"It Should Be Difficult": A Clinician’s Perspective on Medical Decision-Making

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Objectives

• Review predominant medical decision-making models
• Reflect on experiences participating in or observing medical decision-making
• Consider specific challenges encountered in the clinical application of these models through a case-based approach
• Share additional “stuck points”

Reflection
Shared Decision-Making

• Definition: A **collaborative** process that allows patients and clinicians to make health care decisions together, considering the best scientific evidence available, as well as the patient’s values, goals, and preferences.

• Ethical benefits
• Improved outcomes

Shared Decision-Making in the ICU
Shared Decision-Making in the ICU

We use shared decision-making to:
1. Define overall goals of care.
2. Reach major treatment decisions that may be affected by personal values, goals, and preferences.

Patients’ Decision-Making Preferences

- The majority of patients and family members prefer to share responsibility for decision-making equally with clinicians.
- Some prefer to exercise authority in decision-making, and others prefer to defer these choices to clinicians.

<table>
<thead>
<tr>
<th>Decision-Making Model</th>
<th>Value-Normal</th>
<th>Depend</th>
<th>Control</th>
<th>Value-Lower</th>
</tr>
</thead>
<tbody>
<tr>
<td>Juror</td>
<td>1%</td>
<td>1%</td>
<td>0%</td>
<td>10%</td>
</tr>
<tr>
<td>Juror after consulting physician</td>
<td>18%</td>
<td>22%</td>
<td>13%</td>
<td>40%</td>
</tr>
<tr>
<td>Shared responsibility for decision-making</td>
<td>1%</td>
<td>19%</td>
<td>20%</td>
<td>45%</td>
</tr>
<tr>
<td>Physician decides after consulting family’s options</td>
<td>27%</td>
<td>24%</td>
<td>17%</td>
<td>13%</td>
</tr>
<tr>
<td>Physician decides independently</td>
<td>37%</td>
<td>19%</td>
<td>0%</td>
<td>5%</td>
</tr>
</tbody>
</table>

Connor DM, J Gen Intern Med, 2015
Spectrum of Shared Decision-Making

Patient-driven model  Clinician-directed model

Reflection

Clinical Cases
Case 1:
25 y/o man with a history of substance use and seizure disorder presented after out of hospital cardiac arrest.
- Found unresponsive by family and received bystander CPR.
- EMS found patient to be without a pulse and achieved return of spontaneous circulation s/p Narcan x 6 without return of mentation.

Clinical Course:
- Cooled and rewarmed
- Myoclonic status epilepticus despite maximal doses of antiepileptics and sedatives
- CT scan consistent with hypoxic brain injury
- Persistent brainstem reflexes

Prognosis:
- High likelihood that the patient’s recovery would result in a persistent vegetative state dependent on machines

Case 1:
Determine whether to proceed with tracheostomy and PEG tube placement or pursue comfort focused measures.

Case 1: Surrogate Decision-Making
- Approximately one in five Americans die in or shortly after discharge from an ICU.
  - Many of these deaths occur following a decisions to withhold or withdraw life-prolonging therapies.

- Many critically ill patients lack decision-making capacity.
  - Surrogate decision-makers are asked to assist in making these difficult decisions using substituted judgement.

White, Arch Intern Med, 2007
Case 1: Surrogate Decision Making

Potential Challenges:

- Availability of values and preferences:
  - Often, incapacitated patient have never had conversations with loved ones

- Emotional:
  - Surrogates experience high rates of psychological distress (anxiety, depression, PTSD)
  - Critically ill patients often receive more intensive life-extending treatment than they would choose for themselves

- Projection bias:
  - Consciously or unconsciously making decisions based on their own values, or personal wishes, rather than the patient’s values

- Contextual:
  - Time pressure
  - Lack of communication training
  - Absence of pre-existing relationship

SUPPORT, JAMA, 2005
White, Arch Intern Med, 2007

Case 1: Surrogate Decision-Making

- Determine whether to proceed with tracheostomy and PEG tube placement?
  - Elicit the patient’s values and preferences:
    - Mother – “My son would not want to live this way.”
    - Father – “My son would have wanted life.”

