Illness Narratives, Embodiment, and Meaning-Making

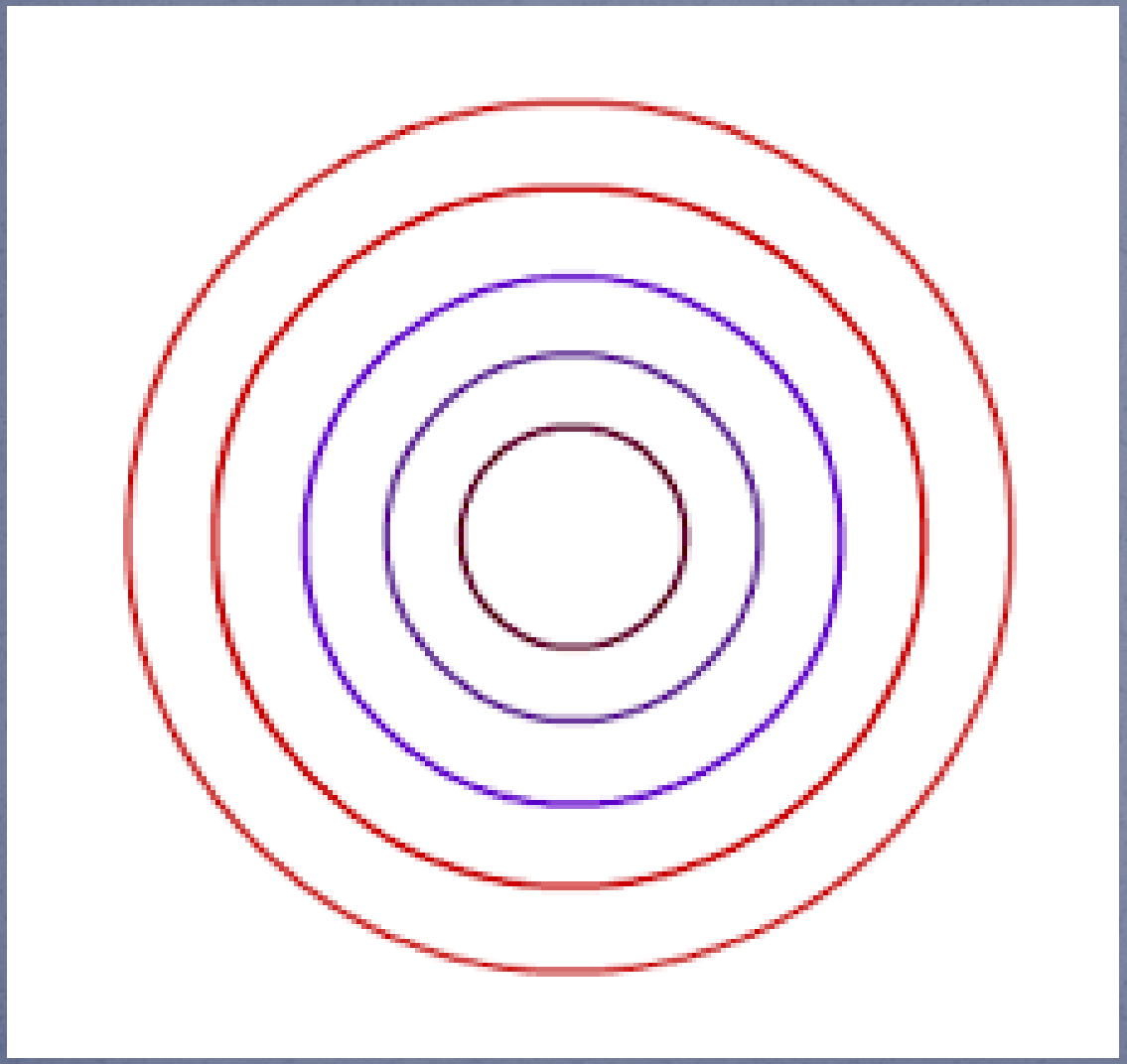
How to make sense of people's experiences of illness and suffering?

Lecture "Roadmap"

- How to understand people's **experiences** of illness and disease? (what **are** "patient's perspectives" how can we access them? how should we contextualize them?)

