

S/A 4071: Social/Cultural Aspects of Health and Illness:
Class 15: The Lived Experience of Being Ill 2:

- * Research on experiencing chronic illness emphasizes:
 - how people come to view themselves as chronically ill
 - how illness affects their lives
 - the patients' perspectives rather than practitioners

- * Social scientific studies of illness took off 40 years ago when ethnographers found structural theories failed to account for how people lived with/made sense of chronic conditions (e.g. Parsons' "sick role").

- * Research moved toward inductive, subjective analysis (e.g. of patient's actively negotiating their roles, careers, managing stigma, selves & identities)

Becoming & Being Ill:

- * Prior beliefs about health & illness vary by culture & group. These inform our bodily experiences, often in an ideological way linking institutional practices to the individual (i.e. how to handle illness)
Example: handling leprosy by Ethiopians vs. Americans.

- * Medical practitioners beliefs/definitions of illness affects individual/collective life: (1) masks social roots; (2) marginalizes sufferers (e.g. Gulf War syndrome); & (3) creates personal, economic, & social consequences (e.g. identity losses, stigmatization)

- * Individual accounts of health & illness reflect identity & reality claims for specific audiences & purposes (e.g. more detailed private vs. public accounts when wary of consequences of being branded "ill")

- * Individual accounts also draw upon cultural values & individual

intentions in certain circumstances

Illness as Biographical Disruption vs. Continuity

* Chronic illness often disrupts one's life, evoking themes of disruption & loss of control

* Becoming ill poses 3 major problems for people:

- (1) Making sense of bewildering symptoms (e.g. defining one's Condition)
- (2) Reconstructing order (efforts to manage illness & regimen)
- (3) Maintaining control over life (concrete daily actions & regaining coherence of self/one's world)

* Definitions of illness may be rejected, challenged, negotiated & redefined in the process of diagnosis between practitioners & patients (e.g. some patients symptoms are discounted as unlikely given age, other patients push hard for a diagnosis)

* Defining illness & being diagnosed occurs in several ways:

- (1) having a crisis (may force a diagnosis, or individual may for a time define it away as an exceptional episode or interpret it through lay beliefs about aging or stress);
- (2) comparing self with sick people (upward/downward comparisons);
- (3) redefining feelings or behavior as symptoms; &
- (4) receiving test findings or medical pronouncements

* Chronically ill people rarely want to be invalids, but to be accepted as valid adults. Symptoms may be intermittent. Hence many delay seeking help to prevent losing valued roles, responsibilities & self images

* Many people don't seek medical explanation until unable to manage, but doctors may not respond quickly with diagnosis. A diagnostic search may result in "diagnostic limbo" for a time

* Diagnostic shock follows an announcement of serious illness found in tests (i.e. unexpected reality/identity disconfirmation/being forced into patient role/learning what being ill "really" means)

Managing Illness: Learning What Illness Means

* To be ill, one must define changes in bodily feeling or function. Otherwise, denial may continue for a time until one's condition/experience forces it (e.g. being unable to do what one could easily before)

* Historical, cultural, social & situational contexts influence the meaning of illness

Normalizing Illness & Regimen

* Normalizing illness & regimen means making them routine, treating whatever changes & improvisations are created as ordinary (i.e. to minimize the impact on daily life, contain it to personal experience, and not intrude upon interaction)

Illness Management Strategies:

* Strategies range from withdrawal, innovation to negotiation

* Younger/middle-aged people often make concerted efforts to manage illness (e.g. support groups, shared information & community; educating themselves, breaking through textbook definitions to create

individualized regimens - not always welcomed by doctors!)

Stigma & Stigma Control:

- * Experiencing stigma is a common consequence of chronic illness, a social threat to one's identity. It separates one from others, often becoming a "master status" that taints all one's statuses & identities
- * Stigma may be enacted by others, or felt & feared by the ill in the event that they are "discovered" (e.g. epilepsy)
- * Guilt & shame increase when chronically ill people view themselves as socially incompetent (e.g. colostomy patients & basic social rules re: bodily functions)
- * Enacted stigma dramatizes difference & magnifies loss, often resulting in restrictive information management/interaction choices with other to preserve self
- * Concealment is much harder for people with visible disabilities. Efforts toward prior identity preservation fail in direct proportion to the degree & extent of visible disability
- * Stigma potential is increased socially when the following characteristics are present: a high incidence within socially disparaged groups, compromised adult status, loss of bodily control, sexual transmission, possible pollution, odor & uncleanliness

Self & Social Identity:

- * Stigma is damaging, forcing unwelcome new ways of conceiving the self & situation

* Serious chronic illnesses alone may necessitate redefining, rethinking how one lives/ who one is becoming - as self & social identities are intertwined with daily activities in a context where social & other resources to preserve old selves/identities may be shrinking

* Then again, this “loss of self” may enable individuals to jettison old identities in a search for deeper meaning

Implications of Studying the Experience of Illness:

* Such research has implications for: (1) institutional changes / health policy reform; & (2) further research.

* A new model for chronic care should have strong participatory/ educational components unlike the current isolating, unidirectional regime that is breaking down in a context of more chronically ill people

* A social, community-based model of care would begin with the chronically ill person’s situation as the unit of concern, not the disease process within the person

* As understanding increases in a context of increased information & options, poor service, blame & conflict will likely decrease

* This will also give individuals more information, coping choices, reduce isolation, improve their sense of control, improve health outcomes, reduce non-compliance, etc.

* Research on the experience of illness is promising. Future studies should:

- concentrate on the body, emotion & health

- focus on subjective stories of health/illness evolve over time
- find ways to reach inaccessible subjects
- focus on interactions in the broader social context