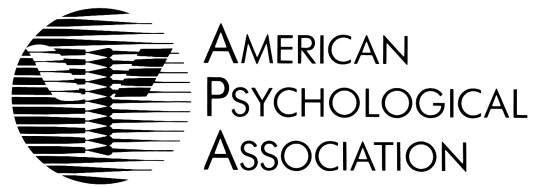


Fact Sheet on End-of-Life Care



WHAT ARE OLDER ADULTS' MENTAL HEALTH NEEDS NEAR THE END OF LIFE?

The US Supreme Court agreed that Americans should expect palliative care, which combines active and compassionate therapies to comfort and support individuals and families nearing the end of life. End of life is defined as that time period when health care providers would not be surprised if death occurred within about 6 months. Older Americans with chronic illness think about how they would prefer their lives to end, and want a "good death" without burdensome pain, symptoms and technology.

Most deaths (70%) occur in those aged 65 and older. Older adults want better discussions, information, and a chance to influence decisions about their care—whether to be at home or in the hospital and to have CPR (cardiopulmonary resuscitation) (Foley, 1995). Most Americans die in hospitals (63%), and another 17% die in institutional settings such as long-term care facilities (Foley, 1995; Isaacs & Knickman, 1997). In addition, most people are referred too late to hospice or palliative care, so they are unable to get the most benefit possible from these specialized services.

WHAT DO OLDER ADULTS FEAR MOST?

People fear that their pain, symptoms, anxiety, emotional suffering, and family concerns will be ignored. Many critically ill people who die in hospitals still receive unwanted distressing treatments and have prolonged pain. Many fear that their wishes (advance directives) will be disregarded and that they will face death alone and in misery. Physicians may use confusing or vague medical terms and talk briefly about treatment options when the patients are too sick to participate. Most people want to discuss advance directives when they are healthy and often want their families involved.

Caregivers reported that a third of 1227 elderly individuals were in unnecessary pain during the 24 hours before their death. Studies show that two thirds of elderly patients have pain in the last month of life (Foley, 1995). Although palliative/comfort care could relieve most of this pain and suffering, patients typically spend 8 days in ICU (an intensive care unit) comatose or on a ventilator and 30% of patients spend at least 10 days in ICU before they die (Isaacs & Knickman, 1997).

When discussing a good end of life with a patient, physicians in one study talked about 5-6 minutes, spoke for 2/3 of this time, and did not consider the patient's values or preferences (Tulsky, Fischer, Rose & Arnold, 1998). If patients were too sick to make decisions, most wanted their family to be given choices about treatment and only 41% wanted the physician to make treatment decisions without consulting them. In 91% of cases in which physicians discussed end of life treatment options, they did so in scenarios in which most patients would not want to be treated, whereas only 48% asked patients about their preferences in reversible scenarios when there was some chance of recovery.

Culture makes a difference in use of advance directives and in decisions about end of life care. Caucasians and Asians use advance directives more than other ethnic groups. Often people who do not complete advance directives think they are a good idea but are not urgently needed and their family or physician will somehow know their wishes (Caralis, Davis, Wright, Marcial, 1993; Miles, Koeppe & Weber, 1996; Weissman, Bloch, Blank, Cain, Cassem, Danoff, Foley, Meir, Schyve, Theige, & Wheeler, 1999).

Says Who?

Barry, B. & Henderson, A. (1996). Value of decision making in the terminally ill patient. *Cancer Nursing* 19(5), 384-291.

Benbasset, J. Pilpel, D., & Tidhar, M. (1998). Patients' preferences for participation in clinical decision making: A review of published surveys. *Behavioral Medicine*, 24, 81-87.

Isaacs, S.L. & Knickman, J.R (1997). *To improve health and health care*. San Francisco, CA: Jossey Bass.

Caralis, P.V., Davis, B., Wright, K., & Marcial, E. (1993). The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. *Journal of Clinical Ethics* 4, 155-65.

Field, M.J, Cassel, C.K (1997). *Committee on Care at the End of Life. Institute of Medicine. Approaching death: Improving care at the end of life: executive summary*. From <http://www.nap.edu/readingroom/books/approach/>.

Foley, K.M., (1995). *Pain, Physician assisted dying and euthanasia*. *Pain* 4, 163-178.

Lo, B., Quill, T. & Tulsky, J. (1999). Discussing palliative care with patients. *Annals of Internal Medicine* 130, 744-9.

