

PROJECT ON DEATH IN AMERICA

Soros Social Work Leadership Awards

Monthly Newsletter

Volume 1/Number 2

November 15, 2000

“Promoting Social Work Leadership in Care of the Dying and the Bereaved”

Inside This Issue:

<i>In the Spotlight: Susan Blacker</i>	1
<i>Awards, Grants and Presentations</i>	2-3
<i>New in Print and Media</i>	3-4

This monthly newsletter is produced as part of the Soros Social Work Leadership Awards for the Project on Death in America.

Questions, comments and ideas should be addressed to:

Soros Social Work
Leadership Awards
Columbia University School
of Social Work
622 West 113th Street
Room 616
New York, NY 10025
212/854-5264 or 212/854-0698
FAX 212/854-9041

Grace Christ, DSW
Program Director

Jennifer Roesch
Project Assistant

IN THE SPOTLIGHT:

Social Work Leader, Susan Blacker

“Johns Hopkins Conference Becomes First National Social Work Conference on Palliative Care”

Susan Blacker, LCSW-C, Director of the Johns Hopkins Oncology Center’s Continuing Education Program in Psychosocial Care, organized a conference on November 10th and 11th that drew together more than 150 participants from across the country. The conference, “Social Work and End-of-Life Care Symposium: Clinical Practice in Palliative Care,” was developed with support from the Project on Death in America in association with the Maryland Chapter of the National Association of Social Workers and the Maryland Society for Clinical Social Work. It was the first national social work conference on palliative care and, by all evaluations, was an extraordinary success. Immediate e-mail responses to the program were unanimous: “An outstanding conference...informative, affirming. So many people said they came away with so much. Rewarding both professionally and emotionally.”

Following Susan Blacker’s overview of the history and recent developments in palliative care, a panel of recognized social work leaders discussed the social work role. James Zabora, ScD, Associate Director for Community Programs and Research at Johns Hopkins Oncology Center, moderated the panel.

Diane Blum, ACSW, the Executive Director of Cancer Care Inc., described the unique base of knowledge and skills that social work brings to the palliative care team: most prominently, the skills in communication, negotiation, problem solving, advocacy, and policy development. Social workers are educated to assess and intervene with the patient within his or her total context of family, community, and larger social and political systems. They also have finely honed skills for intervening with patients from socially and culturally diverse backgrounds.

Matthew Loscalzo, MSW, Director of Patient and Family Services at the new Johns Hopkins Oncology Center, highlighted social workers’ profound understanding of the emotional context of terminally ill patients and their families and the ability to help patients and families find a satisfying, meaningful connection during the indeterminate period of the illness. He spoke of his innovative study on the emotional support of male spouses of patients.

Grace H. Christ, DSW, Director of the Social Work Leadership Program, emphasized social workers’ need to accept the authority of their expertise, knowledge, and skills and assume a leadership role when these qualities are called for with patients and in team meetings: “Finding our voice and giving voice to our patients needs and our own knowledge, skills, and concerns is a core focus of the Social Work Leadership Program.”

Susan Blacker also represents social work on the institution-wide Palliative Care Task Force and Steering Committee and currently is involved in the development of a consultation and education service at Johns Hopkins. She chairs the committee’s Palliative Care Education Subcommittee.



Susan Blacker, LCSW-C

Awards, Grants and Presentations

W. June Simmons, MSW, as President and CEO of the Partners in Care Foundation, is in her second year of conducting research for an evaluation of the Palliative Care Program with a \$220,000 grant from the Garfield Fund, an internal Kaiser Permanente fund to support physician innovations in care. The Kaiser Permanente Palliative Care Project is a multidisciplinary approach to care management for home-based end-of-life care and treatment. This approach is similar to that of the hospice program, and palliative care staff is trained in the hospice philosophy. The Partners in Care Foundation is collecting and analyzing data to compare quality of life and use of services among patients receiving the Palliative Care Program compared with patients receiving traditional care. Preliminary results indicate higher quality of life and lower use of acute care services for patients in the program. Thus, preliminary findings suggest a model of care that is satisfying to patients and families as well as to others.

