

Using the Family Covenant in Planning End-of-Life Care: Obligations and Promises of Patients, Families, and Physicians

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Physicians and families need to interact more meaningfully to clarify the values and preferences at stake in advance care planning. The current use of advance directives fails to respect patient autonomy. This paper proposes using the family covenant as a preventive ethics process designed to improve end-of-life planning by incorporating other family members—as agreed to by the patient and those family members—into the medical care dialogue. The family covenant formulates advance directives in conversation with family members and with the assistance of a physician, thereby making advance directives more acceptable to the family, and more intelligible to other physicians. It adds the moral force of a promise to the obligation of respecting a patient's preferences about end-of-life care. These negotiations between patient, family, and physician, from early planning phases through implementation, should greatly reduce the incidence of family disagreements on what the patient would have wanted. The family covenant ensures advance directive discussions within the family, promotes and respects the autonomy of other family members, and might even spur others in the family to complete advance directives through additional covenants. The family covenant holds the potential to transform moral quagmires into meaningful moral conversation. *J Am Geriatr Soc* 51:1155–1158, 2003.

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THE DOCUMENTATION-BASED MORASS

For more than 25 years, respect for patient autonomy has been the foundation for the ethical and legal consensus that patient preferences should be honored when making treatment decisions. Even the preferences of patients who become incompetent can be respected. Physicians assess what incompetent patients would have wanted had they

been competent and able to speak for themselves, or they rely on statements made when the patients were competent.

In the United States, a documentation approach to preserving autonomy for formerly competent patients has been pursued. The living will and durable power of attorney for health care are documents designed to promote autonomy for patients who are no longer competent to accept or refuse medical treatments, but these legalistic, document-based approaches have been widely criticized as flawed.¹⁻⁷ In response to the vagueness of the standard documents, attempts have been made to develop values-based directives (such as the values history⁸) or scenario-based directives (such as the medical directive^{9,10}).

The results of this approach have been less than impressive. Most Americans do not have an advance directive. Physicians are hesitant to initiate discussions on end-of-life care.¹¹ Advance directives may not arrive with patients at healthcare institutions or may be inaccessible to the ward, where decisions about the patient are actually made.¹² Distraught family members appear at the bedside, urgently requesting care that is different from the documented preferences of the patient. Physicians then have difficulty resisting the demands of distressed, demanding, and potentially litigious family members to honor vaguely expressed preferences of an incompetent patient—preferences that may have been formulated years before, without any understanding of the present medical situation. Most distressing of all, the Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatments demonstrated that, even when patient preferences about end-of-life care are obtained and included in the patient's chart, they are ignored when treatment decisions are actually made.¹³

The unimpressive results of this 25-year effort on advance directives may lead to the conclusion that the document-based approach to advance care planning is not effective—with further efforts unlikely to be productive. If these documents are ineffectual, using them fails to respect the autonomy of patients. But something like an advance directive is needed. Attempts to make treatment decisions for once-competent patients without consideration of their values and preferences are problematic at best. Not all patients want (or refuse) the same treatments. The treatment one patient desperately wants will strike another as repulsive, degrading, or pointless. Moreover, patients

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without advance directives will probably receive more-aggressive—even futile—life-sustaining treatment. For all these reasons, physicians will continue to need to ascertain and document patient values and preferences. This task would require a document like an advance directive—an instructional directive, a durable power of attorney for health care, or preferably, a combination of the two.

The authors submit that the failure of advance directives grows largely out of three faulty premises.

1. A document can be created that will suffice, without a conversation with the patient's physician, to elicit patient preferences about future treatment in enough detail to provide guidance in most medical situations.
2. The patient's dying process is an individual matter in which the patient's family and loved ones have no legitimate interest.
3. The values of the patient's family are immaterial, for only the patient's values and preferences should be relevant to his or her treatment at the end of life.

The authors challenge these three premises. Given patient consent, the patient's physician and family can be involved in a valuable process-based role.

Death is often, to use the common phrase, a "death in the family." Members of the family have important interests and concerns about the dying of their loved one. They have culturally inculcated views about what loving care of a dying relative is, as well as what they consider burdensome, painful, and demeaning. Physicians will always have difficulty resisting the demands of caring and anguished family members. Proxies also face difficulties in the face of disagreement within the family. Proxies are mindful that, although they hold the authority of being the designated proxy, if they use this authority, they may have to live in a family torn by dissent about treatment decisions they made. The authors feel that the deeply held values of family members are morally relevant in planning end-of-life care and the treatment of incompetent patients.¹⁴ Thus, the family covenant—a process-based approach—is proposed as the next evolutionary leap forward for advance care planning.

THE FAMILY COVENANT AND END-OF-LIFE CARE

The family covenant provides an innovative approach to the challenges of working with patients and families in planning end-of-life care. This model of medical care is inclusive, beginning with acknowledgment that the patient's family members usually have valid and important interests in the way their loved one is cared for at the end of life.