Five Approaches – please remember each model has its own strengths and weaknesses…

- Explanatory Models (Kleinman)
- Storytelling/Narrative approach (Good and Mattingly)
- Embodiment (Csordas and J. Jackson)
- Local Moral Worlds (Kleinman)
- Social Suffering (Kleinman, Das, Petryna, Biehl, etc.)



- EMs
- Storytelling/ Narrative
- Embodiment
- Local Moral Worlds
- Social Suffering

Why should we care what people think about their illness episodes?

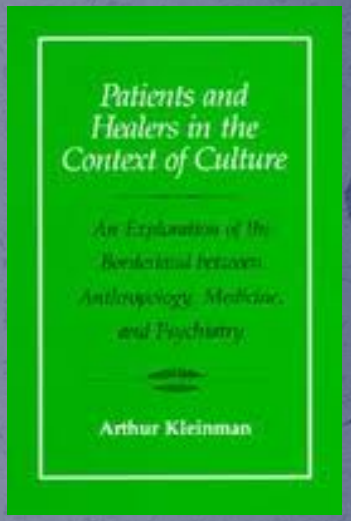
Pain and suffering raises “those existential and spiritual questions of what is most at stake in human experience that query the ultimate purpose of living ….” (Arthur Kleinman)

> But how to access this?

Explanatory Models (EMs)

Kleinman, 1970s)

"the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process."



- Process of making meaning/framing an event
- Always connected to a SPECIFIC illness episode

In general, EM's aim to cover five main questions

- etiology (cause)
- time and mode of onset of symptoms
- pathophysiology: the functional changes associated with or resulting from disease or injury
- course of sickness
- treatment

1) interaction of patient and practitioner's EMs are central to understanding treatment process (processual model)
   - practitioner's EM
   - Patient and family EMs : "how they make sense of given episodes of illness and how they choose and evaluate particular treatments"

"investigating EMs … discloses one of the chief mechanisms by which cultural and social structural context affects patient-practitioner and other health care relationships" (Kleinman)

2) EMs change as understandings of illness event change over time

3) Diff people w/in the same culture hold diff Ems (practitioners, patient, family members, etc)

- **Explanatory models of diabetes: Patient practitioner variation, M. Cohen et al,** (1993) *Social Science & Medicine*
- Same demographics: white, Prot, highly ed, Midwest
- Patients and physicians who know one another
- Intensive patient education program
- Findings:
  - Radically diff ideas of severity of the illness
  - Patients focus on social + relationship probs TODAY, physicians focus on FUTURE complications
  - "Patients and professionals … emphasize diff. domains; patients emphasized difficulties in the social domain and the impact of diabetes on their lives while staff saw diabetes primarily as a pathophysiological prob. with impact on patients' physical bodies."

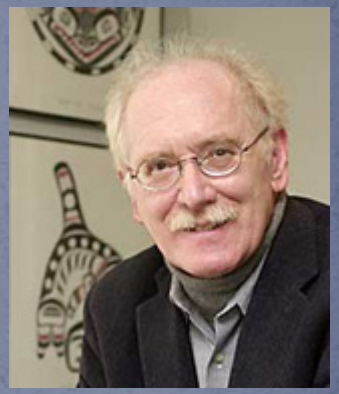
Critiques:

Clinically centred:

> "Eliciting the patient's (explanatory) model gives the physician knowledge of the beliefs the patient holds about his illness, the personal and social meaning he attaches to his disorder, his expectations about what will happen to him and what the doctor will do, and his own therapeutic goals. Comparison of patient model with the doctor's model enables the clinician to identify major discrepancies that may cause problems for clinical management. Such comparisons also help the clinician know which aspects of his explanatory model need clearer exposition to patients (and families), and what sort of patient education is most appropriate. ....." (Kleinman 1976: 256)

- What if med prof's and patient's interests are opposed + their views irreconcilable (Rouse)
- Classism, sexism, racism in society as a whole, not just miscommunication, influence doctor-patient relations (Singer)

Story-telling and narrative



B. Good, Cheryl Mattingly…

1990s,
B. Good on uses of 'reader response theory'
3 analytic concepts for illness narratives:

- Emplotting – creation of order and coherence
- Subjunctivizing – the end is not set, but there are many possible outcomes
- Positioning of suffering in the local discourse – e.g. local power relations

