

Towards a sociology of diagnosis

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HEALTH TECHNOLOGY AND SOCIETY RESEARCH GROUP
INAUGURAL SYMPOSIUM THURSDAY
10 May 2012 10.00am – 4.30pm
BYRNE HOUSE
UNIVERSITY OF EXETER

- What is a diagnosis?
- What is and why develop a sociology of diagnosis?
- 'Absent presence'

- Blaxter, M. (1978) Diagnosis as Category and Process: The Case of Alcoholism. *Soc, Sci & Med* 12 9-17.
 - *The activity known as ‘diagnosis’ is central to the practice of medicine but is studied less than its importance warrants.*
- Blaxter (2009) The case of the vanishing patient: image and experience *SHI* 31 762-778
 - *‘in modern medicine it is much more important for sociology to study what Cussins (1998) called the ‘ontological choreography’ of these ever more complex systems, including the way in which images and records appear to create and control both medical practice and the patient’s medical experience. This is what actually counts’ (776)*

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Whiplash evidence 'could be toughened up'



Britain has more claims for whiplash than anywhere else in Europe and the government is holding a summit on how to tackle the problem.

The Justice minister Jonathan Djanogly told the Today programme that over the last five years the number of accidents has fallen but the number of claims has risen by 70%.

He says that all claims for whiplash should go to independent doctors and "tougher" guidance of doctors' diagnosis might be needed.

No one knows how many claims are false, he adds.

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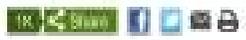
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- Was 'fit and proper' discussed? Listen
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1 May 2012 Last updated at 09:54



Way to spot breast cancer years in advance

By Michelle Roberts
Health editor, BBC News website



Dr James Flanagan, who led the research, says a pre-test for breast cancer could save lives.

A genetic test could help predict breast cancer many years before the disease is diagnosed, experts hope.

Ultimately the findings, in the journal *Cancer Research*, could lead to a simple blood test to screen women, they say.

The test looks for how genes are altered by environmental factors like alcohol and hormones - a process known as epigenetics.

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18 April 2012 Last updated at 18:00

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Breast cancer rules rewritten in 'landmark' study

By James Gallagher

Health and science reporter, BBC News

What we currently call breast cancer should be thought of as 10 completely separate diseases, according to an international study which has been described as a "landmark".

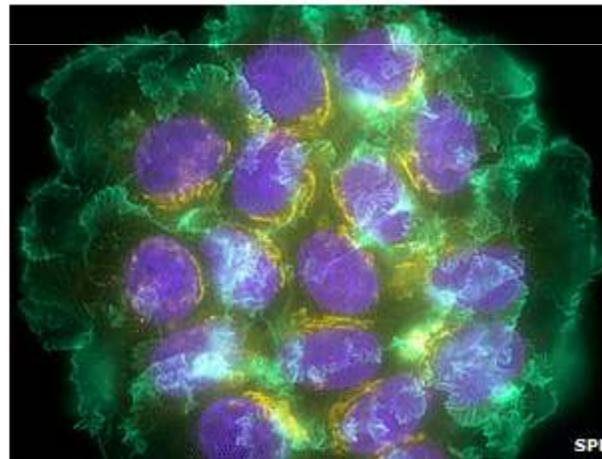
The categories could improve treatment by tailoring drugs for a patient's exact type of breast cancer and help predict survival more accurately.

The study in Nature analysed breast cancers from 2,000 women.

It will take at least three years for the findings to be used in hospitals.

Cancer cartography

Researchers compared breast cancer to a map of the world. They said tests currently used in hospitals were quite broad, splitting breast cancer



Breast cancer cells should be classified into one of 10 different diseases, say researchers.

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20 April 2012 Last updated at 11:07



Baby's parents demand rickets death hospital inquiry

A young couple acquitted of murdering their four-month-old son have called for an inquiry into two London hospitals responsible for his care.



