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The parents' experience of living in the hospital with their sick infant : a phenomenological study

Anne Bourke
Edith Cowan University

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**THE PARENTS' EXPERIENCE
OF "LIVING IN" THE HOSPITAL WITH THEIR SICK INFANT:
A PHENOMENOLOGICAL STUDY**

BY

Anne Bourke (B. Nsg)

**A Thesis Submitted in Partial Fulfilment of the Requirements
for the Award of**

Master of Nursing

at the School of Nursing, Edith Cowan University

Date of submission: 3 October 1997

USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

Abstract

The purpose of this phenomenological study was to describe the essential structure of the lived experience of what it was to be a resident parent on the ward in a public hospital with a sick infant. Many studies have highlighted both benefits and problems associated with the concept of parental participation in care. The role of the parents in hospital needs to be identified and expressed by both the parents and the nurses, in order to elucidate the needs of parents who live in with their sick infant.

Eight parents were interviewed regarding their experiences of "living in" the hospital with their sick infant and the information analysed. Data were generated from audio-taped, open-ended interviews and the researcher's observational field notes. All data were analysed using the method described by Colaizzi (1978), which was to describe, interpret, and extrapolate common themes and meanings from that data. The data included significant statements which were clustered into themes. Validity and reliability were confirmed throughout data collection and analysis.

Four key themes emerged from the data: Internal Reactions, The Issue of Communication, Role Boundaries, and Learning to Deal with Hospitalisation.

The Roy Adaptation Model (1984) was used to provide a second level of analysis.

The Model demonstrated some applicability to the experiences of the participants in the study and showed commonalities with other human responses.

Declaration

"I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text."

Acknowledgements

I would like to thank Miriam Langridge and Yvonne Hauck in the challenging role as my supervisors.

I would also like to thank those mothers who participated in the interviews. They took a risk to disclose their experiences and I greatly appreciate their participation. I felt privileged to have been part of their lives.

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CHAPTER ONE

Introduction

This phenomenological study investigated the experience of parents who resided in the ward with their sick infant from the perspective of the parents. Hospital policy that encourages parents to “live in” the ward with a sick infant or child has only been introduced into hospital life in the past 30 or so years.

Background

Over the past several decades, paediatric care practices around the world have changed in an effort to better support and promote the emotional needs of children (Ahmann, 1994; Way, 1993). These changes have largely evolved from increased health consumer demands (Schepp, 1992), research, and governmental policy (Stower, 1992). A significant United Kingdom study on the welfare of children in hospital, the Platt Report (Ministry of Health and Central Health Services Council, 1959) resulted in alterations in hospital policy and practices to accommodate recommendations from the report. Changes included the commencement of 24 hour parental and sibling visitation, and the introduction of play for children. This Report was the first English governmental document that specifically addressed the issues of the needs of children in hospital. However, implementation was slow and it was used only as an advisory paper. During the same decade, paediatric nurses in the United States of America were describing the influence of psychological theories of child/parent separation on practice (Frank, 1952; Hartrich, 1956). Because of these changes to nursing attitude and practices, there was a move to encourage more contact between parents and children in hospital. A literature search on parent participation in care has revealed a dearth of Australian research in this

area, although current practices in paediatric hospitals indicate the same changes as overseas have taken place, such as 24 hour visitation and increased family involvement.

There is evidence to suggest that while these changes in policy are desirable, implementation has been difficult as hospitals are complex environments and the implications of encouraging parents to stay in the hospital both day and night (resident parents) has ramifications for both parents and paediatric nurses (Darbyshire, 1993). It has been easy to gloss over the implications and to pay lip-service to these new practices, but there is a lack of detailed description of how parents, patients, nurses and other health carers understand this rhetoric and how it actually works in practice in the reality of the hospital ward situation (Darbyshire, 1994a). The parental role has altered with new expectations from both patients and nurses (Callery & Smith, 1991). Prior to the Platt Report (1959), parents were only permitted to visit their child on the ward during restricted visiting hours, were not expected to become involved in any care, and were not permitted to hug or kiss their children. The nursing care given was strict, routine and by the book (Darbyshire, 1994b; Elfert & Anderson, 1987).

Over the following decades, nursing care practices have altered and current paediatric hospital philosophy throughout Australia acknowledges and promotes parent participation and family-centred care. Parents are now encouraged to stay with their hospitalised children, irrespective of the child's age (E. O'Reardon, & A. Johnson, personal communication, February 12, 1996). It is generally recognised that parental presence and involvement in the child or infant's care will have benefits for the child or infant, the parent(s), and the family (Ahmann, 1994). However, the roles of both the resident parent(s) and the nurses caring for these families are not clearly defined, and the rights and the responsibilities in relation to each other are not clear.

The resident parents are entering a situation where they are expected to relinquish some control over their infant and devolve everyday decisions about the infant's care to strangers, such as a large variety of health care professionals. At home, parents have considerable autonomy in caring for their child, and make decisions that affect almost every aspect of their life. In hospital, they may have to negotiate permission to actually participate in their care, even normal, routine care such as bathing and feeding. It appears that there is not an even distribution of power between the parent(s) and the nurses, and issues of stress, anxiety and uncertainty may place the parent(s) in a weaker position (Callery & Smith, 1991). Nurses, because of their continual bedside presence in the main still hold the initiative in decisions about whether negotiation takes place and then whether parent participation can actually occur. Subsequently there are issues of areas of ownership between the nurses and the parent(s) as there are differences in knowing the particular idiosyncrasies of the child and the individual care to be given to that child (Darbyshire, 1994a).

The lived experience of parents who "live in" with their infant has been largely overlooked in previous research. Whilst there have been studies that have investigated the experience of parents "living in" with their sick child where the age range could be from the neonatal period to 16 years of age, there has been no study to date which specifically investigates the experience of parents and their infant (a child less than 12 months of age). The infant has a totally dependent relationship with the parents, especially with the mother if breast feeding and usually requires around-the-clock care. The infant cannot describe signs or symptoms and relies on a care-giver to supply all his/her needs. The lack of research in this specific area has resulted in gaps in the understanding of how parents experience staying in hospital with their infant and how

these parents learn to cope with the hospital stay given that they are the legitimate caregivers.

Significance of the Study

Previous research has predominantly focussed around parent participation within the framework of family-centred care (Darbyshire, 1993; Schepp, 1992) and much of this research provides quantitative data or is anecdotal in nature (Robbins, 1991).

Quantitative research carried out in the United Kingdom and the United States of America in the 1970s indicated that mothers wanted more participation in their child's care (Jackson, Bradham & Burwell, 1978), but there was a discrepancy between the mothers' and the paediatric nurses' expectations of the maternal role. This has been supported by more recent literature (Brown & Ritchie, 1990).

Other literature describes the concept of parental participation as extremely nebulous and ill-defined (Darbyshire, 1993). To those involved in the care of sick infants and the subsequent planning of their care, little is known about how the parents feel about the experience of "living in", and how the parent(s) cope with the period of hospitalisation. There has been little research conducted in this area that specifically addresses the lived experience, which, according to Beck (1992), is how a person experiences the world before reflection. A deeper understanding of the nature and meaning of the experience of being with a sick infant in hospital may be able to offer insights into how best to understand, and, therefore, care for the family who find themselves in such a situation. Feedback of the findings to health professionals caring for families may increase the carer's knowledge, understanding and insight into how a family, specifically the mother, may feel about the hospital experience. It has the potential to improve and strengthen communication between nursing staff and the

families, thereby enhancing the hospital experience for parents who “live in” with their infant.

Purpose of the Study

The purpose of this interpretative field study of parents’ experiences was to explore, describe, and interpret the phenomenon of parents’ perceptions and the meaning of “living in” the ward with their sick infant. This study was conducted to provide an understanding and insight into the parents’ experiences. An increased awareness of this phenomenon for the nurses and other health care professionals who care for these families is vital to ensure quality and holistic care that is meaningful and satisfying for both the parent and the health care professional.

The Research Question and Objectives

The problem underlying this study was the lack of qualitative research on the meaning of parents’ experiences from the perspective of the parent who is “living in” with the sick infant, that is the parent who sleeps in the ward during the night and stays during the day. Therefore, the following research question which guided this study was;

Describe what staying in the ward with your sick infant means to you? (see Appendix A)

Based on the research question, the following objectives were developed:

1. To explore and describe the “living in” experience from the perspective of the parent (or parents if both “lived in”) involved;
2. To analyse and interpret common meanings of the “living in” experience from the parent’s perspective;
3. To expand the paediatric nursing knowledge base related to parents who “live in” with their sick infant.

Definition of Terms

Infant and baby: These terms are interchangeable and in the context of this study refer to a child less than 12 months old.

Child: This refers to a person who is aged between 0 and 16 years and is not specified as an infant.

Resident and “living in”: These terms are interchangeable and used to describe the parent(s) who would stay in the ward or hospital environment 24 hours a day, being available to the infant at all times.

Parent: The term is used to describe either male or female, a blood relation, biological or step-parent, or defacto step-parent.

Family centred care: This is a philosophy of health care that places the family, rather than the hospital and medical staff in the centre of the health delivery system (Ahmann, 1994).

Structure of the Thesis

Chapter one introduces the research topic and discusses the background and significance of the problem. It provides the reader with definitions of appropriate terms used, the purpose, the significance, the research question and the objectives of the study. Chapter two presents a review of the literature that provides a broad overview of the issues and studies surrounding parents who participate in their infant's care. The third chapter describes the study's research methodology, including a description of the design, detailing the research sample, and the method of data collection and analysis. The fourth chapter depicts the findings from the study. Chapter five comprises a discussion of the study's findings, including a second level of analysis in relation to a

nursing theory. The conclusion, implications for health care, recommendations, and suggestions for further research are presented in the final chapter.

CHAPTER TWO

Review of the literature

To situate the findings of this study within the context of current knowledge of this topic, the literature review incorporates a discussion of why human experiences should be considered using the qualitative paradigm and a review of current literature related to parental participation in care.

The Qualitative Paradigm

Traditionally, science is believed to be uniquely quantitative and it has been successful in terms of measuring, analysing, replicating, and applying knowledge that has been gained through these means (Streubert & Carpenter, 1995). However, not all phenomena can be explained by measurement, especially human phenomena where the individual may not necessarily respond in a particular way when stimulated like other subjects in laboratory experiments. Individuals' reactions and beliefs vary due to personal values, attitudes and environments. Therefore, the quantitative paradigm may not be sufficient to explain the realities of individuals in their life events.

The social sciences have been utilised to ground studies related to human phenomena as there are parts of the human system that were not amenable to research through measurement. Qualitative research methodology provides a way to construct meaning that reflects the world of practice because it is more organic than mechanistic and therefore, more suitable to the study of nursing issues (Swanson & Chenitz, 1982). It offers an opportunity to study selected issues in depth (Patton, 1990) to find answers to questions that centre on social experience, how it is created, and how it gives meaning to human life (Streubert & Carpenter, 1995). A qualitative

paradigm, therefore, is conducive to understanding the experience of parents who “live in” hospital with a sick infant from the parents’ perspective.

Historical Perspective

The literature reflects the changes to the care practices adopted by paediatric hospitals over the past few decades. Hospitalisation has long been regarded as a potentially stressful experience for both the child and the parents (Darbyshire; 1993, Jones, 1994). The early 20th century saw the ideology of child rearing to be regimented and mechanistic (Darbyshire, 1993) and the prevailing view of relationships between parent and child to be firm detachment. Changes in health policy in England (Ministry of Health and Central Health Services Council, Platt Report, 1959) in the 1950s saw attempts by paediatric hospitals to “humanise” health care practices by offering open visiting, living-in facilities and encouraging parents to be active in caring for their child (Ahmann, 1994; Darbyshire, 1993; Palmer, 1993). The Platt Report suggested greater heed should be taken of hospitalised children’s emotional and psychological needs. It also suggested including the training of nurses to specialise in paediatrics, provision of play facilities, parental visitation at any reasonable time, and the admission of children to the children’s ward, instead of being admitted to the adult wards as has occurred in a number of hospitals. Progress in implementation was slow and varied across England (Darbyshire, 1993) as the government could only advise and not dictate changes that were desirable.

However, in the 1960s, a group of parents in England founded the National Association for the Welfare of Children in Hospital (NAWCH) (Ahmann, 1994; Hostler, 1991; Palmer, 1993). The Association aimed to persuade hospitals that parents had a role in the care of their sick child as well as encouraging parents to take

on that role. It also monitored the implementation of the recommendations of the Platt Report (Ministry of Health and Central Health Services Council, 1959).

Although the Platt Report had good intentions, considerations of the ramifications for both the parents and the nursing staff, as well as other health carers, were not addressed. Since the 1960s, there has been a strong emphasis on in-hospital parental participation and family-centred care. The implementation has been gradual and according to Hall (1978), at first glance appeared as though it had been complete, but there were still a number of hospitals with restricted visiting hours. This is changing and the new view has gained momentum throughout the Western world. Changes are currently occurring to enable parents to participate in the care of their sick child (Casey, 1988). Jones (1994) commented that parental participation in the hospitalised child's care has benefits for both the child and the parents. Parents feel as though they can have a say in the way their child is managed and can help their child through difficulties (Hayes & Knox, 1983). In addition, the child responds to interventions in a more positive way and is less upset (Hardgrove & Healy, 1984; Jones, 1994). Kostrzewa (1985) described the importance of effective communication between parents and health care workers, especially in relation to significant events such as a dying child. Improved support services and increased education for the nurses in a Toronto hospital helped to advance the partnership relationships between those specific parents with a dying child and the nurses caring for them.

Australian literature is scarce in relation to parents "living in" with their sick infants or children. Accommodating the parents has been a concern to management as many hospitals were not built to house parents. Thomas, Henry, McCoy, and Smith (1989) investigated the factors affecting parents' decisions to stay overnight

with their sick children in a paediatric hospital in Melbourne. There were limited facilities for the parents to stay overnight in the hospital at this time. A questionnaire was distributed to 143 parents who stayed overnight. Results of the survey revealed that the cost and availability of off-ward accommodation did not influence the parents' decisions to stay. The majority of children had pre-planned admissions and none were in immediate danger. The parents wanted to stay with their children in hospital and felt their presence was beneficial for the children. This supported other research from North America and the United Kingdom that revealed parents wished to stay with their sick child.

A documentary ("Where have we been, where are we going?", 1994) on the changes in South Australian paediatric visiting practices illustrated the monumental transformation that took place in the 1970s when visiting hours were removed and parents could stay with their child. Comments were made that the most significant impact on general parental involvement occurred with the formation of the Association for the Welfare of Children in Hospital. The Association for the Welfare of Child Health, formerly the Association for the Welfare of Children in Hospital (AWCH) was founded in Australia as a voluntary organisation in 1973. The Association consisted of professional and non-professional people who were interested in formulating and satisfying the non-medical needs of children and their families in hospital (Hancock, 1995; Hart, 1979). In the 1990s, it is a large national organisation that focuses on policy making and the provision of an information service for all those professional and non-professional people interested in the welfare of children of all ages in hospital.

The Western Australian Association for the Welfare of Child Health has been operational for over 20 years and reports from the organisation suggest that there has been much improvement during this time in the conditions for all children in hospital (Taylor, 1995). However, nothing specifically has been mentioned about the needs of infants. In addition, there appears a dearth of literature pertaining to the Australian picture of parents who “live in” with their sick infant.

Parental Participation in Care

Family-centred care, the philosophy of care that puts the family in the centre of health care delivery, has become a popular focus of discussion in most paediatric settings, with much emphasis on a shift in orientation towards service provision (Ahmann, 1994). The literature has revealed changes in attitudes, protocols and policies in the delivery of all paediatric nursing care. However, little has been research based; most studies are generalised suggestions of changes in care practices (Ahmann, 1994; Gill, 1987; Hardgrove & Healy, 1984; Hostler, 1991) or anecdotal stories (Casey & Mobbs, 1988; Robbins, 1991; Stower, 1992) revealing changing values in who provides the care.

Using a grounded theory approach, Hayes and Knox (1983) discovered ways of reducing stress in parents of children with cancer. Employing Selye’s definition of stress, the researchers examined parents’ understanding of their hospital-related stress. This research highlighted the role that parents have prior to the child’s illness and the necessary adaptation to the new role of parents of a sick child, and perhaps a dying child. This research suggested ways for nurses to help the parents adapt to the diagnosis of cancer, such as information sharing, supporting and individual assessment.

There is only one published study, by Darbyshire (1994b), which has investigated the lived experience of parents who “live in” hospital with their child. This study, conducted in Scotland, used a combination of phenomenology and grounded theory to formulate a detailed and faithful account of parents’ and nurses’ lived experiences that would enable a better understanding of children in hospital. This work has underlined the complexity and intricacies of the feelings of the parent who stays in the hospital ward and the impact of the hospital stay on the family. The study also investigated the relationship between the parent and the nurse from both the parents’ perspective and the nurses’. This significant study sought the experiences of 30 parents of children of all ages, including infants, who “lived in” or stayed with their sick child and 27 nurses of varying experience and expertise, over a six year period. There were 32 interviews in total, including focus groups and individual sessions. This study interprets the experiences of both the parents who stay with their children and the nurses caring for them. Information gleaned from this study can be utilised by health care workers and parents alike to shed light on the many and varied experiences that parents encounter and make sense of.

According to Darbyshire (1993) parental participation is an extremely nebulous and ill-defined concept in paediatric nursing. Not only the parents, but nurses appear to have different attitudes towards the concept and different ideas as to what it means and involves. Parents with children in hospital, when asked, usually wanted to participate in their child’s care (Callery & Locker, 1996; Jones, 1994; Koller, 1991; Snowdon & Gottlieb, 1989). Algren (1985) ascertained that although parents wanted to help in their child’s care, many were not consulted or asked by the nurse to participate. Conversely, there is no consensus amongst nurses about what

form parental participation should take and how far it should extend (Callery & Smith, 1991). Casey and Mobbs (1988) have described a partnership model, developed by Casey that appears to represent paediatric nursing in any setting. This model and accompanying nursing care plan is able to guide nursing care to encompass parental participation, whether "living in" or not. Robbins (1991) described a nursing care plan for "shared care", based on a family centred approach to care that can be utilised by nurses to incorporate parental participation. Both Robbins and Casey and Mobbs (1988) claimed that these care plans were useful in the holistic care of children, but neither completed rigorous research to actually validate the outcomes. Jones (1994) completed a short-term, longitudinal descriptive evaluation of parental participation levels of care in relation to the involvement in the care of the child who had leukaemia. The author used various instruments, for example the Co-operations Scale, used for measuring children's co-operation, and the Parent Participation Assessment Instrument, to assess parental participation in care. The author discovered that there was a positive effect on the child's behaviour if the parents could actively and consistently participate in the care.

