

Are We Making the Right Decision?

Exploring Ethical Deliberation Through Interactive Case Analysis

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If we are not be able to address the issues immediately, we will work on ensuring they do not occur in the future.



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Adventist Bioethics
CONSORTIUM

Road Map

- Robert Orr – Ethics consultation process and format
- Grace Oei – Interactive case presentation

Objectives

- Describe the purpose and process of ethical deliberation and identify different frameworks of ethical deliberation
- Examine appropriate ways of recording ethical deliberation
- Identify pertinent ethical issues and assess the ethical analysis in the case presented

A Process and Format for Ethics Consultations

Robert D. Orr, MD,CM

Functions of Ethics Committee

1. Education
2. Policy
3. Consultation

Purpose of Ethics Consultation

- To identify, analyze and resolve ethical dilemmas in the care of individual patients.
- Documentation of the process and the analysis is extremely important.
 - In the chart
 - Readable
 - Good grammar, syntax, spelling, etc

Methods of Ethics Consultation

- Committee
- Subcommittee
- Individual

Components of Report

- Demographic information
- Ethics question
- Narrative
- Assessment
- Discussion
- Recommendations

Doing the Consult

VS writing the report

The Request

- Who?
 - Hospital policy should state that anyone involved in the patient's care may request an ethics consult, including patient or family
 - Request may come from ward clerk; find out who wrote the order
 - The one who wrote the order may not be the one who raised the issue
 - Talk with requestor; "How can I be of help?"
- The request may or may not be the same as the "Ethics Question"

Review the Chart

- To learn the demographic info
- To learn the history
 - May require looking at old charts
- To determine who to talk with

See the patient

- To determine their capacity/understanding/wishes
- Should you examine the patient?

Talk with.....

- Attending physician
- Bedside nurse
- Consultants/therapists
- Social worker/chaplain/discharge planner
- Primary MD
- Nursing home staff
- Visiting nurse
- Family/guardian
- PATIENT

Management conference?

- Perhaps while collecting information
- More often it is one of your recommendations
- You might set it up yourself, or ask someone else
- You should usually suggest who the attendees should be
- Might be facilitated by you or member of clinical team

Writing the Report

- Demographic information
- Ethics question
- Narrative
- Assessment
- Discussion
- Recommendations
- Sign off

Demographic information

- Patient's name, MRN, DOB
- Date of admission & date of consult
- Location of patient
- Attending physician and what clinical service
- Source of your info [may go in a progress note]
 - Chart review
 - Informants

Request vs Ethics Question, e.g.

- “Can we write a DNR order for this patient?”
- “Is it ethically permissible to ignore this family’s request for full treatment when the clinical team believes CRP would be ineffective?”

Narrative

- The WHOLE story
 - The whole clinical picture
 - What led to the question?
 - Perspectives/positions/opinions of the various stakeholders
- No new information should be added once the Narrative is completed
- This is the info you will use for your analysis

Assessment

- 2 or 3 sentence summary of the dilemma
 - The clinical picture
 - The ethical dilemma
- No need to repeat details
- E.g.: “After a prolonged ICU stay, this man is in multi-organ-system failure with a very poor prognosis for survival. His careteam wants to withhold CPR but his family insists that ‘everything’ be done.”

Discussion

- 2 parts:
 - A brief discussion of the principles/precepts/precedents/law of the ethical issue identified (e.g., autonomy, surrogacy, futility)
 - How this applies “In this case...”

Recommendations

- 2-4 (or 5) conclusions or suggestions; these are almost always optional
- Wording is critical:
 - “It is ethically (or not ethically) permissible to...”
 - “It might/would be appropriate to...”
- NOT “You should/must...”
- Should you make clinical suggestions?
 - Probably not in the chart; perhaps person to person

Sign off

- “Thank you for asking me to participate with you in deliberations about the further management of this patient. If I can be of further assistance, do not hesitate to contact me.”
- Clearly identify yourself
 - Name
 - Role
 - Contact info

The Report

- Call requestor and/or attending MD
- Always include your report in the chart
- Progress note
- Copy for Ethics Consult Service
- Occasionally give copy to patient/family

The Report

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Follow-up

- As appropriate to the case
 - At least once
 - Sometimes until discharge
 - Sometimes after discharge
- Notes for ESC
- Occasionally notes in the chart

Case Presentation

Grace Oei, MD, MA, HEC-C

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy

Case Presentation and Deliberation

- Jeune's syndrome or asphyxiating thoracic dystrophy
 - Rare genetic disorder, form of dwarfism, born with small and narrow rib cage
 - Bones and cartilage do not grow as expected
 - Limited capacity of the lungs to expand → respiratory distress → multiple respiratory infections
 - Other organs usually affected such as the kidneys, liver, pancreas
- Treatment
 - Surgery to expand rib cage
- Prognosis
 - Severely affected children usually die as infants or young children

