

IMPLEMENTING FAMILY-CENTRED CARE: AN EXPLORATION OF THE BELIEFS AND PRACTICES OF PAEDIATRIC NURSES

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ABSTRACT

Objective:

This study explored paediatric nurses' perceptions of how they include and involve parents in the care of hospitalised children.

Design:

This qualitative study used individual unstructured interviews to gather data, the data was analysed using thematic coding.

Setting:

Paediatric wards within two regional area health services of New South Wales, Australia.

Subjects:

Fourteen paediatric nurses were asked to describe their beliefs and practices regarding the clinical application of family-centred care.

Main outcome measure:

Paediatric nurses' beliefs and practices about family-centred care were explored in an effort to explain how the concept was implemented.

Results:

The findings are presented as four interconnected themes. The first describes how participants either allocated tasks to parents or retained them, the second relates to the nurses' professional identity, the third theme identifies barriers and constraints to the implementation of family-centred care, while the

fourth describes the nurses' beliefs about their responsibilities when delivering family-centred care.

Conclusions:

Together these findings suggest that while nurses endorse the concept of family-centred care, the implementation into practice is more problematic. While it is not possible to generalise these findings to other paediatric nurses, the authors believe the insight gained will resonate with paediatric nurses internationally. The findings from this study are being used as the basis for the development of clinical practice guidelines to assist paediatric nurses to more consistently apply the concepts of family-centred care to their practice.

INTRODUCTION

This collaborative project arose from discussions between a group of paediatric nurses and a nurse academic during a paediatric education day held in regional New South Wales, Australia. The discussion centred on how difficult it can be to actively involve parents in the care of their sick child. The clinicians' concerns focused on the variability of the roles and tasks parents are encouraged to undertake in paediatric wards, the power and knowledge differential between health care professionals and parents, and the lack of time available for nurses to build rapport with parents.

The concept of 'family-centred care' is used to describe the way in which families and significant others are included and involved in the health care of hospitalised children (Coyne 1996). In developed countries, most paediatric wards claim to be 'family-centred', which

means that these wards adopt a philosophy where parents are acknowledged as being central to their child's existence, and are therefore vital in the decision-making process regarding the care of their child (Shields 2001).

However, previous research has indicated that family-centred care remains an idealistic notion in many paediatric settings (Espezel and Canam 2003; Fenwick et al 2001; Shields et al 2003).

So, while most paediatric nurses accept that the concept of family-centred care is important, the application of this concept into practice is not always evident. This study sought to explore ways in which a group of paediatric nurses' incorporated this concept into their clinical practice. The results of this study will further enhance nursing knowledge regarding the clinical application of family-centred care, and the findings will be used to develop clinical practice guidelines during the next stage of this project.

BACKGROUND TO THE STUDY

Historically, hospitals maintained rigid visiting policies preventing parents from seeing their child for long periods of time. However, since the early 1950s it has been recognised that hospitalisation is stressful for children. Two reports from the British Ministry of Health (1946, 1959) identified that children in hospital required emotional support and should be visited frequently by their parents. These early reports were among the first to advocate that mothers should be allowed to 'room-in' with their hospitalised child. Within a short space of time similar findings evolved from Canadian and North American studies, so that by 1963 health care practices and policies in most developed countries had recognised the beneficial effect of having a family member stay with a hospitalised child (Poster and Betz 1963).

A review of the more recent literature shows that hospitalisation is considered to be traumatic, particularly for infants and children less than five years of age. This is because young children lack the appropriate coping skills necessary to deal with the stresses of illness, pain, separation from family and an unfamiliar environment (Coyne 1996; Morse and Pooler 2002; Sheldon 1997). Allowing parents to stay with their hospitalised child has been identified as a significant step toward reducing the traumatic effects of hospitalisation on children (Shields 2001).

In 1996, Coyne concluded from a study which examined parental participation in the care of hospitalised children that 'the concept of parental participation was both complex and underdeveloped' and added that this leads to 'different interpretations of parental participation by health professionals in their effort to apply the concept in practice' (Coyne 1996, p.740). In 1997, a literature review by Sheldon identified that nurses acknowledged parents know their child better than anyone, but still believed that, in practice, nurses were better than parents in looking after a hospitalised child.

