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CONSTANT VIGILANCE

**THE LIVED EXPERIENCE OF MOTHERING A HOSPITALISED
CHILD**

A thesis presented in partial fulfilment of the requirements
for the degree
of Master of Philosophy in Nursing
at Massey University

SUSAN GASQUOINE

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DEDICATION

For

SARAH MARY SPEIGHT RUSTON

born 25-4-84 died 10-2-93

and

LUCY ROSE GASQUOINE MCMASTER

born 2-8-94

You have taught me more than I ever expected there was to know about caring for and caring about children and their families.

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ABSTRACT

This phenomenological study describes the lived experience of mothering a child hospitalised with acute illness or injury. Seven mothers who had experienced this crisis within twelve months of our first interview agreed to share their stories with me. The resulting data were analysed and interpreted using van Manen's interpretation of Heideggerian phenomenology.

Four phenomenological themes emerged from this study. Mothers have a **special kind of knowing**. They have a **need to do** with and for their child. **Handing over** to or **leaving** their child in the care of strangers and **waiting** for their child to be returned to their care are very difficult things for mothers to do. Their **constant vigilance** is enabled by their **special kind of knowing** and their **need to do**. The difficulty of **handing over**, **leaving** and **waiting** is emphasised by mothers' **constant vigilance**.

Personal experiences during the course of my study presented significant challenges to my ability to offer an effective phenomenological description of the phenomenon under study. Continuous reflection aided by dialogue with fellow phenomenological researchers has resulted in a meaningful narrative.

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.

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KEY TO TRANSCRIPTS

In the presentation of research findings, and particularly in relation to excerpts from research interviews and field notes, the following abbreviations and conventions have been used:

- italics* the words used by the study participants themselves
- names all study participants and their children are identified by the use of pseudonyms
- I* Interview
- p* page
- (parentheses)* researcher questions or comments made during interviews
- [square brackets] are used when a clarifying or explanatory comment has been added by the researcher
- ... pause contained in original material
- ..//.. material edited out of interview

CHAPTER ONE

INTRODUCTION AND OVERVIEW

Standing in for Mother

Helen and Steve, Sarah's parents, had gone home to have dinner with their other children. I was sitting with Sarah, along with her Grandparents. We knew it was important for her to have someone of her own with her all the time. Suddenly she collapsed and needed active resuscitation. I was terrified that she had started coning¹. As the resus team arrived we left Sarah. While the others rang Helen and Steve I went back to Sarah to see how things were going. The staff felt she was responding. I left again but then I thought to myself: "If Sarah were my child and Helen were me I would want Helen to go in and stay with her." So I went back in and climbed up on the bed with Sarah. I knelt beside her head and held her free hand and started talking to her. (7/2/93)

Mothering a child in hospital occurs in a context of acute crisis. This is my observation as a nurse and my experience as an aunt and mother. This crisis takes all the energy a mother has. It may paralyse her ability to think

¹ A situation resulting from a significant increase in intracranial pressure which results in the brain stem being forced through the opening at the base of the skull.

clearly and act appropriately and it may mean her responses to situations are unpredictable. What is worse is that a mother knows these things are happening to her just when she needs to be functioning at her best because that is what her child needs her to be able to do. It is also what a mother needs to be able to do.

My professional concerns and my personal happenings have combined to create a unique context for my study. This chapter provides a background for my study and will therefore outline the pre-understandings which have stimulated my interest in doing a study of this nature and with which I approached the task of analysing and interpreting the data gathered from participants. These pre-understandings have accumulated from professional interest and experience as a nurse of children and their families and from happenings in my own family when children have been hospitalised.

THE PROFESSIONAL CONTEXT

My interest and therefore the aim of my study, has developed over a long period of time out of my work as a nurse with hospitalised children and their families. This work has included teaching students of nursing about the unique needs of families with children in hospital. Observations of parents of hospitalised children suggests that hospitalisation presents a unique set of stresses and that coping depends on individual circumstances. For example the relationship between the parents of a hospitalised child is strained by different concerns and feelings of responsibility. So while my expectations as a nurse were that the mother

and father of a hospitalised child could and would support each other during this time of significant stress, too often this was not the case. Too often the parents of a child in hospital would seem at loggerheads and my work as a nurse complicated by miscommunication between family members.

The present study focused on the experience of having a child hospitalised with acute illness or injury. Nursing observation suggested and the literature, some of which is reviewed in Chapter Two, confirms that there are both similarities and differences between parenting a child who is acutely ill or injured and a child with a chronic condition. What the parents of children with chronic illnesses may have is the benefit of previous experience with which to approach subsequent hospitalisations.

Another issue which needs to be highlighted is that for all the children who are hospitalised with an acute illness, some will be diagnosed as having a chronic condition thereby increasing their chances of subsequent hospital admission. And for all the children who will be hospitalised because of a chronic condition, there will always be a first admission. The first hospital experience is significant and nurses have a responsibility to influence in a positive way how that admission and therefore subsequent ones are experienced by families.

These observations and concerns have formed the basis of work at undergraduate and graduate levels, the most recent being fieldwork which examined the experience of parents who have a child hospitalised (Gasquoine, 1992). My fieldwork suggested a number of issues which warranted closer examination, including the possibility that the

experiences of mothering and fathering a hospitalised child were sufficiently different to justify close and separate examination. Mothering a hospitalised child is the topic of this thesis. The fieldwork also served as a pilot project for the research process utilised.

THE PERSONAL CONTEXT

Van Manen (1984, p.36) comments that the topics chosen by his students for phenomenological research are always a significant part of that student's personal or professional life. I was clear about the significance of mothering a hospitalised child for my professional concerns. The significance that phenomenology would have for events in my personal life was unexpected.

As the proposal for this thesis was being finalised my nine year old niece, Sarah, was hospitalised and diagnosed as having a brain tumour. While I visited one evening with her grandparents, so her parents could spend time with their other children, Sarah collapsed, required active resuscitation and admission to intensive care. She had emergency surgery 12 hours later because her condition had continued to deteriorate. The brain damage Sarah sustained was such that the medical staff said to her parents they did not feel she would survive. Five days after her admission and diagnosis, Sarah's life supporting technology was removed and she died in her parents arms, surrounded by her family.

My role as family member and nurse in this tragedy of life was an enormous privilege and I needed all the skills I possess as a human being

and a nurse to cope and to help others cope. The need for my research was re-emphasised with urgency by this experience. A colleague interviewed me about my experience with Sarah so that I might begin to reflect on how it would influence the research process planned. The extent of that influence and of subsequent happenings only became clear as I committed to writing, the experience which I shared with the participants in my research.

"In drawing up personal descriptions of lived experiences, the phenomenologist knows that one's own experiences are also the possible experiences of others" (van Manen, 1984, p.51). For me the reverse applied. In spending time with the data I had collected about the lived experiences of mothering a hospitalised child, I became aware that the experiences of others could be mine. For example, while pregnant I found it difficult to spend time working with the data from two particular participants because they described to me experiences when their newborn babies needed hospitalisation. My fear, which seemed irrational at the time, was that this might happen to my baby.

Data collection for my study was complete and the analysis process begun when my daughter was born. When 5 hours old, Lucy was admitted to a special care baby unit with respiratory distress. The experience that others had described to me became my own. At this point I felt my ability to continue with my research was in serious jeopardy. My own hospitalisation for surgery when Lucy was seven weeks old requiring another separation, seemed to put the whole exercise beyond contemplation.

It was the arrival in the mail of a questionnaire from the hospital where Lucy had been admitted, asking me to respond to a series of questions about the quality of service I had received as a consumer which was the catalyst for my finding the energy to recommence this research. Trying to communicate my experience of being the mother of a sick newborn in a series of questions of no consequence to me, with forced choice answers and minimal opportunity for explanation was frustrating in the extreme. Ironically it was a quantitative study of no value to the respondent (me) and, in my opinion, of questionable value to the researchers that once more galvanised me into action.

My roles as aunt and nurse when Sarah needed hospital care and my roles as mother and researcher when Lucy was hospitalised, create a unique context within which my study has been conducted. The process of clarifying the conflicts and insights my experiences have created are explicated in Chapter Three.

THE FAMILY-CENTRED CARE PHILOSOPHY

Nursing care of children must take into account the family context within which children live. For most children the primary care giver is their mother and the relationship between mother and child a critical one. Hospitalisation of a child has the potential to threaten that relationship in many ways. The normal daily routine of a mother and child which is aimed at meeting all the physical, emotional, social and cognitive needs of children will be significantly disrupted by hospital admission. A mother may need to stop breastfeeding a baby temporarily because of diagnostic

procedures the child requires. Bathing a child may be complicated by intravenous infusions or surgical wounds. Such paraphernalia may make picking up a distressed child to comfort her, difficult.

My study explores the perspective of mothers on the hospitalisation of their children. It therefore changes the primary focus of nursing attention from the sick child accompanied by and attached to her parent(s), to the mother of that child, accompanying and equally attached to her child.

Ultimately nursing research that explores this issue aims to contribute to improving nursing care of hospitalised children. It does so by exploring how nurses can contribute to the ability of families to utilise their own coping strategies to deal with such a crisis. This assumes a philosophy of nursing children which considers them an inextricable part of a family. The key to the relationship of the child to that family will usually be the parents as primary care givers, with the major responsibility for that care typically belonging with the mother. Therefore children cannot be adequately or appropriately nursed in a hospital setting without consideration for and access to the child's family and more particularly the child's mother.

Research and debate continue about how much of nurturing a child is innate behaviour and how much is learned socially (Papalia & Olds, 1995). The fact remains that for most children their primary care giver is their mother and it is their mother with whom they develop the attachment so necessary for appropriate growth and development. Acute illness or injury is going to increase that child's need for mothering care.

The family-centred care philosophy assumes that as the child is attached to the family, so the family is attached to the child. Hospitalisation of the child will therefore result in significant stress for both child and family. While the appropriate nursing focus must remain the child, the family must also be recognised as needing nursing care. The nature of that care will depend on the family and more specifically the mother who will most commonly be the family member who chooses and is able to stay with the child.

Berman (1991) gives a comprehensive definition of family-centred care in her study which identified discrepancies between what nurses said they believed about nursing care in such an environment and their nursing actions. The definition with which Berman works is based on that of the Association for the Care of Children's Health, an organisation based in the United States of America and incorporates the following components. Family-centred care:

- 1) Recognises that the family is constant in a child's life while the groups and individuals with which the child comes in contact during hospitalisation are not.
- 2) Facilitates collaboration between parents and professionals.
- 3) Shares complete information with parents in an appropriately supportive manner.
- 4) Implements appropriate policies and programmes to meet the emotional and financial needs of families.

- 5) Recognises and respects different strengths and coping strategies in different families.
- 6) Incorporates the developmental and emotional needs of children in health care.
- 7) Encourages and facilitates parents supporting each other.
- 8) Designs health care systems which are able to be flexible, accessible and responsive to family needs.

A New Zealand organisation, the Children's Health Liaison Group (CHLG) based in Auckland, uses a similar philosophy and works to promote the needs of children and their parents in a rapidly changing health care system. They began with the aim to improve facilities for children requiring hospitalisation especially the promotion of the value of boarder parents². Their activities have now broadened to address health issues as they relate to children generally, rather than just those children requiring hospitalisation.

The twelve principles of health care for children and young persons advocated by the Children's Health Liaison Group CHLG (July 1993) are as follows:

- 1) Recognition of the expertise within the family and of the family's role in the ongoing provision of the child's health care.

² Term used to describe a parent who is staying with their hospitalised child.

- 2) Recognition that the focus of Child Health services is the child.
- 3) Recognition that families and professionals are partners in the care of children at all levels of health care.
- 4) Recognition of the family's right to complete and objective information about their child's care in a manner that is appropriate.
- 5) Recognition of the need for policies and practices that are comprehensive and provide emotional and practical support to meet the needs of family and whanau.
- 6) Child health care services are adequately resourced, affordable, flexible, accessible and responsive to the needs of the child and family.
- 7) Child health services affirm, respect and make provision for the cultural expression and customs of families.
- 8) Child health services must be age appropriate and incorporate the developmental, psychosocial and emotional needs of infants, children and young people.
- 9) Promotion of Well Child Care and disease prevention.
- 10) Health Care services and other services are co-ordinated and resources used efficiently.

11) Standards of care relate to the written mission statement and goals of the service.

12) There is commitment to quality at all levels of service delivery.

The involvement and commitment of nurses to such statements is critical if these philosophies are to make a positive difference to the experience of hospitalisation for children and their families. My hope is that this study will provide the nurses who read it with another piece of information that supports the family-centred care philosophy.

STUDY OVERVIEW

My study examines the experience of mothering a child hospitalised with acute illness or injury using a qualitative research process. Examination of the current literature suggested that a study utilising interpretive Heideggerian phenomenology could contribute to this area of research in a way that would be useful to nurses working with children and their families in hospital settings.

Seven mothers who had experienced the hospitalisation of a child with acute illness or injury in the last twelve months agreed to participate in my study. They were interviewed twice using an unstructured interview technique and the data collected analysed using the phenomenological reflection and writing process described by van Manen (1984, 1990).

A review of the literature relevant to the issue of parenting a hospitalised child is presented in Chapter Two. The review serves to place the present study in an historical, geographical and research context in order that the contribution it makes to existing nursing knowledge is clear.

In Chapter Three I discuss in depth the research method utilised for my study and include reference to some of the increasing volume of literature which debates the value of phenomenological studies. The design of this particular study is also specified in Chapter Three with participant profiles which outline the individual experiences of these mothers and their children. While my study includes male children who have been hospitalised, most of the 'players', including participant mothers and nurses, are female. So, when referring in general to people, I will use the

terms 'her' and 'she' instead of the traditional practice of referring to all people in general as 'him' or 'he'. Where I write specifically about the hospitalisation of the male child of a participant, I will use the appropriate gender specific pronouns.

Analysis and interpretation of data is the focus of Chapter Four. It utilises extensive quotes from participants to illustrate the themes which have emerged from the data and describes the phenomenon of mothering a hospitalised child. The chapter aims to describe the Being-in-the-World of mothering in these circumstances. I make reference to the four existentials of lived time, lived body, lived space and lived relationship to another described by van Manen (1990).

While the practice of nursing provides the focus of the whole thesis, the implications of this study for clinical practice and the education of nurses will be discussed in detail in Chapter Five. The chapter will also evaluate the study and suggest areas warranting further research.

CHAPTER TWO

LITERATURE REVIEW

The purpose of reviewing relevant literature during the research process is to place a study within the context of existing knowledge. In this instance that context is nursing knowledge about the care of hospitalised children, with a particular focus on the needs of the families of those children. Such a review is also able to identify gaps in the literature. These gaps may be associated with a particular issue remaining un-researched or methodological constraints of the research processes utilised in completed studies.

This chapter will review the seminal literature in relation to nursing hospitalised children and their families, specifically their parents. This will place the study in historical context. Contemporary nursing studies will also be reviewed. The chapter will examine in detail the small amount of research which has been done in New Zealand as well as the significant volume of literature from international researchers.

The review identifies two major gaps in the literature. Firstly, the vast majority of research to date attempts to quantify the stresses that parents experience when their child is hospitalised. There is little research which focuses on description of this experience using qualitative research methods as this study does. Secondly, most studies refer to 'parents' by which it is assumed that the findings could apply to mothers and/or fathers. Preliminary fieldwork for this study (Gasquoine, 1992) suggests that the

experiences of mothers and fathers are sufficiently different to require that they be researched separately. This view is confirmed by several recent international studies which are reviewed below.

Nursing research which examines the experience of mothering chronically ill children has also been reviewed. One of the assumptions upon which this study is based is that there will be both similarities and differences between the experiences of mothering acutely ill or injured and chronically ill children.

HISTORICAL CONTEXT

Two particular theorists have made a significant contribution to knowledge about the effects of separation of a young child from her primary care giver. John Bowlby described what he termed 'maternal deprivation' and James Robertson termed his observations 'separation anxiety'. The research supporting these theories was done in the 1950s and 1960s.

