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Paediatric intensive care nursing behaviours to reduce parental stress

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**PAEDIATRIC INTENSIVE CARE NURSING
BEHAVIOURS TO REDUCE PARENTAL STRESS**

BY

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Paediatric Nursing Certificate, Bachelor of Nursing

A Thesis submitted in partial fulfilment of the requirements for the award of

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USE OF THESIS

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

ABSTRACT

A child's admission to a paediatric intensive care unit (PICU) is stressful for the family. Parental presence and involvement with their child in hospital have been recognised as important in reducing their stress. Several studies have identified parental needs in the PICU. Nurses have reported that they felt inadequately prepared to meet those needs. Although principles to guide nursing strategies have been identified, contextual behaviours of PICU nurses to reduce parental stress have not.

A qualitative study, using an ethnographic approach, was designed to describe contextual behaviours of experienced PICU nurses. Participants self identified their level of clinical practice to be at The Competency Standards for Specialist Critical Care Nurses (CACCN Inc., 1996). Fifteen nurses from six Australian PICUs (two each in Brisbane and Sydney, one each in Melbourne and Adelaide) were interviewed. Recalled critical incidents identifying nursing behaviours to reduce parental stress were audiotaped, transcribed, analysed and interpreted. NUD•IST (version 4.0) was used to facilitate the initial data analysis. King's conceptual framework for nursing (1981), was used to illustrate the interactions of the interpersonal relationships between staff and parents and the effect of the culture within the PICU. King's conceptual framework consists of three interacting, open systems; individuals as personal systems, two or more individuals forming interpersonal systems, and larger groups with common interests forming social systems or cultures.

The nurses described parental stressors and behaviours. Nursing behaviours were anticipatory or in response to parental cues. Demonstrating empathy, sensitivity, caring, and encouraging the parental role enabled rapport to be developed. Keeping parents fully informed, listening and talking through problems were also important

stress reducing behaviours. PICU cultural behaviours, such as restricting parents' presence with their child, resulted in increased stress. The nurses found their role more difficult when parents were non English speaking, were of a different culture, religion or social background, or had long stays in the PICU. The nurses' personal challenges included the death of a patient, the need to remain impartial, and the pressure to always perform.

The PICU nurses' ability to quickly establish rapport during a stressful time in the parents' lives was crucial to be able to reduce their stress. Many contextual nursing behaviours to reduce parental stress were described. However, consideration must be given to modifying those behaviours that increased parental stress. From both the perspective of positive and negative nursing behaviours, this study will enable nurses to be aware of behaviours that reduce and exacerbate parental stress in order to improve their practice in supporting parents.

DECLARATION

“I certify that this thesis does not incorporate without acknowledgement 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.”

Signature:

Date: *27th June 2001*

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CHAPTER ONE

INTRODUCTION

I'm always really aware that it is a permanent memory, and it's just going to be just another part of your day, but it's part of their life and they are going to remember exactly what goes on – eventually (Hilda 193).

This study examined Paediatric Intensive Care (PIC) nurses' descriptions of their behaviours to reduce parental stress. The nurse's relationship with parents has an important effect upon parental stress, and supportive, stress-reducing nursing behaviours are developed over time and with PIC nursing experience. The purpose of the study was to provide contextual descriptions of nursing behaviours that novice and less experienced nurses may reflect upon, and will be of value to apply to their day to day practice. In this chapter the background and significance are discussed. The aim of the research and definition of terms for this study are also presented.

Background and significance of study

Hospitalisation is a potentially stressful experience for both children and their parents (Darbyshire, 1994; Graves and Ware, 1990; Knox and Hayes, 1983). Neuman (1982), described stressors as environmental forces that may alter the body system's stability. A child's unexpected admission to a Paediatric Intensive Care Unit (PICU) is particularly stressful for parents (Curley, 1996; Daley, 1984; Meyer, Snelling, and Myren-Manbeck, 1998; Miles, Carter, Spicher, and Hassanein, 1984; Scott, 1998). Stress can greatly diminish parents' ability to maintain their caring relationship with the child (Way, 1993). Parental needs whilst their child is in hospital and/or PICU have been identified (Daly, 1986; Darbyshire, 1994; Farrell, 1989; Neill, 1996). PIC nurses, who are continually at the bedside, can play an important role in meeting the needs of parents and

assisting parents to reduce their stress. PIC nurses, to some extent, are able to control the environment in order to minimise the stress experienced by the parents.

Nurses practising in the PICU may be less or more able to meet parental needs depending on their level of experience, knowledge and educational preparation for the role. There are standards of practice, the CACCN Inc. (1996), Competency Standards for Specialist Critical Care Nurses (see Appendix A), which are accepted by the profession as articulating the level of clinical practice expected of experienced nurses working in critical care settings including paediatric intensive care. The term 'specialist' nurse has been used throughout this study to describe such an experienced PIC nurse.

How the specialist nurse behaves to reduce parental stress whilst also nursing the child in the PICU is not well described in the literature. Neither is this aspect taught well in nursing educational programmes. It has also been suggested by a Canadian study (Fox and Jeffrey, 1997) that intensive care nurses caring for adult patients, perceived that meeting the emotional needs of families was not a realistic expectation of their role. Scott (1998) also described that even in the PIC context during critical periods of stabilisation of the patient, the needs of the parents are considered insignificant by nurses. Yet, caring for the whole family is an essential and important aspect of nursing care for PIC nurses. In fact, caring for the family, specifically the parents, can be the major focus of the nurse's day. Meeting parental needs particularly presents a challenge for less experienced PIC nurses, who typically focus on mastering the necessary skills to be able to meet the physical needs of the patient. Hannah, one of this study's participants, described the importance of the nurse caring for parents below:

We don't learn that...nobody teaches us that...at all. It is all very well for people to say "well I'm not a social worker" but you are the person that they have most contact with, you are the person they know the best, you are the one that they trust basically... they are trusting their child to you (Hannah 75).

In summary, PIC nurses have an important role in reducing parental stress. Whilst there is research that identifies parental stress and parental needs, nurses' parental stress reducing behaviours are usually learnt on the job and with experience. There is a need to identify and describe these behaviours. Such contextual examples will have implications for not only inexperienced PIC nurses but all PIC nurses to be able to improve their practice in reducing parental stress.

Research aim

To identify specialist PIC nurses' behaviours when caring for families in order to reduce parental stress.

Definition of Terms

For the purpose of this study the following terms are defined:

Parent: Mother or father or person acting as mother or father of the critically ill infant or child eg. guardian, grandparent.

Family: Parents, their children and identified other support people eg. grandparents, aunts, uncles, close family friends.

Stress: Emotional and physical strain and tension.

Specialist PIC nurse: An experienced registered nurse meeting the Competency Standards for Specialist Critical Care Nurses (CACCN Inc., 1996), practising in the context of paediatric intensive care.

CHAPTER TWO

REVIEW OF THE LITERATURE

It will always (subconsciously) be part of the conversation – anyone who is in intensive care has an increased risk of dying... You only really need to scratch the surface – they know that if their child is that sick it is always possible (Harry 367).

The aim of this study was to describe contextual nursing behaviours that reduce parental stress. This chapter reviews the literature about parental stress, parental needs, and paediatric nursing, specifically PIC nursing and the relationship between the nurse and the parents. The available literature provides some pointers to nurses about parental needs and suggests some nursing strategies to meet those needs. Outlined are some of the suggested nursing behaviours to assist parents to adapt to the stress of their child being admitted to a PICU.

Parental Stress

Admission of a child to PICU has been described by parents as the most stressful of parenting experiences (Noyes, 1999). In Noyes' (1999) qualitative study of mothers' experiences following their child's unexpected admission to a PICU, the mothers described how in the initial hours they consumed vast amounts of emotional energy which left them feeling totally exhausted.

Alterations in parental role and the subsequent disruption in the parent-child relationship have been consistently identified as the most stressful aspects of the hospital and PICU environment for parents. Other stressful aspects for the parents included separation from their child, the altered appearance of the child, feeling of helplessness, and loss of control. (Curley, 1996; Farrell, 1989; McNab, Emerton-Downey, Phillips, and

Susak., 1997; Neill, 1996; Noyes, 1999). In addition, La Montagne and Pawlak (1990), found that uncertainty over outcome was stressful for parents.

Haines, Perger, and Nagy (1995) found that parents reported their greatest stress arose from the sights and sounds associated with the unnatural environment of the PICU and from painful procedures that were carried out on their children. Other studies have demonstrated that parental stress is complex and dependent on many factors. Shields-Poe and Pinelli (1997) and Meyer, Snelling, and Manbeck (1998) reported on parental stressors in neonatal intensive care Units (NICU). Variables associated with parental stress were related to the parents' background, situational or hospital stresses, the infant's condition, parent perceptions, other concurrent life events and the experience associated with the NICU. Wereszczak, Miles, and Holditch-Davis (1997) similarly hypothesised maternal stressors to be related to personal characteristics, the baby's illness, personal resources, and the NICU environment. Miles, Carter, Spicher, and Hassanein (1984) reported that whilst overall, mothers and fathers found the whole PICU experience equally stressful, there was a difference between mothers' and fathers' level of stress. Fathers were more distressed by their child's altered behaviour and mothers were more distressed by their parental role alteration in the PICU.

Shields-Poe and Pinelli (1997) and Miles, and Carter (1982) found that high parental stress was associated with how sick the parents perceived their infant or child to be. Whilst parents' perceived morbidity of the infant or child may have not been accurate, the perception modified their interaction with their infant or child, and could affect their interactions with the staff. Haines, Perger, and Nagy (1995), used a parental stressor scale to compare a group of parents whose children had been intubated, with a group whose children had been in the PICU without being intubated. There was an assumption made by the staff that the intubated children were sicker than those who were not. Between the two

groups, a significant difference was found in relation to the parents' experience. The parents of the non-intubated children tended to perceive staff as less friendly and caring. The findings suggested that the staff's approach to parents appeared to be related to the child's severity of illness. This was interpreted that the staff may have overlooked the needs of the parents of the non-intubated, less sick children. Parents themselves may have perceived their child to be much sicker than the staff appreciated. It would appear that there may be a danger of PIC nurses underestimating the needs of parents of less sick children.

The interpretation that the level of parental support provided by nurses was related to the child's severity of illness, was supported by Tomlinson, Kirschbaum, Tomczyk, and Peterson (1993) who used a parent satisfaction scale to measure maternal satisfaction with nursing care in a critical care area of a bone marrow transplant Unit. Their findings indicated that maternal satisfaction was related to nursing skill level, and that satisfaction with nursing care increased as the child's acuity or severity of illness increased. It was interpreted that this was because the parents of the sicker children received more attention, as well as more time, from more skilled and experienced nurses assigned to the patient.

Miles and Carter (1982) found that inappropriate staff communication styles and behaviours were aspects of the PICU environment that caused stress to parents. Stressful verbal communication was identified as staff speaking too quickly, using words not understood by parents, using jargon, providing inconsistent or too much information, not talking to parents, not telling staff names to parents, and inappropriate joking. Stress causing nonverbal communication included sending parents out of the Unit without explanation, constantly rushing around, lack of gentleness in caring for the child, acting in a remote way or appearing apprehensive.

Meyer, Snelling, and Manbeck (1998) further stated that issues related to staff communication and behaviour became more important determinants of parental stress as the stay in the Unit lengthened. Parental stressors changed as parents became more accustomed to, and less stressed by the environment over time, expected to be involved in decisions regarding their child's care, and wished to participate in caring for their child (Curley, 1988; Meyer, Snelling, and Manbeck, 1998). PICU staff behaviours had a significant effect upon whether the parents had a positive or negative experience in the PICU. The PIC nurse's behaviour, if appropriate, could help the parents make the transition to parents of a critically ill child, and as well as play an important role in minimising their stress (Curley, 1996).

Parental Needs

Neill (1996) conducted a qualitative study interviewing parents of hospitalised children and found parents wanted to be involved in their child's care, and would prefer to do so through negotiation with the nursing staff. It was also reported that parents found staff to be paternalistic and wanted staff to volunteer more information. Knox and Hayes (1983) interviewed parents of chronically ill children, some of whom had cancer, and found of primary importance to the parents was to become familiar with the environment, staff and routines. Parents also needed to develop an understanding of the child's illness, treatment, learn new terminology and interpret the information to the child and other family members. The parents also tended to seek out one person they believed to be a reliable source of information. Thus parental needs in the PICU may differ depending on whether the child is suffering from an unexpected illness or injury or whether the critical illness has resulted from a chronic disease.

Daly's (1986) study of families of adult patients in Intensive Care Units, conducted by questionnaire, identified six categories of personal need. In this study respondents graded the need for reduction of anxiety as the most important. A study by Kasper and Nyamathi (1988) dealt exclusively with the needs of parents of critically ill children and supported Daly's findings. The other important needs were being with their child, frequently receiving accurate and truthful information, having a place to sleep nearby, participating in the child's care, and feeling assured that their child is receiving appropriate care and treatment (Kasper and Nyamathi, 1988). Scott (1998) used a critical care family needs inventory modified for paediatrics to quantify the significance of perceived family needs, and had similar findings.

It has already been identified that parents wanted to be with their child and find it stressful to be separated from their child. Maxton (1997) surveyed PICU doctors and nurses and found that staff restricted parental presence with their child for many procedures and during resuscitation. One reason for this was to protect parents from stressful events such as resuscitation. Staff expressed this attitude despite being aware that parents wanted to be with their child. A recurring theme in Maxton's (1997) study of staff's attitude towards parental presence in PICU was of power and control. Maxton found that nurses seemed reluctant to relinquish their power role to allow the parents to be able to be with their child. It was the more experienced staff in Maxton's study who expressed concern about parents' ability to cope with distressing sights.

Maxton's findings contrast to a previous study (Callery and Smith, 1991) which found that more experienced nurses were less rigid and had more respect for parents' decision making abilities. Maxton (1997) suggested the staff's approach was paternalistic, and staff should meet parents' identified needs. Jarvis' (1998) findings supported Maxton's study, and, in addition, reported staff concerns about being inadequately trained to support

parents during resuscitation. Meyer, Snelling, and Manbeck (1998) further advised, however, that not all parents want to be present to witness all events in the PICU. Thus, the nurse cannot assume to know what a parent would want in every situation, but can best support parents by asking them how involved they want to be and accepting what they say (Meyer, Snelling, and Manbeck, 1998).

PICU staff usually are not the only source of support for parents. The role of spouse, family, friends and health professionals in supporting parents of critically ill infants was discussed by Shields-Poe, and Pinelli (1997). The persons parents considered most helpful to them were their spouses, then families, then friends and then health professionals. Boardman (1995) described how parents' ability to support one another could greatly reduce their stress. Meyer, Snelling, and Myren-Manbeck (1998) described how mothers relied more heavily on support from their spouses, whereas fathers relied more heavily on support from staff. If a parent did not have the support of a spouse, for example in the case of a single mother or separated couple, more stress was reported (Griffin, Wishba, and Kavanaugh, 1998).

Whilst many parental needs have been identified by parents, parents themselves often neglected, seemed unaware, or did not rank highly their own needs for food, rest and support (Farrell, 1989; Graves, and Ware, 1990; Meyer, Snelling, and Manbeck, 1998; Neill, 1996). Meyer, Snelling, and Manbeck (1998) conceptualised parental needs as a hierarchy, similar to that proposed by Maslow (1968) in which basic needs must be met before higher needs can be considered. The nurse must also consider the physical needs of the parents, as parents may not adequately care for themselves, either by putting the need to be with their child first, or by being unaware of their own needs during the stressful experience (Meyer, Snelling, and Manbeck, 1998).

Paediatric Nursing

There is a lack of clarity about the relationship of paediatric nurses and parents in caring for the sick child. Rowe (1996) and Darbyshire (1993) have suggested that the concepts of parental participation and family centred care remained largely unexamined and unexplained. Neill (1996) described parental participation as parents getting involved or being allowed to become involved in a decision making process or the delivery of care, or the evaluation of care, or to become one of a number of people consulted on their child's care. Jarvis (1998) found that PICU doctors and nurses believed that staff had the right not to have parents present during resuscitation. The inconsistent approach to and interpretation of family centred care by nurses has resulted in additional sources of parental stress (Darbyshire, 1994).

Some of the work that has examined the concepts of parental participation and family centred care in the context of the PICU found that the most common roles assumed by mothers involved no active participation in their child's care (Coyne, 1995). It has been suggested that parents need time to assume the role of parent of an ill child before they can get re-involved in their child's care (Coyne, 1995; Curley, 1988). The PIC nurse role includes helping and supporting parents in the most appropriate manner for individual parents at every stage of their PICU stay.

Curley's (1988) Nursing Mutual Participation Model of Care provided a framework for individualised interactions to clarify the parental role in the PICU setting and increase the parents' confidence in performing their role in a foreign environment. Melnyk, Alpert-Gillis, Hensel, Cable-Beiling, and Rubenstein (1997) piloted an intervention program (Creating Opportunities for Parent Empowerment), to enable mothers to be less anxious and more supportive of their children, and to report less parental role change and better adjustment during and after hospitalisation. The clinical application of these models has

resulted in parents reporting significantly less stress, particularly in the area of parental role alteration (Curley, 1988; Melnyk, Alpert-Gillis, Hensel, Cable-Beiling, and Rubenstein, 1997).

Intensive Care Nursing

The review of the intensive care nursing literature covered both adult and paediatric studies and found some similar issues related to role expectations, and themes of caring nursing behaviours. Thus, whilst some study findings are drawn from adult settings they still have relevance for this study and are discussed below.

Fox and Jeffrey (1997) used a questionnaire to examine adult intensive care nurses' role expectations and performance. The study revealed that nurses not only felt inadequately prepared to meet family needs, but also indicated that it was not realistic to expect them to care for the emotional needs of the family. Being too busy to spend time dealing with family members was identified as an issue. In contrast, Andrew's (1998), phenomenological study, of nurses' experiences working with families of adults and children who died in ICU, described optimising the human experience for families. The study described nurses' endeavours to make the time surrounding death the best possible for families. This is an important and rewarding aspect of intensive care nursing, particularly when the death involves a child. The experienced PIC nurse has the ability to provide physical care to the patient as well as support the family, throughout their stay in the PICU, whatever the outcome.

Caring nursing behaviours were described in a phenomenological study, by adults who had been patients in a critical care Unit (Burfitt, Greiner, Miers, Kinney, and Branyon, 1993). The patients perceived caring behaviours of nurses to be vigilance or alert watchfulness, healing and mutuality. Vigilance, especially to avoid danger, was so

consistently present in their descriptions, that other activities were described in relationship to it. Other sub-themes were attentiveness, highly skilled practice, going beyond the basics and nurturing. Healing was interpreted as lifesaving acts and energy freeing acts. Mutuality was an awareness of having engaged in a reciprocal process with the nurses. This was related to nurse attributes of empathy, understanding and compassion, as well as the nurse caring for the whole family.

