

Narrative Analysis as a Methodology for Disability Research::

Experiences of Pregnancy

My PhD research explores the experiences of disabled women in Northamptonshire who have all gone through at least one pregnancy since 1999 when the DDA Pt III Goods & Services Act was initiated. The logistical decision to base my research in one county only is certainly due to my own needs and abilities as a disabled researcher, but also it is due to me wanting to make a difference at a local level. My research has four main aims

1. To understand women's experiences of statutory and voluntary services during their maternity period.
2. To understand how these women experienced attitudes from friends, family and professionals about them becoming a mother
3. To understand how all this affected the way the woman felt about herself as a disabled woman becoming a mother.
4. To position this as an innovative study my study also aims to understand whether disabled women's experiences of maternity have changed in the light of non-discriminatory legislation being passed.

My presentation today will look specifically at the methodology I have chosen rather than any findings as I want to show how my research is emancipatory.

For my research I wanted to implement a method that conforms to a disability studies approach. Mercer (2002) writes extensively on the paradigm shifts that have taken place over the last twenty years but there is still a big question mark over whether there is such a thing as emancipatory research; Shakespeare had “major reservations about the concept” (1997:251). He was not convinced there could be such a phenomenon; after all, do disabled people really get anything out of any research, either in the short or long term? Is the only person who really benefits from the research the academic who leads the study? Oliver showed that it is both necessary (1992) and although certainly not easy is possible, if research is seen more as a production than as an investigation (2002:14). It is this concept of research as a production that narrative analysis can support.

Stone & Priestly (1996) provide six key principles for emancipatory research practice. Briefly these are

1. Choosing an epistemology that conforms to the social model
2. Surrendering objectivity
3. Ensuring research is relevant to disabled people’s lives
4. Reversing social relations of research production
5. Personalizing the political and politicizing the personal
6. Allowing for plurality of methods.

In order to ensure that my research does conform to an emancipatory disability studies approach I have drawn up my own framework based on these principles.

Framework for emancipatory research

1. Control I agree with Oliver that disabled people should be in control of all aspects of their lives. Research should not therefore be a “rip off” (1997:15). Research should be an area where disabled people can become empowered through participating in saying what should be researched and how this could be done.
2. Challenge At every stage the research process should aim to challenge and provide tools for change in the face of oppressive practices and attitudes. The social model, which is used mainly in the UK, provides a basis on which to focus and position these challenges.
3. Equality As a qualitative researcher, and supporter of feminist works such as those by Oakley (1981), Finch (1981), Ribbens (1989) and more recently Morris (1996) and Froggett (2002) I agree that the research relationship is interpersonal and subjectively based. It is important that power relations are recognised and equalised as much as possible within the research process. This does not mean however that responsibility and accountability should be relinquished. Resolving the complex relations between accountability on one hand and equality on the other is an onerous task but one that must remain in the forefront of the researcher’s mind at all stages of the research process and particularly when involving vulnerable people.

4. Outcome Any social research should have an outcome for those who have taken part in the study. This may be profound and enlightening, or it may be subtler and slower to be realised, depending on the person and their situation. The method must allow for this development through reflection and questioning
5. Partnership There should be partnership with other agencies that will facilitate for an element of change for the better for the people of the future.

Placing this framework around the topic I have chosen led me to choose narrative analysis as a way to accomplish emancipatory research. Narrative analysis is a broad spectrum methodology and may be used in various forms; narratives may be spoken, written or visual and the study of people using these different forms will provide different insight into people's lives. For the purpose of my research I mainly use spoken narratives concerning the past experiences and events of disabled women through their transition through pregnancy. However I am aware that a person lives within a social and environmental space and this space may give visual clues to support a person's spoken narrative. This is one of the reasons why I preferred to meet participants in their home environment.

Polkinghorne(1995) discusses the concern that narratives may be seen to be invalid as scientific data as the concept of 'telling a story' might infer telling an untruth. However he goes on to say that building a collection of narratives

bounded by context, in this case the transition through pregnancy, provides a pool of stories that may be compared and tested on specific dimensions in order to provide empirical evidence. Importantly, each story will retain the uniqueness of each individual narrator. Polkinghorne also notes that narrative reasoning works by noticing the special differences and diversity of people's behaviour and that "stories memories retain the complexity of the situation in which action was undertaken and the emotional and motivational meaning connected with it" (1995:11).

I want to hear the rich and personal stories of the disabled women seated in their own homes and told in their own words. I want to hear the emotion and motivation connected to a very significant event in their lives. Narrative analysis can provide for this. For further support I turned to Mishler who offers a typology of narrative analysis that considers the 'work that stories do'(1995:107). For this study narrative works by requesting recapitulation of the personal experience of each participant's transition through pregnancy in relation to be being disabled, and concerned with everything that accompanies those experiences within their social world. Within the interview situation narrative works by providing a basis for me on which to interpret, question and return those experiences to the narrator for reflection. This co-constructed conversation allows opportunity for learning and will, I argue, be emancipatory.

But aren't individual stories too individualistic, I hear you ask? Where is the social model in all this? Where is the identification of barriers? Jenny Morris (1992:164) argues that the personal is political, and calls for the inclusion of individual's experiences of impairment as well as disability to be included in research methods. We know the social model is based on the premise of a collective, but one might argue that a group is made up of individuals. That iterative sociological question becomes apparent; do we as individuals learn from the social, or as social groups do we learn from individuals? Certainly the process of learning is not static and is very inter-dependant. I argue that using narrative analysis within certain research contexts can unite the personal and the political and if adequately and sensitively supported can lead to emancipation or freedom from oppression.

