Choosing for Others: Emotional, Psychological and Social Challenges of Deciding for Others

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Objectives

- To consider the effect on Surrogates of making treatment decisions for others
- To identify what helps and hinders the experience of making medical decisions for others
- To examine differences in culture regarding surrogacy
- To identify best practices for medical professionals in supporting surrogates
Surrogacy

- Variables:
  - Family History
  - Culture
  - Understanding of medical information
  - Communication issues
  - Family conflict
Medical Decisions

- Surrogate decision-makers
  - Make 75% of the decisions for hospitalized patients with life-threatening illnesses in the ICU
  - Make 44-69% of decisions for nursing home residents
  - Making decisions is stressful for surrogates

- Hiltunene et al., 1999; Kim et al., 2002
Medical Decision Makers

- 1/3 of surrogates who made medical decisions for a loved one in the ICU had symptoms of post-traumatic stress disorder (PTSD)
  - Azoulay et al, 2005

- Conversely, care that supports patient and family concerns (i.e., hospice) may produce better health outcomes for surrogates
  - Christikas, 2003; Bradley et al, 2004
Surrogate-Patient Relationship and Communication

- Duty as a decision maker
- Decisions which result in reduced suffering made decision making less burdensome
- Familiarity with a loved one’s preferences made decision making easier
- “still a hard decision to make”

Vig et al, 2007
Systemic Review of 40 articles

- Most data pertained to end of life decisions (choosing to initiate, withhold, continue, or withdraw life-sustaining treatment)

- 1/3 of surrogates experienced negative burden that was “substantial” and typically lasted months, or in some cases years
Stress, Anxiety or Emotional Burden

- Most common negative effects:
  - Guilt over decisions made
  - Doubt about if they had made the right decisions

- Wendler, Annals of Int Medicine, 2011
Beneficial Effects

- 9 of 40 studies reported beneficial effects for some surrogates
  - Most common: supporting the patient and feeling a sense of satisfaction
  - Knowing which treatment was consistent with patient’s wishes reduced the negative effect on surrogates, and served as a protective factor

Nonetheless.....

- Summary of 30 interviews with family members used these terms to describe the experience:
  - “difficult”, “intense”, “painful”, “overwhelming”, “devastating”, “traumatic”
  - “the hardest thing I’ve ever done in my life”

- Tilden, Tolle, et al, J of Fam Nurs, 1999
Surrogate Satisfaction

- 71% of 789 surrogates were “very” or “completely” satisfied

- 80% had “good” or “excellent” levels of satisfaction
  - Heyland & Tanmer, Jnl of Crit Care, 2001:16

- 5 studies found that surrogates who were satisfied still experienced high levels of emotional burden
  - Meeker, Qual Health Res, 2004:14
  - Caron, et al, Dementia, 2005:4
Stanford Video:
Letting go........

- Surrogates repeatedly “searched their own sense of morality about making a decision that could be interpreted as taking another person’s life”.

- “The thing I love most in life I don’t want to kill. That part I agonized over a lot”.

- “Did I do the right thing?”
  - Chambers-Evans & Carnevale, J Clin Ethics, 2005
Surrogate-Clinician Communication and Relationship

- Availability of clinicians to answer questions and offer support prior to decision making very helpful

- Importance of frank information in lay terms from clinicians about patient’s condition and prognosis, or outcomes needed is important

- Surrogate appreciated when clinicians made treatment recommendations

  - Vig et al, 2007
Surrogates...

- When they trusted their loved one’s clinicians, felt respected by the care team, and felt that their input was listened to and valued by the team, decisions were easier to make

- Problematic: Too many clinicians, with no single person to coordinate communication

  - Vig et al, 2007
Study by Race

- Voices of African American, Caucasian, and Hispanic Surrogates on the Burdens of End of Life Decision Making, Braun et al, JGIM, 2008

- **African American patients** prefer more aggressive treatment than Caucasians

- Preferred that MD’s be more “approachable” and “less abrasive”, more sensitive but truth-telling

- Most believed that “doing everything was the “right thing”, but “the rest was up to God”
Study by Race (cont.)

- **Hispanic surrogates** wished that MD’s would be more proactive in convincing patients to discuss their concerns with families (especially Hispanic men)
- Expressed high level of appreciation if MD’s took time to speak with the whole family
- Expressed the most anxiety about other family members “blaming them” for making the wrong decisions
- Viewed suffering as a “test of faith” but didn’t feel the need to keep going until “God decided”
Study by Race (cont.)

- Some members across all races viewed MD’s as instruments of God
- Some expressed belief in miracles
- All groups asked for better communication with MD’s
- Dominant theme: Surrogates experienced tremendous burden of decision making that transcended race/ethnicity
  - Braun et al, 2007
Two apparent contributors to burden

- Uncertainty of prognosis
- Uncertainty of patient’s wishes

- American College of Critical Care guidelines suggesting staff training to recognize family members’ stress
  - Davidson et al, Crit Care Med, 2007
What helps, and what hampers?

