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An examination of mothering occupations in the context of spinal cord injury

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Recommended Citation

Ghushchyan-Tigranyan, Gohar, "An examination of mothering occupations in the context of spinal cord injury" (2019). *OT Student Capstones*. 50.
<https://scholarworks.atsu.edu/ot-capstones/50>

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Introduction

For many women mothering is an important part of identity (Farber, 2004).

Difficulties related to mothering with a spinal cord injury include breastfeeding, bathing, dressing, cleaning and leisure participation (Holmgren et al., 2018; Kaiser, Reid, & Boschne, 2012; Reid, Angus, McKeever, & Miller, 2003; Wint, Smith, & Lezzoni, 2016).

Health care system is not sensitive enough to accommodate problems of non-medical nature. This leads to many women feeling invisible in the system (Llewellyn & McConnell, 2004).

The aim of this research was to identify mothers' descriptions of their lived experiences of mothering occupation. The objectives of this study were as following:

- To identify occupations that mothers are able to participate with their children
- To identify barriers that mothers experience with mothering occupation
- To identify the role and involvement of healthcare professionals in assisting mothers for successfully accomplishing mothering occupations.

Methods

- Mothers with spinal cord injury were defined as women who have biological or adopted children and who sustained a spinal injury, resulting in paralysis.
- Participants were recruited through word of mouth and personal networks.
- Each mother was interviewed twice approximately two weeks apart. Each interview lasted 60 to 90 minutes.
- Open-ended format was used for interview questionnaires to elicit stories around experiences.
- Study was analyzed using narrative analysis.
- Thematic theoretical analysis was used for coding themes.
- Constructionist paradigm was used to understand themes from socio-cultural perspective.

Participants

Participants	Level of Injury	Mother before/after SCI	Number of children	Age of children at the time of accident	Marital Status	Years with SCI
Grace	T1	Before	3	2, 4, 7	Divorced	7
Jen	C5/6	Before	3	1, 3, 6	Married	2
Anna	T11/12	After	3	0	Divorced	42

Theme	Examples
Loss of Occupation	Grace: This sucks. I want to be able to do that myself. They're asking for their mom, they're not asking for my dad or grandma or the babysitter. It was hard to see the babysitter doing the things that I should be doing.
	Jen: I've had to give up control , to allow other people to be a part of their life, and feel comfortable and not feel insecure that they're not all mine.
Support for Leisure Participation	Interviewer: What would you say was the most challenging part of motherhood from a wheelchair? Anna: Bob played football. The majority of those are on a grass field somewhere that might not be very accessible so I always felt a little bit watching from the sideline further away than the rest of the participants. Unless somebody was with me and pushed me through the grass.
	Interviewer: Would you not take them to playgrounds alone? Grace: Not alone. I'd have to have somebody there. But when they were first little, I have to say that was really tough because playgrounds, I can't help them down. If they're like, "Mommy, I need help." It's like I couldn't get there. I can't get over sand and I can't get over the chips.
Finding Independence	Grace: Bob would get sick at school and I can't just go and go pick them up. If they say, "He's sick and we need you to pick him up," the babysitter would have to go get him and I would be like, "That's my job." I started driving in October. To my family I'm like, " I'm going to take driving lessons. "
	Interviewer: Is there anything else that you feel like is a barrier? Jen: I would say driving. Interviewer: If you go out do you have someone with you? Jen: Most of the time yeah because I don't drive but I am starting to increase my time alone with them"
Therapy Services	Jen: The occupational therapy did what they needed to do to bring awareness to your daily living skills but your mindset is not there to really accept it.... So, we practiced cooking a lot and we practiced using adaptive equipment but I was too weak but now I'm ready to do that stuff. And so, it would be helpful if somebody came in and was like, "Oh this tool would work for that and that tool would work for that.
	Grace: OT was trying to do the transfers in the shower she would say, Oh my gosh, that was all you." And I knew it wasn't all me. I'm like, "Okay I'm gonna test that theory." So a second time I purposely didn't try to do it and to see what she would say and she's like, "That's all you." So that was it. To me I'm like, " You are just lying. You're trying to get progress notes to say I'm doing better.
	Grace: I think if they had more transition of home, not just how adaptable your home is. When you're thrown home, it's like, "Sorry. Peace out, you're on your own." Hopeful you have somebody that's gonna help you, but no caregiver, no mom, no dad, kids, no one knows what you go through. They don't know how to help. They feel helpless. There's nobody here for the transition from the home.

Population Needs as Described by Parents

- Psychological support after trauma needs to coincide with therapy treatment.
- Transitional care services are needed after discharge to support patients in adjustment of new lifestyle.
- Adaptive Aids that specifically support occupations of motherhood are needed.
- Mothers needed more assistance in locating and utilizing resources after discharge including home health services.
- Mothers expressed a greater desire for independence in fulfilling mothering occupations.
- Driving was a major area of need in fulfilling mothering occupations.

What can OT's Learn?

- Occupational therapists can support successful physical recovery by addressing the patient's mental well-being.
- It is essential to understand the patients' needs in order to provide help of non-medical nature. This includes troubleshooting how to adapt to mothering occupations from the wheelchair.
- It is important to support the patients beyond the hospital grounds by providing transitional care services. This includes home evaluations, home health, and driving for independence.
- There is further need for resources and education on life on wheels. "Knowledge leads to planning which leads to independence in childcare" (Kaiser, Reid, & Boschne, 2012).

Conclusion

The research demonstrated the importance of trauma informed care and the importance of meeting the patient at their psychological and physical level. Occupational therapists have a unique role as they work with patients in multiple settings. For successful recovery, it is critical to understand the patients' needs and to provide care beyond the hospital setting and beyond the medical model.

References

References available upon request.

ACKNOWLEDGEMENT

I would like to thank the participants in this study for sharing their lives with me..