Katherine Walsh-Burke, PhD, MSW, received the Trish Greene Award at a reception hosted by the American Cancer Society in Chicago on November 11, 2000, along with her co-author, Carol Marcusen of Norris Cancer Center in Los Angeles. This inaugural award recognizes the best manuscript on quality of life published in Cancer Practice, the American Cancer Society's interdisciplinary journal for oncology professionals. The article, titled "Teaching Self-Advocacy to Cancer Survivors: The Cancer Survival Toolbox," was published in the December 1999 issue of the journal. The article describes the collaborative development of the CST self-advocacy training program by three organizations: the Association of Oncology Social Work, the Oncology Nursing Society, and the National Coalition for Cancer Survivorship. The award was established to honor Trish Greene, RN, who was ACS's National Program Director for many years.

On November 6, 2000 **Norma del Rio, MSW, of the Institute for Multicultural Research and Social Work Practice**, gave a two-hour presentation on end-of-life care issues and bereavement in the Latino community to Caring Hands, a Latino home health care assistance program in San Francisco. Norma also facilitated a discussion on one of the Moyers programs with Latino community leaders. This was the first event of ACCESS's outreach and education campaign on end-of-life issues in the Latino community.

Susan Taylor-Brown, PhD, ACSW, provided testimony to the New York State AIDS Institute in Rochester, NY on November 13, 2000 regarding the needs of HIV-infected parents and their infected or affected children. She advocated for the support services these families need as they cope with one or more deaths. Parents need assistance in confronting their own death, helping their children prepare for this and seeking guardians for surviving children. Currently, most states are not helping families do this. The stigma of HIV/AIDS makes dealing with the death more complex. The testimony is being gathered across the state and will be used to influence future funding within NYS.

Elizabeth Mayfield Arnold, MSW, PhD participated in a panel discussion on end-of-life care at the Duke School of Divinity on October 9, 2000. The other panelists were Keith G. Meador, MD, and A. Bebe Guill, Mdiv. Liz spoke about suffering and how clergy, social workers, and other health care professionals can work collaboratively to address this issue with patients at the end of life. This panel was convened as part of the James A. Gray and Franklin S. Hickman Lectures at the Convocation and Pastors' School at Duke Divinity School.

Barbara Dane, PhD, gave a presentation on November 18, 2000, for the National Association of Social Workers in New York City. She spoke on "Recognizing the Role of Spirituality When Working with Various Populations and Groups: A Focus on Anger and Forgiveness." The presentation was part of the New York City Chapter of NASW's Continuing Education Program.

Awards, Grants and Presentations (continued)

Terry Altilio, ACSW, was an invited speaker at the following conferences:

October 2000, New York, NY: Co-presented with a nurse on "Coping with Fatigue" at the Karpas Health Information Center, Beth Israel Medical Center. Terry discussed etiology, quality-of-life effects, and potential interventions concerning fatigue related to medical illness.

October 2000, New York, NY: With a psychiatrist, Terry delivered a presentation on "Psychosocial Crises" at the First International Geriatric Palliative Care Congress. The presentation was directed to an audience of palliative care professionals and discussed patient and family crises precipitated by such issues as changing goals of care, unrecognized delirium, and cultural conflict in health care domains.

November 2000, Cooperstown, NY: "Multidimensional Perspectives in Pain and Palliative Care" at the Foundations for Long-Term Care's Directors of Social Work Conference. This presentation, directed to social workers practicing in long-term care settings, addressed the multidimensional role of social work in pain and palliative care, focused on new JCAHO standards on pain management.

New in Print and Media

In Journals:

Blacker, S. & Rainess, A. *Community resources for cancer patients.* *Primary Care and Cancer*, 20(9), 2000.

In this article, **Susan Blacker, MSW**, and Alice Rainess have created a primer for primary care physicians about integrating referrals to community resources and educational programs into their plan for care. The article also features a list of national resources.

Dane, B. *Thai women: Meditation as a way to cope with AIDS.* *Journal of Religion and Health*, 39(1), 2000.

Mental health experts often ignore the spiritual and religious beliefs that can enhance a person's ability to cope with a life-threatening illness, such as HIV/AIDS. In this article, **Barbara Dane, PhD**, publishes the results of a study that explored the role of meditation in Thai Buddhist women who are infected with HIV/AIDS.

Dane, B. *Child welfare workers: An innovative approach for interacting with secondary trauma.* *Journal of Social Work Education*, 36(1), 2000.

Although child welfare workers are assigned the crucial role of protecting children, little emphasis has been placed on helping them cope with stress and secondary trauma that can occur when they observe and hear the affect-laden experiences described by clients. This article by **Barbara Dane, PhD**, summarizes two focus groups that provided data for development of a two-day training module for child welfare workers to gain knowledge and skills through didactic and experiential learning. The model offers strategies for coping with job-related stress and vicarious traumatization. Benefits and implications for agency and school collaboration are discussed.

