Stories seldom told: paediatric nurses’ experiences of caring for hospitalized children with special needs and their families

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Aims of the study. This study explored paediatric nurses’ experiences of caring for children with special needs and their families in an acute care setting. The aim of the study was to increase understanding of nurses’ experiences of caring for these children and their families. The study was designed to reveal the caring practices embedded within these relationships through exploring nurses’ stories.

Study design/methods. Gadamerian hermeneutic phenomenology and feminist research principles were the approaches used to guide the study. Interviews were held with experienced paediatric nurses and interpretation of interview transcripts using a Gadamerian hermeneutic phenomenological approach resulted in the identification of four themes.

Findings. The four themes revealed were: Special Relationships; Multiple Dimensions of Who is Expert; Development of Trust Between Nurses and Families; and Feelings of Frustration and Guilt.

Conclusions. The study emphasized the context-specific nature of relationships between nurses and children and their families. The nurses spoke about the difficulties they encountered in their practice and some of the ways that they dealt with these problems. They discussed the things that they valued and those that made them feel guilty and frustrated. In doing so, they revealed their warmth, strength, humanity and caring.

Keywords: nursing, children, families, relationships, caring, hermeneutic phenomenology, feminist research, special needs

Introduction

Nurses experience caring for children with special needs and their families in their various practice settings. This study explored paediatric nurses’ experiences of caring for hospitalized children with special needs and their families. The research setting was a 15-bed paediatric ward providing care for children from 0 to 6 years, in a southern state of Australia. Children with special needs referred to children with disabilities, children with long-term or chronic illness and children who experienced long-term or repeated hospitalizations. The study used a Gadamerian (1960, translation 1989) hermeneutic phenomenological approach, framed by the transformative process described by Reinharz (1983) and underscored by feminist research principles. The essence of the study was lived experience, revealing the stories of four
to providing acute care and such settings are rarely designed that they will likely experience repeated hospitalizations. The chronic nature of their conditions means to enable them to provide family centred care (van der Schyff 1979, Hayes & Knox 1984, Brown & Ritchie 1989, Darbyshire 1993, Barnsteiner et al. 1994). Although integral to the child’s care, there are many barriers to providing family centred care to hospitalized children in general (van der Schyff 1979, Darbyshire 1993, Coyne 1995), and to children with special needs in particular (Robinson 1987, Darbyshire & Morrison 1995). Some barriers include differing understandings of what the term family centred care actually means; different expectations of the parenting role; confusion and uncertainty about the role parents are expected to play; environmental constraints, both physical and attitudinal, and lack of attention to the skills, supports and resources nurses need to enable them to provide family centred care (van der Schyff 1979, Hayes & Knox 1984, Brown & Ritchie 1989, Darbyshire 1993, Barnsteiner et al. 1994). There is a need to emphasize the importance of family centred care for hospitalized children with special needs for several reasons. The chronic nature of their conditions means that they will likely experience repeated hospitalizations. Health care professionals in acute care settings are orientated to providing acute care and such settings are rarely designed to meet the special needs of children with disabilities and chronic illness (Robinson 1987, Ogden-Burke et al. 1991). Parents of children with chronic illnesses are intimately involved with their child’s health care on a day to day basis because the majority of these children are normally cared for at home (Robinson 1987). The stressful experience of hospitalization of their child is often a subset of the stressors the family experiences throughout the life of their child. It is also possible that stressors leading up to and following hospitalization are not recognized by health care professionals (Ogden-Burke et al. 1991).

Research suggests that nurses’ attitudes to parental participation is mixed. There is a lack of consensus among nurses about what form parental participation should take and how far it should extend (Coyne 1995). Surveys of nurses’ attitudes toward parental participation reveal that their attitudes may be associated with levels of education, level of position, and whether the nurses are themselves parents of young children (Seidl 1969, Gill 1987, Johnson & Lindschau 1996). Research by Johnson and Lindschau (1996) suggests that staff attitudes to the concept of parental participation have progressed a long way in a relatively short period of time and this concept is positive and evolving.

