

RETURN

Pegco Inc  
2395 Palm Dr  
Port Orange FL 32128  
(386) 756-4266  
FL Provider #FBN2613

### ROSTER

Program Title: END OF LIFE ISSUE & CARE (2HR)

Date: \_\_\_\_\_ Facility name: \_\_\_\_\_

\*\*\*\*\***PLEASE PRINT**\*\*\*\*\*

CERTIFICATES CAN NOW BE EMAILED.

1. NAME \_\_\_\_\_ PHONE \_\_\_\_\_  
ADDRESS \_\_\_\_\_  
EMAIL \_\_\_\_\_

2. NAME \_\_\_\_\_ PHONE \_\_\_\_\_  
ADDRESS \_\_\_\_\_  
EMAIL \_\_\_\_\_

3. NAME \_\_\_\_\_ PHONE \_\_\_\_\_  
ADDRESS \_\_\_\_\_  
EMAIL \_\_\_\_\_

4. NAME \_\_\_\_\_ PHONE \_\_\_\_\_  
ADDRESS \_\_\_\_\_  
EMAIL \_\_\_\_\_



# **END OF LIFE ISSUES AND CARE**

## **AGENDA**

- I. End of Life Tasks and Decisions**
- II. Issues to Consider when Exploring End of Life Decisions**
  - a. Preliminary Considerations**
  - b. Outline of Issues for Considerations**
  - c. Role of the Psychologist After the Review is Complete**
  - d. Use of Instruments When Reviewing End of Life Decisions**
- III. The Role of Psychology in End of Life Decisions and Quality of Life Issues**
  - a. Clinical Roles**
    - 1. Assessment Activities**
    - 2. Clinical and Counseling Activities**
    - 3. Advocacy Activities**
    - 4. Emerging Models of Service Delivery**
  - b. Education and Training Roles**
    - 1. Education of the Profession**
    - 2. Education of the Public**
  - c. Research Roles for Psychologists in End of Life**
    - 1. Ethical and Methodological Issues**
    - 2. Priority Areas for Future Research**
  - d. Policy Roles**
- IV. Historical Changes Affecting End of Life Care**
- V. Issues of Access and Variability in Health Care at the End of Life**
- VI. Diversity Issues in End of Life Decision Making**
- VII. Terminology, Definitions, and Other Barriers to Communication**
  - a. The Term "Hastened Death"**
  - b. The Term "Assisted Suicide"**
  - c. Futility**
  - d. Advanced Care Directives**

# **OBJECTIVES**

- 1. Understand and verbalize the issues to consider when Exploring End of Life Decisions**
- 2. Discuss the Role of the Psychologist in End of Life Decisions and Quality of Life Issues**
- 3. Identify Areas Regarding How Historical Changes Affect End of Life Care**
- 4. Identify and give examples of Issues of Access and Variability in Health Care at the End of Life**
- 5. Discuss the Diversity Issues in End of Life Decision Making**
- 6. Define the terms: "Hastened Death; Assisted Suicide"; Futility; and Advanced Care Directives**

Notes:

## End-of-life Issues and Care

### End-of-Life Tasks and Decisions

[Next](#) | [Previous](#) | [Home](#)

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

1

person's wish not to discuss death.

## References

Carrese, J. A., & Rhodes, L. A. (1995). Western bioethics on the Navajo reservation. *JAMA*, 274, 826-829.

[top](#)

[Next](#) | [Previous](#) | [Home](#)

[About Public Interest Conferences](#) [Executive Director Messages](#)  
[Public Interest Home Page](#)  
[Program Areas](#) [Publications](#) [Student Information](#)  
American Psychological Association  
[Public Interest Directorate](#)  
750 First Street, NE  
Washington, DC 20002

© PsycNET 2001 American Psychological Association



Notes:

public interest

## End-of-life Issues and Care

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

[Next](#) | [Previous](#) | [Home](#)

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

# NOTES:

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, 1999a; 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.

top

## **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.

# Notes:

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.

top

## **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



# Notes:

- 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

# Notes:

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

# Notes:

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

# Notes:

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.

P

# Notes:

- 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

# Notes:

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

# Notes:

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.

top

## **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.

top

## **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

# Notes:

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 (1999b); and Werth, Benjamin, and Farrenkopf (in press).

