HOSPICE SOCIAL WORK: LINKING POLICY, PRACTICE, AND RESEARCH

A REPORT FROM THE MARCH 25, 2010 SYMPOSIUM
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Planning for the symposium occurred in partnership with the Hospice Social Work: Linking Policy, Practice and Research social work organization (NHPCO), a provider organization with a collaborative initiatives.

In advance of the symposium, the Social Work Policy Institute hospice legislation, standards and credentials, continuing edu activities of national organizations involved with hospice, an research and researchers. This information helped to inform its included in the Appendix of this report.

### Hospice Facts

Source: National Hospice and Palliative Care Organization, 2009

- There are currently more than 4,800 hospice programs in the United States that
- It is estimated that about 38.5% of deaths are under hospice care
- Just under half of hospice care organizations are for-profit (46%), half are non-p the U.S. Department of Veterans Affairs)
- Nearly all hospice care is paid for through the Medicare or Medicaid Hospice Ben Social workers have an average caseload of 30-42 patients; nurses have an aver

### Hospice History

The term, “hospice” originates from the Latin word “hospitium” or guesthouse. It described a house provided for sick persons returning from pilgrimages. The first modern hospice movement, which used a team approach to professionally administer pain management and compassionate caregiving to the dying, was founded near London in the 1960s by Cicely Saunders, a British social worker, nurse and physician. Hospice care arrived in America in 1974, with the first center opening in New Haven, Connecticut (HFA, n.d.; Cicely Saunders Foundation, 2010).
Appendix B included expert presentations (see Appendix C) and facilitated discussions. Following the presentations, the participants engaged in roundtable deliberations on the current status of hospice psychosocial research, emerging practices in end-of-life care, enhancing the social worker’s role on the interdisciplinary team, and strengthening researcher/practitioner/policy connections.

Drawing from the presentations and discussions, recommendations were developed to address the challenges identified in regard to research, practice, policy and professional development.

The symposium was particularly timely since the Conditions of Participation (CoP) that set the minimum federal standards for hospice services were comprehensively revised by the Centers for Medicare and Medicaid Services (CMS) in 2008 and are now being implemented. Thus, the revised standards could both serve as input to the symposium deliberations and be a catalyst for recommendations that emerged from the meeting. In addition, among NASW’s hospice-focused activities, plans were underway for the NASW 2010 Annual Practice Conference, Social Work’s Critical Role in End of Life Care (www.socialworkers.org/nasw/conferences/boston2010/default.asp) to be held August 3-4, 2010 in Boston, MA. The symposium outcomes could help shape the agenda for that conference. In addition, the symposium helped to strengthen the connections between the social work community and CMS by enhancing CMS’s knowledge of social work practice and increasing social work’s awareness of CMS’s rule-making procedures and its priorities regarding quality improvement.

Planning for the symposium occurred in partnership with the National Hospice and Palliative Care Organization (NHPCO), a provider organization with which NASW has several collaborative initiatives.

In advance of the symposium, the Social Work Policy Institute pulled together information on hospice legislation, standards and credentials, continuing education opportunities, the roles and activities of national organizations involved with hospice, and hospice relevant social work research and researchers. This information helped to inform the agenda for the meeting and is included in the Appendix of this report.

Appendix A included representatives from social work research representing hospice programs, federal research and regulatory foundations. The anticipated outcome was the development of state of hospice social work. The symposium agenda (see ABOUT HOSPICE

Hospice services help patients and their families deal with the complexity of end of life and include palliative care and comfort services as well as follow-up bereavement. One of the unique qualities of hospice services is that follow-up bereavement services with the patient’s loved ones after the patient’s death is a core service that is offered. Hospice services may take place in the patient’s own home, in residential hospice programs, and increasingly as an adjunct to nursing home, hospital and assisted living services. Hospice services

Hospice Facts
Source: National Hospice and Palliative Care Organization, 2009

• There are currently more than 4,550 hospice programs in the United States that served 1.45 million people in 2008.
• It is estimated that about 38.5% of deaths are under hospice care.
• Just under half of hospice care organizations are for-profit (46%), half are non-profit (54%), and 4% are operated by the government (e.g., U.S. Department of Veterans Affairs).
• Nearly all hospice care is paid for through the Medicare or Medicaid Hospice Benefit, which covers about 80% of hospice patients.
• Social workers have an average caseload of 24.3 patients; nurses have an average caseload of 12.3 patients per caseload.

ABOUT HOSPICE

Hospice services help patients and their families deal with the complexity of end of life and include palliative care and comfort services as well as follow-up bereavement. One of the unique qualities of hospice services is that follow-up bereavement services with the patient’s loved ones after the patient’s death is a core service that is offered. Hospice services may take place in the patient’s own home, in residential hospice programs, and increasingly as an adjunct to nursing home, hospital and assisted living services. Hospice services
are provided to persons who are considered to be near the end of life (usually with a life expectancy of six months or less) who are living with cancer, HIV/AIDS, Alzheimer’s disease, heart disease, chronic respiratory diseases or other serious medical conditions. Hospice services are provided to individuals in the context of their families, and are provided to both children and adults.

The federal role in hospice care began in 1982 and was made permanent in 1986, by the Medicare Hospice Benefit Amendment to the Social Security Act (Title 18, Section 1861, Subsection d(e). The law defines hospice care and the extent to which a patient must be terminally ill in order to qualify for services. Further, the law stipulates the minimum requirements for services administered such as core services and the required involvement of a doctor, nurse, pastoral or other counselor, and a social worker on the interdisciplinary care team (see Appendix D for excerpt from the Social Security Act). Following passage of the law, the Health Care Financing Administration (HCFA), which is now called the Centers for Medicare and Medicaid Services (CMS), developed Conditions of Participation (CoP) which set the minimum federal standards by which hospice programs must operate.

In addition to the federal minimum standards for hospice care which are monitored through a survey and certification process, national organizations have also developed hospice standards, accreditation guidelines, credentials and certifications for both programs and hospice professionals.

In 2008 after an extensive review process, CMS issued the revised CoP. This revision resulted in a change to the personnel qualifications for social workers providing hospice care that from the profession's perspective somewhat weakened the requirement. Whereas the original CoP required either a bachelor's or master's degree in social work, the revised CoP allows a person with a degree in a field other than social work to serve as a hospice social worker under the supervision and clinical guidance of an MSW. During the symposium, representatives from CMS cited that one reason that the end result was a broadened social work personnel qualification in the newly revised CoP was the lack of a robust body of research that clearly supported the need for individuals to hold a specific degree in social work in order to ensure quality patient care and safety. (See Federal Rules for more discussion of CMS and hospice regulations).

This current requirement is of concern to the social work community, other service providers and advocates because it can result in someone providing social work services in hospice that may have little or no hospice experience or professional training as a social worker. Understanding the social work role in hospice and fulfilling those functions is a critical aspect of ensuring quality psychosocial care.

Federal Social Work Qualifications for Hospice Care
Conditions of Participation 418.114 (b) Standard: Personnel qualifications for certain disciplines:

3. Social worker, a person who:
   (i) (A) Has a Master of Social Work (MSW) degree from a school of social work accredited by the Council on Social Work Education and one year of social work experience in a healthcare setting; or
   (B) Has a baccalaureate degree in social work from an institution accredited by the Council on Social Work Education; or a baccalaureate degree in psychology, sociology, or other field related to social work and is supervised by an MSW as described in paragraph (iii)(1)(A) of this section; and
   (ii) Has one year of social work experience in a healthcare setting; or
   (iii) Has a baccalaureate degree from a school of social work accredited by the Council on Social Work Education, is employed by the hospice before December 2, 2008, and is not required to be supervised by an MSW (CMS, 2009, p.32218).
WHAT IS HOSPICE SOCIAL WORK?

The overall model for hospice services is viewed as a psychosocial model, valuing the importance of the interdisciplinary perspective beyond what a physician and nurse might provide. A hospice social worker is a member of the interdisciplinary team whose primary function is to provide psychosocial support to the patient/family unit, define social service goals for alleviating identified problems, and provide both counseling and casework to meet the established service goals.

Hospice Social Worker Roles and Responsibilities

Hospice social workers help develop and implement the interdisciplinary plan of care with the goal of delivering the highest quality social services to patients and families. This plan of care should aim to ensure that continuity and comprehensive care are provided. Hospice social workers’ responsibilities, as members of the interdisciplinary team include:

- Administering a psychosocial assessment and consultation,
- Providing patient advocacy (on the team, in the program, in the community),
- Educating the family and team on psychosocial issues, family and group dynamics,
- Working toward fostering team collaboration,
- Conducting joint visits with other team members to enhance care,
- Arranging group meetings with multiple members of the family, facility, and hospice care team, and
- Participating in medical social worker on-call rotation/schedule in order to meet the needs of patients and families.

In addition, hospice social workers also:

- Maintain appropriate documentation in the hospice patient chart,
- Attend weekly team meetings for patient chart review,
- Participate in training and in-service education,
- Assist in developing and coordinating relations between the hospice agency and outside medical/health care services, and
- Facilitate bereavement group activities.

Social workers provide a critical element to achieving the hospice care mission by providing insight to the patient’s, caregivers’, and/or families’ psychosocial needs, and are essential in helping to both prevent and cope with crisis and deal with issues as the illness progresses. The NASW Code of Ethics and NASW’s Standards for Practice in End-of-Life Care call hospice social workers to act as an advocate for the patient and family members and to strive to include them in developing treatment plans that work to meet the biological, social, emotional, and spiritual needs of both the patient and family. Social workers must engage the interdisciplinary team, the family, and at times other outside resources and supports, to help develop a comprehensive plan of care.
that minimizes unmet needs. Furthermore, social workers must also seek to understand the treatment philosophies and motivations of other disciplines in developing plans of care.

Hospice Social Worker's Clinical Responsibilities

- **Assessment:**
  - Physical
  - Social network, family
  - Psychosocial
  - Cultural and spiritual
  - Financial and legal
  - End of Life Needs
  - Home and environment safety
  - Protective issues: abuse and neglect (physical, sexual, fiduciary)

- **Interventions:**
  - Specific symptom relief (interventions for fear, grief, depression, anger, pain, etc.)
  - Patient and family education
  - Community and internal resources and referrals: including governmental benefits
  - Discharge planning
  - Assistance in securing documents
  - Patient and family advocacy
  - Identification of abuse and neglect
  - Bereavement care

- **Education and interventions for pediatric patients, siblings and for children of adult patients**

- **Social workers provide to the team:**
  - Psychosocial consultation
  - Patient advocacy — on the team, in the program, in the community
  - Education re: psychosocial issues/family and group dynamics
  - Care Plan Development — Team meeting participation
  - Joint visits with other team members to enhance care
  - Group meetings (patient, family, facility, hospice team, etc.).

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1 Prepared by Beckwith and Fried for presentation at the Hospice Symposium.
CURRENT STATUS OF HOSPICE SOCIAL WORK RESEARCH

Research about hospice by social workers cuts across three major areas. It evaluates social workers' roles in hospice care settings; provides the social work perspective on hospice practices and interventions; and identifies issues related to the education and training of hospice social workers. Social work research about hospice care brings a critical perspective that helps to add depth and meaning to our understanding of these services.

Up to now there has been no rigorous systematic review of hospice social work research and there are few studies that specifically examine the effectiveness of hospice social work practice. The following provides an overview of recent research by social workers and about social work relevant topics (See Appendix K for full citations). It should be noted that this analysis is not systematic in its development and therefore may exclude some related and pertinent research topics and/or authors.

Research on the role of social workers in hospice explores:
- The nature of roles of social workers in various end-of-life and palliative care settings, e.g., hospital palliative care, home hospice, prison hospice, etc. (Bradben, 2005; Bronstein & Wright, 2006; Lawson, 2007).
- Outcomes of social workers involvement in specific interventions and certain stages of hospice service delivery, e.g., assessment, treatment, bereavement (Reese & Raymer, 2004).
- Assessing client and caregiver satisfaction with social work (Archer & Boyle, 1999; Doherty & Deweaver, 2004).

Research on perspectives about social workers' roles considers:
- Addressing ethical issues of care such as “death with dignity” practices in Oregon (Miller, Hedlund & Soule, 2006).
- Managing ethical issues: Consider medical condition, involvement of family, denial of terminality (Calkins, 2004).
- Philosophies on palliative and end-of-life care from oncology social workers vs. hospice social workers v. nursing home social workers (Becker, 2004).

Dual Pathways of Social Work Research
- PATHWAY ONE relates to the expertise and perspective on clients, systems, ethics, cultural competence, and communities that a social work researcher brings to research questions.
- PATHWAY TWO relates more specifically to research on the development and implementation and effectiveness of specific interventions used by social workers.

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- Philosophies on palliative and end-of-life care from oncology social workers vs. hospice social workers v. nursing home social workers (Becker, 2004).
Research on social workers’ roles as a member of the interdisciplinary team addresses:

- Strengths and challenges social workers face in using collaboration in service delivery (Parker Oliver, Bronstein, & Kusznefski, 2005; Parker Oliver & Peck, 2006).
- Interfacing with caregivers about pain management (Parker Oliver, Wittenberg-Lyles, Washington, & Sehrarat, 2009).
- Increasing patient and family involvement with interdisciplinary teams (Parker Oliver, Porock, Demiris, & Courteney, 2005).

Research on family and caregiver involvement examines:

- What, if any, unmet needs the families may have (Arnold, Martin, Griffith, Person & Graham, 2006).
- Conflict within the family at life’s end (Kramer, Roelk, & Auer, 2006).
- The roles of family caregivers in decision-making, assistance with daily living activities, and medication management (Hauser & Kramer, 2004).
- Coping with end-of-life transitions in caregiving, including comprehending terminality, near-acute care, executive functioning, and final decision making (Waldrop, Krenny, Milch & Finn, 2003).
- Relationships between high levels of caregiver grief and Alzheimer’s Disease (Sanders, Ott, Kelber, & Noonan, 2008).
- Psychosocial stressors in end-of-life caregiving (Waldrop, Milch & Krenny, 2003).
- Consideration of the family’s concerns and values in determining care (Cukai, 2004).

