MOTHERS WITH INTELLECTUAL DISABILITIES FROM CULTURAL COMMUNITIES

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Aim: The experiences of mothers with an intellectual disability have been examined in the literature, yet there has been limited exploration of the intersections of mothering, intellectual disability and culture. The aim of this doctoral study is to give attention to the life stories of mothers with intellectual disabilities from cultural communities, by exploring the intersections of these social locations.

Method: This is a narrative study underpinned by intersectionality theory. Thirty-three in depth-interviews and participant observations were conducted with eight mothers.

Results: Three over-reaching and intersecting themes emerged: the social consequences of being a mother with an intellectual disability, keeping face within a cultural community and negotiating power relations. The narratives of these women illustrate the social and culture expectations of being a “good mother” and the social consequences of not achieving this status. In face of oppression, these women illustrate ways in which they challenge and resist these socio-cultural ideals.

Conclusions: The findings of this study have implications for both research and practice as it illustrates the influence of culture on the experiences of mothers with intellectual disabilities.

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WHAT LED ME TO DO THIS RESEARCH

Social Work Experience

My first experience was with a young soon to be mother with an intellectual disability from Haiti. When I asked her how she felt, she told me that she always wanted to be a mother and that her family was there to support her with this role. Being a mother, she told me, was a highly valued role in her culture. When I spoke with my supervisor, at the community organization where I was doing my stage, she suggested that I speak to her about abortion.

What struck me and what has always stayed with me since this experience was the different and competing messages this woman was sent from her family, cultural community and mainstream society. I wanted to further understand and explore these messages and the impact on these women’s experiences.

Research Knowledge Gap

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.

In order to fill in this research knowledge gap, I wanted to begin with an insider’s perspective, by listening to those who know. I used the narrative approach as it allows for an in-depth exploration that is guided by the participants own pace. The narrative approach also allows participants to re-define dominant discourse by providing their own experience and definitions.

FIT BETWEEN THEORY AND METHOD

1) Interconnections of identities

It is beyond the scope of this presentation to delve deeply into my theory and method that underpin my research, but I wanted to illustrate how my theory and method go together in examining the life stories of women who are mothers that have an intellectual disability and come from an ethnocultural community.
Intersectionality theory, examines identity from a holistic perspective, like this image of interconnected hands, this represents to me the interconnections of identities and levels of oppression that persons with intersecting social locations face.

Narrative inquiry also explores identity from a holistic perspective and understands experience as the interweaving of the personal (everyday) and political (macro system).

II) Experience and voice

Both intersectionality theory and narrative inquiry draw our attention to voice, personal accounts and the emotional content of human experience.

III) Empowerment

This image refers to agency. Intersectionality theory and the narrative approach 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 based on how they wanted to be seen.
RESEARCH DESCRIPTION

**Aim:** To explore and document the life stories of mothers with intellectual disabilities from ethnocultural communities.

**Specific Objectives**
- Explore intersecting identities (motherhood, intellectual disability, culture)
- Explore every day experiences within broader socio-culture context
- Explore oppression and agency within narratives

THE MOTHERS

**Purposive Sampling**
- Eight mothers with ID
- Cultures: Indian, Portuguese, Native, Polish, Chinese, Guyanese
- Most women immigrated from country of origin 12 y.o+
- From Montreal and Calgary
- Recruited from RC and NGO
- Children: 2 to 21 years old

I had the privilege of interviewing and getting to know 8 mothers who all received services from a specialized organization, a readaptation center in Montreal or a community center in Calgary.

The mothers were from different cultural communities, but identified as belonging to their particular cultural community as the values and ideals held in their culture shaped their own ideas and interactions within their social world. I did not want to include one cultural community, as my exploration was not how one culture influences actions but on the intersections of motherhood, intellectual disability and culture.
DATA COLLECTION

- In-depth interviews (3-7) over one year period
- Mother’s home
- Total of 33 interviews
- Aide memoire, pictures, visual prompts, observations

Pictures were also used to open up the conversation with the mothers.

Each interview was unstructured and responsive (Mill, Mayes & McConnell, 2009). The focus of the first interview was to develop rapport and familiarity with the mother’s communication style. To open the ‘conversation’, each mother was invited to share her family photographs. Further, in advance of all additional interviews, I developed an ‘aide-memoire’ (Booth & Booth, 1994a, 1998), consisting of topics that were explored in the interview, including, for example, the mother’s own upbringing, (events surrounding) the birth of her child/ren, challenges and rewards of motherhood, childcare rituals/routines, the influence of culture on their parenting. This was successfully used in Booth and Booth’s (1994) study. This aide memoire served as a ‘prompt sheet’ rather than a structured plan: participants were invited/encouraged to tell their own story in their own way and at their own pace.

