Longitudinal qualitative research: techniques for illuminating nursing care in the community

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With acknowledgements to Claire Goodman,
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Outline

• What is longitudinal qualitative research?
• Who uses it (and why)?
• Outline some key considerations in designing and undertaking longitudinal qualitative research,
• Illustrate the above with examples of my own work exploring nursing care in the community and the experience of those with long term conditions,
• Invite you to share your experiences.
Longitudinal studies are not new

- **Anthropological**
  - The Harvard Chiapas project Tzotzil Indians (Mexico) 1957-1980 annual
  - Gwembe, Valley Tonga (Northern Rhodesia) 1956 initially 5 yearly

- **Community and Family Studies**
  - Banbury (UK) 1960, 1975

- **Panel Studies**
  - Household Income dynamics (USA) 1961 annual

- **Age cohorts**

What is longitudinal qualitative research?

“many qualitative research studies have employed longitudinal components, re-interviewing informants or returning to original study sites. What distinguishes longitudinal qualitative research is the deliberate way in which temporality is designed into the research process, making change a central focus of analytical attention”. p185

The meaning of ‘time’

- Time as a physically contextual construct,
- Time as an individually and subjectively interpreted construct,
- Time as a cultural and gendered construct.

Saldana, J. (2003), Longitudinal Qualitative Research: Analyzing Change Through Time, Walnut Creek CA: AltaMira Press.
Types of time

• Present time,
• Time as in a life course or “career”,
• Time as in time as framed by historical events and historical period,

Change is contextual and multifaceted.

“useful research on change should explore the contexts, content, and process of change together with their interconnections through time. The focus is on changing, catching reality in flight; and in studying long-term process in their contexts, a return to embeddedness as a principal of method.”

Types of longitudinal studies in health research

- Patient experience of conditions and care that have a ‘journey’ or ‘career’ e.g. cancer, chronic illness,
- Professionals experience of “work course” e.g. novice to expert,
- Evaluation of innovation e.g. start up and later,
- Investigating service development over time e.g. change processes.
Key considerations in design and undertaking

- Research questions that consider change and/or continuity,
- Appropriate time frame for the questions,
- Sufficient resources,
- Data management,
- Ethics,
- Observation and verification-issues of data collection and degrees of involvement,
- Routes to structured understanding.
Coming to terms with time

• Understanding the phenomena and the time frame for change,
• Understanding the trade off between the desired time frame and funding of the resources,
• Recognising research projects always take more time than the optimism of the protocol,
Research is a social process not just a technical task

Relationships and roles

“We found that on occasion patients did contact the research team for advice or information relating to their diagnosis” Calman et al.. Developing longitudinal qualitative designs: lessons learned and recommendations for health services research BMC Medical Research Methodology, 2013 13:14

“Although families accepted the scientific and Investigational nature of the study, in their eyes the researchers were seen first as nurses. As a result, they were asked for advice about schools, their child’s health status, the health-care delivery system, and/or caregiver/family health-care needs” Sterling YM, Peterson, JW. Lessons learned from a longitudinal qualitative family systems study. Applied Nursing Research 18,2005, 44-49
“the very process of categorizing and coding that lays at the basis for the analysis also ‘shatters’ the data and disembodies it from person who produces it … in contrast narrative data analysis stresses the importance of the ‘story’ .. ‘the voice of the life world’

“p1258

Conrad P Qualitative research on chronic illness:
Data analysis

“Techniques of data reduction and display are crucial mechanisms for structuring and thereby simplifying data. Pattern reduction is a critical intellectual process for all engaged in longitudinal studies.”

Pettigrew 1995 op cit

“Overall we have found that although a combination of narrative and cross-sectional data analysis is highly labour intensive, both are needed in order to gain a coherent and nuanced understanding.”

