CHRD 2022: Abstract & Poster Submission Form

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Presenter Status
- ○ Undergraduate Students
- ◉ Masters Student
- ○ PhD Student
- ○ Post-Doctoral Fellows
- ○ Residents
- ○ Non-Trainee

Research Category
- ○ Basic Science
- ◉ Clinical
- ○ Community Health / Policy

Role in the project
- ☑ Design
- ☐ Perform Experiments
- ☑ Analyze Data
- ☑ Write Abstract
- ☑ Deliver Survey; Conduct Interviews

Title
Exploring the experiences of family caregivers with low income accessing health care services for children with inborn errors of metabolism

Background

Inborn errors of metabolism (IEMs) affect up to 1 in 800 newborns and have been shown to impact the wellbeing of family caregivers, with more challenges experienced by families with lower income.

Objective

The main objective of this study was to explore the experiences of family caregivers with low income accessing care for their children with IEMs in Manitoba.

Methods

A quantitative survey was distributed to 98 family caregivers of children with IEMs who access care in Manitoba and twenty-five surveys were returned. Additionally, semi-structured individual interviews were conducted with eight survey respondents to further explore their experiences. Interviews were transcribed, and constructivist grounded theory was applied to develop a theory to explain the process of family caregiving for a child with an IEM.

Results

Qualitative analysis revealed that participants found caregiving to be overwhelming and consuming, especially throughout the first year following their child's positive newborn screen and diagnosis. Participants also felt they were lacking psychosocial support as well as assistance with navigating financial resources. We present a theoretical model that illustrates the process of family caregiving for a child with an IEM, highlighting five main aspects: (1) Receiving a positive newborn screen and clinical diagnosis, (2) "Getting through that first year" following diagnosis, (3) Factors that cause difficulties for family caregivers, (4) Factors that facilitate family caregiving for children with IEMs, and (5) Adapting to family caregiving for children with IEMs.

Conclusion

This research reveals the unmet needs of family caregivers of children with IEMs in Manitoba, especially in the psychosocial and financial domains. Based on these results, we present five recommendations to improve access to care for children with IEMs in Manitoba. These study findings will enable genetic counsellors and other health care providers to advocate for equitable access to metabolic care in Manitoba and beyond.

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Authors

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