

The patient's son acknowledged that there was a chance that his father might recover, but he gave more weight to the possibility that further treatment would only make his father's death more protracted and painful. He also stated that his father was reluctant to undergo chemotherapy and was "pressured" to do so by his family.

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## **Commentary: Interpreting Patient Wishes**

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The situation presented in this case highlights the difficulties involved in interpreting patient wishes. Healthcare professionals have ethical and legal obligations to respect a decisionally incapable patient's previously expressed wishes when it comes to treatment decisionmaking. However, a lack of clarity in how those wishes ought to be interpreted can lead to confusion about their applicability under particular circumstances. My commentary explores this tricky issue through the case presented here and concludes with suggestions for the management of such situations.

Within the context of North American medical practice, a decisionally capable patient's informed refusal of a proposed treatment is widely accepted as sufficient reason not to proceed with that treatment. U.S. legal precedent over the last four decades is clear on this issue. In the Karen Ann Quinlan and Nancy Cruzan cases, the courts have reaffirmed the right of patients to forgo life-sustaining medical treatments against the opinion of their healthcare providers.<sup>1</sup> These cases also illustrate that a similar stance applies when it comes to proxy decisionmakers acting on behalf of the patient. If a proxy decisionmaker is acting to carry out a patient's previously expressed wishes regarding

the discontinuation of treatment, healthcare practitioners have a *prima facie* obligation to treat those decisions as if they were direct patient requests.

In the case presented, we see a patient who is in a fragile state of health following apparent successful treatment for acute myelomonocytic leukemia. The patient's son, who is acting as the patient's healthcare proxy decisionmaker, informs the medical team that his father would not want to be "kept alive in a debilitated condition or undergo needless suffering." The son presumably believes that, taken together, his father's current state, the attending physician's guarded prognosis, and allegations of abuse in the home environment necessitate the application of his father's wishes to the current situation; in other words, because his father is already in a debilitated condition, any further attempts to prolong the patient's life would only prolong needless suffering.

A major difficulty in this case revolves around a number of uncertainties in how to interpret the patient's wishes. One such uncertainty is how to understand the patient's request not to be kept alive in a debilitated condition. One might ask whether this wish was meant to apply in situations in which the debilitated condition may be a temporary state on the route to a full or partial recovery, as is being suggested by the attending physician. It is difficult to determine what the patient had in mind with this wish without further contextual information. A "reasonable person" standard of interpretation would

suggest that this wish was not intended to apply to conditions in which a realistic chance of recovery exists. A further exploration of this issue with the patient's family and friends might help to clarify the issue in a more direct manner.

An additional source of uncertainty resides in the value-laden language embedded within the patient's wishes. Terms such as "debilitated," "needless," and "suffering" only have meaning within the context of what the patient finds important. Without insight into what the patient thinks is valuable, we risk misinterpreting which sorts of conditions meet the threshold for these three terms. A meeting between the family and the care team could be held to explore the patient's values. Part of this meeting could also be devoted to setting more concrete goals of care that reflect the patient's values. If successful, these efforts could help translate the patient's presently nebulous value-laden wishes into definite clinical goals.

Another issue to note is the son's allegation of abuse and coercion. If they indeed have merit, these are concerns that will need to be addressed by the care team and the proper authorities. Nevertheless, these concerns will not ultimately impact the decision regarding the continuation of treatment for the patient. An abusive home environment is most appropriately addressed at the level of discharge planning rather than bedside care. If abuse is occurring within the hospital, this is an issue that hospital security can attend to. Regardless of whether or where the abuse is occurring, addressing this problem does not require shifting the patient from treatment to comfort care.

The possibility of undue coercion on the part of the family is also concerning in that it may have undermined the ability of the patient to give proper consent to his prior treatment. However, it is difficult to assess how this impacts

the decision at hand. For the issue to become a consideration in this discussion, substantial proof would be required showing that the patient was unduly blocked by his family from pursuing comfort care over chemotherapy. Lacking such evidence, the presumption must be that this was an autonomous and free decision on the part of the patient.

Assuming all the uncertainties mentioned above are clarified, a tricky dynamic still remains to be addressed. This is the issue of how to balance a meaningful chance of recovery for the patient against a possibly needless prolongation of the patient's suffering or death. In our scenario, the attending physician is focused on the former and the patient's proxy decisionmaker on the latter. With no true bright line distinction separating where hope for recovery ends and needless suffering begins, this issue can be a flash point for conflict. A strong therapeutic alliance and open communication between the care team and the family can help mitigate the effects of disagreements. In the event that disagreements persist over how to proceed with treatment, a negotiated agreement between the involved parties may be required.

Although the outcome of the case highlighted here will largely be shaped by the particular interactions between the care team and the family, some general suggestions can be made about how to approach the situation at the level of process. A good initial step would be to clarify the implicit value assumptions at play for both the care team and the family. This could dispel some of the confusion concerning how to understand the patient's wishes for end-of-life care. A meeting involving all the stakeholders might be a good venue for this elucidation of values and has the possible added benefit of fostering mutual understanding between everyone involved. If these efforts fail to

resolve the situation, a negotiated plan of treatment may be necessary. The aim of these efforts should be to set an acceptable trial period for the continuation of care. Presently, the attending physician feels that it is still too early to rule out a recovery for the patient. Unless there is strong reason to believe that the patient would not value a recovery of the sort described by the attending physician, treatment should continue. However, the parties involved must remain cognizant of the patient's desire not to have the dying process extended unnecessarily. A definitive end point to the trial should be set, at which point all the stakeholders can reevaluate whether the treatments have been efficacious in meeting the patient's goals of care.

#### Note

1. See *Re Quinlan*, 70 N.J. 10, 355 A.2d 647 (NJ 1976) and *Cruzan v. Director*, MDH, 497 U.S. 261 (1990).

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### Commentary: The Need for More Questions

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This case is a good example of why it is important to investigate cases thoroughly before making recommendations. On an initial read-through, a few things stand out: (1) according to the attending physician, there is a significant chance that the patient will not recover, and (2) according to the patient's son, the patient would not want to undergo needless suffering—indeed, he did not want to undergo chemotherapy to begin with. If he's not likely to survive, treatment causes suffering, and he did not want to suffer, what's the dilemma? Let him go! And while that may wind up being appropriate, there are many

questions that need to be addressed first.

Acute myelomonocytic leukemia is a cancer that is considered especially curable (albeit predominantly for younger patients), but the treatment for it is punishing. The patient's son should be asked what he understood his father to mean when he said he did not want to be kept alive in a debilitated condition or undergo needless suffering, as well as what he has in mind by stopping treatment. On only day four after completion of chemotherapy, he is not yet being *kept alive* in a debilitated condition. (However, if there is a good chance that he will not recover, he might be undergoing needless suffering.) The state he is in now is not unusual for this point in the course of treatment; that is, this situation should have been part of what the patient agreed to when he consented to chemotherapy. Does the son know this? Perhaps more importantly, does he know if the patient knew this?

Moreover, the attending needs to explain why there is a significant chance that he will not recover. Was this expected? If so, what led to the decision to try this course of treatment? Alternatively, has the patient not responded as well as expected, such that things look worse now than they did when the patient made his decision? If so, some prognostication is owed to the son. Acknowledging one's own epistemic limits is a virtue, but the attending has a better idea of reasonable parameters than the family does and should be transparent about her expectations. It is not clear whether the attending is also the oncologist, or perhaps a hospitalist or intensivist. Certainly, if the attending is not the oncologist, the oncologist should be consulted, and any discussions the patient had with him or her should be taken into account. The son says his father was reluctant to undergo chemotherapy but was pressured by the