

Challenging the philosophy of partnership with parents: A grounded theory study

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Abstract

Background: Parent participation is viewed as a pivotal concept to the provision of high quality nursing care for children and their families. Since the 1990's, the term 'partnership with parents' has increasingly been reported in the literature and adopted as a philosophy of care in most paediatric units in the United Kingdom.

Objectives: To explore children's, parents', and nurses' views on participation in care in the healthcare setting.

Design: Using grounded theory, data were collected through in-depth interviews, and participant observation. Sample consisted of eleven children, ten parents and twelve nurses from four paediatric wards in two hospitals in England.

Results: Most nurses assumed that parents would participate in care and viewed their role as facilitators rather than 'doers'. Nurses reported that the ideology of partnership with parents did not accurately reflect or describe their relationships with parents. Parents could never be partners in care as control of the boundaries of care rested with the nurses. Parents felt compelled to be there and to be responsible for their children's welfare in hospital.

Conclusions: The pendulum of parent participation has swung from excluding parents in the past to making parents feel total responsibility for their child in hospital. It is argued that the current models or theories on parent participation/partnership are inappropriate or inadequate because they do not address important elements of children's, parents' and nurses' experiences in hospital.

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Keywords: Parent participation; Partnership; Hospitalised children; Nurses

What is already known about this topic?

- Partnership with parents is a principle that is valued and promoted across paediatric healthcare systems internationally.

What this paper adds

- Parent-nurse relationships could not be characterised as a partnership.

- Nurses were reliant on parents' contribution as informal carers to the organisation of nursing care.
- Expecting parents to stay with their child constantly and be responsible for care may threaten the stability and functioning of the family unit.

1. Introduction

Parent participation in the hospitalised child's care has been increasingly emphasised in paediatric nursing practice, since the issue of the detrimental effects of hospitalisation upon children was first raised some 60

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years ago, by the Curtis Report (Ministry of Health, 1946). More recently the National Service Framework for Children, Young People and Maternity Services (Department of Health, 2003) has explicitly emphasised the importance of partnership with parents and promoting the role of families in the care of their hospitalised children. The promotion of parent participation in the hospitalised child's care has been driven by evidence spanning a 50 year period, that highlighted the adverse effects of hospitalisation for both children and their parents. The adverse effects of hospitalisation such as separation from parents, anxiety, unfamiliar environment, effects of illness means that children have a strong need for their parents who are the familiar caregivers. It is now well accepted that parent participation is beneficial for the child and the family, and that stress and anxiety can be reduced for both parent and child if a parent or familiar caregiver accompanies the child into hospital (Wolfer and Visintainer, 1975). Thus parent participation is a crucial element in the delivery of quality care for children and families and is seen as a central tenet of paediatric nursing in England. Likewise parent participation is a key issue in children's health care globally, for example: USA (Jackson et al., 1978; Knafl et al., 1988; Ahmann, 1994); Canada (Espezel and Canam, 2003); Sweden (Kristensson-Hallstrom and Elander, 1994; Ygge and Arnetz, 2004) and Australia (Shields and Nixon, 2004). Although parent participation has been promoted for several decades, been formalised in numerous Government policy documents, and embraced by health professionals in hospital and community, there has been little constructive change in guidelines for children's nurses in clinical practice. Policy can identify humane principles for children's care but it is unclear whether these recommendations are truly operationalised. Despite partnership in care being the accepted norm, the philosophy has never been thought through in terms of relationships, benefits and challenges. Significant research by Darbyshire, (1992) and latterly Callery, (1995) provided rich descriptions of the problematic nature of parent participation but from the parents' and nurses' perspectives only. There seemed to be a deficit of research, which included the child's views, along with parents and nurses in relation to participation in hospital care. Hence this research study sought these three differing perspectives using grounded theory in order to uncover the core issues and develop explanatory theory.

2. Background

For many years there was no conceptual model to facilitate the concept of parent participation until Casey (1988) published the partnership model of paediatric nursing. This model was enthusiastically accepted by

nurses and nurse educators as the ideal way of structuring nursing interventions with parents and children in the hospital. This model states that "the care of children, well or sick, is best carried out by their families, with varying degrees of assistance from members of a suitably qualified health care team whenever necessary" (Casey, 1988, pp.8). Subsequent articles reiterated that the 'partnership model' is based on the assumption that parents are able and willing to be effective carers and that the major responsibility for the healthcare of the sick child rests with them, with varying input from health care workers (Casey and Mobbs, 1988; Casey, 1993). Thus the emphasis seems to be on the family doing the care with assistance from the nurses, which implies that the family is the focus of care. However, Casey (1993) states that "the family is not another focus of nursing care, rather the family's central importance to the child is recognised. The paediatric nurse is concerned with the structure of the family, the relationships within it and the forces affecting it, but only so far as they affect the family's ability to care for the child" (pp.8,9). This functional view of parents' role seems to contradict the concept of partnership, as a partnership implies a relationship that is concerned both with the family and the nurse. Partnership implies equality among partners, information sharing, and negotiation of care and shared responsibility.

It is an assumption that partnership with parents is the 'holy grail' desired by all participants, particularly parents. In a literature review Coyne (1995a) found that the continuum of parent participation may range from total involvement to complete deference to professionals, moreover it may change over time. It is an assumption that the term 'partnership' accurately describes the nurse–parent relationship since research studies spanning 4 decades indicate that nurses have difficulty in supporting and facilitating parents' participation and likewise parents' experience difficulty in determining nurses' expectations (Brain and Maclay, 1968; Brown and Ritchie, 1990; Darbyshire, 1992; Gill, 1993; Callery, 1995). The social implications of parental participation on families' and nurse' roles has never been clearly explicated (Coyne, 1995b). These studies are important in illustrating that the organisational features have not changed in line with what is needed. In a comprehensive analysis and evaluation of Casey's model, Lee (1998) concluded that the model is in fact a middle range theory that deals with only one specific concept, namely partnership which is not adequately defined. Furthermore that the notion of partnership is not based on research evidence, there has been no development to its theoretical base since its inception, it has no formal assessment framework, and does not reflect needs of multicultural society or community settings. The most serious criticism is in relation to the model's assumptions and lack of logical congruence

(Lee, 1998). Hence there is a need to research nurses, parents and children's understanding of their role to help determine the effectiveness of the concept of partnership. This paper is a contribution to the knowledge in this area.