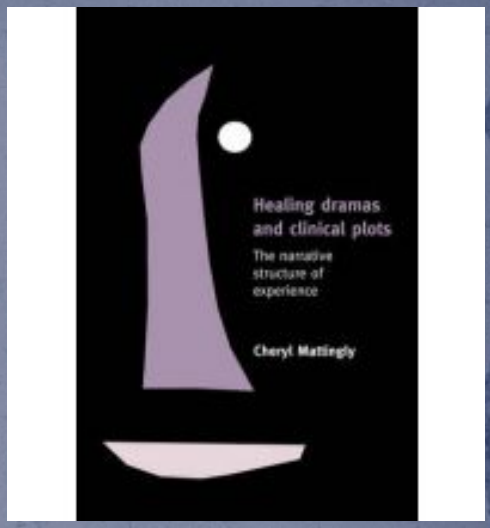
- Turkish accounts of epilepsy, in local terms “fainting” (Good, 1994)

One story (told by daughter-in-law):

“Her father had already married two women… [and then] took a third [wife]. In time, probs arose in the household. …. So it was diff. for her [as a child]. There were people who wanted to marry her, and her father wanted to force her to marry one of them. She didn’t want to be given to that man. In fact, she eloped. After she went off, her father attacked her with a knife. He came to the house that they had gone to. When he was hitting the door like this [she gestured wildly], he was stabbing the door, he smashed the door open, he came in, and when she saw her father with a knife in his hand, she received a shock, she was frightened, and from that day until today, she’s been fainting. Whenever she is nervous, each time there is something upsetting….”

- Mattingly's ex of occupational therapists working w/ quadriplegic patients in a Boston hospital illustrates:

1) co-construction of narratives
2) Subjunctivizing (open-ended futures) as a key element



Moving beyond/outside of language – analysis of Embodiment

- Not everything experienced is expressed via language – Merleau-Ponty's 'pre-objective' (pain, love, etc.)
- Good (1992: 39): "We act in the world *through* our bodies; our bodies are the subject of our actions, that through which we experience, comprehend and act upon the world……"
- At the same time, "I *am* my body." (Merleau-Ponty)
- Subject-object dualism (Cartesian dualism > Rene Descartes (17th C) > the "absent body" (Drew Leder)
- Some states (i.e. chronic pain) confound what is already a tricky situation….

Pain as breaking down worlds

- Jean Jackson (building on B. Good and E. Scary (*The Body in Pain*) > pain shatters the world as we know it.
- "A pain-full body occupies a world different from the everyday world." (Jackson 1994: 213)
- Pain puts us in our own world vs. Wittgenstein
- Objectification: "the pain is in me, but it is **not** me" vs. "In extreme cases, at times phenomenologically, one *is* pain…" > "Chronic pain challenges the notion of the body as object and the self as subject" (p. 207)
- "Moving from what I am calling the pain-full world to the everyday world entails a shock… Yet to some degree, living in chronic pain requires a constant traveling back and forth between these worlds…" (pp. 214-15)

- Embodiment approach suggests:
  - Need to attend to the phenomenological, or experiential realities of people's lives
  - Experience sometimes lies outside of language (but often we get it through language….)

  - How we envision ourselves as subjects in the world changes through time and circumstance (this is my body – versus – this is me)
  - The body as subject/object may be therapeutically relevant

Ok – but what about politics/economics…

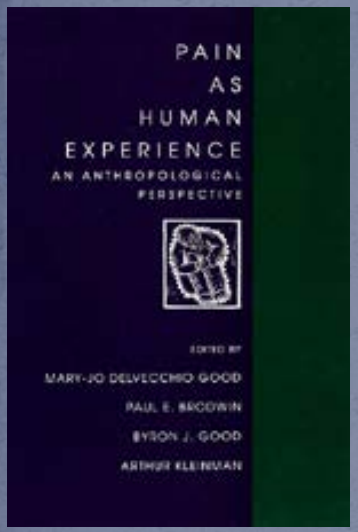
Two key approaches in med anthro:

** “local moral worlds” – Arthur Kleinman

(* “critical events” – Veena Das)

** “social suffering”
– Veena Das and Arthur Kleinman
(and others)

Arthur Kleinman – "local moral worlds"



"[sites] where the experience of illness is constructed. … - be they an East African village, an inner-city neighborhood in Istanbul, or a social netowork in North Amer'.s universe of plural life settings – are particular, intersubjective, and constitutive of the lived flow of experience. They are not simply reflections of macro-level socioeconomic and political forces, though they are strongly influenced by such forces. Within local moral worlds, the micro-level politics of social formations and social relationships … [are key]."(Kleinman 1994: 172)

