

THE ILLNESS EXPERIENCE

HIS MODULE LECTURE 4

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Learning outcomes

- Review different theoretical conceptualisations of illness experience
- Describe how patients' experiences of illness can be understood in terms of narrative, and identify how insights from narrative health research can be used to enhance health care

DISEASE

disease /dis'ease/ (dī-zēz') any deviation from or interruption of the normal structure or function of any body part, organ, or system that is manifested by a characteristic set of symptoms and signs and whose aetiology, pathology, and prognosis may be known or unknown.

<http://medical-dictionary.thefreedictionary.com/disease>

Disease is what practitioners have been trained to see through the theoretical lenses of their particular form of practice. (Kleinman)

ILLNESS

A patient's *illness* 'stands for a patient's interpretation of his or her disease, the feelings that accompany it, the life events it turns into.'
(MoI, 2002 p9).

MEDICAL CONDITION

Any form of illness or abnormality in the body that interferes with a person's usual activities or feeling of wellbeing.

http://www.nps.org.au/bemedicinewise/medicinewise_choices/glossary/medical_condition

PATIENTS

□ The word patient originally meant 'one who suffers'.



□ A patient is any recipient of healthcare services.



LAY PEOPLE

- Understanding populations
- Lay epidemiology – cultural understandings and responses to health and illness
- Cultural understandings are dependent upon the 'local' social context – includes place, time, social group

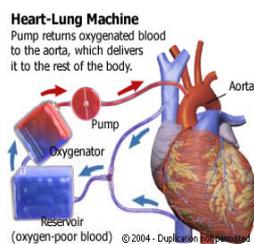


How do lay people explain heart disease? (Davison et al)

- Lay epidemiology – a general explanatory framework that helps people to assess personal risks, obtain reassuring affirmation of predictability, devise appropriate behaviour strategies and explain distressing events
- It is a lay theory of coronary candidacy – helps people assess personal risk and to explain why some people get heart problems and some don't

Gender and heart disease (Emslie et al)

- Heart as machine – 'masculine image of the mechanical heart has shaped the metaphorical character of heart disease'
- Gender is a key element in identification of coronary candidacy





Sir William Osler describes the typical angina sufferer as:

'a keen and ambitious man, the indicator of whose engine is always at "full speed ahead"!'

CHRONIC ILLNESS & IDENTITY

- Chronic illness alters the relationship between the patient's body, self and surrounding world (Hyden)
- People with chronic illness use narrative (unconsciously) to give meaning to events that have on some level affected the course of their lives

IDENTITY

- Adams et al – whether people identify themselves as asthmatic or not influences their approach to managing the disease (including medical treatment)

"I've always been chesty, but since last year they stuck the label of "asthmatic" on me. But I'm no different now and neither is my chest"

- People with clinically identifiable illness may not accept biomedical labels

Resisting diagnosis

...I don't want to be labelled... I don't want them to label me, they treat you differently and I think that makes you worse. I think you live to your label... if I think, 'I haven't got postnatal depression' and I don't want to do something, I can't blame it on my postnatal depression... if I start to label myself that I do [have PND], I can be very negative and I can't be bothered. Whereas once that option isn't there anymore [I say], 'come on, this isn't on', you know, I've got to find that piece of extra [strength] from somewhere and just get on and do it.

Black Caribbean women's response to adversity in early motherhood (Edge and Rogers)

- Women rejected 'postnatal depression' as a way of understanding psychological distress
- Rejection of depression as illness was associated with need to normalise distress and a self-concept which stressed the importance of being 'Strong-Black-Women' for maintaining psychological well-being

Epilepsy, disability and identity (Rhodes et al)

I think ...this disease got bad reputation in our (Pakistani) community. If you got epilepsy, you know, you're not normal person... You can have a heart attack, "Oh, you had a heart attack". But, if you've got epilepsy, there is something - how can I put it? - abnormal. Because heart attack, you don't call yourself disabled but, if you've got epilepsy, people say "Oh, there's something wrong with him."

DISABILITY (Oliver)

- Impairment describes a body lacking part or all of a limb, or having a defective limb or other bodily mechanism
- Disability refers to the many social and other disadvantages imposed by society on people with physical impairments
- Disability rights movements have fought against the medicalisation of disability

Epilepsy

I don't think it's a disability, to be honest. You probably might not find it with other people but, for me, I don't class it as a disability. I don't think it has stopped me from doing anything. (40 year old man)

Rhodes et al (2008)

Future directions for disability studies (Tom Shakespeare, 2005)

- Disability is an interaction between impaired bodies and excluding environments
- Biomedicine and assistive technologies offer new options for curing or alleviating illness and impairment
- How can the politics of disability identity be reconciled with impairment prevention and cure? (rather than as polar opposites)

International Classification of Functioning, Disability and Health

- Integrates *medical* and *social* models
 - Recognises the significance of environment
 - Focus on 'components of health' (rather than 'consequences of disease')
- Key components:
- Body structures and functions (and impairments)
 - Activities (and limitations)
 - Participation (and restrictions)