3. Method

Grounded theory was chosen as the most appropriate method for several reasons. Although there is a plethora of anecdotal literature and studies on parent participation, it remains a problematic issue that is poorly understood. There is no clear consensus about the concept and the information from previous studies seems to be ambiguous, incomplete or even contradictory. This indicated the need for a fresh approach to the topic of parent participation and grounded theory may be used to provide a fresh perspective in a familiar situation (Glaser and Strauss, 1967). Secondly most of the early research on parent participation has been mainly descriptive and there have been few efforts to construct explanatory theory in this area. The past research appears to have focused on identifying facts rather than seeking to uncover the process and patterns in the phenomenon. Grounded theory appeared suitable as it is principally a strategy for analysing data that ensures the "discovery of theory from data systematically obtained from social research" (Glaser and Strauss, 1967, p. 2). Thus the goal in grounded theory is to develop theory to describe a particular social process.

Data were collected through in-depth interviews and observation, with the aim of investigating parent participation from the perspective of children, their parents and nurses from 4 medical/surgical paediatric wards in two hospitals. Hospital A is a specialised paediatric hospital that takes referrals mainly from across London and South of England whilst hospital B is a large district general hospital that cares for a diverse ethnic population in London. The experiences of the participants in a specialised setting (e.g. children's hospital) may be different from those in a generalist setting (e.g. large district general hospital) because of different philosophies of care and different organisational constraints. Selection of two different sites would therefore increase the promise of quality, depth, and richness in the research findings. Ethical approval was sought and obtained from the ethics committees responsible for the two hospitals in the study. Voluntary informed and written consent was obtained from all the participants.

Specific objectives were:

- to examine the conditions, effects and management of parent participation.

- to understand how parents, their children and nurses negotiate roles and relationships within the hospital setting.
- to generate a grounded theory which explains the process of parent participation.

Several observational periods were conducted prior to data collection to establish familiarity with the ward layout and daily routine, the staff and the families. The initial visits concentrated on general observation of the situation, learning names of staff, noting setting details and grasping the usual routine of daily events. This information proved to be very useful in determining 'good times' of the day in which to approach parents, children and nurses. The type of observation was 'observer as participant' in that the predominant activity was to observe and potentially to interview (Streubert and Carpenter, 1999). The observations lasted no longer than 3 hours on any single day and were conducted over 1 year. All observations were written up as field notes after each observational period as this proved to be the least intrusive method of collecting information.

To provide guidance with minimal control, the interview schedule consisted of four topic headings, which were: reason for hospitalisation; parents' participation; nurses' participation and children's participation. The questions served as prompts if the case arose. The nurses were interviewed at a time convenient for them, before or after their shift work. Some interviews were also obtained during quiet periods in the day. Interviewing nurses after work could cause inconvenience for some respondents. Most of the parents noted after the interview that they felt 'better' because they had felt 'listened to'. The children were interviewed by their bedside if they occupied a single room or in a quiet room nearby. The nurses and parents interview lasted 60–90 min. and the children's interviews were of shorter duration, usually 30–40 min. All participants were obtained through purposeful sampling, in that they were present and participating in care. The children ($n = 11$) were aged 7–14 years and had a range of acute and chronic illnesses. The parents ($n = 10$) were aged between 30–56 years and 2 fathers and 8 mothers were interviewed. The nurses ($n = 12$) were aged 23–42 years and 8 were charge nurses and 4 were staff nurses.

3.1. Data analysis

The data were analysed with the aid of File Maker Pro (1992), a computer package that created cards that could be compared and contrasted. The process of generating theory involves deconstruction and reconstruction of the data through the constant comparative method of analysis (Glaser and Strauss, 1967). Thus as each transcript is coded, the constant comparative

analysis begins. Each coded incident is compared with similar coded incidents; new concepts are compared with new incidents and concepts compared with concepts. At the same time that the categories are being formed, the process of developing and integrating the categories is occurring concurrently. This process was like trying to put the pieces of a puzzle together without having the picture available. Several strategies as recommended by Glaser (1978) were used to assist the process which were: constant comparison and reduction; theoretical sampling; theoretical coding; writing memos and drawing diagrams. The constant comparison of concepts contributes to building the core categories that eventually lead to the substantive theory. The rigorous steps of the data analysis process (as described by Glaser, 1978) were adhered to and this process contributed to the trustworthiness of the findings.

4. Findings

The findings revealed that all participants' experienced considerable disruption to their worlds and had difficulty with participation in care. The core concept was 'finding a balance' which appeared to be a process used by children, parents and nurses to achieve equilibrium between their social worlds and the social order of the ward. The main findings in relation to the core concept will not be explored in this paper as the focus is on presenting the data, which challenges the philosophy of partnership with parents.

5. Parents' perspectives

The relationships between the categories from parents' data are illustrated in Fig. 1. The data will be discussed under four concepts: Concern for child; uncertainty about nurses' presence; difficulty providing care; disruption for parents and family.

5.1. Concern for child

The concept of 'concern for the child's welfare' was very prevalent, and presented as an explanation for parents feeling the need to be with their child in hospital, which has been reported elsewhere (Coyne, 1995b). Most parents justified their presence as an unconditional aspect of being a parent or mother and loving one's child. Parents were concerned for their children's emotional welfare and felt that their familiar physical presence would provide reassurance for their children during the hospitalisation. Parents emphasised the importance of normalisation and the provision of emotional care for their children. Keeping the children

occupied would help reduce fears and anxieties, which would encourage their recovery from illness.

Similarly the children talked about how their mother or father provided companionship by chatting with them and playing games, which helped towards relieving boredom. Likewise parents reported that their children demonstrated by their behaviour that they wanted their parent to stay with them in the hospital. 'Whenever I go down to ... I mean just going down for meal times (*child says*) "how long are you going to be" that sorta thing, so he doesn't show, he doesn't put over that he needs me to go away from him more perhaps the other way around' (Mother 11C). Parents' viewed their role as providing items such as: clean clothes, food, drinks, treats, magazines and money for snacks and phone cards. This did not mean that they were not willing to help their children with other needs. Most notably, the parents' primary motive for being there was to provide emotional support for their children rather than to be involved in giving physical care. It involved emotional caring in the sense of *being there* and *being with* rather than having responsibility for providing all physical or practical care.

