

Research Article

Parental participation and mismanagement: A qualitative study of child care in Iran

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Abstract

The purpose of this study was to explore parents' and nurses' experiences of parental participation in child care in hospitals in Iran. Using thematic analysis, the data were collected through interviewing 14 parents and 11 nurses from two pediatric hospitals. The results showed that four major themes emerged, including the necessity of a parent's presence, the unplanned and informal delegation of care to the parents (which itself had five subthemes: the parents as nurses, the delegation of care without sufficient and planned parental training, informal parent-to-parent support, the continuum of parents' willingness to participate, and the neglect of parents' needs), the inconsistency of care, and the parents as informal evaluators of care. Based on the study's findings, effective communication by nurses with parents is required. Nurses need to make an ongoing assessment of parents' wishes for involvement and negotiate care accordingly, with enough support and supervision to warrant quality of care.

Key words

child hospitalization, chronic illness, parent participation, parent partnership.

INTRODUCTION

Society has witnessed considerable technological and medical advances in the last few decades that have significantly reduced the mortality rate of children. However, the result is the survival of a growing number of children who experience a chronic illness or disability (Boyd & Hunsberger, 1998; Charron-Prochownic, 2002) and repeated and/or lengthy hospitalizations (Boyd & Hunsberger, 1998; Nuutila & Salanterä, 2006). For parents, a child's illness and hospitalization invariably stir up intense emotions (Kristensson-Hallström, 2000; Shields & King, 2001a,b; Cimete, 2002; Hallström *et al.*, 2002a,b; Polkki *et al.*, 2002; Hopia *et al.*, 2005).

A family-centered approach is suggested as one way to alleviate potential problems while respecting the child–parent relationship (Hallström & Elander, 2004) and ensuring that care is planned around the whole family, not just the individual child (Shields *et al.*, 2006; Jolley & Shields, 2009). The concept of parental participation is integral to the family-centered care model (Corlett & Twycross, 2006; Power & Franck, 2008). Today, there is widespread agreement that parental involvement is an essential element of the quality of

care for children in hospital (Jolley & Shields, 2009; Power & Franck, 2008).

Parental involvement in the care of hospitalized children can be a demanding experience for both the parents and the staff. The parental roles and responsibilities alter when a child is admitted to hospital. A lack of negotiation about the parents' roles between the nurses and the parents was a common theme in previous studies (Corlett & Twycross, 2006; Power & Franck, 2008). A systematic literature review on the studies about the negotiation of parental roles within family-centered care carried out during the last 15 years showed that each parent is unique in relation to the parenting style, family structure, ability to share emotions and needs with health professionals, and willingness to be involved in the child's care (Corlett & Twycross, 2006).

Another article analyzed 11 qualitative studies that were done between 1991 and 2003 and indicated that the negotiation between staff and families and the perceptions held about the parental and staff roles influenced the delivery of family-centered care (Shields *et al.*, 2006). What the staff thought parents were capable of doing was different from what the parents thought they could do (Coyne, 1995; Shields & King, 2001a,b). In some other studies in the UK (Kawik, 1996) and Sweden (Ygge *et al.*, 2006), parents have expressed difficulties in being involved in the care of their children because of the nurses' reluctance to relinquish control.

Parental participation is a big challenge for all health-care providers, demanding competence, confidence, and interpersonal skills (Ygge *et al.*, 2006). Parents have presented a

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potential threat to nurses' control over their workload because of their demands for nursing time (Callery, 1997; McKiel, 2002).

The role of culture also was emphasized in previous studies. For example, a study by Shields and Nixon in two developing countries (Indonesia and Thailand) and two developed countries (Australia and the UK) regarding the hospitalization of children suggested that culture plays a major role in determining how care is given by health-care providers and how it is perceived by parents (Corlett & Twycross, 2006). The study showed that the parents were expected to provide basic care for their children but, in developing nations, fewer parents thought they should do so. The cultural differences found in the study highlighted the fact that these differences raise the chance of negative interactions unless all of the participants are aware that differences exist and the care subsequently can be adapted (Shields & Nixon, 2004). Two systematic reviews that were carried out by Corlett and Twycross (2006) and Power and Franck (2008) highlighted that there are gaps in the existing evidence base for parental participation in developing countries, which is an important area for future research.

