

## Editorial

# End of Life Research

**Laraine Winter,<sup>1</sup> Helen K. Black,<sup>2</sup> Brian Carpenter,<sup>3</sup> and Nancy A. Hodgson<sup>4</sup>**

<sup>1</sup> Center for Health Equities Research and Promotion, Philadelphia VA Medical Center, 3900 Woodland Avenue, Philadelphia, PA 19104, USA

<sup>2</sup> Behavioral Research Institute, Arcadia University, 450 South Easton Road, Glenside, PA 19038, USA

<sup>3</sup> Department of Psychology, Washington University in St. Louis, St. Louis, MO 63130, USA

<sup>4</sup> School of Nursing and Hopkins Population Center, Johns Hopkins University, Baltimore, MD 21205, USA

Correspondence should be addressed to Laraine Winter, [laraine.winter@gmail.com](mailto:laraine.winter@gmail.com)

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Changes in medical technology have transformed the end of life not only in length but in complexity. The final phase of life poses challenges for patients, families, healthcare providers, and policy decision-makers and encompasses a wide range of topics such as service delivery, health economics, family dynamics, medical decision-making, and advance care planning, among others. The issues entail racial and ethnic differences, reveal health disparities, and cross national borders. Unsurprisingly, they draw upon a very broad range of disciplines and are among the richest and most complex in gerontology. Research to understand these challenges has the potential to inform the design of interventions, influence policy and practice, and improve the quality of life for seriously ill patients (the large majority of whom are older adults) and their families.

This issue of *the Journal of Aging Research* draws together a selection of empirical studies from health services research, health economics, anthropology, and religious studies. Beginning with a Japanese study concerning the setting of death, we proceed to a study of health economics of end-of-life (EOL) care in North America, an ethnographic study of palliative care for elderly hospitalized patients with life-limiting illness, a study identifying themes emerging from open-ended interviews regarding the experience of death and dying in a Catholic nursing home, and finally a study of a single family after the death of the father and husband.

The first paper addresses place of death. Recognizing the strong preference of most Japanese people to die at home, A. Akiyama et al. in "*Factors influencing home death in a Japanese metropolitan region: What types of home care system are needed?*", identify the characteristics of medical practices in the Tokyo metropolitan area that best predict patients' death at home. Although the paper presents data from a single country, the preference for remaining at home until the end of life examined is common, and the characteristics of medical practices that facilitate this outcome are probably quite similar across much of the world. D. N. Guerriere and P. C. Coyte's paper addresses the costs of EOL care in "*The ambulatory and home-care record: A methodological framework for economic analyses in end of life care.*" Because most economic analysis has been limited to publicly financed care, the authors argue that inadequate attention has been paid to measuring the full range of costs incurred by patients and their families. EOL care occurs across multiple settings, making family caregiving an important component of care. This study of economic evaluation of the EOL care environment therefore considers private resources (family time and money) as well as public health support to argue for a more complete economic analysis of these costs than is currently used.

The third paper, by B. A. Powers et al., studied a group of elderly hospitalized patients with life-limiting illness. These investigators use case-centered data of adults in an acute care hospital palliative consultation service. In "*Meaning and*

*practice of palliative care for hospitalized older adults with life limiting illnesses,”* they present a compelling case for a broad conceptualization of palliative care for older patients to help them deal with the uncertainties and transitions within the course of life-limiting illness.

The fourth paper, *“Faith and end of life in a nursing home,”* concerns death in a nursing home. R. L. Rubinstein and his associates address the experiences of people who lived through the death of a relative in the religious setting of a Catholic nursing home. The investigators identify four pervasive themes in their discussions. Finally, H. K. Black and her associates’ case study, *“End of life: A family narrative,”* focuses on a single family following the death of the husband and father. They present findings from ethnographic interviews with the widow and two adult children to explore how a family comes together to construct a collective meaning of his decline and death.

This selection of articles illustrates the complexity and breadth of issues surrounding the end of life from the perspectives of patients, families, and providers. The insights they yield point to directions for both future research and necessary improvements in policy and practice in EOL care.

*Laraine Winter  
Helen K. Black  
Brian Carpenter  
Nancy A. Hodgson*