5.2. Uncertainty about nurses' presence

Being there appeared to be a moral imperative for parents, but at the same time they reported feeling compelled to be there because they lacked confidence in nurses' being available for their individual child constantly. Most parents viewed the nurses as being unable to be there consistently, due to the nature of nurses' shift work system, and focus on technological care, administrative duties and organisational demands. Technological care was highlighted by the way some nurses behaved when they made contact. Their actions were seen as being particularly focused on performing clinical duties such as taking vital signs, giving medicines, and checking the mechanical functioning of equipment, rather than being with the parent and child in an emotional sense. Thus the nurses may have been physically present on the ward but not present in the way parents expected. For example: 'Nurses haven't got the time to sit and listen to the parents and to talk and to listen to the children really and have time to play with the children which is part and parcel of their care really, getting to know them... yeah like I say in some ways it has changed for the better and in other ways I think there's just the bit missing' (Mother 1A).

The fact that nurses were not allocated to a particular child on a regular basis was also seen by some parents as possibly hindering the nurses from knowing the particular details of the child's illness and treatment programme and secondly establishing a relationship with the child. It was seen as important that nurses knew

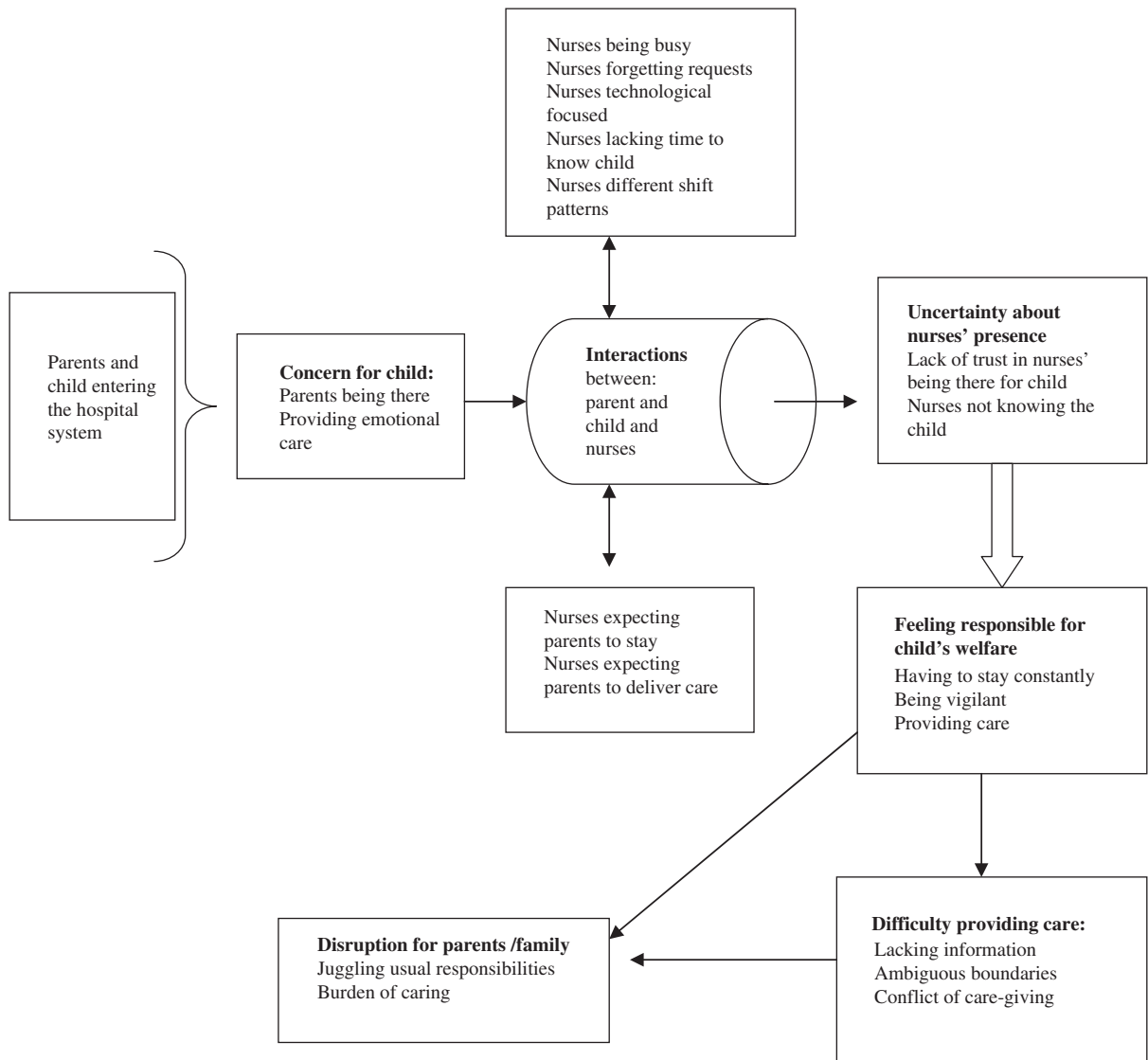


Fig. 1. Parents' data.

the child's typical pattern of responses in order to interpret symptoms accurately and provide quality nursing care which has been reported elsewhere (Galvin et al, 2000). Nurses expressing interest in the child as a person was seen as nursing behaviour that provided reassurance that the child would be safe and would be cared for in the parents' absence. Nurses making a conscious effort to know the child would demonstrate dependability and concern thereby gaining the children's and parents' trust.

Yet some children had developed a friendly relationship with some nurses and appeared to feel confident of their help and support. The children described most nurses as very nice, friendly and helpful. For example: 'Brilliant...they're really friendly and chatty, lot better

than what I thought' (Child 9C). The discrepancy between parents' and children's accounts may be explained by viewing knowing as consisting of different forms of knowing that are characterised by the levels of trust between participants within a relationship. The children may have formed a friendly relationship with the nurses that was not necessarily characterised by trust. This labelling of child-nurse relationship is not meant to denigrate the nature of the relationship as being on friendly terms may be all that is desired by children whilst in hospital. Although the children were relieved to find that the nurses were nice people and this appeared to help assuage some of their concerns they did not explicitly link knowing the nurses with learning to trust the nurses.