Partnership-in-care, where the parents are seen to be "partners" with the health care team is a relatively new concept in Australia. This method of care delivery was introduced into Suzanne and Fielders wards, two paediatric wards (in the Adelaide Women and Children's' Hospital) on a trial basis during 1994 (Johnson, 1995). The focus of the trial was to build on the existing practice of family-centred care and further develop a collaborative working relationship between nursing staff and parents of children in the trial wards. The aims of the trial were to identify barriers to the parents and staff effectively working together and to identify

recommendations made by the parents. Outcomes of the trial would help to plan and implement a way for parents and staff to work collaboratively together, to support the staff, to evaluate the process and make recommendations for further changes. The trial lasted six months and demonstrated positive attitudes of all nurses towards the introduction of this care modality. The nurses felt that it was important for the concept of parental participation to continue and to be supported. The parents felt an improvement in the perception of care and working relationships with nursing staff during the trial. This was a new way of working with parents and children, namely partnership-in-care (Johnson, 1993), and it recognised family members as the constant group of people in the child's life. Parents offered a special kind of expertise in the care of their child in hospital as they do at home. Partnership-in-care comprised a nursing assessment sheet and a special chart that documents how each parent wishes to be involved in the care of his/her child. Nurses would negotiate and discuss these issues with the parents on a daily basis. Evaluation of this model of care is currently being undertaken in the South Australian hospital where it began.

Fore and Holmes (1983) described a "care by parent unit" established in North America, where the parent carried out pre-operative care and discharge planning under the supervision of a primary nurse. Anecdotally, this unit appeared to be successful in meeting parents' needs, perhaps because the specific criteria for admission were clear. However, in other similar "care by parent units" cited in the literature, the parents have felt comfortable about caring for their child's activities of daily living, but felt unsure of more technical or procedural care, such as dressings (Darbyshire, 1993; Palmer, 1993).

Street (1995) described how in one hospital in Victoria, Australia, nurses were interested in examining certain practices on a paediatric ward. The concept of “care by parent” contracts had been introduced, but was unsuccessful. Following interviewing the parents and staff, results directed the practices so the parents and the nurses involved spent time every shift reviewing the current situation of parental participation. Further collaboration between the nurses and the parents increased parent satisfaction.

Stull and Deatruck (1986) in North America, developed a tool for measuring parental participation in the child’s care. The qualitative research leading to the development of this tool, included interviews that identified parental involvement activities and the analysis of daily diaries kept by those parents who were interviewed. Although a tool was developed, there was major disagreement amongst the nurses involved about what care was appropriate for parental participation. The tool has not been used in subsequent research studies.

Nurses and Resident Parents

There appears to be a history of general resistance by nurses towards parents or a parent “living in” the hospital ward (Ayer, 1978). More recent research shows a more tolerant, although still mixed reaction to the concept. Gill (1987) interviewed over 40 nurses of various levels about their attitudes concerning resident parents and found better tolerance to this in nurses with Master’s degrees, head nurses and supervisors. A survey by Berman (1991) found that 83% of nurses surveyed accepted resident parents, but others reported resident parents were excessive in their requests and expected to be waited on. Brown & Ritchie (1990) interviewed 25 Canadian paediatric nurses and found, although appreciating the idea of parental participation,

many felt role confusion and had problems with interpersonal contact. Those nurses who agreed with parental participation saw the child and the parent as a single unit (Gill, 1987).

Although there is an increasing volume of literature surrounding the subject of parental participation, there is little research into the lived experience of resident parents from a phenomenological perspective. A literature search has revealed only one study that has explored areas of paediatric nursing care that is specifically related to the concepts of family-centred care, parental participation and the various components of experiences of the parent(s) and nurses. This research, conducted by Darbyshire in 1994, was an extensive interpretative analysis of interviews of 30 parents and 27 registered nurses, and sought to understand how parents experienced "living in" with their child. The research took place in a general paediatric medical ward and a plastics/burns ward. This provided the researcher with a wide range of illnesses and injuries, thus avoiding a concentration on too narrow and select group of parents and nurses. The age group of the children ranged from the neonatal period up to late teens. There appeared to be no specific criteria for entry into the study, except the parents were "living in" or staying most of the day with their child. This research, conducted in Scotland, offered the paediatric nurse informative accounts and insights that furthered the improvement of the delivery of care and the understanding of what the hospital experience is like for resident parents and their families. The findings from the Darbyshire (1994b) study revealed three key themes which were: the nature of being a live-in parent, parents and nurses: caring and relationships, and caring as a fusion of concerns. The first theme, the nature of being a live-in parent involved investigating the ontological sense of being a live-in parent. Darbyshire (1994b) stood

back and tried to answer the question: what does it mean to be a parent? Every parent brings a background of cultural and caring practices, and understanding to their new situation. Darbyshire believed that this needed to be answered before delving further into the hospital situation. The situated meaning of being a live-in parent described what it was like for parents who were “parenting in public” whilst residing on the ward. Parents had to adapt to a situation where they had to negotiate and adapt to being participants in the care of their own children. Parents described the difficulties they had to face when entering into the domain of so-called child experts. The second and third key themes related to the relationship between the parents and the nurses in terms of caring and the caring relationship. The author described the feelings that the nurses had in relation to the parents which included both mixed positive and negative reactions. However, the parents expected caring to be part of the nurses’ job.

Darbyshire (1994b) described his own battle with the theoretical underpinnings of his work and discussed the implications of the research in these terms. He believed that specific recommendations should not follow the logical positivism of the nature of knowledge, research and practice and defends the use of an interpretative paradigm with “a dialogic rather than didactic approach” (Darbyshire, 1994b, p. 184) to understand the perceptions and experiences of both the parents and the nurses.

Although the work of Darbyshire (1994b) is extensive and informative, it does not include those parental experiences in relation to the child’s particular individual age group. Experiences, feelings and reactions to the hospital process may be different for a parent of an infant compared to a parent of a toddler or an adolescent.

The age and diagnoses of the children in this study were not taken into account and the children's' diagnoses and demographic information were not utilised during the study for reasons of anonymity.

The parental role has been conceptualised as the ability to fulfil the child's physical and emotional needs for love, security and nourishment in a manner that changes according to the child's changing needs (Kraus, 1990). When a child is an infant, s/he is totally dependent on a care-giver for food, shelter, love and safety.

Walker and Montgomery (1994) suggest that by approximately the end of the first month following childbirth, a woman has learned her child's characteristics and patterns and has formed a stable image of her infant and the relationship she has with him/her. Mercer (1985) comments that the transition to the maternal role is a period of re-organisation in a woman's life that incorporates the addition of the mothering role. With these comments in mind, the event of hospitalisation could interrupt this relationship, especially if other people, not known to the family, are involved in the care of the infant.

There has been no study to date that specifically investigates the experience of the parents and their infant, either overseas or in Australia. Other research has studied the experiences of parents of children from a range of ages with no focus on the relevance of the age of the child. Instead of an instrumental understanding of parents' attitudes and feelings, an alternative is to look at those relationships in a particular context at a particular time to hear those voices that are sometimes assumed or ignored. Oiler Boyd (1993) reminds us that there is a growing recognition that statistical significance testing is not always meaningful from a clinical point of view.

This review of the literature has attempted to establish an argument for conducting a phenomenological study into the lived experience of parents who "live

in" the hospital with their sick infant. It illuminates the lack of current literature that specifically relates to this phenomenon. Findings from this study will build on the current body of knowledge associated with paediatric nursing care, specifically the hospitalisation of infants and will address the deficit of knowledge associated with the experiences of those parents.

CHAPTER THREE

Methodology

Background

The purpose of this study was to explore parents' perceptions of living in the hospital ward with their sick infant. In this context it is relevant to the process of understanding human behaviour and functioning (Strauss & Corbin, 1994) from the participants' viewpoint. This investigation is therefore suited to qualitative research methodologies as qualitative research identifies the characteristics and the significance of human experiences as described by subjects and interpreted by the researcher at various levels of analysis (Parse, Coyne, & Smith, 1985).

Methods of qualitative analysis offer a valuable alternative to the logical positivistic methodology to explain the complexities and obscurities in nursing. It is considered appropriate for this study as many of the feelings and experiences of families touched by the hospitalisation of an infant are not quantifiable, yet they must be understood by health carers to enable the satisfactory delivery of quality care. As the researcher does not wish to control variables, manipulate the data, or predict outcomes, a qualitative approach in this instance presents the most congruent approach to uncover human experiences and feelings. Qualitative analysis, according to Cobb and Hagemaster (1987), is an alternative methodology to the quantitative paradigm.

Leininger (1985) claimed that until recently the Western scientific method was the only major, valid and reliable way to approach knowledge and understand people. Both qualitative and quantitative research methodologies have a place in nursing practice depending on the research question. However, Swanson and Chenitz (1982)

suggested that quantitative nursing research has limited meaning in the practice world of nursing as this approach, in which each variable has one single dimension and is isolated to give a correlation between phenomena, produces findings which could contradict what nurses know to be the reality of their daily work. This form of research does not necessarily measure some forms of phenomena, especially human phenomena. According to the authors, some nurse researchers have recognised the inadequacies and limitations of the scientific method in gaining a better understanding of humans and their health care needs. When the research is to find out what people do, know, think, and feel by observation, interview, and analysis of documents, then the qualitative research methodology is considered the most appropriate to use (Patton, 1990).

Phenomenology as a Method

The phenomenological method seeks to describe the essence, and uncover the meaning of humanly experienced phenomena through the analysis of a participant's descriptions (Omery, 1983; Parse et al., 1985; Patton, 1990). It is through this analysis of the descriptions that the nature of a phenomenon is revealed and the meanings for the participant is understood. This will include not only the phenomenon itself, but also the context of the situation in which it occurs, and the relationship the person has to the world (Leonard, 1994). The phenomenological movement grew out of a critique of positivism being applied to human matters or concerns (Cohen, 1987). It strives to be a rigorous science in the service of humanity. Phenomenology seeks to provide answers to important questions and deep human concerns. Cohen (p. 31) quoted Merleau-Ponty as saying "...we are condemned to

meaning”, because the phenomenological approach seeks to understand these meanings.

Husserl has been designated as the founder of the modern phenomenological movement (Cohen, 1987; Omery, 1983; Patton, 1990; Walters, 1995), although his work went through distinctly different phases. He was also the mentor of later phenomenologists, such as Heidegger, Merleau-Ponty, and Sartre (Cohen, 1987; Parse et al, 1985). Husserl, a mathematician, believed that philosophy, and in particular phenomenology, is concerned with “essence” which is a fact or entity that is universal, eternally unchanging over time, and absolute (Walters, 1995). It is related to the ideal or true meaning of something (Streubert & Carpenter, 1995) and it relates to how people describe things and experience them through their senses. Husserlian phenomenology is, therefore, concerned with the clear understanding of the fundamental nature of reality. The focus is a description of the lived world that conceptualises people as detached subjects existing in a world of objects (Walters, 1995).

Husserl described the concept of phenomenological reduction or “bracketing” which is based on the mathematical strategy of placing brackets around part of the equation that needs to be treated differently from the remaining equation. Similarly, “bracketing” refers to when the researcher makes all attempts to acknowledge the awareness of preconceived notions about the phenomenon being studied (Pallikkathayil & Morgan, 1991) and to suspend that perspective when analysing the data (Parse et al., 1985). Streubert and Carpenter (1995) suggest that any researcher’s own perceptions or ideas about the research topic need to be explicated in order to reduce the possibility of biasing or leading the participants in a particular

direction that will support the researcher's beliefs. This may not be what the participants want heard. The researcher must remain neutral in relation to belief or disbelief in the existence of the phenomenon that is being studied. The researcher in this study bracketed any preconceived ideas and presuppositions from both the literature and vast experience as a nurse working in the field of paediatrics, notably infants. This meant attempting to set aside all previous knowledge and personal beliefs that may have hindered an authentic description of the phenomenon. This involved writing the researcher's beliefs in memo format to ensure a conscious awareness if those biases began to emerge at the beginning of the study and rigorous attempts were made throughout the research process to maintain an unbiased stance. Crotty (1996) has suggested that bracketing takes discipline and persistence and it is not easy to accomplish.

Heidegger, a pupil of Husserl, believed the understanding of the person could not occur in isolation from the person's world. His interpretation of phenomenology was a reaction to the "Cartesian subject-object dualism and to the notion of intentionality" (Walters, 1995, p. 794). Crotty (1996) discusses intentionality as bringing a consciousness of mind and an intensified level of meaning and understanding about nature and people which brings subjective data into objective data. Heidegger did not believe it was possible to "bracket" one's being-in-the-world, but suggested that human existence cannot deny the basic actuality that they always exist already in the world. For Heidegger, the human-world relationship is a unity. Heidegger, therefore, describes phenomenology as an attempt to understand the fundamental dimensions of being-in-the-world. His analysis of "being" is a study of the ordinary everyday existence of people. This method of phenomenological analysis

is known as hermeneutics or interpretation, and can be seen as one of the processes that people use in making sense of their world. Hermeneutics presupposes the interpreter's prior understanding of being involved with those who have lived the particular experience, and it is only possible to interpret something according to one's own lived experience.

The phenomenologists cannot be placed in one school or group as the diversity of philosophical underpinnings is too great. However, according to Parse et al. (1985) there can be agreement on the method of inquiry. The phenomenological method seeks to uncover the meaning of phenomena experienced by humans through the analysis of individual descriptions. Phenomenology, says Van Manen (1990), is the study of the lifeworld, as it is immediately experienced before reflection, rather than as it is conceptualised, categorised, or reflected upon.

Spiegelberg (1975) describes the six types of the methodology that are common to all interpretations and variations of phenomenological philosophy. These types include descriptive phenomenology which is a direct investigation, analysis, and description, free from preconceived expectations and presuppositions. The second type is essential or eidetic phenomenology which is the perception and probing of the phenomena for typical structures or essences, looking for the relationship of the structures. The third type is phenomenology of appearances which is giving attention to or watching for the ways the phenomena appear in different forms of clarity. The fourth type is constitutive phenomenology which explores the way the phenomena takes shape. The fifth type of phenomenology refers to reductive phenomenology which suspends the belief in the reality or validity of the phenomena, which occurs through the concept of "bracketing". The sixth type is Heideggerian hermeneutics

which is the interpretation of the hidden meanings in the phenomena that are not immediately revealed in direct investigation, analysis, and description. Each of these six types of phenomenology are inter-related in some part. Whilst there appears to be a variety of strategies which arrive at a common goal, the focus is to capture the essence of the phenomenon under study through the revealed lived experience of the participant (Pallikkathayil & Morgan, 1991).

The researcher used a combination of the second and fifth types in the analysis of the findings. Interpretation of the structure of essences appeared to be the most suitable approach for the data. Bracketing the researcher's beliefs was relevant in this context as the researcher has been involved in this area of care for many years and may have pre-conceived views related to the subject being studied.

Some of the types of strategies for data analysis mentioned above are common to most modifications of the methodology (Salsberry, 1989). These include intuiting, which means grasping the uniqueness of the phenomena; describing, which refers to clarifying the phenomena through the use of metaphor and negation; and analysing, which investigates the elements and inter-relationships of the intuited phenomena.

One process is to discern "...general essences from perceived particulars" (Salsberry, 1989, p. 10) and another process is to discover the essential relationships within and between essences. This last process involves the researcher using free imagination when examining the data and, therefore, imagining the data against a variety of meanings of the experience.

The post modernistic view of the phenomenological method has merit in exploring the meaning of any event that may affect people (Omery, 1983) in order to clarify how things and experiences are meaningfully formed and communicated.

Leonard (1994) proposes that it is to understand everyday skills, practices, experiences and to find commonalities. Holstein and Gubrium (1994) suggested that the social sciences should focus on the ways of the world that are taken for granted by every person and are actually constructed and experienced by those people. The authors believe that this will safeguard what is the subjective view and not allow it to be replaced by a pretend world constructed by the scientific faithful.

In relation to the discipline of nursing, phenomenology is a method that is consistent with the values and beliefs of a humanistic discipline (Knaack, 1984; Leininger, 1985; Lynch-Sauer, 1985; Porter, 1989; Salsberry, 1989). Field and Morse (1990) suggested that findings from phenomenological research studies can help carers to develop an improved understanding of behaviour that goes beyond the physical act of providing care. Knowledge gained from this study has the potential to further enhance the quality of both the delivery of care, and the relationship between the nurse and the parent(s) "living in" with a sick infant. Lynch-Sauer (1985) believes that nursing has a goal to understand those individuals being cared for in order to know how to care for them. Descriptions of the lived world of the patient or the patient's family may provide examples to use as exemplars for further knowledge to ground nursing practice for the nurse delivering the care.

Design

As the purpose of this study was to describe and interpret the shared meanings of the "lived in" experience for the parent(s) with a sick infant, the phenomenological approach represented the most appropriate method. It was expected that the research would allow the researcher to study rich, descriptive data which would enable a

deeper understanding of the experience of “living in” the hospital ward with a sick infant.

A research design within the interpretative framework was selected to explore and discover the parent(s)’ experience of “living in” hospital with their sick infant. It sought to gain insight through as many meanings as possible that were part of a given phenomenon and their relationship to one another (Keen, 1975). These meanings may then be utilised as a guide to change and improve paediatric nursing practice. A deeper understanding of the nature and meaning of the experience of parents who stay with their sick infant in hospital can offer insights into how best to understand and, therefore, care for the family who find themselves in this position.

A semi structured interview guide (see Appendix A) was utilised to guide the in-depth interviews. Observations of the participants’ body language and non-verbal cues, the ease of the interaction and the general impressions of the researcher were noted by field notes which were completed as soon as the interview was finished and the researcher was alone and able to reflect on each interview. The study was divided into two parts, a pilot study and the main study. The pilot study was undertaken to familiarise the researcher with interview technique, writing observational field notes and the circumstances of the process. Following review of the pilot study, the interview technique was modified to be less directive in the use of questions. Streubert and Carpenter (1995) suggest that piloting interview skills can assist in the development of interviewing skills. Refinement of the interview was achieved following the one pilot interview. Following the refinement of the interview techniques, the main study was undertaken to collect data for analysis of the lived

experience of “living in” hospital with a sick infant. The data from the pilot study was not included in the main study.

