

Charting the Course for the Future of Social Work in End-of-Life and Palliative Care

A Report of the 2nd Social Work Summit on End-of-Life and Palliative Care

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Abstract:

This monograph examines the state of palliative and end-of-life care social work. Creating a proactive vision is essential to realizing the profession's potential in this area and to improving care at the end of life. This was the working goal of two Social Work Summits on End-of-Life and Palliative Care. A priority item identified at the 1st Summit in 2002 and the overarching consideration of the 2nd Summit in 2005 was to "create a social work coalition of experts, institutions, organizations involved with end-of-life and palliative care to promote advocacy, education, research and networking." Such a network of organizations would centralize activities, enhance collaboration and maintain the momentum of recent efforts in social work in end-of-life and palliative care. State of the field presentations at the 2nd Summit and the Priority Map of the 1st Summit made it possible to identify key priority initiatives related to those four areas and to develop action plans with the potential to continue to move the field forward. The Social Work in Hospice and Palliative Care Network (SWHPN) was developed after the 2nd Summit to create a forum through which to advance the action steps identified in the areas of practice, research, education and policy. In July 2007 SWHPN was formally launched as a nonprofit 501(c)(3) organization and invited individuals to join as founding members in December 2007. SWHPN now has a large subscriber base for public website updates and growing membership base in its private online community. SWHPN continues to build on the past collaborations with many social work and other organizations working to care for the seriously ill and the bereaved. Additional information is available on at www.swhpn.com.

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The views and opinions presented by attendees at the 2nd Social Work Summit on End-of-Life and Palliative Care do not necessarily reflect the views and opinions of their organizational affiliations

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Introduction

The movement to improve care of patients and families living with life-threatening illness has gained tremendous momentum over the past decade, and social work has made, and will make, important contributions to this improvement. Social workers have long functioned as core team members providing essential services to patients and families coping with life-threatening illness. Their contributions in education, research, administration, and policy development are increasingly recognized and have become integral to the development of this expanding field. This monograph describes advances in leadership and recognition of social work's contribution that have occurred over the past seven years. These accomplishments have led to the launch of a new organization, the Social Work in Hospice and Palliative Care Network (SWHPN), which, with the support of stakeholder organizations, continues to implement the goals that have been established to move the field forward.

Social work has great potential to improve care for people with life-threatening illnesses or those who are dying or bereaved. Social work's broad psychosocial perspective transcends the illness-based diagnostic and treatment paradigm and defines social work philosophy and approach that is multi-level, holistic, and encompassing of the patient, the family, and their larger environment.

With their psychosocial training, social workers have comprehensive skills, not only as practitioners, but also as educators, researchers, and crafters of public policy as well. Viewing patients and families from the perspective of the "person in his or her environment" underlies their understanding of the complex and interrelated physical, emotional, social, and spiritual issues associated with serious illness. It also naturally invites collaboration with the family, the interprofessional care team, and the community. The profession's focus on "starting where the client is" encourages exploration of clients' needs, strengths, and resources that inform the ongoing work of living with advanced illness or end-of-life issues.

Social work's long commitment to social justice positions it for a leadership role in analyzing, advocating, and implementing policy changes that will influence the multiple factors leading to disparities in health care. As stated in the National Agenda for Social Work Research in Palliative and End-of-Life Care published in 2005, social workers have an important role to play,

given their work in varied and divergent practice settings across the life-span, their role in addressing mental health needs, grief and psychosocial aspects of well-being, and their commitment to promoting culturally competent, effective, and humane care, particularly for the most vulnerable and oppressed members of society.¹

Given the broad scope of practice and unique perspective, social workers bring to the field of palliative and end-of-life care and to multidisciplinary teams their unique expertise in ethnic, cultural, and economic diversity; family dynamics; and social support networks. Their expertise in this field includes interventions for dealing with advanced chronic illness, trauma, grief, bereavement, life-course and quality-of-life issues, and disaster relief and interventions for addressing systemic problems, such as fragmentation, gaps, disparities, and inadequacies in the delivery of health care.⁶

Social work researchers have the potential to enrich the focus on palliative and end-of-life care, which involves ethnic, cultural, and economic disparities; substance abuse; incarceration; interventions at different stages in the life course; crisis interventions; and interventions in

community and organizational contexts. Social work expertise in implementing changes in policy through advocacy and leadership should be used to bring about important improvements in care for people who have an advanced chronic illness or are dying or bereaved.

Two surveys of social work practitioners and faculty from schools of social work identified obstacles to social work, advancing and realizing its potential in this specialty.^{2,3} They reported a sense of professional isolation, the lack of visible leaders in their discipline, and a fragmented knowledge base. These barriers were similar to those previously identified by medicine and nursing. In response, the Project on Death in America (PDIA) made a major contribution to improving the professional knowledge and skill base through developing professional leaders in social work as they had already begun to do in medicine and nursing. Participants were supported to create new models of service delivery and professional training, and to advance research within their discipline and across disciplinary boundaries.

Another initiative that contributed to furthering social work's role in this area over the past decade is the Hartford Geriatric Social Work Initiative. This foundation has provided a broad range of training and capacity building opportunities for social workers specializing in research and education with older adults confronting end-of-life issues. The Robert Wood Johnson Foundation initiated and provided support for the first social work summit meeting. Thousands of social work professionals practicing in this area contributed during this period through innovative and committed practice and with the assistance of specialty organizations. Supporting organizations include, among others, the National Hospice and Palliative Care Organization, the American Academy of Hospice and Palliative Medicine, the American Cancer Society, the Duke Institute on Care at the End of Life, the American Cancer Society, the Association of Oncology Social Workers, the Association of Pediatric Oncology Social Workers, the National Association of Social Workers, and the Council on Social Work Education. Many others are listed as participants in the summit meetings.

This monograph examines the state of the social work profession in the field of palliative and end-of-life care. In addition, it highlights the outcomes of a unique effort to bring together national leaders and experts with the goal of shaping the future of social work in this realm.

History of the End-of-Life and Palliative Care Initiative

Creating a proactive vision for social work in end-of-life and palliative care is essential if the profession's potential in this specialty is to be realized. Developing such a vision was the working goal of two Social Work Summits on End-of-Life and Palliative Care. Both were facilitated by Dr. Benjamin Broome and his team at the Hugh Downs School of Human Communication at Arizona State University.¹

First Summit on End-of-Life and Palliative Care, 2002

In March 2002, the First Social Work Summit on End-of-Life and Palliative Care brought together social work leaders in Durham, North Carolina. The summit was co-sponsored by the

¹ The first summit was facilitated by Benjamin Broome, PhD, and graduate assistants Donna Henault-Cole and Julie Wechsler of the Hugh Downs School of Human Communication. For the 2002 summit, Dr. Broome was assisted by Christopher Carey, JD, and Ann Marie Gover, MA.