Gradually Bowlby and Robertson's research findings have been implemented in the practice of the various professional disciplines, including nursing, involved in the care of children in hospital. This has taken some effort at both governmental and parent support group level (Young, 1992).

'Maternal deprivation' (Bowlby, 1965) results from the separation of a child from the person with whom the child has a close, loving relationship - usually her mother. This separation is experienced as abandonment by the child and puts her at significantly increased risk of developing psychological problems in the long term. Hospitalisation of a child may be the cause of such separation. The consequences of brief, one-off hospitalisations have been demonstrated to be much less severe than longer, multiple admissions (Rikard-Bell, 1994).

Robertson (1970) described three phases of 'separation anxiety' when a child is left by her parents in a strange environment. The first, the protest stage, is characterised by inconsolable crying on departure of the parent(s). The conclusion of some parents and professionals is that if parents visit less often, then the child won't have to endure the acute distress of

separation so often. Despair is the second stage Robertson described. It is characterised by apathy and depression in the child. In the past this stage has been misinterpreted by nurses as the child 'settling down' and was reported as such to parents. There was a time when nurses recommended that parents did not visit in case the child became 'unsettled' again. The final stage, denial, may be characterised by a child ignoring a parent who visits and responding to strangers (nurses) in a way that you might expect her to respond to a parent.

Nurses now recognise that it is better for the child to remain in the protest stage of 'separation anxiety' from which she is reasonably easily retrieved by being reunited, as often as possible, with her parent(s). The consequences of the development of the stages characterised by despair and denial are more long term, therefore making recovery from these stages more difficult for both child and parent(s).

In 1959 a report entitled 'The Welfare of Children in Hospital', commonly referred to as the Platt Report, was published in the United Kingdom. The Platt Report is acknowledged in the British nursing literature as a milestone in the development of hospital care for children and their families (Callery & Luker, 1996; Coyne, 1995a, 1995b; Darbyshire, 1993; Palmer, 1993; Stower, 1992; While, 1992; Young, 1992). The report made a series of recommendations to the professionals responsible for the hospital care of children including the need to consider children's psychosocial and emotional needs as having as much significance as their physical needs.

Darbyshire (1993) discusses the Platt Report at length, noting that one of the report's major recommendations was "... that parents should be able to visit at any reasonable time of day or night ..." (p.1671). He also notes that the implementation of the recommendations in the report was "slow and varied" and concluded that the Platt Report was "... narrow in vision and naive in expectation" (p.1672). It ignored, he says, the sociological nature of hospital systems and the difficulties associated with effecting change in such systems.

The research of Bowlby and Robertson and the recommendations of the Platt Report which resulted from their research and that of others, was recognised by some in New Zealand as of significance. McKinlay (1981) documented the contribution to change the work of Bowlby and Robertson made in New Zealand. She concluded that implementation of change had occurred, albeit slowly.

The current situation in New Zealand and most Western countries is that most children are accompanied through their hospitalisation by a parent or significant other who live-in with the child for at least part of the duration of the admission. Visiting hours in children's hospital facilities are now very flexible, usually allowing unrestricted visiting for parents. With the place of parents in hospitals with their children firmly established, the focus of research has changed. Nurse researchers are now interested in the nature of the experience for children, their parents and nurses. Studies now focus on the involvement of parents in the care of their children while they are in hospital and how this can be enhanced. The relationships between nurses and children and their parents are also the subject of research.

NEW ZEALAND RESEARCH

McKinlay's (1981) extensive national survey is the most comprehensive New Zealand work located in this review of literature. It examines trends in the hospitalisation of children both nationally and regionally. It describes the facilities hospital environments provided for children and notes staffing of hospital paediatric services, with particular reference to the need for professionals to specialise in care of children. McKinlay also describes the process of hospitalisation for a child. She pays particular attention to the personal needs of children in hospital and the place of parents with their children and how this was facilitated.

McKinlay suggests that health professionals must remember several issues when considering the needs of the parents of hospitalised children. Firstly, that parents experience considerable anxiety and that this anxiety is heightened by the unfamiliar environment in which they find themselves. Resulting from this, they are unlikely to know what it is they can and cannot do to assist their child. These feelings in turn are accentuated by the fact that they have handed over considerable responsibility for their child because of the illness and hospitalisation and this may further compromise their ability to cope and contribute to their child's care. McKinlay (1981) goes on to remind the reader that the reason parents should be encouraged to stay with their child is because this helps create "the optimum conditions for the child's recovery" and therefore facilitates discharge at the earliest possible opportunity. In order to contribute to this environment parents need "guidance, nurturing and support" (p.139). While remaining relevant for health professionals working with children

and their families, this report is now fifteen years old and needs updating taking into account the current health care environment.

The current environment in the New Zealand health care system includes such factors as the 'funder/provider split'. This means that hospitals contract their services to health authorities which buy the services on offer. The accommodation of parents with their hospitalised children can be considered to be a cost and/or a benefit. Quantifying cost is relatively straightforward. Establishing benefit is more problematic. Research which examines the ability of boarder parents to contribute to their children's recovery in the current environment is overdue.

Dodd (1984) undertook a study that examined the benefits to the child of having a parent boarding with her while in hospital. She also looked at needs of parents boarding with a child, particularly the factors which led to their decision to board and their expectations of being a boarder parent. Unstructured interviews were used to gather data from six parents and Myra E. Levine's conservation principles of nursing used as a framework for the conclusions of the study.

Participant parents stated that they were less worried about their children because they could stay with them. Staying at home would have meant that parents worried more. Dodd's (1984) study emphasised the importance of the nursing function of helping mothers define their changed role when their child was hospitalised. It also identified the importance of information for mothers of sick children and their need to be able to clarify information they had not initially understood. Lack of facilities such as a lounge and availability of meals were identified as problems but the

positive attitude of staff to their presence encouraged mothers to stay. In fact encouragement by nurses of mothers to stay with their child was a significant factor in a mother's decision to do so.

One limitation of the study by Dodd (1984) is that it used the terms 'parent' and 'mother' interchangeably. As far as I am able to tell all parents participating in the study were mothers. This shortcoming is one it shares with many other studies on parents of children in hospital. This will be discussed in detail below, along with the significance this has for the utilisation of these results in nursing practice.

INTERNATIONAL RESEARCH

Measuring parental stress and anxiety

Studies which aim to quantify the stress experienced by the parents of acutely ill children have been conducted for some time. The most recent (Haines, Perger & Nagy, 1995) used the Parental Stressor Scale: Paediatric Intensive Care Unit (PSS:PICU), as have previous studies (Curley, 1988; Miles, Carter, Riddle, Hennessey & Williams Eberly, 1989). 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.

In a study conducted in a large North American children's hospital, Alexander, Powell, Williams, White and Conlon (1988) measured and compared levels of anxiety for rooming-in and non rooming-in parents of hospitalised children. As well as identifying higher stress levels as measured by the Spielberger State-Trait Anxiety Inventory (S.T.A.I.) in parents who did not room-in with their children, the researchers concluded that hospitalisation of a child is more stressful for fathers than it is for mothers. The findings of Alexander et al (1988) were not supported in

another study which used the same instrument to measure anxiety, in which it was found that mothers experienced significantly more stress than fathers (Riddle, Hennessey, Williams Eberly, Carter & Miles 1989). The sample in the Riddle et al (1989) study was larger than that used by Alexander et al (1988) and there were equal numbers of mothers and fathers.

Melnyk (1994) used the S.T.A.I. and other measures of parental behaviour in an experimental study which examined the effect on maternal anxiety of giving mothers information about what behavioural changes they should expect in their child after an unplanned hospital admission. They were also given information on the role changes that mothers experience when their child is hospitalised. The researcher concluded that information has a positive effect on mothers' ability to cope with the unplanned hospitalisation of children.

Jones (1994) measured the effect of parental participation on the behaviour of hospitalised children. She used three instruments to collect data on children's levels of co-operation, upset, and activity. She also measured parental participation using an adaptation of the Parent Participation Assessment Instrument (Deatrick, Stull, Dixon, Puczynski, & Jackson 1986). 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.

Jones' (1994) study has two limitations. The sample size is small for a study of this nature. However this is offset to a certain extent by the fact

that she measured behaviour and participation on three consecutive admissions of the children and their mothers, enabling the researcher to average their scores. The second limitation is that the study claims to have measured parental participation when in fact she has measured maternal participation. Jones (1994) acknowledges that including fathers in the study sample might alter the level of participation measured which in turn might alter the child behaviour measured.

To date most of the research on parenting hospitalised children has used quantitative methods to examine the issue. These studies, 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 a hospitalised child.

Descriptions of parents' experiences

Recently qualitative processes have been recognised as of value when researching the issues related to parenting hospitalised children (Carnevale, 1990; Darbyshire, 1993). Qualitative research has the potential to fill gaps in nursing knowledge unable to be filled by quantitative studies.

Darbyshire (1993) reviews literature which traces the historical development of parental involvement with hospitalised children. He points out that while involving parents in the care of their hospitalised child and providing opportunities and facilities for them to stay with their

children have become "principles of paediatric nursing" (p.1670), there is no research which examines the lived experiences of parents and nurses. His 1994 research, discussed below, aims to contribute to filling this gap. 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).

Having identified the value of qualitative research to the investigation of the experience of parents of children requiring intensive care, Carnevale (1990) interviewed five parents of children in a paediatric intensive care unit. Qualitative analysis revealed five categories of stressors and five categories of coping strategies. He suggests that the principle source of stress for parents is parental role conflict with professional staff. Parents felt they had to work hard to be included in decisions that professionals made about their children and were not offered enough opportunities to participate in care of their children. Carnevale also points out the irony of the situation is that this is a stressor about which much can be done. This may be why it is such a source of stress for parents: they recognise that appropriate management would largely resolve the conflict.

Callery and Luker (1996) used a qualitative process to investigate "user satisfaction" of care children received on a surgical ward. Most of the 'users' who participated in the study were mothers of twenty four children who had been hospitalised for surgery. Conversational style interviews were conducted in their homes after the discharge of the child. The researchers state that they expected to be able to obtain different sorts of

data using a qualitative process than from questionnaire surveys, which are widely used to assess consumer or user satisfaction (p.341). Their study concluded that a qualitative process is able to establish the extent to which parents of children in hospital can exercise choice. Conversational interviews have the advantage of being reflective and therefore may reveal situations that parents do not necessarily recognise as unsatisfactory. "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). In a questionnaire survey the 'agenda' is set by the health service constructing the survey. There is no opportunity to include questions that questionnaire respondents consider important.

Coyne (1995a) used a phenomenological approach to describe parents' experiences of participation in their hospitalised child's care. She found that parents chose to participate in their child's care for a number of reasons. These included a sense of parental duty, previous experiences they had had with hospitalisation and concern for the consistency of the care their child received. One of the factors that she identified that enhanced parents readiness to participate in care was parents' view of themselves as "experts on their child" (p.74). Lack of information and non-negotiation of care were two factors that she suggests inhibits parents' readiness to participate in care. Coyne's findings have relevance for my study and are discussed further in Chapter Five.

Price's (1993) grounded theory study used ethnographic interviewing strategies to collect data from three mothers and one father. Price suggests four stages in the process of receiving quality nursing care. The first stage in this process is manoeuvring and is aimed at increasing the time a nurse

spends with the child and her parent. This time enables the second stage to be reached. Price names this stage the process of knowing. It is represented by the nurse understanding the child and her parents as individuals. Time is also a significant factor in the process of knowing. "Parents describe nurses as having the time, taking the time, or making the time to spend with them" (p.38). The development of the third stage, positive relationship, depends on the time a nurse spends with the child and parent and the nurse's ability to establish trust with and give personable care to them. What results, according to Price (1993) is the fourth stage: quality nursing care. "Quality care is perceived as the nurse being focused on meeting the non-technical needs of the child and parent. Non technical needs described by parents include the need for information, diversion, socialisation, sleep, and decreasing child and parent stress" (p.39). This thesis describes similar themes and identifies corresponding implications for nursing practice.

Darbyshire (1994) gathered data from thirty parents (26 mothers and 4 fathers) about their expectations and understandings of their participation in their hospitalised child's care as live-in parents. Parents' descriptions of their lived experiences suggested that their participation in care was "... an unspoken and haphazard arrangement" (p.198). The extent of participation by parents depended on individual nurses. Some nurses would actively encourage participation. Other nurses, in either overt or covert ways, would exclude parents from situations in which parents felt they could be involved.

The nature of parental participation is also described by Darbyshire (1994). Parents spent a great deal of time playing with their child. The constraints

of the child's illness and the hospital environment meant that parents were often involved in play that was quite different from play activities possible at home with a well child. Keeping vigil is another aspect of parental involvement that Darbyshire describes. He is clear that it is much more than "passive, uninvolved non activity". "By keeping vigil with their child parents felt that they were doing not only the right thing in the moral sense but the only thing they could do. They were being of real help to their child at what were among the most traumatic moments of both of their lives" (p.197).

Neill's (1996a, 1996b) qualitative exploratory study explored parental participation in the care of their hospitalised children. She suggests that parents understood involvement in their child's care to consist of three things. First, being there for the child. Secondly, being able to carry out some of the child's care and finally, being informed about all matters related to their child's care. Neill identified three reasons why parents did or did not wish to be involved in their child's care. They were: benefits to the child; to the parent; and to the nurse. These very recent findings complement those of the other studies reviewed above which explore the parental experience of having a child in hospital.

Parenting or Mothering and Fathering?

Much of the literature does not make clear whether the experience of mothering and fathering a hospitalised child is the same experience and can therefore be described as parenting experience. When researchers describe what they term as parenting, it may be that mothering is actually

the experience under study. Some studies of families coping with chronic conditions of children identify that significant stress develops between the mothers and fathers of these children (Copeland & Clements, 1993; Gibson, 1995; Hatton, Canam, Thorne & Hughes, 1995; Lasby, Newton, Sherrow, Stainton & McNeil, 1994; Whyte 1992). Others do not even indicate whether the parents who are the subject of their studies are mothers or fathers (Bishop, 1988; Coulson, 1988; Turner, 1989). Those that do, typically have many more subjects or participants who are mothers (Alexander et al, 1988; Burke, Kauffmann, Costello & Dillon, 1991; Coyne 1995a; Darbyshire, 1994; Haines et al, 1995; Neill, 1996a). Is it 'mothering' in these circumstances that the studies describe and not 'parenting'?

The fieldwork that served as a pilot project for this study (Gasquoine, 1992) initially included three mothers' and two fathers' descriptions of their experiences of a child's hospitalisation. However, after initial analysis, it became clear that two different experiences were being described: a mothering experience and a fathering experience. Part of the mothering experience was the stress created by the response of the child's father to mothers' expressed fear of the child dying or the mothers' strategies for coping with the hospital environment and routines. The mothers said they felt misunderstood by and unable to share their fears with their partners. They describe situations in which they were chastised for expressing their feelings.

In reflecting on this hurtful part of their experience during interviews, mothers seemed to be sure that the response of the fathers was prompted by stress. Two of the mothers participating in the current study also

described similar experiences. The experience of having a child hospitalised puts significant stress on the relationship between the mother and father of the child. That stress is sufficient to make the respective experiences of mothers and fathers very different. This confirms my decision that this study should focus on the experience of mothering.

The literature on the mothering experience suggests it is unique (Block, 1991). It may therefore be a mistake for the literature on the experience of parenting hospitalised children to assume that mothers and fathers have the same experiences.

Mothering chronically ill children

My study examines experiences that involve children admitted to hospital with acute illness or injury. I expected that there were sufficient and important differences between having a child with a chronic illness and a child with an acute illness or injury hospitalised, to warrant separate study. These differences may include familiarity with the hospitalisation process and with a particular hospital environment for a child whose chronic condition requires hospital treatment on a regular basis. This familiarity will also extend to the various procedures, drugs, and their expected outcomes. It can also be expected that the mother of a child with a chronic illness will be so familiar with the condition and its particular manifestations in her child that she may be able to anticipate hospitalisation. In some cases she may be able to prevent it by acting early enough when she recognises subtle changes in a child's behaviour that no one else can.