Research that tests and examines interventions includes:

- Study of the FACES Project, a tool to assess caregiver strain (Townsend, Ishier, Vargo, Shapiro, Pitorak & Matthews, 2007).
- Use of formally structured social work visits to accomplish advanced care planning at home (Ratner, Norlander & McSteen, 2003).
- Lessons learned from “model” programs (Kramer & Auer, 2001).

Social work research also seeks to understand a patient’s perspective on the process of dying by assessing:

- How patients seek control over decision-making, independence, mental attitude, daily living activities, and relationships (Schroepfer, Noh & Kavanaugh, 2009).
- The reasons people desire to hasten death, e.g., poor quality of life and concern for suffering (Arnold, Atkin, Person & Griffith, 2004).
- How conflictual social support systems predict the consideration of hastening death (Schroepfer, 2009). 

With the field of hospice care continually expanding, research and development are needed to ensure competent social workers for careers in hospice. Research on hospice social workers:

- The ambiguity of dying and the decisions behind dying (Bern-Klug, 2008).
- “Possible” or “ambiguous dying” among nursing homes (Bern-Klug, 2006).
- How older adult dyads negotiate the ambiguity of dying at life’s end (Gardner, 2008).
- Short hospice utilization: Can this be enough? (Waldrup & Krenny, 2006).
- The relationship between terminal restlessness with pain and family (Parker Oliver & Peck, 2006).
- The under-utilization of hospice services in long-term care facilities (Rachlin, 2007).
- The roles of family caregivers in decision-making, assistance with daily living activities, and medication management (Hauser & Kramer, 2004).
- Investigating what matters to older African American patients (Kramer & Auer, 2005).
- Examining the specific social stressors and facilitators of social support systems that predict the consideration of hastening death (Schroepfer, 2008).
- Identifying factors that contribute to the under-utilization of hospice services (Waldrop & Krenny, 2007).
- How comfort care should be defined (Waldrop & Krenny, 2003).
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“Possible” or “ambiguous dying” among nursing home residents (Bern-Klug, 2005; Bern-Klug, 2006).

How older adult dyads’ negotiate the ambiguity of dying and the search for meaning at life’s end (Gardner, 2008).

Short hospice utilization: Can this be enough? (Waldrop & Rinfrette, 2009).

The relationship between terminal restlessness with psychosocial & spiritual distress (Head & Faul, 2005).

Research on the quality of dying in long-term care facilities analyzes:

- Family perspectives on what defines a good death in a long term care setting. Factors examined include staffing adequacy, training, consistency, facility environment, staff empathy, hospice contributions (Munn & Zimmerman, 2006; Munn, Dobbs, Meier, Williams, Biola & Zimmerman, 2008),
- The under-utilization of hospice services in long term care (Chapin, Gordon, Landry & Rachlin, 2007).
- How comfort care should be defined (Waldrop & Kirkendall, 2009).

Social work research evaluates the experiences of diverse and under-represented populations who are facing issues of advanced illness and end-of-life care by:

- Investigating what matters to older African Americans at life’s end and what influences their decisions to complete or not complete advanced directives (Bullock, McGraw, Blank & Bradley, 2005).
- Exploring racial variations in end-of-life decision-making (Hopp & Duffy, 2000).
- Examining the specific social stressors and facilitators in the inner city and with minority populations who reside there (Francoeur, Payne, Ravas & Shim, 2007).
- Examining caregivers experiences with hospice and patients who have end-stage dementia (Sanders, Butcher, Swails, & Power, 2009).
- Identifying factors that contribute to the under-utilization of hospice services by African Americans (Washington, Bickel-Swenson, & Stephens, 2008).

With the field of hospice care continually expanding, research also addresses the efforts to prepare competent social workers for careers in hospice. Research on the education and training of hospice social workers:

- Stresses the need to expand curriculum in MSW programs and better define the role of social workers in hospice care through education and training (Huff, Wesenfluh, Murphy & Black, 2006).

SOCIAL WORK POLICY INSTITUTE

• Communication
• Mental health concerns and services
• The policy/practice nexus
• Diversity and health care disparities
• Continuity, gaps, fragmentation, transitions in care


In addition to the social work research agenda, national organizations, such as the NHPCO (2004) and the Hospice and Palliative Nurses Association (HPNA) have released agendas focusing on various elements of care and service administration for palliative and end-of-life care. The efforts of social work researchers contribute both to the discipline-specific and interdisciplinary research agendas. In the coming year, the effort to increase interdisciplinary research will result in the release of a collaborative research agenda from the American Academy of Hospice and Palliative Medicine (AAHPM), NHPCO, HPNA, and the Social Work Hospice and Palliative Care Network (SWHPN).

John A. Hartford Foundation's
The Geriatric Social Work Initiative www.gswi.org

Launched in 1999, the John A. Hartford Foundation’s Geriatric Social Work Initiative has 2 key programs that have helped to support hospice and end-of-life focused research by social workers. The Hartford Faculty Scholars Program supports early career social work researchers interested in aging. The Hartford Doctoral Fellows Program provides dissertation support to those social work doctoral students examining gerontology relevant topics. Appendix O provides information on Hartford Scholars and Fellows who have pursued hospice-relevant studies.


Research Agenda

- Individual and family care needs and experiences
- Quality of care
- Decision-making
- Grief and bereavement
- Pain, symptom management
- Curriculum

In addition to these areas, national organizations such as the NHPCO, HPNA, and the Social Work Hospice and Palliative Care Initiative have released agendas focusing on the development of hospice-specific educational programs. The agendas align with the social work professions’ mission and agenda emerged from the 2002 and 2005 Social Work Hospice and Palliative Care, organized by the Social Work Leadership Institute funded by the Open Society Institute’s Project on Death in America. The Leadership Development Program provides dissertation support to those social work doctoral students examining issues in palliative and end-of-life care. The Hartford Faculty Scholars Program supports early career social work researchers with a focus on hospice-relevant studies.

Hospice Social Work: Linking Policy, Practice, and Research

Revising and Implementing the Conditions of Participation

The Centers for Medicare and Medicaid Services (CMS) regulates hospice programs in the United States. Hospice providers and suppliers must be paid by Medicare for the hospice services that they administer to Medicare beneficiaries. This is enforced by the State Survey Agency. To be Medicare-certified, hospice agencies must meet the established Conditions of Participation (CoPs).

It took approximately ten years to fully revise the Hospice CoPs. The process required approval within CMS, the Department of Health and Human Services (DHHS), and the Office of Management and Budget (OMB) as well as input from the public that was provided through a prescribed public comment period. The final rule was published in the Federal Register in June 2008, and implementation of the new CoPs began in December 2008.

A wide variety of comments regarding the need and feasibility for higher qualifications for hospice social workers was discussed in CMS’s publication of the final rule in the Federal Register on June 5, 2008. CMS’s response indicated several reasons for a broadened personnel requirement. It noted that because not all states administer equivalent social work licensure, the personnel qualifications CoPs defer to states’ regulations for social workers to dictate requirements for licensure. All hospice social workers must be licensed in accordance with the licensure requirements of the state(s) in which they practice. Commenters also raised concerns about the potential need to provide waivers to rural hospice agencies because of limited access to supervision and qualified social workers if the personnel qualifications were increased (Medicare and Medicaid Programs, 2008). CMS stated that it encourages hospice agencies to employ the most qualified social workers possible, but expressed that because “no standard or consensus in the hospice industry on this issue,” personnel qualifications could not be raised during the present rewrite of the CoPs (Medicare and Medicaid Programs, 2008, p. 32160).

Highlights of the Revised CoPs

An important theme of the revised CoPs is the use of a patient-centered focus. The CoPs also reinforce the interdisciplinary team approach and seek to advance quality measurement and service improvement. Highlights of the provisions of the revisions to the CoPs are noted below. (For more detail on the revised CoPs see Appendix E):

- The establishment of patient’s rights CoP in hospice care settings and a method for reporting violations of those rights.
- The requirement of an initial assessment of the patient within 48 hours of the election of hospice care and a comprehensive assessment within 5 calendar days of the election of hospice care.
- The creation of interdisciplinary groups (IDG) that include a doctor, a registered nurse, a social worker, and a pastoral or other counselor; all of which must meet to assess and meet the patient’s and family’s needs during treatment.
- The requirement that the IDG create a comprehensive plan of care for the patient that is regularly reviewed and revised to best meet the patient’s needs and goals.

The Hartford Faculty Scholars Program supports early career social work researchers with a focus on hospice-relevant studies.
ACCRREDITATION AND PROFESSIONAL PRACTICE OF HOSPICE CARE

Accreditation of Hospice Programs

CMS has granted deeming authority to the Joint Commission on Accreditation Program (CHAP), and the Accreditation Commission for Health Care (ACHC). Each has established standards for accreditation to home care and hospice programs and the agencies that provide home and hospice care. The standards consist of ten components that seek to improve the quality of care for hospice patients and their families by focusing on patient and family-centered care. The standards are designed to improve clinical excellence, ensure inclusion and accessibility of care, and provide comprehensive quality service evaluations.

The NASW has established standards for social work practice in hospice and palliative care. These standards expand upon the NASW Standards for Practice in Social Work with Individuals and Families, 6th ed. The standards consist of ten components that seek to improve the quality of care for hospice patients and their families by focusing on patient and family-centered care. The standards are designed to improve clinical excellence, ensure inclusion and accessibility of care, and provide comprehensive quality service evaluations.

The methods and quality of record keeping and reporting by hospice social workers and other clinicians can positively impact a hospice’s ability to measure quality in a consistent and meaningful manner. Lack of access to electronic clinical records and non-social work-focused electronic record formats can, however, diminish the quality of records social workers provide to interdisciplinary care files.

Quality Assessment and Performance Improvement (QAPI)

A key focus for CMS is the effort to enhance the quality of care for hospice patients and their families. This is to be accomplished through provisions for quality assessment and performance improvement (QAPI) that are incorporated into the newly implemented Conditions of Participation.

QAPI operates at both a patient level and a hospice agency level, requiring data collection at both levels to assess quality. For the patient level portion of QAPI, a hospice collects data on an individual patient’s assessment/reassessment, care plan, and clinical notes with the goal of improving patient outcomes. The hospice level portion of QAPI looks at the clinically-focused aggregate data of the patients, as well as data from other sources such as client satisfaction data, administrative data, marketing data, profitability data, and data on fundraising for the entire hospice agency with the goal of improving clinical and non-clinical operations. Data is used to identify opportunities for improvement, and demonstrate performance improvement in one or more areas. The goal is to use data in conjunction with clinical and managerial expertise and experience to drive decision-making at the patient level and hospice agency level. CMS is currently developing quality measures to comprehensively evaluate hospice services.

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ACCREDITATION AND PROFESSIONAL STANDARDS FOR PRACTICE OF HOSPICE CARE

Accreditation of Hospice Programs

CMS has granted deeming authority to the Joint Commission, the Community Health Accreditation Program (CHAP), and the Accreditation Commission for Health Care (ACHC) (See Appendix G for more details of these programs). Each organization administers accreditation to home care and hospice programs and the deeming is based on the minimum standards established by CMS and the established standards of the group.

National Hospice and Palliative Care Organization (NHPCO) Standards for Practice

www.nhpco.org/i4a/pages/Index.cfm?pageID=4900

NHPCO provides a framework of standards for both clinical and non-clinical areas of care for hospice organizations to have a means for measuring, evaluating, and improving all areas of care. The standards consist of ten components that seek to increase quality of care for patients and families by focusing on patient and family-centered care, adhering to ethical practice, striving for clinical excellence, ensuring inclusion and access, and regularly conducting comprehensive quality service evaluations (see NHPCO Standards for Practice Details, Appendix H).

National Association of Social Workers Standards for Palliative and End-of-Life Care

www.socialworkers.org/practice/bereavement/standards/default.asp

The NASW has established standards for social workers practicing in the field of palliative and end-of-life care. These standards expand upon the NASW Code of Ethics and provide a framework for roles and responsibilities of a hospice social worker. Standards discuss ethics and values, required knowledge for practice, assessment of clients, intervention and treatment planning, attitude and self-awareness, empowerment and advocacy, proper and quality documentation, interdisciplinary teamwork, cultural competence, continuing education, and supervision, leadership, and training (see a summary of NASW Standards, Appendix I).

National Association of Social Workers Credentials

Advanced Certified Hospice and Palliative Social Worker (ACHP-SW)

www.socialworkers.org/credentials/credentials/chpsw.asp

Certified Hospice and Palliative Social Worker (CHP-SW)

www.socialworkers.org/credentials/credentials/chpsw.asp

The premier credentials for social workers in hospice and palliative care, NASW developed a BSW and MSW level credential jointly with the National Hospice and Palliative Care Organization (NHPCO). These credentials were designed by social work leaders in hospice and palliative care for social workers who meet national standards of excellence.
CONCLUSIONS

Social Workers' Roles in Hospice Care

Social Work Expertise is Essential in End-of-Life Care

Working with individuals and families through transitions during life's final chapter, including hospice, requires competent social workers with requisite knowledge, skills and values. Encouraging social workers toward careers in end-of-life care necessitates that social work education programs at both the BSW and MSW level offer specialized and infused curriculum as well as field placements and collaborations with community-based programs. Continuing professional development is also critical.

Roles Need On-Going Clarification and Advocacy

Although the social worker's roles in hospice and the importance of having professionally trained social workers deliver such services may be well articulated within the profession, it is not as clear to policy makers, hospice administrators, and other professions involved in hospice care. This unclear role definition is compounded by the increasing medicalization of hospice which may limit social workers' opportunities to fully assess and treat the psychosocial needs of the patient and their family,

Since a number of agencies may provide both hospice and home health services, such agencies need to be clear that hospice and home health regulations differ. For example, in hospice the social worker might be the first person to engage with a patient and their family; in home health it is required that a nurse be at the initial meeting and recommend social work services.

Credentials are a Resource to Use

The recent launch of two credentials for hospice social workers (see NASW credentials), offered through NASW and jointly developed between NASW and NHPCO provide an excellent opportunity to further clarify and quantify the skills and knowledge required for hospice social work practice. Encouraging agencies and hospice social workers to pursue the credential and advocating for hospice agencies to recognize the value of such credentials will be critical.

Interdisciplinary Team Participation

Social workers should continually strive to be integral members of the interdisciplinary care team and remain active and engaged in developing and maintaining a patient's plan of care. The competencies articulated through NASW standards and credentials as well as the growing research base provide a strong framework to use in increasing awareness and understanding of social work's valuable role in hospice.

