

## Downstream Effects of End-of-Life Care for Older Adults with Serious Illness on Health Care Utilization of Family Caregivers

Katherine A. Ornstein, PhD, MPH,<sup>1,2</sup> Kathrin Boerner, PhD,<sup>3</sup>  
 Albert L. Siu, MD, MSPH,<sup>1</sup> and Richard Schulz, PhD<sup>4</sup>

Dear Editor:

High-intensity, costly treatments for patients are common at the end of life (EOL). The impact of such treatments may go beyond their influence on the individual patient and additionally impact family caregivers, who are increasingly relied upon for provision of informal care and EOL decision making. While evidence suggests that treatment intensity impacts the stress and mental health of caregivers (e.g., increased stress for caregivers post ICU usage<sup>1</sup> and decreased depression for surviving spouses post hospice care<sup>2</sup>), the

impact of patient EOL care on family caregivers' own health care choices and spending has not been studied. Current EOL health care cost estimates do not consider potential downstream costs associated with the health care expenditures of family caregivers.

We present a framework for conceptualizing how EOL costs for patients may impact health care utilization for family caregivers that suggests that family health care utilization is impacted by patient treatment intensity because of shared social networks, the financial burden of costs, and the

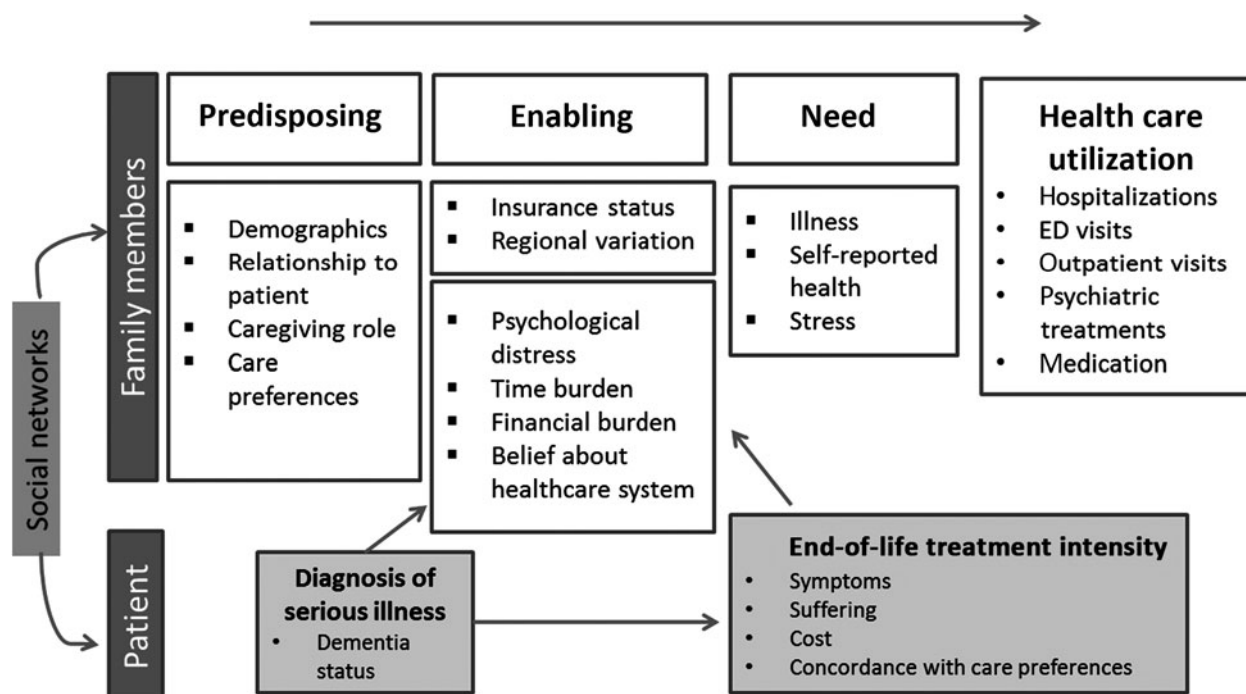


FIG. 1. Conceptual framework linking patient end-of-life and family member health care utilization.

<sup>1</sup>Department of Geriatrics and Palliative Medicine, <sup>2</sup>Institute for Translational Epidemiology, Icahn School of Medicine at Mount Sinai, New York, New York.

<sup>3</sup>Department of Gerontology, John W. McCormack Graduate School of Policy and Global Studies, University of Massachusetts, Boston, Massachusetts.

<sup>4</sup>Department of Psychiatry, University of Pittsburgh, Pittsburgh, Pennsylvania.

impact of treatments on patient symptom burden (see Fig. 1). Our model is guided by an adapted version of the Aday-Anderson behavioral model of health care utilization,<sup>3</sup> which proposes that predisposing, enabling, and need characteristics influence access to and use of health care and incorporates the stress process model of caregiving,<sup>4</sup> which conceptualizes caregiving as a chronic stressor that gives rise to strains in multiple domains. Furthermore, we include patient suffering as an independent source of distress for caregivers.<sup>5</sup>

We posit that the intensity of health care treatment received by a patient influences patient symptoms, suffering, and costs, which in turn impact enabling factors for the family caregiver, such as financial and time burden and lack of belief in the efficacy of the health care system. Because of this burden, there is a decrease in preventive and self-care behaviors, which ultimately results in increased urgent care use and health care spending for bereaved family members. Finally, we propose that family health care utilization is impacted by patient health care utilization within the context of shared social networks. Behaviors such as use of high-intensity treatments at EOL may be impacted by shared experiences within these social networks.

The impact of EOL treatments may go beyond their influence on the individual patient and additionally impact family caregivers' own health, health care decisions, and future health care utilization. As large datasets of patients with serious illness increasingly survey caregivers and allow for linkages to health care utilization data (e.g., the Health and Retirement Study [<http://hrsonline.isr.umich.edu>]), these questions can and should be readily answered. By reframing the impact of EOL health care beyond an individual patient, research may influence EOL health care decision making, improve health of family caregivers, and provide a comprehensive estimate of EOL care cost. As such, we will meet a

critical need for individuals and families as well as for policymakers in our current era of Medicare reform.

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Address correspondence to:

*Katherine A. Ornstein, PhD, MPH*  
*Department of Geriatrics and Palliative Medicine*  
*Icahn School of Medicine at Mount Sinai*  
*Box 1070*  
*One Gustave Levy Place*  
*New York, NY 10029*

*E-mail: Katherine.ornstein@mssm.edu*