Some non-caring nursing behaviours were recalled by mothers of premature infants in a NICU (Wereszczak, Miles, and Holditch-Davis, 1997) as nurses acting too busy to talk to parents, whose attitudes were distant and uncaring, being rough, and not answering the monitor alarms quickly enough. Such behaviours provoked more parental stress. To be able to support parents, PIC nurses must include appropriate caring behaviours and take care not to demonstrate behaviours that could be interpreted as non-caring.

Meyer, Snelling, and Myren-Manbeck (1998) emphasised the need for nurses to avoid making assumptions about what parents needed, warning against PIC nurses intervening prematurely to provide parental psychosocial support. They recommended that nursing staff supported parents best by determining what parents wanted, by asking directly as well as listening to cues. They further suggested there was potential value in parent-to-parent support and advised that nurses were positioned to make introductions between families. However, suggesting new coping strategies to parents, according to Meyer, Snelling, and Myren-Manbeck (1998) must be undertaken with caution, as parents in a crisis situation were unlikely to be able to adopt new coping mechanisms. On the other hand, unalleviated parental stress could result in dysfunctional behaviour that included withdrawal, preoccupation with physiological aspects of care, and mental restructuring focusing on specific parts of the child and illness (Macnab, Emerton-Downey, Phillips, and

Susak, 1997). Just what exactly are appropriate nursing behaviours to support individual parents, in their unique circumstances can be hard to conceptualise.

Nurse - parent relationship

Features of a positive nurse - parent relationship have been described as being based on trust and respect, in which there is open and honest communication, mutual understanding, negotiation initiated by the nurse, a clear understanding about parental involvement in care, where the parents are invited to participate in their child's care, as well as providing for continuity of the parental role (Hill, 1996; Kawik, 1996, Neill, 1996; Rowe, 1996; Way 1993). Continuity of care by medical and nursing staff, with parents, has been recommended to enable the development of trust (Meyer, Snelling, and Myren-Manbeck, 1998). Darbyshire (1995) recommended that the opportunity be provided for nurses and parents to discuss their experiences in an atmosphere of mutual respect and openness, in order to learn from each other. Neill (1996) provided guidelines for parental participation: facilitating parents' choice of coping strategies; providing for parents' physical needs; acting as mediator between parents and medical staff and providing parents with opportunities for their views to feedback their feelings in order to inform practice. Thus the nurse-parent relationship depends on communication, including both verbal and nonverbal parental feedback.

The communication role of nurses was described by Miles (1979) as being supplemental to physicians, by building on initial explanations and assisting parents in asking questions. Wereszczak, Miles, and Holditch-Davis (1997) found that mothers appreciated simple explanations from physicians but often depended on nurses for clarification. Being provided information that was anticipatory in nature by sensitive and caring nurses was also valued by parents (Meyer, Snelling, and Myren-Manbeck, 1998).

Some nonverbal communication by parents was illustrated by Macnab, Emerton-Downey, Phillips, and Susak's (1997) study using questionnaires for parents and nurses to find out why photos were displayed at the child's bed in the PICU. The study found that parents believed that photos would make the nurses more caring, and that photos comforted and helped parents have a happier, more optimistic state of mind. It was suggested that the practice of displaying photos provided an opportunity for the nurse to communicate more fully with parents, who may not be able to verbalise their wish for staff to strive harder in the care of their child. This example of nonverbal parental feedback serves to highlight the complex nature of the nurse-parent relationship, including the subtle nonverbal communication, cues and indirect feedback to be interpreted and responded to by the PIC nurse. Carreiro, Boyce and Nolte (1998) surveyed parents following their child's stay in PICU, and found that feedback was mostly positive with very few negative comments. Perhaps this is also an example that PIC nurses had received and appropriately responded to nonverbal parental feedback at the time.

Although the nurse hopes to develop a supportive, positive relationship with the parents, Meyer, Snelling, and Myren-Manbeck (1998) advised that seemingly maladaptive behaviour by parents may in fact be useful and necessary under the circumstances of their critically ill child. In relation to 'difficult' or dysfunctional parents, Groves and Beresin (1998) categorised families into three kinds; a) those who are never difficult for caregivers, b) those who are difficult because of the crisis of a critically ill relative, and c) those who are difficult regardless of what is going on. The nurse's role to be appropriately supportive in situations when parents may behave irrationally, and unexpectedly, is complex and daunting for the novice PIC nurse.

Summary

There have been many quantitative studies identifying the issues of parental stress in hospital and in the PICU. However, the use of questionnaires and rating scales have not provided in depth examination of parental experiences. There have been a paucity of qualitative studies that have revealed parents' perceptions and feelings. The literature has thus identified that parental stresses in the PICU are varied and complex. It has been shown that the nurse can intervene to minimise the stressful effects of alteration in the parental role, separation from the child and the child's altered appearance. From the literature it has been identified that it is the responsibility of the nurse to find out about and take into consideration each parent's background and individual experience of stress. Being aware of the effect of the environment as well as one's own behaviour is also essential. Inappropriate behavioural styles have been found to exacerbate parental stress.

To support parents and reduce their stress, the nurse can attempt to meet their identified needs such as facilitating the parents being with and parental involvement in the child's care through negotiation, provide the appropriate amount of information, including familiarising parents to the environment, make parents feel important, and provide more or less support depending on the individual parent's own support network. What has not been provided by previous studies, is the clinical application of how to do all of these things. For example how does the PIC nurse apply these principles to clinical practice, and how does the nurse involve parents in the care of their child, make parents feel important, and provide just the right amount of support?

The nurse-parent relationship has a significant effect upon parental stress. Such appropriate nursing behaviours that the specialist nurse has developed with experience can be hard to articulate. This study is important because it was designed to illustrate PIC nursing practice supporting parents by providing the contextual descriptions of nursing

behaviours to reduce parental stress that are missing from the reviewed literature. This study has implications for all nurses, and in particular novice and less experienced nurses, to reflect upon, and to apply to their day-to-day practice.

CHAPTER THREE

METHODOLOGY

I think we need more education... like you said before it is not written in stone what the right thing to say is or do is ... but you need some grounding (Hannah 77).

Introduction

This chapter describes the research design and methodology of the study. The sample, method of data collection and analysis are presented. The cultural context of paediatric intensive care nursing is also described in this chapter for two purposes: to both set the scene and link the conceptual framework to its use for data analysis. The chapter concludes with discussion of the trustworthiness of the study and the ethical considerations.

Design of study

The aim of the study was to identify behaviours of specialist PIC nurses caring for families to reduce parental stress. The design involved using a qualitative methodological approach of ethnography to examine the study aim. Ethnography was used because it was considered to be useful to identify the contextual roles and behaviours of a culture-sharing group, PIC nurses, in their relationships with parents (Creswell, 1998). Participants in the study were PIC nurses, recruited from six PICUs in Australia, who identified their clinical practice to be at or above the level of 'specialist' (see Appendices A and B).

During the development of an Australian set of Competency Standards, The Competency Standards for Specialist Critical Care Nurses (CACCN Inc., 1996) (see Appendix A.), consensus was reached on the attributes of the specialist level critical care

nurse (see Appendix B.). These attributes were used to establish selection criteria for participants for this study.

During November 1997, individual semi-structured interviews were conducted to capture the nurses' recalled critical incidents illustrating their behaviour to reduce parental stress when caring for families. Creswell (1998) described interviewing as a method of data collection in an ethnographic study, to collect descriptions of behaviour as the participant perceives it occurring in the cultural setting.

Research Methodology

Ethnography

Ethnography, a naturalistic approach, was used to examine the behaviours of specialist PIC nurses. Naturalism is seen as the underpinning methodology for ethnography: the task of describing cultural scenes or settings (MacKenzie, 1994). The ethnographer seeks to understand what one has to know, as a member of a particular group, to behave effectively as a member of that group (Van Manen, 1990). For nursing, the setting for ethnography can be wherever there are people and activities related to nursing and health care that need to be addressed in context (Munhall and Oiler, 1986). In focused ethnographic research, the specific area of investigation is defined prior to data collection (Morse and Field, 1996). This study borrowed from the ethnography principles to focus on an aspect of specialist PIC behaviour, namely parental stress reducing behaviour, within the broader context of PIC nursing practice.

Hilton, cited in Mackenzie (1994) summarised the assumptions, drawn from naturalism, underpinning the ethnographic method. These were:

1. A person's behaviour is inextricably linked with the meaning that the situation has for him/her.
2. A person's understanding, and hence behaviour, changes as he/she interacts with others.
3. Within a situation there will normally be different perspectives.
4. A person's behaviour and beliefs can only be fully understood in the light of broader aspects of organisation or culture.
5. The group or culture must be studied "as it is".

Ethnography was thus an appropriate methodology to use for this study, in that the PIC nurses' behaviours identified were examples which related to real situations seen from the nurses' perspective, when the nurses were working in the PICU environment, caring for sick children and interacting with parents and other staff.

Interviewing Technique

The methodology of ethnography was modified for this study because of both time constraints and because the researcher was an experienced PIC nurse and already knew the culture of the PICU. The researcher chose to interview PIC nurses using the critical incident technique. This technique, as a form of interview was originally described by Flanagan (1954) as collecting observed incidents having special significance. The technique is frequently used to collect data on observations previously made which are reported from memory. Brookfield (1990) described critical incidents as brief written or spoken depictions of vividly remembered events. Requesting the participants to provide verbal descriptions of critical incidents when they provided care to families to minimise parental stress provided the opportunity for reflection, discussion and explanations about the behaviours. It would have been logistically difficult, and may have been ethically

inappropriate to have undertaken fieldwork to observe the behaviour of nurses caring for parents of critically ill infants and children in clinical practice. It may have been distressing for parents to gain their permission to observe the nurse's relationship with them, such observation may have affected their relationship with the nurse, as well as it would have been unpredictable when appropriate nurse-parent interactions may have taken place. Therefore, the nurses' recollections of critical incidents was a practical data collection technique for this study.

Participants

Mackenzie (1994) advised that sampling is inherently associated with validity and should be described with reference to the research question. Participants for this study recognised their level of practice to be at or above the specialist level (see Appendices A and B), and were selected as follows: one each in Victoria and South Australia, and two each in New South Wales and Queensland. This sampling method enabled investigation into the Australian PICU environment, and the analysis then reflected Australian PICU culture rather than reflecting hospital or state idiosyncrasies. The seventh PICU, in Western Australia, was the Unit where the researcher worked and was not included for the study. This was because the researcher knowing and working with the staff may have had an effect on the study and findings. Creswell (1998) advised against it, cautioning the study of people in whom one has a vested interest.

Pilot Study

A pilot study was undertaken to gain insight into the type of data to expect to be collected. Two specialist PIC nurses in West Australia were interviewed during September 1997. The interviews provided the opportunity to refine the interview guide questions (see

Appendix E), and interview technique (Sorrell and Redmond, 1995). The pilot interviews also provided an opportunity for the researcher to practice and refine her interview skills. Data from the pilot study were not used in the final analysis.

Self as Instrument

In qualitative studies the researcher serves as the “instrument” through which data are collected. The responses of each participant guided data collection by the researcher probing for more information as needed for depth and clarity (Sorrell and Redmond, 1995). In this study, the researcher, an experienced PIC nurse, held some assumptions about the nursing care of the family, in that she believed PIC nurses’ endeavoured to minimise parental stress, and that junior or less experienced nurses were less able to provide this aspect of family care. Holland (1993) acknowledged that an ethnographic description is an individual’s perception of that reality based on her/his own personal view.

The researcher was clear about using self as the instrument for data collection, in that the relationship with the participants was for the purpose of research. Although a stranger to the participants, the researcher was already a member of the overall culture of PICU nursing, thereby avoiding the experience of the culture shock, which Holland (1993) described that a non-member researcher can experience. There was no conflict between clinical and research roles as the researcher had not worked in any of the Units or with any of the participants (Lew, Betchel and Sapp, 1993). The researcher may also have been more sensitive, than a non-member researcher, to aspects of nursing behaviour described by the participants (Holland, 1993).

Because the researcher is current practicing PIC nurse at a senior level, her credibility and authenticity in the field was an advantage in establishing rapport and trust with the participants (Rew, Bechtel and Sapp, 1993). Any concern about overlooking data

because of the researcher's familiarity with the study culture, was addressed by the recording and transcribing of the complete interviews. During the data analysis, the researcher's own experience and knowledge of the PICU culture provided confirmation that the participants' descriptions reflected PIC nurses' day to day relationships with parents in PICU.

Sampling strategy and interview process

The researcher contacted participants at the annual national Paediatric and Neonatal Intensive Care Conference held October 1997 in Hobart, Tasmania. This conference was followed by a three day Annual Scientific Meeting on Intensive Care. Up to 200 paediatric and neonatal intensive care nurses from most States in Australia annually attend the conference and the meeting. Permission was sought from the conference organising committee to access the study sample (see Appendix C). An introductory letter including an informed consent form and contact details were distributed to all nursing registrants in the conference registration documents (see Appendix D). PIC nurses who were not currently practising in PIC as well as nurses who attended the meeting from the PICU in Western Australia were excluded from the study (as explained earlier in participant sampling). The distributed information (see Appendix D), requested that potential participants arrange a convenient date and time for an interview to be held. Prior to the interview, each participant was requested to reflect upon recent clinical practice that included nursing strategies to minimise parental stress. This request was reiterated by the researcher when each interview appointment was made.

The sampling strategy resulted in three nurses contacting the researcher, whereas the intended sample size was approximately 15. Ten to twenty interviews were usually considered to be sufficient, although fewer could still provide rich data (Wilson and

Hutchinson, 1991). The researcher subsequently contacted colleagues, or “gate keepers” (Spradley, 1979) at each PICU to call for volunteers of appropriately experienced nurses. The researcher was invited to, and visited, one Unit to talk to the nursing staff about the study. Volunteers were then able to contact the researcher to participate in the study. These recruitment strategies were more successful and resulted in a further 12 volunteers, making a total of 15. During November 1997, the researcher spent one to three days in each state conducting the interviews. Table 1 shows the number of participants from each PICU (see Table 1).

Table 1. Number of participants from each PICU

	PICU 1	PICU 2	PICU 3	PICU 4	PICU 5	PICU 6
No of participants	3	2	3	2	3	2

The semi- structured interview, steered by the use of an interview guide, focused on critical incidents when the participant had provided care of the family to reduce parental stress. It aimed to provide examples of nursing behaviours that reduced parental stress. The interview guide was refined after each interview so that participants’ behaviours and perceptions could be further explored and explained.

Data collection

Organisation

Interview times were arranged at the convenience of the participants. The interviews took place in venues chosen by the participants, which were mostly at the participants’ workplaces (14), and for one in the participant’s own home. Some interviews

were conducted whilst the participants were at work but taking a break from their clinical work, and some were conducted when the participants were not working. Each interview was between 40 minutes and 100 minutes and was audiotape recorded with the participant's permission. Some interviews were recorded in the clinical area or in a room that was also used by other people. Recording in these areas did present some problem as some background noises obscured conversation. The researcher also took supplementary notes about non-verbal cues, interruptions and the context of the interview, and these notes were used for contextual clarification.

Conduct of Interviews

The researcher discussed critical incidents with the participant using the interview guide (see Appendix E) which had been developed and tested in the Pilot Study. The guide was further refined as the participants provided information, and the researcher identified themes that were to be developed in subsequent interviews (in keeping with accepted methodological practice for qualitative interviewing [Creswell, 1998; Minichiello, Aroni, Timewell, and Alexander, 1995]). For example, when it had been identified that PICU visiting restrictions were a source of parental stress, in subsequent interviews, further questioning in this area identified the reasons for and the influences upon the specific restrictions.

The data collected also included years of experience working in PICU and qualifications relevant to PIC nursing. These data were collected to establish the credibility of each participant and to provide supportive information that each one met the specialist critical care nurse selection criteria (see Appendix B.). Table 2 shows the participants' pseudonyms, years of PIC nursing experience and relevant qualifications (see Table 2).

Although the ethnographic interview incorporates a free flowing approach, Spradley (1979) identified three elements: explicit purpose, ethnographic explanations and ethnographic questioning. The researcher made clear the purpose of the interview before explaining to the participant what was required. The participant was asked to describe an occasion when he/she provided nursing care to minimise parental stress. The researcher avoided the term 'critical incident', so that the participants freely spoke about their day-to-day care of the family (Benner, 1984). The purpose of the interview was to collect descriptions of the nurses' behaviours when caring for families to reduce parental stress. Descriptive, structural and contrast questioning were used (see Appendix E.). Descriptive questions were the easiest to ask, such as "describe your role in caring for the family". Structural questions were asked in order to gain more specific information such as "how do you know when to invite parents to participate in care?" Contrast questions were used to uncover specifics about the meaning of data such as "what makes one parent more challenging than another?" (Sorrell and Redmond, 1995).

Table 2. Pseudonym, experience and relevant qualifications of participants

Participant	Pseudonym	No.of years PIC experience	Qualifications relevant to PIC nursing (All participants were Registered Nurses)
1	Alice	8	Registered Sick Children's Nurse (RSCN) Bachelor of Nursing (BN)
2	Hilda	7.5	BN Paediatric cardiothoracic certificate
3	Kate	2	BN Graduate certificate in Paediatric critical care
4	Bree	12	RSCN
5	Amy	11	RSCN PICU certificate
6	Hannah	15	
7	Lily	3	Midwifery, Maternal and Child Health Diploma
8	Rose	3	Paediatric Graduate diploma
9	Sam	10	BN (Hons)
10	Jo	8	BN Paediatric certificate, Graduate certificate in paediatric critical care
11	Chris	15	Renal nursing certificate
12	Chloe	2.5	RSCN Graduate diploma in PIC
13	Harry	5	BN Midwifery, PIC Certificate
14	Jane	15	Paediatric certificate Midwifery PIC certificate, Acute care graduate diploma
15	Max	4	IC certificate

Analysis of data

Following each interview, the interview and notes were reflected upon in order to incorporate emerging ideas in subsequent interviews (Creswell, 1998; Minichiello, Aroni, Timewell, and Alexander, 1995). When all the interviews were transcribed, they were checked against the tapes for accuracy. Each participant was sent the transcript from her/his interview and asked to check it to ensure the transcript was a true record of the interview. Spradley (1979) advised that ethnographic analysis is as conceptualised by the participants. As part of the validation process, the major themes that were developed and a section of the findings were returned to three participants to judge the accuracy and credibility of the data interpretation. Feedback was that the interpretation was accurate. There were two suggestions: an expansion of an interpretation, which was incorporated into the findings, and a concern about patient anonymity, resulting in further editing of the relevant excerpts.

Development of coding categories

Each transcript was read and reread for the overall 'feeling' or for a sense of the whole (Wilson and Hutchinson, 1991). Data analysis was facilitated by using NUD•IST (Non-numerical unstructured data indexing, searching, and theorizing; Qualitative Solutions and Research Pty Ltd., 1997) v4.0 (Macintosh), a computer software programme for qualitative analysis of unstructured data (such as interviews). The transcripts, as word processing documents, were converted to files in NUD•IST. This software was used to store and organise files, code and store codes, facilitate searching for themes, relate themes and categorise information as a hierarchical tree. The programme has been favourably evaluated in comparison to other similar software packages (Weitzman and Miles, 1995). Using a computer based analysis tool such as NUD•IST allows for a more systematic and

complete analysis of interview transcripts than is otherwise possible (LeCompte and Preissle, 1993).

