
The Health Care Agent: Selected but Neglected

by Arline Lane and Nancy Neveloff Dubler

The health care agent or "proxy" whose involvement in medical treatment decision making is triggered by the patient's incapacity, frequently faces a potentially awesome responsibility alone and unprepared. Often neglected or excluded from patient-care planning, the proxy has informational and emotional needs that must be met by the health care team in the very same manner as would those of the patient. By establishing a triad of provider, patient, and proxy early on in the patient's care, much of the angst of proxy decision making could be eased.

An estimated ten to twenty-five percent of adults complete advance directives. These include the designation of health care agents through durable powers of attorney for health care, also called health care proxies (Gamble, McDonald, and Lichstein 1991; Stetler, Elliott, and Bruno 1992). These formally appointed surrogate decision makers, empowered to make medical treatment decisions often with life or death consequences, frequently lack guidance, information, and emotional support from the patient's care team (anecdotal information gathered from focus groups by researchers at Montefiore Medical Center). The health care agent or "proxy" whose involvement in medical treatment decision making is triggered by the patient's incapacity frequently faces a potentially awesome responsibility alone and unprepared.

Occasionally, however, a physician and a proxy, sharing a community of concern for the patient, work together to develop a medical treatment plan that serves the patient in the best manner possible. The following case illustrates such a successful interaction.

The Elderly Twin Alone

Mr. B., eighty-five years old, broke his hip two months prior to the ethics consult described below. The patient, who suffered from moderate demen-

tia, had been sent for rehabilitation, briefly returned home, and then was readmitted for dehydration.

Issues arose concerning Mr. B.'s advance directives. The living will was a wordy, complicated, unwieldy document prepared for him by an attorney. An attached health care proxy form delegated decision-making responsibility to Mr. B.'s grandniece, Fran, one of his few remaining relatives. Mr. B., never married, had lived all his life with his twin brother who had died about eight months earlier. They lived in their own home with full-time aides to care for them.

Mr. B.'s doctor had been in contact by phone with Fran — a highly educated, articulate businesswoman in her late 30s — who had been designated as Mr. B.'s health care agent a few years earlier. "They thought I could deal with it," said Fran, referring to the twins and other family members.

Fran had been seeing her then mildly demented twin granduncles twice yearly. Her involvement until now was limited to paying their bills and overseeing, from her own home in New Jersey, the running of her uncles' Bronx household. She had never discussed Mr. B.'s medical treatment wishes with him and offered that she had not known her granduncles well.

Two weeks after being admitted to the rehabilitation hospital, Mr. B. still grieving for his

lost twin and thinking he was in a nursing home, began spitting out his food and became lethargic and dehydrated. Fran decided she had made a mistake placing her granduncle in the rehabilitation facility and returned him to his own home where, once again, his familiar aides cared for him. However, the dehydration recurred and Mr. B. was readmitted to the hospital.

Fran, now in constant communication by phone with Mr. B.'s aides and the doctor, left on a brief business trip abroad, planning to speak with the doctor daily and meet with him, the nurses, and the bioethics team upon her return.

At the scheduled meeting, Fran — tall, attractive, assertive, and professional — seemed anxious and burdened. She mentioned her frustration at having been called by an emergency room doctor just before leaving and at being "a wreck" throughout the trip.

As health care agent, Fran was expected to decide for Mr. B. as he would decide for himself were he able to do so and not substitute her own wishes, values, and beliefs for those of the patient.

Mr. B.'s doctor began the discussion with a review of the patient's current condition. A gastric feeding tube was needed to provide nourishment to sustain him. A nasal tube would be uncomfortable and, in his demented state, Mr. B. would probably attempt to pull it out. Without tube feedings, he would die.

