

## To Continue or Discontinue Treatment: What Should Families Consider when Deciding for an Incompetent Patient?

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Letting go of someone you love is never an easy task, under any circumstances. Surrogate decision-making for ending the life of a beloved one is perhaps the toughest of all. In the absence of a living will from incompetent patient, family members are considered the best option for this decision-making,<sup>1</sup> as they (presumably) *know* the patient's preferences, and they would (presumably) *cogitate* the patient's interest as the "only" consideration in the decision-making process. Both the presumptions are arguable; however, they pose the two most important questions for the families to consider while deciding for an incompetent patient: 1) what would the patient have wanted under these circumstances?; and 2) which option is in the best interests of the patient? The two questions need to be approached in different ways: the first can only be answered by someone who knows the patient well enough to understand her values and preferences in life; the second requires complex scientific details regarding prognosis, options and associated sufferings for the patient (without any consideration for sufferings of others). Most families would keep both considerations while making the decision; however, information regarding one may take precedence over the other.

The given case seems to have multifactorial interrelated issues. What the patient would have wanted is not clear as she had given conflicting statements previously, which are likely to be desperate. The patient's spouse, as the first choice for surrogate,<sup>1</sup> is weak and hesitant in decision-making, plus there is an element of conflicting interests in his approach towards the patient's care, considering the continuity of disability pension while the patient is alive. Would his wife also want the same for the benefit of her family?

A daughter, compared to sons, is generally considered to be emotionally closer to the mother. However, in this scenario the only daughter is unwilling to participate in the process of decision-making. (Does she know something about her mother's wishes that she does not want to share with others?)

The eldest son, though not living with his parents, nevertheless, is willing to make the decision (probably filling in for his undecided father). The younger son is incompetent to undertake decision-making.

The complexity of family situation is not uncommon, especially in Eastern societies where individuals face difficulty in bearing the burden of decision-making and decisions are reached by the whole family as a unit, guided by the "functional-head" of the family.<sup>2,3</sup> The situation gets worse if a family's main decision-maker becomes incompetent and the rest of the members unexpectedly find themselves in a plight to make decisions. Under such circumstances, the family can be encouraged to discuss their concerns, values, fears and their perceptions of what the patient would have wanted before collectively coming to an appropriate decision. The process can be facilitated by the attending physician.<sup>4</sup> The process of collective/shared decision-making in resolving issues during end-of-life care has shown to be effective and satisfactory for the family as well as the physician.<sup>3,4</sup>

The role of the attending physician is extremely significant in facilitating the process of decision-making, whether individually or shared.<sup>5</sup> Moreover, in many societies (in Asia, Eastern Europe and Russia), physicians are culturally assigned an authoritative position of respect and reverence.<sup>6</sup> Also, they may have more directly relevant information regarding a patient's wishes about end-of-life care than any family member, as evident in this case also. Patients and their families have high expectations from them to provide recommendations in addition to factual information to help families in decision-making.<sup>3,7</sup>

The question "What would the patient have wanted?" can be technically challenging in the context where patient has previously shown more than one aspiration. Especially in societies where benefits of the family as a unit supersede the individual's best interests, a patient may want an option which is not "the best" for her but harmonious for the unit. Decisions in such circumstances can be extremely difficult.

To resolve issues like the one at hand, the role of physicians and ethics committees become central in facilitating discussion within the family unit. The family members need reassurance and confidence regarding diagnosis, treatment options and their role in the process of decision-making. On the other hand, the family members themselves need to open up and put forth their queries, fears and insecurities. Families should consider what is best for the patient in her condition, given the available options of treatment.

## Notes

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