

# DISABILITY AND THE SOCIOLOGY OF LONG TERM CONDITIONS

SASHA SCAMBLER



# Objective

---

To explore the ways in which sociological research on the implications of living with long term conditions can add to our wider understanding of disability.

# Content

---

- The Sociology of Long-Term Conditions
  - Theoretical approaches
- Key themes within a sociological understanding
  - Uncertain and unpredictable futures
  - Impact on social relations
  - Assaults on self-image and self-esteem
  - Biomedical concerns
- Locating long term conditions in disability studies
- Diabetes and the medicalization of empowerment
- Batten disease and the primacy of the biological

# Why Long Term Conditions?

---

- Conditions that require management over a period of years or decades, affect multiple areas of daily life and have no cure
- Can include anything from cancer to MS, diabetes or Batten disease
- Vary according to diagnosis, trajectory, prognosis and prevalence
- Most common cause of disability in the developed world
- And yet often relegated to the side-lines in mainstream disability studies texts
- Long term disabling conditions offer consideration of a different 'type' of disability and a fresh insight into ongoing debates in disability studies

# Sociological Approaches

---

- Functionalist
  - Parsons (1951) sick role, legitimised
  - Friedson (1970) challenged acceptance of the sick role by society
- Interactionist
  - Goffman (1968) ill health as deviance, labelling, stigma
  - Barnes (1999), Bogdan & Taylor (1989), Scambler (1989)
- Conflict
  - Waitzkin (1989) power relations, links to expert patient, empowerment
- Social Constructionist
  - construction of the impaired body as negative

# Interpretative Studies

---

- Explores the subjective experiences of people living with disabling conditions
  - Epilepsy (Schneider and Conrad 1983; Scambler 1989),
  - Multiple Sclerosis (Strauss 1984; Robinson 1988, 1998),
  - Parkinson's Disease (Singer 1973, 1974; Pinder 1998),
  - Rectal Cancer (Macdonald 1998),
  - Psoriasis (Jobling 1998),
  - Arthritis (Bury 1997),
  - Tuberculosis (Roth 1963),
  - Motor Neurone Disease (Locock et al. 2009),
  - Diabetes (Balfe 2007)
  - HIV and AIDS (Aggleton et al. 1989; Ridge et al. 2008; Harris 2009)

# Key Themes

---

- Uncertain and unpredictable futures
- Impact on social relations
- Assaults on self-image and self-esteem
- Biomedical concerns

# Uncertain and Unpredictable Futures

---

- Variable symptoms
- Lengthy diagnosis process/legitimation
- Uncertain trajectory
- Uncertain or complex treatments
- Fluctuating symptoms
- Long/short term planning problems



# Impact on Social Relations

---

- High level care and support
- Physical, emotional and personal
- Feeling of being a burden
- Isolation of the individual and family
- Financial strain
- Macdonald (1998) rectal cancer
- Bury (1998) Rheumatoid Arthritis

# Assaults on Self-Image and Self-Esteem

---

- Threat to self-identity
- Restructuring of biography to account for illness
- Continual process
- Loss of self – powerful form of suffering
- Robinson (1988) MS
- Macdonald (1998) Rectal Cancer

# Biomedical Concerns

---

- Managing both symptoms and medicine
- Control is exerted by manipulating regimen
- Life may be altered to fit regimen
- Jobling (1998) Psoriasis
- Pinder (1990) Parkinson's Disease

# Locating Long Term Conditions within Disability Studies

---

- Many of the themes outlined above can be found in the disability literature
  - Normalisation, identity, stigma etc. incorporated in debates about the identity of disabled people
- Watermeyer (2009) political constructions disassociating disabled people from loss and struggle are politically necessary but can be personally damaging and alienating for those disabled people who do experience them
- There are some studies looking at long term conditions from a disability perspective but relatively few
- Need to bridge the gap between the 'coping/loss' and 'oppression' paradigms

# Empowerment and Diabetes

---

- Strong policy move to self-management in NHS
- Based on the Kaiser model – professional, shared and self-care
- Tools for individuals to manage daily, linked to patient centred practice.
  - BUT:
  - What is empowerment?
  - How is it measured?
  - Who decides when it is successful?