The hospitals in developed countries are well resourced, while many in developing countries, such as Iran, function with limited resources. Nurses from the developing nations might apply the knowledge base from the developed countries, but this might be culturally inappropriate (Shields & Nixon, 2004). On the whole, the literature highlighted the importance of nurses' and parents' experiences of parental involvement. It showed that the ways to provide nursing care are influenced by the characteristics dominant in the society and its health-care system. Family caregiving is a phenomenon that reflects the social values and norms of a family and its function in a society (Cho & Kim, 2006). The Iranian tradition has maintained a strong family bond and parental responsibility for the care of children. Parental contribution to hospital care is a symbol of the strength of the Iranian tradition. The National Health Services (NHS) in Iran has begun a movement for improving health-care services in different settings, based on consumers' needs. It was assumed that a study of the experiences of parents and staff of child care in hospital can provide important insights and could contribute to the discussion on how child health care should be organized so as to function optimally (Corlett & Twycross, 2006). This study was designed to explore the experiences of parents and nurses of parental participation in the care of chronically ill children in hospitals in Iran.

METHOD

A qualitative approach using thematic analysis (Braun & Clarke, 2006) was adopted for this study to facilitate an in-depth investigation of the individual experiences and perceptions of participation in care.

This study comprised 25 unstructured thematic interviews with 14 parents and 11 nurses who were recruited from two large, central pediatric hospitals in Tehran, Iran, from July 2007 to March 2008. Those hospitals take referrals mainly from across the country. Ethical approval was

obtained from the ethical committee of Tarbiat Modares University. Informed and written consent was obtained from all the participants. All the interviews were carried out by one female interviewer. At the interview, the main questions explored the parents' participation in the care of their child during hospitalization. The interview schedule consisted of two headings, which were: the reason for hospitalization and the parent's role. The questions served as prompts if the case arose. The nurses and the parents were chosen by using purposeful sampling with a maximum variance approach and they were interviewed individually at a time convenient to them during the quiet periods in the day in a quiet room nearby. The interviews lasted between 30 and 100 min. All the parents had a child with a diagnosed chronic condition (i.e. diabetes, blood disorder, cystic fibrosis, metabolic disorders, gastrointestinal disorders, or renal disorders) and were interviewed individually at least 3 days after the child's admission to hospital. A non-categorical approach to chronic conditions was used as children with a variety of chronic conditions were included in the study. The non-categorical approach assumes that different chronic conditions share common characteristics that affect all children and families, regardless of the different characteristics (Boyd & Hunsberger, 1998). The participants' selection, data collection, and data analysis continued until data saturation was reached and a rich description of the experiences had been obtained. The data collection ceased after 25 interviews, as after 23 interviews, it was clear that no new themes had emerged.

Prolonged engagement, peer debriefing, and a member check with the participants were used to strengthen the credibility of the study (Streubert & Carpenter, 2007).

Data analysis

Thematic analysis was conducted through the five phases of the analysis (Braun & Clarke, 2006). In the first phase, we transcribed the data and started taking notes or marking ideas for coding. The second phase involved producing the initial codes from the data by identifying the interesting aspects in the data items that might form the basis of repeated patterns (themes) across the dataset.

The third phase involved sorting the different codes into potential themes and collating all the relevant coded data extracts within the identified themes.

In the fourth phase, we read all the collated extracts for each theme and considered whether they appeared to form a coherent pattern. Then, we considered the validity of the individual themes in relation to the dataset and whether our candidate thematic map "accurately" reflected the meanings evident in the dataset as a whole. In the fifth phase, we defined and further refined the themes.

FINDINGS

In total, 14 mothers and 11 nurses participated in the study. We included the mothers only because the fathers were not allowed to stay with the child in hospital due to cultural and organizational limitations. The nurses were aged between 24 and 50 years and had between 5 months and 30 years of work

experience in pediatric wards. Eight nurses were ward nurses who were responsible for the direct care of the children, two were nurse managers of the wards, and one was a staff nurse who coordinated the care of the children but was not responsible for the direct care of the children. All of them had a bachelor degree in nursing. The mothers were aged between 25 and 42 years, had a chronically ill child, had different educational backgrounds, and came from various regions of Iran.

