

Family-Centred Care and the Relationships Between Hospital Staff and Parents

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Abstract

Family-centred care (FCC) is widely used in paediatrics, but is largely untested by rigorous research. As such a critical discourse on its implementation is necessary. Underpinning FCC, and probably the cause of most of the difficulties in its effective implementation, is the importance of effective relationships between the parents of admitted children and health professionals. This paper discusses the relationships between parents and staff and their effect on the delivery of FCC, and is a

descriptive review using some historical studies as well as modern research. Aspects of the relationships between parents and staff discussed include communication with doctors, nurse-parent relationships, and the role of partnership with parents in the delivery of care to children and families. These are then examined in relation to FCC and the conclusions support the assertion that if no rigorous research supports FCC as a model of care, then it is time to question its widespread use.

Family-centred care (FCC) is a term familiar to all who work in paediatric health care world wide. Most institutions (hospitals, clinics, long-stay facilities and ambulatory and primary care units) where children are cared for have either a formal, written policy about FCC, or will espouse the concept informally and most paediatric health professionals will say that their practice is underpinned by FCC. However, while a large body of literature about FCC exists, in the main it is untested by rigorous research (Shields, Pratt, Davis & Hunter, 2007). In addition, and because of the lack of evidence about it, its widespread use must be examined critically (Shields, 2010). As Darbyshire said in 1994, FCC is a wonderful ideal, but difficult to implement effectively (Darbyshire, 1994).

Underpinning FCC, and probably the cause of most of the difficulties in its effective implementation, is the importance of effective relationships between the parents (however defined) of the children who come to an institution for health care, and the health professionals who work in those institutions. The importance of the effectiveness of such relationships lies across all disciplines and levels of workers, from the domestic staff who deliver the meals, to the directors of nursing, medicine, allied health and administration. This paper discusses the relationships between parents and staff and their effect on the delivery of FCC, and is a descriptive review using some historical studies as well as

modern research. Aspects of the relationships between parents and staff discussed include communication with doctors, nurse-parent relationships, and the role of partnership with parents in the delivery of care to children and families. These are then examined in relation to FCC, implications for practice are discussed, and ethical issues surrounding them are considered.

Relationship between parents and doctors

Seminal to relationships between health professionals and parents is communication, and breakdown of communication is one of the main reasons for the unsuccessful implementation of FCC (Shields et. al, 2007). Several studies were found examining communication between doctors and nurses, parents, and, at times, children, and those included here range from the early 1970s to the present day.

In a study from 1972, doctors were perceived by parents to be often in a hurry, to show signs of impatience (frequently by body language) and parents were reluctant to ask questions, or if anxious, forgot to ask about things they wanted to know. Successions of different doctors damaged the relationship; few doctors introduced themselves or stated what they were going to do for the child, though all medical staff were enjoined to view the child as an individual whose parents had a right to be concerned (Bradley, 1972).

A Canadian study from 1989 (Bourhis, Roth, & MacQueen, 1989) examined convergence of

medical and everyday language in conversations with patients, doctors and student nurses. Forty respondents from each group self-reported on the percentage of medical and everyday language used in the hospital, by them and in conversations they had with other groups, and rated the importance of medical and everyday language use in hospitals. Doctors saw themselves as converging their use of medical language to the everyday language of their patients, but the patients' and student nurses' evaluations disagreed. Patients tried to use medical language more than was expected. The nurse was the "communication broker", who converged linguistically the everyday language of the patient with the medical language of the doctor.

In 1994, a study found that disclosure by mothers of psychosocial issues was enhanced when doctors used simple communication skills (Wissow, Roter, & Wilson, 1994). Interviews with 234 mothers who brought their children for a regular check-up to a primary care clinic in a large American hospital were audiotaped. The interactions of 52 junior doctors with the mothers were examined using a validated conversation analysis technique. Disclosures of psychosocial information were associated with doctors' questions about psychosocial issues, expressions of support and interest, and attentive listening, which were measured by counting categories of types of utterances by the doctors. While valuable for showing that communication styles are important when

interacting with patients/parents, results such as these may have differed if the sample comprised of parents from dysfunctional families, who are commonly more reluctant to disclose personal information.

