

# Applying NASW Standards to End-of-Life Care for a Culturally Diverse, Aging Population

Cindy Raybould, LMSW  
Aiken County Government

Geri Adler, Ph.D., MSW  
University of Houston

*Journal of Social Work Values and Ethics*, Volume 3, Number 2 (2006)  
Copyright © 2006, White Hat Communications

This text may be freely shared among individuals, but it may not be republished in any medium without express written consent from the authors and advance notification of White Hat Communications.

## **Abstract**

The National Association of Social Workers (NASW) developed eleven standards for social work practice in end-of-life care. This review examines these standards and their relationship to current bioethical literature. Recommendations are made for training, research, and policy initiatives that support quality care at the end of life.

**Key Words:** Code of Ethics; Ethical Guidelines; Social Work Practice, Aging, Cultural Diversity

## **Introduction**

In response to increasing numbers of elderly with chronic illnesses and advances in medical technology that extend life spans, NASW (2004) issued standards for practice in end-of-life care. Eleven basic standards have been compiled to guide social workers in assessment, treatment, resource linkage, advocacy, and leadership in work with the dying.

NASW asserts that social workers in all practice settings must be aware of the skills, knowledge, values, and methods needed to work effectively with clients and their families in end-of-life situations. At the same time, social workers need to be able to apply these standards within the context of an aging population and culturally diverse families and communities who may hold different beliefs about illness, wellness, and medical care. The purpose of this article is to examine in greater detail the NASW standards and their relationship to current medical and bioethical literature and social work practice with older adults and diverse populations.

## Standards

### Standard 1: Ethics and Values

The first standard for professional practice with end-of-life care expects that social workers be guided by the values and ethics of their profession as well as contemporary bioethics. They should be familiar with social and legal issues, able to address questions confronting modern medicine, and show special consideration to vulnerable populations. As such, social workers require a minimum knowledge base and understanding of the ethical principles of justice, beneficence, nonmaleficence, understanding/tolerance, publicity, respect for the person, universality, veracity, autonomy, confidentiality, equality, and finality.

United States bioethics and healthcare, based on European-American values, emphasize patient autonomy and informed consent (Candib, 2002; Crawley, Marshall, Lo, & Koenig, 2002; Drought & Koenig, 2002; Kagawa-Singer & Blackhall, 2001; Luptak, 2004; Turner, 2002; Werth, Blevins, Toussaint, & Durham, 2002). This is reflected in the Patient Self-Determination Act (PSDA) of 1990, which mandates that patients admitted to healthcare facilities be provided with a statement of rights related to healthcare decisions and asked whether or not they have advance directives. It gives patients the right to be informed about their condition and to refuse life-sustaining treatment (Kagawa-Singer & Blackhall, 2001; Luptak, 2004; Teno, Lynn, Wenger, Phillips, Murphy, Connors, Desbiens, Fulkerson, Bellamy, & Knaus, 1997a). Whereas only 15 percent to 20 percent of all Americans have completed advance directives (Luptak, 2004), those of European descent are more likely to have written advance directives than persons from other ethnic backgrounds (Werth et al., 2002). Furthermore, the elderly and members of some cultural groups may eschew completing an advance directive, believing that their physician is best able to make health care decisions in their interest (Werth et al., 2002).

Autonomy and self-determination have been criticized as culture bound and insensitive to individuals from other cultures that are less individualistic, more family centered, and less disclosing of medical information to patients (Candib, 2002; Crawley et al., 2002; Drought & Koenig, 2002; Kagawa-Singer & Blackhall, 2001; Luptak, 2004; Turner, 2002; Werth et al., 2002). Disclosing diagnoses or talking about the possibility of death with patients from some cultures may even be viewed as malevolent (Candib, 2002; Turner, 2002). Drought and Koenig (2002) note the lack of empirical evidence supporting the autonomy paradigm of patient "choice" in end-of-

life (EOL) decision making. They state that the choice model is flawed because one cannot choose not to die of a terminal illness and because one's choice is based on the interpretation and presentation of information from the clinician. Studies have shown that even with advance directives in place, patients' wishes are not always followed (Bern-Klug, Gessert, & Forbes, 2001; Galambos, 1998; Teno et al., 1997b). Broadening the meaning of autonomy to include different ways of understanding health and illness and giving greater latitude to patients and their families in how they respond to illness and the end of life is merited (Turner, 2002). For example, Candib (2002) suggests the use of "autonomy-in-relation" (p.225), a concept that incorporates family context into end-of-life decision-making.

