

Chronic Disease, Illness

Illness and Disease¹

In the West, when a sufferer seeks help

Disease is recast from the practitioner's perspective

Into narrow biological terms of the biomedical model

It tends to be reconfigured only as an alteration in biological structure or function

In many other [traditional] societies

Disease is construed as the embodiment of the symbolic network

Linking body, self, and society

The body is seen as an open system

linking social relations to the self,

A vital balance between interrelated elements in a holistic cosmos

¹ Material from Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition*. 1988, New York: Basic Books, pp. 3-55.

Emotion and cognition are integrated into bodily processes

Body-self is not a secularized private domain of the individual person

But an organic part of a sacred, sociocentric world

A communication system involving exchanged with others

Including supernatural—God, the saints, spirits, ancestors

So bodily complaints are also moral problems

Signs of disharmonies in social relationships and in
the cultural ethos

Remember: biological processes are known only

Through socially constructed categories

That constrain experience as much as does disordered physiology

Chronic illness

Practitioners, trained to think of “real” disease entities

With “natural” histories and precise outcomes

Find chronic illness messy and threatening

They are taught to regard with suspicion patients’ stories and their beliefs about cause

And patients can come to experience their care as a problem in the health care system

Chronic illness

Tends to oscillate between periods of exacerbation

To periods of quiescence

When disability is less disruptive

Lots of evidence that psychological and social factors

Are often the determinants of the swing toward amplification

Psychological:

Anxiety

Giving up

Social:

Life event changes

Impaired social support

Oppressive relationships

Dampening occurs with:

Strengthened social support

Enhanced sense of self-efficacy

Rekindled aspiration

Such dampening can be associated with a paradigm of care

That substitutes a pragmatic notion of illness maintenance and disability reduction

For the myth of cure

There can be a practitioner/patient and family denial

That chronic disorder is influenced by psychosocial factors

Which can lead to pessimism and passivity

Worsening outcome

Importance of **meanings** in chronic illness

All chronic illnesses assimilate to a life course

A chronic illness becomes a big part of a life history

An illness communicates meanings to all concerned

These meanings can amplify or dampen symptoms

They can exaggerate or lessen disability

They can impede or facilitate treatment

The caregiver in chronic illness and these larger meanings:

Empathic witnessing of the experience of suffering

Attention to practical coping with major psychosocial crises

That constitute the menacing chronicity of that experience of suffering

Symptoms aren't only "natural", they have meaning

Look at the metaphors people use

Football helmet 7 sizes too small

Some therapy is based on patient-constructed images

Pain Center: crab, anvil

Kinds of Meanings:

Medicalization

Is also meaning

Earlier explanations: moral, religious, criminal

Redefined as disorder

Therapy rather than burning, prison

Stigma

Leprosy

Quarantine the sick

Why the disease?

Plague (Black Death) symbol of evil and terror

Wrath of God, sin, death as transcendence of the immortal soul

Quarantine the victims

Illness caused by witchcraft

Explanatory model of malignant illnesses

Fears regarding threats to procreativity, productivity

Threats to village unity

Salem, Africa, the Bocage

You brought it on yourself

STDs

Addiction

Cancer: why me?

Foods, radiation, invisible pollutants

Heart disease

Wrong lifestyle

Murphy?

Blame the victim

Gives us a sense of control

Meanings: your papers

Neurasthenia

T.B.

Where does meaning lie?

One model: lies in the space between the actual experience and how each of us relates to that experience as an observing self

But meaning can come *before* the experience, influence it

Brain changes in anticipation of pain

Is this *meaning*?

If not, what is it?

Conclusion: in general, illness is what it is because of meaning

Embarrassment?

Divine gift?

Epilepsy

Psychosomatic?

He died of a broken heart

Problems with meaning-centered approaches to illness, in particular chronic illness?

Meaning assignment can evolve into “shoulds” and “should nots”

PMS: ambivalence to traditional procreative functions

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