Some parents reported that nurses always appeared very busy elsewhere and observed that care was left undone, which implied to them that they could not rely on nurses being there for their particular child. Imposing on nurses time was revealed in parents' accounts of waiting for opportune moments to get the nurses' attention, or trying to ask for help in a discreet polite manner. Some parents described situations where they sought nurses' assistance but then the nurse appeared to forget the requests, which resulted in parents being reluctant to ask for assistance again. The difficulty with attracting a nurse presence appeared to cause concern for parents and they worried about their children having unmet needs. The fact that some parents had difficulty getting help for their children implied to them that their children would have less chance of getting help from the nurses because of their relatively powerless position (being children) and potentially could experience neglect. 'Sometimes the ward is really busy they don't have the one to one attention for Tom (pseudonym) and you feel as a parent that you are better here... you would never forgive yourself if you weren't there and something went wrong' (Mother 4A). It is therefore, not surprising that under these circumstances some parents felt compelled to be present for their children and being there became a critical requisite rather than a personal choice. For example: 'I think everything is changed so much more...for parents...they've got to stay' (Mother 1A). Similarly other parents have reported feeling responsible for their children's care and being forced to maintain a vigilant presence because of concerns about nurses' ability to be there and children potentially having unmet needs (Anonymous, 1992; Ygge and Arnetz, 2004). The link between lack of trust in nurses' presence and parents having to ensure a vigilant presence has been reported in other research studies (Burke et al, 1991; Kirschbaum and Knafl, 1996; Hupcey, 1998).

5.3. *Difficulty providing care*

Parents' concerns about nurses availability for their children, coupled with nurses' expectations of their role resulted in parents feeling responsible for their children's physical care and emotional welfare in hospital. Parents were willing to provide basic childcare but were generally reluctant to perform technical nursing care in case this would cause pain, harm or discomfort to their children. The exceptions were parents of chronically ill children who considered themselves experts in particular aspects of nursing care, so were willing to continue providing such care. Inflicting pain on one's child went against the natural impulse of being a parent and protecting one's child. Parents were also anxious about performing technical nursing care in case their inexperience or lack of knowledge about medical and nursing

matters could cause potential harm to their children. If the technical nursing care was necessary for their children's subsequent care at home, then parents were willing to learn such care. Technical nursing care was generally viewed as the nurses' responsibility because of their training and expertise. For example: 'She'd sooner let the nurses put the calamine on her...they get paid for it, they take more care...they know how to do it, I'm a bit heavy handed at times. I think she's more confidence in them because she knows it's their job, they're trained for it...If they asked me I would but I wouldn't want to, I'd be frightened I was going to hurt her. They know exactly how to do it' (Mother 7B).

Expecting parents to provide care that they were not comfortable with or which parents felt that staff should have provided was considered negatively. Yet parents were willing to help with the care because they would not neglect their children. Equally they were willing to adapt their role to comply with nurses' expectations in order to establish good relationships. Harmonious relationships were seen as increasing the likelihood of quality care for their children. However parents encountered difficulties finding a balance between their role and the nurses' role on the ward due to lack of information and ambiguous boundaries. All of the parents commented on the deficit of information generally, particularly in relation to nurses' expectations of their role. They described being left 'to get on with things' in that the nurses appeared to allow them free reign with their children's care. For example: 'I wasn't quite sure of what I was allowed to do and what I wasn't allowed to do, whether really the nurses should have been doing some or the things or not but I suppose that should have been set out from the beginning. What did they expect us to do' (Mother 9C).

Parents were anxious in case they neglected to do something that the nurses expected them to do or exceeded their role remit and encroached on professional territory. Either action could incur nurses' displeasure. Hence being placed in a 'laissez-faire' situation wherein expectations of them were not clearly delineated created anxieties for some parents. Parents were anxious to avoid interactional difficulties with nurses in case this could adversely affect the quality care provided for their child. The data revealed that parents learned about nurses' expectations through three processes, which were: seeking permission for actions; learning through trial and error; and learning about norms and expectations over time. For example: 'I used to feel that I couldn't ask them to do anything for me. I felt guilty everything I asked them for...you don't want to go in their cupboards you know. With repeated admissions, you gradually learn what the ward routine is, what's likely to happen at what times of the day, where to get things from, you learn it partly by observing what happens to other people and partly by

asking and partly by experiencing' (Mother 1A). One parent commented that although care was very regimented in the past, the advantage was that nurses' role was clearly defined in that the nurses were the professionals who did all the nursing care with no contributions from lay people. Consequently there were no hidden expectations and this was reassuring for parents.

Parents' difficulties in trying to find a balance between their role and the nurses' role due to lack of information, non-negotiation of roles and ambiguous boundaries have been reported before (Callery and Smith, 1991; Coyne, 1995). Likewise parents' need for information on roles and boundaries has been a consistent finding in other research spanning four decades (Skipper and Leonard, 1968; Stacey et al., 1970; Algren, 1985; Darbyshire, 1992). Similarly in other studies, parents reported that they were expected to adapt their role in accordance with nurses' expectations, but they were not informed directly of those expectations (Hayes and Knox, 1984; Robinson, 1985, 1987). The lack of explicit information and explanation about respective roles meant that parents could be left to 'muddle along' learning their role through trial and error. Similarly parents of children with chronic illness reported "figuring out" the system over time through a process of trial and error (Thorne and Robinson, 1988). Most parents felt that it was quite important to stay on the "right side" of the nurses and this required delicate social balancing as some parents were unsure of role boundaries. These actions and the issue of social balancing have been reported in other studies of parent participation in care (Darbyshire, 1992; Callery, 1995).