Darbyshire (1994) sought to understand the experience of parents who ‘live in’ with a sick child in hospital and their relationships with paediatric nurses. This study highlighted many of the tensions involved for both parents and nurses in relation to the philosophy of family centred care and also revealed caring practices, therefore recognizing the possibilities of transformative caring practices.

Totka (1996), who conducted a study exploring paediatric nurses’ struggle to find the right level and kind of involvement with children and their families, found that highly synchronous relationships usually occurred in long-term relationships and they appeared to occur more frequently, though not exclusively, with chronically ill, or terminally ill patients. Totka stated that nurses’ struggles to determine interpersonal boundaries can only be understood through the stories of nurses themselves, a sentiment echoed by Benner and Wrubel (1989, p. 402) who wrote that the exploration of nursing practice allows the possibility of uncovering new areas of knowledge and understanding not yet described or outlined in the literature.

This review of the literature supports the notion that it is timely and appropriate to consider nurses’ experiences of caring for hospitalized children with special needs and their families through exploring the practice stories of paediatric nurses.
The study

Methodology

Hermeneutic phenomenology as described by Hans Georg Gadamer (1989) was the approach chosen to guide this study. Gadamer did not present a method of phenomenology, however, his central notions were used to guide the development of procedural steps for this research (Annells 1996). Significant concepts from Gadamer that were embraced throughout the conduct of this study were notions of the hermeneutic circle of understanding, prejudice, linguisticality of understanding, historicity, fusion of horizons and lived experience. This study also employed a feminist perspective as it included central tenants of feminist belief; that the voices of the participants were heard, and that there was nonhierarchical, reflexive and interactive relationships between the researcher and participants. The authoritative, objective view of knowledge was questioned and understanding of feelings, problems and needs was sought (Sigsworth 1995).

Method

The caring practices of the participant nurses were revealed through exploring their stories about their caring relationships with special needs children and their families. Stories and narrative have an important role in nursing, as stories told by nurses can help us to uncover the knowledge in practice that we take for granted.

The study was framed by the phenomenological transformative processes described by Reinharz (1983) who described five steps in the process that transforms private experience into action and language. A detailed discussion of this process is described under the data analysis section of this paper. The research setting for this study was a 15-bed paediatric ward providing care for children from 0 to 6 years in a southern state of Australia, in which the principal researcher worked. All nurses from this practice setting were given a plain language statement describing the study and participation requirements. It specified that participation required an audiotaped in-depth interview, as well as a possible follow-up interview if further clarification was required and as a form of confirmation of meanings. Registered nurses that had worked in the unit and had cared for children with special needs for at least one year were invited to participate. It was considered these nurses would be familiar with the practice setting and have meaningful experiences to draw upon. Those who were interested in participating were asked to use a preaddressed envelope supplied by the researcher to return their consent form. Upon receipt of this form, the researcher met with the four (4) nurses who returned their signed consent form to arrange an interview on a date and time that was mutually convenient.

Ethical considerations

Prior to data collection, formal approval to proceed was obtained from the relevant research and ethics committees. Voluntary, informed and written consent was obtained from the participants. Participants were aware of the purpose of the research and the structure of their contribution, including the audio taping of interviews. Nurses participating were aware they could control the interviews, that they were free to divulge as much or as little information as they wished and that the audio tape could be turned off at any time in the interviews.

The relationship between the researcher and participants was one of collegiality and mutual respect that was characterized by openness and a willingness to consider respectfully what the participants had to say. The researcher was not employed in a position that required her to evaluate the participants' performance in the practice setting and it was made clear to all participants that there was no intention, directly or otherwise, to evaluate or judge any aspect of the participants' nursing care. Rather, it was stated clearly that the study provided the participants with an opportunity to tell their story of caring for hospitalized children with special needs and their families. Reinharz (1991) argues that when the participants know the researcher, there is an increased possibility of openness and revelation that may not occur when the researcher is unknown to the participants.

