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The Health of Mothers of Children with a Life-limiting Condition; A Qualitative Study

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Background

- Mothers most likely to be their child's primary caregiver.
- Need to be well in order to care for their child.
- Call for more research surrounding the health of these mothers.
- Several studies have attempted to quantify psychological health in mothers of children with special needs or with specific disabilities but not specifically life-limiting conditions.



This Study

Workstream 1: Secondary data analyses- CPRD comparative cohort study. Incidence of common mental and physical health conditions higher in mothers of children with a life-limiting condition than in mothers of children with no long-term condition.

Workstream 2: **Qualitative study: mothers' accounts of their own health, impact of conditions identified in WS1 and identify which services they think should support them.**

Workstream 3: Stakeholder workshop

Workstream 4: Intervention development



Methods

- Exploratory qualitative study
- Participants recruited through hospices and via social media (Facebook, Twitter).
- Audio recorded semi-structured interviews; zoom or telephone
- Thematic analysis:
 - Coding of transcripts
 - Collating the codes into potential themes
 - Reviewed in relation to the data
 - Defined and named
 - Summarised with examples from the data
- Aim to identify patterns of meaning



Results

30 mothers took part in the study
Data collected Nov 2020- July 2021

SAMPLE CHARACTERISTICS

- Mother's age: 30-60 years
- Child's age: 1-25 years
- Child's condition: Genetic, neurodevelopmental
- Child's age at diagnosis: majority infancy or early childhood.



Findings

THEMATIC ANALYSIS

- 1. The unique experience of parenting a child with a life-limiting condition: a need for understanding**
- 2. Mothers' reluctance to prioritise their own health and needs**
- 3. Stress resulting from battles with services, rather than as a direct result of caregiving**
- 4. Establishing connections; feeling recognised**



The unique nature of parenting a child with life-limiting condition: a need for understanding

- Mothers perceptions that their needs as mothers of children with a life-limiting condition unrecognised- healthcare
- Access to timely and appropriate treatment- particularly MH concerns
- Inappropriate therapies
- Not a mental health condition
- 'Normal' response to a difficult situation

"It had reached points where I couldn't even stand in the last 8 months but it has been virtually impossible to get a GP appointment. Because I have to phone to renew [child's] medication, if I can get through to reception, that's my priority. It has taken 28 phone calls on occasion to get through to anybody" [Mother 2].

"I didn't feel like I did have anxiety or depression. I suppose it is anxiety, but it's a different anxiety.... when your child stops breathing, it's reasonable anxiety" [mother 19].



Mothers' reluctance to prioritise their own health and needs

- Time consuming and emotionally draining caregiving responsibilities made it difficult for mothers to address own needs, seek support.
- Deeper sense of unwillingness to think about own health/ needs
- “Get on with it”.
- No-one else could look after their child
- Lack of trust
- Fear that they would become unwell and not be able to look after their child.
- Perceived as not coping or as a burden

“I don't trust family to look after [child]. Not that I don't trust them, I don't trust their medical ability to cope in a crisis. It's difficult and incredibly stressful and takes a lot of inner strength to cope with it” [mother 25].

“There's not the holistic family approach, it's just focused on [child] and we just have to, you know, do our best, but our wellbeing isn't really considered” [mother 30].



Stress resulting from battles with services, rather than as a direct result of caregiving

- Ongoing “battles” or “fights” with services
- Appropriate equipment, support, housing, information
- In response to questions surrounding their own health- demonstrates the relationship between their child’s unaddressed needs and their own wellbeing

“I will hold my hands up and say yes it is hard. But it would be easier if we didn’t have to fight for the help that we need and have to chase people who don’t do what they say they are going to do. It just adds to the feeling of general tiredness and exhaustion really” [mother 30].

“Not having the correct equipment is a big one. Because of COVID things have slowed down. I’ve waited 6 months for a sling. The sling is the most important thing in our house at the moment. We need it. She’s a big girl and as a result of us not having a sling, me and dad have now got back problems. I’ve been waiting months for a hoist. It was like this even before COVID” [mother 27].



Establishing connections; feeling recognised

- Importance of support and relationships in mothers' lives
- Recognised as being fundamental in their child's care
- Hospice support
- Social workers
- Other parents
- Building relationships, feeling valued

"To be able to look after [child], I need to look after myself. It's a full-time job and when things go wrong, it happens quickly. So I just need any support I can get and to look after myself so that I can cope when that happens" [mother 25].

"There's not the holistic family approach, it's just focused on [child] and we just have to, you know, do our best, but our wellbeing isn't really considered". [Mother 30]



Conclusions

- Through mothers' accounts of their own health the study highlighted the importance of recognising their social, practical, physical and psychological needs.
- Unique set of challenges meaning that mothers may find it difficult to address their own health concerns.
- Mental and physical health concerns should be taken seriously and addressed in a timely and appropriate manner.
- However, it is equally important to recognise when mothers are not in need of physical or psychological intervention but greater support in addressing their child's needs.
- Mothers' wellbeing was linked to ongoing battles with services rather than as a direct result of caring for their child.



Fathers....



OPEN ACCESS

Experiences of fathers of children with a life-limiting condition: a systematic review and qualitative synthesis

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► Additional supplemental material is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/bmjspcare-2021-003019>).

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ABSTRACT

Background Children with a life-limiting condition often require extensive and complex care, much of which is provided by their parents at home. There is a growing body of research that aims to understand the **experiences** of these parents, but the majority of this research is from mothers' perspectives, meaning that fathers' experiences are not well understood.

Objectives To identify and synthesise findings from existing qualitative studies that have explored the experiences of fathers of children with a life-limiting condition.

Methods A systematic review of qualitative research was conducted using thematic synthesis. Searches were conducted in MEDLINE, CINAHL, EMBASE, PsycINFO and Social Science Citation Index.

Results Findings from 30 studies were included,

Key messages

What was already known?

- Fathers are significantly under-represented in parental studies of children with a life-limiting condition.

What are the new findings?

- Fathers describe uncertainty related to their child's condition and to their own role.
- They describe challenges in forming relationships with and seeking support from healthcare staff.

What is their significance?

- Healthcare professionals should be accommodating of fathers' concerns and contributions to their child's care as the role of the father evolves.
- Research that focuses on the mental health and well-being of these fathers is



Questions

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