Last Acts Provider Education Committee of The Robert Wood Johnson Foundation, the Duke Institute on Care at the End of Life, and PDIA. Participants were asked to work within the following context:

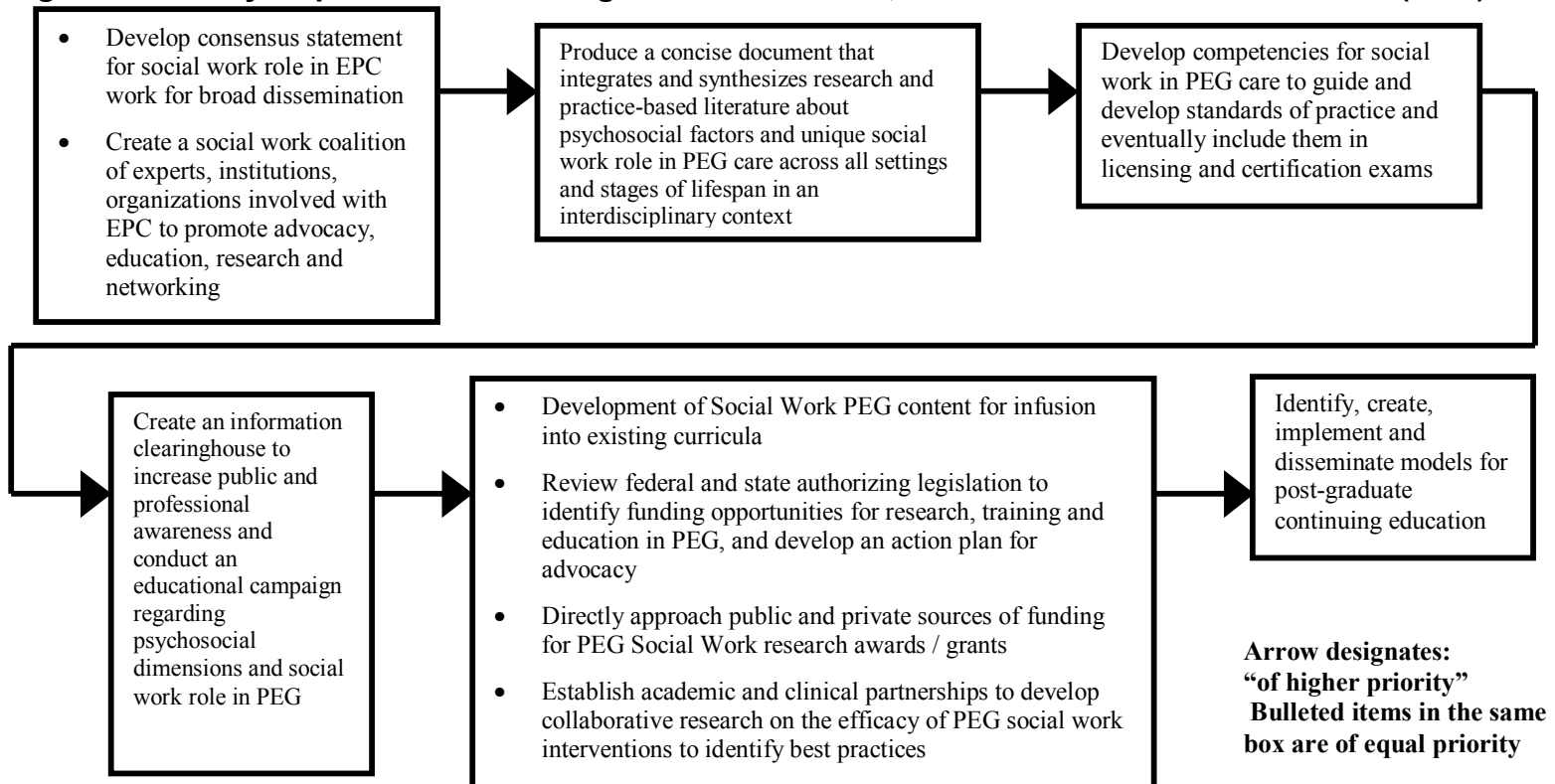
End-of-life and palliative care is emerging as one of the central concerns of U.S. society in the 21st century. Individuals and organizations in the social work arena play a crucial role in meeting the challenges associated with these care issues. The time is ripe to develop an agenda for social work in end-of-life and palliative care and develop programs that will have a positive and significant impact on American life.⁴

The participants began by examining the following question: “What are anticipated challenges related to end-of-life and palliative care—within the policy, research, education, and practice domains of social work—that need to be addressed during the next decade?”⁵ Among the more than 200 responses submitted by the participants, 10 key domains stood out:

- Definition of end-of-life care
- Role of social work in end-of-life care
- Attitudes and perceptions about death and dying
- Definition of scope and standards of practice
- Policy change/improvement of care systems
- Social work foundation training
- Postgraduate training
- Funding and training for research on end-of-life care
- Identification of a research agenda
- Leadership for social work

The overall process of the summit consisted of three phases: (1) defining the challenges related to end-of-life and palliative care, (2) identifying options for responding to anticipated challenges, and (3) prioritizing selected options to form an agenda for moving forward. Through this process, participants identified 10 priority items for advancing the field and created the Priority Map of the Social Work Agenda for Palliative, and End-of-Life Care and Grief Work shown in Figure 1.⁵

Figure 1: Priority Map of Social Work Agenda for Palliative, End-of-Life Care and Grief Work (PEG)



Progress toward Reaching the Goals of the Agenda

After the 2002 summit, a number of participants joined with other social work colleagues to develop and implement projects related to the objectives set forth in the Priority Map. These accomplishments focused the work of the 2005 summit, just as the latter summit has furthered the profession's current agenda. Selected accomplishments in end-of-life and palliative care have fulfilled the priorities established during the two summits. Among these are the publication of two professional papers on best practices and core competencies and a research agenda.^{6,1} Box 1 contains significant textbooks published by awardees of the PDIA SWLDA program.

Box 1. Significant Texts of the PDIA Social Work Leadership Development Awards Program

Berzoff, J., & Silverman, P. (2005). *Living with dying*. New York: Columbia University Press.

Christ, G. (2000). *Healing children's grief: Surviving a parent's death from cancer*. New York: Oxford University Press.

Csikai, E., & Chaitin, E. (2006). *Ethics in end-of-life decisions in social work practice*. New York: Haworth Press.

