

NHPCO Project ECHO

Ethical Dilemmas Across Health Equity: 2024

Appointed Guardianship and Balancing Legal, Ethical, and Equitable Responsibilities

August 13th, 2024

Disclosures

Disclosure

The faculty and planners for this educational event have no relevant financial relationship(s) with ineligible companies to disclose.

Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

Evaluation

Please complete program evaluation materials following each session.

Ground Rules and Video Teleconferencing Etiquette

- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants – introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

Today's Agenda

- Introduction of Faculty – NHPCO Team
- Didactic Presentation – Faculty
- Case Study Presentation – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team

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Didactic Presentation

Appointed Guardianship and Balancing Legal, Ethical, and Equitable Responsibilities

Introduction to Appointed Guardianship

- Definition of Appointed Guardianship
- Types of Guardianship (e.g., Full, Limited, Temporary, Emergency)
- Purpose and Importance

Legal Responsibilities of Guardians

- Understanding Legal Authority and Limits
- Key Legal Duties (e.g., financial management, healthcare decisions)
 - Substituted judgement standard
- Compliance with State and Federal Laws

Ethical Responsibilities of Guardians

- Principles of Ethical Guardianship
(e.g., Beneficence, Non-maleficence)
- Maintaining Integrity and Trust
 - Informed consent
- Confidentiality and Privacy Concerns



Equitable Responsibilities of Guardians

- Ensuring Fair Treatment and Non-Discrimination
- Cultural Humility* and Sensitivity
- Advocacy for the Ward's Rights and Best Interests

Balancing the Responsibilities

- Case Studies or Examples of Conflicting Responsibilities
 - Legal vs. Ethical Responsibilities
 - Ethical vs. Equitable Responsibilities
 - Legal vs. Equitable Responsibilities
 - Guardian's Personal Beliefs vs. Ward's Best Interest
 - Financial Management vs. Quality of Life
 - Informed Consent vs. Best Medical Advice
- Strategies for Balancing Legal, Ethical, and Equitable Duties

Ethical Decision-Making Framework: 4-Box Model

<p>Medical Indications</p> <p><i>The Principles of Beneficence & Nonmaleficence</i></p>	<p>Patient Preferences*</p> <p><i>The Principle of Respect for Autonomy</i></p>
<p>Quality of Life*</p> <p><i>The Principles of Beneficence, Nonmaleficence & Respect for Autonomy</i></p>	<p>Contextual Features</p> <p><i>The Principles of Veracity & Justice</i></p>

* From patient's voice/patient's perspective

Didactic Presentation Q&A

Case Study Presentation (Angela & Imposing Guardianship)

Situation and Background: Angela's Story

African American, 66-year-old female	Hospice Dx – Cirrhosis of the Liver; Comorbid – Dementia, DM II, SUD
On this hospice for 2 months; with previous hospice for 4 months; with other hospice agencies before – currently in 4 th benefit period	Patient signed own consents and was at home at admission
Patient currently on IPC unit post-stroke and fall with injury, no longer decisional	Family history of SUD and trauma history (generational abuse)
Patient flipped routine (no longer GIP eligible) on unit and needs placement	Adult children escalated threats of harm and physical aggression at staff Hospital security removed them Hospital has placed them on a “no admittance” list
Open APS case – neglect and presumed financial exploitation History of CPS cases (yes, plural)	No living legal agent – DPOA is deceased
Adult children with complex SUD history – are not accessible decision makers DO NOT meet the state’s definition for surrogate decision-making Potential neglect/exploitation We are revoking their rights as decision-makers	Court-appointed guardianship process What about the grief journey of the family?

Assessment

- Medical Indications
 - Eligibility? Yes.
 - Code Status. Hospice benefit does not require patient to elect DNR status
- Patient Preferences*
 - Remain at home – but no longer possible without full-time caregiving
 - Rejects treatment for comorbid dx
- Quality of Life*
 - Bedbound
 - Non-decisional
 - Is patient's quality of life *less than minimal* in their own words? Yes, according to previous discussions
- Contextual Features
 - Trauma history
 - Licensure of IPC unit – cannot provide custodial care indefinitely
 - Aggression
 - Revocation of surrogates
 - Guardianship process – no *eligible* decision-maker
 - Grief journey for family

Discussion and Recommendations

Discussion and Recommendations

- Considering the 4-Box model for ethical decision-making, was the outcome of the case an ethically-sound direction? Why or why not?
- What about the impact on the grief journey of the family?
 - What supersedes? The patient rights? The family rights? Why?
- Share examples from your own work where court-appointed guardians were involved or needed to be involved.
 - Were the appointed guardians and you/your team able to preserve the patient's rights/voice?

Key Takeaways

Key Points

- Every case is different!
- Understand the decision-making sequence. If your state doesn't have a hierarchy, ensure your agency/organization has a policy to follow!
- Substituted judgement is both an ethical standard and a legal one. Ensure you/your teams have a good grasp on what it means.
- Cognition and capacity are not the same! Assessing for cognition (examples: SLUMS, mini-mental, etc.) varies from completing a capacity evaluation.

Actionable Steps

- Do your due diligence in identifying the correct decision-maker to preserve the patient's voice.
- Practice informed consent. A comprehensive informed consent process also includes limitations. This may be vital to cases (like today's) where there is a need to approach court-appointed guardianship and/or revocation of a decision-maker.

Conversation Starters/Questions to Consider

- What are the laws of your state in terms of decision-making sequence? Is there a hierarchy?
- Do you know what your court-appointed guardian is allowed to do? They don't have blanket rights!
- For teams – analyze a recent patient case that involved an appointed guardian. Were decisions that were made along the healthcare journey for the patient based on legal statutes? Based on ethical foundations? Or both?

References

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- Schweikart, S.J. (2019). Who makes decisions for incapacitated patients who have no surrogate or advance directive? *AMA Journal of Ethics*, 21(7), E587-593. DOI: 10.1001/amajethics.2019.587.

Session Evaluation and Certificate of Completion

- Your feedback is valuable as we plan upcoming sessions! Please complete the Project ECHO: [Ethical Dilemmas Across Health Equity Session Post-Session Evaluation](#)
- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for participants who attend at least four live sessions and complete all session evaluations as well as a final miniseries evaluation.

Upcoming Sessions

Date: August 20

Topic: Confronting Ethical Dilemmas: Real-Life Challenges and Insights

Date: August 27

Topic: Summary Wrap-Up: Conducting an Ethics Review

Additional Information

NHPCO Project ECHO webpage:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/>

For more information:

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