebound and need part-time or intermittent skilled nursing care or they must require physical or speech therapy. Some dying individuals would benefit significantly from home palliative care before they become completely homebound.

Yet another primary concern about Medicare's payment scheme is that its payment categories and payment levels for outpatient support services may not appropriately recognize the time and resources required to care well for the complex psychological and psychosocial problems presented by people with advanced disease that is expected to prove fatal. For example, it is often necessary for psychologists and other outpatient providers to meet with individuals and families in the home or in the hospital. It is also necessary to meet with other professionals in order to coordinate care. Unfortunately, traditional financing mechanisms pay for circumscribed procedural services (e.g., 50-minute session of psychotherapy) but not the actual time required for home and hospital visits, the time devoted to coordinating care with other professionals; the time required for the thorough and ongoing assessment of individual and family needs; or the time involved with psychoeducational interventions for persons, families, and other healthcare providers that are so critical for quality end-of-life care. Advocacy is desperately needed for the development of Medicare reimbursement policies that promote holistic and coordinated care.

A third major area of deficiency cited in the IOM Report has to do with the fact that the education and training of psychologists, physicians, and other health care professionals fail to provide them with the attitudes, knowledge, and skills required to care well for dying people and their families. As Field and Cassel (1997) point out, current deficiencies in practice basically stem from prior failures in professional education. Advocacy is needed to encourage the allocation of federal funds to establish comprehensive programs of undergraduate, graduate, and continuing education. These programs should prepare psychologists and other health professionals to understand and manage their own reactions to dying and death, to deliver science-based interventions that are responsive to the needs of individuals and families, and to communicate sensitively and effectively with dying people and those close to them. Because quality end-of-life care is predicated on effective teamwork and coordination, it is critical that professional education programs utilize multidisciplinary approaches to training that prepare professionals involved in end-of-life care to participate effectively in multidisciplinary care teams organized to assist individuals and families at the end of life.

A fourth area of deficiency that suggests the need for advocacy and policy change has to do with the level and type of funding available for social, behavioral, and health services research dealing with end-of-life issues. The preceding section of this report outlines many areas in need of investigation. However, these areas are unlikely to be pursued without leadership from Congress as well as key officials at federal agencies responsible for directing research funding for behavioral and biomedical sciences. Advocacy is needed to encourage the National Institutes of Health (NIH), the Health Resources and Services Administration (HRSA), the Health Care Financing Administration (HCFA), the Agency for Healthcare Research and Quality (AHRQ), the National Center for Health Statistics (NCHS), and other federal agencies to provide leadership in organizing workshops, consensus conferences, and other initiatives that serve to clarify what is known, what is not known, what areas are of highest priority, and what types of funding mechanisms are most likely to support the rapid development of knowledge.

As knowledge from basic research develops, advocacy will also be needed to ensure that Congress and relevant federal agencies support the application, dissemination, and transfer of new information through funding for demonstration projects to test new models, funding for the

development of clinical practice guidelines designed to promote the replication of proven interventions, and funding for national continuing education programs designed to get the word out to professionals in the field. Additionally, advocacy is needed to encourage NIH and other biomedical research groups to gather information about death, dying, and end-of-life care in the context of current clinical trials associated with potentially fatal diseases.

A fifth area of deficiency around which advocacy and policy efforts could be organized has to do with the reality that most people in this country have not yet learned how to confront and discuss the topic of death and dying in an open and effective manner even when their culture or religion does not consider this a taboo subject. Psychologists are in a unique position, by virtue of their recognized expertise in facilitating the exploration and examination of emotionally charged issues, to promote open discussions about death and dying with individuals and with other professionals. Psychologists are also uniquely qualified to advocate for the ongoing discussion of these topics in the media, in the community, and in professional meetings.

A final area of deficiency that could become the focus of advocacy efforts has to do with the fact that there is often inadequate care for people with disabilities (National Council on Disability, 1998). Unfortunately, popular beliefs among the non-disabled that they would rather be dead than disabled sometimes combine with the medical industry's emphases on cost savings and leads to decisions to withhold crucial services from patients with severe disabilities.

### Conclusion

*There are numerous opportunities at federal, state, and local levels for psychologists who are interested in assuming advocacy or policy roles to advance the quality of care at the end of life. Psychologists can promote a wider societal commitment to caring well for people who are approaching death by working with other health care professionals and managers, researchers, policymakers, funders of health care, and the public at large to improve policy and practice. The goal of widespread quality care at the end of life is attainable, but realization of that goal will require many system-wide changes in attitudes, policies, and actions.*

### Recommendations

- 1. Develop a federal policy agenda to improve end-of-life care. The APA Public Interest Policy Office, in collaboration with a multidisciplinary group of experts in the area of end-of-life care, should develop such an agenda, outlining and prioritizing advocacy objectives and strategies designed to promote legislation and federal agency action directed toward the improvement of care at the end of life.*
- 2. Solicit input from division interest groups with respect to end-of-life policy.*
- 3. The APA Public Interest Policy Office, in collaboration with a multidisciplinary group of experts in the area of end-of-life care, should develop and publish an orientation and information packet for psychologists interested in playing policy roles to advance the quality of care at the end of life at federal, state, and local levels.*

## SECTION FOUR

### **CHARGE C: Consider and make recommendations on whether it might be appropriate for APA to take a position on the issue of assisted suicide and end-of-life decisions**

The issues of assisted suicide and end-of-life decisions will be discussed separately in this section. End-of-life decisions will be discussed first as assisted suicide is subsumed under this topic.

#### Position on End-of-Life Decisions

##### Guiding Principles

Psychologists can make significant contributions to improve the quality of end-of-life care and decision-making by actively engaging in these issues in the contexts of practice, education, research, and public policy. As psychologists begin to work in the end-of-life arena more fully and consistently, their actions should be guided by a set of working principles and values. The report of the Institute of Medicine (IOM) on end-of-life issues (Field & Cassel, 1997, pp. 22-23) articulated a set of principles that can serve as an excellent guide for organizing thinking and action in many disciplines, including psychology. These principles are as follows:

- Care for those approaching death is an integral and important part of health care.
- Care for those approaching death should involve and respect both patients and those close to them.
- Good care at the end of life depends on clinicians with strong interpersonal skills, clinical knowledge, technical proficiency, and respect for individuals, and it should be informed by scientific evidence, values, and personal and professional experience.
- The health community has a special responsibility for educating itself and others about the identification, management, and discussion of the last phase of fatal medical problems.
- More and better research [in the areas of biomedical, clinical, psychosocial, and health services] is needed to increase our understanding of clinical, cultural, organizational, and other practices or perspectives that can improve care for those approaching death.
- Changing individual behavior is difficult, but changing a culture or an organization is potentially a greater challenge---and often is a precondition for individual change.

Building upon these principles, the IOM report identified four broad deficiencies in end-of-life care, each of which deserve attention from psychologists (pp. 264-265). First, errors of omission and commission occur too frequently at the end of life. Caregivers frequently “fail to provide palliative and supportive care known to be effective” and they often “do what is known

to be ineffective and even harmful.” Second, there continue to be “legal, organizational, and economic obstacles [that interfere with] excellent care at the end of life.” Third, “the education and training of physicians and other health care professionals fails to provide them with the knowledge, skills, and attitudes required to care well for the dying patient.” Fourth, existing knowledge of how people die and how to meet their needs during this stage of life is inadequate.

### IOM Recommendations and Implications for Psychologists

Recognizing these deficiencies, the IOM report made seven recommendations, many of which are appropriate to the discipline of psychology as it becomes more knowledgeable and involved in this area. Implications for psychologists of each recommendation in the IOM report are indicated.

1. "People with advanced, potentially fatal illnesses and those close to them should be able to expect and receive reliable, skillful, and supportive care" (p. 266).

Implication: Psychologists have skills to provide such care and to support dying persons and their family members as they engage in advance planning, identify appropriate surrogate decision-makers, and help the family and the medical community avoid narrow preoccupation with written directives.

2. "Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for dying patients and to using existing knowledge effectively to prevent and relieve pain and other symptoms" (p. 267).

Implication: Psychologists have contributed to research on the measurement and treatment of pain (Eimer & Freeman, 1998). Their continuing efforts in this area should be encouraged, expanded, and highlighted.

3. "Because many deficiencies in care reflect system problems, policymakers, consumer groups, and purchasers of health care should work with health care providers and researchers to:

- a. strengthen methods for measuring the quality of life and other outcomes of care for dying patients and those close to them;
- b. develop better tools and strategies for improving the quality of care and holding health care organizations accountable for care at the end of life;
- c. revise mechanisms for financing care so that they encourage rather than impede good end-of-life care and sustain rather than frustrate coordinated systems of excellent care; and
- d. reform drug prescription laws, burdensome regulations, and state medical board policies and practices that impede effective use of opioids to relieve pain and suffering" (p.267).

Implication: Psychologists can provide significant contributions in all these areas through their research, assessment, and policy activities.

4. "Educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have the relevant attitudes, knowledge, and skills to care well for dying patients" (p.269).

Implication: This is obviously true and the earlier recommendations for study and revision of the undergraduate and graduate preparation of psychologists become more germane in light of this recommendation.

5. "Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research" (p.269).

Implication: Because the model for palliative care stresses "interdisciplinary, comprehensive, and continuing care of patients and those close to them" (p. 269), psychologists can take a proactive role in extending the boundaries of quality care through education and extended research into the behavioral components of end-of-life care, including pain prevention and relief.

6. "The nation's research establishment should define and implement priorities for strengthening the knowledge base for end-of-life care" (p. 269).