Rohan Wray and Charma Al-Alas said they felt like one doctor was accusing them of harming their child

Rohan Wray, 22, and Charma Al-Alas, 19, of London, were accused of abusing baby Jayden but his fractures were later found to have been caused by rickets.

They told the BBC that the Great Ormond Street and University College hospitals should have diagnosed the disease.

The hospitals have defended their care of Jayden before his death in 2009.

A University College Hospital spokesman said its clinicians "acted with Jayden's interests at heart"

"We regret that we were unable to reverse his deteriorating condition despite our intensive efforts in the short time he stayed with us. We would like to offer our sincere condolences to Jayden's parents," he said.

Great Ormond Street said the rickets abnormalities had been less obvious to hospital radiologists than at the later autopsy and that it recruited the family's

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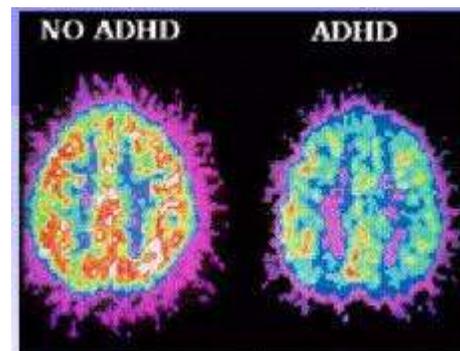
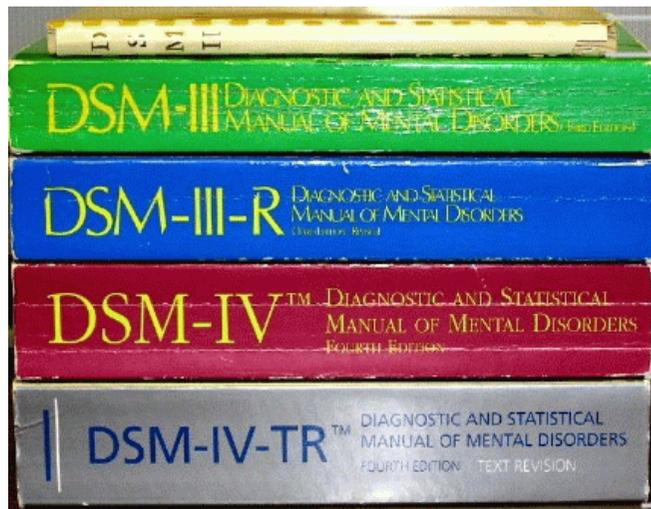
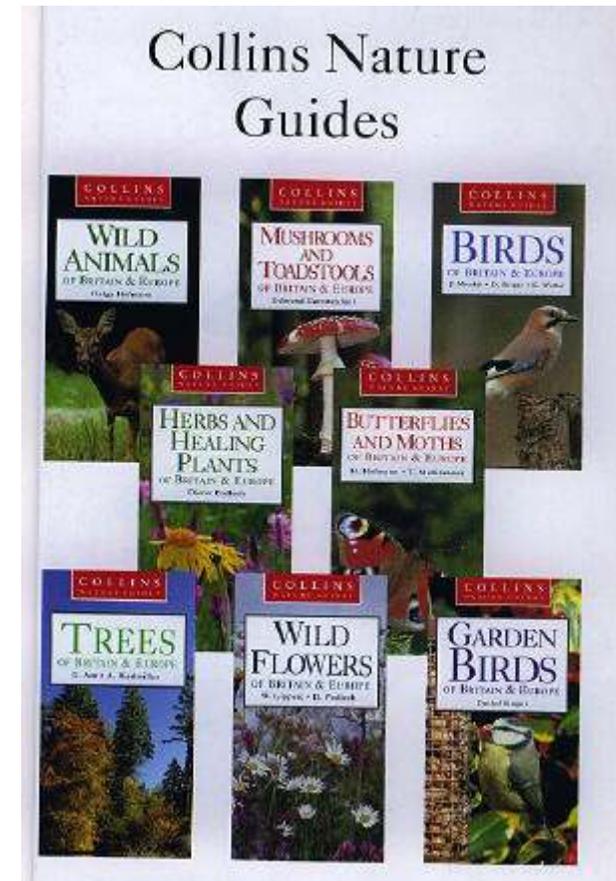
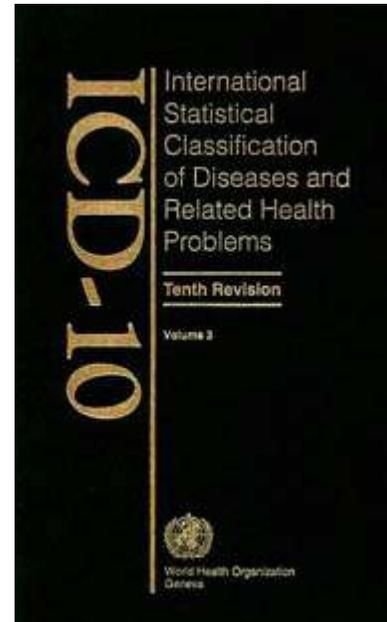
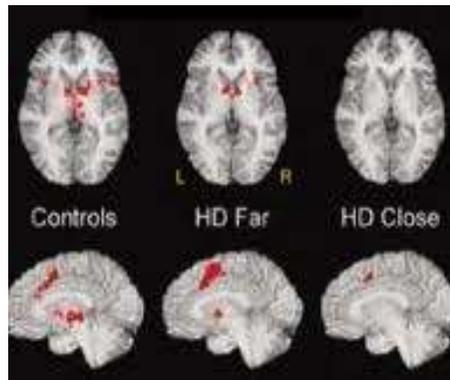
- Her Majesty's air miles: How well-involved are you compared with the Queen?
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Halpin (2011) Diagnosis, psychiatry and neurology: the case of Huntington Disease *Social Science & Medicine* 858-865