In NUD•IST, hierarchical categories or nodes to which appropriate segments of text may be assigned, form “trees” whose branches are referred to as “children” of the original node and “siblings” of one another. Each node receives a number in the indexing system which indicates its position in the hierarchy. Categories can be created using a bottom-up or data driven method or top -down or theory driven method or a combination of both. The analysis of segments of texts into these categories generates data which can be examined as a collection.

An initial set of categories, called an index system in NUD•IST, was developed which included nodes related to the interview guide questions, parental stressors, parental and nursing behaviours, and specific specialist nurse behaviours.

Interviews were coded using a sentence of text as the text (coding) Unit. Text Units are the smallest Units of texts recognised by NUD•IST (1997, p. 33). They are set by the researcher and are automatically numbered for identification and retrieval of text within documents (interviews). The researcher coded each text Unit to a node, developing new nodes when the data didn't fit into the existing categories. The interview questions were used as the starting points for the category coding. As coding was carried out, the researcher refined, added and deleted as necessary.

Reliability of coding (Burns and Grove, 1993) was checked by means of:

- Cross checking the definitions or meanings of nodes by the researcher and supervisor coding together and making joint decisions about material which was difficult to code
- Comparing text Units coded on the same nodes within and across interviews for consistency of definition and meaning
- Re-reading the interviews to ensure that the overall feeling and meaning was represented by the coding

Use of conceptual framework for data analysis

A further stage of data analysis was carried out using an adaptation of Imogen King's Conceptual Framework for Nursing (1981). This framework provided a structure to be able to analyse the components of the complex relationship between nurses, parents and the PICU environment. The cultural context of PICU nursing is first described below to explain and clarify the contextual environment for the nurse-parent relationship within the PICU. The description is based upon the supplementary notes taken during the participant interviews, the researcher's own experience of PIC nursing, and the researcher's discussions with some inexperienced PIC nurses to understand the PIC culture from their perspective. This description sets the scene to understand the environment within which the nurse practices and develops often an intimate relationship with parents. It also provides a background to understand the use of the research conceptual framework for data analysis and presentation of the research findings.

The cultural context of PIC nursing

When a child comes into hospital there is an attitude some people have that says- "right you've just relinquished your hold on this little person, it is ours now until they go through these doors"... we need to get rid of that attitude (Chris 194-195).

Most nurses, in fact, do not work in or even venture into a paediatric intensive care Unit. The culture within the PICU is foreign to anyone who does not work there. The PICU is a highly specialised area within a children's hospital, where the nurse's domain is at the bedside. Here, the nurse spends his/ her working day, providing nursing care to the occupier of the bed - the sick child. Over a 24 hour period, a critically ill child is continuously provided with the same level of care, often with bright lighting continued throughout the night to permit adequate monitoring. The nurse interacts with the child, the family, other nurses, medical staff, and allied health workers. Usually responsible for one patient, the nurse refers to the critically ill child lying in the bed as 'my child /baby' or 'my patient'.

There are three distinct divisions to each shift. At the beginning of the shift the previous nursing shift will usually provide an overall handover about all of the patients. Then the nurse will receive a more detailed handover at the bedside about the patient he/ she will look after. This is followed by examination and assessment of the patient, checking of emergency equipment, electrical safety, ventilation settings, security of intravenous lines and endotracheal tubes, monitor alarm parameters and recalibration of pressure monitoring. Drug charts, drug infusions and medical orders are also checked. The middle part of the shift is divided into hourly intervals, between the 'obs' (documentation of patient progress), during which patient care is carried out. The end of the shift is identified by evaluation of patient progress, writing a summary in the patient record, and handover to the nurse caring for the patient on the next shift.

Access to the bedside and the child, by staff and visitors, is sought and obtained from the nurse. Requests may include X-rays, imaging or other investigations performed in the Unit, medical staff who may wish to examine the patient or perform a procedure, or visitors to see the patient or parents. The nurse will then readjust his/her nursing care plan for the child for the shift to accommodate these activities and may need to reprioritise or reschedule the tasks yet to be completed.

The child may be nursed in the main open area of a PICU or under certain circumstances be nursed in a single room or cubicle. Reasons for being nursed in a single room include being infectious, neutropaenic or immunocompromised, very sick and likely to die, or dying. In the open main area, there may be several patients lying in adjacent beds, which are separated by trolleys containing disposable equipment such as syringes, needles, suction catheters and linen, the ICU observation charts, and by the arrangements of chairs. Curtains are only drawn around a bed when there is 'something going on', such as a procedure, the patient is being resuscitated, or is dying. The close proximity means that a limited amount of privacy is afforded and maintaining patient confidentiality can be difficult. The purpose of this geographical layout is to facilitate observation and immediate access to the patient should some treatment, procedure or resuscitation be necessary.

The ventilated critically ill child requires close and constant assessment, to detect changes in condition as well as to anticipate and prevent sudden events such as the child coughing and blocking the endotracheal tube. In such a situation, the nurse needs to immediately assess the problem, and respond appropriately, which may mean performing endotracheal suctioning to allow adequate ventilation to be re-established. The ventilated, chemically paralysed child is completely dependent upon the nurse who must anticipate all of the child's needs. When caring for ventilated, non-paralysed children, who do not understand what is happening to them, sudden patient movements such as raising the arms

to the face in an attempt to remove the endotracheal tube, must always be anticipated. Anticipating the unexpected means the nurse must be constantly at the bedside unless another nurse takes over the responsibility. Certain tasks require more than one nurse, such as endotracheal suctioning, position changes and medication checking. In a side-room, separate from the main area, it is more difficult, to be assisted or relieved of responsibility from the bedside. Thus the nurse may feel isolated when caring for a child in a side-room.

Typically the critically ill child is attached to haemodynamic and respiratory monitoring, has multiple intravascular lines, requires frequent interventions, as well as continuous and intermittent administration of medications. The nurse monitors the patient's condition and progress, documenting or 'doing the obs' at least hourly. Gathering and integrating of assessment data from multiple sources is made frequently. Differentiation must be made between actual changes in patient condition and artefacts or equipment malfunction. Therefore troubleshooting equipment problems is rapidly and frequently performed.

Determining the significance of findings and subsequent decision making, through synthesis and analysis of gathered patient data, may result in, for example, altering a drug infusion rate, measuring arterial blood gases, administering a muscle relaxant drug, deciding that the patient is too unstable to tolerate chest physiotherapy or alerting medical staff. The nurse must anticipate changes that may be related to alterations in therapy. Further the nurse must act pre-emptively to avoid potential complications, frequently evaluating and responding to the changing condition of the critically ill child. Unit protocols and standards are used as guidelines for general nursing care. In addition, the nurse will liaise with medical staff to establish parameters for specific patient goals. Parameters may be written as orders such as the desired hourly negative fluid balance in

renal replacement therapy, or communicated verbally such as desired mean blood pressure or minimum cerebral perfusion pressure.

The nurse plans to complete the necessary work within timeframes, such as between documenting observations, before leaving the Unit to undergo a Computerised Axial Tomography (CT) scan, when drugs are due, and within the shift. There is a tacit rule that routine tasks are completed and not handed over to the nurse caring for the patient on the next shift, unless this becomes impossible due to changes in the patient's condition or increased activity in the Unit resulting the nurse becoming too busy. Routine tasks include; intravenous line changes, ventilator circuit changes, preparing intravenous drug infusions, and attention to the child's hygiene needs. Allowance must be made for changes to the plan such as organising for and accompanying the child to theatre or CT scan, or assisting with a procedure.

The experienced bedside nurse will directly communicate with medical staff or if the intensivist (intensive care specialist) or registrar (trainee intensive care specialist) is not 'around' in the Unit, use the paging system to contact him/her. The shift coordinator and 'float' (an experienced nurse who is helping out the bedside nurses) are utilised as resources with whom to initially discuss the concern or problem. The float may not be allocated a patient or may be expecting an admission later in the shift. The shift coordinator is the nurse in charge of the shift, and usually does not have a patient load, this nurse is a resource to all the nurses on the shift, and has an overall appreciation of 'what's going on', coordinating the care of all the patients. He/she will have a more direct supervisory role if the bedside nurse is inexperienced. Overall there is collaboration and a sense of working as part of a team, with inexperienced nurses mentored and supported by those more experienced. In particular there is a close working relationship between the nurses and the medical staff.

While the setting is natural to the PICU team, the environment is alien, intense, stressful and frightening for parents (Curley, 1996; Daley, 1984; Groves and Beresin, 1998; Haines, Perger, and Nagy, 1995; Meyer, Snelling, and Myren-Manbeck, 1998; Miles, Carter, Spicher, and Hassanein, 1984; Scott, 1998). The impact of the critical care environment on parents cannot be overemphasised; the proximity to death, the high technology, and the large number of strangers involved with their child's care, exacerbate parents' apprehension and fear over the uncertainty of the outcome from the critical illness or injury.

The child's parents are usually welcome to be with their child in the PICU, although there are occasions when they are either prevented from being present or are asked to leave. There is an intercom or 'buzzer' system which all non-staff are required to use for permission to enter the Unit. In some Units parents are required to leave for medical and/or nursing handovers, for procedures such as insertion of central venous lines or intercostal drains, or if a child is being resuscitated in the Unit. At the bedside, the number of visitors is usually restricted to two at a time, unless the child is dying, when restrictions are lifted. There are no specific visiting times, although parents are encouraged to leave the Unit to get some sleep at night. This is also beneficial to the nurses who prefer a few hours during the night to be parent-free, when they can be more relaxed.

Other family members and friends are welcome to visit the child and support the parents. The nurse may, after discussion with the parents, restrict the visit duration and number of visitors and phone inquiries. Sibling visiting is encouraged and believed to be important for the whole family. However, the PICU environment is not designed to be child friendly and affords few facilities for caring for siblings.

Facilities for parent accommodation vary. Sleeping may be at the bedside on recliner chairs, in bedrooms near to the Unit or on fold-out beds in a parents lounge which

is shared with other parents. Private accommodation and showering facilities may be offered elsewhere within, or nearby, the hospital. Some Units have parents' lounges with tea and coffee facilities and television. In some Units parents are permitted to use the staff kitchen to store and prepare their own food. Parents are usually not permitted to eat at the bedside, hot drinks are not encouraged for safety reasons, whilst cold drinks are permitted. Some Units have a more relaxed approach in relation to these rules.

The relationship between parents and PICU staff is not always harmonious. When conflict occurs in the PICU, it is usually considered to be because of a "difficult" family or parent. Groves and Beresin (1998, p.336), articulated the situation facing PICU staff... "There is hardly anything worse than working with an uncooperative, irritating and at times hateful family member". Further, Groves and Beresin (1998) described such individuals in terms of having personality disorders. In these challenging situations, the reactions and strategies of PICU staff, and in particular nurses are most important. Inadvertent negative reactions may worsen the situation. Experience in facing aggression, conflict and manipulative parental behaviours are needed for relationships to be successful.

In summary, the culture within the PICU is only experienced by the staff and the families whose children are critically ill. The family, and more specifically the parents, must learn the rules, both explicit and implicit, in order to fit into the culture. The role of the nurse is central to the life of the parents during this alien and stressful time in their lives. There is very little privacy, a high level of technology, and activity is centred around the child in the bed. The nurse attempts to assist the parents to adapt to the foreign environment. Some parents, for a variety of reasons, are more difficult to support, thus presenting a greater challenge to the bedside nurse. Nursing must be individualised to be appropriate to each nurse-parent interaction to be able to reduce parental stress. Whilst the ability to be able to support parents is an important aspect of PIC nursing, novice and

inexperienced nurses have not been prepared to enter into challenging relationships with parents.

King's Conceptual Framework

King's conceptual framework for nursing (1981) was adapted for this study to illustrate the complex relationships between nurses, parents and the PICU environment. King's conceptual framework consists of three interacting, open systems; individuals as personal systems, two or more individuals forming interpersonal systems, and larger groups with common interests forming social systems. The relevant concepts integral to King's conceptual framework that have been interpreted in the context of this study are identified as subheadings under each of the open systems (see Figure 1).

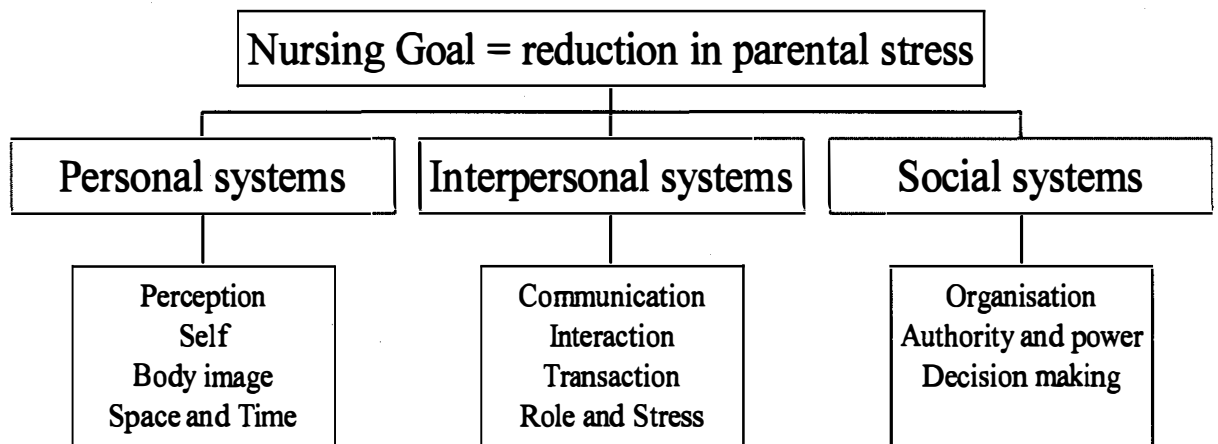


Figure 1. Adaptation of King's Conceptual Framework (1981).

The schematic diagram adapted from King's conceptual framework (Figure 1), illustrates the organisation of three open systems in a dynamic interacting framework. An overview of the personal, interpersonal and social open systems below has been provided to explain the conceptual framework. Concepts relevant to this study have been identified within each of the open systems. These concepts have been used as subheadings in the

findings Chapters Four, Five, and Six, and are further developed in the discussion of the findings in Chapter Seven: Discussion.

Personal Systems

In the context of this study, individuals as personal systems, relates to both the nurse's frame of reference and that of the parents'. In terms of interactions, individuals react to persons, events and objects in the environment because of their perceptions, expectations and needs. The concepts to explain individuals as open systems are perception, self, body image, space, and time (King, 1981, p. 19).

Perception

According to King (1981, p. 20) one's perception is related to the individual's past experiences, concept of self, biological inheritance, educational background and socioeconomic groups. Perception is each person's representation of reality. Perception influences behaviour and may be distorted by high emotional states such as stress. Perception is one of the concepts affecting the interactions between individuals and groups.

Self

The values and beliefs of individuals help them maintain some balance in their lives. One's attitude towards oneself is often reflected in attitudes towards others. One's bias and prejudices have an impact upon relationships (King, 1981, p. 26).

Body image

Individuals identify self in relation to their body appearance and other's reaction to them. Body image is thus the result of other's reaction to self (King, 1981, p. 32). In the context of this study, the focus is the parents' identification with the body image of their child, and other's reaction to their child's appearance.

Space

This concept is related to perception, body image and the way individuals use space. Proxemics is a term that has been used to describe the use of space as "an elaboration of a culture" (Hall, 1963, cited in King, 1981, p.35). Individual differences as well as different cultures use more or less distance for their own personal space. In the PICU environment, parents can lose their personal space, when at the child's bedside, as the area is the domain or territory of the nurse. The parents' intimate space is also often invaded by the nurse and vice versa.

Time

Time is perceived as one event following another, making time continuous. Time also gives order and duration to events. Time is subjective and can be experienced as moving slowly or quickly (King, 1981, p. 41). Stress can result in a loss of the concept of time for the parents in PICU, especially when combined with loss of perception of night and day and long periods without sleep.

Interpersonal Systems

The interpersonal systems, in this study, include the interactions between the nurse and the parent, between parents, and between PICU staff. To understand two or more persons interacting in interpersonal systems, the following concepts are described; communication, interaction, transaction, role and stress (King, 1981, p. 59).

Communication

Communication continually takes place between individuals. It is not possible to separate nonverbal and verbal communication. It is each individual's perception of the communication as a complete process that determines the interaction between the individuals (King, 1981, p. 62).

Interaction

King (1981, p. 59) described how behaviours of individuals are interpreted as actions. Individuals' perceptions and judgments are involved in every type of human interaction. Interaction is the process of perception and communication. A process of human interaction is shown schematically in Figure 2.

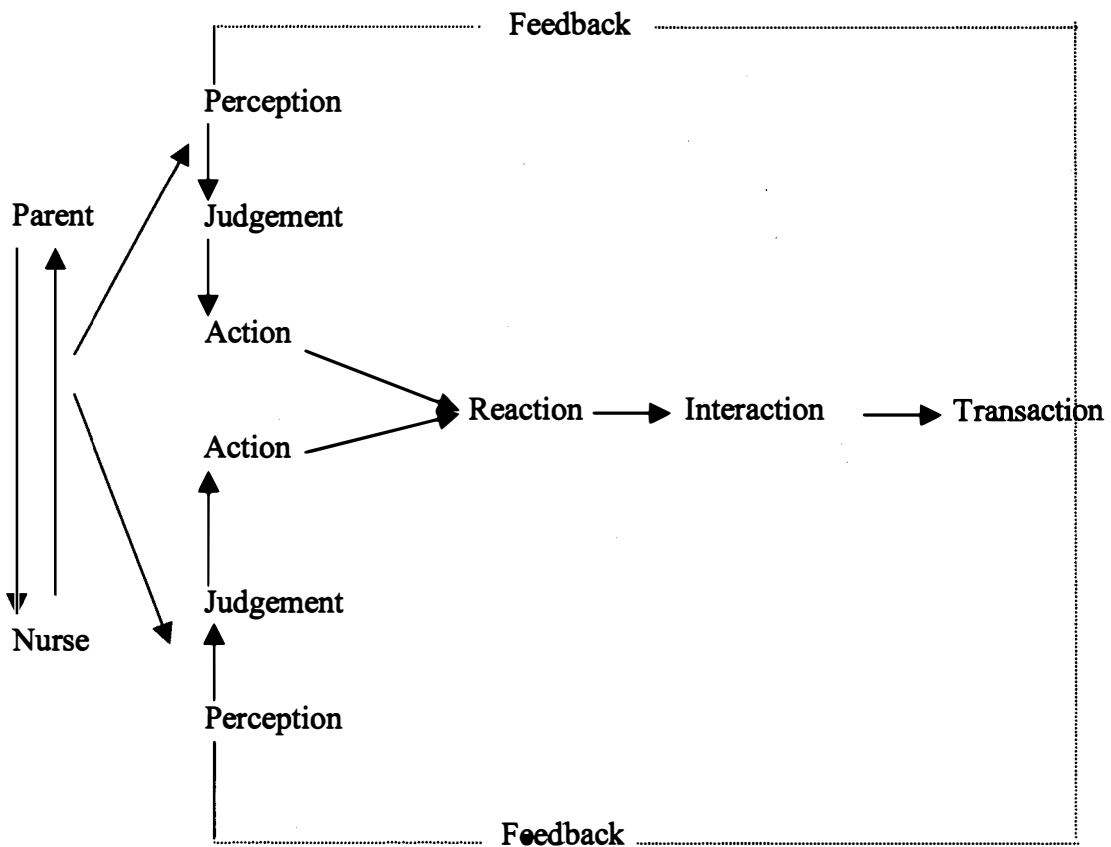


Figure 2. King's process of interaction (1981, p. 61).