[top](#)

## References

Block, S. D., & Billings, J. A. (1998). Evaluating patient requests for euthanasia and assisted suicide in terminal illness: The role of the psychiatrist. In M. D. Steinberg, S. J. Youngner (Eds.), *End of life decisions: A psychosocial perspective* (pp. 205-233). Washington, DC: American Psychiatric Press.

Emanuel, L. L. (1998). Facing requests for physician-assisted suicide: Toward a practical and principled clinical skill set. *JAMA*, 280, 643-647.

Farberman, R. K. (1997). Terminal illness and hastened death requests: The important role of the mental health professional. *Professional Psychology: Research and Practice*, 28, 544-547.

Farrenkopf, T. & Bryan, J. (1999). Psychological consultation under Oregon's 1994 Death With Dignity Act: Ethics and procedures. *Professional Psychology: Research and Practice*, 30, 245-249.

Fenn, D. S., & Ganzini, L. (1999). Attitudes of Oregon psychologists toward physician-assisted suicide and the Oregon Death With Dignity Act. *Professional Psychology: Research and Practice*, 30, 235-244.

Ganzini, L., Fenn, D. S., Lee, M. A., Heintz, R. T., & Bloom, J. D. (1996). Attitudes of Oregon psychiatrists toward physician-assisted suicide. *American Journal of Psychiatry*, 153, 1469-1475. Goldblum, P., & Martin, D. (1999). Principles for the discussion of life and death options with terminally ill clients with HIV. *Professional Psychology: Research and Practice*, 30, 187-197.

Grisso, T., & Appelbaum, P. S. (1998). *Assessing competence to consent to treatment: A guide for physicians and other health care professionals*. New York: Oxford.

Jamison, S. (1997). *Assisted suicide: A decision-making guide for health professionals*. San Francisco: Jossey-Bass.

Miller, P. J., Hedlund, S. C., & Murphy, K. A. (1998). *Social work assessment at the end of life: Practice guidelines for suicide and the*



# NOTES:

terminally ill. *Social Work in Health Care*, 26(4), 23-36.

Muskin, P. R. (1998). The request to die: Role for a psychodynamic perspective on physician-assisted suicide. *JAMA*, 279, 323-328.

National Association of Social Workers. (1994). Client self-determination in end-of-life decisions. In *Social Work Speaks: NASW Policy Statements* (3rd ed.) (pp. 58-61). Washington, DC: NASW Press.

Sanson, A., Dickens, E., Melita, B., Nixon, M., Rowe, J., Tudor, A., & Tyrrell, M. (1998). Psychological perspectives on euthanasia and the terminally ill: An Australian Psychological Society discussion paper. *Australian Psychologist*, 33, 1-11.

Sullivan, M. D., Ganzini, L., & Youngner, S. J. (1998, July/August). Should psychiatrists serve as gatekeepers for physician-assisted suicide? *Hastings Center Report*, 28 (4), 24-31.

Veterans Affairs National Center for Cost Containment. (1997). *Assessment of competency and capacity of the older adult: A practice guideline for psychologists*. Milwaukee, WI: Author.

Werth, J. L., Jr. (1999a). Mental health professionals and assisted death: Perceived ethical obligations and proposed guidelines for practice. *Ethics and Behavior*, 9, 159-183.

Werth, J. L., Jr. (1999b). Clinical depression and desire for death among persons with terminal illnesses. *Social Pathology: A Journal of Reviews*, 5, 22-26.

Werth, J. L., Jr., Benjamin, G. A. H., & Farrenkopf, T. (in press). Requests for physician-assisted death: Guidelines for assessing mental capacity and impaired judgment. *Psychology, Public Policy, and Law*.

Werth, J. L., Jr. & Gordon, J. R. (1998). Helping at the end of life: Hastened death and the mental health professional. In L. Vandecreek, S. Knapp, & T.L. Jackson (Eds.), *Innovations in clinical practice: A source book* (Vol. 16) (pp. 385-398). Sarasota, FL: Professional Resource Press.