- *He [her father] had been under psychiatric care, when my mom and him got separated that's when he had a "nervous breakdown" and that's when he had been going to a psychiatrist. But it was Huntington's and nobody knew. That's when they put him out to the crazy clinic and he was probably out there for four or five months and they ended up giving him shock treatments to bring him back because he would just sit there. But they had no idea that it was Huntington's ...and my brother got sick right after my father died and they thought it was depression. Which was what my father was misdiagnosed with as well (p.861)*

Psychiatry and neurology

- ‘We can understand neurology and psychiatry as constituting two distinct oligopticons, each observing, describing and operating in relation to the brain. Latour’s concept would suggest that, even though these disciplines do observe aspects of the brain in great detail, neither of them perceives it in its totality, with neurology focusing on alternations and injury to organic matter, in contrast to psychiatry’s observation of changes in mood and personality and mental disorders’ (862).
- Bakhtin’s -‘speech genres’ distinct language styles that hamper communication - ‘It is not that the psychiatrists are inept, but rather are framing HD symptoms through a psychiatric, rather than a neurological or neuropsychiatric, diagnostic genre’ (863).



Illustrative examples ...

- Institutional proximity of legal, insurance and medical systems
- Technologies mediated by perception, interpretation
- Complex socio-technological processes speak to epistemological and ontological issues and debates
- Fragmentation: disciplines, body (multiple)
- Diagnosis - resource for patients, professionals, industry, administrative regimens, governments

Diagnosis as a powerful tool with many functions ...

- **Category** - official label that classifies and names a disease or medically-related problem.
- **Process** – activity that identifies a disease – either in the clinic or institutional politicised arena
- **Consequence** – administrative (access and distribution of resources health care); legitimates sickness/deviance ; cultural expression (ab)normality, guides research, treatment; evidence base ...