The mothers in my study had experiences similar to those reported in the literature concerning mothers whose children have chronic conditions. Studies reviewed in the literature identify that mothers, rather than fathers, play a different and often much more significant role as care giver both in hospital and at home. The studies examined therefore make it clear that it is the mothers' experience under study (Lasby et al, 1994; Gibson, 1995).

In their case study that used interpretive hermeneutic analysis, Lasby et al (1994) describe what they identified as "maternal work" by the mother of a premature newborn. One of the features of this maternal work is the "elongation" of time (p.154) expressed by the mother as long periods of waiting. This change in the experience of time is also a feature of the experience of the mothers in my study.

Gibson (1995) uses a qualitative process to describe "the process of empowerment" of mothers of children with chronic conditions. She identifies the first step in this process as "discovering reality" (p.1203-5). This step fits well with experiences described by mothers with acutely ill children admitted to hospital and includes such issues as mothers initially being recipients of care rather than participants in their child's care. The ability of mothers to discern changes in their child's condition necessitating intervention is also identified by Gibson (1995, p.1204).

Lack of communication between mothers and fathers about their child's illness is a significant frustration identified by mothers in my study. Frustration was a feeling that predominated the interviews that Gibson (1995) conducted with the mothers participating in her study. One of the key frustrations was miscommunication with their husbands, the fathers of

the hospitalised children. Other studies have identified similar frustrations. Hatton et al (1995) conducted a phenomenological study to describe parents' perceptions of caring for a child with diabetes. They interviewed eight couples who, among other things, identified significant stress and conflict between each other as being a feature of their experience of managing the day-to-day care of a young child with a chronic condition.

Whyte (1992) describes "the experience of crisis" and the "chronic burden of care" experienced by families of children with cystic fibrosis. Her ethnographic study included four families over a five year period. Again, the stress and conflict arising within families, particularly between the child's parents, are a feature. As with Gibson's (1995) study, Whyte's conclusion is that "the burden of care" is largely born by the mothers of the sick children.

The nature of parental stress resulting from repeated hospitalisations of a child with chronic illness or disability was the purpose of a grounded theory study by Burke et al (1991). The resulting mid-range theory describes a process whereby parents have to work at establishing trust with health professionals. The parents participating in the study often found themselves in situations in which their previous experiences meant that they had a great deal of knowledge about how things should and should not happen. Deciding when and how to 'act' with their knowledge was a significant source of stress.

The nursing perspective

Reviewed above is the growing body of research that examines the parental experience of having a child hospitalised. This followed examination of the research establishing clear benefit for the child of having a parent closely involved in their hospital experience. The literature that examines the perspective of the third party in the triad of child/parent/nurse, the nursing perspective, also needs to be reviewed.

Berman (1991) points out that there is a discrepancy between what nurses say they believe and their actions as individual practitioners. She reports on a project aimed at formulating a philosophy of nursing for a children's hospital. All nurses working in the study area were invited to participate by coming to meetings during which they were asked open-ended questions and given the opportunity to share their beliefs and values about nursing children and their families. Twenty two nurses participated and although they expressed explicit support for the concept of family-centred care, their comments and actions suggested that they had not considered the implications of such a philosophy for their individual practice. Berman (1991) concludes that "... substantial ambiguity and confusion remain ..." (p.153) about the implications for nursing practice of family-centred care.

Two studies, Callery and Smith (1991) and Brown and Ritchie (1989), have examined nurses' perspective on the quality of their relationships with parents of hospitalised children. The data for these studies were collected in a qualitative way. The findings highlighted an urgent need for nurses to improve their communication skills and at the same time acknowledge that

these are very significant skills for nurses to have and use because of the potential that nurses have to provide effective emotional support.

"Little foundational knowledge is available about the experience of engagement in nursing practice with children and their families" (Burns, 1994, p.211). Burns conducted a hermeneutic-phenomenological study that examined the meaning of engagement for nurses. Eight nurses were asked to recall and describe specific occasions on which they felt engaged with children and their families in a hospital setting. She uses the metaphor 'Creating a Safe Passage' to describe the lived experiences of nurses working with children and their families. This is a metaphor for the process of engagement that nurses enter into with families.

Darbyshire (1994), in the other part of his study introduced on page 20, interviewed 27 nurses to establish how nurses perceived the process of fostering parent participation. He identifies "unrecognised tension" between what nurses say they do to encourage parental involvement and their unspoken expectations of parents. "This tension had a direct impact on parents' lived experience of their participation. For although they received encouragement from nurses that they themselves should determine the nature and extent of their participation by carrying on in ways that were normal for them, there were clearly discernible nursing and institutional expectations and practices that contradicted this seemingly laissez-faire approach" (p.207). The findings of Darbyshire's study have significance for this study of mothers' experiences, particularly associated with the theme the need to do described in Chapter Four.

SUMMARY

This chapter has reviewed the literature about the experience of parenting a hospitalised child. Both quantitative and qualitative studies have been identified and discussed with particular reference to whether the designs of the studies have examined parenting or mothering. My current study examines the experience of mothers because the literature reviewed is clear that they carry 'the burden of care' and that the crisis of having a child hospitalised is experienced differently by mothers and fathers. Studies that investigate the nursing perspective of caring for children in hospital have also been reviewed.

CHAPTER THREE

RESEARCH METHOD AND DESIGN

This chapter discusses the contribution nursing research using the phenomenological method can make to nursing knowledge. Heideggerian phenomenology is identified and discussed as the method of my choice for this study because of the empathy I found with the philosophy. Van Manen's (1990) work on writing and rewriting and the place of the personal experience of the researcher in the process of Heideggerian phenomenology are also discussed.

The chapter also includes a description of the design of this study. The ethical approval process is outlined and each participant is profiled. The data collection process is described, with detailed discussion about the nature of the interviews conducted with study participants. The data analysis strategy is documented and discussed with particular emphasis on how I have conducted the thematic analysis that van Manen (1990) suggests.

My personal circumstances, as outlined in Chapter One, have had a significant impact on the dynamics of this study. It is important that my strategy for accommodating these circumstances are detailed. This chapter contains discussion relevant to this issue in several places because the way I have utilised the phenomenological research method and design for this study has been influenced by my personal experience. However, it must be acknowledged that one of the advantages of qualitative research, and

hermeneutic phenomenology in particular, is that it allows for the researcher to respond in different ways to the different situations which arise. Readers need to be reassured that this study benefits from, rather than focussing on my personal experiences.

STUDY METHOD

Nursing research and phenomenology

"There are many common threads that bind nursing and phenomenology. The views of nursing and phenomenology towards people are that they are whole beings who actively create their own meanings. People are subjective beings-in-the-world whose lives are experienced in a particular context" (Walters, 1994, p.135). This study is about the being-in-the-world of a mother in the context of having a child hospitalised. A phenomenological description of this experience as it is lived by mothers, results from this study.

One of the greatest advantages of using the phenomenological method is the ability it gives researchers to acknowledge and emphasise the context of the experience being described. Nursing is about meeting, assessing and accepting people in their immediate context. It is also about identifying the possible constraints and advantages to well-being that an individual's context presents. A research process which enables nursing to take this context into consideration will enhance the development of nursing knowledge.

Koch (1995) highlights what she considers to be one of the most important features of Heideggerian phenomenology. That is the "... indissoluble unity between the person and the world" (p. 831). This unity between the person and their world is reflected in the four concepts generally accepted as central to the discipline of nursing. These are: person, environment, health, and nursing. All existing models of nursing describe these concepts, including the **person** receiving nursing care and their **environment** (Leddy & Pepper, 1993, p.105).

"Listening to client's 'lived experience' can provide nurses with richer feedback (and opportunity for improving the things that really matter) than can ever be gained through a paper questionnaire. Getting such feedback from clients should be a planned, integral part of nursing" (Tuffnell, 1993/4, p.28-9). I hope that by providing nurses with "richer feedback" I will be able to make a significant contribution to nurses knowledge of the things that really matter to mothers with children in hospital.

Jasper (1994) reviews some of the criticisms levelled at qualitative research processes by proponents of the quantitative paradigm and highlights what she considers to be potential data analysis problems. "The experience may ... be sifted in the participant's mind to exclude parts of the experience that are painful or confidential ... the expression of the experience may not represent the true experience" (p. 312). My experience is that participants are telling you their truth. It is this truth with which I have worked, and this truth with which phenomenology is concerned. It is also this truth which is relevant to nurses and nursing, because the aim of this phenomenological research project is to improve nurses' understanding of mothers with children in hospital.

Sandelowski (1993, p.3) supports this view in her article exploring the issues of rigour in qualitative research. She points out that "...in the naturalistic/interpretive paradigm, reality is assumed to be multiple and constructed rather than singular and tangible." Sandelowski makes two other important observations about this research process. Firstly, she acknowledges that the very fact a researcher asks participants to put experience into words that can describe it to another for interpretation, will change that "truth". And secondly, she points out that "... the research process is inherently social ..." (p.7). For this reason the research process is subject to the same constraints as social processes such as politeness. So, the conversational interviews described below (p.42) as the main source of data were subject to the same norms as those of everyday conversations. For example, it would have been most inappropriate for me to question the 'truthfulness' of the stories the mothers in this study shared with me.

Conversely, the research process I used was subject to the same freedoms as social processes. Participants and researchers were free to have conversations which involved humour, the exchange of ideas, the telling of stories and the clarification of detail that is usually not possible or sanctioned in the empirico-analytic paradigm because of the need for reliability and replicability. These are the same freedoms that nurses use everyday to develop rapport with patients/clients in stressful settings and crisis situations. Phenomenology therefore reflects much more accurately the everyday settings in which nursing occurs.

Nursing literature has begun to demand that nurse researchers identify which of the two main phenomenological approaches they are using.

Walters (1994) and Koch (1995) emphasise the necessity for this when they specify the clear differences there are between Husserlian and Heideggerian phenomenology. They suggest that these processes are sufficiently different to warrant the demand for clear differences to be specified in all parts of the nursing research process. This thesis uses Heideggerian phenomenology. The characteristics of this research process therefore need to be discussed in detail.

Heideggerian phenomenology

"Being is the most universal concept of Heidegger's hermeneutic phenomenology... to ask for the Being of something is to enquire into the nature or meaning of that phenomenon" (van Manen, 1990, p.175). The philosophy underlying this thesis is Heideggerian and therefore must examine the experience of "being-in-the-world" as the mother of a child hospitalised with acute illness or injury. This examination should include detail of how a mother exists, acts and is involved in the world through this experience.

Heidegger discusses the human capacity and inclination to wonder about and explore humanness. Van Manen says: "Phenomenological research is a search for what it means to be human" (1990, p.12). Nursing is a human science. Science is knowledge arrived at after systematic observation, reflection and documentation. Nursing knowledge will benefit from research which explores humanness in the nursing context.

"Heidegger's hermeneutics has been described as an interpretive phenomenology" (van Manen, 1990, p.180). This interpretation is not aimed at experiencing what someone else experiences. Rather the aim is to describe pre-reflective experience which reveals possibilities of being-in-the-world. Walters (1994, p.137) says: "Heidegger considers that hermeneutics is one of the processes that people use in making sense of their everyday lives." It is the everyday lives of mothers of children in hospital with which my research has been concerned.

There are four existentials which make up the human lifeworld, "...the lived world as experienced in everyday situations and relations" (van Manen, 1990, p.101). Lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relation (relationality or communality) all make up the lifeworld of a mother. Hospitalisation of her child will change that lifeworld dramatically. As guides for reflection, interpretation and description in this research process, the four existentials have been invaluable.

The hermeneutic circle

Another significant feature of Heideggerian phenomenology is the concept of the hermeneutic circle. This is a process which requires the researcher to move back and forth between examination and interpretation of parts and the whole of the phenomenon under study. Identification of new detail may shed new light on the whole which in turn enables the identification of a new and significant detail.

Koch (1995) clarifies the significance of the relationship between the historicity of understanding and the hermeneutic circle. She suggests that rather than 'new' information being identified as the researcher moves back and forth between the parts and the whole of a phenomenon, it is the modification of understanding which takes place. This is because of the pre-understanding that a researcher working within the Heideggerian framework brings to her research. "Pre-understanding is a structure of our 'being-in-the-world' " (p. 831). The world in which we live is interpreted with our pre-understandings as points of reference. So, as Walters points out "... it is not possible to separate facts from their meanings" (1994, p.138). Pre-understandings come with the researcher to the research situation.

The pre-understandings with which I have come to this research process and subsequently this writing and rewriting process need to be discussed in detail because of my personal circumstances outlined in Chapter One. The planning stage of this project was influenced by the hospitalisation and death of my niece. The analysis and interpretation process was influenced by my pregnancy and the hospitalisation of my daughter. The magnitude of that influence has become clear during this, the writing stage. "To write is to measure the depth of things, as well as to come to a sense of one's own depth" (van Manen, 1990, p.127).

My experiences are part of me. **I** am an aunt whose niece needed my nursing skills. **I** am a researcher whose study participants told **my** story as they told me theirs. **I** am a mother whose child has been hospitalised. **I** am a mother who had to leave her child in the care of others while I had surgery. And **I** am the author of a phenomenological description of the

lived experience of mothering a child hospitalised with an acute illness or injury.

There have been occasions through my research when this unique combination of roles have been in conflict. For example while pregnant I found it difficult to 'dwell' with the data from Lyn whose ten day old son was hospitalised with pneumonia. I seemed to need to avoid considering the possibility of my newborn needing to be hospitalised, in case doing so precipitated that occurring. My role as mother and researcher were in conflict.

I recall acute discomfort while interviewing Des and again when listening to the tapes of our conversations and reading the transcriptions. Her visualisations of the surgical process her son was experiencing, made possible by her knowledge as a nurse, reminded me of the vividness of the visualisations I experienced while waiting for my niece Sarah to come back from theatre. When I closed my eyes I visualised the detail of the surgical process I knew she would be going through. My roles as aunt, nurse and researcher were in conflict.

It has taken some time for me to bring these experiences together, to write about them together, be clear about and find meaning in the fact that the experiences in which I was interested as a researcher had been my experience as an aunt and became my experience as a mother. My research process had to recognise and accommodate my pre-understandings.

My personal experiences have given me a unique opportunity. Examination and reflection on my experiences through dialogue with a colleague and the requirement of the phenomenological method for writing and rewriting, revealed my opportunity as the ability to recognise unique insights. My experiences as nurse, aunt, researcher, mother and writer have given me insights which became possible because of this unique combination of roles.

My way of being-in-the-world has influenced the phenomenological description I have produced. "Human science research is concerned with meaning - to be human is to be concerned with meaning, to desire meaning" (van Manen, 1990, p.79). My desire for meaning has given meaning to this research which has in turn identified meaning in my experiences. This is the 'hermeneutic circle' at work.

Van Manen's phenomenological method

Van Manen (1990) describes in detail the hermeneutic phenomenological method and emphasises the significant role writing has to play in this process. "In phenomenological human science, writing does not merely enter the research process as a final step or stage. Creating a phenomenological text is the object of the research process" (p.111). The use of language in this writing and rewriting process is critical. Its contribution to phenomenology reflects the part language plays in the taken for granted world of the person. "The object of human science research is essentially a linguistic project: to make some aspect of our lived

world, of our lived experience, reflectively understandable and intelligible" (van Manen, 1990, p.125-6).

Writing, instead of being the final act in the research process, is much more an essential part of the process itself. "Language is a central concern in phenomenological research because responsive-reflective writing is the very activity of doing phenomenology" (van Manen, 1990, p.132). In order to produce quality phenomenology, writing and re-writing is necessary because reflection is part of that process. In this method it is essential that... "Writing gives appearance and body to thought" (p.127).

