

Susan E. Gasquoine

NZRCpN; BA; MPhil(Nursing)

Contact details

c/-School of Health and Community Studies,
UNITEC, Auckland, New Zealand

Address: Private Bag 92025, Auckland, New Zealand

Telephone: Wk: 64 9 8154321 ext5060

Hm: 64 9 6262008

Fax: 64 9 8375947

Email: sgasquoine@unitec.ac.nz

Biography

I am currently employed as a Lecturer in the School of Health and Community Studies at Unitec New Zealand and the School of Health Sciences at Massey University. My current research interest is in the epidemic of obesity in children and the sociopolitical influences on parents working to keep their children healthy.

Mothering a hospitalised child: it's the 'little things' that matter.

Abstract

This paper reports one aspect of a phenomenological study that described the lived experience of mothering a child hospitalised with acute illness or injury (Gasquoine, 1996). The significance for mothers of nurses doing the 'little things' emerged in considering the implications of the findings of my study for nurses in practice. Seven mothers who had experienced this crisis within twelve months of the first interview agreed to share their stories. The resulting data were analysed and interpreted using van Manen's (1990) interpretation of phenomenology.

This description of mothering in a context of crisis is useful in the potential contribution it makes to nurses' understanding of mothers' experience of the hospitalisation of their children. It supports the philosophy of family-centered care and highlights the ability of individual nurses to make a positive difference to a very stressful experience by acknowledging and doing 'little things' because it is the little things that matter to the mothers of children in hospital.

Keywords: family-centred care; hospitalised child; mothering; phenomenology

Introduction and background to the study

This paper reports on one aspect of the findings of a study completed as a masters thesis (Gasquoine, 1996). Seven mothers agreed to be interviewed and shared their experiences of mothering a child hospitalised with acute illness or injury. The nurses who were memorable for these mothers were those who gave care that took account of the 'little things'. It is the 'little things' that matter to the mothers of children in hospital. This finding will be discussed in detail in this article and examined in relation to other nursing literature which supports nurses doing the 'little things'. Firstly a summary of the phenomenological themes that emerged from the study is appropriate in order that the context in which 'little things' matter to a mother are apparent.

Phenomenological themes

Using van Manen's (1990) thematic analysis process, four themes were identified from the data and described. 'Mothering is a special kind of knowing'; 'The need to do' and 'Handing over, leaving and waiting' are overarched by the fourth theme: 'Constant vigilance'.

The first theme, the special kind of knowing which is mothering is pivotal to the experience of mothering a hospitalised child. The need to do and handing over, leaving and waiting, the other two themes identified in this phenomenological study, are

contingent upon the knowing of a mother. A mother's special kind of knowing creates her need to do, maintains the responsibility in handing over and leaving and dictates the wait in waiting.

Mother's need to do, the second phenomenological theme, is felt in a physical way. There is a need to do the physical things that are part of everyday mothering such as picking up a distressed child and feeding a hungry child. The child's illness and hospitalization makes these things more difficult and sometimes impossible to do.

Handing over, leaving and waiting are unavoidable parts of the experience of mothering a hospitalised child and constitute the third phenomenological theme. A mother remains responsible for her child even though she has handed her over to professionals. Leaving her child is an incredibly difficult thing for a mother to do without encouragement. Waiting for procedures, results and discharge is an exercise in endurance. But at least it can be done with her child. Waiting without the child, waiting for her to be returned so that mothering can recommence, is the most difficult wait of all.

After extensive reflection on and writing about the three themes described above, there remained an aspect of this mothering experience that seemed veiled. It was identifiable as a questioning stance that mothers seemed to adopt in relation to their child. There was a tremendous feeling of relief when the surgery was successfully completed or the chest x-ray clear of signs of pneumonia or the peak flow measurement rising. But the concern for the next step followed closely and quickly. It was not a pessimistic preoccupation with negative scenarios and unlikely possibilities. It was a realism that was necessary in order for the mother to cope: to feel in control, prepared, and one step ahead.

Development of this issue as a separate theme was not successful. Further reflection and discussion suggested that it was in fact a feature of the three themes described above and that this questioning stance, this constant vigilance is an umbrella, the frame of which is the special kind of knowing which is mothering, the need to do and handing over, leaving and waiting.

