

NHPCO Project ECHO Key Takeaways

Ethical Dilemmas Across Health Equity: Building an Ethical Organizational Culture 7.23.24

Key points:

- Organizations with a strong ethical culture are more likely to provide equitable care and have improved employee and patient/family satisfaction.
 - Higher rates of collaboration among teams yield:
 - Improved patient quality
 - Lower burnout and higher work engagement
 - Team members who drive meaning and significance in their work are 3x more likely to stay with an organization
 - Many are willing to forgo financial benefits to work for an organization with a better reputation for ethics
- Privilege does not always equate with access
- Minorities have significant challenges in accessing care
- Difference between equity and equality?
 - Equity refers to fairness or justice in the way people are treated, and especially freedom from bias or favoritism, as in “governed according to the principle of equity.”
 - Equality refers to the quality or state of having the same rights and opportunities
 - Health Equity - means the attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes.
- What is ethics?
 - The discipline is concerned with what is morally good and bad and morally right and wrong. The term is also applied to any system or theory of moral values or principles.
- Issues with respect to ethical dilemmas in end-of-life care:
 - Challenging the Autonomy – a decision-making impasse
 - Physician-aided dying
 - Truth-telling
 - Permanent vegetative state
 - Denial of treatment
 - Limitations of advanced directives

Actionable Steps:

- Determining a process to address moral dilemmas, which often indicate an ethical issue



- Establish an ethics committee or partner with another organization for ethics consults
- Seek/provide training in ethics, ethical review, moral dilemmas

Conversation Starters:

1. What makes you uncomfortable about this situation?
2. What are the medical implications?
3. What are the patient preferences?
4. What is quality of life for the patient?
5. If the patient is not able to speak for themselves, who is speaking for them?
6. What are the contextual aspects that might be impacting the issue under review?

Participant Perspectives:

- “I love hearing [about] person-centered care...keeping that at the heart of what we do. Thank you for making that evident throughout.”
- “Her disease progression and the prognosis were hiding behind the 6-month rule. Bless her and your family. I think this certainly shines a light on continuous need for social work, IDT care and work, and follow up.”
- “And this is why lengths of stay are so short! We consider it a success when a person outlives the 6-month prognosis. As long as clinically they are still eligible it 'is' possible to advocate. Sometimes it will be a win and sometimes a loss but it needs to be done if we are advocating on behalf of a patient and the patient's best interest.”
- “If there is a question about whether a pt is appropriate to stay under hospice care, we have QA meetings where the IDT, Medical Director, and Clinical Dir [to] analyze facts.”

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NHPCO Project ECHO Key Takeaways

Ethical Dilemmas Across Health Equity: Who Ya Gonna Call? 7.30.24

Key points:

- Clarity about who does what is essential to high-quality care.
- Focusing on the question/issue at hand provides clarity on who one should call.
- Overlapping between services is frequent and should not deter team members from calling various services.

Actionable Steps:

- Identify who is the point of contact for each of the services identified during the discussion, e.g., risk, compliance, legal, ethics, etc.
- When issues are identified practice using the identified tool to ensure request goes to appropriate resource

Conversation Starters:

1. What training does our staff get to clearly identify what services do within our organization and can it be improved?
2. Have we thought about how health equity is involved in our ethics cases and how do we get training to ensure proper identification?

Participant Perspectives:

- “I appreciate the comment about compliance and ethics as being distinct entities- I am the compliance officer, yet I have taken 12 college hours of Ethics Training and attained a Healthcare Ethics Certificate and co-chair our Ethics Committee. Depending on the size of an agency, roles that are clinically related yet separate often have to wear multiple hats.”
- “I think as soon as the RN recognizes a potential conflict, should be a family conversation with a medical interpreter. And then after that, include any spiritual leaders. The goal is to align everyone before Mom passes.”
- “Every hospice SHOULD utilize a language translation service.”
- “There could also be an issue with what type of ethics service you have. Some may do actual consults at the bedside and may help with some communication with the patient and staff, while others may provide an opinion only with no bedside evaluation.”
- “Competency of the patient matters- if she is competent, then there is no role for the legal surrogate.”
- “We also need to determine what is medically indicated. Doing "everything" still falls within what is indicated- which may or may not be much.”
- “Another interesting issue is who actually leads the discussion with the patient and family practically and this can be very different in different settings, such as hospice, where the family



may have more relationship and trust with the social worker or other IDG members. A hospital that has a robust ethics service may guide the discussion, Often, this lands in the lap of the palliative medicine provider in the inpatient setting.”