Van Manen (1990) also comments on the quality of the writing for which the researcher aims in phenomenology. "If the description is phenomenologically powerful, then it acquires a certain transparency, ... it permits us to "see" the deeper significance, or meaning structures, of the lived experience it describes ... A description is a powerful one if it reawakens our basic experience of the phenomenon it describes, and in such a manner that we experience the more foundational grounds of the experience" (p.122). This can occur because of the essential reflective activity that the descriptive writing of lived experience enables and requires.

I recall the impact which reading a phenomenological description of pain (Madjar, 1991) had on me. It stimulated vivid recall of situations in which I had nursed people experiencing pain. Some of those situations I remember with a sense of frustration and inadequacy because I had been unable to help that person achieve an acceptable level of comfort. Others I remembered with satisfaction because comfort was successfully achieved.

My experience of reading phenomenological description was powerful and I believed powerful enough to make a difference to the way I practice as a nurse. Such description therefore has the potential to affect others in the same way.

If the aim of nursing research, perhaps all research for that matter, is to bring about beneficial change, then phenomenological research has the potential to do that. More importantly, it has the potential to do that with the aspects of nursing that are difficult to quantify. Studies that have quantified the experience of parents of children in hospital have been successful in highlighting the issues of concern for nurses. A powerful phenomenological description of the lived experience of mothers of children in hospital has the potential to change the practice of nurses.

In reviewing van Manen (1990), Walters (1994) says: "Readers of research reports should be provided with a description of the participation of the researcher(s) as a way of understanding the situatedness of the researcher." He goes on to say that: "The hermeneutic process ... should include the researcher's personal reflections as sources of insight about the phenomena" (p.140). I have found the methodological guidance about the place of personal experiences in phenomenological research provided by van Manen (1990) invaluable.

As outlined in Chapter One and on page 31 above, this reflection has been critical in my research because of my personal context within which I undertook this study. It would be simply naive to attempt to set aside my personal experiences and suggest that my analytical and interpretive processes were unaffected. To do so would invalidate those processes.

The only alternative to identifying and acknowledging personal experience as part of the reflective context, would be to leave issues such as these un-researched in a phenomenological way. However, as identified by the review of literature, this methodology has a great deal to contribute to nursing knowledge and therefore to the nursing care of sick children and their families. I believe it would be difficult to find a nurse interested in doing phenomenological research who had not been affected in a personal sense by her work with children. A nurse who was able to remain personally unaffected by working in this setting is unlikely to believe that phenomenological research methods have anything to contribute to her work.

The effect of my emotional response to some of the data collected has required careful consideration. Discussion with my supervisor and fellow researchers has helped me clarify the place of personal experiences in this description and reassured me that being involved in research of this nature did not precipitate events, as I had begun to suspect! Most importantly, this discussion has highlighted the phenomenological purpose of describing taken for granted life events in a way which will help others begin to understand them. Doing phenomenological research is a way of life in the sense that leaving it at work is not possible. It becomes embodied by the researcher on whom it often has a transformative effect (van Manen, 1990, p.163).

My study has utilised the hermeneutic phenomenological research method discussed above. A detailed description of the design of the study follows.

STUDY DESIGN

Ethical considerations

Approval for this study was gained from the Massey University Human Ethics Committee in April 1993. My thesis proposal and application for ethical approval identified a number of ethical concerns. These related to the mothers who volunteered to participate and the information gathered from them during the study. Each of these is discussed in detail below.

Mothers who had had the experience of having a child hospitalised with an acute illness or injury were asked to volunteer to participate in this study. Potential participants were approached via my family and friends who were aware of the nature of my study. Therefore participants were not accessed through any health care agency, either public or private, but rather were identified from my own community. Arrangements were made by telephone to meet and discuss the proposed study and gain consent from potential participants.

Informed consent was obtained from all the mothers who agreed to participate. Consent was voluntary, was only sought from participants who had the capacity to consent, and was informed with a verbal explanation from me and the Information Sheet (see Appendix 11) which I left with the mothers. The Information Sheet states that participants have the right to ask for further information about the study during their participation. It also gave my contact addresses and phone numbers to enable participants to contact me whenever necessary. Participants retained the right to withdraw from the study at any time and were

reminded at the beginning of both interviews that they may withdraw from the study if they so wished.

Participants in a study also have the right to decline to answer any particular question. The willingness of mothers in this study to share with me the detail of their experiences, including such detail as marital stress associated with their experience, indicated to me the need that these mothers had to share their stories. Their hope was that doing so might benefit mothers who will have similar experiences in the future. In their effort to benefit others, some of the participants recognised benefit for themselves.

Reference is made on the Information Sheet to the fact that participants may find reflecting on and describing their experience in detail, distressing. None of the participants in this study verbalised acute distress or behaved in a way which suggested acute distress. One participant seemed reluctant to be interviewed a second time. In consultation with my supervisor I decided to try making another arrangement for the interview. If that interview did not take place I planned to share with this mother my concern that she was participating reluctantly and to remind her that she could withdraw from the study at any time for any reason. The third arrangement for interview took place without any apparent reluctance on the part of this participant.

Hutchinson, Wilson and Skodol Wilson (1994) point out potential benefits of research participation such as: catharsis, self-acknowledgment, sense of purpose, self-awareness, healing and empowerment. Several mothers in my research process identified 'talking about it' and self-acknowledgment,

as benefits they had experienced as participants. To put into words feelings and fears they had never had the opportunity to express about such a life crisis, in an emotionally safe environment, is undoubtedly beneficial.

One participant wondered if I could return and talk with her husband, because she felt he would benefit from the opportunity to discuss his experience. My response to her included an explanation that mothers were the focus of the current study and that talking with her husband might affect my ability to focus on her individual experience. When I returned six weeks later for the second interview, she said that our first conversation had precipitated discussion with her husband about their son's hospitalisation and that this had made a positive difference to how they both felt about the experience.

As a researcher I found it daunting that what was essentially my research process, could make a difference, positive or negative, to participants' significant relationships. Van Manen (1990, p. 98) identifies that "...participants of the study often invest more than a passing interest in the research project...They begin to care about the subject and about the research question." This is part of the 'conversational relation' that develops between phenomenologist and voluntary participant. It is also in part a measure of the success of a phenomenological study. If participants in a phenomenological study are involved to the extent that they seek to extend their involvement and have an expectation of and express personal benefit, then the study can be seen to be relevant and to be using a research process that is emotionally and culturally safe. This improves the chances of the study successfully achieving an effective description of lived experience.

Confidentiality for participants and their children is ensured by using pseudonyms. The woman who transcribed the tapes of the interviews with participants had done similar work for other masters students, with study participants in similarly vulnerable positions. She was therefore well aware of the need for absolute confidentiality of the material.

All details of the interviews, the tapes and transcriptions were kept separately in locked filing cabinets. Access to the tapes and interview transcriptions was only possible for me, my supervisor and the transcriber. After examination and acceptance of this thesis, the tapes of the interviews will be erased.

Some of the mothers who agreed to participate in this study specifically requested copies of their interviews and these have been provided. All participants will be contacted on completion of this thesis and offered an opportunity to read it and have any questions they may have about my conclusions answered.

The necessity for approval from the Ethics Committee of the local Area Health Board, as it was at the time, was debated with the Massey University Human Ethics Committee and the Department of Nursing and Midwifery. It was concluded that because it was planned that none of the participants currently be consumers of health care related to the experience of relevance to the study, that this would not be necessary. When contacted, the local Area Health Board Ethics Committee agreed.

Study participants

Mothers

Family, friends and colleagues were aware of the nature of my proposed study. When they suggested to me someone who might be a potential participant, I asked them to talk with the woman concerned and ask her permission for me to ring them. I had no difficulty in finding seven women who were willing to participate in my study. The fact that I was known by a family member or friend of all potential participants, may well have contributed significantly to my credibility with them prior to my contacting them for the first time. This referral network has been particularly effective and had the study necessitated it, many more participants could have been accessed in this way.

The seven mothers who agreed to participate had experienced the hospitalisation of a child within twelve months of their first interview. One mother approached declined to participate, all others agreed. The group included an English woman, a Sri Lankan woman and a Maori woman. Four of the participants are full-time mothers, two work full-time and one works part-time outside of her home. For four of the participants, the hospitalisation experience which was the focus of the study was the first such experience they had had with a child.

Children

Although none of the children whose experiences are related in this study were participants in the formal sense of the word, these are their stories and details of them as individuals are significant.

The study proposal specified that the hospitalised child should have been under fourteen years of age at the time of hospitalisation. The rationale for this age inclusion criteria is so that this study can be viewed alongside the statistics on childhood illness and hospitalisation which includes children up to fourteen years. As a rule, in the geographical area in which the study took place, admission to hospital facilities for children is for individuals up to fourteen years. The ages of the children at hospitalisation ranged from 10 days to 13 years. Four of the children were boys and three girls.

Participant profiles

The names used in these profiles are pseudonyms. They are used to help prevent identification of participants by readers of the study. The participant mothers and their children are referred to using these pseudonyms all the way through this thesis.

Deb's daughter, her second child, was hospitalised at the age of thirteen years for what Deb describes as 'quinsy'. The description she gives suggests that Fee was experiencing acute airway obstruction due to bacterial tonsillitis. At the time of her daughter's hospitalisation, Deb was working full-time outside of her home and such was her work environment

that she did not feel able to request any time off to stay with Fee. Her elder child, a son, had been hospitalised as a toddler and in early childhood with asthma. Deb coached her daughter through a frightening experience. She knew that it was possible for her daughter to compound her breathing difficulties by becoming acutely anxious.

Lyn is a full-time mother and described her first experience of having a child hospitalised. Her younger son, Robin, was hospitalised when 10 days old with pneumonia. Lyn knew that something was wrong with her newborn son and worked hard to get him the attention required on two specific occasions. She had to persist with her requests for assistance when her husband and on a different occasion a nurse, tried to persuade her nothing was wrong. She was unable to specify what made her believe Robin needed urgent attention. But she described him as having a certain look about him and that he seemed frightened.

Nell's first child, Mike, was hospitalised with asthma as a toddler. At the time of interview Nell was a full-time mother but was planning to return to work in the near future. She tells a story of increasing confidence and expertise in mothering a child with a chronic condition. This developing expertise is aimed at preventing further hospitalisations. The hospitalisation she describes suggests an experience of nursing care which was frustrating and thoughtless.

Cyn has three children, a boy and two girls. Her youngest daughter, Kasey, was admitted to hospital at the age of six years for elective surgery to correct a congenital urinary tract deformity. She had experienced the hospitalisation of her other daughter as a toddler with a medical condition.

Cyn has been at home full-time since her marriage. Cyn's experience seemed to be summarised by her stated aim to share her daughter's experience. Her ability to say "I know you don't like this but I am here" is a central part of the experience she describes. This is how she coped with this stressful experience and she felt that her ability to cope was essential if her daughter was to cope.

Cyn was an informant who was able to express herself descriptively and in a way which easily gave words from which a phenomenological description could arise. " ...some descriptions are richer than others" (van Manen, 1990, p. 92). The richness of her descriptions means that Cyn has been quoted extensively and at length because the way she uses words should enable the reader to readily identify with her experience and therefore the phenomenon being described.

Des's son Mark, her only child, was hospitalised at six months of age for surgery to correct a congenital urinary tract deformity. Des has returned to part-time work as a registered nurse. Throughout her experience of the health system with her son, which included preoperative checks, hospitalisation for surgery and postoperative follow-up, she struggled with combining her nursing knowledge and her mothering experience.

" ...when it is your own child everything you know as a nurse goes out the window... " (Des 1 p4)

" ...the trouble was I was visualising what was going to happen,... it is the trouble with being a nurse really... I didn't only visualise an anaesthetist trying to find a vein... I visualised the surgeon cutting him, which is just dreadful... " (Des 1 p21)

Yve's daughter, Tania, was hospitalised with viral meningitis at the age of twelve years. Her daughter is her elder child. She has a younger son who was hospitalised at six months of age because of a febrile convulsion associated with otitis media. Yve works full-time outside her home. Through her fear she maintained an unwavering belief that her daughter would recover. This was to do with her 'mothering knowledge' of her daughter. Yve was sure that her daughter's inexplicable behaviour, for example screaming, loss of motor function and lack of recognition of her mother, was to do with a physiological illness and not as was suggested at one point, an emotional hysteria or an experimentation with drugs.

Jos has three sons, the youngest of whom has been hospitalised three times in the eighteen months of his life with acute allergic responses including bronchiolitis, infected eczema, failure to thrive and complications of chicken pox. Tyler's eczema and failure to thrive remain chronic problems. Jos is a full-time mother. Jos' experience was characterised by her continuing search for the factor(s) that precipitated her son's acute illnesses. She remained open to any suggestion that might help her son, even stopping breastfeeding when it was suggested that this might help. She tried a number of 'alternative' therapies despite their cost and the disapproval of the medical specialists.

Data collection

Interviews

Unstructured in-depth interviews were my primary source of data in this study. The nature of these interviews is discussed below. Field notes associated with each interview were also made and noted contextual information.

Interviews were conducted in a place and at a time of the participants' choosing. In most cases this was in the participant's home, although one participant preferred to come to my home, and for another it was convenient for her to be interviewed at her place of work. In making arrangements for interviews, I explained that the possibility of interruption from other people might make the discussion and recording of their experience difficult and that we would therefore need privacy and relative quiet.

I began the first interview by asking the participant to describe the circumstances in which her child was hospitalised. With questions of clarification from me, this generally took about half of the interview. During the second half of the interview I asked the participant to describe specifically how she was feeling at particular points of the process of hospitalisation that she had described. The focus during this part of the interview clearly turned from a factual description of the hospitalisation of the child to a reflection on behalf of the mother on how she was feeling during different stages of this event. For example, having sought a description of the admission of a child for elective surgery, I would then

ask the participant to describe her feelings while she waited to be called by the recovery room staff to say that her child's surgery was complete. She might also be asked to describe getting to her child in the recovery room and what she saw and heard and did.

All participants were interviewed a second time. I began this interview by asking the mother if there was anything she had remembered since the first interview that she wished to say or any questions she wished to ask about the subject or process of the research. We would then spend time going through the transcription of her first interview. I would explain my beginning analysis of the data and ask for confirmation and clarification.

One mother requested a copy of the transcriptions of her interviews. These were provided. Another asked that I return at a later date with her transcriptions and the data analysis and go through the process and the findings of the research with her. Another mother seemed embarrassed by the volume of the transcriptions and made comments like "Did I say all that?" I pointed out that the transcriptions were double spaced and included all that I had said as well.

In all cases the second interview was shorter than the first with the average length of the first being 90 minutes and the second, 60 minutes.

Field notes were made after each interview, documenting significant points about the context of the interview; for example the time and place of interview and any interruptions that had occurred. Part of the life of mothers is living with interruptions from children. All the participants in this study took extraordinary measures on my behalf to minimise

interruptions. The interview process must accommodate interruptions such as a baby needing feeding or an injured child needing comfort. My field notes documented these interruptions to the flow which had the potential to change the tone and topic of the discussion.

Conversations

Interviews of the type used in this study are characterised by their conversational nature (van Manen, 1990, p.66-68). As I have worked with the data collected through the course of this research I have come to view the interviews I conducted as **conversations** between storyteller and listener. The participants told their stories and I listened. We were all mothers. The participant mothers gave much more than might be expected in a formal research interview. The term 'conversation' seems to better imply the process of those meetings. They were usually accompanied by refreshment of some description. Other 'ice breaker' activities included being introduced to children or animals and talking about the person who had put me in touch with the participant.

Initially I felt anxious about the time these activities consumed as the participants would often go to significant lengths to organise to spend time with me free from children and work. And accepting refreshments seemed to put them to further trouble. However as Smythe, Spence and Gasquoin (1995) concluded, all these rituals are part of preparing to share and to be vulnerable in that sharing of a significant life event. The conversations resulted in rich data full of meaning.

