

Promising Practice

Informing the Patient-Proxy Covenant: An Educational Approach for Advance Care Planning

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Introduction

Previously, we speculated that the patient-proxy relationship had both contractual and covenantal elements.^{1*} To test this hypothesis we conducted an empirical study of patients and proxies using structured vignettes about common end-of-life choices. We have modified our survey instrument to create a workbook and instructional video entitled, *Fidelity, Wisdom, and Love: Patients and Proxies in Partnership*. We hope that these patient and proxy friendly materials foster and improve advance care planning. In this paper, we describe our rationale for this educational effort.

Background

Many commentators have struggled with the utility and effectiveness of advance directives as mechanisms for improving end-of-life care ever since SUPPORT revealed their inadequacies.² In response, we speculated that our collective approach to advance care planning hinged too heavily on prevailing notions of self-determination and failed to acknowledge that the relationship between patient and proxy was more than an exercise in unbridled autonomy. We pointed out that the patient-proxy was a dynamic which transcended the self in *self-determination*, and which required more than a contractual notion of responsibility to articulated preferences. We suggested that the failure of the SUPPORT intervention could be understood by its implicit reliance upon the contractual dimensions of the patient-proxy relationship. We commented upon the limitations of this *contractual* model and proposed a *covenantal* model of advance care planning that was more consonant with how patients and families make other important decisions. We speculated that our collective over-emphasis on the contractual elements might be responsible for the apparent under-use and ineffectiveness of advance directives. We argued that a contractual approach neither captured the complexity of clinical reality nor the interpersonal dynamic of surrogate decision-making.

For instance, in a contractual model of advance care planning, a proxy may be forced to adhere strictly to a patient's past wishes even when they are counter-intuitive and against the proxy's deeper knowledge of the patient. He may be unable to use personal judgment to match the patient's wishes and values to a specific medical circumstance because he was given rigid instructions and had entered into a contractual arrangement that prized adherence to wishes over discretion. This constraint may have the unintended consequence of compelling a proxy to contradict the patient's

* For the purposes of this paper, we will use the colloquial term "proxy" to describe a durable power of attorney for health care.

actual intentions. For example, a patient who once said that she never wanted to be kept alive by machines needs to be put on a ventilator. She is now unconscious and in need of mechanical ventilation in order to recover from a curable pneumonia. If the proxy literally adheres to her original instructions, an unintended outcome might occur.

While this example is a bit hyperbolic, it illustrates the flaws in a purely contractual framework. This is not to imply a *contractual* model is without utility. On the contrary, when the patient's preferences for care and the clinical situation are clear, this approach protects those preferences from major deviation and from ill-chosen decisions made by an uninformed or self-interested proxy. However, the rigidity and narrowness of contractual instructions provides little support to the surrogate when the situation is clinically or morally ambiguous.

The Covenantal Model

Surrogate decision-makers are usually close family members or friends. Defining a surrogate as the sterile instrument of the patient's self-determination, whose sole purpose is to convey accurately the patient's preferences, fails to acknowledge the loving ties and shared experiences that frequently bind patient and surrogate. These ties not only define the relationship, but also provide the basis for informed decision-making, particularly in the face of prognostic uncertainty.

The dissonance between the reality of surrogate decision-making and prevailing philosophical norms suggested the need for an alternative and yet complementary *covenantal* approach, which prized relationships and valued the deeper knowledge that proxies often bring to the bedside of a loved one. If we consider the nature of families, we are quick to realize that intimates and close friends are not bound to each other by contracts, but by covenants and binding acts of devotion. They are not motivated by a quid pro quo nor time-limited like contracts, but instead catalyzed by *fidelity, wisdom, and love*. In many cases, then, the covenant binding patient and proxy is itself the greatest source of moral guidance.

Moreover, these relationships are not atomistic as presumed by current autonomy theory. Rather they are molecular, involving a unifying and *mutual* set of obligations between patient and proxy.