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy

- S/p implantation of titanium rib expanders
- Also with chronic respiratory failure with tracheostomy and ventilator dependence, liver cirrhosis, developmental delay
- Lived at a long term care facility for children
- 1 year prior to current admission parents agreed to forgo chest compressions in the event of cardiopulmonary arrest

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment

- Increased respiratory distress → ED → code blue → 3 rounds of epinephrine → return of spontaneous circulation
- Hypoxic ischemic brain injury from code blue → severe permanent neurologic injury

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment now with severe permanent neurologic injury

- 2 months later in the PICU...
 - Limitation of treatment expanded to exclude defibrillation and dialysis in addition to chest compressions
 - Still OK to give epinephrine and other “code” medications
 - Multiple episodes per day of severe hypoxia and hypercarbia requiring increased sedation and paralysis
 - Code blue called 2 days ago

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment now with severe permanent neurologic injury

- 2 months later in the PICU...
 - Parents would like patient to be able to go back to her long term care facility
 - Ethics consulted requested: "Is this child receiving futile treatment?"

The Request

- Who?
 - Hospital policy should state that **anyone involved in the patient's care may request an ethics consult**, including patient or family
 - Request may come from ward clerk; **find out who wrote the order**
 - The one who wrote the order may not be the one who raised the issue
 - Talk with requestor; **“How can I be of help?”**
- The **request may or may not be the same as the “Ethics Question”**

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment now with severe permanent neurologic injury, still requiring intensive and aggressive therapy 2 months into the hospital stay

- Request came from the attending physician

Question 1

Is this primarily an ethics question or a medical question?

- A. Primarily a medical question
- B. Primarily an ethics question
- C. Both
- D. I'm not sure

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment now with severe permanent neurologic injury, still requiring intensive and aggressive therapy 2 months into the hospital stay

- Request came from the attending physician
 - Patient is not getting better and will likely never go back to her long term care facility because of her required level of care
 - Repeated events of “trying to die”
 - “What are we doing?”

Question 2

What is the ethical issue(s) under discussion? (Choose all that apply)

- A. Futile treatment
- B. Non-maleficence – physician is doing harm by continuing treatment
- C. Physician / family disagreement on goals of treatment
- D. Physician / family disagreement on prognosis (unrealistic family expectation)
- E. Institution of unilateral withdrawal of support by physician
- F. Clinician moral distress

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment now with severe permanent neurologic injury, still requiring intensive and aggressive therapy 2 months into the hospital stay

- Consultation request was not the same as the underlying ethics question
- “Is this child’s treatment futile?” is not the same as “Can we stop treatment?”

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment now with severe permanent neurologic injury, still requiring intensive and aggressive therapy 2 months into the hospital stay

- Chart review
- Patient examined
- Conflict of interest discussed

Talk with.....

- **Attending physician**
- **Bedside nurse**
- Consultants/therapists
- Social worker/chaplain/discharge planner
- Primary MD
- Nursing home staff
- Visiting nurse
- **Family/guardian**
- PATIENT

Narrative

- The **WHOLE** story
 - The whole clinical picture
 - What led to the question?
 - Perspectives/positions/opinions of the various stakeholders
- This is the info you will use for your analysis

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment now with severe permanent neurologic injury, still requiring intensive and aggressive therapy 2 months into the hospital stay

- RN
 - No clear goals of treatment – clinicians change too often to set clear goals
 - Unknown who is talking with the parents
 - Devoted parents

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment now with severe permanent neurologic injury, still requiring intensive and aggressive therapy 2 months into the hospital stay

- Parents (with Spanish translator)
 - Grateful for the care their daughter has received
 - Know she is very sick and if she cannot get better, would like for her to not be in pain

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment now with severe permanent neurologic injury, still requiring intensive and aggressive therapy 2 months into the hospital stay

- Parents (with Spanish translator)
 - “They expressed that whenever a doctor asks them what they would like to have done for their daughter, they feel that they do not know the answer that the doctor is looking for.”

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment now with severe permanent neurologic injury, still requiring intensive and aggressive therapy 2 months into the hospital stay

- Parents (with Spanish translator)
 - Denied that withdrawal of therapy was ever discussed with them
 - Did not know that withdrawal of therapy was an option
 - Believe that God will take the patient when the “time is right”

Case Presentation and Deliberation

- A. Futile treatment
- B. Non-maleficence – physician is doing harm by continuing treatment
- C. Physician / family disagreement on goals of treatment
- D. Physician / family disagreement on prognosis (unrealistic family expectation)
- E. Institution of unilateral withdrawal of support by physician
- F. Clinician moral distress

Case Presentation and Deliberation

How can the physician and the clinical team partner with the family to make the best decisions for this patient that are consistent with the family's goals and values?