Implication: The expertise that psychologists can bring to this recommendation is obvious. Elsewhere in this report, there are suggestions for a psychological research agenda. It is important to reiterate that no research agenda on end-of-life issues can be complete unless the voice of psychology is represented on such areas as pain control, life satisfaction, assessment issues at the end of life, behavioral correlates of end-of-life decision-making, and a host of other psychosocial concerns.

7. "A continuing public discussion is essential to develop a better understanding of the modern experience of dying, the options available to dying patients and families, and the obligations of communities to those approaching death" (p. 270).

Implication: The IOM report noted that it is important to keep the goals of improving care for dying persons in the public consciousness. To that end, the American Psychological Association can play an instrumental role in keeping the public discussion going by implementing the recommendations contained in this *Report to the Board*.

### Conclusion

*The discipline of psychology and individual psychologists have much to offer in increasing the quality of care at the end-of-life for dying individuals and their families. Many of the specific assets that psychology can bring to the table are referred to in previous recommendations of this Report to the Board of Directors. However, it is clear that psychology*

*must make the end-of-life period a priority if it is to assume significant responsibilities and become an active participant in research, education, practice, and policy formation. The historical absence of the discipline makes it imperative that this subject receive focused attention by the American Psychological Association.*

### Recommendations

- 1. In recognition of the importance of interdisciplinary efforts to improve end-of-life care, and in view of the fact that the principles contained in the IOM report seem to invite participation from fields other than medicine, the Working Group recommends that the APA formally endorse those principles to guide our discipline in expanding its role in end-of-life issues.*
- 2. The Working Group recommends that the APA Board of Directors support a resolution that encourages psychology to focus its expertise and resources on the goal of improving the availability of quality care at the end of life (see Appendix D for a resolution offered by the Working Group for consideration by the APA Board of Directors and the APA Council of Representatives).*
- 3. The Working Group recommends that the APA Board of Directors appoint a three-year Ad-Hoc Committee on End-of-Life Issues that will be responsible for providing oversight and leadership in implementing recommendations contained in this Report to the Board.*
- 4. The Working Group encourages the APA Board of Directors and Council of Representatives to approve allocation of three years of funding to support a full-time staff person and the operations of the proposed Ad-Hoc Committee on End-of-Life Issues.*
- 5. The Working Group recommends that the proposed Ad Hoc Committee on End-of-Life Issues prepare a report similar to this one on end-of-life care and decisions involving minors, and involving persons who have been determined incompetent to make their own health-care decisions.*

### Position on Assisted Suicide

Assisted suicide is one of the most controversial issues of our time. This section of the *Report to the Board* contains a brief summary of the arguments commonly used to support positions either for or against assisted suicide as an end-of-life choice. Material for the arguments borrows heavily from other sources (Abeles & Barlev, 1999; Battin, 1996; Callahan, 1992; Canetto, 1995; Canetto & Hollenshead, 1999; Gallagher-Thompson & Osgood, 1997; Hendin, 1994, 1995; Kass & Lund, 1996; National Council on Disability, 1998; Miller, 1996; Mishara, 1999; Sanson et al., 1998). The section includes a review of assisted suicide data from Oregon and the Netherlands and the differing interpretations placed on these data. It also summarizes data from a variety of other studies on assisted suicide. The section concludes with a recommendation concerning the position APA should take on assisted suicide.

Arguments supporting or opposing assisted suicide are generally made from several frames of reference. These include ethical and moral arguments, legal arguments, medical arguments, and arguments regarding safeguards and the slippery slope.

### Arguments in Support of Assisted Suicide

Ethical and moral arguments include the principle of self-determination to control the time, place, and nature of one's death, placing quality at the end of life above the sanctity of life. Other factors include the desire to preserve dignity and personhood in the dying process and opposition to prolonging life by using sophisticated medical technology when it is recognized that care is futile. Closely related to self-determination is the principle of autonomy. This principle states that persons should have the right to make their own decisions about the course of their own lives whenever they can. By extension, they should also have the right to determine the course of their own dying as much as possible.

According to these arguments, even when choices are socially shaped they should be respected as autonomous as long as there is appropriate evaluation of decisional capacity. No person should have to endure terminal suffering that is unremitting, unbearable, or prolonged. When the burdens of life outweigh the benefits because of uncontrollable pain, severe psychological suffering, loss of dignity, or loss of quality of life as judged by the patient, and when the circumstances are not remediable, the dying person should be able to ask for and receive help in assisted suicide. It is further argued that assisted suicide for incurably ill persons experiencing extreme suffering can be distinguished from euthanasia used for the purpose of genocide on the grounds that it is based on principles of dignity, honor, and respect and is chosen and enacted by the dying individuals, rather than being forced on them against their will.

Legal arguments state that it would be in the best interest of dying patients to be able to regulate practices that are currently being used covertly for assisted suicide. Such regulations would also provide safeguards for practitioners who are currently complying illegally with patient requests out of compassion.

Medical arguments contend that competent terminally ill patients wishing to choose assisted suicide may feel abandoned by physicians who refuse to assist. The criticism that medical doctors agreeing to assist in suicide would be violating the Hippocratic Oath is refuted on several grounds. First, the original Oath prohibiting killing also prohibited abortions, surgery, and charging teaching fees, all of which have been modified to meet contemporary realities. Second, assisted suicide, unlike euthanasia, does not involve the ending of life by a physician, as it is the dying person himself or herself who takes the steps to end his or her life. Third, the Oath requires physicians to take all measures necessary to relieve suffering, and some interpret this to include assisted suicide when that is the only way suffering can be relieved.

The argument regarding safeguards and the slippery slope holds that it is possible to protect people from abuse through appropriate regulation which would provide oversight by a combination of state legislation and professional regulation by palliative care consultants and ethics committees that would include professionals and community representatives. Several

models for safeguards have been proposed and typically include confirmation of diagnosis, prognosis, treatment options, and decision-making capacity; assessment for alternative means of alleviating suffering; nondirective counseling; education of physicians; and education of the public.

It is further argued that widely utilized and commonly accepted legal end-of-life interventions such as withholding or withdrawing treatment, double effect, and terminal sedation are also subject to the slippery slope or to abuse and yet are considered to be controllable by standards of care and appropriate regulation and oversight. Likewise, financial concerns may be a factor in requests for legal interventions as well as in requests for assisted suicide and yet are not considered as a justification for prohibiting these other interventions.

The safeguards argument posits that involving mental health professionals to provide appropriate and comprehensive treatment planning would improve quality of care and reduce the potential for abuse regarding all end-of-life interventions that may affect the time of death. Regarding the issue of depression which, if treated, could change a terminally ill person's request for assisted suicide, it is pointed out that first, treatment of depression does not always change the desire for assisted suicide, and second, psychologists can play a major role in assessment and treatment of depression and other psychological factors that may affect judgment and requests for a variety of interventions that affect the time of death including but not limited to assisted suicide.

#### Arguments in Opposition to Assisted Suicide

Ethical and moral arguments begin with the principle of protection of the socially and economically disadvantaged. Concerns are raised that persons whose autonomy and well-being are compromised by poverty or by membership in a stigmatized social group, (such as women, persons with disabilities, ethnic, sexual, and other minorities, and ill older persons in general) will be coerced into assisted suicide. The pressure to choose suicide may not be explicit and personal, because persons who experience stigma may internalize a diminished sense of entitlement to resources, and may be the ones who most strongly argue for their own demise. The principle of individual choice in dying is viewed as a fiction in a highly stratified society, such as the United States, where access to basic health care is highly variable and dependent upon personal income and private insurance. Many seriously ill persons may not have the resources necessary for implementation of the choice to live.

From within this perspective, the individual paradigm of decision-making, with its emphasis on independence and choice, is seen as obscuring the reality that decisions about care at the end of life are typically made by physicians with some consultation with family members and with cost containment being an important factor in these decisions. Another ethical argument opposing assisted suicide comes from the principle of respect for human life and the related beliefs that killing is wrong, even if a person consents to it. Some, who see assisted suicide as similar to euthanasia, believe that moral objections to assisted suicide are strengthened by examining historical precedents, specifically the experience of Nazi Germany in which "undesirable" groups of people (including Jews, persons with disabilities, and sexual minorities) were put to death.

Legal arguments against assisted suicide include concerns about civil suits resulting from premature or unnecessary termination of life following a diagnostic error or incorrect prognosis. There are also concerns about enforcement of legal procedures devised to prevent against misuse, abuse, and improper application or coercion in assisted suicide.

Medical arguments against assisted suicide include the possibility of misdiagnosis, the potential availability of new treatments, and the probability of incorrect prognosis. Because medicine is fallible and research is ongoing, incorrect diagnoses may result in unnecessary requests for assisted suicide or in requests that are carried out just before the introduction of a new treatment that could prolong life. Another medical argument is that requests for assisted suicide may indicate that improved palliative care, aggressive pain management, and better psychosocial support are needed. Further, there is serious concern that the availability of assisted suicide may create a disincentive to providing appropriate but costly medical treatments or to improving the quality and availability of palliative and hospice care.

In addition, the American Medical Association has asserted that physician-assisted suicide is fundamentally incompatible with the physician's role as healer and that it poses serious societal risks, such as ill persons' feeling abandoned or losing trust in the health care system if providers participate in this practice. Finally, it is argued that physicians are barred from helping persons to die because of the Hippocratic Oath, which states that doctors should not kill.

The argument against assisted suicide regarding safeguards and the slippery slope maintains that once assisted suicide is accepted as an available option for competent terminally ill adults, it may be permitted for ever-larger groups of persons, including the nonterminally ill, those whose quality of life is perceived to be diminished by a physical disability, persons whose pain is emotional instead of physical, and so forth. Critics point to the fact that permitting euthanasia and assisted suicide, as is done in the Netherlands, does not prevent violation of procedures (e.g., failure to report) or abuse (e.g., involuntary euthanasia).