[top](#)

[Next](#) | [Previous](#) | [Home](#)

[About Public Interest Conferences](#) [Executive Director Messages](#)  
[Public Interest Home Page](#)  
[Program Areas](#) [Publications](#) [Student Information](#)  
American Psychological Association  
[Public Interest Directorate](#)  
750 First Street, NE  
Washington, DC 20002

© PsycNET 2001 [American Psychological Association](#)

© 2007 American Psychological Association  
Public Interest Directorate  
750 First Street, NE • Washington, DC • 20002-4242  
Phone: 202-336-6050 • TDD/TTY: 202-336-6123  
Fax: 202-336-6040 • [Email](#)  
[PsychNET®](#) | [Terms of Use](#) | [Privacy Policy](#) | [Security](#)



public interest

Notes:

## End-of-life Issues and Care

The Role of Psychology in End-of-Life Decisions and Quality of Care Issues

[Next](#) | [Previous](#) | [Home](#)

- [Clinical Roles](#)
- [Education and Training Roles](#)
- [Research Roles for Psychologists in End-of-Life](#)
- [Policy Roles](#)

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

# Notes:

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.

top

---

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)

top

15

# Notes:

## 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:

- 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

# Notes:

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.

[top](#)

## **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

# Notes:

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.

# Notes:

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.

[top](#)

## **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

# Notes:

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).

top

## **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).

top

## **References**

- Back, A. L., Wallace, J. I., Starks, H. E., & Pearlman, R. A. (1996). Physician-assisted suicide and euthanasia in Washington State: Patient requests and physician responses. *JAMA*, 275, 919-925.
- Block, S. D., & Billings, J. A. (1998). Evaluating patient requests for euthanasia and assisted suicide in terminal illness: The role of the psychiatrist. In M. D. Steinberg, S. J. Youngner (Eds.), *End of life decisions: A psychosocial perspective* (pp. 205-233). Washington, DC: American Psychiatric Press.
- Canetto, S. S., & Hollenshead, J. (1999). Gender and physician-assisted suicide: An analysis of the Kevorkian cases, 1990-1997. *Omega*, 40, 165-208.
- Chin, A. E., Hedberg, K., Higginson, G. K., & Fleming, D. W. (1999).



# Notes:

Legalized physician-assisted suicide in Oregon -- The first year's experience. *New England Journal of Medicine*, 340, 577-583.

Cohen, J. S., Fihn, S. D., Boyko, E. J., & Jonsen, A. R. (1994). Attitudes toward assisted suicide and euthanasia among physicians in Washington State. *New England Journal of Medicine*, 331, 89-94.

Conwell, Y., Pearson, J., & DeRenzo, E. G. (1996). Indirect self-destructive behavior among elderly patients in nursing homes: A research agenda. *American Journal of Geriatric Psychiatry*, 4, 152-163.

Coombs Lee, B. & Werth, J. L., Jr. (in press). Observations on the first year of the Oregon Death with Dignity Act. *Psychology, Public Policy, and Law*.

Cummings, I. (1998). The interdisciplinary team. In D. Doyle, G. W. C. Hanks, & N. MacDonald (Eds.), *Oxford Textbook of Palliative Medicine* (2nd ed.) (pp. 9-30). Oxford: Oxford University Press.

Field, M. J., & Cassel, C. K. (Eds.). (1997). *Approaching death: Improving care at the end-of-life*. Washington, DC: National Academy Press.

Ganzini, L., Nelson, H. D., Schmidt, T. A., Kraemer, D. F., Delorit, M. A., & Lee, M. A. (2000). Physicians' experiences with the Oregon Death with Dignity Act. *New England Journal of Medicine*, 342, 557-563.

Grisso, T. (1986). *Evaluating competencies: Forensic assessments and instruments*. New York: Plenum.

Grisso, T. (1994). Clinical assessment for legal competence of older adults. In M. Storandt & G. VandenBos (Eds.), *Neuropsychological assessment of dementia and depression in older adults: A clinician's guide* (pp. 119-139). Washington, D.C.: American Psychological Association.

Koenig, G. G., Meador, K. G., Cohen, H. J. & Blazer, D. G. (1988). Self-rated depression scales and screening for major depression in the older hospitalized patients with medical illness. *Journal of the American Geriatrics Society*, 42, 490-492.

Kubler-Ross, E. (1969). *On death and dying*. New York: McMillan.

