EVALUATION OF A RAPID DISCHARGE PATHWAY FOR IMPROVING PALLIATIVE DEMENTIA CARE

As the number of children in the UK with life-limiting and life-threatening conditions are increasing, providers of palliative care services, such as children’s hospices are considering how best to support families. However, evidence suggests that only a small percentage of parents of children with such conditions choose to access hospice services.

This exploratory study examined parents’ perspectives of existing hospice services, the types and characteristics of hospice services parents wanted, the barriers and facilitators to accessing services, and how best these services could be delivered to meet the needs of the population of children with life-limiting and life-threatening conditions in one region in England.

A two phase qualitative study underpinned by a constructivist grounded theory methodology was employed. In Phase 1 focus groups were used to collect data from twenty four parents of children accessing services at the hospice. In Phase 2 in-depth semi-structured interviews were conducted with seven parents of children who did not use services at the hospice and with a further seven parents who had either previous experience of the hospice or were using a hospice outside of the region.

Findings showed the desire, the sense of searching that parents had in seeking out a place, other than their actual home, where their child could access a caring environment and the parent/s receive some respite from caring. Over time affective bonds developed between parents and the hospice. Finding a place where they belonged and where they felt at ‘home’ made the decision to accept help in caring for their child with a life-limiting condition more manageable.

A theory of place bonding was developed which has the potential to influence practice for children’s hospices and also provide a platform for service development for other respite situations for children and young people with life-limiting conditions.

Improving Palliative Dementia Care – Evaluation of a New Education Programme

As the number of children in the UK with life-limiting and life-threatening conditions are increasing, providers of palliative care services, such as children’s hospices are considering how best to support families. However, evidence suggests that only a small percentage of parents of children with such conditions choose to access hospice services.

This exploratory study examined parents’ perspectives of existing hospice services, the types and characteristics of hospice services parents wanted, the barriers and facilitators to accessing services, and how best these services could be delivered to meet the needs of the population of children with life-limiting and life-threatening conditions in one region in England.

A two phase qualitative study underpinned by a constructivist grounded theory methodology was employed. In Phase 1 focus groups were used to collect data from twenty four parents of children accessing services at the hospice. In Phase 2 in-depth semi-structured interviews were conducted with seven parents of children who did not use services at the hospice and with a further seven parents who had either previous experience of the hospice or were using a hospice outside of the region.

Findings showed the desire, the sense of searching that parents had in seeking out a place, other than their actual home, where their child could access a caring environment and the parent/s receive some respite from caring. Over time affective bonds developed between parents and the hospice. Finding a place where they belonged and where they felt at ‘home’ made the decision to accept help in caring for their child with a life-limiting condition more manageable.

A theory of place bonding was developed which has the potential to influence practice for children’s hospices and also provide a platform for service development for other respite situations for children and young people with life-limiting conditions.