Abstracts

Death. Little is known however, how parents make decisions around end of life care. Better understanding of the parental decision making process could lead to more effective care for families in similar circumstances as well as a better allocation of resources. **Method** This qualitative study used semi-structured interviews with four bereaved parents and subsequent analysis by IPA to describe the parental decision making process. **Results** During curative treatment, the child’s consultant was regarded as the main decision maker. At the end of life however, the responsibility for decision making lies solely with the parents (the children in this study were not informed of their impending death). Importantly, all participants describe disagreements with their partner, especially with regards to medical treatment decisions. In all families, the disputes were resolved by the mother acting as the main decision maker.

The most important factor in deciding in favour of further treatment was a belief that further treatment could be successful. The principal argument against further treatment was a concern regarding the quality of life for the child should the treatment succeed. The most important reason to take the child home to die was the parental perception that the child did not like the hospital. However, in deciding the place of death it was very important to ensure parental perception that the child did not like the hospital. How-ever, in deciding the place of death it was very important to ensure continued involvement of family and friends who had been supportive during the treatment. After the death of the child, engagement in altruistic and reciprocal activities was described as most helpful in bereavement. **Conclusion** This retrospective pilot study allows some insight in the parental decision making process at the end of life of their child and calls for further study.

This study demonstrates that similar barriers to ACD exist internationally. Junior and senior doctors identified particular concerns which could help enhance and target teaching at specific training levels. Findings from nurses suggest that doctors should reflect upon whether sufficient emphasis is given to ACDs and whether priorities should be revised.

**REFERENCE**


**G40(P)** WHAT DELAYS DISCHARGE IN CHILDREN WITH LIFE LIMITING CONDITIONS? A QUALITATIVE STUDY OF THE PERCEPTIONS OF PARENTS AND MEDICAL PROFESSIONALS
doi:10.1136/archdischild-2013-304107.052

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**Background** It is important that any family of a child with a life limiting condition (LLC) have the option of where they would like their child to receive care (ACT 2010, DOH 2008) and do not have unnecessary protracted periods of hospital admission.

**Aims** The aim of the project was to establish the perceptions of professionals and parents regarding perceived delay in discharge of children admitted acutely who had a LLC; also to look at ways to expedite discharge if appropriate.

**Methods** This study took place in a large tertiary teaching hospital. A qualitative approach was taken – one to one interviews with parents and focus groups with professionals. Inclusion criteria included parents of children with life limiting conditions admitted with acute illnesses.

**Results** The data was analysed using grounded theory. A model emerged of “separateness of expert knowledge” from the parents, community and hospital teams.

**Conclusion** This study, although limited in terms of participant numbers, explored the perceptions of parents and professionals around discharge in children with LLC admitted with acute conditions. The main finding was the “separateness of expert knowledge” between parents, community teams and hospital teams. All the groups included valued access to a professional who knew the patient well. Hospital staff and community teams felt that co-morbidities resulted in longer lengths of stay.

The reason for admission was not solely due to the acute diagnosis, but also lack of other adequate services for this group of children out of hours. There was no specific treatment identified that prevented discharge.

A multi-professional approach to the care of these children, with a robust system for discharge planning may enhance the service. A multi-professional out of hours telephone service for families of children with LLC may help reduce admissions.

**REFERENCES**


**G41(P)** HANDLE WITH CARE: ADVANCE CARE PLANNING (ACP) IN PAEDIATRIC PATIENTS WITH PALLIATIVE CARE NEEDS: QUALITATIVE STUDY OF EXPERIENCES AND PERCEPTIONS OF PAEDIATRIC INTENSIVE CARE UNIT (PICU) MEDICAL AND NURSING STAFF
doi:10.1136/archdischild-2013-304107.053

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