Recently, the concept of parental involvement in the care of hospitalised children has also come to include parental involvement in decision-making as well as participation in the care provided. This concept has been linked to an increase in consumerism in healthcare (Galvin et al 2000; Espezel and Canam 2003).

Today, parents, families, or the child's primary care giver expect to be actively involved in health care decision-making as well as the delivery of care. However, parental involvement in the health care of hospitalised children does not always occur. Kristensson-Hallstrom (2000, p.1029) believes the reason for this is that while paediatric nurses claim to support family-centred care, their practices do not always reflect this claim. Galvin et al (2000, p.625) agrees, stating that 'within the hospital culture there may be resistance to incorporating the patient and family into decision-making and involvement with care'. Similarly, Hutchfield (1999) found family-centred care remains an idealistic notion and while nurses espouse the concept of family-centred care, in reality they 'regulate the amount of parental participation in the child's care' (Espezel and Canam 2003, p.35).

The findings of a recent study by Shields et al (2003) identified that unless nurses have the time, energy and motivation to build rapport with parents then effective collaboration regarding the child's care is unlikely to occur. So, while the literature indicates paediatric nurses accept the concept of family participation in the care of hospitalised children there is a lack of empirical evidence regarding its implementation. This study sought to explore paediatric nurses' perceptions of this concept and its incorporation into their clinical practice.

Clinical practice guidelines

At present there are no evidence-based clinical practice guidelines available in NSW, Australia, that articulate how paediatric nurses can best implement the concept of family-centred care into their practice. Clinical practice guidelines in nursing are a way of providing consistently high quality care, by adhering to recognised, evidence-based standards. The care provided should then be evaluated using continuous quality improvement strategies (Whittenmore and Grey 2002). However, to be effective, clinical practice guidelines need to be based on current evidence and appropriate for the clinical environment in which they are to be implemented (Whittenmore and Grey 2002; Sabatier 2002). Thus, the research team for this study consisted of nurse academics and paediatric clinical nurses who worked together on every phase of this pilot study. The aim of the next stage of this project is to introduce clinical practice guidelines that will be relevant to paediatric nursing practice throughout New South Wales, Australia.

METHOD

The aim of this collaborative study was to explore how paediatric nursing staff included and involved family members in the care of the hospitalised child.

The specific objectives were to:

- explore paediatric nurses' beliefs regarding the involvement of family members in the care of hospitalised children;
- identify whether paediatric nurses include and involve family members in the care of sick children in hospital;
- identify the challenges and/or barriers faced by paediatric nurses in implementing family-centred care; and,
- the data to develop clinical practice guidelines that will assist paediatric nurses to provide family-centred care.

STUDY DESIGN

A qualitative approach was used as beliefs, perceptions and experiences needed to be explored. According to Rowe and McAllister (2002, p.8) qualitative inquiry can provide a means of understanding the contextual nature of nursing and informs clinical practice in a way that may allow for changes to occur.

Population and sample method

The population from which the sample was drawn was paediatric nurses who care for hospitalised children in the paediatric wards of two hospitals in regional NSW.

A purposive sample was recruited by inviting paediatric nurses employed in both hospitals to participate in the study. Willing participants with a diverse range of paediatric experience were selected to be interviewed, by one of two interviewers.

Procedures

The data collection consisted of individual interviews and validation of themes was conducted to ensure rigour and trustworthiness. Fourteen participants were individually interviewed, using broad prompting questions such as: 'Can you describe how you involve parents in the care of their children during hospitalisation? Or 'In your practice how do you apply the concept of family-centred care'? Each 30-50 minute interview was audio taped with the participant's permission and the tapes transcribed.

Data analysis

The transcripts of the interview tapes were read and re-read by all members of the research team. The analysis used thematic coding to identify key concepts and themes in the data. This method of data analysis allowed the researchers to extract the essence of the experiences as described by the participants and present these as themes designed to describe the key elements (Roberts and Taylor 1998).

In order to agree on the emerging themes a two-step method of analysis was used. First, the transcripts from each of the two locations were analysed by the interviewers. Second, clean copies of the transcripts were exchanged and re-analysed by each member of the team in order to check for consistency of the emerging themes.