It is further contended that adequate safeguards are not possible. For example, requiring written requests to be repeated over a period of time and witnessed by two unrelated witnesses while at the same time involving at least two physicians and a psychiatrist's or psychologist's examination is unrealistic. Persons at the end of their lives typically have neither the energy nor the ability to meet such conditions. A related argument is that the option of assisted suicide for mentally competent, terminally ill people could give rise to a new cultural norm of an obligation to speed up the dying process and subtly influence end-of-life decisions of all sorts.

### What Experience Teaches: Oregon and the Netherlands

#### *The Oregon Experience*

When controversy surrounds an issue, psychologists have been trained to turn to research and data for enlightenment. However, in the area of assisted suicide, which only recently has been explicitly legalized in the United States in the state of Oregon, there is an understandable dearth of research. Nevertheless, the experience with assisted suicide in Oregon is relevant to

the recommendations in this report. It is, therefore, worth exploring in some depth.

The Oregon Death with Dignity Act states the following:

An adult who is capable, is a resident of Oregon, and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his or her life in a humane and dignified manner in accordance with ORS 127.800 to 127.897. (Task Force to Improve the Care of Terminally Ill Oregonians, 1998, p. 57)

Other sections of the law are designed to provide safeguards for the practice. For example, the written request must be witnessed by two unrelated persons; there must be a consulting physician; the patient must make an informed decision; the attending or consulting physician can request a referral to a licensed psychologist or psychiatrist if they suspect that a psychiatric condition or depression may be causing impaired decision-making; and family notification is recommended.

A study of Oregon's first year of legalized assisted suicide analyzed data for all terminally ill Oregon residents who received prescriptions for lethal medications (Chin et al., 1999; see also Coombs Lee & Werth, in press). A total of 23 persons receiving prescriptions were reported to the Oregon Health Division; 15 died after taking the medications, six died from the underlying illnesses, and two were still alive as of January 1, 1999. The 15 assisted suicides accounted for five out of every 10,000 deaths in Oregon in 1998. Eight of the 15 were male and seven were female, and all were of European American descent. Only four of the candidates had psychological or psychiatric consultations.

The researchers reported that the primary factor cited by the physicians of those who requested assisted suicide was the importance of autonomy and personal control. No person who chose assisted suicide had expressed financial concerns to their doctors, nor was pain associated with the illness cited as a major factor. The researchers concluded that requests for and use of lethal prescriptions to end life were associated with views on autonomy and control rather than fear of pain or economic concerns. The only statistically significant differences between those who died by lethal medication and matched controls were that the former were more likely to be divorced or never married and they were higher in physical functioning.

Advocates for and opponents of assisted suicide have different reactions to these findings. Advocates view these results as evidence that independence and autonomy are strong personal values for persons seeking assisted suicide. Opponents argue that if those persons had better psychosocial support and close caregivers they may not have chosen to die at that time. Advocates also interpreted the difference in physical functioning to demonstrate values of independence and control. Opponents expressed concerns about the influence of internalized negative views concerning physical disabilities and suggested that with more time to adjust to disabilities, as well as better services and less social stigma, these individuals might have chosen to live longer.

There has been criticism of the study and its conclusions on methodological grounds (Foley & Hendin, 1999). All information about the cases was provided by the physicians; thus, there are no data in the study from the individuals who died of assisted suicide or their family members, so there are only anecdotal discussions (e.g., Coombs, Lee, & Werth, in press; Reagan, 1999) of the psychological motivations of the person requesting assisted suicide and the interpersonal cultural context in which the decision to use the Death with Dignity Act developed. Information about the health of patients is limited to diagnosis and prognosis and no data are available regarding the basis on which the physicians made the diagnoses and prognoses. There is no independent way to ascertain how adequately physicians addressed palliative and hospice care options, how thoroughly they assessed the reasons for requests for assisted suicide, or whether they were fully informed about the economic and social circumstances of patients. The report also does not indicate the basis on which physicians referred the four patients for psychiatric or psychological evaluation and what, if any, assessments were conducted following referral.

The report of the second year of the Oregon Death with Dignity Act was released in late February, 2000 (Sullivan et al., 2000a, b). The document updated the 1998 data and provided information for 1999. The analyses for the second year report included 26 people who received prescriptions and used them in 1999 as well as one person who received the medication in 1998 but did not use it until 1999. The median age of these 27 people was 71, 16 were male, 26 were European Americans, and 17 had cancer. All of them had health insurance and 21 were enrolled in hospice prior to death. One person became unconscious before consuming all the prescribed medication and, as a result, took 26 hours to die. Two others took more than 11 hours to die. The relatively long period from when the medication was taken to when death occurred would have been considered a “clinical problem” in the Netherlands (Groenewoud et al., 2000); however, variations in the length of time from ingestion to death are expected (Schnabel & Schnabel, 1998).

The 27 people who died were demographically similar to the people who used the Act in 1998, except they were significantly more likely to be married. These individuals were demographically similar to other Oregonians who died of similar diseases except they were significantly more likely to be college educated. Ten of the 27 people who used the Act had been referred for a mental health evaluation. These 27 people accounted for nine out of every 10,000 deaths in Oregon in 1998.

Similar to 1998, the most frequent concerns recorded by physicians about those who died of assisted suicide were loss of autonomy and decreasing ability to participate in activities that made life enjoyable. The 1999 report also contained the results of interviews with family members of 19 people who died between mid-September, 1998 and mid-October, 1999. These significant others cited individual concerns about losing autonomy, losing control of bodily functions, and physical suffering. Nearly 75% of the family members also volunteered that the dying person wanted to control the time and manner of death.

Another research study related to the Oregon Death with Dignity Act was released at the same time as the second year report. This article examined physicians' experiences with the Act (Ganzini et al., 2000). The researchers reported that their survey of all eligible Oregon physicians

revealed that 144 of the respondents (65% response rate) had received 221 requests for assisted suicide under the Act. Twenty-nine of these individuals received medication and 17 used the prescription to die. Twenty percent had symptoms of depression and none of these received a prescription. Physicians implemented substantive palliative care interventions for 68 patients, 10 of whom eventually used the prescribed medication; 46% of those who received an intervention changed their minds about using the Death with Dignity Act, whereas only 15% of those who did not receive a substantive intervention decided against assisted suicide.

The data contained in the second year report (Sullivan et al., 2000a, b) and in the Oregon physician experience study (Ganzini et al., 2000) are too new to have been broadly examined by proponents and opponents of the Oregon law (see Nuland, 2000). However, just as the data from 1998 were used by both sides of the debate to bolster their arguments, the same process is bound to happen with the new reports.

### *The Netherlands Experience*

A second example of differential interpretation of data concerning assisted suicide is apparent in the research published on assisted suicide and euthanasia in the Netherlands. Before discussing the data, it must first be noted that the policy and practice of assisted suicide, and the context of such practice in the Netherlands, are different from those of assisted suicide in the United States (Griffiths, Bood, & Weyers, 1998). Unlike the United States, both assisted suicide and euthanasia are decriminalized and permissible in the Netherlands under prescribed circumstances. Also, in the Netherlands, there is universal health coverage; the population is more homogeneous, with a smaller range of cultural diversity; and family doctors have typically known their patients for long periods of time. Thus, it is difficult to generalize from Dutch policy and practice to the situation in the United States. However, with these differences in mind, it is useful to examine the data from the Netherlands.

A 1991 article summarized the findings of a nationwide study of physicians reporting on their practice of assisted suicide and euthanasia in the Netherlands (van der Maas, van Delden, Pijnenborg, & Looman, 1991). This report indicated that out of the roughly 130,000 deaths that occurred in the Netherlands in 1990, 2300 (1.8%) were the result of euthanasia. Another 400 (0.3%) were assisted suicides. The report found that in the 2700 cases reviewed, the medical guidelines were met. This means that the patients were mentally competent adults who were suffering without alternatives and who requested assisted suicide or euthanasia voluntarily, consistently, and repeatedly over a reasonable time. The requests were documented. According to the reporting physicians, the patients were suffering intolerably with no prospect of relief and the primary doctors consulted with another physician not involved in the case. However, the report also noted that there were an additional 1,000 deaths (0.8%) caused by euthanasia in which the patient was not concurrently competent, a clear violation of the guidelines. About a quarter of the physicians admitted causing death without an explicit request.

Opponents of assisted suicide in the United States point out that data that is based on physician's reports is unreliable. They also argued that the deaths of the 1000 people who were not concurrently competent was evidence that the slippery slope is occurring. They suggested that further erosion of the guidelines could occur, resulting in involuntary euthanasia being

performed on older adults, persons with disabilities, and adults who were not mentally competent (Gomez, 1991; see also Angell, 1996).

Proponents of assisted suicide, referring to the same data, pointed out that the results showed a very cautious use of euthanasia and assisted suicide, accounting for only a small fraction of the total deaths. Moreover, only one in three people who requested assisted suicide and euthanasia were granted it, which did not indicate any great trend on the part of physicians to accede to such requests. With regard to the 1,000 persons who died from euthanasia without any consent, interviews with the attending doctors indicated that over half had earlier stated a desire for euthanasia and that most were "moribund" at the time euthanasia was performed, so that these were cases of euthanasia without concurrent consent (i.e., nonvoluntary) rather than euthanasia without any consent (i.e., involuntary).

A follow-up study, completed in 1995, focused on two issues. The first was whether a slippery slope existed with regard to medical care at the end of life (van der Maas et al., 1996). The second concerned the efficacy of a new notification procedure designed to enable better monitoring of euthanasia and assisted suicide that became law in 1994 (van der Wal et al., 1996). The authors of the first report concluded that there was little evidence of a slippery slope occurring. Dutch doctors seemed to "continue to practice physician-assisted dying only reluctantly and under compelling circumstances" (Angell, 1996, p. 1677). The notification procedures, however, had only partial success. The numbers of reported physician-assisted deaths increased but doctors found the procedures unduly difficult and were still concerned about the legal status of admitting to euthanasia.

