When Sharing Fails: Ethical Strategies for Clinicians when Surrogates Disagree.

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Some goals of “ethics talks.”

• To assist, clarify, and share thoughts on common ethical situations.
• To promote reflection, and self-reflection, in clinical practice.
• To acknowledge and respond to the presence of complexity and uncertainty.
• To encourage the use and development of judgment in situations that demand it.
• To share discussion around difficult questions.
• To explore practical solutions to real dilemmas.
Examples of Disagreement

• Family of patient with end stage dementia insists that patient would not want to be spoon fed, while team insists that this basic care is due to all human beings.

• Senior with previously well-controlled schizophrenia is hospitalized after daughter removes meds, insisting that “natural remedies are better.”

• Patient’s son who witnessed his mother fall after trying to get up insists that she be restrained by a belt at all times.
Typical Dilemmas

• Curative Care or Comfort Care?
• Respect Liberty or Maximize Safety?
• Feeding tube or oral feeding at risk?
• Attempt at CPR or not?
• Send to hospital or treat in place?
• Respect an agent’s “unreasonable” requests, or not?
• Support alternative therapies, or not?
• Many others.......
Shared Decision Making

• Goal is consensus via genuine communication.
• Shared among patient, official surrogate, family, physicians, and clinical teams.
• Shared via patient chart, conversations, and meetings.
• Often “serial sharing” among physicians nurses coming on and off service. Depends on effective hand-off of information.
Communications and Relationships

• The first elements to consider in a situation of disagreement.
Natural Progress of an Ethical Challenge

• First, the problem is identified by some member of the care team.
• Then it is generally addressed by that team, as well as by immediate colleagues.
• Next, advice might be sought from trusted and experienced members of one’s local community.
  • Administrators, leaders, experienced colleagues.
• Or, after “ethics escalation....”
• Experienced clinical ethicists.
• Ethics Committees.
  • Select “Community of Peers.”
  • Usually accessed via an ethicist.
Defining the question

• True ethical dilemma?
• Communications breakdown?
• A grief reaction?
• Moral distress?
• Is advice needed around the process for addressing the problem, or solutions to the problem itself?
The Clinical Ethics Consultation

- Offers *advice* on ........
- How might this problem be solved?
- How should this decision be made?
- Who should be involved?
- What should a decision be?
- Why might this patient and family lack trust?
- What values are at stake and what compromises are possible?
- Etc.
Conventional Ethical Analysis

• Applying Principles....
  – Respecting persons
  – Doing good
  – Minimizing harm
  – justice

• Working for good outcomes
  – Seeking the good and making it happen
“Narrative” Ethical Analysis

• Gathering the story of this patient, and understanding the context of this illness in the patient’s life.

• Gathering and recording this, accurately, is the key to preventive ethics.
Story gathering and Prevention

• Gathering the right story is what enables us to help set the right goals for a patient.

• Ultimately, good, robust, thorough advance planning, supported by good, thorough current thinking, prevents ethical breakdown.
Confounders

• When exactly is surrogate needed?
• When are personal directives to be followed precisely, and when, maybe, not?
• Disagreement among family members.
• Conflicts of interest in family members.
• Capacity uncertainties.
Process suggestions if Disagreement is developing:

• 1. Ask patient for direction, whenever possible.

• 2. Provisionally identify issue – is it about a process, or a substantive decision?
  • What are your duties? How important is it? How certain are you of “right thing to do?”

• 3. Set up specific meeting to discuss issue, with as much of the “sharing team” as possible.
To consider:

- Does surrogate have a general mistrust of you and/or the medical system?
- Does the surrogate have a reason, perhaps, to be mistrustful?
  - If so, then addressing this specifically can build trust.
- To what degree might this surrogate be influenced by conflicts of interest – both consciously and unconsciously?
To consider:

- How rational is the surrogate/family?
- How rational are you?
- Are grief processes playing a role?
- Do any other clinicians know this patient and family well?
- How entrenched is this disagreement currently?
- Ethics service, legal advice, etc.
- What key parts of the story might you be unaware of?
Goal of practical ethics:

• Answering the general question:

• **What should be done?**

• How, why, when, and by whom are all relevant questions as well.

• Such questions arise hundreds or thousands of times each day in a typical health care facility.
Goal of descriptive ethics:

• What have we done?
• What are we doing?
• Why?

• Need to understand these before determining what should be done.
Preventing/minimizing disagreement

- Open Communication
- Respect for patients and Colleagues.
- **Trust Building.**
- Good care planning. Charted.
- Caring professionals.
- Learn from adversity and improve systems.
- **Personal relationships.**
Toward Shared Decision-Making

• Consult with patients for as long as possible.
• Ensure voice of patient is maintained.
• Coach agents to consider BOTH the “patient’s wishes,” and “best interests.”
• Get to know your patients and their loved ones, and strive to build trust.
• Decision is “shared” between patient, loved ones, and physician/clinician.
• Pay attention to potential conflicts of interest.
Trust and its value in healing

• We know that a positive attitude in a patient can significantly influence clinical outcomes.

• During illness, when people are most vulnerable, fear and mistrust are exacerbated when caregivers are strangers.
Thanks – Comments or Questions?

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