Local moral worlds, cont:

- Focus on **localized, inter-personal** processes of meaning-making + attributions of value ….
- …. and their inter-relation to larger processes – i.e. globalization, politics, economics, historical change

Local moral worlds look at personal, interpersonal, and political

> Chinese Cultural Revolution (Arthur and Joan Kleinman) – 1966-76, led by Chairman Mao, purging of non-Maoists, millions displaced, subject to harsh punishment

>Huang Zhenyi, banner at his school, "Throw down Chairman Mao!", his relationship with his mother

> Other ex. (e.g. Stella Hoff – scientist – academia, productivity, religious suffering)

Local Moral World vs Social Suffering

- Local Moral World is very tightly focused (individual in broader context)
- What about if you want to study a broader group of people and how politics/economics effects them?

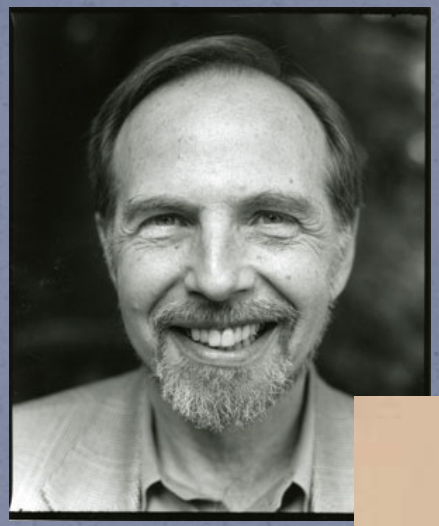
> Studies of **crisis** (i.e. political violence/disaster/etc) and their impact on social groups (Das' 'critical events') when 'time gets suspended' and people are at a loss… (Achille Mbembe and Janet Roitman on Cameroon)

"Instead of detailed descriptions of specific episodes laid out in chronological sequence and deftly connected by logical connections (because . . ., in spite of . . ., and the like), Mariusan men could only provide fragmentary and disjointed stories [of the cholera epidemic]. . . . The Mariusans were adept at using the sense-making power of storytelling to reinforce established cognitive and social orders. What happened to these narrative skills when cholera entered their lives? Why were the men in particular capable of telling only stories that they knew were grossly inadequate to depict their experiences and encourage their tenacity? As they related their stories . . . [they] were clearly attempting to make sense of their most baffling and terrifying moments - but terror can make a mockery of sense-making." (2003, 76-77)

- But what about when “crisis” is/becomes part of life as usual? How to study more broadly how social/political/economic structures impact our health? Particularly for those who are disadvantaged?

What is 'social suffering'?

- History of this concept in medical anthropology
  - 1997, *Social Suffering*, eds, A. Kleinman, V. Das and M. Lock



- Not JUST an event but a broader analysis of social-political-economic structures and their roles in health and illness…

Social Suffering

Focus away from individualized conditions of illness/suffering

and individualized remedies (PTSD, 12 steps, etc)

and onto the political

economic

and institutional forms of power

that generate detrimental social conditions

and underpin our responses to these problems

To understand suffering, we need to understand….

- Social **Experiences**

A. Individual stories

B. Cultural scripts – shared myths, narratives and metaphors

"Collective modes of experience shape individual perceptions and expressions." (Kleinmans 1997)

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INDIAN HERALD

NATIONAL ENGLISH DAILY

Founder & Editor: THAKUR V. HARI PRASAD

SPECIAL SUPPLEMENT

2 Pages HYDERABAD, Thursday, June 26, 1975 PRICE 15 Paise

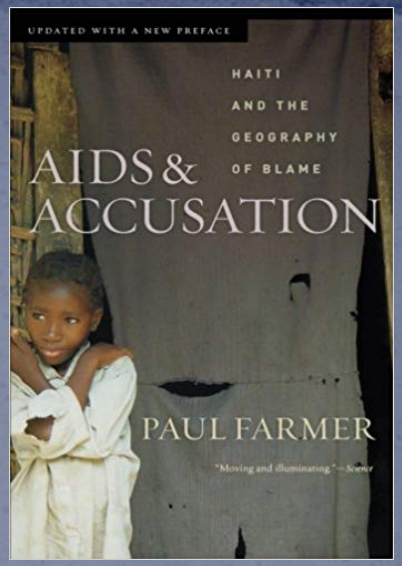
EMERGENCY DECLARED

JP, Morarji, Advani, Asoka Mehta & Vajpayee arrested

Raj Narain, Mody & Chandra Sekhar held

>> Emma Tarlo's ex. of collective narratives of the Emergency

Emergency in India– 1975-77, PM Indira Gandhi, Delhi >> slum clearance (700,000 displaced) + family planning (16,000 sterilized), sterilization certificates