Critics of assisted suicide in the U.S. have challenged the findings of the second study. They disagreed with the conclusion that there is no evidence that "physicians in the Netherlands are moving down a slippery slope" (Hendin, Rutenfrans, & Zylicz, 1997, p.1720). They pointed out that

in the past two decades, the Netherlands has moved from considering assisted suicide . . . to giving legal sanction to both physician-assisted suicide and euthanasia; from euthanasia for terminally ill patients to euthanasia for those who are chronically ill; from euthanasia for physical illness to euthanasia for psychological distress; and, from voluntary euthanasia to nonvoluntary and involuntary euthanasia. (p. 1720)

These opponents of assisted suicide also reanalyzed the data and showed an increase over time in the estimated number and percentage of deaths caused by active physician intervention.

Thus, the results of the same study have been interpreted in widely different ways depending on the point of view of those studying the data. As was the case with the Oregon data, the meaning and implications of the Netherlands data have varied.

#### *Other Related Studies*

In addition to research conducted where assisted suicide is legal or decriminalized (e.g., Oregon and the Netherlands), there have been other studies conducted where the practice

continues to be illegal. Predictably, only a few involved terminally ill people who actually died as a result of assisted suicide. These studies (Back et al., 1996; Canetto & Hollenshead, 1999; Preston & Mero, 1996) indicate that pain plays a minor role in the reasons why people die by assisted suicide; factors such as concerns about loss of control, perceived loss of dignity or sense of self, and suffering other than physical pain appear to be crucial issues (Wilson et al., 1998).

Some investigations on end-of-life decisions have included people who are terminally ill (Breitbart, Rosenfeld, & Passik, 1996; Brown, Henteleff, Barakat, & Rowe, 1986; Chochinov, Wilson, Enns, & Lander, 1998; Chochinov et al., 1995; Ganzini et al., 1998; Rabkin, Remien, Katoff, & Williams, 1993; Suarez-Almazor, Belzile, & Bruera, 1997; Wilson et al., in press). The results of several of these studies reveal that high levels of clinical depression and hopelessness, low perceived levels of social support, the perception that suffering is inevitable, and the perception of being a burden are associated with increased interest in assisted suicide or a desire to die. Similarly, some studies of chronically, but not necessarily terminally, ill individuals (e.g., Emanuel, Fairclough, Daniels, & Clarridge, 1996) have found that depression is an important influence on the desire for assisted suicide whereas others (e.g., Sullivan, Rapp, Fitzgibbon, & Chapman, 1997) have found that symptom level is more important than the degree of depression in determining the acceptability of assisted suicide. Furthermore, some research has revealed that concerns about costs (together with age and depression) can influence a person's decision to give up on life-extending measures (e.g., Covinsky et al., 1996). A retrospective study of Dr. Kevorkian's cases also showed that general psychological distress and concerns about being a burden were common among the women who died with his assistance (Canetto & Hollenshead, 1999).

There have been a few investigations of the impact of assisted suicide on significant others (Cooke et al., 1998; Jamison, 1995; Ogden, 1994). This research indicates that loved ones of people who have died by assisted suicide are not necessarily traumatized by their awareness of or involvement in the actions that lead to death. Rather, it appears as though concern about legal repercussions can lead to significant anxiety, and that trauma can occur if loved ones felt obligated to take an active role in the death in unanticipated ways because the planned method was unsuccessful.

Research involving health care professionals is also relevant to this discussion (the *Resource Guide* will contain a review of surveys of attitudes of health care providers about assisted suicide). For example, some evidence suggests that physicians tend to under-recognize depression (Conwell & Caine, 1991; Peruzzi et al., 1996). In addition, primary care physicians underestimate older persons' preferences for life-extending care while hospital-based physicians (emergency and critical care physicians), like family surrogates, overestimate older persons' preferences for life-extending care (Coppola, Ditto, Danks, & Smucker, in press). In addition, there are data indicating that physicians' training and experience with serious medical illness affects their perception of the desirability of different options. Specifically, clinicians with the least exposure to seriously ill and dying patients are more willing to endorse assisted suicide and/or euthanasia than oncologists; this is also true for social workers, compared to nurses (Bachman et al., 1996; Portenoy et al., 1997). Other factors that contribute to greater willingness to support assisted suicide are a limited knowledge of pain management (Portenoy et al., 1997) and a conservative attitude toward resource use (Sulmasy, Linas, Gold, & Schulman, 1998).

Finally, there is evidence to suggest that the majority of those willing to serve as consultants to evaluate a person's competence for assisted suicide favor the practice (Fenn & Ganzini, 1999; Ganzini, Fenn, Lee, Heintz, & Bloom, 1996). This may be the result of the fact that many health professionals who are opposed report that they would refuse to participate in the process. Bias in the mental competence evaluation may result, because those who support assisted suicide as an option may be more willing to find a dying person's judgment to be unimpaired while opponents indicate that even if they found the person's judgment to be unimpaired, they would attempt to prevent the person from receiving assisted suicide.

### Conclusion

*Reasonable and well-informed people come to different conclusions on the meanings and implications of the data concerning assisted suicide. These positions grow out of different philosophies, value systems, and life experiences, and each can represent high levels of moral development. Individuals may strongly oppose or support assisted suicide, believing that it is the appropriate position of compassionate and socially responsible citizens. Both proponents and opponents of assisted suicide agree that there are costs and benefits to permitting versus banning the practice. However, they differ in their assessment of these relative costs and benefits. Furthermore, the current state of understanding of all of the issues surrounding assisted suicide is incomplete. The data that do exist are far from definitive and the lack of consensus on the interpretation of these data contribute to the differences in opinion about assisted suicide. Finally, there currently is no way of identifying the sequelae of legalizing assisted suicide in the United States, which remains a diverse culture with unequal access to medical care. Given the current state of the discourse on assisted suicide, it seems premature for the discipline of psychology to take a stand supporting or opposing assisted suicide.*

### Recommendations

*The Working Group, like similar committees formed by other associations, found a variety of views about assisted suicide represented in its membership. There will inevitably be similar differences of opinion in the general membership of the APA. Thus, recommending a position that either endorsed or opposed assisted suicide would not reflect the opinion of the Working Group nor of psychologists as a whole. The Working Group therefore recommends that the APA:*

- 1. Take a position that neither endorses nor opposes assisted suicide at this time;*
- 2. Take an active role in monitoring legal, policy, and research developments; support research concerning the effects of assisted suicide on individuals with terminal illnesses, survivors, health care providers, and society in general; and support education and training for psychologists in areas that are critical to assisted suicide;*
- 3. Be prepared to revise its official statement regarding assisted suicide periodically as appropriate;*

*4. Pass a resolution expressing the foregoing recommendations (see Appendix E for a draft resolution offered by the Working Group for consideration).*

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## APPENDIX A

### Resource Guide Outline

The Resource Guide is intended to be a companion document to the *Report to the Board of Directors from the Working Group on End-of-Life Decisions and Assisted Suicide (Report to the Board)*. It is divided into nine chapters, each of which provides more depth coverage than was possible in the original *Report to the Board*. Each chapter includes an introduction and overview of the material, a summary of the empirical research with an emphasis on synthesizing the information, and a summary and conclusion section that explicates the implications for psychologists in their roles as clinicians, educators, researchers, and/or policy advocates.

After the nine chapters, there is a set of references, a glossary of terms used in discussing end of life decision-making, a list of Advisory Committee Members who provided feedback on an earlier version of the document, a list of resources, and an annotated bibliography.

Chapter One is designed as an provide a foundation for the rest of the guide. It provides an introduction, a discussion of the historical context within which death has occurred, and an overview of recent key developments related to end-of-life decisions.

#### I. Chapter One--Introduction and Overview

##### A. Introduction

1. Formation of Working Group on Assisted Suicide and End-of-Life Decisions
2. Description of the Working Group's *Report to the Board of Directors*
3. Organization of the Resource Guide
4. Scope of the Resource Guide

##### B. Historical Context

1. Demographic Changes
2. Changes in Medicine and Technology
3. Changes in Place and Causes of Death
4. Shifts in Attitudes Toward Healthcare

##### C. Overview of Key Recent Developments

1. Oregon
2. Supreme Court Cases
3. United States Congress

Chapter Two reviews the context in which end-of-life decisions in the United States are made. It begins with a review of the cultural considerations that affect end-of-life decision-making, then discusses how differential issues of access and the involvement of others are important at the end-of-life, and concludes with an overview of seven different end-of-life decisions.

#### II. Chapter Two--The Current Context of Death

##### A. Cultural Considerations

1. General Issues

2. Longevity Among Various Sub-Groups
3. Health Overview
4. Health Care
5. Marital Status as a Mediator of Longevity
6. Finances as a Mediator of Longevity
7. Education as a Mediator of Longevity
- B. Issues of Access
- C. Involvement of Others
- D. Examining the Full Array of End-of-Life Decisions
  1. Advance Directives
  2. Decisions About When Care is Futile
  3. Voluntarily Stopping Eating and Drinking
  4. Withholding or Withdrawing Treatment
  5. Aggressive Palliative Care
    - a. Double Effect
    - b. Terminal Sedation
  6. Assisted Suicide
  7. Euthanasia

Chapter Three is designed to provide an overview of the experience of dying. The chapter reviews generic issues of loss and trauma, important elements for assessment and intervention, and three types of models for the experience of dying. It then describes the experience of the dying person, followed by the experiences of significant others, and concludes with a review of physical and psychological issues that may be faced by both the person who is dying and this individual's loved ones.