Participant Selection

The participants came from a population of parents who “lived in” with their sick infant in the general medical and surgical infant’s ward within a tertiary paediatric hospital. This hospital is the only major teaching paediatric hospital in Perth, Western Australia and is located within a four kilometre radius of the city centre. There are about 1000 medical and surgical admissions to the infants’ ward per annum, 20 cots in the ward and the age range for admission is one week old to fifteen months of age. Length of stay varies from one day (less than 24 hours) to a number of weeks or months, depending on the diagnosis and circumstances of the infant.

Patton (1990) described purposive sampling as that sampling which is rich in information and suits the purpose of the study. The participants in this research comprised mothers who had lived the phenomena of concern. Eight mothers were interviewed for the study. Fathers were not included in this study as none “lived in” with their infants for the duration of the data collection. Small numbers are required for qualitative studies and the number depends on the diversity and variation of the findings (Rissmiller, 1991). Both Patton (1990) and Morse (1991) suggest that the sample selection should continue until a point of redundancy of information has been reached. This occurs when there is no new information forthcoming from the data being analysed. Data for this study reached saturation after seven interviews.

The criteria for this study was that a parent, irrespective of sex, who was staying in one of the “ensuite” rooms, that is a single room which contains a cot for the infant, a single bed for the parent and ensuite bathroom facilities, was considered

for inclusion in the study. There are currently four of these rooms available on the ward for parents to stay in with their infants. Excluded from the study were parents who normally lived in non-metropolitan areas, unless staying in Perth following discharge, parents of infants who were admitted with possible or confirmed non-accidental injuries, non-English speaking parents, and parents with an infant with congenital or chronic disease, such as cardiac disease, cystic fibrosis or cerebral palsy.

Procedure

All infants and their parent(s) admitted to any of the four "ensuite" rooms in the hospital ward were scrutinised to meet the criteria. There were great difficulties in the selection process due to many reasons. Initially, some of these reasons included a significant decrease in patient numbers due to seasonal alterations in numbers, apparent increase in chronic conditions, such as newly diagnosed cystic fibrosis and encephalopathies, which could result in a brain damaged infant, and, finally infants whose families came from the rural northern and southern parts of Western Australia. Later on in the course of data collection, the patient numbers increased, but there were many short-stay patients who were only admitted for two or less than two days. These families appeared unsuitable for interview as the researcher felt as though their stay was too short lived for a detailed interview.

The researcher in this study, a senior member of the nursing staff on the infants ward in a major teaching hospital, was not involved in direct care with any of the participants or their infants. Prior to commencement of the data collection, all nursing staff on the ward were notified of the research topic and that some of the parents would be involved in interviews after the infants had been discharged and were at home. No notification of who was going to be interviewed was divulged and

no questions were asked by the staff. At no stage during the data collection did the staff realise who was to be a participant and that data collection was occurring.

Eight participants, all mothers, were identified by the researcher to participate in the study. The researcher was aware of all patients who had been admitted to the ward during the day and checked every morning, Monday to Friday, to see who had been admitted overnight. Data collection was conducted over a six month period.

Within a few hours of admission, and only when the infant's condition was medically stabilised, the mothers were asked by the researcher to voluntarily participate in the study. This initial inquiry was informal, with no specific information about the study given at this time. Once a parent was identified as a potential participant, arrangements were made just prior to discharge to visit the family home to conduct an interview within 48 hours of discharge. Following the researcher's arrival at the participant's home and after a settling-in period, an information sheet (see Appendix B) was given to the participant and written consent was obtained (see Appendix B). Explanations of the use of the tape-recorder and the nature of the questions was discussed prior to commencement of the interview to alleviate the potential for participant anxiety. However, there were no problems associated with this.

Two parents who were invited to participate in the research declined. Although agreeing when approached, one mother stated she was not interested when the researcher rang to check if the interview time was suitable. There was no reason given. Another mother declined when the researcher initially sought consent as she felt her command of the English language was not fluent enough for an indepth interview.

Prior to the commencement of each interview, the researcher rang each participant to ensure the meeting time was convenient and gave the participant time to get organised, if required. If the time was inappropriate, another more suitable time was arranged. Only once was the time changed with one mother. She had forgotten a prior arrangement and could not alter this commitment. All the indepth interviews, except for this one, took place within the 48 hour time frame.

Because of working in the area for many years, the researcher was familiar with the normal routines in the ward and the diagnosis of, and care required for each of the sick infants whose parents were interviewed. The researcher had a supervisory role on the ward and had been acquainted on a superficial level with the participants while in hospital. This entailed seeing each parent on a daily basis to assess if there were any individual outstanding issues to be addressed. If further intervention was required by the researcher in the role as Clinical Line Manager, for example, counselling, involvement of a direct clinical nature, then those parents would not be interviewed for the study. However, this did not occur.

In each interview, an attempt was made to create an atmosphere of empathy and caring, where the participant could relax enough to talk easily and spontaneously. On development of a rapport, general conversation took place before and after each interview. Knaack (1984) describes the essential ingredient in the relationship between the participant and the researcher as one of trust. Field and Morse (1990) describe the researcher as an instrument, and the depth of the data analysis will depend on the sensitivity, perceptivity, informed value judgements and knowledge of the researcher.

The time of interviews ranged from 45 minutes to one hour. An interview sheet which comprised open ended questions and prompts (see Appendix A) was used during each interview. Prior to each interview, there was general discussion about the infant's condition and settling back into home life and normal routine. Prior to turning on the tape-recorder, the participant was thanked for participating in the study and given the opportunity to ask any other questions that related to the interview or study. An opportunity to decline continuing with the interview was given, but no participants chose this option. The tape-recorder was turned on and then the open question was asked. This first question was "Tell me about your experiences while "living in" the ward with your sick infant?" The researcher encouraged the participants to describe their experiences as fully as possible, but did not suggest to them what to say. Successive questions from the interview sheet were only asked when appropriate, or following a long period of silence and were not used in any order. Much of the information was given during the course of the interview with only some prompting and re-direction being required.

The researcher was required to set up for each of the interviews in the participants' home, therefore, there were variations regarding positioning of the participant and researcher. The participants offered seating arrangements to the researcher who deferred the decision back to the mother to enable her to be comfortable and relaxed. In six cases, the infant was not present during the interview. In most instances, the researcher sat on opposite sides of a table from the participant with the tape-recorder in between. The researcher maintained eye contact with responses of nodding, and changes in facial expression encouraged participant

conversation. Verbal responses by the researcher were kept to a minimum to encourage continued conversation.

Support and empathy was conveyed to the participants by conscious attending to each mother. Knaack (1984) suggests that to be a good interviewer, the researcher must be a good listener. Field notes were not taken at this stage to avoid interruption to listening and attention. Bolton (1986) describes effective listening that is required for a successful interaction should include attending skills, following skills and reflecting skills. Attending skills include a posture of involvement, appropriate body movement, eye contact and a non-distracting environment. Following skills include "door openers", minimal encourages, infrequent questions and attentive silence and reflecting skills include paraphrasing, reflective feelings, reflective meanings and summative reflections.

Although verbal interaction was kept to a minimum, the researcher maintained an active involvement. Observation of the participants' verbal and non-verbal behaviour was made, as well as those of the environment, and the researcher's own reactions and feelings about each interview interaction. These observational field notes were completed as soon as the researcher was alone, such as in the car.

Following cessation of the interview, the researcher spent further time with each participant discussing the individual experiences that the participants had while in hospital or personal issues. After assurance that any information used would remain anonymous, the majority of participants continued to discuss specific aspects of ward management, nursing care, other issues that were relevant to the delivery of care in the ward or to themselves. None of this "off-tape" discussion was used in the data as

it related to specific individuals, gossip or personal issues not directly related to the hospital stay. The purpose of this was to give the mothers the opportunity to debrief.

Observation of each of the participants' behaviour during the interview was noted by the researcher. Notes taken following the interview as well as information regarding the non-verbal communication were used as a way of triangulating the data sources for enhanced claims for validity (Kimchi, Polivka & Stevenson, 1991).

Data Analysis

Data collection and analysis occurred at the same time, commencing from the first interview. The researcher was analysing and reflecting on the data as each of the participants were talking. The process of intuiting, analysing, and describing continued throughout each phase of the analysis.

Oiler (1982) suggests that intuiting encompasses looking at the experience with open eyes with knowledge, facts and theories kept away. Concentration and holding fast to the superficial meaning of the phenomena as described by the participants is the key to intuiting (Parse et al., 1985). According to Oiler (1982) and Parse et al. (1985) analysing refers to the comparing and contrasting of recurring themes and the identification and relationships of the ingredients of the phenomena, describing is an integral part of intuiting and analysing. It is the description of what has been seen. This description is to guide the reader through the phenomena by giving the reader signposts and directs the reader to his/her own experience (Oiler, 1982; Parse et al, 1985).

Data were formally analysed using the method outlined by Colaizzi (1978). Drew (1989) suggests that this particular methodology supports validity of the data. Colaizzi's method, according to Oiler (1986), is more liberally treated to include

interview, observation of nonverbal communication and cues, observation of the context, and the researcher's responses. The method consisted of the following steps:

1. The taped interviews were transcribed verbatim by a professional typist.

The researcher listened to the tapes to verify the completeness of the written transcripts and any incompleting or incorrect portion was adjusted.

2. The researcher read and re-read the written transcripts to gain a feeling of familiarity for each participant's stated or implied meanings. Significant statements and phrases of each transcript which pertained to the experience of parents "living in" hospital with their sick infant were extracted and coded.

3. The transcripts were read again to gain an overall "feel" of the complete content and to triangulate the data. Reflection and intuiting took place to enable the researcher to grasp the uniqueness of each description and to identify any areas for further elaboration.

4. For each interview, significant statements and phrases were identified by verbatim quotes and provisional themes were identified as they emerged from the data. Quotes, significant statements and thematic descriptions were clustered around each proposed theme.

5. Step 4 was completed for each of the remaining participant's transcripts. All transcripts were compared to each of the other transcripts. Themes emerged from the data and continued until no new themes could be identified and saturation of the data had occurred. Morse (1995) describes saturation of data as "data adequacy" where no new information is obtained. The data analysis and description of the findings were then completed.

6. Findings of the data analysis were integrated into an exhaustive description of the experience of “living in” hospital with a sick infant. Eight provisional themes were originally identified, and these were collapsed down to the final four.

7. The descriptions were then checked with two of the participants for clarification and validation. Any new data from this check was analysed and incorporated into the final report.

Validity of the Study

Suggestions for demonstrating rigor in qualitative research studies have been the subject of much discussion in the literature (Appleton, 1995; Beck, 1993; Brink, 1991; Burns 1989; Hinds, Scandrett-Hibden & McAulay, 1990; Rodgers & Cowles, 1993; Sandelowski, 1986; Sandelowski, 1993; Tilden, Nelson & May, 1990).

Validity, according to Silverman, Ricci and Gunter (1990), refers to the best available estimation of the truth or falsity of propositions.

Sandelowski (1986) based her guidelines of credibility, fittingness and auditability on the four criteria proposed by Guba and Lincoln (1985) to meet the test of rigor in qualitative inquiry. These included truth value, applicability, consistency, and neutrality. Credibility is the proposed criterion against which the truth value should be judged. Fittingness is the criterion against which the applicability of the study should be evaluated and auditability is the suggested criterion for evaluating the consistency. Confirmability is the criterion of neutrality in qualitative research.

Credibility or truth value of this study was based on the verification of the participants' perceptions of the experience of “living in” hospital. Two of the participants were contacted two months after the initial interview and information from the transcripts was discussed to validate and confirm that the themes identified

by the researcher represented the participants' experiences. Any deletions, changes or corrections were invited but none were forthcoming. The second credibility check included sharing the descriptions, themes and phases of the analysis with two experienced nurse researchers who were the researcher's supervisors. A further credibility check is the ability of the researcher to 'feel' the experiences of the participants as likely and therefore a true account of those experiences. The researcher has had many years in the field of neonatal and infant nursing in differing roles, and has an intimate knowledge and experience of dealing with parents in hospital. This can assist in the verification of the participants' perceptions.

Fittingness or applicability of a study refers to the likelihood of the research findings having meaning and is applicable to others in similar situations. In phenomenological research, the recounting of past experience is regarded as reliable data as it is an expression of the feelings, thoughts, and emotions included in the phenomena being described (Colaizzi, 1978; Drew, 1986). Crotty (1996) discusses intentionality in terms of the interpretation of how the subjective experience fits into the objective world. Sandelowski (1986) purports that fittingness is achieved when the findings can fit into contexts outside the particular study situation and the audience sees the findings as meaningful and applicable in terms of their own experience. However, Sandelowski (1993) disputes the concept of member checking to be potentially problematical, as members may not remember accurately or want to remember certain parts of the transcripts.

Auditability or consistency refers to when another researcher is able to follow the method of sample selection, procedure, data collection and analysis, and is able to report comparable findings (Appleton, 1995; Sandelowski, 1986). This produces a

decision trail from the beginning to the end of the study. In this study, a sample of a coded transcript (see Appendix C) is included to further clarify the transition of formulated meanings to theme clusters.

Confirmability (neutrality) is achieved when auditability (consistency), credibility (truth value), and applicability (fittingness) have been achieved (Sandelowski, 1986). Each of the processes described were conducted to meet the rigor required for this study.

Leonard (1994) suggests that there are effective tools for evaluation. Criteria such as coherence, consistency and plausability do not help us determine the degree of correspondence between an account and the ways things really are, rather they help to determine how well an account serves to address the original question that initiated the line of inquiry leading to the research in the first place. It does not seek to merely describe a phenomenon but is concerned with the essence of that phenomenon.

Limitations of the Study

The sample group was a purposive and convenience sample, and therefore those perceptions of the parents interviewed cannot be generalised to other parents in the same situation. The range of experiences was limited by participant bias of one group of parent, that is the mother, and some of those mothers had been in hospital with their sick infant on previous occasions. Having the experience of a previous hospital admission can increase familiarity with hospital routines and therefore, may lessen or increase the anxiety of the admission. In addition, if fathers, single parents or a more mixed racial and cultural sample were interviewed, a more diverse range of responses may have occurred.

Ethical Considerations

Permission to commence this study was obtained from the Committee for Conduct of Ethical Research at Edith Cowan University and the Research and Ethics Committee at Princess Margaret Hospital for Children. Each participant involved in the study did so on a voluntary basis and was given the opportunity to withdraw at any time. A written informed consent (see Appendix B) was obtained from each parent prior to the interview and a copy was given to the participant. An information sheet containing an explanation and reasons for the research, and some of the researcher's background (see Appendix B) was also given to the mother as the participant. Participants were also informed of the confidential nature of the selection process and interview, including the assurance of anonymity. Furthermore, participants were informed that although the ward staff knew about the research, the staff did not know who was to be interviewed or when the interviews took place. No names were identified on records and any names mentioned during the interviews were given a pseudonym. Participants were also re-assured that on publication or presentation of the research, no names would be associated with the data. Only the researcher and the research supervisors had access to the raw data. The audiotapes, transcripts and computer discs, including a password securing the hard drive were kept by the researcher. Each of these items were stored in a locked cabinet belonging to the researcher and destroyed after five years. The audiotapes would be erased on completion of the transcripts.

The phenomenological method was appropriate for this study as is evidenced by the obsessive search for true understanding of the particular phenomenon from the individual who is experiencing "living in" hospital with his/her infant. It is an attempt

to uncover the meaning of lived experience by analysing, intuiting, and describing a phenomenon from individual descriptions of these experiences. It also seeks to understand the experience of a particular phenomenon, not the concept of that phenomenon (Salsberry, 1989), therefore, the reality for that individual is what is lived through prior to reflection, not what is thought about or conceived. The use of this methodology directs energy of the researcher towards an understanding of the self as a person as well as an understanding of the participant as a person. Through this encounter, the phenomenon as experienced by the individual becomes known to the researcher as well as the research participants.

The phenomenological method provides a sense of the “whole”. Because lived experience is the centre of attention, emphasis is not on segments or sections, but rather on the wholeness of the lived experience. The researcher is intimately involved with the participants during the interactions and focuses on understanding the participants’ lived experience, disregarding their preconceived ideas (Pallikkathayil & Morgan, 1991). Benner (1985) is quoted by Darbyshire (1994, p. 186) as claiming that “...lived experience was understood to be the ways in which people encountered situations in relation to their interests, purposes, personal concerns, and background understandings”. Phenomenology, therefore is suited to the discovery of the life experience of people, in this case mothers, and was well suited to the investigation of particular phenomena related to those “living in” with their sick infant. The philosophy of phenomenological research made the study of the human experience possible.

CHAPTER FOUR

Findings of the study

This qualitative study interpreted the common shared meanings of the experience of parents who chose to “live in” hospital with a sick infant.

The Participant Mothers

Whilst, the participants comprised eight biological mothers, no fathers were interviewed for the study. Very few fathers stay overnight in the hospital, perhaps due to work or other commitments. The female participants were all Caucasian women, aged between 25 and 35 years of age. All the women were married, and seven of the eight mothers had other children besides the sick infant. The participants were from a working class to middle class background, with all husbands in gainful employment. Each participant interviewed stayed at home with her child/children and at the time of interview had either given up work or had not worked for some years.

Although infants with a firm diagnosis of chronic illness were excluded from the study, sick infants with problems that may have long term ramifications were included. An example of such a situation involved two infants with the diagnosis of meningitis. Both infants had spent time in the hospital’s intensive care unit, recovering from the infection. The outcomes for both were positive, however, one infant had a prolonged period of recovery. The mother of this particular infant had a rich, thick description of her experiences and met the remaining criteria for inclusion in the study. Other diagnoses of the infants included five infants with bronchiolitis, a respiratory condition common to this age group, and one infant with dehydration. The length of stay for both mother and infant ranged from four days to eight weeks.

All participants were willing to share their experiences with the researcher. They were happy to allow the researcher into their homes and appeared to welcome the opportunity to air their feelings about the phenomenon under study.

Interview responses were categorised by examining the interview transcripts and identifying significant statements and common meanings. The Husserlian phenomenological stance seeks to reveal common meanings that are embedded in

day-to-day lived experiences (Diekelmann, 1992). Shared experiences and common meanings were identified and coded as themes and patterns. The researcher's observational field notes were frequently referred to for comparison of the participants' verbal responses to the researcher's own comments that were made following each interview. Provisional themes that emerged from the statements and meanings were identified and cross-case comparisons were made. The provisional themes were then collapsed in a series of stages until four essential themes remained. For example, the sub-headings of Isolation, Loss of Control and Powerlessness, Fear, Anger, Concern, Confusion, Guilt, Frustration and Stress were collapsed into the theme of Internal Reactions. A sample of the data with codes and tentative themes is included in Appendix C.