To be constantly vigilant is to keep on asking, to continue to wonder what other options or possibilities there might be and knowing that the answer is unlikely to be simple or singular. What is being sought is complex and multiple and while it may provide relief or explanation, it may not be a permanent answer. The constant vigilance of a mother is motivated by her need for her child to have the best care possible.

Literature review

The literature contains a number of studies that sought to measure the levels of stress and anxiety of parents of hospitalised children. For example the PSS:PICU was devised by Miles and Carter (1982) and is made up of seven dimensions which parents are asked to score on a Likert scale. These dimensions include: painful procedures conducted on the

child, sights and sounds of a paediatric intensive care unit, the child's behavioural and emotional responses, the child's appearance, alteration in the parenting role, staff communication and staff behaviour. The only one of these dimensions which does not apply to a child and her parents in most hospital situations is the one dealing with the sights and sounds of a paediatric intensive care unit. The conclusions of these studies therefore may have nursing implications outside of paediatric intensive care units.

Jones (1994) measured the effect of parental participation on the behaviour of hospitalised children. She collected data on children's levels of co-operation, upset, and activity and measured parental participation. Thirteen mother-child dyads were studied during three consecutive admissions for scheduled chemotherapy for leukemia. A positive relationship was identified between the level of parental participation and the child's behaviour.

The research on parenting hospitalised children that has used quantitative methods to examine the issue, while giving nurses and other health professionals valuable insight into the possible stresses associated with such a life crisis, do not provide a description of the experience that identifies the phenomena that are essential to parenting in this context. Darbyshire (1993) concludes that: "If paediatric nursing is to continue to advocate and develop a philosophy of care based upon mutuality and partnership with parents, then nurses need a deeper understanding of the nature of parents' experiences and how these relate to their own nursing practices" (p.1678).

Callery and Luker (1996) used a qualitative process to investigate "user satisfaction" of care children received on a surgical ward. "Parents were not making statements about whether or not they were satisfied with the service but explaining their experiences in a reflective manner" (p.344). The study outlined below does just that: explains the experience of mothering a hospitalised child in a reflective manner.

Methodology

Philosophical framework

The philosophy underlying this research is 'phenomenologic' and therefore examined the experience of 'being-in-the-world' as the mother of a child hospitalised with acute illness or injury. The development of the themes identified and described above capture the

lifeworld of a woman mothering in hospital. Her lived space, lived time, lived body and lived human relation are changed dramatically by the hospitalisation of her child.

Ethical Considerations

University and Area Health Board ethics committees approved the application to interview mothers who met the inclusion criteria as long as the relationship between the mothers and researcher was for the purpose of conducting the research and not as their child's nurse. None of the children were receiving hospital care while the study was underway.

Sampling

Using purposive, snowball sampling, there was no difficulty locating seven women who had had the experience of having a child hospitalised with acute illness or injury within 12 months of their first interview. Two of these mothers had children who had required elective surgery for congenital conditions. The other children had all been hospitalised with acute medical conditions such as pneumonia, asthma and viral meningitis.

Data collection and analysis

Two unstructured in-depth, audiotaped interviews were conducted with each of the participants. Following transcription of the interviews, van Manen's (1990) approach to thematic analysis was used to analyse and interpret the data. Two of the three approaches he suggests to identify phenomenological themes in text were used. Selection of phrases from the text itself which seem particularly revealing about the phenomenon is one approach used and the detailed approach which examines each sentence and paragraph for the meaning they hold about the phenomenon was the other.

Limitations of the Study

The study is bounded by the factors that commonly limit all studies of this nature. It examines the particular experience of a specific group of women within a context defined by time and location. In keeping with the phenomenological research process the number of participants in the study was small and the findings cannot necessarily be transferred to other groups.

Although recent, the experiences of the participants in this study were complete in the sense that none of the children are receiving ongoing nursing or medical care related to the acute illness or injury which resulted in their hospitalisation. The stories collected from the mothers participating in this study have been told after reflection and discussion. Different stories would have been collected had the researcher sought the participation of mothers during the hospitalisation of their children.

Discussion of interpretations

The conclusions of the research summarised above differentiate between 'thought-full nursing and nursing without thought'. The difference is that thought-full nursing recognises the 'little things' as an essential part of nurses work and values those 'little things' as meaning that the mother of a child in hospital feels cared for and cared about. Many other nurse researchers, among them Price (1993); MacLeod (1994); Bottorff (1995); Smythe (1998) and Euswas & Chick (1999) have described the significance of the 'little things' which nurses do. How the findings of the study outlined above fit with the work of these scholars is discussed below.

