

Surrogate Decision Making in the Hospital: Guidance for Families

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Patients: Mr. L

- 72 year old man who is a retired accountant and father of three children
- He has Alzheimer's disease and emphysema
- Lives with his son. Needs help with bathing and dressing.
- He is admitted to the hospital with pneumonia
- On the second day, he becomes very short of breath and is placed on a ventilator in the ICU
- After a week on the ventilator, he is not getting better.
- The physicians approach the patient's son to talk about whether to continue aggressive, life-sustaining care



Ms. B

- Ms B is a 78 year old woman with moderate Alzheimer's disease
- She lives alone although her daughters have been very worried about her using the stove and getting lost
- When her oldest daughter goes to visit, she finds her mother very confused
- She takes her to the emergency room, where the doctors find Ms B. is having a heart attack.
- They ask the daughter for permission to perform a cardiac catheterization to see if there are any blocked arteries in the heart.



Outline

- What is surrogate decision making
- Advance care planning
- Communication with the health care team
- How to make the decision
- Lessons learned

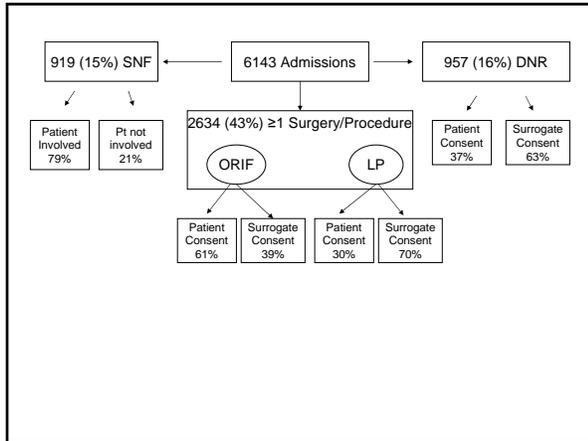
What is surrogate decision making?

- The process of making health care decisions for others
- When a patient no longer has the capacity to understand, reason and make a choice about a health care decision.
- A surrogate is usually someone close to the patient
 - Family members
 - Legally authorized health care representatives
 - Legal guardians

Surrogate Decision Making in the Hospital

- How common is it?
 - Looked at the medical records of all adults 65 and older admitted to Wishard over 3 years
 - 56% of patients made a major decision requiring informed consent





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Surrogate Decision Making in the Hospital

- Who makes the decisions?
- Observational study of 189 patients
 - Daughter 54%
 - Son 17%
 - Spouse 9%
 - Other relative 43%



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Problems are common

- Up to 1/3 of family members report serious problems with communication and decision making (SUPPORT, JAMA 1995;274:1591-8; Baker, Wu, Teno et al, JAGS 2000)
- Almost half of ICU families report conflicts with medical staff (Abbott et al, Crit Care Med 2001;29:297-301)
- Physicians report
 - Disagreement with families about 10% of the time
 - Ineffective communication with families 22% of the time (Tolle et al)

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Outcomes of decision making may be poor

- Surrogate distress
 - PTSD symptoms in ICU family members
 - 33% of all family members
 - 48% of those who made decisions
- Unwanted treatment
 - 41% of those who preferred comfort care reported that care was inconsistent with their preferences (Teno et al, JAGS 50:496-500.)

Advance Care Planning

- A process of communication and decision making to plan ahead for major illness and death
- Includes:
 - Communication
 - Written documents

Talking about the future

- What should I know about the kind of medical care you want?
- Can you imagine a time in the future when you would want some limitations on the medical care you receive?
- If you are unable to make your own decisions, who should make decisions for you?

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Advance Directives

- Statements of a person's wishes for future care
- Based on the legal and ethical belief that individuals have the right to refuse any medical care
- Only take effect if the person loses decision making capacity
- Are DIFFERENT from statutory wills and powers of attorney for finance
- Two types
 - Living Will
 - Health Care Representative form

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Indiana Living Will

LIVING WILL DECLARATION

Declaration made this _____ day of _____ (month), year 20____, being at least eighteen (18) years of age and of sound mind, willfully and voluntarily make known my desires that any drug shall not be artificially prolonged under the circumstances set forth below, and I declare:

If at any time any attending physician certifies in writing that (1) I have an incurable injury, disease or illness; (2) my death will occur within a short time; and (3) the use of life prolonging procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally from the performance or provision of any medical procedure or procedure necessary to provide me with comfort care or to relieve pain, and if I have so indicated below, the provision of artificially supplied nutrition and hydration. (Indicate your choice by initialing or making your mark before signing this declaration.)

