

Qualitative study - other

Advocacy for the dependent children of parents with a life-limiting condition

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Alison Booth

Department of Health Sciences, University of York, York, UK

Correspondence to: Dr Alison Booth, Health Sciences, University of York, York, UK; alison.booth@york.ac.uk

Commentary on: Marshall S, Fearnley R, Bristowe K, *et al*. 'It's not just all about the fancy words and the adults': recommendations for practice from a qualitative interview study with children and young people with a parent with a life-limiting illness. *Palliat Med* 2022;2692163221105564. doi: 10.1177/02692163221105564.

Implications for practice and research

- ▶ Health professionals can play a key role in helping parents with life-limiting illnesses understand the needs of, and provide support for their dependent children.
- ▶ Future research seeking to engage with children should avoid making assumptions about age as an automatic indicator of vulnerability.

Context

There is evidence of long-term effects the premature death of a parent can have on dependent children.¹ Understanding the perspective of children of a parent living with a life-limiting condition is not the same as understanding the impact of the early death of a parent on the child. Marshall *et al* obtained the views and experiences of children with a parent living with a diagnosis of any life-limiting condition.² The aim being to find evidence-based ways to support parents to minimise the impact of their condition and untimely death on their children.

Methods

In their study, Marshall *et al* used qualitative methods to collect the views, opinions and experiences of dependent children experiencing life with a parent with a life-limiting illness and synthesise the results.² Based on the epistemological assumption that children have a unique perspective, semistructured interviews were undertaken. Inclusion criteria allowed for the children to be any age between 6 and 17 and the parent to be at any stage of any non-curative condition. Potential participants were identified through clinicians and via social media; parents were involved in the recruitment and consent processes, and in some cases the interview as well. The interview transcripts were synthesised by an experienced team using thematic analysis, a method suited to the large volume of data collected.

Findings

The 32 children interviewed (16 boys/16 girls) came from across the UK and their parents had a diverse range of life-limiting illnesses. Over half

the participants were preteens, and 44% were from black, Asian and ethnically diverse backgrounds. The analysis showed children want to be involved and identified four themes: looking after the family; negotiating healthcare; maintaining some normality and managing the sadness. From this analysis, the authors produced five recommendations for use by healthcare professionals caring for a parent with a life-limiting condition: agency, caring, trust, normality and emotions.

Commentary

Concern for the well-being of their family and the child's future will understandably have an emotional impact on a parent. Approaches to holistic care generally account for the physical, emotional and spiritual welfare of patients,³ but starting a conversation about feelings and emotions is not easy. Healthcare professionals are often in a unique position to identify where a patient may be stressed and anxious about more than their own physical health. Developing and using good communication skills to build up a rapport with a patient can create the opportunities to start the difficult discussions.³ Dalton *et al* provided comprehensive guidance for health professionals based on a review of the literature and expert consensus opinion, in the absence of empirical evidence.⁴ Marshall *et al* provide the evidence and put the voice of children at the heart of their five simple recommendations for health professionals.² By encouraging parents to have discussions with their child, promoting active participation and giving children a role where appropriate, health professionals can ease anxiety for parents and children. The key is to provide the opportunity at the right time and in the right way and tailor information and involvement to the situation and the child.⁴

Children across a wide age range want and need the opportunity to be informed, involved and to be part of decision-making about their parent. Marshall *et al* have shifted the ground on research including children who have a parent living with a terminal condition. Responsible research involving children is essential to advance knowledge where only children can provide the information recognised.⁵ Future research needs to avoid making assumptions about participant age and perceived vulnerability and recognise the importance of giving children a voice where theirs alone is valid.

Competing interests None declared.

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ORCID iD

Alison Booth <http://orcid.org/0000-0001-7138-6295>

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