

Abstract

Background

Hospitalisation of a child with cancer can be an exceptionally stressful time, not only for the child but for members of the entire family unit. With growing awareness globally of the impact of hospitalisation on children, many hospitals are adapting more child friendly spaces. As advocacy for family centred care strengthens, the lived experience of parents of hospitalised children remains at times incongruent with the family centred care approach that continues to be promoted clinically. Family Huddles are one consumer-engagement initiative being introduced to clinical settings in support of family centred care principles. Family huddles are envisaged to enable shared decision making and allow parents and carers a pathway to be heard, to understand what the consumer believes to be important to enhance quality, comfort and safety of care provided. Whilst promotion and implementation of Family Huddles in support of family centred care principles increase, the relationship between advocated practice and actual lived experiences of parents and carers whilst in hospital participating in a Family huddle, is yet to be fully established.

Aim

The aim of this study was to explore what parents and carers of hospitalised children within a paediatric haematology/oncology unit, experience from participating in a Family Huddle.

The specific objectives of the study were:

1. To identify and explore parental/carer experiences/perceptions of a Family Huddle.
2. To identify and explore perceived barriers, motivators, enabling factors and parental/carer willingness to participate in a Family Huddle.
3. To explore and relate how a Family Huddle enhances the principles of family centred care.

Methodology

Full ethical approval for this study was granted by the human research ethics committee of the major metropolitan hospital the study was undertaken within as well as the Flinders University Social and Behavioural Research Ethics Committee. A two-phase qualitative, ethnographic method was utilised to address the aims of this study. Eligibility criteria included parents and carers of hospitalised children within the haematology/oncology unit.

Purposive sampling recruited ten parents to Phase One which consisted of three audio-recorded observed Family Huddles. One parent and one teenaged patient were recruited to Phase Two which comprised semi-structured audio-recorded face-to-face interviews. Audio recordings from observed Family Huddles and face-to-face interviews, were transcribed verbatim by a confidentiality-bound transcriptionist and subsequently thematically analysed in accordance with Braun & Clarke's (2006) guidelines for thematic analysis. Dedoose™ software was utilised to code and organise data into themes.

Findings

Four primary themes emerged through analysis of transcripts from three observed Family Huddles and one face-to-face interview. The first theme 'Service accessibility', encompassed three subthemes including 'Unit accessibility', 'Staff accessibility' and 'Connectivity', and identified parental desire for ease of access to services and physical locations throughout the child's hospitalisation. 'Family Centred Care' illustrated parental desire of physical comfort for the hospitalised child as well as themselves and other members of the family unit. 'Information sharing' was deemed vital throughout the period of hospitalisation, with effective two-way communication central to parents obtaining new information and effective communication between parents, patients, and health care professionals. Finally, 'Role uncertainty' identified inconsistencies in clinical practice of health professionals as well as inconsistency of nursing expectation of parents, leading to parental role uncertainty and at times frustration. Furthermore, themes generated from this study highlighted the importance of Family Huddle delivery in alignment with the values underpinning Family Huddles, including person and family centred care, partnership, transparency and access to information. Recommendations relating to how organisations and health care professionals can promote and support parental/carer attendance at Family Huddles were made as a result of findings.

Conclusion

This study provides an important first insight to the lived experience of parents of hospitalised children within a haematology/oncology unit, participating in a Family Huddle. Study findings suggest parental participation in Family Huddles offers benefit to parents and patients as consumers and enhances the principles of family centred care. Organisational investment in health care worker professional development of the Family Huddle Framework, may enhance promotion and support of Family Huddle success.