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When Doctors and Daughters Disagree: Twenty-Two Days and Two Blinks of an Eye

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Abstract

A cornerstone of American medical ethics is the right to say, “Keep your hands off of me,” to decline medical treatment. A central problem is how to decide about individuals who have become incapacitated and can no longer request or refuse potentially life-sustaining treatment. An advance directive is a formal attempt to protect people’s right to autonomy when they are no longer autonomous. As such, it assumes that previously expressed wishes are precise and immutable, but many families make decisions together, and individuals may negotiate, compromise, and modify their genuine preferences, especially when novel threats arise, and the stakes are high. The current article describes a case in which two daughters overruled a patient’s explicit preference to refuse life-sustaining treatment, leading to burdensome illness before death. In the end, the mother seemed to understand her children’s needs and seemed willing, at least in retrospect, to have met those needs. After the death of this individual, we continued to talk with the daughters and videotaped an interview in which they shared their perspectives on the case. The daughters consented to be videotaped and to share the video with the medical community (available in online version of article). Their forceful devotion to their mother and their search in retrospect for what could have been done differently has completely changed our understanding of events. We believe that the daughters’ behavior is not the indefensible breach of respect for person that it seemed to be. Their mother’s true wishes might well have included a desire to help her children during her own dying. Family members’ preferences are likely to be important considerations for many people, although the possibility of coercion has to be acknowledged as well. Accommodating this level of decision-making complexity is highly problematic for our understanding of advance directives.

Mrs. GF was an 83-year-old woman with diabetes mellitus, hypertension, stroke, coronary artery disease, amputation, heart failure, renal insufficiency, chronic bronchitis, cholecystostomy, and biliary drain. For several years in our Program of All-Inclusive Care for the Elderly day health center, she had consistently expressed her wish to forgo intubation and attempted cardiopulmonary resuscitation and had completed, then reconfirmed the

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relevant documents, the legal advance directives. She designated her elder daughter as healthcare agent but asked that our discussions not be conveyed to her.

She presented to her primary care clinic acutely ill and was promptly taken to the emergency department (ED) with her advance directives. She appeared septic. ED personnel asked the family for permission to intubate and available family (two daughters) agreed, although all were aware of the patient's previously expressed wishes. Overhearing a daughter and the ED physician planning for intubation, the patient appeared to understand the situation clearly; she became agitated, moving her index finger back and forth to signal "no" and making sounds like "nuh-nuh." Despite this, she was intubated and admitted to the intensive care unit (ICU).

The primary care physicians (PCPs), ICU staff, and hospital ethics committee met repeatedly with the family, who insisted on continued ventilatory support and, if cardiac arrest occurred, an attempt at resuscitation. When it became medically necessary, the family did not refuse hemodialysis. After 22 days of highly burdensome treatment, when her daughters asked her, the patient clearly indicated her desire to be taken off the respirator, then mouthed clearly, "I love you" to her daughters. She was taken off the ventilator and died peacefully within an hour.

ADVANCE DIRECTIVES

Her PCP had interviewed Mrs. GF 1 day before her final hospitalization. In a well-documented conversation, and in several prior similar conversations, the patient had stated, "I don't want extended medical treatment or a breathing machine. My sister was on the machine. I don't want any of that. … I do not want you to tell my daughters because they would not understand."

The PCP later said, "We believed that our patient knew what she was talking about and expressed a genuine preference for how she wished to be treated. We completed all the necessary formalities in documenting her wishes to forgo intubation and attempts at resuscitation. We completed her do not resuscitate/do not intubate [DNR/DNI] forms and the emergency medical service forms, which are legally valid in the ambulance and ED."

Interviewed after the patient's death, the daughters saw this process quite differently. Daughter E (a nurse's aide), remembered: "About a month before it happened, me and her were sitting in the living room, and she told me, she said, 'Emma, please don't ever put me on a respirator, life support, anything. I don't want none of that.' I was just like, 'OK, Mom.' You never think [that something like this would happen]. 'That's OK, Mom, you'll be OK.'"

Daughter P, a telemetry technician, said, "Few years ago, I went to her house and she had a DNR/DNI form on the refrigerator. I said, 'Do you know what this is? If you have this on your refrigerator and someone walk in here, and you pass out and 911, the ambulance come in here and they see this form on the refrigerator, they are not going to try to bring you back if you are dying, you are just going to die because you got this form here and you already signed this form. This is what this form is. You do not need this.' I took it off the refrigerator and tore it up. They do not explain to you in English what is going on, and these little old people do not understand. They should explain it in a way that they do understand and know what they are talking about."

The primary care team felt they had accomplished an important task in protecting Mrs. GF from unwanted treatment. Her wishes were authentic, clear and convincing, thoroughly justified by the patient, and consistent over years.

The family members, absent during all of these discussions, did not believe that Mrs. GF knew what she was saying. These directives were purely abstract, addressing circumstances and events that are hard for most people to imagine. For these daughters, at least, it was clear that she had not understood the implications of her decisions, and it was their loving duty to interpret the decisions in context, on her behalf.

