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What Does She *Really* Want? Coercion, Persuasion, and the Family¹

Key Terms: Autonomy, Informed Consent, Surrogate Decision-Making, The Family in Medical Decision Making

Narrative

Mrs. L is a 50-year-old woman who was transferred to this tertiary care facility from a primary care hospital. She has a husband who visited frequently, if not daily. She also has several brothers and sisters but no children. Mrs. L is currently suffering from multiple external lacerations on her hands, chest, and groin area as well as kidney failure. These health problems are related to her long-term insulin dependent diabetes. She has suffered from diabetes since childhood but the complications and consequences of this illness have increased recently with a leg amputation being necessary about a year ago. She began dialysis shortly thereafter.

Mrs. L was transferred to this tertiary care facility to have the lesions biopsied for diagnostic purposes. The lesions were open, draining, and very painful to the patient. Initial work-up ruled out vasculitis as the causal agent. Finding the source of the lesions proved difficult and the hospitalization became prolonged as other complications developed. Mrs. L was in great pain and was placed on a sand bed and given a patient-controlled analgesia machine (PCA) to help provide relief. Despite these measures, pain continued to be a factor in the slow process of diagnostic testing.

After three weeks of hospitalization that included a variety of diagnostic tests and treatment of many complications including adjustment disorders and depressive moods, Mrs. L required surgery for perforation of gastric ulcers. She was placed in the Intensive Care Unit (ICU) post-operatively due to atrial fibrillation and she remained intubated. After six days in the ICU, she was extubated. The patient, however, refused to be suctioned by the nursing staff after extubation. She was transferred out of the ICU ten days after her admission to that unit.

Mrs. L began to ask the nurses to stop dialysis. These requests began about two weeks into this hospitalization and continued at intervals. Each time a request was made, a discussion would be held with Mrs. L, her husband, and the attending physician. In these meetings, Mr. L would often ask Mrs. L to change her mind regarding the dialysis or other tests she was resisting "for him." Each time, the request was granted by the patient after some resistance. On a couple of occasions, the patient agreed to further diagnostic work if her husband would be able to be with her through the test. The nursing staff became increasingly unnerved by the situation as Mrs. L would often continue to tell the nurses that she "really" wished to stop and "just wanted to die in peace." This particular wish was always superseded by the results of the patient-husband-physician conferences.

The patient and her husband grew tired of the long hospital stay. However, neither discharge to their home nor transfer back to the primary care facility near their home was ever seriously considered as a treatment option. At one conference, it was explained to the patient that transfer to another facility might entail some of the painful diagnostic tests being repeated. This information ended all further requests for transfer.

The Language and Issues of the Case

The stability of the patient's treatment wishes is clearly at issue. Because she wavers in her statements regarding her wishes, we are not sure whether to question her decision-making capacity or to focus on possible coercion by Mr. L. Several questions are clearly on the mind of the nursing staff:

1. Which of Mrs. L's wishes are her "real" ones, e.g., what she tells the nurses or those she agrees to in conference with husband and physician?
2. Is the patient being coerced by the pressures implicit in the conference discussions or are the wishes she expresses to the nurses "off the cuff" comments that should not be taken seriously?
3. Does family (e.g., Mr. L) have a legitimate right to have their views made a part of the treatment decisions?
4. Does the lack of diagnostic certainty mean that we should err in the direction of preserving life? Or, does the great suffering this patient has endured make her desire to stop treatment more important than the desire to diagnose and help the patient?
5. Should the lack of diagnostic certainty lead us to set a high threshold of patient competence before agreeing to terminate life-sustaining treatment?

Perspectives and Key Points of View

Mrs. L: Her views of treatment seem to vacillate somewhat depending on the degree of pain she feels, the level of optimism regarding restoration of health (i.e., relief from the lesions), and the parties she is addressing (husband or nursing staff). There is more we would like to know about her. For instance, when she asks her husband to be with her during diagnostic testing, is this because his presence makes the test bearable or because she hopes he will be persuaded by witnessing her suffering? Nevertheless, it is becoming clear that she does not find a life in the hospital, suffering greatly from the open lesions, to be valuable or acceptable.