Part of the quality of the data is the acceptance of silence that 'conversations' accommodate better than 'interviews'. A significant life event, and in this case a life crisis, was the topic of conversation, and there were bound to be moments when the appropriate words were hard to find or it was difficult to speak because of emotion. It was important to resist the temptation to fill the silence or find a word. We were 'in conversation' rather than conducting an interview and so the silence was able to be shared by participant and researcher. The silence needs to part of the data collected. Silence is part of the context of the storytelling and is therefore meaningful.

Data analysis

Lo Biondo-Wood and Haber (1990) suggest that: "The primary concern in phenomenology with lived experience requires the researcher to design ways of transcending the automatic interpretation people customarily adopt and accept as the truth" (p.198-9). While highlighting the nature of the analysis process in phenomenological research, Lo Biondo-Wood and Haber also indicate the contribution this research can make to nursing. It is the "automatic interpretation" of events and circumstances with which nurses usually work. Transcending that "automatic interpretation" to explore in detail mothers' lived experience of having a child hospitalised and how this can be influenced by nurses must be the outcome of this thesis. Such an outcome will make the findings and conclusions of this research useful to nurses working in this sphere of practice.

For example, "automatic interpretation" identified helplessness which was expressed by the mothers interviewed. They said there was nothing they could do for their children. However, further examination of the data identified a large number of things these mothers did do with and for their children. Part of all that a mother does for her child is her need to do these things. She is meeting her own needs while meeting those of her child. This **need to do** only became clear after repeated examination of and reflection on the stories of individual mothers and the data as a whole. The **need to do** is one of the themes described in Chapter Four. The implications for nurses and their practice of a mother's **need to do** is discussed in Chapter Five.

Van Manen (1990, p.92-5) suggests three approaches to identifying themes of a phenomenon in text:

- 1) the wholistic or sententious approach - a statement which attempts to interpret the meaning of the text as a whole.
- 2) the selective or highlighting approach - selection of phrases from the text itself which seem particularly revealing about the phenomenon
- 3) the detailed or line-by-line approach - each sentence and paragraph is examined for the meaning they hold about the phenomenon.

I found two of these three approaches of value during the analysis of the data I collected. The phenomenological descriptions of themes given in the following chapter use, whenever possible, the words that the mothers themselves used and illustrate the selective approach. I have used long

quotes on several occasions in Chapter Four. The meaning they contain is revealed in each line and often it is the repetition of words and phrases used which give clarity to their meaning. These are examples of the detailed approach.

The data collected in this research process will be presented in a way which gives the reader "a sense of the whole" (Sandelowski, 1995, p. 372). In her article detailing the qualitative data analysis process Sandelowski warns against trying to present all data collected, the danger being that a superficial survey or "catalogue" of qualitative findings results, without any interpretation of the meanings of the experiences gathered.

This sense of the whole applies to each individual participant whose stories need to be seen as complete and to all the data collected during this study from all the participants. So, while there are many overt differences in the detail of the experiences of the mothers interviewed, common themes present themselves when the data are analysed and interpreted as a whole. These themes are revealed through the 'conversational relation' I developed with the data.

The 'Conversational Relation'

Van Manen (1990) identifies and describes the importance of the 'conversational relation' in phenomenological research. This is the relationship that the researcher develops between herself and participants, or 'co-researchers' as they usually become during the course of such research. Participants who become co-researchers develop some

ownership of the research and a desire for the research to progress. The relationship that develops between researcher and co-researchers - interviewer and interviewee - and the phenomenon that is being examined is also a feature of the conversational relation. Uncovering meaning in descriptions of lived experience requires that a conversational relation is maintained.

The hermeneutic circle is achieved and maintained by the conversational relation. The researcher repeatedly questions the data in parts and as a whole to reveal new meanings and understandings. Subsequent 'conversations' with these new interpretations enables the researcher to establish their robustness when these new insights are examined alongside previous interpretations.

Questioning, in depth and on repeated occasions for the duration of a research project, offers opportunities to explore the phenomenon of interest in a collaborative way. The common orientation of interviewer and interviewee to an issue explored through "collaborative hermeneutic conversations" (van Manen, 1990, p.99) enables development of themes and results in a phenomenological text.

Smythe et al. (1995) also describe the value of a conversational relation with each other as fellow phenomenologists. Discussion between researchers using a phenomenological process assists clarification of methodological and design details as they relate to the phenomenon being studied. It was such discussions which enabled me to clarify and validate my analysis and interpretation processes when I experienced the role conflicts identified on page 31. The questioning of fellow

phenomenologists is a collaborative process which facilitates the evolution of themes and text with significance and value.

During the development of the phenomenological text it is critical that the conversational relation the writer has with the phenomenon is maintained through reading and writing. This is part of the writing and rewriting process that van Manen (1990) emphasises and which is discussed above.

The conversational relation is what stimulates the beginning of a phenomenological research project. A researcher recognises something about which she feels a concern and that this concern would benefit from phenomenological research. It is the conversational relation which gives the research process momentum and direction. And it is what enables the researcher to recognise that she has completed a description which is thematically powerful and therefore effective. The relationship is a critical part of the whole process.

SUMMARY

This chapter has detailed the method used for my research. Van Manen's (1990) interpretation of the hermeneutic phenomenological approach to research has been discussed and related to the potential value of its contribution to nursing research and therefore nursing knowledge. The design of this study has also been described. Attention to ethical concerns has been detailed, the study participants profiled, and the data collection and analysis processes documented.

Chapter Four uses phenomenological themes to describe the lived experience of mothering a hospitalised child. An overarching theme of **constant vigilance** is sustained by the three key themes which capture the essence of the phenomenon of mothering in these circumstances.

CHAPTER FOUR

MOTHERING A HOSPITALISED CHILD

This chapter will describe the lived experience of mothering a hospitalised child. This crisis changes the being-in-the-world of a mother beyond recognition when, as a result of her child's hospitalisation, a mother's experience of time, space, body, and her relationships with others take on different and complex meanings.

Firstly, the context of mothering a child in hospital needs to be outlined. It is a context of crisis which is full of paradox and challenges a mother's ability to cope in unexpected ways.

The themes which are the essence of the phenomenon of mothering in this situation will then be presented. These are: **mothering is a special kind of knowing, the need to do, and handing over, leaving and waiting.**

A description of the overarching theme of **constant vigilance** will follow.

A CONTEXT OF CRISIS

Hospitalisation of a child is a crisis for the mother. This crisis challenges a mother's habitual way of mothering. The experience and context of this crisis needs detailed description in order that the phenomenological themes which follow are presented in a context of crisis.

Cyn's daughter, Kasey was hospitalised for elective surgery to correct a congenital urinary tract deformity. Cyn describes the emotional energy required to cope in this situation even though her daughter's admission was planned. It may be that the emotional energy necessary to cope with an emergency admission is much greater.

It is very draining. It really is very draining when you are in the hospital. I mean you do nothing basically but wait around, sit around, it is not like you are physically... but you are, you are just emotionally you are drained although you probably don't realise it until after, because you are busy coping with it, you know, at the time you just get on with it and do it and it probably hits you afterward. (Cyn 1 p8-9)

At the time her daughter was admitted to hospital Cyn was too involved in the crisis to recognise it as such. It was as she looked back on the experience that she recognised the emotional exhaustion involved.

Jos described the anticipation of her son needing hospitalisation. It had happened before, so it was not a new, unknown process. But still she dreaded it even though she recognised it as necessary.

And it is just a constant... it is just a constant... like when I think that he might be getting worse, I sort of think, oh I will have to go through again going into hospital, and I get this real scared horrible sort of ache, you know it is a terrible, what is the word - can't think of the word I want, it's a sort of foreboding you know - horrible feeling if I think he has to go into the hospital. (Jos 1 p14)

The paradox in this situation which is experienced as a crisis is that it is recognised as necessary but none the less dread-full. It is a necessity full of dread, a dread full of necessity.

The energy of the mother is focused very closely on the child in an attempt to achieve balance again for her child and herself. Being with her child and as close as possible is very important. It is difficult even to be away for a meal. There seems to be a feeling of responsibility about being there. Mothers say that they made the decision that the child needed to go to hospital so they need to stay too.

Cyn found that even leaving her child briefly for a drink or a meal put an unacceptable distance between them. She worried about being "out of range" when contact between mother and child for their mutual support and comfort was critical.

As I say it was great being there, not having to go in and out of hospital, which I had done before, because that was really hard to walk away and leave your kid in hospital, ... even when you are in the hospital and she is asleep,... I would go down and get a sandwich or a coffee but you are on needles and pins because you are out of. you are out of calling range, sort of out of sight range, I mean you just, what if she wakes - oh dear me! ... you know that you are not going to be able to do anything, it is just that you just want to be there. (Cyn 1 p9)

For Cyn re-establishing the balance for herself and her child was achieved in part by being able to stay with her child.

Des expresses the responsibility she and her husband felt for having made the decision that their son, Mark, should have surgery. Part of their responsibility was to stay with him and see him through the process.

We were the ones that had put him through this, we were the ones that had decided that he was going to have it done, and so we should be there for him. (Des 1 p24)

Like other mothers Des needed to stay with her child in an attempt at re-establishing balance.

Deb was unable to stay with Fee when she was hospitalised because she was not confident that her employer would consider it appropriate to be absent from work for this reason. She had to work extra hard to establish any sort of balance between her need to be with Fee, her anxiety about her work situation and needs of other family members. And all these activities were focused around getting back to Fee.

Balance or equipoise, so necessary to mother and child, is about working towards equilibrium and familiarity within this context of crisis. When a mother can once more feel confidence in her being-in-the-world, she feels she has more control.

While hospitalisation is experienced as a crisis which significantly disrupts the balance of the mother/child dyad, the hospital environment is identified as an appropriate place to be with a child whose care has become complex to the point that special skills and knowledge are needed. In fact Jos

realises that she and her son would have benefited from hospital admission sooner.

*Once he got into hospital they really sorted him out and that's when looking back I think he should have been put in hospital earlier and I really needed, I really needed the help with the weaning that I couldn't do by myself. I wasn't able to do it on my own at home, I just used to give in...that was definitely the turning point...
(Jos 1 p5-6)*

However, this benefit associated with a place that is usually avoided can probably only be recognised on reflection. Hospitalisation is something that is resisted because it requires in part an acknowledgement of the fact that for this child, at this time, mothering is no longer enough. That is a very difficult situation for a mother to be in.

While viewed as appropriate and offering care that a mother cannot give, hospitalisation often works to emphasise the experience of stress because of its strangeness. This strangeness is often exacerbated by the overt comfort of nurses and other health professionals within that environment. Although hospitals and the health professionals working in them would probably say that they worked hard to meet the needs of their patients/clients/consumers, the perception of mothers as Lyn expresses it, is that the hospital is the *domain* of the people who work there.

*It's their domain, it is not yours, they are running the show.
(Lyn 2 p6)*

Lyn's experience was that she was entering foreign territory. She did not know about how things were done in this new culture. And the staff were so enculturated that they were unable to identify the 'rules' let alone explain them to her. Lyn describes the horror she felt when she realised that she had been using staff facilities. Her realisation was all the more horrifying because none of the staff had told her that she was 'breaking the rules'. She simply saw a notice on a closed door. A door that until that point had remained open, obscuring the sign which asked parents not to use the room.

And up until then I had been using the staff quarters, which I didn't realise was the staff kitchen until that same night suddenly the door was closed and there was a sign on the doors saying ... out of bounds to parents - you have got to use the parents room ... well that was a bit of a shock because here I had been using it sort of well freely and suddenly realised that oh may be I shouldn't have been using it and may be everyone was talking about me ... but the door had never been closed before so I hadn't seen this sign. And I didn't want to use the staff... I didn't want to use the family room because it was filthy. (Lyn 1 p23)

Lyn had broken the 'rules' and unintentionally put a barrier between herself and the people on whom she needed to rely for care for her child. She was left feeling disempowered and angry.

The strange environment puts distance between a mother and her hospitalised child and disempowers a mother. This is on top of the distance created by the child's illness. Mothers who participated in my

study had an expectation that nurses would negotiate this strange environment with ease on behalf of them and their child. Darbyshire's (1994) research, reviewed on page 20, supports their experience. He identified the differing expectations that parents and nurses have of each other during a child's hospitalisation. These differences in expectation created barriers and emphasised feelings of disempowerment.

When her son was hospitalised for elective surgery, Des had an expectation that she would get 'instructions' from nurses about her new role as "*mother rooming in*". She needed to be given guide-lines about what to do and when.

I had taken on the role when I walked through the door that I was the mother rooming in and that meant that I would be directed to what I could do next and no one actually directed me... (Des 1 p36)

Without these 'instructions' a strange enough environment is experienced as alien. Mothers are not familiar with some of the language and jargon used in hospital environments. Neither do they know the 'rules'. Nell experienced this feeling of alienation when her son Mike was hospitalised with asthma. The medical ward was full so they were admitted to a surgical ward.

We turned up and weren't wanted...I think we were a bit...sort of slightly alien there, aliens there because we didn't really belong to that ward and they were doing it as a special favour to the other ward...(Nell 1 p11&13)

Benner and Wrubel (1989) distinguish between care-giving by nurses and family members. "It is easy for the nurse to experience patient care as 'routine', whereas patients and families seldom experience being sick as 'routine' " (p. 391).

Des articulates clearly the point Benner and Wrubel (1989) make when she recognises that an investigative procedure is just that to the health professionals. To her as Mother, the ultrasound performed when he was three days old to confirm Mark's congenital urinary tract deformity has much broader implications than being just a procedure to confirm something she already knows from antenatal scans. It has the potential to dictate what happens next and to change her life as Mother.

This is another ultrasound of another baby but to me it wasn't... it was an ultrasound of my baby... (Des 1 p16)

The ultrasound of her newborn confirmed the anomaly identified in utero. Des took home a 'sick' baby. She was from that moment the mother of a 'sick' baby, not a healthy baby boy. Her life as Mother was changed.

Hospitalisation of a child may serve to distance the mother from the very person from whom she may expect most understanding and support, the child's father. The decision based on previous fieldwork (Gasquoine, 1992), to focus on mothers' experiences, is confirmed by comments from mothers in this study about the effect on their relationship with their partners of the hospitalisation of their child. Mothering and fathering of hospitalised children are different experiences. And they are sufficiently different to create another stressor. The literature reviewed in Chapter

Two suggests that this extra stress is characterised largely by lack of effective communication.

In our second interview Cyn described a conversation she had with her husband, precipitated by taking part in my study. Cyn realised that she had not talked with her husband about how they had felt about their daughter's impending surgery. To her alarm she discovered that he had been fearful that their child might die and yet he had never indicated that anxiety to her. Cyn felt that this was partly his inability to express such fearfulness and partly an attempt to be supportive of her. She thought he was worried that expressing doubts about the outcome might have shattered Cyn's confidence and therefore her ability to cope. And he needed Cyn to continue to cope on behalf of them all but particularly for their daughter. So at a time when expression of doubts and fears might be assumed to be helpful for both partners, those same doubts and fears inhibited communication of feelings about a dramatic and significant event in their lives as parents and marriage partners. The context of crisis is therefore emphasised by the tension which often results between the parents of the child in hospital.

An outcome of the crisis for the mothers participating in this study seems to be a feeling of frustrating helplessness. Deb and Cyn both verbalised this sentiment of impotence. *Oh! just not being able to do anything, you know, and seeing them [children] there suffering...(Deb 2 p1)*. Deb's feeling of helplessness was compounded by the fact that she was unable to stay with her child because her work environment was not supportive in this way.

Cyn said "*There's absolutely nothing you can do!*" (Cyn 1 p4). However having expressed this feeling Cyn then goes on to describe in great detail the many things she did do for her daughter. Among many other things this included care of Kasey's postoperative supra-pubic catheter. Yet Cyn still felt helpless.

The hospitalisation of a child takes place in a strange environment where mothers are challenged to re-establish balance with their children. This is made very difficult by the feelings of helplessness and responsibility mothers retain even though they have handed over to the professionals. The lived experience of mothering a hospitalised child takes place within a context of crisis. The phenomenological description which follows needs to be considered within this context.

