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Understanding the views of parents of children with special needs about the nursing care their child receives when in hospital: a qualitative study

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Abstract

This article reports a qualitative study designed to explore parents' views on how their child with additional needs had been cared for by hospital nursing staff, focusing on how well their own and their child's needs had been identified and met. Twelve interviews with parents of children with additional needs and a thematic analysis of the interview data was conducted. Four themes were developed to provide an insight into parents' views about their experiences: their prior experiences of hospital care, including the process of being told the original diagnosis; communication with staff; nurse–parent relationships; and perceptions of nurses and nursing care. It concludes that parents experience some difficulties in developing a trusting relationship with the nurses caring for their child with additional needs. Parents perceive that nurses are not always able to recognize and respond to their needs when caring for their child. Failure to address these needs can interfere with the development of effective nurse–parent relationships.

Keywords family centred care • nurse–family relationships • learning disabilities • complex care

Introduction

The term 'child with special needs' (Burke and Cigno, 2000) is used to refer to 'young people experiencing serious and persistent physical, psychological and/or social problems' (Mahon and Kibirige, 2004: 165). It is suggested that this term is acceptable to young people and their families (Department of Health, 2004a). The number of children in the UK with physical and developmental disabilities has increased over the past 15 years (Hancock, 1995; Warner, 2000). A recent estimate suggests there are 700,000 children with disabilities in the UK, the majority of whom are cared for at home by their families (Department of Health, 2004b). The growth in numbers of children with complex needs can be attributed to developments in the care of preterm infants, children suffering trauma and improved clinical management of long-term conditions (Hancock, 1995; Newacheck et al., 2004).

Children with additional needs have a greater frequency and length of hospital admission than children without disabilities (Mahon and Kibirige, 2004). Their distinctive service requirements are acknowledged in the *National Service Framework for Children, Young People and Maternity Services* (Department of Health, 2004a), as well as government policies such as *Valuing People* (Department of Health, 2004b) and *Together from the Start* (Department of Health, 2003). The latter stresses the significance of effective communication, integration of care and recognition of the impact upon families with ill children.

Hospital-based children's nursing care has been based on the principle of family-centred care (Darbyshire, 1995), which puts an emphasis on the development of nurse–parent partnerships and a more equal balance of power (Coyne, 1996; Hugman, 1991). There is some evidence to suggest that children's nurses have experienced difficulties in putting some of these principles into practice. There have been reports of nurses' unwillingness to relinquish control (Neill, 1996) or feelings that their 'expert' role is threatened (Kawik, 1996). A recent review on the subject (Warner, 2000) found that parents carry the burden of care in hospital and that, as a result, the integration of nursing care can be lacking.

The application of the concept of family-centred care in the delivery of care to children with additional needs raises further questions because in this situation, parents are particularly likely to need support and advice while being regarded as experts in the care of their child (Ford and Turner, 2001; Simons et al., 2001). Ford and Turner's (2001) small study of nurses' experiences of caring for children with additional needs in hospital highlights their concerns over recognition of parental expertise, feelings of frustration and guilt and difficulty in developing trusting relationships. This study was designed to examine these findings further by exploring parents' views of the nursing care that their child with additional needs had received in hospital.

Method

A qualitative methodology was used to meet the aim of exploring parents' views of the nursing care for their child with additional needs while receiving care in hospital. The specific research questions that the study was designed to answer were as follows.

> RQ1: What do parents identify as the positive and negative aspects of the nursing care that their child received in hospital?
>
> RQ2: What do they think would have improved their experience or their child's experience?
>
> RQ3: What are their views on nurses' attitudes towards their child and themselves?

The purpose was to generate detailed, contextualized narrative information that would allow for identification of explanatory themes which could be used to understand parents' views. Semi-structured interviews were selected for this purpose due to their suitability for developing open questions with small sample sizes (Polit and Hungler, 1999).

Sample

A purposive sampling strategy was used to recruit parents whose experiences would be relevant to the research questions (Mason, 2002). The aim of purposive qualitative sampling is to identify and recruit people with a range of experiences and opinions that will allow the research questions to be answered. An effective purposive sampling strategy should lead to data saturation (Streubert and Carpenter, 1999). Data saturation occurs when data generation processes, such as interviews, are unable to yield new information that cannot be incorporated into the explanatory themes being developed. In relation to the study aim stated above, it was anticipated that between 10 and 20 interviews would be required for data saturation.