DATA ANALYSIS

I used narrative inquiry to guide my interviews and data analysis. 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 interwove 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.
Intersecting storylines of participants (as opposed to solely analyzing individual narratives) was also used in narrative studies (Booth & Booth, 1994, 2000; McDonald, Keys & Balcazar, 2007) in order to further understanding of experiences within a larger social framework. This allows us to see the personal as social (Clandinin & Connelly, 1994). In this study, the data is represented in narratives (ontological narratives) and is further analyzed by making links across the narratives (meta-narratives) that can be found in the discussion section. This also allows for a full analysis of intersecting identities and oppression within the matrix of domination.

**RESULTS**

- **Narratives of each woman**
  Ontological narratives (Somers, 1994)

- **Links across the narratives**
  Meta narratives (Somers, 1994)

- **We are Mothers**
  (Composite Poem)

Within my study, the results are represented in two ways:

1) In the narratives

2) Across the narratives

Eight narratives were created through a collaborative process, which integrates the mother’s voice, storylines that interweave and intersect. Each narrative is different, but there were common tensions and experiences that I will further describe in the next section.

Before we get to that, I wanted to share with you a poem that I wrote in collaboration with the themes inherent within the mother’s stories, which I shared with a few mothers who validated its meaning.
We are Mothers

A Poem

We are women who were born or grew up in a cultural community. We are Portuguese, Native, Indian, Polish and Chinese. We have gone through ups and downs in our lives. We have been taught that family and culture tell us who we are and how we should act. We have been called ‘stupid’, ‘lazy’ and ‘dumb’ by important people in our lives. We have been told what a good woman is and is not. We have tried to play the role of the ‘good girl’ that we were cast to play in. So that we can be ‘normal’; So we can fit it; And bring pride to our family. We have experienced what it is like to be different, To feel like we do not belong, Because of who we are. We have married and had children. This has brought us the most joy: Being a mother. We have had our ups and downs. We have battled abuse, rape, poverty, divorce, And had our children taken away. But we do not give up. We have not let other people’s words, ideas and actions define who we are. We question some of the values that have been enforced on us. We resist some of the actions that have been imposed on us. We have re-defined who we are, So that the world can see: We are women, from cultural communities, that sometimes have disabilities. But most of all, we are mothers. (Pacheco et al, 2011)
RESULTS: THREE THEMES

Now I want to take some time to discuss some of the preliminary themes that came out of my study.

These three themes are: ideas that shape identity, power relations that shape experiences and re-creating identity.

These three themes are inter-related, and can only be understood from a holistic perspective.

**IDEAS THAT SHAPE IDENTITY**

Within the narratives of these mothers, they described their experiences as being influenced by wider social constructs. They faced ideas about what are desirable and undesirable social locations. This was in regards to their intellectual disability, being a mother with an intellectual disability and being a woman and wife. These ideas about who they are come from society, cultural community, family and social milieu (school, neighborhood).

The stigma of having an intellectual disability and the impact on identity is described by Sheira:

“I think it’s kind of a taboo thing because somebody has done this to you and no one wants to talk about that! That they have done this to another human being. But I have to live with this shame. I have to live with the fact that the world looks at me differently” (IT 4, pg. 6).
Many of the mothers also spoke about how having a disability is seen within their cultural community.

“In my culture, people with the disability, they think they are sick. Or stupid. They don’t say they have a disability. They just use bad words like sick, dumb stupid. And in my country they hide them. They hide them in the home so no one knows. Because that make the family look bad. Or sick” (IT 3, pg. 9).

The mothers also discussed their culture as being important and the tensions that came from values that were taught and expected and their own desires and ideals. They also spoke about “passing as good women and mothers” and the social consequences.

**POWER RELATIONS THAT SHAPE EXPERIENCES**

The silent questioning of their religion and culture could go unnoticed. But once they were no longer ‘passing’ as ideal women within their cultural communities and within society as a whole, they were ‘socially failing’. Many of the mothers described ways in which they were deemed inadequate as a wife and mother within cultural and family standards. This ranged from negative messages, temporary ignorance from family and or shutting them out from the family all together.

