

Health Care for the Homeless

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Bibliography #20

Hospice Care, Living Wills, and Other End of Life Issues

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Policy Research Associates, Inc. • 345 Delaware Avenue, Delmar, New York 12054
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2004

Born W, Greiner KA, Sylvia E, Butler J, Ahluwalia JS. **Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos.** J Palliat Med 7(2):247-56, 2004.

OBJECTIVE: This project explored end-of-life care preferences and barriers among low-income, urban African Americans and Latino/Hispanic Americans (Latinos) to uncover factors that may influence hospice utilization. **METHODS:** Focus groups were conducted separately for African Americans and Latinos. Transcripts were coded and analyzed using consensus and triangulation to identify primary themes. **RESULTS:** Four preference themes and four barriers were identified. Results were largely similar across the two groups. Both preferred having families provide care for loved ones but expressed desire to reduce caretaker burden. Groups emphasized spirituality as the primary means of coping and valued the holistic well-being of the patient and family. Barriers reported were closely tied to access to care. Participants reported low hospice utilization because of lack of awareness of hospice and the prohibitive cost of health care. Latinos were more likely to report language barriers, while African Americans were more likely to report mistrust of the system. **CONCLUSIONS:** African Americans and Latinos in this study were highly receptive to end-of-life care that would provide relief for patients and caregivers and emphasize spirituality and family consensus. Improving awareness of hospice services would likely increase utilization.

2003

Fins J, Peres J, Schumacher J, Meier C, Grant-Tougas J, Nisely-Long K, Birnbaum-Sherman H. **On the road from theory to practice: A resource guide to promising practices in palliative care near the end of life.** Washington, DC: Last Acts National Program Office, 2003.

This resource guide is based on the fundamental belief that the delivery of quality care at the end of life should be seamless across all health care settings and independent from variables such as institutional largesse, charismatic leadership, funding sources and blind luck. Patients and their families from all futures should expect to receive competent and compassionate end-of-life care no matter who they are or where they are. This resource guide are offered as a map for legislators and policy makers to explore what must change at the policy level and for administrators and practitioners to develop workable solutions within their care settings (authors). Available from: Last Acts National Program Office, 1620 Eye Street, N.W., Suite 202, Washington, DC 20006, (800) 341-0050, www.lastacts.org

Reb AM. **Palliative and End-of-Life Care: Policy Analysis.** Oncol Nurs Forum 30(1): 35-50, 2003.

To present an overview of policy issues affecting hospice and palliative care focusing on the nursing home and hospital settings and to discuss factors affecting end-of-life care, policy initiatives, recent legislation, and nursing implications. Improvements are needed in end-of-life care, especially with regard to access, delivery, and financing of such services. Legal, organizational, and reimbursement policies, as well as healthcare professional education, have been identified as areas that need improvement. The nursing shortage and variable reimbursement policies for nursing services have a significant impact on access to quality end-of-life care, especially for underserved populations. A need exists for further research, including demonstration projects to test new ways to deliver and integrate hospice and palliative care throughout the illness continuum. Education and research are needed regarding symptom management, communication and decision making, caregiver support, and other end-of-life issues. Nursing interventions, palliative care networks, and other models that promote a coordinated approach to

care delivery have been shown to decrease costs and improve quality of care. Nurses play a key role in advancing improvements in palliative and end-of-life care through their involvement in educational, quality improvement, research, and legislative initiatives. Nursing activities in these areas may contribute to improved access, lower costs, and improved quality of care in advanced illness.

Rosenfeld K, Rasmussen J. **Palliative care management: A Veterans Administration demonstration project.** *J Palliat Med* 6(5):831-9, 2003.

As part of a Veterans Health Administration (VA) commitment to improve end-of-life care the VA Greater Los Angeles Healthcare System (GLA) implemented Pathways of Caring, a 3-year demonstration project targeting patients with inoperable lung cancer and advanced heart failure and chronic lung disease. The program utilized case-finding for early identification of poor-prognosis patients, interdisciplinary palliative assessment, and intensive nurse care coordination to optimize symptom management, continuity and coordination of services across providers and care settings, and support for families. Program evaluation used patient and family surveys as well as reviews of medical records and administrative databases to assess processes and outcomes of care. Despite significant programmatic challenges including organizational instability and evaluation design issues, the program achieved measurable success including high rates of advance care planning, hospice enrollment, and death at home, and low end-of-life hospital and Intensive Care Unit (ICU) use. As a result of its success, the program will be expanded and its care model extended institution-wide.

