Developments in health activism: citizenship and social inclusion

Sophie Day

Professor of Anthropology

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Learning outcomes session 5

- Appreciate the significance of claims to health and/or health care
- Appreciate the range of health movements, the variety of organisations and causes and the tensions within them
- Be able to appreciate that health care is influenced by patients as well as those providing healthcare
- Understand how the specificity of patients and organisation may systematically distort the outcome of evidence-based interventions
- Explore evidence that doctors stand up for health rights, when and how (e.g. asylum seekers' rights to health)
- What difference do I want to make (and how will I)?

Activism

- Discuss different forms of health action with your neighbour

  Remember lecture 2

  (John Chetwood, Kush Naker)

GLOBAL HEALTH • LOCAL ISSUE

medsin imperial

Diversity of health actions

- Who is the patient and how do they make claims
  - Individual or group; patients & advocates; everyone or just some people; moral, economic, political, social pressures
- Collaboration, alliance and opposition
  - With doctors and health care workers, other social movements, philanthropy, the family, protest
- Does health activism make a difference?
  - Funding (services and research)
  - Access & appropriate care/treatment
  - Social inclusion (stigma; challenges to concepts of the norm and of normal)
  - Social causes of health and illness

Key drivers: power differentials

(*lec 4 Mariam Sbaiti*)

- The individual patient can be: 'passive object' rather than 'active subject'
- The individual healthcare worker can be: 'manager', 'decision-maker' and 'expert'
- Treatment can intensify power dynamics (dependency & medicalisation, including side effects)

Key drivers: PtEx

(*lec 8 Sophie Day*)

- Pts can request, complain & rank healthcare as ‘consumers’
- In extremis, can litigate
- Does this make it patient-centred (rather than doctor-centred)?
- From individual to collective advocacy…

The impact of patient or health movements

- Citizenship and civil rights; democracy; participatory medicine associated with growing distrust science, medicine, government; dehumanising aspects of biomedicine & bureaucracies (1960s-)
- Turn to 'person centred' alternative and complementary treatments and to self care (especially since 1980s)

See Seckinelgin (2003)

Range of examples

- From occupational health & safety 1st eg

  To the women's health movement 2nd eg

  And HIV/AIDS 3rd eg – in following lecs

    Especially important since 1960s have been movements in *disability rights* and *mental health*, and the impact of *health consumer* movements

    Many alternative classifications of types of movements eg disease focus vs population or constituency focus (see textbook)

1. General, Municipal, Boilermakers and Allied Trades Union (today's GMB)

'Hundreds of GMBATU members employed in making or handling town gas, dyestuffs, rubber goods, asbestos … have been killed by the [substances] they worked with. They suffered, then died, from cancer. In many cases, important clues to the cancer risks were ignored, sometimes for decades, by their employers and government departments responsible for their health…"

Cancer and Work: Guidelines for Workers Taking Collective Action over Health Hazards p.348

(Further reading, text on intranet from lec 8)

- 1920s gas workers complain of early deaths
  - 1950s excess lung and bladder cancer shown conclusively by epidemiologists
- 1930s dyestuffs & rubber workers complain of early deaths
  - 1950s excess bladder cancer (earlier in Germany and Switz)

GMBATU action towards health provision and disease prevention

Including otherwise patchy or absent

- Use of substitute chemicals
- Handling in closed systems with monitoring
- Risk information and training
- Labelling (‘cancer hazard’) & protection
- Medical and epidemiological checks
- No fault compensation

GMB
BRITAIN’S GENERAL UNION

2. & 3. And alliances 1980s-1990s

- AIDS & feminist alliances on many issues
- Sisters, mothers, daughters form charities and actions for breast cancer
- Which have a major impact on PtEx and other issues
- What is celebrated this week (Dec 1)?

Pink ribbons, adopted 1992

Visual Aids (NY) 1991, gallery space PS122 East Village

BBC, 2011 (http://www.bbc.co.uk/news/world-us-canada-13597312)

The complexity of health actions

- Corporate funding of health movements.
  - Philanthropy and/or marketing brand

    Pink Ribbons, Inc.

    See for example Ehrenreich (2001) on cause-related marketing. Also concepts of captive companies & pinkwashing
  - Major pharmaceutical donations to breast cancer activism are a particularly controversial issue for the environmental wing. So too in HIV actions is such funding debated.
- Q But does it counterbalance the power of state & other professionals in healthcare?