While role conflicts are not always the case, in some instances role conflicts do occur – sometimes between the social worker and the nurse, and in some cases between the social worker and pastoral counselor or other spiritual/religious provider. Efforts to enhance interdisciplinary team functioning includes:

- Holding regular trainings about increasing team functioning and educating each team member about the responsibilities and perspectives of all the professions in hospice care.
- Stressing the uniqueness and responsibilities of each team member in providing quality hospice care.
• Addressing tensions between different team members and providing a framework for resolving disagreements related to assessing and treating a patient's needs.

• Encouraging all team members to provide quality documentation of their efforts in developing, implementing, and evaluating care plans.

Workload and Organizational Supports May Be Challenging

As in several other fields of social work practice, hospice social workers often struggle with high caseloads, low salaries, limited access to training, lack of social work supervision, and a lack of administrative support. As noted in Assuring the Sufficiency of a Frontline Workforce: A National Study of Licensed Social Workers - Special Report on Social Work Services In Health Care Settings (NASW, 2006), social workers in health care settings have caseloads that are increasing in size and complexity. This is occurring as resources and supports are decreasing. Specifically for hospice social workers, the study found that continuing education is often unavailable; vacancy rates are higher than in other healthcare settings and salaries are the lowest in hospice.

Documentation

CMS surveys of hospice programs exposed some challenges that social workers experience in providing thorough, timely, and quality documentation pertinent to a patient's care. Social workers are often out in the field and may have limited access to patient clinical records. Many electronic case files do not have space to easily note social worker-related items for a patient's care. Lastly, some social workers may default to the nurse, the case coordinator, to make notes about the patient's plan of care. Without this quality documentation, hospices and surveyors alike cannot recognize the valuable work that social workers perform.

One step to advocate for the documentation of social workers’ activities is related to documentation of services provided over the telephone. For social workers, the contacts are often not just with the family or the patient, but may also include other service providers and/or community resources (CR 6440).

Clarity of Roles across Different Service Settings

With the expansion of eligibility for hospice services to those who are in hospitals, nursing homes, group care and assisted living settings, the hospice social worker may need to coordinate with social workers, nurses, or other professionals in the other settings. Efforts must be made to have clear roles and functions, and clear communication channels with the patient and the family members.

Research and Hospice Social Work

There is a growing body of social work research on hospice and social work involvement in interdisciplinary hospice research (see Annotated Bibliography, Appendix X). Social work research agendas have sought to demonstrate the effectiveness of hospice social workers, yet no rigorous review of the research conclusively demonstrates this effectiveness of social workers in hospice care and the interventions used in practice. The PDA program, participation in SWHPN and the Hartford Faculty Scholars and Doctoral Fellows programs have provided support and visibility for hospice social work research. The launching of the Journal of Social Work in End of Life Care & Palliative Care has provided an important venue for publication of relevant articles.
**Funding for Hospice Social Work Research**

Beyond the pilot research funding still available through the Hartford Scholars and Fellows program, there is limited research funding available for hospice social work researchers. While the new health care reform legislation Patient Protection and Affordable Care Act (PPACA (Pub.L. 111-148)) includes provisions related to hospice services for children, there is little research by social workers focused on services to children in hospice.

Only a few social work researchers have been successful in garnering National Institutes of Health (NIH) funding for their scholarship (e.g., Social Work Principal Investigators Otis-Green, Parker-Oliver, Schroepfer, Waldrop, and Zimmerman). In most instances, the successful applicants previously had received support as Hartford Faculty Scholars and/or Hartford Doctoral Fellows, and may also have attended summer institutes offered to social work researchers to enhance their skills and success at applying for NIH funding.

Although NIH hosted a State of the Science Consensus meeting on End of Life Care in 2004 (http://consensus.nih.gov/2004/2004EndOLLifeCare603026html.htm), social work research was not a contributing discipline to this effort. The National Institute on Nursing Research (NINR) has a lead role in the trans-NIH efforts related to end-of-life care. However, there is no stand-alone review group that reviews grant submissions on hospice and end-of-life care nor is there an NIH effort to particularly develop the research careers of end-of-life and hospice researchers. This is a gap identified across multiple disciplines.

**Research/Practice Disconnect**

Another challenge identified at the symposium included the oft identified problem of the disconnect between the questions that researchers might seek to ask and the concerns that practitioners have in regard to practice and/or patient care. Practitioner involvement in research development can help to create study questions that are relevant for practice. Incorporating the experiences of patients and families within hospice research is also important. However patient involvement can be difficult given the deteriorating physical and mental health of the patient.

Creating research that is more relevant and applicable to practice will encourage hospice social workers to value research in practice and help to legitimize the field of social work as driven by evidenced-based interventions.

**Research Design and Methods**

Use of multiple methods of research is important in order to expand and better define our knowledge on the role and interventions of hospice social work. Qualitative research methods can help to give insight about quality indicators and better understand the nuances of hospice. Quantitative research techniques will help to establish the effectiveness of hospice social workers and the interventions used to treat hospice patients and families. Further research will also help to identify gaps and challenges in care.

Future research on social workers in hospice care would also benefit from considering elements of cost effectiveness. Cost effectiveness research can focus at multiple levels including examining outcomes related to the well-being of the family and loved ones after the patient dies.

Building a sufficient body of research so that there is opportunity to complete systematic reviews will also help build the evidence-base for hospice social work services. Entities like the Campbell Collaboration (www.campbellcollaboration.org) with active involvement of social work researchers can provide a venue for undertaking such a rigorous and transparent review.

**Interdisciplinary Research**

Since hospice is an interdisciplinary team model, interdisciplinary approaches should be used to examine service delivery that can result in optimal quality care. Joint research teams that use multiple perspectives and instruments can provide a multi-faceted view of interdisciplinary team functioning, and demonstrate the integration of research into practice.

**Dissemination**

Dissemination of research to practitioners is a dilemma in many research areas. Social workers acquire information used in clinical practice from multiple sources, including published in peer-reviewed journals and is not necessarily or always in a format that is readily digestible by practitioners. Enhanced tools for dissemination are needed to get pertinent research into the hands of practitioners and better use might be made of various on-line resources to share research interpreted for practice.

**Addressing Disparities in Access to and Use of Hospice Care**

There are demographic disparities in both the hospice workforce and patient population. The research needs to develop new methods for reaching these underrepresented communities, which would be extremely beneficial to enhance the involvement of marginalized individuals. Social work researchers can contribute to new research efforts that are aimed at understanding and improving access and use of hospice care for vulnerable populations.

**Hospice Social Work/Policy Connections**

The symposium highlighted the value of building and strengthening collaborations between hospice social work and federal agencies in regard to social work's role in CMS. There are potential for fostering new research partnerships between the Social Work Program Office and the Department of Health and Human Services. The National Social Work Workforce and Education Improvement Act (P.L. 108-199) provides new opportunities for social work researchers to develop innovative methods for reaching underserved communities and populations. There is the potential for forming new exchanges among federal agencies, and national organizations with the goal of advancing the value of social work in improving patient outcomes. Enhanced tools for dissemination are needed to get pertinent research into the hands of practitioners and better use might be made of various on-line resources to share research interpreted for practice.
Interdisciplinary Research

Since hospice is an interdisciplinary team model, interdisciplinary research is a critical avenue that should be used to examine service delivery that can result in outcomes and insights to achieve optimal quality care. Joint research teams that use multiple practice philosophies can also provide a multi-faceted view of interdisciplinary team functioning, and could help solve current gaps and challenges.

Dissemination

Dissemination of research to practitioners is a dilemma in many fields. Although many hospice social workers acquire information used in clinical practice from books, most new research is published in peer-reviewed journals and is not necessarily or readily seen by practitioners. Enhanced tools for dissemination are needed to get pertinent research into the hands of practitioners and better use might be made of various on-line web resources and newsletters to get research interpreted for practice.

Addressing Disparities in Access to and Use of Hospice Care

There are demographic disparities in both the hospice workforce and for those who choose to have access to, and/or receive hospice care. Social workers should explore the nature of the demographic disparities in both the worker and patient populations. Policy makers can use this research to develop new methods for reaching these underserved populations and recruiting a more diverse workforce. As one step to give greater visibility to this need the 2010 SWHPN preconference that was held in conjunction with the annual AAHPM/HPNA Annual Assembly included the session Understanding Diversity: How culturally based interventions impact hospice and palliative care with presenters Karen Bullock, Karen Kayser, and J. Ernest Aguilar.

Hospice Social Work/Policy Connections

The symposium highlighted the value of building and strengthening the connections between social work and federal agencies in regard to social work's role in hospice. The representatives from CMS were actively engaged in the think tank and valued the opportunity to become more familiar with the social work researchers and practitioners who were their fellow participants. There is the potential for forming new exchanges among federal agencies, hospice researchers, practitioners, and national organizations with the goal of advancing quality hospice service delivery and the role of various members of the interdisciplinary team. While CMS staff are regularly engaged with representatives from NHPCO and other hospice provider organizations, it would be extremely beneficial to enhance the involvement of social workers and social work organizations with CMS and other federal agencies. This would heighten the social work role as well as outcomes from social work research.

CMS's development of new quality measures is a prime area for hospice social work practitioners and researchers to contribute. Social work ethics and standards for practice align closely with the CMS goals of providing patient-centered and quality care. Therefore, social workers are poised to provide valuable insight to quality indicators, specifically in evaluating the psychosocial elements and outcomes of hospice care.

Since the National Institutes of Health (NIH) already has a plan to enhance social work research (see http://obssr.od.nih.gov/pdf/SWR_Report.pdf) highlighting the fit of that agenda with the need to build hospice social work research is relevant to multiple institutes and offices beyond NINR. This would include the National Cancer Institute, the National Institute on Aging, the National...
**RECOMMENDATIONS FOR ACTION**

To Advance the Role of Hospice Social Work and Address Challenges:

- Hospice social workers can:
  - Continually reinforce their role on the interdisciplinary team and co-workers, and with other organizations that interact with hospice agencies.
  - Utilize information provided in the NASW Standards for Social Work Practice in Health Care to develop and implement professional development strategies to implement and administer practice in the hospice setting.
  - Advocate for hospice administrators to promote tools to provide quality documentation (electronic records) for care. This will help CMS better document care provided by hospice social workers.
  - Participate in research on hospice social work to identify practice challenges and develop evidence-based practices.
  - Remain abreast of hospice social work research and apply it to their own practice.
  - Develop group supervision and peer support networks to enhance skills for practice.
  - Partner with social workers in other areas (e.g., hospice nurses, oncology social workers) to promote quality care at the end of life.

- Hospice agencies can enhance the quality of services provided to patients and families by:
  - Decreasing caseloads.
  - Offering competitive salaries that reward social workers based on qualifications and acquired licenses and credentials.
  - Offering incentives for social workers that seek to incorporate research into practice.
  - Providing quality and consistent supervision and support to social workers to help build practice skills and evaluate performance to increase effectiveness and efficiency.
  - Helping define and support the social worker’s role in the interdisciplinary care team.
  - Ensuring electronic case notes have sections designed to capture time-service delivery.

- National social work organizations can:
  - Work with CMS and other federal agencies in order to ensure the value of hospice social work in efficiently administering the hospice benefit.
  - Work with NIH to support research to evaluate the role of hospice social workers in the interdisciplinary care team and explore innovative mechanisms to improve access to care.
RECOMMENDATIONS FOR ACTION

To Advance the Role of Hospice Social Work and Address Practice Issues

- Hospice social workers can:
  ◊ Continually reinforce their role on the interdisciplinary care team with administrators and co-workers, and with other organizations that serve hospice patients.
  ◊ Utilize information provided in the NASW Standards as a guide, including creation of professional development strategies to implement social work competencies.
  ◊ Advocate for hospice administrators to promote the need for social work relevant tools to provide quality documentation (electronic or paper format) of the patient’s plan of care. This will help CMS better document and recognize the role of hospice social workers.
  ◊ Participate in research on hospice social work to better establish its effectiveness and to identify practice challenges and develop evidence-based practices.
  ◊ Remain abreast of hospice social work research and how its outcomes are relevant to their own practice.
  ◊ Develop group supervision and peer support networks in order to decrease isolation and increase skills for practice.
  ◊ Partner with social workers in other areas (e.g., hospital social workers, nursing home social workers, oncology social workers) to promote hospice services as a valuable asset in providing quality care at the end of life.

- Hospice agencies can enhance the quality of services provided by social workers by:
  ◊ Decreasing caseloads.
  ◊ Offering competitive salaries that reward social workers for educational achievements and acquired licenses and credentials.
  ◊ Offering incentives for social workers that seek training opportunities and continually incorporate research into practice.
  ◊ Providing quality and consistent supervision and consultation of social workers by social workers to help build practice skills and efficacy; document outcomes; and evaluate performance to increase effectiveness and efficiency of service delivery.
  ◊ Helping define and support the social worker’s roles and responsibilities on the interdisciplinary care team.
  ◊ Ensuring electronic case notes have sections designed for capturing elements of social work service delivery.

- National social work organizations can:
  ◊ Work with CMS and other federal agencies in order for them to better understand the value of hospice social work in efficiently administering hospice services.
  ◊ Work with NIH to support research to evaluate the social work role on interdisciplinary care teams and explore innovative techniques in practice.
To Promote Interdisciplinary Team Functioning

- Social workers can help build a dialogue with agencies to understand the nature of each role on the care team.
- Work to build trust and communication with other care team members.
- Conduct trainings on the role of social work and members about their role in hospice service delivery.
- Partner with other hospice agencies and national interdisciplinary collaboration in practice.

Hospice agencies can:

- Develop quarterly or annual team building exercises for all disciplines to understand the value of each team philosophy.
- Provide tools to increase collaboration in treatment disciplines on elements of the plan of care.
- Model expectations for mutual respect of interdisciplinary collaboration and the uniqueness and importance of each team member for providing quality and comprehensive hospice care.
- Provide tools that increase trust and communication.
- Provide incentives to team members for taking effective action.

Social work educators can:

- Develop a curriculum track that prepares social workers for a career in end-of-life care.
- Increase infusion of information about hospice services into the curriculum.