A family covenant incorporates other family members—as agreed to by the patient and those family members—into the medical care dialogue. It is a means for people who consider themselves family (related or not) to facilitate communication and to work out the resolution of their conflicts in ethically sensitive circumstances. Covenants differ from contracts in that they are open-ended and flexible; covenants anticipate the unexpected, whereas contracts tend to be narrow and focused on the letter of the agreement. The notion of covenant in health care has been in the medical lexicon for a quarter century,¹⁵⁻¹⁸ with one writer having focused on end-of-life care,¹⁹ but none of these prior efforts has incorporated a family-based approach to medical treatment decisions. The

family covenant approach to treatment decisions was first conceptually introduced in 1991²⁰ and was specifically applied to genetic testing in 2001.²¹

Applied to the planning of end-of-life care, the family covenant would be a negotiated set of boundaries about what the family will do when faced with proxy decisions, with the physician agreeing about what care he or she will deliver at the end of this patient's life. The family covenant begins with a promise from each participant to each other that they will follow their agreement about end-of-life care. The family covenant is preventative ethics,²²⁻²⁶ an agreement designed to help avoid the moral predicaments that families and physicians fall into when health care must be provided to incompetent patients and the toll of such predicaments on both physicians and families.

Advance care planning currently invites patients to think of their well-being in a narrow, atomistic fashion—in a vacuum, without explicitly addressing how their decisions affect their loved ones. It also asks patients to consider their values without the benefit of input from family members (although this input can and does occur). Yet, advance directives can have great meaning to all family members, and the values of other family members can have great bearing on the planning of end-of-life care, just as they often do later when that care is administered. Although the covenant is a means to enhance and uphold the autonomy of the patient, it recognizes the legitimate interest of other family members in the end-of-life care a member of their family receives.

The effect of end-of-life care on their families also has great import for many patients. Empirical research has revealed that patient concerns about shielding their loved ones from emotional and financial burden in large part drives consent and refusal in advance directives.²⁷ Acknowledging these family based values is part of what it is to respect patient autonomy. For many patients, the values of other members of the family will be important in determining the care they want.

Just as informed consent is a process, not an event, the family covenant is an evolution of advance care planning beyond the execution of a document.²⁸⁻³¹ This process begins with a conference between patient and physician in which the physician helps the patient to articulate her or his values and treatment preferences. A meeting is then called with all family members whom the patient chooses to include. The physician's obligations to family members are negotiated and clearly articulated. Before agreeing to the covenant, the physician and family discuss how disputes would be managed and how they envision the physician's and family members' role in care-giving, with the physician identifying future potential concerns involving autonomy and benefit claims and illustrating means by which the family and physician would respect these claims. This process will normally lead all members of the family to think about what kind of care they themselves would want and might well lead to additional advance directives (and covenants).

No violation of confidentiality or autonomy is involved in this process, for the patient must consent to its formation and agree which family members will be given an opportunity to participate. The family covenant encourages respect for persons as moral agents by ensuring communication of autonomous preferences to others as the patient permits them to be shared. The parameters of

the family covenant are documented in the patient's record with other information on advance care planning, and family and physician promise to implement them.

One powerful aspect of the family covenant is the discussion and negotiation process itself. Family discussion about end-of-life care is started early, and participants are encouraged to listen respectfully to what others have to say. The family covenant brings potential disagreements into the open where they can be discussed and accommodated. As the patient describes her or his intent and shares it in the discussion process, the obligation to implement the patient's preferences is strengthened. If no agreement can be reached, a proactive decision can be made about how to proceed in the face of the disagreement. Those who cannot agree with the patient or the rest of the family may decide to drop out of the covenant at this point. They are not bound by the covenant, but neither are they part of it. The patient chooses a proxy from among those participating in the covenant and may also decide not to share medical information with those outside the covenant.³²

The promise is another compelling aspect of the family covenant. Those family members who consent to the family covenant are bound to it—by their own promise. Promises have widely recognized moral force. Promises to family members can be especially powerful. The promise to the patient and to other family members provides the ethical leverage needed to implement the wishes of the patient. A promise created the covenant, so promise keeping is required of family members and healthcare providers when agreed-upon care is to be delivered.

The family discussion may indeed alter the patient's preferences. The authors do not think this is necessarily bad. One of the benefits of family dialogue (about medical and nonmedical issues alike) is that loved ones are often able to help each other see things more clearly. For instance, family members may counter patient concerns about reducing financial burdens by telling them that these concerns are groundless. Because many patients care deeply about the effect of their decisions on their loved ones, it should not be surprising that they might change their directive once they more fully understand its implications for the rest of their family. The physician is present partly to witness that other members of the family do not unduly pressure the patient. The family covenant, thereby, promotes advance directive discussions but also promotes and respects the autonomy of other family members (as permitted by the covenant's structure).

