Surrogate Decision-makers: Who Do They Think They Are?

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Objectives

By the end of this presentation, participants will be able to:

- Discuss the different types of surrogate decision-makers and how they are determined in the hospital setting
- Assess different strategies for communicating with surrogate decision-makers
I have no financial disclosures.

What is a surrogate decision-maker?

- **Surrogate decision-makers make medical decisions on behalf of a patient.**
  - Incapacitated patients require a surrogate
  - Capacitated patients may voluntarily use a surrogate if they do not wish to make their own medical decisions

Surrogate decision-makers preserve patient autonomy.
Ethical Frameworks for Surrogate Decision-making

- Surrogates protect patient autonomy in two main ways:
  - Using **Substituted Judgment**, when possible, in order to make decisions
  - Defining and acting on the patient’s **best interest**

Substituted Judgment

- Surrogates may have insight into patient preferences that are relevant to medical decisions.
  - “My wife told me she doesn’t want people breaking her ribs and trying to bring her back.”
  - “I know she would want to do everything to make sure she can see our son after he graduates next week.”

**Surrogates have an ethical obligation to choose on the basis of known patient preferences.**
Substituted Judgment

- Insight into patient preferences may come from many sources: family, friends, primary care providers, or hospital medical team, or advance directive
  - The legal surrogate is not the only one who can help us figure out patient preferences.

- Surrogates are expected **not** to choose based on their own preferences.
  - The religious beliefs of surrogates, if not shared by the patient, are not an ethical basis for surrogate decisions.

Subrogates have an ethical obligation to choose on the basis of known patient preferences.

Substituted Judgment

- We frequently ask surrogates to justify their choices for the patient in terms of “what the patient would want.”

- Trust between team and surrogate is the best way to enable agreement about patient preferences and goals moving forward
Best Interest

- Sometimes, there is no relevant information about what the patient would want.
- In these cases, surrogates are asked to think in terms of the ‘best interest’ of the patient.
  - Surrogates, via their relationship with the patient, are presumed to be in the best position to define patient best interest.
  - But best interest, like patient preferences, is established via a conversation with surrogate and relevant stakeholders.

Best Interest

- Medical Providers are ethically obligated to offer only “beneficent” care.
- Medical expertise is highly relevant in determining best interest.

Surrogates are ethically obligated to choose in the best interest of the patient.
Surrogate decision-makers may be determined by:

1. Obtaining verbal or written designation by a capacitated patient
2. Reading a surrogate determination in living will or advance directive
3. Securing paperwork that establishes a Power of Attorney that includes medical decisions (not all POAs have the power to make medical decisions)
4. Securing paperwork that designates a legal guardian
5. Using the surrogacy hierarchy in order to establish the proper family member to offer the right to make medical decisions for patient
6. Via a petition for emergency guardianship or full guardianship

KY Surrogacy Hierarchy

KY Hierarchy (KRS 311.631):
- a) The judicially-appointed guardian of the patient, if the guardian has been appointed and if medical decisions are within the scope of the guardianship;
- b) The attorney-in-fact named in a durable power of attorney, if the durable power of attorney specifically includes authority for health care decisions;
- c) The spouse of the patient;
- d) An adult child of the patient, or if the patient has more than one (1) child, the majority of the adult children who are reasonably available for consultation;
- e) The parents of the patient;
- f) The nearest living relative of the patient, or if more than one (1) relative of the same relation is reasonably available for consultation, a majority of the nearest living relatives.
KY does not recognize common law marriages. Until legal paperwork supporting claims of guardianship, Power of Attorney, or surrogate decision-maker designation (such as a living will), use the KRS Surrogacy hierarchy. Individuals who have a legal right to serve as surrogate decision-maker are not obligated to serve in this role. Individuals who decline their right to serve as a surrogate may not name a different surrogate—we turn to the KRS surrogacy hierarchy. Individuals may also be denied their status as surrogate decision-maker if they demonstrate an inability to act in the patient’s best interest, have a clear and impeding conflict of interest, do not themselves have capacity, or are not available for timely surrogate decision-making. Surrogate decision-making right falls to the next individual on the hierarchy.

