Clinical Ethics: 
Supporting and Advocating for Family Choice
Timothy W. Kirk, PhD
Patrice Tadel, MSN, RN

Session objectives
- Identify opportunities to create grounded and trusting relationships with patients and families;
- Explain an approach to using ‘advocacy’ as a core ethical theme in hospice care that supports patients and families in identifying, exploring and integrating values in setting care goals;
- Describe mediation strategies that promote discussion characterized by openness, presence and the goal of understanding—rather than evaluating— the values and preferences of all involved.

PART I
CONCEPTUALIZING ADVOCACY
Nursing
“The nurse promotes, advocates for, and strives to protect the health, safety and rights of the patient.”

[ANA, Code of Ethics, 2001]

Social Work
“Social workers should advocate for living conditions conducive to the fulfillment of basic human needs and should promote social, economic, political, and cultural values and institutions that are compatible with the realization of social justice.”

[NASW, Code of Ethics, 2018]

Chaplaincy
“advocate for professional accountability that protects the public and advances the profession”

**Medicine**

“The physician's duty further requires serving as the patient's agent within the health care arena, advocating through the necessary avenues to obtain treatment that is essential to the individual patient’s care regardless of the barriers that may discourage the physician from doing so.”

(ACP, Ethics Manual, 2012)

**Kinds of Advocacy**

- Advocating for social change
- Advocating for a group (lobbying)
- Advocating for a specific action
- Advocating for specific outcome
- Advocating for self
- Advocating for specific party/client

**Clinical Advocacy**

- Ensure autonomy of patient respected
- Protect
- Fight for
- Challenge/question
- Give voice to
- Support/empower
- Explore/clarify

**Autonomy (version 1)**

- Self-governance
- Freedom
- Control
- Rights
- Consent to/refuse treatment

**Advocacy as Rights Protection**

- Consumer rights model
  “To protect patients, particularly those at a disadvantage, within the hospital context (the young, the illiterate, the uncommunicative, those without relatives, those unable to speak English) by making available a series of processes and procedures.”

(Avins & Massey, 1984)

- Nursing adds “advocacy” to 1976 version of Code of Ethics:
  “The nurse’s primary commitment is to the client’s care and safety. Hence, in the role of client advocate, the nurse must be alert to and take appropriate action regarding any instances of incompetent, unethical, or illegal practice(s) by any member of the healthcare team or the healthcare system itself, or any action on the part of others that is prejudicial to the client’s best interests.”

(as quoted in Winslow, 1984)
Questions

- What is contributing to the vulnerability of this patient?
- Are there threats to this patient’s autonomy? What are they?
- How could a clinician best advocate for this patient to ensure that his autonomy is respected?

Autonomy (version 2)

- Authenticity
- Explore, explain, apply values
- Restore/repair sense of self
  - Integrate illness/diagnosis

Case study 2: Mr. & Mrs. T

- Hospice referral to 32 yo Mrs. T
- BRCA in remission 5 years
- newly married, developed pain/disorientation on honeymoon
- mets to liver, bone and brain
- 1st round Tx (chemo/WBRT) unsuccessful
- PT/FAM unsure how to proceed

Questions

- What is contributing to the vulnerability of this patient?
- Are there threats to this patient’s autonomy? What are they?
- How could a clinician best advocate for this patient to ensure that her autonomy is respected?

Conditions Contributing to Vulnerability in Hospice Care

- Illness
- Disorientation—interrupted future
- Anticipatory grief
- Social hardship/disadvantage
- Financial hardship/disadvantage
- Knowledge/resource imbalance
- Power imbalance

Advocacy Without Adversary

Existential Advocacy

“help patients become clear about what it is they want to do by helping them discern and clarify their values in the situation and only on the basis of that self-examination, to reach decisions, which express their reaffirmed, perhaps recreated, complex of values”

(Yeo et al., 2010)
Existential Advocacy

CONDITIONS OF VULNERABILITY

FAMILY

FAMILY

PATIENT

CONDITIONS OF VULNERABILITY

How can a shift from rights protection to existential support change what it means to be a clinical advocate in hospice care?

PART II

IMPLEMENTING ADVOCACY:
Mediation as Advocacy

Authenticity

• “Tied into notion of integrity and wish for one’s life to have a coherent narrative”
• Beyond choosing, person has the capacity to be a distinct individual
• Best interests is not the same as self-determination or authenticity but both are elements of best interest
  • “Does the decision fit with his/her prior beliefs and values?”
  • “Making my own decisions is linked to living a life that is mine”
  • Decisions should not “run the risk that the person would end up in a life” that would not be his/her own
• False beliefs and poor reasoning by surrogates may have to accede to best interest considerations
• Patient’s interests include not only living in accordance with his own values but being conscious of doing so
  (Brudney, 2009)

Missed Opportunities

• Hearing the essence of the patient
• Listening and responding to families
• Acknowledging and addressing family emotions
• Hear facets of the patient narrative
• Pursuing key principles of clinical ethics and palliative care
  • Exploration of patient preferences and authenticity
  • Explanation of surrogacy decision-making
  • Affirmation of non-abandonment
  (Hoffman, 2009)

Facilitation of Decision-making: Challenges

• Limited discussion of underlying health status and disease trajectories
• Too many choices rather than a focus on goals
• Symbolism of interventions/what they will and won’t achieve
• Recognition of legitimacy of patient’s culture and validation of this specific to each individual within a culture
• Time to allow patient and family “to catch up”
  (Gillick, 2009)
Moral Distress
- Discomfort with acceptance of patient desires for care and autonomy
- Unable to keep own values and opinions separated from engagement with patient
- Not equipped to deal with complex issues and tough decisions faced by dying patients and their families
- Self-perceived lack of education or self-efficacy
- Disagreement with other medical professionals regarding treatment of patient
- Personal beliefs or motivations in conflict with patient/family