5.4. *Disruption for parents/family*

The effort of maintaining a constant presence in the hospital resulted in considerable disruption for parents and their family life. Parents experienced difficulty finding a balance with being there in hospital due to competing needs of other family members, occupational role, usual responsibilities, personal needs, and housework. Ensuring a constant presence in hospital caused parents to incur financial costs (e.g. cost of food and drink, travel expenses, loss of income); personal cost (e.g. disruption and distress); and social costs (relying on family, neighbours), which have been reported elsewhere (Callery, 1997). The effort of being there was potentially more stressful for parents who had minimal resources to call upon in the sharing and balancing of other responsibilities. The burden of maintaining a constant presence and juggling other responsibilities meant that many parents neglected their own personal needs and frequently reported 'going without' the basic necessities such as food and rest. Being compelled to provide nursing care for their children resulted in some parents

feeling pressurised, unsupported and burdened. Consequently some parents appeared to feel that their coping resources were "stretched to the limit". For example: 'Basically as a parent it feels like you are doing everything and it's very exhausting...I find it very very tiring so does my husband, partly because your emotionally quite stressed in that she's on the whole not very happy and you're worrying about the fact of the operation tomorrow or whatever happens to be but partly cos you are basically doing all the caring' (M10C.27). Parents were acutely aware that they were in a relatively powerless position and that they needed to comply with the nurses' expectations and the usual routine of parents being there throughout the day. This led some parents to conceal their anxieties as they spoke about pretending to cope in order to be seen as a 'good' parent. Similarly, other research with patients have reported that they "toe the line" as they do not want to miss out on care or be labelled as difficult by health professionals (Waterworth and Luker, 1990; Henderson, 1998). The link between being a "good" parent and attracting a nursing presence was also supported in the nurses' data and identified in other extant studies of nurse-parent relationships (Darbyshire, 1992; Price, 1993). It seems that being a compliant parent had the potential to increase nurse-patient contact as some nurses reported using avoidance strategies with parents who exhibit prolonged anxiety.

6. Nurses' perspectives

The relationships between the nurses' categories are illustrated below in Fig. 2. The data will be discussed under four concepts: Assuming parents will participate; relying upon parents; fitting in with parents; and pretending it is a partnership.

6.1. *Assuming parents will participate*

It is understandable that the parents were under the impression that they had to get involved in doing the care as the nurses did expect the parents to be there and to participate in the children's care. Nurses usually justified the need for parent participation with reference to literature on maternal deprivation. Parent participation was viewed as essential for both parents and their children's welfare as it reduces separation anxiety and stressful aspects of hospitalisation. Parents' presence was also seen as the unconditional aspect of being a parent, meaning being a 'good' parent and loving one's child. Although some nurses seemed aware that parent participation could place unrealistic expectations on parents because of family commitments, care of dependent siblings, and work responsibilities, they nevertheless assumed parents would participate as this

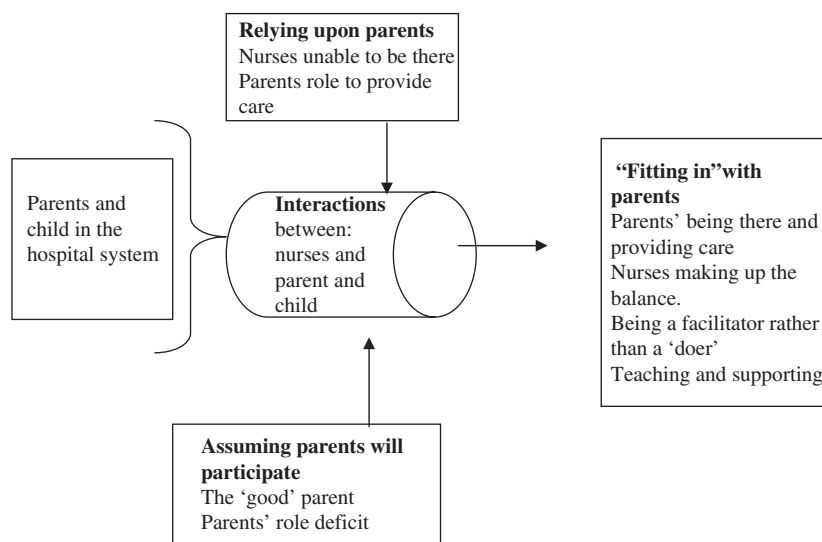


Fig. 2. Nurses' data.

was the norm and it would be very unusual for parents to deviate from the norm. For example: 'We assume when they are here that they will get on and do it and we don't always ask them if they want to do it. We take it for granted that they will do it' (Nurse 4A).

It was a general assumption that parents, particularly mothers experienced a role deficit with the hospitalisation of their child because they were no longer responsible for the care for their child, which was not supported in the parents' data. This role deprivation was seen as causing feelings of inadequacy, hopelessness that had the effect of hampering parents' ability to care for their child long term. Hence parents needed to be encouraged to become active in doing the care as this would help restore parents' confidence, self-esteem and re-establish their role as parents. 'If we don't involve them they might feel sort of threatened or they might feel failures' (Nurse 8A).

Although nurses emphasised the importance of being open to parent participation by allowing parents to dictate their level of participation, they nevertheless assumed that parents would participate in care, as this was the norm. Similarly Darbyshire (1992) found that nurses assumed that the parents themselves would determine participation yet paradoxically the nurses had definite but unexpressed expectations of parents. Some nurses could be critical and dismissive of parents who did not stay and participate in care. For example: 'You know if parents want children you know...all right if you have a problem with the child and the child is very sick in hospital and they are separated then fine they have an excuse...but if you want a child, you bring a child into this world, you should be prepared to take the consequences. Like I said to you just now we have got

parents who choose to use this place like a babysitting service...they use it as a free for all.... Sometimes it really annoys me' (Nurse 7B).

6.2. Relying upon parents

It appears that the laudable sentiment of giving parents a choice was just rhetoric as nurses were very reliant and dependent upon parents being there and being responsible for general care. Nurses needed parents to be there all the time as nurses could not be there all the time for each individual child. For example: 'You see most of the things parents can do and if the parents are there to look after the child we don't have to sit with them... but most of the time we don't spend that much time with them. We rely a lot on the parents and the families to be there' (Nurse 11C). The norm was parents being there and being involved in care, and therefore, most nurses did not see their role as being there and performing the usual childcare. Furthermore they cited organisational factors such as inadequate staffing levels, patient acuity, increasing technical care as preventing them from being there constantly for parents and children which are factors that have been reported elsewhere (Rushton, 1990). Nurses were hindered from providing 'everyday childcare' because a significant component of their role now involved technical procedures, monitoring machines and undertaking delegated tasks from doctors. Other inhibiting factors included: administration duties, paperwork, being in charge, supervising staff, and co-ordination of procedures from other departments.

