What is it like parenting a child with haemophilia and living in a non-metropolitan area

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INTRODUCTION

- Moderate & severe haemophilia is diagnosed within the first 5 years of life.
- Treatment is demanding & child may require treatment up to 4 times/wk.
- Only three previous studies explore the experience of parenting a child with haemophilia but none of these studies explicitly investigated non-metropolitan families.

OUR STUDY

- Aimed to gain an understanding of the experience of parenting a child with haemophilia and living in a non-metropolitan area using qualitative methodology.
- Focused on two themes: experiences of being a parent of a child with haemophilia and administering the treatment regime.

METHOD

- Interpretative phenomenological analysis employed.
- Six parents where interviewed using semi-structured format.
- Data transcribed and analysed in accordance with Smith & Osborne (2008) recommendations.

RESULTS

Four themes emerged:

- Bearing the brunt of diagnosis
  "We had this child that had something wrong with him ... and how are we going to proceed with that and how was it going to affect our life ..?"
- If you can't help me, who can?
  "My husband took him to the doctor and the doctor basically said, "you need to drive another 200 kilometres because I don't know how to treat him..."
- Tackling the challenge of treatment
  "I think sometimes I get very down about the constant grind of it."
- I need you to understand
  "They were far more appreciative of what we had to go through, which makes me feel a bit better."

SUMMARY & FUTURE RESEARCH

- The study provided insight of the emotional struggles, management challenges, need for support, and access to specialists.
- The themes should be included in survey development to test generalisablity of the themes.
- Quantitative research could explore associations between themes and adherence or distress.
- The themes could be used to guide the development of interventions and support programs.

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