Figure 2 shows the interaction between two people. In the context of this study, the interaction is between a nurse and a parent, for example, when the nurse is providing information to parents. Perception, judgement, action and reaction in the diagram are behaviours that cannot be directly observed, but are inferred. The next step, interaction between the nurse and the parent, can be directly observed as verbal and nonverbal communication behaviours. In the context of this study the "transaction" is the establishment of rapport, the goal being the reduction in parental stress. Finally, feedback continuously informs the process of interaction.

Transactions

Transactions are goal directed human behaviours that are observable (King, 1981, p. 82). In this study, such goal directed nursing behaviour is the reduction of parental stress.

Role

Roles identify interactive relationships and modes of communication. Roles identify self in relation to others (King, 1981, p. 89). Others, depending on culture and past experiences, may perceive the role of the nurse or of the parent in PICU differently.

Stress

King uses a definition from Monat and Lazarus (1977, cited in King [1981, p. 96.]): that “undue stress decreases ones perceptual field, decreasing the information one senses and the ability to cope with events”. Perception is an important factor in the way a person attaches meaning to events. Stress is therefore individual, personal and subjective. Both parents and nurses experience stress in the PICU. These stresses are described in the findings.

Social Systems

The social system or group in this study is the environment or culture within the PICU, as previously described in Chapter One. King’s concepts explained in relation to social systems are organisation, authority and power, and decision-making (1981, p.119).

Organisation

An organisation is composed of human beings with prescribed roles and positions who use resources to accomplish personal and organisational goals (King, 1981, p. 119). As described earlier in Chapter One, nurses provide constancy and continuity and coordinate patient care activities in the health organisation.

Authority and power

The concept of authority is described as power to make decisions that guide the actions of self and others. King (1981, p. 122) believes that authority is essential in formal organisations, where one individual influences another and the other accepts that influence. Authority gives power to regulate and to enforce rules or norms. Power implies a dependency relationship, which is seen within the PICU culture, in the nurse -parent relationship, in which clearly it is the nurse who has authority and it is the parent who is dependant. Peer groups exert power over individuals influencing that behaviour. Power is the process whereby one or more persons influence other persons in a situation (King, 1981).

Status and Decision making

Decisions are usually based on one's values, goals, knowledge and past experience, and requires information (King, 1981 p. 133). In the unfamiliar PICU environment, parents are often not in a position to make any decisions about their child. Nurses can minimise the effect of this on parents by the manner of communication with parents and respecting parents' wishes as much as possible.

Finally presented in this chapter, is the discussion about the trustworthiness of the study and the ethical implications.

Trustworthiness

Ethnography builds in the subjective experiences of participants and researcher (LeCompte and Preissle, 1993), making explicit what is implicit and tacit to participants, or giving them “voice” (Creswell, 1998). To determine whether a study is a good ethnography can only be answered by whether the study contributes to our understanding of the research question (Creswell, 1998).

Five standards, that were described by Howe and Eisenhardt (1990), were applied to this study. Firstly, the research question drove the data collection and analysis rather than the reverse being true. Secondly, data collection and analysis techniques were competently applied in the technical sense as discussed previously in this chapter. Thirdly, the researcher’s assumptions and subjectivity were made explicit, and fourthly, the study was robust and worthy, which was demonstrated by the verification procedures outlined below. The fifth standard was that the study had value, in the implications to improve nursing practice, caring for families of critically ill children, whilst it protected the confidentiality of the participants.

Creswell (1998), recommended that at least two verification procedures are undertaken in any given study. In this study five verification procedures have been addressed.

1. The researcher reflected upon the data, codes and themes several times.
2. Two reviewers (one was the researcher’s supervisor) who were methodological experts, checked the coding and themes.

3. The researcher's supervisor asked questions about meanings and interpretations and acted as a "devil's advocate", providing an external check of the research process.
4. Negative case analysis was used in refining and revising the themes; participant's reflections upon how their behaviour could have been improved or examples of how parental stress was caused by inappropriate behaviour supported the interpretation of data.
5. The researcher discussed the PICU culture with some novice PIC nurses to understand it from their perspective, in order to clarify any researcher bias and assumptions that may have impacted on the interpretation and approach to the study.

(Creswell, 1998).

The study was also subjected to "member checks" or participant validation, when three participants were asked for their views on the credibility of the findings and interpretations. This approach is sometimes considered to be the most important technique for establishing credibility (Creswell, 1998; Lincoln and Guba, 1985). By describing the characteristics of the participants and the detail of the PICU setting, the researcher has provided rich, thick description. This will enable the reader to interpret the information in relation to other settings. For auditability (Burns and Grove, 1993) a record of the decision trail used in the analysis of data and theme development was kept using the NU•.DIST software

Ethical Considerations

To ensure confidentiality, the participants were identified in the transcripts by pseudonyms. Participation in the study was voluntary and the recruitment strategy of calling in writing for volunteers, and then indirectly calling for volunteers through

colleagues, and not directly asking individuals, avoided any possible coercion. The interviews were held at convenient times and venues for the participants and were consistent with preserving the participants' autonomy. The status and conditions of employment of the participants were not affected in any way by participation in the study.

A participant was able to withdraw from the study without penalty at any time with the data collected from that interview being destroyed. There were no known risks associated with the study, while the potential benefits for PIC nurses are to enhance their care of the family to reduce parental stress.

Descriptions, characteristics and particular meanings are not discernible to any individual participant. All interview transcripts remain confidential and any resulting publication will not identify individuals. The interview tapes were erased following transcription, checking of accuracy and contextual tone of voice. The transcripts will be kept in a locked cabinet at the researcher's premises for five years and will then be destroyed.

The researcher was prepared for the possibility of eliciting unanticipated emotional responses from the participants that may have been related to reflection upon the critical incidents during the interview. This did not occur. Wilde (1992) advised that although it can be problematic for the beginning nurse researcher; one must avoid counselling, teaching or presenting one's own perspective during the interview. Referral to appropriate support or professional counselling may have been, but was not required.

Summary

This study's methodological approach of ethnography was particularly appropriate to identify specialist nurses' descriptions of their behaviours (examples of real situations seen from the nurses' perspective), to reduce parental stress within the environment of the

PICU. The cultural context of PIC nursing was described to set the scene and link the conceptual framework which was used in analysis of the interview data, and to structure the study findings. King's Theory for Nursing (1981) was a useful framework to structure the findings of this study, because whilst it allowed the complexities of nurse-parent relationships to be analysed by separating personal, interpersonal and cultural issues, the inter-relationship of interpersonal relationships between staff and parents and the effect of the culture within the PICU remained apparent. The analysis and findings in relation to this complex topic are now explained and presented in a way that can be followed by the reader. The trustworthiness and ethical considerations for this study were adhered to as previously referred to in the chapter. Analysis of the data resulted in the findings presented in the following three chapters of Findings and Interpretation: Personal Systems, Interpersonal Systems and Social Systems. The framework is also used to structure Chapter Seven: Discussion.

CHAPTER FOUR

FINDINGS AND INTERPRETATION: PERSONAL SYSTEMS

King explained that personal systems refer to the knowledge that helps one understand individuals (1981, p.19). King's concepts have been interpreted in the context of this study to explain personal systems are perception, body image, space and time. The relevant findings from this study are schematically presented below using King's concepts as headings in the blue text, and new subheadings that emerged in black text (see Figure 3). Excerpts illustrating themes have been taken from rich descriptions during the interviews. Because of the volume of data collected, not all data is presented.

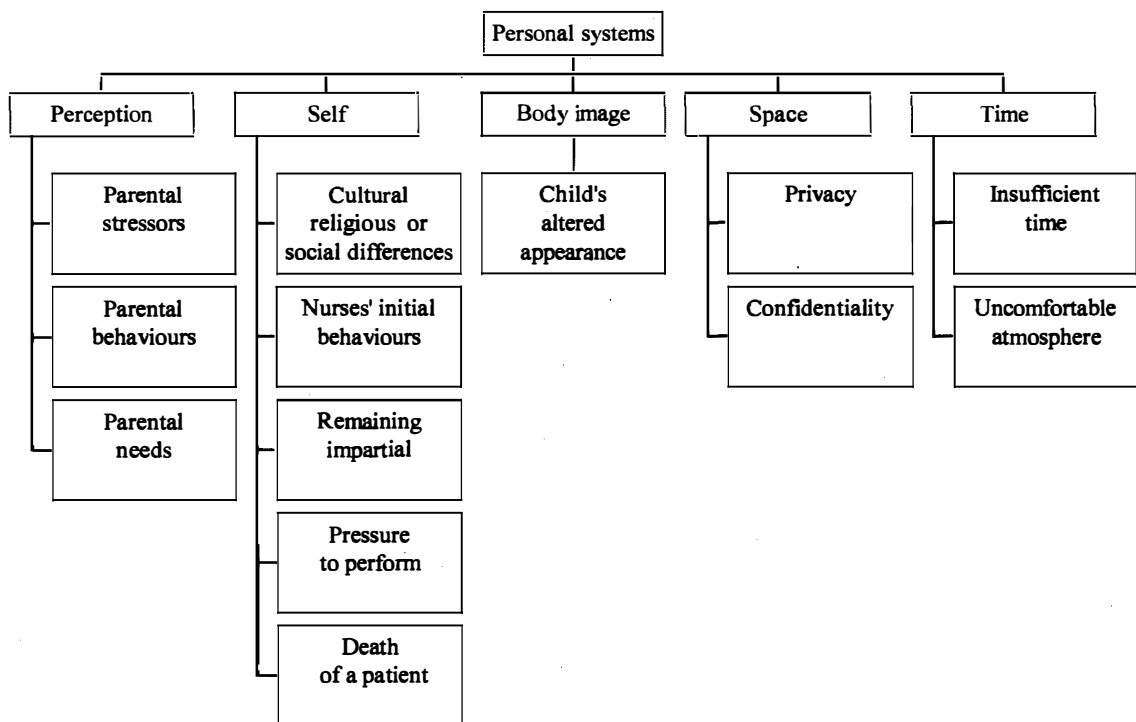


Figure 3. Personal systems

Perception

King described perception as each human being's representation of reality (1981, p. 20). The nurses described their perceptions of parents' representation of reality. Until

now, reality, for parents was to have a healthy child. The parents may have experienced their child being unwell with the usual childhood illnesses, however, most parents will never have faced anything like a critical illness, the most stressful of all parenting experiences (Noyes, 1999). This event represented a complete change in the parents' reality.

The nurses' perceptions of the stresses parents faced were: their fear of the child dying; not knowing what was wrong with the child; guilt; situational stresses; external stresses and additional stresses experienced by parents of chronically ill children. The nurses perceived parental behaviours in terms of their responses to stress. Such behaviours were: numbness, wanting the security of the nurse's presence, hysteria, anger, denial, no rapport, not involving the rest of the family, and vigilance. It was also perceived as important to provide for the parents' physical needs, even though the parents themselves might not identify their own needs.

Parental stressors

Fear of child dying

Harry described how it was always in the minds of parents and staff that the child could die.

It will always (subconsciously) be part of the conversation - anyone who is in Intensive Care has an increased likelihood of dying. Whether they get out alive or not, there is always a higher risk, a higher chance that they could die. So it is always in the back of our minds that, you know, this child might not live. And I think parents realise that if their child is in Intensive Care they are there for a reason, they are sick, there is a likelihood of the child dying...they know that if their child is that sick it is always possible (Harry 367-387).

It was important for staff to remember that parents would always be concerned about their child dying, even if staff didn't consider the child's condition to be critical. Chris used an example of a child with croup.

I always make an effort to be there when parents are being spoken to (by the medical staff) about anything -it doesn't matter how minor it is, because to them it might be a big thing, because when a child comes in here to most people it is fairly horrendous, and they need lots of support -it doesn't matter how sick or bad the illness is. For example there is always that phrase 'it's just croup.' But it's not just croup it's a child whose airways are in danger of threatening their life and therefore their needs are just as great as other kids and their parents see it -you know if their child is admitted to Intensive Care -they need a lot of support, especially at first (Chris 81-82).

Not knowing what is wrong with child

It was recognised to be stressful for parents not to know what was wrong with their child.

The hard bit for mum was that we couldn't tell her what was going on (Jane 53).

Her diagnosis took a long time coming and so that by the time they learned what was wrong with her they were really very stressed (Chris 5).

Guilt

The nurses perceived that parents may experience a feeling of guilt associated with the cause of the child's injury / illness.

She was feeling really guilty, obviously that was stressing her (Hilda 6-7).

I can identify with that guilt, I don't know what it is like. I have no idea what it is like ... if only we had watched her 2 mins before. I have no concept of how overpowering it must be for them, I can just imagine what it is like (Hannah 97).

Hannah explained how she acknowledged parents' feelings, such as guilt or denial, as it was not appropriate to try to convince them otherwise.

Don't try to hide it and say "there there it's OK it's not your fault." They don't believe you, they feel it's their fault at the time, its not going to be until its way down the track that they couldn't have done anything about it. Or maybe they could

have done something about it and their guilt is justified it is not up to us to take that away from them. I think it's like a knee jerk reaction ... try to make it better put a band aid on it. We can't do that (Hannah 101).

Situational stresses

Situational stresses were related to what the nurses saw as related to the care of the family and the effect upon the parents of being exposed to the culture within the PIC environment. The nurses identified that some of the causes of parental stress were related to nursing behaviours, and some of the stressors they felt were beyond their control. Parents became used to a particular nurse or routine. A change in the way of doing things by the nurse could be stressful for parents.

They have seen a certain person looking after their kiddy for 3 or 4 days perhaps and have done something the same way all the time, somebody new comes on and does it slightly different. "So and so didn't do it that way"... immediately they get stressed up (Bree 118).

Parents not being informed about changes in treatment or the child's condition caused stress.

People say "yeah yeah we will ring you" and they don't and the parents come in and all these changes have been made overnight (Hannah 133-134).

Not all nurses negotiated with parents. These different styles of nurse - parent relationships caused stress.

Some don't see the importance of giving the parents the choice (Alice 69).

If the nurse looking after their child was less experienced in PIC nursing, this increased parents' stress.

A lot of the nurses don't have a lot of paediatric background, which is not bad in itself, they are just not used to family centred care (Alice 299).

When we got busy, and because he had been here for a long time and he was very stable he would be a patient who would more often than not get the Agency staff - the 'on-call' staff and the family would get upset (Jo 89-90).

If parents were unhappy with their child's care or treatment, they may not openly discuss this with the staff, although it may be a source of stress.

It would agitate them that the nurse would forget to come back and do the feeds, but they were such nice people that they wouldn't complain because they would think, no she is doing something else more important, but as they said, "you know, our child is still in intensive care and she has a right to have these things done." And it was pointed out to them that it really doesn't matter if the feed is half an hour late, they would just be half an hour later in the morning, but they said "yes, but then she's not hungry at breakfast time" so while it might not seem that important to them, the parents' whole focus is this baby and her development and if that's going to put the next day's routine out it's a major thing (Jo 187-188).

Once their child had recovered and was ready for transfer to a ward, the move to a different, less intense environment, was a new stress for the parents.

The transition to the ward is a big difficulty. (Hannah's child had been a patient in the PICU) It just amazed me... that we were only here for 24 hrs and I was fine but my husband was like "where is the monitor... how are they going to know if he is OK?" ...after 24 hrs here he was in ICU mode and I just couldn't believe it. So I imagine that these poor parents who are here for a month or 6 months and then go to the ward... it must be absolutely terrifying (Hannah 286-288).

The longer term patients... some that we have had here for a year to 18 months that is so much harder for them, they are so used to being one on one (nurse to patient ratio) and going to an area where there will be 6 children, really freaks them out (Amy 235).

When the child was well enough to be transferred to the ward, there was information provided to prepare the parents for the transition to the different environment.

If we have got them in from another hospital or the casualty department or they have been sick for a long time we try to do it over two or three days to get them used to the fact that they will be going to the ward (Bree 317).

In addition, Chris talked about preparing the parents to anticipate the transfer.

Usually it's been talked about beforehand anyway and usually they've known either from first thing that morning...but often you will have an idea the day before and you will let them know that this is going to happen.

Usually by the time they go upstairs, they have only got minimal monitoring -but we do tend to monitor to the last minute -which I've always said is a bit of a farce. I tend to disconnect it about 1 hour. If you've still got the monitor you say "I just don't know what to do with this -it's easier than doing it manually -that's why I'm leaving this attached for the time being -you know -they won't have all of this upstairs." And they understand that and are a bit more happy about that because I find most of them that once they get the monitoring system off them the child is OK (Chris 266-267, 279-283).

Max also emphasised informing the parents about what time to expect the move to the ward.

On the day that they are going to be discharged (to the ward) letting them know times so that they can plan whether to be in the Unit or not, I think helps - if they know they are going up the ward at 2 o'clock (Max 265).

External stressors

These stressors were related to the parents' life outside the PICU. Parents were stressed by having to organise to take time off from employment to be with their child, and to arrange for the care of their other children.

We write letters for companies - you would think that if you told your employer my child is in ICU then they would be believed but we have had to write letters to say yes this is true and will be for the next x number of days (Lily 144).

What do you do with the other kids, you are worrying about them and I guess we tend to focus on the long term ones but not for the ones who are here for 2 days ... it's just as bad for them having .. disrupting their life for 2 days as opposed to 2 weeks... it's still a disruption (Hannah 50-53).

Additional stressors

It was identified that parents who had a child with cancer (oncology parents) and so had previous experience with being hospitalised and/ or were more knowledgeable than most parents (because of their health background), found the intensive care environment more stressful. The nurses also found these parents more challenging and more difficult to support. Oncology parents were used to taking responsibility for their child's needs in

hospital, such as feeding and bathing. Not being able to care for their child in PICU was seen as a source of stress.

Upstairs there might be one nurse per three or four patients and all they seem to do all day is give drugs and the parents will do all the cares. When they come down here if they are intubated, the parents can't do as much as they used to and the parents find it very frustrating (Bree 131-132).

Amy explained the difficulty for the nurse and parent:

I think that a lot of them would be much more knowledgeable than certain individuals (nurses) on certain things and I think you have to give them that credit. They may know the ins and outs of doing a certain thing and you have got no idea about it. They have obviously gone out and studied it and know the ins and outs but it can make it awkward they start dictating ... that's when it becomes awkward... and they get stressed and you get stressed... when they are questioning what you are doing. I think it would depend on what it was... if it is a minor little thing ... they want something done in a particular fashion... if it is going to cause them that much angst it's not any skin off your nose to change ... but if it's a procedure as such then I think they may get to the stage where they might start dictating what they want done and stuff... so you have to draw the fine line... and yes we are willing to change certain things but certain things are done this way and that's what the practice is. Certainly things involving their cares and stuff that's fine... but something more on a technical point of view you tend to stick to what your practices are (Amy 88-90).

