“Using field notes, case notes and participant observation to understand the meaning of support in the life experience of vulnerable groups in social care: perspectives from an occupational therapist practitioner-researcher”

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Aims of the presentation

1. To take today’s audience through the journey I made as a researcher.

2. To go through an abridged version of chapter 4: Research Methods from my publication – The Politics of Lupus.

3. To describe some of the challenges I experienced – both subtle and demanding – and how I overcame this.

4. To summarise the issues
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Defining Ethnography

Ethnography: scientific description of the culture of a society by someone who has lived in it, or a book containing this: One of the aims of ethnography is to contribute to an understanding of the human race. Malinowski wrote several ethnographies of the Trobriand Islands.

Four modes of enquiry

- Observation of informant one in the community & Ward setting
- Ethnographic Case Study
- Use of secondary data to inform substantive chapters
- Interviews with MP & Lupus UK CEO
- QDA - thematic analysis of: Lupus diaries

“It wasn’t always like this”
Qualitative Data Analysis techniques used?

QDA techniques included:

- Line-by-line coding
- Thematic analysis
- Constant comparison and
- Framework tables

The author as ethnographer

As an ethnographer I became the instrument of data collection.

‘[T]he self must not only be offered, it must be accepted’ (Goffman 1979 p 41).

[Implications: Practical examples – professionals that use immersion/infiltration; the need for reflection, debriefing & supervision]
Uncovering the issues
Line by Line coding
Diary Commences on 18th June 1996.

Very stiff and very painful in all joints from head to toes. Also had banging feels sore and very itchy. Put on sunblock (didn’t help). By dinner time felt needed very tired. Put on neck collar, wrist splints and tube grip on elbows.

Tried to sleep during the afternoon but pain wouldn’t let me go. Every major effort because of pain and feeling weak. Going to the toilet after approximately 12 feet from living room feels like a marathon. Del is trying to keep me cheerful with his witty remarks. Keep moving all joints now and again to avoid them ceasing up.

19.06.96

Had reasonable nights sleep last night. Better than expected woke up feeling very stiff and extremely painful all over. Felt full of cold and covered in rash. Did exercise routine but couldn’t manage many. Pain still has not settled down at all. Lunch
time headaches returned and feel very washed out. Having to be careful how I move because muscles and ligaments feel as though they are pulling. All I can do is rest and hope it passes.
Framework Tables
Informant One theme

theme: Event

didn’t want to be home when your father came from work..... I want to get out of this waiting at home when he comes from work business. He takes me for granted.

09.08.95 ...I had my fair share of feverish pains in my knees

10.08.95 I had a very good nights sleep

15.08.95 I have my stomach griping me. I feel like going to the doctor but I already told him about this...

16.08.95 My stomach is just griping me; there is a scrapping feeling in my stomach

22.08.95 ..I am going to see the doctor today, about my leg (swelling - phlebitis around the calf region). The swelling has gone down though.

24.08.95 (Morning)
Blaine: What are you thinking about mum ?
Mum: About that letter I sent into work...
(Silence).... my elbow is also hurting me....and my side (points and gestures to left side whilst lying in bed)
(Evening)
Blaine: How are you keeping mum ?
Mum: Alright...(10 - 15 seconds passes ) just my stomach keeps aching
Thematic Analysis
What is going on in their lives?
Event
1a. Evaluation of activity e.g. previous nights sleep
1b. Positive and negative outcome
1c. Negative personal experience e.g. unusual symptoms
1d. Multiple Events and Overload Event

Strategy
2a. Idea
2b. Psychological planning
2c. Support from spouse e.g. maintaining sense of Humour
2d. Carer struggling to cope
2e. Positive interaction with others
2f. Use of Equipment
2g. Exercise
2h. Being
2i. Yielding to the symptoms passive
Remaining objective: A grief observed

Reconciliation through “objectivities”?

The death of a lupus sufferer - resilient mentality as resistance
Mixed narratives
Thank you

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Remaining objective: A grief observed

The death of a lupus sufferer - resilient mentality as resistance
Death and dying
What can we learn from bad practice and how can we go forward?
Social context of dying

On reflection the process of dying had commenced weeks before the my mother’s finally died. For me it comprised increasing moments of dependency on other people to perform routine dignity tasks of feeding, washing and toileting. She was unable to self-toilet to pass faeces or urine. She lay on her back with large pressure sores on her buttock, which often came into contact with urine and faeces.

She relied on a “male” catheter to pass her urine and her body had to be turned in order for her pads to be removed and changed without damaging the injured skin surrounding the site of the pressure sores. In addition she became unable to press the call alarm for help and assistance. The encroaching social death in mum’s situation was a precursor to actual physical/biological death (cf. Mulkay 1993). This process of social death began to appear to me as a series of power plays between others and mum. This began as others began to take control of mum’s body.
For me mum never lost the respect of her children. She never became less of a mother because she was in an advanced state of illness. If anything they counterbalanced for her gradual loss of function, by ensuring that they remained committed to her state of personhood in the presence of themselves and others thus displaying how they would expect others to behave in her presence at this time. Mum was a heroine to her children (cf. Seale and Cartwright 1994). When required they cared for her and tended to her as if they were nurses, without shame, embarrassment or any other reservations. She deserved this status.
Linking evidence to practice

From Report of the Mid Staffordshire NHS Foundation Trust Executive summary
The first inquiry heard harrowing personal stories from patients and patients’ Families about the appalling care received at the Trust. On many occasions, the accounts received related to basic elements of care and the quality of the patient experience. These included cases where: Patients were left in excrement in soiled bed clothes for lengthy periods; Assistance was not provided with feeding for patients who could not eat without help; Water was left out of reach; In spite of persistent requests for help, patients were not assisted in their toileting; Wards and toilet facilities were left in a filthy condition; Privacy and dignity, even in death, were denied; Triage in A&E was undertaken by untrained staff; Staff treated patients and those close to them with what appeared to be callous indifference.

Bibliography