The Experience of "Living In"

Four key themes emerged from the analysis of the data. These were Internal Reactions, Issues of Communication, Role Boundaries and Learning to Deal with Hospitalisation. The subthemes related to each theme can be found in Figure 1. All participants reported feelings of isolation from their normal world as well as the physical isolation of being in hospital. The common, most important experience for the participants appeared to be the ability to adapt to both the infant's illness and the period of hospitalisation. The experience of "living in" for most participants meant that their lives on the whole, would return to the pre-hospitalisation normal routine. Five of the infants had conditions that were acute medical conditions that would improve with minimal or no sequelae and one infant went on to develop asthma. The remaining two infants had longer recovery periods, one of which had subsequently recovered fully at the time of this report and the final infant is taking more time.

The data contributed by each participant was coded using a number in parenthesis that supported each emergent theme, for example number (1) reflected the speaker from the first interview. Pseudonyms were used for the mothers and infants' names.

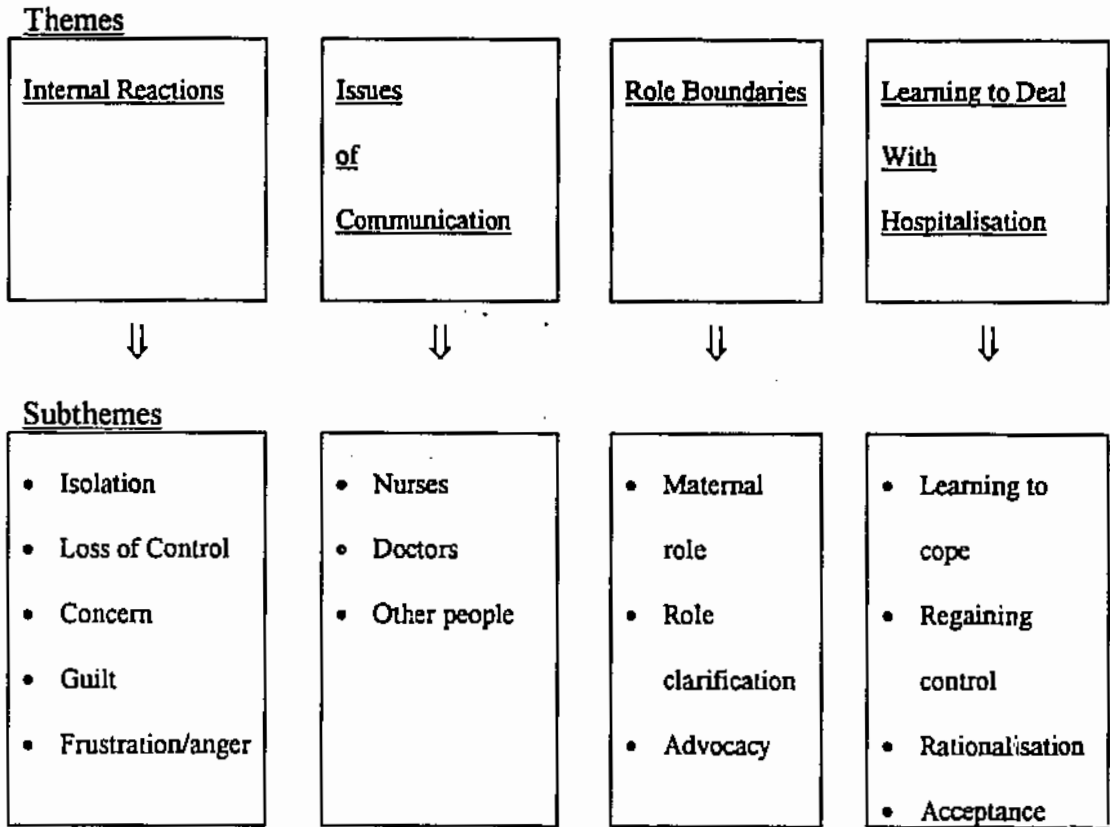


Figure 1. The parents' experience of "living in": Themes and subthemes

Theme One: Internal Reactions

All the mothers who participated in the study spoke at length about a variety of emotional responses they had during the course of their time in hospital. Subthemes that emerged from the data included feelings of isolation, loss of control, concern for the baby's well-being, fear, confusion, anger, stress and frustration. Although the word stress was not mentioned, many of the reactions and feelings discussed by the participants was interpreted by the researcher as stress. Stress, according to Selye (1956) is a psychophysiological response to a person-environment interaction, whereas Monsen, Floyd and Brookman (1992) view stress as demands which are said to exceed resources and that well-being is endangered. Biley (1989) describes the physical signs and symptoms that may occur as a result of stressors. These include feeling and looking ill, sleep disturbances, fatigue, aches and pains, intestinal disturbances, weight loss and infections. The psychological symptoms may include depression, and other psychological problems. Five mothers who were

interviewed for this study exhibited one or more of these symptoms during their time in hospital with their sick infant.

Isolation. The information provided by the participants in the study suggests that each mother felt isolated. Being away from the normal routine and the usual family life was viewed as difficult to cope with. Mothers who had other children missed them.

“I felt lonely more from a family perspective because I am out of what I am normally in, and I had so many at home that I was missing.” (2)

Another mother expressed a similar story.

“...I miss my other kids, I want to get home to them, I want to get back to normal family life.” (6)

A third mother claimed she felt lonely.

“... felt more lonely from a family perspective...” (2)

Looking past those feelings of isolation, the mothers who were in for more than a few days, going home and getting back to a normal routine was something to look forward to.

“I am going home and see how it goes...I'll start doing the shopping and get back to normal.” (5)

Isolation from friends and social contacts appeared to be a common occurrence, especially for those who were in hospital for a longer than the average length of stay. The average length of stay for all patients in the Infants Ward is about four days.

“I felt isolated from the outside world, so it was really good to have my husband come in twice a day, bringing our things in...” (3)

The normal occurrences of everyday life, for example going to the shops, interaction with friends and family did not exist when a mother stayed in the hospital with her sick infant. She was ‘cut off’ from her ordinary routines.

Isolation could also mean a psychological isolation. One mother expressed strong feelings of being alone in the world, although having many people around her. Her family was away from her and she felt desperately lonely. Furthermore, after the

infant was transferred out the intensive care unit to the ward, she longed to go back there, to a familiar place with familiar people.

“I felt very isolated, although you are surrounded by so many people, I felt very, very isolated and very uncertain and wanted to go back to ICU.” (7)

However, a different, more positive perspective of isolation was that being in a single-room was a safer place to be. Not only physically isolated in the medical sense, where the patient was nursed in a single room and not allowed near others nor permitted to socialise, but as a place where the mother could be on her own with her infant and be apart from other people.

“I didn’t feel uncomfortable about being separate from the other mothers...I know how grateful I would have been for that lovely chat I had with Mrs X who passed on influenza to my child...So I don’t hold any grudges towards sort of feeling isolated.” (2)

“Once we had moved into the room...it was my sanctuary. I had created a sort of a world in there and I was very comfortable in there.” (7)

“It just seemed a cosier place to be and there was nobody there, and this was going to be our room for x number of days.” (3)

A variety of feelings related to isolation were common to all mothers who “lived in” hospital with their sick infant. Both positive and negative aspects of isolation were experienced.

Loss of control. The participants believed that the hospitalisation period created feelings of loss of control and a sense of powerlessness, especially at the beginning of the stay. Six of the mothers felt they did not know what to expect, therefore, each felt at a disadvantage. Besides having feelings of concern and worry for her sick infant, each mother had to deal with a myriad of other issues, for example being kept waiting in the Emergency Department for sometimes many hours. One mother revealed:

“We were waiting downstairs [in the Emergency Department] for 2 hours...and I was worried.” (2)

Similarly, a second mother commented:

“...Usually a good few hours waiting downstairs [in the Emergency

Department], I think-even when we came in by ambulance. You really worry.” (6)

Feelings of powerlessness were common amongst the mothers. Not knowing the routines on the ward or how the hospital system worked placed the mothers in a vulnerable position.

“I did not know what was going to happen...” (1)

One mother felt as though she was superfluous when her infant was recovering from the illness.

“...It’s a loss of power. You can’t even take them [the baby] off the bed and give them a cuddle... You feel like you’re not needed. But there is nothing you can do about it.” (7)

Waiting for test results was another source of powerlessness. One mother felt the worry and loss of control when she could not get test results and had to wait for a number of hours.

“...You are hanging out waiting to know [the results] and basically anyone who comes in to look at the baby, you will ask them. I think that half an hour to somebody who has 20 jobs to do might not seem much, but to somebody who is just sitting there with the baby, wondering whether they are going to be OK or what the problems are, that can be really immense you know.” (2)

“We hadn’t had much to do with hospitals ...[and] it made it a little intimidating.” (3)

The mother of a baby who was re-admitted for the third time with meningitis commented how devastating the experience was for her. She felt bewildered and at a loss as to why it occurred. She stated she felt:

“...Confusion and feeling cheated as to why she [the infant] got sick again. She’s been through it all before why had she got to go through it again. I felt anger - I was furious...I was so angry...I thought this can’t be happening again, it can’t be, it can’t be. I just couldn’t believe it - the night that I brought her in, I just found it incredible.” (5)

Loss of control and a sense of powerlessness were internal reactions felt most poignantly at the beginning of the hospital stay, and at certain times throughout the stay in hospital when other factors exerted certain influences, such as test results.

Concern for the infant's well-being. The powerful and most common emotion that each participant reported was her concern and worry for her infant's well-being and health. These feelings were expressed throughout the course of every interview. Each participant recounted how everything that happened to the infant, whether it was a change in condition, a procedure, or a change in the infant's routine or habits, was a source of anxiety, stress and apprehension to them. The intensity of the mothers' feelings was overt and clearly obvious to the researcher.

"Well, you really worry about the baby...It was pretty scary... I thought he was going to die... I thought I was going to lose him." (6)

"If anything it just seems to be very draining because you are emotionally so worked up when you are really worried about a child. I mean I was worried about his oxygen...He was sitting on 87 (oxygen saturation) when I brought him in, so that made me quite concerned because I had seen how it affected him and I was wondering what else affects that sort of level of oxygen my little son could have..." (2)

"...I think we started to worry..., then they told us it was something to do with an infection so then I became alot more worried and I felt quite teary at this stage-I became quite emotional because I wasn't prepared for that news." (3)

Mothers would sleep on a foldabed or even a chair next to the cot if they could not have an ensuite room, rather than be away from the baby. This demonstrated the acute and powerful need to be not only there with the infant, but be there for their infant. This demonstrated the overwhelming concern the mothers had for their infants.

"Really all I wanted was a foldabed next to him, and I think the first night I just slept on one of those chairs..." (2)

The large numbers of health care workers, especially nurses involved in the care of the infant and therefore the lack of familiar faces, was worrisome for three of the mothers. The thought of a variety of strangers caring for their infant was seen as not being the best possible option for the infant.

“...It did feel like an endless stream of faces as they were constantly changing. I think it would have been nice to have some consistency of the nursing staff.”
(8)

Contrary to this, one mother had the benefit of primary nursing. Unfortunately, primary nursing care is only practised in certain circumstances when the infant is expected to be in hospital for a long period. She stated that:

“Since I’ve had the primary nursing team it has been really good getting regular nurses, the same nurses all the time, it has been really good because you get a bit of rapport with the nurse.” (5)

One mother described in detail how fearful and scared she felt, not knowing if she had made the correct decision to bring the infant into hospital.

“You question whether or not you have made the right decision by going to the hospital.” (2)

All mothers in this study expressed very powerful reactions in relation to the well-being of their infant. They experienced strong feelings about anything that happened to or affected their infant.

Guilt. One mother felt guilty because of her decision to have the infant in the Birthing Centre where mothers have natural uncomplicated births and can only stay 24 hours postpartum. When the infant became ill, that is, “grizzly” and stopped feeding, the mother felt as though it was her fault. She said:

“Probably one thing I felt early on was guilt for myself that I really wanted to have Monica at the Family Birthing Centre, and a lot of people have said to me ‘Oh, they send you home after a day’. I was happy with that idea...and thought I could cope with that very well, but then this happened and I felt guilty that maybe I should have gone to a normal hospital where you stay for a few days.” (3)

Guilt was another subtheme that was identified as an internal reaction by three of the mothers.

Frustration. Being in hospital, and not knowing what was going to happen to either themselves or the infant was a source of frustration for the mothers. Having an infant who was sick enough to be admitted to hospital was difficult enough, but not knowing what was wrong with the infant was distressing. This appeared to be

compounded by the staff not always explaining the diagnosis or treatments. These diverse feelings accumulated to produce frustration in the mothers when things did not go smoothly. One mother had spent many hours waiting for the admission process and subsequent procedures before arriving on the ward. She stated that she felt:

“...A bit impatient and frustrated with procedures...” (3)

Another source of frustration for one mother was that she felt the staff did not believe her when describing the baby’s sickness.

“...Like when I fed, there was no-one to watch him be sick...I would say to them ‘Well he’s been sick’, but then they would say that it was just a little bit, you know when I am trying to explain to them that it was a lot because I saw it.” (4)

This mother felt angry and frustrated as she did not feel the staff were giving her and her infant enough attention, time and credibility. She said:

“I didn’t believe that they were doing their job properly...They are there to keep an eye on the child to see...They weren’t watching his symptoms at all.” (4)

Another source of frustration was the apparent lack of communication between the mother and the ward staff.

“I talked to the doctor and basically asked him the same thing I had asked him four times already.” (1)

“...For a while there I didn’t understand what was going on and every one seemed to say something different...in the end you think, What the hell is going on.” (6)

Receiving some important test results for the infant was important for one mother’s state of mind. When test results were delayed, she was very concerned as well as frustrated.

“I think Friday was my most horrendous day because I waited for the results. And that’s one thing if anything I would say was of the greatest concern, that is when you are waiting for results to confirm something pretty nasty, I suppose you would like to be told that you are going to be told as soon as the results come through - um - that would help. You are hanging out waiting to know...” (2)

Some of the mothers' reactions to nurses and other health professionals caring for those infants who had no family with them, differed. One mother said:

"When you see that they are dealing with other kids that are crying constantly, and I mean I was surprised actually at the number of kids that are in the ward without any of their parents with them, and in that case I didn't resent it, you know what I mean, I didn't want to take up their time..." (2)

Another mother's reaction was different. She was angered by the nurses' differing treatment of infants with mothers who "lived in" and infants whose mothers went home.

"It's just really frustrating because you start to get envious of the ones [mothers] who have gone home because everything gets done, whereas when Cameron wakes up, it's me that goes to him. Frustrating because if the baby in the next room woke up, the nurses rush in and stick in the dummy." (7)

The mothers in this study all reported a variety of emotions and feelings about the time they spent in hospital with their sick infant. Many issues created stress for the participants when "living in" with their sick infant. These reactions were manifested in various ways and discussed by the participants using different explanations to clarify them.

Theme Two: Issues of Communication

Communication was a significant element in the experience of the mothers who were interviewed for this study. The importance of communication was evident throughout all accounts of the "living in" experience in hospital. Correct and timely information was vital for these mothers, as well as having their questions answered. Subthemes of communication with nurses, communication with doctors, and communication with other people were revealed by the mothers. Many of the communication issues the mothers spoke about were enmeshed in other matters, for example frustration could be actually caused by problems with communication.

Communication with nurses. According to four of the mothers in this study, the personality of the individual nurse played a large part in the structure and formation of the relationship between the mother and the nurse and the general feelings the mother had about the hospital stay. Nurses spend the most time with the

parents, being there 24 hours a day, seven days a week and therefore would exert an important influence on the parents. Whether the nurses effectively communicated appeared to be dependent upon individual personalities. These personality traits included friendliness and the presence of openness as opposed to the lack of openness. This had an effect on the way each mother experienced her time in hospital with her sick infant.

“Sometimes, I mean you get a nurse who doesn’t seem very friendly, and when you are in such a confined space, you have to communicate with everyone because it might be the person looking after your child...” (5)

Another mother accepted that people, including nurses, had their own differing personalities. This mother commented:

“...Just like every other profession, every nurse is different. Some of them come in and they sit, stay and they’ll talk to you and they are the ones I got to know...they will open up to you and you open up to them. They are the ones that you tell your feelings to. Others come, they do their job and you don’t get to know them at all.” (7)

The following mother had similar views:

“It depends on the personality of the nurse you are dealing with. For a couple of days it has just been a different personality-it might just be days where you just don’t feel you can ask-you feel you are asking too much.” (2)

This mother also spoke about how the personality of the individual nurse made a difference as to what the nurse would do for her and the infant. There was an implicit acceptance or understanding of each individual nurse by the mother. She acknowledged that some nurses would do some things and other nurses would not.

“...But if I was awake , normally I would do it [change his nappy], but it depended on the personality of the nurse. She would sometimes say ‘Oh look, I’ll do that, don’t worry’...or they might come in to bath him in the morning, for instance, and I would say ‘I’ve already done that’ and they would say ‘Oh, great’-you know-as if I’m doing them a favour...I think it sort of got down to sort of understanding that it’s just the same as being in an office. Some people are more helpful than others. That gets down to personality traits, so you got to understand it, like if someone comes and tells you these are the rules, they are different from who was on last...” (2)

Personalising the communication between the nurse and the mothers regarding the care given to individual infants endeared the nursing staff to the mothers.

“I think the nurses were attached to Monica as well. She was a tiny baby on the ward - she was given a little bit of extra attention from the nurses - so I found everyone actually very friendly and approachable.” (3)

One mother commented how important it was to her for the nursing team to communicate with each other and work well together. She compared this hospital stay to another in a different hospital and felt when a team did not work well together, it made a significant impact on the way she felt.

“..You could just tell that they just didn’t get on with each other. It was just really uncomfortable...because it wasn’t as though they were putting the patients’ needs first, they were putting their own personal position in the little pyramid of their minds, you know first, and that shows...When someone looks as if they’ve got their minds on other things, you worry about the sort of care that they are able to give.” (3)

Time spent communicating with nurses in general, was supportive and positive for some of the mothers. Those nurses who would spend more time with the infant and mother, related more easily to the mother, offering support, guidance and advice which the mothers felt was beneficial and helpful. One mother said:

“...I have always found the support to be really, really good...” (2)

Another mother whose infant was in hospital for five days said:

“...There was one nurse who was sort of looking after us, and she kept popping in, I think she was doing her best, and that seemed to take the edge off. They were all very helpful and friendly and chatty, so the time came when I was relaxed and able to chat to them.” (3)

Consistency in the nursing staff who provided care for the infant promoted effective communication between the nurses and the mother.

