Palliative Care Rounds: Towards Evidence-Based Practice

Edited by Stephanie Harman, MD, and Robert M. Arnold, MD, on behalf of Society of General Internal Medicine End-of-Life Interest Group

Patients Who Lack Capacity and Lack Surrogates: Can They Enroll in Hospice?

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Abstract

Patients who lack capacity and lack surrogates are among the most vulnerable patients we care for in palliative care. In the case we present here, we have considered how to make end-of-life decisions for a patient who lacks both capacity and surrogates, who has a terminal illness, and who is not a candidate for disease-modifying treatments. We first define and characterize this population of patients through a review of the literature and then explore some decision-making quandaries that are encountered at the end of life. Finally, we make recommendations on how best to proceed with decision making for this vulnerable population. J Pain Symptom Manage 2014;■:■−■. © *2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words

Capacity, hospice, unbefriended, advance care planning, shared decision making, end of life, palliative care

Introduction

Most U.S. jurisdictions have failed to adopt health care decision-making policies for patients who lack capacity and who do not have a surrogate.[1,2] We will use the term "unbefriended" to refer to patients who lack capacity and lack surrogates throughout this article.[3] Even when such policies exist, their recommendations tend to be vague and imprecise, overly broad or cumbersome, rather than context or time sensitive.[3] Specifically, existing policies do not always adequately cover how enrollment in hospice can be facilitated when there is the need to admit to hospice. For example, they fail to highlight time-sensitive difficulties that are often inherent in obtaining consent for admission to hospice, even when a guardian has been appointed by the courts. Or, they fail to acknowledge the difficulties that are sometimes inherent in securing a guardian.[4] Consequently, hospice-eligible patients end up not being enrolled in hospice.

Similarly, clinical situations with unbefriended patients are often challenging when their preferences pertaining to end-of-life

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Accepted for publication: December 12, 2013.

0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2013.12.244

care are unknown or undocumented. In the absence of an advance directive, a surrogate, or capacity, how can decisions be made in ways that preserve the autonomy of the unbefriended? How can informed consent be obtained when the need to admit to hospice is immediate and compelling? Because surrogate consent is not an exemption from consent,[5] this article also examines the issues that guardians may encounter during consent.

We hypothesized a priori that patients who lack capacity and surrogates can enroll in hospice, but that their successful enrollment in hospice will be determined by at least one or more of the following key variables, such as cost of care, prognostic uncertainty, and health system barriers pertaining to eligibility.

Case Example

A homeless 65-year-old man with alcohol dependence and cirrhosis is admitted for encephalopathy and ascites to a medicine service. The patient decompensates on the floor with hypotension and worsening mental status, is intubated, and transferred to the intensive care unit (ICU). Multiple efforts are made, including calling the local police, to locate family or friends for this patient. No one has come forward or been identified. He does not have an advance directive on file.

The ICU team works to reverse his encephalopathy and are able to successfully extubate him. He is transferred to a monitored unit but remains altered. He has not regained capacity to make medical decisions.

His imaging has revealed multiple masses in the liver and the lungs, consistent with metastatic hepatocellular carcinoma. The primary medicine team is now considering how to proceed. In speaking with hepatology and oncology consultants, he would neither be a candidate for transplant nor for chemotherapy at this time because of his poor functional status. They believe that hospice would be the best care approach for him.

Methods

Literature Search and Data Extraction

We performed a search of three databases, namely MEDLINE (1988–2013), the Cochrane Database of Systematic Reviews (2005–2013), and Embase. We also carried out a search in Google Scholar and clinicaltrials.gov. The PubMed citations related to the topic also were handpicked by a librarian. The search strategy for the Cochrane Database of Systematic Reviews can be found in the Appendix (available at jpsmjournal.com). We also searched the gray literature. Our search was limited to studies in English. A PubMed search of the term "unbefriended" yielded six articles, three of which are included in this review. A search of "unbefriended" and "hospice" did not yield any results. A total of 32 articles underwent full-text screening based on predefined criteria. Codes were randomly generated from pertinent studies. Each included study was then randomly allocated to a code using the EPPI-Reviewer 4 Software (EPPI-Centre, University of London, London, U.K.)[6] After code allocation, qualitative/quantitative data were extracted to inform the analysis.

Results

Eight primary themes emerged after code allocation, namely surrogate decision making, medical decisions, hospice care, incapacitated, best interests, nursing home, consent, and homelessness. Four subthemes emerged for the theme surrogate decision making, namely end-of-life decisions, decisional capacity, dementia patients, and ICU. Our analysis and recommendations are guided partly by each of the eight themes and four subthemes, as well as our hypothesis.

Comment

Recent estimates point to the fact that nursing homes and hospitals comprise the largest population of unbefriended patients.[4] Similarly, experts have speculated that approximately 3–4% of the nursing home population is unbefriended.[4] For some of these patients, hospice care may be their best option in terms of reducing suffering.

Furthermore, for those approaching the end of life, hospice is a key provider of palliative care. Patients enrolled in hospice have been shown to experience better pain and symptom management, fewer invasive treatments, fewer terminal hospitalizations, and a much higher overall satisfaction with end-of-life care.[7,8] In contrast, pain is often poorly