Dane, B., Tosone, C., & Wolson, A. (2001). *Doing more with less: Long-term skills in short term psychotherapy*. Northvale, NJ: Jason Aronson

Hooyman, N., & Kramer, B. (2006). *Living through loss: Interventions across the life span*. (Foundations of Social Work Knowledge). New York: Columbia University Press.

Walsh-Burke, K. (2005). *Grief and loss: Theories and skills for helping professionals*. Boston, MA: Allyn & Bacon.

In addition, leaders of the initiative published several academic series that increased the visibility of social work's contributions to the field. A special "Social Work Series" was launched in the *Journal of Palliative Medicine* in 2005, edited by Grace Christ and Susan Blacker. The Haworth Press launched the *Journal of Social Work in End-of-Life & Palliative Care* in 2005, edited by Ellen Csikai, to acknowledge this emerging specialization. Three journals—*Smith College Studies*,⁷ *Health and Social Work*,⁸ and *Illness, Crisis, and Loss*⁹—published special issues on palliative and end-of-life care. In addition, two social workers have been authors or co-authors in the JAMA series "Perspectives on Care at the Close of Life."^{10,11}

Other priorities identified at the 2002 summit and expanded during the 2005 summit concerned increasing the educational programs and resources for practicing social workers. Multiple courses have been given online, such as those by the Association of Oncology Social Work (AOSW) and Cancer Care, Inc. Courses have been offered at national meetings, such as the National Hospice and Palliative Care Organization, and through established MSW and continuing education certificate programs offered by schools of social work, such as Smith College and New York University. The National Association of Social Workers (NASW), under the direction of PDIA Social Work Leader Betsy Clark, the association's executive director, developed and distributed the *NASW Standards for Social Work in End-of-Life and Palliative Care* in 2004.¹² Nearly 30,000 social workers have completed a related NASW on-line course so far.¹³ Curriculum and teaching materials have been developed and disseminated online, at national meetings, in BSW and MSW programs, and during interdisciplinary forums. Two

clinical fellowship programs in end-of-life and palliative care social work were developed by the Department of Pain Medicine and Palliative Care at Beth Israel Medical Center,¹⁴ which is ongoing, and the Department of Oncology Social Work at the Sidney Kimmel Cancer Center at John's Hopkins. Two certificate programs in end-of-life and palliative care, one at NYU School of Social Work¹⁵ and one at Smith College School for Social Work.¹⁶ An important resource for practicing social workers is an ongoing listserv with nearly 500 participants developed by PDIA Social Work Leader Terry Altilio (taltilio@chpnet.org).

Social workers have also acquired substantial funding for projects and initiatives in end-of-life and palliative care. Foundation, programmatic, and NIH grants obtained by recipients of Social Leadership Development Awards have more than doubled PDIA's initial investment. Most recently a five-year \$1.5 million NCI grant for transdisciplinary training was funded in 2006 and awarded to PDIA Social Work Leader Shirley Otis-Green. To date over 150 participants from 41 states have benefited from this training. Faculty includes PDIA scholars David Browning, Terry Altilio and Betty Kramer.¹⁷

Second Summit on End-of-Life and Palliative Care, 2005

During preparation for the 2005 summit, the Planning Committee asked organizations that had participated in the first summit to provide feedback concerning the impact of that meeting on the activities of their organization. The earlier summit had been successful in raising awareness about the importance of social work in palliative and end-of-life care. For example, the number of relevant conference presentations increased, and information was disseminated through online organizational newsletters and reports to board members.

The second summit was sponsored by the Open Society Institutes' PDIA Social Work Leadership Development Awards program. Between 1999 and 2004, the program funded 42 social workers whose projects demonstrated leadership in end-of-life and palliative care. More than 60 representatives of 38 social work and related organizations collaborated during the three-day 2005 summit. Hosted by NASW, with support from the National Hospice and Palliative Care Organization, the summit drew participants from Canada, the United Kingdom, and Singapore as well as the United States.

“The process was very effective in taking many ideas and making a roadmap out of them.”
Jeanne Twohig, Duke University

The 2005 summit had three specific objectives:

- To continue the momentum within the profession to make end-of-life and palliative care an important strategic focus.
- To further the efforts to develop a network of organizations and leaders, create a mechanism for collaboration, and advance the profession's evolution in this area of practice, research, education, policy, and advocacy.
- To identify key strategies, initiatives, and action plans.¹⁸

The following high-priority item identified during the first summit became the overarching consideration of the second one: “Create a social work coalition of experts, institutions, organizations involved with end-of-life and palliative care to promote advocacy, education, research and networking.”⁴ Such a network of organizations and entities would centralize activities, enhance collaboration, and maintain the momentum of recent efforts in social work in end-of-life and palliative care. Shortly after the 2005 summit, the Social Work in Hospice and Palliative Care Network (SWHPN) was formed.

"The dynamic group of leaders in attendance at the summit generated innovative ideas for enhancing the role of social workers in the provision of quality end-of-life care." Kathy Brandt, National Hospice and Palliative Care Organization

On the first morning of the 2005 summit, “State of the Field” presentations set the stage for participants to focus on the four areas listed in second specific objective cited above: practice, research, education, and policy. Three of the four presentation

summaries in this monograph had been published as full articles as of this writing.^{1,19,20,21} Two international participants provided overviews of the state of end-of-life and palliative care in their countries and their activities in other regions of the world. Barbara Monroe of St. Christopher’s Hospice in the United Kingdom described St. Christopher’s efforts to advance social work practice.²² Sharon Baxter of the Canadian Hospice and Palliative Care Association provided an overview of palliative care in Canada and recent developments related to policy there.²³

The state-of-the-field presentations and the Priority Map paved the way for participants at the 2005 summit to identify key priority initiatives related to practice, research, education, and policy and, subsequently, to develop action plans and establish work groups with the potential to carry out action items and advance the field. Work groups were identified and established for the four areas to carry out these action plans after the summit ended.

“The summit went a long way toward ensuring the future of social work in palliative and end-of-life care. It was an exciting three days.” Betsy Clark, NASW

SWHPN has since become incorporated as a non-profit organization with a board of directors to oversee the next steps and foster increased collaboration between participating organizations and to provide ongoing guidance concerning organizational development.

Items Recommended for Priority Action

Using an interactive approach facilitated by Dr. Benjamin Broome of Arizona State University, participants at the 2005 summit identified five items for priority action for each of the four areas in social work in end-of-life and palliative care listed earlier: practice, research, education, and policy. (See Box 2).