“It’s been really good getting regular nurses, the same nurses all the time, it’s been really good because you get a bit of a rapport with them.” (5)

Verbal interaction between the nursing staff and the mother maintained feelings of support. Two mothers commented:

“They [the nurses] talk to you all the time. I feel like I can ask them more than the doctors. Probably it’s because they are with the baby more...” (6)

“Some people would sit and talk to you and ask you what you’re doing.” (7)

Information and answering questions about the condition of the infant were important to the participants. All of the mothers mentioned that they needed to be aware of what was planned for the infant's treatments and care, and to be kept fully informed.

"I like to know what is going on and to be fully informed." (5)

Nurses who answered the mothers' questions and concerns less than honestly were mentioned by one mother as being difficult to accept.

"You might ask one [a nurse] that doesn't know what is going on a question and rather than say I will find out or, you know, I'll get someone for you, they give you really a cockamamy sort of a story. They just don't know, they are just giving you any answer, cause they feel they have to give you an answer. And that's worse, you know what I mean. Better not to...It's better to say I don't know." (2)

Each participant spoke about the lack of discussion between themselves and the nurses about what they could or could not do in relation to care given to the infant on a daily basis. There was no clarification of any guidelines that the mother could use in the participation of care. None of the mothers asked for, nor did the nurses offer, any information about who would do what in relation to the infant's care. Communication relating to clarifying goals, outlining tasks and sharing the care was not explicit.

"It's never been said or anything, but I think I made it clear without saying that, You know, I'm her mum, I'm here and this is my job." (5)

"There wasn't any sort of role defined. I just dealt with the nappy changes." (8)

Communication with the nurses was an integral part of the hospital experience for the mothers. As nurses were there every day and night to provide the care and assistance required for the infant's condition, effective interaction was seen by the mother to be important. Effective communication between the nurses and the mothers may reduce role ambiguity.

Communication with doctors. The participants' communication with doctors appeared to be related to information receiving, whether in the form of diagnosis,

explanation of procedures, a condition report, or an explanation or results of tests. A mother who had been there for seven days stated:

“I saw the doctors every day. Some of the test results took a little while... everyone was very open and explained things clearly...” (3)

“...I ask daily, I don’t know how many doctors, to try and get the information.” (6)

Another mother felt she could cope because she was told about the infant’s possible outcome following a severe illness.

“The doctor came and told me what to expect... and I can cope with that.” (7)

One mother asked the doctor for information related to her infant’s condition and treatment so she could feel more knowledgeable and therefore able to confirm treatment with the nurses.

“I’d asked the doctor often enough. I had sort of worked out if you asked the doctor what was going to happen, then if any nurses come in who aren’t perhaps certain what the background is quite, you can either ask them to read the notes [the doctor writes in the notes] or you have been told such and such [and therefore could tell them].” (2)

However, poor communication with the doctors could be seen as a negative experience. One mother whose infant had previously been in hospital, spoke about her time in hospital as difficult, confusing and hard to understand. She commented:

“I was happier about the nurses, the nursing staff and that, but I sort of didn’t really like what the doctors were doing, because they started giving me the run-around. It was, I had to ask these questions and mixed feelings and stuff that I wanted to ask, and like for a person who doesn’t understand the medical you know, I don’t know how to get the words out and ask them... They leave a lot of gaps ...when you ask them things.” (6)

Communication with the medical staff, according to the mothers was, for the most part for technical purposes.

Communication with other parents. Some of the mothers spent time with other parents when they were “living in” with their infant. This time was used for information sharing and support. Two mothers felt as though they supported other mothers with infants in hospital.

“Sometimes, some of the mums seem very private...Occasionally, you become

a listening post for them.” (5)

One mother developed relationships with two other mothers while “living in” due to sharing common experiences. This mother provided support for one mother in particular as a result of the communication between each other.

“I became friends with two mums, we met about six times. We have met up and exchanged news...I became support [to another mother] when she was screaming out...” (7)

One mother felt very positive about sharing her experiences with other mothers in the same situation. She felt that having other parents to chat to was reassuring, supportive and helpful. Listening to another mother describe the infant’s same signs and symptoms was reassuring.

“I met Kylie in the Emergency as she was in the next bed explaining her baby’s symptoms to the doctor and I had just got through explaining mine, she was exactly the same symptoms as my baby and we got talking down there and she was up in the ward as well. They are going through the same thing as you and their baby is going through the same as well.” (8)

One mother, however, felt it inappropriate to speak to others in case she spread the infant’s virus. She stayed away from other people in the ward. However, general conversations with friends and visitors were sometimes limited as life in the ward was repetitive and boring. Hospital life seemed distorted when compared to life outside, and normal conversations were difficult.

“Conversations are so limited with other people. My mum comes up here and half the time we sit there and don’t say anything...and I said ‘I’m really sorry the conversation’s a bit thin’. She said ‘Well, don’t worry, I understand’. That’s because there’s not a lot to do in hospital, apart from reading, or going for a walk and constantly eating.” (5)

It’s just that you don’t really have any interest in the outside world because it’s not your outside world. “ (7)

Communication was seen by the mothers interviewed for this study as an integral part of the hospital experience. Interactions with nurses and doctors appeared to be an essential component to the hospital experience. Poor communication could have a negative effect which could lead to added confusion and

increased anxiety. Interaction with other people could be either supportive or a burden for the mothers.

Theme Three: Role Boundaries

All the mothers interviewed in this study commented that there was very little communication with the nursing staff about what role the mothers were expected to take when “living in” hospital with their sick infant. Nurses, according to the mothers in the study, did not discuss either their role or the mother’s. The role of being a mother to a healthy infant is different to the role of being the mother of a sick infant. However, the mothers ultimately assumed their own maternal role while “living in”, which they had prior to being admitted to hospital, although some mothers mentioned how unsure they felt about doing that.

“I didn’t understand what the role of different people actually was. You had no understanding of what was your role and what was their’s and all of that.” (2)

“I didn’t know whether I was supposed to be there full time or whether I was allowed to, but I mean I felt silly asking, but I didn’t know whether I was allowed to leave for an hour or two, but I just felt like I should be there holding him. I mean I wanted to be there holding him too, but I felt I had to be responsible for my own child. But that’s because I didn’t know any other way...I saw other people going out for two hours or whatever, but I didn’t know whether I was allowed to do that sort of thing...” (1)

Maternal Role. The maternal role was described as the mothers’ ‘raison d’etre’, why they were there with their infants. Given time, the following mother was able to assume her own maternal role. She stated:

“I worked out what to do for him through his needs. If I thought he needed a nappy change - I would change it - the same as I would do at home. I just did it. So I had the role of ‘care mum’ as they [the nurses] were the professionals.” (2)

Meanwhile another mother simply tried to continue her mothering role. In her words:

“Well, I just fed him normally when he could feed, because sometimes he couldn’t feed because they had him on drips, and then I just changed him and bathed him and just did those things...” (6)

By contrast, another mother could not continue her role immediately following admission. She observed from a distance and started to become involved when she felt she could:

“I would just stand back watching. Because he was so dependant at that early stage, there was little I could do. Slowly, I was to feed him with the syringe and so forth...” (7)

Role clarification. Roles were not clarified at any time during the period of hospitalisation. One mother believed that this would be difficult for mothers if it was the first time in hospital with the infant. This particular mother had three other children and felt as though she had the advantage of previous illnesses and hospital experiences.

“It was never made clear that this would be the case and that would be the case [that is the nurses discussed with the mother what each role entailed]. I think it could lead you to feel that either the other person’s not doing their job or you are looking like an idiot for not doing your bit. It can leave a funny feeling.” (2)

Another mother was able to see it from the nurses’ perspective:

“On their part, I guess they [the nurses] knew it was a traumatic experience for the parent and they did not want to burden the mother with having to take on all these extra things.” (8)

For one participant, it depended on the individual nurse as to what role the mother could take. Different personalities seemed to influence the communication.

“Like if someone just walked in and changed his nappy whilst you were also in the room reading the paper, for instance, I didn’t jump up and say ‘Don’t do that’. But I mean, it didn’t happen that often, you know what I mean, and that’s why I’m saying it depends on the person on the shift as to what sort of role they wish you to take...” (2)

Not knowing the ‘rules’ related to roles could be difficult and confusing for the mothers. One mother who had felt this stated:

“It was terrible...you had no understanding of what was your role and what was their’s and all of that.” (2)

Mothers who had not been in this situation before believed they did not know what to expect. One mother claimed:

“It [the need for hospitalisation] came along so unexpectedly that I didn’t have time to build up an image [of my role] in my mind.” (3)

Roles appeared mixed, sometimes nurses would ‘help’ the mother, for example during the night the nurse would change the infant’s nappy. Although the nurses took over some of the mothering tasks, two mothers found it to be helpful. Their responses included:

“...Actually one thing I found good was at night time a night nurse would come in and take his obs and that and ...they had already undone his nappy, sort of changed it , so that was really good.” (2)

“They [the nurses] said if you want to have a sleep, we’ll get baby up, you know like, we’ll get baby up and we will bottle feed him tonight...” (4)

Although roles were mixed and left unsaid, the mothers tended to assume their roles as they had them prior to hospitalisation, for example mothering tasks such as feeding, bathing and cuddling, albeit with uncertainty at times.

“Initially I didn’t know, no-one really told me that I had to look after Monica myself, and I just assumed that the nurses would. It then dawned on me that that was my job, I was Monica’s mum and I had to do all the mothercraft for her - it didn’t take too long.” (3)

Even in the early stages of the hospital stay, although the mothers felt unsure about the “rules” pertaining to what they could or could not do, two of the mothers still attempted to maintain their mothering roles.

“It just came naturally...I just did it.” (5)

“I just done what I done at home.” (4)

Seven of the mothers stated that they picked up signs from their infant’s condition as to how much they should be involved in the care. As there was minimal interaction with the nursing staff related to specific roles, some mothers had to assume what they were doing was acceptable, to both the infant and the staff.

“When her temperature had stabilised and she could be handled and she seemed to be happy to be handled. Before when I picked her up she would get upset with that. I’d just give her a gentle cuddle...” (5)

“He is my baby so I just did it [looked after the baby]. Well I cuddled him and fed him and bathed him and did all the normal things you do...” (6)

Advocacy. The advocacy role was assumed by some of the mothers when they believed they needed to intervene on behalf of their infant, whether it was for general or specific information or issues relating to the actual care given. One mother felt her infant and his siblings were contracting too many infections and spoke to the consultant physician about the possibility of doing specific tests to discover why.

“I talked to the doctor [name supplied] about it, she sort of explained that with number of kids that you had that you tend to bring [diseases] home. I also made it quite clear to her that I was concerned about the others because they spent every winter with virus, ear infections, the works, you know - it’s not something you can handle. So I just wondered if there was something - I did suggest to her then, are there any tests that you can do on the other three to sort of check and see what they are like.” (2)

The same mother would also ask the nursing staff to perform extra tasks, for example taking the infant’s temperature if she felt the infant was too warm. The advocacy role, however, was sometimes ignored by the medical and nursing staff. This produced negative responses in the mother. Her interpretation was that no-one listened to her.

“...and like I would say to them, well he’s been sick, but then they would say that it was just a little bit, you know when I am trying to explain to them that it was a lot because I saw it...” (4)

Trying to ‘normalise’ the hospital stay, to make it more like home for the infant was another advocacy role the mothers assumed.

“Reading, walking around the ward, talking to people. Because she needed a lot of stimulation - she needs the same stimulation she would get at home. She’d get that same sort of treatment at home, but had I been at home and just come to visit each day, I couldn’t give her the stimulation she needed being in the hospital and away from home and family. I know the nursing staff can’t sit around with her 24 hours a day, so it’s logical for me to be with her and bond with her...” (5)

There were no clear role boundaries for the mothers in this study. No specific information was given to the mothers to enlighten them regarding what they could or could not do in relation to their infants’ care. However, as time went on, these mothers assumed that they could perform mothering tasks for their infants.

Theme Four: Learning to deal with hospitalisation

The hospital experience was essentially unknown to five of the eight mothers interviewed in the study. Giving birth to the infant and the consequent stay in hospital following child birth was no preparation for this type of unexpected admission, that is, an acutely sick infant. It was a frightening occurrence for mothers when their infant became ill, the process of admission, the wait in the Emergency Department and then the move to the ward with a sick infant. Once established in the ward, the mothers could gradually begin to acclimatise to the surroundings and as the infant's condition improved, relax and feel safer in the environment. For six of the mothers interviewed in this study, at the time of discharge, their infant's condition had improved until the infant's health status was back to nearly normal. However, two of the infants had a serious condition and the recovery phase lasted longer than the time they spent in hospital. Therefore, at the time of interview, the infant's condition was still in the rehabilitation stage.

Learning to cope. In the beginning of the hospital stay, the mothers felt they could not participate in the care of the infant. This was for two major reasons. The first being they did not know what to do and did not understand the hospital system. The second was the infant was too sick to be handled. One mother said it all in one simple sentence:

“You can't know or be prepared to go into hospital, in our case you don't know what is going to happen, so you can't go there for a rehearsal and become accustomed to the environment...” (3)

Another focussed on the severity of the infant's illness and claimed:

“I knew that there wasn't alot that I could do in the first couple of days when she was very sick...” (5)

As time went on, one mother commented that she watched other mothers to see what they did and assumed she could do the same. The modelling by other mothers who had been there before, enhanced the following mother's own way of coping with her painful experience.

“Perhaps seeing other mums in the rooms next door, and I could see they were

doing it [physically caring for their baby] all the time, I just took it upon myself to follow along.” (3)

As the infant’s condition improved, the mothers commented that they felt more comfortable being involved in the care.

“...As she started to get better and I could start feeding her again, bathing her, and just being a mum again, but when they are sick you can’t do that.”(5)

“Well, I just fed him normally, when he could feed, because sometimes he couldn’t feed because they had him on drips, and then I just changed him and bathed him and just did those things, cuddled him...” (6)

The experience of having to stand back and watch while the infant’s health slowly improved promoted gradual acceptance of the situation for one mother whose infant had been very ill in the intensive care unit and had subsequently been transferred to the ward. Recovery was slow and so maternal participation was limited.

Regaining control. Two of the mothers felt that they became more involved in the care after some time had passed and could feel more in control of their circumstances.

“...So the time came when I was relaxed...As time went on and I relaxed and things started to improve, I was able to chat with the nurses a bit.” (3)

“It’s changed as the weeks had gone by and then I got to a point where I could sit and read and could do needlework, and I could leave the TV on and that kind of thing. In the beginning, I couldn’t concentrate on anything, I couldn’t read a book, even though I had the time and had it in front of me, my brain could not relax. Your brain is so stressed out by everything, and it’s so tired, you cannot read, you put the book in front of your face and you cannot read the words. I became relaxed and I got more sleep, so I could read and could do things.” (7)

One mother made the comment that she watched what the nurses did to work out what she could do for her infant. This could help her to adapt to the physical aspects of the infant’s care, for example intravenous therapy, various tubes and oxygen equipment and be able to help with the on-going care of her infant.

As nursing roles remained implicit, rather than explained, areas of nursing responsibility appeared to be worked out by default, rather than by design. The

mothers, it would seem, were expected to be able to be intuitive and automatically adapt to the situation without any assistance.

“Because I had worked out what was their area of responsibility and I thought that they probably wouldn’t be able make any difference- do you know what I mean?” (2)

Towards the end of the stay in hospital, all of the mothers appeared to know what was expected of them and they participated in the on-going care of their infant. They believed they got to know the routine of the ward, recognised more familiar faces and became more confident in handling their sick infant.

“I understood how the system worked...[and] I think it’s an advantage...I like to know what is going on and to be fully informed...” (5)

“I just did what I wanted to do. I think alot of it was because I knew the limits. I knew what I could do down at [another hospital] and the things that you are allowed to do, I did, and I knew while she was sick there wasn’t alot that I could do, it was best if I left her to rest...and then as she started getting better and she could be bathed, and cuddled and I knew that I could sit by her cot and hold her hand and things like that...” (5)

Another factor mentioned by the mothers was they felt relieved and more relaxed as the infants’ physical condition improved.

“...Once he gets over that initial first few days and he starts to come a bit betterthen I feel alright. I know he’s in the right place he could be.” (6)

Rationalisation. Coping skills were exhibited by seven of the mothers. From the beginning of the stay in hospital until discharge, these participants showed implicitly how they learned to cope with the episode of their infant’s illness and the period of hospitalisation. Although coping occurred in individual ways, many of the participants used similar approaches. Mothers who had had prior experience appeared to cope better than the mothers who were “living in” for the first time.

Rationalisation of the hospital experience was a common method used. One mother needed to justify her decision to bring the infant into hospital.

“After a little while I thought this is the best place for us to be because if there was a problem with an infection then hospital is the best place for her to be.” (3)

Acceptance. As the time in hospital progressed, seven of the mothers felt they had no choice but to accept what was happening and just get on with it all.

“He’s in here really because of the care he needs and when he needs oxygen, he can’t have that at home, so you have to sort of think, well you don’t really like it, but that’s the way it’s got to be.” (6)

“You have to tell yourself that it’s all for the best for him to get better.” (7)

Support from other people, including husbands and families, helped the mothers cope with their time in hospital. Support appears to be conditional to learning to cope. One mother said she was glad when her husband spent the day with her. Another mother felt more able to cope with the hospital experience because her husband would spend time with her during the day for lunch and dinner.

“Andrew [the husband] would come in for lunch and dinner, so I would really look forward to and usually have a break and a bite to eat or Andrew would bring in some lunch and we would have that together...that was great to get out of that hospital environment...” (3)

A third mother revealed the significance of family contact.

“My family have been unreal. I mean they always are - they stand by you, and the two families pull together which is really good, they’ve been great.” (7)

The commitment of all the mothers to their infant was evident throughout the course of the hospital stay. They chose to stay with their infant and therefore their lives were dramatically altered, however this is not to say that mothers who did not live in were not committed to their infants. Their particular circumstances may have dictated different situations. The commitment appeared to enable these mothers to persevere and continue on throughout the most difficult times.

