The Truth and Nothing but the Truth: Truth Telling in the Palliative Care Setting

Deborah Bourgeois APRN, ACNS-BC, ACHPN
Abdul M. Khan M.D.
Objectives

• Increase the knowledge base concerning the principal of veracity (truth-telling) within the context of relational ethics

• Illustrate the effective use of truth-telling within the palliative care clinical setting
Truth-Telling

• Truth-telling can be defined simply as the ethical principal of Veracity.

• It is the avoidance of lying, deception, and misrepresentation of relevant clinical information with patients.
Why is Truth Telling Important

- **Prima facie wrong**: Lying - inherent wrong
- **Barrier to Patient Autonomy and Informed Consent**
- **Destroys patients trust**
- **Lying is impractical**: One lie leads to another
- **Most patients want to know**
  - 94% of patients said they “would want to know everything” about their medical condition, “even if unfavorable.”

Steven Pantilat, MD
Associate Professor of Medicine
UCSF School of Medicine
Styles of Truth-Telling

• What the patient **Wants** to know
• What the patient **Needs** to know
• **Translation** of information into terms the patient / loved ones intellectually/emotionally can handle
Shared Dynamic Truth

All illness has objective, subjective, and relational aspects
Barriers to Truth Telling

- Mentally ill patient who may cause harm to himself
- When the patient doesn’t want to know
- Loved ones do not know how to tell the truth
- Loved ones believe it is unnecessary to tell aged patients the truth
- Loved ones believe patients can be happier without knowing the truth
Relational Ethics

Based on the assumption that ethical practice is situated in relationships.
Relational Ethics

• The balance of truth-telling in personal interactions in order to convey difficult information

• Based on developing authentic dialogue, respecting emotions, as well as finding the reason for developing those emotions

Video Clip

http://www.youtube.com/watch?feature=player_detailpage&v=O7epNY_9eYw
Influencing Factors

• Culture
  – Shapes a persons views and belief systems
  – Attitudes toward life and death

• Suffering

• Treatment compliance

• Healthcare Team Self Protection

• Reconciling Hope /Truth Dichotomy

‘Hope means different things to different people, and different things to the same person as he/she moves through stages of illness.’

Brody H. Hope. JAMA. 1981; 246:1411-1412
Hope Management

**Increase Hope**
- Feeling valued
- Meaningful Relationships
- Reminiscence
- Humor
- Realistic Goals
- Pain/Symptom Relief
- Listening

**Decrease Hope**
- Feeling Devalued
  - Abandonment / Isolated
    - “there is nothing more that can be done”
  - Lack of direction and goals
- Unrelieved pain and discomfort
Overview

• Case 1: Pulmonary Alveolar Proteinosis
  – Medical student perspective
  – Significance of Truth Telling

• Case 2: Heart Failure
  – Medical Resident perspective
  – Relational Ethics

• Summation
  – Barriers to effective truth telling
  – Incorporating principles into daily practice
Case 1

- **C.C.: Progressive SOB**
- Patient is a 58 y/o male with a pmhx of htn, etoh abuse, L3-L4 compression frx who presents to OMC after being transferred from outside facility. Patient is on BiPap 10/5 and visibly distressed.
- Patient’s social support consists of only his fiance’. Patient and fiance’ are estranged from his 3 brothers who live in Colorado.
- At the outside facility patient has received a BAL as well been treated aggressively with a regimen of steroids.
- Decision made on rounds to **electively intubate** patient in advance of repeat BAL.
Palliative Care Involvement

- Before intubation, patient’s fiancé voices concern. She states, “his only wish is to be able to die at home on his farm.” To that end, attending physician states, “We’ll talk about that later.”

- As patient’s disease process worsened, aggressive treatment was delivered including Intubation, Nitric Oxide, and Paralytics.

- Palliative Care consulted before the latter two therapies initiated and then consult rescinded in favor of possible total lung wash out in the OR.

- Patient expired 21 days after transfer. Total of 4 attendings and 8 Resident physicians provided care.

- Medical students involved throughout the course of care and often voiced objections in private.
Discussion

What would you have done?
Truth Telling from the Student Perspective

- **Ethical decision making on truth telling in terminal cancer: medical students’ choices between patient autonomy and family paternalism**
  
  --Moral reasoning existed prior to the class and the students initially tended to overlook the complexity of truth telling in terminal cancer

- Group discussion seemed to be able to enhance ethical consideration

- Increase need for medical students to realize the complexity of truth telling in terminal cancer

- Discussion and reflective learning, students are able to acknowledge the vulnerability of both the patient and his or her family, and to make decisions based on more comprehensive considerations

Case 2

• C.C: Dyspnea at rest

• Patient is a 67 y/o male with multiple co-morbidities including systolic heart failure with an E.F. of 25%, CAD, DM II who presents as a transfer to OMC for evaluation of acute on chronic heart failure. Patient has been aggressively diuresed at OSH without improvement

• Decision made to initially begin ionotropic agents and then care advanced to balloon pump.

• Patient with a sudden episode of apnea on Day 14 at OMC and decision to intubate made by overnight Cardiology Fellow secondary to code status
Palliative Care Involvement

- Primary team believed, “nothing more could be done.”
- Decision made to initiate withdrawal of care, however patient’s wife did not agree with plan of action.
- Patient cared for by 3 Attendings, 2 Fellows, 1 Resident.
- Palliative Care consulted Day 13, Day before intubation.
- Plan of action initiated and withdrawal initiated 2 days later only after listening and addressing patient’s wife’s concerns.
- Fellow with many questions as to the process of withdrawal of care and comments after family meeting, “That went so smooth.”
Discussion

What would you have done?
Truth Telling and Relational Ethics from the Resident Perspective

• **Balancing truth-telling in a preservation of hope: A relational ethics approach**
  -- Different views on what consequence truth-telling has for giving or diminishing hope.

• Balancing of truth-telling needs to be decided in a mutual understanding in the caring relationship

• Relational ethics can serve as a meaningful perspective in balancing truth-telling

Incorporating Principles into Practice

- Listen for understanding to establish rapport and trust
- Determine what they want to know and discuss the illness compassionately
- Disclose information based on patients' expectations and support them.
- Communicate with and encourage loved ones to accept patients' prognosis
- Provide enough time to reflect on their illness
- Prepare them for the possible emotional reactions and how to provide support

Hu WY, Chiu TY, Chuang RB, Chen CY. "Solving family-related barriers to truthfulness in cases of terminal cancer in Taiwan. A professional perspective." *Cancer Nursing Journal* 25, no. 6 (December 2002): 486-92.
Questions?