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

Psychologists can contribute to end-of-life care before illness strikes, after illness is diagnosed and treatments begin, during advanced illness and the dying process, and after the death of the patient, with bereaved survivors.

Findings

Medical doctors, nurses, social workers, and the clergy have traditionally been the main players in helping care for people near death, but psychologists are increasingly using their expertise to help people have a so-called "good death" or perhaps the more accurate "least worst death." End-of-life - defined as the period when health care providers would not be surprised if death occurred within about six months - is a time when psychologists can treat depression and anxiety associated with pending death, offer grief counseling, help people understand confusing medical terms, and help provide compassionate care for the dying and their loved ones.

Several factors are shaping the expanding role of psychological practice in end-of-life care, according to psychologist William E. Haley, PhD of the University of South Florida. Psychologists are already trained and involved in the mental health treatment of major chronic illnesses such as heart disease, cancer, AIDS, dementia and chronic pain. Psychological intervention with these people includes psychotherapy for depression and anxiety, stress and pain management, relaxation training and family and group psychotherapy. Also, a broad-based movement to improve the final moments of life has led to research identifying major failures in hospital care of the seriously ill. This research finds that many patients are dying following prolonged hospitalization or intensive care in which their final days involve unrelied pain and their preferences concerning life-sustaining treatments are not fully discussed, documented or followed. These findings have led to the rapid expansion of the end-of-life field, allowing for expanding contributions of psychologists.

Dr. Haley and other members of the American Psychological Association's (APA) Ad-Hoc Committee on End-of-Life Issues, identify four time periods when psychologists can contribute to end-of-life care:

- Before illness strikes;
- After illness is diagnosed and treatments begin;
- During advanced illness and the dying process; and
- After the death of the patient, with bereaved survivors.

As psychologist Phillip M. Kleespies, PhD, notes in his 2004 book, Life and Death Decisions: Psychological and Ethical Considerations in End-of-life Care, (pubs/books/4317027.aspx) it is difficult to think of a more intensely emotional and psychological time than when a patient is facing his or her decline and eventual death. "Working with professionals from other health fields, psychologists have much to offer dying patients, their families, and those who bear the burden of caregiving," according to Dr. Kleespies.

The role of psychologists in helping people with HIV and AIDS offers a powerful example of how psychological interventions can make a difference in coping with and adapting to loss and advanced illness across time, from prevention (see Understanding How People Change Is First Step in Changing Unhealthy Behavior /research/action/understand.aspx ) to helping people who have contracted the life-threatening disease (see APA Office on AIDS-HOPE Program /pi/aids/programs/hope/index.aspx ).

Significance

The U.S. Supreme Court says Americans should expect palliative care, which combines active and compassionate therapies to comfort and support people and their families nearing the end of life. Psychologists can make significant contributions to improve the quality of end-of-life care and decision-making.

Practical Application

Psychologists are increasingly taking a more active role in end-of-life issues. The American Psychological Association identifies the following four main roles that psychologists play in this area:

1. **Clinical Roles** - Psychologists treat clinical depression if and when it arises in end-of-life matters, as well as other mental health problems associated with pending death. Psychologists also help caregivers and family members with facilitating emotional expression and how to effectively be good listeners for people who are dying. Properly trained psychologists also work effectively with issues of mourning and loss, traumatic stress, and serve as advocates for good medical care. The participation of psychologists in hospital ethics committees, palliative care, and other multidisciplinary teams is equally important.
2. **Education and Training Roles** - Psychologists are teaching people to understand loss, grief, and mourning and to understand the differences between normal sadness and clinical depression at the end of life. They are also providing information about advance care planning and decisions (including "living wills") and teach coping mechanisms. In 2004, APA received a grant from the National Institutes of Health Small Business Innovation Research program to develop an Internet-based program for educating psychologists and other mental health providers about helping those near the end-of-life and their loved ones. APA is working with a small business in Seattle to develop the program. Psychologists, such as Dale Larson, PhD, of Santa Clara University, were also major players in the Finding Our Way: Living With Dying in America (http://www.findingourway.net) community education project which reached millions of Americans through newspaper articles and website.

3. **Research Roles** - Psychologists have played key roles in conducting research on major issues relevant to the end-of-life such as death anxiety; decision making at the end-of-life; family caregiving; psychological aspects of pain and symptom management; and grief and bereavement. For example, psychological research has increasingly demonstrated that most individuals who experience bereavement are more resilient than was conventionally thought to be the case. This research has demonstrated that individuals who do not experience intense grief symptoms after a loss are not at high risk for subsequent pathological grief reactions.

4. **Policy Roles** - There are numerous opportunities and the federal, state and local levels for psychologists to advance the quality of care at the end of life. Many times dying people and their families are not fully aware of various end-of-life care options or not fully apprised of the probable benefits and burdens of these various options. Psychologists can work with other health care professions in advocating for the development of policies to ensure that people know what types of interventions and services are available to them. Other policy issues that psychologists can address include advocating for systemic changes in legal and organizational obstacles to quality care, advocate for ongoing discussion of death and dying issues in the media, the community, and in professional meetings to overcome society's reluctance to address these issues that many consider a taboo subject, and to advocate for more equitable end-of-life care for people with disabilities.

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**Cited Research**


End-of-Life Issues and Care: The Role of Psychology in End-of-Life Decisions and Quality of Care Issues (topics/death/end-of-life.aspx)

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