DETERMINING THE BENEFITS AND DRAWBACKS OF PARENTS USING PERSONAL AND SOCIAL NETWORKS FOR RECRUITMENT IN RESEARCH PROJECTS: A QUALITATIVE STUDY

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INTRODUCTION

Patient-Oriented Research refers to the meaningful and authentic involvement of patients, parents/caregivers, and community members in the research process to improve research relevance and impact. Patient-partners often support research by sharing recruitment materials through their personal and social networks. Understanding the perspectives of parent research partners regarding the use of their personal networks for recruitment can help to inform best practice recommendations.

METHODS

A qualitative descriptive study was performed of Canadian parents with children with additional medical needs who have participated in research partnership. The participants were recruited through research network communications or social media. Parent participants completed an online survey that assessed a) their family's demographics, b) their experience as a parent-partner, and c) their child's diagnosis. Participants then took part in a semi-structured interview or focus group. The interviews and focus groups were audio-recorded and transcribed verbatim then analyzed via thematic coding. Interrelated themes were then further developed from the codes to encapuslate the data.

RESULTS

Three themes were identified in this preliminary data, related to the study objective:

Survey findings

All 12 participants were female caregivers who had partnered on a range between 1 to over 10 projects across a span of 2 to 21 years. 3 focus groups and 3 interviews have been conducted to date, ranging from being 20 to 90 minutes long. The most common roles that the participants had when partnering were a) defining the project idea, b) actively recruiting participants, and c) developing recruitment methods.

What will I endorse?

"...I'm pickier about who I partner with because initially I was involved in some projects where I didn't feel great about them. Where I didn't feel like our partnership was authentic, I didn't feel like my contributions were being respected."

Sharing recruitment information can be viewed as endorsing a study or research team, therefore many parents described how they made decisions on what projects to partner on based on the team and study. Parents also described both broad and specific approaches when choosing what to share, as well as feeling the expectation to share.

How will I share?

"...Like the parent groups and stuff, that's like my professional medical parent face... and then there's like the falling apart mom who's like posting quotes on her facebook thing like it's just that there's a line there, I guess."

Many parents reported designating specific social media platforms for "personal" versus "professional" use (e.g. using Facebook for research-related topics, but Instagram for non-research related topics). These designations affected what they were comfortable sharing in each space.

Whose story is it?

"...it's our story, it's their story and it's my story, and at what point, where are those lines? Right? Particularly as mine are now young adults, right? So it's not my story anymore."

Decisions regarding what personal information to share in a research context are complex and evolve over time. Several parents conveyed concerns over sharing their children's stories and crossing boundaries, and many described refining their decisions about what to share with time and experience.

In general, relationship building, clear communication, learning through experience, and appropriate compensation were important recurring topics related to positive experiences in research.

CONCLUSION

To date, parents have described a range of perspectives and approaches regarding the use of their personal networks for recruitment, which they refined with experience. Findings can be used to support decision making for parents who are new to research partnership. Emphasis on relationships, communication, and compensation by participants reinforce the importance of authentic support of patients as equal members of the research team.

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