Levels of analysis

- **Individual** – biographical, experiential, self, identity, sick role
- **Institutional/social** – negotiated in the clinic; political arena, social movements
- **Societal** - classificatory/administrative/bureaucratic systems, statistics, planning; framing, models and ideologies of disease (allopathic, pathological medicine)

Rosenberg, C. (2002) The Tyranny of Diagnosis: specific entities and individual experience *The Milbank Quarterly* 80 (2) 237-260

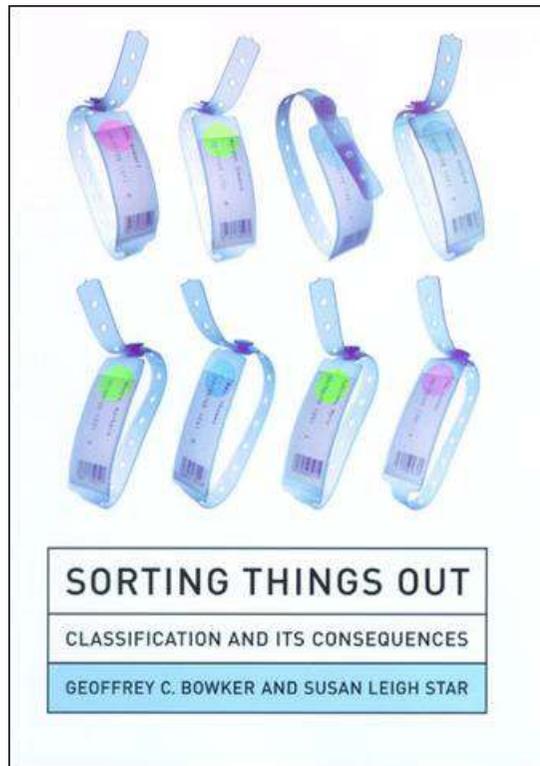
- ‘Now disease was equated with specificity and specificity with mechanism, all the while decoupling this increasingly ontological conception from idiosyncrasies of place and person’ (p243)
- *instruments of precision* (thermometer, x-ray urine chemistry) results could not be feigned and could be expressed in standard units
- ‘all promised to provide ways of describing disease that could be built into tight, seemingly objective pictures, useful in diagnosing and monitoring particular cases yet capable of being generalised’ (p243)
- Medical case record – technology links person to collective

Rosenberg, C. (2002) The Tyranny of Diagnosis: specific entities and individual experience *The Milbank Quarterly* 80 (2) 237-260

- ‘Although diagnosis has always been important in the history of clinical medicine, it became particularly significant in the late 20th century with the proliferation of chemical, imaging, and cytological techniques and the parallel conflation of diagnosis, prognosis and treatment protocols’ (240).
- ‘Specific disease categories are omnipresent’ [...] ‘indisputable **social actors**, real inasmuch as we have believed in them and acted individually and collectively on those beliefs’ (p.240 my emphasis)
- The *specificity revolution*

Disease/diagnostic categories as social actors

- *International Statistical Classification of Disease, Injuries and Causes of Death (ICD) the Diagnostic and Statistical Manual of Mental Disorders (DSM), Systemized Nomenclature of Medicine (SNOMED) and so.*
- Classification systems and diagnostic categories - unique histories 'a museum of past and present concepts of disease'
- Mortality statistics, monitoring flow of diseases, planning services, resource in clinical practice



“What we found was not a record of gradually increasing consensus, but a panoply of tangled and crisscrossing classification schemes held together by an increasingly harassed and sprawling international public health bureaucracy. Spirit possession and superstition never do reconcile, but for some data to be entered on the western-orientated death certificate, it becomes possible from the WHO point of view for death to be assigned the category “non-existent disease”” (Bowker & Star, 1999 p21).

