Special Article

Recommendations to Surrogates at the End of Life: A Critical Narrative Review of the Empirical Literature and a Normative Analysis

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Abstract

Physician recommendations have historically been a part of shared decision making. Recent literature has challenged the idea that physician recommendations should be part of shared decision making at the end of life, particularly the making of recommendations to surrogates of incapacitated patients. Close examination of the studies and the available data on surrogate preferences for decisional authority at the end of life, however, provide an empirical foundation for a style of shared decision making that includes a physician recommendation. Moreover, there are independent ethical reasons for arguing that physician recommendations enhance rather than detract from shared decision making. J Pain Symptom Manage 2015;50:693–700. © *2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

End-of-life care, surrogates, recommendation, patient-physician relationship, shared decision making, ethics, communication

Introduction

Patients have long looked to physicians for recommendations about end-of-life medical decisions. However, as the age of the U.S. population has advanced and life-sustaining technologies have become more sophisticated, it is common for patients to be incapacitated when faced with end-of-life decisions. Physician recommendations as part of the beneficent sense of duty to appropriately and fully inform end-of-life decisions have been considered an integral part of shared decision making in these circumstances, including as part of shared decision making with surrogates. However, although most physicians feel a responsibility to provide end-of-life recommendations to surrogates,[1] some may not do so even when explicitly asked by surrogates because they are concerned that recommendations could be perceived as paternalistic. Additionally, recently some have questioned whether physician recommendations to surrogates at the end of life are a part of good shared decision making or welcomed by surrogates when a patient is incapacitated.[2]

In this article, we review the available empirical evidence regarding surrogate and patient preferences for physicians to make recommendations to surrogates regarding end-of-life care and assess the theoretical normative arguments for such recommendations. After critical examination, we conclude that the best available evidence supports physician recommendations as a crucial part of shared decision making with surrogates at the end of life and that there are independent ethical and normative reasons that recommendations improve rather than detract from good shared decision making with surrogates.

Shared Decision Making with Surrogates

End-of-life discussions and decision making between physicians and surrogates of incapacitated patients can be difficult. The dynamics of decision making with surrogates and factors that affect specific choices are different from the physician-patient relationship,[3] and it is these differences that can sometimes lead to

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Accepted for publication: May 21, 2015.

0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2015.05.004

conflicts between physicians and surrogates.[4–7] For physicians, prognostication alone can be challenging,[8] notwithstanding the difficulty in appropriately articulating clinical uncertainty and complex clinical circumstances to families. Surrogate decision makers are prone to post-traumatic stress disorder.[9–12] A systematic review found that at least one-third of surrogates suffer emotional stress and burden;[13] these effects can last for months to years[14] and affect surrogates of all ethnic and racial backgrounds.[15] Further complicating the physician-surrogate relationship is the fact that both surrogates and physicians are poor at predicting what choices patients themselves would make in specific clinical circumstances.[16–24]

Critical care societies have recognized these difficulties and have called for a family centered approach to end-of-life care, including shared decision making.[25,26] Shared decision making fosters a collaborative exchange in which clinicians help families navigate the prognostic uncertainty of complex medical conditions and life-sustaining technologies.[27–29] Surrogates, in turn, share the unique relationship they have with the patient and their understanding of the patient's values, wishes, and interests as they relate to specific medical decisions. Shared decision making with surrogates has been interpreted by some as the physician facilitating a decision made by the surrogate,[30] whereas others view the aim as a decision made jointly by the physician and surrogate that promotes the authentic values and real interests of the patient as a unique individual.[31]

Regardless of one's interpretation of shared decision making, a physician recommendation has been thought necessary and philosophically justified to fully inform decision makers and to respect the patient as a person.[28,32] Therefore, shared decision making has classically included a physician recommendation. Thus understood, shared decision making has been shown to be preferred by surrogates and families.[33–36] Until recently, however, the assumption that shared decision making includes a physician recommendation has not specifically been probed.

Empirical Review of Surrogate Preferences in End-of-Life Decision Making

Although no studies have directly asked surrogates their preferences for a physician recommendation in making end-of-life decisions, good approximation comes from studies designed to gauge the preferred decisional role of surrogates in such circumstances. Five such studies ask *surrogates* their preferred level of involvement in decision making for a loved one or family member. One study asks *patients* their preference for how their surrogates and physicians should make decisions for them if they were to become incapacitated. These six quantitative studies have used a modified version of the Control Preferences Scale developed by Degner et al.,[37] asking along a continuum whether surrogates prefer to make final end-of-life decisions themselves, they would like a balance of their own views and those of the physician, or they would defer to physicians. An additional study simply asked families' preferences to be involved or not involved in end-of-life decision making, without using a preference scale. Last, one final study addressing surrogate preferences for physician recommendations used a mixed-methods video recording of an intensive care unit (ICU) conference to assess surrogate preferences (Table 1).

Of the studies assessing *surrogate* preferences for decisional authority, the largest study included 789 substitute decision makers.[33] Of these, 14.8% preferred to leave all decisions to the physician, 23.8% preferred that the physician make the final decision after considering their opinion, 39.1% preferred that the physician share responsibility in making decisions, 21.8% preferred to make the final decision after considering the physician's opinion, and 0.5% preferred to make the treatment decision alone.

A similar study looked at the role that family members (rather than substitute decision makers) preferred in making decisions for their dying loved one.[38] Of the 256 respondents, 8.4% preferred to leave all decisions to the physician, 15.6% preferred that the physician make the final decision after considering their opinions, 42.8% preferred that the physician share responsibility in making decisions, and 32% preferred to make the final decision after considering the physician's opinion. Only 1.2% preferred to make the treatment decision alone.

In a study of ICU patients, 48 surrogates were asked for their preference among different levels of involvement in decision making.[39] None preferred an active role in which they made decisions absent consideration of a physician's opinion. Most (58%) chose a shared level of decision making with the physician, 25% preferred to make the final decision on their own after seriously considering the doctor's opinion, and 17% preferred that the doctor make the decision after considering their opinion.

Outside the U.S, in a study of 544 family members of ICU patients,[40] families were asked whether they would have preferred to be involved in medical decisions related to personal values (decisions about quality vs. quantity of life and withdrawal of life-supporting treatments). Fifty-three percent of those surveyed preferred to leave decisions entirely to the physicians, and 47% of families preferred to participate in decision making.