Box 2. Priority Action Items Identified at the 2005 Summit

PRACTICE: *The Role of Social Work in End-of-Life Care / Defining Scope and Standards of Practice*

- Use outcomes measures/ evidence-based research to build a business model of clinical practice in order to ensure funding and gain acceptance within and across organizations (CFOs, other disciplines, decision-makers).
- Develop, disseminate, and evaluate a social work assessment, intervention and outcomes tool kit appropriate for clinical practice for patients and families across the life span.
- Clarify social work roles, social work's unique training, and social workers' responsibilities to influence federal, state legislation, regulation and accrediting bodies.
- Develop a strategy to increase/elevate the recognition/perception of psychosocial emotional spiritual existential distress/suffering as equal to physical pain and to highlight the role of social work.
- Obtain funding for a marketing plan to educate consumers, professionals, decision makers regarding the role of social work in palliative end-of-life care.

RESEARCH: *Identifying a Research Agenda and Funding / Training for Palliative & End-of-life Care Research*

- Build research capacity and training for leaders and mentors to increase the quality and quantity of social work research.
- Develop standardized measures to document effectiveness of social work interventions in end-of-life care and develop research on efficacy and cost-effectiveness on social work practice in end-of-life care.
- Provide and promote research leadership to establish inter and intra disciplinary practice-based research and assure the integration of the social work research agenda.
- Advance social work research agenda through representation on national research bodies and through establishing infrastructure for end-of-life research.
- Advocate for and develop funding in end-of-life and palliative care social work research and ensure broad dissemination of findings.

EDUCATION: *Social Work Foundation and Post-graduate / Continuing Education & Training*

- Identify, promote, and market the existing education and training models in social work and end-of-life care (including interdisciplinary).
- Build community based mentoring programs.
- Develop and implement training for social work educators in end-of-life care.
- Continue to develop and maintain the information clearinghouse (annotated bibliography, list of post MSW/PhD training programs in end-of-life and palliative care)
- Identify gaps in education and training; develop curriculum to address them.

POLICY: *Leadership, Advocacy and Capacity-building for Social Work*

- Develop organizational structure to address policy for social work in end-of-life care.
- Define role and interventions of social work in improving care systems for end-of-life and palliative care.
- Advocate for change in reimbursement model.
- Develop social work leadership training.
- Enhance national policy dialogues on end-of-life care to include the voice and objectives of social work.

Summary of Presentations on State of the Field Delivered at the 2005 Summit

In preparation for the 2005 Social Work Summit on End-of-Life and Palliative Care, individuals with specific expertise in practice, research, education, and policy were asked to prepare state-of-the-field presentations, which provided summit participants with an overview of the current status of end-of-life and palliative care in each of these crucial areas. Thus far, three presentations have been adapted into articles and published. The presentations provided a background to help participants as they worked toward recommending the items for action mentioned earlier.

The State of Social Work Practice

Terry Altilio, MSW, LCSW, ACSW; Department of Pain Medicine and Palliative Care, Beth Israel Health Care System; Gary Gardia, MEd, LCSW, Hospice Consultant, St. George, Utah; and Shirley Otis-Green, MSW, LCSW, ACSW, OSW-C, Senior Research Specialist, City of Hope National Medicine Center.

The following material is in press in the Journal of Social Work in End-of-Life and Palliative Care.

Current State:

The practice venue of the social work profession is the point at which education, research, and policy come together to inform the services provided to clients. Social work practice in end-of-life and palliative care is enhanced by reciprocal relationships in the work of research, education, and policy. Just as these aspects of practice are related, the challenge of exploring the state of social work practice focused on endorsing rather than duplicating the work of social workers and interdisciplinary colleagues while simultaneously suggesting paths and directions that might enhance and expand the profession's influence in a clinical area that so elegantly validates its core values and perspectives.

In the past six years, many initiatives, programs, and publications have focused on improved care for patients and families living with life-threatening illness. Philanthropic organizations, such as The Robert Wood Johnson Foundation and the Open Society Institute, committed millions of dollars to support programs, research, policy initiatives, education, and development of the literature. The curricula developed for the End-of-Life Nursing Education Consortium and Education for Physicians in End-of-Life Care were created to enhance continuing education among nurses and physicians, and the PDIA Faculty Scholars Program fostered the development of experts in palliative and end-of-life care.

Additional funding supported Social Work Leaders who actualized projects focusing on practice, research, education, and policy and expanded the opportunities for social workers to enhance their expertise in these areas. With curricula already established for medicine and nursing, PDIA's support resulted in the creation of social work initiatives that included documents regarding standards, guidelines, competencies, and scope of practices and the Social Work End-of-Life (SWEOL) Education Project, a two-day course developed by PDIA leaders Mary Raymer and Ellen Csikai. A variety of curricula, including online courses as well as postgraduate continuing education programs, were accompanied by *Living with Dying: A Handbook for End-of-Life Healthcare Practitioners*, a text authored primarily by social work experts.²⁴

At the same time that practitioners in individual disciplines expanded the literature and developed practice standards, a group of interdisciplinary experts received institutional, foundation, and organizational support and funding to create a National Consensus Project for Quality Palliative Care that would eventually produce a document detailing the elements and scope of palliative care:

The purpose of the National Consensus Project for Quality Palliative Care is to promote the implementation of Clinical Practice Guidelines that ensure care of consistent and literature high quality and that guide the development and structure of new and existing palliative care services.²⁵

Given the national interdisciplinary consensus concerning the elements and scope of palliative care, this project was chosen as the landscape against which to examine social work practice.

We reviewed established social work literature on palliative and end-of-life care and compared the content to state-of-the-art care, as reflected in the National Consensus Project. These guidelines for quality palliative care were adopted by the National Quality Forum in 2006 and the 38 preferred practices were established to assist clinicians to achieve quality practice within the following eight domains, which provided the lens through which to view key social work documents: (1) structure and process of care, (2) physical aspects of care, (3) psychosocial and psychiatric aspects of care, (4) social aspects of care, (5) spiritual, religious, and existential aspects of care, (6) cultural aspects of care, (7) care of the imminently dying patient, and (8) ethical and legal aspects of care.²⁵

The intent of this review process was to recognize previous accomplishments and shape a direction that would respect the past, embrace collaboration, and build on the expertise and commitment of colleagues and organizations. As the work evolved, the following objectives were established:

- To determine whether social work literature identified skills and standards congruent with the interdisciplinary expert consensus reflected in the National Consensus Project.
- To enhance and assert social work leadership in specific areas of practice.
- To inform the educational preparation of practitioners.

The sources listed in Box 3 were written by leaders in the field; were selected from respected journals, books, and organizational publications; or were summaries of social work practice both historical and current and national and international. They defined a self-determined scope of practice and knowledge and outlined skills in the generalist and specialist roles.

