CASE 3

Ethical Considerations in the Risk-Benefit Analysis for Patients with Diminished Capacity

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PRESENTATION

Ms. Y is a 64-year-old woman who presented to the Emergency Department (ED) with chest pain, shortness of breath and a history of fainting. She consented to admission to a medical unit. She was diagnosed with aortic stenosis, presumably severe. The clinician recommended that Ms. Y receive cardiac catheterization for a more precise evaluation of the aortic valve, as well as to assess any narrowing of the coronary artery, and likely undergo aortic valve replacement surgery. Ms. Y told the clinician she was not interested, but would take her vitamins and be fine. When the clinician explained that her prognosis without surgery to replace the aortic valve was not good, Ms. Y indicated that toxins were poisoning her home. When pressed for details she was non-specific, except to say that to avoid the toxins she had been living in her car and in hotels for the past several months. Concerned that she lacked capacity to give informed consent, the staff suggested Ms. Y remain in the hospital to receive appropriate psychiatric evaluation, to which she readily agreed. Upon assessment, the psychiatric team determined that Ms. Y lacked sufficient capacity, due to a psychotic illness, to make her own decisions regarding her aortic stenosis, her psychiatric illness, and related treatment recommendations. Ms. Y continued to decline all interventions and requested to leave the hospital.
Ms. Y allowed the care team to contact her family, a brother and sister. After she again refused all interventions, the family indicated to the care team that they felt there was an obligation to save Ms. Y's life by performing the cardiac catheterization and subsequent valve replacement, even without her consent. In their view, Ms. Y was a danger to herself because of her delusion about toxins, and they believed she needed to be held in the hospital if necessary and be treated. At the very least, the family believed the care team should try to modify Ms. Y's delusions. They stated that they would sign any necessary consent forms, even if that meant they had to obtain legal guardianship.

For their part, the cardiac surgeons were reluctant to move forward without the cooperation of the patient. Although they were not confident that good postoperative management was possible with a patient unlikely to cooperate, they wondered if they should go ahead with the surgery anyway, given the risks posed by her condition if not addressed surgically. The surgeons were not sure whether not operating was abandonment of a vulnerable patient, or if doing surgery without her cooperation was justified given that it might be harmful. The psychiatric team recommended a trial of antipsychotic medication, which the patient adamantly refused. Injectable medication was considered, but it was anticipated that she would require restraint for administration. The treatment team's assessment was that the patient would be frightened by physical restraints and that the ensuing stress could precipitate a cardiovascular event. After listening to one another's concerns, the care team and Ms. Y's brother and sister agreed to seek assistance from the bioethics consult team.

**BIOETHICS RECOMMENDATION AND CHART NOTE**

On the recommendation of the bioethics consult team and the care team, the patient's family agreed on the use of a decision-making algorithm (figure 1) developed for ethically managing patients who are unable to give informed consent and are refusing recommended treatment. Once a lack of capacity has been determined, the algorithm helps surrogates and health care providers consider the potential safety or feasibility impact of a lack of cooperation on the risk-benefit equation. Similarly, the algorithm also helps surrogates and providers consider the potential negative impact of forced treatment on the patient's personhood, and to balance that consideration as well in the risk-benefit analysis.

**REASONING**

Many patients cannot grasp the significance of their illnesses or give adequate consideration to the medical options presented to them. They lack decision-making capacity, and reliance on surrogates is necessary. When providers and surrogates consider the risks of a procedure or treatment, the focus tends to be on such things as the risk of infection or bleeding in the case of surgery, or on potential side effects of medication, including weight gain or depression. In this article, we call attention to additional potential risk in the form of suffering or harm that may arise in patients who are unable or unwilling to cooperate, and on potential suffering or harm that patients may experience as a result of treatment being forced on them.

