

# Epidemiology of Care for Patients with Serious Illness

Amy S. Kelley, MD, MSHS

## Abstract

The U.S. health care system is struggling to improve the quality of health care while containing costs. The rapidly expanding population of older adults with serious illness presents both the greatest challenge and potentially the greatest opportunity to achieving this goal. In order to capitalize on this opportunity, we must first examine the epidemiology of the care of older adults with serious illness, that is, a full description of the characteristics and quality of care from the time of diagnosis through the full course of illness, including measurement of all factors that may influence or impact that care.

Several methodological challenges exist in this area of study, including but not limited to, defining the onset of serious illness, avoiding bias in sample selection, and measuring the full breadth of personal, social, local, regional and provider factors that may influence care. Yet, this work is possible through a combination of targeted primary research and efficient leveraging of ongoing studies and existing data sources. Through these studies, we may identify those factors and services associated with high value health care, and learn to develop and refine policies and health care delivery models that yield the greatest improvements in care for seriously ill older patients and their families.

## Introduction

**G**IVEN THE CONVERGENCE of the aging population and rising health care costs, maximizing value (i.e., increasing quality while reducing costs) in the care of seriously ill older adults is the single most important challenge facing the nation's health care system.<sup>1-4</sup> Meeting this challenge will require substantial expansion of the palliative care evidence base. Particularly urgent is the need to examine the epidemiology of the care of patients with serious illness, that is, a full description of the characteristics and quality of care from the time of diagnosis through the full course of illness, including measurement of all factors that may influence or impact that care.

Only through such comprehensive analyses will we achieve the goal of increasing the value of health care for the seriously ill. First, thorough study of the course of care for those with serious illness will provide an assessment of current patterns of care while identifying areas needing improvement. These studies will also serve to refine methods to evaluate change in patterns of care and its quality over time, and thereby provide knowledge fundamental to the development and refinement of health care policy and models of health care delivery.

### *Existing evidence and knowledge gaps*

Current evidence supports that myriad factors influence or are associated with the medical treatments provided to pa-

tients with serious illness.<sup>5</sup> These range from the patient and family's demographic, psychosocial, cultural, medical, and functional characteristics to regional patterns of care, local supply of medical resources, structure of reimbursement models, and the incentives influencing provision of specific treatments, and individual provider factors (see Figure 1).<sup>5-25</sup> In addition, these factors may interact or contribute varying levels of influence on treatment selection among patient subgroups. For example, Nicholas and colleagues found that treatment-limiting advance directives may influence health care use in areas with local patterns of high-cost, high-intensity treatment, while having no significant effect on costs of care in other regions.<sup>26</sup> This evidence suggests that consideration of all factors simultaneously is necessary due to the complexity of these relationships.

Despite this understanding, very few studies to date have incorporated the full range of factors related to the care of older adults with serious illness. Indeed, no primary data collection studies have adequately considered all factors. And existing or 'secondary' data sources also lack needed data elements. For example, the largest proportion of health services research uses administrative and claims data, yet these data offer no psychosocial, financial, cultural, or functional measures, which are often central to the research question at hand. Furthermore, the few large survey-based datasets that may be relevant to the study of older adults with serious illness do not have adequate measures of several factors:

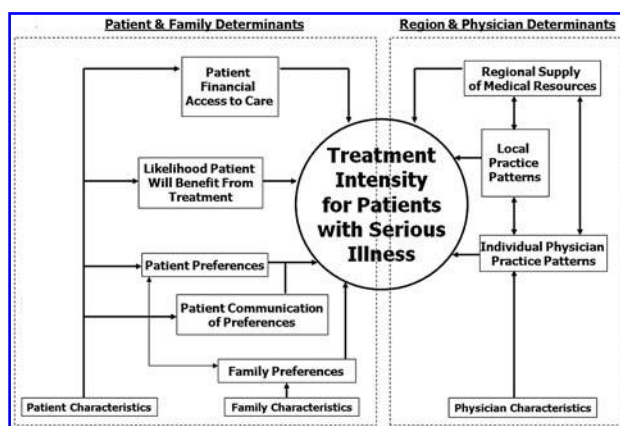


FIG. 1. Model of factors affecting treatment intensity for patients with serious illness.<sup>5</sup>

individuals' preferences or goals for medical care, symptom assessments, spiritual concerns, social supports, and others. Those that do have some of these measures (e.g., the Health and Retirement Study,<sup>27</sup> the National Health and Aging Trends Study<sup>28</sup>) collect data too infrequently to capture the onset of serious illness and the evolution of many factors (symptoms, function, preferences) over the course of illness.