Peruzzi, N., Canapary, A., & Bongar, B. (1996). Physician-assisted suicide: The role of mental health professionals. *Ethics and Behavior*, 6, 353-366.

Quill, T. E., Meier, D. E., Block, S. D., Billings, J. A. (1998). The debate over physician-assisted suicide: Empirical data and

# Notes:

convergent views. *Annals of Internal Medicine*, 128, 552-558.

Rando, T. A. (Ed.) (2000). *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, their loved ones, and their caregivers*. Champaign, IL: Research Press.

Sullivan, A. D., Hedberg, K., & Fleming, D. W. (2000a). *Oregon's Death with Dignity Act: The second year's experience*. Portland, OR: Oregon Health Division.

Sullivan, A. D., Hedberg, K., & Fleming, D. W. (2000b). Legalized physician-assisted suicide in Oregon -- The second year. *New England Journal of Medicine*, 342, 598-604.

Veterans Affairs National Center for Cost Containment. (1997). *Assessment of competency and capacity of the older adult: A practice guideline for psychologists*. Milwaukee, WI: Author.

Wilson, K. G., Viola, R. A., Scott, J. F., & Chater, S. (1998, April). Talking to the terminally ill about euthanasia and physician-assisted suicide. *Canadian Journal of Clinical Medicine*, 68-74.

Weisman, A. (1972). *On dying and denying: A psychiatric study of terminality*. New York: Behavioral Publications.

top

---

## **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;

# Notes:

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).

top

## **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

# Notes:

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.

top

## References

Abeles, N. , & Barlev, A. (1999). End-of-life decisions and assisted suicide. *Professional Psychology: Research and Practice*, 30, 229-234.

International Work Group on Death, Dying, and Bereavement. (1991). A statement of assumptions and principles concerning education about death, dying, and bereavement. *Death Studies*, 16, 59-65.

Stillion, J.M. (1983). Where thanatos meets eros: Parallels between death education and group psychotherapy. *Death Education*, 7, 53-67.

Stillion, J. M. (1999). Rational suicide: Challenging the next generation of caregivers. In J. L. Werth, Jr. (Ed.), *Contemporary Perspectives on Rational Suicide* (pp. 160-167). Philadelphia: Taylor & Francis.

top

---

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.

# Notes:

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

# Notes:

- 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.

# Notes:

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.

top

## References

Rosenfeld, B. (in press). Methodological issues in assisted suicide/euthanasia research. *Psychology, Public Policy, & Law*.

top

---

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

# Notes :

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



# Notes:

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

# Notes:

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

# Notes:

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.

[top](#)

## References

Field, M. J., & Cassel, C. K. (Eds.). (1997). *Approaching death: Improving care at the end-of-life*. Washington, DC: National Academy Press.

National Council on Disability (1998). *Assisted suicide: A disability perspective*. *Issues in Law and Medicine*, 14, 273-300.

[top](#)

[Next](#) | [Previous](#) | [Home](#)

[About Public Interest Conferences](#) [Executive Director Messages](#)  
[Public Interest Home Page](#)  
[Program Areas](#) [Publications](#) [Student Information](#)  
American Psychological Association  
[Public Interest Directorate](#)  
750 First Street, NE  
Washington, DC 20002

Notes:

## End-of-life Issues and Care

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

[Next](#) | [Previous](#) | [Home](#)

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).

# Notes:

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

# Notes:

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.

top

## References

Battin, M. P. (1996). The death debate: Ethical issues in suicide (pp. 175-203). Upper Saddle River, NJ: Prentice-Hall.

Benoliel, J. Q. & Degner, L. F. (1995). Institutional dying: A convergence of cultural values, technology, and social organization. In H. Wass & R. A. Neimeyer (Eds.) *Dying: Facing the facts* (pp.

117-141). Washington, DC: Taylor and Francis.

Bureau of the Census, U.S. Department of Commerce, Economics and Statistics Administration (1996). Sixty-five plus in the United States. (Current population reports, special studies, 23-100). Washington, DC: U.S. Government Printing Office.

Centers for Disease Control and Prevention (1999, July 30). Control of infectious diseases. Morbidity and Mortality Weekly Report, 48(29), 621-629.