The themes that were identified following the thematic analysis of the nurses' and parents' interviews are presented under four major themes: (i) the necessity of a parent's presence; (ii) the unplanned and informal delegation of care to the parents; (iii) the inconsistency of care; and (iv) the parents as informal evaluators of care.

Necessity of a parent's presence

This theme was very prevalent, as all the parents and most of the nurses stated that a parental presence meets the needs of the child, reduces the child's emotional stress, increases the child's security and cooperativeness, and decreases behavioral issues. The hospitals' policy also emphasized the need for a parental presence in order to provide for the child's safety and emotional support. One nurse said:

[The] presence of [the] mother is very important from the emotional viewpoint. [The] child experiences a particular sense of comfort in the mother's arms . . . A mother is able to understand her child and explain him well.

A mother said:

I must stay here. My child would never settle here without me . . .

Being there was a moral imperative for all the parents but, at the same time, some parents cited not feeling confident that the nurses would be available for their individual child constantly due to the heavy workload of the wards and they worried about meeting their children's needs, so being there became a critical requisite. A mother stated:

I don't dare leave my child alone . . . I cannot be at all confident of the care he will receive if I leave him. . . . Nurses are so busy. They have much . . . work to do . . .

Although the nurses emphasized that the parent's presence reduced the child's emotional stress and increased the child's security, most of them were not in favor of it during painful procedures because the parent's presence adversely affected the child's cooperativeness and increased the nurse's stress. As a nurse stated:

When [the] mother is present at the time of venepuncture, either the child becomes more restless, as he wants to go to the mother's arm, or shows more reactions . . . not only [is] the mother . . . agitated, but we also feel . . . under more stress.

The parents laid aside their family and occupational roles in order to stay with their child all day and to care for their child. One mother left her job because the child needed care, both during hospitalization and at home, while another mother stated:

I have one older son. I've left him in the care of God . . . I am really concerned about him but I focus all my effort on my ill child.

Unplanned and informal delegation of care to the parents

This was a major theme in explaining the concept of parental participation and had different dimensions, which included the parents as nurses, the delegation of care without sufficient and planned parental training, informal parent-to-parent support, the continuum of the parents' willingness to participate, and the neglect of the parents' needs.

Parents as nurses

Though hospital policy emphasized that the nurses should not delegate the nursing care to the parents, the parents reported their role as providing both basic care and nursing care. The parents' ability to stay with the child in the hospital provided a good opportunity for the nurses to make them participate in the child care. Through this mechanism, the nurses gradually delegated some aspects of nursing care to the parents to diminish their own workload, regardless of the child's age. The low staffing levels of the wards made the nurse managers ignore the hospital policy unless the performance of nursing care by the parents led to harm of the children, as a nurse manager stated:

When we allowed the parents to be here, initially all the tasks were done by nurses. Gradually, nurses learnt that once the mother was there and could take the temperature or report I&O [intake and output], so they let her do them . . . Because my nurses have not had enough time, delegate nurses' tasks to parents. When I have enough staff in the ward, I can expect nurses do all nursing care, but now, I can't expect it, unless it harms . . . the child.

The delegation of these aspects of care to the parents resulted in decreased child–nurse communication. Relying upon the parents shifted the responsibility of direct child care from the staff to the parents and turned parents into trainee nurses. The nurse manager said:

This new idea, that parents should stay with the child, has led to nurses moving away from their core responsibilities. Mothers have actually become our trainee nurses . . .

The norm was parents being there and being involved in care. Furthermore, the nurses cited organizational factors, such as inadequate staffing levels and increasingly complex technical care, as preventing them from doing all the child care. Another nurse manager said:

With the development of science, our works [*sic*] become more specialized. We didn't have nebulizer [*sic*] in the past. Each nebulizer takes 20 min. Our wards suffer from low staffing levels.

