

BRIEF REPORT: Identifying a Proxy for Health Care as Part of Routine Medical Inquiry

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BACKGROUND: Physician-initiated advance care planning is desirable, effective, and routinely indicated for competent adult patients, but doctors are often reluctant to begin the necessary conversations.

OBJECTIVE: To determine whether patients are willing and able to designate a surrogate for medical decision making, when asked to do so as part of routine medical inquiry.

DESIGN, PATIENTS, MEASUREMENTS: A survey asking patients to name a health care agent was designed and administered in the context of routine clinical care. Participants were drawn from a consecutive sample of 309 competent adult outpatients. Data were analyzed using ordinary descriptive statistics.

RESULTS: Two hundred ninety-eight of 309 patients (response rate, 96%) completed the survey and were willing and able to specify a proxy for health care. One third of married participants did not choose their spouse as proxy.

CONCLUSIONS: Asking patients to identify a surrogate for medical decision making opens the door for ongoing individualized medical care planning in the context of ordinary patient-physician interaction. This approach is applicable to all competent adults. Documenting proxy choice protects a patient's wishes and preferences until more definitive planning is accomplished.

KEY WORDS: proxy; advance care planning; advance directives; decision making; physician-patient relations.

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"Physicians should routinely raise the issue of advance planning with competent adult patients. . ."—American College of Physicians' *Ethics Manual*, 5th ed.¹

BACKGROUND

The current approach to advance care planning (ACP) using formal written documents (i.e., advance directives) is not well integrated into ordinary medical practice and has failed to achieve desired outcomes (Table 1).²⁻⁷ Advance care planning is not about documents—it is about persons and their relationships.^{8,9} Emphasis on end-of-life care, terminal illness, and the use or discontinuation of life-sustaining medical treatment has obscured the need for advance planning in the regular care of all competent adult patients.¹⁰

Doctors do not ordinarily consider advance planning, unless patients are elderly or seriously ill.^{11,12} Reluctance of primary care physicians to routinely raise these issues¹³⁻¹⁵ is

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considered "a primary reason that most Americans do not have an advance directive" (p. 2443).¹⁴

At the same time, studies reveal that most patients are willing to discuss plans for their future medical care.^{10,11,15} They say they are waiting for their physicians to begin the conversation and to raise the necessary questions.⁴ When ACP conversations take place between patients and doctors, they are shown to have positive therapeutic effects and to result in improved patient care.¹¹

OBJECTIVE

A simple first step toward comprehensive ACP has been suggested; namely, asking patients to identify their desired proxy for medical decision making in the course of ordinary medical treatment.¹⁶ Although similar proposals have appeared in articles or discussions about ACP,^{2,17-20} this practice has not been investigated or implemented. We were unable to find any other studies asking a sample population of competent adult patients to designate a proxy in a clinical setting.

Our investigation was undertaken to examine the effectiveness of a straightforward method for eliciting proxy information. The purpose of the study was to determine whether patients are willing and able to designate a specific person to act as a surrogate for medical decision making when they are asked to do so as part of routine medical inquiry in an outpatient health care setting.

METHODS

Subjects were drawn from a consecutive sample of 309 competent adult patients arriving for regularly scheduled appointments at the General Eye Clinic of the University of Chicago during a 6-week period in March/April 1997. There were 2 data collection activities: (1) a survey of all enrolled patients (the survey asked patients for contact and health care agent information); (2) a follow-up interview with approximately half of the survey respondents.

The survey instrument ("Medical Treatment Planning Survey") was developed to determine whether patients were willing and able to designate a proxy for health care as part of routine medical inquiry. The survey consisted of 2 questions—a "CONTACT question" followed by a "PROXY question." Pairing the 2 questions placed the proxy question in a familiar and conventional framework for requesting medical information.

(a) *Contact question:* "In case you had a medical emergency, who is the person you would want your doctor to notify?"
Name _____ Relationship to you _____.

