Ethical Issues in Rehabilitation

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Disclosures: None
Session Learning Outcomes

Identify three ethical challenges in the continuum of stroke rehabilitation and describe a practical approach to the application of ethical principles in meeting these challenges.
Which of the following is the most frequent ethical issue in your practice?

A. Assessing Decision-Making Capacity 14%
B. Decisions to withhold or withdraw life-sustaining tx 14%
C. Treatment decisions dictated by a payor 14%
D. Conflicts between members of the care team 14%
E. Conflicts between the care team and patient/family 14%
F. Moral Distress 14%
G. Other 14%
Ethical Challenges in Rehabilitation and Disability

Kirschner et al. (2001), Ethical issues identified by rehabilitation clinicians

Goals -
1. To describe the ethical challenges faced frequently by rehabilitation clinicians
2. To determine what issues clinicians wished to have more information about
3. To identify how clinicians wanted to learn about these issues
Ethical Challenges in Rehabilitation and Disability

Kirschner et al. (2001), Ethical issues identified by rehabilitation clinicians

Primary issues identified –
1. Pressures around reimbursement (24%)
2. Conflict among team members (including patient and family) around goal setting (17%)
3. Difficulty assessing DMC (7%)
Ethical Challenges in Rehabilitation and Disability

Blackmer (2000), Ethical Issues in Rehabilitation Medicine

Primary issues identified –
1. Patient selection and resource allocation
2. Ethical issues in teamwork
Ethical Issues in the Care of the Stroke Survivor (Brady Wagner, Morris, Kirschner, 2013 in press)

• The effects of stroke on decision-making capacity and informed consent
• Balancing a person’s best interest and that of the family
• Dysphagia (need for alternative nutrition and hydration)
• Evidence and resource allocation in use of therapies and technologies
• Team conflict regarding the goals of rehabilitation
<table>
<thead>
<tr>
<th>Medical (Clinical) Indications</th>
<th>Patient Preferences</th>
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<tbody>
<tr>
<td>(Beneficence)</td>
<td>(Autonomy)</td>
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<tr>
<td>Quality of Life</td>
<td>Contextual Features</td>
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<td>(Non-maleficence)</td>
<td>(Justice)</td>
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Clinical Ethics Decision-Making Models

Medical Indications - The goals of medicine, what is felt to be clinically important and efficacious taking into account the medical history, accurate diagnosis, accurate prognosis and all treatment options
Clinical Ethics Decision-Making Models

- **Patient Preferences** - Examination of the patient’s ability to participate in decision-making must be considered. The patient’s personal history, religious and personal values, communicated preferences, advance directives, and self-assessed quality of life are all relevant here.
Clinical Ethics Decision-Making Models

- **Quality of Life** - Third-party assessment (Whose responsibility is it to decide when the patient cannot?)

- **Contextual Features** - External issues to consider such as economic constraints, family preferences, burdens on caregivers, other psychosocial parameters, and legal issues. Is it prudent to consider these features ‘at the bedside?’
“When you go to sleep, do you want to stay asleep and never wake up, or do you want to wake up again?” His eyes widened, “Wake up,” he said. (p. 52)

“Jeffrey,” I said, “you are not your legs. Jeffrey is not in your legs. Jeffrey is up here.” I tapped his head. “Jeffrey is up here, and that means you are still here, all of you.” (p. 44)
Healthcare providers and others tend to rate the quality of life of a person with a disability or chronic illness as lower than their own and lower than the person with the lived experience of disability would rate their own quality of life.

- Gerhardt et al., 1994
- Bach et al., 1994
- Albrecht and Devlieger, 1999
Refusal of medical intervention – specifically life-sustaining treatment (LST)

- Patients who are considered to be competent or who possess decision-making capacity have the right to refuse any medical treatment, including LST.