Delegation of care without sufficient and planned parental training

The parents often had not received any planned training for how to carry out nursing tasks, such as taking the temperature or collecting a urine specimen. One illiterate mother stated:

They ask me to take the temperature and urine sample. I'm not very literate and not well informed either. They don't teach me . . .

The nurses trusting parents' ability to carry out technical care depended on the nurses' experience, as the senior nurses did not believe automatically that the parents could do complex nursing care. A senior nurse stated:

I always ask my colleagues [to] do complex nursing care themselves because, when a mother states that she can do feeding by NG [nasogastric] tube, it should not be taken at face value . . . But, most [of] our nurses are inexperienced, so they believe [the] mothers' claim. I never let mothers do these kinds of nursing care unless under my supervision.

For more complex technical nursing care, such as insulin injections, though all the nurses reported providing formal training to the parents, the parents did not feel that they received effective and complete information, which led to parental dissatisfaction, as a mother of a newly diagnosed diabetic child stated:

. . . We have even been discharged without enough information . . . Even nurses instruct me differently. One tells me to put [the insulin] injection each time on one hand, another says if one hand is overinjected, use the other hand. Actually, I don't know what to do.

The indirect observation of the nurses' practice in order to use them as role models was one mode of learning for the parents. A mother said:

I saw the nurses doing these jobs [taking the temperature]. I also learnt how to do the same.

Informal parent-to-parent support

The parents were not always provided with sufficient information, so they always had to glean that needed information from other parents rather than the nurses. The nurses were aware of this mode of information transfer but they did not supervise it. A mother declared:

Now, I know how to take the temperature but many mothers don't know how to do it. There is no one to do it for them either. Mothers teach each other how to.

A nurse admitted:

No, there isn't any supervision. How can I have any control on it when parents teach each other? . . . We have no time for it.

Most of the nurses stated that they left the parents to get on with it and to learn about expectations over time. In fact, with repeated hospitalizations, the parents gradually learnt the ward routine, learning it partly by observing what happened to the other parents, partly by asking the other parents, and partly by experiencing it; for example, one nurse stated:

It's not [the] mother's duty, but they learn through experience during [the] child's hospitalization . . . The moment they come to the hospital, they become self-learners . . .

Continuum of parents' willingness to participate

It was clearly evident that the nurses viewed the parents' role as providing psychosocial care, usual child care, and some nursing care. In fact, the parents' willingness to participate in care presented itself along a continuum. At one end, it involved emotional support, in the sense of being there and being with the child rather than having the responsibility of providing care. The parents were willing to provide basic child care, but some were reluctant generally to perform nursing care. Some parents were also anxious about doing technical nursing care due to their inexperience or lack of knowledge about nursing matters, believing they could cause potential harm to their child. Though the parents felt that they had to fulfill the nurses' expectations, nursing care was generally viewed as the nurses' responsibility because of their training and expertise. As a mother said:

I prefer the nurse to take the temperature as she does it better . . . Nurses must do this job as it is their duty.

Some nurses cited that, if the technical nursing care was necessary for their child's care at home, then the parents were willing to learn by doing such care:

[The] first time, when we want to instruct them about [the] nebulizer, they feel that we want to shift our responsibilities to them. But, when they come to [the] ward [the] second time, they saw [*sic*] that they must perform it at home. Therefore, we had been a trainer for them. Now, if we leave it for them to do, they never complain . . .

Conflict arose when the parents did not fit the expectations that the nurses had of them. The parents have to pay for care in Iran, so some might have felt that they should not have to do it themselves. As a nurse stated:

They complain, "Why should this be the case?" They say, "Haven't we paid? . . . These are your duties".

At the other end of the parents' willingness continuum, there were some parents who chose to participate in the care of their child for three reasons. These included a concern about the handing over of care to strangers, the consistency of the care required to avoid their child becoming neglected, and parental duty:

Since a mother is more compassionate than a nurse, she does a better job and that's why I love to do these tasks. I am more comfortable this way, rather than troubling the nurses. If I ask the nurse to change the serum, it will take a quarter or half an hour to attend [to] my child . . .

Well, if I don't do this, then who else would? . . . nurses would not come to do the job.