### III. Chapter Three--The Experience of Dying

- A. Generic Issues of Loss and Trauma
  1. Types of Loss
  2. Grief and Mourning
  3. The Course of Bereavement
  4. Anticipatory and Preparatory Mourning
  5. Traumatic Stress
- B. Influencing Factors: Critical Elements for Assessment and Intervention
  1. Psychological Factors
  2. Social Factors
  3. Physiological Factors
  4. Quality of Life
- C. Psychological Models of Experience of Dying
  1. The Stage Model
  2. The Task Model
  3. Continuing Bonds Model
- D. The Dying Person's Experience
  1. Types of Death
  2. The Living-Dying Interval
  3. The Dying Trajectory

- 4. Denial and Acceptance, Control, Suffering, and Hope
- E. Family, Significant Others, and Caregivers
  - 1. Societal and Cultural Influences on the Family
  - 2. Coping with a Loved One's Terminal Illness
  - 3. Post-Death Coping
- F. Physiological/Psychological Issues
  - 1. Experiences in the Medical System
  - 2. Changes in Perception of Self
  - 3. Pain and Suffering
  - 4. Cognitive Changes
  - 5. Psychosocial Developments

Chapter Four provides a discussion of controversial end-of-life decisions -- assisted suicide and euthanasia. After an overview and a review of legal considerations there is a summary of the research and experiences with assisted suicide and euthanasia both in the United States and in other countries.

#### IV. Chapter Four--Controversial End-of-Life Decisions

- A. Overview
  - 1. Definitions
  - 2. Controversies
- B. Legal Considerations
- C. Research and Experience with Assisted Suicide and Euthanasia
  - 1. The Oregon Experience
  - 2. Research from Other Parts of the United States
  - 3. The Netherlands' Experience
  - 4. Assisted Suicide in Australia
  - 5. The Experience in Other Countries
  - 6. Difficulties in Interpreting Data
    - a. Methodological Issues
    - b. Variety of Assumptions and Perspectives
  - 7. Open Questions

Chapter Five reviews the research that has been done on attitudes about end-of-life issues. Data from members of the general public, older adults, people who are ill, and caregivers are provided. This material is then analyzed and interpretations are provided, given the limitations in the data.

#### V. Chapter Five--Attitudes About End-of-Life Issues

- A. General Public
- B. Older Adults
- C. People Who are Ill
- D. Caregivers
- E. Analysis and Interpretation
  - 1. Methodological Problems

## 2. Diversity Issues

Chapter Six gives an overview of issues for health care and mental health providers, including cultural aspects of the care system, financial matters, and ethical and legal constraints.

### VI. Chapter Six--Provider Issues

#### A. Issues for Health Care Professionals

1. Training and Culture
2. Attitudes
3. AMA's Positions on Various End-of-Life Decisions

#### B. Health Care System

1. Reimbursement Issues
2. Priorities
3. Responsiveness to Changing Demographics

#### C. Mental Health Professionals

1. Ethical and Legal Issues
  - a. Case Law
  - b. State Statutes
  - c. APA Code of Ethics
2. Attitudes
3. Experience and Education

Chapter Seven delves more deeply into practice issues confronting psychologists. Emphasis is placed on issues that need to be considered for assessment when end-of-life decisions are being discussed and other considerations for psychologists who are providing clinical services to people who are dying and their loved ones.

### VII. Chapter Seven--Practice Issues for the Psychologist

#### A. Assessment of End-of-Life Decisions

1. Diagnosable Mental Disorders
  - a. General Factors to Consider
  - b. Anxiety Disorders
  - c. Clinical Depression and Other Mood Disorders
  - d. Delirium and Dementia
  - e. Personality Disorders
  - f. Substance Abuse
2. Other Mental Health Issues
  - a. Autonomy/Control
  - b. Capacity to Make Decisions and to Give Informed Consent
  - c. Existential Issues and Spiritual Beliefs
  - d. Hopelessness
  - e. Mourning/Grief/Loss
  - f. Underlying Psychological Issues
3. Interpersonal/Environmental Issues

- a. Being a Burden
- b. Cultural Factors
- c. Financial Variables
- d. Presence/Absence of Significant Others
- e. Pressure/Coercion
- 4. Issues to Consider When Exploring End-of-Life Decisions
  - a. Preliminary General Considerations
  - b. Overview of Issues for Consideration
  - c. Role of the Psychologist after the Review is Complete
  - d. Use of Instruments when Reviewing End-of-Life Decisions
- B. Providing Clinical Services
  - 1. Content
  - 2. Objectives for Intervention
  - 3. Necessary Perspectives
  - 4. Addressing Spiritual and Existential Issues/Values Clarification
  - 5. Couple/Family/Group Counseling
- C. Other Important Clinical Roles
  - 1. Advocate
  - 2. Consultation-Liaison Professional
  - 3. Educator
  - 4. Multidisciplinary Team Member

Chapter Eight provides a discussion of three major areas: Education, research and policy. The first section reviews how end-of-life issues can be incorporated into undergraduate, graduate, and post-graduation education and training. The second section provides a set of research issues for psychologists who want to explore end-of-life issues through empirical work. The final section reviews how individual psychologists, state psychological associations, and the APA can influence policy on these matters.

## VIII. Chapter Eight--Education, Research, and Policy Issues

- A. Education and Training Issues
  - 1. Undergraduate
  - 2. Graduate
  - 3. Post-Doctorate and Continuing Education
  - 4. Learning from Other Disciplines
- B. Research Issues for Psychologists
  - 1. Ethical Considerations
  - 2. Methodological Considerations
  - 3. Key Areas of Need
    - a. The Dying Individual
      - 1) Psychopathology and the Desire for Death
      - 2) Assessment
      - 3) Ways of Dying
      - 4) Involvement of Psychologists
    - b. Intimate Network
    - c. Creation of New Outcomes Measures for Assessing Efficacy of Psychologists'

## Involvement

4. Policy Issues for Psychologists
  - a. Individual Psychologists
  - b. State Psychological Associations
  - c. American Psychological Association

Chapter Nine provides conclusions and recommendations for psychology as a discipline and for individual psychologists.

## IX. Chapter Nine--Conclusions and Recommendations

- A. Conclusions for Psychology as a Discipline
- B. Recommendations for the APA Contained in the *Report to the Board of Directors*
- C. Conclusions for Individual Psychologists
- D. Recommendations for Psychologists Working in Areas Associated with the End of Life

## X. References

## XI. Glossary

## XII. Appendix A: Advisory Committee Members Who Provided Feedback

## XIII. Appendix B: Resource List

## XIV. Appendix C: Annotated Bibliography

## APPENDIX B

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## APPENDIX C

### Glossary

**Advance care directives** (or simply advance directives) are written documents meant to make explicit the conditions under which individuals expect to wish to receive certain treatment or to refuse or discontinue life-sustaining treatment, in the event that they are no longer legally competent to make their own decisions.

A **durable power of attorney** (sometimes referred to as a health-care proxy) is a form of advance directive that designates an individual who can make decisions if the dying person is no longer competent to do so.

A **living will** is a form of advance directive that specifies in writing what kinds of treatment are and are not wanted.

**Aggressive pain management** is an essential component of palliative care intended to provide relief from physical suffering at the end of life.

The **double effect** is a term given to the practice of providing large doses of medication to relieve pain even if the unintended effect of such medication may be to hasten death.

**Terminal sedation** is the term given to the practice of administering sufficient pain medication to render a dying person who is suffering severe, intractable pain unconscious (i.e. to induce an artificial coma). Generally, artificial nutrition and hydration are also withheld or withdrawn, and the state of unconsciousness is maintained until death occurs.

**Assisted suicide** refers to the situation in which persons request the help of others, in the form of access to information or means, the means, and/or actual assistance, in order to end their own lives.

**Physician-assisted suicide** refers to cases in which a physician deliberately and knowingly helps an individual to die (American Association of Suicidology, 1996).

**Euthanasia** generally refers to situations whereby someone intentionally takes a person's life with stated intent to alleviate or prevent perceived suffering (American Association of Suicidology, 1996).

**Active euthanasia** is the practice of shortening an individual's life by taking a lethal action such as administering a lethal dose of medication with the intent to hasten death. It is illegal in the United States.

**Passive euthanasia** is an older name given to withholding or withdrawing life-sustaining treatment that could otherwise prolong life. The term is no longer in wide use in the United States.

**Voluntary euthanasia** occurs when a competent dying individual has given voluntary, informed consent to actions that will result in death.

**Nonvoluntary euthanasia** occurs when a person, who is not currently capable of giving consent to actions that will result in death, receives such actions. It applies to situations when death by euthanasia is believed to be consistent with the person's prior wishes.

**Involuntary euthanasia** occurs in situations in which the euthanasia is carried out without consent or against the will of the recipient. Active euthanasia of all kinds is illegal in the United States, and all involuntary euthanasia, whether passive or active, could lead to charges of homicide.

**Hastened death** is an inconsistently defined term meaning to end one's life earlier than would have happened without intervention. Some use it to refer to assisted suicide and euthanasia only. Others, however, include in this category withholding and withdrawing treatment, death caused by aggressive pain management, and voluntary cessation of eating and drinking.

**Hospice** refers to programs that focus on quality of life for dying persons. The first modern hospice, St. Christopher's Hospice in London, was founded by Dr. Cicely Saunders in 1967. The defining components of the hospice approach are as follows (Lattanzi-Licht & Connor, 1995, p. 145):

- The patients and family are the unit of care.
- A comprehensive, holistic approach is taken to meet the patient's physical, emotional, social, and spiritual needs, including major attention to effective symptom control and pain management.
- Care is provided by an interdisciplinary team, which includes medical supervision and use of volunteers.
- The patient is kept at home or in an inpatient setting with a homelike environment where there is coordination and continuity of care.