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Table 1. Definitions

MeSH Heading	NLM-Controlled Vocabulary	Year of Entry	Previous Indexing
Advance care planning*	Discussions with patients and/or their representatives about the goals and desired direction of the patient's care, particularly end-of-life care, in the event that the patient is or becomes incompetent to make decisions	2003 use Advance Directives 1999 to 2002	Advance Directives (1994 to 2002)
Advance Directives†	Declarations by patients, made in advance of a situation in which they may be incompetent to decide about their own care, stating their treatment preferences or authorizing a third party to make decisions for them	1991	Right to Die‡ (1987 to 1990) Wills (1966 to 1990)

Source: Medical Subject Heading (MeSH) Database; National Center for Biotechnology Information (NCBI); U.S. National Medical Library (NLM) <http://www.ncbi.nlm.nih.gov.ezproxy.galter.northwestern.edu/entrez/query.fcgi?db=mesh>. Accessed April 17, 2006.

*Advance Care Planning (ACP) is the process of planning ahead for medical care. ACP is an ongoing "conversation" between patients, physicians (and other caregivers), family, and surrogates. Emphasis is on relationships and the clarification of patient/family values.

†Advance Directives (ADs) are the products of advance care planning, i.e., the formal legal declarations designed to authenticate patient wishes and preferences (living wills) and/or to empower a proxy [power of attorney for health care]. Problems: Living Wills may not reflect an interactive advance care planning process; the instruments may not be up-to-date; they may be unavailable when needed; or they may be misinterpreted (sometimes even ignored).

‡As a result of court decisions in "right to die" cases, Congress passed the Federal Patient Self-Determination Act (PSDA) as an amendment to the Omnibus Budget Reconciliation Act of 1990. This legislation affirmed the right of competent persons or their duly appointed agents to accept or refuse medical treatment—including life-saving or life-sustaining care. The origins of Advance Directives in jurisprudence and law impeded the development of advance care planning as part of ordinary medical practice. The lack of physician initiation of ACP and the failure of doctors to participate in ongoing planning with patients/families continue to be significant limiting factors for establishing advance care planning as part of commonplace health care.

(b) Proxy question: "In case you were unconscious or too sick to make decisions about your medical care, who is the person you would want your doctor to talk with (the person that you would pick to represent you and to make any needed health care decisions for you, in case you couldn't make medical decisions for yourself)?"
Name _____ Relationship to you _____.

Patients were approached in order of their arrival at the clinic. After a patient completed routine clinic check-in, an investigator asked for participation in the study and completion of the survey. Informed consent was obtained verbally. (A copy of the Survey is available online as Appendix A. The "script" for consent is included.)

We also prepared a 12-question Interview to explore patients' attitudes, reactions, or concerns related to choosing a surrogate for health care. The patients were asked whether the contact and proxy questions were clear and understanda-

Table 2. Characteristics of Patients

Characteristics	n (%)	Proxy Choice, n			
		Spouse	Child	Sibling	Parent
Age, y (N=298)					
<25	8 (3%)				
25 to 44	78 (26%)				
45 to 64	90 (30%)				
65 to 84	114 (38%)				
>85	8 (3%)				
Sex (N=298)					
Women	181 (61%)				
Race/ethnicity (N=298)					
White	111 (38%)				
Black	171 (57%)				
Hispanic	7 (2%)				
Other	9 (3%)				
Marital status (N=298)					
Married*	133 (45%)				
Proxy = spouse	89 (67%)	89			
Proxy = not spouse†	44 (33%)		27‡	7	4
General health (n=152 of 153§)					
Excellent	27 (18%)				
Good	84 (55%)				
Fair	35 (23%)				
Poor	6 (4%)				
Education (n=151 of 153)					
<8th grade	2 (1%)				
Some high school	8 (5%)				
High school graduate	63 (42%)				
College graduate	78 (52%)				
Religion (n=150 of 153)					
Protestant	75 (50%)				
Catholic	36 (24%)				
Jewish	10 (7%)				
Other or none	29 (19%)				
Household income, \$ (n=148 of 153)					
<20,000	29 (19%)				
20,000-40,000	50 (34%)				
>40,000	69 (47%)				
Have DPAHC* (n=152 of 153)	28 (18%)				

*Marital status: married—determined directly = 116; from medical record = 17.