To safeguard their identity participants chose the pseudonyms of Evelyn, Gabrielle, Jenny and Susan. If clients' names were revealed in the nurses' practice stories, randomly assigned pseudonyms were used so that children and their families were not readily identified. Within written reports, children's gender was randomly assigned and references to specific conditions were changed, while retaining the essential nature of those conditions. These alterations to the data were made when transcribing the audiotapes.

Data collection

Individual, in-depth, semistructured interviews that were conversational in style, were held with the participants, who were asked to talk about their experiences of caring for children with special needs in hospital. Throughout the interviews the participants were encouraged to tell their stories. Topic areas included the nurses' perceptions of their relationships with children with special needs, features of the relationships that were meaningful, difficulties they identified and positive aspects of caring for these children and their
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families. Interviews lasting between 45 and 90 min were conducted in each of the participants' own homes. The tape-recorded interviews were transcribed verbatim by the researcher to create the text for analysis.

Data analysis
The researcher engaged in continuous dialogue with the text to understand what was there and to use the understandings gained to explore meaning further. An imperative of the analysis was to listen to the tapes over and over again whilst reading the transcripts in order to develop initial impressions and to confirm insights. The phenomenological transformative processes described by Reinharz (1983) were used to illuminate themes of meaning explicated by the participants. That is, through listening to the stories of paediatric nurses about their relationships with children with special needs and their families whilst undertaking a transformative analysis, the caring practices embedded within their relationships were revealed. In using this method the first transformative process was performed by the participants as their experiences were transformed into actions and language. The second transformation was undertaken by the researcher, who transformed hermeneutically what was said into an understanding of the original experiences of the participants. This step required much patience, as the researcher was required to remain open, embrace more universal points of view and move constantly from the whole to the part and back to the whole again (Gadamer 1989). The desire of the researcher to portray accurately the phenomenon of caring for children with special needs and their families included special relationships. Special relationships were revealed in a myriad of ways and included concepts such as having long-term memories of the child, becoming known, developing boundaries and acknowledging that each relationship was different one from the other. In talking about their experiences participants frequently referred to special relationships they had and discussed these in some detail. Susan said:

Probably when I first read it [information about the research] a few particular children came to mind and I thought they're obviously the ones that for some reason I've had some special relationship with (Susan)

And I still think about him
The nurses' discourses revealed that a wealth of past experiences shaped and molded their present world. Some told stories from their distant past in the traditional sense of lived time. For example, Susan discussed a special relationship with a baby and parents and although this was 10 years ago, the memories were still very clear:

... I still remember him.
It was 1988, when he died (Susan)

Likewise, Gabrielle spoke of a relationship with a child with a terminal illness whose family asked her to come from home to care for the child after her death at two o'clock in the morning:
... it's a long time ago, but it's always stuck in my mind ... I had a special relationship with this family. And when the little girl died, I was the one that they wanted to come from my house to actually tend her (Gabrielle)

You get to know them and their families
Participants saw special relationships they formed as different to 'routine' admissions of children, as there was an opportunity to get to know the special needs child and family. Relationships were referred to as 'friendship' by some. Some set definite boundaries and limits, but not others. However, each spoke of an increased level of involvement and investment of self that was more than usual:

We see them quite regularly ... And we get to know more about them. It's not quite the same as other kids who come in for Ts and As [tonsillectomy and adenoidectomy]. You get to know them and their families and it's different ... and it is more special. A chance to form a friendship (Evelyn)

Or as expressed by Gabrielle:
... and I think the relationships evolve because invariably they're long-term... I don't ever view it as a friend ... it has aspects of friendship, but it's still got that professional edge to it (Gabrielle)

Bridges and boundaries
The formation of special relationships caused the nurses to cross over boundaries and this notion was frequently referred to:

I don't think you can ever put a definite boundary on what you do... Sometimes there is a need for you to overstep what you would normally do (Jenny)