In a 1998 study from Holland (Van Dulmen, 1998), 21 paediatricians in an outpatients clinic were video-taped while interviewing children and their parents. The mean age of the children was 5.3 years, (SD = 4.6). Verbal communication during the visit was dominated by the paediatrician, and children's contribution seemed meagre and limited to social conversation. Only a small amount of medical information was directed at the child. Boys were more likely to interact with the doctor than girls, interaction by the child increased with age, and episodes of orientation interactions decreased if the visit was a follow-up, rather than initial consultation. Closer examination of the results illustrated that the paediatricians did not interact with the children as much as with the parents. In 36% of encounters, the child did not verbally participate at all, (the ages of the children in these encounters were not stated). In 8.6% of encounters, the paediatrician did not engage in any communication with the child, and only one in every four statements were directed at the child.

By 2004, little had changed, and despite the fact that communication is now often a part of medical education, the relationships between parents and doctors seem to still be fraught with difficulty. Communication between doctors, parents and

children was the focus of a study (Wassmer, Minaar, Abdel Aal, Arkinson, Gupta, Yueu, & Rylance, 2004), where 51 paediatrician consultations were recorded and analysed by categorising the doctors', parents' and children's behaviour according to a validated system of communication analysis. The main contributor to these interactions was the doctor who took control of conversation in 61 episodes, while the parents' contribution was recorded as only 25% of the time and the child's only 4%. However, 66% of the parents stated they were very satisfied with the doctor and his or her communication skills. Only audio recordings were used and therefore body language and other dynamics of communication could not be observed. The small sample precludes any generalisation.

Conclusions to draw from this include the idea that medical encounters with parents are based on a relationship in which the doctor holds all the power, and while some parents (and children) do not see this as a problem, in fact, it may be that they regard it as the norm and expect such interaction, the relationship between parents and doctors is always weighted in the doctors' favour, leaving little room for open and honest questioning and explanation. We must wonder if nurses have fared any better.

Relationship between parents and nurses

Nurse-parent relationships have been studied by a number of investigators using a variety of

approaches. Studies from before 2000 were included to see if changes have occurred in FCC over time. Knafl, Cavallari and Dixon (1988) interviewed 62 families of hospitalized children and 47 nursing staff at three American paediatric units. Relationships between parents and nurses were found to be affected by environmental and functional issues such as organization of the nursing workforce and staffing levels. In units where primary nursing was used, open communicative style and flattened hierarchy of authority facilitated negotiation between parents and staff. In units where team nursing was used, communication between parents and staff was inhibited because the ward processes were bureaucratic and less flexible in delivery of care. Little variation was found amongst perceptions of the nurses about the parents' roles. They were expected to visit regularly, participate in routine care, interpret for the child and encourage his or her co-operation in treatment, prepare the child for procedures, support the nurse in teaching programmes and maintain respect for and co-operation with the nurses. All nurses focused on the child, rather than the family, and parents were considered either a help or a hindrance. Parents tended to fall into two groups-those who expected little interaction with the nurses and were grateful for the services received, and those who wanted to take an active role in their child's care. The second group was viewed more negatively by the nurses than the first. Parents' views of their, and the nurses' roles,

differed widely. Areas of conjunction between the perceptions of roles included the nurse as giver of information, as teacher, and supporter for the child.

In 1993, in a qualitative study of relationships (Johnson, 1993) between parents and nurses, ten parents who accompanied their admitted children were investigated using structured interviews. Two parents kept diaries during the admission. Perceptions of parents' and nurses' roles, barriers to effective working relationships and recommendations for working together were investigated. This descriptive study highlighted examples of parents' perceptions. Although valuable for its descriptive analysis, statistical analysis of comparisons between what the parents and nurses said would have provided insight into communication barriers. Parents perceived their role to be that of worker; while nurses were seen to be teachers, providers of medical and technical care, and emotional and physical support. Barriers to working in partnership were found to be ineffective communication, staffing issues, confusion about roles and environment. To enhance partnership, improved communication, role clarification and acknowledgement that the parent knows his or her child best was necessary.

