

End of Life Care

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PRACTICEUPDATE

SOCIAL WORKERS IN HOSPICE AND PALLIATIVE CARE SETTINGS

Karyn Walsh, ACSW, LCSW
Senior Policy Associate
End of Life Care
kwalsh@naswdc.org

“The hospice and palliative care movements in recent decades are reactions to the emphasis on cures, providing more caring and compassion to those in pain or at the end of life. It is in this area of caring for the whole person and nurturing him or her not only through the direct medical interventions, but also the psychosocial-spiritual consequences of illness that offer an opportunity for social workers” (NASW News, 2003).

Historically, social workers have been part of hospice care teams and are now becoming more integrated into palliative care teams and work. The knowledge needed for these areas of practice is highly specialized and constantly changing. This practice update examines the definitions of hospice and palliative care, the social work role in these areas, and current work and resources for social workers seeking knowledge and expertise for practice. The term “end of life” is used throughout this document in relation to palliative and hospice care.

HOSPICE AND PALLIATIVE CARE

Hospice/palliative care is a model of quality, compassionate care for individuals facing a life-limiting illness or injury. Using a multidisciplinary approach, care is assessed and delivered addressing all facets of a person’s illness, injury, or pain. Attention is given to physical and psychosocial needs, pain management, and emotional and spiritual support tailored to the person’s needs and wishes. Support is given to the individual’s loved ones as well. At the heart of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary

support to allow us to do so (National Hospice and Palliative Care Organization [NHPCO], 2003).

“**Hospice** focuses on caring, not curing and, in most cases, is provided in the patient’s home. Hospice care is also provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations” (NHPCO, 2003).

Over time, the hospice approach has grown to include persons who have life-limiting illnesses, including cancer, and also whose prognosis is longer than six months. Those persons who follow a disease trajectory of a chronic and unpredictable course—who may be referred to as the “chronically dying,” or the “chronically terminally ill.” The expansion of the hospice philosophy to extend care correlates with the approach of palliative care to offer the best quality of life for individuals and their loved ones to have control of pain, of other symptoms, and of psychological, social and spiritual problems (The Hastings Center, 2003, p. 7).

Palliative care is a care model that improves the quality of life for individuals and their loved ones “facing the problems associated with life-threatening illness, through the prevention and relief of suffering of early identification, and impeccable assessment and treatment of pain and other problems, psychosocial and spiritual” (World Health Organization, 2003).

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Palliative care also:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor to postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Enhances quality of life, and may also positively influence the course of illness; and
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes investigations needed to better understand and manage distressing clinical complications (World Health Organization, 2003).

PALLIATIVE AND END OF LIFE CARE EMERGING AS IMPORTANT PRACTICE AREAS FOR SOCIAL WORKERS

With the U.S. population aging, and advances in medical technology prolonging life, social workers are increasingly called into this specialized field. The use of medications is at an all time high, and medication misuse or underusage is a social issue, so social workers are in a unique position to increase their skills and knowledge in palliative care.

In a recent study of almost 400 health care social workers practicing (both directly and administratively) in end of life care, researchers found that social workers identified skill competence “as the most needed in assessing complex needs of patients and families; communication of psychosocial needs of patients and families to team members; facilitation of effective family and team communication; and provision of crisis intervention.” (Csikai and Raymer, 2003) Specialists in end of life care should possess generalist skills such as resource linkage, case management and advocacy, as well as advanced skills such as conducting bioethics consultations; assessment and management of pain and suffering; and resolution of ethical problems in end of life care (Csikai and Raymer, 2003).

Hay and Johnson (2001) looked at the fundamental skills and knowledge for hospice and palliative care social workers. Using various theoretical perspectives, core clinical competencies were identified and are summarized below.

I Assessment Process

- Psychosocial history
- Mental health status
- Sexuality
- Spirituality
- Risk assessment
- Care plan development
- Long term care planning

II. Co-Case Management/Team Work

- Hospice program criteria
- Confidentiality
- Advocacy
- Proactively accessing resources
- Insurance benefit
- Care planning with multiple disciplines
- Working closely and proactively with RN/Case Manager
- Documentation
- Infection control

III. Interventions/Counseling

- Working with diversity
- Interviewing skills
- Supportive counseling/with adults, children, and adolescents
- Patient/family education
- Life review
- Crisis intervention
- Suicide precautions/interventions
- Symbolic messages of the dying
- Loss and grief theory

IV. End of Life Care Planning

- Knowledge of durable power of attorney/living wills/directives to physicians
- Decision-making capacity/patient representation
- Provision of care for dependents
- Signs and symptoms of impending death
- Rituals/practices
- Funeral planning

(NHPCO, 2001, pp. 12-13)

Pain in America: A Research Report, released in 2000, found that nine in ten Americans suffered from regular pain, and that close to 26 million citizens suffered from severe pain (American Pain Foundation, 2003). The results are needless and agonizing suffering, lost productivity economically, and pervasive psychological damage, including depression, disability, anxiety, poor self-esteem, family dysfunction, social isolation and even suicide. There is a need and an opportunity for social workers to practice palliative care. Social workers in all practice settings should be aware of pain and its symptoms. Across all practice settings, social workers' ability to empathize with those experiencing pain is critical, so that they can intervene to improve their clients' quality of life.