Mr. L: He clearly loves his wife and his deep attachment to her is manifest by the amount of time he spends at her side in the hospital including helping her through difficult and painful diagnostic tests. There is a question being raised by the nursing staff as to whether he truly has her best interest at heart or is merely serving his own interests and fear of abandonment.

The Attending Physician: The physician initially hoped to make a quick diagnosis of the lesions and provide treatment to relieve this source of pain. As such, he had little trouble during the early part of the hospital course imparting hope to the patient and her husband and counseling that withdrawal of treatment be postponed in favor of diagnostic progress. As the diagnosis proved to be elusive, the physician began to worry that he has misled the patient and her husband. He, nevertheless, feared that the patient's wishes to stop dialysis may be temporary expressions of pain that pass when she is enjoying time with her husband.

It was also an initial hypothesis of the attending physician that some of Mrs. L's statements regarding the desire to stop treatment emanated from fear of abandonment and that she made these statements to elicit commitment from her husband. However, this hypothesis dissipated with time and the physician became increasingly concerned about how to reconcile the feelings of the patient and her husband.

The Nursing Staff: The nurses are convinced that they know that the patient "really" wishes to stop dialysis and die peacefully. The nurses believe that the physician should take the patient's statements to them as definitive of her wishes and not subject her to the "coercion" of the three-way conferences.

What Actually Happened

About five weeks into her hospitalization, Mrs. L remained adamant in her treatment refusals during the conference with her husband and physician. Mr. L then agreed to accept her wishes and agreed to stay by her during her death. The physician wrote a do-not-resuscitate (DNR) order and an order to discontinue dialysis. Palliative care continued to be provided. The patient died within forty-eight hours accompanied by her grieving husband.

Possible Alternative Endings

It is difficult to fault the course of action as it developed. A number of factors had to be balanced. It took time to be sure that there was little benefit that could be provided to Mrs. L and that her expressions of a desire to withhold treatment were stable and abiding. Some suggestions include offering her husband psychological or other services to process his grief and also some mention to Mrs. L of alternative facilities such as hospice care that might help her to achieve her treatment goals. Furthermore, once diagnostic uncertainty prevailed, investigating transfer back to the hospital closer to home may have at least made life easier for her husband for those weeks. It is difficult to understand why the patient and her husband received such pessimistic advice when they raised the issue of transfer.

Commentary

This case presents an interesting study in the concept of patient autonomy. This patient raises questions for the staff concerning her decision-making capacity as well as which statements should be considered her real wishes. Mrs. L's competence is at issue because the vacillation of her moods and wishes makes it difficult to know if her desire to cease dialysis is a fixed and abiding judgment based upon firm values. The persistence of wishes and values is an essential element of a fully competent patient (Buchanan and Brock 1989, 25).

The consensus on evaluating the capacity to consent to or refuse treatment emphasizes that we should set a high threshold when the risk to the patient is high and lower the standard when the risk is lower (President's Commission 1982, 60-62; Drane 1984, 1985; Buchanan and Brock 1989, 51-57). In this case, such reasoning seems to have prevailed. Early in the case, when the hope of alleviating the patient's pain was high, a higher standard was set. As the burdens of treatment become clearer and the hope of benefit fades, the patient's wish to stop treatment is taken more seriously. The physician also became convinced of the patient's firmness of opinion, the inclination toward honoring those expressions grew.

Finally, an important question concerns what exactly an autonomous choice is. Is it one which the patient makes after deliberating by herself or is it one made in community with the significant others that have always influenced us? Clearly, the way people test their momentary preferences and they come to reflect deeply held values involves their families (Nelson and Nelson 1995, 80-81; Kuczewski 1996). But some balance must be struck between "treating the family" (Macklin 1987, 131-148; Hardwig 1990, Nelson 1992) and submitting a vulnerable patient to familial coercion (Blustein 1993). In general, it seems as if the risk-related standard the physician employed in balancing these considerations was appropriate (Kuczewski 1996).

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¹ Versions of this case accompanied by variations in the commentary have been previously published in two venues: Mark G. Kuczewski, 1996. "Reconceiving the Family: The Process of Consent in Medical Decisionmaking." *Hastings Center Report* 26(2): 30-37; and Mark G. Kuczewski, 1997. *Fragmentation and Consensus: Communitarian and Casuist Bioethics*. Washington, DC: Georgetown University Press, pp.143-144.