We read the selected literature to determine whether it reflected, either explicitly or implicitly, a consensus on standards and practice expectations that potentially guide the social work contribution to the field of palliative and end-of-life care. The results indicated that 90% of the sources reviewed echoed consensus guidelines validating the importance of care plans based on patient goals, values, needs, beliefs, and decision making and articulating the need for competent psychological and psychiatric assessment and treatment. Most of the remaining guidelines, which included such issues as culture, pain and symptom management, continuity, ethics, grief, law, team, and spirituality, were endorsed at the level of 50% to 80%. These findings point to a solid base on which to build specialized expertise in palliative and end-of-life care.

Although many core social work values are implicit in this specialty, competent clinical practice goes beyond values. It includes knowledge and skills that clearly demonstrate social work's contribution to the care of patients and families and to the teams of caregivers with whom we work. As the definition of scope of practice becomes more specifically defined, the

Box 3. Social Work Literature Reviewed

- Black R. B. (1989). Challenges for social work as a core profession in cancer services. *Social Work in Health Care, 14*(1), 1-14.
- Brown, S. T., Blacker, S., Walsh-Burke, K., Christ, G., & Altilio, T. (2001). *End of life care giving* (Rev. ed.). "Society for Social Work Leadership in Health Care—Best Practice Series." Philadelphia, PA: Society for Social Work Leadership in Health Care.
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- Smith E., Walsh-Burke, K., & Crusan, C. (1998). Principles of training social workers in oncology. In J. C. Holland (Ed.), *Psycho-oncology*. New York: Oxford University Press.

National Consensus Guidelines and evolving evidence-based outcomes provide a background against which social work clinicians and educators can evaluate and enhance their training and contribute to the growing knowledge base and practice wisdom.

In addition to the social work literature, we reviewed sources in the medical and nursing literature representing emerging and valued efforts to incorporate palliative and end-of-life care into specialties, such as pediatrics, renal disease, and intensive care (see Box 4). Evaluating these articles and books enabled us to determine whether social work was represented in the authorship and whether our professional role was clearly articulated in those specialties. In this literature, we also discovered areas to celebrate and challenges to meet. Although social work content, presence, and authorship was lacking in the literature on intensive care and cardiology, social work's voice was clear in the literature on renal disease and was emerging in pediatrics.

Box 4. Literature Reviewed from Disciplines Other Than Social Work

- Chambers, E. J., Germain, M., & Brown, E. (2004). *Supportive care for the renal patient*. New York: Oxford University Press.
- Clarke, E. B., Curtis, J. R., Luce, J. M., Levy, M., Danis, M., Nelson, J., & Solomon, M. Z. (2003). Quality indicators for end-of-life care in the intensive care unit. *Critical Care Medicine*, 31, 2255-2262.
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Future Directions:

Social workers are often key figures in current practice in palliative and end-of-life care. In addition, the more than 600,000 social workers throughout the United States provide clinical services in settings where illness and end-of-life issues have an impact on the lives of clients, families, and communities. The 2005 summit was preceded by the Social Work Congress at NASW office in Washington, DC. Twelve imperatives were identified to guide the profession. They reinforced the need for professional advances, leadership development and commitment to social justice for vulnerable populations and they can serve to expand and strengthen the basis for social work in the specialty of palliative and end-of-life care. In addition, the imperatives provide a framework within which to maximize social work's impact on the multiple policy, clinical, and ethical issues that converge when practicing in this specialty area.

In addition, the NASW standards¹² and the related course provide practicing clinicians with the opportunity to enhance their potential impact in their respective settings. Existing competencies, guidelines, and standards, combined with the interdisciplinary National Consensus Guidelines and National Quality Forum preferred practices, provide a rich context within which we can evaluate, build, and ensure high-quality practice.

Recognizing the growing need for consistency of practice in end-of-life and palliative care, we considered whether endorsing a common knowledge base for standards, guidelines, and credentialing might strengthen the profession and help to make operational the particular

imperatives that speak to professional competence, standards, and educational rigor. Developing a certification that validates the skills required for all social workers yet identifies skills specific to specialties, such as oncology, pediatrics, and geriatrics, might hold the promise of strengthening practice in these areas.

In research, expanding studies of social work practice and outcomes is an important way to increase the visibility and credibility both within the profession and among related disciplines. This work can be advanced by connecting research and practice through partnerships among researchers, practitioners and communities. Such partnerships would expand the collaborations begun through the PDIA Social Work Leadership Awards program.

In the areas of policy and leadership, social work practitioners can add richness to the local, state, and national dialogues on palliative and end-of-life care. If they can embody the leadership role suggested by the values and skill sets of their profession, they have the potential to increase their impact beyond health care settings and influence the quality of care and service to patients and their families.

The State of Social Work Research

Betty J. Kramer, PhD, MSSW, Professor, School of Social Work, University of Wisconsin-Madison; Richard B. Francoeur, PhD, MSW, MS, Assistant Professor, Columbia University School of Social Work; and Mercedes Bern-Klug, PhD, MSW, Assistant Professor, University of Iowa School of Social Work

The following material was published in full in the Journal of Palliative Medicine Apr 2005, Vol. 8, No. 2: 418-431

Current State:

Before the 2005 summit, the research agenda presented there appeared in an article published in the *Journal of Palliative Medicine's* "Social Work Series."¹ The article, titled "National Agenda for Social Work Research in Palliative and End-of-Life Care," was coauthored by Betty J. Kramer, PhD, Grace H. Christ, DSW, Richard B. Francoeur, PhD, MSW, MS, and Mercedes Bern-Klug, PhD, MSW. Betty Kramer, the article's primary author, presented the agenda and the status of social work research during the summit.

Creating a national research agenda for social work in end-of-life and palliative care was among the priority items that emerged from the 2002 summit. The research agenda was developed by a multimethod process that included an extensive review of the literature, discussions with a purposive sample of social work leaders working in palliative or end-of-life care, and consideration of other national research priorities. This process culminated in the identification of the following 11 domains as having the highest priority:

- Continuity, gaps, fragmentation and transitions in care
- Diversity and health and health care disparities
- Financing and the policy practice nexus
- Mental health concerns and services
- Individual and family care needs and experiences
- Communication
- Quality of care and services
- Decision making, family conferencing, and family caregiver support
- Grief and bereavement

- Pain and symptom management
- Curriculum development and evaluation

These priorities and the recommended research objectives based on them should serve as a guide for future research that will be relevant to social work's mission and value base and address critical needs in the field. We anticipate that the agenda will serve to stimulate social work research that will improve palliative and end of life care and inform direct practice, policy, and education.