The sample of parents was recruited from one National Health Service (NHS) Children's Centre in the East Midlands, which provides respite care for approximately 50 parents and children with learning disabilities and complex health needs. The inclusion criterion was that participants should be the parents of a child using the Children's Centre who had been admitted to hospital for acute care within the previous year. It was planned that parents whose situation would have made contact inappropriate due to illness, stress or other family problems, would be excluded on the advice of the Children's Centre manager. However, this did not prove necessary. All parents who met the inclusion criterion received a letter from the Children's Centre manager informing them of the study and inviting them to take part. There were 16 positive responses to the invitations to take part (32% of the 50 parents who use the service). The parents who replied that they were interested in taking part in the study were contacted

by telephone to arrange a convenient time for an interview. Twelve interviews were successfully carried out. Written informed consent was obtained from participants prior to starting the interview. A sampling frame was drawn up to ensure that the sample included:

- parents with more than one child;
- parents of a male child;
- parents of a female child;
- parents of a child aged under five; and
- parents of a child aged five or over.

Six interviews were carried out at first, and after a preliminary analysis it was decided to conduct a further six interviews to include additional parents with more than one child and parents from black and minority ethnic backgrounds. This would allow the preliminary themes to be tested further and approach data saturation.

An interview schedule was designed in the form of seven open questions, with optional follow-up questions or prompts, to promote participant-guided, flexible conversation. The questions covered topics including parents' views on the nursing care received while their child was admitted to hospital, the positive and negative aspects of this care, what would have improved their experience or their child's experience, and the nurses' attitudes towards their child and themselves. An effort was made by the interviewer to maintain an open, informal approach which gave opportunity for the participants to develop trust in the interviewer and to express their views honestly without constraint. The interviewer's position as a student nurse was acknowledged during the interviews in order to encourage parents to feel that the researcher could learn from their experiences.

Research governance

A favourable ethical opinion for the study was obtained from the local research ethics committee and approval was obtained from the relevant Primary Care Trust research and development directorate. Interviews were carried out in a room within the Children's Centre; a familiar setting for parents which also provided the necessary privacy. Anonymity for the participants was maintained by removing names and identifying features from tapes and transcripts immediately after interview. Only the researchers had access to the interview transcripts and they were kept in a locked filing cabinet during analysis.

It was recognized that the interviews would cover personal and sensitive issues that may upset participants. Thus it was agreed that the Children's Centre manager would be available to provide support and information if required, and an information sheet providing details of a variety of self-help organizations was made available to parents.

Analysis

A pragmatic thematic analysis of the data was used (Mason, 2002), which did not adopt a particular qualitative approach such as grounded theory or phenomenology. It has been argued that use of a particular methodological theory to guide analysis can limit integration and testing of the findings against the existing literature (Avis, 2003). Interviews were taped and then transcribed. The transcript data was analysed by reading, rereading and identifying salient sections of text in response to the questions. These chunks of text were then coded so that text expressing similar ideas could be linked (Mason, 2002). The codes were recorded on index cards with associated quotations, then the accumulated index cards were grouped together according to topics, which eventually led to the identification of four themes that could provide a coherent account of parents' views. The researchers tested these themes against the interview data by examining them for coherence and comprehensiveness, actively searching for instances in the parent interviews where there was inconsistency with the themes and checking that all the parents' views had been accounted for; the researchers also checked the consistency of the themes with the literature reviewed.

The researchers followed qualitative research practice on reflexivity to manage the influence of their own beliefs and hypotheses on the data analysis (Mason, 2002). Reflexivity requires that qualitative researchers actively consider their influence upon the data generated during a qualitative study as a result of their role, beliefs or emergent hypotheses. Reflexivity was accomplished by the interviewer keeping a contemporaneous record of their thoughts and ideas during planning and carrying out the interviews: these ideas were discussed by both researchers during the analysis phase in an effort to recognize assumptions, correct misapprehensions and avoid premature interpretations of the data.