C. Social, political and economic underpinnings of distress

Paul Farmer on health (esp. HIV/ AIDS) in Haiti

- Personal stories – Acéphie (girl involved with older, married soldier) and Chouchou (man subj to pol. violence)
- Analysis in terms of gender, race/racism, political violence, and class (poverty), geopolitics (slavery/ World Bank Dam project/land loss)
- "One must embed individual biography in the larger matrix of culture, history and political economy" (p. 20)

Crisis? What crisis? “Suffering is certainly a recurrent and expected condition in Haiti’s Central Plateau, where everyday life has felt like war.” (p. 12)

Who suffers the most?

“The poor are not only more likely to suffer’ they are also more likely to have their suffering silenced” (p. 25)

3. Political and professional processes

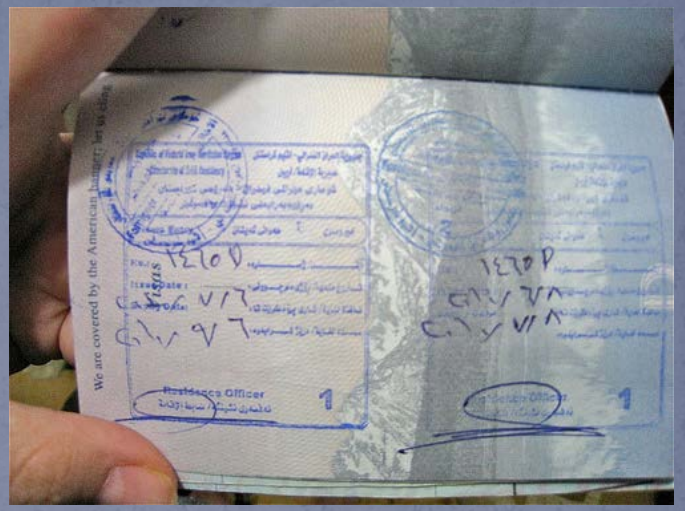
A. Medicalization – ADHD, PTSD, etc.

"Biomedical interpretations of illness have properly been criticized for leaving the experience of suffering out of assessment of the disease." (Kleinmans 1991)

"The idea of posttraumatic stress disorder in North Amer psychiatry, which is increasingly being applied to victims of political trauma such as Cambodian and Salvadoran refugees, is that latest example of this invalid transformation of moral into medical meaning of suffering. For here the intimate physiological consequences of political violence are converted into an anonymous medical euphemism. In doing so, their moral significance is weakened or even denied entirely." (Kleinmans 1991)

B. Bureaucratization

- Das and the paperwork needed after a massacre



- Tarlo on sterilization certificates

- Petryna and the “tie”

Not just Experiences, but also **REPRESENTATIONS** of social suffering in popular culture and media

A. Social uses

Nationalism, identity, political rights

B. Economic uses

"suffering" sells – not just for corporations, the media, but also for NGOs

Framework of "social suffering" aims to:

* Focus on experience of survivors/[patients]/persons
* Describing 'local moral worlds'
  - Localized, interpersonal spaces
  - Morality as central to suffering/illness/wellbeing
  - Cultural grounds or 'worlds' of living

*But in the framework of analysis of attentive to much wider pol., econ., social processes

