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RESEARCHING ILLNESS IN ITS SOCIAL CONTEXT

HIS MODULE LECTURE 2

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Research topics

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235 million people worldwide suffer from asthma...

- Asthma is the most common chronic disease among children
- Asthma is not just a public health problem for high income countries: it occurs in all countries regardless of level of development. Over 80% of asthma deaths occurs in low and lower-middle income countries
- Asthma is under-diagnosed and under-treated, creating a substantial burden to individuals and families and possibly restricting individuals' activities for a lifetime



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From research topics

→ research questions

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Social research

- Considers (health) issues in terms of their social nature and the social contexts in which they exist
- Can look at the social nature of health at different levels – from macro to micro
- Can be 'basic' or 'applied'
- Social research is cumulative – it aims to add to evidence/knowledge and build theory
- The aim is to be critical and ask questions of the data during analysis, not just describe the content – this means that you need to set your study up in such a way that you can do this

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Drawing on the literature

- Building on earlier research – using it to inform your analysis
- Social science - cumulatively building knowledge
- Using literature to build theory – using concepts and models

Clinicians and theory

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Clinicians have tended to ignore theory because they believe they are working directly with reality:

'Blood is blood and diabetes is diabetes... We readily acknowledge the existence of real blood, but we can only see it, talk about it, and relate to it as we have learned from our culture... There will always be a cultural filter between us and reality'

Crabtree and Miller (Doing Qualitative Research, 1999)

What do we mean by asthma?

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- Patient's lung function or exercise tolerance (clinical)
- What patient can do (functional)
- Affect on social relationships (social)
- Health beliefs regarding asthma (cultural)

Types of research question

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Describing	What forms do political protests take?
Taking an aspect of the issue of interest and examining it in detail	What form does women's involvement in climate change protests take?
Explicitly drawing upon theory to examine an issue	Does social movement theory explain the emergence of climate change protest groups?
Comparing attributes	Does age group affect the likelihood of participating in a political protest?
Explaining	Why do some political protests involve violent conflict and not others?
Assessing whether an intervention works	Does specialist training for police officers who police large political protests reduce arrests?

Methods and methodology

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- Methods are the technical tools you use to conduct your research
- Methodology refers to the epistemology or theory that underpins your research design

Methodology

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Rationale for how will go about studying asthma, how the analysis will be done and the findings understood.

It is also the basis for establishing the quality of a research study.

Social research

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- Searching for patterns – identifying social rules and norms
- Developing theory and models through identifying and investigating key issues in the data, including hypotheses

Quantitative research

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- Positivist – search for social facts
- Deductive - decide on what your findings may be in advance



- Identify the issues you wish to investigate and define them so they can be accurately measured

Social surveys

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What people with asthma say

- 42% of people with asthma tell us that traffic fumes discourage them from walking/shopping in congested areas.
- 33% of children with asthma (or their parents) say that asthma can result in being left out of sports activities at school.
- Over a quarter of people with asthma have missed days off work in the past year because of their asthma.
- 65% said that they have had an asthma attack where they have been unable to talk.



Exploring neighborhood-level variation in asthma (Cagney and Browning J Gen Intern Med 2004)

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Objective – to explore differences in the prevalence of asthma and other respiratory diseases at the neighbourhood level

Methods – multilevel statistical approach involving survey-based response to physician diagnosis + pre-existing neighbourhood surveys

Results

Individual factors e.g. being female, smoking, are associated with asthma

Neighbourhood factors – collective efficacy is protective against asthma

Qualitative research

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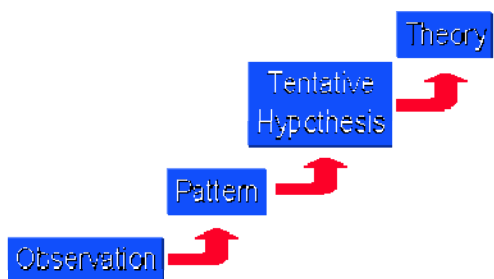
Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that makes the world visible. These practices... turn the world into a series of representations including field notes, interview, conversations, photographs, recordings and memos to the self.

This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them.

(Denzin, 2000 cf Snape and Spencer2003)

Analytic induction

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Medication, chronic illness and asthma (Adams et al, SSM, 1999)

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Aim – to provide an explanation or the observed variation in the way people diagnosed as asthmatics conceptualise and use their prescribed medication

Methods – inductive hypothesis generating study, in-depth interviews with people prescribed asthma prophylaxis

Findings

The diagnosis of asthma was interpreted by patients in relation to their social lives. Differed in their readiness to accept the identity of asthma sufferer.