Mr. B.'s complex living will was presented by his grandniece, and the detailed language was read with care by the bioethicist who was also an attorney. It stated that Mr. B. did not want

artificial feeding if he was in a condition that was irreversible. The doctor assured Fran that Mr. B. had no immediate life-threatening medical problems other than his reversible dehydration and malnutrition and, with tube feeding, he possibly could continue to live much as he had in the weeks following his hip fracture. It was unlikely, however, that he would walk again. Mr. B.'s condition was not irreversible and he did not appear to be terminally ill — conditions required for his living will to take effect.

This would seem to settle the issue and to permit Fran, as the health care agent, to consent to tube feeding. However, Fran took the case beyond the limitations of the living will language. Since she did not know her uncle well enough to know what medical treatment he would or would not want, she and the physician sought an ethical analysis. Such an analysis always begins with an examination of the goals of treatment. In this case, the key questions were:

- Was the patient likely to get better?
- Did he have some pleasures in life that would outweigh the burdens of treatment?
- Could minimal medical intervention give the patient more time to enjoy those pleasures in his life?

Questions remained as to what Mr. B. really wanted when he wrote his living will and what he needed in his current debilitated and demented state. As the health care agent, Fran was expected to decide for Mr. B. as he would decide for himself were he able to do so and not to substitute her own wishes, values, and beliefs for those of the patient. Mr. B., despondent since the death of his closest and, for most of his years, his only companion in life — his twin brother — had recently been asking his care givers to let him die. Yet, when asked about Mr. B.'s life after his twin's death and since he fractured his hip, Fran replied that he had attended church with a friend and seemed content to watch TV. Until recently, he had thoroughly enjoyed food. Would having to receive nutrition through a tube and the likelihood of

permanent immobility be acceptable to Mr. B. were he able to make that decision for himself?

Fran felt affection for her granduncle and was conscientious about fulfilling her responsibilities as his proxy. She did not want to be responsible for his death by refusing consent for a feeding tube, but she did want to honor the underlying intent of his wishes as expressed in his living will. Other relatives and friends compounded her concerns by telling her that they did not want Mr. B. "killed" by withholding the feeding tube. Should she, and could she, decide for Mr. B. that he continue to live?

During the ensuing discussion, insights and options emerged. Mr. B. could be sent home with a gastric feeding tube and his aides trained to care for him with the assistance of a home care agency. If he again began to take food by mouth, the tube could be clamped off but not removed, which would require a surgical procedure. Most important, the gastric tube could be tried and later, after appropriate discussion, be discontinued if circumstances warranted that decision. Deterioration in Mr. B.'s medical condition, continued expression of his wish to die, and lack of pleasure in living would trigger such a discussion. Fran was encouraged to call on the bioethicist should these events occur or if she had further concerns.

Fran's relief was evident. She was not forced to let her uncle die by the specific and narrow terms of his living will. Moreover, as health care agent, she could make different decisions in the future if circumstances warranted it. The feeding tube was placed and Mr. B. returned home.

In this case, an informed and caring physician recognized the need to review and interpret the patient's advance directive. With the bioethicist clarifying the issues and serving as facilitator for discussion, the physician and proxy were able to work together toward a solution that served the present best interests of the patient and also addressed future concerns. Although most cases involving proxies do not progress this smoothly, the present case does illustrate the anxious plight of a proxy who, although deeply concerned and

intent upon doing the right thing is uncertain as to what that is.

As a patient in a New York hospital, it was fortunate that Mr. B.'s health care proxy specifically addressed both artificial feeding and hydration. The New York State Health Care Proxy Law (Public Health Law Section 2980 et seq.) denies the proxy power to make decisions about food and fluids unless the patient's wishes regarding artificial nutrition and hydration are known or can reasonably be ascertained. Therefore, the living will in combination with the proxy appointment enabled Fran to permit placement of the feeding tube and also allowed her to authorize its removal.

Why then, if proxy input could enhance the process of medical treatment decision making, is the proxy often neglected or even actively excluded from patient care planning?