In addition to gaps in the breadth of needed measures, few studies or data sources capture the necessary time period. Most notably, the onset of serious illness is a critical period for evaluation, as this period may capture both the elements leading to diagnosis as well as the factors influencing or associated with initial treatment decisions and their outcomes. Yet significant challenges exist in studying this period. Studies targeting a specific illness generally do not enroll patients prior to the diagnosis of that illness. Secondary data sources that were not designed for this purpose are limited by the arbitrary timing of data collection and because of difficulties retrospectively defining when serious illness began. The full span of illness also has not been adequately studied. Improvement in the quality and value of care for patients with serious illness requires this longitudinal data so that we may understand (1) how symptoms change or respond to treatment over time; (2) how patient-centered measures of quality of life change and are effected by various treatments or models of care; and (3) how patients' preferences and goals of care evolve and whether or not they are congruent with treatments received.

### The challenge of sample selection

A challenge fundamental to the study of patients with serious illness is accurate sample selection, i.e., who are the "seriously ill" and when did illness begin? Many studies to date have relied upon death as the primary marker of serious illness.<sup>6-11,16,17,19-23,26</sup> This is a major limitation of all evidence drawn from mortality follow-back studies. This retrospective approach artificially removes the prognostic uncertainty faced by patients and physicians when making treatment decisions and thereby is subject to selection bias.<sup>29</sup> The mortality follow-back design also fails to specify the period of the onset of serious illness and instead often arbitrarily sets a cut point of six months or one year as the study period of interest. Thus, the critical period when serious illness

begins and many treatment decisions are made is either not captured or is diluted by the inclusion of a period prior to the onset of illness.

In addition, many serious illnesses, with the possible exclusion of cancer, do not have a clearly identifiable time of onset or diagnosis. This creates a methodological challenge and is an issue of critical importance to research involving older adults, for whom a chronic illness managed for many years may ultimately become a life-limiting serious illness. Studies of end-stage organ failure are particularly challenging in this respect. For example, congestive heart failure (CHF) may be a stable or slowly progressive condition over many years. In a primary data collection study, researchers may be challenged to identify when CHF becomes a serious or life-limiting disease. On the other hand, identifying this clinical transition is far more difficult when one is limited to administrative or claims data alone. Identifying the onset of serious illness may be even more complicated in the setting of multimorbidity. Nearly half of noninstitutionalized Medicare beneficiaries have three or more medical conditions.<sup>30</sup> For some, the cumulative burden of disease and debility becomes a serious illness. While this population is large and evidence is critically needed to evaluate and improve the quality of their care, to date there is no consensus regarding how to define and identify this seriously ill group.

### Priorities for future research

The areas requiring further research within the field of epidemiology of the care of patients with serious illness are vast and methodologically daunting. However, work in this area may provide the solution to the health care value equation by elucidating models of care that will increase health care quality while reining in costs among seriously ill older adults. Below, I highlight four of the top priorities for advancing this area of research.

First, a longitudinal prospective stepwise cohort study must be designed to evaluate and improve the care of older adults with serious illness. Briefly, the study would recruit a large diverse sample of older adults from geographic regions that exhibit variability across a range of regional characteristics previously shown to be associated with treatment quality and intensity. Subjects would provide baseline data on a comprehensive range of demographic, psychosocial, functional, and medical characteristics, and pertinent measures of personal values and beliefs. They would also be asked to authorize access to their Medicare claims data. The subjects would then be followed with brief yet frequent queries for signs of new serious illness or progressive debility. Those positively identified as possibly having serious illness would be interviewed regarding the period surrounding the onset of the illness and followed with serial interviews throughout the course of illness. Following a subject's death, a knowledgeable proxy would complete a final interview. This study would address many of the current knowledge gaps by enrolling subjects prior to the onset of serious illness and measuring pertinent factors and potential confounders *a priori*. The sample selection would not be dependent upon time of death or even prognosis, and thereby would capture the full range of serious illness experiences. The stepwise prospective design would minimize sampling bias and allow for focused data collection among those with serious illness when and if it develops while minimizing the study's burden on subjects.