Hospice social work researchers can:

- Conduct rigorous research and systematic reviews of interdisciplinary team functioning.
- Engage in partnerships with national hospice organizations and accrediting bodies to educate and promote the role of the social worker and the value it provides in hospice service delivery.

• Hospice social work researchers can:

- Develop research agendas that incorporate evaluations of hospice social worker effectiveness including cost effectiveness.
- Conduct rigorous systematic research that examines the effectiveness and cost effectiveness of hospice social workers at different levels of qualification (e.g., MSW vs. BSW, related degree vs. social work degree, supervised vs. not supervised, etc.).
- Use mixed methods to explore and conclusively define the roles and responsibilities of hospice social workers.
- Seek to develop tools for capturing and evaluating quality indicators related to psychosocial needs that can be useful to CMS's development and implementation of the QAPI program.

To Enhance Diversity in Hospice Services

- Hospice social workers and social work and hospice organizations can:

  - Advocate for the expansion of services and outreach to more ethnically and culturally diverse populations by engaging with members of the local community and other health care professionals to educate them on the value of hospice.
  - Incorporate patient's and family's involvement in developing a plan of care, which includes the patient's and family's cultural considerations of care.
  - Partner with other hospice organizations to develop awareness campaigns geared at populations that are not utilizing hospice services to demonstrate the benefits of hospice care.
  - Encourage hospice agencies to increase access of services to populations not utilizing hospice services.
  - Encourage hospice agencies to seek out employees from diverse backgrounds to help enrich the cultural richness of their care teams.
  - Help recruit qualified social workers from diverse backgrounds to explore careers in end-of-life care.

Social work researchers can:

- Explore the reasons for racial and ethnic disparities in both the hospice workforce and patient population and seek to develop methods for adding cultural diversity to the hospice care environment.
To Promote Interdisciplinary Team Functioning

- Social workers can help build a dialogue with agencies and interdisciplinary team members to understand the nature of each role on the care team. For example, social workers could:
  - Work to build trust and communication with other members of the interdisciplinary care team.
  - Conduct trainings on the role of social work and develop trainings with other team members about their role in hospice service delivery including treatment philosophies.
  - Partner with other hospice agencies and national organizations seeking to foster interdisciplinary collaboration in practice.

- Hospice agencies can:
  - Develop quarterly or annual team building exercises to foster team cohesion and help all disciplines understand the value of each team member and differing treatment philosophies.
  - Provide tools to increase collaboration in treatment planning and include all disciplines on elements of the plan of care.
  - Model expectations for mutual respect of interdisciplinary team members by stressing the uniqueness and importance of each team member's roles and their responsibilities for providing quality and comprehensive hospice services.
  - Provide tools that increase trust and communication among team members.
  - Provide incentives to team members for taking efforts to increase collaboration.

- National social work and hospice organizations can:
  - Develop and disseminate tools to hospice leaders and employees to foster interdisciplinary collaboration and team functioning.
  - Advocate for federal agencies involved in hospice regulation and research to evaluate methods for increasing interdisciplinary team functioning.
  - Advocate for federal agencies involved in hospice regulation to stress interdisciplinary collaboration and valuing different practice philosophies in developing comprehensive plans of care.

- Hospice social worker researchers can:
  - Conduct rigorous research and systematic reviews that evaluate elements of successful interdisciplinary team functioning.
  - Engage in interdisciplinary research on hospice care to better understand the varying treatment philosophies in treatment planning and implementation. This research can also help discover the reasons for gaps and challenges to interdisciplinary collaboration in hospice care.
To Promote Research-Practice Linkages

- Hospice social workers can:
  ◇ Seek out connections with local or prominent hospice social work researchers to help originate relevant practice research questions and develop valuable and effective research methodologies.
  ◇ Maintain quality patient records that can be used in larger evaluations of hospice social work outcomes, and also in the social workers’ own practice evaluations.
  ◇ Develop strategies for conducting outcome evaluations in the agency and then using the findings to enhance practice.
- Hospice agencies can:
  ◇ Increase accessibility for practitioners to research journals.
  ◇ Provide incentives to clinicians that incorporate research into practice.
- National hospice social work organizations could incentivize credentials, such as the Advanced Certified Hospice and Palliative Social Worker (ACHP-SW) by offering access to journals targeted at social work in hospice and palliative care.

- Hospice social work researchers can:
  ◇ Incorporate practitioners in the research design process from the outset, including in development of the research questions.
  ◇ Promote the use of community-based participatory research strategies.
  ◇ Structure journal articles to be geared toward implementation in or consideration for practice.

To Promote Research on Hospice Social Work

- National hospice and social work organizations can:
  ◇ Advocate for increased funding from Congress to explore and enhance the social work role in research (e.g. The National Centre for Social Work Research Act, S.114).
  ◇ Develop a network of researchers that can collaborate to design high quality studies that may be more eligible for grant funding, and that would also increase the scale and rigor of the research.
  ◇ Promote the value of research to its members who are clinicians as essential for increasing the value and legitimacy of the social work profession in hospice care.

Psychosocial Outcomes

“Hospice is one (if not the only) area of health care in which psychosocial outcomes out shadow physiological outcomes in a profound and demonstrable way. If the research bridge can be built, the standing of social work/psychosocial intervention in this and other areas of health care will rise significantly.” — A think tank participant
Hospice social work researchers can:
- Develop relationships with CMS to regularly and effectively communicate the outcomes of research on hospice social work and interventions.
- Seek dissemination methods that will most effectively reach practitioners, such as NASW member updates, webinars, tele-training, inclusion in hospice social work practice books, inclusion in newsletters, and other publications.

To Promote Collaborations with Federal Agencies
- Hospice social workers can:
  - Engage with CMS surveyors to illustrate areas of concern for practice and work to ensure that quality indicators represent the services administered by social workers.
  - Report concerns and violations of the regulation to CMS to help ensure that social workers are not asked to perform duties outside of their assigned role.
  - Hospice agencies can work with CMS to develop quality indicators that accurately assess all areas of service delivery including psychosocial elements of treatment.
  - Hospice social work researchers and national organizations can develop stronger connections for researchers with CMS to better inform regulation development and changes.

Hospice is a patient and family-centered service delivery paradigm that provides a model for interdisciplinary collaboration and highlights the importance of attending to psychosocial and quality of life needs. Social workers are a key part of that service. Implementing this action agenda will help not only those current and future social workers in hospice but the well-being of the patients and families served by hospice as well.
REFERENCES


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APPENDIX A: PARTICIPANT LIST

Suzanne Adelman, DCSW
Clinical Supervisor
Hospice of Jewish Social Services Agency

Robert Arnold, MPS
Director
National Association of Social Workers Foundation

Samira Beckwith, ACSW, LCSW, FACHE
President & CEO
Hope Hospice

Pamela Bennett, RN
Executive Director of Healthcare Alliance Development
Pulicis Pharma

Kathy Brandt, MS
Vice President
Innovation and Access
National Hospice and Palliative Care Organization

Laura Brenneman, PhD, ACSW
Associate Professor & Department Chair
College of Community and Public Affairs
Binghamton University

Gretchin Brown, MSW
Board Chair
National Hospice and Palliative Care Organization
President & CEO
Hospice of the Bluegrass - Lexington

Karen Bullock, PhD
School of Social Work
University of Connecticut

Elizabeth J. Clark, PhD, ACSW, MPH
Executive Director
National Association of Social Workers

Paul Clark, PhD
Assistant Professor
Department of Social Work
George Mason University

Miream Coleman, MSW, LCSW
Senior Practice Associate – Clinical Social Work
Center for Workforce Studies and Social Work Practice
National Association of Social Workers

Stacy Collins, MSW
Senior Practice Associate – Children and Adolescent Health
Center for Workforce Studies and Social Work Practice
National Association of Social Workers

Doireann Downes, MSW, LCSW
Social Work Manager
Joshua Home Care

Michael Franccum
MSW Intern
National Association of Social Workers

Ronald Fried
Vice President
Public Affairs
VITAS Innovative Hospice Care

Barbara Guest, MSW, MPH
Program Analyst
Office of the Associate Director
National Cancer Institute

Bernice Harper, MSW, MSPH, SSD
NASW Fellow

Chris Herman, MSW, LCSW
Senior Practice Associate – Aging
Center for Workforce Studies and Social Work Practice
National Association of Social Workers

Elizabeth Hoffer, MSW, ACSW
Special Assistant to the Executive Director
National Association of Social Workers

Ayasha Jones
MSW Intern
National Association of Social Workers

James J. Kelly, PhD, ACSW
President
National Association of Social Workers

Donald List, LCSW-C
Palliative Care Social Worker
The Harry J. Duffey Family Pain and Palliative Care Program
Johns Hopkins Medicine

APPENDIX A: PARTICIPANT LIST

Judi Lund Person, MPH
Vice-President
Compliance and Regulatory Leadership
National Hospice and Palliative Care Organization

Jeri Miller, PhD
Thea
UNN Office of End-of-Life Palliative Care Science, Involvement, Engagement, and Education
National Institute of Nursing Research

Sherri Morgan, JD, MSW
Associate Clinical Director
UP and Office of Ethics and Professional Review
National Association of Social Workers

Scarlett Myers, LSW, ACSW
Director
External Relations
National Association of Social Workers

Bekki Ow-Arhus, ACSW, DCSW, C-ACYFSW
Senior Practice Associate
Professional Development
National Association of Social Workers

Debra Parker Oliver, PhD, MSW
Associate Professor
Rural Sociology, Social Work
University of Missouri

Judith Peres, MSW, LCSW-C
Supporting Successful Transitions

Kim Roche, BSN, MA
Nurse Consultant
Survey and Certification Group
Centers for Medicare and Medicaid Services

Mary Rossi-Coajou, MS, RN
Captain, U.S. Public Health Service
National Association of Social Workers

Annette Schmidt
Director
U.S. External Affairs
sanofi-aventis U.S.
Judi Lund Person, MPH  
Vice-President  
Compliance and Regulatory Leadership  
National Hospice and Palliative Care Organization

Jeri Miller, PhD  
Head  
NINR Office of End-of-Life Palliative Care Science, Investigator Training, and Education  
National Institute of Nursing Research

Sherri Morgan, JD, MSW  
Associate Comptroller  
LDIF and Office of Ethics and Professional Review  
National Association of Social Workers

Rebecca Myers, LSW, ACSW  
Director  
External Relations  
National Association of Social Workers

Bekki Ow-Arhus, ACSW, DCSW, C-ACYFSW  
Senior Practice Associate  
Professional Development  
National Association of Social Workers

Debra Parker Oliver, PhD, MSW  
Associate Professor  
Rural Sociology, Social Work  
University of Missouri

Judith Peres, MSW, LCSW-C  
Supporting Successful Transitions  
National Association of Social Workers

Kim Roche, BSN, MA  
Survey and Certification Group  
Centers for Medicare and Medicaid Services

Mary Rossi-Conop, MS, RN  
Senior Nurse Consultant  
Centers for Medicare and Medicaid Services

Annette Schmidt  
Director  
U.S. External Affairs  
sanoformam U.S.

Tracy Schroepfer, PhD  
Assistant Professor  
School of Social Work  
University of Wisconsin-Madison

J. Donald Schumacher, PsyD  
President & CEO  
National Hospice and Palliative Care Organization

Danielle Shearer  
Senior Health Insurance Specialist  
Centers for Medicare and Medicaid Services

Deborah Wallis, PhD, MSW  
Associate Professor  
School of Social Work  
University at Buffalo

Karyn Walsh, MSW, LCSW, ACSW  
Senior Practice Associate – Health, Cancer, & WebEd  
Center for Workforce Studies and Social Work Practice  
National Association of Social Workers

Briana Walters  
MSS Intern  
Social Work Policy Institute  
National Association of Social Workers Foundation

Jennifer Watt  
Assistant Director  
National Association of Social Workers Foundation

Sherri Waisenzuhl, MSW, LCSW, ACHP-SW  
Associate Clinical Officer of Counseling Services  
Hospice of the Bluegrass

Tracy Whitskar, DSW  
Director  
Center for Workforce Studies and Social Work Practice  
National Association of Social Workers

Gail Woods-Waller, MSW, LCSW  
Director of Communications  
National Association of Social Workers

Joan Levy Zlotnik, PhD, ACSW  
Director  
Social Work Policy Institute  
National Association of Social Workers Foundation
APPENDIX B: SYMPOSIUM AGENDA

Thursday, March 25, 2010
NASW National Office
7th Floor Conference Center

8:30 AM  REGISTRATION & CONTINENTAL BREAKFAST
9:00 AM  GREETINGS & INTRODUCTIONS
        Joan Levy Zlotnik, PhD, ACSW, Director, Social Work Policy Institute
        Elizabeth J. Clark, PhD, ACSW, MPH, Executive Director, National Association of
        Social Workers
        Gretchen Brown, MSW, Chair, National Hospice and Palliative Care Organization
9:30 AM  PART 1: FRAMING THE ISSUES
        Building Comprehensive Community-Based End-of-Life Care – Social Work
        Contributions and Challenges for the Future
        Samira Beckwith, ACSW, Hope Hospice, Fort Myers, Florida
        Ronald Fried, Vitas Innovative Hospice Care, Washington, DC
        Social Work’s Role in Hospice – An Overview of Research
        Deborah Waldrop, PhD, School of Social Work, University at Buffalo
        Promoting the High Quality Psychosocial Care in Hospice
        Mary Rossi-Coajou, MS, RN & Danielle Shearer,
        Centers for Medicare and Medicaid Services, Office of Standards and Quality
11:00 AM Break
11:15 AM  Questions and Discussion
11:45 AM  Overview of NASW Hospice and Palliative Care Resources and Activities
        Elizabeth J. Clark, PhD, ACSW, MPH
12:00 PM Lunch (Provided)
12:45 PM  PART 2: IDENTIFYING GAPS, CHALLENGES, AND EMERGING PRACTICES
        Roundtable Facilitated Discussions
        • Current Status of Hospice Psychosocial Research – Answered and Unanswered
          Questions
        • Emerging Practices in End-of-Life Care – Opportunities for Social Work
        • Enhancing Social Worker’s Role on the Interdisciplinary Team
        • Enhancing Researcher/Practitioner/Policy Connections
3:00 PM Break
3:15 PM  Report Out and Identification of Action Steps and
3:45 PM  Wrap-up & Next Steps
4:00 PM  Adjourn
1:45 PM Report Out on Gaps, Challenges, and Emerging Practices for Hospice Social Workers

2:15 PM PART 3: DEVELOPING AN ACTION PLAN
   Action Planning Work Groups
   • Building the Science – Agenda and Research Training
   • National Collaborations and Partnerships
   • Creating Research-Practice Bridges
   • Implications and Recommendations for Policy

3:00 PM Break

3:15 PM Report Out and Identification of Action Steps and Targets

3:45 PM Wrap-up & Next Steps

4:00 PM Adjourn
Deborah Waldrop, PhD, LMSW

Deborah Waldrop, PhD, LMSW is an Associate Professor at the UB School of Social Work. Deborah joined the UBSSW faculty after spending 15 years in a variety of healthcare settings. Drawing from her experiences working with families, Dr. Waldrop now conducts research about the needs of patients as they make decisions about the timing of that decision. She is also involved in an ongoing death and dying study, a newly emerging model for care at life's end. Deborah is currently studying how people make decisions about the timing of their care, the newly emerging model for care at life's end.