Issues in Surrogate Communication

Surrogates are almost always trying to do what is best for the patient. Surrogates are asked to make difficult and consequential decisions. Surrogates must figure out the best interest of their loved one by trusting medical persons they may have just met. Surrogates are left with the burden of their choices, and the fallout from other family members.
Patient Preferences- Helpful Until They Aren’t

Often, the types of “preferences” surrogates work with are vague:

- “She always was a fighter.”
- “He told me not to ever give up on him.”
- “She told me yesterday when no one else was there that she wanted to keep going.”
- “I haven’t talked to him about this because he always hated the thought of dying.”
- “She said she wouldn’t want to be kept alive with machines.”

Tips

- If known, patient preferences can be helpful for framing surrogates’ decision, and removing their burden
  - Strive to establish these early via conversations with patients before a crisis moment occurs
    - When done in this way, preferences can be stated specifically for expected medical reality.
  - Break through vague patient preferences by highlighting unique features of medical scenarios, which few individuals anticipate when making generalized statements
  - Break through guilt about choices by reassuring surrogate that choosing to stop is not giving up, ensuring them that loved ones know they are trying to do what’s best for them, they are not responsible for the medical reality their loved one is faced with.
Medical Teams are taught to offer care that is “beneficent” – offering potential for benefit that outweighs the risk of harm.

- They bring some concept of ‘best interest’ to the table: what happens when this is in conflict with surrogate’s definition?

- In risky, complex, or end-of-life scenarios, disagreement about “best interest” is common

- How much risk is acceptable when deciding to undergo a life-saving procedure?
- What quality of life is acceptable for this patient?
- How much should we try before giving up?

Tips

- Build trust by being clear that the medical team is always thinking in terms of the patient’s best interest.
- Be clear that the surrogate is allowed to disagree with the team about what the patient’s best interest is, and encourage them to be open about their perspective.
Cases

- Case 1: Ms. Stephens
- Case 2: Mrs. Young

Ms. Stephens was admitted due to complications from kidney transplantation, including persistent GI bleeding and difficulty with oral intake that resulted in a 20-30 pound weight loss in the past month. Her medical history includes end-stage renal disease. Per nephrology, her kidney function is currently compromised but stable. In the future, her kidney function will decline further, but she is unlikely to be a candidate for dialysis given her other co-morbidities.

During her stay at the hospital she has refused to eat almost anything, and has become malnourished. She has relayed to both the ethics team and nursing staff in past weeks that she would eat the food at her home, but does not like the hospital food. However, now she reports that she cannot tolerate food in her stomach anymore. She has had a Dobhoff placed twice but removed it each time. Per her attending, she is not a candidate for a PEG tube given her ascites and the danger involved if she were to pull that tube out.

Ms. Stephens is 20 years old with a developmental delay. She lives with her foster father, and has a state-appointed guardian. (She has been deemed incompetent by the state, and lacks decisional capacity.) She has a good relationship with her foster father, but he does not have medical decision-making authority.
Ms. Stephens

The team is debating attempting another Dobhoff tube placement, and what steps are appropriate, if any, to ensure that she keeps it in.

**Discussion Questions**
- Next steps: What is the best process moving forward for establishing the best outcome for Ms. Stephens?
- How do we establish the best interest of this patient?
- What relevance do patient preferences have in this scenario?

**Key Ethical Features**
- How to best address the preferences of an incapacitated patient
  - Realities of treatment options should be considered
  - Insight about the patient given by those who know her best should be the foundation of a legal surrogate’s decisions
  - When the legal surrogate does not know the patient well, the medical team may be asked to offer extra insight regarding patient’s best interest

**Communication Strategies**
- If the legal surrogate permits, allow those who know patient best to be a part of decision-making process
- Address the preferences of patient – is there a compelling reason to override them that is rooted in her best interest?
- Encourage medical teams to form a thorough plan of care when surrogates ask for their expertise of defer to their judgment.
Ms. Stephens

Resolution
- Ms. Stephens's Dobhoff tube was not replaced. Her foster father was supportive of this, expressing concern about the possibility of using restraints to force her to keep the tube in. Given her other co-morbidities, and her preference to eat on her own terms, Ms. Stephens was discharged to her foster home with hospice arrangements.

