Summary: Ethics for Lunch May 17, 2022
Challenges in Surrogate Decision Making

Panelists: Mark Hughes, MD, MA; Lourdes Carhupoama, MS, CRNP, CCRN; Jeffrey Natterman, Esq; Mollie Selmanoff, LMSW, CCM

The May Ethics for lunch focused on the role of surrogate decision makers. The majority of patients cared for in an intensive care unit will require the involvement of a surrogate decision maker. Patients can complete an advance directive to name a health care to be their authorized decision maker, but less than 30% of people complete advance directives. Even with an advance directive in place, surrogate decision makers have to interpret the document in light of the in light of the current clinical circumstances and what the future might hold for the patient.

The panel used illustrative cases to highlight some of the challenges encountered in surrogate decision making. Key themes included:

1. If a patient informs clinicians that they have completed an advance directive or appointment of a health care agent, the first step is for the team to review it with the legal department to ensure it is a valid document (i.e., in accordance with the jurisdiction where it was completed or in accordance with Maryland law).
2. For appointment of a health care agent, it should be clarified when it becomes effective—is it immediately or is it only when the patient loses decision-making capacity?
3. An advance directive should also be reviewed to determine if there has been appointment of one or more health care agents and it there is any prioritization of the agents.
4. If a patient does not come with their advance directive, the team should ask them or a family member to provide it (or the team can try to find it within the electronic record or CRISP).
5. In Maryland, the person named as health care agent cannot serve as a witness that verifies the patient signed the advance directive.
6. Informed consent should include the description of the procedure, who will be performing the procedure, risks, benefits, and alternatives (including their risks and benefits) of the procedure. The process should come first and then documentation. Documentation should include signature by the patient and clinician obtaining consent along with the date of signatures.
7. Negligence with regard to informed consent includes several elements:
    a. There must be an established patient/physician relationship
    b. A duty exists for the physician to disclose certain risk information
    c. The practitioner does not meet applicable standard of care
    d. If the information had been disclosed, the patient would not have consented
    e. It must be demonstrated that the lack of disclosure caused the injury with damages
8. The attending physician and a second licensed physician or nurse practitioner may determine that a patient is incapable of making an informed decision (i.e., lacks decision-making capacity).
    a. One of the providers has to document their assessment within 2 hours of the examination.
    b. When the patient is incapable of communicating by any means, then only the attending physician is needed to certify incapacity.
    c. The state defers to practitioners to conduct and assessment and make that determination.
9. If a health care agent has not been named, then the Health Care Decision Act stipulates a prioritized list of individuals to serve as surrogate decision makers: legal guardian, spouse or

domestic partner (cannot have both at the same time), adult child, parent, adult sibling, friend or other relative (who completes an affidavit attesting that they know the patient).

10. Maryland has reciprocity with other states with regard to advance directives (and orders for life sustaining treatment). If the document is valid by Maryland standards or by the standards of the state in which it was executed, the document will be construed as effective to the extent permitted by Maryland law.
11. If a patient from another state is being treated in Maryland, they can execute an oral advance directive even if their home state does not have provisions for oral advance directives. If an oral advance directive is made, the patient should be encouraged to complete a written advance directive that is consistent with their state's requirements for use when they are back home.
12. In the electronic medical record (Epic at Johns Hopkins), it is possible to document the legally authorized decision maker and create an oral advance in the Advance Care Planning (ACP) section.
    a. An oral advance directive has to be witnessed by an employee of The Johns Hopkins Health System acting in good faith and must cosign the oral advance directive note.
    b. Once the note is attested, a copy should be printed and sent to Health Information Management for scanning into the Advance Directive section of the chart and a copy should be printed and given to the patient.
13. In an emergency situation where there is a substantial risk of death or immediate and serious harm to the patient (i.e., threat of “life or limb” if treatment is delayed), then a health care provider may treat the patient if the patient is incapable of making an informed consent or the legally authorized decision maker is not immediately available.
14. For patients who are brought to the hospital unconscious and without identification (“John/Jane Does”), there can be several ways to try to find out their identity:
    a. Checking the police or the emergency medical services report to know if someone who knew the patient had called 911 or left any information about the patient. Someone at the scene where the patient was found might have told something to the police that is not in the information sent to the hospital with the patient.
    b. If the address where the patient was found is known, then hospital security can perform reverse searches to know who lives there or around there, or else police can be asked to canvas the area to see if they might know the patient.
    c. If the patient has specific tattoos, hospital security may be able to search a database for the tattoos to help in identifying the patient.
    d. If the patient has dentures, the dentures might have specific information on who molded them and then patient identity could be determined from that.
    e. Hospital security could also be called upon to assist with finger prints, although with the COVID-19 pandemic, this is not as readily available and police may only want to perform the finger printing if the patient has been a victim of crime.
15. If a person is found who was at the scene and might have information, then a social worker, hospital security, or the police could contact that person to see if they know the identity of the patient.
16. For unbefriended, incapacitated patients whose identity remains unknown, guardianship needs to be pursued for any procedures or treatment requiring informed consent. Two physicians must certify that the patient lacks decision-making capacity and is in need of a guardian. The court is then petitioned for guardianship, a process that can take time.
17. For patients who have been identified but no surrogate decision maker has been found, then guardianship also needs to be pursued. This will also need to be done if the patient is nearing discharge and needs to be signed in to a nursing home or rehabilitation facility.

