

S/A 4071: Social/Cultural Aspects of Health and Illness:
Class 14: The Lived Experience of Being Ill 1:

* Today we move from “objective” causal explanations to subjective, meaningful understandings: we begin considering the conscious meaning of health & illness for those who experience them in various social contexts

* Sociological distinctions:

(1) Disease: diagnosed by doctor: found in body & biomedically treated as such

(2) Illness: personal experience of a person claiming not to feel well

(3) Sickness: social actions taken by a person as a result of 1 or 2

* These may operate independently of each other (acting sick without feeling ill or being diagnosed; being told nothing wrong when feeling ill). However, they may also reinforce one another

* Social/cultural factors influence each of these (e.g. Steinem on men & menstruation)

Variations in the Experience of Being Ill:

* In the non-western world, non-empirical explanations & cures for disease seem to dominate (e.g. the spiritual is mixed with the mental/physical)

* The experience of pain varies culturally as well (e.g. NYC Jews & Italians reacting emotionally/ “old Americans” reacting stoically)

* What is viewed as disease/undesirable varies culturally (e.g.

obesity/epilepsy)

Popular Conceptions of Health, Illness & Disease:

* Cornwell: medicalization from *above* vs. from *below*: the former refers to claims by allopathic medicine; the latter to its acceptance/rejection by lay people

* Popular conceptions of health & illness:

- (1) *Illness as choice*: the mind acts to both sicken & heal the body (e.g. imaging in cancer treatment)
- (2) *Illness as despair*: common, negative emotional experiences precede illness: focusing on positive emotions can help
- (3) *Illness as secondary gain*: (e.g. avoiding work or unpleasant responsibilities; legitimating one's social position)
- (4) *Illness as a message of the body*: symptoms indicate that the whole person is responding to a challenge: a "healing crisis"
- (5) *Illness as communication*: (i.e. one part of the body is alienated from the self: different diseases express different frustrations)
- (6) *Illness as Metaphor*: cultures bestow meanings on particular diseases, often with destructive, harmful effects on the patient (e.g. AIDS)
- (7) *Media images*: cancer: invasion by evil predator to be avoided; heart disease: objective, morally neutral event; AIDS: stigmatization of "immoral" lifestyles & fear of contagion
- (8) *Illness as statistical infrequency*: i.e. it is rare: common things such as colds & flu don't count
- (9) *Illness as sexual politics*: the constraints & limitations of gender roles are associated with the conceptualization & diagnosis of various diseases (e.g. 19th century hysteria, eating disorders today among western, mid-upper class women)

The Insider's View: How Illness is Experienced:

* We turn to look at the inner meaning & experience of illness at the individual (but socially contextualized) level

* There has been much work done in this area:

- Bluebond-Langer: children dying of leukemia
- Speedling: the family experience of a member's heart attack
- Thomas: the experience & identities of individuals with impairment, disability & handicap (careful distinctions)
- Schneider & Conrad: people experiencing epilepsy
- Paget: the experience of medical errors
- Strauss & Glaser: common concerns of people with chronic illnesses & those of their families:
 - (i) Crisis management (e.g. avoiding/ accounting for epileptic seizures)
 - (ii) Managing medical regimens (e.g. the side effects of chemotherapy)
 - (iii) Control of symptoms
 - (iv) Organizing & scheduling time
 - (v) Preventing & coping with isolation
 - (vi) Dealing with uncertainty
 - (vii) Normalizing social relationships
 - (viii) Managing stigma (e.g. cancer, epilepsy)
 - (ix) Managing information (e.g. "In the closet" vs. the "revolving door")
- Corbin & Strauss: the "BBC chain" : as the body changes in chronic illness, so does one's self-conception & biography
- Charmaz: the struggle for self through a hierarchy of preferences in identities

- Frank: self narratives: the rediscovered self, the new self, the same self
- Clarke: women & cancer: experiential themes as diagnosis of cancer is assimilated, changes in identity, re-examination of lives, searches for explanation & control, changed social interactions with others