Situations had occurred where nurses had to rely upon parents being there as staffing levels were often

inadequate for the number of patients. Some nurses described feeling stressed because of the pressure of needing to get work done on time and about lacking time to obtain rest breaks. As one nurse explained: 'I think we need to increase the nurse/child ratio. We need the paediatric nurses to look after fewer children than they look after. I think that three children can be quite a handful or can keep you on your toes, five children is just too much. I would like to see more parent participation. I don't know how we're going to change that because I think in this country especially a lot of things are taken for granted and the paediatric nurses are there and they will look after children' (Nurse 13D). The crucial importance of parents being there was illustrated by the fact that a child's admission could be refused if a parent was unable to be there with the child. For example, a senior nurse explained that due to shortage of nurses: 'The first question here would be if we are getting an admission from a ward would be, if there are parents staying and if the parent cannot stay then perhaps we'd consider not taking them' (Nurse 10C).

6.3. *"Fitting in" with parents*

It was clearly evident that nurses' viewed the parents' role as providing psychosocial care, usual childcare, and some nursing care. They directed their actions towards helping parents to re-establish their parenting role in hospital, through letting parents 'get on with it' and slowly encouraging and involving parents in the care. Nurses viewed their role as supervising and assisting parents in their role as carers. Nurses were fitting in with parent being there and doing care, which implied that nurses, were 'making up the balance' of care left over. 'I think it's for the nurse to actually facilitate the stay of the parent, not to be the doer, but to work alongside parents and to be an informer, keep the parents and the patient up to date with what's going on and be their assistant' (Nurse 9C).

The ideal situation was nurses working with parents towards the goal of getting the work done which they termed 'sharing the care'. Parents usually complied with nurses' expectations once they were aware of the ward routine. The findings indicated that nurses controlled the nature and extent of parents' participation through positive and negative actions. Parents who were present and involved in care were considered co-operative, and were generally labelled as 'good' parents and consequently rewarded with time and moral approval. In contrast parents who did not maintain a constant presence, who were time consuming from the norm and who did not get involved in care, were considered uncooperative, and were generally labelled as 'problem' parents.

6.4. *'Idealising partnership'*

Nurses' role was to facilitate parents to be the 'doers' through strategies such as encouraging, explaining, and teaching. This arrangement was seen as 'partnership in care'. The nurses described a 'good' relationship with parents as one where parents felt able to talk freely to nurses and were never reluctant to ask for help. This implies that a good relationship was one where parents were self-reliant, very involved in doing the care and were supportive towards nurses, which is illustrated by these comments. 'It's lovely when you've got a parent there 24 h a day because it's really family centred care and you just go in and do your bits' (Nurse 15D). The partnership philosophy was seen as being akin to the ethos of shared responsibility, where everyone helped with the care. However the disadvantage of this approach was that parents felt that they held major responsible for care. This ethos of shared responsibility was seen as penetrating through to all levels of staff so that responsibility was avoided or abdicated and no particular nurse could be held accountable for omissions in care. For example: 'I know from my experience that there are huge expectations on parents from nurses and it is contributing to nurses being laissez-faire. Partnership can be destructive and it is how nurses use it cause they have abused it in the sense that it is an escape.... escape from entering into a relationship maybe and entering into the practical things with the parents and maybe it is contributing to the lack of responsibility and the accountability on the nurses part' (Nurse 10C).

As the statement above indicates, nurses had problems applying the philosophy in practice. Nurses of varying grades admitted that partnership with parents was a complex concept that was difficult to understand and to apply in practice. Some nurses reported difficulty adjusting to the changed role where nurses were not the 'doers'. They felt unsure of a facilitator role and felt that the nurses' role was increasingly becoming redundant as parents were doing all the care. Likewise student nurses experienced difficulties facilitating parent participation due to their need for practical experience and their inexperience caring for children and parents. It was also suggested that having a relationship with a parent was not always desirable as it could complicate nursing practice. Parents could become overly dependent on a particular nurse that could not be sustained due to needs of other patients and demands of the organisation. Most nurses felt that a partnership relationship was rarely achieved, and that it was not possible to develop any type of relationship with 'problem' parents. Nurses did not use the term 'partnership' to describe their practice with parents; instead the nurses generally used the term 'involvement in care'.

Although it was evident that nurses had problems with the partnership philosophy, they all noted that the

philosophy was sanctioned and perpetuated by educators and administrators, which further emphasised the ideology importance for practice. This implies that failure to incorporate and apply this ideology into one's practice may have been viewed as tantamount to unprofessional practice. Hence there could be considerable covert and overt pressure on all nurses to comply with the ideology of partnership with parents, which is borne out by this statement from a senior nurse. 'I like the idea of partnership/ family centred care. In the right environment it works very well but I think an awful lot of pressure is put on to the nurses to get everything done and pretend that we're doing a partnership' (Nurse 13D). It was suggested by some nurses that the ideology was a label and a 'trendy buzz word' that caused difficulties for them, as it did not reflect actual practice.

7. Discussion

Some nurses appear to have interpreted the partnership in care philosophy as one where parents provide care with nurses' assistance. Nurses used the strategy of letting parents determine their level of contribution and parents 'left to get on with it' rightly or wrongly assumed that they had to be there and provide the care otherwise their child could experience neglect. Parent participation, therefore, was more a set of unexpressed expectations than any form of mutual agreement between nurses and parents which confirms earlier findings of [Darbyshire \(1992\)](#) and [Callery and Smith \(1991\)](#). It appeared that parent's primary motive for being there was to provide emotional support for their children rather than be involved in providing nursing and general care. Parents wanted to be in the 'background' meaning that they wanted to be there as a parent rather than have responsibility for their children's nursing care. The concept of being there was not viewed by the parents as being synonymous with providing care. This did not mean, however, that parents were unwilling to help with care; rather that providing care was not their primary motive for being there in the hospital, which is an important distinction. But as demonstrated earlier parents interpreted nurses' actions as nurses being unable to be there and they felt abandoned and compelled to be there. The effort of maintaining a consistent presence, and providing childcare and nursing care placed some parents under considerable burden.

It may be suggested that parent participation as it is practised is clearly about administrative efficiency, not consumer empowerment. Parent participation, therefore, derives its value from its role in the organisation and delivery of the work. The delineation of the benefits of parent participation for parents and children, served to obscure or camouflage that parents' participation was an integral part of the organisation of nursing care.