- Medical team continued discussions, ultimately the patient’s mother agreed.
  - Patient underwent tracheostomy and PEG tube placement.
  - The medical team is working to control seizures with oral medications.
  - Family’s goal – for the patient to be discharged to a LTAC where they are hoping for a miracle.

Case 2:

58 y/o male with bipolar disorder and recently diagnosed stage IV NSCLC admitted with altered mental status found have renal and liver injury.

- 8 weeks prior presented with right shoulder pain and found to have a lung mass with enlarged lymph nodes.
  - Completed a POLST
  - Discharged to follow-up for outpatient biopsy
- 2 weeks prior presented with intractable back pain and found to have extensive skeletal metastasis.
  - Biween poorly differentiated NSCLC
  - Given poor performance status, he was deemed to be a poor candidate for chemotherapy.
  - Possible candidate for palliative immunotherapy, pending studies.
  - D/C to SNF for follow-up outpatient
Case 2:

- **Clinical Course:**
  - Imaging with new omental and hepatic metastasis, consistent with rapid progression of disease.
  - Molecular markers were negative
  - Intubated for severely depressed mental status in the context of multisystem organ failure

- **Prognosis:**
  - Very poor overall prognosis and low likelihood of clinical response to treatment due to poor functional status and multiple comorbidities, including encephalopathy, respiratory failure, renal failure, and liver injury.

Case 2:

- Operating under emergent implied consent
- **How to clarify goals of care?**
  - Patient is unable to provide any meaningful history or identify a surrogate decision-maker
  - Extensive next of kin search
    - Adoptive parents deceased for years, no other siblings or family members
    - Case manager listed as emergency contact
  - He has not outlined his wishes in advance

Case 2:

<table>
<thead>
<tr>
<th>Decision-Making Type</th>
<th>Decision-Maker</th>
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<tbody>
<tr>
<td>Informed</td>
<td>Patient and family members</td>
</tr>
<tr>
<td>Uninformed</td>
<td>surrogate decision-maker designated by patient</td>
</tr>
<tr>
<td>Deferred</td>
<td>Default surrogate (family) as defined by law, carrier by close relatives</td>
</tr>
<tr>
<td>Explicated</td>
<td>Medical Interventions (e.g., Blood transfusion)</td>
</tr>
</tbody>
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Page Ten, Due 2022
Case 2: The Unbefriended Patient

• Definition: Adults who lack decision-making capacity, a surrogate, and an advance directive.
• A growing epidemic in the U.S.
  • 5% of ICU decedents
  • 3-4% of long-term care residents
• Outcomes:
  • Compared to those with a surrogate, adults without a surrogate tend to have lower quality of end-of-life care
    • Fewer palliative care consults, chaplain visits, and do-not-resuscitate orders
  • Increased risk of receiving care that is not consistent with the person's values or preferences
    • Exposed to potential overtreatment or undertreatment

Karp N, American Bar Association, 2003
White DB, Ann Internal Medicine, 2007

Case 2: The Unbefriended Patient

• When a patient's prior wishes are unknown, clinicians are limited to use of the best-interest and substituted judgement standards.

• When patients have no advocates to oppose our recommendations, special scrutiny is needed.
  • Judicial intervention (guardianship)
  • Multidisciplinary ethics committees

Case 2: The Unbefriended Patient

Multidisciplinary ethics committee:
• Nursing, social work, care management, VPMA, physicians (renal, psych, palliative care, CCM), legal, community members, bioethicists

Question before the multidisciplinary committee: Is it ethically acceptable to forgo life-sustaining treatment and allow a natural death?
Case 2: The Unbefriended Patient

Forgoing life-sustaining treatment may be ethically acceptable if all the following conditions are satisfied:

a) Reasonable efforts have been made to identify an appropriate person to serve as a surrogate
b) There is consensus among physicians involved with the case that there is no significant change of meaningful recovery and life-sustaining treatment is of no expected benefit to the patient
c) There is unanimous consensus at a meeting of the Medical Ethics Committee that:
   1) Reasonable efforts have been made to identify an appropriate person to serve as a surrogate
   2) Considering the patient's condition and prognosis, a reasonable person would conclude that life-sustaining treatment is of no expected benefit and, therefore, not wanted.
   3) Reasonable efforts have been made to determine whether pertinent members of the health care team object to the forgoing of life-sustaining treatment for this patient, and insufficient reasons have been offered to conclude that forgoing treatment is ethically unacceptable.