### **Standard 2: Knowledge**

Understanding the theoretical and biopsychosocial domains of end-of-life care is an important component to effective social work practice with the dying. This standard requires social workers to be knowledgeable about medical and social systems, including the socioeconomic, cultural, and spiritual dimensions in family life, and barriers to healthcare that may impede access to services. They must also be aware of the tenets of palliative care, whereby the control of pain and other physical symptoms along with meeting the patient's psychosocial needs are emphasized, rather than lifesaving measures (Kart & Kinney, 2001). Social workers apply their knowledge in direct work with families and as members of interdisciplinary treatment teams.

The need for further education and training in EOL issues for social workers has been well documented (Csikai, 2004; Kramer, Pacourek, & Hovland-Scafe, 2003; Luptak, 2004; NASW, 2004). Results from a survey by the Social Work End-of-Life Care Education Project revealed that 54% of health and hospice social workers had had no EOL content in their coursework, and only 31% of hospice social workers reported having adequate EOL preparation in their MSW programs (Csikai & Raymer, 2003). Ethical content, particularly principles of biomedical ethics and emerging ethical issues, received little attention. To assess the quality and scope of EOL content in social work textbooks, Kramer, Pacourek, and Hovland-Scafe (2003) examined 50 texts. They found that only three percent of the total pages reviewed were related to EOL care. Similarly, Luptak (2004) states that "references to care of older people at the end of life are more noticeable by their absence than by their presence in the social work literature" (p.12), adding that social workers need both a comprehensive knowledge base of practice and policy issues and finely tuned

skills related to end-of-life concerns. They further suggested that social work textbooks, like those of nursing and medicine, be revised to include more current information and citations on issues such as social workers' roles in pain management, equity and social justice, and advocacy.

In addition to a basic understanding of the biopsychosocial aspects of EOL care, social workers need to be aware of disparities in and barriers to medical care. The use of hospice and other palliative care services varies by age (Buntin & Huskamp, 2002), location (Virnig, Moscovice, Durham, & Casey, 2004), insurance coverage (Krakauer, Crenner, & Fox, 2002), and across populations (Candib, 2002; Crawley et al., 2002; Krakauer et al., 2002). Issues of mistrust, language differences, and lack of diversity in health care staff further complicate the ability to provide appropriate care to patients with values and beliefs different from the mainstream (Candib, 2002; Drought & Koenig, 2002; Kagawa-Singer & Blackhall, 2001; Krakauer et al., 2002; Reese, Ahern, Nair, O'Faire, & Warren, 1999; Werth et al., 2002).

### **Standard 3: Assessment**

The third standard requires that social workers include relevant biopsychosocial factors and the needs of the client and family, as expressed by the client, in a comprehensive culturally competent assessment. Several frameworks for assessment sensitive to cultural competence have been developed.

Panos and Panos (2000) provide a model for culturally sensitive assessment in health care settings that may be useful for EOL assessments. Their model includes six domains. The first domain requires social workers to examine their own cultural identity. The second and third domains stress the importance of assessing the patient's level of acculturation and its accompanying stresses. The fourth domain discusses assessing the patient's support systems. The fifth domain recommends that the patient's concepts and definitions of health, disease, healthcare utilization and healing be understood. Each of these components must be addressed before completing the final step of care planning.

Another approach for evaluating the level of cultural influence for patients and families uses the mnemonic ABCDE. Practitioners must evaluate the attitudes of patients and families toward truth telling and death and dying; beliefs related to death, afterlife, or miracles; context; decision-making style; and environment (Kagawa-Singer & Blackhall, 2001).

