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 form 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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