Nettleton, S. (2006) 'I just want permission to be ill towards a sociology of medically unexplained symptoms *Soc Sci & Med* 62 1167-78

Medical knowledge

Certain

Uncertain

Agreed	<p>A</p> <p><i>Disease and (often) illness:</i> diagnosed - treated, cured or managed (e.g. cancer).</p>	<p>B</p> <p><i>'At risk' of disease,</i> may or may not experience illness - risk factors rooted in probability treated, managed or cured (e.g. obesity)</p>
Consent	<p>C</p> <p><i>Healthy:</i> no illness, no disease: may be encouraged to subject body to monitoring and assessment</p>	<p>D</p> <p><i>Illness and no disease</i> – no diagnosis, assessment but limited treatment, management or cure</p>

Aronowitz, R. A. (2009) Converged experience of risk and disease *The Milbank Quarterly* 87 (2) 417-442

- Chronic disease has become a kind of risk state in which diagnosis, treatment, and “disease management” are directed at reducing the changes of **anticipated**, feared developments (419)

What has made chronic disease more risky? (Aronowitz, 2009)

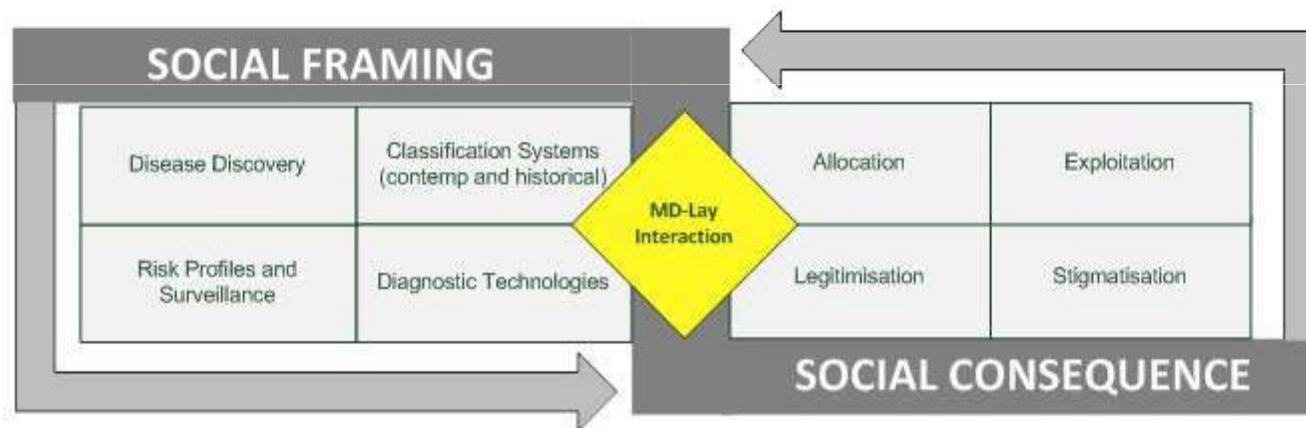
1. Clinical interventions altered natural history of disease
2. Greater biological, clinical, epidemiological knowledge of chronic disease risk
3. Increased numbers with diagnosis due to screening, diagnostic technologies and disease definitions
4. New ways of conceptualizing efficiency
5. Intense diagnostic testing and medical intervention

Aronowitz (2009)

- Blurring the boundary between risk and disease in decision making is facilitated by the way that we name and classify risk and disease. Many clinicians now recognize that a pathological diagnosis after biopsy of *Lobular carcinoma in situ* is, in essence, the discovery of an underlying state of risk but that the cancer terminology, along with its embodied character, makes it much more frightening and encourages decision making styles typically used in symptomatic and more advanced cancer. This semantic slippage and other negative aspects of the converged disease experience, such as the overselling of fear and fear reducing interventions by the pharmaceutical industry and others, might be mitigated by more critical attention to the way we define, name, and classify cancer and other diseases (435)

Jutel, A. (2011) *Putting a Name to It: Diagnosis in Contemporary Society* Baltimore: Johns Hopkins University Press

Social Understanding of Diagnosis



Implications ...

- Qaseem et al (2012) Appropriate use of screening and diagnostic tests to foster high value, cost conscious care *Ann Intern Med* 156 147-149
 - ‘You need to screen 1,900 women in their 40s for 10 years in order to prevent one death from breast cancer, and in the process you will have generated more than 1,000 false-positive screens and all the overtreatment they entail (Aronowitz, 2009 NYT)
- Context rather than communication