Although nurses emphasised the voluntary nature of parent participation, they appeared reliant on parents' contribution as informal carers to the organisation of nursing care. It seemed that parents were viewed unofficially as 'another pair of hands'. Thus parents were part of the hospital's division of labour, but not formally so. Some nurses seemed aware that parent participation had become 'corrupted' and claimed that nurses were using the philosophy to avoid being there and being responsible for care. It is questionable how much support is provided for parents when their contribution remains hidden or taken for granted. It is significant that most nurses felt that the ideology of partnership with parents did not accurately reflect or describe their relationships with parents. The data suggests that parents were never treated as partners as control of information and boundaries of care rested with the nurses. This challenges the ideology that parents are consumers who are in partnership with nurses.

8. Recommendations

It is argued that the value of parent participation should not be taken for granted; instead future research should focus on the impact/outcome of such an ideology on all participants in the health system. The impact of the burden of caring and providing a consistent presence on parents and their families could be considerable and adversely affect parents' welfare in the long term. Therefore nurses could help alleviate parents' distress and anxieties by maintaining constant contact with parents and not leaving parents to care for their child alone. Most parents were willing to help but lacked guidance from nurses which indicates that nurses should clearly outline what care they can be involved in and provide support accordingly. To avoid making assumptions about parent participation, nurses need to make an accurate assessment of parents' wishes for involvement and negotiate care accordingly. This could be accomplished if all nurses made a conscious effort to sit down with parents on admission and document what role parents would like to perform. Such assessments should be on going especially for admissions lasting more than three days, as parents' expectations will alter depending on circumstances. Nurses should not assume that parent participation means that they cannot help with the performance of basic childcare. Many parents would welcome the help from nurses at a time when they are feeling vulnerable and unsure of their position on the ward.

It is of concern that in the current context of financial constraints in healthcare, pressure for early patient discharge, and increased family care in the community, parent participation will be an essential requisite and

parents may be coerced to comply. Nurses, therefore, need to be vigilant to ensure that parents are treated with respect and dignity, since their welfare affects the family welfare. Expecting parents to be there and be responsible for care may threaten the stability of the family unit and consequently be detrimental for overall family functioning. Therefore nurses need to acknowledge the family context and assess its support system so that options for parental involvement are designed which minimise the disruption to family life and routines. Parents performing nursing care may harm the parent–child relationship, rather than reduce anxieties.

The partnership philosophy does not take account of the organisational context in which nurses operate with the emphasis on getting the job done in a hierarchical environment. The impact of resident parents on nurses' workload appears to have been neglected or overlooked in the nursing literature. Equally the fact that nurses were very reliant on parents being there and helping with care in the hospital setting needs to be acknowledged as this has potential resource consequences. The findings strongly suggest a need for examination of staffing levels to ensure that nurses have time to support parent participation adequately and appropriately. The potential also exists for the children's autonomy and self-determination to be overlooked when terms such as 'partnership' are used as this implies a dual relationship. There is a need for a more appropriate philosophy of care that supports parents and children's actions in re-establishing equilibrium in their own social world. The hospital admission represents but a sub-set in the world of the families. Services should be designed and delivered around the needs of children and their families not around organisations or professionals.

9. Limitations

The majority of the participants were white and mothers which is not reflective of fathers' views or our multicultural society. Only parents of children aged 7–14 years were accessed. Parents with younger children may have a different attitude towards participation. Parents, particularly mothers' perceptions of the helplessness of babies, may have a heightened awareness of their needs and consequently may experience less role strain and be socialised more easily into the role of active participant. Repeating this study in other care settings, including home care of children, may yield important knowledge about the boundary interface (between social worlds) in more personal settings. Further research could focus on developing the core concept 'finding a balance' through comparative studies which could result in a substantive theory with wider applicability. The strength of substantive grounded theories is that they are modifiable

which means that the theory and major categories may be used as comparative data in further studies (Wuest, 2000) and as a theoretical framework for analytical purposes (Cowley and Billings, 1999). More research could be done to expand knowledge of how factors such as culture, social disadvantage, family structure, and ethnicity may affect family needs/abilities in finding a balance in hospital setting. The findings could be extended by comparative studies focused on parents and children with chronic illness, since the process could vary due to nature of the long-term family/nurse relationship. Replication of the Parent–staff Interaction Model of Pediatric Care by Shields (2003) would be useful for the purpose of supporting and refuting findings.

10. Conclusion

The philosophy underpinning the partnership philosophy is to be commended, as it seeks to empower and promote the respect of parents as individuals. The underlying basis of parent participation is for parents to be able to be present, to love and emotionally support the child, and to reduce separation anxiety. It is essential that parents be allowed to provide emotional care and support for their sick children. The philosophy of partnership means that parents have a choice and that they can determine their level of involvement in negotiation with nurses. It means that parents and nurses work together in the delivery of care. It does not mean that parents will substitute for nurses in providing the nursing care. The pendulum of parent participation appears to have swung from exclusion of parents to parents feeling responsible for the care. Children's nurses need to find a more appropriate balance which supports parent participation, provides individualised support and which does not threaten family functioning and stability.

References

- Ahmann, E., 1994. Family centred care: the time has come. *Pediatric Nursing* 20 (1), 52–53.
- Algren, C.L., 1985. Role perception of mothers who have hospitalised children. *Children's Health Care* 14 (1), 6–9.
- Anonymous, 1992. Who's nursing? A story of children in hospital. *Queensland Paediatric Nurses Journal* 4 (3), 2–4.
- Brain, D.J., MacLay, I., 1968. Controlled study of mothers and children in hospital. *British Medical Journal* 1 (5587), 278–280.
- Brown, J., Ritchie, J.A., 1990. Nurses' perceptions of parent and nurses roles in caring for hospitalised children. *Children's Health Care* 19 (1 Winter), 28–36.
- Burke, S.O., Kaufmann, E., Costello, E.A., Dillon, M.C., 1991. Hazardous secrets and reluctantly taking charge: parenting

