



Exploring what motivates parents of children living with medical complexity to participate in research studies: An Interpretive Phenomenology study

PRESENTER: Laesa Kim

BACKGROUND

Family-centered and a patient-oriented focus to research requires health care professionals to appreciate how families understand and experience their role and participation in their child's health care and the potential of health care research to optimize their child's care. **This qualitative study aims to understand the experience and identify the motivations for parents participating in research that indirectly or directly affects their child.**

 Moving beyond a standard feedback form, simply "positive" or "negative".

 Towards hearing the nuances in each person's experience.

METHOD

We engaged 12 parents of children with medical complexities, from a previous study: Pain & Irritability of Unknown Origin

12 semi-structured interviews were conducted and transcribed by a parent peer research member

a collaborative interpretive phenomenology methodology was used to analyze the parents' responses

RESULTS

Parents' descriptions about the reasons they participated in research studies with and about their child fell within four themes:

- 1 FEELING HELPLESSNESS & HOPEFULNESS
- 2 CHILD-CENTERED MOTIVATION
- 3 BEING PART OF SOMETHING GOOD
- 4 EXPERIENCING RELATIONSHIP WITH THE RESEARCH TEAM

Parents also described the factors that detracted from their ability or desire to participate: Time required, Personal capacity, & The level of invasiveness for their child.

REFLECTIONS BY PARENTS EMPHASIZED THEIR UNIQUE LIVES IN CARING FOR THEIR MEDICALLY COMPLEX CHILDREN AND THE NEED TO INTEGRATE THEIR LIVED EXPERIENCE WITH THE RESEARCH THEY ENGAGE IN.

CONCLUSION

This research demonstrates that parents who are already entrenched in high demand care for their child with medically complex conditions and their families often sacrifice their time and energy on behalf of contributing to better outcomes for their child and others. Further, when asked, they bring rich and meaningful data to the research being conducted. **Recognizing families' motivation** for research participation can help researchers **enrich their engagement** and create **more meaningful experiences** for themselves and their participants.

"I understood that it was something that was dealing with children like mine and was just so excited that somebody was finally saying, hey, there's something we might be able to do."

"She saw him, as a whole person. From his being... That moved me."



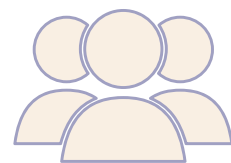
"It's nice to feel like we can do something to help."

"This study gave us like a celebration of humanity that we were needing."

"To have a different lens of how our child was struggling meant the world to us. Regardless of the outcome."

REFLECTION

The study lead on this project is a parent partner embedded within our research team. Her lived experience as a parent to a medically complex child adds a shared context and lends to creating meaningful and open conversations with our parent participants.



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