- Identified 2 main groups – *deniers* and *accepters*
- Deniers did not identify themselves as asthmatic

Qualitative methodologies

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- Discourse analysis
- Narrative health research
- Ethnography
- Documentary analysis

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Qualitative data

Ethnographic data

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- Observation and interview
- Glaser and Strauss 'Awareness of Dying' (1965) – how people die in hospitals
- Developed 'grounded theory' approach

Documents

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- Official statistics
- Policy documents
- Patient documents e.g. 'asthma self care plans'
- Diaries
- Media
 - Newspapers
 - TV and radio
 - Social marketing
 - Internet

Interviews

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Type

- Structured (survey research)
- Semi-structured
- Open-ended

Form

- Narrative
- Ethnographic
- Data treated as resource or topic

Patient with asthma

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So it was your first admission last week?

Yes. I mean I am 45 and I've been working since I was 16 1/2 apart from periods. Faking illness just doesn't comprehend with me. Whenever people do it I always think 'skiver'. Unless I know it's genuine, because a lot of people just use sickness to take a day off and I've never been like that...

Interview topic guide - example

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ASTHMA STUDY - PATIENT INTERVIEW TOPIC GUIDE

Story of admission/route of admission

Could you tell me the story of your admission (including the lead up to it)?
Reason for admission (causes, triggers, reactions, anxieties/worries).
What do you think set off your attack this time?

Understanding of asthma

Could you tell me a bit about your views on asthma and how it affects you?
People cope in many different ways with their asthma – how do you try to keep in control?

Profile of psychosocial factors and life events

Could you tell me a bit about your personal circumstances?

Relationship with practitioners/way people access care

Can you tell me a bit about the health services you have received for your asthma?
What are your views about the health services you have received for your asthma?

Networks and social support

Could you tell me a bit more about your social networks – family, friends, work colleagues...
Is there anything else you would like to add?

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Collecting data

Collecting data for an asthma study

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Issues to consider:

- Sampling
- Research sites?
 - gatekeepers
- Research participants?
- Hard-to-reach groups?
- Data governance

28 Data analysis

29 Survey study analysis

- Data cleaning and inputting
- Statistical analysis
- Initial cross-tabulations
- Investigating relationships between variables using statistical tests
- Discussion and interpretation of the findings

30 Survey study process

- Assess current evidence (literature review)
- Identify new research questions and hypotheses
- Aim and objectives (including hypothesis)
- Ethics
- Sampling and recruitment
- Construct a questionnaire
- Collect and analyse data
- Report on content
- Explore relationships between variables and identify statistically significant differences
- Discuss findings

Qualitative interview study analysis

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- Transcribe interviews
- Initial reading, re-reading and put together a coding frame
- Computer assisted qualitative data analysis
<http://www.surrey.ac.uk/sociology/research/researchcentres/caqdas/>
- Thematic analysis of content (codes and categories)
- Identification of research questions for further analysis
- Iterative process + link to the literature
- Discussion and interpretation of findings

Assessing the quality of qualitative research

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- Analytic induction
- Constant comparison across data
- Theoretical sampling
- Search for deviant cases

In-depth analysis of questions identified during first stage of analysis

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Adams et al study of asthma

Secondary aim of their qualitative study was to generate hypotheses to account for the findings, developing and extending concepts already used in the chronic illness literature – identity and stigma

Iterative process – going backwards and forwards between the data and exploring relevant concepts from the literature

Qualitative interview study process

- 34 Assess current evidence
- Examine qualitative literature on illness and work
- Aim and objectives
- Ethics
- Sampling and recruitment
- Collect data – semi-structured interviews
- Analysis of content
- In-depth analysis of questions identified during first stage of analysis
- Discuss findings

Rigour/quality

35 Are the findings of this study valid and reliable? Is this a good research study? Can we 'trust' that findings?

Validity – are the reported findings true?

Reliability – concerned with the consistency with which research procedures deliver their results

Additional resources/bibliography

36 Adams, S., R. Pill, and A. Jones, *Medication, chronic illness and identity: the perspective of people with asthma*. *Soc Sci Med*, 1997. **45(2): p. 189-201**.

Crabtree, B.F. and W.L. Miller, (Eds) *Doing qualitative research*, Sage: Thousand Oaks, California, 1999.

<http://www.socialresearchmethods.net/kb/dedind.php>
