NHPCO Project ECHO
Ethical Dilemmas Across Health Equity: 2024

Building an Ethical Organizational Culture

July 23, 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)**

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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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Poll Questions

✓Do you see equity as an ethical issue?

✓Does your organization have an ethics committee/ are you involved with ethical dilemmas or cases within your organization?

Didactic Presentation

Ethical Dilemmas in Delivering Equitable Care at End of Life

Objectives

❖Building an Ethical Organizational Culture

❖Determine how ethics is built into the organizational structure.

❖Discuss how an ethical culture impacts equity.

❖Identify how organizations protect and service employees with an equitable and ethical culture.

❖Illustrate how we turn ethical challenges into change agents for our organizations

What is Equity?

Fairness and Justice

"Justice according to natural law or right"

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 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.

Britannica

The palliative care services ethical principles recognized universally are:
- Autonomy
- Beneficence
- Non-maleficence
- Justice

Gelegjamts, D., Gaalan, K., & Burenerdene, B. (2023). Ethics in Palliative Care. In New Research in Nursing-Education and Practice. IntechOpen.

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
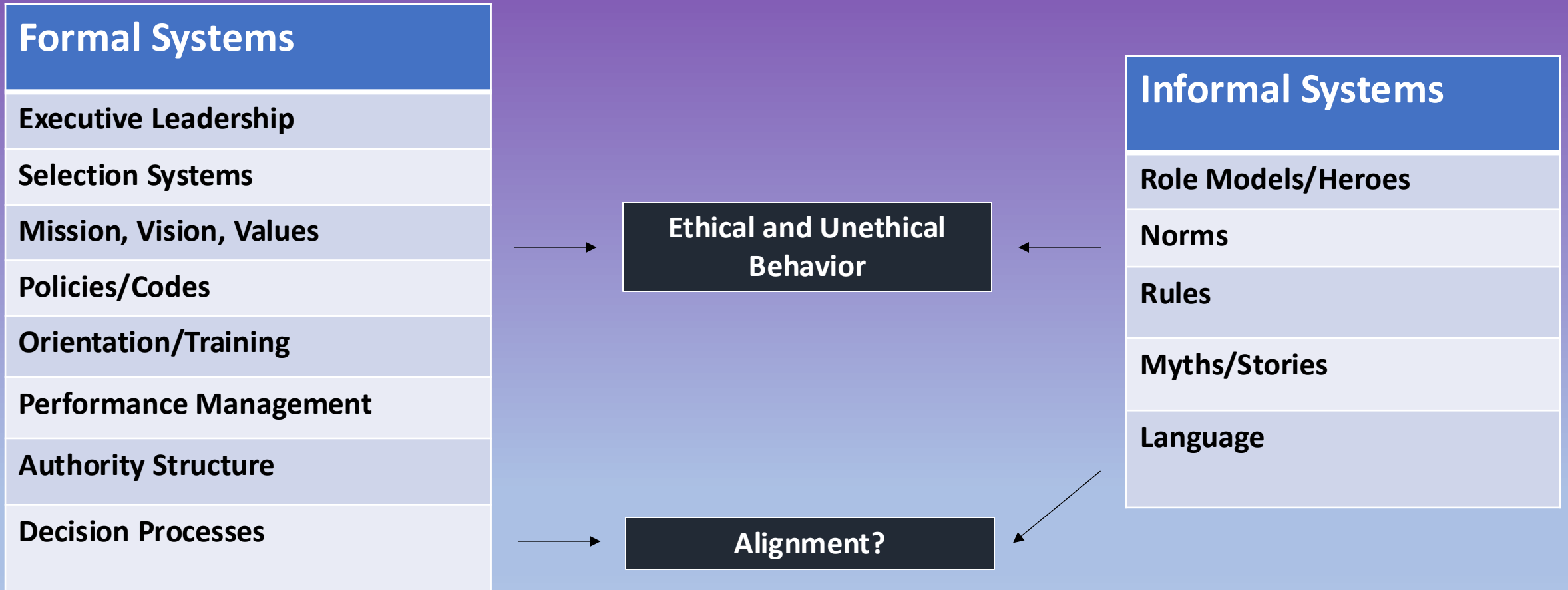- Limitations of advanced directives   *https://www.thehastingscenter.org/briefingbook/end-of-life-care/*