Callery and Smith (1991) examined nurses' explanations of their relationships with parents. Sixty-four nurses described 112 critical incidents from their practice. The balance of power in the nurse/parent relationship was found to be weighted in the nurses'

favour. Senior nurses used negotiation and explanation when persuading parents to do what the nurse wanted or to act in a certain way. It would be valuable to examine parents' responses to critical incidents and compare the nurses' responses.

A 1995 literature review (Coyne, 1995) found wide variations in the amount of care that parents were willing to undertake; that confusion existed over parents' roles and their expectations; and that there was lack of role definition for both parents of hospitalised children and the hospital staff caring for them. Coyne used concept analysis to explore the meanings of parent participation in the British literature. She found the descriptions usually comprised issues to do with negotiation, control, willingness, competence and authority, but in the main, was poorly defined, and recommended that major rethinking of the topic would be necessary before parent participation would be fully understood (Coyne, 1996).

As with the doctors described earlier, it seems that little has changed over time. Coyne and Cowley (2007) and Coyne (2008), in a study of British children's hospitals and using a grounded theory approach, found that nurses, acting as gatekeepers, controlled what parents did while accompanying their child to hospital. Parents who did not comply with what the nurses thought should occur were "punished" or excluded from activities with their children. The parents had to use strategies to ensure that what they needed during their child's hospital admission was

supplied. These findings are similar to those of Kristensson-Hallström and Elander (1994, 1997) in children's hospitals in Sweden, where parents used strategies to make sure their (and their children's) needs were met, rather than relying on good practice of the nurses.

Are relationships different in non-Western countries?

In recent years, the topic of the interaction between nurses and parents has been explored in some non-Western countries. Nurse-parent relationships in a children's ward in a hospital in Tanzania were the subject of a study in 2009 (Manongi, Nasuwa, Mwangi, Reyburn, Poulsen, & Chandler, 2009). A series of workshops which encouraged health workers to examine the way they relate to their patients were attended by all nurses on the paediatric ward. The emphasis of the workshops was the relationship with parents of admitted children. A questionnaire was used to determine parent satisfaction in this before and after study. In addition, focus groups were carried out six months after the first visit to the hospital by the family after the workshops were implemented. Of the 288 parents surveyed, the number of parents reporting problems in the interaction with nurses was not statistically different post workshop to the pre-workshop survey. This was thought to be because the priorities of the intervention, which was to improve nurse-parent relationships, did not match the

priorities of the nursing staff who saw working conditions, salary, and respect from colleagues and a feeling of being undervalued by patients as important.

Parental participation in a children's hospital in Iran (Aein, Alhani, Mohammadi, Kazemnejad, & Anoshirvan, 2009) was explored using a thematic analysis of data collected in interviews of 14 parents and 11 nurses. Five themes were found which influenced the relationship between the nurses and parents. The first theme explained that despite hospital policy declaring that nurses should not delegate nursing care to parents, low staffing levels of the wards encouraged the nurses to make the parents undertake some of their role, thus causing dissatisfaction amongst the parents. The second theme, delegation of care without adequate training for the parents, also caused friction and discomfort. The third theme of informal parent to parent support developed because the nurses had not provided the parents with adequate support. Theme four described the continuum of parents' willingness to participate, and involved emotional support at one end, that is, the parent was supporting the child rather than having to provide care, while the other extreme of the continuum meant parents provided most of the care. This caused anxiety among some parents who were inexperienced in nursing care or did not understand or have knowledge about it, and were concerned that they could cause harm to their child. The final theme, neglect of the parents' needs, was described by parents who found it

difficult to find a balance between their needs and the roles expected of them as parents, by the nurses. This paper concluded that nurses needed much education about parental participation so that the relationship between parents and nurses could be more constructive.

Another Iranian study (Sanjari, Shirazi, Heidari, Salemi, Rahmani, & Shoghi, 2009) also examined the relationship between nurses and parents of hospitalised children, looking particularly at support provided by nurses. This used the Nurse Parent Support Tool, a validated instrument, which was translated from English into Farsi. In this study parents received a high level of support from nurses. It is interesting that this study found such very different results to the previous one from Iran. While it is not possible because of ethical considerations to know the names of the hospitals where these studies were carried out, both were from the capital city Tehran.