Following analysis of the interview data a summary of findings was disseminated to all participants, who were then invited to make suggestions and comments. Together both sets of data will be used to develop preliminary clinical practice guidelines.

Ethics

Ethical approval to commence this project was given by a university human research ethics committee and both relevant area health service human research ethics committees. Willing participants were provided with an information sheet asked to sign a written consent form prior to participating in the study. Participants were informed that their identity and place of employment would not be revealed.

RESULTS

The researchers identified four major themes in relation to paediatric nurses descriptions of how they implement the concept of family-centred care. These themes are titled; 'tasks and roles', 'empowerment issues', 'barriers and constraints' and 'care and protection'.

Theme 1: Tasks and roles

All participants described particular tasks or roles they commonly allocated to willing parents or primary caregivers, as well as tasks and roles felt were best left to nurses. In some instances participants indicated they made decisions about which jobs and roles to allocate to parents based on the nurses' assessment of the motivation and/or perceived skill level of the parents. The following is a list of tasks and roles all the participants regularly allowed willing parents to perform:

- Staying with the child at all times to calm and comfort (generally this applied to only one parent or care-giver at a time).
- Meeting hygiene needs (eg bathing, showering, washing).
- Feeding or helping at meal times.
- Meeting elimination needs (eg taking the child to the toilet, changing nappies, emptying urine bottles).
- Accompanying the child to the anaesthetic bay (if allowed by the medical officer).
- Entertaining the child (eg organising games, stories, videos).
- Advising nursing staff of the child's status (particularly any changes in the child's condition).

Only a few participants described allowing some parents to perform the following tasks, but this only occurred after the parent had been instructed and observed for competency:

- Giving medications.
- Changing dressings.
- Recording fluid balance.

All participants felt strongly about the importance of performing their nursing tasks and roles. Many of the

participants made comments about caring for the patient and the family by protecting them from unpleasant sights and sounds, and particularly unpleasant procedures. All participants talked about the importance of retaining their professional role, with one participant commenting: *'We cannot expect parents to take on our role as nurses... nurses have to continue to be nurses'*. This is consistent with Galvin et al (2000, p.626) who found that 'staff member perceptions are that working collaboratively with families is a threat to their professional identity'. One participant obviously felt this threat when commenting: *'Things are being taken away from us and handed over to the parents'*. These comments highlight the concerns a number of the participants felt regarding role erosion. For example, one participant stressed that: *'as nurses we can't lose the skills we trained for... the parents are there to support the child... I mean they can be involved but not take away our role.'*

These comments are consistent with the findings of a recent study conducted by Espezel and Canam (2003, p.40) who found that even when parents described the parent-nurse relationship as positive it was rarely collaborative in nature.

Evident in all the interviews was the important role nurses believed they played in providing a communication conduit between the medical officers and the child and parents, by 'translating' medical terms into layperson's language and by checking for parents' understanding of the child's condition and care requirements. One participant explained this role; *'It's up to us to keep the parents fully informed'*. While another participant explained that after the doctors' rounds the nurse goes back to the family and explains the jargon by *'acting as an interpreter between the doctor and the family'*.

Again, according to a study by Espezel and Canam (2003) parental expectations of a nurse's role included nurses acting as a mediator between parents and doctors. Furthermore, Espezel and Canam (2003) found parents viewed nurses positively as long as they 'translated' medical information successfully.

Theme 2: Empowerment issues

This theme related closely to the participants' assumptions and beliefs about their professional identity as a nurse. Each participant made comments concerning their power as health care professionals. In all instances the participants' descriptions were consistent with those of Hewitt (2002, p.440) who describes the power exercised by health care professionals as 'benevolent paternalism'.

Hewitt (2002) goes on to say that, despite the best intentions of the nurse, this form of power restricts the autonomy of patients and families. All participants discussed these empowerment issues in terms of what they would 'allow' parents to do, making it clear that the decision to include parents in care delivery rested with the nurse. Their comments are condensed into the following key points:

- Nurses believe they are the ones to 'set the boundary' regarding the role and tasks that parents can perform for the hospitalised child.
- Nurses assume control of the decision-making processes for the care of the child by educating, 'telling' and advising parents of their child's condition and treatment.
- Parents must ask nurses' permission before making any decisions in relation to the care of the hospitalised child.
- Nurses discourage parents from assuming responsibility for anything other than basic parental duties during hospitalisation and 'nursing' skills are only taught if parents need 'advanced' skills to provide home care.
- Nurses feel strongly that parents should not take on 'nursing' responsibilities, as they need to focus on the child, not the nursing tasks.