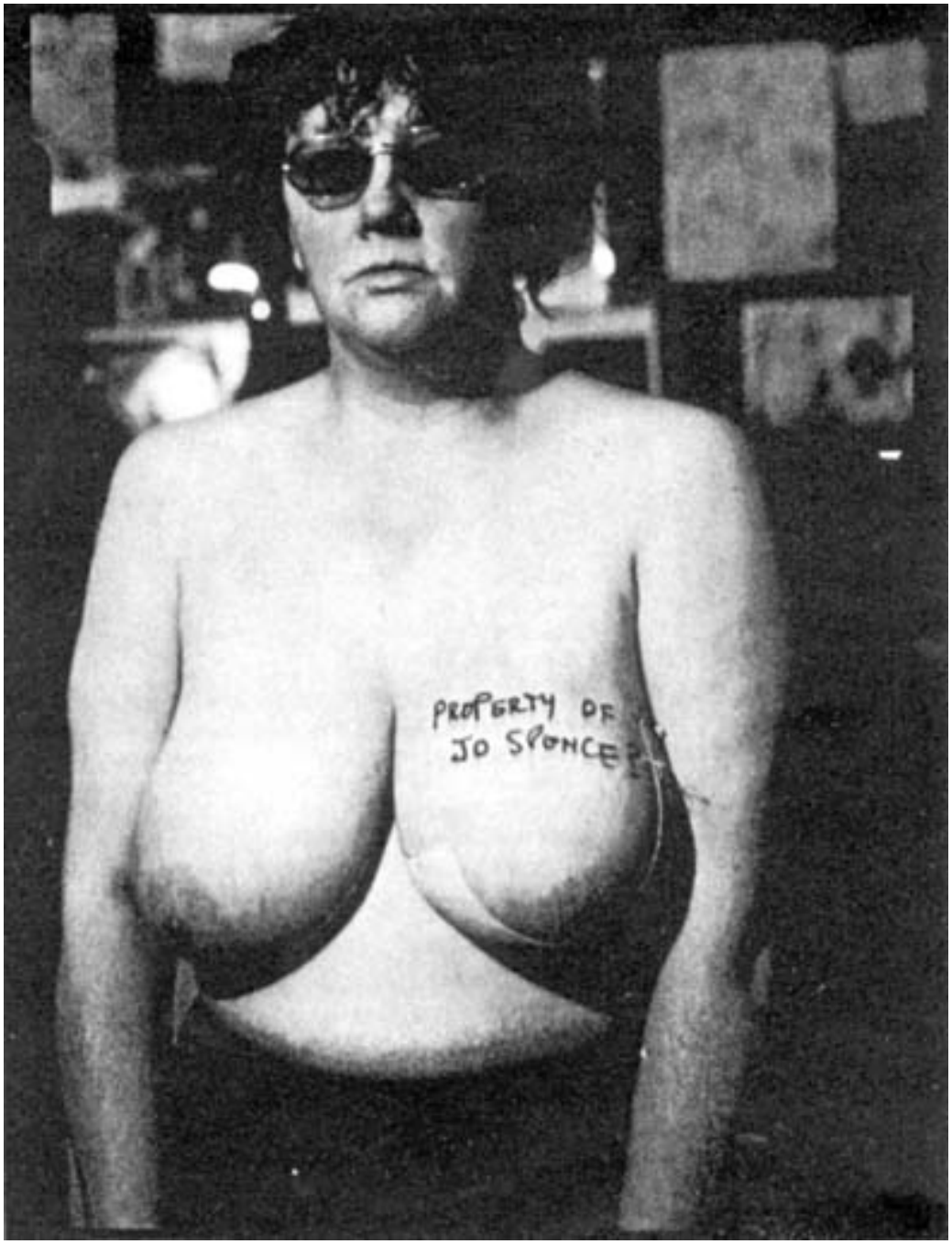
  Assess with neighbour

What's wrong with pink?

- Pink - traditional feminine roles such as caring for other people, being cooperative
- But and also social movement for screening, counselling, patient rights, access to care & anti-pollution legislation
- Klawiter (2004) shows impact of movement on a single woman over a 20-year period of treatment in the Bay Area: more support and care inside and outside hospital; less taboo. Key measure of impact of movement on PtEx, regardless of involvement in activism

Jo Spence
(1934-1992, London)

Our Bodies Ourselves
(1970, continually updated)