An algorithm that raises key ethical concerns can help find this ethical balance between not doing enough and causing unintentional harm. The algorithm proposed here reflects the ethical conviction that respect for a patient as a person means treating individuals as autonomous persons. If the person has diminished capacity, not only does he or she deserve the opportunity for treatment to be considered, additionally careful consideration of the inadvertent but potentially harmful side effects of treatment is required. The values of patient-centered care may help us
understand the many ways a patient may suffer or be harmed by challenging us to appreciate the patient’s world view, values, preferences, and expressed needs “through the patient’s eyes” and to work in partnership with the patient.\textsuperscript{3} Harm may not only be caused by the physical or emotional side-effects of treatment, but also from the potential adverse impact that may occur if a patient resists or refuses to cooperate with treatment, including, for example, post-operative rehabilitation. In addition, a patient may be harmed by the experience of forced treatment. Assuming that a previously impaired patient regains capacity, it cannot be taken for granted that the now-capacitated person will agree with and be thankful for the treatment focused on him or her during the period of incapacity. The patient’s “personhood” may suffer harm by forced treatment, and this injury may not be healed simply by restoration of capacity.\textsuperscript{4}

The proposed algorithm begins with a team-oriented assessment of the patient’s capacity to make health care decisions. Due to the complexity of cases such as this one, this assessment should be performed by a psychiatrist, to determine whether this patient has

1. communicated a choice;
2. demonstrated a sufficient understanding of the illness, treatment options, risks, and benefits of the proposed treatment and alternatives;
3. demonstrated sufficient ability to deal with the complexities of this particular situation and its potential consequences; and
4. explained his or her decision in such a way that a logical basis for it may be discerned.\textsuperscript{5}

The patient should be given every possibility to demonstrate sufficient capacity necessary, in light of the potential benefits and risks of his or her situation, before moving toward the substituted judgment of a surrogate. Maintaining the patient-family-treatment team alliance is paramount as these challenging issues are worked through. Depending on the requirements or standards of particular jurisdictions, a judge ultimately may need to determine whether capacity is impaired and, if so, to appoint a surrogate. If sufficient capacity exists, informed refusal should be respected. In this case, the use of the algorithm reaffirmed that Ms. Y did not possess sufficient capacity to make the decisions needed in this situation.

When sufficient capacity does not exist, the algorithm recommends an assessment of whether the patient is likely to be cooperative or non-resistant. If the answer is “no,” avenues of persuasion and treatment should be sought, in an effort to allow the procedure to ethically proceed, on the assumption that cooperation will help ensure success and not introduce additional risks inherent with non-cooperative or combative patients. If the patient is unlikely to cooperate or to be at least
non-resistant, or if there are no persuasive influences that can be successfully brought to bear, as was the case with Ms. Y, the algorithm recommends assessing whether proceeding without patient cooperation is safe and feasible. If the surrogate and clinicians determine that the risk of a lack of cooperation together with all the other risks carries such a hazard as to outweigh the benefits of the procedure, the procedure can be ethically omitted. The ethical principle of not doing harm to a patient—non-maleficence—should be respected whether or not a patient lacks capacity.

If proceeding without assent or cooperation is determined to be safe and feasible, the algorithm then recommends a final assessment: What is the likely harm that may come to the person of forced treatment, or what is the likely impact on the patient’s ability to cope with life generally? Whatever may be the objective assessment of the patient’s clinical best interest, the patient still will be required to cope with what has happened. Here the insights of surrogates are essential. The clinical outcome may be that patients like Ms. Y benefit from treatment in the form of mitigation of illness or survival as a result of forced treatment. The ultimate reality, however, may be that we create a situation of human suffering if the patient’s quality of life is substantially diminished or the patient is harmed by the treatment.5

If at this point the surrogates agree that the impact of proceeding with treatment on the patient’s ability to cope with life in general will be a negative one with likely personal suffering, which is assessed to be more important than the estimate of benefit that is expected to come from treatment, it is ethical for the care team to recommend and the surrogates to agree to not proceed with the proposed treatment. On the other hand, if it is concluded the impact will be minimally negative or only negative for the short term, it can be ethically appropriate to create a care plan to proceed. Such a plan should entail checks and measures to ensure that previous assessments, such as that the procedure can be performed safely, were accurate. It may be necessary to withdraw from a care plan for which clinicians or surrogates misjudged the good.

After careful consideration of the concerns in this algorithm, a consensus was reached by the care team and surrogates that it would be best to try to manage this patient medically, without surgery, as best as possible. Within hours, she experienced a cardiac arrest while hospitalized, received CPR, was intubated and admitted to the intensive care unit (ICU). After emergency treatment, stabilization, and extubation, she requested to be discharged from the ICU, adding “if surgery means going through anything like that,” she was definitely not interested. This reflection on her experience suggested to the care team and surrogates that she was capable of appreciating the harm that could come from major surgery that might very likely include a repeat experience of intensive care treatment and intubation, and was helpful in re-affirming the care team and family’s conclusion that not forcing surgery was in her best interest.6

References