UNDERSTANDING NURSES’ AND PARENTS’ PERCEPTIONS OF FAMILY-CENTRED CARE

Megan Stuart and Sally Melling describe the findings of a study exploring how professionals and families view their roles in the care of a child in hospital

Abstract

Aim To explore and compare differences between parents’ and nurses’ perceptions of family-centred care (FCC) for children’s acute short-stay admissions.

Methods Mixed-method questionnaires were designed to compare care task delegation between nurse and parent participants in the study.

Findings Parents and nurses had similar perceptions of task allocation in FCC. Parents generally were prepared to undertake basic care tasks only, rather than help with nursing interventions. Nurses had a comprehensive understanding of FCC. Most parents were not able to define FCC but carried it out naturally.

Conclusion In the UK, nurses and parents have similar expectations of FCC. It is unusual for parents to be given information or opportunities to engage in the care of the child beyond everyday tasks. The investigation highlighted the importance of negotiating with family members on each separate admission because, although most parents would be comfortable undertaking care tasks, each family and each situation is different.

Keywords Care tasks, children’s nursing, family-centred care, short-stay admission

FAMILY-CENTRED CARE (FCC) has become an integral part of children’s and other nursing areas, and is central in UK nurse education and practice. According to the British Society for the History of Children’s and Child Health (2014), Great Ormond Street Hospital opened in 1853 as the UK’s first children’s hospital. Since then, there have been many shifts in attitude towards the hospital admission of children, leading to the contemporary principle that the presence of parents or family on the ward is an essential aspect of children’s nursing.

The Platt Report pointed to the need to give more attention to achieving care that fulfils the holistic needs of children (Platt 1959a). In particular, Platt (1959b) emphasised the importance of maintaining normality and continuity for the child in hospital, in an attempt to minimise the emotional disturbances of admission. A number of further publications have followed and have continued to highlight the need to include parents and family in their child’s care.

Further data have been collected since 2012, when the study reported in this article was conducted. However, the same definition of FCC has been used throughout the research, namely that of Smith (2002), which is ‘the professional support of the child and family through a process of involvement, participation and partnership underpinned by empowerment and negotiation’. This article refers to Smith (2002) when describing FCC.

Over the years, there has been a change in children’ hospital nursing in the UK: the trend has been towards shorter hospital stays, alongside greater numbers of short-stay patients (Purdy 2010).
Examples of tasks related to activities of daily living and nursing interventions

<table>
<thead>
<tr>
<th>Box 1</th>
<th>Examples of tasks related to activities of daily living and nursing interventions</th>
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<tbody>
<tr>
<td><strong>Activities of daily living</strong></td>
<td><strong>Nursing interventions</strong></td>
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<tr>
<td>- Washing the child.</td>
<td>- Passing a nasogastric tube.</td>
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<tr>
<td>- Nappy changing.</td>
<td>- Giving oral medication.</td>
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<tr>
<td>- Fetching snacks and drinks.</td>
<td>- Administering injections.</td>
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<tr>
<td>- Playing with the child.</td>
<td>- Testing blood sugar.</td>
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<tr>
<td>- Making cot/bed for the child.</td>
<td>- Taking temperature.</td>
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<tr>
<td>- Feeding the child.</td>
<td>- Distracting the child for a procedure.</td>
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<td></td>
<td>- Measuring fluid balance.</td>
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These changes increase the pressure and reliance on short-stay children’s wards. If the effects of hospital admission identified by Platt are still relevant (Platt 1959a), and there is a shift in the duration of admissions, this should be reflected in the literature on FCC in acute children’s wards.

**Literature review**

The involvement of parents during their child’s admission has become common, and families often expect to participate in care (Palidelis et al. 2005). Nevertheless, Corlett and Twycross (2006) have warned that, despite apparently working in partnership, it is still in the hands of nurses to decide when, how and with which parents to negotiate about which tasks. The research found that parents wanted to participate, but felt powerless to discuss this with nurses; the researchers suggest that greater empowerment of families is vital to any FCC, without which the care provided could be affected adversely (Corlett and Twycross 2006).

Coyne et al (2011) have reported variations in nurses’ opinions about FCC. While front line staff have the opportunity to negotiate with families about the care that they provide, this is limited to the parameters and boundaries of an individual nurse’s knowledge, skills and experience. Previous and more recent publications emphasise the importance of developing a good rapport between nurses and families, to ensure delivery of high quality care (Espezel and Canam 2003, Coyne et al. 2011).

