Getting Real with Surrogate Decision Makers: Ethical Roles and Limits of Surrogate Decision Making

Jason Lesandrini
Executive Director of Medical and Organizational Ethics
WellStar Health System
Objectives

• Describe examples of ethically problematic surrogate decision making.
• Explain the accepted ethics standards for surrogate decision making.
• Identify solutions to resolve ethics problems with surrogate decision making.
Mr. Smith

• 53 year old man presenting to ER after being found by mother unresponsive
  – Intubated
  – Workup reveals
    • Stage IV Metastatic cancer—“spread everywhere”
    • No intervention available
  – Clinical team sits down with mother to explain situation
    • She requests all aggressive measures
      – “I want him to live—Do what you have to do.”
Mr. Smith

• An advance directive is located
  – “Allow my natural death....”
  – Mother is named as POA

• Clinical team explains this new finding and asks her about directive
  – She acknowledges but still “demands” aggressive interventions.
Mr. Smith

• Five days into hospital course
  – On 3 pressors
  – Showing outward signs of extreme pain
  – Clinical team agrees that patient will die in the near future

• Clinical team learns that patient had discussed with PCP that he would not want to live on “machines for the rest of his life”

• Discuss with mother—She states, “He will pull through. He has done this before.”
Who’s that guy or girl?

- Consider the person you would want to grant this privilege—you will not have to identify them by name—and think about the reasons for your decision.
- Please be clear about which qualities and/or characteristics you associate with your chosen person that you think are important in making your decision. It may be helpful for you to think about how you know that (s)he has these qualities/characteristics’.
Identify the number one quality/characteristic for choosing your surrogate

A. General Competence
B. Caring
C. Veracity
D. The “right” choice
E. Knowledge of me
F. Similarity in outlook
G. Concern for the surrogate
H. Fear of offending someone or social role
I. Other quality/characteristic
And the survey says...

- A 2011 study showed the following:
  - Choose someone who was caring and competent in certain ways.
    - “Karen is clever and well organized.”
    - “He's good with details and complicated projects.”
    - “She is also very organized at home with children and with her five dogs.”
    - “She ... thinks of others first and goes out of her way to help.”
  - Surprisingly few highlighted how well they thought their chosen surrogate knew their preferences and would be able to make a decision as they would
Other interesting findings

- Few specified that their chosen surrogate had similar attitudes and values to their own and so would make a similar decision to theirs in the circumstances presented.
- Some respondents also referred to the social role of their chosen surrogate or the social dynamics of their situation which influenced their choices,
  - “My son is much more even-tempered than his mother (my wife Dorothy) ... decision-making wouldn't stress him in the same way.”
  - “… it would be strange for Jen to not have control over the family situation. She wouldn't like that – it would cause trouble …”
**Surrogate order in GA**

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<thead>
<tr>
<th>Consent Statue</th>
<th>DNR Statue</th>
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<tbody>
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<td>DPOA</td>
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<td>Spouse</td>
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<td>Parent for a minor child</td>
<td>Guardians</td>
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<td>Locos parentis and Guardians</td>
<td>A Son or Daughter 18 years of age</td>
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<td>Female in connection with pregnancy</td>
<td>A Parent</td>
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<td>A Brother or Sister 18 years of age</td>
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<td>Any Parent</td>
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<td>Any Adult Niece, nephew, aunt, uncle</td>
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<td>Adult Friend</td>
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Duties of Surrogates

• Someone to stand in for patient
• Make the medical choice that the patient would have made for themselves
• Obligated to suppress their own judgement
  – even if the decision goes against the way the surrogate would decide for themselves
Standards

• Widely recognized standards for surrogate decision making
  – Law
  – Ethics

• Sequential
  – Expressed wishes;
  – Substituted judgment;
  – Best interest.
Expressed Wishes

Georgia Advance Directive for Health Care

By: [Print Name]  Date of Birth: [Month/Day/Year]

This advance directive for health care has four parts:

PART ONE—Health Care Agent. This part allows you to choose someone to make health care decisions for you when you cannot (or do not want to) make health care decisions for yourself. The person you choose is called a health care agent. You may also have your health care agent make decisions for you after your death with respect to an autopsy, organ donation, body donation, and final disposition of your body. You should talk to your health care agent about this important role.

PART TWO—Treatment Preferences. This part allows you to state your treatment preferences if you have a terminal condition or if you are in a state of permanent unconsciousness. PART TWO will become effective only if you are unable to communicate your treatment preferences. Reasonable and compassionate care may be provided even if you have not completed this part of the form. The reasonableness and compassion of care will be determined by a health care provider. You should talk to your family and others close to you about your treatment preferences.

PART THREE—Guardianship. This part allows you to nominate a person to be your guardian should one ever be needed.

PART FOUR—Effectiveness and Signatures. This part requires your signature and the signatures of two witnesses. You must complete PART FOUR if you have filled out any other part of this form.

You may fill out any or all of the first three parts listed above. You must fill out PART FOUR of this form in order for this form to be effective.

You should give a copy of this completed form to people who might need it, such as your health care agent, your family, and your physician. Keep a copy of this completed form at home in a place where it can easily be found if it is needed. Review this completed form periodically to make sure it still reflects your preferences. If your preferences change, complete a new advance directive for health care.