Case 2: The Unbefriended Patient

- Ethics committee unanimously agreed that life-prolonging care should not be escalated further. Goals of care shifted towards providing comfort.
- Patient passed away several days later.

Case 3:

19 y/o female 6 months post-partum who presented via transfer for bilateral pneumonia and myocarditis secondary to parainfluenza virus.

- Clinical course complicated by:
  - ARDS and cardiogenic shock requiring VA with persistent respiratory failure s/p trachea and ventilator dependence
  - Malnutrition and deconditioning
  - Anxiety

- Social course complicated by:
  - Lack of dedicated and reliable social support
Case 3: Timeline

- 6/21: Admitted to CTICU via transfer on VA ECMO
- 7/26: Tracheostomy
- 9/4: Decannulated from ECMO
- 9/11: Transferred to the MICU
- 6/22: Mother refuses blood products. Ethics is consulted.
- 9/29: Family raises question of transplant candidacy
- 10/11: Multidisciplinary family meeting with Transplant and PACCM team
- 10/1: Family meeting with PACCM team, patient and mother – relayed patient is not a transplant candidate
- 8/28: Discussed at Transplant Committee Meeting

Case 3: Transplant Decision-Making

- Committee based decision-making process to select suitable candidates
  - Use medical and psychosocial criteria
  - Survey of heart transplant programs: Proportion of patients declined based on these reasons ranged from 0% to 37.5%
  - Transplant regulatory bodies have established medical standards for identifying appropriate medical candidates for transplantation but have not developed policies to standardize psychosocial criteria


Case 3: Transplant Decision-Making

Psychosocial Criteria

- Demonstrate psychosocial stability and ability to adhere to a complex, lifelong regimen of care
  - structural and instrumental support factors, both of which can serve a protective function for transplant patients
  - Research has demonstrated a strong relationship between good social support, medical adherence rates, and overall health outcomes.
  - Similarly, poor social support has been identified as a substantial risk factor for post-transplantation and predictor of graft failure.

Dimatteo, Health Psychology. 2004
Case 3: Transplant Decision-Making

Challenges:
• When and how to disclose to patient and/or family they are not eligible for a medically necessary procedure?
• How to compassionately communicate to a patient and their loved ones that the prohibitive issue is psychosocial?

Case 3: Transplant Decision-Making

• Conclusion: The patient was transferred to a hospital closer to home where she could spend time with her son.
  • She continued to work on rehabilitation and nutrition and was liberated from the ventilator 6 months later.

Take Home Points

• Shared decision-making is a collaborative process that involves the exchange of information and joint decision-making
• Clinicians frequently do not accomplish the basic steps of shared decision-making
• Medical decision-making is difficult, and further complicated when we lack access to patient’s values and preferences
• The paternalistic model remains used in specific clinical circumstances
Discussion Points

• What is something you have heard or made you feel stuck during decision-making?
• Have you been in a family meeting where decision-making was complicated?

Introduction

• Bachelor of Science in Philosophy and Biology – Boston College
• Medical Doctorate – University of Vermont College of Medicine
• Internal Medicine Residency – University of North Carolina
• Hospice and Palliative Medicine Fellowship – UPMC
• Master’s Degree in Clinical Research – University of Pittsburgh
• Pulmonary and Critical Care Medicine Fellowship – UPMC

UPMC Transplant Evaluation Process

• Formal versus informal evaluations
  • Formal:
    • Referred to a transplant center - thorough medical and psychosocial evaluation
    • Suitable for listing
    • Deferred from listing until medical and/or psychosocial concerns are resolved
    • Not a candidate due to unresolvable medical and/or psychosocial concerns
  • Informal:
    • Request from CCM team two months into the hospitalization in the context of known challenges
    • CTICU/Transplant social work asked to investigate
    • Discussed at selection committee with CCM, Transplant surgery, Transplant medicine, Social work
    • Risk factors significant enough to be considered prohibitive risks for transplantation.