Candib (2002) likens her assessment to a conversation that assesses the patient within the context of family. Culturally competent practice requires that clinicians first show their interest in understanding their patient's culture and beliefs before proceeding with structured questions.

Finally, the World Health Organization Quality of Life (WHOQOL) instrument is a tool that can be used to assess quality of life for the dying (Saxena, O'Connell, & Underwood, 2002). Developed for use in a wide range of cultures, the WHOQOL assesses six domains believed important to quality life. These domains include physical well-being; psychological well-being level of independence; social supports and activities; environmental factors; and feelings about spiritual, religious and personal beliefs.

#### **Standard 4: Intervention/Treatment Planning**

It is imperative that social workers are competent in intervention and treatment planning. This standard notes several skills essential to successful practice with the dying, including preparing families for impending death of a loved one, facilitating communication, integrating grief theories into practice, and advocacy. Social workers must be able to effectively work with patients and families from different age groups, cultures, socioeconomic and education backgrounds, lifestyles, and states of mental health.

EOL interventions are complicated by the fact that more than half of those that die in a given year have never been considered to be terminally ill (Bern-Klug, 2004). The signs and symptoms of impending death are not easy to define even for physicians, let alone social workers. Covinsky, Eng, Li-Yung, Sands, and Yaffe (2003) concluded that frail elderly "have an end-of-life functional course marked by slowly progressive functional decline, with only a slight acceleration in the trajectory of functional loss as death approaches" (p.492). Bern- Klug (2004) suggests that social workers can honor patients' self-determination during this period of ambiguity. On a client level, social workers can help patients and families understand the medical situation and its potential impact on their lives. Using active listening skills, clinicians can normalize common feelings of doubt, frustration, and sadness. Finally, advance care plans can be made within the parameters of an uncertain death. At a societal level, social workers must advocate for policy level changes that acknowledge the ambiguity of end-of-life situations.

### **Standard 5: Attitude/Self-Awareness**

Social work attitudes and practices that convey empathy, sensitivity, and compassion are central to this standard. In their daily activities, clinicians must be flexible, respect the primacy of the patient and family in all aspects of care, be able to work with team members, act as advocates, be aware of compassion fatigue, and be secure in their professional identity and roles.

NASW (2004) recognizes the controversy of end-of-life issues related to multicultural value systems, and, whereas the organization does not take a position on the morality of these issues, NASW affirms the right of individuals to determine the level of their care. Issues such as assisted suicide, truth-telling, euthanasia, health care rationing, futile treatment, medical racism, and the right to refuse, withdraw, or withhold life-sustaining therapies (Bern-Klug et al., 2001; Crawley et al., 2002; Csikai, 2004; Ditillo, 2002; Krakauer et al., 2002; NASW, 2004; Reese et al., 1999; Turner, 2002; Werth et al., 2002) can pose ethical dilemmas. Social workers need to deal with these situations thoughtfully and with awareness of how their own beliefs and values influence their practice (NASW, 2004).

### **Standard 6: Empowerment and Advocacy**

This standard describes social workers' responsibilities to empower and advocate for their clients. Social work knowledge and skills in communication, group process, systems, social justice, values and ethics, and spirituality add a unique and important role to end-of-life care. On an individual level, social workers need to link clients with resources, support caregivers and families, address quality of life issues, and monitor and manage symptoms. On a broader level, social workers need to advocate for special populations, such as minorities, those with physical, mental or emotional disabilities, the elderly, and those in institutions (NASW, 2004).

Recommendations for empowering and advocating for clients can be found in much of the current literature. Bern-Klug, Gessert, and Forbes (2001) recommend that social workers advocate for their clients by helping them access medical care where they want to receive it, pursuing aggressive pain relief, securing financial support, negotiating with authority figures, and assisting with mental health and spiritual services. Luptak (2004) and Candib (2002) suggest that, in view of escalating controversy about the high cost of health care and the possibility of rationing, social workers need to advocate for the elderly by speaking out against the use of age as a criterion for withholding treatment in a culture that values youth. To eliminate barriers to hospice and palliative

care, social workers are encouraged to provide public education programs and to work with respected community members (Reese et al., 1999; Turner, 2002).