- In addition to regularly scheduled home care visits, services are available on a 24-hour, 7 day-a-week, on-call basis.
- The focus of care is on improving the quality of remaining life; that is, on palliative, not curative, measures.
- Bereavement follow-up services are offered to family members in the year after the death of their loved one.

**Palliative care** refers to the type of care an individual may receive at the end of life after it becomes obvious that no cure is possible. The World Health Organization (1990) stated that good palliative care:

- Affirms life and views dying as a normal process;
- Neither hastens nor postpones death;
- Provides relief from pain and other distressing symptoms;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death; Offers a support system to help family members cope during a patient's illness and during their own bereavement.

The **Patient Self-Determination Act** (Omnibus Budget Reconciliation Act, 1990) is a bill passed by Congress that requires all hospitals, HMO's, hospice, and extended care nursing homes participating in Medicare or Medicaid to ask all adult inpatients if they have advance directives, to document their answers, and to provide information on related state laws and hospital policies.

**Withholding or withdrawing life-sustaining treatment** is an ethically and legally accepted practice that may be specified in advance care directives. It permits patients to forego or terminate life-sustaining equipment such as ventilators, dialysis machines, feeding tubes for artificial nutrition and intravenous fluids for hydration, and the sophisticated technology of the intensive care unit. In addition, it allows for aggressive treatments to be foregone or terminated (e.g. chemotherapy or radiation therapy except for comfort care, antibiotics, certain anti-seizure medications, or anti-inflammatory agents that control brain swelling).

The **Do Not Resuscitate request** is a form of withholding life-sustaining treatment that requires that no attempt be made to revive a person who has died.

**Voluntary cessation of eating and drinking**, sometimes referred to as voluntary stopping of eating and drinking, is a form of withholding or withdrawing life-sustaining treatment. Some individuals near the end of life who wish to die several days to a few weeks sooner than would happen naturally may choose it. During this time palliative care may be provided to keep the person comfortable during the time it takes for death to occur from the underlying disease (Miller & Meier, 1998).

## APPENDIX D

### Resolution on End-of-Life Issues and Care

1 Whereas the nature of dying and death has changed across the twentieth century, occurring  
2 primarily in an institutional setting rather than at home (Benoliel & Degner, 1995); and  
3

4 Whereas death has become more frequently the result of chronic illness (Battin, 1996); and  
5

6 Whereas medicine and technology have evolved to the point where the terminal period can be  
7 significantly prolonged (Field & Cassel, 1997); and  
8

9 Whereas there are many more people living longer with terminal diagnoses and thus having more  
10 time to make end-of-life decisions; and  
11

12 Whereas end-of-life decision-making is complex, involving areas of ethics, religion, medicine,  
13 psychology, sociology, economics, the law, public policy, and other fields; and  
14

15 Whereas the population of the United States is aging, resulting in larger numbers of people who  
16 may request psychological support in making end-of-life decisions; and  
17

18 Whereas in the United States there is significant social stratification related to cultural, ethnic,  
19 economic, and religious differences; and  
20

21 Whereas this diversity in our society leads to an equally diverse range of views regarding  
22 end-of-life care and decisions;  
23

24 Whereas reasonable, well-informed people starting from different values and priorities  
25 concerning what is valuable at the end of life can and do hold different positions regarding  
26 end-of-life care and decisions; and  
27

28 Whereas autonomy is an important guiding principle in the law and in medical, ethical, and  
29 psychological aspects of decision-making, but in and of itself is insufficient to capture the full  
30 range of complex medical, familial, social, financial, psychological, cultural, spiritual, and legal  
31 issues involved in end-of-life decision-making; and  
32

33 Whereas there is increasing public support for control over end-of-life decisions but this support  
34 is weakest among groups who express concerns about being pressured to die (i.e., older adults,  
35 people with less education, women, and ethnic minorities) (Blendon, Szalay, & Knox, 1992); and  
36

37 Whereas in the United States medical end-of-life decisions are made in a context of serious  
38 social inequities in access to resources such as basic medical care; and  
39

40 Whereas some evidence suggests that there are fluctuations in the will to live (Chochinov,  
41 Tataryn, Clinch, & Dudgeon, 1999) and in wishes regarding life-sustaining treatments  
42 (Weisman, Haas, & Fowler, 1999); and

43 Whereas pain and clinical depression are frequently under-treated, which can lead to suffering  
44 that may result in requests for, or assent to, medical interventions that affect the timing of death  
45 (Foley, 1995); and

46  
47 Whereas more people are aware of the possible benefits to be gained by using psychological  
48 services to help them make end-of-life decisions; and

49  
50 Whereas psychology has been largely invisible in the end-of-life arena; and

51  
52 Whereas psychologists have many areas of competence, including assessment, counseling,  
53 teaching, consultation, research, and advocacy skills that could potentially contribute to the  
54 science of end-of-life care and to the treatment and support of dying persons and their significant  
55 others; and

56  
57 Whereas psychological research on end-of-life issues is limited in comparison with the  
58 magnitude of the issue; and

59  
60 Whereas there have been no systematic efforts to educate psychologists about end-of-life issues;  
61 and

62  
63 Whereas psychologists in clinical practice have not typically been involved in end-of-life  
64 decisions to the degree that they could be; and

65  
66 Whereas psychologists could assume a significant role in helping health care providers to  
67 understand and cope with the concerns and needs of dying individuals and their families; and

68  
69 Whereas psychologists could be instrumental in supporting public education efforts to raise  
70 awareness of issues related to dying, death, grief, mourning, and loss;

71  
72 Therefore, be it resolved that the American Psychological Association, an organization  
73 committed to promoting the psychological well-being of individuals across the life span, should  
74 redress psychology's historical under-commitment to end-of-life care by actively promoting and  
75 supporting psychology's involvement in end-of-life care. In order to advance this involvement,  
76 be it further resolved that the American Psychological Association:

77  
78 Promote and encourage research and training in the area of end-of-life issues within psychology  
79 programs at all levels; and

80  
81 Encourage and promote the development of a research agenda on end-of-life issues; and

82  
83 Support efforts to increase funding for research associated with end-of-life issues; and

84  
85 Promote and facilitate psychologists' acquisition of competencies with respect to end-of-life  
86 issues, including mastery of the literature on dying and death and sensitivity to diversity  
87 dimensions that affect end-of-life experiences; and

88

89 Encourage practicing psychologists to be aware of their own views about the end of life,  
90 including recognizing possible biases about entitlement to resources based on disability status,  
91 age, sex, or ethnicity of the client making end-of-life decisions; and

92  
93 Encourage psychologists to be especially sensitive to the social and cultural biases which may  
94 result in some groups and individuals being perceived by others, and/or being encouraged to  
95 perceive themselves, as more expendable and less deserving of continued life (e.g., people with  
96 disabilities, women, older adults, people of color, gay men, lesbians, bisexual people,  
97 transgendered individuals, and persons who are poor); and

98  
99 Support interdisciplinary efforts to increase the competency of psychologists and other health  
100 care professionals in end-of-life issues; and

101  
102 Promote quality end-of-life care including palliative care, access to hospice services, support for  
103 terminally ill people and family members, accurate assessment of depression and cognitive  
104 capabilities of dying persons, and assistance with end-of-life decision-making; and

105  
106 Advocate for access to, and reimbursement for, professional mental health services for seriously  
107 ill individuals and their families; and

108  
109 Promote and support public policies that provide for the psychosocial services for dying  
110 individuals and their families; and

111  
112 Support psychologists who wish to participate in ethics committees dealing with end-of-life  
113 issues; and

114  
115 Support practicing psychologists as they work cooperatively with caregivers, medical providers,  
116 and multidisciplinary teams to enhance understanding of the psychological aspects of dying and  
117 death and to improve quality of care for the dying; and

118  
119 Endorse the following principles on end-of-life care as articulated in the Institute of Medicine  
120 Report entitled *Approaching Death: Improving Care at the End of Life* (Field & Cassel, 1997):

121  
122       ▪ Care for those approaching death is an integral and important part of health care;

123  
124       ▪ Care for those approaching death should involve and respect both patients and  
125 those close to them;

126  
127       ▪ Good care at the end of life depends on clinicians with strong interpersonal skills,  
128 clinical knowledge, technical proficiency, and respect for individuals, and it should be  
129 informed by scientific evidence, values, and personal and professional experience;

130  
131       ▪ The health community has a special responsibility for educating itself and others  
132 about the identification, management, and discussion of the last phase of fatal medical  
133 problems;

134

- 135           ▪       More and better research [in the areas of biomedical, clinical, psychosocial, and  
136 health services] is needed to increase our understanding of clinical, cultural,  
137 organizational, and other practices or perspectives that can improve care for those  
138 approaching death;  
139
- 140           ▪       Changing individual behavior is difficult, but changing a culture or an  
141 organization is potentially a greater challenge -- and often is a precondition for  
142 individual change.