Crossing over boundaries was described as important and rewarding, but not without problems. One participant described needing to step back when there was over involvement:

I needed to say I'm sorry but I can't cope with this at the moment, and I need to step away from this (Jenny)

Why with some, and why with others?
Participants acknowledged that nurses did not have special relationships with everyone. Reasons for different levels of involvement included associating the child with someone close:

... when I saw him cry I thought – Oh what if that was my niece lying there in the cot crying (Susan)

or connections that attract us to people generally in our lives:

Sometimes you just sort of click with people., and you get on with them really well (Susan)

and having a shared history:

... sometimes it's because you happen to be there at a crisis. Maybe they see you as 'You were there when my child needed you' And so they seek you out at different times (Susan)

You can't do it all the time
As explained by the participants, special relationships could not be entered into all the time:

I don't believe you can do it all the time..., you can't keep investing. Because I think you'd kill yourself. You know, you have to recover... before you can invest again (Gabrielle)

Also discussed was the notion of 'sharing the load.' As Gabrielle said:

I think that that's one of the beauties of nursing. That there are people that I work with that develop close relationships with a certain family and I couldn't in a million years... And thank God it's like that. Because hopefully every family with special needs gets someone along the way, and every nurse gets enriched along the way... And even if it only happens once, it's good enough (Gabrielle)

Something that is quite privileged
Periods of intimacy and of sharing special moments occurred where the nurses felt privileged. Participants talked of being with the family when a child died:

you're receiving heaps from the family as well, ... they invite you in to something that is quite privileged really (Gabrielle)

And it was just Gabe, Jane and I. And I was very privileged that she asked me to do that. It was very special (Evelyn)

Multiple dimensions of who is expert
In relation to the notion of expert, the nurses' stories showed that multiple realities exist. Expertise was in the hands of all of the players; sometimes this was in transition, sometimes it was acknowledged readily and sometimes there were frictions and difficulties.

Their care should be learnt from their parents
Participants recognized the parents as experts who taught the nurses how to care for the children. They perceived that:

you really need to take a lot of advice from the parents (Susan)

and

the basis of their care should be learnt from [them] (Jenny)
There's a total role reversal
Participants described a period of transition where roles changed:

at the beginning you're the teacher, the educator, the supporter, the informer. And you're probably the primary care giver. And... within a very short space of time, those parents, most of them will be well read, well versed, informed and expert about what they do, and how they do it (Gabrielle)

Development of trust between nurses and families
Parents' need to trust was recognized as important by the participants who felt that parents needed to see their care and to get to know them to enable trust to develop.

Until they actually see
Evelyn described one parent saying:

she [the mother] didn't realize she could trust the staff until she saw Mary bathing him and dressing him, just like she would... (Evelyn)

Trust was also affected if parents did not see the nurses providing the care that they believed was necessary for their child:

But the parents come in and find them like that and it's like: you haven't looked after him. You're not doing what you ought to be doing for him (Susan)

I let them see who I am
The nurses spoke of revealing themselves as person to the parents not just competent professionals:

I always maintain my role as the nurse, but I let them see that I'm also Jenny and I let them see who I am. And I just talk to them and listen to them (Jenny).

Feelings of frustration and guilt
Participants talked about difficulties they experienced in caring for children with special needs in an acute care setting. One difficulty had to do with the amount of time required to perform or assist with special care needs and the conflicts of other calls on the nurses' time. They described feeling frustrated and guilty when they could not provide holistic care. They had limited time available, therefore caring for the more immediate needs of acutely ill patients often took priority.

But you're safe
Sometimes when the nurse experienced more than one demand on their time, keeping the child safe was as much as they could do.