### **Standard 7: Documentation**

The seventh standard emphasizes the importance of documenting all aspects of social work services rendered. It further requires compliance with agency policies and all federal and state laws, particularly those with regard to confidentiality and privacy of medical information.

### **Standard 8: Interdisciplinary Teamwork**

The eighth standard acknowledges that the complex issues associated with end-of-life care frequently require the work of interdisciplinary teams. Social workers, with their expertise in group work and communication, play a pivotal role in the functioning of interdisciplinary teams, fostering team collaboration and being leaders in identifying biopsychosocial issues. While the strength of the team lies in the ability of diverse professionals working together, therein also lie challenges. Role blurring, differing professional values and theoretical bases, power differentials, and lack of knowledge about other professions' roles can act as barriers to effective inter-professional collaboration. To be successful, team members must recognize the expertise of other disciplines, communicate without professional jargon, clarify their roles, develop procedures for appropriate referrals, assign tasks on the basis of strengths, rotate leadership, and maintain a client-centered focus (Reese & Sontag, 2001).

### **Standard 9: Cultural Competence**

This standard reinforces the need for social workers to respect and understand how the history, culture, values, beliefs, and traditions of patients and their families affect their views about palliative and end-of-life care. Current literature about palliative and end-of-life care pays much attention to issues related to cultural competence and sensitivity. Areas of particular focus include the history of medical racism and unequal access to health care (Bern-Klug et al, 2001; Candib, 2002); ethnocentric values and ethics (Candib, 2002; Kagawa-Singer & Blackhall, 2001); communication, language barriers, and use of interpreters (Crawley et al, 2002; Office of Minority Health, 2001); and stereotyping individuals on the basis of their ethnic or cultural identity (Candib, 2002; Kagawa-Singer & Blackhal, 2001; Mazanec & Tyler, 2004; Panos & Panos, 2000).

To improve the medical care and eliminate racial and health disparities of the increasingly diverse U.S. population, the Office of Minority Health (2001) established fourteen national

standards for culturally competent care. The aim of these standards is to educate and familiarize health care providers and organizations with ways to understand and respond appropriately to the cultural and linguistic needs of their patients. Three standards are federal mandates, whereas the others are recommendations. The mandates require organizations to provide services that are compatible with their patients' values, beliefs, and traditions; to have a diverse staff representative of their service area; and to offer staff education and training in culturally competent care. Recommendations include providing language services through bilingual staff and interpreters; having written materials and signage in the language of commonly encountered groups; and maintaining current demographic, cultural, and epidemiological profiles of the community.

### **Standard 10: Continuing Education**

This standard requires social workers to stay current in their knowledge of the rapidly growing field of end-of-life care, participate in research, and collaborate with other organizations and institutions. Csikai and Raymer's (2003) assessment of social workers' educational needs noted that 87% of respondents received their continuing education units (CEUs) through seminars and conferences. They recommend a CEU curriculum that enhances competence in skills such as conducting bioethics consultations, assessing pain and suffering, and facilitating family communications. Because end-of-life issues are especially cogent for the elderly, educational efforts should be made that address the needs of this group (Luptak, 2004).

### **Standard 11: Supervision, Leadership, and Training**

Standard 11 requires social workers with expertise in palliative and end-of-life care to assume leadership roles. In addition to taking leadership in interdisciplinary teams as addressed in Standard 8, social work specialists can provide mentoring experiences for students and new social workers, advocate for and offer training, and develop and participate in research projects (Bern-Klug et al., 2001; Csikai, 2004; Reese & Sontag, 2001).

### **Conclusion**

Social workers play a significant role in meeting the complex psychosocial, economic, and medical needs of the dying. As an already aging population grows even larger with the addition of the baby boomer generation, the demand for social workers with expertise in palliative and end-of-life care in health and social services is expected to increase (Occupational Outlook, 2004). At the same time, the increasingly diverse older population will require that social workers be

prepared to deal with their clients' cultural values and traditions that, at times, may be in conflict with those of the profession.