““You do it [be there for the infant] because there is this inner strength of ‘I love you because you are mine’ and you still have those moments when you cuddle him up and things...” (7)

“There was no way I was going to just brush it off (the symptoms) and say she’s going to be okay - she was sick - and that’s why I had to get myself together to drive to hospital, so I gathered everything together and got the strength as you do, from somewhere, wherever it is and drove here.” (5)

Two of the participants suggested that this particular episode in hospital was a “life experience”, that their lives were being tested and that they would never be the

same again. There were no choices when it came to looking after the sick infant, and consequently the situation had to be managed and accepted. The majority of mothers coped out of pure necessity, to put their own concerns and fears aside and focus on being there for their sick infant.

“A lot of the mums say that they don’t think they could cope, but I think you cope because you have to.” (5)

Summary of Themes

The experiences of the parents who “lived in” the hospital with their sick infant in this study were viewed in terms of what the experience meant to each of the mothers. Each of the women experienced powerful emotional changes which included feelings of isolation, loss of control, concern for the infant’s well-being, guilt and frustration. These emotions were collapsed into the theme of Internal Reactions. Issues of communication played an important part in the experiences of the mothers who were involved in the study. Communication between the nurses and the mothers helped to support the mothers while the interactions with the doctors appeared to be for information. Both negative and positive forms of communication were experienced. For all the participants, their own individual role in their infant’s care was not always clear and boundaries were not defined. The mothers described how they assumed normal mothering tasks as time went on and at times needed to act as an advocate for their own infant. The period of time in hospital seemed to be a difficult time for mothers who had to learn to cope and adjust to a sick infant while living on the ward. Regaining control and finally acceptance were noted as part of the coping and adapting processes for these mothers.

CHAPTER FIVE

Discussion

In this chapter, the findings from the study are discussed in relation to each of the themes and the relevant literature. A second level of analysis utilising a nursing theory is undertaken to further validate the findings and encourage additional discussion relating to the application to existing nursing knowledge and theory.

The Themes

Different aspects of the phenomenon of parents who are “living in” a hospital ward with their sick infant are discussed under the four key themes of Internal Reactions, the Issue of Communication, Role Boundaries, and Learning to Deal with Hospitalisation.

Internal Reactions

The findings from this study suggest that parents who “live in” the hospital ward with their sick infant experience various internal reactions. Many different emotions and feelings were expressed by the participants as being part of the hospital encounter.

Feelings of isolation were described by the participants as being common in the hospital experience. Being isolated from the family and the other children generally had a negative impact on the mothers, but there were periods when the isolation and being able to shut the door, was seen as a haven away from the bedlam of ward life. Stull and Deatrack (1986) described that parents actually want some time alone in order to rest, to have some relaxation and to “refuel”.

Mothers who had other children at home felt isolated from them, missed them and wanted to get home to be with them to resume a normal routine. The mothers

felt a loyalty dilemma between the sick infant and the other children who were often left in the care of family or friends. However, it was generally felt that because the infant was ill, the infant's needs were the most important issue for the family at that particular time. This required the parents' devoted time and energy. Gill (1987) describes children in hospital as having "separation anxiety" if parents are not there, and comments that parental participation actually reduces both the children's and the parents' anxiety. One mother commented that she had no choice and had to be with her infant, otherwise she would not be able to cope.

The participants discussed feelings that related to loss of control. These feelings were mentioned in the literature as being common (Callery & Smith, 1991), especially in parents with a chronically ill child either as a patient in hospital or being cared for at home. Although in this study, chronically ill children and their families were excluded, parents of infants could be said to care for their infants a similar way that a child with a chronic illness is cared for. These chronically ill children are dependent on the family and health carers for food, shelter, care and love (Ayer, 1978).

The mothers in the study felt they were at the "mercy" of the staff, and those mothers who had not experienced hospital life previously, felt at a disadvantage as they did not know how the hospital "system" worked. This minimised their feelings of control and decision-making regarding their infant's care in hospital.

A very young child is dependent on caregivers to meet his/her needs. Through the bonding process, mothers become the expert in the interpretation of their own infant's behaviour and meeting his/her needs. Schepp (1992) claims that mothers may not always feel confident about other people who have not bonded to the infant, and

therefore, not be able to meet the infant's needs accurately or in a timely fashion. The mothers who participated in this study believed that this was the case for them and that no nurse could ever know their infant as well as they did. The mothers mentioned their worry about the many various people who were involved in the care of their infants.

Parents are assumed to know and want what is best for their children, therefore parental autonomy in making decisions is highly valued in our society (Casey, 1988). However, the participants felt that although they make all the decisions for their babies at home, by coming into the ward situation, some of those decisions were ignored or disregarded. They had to hand over the control to virtual strangers.

Schepp (1992) comments that parental control preference, that is when the parent chooses what care they wish to become involved in, is one of several concepts that may contribute to mothers' satisfaction with the care given to their child in hospital. It may reduce the amount of stress that mothers experience when their child is admitted. Mothers feel more in control if they feel they are "doing" something for their infant. Similarly, Stower (1992) describes her children's unit nurses as being partners in care. The family is encouraged to continue caring and the nurses are actually the ones to "deskill", rather than the parents. The nurses teach the parents tasks and skills and act in an educating role rather than delivering the care. Taking away the skills of parenting from the child's natural carer may have destructive effects on both the child and the parents.

By contrast, Callery and Smith (1991) suggest that there has to be a balance of power between nurses and parents in the control of care of the child. Implicit in the

decision to take a child to hospital is a degree of relinquishment of control by the parents. Mothers in the study mentioned that there were nurses with certain personalities who encouraged parental participation, others who helped the mother with the infant, and others who would just "do their job" and that was all.

"...only because I wouldn't have understood what the role of different people actually is. And it depends also on the personality of the nurse you are dealing with. For a couple of days it has just been a different personality - it might just be days where you don't feel you ask - you feel you are asking too much."

(2)

The mothers in this research, although accepting of the variety of personalities of the nurses, would like to see consistency in practices. This would help clarify roles for the mothers or establish a pattern of care that was likely to be acceptable and consistent to all carers concerned, including the mother.

Each mother emphasised the worry, anxiety and stress she felt when her infant became ill and she realised that the infant had to go to the hospital. The findings in this study are similar to other research findings which describe anxiety and stress as common reactions parents have when a child is admitted to hospital (Etzler, 1984; Knox & Hayes, 1983; Monsen et al., 1992). Darbyshire (1994a) describes the uncertainty and anxiety that parents feel as they face their child's illness. He believes it to be part of the dread they experience when they are confronted with the possibility that their child, and therefore themselves are threatened.

Schepp (1991) describes how the anxiety levels of parents were found to influence outcomes such as the parents' satisfaction with the care given to their children, their co-operation with the treatment program for their children, and their perception of the seriousness of their children's illness. High anxiety levels seem to have a negative impact on parental outcomes. Each mother in this study stated how the experience of having a sick infant and having to be admitted to hospital was an

extremely anxious and difficult time for her. One mother felt that her anxiety and stress levels decreased as the infant's condition improved and she became more involved in the day to day care. This concurs with research described by Schepp that suggests that parental anxiety levels decreased as they became more involved in the children's care and when they were able to assist in the decision-making process.

Schepp (1992) suggests that mothers who had only one child reported experiencing more stress during the period of hospitalisation than did mothers who had more than one child. This finding concurs with comments made in this study by one mother who felt like an 'old hand', dealing with the illnesses and problems of her children after her fourth child.

Gill (1987) states that parents experience a variety of emotions that include fear, guilt and separation anxiety. Graves and Ware (1990) describe stressful stimuli, as being parents seeing their child suffer pain, having a lack of understanding about hospital routines and knowing that the child has to undergo painful treatments. However, encountering this form of stimuli often leads to stress, but the degree of stress may vary from person to person. The response from the mothers in the current study described intense emotions encompassing the admission and hospitalisation of the infant. Concerns included worry about the infant's health and the outcome of the disease process. One mother was too frightened to ask if her infant was going to die and was relieved to the point of tears when told the infant would survive. Her relief was not achieved until she was being discharged home.

Literature supports the views of the parents in this study that feelings of anxiety and depression, and lack of information are key issues for the parents

(Carpenter, 1980; Palmer, 1993). In this study, many of these emotions abated as the infant's condition improved. This is different from the parents of a child who has been diagnosed with a chronic disability who, according to Wyckoff and Erickson (1987), have feelings of grief, anger and depression as they come to terms with a different child and mourn the loss of the previous healthy, normal child. One mother in this study described these same feelings, as she had to come to terms with a infant who was very slowly recovering from a serious brain infection.

Kostrzewa (1985) described the two dimensions of stressful circumstances for parents, firstly the immediate stress experienced on an individual basis and/or a family level and secondly, the stress involved in existing in the larger system, namely the complexity of the hospital. Becoming part of hospital life and understanding the way it worked and how one fits into it, were experienced by the mothers in this study. More than one admission helped the mother become accustomed to the system and therefore understand it and cope better with the hospital admission.

Feelings of guilt were mentioned as part of the hospital experience. One mother felt that she may have caused the problems that led to the hospitalisation of her infant.

“One thing I felt early on was guilt for myself that I really wanted to have Monica at the Family Birthing Centre, and a lot of people said to me ‘Oh, they send you home after a day’. I was very happy with that idea and had sort of said to people ‘Oh, that’s not a problem...’and I felt I could cope with that very well, but then this happened I kind of felt guilty, that maybe I should have gone to a normal hospital where you stay three or four days. That was probably a bit of guilt coming through...” (3)

Knox and Hayes (1983) suggest that parents sometimes may feel partly to blame for their child's illness as well as questioning their own abilities as parents.

Internal reactions are a common experience of mothers who reside in the hospital ward with a sick infant. Feelings of isolation from families and friends, and loss of control add to feelings of powerlessness. Frustration and guilt are emotions described by mothers when they are "living in" the hospital with their sick infant.

Issues of Communication

Communication is the basis of all human interaction and involves the sending and receiving of messages between two or more people (Hein, 1980; Porritt, 1984). Communication has been seen in the hospital as problematic (MacLeod Clark, 1985) and a lack of information is seen as an issue for the parents of sick children (Carpenter, 1980; Palmer, 1993). Parents who have a sick child in intensive care felt that the need for information and participating in the child's care were very important issues (Farrell, 1989). Hostler (1991) states that parents want all available information, both the information that pertains to the child's condition and the information about the emotional issues related to the illness. Melnyk (1994) suggests that accurate information for mothers will enable them to understand what is to be expected from the hospitalisation of their child and will help to develop strategies for their coping. Findings from this study revealed these mothers had similar expectations or perceptions.

According to the findings in this study, nurses and doctors had different roles in the issue of communication. Each parent has different wants and needs, therefore it may be necessary to communicate in different forms (Jackson et al., 1978). Etzler (1984) commented that physicians were the primary source of information concerning diagnosis and prognosis. The findings from this study suggest the same.

The mothers in this study believed the communication with nurses was important to the overall experience of the stay in hospital. Individual nurses had individual relationships and reactions with parents and their children. Darbyshire (1994a) commented that nurses who were warm and friendly were appreciated and sought out by some parents. Parents were more enamoured with nurses who took time and had a special interest in their child. This was reflected by the remarks made by mothers in this study.

“It’s been really good getting regular nurses, the same nurses all the time, it’s been really good because you get a bit of a support from them.” (5)

Ayer (1978) nearly two decades ago made some pertinent comments relating to the nurses’ perceptions of parental participation in care which appear to be relevant to the findings in this study. These comments included that nurses may make assumptions about the amount of care that a parent wants to participate in and this may not clearly represent the parents’ wishes. This has been shown to be relevant in this study as some mothers noted that the nurses did not appear to discuss parental wishes in the care of the infant, but assumed that the parents would implicitly know what to do. This could put the mothers in a very awkward position and could even limit the willingness to communicate effectively with the nursing staff.

Schepp (1991) described a study where mothers in a paediatric hospital were interviewed about their child’s admission. This study found that there were certain variables, predictability of events and anxiety that could predict outcomes about maternal coping. Findings from that study showed that if mothers felt they had information about what to expect, they would feel better about the event. This was reflected in this study as the participants believed the more information given to them about the infant’s condition, the better and more confident they felt. However, whilst

one mother said the information received from the nurses was useful, the doctors could not explain things to her in a way she could understand. This precipitated feelings of anger and negativity about the phenomenon of concern.

As an adjunct to the issue of communication, negotiation skills have long been seen as an important part of nursing care (Stower, 1992). Negotiating the care between the nurse and the parent keeps channels of communication open and emphasises the important role that parents can play. According to Stower, the ability to share the care has benefits for the child, the parents and the nursing staff. The mothers in this study concurred with these comments and felt that there were benefits for both themselves and their infants if they could participate in the infant's care. These benefits included feelings of being valued and being able to make a difference to their infant's care.

Palmer (1993) suggests that parents who are informed and aware of what is happening to their child are able to demonstrate appropriate behaviour and positive attitudes towards hospitals, staff and medical treatment. More involvement in the care encourages parents to learn, and therefore, be more educated about the discharge care for their child (Palmer, 1993). This was evident in this study as one mother demonstrated this by learning how to tube feed the infant prior to discharge and was able to continue once at home. This mother felt her ability to do this was because some of the nursing staff had encouraged her through their educative practices with the mothers.

“People would ask if I wanted a go at doing something like feeding him with a syringe or even giving him medications and feeding him with the tube.” (7)

Melnyk (1995) proposed that giving specific information to mothers about their children's hospital behaviour could reduce maternal anxiety levels. This she

believed could be due to an increased understanding, predictability, and confidence because they had been informed about what behaviours to expect. The mothers in this study felt more confident and less anxious when they were given the information they wanted.

Furthermore, parents can be seen as support for other parents who are experiencing similar problems and fears (Palmer, 1993). Hostler (1991) suggests that parent-to-parent support is unique and different from support from health care professionals and comments that parents described the shared experience as very powerful. This support is seen as respect and empathy between parents without the issue of clinical assessment. Parents who are encouraged to get together with other parents can form relationships that can create a sense of belonging (Hardgrove & Rutledge, 1975), especially when the parents share similar experiences and issues. Although that particular study occurred over two decades ago, it still holds true for some of the mothers in this current study. Only one mother mentioned her role as a support person for others as being difficult for her because she was tired, weepy and totally concerned about her infant's future. However, she sought other mothers for support during her own troublesome times.

“I spoke to other mums...I told them what I thought about doctors and stuff, and they had similar reactions...I spoke to other mums who had little kids in there, little babies” (4)

Role Boundaries

One of the most stressful experiences for parents when their child is hospitalised is the sudden change in the parenting role (Miles, Spicher & Hassanein, 1984; Schepp, 1992; Snowdon & Gottlieb, 1989). The role relationship most disrupted is that between the parent and child. Literature supports that parents would

like to participate in the care (Snowdon & Gottlieb, 1989) but little has been demonstrated as to what role/s the parents take when in hospital. The findings from this study would concur with this, as the mothers, although wanting to be involved with their babies' care, did not know what to do, or how to go about doing it.

Palmer (1993), and Snowdon and Gottlieb (1989) claimed that the parent who has to make the change from the role of "parent-healthy child to parent-ill child" will experience a great deal of role conflict. Jay (1977) called this "role revision". The role of a parent of a healthy child is predictable, however, when the child is ill it is difficult to forecast how the child will behave and how the child will react to the parents (Palmer, 1993). Once the parents can learn the new role they have to assume that role fulfilment can then occur. The family is generally responsible for the health, physical and emotional needs of the child at home (Hostler, 1991). However, in hospital this changes and the parents feel they take a back seat to the health care professionals in the care of their infant. This may affect the relationship the parents have with the nursing staff. This study confirmed that this can occur as once the mothers were permitted to participate in the delivery of some form of care, they felt more comfortable and more relaxed in the ward situation. Darbyshire (1994a) suggests that if the parent-child relationship is characterised by power, then hospitalisation will disrupt that understanding. The parents who usually dictate the terms of how the child's life is run do not have that power once the child is hospitalised. They are powerless in terms of the illness and even have to relinquish some or all of the care to the health care professionals.

Research suggests that a re-alignment of roles cannot take place if there is not major adjustment by both the nurse and the parent (Callery & Smith, 1991) and

although it has been suggested these roles should be negotiated, there is a question as to whether it actually occurs in practice. Findings from this study indicated that negotiation about roles did not take place with the mothers at any time during the infant's admission in hospital. As a consequence of this, adjustment to the new role occurred at the mothers' own instigation, thereby delaying adjustment to hospital and increasing the risk of a more difficult stay in hospital for the mother. Brown and Ritchie (1990) agreed with Darbyshire (1994a) who found similar patterns and that parents who resided in the ward with their child seemed to have no clear idea as to what the nature or extent of their participation in the child's care might be.

The transition to the maternal role is a period of re-organisation in a woman's life that involves adding the mothering role to a set of roles that already exist and vary according to a particular stage in life (Mercer, 1985). Maternal role attainment (Mercer, 1985; Rubin, 1967 a & b) is when the mother achieves competence in the role and integrates mothering behaviours into her life and she feels comfortable with her identity as a mother. Walker and Montgomery (1994) suggest that a mother has learnt her child's characteristics and patterns by the first month and has formed a stable image of the child and of herself in relation to the child. At this point, there exists security and confidence in knowing herself and the infant. Judging from this finding, it is no wonder then that mothers with young infants express concerns when strangers who have not bonded with their infants must care for them. Jay (1977) discusses the maternal role first described by Rubin (1967 a & b). Rubin's theory described maternal role acquisition, crisis intervention, and maternal touch when a woman becomes a mother for the first time. It was purported that each time a mother has an additional child, she must again go through the entire process of griefwork,

mimicry, and projection-introjection which will end in the mother's sense of identity, as mother to the new child. Jay (1977) believed that a similar process occurs in parents when a child becomes acutely ill. These stages help in adaptation to the experience of the hospital admission. The mothers in this study exhibited some of the characteristics described by Rubin. An example could be griefwork, where the mother must let go of a former identity in some role that is incompatible with the assumption of a new role (Rubin, 1967a). Griefwork is a review of a former self and this was demonstrated in this study by each mother whose previous role was altered to accommodate the new role as mother of a sick infant.