†Of the 44 married subjects that did not choose spouse: 27 (61%) chose a child.

‡Of the 27 children, 20 = daughters; (3:1 daughters to sons);

χ² = 6.26; P = .012.

§N = 153 (153 = the number of participants interviewed, i.e., 153 of 298). (< 153 of 153 = the number of interviewed participants providing the requested information and indicated as n).

*Subjects that had a formal DPAHC were more likely to be white (64% vs 36%; P = .007); college educated (96% vs 73%; P = .009); and 59 years of age or older (61% vs 32%, P = .005).

Of the patients with a DPAHC: 14 (50%) were married; 3 (21%) did not choose spouse as proxy.

ble and whether the questions had ever been asked of them before. Did they think the proxy question should be asked routinely? If asked by their doctor today, would they want to choose someone now to act as a surrogate for medical decision making? Did they already have a durable power of attorney for health care (DPAHC)? Did their doctor know about it? Was a copy in their medical record? (A copy of the Interview is available online as Appendix B.)

We wanted to examine the process with persons of different ages in various states of health, who were electively seeking medical evaluation or treatment and who were considered competent to make their own medical decisions (target population). Outpatients coming to a general eye clinic for regularly

scheduled appointments met those criteria (accessible population; convenience sample). Data were collected during regular clinic hours, while patients were waiting to see their doctor. Demographic information was determined directly or collected from medical records (Table 2). Competence was presumed unless there was evidence to the contrary.

Data were ordered, grouped, or summarized using basic descriptive statistics. Associations among variables were examined for statistical significance using χ^2 or *t*-test. The study protocol was IRB approved.

RESULTS

Of the 309 competent adult outpatients, 299 agreed to answer the survey (97% recruitment rate). Only 1 patient was unable to complete the survey, leaving a study sample of 298 persons—a 96% response rate (298 actual subjects out of the intended sample of 309 patients).

The patients in our sample ranged in age from 19 to 96 years. The median age was 57 years. Forty-five percent were married.

All subjects were able to identify a specific person to act as a surrogate for medical decision making (Fig. 1). Eighty-four (28%) chose someone other than the contact person to act as their proxy for medical decision making. Thirty-three percent of the married patients in our sample did not choose their spouse as surrogate (Table 2).

After patients completed the survey, every second subject was offered an interview. One person declined. We obtained 153 interviews. Of the patients interviewed, 91% supported the idea of asking patients to designate a proxy for health care on a routine basis. Only 26% had previously been asked to identify a surrogate. When asked if they would want to name a

proxy for health care *now* (i.e., if their doctor asked them to do so at this time), 87% answered *yes*.

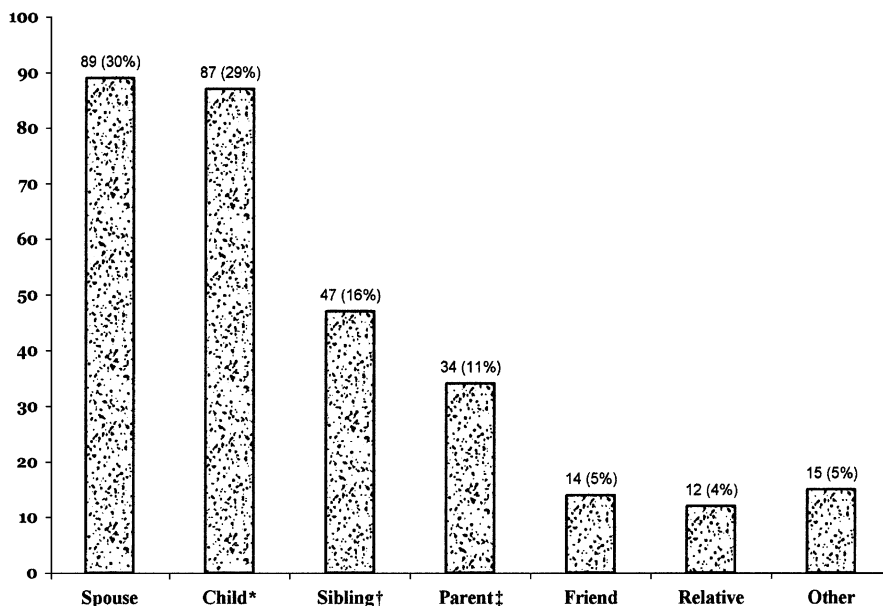
Twenty-eight of the 153 interviewed subjects (18%) already had a DPAHC (Table 2). Only 8 patients (5%) were known to have a copy of their advance directive in the medical record.