In preparation, NASW developed eleven standards for social work practice in end-of-life care. These standards provide a useful framework to guide and inform social workers of the skills, values, and knowledge needed to practice effectively and ethically; however, the social work profession needs to take responsibility for ensuring that these standards are met. As evidenced in this review, several areas require continued attention and strengthening.

Assuming a strong leadership position in palliative and end-of-life care requires specific actions on the part of social work educators, practitioners, researchers, policy makers, and advocates. At all levels of social work education, there is a need to increase the amount and type of EOL training provided. Continued and added emphasis on ethics, multidisciplinary collaboration, aging-related education, and multicultural understanding is warranted. Practitioners must facilitate cooperation and collaboration with members of interdisciplinary treatment teams. As individual clinicians, they must provide exemplary psychosocial care – developing appropriate and effective treatment plans, counseling patients and their families, and providing bereavement support. Social workers would also benefit from a strong research agenda whereby interventions, pain management, quality-of-life, and other issues important to psychosocial care are examined. Finally, social workers must be active in policy development, advocating for policy changes that affect funding of and access to care at the end of life.

In conclusion, it is vital that social workers be prepared to assist our rapidly growing elderly and diverse populations as they enter the final stage of their lives. Utilizing these standards in combination with the Code of Ethics (2000) and a framework for cultural competency (NASW, 2001) all social workers will be able to practice responsively, appropriately, and ethically in ways that respect, honor, and acknowledge the values, beliefs, and customs of their clients.

## **References**

- Bern-Klug, M. (2004). The ambiguous dying syndrome. *Health & Social Work, 29* (1), 55- 65.
- Bern-Klug, M., Gessert, C., & Forbes, S. (2001). The need to resolve assumptions about end-of-life practice: Implications for social work practice. *Health & Social Work, 26*(1), 38- 47.
- Buntin, M. B., & Huskamp, H. (2002). What is known about the economics of end-of-life care for Medicare beneficiaries? *The Gerontologist, 42*, 40-48.
- Candib, L. (2002). Truth telling and advance planning at the end of life: problems with autonomy in a multicultural world. *Families, Systems & Health, 20*(3), 213-228.