Linder, J., Blais, J., Enders, S., Melberg, S., Meyers, F. *Palliative education: A didactic approach to teaching end-of-life care.* *Journal of Cancer Education*, 14(3), 1999. The training in palliative care that health professionals receive is inadequate. An aging population, changing systems of health care delivery, and the debate about euthanasia and physician-assisted suicide increase the importance of ongoing education about palliative care. In this article, **John Linder, MSW**, and his colleagues describe a module offered by the UC Davis, West Coast Center for Palliative Education which trains inmate volunteers to provide end-of-life care. This training focuses on developing communication skills and the ability to empathize through experiential exercises, dialogue, and role playing.

Terry Altilio, ACSW
Department of Pain Medicine and
Palliative Care
Beth Israel Health Care System

Elizabeth Mayfield Arnold, MSW, PhD
Graduate School of Social Work
University of North Carolina-Chapel Hill

Joan Berzoff, EdD, MSW
Smith College School for Social Work

Susan Blacker, MSW, LCSW-C
Continuing Education Program in
Psychosocial Cancer Care
The Johns Hopkins Oncology Center

Iris Cohen, MSW, LCSW-C
Beth Israel Deaconess Medical Center

Barbara Dane, PhD
Ehrenkranz School of Social Work at NYU

Norma del Rio, MSW
Institute for Multicultural Research and
Social Work Practice
San Francisco State University

Jim Keresztury, LCSW, MSW, MBA
Center for Health Ethics and Law
West Virginia Initiative to Improve End-
of-Life Care

John F. Linder, LCSW
UC Davis Cancer Center

Margo Okazawa-Rey, EdD
Institute for Multicultural Research and
Social Work Practice
San Francisco State University

W. June Simmons, MSW
Partners in Care Foundation

Mary Sormanti, PhD
Columbia University School of Social Work

Gary L. Stein, MSW, JD
New Jersey Health Decisions

Susan Taylor-Brown, PhD
Greater Rochester Collaborative MSW Program
Nazareth College

Katherine Walsh-Burke, PhD, MSW
Springfield College of Social Work

New in Print and Media (continued)

In the Media:

Grace Christ, DSW, recently appeared on a cable television series hosted by the Jewish Board of Family and Children's Services titled "Coping with Contemporary Issues." Grace's segment, which aired the first week in October throughout New York City, addressed the issue of children's bereavement and was hosted by Robert H. Abramovitz, MD, chief psychiatrist of the Jewish Board of Family and Children's Services.

Katherine Walsh-Burke, PhD, is one of six authors of the [Cancer Survival Toolbox](#), which received this year's CPEN Gold Star Award sponsored by the NCI. The toolbox is a self-learning program that teaches self-advocacy skills. It is available free of charge to all cancer survivors and caregivers and was developed with support of an unrestricted educational grant from Genentech BioOncology. The audiocassettes are available in Spanish and on the web at cansearch.org in Chinese. Additional modules include "Finding Ways to Pay for Care," "Topics for Older Persons," and "Caring for the Caregiver." More than 100,000 copies of the toolbox have been distributed since its publication in June 1999. Dr. Walsh-Burke also edited a [Training Manual for Group Facilitators](#) as part of an international training program for oncology professionals and advocacy organizations. She has provided training sessions this year, based on the toolbox and manual, at the Pan-American Congress of PsychoOncology, the joint conference of the Canadian Association of Psychosocial Oncology, the American Society of Psychosocial and Behavioral Oncology/Aids, the ONS Fall Institute, and the Patient Advocacy Congress.

Resources

The Department of Pain Medicine and Palliative Care at Beth Israel Medical Center has created a Caregiver Resource Directory to respond to the educational and emotional concerns of family caregivers coping with pain and palliative care issues. The directory is a user-friendly, comprehensive collection of key resources, fact sheets, and information for caregivers. It is free of charge and is available to all patients, family caregivers, health care professionals, and the public. To order a copy, contact *The Resource Center for Pain Medicine and Palliative Care, Department of Pain Medicine and Palliative Care, Beth Israel Medical Center*.

Safe Crossings is a Hospice of Seattle program designed to meet the needs of children up to the age of 18 who are facing the loss of a loved one. Their website, providence.org/safecrossings, provides activities and resources for grieving children and the families and professionals who work with them.