Findings and discussion

Overview of themes

Four key themes relating to parents' views of the acute care delivered to their child by nurses on children's wards were identified from analysis of the interviews. Without doubt, the most important theme was communication with staff. However, to some extent the other themes of prior experiences of hospital care, nurse–parent relationships and parents' perceptions of nurses and nursing do overlap. The distinctions between themes are based on the need to provide a coherent explanation of parents' views.

Prior experiences of hospital care

The influence of extensive experience of health care encounters which had been accumulated over their child's lifetime was evident when interviewing the parents. One mother described it as their 'hospital career'; parents tended to see each health care encounter as part of a developing story, as has been noted in other contexts (Avis et al., 1997). The impact of the diagnosis of a child with additional needs on the family was central, as one of the parents noted; it 'scars you for years to come'. One parent vividly described the diagnosis being given by a doctor before he went 'home for his Friday fish and chips', and that subsequently there had been 'no back up at all, terrible'. This parent also remembered the nurse who was caring for her child that day as someone who 'tried . . . but it was too much for them at the time'. Clearly, such memories had influenced subsequent experiences (Fleitas, 2000). In addition, the persistence of these memories could be linked to the idea of 'chronic sorrow' (Fraley, 1990), where the loss of an expected 'perfect' child can lead to a sustained grieving process for parents and siblings (Savage, 2004) which is reawakened at times of hospitalization. The idea of chronic sorrow may be linked to another aspect of parents' experiences, that their daily life was felt to be a 'struggle'. They described their day-to-day life as presenting many challenges to 'cope', focused around meeting the needs of their child and, in particular, dealing with the responses of other people. Their talk of the struggle was characterized by phrases such 'dealing with problems', 'fighting' for things and living with 'baggage'. One parent spoke about her sensitivity to the views and attitudes of other parents in the hospital who had 'normal' children and other parents' 'ignorance' about her child. The nature of the struggle that parents with children with complex needs experience has been reported elsewhere (Carnevale et al., 2006; Kirk, 2001). The uncertainties that these parents' experience in working towards a notion of family 'normality' and striving for stability are closely linked to their anxieties about failure.

Communicating support

All the participants mentioned the significance of communication with staff when discussing the care that their child had received in hospital. However, it was clear that there were several dimensions to parents' views about the quality and significance of communication with staff. First, they placed a high value on 'direct' communication between the nurse and their child. They acknowledged that communication with their child could be 'difficult' but also that, in most cases, it was lacking. From the parent's perspective this was often related to their child being able to understand more than nurses had assumed. As one parent described it: 'All the time he's having things done to him and at him without being told what's going to happen.' Second, parents spoke about their own communication with nurses. Various parents spoke about nurses needing to 'communicate better with parents': they highlighted the importance of their need

to be informed about their child's care because 'you want to feel in control'. This is particularly significant in a context where parents feel that life is a daily struggle and any sense that may be a loss of control can equate to a feeling of losing that struggle. Third, communication between health care staff was discussed, but usually in a positive light in terms of nurses: 'They do pass messages on to each other.' However, parents had concerns about communication with the rest of the health care team, giving examples of having to explain to nurses what the doctors had said would happen next.

The essence of nursing, it has been claimed, is about communicating care (Crawford et al., 1998) and some shortcomings in the processes of communication were clearly identified by the parents interviewed in this study: 'It's the communication that's the big thing that's lacking, isn't it?' This was underlined by one mother, who discovered that nurses were given at least some communication training:

> You've shocked me . . . I thought that [lack of education] was why they were so bad with him . . . I'm really disgusted now.

Simons et al. (2001) concluded that good communication was integral to quality care for children with additional needs in hospital, especially so in a context where nurses' assessments of parents' need for support are likely to be based on assumptions rather than discussion with parents (Brown and Ritchie, 1990).

Nurse–parent relationships

The parents interviewed acknowledged that they were deemed the 'experts' by nurses; and parents recognized that they did possess extensive knowledge regarding their child's varied and complex needs. However, in practice this meant that parents felt that they were left to give medicine, food and personal care. Although parental involvement in care is consistent with principles of family-centred care, parents reported that this tended to be assumed rather than negotiated. Parents thought that their involvement had been expected rather than negotiated: 'It's absolutely assumed.' One consequence of this assumption was that parents perceived it as a lack of attention on the nurses' part towards their child. It also left them feeling unable to leave the bedside: 'I am too frightened to leave the room because he's going to be ignored.' Parents who are struggling to remain in control need to trust nurses to recognize their child's needs, as well as their own. This was linked to a lack of recognition of their needs for emotional support from nurses: 'Our issues are complex really – emotionally as well as physical.' In addition, an understanding of cultural issues was mentioned, with an Asian father noting that fathers can have 'little to do with children in our culture' and that nurses need to be aware that, as a result, the father sometimes 'needs more input'. It appeared to most of the parents interviewed that nurses had assumed that recognition of the needs of the child could be left to the parents without an

acknowledgement of the parents' need for emotional support and information. This undermined the parents' development of trust in nurses.