In order to show that narrative can be an emancipatory method I will show how my study fits the framework I have drawn up.

1. Control: At the planning stage my research was tested with disabled people who commented and advised on my proposal before it was carried out. Narrative as an interaction is non-intimidating and could be easily understood by the disabled people I worked with in the early stages. The prospect of telling your story. Participants are offered the opportunity to

comment on the interview and the interpretations I have made from our conversation, both within the interview and afterwards.

2. Challenge: At the beginning of the interview I asked the women to tell me about themselves. I found that identifying their narratives of identity gives me a basis on which to interpret their individual experiences. As the conversation progressed I probe with questions that seek to challenge apparent oppressive practice. Using shared conversation gives the opportunity to understand other ways of understanding experiences. For example, one participant whom I shall call Rose, told me that her community midwife and health visitor were both 'brilliant', which on the face of it seems acceptable. Certainly they provided for Rose's needs as a pregnant woman and new mum and treated her, as Rose said, 'normally'. Further questioning however revealed that Rose was not offered information about Disabled Parent's Network, Disability, Pregnancy and Parenthood *International*, or any other support network that might help her as a disabled mum. Consequently she was unable to recognise her specific needs or meet with other disabled mums. This knowledge can be taken forward to be later shared with partners as an issue for action.

3. Equality: Narrative can be egalitarian in that shifts of control can be allowed to happen as a natural occurrence within the conversation. In my study

some participants took control by asking me questions about disability and my own experiences and understanding. As I want equality of power and I believe in give and take in a conversation I respond openly and honestly to any question posed to me. I will give you an example

Extract 1

404. J do you see yourself as a disabled person?

405. R No, that's the other difficulty I have. I think of myself as someone with an illness. You know I've got an illness because you know I can walk but sometimes when I am feeling weak I have problems walking () I drag my leg and have to hold onto things but still I don't say I'm disabled

406. J no

407. R I find it hard cos like you say, it's not something you can see. () I do find that difficult. But when I was in a wheelchair that was different because people could see there was a problem but that was even worse then cos I just felt really degraded in a wheelchair

408. J mmm

409. R It was horrible () did you feel like that?

Within a social model context Rose was identified as a 'tragic dependent' person, not as a socially oppressed person however the research relationship was equal enough for her to seek validity of her experience from me. In line with my previous point of 'challenge' I am able to answer by relating in simple terms about the social model and the difference between it and the individual

model. I explain how I had learned about alternative ways of seeing disability through my own experiences as well as through study. We learn from one another through our narratives.

4. Outcome: From the perspective of providing an effect for the participants narrative offers people the opportunity to talk about their experiences. Many participants told me that just talking through their experiences was in a sense, cathartic. Although not meant as a therapeutic exercise *per se*, through engaging in a co-constructed conversation the women were encouraged to reflect and recall experiences that would enable themselves to see a topic differently if they so wished. In support of this I offer Lieblich et al (1998), who declare individuals know or discover themselves, and reveal themselves, by the stories they tell. Also, Polkinghorne (1988) proposes that a person identifies with the self through reflection on the content and meanings of one's own stories and the way that those stories are told. So a narrative method can permit personal development and understanding of oneself.

I can demonstrate this through a second extract from Rose who provides me with her own example of how she implicitly identifies with the social model and provides for herself through her narrative a basis on which to understand oppression.

Transcript 2

5. R ...as I say after a while Independent Choices got involved and I cant remember how they got involved but it just turned my life around - that I could choose () you know() who came and worked for me and what they did

6. J yeah

7. R and it is, I don't know if you know how it works but someone is there who would do what you would do if you hadn't got MS. And I think that is just brilliant it made just everything

8. J yeah

9. R So much better

21. R yeah you're right I mean the girl who works for me now erm well I say works with me

22. J mmm

23. R erm you know is absolutely () She does things with not for

24. J mmm It makes a difference to how it makes you feel about yourself

25. R oh yes, it does make a difference.

By returning this narrative to Rose and facilitating her reflection on the context following our conversation about the different ways of viewing disability Rose can see how the social model as a concept can alter her perspective and change her perception of her experiences.

5. Partnerships: Although not unique to the narrative method the production of the narratives must, as Oliver said, have an outcome for the future. To facilitate this I built partnerships by working with Health Visitors, Care managers and local disability organisations by meeting with them, talking about my project and asking them for referrals. I also offered them a report at the end of the research. I found from talking to some of the service providers, particularly health visitors who have a duty of care to all children under five and their mothers, that awareness exists of disabled women not being supported adequately in their transition through pregnancy. Therefore I hope my research can be used to inform local policy. I realise it is important to highlight areas of good practice and offer praise as well as criticism in any report. Any criticism I do need to make will be supported with recommendations for change.

Conclusion

This paper set out to show how narrative can be an emancipatory method of research. I have shown how I formulated an emancipatory framework based on

previously publishes work and how I have used this framework to support narrative analysis as a suitable methodology for the topic of researching the experiences of disabled pregnant women. Through this presentation I have shown how the production of the interactive discourse that elicits narratives provides a basis on which to extend thinking and talking by both parties, and later by others. Individual participants have had the opportunity to re-live and share their experiences and through this become aware of alternative discourses of disability. Through collaboration with the partnerships I have made during the research process consideration can then be made as to how services can be improved to make the transition through pregnancy smoother and more inclusive for everyone. For this study I stand by my claim that narrative is an emancipatory research method.

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