

Motivations Study

Exploring the experience of participating in a Patient Oriented Research Study

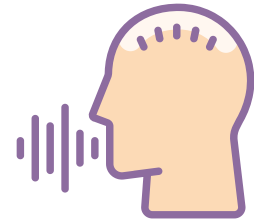
PRESENTER: Laesa Kim

Intro:

Pulled from our experience of recruiting children with medical complexity for research studies, the "Motivations Study" will help us understand the complex barriers to research participation for parents of a child with a serious illness. In this qualitative research study, we are asking parents important questions about what research means to them and why or why not they have chosen to participate in it.



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



Towards hearing the nuances which make up each person's experience.

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 conversations with our parent participants.

Aim:

- Understand what motivates families to participate in research
- Describe common elements of their experience
- Evaluate Patient Oriented Research (POR) strategies

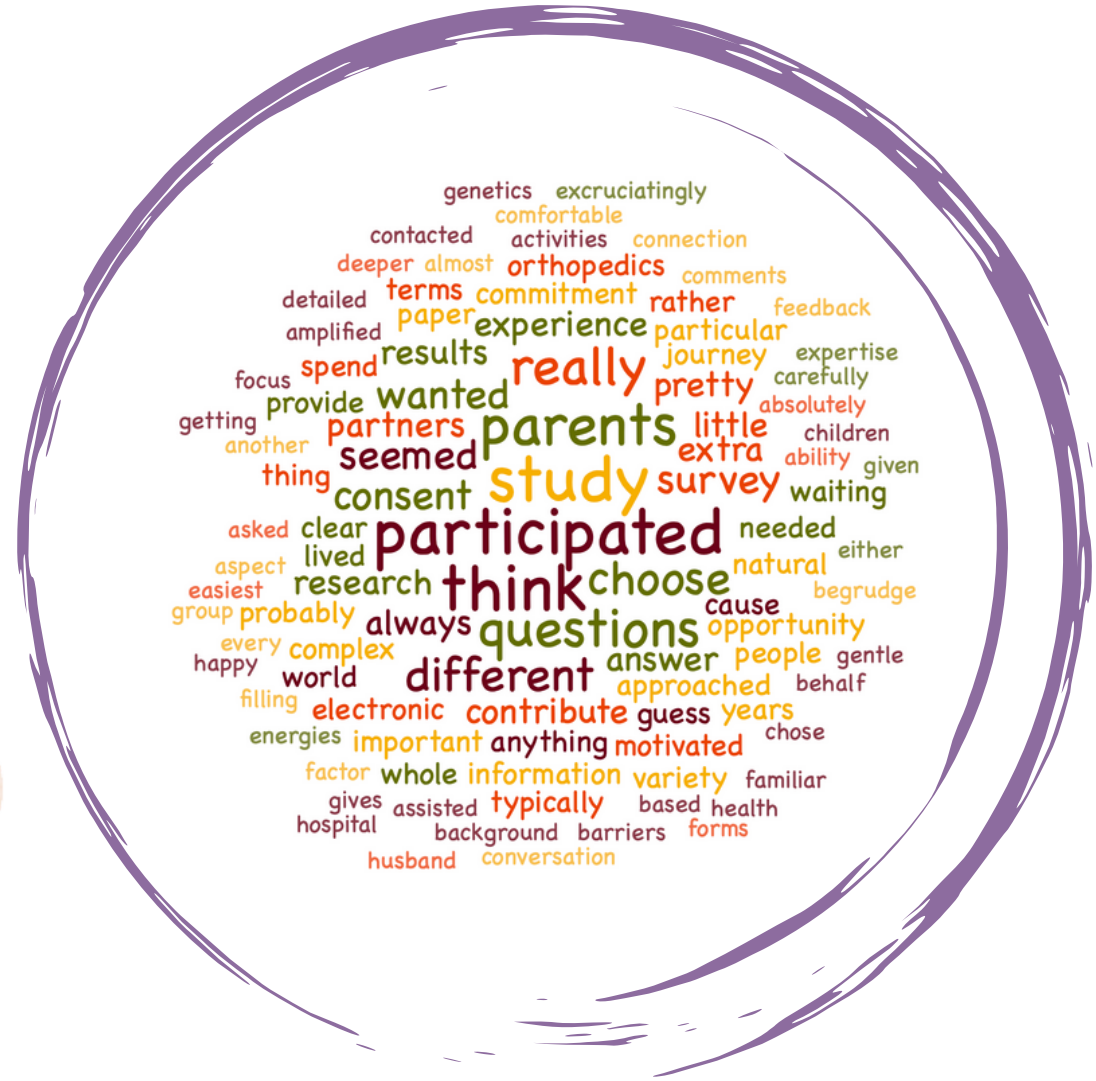
Process:

- use a parent-partner in the collection & co-analysis of data
- conduct 15 semi-structured interviews
- gather a rich collection of stories
- collect data using qualitative research methods



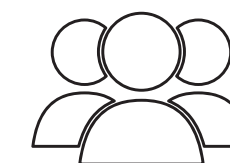
What are the motivators and barriers to research participation?

tell me about your experience...



Understand:

- Use Interpretive Phenomenological Analysis to describe and interpret participants lived experiences in research.
- Follow an iterative process while gathering and analyzing data.
- Allow interviewees to reflect and comment on the transcripts of their interviews.
- Form recommendations for future Patient Oriented Research studies.



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