

Summary of Ethics for Lunch – September 20, 2022

Determining the Appropriate Authorized Decision Maker

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The September Ethics for Lunch presented the case of an elderly man with advanced heart disease who lacked decision-making capacity and his health care team needed to determine who his authorized decision maker should be between his significant other and his children. The case provided an opportunity for the panel to review the process for determining an authorized decision maker and the requirements of the Health Care Decisions Act with respect to decisions by authorized decision makers about life sustaining treatments.

Key points:

1. If a patient is admitted to the hospital and lacks decision-making capacity or is at risk of losing capacity during the hospitalization, one of the first steps is to inquire whether they have ever completed an advance directive (either written or oral).
2. To determine the appropriate authorized decision maker if the patient does not have an advance directive, the team needs to rely on a good psychosocial history, which includes whether the patient:
 - a. is married
 - b. has a significant other (AKA fiancé, partner, boyfriend, girlfriend, friend) and whether they live together
 - c. has adult children (biologic or adopted), and if so, how many
 - d. has adult siblings (biologic or adopted), and if so, how many
3. Sometimes a patient will have a complex social circle and families may be defensive as to why relationships are being asked about.
 - a. It is important to explain why the team is asking about family dynamics.
 - b. Informal kinships need to be teased out to determine where a person stands in the legal hierarchy of decision makers.
4. From a legal standpoint, before moving to an authorized decision maker, it is important to confirm there is appropriate documentation in the medical record that the patient lacks decision-making capacity.
5. An oral advance directive can be created by the attending physician in the presence of a witness. The documentation must then be available for future use in other care settings.
 - Naming a health care agent requires some degree of ability to weigh the pros and cons of choosing a particular person as the agent
6. If a family member or friend claims to be a health care agent, it is important for the attending physician and health care team to see the document to confirm the designation by the patient. It needs to be verified that the advance directive is valid (e.g., appropriately witnessed).
7. In the absence of a health care agent, the priority list of legal surrogate decision makers is:
 - a. A legal guardian appointed by the court
 - b. A spouse or domestic partner (cannot have both). If a significant other claims to be a domestic partner, the team accepts this without additional evidence unless someone challenges this

- c. Adult children, all of whom have equal authority under the law. Attempts should be made to contact all adult children. If a child is estranged from the patient and defers to their siblings, this is acceptable.
 - d. The patient's parent(s)
 - e. Adult siblings
 - f. A relative or friend who completes an affidavit indicating how they know the patient, how long they have known the patient, and the nature of their relationship (i.e., familiar with the patient's health and beliefs).
8. Sometimes the person authorized to be the surrogate decision maker based on the legal hierarchy may not be the person most familiar with the patient's life and health condition. This can cause distress within the health care team, which must balance supporting the law and encouraging collaboration with other family members who may be more intimately involved in the patient's life. This can be important to keep the patient's voice at the center of the decision-making process. The goal is to have everyone invested in the care of the patient.
9. Chaplains in spiritual care can serve as a mediator or navigator in crisis situations. The psychospiritual assessment starts with how important faith is in the patient's life and what differences exist between the people in the patient's life. The chaplain can help the family reach consensus and get everyone on the same page.
 - Examples of complicated scenarios include:
 - 1) a patient who has a significant other but is not formally divorced
 - 2) a surrogate decision maker who does not want other family involved in decision making or getting information about the patient's condition
 - 3) families with multiple decision makers who do not agree on a plan
 - 4) children from previous relationships who do not agree with children from more recent relationships
 - 5) surrogate decision makers who are not readily available (e.g., live out of town, live out of the country, or are incarcerated)
 - 6) a patient with enough capacity to express an interest in marrying their significant other, which would change the decisional and financial status of adult children
10. Even though a patient may lack health care decision-making capacity, they may still be able to communicate wishes, needs and/or preferences, and it is important to still take account of these and not disregard them completely.
 - For example, for an incapacitated patient who is saying they want to go home, the authorized decision maker should be encouraged to take this into account when making decisions on their behalf
11. Authorized decision makers need to be available to participate in decision making. It is important to have contact information for all decision makers on the same level of the legal hierarchy. Efforts should be made to find times when an authorized decision maker is available (e.g., perhaps they live in a different time zone or are working during the day).
 - a. It is important to document when and how the clinical team tried to contact the authorized decision maker
 - b. If an authorized decision maker is not reachable by phone, then it may be necessary to send registered mail
12. An authorized decision maker who does not wish to participate in decision making cannot name who they want to be the decision maker. If they decide not to serve in the role, then the clinical team goes by the next person in the legal hierarchy to determine the surrogate decision maker.

13. It is important for the health care team to convey what it means to be an authorized decision maker (either a health care agent or surrogate decision maker). It is an important task that has consequences for the patient's outcome. They have to be educated about what the role entails.
14. The decision-making process takes time, even though there can sometimes be a feeling of urgency in trying to reach a decision.
15. Authorized decision makers are often put in these situations under heightened stress and pressure, and this may be in a background of complicated family dynamics, which the team may get swept up in.
16. Being an authorized decision maker for medical decisions (or deferring to be one) does not have any bearing on other issues such as responsibility for the hospital bill, what happens to the patient's property if the patient dies, how organ donation decisions are made, etc.
17. Some authorized decision makers will have difficulty making decisions because they feel the weight (or burden) of being responsible for making decisions (such as withholding life-sustaining treatment). Their burden can be eased by the health care team providing recommendations and guidance based on their experience and expertise; in that way, the team is sharing the burden with the authorized decision maker.
18. For decisions to withhold or withdraw life-sustaining treatment, surrogate decision makers can only make these decisions if the patient is certified to have a terminal illness, end-stage condition, or persistent vegetative state. Health care agents can make these decisions even if a patient does not have one of these certified conditions.
19. When there are multiple surrogate decision makers with equal authority and there is disagreement between them, the goal is for them to reach consensus (perhaps with the assistance of the ethics consult service), not that the majority vote wins.
20. In trying to resolve disputes, the clinical team should base their recommendations on the standard of care.

References:

1. The American Bar Association, Commission on Law and Aging In Collaboration with The Maryland Office of the Attorney General. Making Medical Decisions for Someone Else: A Maryland Handbook. <https://www.marylandattorneygeneral.gov/Health%20Policy%20Documents/ProxyHandbook.pdf>
2. Making Medical Decisions for Someone Else: A Guide for Marylanders: https://www.marylandattorneygeneral.gov/Health%20Policy%20Documents/Proxy_guide_brochure.pdf
3. [Office of the Attorney General](#). Health Care Decisions Act: Text and Educational Materials