All participants felt strongly that they were 'the knowledge experts' in providing nursing care for sick children. This belief was reflected in many of the comments such as:

'Skilled nursing jobs should be done by the nursing staff, and the nurturing and comforting and the unskilled jobs, like bathing and changing, left to the parents.'

'Nurses just go and do things because sometimes nurses know best and kids are better with nursing staff than they are with parents.'

'I wouldn't encourage parents to be giving drugs and things like that... because if anything goes wrong I'm the one who takes the rap.'

One participant commented that *'I don't believe we should involve parents [in nursing duties] unless it's teaching them something for when they go out of the hospital environment.'*

This sentiment was echoed in all the interviews. However, in many of the interviews the participants qualified their comments by explaining that if they had more time to spend with families, providing education and support then they may be more comfortable in allowing parents to assume greater responsibility for the nursing care of the child.

According to Espezel and Canam (2003) and Shields et al (2003) paediatric nurses readily promote family-centred care as a concept but the clinical application remains problematic, for a number of reasons, which are described in the next theme.

Theme 3: Barriers and constraints

All participants described barriers and constraints they believed prevented them from providing family-centred care as effectively as they might. Unanimously, all participants stressed they would like more time to involve and educate parents. This included more time to assess parental competence and provide more advanced knowledge and skills.

The barriers described were varied but all participants agreed staff shortages, heavy workloads, and time constraints

impacted on their ability to give sufficient time to each family. Some of the comments related to these barriers were:

'We're often under time pressure and understaffed so it isn't always possible to explain procedures.'

'In a very busy ward it's easier to do it yourself... it's a timeframe thing.'

'When it's really busy it's hard to be able to spend time with them [parents], teaching them things.'

Espezel and Canam (2003) believe inadequate staffing levels and the desire for cost-effectiveness in health care significantly influences the incongruence between the theory and practice of family-centred care.

Other issues participants described as constraints in providing effective family-centred care are summarised below:

- A lack of guidelines and/or policies for the nurse regarding the role of parents when children are hospitalised.
- Nurses' concerns regarding the extent of their legal and professional responsibilities for the care of the hospitalised child.
- Parents who indicate an unwillingness or inability to be involved.
- Lack of structure and guidance about how to implement family-centred care, particularly for staff new to a paediatric setting.
- Outdated nursing habits, eg 'doing the job yourself' because it is quicker.
- Poor communication between nurses and parents.
- Nurses and parents lack of confidence in their respective roles; new parents who were unsure of their parenting skills and nurses who lacked confidence in their knowledge and/or skills.
- The nurses' need to be seen as 'the expert'; exemplified by an inability/unwillingness to share knowledge.
- Nurses who do not have the energy or motivation to teach and involve parents, often because they are overworked and/or 'burnt out'.
- The nursing management practice of reducing staffing levels when parents are present to 'care' for young children and infants, in the belief that the nurses' workload is reduced by their presence.

Many of these barriers are consistent with those described in the literature (Espezel and Canam 2003; Galvin et al 2000; Hutchfield 1999; Shields 2001; Shields et al 2003). However, the researchers suspect that removal of these barriers may not address the problem of including parents as more equal partners in care, for the reasons discussed in the final theme.

Theme 4: Care and protection

All of the participants described the importance of assuming responsibility for the care and protection of families, not just the individual patient. Therefore, at

times the nurses made decisions regarding the involvement of parents, based on the assumption that parents expected nurses to make such decisions.

All the participants talked about protecting the parents from stress when children were acutely ill and had to have painful or unpleasant procedures performed. The rationale for this belief was that parents needed to provide the nurturing and comfort for their children, thus it was not acceptable for nurses to expect parents to be involved in painful or unpleasant procedures which would only add to their stress levels.

These assumptions are evident in all the transcripts, some examples are:

'I asked "would one of you like to come in"... but by the looks on their faces, they were scared stiff. So I said I'll just bring him back to you when it's over, for a cuddle.'