Parents' perceptions of nurses and nursing

The idea of nursing as a caring profession influenced parents' expectations and perceptions of nurses. Some parents commented that they felt that the attitudes of some of the nurses lacked a caring element; they observed nurses that were 'just doing the job'. One parent thought that nurses 'build up a hardness' in response to the challenges of the job. However, other parents spoke extremely highly of nurses and the role that they fulfil: 'Nurses are the ones that mop up the blood . . . and do the actual work.' And some parents expressed trust as well as respect for nurses: 'I know that he's safe . . . [the nurses are] there all the time.' This variation in their observations of nurses was commented upon by parents: '[Some] are busy, but have time for you and there are other [nurses] who are just busy.' However, a belief that nurses should be caring and trustworthy 'should be the norm, not the exception'.

The variation in perceptions of nursing is worth considering in terms of what makes a parent view nursing care in a positive or a negative light. One explanation of this could be that parents' beliefs about who ought to take responsibility for the care of their child will influence this judgement. A lack of discussion or failure to obtain clarity over parents' involvement in the care of their child creates the potential for parents to feel anxious about who is in control of their child's care. It could point to the tension that parents feel in integrating their own experiential knowledge about their child's health needs with the less individualized care that nurses might provide (Kirk et al., 2004). Also, it may reflect parents' concerns about who will recognize their child's health care needs or their own needs for information and reassurance.

Strengths and limitations of the study

It should be acknowledged that the study was carried out on a small sample of 12 parents whose experiences of hospital care for their child varied depending on the nature of their needs and reason for their hospital admission. All the parents were recruited through one respite care Children's Centre, and this will have limited the diversity of views obtained. However, the interviews yielded rich and detailed information: it appeared to the researchers that the interviews had acted as a release for parents, providing an opportunity to talk about their views and experiences and to be heard by an impartial listener.

Conclusion

The four themes presented above provide an insight into the views of parents about their child's nursing care in hospital. Children's nursing policies emphasize the value of family-centred care, and this study is not the first to raise questions about a theory–practice gap in terms of the negotiation of responsibilities in family-centred negotiated care (Newton, 2000). The parents interviewed indicated that boundaries between the roles of nurse and parent were not discussed and that questions over responsibilities for recognizing and meeting their child's needs were not resolved. It is understandable that parents of children who have additional needs are deemed 'expert' (Geeter et al., 2002). However, it was found that this assumption can lead parents to think that there was a lack of nursing input in terms of practical and emotional support. In particular, parents felt that nurses did not understand their experience of daily struggle, or the way that 'chronic sorrow' and stigma can make them susceptible to feelings of being excluded or belittled. As a consequence, their needs for communication and reassurance were not being recognized by nurses. Therefore, it is unsurprising that parents' perceptions of nurses and nursing were not always inspired by trust in their capabilities and caring attitudes. To some extent, the lack of trust and confidence that parents felt in nurses mirrors the guilt and lack of confidence described by Ford and Turner (2001) in their study of nurses' experiences of caring for children with additional needs.

Although this was a small, exploratory study and the findings should be treated as preliminary, we found some reasons to be concerned about the approach that nurses take to the care of children with additional needs and, in particular, their ability to recognize their parents' needs. Although the study provided some examples that indicate that nurses are capable of effective communication with children and their parents, there were other examples that suggest that these skills are not utilized in negotiating care or identifying the child's and parents' needs. It is suggested that further studies are necessary of the factors that influence nurses' confidence and abilities in their direct communication with children with additional needs and their approach to recognizing parents' needs. Our conclusions lend weight to the need to develop an educational model for improving communication between nurses, families and children (Lyte and Jones, 2001).

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