Miles, S.H., Koeppe, R., Weber, E. (1996). Advance end-of-life treatment planning: A research review. *Archives of Internal Medicine* 156(10), 1062-1068.

Patient Self Determination Act, Public Law 101-508; 42 U.S.C. Sections 1395 cc. 1396.

Says Who?

Reilly, B.M., Magnussen, R., Ross, R., Ash, J., Papa, L., Wagner, M. (1994). Can we talk? Inpatient discussions about advance directives in a community hospital. *Archives of Internal Medicine* 154, 2999-3008.

Tulsky, J.A., Fischer, G.S., Rose, M.R., & Arnold, R.M. (1998). How do physicians communicate about advance directives. *Annals of Internal Medicine*, 129, 441-449.

Weissman, D.E., Block, S.D., Blank, L., Cain, J., Cassem, N., Danoff, D., Foley, K., Meier, D., Schyve, P., Theige, D., & Wheeler, H. B. (1999). Recommendations for incorporating palliative care education into the acute care hospital setting. *Academic Medicine*, 74, 871-877.

WHAT ARE THE OBSTACLES TO A GOOD DEATH?

Physicians want to preserve hope. They have difficulty saying when a cure is not possible and many are uncomfortable asking about a patient's choices (e.g., hospital or home treatment, breathing machines or feeding tubes, and comfort care). Many are not experts in symptom management and emotional support. Others believe that they must do everything to prolong life regardless of the pain and suffering involved and fear that offering comfort care may suggest they have given up or failed. Medical education has often not included palliative or comfort care and compassionate care near the end of life. Talking about end of life is difficult for many physicians and their patients and has been a taboo topic in society generally.

The Institute of Medicine (Field & Cassel, 1997) indicated that formal medical education should include palliative care. Lo, Quill, and Tulsky (1999) suggest that palliative care is the standard of care for dying patients.

Our knowledge of how culture influences choices about end of life is scant [Phillips, True, Pomerantz, 2000; Ersek, Kagawa-Singer, Barnes, Blackhall & Koenig, 1998]. Inadequate knowledge of patients' cultures, preferences for communication, palliative care, decision-making, and choices at end of life inhibits care. Unless their preferences are known, patients may undergo unwanted, distressing, and costly treatments that impair their quality of life, increase suffering, and distress loved ones. The sociocultural values of many culturally diverse groups conflict with the values on which the use of advance directives is based.

Clinicians may lack sensitivity to the sociocultural beliefs that influence decisions affecting end-of-life care and may not have the knowledge to increase flexibility in practices and standards in the application of advance directives (Ersek, et al, 1998).

WHAT IS WORKING?

An expert such as a clinical or counseling psychologist trained in palliative care can help improve communication, explain end-of-life choices, and identify resources (e.g., home care, hospice care, pain management experts, spiritual support). Clinical or counseling psychologists are skilled in helping the health care team understand the patient's concerns and values and in helping families talk to each other. The psychologist can help people understand confusing medical terms and put their choices on paper, including decisions about feeding tubes or breathing machines and restarting the heart (CPR). Psychologists can also help treat the anxiety, depression, and other mental health distress that may result from your disease or stress near the end of life. Psychologists work with other professional caregivers such as nurses, social workers, and chaplains who also have important roles to play in helping provide compassionate care near the end of life.

Patients can plan ahead, write down their choices, and share these with loved ones and physicians. Advance planning for health care helps people determine their own futures, often with the support of significant others (Barry & Henderson, 1996). Respect for patient autonomy has been included in the medical codes of ethics and in United States law (Benbassat, Pilpel, & Tidhar, 1998). Since 1990, The Patient Self Determination Act (PSDA) has required health care providers to document advance directives and educate patients about their rights to accept or refuse treatment.

WHAT NEEDS TO BE DONE?

Researchers and service providers need a better understanding of how to provide compassionate care near the end of life to older adults from diverse cultures and backgrounds and of the role of cultural, religious, and socioeconomic factors influencing end-of-life decisionmaking. Improving healthcare providers' education, communication skills, and cultural sensitivity, conducting research, and creating policies that improve end of life care are recommended.

Reproduction of this text is encouraged. However, copies may not be sold. Comments and questions about this material should be directed to John Anderson, PhD, Staff Liaison to APA Ad Hoc Committee on End-of-Life Issues (Phone: (202) 336-6051; E-mail: janderson@apa.org).