The research agenda was created in four phases: (1) review of the literature, (2) initial generation of the profession's research needs, (3) integration of professional mission and national priorities, and (4) confirmation of final priorities.

Phase 1 involved a search of four primary databases spanning a 37-year period from 1965 to 2002. Literature relevant to social work and palliative and end-of-life care was reviewed and categorized to determine the types of publications, the domains addressed, and gaps in research topics studied.

Phase 2, the generation of research needs, took place during the PDIA Social Work Leadership Development Awards program retreat in 2002, when a workshop allowed PDIA social work leaders to see the results of the literature review, set priorities for the research needs of social work and palliative care, and generate ideas for inclusion in the research agenda.

In Phase 3, conceptual categories for priority areas were created to integrate research needs with social work's professional mission and value base and to establish national research priorities that reflected critical gaps in research.

In Phase 4, a roundtable session was held at the PDIA Social Work Leadership Development Awards retreat in 2003 as a follow-up to confirm and validate the priority areas for the proposed research agenda.

Several individual objectives were subsequently developed for each of the high-priority domains identified as a component of the national agenda for social work research in end-of-life and palliative care.

Future Directions:

To counteract inherent challenges and barriers to implementation of the research agenda, we recommend several strategies for moving the agenda forward.

The first strategy is to build social workers' capacity for leadership and engagement in end-of-life and palliative care research. The PDIA Social Work Leadership Development Awards program should be seen as a model for how to accomplish this goal. Between 1999 and 2004, the program provided grants to 42 social work leaders to develop curricula in palliative and end-of-life care and innovations in research and practice in the United States in both academic and practice settings. These grant recipients have produced four major social work textbooks, more than 150 other publications, and 3 special issues or series in professional journals and have received more than 50 program and research grants in addition to the original 42 from PDIA. Another program that exemplifies effective building of research capacity is that of The John A. Hartford Foundations Geriatric Social Work Initiative, which is funding and providing strong mentoring to several scholars who are conducting research in palliative and end-of-life care.

The second strategy is to establish practice-research partnerships, which is in line with the

National Institutes of Health's "State-of-the-Science Conference Statement: Improving End-of-Life Care,"²⁶ which calls for more interdisciplinary research to address the multifaceted aspects of palliative and end-of-life care.

The third strategy is to advocate for funding of social work research. The Institute for the Advancement of Social Work Research is the leader in this task. Since 1993, the institute has been a key resource for social work researchers in this field, and it works closely with the NCI, other federal programs, and professional organizations to promote funding for social work research.

The final strategy is to establish a professional leadership network—the primary purpose of holding the second summit in 2005. The creation of such a network would build consensus within the profession, encourage intraprofessional and interprofessional partnerships, improve social work knowledge and skills in end-of-life and palliative care and dissemination of social work research materials, and increase collaboration and the capacity to advance the field.

The State of Social Work Education

Katherine Walsh, PhD, MSW, Professor, Springfield College School of Social Work; and Ellen L. Csikai, MSW, MPH, PhD, Associate Professor, University of Alabama, Editor, *Journal of Social Work in End-of-Life and Palliative Care*,

The following material was published in full in the Journal of Social Work in End-of-Life and Palliative Care, Issue 1(2) pages 11-26.

Current State:

Both bachelor's-level and master's-level social work courses are missing vital content about end-of-life and palliative care and bereavement. Though many social workers confront end-of-life issues on a daily basis in practice settings, training opportunities through continuing education programs have been limited as well. In recent years, however, social work leaders have developed many programs and models for professional education and training in end-of-life and palliative care, mostly the result of such initiatives as the PDIA Social Work Leadership Development Awards program and the Hartford Geriatric Social Work Initiative. Achievements include courses in end-of-life care, symposia, training manuals, certificate programs, and fellowships.²⁰

In 1997, the Institute of Medicine (IOM) issued *Approaching Death: Improving Care at the End of Life*, a report documenting deficiencies in end-of-life care.²⁷ Since the report's release, several national education programs have emerged for professionals working in end-of-life and palliative care, including Educating Physicians in End-of-Life Care in 1997 and the End-of-Life Nursing Education Consortium in 2000. The consortium was created by the American Association of Colleges of Nursing; and the City of Hope National Medical Center and funded by The Robert Wood Johnson Foundation and the National Cancer Institute (NCI).

In 2001, the Society for Social Work Leaders in Healthcare asked social workers to develop *Care at the End-of-Life*, a monograph on social work roles and competencies in end-of-life and palliative care and grief work.⁶ During the first social work summit, social workers in the field created a national agenda highlighting the need for "increased educational preparation at all levels of social work education."⁴

Efforts from the first summit to formalize standards of care culminated in release of the NASW standards,¹² made possible by a PDIA Social Work Leadership Development Award to

Betsy Clark, NASW's executive director.

Future Directions:

The state-of-the-field report for the second social work summit states the following.

The development and institutionalization of social work education for practice in this arena is necessary for the profession in order for social workers to competently fulfill these recently formulated standards and work toward improving care at the end of life.²⁰

Although family health care is a component of curricula the Council on Social Work Education requires in BSW and MSW programs, courses in end-of-life care are still offered primarily as electives. A review of 50 social work textbooks showed that of 19,377 pages of text, only 651 pages (3.35%) were related to end-of-life care.¹ Continuing education programs also have failed to provide adequate training in end-of-life care, and many excellent courses that are provided are not readily accessible to most practitioners.

Through the initiative of the PDIA Social Work Leadership Development Awards program, many educational resources devoted to palliative and end-of-life care have been developed, tested, and evaluated. Of 38 projects among the 42 awardees in the program, some 28 involved developing educational programs, models, and resources for improving the skills of social workers, other professionals, and client populations. For these many programs, PDIA social work leaders collected data from experts in the field, educators, samples of practitioners, and target client populations. Many of these social workers conducted focus groups, networking luncheons, round-table discussions, or individual interviews or relied on advisory groups, course evaluations, surveys, and other methods to ascertain educational needs and the value of current programs. Through this work, social work leaders identified specific content in curricula that was delineated for generalist education and training and for post-master's continuing education and specialist practitioners.

The content recommended for generalist education ranges from the roles of social work in end-of-life care, psychosocial distress in individuals and families, and end-of-life decision making to ethical issues, crisis intervention, interdisciplinary teamwork, group work, and financial problems and resources. For advanced education, the recommended content includes such topics as interventions with people of varying economic, ethnic, racial, cultural, religious, and sexual orientation or those with a broad range of mental and physical disabilities/other vulnerabilities; advocacy at the institutional and legislative levels; methods of dealing with role differentiation and interdisciplinary teamwork; and bioethics consultation.