Discussion

The works discussed above raise several questions. The relationship between parents and hospital staff is the cornerstone of FCC (Shields, 2010). If such results as those above demonstrate that there has been no real change over time, is it worth health institutions continuing to pursue FCC, what Darbyshire (1994) has always contended is a wonderful ideal but very difficult to implement properly? What do the

nurses see as “participating fully in the care of the child” and is their perception of what this participation should be, clinically appropriate? How much influence do such perceptions have on the relationship between nurses, parents, children, and other health professionals? Even if they do perceive the mother’s role as a soothing and calming one, health professionals’ education may not have provided them with an understanding of attachment research which has found that not all parents are able to tune into and/or respond sensitively to children’s needs for comfort and protection (Priddis & Howieson, 2009; Schore, 2001).

The relationships between parents and staff have often been contingent on the degree of participation allowed, or encouraged, or discouraged. There has been a steady increase in parental participation in hospital paediatric wards in recent years though it is by no means widely established practice. Even in countries where such a policy is mandated, whether or not a hospital encourages parents on the wards depends to a certain extent on the attitudes of staff and administrators. Where parent participation does exist it is rarely in a systematic and planned way.

An important point of clarification is necessary about parent participation, and health professionals’ (in particular, nurses’) relationships with parents in developing countries. In wealthy Western countries, it is common to hear a health professional

tell another that in developing countries, FCC is well practiced, as the parents always stay with the child. Many developing countries do implement FCC very effectively; however, as shown in studies described in this paper (Aein et. al, 2009; Manongi et. al, 2009; Saranji et. al, 2009) this is not always true. While it may be the case that parents (and other family members) are present, often it is the case that in countries with limited resources in their health systems, parents have to stay with the child to give the nursing care, because nursing staff are not available. This is not FCC, as the parents have no choice in whether or not they stay with their admitted child. Consequently, the relationships between parents and health professionals in such situations are necessarily coloured by this lack of choice.

Research into variables affecting how comfortable both the parents and hospital personnel are with their inter-relationships is largely qualitative and has yielded quite consistent evidence that education of staff, their family status and their ability to negotiate constructively with parents affects the health professionals' level of acceptance of parents (Coyne, 2008; Kristensson-Hallström & Elander, 1997; Shields, Pratt, & Hunter, 2006).

Education of health professionals about FCC, effective communication, family dynamics and conflict resolution would improve acceptance of parents (Coyne, 2008; Shields, 2010), thereby enhancing the relationships between the two. The need for a system-wide approach to parental participation is necessary as staff-parent interactions are coloured

by the organisational structure used on the wards, with flexible models of care delivery possibly providing opportunities for positive interaction. Education of parents and other family members is just as important, through consumer groups and the media. This could include realistic expectations of care delivery, FCC and what it means for a child and family, and ways of communicating within the labyrinth of a hospital.

Implications for practice

If the education described above was implemented, health practitioners would understand how a hospital admission impacts on a family, and how their communication can be geared to ensure that the parents know what to expect of the hospital and staff. Parents would be able to communicate effectively with staff, and so the relationships between parents and health professionals would be enhanced. Consequently, care of the admitted child would be truly family-centred.

Implications for research

While there is a wealth of research about interactions between nurses and parents, the evidence is rather sparse on that between doctors and parents; therefore this is an important area requiring further examination. In addition, the misconception that FCC is effective in developing countries needs in-depth and long-term study. Such research would help both parents and the staff caring for them and their children by providing evidence that would help health policy makers and governments see that funding needs

to be increased if FCC is to be effectively implemented.

Conclusion

Good relationships between parents and health professionals are necessary for the appropriate implementation of FCC, and the consequent delivery of high quality health care to a child admitted to hospital. Research into the relationships between doctors and parents, though somewhat sparse, shows that little has changed over time, and that the doctors usually hold the balance of power in such interactions. While there is much more research about nurses' interactions with parents, much of it based on the concept of parental participation in care, there, too, little improvement has been seen over the last 20 years. This is just as problematic in developing countries as in wealthy Western nations. As such relationships are the cornerstone of FCC, we suggest that Darbyshire's conclusion that family-centred care is a wonderful ideal, but very difficult to implement effectively is right, and so a critical discourse on FCC is to be encouraged.

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