The thesis (Gasquoine, 1996) identifies a number of implications for nurses and nursing of this phenomenological description of the lived experience of mothering a hospitalised child. One of these implications is that all the participants in the research talked of the little things that meant a lot to them as they endured their child's hospitalisation and this is the subject of discussion for this article. Subsequent articles will identify and describe other issues.

Doing the 'little things'

Nurses acknowledged these mothers' special kind of knowing and they enabled the need of these mothers 'to do' for their child. Nurses supported mothers as they handed over the care of their child to strangers, left their child at hospital or waited for their child to return from theatre or for the results of tests.

When asked for the specifics of what exactly it was that nurses did that made their stay more tolerable, the participating mothers had difficulty putting it into words.

Just their attitude...they treat you on a personal level...they come in and say 'Oh hi Kasey' as though they know her...you know almost as if you are an old friend...and I think that is important, even for adults to feel welcome and liked.

This is how Cyn, mother of 6 year old Kasey hospitalised for elective surgery for congenital urinary tract deformity, responded when asked what it was that meant she felt she and her daughter had been well cared for by nurses.

Lyn's 10-day-old son Robin was hospitalised for pneumonia and she tries to describe the different approach used by the nurse who identified that the oximeter wasn't working properly. *She said that she treated him as if he was her own and so she was really cautious...She seemed to have a little bit of love for him.*

Yve uses a Maori term to summarise how she felt about the care she got from the nurses who cared for her 12 year old daughter who was admitted acutely unwell and was eventually diagnosed as having a viral meningitis.

Manaakitanga...which is your ability to look after...to make welcome...everything to do with giving care...and that was just great.

Maori are the tangata whenua, the indigenous people of New Zealand. Mitchelson and Latham (2000) are in the process of developing a Maori nursing conceptual model and they explore Durie's (1999) 'capacities framework' in the nursing context. Manaaki is the capacity to care and Manaakitanga "...the process whereby mana (power and authority) is translated into actions of generosity" (Durie, 2001, p.83)

So Yve seems to be describing nurses using their mana to welcome her and to leave her feeling as if she had been cared for and cared about through actions of generosity. For Maori these aspects of nursing care are essential and very much a part of safe nursing care (Mitchelson & Latham 2000,p.17).

The mothers in this study were describing an attitude and a capacity to care that is demonstrated by a nurse who 'has a little bit of love' for the child for whom she is caring. It is more than what is done or said by nurses that makes the difference, it is an attitude, an approach which is 'read' by the mothers of children in hospital as being welcomed and liked.

What are these little things that nurses do? The mothers who participated in the research told of nurses who remembered their child's name and used it. They took the time to acknowledge the mother waiting for her child to return from theatre. And they recognised that explaining how to get from the 'wrong' place to the 'right' place wouldn't achieve anything for this tired and very anxious mother, so escorted her to the 'right' place.

Price (1993) described parents of children in hospital 'maneuvering' to achieve more time with their child's nurse to enable a 'process of knowing'. The achievement of this process is 'the nurses understanding of their individuality (p.38).' A 'positive relationship' is achieved with the nurse as a result of this process and the nurse gives 'personable care'. This type of care recognises individuals and their needs, acknowledges their situation and how it changes from moment to moment and communicates meaningfully. Price says that unless a positive relationship is achieved with parents within which nurses give personable care, parents will not get quality nursing care.

The excerpts of the stories of Cyn, Lyn and Yve presented above suggest 'personable care' and recognition of the individuality of the child and mother. Despite their difficulty in putting into words their experience, these mothers did feel cared for and cared about by nurses who through a 'process of knowing' developed a positive relationship with them.

Sometimes the 'little things' are noticeable by their absence. Lyn describes the hesitancy with which she approached the previously routine mothering task of bathing her baby. He was ten days old, had a luered intravenous catheter in his hand, which was splinted, and was receiving oxygen through nasal prongs. Lyn gladly accepted an offer of help from a nurse. However, the nurse did not return as promised to assist. And while she recognised that giving her baby a bath was not essential to his treatment, it was something Lyn needed to do to feel *normal*. It was one of those 'little things'

I was going to bath Robert about the second or third day and he still had the oxygen tubes up his nose and you know all this sort of stuff and I told my nurse that I was going to do this and she said I'll be back to help but of course she didn't come back and I sort of left it and left it and thought oh look I have got to do it, you know, and I didn't feel I could ring and ask her... or go out and ask and say look I am going to bath the baby do you want to give me a hand, because I did feel I needed a hand.