From the combined efforts of the PDIA social work leaders and other leaders in social work education, several resources have now been developed to improve social work training at all levels. However, additional resources are needed.

Resources in BSW programs include the NASW standards,¹² reviews and recommendations regarding textbooks, NASW distance learning,¹³ *Dying, death and bereavement in social work practice: Decision cases for advanced practice*,²⁸ *An Approach to Develop Effective Health Care Decision Making for Women in Prison*,²⁹ training in end-of-life care for people with disabilities, and end-of-life and social work websites (e.g., www.swhpn.org or www.eol-resource.htfd.uconn.edu).^{30,31}

Some of the resources available in MSW programs are the same as those included in BSW programs: the NASW standards,¹² textbook review and recommendations, NASW distance learning,¹³ and *Dying, death and bereavement in social work practice: Decision cases for*

advanced practice.²⁸ In addition, however, the list includes an end-of-life textbook⁷, infusion of end-of-life content, elective courses, interdisciplinary courses, a culturally sensitive training manual, specialized field placements, end-of-life specialization through course sequence and field, and concentration on end-of-life.

Finally, in addition to NASW distance learning and an end-of-life textbook,⁷ resources in post-BSW/MSW continuing education programs include AOSW distance learning, an end-of-life symposium, end-of-life fellowships, bereavement training for social workers serving the rural poor, intensive multiday training for social workers offered by the National Hospice and Palliative Care Organization and other professional organizations, intensive/modular interdisciplinary multicultural trainings, intensive/modular pediatric palliative care interdisciplinary trainings, specialized supervision and mentoring, and end-of-life post-master's certificates.

In addition to the curricula listed in the previous paragraphs, the PDIA leadership development initiative also brought about three textbooks on end-of-life care, two with a clinical practice focus^{24,32} and the other a casebook on end-of-life decision making.³³ Other resources include two listservs, a resource website,³¹ other training manuals, and the recently launched *Journal of Social Work in End-of-Life and Palliative Care*. Still, more resources are needed to improve the materials needed to educate social workers about contemporary issues in end-of-life and palliative care.

Ongoing roadblocks to this education involve dissemination of the materials that have been and are being generated and funding for additional projects. One way of to improve dissemination would be to create a central repository for model syllabi, exercises, and assignments for social work end-of-life courses. Funding is needed to enable social workers to gain access to vital courses and to enhance the shrinking budgets in both university and practice settings. Encouraging partnerships between academia and practice settings is necessary to incorporate teaching models into continuing education for practitioners and to inform university students of current innovations in practice.

The State of Social Work Policy

Gary L. Stein, JD, MSW, Associate Professor, Wurzweiler School of Social Work, Yeshiva University, and Patricia A. Sherman, PhD, LCSW, Assistant Professor, Kean University.

The following material was subsequently published as a full article in the Journal of Palliative Medicine "Social Work Series" Issue 8:6 (2005), pages 1271-1281.

Current State:

Social work practice in end-of-life and palliative care settings is strongly affected by policy developments in general health care and by specific policy decisions in end-of-life and palliative care. Presenters at the 2005 summit analyzed policy developments primarily in ethics and law, disenfranchisement, and disparities in the quality of health care and subsequently published a full state-of-the-field report in the *Journal of Palliative Medicine*.³⁴

Recent seminal reports in end-of-life and palliative care should inform social work program and policy development. These include the recommendations for palliative care practice and policy for adults and children developed by the Institute of Medicine (IOM). Last Acts, a Robert Wood Johnson Foundation campaign, developed a comprehensive state-by-state analysis of

key policy indicators, including state policies concerning advance directives, place of death, hospice use, provision of hospital-based palliative care services, use of intensive care units, pain among nursing home residents, and state policies regarding pain management.³⁵ Finally, the Pain & Policy Studies Group at the University of Wisconsin Comprehensive Cancer Center published a “report card” on state pain policies, with special attention to policies that impede access to adequate pain care.³⁶ Both Last Acts and the Pain & Policy Studies Group were under the directorship of social workers.

One crucial area for policy and leadership is ethics and law, which has a profound impact on the delivery of end-of-life and palliative care services. Recent right-to-die cases illustrate this phenomenon. In a policy statement issued in 2003, NASW stated that social work as a profession is committed to “the right of the individual to determine the level of his or her care” and make informed choices.³⁷ A year later, NASW introduced its standards for palliative and end-of-life care,¹² which promote integration of the principles of bioethics into professional practice.

Future Directions:

We recommend that social workers promote their roles in ethics consultation, public policy, and advocacy and work to integrate further the perspectives and concerns of diverse communities into practice, education, and policy with regard to palliative care. The presenters called on 2005 summit participants to identify additional strategies that would enable social workers to become more involved in major policy decisions in health care, particularly in end-of-life and palliative care.

Notable works on health care, such as IOM’s overviews and recommendations; Last Acts’ policy indicators; or the Pain & Policy Studies Group’s report card, should inform the development of new initiatives in social work practice, education, research, and policy in end-of-life and palliative care. Despite commitments and guidelines—e.g., those put forth in NASW’s policy statement³⁷ and its standards for palliative and end-of-life care,¹²—demonstrating social work’s dedication to caring for patients, social workers often struggle to assume a predominant role in shaping end-of-life care policy and practice at the institutional level. To enhance the impact of the profession, social workers need to become members and leaders of hospital ethics committees. PDIA Social Work Leader Ellen Csikai reported that although social workers were members of approximately 75% of hospital ethics committees, their “participation was moderate with greatest involvement in ‘traditional’ social work activities, such as providing knowledge of community resources and acting as liaisons among patient, family and providers.”³⁸

In a survey on the social worker’s role as mediator or advocate for patients and families, Landau³⁹ found that if social workers were viewed as a source of valuable knowledge and perspective, they were often better able to affect ethical decision making. Csikai and Bass⁴⁰ surveyed social workers from Texas and found that most of them had little or no formal training in ethics, despite the fact that end-of-life decision-making is among the most difficult practice situations facing health care social workers. Furthermore, Manetta⁴¹ reported that social workers in hospital settings received no grounding in ethics during their professional training or from NASW policies. These studies conclude that, to be prepared adequately for leadership roles as well as for the clinical work they do on a daily basis, social workers need better training in ethics.

Federal and state legislation also influences social work practice in health care settings.

Social workers' expertise in patient advocacy must be part of this dialogue. For example, in response to the case of Terry Schiavo, Congress considered legislative proposals to increase federal jurisdiction in certain medical situations involving end-of-life care, revisiting and reversing principles in health care law and bioethics that had been regarded as settled. The exceptions are the Advance Directives Improvement and Education Acts introduced in the House of Representatives and the Senate in 2005 and 2007, respectively, which would create a national public education campaign promoting the use of advance directives.^{42,43} With our commitment to patient autonomy and self-determination, social workers must be more active in policy debates, in legislatures, on ethics committees and with the media.