Neglect of the parents' needs

Some parents experienced difficulties in finding a balance between their own needs and their roles due to unnegotiated roles. This appeared to lead to a kind of abuse and dissatisfaction of the parents. They wanted more support from the nurses so they could attend to the roles that they had and to care for themselves while their child was in hospital:

No, they didn't ask me about my wishes, it is what they say themselves, I didn't want it. I was shocked the first night. Well, they called me while I was asleep . . . Now, I wanted to take a nap, suddenly they called me, "Mother of Reza! Give his medicine", or again, "Drain this water [peritoneal fluid dialysis]". . . showing no consideration, asked me to do this or do that. This continued till morning . . .

Inconsistency of care

The delegation of the nursing care, without assessing the parents' ability and needs and supervising them, led to an omission of care in some cases and inversely affected the consistency of care as a consequence. As a mother of a child with cystic fibrosis stated:

I have become tired. It is almost 2 months [that] we have been here. They have asked me to give [a nebulizer] every 2 h but I give [it to] him once every 6 h. I am tired and fed up . . .

Insufficient information led to some parents unknowingly interfering with the nursing interventions, which could have adversely affected the quality of child care. For example, this nurse complained that:

Once child is NPO [nil per orally], the 4–5 kg child should take 60–70 cc i.v. fluid to become calm. The mother thinks that the more her baby takes of the serum, the sooner he will be better. This is because of shortcomings in our training for parents . . . she increased the flow, two or three times faster . . . Well, this would adversely affect the child.

Parents as the informal evaluators of care

Being there and a concern for the child's welfare led to the parents being keen to informally observe the nurses' practice and to report their failures in providing adequate care of the child to the managers. In this way, the parents became an

informal and helpful control tool for the managers, one of the advantages of the parents' presence for them, as one of the nurse managers verified:

Mothers are there and see what the nurse is doing for the child, which they later report to me . . .

In some cases, the parents' acute concern for their child's well-being was advantageous in preventing the potential neglect of their child. One nurse said:

Many mothers are well informed. Often, the nurse doesn't see many signs that she needs to report to the doctor but, instead, the mother does this job . . . Our nurses ask the mothers to be keen to these signs and report them to nurses or [the] doctor.

DISCUSSION

Our findings showed that the parents' experience of being there with their child does not actually reflect parental involvement, participation, partnership, or family-centered care, based on a concept analysis of family-centered care by Hutchfield (1999). This is because the parents felt that they had to participate in nursing care without negotiation with the nurses and without receiving adequate support.

Staying with their hospitalized child was an unconditional aspect of being a parent in Iranian culture. The parents laid aside their family and occupational roles in order to remain with their child all day, similar to Callery's (1997) study in the UK.

Although taking responsibility for the basic care of their child seems to be an international need of mothers (Coyne, 1995; Blower & Morgan, 2000; Espezel & Canam, 2003; Roden, 2005; Lam *et al.*, 2006; Soderback & Christensson, 2007; 2008; Power & Franck, 2008) and most of the parents in our sample expected that parents should give basic care as a mother, in other developing countries, such as Indonesia and Thailand, fewer parents thought they should be providing basic care (Shields & Nixon, 2004). It might be related to the Iranian tradition that preserves a strong parental responsibility for the care of children. But, at the same time, the concept of "parental presence" was not considered by most of the parents as being exactly synonymous with providing nursing care. It appeared that the parents' primary reason for being there was to support their child emotionally rather than be involved in providing the nursing care. As demonstrated earlier in Australia (Paliadelis *et al.*, 2005), some parents perceived that the nurses were not there constantly, so the parents felt coerced to be there. Such experiences might reduce the parents' confidence in the nurses. This is not in line with the parent partnership, as developed in the Western health system, where mostly there is one primary nurse during a work shift for each family (Coyne & Cowley, 2007).

Although there was some willingness to participate in their child's care, Western parents (Kawik, 1996; Coyne, 2007; Power & Franck, 2008) and some Asian parents, such as in Hong Kong (Lam *et al.*, 2006), participated in nursing tasks by choice. However, similarly to parents of other non-Western countries, such as Mozambique (Soderback &

Christensson, 2007; 2008) and Thailand (Pongjaturawit & Harrigan, 2003), Iranian parents had no choice about participation, as parental participation is a routine expectation due to the understaffing of the wards.