Captain Mary Rossi-Coajou, MS, RN

Captain Mary Rossi-Coajou serves as a Senior Nurse Consultant with the Centers for Medicare & Medicaid Services (CMS), Office of Clinical Standards and Nursing. Captain Rossi-Coajou has a Bachelor of Science in Science and Nursing from the State University of New York, and a Master of Science in Community Health from the University of Maryland. Captain Rossi-Coajou began her career in Federal service in 1989 at the National Institutes of Health, Bethesda, Maryland where she worked in the areas of occupational health, clinical staff nursing, and hospital infection control. She is currently employed at CMS, Baltimore office as a senior nurse consultant responsible for hospice and community mental health programs, where she is involved in the formation of CoPs (Collaborative Practice) for hospices and CoPs for community mental health programs.

Danielle Shearer

Danielle Shearer is a senior health insurance specialist at the National Institutes of Health, where she serves as a Senior Consultant on the National Hospice and Palliative Care Organization (NHPCO) Strategic Work Group and the CoPs (Collaborative Practice) Working Group. Danielle is responsible for leading and conducting hospice quality measures. Danielle is also responsible for overseeing the development of hospice quality measures and CoPs for all Medicare and Medicaid facilities.

APPENDIX C: PRESENTER BIOGRAPHIES

Samira Beckwith, ACSW, LCSW, FACHE

Samira K. Beckwith, ACSW, LCSW, FACHE, has over 30 years' experience in professional health care and social services. She has served as President and CEO of Hope Healthcare Services, based in Fort Myers, Florida, since 1991. When she joined Hope, the agency was caring for a small number of hospice patients in the immediate Fort Myers area. Under her leadership, Hope has expanded to more than 2,200 patients in a 10,000 square-mile area throughout southwest and mid-Florida. She earned her BA in Sociology and Master's in Social Work at The Ohio State University. Ms. Beckwith has been an active leader in the field of hospice care, serving as President of the Florida Hospice Association and as a member of the State of Florida's Long-Term Care Policy Board. In recognition of her contributions to the field, Ms. Beckwith was named the 2009 recipient of the NASW Foundation's Kneer/Wittman Lifetime Achievement Award for Health & Mental Health Practice.

Ronald Fried

Ron Fried brings more than 15 years of hospice management and administrative responsibilities and more than 30 years of experience in legislative and regulatory affairs to his role as Senior Vice President of Development and Public Affairs for VITAS Innovative Hospice Care. Ron identifies and develops partnership opportunities with hospices around the country. In addition, he handles strategic growth opportunities, such as relationships with health care providers that complement VITAS’ service such as disease management and palliative care. Ron also oversees public policy issues for VITAS and manages those activities at both the state and federal level. Ron serves on the Boards of Directors of the National Hospice and Palliative Care Organization and Florida Hospices and Palliative Care. He is a member of the Executive Committee for each organization. Ron brings to VITAS more than 15 years of experience in domestic and international strategic development, including eight years previously spent with VITAS – first, as a public policy consultant and, subsequently, as Director of Development. Ron's areas of expertise include strategic business planning, public policy, acquisition strategy, analysis, negotiation and operations integration. Ron served as Director of Development for VITAS from 1992-1997 and provided public policy guidance to VITAS from 1988-1992. During his tenure, VITAS successfully added the California hospice programs—formerly known as Community Hospice Care—as well as Hospice of Miami Valley in Cincinnati and Florida's first not for profit hospice program, Hospice of Central Florida in Orlando. Those programs have continued to grow as a part of VITAS and today care for more than 3,000 patients and families each day. Early in Ron's career, he served on Capitol Hill as Legislative Assistant to Congressman Claude Pepper, public health policy advisor to former Florida Governor Bob Graham and National Finance Director for Senator Bob Kerrey's 1992 Presidential Campaign. Ron received his bachelor’s degree in government and politics from the University of Maryland in College Park, MD.
Deborah Waldrop, PhD, LMSW

Deborah Waldrop, PhD, LMSW is an Associate Professor at the University at Buffalo School of Social Work. Deborah joined the UBSSW faculty after spending 20 years as a social worker in a variety of healthcare settings. Drawing from the experiences of older adult patients and their families Dr. Waldrop now conducts research about the needs and concerns that emerge at life’s end. Deborah is currently studying how people make decisions about hospice utilization and the timing of that decision. She is also involved in an ongoing descriptive study of residential hospice care, a newly emerging model for care at life's end.

Captain Mary Rossi-Coajou, MS, RN

Captain Mary Rossi-Coajou serves as a Senior Nurse Consultant with the Centers for Medicare and Medicaid Services (CMS), Office of Clinical Standards and Quality. She holds a Baccalaureate degree in Science and Nursing from the State University of New York at Brockport and a Masters degree in Community Health from the University of Maryland. CAPT Rossi-Coajou began her Federal service in 1989 at the National Institutes of Health, Bethesda Maryland. She has worked in the areas of occupational health, clinical staff nursing, nurse manager, and nurse consultant. She is currently employed at CMS, Baltimore office as a senior nurse consultant and analyst for the hospice and community mental health programs, were she is responsible for the Conditions of Participation (CoPs).

Danielle Shearer

Danielle Shearer is a senior health insurance specialist at the Centers for Medicare & Medicaid Services. She has worked with the Medicare hospice program for the past seven years, drafting the proposed and final hospice rules, teaching hospice surveyors, and managing a special project to develop hospice quality measures. Danielle is also responsible for writing the Home Health Agency CoPs and Life Safety Code CoPs for all Medicare and Medicaid-certified health care facilities.
APPENDIX D: THE SOCIAL SECURITY ACT REGARDING HOSPICE

Title 18, Section 1861, Subsection dd

“(dd) (1) The term “hospice care” means the following items and services provided to a terminally ill individual by, or by others under arrangements made by, a hospice program under a written plan (for providing such care to such individual) established and periodically reviewed by the individual’s attending physician and by the medical director (and by the interdisciplinary group described in paragraph (2)(B)) of the program.

[A] nursing care provided by or under the supervision of a registered professional nurse,

[B] physical or occupational therapy, or speech-language pathology services,

[C] medical social services under the direction of a physician,

[D] (i) services of a home health aide who has successfully completed a training program approved by the Secretary and

(ii) homemaker services,

[E] medical supplies (including drugs and biologicals) and the use of medical appliances, while under such a plan,

[F] physicians’ services,

[G] short-term inpatient care (including both respite care and procedures necessary for pain control and acute and chronic symptom management) in an inpatient facility

[H] counseling (including dietary counseling) with respect to care of the terminally ill individual and adjustment to his death, and

[I] any other item or service which is specified in the plan and for which payment may otherwise be made under this title.

(2) The term “hospice program” means a public agency or private organization (or a subdivision thereof) which:

[A] (i) Provides the services listed above as well as “bereavement counseling for the immediate family of terminally ill individuals” and

(ii) Provides for such care and services in individuals’ homes, on an outpatient basis, and on a short-term inpatient basis, directly or under arrangements made by the agency or organization,
A hospice program under a written agreement established and periodically reviewed by the medical director and by the interdisciplinary group program, by or under the supervision of a registered professional, physical therapy, or speech-language pathology services, under the direction of a physician, a health aide who has successfully completed a training program, and the use of medical drugs and biologicals and the use of medical equipment according to a plan, including both respite care and procedures necessary for care and chronic symptom management, in an inpatient facility or a public agency or private organization (or a subdivision thereof) as a public agency or private organization (or a subdivision thereof) as listed above as well as bereavement counseling for the terminally ill individuals and care and services in individuals’ homes, on an outpatient basis, on an outpatient basis, on an outpatient basis, or under arrangements made for the terminally ill, and the use of medical drugs and biologicals and the use of medical equipment according to a plan, including both respite care and procedures necessary for care and chronic symptom management, in an inpatient facility or a public agency or private organization (or a subdivision thereof) as a public agency or private organization (or a subdivision thereof) as listed above as well as bereavement counseling for the terminally ill individuals and care and services in individuals’ homes, on an outpatient basis, on an outpatient basis, or under arrangements made for the terminally ill, and

Social Security Act, 2008, Title 18, Section 1861, Subsection dd

3. (A) An individual is considered to be “terminally ill” if the individual has a medical prognosis that the individual’s life expectancy is 6 months or less” (Social Security Act, 2008, Title 18, Section 1861, Subsection dd)

(B) has an interdisciplinary group of personnel which—(i) includes at least—

(II) one registered professional nurse, and

(III) one social worker

Social Work Policy Institute
APPENDIX E: CMS CONDITIONS OF PARTICIPATION

Conditions of Participation Development Process:

The CoPs were drafted during the regulation development period and then proceeded to a clearance process within CMS to ensure the new regulations concur with other CMS components. After an internal review, the CoPs are approved and sent to regulatory clearance process within DHHS to ensure that the CoPs concur with other department agencies and are then approved by the Secretary of the DHHS. Finally, the Office of Management and Budget (OMB) reviews and approves the CoPs and are then published in the Federal Register.

Overview of the Conditions of Participation Requirements

The CoPs focus on enhancing patient rights; initial and comprehensive assessment of the patient; interdisciplinary group, care planning, and coordination of services; and quality assessment and performance improvement.

§ 418.52 Patient’s rights

The patient must be given a notice of their rights and responsibilities during the initial assessment visit and in advance of furnishing care, both verbally and in writing in a language that the patient understand. The patient must also be informed about developing advanced directives and the notice of rights and responsibilities must be signed by the patient or representative. Patients have the right to exercise their rights, be treated with respect, voice grievances, and be protected from discrimination or reprisal for exercising their rights. Hospices must immediately investigate all alleged violations and complaints, take appropriate corrective action, and report all verified violations. The rights of the patient include:

- Pain management and symptom control
- Be involved in developing plan of care
- Refuse care or treatment
- Choose attending physician
- Confidential clinical record/ HIPAA
- Be free of abuse
- Receive information about hospice benefit
- Receive information about scope and limitations of hospice services

§ 418.54 Initial and comprehensive assessment of the patient

The patient must receive an initial assessment by a registered nurse (RN) within 48 hours of the election of hospice care. Assessments are frequently done in conjunction with a social worker, but social workers are not required to be present during the initial assessment. Other members of the interdisciplinary group (IDG), including social workers, may visit the patient prior to the nurse’s assessment. A comprehensive assessment must be completed by the hospice IDG in consultation with the attending physician within 5 calendar days of the election of hospice care. Comprehensive assessments should be updated by the IDG as required and at a minimum of every 15 days.

Comprehensive assessments must include an evaluation of the following:

- Physical, psychosocial, emotional, and spiritual needs
- Nature and condition causing admission
- Complications and risk factors
- Functional status
- Imminence of death
- Symptom severity
- Drug profile
- Bereavement
- Referrals

Hospices organizations must include patient level data from individual patient outcomes. These data elements must be used for evaluation and in the hospice’s quality assessment performance.

The data elements collected must be documented in a consistent manner across hospices.

§ 418.56 Interdisciplinary group, care planning, and coordination of services

The interdisciplinary group (IDG) includes a doctor of medicine, physician, and a pastoral or other counselor and works together with the patient and family. The RN is tasked with coordinating care, ensuring the patient and family’s needs, and ensuring the implementation and review of the plan of care. The plan of care is developed, it must include consultation with the attending physician or representative, and the primary caregiver. All hospice services, plan of care, and patients and primary caregiver(s) are instructed of their responsibilities. The plan of care should include:

- Patient and family goals
- Interventions for identified problems
- All services necessary for palliation and management conditions
- Scope and frequency of services
- Measurable outcomes
- Drugs and treatments
with the attending physician within 5 calendar days of the election of hospice care. These comprehensive assessments should be updated by the IDG as frequently as the patient’s condition requires and at a minimum of every 15 days.

Comprehensive assessments must include an evaluation of the following:

- Physical, psychosocial, emotional, and spiritual needs
- Nature and condition causing admission
- Complications and risk factors
- Functional status
- Imminence of death
- Symptom severity
- Drug profile
- Bereavement
- Referrals

Hospices organizations must include patient level data from each assessment to measure individual patient outcomes. These data elements must be used in patient care planning and evaluation and in the hospice’s quality assessment performance improvement (QAPI) program. The data elements collected must be documented in a consistent, systematic, and retrievable way.

§ 418.56 Interdisciplinary group, care planning, and coordination of services

The interdisciplinary group (IDG) includes a doctor of medicine or osteopathy, a RN, a social worker, and a pastoral or other counselor and works together to meet the needs of the patient and family. The RN is tasked with coordinating care, ensuring continuous assessment of each patient's and family's needs, and ensuring the implementation and revision of the plan of care. As the plan of care is developed, it must include consultation with the attending physician (if any), the patient or representative, and the primary caregiver. All hospice services must follow what is stated in the plan of care, and patients and primary caregiver(s) are instructed on their identified care responsibilities. The plan of care should include:

- Patient and family goals
- Interventions for identified problems
- All services necessary for palliation and management of terminal illness and related conditions
- Scope and frequency of services
- Measurable outcomes
- Drugs and treatments
APPENDIX F: CMS QUALITY ASSESSMENT AND PERFORMANCE IMPROVEMENT (QAPI) § 418.58 Quality assessment and performance improvement

As the core of the patient-focused and outcome oriented revision Participation, CMS developed the Quality Assessment and Performance Improvement (QAPI) Program. The goal is to achieve desired outcomes by monitoring quality opportunities for improvement, and making changes to achieve outcomes that are specifically tied to the other regulations (e.g., patient rights, comprehensive assessments, interdisciplinary group, care plans).

