Mothers with Intellectual Disabilities from Cultural Communities

A Narrative Study

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Aim: Research on parents with intellectual disabilities has focused on parents from majority cultures with limited attention given to the influence of gender and culture. There are few studies that explore the intersections of these dynamic social locations. The aim of this doctoral study is to explore the intersections of motherhood, intellectual disability and culture embedded within the life stories of eight women with intellectual disabilities.

Method: This is a narrative study underpinned by intersectionality theory. The data were gathered through multiple in-depth interviews and participant observation within a two-phase study.

Results: Preliminary findings from the first phase of my doctoral research will be presented. Four over-reaching and intersecting themes emerged: the social consequences of being a mother with an intellectual disability, keeping face within a cultural community, negotiating power relations and reclaiming motherhood. The narratives of these women illustrate the competing messages they receive from their social and cultural milieu about being a 'good' mother. It also illustrates how these women tried to find a place for themselves as they struggled, challenged, conformed and resisted dominant forces.

Conclusions: Preliminary data provides a holistic understanding of the experiences of women who are living between borderlands, as mothers with intellectual disabilities within different cultural communities.

Outline

- Research-knowledge Gap

- Intersectionality Theory

- Narrative Inquiry

- My research

- Concluding thoughts

Research-Knowledge Gap
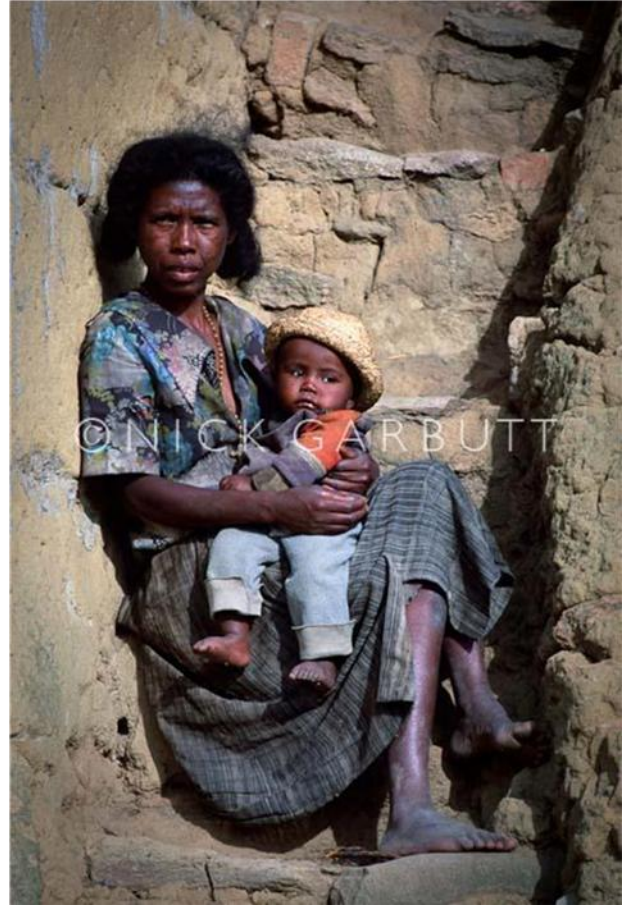
- De-gendered stance within the field of parents with ID
  (Johnson & Traustadottir, 2000)

- Lack of exploration of culture within the field of parents with ID
  (IASSID, 2008)

- Lack of exploration of intersecting identities
  (Bjornsdottir& Traustadottir, 2006)

- Lack of integration of intellectual disability in feminist research
  (Johnson & Traustadottir, 2000)

The three decades of research on parents with intellectual disability has usually focus on majority culture parents with little emphasis on gender and culture. There is also a lack of exploration of intersecting identities, especially the integration of intellectual disability within feminist disability studies.

Intersectionality Theory

Intersectionality theory arose out of the need of a theory that would provide further understanding of intersecting identities and interconnected levels of oppression and agency. Kimberly-Crenshaw coined by feminist jurist in 1991. Before this time The additive approach misses 'the social relational connections' of intersecting identities and how they influence each other (Traustadottir, 2006). Rather than examining various social locations (such as gender, ethnicity and disability) as distinctive hierarchies, **intersectionality theory, examines how they depend and mutually construct one another** (Collins, 1990 ; Crenshaw, 1991 ; Razack, 1998). The following example clarifies this point,

These three pictures visually represent the three most important tenets of intersectionality theory.

The first is a picture of a puzzle, this to me represents that interconnections of identities and levels of oppression that persons with intersecting social locations face. If you take

away a piece of the puzzle, you will not be able to understand their experience. **For example, in my study the women described how when they did not adhere to social and culture ideals i.e. behaving differently that they were consequences. That experience can only be understood as from a mother with an intellectual disability from an ethno-cultural community.**

The chameleon picture symbolizes **fluidity of identity**, in that one part of their identity might be more apparent than others, for example the women described that when they gave birth they were seen as competent and their disability was muted temporarily.