The social consequences of not fitting cultural standards is described by Maria:

“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)

Many of the mothers also described their experience with poverty and their experience in losing a child to placement temporarily or permanently. Loss of their children was described from a systemic perspective where they identified stereotypes that they fought against and the emotional experience of losing a child.

Systemic issues is described by Sheira:

“And I don’t even know my baby and you think that I am going to hurt her. Why are you judging me? Why don’t you take her away if I do something to her?” (Sheira, IT 3, pg. 3)
Mary describes the deep seated pain associated with losing your children to adoption:

“I remembered the last few moments together. I gave them each a prayer angel, a big hug and told them that I loved them. I held my tears back. Especially when I heard Elizabeth yelling “mommy, no”. That was really hard “ (IT 3, pg. 2).

**RE-CREATING IDENTITY**

The mother’s narratives reveal the messages and actions that they have been exposed to and have experienced have often devalued and negatively impacted their personhood. Though these women encountered oppression, they are not as Barron (2007, p.60) states “passive recipients of social norms and values”. These women’s stories, illustrate, how they questioned, resisted and fought back socio-cultural expectations and standards.

Many mothers described having an intellectual disability but were able to choose their own words to describe themselves or only saw their disability as a small part of who they are. Some mothers used the labels that were enforced upon them to reclaim themselves.

Many of the mothers also described being a mother with a disability as being a positive as they were further able to understand their children with a disability and described their family as simply being different.

Being a mother was described as the most important thing to many of the mothers and it was no wonder that holding on to this role, no matter the circumstances, was expressed by these mothers.

“And I didn’t realize that my job wasn’t over, I can do a mothering job, not in the same house, but in a different way. So far it’s working. We even say that we like each other. Even that we love each other. I am just grateful that my daughter and I will be ok” (Sheira, IT 2, pg .11).

“Being a mother was always something that I wanted. Something that I dreamed about. No matter if I don’t see them every day; I am still Mary and Manuel’s mother. I am always their mother “ (Maria, IT 7, pg. 9).
SUMMARY

Like this painting, the narratives of the women in my study tell a story. The storylines and tensions within the narratives reveal many insights on the intersections of mothering, intellectual disability and culture such as the following:

- Tension between ideas that come from society, cultural community, family and their own ideas
- Struggle to belong to social worlds i.e. mainstream mothering, disability world, cultural community
- Caught within a world wind of acceptance and rejection
- Reconstructing identity based on their own definitions
PRACTICE AND RESEARCH INSIGHTS

1) Empowerment (personal & collective)
2) Increases understanding and knowledge
3) Shapes thinking on disability

The mothers described the different ideas and experiences they encountered as women with intellectual disabilities from ethnocultural communities. Many of the mothers described sharing and hearing their story as therapeutic in a sense. The sharing of their stories seemed to bring a renewed sense of self as they were increasing their awareness on how they came to be and who they wanted to be.

This research also surfaced important facets that can impact clinical practice and research. Let me begin with some reflections for clinical practice.

1) Using narratives within clinical practice to further understand their perspective to build clinical interventions instead of solely relying on reports from experts
2) Using narratives to increase understanding for family members, partners and anyone supporting the family as it reveals what is important to them
3) Using narratives as training tool to new professionals and students
4) Building practice strategies in supporting these families

Further, there are some implications for research. Narratives help us begin to understand a research-knowledge gap as the narrative approach allows the participants to take the lead within the research process. Many narrative threads have been explored but there are many that were under-developed within my research that could be further explored in future research:

1) The everyday experiences of mothering with an intellectual disability within a cultural community
2) The impact of culture on parenting styles and abilities
3) Families and social networks of mothers with intellectual disabilities from different cultural communities (role, function etc.)
4) Integrating cultural sensitivity within best practice of parents with intellectual disability

The narratives themselves and the narrative threads that run across also contribute to our thinking on disability and what it is to be human.
CONCLUDING THOUGHTS

I want to end this presentation with two quotes from Sheira and Sheri, two mothers in my study. I think it speaks to the importance of doing this type of research ...

“For me it’s really important that people are listening, that they can relate. That they can hear what it’s like. Like its kinda like I am giving them a gift, for them to understand what it’s like for people like me. I don’t want the whole world to look at people like me and hate me” (Sheira, IT 2, pg. 7).

“Nobody has been interested in what I has to say, no one has been interested in my story. I don’t only want to be judged by my past. I have changed a lot and things are different” (Sheri, It 3, pg.9).

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