QAPI operates on both a patient level and a hospice agency level. The goal is to use data to identify opportunities for improvement in one or more areas. The hospice must ensure that their QAPI program:

- Reflects the complexity of its organization and services (including those services that are contracted or arranged for)
- Involves all hospice services (including those services that are outsourced or contracted)
- Focuses on indicators related to palliative outcomes
- Takes actions to demonstrate improvement in hospice level operations (e.g., reduced hospital admissions, decreased access to electronic record formats)

Additionally, the hospice must maintain documentary evidence to demonstrate its operation to CMS:

- Program Scope
  - Measure, analyze and track indicators to assess patient outcomes
  - Show measurable improvement in indicators of patient outcomes

A revised plan of care includes information from the updated comprehensive assessment and track progress toward specified outcomes and goals and should be completed at least every 15 calendar days. The hospice will coordinate the services administered to the patient and should develop and maintain a system of communication. The IDG is responsible for directing, coordinating, and supervising the care and services provided, and ensuring that the plan of care is followed. Information about a patient’s condition and needs should be shared between all disciplines involved in care and with other non-hospice healthcare providers.
Appendix F: CMS Quality Assessment and Performance Improvement (QAPI)

§ 418.58 Quality assessment and performance improvement

As the core of the patient-focused and outcome-oriented revision of the Conditions of Participation, CMS developed the Quality Assessment and Performance Improvement (QAPI) CoP. The goal is to achieve desired outcomes by monitoring quality and performance, identifying opportunities for improvement, and making changes to achieve improvement. These desired outcomes are specifically tied to the other regulations (e.g., patient’s rights, initial and comprehensive assessments, interdisciplinary group, care planning, and coordination of services).

QAPI operates on both a patient level and a hospice agency level, both of which must collect data to assess quality, use the data to identify opportunities for improvement, and demonstrate performance improvement in one or more areas. The goal is to use data in conjunction with clinical and managerial expertise and experience to drive decision making at the patient level and hospice agency level. CMS is currently testing multiple quality measures to evaluate hospice services that hospices may be able to use in their future QAPI efforts. The patient level portion of QAPI collects data on an individual patient’s assessment/reassessment, care plan, and clinical notes with the goal of improving patient outcomes. The hospice level portion of QAPI looks at the clinically focused aggregate data of the patients, and other data sources such as client satisfaction data, administrative data, marketing data, etc. for the entire hospice agency with the goal of improving clinical and non-clinical operations.

The method and quality of reporting by hospice social workers will have a direct impact on the outcomes of a hospice’s QAPI. Decreased access to electronic case files and inappropriate electronic record formats can diminish the quality of records social workers can contribute to interdisciplinary care files.

The hospice must ensure the development, implementation, and maintenance an effective, ongoing, hospice-wide, data-driven QAPI program that:

- Reflects the complexity of its organization and services
- Involves all hospice services (including those services furnished under contract or arrangement)
- Focuses on indicators related to palliative outcomes
- Takes actions to demonstrate improvement in hospice performance

Additionally, the hospice must maintain documentary evidence of its QAPI program and be able to demonstrate its operation to CMS

- Program Scope
  - Measure, analyze and track indicators to assess processes of care, hospice services and operations
  - Show measurable improvement in indicators of palliative outcomes and hospice services

The hospice must ensure the development, implementation, and maintenance an effective, ongoing, hospice-wide, data-driven QAPI program that:

- Reflects the complexity of its organization and services
- Involves all hospice services (including those services furnished under contract or arrangement)
- Focuses on indicators related to palliative outcomes
- Takes actions to demonstrate improvement in hospice performance

Additionally, the hospice must maintain documentary evidence of its QAPI program and be able to demonstrate its operation to CMS

- Program Scope
  - Measure, analyze and track indicators to assess processes of care, hospice services and operations
  - Show measurable improvement in indicators of palliative outcomes and hospice services
Two Levels of QAPI

- Patient-level QAPI: Individual patient's outcomes or events
  - Collect data on what happened for an individual
  - Assessment/reassessment (§418.54)
  - Care plan (§418.56)
  - Clinical notes
  - Use the data to improve quality of care and outcomes

- Hospice-Level QAPI
  - Clinically focused
    - Aggregate (patient-level) data
    - Collect satisfaction data
  - Non-clinically focused
    - Administrative data
    - Marketing - Referral source contact
    - Outreach to community
    - Profitability
    - Fundraising
  - Data from both levels is used to improve clinical outcomes

Other CoPs that Integrate QAPI

<table>
<thead>
<tr>
<th>CoP Reference</th>
<th>CoP Description</th>
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<tbody>
<tr>
<td>418.54</td>
<td>Comprehensive Assessment of the Patient (c) Standard: Patient outcome measures</td>
</tr>
<tr>
<td>418.60</td>
<td>Infection Control (b) Standard: Control</td>
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<tr>
<td>418.62</td>
<td>Licensed Professional Services (c) Licensed professionals must participate in the hospice’s quality assessment and performance improvement program</td>
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<tr>
<td>418.76</td>
<td>Hospice aide and homemaker services (g) Standard: Hospice aide assignments and duties</td>
</tr>
<tr>
<td>418.100</td>
<td>Organization and administration of services (b) Standard: Governing body and administrator</td>
</tr>
</tbody>
</table>
Two Levels of QAPI

- **Patient-level QAPI**: Individual patient's outcomes or events. Tasks include:
  - Collect data on what happened for an individual patient
  - Assessment/reassessment (§418.54)
  - Care plan (§418.56)
  - Clinical notes
  - Use the data to improve quality of care and outcomes for that patient (§418.56)

- **Hospice-Level QAPI**
  - Clinically focused
    - Aggregate (patient-level) data
    - Collect satisfaction data
  - Non-clinically focused
    - Administrative data
    - Marketing - Referral source contact
    - Outreach to community
    - Profitability
    - Fundraising

- Data from both levels is used to improve clinical operations and non-clinical operations
QAPI Next Steps

  - Completed in February 2008
  - Listed 34 suggested measures along with data definitions and a tool for data collection
  - Available at www.medqic.org
  - Completed by the Carolinas Center for Medical Excellence, the North Carolina QIO

- AIM Project (Assessment. Intervention. Measurement.)
  - Uses the PEACE quality measures and a modified version of the PEACE data collection tool to assess the quality of care in participating hospice sites, identify areas for performance improvement, and measure quality of care improvements after performance improvement projects are implemented.
  - Examines various factors related to the quality of the data collection tool and quality measures in accordance with NQF standards.
  - Identifies factors contributing to disparate and inequitable access to and use of hospice services.
  - August 2009 – November 2010
  - Conducted by IPRO, the New York State QIO
  - Implemented in 7 hospices and 1 palliative care site within the state of New York that volunteered to participate in the project. The participating sites are representative of hospices nationwide.
  - AIM Project is testing 12 quality measures
    - M1: Percentage of patients admitted to hospice who had a screening for symptoms during the admission visit.
    - M2: Percentage of patients who had a comprehensive assessment completed within 5 days of admission.
    - M3: For patients who screened positive for pain, the percentage whose pain was at a comfortable level within 2 days of screening.
    - M4: For patients who screened positive for dyspnea, the percentage who improved within 1 day of screening.
    - M5: For patients who screened positive for nausea, the percentage of patients who received treatment within 1 day of screening.
    - M6: Percentage of patients on opioids who have a bowel regimen initiated within 1 day of opioid initiation.
    - M7: For patients who screened positive for anxiety, the percentage of patients who received treatment within 2 weeks of diagnosis.
    - M8: Percentage of families reporting the hospice attended to family needs for information about medication, treatment, and symptoms.
M9: Provision of interpreter or translator for non-English-speaking or deaf patients.

M10: Percentage of patients who had moderate to severe pain on a standard rating scale at any time in the last week of life.

M11: Percentage of patients with chart documentation of an advance directive or discussion that there is no advance directive.

M12: Selected number of occurrences per 1000 patient days

- Four types of issues are tracked: falls, medication errors, DME issues (complaint, malfunction, or error), and patient/family complaints.

The AIM Project is divided into 8 tasks and will result in 4 major products:

1. A comprehensive literature review of existing research related to disparities in end-of-life care.

2. An intervention package, including the appropriate quality measures, data collection tools, and education and instruction materials, which hospices and QIOs can use to measure and improve the quality of care provided to hospice patients.

3. A report on the quality measures and data collection tools that provides all relevant information for the quality measure and tool endorsement process by a national consensus body.

4. A final report that describes the entire project, including the experiences of participating sites, challenges encountered and overcome, lessons learned, and possibilities for future hospice quality measure and improvement efforts.
APPENDIX G: CMS APPROVED HOSPICE DEEMED STATUS PROGRAMS

The Joint Commission’s 2010 Standards for Home Health, Personal Care and Support Services, and Hospice


Since 1999, The Joint Commission has been the organization authorized to administer accreditation for hospice programs in the United States. Accreditation is granted to programs that are in compliance with the CMS’s Conditions of Participation and meet the Joint Commission’s 2010 Standards for Home Health, Personal Care and Support Services, and Hospice. These accreditation requirements focus on the following areas:

- Ethics, rights and responsibilities
- Provision of care, treatment, and services
- Medication management
- Surveillance, prevention, and control of infection
- Improving organization performance
- Leadership
- Environmental safety and equipment management
- Management of human resources
- Management of information

Community Health Accreditation Program (CHAP)

www.chapinc.org/

CHAP has also been accrediting hospice programs since 1999. Their accreditation process involve six steps:

Step 1: Application/Contract: An application and $500 fee are submitted and upon approval, an accreditation service agreement (contract) is sent back to the agency.

Step 2: Self Study: Core services and service-specific services are evaluated by the hospice agency, using tools provided by CHAP. Additional documents and evaluations are required for home health and hospice programs.

Step 3: CHAP will then assign a reviewer to conduct a site visit and take a census of the patients being served.

Step 4: Plan of Correction: If any deficiencies or required actions are determined, the hospice program receives a tool kit and has about 3-4 weeks to make corrections. Another site visit will be conducted.

5. Step 5: Board of Review: A board will review the hospice materials completed and make a final accreditation decision.

6. Step 6: Accreditation: If the hospice organization is approved, they will receive their accreditation and marketing materials.

Accreditation Commission for Health Care (ACHC)

www.achc.org/index.php

ACHC has accreditation for programs in:

- Home Health
- Infusion Nursing
- Hospice
- Sleep Lab
- Home/Durable Medical Equipment Services
- Clinical Respiratory Care
- Medical Supply Provider
- Complex Rehabilitation and Assistive Technology Supplier
- Fitter Services
- Pharmacy Services
- Non-Certified/Private Duty Program
- Private Duty Nursing
- Private Duty Aide

The accreditation process is as follows:

1. Determine if Program meets the Eligibility Criteria

   ◊ Your organization has been actively providing in-home care and has served a minimum of ten (10) clients within the last year.
   ◊ Your organization agrees to accept the standards and grant ACHC and/or CHAP access to the program to conduct an inspection.
   ◊ Your organization agrees to pay fees according to the standards set forth by ACHC.
   ◊ Your organization agrees to pay fees according to the standards set forth by CHAP.
   ◊ Your organization agrees to pay fees according to the standards set forth by CMS.

   The Medicare Conditions of Participation can be found at: www.cms.gov/Medicare/Provider-Enrollment-and-Certification/Certification-and-Payment-Codes/Conditions-of-Participation-
   and-Certification.html

APPENDIX H: THE JCAHO’S 2010 STANDARDS FOR HOSPICE

www.jcrinc.com/Accreditation-Manuals/2010-Standards-for-Hospice/1932/

Since 1999, The Joint Commission has been the organization authorized to administer accreditation for hospice programs in the United States. Accreditation is granted to programs that are in compliance with the CMS’s Conditions of Participation and meet the Joint Commission’s 2010 Standards for Hospice Care. The accreditation requirements focus on the following areas:

- Ethics, rights and responsibilities
- Provision of care, treatment, and services
- Medication management
- Surveillance, prevention, and control of infection
- Improving organization performance
- Leadership
- Environmental safety and equipment management
- Management of human resources
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Step 2: Self Study: Core services and service-specific services are evaluated by the hospice agency, using tools provided by CHAP. Additional documents and evaluations are required for home health and hospice programs.

Step 3: CHAP will then assign a reviewer to conduct a site visit and take a census of the patients being served.

Step 4: Plan of Correction: If any deficiencies or required actions are determined, the hospice program receives a tool kit and has about 3-4 weeks to make corrections. Another site visit will be conducted.

Step 5: Board of Review: A board will review the hospice materials completed and make a final accreditation decision.

Step 6: Accreditation: If the hospice organization is approved, they will receive their accreditation and marketing materials.

Accreditation Commission for Health Care (ACHC)

www.achc.org/index.php

ACHC has accreditation for programs in:

- Home Health
- Infusion Nursing
- Hospice
- Sleep Lab
- Home/Durable Medical Equipment Services
- Clinical Respiratory Care
- Medical Supply Provider
- Complex Rehabilitation and Assistive Technology Supplier
- Fitter Services
- Pharmacy Services
- Non-Certified/Private Duty Program
- Private Duty Nursing
- Private Duty Aide

The accreditation process is as follows:

1. Determine if Program meets the Eligibility Criteria

   ◊ Your organization has been actively providing in-home care and has served a minimum of ten (10) clients within the last year.
   ◊ Your organization agrees to accept the standards and grant ACHC and/or CHAP access to the program to conduct an inspection.
   ◊ Your organization agrees to pay fees according to the standards set forth by ACHC.
   ◊ Your organization agrees to pay fees according to the standards set forth by CHAP.
   ◊ Your organization agrees to pay fees according to the standards set forth by CMS.

   The Medicare Conditions of Participation can be found at: www.cms.gov/Medicare/Provider-Enrollment-and-Certification/Certification-and-Payment-Codes/Conditions-of-Participation-
   and-Certification.html
5. Step 5: Board of Review: A board will review the hospice organization based on the materials completed and make a final accreditation determination.

