Parents of Children with Haemophilia:
An Exploration of Their Experiences

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Introduction

What is haemophilia?

- ✻ Deficiency of Factor VIII (haemophilia A) or Factor IX (haemophilia B)

Treatment

- ✻ Results in ↑ quality of life, ↓ joint bleeds, ↓ hospitalisation, & less missed school

Adherence

- ✻ Poor: <50% of dose/frequency; at night instead of in the morning

Existing literature

- ✻ Largely focused on children
- ✻ Few qualitative studies about experiences of parents

Our Research

- ✻ Explore experiences of parents with children who have severe haemophilia A
- ✻ Identify influences on treatment adherence and nonadherence, using inductive methodology to understand the livid experience of the parents

Method

Participants

- ✻ Seven urban biological mothers of children (aged between 2 and 16 years) with severe haemophilia A

Procedure – Interpretative Phenomenological Research

- ✻ Semi-structured interviews with parents
- ✻ Themes elicited from statements for each transcript
- ✻ Themes checked cross-case, with authors, and haemophilia

Results

1. *Parental responsibility to protect*

   Mothers perceive a fundamental duty to ensure their child's safety & well being, & so, in fulfilling this role as protector, often fear potential injuries & administering treatment, both of which can result in pain.

2. *Acceptance*

   Mothers demonstrated resiliency in their attitude of acceptance, enabling them to continue treatment administration, & for both child & family to live a relatively normal life.

3. *Appreciation*

   Mothers' appreciation for the treating team & medication effectiveness ↑ feelings of safety, trust & motivation.

4. *Self-efficacy: I can make a difference*

   A sense of control is critical in what can sometimes be an uncontrollable illness. Being able to treat at home ↑ mothers' sense of mastery, while social support helps mothers to not feel alone in treatment management.

5. *This is dangerous and others don't get it*

   Perceived danger and distrust arise out of mothers' innate responsibility to protect; they are unsure if others can protect their child as well as they do.

6. *Treatment: Importance versus practicality*

   Although treatment becomes easier with time, prophylaxis is time-consuming and frequently causes frustration in the context of busy family schedules. Mothers employ a flexible approach so life can go on.

Summary and Future Research

Future research should test the hypothesis that targeting these six themes might result in improved parental adherence to managing their child's treatment regime. In particular, recommendations include:

1. Resolving ambivalence over parent's desire to protect but avoid causing immediate pain to the child
2. Increasing acceptance of their child's haemophilia
3. Increasing a sense of appreciation by finding the positives in parents' already challenging situation
4. Increasing self-efficacy, through education, mastery, & social support
5. Decreasing fear of danger and sense of being misunderstood by others
6. Validating challenges and time-management

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