

An exploration of the experience of caring for a child with a non-malignant life-limiting condition from the perspective of parents.

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The research in context

This research is part of a larger PhD study exploring access, decision-making and experiences of palliative care services for families of children with non-malignant life-limiting conditions (NMLLCs) on the island of Ireland (both north and south).



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Aim

Provide an in-depth understanding of the experiences of parents caring for a child with a NMLLC.

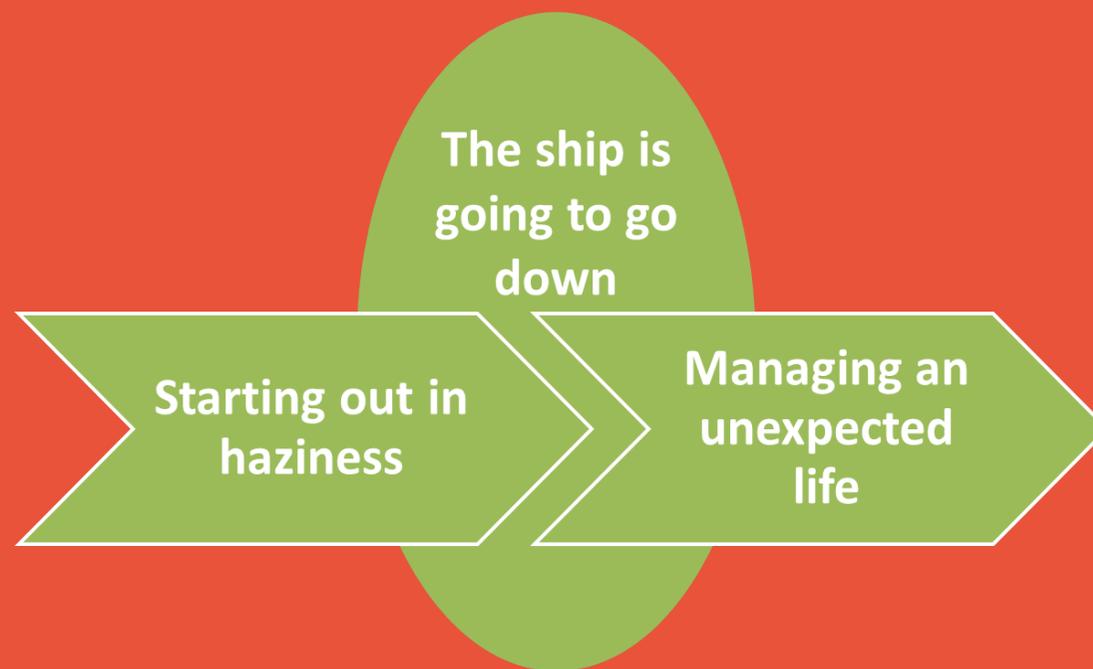
Methods

- Semi-structured interviews were used to collect data from parents regarding their experience of caring for their child.
- A total of twenty-three parents (eighteen mothers and five fathers) participated in the study.

Findings

Three dominant themes and eight subthemes emerged, charting parents' journeys and unique experiences of caring for a child with a NMLLC.

The three dominant themes



Relationship between the themes

- A chronology became apparent across Theme 1 and Theme 2.
- Each of these themes marked a distinct period of time with each theme/period of time containing its own specific issues in relation to caring for a child with a NMLLC.
- Theme 3 contained specific issues which were present and pervasive throughout the parent stories and each of the two themes.

Starting out in haziness

Represented the time period from diagnosis or recognition of a life-limiting condition and marked the beginning of an unknown journey filled with emotional turmoil.

"I know I cried a lot, but I remember that day to me it was one of the worst days. I remember just being so hysterical and going down to the car because I knew I couldn't go up to the ward because I was hysterical. It was the first time and last time I ever thought this thought, but I did think, will I just get into the car and drive into a wall?" [P4].

Managing an unexpected life

Captures the time period after the haziness started to settle in the component of the parents' stories and where they attempted to respond to the resultant emotional and practical impact of their child's condition on their life and that of their family.

"I was utterly devastated. But you just have to get on with it. There's nothing else for it. It's not her fault. That wee one was lying in your arms and the two of us just wanted to do whatever we could, for however long we had her." [P6].

The ship is going to go down

Represented the parents' often never verbalised but ever present experience of living with the knowledge and uncertainty that whilst death was inevitable, they did not know when it was likely to occur.

"We're all on board the same ship, and we're all going in the same direction. We don't know what direction the ship is going but somewhere the ship's going to go down. Everybody that's on the ship is going down with it. There's no getting away from that. It's scary." [P15].

Not about dying...

- CPC is focused on ensuring the best possible quality of life for children and their families.
- Throughout the interviews the parents described positive feelings of parenting a child with a NMLLC.

To conclude

She's very clever in her own way. She's cleverer in a lot of ways than what the doctors said or thought. She knows the Mr. Tumble signs. She knows the Incy Wincy spider signs. She knows the wheels on the bus. She can do all those. [P11].