This bottom picture refers to **agency**. Intersectionality theory explores oppression but also assumes that persons entrenched in interconnected levels of oppression can exercise agency, as was demonstrated in the narratives of the women in my study : Standing up for themselves, rejecting labels, creating their own narratives.

Narrative Inquiry

- Research about stories/narratives
  (Clandinin & Connelly, 1994)

- Narratives provide links, connections, coherence, meaning and sense of people's stories
  (Polkinhorne, 1995)

- Personal, individual and or intersecting human experiences within a social and cultural context
  (Booth & Booth, 1994)

- "Listening to those who know" – expert witnesses in their lives
  (Bruner, 1994)

The purpose of narrative research is to further examine meaning within the stories people tell as it provides a sense of who they are and how they act and react within their social world. One strength of this approach is that it can reveal the historical dynamic behind human experience (Maynes, Pierce & Laslett, 2008). Another is that it fosters a more holistic understanding by revealing the influence of intersecting identities (gender, race and disability) (Maynes, Pierce & Laslett, 2008). A third strength is that **it restores the emotional content of human experience often suppressed by objective methods of reporting (Booth, 1995).**

- It's purpose is not generalization but 'transferability'

- Students in my rehab med course had difficulty wrapping their head around the concept of truth within my research study, they did not understand ...

Stories are in constant revision, researchers are not looking for fixed truth, on only the 'shifting web of meanings'

Research Description

Research Question: What is it like to be a mother with an intellectual disability from a cultural community?

GOALS:
- Explore intersecting identities ; motherhood, culture and intellectual disability

- Explore everyday experiences within broader socio-cultural context
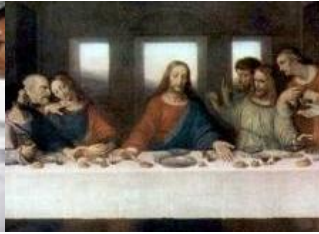
- Explore oppression and agency
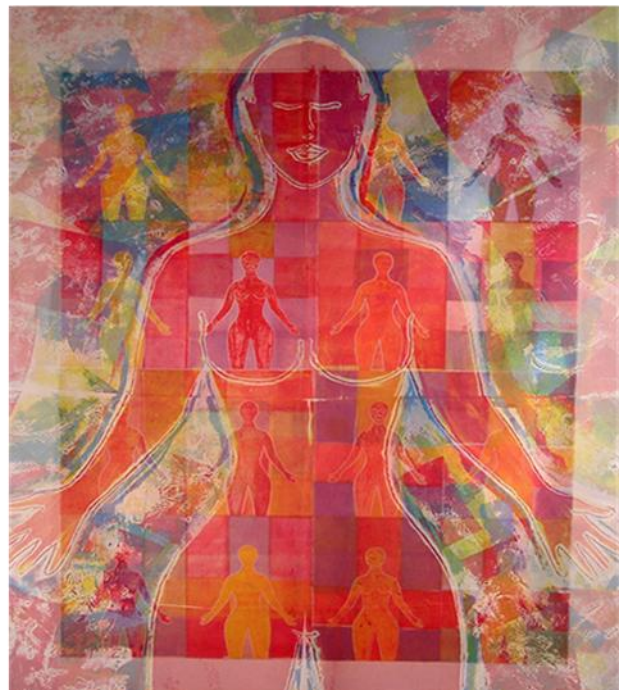
Introducing the Moms

Harah

Selia 12, Hazar 9
Indian

Maria

Mary 21, Manuel 20
Portuguese

Shirley

Monica 21, James 15
Polish

Pria

Sunjaya 3
Guyanese

Mary

Lisa 13, Maya 10, Pat 6
Native American

Sheira

Moon 13
Native American

Dung

Ralph 23, Daniel 21, Jordan 15
Chinese

Sheri

Tyrone, 2
Trini Indian

These are the 8 moms that allowed me in their lives, where I interviewed and spent time with for approximately two years. The pictures that are included represent some of the images and symbols that were in the mothers homes, or represent a part of their lives, and or identity.

- 🟡 Purposive Sample: 8 moms in total, 3 in phase 1 and 5 in phase 2

As you can see, different cultures are included within my sample, I did not include one culture as I am exploring the intersections of motherhood, intellectual disability and culture.

"Culture is… the whole complex of distinctive spiritual, material, intellectual and emotional features that characterize a society or a social group. It includes not only arts and letters, but also modes of life, the fundamental rights of the human being, value systems, traditions and beliefs."