- Covinsky, K., Eng, C., Li-Yung, L., Sands, L., & Yaffe, K. (2003). The last 2 years of life: Functional trajectories of frail older people. *Journal of the American Geriatric Society*, 51(4), 492-498.
- Crawley, L., Marshall, P., Lo, B., & Koenig, B. (2002). Strategies for culturally effective end-of-life care. *Annals of Internal Medicine*, 136, 673-679.
- Csikai, E. (2004). Social workers' participation in the resolution of ethical dilemmas in hospice care. *Health & Social Work*, 29(1), 67-76.
- Csikai, E. & Raymer, M. (2003). The social work end-of-life care education project: an assessment of educational needs. *Hospice & Palliative Care Insights*, 2, 8-9.
- Ditillo, B. (2002). Should there be a choice for cardiopulmonary resuscitation when death is expected? Revisiting an old idea whose time is yet to come. *Journal of Palliative Medicine*, 5(1), 107-116.
- Drought, T. & Koenig, B. (2002). "Choice" in end-of-life decision making: Researching fact or fiction? *The Gerontologist*, 42(Special Issue III), 114-128.
- Galambos, C. (1998). Preserving end-of-life autonomy: The Patient Self-Determination Act and the Uniform Health Care Decisions Act. *Health & Social Work*, 23(4), 275-281.
- Kagawa-Singer, M. & Blackhall, L. (2001). Negotiating cross-cultural issues at the end of life: "You got to go where he lives." *Journal of the American Medical Association*, 286(23), 2993-3001.
- Kart, C. S., & Kinney, J. M. (2001). *The Realities of Aging: An Introduction to Gerontology* (6th ed.). Boston, MA: Allyn and Bacon.
- Koenig, B. & Gates-Williams, J. (1995). Understanding cultural differences in caring for dying patients. *The Western Journal of Medicine*, 163(3), 244-249.
- Krakauer, E., Crenner, C., & Fox, K. (2002). Barriers to optimum end-of-life care for minority patients. *Journal of the American Geriatric Society*, 50(1), 182-190.
- Kramer, B., Pacourek, L., & Hovland-Scafe, C. (2003). Analysis of end-of-life content in social work textbooks. *Journal of Social Work Education*, 39(2), 299-320.
- Luptak, M. (2004). Social work and end-of-life care: a historical perspective. *Health & Social Work*, 29 (1), pp.7-15.
- Mazanec, P., & Tyler, M. (2004). Cultural considerations in end-of-life care: how ethnicity, age, and spirituality affect decisions when death is imminent. *Home Healthcare Nurse*, 22(5), 317-324.
- National Association of Social Workers. (2000). *Code of Ethics*. Washington, DC: Author.
- National Association of Social Workers. (2001). *NASW Standards for Cultural Competence in Social Work Practice*. Washington, DC: Author.
- National Association of Social Workers. (2002). *NASW Standards for Continuing Professional Education*. Washington, DC: Author
- National Association of Social Workers. (2004). *NASW Standards for Social Work Practice in Palliative and End of Life Care*. Washington, DC: Author.
- Occupational Outlook (2004). Social Workers. U.S. *Department of Labor, Bureau of Labor Statistics*. Retrieved on October 21, 2004, from <http://www.bls.gov>
- Office of Minority Health. (2001). *National Standards for Culturally and Linguistically Appropriate Services in Health Care, Executive Summary*. Washington, DC: U.S. Department of Health and Human Services.

- Panos, P. & Panos, A. (2000). A model for culture-sensitive assessment of patients in health care settings. *Social Work in Health Care, 31*(1), 49-62.
- Reese, D., Ahern, R., Nair, S., O Faire, J., & Warren, C. (1999). Hospice access and use by African Americans: Addressing cultural and institutional barriers through participatory action research. *Social Work, 44*(6), 550-559.
- Reese, D. & Sontag, M. (2004). Successful interprofessional collaboration on the hospice team. *Health & Social Work, 26*(3), 167-174.
- Saxena, S., O'Connell, K., & Underwood, K. (2002). A commentary: Cross-cultural quality-of-life assessment at the end of life. *The Gerontologist, 42*(Special Issue III), 81-85.
- Teno, J., Lynn, J., Wenger, N. Phillips, R. S., Murphy, D. P., Connors, A. F. Jr, Desbiens, N., Fulkerson, W., Bellamy, P., & Knaus, W. A. (1997a). Advance directives for seriously ill hospitalized patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention. *Journal of the American Geriatric Society, 45*(4), 500-507.
- Teno, J. M., Licks, S., Lynn, J., Wenger, N., Connors, A. F. Jr, Phillips, R. S., O'Connor, M. A., Murphy, D. P., Fulkerson, W. J., Desbiens, N., & Knaus, W. A. (1997b). Do advance directives provide instructions that direct care? *Journal of the American Geriatric Society, 45*(4), 508-512.
- Turner, L. (2002). Bioethics and end-of-life care in multiethnic settings: cultural diversity in Canada and the USA. *Mortality, 7*(3), 285-301.
- Virnig, B., Moscovice, I., Durham, S., & Casey, M. (2004). Do rural elders have limited access to Medicare hospice services? *Journal of the American Geriatric Society, 52*(5), 731-735.
- Werth, J., Blevins, D., Toussaint, K., & Durham, M. (2002). The influence of cultural diversity on end-of-life care and decisions. *American Behavioral Scientist, 46*(2), 204-219.

## Appendix

The full text of the NASW Standards for Social Work Practice in Palliative and End of Life Care can be found at:

<https://www.socialworkers.org/LinkClick.aspx?fileticket=xBMd58VwEhk%3D&portalid=0>