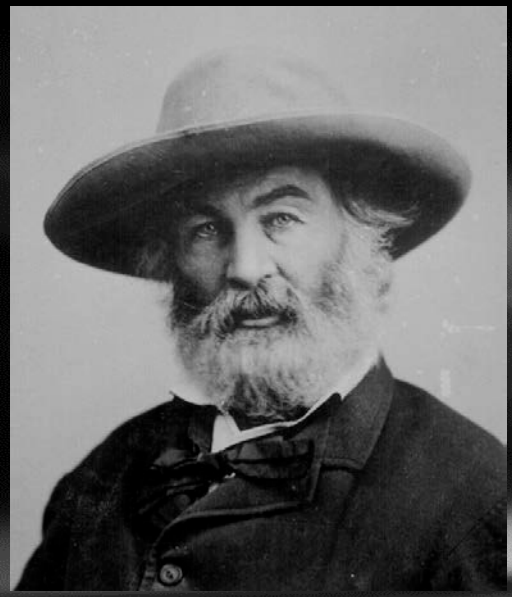

Health: objective, subjective, or other?

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Psychiatry and Behavioral Sciences

Anesthesiology and Pain Medicine

Bioethics and Humanities

Agenda

Difficulties with health as a scientific object and clinical goal

Objective health: the clinical argument and the policy argument

Chronic disease: epidemiological and epistemological transition

Subjective health: “outcomes that matter to patients”

Health-related quality of life (HRQL): adds subjective to objective

HRQL as failed transitional concept

Health: as capacity for meaningful action, niche construction

Health as scientific object and clinical goal

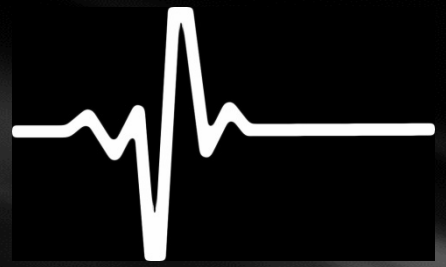
Scientific object

- Not observable with clear necessary and sufficient criteria
- WHO definition expands to include all well-being
- Biological science cannot explain self-healing or self-movement

Clinical goal

- Disappears as a concern when it is present; from barrier to window onto life
- Health, like autonomy, is difficult to deliver to another (but parenting)
- Explicit, anxious pursuit is often self-defeating (like happiness)
- Health is a basic, but instrumental good.

Objective health: clinical arguments



Objective health- the clinical case

- Until 1800, disease is the sum of experienced symptoms and observed signs
- Around 1800, the autopsy is integrated into hospital care, so tissue diagnosis becomes the gold-standard for clinical diagnosis
- This means that medical diagnosis now can completely bypass patient experience of illness. Dead body more knowable than the living body.
- This grants medical science a stable scientific object and medical practice a focus distinct from poverty, dysfunction and suffering
- Scientific physician becomes most authoritative judge of the presence or absence of disease, and therefore, health
- (Foucault, *The Birth of the Clinic)*

Objective health: policy arguments

Objective health- the policy case

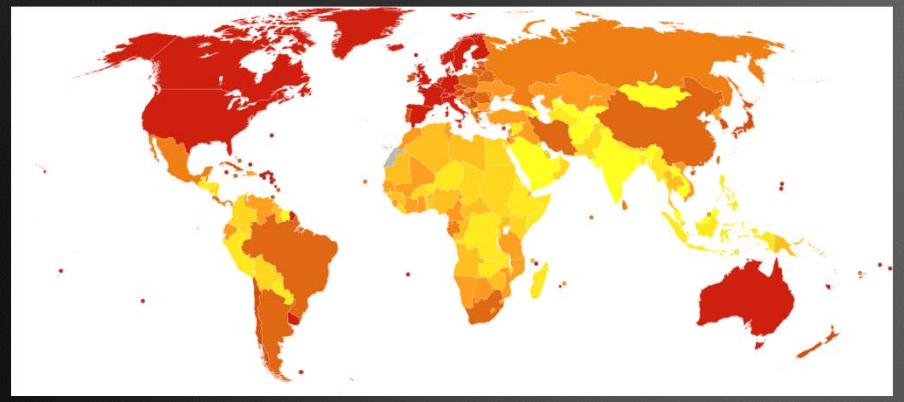
- After the French Revolutionaries declared a right to health care for all citizens, some triage principle was necessary to delimit this right
- Health services cease to be focused on deserving patients (religious) became focused on patients with curable disease (secular)
- Hospitals, public health agencies, medical training, and health insurance come to be organized according to objective disease diagnoses

Chronic disease: epidemiological transition

Public health traditionally measured in objective mortality and morbidity

But ‘epidemiologic transition’ from acute/infectious to chronic conditions has occurred in industrialized countries.

Few cures are achieved for chronic and degenerative disease, so the effect of medical care must be gauged in some other way that better captures the burden of chronic disease for both countries and individuals.