From Contract to Covenant in Advance Care Planning

Although other investigators have indicated that patients and proxies may be less interested in fostering patient autonomy than in minimizing the burden imposed on the proxy decision-maker,³ none had sought to determine whether this relationship could be understood as having both contractual and covenantal elements.

To further understand the nature of the ethical responsibilities between patients and proxies, and to test our hypothesis about the existence of a contractual/covenantal continuum, Weill Cornell Medical College and the Missoula Demonstration Project undertook a two-year empirical study. The research focused on 50 patient-proxy pairs and 52 individuals who had acted as proxies for someone who died. Our data, which will be published in a forthcoming article, indicate that the patient-proxy relationship exists on this continuum, and is determined by variables such as prognosis and the nature of the patient's instructions to the proxy.

This finding has implications for advance care planning, most notably that patient and proxy are bound by mutual responsibilities. A concept of advance directives that considers only patients' rights is flawed because it fails to consider the obligations and burdens assumed by proxies. Proper advance care planning, informed by the implicit covenant in this relationship, obliges mutual

preparation and discourse. Part of that preparation is for the partners to understand that complex situations may arise that require the proxy to use interpretative judgment. A proxy who receives adequate guidance from the patient and has a reservoir of discretionary trust is able to act ethically and effectively. Such an empowered proxy is less likely to be burdened by the guilt and emotional pain that can result when making life and death decisions.

Fidelity, Wisdom, and Love: Patients and Proxies in Partnership

After conducting this research, we asked ourselves how we might employ this information so as to have a positive influence on the patient-proxy relationship and decision making at the end of life. Our answer was to design a self-contained, educational kit, *Fidelity, Wisdom & Love: Patients and Proxies in Partnership*, which can be used by individuals or in a group setting to help people execute effective advance care planning. The kit contains an 11-minute introductory video, a 40-page interactive workbook, and a leadership guide. In some cases, the workbook will also contain a state-specific proxy form. Whereas individuals or patient-proxy pairs can use the different elements of the kit on their own, we also plan to target "captive" audiences, that is, members of organizations that run regular educational meetings. By doing so, we hope to reach many people who would not necessarily know about or seek out such information.

The kit's leadership guide makes it easy to use and allows someone unfamiliar with the subject to run a meeting that lasts from an hour to an hour and a half. This suggested timeframe is based on our own experiences. Since people will take the workbook home with them, it is not crucial that everyone finishes it during the meeting. Some groups may want to spend more time in discussion, for instance.

Patients and proxies will be introduced to the workbook by an accompanying videotape.⁴ The video features Kathleen Chalfant, who starred in the Pulitzer Prize-winning play *WIT*, and her husband, Henry. They talk about what they would want from each other should either of them have to serve as the other's proxy. Their discussion is initiated by our case vignettes and their follow-up questions. The video segment, filmed in their home, with their dog running in and out of some scenes, conveys a warm and trusting environment, necessary for the emotionally challenging nature of these discussions.

Interestingly, despite Kathleen's experience in *WIT* and her service as proxy for others, the Chalfants, like so many other people, had not completed their own advance directives. The lack of preparation by such a well-informed couple demonstrates how easy it is for each of us to deny our own mortality and finitude. Their failure to complete an advance directive and their subsequent resolve to do so, captured on tape, should motivate viewers to take advance care planning more seriously.

The centerpiece of the kit is the interactive workbook that people would use after watching the video.⁵ Fundamentally, it is both a source of information about advance care planning and a means to structure conversations between patients and proxies on this topic. And *if* patients choose to note their preferences in the space provided, the document itself could serve as an advance directive. In order to reach the largest number of people, it is written at an eighth grade literacy level, as tested by a variety of focus groups. Its cross-cultural value is yet to be tested, but its content is informational and its emphasis is on encouraging the process rather than the content of communication between patient and proxy.