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# APPENDIX E

## Resolution on Assisted Suicide

1 Whereas the issue of assisted suicide is complex, involving areas of ethics, religion, medicine,  
2 psychology, sociology, economics, the law, public policy, and other fields; and  
3

4 Whereas in the United States there is significant social stratification related to cultural, ethnic,  
5 economic, and religious differences; and  
6

7 Whereas these differences in our society are associated with an equally diverse range of views  
8 regarding assisted suicide; and  
9

10 Whereas in the United States decisions about assisted suicide are made in the context of serious  
11 social inequities in access to resources such as basic medical care; and  
12

13 Whereas autonomy is an important guiding principle in the law and in psychological and medical  
14 aspects of decision-making, but in and of itself is insufficient to capture the full range of  
15 complex medical, familial, social, financial, psychological, cultural, spiritual, and legal issues  
16 involved in the practice of assisted suicide; and  
17

18 Whereas there is increasing public support for assisted suicide, but this support is weakest among  
19 groups who express concerns about being pressured to die (i.e., older adults, people with less  
20 education, women, and ethnic minorities) (Blendon, Szalay, & Knox, 1992); and  
21

22 Whereas reasonable, well-informed people starting from different positions about costs and gains  
23 associated with assisted suicide disagree about the potential effects of legalizing the practice; and  
24

25 Whereas people with different values and priorities can reach different conclusions about the  
26 advisability of assisted suicide; and  
27

28 Whereas some evidence suggests that there are fluctuations in the will to live (Chochinov,  
29 Tataryn, Clinch, & Dudgeon, 1999) and in wishes regarding life-sustaining treatments  
30 (Weisman, Haas, & Fowler, 1999); and  
31

32 Whereas pain and clinical depression are frequently under-treated, which can lead to suffering  
33 that may result in requests for assisted suicide (Foley, 1995); and  
34

35 Whereas evidence suggests that some people rescind their requests for assisted suicide when they  
36 receive more aggressive and comprehensive care (Ganzini et al., 2000); and  
37

38 Whereas psychological, familial, social, and financial factors seem to be more important than  
39 physical factors in requests for assisted suicide (Breitbart, Rosenfeld, & Passik, 1996; Emanuel,  
40 Fairclough, Slutsman, & Emanuel, 2000; Sullivan, Hedberg, & Fleming, 2000); and  
41  
42

43 Whereas little empirical data exist to determine the effects of assisted suicide on survivors and  
44 on society (Cooke et al., 1998); and  
45  
46 Whereas the empirical database, legal developments, and policy discourse related to assisted  
47 suicide are evolving rapidly;  
48  
49 Therefore, be it resolved that the American Psychological Association take a position that neither  
50 endorses nor opposes assisted suicide at this time.  
51  
52 However,  
53  
54 Given that psychologists have many areas of competence, including assessment, counseling,  
55 teaching, consultation, research, and advocacy skills that could potentially enlighten the  
56 discourse about assisted suicide, end-of-life treatment, and support for dying persons and their  
57 significant others; and  
58  
59 Given that psychologists could be instrumental in helping health care providers to understand  
60 and cope with the concerns and needs of dying individuals and their families; and  
61  
62 Given that practicing psychologists may receive requests to be involved in the education of  
63 various groups regarding assisted suicide; and  
64  
65 Given that there is one state in which assisted suicide is legal and psychological or psychiatric  
66 assessment and consultation is required under certain circumstances; and  
67  
68 Given that practicing psychologists may be part of multidisciplinary end-of-life care teams  
69 including ones exploring requests for assisted suicide;  
70  
71 Let it be further resolved that the American Psychological Association will assist in preparing the  
72 profession to address the issue of assisted suicide by taking the following actions:  
73  
74 Advocate for quality end-of-life care for all individuals; and  
75  
76 Encourage and promote the development of research on assisted suicide; and  
77  
78 Monitor legal, policy, and research developments that may require or encourage psychologists to  
79 involve themselves in assisted suicide cases; and  
80  
81 Promote policies that reduce suffering that could lead to requests for assisted suicide; and  
82  
83 Promote psychologists' involvement in research on ethical dilemmas faced by clinicians and  
84 researchers dealing with issues related to assisted suicide; and  
85  
86 Promote psychologists' participation in multidisciplinary teams and ethics committees involved  
87 with reviewing end-of-life requests; and  
88

89 Encourage practicing psychologists to inform themselves about criminal and civil laws that have  
90 bearing on assisted suicide in the states in which they practice; and  
91  
92 Encourage practicing psychologists to recognize the powerful influence they may have with  
93 clients who are considering assisted suicide; and  
94  
95 Encourage practicing psychologists to be aware of their own views about assisted suicide,  
96 including recognizing possible biases about entitlement to resources based on disability status,  
97 age, sex, or ethnicity of the client requesting assisted suicide; and  
98  
99 Encourage psychologists to be especially sensitive to the social and cultural biases which may  
100 result in some groups and individuals being perceived by others, and/or being encouraged to  
101 perceive themselves, as more expendable and less deserving of continued life (e.g., people with  
102 disabilities, women, older adults, people of color, gay men, lesbians, bisexual people,  
103 transgendered individuals, and persons who are poor); and  
104  
105 Encourage practicing psychologists to identify factors leading to assisted suicide requests  
106 (including clinical depression, levels of pain and suffering, adequacy of comfort care, and other  
107 internal and external variables) and to fully explore alternative interventions (including  
108 hospice/palliative care, and other end-of-life options such as voluntarily stopping eating and  
109 drinking) for clients considering assisted suicide.

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## APPENDIX F

### Issues to Consider When Exploring End-of-Life Decisions

Many factors can impact the decisions people make at the end of life. Below is a categorized list of issues that have been identified in the literature as potentially influencing what particular decisions are made and the process by which such options are selected. The following should be considered a general outline of what a psychologist may want to explore when faced with a person who is trying to make an end-of-life decision, such as voluntarily stopping eating or drinking, withholding or withdrawing treatment, or receiving assisted suicide. No definitive guidelines for assessment in the terminal stages of life have been established and endorsed by a nationally recognized organization. Further, the material below is based on theory, anecdote, and clinical experience – it is not empirically based and needs to be researched and validated. There are some who would therefore argue that mental health professionals should not engage in anything that appears like an “evaluation” because the issues listed below and the manner in which they are explored are socially constructed. Therefore, the list below should not be interpreted as being prescriptive or as a standard of care. Nor should it be used to evaluate the adequacy of an “assessment” undertaken by a clinician.

The outline is based on a variety of sources in the literature (Block & Billings, 1998; Emanuel, 1998; Farberman, 1997; Farrenkopf & Bryan, 1999; Goldblum & Martin, 1999; Jamison, 1997; Miller, Hedlund, & Murphy, 1998; Muskin, 1998; National Association of Social Workers, 1994; Sanson et al., 1998; Veterans Affairs National Center for Cost Containment, 1997; Werth, 1999b; Werth, Benjamin, & Farrenkopf, in press; Werth & Gordon, 1998). Note that the process described is quite comprehensive and not every component will be relevant to each situation. It is also important to note that some authors (e.g., Sullivan, Ganzini, and Youngner, 1998) have been critical of a mental health professional merely assessing capacity for assisted suicide, and therefore acting as a “gatekeeper”. Therefore, clinicians may want to view their role as helping to determine if the person has impaired judgment, not merely whether she or he has capacity to make health care decisions.

It should be emphasized that the following process is designed to be used with a wide variety of end-of-life decisions, not just those involving a decision that may affect the timing of death. For example, dying individuals will need to make decisions about what they want to say to other people; whom they want at their side during the dying process; what they want in their wills; whether they want someone to have durable power of attorney for health care for them and, if so, who; how they want to structure their final days; and so forth. Note that the list of ideas for how to proceed is focused on reviewing the terminally ill individual’s decisional process since this document is not addressing the extremely complex topic of surrogate decision making.

#### Preliminary Considerations

The following five steps are not a part of the actual outline but are intended to be general issues for professionals to consider.

1. Psychologists need to assess their own personal and professional beliefs about the dying process and different end-of-life decisions and consult with others regarding the degree to which their attitudes, values, and beliefs could affect or bias the review process.
2. If, following this personal/professional assessment and consultation, psychologists believe they can participate in end-of-life discussions, they must obtain appropriate training in relevant end-of-life-related issues.
3. If professionals plan on being involved in this area, they need to find at least one experienced colleague with whom they can consult during reviews to determine if the discussion and interpretations are appropriately comprehensive, if the psychologist's own values are affecting the process, or when referral to another professional may be necessary.
4. The dying person's health care team must be integrated into the review process, through asking them questions, providing them with information, and making appropriate referrals.
5. Throughout the review process professionals need to keep detailed case notes describing why they covered what they did and why other areas were not explored in more depth.

#### Outline of Issues for Consideration

The issues to be considered are divided into four broad areas. Depending on the prognosis for the dying person, his or her physical ability to participate in an extended interview or multiple meetings, and the referral question(s), one or more of the last three sections may need to be reduced in emphasis or eliminated. Striking an appropriate balance between the person's physical condition (so that he or she is not over burdened by the review) and the psychologist's needs (in order for a comprehensive review can be conducted) will be difficult, and therefore may increase the possibility that the professional's values may enter into the situation (Fenn & Ganzini, 1999; Ganzini, Fenn, Lee, Heintz, & Bloom, 1996). However, if time and the client's condition permit, all of the following topics may be relevant and therefore should be considered areas to be explored, and the professional should utilize the consultant to determine if value judgments are interfering with making unbiased interpretations.

1. A necessary first step is to determine if the individual has capacity to give informed consent to participate in the review and, further, the capacity to make informed health care decisions.
  - a. Conduct a Mental Status Evaluation, using standardized procedures and scoring, being especially vigilant for signs of dementia and/or delirium;

b. Determine if the individual can perform all of the following tasks as they pertain to the review:

- Understand and remember relevant information, including the fact that the professional will need to confer with members of the individual's health care team as well as the person's significant others,
- Appreciate the consequences (i.e., costs and benefits) of different possible decisions,
- Demonstrate a clearly held and consistent underlying set of values that provide some guidance for making the decision,
- Communicate the decision and explain the process used for making it;

c. Determine if the person can perform the following tasks as they pertain to his or her health care:

- Understand and remember relevant information about his or her diagnosis, prognosis, and treatment alternatives (especially hospice and palliative care and advance directives),
- The last three items in (b) above;

d. If the person has the aforementioned capacities, then the professional should have the dying person sign a release of information form and the psychologist should then obtain medical records so that members of the health care team can be consulted. The records need to be available for the next steps in the outline, while the interviews with health care team members can take place either before or soon after the first interview with the dying individual. These consultations should review the team members' (1) perceptions of the individual's condition, prognosis, and treatment options, and (2) beliefs about what they told the person about his or her condition, prognosis, and treatment options. These meetings should take place before the process is considered complete because they will often lead to a need to clarify discrepancies between what the health care team reports and what the dying person states.