PHENOMENOLOGICAL THEMES

The phenomenon of mothering a child hospitalised with acute illness or injury will be described by focussing on the phenomenological themes identified. "Themes have phenomenological power when they allow us to proceed with phenomenological descriptions" (van Manen, 1990, p. 90). Each theme will be described in detail below. The detail needs to be sufficiently descriptive in order that the 'phenomenological power' to which van Manen refers is realised.

Description of the themes is facilitated by the four existentials of the lived world. Some existentials are more strongly present than others in a particular theme. For example, the theme the **need to do** is more strongly

characterised by changes in mothers' lived body and lived relation to another than by lived space or lived time. The theme **handing over, leaving and waiting** however is more strongly characterised by temporality.

The themes used to describe the experience of mothering a hospitalised child are inextricably intertwined. So, while the themes are described and discussed separately, they are all very much intertwined and together make up the experience that these mothers lived. "We can temporarily study the existentials in their differentiated aspects, while realising that one existential always calls forth the other aspects" (van Manen, 1990, p. 105).

Mothering is a special kind of knowing

Mothering is knowing your child in a unique way. No one else can do that. Hospitalisation of a child suddenly means there are things that a mother does not and cannot know. A mother may therefore feel a sense of relief when her child is hospitalised. Lyn's assumption was that someone else would know what to do.

It was really nice to know that somebody else was in control and that there was something wrong with him, it wasn't just my imagination and that basically he was in good hands. (Lyn1 p14)

In most circumstances a mother who passed the care of her child to strangers would be considered irresponsible. In these circumstances Lyn

trusts those strangers because she has an expectation that they have knowledge and skills upon which her son's life may depend.

There is a physical-ness in the way a mother knows her child. Handling her child in a physical way is something she does all day and every day. Any change in the way she handles her because of changes to the child's physical body feels very awkward. For example if the child has an intravenous line in an arm or a leg the child feels much more awkward to her mother than might be expected by the addition of something quite small. There is no debate about the necessity of that piece of equipment but the changes that result to the way a mother handles her child leaves the mother feeling bereft because she is no longer able to do even the simplest things with her customary ease.

A strange situation is made to feel more strange to both mother and child. The child must also experience the awkwardness with which she is now handled by the very person on whom she has come to rely for expertise. An observer, perhaps a nurse, may well wonder at the awkwardness she observes in this mother, and the requests she gets for help with the simplest things which it would seem the mother could achieve quite easily on her own.

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* and to try and re-establish the balance between herself and her child.

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 maybe 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)

The hesitancy with which Lyn approached the skilled habitual action (Benner & Wrubel, 1989) of bathing a baby illustrates a significant change of her lived space and lived relation to another resulting in a change to her

lived body. Lyn's **special kind of knowing** as a mother is somehow diminished by her son's hospitalisation.

This is the same mother whose **special kind of knowing** as a mother, had persuaded her protesting husband that they needed to take their baby to the hospital emergency department in the middle of the night because...

He looked frightened, you know, and that was really awful, this little wee baby with this sort of look in his eyes. (Lyn 1 p1)

This mother, who acted so decisively and whose actions were subsequently justified by a diagnosis of pneumonia, is rendered helpless to the point where she feels unable to bath her baby without help, by the dramatic change in her lived world.

The physical-ness of the mother and child relationship is at the very essence of mothers' lived body and relation to her child. The surge of adrenalin a mother experiences when she hears her child scream is a physiological example of this physical-ness. It is not controllable and in most circumstances some action on behalf of the mother is appropriate. Usually she would be able to pick the child up and remove her from the cause of the screaming. Illness and hospitalisation may mean that this fundamental action is no longer appropriate or possible.

Lyn describes how torn she felt when she recognised her son needed comforting through a painful procedure but she needed to get away so that her own torment didn't cause him further distress.

They couldn't take any blood from him and they... I think that sort of distressed me as well because I had to... because I couldn't stay because he was screaming so much and they were all sort of trying different feet, different hands. I couldn't cope with it. No I couldn't. And I couldn't cope with listening to them saying "oh this one [venepuncture] hasn't worked" ...//.. But knowing that may be if I was holding him it could have made it worse for him because I would have been just too upset. (Lyn 1 p10-12)

Unable to 'rescue' her son from the source of his distress, Lyn felt she needed to leave the situation in order to cope. The alternative of staying and helping restrain him was not an option because she was sure her distress would only make his distress more acute. So her frustrated **need to do** and her decision to **leave** her child are inextricably a part of the **special kind of knowing** that is mothering.

There were a number of occasions on which Des felt that the professionals involved with her son's care were attending a child, any child but not necessarily her child. She needed to believe that those to whom she was to pass responsibility for her child would acknowledge him as an individual with a name, and more than just a genitourinary system which needed surgical restructuring.

*Because it was something internal they never actually ever looked at **him**, like (surgeon) never looked at **him** really... They actually didn't acknowledge him as a little person. (Des 1 p17)*

Spatiality and relationality constitute a large part of Des' **special kind of knowing**. When 'the system' relates to her child as an organism requiring surgical intervention, it relates to her as mother in an unfamiliar and uncomfortable way. She becomes mother of 'an organism requiring surgical intervention' rather than mother of Mark with whom she has a **special kind of knowing**.

A confidence shattering awkwardness arises when the child's behaviour is unfamiliar. Yve described finding her 13 year old daughter in the sick bay of the school, difficult to rouse, not seeming to recognise her, and unable to get to the toilet without significant assistance. When she got Tania to the closest emergency clinic, Tania started spitting in response to finger pricks and needed to be forcibly restrained by several people while having an intravenous cannula inserted.

A mother's child becomes hard to recognise as her own in such circumstances. Sometimes a mother may feel embarrassed, sometimes she may feel angered by behaviour which is not normal behaviour for her child. This is part of how uncomfortable it feels not to be able to recognise her child in this unacceptable behaviour. A mother also experiences anxiety as she wonders why her child is behaving like this. When she says to staff that this behaviour is out of the ordinary, it does not help to feel that they do not believe her. Despite her embarrassment, Yve tried to persuade the professionals concerned that her daughter's bizarre behaviour is quite out of character.

Especially because it affected her that way. Yeah I mean to do with the brain... its really worrying and because they met her the next

*day and they kept...even though I was embarrassed and kept saying "This isn't her, this isn't her!" I could see that they thought "Oh yeah, this **is** her" you know, "She **does** scream like this." Well that is what I thought and the next day, you know, the doctors said "Gosh, she is a different girl!" So to me it was like they weren't as concerned as I was you know when she was doing all these weird things. (Yve 1 p8)*

Yve's level of concern about Tania was increased because she felt unable to convince the professionals that there must be something badly wrong for her daughter to behave in that way. She acknowledges that they needed to consider drug experimentation and hysteria when confronted by an adolescent behaving in a bizarre fashion. However, in retrospect she wonders if a diagnosis might have been made more quickly if she had managed to be more persuasive. How persuasive does a mother need to be? Even if a viral meningitis is the least likely possibility, Yve did need to feel as if she was being listened to and taken seriously in such circumstances.

And that would be good if people would say to you well we trust what you are saying, you know we believe what you are saying, you know your daughter and we believe the things that you're saying to us about her, you know that this behaviour is very different to how she behaves normally and that there is something very wrong. But at no stage did they... did I get the feeling that what I was saying was being taken on board. (Yve 2 p8)

Jos describes her grief when it was suggested that she needed to consider weaning her son from her breast because of his eczema, weight loss and subsequent diagnosis of failure to thrive. The health professionals believed that if he was weaned he could be fed a high calorie, high carbohydrate diet to reverse the weight loss. Jos' grief at the suggestion that breast feeding was inadequate represented a very significant change to Jos' lived relation to her child.

It was such a really terrifically hard choice to take their advice and wean him or whether I was doing the best thing by breast feeding, because it is what everybody says, breast feed, breast feed, you know until you drop just about. And I really thought I was doing the best thing because he loved it and that is all he would drink and you know he wouldn't take a bottle and it was really hard. (Jos 1 p5)

A diagnosis of failure to thrive is much more to a mother than a name for her child's condition. A thriving child is synonymous with mothering care. To a mother a diagnosis of failure to thrive may suggest failure to mother. A mother's lived world is threatened in every way because somehow such a term suggests a lack of mothering care and action is the cause of the child's illness. Jos' **special kind of knowing** and her **need to do** are acted out by breastfeeding. The diagnosis of 'failure to thrive' and the suggestion that she wean her son are the antithesis of mothering as Jos experiences it.

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**.

The need to do

'Mothering' is a term that has multiple meanings. Of the many ways in which the word is used, it will most often imply actions of an enormous variety. These actions are both instinctive and learned and are as much about the needs of the mother as they are about the needs of the recipient of those actions. As a child grows and develops, the needs which are met by mothering actions change and so may the needs of the mother which are met by this activity. Mothering implies the meeting of physical and emotional needs in a particular way that is unique to a relationship.

Hospitalisation of a child threatens the need of the child for mothering. Bowlby and Robertson's early research in the 1950's and 60's, reviewed in Chapter Two, suggests that this need cannot be met by nurses and other health professionals however hard we try. The need of a mother to 'mother' is also threatened by hospitalisation and is central to the lived experience of mothering in this situation.

Part of the need of mothers whose children are in hospital is the **need to do**. Mothers **need to do** as many of the mothering things they usually do for their child as are possible given the constraints of the illness or injury and the specialised environment of the hospital. They also **need to do**

whatever is appropriate to contribute to their child's nursing and medical care.

What is appropriate seems to vary enormously from mother to mother. For example, Cyn learnt about caring for the suprapubic catheter Kasey had in place following surgery to correct a congenital urinary tract deformity. Cyn's reasoning was that it made the procedure less of a *drama* if she did whatever was necessary instead of a nurse doing it. When a nurse arrived to do something, Kasey's assumption was usually that it would hurt. If Cyn did whatever was necessary she suggests Kasey felt: *Oh well this is okay. Mum can do this, this is alright..!.. Mum is just Mum (Cyn 1 p36)*. Cyn believed a scary situation was rendered normal in her child's eyes because it was *just Mum*.

Yve, on the other hand, needed to feel that the medical and nursing staff were in control and would do whatever was necessary. She needed to be present rather than involved. She needed someone else to make the decisions and then inform her of what was to happen, when it was to happen and what her role would be.

I didn't want to be part of her care, like I placed... I wanted to be with her, you know later, but I placed all my faith in the people who were looking after her. And all I wanted to hear from them was what was wrong and how they were going to fix it. (Yve 2 p4)

The strange environment in which mothers of children in hospital find themselves may initiate a feeling of helplessness because of the very strangeness of that new environment. The ease with which they may do

the simplest of things for their child in a familiar environment has gone. It is replaced by an awkwardness which changes the mothers experience of her lived body and lived relation to another. For example touching or picking up a child to comfort her, something which mothers do dozens of times each day, may suddenly be very difficult in a hospital environment with a child in an incubator or with an intravenous line or urinary catheter. So while there is in fact a great deal a mother can and should do for and with her child, her experience of lived space is sufficiently changed to result in a feeling of helplessness.

The need of a mother **to do** something for her sick child is felt in a physical way. There is a **need to do** the physical things that are part of everyday mothering. To pick up a crying, distressed child. To feed a hungry child. The child's illness and hospitalisation make these things more difficult and sometimes impossible **to do**.

Sometimes the things a mother does which she considers right and beneficial for her child, instinctive almost, prove to be potentially harmful. One possible cause of Lyn's son's pneumonia was aspiration. She described her feelings when she discovered that there was a possibility that the most essential and primary of mothering actions, feeding, may have caused her son's pneumonia. They are similar to those that Jos described above (p.59) when encouraged to stop breastfeeding her son.

Dreadful, dreadful! Here I was thinking gosh these last few days when he has been, well obviously quite sick and I had been thinking that I need to keep his fluids up and feeding him and

feeding him and to think that I could be bringing all this on to him, you know, yeah it was awful. Yeah that was an awful feeling to think that I could have been contributing to the way he was, and here I was supposed to be giving him a good start in life.

(Lyn 1 p15-6)

Lyn felt responsible and somehow betrayed because the most logical of mothering actions was the possible cause of his illness. When health professionals ask mothers to stop doing something like breastfeeding a child, especially a sick and therefore vulnerable child who is comforted by breastfeeding, we are asking a great deal of mothers. We are asking them to change their habitual way of being with their child. Mothers therefore experience a significant change in their lived body and their lived relation with their child.

Changes in lived space and lived body are combined and increase in complexity, to result in a change to relationality. Frustration of a mothers **need to do** and a dramatic change in the environment in which **to do**, changes the relationality of mother and child. The relationship between the **need to do** and temporality is less obvious. To some extent **to do** is a way of coping with the significant change a mother experiences in time as it is lived when her child is hospitalised. Time passes very slowly. A great deal of time is spent waiting, as described below. Having something **to do** helps fill the time. Mothering action may help diminish the impact of changes in lived time.

Handing over, leaving and waiting

The experience of having a child hospitalised is uniquely stress-full. It is an experience full of stress and stress full of experience. The feelings that arise seem paradoxical. Mothers are usually acting on the advice of health professionals when they take their child to hospital. There is relief in the feeling that their child is in the right place and that skilled people will assume the responsibility of the child's care because the care a mother can give is no longer adequate. At the same time a mother feels enormous responsibility for a child in hospital. She is constantly asked to consent to procedures such as blood tests, administration of drugs and monitoring of vital signs. While in theory she has a choice about giving consent, the fact that she has **handed over** responsibility means that she feels that she would be being irresponsible if she did not act on the advice given. Mothers feel responsible for making those decisions which mean their child has surgery or is given a drug. The paradox therefore is that a mother has **handed over** responsibility because that is the responsible thing to do and yet remains doubly responsible because her child is vulnerable.

The stories of the two mothers whose children were hospitalised for planned surgery illustrate with absorbing clarity the implications for their lived world of **handing over, leaving and waiting** for a child to be returned. Initially I wondered if I was describing an experience specific to mothers whose children require surgery. Re-examination of the data from other participants suggest a similar experience while waiting for their child who is having an investigative procedure such as an x-ray or lumbar puncture.

Cyn described what it was like waiting for her daughter's surgery to finish. The loss of normal daily routine and the failure of attempts to fill the **waiting** time mean that Cyn became absorbed in *just waiting*.

(What is the time like?)

Oh, vague-ish, it is sort of, I don't know I suppose you mark it, you watch it. Its... in hospital you sort of get that sort of get that lulling feeling anyway you know you get that like reception rooms, and physiotherapists they have sort of got this lull type where it blends into one like, you know what I mean, it sort of... not like at home where you know it is morning and you know its lunchtime and then you sort know it is teatime and the day is getting later, you can feel the day progressing, you don't get that sort of in a hospital it tends to go into a bit of a lull because it is all indoors and it's, I don't know, it's....

(So you lose your sense of time?)

Well you know you don't lose your sense of time because you are watching it, but it's.... you just wait. I didn't read a book, I took a book and I actually did some reading when I was in there but not during the operation. I think you just wait, you just wait. But you just wait, like I say you are just waiting. So I wasn't so much worried, I mean it is, you know, I think you go through all that before, well I did. I, as I say, you know, how will she take the anaesthetic, how will she do the... I think I had sort of already gone through that so now it was.... it was as I say once she had

gone that was it. Isn't... you know, now it is up to them sort of thing and I just sort of waited really. I didn't really think about it too much, only the time - oh she has been down there so long, so many hours had gone past but I didn't consciously think oh I wonder what they are doing now, what stage they are doing, and is she...you know what I mean, sort of I just waited really. I didn't think about anything much except the time. Went for a walk, went and got a cup of coffee, I did... you know I wasn't as I say too bad or anything like that. I wasn't sort of chewing nails or anything but yeah. (Cyn 1 p22-3)

This mother's description of time as it is lived while she waits for her daughter to return from planned surgery emphasises the **waiting** for time to pass. Her repetition of the words 'wait', 'waited' and 'waiting' highlight the experience of time in this situation. There seemed to be an acceptance of the wait and no expectation that anything might speed the time of **waiting**.