There was also the stress of trusting their child with strangers, the PICU staff, instead of the more familiar oncology Unit staff:

That stresses them as well as us... we don't know them. You know if we have them here for a week and they die... the parents don't know us and we don't know them (Bree 140).

We are sort of seen as the outsiders who are coming in as opposed to their inner circle of confidants. So I think they find it a bit more difficult to talk to us (Hannah 25).

They are used to their nurses and - you know - they are like a family up there, it's very traumatic for them to come to ICU (Jo 121-122).

Whilst it was appreciated that the parents were very stressed, these oncology parents were seen to be more demanding than most.

They are very challenging (Kate 113).

They are different, in that you have to acknowledge that they have a higher level of medical knowledge than other families, and they want details more than other families do, and if you don't give it to them they get - not aggressive, but they are just more up front in demanding information, and that can vary from day to day as to whether that is an ok thing for you to cope with, or whether its a day when you feel you just want to cope with the kid today (Jane 317).

Hannah thought the parents' behaviour was related to things being done differently in the PICU.

I think because we do things differently first not necessarily because we are strangers. Definitely because we do things differently. We get them all the time "that is not what they do with a central line"... you get that a lot but that is OK because they are comfortable with what they know and then you come in and do something different (Hannah 29).

Bree and Harry advised being accepting of their behaviour.

You have to accept the fact that they are going to tell you something whether you want to know it, they are going to tell you and you have to learn to accept that and not get twitched up about this mother's telling me so and so. They probably do know more than you do about it (Bree 148-149).

Oncology parents are usually well informed and they often do things and expect things at a much higher standard. They come from an Oncology Ward where they are strict on hygiene, strict on all procedures, whereas ICUs are generally not as strict on hygiene, they should be, but they are not and oncology parents would pick up on those things. If there is a particular problem I say - "well you are the expert in this, how do they do it upstairs?" and find out how they do things upstairs (Harry 280-294).

You've got to adjust to them - the parents are the consumers - so you really have to fit in what they expect (Harry 298-300).

Jane indicated that whilst in the PICU, the focus of the child's care was different and the parents were less likely to challenge the nurses about technical aspects of care.

We get the oncology kids when they are critical, so parents are prepared to back off and if they have been doing needling of ports and doing drugs and stuff like that they are happy to back off and let us do what is necessary. But they are particular about other things like having their own ways of caring for them in terms of positioning and clothing and stuff like that. That's easy to accommodate, that's not

a problem. It's very rare that they get into how you actually give medication and whether you are drawing them up properly or whatever - their focus has changed by the time they get to us (Jane 321-323).

Oncology parents were also described as putting on a 'brave face', a strategy to avoid hearing bad news.

They think like we have kept this brave face on all of this time and we have got to be tough, "you don't have to tell us any thing we have been coming to this hospital for 12 months and we know it all." I think they have to put up that bravado so that you don't tell them something that they don't want to know (Hannah 24).

Kate also described parents who were knowledgeable because of their health background.

These parents experienced additional stress as they became overly concerned about particular aspects of their daughter's care, which could be inappropriate.

If their daughter was having a blood transfusion or (the doctor was) talking about giving platelet, things like that they would ring up their friends at ** hospital and ask them if we should be doing that and whether or not we were going at it right. It was because they were just really highly stressed. We would get white cell counts back and they were elevated as they usually are after cardiac surgery a little bit. We would do (blood) cultures and they would just grab on to it because it was something that they knew and they would really panic and the mother would almost be in tears. Saying that she has got to be on antibiotics and making sure she is going to be all right (Kate 3, 9).

Parental behaviours

The nurses described their perceptions and interpretations of parents' behaviours in the PICU. The parental behaviours were perceived in terms of their responses to stress. These behaviours or responses were numbness, wanting the security of the nurse's presence, hysteria, anger, denial, no rapport, not involving the rest of the family, vigilance, and parents not being supportive of each other. As Chris related, parents could display many behaviours when their child was critically ill.

Initially ... you've got to be prepared for a whole range of emotions (Chris 83).

Hysteria

Hysteria was described as an extreme expression of stress.

Mum was just couldn't calm down, she kept saying that she felt sick, physically sick. She was hyperventilating (Rose 69).

She just wanted to sort of pace and stand and cry (Rose 79).

Anger

Anger was described in circumstances when it was perceived as appropriate.

She was still angry at the fact that she had not been allowed to be in with her daughter (Alice 50).

Amy attributed anger to not understanding what was going on.

They are really angry or just don't understand what is going on and they want you to tell them all the answers there and then and you can't (Amy 22).

Angry behaviour when it was perceived as being inappropriate, Chloe suggested, was a parental coping strategy.

Mainly because of the stress - I think because of the stress. We've had two aggressive parents in just lately and you can understand it because they just want the best care for their child and that's understandable, but there are other children in the Unit as well, and it's like "why did they get sent here before me, what's the story here?" and so they won't listen to any explanation. I don't know if they need to be angry to keep the interest up, or something like that, or whether they need the anger to get them through the situation, because if they aren't angry they'll cry (Chloe 251-252).

The angry behaviour was perceived to be inappropriate when it was considered by the nurses to be out of proportion to what was happening with other families at that time.

We had their daughter curtained off - but these parents wanted to stand over the dying baby's bed waiting for their child who was in the (other) bed - there was only room for two in the room. I had to explain to them that that wasn't appropriate because the other child was really sick 'but our child 's sick are you saying our child's not sick?'... but there was a bit of a difference in that their child was (just) having IV lines inserted (Chloe 261).

The behaviours of angry, aggressive parents were described.

It was their mannerisms... they were confrontational, they were aggressive (Lily 100).

The father ... didn't come into the hospital very often because he found it all very disturbing so it made it difficult for mum. So for him I organised a meeting between him and the medical staff and I sat in on that as well, and he wouldn't let his anger go and he kept saying he wanted to take his son home and in the end the doctor said "well that's fine you can take your son home" which obviously he couldn't because he hadn't been in for any of the training to take his son home and that sort of made him realise that we weren't actually against - we were trying to get his son home (Chloe 267).

Denial

Denial or disbelief of the truth about what was happening to their child was perceived to be a coping strategy for parents.

She often left the ward whenever something was happening. The child would have difficulty with breathing and would sometimes have an acute episode where she was gasping and not coping well, becoming hypoxic etc, and Mum would just up and leave the Unit and perhaps not come back for a long time until it was all over, so that she didn't actually witness a lot of these episodes early in the piece because she just couldn't face them and she shielded herself in that way, so she had to sort of be made to understand that this was happening frequently, and why it was happening frequently (Chris 10-11).

Some parents appeared to deliberately choose to misunderstand information.

It wasn't because she didn't understand, it was because she didn't want that to be the answer (Rose 39).

We still kept saying "we don't think he is going to survive" but she just wouldn't listen. Whenever you said something or were going to raise something she would just say "we'll talk it through" (Jo 212 - 213).

Hilda attributed denial to some parents having unrealistic expectations of intensive care.

They think that you will make their child better. That's the way it is in the media isn't it? I think they think we can do magic tricks and they will get better (Hilda 61).

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No rapport

Establishing rapport with parents was identified as fundamental to reducing parental support. Other than not being able to support the family, it was also more difficult to work with the family if rapport had not developed between the staff and parents. In addition the resulting atmosphere made the work less satisfying.

There are certain people who just won't take it no matter what you tell them or who you are They just want to hear it from one person or they will go to various people until they hear what they want to hear... which is hard, you are trying to do your bit and keep them informed and then they start playing people off against each other (Amy 48).

When you are working with patients who have got no control of what is going on, you can't walk away and you have to deal with the family. You can judge if you develop a rapport with the parents, sometimes you don't and have to try to work around it and sometimes even not look after that patient - but that's pretty unusual (Hilda 102–103).

Sometimes the nurses needed to provide all the parental support because the parents did not develop rapport with any other staff.

I questioned them about having the Social Work Department involved. They did become involved to a certain extent, but there was never any rapport between the family and the Social Work Department, so that made it more difficult (Chris 18-19).

Not involving the rest of the family

Some parents behaved by not involving the rest of their family during the child's critical illness. The nurses interpreted this as a mechanism to protect themselves, the other children and the grandparents from reality.

They (the grandparents) didn't really come around much and I think it's the parents not wanting them to (Kate 33).

This protector thing of the other three children, by pushing them away she was protecting them (Lily 107).

Vigilance

The following excerpt captured vigilant parental behaviour of focusing upon numbers such as blood pressure and heart rate values, whilst ignoring the parent's own needs. This behaviour was accompanied by also not understanding the significance of the clinical data.

She was sleep deprived, she hadn't slept for 5 days and she became the really vigilant Mum, if I went up there and said "how are things?"... she would say "his blood pressure is.. his heart rate has been" ... I would say "but how are you?" and .. "I can't worry about me, I'll worry about me when we get out of here." She became so focused on the numbers that she lost sight of the rest of things (Lily 37-38).

Parental needs

During the very stressful period following the child's admission to the PICU, parents tended to neglect their own needs. The nurses perceived that it was their role to anticipate this and described providing for the parents' physical needs, such as somewhere to sleep nearby, organising food and drinks, and encouraging parents to look after themselves. The accommodation facilities available to parents differed amongst the hospitals. The nurses described organising for the parents to be comfortable sleeping at the bedside or somewhere nearby, depending on parental needs at that time. Parents were generally encouraged to sleep in a bed rather than at the child's bedside. Overall the

facilities for parents were considered to be inadequate and prevented the nurses being able to ensure that parents properly ate and rested. Jane described literally looking after some parents.

Make certain they know where they can go to the toilet and get a drink, and by that you literally have to take them and wait and bring them back because they get lost (Jane 258).

Somewhere for parents to sleep

The nurses' usual approach was to arrange for parents to sleep nearby their child.

Sometimes they do want to sit up all night by the bed, sometimes they're happy to sleep out in the parents' lounge and just kind of come in a couple of times during the night (Rose 141).

The parents were not encouraged to continually remain at the bedside. Bree described how it was not in the parents' best interest to miss out on sleep.

They can sit by the bedside but we try not to encourage that too much. They don't get any sleep and are fit for nothing by the morning ... usually (Bree 44-45).

The parents' sleeping facilities that were available were also perceived to be inadequate

We've got a parent's room but it's... not very big, and it's got one concertina door across the middle so really only two parents can stay in there with any sort of privacy, otherwise they are just all in there together. And that's sort of the only area if people want to go and have a cup of tea or whatever, it's not very good at all (Jo 136-137).

There is no accommodation attached to the Unit. So often they sleep in the waiting rooms, we've got two waiting rooms - but somebody has stolen the mattresses off the couches so - it's not a comfortable night - whereas on the wards there's a bed next to the patient's bed (Chloe 72).

We don't even have toilets on the same floor, so that we are always getting visitors to go downstairs or quite a distance away (Max 70).

Eating and drinking

It was highlighted that parents tended not to think about looking after themselves.

The nurses perceived their role was to remind or encourage them to eat and drink.

Reminding her that she still has to eat and drink (Hilda 79).

You see them just with a bit of toast and that's all they will have all day (Bree 213).

The facilities available in the Units were seen as inadequate for the nurses to care for the parents' needs.

I come from the old school where you can provide parents with meals and things like that - it doesn't happen these days that's for sure. I would like to be able to give them a meal or - we do make them cups of tea (Harry 462-467).

If the facilities were not nearby, it was perceived that parents were unlikely to use them.

I think with a kitchen here helps because they can make themselves drinks. Now there is a cafe just downstairs which is really good where as before they had to trek across to the adult side to the canteen over there (Bree 209).

The catering facilities provided at the hospital were also seen to be inadequate, the hospital systems not meeting the family needs.

I actually think for a children's hospital we don't look after the parents - we pretend to look after the parents, but we don't do it very well because we provide meals for the parents if they need - if there is a need for a meal we give them a meal voucher and tend to send them over to the cafeteria which is over at the adult Hospital so many of them won't go - if we want meals sent here, it is always a major drama (Jo 142).

They (parents) can't understand why the siblings cannot go over to the cafeteria - because it's in the staff cafeteria and staff complained that children were in the cafeteria, so the Hospital in its wisdom made the rule that no children can go to the cafeteria, which is really abysmal. I don't know how they get to eat. They will provide sandwiches for children, they will send sandwiches over here but they don't provide hot meals for the children. So we can get meals, but they are not very good quality (Jo 144).

They can have toast and cereal, because we always have got something here, otherwise they've got the cafeteria which is open regular hours, but other than outside those hours it is quite difficult to get meals (Max 97).

Lily felt that the parents' physical needs were not fully met, and explained what she thought would be ideal.

It is very much... there are the beds, there is the tea and coffee, there is the shower, toilet therefore we have met your physical needs. There is more that we could do but I think what we have got is reasonable but I would like a parents lounge where everyone has coffee together and then there are little rooms like motel style rooms, very small, just a bed and you can walk around but it actually gives the parents somewhere to go. In our parents lounge there are pull out sofas so but if you are the kind of person who isn't comfortable sleeping in those surroundings you are not going to get much sleep (Lily 125-126).

Lily also made reference to the hospital culture of providing meals only to breastfeeding mums and not to all parents. It would be preferable if the nurses could make an assessment of parental needs and be able to organise meals.

There seems to be the strange mentality that breast feeding mothers need to be fed but nobody else does. So we have tea and coffee and toast but you can only survive on bread and butter and jam for so long. I would rather see a system when we could assess which families need support and we can use our own discretion... I can't see the point in the blanket rule that breastfeeding Mums get food and the others don't (Lily 128-132).

Offering and making a cup of tea or coffee for parents could be used as a comfort and distraction as well as the opportunity to talk to the parents away from the bedside.

There was someone else who could stay with the child so I took her and gave her some coffee (Alice 88).

The activity appeared to have much more importance than just meeting the parents' physical needs of eating and drinking. Chloe described relieving the tension by getting the parents to have a break and have some food.

I explained everything to them and asked if they had had anything to eat or - some parents just sit and wait the whole day and then end up not eating at all - and they hadn't. All they had had was coffee, so once they felt confident that the baby was OK - I sent them out to get something to eat and have coffee and a smoke, and when they came back I went through all the lines again and everything, and by then they started asking questions (Chloe 31).

The lack of parking facilities was also identified as an additional and unnecessary stress for parents.

A lot of them used to get parking fines which was quite stressful... they would be running out every two hours trying to move the car to find another spot. They would be sitting watching saying "I've got to go in five minutes" (Amy 182).

It's all 2 hours or metered. I've written to the city council to get exemptions for people. We had one Mum who had three parking tickets by the time she got back there (Lily 142-143).

Self

The concept of self, according to King (1981, p.27) includes each individual's values and beliefs, which affect their relationship with others. The concept of self has been used to illustrate the personal and individual values, beliefs and feelings experienced by the nurses when caring for parents.

The nurses described how the more challenging relationships with parents were often related to differences in values and beliefs. These differences between the nurses and parents were identified as affecting the interpersonal relationships. The nurses were cognisant of the impact of their behaviours upon parents, and worked at developing rapport and remaining impartial. The nurses were aware that their initial behaviours at first contact could influence the parents' whole experience in the PICU. Specific effort was made to establish rapport.

Because the nurses were conscious of the effect of their behaviour upon the parents, they experienced a sense of responsibility to always give their best or to 'perform'. This could mean that the job was more demanding because of the pressure they imposed upon themselves. Additional personal pressure was experienced when caring for a family

of a dying patient. The experienced nurse could more effectively support the family at this time.

Difference in culture, religion or social background

There were personal nursing challenges when caring for families with a different religious, cultural or social background that was unfamiliar to the nurse. It was more difficult to establish rapport in such situations.

I work really hard at getting on with patients and families and - but there are categories of people that you think - oh yes. You see them come in and it's ethnic families so they are going to be more emotional - but that is just a bias I think that everyone has, and you - even you might say that when you are in the tea room - they are loud and crying and all emotional - I don't let that - or I don't think I let that affect my approach to the work (Max 116).

Chris explained that it appeared some nurses were unable to develop a rapport with some parents. This was perceived to be because of differences in social background.

Not being sensitive to the situation... And they don't know how to deal with these people because they don't know where these people have come from and they don't understand the simplicity of their minds sometimes, and their difficulties and the way these people grow up -the whole social background. They might learn about it, I don't know frankly, but they might learn about it, but it is very obvious that they certainly have very little comprehension at all - and not everybody does, for heavens sakes (Chris 93).

Lily explained that for some groups of families, it was the combination of language and cultural barriers that resulted in the nurse's role being less supportive.

We have certain patient groups who are culturally diverse and the biggest group is the liver transplant group and we have kids who are coming from NZ, Hong Kong and Japan. I don't think we do very well for support of these groups. The non Caucasian groups...most of the Japanese don't have any English and most of us don't have fluent Japanese. We have a translator and they do tend to close shop. I guess they do tend to become...they look towards their support group, we (PICU) don't seem to play a big role in that support group...They get their own accommodation, have a transplant co-ordinator so they look after them as well, so a

lot of the contact that we have with them is very ... "this is what is happening today" (Lily 69-70).

The parents themselves could experience stress when their religious or cultural expectations were different from their own personal wishes when their child was sick.

Sometimes they don't actually know... say about their religion. They know that something should be done in a certain way but they haven't come across this situation before so they don't actually know themselves (Hilda 165).

Amy added

You try, I think without sort of messing up what their cultural beliefs are sort of involve them, quite often without being here Mum would have everything to do with the child and stuff like that and so you try and tell its all right to do this and stuff. Its important to try and respect their views but also at the same time try and get a fine line where you can actually help them do what they want to do despite the fact that they may have that restriction on them from their partner (Amy 39-40).

Jane provided an example of the parental stress caused by cultural pressure.

For instance, Italian, Greek, Mediterranean type families where the grandfather particular in a matriarchal type families is overwhelming...mum and dad wanted to pull out in terms of just wanting to do palliative care but they couldn't because their culture said that they had to continue treatment of the child - this child had been intubated and ventilated and was dying at the end of a ventilator because mum and dad said that they would be ostracised if they withdrew treatment ...and after the child died they wanted to spend time by themselves with the child, and they weren't allowed to. Every relative who hadn't seen the child for 20 years turned up and they had to be ready. So that death was completely the opposite - that happens occasionally. Mum and dad want to do a particular thing or be there and do whatever - grandma will come in and say "no, no, no, Nonna's going to do this" ... All the usual cues you get that you use to build a rapport with the family are ok when they are alone but when the rest of the family come in they change (Jane 223-226).

It was also difficult for the nurse to know how to behave appropriately in regard to aspects of different cultures.