- a child with repeated hospitalisations. *Image: Journal of Nursing Scholarship* 23 (1), 39–45.
- Callery, P., 1997. Paying to participate: financial, social and personal costs to parents of involvement in their children's care in hospital. *Journal of Advanced Nursing* 25, 746–752.
- Callery, P., Smith, L., 1991. A study of role negotiation between nurses and the parents of hospitalized children. *Journal of Advanced Nursing* 16, 772–781.
- Callery, P., 1995. An investigation into the role of parents in the care of hospitalised children. Unpublished PhD Thesis. University of Liverpool, Liverpool.
- Casey, A., 1988. A partnership with child and family. *Senior Nurse* 8 (4), 8–9.
- Casey, A., Mobbs, S., 1988. Partnership in practice. *Nursing Times* 84 (44), 67–68.
- Casey, A., 1993. Development and use of the partnership model of nursing care. In: Glasper, A., Tucker, A. (Eds.), *Recent Advances in Child Health Care*. Scutari Press, London.
- Cowley, S., Billings, J., 1999. Resources revisited: salutogenesis from a lay perspective. *Journal of Advanced Nursing* 29, 994–1004.
- Coyne, I.T., 1995a. Parental participation in care: a critical review of the literature. *Journal of Advanced Nursing* 21 (4), 716–722.
- Coyne, I.T., 1995b. Partnership in care: parents' views of participation in their hospitalised child's care. *Journal of Clinical Nursing* 4, 71–79.
- Darbyshire, P., 1992. Parenting in Public: a study of the experiences of parents who live-in with their hospitalised child, and of their relationships with paediatric nurses. Unpublished PhD thesis. University of Edinburgh, Edinburgh.
- Department of Health., 2003. Getting the right start: The National Service Framework for Children, Young People and Maternity Services—Standards for Hospital Services. Stationery Office, London.
- Espezel, H.E., Canam, C.J., 2003. Parent-nurse interactions: Care of hospitalized children. *Journal of Advanced Nursing* 44 (1), 34–41.
- Galvin, E., Boyers, L., Schwartz, P.K., Jones, M.W., Mooney, P., Warwick, J., Davis, J., Ahmann, E., 2000. Challenging the precepts of family centered care: Testing a philosophy. *Pediatric Nursing* 26 (6), 625–633.
- Gill, K.M., 1993. Health professionals' attitudes toward parent participation in hospitalized children's care. *Children's Health Care* 22 (4), 257–271.
- Glaser, B.G., 1978. *Theoretical sensitivity*. Sociology Press, Mill Valley, Cal.
- Glaser, B.G., Strauss, A., 1967. *The discovery of grounded theory*. Aldine, Chicago.
- Hayes, V.E., Knox, J.E., 1984. The experience of stress in parents of children hospitalised with long-term disabilities. *Journal of Advanced Nursing* 9, 333–341.
- Henderson, S., 1998. Nurses and the ideal of patient participation. In: Petersen, A., Waddell, C. (Eds.), *Health matters: A sociology of Illness, Prevention and Care*. Open University Press, Buckingham, pp. 272–287.
- Hupcey, J.E., 1998. Establishing the nurse–family relationship in the intensive care unit. *Western Journal of Nursing Research* 20, 180–194.
- Jackson, P.B., Bradham, R.F., Burwell, H.K., 1978. Child care in the hospital—a parent–staff partnership. *MCN: The American Journal of Maternal-Child Nursing* 3 (2), 104–107.
- Kirschbaum, M., Knafl, K.A., 1996. Major themes in parent-provider relationships: A comparison of life-threatening and chronic illness experiences. *Journal of Family Nursing* 2 (2), 195–216.
- Knafl, K.A., Cavallari, K.A., Dixon, D.M., 1988. *Pediatric hospitalization: Family and Nurse Perspectives*. Scott, Foresman, Illinois.
- Kristensson-Hallstrom, I., Elander, G., 1994. Parental participation in the care of hospitalized children. *Scandinavian Journal of Caring Sciences* 8, 149–154.
- Lee, P., 1998. An analysis and evaluation of Casey's conceptual framework. *International Journal of Nursing Studies* 35, 204–209.
- Ministry of Health, Central Health Services Council, 1946. *Report of the care of children committee (The Curtis Report)*, London, HMSO.
- Price, P.J., 1993. Parents' perceptions of the meaning of quality nursing care. *Advances in Nursing Science* 16 (1), 33–41.
- Robinson, C.A., 1987. Roadblocks to family centred care when a chronically ill child is hospitalised. *Maternal-Child Nursing Journal* 16 (3), 181–193.
- Robinson, C.A., 1985. Parents of hospitalised chronically ill children: competency in question. *Nursing Papers* 17 (2), 59–68.
- Rushton, C.H., 1990. Family centred care in the critical care setting: myth or reality? *Children's Health Care* 19 (2), 68–78.
- Shields, L., 2003. The parent–staff interaction model of pediatric care. *Journal of Pediatric Nursing* 15 (5), 1–8.
- Shields, L., Nixon, J., 2004. Hospital care of children in four countries. *Journal of Advanced Nursing* 45 (5), 475–486.
- Skipper, J.K., Leonard, R., 1968. Children, stress and hospitalisation: A field experiment. *Journal of Health and Social Behaviour* 9 (4), 275–287.
- Stacey, M., Dearden, R., Pill, R., Robinson, D., 1970. *Hospitals, Children and Their Families: the Report of a Pilot Study*. Routledge, London.
- Streubert, H.J., Carpenter, D.R., 1999. *Qualitative Research in Nursing: Advancing the Humanistic Imperative*. Lippincott, Philadelphia.
- Thorne, S.E., Robinson, C.A., 1988. Health care relationships: The chronic illness perspective. *Research in Nursing and Health* 11, 293–300.
- Waterworth, S., Luker, K.A., 1990. Reluctant collaborators: do patients want to be involved in decisions concerning care. *Journal of Advanced Nursing* 15, 971–976.
- Wolfer, J.A., Visintainer, M.A., 1975. Pediatric surgical patients' and parents' stress responses and adjustment. *Nursing Research* 24, 244–255.
- Wuest, J., 2000. Negotiating with helping systems: An example of grounded theory evolving through emergent fit. *Qualitative Health Research* 10 (1), 51–70.
- Ygge, B.M., Arnetz, J.E., 2004. A study of parental involvement in pediatric hospital care: Implications for clinical practice. *Journal of Pediatric Nursing* 19 (3), 217–223.