To believe that her primary care physicians were “correct” in this circumstance is to believe that Mrs. GF had developed and communicated immutable, comprehensive plans that envisioned and resolved all possible contingencies of her purely hypothetical final illness and death. This seems debatable; for example, would she have insisted that her children stand by and witness her death without potentially lifesaving treatment if this would impose significant suffering on her children?

To believe that her daughters were “correct” is to believe that Mrs. GF did not have the right to refuse potentially life-sustaining treatment or that she was unable or unwilling to exercise that right.

There is a third possibility. Perhaps within some families, the language of “rights” is not a good tool for making major decisions.[1–4] A mother might find it a highly desirable to act, perhaps even to sacrifice, to benefit another family member.[5–7] Perhaps the best way to honor Mrs. GF as a person was something other than enforcing her documented wishes or ignoring them. Several authors have discussed the weaknesses of the formal “advance directive” model and how difficult its implementation may be. One study describes problems for physicians and surrogates and shows how disagreement between the two sides can easily arise.[8] Another study suggests that individuals may want substitute decision-makers to have “leeway” in making these decisions, to consider family consensus, quality of life, and recommendations from professionals in addition to preferences that these individuals had expressed previously.[4] An important preference for Mrs. GF was the desire to avoid confrontation and conflict.

When confronted by the family on two different occasions before her terminal hospitalization, she did not insist on her rights. Complicating this approach, when talking with the primary care team, she had asked that her daughters be excluded from the conversation. In her last opportunity to respect her wishes in the ED, neither her family nor the ED physician acknowledged her wish to forgo intubation.

EMERGENCY DEPARTMENT

In the ED, Daughter E recalled, “The doctor approached me and said, ‘I need your permission to put her on the ventilator.’ I didn’t have time to think. I didn’t have time to think. You know, seeing her turning gray, I just said OK. I thought maybe if they put her on tonight, maybe she’ll come off tomorrow, and that’s the way I was thinking.”

Daughter P said, “I’m glad my sister made the decision to put her on, because my family got a chance, everybody got a chance to see her alive.”

The ED physician reported in retrospect that “[This case] falls into a gray zone, where, while the DNR/DNI orders remain respected, we are faced with a possibly reversible clinical condition. … At that point, it is difficult to stand there and let the patient slip away, knowing that ‘perhaps it is just a pneumonia that could be cured with antibiotics and a couple of days of life support. After all, this is why I am here, to help save lives and make people feel better.’ So in that moment, the DNR/DNI form may become a ‘relative’ item, and abiding by it might shake the sense of purpose of the ED physician, for whom this decision ends up becoming a suffered one, as we physicians come with our own cultural and religious background, education, and personal problems, which whether we like it or not, influence our decisions. So, if the patient comes alone, and no family can be reached, his or her DNR/DNI form will hold, but if a patient comes with family and is incapacitated, then the family makes the decision regardless of his DNR/DNI status, after the doctor has provided them with a rational and logical explanation. I must say that, as long as the patient was wagging her finger, she did not get any intubation. That came after she became unresponsive and because obviously her daughters were not ready to see their mother go. I am not denying or abdicating responsibility, but because of the sense of tragedy present, because of the courtesy I believe we owe another human being in that moment of tragedy, because there had to be a sense of closure for the family in that moment, I had to ask the question 'What should I do now? Do you want me to continue or should I stop?' And her daughters, with whom I had been able to establish very good rapport, decided to go on. Was that a bad decision, because retrospectively things did not work out? A bad decision because it was ethically wrong? What type of a decision would it have been if, three days later, she had been extubated successfully? I don't know the answer."

With the patient critically ill, the ED physician did not follow the "directions" of the nonverbal communication described above, nor did he adhere to her advance directive. Instead, he talked with her daughters and let them decide. Precisely what the daughters knew about their mother's advance directives, and when they knew it, is uncertain. For the daughters, the enormity of seeing their mother die abruptly was overwhelming, and prompt application of life-sustaining treatment during this sudden illness seemed natural, expected, mandatory. As Camus said, we are all "duped by our blind human faith in the near future."[9]

TWENTY-TWO DAYS OF INTENSIVE CARE

An ICU standoff arose promptly and was quickly exacerbated by events. An admission note stated simply, "This patient should have never been intubated as she clearly stated that she did not wish to be intubated. We will work with the family to soon correct this." The PCP was in close agreement. "We had respected Mrs. GF's autonomy prospectively—had planned in advance, completed the formalities, conveyed them with paperwork to the ED, and counseled the family. The actual situation was unusually clear—significant suffering with little chance of survival. Despite this, the family was focused on a set of completely different considerations. And here she was, intubated."