The interesting one are from Saudi Arabia and the Arabic countries - we are not allowed to talk to the women, we are only allowed to talk to the man and you are not allowed any contact and you are not allowed to expose - you know a female child - you are not allowed to expose the genitals because that's taboo and - how do you change a nappy without exposing the child. You feel like you are trampling on the beliefs, but you have to do some of these things just to give the care. Another

group I find difficult are Aboriginal families. Particularly the ones who come from the Northern Territory...I suppose like you would think of in Papua New Guinea or something, but they are tribal in - a lot of them don't speak English - they only speak Pidgin Injara or whatever - and they are not allowed to look at you - they are not allowed to look at men, or talk to them- and in the terms of eye contact - so building up any sort of rapport is almost impossible (Jane 236-237).

The women have no say in anything and are not allowed to do anything and they don't like you sort of touching and the men come in and take control and "this, this this" and the women sit in the background (Amy 35).

We get such a variety of cultures and religions and that's hard because our culture is such that you just want to chat, a bit of physical contact and a lot of them don't want that. You just have to step very warily (Alice 138-139).

The following excerpts illustrate the nurses' difficulty in understanding different beliefs.

It was fine for us to - you know - we've got the CIS (Clinical Information Systems) and it was fine to have everything computerized and their child was on a ventilator and yet they said how bad technology was, you know it was really quite interesting. The children couldn't watch television but they were quite prepared to have all of this technology (Jo 65).

I think nursing in Japan is very different to nursing here. They are very polite and it's as if you actually gave up part of your liver for that child, they are that grateful. We only see the kids for a brief period... only the ones with complications that we see time and time again. With time you do slowly break down those barriers of politeness and you do develop a rapport but it's a lot harder than it is with Caucasians because they are so poised. Not getting feedback ... they just smile and say "thank you." What are you thanking me for? (Lily 76-77).

The nurses' initial behaviours

The nurses made an effort to ensure that their first contact with parents was a positive one. Making the parents feel at ease with the nurse set the scene to go on to establish rapport. Bree captured the nurses' approach towards parents.

They might just sit there and look stunned and usually it's they just won't talk ... then again others might be equally stressed but you tend to be able to pick them out... not talking, not touching just sitting where as someone comes in and starts immediately talking to the kiddy and touching them you think perhaps they are OK. It might be a couple of days down the track you realise how bad they are and they say something or do something and you think woah...they are a bit stressed. So I don't think there is any across the board way of telling who is stressed and who isn't. You expect it, you take it that any parent coming in with a child who is in

Intensive Care is going to be stressed. You try and put them at ease really as much as you can (Bree 110).

The following excerpt illustrates an initial time following the child's admission.

If a child is brought in by helicopter, ambulance or whatever, if a parent comes with that child they will usually come straight into the room. Once we start putting them on to the bed and doing things, somebody else in that room will take them and pop them in the waiting room, depending on the severity, they'll get them a cup of coffee and maybe talk. I will always -depending on the child as I've said -I will just go and get them a drink and sit and have a talk to them, organise for them to use the phone to ring other relatives and things, other family members, a husband if they need to, or whatever (Chris 260).

In some circumstances, such as when the child was being retrieved from another hospital to the PICU, Jane explained how to develop rapport in a very short time.

Parents often say that they feel totally out of control in this sort of situation and they have to place their child in your care and suddenly you are saying "well we've got to strap your child into the back of a helicopter and drive across xxx. You can come with us but basically you will have to trust us to look after your child." So basically we had about 15 or 20 minutes to actually develop enough rapport with the mum. I mean, she wasn't going to say no, but it was a - she had to feel confident that we were going to care for her child and we only had a tiny window, and I felt that my skills enabled me to create enough time for them to do that.

We talk to them, we make a point of identifying ourselves on a first name basis and we know their name and they know ours, but also keeping in contact with them actually whether we are in the helicopter or in the plane when we are doing a retrieval - making sure that they are not forgotten. Because on a retrieval, you are doing everything in front of the parent 90% of the time. It's very rare that the parents aren't there actually watching you - and they have to be confident that you are going to look after their child... Making her feel that she was part of what was happening, that we had not forgotten the she was coming along with us, and that it wasn't my child, it was her child. (Jane 11, 15-16, 35).

Amy described introducing herself to the parents at the beginning of the shift.

Usually it's just a case of "hi I'm Amy I'm looking after such and such for the shift"...and then you are getting their names, instigating some sort of contact there. Everybody is doing horrible things to the child so it's nice to have a first name basis (Amy 9).

Hannah advised starting a conversation with the parents, rather than asking direct questions. She emphasised that unless there was a conversation flowing, the nurse couldn't begin to help the parents.

You just need to maybe not ask so many questions... maybe you just need to talk to them... instead of saying "is there something that you need to know?" or giving them a direct question where they have to answer you, I think you just have to get the conversation going and get them feeling comfortable with you. Then they will tell you what they want to know without even knowing that they want to know it... They are all different but I don't know if you can immediately recognise them from the look on their face or their actions, obviously the more stressed out ones you can ... but you can't recognise anything unless you are talking to them, and get them to talk to you (Hannah 37-38, 61).

Hannah also identified that it helped to establish rapport when parents realised that the nurse also had children.

If it comes up in conversation... their whole attitude changes, which I never used to think. I used to think was a whole heap of crock before I had children that it would make a difference to you but their attitude changes when they know you have children, when they know you have had a child who has been sick. Not that I felt their attitude was bad before I had children but it is just this subtle shift now (Hannah 48).

Once rapport had been established, the result was that parents were less stressed and able to rest.

It's a trust thing... they are not going to leave... then when they have spent a few hours there and then are happy to go and have rest (Hannah 130-132).

Harry's strategy for developing rapport was to be a friend to the parents, to go beyond talking about clinical issues.

Just try and be there and be a friend to them rather than some of the nurses stay round the bed all the time talking about clinical things (Harry 27-33).

Remaining impartial

Sometimes the nurses found it difficult to remain impartial, or non-judgemental, particularly in cases of child abuse. This personal challenge and the strength of feeling are reflected in the following excerpts.

I find it more difficult looking after the parents who have done something to their child rather than those who haven't done something to their child (Hannah 97).

I want to kill the person! We've had about half a dozen serious non-accidental injuries per year. By that I mean kids who are ventilated, severely brain damaged and/or die. What I really have difficulty with is the lying. None of them ever come in and say "I hit the child because I was stressed, I was angry, he wouldn't stop screaming for 10 hours or whatever," they lie, they all deny it, they never say "I am sorry," but you are supposed to treat them like they are still important. I mean, they are important, and 95% of the time the child will go back into their care - hopefully with adequate support - but I don't feel any more. People keep telling me that they love their child, and I have to believe that. We had one case where the father actually come into the Unit armed, he had a knife, and he tried to strangle the child in the Unit. Whilst the child was being extubated, he was trying to strangle the child because he wanted to make sure the baby died. And the baby was going to die anyway, but that was very frightening, and I was very concerned about what was going to happen to the mother because they all knew that the father had killed his child. The couple that were making the drug deals behind my back while we were taking the child down (to CT scan) to see if the child had a brain left. That really stretched the bonds of loving that day ... and the mother always supports the father because 90% of the time it's the defacto who has done it. She always supports him. You know, this man has physically hurt your child, can't you just tell him to "rack-off." But they don't (Jane 311-313).

You can see the junior staff grappling with ... the suspected child abuse because they want to support them because they are a family who have got needs and yet you have this horror story coming before your eyes. Just recently we had three fractured ribs with no explanation and (the baby) only 6 weeks of age and that is really hard (Lily 110).

Lily explained how she dealt with issue.

They are hard particularly if the children don't survive and you have a stereo type of the sort of family in their mind and what sort of support things you do and there is that development of a rapport with the family that precedes that and some of them ... it's almost a repulsion... I have to consciously say that these people didn't do this or didn't do it deliberately ... something drove them to it. With no other family do I have to remind myself why they are there. The same could be said for a drowning but you just accept their guilt as part of the big picture that it was one of those things that happens but with child abuse it's different, what has a poor little baby done? But I have to justify it so I can get a little closer to them to support

them which is difficult. While they are here we care for them and the child and if there is anything untoward we have to report it but it is not our job to convict. You just don't know what their family history was and were they abused as children ... you can't take it all on board ... that is beyond my brief which is to support the family through their ICU stay (Lily 117-121).

Whilst there were many descriptions of this behaviour, Max and Hilda encapsulated how to objectively manage the situation.

If I know that the police have been involved and the Child Accident Prevention Unit are involved, then I will say that they suspect that someone injured the child ... talk about maybe the actually things that have gone wrong rather than the evidence - more the physiology. Wait until they might say "I feel so guilty, if only this or that" and you have to be very careful how you word it so that you don't make the parents feel worse or that you don't just treat it "oh no come on, you can't think like that." Then the parents won't talk to you (Max 183, 200).

I needed to be impartial and not to make her feel like she was in question that she caused this to happen to her child. Not to judge her and the situation that she's put her child through. And not to make it like we are the bad guys, we are actually there to support her (Hilda 18, 20).

Sam talked about parents who had not accepted that nothing else could be done for their child. It was personally difficult to remain impartial in order to be able to support parents who wanted measures taken that were considered inappropriate.

The other situations we often see that are more difficult are where parents are having a great deal of difficulty in accepting the child's condition. They may want extraordinary measures taken or interventions that you ethically feel are not at all appropriate. The nursing staff tend to bear the brunt (Sam 37-38).

Rose further described how it was difficult supporting parents, when the child's medical treatment was not what the parents wanted.

I kind of felt like I had my doubts about the way everything was being handled, and what they were doing anyway. You know, the fact that if the parents wanted him treated really aggressively, well, shouldn't we be treating him really aggressively? Do you know what I mean? I kind of thought that you know they're the ones that are the decision makers ultimately for their child. So I guess I was kind of a bit confused about why everyone was... that we withdraw treatment (Rose 41).

The pressure to perform

The nurses felt a responsibility to always provide the best care for parents. The nurses were aware that the parent's experience in the PICU would be affected by their own interactions with parents. Thus there was a self-imposed pressure to perform, and not have an 'off' day. Sam identified that nurses sometimes needed a break from the environment.

I think you can work in the environment for too long I think I'm not convinced it's good to be around sick children for too long. I like to empathise with people and if you are really busy you feel quite drained and sometimes you feel that you don't give enough. Sometimes you are called upon to give extraordinary amounts of yourself and need to put it into perspective and come back. We all know when we need a break. It gets hard to come to work and all the time worry about the consequences of your actions, if you are having a bad day (Sam 102-104, 108).

Kate talked about the pressure to always be happy and cheerful.

I'm sure you have your bad days too when you come to work and you are feeling horrid and I'm sure parents sense that. You might not necessarily snap at them but may not be as approachable as you normally are. I hope I'm not like that very often but certainly I'm sure they can sense changes in mood. It's hard to be happy and cheery all the time (Kate 186-188).

This challenge was heightened by the parents' continuous presence.

I find it challenging to be looking after a patient whose parent is there all the time. You know what I mean? I mean just all the time. And it doesn't matter whether they're easy to get along with or not, just the fact that they're there at the bedside watching you do what you do the entire shift. I find that really challenging. Really... I mean some days it wouldn't bother you, but other times you just feel like "oh I wish they'd just go away and let me have 5 minutes peace" (Rose 127)

They (the nurses) probably do (prefer to have a break from the parents) but they don't have a choice. No I don't think it's as bad as it used to be. I think people are much more accepting now, if you have a parent at the bedside... I think it's because they feel like "that's fine you are welcome to stay if you want to"... whereas once upon a time "we really don't like you at the bedside...you should really go and rest" (Hannah 126-128).

The nurses found it a particular pressure when there was a lack of rapport with parents.

I don't think it happens often (don't have a rapport with parents) but if it does happen it can be stressful. If you have a particular parent who is particularly irritating it's just another stress to the day which you can do without (Hilda 107).

You don't click with every family - some families you just do the work and you come out - the next person who comes on gets on brilliantly with them and can do all the things you wanted to do but didn't feel comfortable doing (Jane 142).

Hannah recommended accepting that it wasn't possible to get on with everyone.

There are some parents where we just didn't get on.. Maybe you just need to acknowledge that and say fine, not try and make it better (Hannah 107).

Death of a patient

The following excerpts illustrate the feelings of personal difficulty experienced by the nurses when a child died.

That's a time when you are challenged into trying to support the family at a really stressful time (Hilda 197).

Kate referred to her feeling of inadequacy at supporting parents at this time.

I also find it hard too with parents of dying children because I never know quite what to say because it seems silly asking them if they are all right because of course they are not all right. It's hard to gauge because people deal with grief in so many different ways that it's really hard to sometimes assess and work out which way that person's dealing with it and whether or not you are giving them enough time with the child alone or not giving them enough time or too much time. It would be good to know how to help the family through, to have experienced death so many times that you know exactly what to do (Kate 78-79, 85).

Sam explained how her attitude to a patient's death had changed over time and with experience.

I think it changes... when I was younger I used to very much take the attitude ... I think you need something to fall back on. I had had a fairly Catholic upbringing and used to adopt the approach, these things happen for a reason and that is quite a bad thing to say to parents in my experience. I am more likely to say now that "this is a terrible thing, it's understandable that you are feeling so dreadful because it's terrible," don't beat yourself if you can't find anything positive in the situation because often there's not.

Unfortunately the child died on my shift. What I think was unfortunate ... I think I have enough confidence in my own skills to know I did everything that could be done... but I felt it was unfortunate that they felt that if something had been different it might not have happened. If I was less experienced I might have felt that I didn't do enough (Sam 16, 63-68).

Hilda also referred to the benefit of experience in dealing with death.

I suppose I am less scared of telling parents bad news now. I've got more experienced to interpret what's going on. When you first start you don't know what's bad and what's normal and you don't have a perception of how things will go (Hilda 42-44).

Sam described how she handled death.

I had got to the point after quite a few years of working here, absolutely accepting the limits to what you can do in ICU. In the beginning I agonised over every death, I was absolutely tortured, the more experienced I became I accepted that we do all we can do. I think that removes some stress from yourself as a practitioner (Sam 8).

Lily and Sam talked about supporting or even protecting less experienced staff from the experience of caring for a family when a child died.

If I can support them then I will put them in that situation and work with them but I always find that is the hardest decision to make - if you know that the patient is going to die that shift, normally I will allocate myself. It is a hard enough situation for them and if I said this is what I was going to do as far as allocation goes and they would feel comfortable enough to say "give me a break," you have to respect that (Lily 87, 91-92).

Ordinarily you would certainly not be putting someone in the situation that they didn't have the experience to deal with it. Sometimes that isn't always possible, also providing support for staff in that situation (Sam 52).

Body Image

King's concept of body image related to body appearance and others' reaction to it (1981, p. 33). Body image results from others' reaction to self. In this study, body image is considered in terms of the child's altered appearance and its effect upon the parents. The

nurses were conscious that the child's altered appearance in the PICU was distressing for parents. They endeavoured to prepare parents to expect the changed appearance before seeing their child and tried to improve the appearance by dressing the child, normalising the bedside and paying attention to details that mattered to parents. Photographs were used for the purpose of preparing parents to see their child, as well as for a permanent memory, and the practice of displaying photographs of the child when healthy was seen to be beneficial for both the staff and parents.

Child's altered appearance

The different appearance of their child, related to the injury or illness was seen as a source of parental stress.

Although she had seen her intubated for transit I think it was the first initial shock when we took everything off her and she was on the bed and looked so much more sick than she had done before (Alice 86).

Information was given to the parents to prepare them to see their child.

If I was looking after the child, bring them in usually on the way down to where the bed is, I'll say "you know he's got lots of tubes in" before you actually get there. "He's got one down his nose and various drips and things, this is just to let you know there is all these things." So they don't just walk up and see all these wires coming from everywhere and not have realised (Bree 98).

It helped the nurses themselves to develop rapport with the child and family if a photograph of the healthy child was displayed at the bedside.

Particularly with burns patients we do like photos - usually they look horrendous (Alice 261).

It's nice for us and them to see what they were like before this particular incident. Quite often we will have pictures. I think it's nice for families as much as us. It's very hard when you see them lying there all attached (to monitoring lines, ventilator etc) (Amy 139)

When you see a kiddy who is sick or very damaged or what ever and you see them before and you think this is what we are working for (Bree 306).

Hannah explained that they didn't seem to need to suggest bringing in photographs to the parents

Once upon a time we used to say to bring them in and now they just seem to appear. I don't know how and why that has changed. Particularly with the MVAs they are normally the ones that do it, I have noticed, may be it is that they want you to see what their child is like "here is my beautiful baby" (Hannah 176).

For elective surgery, parents' visual preparation might include viewing other patients who had a similar condition in PICU, to prepare them for how to expect their own child to look after surgery.

The parents can come up (to the Unit) before their child has been to surgery and see another child with similar (operation) to theirs and see what lines are going to be attached (Chloe 111).

Photographs were also taken of the child who had died or was very sick, as a permanent memory.

If it's not likely that the child is going to live - if we extubate and if we think the baby is going to be intubated again, then we take it for the parents so that they can see how the child looks without the tubes in (Chloe 107).

We used to do lots of polaroids but I am trying to encourage the staff to use a 35mm camera to use a roll of film because then they have got the negatives as well whereas the polaroids tend to fade over time. We should just give them the roll of film to get printed themselves. I usually give it to one of the other family members not the parents but just tell them who has got it so that they can hang on to it for as long as they want before they get it printed. That way they have got it permanently and can do whatever they like (Lily 53-54).

We do it even if they say no... in a moment when they are not there we do it and we have got it if six months down the track they change their mind and they often do (Hannah 272-274).

Bree described how being particular about the child's appearance also demonstrated caring about the parents' image of the child.

Treating her like she was conscious, speaking to her, washing her and doing her hair and dressing her, making her look as though she was cared for. To me that's a natural thing but you will find the baby hasn't got a nappy on, just that little effort makes the parents feel a little bit happier and they will say "look he's got booties on." There are all these machines and things but they pick up the fact that they have got booties on. It makes them look as though you've cared for them, especially someone in intensive care it's very important (Bree 4, 92).

This included caring about the child's appearance after death.

We tend to put them in the Moses basket when they are washed and dressed as well because they look nice in that (Bree 259).

I just try to make it as nice as possible and I think you can do that. Making the child look nice afterwards, really taking care and attention (Hilda 194-196).

Space

King (1981, p. 34), used the concept of space in relation to proximity. In hospital, nurses can violate patients' personal space. In the PICU environment, parents and staff share a small space at the child's bedside. This territory is seen as the nurse's domain, to which parents are visitors. Parents' privacy and confidentiality inevitably can be compromised because of the environment, patients' close proximity to each other and the need for monitoring. Some nurses saw lack of confidentiality in the PICU environment as a problem, whilst others held opposing views. The environment resulted in parents being aware of what was happening to other patients. The principle of maintaining patient confidentiality was dealt with in the most pragmatic way.

Privacy

Bree described that in the PICU, if the child was dying, the focus of care was different and more privacy was possible. Usually, it was not possible for the parents to be alone with their child because of the need for close monitoring.