I wish to receive artificially supplied nutrition and hydration, even if the effort to sustain life is futile or excessively burdensome to me. _____

I do not wish to receive artificially supplied nutrition and hydration, if the effort to sustain life is futile or excessively burdensome to me. _____

Artificially means an device concerning artificially supplied nutrition and hydration, including the devices in any health care consent form approved under IC 16-30-17 or any device on that web health care consent under IC 16-30-17.

In the absence of my ability to give directions regarding the use of life prolonging procedures, it is my intention that this declaration be honored by my family and physicians or the final expressions of my legal right to refuse medical or surgical treatment and accept the consequences of the effort.

Witnessed for the full impact of this declaration. Signed _____

City, County, and State of Residence _____

This document has been personally known to me, and I believe that but to be of sound mind, I did not sign the document's signature device for or at the direction of the declarant, I am not a parent, spouse, or child of the declarant, I am not entitled to any part of the declarant's estate or already financially responsible for the declarant's medical care, I am competent and at least eighteen (18) years of age.

Witness _____ Date _____
 Witness _____ Date _____

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Promoting advance directives

Understanding Advance Directives

- 1. What are advance directives?
- 2. What is a living will?
- 3. What is a health care power of attorney?
- 4. What are some common myths about advance directives?

PUT IT IN WRITING

Yale University Health Services

Advance Directives

*Your rights
Your wishes*

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Criticizing advance directives

Advance Directives: Time To Move On

Enough

THE FAILURE OF THE LP

Substituted Judgment: The Limitations of Autonomy in Surrogate Decision Making

Advance Directives: A Call for Action

Advance Directives: A Call for Action

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Problems with Advance Directives

- Few people have living wills, in spite of major efforts to increase their use
 - Want families to make decision making
 - Don't want to think about death
- People cannot make informed choices about future situations they've never faced
- They aren't available when they are needed
- They don't affect decision making
 - » Fagerlin and Schneider, 2004

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Advance directives are a good idea if you...

- Can still understand, reason and make a choice about
 - Wishes for the end of life
 - Who should make health care decisions
- Have a serious illness that is expected to be life limiting
- Prefer a high degree of control about health care decisions
- Have strong wishes about limiting life-sustaining care
- Are concerned there may be disagreement among family about how decisions should be made or who should make decisions

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Communicating with the health care team

Interviews with surrogates

- Prospective, observational study of surrogate decision making
- 30 surrogates
- Audiotaped interviews
- During or soon after patient's hospital stay

Communication Challenges

- Lack of personal relationships
 - Many different clinicians
 - Frequently changing teams


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We usually take her to emergency and there is a team of doctors that is caring for her while she is in emergency. Then it's out of their hands...and once they say she has to stay then it goes to some other doctors...the only thing I knew about those was after she called me, Dr. B called me, that I knew it was Dr. B taking care of her.

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The doctors came in and reviewed, on the screen reviewed her history, et cetera, and the...I'm sorry I don't remember the two doctors' names, but they were actually part of the respiratory care area.

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Communication Challenges

- Lack of personal relationships
 - Many different clinicians
 - Frequently changing teams
- Getting information
 - Reaching the physician
 - Use of jargon

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The nurses were good. The doctors were...spotty at best. And unfortunately at this day in age where doctors have pagers, Blackberry's and cell phones, at best, they're noncommunicative and, at times, unavailable.....information that was kind of shared haphazardly...mainly by the nurses who were saying that there was some discussion about some kind of procedure.

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I think particularly young doctors are more prone to use jargon, and if you don't stop them and say, excuse me, I don't understand what you're talking about...you lose that.

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What is good communication?

- Frequent, timely
- Jargon-free
- Listening as well as giving information

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One thing I will say is that the staff here, with their having team members and...three different teams for mom, um, they were in contact with me on almost like a daily basis...I was extremely impressed that I had gotten so many calls from a team member from Wishard Hospital.