Field, M. J., & Cassel, C. K. (Eds.). (1997). Approaching death: Improving care at the end-of-life. Washington, DC: National Academy Press.

In re L.W., 482.N.W.2d 60 (Wis. 1992).

Kramarow, E., Lentzner, H., Rooks, R., Weeks, J., & Saydah, S. (1999). Health, United States, 1999 with health and aging chartbook. Hyattsville, MD: National Center for Health Statistics.

Martin, J. A., Smith, B. L., Matthews, T. J., & Ventura, S. J. (1999). Births and deaths: Preliminary data for 1998. National Vital Statistics Reports, 47(25), 1-48.

Vacco v. Quill, 117 S.Ct. 2293 (1997).

Webb, M. (1997). The good death: The new American search to reshape the end of life. New York: Bantam.

Washington v. Glucksberg, 117 S.Ct. 2258 (1997).

[top](#)

[Next](#) | [Previous](#) | [Home](#)

[About Public Interest Conferences](#) [Executive Director Messages](#)

[Public Interest Home Page](#)

[Program Areas](#) [Publications](#) [Student Information](#)

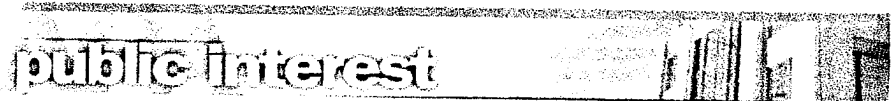
American Psychological Association

[Public Interest Directorate](#)

750 First Street, NE

Washington, DC 20002

© 2007 American Psychological Association  
Public Interest Directorate  
750 First Street, NE • Washington, DC • 20002-4242  
Phone: 202-336-6050 • TDD/TTY: 202-336-6123  
Fax: 202-336-6040 • [Email](#)  
[PsychNET®](#) | [Terms of Use](#) | [Privacy Policy](#) | [Security](#)



Notes:

## End-of-life Issues and Care

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

[Next](#) | [Previous](#) | [Home](#)

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



# Notes:

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.

[top](#)

## References

Covinsky, K. E., Landefeld, C. S., Teno, J., Connors, A. F., Jr., Dawson, N., Youngner, S., Desbiens, N., Lynn, J., Fulkerson, W., Reding, D., Oye, R., & Phillips, R. S. (1996). Is economic hardship on the families of the seriously ill associated with patient and surrogate care preferences? *Archives of Internal Medicine*, 156, 1737-1741.

Field, M. J., & Cassel, C. K. (Eds.). (1997). *Approaching death: Improving care at the end-of-life*. Washington, DC: National Academy Press.

Mishara, B.L. (1999). Synthesis of research and evidence on factors affecting the desire of terminally ill persons to hasten death. *Omega*, 39, 1-70.

SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT). *JAMA*, 274, 1591-1598. [Erratum, *JAMA*, 275, 1232 (1996).]

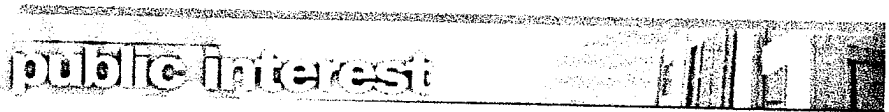
[top](#)

[Next](#) | [Previous](#) | [Home](#)

[About Public Interest](#) [Conferences](#) [Executive Director Messages](#)  
[Public Interest Home Page](#)  
[Program Areas](#) [Publications](#) [Student Information](#)  
American Psychological Association  
[Public Interest Directorate](#)  
750 First Street, NE  
Washington, DC 20002

© PsycNET 2001 [American Psychological Association](#)

© 2007 American Psychological Association  
Public Interest Directorate  
750 First Street, NE • Washington, DC • 20002-4242  
Phone: 202-336-6050 • TDD/TTY: 202-336-6123  
Fax: 202-336-6040 • [Email](#)  
[PsychNET@](#) | [Terms of Use](#) | [Privacy Policy](#) | [Security](#)



NOTES:

## End-of-life Issues and Care

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

[Next](#) | [Previous](#) | [Home](#)

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;

# Notes:

- 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

# Notes:

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'ajɪniidah'" (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.

[top](#)

## References

Canetto, S. S., & Hollenshead, J. (1999). Gender and physician-assisted suicide: An analysis of the Kevorkian cases, 1990-1997. *Omega*, 40, 165-208.