**Aim**

The aim of the survey was to explore and compare differences in parental and nursing perceptions of FCC delivery in children’s acute short-stay admissions. The three objectives were to:

- Explore the variety of care tasks parents were willing to undertake for their child and the rationale behind this decision-making process.
- Compare the views of parents and nurses about implementing FCC in acute short-stay admissions of children.
- Formulate recommendations to improve FCC implementation and the quality of care provided.

**Methods**

The research used two questionnaires designed by one of the authors (MS) – one for parents and one for nurses. The sole difference between them was the demographic information gathered at the start of the survey. Both asked for information based on the same list of care tasks and were based on a similar questionnaire from a study by Blower and Morgan (2000), also undertaken as part of a dissertation; thus the researchers faced similar academic limitations.

The questionnaires used a list of care tasks derived from a review of the literature, which are typical on a children’s short-stay ward (Box 1). The activities of daily living (ADL) tasks were those undertaken daily to meet physical, mental and emotional needs (Smith 1995), while the nursing interventions were selected as a range of commonly undertaken nursing duties, of varying degrees of technicality, and were experienced by the researcher (MS) in practice.

**Study sample**

There were two accessible target populations (parents and nurses) in a single short-stay acute children’s ward in a teaching hospital in the East Midlands. Data were collected over two months in 2012. As the nursing team on the ward was comparatively small, all 29 staff were invited to participate and eight returned the questionnaire. These responders were between bands 1 and 5 and had a range of experience, from newly qualified to more than five years’ in the role. Any parents/carers attending the ward with their child during the data collection period were also invited to participate; 25 parents/carers responded. Of these, 24 were parents and one a grandmother.

**Ethical considerations**

Ethical approval was obtained from the health research authority, and the trust’s research and innovation team. Informed consent, confidentiality and anonymity were all considered by the researcher as suggested by the Royal College of Nursing (2009).

**Data collection and analysis**

Parents were invited to participate when their child was being discharged; nurses were invited via posters and emails, and questionnaires were put in their pigeonholes. All participants were asked to return the questionnaire to the sealed box behind the ward reception desk. Once returned, the data were coded numerically by the researcher; SPSS software was used to analyse the data via cross-tabulation of the key themes.
Findings
Most parent/carer participants were mothers. This reflects the conclusions of Tedford and Price (2011), that mothers are the parents typically resident with their child in hospital, while fathers are more likely to stay at home tending to other siblings and continuing to work. In addition, 15 parents had never been in hospital with their child before, minimising the chance that they would know what to expect or what would be expected of them.

Defining family-centred care
One of the earliest questions asked of both study groups was whether they had heard of FCC and could provide a definition of the concept. All nurse participants had heard of it and were able to offer definitions, all of which included the principal terms featured in Smith's (2002) definition, for example: 'Family-centred care is all about nursing care involving all the care for the patient and also caring for the family of that patient too' (nurse participant 5). This supports older research indicating that nurses are able to provide a concise definition of FCC (Baker 1995).

Parent participants were less knowledgeable about FCC. Less than one quarter answered that they had heard of FCC and were able to define the concept. A further three were unsure, but were able to guess what it encompassed. Parents' definitions were less concise than those of the nurse participants; they used colloquial phrases such as 'considering the family' and 'putting the family first'; they used positive terms. One parent wrote: 'I think it’s the term used for the best methods of care based on the family’s wishes and circumstances' (parent participant 5).

Comparing expectations
The findings show that none of the nurse participants viewed ADL to be entirely their role but, rather, something to be shared with the parents and family. The comments revealed that nurses thought it was actually parents' responsibility to undertake these care tasks. However, the nurses were accountable for the care provided so, if the parent was absent, they would undertake these tasks, supporting findings in the literature (Palidelis et al 2005).

The parents generally thought that ADL duties were entirely their responsibility, with a few (3/25) stating that these tasks should be carried out together with nurses. This discrepancy could lead to role confusion for parents; as early as 1995, Coyne concluded that the expectations of parents and nurses needed to be discussed to ensure that all those involved were aware of their responsibilities. Blower and Morgan (2000) found that parents actively wished to continue with their parental role when their child was in hospital, and this is evident in the responses in the present study.

The answers to questions about the delegation of nursing interventions show that the parents were more likely to be prepared to undertake ADL duties than nursing interventions, with a clear distinction created by parents between the task domains. Nurses also expected the parents to undertake ADL duties, whereas nursing interventions were nurses' responsibility. One point to note is that the questionnaire did not ask whether parents were offered the opportunity to participate in suitable interventions, which could have affected the answers.

However, there were three nursing interventions where parents or family could assist: administering oral medications, measuring fluid balance and distracting the child during painful procedures.