Fran and the doctor were diligent in pursuing the "right" decision. They went beyond the four corners of the patient's living will — a static, inflexible document that is fixed at the time of its execution.

A problem with most living wills, as was the case with Mr. B.'s, is that they are written by others, often lawyers, and do not generally reflect individual choice. They have become lawyer-driven documents and tools for risk management. However, living wills do have a role, even though health care agents — concerned, human decision makers with whom options for treatment can be discussed — are usually more effective. The living will can guide the health care agent in understanding the patient's health care philosophy, instead of providing specific instruction on particular treatment decisions.

Unlike Fran, most health care agents are spouses, parents, or children of patients. While perhaps in greater need of support and guidance, they may know the patient's life patterns and interests more intimately. A close and trusting relationship with the patient and an understanding of his or her values and health care preferences places the health care agent in a unique position to guide treatment decisions and to provide richness and detail about the patient's life that adds substance to the black and white dictates of a living will. Health care professionals, if receptive to the proxy's input, will benefit from a more complete picture of the patient. In concert with the proxy, they then can provide care that is best for that individual.

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If proxy input can enhance the process of medical treatment decision making, why is the proxy often neglected or even actively excluded from patient care planning? Why is the proxy sought out only for "big" decisions about life or death? One reason may be that physicians and other health care providers feel uneasy interacting with a proxy, uncertain as to their obligations toward this surrogate decision maker. They may view the proxy as a convenient decision maker to be called upon sporadically on an as-needed, rather than on an ongoing, basis (Dubler 1995). The proxy, then, is left to make critical decisions in isolation, perhaps without clear knowledge or understanding of prior treatments or present options. Vulnerable and emotionally distraught over the condition of a loved one, a proxy must simultaneously cope with personal grief and fulfill weighty responsibilities.

The theory of health care agency implies that

an agent takes on the persona of the patient when acting on his or her behalf. Therefore, the doctor's obligations to the patient of support, truthfulness, compassionate caring, and respect should extend as well to the proxy. The informational and emotional needs of the proxy must be tended to by the health care team in the very same manner as would those of the patient.

Unlike relationships between doctor and patient, the doctor-proxy relationship has not been significantly explored. More needs to be learned about how these parties interact and what barriers to communication exist between them. Improved communication, supportive of the proxy as a person as well as the surrogate decision maker for the patient, could facilitate more effective end-of-life decision making to the benefit and increased comfort of all parties. Moreover, it could provide necessary emotional support for the proxy, who confronts complicated and anxiety-provoking medical treatment decisions on behalf of another. By establishing early a triad of provider, patient, and proxy, much of the angst surrounding such decision making could be eased.

To better understand neglect of the proxy by health care providers, the Division of Bioethics and the Division of Geriatrics at Montefiore Medical Center, Bronx, New York, is currently engaged in a project, funded by The Greenwall Foundation, to identify barriers to effective communication and interaction between these parties. Through a series of focus groups with doctors, nurses, social workers, patients who have designated health care agents, and the agents themselves, the project has identified issues for further clinical study. Legally designated proxies and physicians of participating patients (primarily those over the age of sixty-five) will be interviewed separately after the patient's discharge or death to determine the nature and quality of their interaction during the patient's hospital stay. Data from these interviews will provide a basis for the development of guidelines to aid health care professionals in communicating and working with health care agents. Case

studies, such as the story of Mr. B., will illustrate sequential steps in the proxy decision-making process and detail the continuum of situations, from most to least common, in which health care proxies are called upon to make decisions for incapacitated patients.

A companion project, funded jointly by The Altman Foundation, The Nathan Cummings Foundation, and The New York Community Trust, will develop training programs and educational curricula for both health care agents and those who interact with them, including physicians, nurses, social workers, clergy, and community workers. While these materials are being developed in New York State, which has a restrictive health care proxy law, they will be adaptable to other states.

It is hoped that this research will ultimately help provide new ways to approach, support and involve proxies in relationships with care givers.

References

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