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Journal of Pediatric Nursing

Volume 36, September–October 2017, Pages 163-172

Parental expectations of support from healthcare providers during pediatric life-threatening illness: A secondary, qualitative analysis

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<https://doi.org/10.1016/j.pedn.2017.05.008>

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Highlights

- â€¢ Parents grapple with conflicting feelings regarding competing needs of their ill and healthy children and the expectations held of them as parents.
- â€¢ Nurses can influence parentsâ€™ management of the situation and be a source of support as parenting roles change over illness course and time.

â€¢ Despite a child's LTI, parents want pediatric healthcare providers to engage with them to promote survival and growth of family relationships.

Abstract

Purposes

To explain parental expectations of support from healthcare providers for their parenting roles and goals during a child's life-threatening illness (LTI).

Design and Methods

Qualitative interpretive study guided by the Family Adjustment and Adaptation Response Model. Thematic analyses were conducted with data from 31 semi-structured interviews of parents of children with LTI using systematic strategies to ensure rigor including audit trails and prolonged engagement.

Results

We identified three themes and one meta-theme or overall theme: (1) â€œHelp us survive this,â€ (2) â€œLet's fight together: please fight with me, not against me, to care for my family,â€ and (3) â€œGuide me through the darkness: I am suffering.â€ Overall, the parents conveyed that they expect mutuality with the health care providers and system in order to keep *Fighting together for my family survival*.

Conclusions

In the daily work of caring for their families, parents of children with LTI consider survival on multiple levels. They consider the life, illness, and potential death of one child while considering the on-going survival and sustenance of family relationships.

Practice Implications

Parents are distressed and grapple with conflicted feelings about managing competing needs of various family members. Relationships with health care providers can influence parents' management of the situation and be a source of support as their parenting role changes over the illness trajectory, time, and in response to adversity.



Keywords

Parenting; Palliative care; Qualitative; Secondary analysis

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