More images at
http://www.studiovoltaire.org/exhib-spence.htm

Inside as well as outside healthcare organisations

WE ARE MACMILLAN. CANCER SUPPORT

LIVING WITH CANCER?
WE'RE HERE TO HELP

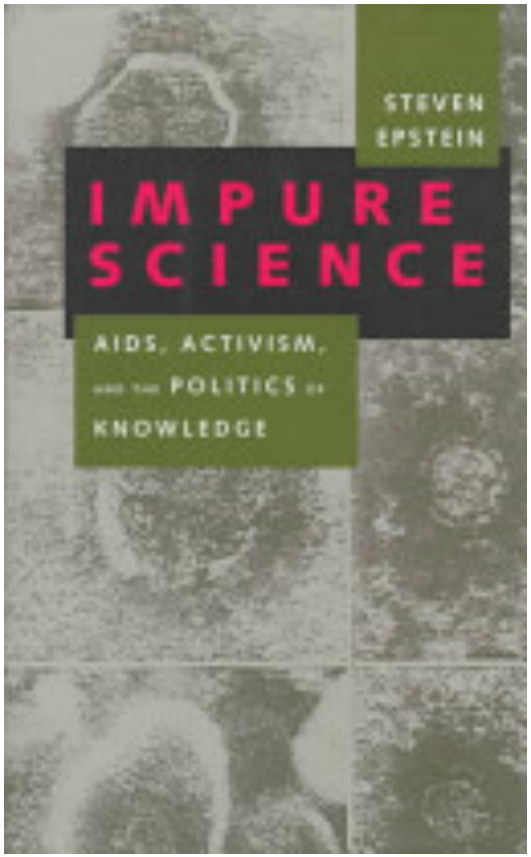
CANCER RESEARCH UK

Different conditions

- How does the success of HIV health action compare with that of lung or liver cancer?

Discuss what it is that makes some conditions and demographics very hard for those directly affected from representing the voice of a health movement.

AIDS activism, Epstein (1996)



- Questioning biomedical knowledge and treatments; Challenging what constitutes 'authoritative' and 'credible' knowledge

- "Critical engagement with the nuts and bolts of clinical research"

- "Expertification" and alternative bases of expertise

"The AIDS movement can best be compared with the relatively short list of movements that neither simply enlist experts nor attack them but, rather, undergo the process of 'expertification'" (Epstein 1996: 13)

"The interventions of laypeople in the proclamation and evaluation of scientific claims have helped shape what is believed to be known about AIDS - just as they have made problematic our understanding of who is a "layperson" and who is an "expert" (ibid. 3)

Unexpected implications of humanitarian care

Asylum seekers in France (sans papiers movement)

- Medical examinations & exercising compassion (for residency
- "In the case of undocumented foreigners, … health and illness have increasingly become the most legitimate ground for awarding legal status …The *suffering body* has imposed its own legitimacy where other grounds for recognition were increasingly brought into question" (Fassin 2001: 3)
- *Bare life*: recognition of human only through pathology. Right to stay for treatment (if not otherwise available) conditional, eg no right to work (1/10 asylum cases approved 1990s).

Further reading, Fassin (2001)

Recent focus on health & citizenship

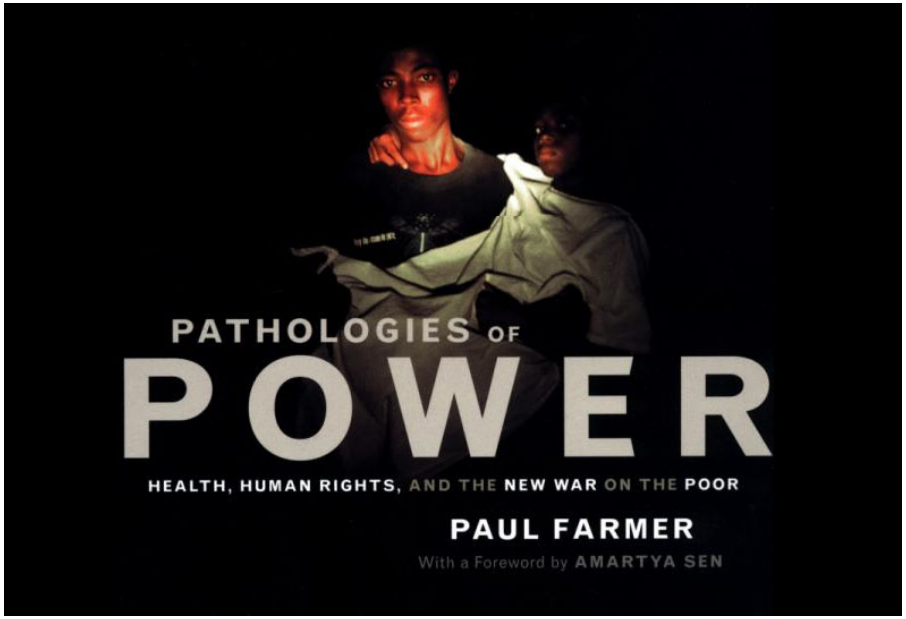
- "the right to health is perhaps the least contested social right"

Paul Farmer, *Pathologies of Power* (2003) (see also Partners in Health, http://www.pih.org/)

Health as a right (or entitlement, a core element of citizenship).

How do we then conceive of growing health inequalities?

Introductions to Professor Jonathan Weber & Grace Laker



Additional references

Ehrenreich B (2001) Welcome to Cancerland. *Harper's Magazine*

Fassin D (2001) The biopolitics of otherness: undocumented foreigners and racial discrimination in French public debate. *Anthropology Today* 17:3-7

Klawiter M (2004) Breast cancer in two regimes: the impact of social movements on illness experience. *Sociology of Health & Illness*, 26 (6): 845-874