

# NHPCO Project ECHO Miniseries Ethical Dilemmas Across Health Equity: 2024

Summary Wrap-Up:  
Conducting an Ethics Review

August 27, 2024

# Disclosures

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## **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

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- 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

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- 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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# Session Faculty



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Chair, MJHS Hospice Ethics Committee

# Didactic Presentation

# Objectives

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- ❑ Summarize key ethical challenges confronting hospice and palliative care providers related to health equity.
- ❑ Discuss and distinguish between Ethics Review and Ethics Case Consultation
- ❑ Identify ethical considerations of hospice referrals for unrepresented patients without decisional capacity
  - Due diligence – state laws and guidelines
  - Family Health Care Decisions Act, Isolated Patient Bill



# Didactic Presentation

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Review of previous Project ECHO Ethical Dilemmas Across Health Equity in Hospice & Palliative Care Miniseries Sessions

- Building an Ethical Organizational Culture (7/23)
- Who Ya Gonna Call? (7/30)
- Equitable Ethics in Pediatric Care (8/6)
- Appointed Guardianship and Balancing Legal, Ethical, and Equitable Responsibilities (8/13)
- Confronting Ethical Dilemmas: Real-Life Challenges and Insights (8/20)
- Conducting an Ethics Review (today)

# Didactic Presentation

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Required starting point for an Ethics Review is having a vehicle for conducting the Review/Analysis.

- ❑ IDT's are not an effective vehicle related to lack of focus, time, expertise and diversity of membership.
- ❑ Ethics committee or consult team is ideal.
  - Knowledge of ethical review
  - Diversity of members
    - IDT – nurse, doctor, social worker, chaplain, aide, volunteer
    - Community – doctors, clergy, lawyer, community member
    - Members should represent your team, and patient and community make-up

# Didactic Presentation

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Defined ethics review process

- Review team has been educated on process
- Review team has practiced utilizing the process
- Process should align with needs of organization (key issue is complexity of process needed to meet patient, team and community needs)
  - Simple review – MDP Ethics Course review tool
  - Detailed review - Consultation model

# Hospice Ethics

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Hospice ethics: a care philosophy, informed by specialized context of care:  
**“Kirk, 2014”**

- Dying as meaningful experience
- Suffering managed through interdisciplinary care
- Patient supported through family/friend and significant relationships
- Care plan driven by respecting patient’s personhood

# Ethical Decision-Making Framework

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## **Identify Ethical Dilemma:**

Recognize the ethical issues involved.

## **Gather Information:**

Collect relevant data and perspectives.

## **Evaluate Options:**

Consider possible courses of action.

## **Make a Decision:**

Choose the most ethical and equitable option.

## **Implement and Reflect:**

Act on the decision and evaluate the outcomes.

# Ethical Decision-Making Framework: 4-Box Model

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

\* From patient's voice/patient's perspective

# Ethical Analysis Tool from NHPCO MDP Ethics Course

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1. What additional facts would be helpful, were they available? (Consider clinical facts; known patient or surrogate decision- maker preferences; contextual features such as the patient's race, ethnicity, religion, economic conditions for the family and providers, laws, regulations, caregiver concerns and resources; and quality of life.)
2. What are the morally relevant issues? (Consider rights, duties, and likely consequences and the ethical principles of respect for autonomy, beneficence, nonmaleficence, justice, and veracity. Which principles are in play? Which are in conflict?)
3. The case may present several ethical concerns. For each ethical dilemma, state it using the following format:
  - A. On the one hand, we have a moral obligation to \_\_\_\_\_ because the ethical principle \_\_\_\_\_ demands such a response.
  - B. On the other hand, we have a moral obligation to \_\_\_\_\_ because the ethical principle \_\_\_\_\_ demands such a response.

# Ethical Analysis tool from NHPCO MDP Ethics Course (continued)

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4. Write the ethical principle that you determine has the greater weight.
5. Resolve the case and make a recommendation for practical next steps.
6. Justify your resolution.



# Didactic Presentation

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## MJHS Ethics Resources and Processes:

- Ethics Consultant and Ethics Committee
- Policies and Procedures for-
  - Ethics Committee
  - Ethics Case Consultations
  - Ethics Review Committees
- NYS PHL 29-CC, Family Health Care Decisions Act (FHCDA)
- Isolated Patient Bill

# MJHS Ethics Resources

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## Hospice Ethics Committee

- Interdisciplinary
- Team representation
- Health care ethics skill set as per American Society for Bioethics and Humanities recommendations

## Clinical Case Consultation

- Support for patients/families/clinicians encountering ethical questions/disagreements/challenges
- Email [hospiceethics@mjhs.org](mailto:hospiceethics@mjhs.org)

# MJHS Clinical Ethics Case Consultation:

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- ❑ Aim is to support decision making and care delivery consistent with values and ethical obligations of all participants, respecting the values, preferences, cultural beliefs, and best interests of the patient.
- ❑ The consultation process achieves this aim by:
  - Identifying ethically salient aspects of giving and receiving care in specific cases;
  - Offering systematic, principled analysis of questions and care options;
  - Encouraging effective communication and facilitating mutual respect and understanding among all involved
  - Empowering patients, caregivers, and clinicians by educating them to identify and engage ethical aspects of care