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NHPCO Project ECHO Key Takeaways

Ethical Dilemmas Across Health Equity: Equitable Ethics in Pediatric Care 8.6.24

Key points:

- Willingness to try different models of care i.e., partnering with pediatric experts
- The importance of equity in pediatric palliative and hospice care to improve access to services.
- Commitment to ongoing education, policy advocacy, and commitment to equitable care practices
- If we do not keep talking about the need for services for our most vulnerable children and their families, this downward trend will continue. The challenges are significant but if we use our voices, and partner with our state coalitions and national organizations we can make a difference.
- **Definition of Equitable Ethics:**
 - Ensuring fair treatment and opportunities for all patients, regardless of background, age, gender, race, circumstance, or other factors.
- **Key Principles of Equitable Ethics**
 - Justice: Fair distribution of healthcare resources.
 - Non-maleficence: Avoidance of harm.
 - Beneficence: Act in the best interest of the patient.
 - Autonomy: Respect for patient and family choices. For children this means determining assent if able.
- **Strategies for Equitable Palliative and Hospice Care**
 - **Interdisciplinary Teams:**
 - Collaboration among healthcare professionals to address the holistic needs of the patient and family.
 - Creating partnerships to increase access and education to enable the provision of care
 - **Cultural Humility Training:**
 - Equip healthcare providers with the skills to understand and respect diverse backgrounds enabling to learn from their patients and families.
 - **Community Outreach Programs:**
 - Increase awareness and accessibility of palliative and hospice care services
 - **Family-Centered Care:**
 - Involve family members in care planning and decision-making processes.

Actionable Steps:

- Complete a needs assessment of your organization.
 - Determine staff skill levels



- Determine how many patients were refused services and why
- Evaluate interventions that would allow for improved access
- Look to referral sources for potential partnerships, guidance, and education

Conversation Starters:

1. Why should we take care of pediatric patients and their families?
2. What makes you think you cannot take care of a child?
3. What would make you feel supported and more comfortable to provide care to this vulnerable population?
4. Do you believe we should provide services to all who would benefit? What do you think we need to make that happen?

Participant Perspectives:

- “We provide pediatric care - mostly palliative and some hospice care - the challenges is our state is all Medicaid Managed Care for Pediatrics and they require prior authorization at times which can be a barrier.”
- “We have one Nurse who is specifically trained to provide Peds care. We are currently training a second Nurse so we have better coverage.”
- “I think the key is educating the hospice and staff. In my experience, those without peds experience are uncomfortable. However, with education, they do become more comfortable.”
- “From a competency perspective we have pediatric competencies for RNs.”

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- Center to Advance Palliative Care: <https://www.capc.org/>



NHPCO Project ECHO
Key Takeaways

Ethical Dilemmas Across Health Equity: Appointed Guardianship and Balancing Legal, Ethical, and Equitable Responsibilities: A Palliative and Hospice Care Lens
8.13.24

Key points:

- **Equitable Responsibilities of Guardians**

- *Equitable Responsibilities of Guardians:* Guardians have a duty to ensure fair treatment and non-discrimination in their care, making sure that all decisions and actions prioritize the individual's dignity and rights.
- *Cultural Humility and Sensitivity:* Guardians should approach their role with cultural humility, being aware of and sensitive to the cultural backgrounds and personal identities of the individuals they care for. This involves ongoing self-reflection and a commitment to understanding and respecting the individual's unique cultural needs and perspectives.
- *Advocacy for the Individual's Rights and Best Interests:* Guardians must advocate strongly for the individual's rights and best interests, ensuring that their voice is heard, and their needs are met in all legal and ethical matters. This includes safeguarding their well-being and making informed decisions that reflect their preferences and values.

- **Ethical Decision-Making Framework: 4-Box Model**

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



- **Medical Indications**
 - **Principles of Beneficence and Nonmaleficence:** This principle aligns with ensuring that any decisions made by the guardian are in the best interest of the individual, focusing on doing good (beneficence) and avoiding harm (non-maleficence). The guardian must ensure that medical decisions are based on accurate information, aimed at improving the individual's health and well-being.
- **Patient Preferences**
 - **Principle of the Respect for Autonomy:** This principle is directly related to respecting the individual's right to make their own choices. Ethical guardianship requires honoring the individual's preferences, values, and wishes, even if they differ from what the guardian might personally believe is best. This involves effective communication and supporting the individual in making informed decisions.
- **Quality of Life**
 - **Principle of Beneficence, Nonmaleficence, and Respect for Autonomy:** This principle ensures that decisions made by the guardian enhance the individual's quality of life while avoiding harm. It also involves respecting the individual's autonomy by considering how their choices will impact their life and ensuring that the outcomes align with what the individual values and desires.
- **Contextual Features**
 - **Principles of Veracity and Justice:** These principles ensure that all decisions are made truthfully and fairly, considering the broader context of the individual's life. The guardian must advocate for the individual's rights within the legal, social, and cultural context, ensuring that they are treated with honesty and fairness in all situations.
- Remember: 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 judgment is both an ethical standard and a legal one. Ensure you/your teams have a good grasp of 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:

1. What are the laws of your state in terms of decision-making sequence? Is there a hierarchy?
2. Do you know what your court-appointed guardian is allowed to do? They don't have blanket rights!