Unless the child is really really sick it might be just me but I don't feel like they need privacy as such with their child, I mean (whilst) they sit with them we won't particularly sit by the bottom of the bed with somebody while the parents are there we will come away but not to the extent of leaving a single room (Bree 185-187).

Rose added that drawing the bedside curtains did create some privacy from other families.

Drawing the curtains between the beds to sort of make it a little bit more separate from the patient next door (Rose 219).

Max described how parents particularly needed privacy from other people, when a child was dying.

You give them a lot more privacy from other people - not necessarily privacy from me. But I will do that as well if they - I'll ask them if they need time alone and I will tell them that I am there for them but I will leave it up to them to sort of approach me. Yes, I think the extra thing that we do is give them more privacy. You feel like you are protecting them from all the other people in the Unit (Max 236-237).

Alice described providing the parents with private time alone with their dying child, whilst still being available.

Even if the child has not been withdrawn (from treatment) at that time we'll shut the door and shut the curtains and hang around outside basically to be there if they want us but give them as much time as they need. Sometimes that can be hours and hours (Alice 355).

Chloe described providing privacy for parents to make phone calls.

We give them a room where they can all go into with a phone so that they can make calls if they want (Chloe 174).

One long-term parent was described as having additional stress caused by listening to and talking on the worries of other families in the Unit.

I think privacy is a real issue - one of our long term Mums Ann - she has been here since March - she doesn't go to the parents lounge any more now - she says that "I have enough to deal with without hearing everybody else's problems" (Lily 166).

Confidentiality

The nurses didn't talk about whether parents might benefit from sharing their concerns with other families. The following excerpts illustrate the difficult position of the nurse in maintaining confidentiality, when families talked to each other and also when events occurred which were visibly obvious to all the families in the Unit.

We can't (be confidential) unless they are in a private room. I think we try damn hard to do that but I think it becomes difficult because they are in an open area. The minute you draw the curtains everyone knows that something is going on. I think that parents tend to network themselves anyway ... they go out in that parents lounge and talk about a lot of things. You are trying to maintain their privacy but in the meantime they are outside telling every other parent in the Unit about their kid. Which is fine ... but it just becomes an issue when all the other parents think they have ownership and start asking and try to get information out of you. If they are in a room that is fine... but it is hard to disguise the fact that you are resuscitating the patient behind the curtain or that you have moved them into a room because they are about to die... they are not there a few hours later or the next day. So you do have to address that with other relatives and I find that difficult (Hannah 180-182).

If a child is dying in the same room, we try to put them into a separate room, but - we would probably try and inform the other parents of what is happening, not give them the details, but just say "look - such and such has died, or is dying" (Harry 579-584).

The other families were briefly told that a child was dying so that they could respect the parents' privacy. As the other families were already aware of what was happening, this information was not considered to be a breach of confidentiality.

I think we are very good at saying "we don't give that information over the phone" often if you've got a child that's very sick it's normal for other parents to say "it's terrible" and we say "yes, it's very bad," but we won't give any details. If we know a child's going to die or the child dies, we actually tell the other parents what's happened so that they can give the other family a chance to have some time and space alone (Sam 186-187).

Being sensitive to how the parents may react to what has happened to another child in the Unit was described.

Usually I don't bring it up, but if they do, then that's fine and I always make sure that they know that the baby's got a different condition to what theirs has - because I can imagine that would be a great stress. If someone has died in this Unit - is their baby next? (Chloe 219).

Several of the nurses described how when the intensivist talked with the parents, this was done away from the bedside. An interview room, tearoom or office would be used. The nurse looking after the patient would sometimes be present.

What we tend to do if possible is take them out of the Unit, we have two little interview rooms here and usually the doctor and which ever nurse is looking after that kiddy can go out so we know exactly what is being said (Bree 11).

It was perceived that the behaviour of interviewing parents in a private room could draw attention that they were receiving bad news.

We have an interview (room) ... that is really difficult too... they come out of that room and still the whole Unit can see them (Hannah 198).

When organ donation and transplant occurred within the same Unit, maintaining confidentiality was particularly challenging.

Maybe not so much for the donor but for the recipient you have to be thick (not) to realise that that kid is being wheeled down the corridor and didn't come back and now yours is being wheeled down behind it and has got a new liver (Hannah 188-194).

Harry and Chris held contrasting views about the issue of confidentiality.

If your child's death is going to be imminent, you aren't really giving any confidential information away. If you are taking this child out of the room into another room they are going to put two and two together. I don't feel I have been breaching confidentiality by saying that this child is very sick Harry (590-597).

I don't care who's asking me, I don't tell them anything. Well -I just say "I am sorry I am not at liberty to discuss this I can't tell you anything because that's up to the parents, if they want to discuss things with you, then that's fine" (Chris 224).

Harry provided an example of his interpretation; taking a pragmatic approach whilst not disclosing further information.

Occasionally you will get parents asking you what is the matter with this child - and you just explain that "for the same reason you don't want people knowing about your child" you might say "the child has had a heart operation," because it is so obvious, but otherwise you wouldn't give them the prognosis (Harry 668-674).

Jane described how she dealt with the issue when a parent encroached into another family's private space.

We had a problem last night where the mother of the patient next to the child who was dying, was very nosy. And she was spending most of her time trying to stare around curtains and watch what was going on - it was a bit tricky. We actually, very subtly, moved the curtains a bit closer, and I think in the end one of the girls (because I was in with the patient) cottoned on to what was happening and asked her to move round to the other side of the bed, she was actually in the way of the family. But we don't have a lot of problems. If we are up front and explain to parents that unfortunately the child is dying, often they will say "oh isn't that awful it makes my case look - you know..." it puts life into perspective (Jane 166-171).

Jane identified how the nurse's perception of a breach of confidentiality may have been different from the parents.'

I feel uncomfortable thinking - you know - I wasn't sure how this mother would react - but when I really stood back and looked at it - she wasn't even aware of what was going on. The curtains were around the bed, so what (Jane 189).

Jane advised dealing with it individually as each occasion arose, and provided another example when a mother was purely concerned about her own child.

The only thing that I got from the mother of the child I was looking after was - she asked if the child had died - and I said "yes he had," she wanted to know why - and she said "I'm so glad it's not my child" (Jane 201-202).

Time

King (1981, p. 41), described the concept of time as being subjective or experiential. It is not only the order of events but also the duration experienced by each person. The nurses in this study perceived that they often had insufficient time to care for the sick child as well as support the family. The more experienced nurse was better able to do this or was able to delegate some tasks. Time could also move slowly when rapport had not been established with parents, and there was a resultant uncomfortable atmosphere.

Insufficient time

The nurses described having insufficient time to support the family whilst providing the physical care required by the sick child.

They (the child) are very very sick and you are trying to do the technical stuff and you don't feel that you are giving them the quality time that they need to support them (the parents) (Amy 111).

You don't have enough time to spend speaking to parents (Hilda 113).

The more experienced nurse could simultaneously perform technical tasks, providing physical care, whilst talking to parents.

It's really hard to put into words but I think what you do notice is when there are less experienced nursing staff who are doing the same job but find it impossible to say, calibrate an arterial line and talk to the parents at the same time (Alice 103).

Use your time when you are caring for the patient to talk to them... there are times when you can take advantage, getting them involved talking through what you are doing. If you just leave them sitting there and don't talk through what you are doing you don't tell them what's happening there is no opportunity to really talk and have a conversation and try to work out what their needs are (Hilda 117-118).

Jane realised when delegation was necessary.

I had to delegate a little bit of time to other staff to do a little bit more of the hands on comforting stuff at times that mum needed because I was physically, actually caring for Mary. But I think that itself - it takes a bit of skills to realise whether

you are out of your depth in terms - you've just literally got too much to do. You need to say "I can't actually help the mum at this stage, I might have to let someone else take over that side of things" (Jane 46-48).

Alice described how important it was that someone stayed with the parents to support them, especially during a crisis, when staff were occupied caring for the child.

Most of the staff were concentrating on stabilising the child which is normally what happens and in that instance, there was no one who went out to speak to her for a couple of hours at least so she was left not knowing really what was going on. It was really that that precipitated that when we changed our guidelines there will be a designated person, be it a nurse or social worker or chaplain who will stay with the parent during the time, even during resuscitation and we will encourage parents to stay during resuss. The benefit is not really documented yet but parents seem to think it does benefit them (Alice 46).

The nurses' perception was that the social worker had more time to spend with the parents, particularly when the nurses were busy with physical care of the child, which took priority over supporting the parents.

That's usually when the social worker comes in very handy because you are a bit more tied up with what you are doing with the child but you don't feel like you are giving them enough time... that's frustrating ... you have got to get so tied up with the technical stuff that you can't be there and support them like you want to (Amy 112).

Uncomfortable atmosphere

The time spent at the bedside with parents could be uncomfortable if rapport had not been established.

What I tend to do in those instances is shut up and don't say anything and that not the best way around it but it works (Alice 110).

Lily talked about experience being important in feeling comfortable with silence.

That is one of the other things that I find with a lot of the younger ones is that they feel like there has to be constant chatter ... some of them don't feel very comfortable with just sitting in silence with parents and if they are not actually talking to them they will often say "do they have to sit here 24 hrs a day? Don't they know I have got work to do?" (Lily 19)

Summary of Personal Systems

In this chapter of Personal systems, findings relevant to the concepts of perception, self, body image, space and time have been presented. The nurses described their understanding or perceptions of the stress experienced by parents in the PICU. They related some parental behaviour to their response to the stress. Supporting parents was felt to be personally more difficult when there were cultural, religious, social differences or a language barrier. It was more difficult to support parents when a patient died and in cases of child abuse.

The nurses were very aware of the effect of their initial contact with parents and endeavoured to make that first contact a positive experience for the parents. The feeling that the parents always deserved their best care could sometimes become a pressure for the nurses, particularly when parents were continuously present at the bedside. The nurses were aware of the parental stress related to the altered appearance of the child and prepared parents for what to expect and made an effort to make the child look as normal as possible. Photographs were used for the benefit of staff and parents. Lack of privacy and confidentiality were identified as issues in the PICU. Lack of time was identified as a limitation to the amount of support the nurses could provide to parents. More experienced nurses were able to more effectively utilise their time.

FINDINGS AND INTERPRETATION: INTERPERSONAL SYSTEMS

King (1981, p.59) identified concepts essential to understanding interpersonal systems, or two or more persons interacting in concrete situations. These concepts are communication, interaction, transaction, role and stress. Although King did not explicitly identify feedback as a concept, it has been added to the interpersonal systems for the purpose of these study findings. Feedback is part of King's process of human interaction. The process of human interaction is again presented below (see Figure 4), this time illustrated with an example of the process in the context of this study in red text.

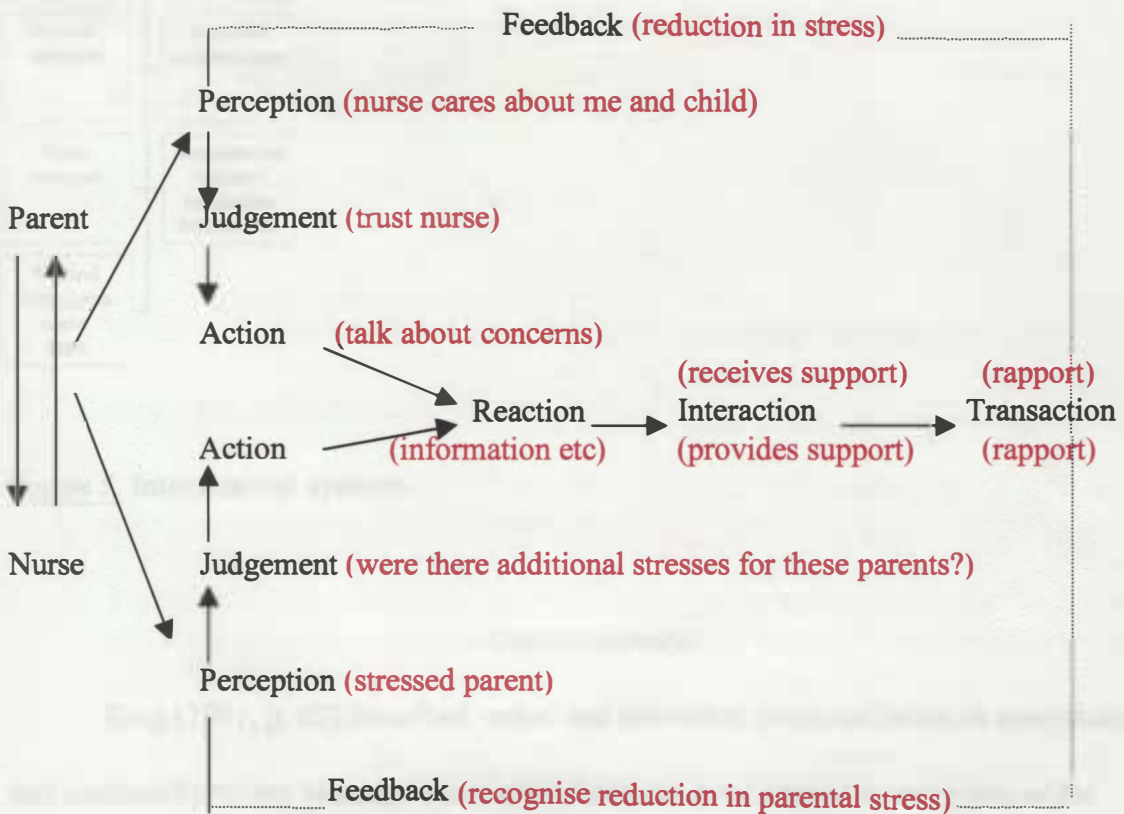


Figure 4. Illustration of a process of human interaction (Adapted from King, 1981).

The relevant findings from this study are presented below using King's concepts as headings in the blue text, and new subheadings that were identified from this study's data in black text (see Figure 5).

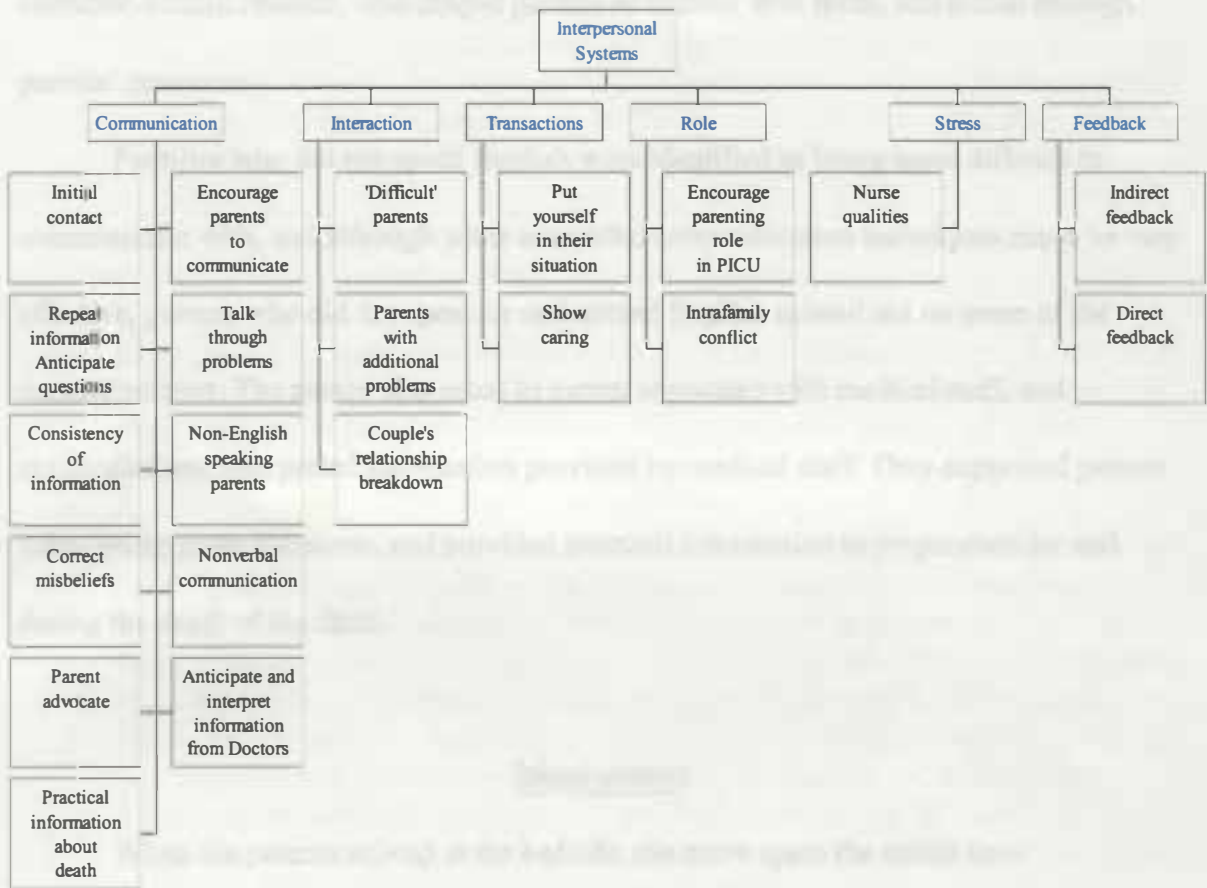


Figure 5. Interpersonal systems.

Communication

King (1981, p. 62) described verbal and nonverbal communication as inseparable and continually taking place between individuals. Each individual's perception of the communication determines how the interaction occurs. In this study, the nurses described how communication between themselves and the parents was continually taking place. Providing information to parents was identified as an important behaviour, from the initial contact as well as throughout their stay in the PICU. The nurses explained how they kept

parents fully informed, repeated information, anticipated questions, and talked to other family members. Inconsistent information was identified as a potential source of parental stress, and the strategy of primary nursing was seen to minimise the problem. The nurses corrected misinformation, encouraged parents to interact with them, and talked through parents' concerns.

Families who did not speak English were identified as being more difficult to communicate with, and although some nonverbal communication techniques could be very effective, parents who did not speak or understand English missed out on some of the nursing support. The nurses also acted as parent advocates with medical staff, and anticipated and interpreted information provided by medical staff. They supported parents when being given bad news, and provided practical information in preparation for and during the death of the child.

Initial contact

When the parents arrived at the bedside, the nurse spent the initial time communicating information to the parents.

I start by really observing very closely, not saying much initially just giving them information about their child (Sam 20).

Trying to explain what is going on, what you are doing to them all the time, I mean half the time you are putting drugs and all sorts in and they have no idea what you are doing to them (Amy 10).

Rose talked about establishing the baseline, finding out how much knowledge about Intensive Care the family had prior to the child's admission.

You know sometimes like Grandad I ask them that, he goes “oh I've been in Intensive Care before” and I said “oh I guess you'll know a bit about what to expect then.” But then other people will say “no.” So I guess that gives you a kick off to know that first of all they've probably never seen anything like this, they don't want to know about arterial lines and intracranial pressure and all that, they just want to know is the child actually in there. And by asking them questions. Like I often kind of say “have you seen one of these monitors before?” and they might say “no,” “you might have seen them on TV,” you know, they often have... “you know these are the ones like they have on TV,” or somewhere. Because like that's where people get their knowledge of Intensive Care if they have no medical background or they've never had a family member in Intensive Care before (Rose 154-156).