The workbook's first section provides basic information about why it is important to have a proxy and how to appoint one. It emphasizes the elements of how to be a "good" proxy, with a focus on

the mutual responsibilities of the patient-proxy pair.

The second section contains four paradigmatic, end-of-life scenarios focused on patients with cancer, stroke, congestive heart failure, and Alzheimer's disease, respectively, modeled on the case vignettes from our study. Each scenario is followed by questions for both patient and proxy. Readers are assisted by an additional set of prompts entitled "Helpful Hints" and "Commentary," which suggest ways to think about the issues and the process of decision making.

Each scenario was constructed to illustrate a variable prognosis. The cancer case illustrated a slow, progressive decline and often precipitous deterioration seen with a malignancy. The stroke case portrayed a devastating and certain prognosis. In contrast, the heart failure case had an uncertain prognosis with a variable and unpredictable disease trajectory. The final case demonstrated the challenges of a chronic, debilitating illness like Alzheimer's disease. The scenarios were constructed to show different types of instructions from patient to proxy. All four scenarios concluded with the same question—whether or not to withdraw the patient from a ventilator.

Below is a sample of one of these vignettes:

IMAGINE THAT YOU HAVE CONGESTIVE HEART FAILURE

Imagine that you are a patient with a heart condition called congestive heart failure. For several years you have had periods of difficulty breathing because of a weak heart. Generally, these episodes can be treated by your doctor with adjustments in the medications you take at home. A few times you needed to be hospitalized in the Intensive Care Unit because you were very sick. Between these episodes you remain active, although you are unable to walk as far or as fast as you once did.

Over the past six months you have had more of these spells and have been admitted to the hospital three times. One time, you were admitted to the Intensive Care Unit and needed to be put on a breathing machine. After that experience you appointed a health care proxy. You are now admitted to the Intensive Care Unit, unconscious, with a fever and difficulty breathing. The doctor puts you on a breathing machine. After careful evaluation, the doctor believes you may have a lung infection in addition to your heart problem. The doctor is not certain whether you will live or die.

Patient Instructions

Imagine that at the time you appointed a health care proxy you told your proxy that you "wanted everything done, no matter what." In the last year you have had some discussion about your illness with your proxy. You said that you were fed up with your frequent hospitalizations and you are less hopeful about getting better. You have had no further conversations about this with your proxy.⁵

This scenario is followed by questions that ask both patients and proxies what decision(s) they would make, and whether they are in agreement. We also ask them what additional information might assist them and how each would feel if the proxy "went against" the patient's initial instructions.

A close reading of this scenario and these questions illustrate our pedagogical intent. We want to help patients and proxies confront the complexity and ambiguity that arise from the prognostic uncertainty embedded in so many end-of-life situations. By working with clinically realistic scenarios, patients and proxies have the opportunity to understand that what they may have to confront in the future. In particular, these scenarios make it clear that simple "yes" and "no" answers to questions

about specific interventions or value clarifications may not, in reality, provide proxies with enough useful guidance.

Our second objective is to provide an opportunity for two-sided discussions that might serve as a template for their own personal scenarios, acknowledging and reinforcing the interpersonal aspects of the patient-proxy relationship and the place for interpretative judgment.

The effectiveness of this kit and its individual components will be judged on two levels. The first is purely quantitative: that is, the number of kits, videos, or workbooks ordered and whether those orders increase over time. Second, we hope to do follow-up interviews with organizations that have used the kit to get feedback about the participants' experiences and reactions.

Conclusion

Our goal was to create novel educational materials, building upon our theoretical and empirical work delineating the contractual and covenantal dimensions of advance care planning. By directing educational materials to the *relationship* that underlies all surrogate decision-making, we believe we have transcended a construct of advance care planning that relies too heavily on the patient's self determination and discounts the moral burden imposed on the proxy.

Fidelity, Wisdom, and Love: Patients and Proxies in Partnership will be available in May of 2003. For more information, please contact Barbara Maltby at (212) 746-1102.

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