3. 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?

Participant Perspectives:

- “Continuous education and training are vital to staying informed about best practices, legal requirements, and healthcare advancements.”
- “The definition in the state around surrogate decision-making is that they need to be accessible decision-makers. We need to be able to reach them. We need to be able to communicate with them, and they need to want and agree to this role.”
- “The terminology for discrimination has changed for healthcare providers. That also now includes mental health issues and substance use disorders.”

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NHPCO Project ECHO Key Takeaways

Ethical Dilemmas Across Health Equity: Confronting Ethical Dilemmas: Real-Life Challenges and Insights

8.20.24

Key points:

- Organizations should make sure they have access to Ethics Resources, e.g., ethics committees, ethics consultants
- These resources should be appropriately trained and knowledgeable of the challenges unique to Palliative and Hospice Medicine.
- Ethics Resources should use a systematic process to work through complex ethics situations to ensure that sufficient information is obtained, analyzed, and ethically acceptable options are offered

Actionable Steps:

- Identify the method in which to contact the ethics resource when you have a conflict or uncertainty about values.
- Consider joining the ethics resource within your organization

Conversation Starters:

1. What are ways we can improve the education and training of our ethics resources?
2. What are the frequent ethical issues we experience?
3. What can we do to be more aware of the ethics issues that occur for us as an organization?

Participant Perspectives:

- “Medication Management is an issue... and the length of time it had been since she answered questions about her terminal illness.”
- “I think reviewing education about the process of death and dying would certainly be a benefit.”
- “Our intake nurse here always says 'It's not giving up, but it's taking a different path towards comfort.'”
- “The situation is an opportunity for application of Emotional Intelligence + Cognitive Empathy”
- [Regarding Cognitive Empathy] A practice or formalized healthcare/education/psychology term used. For, Cognitive empathy... let's think of it concerning a person's ability, education, or training, and having the ability to understand how a person feels and what they might be thinking... therefore allowing it to help form, shape, and consistently edit our emotional intelligence.”
- “Sometimes in situations like this we have to take the time to review the various options and next steps we have available to us and what the consequences of those actions are.”



- “[It] sounds like a goal of care discussion is warranted with family and a determination as to what Mom's best interests would be (to maintain her moral agency). In the absence of consensus then there should be an ethics review and case consultation.....”

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NHPCO Project ECHO Key Takeaways

Ethical Dilemmas Across Health Equity: Summary Wrap-Up: Conducting an Ethics Review

8.27.24

Key points:

- Understand the potential ethical challenges unique to your organization.
- Have a process for conducting an 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 them.

Actionable Steps:

- Evaluate the process that is used for ethics review.
- Reflect on the diversity and composition of the ethics review team/committee. Does it represent your team, patient, and community make-up?
- Identify key potential ethical challenges unique to your organization.
- Ensure your organizational board, leadership team, clinical teams, office staff, and volunteers are trained in recognizing potential ethical issues and how to respond when they arise.

Conversation Starters:

1. Do the members of the Ethics review team/committee represent our team, patient, and community make-up? If not, what's missing?
2. Does the structure of our process meet the needs of our patient, team, and community?
3. What is one change that our organization could make to enhance the ethics review process?
4. Do we have a skill-based team trained to conduct ethics reviews?

Participant Perspectives:

- "I really think that we're fortunate here in New York, because when you have legislation. It gives you guardrails. It gives you a process that you could follow up kind of makes it easier, because there's more transparency as long as you could meet the criteria."
- "We have a home community care Ethics Committee, so we would review that. You have to have at least 3 members on there at the time, and you have to have people who are not involved in the patient's care."
- "I feel that there is a large disconnect with the need, why do we really need it, and why the ethics structure, is so important."
- "In our organization, if there's an ethics review of a case and there is still an indecision or an inability to get consensus around the admission, then it will move into an ethics case consultation process, which is much more comprehensive."



- “At least, there's a due diligence process that we could keep our head up high and say we are doing what is in the best interest to the best of our ability for the patients.”
- “At our organization our Ethics and Compliance department is present and accounted for in every facet of our business. It's at the core of everything we do. Our corporate budget, training, education, and our company's best foot forward are rooted in our organization's culture of Ethics and Compliance. Without it, we can't ever get to the Mission and vision, or emulate our Core Values as an organization. We have internal and external ethics advisors who assist our organization at providing the best care, at the right time, for every patient. We include an organizational culture deep dive in our new hire onboarding and when we acquire other health systems in the US. I'll also add...It's nice when you are at work, in the moment, outside of a training module... and you see ethical and moral decision-making in practice during day-to-day business. It's so reaffirming as a team member.”

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