An Ethical Culture

Ethical Culture Systems

Formal Systems
Executive Leadership
Selection Systems
Mission, Vision, Values
Policies/Codes
Orientation/Training
Performance Management
Authority Structure
Decision Processes

Informal Systems
Role Models/Heroes
Norms
Rules
Myths/Stories
Language

Ethical and Unethical Behavior

Alignment?

Connecting Ethics and Culture

Formal Systems
Executive Leadership
Selection Systems
Mission, Vision, Values
Policies/Codes
Orientation/Training
Performance Management
Authority Structure
Decision Processes

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The Interface – Closing the Divide

❖ Access to pain control in palliative care varies due to many factors

❖ Underrepresented racial or ethnic groups benefit the most from structured educational programs related to advance care planning and advance directives

❖ There is a high need to engage marginalized and underrepresented populations designing educational interventions that led to increased awareness and education of palliative care services.

❖ The effectiveness of advance care planning, end-of-life, and palliative care interventions in improving outcomes for underrepresented racial and ethnic populations remains uncertain.

Jones, T., Luth, E. A., Lin, S. Y., & Brody, A. A. (2021). Advance care planning, palliative care, and end-of-life care interventions for racial and ethnic underrepresented groups: a systematic review. *Journal of pain and symptom management, 62*(3), e248-e260.

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The Person, the Provider and the Organization

❖ First and foremost, it is vital to assess needs of your population and the communities you serve

❖ What reports or data sources may be available? For example, the CDC Health Disparities and Inequalities Report is a series of periodic, consolidated assessments that highlight health disparities by sex, race, and ethnicity, income, education, disability status, and other social characteristics in the U.S.

❖ Addressing disparities is a biomedical and ethical issue because it addresses the concepts of autonomy, beneficence and justice.

❖ What other information and resources are needed? What does the evidence indicate?
   - ✓ An evidence-based approach addressing health inequities is the organization's focus on developing the <u>cultural competence</u> of health-care providers and the health-care system.
   - ✓ As part of care design, the organization, community stakeholders and care teams must reaffirm a commitment to equity, fairness and caring as key building blocks to a new health care delivery system.
   - ✓ Addressing disparities and building an infrastructure that caters to a wide base of unique populations in a culturally competent, manner remains not only vital for equitable care delivery, but also establishes safe, effective and person-centered care.

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Factors Involved / Key Terms

❖ Decision Making

❖ Beneficence

❖ Non- maleficence

❖ Justice

❖ The cost of caregiving – where is equity?

❖ Access to care – for all – right person, right setting, right time

Didactic Presentation Q&A

Case Study Presentation 1

Situation

- Widowed from first marriage, has been married twice and currently divorced
- Previously lived with youngest son and his family – unable to meet her care needs
- Moved to a home in the same community owned by her oldest son (healthcare professional)
- Lives Alone
- Received Home and Community Based Waiver services prior to admission
- Daughter in law is employed – ability to work from home at times and stayed with the patient at night (healthcare professional)
- Son lives next door, and grandchildren live next door and two doors down
- Daughter lives out of state – visits/assists (initially) on the weekends
- Other son lives in same community – infrequent visits and no care responsibilities

Background

85 years F with pulmonary fibrosis due to rheumatoid lung disease.

Related diagnosis:

- Dementia
- Depression
- Anxiety
- Blood loss (iron deficiency) anemia due to Gastrointestinal (GI) bleed
- Barrett's esophagus,
- Hand contractures
- Hallucinations
- Dysphagia.

- Dyspnea on exertion (DOE)
- Tachycardia with minimal activity.
- O2 dependent.
- Previously on Eliquis due to extensive Left Lower Extremity (LLE), Deep Venous Thrombosis (DVT) (2/2019), s/p IVC filter.