Recommendations regarding ethics, law, and policy put forth by presenters at the 2005 summit also included the following:

- Greater knowledge of the NASW Standards for Palliative and End-of-Life Care.¹²
- Improved training and curricula on bioethics for health care professionals at all educational levels.
- Improved leadership, communication, and assertiveness skills for more effective collaboration on ethics committees and with other health care professionals.
- Promotion of a "language of caring" to counteract the false dichotomy regarding a culture of life and a culture of death.
- More educational training and community outreach on advance directives.³⁴

A key focus of the policy and leadership presentation at the 2005 summit was disenfranchisement and disparities in health care. The topic was explored on many levels, not only concerning racial, ethnic, gender, and age discrimination, but also regarding differences in care relating to socioeconomic status, religious and cultural beliefs, sexual orientation, disability, and medical condition.

Despite the many initiatives to examine ways to end disparities in health and health care, only a few such efforts have focused on palliative and end-of-life care. In 2004, The Robert Wood Johnson Foundation held a symposium on disparities in care at the end of life. Later the same year, the World Health Organization cosponsored the first Global Day Against Pain, and both the IOM and The Robert Wood Johnson Foundation have reported that members of racial and ethnic minority groups are undertreated for pain compared with non-Hispanic Whites.⁴⁴ In many cases in which needs are not properly met, it has been discovered that disenfranchised patients often mistrust the health care system and thus are reluctant to seek treatment.

Suggestions for reducing disparities in palliative and end-of-life care include:

- Community outreach programs or other community initiatives
- Inclusion of lesbian, gay, bisexual and transgender health issues in research, education, and prevention
- Involvement of more businesses in efforts to reduce disparities in care; and improved cultural proficiency among health care providers.

One example of a community initiative is *Bronx Health REACH*, a coalition of health care providers and community and faith-based organizations working to end racial and ethnic disparities in health care.⁴⁵ Beal⁴⁶ recommended the creation of health and education empowerment zones similar to those created for businesses and the development of programs that would link education to health care to improve outcomes in high-risk communities.

Collecting more data on cultural beliefs about illness and death and providing insurance reimbursement for translation services also could improve cultural sensitivity in health care. In addition, hiring more professionals who represent minority patients' communities would not

only improve the comfort level among minority patients seeking treatment but serve to educate other professionals who work with patients from minority communities.

Advancements in policies regarding end-of-life and palliative care can improve practice if social workers assume greater leadership roles in the creation of policies. Their skills as patient advocates must be expanded to include advocacy designed to influence legislators, administrators, and others who make health-care decisions at the institutional level.

Development of the Social Work in Hospice and Palliative Care Network

The Social Work in Hospice and Palliative Care Network, was formed to advance the vision created at the second summit: to create a forum through which to advance the steps for action identified in the areas of practice, research, education, and policy. The network's website (www.swhpn.org) is evolving as a centralized source of information for social workers in end-of-life and palliative care.

SWHPN began as a post-Summit steering committee made up of a number of the Summit participants (see Summit Participants, pp. 22-23), and was officially incorporated as a nonprofit 501(c)(3) organization in July 2007. A Board of Directors was formed in the Spring of 2007 and the Network began inviting founding members to join in December 2007. SWHPN launched a dynamic private online community for SWHPN members in spring 2008 linking social workers via discussion threads and resource sharing.

It is also notable that in November 2005, the Network received funding to administer the annual PDIA Social Work Leadership Award in Palliative Medicine. A social worker demonstrating excellence in research, education, practice, leadership, or international efforts will be presented with the award, raising public awareness of the important contributions social workers are making to end-of-life and palliative care. In 2007, the award went to Debra Parker Oliver, Director of Doctoral Studies and Associate Professor at the University of Missouri School of Social Work. In 2008, the award was presented to Shirley Otis-Green, Senior Research Specialist at City of Hope National Medical Center.

As it continues to grow, the Social Work in Hospice and Palliative Care Network is increasing its ability to sustain the movement and to build leadership and professional capacity to champion the advancement of the social work profession in end-of-life and palliative care.

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◦ **Summit Co-Chairs**

Summit Schedule

DAY 1: Wednesday, June 1st, 2005

9:00 am Welcome and Summit Objectives from Co-Chairs Susan Blacker, MSW, RSW, and Grace H. Christ, DSW

9:30 am *State of the Field Presentations: State of Policy and Advocacy* by Stuart Kaufer, LMSW, Patricia Sherman, PhD, LCSW, and Gary Stein, MSW, JD

10:00 am State of Best Practices by Terry Altilio, ACSW, Gary Gardia, MEd, LCSW, and Shirley Otis-Green, MSW, LCSW, ACSW

10:30 am State of Research by Betty J. Kramer, PhD, MSSW

11:00 am State of Education by Ellen Csikai PhD, MSW, MPH, and Katherine Walsh-Burke, MSW, PhD

11:30 am Open Discussion

12:00 pm Buffet Lunch

1:00 pm Overview of Process and Agenda for Facilitated Sessions

1:45 pm Break

2:00 pm Facilitated Group Work

3:30 pm Break

3:45 pm Facilitated Session: Presentation of Priorities

5:00 pm Break until Thursday Morning

7:00 pm NHPCO Reception and Address from Don Schumacher, PsyD, President and CEO of NHPCO (Holiday Inn on the Hill, 415 New Jersey Ave. at D St.)

DAY 2: Thursday, June 2nd, 2005

9:00 am A View from Elsewhere - Words from Sharon Baxter, MSW, Executive Director of the Canadian Hospice Palliative Care Association and Barbara Monroe, MSW, Chief Executive of St. Christopher's Hospice

9:30 am Review of Previous Day and Survey Data

10:15 am Break
 10:30 am Facilitated Group Work
 12:00 pm Buffet Lunch
 1:00 pm Facilitated Group Work
 2:30 pm Break
 2:45 pm Action Plan Presentations: Groups A and B
 3:45 pm Break
 4:00 pm Action Plan Presentations: Groups C and D
 5:00 pm Break until Friday Morning

6:00 pm Informal Networking / Social Time at the Dubliner Restaurant and Pub (Number 4 F Street at Capitol St.)

DAY 3: Friday, June 3rd, 2005

9:00 am Review of Previous Day, Immediate Next Steps
 10:15 am Break
 10:30 am Post-Summit Follow-up Plan
 11:15 am Wrap Up
 11:30 am Adjourn

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