



AT THE FOREFRONT

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When The Surrogate Can't Decide

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Disclosures

I have no relevant financial disclosures.

Objectives

- Present a case of a non-decisional patient whose surrogate was ultimately removed from decision-making
- Discuss challenges relating to surrogate decision making, focusing on the removal of a surrogate

The Case

63 year-old male with a past medical history of cerebral palsy, seizures, SDH, progressive dysphagia, recurrent aspiration pneumonia who was accepted as an ICU to ICU transfer from an outside hospital with respiratory failure.

A fellow walks into a workroom...

- Patient's mother is the surrogate
- She is difficult to communicate with
- She has repeatedly declined recommended interventions



Can we help with a family meeting?

Sunday Evening Chart Review

- Care Everywhere reveals that at the most recent OSH the patient was being followed by Palliative Care and Ethics
 - Ethics Committee “had made a decision to pursue guardianship in order to provide proper care for the patient”
 - Patient was transferred to our institution the next day



The Full Timeline



- 10/15/23: Admitted OSH
- 11/14: OSH Ethics consulted
- 11/17: OSH guardianship suggested
- 11/18: Transfer to UCMC ICU
- 11/29: Extubated 11/29 and transferred to the floor
- 12/9: Reintubated and back to the ICU
- 12/10: **Palliative Consult**
- 12/10-12/14: **nine attempts made to contact the surrogate by the palliative team**
- 12/13: Surrogate verbally and physically threatens the overnight ICU resident
- 12/14: Ethics reviews case with MICU, Palliative, SW
- 12/17: UCMC Ethics consult documented
 - Primary service and Palliative service “will continue to call and engage mom in establishing GOC”
 - It was suggested to the residents that “when surrogate presents to care unit, that they speak with mom in pairs due to her behavior noted in MICU resident note”
- 12/17: UCMC SW files paperwork requesting State guardian

Illinois Surrogacy Law

- This Act is intended to define the circumstances under which **private decisions** by patients with decisional capacity and **by surrogate decision makers on behalf of patients lacking decisional capacity to make medical treatment decisions** or to terminate life-sustaining treatment **may be made without judicial involvement of any kind.**
- This Act is intended to **establish a process for that private decision making.**
- This Act is intended to clarify the **rights and obligations** of those involved in these private decisions by or on behalf of patients.

What Makes a Surrogate in Illinois?

- "Surrogate decision maker" is an adult individual or individuals who:
 - (i) **have decisional capacity**
 - (ii) are **available upon reasonable inquiry**
 - (iii) are **willing** to make medical treatment decisions on behalf of a patient who lacks decisional capacity
 - (iv) are identified by the attending physician in accordance with the provisions of this Act as the person or persons who are to make those decisions in accordance with the provisions of this Act.

Hierarchy of Surrogate Decision Makers

- The patient's legally appointed "guardian of the person"
- The patient's spouse
- The patient's adult children
- The patient's **parents**
- The patient's adult siblings
- The patient's grandchildren
- A close friend of the patient
- The judicially appointed tutor or curator of the patient, if one has been appointed
- An agent acting pursuant to a valid mandate, specifically authorizing the agent to make health care decisions
- Any parent, whether adult or minor, for his child



So what does it mean to be available, anyway?

Relevant Definitions for this Case



- "Available" means that a person is not "unavailable."
 - A person is unavailable if:
 - (i) the person's existence is not known,
 - (ii) the person has not been able to be contacted by telephone or mail
 - (iii) the person **lacks decisional capacity**, refuses to accept the office of surrogate, or is **unwilling to respond in a manner that indicates a choice among the treatment matters at issue.**

Hierarchy of Standards of Surrogate Decision Making

1. Known wishes
2. Substituted judgments
3. Best interests



Complicating Factors in this Case

- Poor continuity
 - Patient had been to at least four institutions in the recent past
- Social factors
 - Only one other family members
 - Non-business hour communication
- Long and complex history of chronic disease
 - Unknowable wishes of the patient

Did she have capacity?

Surrogate Removal

- Surrogate appears to lack capacity to make decisions
- Surrogate acts contrary to the patient's wishes or best interests
- Mediation is a priority
- Appointment of a guardian is a last resort

The Outcome

- 12/21: Petition for Appointment of Guardianship & Petition for Temporary Guardian signed and returned to [Legal]
- 1/19/24: “The court met this morning and have suspended all powers or authority for mom to make any decisions for pt. She no longer is able to make decision starting at this moment.
12:20 pm. [Legal group states] ‘Do not take direction from her.’
They will get us a contact for state guardian.”

Take home points

1. Know your laws, policies and ethics resources
2. Be attentive to documentation
3. Prioritize the patient while being mindful of the cultural, family and social contexts

Sources:

<https://www.reliasmedia.com/articles/143920-ethical-responses-if-surrogate-is-unfit-for-role>

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VeriGeri podcast S1 E2 March 19, 2024 Balancing Independence and Safety in an Older Adult with Annie Vernon-Cwik, LCSW, ASW-G



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