The Trouble with Surrogates

The covid pandemic sent droves of patients, gasping for air, to my emergency department. Many of them were young and surprised to find themselves battling a life-threatening illness. Among other challenges, this crisis forced us to lean heavily on often unprepared surrogate decision makers who were forbidden from coming to the bedside to see what was happening to their loved ones. Some of these surrogates had agreed to the role ahead of time, but many were called upon without warning as the next in the line of succession by state law. We pressed these surrogates over the phone or outside where they waited in the parking lot for quick answers as their loved ones grew cyanotic and confused.

In the middle of all of this, I met Jane. Six months earlier, she'd had a CT that showed a large mass in her lung. As she stared at the images of the tumor and its destructive invasion of her spine, she decided that she wanted no part of biopsies, radiation, or chemotherapy. She enrolled in hospice and went home. She named her son as her medical power of attorney but did not complete a living will.

Jane spent most of her time alone. Her son worked two jobs and couldn't get by to see her more than once or twice a week. The hospice nurses checked in, but they could only stay for a short visit. Jane marked the passage of time with frozen meals that she microwaved and ate alone at her kitchen table. As the months passed, she grew thinner, and her pain grew fierce. She started thinking about what a relief it would be for everyone if she didn't wake up the next morning. At bedtime one night, she took a handful of Ativan–but not enough. The next morning, she awoke, despondent, and called her son. He called an ambulance.

Because she had attempted suicide, we needed time to assess her decision-making capacity. So, her son signed her treatment consent forms. He wanted her to be admitted to a psychiatric hospital. Under no circumstances should she go home, he said, and it was the hospital's responsibility to ensure her safety. He could not stay with her or care for her in his home. Then, he left to go to work.

This case ate at me for days. Jane was in a dark place, and her surrogate was overwhelmed, exhausted, and embroiled in his own crises. He could not be her advocate. Of the two of them, I felt Jane had better decision-making capacity, and she had just swallowed a whole bottle of pills.

End-of-life care was far simpler in the first half of the 20th century, when most patients died at home. Families were used to witnessing death. They understood the natural progression of aging and illness and were comfortable with the unraveling of life. Then, in the 1950s,

the polio epidemic filled hospitals with patients in respiratory failure (1). This crisis prompted physicians to improve the method of positive-pressure ventilation and, ultimately, led to the creation of intensive care units in the 1960s, with widespread use of mechanical ventilation for treatment of all sorts of airway and breathing maladies (1). However, this new technology erased the line between saving a life and prolonging suffering and death (2). At this, the dawn of critical care medicine, paternalistic physicians were reluctant to discontinue invasive medical interventions once they had been started (3). An article in *Time* in 1975 explored this controversy during the landmark case of Karen Anne Quinlan, a young woman kept alive by physicians in a

vegetative state despite her parents' plea to let her die peacefully: "Many regard 'pulling the plug' as an act akin to euthanasia, which is forbidden by both law and the medical code" (3).

The New Jersey Supreme Court ultimately decided in favor of the parents in the Quinlan case in 1976, allowing them to discontinue ventilatory support and prompting states to begin to write legislation empowering living wills (2). With this new case law on their minds, state legislators crafted their laws using legal jargon, perhaps neglecting to consider that at the core of these laws were regular people dealing with issues that were more medical than legal (2).

Once the living will laws took effect, problems with their narrow scope prompted lawmakers to enact new laws to empower designated surrogate decision-makers. Legislators chose to adapt the existing concept of durable power of attorney, originally developed and used in property law, for use in health care (2). With passage of this legislation, states intended to ensure patient autonomy (2). However, the documents—written in the language of law instead of the language of medicine—caused problems from the start, as the forms were difficult for patients to understand and often provided incomplete guidance to the medical team (2). Dr. Harry Perkins, an outspoken critic of advance directives, laments, "30 years of Herculean efforts to clarify, advertise, and distribute advance directives; to educate people about them; to encourage patients to sign them; and to teach faithful implementation by health professionals have yielded few successes but many disappointments" (4).

Though advance directives have been linked to significantly lower healthcare costs, wider enrollment in hospice, and fewer deaths in the hospital (5), studies estimate that only 7-42% of Americans have completed them (6). Researchers have identified numerous barriers to completion. People don't like to think about death, so they avoid doing so (4). Many people haven't heard about advance directives or have convinced themselves that they don't need them (4). Physicians have little time to engage patients in discussion (4). Patients find the legal language of the documents confusing and the requirements for completion too difficult (4). Those who are more likely to have overcome those barriers and completed advance directives are often older, white, more highly educated, wealthier, and report having a chronic disease and regular access to medical care (5).

Another challenge of end-of-life care decision-making is that many people do not understand that most patients in cardiopulmonary arrest will not recover (6). Television shows like *Grey's Anatomy* and *House* only deepen this misunderstanding, fictionalizing successful CPR 70% of the time, while CPR actually succeeds 37% of the time, with only 13% of patients surviving to hospital discharge (6).

Choosing the right surrogate isn't easy. Surrogates must recognize that the underlying disease or injury is causing death, not the removal of lines and tubes. They must understand the goals and values of the patient and have the stomach to decide what the patient would want, even when it differs from what the surrogates would choose for themselves. But surrogates "are not simply channels or psychic mediums;" they are regular people who are scared and confused and often find it unbearable to accept the impending death of their loved ones (7).

It's not surprising, then, that at least a third of surrogates report feeling a heavy emotional burden when faced with these decisions, sometimes interpreting a recommendation to withdraw life-sustaining interventions as being asked to kill (7,8). Family members who have had to make these decisions have used the words *difficult, intense, painful, overwhelming, devastating*, and *traumatic* to describe their experiences (8). One study found that the stress of surrogate decision-making was higher than that of involvement in ferry disasters, construction disasters, or house fires and that this increased stress plagued surrogates for months or sometimes years (8). It seems unfair and unhealthy to place this burden on surrogates, turning one sick person into two.

One study found that almost one in three patients wanted their doctors to make decisions for them, including 21.8% of patients who had already chosen a surrogate decision maker, prompting the author to ask, "Might reality force us away from a strongly patient-centered approach?" (7). We should not return to the paternalistic days of the Quinlan case, when physicians strayed from the path of beneficence, but is it good medicine to leave end-of-life decisions to poorly equipped surrogates such as Jane's? We must work tirelessly to improve communication among healthcare providers, patients, and surrogates. But patients will continue to arrive in the emergency department without advance directives. And, in many of those cases, the legally designated surrogate will fail to make informed and timely decisions about care, often defaulting to, "Just do everything." This approach does not achieve the goal of patient autonomy beyond the loss of decision-making capacity. Though physicians have historically been excluded from serving as surrogates due to concerns about conflicts of interest, it's time to reconsider our role in guiding care when a surrogate is unable or unwilling to be a strong patient advocate.

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