6. Step 6: Accreditation: If the hospice organization is approved, they will receive a certificate of accreditation and marketing materials.

Accreditation Commission for Health Care (ACHC)
www.achc.org/index.php

ACHC has accreditation for programs in:
- Home Health
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- Complex Rehabilitation and Assistive Technology Supplier
- Fitter Services
- Pharmacy Services
- Non-Certified/Private Duty Program
- Private Duty Nursing
- Private Duty Aide

The accreditation process is as follows:

1. Determine if Program meets the Eligibility Criteria
   - Your organization has been actively providing in-home and/or alternate site services and has served a minimum of ten (10) clients with seven (7) active clients before submitting an application.
   - Your organization agrees to grant ACHC and/or its designated agent’s full access to all records (including client and personnel) that are necessary to ascertain compliance with the standards.
   - Your organization agrees to pay fees according to the terms specified in the Contract for Survey.
Your organization agrees to submit applications for all branch offices.
Your organization must be operating within the United States and/or its territories.

2. Register for the ACHC Interpretive Guide for Accreditation Standards

3. Preparing your Preliminary Evidence Report (PER)

4. Submission of the Application, Deposit and PER

5. Fee Estimate and Contract

6. Scheduling the Survey (3-7 months)

7. Desk Review

8. On Site Survey. A survey agenda consists of the following:

   - Opening Conference
   - Tour of the Facility
   - Company QI/Performance Improvement Presentation
   - Review any PER correction (if applicable)
   - Client/Patient Home Visits
   - Client/Patient record reviews
   - Personnel record reviews
   - Interview with staff and management
   - Exit conference

9. Scoring Your Survey and Decision. Outcomes:

   - Accredited – Very minimal or no deficiencies found. Overall the company is compliant with ACHC standards. Accreditation is granted, but a POC (Plan of Correction) for any deficiencies found must be developed and sent to your Account Manager within 30 days.

   - Deferred – Enough deficiencies that the company did not score high enough for accreditation status. The company will have an opportunity to submit a POC (Plan of Correction) for all standards that were “partially met” or “not met” and this POC will be reviewed by a clinical advisor. If all deficiencies have been resolved, the company will be granted accreditation.

   - Denied – Many severe deficiencies that cause a company to be outside of the deferred range. In this instance, the company is out of compliance with ACHC standards and must re-apply for accreditation. All fees and application documents must be re-submitted in order to re-apply.

10. Accreditation Status

11. Renewal

APPENDIX H: NHPCO STANDARDS FOR

National Hospice and Palliative Care Organization (NHPCO)

www.nhpco.org/4d4/pages/index.cfm?fa=DO=4900

1. Patient and Family Centered Care: Providing care and meeting the needs and exceed the expectations of those we serve.


3. Clinical Excellence and Safety: Ensuring clinical excellence and providing safe care.

4. Inclusion and Access: Promoting inclusiveness in our organization — regardless of race, ethnicity, color, religion, gender, sexual orientation, age, disease or other characteristics — have access to our services.

5. Organizational Excellence: Building a culture of quality organization that values collaboration and communication.

6. Workforce Excellence: Fostering a collaborative, inclusive work environment that promotes inclusion, individual accountability and shared professional development, training, and support to all.

7. Standards: Adopting the NHPCO Standards for Hospital and Ambulatory Care.

8. Compliance with Laws and Regulations: Ensuring compliance with laws, regulations, and professional standards of practice, including those that prevent fraud and abuse.

9. Stewardship and Accountability: Developing a qualified and senior leadership team who share the responsibilities of the organization.

to submit applications for all branch offices.

- operating within the United States and/or its territories.

- Effective Guide for Accreditation Standards

- Deposit and PER

The application consists of the following:

- Improvement Presentation

Outcomes:

- or no deficiencies found. Overall the company is compliant with accreditation is granted, but a POC (Plan of Correction) for deficiencies that the company did not score high enough for the company will have an opportunity to submit a POC (Plan of Correction) that describes deficiencies that were “partially met” or “not met” and this POC will be sent to your Account Manager within 10 days of the survey.

- or a deficiency is found, the

- that cause a company to be outside of the deferred time period. All fees and application documents must be complete and submitted to ACHC within the time frames provided.

APPENDIX H: NHPCO STANDARDS FOR PRACTICE

National Hospice and Palliative Care Organization (NHPCO) Standards for Practice

www.nhpco.org/i4a/pages/index.cfm?pageID=4900

1. Patient and Family Centered Care: Providing care and services that are responsive to the needs and exceed the expectations of those we serve.

2. Ethical Behavior and Consumer Rights: Upholding high standards of ethical conduct and advocating for the rights of the patients and family caregivers.

3. Clinical Excellence and Safety: Ensuring clinical excellence and promoting safety through standards of practice.

4. Inclusion and Access: Promoting inclusiveness in our community by ensuring that all people - regardless of race, ethnicity, color, religion, gender, disability, sexual orientation, or other characteristics – have access to our programs and services.

5. Organizational Excellence: Building a culture of quality and accountability within our organization that values collaboration and communication and ensures ethical business practices.

6. Workforce Excellence: Fostering a collaborative, interdisciplinary environment that promotes inclusion, individual accountability and workforce excellence, through professional development, training, and support to all staff and volunteers.

7. Standards: Adopting the NHPCO Standards for Hospice Programs and/or the National Consensus Project’s Clinical Practice Guidelines for Quality Palliative Care as the foundation for our organization.

8. Compliance with Laws and Regulations: Ensuring compliance with applicable laws, regulations, and professional standards of practice, implementing systems and processes that prevent fraud and abuse.

9. Stewardship and Accountability: Developing a qualified and diverse governance structure and senior leadership who share the responsibilities of fiscal and managerial oversight.

10. Performance Measurement: Collecting, analyzing, and actively using performance measurement data to foster quality and performance improvement in all areas of care and services.
APPENDIX I: NASW STANDARDS FOR PALLIATIVE AND END-OF-LIFE CARE

National Association of Social Workers Standards for Palliative and End-of-Life Care
www.socialworkers.org/practice/bereavement/standards/default.asp

The NASW has eleven standards for practitioners working in palliative and end of life care:

1. Ethics and Values – The values, ethics, and standards of both the profession and contemporary bioethics shall guide social workers practicing in palliative and end of life care. The NASW Code of Ethics (NASW, 2000) is one of several essential guides to ethical decision making and practice.

2. Knowledge – Social workers in palliative and end of life care shall demonstrate a working knowledge of the theoretical and biopsychosocial factors essential to effectively practice with clients and professionals.

3. Assessment – Social workers shall assess clients and include comprehensive information to develop interventions and treatment planning.

4. Intervention/Treatment Planning – Social workers shall incorporate assessments in developing and implementing intervention plans that enhance the clients' abilities and decisions in palliative and end of life care.

5. Attitude/Self-Awareness – Social workers in palliative and end of life care shall demonstrate an attitude of compassion and sensitivity to clients, respecting clients' rights to self-determination and dignity. Social workers shall be aware of their own beliefs, values, and feelings and how their personal self may influence their practice.

6. Empowerment and Advocacy – The social worker shall advocate for the needs, decisions, and rights of clients in palliative and end of life care. The social worker shall engage in social and political action that seeks to ensure that people have equal access to resources to meet their biopsychosocial needs in palliative and end of life care.

7. Documentation – Social workers shall document all practice with clients in either the client record or in the medical chart. These may be written or electronic records.

8. Interdisciplinary Teamwork – Social workers should be part of an interdisciplinary effort for the comprehensive delivery of palliative and end of life services. Social workers shall strive to collaborate with team members and advocate for clients' needs with objectivity and respect to reinforce relationships with providers who have cared for the patient along the continuum of illness.

9. Cultural Competence – Social workers shall have, and shall continue to develop, specialized knowledge and understanding about history, traditions, values, and family systems as they relate to palliative and end of life care within different groups. Social workers shall be knowledgeable about, and act in accordance with, the NASW Standards for Cultural Competence in Social Work Practice (NASW, 2001).

10. Continuing Education – Social workers shall assume continued professional development in accordance with Continuing Professional Education (NASW, 2002) and continuing education requirements of the licensing agency.

11. Supervision, Leadership, and Training – Social workers of life care should lead educational, supervisory, administrative, and organizational activities.
Continuing Education – Social workers shall assume personal responsibility for their continued professional development in accordance with the NASW Standards for Continuing Professional Education (NASW, 2002) and state requirements.

Supervision, Leadership, and Training – Social workers with expertise in palliative and end of life care should lead educational, supervisory, administrative, and research efforts with individuals, groups, and organizations.
APPENDIX K: CITATIONS FROM CURR HOSPICE SOCIAL WORK RESEARCH S (prepared by Deborah Waldrop - see pages 6 to 9)


This article summarizes research on social work in hospice care from 1990 through July 2004 and provides a deeper background to the more recent articles listed in this bibliography. Discussion centers on articles that evaluate the roles, practices, and core values of social workers, and the barriers they experience in providing end-of-life care. Social workers provide psychosocial support to patients and families including counseling, assessment and referrals to further services, developing and implementing Advanced Directives, patient advocacy with other care professionals, case management (e.g., financial information, referrals to community resources, etc.), bereavement care, ethical considerations for treatment plans, education about death and dying, assistance with funeral arrangements, and at times spiritual counseling.

When working with other professionals in organizations, social workers assist in giving difficult diagnoses, assessing a client system to develop treatment plans, facilitating communication between staff, mentoring and supervising other social workers, educating colleagues on a client's social context, developing policies and programs for services related to end-of-life care and managing staff development and volunteer training. Social workers identify core values as advocating for a patient's right to self-determination, pursuing care for the common good, providing care for patients that address all areas of pain (physical, social, emotional, spiritual), and maintain respect for those who are dying or important to the dying person.

Research highlights the need for social workers to be involved at the policy level in educating hospice stakeholders and decision-makers about the social work roles, values, and barriers to providing quality end-of-life care. Research also lists the barriers to service delivery as insufficient educational preparation, role conflicts with other staff in delivering services, ambiguities in hospice agency policies regarding service delivery, and varying expectations from administrators. Further, a lack of knowledge between professions about each other's roles leads to interdisciplinary communication challenges and differing goals. Lastly, there is an overall lack of empirical research and funding for research, which can result in the devaluing of social workers as hospice agency policies regarding service delivery, and varying expectations from administrators.

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HOSPICE SOCIAL WORK: LINKING POLICY, PRACTICE, AND RESEARCH REPORT


These researchers conducted a quantitative survey with patients, social workers, and hospice directors to explore outcomes related to social workers' level of involvement in hospice care teams. The sample included 330 patients, 66 social workers, and 66 hospice directors from 66 agencies (registered with NHPCO) throughout the country. Each participant was mailed a questionnaire about social worker involvement in care, hospice care processes, and hospice outcomes. Results show that social workers have little involvement during the intake process (only 38% include social workers at intake). However, when social workers are involved in assessment, it increases their ability to plan for potential barriers to treatment as well as prevent future crises, thereby decreasing future costs of care. Results also indicate a positive correlation in team functioning as a social worker's credentials increase (e.g., BSW to MSW). Social workers also continue to have higher case loads (16.7 patients to 1 social worker vs. 5.5 patients to 1 nurse) and only 18% are supervised by a social worker. Social workers report frustrations with team integration and feeling equally respected as other team members in the care process. The authors recommend establishing higher social worker salaries, hiring social workers with more education and experience, obtaining social work supervision for social workers, including social workers in intake interviews, and hiring a sufficient number of social workers dedicated to client care.


The researchers also list the barriers to service delivery as insufficient training, lack of expertise in pain management, hiring insufficient number of social workers dedicated to client care, and only 18% are supervised by a social worker. Social workers report frustrations with team integration and feeling equally respected as other team members in the care process. The authors recommend establishing higher social worker salaries, hiring social workers with more education and experience, obtaining social work supervision for social workers, including social workers in intake interviews, and hiring a sufficient number of social workers dedicated to client care.


These researchers evaluated hospice social workers' delivery of services as a member of an interdisciplinary team, specifically how they assessed and treated pain as described by patients and caregivers. A mail survey was sent to social workers using the Population-Based Palliative Care Research Network (PopCRN), which yielded 90 respondents from 19 states across the US. Questions focused on social workers' delivery of services, interaction with caregivers and team members, and interdisciplinary team structure. Results show that 74% of social workers surveyed had an MSW, an average of 6 years experience, and an average of 23.4 cases (compared to nurses' average of 11.2 cases). Additionally, social workers can, but do not regularly assess caregiver attitudes in pain management. However, they are regularly consulted by non-social worker colleagues and feel like active team participants in team meetings. There were some concerns about the increased focus on the medicalization of hospice, the need to presentively assess, address, and interface with caregivers about beliefs and about pain management and other aspects of care. While this study and others by the lead author describes higher perceived levels of hospice social work integration with hospice teams, the findings are not generalizable, because the sample was drawn from a network of hospice organizations that are more likely to participate in hospice research and encourage progressive hospice care practices. Nonetheless, this research still adds to the growing body of knowledge on hospice social work.

Care. Home care hospice social workers have exposure to the patient's home environment and therefore should adapt care to carefully consider this environment, and include caregivers (who may be administering care) in the assessment and planning of care process. Interdisciplinary teamwork is required in both environments. However, hospice social work allows for a more balanced role of care planning than hospital palliative care social workers. The author suggests that social workers' skills and knowledge base for each environment are different and should be defined in order to focus the scope of practice for palliative care and hospice social work practice standards.
Interdisciplinary Collaboration


The authors evaluated hospice social workers to determine aspects of successful interdisciplinary collaboration within hospice care teams. The sample consisted of 146 social workers who were mailed quantitative surveys. All participants were from state licensed hospice agencies in Missouri. Results show that 53% of respondents had an MSW and 31% were the only social worker in their agency. The overall perception of interdisciplinary collaboration was high, but with a wide range in responses. Perceptions of interdisciplinary collaboration were not related to the social worker’s level of education, the make-up of the hospice agency staff, or the quality of care delivered by the hospice program. The authors cite many limitations to their study, such as a low response rate and the use of a sample from only one state. The article calls for more research on the topic to explain the lack of correlation among variables. Parker Oliver (2006) later uses a qualitative study to evaluate similar topics (Parker Oliver & Peck, 2006).