Caralis, P. V., Davis, B., Wright, K., & Marcial, E. (1993). The influence of ethnicity and race attitudes toward advance directives, life-prolonging treatments, and euthanasia. *Journal of Clinical Ethics*, 4, 155-165.

Carrese, J. A., & Rhodes, L. A. (1995). Western bioethics on the Navajo reservation. *JAMA*, 274, 826-829.

Field, M. J., & Cassel, C. K. (Eds.). (1997). *Approaching death: Improving care at the end-of-life*. Washington, DC: National Academy Press.

Hallenbeck, J., Goldstein, M. K., & Mebane, E. W. (1996). Cultural considerations of death and dying in the United States. *Clinics in Geriatric Medicine*, 12, 393-406.

Koenig, B. A. (1997). Cultural diversity in decisionmaking about care at the end of life. In M. J. Field, & C. K. Cassel (Eds.), *Approaching death: Improving care at the end-of-life* (pp. 363-382). Washington, DC: National Academy Press.

Morrison, R. S., Zayas, L. H., Mulvihill, M., Baskin, S. A., & Meier, D. E. (1998). Barriers to completion of health care proxies: An examination of ethnic differences. *Archives of Internal Medicine*, 158, 2493-2497.

New York State Task Force on Life and the Law (1994). *When death is sought: Assisted suicide and euthanasia in the medical context*. Albany, NY: Health Education Services.

Orentlicher, D. (1997). The Supreme Court and physician-assisted suicide: Rejecting assisted suicide but embracing euthanasia. *The New England Journal of Medicine*, 337, 1236-1239.

Wolf, S. M. (1996). Gender, feminism, and death: Physician-assisted suicide and euthanasia. In S. M. Wolf (Ed.), *Feminism and bioethics: Beyond reproduction* (pp. 282-317). New York: Oxford University

Press.

[top](#)

[Next](#) | [Previous](#) | [Home](#)

[About Public Interest](#) [Conferences](#) [Executive Director Messages](#)  
[Public Interest Home Page](#)  
[Program Areas](#) [Publications](#) [Student Information](#)  
American Psychological Association  
[Public Interest Directorate](#)  
750 First Street, NE  
Washington, DC 20002

© PsycNET 2001 [American Psychological Association](#)

© 2007 American Psychological Association  
Public Interest Directorate  
750 First Street, NE • Washington, DC • 20002-4242  
Phone: 202-336-6050 • TDD/TTY: 202-336-6123  
Fax: 202-336-6040 • [Email](#)  
[PsychNET®](#) | [Terms of Use](#) | [Privacy Policy](#) | [Security](#)



public interest

Notes:

## End-of-life Issues and Care

Terminology, Definitions, and Other Barriers to Communication

[Next](#) | [Previous](#) | [Home](#)

- [The Term "Hastened Death"](#)
- [The Term "Assisted Suicide"](#)
- [Futility](#)
- [Advance Care Directives](#)

Discussions about end-of-life issues can be difficult for many

# Notes

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. Many terms 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."

top

---

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

# Notes:

permissible under what circumstances as well as different views about the potential for abuse associated with different end-of-life interventions.

top

---

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



# Notes:

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.

top

---

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.

top

---

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

# Notes:

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.

top

## References

Alpers, A., & Lo, B. (1999). The Supreme Court addresses physician-assisted suicide. *Archives of Family Medicine*, 8, 200-205.

American Association of Suicidology. (1996). Report of the Committee on Physician-Assisted Suicide and Euthanasia. *Suicide and Life-Threatening Behavior*, 26(Suppl.), 1-19.