World Conference on Cultural Policies 1982

Culture can oppress or liberate, empower and or disempower (Collins, 1986)

Research Description

Sample
- Purposive sampling
- 8 mothers with intellectual disabilities from cultural communities
- Recruitment: Readaptation center & specialized community organization

Data Collection
- In-depth interviews (3-7)
- 33 interviews in total
- Aide Memoire, pictures, visual prompts, observations

Data Analysis
- Systemic thematic analysis
- Mother's voice: storylines interweave and intersect
- Narrative Threads
- Member checking

I used narrative inquiry to guide my interviews and data analysis. Analyzing narratives is labor-and-time-intensive (Gilbert, 2002, p.233). Plumer (1983, p.99) describes the process as "brooding and reflecting upon mounds of data for long periods of time until it makes sense…" In line with Booth & Booth's (1994) research, I used 'systematic thematic analysis' of the data (Riessman, 1993), which happened into two phases. The first phase of data analysis was paying attention to the mother's voice, this is referred to the participant's storyline; where 'critical incidents' or 'cross-roads' within the narrative. This is where I highlighted the story lines that interweaved and intersected within each of the mother's stories. This is consistent with the techniques used by the pioneers in narrative inquiry Clandinin & Connelly (2000). Within the second phase, the mothers' voice was sought, referring to 'generic elements or commonalities that bind their accounts together as stories" (Booth & Booth, 2006, p.95). This is where patterns, themes and 'narrative threads' were sought across the different narratives to create composite narratives. Once a

summarized or chronicled account of the narratives has been established, verifying the interpretations of the life stories was done with each participant.

Before I begin this section, I wanted to read a quote of a mother from my study that draws our attention to what it is like to be a mother, women with an intellectual disability from a cultural community.

They used to say to me, you are not a good mother, you have a mental handicap and had the children replaced (placed in foster home) Now I am abandoned. Abandoned from my family and my Portuguese culture" (Maria, It6, pg.6)

Now I want to take some time to discuss some of the pre-liminary themes that came out of my first phase of my study.

These three themes are: being a mother with an intellectual disability, keeping face with cultural community and negotiating power relations. These three themes are inter-related, and can only be understood from a wholestic perspective.

Theme 1

Being a mother with an intellectual disability

- What it means to be a woman with an intellectual disability	- Challenging the good mother discourse	-Being trapped in the child welfare quicksand

The mothers within this study described their experiences as women and mothers within maintream society and within their cultural community.

All of the mothers identified as having a disability in one way or another and the powerful messages they received from society. Most of them chose their own words to describe themselves and refuted negative labels.

"I have a disability sometimes and sometimes no. I cannot think about what I should do, how to deal with my children. But no I am not disability because I can cut hair, I can cook, I can drive and I love my family" (M6, I1)

All of the moms spoke about their experience with child welfare and how they felt they were inadequate as mothers based on the negative messages they received from informal and formal support systems.

One mom describes her experience as follows:

" I was just, humiliated. I felt small. I felt unimportant. I did not think I was good and I would think, I can walk, I can talk, I move forward and backward, why are they looking at me so differently? But they had in for people like me." (m6, It2).

Theme 2

Keeping face within cultural community

The influence of culture	Confronting cultural ideals	Consequences of socially failing

The mothers in my study spoke about socially expected ways of being within their culture. All the mothers spoke about "passing" as a good mother within a cultural context and the negative consequences of not achieving cultural standards. Being a mother and wife most valuable social role that they all socialized and strived to be.

'In my culture. Yeah, that's what the women do. They get married and they have the children. If you don't have babies then you always live at the home with your parents. Very important thing I knew I wanted to have kids' (M1, IT 1, p. 3).

Though this woman spoke about the influence of their culture and family and the importance this had in their lives, they also confronted these ideals and questioned certain practices.

'So my family was not happy about it about me leaving him because they said that marriage is like until death do you part you know what I mean, the Portuguese way. Yeah, but I couldn't handle it no more, too much stress and he didn't behave the way he was supposed to behave" (IT 4, pg. 1 line 10).

When they did not meet cultural benchmarks, these moms described receiving negative messages, isolated within particular periods and being abandoned

"My family they don't think that I am disability, they think that not smart, that I am stupid. My family thinks I am stupid, pause, but that's ok. My family thinks that I am stupid, pause, but that's ok. My family thinks that I am stupid, but that's not ok". (M6, It 1)

Theme 3

Negotiating Power Relations

- Oppression	- Exercising agency	- Reclaiming motherhood

The narratives of these women described how they negotiated power relations, how in the face of oppression (rape, abuse, discrimination) they exercised agency by resisting labels, speaking up for themselves, questioning practices, creating own identity; reclaiming motherhood.

Motherhood was described as their most important role, regardless if their children were permanently placed. This is exemplified in the following quote:

"People asks me why I have this tattoo. It's for my girls. My girls that were taken away. The heart is how much I love them with their names. The feather is a part of our native

tradition. It is there because even though I will not see maybe even ever again, I can look at it and it reminds me of them and how much I love them" (M5 IT 1)

The women also described how mothering can be empowering and disempowering:

"I don't know how to explain it, but it was the best day of my life. The best day of my life. It was the best day that I ever had' (M2 IT 2 pg. 8 line 18).

"Children is very important in my culture. Without my children I am nothing. That the woman has nothing" (M1, IT 3, pg 4).

THANK-YOU

To the moms

Dr. David McConnell

NNDR

Research Team in the Family and Disability Studies Initiative , Faculty of Rehabilitative Medicine, University of Alberta

The Faculty of Graduate Studies and Research : The J Gordin Kaplin Graduate Students Award

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