Under the conceptual framework of the Bronstein Model for Interdisciplinary Communication (Bronstein, 2003), the authors used a qualitative research design to randomly evaluate a convenient sample to determine self-identified strengths and challenges of teamwork for hospice social workers. Bronstein’s model views successful collaboration through (1) interdependence, (2) newly created professional activities, (3) flexibility in traditional roles, (4) collective ownership of goals, and (5) reflection on process. The sample included 23 social workers from 20 hospice programs who discussed their employment and involvement with hospice programs, educational preparation for employment, supervision of performance, and the make-up of the hospice care team. Results show that teamwork is enhanced when team members have strong communication and trust among the group, engage in joint home visits with other colleagues, participate in team building activities, feel equally respected as a member of the team, and receive support from hospice administration. Challenges of interdisciplinary work for hospice social workers include large caseloads, the medicalization of hospice care diminishing the social work role, limited number of allowed visits, the lack of staff flexibility and administrative support, and personality conflicts among team members. Lastly, the authors highlight the importance of evaluation to determine team effectiveness. Only four social workers said this was done at their agency, but indicated that it was helpful in making changes to enhance the effectiveness of the interdisciplinary team.

Hospice Services with Families


The authors evaluated hospice social workers in two Southeastern states to determine the unmet needs of patients at the end of life. A total of 212 surveys were collected from social workers asking them to identify patients’ and caregivers’ unmet needs, and the reasons, interventions and outcomes, and barriers to addressing these unmet needs. Findings show that the majority of social workers responding were Caucasian (91.9%), females (91.7%), had an MSW (71.2%), and were employed with a hospice agency for an average of 4.24 years. Social workers stated that patients...

Workers to determine aspects of successful interdisciplinary care. The sample consisted of 146 social workers that were identified strengths and challenges of teamwork for hospice social workers. Caregivers' unmet needs, and the reasons, interventions and why the authors highlight the importance of evaluation to the Bronstein Model for Interdisciplinary Communication. Parker Oliver (2006) later uses a qualitative study to total of 212 surveys were collected from social workers in two Southeastern states to determine the unmet needs were patient-related psychosocial and family conflict issues, such as a fear of losing independence and being a burden on family and friends. Social workers perceive that these unmet needs are treatable with psychosocial interventions and referrals, and suggest that hospice care professionals need to assess and intervene effectively to increase the quality of care. Barriers to addressing unmet needs include societal and cultural issues related to death and dying, such as lack of understanding or knowledge about dying or the hospice care philosophy.


The authors assessed the methods of supervision for hospice social workers in five Southeastern states. A mail questionnaire was collected from 109 social work supervisors. Results indicate that 99% of social workers are evaluated in some way with a great variability in the method of evaluation. The most common evaluation methods were review of the social workers' written work (92%), input from other hospice team members (86%), individual supervision (81%), and direct observation (70%), with 33% being evaluated once a year. Supervisors do not often look to patient input because of concerns that it is not a useful method of evaluation given the physical and emotional conditions of some patients. The authors identify that supervisors more often use indirect evaluation methods, which may be attributed to lack of time on the part of the supervisor or the social workers. Suggestions for enhanced quality of care include increased efforts of supervisors to directly observe social workers and to seek patient feedback to learn about client satisfaction. They use the NASW code of ethics to cite the social work profession's commitment to advocate for a client's self-determination as a justification for obtaining patient feedback.


Purpose: Guided by an explanatory matrix of family conflict at the end of life, the purpose of this article was to examine the correlates and predictors of family conflict reported by 155 spouses and adult children of persons with lung cancer. Design and Methods: A cross-sectional statewide survey of family members of persons who died from lung cancer was conducted as part of the larger study on the Assessment of Cancer Care and Satisfaction in Wisconsin. Results: Significant bivariate correlations were found between family conflict and family context variables (i.e., a history of conflict, younger respondent age, race, and specified end-of-life care wishes of the patient), conditions (i.e., greater physical and psychological clinical care needs of the patient), and contributing factors (i.e., communication constraints and family asserting control). In the multivariate model, significant predictors of family conflict included prior family conflict, race, communication constraints, and family members asserting control; the model explained 72% of the variance in conflict. Implications: Implications for routine assessment and screening to identify families at risk and recommendations for the development and testing of interventions to facilitate shared decision making and enhance open communication among at-risk families are highlighted.

The authors examine family members of recently deceased patients from nursing homes and residential care/assisted living facilities to determine aspects of care that lead to positive quality of end-of-life care outcomes in long-term care environments. Family members of 457 recently deceased residents from 26 nursing homes and 105 from residential care/assisted living facilities were interviewed by telephone about the residents’ experiences, care provided during the last month of life, the expectation of death, the process of death, the family and staff involvement, and the satisfaction of care. The sample was mostly white (91%), female (75%), an average age of 61 years old, and the adult children of the resident (66%). Results indicate outcome measures as the structure of services, the process of dying, and the outcome of services up until death. Under structure of services, family members cited a need for more staff, specifically those that are more educated about end-of-life issues. In regard to the process of care prior to death, social support from family and staff was seen as instrumental in increasing the quality of care at the end of life. The highest levels of dissatisfaction in any area were due to a lack of attention and positive support from staff. Third party care providers (e.g., hospice care providers) were described as even more helpful in increasing the quality of end-of-life care because of the increased attention the patient received. The most frequent outcome of services up until death for each patient was “being comfortable” at the time of death and one-third indicated no additional service would have increased the quality of care the resident received. The authors cited the need for emotional and social support during end-of-life care and highlighted many ways in which social workers are trained to provide these services. However, because of diminished federal care requirements for nursing homes and residential care/assisted living facilities, social workers are not often enough involved in administering these services. The article also suggests that hospice care social workers should consider these elements when working with families in nursing homes and residential care/assisted living facilities.


End-of-life care has gained recognition as an important interdisciplinary clinical domain during the past three decades largely because scientific and medical advances have changed the nature of dying in the US. Advances in the treatment of life-limiting illness have typically focused on medical issues and on treating the physical symptoms that accompany the final stage of a terminal illness. However, because the lengthening life span has made more choices available at the end of life, there is also greater need for evidence-based psychosocial treatment to diminish some of the prolonged emotional, psychological, social, and spiritual distress that accompanies dying. Both terminally ill older adults and their caregivers can be helped by interventions that address the need for information, education, preparation, communication, emotional support, and advocacy. This paper presents a review of evidence-based psychosocial treatments at the end of life for both older adults and their caregivers.
OFFICE OF HOSPICE RESOURCES

Government Agencies

Centers for Medicare and Medicaid Services (CMS)
www.cms.hhs.gov/

- Hospice Center
  www.cms.gov/center/hospice.asp
  This website provides links to reports and resources on a variety of issues related to hospice care.

- Data on Medicare Hospice Care
  This link includes the 20 most frequent diagnoses, the number of patients, average length of stay, and trends over time in length of stay, by diagnosis from 1998-2008. A summary document of the research is also included.

- Regulations (excerpts listed in brief):
  ◊ Department of Health and Human Services (DHHS), Centers for Medicare & Medicaid Services (CMS), Federal Register Part II, 42 CFR Part 418, Medicare and Medicaid Programs: Hospice Conditions of Participation; Final Rule (Page 32218 details personnel qualifications for hospice social workers)
  ◊ Social Security Act, Title 18, Section 1861 (Subsection dd)
  www.ssa.gov/OP_Home/ssact/title18/1861.htm

Agency for Healthcare Research and Quality (AHRQ)
www.ahrq.gov

- Research in Action Newsletter – (March 2003, Issue 12) – Advance Care Planning:
  Preferences for Care at the End of Life
  www.ahrq.gov/research/endliferia/endria.pdf

- Regulations (excerpts listed in brief):
  ◊ Department of Health and Human Services (DHHS), Centers for Medicare & Medicaid Services (CMS), Federal Register Part II, 42 CFR Part 418, Medicare and Medicaid Programs: Hospice Conditions of Participation; Final Rule (Page 32218 details personnel qualifications for hospice social workers)
  ◊ Social Security Act, Title 18, Section 1861 (Subsection dd)
  www.ssa.gov/OP_Home/ssact/title18/1861.htm

Accreditation Organizations

The Joint Commission
www.jointcommission.org/

- 2010 Standards for Home Health, Personal Care and Support Services, and Hospice

Community Health Accreditation Program (CHAP)
www.chapinc.org/
Accreditation Commission for Health Care (ACHC)
www.achc.org/index.php

National Organizations
National Hospice and Palliative Care Organization (NHPCO)
www.nhpco.org/templates/1/homepage.cfm
  • NHPCO Facts and Figures: Hospice Care in America
  • Social Work Competencies Module
    www.nhpco.org/4Arpages/index.cfm?pageid=3913
National Association of Social Workers (NASW)
www.socialworkers.org
  • Credentials
    ◊ Advanced Certified Hospice and Palliative Social Worker (ACHP-SW)
      www.socialworkers.org/credentials/credentials/achpsw.asp
    ◊ Certified Hospice and Palliative Social Worker (CHP-SW)
      www.socialworkers.org/credentials/credentials/chpsw.asp
  • Standards
    ◊ NASW Standards for Social Work Practice in Palliative and End of Life Care
      www.socialworkers.org/practice/bereavement/standards/default.asp
  • NASW Policy Statements
    www.naswpress.org/publications/practice/speaks.html
    • End-of-Life Care
    • Hospice Care
  • Help Starts Here
    www.helpstartshere.org
    ◊ Death and Dying
    ◊ Death and Dying – How Social Workers Help – The Role of Social Work in Hospice and Palliative Care by Mary Raymer, MSW, ACSW
    ◊ Death and Dying – How Social Workers Help: How Social Workers Keep the HOPE Alive in Hospice by Margo W. Steinberg, MSW, LCSW
      www.helpstartshere.org/health-and-wellness/hope-and-hospice.html
    ◊ Death and Dying Trends – Creativity at the End of Life by Hannah Fiske
APPENDIX N: PENDING LEGISLATION


http://warner.senate.gov/public/index.cfm?p=PressReleases&ContentRecord_id=8aa800a1-5e6f-42cf-a5f1-4f2e3e841093&ContentRecordType_id=0956c5f0-e7c-478d-95e7-1339e7753bab&MonthDisplay=6&YearDisplay=2009

Senator Mark Warner has introduced legislation that would expand education and services for families and individuals dealing with terminal illnesses. The bill calls for patients with Medicare to receive hospice services when diagnosed with 18 months to live as opposed to the current standard of 6 months to live. Services such as palliative care consultation, patient and family counseling, respite care, and in-home caregiver training would be provided while allowing the patient to still seek curative treatments. Medicare payments would also be withheld from physicians and healthcare providers until a patient diagnosed with a terminal illness receives advanced care planning information. Incentives would be offered from 2011 to 2020 to in-patient hospitals, nursing homes, etc. who obtain accreditation and certification to implement a hospice and palliative care program. After 2020, these providers would receive a decrease in Medicare payments (with exceptions) until the accredited and certified hospice and palliative care program is in place. Even more comprehensive discharge planning would be required for hospitals, skilled nursing facilities, home health agencies, and hospice programs. Lastly, the Department of Health and Human Services would develop a public awareness campaign to highlight the importance of end-of-life planning.

The National Center for Social Work Research Act (S.114 – January 2009)

www.govtrack.us/congress/bill.xpd?bill=s111-114

Senator Daniel Inouye has introduced this legislation in each Congress since 1999. It amends the Public Health Service Act to establish the National Center for Social Work Research as an agency of the National Institutes of Health (NIH) to conduct, support, and disseminate targeted research on social work methods and outcomes related to problems of significant social concern. The legislation authorizes the Director of the Center to: (1) provide research training and instruction; (2) establish research traineeships and fellowships; (3) provide stipends and allowances; and (4) make grants to nonprofit institutions to provide such training, instruction, traineeships, and fellowships. It directs the Secretary of Health and Human Services to establish an advisory council for the Center.
HARTFORD FACULTY SCHOLARS AND DOCTORAL FELLOWS RESEARCHING END-OF-LIFE CARE

Mercedes Bern-Klug, PhD
University of Iowa
Research Topic: National Survey of Nursing Home Social Workers

Karen Bullock, PhD
University of Connecticut
Research Topic: Preference for Utilization of Medical Treatment among Older African Americans at End of Life

Jean Correll Munn, PhD
Florida State University
Research Topic: Social Work Involvement at the End of Life in Long-Term Care

Daniel S. Gardner, PhD
New York University
Research Topic: An Exploratory Evaluation of a Psychoeducational Multifamily Group for Older Adults with Advanced Cancer and their Family Caregivers

Betty J. Kramer, PhD
University of Wisconsin, Madison
Research Topic: Innovations in End-of-Life Care for Elders with Advanced Chronic Disease

Hong Li, PhD
University of Illinois, Urbana-Champaign
Research Topic: Study of Providers of End of Life Care for Frail Elders in Managed Care

Sara Sanders, PhD
University of Iowa
Research Topic: Hospice Care for Individuals with Progressive Dementia: Beliefs and Practices of Social Work Providers and Familial Caregivers

Tracy Schroepfer, PhD
University of Wisconsin, Madison
Research Topic: Assessing the Psychosocial Needs of Terminally Ill Elders

Deborah Waldrop, PhD
University at Buffalo
Research Topic: At the Eleventh Hour: Psychosocial Factors that Contribute to Delayed Hospice Care for Terminally Ill Older Adults
ABOUT THE SOCIAL WORK POLICY INSTITUTE

The Social Work Policy Institute was established in 2009 by the NASW Foundation. Its mission is:

• To strengthen social work’s voice in public policy deliberation
• To inform policy-makers through the collection and dissemination of evidence-based research on social work effectiveness
• To create a forum to examine current and future issues in social work policy and practice

Social Work Policy Institute / NASW Foundation
750 First Street NE, Suite 700 • Washington, DC 20002
Director: Joan Levy Zlotnik, PhD, ACSW

www.SocialWorkPolicy.org • swpi@naswdc.org
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- To inform policy-makers through the collection and dissemination of information on social work effectiveness.
- To create a forum to examine current and future issues in health care and social service delivery.

Social Work Policy Institute / NASW Foundation
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Director: Joan Levy Zitnik, PhD, ACSW
www.SocialWorkPolicy.org • swpi@naswdc.org