DISCUSSION

Clinical Implications

In addition to securing preferences for future treatment, identifying a proxy for health care as part of routine medical inquiry offers several immediate clinical advantages. First, the door is opened for ongoing ACP conversations between patients and their doctors. Second, the benefits of choosing a health care agent are made available to all competent patients—not only to the terminally ill, the very sick, or the very old. Third, the documentation of a competent patient’s proxy preference in his/her medical record constitutes “clear and convincing evidence” of prior patient wishes in case of incapacitation—providing a safety net until more definitive planning is accomplished.

When patients choose a surrogate who is not the person with whom doctors would usually consult or who would not become empowered as a substitute decision maker under state laws, physicians are alerted to engage these patients in an ACP process that ensures the formal appointment of their desired health care agent. The finding that 33% of the married patients did not choose their spouse as surrogate is noteworthy, because physicians regularly look to spouses as informal surrogates. There is a scarcity of information in the medical literature regarding the proxy choices of adults in the general population. In a survey of a representative population of elderly persons living in the community (Detroit area), over 50% of married individuals with DPAHCs did not choose their



*†‡When a child, sibling, or parent was chosen as proxy, women (mothers; daughters; sisters) were preferred.

*Child: Daughters = 64; Sons = 23 (nearly 3:1 daughters) χ^2 (1 df) = 19.32; *p* < .001

†Sibling: Sisters = 31; Brothers = 16 (nearly 2:1 sisters) χ^2 (1 df) = 4.79; *p* = .029

‡Parent: Mothers = 28; Fathers = 6 (nearly 5:1 mothers) χ^2 (1 df) = 14.24; *p* < .001

FIGURE 1. Proxy Choice (N=298).

spouse.²¹ In a random sample of 8,000 adults in France, subjects were asked if they would like to designate a surrogate to represent them should they be incompetent and admitted to an ICU.²² Among married respondents, 21% would not designate their spouse to speak for them. The specific findings and variables that determine proxy choice are important but not necessary for answering our study question. Instead, the findings are a clarion call to *ask* our study question.

Limitations

Any approach to ACP will generate its own set of difficulties. We cannot in this brief report fully address the limitations of this research or the concerns associated with asking patients to name a proxy for medical decision making. We do note that the study population is based on a convenience sample and is not necessarily representative of the general medical population. Similarly, the physicians providing care to the study participants were not necessarily representative of the primary care physician work force. Finally, we do not know how ACP conversations will actually be implemented in practice and the challenges that may be involved. However, bringing ACP into ordinary physician-patient interaction will make it possible to address ACP issues *in terms of medical practice*—rather than as matters for the courtroom, the legislature, or executive decision.

Conclusions

In the wake of the Terri Schiavo case,^{8,23,24} physicians have an unprecedented opportunity to create a different paradigm for ACP. This study introduces a simple, powerful strategy to open the door for medically based, relationship-centered planning. We hope that it will stimulate further discussion, inquiry, and direct clinical application.

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Supplementary Material

The following supplementary material is available for this article online at www.blackwell-synergy.com

Appendix A. Survey.

Appendix B. Interview.