2. If a person has capacity to make decisions about involvement in the review and about his or her health care, the next step is to discuss the decision-making process the person has used, focusing on the issues that the individual stated (in 1c, above) were important parts of his or her thinking on the matter. Important areas to explore may include:

a. Physical pain and suffering: Although most physicians have training in pain management and alleviating distressing symptoms, it is widely

recognized that pain is undertreated and some symptoms are poorly controlled; therefore, even though the psychologist may not be an expert in physical symptomology, the degree to which physical pain as well as other aspects of suffering are involved in the person's decision making must be reviewed.

b. Comorbid psychological conditions: Disruptions of thought and affect caused by the following conditions may not be severe enough to make a person incapable of making decisions, but they can significantly affect decision making as well as impair quality of life (note: the psychologist may utilize appropriate standardized assessment tools as long as the instruments can be justified because of a need to document a condition the professional has detected and are not used merely to rule out hypothetical problems):

- Clinical depression and other mood disorders,
- Clinical anxiety disorders (including acute stress disorder and posttraumatic stress disorder),
- Early-stage dementia,
- Fluctuating states of delirium and/or psychosis,
- Personality disorders (note: the presence of a diagnosable personality disorder would not disqualify a person's end-of-life decisions; however, awareness of such a diagnosis would help the professional put other aspects of the discussion into the appropriate context),
- Substance abuse (including accidental or purposeful abuse of/dependence on prescribed medication);

c. Other psychological issues: In addition to formally diagnosable conditions, there are a host of other issues associated with the individual himself or herself that need to be reviewed:

- Ambivalence or rigid thinking,
- Fears (e.g., of pain, loss of mental status),
- History of actual and perceived trauma and loss (including traumatic head injury),
- Hopelessness and despair,
- Internalization of societal rejection (e.g., self-hatred due to sexual orientation – “internalized homophobia”; internalized low sense of entitlement in women),
- Religious, spiritual, and existential beliefs, expectations, experiences, and values; sense of personal meaning and fulfillment in life; philosophy of life and life values; assumptive world components;

d. Fear of loss of control/loss of autonomy/loss of dignity: Research has indicated that these issues are the primary reasons given by people who want to take an action that may impact the timing of death and therefore they deserve careful exploration;

e. Financial concerns: Issues associated with the cost of medical care may play a role in end-of-life choices so a discussion of the degree to which monetary matters are a part of the decision is important. (Note: there is some debate in the literature about whether the presence of financial concerns should disqualify a person's decisions. For some this is perceived to be a form of societal coercion while for others it is a natural consideration that may be seen as altruistic. It will be up to the professional, perhaps after peer consultation, to determine whether any financial concerns that are present are impairing the dying person's judgment);

f. Cultural factors: As reviewed earlier, people of diverse backgrounds hold differing attitudes toward various end-of-life decisions so exploring ways in which culture may be affecting decision making must be included in the review:

- Cultural expectations and traditions associated with decision making, end-of-life issues, and values,
- Impact of personal characteristics, such as age, ethnicity, gender, economic status, and disability;

g. Review possible underlying issues: Resolution of the following issues, if present, should not be expected, nor required. These areas are listed because of their potential for decreasing quality of life and impacting relationships:

- Is the request for assistance in dying a form of communication and what is being communicated?
- Is there a "split in the experience of the self" such that the person wants the sick part of the self to die but the healthy part to live? If so, what impact is this having on the decision making?
- How is the person's ego functioning and related issues (e.g., coping and defense mechanisms, frustration tolerance, character scripts, locus of control and processing, cognitive style and biases, problem-solving skills, and ways of managing psychosocial transitions) affecting the decision?
- How are the person's specific strengths, skills, and assets, vulnerabilities, and liabilities influencing the decision-making process?
- Are rage, revenge, and helplessness involved in the process and what do they represent to the person?
- Are guilt, shame, self-punishment, and atonement affecting the quality of life and the end-of-life decision?
- Is the person viewing life as having already come to an end and how is this impacting the decision-making process and review?

h. Overall quality of life: Generally speaking, how good does the individual believe his or her quality of life is at the present time, what does

he or she envision for the near future, and what could change the present and prospective quality of life for the better?

i. Other issues to explore: If these issues have not already been discussed, the following topics deserve consideration:

- Has the person been suicidal in the past?
- How long has the person been thinking about his or her end-of-life options?
- How long ago was a decision made?
- Why was the decision made when it was and, if there is a significant time gap between when the decision was made and when the review is being conducted, why is the discussion being held now?
- If the person was going to follow through with the end-of-life decision, when would action take place and why then?

3. The next major area for review is the person's social support system. Releases should be signed so that the professional can talk with the important people in the dying individual's intimate circle.

a. Consideration of significant others: How has the presence or absence of significant others impacted the person's decision making:

- Review the beliefs the person has about the potential impact on the significant others (including those yet-to-be-born), if any, of a particular decision,
- If the individual insists there are no significant others, including friends, discuss the degree to which this isolation (and, possibly, loneliness) may be amenable to change and the effect such a change might have on a decision,
- Examine the degree to which concerns about being a burden on others (physically, emotionally, financially, etc.) are influencing the decision;

b. Involvement of significant others: Discuss the presence of significant others in the client's life and consider suggesting that, if possible, they become involved in the decision-making process in some way:

- If the individual is unwilling to have significant others involved, review the reasons for this decision and discuss the impact their lack of involvement may be having on his or her decision making,
- If the person is willing to have significant others involved but has not included them to this point, discuss how such involvement will occur and how this plan impacts the review,
- If the dying person is uncertain about involving significant others, discuss the issues until some decision can be made and then follow the first two bullets in this item, depending on which is most appropriate given the decision made,
- If significant others have been involved, find out what the dying

person believes took place in the discussions and whether there is any unfinished business,

- Review if there has been any direct or indirect, subtle or overt, actual or perceived, pressure from significant others on the decision-making process;

c. Interviews with significant others: Consider reviewing at least the following issues related to the terminally ill person with members of his or her support system; if any areas of concern arose during the interview with the ill individual, ask about them in this section as well:

- Current functioning,
- Recent changes in physical, mental, or emotional health,
- Medical and psychosocial history, especially psychological problems and substance abuse/mis-use,
- Typical pattern of adjusting to loss, change, and illness,
- Personality style,
- Reasons for considering particular options and the significant other's reactions to these reasons,
- Areas of unfinished business,
- Extent of financial concerns of all involved,
- Other issues of concern related to the interviews with the dying person (e.g., if the dying individual's response to questions about his or her fears of dying and death need clarification or raised concerns in the professional, questions about this area can be asked of the significant others).

4. The final broad area that should be reviewed includes systemic and environmental issues. The goal here is to explore for the presence of any pressures from outside sources that may be impinging on the person's decision making.

a. Indirect external coercion: To what extent are pervasive societal conditions and attitudes negatively impacting the individual's life and, perhaps, causing him or her to feel as if there are no satisfactory options that will provide for a decent quality of life, such as:

- Negative biases toward older persons, persons with disabilities, women, members of minority ethnic groups,
- Lack of funding for basic health care needs, inadequate resources for persons with chronic and disabling conditions, poorly trained professional caregivers, and other problems;

b. Direct external coercion: Pressure to make a particular decision may be subtle or overt, may be actually occurring or merely a perception of the individual, could occur intentionally or accidentally, for example:

- Are health care providers, administrators, and/or insurers/payers

pressuring the client to make a decision that will cut expenses, open up space, or for some other reason?

- Has a medical provider suggested scaling back treatment or offered some specific options, leading the person to believe he or she has been given up on or abandoned by professional caregivers.

### Role of the Psychologist after the Review is Complete

After conducting a review the professional must prepare detailed case notes. These notes should thoroughly document whether the psychologist believes the dying person has capacity to make health care decisions and, if so, whether there are any factors that are impairing the individual's judgment regarding the end-of-life decision. If no impairment is detected, the notes should describe the review process and highlight how potential areas of concern were covered and eliminated. If impairment is found, the notes should detail how the professional came to this conclusion and offer treatment recommendations, with the strong stipulation that the person needs to meet with a professional to determine capacity before any end-of-life decisions are implemented. Finally, appropriate referrals (e.g., to attorneys, spiritual advisors, etc.) should be included in the recommendations section, regardless of whether capacity is present.

### Use of Instruments when Reviewing End-of-Life Decisions

At times it may be helpful for a psychologist to use objective or subjective measures to gather more information. The use of such instruments must be carefully considered and the potential utility must be balanced with the person's physical state and abilities, tolerance for completion of questionnaires, and the concerns of the professional. The only instrument that may be warranted for use with most individuals is the MacArthur Competence Assessment Tool - Treatment (Grisso & Appelbaum, 1998) because its semi-structured format provides a framework within which assessments of capacity can be conducted.

The decision of which additional measures would be warranted will have to be made by the psychologist on a case-by-case basis, given the unique characteristics of the situation and the constellation of issues presented by the dying person. A comprehensive list of measures that may be appropriate for use with individuals at the end of life may be found in the Center to Improve Care of the Dying's "Toolkit of Instruments to Measure End of Life Care" (<http://www.gwu.edu/~cicd/toolkit/time.htm>). For suggestions of other instruments see Farrenkopf and Bryan (1999); Werth (1999a); and Werth, Benjamin, and Farrenkopf (in press).