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Good Days and Bad Days:
A Grounded Theory study of Disabled Women's Sexuality

A thesis submitted in partial fulfilment of requirements for the degree of Master of Arts in Nursing at Massey University, Albany, New Zealand.

Susan Mary Sherrard
2000
Abstract

Disabled women have been considered asexual for too long. Disabled women have experienced prejudice and oppression as a result of living within a social environment that expects its members to conform to a socially defined normality. Historically, disabled people have been considered the tragic victims. This has been acknowledged as the ‘medical model’ approach to disability. That is, that an individual is disabled, and it is the responsibility of the health professionals to cure or care for them. By contrast, disabled people have developed the ‘social model’ of disability. This model recognises that society disables people with impairments by excluding them. Barriers to inclusion are both environmental and attitudinal. Nurses and other health professionals have been educated in the medical model of understanding disability. The results have been that disabled women have not been treated appropriately.

The aim of this thesis was to uncover how disabled women understand and experience their sexuality. As a disabled researcher, I am in a unique position to undertake this study. Very little has been researched about disabled women by disabled women. We have tended to be studied by nondisabled health professionals. This study includes information provided by nine disabled women, literature written by disabled women, and resources from a broad academic perspective.

The methodology used to guide this research is grounded theory as described by Glaser (1992). The process included semi-structured interviews, which were transcribed and then coded. The constant comparison method was used to discover six categories. By using the comparison method, the basic social process emerged from the data. The basic social process or pattern of behaviour was called good days and bad days. Simply, disabled women feel more sexual on good days as compared to bad days.

Society and nurses have an impact on disabled women’s experience of having good or bad days. If nurses are to make a positive contribution they need to understand disability from a social model perspective so that they can work with disabled women in partnerships. Change is needed in society to value us. Disabled women need to speak out and support each other in promoting social change. Disabled women are sexual beings and we can be proud to be all that we are.
Acknowledgements

There are a number of people I would like to acknowledge and thank for their assistance in producing this thesis. Without their contributions, help, guidance, support and love this study would not have been possible.

The participants of this study shared with me their very personal and private stories. I am in awe of their generosity and willingness to contribute. They trusted me with their stories and I am forever in their debt. I have presented their contributions accurately, and in their own words. I hope I have done justice to their generosity.

There were a number of individuals who I wish to acknowledge:

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I also want to acknowledge my disabled friends and colleagues. You have supported and encouraged my development as a disabled woman. You have welcomed me into your community and challenged me to take pride in who I am. I am now able to say that I am proud to be disabled.

Finally, I wish to acknowledge those in the disabled community who have struggled against oppression and fought for the civil rights of disabled people. They were the consciousness raisers and without their efforts, I would not have been in the privileged position to complete this research. The challenge continues for us to fight for the emancipation of disabled people.

This research was approved by two ethics committees: Massey Human Ethics Committee and the North Health Ethics Committee.
A Poem

In My Disabled Women’s Group

In my disabled women’s group
The facilitator asked me
“What goals do you have
For yourself in the next five months?”
I felt the panic rise in me
Thinking of the days
Without a job
The weeks without the money
Or the energy
To move my furniture
From the garage where it is stored
Six hundred miles away.
How many times will my stomach hurt
In the next five months?
How many times will I throw up?
How many times will I go to the welfare office?
In the last three weeks
I’ve been seven times, and still no check.
I remember articles I’ve read on time management.
How you plot out goals
For the next ten years
Then one year
Then six months
One month
This week
Then you figure out
What you’re going to do that day
And how it relates to the master plan.
I realize her question is quite reasonable
It’s what other people do.
I don’t live that way, anymore
I divide the days into smaller sections-
A whole day is just too much pain
Too much responsibility to get through.
It started in the hospital
When I got morphine every three hours.
I’d watch the clock: the shot took 45 minutes to take effect
Then I slept for an hour and a half
The 45 minutes till I could have another.
It’s the way I passed the days.
Now I divide it up with vitamins
I tell myself if I’m still awake at midnight
I’ll take another C; calcium if I haven’t got to sleep by 1:00.
I write down the things I have to do
On a good day I'll have checked off almost half the list.
Five months from now? Maybe if I'm lucky
I'll be living then
A whole day at a time.

We met in a small, gray institution office. This was the outpatient’s clinic, which didn’t make sense to me because I was still an in-patient at the time. He was an older man, probably only late forties, but I was twenty-one. To me, he was old. He was also one of my doctors, a specialist and I had only met him once before. He seemed to be quite a big man, with dark hair going gray at the temples. This was the man who knew all about bladders and bladder functioning. I needed his expertise.

I had been in the unit for about four months. By this stage I was beginning to get used to sitting in a wheelchair. I wore the uniform of a rehabilitation patient of t-shirt and track-pants. The nursing staff seemed to take pleasure in dressing me in socks that matched my t-shirt. I had become institutionalised.

Authority figures scared me. Even though I was a registered nurse I felt helpless and totally vulnerable when meeting with doctors. My fear had come from my experience of not being respected and also I had picked up the fear nursing staff seemed to have of doctors. I remember being told, “Oh, he’ll never let you do that.”

I don’t remember a lot about the meeting. But somehow right at the end I summoned enough courage to ask the doctor a question I had been thinking about for a long time. “Can I still have children?” The response from this highly qualified professional was, “Oh, I’ve got three kids already and they’re such a handful, you wouldn’t want any.”

I was totally devastated. The truth was that I did want to have children. I always had, and having my accident hadn’t changed that desire. What I didn’t know was if my accident had changed my ability to.

My question was also a way of asking if I could still be sexual. I was too embarrassed to ask that one. And it was not something talked about in the unit. I was one of the few women on a predominantly male ward. There were always lots of jokes and innuendo about male sexuality. But female sexuality didn’t seem to exist.

Thirteen years later, I am very aware that disabled women are sexual and do have children. As a group, we seem to know a lot about this subject and health professionals still don’t know much. My aim is that this thesis will encourage disabled women to talk more about their sexuality and that health professionals will listen and learn from us, the experts.
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