THE ROLE OF SOCIAL WORKERS IN HOSPICE AND PALLIATIVE CARE

Both the National Hospice and Palliative Care Foundation's *Standards of Practice for Hospice Programs* (2000) and the Joint Commission on Accreditation of Healthcare Organizations' (JCAHO) *Standards Manual for Hospice* (2002) include standards that have a direct impact on hospice and palliative care social work practice. The standards for both organizations relate to staffing ratios, competency and staff development, supervision, credentials, professional standards, documentation, assessment and plan of services, and continuity of care/services.

Pain management is complex to learn. Social workers may obtain this knowledge through educational courses or in practice from supervisors or mentors. Many social workers learn about palliative care and pain management as they actively gain practice experience.

The role of social workers in palliative care/pain management can include:

Education: Social workers can help patients describe pain, so they can communicate better with health care providers. Social workers can inform patients what their rights are in pain management and provide information on complementary therapies such as physical therapy, massage, acupuncture, and meditation.

Advocacy: Social workers can advocate for patients by suggesting a pain evaluation with team members. Social workers can advocate for those who are underserved in the treatment of persistent pain.

Interventions: Social workers can offer interventions such as problem solving, relaxation, cognitive coping statements, hypnosis, therapeutic use of pain diaries, reframing, pacing, distraction, and visualization.

THE SOCIAL WORK ROLE WITH UNDERSERVED POPULATIONS IN PALLIATIVE AND END OF LIFE CARE

The NASW *Code of Ethics* (1999) states, "The primary mission of the social work profession is to enhance human well-being and help meet the basic needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty." Further, social workers are sensitive to "cultural and ethnic diversity and strive to end discrimination, oppression, poverty, and other forms of social injustice" (NASW *Code of Ethics*, 1999, p. 1). The need and opportunity for social workers to serve and advocate for vulnerable populations in palliative and end of life care is enormous, and addressing it is an essential part of practice.

Addressing health disparities in palliative and end of life care is an increasingly important practice area for social work. "In 2000, 82 percent of all hospice patients in the U.S. were white; eight percent were African American, two percent were Hispanic, two percent were identified as "other," and six percent were not classified by race or ethnicity. These data, together with reports that African Americans and Hispanics receive less pain medication than whites and a growing body of cultural research on death and dying, indicate that race and ethnicity are associated with barriers to hospice care" (The Hastings Center, 2003, p. 39). Identifying and overcoming these barriers is important in improving access to palliative and end of life care currently and will be more crucial in the future. "Between 1999 and 2030, the proportion of people of color age 65 and older in the U.S. is projected to rise from 16 percent to 25 percent" (The Hastings Center, 2003, p. 39).

The lack of treatment of pain is highest among underserved, vulnerable populations, including the elderly, nursing home residents, minorities, and low-income socioeconomic classes. Impoverished individuals have difficulty paying for, and having access to, pain medication and evaluation. The Hospice News Network (2003) refers to several studies that demonstrate racial and ethnic groups have more pain and receive less treatment. Examples include:

- Emergency room studies found that Hispanics with broken bones were twice as likely as non-Hispanic whites to "go without pain medication" while in the ER.
- A study of pain in cancer patients reported Hispanics and African Americans were less likely to be assessed for pain, and failed to receive the level of pain medication recommended by the World Health Organization.
- African American nursing home residents with cancer had a 64 percent greater chance of getting no pain medication than non-Hispanic whites.

Social workers can address health disparities in palliative and end of life care by using several approaches. With their training in cultural competence and awareness, social workers can work with racial and ethnic communities or as representatives of organizations to improve understanding of how pain and end of life care and decisions are perceived and managed. Through this knowledge and collaborative work, social workers may be able to help underserved populations access needed care. Social workers can also assist vulnerable persons in accessing available resources, or may participate in the development of new resources to help pay for these services. Social workers can also become political advocates for funding and awareness of the health disparities and other important issues in palliative and end of life care.