* Often involves an explicit social justice approach

* Allows for multiplicity

- Recognizing different ‘categories’ of similar experience

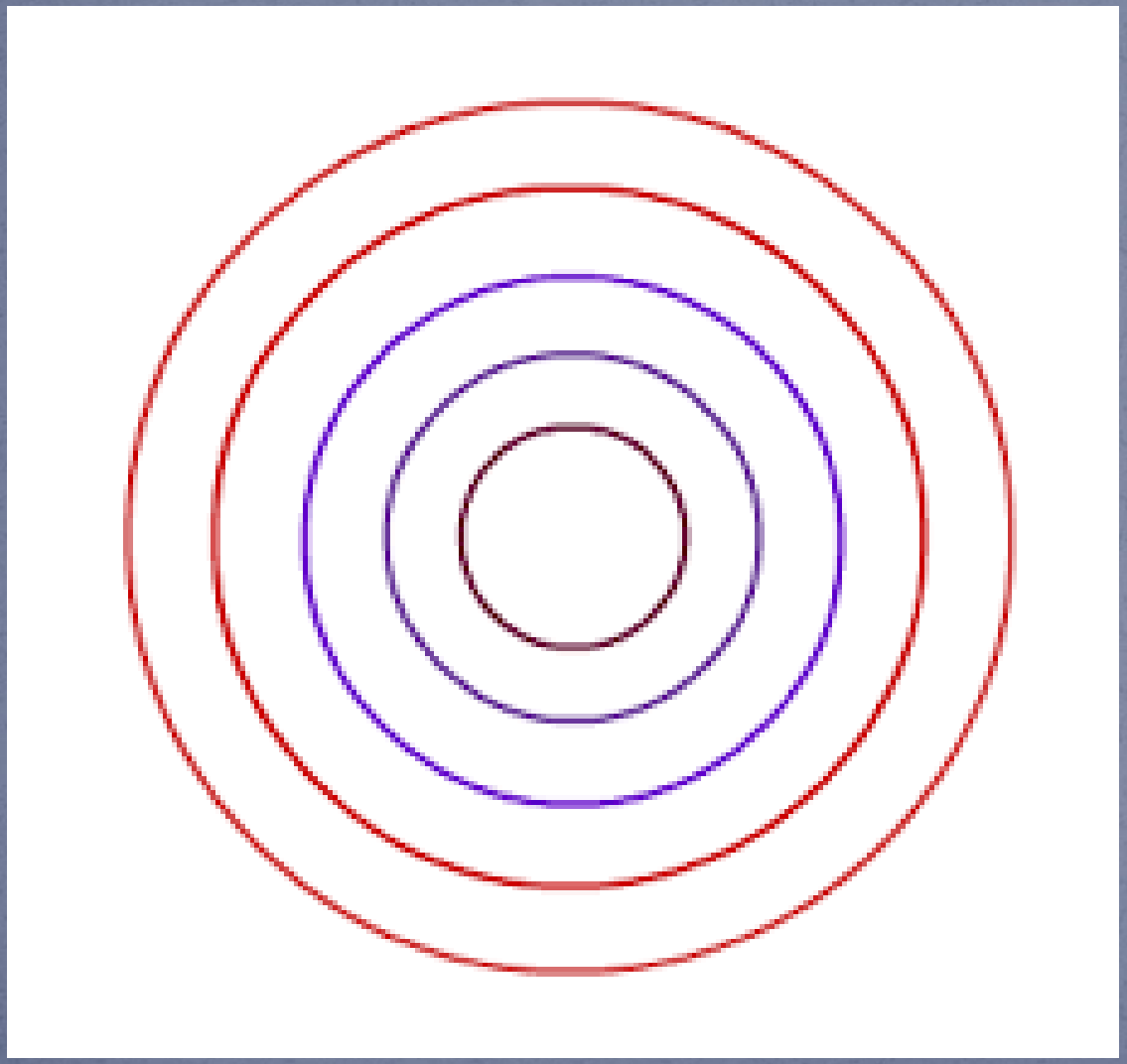
  “Included under the category of social suffering are conditions that are usually divided among separate fields, conditions that simultaneously involve health, welfare, legal, moral and religious issues.” (Das and Kleinman 1997)

- Recognizing that they may happen simultaneously

  “The clustering of substance abuse, street violence, domestic violence, suicide, depression, PTSD, sexually transmitted disorders, AIDS, and TB among people living in disintegrating communities runs against the professional medical idea that sufferers experience on or at most two major problems at a time.” (Das and Kleinman 1997)

Five Approaches

- Explanatory Models – focused on a clinical setting (how drs talk to patients, how patients talk to drs)
- Storytelling/Narrative approach – useful for understanding how people make sense/ meaning in their lives
- Embodiment (Csordas and J. Jackson) – focusing on the experiences that cannot be put into words – how we live in the world, rather than narrate living in it
- Local Moral Worlds (Kleinman) – focused on indiv and direct inter-personal rel, but in intl-political frame
- Social Suffering – broader political framing



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