



PALLIATIVE CARE CASE OF THE MONTH

“Undue Influence or Relational Autonomy? When Family Members Steer Medical Decisions”

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Case: Mrs. S is a 60-year-old woman with diabetes, stage IV chronic kidney disease, heart failure with an ejection fraction of 20%, and COPD. She has been admitted to the hospital for two months, initially coming in with pneumonia, but then suffered multiple other problems including rapid atrial fibrillation and acute renal failure now on dialysis. She has been transferred to the ICU several times and was intubated for about a week. She was extubated about four days ago and transferred to a regular hospital floor. The medical resident discussed code status with her, and she told him she would not accept intubation again. The resident entered a code status order of DNR/DNI; however, when her husband heard about this decision the next day, he persuaded his wife to agree to a “full code” order. When her husband is not there, Mrs. S tells the nurses that she is “sick of this” and “just wants to go home and die.” However, whenever her husband is present she expresses willingness to accept life-sustaining medical treatments. The nurses are distressed by this and feel that her husband is “bullying” her into accepting aggressive medical care, and this is not what she wants. The resident asks you to help get the husband to see that these decisions are his wife’s choice, not his. How should you approach this situation?

Discussion: Norms for medical decision-making have moved away from a paternalistic model over the past 50 years. We generally consider patients who have decision-making capacity to have the right to receive information about their medical conditions, including fatal illnesses, to provide informed consent for procedures, and to make the final decision about whether they would wish to have resuscitation attempted. In the United States, this is enshrined into law through the Patient Self-Determination Act of 1990, which requires hospitals and other facilities to inform patients of their right to participate in medical decisions, to accept and refuse treatment, to appoint a surrogate, and create an advance directive.¹

These rights are grounded in the philosophical concept of autonomy. One classic definition describes autonomous decisions as those that are “made intentionally and with substantial understanding and freedom from controlling influences.”² In some interpretations of this view of autonomy, the individual is seen as making decisions in isolation. Their priorities are their own, distinct from those of their family or community. The individual cultivates their own values and creates a life that actualizes those values. Thus, if a person has completed an advance directive stating that they would want comfort-focused care at the end of life, the ideal death is one in which those individual views are honored. With this view of medical decision-making, which is commonly applied in medical settings in the United States, some would interpret Mrs. S’s husbands

involvement in the decision about her goals of care as exerting an undue influence and obscuring the patient’s true values and priorities.

The interpretation that patient autonomy means that individual decisions must be based on the patient’s own values and needs alone has come under criticism from a number of perspectives. One alternate perspective is based on the concept of relational autonomy. Relational understandings of autonomy emphasize that an individual does not approach the world in isolation – rather, each individual is interdependent on social networks.^{3,4} One individual may have multiple social identities that are dynamically changing. In the real world, individuals take these social identities into account when making medical decisions, and often defer to the judgement of their family members. Studies of individuals with serious illness show that, when asked if they would want their surrogates to follow their advance directives strictly or to make the decisions the surrogates think are best, 50 – 80% of patients would want their surrogates to decide. While some patients request that surrogates decide based on the patient’s best interest and degree of suffering, often the patients’ reasoning includes concern for their family members’ best interest, including their emotional wellbeing and financial burden.⁵⁻⁸

The degree of family involvement in medical decision-making varies across cultures and ethnic groups. In a 1995 study of individuals in the U.S. from four different racial groups, 57% of Korean-Americans and 45% of Mexican-Americans believed that family members (not the patients) should make decisions about the use of life support, while 60% of African-Americans and 65% of European Americans believed that the patient should make those decisions.⁹ In China, the model of medical decision-making is based in Confucianism, which views individuals as inseparable from their family and community networks. Group decisions are thus the norm, and family harmony may be weighed as heavily (or more so) than individual preferences.^{10,11}

In the setting of serious illness, the relational aspect of decision-making may come to predominate, even if when the patient was making more independent decisions as a healthier person. When a hospitalized patient is within the foreign medical environment, surrounded by strangers speaking unfamiliar medical terms, family members may step in and adopt a protective stance to lessen isolation and advocate for the patient. Older and sicker patients who still have capacity to make decisions often become increasingly willing to have their surrogates take an active role in making decisions for them.⁶

Personal details in the case published have been altered to protect patient privacy.

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Discussion Continued

From the perspective of relational autonomy, final decision-making remains with the patient. However, illness is an interpersonal event. Patients not only seek the guidance of their loved ones in making decisions, but may even prioritize the needs of their family members more than their own needs, making choices that would not be their individual preference.¹² Clinicians caring for patients who are relying on family members to assist with decision-making should explore how the patient views the role of their family members, and how they prioritize their own needs and those of their family. Autonomous medical decision-making extends to individual choices about how influential patients allow their families to be. Many patients may be willing to allow their surrogate to adopt most or even all of the decision-making role, and that choice should be respected. However, if a patient is unhappy with the degree of influence their family member is exerting, the clinician might then explore the patient's willingness to renegotiate decision-making roles and offer to assist the patient in expressing their views in a family meeting with the surrogate.¹³

Resolution of the case: The clinician first met Mrs. S and her husband together and explored both of their understanding of her illness and the decisions that had been made. Mr. S expressed that he thought that the patient had not really been thinking things through when she stated that she wanted to limit interventions, and that she was a "fighter" and "not ready to give up." Mrs. S concurred. Later, the clinician returned when Mrs. S was alone to discuss Mrs. S's view of decision-making about her medical condition. The clinician described what the staff had observed, saying, "We are hearing when you are by yourself, you are expressing that you want to limit interventions. But when your husband is here, he seems to be the one guiding the decisions, and very much wants you to continue to accept interventions. Tell me how you want to approach making these decisions and your husband's input."

Mrs. S said that she and her husband had been married for 40 years, and that she knew he would have trouble managing emotionally if she died. In addition, he was always the dominant voice in their relationship, and used to the role of decision-maker. She acknowledged that she did not want to go back to the ICU and felt that she was ready to die. However, she felt it would be too difficult for both herself and for him for her to go against her husband in this decision. Therefore, though it was hard not to complain about the situation when he was around, she had no interest in asserting her right to make a decision independent of his view. The clinician and the patient discussed ways in which the palliative care team could continue to support her husband during his wife's serious illness. The clinician also met with the nurses and housestaff to help them understand that, though Mrs. S might express different preferences when alone, these were not preferences that she wanted to act on at this point.

She had decided to be full code based on long-standing roles in their marriage and on prioritizing his needs, and this decision should be respected.

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