- Most internists receive little (if any) training about how to work with surrogates
  - Anzoulay & Sprung, Crit Care Med, 2005:17

- The education may be limited to descriptions of the ethical principles guiding surrogate decision making
  - Weissman & Block, Acad Med, 2002

- As a result, clinicians may focus primarily on the patient’s needs neglecting the surrogate’s perspective and need for support
  - Meeker, Qual Health Res, 2004
Need for clear communication

- Availability of clinicians to answer questions and offer support prior to decision making helpful

- Importance of frank information in lay terms that they can understand about patient’s condition and chances for recovery

- Some surrogates wanted more clear guidance from MD’s about decisions

- White et al, Crit Care Med, 2010
Maternal Beneficence

- Kind, compassionate guidance from MD’s
- Clinicians may want to ask surrogates to identify the most difficult aspects of the decisions at hand
- Social workers and chaplains can add a layer of support
- Designation of one MD as a spokesperson for the team is helpful
- Offering reassurance that the surrogates have made a good decision may help with closure and reduce distress

Substituted Interests and Best Judgments

- Substituted interests model is individualized and patient-centered and combines universal principles with empirical evidence about what individuals value.
- The model emphasizes authenticity (true to who the person is) vs. autonomy (that the person cannot exercise).
- Asks surrogates to provide knowledge of the patient’s authentic values and interests (substituted interests), and to make a “best judgment” about what decisions would advance the good of the patient.

  - Sulmasy & Snyder, JAMA, 2010-Vol. 304
Substituted Interests and Best Judgements

- The hierarchical model emphasizes information and the intellectual process of decision making.

- The hierarchical model emphasizes patient preferences (despite only 5%-25% of patients having advance directives).

- Most patients cannot anticipate all future circumstances and preferences may change in actual illness.
  - Sulmasy & Snyder, JAMA, 2010-Vol. 304
Substituted Interests and Best Judgments

- Knowledge of the patient’s values, commitments, and relationships, including the patient’s beliefs about how decisions should be made and by whom is important.

- In this model, decision making is shared with, rather than delegated to, the surrogate.

- The clinician draws on expertise and clinical experience to help the surrogate define the patient’s interests.
Shared Decision Making

- Delegating decisions to surrogates leaves families less satisfied and more distressed.

- Advance directives still serve as an important guide, but more important is encouraging discussion with loved ones about process of decision making is essential.

- Sulmasy & Snyder, JAMA, 2010- vol. 304.
Substituted Judgement

- Empathy and Connection
- Authentic values: understanding the patient as a person
- Clinical data: patient’s circumstances and prognosis
- Substituted interests: patient’s real interests and values
- Clinical judgment: understanding of options and offering recommendations based on patient’s real interests
- Best judgments for the patient

- Sulmasy & Snyder-JAMA, 2010-Vol. 304
Expanding the Paradigm of the MD Role

- Three possible approaches to decision making:
  - Paternalism
  - Informed Choice
  - Shared Decision Making
    - White et al, Crit Care Med, 2010
Physician-surrogate relationships

- Informative role
- Facilitative role
- Collaborative role
- Directive role

White, et al, Jnl Crit Care Med, 2010
Informative Role

- Provide information about condition, treatment options, and prognosis
- Gave all responsibility for decision making to surrogates
- Did not give an opinion
- Did not clarify patient’s values
  - White, et al, Crit Care Med, 2010
Facilitative Role

- Assist surrogates by clarifying patient’s values
- Maintained position of neutrality and offered no opinion about withdrawal of life support
- This approach goes beyond the informative role by attempting to clarify values

- White et al, Crit Care Med, 2010
Collaborative Role

- Gives information
- Clarifies patient’s values
- Provides a recommendation about if life support should be continued

- White, et al, Crit Care Med, 2010
Directive Role

- Assumes control over decision making
- Offers minimal information
- Makes decisions independently

Families often asked for a recommendation. Many MD’s reluctant to offer one, for personal or ethical reasons, recognizing the power differential between patient/family and MD’s.

- White et al, Crit Care Med, 2010
Recommendations

- Facilitative role - MD takes an active role in coaching the family. Allows MD’s to use their expertise to guide families while minimizing undue influence.

- Suggest that MD’s be flexible in approach, depending on the needs of the family.

- If surrogates request recommendation from MD, it may not be in the patient’s best interests to withhold assistance from decision-making.

- Need to train MD’s to discern surrogates needs and adapt approach.

  - White et al, Crit Care Med, 2010
Conclusions

- Surrogacy, deciding for others, can be burdensome
- MD’s and other health care professionals can benefit from identifying what is most helpful to surrogates
- Having AD’s is very helpful to surrogates, and can reduce distress
- “Maternal Beneficence” and shared decision-making can be helpful
Conclusions:

- Family members and surrogate-decision makers must live with the decisions they make long-term.

- Health care professionals can help reduce the burden by partnering with them and giving clear information in lay terms and guidance as requested.

- This may reduce the guilt and the burden, and allow family members to grieve with fewer complications.
Conclusions:

- The goal is to help patients to “finish well” (as is possible) and for families to maintain a sense of congruence and meaning even as they navigate the loss of a loved one.