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Case Study Challenges

- **Ethical Dilemma #1**

- **Management of Patient Risk Areas/Symptoms:**

  - Coagulation due to history as well as inactivity

  - Pain/Symptom Management

  - Hallucinations/Agitation

Assessment

- **Ethical Dilemma #2**
- Length of stay
- July 2023- Fast 6e MAC is 17.1 (unchanged) PPS is scored at 30%
- Sleeping 20-22 hours per day
- Bilaterial Lower extremety PAD wounds with healing noted
- Low air mattress due to prominent bones and risk of skin breakdown bed bound Oxygen prn (no exertion or participation in case)
- Maximum assist with all ADL's

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Live Discharge

- Provided a notice of non-coverage on 09/20/2023 prior to the 11th benefit period

- Family Appealed the discharge after receiving the NOMNC

- The BFCC- QIO had no "option" for hospice on their automated phone system

- The "customer service representative was not an active listener and took minimal information from the family

- Family lost their appeal

- Discharged Alive on 09/22/2023 with documentation that indicates that the team presumed the patient would live longer than six months

- Family agreed to call hospice back if they felt services were needed

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Marlene Gay Wasson Smither Simpson, 87

Death: Friday January 26, 2024, at her home in Versailles

Discussion and Recommendations

Case Study Presentation 2

Background

- 18 y/o male patient with end-stage renal cell carcinoma
- Primary providers are pediatric oncology at local children's hospital
- Patient is awake, alert, and hoping to start college
- Significant pain and symptom challenges
- Family speaks Cantonese only; have been in the US legally for 7 years
- Culturally, the father makes all decisions; Death is a natural part of life
- Patient is the only son
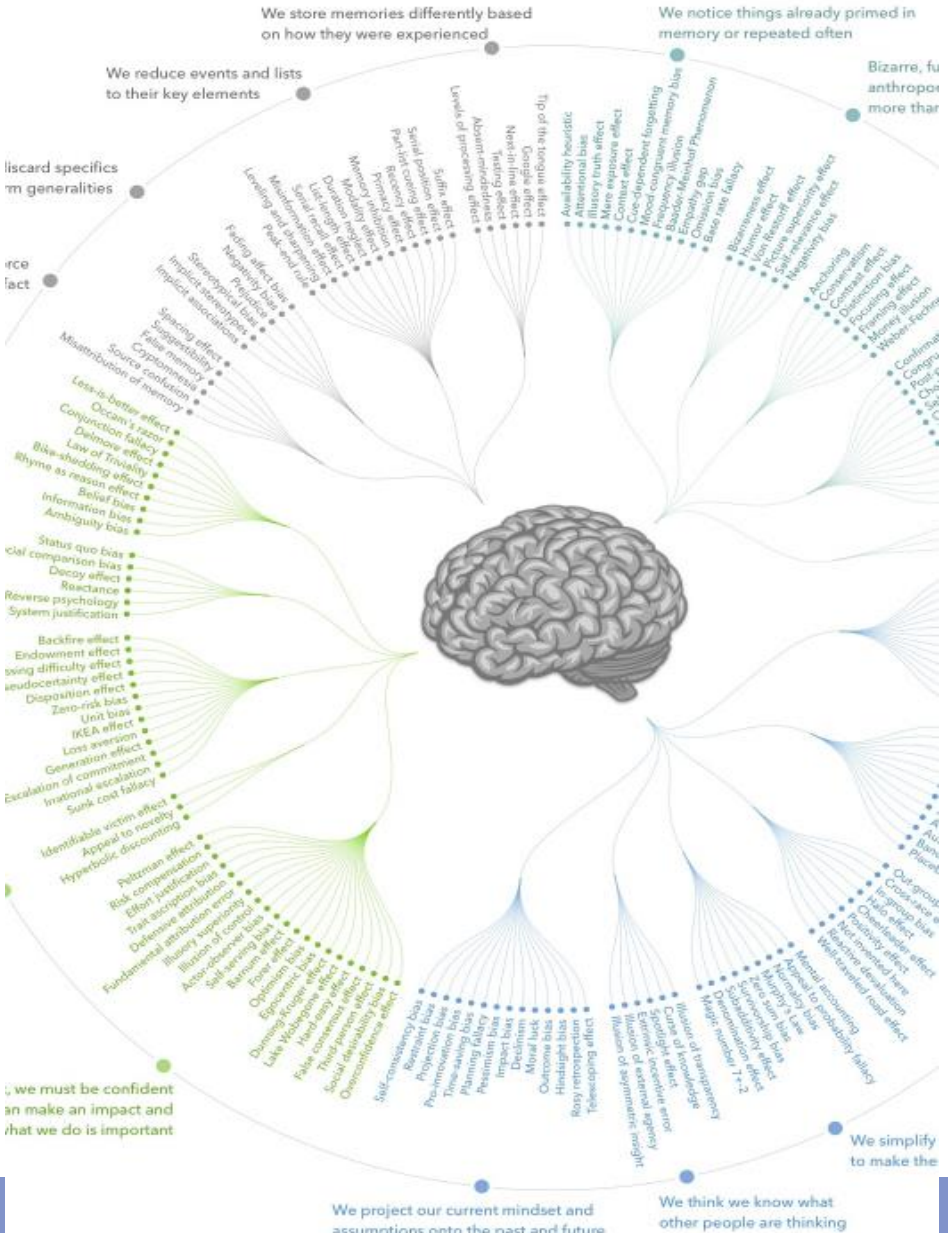- Live in a large urban area, with a large Chinese population