Daughter P reacted to this mind-set. "They're telling me 'She wanted to be on DNR/DNI, this is what your mom wanted; this is what your mom would have wanted.' I don't want to hear that. They don't know my mom like I know my mom." Daughter E also noted that "To me, it was confusing. You got one person on this night, another person on the next night telling you this and that. It's just confusing. …"

The daughters spoke dismissively of their mother's previously expressed wishes, to doctors who had never known Mrs. GF but who explained impatiently how she would have wanted to be treated. To make matters worse, the daughters asserted that "My mom would tell you something and come home and tell me a different thing," demonstrating the daughter's interpretation of Mrs. GF's unassertive personality.

Daughter E became uncertain. "In my mind, I was thinking, I didn't want to express it to anybody else, but I was feeling that it is my fault I made the decision to put her on the respirator. … A whole lot of times when I went in her room, she opened her eyes and looked at me, like she was saying 'You know what I wanted. Why is you doing this to me? Just let me go; I'm ready.' It seems like that's what came into my mind. It was just terrible, just terrible."

Despite being completely off of sedation by the second ICU day, Mrs. GF's capacity to make treatment decisions was the object of disagreement. She inconsistently opened her eyes, appeared to attempt to talk to daughters, and recognized and resisted the appearance of the suction devices.

Burdensome treatment continued. The daughters were under substantial pressure to allow discontinuation of life-sustaining treatment. The family gathered and visited. The prognosis became clearer as the days passed with suffering and without improvement. The family's opinion began to change. One daughter later reported that she had been moved by guilt. "Every time she looks at me, I feel she says 'why are you doing this to me?' "

On Day 22, the daughters asked the patient to blink twice if she wanted to be taken off the ventilator. Mrs. GF blinked her eyes dramatically, clearly reiterating her desire not to continue these burdensome treatments, and in this, her last clear communication to her daughters, she mouthed clearly to them, still intubated and after 22 days of potentially unwanted, burdensome treatment, that she loved them.

HOW CAN WE DO BETTER?

In the months after Mrs. GF died, the primary care team changed their approach to end-of-life discussions, including advance directives (code status and designation of health care agents). The role of the family is now regularly incorporated into routine discussions of advance directives. The medical team emphasizes to patients that family can be influential in how advance directives are implemented and that misunderstanding and thus family involvement in the planning may avoid or mitigate nonadherence to patient wishes. Patients are encouraged to have all family members present for conversations about advance directives, by telephone if necessary.

We acknowledge to patients and families that the patient may perceive physician values and biases, which may influence the patient's decisions. One study outlined the difficulties of creating a legitimate advance directive: the quickly branching decision trees, the pressure of time during clinical encounters, the general reluctance to plan for the specifics of dying.[10,11] Instead, that study describes the extreme instability that can occur in the moments when a patient might be dying while potentially lifesaving treatment is available. The authors recommend "that the objective for advance care planning ought to be the preparation of patients and surrogates to participate with clinicians in making the best possible in-the-moment medical decisions."

Another study has proposed that substitute decision-making should emphasize "authenticity" (a decision true to who the person really is) rather than autonomy that the patient cannot exercise.[6] This requires extensive knowledge of patients as persons, especially their values and interests, and allows agreement on "substituted interests." Then a "best judgment" follows, acknowledging that "patients make decisions in light of interpersonal relationships and cultural, religious, and other commitments." There is no "guessing what the patient would have decided." This patient-centered collaborative decision-making could have avoided the devastating observation that, "You don't know what my mother would want. …"

In this case, when sudden high-stakes decisions were required, and available information was limited, substitute decision-makers seemed to have acted without careful philosophical analysis; these daughters, of unquestioned devotion and some medical sophistication, somehow concluded that intubating their mother was the right thing to do. Had they been included in prior planning, a collaborative decision-making might have developed, as proposed by both previous studies.

If family members are not included in discussions, patients should be encouraged (and reminded) to share the specifics of their decisions with all involved family members. At annual visits, where advance directives are reviewed and updated, patients are again reminded and encouraged to keep family members aware of the directives and the underlying values. This process is carefully detailed in the medical record after every relevant encounter. Encouraging family participation can also limit the potential of the family to misunderstand the intent of those who helped establish the advance directives.[12]

Absolute reliance on formally correct advance directives is not what many patients say they want. A slight majority of terminally ill patients say they would prefer that a loved one make the decision, even if it contradicts a hypothetically “perfect”[13] living will. Many terminally ill patients say they prefer shared decision-making with loved ones and physicians.[6,14] This is tacit acknowledgment that they do not have fixed well-formed treatment preferences for the times when they are desperately ill and incapacitated.[12,15,16]

The final lesson learned is that medical providers should humbly accept the many limitations of advance directives and the inappropriateness of a legalistic model. Doing so with open-minded awareness and good will, rather than a fixed belief in the rightness and authority of an advance directive, physicians may find it easier to create an alliance with family members in seeking through dialogue how best to care for a vulnerable, perhaps dying, patient.

EXPERIENCE THIS STORY WITH HER DAUGHTERS

To further enhance this powerful end-of-life story, authors produced a video of this interview with the two daughters of Mrs. GF. This can be accessed online in the supporting information section.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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