2002

Passik SD, Whitcomb LA, Kirsh KL, Donaghy K, Theobald D, Holtsclaw E, Edgerton S, Dugan W. **A pilot study of oncology staff perceptions of palliative care and psycho-oncology services in rural and community settings in Indiana.** *J Rural Health* 18(1): 31-34, 2002.

Although there has been an increased interest in health care delivery for rural community populations, concerns remain regarding the lack of access to primary health care and specialty services (such as palliative care), particularly in rural areas that are medically underserved (MU). This survey was conducted to examine the perceptions of palliative care services in rural communities and toward identifying perceived barriers that interfere with accessing palliative care services. In conducting the study, personnel from various disciplines throughout the Community Cancer Care (CCC) network (the largest private provider of oncology services in Indiana) completed a survey that assessed their perceptions of the strengths and weaknesses of the available palliative care services in their communities. These responses, which indicate discrepancies in perceptions among staff within sites, suggest problems of integration of palliative care in given locations. Results revealed three particularly problematic areas: accessing pain control, accessing psychological or psychiatric services or both, and overcoming barriers to hospice care. Although no significant differences were found for any variables between MU and adequately medically served areas, in general palliative care is limited and unintegrated into oncology care. Confusion among staff at a particular oncology program likely contributes to the haphazard delivery and poor integration of palliative care. Conclusions are tempered by important study limitations but the results suggest the need for programs that improve delivery of palliative care in rural Indiana.

Sabin LE. **Rose Hawthorne Lathrop. Servant of the dying poor.** *J Christ Nurs* 19(2): 24-27, 2002.

2001

Hwang SW; O'Connell JJ; Lebow JM; Bierer MF; Orav EJ; Brennan TA. **Health care utilization among homeless adults prior to death.** J of Health Care for the Poor and Underserved, 12(1):50-8, Feb 2001.

This study characterizes health care utilization prior to death in a group of 558 homeless adults in Boston. In the year before death, 27 percent of decedents had to outpatient visits, emergency department visits, or hospitalizations except those during which death occurred. However, 21 percent of homeless decedents had a health care contact within one month of death, and 21 percent had six or more outpatient visits in the year before death. Injection drug users and persons with HIV infection were more likely to have had contact with the health care system. This study concludes that homeless persons may be underusing health care services even when they are at high risk of death. Because a subset of homeless persons had extensive health care contacts prior to death, opportunities to prevent deaths may have been missed ,and some deaths may not have been preventable through medical intervention.

1998

Cox C. **Hospice care for persons with AIDS: Findings from a national study.** Hosp J, 13(3):21-34, 1998.

Hospices are in a position to play major roles in the care of terminally ill patients with AIDS. These findings from a national survey of hospices in the United States show that the majority of hospices have cared for at least one PWA. Major factors determining hospice involvement include geographic location and resources. In comparison to other patients in hospice, PWAs are younger, more likely to be male, Black or Hispanic, and covered by Medicaid. The results indicate that hospices are reaching women with AIDS and IVUDs but that minorities continue to be underrepresented in comparison to their distribution among the total AIDS cases in the United States.

Eischens MJ; Elliott BA; Elliott TE. **Two hospice quality of life surveys: A comparison.** Am J Hosp Palliat Care, 15(3):143-148, May 1998.

This study tested the utility of two quality of life (QOL) forms -- the McGill Quality of Life Questionnaire (MQOL) and the Hospice Quality of Life Index-Revised (HQLI)-- in a hospice setting. Hospice nurses first administered one survey to eligible patients and then, in the study's second phase, administered the other survey to newly enrolled eligible patients. Nurses were interviewed regarding each form and possible changes in patient care that were made due to the assessment. Hospice care plans were reviewed looking for specific changes resulting from the surveys. Results showed that the QOL assessments were useful for the nurses and that the MQOL was preferred by the nurses over the HQLI.

Rousseau P. **The homeless terminally ill and hospice & palliative care.** Am J Hosp Palliat Care, 15(4):196-7, 1998.

1997

Brenner PR. **Issues of access in a diverse society.** Hosp J, 12(2):9-16, 1997.

This article discusses the need to provide better access to care within diverse settings and for diverse populations. Ethnic minorities, marginalized persons and those without stable home environments or living in nontraditional ways are not well served by hospice at the present time. To improve access to hospice care, hospices need to address the distinctive profiles of their staffs and make them more inclusive and representative of the total community for their service area, create a broad range of programs of outreach, build bridges with other programs, develop expanded resources to manage the needs of patients and families, and train volunteers and staff to work in non-traditional home settings.