Situation

- Patient has been in the hospital for 3 months
- Family is very comfortable with the hospital and staff; have a close relationship with their primary interpreter and oncology team
- Patient wants to go home; Oncology team working to make it happen
- Family lives in an apartment, all utilities, elevator, separate bedrooms
- Family wants the patient home to die but does not want him to suffer.
- Fear of being able to manage pain and symptoms.
- SIGNIFICANT challenges in finding a hospice that will accept the patient

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Case Study Challenges

- Although the patient is 18, he is 'seen' as a pediatric patient
- SIGNIFICANT challenges in finding a hospice that will accept the patient
- Parents are comfortable in the hospital; hesitant about new providers
- Willing to accept hospice so their son has the support needed
- One hospice agrees to take a patient; 1 hour before the admission appointment cancels, stating they cannot take a pediatric patient.
- Patient dies in the hospital

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- Are there any potential blind spots in your thinking that need to be addressed?

- https://www.visualcapitalist.com/wp-content/uploads/2017/09/cognitive-bias-infographic.html

Discussion and Recommendations

- **How can a solid ethical foundation impact organizational culture, decrease inequities and distress, and increase staff/patient/family satisfaction?**

Discussion and Recommendations

Key Takeaways

❖ **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 team yielding 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**

References

- Great Place to Work Institute. (2012). What are the benefits of great workplaces? Retrieved from http://www.greatplacetowork.com/our-approach/what-are-the-benefits-great-workplaces

- Schwartz, Tony, and Christine Porath. "Why you hate work." *The New York Times,* The New York Times, 30 May 2014.

- Huhtala, M., Tolvanen, A., Mauno, S., & Feldt, T. (2015). The associations between ethical organizational culture, burnout, and engagement: A multilevel study. *Journal of Business and Psychology, 30*(2), 399–41

- Lesandrini, Jason; Reis, David. Ethical Challenges in Staffing: The Importance of Building Moral Muscle. Frontiers of Health Services Management: Summer 2022 - Volume 38 - Issue 4 - p 33-38.

- National Hospice and Palliative Care Organization, (2023). Hospice and palliative care code of ethics.

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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: July 30

Topic: Who Ya Gonna Call?

Date: August 6

Topic: Equitable Ethics in Pediatric Care

Date: August 13

Topic: Appointed Guardianship and Balancing Legal, Ethical, and Equitable Responsibilities

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.nhpco.org/regulatory-and-quality/quality/projectecho/

For more information:

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