- Beneficence and non-maleficence (practicing good medicine)
- Physician's moral authority and moral responsibility for decision making
- Truth-telling
- Conflicts of interest
- Reflection on what to do if personal values differ from family's values

Assessment

- 2 or 3 sentence summary of the dilemma
 - The clinical picture
 - The ethical dilemma
- “This chronically ill child suffered severe hypoxic brain injury a month ago, and her prognosis for meaningful recovery is unlikely. Her parents have agreed to some limitations of treatment, but a specific care plan is not in place. Her team believes her current level of treatment is futile.”

Discussion

- 2 parts:
 - A brief discussion of the principles/precepts/precedents/law of the ethical issue identified (e.g., autonomy, surrogacy, futility)
 - How this applies “In this case...”

Question 3

What is the definition of futility or futile treatment?

- A. If the probability of the treatment's success is exceedingly small
- B. If the treatment cannot restore the patient to his or her pre-hospital state
- C. If the treatment appears to be causing more harm than good
- D. If the physician strongly recommends against the treatment
- E. If the treatment cannot physiologically accomplish the stated goal

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment now with severe permanent neurologic injury, still requiring intensive and aggressive therapy 2 months into the hospital stay

- **Futility is goal dependent**
- If the treatment will accomplish the goal, it is not futile
- There is likely disagreement about the goal of treatment

Case Presentation and Deliberation

How can the physician and the clinical team partner with the family to make the **best decisions** for this patient that are consistent with the **family's goals and values**?

- Best interest standard, informed by the parents' goals and values
 - Burden / benefit analysis
 - Physician's moral authority and moral responsibility for decision making
 - Truth-telling (conflicts of interest)
- Reflection on what to do if personal values differ from family's values

Question 4

Is it ethically permissible for physicians to offer a recommendation for or against treatment in end of life decision making?

- A. Yes
- B. No
- C. It depends...

Case Presentation and Deliberation

How can the physician and the clinical team partner with the family to make the **best decisions** for this patient that are consistent with the **family's goals and values**?

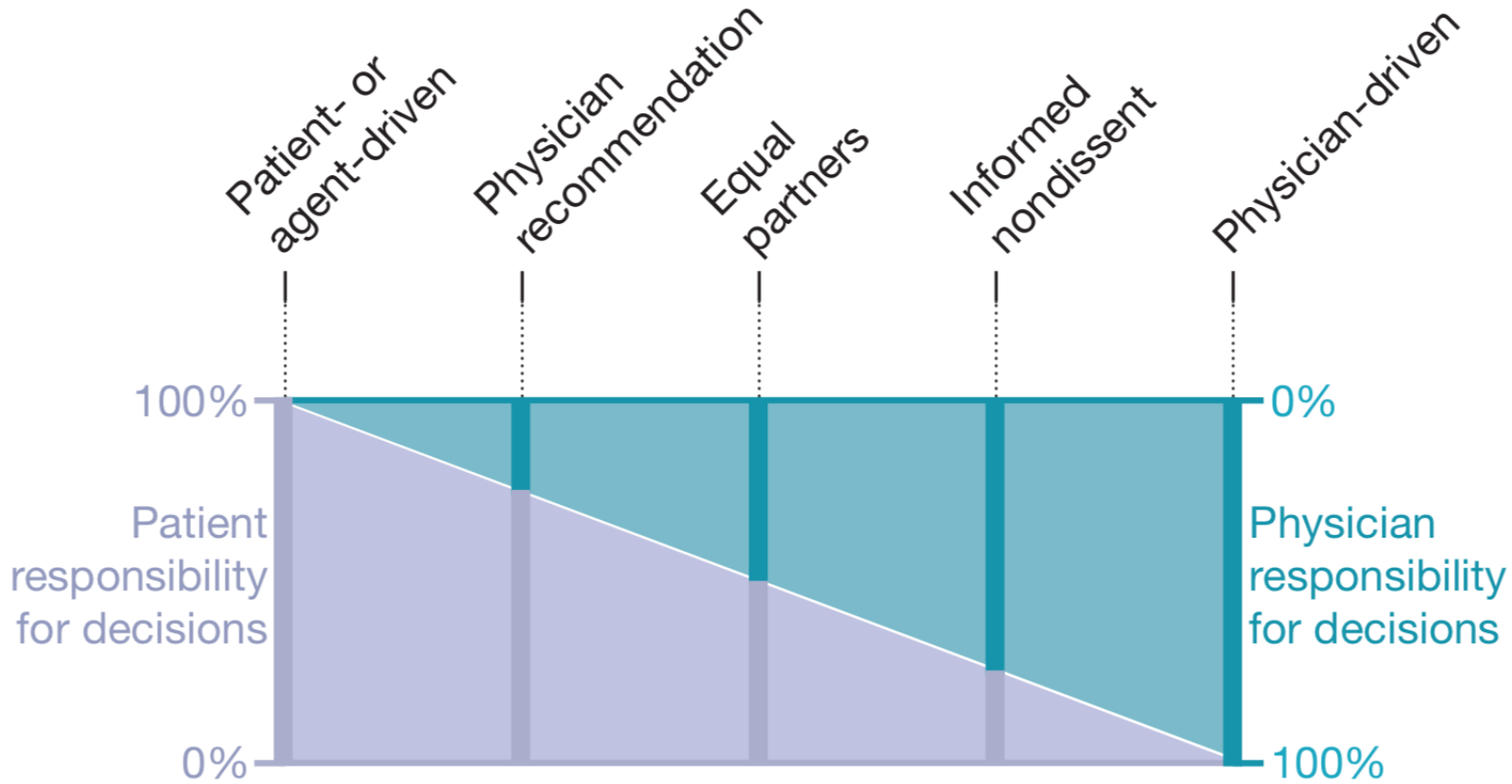
- Best interest standard, based on parents' goals and values
 - Burden / benefit analysis
 - **Physician's moral authority and moral responsibility for decision making**
 - Truth-telling (conflicts of interest)