The wait is still stress-full. A wait full of stress; stress full of waiting. The wait is all embracing. Nothing can distract a **waiting** mother from the **waiting**. There has to be a wait while the people to whom she has **handed over** her child do whatever it is that is necessary. And it remains a wait while she, the mother, does not have access or jurisdiction as mother. The temporality of **waiting** is therefore closely associated with handing over and leaving your child.

This **waiting** time also takes place in an unfamiliar space. The mother's experience of lived space was changed by the **waiting**. She went for a

walk and had a cup of coffee but that did not seem to make an appreciable difference. She identified that time at home and time in hospital passes differently but leaving the immediate proximity of the hospital to wait at home would have been very difficult to do especially at such a critical time.

Handing over and **leaving** a child also disrupt the existentials of corporeality and relationality. In a strange environment in stress-full circumstances, waiting with a child is a physical activity that is part of the lived body as it is experienced in these circumstances. Waiting with a child is done as near as possible to the child and involves holding, cuddling, talking and activity designed to fill the time for the child and perhaps with preparation for the forthcoming event.

Part of the difficulty a mother experiences in **waiting** for a child to be returned is that the child is not there. She cannot wait with the child. The child-less wait is what makes the **waiting** stress-full. Mothering has somehow been suspended while she does not have a child to mother.

When asked to differentiate between handing over and leaving her child Cyn indicates the active and passive roles of the mother. **Handing over** is a passive decision; **leaving** is an active decision. *When you leave you're leaving, when you are waiting they have already been taken from you. (Cyn 2 p24)* Cyn goes on to clarify the issue of responsibility when she made the decision to hand over her daughter. *The responsibility of you giving them that responsibility is yours. (Cyn 2 p25)*

So the responsibility was handed over, yet it was retained. This responsibility, felt so deeply and retained no matter what, has tremendous significance for the lived relationship between mother and child. A mother remains responsible for everything that happens to her child. It is an all encompassing responsibility which has much broader boundaries than responsibility in a formal or legal sense. It is the foundation on which the lived relation between mother and child grows. When a child is hospitalised this foundation can become shaky.

Handing over, leaving and waiting are unavoidable parts of the experience of mothering a hospitalised child. 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.

Constant vigilance

After extensive reflection on and writing about the three themes described above, there remained an aspect of this mothering experience which 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.

'What's next?' was felt more urgently by mothers for whom the cause and treatment of their child's illness was not clear and decisive. Yve's daughter's diagnosis of viral encephalitis was arrived at by a process of elimination which had covered such possibilities as hypoglycaemia and experimentation with an illicit drug. During this process Yve knew that neither of these scenarios was likely but accepted that the investigation of these possibilities was part of the process.

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**.

When mothering a child in hospital there was always a sense of 'What's next?' It was mothers' **special kind of knowing**, the intimacy with which they know, that means they were constantly vigilant. They may not have been able to articulate what had changed or how it had changed, but they did know it had.

On two specific occasions Lyn knew that her son needed help. In the middle of the night she felt alarmed by *the look in his eye* and persuaded her husband that they needed to get medical attention for him immediately

and not wait for morning. While in hospital Robin's condition deteriorated, a change that the malfunctioning technology did not detect. In both situations Lyn persisted in her requests for action until she got it. Her **constant vigilance** paid off. Her **special kind of knowing** enabled her vigilance.

A mother's **need to do** is also enabling of **constant vigilance**. It is the act of doing with or doing for which results in the embodiment of vigilance. Doing is very much a part of everyday mother and child relationships. In fact it is the vigilance that comes from doing that usually means the mother seeks expert assistance for her child and hospitalisation is the consequence. Hospitalisation does not remove the **need to do** or the **constant vigilance**.

The **constant vigilance** of mothers was significantly challenged by **handing over, leaving and waiting**. This was part of what made **handing over, leaving and waiting** so difficult. This difficulty was to do with access in a physical sense, of mother to child. It was also associated with **handing over** responsibility for decision making and care. When the proximity of mother and child was interrupted and some of the responsibility was delegated, a mother's ability to be constantly vigilant was dis-abled. This disabling of vigilance may be what precipitated the feeling of helplessness discussed above.

It is the connection of biology, time and experience that enables a mother to be constantly vigilant. While nursing and mothering have much in common, nurses do not have the connection with a child that enables this vigilance. The **constant vigilance** of mothers enabled by their **special**

kind of knowing, is the critical difference between mothering care and nursing care.

The context of crisis constituted by the hospitalisation of a child heightens a mother's ability to be constantly vigilant. Her fear and anxiety whet her watchfulness. Fear full of watching; watching full of fear. The watchfulness of a mother with an acutely ill or injured child is a way of watching that is fearful but it is also a watch full of hope and expectation. Fearful and hopeful watching are part of the **constant vigilance** of a mother.

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.

SUMMARY

A **special kind of knowing, the need to do and handing over, leaving and waiting** are the phenomenological themes upon which the overarching theme of **constant vigilance** is founded. These themes describe the essence of mothering a child in hospital, in a context of crisis.

The implications for nursing practice of this phenomenological description of the lived experience of mothering a hospitalised child, along with an evaluation of my study will be discussed in the following chapter.

CHAPTER FIVE

DISCUSSION

As I speak with colleagues about what has emerged from this study they invariably ask me what it is that needs to change so that mothers of children in hospital have their needs met. Very early in this process it became clear that it is the 'little things' that nurses do which make an enormous difference to a mother's experience of the hospitalisation of her child. Major system change is not necessary.

Having identified that the things that nurses need to do for mothers are 'little things', the number of things that nurses can do and the significance of what they do is enormous. It is these things which means a mother feels cared for and cared about. It is these things which makes the difference between nursing care that is thought-full and nursing action that is not grounded in thoughtfulness.

This chapter will identify and discuss the implications of the findings of this research for nurses in clinical practice and education. My hope is that having read this thesis practitioners will reflect on and value the importance of the numerous 'little things' they do with and for mothers of hospitalised children. Educators need to help students of nursing do similarly. Our students need to know that the 'little things' count. Reference to relevant nursing literature will facilitate this discussion. Strengths and limitations of this piece of research also need to be

documented and discussed, as do the areas in which further research is needed.

Nurses are trusted strangers

A mother brings her child to hospital because she recognises that mothering care is no longer enough. She brings her child to hospital for the knowledge and skills that nurses and other health professionals have. A consequence of this is that the mother is put in a situation where she has to trust strangers with this most precious being, her child. Nurses are trusted strangers.

Nurses need to recognise the trust that is placed in them and reciprocate. A mother doesn't have a choice about trusting. But too often nurses are not sufficiently trusting of the **special kind of knowing** that a mother has about her child. This knowing is accentuated by the concern and anxiety associated with the child's illness or injury. A mother knows things about her child that no one else can know. Nurses need to trust this knowing for the information it gives them and for the safeguard it provides. Nurses can be sure that if a mother feels something is wrong she will say so. They can also be sure that if a mother feels something is wrong she is usually right and it is worth acting on. And mothers have to trust that in such circumstances nurses will act appropriately.

Cunningham-Burley (1990) identified what she described as watchfulness in her study of mothers beliefs about and perceptions of their children's illnesses. "The mothers were aware of subtle changes in their children"

(p.93). This watchfulness is part of the **special kind of knowing** of mothering and means that a mother can see things that no one else can. Behavioural change is also identified by Cunningham-Burley as being something that mothers can recognise and that they may rely on more than nurses can as an indicator of illness. Nurses have to rely on physical signs and symptoms. They can therefore utilise the watchfulness of mothers to benefit all three parties in this relationship: the child, her mother and the nurse with the responsibility for the care of the child.

It is in situations in which nurses don't act appropriately in response to a mother's concerns that they diminish the trust that a mother has in all nurses. A mother arrives at hospital with her child having trust in all nurses. This is not a choice but a sociologically dictated situation. People are expected to and do trust nurses to act appropriately. This is part of the relationship nurses and nursing have developed with society through history.

This initial trust is developed and maintained by the way in which nurses act towards a mother and her child. Enduring trust is not only based on how a particular nurse acts towards a mother and her child. It is also influenced by how a mother sees and hears that same nurse act towards other children and their families.

Trust, in these circumstances, does not require the demonstration of a high level of technical competence on behalf of nurses in order for it to be maintained. Price (1993) says that the parents in her study "assumed trust in nurses technical abilities" (p.39). Rather, trust is maintained by the 'little things' that nurses do with and for a mother and her child. If a nurse

says she will come back and assist a mother with bathing her baby then she must return in order to maintain trust.

Mothers in my study and in that described by Price (1993), were very accepting of the busy-ness of nurses. The mothers excused nurses inaction on a number of occasions because of busy-ness. They expect that nurses are busy. So, while the bathing of a baby may take more time than a nurse has, returning at brief intervals to a mother who is actually doing the bathing, to offer support and encouragement, is a way of maintaining trust.

Responsibility

Responsibility is experienced as a paradox by a mother of a child in hospital. One of the positive aspects of hospitalisation for a mother is that she can hand over the care of her sick child to the experts. She recognises that her resources as mother are no longer enough. The opportunity to access expertness offers some relief. However, having handed over the responsibility of her child because she requires care a mother cannot give, a mother remains responsible for having handed over.

The feelings of responsibility that a mother has are closely associated with the issue of nurses as trusted strangers. Handing over is easier to do if a mother trusts that nurses will act in her place. The difficulty of leaving a child can be eased by nurses who have established trust with a mother and her child.

Partnership between parents and health professionals, which is the next issue for discussion, is advocated in the literature and suggests that such a relationship offers optimal care to a child in hospital. Nurses need to remember that no matter how effective such a partnership may be, the feeling of responsibility that a mother experiences is not diminished. This particular responsibility cannot be lightened by partnership.

Partnership

Terms like 'partnership' are used a great deal in the nursing literature to describe the desirable relationship between nurses and parents (Berman, 1991; Coyne, 1995a, 1995b; Darbyshire, 1993; Gibson, 1995; Kruger, 1992; Lasby et al, 1994; Neill, 1996b; Palmer, 1993; Stower, 1992; Way, 1993; Whyte, 1992). In fact Coyne (1995b) points out that the concept of partnership with parents is enshrined in law in the United Kingdom by the Children Act (1989). These researchers suggest nurses and other health professionals should negotiate roles with parents of children in hospital so that everyone is aware of what it is a parent will do for her child and what it is nurses will do.

Such suggestions are admirable. But nurses need to remember that when meeting a mother whose child has just been admitted to hospital, they are meeting a very stressed individual whose ability to negotiate anything is questionable. As Des said, she expected and needed to be "directed". At this point in time she would have been unable to enter into meaningful negotiation because all her energy was directed towards coping with the crisis of having a child in hospital.

Nurses may experience significant discomfort with this expectation of partnership for several reasons. They may have a clear definition for themselves of what constitutes nursing care and what constitutes mothering care. Negotiating care may require re-defining the role with which a nurse feels comfortable and confident. Nurses may not have the communication skills necessary to negotiate an effective mother/nurse relationship. Nurse educators urgently need to attend to the lack of effective interpersonal communication skills of nurses that the literature suggests (Brown & Ritchie, 1989; Callery & Smith, 1991; Darbyshire 1994; Neill 1996b).

True partnership is only possible when the partners in the relationship are equal. A situation in which one potential partner perceives the hospital as the "domain" of the health professionals as Lyn did, it is going to be extraordinarily difficult to negotiate an effective partnership.

The nature of the situation and the environment invests a great deal of power in nurses. It is easy for nurses to underestimate the extent of the power they have in their relationships with patients. Benner (1984) clearly articulates the nature of this power relationship and how it should be used to empower patients and their families. She also warns of the devastation that misuse, which includes unintentional misuse, of this power can cause. "Nursing without caring is powerful and devastating" (p.216). Some of the distress in the stories of the mothers who participated in this study resulted from situations in which nurses misused and misunderstood the negative impact of nursing without caring, nursing without thought.

There are also stories which clearly describe nurses using their power to empower mothers. What amounted to relatively straightforward and uncomplicated actions on behalf of nurses made an enormous difference to how the mothers of these children coped and were enabled to help their children cope. Nurses listened, they used the child's name, they walked with the mother to show her the way, they supported the child experiencing pain when 'shushed' by the doctor performing the procedure, they explained in understandable terms what was happening to the child and why.

Much of the literature accessed identifies the need of parents for information regarding their child's condition and care and their role as parents (Coyne, 1995a, 1995b; Gibson, 1995; Hatton et al 1995; Melnyk, 1994; Neill, 1996b; Palmer, 1993; Way, 1993). The three themes identified from the phenomenological data collected in my study and described in Chapter Four, do not specifically include a need of mothers for information.

Why isn't this need more clearly evident in their descriptions of their experiences? One possibility is that this particular group of mothers had had this need well met during the hospitalisation experience. Another possibility, is that like technical competence (Price, 1993), it is assumed and only obvious in its absence. So, mothers assumed they would be informed and have their questions answered.

Another responsibility of nurses in their relationship with mothers is to help them preserve their ability to cope. The coping of mothers in this study and the enduring that Morse and Carter (1995) describe, have

similarities. "Situations that must be endured are usually situations that the person is forced to undergo; the individual has no alternative but to endure" (p.39). Mothers need to live through and endure the hospitalisation of their children. There is no alternative but to continue to cope.

The therapeutic nature of talking about a crisis such as the hospitalisation of a child is identified in Chapter Three. However, care needs to be taken that an individual's way of coping is not compromised by well-meaning but inappropriate intervention. It needs to be remembered that the therapy is in the reflection on an historical happening. For a nurse to precipitate expression of feeling in the midst of a crisis may not be therapeutic at all, especially if a mother's way of coping is withdrawal or remaining calm or keeping a smile on her face.

Chapter One identifies and Chapter Four discusses the observation that the mother and father of a hospitalised child may not be able to support each other in this crisis they share, because they experience the crisis differently. The literature supports this observation (Copeland, 1993; Copeland & Clements, 1993; Hatton et al, 1995 & Whyte, 1992). Nurses therefore need to be cognisant with this so that they can offer appropriate support to both parents. For some mothers simply observing that such a crisis is experienced differently by mothers and fathers will be enough. Sometimes the role of the nurse will be to offer significant support to the child's father so that he can support the mother. At other times the role of the nurse will be to access appropriate support for the child's father so that his distress does not undermine the ability of the mother to continue to

cope. Determining which of these courses of action is appropriate will involve careful nursing observation and intuition.

Mothering care and nursing care

Mothers believe that there is a difference between nursing care and mothering care. They consider that they have taken their child for expert care when their child is admitted to hospital. Mothers expect that their child will benefit from knowledge and skills that they do not have.

While in hospital with acute illness or injury, a child needs both mothering care and nursing care. Benner and Wrubel (1989) discuss the nature of care and suggest that "Caring ... is a word for being connected and having things matter ... it fuses thought, feeling and action" (p.1). This definition can be applied to both mothering care and nursing care.

Lasby et al (1994) suggest that: "Caring is the primary source and driving force for both maternal and nursing care" (p.148). However for the purposes of this thesis it is worth identifying the similarities and the differences between the two. Nursing as women's work and therefore akin to mothering has been explored in the nursing literature many times and is blamed for many things including the low status of nursing as a profession and the continuing battle to have nurses given professional status (Benner & Wrubel, 1989; Johnstone, 1989, 1994)

What are the differences between nursing care and mothering care? The most obvious is that there is a biological connection in most cases between

mother and child but not nurse and child. However adoptive mothers would say that they give mothering care to their adopted children. Does this suggest that mothering care can be and is learned? The literature about bonding between baby and mother and development of infant attachment may be useful. There is often an historical difference between the relationships. The mother and child have a history of time, experience and connection. Usually a nurse meets a child for the first time on her admission to hospital.