# Defining Empowerment

---

- A process of education and skill development which enables people with long-term conditions to take responsibility for the daily management of their illness.
- Empowerment is widely seen as a positive move within diabetes care
- Moving from the patriarchal notion of 'compliance' to a more patient-centred notion of self-management (Asimakopoulou 2007).
- This ties in with the ideological shift towards consumer healthcare and patient choice
- Little clarity and shared understanding of empowerment
- Disagreement about the degree of freedom a patient should have in making choices

# Measuring Success

---

- No formal consensus on the definition or measure of 'successful' empowerment (Scambler, Newton, Asimakopoulou 2012)
- Biochemical targets were used as the main tool in ascertaining success.
- Talk of giving patients the tools with which to manage illnesses
- In practice patients were coached in how to meet biochemical targets
  - Control of glycaemic levels
  - Adoption of a healthy diet
  - Weight loss targets
  - Regular physical activity
  - Monitoring blood glucose levels
- Patient choice and control turns to disease management and biochemical symptom control.

# Policy v Lived Experience

---

- Illustrates the tension between policy initiatives and the lived experience of long-term conditions.
- Evidence suggests programmes are less effective than was hoped
- And have not reduced the demand for health services.
- This brings into question the continued state support for empowerment and self-management programmes.
- Bury (2010) suggests that the rhetoric has changed from a challenge to the state sponsored dominance of biomedicine and has been colonized by the very system it sought to challenge
- This can be seen as a way of placing the patient at the centre of care
- Or as a way of glossing over the complexities of living with conditions of this kind over an extended period of time and the very real need for quality healthcare.



# In conclusion .....

---

*“By promoting the idea that patients are in control and make choices over their care which affect the likelihood of achieving symptom control (self-management), whilst maintaining control over the mechanisms through which the ‘success’ of this self-management is measured, the power of the patient choice/shared decision-making/empowerment agenda is neutralised. .... Empowerment cannot be used as a way to resist those oppressive processes of normalisation associated with biomedicine, if the very measures used to judge the success or failure of empowerment are biomedical. Indeed, this kind of empowerment looks very like disempowerment.”*

# Batten Disease

---

## **The Disease**

- Metabolic, neurodegenerative, autosomal recessive heredity
- Prevalence of 1:12500
- 4 main types of Batten disease classified by age of onset

## **Common symptoms**

- Epilepsy; visual impairment; cognitive and motor degeneration; shortened life expectancy
- There is currently no cure
- Treatment is symptomatic and palliative and may extend over a considerable timeframe
- Batten disease lasts over an extended period of time and affects multiple areas of daily life

# Batten Disease and the body

---

- Physical reality is all encompassing
- Cannot be less significant than the social reality
- The impaired body cannot be separated from the lived experience of the disease
- Social reality is an embodied experience shaped and curtailed by the nature and functioning of the body in which it is being lived
- The biological impact of the disease is direct in its determination of the symptoms of the disease itself and the nature of the trajectory
- And it is indirect in its impact on every, or almost every, aspect of daily life.

# Rethinking the Impairment Debate

---

- Uncertain and unpredictable futures
- Impact on social relations
- Assaults on self-image and self-esteem
- Biomedical concerns

# The Body, Biology and Impairment

---

- The impairment/disability, body/oppression debate is ongoing
- Hughes (2004) suggested we need to see disability as embodied and impairment as social
- More research is needed into the permeable barrier between the embodied experience of disability and the social experience of disability
- Research into the lived experience of people with long term conditions gives a means of doing this
- Sherry (2002) and Lock et al (2005) suggest that experiences cannot be classified as 'either' impairment 'or' disability
- These categories are best conceptualised as a fluid continuum

# Future Directions and Collaborations

---

- Long term conditions are the main cause of disability in the developed world
- Yet they are largely absent from mainstream disability studies
- Small, but increasing numbers of medical sociologists and disability theorists are calling for more collaboration
- There is a disability stream in the BSA annual conference this year for the first time and a new BSA Disability Studies group
- The wealth of research documenting what disabled people experience, feel and think needs to be incorporated in to the wider debates
- And sociologists need to be more aware of the prevailing paradigm within medical sociology and to incorporate the social oppression paradigm

THANK YOU

SASHA SCAMBLER  
SASHA.SCAMBLER@KCL.AC.UK