The Shared Decision-Making Continuum

Alexander A. Kon, MD

tinuum (FIGURE). At one end is patient- or agent-driven decision making, at the opposite is physician-driven decision making, and in the middle are many possible approaches.

Figure. Shared Decision-Making Continuum



Case Presentation and Deliberation

How can the physician and the clinical team partner with the family to make the **best decisions** for this patient that are consistent with the **family's goals and values**?

- Best interest standard, based on parents' goals and values
 - Burden / benefit analysis
 - **Physician's ethical duty can include shouldering increased moral responsibility for decision making, including at the end of life**
 - Truth-telling (conflicts of interest)

Recommendations

- It is ethically permissible for the medical team to determine a reasonable course of action in the hopes of stabilizing her medical status for transfer back to TK.
- It is not unacceptable to recommend this course of action rather than to ask for parental consent.
- Communication between the medical team and the parents has not been clear in regards to other options for the patient, including palliative care. Cultural and family dynamics may necessitate increased emotional support from the medical team to help the family make these very difficult decisions.

The Report and Follow-up

- Call requestor and/or attending MD
- Check in afterwards with the team and family
- Copy for the Ethics Service for peer review

Case Presentation and Deliberation

11 year old female with Jeune's syndrome or thoracic asphyxiating dystrophy with multiorgan involvement and prior limitation of treatment now with severe permanent neurologic injury, still requiring intensive and aggressive therapy 2 months into the hospital stay

- Expanded limitation of treatment
- Pain control
- Died in the hospital

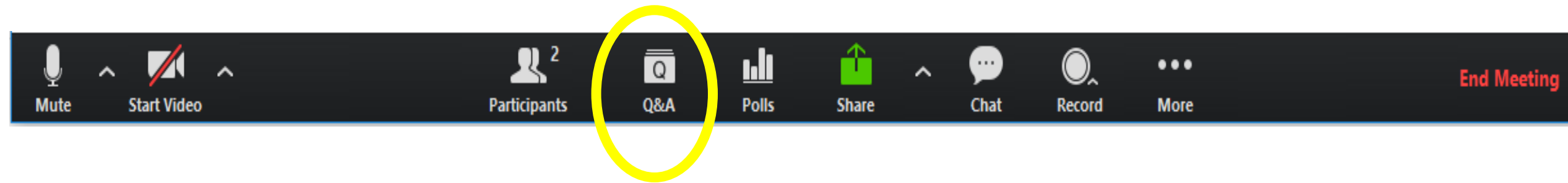
Ethics Consultation Process and Format

Did we do the best we could given the information we had at hand?

- Have a process and stick to the process
- Gather the appropriate information
- Seek multiple viewpoints including the patient and/or family
- Advocate for all clinicians to practice good medicine
- Examine conflicts of interest closely
- Reassess when clinical condition changes
- These are hard questions and sometimes there is no good answer

Question and Answers: (Ask Dr Oei. I'm retired!)

- To ask a question of the panelists, click on the Q&A button located in the Zoom toolbar and type your question.



- We may not be able to respond to all questions asked during the webinar. Questions that did not receive a response during the webinar will be followed-up at a later date.