No family is perfect. There can be family members who are estranged and families with poor lines of communication. The family covenant helps to reinforce lines of communication and to clarify the role of each family member, whether by negotiation and inclusion or by their exclusion due to intractable disagreements.

Of course, some patients do not want to discuss end-of-life decisions with their health professionals^{33,34} or anybody else.³⁵ Although this refusal to engage falls within the patient's rights, the patient should be made aware that when she or he becomes incapacitated, someone will have to make medical decisions, and without at least the appointment of a proxy, future decisions may be problematic. Pointing out how some states now require "clear and convincing" evidence of advance directive intent to withdraw

or withhold treatment will illustrate why discussion and appointment of a surrogate is prudent. Finally, most patients will see the unfairness of leaving their family burdened with decisions about what "the patient would have wanted" without any information from the patient about those preferences.

The family covenant should be flexible and responsive to future circumstances. No one can foresee the future, but patients may articulate their important values and preferences and allow for extrapolation from them to future events. To change the initial agreement—or to refuse to abide by it—a family member would need to explain how new information or altered circumstances have changed the original agreement. The negotiation process could then be reopened. If the patient is incompetent, her or his advance directive can no longer be changed, nor can the promises made to her or him, but the promises of those who participate in revisiting the original contract are reinforced. The passage of time and successful management of family issues allows for trust to accumulate in the covenant, which can often prevent future familial emotional and psychological discord. People who trust each other through sustained interaction will be more likely to respect each other's values and preferences.

The physician is a facilitator in the family covenant. Healthcare providers already often act as facilitators and mediators in family conflicts. Although not all physicians have the same level of mediation skills, mental health and pastoral care providers can be helpful adjuncts in the family covenant process. In extreme circumstances, ethics committees could also assist families and physicians when difficult dilemmas occur. Physicians do bring their own values, and there may be evident differences between family and provider. The doctor's values are not intended to shape the covenant but will play a role in whether he or she will be willing to deliver the agreed-upon care. When end-of-life preferences are to be implemented, the physician shifts into the participant—and promise-keeping—role, and it is advantageous to clarify any discord of values before this point. Although preferable, it is not necessary that the physician involved in creating the covenant deliver the agreed-upon care. If the doctor who negotiated the covenant is not involved in the patient's end-of-life care, that does not alter the promise made by the family. The negotiated agreement should still help reduce the incidence of demands for care that was not agreed upon, and the covenant would still provide important information for the inpatient team. The written covenant with explanatory notes by the physician would allow for the communication to pass from one physician to another.

Advance directives are far from perfect, and one paper recommending modifications of the process will not remedy all the difficulties with advance care planning. Among the challenges, one of the most notable is the lack of a clear way to bill for time spent facilitating such family covenants. For capitated patients, time needed for advance directive counseling can be accounted for under the preventive services coding, but for fee-for-service patients, this remedy is less clear. Without a way to bill for time spent, physicians may be reluctant to engage in this process unless they have a special interest in end-of-life care, but this reluctance results in labor shifting that runs counter to the

patient's best interest. The process the authors advocate is time consuming on the front end, but in the long run, family covenants might save the physician (and health system in general) time and energy as physicians confront fewer anguished and hostile family members when end-of-life decisions have to be implemented.

Much more needs to be done. Although one of the authors (DD, a practicing family physician and medical ethicist) has used the family covenant informally in planning end-of-life care to positive effect for patients and families, this model needs to be subjected to empirical trials to ascertain the covenants' efficacy and demonstrate the improvement of family covenants over the status quo. The challenge of the work ahead does not change an important aspect of medical care; many patients want to involve their families in their health care, family members may be helpful to their loved ones in formulating end-of-life care preferences, and physicians can be facilitative caregivers in the family covenant.

CONCLUSION

Physicians and families need to interact better with each other to clarify the values and preferences at stake in advance care planning. The authors have suggested an effective, inclusive, process-based approach to such planning. The family covenant could improve advance care planning by facilitating more-meaningful conversations about end-of-life preferences, starting the discussions much earlier, and formulating advance directives with the assistance of a physician, thereby making them more realistic and intelligible to other physicians. This process could also extend end-of-life planning beyond the "treatments to be administered" mode, providing the framework within which other important things could be discussed and critical family connections strengthened before incompetence thwarts all attempts to make things right. It adds the moral force of a promise to the obligation to respect a patient's wishes.

Two evident advantages arise with this model of advance care planning. First, these discussions can bring about values clarification before a health crisis, when all covenant members can best represent and convey their wishes to their trusted others. This process can also elicit discussion of inconsistent values, irrational beliefs, and areas of needed education in the advance directive process. Second, if there are intractable values discrepancies among family members, or between family members and the health provider, the covenant can be reformulated with other providers or a change in participants. Although this process may require time and effort, it is far more respectful of the values of patients and their family members. It holds the potential to transform moral quagmires into meaningful moral conversations.

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