'If a child is going to die I want to protect them [parents] from it, instead of saying "yes, it may happen".'

'Some may think you should say to parents "you need to do this", but it's not fair when parents are stressed anyway. We need to fulfil our role and look after the child and the parents.'

Sometimes I ask parents to leave because it's easier for them and the child to cope.

There were many other comments related to this theme and they have been summarised as follows:

- Nurses felt parents should assume their usual caring role while the child is hospitalised and not participate in nursing duties because this would cause the parents additional stress in an already stressful situation.
- Nurses believe parents are often very tired when a child is hospitalised and therefore nurses should protect them from any additional responsibilities.
- Nurses felt strongly that parents have clear expectations of what a nurse should do, and nurses need to live up to those expectations in order to build a positive relationship with parents.
- Nurses assumed parents may feel guilty when their child is sick, because they may not have the time or energy to give undivided attention to that child, particularly if there are other children at home or unavoidable work commitments, therefore nurses need to assume a primary caring role.
- Nurses were role models for parents, and as such nurses need to reassure and educate parents regarding the care of the child, and nurses should not abdicate this responsibility.
- Nurses believe parents do not want to make decisions at this time, but look to the experts, eg doctors and nurses to decide the care/treatment needed.

All participants described adopting this protective paternalistic role, explaining it was this responsibility that motivated them to exclude parents at times. In particular, all participants described discouraging parents from witnessing procedures that could be distressing.

In their capacity as carers, the participants felt they had a responsibility to assume the decision-making role when parents were tired or stressed. Furthermore, all participants believed that by protecting parents from unpleasant events they were 'caring' for the whole family, that is, they were actually implementing 'family-centred care'.

Interestingly, Shields et al (2003) describes the hospitalisation of a child as an indication that help is needed. The nurses in this study all believed that by caring for and protecting the family they were providing the help needed in a 'family-centred' way.

ASSUMPTIONS AND LIMITATIONS

The findings from this qualitative study cannot be generalised to a wider population of paediatric nurses, but the results may resonate with nurses who work with sick children. One assumption on which this study is based is that the implementation of family-centred care is a positive practice worth striving toward. Additionally, the research team acknowledges that observation of practice and interviews with other stakeholders (for example, children, parents and families) would have added further valuable dimensions to this study, but financial and time constraints did not allow for these additional data collection strategies at this stage of the project. However, it is anticipated that further studies will include interviews with other stakeholders and observation of practice as data collection methods.

IMPLICATIONS AND CONCLUSION

The findings of this study showed that the paediatric nurses who participated all believed strongly in the 'family-centred care' concept, yet they found the application in practice to be somewhat challenging.

The challenges described by the participants were linked to the nurses' beliefs about their own professional role, their desire to see themselves as the 'experts' in the care of hospitalised children, and the barriers they identified that make implementation of family-centred care difficult for them.

Overwhelmingly, all participants described their role as involving not only providing nursing care for the patient and family but also protecting family members from painful or unpleasant experiences. This belief seems to cause the nurses the most conflict when they discussed the practical implications of parental participation.

The clinical implications of this small study are that the decisions of the participants about the degree of involvement of parents were influenced by the nurses' need to fulfil their caring role. As well, there were legitimate concerns about the legal implications of parents assuming traditionally 'nursing' duties.

Based on these findings, the next stage of this project will focus on the development of clinical practice guidelines, aimed at clarifying the nurses' professional and legal responsibilities when delivering family-centred care. In addition, the findings

of this study may encourage nurses to reflect on how they involve families in caring for a sick child. The next stage of this study involves talking to larger groups of paediatric nurses, who will be asked to comment on the clinical applicability of the draft guidelines, prior to introducing them into a number of paediatric settings in New South Wales

In summary, this collaborative project has provided significant insight into nurses' assumptions, beliefs and experiences of implementing family-centred care.

The findings have explicated an aspect of paediatric nursing practice from a clinicians' perspective, and will be invaluable as the basis for the development of clinical practice guidelines to assist nurses in the implementation of this concept into practice.

Finally, the significance of this project is grounded in the belief that children are hospitalised in order to receive expert nursing care, therefore enhancing the consistency of nursing practice will be beneficial to children and families during hospitalisation.

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