18. For patients who have an advance directive, the document may be difficult to interpret and apply when the patient's prognosis is uncertain (i.e., their clinical situation does not exactly match the condition stipulated in the advance directive).
    a. Surrogate decision makers may lack sufficient information about patient preferences and values, especially when the patient has a sudden onset illness with a precipitous decline in health.
    b. An added complexity is that it is unclear whether or not the patient's wishes prior to the decline may be applicable in a new health state.
19. In patients who have a sudden devastating neurologic insult (e.g., stroke), they might end up in persistent vegetative state or they might improve but have some residual disability. At the point of needing to make critical decisions about life support, the surrogate decision maker will be faced with uncertainty about which path the patient will follow. If the surrogate decision maker decides to withdraw or withhold life-sustaining treatment, then the outcome will be death.
    a. The surrogate decision maker will have to make a decision uncertain of the patient's future quality of life
    b. The difference between the expectations for quality of life and the actual experience of quality of life is known as the *quality of life gap*.
    c. If expectations about quality of life change in the future (e.g., the patient learns to adapt to their disability), then even though the quality of life has decreased from an "objective" viewpoint, the quality of life gap has narrowed.
    d. If the patient's experience with the disability actually improves their quality of life through adaptation, then the quality of life gap may be better than it was before the neurologic event. This is known as the disability paradox.
    e. Asking surrogate decision makers what the patient was like before the neurologic event to help in deciding what to do when critical decisions need to be made is empathetic but may not account for the possibility of adaptation in the future.
20. Surrogate decision makers express doubt, guilt, and regret surrounding their decision for critically ill patients. Many experience post-traumatic stress and are at risk for psychiatric illness or complicated grief.
21. Clinicians can support surrogate decision making in several ways:
    a. Prior to family conferences, conduct "huddles" that gather input from all clinicians to provide a common message.
    b. Discuss not only chances for survival, but also the potential for disability and the function that may be reserved.
    c. Explore the patient's values and preference with the surrogates within this context (e.g., what was important to them? Had there been any prior conversations about what is meaningful in the patient's life? How important is being independent for the patient?)
    d. Offer adequate time to consider goals of care decisions
22. Advance directives do not expire (unless specified in the document) but should be periodically reviewed to be sure that the wishes expressed are still consistent with the patient's preferences.
    a. Knowing it can be hard to interpret standard advance directives, some patient may opt to provide more specific written information on what is important to them in making decisions or health or functional states they would find intolerable.
23. Other patients may indicate in their advance directive that they give discretion to their health care agent to use their best judgment in deciding best interests.
24. It may help surrogate decision makers to connect with other experienced surrogate decision makers through social networks (as long as privacy issues are sorted out).

References:

1. Health Care Decisions Act: Text and Educational Materials
2. Torke AM, et al. Scope and outcomes of surrogate decision making among hospitalized older adults. JAMA Intern Med. 2014 Mar;174(3):370-7. doi: 10.1001/jamainternmed.2013.13315. PMID: 24445375
3. Frontera JA, Curtis JR, Nelson JE, et al. Integrating Palliative Care Into the Care of Neurocritically Ill Patients: A Report From the Improving Palliative Care in the ICU Project Advisory Board and the Center to Advance Palliative Care. Crit Care Med. 2015;43(9):1964-1977. doi:10.1097/CCM.0000000000001131
4. Creutzfeldt CJ, Holloway RG. Treatment decisions after severe stroke: uncertainty and biases. Stroke. 2012;43(12):3405-3408. doi:10.1161/STROKEAHA.112.673376
5. Curtis JR, Treece PD, Nielsen EL, et al. Randomized Trial of Communication Facilitators to Reduce Family Distress and Intensity of End-of-Life Care. Am J Respir Crit Care Med. 2016;193(2):154-162. doi:10.1164/rccm.201505-0900OC