Block, S. D., & Billings, J. A. (1998). Evaluating patient requests for euthanasia and assisted suicide in terminal illness: The role of the psychiatrist. In M. D. Steinberg, S. J. Youngner (Eds.), *End of life decisions: A psychosocial perspective* (pp. 205-233). Washington,

Name \_\_\_\_\_ Date \_\_\_\_\_

## END OF LIFE ISSUES QUIZ

1. Give three examples of some of the choices people and families must face as they approach the end of life: \_\_\_\_\_

\_\_\_\_\_

2. Name the four issues identified on the categorized list when exploring End of Life Decisions: (1) \_\_\_\_\_

(2) \_\_\_\_\_

(3) \_\_\_\_\_ (4) \_\_\_\_\_

3. Regarding Preliminary Considerations, which of the five steps identified the dying person's health care team? \_\_\_\_\_

4. In the section: Outline of Issues for Consideration letter B refers Comorbid psychological conditions. List three of the six conditions (1) \_\_\_\_\_ (2) \_\_\_\_\_

(3) \_\_\_\_\_

5. After conducting a review, the psychologist professional must prepare what? \_\_\_\_\_

6. What is the only instrument that may be warranted for use when reviewing End of Life Decisions? \_\_\_\_\_

7. Since psychology as a discipline does not have a strong history of working in the arena of terminal illness and End of Life issues, what e things are recommended they do for getting up to speed?(1) \_\_\_\_\_ (2) \_\_\_\_\_

(3) \_\_\_\_\_

8. Psychologists are well prepared to do what with individuals, family members, and providers? \_\_\_\_\_

9. Regarding Assessment Activities, list four of the six key questions for exploration: (1) \_\_\_\_\_;

(2) \_\_\_\_\_; (3) \_\_\_\_\_;

(4) \_\_\_\_\_.

**10. Within communities, psychologists can help dying persons raise and resolve issues of meaning in their lives through what?**

**11. Advocacy for quality care for terminally ill individuals and their families may involve what?**

**12. What are the two emerging models of service delivery?**

(1) \_\_\_\_\_ (2) \_\_\_\_\_

**13. List six content areas that a free standing course in the psychology of dying and death curriculum could include(1)**

\_\_\_\_\_ (2) \_\_\_\_\_

(3) \_\_\_\_\_ (4) \_\_\_\_\_

(5) \_\_\_\_\_ (6) \_\_\_\_\_

**14. Give four examples of how psychologists can educate the public: (1)**

(2) \_\_\_\_\_

(3) \_\_\_\_\_ (4) \_\_\_\_\_

**15. What is one of the potential benefits of participating in research?**

**16. What is the name of the group that gave a report which identified five broad areas of deficiencies in current care for people with life threatening and incurable illnesses?**

**17. To qualify for Medicare hospice benefits, individuals must be certified as having what?**

**18. Authorities use the term "hastened death" to refer to what?**

**19. What definition refers to the discontinuing of life extending treatment?**

**20. Define "Assisted Suicide."**

**PEGCO Inc.**

532 N. RIDGEWOOD AVE  
DAYTONA BEACH, FL. 32114

**Phone: (386) 756-4266 Fax (386) 492-7821**

WEB SITE: www.VolusiaCPR.com EMAIL: Bill@VolusiaCPR.com

NURSING HOME #NH 2772  
ASSISTED LIVING #ALF 909  
HOME HEALTH CARE #HH 1175

PROGRAM EVALUATION

COURSE TITLE: **END OF LIFE ISSUES & CARE (2 HR)**

DATE: \_\_\_\_\_ LOCATION: PEGCO, Inc.

*Please evaluate by circling the appropriate rating:*

*5-Excellent 4-Above average 3-Average 2-Fair 1-Poor*

- |   |                      |
|---|----------------------|
| 1. Overall quality of the program                         | 5 4 3 2 1            |
| 2. Overall content of the program                         |                      |
| a. content can improve my ability to perform my job       | 5 4 3 2 1            |
| b. content reflected knowledge level and needs of learner | 5 4 3 2 1            |
| c. the material was current                               | 5 4 3 2 1            |
| 3. Achieved stated objectives                             |                      |
| a. total number of objectives in program _____            |                      |
| b. circle the number of met objectives                    | 1 2 3 4 5 6 7 8 9 10 |
| c. the test material reflected the objectives listed      | 5 4 3 2 1            |
| 4. Overall organization of the program                    |                      |
| a. material was organized to facilitate learning          | 5 4 3 2 1            |
| b. material covered was adequate and accurate             | 5 4 3 2 1            |

What did you like best about the program?

---

Your suggestions for improving this program.

---

Any topic ideas for future in-service programs

---

**THANK YOU FOR USING PEGCO INC. WE APPRECIATE YOU.**