THE ROLE OF NASW IN PALLIATIVE AND END OF LIFE CARE

NASW leadership participated in the Social Work Summit on End of Life and Palliative Care in 2002 which brought together 35 social work professionals involved in palliative and end of life work to design an agenda to improve care for the dying and their families. The final agenda included organized professional leadership, standards of practice, and increased preparation at all levels of social work education. "Often limited education is given to strengthening these areas in multidisciplinary education, practice, research, and policy development. Participants agreed that, in order to more adequately reflect the breadth and depth of social work practice and patients' and families' needs, social work should encompass palliative care, end of life care and grief work" (Project on Death in America, 2003).

This summit is one of many examples of social work leadership in palliative and end of life care. NASW has also developed *Standards for Social Work Practice in Palliative and End of Life Care*, funded by a grant from the Project on Death in America. These practice standards look at the competencies needed for social workers in this field. NASW brought together social work experts from the field of palliative and end of life care who contributed to standards development. The standards will go to the NASW board of directors for approval in January 2004, and will be available for NASW members in 2004.

With funding from the Emergency Medical Services for Children, NASW collaborated with many of its state chapters in both 2002 and 2003 to present 30 workshops on the *Bereavement Practice Guidelines for Social Workers in Emergency Departments*. In December of 2003, all trainings will be complete, and approximately 750 social workers across the U.S. will be trained in these guidelines.

Information about these trainings and information on how to obtain related workshop documents can be accessed from the NASW Web site at <http://www.socialworkers.org/practice/bereavement/bereavement.asp>

NASW is active in policy development and projects in palliative and end of life care for the social work profession and those affected by palliative and end of life care. For example, the Association participated in a multidisciplinary conference with the Ambulatory Pediatric Association on the development of a consensus statement for family presence during a child's resuscitative and treatment procedures. Many practicing social workers, primarily in health care settings, are aware of this growing trend to allow parents and caregivers to be present during treatment and resuscitative procedures. There is overwhelming data to support family presence in these situations, and strategies to overcome medical provider hesitance and lack of knowledge of its benefits. The Ambulatory Pediatric Association will be drafting a consensus statement on this practice next year.

IMPLICATIONS FOR SOCIAL WORKERS

NASW's Policy Statement regarding end of life decisions is centered on the principle of self-determination. Client self-determination and choice in matters of life and death are at the heart of the profession's stance in end of life care and decisions (*Social Work Speaks*, 2003). With that said, social workers in palliative and hospice care settings are presented with ethical dilemmas every day in practice. Social workers are constantly reminded of their profession's values and code of ethics. Knowing where to turn for consultation, education and resources relevant to social work practice in this field is crucial to one's practice and self-awareness. A list of resources is included with this practice update for social workers.

CONCLUSION

The need for social workers in palliative and hospice care settings is increasing, as are the issues and dilemmas presented in practice due to longer life spans, medical advances in technology, and the implications of such technology for clients, families and systems providing care. Social workers are challenged by time and funding limitations to provide the services to clients in demanding practice settings. Yet, social workers need to have opportunities to contribute and participate in research, policy making, education, and practice initiatives for this specialization in social work. Social workers are also becoming well-versed in cultural competence, which will help them address current and future needs for all persons impacted by palliative and end of life care.

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RESOURCES

- Center for the Advancement of Palliative Care** provides important information on palliative care. Available at <http://www.capc.org>
- Last Acts** is a national coalition of organizations dedicated to improving care for people who are dying and their families. An electronic newsletter is available for clinicians to receive weekly updates on activities in end of life care. Available at <http://www.lastacts.org>
- National Association of Social Workers** provides practice information and palliative and end of life activities on its website. Available at <http://www.socialworkers.org/practice/bereavement>
- National Hospice and Palliative Care Foundation** has printed and electronic resources for social workers. Available at <http://www.nhpco.org>
- Promoting Excellence In End of Life Care** offers an electronic newsletter by the aforementioned national program office of The Robert Wood Johnson Foundation. Available at <http://www.promotingexcellence.org> (You can sign up to receive the electronic newsletter.)
- Resource Enrichment Center** for improving care at the end of life is a social work online resource at the University of Connecticut School of Social Work. The resource aims to create access to end of life care training, education, reference library, resource links, legislative and services updates. Available at <http://www.eolresource.htfd.uconn.edu>
- Social Work Leadership Development Awards**, Project on Death in America, highlights the work of leading social workers in the field of palliative and end of life care. Available at <http://www.swlda.org>
- Social Work Network in Palliative and End of Life Care Listserv**, Department of Pain Medicine and Palliative Care, Beth Israel Medical Center. If you would like to join, send an email to taltilio@bethisraelnv.org
- The Life Institute** is a nonprofit educational organization that develops and implements programs in advanced illness and end of life care. *Conversations from the Heart*, a booklet which compiled resources for talking with children about a parent's serious illness and/or death, can be downloaded free of charge from the home page Web site at <http://www.thelifeinstitute.org>