Hwang S; Orav J; O'Connell J; Lebow J; Bennan T. **Causes of death in homeless adults in Boston.** Annals of Internal Medicine, 126(8):665-628, 1997.

This article describes a study of 17,292 adults seen by the Boston Health Care for the Homeless Program from 1988 to 1993. Its objective was to ascertain causes of death in a group of homeless persons. The results showed that the leading causes of death varied by age group: (1) homicide - men 18-24; (2) HIV/AIDS - persons 25-44; and (3) heart disease and cancer - persons 45-64. The authors conclude the most common causes of death among homeless adults who have contact with clinicians vary by age group and efforts to reduce the rate of death among homeless persons should focus on these causes.

O'Connell J. **Death on the streets.** Harvard Medical Alumni Bulletin, Winter 1997.

The author chronicles his experiences inside the clinics and shelters which are part of Boston's Health Care for the Homeless (HCH) program. The prevalence rate of death among people who have been patients in the Boston HCH program is examined and discussed. The authors explain that the causes are complex: exposure to extremes of weather and temperature; the spread of communicable diseases, such as tuberculosis and pneumonia, in crowded shelters with inadequate ventilation; neglected chronic illnesses; horrifying violence; the high frequency of co-morbid medical and psychiatric illnesses; substance abuse; and inadequate nutrition. Several stories of patients who display these complexities are described.

1996

Gordon AK. **Hospice and minorities: A national study of organizational access and practice.** Hosp J, 11(1):49-70, 1996. Published erratum appears in Hosp J, 11(4):97, 1996.

Hospices in the U.S. were surveyed in 1990 to find out whether service to blacks and Hispanics was affected by admission criteria and hospice service characteristics of hospices located in or near these populations. Hospice characteristics such as reimbursement patterns, staff interventions, and admission criteria were different depending upon the percent of blacks and/or Hispanics in the hospice service area or actually served by the hospice. Care for Hispanics was more dependent on Medicaid and free care than blacks whose care was financed primarily by Medicare and Medicaid. Hospices identified problems in serving Hispanics as language, reimbursement, and severity-of-illness issues. Hispanics were perceived as presenting the most access and service problems and as the most underserved.

Hallenbeck J; Goldstein MK; Mebane EW. **Cultural considerations of death and dying in the United States.** Clin Geriatr Med, 12(2):393-406, May 1996.

Culture is not something apart from us. It is always here, and we, like fish in an ocean, may be blind to the water in which we swim. We recommend that, in addition to learning as much as possible about people from cultures other than our own, we consider carefully the cultural roots of our own thoughts and actions. A combination of respectful behavior and a conscientious effort to understand individuals from another culture will go far in enabling us to work well with dying patients from many backgrounds.

Moorhouse A; Weisstub DN. **Advance directives for research: Ethical problems and responses.** International Journal of Law and Psychiatry, 19(20): 107-141, 1996.

Advance directives for health care, better known as living wills, have become widely accepted as a necessary tool to guarantee the civilized management of one's life during increasingly protracted periods of aging and frail health. Although gaining wide public acceptance, these directives have received varying degrees of support from ethicists, lawyers, and healthcare professionals. In this article the authors examine clinical need, ethical considerations, and legal considerations in an analysis of the pros and cons of research directives. They emphasize that research is fundamentally different from health care, and the rights ascribed to research subjects are jeopardized when they are incompetent. Furthermore, to ask proxies to volunteer their dependents to be research subjects requires a redefinition of the moral responsibilities of proxies asked to respect advance instructions about research participation.

1994

McCuistion PO. **Increasing minority access to hospice care.** Am J Hosp Pall Care, 11(5):19-21, 1994.

Undated

Annual death review by the San Francisco Department of Public Health HCH. Unpublished research.

This annual review by the SF Dept. of Public Health counts the number of homeless deaths and identifies gaps in the system. Using data provided by the Medical Examiner, the number of homeless persons who die each year are identified. It is acknowledged that the numbers are an undercount since not all deaths are reported to the Medical Examiner. Results of the review indicated that the number of homeless deaths increased over the last year and that the vast majority of these deaths were preventable. Drug poisoning remained the leading cause of death among homeless people, followed by liver and pancreatic disease and heart disease. Two-fifths of the deaths occurred outdoors; the average age of persons homeless in San Francisco was 44 years. Many of the deaths occurred among persons with recent contact with the health and social services system. This indicates both the limitations of existing services and the potential for using our contact with homeless individuals to improve the circumstances of their daily lives.