Qualitative study - other

Parenting concerns, parental identity and functional status influence medical treatment decisions of patients with advanced cancer

10.1136/eb-2017-102704

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Commentary on: Park EM, Check DK, Song MK, *et al.* Parenting while living with advanced cancer: A qualitative study. *Palliat Med* 2017;31:231–8.

Implications for practice and research

- ▶ Parents with advanced cancer would benefit from having clinicians engage in explicit discussions regarding their needs, concerns and plans pertaining to parenting as end-of-life gets nearer.
- ▶ Future research also should explore some of the positive aspects that may come with parenting while experiencing advanced stages of cancer (eg, concepts of gratitude, emotional closeness and closure, and post-traumatic growth).

Context

The extant literature suggests that parents with advanced cancer with dependent children are prone to higher psychological distress than those without. Past studies have mainly focused on parents with early-stage cancer communicating information about their diagnosis to underage children.^{1,2} Few have explored the realities of raising children while coping with advanced cancer and its effect in the context of palliative and end-of-life care. Park and colleagues undertake an important exploration of such issues with a particular focus on the role of functional status in contributing further to distress.

Methods

This qualitative cross-sectional study relied on semi-structured interviews to explore parental perceptions, concerns, the impact of an advanced/metastatic cancer diagnosis and treatment demands on parenting roles and treatment-related decision making. Purposive sampling was used to ensure a broad spectrum of experiences. Thematic saturation was reached following the conduct of 46 in-depth interviews, with four of these not included due to cultural diversity issues. The Performance Status Scale was used to measure functional status. Following thematic analysis, several key themes emerged using independent coders and NVivo V.10.

Findings

The final sample ($N=42$) was composed of parents with various cancer diagnoses, with a significant proportion of women with breast cancer. The four resulting themes included parental concerns about the impact of their

illness and death on their children, 'missing out' and losses of parental role and responsibilities, maintaining parental responsibilities despite life-limiting illness, and parental identity. The findings suggest that psychological concerns are intensified among parents with poorer functioning status.

Commentary

Many participants reported struggling with guilt mainly due to a reduced ability to fulfil their previous parental functions. Their desire to be present for their children greatly influenced the nature of treatment-related decisions made and their psychosocial reactions to this life-limiting illness. As such, the study addresses an important gap in the literature as little is known about concerns of this population with regard to parenting issues and concerns. The use of in-depth interviews allows for a rich and detailed portrait of these experiences.³ The large sample for a qualitative enquiry and the variety of cancers and functional status are important strengths of this study. However, the study was limited to some degree by sampling only from one institution and by having fathers relatively under-represented within the participant group.

Interestingly, parents with advanced and metastatic cancer perceived themselves primarily as parents and secondarily as individuals with cancer.⁴ As functional status declined, more distress took place in terms of participants' perceived reduced adequacy in coping with parental demands.⁵ This raises the question of how parental needs and concerns evolve as the illness experience becomes more difficult and nears death.

Whereas participants actively continued to develop strategies to optimise parental roles and responsibilities such as mobilising their social network to address gaps in parenting, studies such as this and others show that parents would like more parenting-specific cancer support.⁴ Healthcare professionals are in a strategic position to mobilise these sources of support, such as relying more on volunteer associations and community peer groups. It is all the more important for care providers to initiate discussions of needs when parental functional status deteriorates. Incorporating this dialogue as part of routine care could be an important step towards enhancing person-centred cancer care, well-being and reducing psychological distress in this population. In addition, it would be informative to study differences in parental concerns when one is diagnosed initially with metastatic cancer as opposed to their initial health status being at early stages of cancer and gradually deteriorating. As alluded to by the authors, key cultural differences in the overall experience of parenting in advanced disease stages would be important to document to ensure optimal tailored cancer support.

Competing interests None declared.

Provenance and peer review Commissioned; internally peer reviewed.

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