And... minimizing long-term problems for us is usually not a priority. If... we don't lay them the way they're supposed to be, for this minute because I have to put you down and go and stop this child from choking on their lunch, then you will put them down... If I put you in your cot, lying on your back, yes, you're safe for this minute (Susan)

Things do take longer with them. And I think its easy to just let them sit in the chair... when you've got four other patients to look after... And this sounds awful, I know – but if they're sitting in their chair, or their bed or whatever, you know they're safe (Jenny)

Another cause for feelings of frustration and guilt arose from differences between parents' expectations of their child's care needs and the nurses' perceptions of those needs, or perhaps in the nurses' ability to meet parent expectations:

...often their expectations of what we provide are really quite high. Which is not necessarily good or bad. But... they do have high expectations and sometimes ... you can only give what you can give (Evelyn)

The friction that sometimes existed between nurses and parents was explored by Susan when she said:

Actually there’s another child I got the guilts about too... And the mother was very ... she'd just been taught like how to lay him this side, you mustn't do this, and mustn't do that and was verging on being a little aggressive with people who did the wrong thing ... And we all got to know and like and respect this mother very much but to start with it was like 'Don't lay him on the bed. Don't do this and don't do that'. And you felt like you were really being badgered (Susan).

Discussion
These participants' stories revealed a wealth of past experiences that shaped and molded their present world. The stories the nurses told remained with them and according to Gadamer (1989), these experiences constituted the historical reality of their being as well as their horizon of understanding.

The participants acknowledged that special relationships were an important part of caring for this group of children and their families, causing them to cross over boundaries, referred to by Barnsteiner et al. (1994, p. 37) as the place where self leaves off and other begins. Benner and Wrubel (1989, p. 375) refer to a narrow path that nurses tread lightly in determining the right level of involvement, indicating that it is an art to know what one can offer without becoming over-involved. Within these narratives the participants revealed that there was a separate-but-related balance in their caring relationships that was affected by many things, including the family's needs, the child's illness or condition,
the frequency of admissions, shared history, and the fit between the nurse and family. As the findings of this study revealed, there are so many variables, and each relationship is different and unique (Barnsteiner et al. 1994, p. 37).

The participants valued relationships where they experienced increased involvement and reciprocal and authentic relationships with families. Yet how do these experiences differ to relationships of over-involvement and when does increased involvement become problematic? Within the literature it is implied that viewing a child as special over other patients suggests over-involvement (Rushton et al. 1996). However, the experiences revealed by these nurses provide understandings that are in contrast with this limiting and prescribed view. Thus there is a need for further exploration of the concept of over-involvement and its application and relevance to nursing practice. Further, Totka’s (1996) study explored notions of the right level and kind of involvement; however, Totka’s findings are problematic because the authors struggle to define involvement accurately, opting to call positive relationships over-involvement ‘only because no one could think of a better term’ (Totka 1996, p. 193).

These participants’ stories revealed that the special relationships they developed with special needs children and their families required more from them than routine encounters with children and families. They found the demands these relationships made of them meant they could not be entered into all the time and that a period of healing was required before entering into another relationship. This finding is supported by Rashotte et al. (1997, p. 381) who found that nurses need to disengage from relationships with children who have died before they are able to reinvest in new relationships.

As well as recognizing the demands the relationships made upon them, the participants appreciated the reciprocal nature of the relationships, valuing them and finding them personally rewarding. Participants described periods of intimacy and of sharing special moments with families and in doing so described themselves as privileged. Benner and Wrubel who wrote of the privileged place of nursing (1989, pxi) affirm the experiences of these participants, in that being there for the families and being with them held importance and value for these nurses.

The participants believed that it was important for parents to be able to see nurses providing care in order for the parents to be able to trust them. Darbyshire (1994) described parents caring for their hospitalized children as ‘parenting in public’ and it is worth noting that nursing too is practiced in public and is therefore subject to surveillance and scrutiny. Traditionally, notions of surveillance and scrutiny tend to hold negative connotations. However, the stories of these nurses revealed that observation of their practice had a therapeutic effect for the family and on the subsequent development of trust.

