

THE PATIENT'S EXPERIENCE THROUGH LITERATURE AND ART

I. Objectives

- A. Increase empathy for patients' experiences**
- B. Develop sensitivity to meaning**
- C. Stimulate imaginative and creative thinking about patients**

II. The Nature of Illness

- A. A single reality or multiple realities?**
- B. Different systems of relevances**
- C. Different habits of mind**
- D. Distinct interpretational schemata**

III. The Nature of Knowledge

A. Logico-scientific knowledge

- 1. Emphasizes objectivity, facts, replicable procedures, universal rules, generalizability**
- 2. Derived from hypothesis-driven empirical research**
- 3. Biophysical understanding of illness**

B. Narrative knowledge

- 1. Realities are socially constructed through language and narrative**
- 2. Multiple truths co-exist**
- 3. Derived from reflecting on and sharing stories**
 - a. How we make sense of experience, including the illness experience**
 - b. A way to explore and understand questions of suffering and meaning**
- 4. Biopsychosocial-cultural understanding of illness**

IV. Implications of Two Types of Knowledge for Health Care

A. What is important about experience? (How can we best understand the patient's reality?)

- 1. Logico-scientific: particulars of personal experience eliminated in favor of abstractions, generalizations, systems of classification and diagnosis**
- 2. Narrative: emphasis is on particulars of individual experience**

B. Whose point of view and voice are important?

- 1. Logico-scientific: patient's point of view is subjective, therefore suspect**
- 2. Narrative: patient's point of view and voice are essential**

C. How should physicians and health care providers position themselves in relation to the patient?

- 1. Logico-scientific: emphasis is on objectivity, detachment, distance in professional relationships**
- 2. Narrative: requires emotional engagement and presence**

V. The Illness Experience

A. Meaning

- 1. Loss**
- 2. Separation**

B. Suffering

- 1. Involves the whole person, not mind-body dualisms**
- 2. Threatens the intactness of the person**
- 3. Can involve any aspect of the person**

C. Meaning Revisited - Alleviation of Suffering

- 1. Relief from suffering comes from**
 - a. Changing the meaning of the experience**
 - b. Restoring the disrupted connectedness between sufferer and others**
- 2. Revisioning meaning and connectedness occurs primarily by telling stories about them**

VI. Pathography

A. Definition: A form of autobiography or biography that describes personal experiences of illness, treatment and sometimes death

B. Modernist view of disease

- 1. Body is a machine**
- 2. Disease is a break-down of functional operation**
- 3. Physician is expert**
- 4. Patient is passive object**

C. Post-modern view of illness

- 1. Mind, body, and person inextricably linked**
- 2. Illness occurs in all parts of the self the one's social relations**
- 3. Physician has expertise, but is also fallible and limited**
- 4. Patient has expertise about self and experience**

D. Classic bio-pathography: Kleinman's *The Illness Narratives*

- 1. Narratives of illness illuminated how the life problems created by sickness are controlled, adapted to, and made meaningful**
- 2. Through narrative, patients make sense of and give value to their experiences**
- 3. Interpretation of illness narratives is a core task of doctoring**

VII. Models of Pathographies

A. Narrative trajectories

- 1. Sad - basic downward slope across life**
- 2. Tragic - positive life, then crashes down**
- 3. Heroic - upward trend, with detours or blips for disease**
- 4. Transformative - stable line, interrupted by illness, leads to consolidation at higher level**

B. Mythic

- 1. Death and rebirth - individual dies to old way of life and is reborn a new person**
- 2. Battle - disease is the enemy, treatment is warfare**
- 3. Journey - hero receives "call"; encounters trials and challenges; endures suffering; accomplishes mission and returns to land**

C. Arthur Frank

- 1. Chaos - anti-narrative; formless pile-up of calamities**
- 2. Restitution - broken, then restored to previous wholeness**
- 3. Quest - journey (see above)**

4. **Testimony - patient offers a truth generally unrecognized or suppressed; implies relationship, always about self in relation to others; requires a listener**

VIII. Functions of Pathographies

- A. **Orient narrator into the world of sickness**
- B. **Develop symbolic integrity (life is still meaningful)**
- C. **Create sense of movement (capacity for change)**
- D. **Connection between self and others**
- E. **Telling and listening to stories as moral actions**
 1. **Telling and listening to stories joins people in shared vulnerability through suffering**
 2. **As storyteller, ill person is healer as well as sufferer**
 3. **Storytelling a moral obligation, to tell unpopular or idiosyncratic truths**
 4. **Listening to the storytelling becomes a moral act as well, a way in which we bear witness, and recognize, the suffering of others**

IX. Specific "Knowledge" Listener Develops through Witnessing

- A. **Presence - close, respectful attention to patient**
- B. **Empathy**
- C. **Sensitivity to meaning of patient's experience**
- D. **Emotional connectivity and engagement**
- E. **Whole person understanding and appreciation**

X. Discussion of specific poems: cancer, heart disease, disability, death