This article looks specifically on measuring fluid balance, which most (6/8) nurses thought was part of the nurse's role; however, it was most (15/25) parents' expectation that they should be involved. Some nurses asked parents to keep a check of their child's fluid intake, documenting their request in the nursing notes. This questions where responsibility lies: without the family keeping track, the nurses would not know how much the child had drunk and passed. Yet, without the nurses, a hydration assessment of the child could not be made and the correct paperwork would not be completed.

Discussion
The findings about fluid balance are an important example of equal partnership in FCC working. FCC can be a simple shift in the focus of a task, empowering parents to participate by keeping track of their child's fluid intake. This shift in responsibility is perhaps in response to the parents' perceptions of the task, highlighted by different answers to the questionnaires.

The similarity between the descriptions of FCC provided by parents and staff will have a positive effect on the child and care provided, as the nurses and family will be following the same principles. The reports of Espezel and Canam (2003) and of Coyne et al (2011) suggest that, in a ward where nurses and parents hold similar principles, the rapport between them and the work environment will benefit.

This study found that less than one quarter of parents (6/25), understood and could define FCC, but all participated in the care of their child, undertaking it without realising that they were doing so. Hughes (2007) conducted a comparable study in Ireland, also documenting similarity between nurses' and parents' understanding of FCC.
In parents’ and nurses’ responses there is a distinct separation between the two domains of ADL and nursing interventions. Previous research by Coyne (1995) showed that parents were more willing to undertake activities that would not cause their offspring pain. On the other hand, carrying out familiar care tasks gave them a sense of some control during the stressful period of the admission (Coyne 1995), the child was reassured and the parents thought they could be helpful in the strange environment (Blower and Morgan 2000).

Generally, families and nurses were working to the same expectations of care. This can be linked with parents’ natural instinct to care for their children. They may not have expectations of FCC, but they know they want to be with, and care for, their child. They are, on the whole, not given information or opportunities to engage in the care of the child beyond basic care tasks, but conversely may be expected to assist in nursing interventions if they are willing and able. The investigation highlighted the importance of negotiating care with the family, as each family’s views and abilities are different.

**Limitations** First, there were obvious limitations due to the small scale and sample size, so the data were not robust and the results could not be extrapolated. Second, the cultural and ethnic demographics of participants were not included in the questionnaires. On reflection, this would be an insightful area to explore further. A third limitation was that previous experience of a child’s hospital admission was not considered. Finally, the absence of fathers from health care was revealed but not investigated. Perhaps father-specific research needs to be undertaken to ensure FCC can be assessed for the whole family.

**Conclusion** The research found that parents were prepared for, and wanted to undertake, some elements of care for their child. While all nursing participants were able to provide a definition of FCC, the parents did not appear to have similar knowledge of the terminology, and less than half were able to provide a definition. Despite this, they carried out FCC naturally.

Most parents selected tasks from the ADL domain, continuing what they would be familiar with doing at home. This allowed continuity of care and empowered parents in their natural instinct to look after their offspring. Some parents indicated that they would like to get more involved. The nurses agreed that families should be involved in ADL, but disagreed with parental involvement in certain nursing tasks. This suggests a power imbalance, where parents do not feel able to ask to participate and nurses perceive parents as unable to carry out the tasks to the required standard.

Despite the small scale of the study, it adds to the evidence base for improving nursing practice and therefore the experience of children and families in an acute children’s ward.

**Implications for practice**

- Family-centred care (FCC) involves the collaboration of nurses and families in the care of the child.
- FCC care has to be negotiated separately for each admission.
- Expectations, roles and problems should be discussed openly.
- To empower families, planning and decisions should be shared.
- Families can be offered information and opportunities to participate in some nursing interventions in addition to everyday care tasks.
- FCC helps maintain a sense of normality and continuity for client and family.

**References**


What parents of children with cystic fibrosis expect of educational events

Feedback about an annual activity for carers highlighted the benefits of contact with others in a similar situation and the wish for more involvement in organising the event, say Hannah Gormley and colleagues

Abstract

The aim of this study was to evaluate a parent/carer hospital-based educational event and increase future participation by tailoring the format to meet parent/carer preferences. Fifty parents/carers of children with cystic fibrosis (CF) completed semi-structured telephone surveys, interpreted using frequency data and content analysis. Most were satisfied with the topics covered, presentation mode, hospital location and day of the week, but 29 were dissatisfied with a 6pm start. The main benefit perceived was contact with other parents/carers, rather than the educational content. Of the non-attenders, some reported actively limiting participation in CF education and support groups as part of their coping style. No differences were observed between the health outcome measures of children of parents who attended compared with those of parents who did not. The active promotion of social contact between parents/carers and the tailoring of events to achieve this are paramount for increasing attendance.

Keywords
Cystic fibrosis, parent/carer education, parent/carer social contact

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