Johnson (1993) described the identification of possible roles that the parents may assume when "living in" hospital with their sick child. These roles were predominantly the worker role, with the visitor role and patient role evident to a lesser degree. The worker role included emotional support, physical care, monitoring care provided by medical/nursing staff, advocate for the child, the helping role, and decision making role. These roles were corroborated by the findings in this study. The visitor role represented those parents who, although they were in the ward actively caring for their child, they wanted at times to be able to take on the role of visitor and allow the nurses to provide the care to the child. This was apparent in this study as occasionally the mothers wanted a break and wished the nurses would take over.

"You start to get envious of the one who's gone home because everything gets done, whereas when Cameron wakes up, it's me that goes to him. It's frustrating because if the baby in the next room wakes up, the nurses rush in stick in the dummy." (7)

The patient role, described as being dependent on the nurses as well as the child, was not apparent in this study.

Jackson et al. (1978) described research that ascertained parents' roles in the care of their sick children. They described that there was very little difference between what parents preferred to do on day three and what they actually did on day three, and most were involved to the extent that they wanted. Although this research is relatively dated, this is reflected in this current study, although specific days were not mentioned. Parents eventually did what they wanted to do in terms of participating in their infant's care, but they did it without discussing guidelines or negotiating any rules.

Hardgrove and Rutledge (1975) claimed that supporting and coaching parents in tasks beyond just the mothering tasks, for example watching intravenous therapy and weighing nappies, would engender feelings of being part of the team and would help in the quest for holistic family-centred care. The mothers in this study agreed that being part of the team was a positive step for them. Hardgrove and Rutledge made the comment that parents are willing to help the nurses, but they may hesitate for fear of doing the wrong thing. Van der Schyff (1979) reported similar findings and suggested that parents felt uncertainty about their role in hospital and therefore sought approval from the medical staff.

Farrell (1989) found that parents felt very strongly about their need to be their child's advocate and a number of parents felt that the staff did not always listen or appreciate the background knowledge of their child. Findings in this study agree with this, although in one instance when the infant was admitted with a repeat illness, the medical staff believed the mother's intuitive feelings about her infant's condition.

Learning to deal with hospitalisation

As the parents in the study became used to life on the ward, they appeared to adapt to their surroundings and change in roles. Callery and Smith (1991) described the changes that are required by parents to cope with the hospital experience. These are that parents need to understand the illness experience, become familiar with the hospital environment, adapt to the changing relationship between the child and the other family members, and negotiate with the health care professionals about their child's care. These changes are mentioned at length by the mothers in the study. Although the mothers did not explicitly state these issues in those terms, the researcher of this study interpreted that this in fact was what had occurred. Each mother described the need for information about the infant's illness and stressed how important information and effective communication with the staff was to them. The mothers who had been exposed to hospital life before, believed they had an advantage over parents who were there for the first time.

Philichi (1989) described family coping on two levels of interaction: the first being the way a family internally deals with problems and difficulties with its members and secondly, the way a family works externally with problems in the environment that affect the family and its members. Childhood illness affects the entire family and interferes with the structure and function of the family, as well as challenging the established patterns of behaviour. To maintain a balanced system during a child's hospitalisation, the family must be able to adapt to the situation while maintaining the emotional bond. Mothers in this study exhibited a range of strategies for adaptation to hospitalisation. Although adaptation was not seen as a conscious decision by the mothers, various behaviours were expressed and interpreted as adaptation by the

author. Accepting the ways things were was one instance where the mothers appeared to adapt.

Etzler (1984) believed that encouraging parental participation in the care of their child helped to facilitate adaptation to the hospital admission. However, trust must first be established between the mother and the health care team. This was not explicitly stated during this study, however, comments regarding the relationship of the mother and the staff inferred trust had developed in all mothers except one. This mother felt let down by the whole experience in hospital with her infant.

“Well, I don’t think I’ve come any further than what I had the week before, and I was only in there for one day, and I was there for seven days this time...I didn’t get anything out of it. They were not giving me any straight answers and I was frightened.” (4)

Parental reactions to hospitalisation can vary tremendously, and much depends on the individual’s coping strategies as well as the number of times the family has been exposed to the experience of hospitalisation. In this study, mothers who had experienced hospitalisation with their infants before, felt they had an advantage over mothers who were there for the first time. Previous admissions had prepared them, in fact had allowed adaptation to occur more quickly.

Relationship of the Study Findings to Nursing Theory

Although the study was not guided by a specific conceptual or theoretical framework, it became evident as the themes emerged that the findings corresponded to a well known nursing theory. The experience of parents “living in” hospital with their sick infant illustrated the profound effect hospitalisation had on these families. Roy’s Adaptation Model (Roy, 1984) was therefore selected to provide a second level

of analysis for the findings. The findings relate to the mothers' experiences of "living in" hospital with a sick infant.

The person as an adaptive system

The Roy Adaptation Model (Roy & Andrews, 1991) views the person as an adaptive system that exists in a state of constant interaction and strives to maintain a relative state of equilibrium, both within itself and in the relationship with the outside world. Each system within the person is motivated towards conditions of balance and homeostasis and aims to achieve a certain constancy of function (Aggleton & Chalmers, 1984). The person is an open living system and receives inputs or stimuli from both the environment and the self. Adaptation occurs when the person responds positively to the environmental changes (Blue et al., 1994). This model provides a framework (see Figure 2) to organise knowledge that addresses adaptation and ineffective behaviours (Meleis, 1991).

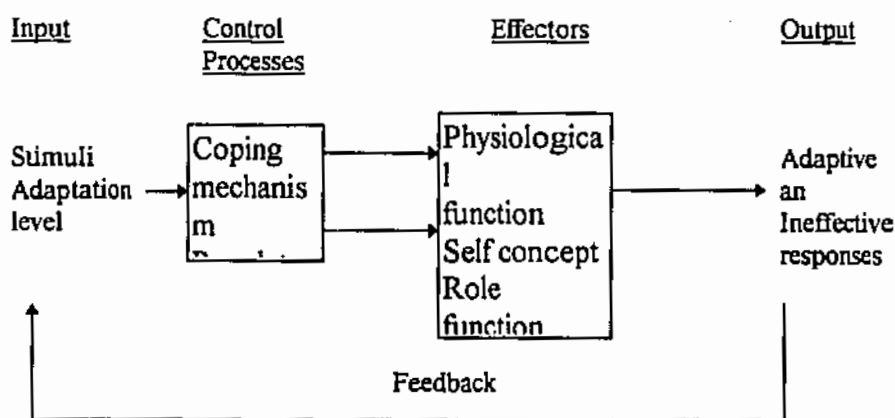


Figure 2. Modification of Roy's Adaptation Model.

From "Sister Callista Roy: Adaptation Model" by Blue et al., 1994, In A. Marriner Tomey (Ed.), Nursing theorists and their work. (3rd. ed.) p. 251. St. Louis: Mosby.

Input

Roy and Andrews (1991) describe the input as something that can produce a response. The input or stimuli can be internal or external and includes all conditions, circumstances and influences that surround and affect the development and behaviour of a person. Classifications of stimuli which can affect the adaptation of a person are focal, contextual and residual stimuli.

The focal stimuli are the stimuli that are immediately present for the person (Appleton & Chalmers, 1984) and require an adaptive response. In this study, three of the focal stimuli immediately confronting the person appeared to be the sick infant, the severity of the disease and the course of the disease process. Other focal stimuli could be the nursing staff and other medical personnel who were associated with the delivery of care while the infant was a patient in hospital. The equipment that was used in the management of the sick infant as well as other paraphernalia could also be considered as focal stimuli. The monitoring equipment used for the care of sick infants was both worrying and reassuring to the mothers in the study.

The contextual stimuli are those occurring alongside focal stimuli and are the environmental factors present in the situation. These stimuli contribute to the effect of the focal stimuli, therefore effecting the person's behaviour while not being the centre of the person's attention. The contextual stimuli in this study could be said to be the actual ward environment, where there were other sick crying infants and more specifically, the single rooms where the mothers in this study resided with their sick infant. These rooms were isolated from the rest of the ward and added another dimension of separateness from not only the rest of the ward, but from familiar surroundings.

The residual stimuli are those from past learning experience and its effects.

These refer to stimuli that have an indeterminate effect on the person (Roy & Andrews, 1991). Roy (1984) suggests that the influences of age, gender, culture and spiritual belief may also be determined as residual stimuli. Once residual stimuli have been recognised as no longer a possible influencing effect, but when they become confirmed, then these become contextual or focal. These can be beliefs, attitudes and traits (Appleton & Chalmers, 1984). Past memories of prior hospitalisation and the care experienced as was the case in this study may be construed as residual stimuli and once validated become either contextual or focal.

Coping mechanisms

Roy (1984) suggests that three types of stimuli, the focal, contextual and residual form the adaptation level or the ability of a person to cope with the changes that have occurred. According to Appleton and Chalmers (1984), the adaptation level at any one moment will be the result of the three types of stimuli which establish a range of conditions of balance for the individual within which s/he can cope adequately with new experiences. The adaptive system has two major internal control processes: the regulator and the cognator subsystems (Fawcett, 1995). The regulator subsystem responds in a physiological way, where the response is automatic and unconscious, through neural, chemical and endocrine coping processes. These processes affect target organs or tissues which then in turn affect body responses that serve as feedback. The cognator subsystem responds to inputs from internal and external stimuli that involve psychological, social, physical, and physiological factors (Fawcett, 1995). Individual responses to the new input allow the person to either increase or decrease his/her coping strategies.

Effector modes

The regulator and cognator subsystems produce behavioural responses in four effector modes. These adaptive modes interrelate with one other. They are the physiological mode, the self-concept mode, the role function mode, and the interdependence mode. Kenney (1990) suggested that the person's behavioural responses in these four modes determine whether the adaptation is an effective or ineffective response to stimuli. Adaptive responses promote the integrity of the individual by conserving energy and promoting the survival, growth, reproduction, and mastery of the human system.

Physiological mode. This mode is extremely broad and encompasses responses to the body's basic physical needs. In this study, the mothers described the extreme tiredness they felt during their stay in hospital. This would appear to be part of the new maternal role with the infant requiring feeds, but was exacerbated in hospital with other infants crying at different times all night and interventions for their infant, for example observations that needed to occur. Due to the circumstances of ward life and the mothers not wanting to leave the infant, mothers mentioned that they ate too much and consequently put on weight while in hospital with their sick infant which was most unacceptable to them. Eating food may be a way of filling a void. Because the mother made a decision to stay in the ward with the infant, there were limited opportunities for exercise.

Self-concept mode. The self-concept mode is a psychosocial mode that focuses specifically on the psychological and spiritual aspects of the person (Roy & Andrews, 1991). It consists of the individual's feelings and beliefs at a given point in time that influence behaviour (Kenney, 1990).

The self-concept mode is viewed as having two sub-areas: the physical self and the personal self. The physical self is described as the individual's appraisal of his/her attributes, appearance, functioning, sensation, sexuality, and the wellness-illness status. The personal self is defined as appraisal of the individual's own characteristics, expectations, values and worth.

The physical self has two components: the body sensation and body image. Body sensation applies to the ability to feel and to experience as a physical being. The fatigue felt by the mothers in this study reflected the body sensation behaviour. Body image applies to how the individual views him/herself physically and the general appearance. Many of the mothers neglected themselves during the course of their time in hospital with their infant. Priority was not with how they looked or dressed, but to be with the infant.

The personal self is viewed as having three components: self-consistency, self-ideal, and moral-ethical-spiritual self (Roy & Andrews, 1991). The self-consistency mode is described as the individual trying to maintain a consistent self-organisation to avoid imbalance. Self-ideal is related to what the person would like to be or is capable of doing. The moral-ethical-spiritual self includes the belief system and the evaluation of who the individual is.

The function of the self-consistency mode is to maintain equilibrium. Behaviour related to the self-consistency mode was observed during this study when the mothers claimed how anxious they were feeling about the infant's condition. Emotional balance was disturbed for all participants in this study. Several of the mothers reported that they were unsure of the outcome for their infants' health status

and therefore had fears for the future. As the infant's condition improved and the mothers became more familiar with the hospital routines, most balance was regained.

The self-ideal mode of the study participants were disrupted by the illness of their infant. The participants felt that their job as mothers was disturbed and the time in hospital affected their view of themselves as mothers. Mothers who had other children believed that the infant had priority and they could deal with the issues caused by separation when they were all together again. The physical relationship with their husbands altered as they were living apart, however, most of the mothers accepted this as part of the whole experience. None of the mothers mentioned that this was a problem for them.

The moral-ethical-spiritual self relates to the belief system of each individual and evaluates an individual's understanding of whom s/he is. It pertains to the individual's view of him/herself in the world. Participants in this study questioned their beliefs about their own maternal roles and whether they had in some way contributed to the infant's illness. Each of the mothers in this study felt as though it was their responsibility to be there for the infant and to sacrifice their time, commitments and the rest of the family for the sake of the sick infant.

The self-concept with all its related components addresses for the person the question of "Who am I?" and refers to the individual's "psychic integrity" (Roy & Andrews, 1991). Self-esteem, the individual's perception of worth is inherent in each component of the self-concept mode. Each of the participants in this study believed that they were mothers before anything else and their responsibility rested with the sick infant. This did not alter during the course of the stay in hospital. However, certain feelings of powerlessness described by most of the participants reflected a

personal or internal lack of control over the situation when the infant was admitted with an illness to a hospital ward. Anxiety, another emotion commonly described by the participants, reflects the uneasiness of mind due to a vague non-specific threat. The event of an infant's illness and the subsequent admission to hospital caused great anxiety to the mothers in this study. In response to alterations in the self-concept mode, the participants enhanced their inner strength by acceptance of the situation in which they found themselves. Trying to have a positive outlook about the infant's illness was one method used to get through the period of hospitalisation. One mother who had negative feelings about the hospital experience relied on her husband and family to help her through the encounter, rather than looking inward to herself.

Role function mode. The role function mode emphasises the need for social integrity (Fawcett, 1995) which relates to the relationship one has with others so one knows how to act. Roy (1984) suggests that people have their own roles in society and people have a need to know who they are in relation to others and the expectations about those roles. Roy and Andrews (1991) describe the three classifications of roles as primary, secondary and tertiary. The primary role determines the majority of behaviours engaged in by an individual at a certain time in that person's life. It is determined by age, sex, and developmental stage of life. The secondary roles are those that an individual assumes to complete the tasks associated with the development stage and the primary role. Secondary roles are normally achieved positions and require specific role performance. These are generally stable and not easily relinquished. The tertiary roles are related to how an individual meets his/her role-associated obligations. These are usually temporary in nature, freely chosen by the individual and may include hobbies.

For the participants in this study, the maternal role was altered during the period of illness and hospitalisation of their sick infant. Rubin (1967a & b) described the attainment of the maternal role as a period of continuous process which was not passive and categorised by mimicry, role-play, fantasy, introjection-projection-rejection, and griefwork. The role transition from nonmother to mother begins in pregnancy (Rubin) and continues with each subsequent pregnancy. One participant whose infant was only five days old when admitted to the hospital had not established her role as a mother and felt inadequate and unsure of what to do. For the other participants, the normal established role as mother was disrupted as living in the hospital ward was far different from the normal home environment when the mother's role was clearly defined and established. When the infant was admitted to hospital and the mother chose to stay, her relationship with the other members of the family was also disrupted. The primary role of mother of the infant, although disordered, was re-established as time went on and the mother became used to the new situation. Secondary roles of caretaker and nurturer were assumed once the sick infant's condition improved.

The secondary role of wife was neglected for the period of time the mother was in the ward with the sick infant. The mothers could not be at home with the rest of the family, therefore, could not carry out those duties. Most of the participants mentioned that sexual intercourse was not seen as very important in their own lives during this time. It appeared that the role of mother with a new infant meant that sexual activity was reduced. The role as mother to the other children was consciously suspended because the mother chose to stay in the hospital with the sick infant.

Tertiary social roles appeared to be put on hold while the infant was sick. Life for each of the participants, as they knew it, changed. Some of the participants' social lives were to change dramatically. Social interaction slowed right down and, in some situations, stopped completely as the infants' time in hospital was much longer than anticipated. Circumstances of the infant's illness necessitated a complete change of life-style for one mother. For those participants whose infants had a temporary condition, for example, bronchiolitis, a normal social role for the participants could be resumed once the condition improved.

Role conflict is when an individual fails to perform the prescribed behaviours for a role (Roy & Andrews, 1991). For most of the mothers in this study this occurred when the nurses did not explain their own particular role or what was expected from the mothers in the care of the sick infant. The mothers perceived that the nurses did not appear to clarify either their role or the mothers' and this caused some conflict.

Interdependence mode. The interdependence mode is when the an individual strives to attain conditions of relative balance in terms of friendliness, dominance and competitiveness (Aggleton & Chalmers, 1984) or when the individual's affectional needs are met (Galbreath, 1995). It focuses on a social interaction related to giving and receiving love, respect, and human values (Roy & Andrews, 1991). It is the feeling of security in nurturing relationships as a basic need. Significant others, partners and support people are facets of this mode. The close relationship a mother has with her infant is another, and this was clearly demonstrated in this study. Each individual mother put the sick infant before herself and before the rest of the family. Life before the illness was deferred until the infant regained health.

Feelings of aloneness and loneliness by the mothers when they were staying in hospital with their sick infant are common examples of ineffective adaptation resulting from a disruption of the interdependence mode (Roy & Andrews, 1991). However, most of these feelings were temporary as most mothers mentioned these feelings disappeared when they returned home again and the infant's condition improved. One mother has described how her circle of friends diminished as she was so involved in her infant's health program, for example physiotherapy classes and the 'follow-up' clinic. This particular participant also expressed her concern about her relationship with her husband. She felt that he was not supporting her while she was so involved in the many and varied treatments for the infant and they were growing apart. Their relationship in fact had become estranged with attempts at reconciliation and counselling appearing to fail. However, it must be stated that the researcher has no prior insight into the nature of the relationship before the illness of the infant.

Mothers described how important the support from the nursing staff was for them. The nurses gave emotional and educational support which facilitated the interdependence mode. Many of the mothers considered the nurses to be friends.

Summary of Adaptive Responses

According to Tiedemann (1989), when viewing a person as an adaptive system, adaptation is considered to be both the process of coping with stressors and the end product of coping. Adaptive responses are those that promote the integrity of the person (Galbreath, 1995). Adaptation involves all the person's interactions with the environment and is a two-part process. The first part of the process is initiated by changes in the internal or external environment that demand a response. These changes are stressors or focal stimuli and are mediated by contextual and residual

factors. The second part of the process is coping mechanisms that are triggered to produce adaptive or ineffective responses.

