PALLIATIVE CARE
CASE OF THE MONTH

"Identifying the Surrogate"
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Case: Mr. Jones is a 92-year-old man admitted to the neuro intensive care unit with a large, right MCA stroke. His PMHx is remarkable for mild dementia, high blood pressure, Type II diabetes and benign prostatic hypertrophy. He has been living in a nursing home. Twenty-four hours, given the size of the stroke and his repeat CAT scan showing edema and a mass effect, you worry that he will need intubation. Given his incapacity, you are not sure who should serve as his surrogate. The nursing home shows a grandson as the person who should be called, but he is not answering his phone. Moreover, the nursing home says they have never seen him visit his grandfather. They report a partner comes by two or three times a week, but they do not know very much about her relationship. Given the confusion, both ethics and palliative care are consulted**.**

Comment: In the hospital, decisions for seriously-ill patients are often made by the patient's surrogate or proxy as the patient lacks decision making capacity. A 2014 JAMA article found that after 48 hours of hospitalization, 48% of older adults required at least some surrogate involvement, and 23% had all decisions made by the surrogate. Among patients who required a surrogate for at least one decision, 57% required decisions about life-saving treatment (code status), 48% about procedures and interventions, and 47% about discharge planning. Moreover, patients who need a surrogate were sicker and more likely to be in the ICU and require ventilatory support.

Health care decisions are deeply personal and often reflect a patient's values regarding what makes one's life worthwhile or how to balance quality of life versus quantity of life. For this reason, if the patient lacks capacity, clinicians must find a surrogate who can represent the patient's point of view. Clinicians often focus on finding the "one" person to speak for the patient. However, family members often make important, life and death decisions based on consensus. There are two reasons for this. First, individual family members may have different information regarding the patient's values or best interest. Second, the surrogate cares about promoting family relationships independent of any particular decision. (The way to figure this out is to ask, "How does your family typically make difficult decisions?") To keep "peace" in the family, a consensus is optimal, and the surrogate may hesitate on moving forward if a family member feels strongly. (The data suggests that most patients want their surrogate to have flexibility to promote these family values).

Deciding on the surrogate can be approached from a moral and a legal point of view, although hopefully the two methods will arrive at the same decision. Morally, the surrogate's primary job is to reflect the patient's values. Thus, the surrogate is the person who knows the patient the best and will most strongly advocate for the patient's values. While this may be family, it is not necessarily a family member (as in our case).

Legally, it is more complicated. If the patient has chosen a surrogate, obviously that person is the one who should serve as the proxy to make these decisions (this is also true morally). Unfortunately, less than one third of elderly Americans have a living will or a durable power of attorney. If the patient has not chosen a surrogate, the choice of a surrogate is typically legally mandated. The majority of states have laws which define who the surrogate should be. In Pennsylvania, the order is: spouse, adult children, parent, adult sibling, and adult grandchildren. There are, however, complexities. For example, if there is both a spouse and a child who is not a child of the current spouse (typically a child from one's first marriage), they have equal legal weight. Moreover, there is no ordering of adult children or adult siblings – typically, the assumption is that decisions will be made by consensus.

Obviously, these legal standards and the moral principles can conflict. For example, imagine a person who is estranged from one's adult children but has a live-in significant other for the last 10 years. While morally one might believe that the significant other is a better surrogate (e.g., knows the patient's values and will be better able to represent them) legally the children are the proxy. Often this can be resolved by talking to the children and asking if the significant other can be the surrogate ("Give how well XX knows your dad, how can we involve them in this process?") If there are conflicts in these cases, one should request an ethics consult and/or talk legal counsel to help choose a surrogate.

This possible conflict is one of the reasons it is so important to ask patients who they want to be their surrogate and to urge them to talk to their surrogate about their values ("Who would you trust to talk for you if you are so sick I cannot talk to you? Have you talked to them about what is most important to you if you should get sicker?). If this person is not the patient's spouse or children, you should make sure this is well documented in your note (depending on the family dynamics, having a legally valid durable power of attorney form filled out may be important). Also, you should advise the patient to tell their family about their surrogate choice so that should that time come, the family is not upset/surprised and does not contest their choice.

As important as the choice of a surrogate is, how one frames the discussion with the family also is very important. If the moral choice of a surrogate is based on their knowing and representing the patients interest, it is particularly important that one educate the surrogate regarding that role ("The reason we talk to families is because they know what would be important to the patient more than we do") and frame the questions to the surrogate,

Comment Continued: "If your dad was sitting here, what would he say," in a way that encourages the surrogate to reflect on the patient's values rather than focus on what they would want in a similar situation.

Resolution of the Case: While Mr. Jones' wife had died 20 years ago, and his grandson was estranged from him, he did have a significant other who visited him weekly in the nursing home. When the grandson was contacted, he deferred decision making to the significant other. Once contacted, she was quite clear about the patient's values (which emphasized quality over quantity of life) and the patient was extubated and died a few days later.

References:

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