Mrs. Young

- Mrs. Young is a 64-year old woman admitted to our ED. She has multiple co-morbidities: cirrhosis, severe abdominal ascites, stage IV renal failure, history of endocarditis/MRSA, and a severe pressure wound on her backside. She has fungemia- all her lines have been pulled. She cannot receive dialysis until this is resolved and access has been reestablished. Because of her lack of access, her wound pain is very poorly controlled.
- Mrs. Young often refuses to speak to medical staff, asking that her son be spoken to instead. A neuropsych evaluation could not be completed because she would not participate. Her son claims that she often gets confused and is unable to understand the consequences of her decisions. However, she has expressed clear wishes to several team members. Up until recently, she consistently stated that she wanted aggressive treatment, but a recent chart note documents a conversation in which she refuses dialysis and acknowledges that this will lead to death. Mrs. Young has now refused dialysis several times.
- Mrs. Young has had health complications throughout her life. Her son says she has a pattern of exceeding expectations of health professionals, and that medical people have been trying to write off his mother for years. The note indicating Mrs. Young was considering comfort care was followed by a conversation between her and her son, after which she decided to continue with aggressive care and confirmed this verbally to medical staff. Mrs. Young’s son often explains that his mother is a fighter who would never want to “just give up,” and that he is hopeful that with treatment, she gain regain hope and some quality of life.
Mrs. Young

The team is concerned about restarting dialysis, and given her uncontrolled pain, feel that Mrs. Young is suffering. They have trouble distinguishing between Mrs. Young’s preferences and those of her son.

**Discussion Questions**
- What is the key goal moving forward in Mrs. Young’s care?
- How should the team navigate disagreements about “how much is too much”?
- Should we encourage Mrs. Young and her son to embrace comfort care?

**Key Ethical Features**
- How do we ensure that we respect Mrs. Young and her preferences?
- When, if ever, is it ethically appropriate for medical teams to refuse to offer life-saving intervention?
- How do we respect Mrs. Young’s son as well as his knowledge of his mother and her past?

**Communication Strategies**
- When patients present with multiple co-morbidities and/or unclear preferences, team meetings should be held early to discuss assessments of appropriate care, and to get on the same page about communication with patient and family.
- Transparency about the concerns of the team can powerfully break through mistrust and skepticism toward medical professionals.
- The goal of communication is not to win over the surrogate, or necessarily convince them to do what we advise.
Resolution
- Mrs. Young remained at our hospital for 2 months, and received dialysis as needed during this time. Her son voiced eventual support for a DNR/DNI status. She passed away at our hospital.

Conclusion
- Medical teams must communicate with one another to establish strategies for speaking with surrogates.
  - Limiting what is offered to medically appropriate treatment options
  - Consider identifying one or two individuals to act as points of contact with surrogates.
    - Limits confusion and different medical explanations that lead to slightly different interpretations of prognosis or recommendations
    - Builds trust if surrogate is feeling overwhelmed
    - Reduces opportunity for fracturing among teams
  - Strive to come to agreement within the team before speaking to surrogates.
- Transparency about the team’s perspective, including their concerns and their medical expertise in prognosis, complications, and best-case scenarios, can help build trust with surrogates
Conclusion

- Ethical care for patients does not require us to always agree with surrogate choices – it is ethical for us to respect the role of the surrogate decision-maker.
- Ethical care also does not mean we must do everything a surrogate wants - medical teams should limit what they offer to families to include only those things they feel comfortable doing, and when families request something not offered, be clear about why it's not medically appropriate.
- When making decisions with a surrogate, take into account family dynamics and the often burdensome reality the surrogate is faced with. Minimize this with communication that reframes choices and offers medical expertise that contextualizes decisions.
- Respect patient autonomy by ensuring surrogates have an understanding of their ethical obligations.
- Respect your patient by addressing their preferences even when they are not capacitated, and ensuring the surrogate does this as well.

Thank you!

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References:

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