Illustrating the issues from:

A study of the effectiveness of inter professional working for community dwelling older people (TOPIC).
http://www.netscc.ac.uk/hsdr/projdetails.php?ref=08-1819-216

Nurses as case managers in primary care: the contribution to chronic disease management (ENCAM)

Acknowledgment and disclaimer: Both studies are independent research funded by the National Institute of Health Research (NIHR). The views expressed are those of the researchers and not necessarily those of the NHS, the NIHR or the Department of Health.
One element of each study:

- **ENCAM:** followed over nine months the experience of older patients and families in receipt of different types of nurse case management,

- **TOPIC:** followed over nine months the multi-agency care received by community dwelling older people as they experienced it.
Recruitment, retention and loss to study

- Understanding the research
- Understanding the process
- Understanding the participant group
Preparing for entry, continuing and exit from peoples’ lives (‘the field’)

- Researchers
- Older participants
- Professionals
The data management and analysis

Person 1 Time one  Time 2  Time 3

Person 2 Time 1  Time 2  Time 3

Person 2 time 1  Time 2  Time 3
The data management and analysis

Person 1 Time one  Time 2  Time 3

Person 2 time1  Time 2  Time 3

Person 2 time 1  Time 2  Time 3
## ENCAM visual representations

<table>
<thead>
<tr>
<th>Baseline usual services:</th>
<th>Services received for months 2 to 9 → frequency of contact</th>
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<tbody>
<tr>
<td><strong>MONTH 1:</strong></td>
<td><strong>INTERVIEW</strong></td>
</tr>
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<td></td>
<td>**F:**INTERVIEW</td>
</tr>
<tr>
<td><strong>MONTH 2:</strong></td>
<td>**T:**INTERVIEW</td>
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<tr>
<td><strong>MONTH 3:</strong></td>
<td>**T:**INTERVIEW</td>
</tr>
<tr>
<td><strong>MONTH 4:</strong></td>
<td>**T:**INTERVIEW</td>
</tr>
<tr>
<td><strong>MONTH 5:</strong></td>
<td>**F:**INTERVIEW</td>
</tr>
<tr>
<td><strong>MONTH 6:</strong></td>
<td>**T:**INTERVIEW</td>
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<td><strong>MONTH 7:</strong></td>
<td>**T:**INTERVIEW</td>
</tr>
<tr>
<td><strong>MONTH 8:</strong></td>
<td>**T:**INTERVIEW</td>
</tr>
<tr>
<td><strong>MONTH 9:</strong></td>
<td>**F:**INTERVIEW</td>
</tr>
</tbody>
</table>

- **CM 2x month**
- **DN 4 x week**—dressings, BP., Lung function
- **GP weekly**
- **OP 3 monthly**
- **OP COPD 6 monthly**
- **OP geron 1x year**
- **OP VS 6 monthly**

### Exacerbations and falls

- Change in condition
- Referred to ophthalmologist – failing sight
- MD diagnosed
- Chest pain
- New ulcer
- Infected ulcer
- Ulcer eviscerated
- New ulcer

### Treatment/Referrals

- In hospital for observation
- Antibiotics
- Honey dressings
- Antibiotics

### Euroqol scores:

<table>
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<tr>
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<th>80</th>
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*Reproduced from Goodman et al. 2010 p 303*
Patient experience exemplars:

“I know I’m ill, and I know it isn’t going to go away. It’s the uncertainty I hate. The always wondering when my breathing will suddenly go, just like that and then I collapse or just can’t move. It’s awful, hard to explain, just awful”. Community Matron Patient 8T1

“So, I can’t walk at the moment. Who cares? I will and that’s what matters. I’m not going to let all of this stuff get me down, no way. I have escaped my old bad life now so I am going to do all I can to make this new life good, ****(expletive) the illnesses, why should they get in my way?” District Nurse Patient 29T1

Goodman et al 2010 p140
TOPIC Visual representations

Reproduced from Goodman et al 2012 p117
Alongside the illustrative exemplars:

‘The professionals actually communicate through me, not with one another, they do it through me because in my opinion the priority must be for the district nurses because of my leg... and I meet everyone around them (the district nurses) like the physiotherapists...they don’t know what’s going on with each professional, I tell them, if I didn’t tell them they wouldn’t know.’ 64A5T2

Reproduced from Goodman et al 2012 p 122
Research is craft work

- I’ve outlined some key considerations in designing and undertaking longitudinal qualitative research,
- I’ve illustrated the above with examples of my own work exploring nursing care in the community and the experience of those with long term conditions,
- I now invite you to share your experiences.

Thank you
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