Second, ongoing studies could be leveraged to expand the use of their data and maximize their contribution to aging research. For example, the Health and Retirement Study (HRS) has significant potential to address many areas of palliative care research, in particular the epidemiology of the care of seriously ill older adults. Funded by NIA and collecting data since 1992, HRS is an ongoing prospective cohort study designed to be representative of the U.S. population over age 50 years. HRS conducts biennial waves of core interviews with approximately 20,000 participants and, following a participant's death, conducts a postdeath interview with a knowledgeable proxy, usually a surviving spouse or family member. Together, the core and postdeath interviews contain detailed survey data including demographics, health and functional characteristics, information on family and caregivers, and personal finances. The HRS can be linked with Medicare claims data and many other data sources: U.S. census, Dartmouth Atlas, etc. The Medicare linkage, in particular, provides an exceptional opportunity to pursue policy-relevant research questions that are central to the advancement of high quality and high value health care for seriously ill older adults in the United States. While the longitudinal design ensures that subjects with serious illness continue to be enrolled, the infrequent interviews often miss the onset and rapid evolution of a serious illness. In addition, the HRS surveys were not intended for the study of patients with serious illness and therefore omit many important topics, such as symptom assessments and preferences regarding the goals of medical care. A supplement to the HRS could include targeted interviews for a subgroup identified as seriously ill. This interview could assess relevant measures, including symptoms, spiritual distress, preferences regarding care, and caregiver stress, to name but a few. Alternatively, an ancillary subgroup study could collect complementary data via chart abstraction or physician interviews. Other large, prospective cohort studies may offer similar opportunities, including the National Health and Aging Trends Study, Baltimore Longitudinal Study of Aging, National Health and Nutrition Examination Survey, Medical Expenditure Panel Survey, Medicare Current Beneficiaries Survey, and others. These steps would amplify the impact of the resources already devoted to large federally funded studies and capitalize upon existing data to address some of the most pressing geriatrics research questions.

Third, Medicare claims are a key source of data for health services research. However, as described above, these data are lacking elements critical to any analyses of health care services. In particular, functional limitations and debility are major predictors of health services utilization, yet are not available in claims data.<sup>17,31</sup> Therefore, the Centers of Medicare and Medicaid Services (CMS) should require the collection of functional status data with all inpatient, skilled nursing facility, home health, and hospice Medicare claims. Functional status measures are already collected for clinical purposes in all of these settings. This single addition to standardized claims requirements would have a large impact on improving the validity of vast areas of health services research and would add precision to risk and illness-severity adjustments.

Finally, the Patient Protection and Affordable Care Act<sup>32</sup> established the Centers of Medicare and Medicaid Innovation (CMMI) and provided support for several CMS demonstration projects, all with the aim of improving the value of Medicare and Medicaid services. Many new initiatives and demonstra-

tion projects are specifically intended to impact the quality and value of care for older adults with serious illness. This is a tremendous opportunity to study effects of new and innovative models of care delivery and reimbursement. In order to maximize the relevance and contribution of these projects, CMS should mandate the collection of adjunct data on a 5% sample of all CMMI and CMS demonstration projects. Studying additional measures of patient characteristics and goals of care among a random 5% sample within each of these projects would vastly expand the evidence base and directly contribute to the improvement in care of older adults with serious illness.

## Conclusion

The U.S. health care system is struggling to improve the quality of health care while containing costs. The rapidly expanding population of older adults with serious illness presents both the greatest challenge and potentially the greatest opportunity to achieve this goal. We must first examine the epidemiology of the care of older adults with serious illness, through a combination of targeted primary research and efficient leveraging of ongoing studies and existing data sources. By doing so, we will identify those factors and services associated with high value health care, and learn to develop and refine policies and health care delivery models that yield the greatest improvements in care for this vulnerable population.

## Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:

Amy S. Kelley, MD, MSHS

Brookdale Department of Geriatrics and Palliative Medicine

Icahn School of Medicine at Mount Sinai

One Gustave L. Levy Place

New York, NY 10029-6574

E-mail: amy.kelley@mssm.edu

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