Referring to the four adaptive modes, the mothers interviewed in this study utilised strategies to effectively respond to the event of a sick infant and hospitalisation. They attempted to look after themselves physically to remain as healthy as possible. They were encouraged by the nursing staff to rest and to eat properly while in hospital, although eating too much was a problem for some of the mothers. They participated in the care of their infants and became involved in the ongoing management of each infant. Feelings of hope, sharing their experiences with others and seeking support were adaptive responses.

In addition, Roy (1984) suggested that in order to judge the effectiveness of adaptation, the effect of behaviour on the general goals of adaptation, that is survival, growth, reproduction and mastery, were determined as well as considering each person's individual goals. A mother's own survival may not be the most important goal when her infant is ill, and she may choose to put herself and her needs last in order to support the infant. Ineffective responses are those that do not contribute to the person's own adaptive goals.

One mother displayed an ineffective response in this study which was identified mainly as anger. This behaviour consequently became a negative contextual stimuli for the individual. An example included her demonstration of anger about the hospital system per se. Not knowing or understanding the hospital system in the first instance was a source of frustration and anxiety.

In a very broad sense, Roy's Adaptation Model may be used to explain the lived experiences of mothers who "live-in" hospital with their sick infant. Certain

aspects of human response need to be discussed. The mothers in this study felt that they had no other option but to accept what was occurring to both them and their sick infant. They utilised coping mechanisms and “survived” the ordeal of having a sick infant and “living in” the hospital ward together. Most of the participants in this study adapted to the experience of “living in” the hospital ward with their sick infant.

In conclusion, the findings from this study appear to correspond to Roy’s Adaptation model (see Figure 3.).

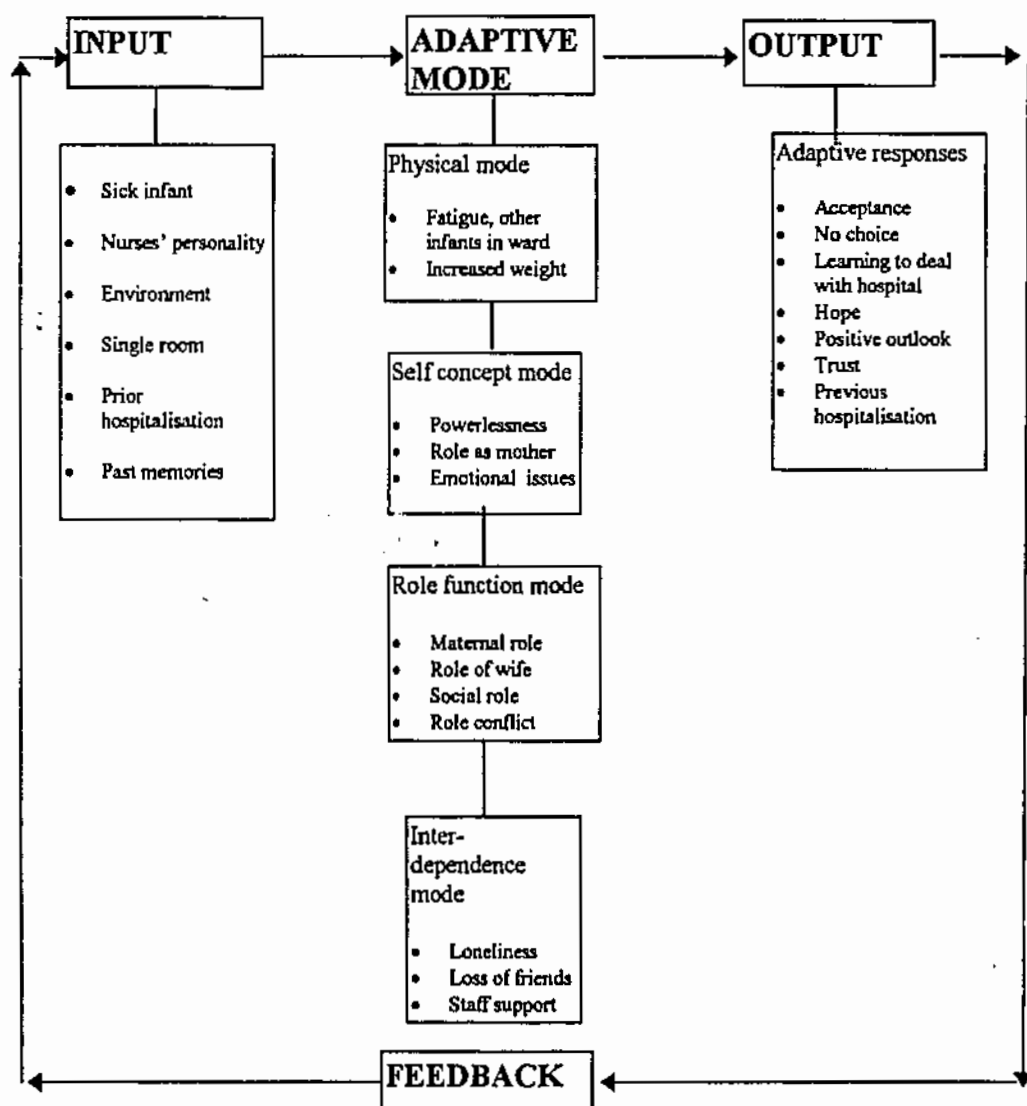


Figure 3. Adapting the lived experience of mothers who “live in” the hospital ward with their sick infant to Roy’s Adaptation Model

The mother who "lives in" the hospital ward with her sick infant has a profound experience that has far reaching implications for her, the infant and the family. Overall, areas of physical, personal and social adaptive modes were involved. The findings revealed mainly adaptive behaviours of those mothers in the study.

CHAPTER SIX

This chapter includes the conclusion of the study, implications for health care practices and recommendations for future research.

Conclusion

Summary of the Study

The purpose of this study was to investigate the experience of parents who have "lived in" the hospital ward with their sick infant from a phenomenological perspective. Oral accounts of the parent'(s) experiences and researcher's observations were incorporated. The findings indicated that this event had a profound effect on both the mother and the family. The meaning of residing in the hospital ward with a sick infant for the participants in this study was captured in four major themes which included Internal Reactions, Issues of Communication, Role Boundaries and Learning to Deal with Hospitalisation.

The internal reactions by the participants included feelings of isolation, loss of control, concern for the infant's well being, frustration and guilt. These emotional feelings were common to each mother when she was confronted with her sick infant and the impending admission to hospital. It is noted however, that these feelings abated for some of the participants as time progressed and the infant's condition improved.

For the participants, several different issues relating to communication were experienced while resident in the hospital ward. Effective communication was seen as an important aspect of dealing with the hospital experience for each participant in this study. However, there appeared to be different forms of communication that satisfied different needs. Communication with nurses was informative, but mainly of a

supportive nature while communication with doctors was seen as mainly information giving about test results and the disease process. Communication with other parents, either of a social nature or therapeutic, where there were discussions of similar scenarios with other parents, could be both helpful and in one particular case, a burden.

The study participants felt that their roles as mothers were blurred and that they did not know what to do for their infants when admitted to the ward. The mother was by the infant for most of the time, but there was no direction or overt permission about what she could physically do for the infant. The original established role of mother for most of the participants was disrupted and the role of mother to a sick infant in an alien environment had to be assumed. This produced role conflict for some of the participants.

The participants did not know what role to assume while staying in hospital with their sick infant. They were unsure of how involved they should be with the care of their infants, in fact they did not know whether they could be involved or not. This compounded the emotional feelings many of the participants were experiencing. The health care staff did not clarify these issues for any of the participants during their stay in the ward.

Several participants acted as the infant's advocate, however, they mentioned that there were mixed reactions by the staff about this role. One participant felt the staff did not listen to her when she described her infant's problems. This caused anguish for this mother. On the other hand, another mother was relieved when the staff believed her feelings about her infant's deteriorating health.

The study participants tried to deal with their difficulties by utilising various strategies. For most of the participants, they believed they had no choice. They had to learn to cope regardless. There was no-one else and it was their job to be there for the infant. The participants accepted the fact they were in this particular situation and therefore, they did the best they could. Each participant tried to keep a positive outlook and look on the bright side of things. The participants described how they rationalised the situation in order to survive the experience.

One participant, however, felt the admission to hospital was a waste of time and appeared to remain angry about her stay, even after she was home and the infant was improving. While in hospital, this mother had a limited understanding of her infant's condition and following discharge she felt that her understanding had not increased. Her infant's particular condition was often not curable, but controlled with medication. It can be a very frustrating illness for the mother to cope with as the infant may cry more than average and be difficult to settle. This particular mother believed that she did not have her or the infant's needs met and felt let down by the hospital.

The mothers appeared to gradually regain control over the situation. As the hospital admission progressed, they became more accustomed to the hospital routine and more familiar with the staff. Mothers watched other mothers as well as the nurses to learn what to do and how to act. However, at the same time the infants' condition was also improving which may have allayed some of the mothers' fears.

The experiences of "living in" the hospital ward with a sick infant captured in this study lead to the conclusion that the episode of staying in a hospital ward had a profound effect on each one of the individual participants. In many instances this

effect may spill over into the rest of the family. Each of these factors that were consistently revealed in this study indicated that people in this situation needed support and help to cope with each of these episodes. Support may come from the health care team, other parents, significant others and family.

Furthermore, the application of Roy's Adaptation Model has helped to explain and discuss the responses to the experience of "living in" the ward. The findings revealed the participants reacted to this episode by coping with certain adaptive responses.

The meaning of the experience to these mothers supports the affective notion of human responses to a particular phenomenon and therefore, describe the essence of "living in" the hospital ward with a sick infant. These interpretations by the researcher bring those events that may not be considered as significant to health carers to a level of consciousness of mind and intensified meaning. The researcher has sought to interpret the true meaning of the hospital experience and how it relates to the mothers who describe and experience it. The experiences have been articulated in a certain way and the interpretations of the researcher who is an experienced senior nurse may be able to help validate the findings.

Implications for Health Care

The findings from the study highlighted that the central activity of care within a ward situation appears to be completing the tasks that are required and focusing on technological and physiological aspects of care. It is seen that implicit assumptions are being made by certain staff members about the way things are done and the roles the parents take while staying in the hospital. The findings from this study will enable

health care professionals to understand more clearly the experiences for the parents during the hospital stay.

As a phenomenological study can guide nursing knowledge and practice, this study has highlighted the need for a deeper understanding of the relationship between the health care professional and the “live in” parent. Support, communication and trust are needed for resident parents who are experiencing a difficult period when their infant is ill and requires hospitalisation. Nurses have an opportunity not afforded to other members of the health team, to be there for these parents and their families. Difficulties with time allocation and workload are reasons often heard for not spending the time, but there are opportunities for meaningful interaction during the day’s work. During the early stages of hospitalisation, when the mother is upset and worried, may not be the best time to discuss her involvement, but rather a time to help and support her. As time progresses and the mother is feeling more confident, discussion and negotiation about her involvement in her infant’s care would be most beneficial. The possibility of written contracts between the staff and the mother may reduce the issue of role confusion. Whether or not the parent wishes to be involved must be clarified as early as possible in the hospital stay.

Findings from this study may have implications for educators and managers within the hospital system. Encouraging parental participation in care is a relatively new concept in nursing, a shift from the patriarchal model of care and facilitating cultural change within a large organisation is a big undertaking. Nurses will need support and education if this partnership is to occur. Parental participation in care has undergone several stages in development and appears as though it may be now at the stage where the parents are to a certain degree accepted as residential members of the

ward team. To increase further acceptance of the parents on the ward to the point where they are involved in decision-making and influencing policies, requires more education and insight by the nursing and medical staff and an on-going dialogue and cooperation between parents and staff.

Another aspect of this care model is that the nurses may become too involved with families and professional boundaries may become blurred. Further education, support and opportunities to highlight and discuss these problems will be required. Education and support for the nurse and other health care professionals would in the long run benefit the parents who were in the ward environment.

Negotiation skills and communication skills are an important part of a nurses' daily work. Maintaining these skills would enhance the relationships nurses have with both the staff and the families involved in care delivery.

Limitations

The limitations of this study are similar to limitations of all phenomenological studies. Van Manen (1990) suggested that there is a lack of proof that the findings of a phenomenological study are reliable, generalisable and objectively valid. Plager (1994) proposes that the findings may be of no assistance to prediction. However, the aim of a phenomenological study is to reveal the phenomena and meanings, not to predict. The sample group was a purposive sample of participants, rather than a random selection and therefore the perceptions and experiences revealed by the participants cannot be generalised to any other group of parents. However, the stories reflect the most authentic account of the phenomenon of concern.

The participants involved in this study were obtained from one ward in one hospital with the same staff members caring for them. The findings may therefore, not

be representative of other parents who are hospitalised elsewhere with a sick infant whether in another ward or another hospital.

Only female Caucasian participants took part in this study. Further study with a broader range of participants may tell a different story. Perhaps fathers and those from different cultural backgrounds may add a different dimension to the information. Researching first time mothers in hospital with their sick infant as opposed to mothers with other children, and mothers who have been through the “living in” experience compared to those who have not would add another dimension to the current knowledge base.

Recommendations

Mothers who “lived in” the hospital ward with their sick infant may not represent the larger group of parents in the same situation. Therefore, it is essential that further validation for the phenomenological perspective and the human understanding of this phenomenon, be researched. This would enhance the understanding surrounding the hospital experience for these people and may therefore add to the current knowledge base. As this study focussed on the mother with the infant only, a study for the range of age groups would be recommended to incorporate strategies for the range of ages.

As a result of this study it is recommended that there is additional research into the relationship between the “live in” parent and the hospital staff, especially nurses, as they spend the most time with the parents. Further research into nurses’ perceptions of parental participation in care could be carried out. Nurses should be encouraged to examine their attitudes towards parental participation and the influences on it, such as policies, philosophy, role interpretations, power and

powerlessness in their positions, university curricula and possibly their own experiences with families (Gill, 1987).

The knowledge gained from this study provides a framework from which health carers may contemplate issues that are of significance, benefit and satisfaction to the customers of health care. Whilst the stories from those mothers who have lived the phenomenon of concern are the intrinsic truth, realistic, factual and trustworthy, they may often be disregarded by health carers. Therefore, the ontology from the mothers' perspective will establish a framework from which a plan of care may be truly developed, rather than established from a generalisable pattern of interventions readily developed from the more quantitative perspective of human behaviour.

The interpretive paradigm is an authentic way of gaining knowledge to discover the true essence of the experiences for the mothers in this study. To grapple with current nursing issues and seek solutions through the genuine interpretation of the taken-for-granted ways of the world will give true meaning and value to those experiences we seek to discover.

This study has provided current, relevant information that may be used as a basis for further research in this area. It may also lead to future changes in care practices for paediatric nurses. Regardless, the development of nursing knowledge related to the family in hospital is of great benefit to nursing managers, nursing caregivers and ultimately, the families themselves.

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Appendix A

Prompt questions

1. Can you describe what staying in the ward with your infant meant to you?
2. What feelings did you have when you were staying in the ward?
3. Can you tell me how spent your days while in hospital?
4. Describe what you think you should have been doing when you were in the ward?
5. Tell me how did you get to know the staff?

Appendix B
Information Sheet and Consent Form

Information Sheet

Dear Parent

I am a registered nurse with many years experience caring for sick children. As part of the requirements of a Master Degree in Nursing at Edith Cowan University I am currently conducting research into the feelings parents experience when they "live in" with their sick infant. These results will form the basis of my thesis.

Because you are a resident parent on Ward 5D I am inviting you to participate in this study. If you decide to take part I will be asking you if I may visit you at home to ask you some questions about your experiences during your infant's hospitalisation. I will need to tape record the interview which will take approximately one hour. I may need a follow up interview at a later date just to confirm things with you.

The information will be confidential and will not be able to identify you or your infant. False names and a coding system will be used instead of your names and only I will have access to the original transcripts which will be destroyed later. Although the ward staff will be aware of the study, they will not be told who is participating in my research project,

Your comments will be very valuable and important to future nursing practice. Your participation is entirely voluntary and you can withdraw at any time without any problems. Your infant's care will not be affected in any way by your decision.

Should you have any questions, please feel free to contact me any time you wish.

Thank you for your time.

Anne Bourke

Work [REDACTED]

Home [REDACTED]

Consent Form

I.....

Family name**Given name**

of.....

Address**Postcode**

have read and understood the information. Any further questions I have regarding the study have been answered to my satisfaction. I agree to participate in this study that relates to "living in" with my sick infant.

Signed Parent.....Date.....

Signed Researcher.....Date.....

Appendix C

Coded Transcript Sample

Content/Verbatim quotes	Codes/Tentative Themes
<p>Participant 2 I suppose the first time round I probably wouldn't have called someone if I was concerned, only because I wouldn't have understood what the role of different people actually is. And it depends also on the personality of the nurse you are dealing with. For a couple of days it has been a different personality - it might just be days where you didn't feel you can ask - you feel you are asking too much. You are concerned for the child...so you are looking at getting as much information as you can.</p>	<p>Understanding the system LEARNING TO DEAL WITH HOSPITALISATION Individual personalities COMMUNICATION Worry, concern Need for information COMMUNICATION</p>
<p>Participant 3 No-one really told me that I had to look after Monica myself, and I just assumed that the nurses would. It then dawned on me that that was my job, I was Monica's mum and I had to do all the mothercraft for her- it didn't take long. As time went on and I relaxed and things started to improve, I was able to chat to the nurses.</p>	<p>Lack of communication COMMUNICATION Lack of role clarification ROLE BOUNDARIES Adapting to the environment LEARNING TO DEAL WITH HOSPITALISATION</p>
<p>Participant 5 I felt confusion and cheated as to why she got sick again. She's been through it all before why had she had she got to got through it all again. I felt anger, I was furious I thought this can't be happening again. I think I understand how the system works, which is an advantage. I like to know what is going on and be fully informed. I knew what to do - it came naturally. I knew what would upset her. I knew the limits.</p>	<p>Feelings Concern for the infant Disbelieve INTERNAL REACTIONS Adapting to hospital COMMUNICATION Knowing the infant Mothering ROLE BOUNDARIES</p>
<p>Participant 6 For a while there I didn't understand what was going on, and every one seemed to say something different, and then you end up - in the end you think "What the hell is going on?" I thought he was going to die. It was pretty scary. I thought I was going to lose him. You sort of think "Why my, why me?"</p>	<p>Problems with communication Frustration COMMUNICATION Concern for the infant Worry, fear INTERNAL REACTIONS</p>