Nursing knowledge also makes a difference to nursing care. Part of nursing knowledge is the experience of similar situations in the past. A nurse has a clear idea of the outcome of the surgery or how long it might take for a child's condition to improve after antibiotics have been started. Mothers often don't know these things. However they know different things. They know when their child's behaviour is out of the ordinary. They know what that particular cry of the baby's means: hunger, fear, or pain. Mothers know how much and when a child will eat. They know the physical and emotional needs of their child.

Although not articulated specifically, mothers express needs of their own which indicate that they are in need of nursing care for themselves - nursing care that is different from but closely related to their child's care. Among other things they need information, reassurance, and assistance to meet the needs they know their child has and to meet their own needs.

Mothers need nursing care too

This study highlights the fact that mothers need nursing care too. When it is identified that mothers need support, to be able to trust those to whom they have entrusted the care of their child, that they have an expectation of technical competence and that it is the 'little things' which constitute thought-full nursing care, what is actually being said is that mothers need nursing too. "It is the meeting of these biopsychosocial needs that is described as quality nursing care" (Price, 1993, p.37).

Darbyshire (1993) suggests that the literature provides an "instrumental and technological" understanding of parents and highlights their "functional value". "From this perspective, parents too readily became problems to be managed or resources to be more effectively used by ward staff" (p.1678). It is common practice in the clinical setting when assessing nursing workload, to take into account how many boarder parents are being accommodated with their children. This is a logical practice as the presence of a parent with a child can increase or decrease the type and level of nursing input the child requires. The danger is that we make assumptions about which of the child's needs a parent can meet. It may be that the presence of an intravenous line or a dressing on a surgical wound puts a normally simple parental function of washing or dressing a child beyond what the parent feels she is able to do safely. We assume that parents are willing and able to continue to take responsibility for their children in a strange and often frightening environment. And too often we forget that the circumstances that have hospitalised their child mean that the parents are in need of nursing care themselves.

In this study Lyn expressed the belief that she had to stay with her son to care for him.

That is why I am there isn't it? To change his nappies and to do all that because they would need more staff if the mothers couldn't be there. (Lyn 1 p18)

Lyn believed she was in hospital with her son for her "functional value". For forty years the literature has been documenting the psychosocial benefits to children and their parents of maintaining close contact between a hospitalised child and particularly her mother (Coyne, 1995; Darbyshire, 1993; Neill, 1996a, 1996b; Palmer, 1993; Rennick, 1995; While, 1992; Young, 1992). And yet mothers in this study experienced hospitalisation with their child as filling a resourcing gap and for the convenience of staff. The presence of mothers is imperative if we are to meet the needs of sick children in hospital.

My study also supports and re-emphasises the value of the family-centered care philosophy which is widely advocated in the literature (Berman, 1991; Burns, 1994; Palmer, 1993; Rennick, 1995; Stower, 1992; Way, 1993; Whyte, 1992). The implications for nurses in clinical practice and education of this well articulated philosophy is that it is the whole family who need nursing care. The whole family requires assistance from nurses to meet their biopsychosocial needs. The lived experience of mothers described in this study gives insight into and understanding of the specific needs of mothers with children in hospital.

Thought-full nursing and nursing without thought.

As identified above and by other nurse writers (Bottorff, 1995), it is the 'little things' that really matter for a mother with a child in hospital. It is these 'little things' which nurses do to help a mother endure the waiting. They facilitate a mother leaving her child when that is appropriate, nurture her need to do in an environment in which she feels helpless and which challenges her ability to do. These 'little things' are what make the difference between thought-full nursing and nursing without thought. And it is these little things that mean a mother feels cared for and cared about.

The most obvious antonym for thought-full nursing is thought-less nursing. The term thought-less has come to have connotations of carelessness and neglect. None of the stories collected during this research suggested that mothers experienced neglect. But what their stories do contain are situations in which a nurse could have made a big difference to a mother and her child by being more thought-full. And it is the 'little things' which mean a mother experiences thought-full nursing.

Mothers have no expectation that nurses will be able to take away the enduring associated with waiting. Waiting for the child to come back from surgery, waiting for the test results, waiting for the diagnosis. Nurses can acknowledge the enduring just by spending time being with a waiting mother. And 'being with' a waiting mother does not mean sitting with her the whole time. It may mean popping backwards and forwards as other nursing responsibilities permit. It may mean asking the mother if she can contact someone to wait with her. It may mean asking a student nurse to make her a drink or show her where she can get one.

The ease with which a mother leaves a child is closely associated with her level of trust in those with whom she is leaving the child. Yve heard a nurse comfort and advocate for her distressed daughter who had been 'shushed' by the person performing her lumbar puncture. The nurse's actions maintained the trust Yve had to put in the nurse to be with her child in her absence and validated Yve's need not to be present during this procedure.

Nurturing a mother's need and ability to do with and for her child also involves nursing thoughtfulness. Nurses need to take account of each situation. Some mothers will comfortably assume responsibilities that would normally be considered to require nursing knowledge and skill. Other mothers will need encouragement and support just to remain with the child or even to leave the child if that is what they need to do.

Nurses may demonstrate a high level of technical competence but may still have the care they give experienced as lacking thoughtfulness. Again Price's (1993) study confirms this finding. "Nursing actions directed at meeting the technically related needs of the child were not viewed as being part of the description of quality. They were perceived as a given from which quality could then be developed and delivered" (p.40). Mothers in my study assumed nurses technical ability. It was nurses who did the 'little things' that meant they were perceived by mothers as giving quality nursing care.

The vulnerability in caring

Benner and Wrubel talk of the "risks and vulnerability inherent in caring" (1989, p.2). The risks and vulnerability in mothering care are perhaps more obvious than the risks and vulnerability in nursing care. A mother has much more to lose. The risk about which a mother of a child needing hospitalisation feels most vulnerable, is the greatest risk of all. Her child might die. She might lose this very precious irreplaceable being. The actual likelihood of that occurring might be very remote. That does not prevent it entering the consciousness of mothers.

Nurses have a much more clinical sense of how likely it is that a particular child will die, based on knowledge and nursing experience. The first time I visited Sarah in hospital I happened to see a nurse I knew from working with students. When I said who I had come to see and explained my relationship, a look came onto her face which in retrospect I recognise was a mixture of sympathy and vulnerability that she should know in a professional sense someone who was about to experience tragedy. She knew that Sarah was going to die. At the time I chose not to recognise that look on her face. I just thought to myself "What is she looking at me like that for?" So in caring for and caring about Sarah, knowing she was going to die, and in knowing me, that nurse was vulnerable.

SUMMARY

Thought-full nursing involves doing 'little things' for mothers of children in hospital. Such nursing develops trust between nurses and mothers and their children. Mothers experience thought-full nursing as taking account of their needs as mothers in crisis and not being considered as just pairs of hands. Thought-full nursing acknowledges the responsibility that mothers feel while recognising opportunities to both include them in decision making and give them a break. It recognises mothers' vulnerability and maximises their ability to cope emotionally. Thought-full nursing of children and their mothers acknowledges and takes account of the special knowing of mothers. It empowers a mother's need to do enables handing over and leaving, and eases her waiting.

STUDY EVALUATION

The usefulness of any piece of research depends on the potential research 'consumers' certainty that the findings and implications for practice as stated are credible. In this case potential 'consumers' are nurses. Nurses reading this study need to take into account the boundaries of my work in order that they may be realistic about the practicalities of utilisation in their practice of the issues discussed above. This section discusses the boundaries that pertain to my study.

The nursing literature which discusses the critique of qualitative research studies emphasises the importance of using criteria for critique which have been designed for qualitative studies and not adaptations of criteria for

assessing quantitative studies (Burns & Grove, 1995; Leininger, 1994). "Qualitative researchers should not rely on the use of quantitative criteria such as validity and reliability to explain or justify their findings. Such dependence reflects a lack of knowledge of the different purposes, goals, and philosophical assumptions of the two paradigms" (Leininger, 1994, p.96).

Leininger advocates six criteria with which to appropriately evaluate all research methods used within the qualitative paradigm. These include: credibility; confirmability; meaning-in-context; recurrent patterning; saturation and transferability (Leininger, 1994, p.104-107). The criteria particularly pertinent to phenomenological studies are those of credibility, meaning-in-context and saturation, and are therefore worth explicating further in an attempt to identify the limitations of this study.

The credibility of a study is the "believability of the findings that have been established by the researcher ... and ... refers to the truth as known, experienced or deeply felt by the people being studied" (Leininger, 1994, p.105). A credible phenomenological description should seem plausible and a reader be able to identify with what is being described.

Meaning-in-context refers to data which becomes understandable because they have been considered within the context of the lived experience that has been described by participants. The interpretations and understandings of the data have meaning for the participants if this criterion has been met. There is no meaning without context. So, a phenomenological description should be explicit about the context within which participants have lived their experiences.

Saturation, and the extent to which this is achieved, is a feature of the relationship between the researcher and the study participants and their stories. Terms such as 'full immersion' and 'thick description' describe how saturation is accomplished. When no new information is forthcoming the researcher is considered to have met this criterion.

The three criteria discussed above have been achieved in this study. On several occasions I have had opportunities to share the themes emerging from this study with colleagues and students. The readiness with which they identified with the beginning descriptions, suggests this study has credibility. The context within which this study took place is clearly outlined in Chapters One and Four. Meaning-in-context is achieved by explicating the context within which the experience of mothering a hospitalised child is lived. The critical contribution of the 'conversational relation' to phenomenological studies in general and to this study in particular is discussed in Chapter Three (p. 44-46). Saturation can be considered to be achieved through an effective 'conversational relation'.

Limits of this study

All empirical investigations are bounded by limitations resulting from such factors as the study method and design utilised, the sociopolitical and physical context within which a study takes place, and the humanness and consequent variability of participants and researchers. There is no such thing as a perfect piece of research.

My study is bounded by the factors which 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 my study was small and the findings cannot necessarily be generalised 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 I sought the participation of mothers during the hospitalisation of their children.

Another potential limitation of this study was the possibility of analysis and interpretation processes being directed by my presuppositions and assumptions. Personal circumstances have meant that I have been aware of this issue from the early planning stages of my study. The strategies used to acknowledge and accommodate this influence have been discussed in detail in Chapters One and Three. Reflection and discussion have enabled me to identify my experiences as strengthening my study rather than limiting its usefulness.

Strengths of this study

The aim of phenomenological research is to produce powerful and therefore effective description of lived experience. The effectiveness of such a description is judged by the readiness with which a reader identifies with what is being said. This study will be effective if, when nurses read it, they reflect on their practice with children and their families and think about how they as individual nurses might change the way they approach the mother of a child admitted to hospital. It is a strength of this study that it is aimed at making a difference to the practice of individual nurses. No major organisational or structural change or expense is required to implement findings. The results of this research are immediately identifiable and available to individual practitioners to use in a way which is personally relevant. This being the case, the criterion of credibility identified by Leininger (1994) and described above is well met.

In a society which remains significantly influenced by the positivist paradigm which places such trust in empirico-analytic processes, it was difficult at first not to see my experiences as a mother of a child in hospital as anything but a potential for bias and a major threat to the validity and reliability of my study. However, this research fits within the interpretive paradigm and, as identified in Chapter Three, the particular method used recognises personal experience as a stimulus for phenomenological research. Hermeneutics, as van Manen (1990) describes it, facilitates the use of personal experience as data of relevance in this enquiry process. My personal experiences need to be reinterpreted as a strength of this study rather than a source of bias and invalidity as they certainly would be if a different research process had been used.

The particular strength that personal experience gives this study is an ability to identify the deeper meanings of the experiences described. Description of my experience either in conversation or by writing, sets it down and makes it available for examination alongside, but not as part of the data collected from study participants. In this way my personal experiences have added to the meaning-in-context of this study. The deeper meanings of the data are apparent to me. The clarity of those meanings are in large part due to the context within which this study has taken place.

Areas for further research

When discussing this study with participants and colleagues one of the most frequently asked questions I have faced was why fathers were not included as participants. Their exclusion from this study has been justified in Chapters One and Four. The need for research exploring the experience of fathers whose children are hospitalised is also clear. The participant mothers in this study emphasised that need. Such research has the potential to add to the knowledge of nurses and to improve the experience of families with children in hospital.

Another issue in need of nursing research that this study has identified is the quite specific needs that nurses and other health professionals have when their children are hospitalised. Having professional knowledge and skills does nothing to decrease anxiety. If anything parents who are health professionals are probably more anxious. Their knowledge and skills mean that they are aware of potential complications and they may judge

how professional colleagues perform (Nicholson Burr, 1995). It is very difficult to trust in the way that other parents describe.

There is also little in the way of research which examines the nursing perspective on nursing the parents of sick children. In some situations more nursing time and energy is spent with the parents of the sick child than the child herself. The importance of this nursing role needs to be validated and supported by appropriately conducted research. There is much expertise in nursing practice that has yet to be explicated and shared so that it may improve families experiences of having a child hospitalised.

Nursing research which examines the perspective of children in this situation is also needed. The special challenges that collecting data for research purposes from children present would need careful consideration and attention. Their potential contribution to nursing knowledge in this area is enormous.

CONCLUDING STATEMENT

This study arose from professional concerns I had about the experience of mothers of children who required hospitalisation. It has been conducted within a context of personal experiences closely related to those under study. The resulting phenomenological description of mothering a hospitalised child contributes to the growing body of literature which examines nursing knowledge and skill about the care of sick children and their families.

The ongoing challenge is to have the understandings contributed by this study and others translated into action by educators and practitioners. Action that means that mothers experience nursing care as taking account of their **special kind of knowing** as mothers; as empowering of their **need to do** and enabling of **handing over and leaving** and easing their **waiting**. The **constant vigilance** of mothers needs to be acknowledged by nurses in order that care of hospitalised children is optimised.

Appendix I**THE LIVED EXPERIENCE OF MOTHERING A CHILD HOSPITALISED WITH AN
ACUTE ILLNESS OR INJURY****CONSENT FORM**

I have read the Information Sheet for this study and have had the details of the study explained to me. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I also understand that I am free to withdraw from the study at any time, or to decline to answer any particular questions in the study. I agree to provide information to the researchers on the understanding that it is completely confidential.

I agree to participate in this study under the conditions set out on the Information Sheet, of which I have a copy.

Signed:

Name:

Date:

Appendix II

THE LIVED EXPERIENCE OF MOTHERING A CHILD HOSPITALISED WITH AN ACUTE ILLNESS OR INJURY

INFORMATION SHEET

My name is SUE GASQUOINE. I am a graduate student of the Department of Nursing Studies at Massey University. I am currently enrolled in my Masters thesis.

Information gathered during this study is for this purpose only. I am a Registered Comprehensive Nurse and have spent much of my professional life working with sick children and their families or teaching student nurses about nursing care of sick children and their families.

This study has grown out of my interest in sick children and their families. Nursing literature contains little information about what parents experience when their child is hospitalised with an acute illness or injury. I am interested to find out what mothers remember about having a sick child in hospital. Remembering your experience and how you felt at the time may be stressful for you. You may also find that talking about it is helpful.

You will be asked to consent to being interviewed two or three times. Interviews will be audio taped. The first interview will take approximately 1 hour and subsequent interviews approximately 30 minutes. Information collected during the first interview will be analysed before subsequent interviews and you may be asked to comment on that initial analysis during a subsequent interview.

If you take part in the study you have the right to:

- * refuse to answer any particular question, and to withdraw from the study at any time,
- *ask any further questions about the study that occur to you during your participation,
- * provide information on the understanding that it is completely confidential to the researcher. All information transcribed from the tapes will only include codes for any

names of people or institutions, and it will not be possible to identify you in any reports prepared from the study,

*be given access to a summary of the findings from the study when it is concluded.

Sue can be contacted:

at work - Faculty of Health **or** Staff Development

Carrington Polytechnic

Private Bag

Mt Albert

Auckland 3 Ph: 8494180

at home - 19 Mons Ave.

Mt.Roskill

Auckland 4 Ph: 6205578

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