As discussed by Corlett & Twycross (2006), in our study, we noted that though nurses had clear expectations of the parents, they did not openly discuss these with the parents, knowing that the parents picked it up as they went along (). In fact, negotiation between the parents and the nurses was often the key element to the success of interactions during a child's hospitalization (Espezel & Canam, 2003; Corlett & Twycross, 2006). Research to date suggests that this negotiation is not routinely planned or conducted (Neill, 1996a,b; Shields et al., 2002; Ygge et al., 2004; Young et al., 2006; Power & Franck, 2008). In addition, previous studies suggested that health professionals' expectations of parental participation can be a barrier in the negotiation of roles (Krik, 2001; Corlett & Twycross, 2006). It was obvious from our study that the nurses controlled the nature of parental participation rather than the parents.

This lack of negotiation that was highlighted by our study led to the parents' needs being neglected and the consistency of care being put at risk; in some cases, without the nurses' awareness. Similar to the findings of the systematic review by Power and Franck (2008), some parents in our sample thought too much pressure was placed on them to do what they saw as the nurses' work. That more staff than parents in developed countries (Australia and the UK) thought parents had too much pressure shows an awareness of the pressures that families undergo during a child's hospitalization (Shields & Nixon, 2004). Our study indicated that the staff in Iran was not that sensitive to the parents' needs because of the nurses' heavy workload and time limitations. Espezel and Canam (2003) believed that inadequate staffing levels and a desire for cost-effectiveness in health care significantly influence the practice of family-centered care. The nurses in our sample believed that the support they provided was more consistent than the parents believed they received. It shows that the parents needed more support to take part in their child's care and that the nurses were aware of the parents' need for more educational support, indicating that the nurses already knew that the situation needed serious improvement.

Our findings supported the findings of earlier studies from both developed (Australia and the UK) and developing (Indonesia and Thailand) countries (Shields & King, 2001a,b) that more parents than staff thought that the parents should be required to stay with their child. In our sample, some negative effects of the parents' presence on the quality of care, related to poor communication between the parents and the nurses, was the main reason for some nurses' disagreement with the parents staying with the child despite stating its advantage in reducing the child's anxiety and uncooperativeness.

Our study demonstrated that, beyond the attitudes and beliefs of the nurses, organizational constraints had a major influence on parental participation. Nevertheless, the nurses assumed that the parents would participate, as this was the norm and it would be very unusual for the parents to deviate from the norm. Interpersonal conflict arose when the parents

did not accept automatically the expectations that the nurses placed upon them and that have been reported before (Coyne & Cowley, 2007; Power & Franck, 2008).

Thus, for the nurses, the parents were part of the hospital's division of labor, but not formally so. It is notable to consider how much support is provided for parents when their participation is informal?

CONCLUSION

The nurses' reliance on the parents in the delivery of care indicates that parental participation in our sample is about organizational constraints, not parental empowerment. The current debates in the NHS in Iran show the extent to which economic issues are becoming paramount. The parental participation philosophy, which was introduced as a moral issue, might be driven now by financial factors. However, using parents as unpaid care-providers might lead to parental resentment, jeopardize the child's safety, and challenge parent-nurse partnership ideology. The findings strongly suggest a need for the examination of staffing levels to ensure that the nurses have sufficient time to support parental participation adequately and appropriately. The services should be designed around the needs of the children and their family because the nature of chronic illness in our sample necessitates parental empowerment in order for parents to provide successfully the care of their child at home.

Therefore, nurses could alleviate parents' anxiety by maintaining constant contact with them and not leaving the parents to care for their child alone. Most of the parents were willing to help but lacked adequate guidance and support from the nurses, indicating that the nurses should provide support accordingly.

Nurses need to make an accurate assessment of the parents' wishes for participation and negotiate care with a view to empower the parents to engage and participate. It might help to remove the risk of the inconsistency of care and improve nurses' attitude towards parental participation in the care of the child.

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