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...taking the time out to really sit there with me to explain that to me, that meant a lot to me cause some doctors they will tell you and explain it to you and then they move on. But she actually, I felt like she really cared about what was really going on with my mom.

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The surrogate's experience

- Decision making is stressful
- May bring up unresolved grief, family conflict or other difficult emotions

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The one thing they kept pushing and adamantly pushing is that we had to make a decision whether they were going to resuscitate her if anything happened because she was in pretty bad shape...It was difficult because we just buried the two nieces that were there, we just buried their mother on (date) and they had to make the same kind of decision for her.

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I have one niece that sees her quite often, and she just point blank told me privately...one of the reasons I don't go down and see her very often is I do not want to be forced into making those decisions.

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Surrogate strategies

- Navigating the system
- Enhancing communication
- Finding support

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Well, they explained to me in their terminology and then I asked them to, you know, to break it down into layman's terms pretty much. The doctor that she had, I can't think of her name, but she was so helpful in explaining that to me once I allowed her to know that I really didn't know what she was talking about in the beginning.

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...probing, pushing...being polite and not aggressive, but firm. I had noted from the experience of being in the emergency room that if you became somewhat agitated, even to the point of being hostile, your treatment was at best lousy. And...it didn't help. So...I soon realized that it needed a gentler touch, and to be frank with you, it also meant that I dressed up whenever I came in.

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My brothers. I have two brothers. They are my rock. We are the three musketeers. Jeff, Jim, and myself.

I asked God to lead me and I know that I'm gonna make it because my mom is still there to me and if you don't put God first, then you don't have nothing.

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How to make the decision

- Standard ethical guidelines
 - Advance directives
 - Substituted judgment
 - Best interests
- Other considerations
 - Surrogate wishes and beliefs
 - The medical condition
 - Patient's prognosis
 - Family concerns

How do doctors make decisions?

Factor	"Extremely Important" or "Very Important"	"Most Important" of all factors listed
Patient's prognosis	99	12
What was best for the patient overall	98	33
Respecting the patient as a person	97	5
Patient's pain and suffering	95	13
What the patient would have wanted you to do	82	29
Providing the standard of care	81	2
Respecting the wishes of the family or surrogate(s)	81	3

...the niece then said, I spoke with her three days ago, and I know that she was coherent because she was saying things that only she would have said, you know. I asked her if she would want a colostomy and she said no. So it was actually a very good conversation because the niece felt very confident about what the patient would have wanted.


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I think when it came down to the question of should he stay in the hospital or should he be allowed to go home...the feeling of the patient's daughters and his wife were that it would be too hard emotionally for them to take care of him and let him... pass at home

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How do families make decisions?

- Best interests
- Patient wishes
- What the surrogate would want for self

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... but then I have to not think about myself. I have to think about her and her well being and how she feels, you know. So that's what makes it difficult but I feel that that will be the best decision for her and if her heart was to stop beating, I feel like that God was calling her home.

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... there was ..a Do Not Resuscitate order that, um, my younger brother in Florida, who had Power of Attorney at the time, did have that, ..she came up here, there was a copy of that, that she always told us, even when we were younger, that she never wanted to be a burden on anybody, where, um, she was just like a vegetable laying there hooked up to the machines and really wasn't productive or...or couldn't live a life, she doesn't want that.

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Lord, do I have the right to do this? But, I wouldn't want to suffer like that and I know I always tell my daughters and everything, I don't wanna be on no machines. I don't wanna lay there.

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Guidelines for Decision Making

- Focus on consensus building
- Emphasize patient-focused decision making principles
 - Advance directives and patient preferences, when known
 - Best interests
- Acknowledge the impact of family concerns
 - Resources
 - Other family members
 - Family conflict

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Lessons learned

- Participate in advance care planning, when possible
 - But understand that you can't plan for everything
- The family has an important role to play in decision making
- You need and deserve information about your family members condition, medical options, and possible outcomes
- Surrogate decision making can be highly stressful. Get support.
- There are strategies to help you navigate the hospital.
- There are many factors to consider in each decision and no single "right" answer.
 - Strive for consensus
 - Emphasize patient-focused decision making principles
