Illness without disease - a challenge to the paradigm of modern medicine

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26th Conference of the Nordic Sociological Association
16th to 18th of August 2012, Island (18.8 kl. 11.30 – 12.00)

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Illness (subjective experiences)

Sickness (culturally defined)

Disease (biologically defined)

Relation between concepts (Twaddle)

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Perspective: Cultural understanding of health and illness

• Every concept of health and illness is based on culturally defined norms about what we (in a given society) regard as normal or desirable

• To define something as healthy/sick therefore always involve normative judgments, that are constantly changing and varies with time and place

• Health and illness are culturally defined concepts

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Setting the scene: The main challenge for modern medicine is chronic diseases

- On a global population-level, chronically ill patients have increased in numbers and complexity:

- New medical knowledge and technology enable people to survive conditions that used to be lethal; our way of living creates new problems, etc.

- Doctors have limited or no means to explain or cure many of these illnesses

Main objective

- How can sociological theories and perspectives help us to better understand major challenges and paradoxes in contemporary medicine?

- The battle between doctors and ME-patients serves as a case

ME (myalgic encephalopati)

- Main symptoms: a persistent or recurring chronic fatigue and post-exertional malaise/loss of physical or mental stamina - not directly associated with a confirmed disease (but 3 of 4 cases begins with a known infection)

- 3 of 4 are women, often from higher social classes. The typical patient is stereotyped as a well educated perfectionist woman, and attached to the somatisation of stress

Classified as a neurological brain-disease (code G93.3 in ICD-10)
Biomedical ME-research is rejected by a vast majority of doctors

- “There are more than 5000 research papers which show that ME has an organic basis with abnormalities in the immune, nervous and gastrointestinal systems and that it is influenced by genetic and environmental factors”

- “... this information does not reach professional healthcare personnel, and the disease is still not taken seriously.” (Luc Montagnier, virologist, quote from European Society for ME 2009)

The ME case is a «battlefield»

- Despite clear indications of an organic disease, the ME diagnose is disputed; it has low validity, no clear cause, and diagnostic procedures are difficult

- There is something that resembles a war going on between doctors and patients, with a strong polarization of arguments and viewpoints

ME etiology according to the Norwegian Knowledge Centre for the Health Services

- ME is explained by cognitive activation theory of stress (CATS): “Ill-effects occur only when there is a lack of coping [and] may lead to somatic disease through sustained arousal [or] to somatic disease and illness through a lack of motivation to engage in positive life styles.”

(Ursin and Eriksen 2004:588; Kunnskapssenteret 2006:12)
A male GP in Norway on Eyr

“Why people lay down when they are not really (actually) seriously physical ill is difficult to understand.”

He is not alone:

• Research has shown that a vast majority of Norwegian GPs view ME as a psychiatric disease and/or a disease «created» by the patients themselves (and they also have little knowledge about the disease) (Lippestad et al. 2011).

Typical answers to ME-sufferers trying to prevent a one-dimensional psychological understanding of their problems (often called «ME-talibans»)

• Their reactions are defined as being part of the disease (as for psychiatric patients). Conclusion: Send them to psychiatrists.

• References to psyche and soma as two parts of the same coin (only in words, as the causes attributed to psyche first of all)

• It is “fashionable” to get this illness, and you can “think yourself well”
THE BATTLE BETWEEN DOCTORS AND ME-PATIENTS: WHY?
PART OF THE ANSWER LIES IN THE DEVELOPMENT OF MODERN MEDICINE ITSELF

The hallmark of modern biomedicine: Scientific and technology based

1. Ought to be based on scientific knowledge about causal relations in the nature, experimentally tested and theoretically explained;
2. Practiced by the use of technology;
3. Specialised in narrow fields classified by the localisation of conditions (places in the body);
4. A classification perspective with diagnosis as main classification tool; and
5. Ideologically funded on a biological view on human beings, with value-neutral assumptions.
Implication no. 1

- The understanding of human problems becomes one-dimensional (disease-perspective), and disciplines like biology, physics and chemistry are used to describe and explain (causes).

Implication no. 2

- Diagnostics based on technologically generated findings, evaluated via an assumed objective view.
- Patient narratives and non-technological observations less relied upon.

Implication no. 3

- Symptoms are no longer «a goal in itself», but a means (or a key) to reveal something underlying and more important: the pathological organ.
- Ill people are seen as bodily physical objects.
Implication no. 4
Categorisation a key element of medical reasoning and decisionmaking, with diagnoses as main classification tool

Implication no. 5
Medical jurisdiction expands including the right to define what counts as disease in a process of medicalisation which leads to more and more aspects of human life to be defined as relevant for medical intervention (Freidson 1970; Illich 1996)

Conclusion: Who will not get «approved»?
Physical conditions which doctors unable to identify and explain by so-called «objective» technological generated findings, does not make a person entitled to the stamp «approved as ill»
Theories of energy failure and exhaustion in anatomic-physiologic explanatory models

- Women are designed differently (weaker) than men, anatomically and physiologically (women are constitutionally weaker)
- Women are passive creatures which consumes most of their energy in the reproductive process, and therefore must live a life with reduced activity (compared to the man)
- Overload of the female organism will be punished by "lifelong impairment, morbidity and sterility" (Johannisson 1996).

Theories of energy failure anno 2012

- The CATS theory used today to explain ME resembles theories from the 19th century ("over-exertion theory"); ME be explained on the basis of women's weakness in relation to cope with stress/strain that occurs when they do not respect the limits of their capacity (an equally value laden theory as the one used now in the 21th century)

Conclusion: Explanatory factor no. one

- Making medicine a one-dimensional biological science based on technological findings, while disguising normative judgements as value-free scientific knowledge, modern medicine becomes incapable of meeting situations where scientific knowledge is still lacking
- Choosing this narrow path, combined with an attitude towards knowledge that is far from humble (humble in the sense of admitting that knowledge is uncertain and temporary, and that there is a lot of things we do not yet know), modern medicine undermines its own position as the major foundation of health systems in the Western world
Conclusion: Explanatory factor no. two

- Culture. Ideas about health and cultural norms and values in a society are mutually connected. Hence, ideas about health are influenced by
  - our view of human beings and life (the meaning of it all)
  - femininity and masculinity
  - normality and deviant action
  - aging, body and sexuality, etc.

- The battle between doctors and ME-patients can be seen as a battle between women and people with an old-fashioned view on women, disguised as medical knowledge.

This work is a continuation of