Participants spoke of being seen in their professional role and of also revealing themselves as person to parents. While they felt it was important for parents to see them as competent professionals, the nurses valued the humanness and humanity of sharing with the parents as people. This concept is referred to by Gadamer (1989, p. 361) who described I-Thou relationships where there is shared communication and openness between individuals. In sharing something of themselves through sensitive self-disclosure or openness the nurses entered into an I-Thou relationship, enabling them to fuse their concerns with those of the parents (Gadamer 1989, p. 178).

In their discussions about the development of trust in relationships, the nurses revealed their own interpretive skills. These skills are at the heart of expert clinical nursing ‘because nursing practice is always concerned with the human world’ (Benner & Wrubel 1989, p. 17). Conversely, the participants also recognize the knowledge and abilities of parents as they described learning caring practices from the parents. Their descriptions however, sharply contrast with assertions within the literature that parents often have their expertise devalued or ignored when their chronically ill children are hospitalized (Robinson 1985), suggesting that further exploration is warranted. Whilst this research focused on nurses’ experiences of caring for children with special needs it is important to note that children with special needs and their families also have a story to tell. Further research exploring their experiences of care and their relationships with nurses is needed.

The participants of this study experienced dilemmas in caring for children with special needs in an acute care setting. They found it difficult to support the individual children in their activities of daily living. With the limited time available to them, caring for the more immediate needs of acutely ill patients often took priority over the care needs of these children. Institutional constraints affecting nurses’ ability to care for children with special needs in the acute setting are recognized by other researchers including Robinson (1987), Brown and Ritchie (1989) and Ogden-Burke et al. (1991). However, further exploration regarding the effects of time and resource constraints on nursing practice is warranted, particularly in the current climate of economic rationalism.

Conclusion

This study explored four nurses’ lived experiences of caring for hospitalized children with special needs and their families
in the acute care setting, achieved through exploring their stories. The inclusion of the nurses' spoken words liberated meanings and experiences of caring for the children and their families, permitting insight into the intricacies of relationships as seen through the nurses' eyes. Understandings were discussed within the themes identified which were Special Relationships; Multiple Realities of Who is Expert; Development of Trust Between the Nurses and Families; and Feelings of Frustration and Guilt.

An understanding of the phenomenon was obtained from the integration and synthesis of the four themes. Each theme by itself is not sufficient to illuminate the lived experiences of the nurses. Each is dependent on the others, just as the word is to the sentence and the sentence to the page. As Gadamer's hermeneutic rule requires, 'we must understand the whole in terms of the detail and the detail in terms of the whole' (1989, p. 291).

This study presents one possible way of interpreting the participants' experiences and exploring their stories has revealed the complexity of the phenomenon of caring for children with special needs. The results have not been a neat development of Trust Between the Nurses and Families; and discussed within the themes identified which were Special Relationships; Multiple Realities of Who is Expert; Development of Trust Between the Nurses and Families; and Feelings of Frustration and Guilt.

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This study presents one possible way of interpreting the participants' experiences and exploring their stories has revealed the complexity of the phenomenon of caring for children with special needs. The results have not been a neat closure in the form of answers to a research question but rather the formation of new ways of understanding the experiences of nurses' caring. The study has generated questions regarding notions of increased involvement and over-involvement that require further exploration, as well as questions about how experiences of increased involvement differ to relationships of over-involvement and when increased involvement might become problematic.

The nurses participating in this study revealed areas of their practice of importance to them. They spoke about difficulties they encountered and some of the ways they dealt with those problems. They discussed those things in their practice that they valued and those that made them feel guilty and frustrated. In doing so, they revealed their warmth, strength, humanity and caring.

The study has increased the researcher's understandings and has the potential to influence others. The fifth step of the Reinharz' transformative process involves the reader's interpretation of this work and creation of their own interpretations of the experience. Thus it is acknowledged that in reading this work there is a possibility that it may help to clarify experiences in ways leading to 'insights about new actions that we want to take' (Reinharz 1983, p. 79).

References


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