(Duke & Norham, 2009; Hartman, 2009)

Qualities of Mediation
- Self-awareness
- Presence
- Authenticity
- Congruence
- Integration
- Narrative Consensus

Managing Moral Distress at the Bedside
“Moral distress is a feeling that occurs when one believes that he/she knows the correct thing to do but is unable to pursue the right course of action”
Growing issue linked to
- Poor performance
- Burnout
- Poor retention at bedside
Resource most commonly used for ethical or moral issues is peers
Balancing open communication with opportunity for ethical dimension of care within discussion
Naming and analyzing components of issues and facilitation learning and openness to other world views important for diminishing distress and allowing growth and positive customer encounters

(Helft, Beekes, Hancock & Wood, 2003)

Case Study 3
Catastrophic cerebrovascular event of 88 yo gentleman with previous CVA and cardiac history, brought into ER after being found in garage by daughter. Fairly independent for ADLs with use of walker and oxygen in home. Living at home with wife and one daughter, who moved back in to “help”. Four other children, this dtr and wife, 84 yo, at bedside. Argumentative with physicians, each other, and intermittently crying and arguing with each other. Care team frustrated and want resolution and to move forward. “Get the DNR and get them to agree to hospice”.

Questions
- What are the advocacy issues here?
- How do we facilitate the voice of the patient in the room with so much chaos?
- Where do we start and how do we stay focused on the goal?

Hearing the Narrative
- Stories, motivations, values and goals that are woven together constitute the substance of real lives
- Text of past life, what said, how said, and what was important to the patient
- Participants must illustrate the narrative not only as:
  - What they believe
  - But why and what lead to this belief
- Happens through properly timed open-ended questions by the literary coach/mediator
Existential Support: Elements of Drawing In
- All have equal standing
- Introduce the purpose of conversation
- Prompt family to tell how they understand the illness
- “Explanatory model” is their account of the illness trajectory
- Sensitivity to labeling which may thwart development of the narrative consensus
- Mediator guides the discussion

Successful Mediation
- Authenticity and fully present
- Not attached to the results
- Centering oneself in peace
- Non-judgmental place within

“Mediators can withstand the heat by removing their protective armor” (Hoffman & Vidmar, 2010)

Self-led Personhood - Schwartz
- Calmness
- Clarity
- Curiosity
- Compassion
- Confidence
- Courage
- Creativity
- Connectedness

Stepping in as Mediator
- Center oneself
  - An image, symbol or concrete touch (hold on to the door handle a brief moment longer)
- Provide neutral safety space to participants
- State the purpose of mediation
  - Hear the voice of the patient through the narrative
  - All have a piece, allow all stakeholders a voice
  - All have a common focus, what is best for the patient
  - Model through body language, tone and listening how all can be part of process
  - Engaged in the process not outcome
  - Know your BANTA (Best alternative to a negotiated agreement)

Examples of Engaging
- “I hear in your voices how unique the relationship each of you had to this person”
- “I am not fortunate enough to know your dad, can you tell me about him”
- “If she could speak for herself right now, what would she have to tell us”
- “How would you describe the past year or so and how his illnesses have impacted him?”
- “Has she ever talked about what matters for her, what she still wants to do?”
- “You both are saying you want respect, for you that means… and for you it sounds like that means…”
- “Let me see if I can clarify what you are saying…”

Ask Questions
... to focus on the present and the future
- Obtain broad overview
- Seek more information
- Clarify generalizations or abstract ideas
- Focus discussion
- Encourage all to evaluate options
- To introduce new or hypothetical solutions
Remember to...
- Demonstrate transparency through clarifying statements
- Keep in mind the family, not we must live with the decisions
- Not repeat hostile or volatile words, but acknowledge the feelings behind them or summarize the information in them
- End summaries with a question to move the discussion forward
- Ask clarifying questions which draw all in
- Offer solutions for all or part of the dispute

“Integrated’ Mediation
“Presence is a quality that can be developed in all areas of our life. In the heat of any personal conflict, one can work on developing the capacity to be present to every aspect of that conflict, while stepping aside from one’s own point of view and learning to distinguish one’s thoughts, from one’s emotions, from one’s perceptions, from our conflict partner’s point of view, to embrace a broader, more integrated view…to be peace”

(Bowling & Hoffman, 2000)

“While many would say that the settlement of the dispute constitutes a successful outcome, others contend that empowerment and recognition, not settlement, are the hallmarks of success.”

(Bowling & Hoffman, 2000)

A Process that Grows
- Learning technique
- Deep understanding of how and why it works
- Awareness of how our personal qualities influence the process for better or worse
  - Active listening
  - The echo in the words

Self-Leadership
“to maintain Self-leadership in the face of provocation, our parts must be able to trust our Selves enough to quickly step back and let our (authentic)Selves handle the situation….When this works, I will feel upset inside but will not be overwhelmed by the upset parts and will remain the “I” in the storm – dealing calmly, confidently, and even compassionately with the situation, while sensing parts that are seething or cowering inside.”

(Schwartz, 2001)

A Jigsaw Puzzle
Putting together the pieces of a puzzle, one tries to imagine how what looks like it cannot fit together indeed does.

“A mediator has a similar task. To be fluid and detached to the extent necessary to put the pieces together while at the same time being mindful of changes”.

(Seff, 2004)
Thank you!

Further questions or comments?

timothy.kirk@york.cuny.edu
patrice.tadel@vitas.com

Bibliography


Bibliography


Bibliography


Bibliography

Bibliography