- Patients’ recognized proxy or surrogate decision makers are also allowed to refuse LST on behalf of a patient.
Wanting to live, wanting to die. . . To the extent that he wanted the nothingness of death, it was certainly only a reaction to the fact that at present he couldn’t get anything else he wanted. (p.52)
Allow patients time to adjust to the new sense of self (living through a liminal state, Kirschner, 2006)

- Time-limited trials and combination treatment
- Focus on alleviating suffering and handicap

*The stories of Christopher Reeve and David Rivelin*
Assist surrogate decision-makers and caregivers through this time as well

*The Case of Mr. D, Brady Wagner, 2001
(Mis)Application of the Golden Rule, Kothari and Kirschner, 2006

Use care when exercising “the golden rule” when you are in the position to support or validate another person’s decision if you have not personally lived their experience
ETHICAL ISSUES IN THE TEAM CARE CONTEXT

“Interdisciplinary teams share many ethical dilemmas with traditional medicine, but there are also a number of issues unique to the interdisciplinary team. Teams may apply much of the growing literature in bioethics to resolving ethical dilemmas, but they may also need to develop some new methods for approaching ethical questions that arise in the context of interdisciplinary patient care.”

H. Sharp, 1995
PHASES OF TEAM BUILDING

• Becoming Acquainted
  • Trial and Error
  • Collective Indecision
  • Crisis
  • Resolution
• Team Maintenance

Lowe and Herranen, 1981
ETHICAL ISSUES IN THE TEAM CARE CONTEXT

Lowe and Herranen (1981) discuss the goal of establishing consensus but they caution against ‘group think’ or enmeshment.

Enmeshment occurs when members of the team make decisions within the group for social benefit and lose the focus on the good of the patient. Opinions are given in order fit in with the group and not because the team member feels it is the ‘right’ recommendation for the patient.
ETHICS CONSULTATION IN TEAM CARE FACILITATION

“. . .proposed using a “counseling” or “educational” model of ethics consultation provided proactively in anticipation of difficult choices.”

Dowdy et. al., 1998
“At the conclusion of the study, we met with physicians, nurses, and allied health professionals to discuss their views of the study and to prepare a report for administration. Anecdotal observations suggested that the staff perceived a shift in attitude, one which placed a greater value on collaboration among all members of the team.”

Dowdy et. al., 1998
Ethical Challenges Across a Rehabilitation Network

2009 the Spaulding Rehabilitation Network Ethics Working Group was formed.

Each representative completed a needs assessment [informal] survey among staff.

The single most common challenge ethics representatives at each of the entities described was moral distress.
Moral Distress

Mukherjee et al. (2009) – Moral Distress in Rehabilitation Professionals: Results from a Hospital Ethics Survey

Definitions of Moral Distress =

McCarthy and Deady (2008) – the experiences of individuals who feel they are morally constrained

Zuzelo (2007) – making a moral decision that cannot be acted upon because of real or perceived limitations

Moral Distress

Mukherjee et al. (2009) – Moral Distress in Rehabilitation Professionals: Results from a Hospital Ethics Survey

Researchers described 3 broad categories of moral distress in the data:

• Institutional ethics
• Professional practice
• Clinical decision-making
Moral Distress

Epstein and Hamric (2009) – Moral Distress, Moral Residue and the Crescendo Effect

Attempted to quantify the observation that issues of moral distress in healthcare are often not isolated but re-occur with similar patient scenarios. When a situation results in distress it will peak and subside when the issue is no longer in play. When another similar issue is faced the wave of moral distress will be greater with the force of the remembered distress ("here we go again")
“Unsafe Discharge” –

Mrs. Y appears to be marginal in her ability to function at home. Her supports are limited/poor. She is choosing to return home and is able to recognize the challenges. Pt. is making appropriate choices, knows her limitations, but believes the quality of her life would be better at home. Some members of the treatment team feel she would be “safer” in a nursing home.

