**Decision Making for the Unbefriended Patient Who Lacks Decision Making Capacity**

**Panelists: Mark T. Hughes, Adrienne Dixon, Caitlin McGeehan, Allyson S. Mitchell, Rev. John V.P.R. Ponnala, and Cynda Hylton Rushton**

The January Ethics for Lunch presented the case of a 68 year old man with multiple medical problems, foremost of which is end-stage congestive heart failure. He has had multiple hospitalizations and periods of losing his decision-making capacity. He is homeless and does not have any identifiable family or friends who could serve as a surrogate decision maker if he were to lose capacity in the future. The panel discussed the issues involved when caring for an unbefriended patient.

Key points:

1. Members of the interdisciplinary team should work together to gather as much information as possible about who the patient is, what he understands about his condition, and what is important to him in his life.

2. The social worker on the team can be a source of support for the patient, helping him cope with his diagnosis and prognosis, and gathering information from him and about him that will assist in planning for the future.

1. The psychosocial assessment can include past addresses where he has lived (including shelter names so that contacts at those facilities can be reached to get collateral information), his feelings about his current living situation, and the names of past friends and acquaintances.
2. Discussions with the patient can review the importance of advance directives, especially knowing that his capacity status to make his own decisions could change in the future. Asking, “Who will speak for you when you cannot speak for yourself?” can at least get the patient to consider if he could identify anyone to be his authorized representative (Note that a “health care buddy” is not the same as a health care agent).
3. The social worker can work with hospital security to try to track down next of kin information with the patient’s name, date of birth, and/or social security information.
4. The social worker can also offer to contact the local police to do a “well-check” of the patient’s current residence and to identify any acquaintances at that location.

3. The bedside nurse on the team may want to explore why a surrogate decision maker or health care agent has not been identified for the patient over the many years he has been in our health care setting—has it been reluctance on his part to provide this information, no one previously asking, or truly that he has no one to ask to be an authorized decision maker for him?

1. This hospitalization may be different from past ones in that it is now recognized he has a terminal illness and important decisions will need to be made in the future.
2. It is therefore important to explore his values, which may be different than those of the health care team members. If the patient’s values differ from the goals that the team is trying to achieve, then identifying these differences can inform the care plan discussions.
3. Communicating with the patient about what the nurse is hearing from the patient can set the stage to express the worries that the team would have were the patient to get sicker, progress in his disease process, or lose decision-making capacity.
4. It is a matter of helping the patient to anticipate what might happen to him and what treatments or outcomes would be acceptable or unacceptable to him.

4. The chaplain on the team would also work to understand the patient’s perspective. Sometimes the treatment plan is dictated by the physician perspective or the care team’s values, so it is the chaplain’s role to highlight the patient’s voice.

1. Exploring the patient’s narrative include learning about his family of origin, what the issues were that led to his alienation, abandonment, or estrangement from his family, and what gives his life meaning now.
2. Sharing the patient’s story with the team can be one safeguard against the patient being either over-treated or undertreated. Discussions with the team can clarify why treatments are either being offered or are not being offered: “Are we treating this patient any different than we would another patient? If so, why?” These are issues of justice and fairness.

5. The physician on the team would have the goal of optimizing the patient’s medical regimen to prevent or delay problems in the future but also anticipate how those problems (e.g., exacerbation of his heart failure) would be handled.

1. While the patient has capacity, it would be important to discuss with him corollary considerations to his care including non-invasive pulmonary ventilation, intensive care unit management, vasopressors to know if they would be instituted if he lost capacity in the future.
2. The physician would also be responsible in creating, with the rest of the health care team, a safe discharge plan in which the patient can take his medications regularly, avoid re-hospitalization if possible, and find a living situation that can attend to his quality of life and incorporate a palliative care philosophy to his management.
3. It is important for the physician and other members of the team to talk to the patient in “human” language, not so much focused on particular treatments but more on where the patient sees himself in terms of functional status—walking, eating, breathing, etc.

6. It is important to discuss code status with an unbefriended patient who has a terminal illness. If this is not discussed and the patient lacks capacity in the future, the default assumption is that he would wish for cardiopulmonary resuscitation (CPR) to be attempted.

1. In instances in which CPR would be known to be unsuccessful beforehand, in the absence of a DNR order already arranged with the patient, then the team could consider contacting the ethics committee and the legal department to consider the determination of medically ineffective treatment.
2. In instances in which CPR might be successful but the patient may never return to his baseline function, then it would be important to discuss with the patient whether he would want or not want to escalate his care knowing his clinical condition could continue to deteriorate.

7. If a patient loses decision-making capacity, it is the prerogative of the attending physician to certify that the patient can no longer make his own health care decisions. A safeguard for the patient in this process is that two licensed physicians make the determination of incapacity through independent assessments in a proscribed time period.

1. The health care team should be proactive in contacting the legal department if they anticipate the patient lacks (or will lose) decision-making capacity and will need a procedure, surgery, or treatment that requires informed consent. Guardianship proceedings take time.
2. The legal department files a petition to the court for guardianship, in essence asking the court to declare that the patient “disabled”—clear and convincing evidence that this individual is incompetent to make his own decisions.
3. Guardianship should be the last resort. All other lesser restrictive alternatives have been explored and exhausted prior to filing a petition for guardianship of the person and property. Once guardianship is granted, then the person’s rights to make decisions about basic functioning (housing placement, managing financial affairs, managing medical treatments, etc.) are given over to a guardian.
4. The guardianship certificates completed by the physicians have to be filled out properly and can specify whether the guardian is being asked to make decisions about life-sustaining treatments (i.e., the clinicians can make recommendations about limitations in offering treatments).
5. Different jurisdictions, depending on the patient’s place of residence, may have different practices with regard to hearing guardianship petitions, appointing an attorney to represent the interests of the patient, and soliciting input from other interested parties.

8. It is important to document a patient’s wishes before they lose decision-making capacity. Especially for an unbefriended patient for whom a guardian may one day need to make decision, advance care planning can be one means to respect a patient’s wishes and preferences regarding end-of-life care.

1. Documentation of a patient’s prior wishes may be found in records from other institutions, These can be accessible through the Epic tool “Care Everywhere” if the patient has given permission for these records to be made available elsewhere in the health care setting. CRISP also provides linkage to previous documents, including the possibility of an advance directive if the patient has previously completed one.
2. At Johns Hopkins, the Capacity and Advance Care Planning (ACP) Activity can be a site to document an unbefriended patient’s goals with regard to future health care decisions. When a patient has capacity, an oral advance directive can be completed in this section (documented by the attending physician and cosigned by a witness who is a member of the healthcare team). Living Will instructions and a narrative account of the patient’s values and preferences can be documented in this section and available in one place for future reference by other providers.

9. These are challenging cases and can cause distress in team members who are committed to providing good care in hard circumstances. The ethics committee can help provide a holistic view of the patient and its recommendations about the ethical permissibility of treatment options and the best interests of the patient can be used in the court proceedings on guardianship.