Illness, biography and narrative (Lawton, 2009)

- 2 strands of work:
- Impact of illness on patients' biographies and identities
 - How people use narratives to give meaning and voice to their suffering over time

'Cultural transition' (Bury, 1997)

- Demographic transition → 'cultural transition'
- We expect to live more predictable lives in the context of a relatively safe environment
- Emphasis on life planning and self-identity (Berger et al of Bury, 1997)
- Chronic illness interferes with our sense of agency

Biographical disruption

- From Bury's research on people recently diagnosed with rheumatoid arthritis
- Onset of chronic illness is biographically disruptive – it undermines a person's self concept – shifting someone from a perceived normal trajectory to one fundamentally abnormal and inwardly damaging
- Has consequences at the practical and social level
- The illness will have significance for a person's identity

Loss of self

- Kathy Charmaz (1983) – US study of people with serious chronic illness
- 'a narrow medicalized view of suffering, solely defined as physical discomfort, ignores or minimizes the broader significance of the suffering experienced by debilitated chronically ill adults'
- 'Loss of self' is tied to:
 - Restricted lives
 - Social isolation
 - Being discredited
 - Burdening others

Biographical flow

- Chronic illness may be experienced as an expected part of life experience – linked to ageing – and experienced less as disruption, but rather 'biographical flow' – becomes integrated into someone's biography (Faircloth et al – stroke study US)
- Cultural factors such as social class also impact on responses to chronic illness, with people from lower social classes found to be more accepting (Pound et al – stroke study UK)

Narrative reconstruction

- Gareth Williams' work on rheumatoid arthritis – people make sense of their illness experience by choosing causal explanations which they use to 'reconstruct' their biographies
- Why me? Why now?
- This work marks a shift in research interest from 'health beliefs' to 'accounts'

Narrative accounts of illness

- Patients' narratives give voice to suffering in a way that lies outside the domain of the biomedical voice (Hyden)
- Accounts of illness are a form of self-presentation, so the social situation and audience influence the construction of the narrative (friends, doctors, researcher, employer)

Where do we find illness narratives?

- Qualitative narrative interviews e.g. life history interview
- Narratives within qualitative interviews
- Narratives of illness experience in the media – news media, websites etc
- Analysis of what is said and/or how it is said

Functions of illness narrative (Hyden)

- To construct an illness experience
- To reconstruct life history
- To make disease and illness understandable
- To collectivise the illness experience

Types of narrative

- Frank – storylines – ‘restitution’, ‘chaos’, ‘quest’
- Robinson – different life trajectories ‘stable’, ‘progressive’ and ‘regressive’
- Which types of narrative are (culturally) available to people?

Which illness stories get told?

- Narratives are edited versions of reality, not objective and partial descriptions of it.... Interviewees always make choices about what to divulge (Reissman, cf Bury)
- Which illness stories don't get told?



Culture and narrative

- White and South Asian respondents' accounts of diabetes causation (Lawton et al)
- White patients – accounts highlighted their own lifestyle 'choices' and personal failings (blame) blame
- South Asian patients – more likely to externalise responsibility – highlighting their life circumstances in general

Pauline: **Well I thought it was eating so many sweetsies . . . I thought maybe this [diabetes] is making up for all the years of,** I'll give you an example, when I was having my . . . third child n' I told my mum I was expecting, she went absolutely ballistic right cos a third child. My granny had 13 and she says 'what, are you trying to up yer granny..?'[laugh] I was about 28 then, y'know, n' eh 'how did you fall pregnant?' I says 'well how everybody falls pregnant', 'but you were taking the pill' n' I says 'I forgot the pill' . . . She says 'if there was a bloody Mars Bar you wouldna have forgot that would you'. **So that'll give you an idea o' how much sweetsies I used tae eat. When I was younger, I'd rather have a Mars Bar than a meal.**

Manzoor: **It's the result of eating the wrong kind of food.** You see I was a vegetarian for most of my life . . . It's funny because when I first came to the UK . . . **I used to live on Mars Bars because there was nothing that I could eat, right, in a student sort of environment.** They were only catering for non-veg[etarians]. I mean nowadays it's much different because veg[etarianism] is sort of, in this era, a lot of people are on that sort of diet. But in those days there was nothing. And so the landladies couldn't make stuff for me, so **I was forced to eat sugary things.**

Implications for health care

- A critical approach – what is the role of medicine in chronic illness?
- Patient-clinician relationships - partnership working
- Understanding of people's experiences of diagnosis and living with chronic illness
- Improved patient satisfaction with care and compliance with treatment and management

Taking research on illness experience forward

- Interviews are commonly used in studies of illness experience, but we need to use other forms of data
- Narratives take many forms, have many uses and serve many purposes' – be critical (Bury, 2001)
- Do people provide different accounts to different audiences, at different points in the disease trajectory?
- Need more cross-cultural comparisons (including age, gender, ethnicity, social class)
- Need to consider experiences beyond the individual – families, friends, work
