Using Illness Narratives of Cancer/Palliative Care Patients to Teach the Meaning of Illness

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Purpose of Presentation

To describe how narrative (story) is used:

1) In teaching graduate students to gain insight into what it means to be chronically/seriously ill

1) To enable students to become a witness to how the very being and structure of an individual’s life can be governed by illness
**Background**

- Why is this work important?
- Nursing & Medical students healthy & young
- May not have experienced chronic/serious illness
- Assist to understand illness from a physical, social, psychological & spiritual perspective
- Learn to be listen and become therapeutic

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**The Meaning of Illness**

- “The experience of illness is very personal and, at the same time, universal. The personal experience is that illness always has a story. It is the story of a life interrupted” Younger, p. 316

- You tube—Rita Charon, MD
  Honoring the Stories of Illness
  [http://www.youtube.com/watch?v=24kHX2HtU3o](http://www.youtube.com/watch?v=24kHX2HtU3o)
Arthur Kleinman—Illness Narratives

- Patients order their experience of illness - what it means to them and to significant others - as personal narratives. The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering... To fully appreciate the sick person's and the family's experience, the clinician must first piece together the illness narrative as it emerges from the patient's and family's complaints and explanatory models; then he or she must interpret it in light of the different modes of illness meanings - symptom symbols, culturally salient illnesses, personal and social contexts... Telling this tale is of great significance... For the care giver what is important is to witness a life story, to validate its interpretation, and to affirm its value.

What is an Illness Narrative?

- Three types of Illness Narratives (Frank, The Wounded Healer, 1988)

- Restitution—most common type
  - Desire is to be well again
  - Discuss diagnosis, diagnostic tests, and effect on the individual experiencing

- Chaos—opposite of restitution
  - Life will never be any better
  - Usually no happy ending
What is an Illness Narrative?

- Quest Narrative—third type
  - “the ill person meets suffering head on”
  - Accept illness and seek to use it
  - Illness is the occasion of a journey that become a quest

- Who writes Illness Narratives?
  - Individual experiencing
  - Family member
  - Health care professionals/students

Illness Narrative Process

- Can write a narrative about one’s own illness experience

- Can be real or imagined

- Ask our students to interview a patient—hopefully someone that they will work with in the clinical setting
Illness Narrative Process

- Factors crucial to this process:
  - Communication skills
  - Ability to listen
  - Cultural implications

Patient/Family Expectations

- Be honest
- Elicit values and goals
- Take time to listen
- Be alert to cultural considerations
Illness Narrative Process

- Best to ask patient to share his/her story
- Use open-ended questions
  - Key questions
  - Allows patient to tell story
- Ex of questions—if needed
  - What concerns you about your illness?
  - What are your hopes/goals?
  - Relationships/unfinished business?
  - What gives meaning to your life?

Illness Narrative Process

- Ask open-ended questions—if needed
  - Tell me about your illness?
  - How much information do you wish to know?
  - How do you make decisions?
  - Is there anyone else that you wish to know or include in discussion
  - Any cultural considerations to your health care that I should know?
**Listening Principles**

- Being present, being silent
- Occurs at 5 levels
  - Hearing
  - Understanding
  - Retaining information
  - Analyzing
  - Active empathizing

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**Presence**

Some techniques:

- Knowing and being comfortable with oneself
- Knowing the other person
- Connection
- Affirmation and valuing

Stanley, 2002
Presence (cont.)

- Acknowledging vulnerability
- Intuition
- Empathy
- Being in the moment
- Serenity and silence

Stanley, 2002

Reflective Engagement

- Term seems to be defined somewhat differently depending on discipline defining it

- Our definition—encourage student to spend some time ‘being with’ an illness narrative:
  - Deciding type of narrative
  - Defining if there is a moral/ethical context
  - Respond back to patient from a reflective perspective—acknowledge what student heard patient saying—helps to give a “voice” to patient’s narrative
What Students Say After the Experience

- Graduate students write illness narratives
  - Report that they understand illness in a different way
  - Personal—had to work on being “intentional”
    - Being reflective takes some practice
  - Changes how they view a patient and his/her experience
  - Allows them to better understand patient/families “goals for care”
  - Assists in planning interventions for nursing care
    - Plan with patient/family

Summary of the Illness Narrative Experience

- Becoming a witness to a patient’s story can assist the health care professional
  - To understand the patient’s story—“voice”
  - Understand the patient’s goals for care
  - Greater appreciation for how illness can affect life plans
  - Can result in provision of care that is more timely for the patient