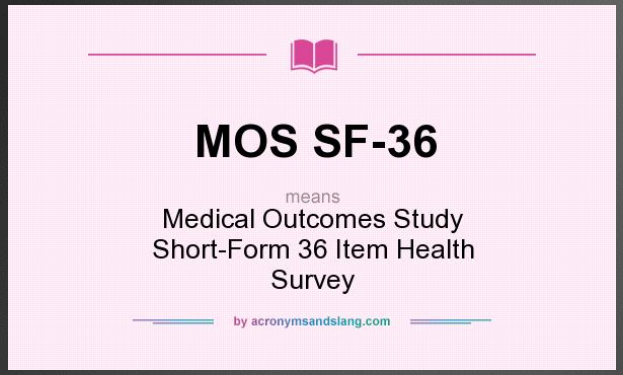
Chronic disease: epistemological transition

Because medicine is interested in new types of health, it must also be interested in new types of scientific evidence concerning health

Laboratory and physical exam measures are inadequate to capture important effects of chronic disease and its treatments on patients.

- 1949 Karnofsky Index provides ranking of cancer patients' physical functioning
- Followed by clinimetrics and clinical epidemiology to support clinical decisions where not enough guidance from diagnosis and pathophysiology
- Weak associations between objective disease severity and severity of symptoms, functional impairment, loss of well-being

Need to ask the patient directly: how are you doing?



Subjective health:
"outcomes that matter to patients"

Manifesto: Paul Ellwood's 1988 article in *The New England Journal of Medicine* sought to alert physicians to a "technology of patient experience" by which they were going to be evaluated—like it or not.

"The intricate machinery of our health care system can no longer grasp the threads of experience.... Too often, payers, physicians, and health care executives do not share common insights into the life of the patient.... The problem is our inability to measure and understand the effect of the choices of patients, payers, and physicians on the patient's aspirations for a better quality of life. [*my emphasis*] [31]

Without explicit scientific argument, Ellwood shifts the object of medical science from the patient's body to the patient's life.

Health-related quality of life (HRQL): adds subjective to objective health measures

HRQL accepts "perspective" as unavoidable in clinical medical science. It thus rejects the ideal of completely objective medical measurement.

Previously, the foremost value in medical outcome measurement was rigor. The most rigorous or "hardest" outcomes, with the lowest possibility of bias, were the most favored.

But the need to measure chronic disease burden shifts attention to an entirely different value: outcomes that matter to patients.

Now patient-reported outcomes are valid not *despite* being subjective, they are valid *because* they are subjective. The link with the patient's perspective now adds rather than detracts from their validity.

Problems with HRQL as a measure of health

HRQL usually seen as patient experience of an objectively defined health state but:

Self-rated health is not secondary to objective health

- Causal: SRH independently predicts mortality, hospitalization, disability, complications
- Conceptual: Disease discovery follows illness; cannot sort malign vs benign variation in tissue structure w/o pt.
- Experiential: Response shifts show how different illnesses arise from the same disease

Self-rated health is not simply caused by objective health

- For as long as a decade, SRH predicts mortality, hospitalization, disability, complications, after controlling for observed health indices and risks

  - Meta-analysis of 22 studies: increased mortality vs excellent SRH (DeSalvo, 2006)
    - 23% "good", 44% "fair", 92% "poor" SRH.
    - Adjusted for comorbid illness, functional status, cognitive status, and depression
    - Increased in all gender and ethnic subgroups

Pathological diagnosis begins with patient report, so cannot be purely objective

- *"Thus it is first and foremost because men feel sick that a medicine exists. It is only secondarily that men know, because medicine exists, in what way they are sick."* – Georges Canguilhem
- Disease discovery follows illness report; first dysfunction, then causes of dysfunction
- Scientist cannot sort malign vs benign variation in cells or organs without patient report, context.
- Examples: tongue rolling, bulging/herniated discs

Over time, the same disease causes different illnesses

- "Response shift" or "disability paradox": marked improvements in HRQL for SCI patients in 1 yr.
- This adaptation occurs in most chronic illnesses
- "Illness battered its victim until they got along with one another: the senses were diminished, there were lapses in consciousness, a merciful self-narcosis set in--all means by which nature allowed the organism to find relief, to adapt mentally and morally to its condition, and which the healthy person naively forgot to take into account." Thomas Mann, *The Magic Mountain*

Example: the failure of objective and subjective models of health in CLBP

Failure of objective model (cause-focused)

- No broken part can identified in most cases
- Broken parts also found in many with no LBP
- Repair of broken part often does not relieve pain

Failure of subjective model (symptom-focused)

- Seeks to reduce pain intensity to improve health
- Has led to widespread opioid use, abuse, overdose
- Reducing chronic pain intensity often does not improve function or ability to move life forward

Health as capacity for action neither objective nor subjective

Health is not a state of body or of mind, but the capacity for meaningful action

- Consider older persons who are thriving –e.g., Walt Whitman
- Health and disease are not opposites and do not exclude each other

Health is the ability to do things of value

- It is a form of capability and more basic than welfare or well-being (Sen)
- Similar to the organism's capacity for niche construction (Lewontin)

Amartya Sen: impossible to understand the well-being of persons without understanding their agency -- both a means to well-being and an intrinsically valuable component of it.

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