When confronted with this option Mrs. Y indicates she would prefer to live with her limitations, but wants to live the rest of her life in her own home.
What is the best option in Mrs. Y’s case?

A. Discharge Mrs. Y Against Medical Advice
B. Request formal psychiatric assessment
C. Prepare a discharge plan for home with the maximal services available in a harm-reduction model
D. Agree that the team must discharge the patient home, but you sign off the case to protect your license
E. Prolong her LOS as long as possible
Case Discussion

Dysphagia, feeding tubes and life-sustaining treatment –

• Following her stroke, Marjorie’s family makes a decision to have a feeding tube inserted at the acute care hospital feeling that they will give her time for recovery and monitor her progress. Six weeks after admission to a rehabilitation facility, Marjorie has global aphasia, requires maximal assistance for physical care and the family is unable to provide care at home. Just before discharge, Marjorie’s family ask the doctor to pull her feeding tube. They indicate that Marjorie had stated that she would not want to be kept alive by artificial means if she could not function “normally.”
Case Discussion

Dysphagia, feeding tubes and life-sustaining treatment (cont.) –

• Marjorie has made progress in her swallow function and is now eating a diet of basic soft solids and thin liquids. The team is concerned because Marjorie’s family does not seem to understand that the feeding tube is no longer a life-sustaining measure and that while enteral feeding is a medical treatment, offering food and assisting a patient in eating is not a medical treatment. Marjorie readily accepts her meals but needs assistance and extra time to eat safely.
What is the best option for Marjorie’s case?

A. Negotiate a time-limited trial to help determine Marjorie’s need for ANH
B. Request a change in clinician as you have conscientious objection and believe the family is killing Marjorie
C. Seek legal counsel with the goal of removing Marjorie’s family as healthcare proxy because they do not appear to be acting in her best interest

33% 33% 33%
Case Discussion

“Special Treatment”?? –

Mrs. W is a 66 year old woman who suffered a brain injury during a skiing accident. During her stay she made some slow improvement. Her son held a high position at a prominent news organization in town and her husband had hired 24 hour private duty nursing assistants to stay with her during her hospitalization. He also paid privately to ‘block’ the semi-private room his wife occupied. She was admitted to the rehabilitation facility 3 weeks following the accident at which time she still experienced very severe functional impairments.
Case Discussion

“Special Treatment”?? (continued) –

The team had recommended a 5 week length of stay at which time they anticipated she would have progressed to a mod-max assist level for mobility. As the time drew closer to discharge it became clear to the team that the patient’s family was uncomfortable with the plan. Understandably, they were all devastated with the patient’s injury and were very grateful she had come to intensive inpatient rehabilitation where she was making wonderful progress and where they felt completely confident in her care team.
During her stay, the family often ask for more therapy than she was originally scheduled for on the weekends. They now say that they are not ready to take her home and that if her insurance stops reimbursing the stay, that they will pay privately for her continued treatment here.
Should Mrs. W be allowed to stay by paying privately?

A. YES
B. NO
Ethical Challenges in Rehabilitation and Disability

Daniels and Sabin (2002), *Setting Limits Fairly*

Accountability for Reasonableness =
1. The allocation process is fully transparent and public
2. The basis of decisions seeks a consensus of all stakeholders
3. Guidelines and rules can be amended as new salient information becomes available
4. Institutions implement a format for review and assessment to ensure that 1-3 are operationalized

Must promote “Emperical inquiry and deliberation about values”
Moral Distress

Moral Distress cannot be eliminated in the healthcare/rehabilitation environment!

How can we learn to communicate, cope and create solutions?
Moral Distress

Solutions =

1) Communication
2) Options
3) Education – focused on the issues that re-occur
4) Institutional openness and access to mechanisms to report and address moral dilemmas and moral distress
5) Identify processes and policies that ensure systematic approach to issues as they arise (to avoid or minimize the crescendo)
YOUR CASES, COMMENTS AND QUESTIONS