(What was it that you needed help with?)

It was support!...support, just so as I knew I wasn't going to rip something out which... or just an extra pair of hands to hold the towel or whatever... I mean he was a new baby.

Also he was floppy. And then I didn't want to not bath him either. I mean I could have just said oh well I won't bath him it is no big hassle, but I didn't because I felt may be that... I mean it was something that I wanted to do with him I think. You know - I wanted to be normal. (Lyn 2 p8-10)

It is easy to understand the nurse who had promised to come back and help Lyn with Robin's bath, discovering something more pressing she needed to do and deciding that she did not have time to help with something a mother would normally do unaided and that it was nonessential work. What the nurse was not aware of was that this was one of the 'little things' that would help this mother feel normal.

If the nurse had noticed how important it was for Lyn to bath her baby, and had understood why a bath was important to help her feel normal and had acted by returning and explaining how her priorities had changed or had asked someone else, perhaps a student, to go and help Lyn, then this mother would not have been left feeling so unsupported.

Valuing the 'little things'

MacLeod describes nurses noticing, understanding and acting, a process which is patient focussed and goal-directed. "Through her involvement in the situation, the nurse notices salient features in the context, understands their meaning and acts, caring for the patient..." (1994,p.365). Lyn's story of wanting to bath her baby suggests the nurse did not notice, understand and act as MacLeod expects she would.

Bottorff (1995) agrees that it is the little things that count. In writing about being comforted by a nurse, she identifies some of those little things that nurses do. Being present, a belief that comfort is possible, spending time, acknowledgement of the

individual and their experience, talk, touch. She too recognises that nurses and the care they give can be skill-full but not necessarily care-full, concern-full nor thought-full.

Perhaps these actions are 'just commonsense'? Symthe, (1998,p.212) in her hermeneutic study of the meaning of being safe in childbirth, uses the term 'concernful' care. Concernful care takes account of the things that 'matter'. The things that matter are often the 'little things'. Concern is also a feature of Euswas and Chick's (1999) phenomenological description of caring and being cared for. They conclude that the episodic nature of 'caring moments' although powerful also make them fragile, their fragility being a consequence of their unpredictability.

Why is it that we need to be constantly reminded of the importance and significance of the 'little things' we do with and for our patients or clients and their families and significant others? Euswas and Chick (1999) suggest that the adage 'it's the little things that matter' has become a cliché. Thomlinson (2002) confirms the 'mattering' of the 'little things' in her study describing the lived experience of families of children who are failing to thrive. One of the themes she identifies and describes as 'being nurtured'. She gives examples of health professionals who 'validated, strengthened and encouraged families in their efforts' to nurture their children (p.541). Acceptance by health professionals of the family's assessment of their child's condition enabled mutual respect and trust to develop.

A generation of nurse scholars, for example Benner and Wrubel (1989), in their seminal work 'The Primacy of Caring' have written about caring and comforting in nursing. They define caring (p.1) as 'being connected' and 'having things matter'. As the technological and pharmacological tools which nurses use become increasingly complex, is there a diminishing valuing of what we offer as human beings to our clients?

"As long as society overvalues technology's heroic promises of disburdenment and freedom from pain and fails to recognise the care required ...those who provide care will feel the stress of being invisible and undervalued..."(Benner and Wrubel 1989,p.368).

Conclusion

Nurses use their hands to stroke, squeeze and rub. They use their voices to focus, soothe and reassure. They listen for those ever so slight variations of tone and inflection that highlight the discrepancy between what someone says and what they mean. And nurses use their gaze to convey an infinite variety of messages. These 'little things' that are non-technological and non-pharmaceutical make the critical difference between the mothers and their children who are hospitalised feel that they are cared for and cared about. Caring is our responsibility and we need to own and value that responsibility in an increasingly hostile environment. This article is my contribution to valuing the work of nurses who care for, care about and do the 'little things that matter' for the mothers of children in hospital.

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