# MJHS Ethics Review for Unfriended Patient Referrals

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- ❑ Initiated by the hospice care planner upon referral from hospital or NH, when pt lacks decisional capacity and no surrogate identified
- ❑ Hospice physician or NP must ensure an ERC is engaged
- ❑ Ethics Review Committee process is required by NYS PHL 29- CC to ensure due diligence on behalf of the isolated patient
  - Comprehensive search for any known family or close friends
  - Identify any known or documented wishes in regard to care
  - Raise awareness to values or beliefs that may guide care decisions in alignment with the patient's lived experiences and best interests

# Isolated Patient Checklist

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1. Confirm medical eligibility for hospice care
2. Confirm patient lacks decision making capacity
3. Confirm information regarding patient values/preferences relevant to hospice care admission is not available
4. Confirm no guardian, agent, or surrogate reasonably available
5. 5. Confirm patient's referring & attending MD/NP will consent to admission
6. Confirm referring facility has held ethics review committee mtg endorsing hospice admission
7. Confirm referring MD/NP are willing to have MJHS MD/NP act as pt surrogate. If not, insert name/contact of MD/NP who will continue as surrogate
8. Confirm MJHS ethics committee review and endorse the admission. Ethics summary note entered into patient's EMR

# Didactic Presentation Q&A

# Case Study Presentation

## Isolated (Unfriended) Patient Referral for Hospice

# Situation

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- 84yo man living in his current LTC since 2019. Placement was to be short term but became residential. On admission he reported he was Catholic but was not practicing and it was not important to him. He has vascular dementia (FAST 7E; PPS 20%) and has lost >20% body mass in last 5 mos. The facility seeks hospice admission for EOL care.
- Overseeing MD documents her lack of decisional capacity due to dementia on 11/15/22. Two clinicians from LTC will attest to lack of capacity upon admission to hospice.



# Background

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- Pt had a health care surrogate who historically made decisions for him. However, LTC staff and MJHS hospice spoke with the surrogate, and she is no longer able to make decisions for the pt as she is going through her own health challenges. She verbally endorsed hospice, and no one is aware of any beliefs/preferences that would be contrary to hospice admission.
- As such, the decision for hospice admission is proceeding using the Isolated Patient process as articulated in PHL 2994-g(5a).

# Assessment

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- Hospice Medical Director, clinical note entry:
- “84 yo M with vascular dementia, FAST score 7E, PPS 20%. Pt is nutritionally declining with a 20 lb weight loss in last 5 months from 128 to 108lbs. Pt lost almost 20% of his weight in less than 6 months. Pt has comorbid HTN, HLD, GERD, osteoporosis and anemia. Pt is eligible for Hospice with a prognosis of 6 months or less if the disease follow its expected course.”
- **Three step process for admission**
  1. NH attending physician and confirming NH physician;
  2. Ethics Review committee endorsing hospice admission based on best interest standard;
  3. NH ERC note documented in Isolated Patient checklist

# Discussion and Recommendations

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## Questions:

1. What ethical analysis/review tools does your organization utilize?
2. What is one change that your organization could make to enhance your ethics review process?

# Discussion and Recommendations

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## Hospice Ethics is a Need to Have

### When:

- Confusion about appropriate decision maker
- Confusion or conflict about goals of care
- Struggle to understand values of patient/family/team
- Disagreement about which and who's values and preferences should be honored
- Struggle about which care options best honor the patient's values and preferences
- General questions/education/support needs

### Why:

- Because sometimes extra support from colleagues trained in ethics can help clarify values, offer insight into disagreements, disrupt unproductive communication patterns, identify options not previously considered, and explain the ethical reasoning supporting different courses of action

# Key Takeaways

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- Understand the potential ethical challenges unique to your organization.
- Have a process for conducting ethics review.
- Have a skilled trained team to conduct the ethics review.
- Ensure your organizational board, leadership team, clinical, office and volunteers are trained in recognizing potential ethical issues and how to report.

# References

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- Ethical Evaluation Tool (2023) NHPCO. MDP ETHICS MODULE
- Ethical Decision-Making Framework (August 6, 2024). NHPCO Project ECHO. Ethical Dilemmas Across Health Equity. Equitable Ethics in Pediatric Care: A Palliative and Hospice Care Lens Session. PowerPoint
- Ethical Decision-Making Framework: 4-Box Model (August 13, 2024). NHPCO Project ECHO Ethical Dilemmas Across Health Equity. Appointed Guardianship and Balancing Legal, Ethical, and Equitable Responsibilities Session. PowerPoint
- Decisions Regarding Hospice Care for Isolated Patients. *A Guide to the 2015 Amendment of the Family Health Care Decisions Act*, by Timothy W. Kirk and Randi Seigel. Health Law Journal, NYSBA (Winter 2016, Vol. 21, No. 3)
- Unbefriended And Unrepresented: Better Medical Decision Making For Incapacitated Patients Without Healthcare Surrogates. Thaddeus Mason Pope, *Mitchell Hamline School of Law*. (7.13.2017)
- *Handbook for Health Care Ethics Committees*, 2<sup>nd</sup> Edition, Linda Farber Post, Jeffrey Blustein, Johns Hopkins University Press, Baltimore, 2007, 2015
- Kirk, Timothy W. “Hospice as a Moral Practice: Exploring the Philosophy and Ethics of Hospice Care.” In Timothy W. Kirk & Bruce Jennings, eds. <https://www.nhpc.org/regulatory-and-quality/quality/projectecho/ethical-dilemmas-across-health-equity-summer-2024/>

# Session Evaluation and Certificate of Completion

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- 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.



# Additional Information

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NHPCO Project ECHO webpage:

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

For more information:

[projectecho@nhpcoco.org](mailto:projectecho@nhpcoco.org)