Using this form of advance directive for health care is completely optional. Other forms of advance directives for health care may be used in Georgia.

You may revoke this completed form at any time. This completed form will replace any advance directive for health care, durable power of attorney for health care, health care proxy, or living will that you have completed before completing this form.

PART ONE—Health Care Agent

PART ONE will be effective even if PART TWO is not completed. A physician or health care provider who is directly involved in your health care may not serve as your health care agent. If you are married, a future divorce or annulment of your marriage will revoke the selection of your current spouse as your health care agent. If you are not married, a future marriage will revoke the selection of your health care agent unless the person you selected as your health care agent is your new spouse.

1. Health Care Agent

I select the following person as my health care agent to make health care decisions for me:

Name: [Name]
Address: [Address]
Telephone numbers: [Telephone numbers]
Expressed Wishes

• Surrogates role is constrained by expressed preferences
  – Surrogates are second best for exhibiting patient’s autonomy
    • Preference is first hand evidence of patient’s decisions/preferences.
Erica

- 43 year old woman
  - Fell 10 days ago
  - Presents with back pain
  - Respiratory failure requiring intubation
  - MRI shows hemorrhage near spine and unassisted re-absorption likely.
Erica

- Sister is POA
- Advance directive
  - “No intubation or mechanical ventilation.”
- Sister
  - “Ignore the directive”
  - “Told me on many occasions that she did not want intubation.”
Should we listen to sister’s request?

A. Yes
B. No
C. Unsure
Substituted judgment

• Without express, specific instructions to guide them, surrogates must engage in some alternative means of decision making
• Under this standard, surrogates “infer” the patient’s wishes from prior behavior, statements, values.
How accurate do you believe your surrogate will be able to predict your health care preferences?

A. 94%
B. 72%
C. 50%
D. 37%
Concordance anyone??

- Analyzed 19,526 paired responses
  - Asked patients what they would want and the independently asked the surrogates want their loved one/friend would want

- Overall, surrogates predicted patients' treatment preferences with 68% accuracy.
- Patient-designated and next-of-kin surrogates incorrectly predict patients’ end-of-life treatment preferences in one third of cases

- Neither patient designation of surrogates nor prior discussion of patients’ treatment preferences improved surrogates 'predictive accuracy significantly.
Whose preferences?

- Studies suggest that surrogates project their own beliefs onto the decision being made
  - Examined 144 patient-surrogate pairs in which surrogates inaccurately predicted patients' CPR (cardiopulmonary resuscitation) v. DNR (do not resuscitate) decisions
    - Of the patient-surrogate pairs who disagreed on CPR v. DNR, 62% demonstrated projection of their personal beliefs.
  - They also looked at 294 pairs in which surrogates inaccurately predicted patients' extend life v. relieve pain preferences.
    - Of the patient-surrogate pairs who disagreed on extend life v. relieve pain preferences, 88.4% of surrogates demonstrated projection of their personal beliefs.
What can we learn

• Surrogate inaccuracy is strongly biased toward overestimating patient desires for treatment.
• Surrogates are more likely to request aggressive life-sustaining treatment for a patient than the patient would for herself.
Best Interest

• When a patient’s wishes, values or beliefs are unknown we turn to the best interest standard
• Shift from patient autonomy to patient welfare.
• This standard is a completely impersonal standard.
  ▫ Attempt to be objective
• Base the decision on what a hypothetical reasonable person would want
Best Interests

• Factors to consider
  • (1) the patient's present levels of physical, sensory, emotional, and cognitive functioning;
  • (2) the quality of life, life expectancy, and prognosis for recovery with and without treatment;
  • (3) the various treatment options and the risks, side effects, and benefits of each;
  • (4) the nature and degree of physical pain or suffering resulting from the medical condition;
  • (5) whether the medical treatment being provided is causing or may cause pain, suffering, or serious complications;
  • (6) the pain or suffering to the patient if the medical treatment is withdrawn; and
  • (7) whether any particular treatment would be proportionate or disproportionate in terms of the benefits to be gained by the patient vs the burdens caused to the patient.
Happiness
In one year, would you be happier as a lottery winner or as a quadriplegic?

A. Lottery Winner
B. Quadriplegic
Happiness in 1 year

![Bar chart showing happiness in 1 year for Lottery and Quad categories.]
Solutions

• Surrogate Replacement
• Shared Decision Making
• Meetings
• Education of Role
Surrogate Replacement

- Surrogates fail on their duties
  - Do not know patient preferences
    - Data above
  - Don’t follow the patient preferences
    - Lack of understanding of clinical picture
    - Interference of their beliefs

- Ethical obligation to ensure authentic decisions are made on patient’s behalf
Challenges

• Reluctance to replace

• Time requirement
Shared Decision Making

• “Shared decision making is a collaborative process that allows patients, or their surrogates, and clinicians to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient’s values, goals, and preferences”
Informed Non-Dissent

• With informed non-dissent decision making, the physician, guided by the patient's values, determines the best course of action and fully informs the patient.
  – Concerns
    • Power Imbalance
What is your role

• Educate about role of surrogate decision maker
  – Lack of preparation for surrogate roles.
Questions

Thank you

jason.lesandrini@wellstar.org
References


