



How do grandparents experience the death of a grandchild following a life limiting condition?

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Background

Traditionally, bereavement support for families extends to parents and siblings of children who have died following a life limiting condition (LLC). Few research studies have focused on the needs of bereaved grandparents, who play an increasing role in the care of children with LLCs and their families.

Family-centered care is a core principle of children's palliative care and therefore understanding of 'family' should be congruent with contemporary society. This study aimed to explore how grandparents experience the death of a grandchild from a LLC.

Method and design

Research ethics approval was granted by Lancaster University.

A total of seven participants were included in the study. Semi-structured, individual, face-to-face interviews were conducted in participant's own homes. Field notes were taken during and immediately following the interviews. **Interpretative phenomenological analysis** was used to analyse the data.

Grandparents who were the principal carers of the deceased grandchild were excluded.

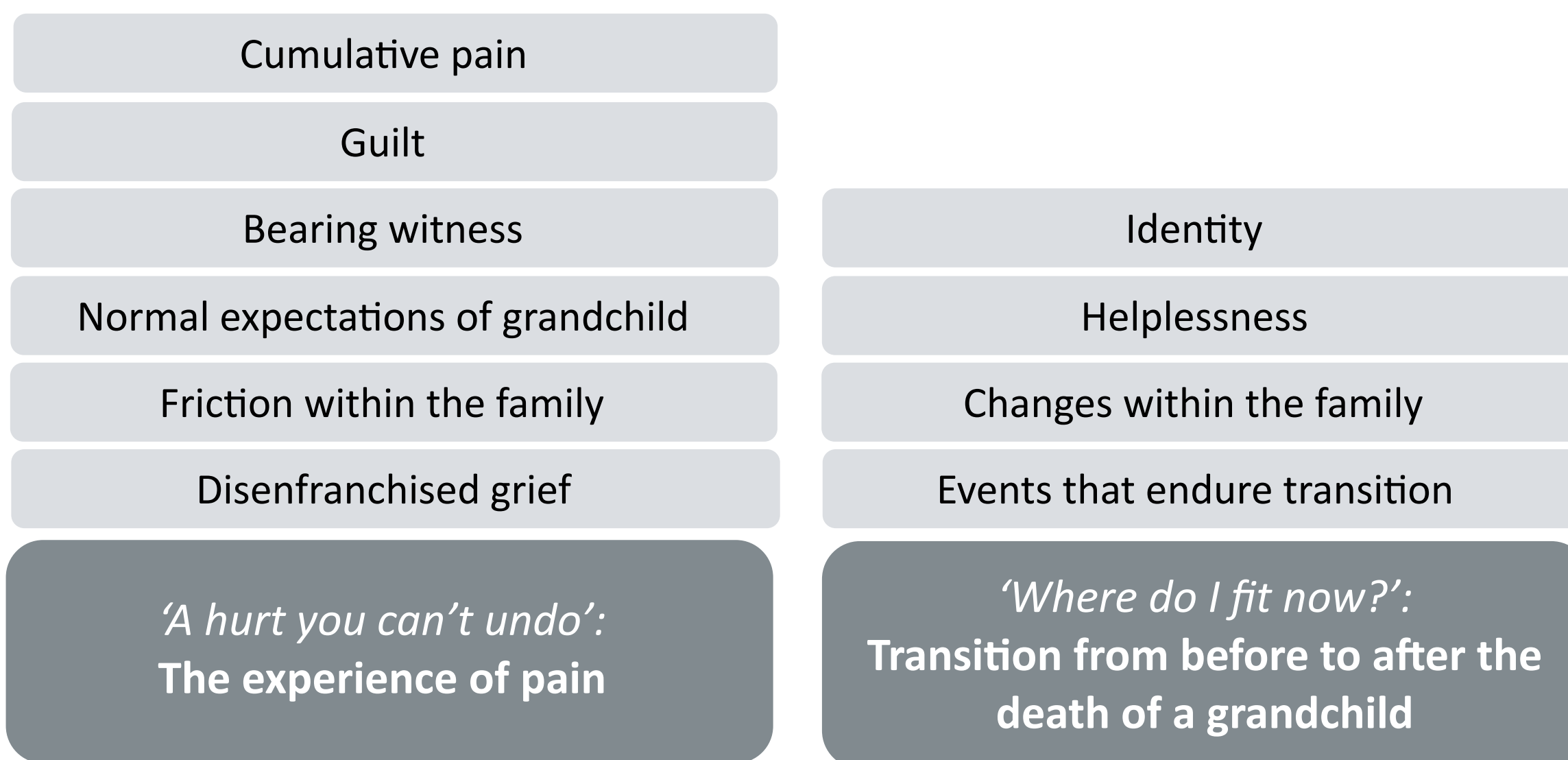
'I felt inadequate. You want to make it right and you can't, and I think that's a driving force with any sort of mum.

She wants to make it right and explain it but you can't. That was incredibly hard to see.'

'The pain of losing Hannah will never go away; she's in our hearts, but I can see Kate's levelling out now, and I'm backing off. I'm not having the need to support.'

'All I could give my granddaughter was love and time and by giving time and all the support to her mummy and daddy that enabled them to be at their best as possible to look after their little girl.'

'When she was ill I felt very strongly that I'm in the background, that it's her parents, that are in the driving seat, and we're there to come along with them in the backseat as it were. All the time when she was ill I was very aware of being supportive, but not being the leader or anything like that - that wasn't my role.'



'When she died, it had to be them as a family, not us - they were together. Yeah, we are on the edge, it looks as that you're looking in on something to be honest. It's like you're looking in on something.'

'I'd just had my 60th birthday when Hannah was born - It was the best birthday present! All my friends who were grandparents shared the thrill of us finally being grandparents!'

'We had to just support them two, to give them strength, to take away a lot of every day pressures so they could be as best as they could, still in pieces - we had to support them to cope with what they were given.'

'I had a phone call to say that it was bad news - that it was leukaemia. My instant thing was, because I'd come across other children though my teaching was 'don't worry, these days there are marvellous things. Give it a few months and treatment and she'll be fine'. So you know, we started off, me being incredibly buoyant and positive.'

Grandparents' experience

*'The other hat':
The roles of a grandparent*

Parental role

Boundary between parenting and grandparenting

'Total' support from grandparents

Validation

*'It's a love that gets you going':
Drive*

Sense of duty

Responsibility for the family

Continuum of hope

Love

Conclusions

The research identified that in the present study, the primary motivation of grandparental support stems from their role as a parent, and not as a grandparent.

The **breath of pain** experienced by grandparents is **complicated by the multigenerational positions they occupy within the family**. The **transition** from before to after death **exacerbated the experience of pain**. Grandparents discussed a **duty to maintain a sense of hope**, owing to **their perception as an elder in the family**.

For further information

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Implications for practice and research

The findings from this study should assist the development of practice to better understand, and therefore support, grandparents of children with a LLC **during life, in addition to bereavement support**.

In order to meet the needs of grandparents, we must acknowledge and enable their **dual, simultaneous multigenerational roles** of both a parent and grandparent.

Further research should focus on the experiences of grandparents from other **ethnic backgrounds**, and where their **grandchildren did not had a diagnosis**.