The nurses' role was to ensure the parents were fully informed

At all times I try and keep them informed about absolutely everything, so they had the best and clearest understanding of the child's condition, so just inform them of everything that is going on. You know, things that stress parents out more than anything are - not knowing, or not having been told (Harry 104-112).

Often after they've been there for a little while, and you know, the parents come in and they say... they recognise on the ventilator that their oxygen's been turned down, or that such and such... so then you can kind of go on and say “well, do you want me to show you something on the ventilator? I'll show you... see this number here, this is how many breaths per minute the ventilator is giving little Johnnie, and this number here is how many breaths little Johnnie's taking in total. So obviously he's not breathing any more than the ventilator's giving him, or he is breathing more than the ventilator's giving him.” And then the next time they come in they can look at that and say ... for them to actually know a bit more about what's going on (Rose 183).

Repeating information and anticipating parents' questions

The nurses provided many examples of repeatedly giving the same information to parents, well encapsulated by Chris and Rose below.

You have to be prepared to explain things half a dozen times over a period of 3 hours sometimes, or if they are in for a week, you know, you might have to tell them the same thing -and not say “well, we've already told them that” (Chris 84).

We talked for hours and hours and hours about why, why were we withdrawing, I mean, and this is on night duty and sitting by the bed with her trying to explain everything and answer the questions that she had. I'd answer her questions and she'd just ask the same question again (Rose 35).

A feature of the nurses' behaviour was also reinforcing and repeating information that had already been provided to parents.

Reinforcing how she was doing at the time and how things had progressed. Sometimes nothing may change but to reinforce where we are up to and what the plan for the day is (Hilda 33-34).

The communication included talking to other family members about the child's condition.

I guess (I) acted as the informant if you like with the other relatives that had started arriving by the early hours of the morning and talking to them about what was going on with the kid, because mum and dad wanted to be by the bed, they didn't want to be out in the parent's lounge room with relatives. I kind of did that, backwards and forwards, and letting his grandad and everybody know what was going on (Rose 85-86).

Consistency of information

Harry described how continuity of care facilitated consistency of information.

I usually pass it on verbally, I don't document it - I wouldn't say I document a lot... I prefer to give people the story about what I've been doing and patients come in at all times, I will try and follow them through until - so if I've looked after a child for a few shifts - so that I become their primary care nurse (Harry 64-72).

Receiving different or conflicting information from staff was perceived to be stressful for parents.

Inconsistency seems to be the key (laughs) at the moment here in this Unit which is more confusing when one person says something different from another and the ward clerk says something completely different (Alice 297).

The strategy of primary nursing was used for very short stay elective admissions for continuity of nursing care.

Quite often you do a little (pre -op) tour and say I'll be on the shift or I may or may not be looking after him... you can ask depending where you are in the scheme of things, to take that patient. Which is nice as you have already met them and seen the child pre-op, familiarity when they get there (Amy 155).

Primary nursing was also used to enhance the provision of consistent information, particularly for parents of the longer term PICU patients and if the parents were considered 'difficult'.

I think you fairly quickly suss out that they are that sort of person and you get a little group going and make primary nurses and so you are a bit more consistent that way and there is not so many people involved and make sure that the information you are giving out is the same information as the next person, so it's the importance of handovers and things so that people know what the family dynamics are. So that you know that they are going to ask you this, this and this and I have told them this and the doctors have told them this so then they are getting the same information regardless of the person (Amy 52).

They needed to have some continuity with nursing staff and people who could (phone) people who they knew who would say the same things to them all the time (Chris 22).

Correct misbeliefs

An aspect of communicating was attempting to correct parents' misbeliefs or misunderstandings.

There were constant explanations, and he (the father) would tell me what somebody had said to him and this is what they said, so why are you telling me something different now? And I would say "I'm sorry I know this person very well, I know they wouldn't have said it quite like that, you know," knowing that this person was experienced and wouldn't have done it that way- but this is how he (the father) has grasped the situation (Chris 27-28).

He was very hypertensive and mum was... getting really worried about that, and then all of a sudden his blood pressure was normal. And she's saying "oh that's good isn't it? His blood pressure's normal, you know, that's really good." And I'm going, "well, yes, you know, it's a good number but you know quick changes like that aren't good," and then to try and sort of prepare them for the possibilities (Rose 75).

Dealing with and correcting a parent's misbeliefs could be a very challenging nursing behaviour to perform.

I found it extremely draining. Just going home after a shift, because the whole shift was spent more on social work really than, you did look after their child to the best of ... gave the best service to them too, it's just the whole thing was helping this couple overcome their grief, help them to cope (Chris 76-77).

Kate described redirecting parents' misguided concerns to be more positive, develop rapport and reduce their stress.

The way that I dealt with that most was to try to involve them in the care of their daughter as much as possible and to get them doing things they liked to do and try to explain things fairly thoroughly and point out the things they should be looking at as opposed to the things they shouldn't be looking at and encouraging them to go out and take regular breaks and look after themselves. Eventually once the trust built up it was a lot better (Kate 4).

Encouraging parents to communicate

An important communication and information providing behaviour was the nurse talking to the parents about what he / she was doing as he / she was providing physical care and providing the parents with the opportunity to ask questions. As identified earlier, the more experienced nurses had the ability to provide physical care to the child at the same time as talking to the parents.

What I tend to do is I am doing the physical bits that you tend to do to maintain stability but always talking to the parents asking them is there anything they don't understand repeating things because particularly during that first 24 - 48 hours they just don't seem to take it in. So just constantly telling them what I'm doing asking if they have any questions (Alice 104).

Amy pointed out that it was essential that the information given to the parents was the truth. This was crucial in achieving rapport.

I think you just try and explain that it takes time to do all the tests and things like that. Sometimes at the end of the day you may not know what it was but as long as they keep asking questions and feel that we are telling them and being as up front as we can then that is all we can do. You have to be as up front as honest with them as you can... if you don't know there is no point in telling them "yes we do know and blah blah blah" because then there is no sort of trust there to establish a trust... then they will believe what you say (Amy 27).

Encouraging parents to ask questions was emphasised, as well as encouraging the parents not to think that any questions were foolish.

I always try and say “now, we're pretty friendly here, and we're good at answering questions, so don't be afraid to ask any questions that you want, even if you think they're a bit silly. I promise you they're not, and if I don't know the answer I'll go and find somebody who does” (Rose 169).

She said “that's a dumb question isn't it?” and I reassured her then saying that no question was actually dumb - it would be much better for her to actually ask them than for her to mull over it and not be sure about it (Chloe 64).

Encouraging communication included encouraging parents to ring at anytime of day or night.

Sometimes they will say “do you think it's alright if I go home?” We will say “yes we can ring you and you can ring us... ring us at any time.” I always make sure that I give them the phone number and make sure you tell them if they are up at 3 in the morning, give us a ring (Bree 51-52).

If the child's condition was changing and a lot of physical care was required, the following excerpts described Rose being separate from the child's care and standing with the parents to provide information and answer their questions.

I was very much standing back from all that, and standing back with them, so there were all these actions going on and just saying “John's trying to fit an arterial line, now an arterial line is like a little drip that you know goes into an artery that means that we can keep a really close eye on his blood pressure and they can take blood samples without using needles and things like that. And because it looks like he's getting worse it's pretty important for us to be able to keep a close eye on his blood pressure.” Then John couldn't get an arterial line in so I said to them “well, sometimes these arterial lines are pretty tricky to get in, it's fairly common that when kids are like that it becomes a bit difficult. So we'll get Sue to come in and she might be able to.” You know, like just kind of reassuring them that what was happening, telling them what was happening. Because nobody else had time to... like the doctors didn't have time to sort of come and talk to mum and dad. So I guess I was taking very much that explanatory role (Rose 63, 73-75).

Talking through problems

Being able to talk through the issues which were concerning parents was an important stress reducing behaviour.

You just key into what you are hearing from them, but I think that all nurses could do with some listening skills so that they could actually read what parents are

saying. I think nurses are pretty good at listening on the whole, but I don't know how well they counsel. When you first start doing it (reflective listening) it is a funny thing to try and put into practice because you are very aware of listening to the question, now what exactly did that person just say - so that you can answer it back to them. But sometimes I hear people talking and I think that you have completely alienated that person just by that simple answer. You had the opportunity to really get and counsel people (Max 205-206, 214-215).

Bree gave an example of talking through the concerns of a pregnant Mum whose daughter had leukaemia and was sick and ventilated in the PICU.

It was just the case of going through what her major problems were, she was very very stressed about this new diagnosis of leukaemia and the fact that they thought she was in remission and had suddenly got sick again and had to come down to ICU... so just talking through what her major worries were about when the new baby came (Bree 20-22).

Non-English speaking parents

For non-English speaking parents, when verbal communication was difficult, not understanding what was happening was seen to be a cause of parental stress as well as a source of nursing frustration.

If they don't speak much English they don't visit much - whether or not it's because they are frightened by it all or because they don't speak English you are not going to tell them anything anyway (Bree 62).

Everybody feels frustrated and we haven't really addressed the issue at all (Alice 127).

Some essential pieces of information were written down in the family's language.

We have a little sheet of paper with various little bits on and a phone number (Bree 103).

As Lily, Hilda and Alice pointed out, the support provided to this group of families was felt to be unsatisfactory.

Because there is the language barrier I don't think you can sit down and get the same rapport as when you are sitting supporting another person who speaks the same language as you (Lily 750).

I think we do try - we may not get it right but we do try - I think. Our interpretation of what they want may be a bit different from what they actually want but we do try (Hilda 163-164).

It's very hard other than the hand gestures, supporting them when they feel a bit wobbly or whatever (Alice 124).

When talking to parents, the nurses explained what they were doing to their child. This level of communication was not possible for non-English speaking families. Max felt concerned that non-English speaking parents were therefore unable to give their consent to the care given to their child.

It isn't very good because you feel you are not - that you are doing things for the patient without actually getting the parents agreement because how can they give their consent to what you are doing if they don't really understand what it is that you are doing? (Max 129-131).

The approach towards indigenous families was with different body language and style of communication.

If you just persevere that in the end - you just have to keep talking to them and assume that they are listening, because every now and again they will come up with something and I'd think, you did hear what I was saying to you. Don't try and force eye contact with them, because they won't give it to you, but I've been caught a few times thinking that they're not listening and they are and they hear everything you are saying. I probably don't use as complicated language with them as I would with a European type family (Jane 241, 261).

The interpreter service was organised by the nurses for non-English speaking families.

We use the interpreter service quite a lot (laughs). They are really good actually. You can always do it over the phone or you can have a face to face session if they like (Amy 68).

Lily also talked about the use of a book translating common words and using pictures.

The other the thing we have done is ...we have a Japanese book with basic things we are trying to say that is written in picture format so it has written and the English form so we can get the most of the basic things (Lily 74).

If there was a family member who spoke some English, they were used to translate simple information. For more important information, a professional interpreter was employed.

They usually say who they want us to talk to and they push somebody forward and say tell them. We don't if it's a diagnosis or conveying critical information, but we do for general things like "baby will be able to drink milk at this time and so forth" (Chloe 238).

Nonverbal communication

The nonverbal cues demonstrating stress which were displayed by parents, consisted of subtle signs, such as facial expression. The interpretation of subtle body language signs indicated astute assessment behaviours by the nurses.

I think a lot of it is nonverbal. You can see by looking at people that they are stressed. They are very stiff, they won't talk much, they won't touch the baby or anything (Bree 109).

It's probably a little bit unconscious. You just get a funny feeling about the way the parents are behaving and just the way that they look at each other. When they first come in they are always pretty anxious about the operation, but these parents had been through it all before, and as the prognosis became worse you could see their facial expressions change, their relationship to each other changes - just little clues that add up to - stress (Harry 89-99).

There were some strategies described to try to overcome the language barrier

I think still talking to the parents even though they can't understand you are still communicating. It's better than not talking to them (laughs) because they don't understand. You can still talk to them at least you can get some kind of rapport with them at least say "hello" and that kind of thing. I think that sometimes some people don't talk to them because they don't understand what you are saying but at least greeting them and encouraging them to come over (Hilda 153-157).

The following excerpt illustrates nonverbal nursing behaviours of touching parents and demonstrating that the parents could touch the child.

A lot of hand gestures, facial things, and like if you want mum or dad to help you clean teeth and such, you sort of do the hand gestures and if you need more intervention we use the interpreter services, but I manage with a lot of facial expressions, tone of voice, showing them that they are able to touch the child (Jane 235).

It was described that in fact, nonverbal communication could be very effective.

Just be there for them, you can give them a hug, that is more than a lot of words trying to say (Hannah 102).

They know that everything is going to be all right one way or another. Even for people who can't speak English, I think they actually pick up on this. You still get this non-verbal thing, you get their smiles and they will try to start and communicate and to let you know that they are accepting of you (Harry 268-275).

Harry also talked about parents feeling reassured, when observing confident nursing behaviour.

If they feel that you are caring for their child...they do get an understanding of what's going on. You don't necessarily have to communicate verbally for them to understand that, you know, everything is going to be ok. I think it is probably better for someone to be observing what you do - you know yourself that if you go about your job confidentially, then you know, people will think - OK everything is going to be ok (Harry 252-265).

Other communication techniques described were visual imagery and drawing diagrams to explain concepts to English speaking and no-English speaking parents.

Give them an example that if this happens this is what it is going to look like...then they can get a picture in their mind...instead of you know damn well they don't understand (Hannah 237).

I am a big fan of drawing - it's an easy way of communicating with people. If they can see something they can usually understand it. Where as the dialogue doesn't always sink in. So that's probably the way I would do it, particularly with these sorts of kids - it's a bit easier to explain quite complex things by just drawing a picture, and often people will take them away with them - they understand it, they go home and learn it. You can't take a piece of wording away (Harry 117-129).

This included using the patient's observation chart to illustrate a point.

If they ask how the child's been I might show them and say "look, you can see here he's was going along just fine and then suddenly became very... blood pressure shot up" and the parents can actually see the way... or "his temperature's gone up" and you can see the way it's traced on there (Rose 288).

The possible benefit of showing parents an informational video was also described.

We are putting some photos together in the parents' room and were thinking about doing an introductory video as well but concerns have been raised (laughs) that it might go missing if we leave it in the parents' room. But it's something that we are thinking about and again to have something on paper or TV that you can have another look at and another look at - OK that's what a ventilator looks like would be good. I remember at **hospital they have this introductory video that they show to parents after about 24 hours. So they have seen their child first and then it reinforces what everything is (Alice 225-227, 240-242).

Parent advocate

Bree described the communication role of speaking on behalf of the parents to medical staff.

The parents will talk through you rather than directly to the doctor, ask you questions for you to ask for them. If you have been looking after the kiddy you know what their feelings are as well. They might have asked you questions that they obviously want to know the answers but once they are in the situation of having a big talk with the doctors it goes out of their head. So you can say ... "you were asking me this," and you can go on from there. It comes from you as well as them but you know that this is what they wanted to ask. I think that is really important. Sometimes they just get stuck and only afterwards think of things (Bree 12,16).

Rose described suggesting to parents that they wrote down questions so they wouldn't forget what to ask the doctor.

"Write down your questions". You know, go away and think about them, write them down and then next time the consultant comes in you'll say, "I've got a couple of questions, I've written them down, have you got a few minutes to answer them?" (Rose 170).

Anticipate and interpret information provided by medical staff

The nurses prepared the parents to hear bad news by, for example setting the scene that the child was extremely ill and may die.

I don't hesitate to say it (the child may die) (Hilda 62).

I think they have usually clued in before then that things are extremely grim. You will get that from everybody...that the child is very sick and could die. You stress that and when things are imminent. The doctor will say... but you have already pre-empted that by telling them that they are extremely ill and may die (Amy 226).

The nurses also repeated and interpreted the information that the parents had received from the medical staff.

The parents will ask us questions as they won't understand what the doctors have told them. The medical staff tend to use more jargon terms so again we reiterate what they have said (Alice 341-342).

Rose indicated that her approach was to be truthful yet still retain some hope for parents.

Sue and the Neurosurgical Reg had basically told them the bad, bad, bad news. I was very much the... “ it's really serious and I'm preparing you for the worst, but that doesn't mean there's no hope” (Rose 99-101).

The nurses' role was also to be supportive when parents were informed of bad news by the medical staff.

If it's in a meeting situation the nursing staff will go in with them as well in a supportive role (Alice 326).

Practical information about death

The following excerpts provide examples of what might be said to parents when a child was going to die. The information was to prepare the parents for what to expect in the situation when treatment was withdrawn.

Our role is more practical in that we can tell them what happens next. What they do about funeral arrangements, what happens in an autopsy, when can the body be released (Alice 342-343).

I would tell them what they may expect or what they could expect to happen - that we move the baby or child into the other room, that they may gasp, that we would give them morphine infusions if they're in pain, that it may be quick, it might take a couple of hours, but they can get the child out (of bed) (Chloe 179).

Interaction

The concept of interaction, according to King (1981), was explained as the actions, or behaviours of individuals with each other. The individuals' perceptions and judgements of other individuals affect every interaction. The process of interactions between two or more individuals represents verbal and nonverbal behaviours that are goal directed. In the context of this study, the nurses' goal was to reduce parental stress.

Under this heading is presented the nurses' interactions with parents whose behaviour was described by the nurses as 'difficult', parents who had additional problems, and parents whose relationship had broken down. Interactions with difficult parents required more experience, interpersonal skills and effort from the nurse in order to be able to support them and reduce their stress.

Difficult parents

'Difficult' parents were those parents whose perceived behaviours resulted in the nurses being unable to establish rapport. This could be because of the effect of the stress on the parent, because of the effect of other issues in their lives, or individuals who were seen to have personality disorders. Unpopular, aggressive, highly critical and irrational parental behaviour were identified as difficult to interact with. Also more challenging, were parents with additional or pre-existing problems in their relationship and those who were not together as a couple. The more experienced nurse could have more successful interactions with these challenging parents.

What was it that made a parent 'difficult'? There were examples of when a parent behaved in an aggressive or angry manner.

Aggressive families and even the passive aggressive parents tend to take me aback and, I guess in some ways intimidate me. I find them very hard to cope with (Kate 62 –63).

This scenario was a child from ** who was in liver failure, they decided that they would not transplant this child. This mother was particularly angry, not at us but at the way that everything had gone from the minute that ** had said to come here. So they arrived here angry and we bore the brunt of their anger when they were told this (Hannah 6).

If people are aggressive they usually are aggressive for a reason... (if) you hear that people are having trouble getting on with these particular parents - I would see that as a challenge to actually try and do something about it - smooth it over - instead of letting it go on, and on, and on, so that staff end up hating them (Harry 224-238).

Hannah described the behaviour of a 'difficult' mother who didn't agree with the conservative management of her child with liver failure.

"You lied to us ... you said that you would give her a liver transplant." Everything you did for them... when we started trying to withdraw things it was the most anger... like "you have given up on my child... you are just going to let her die and you are not going to do anything for her." That was a particularly difficult situation and particularly difficult for the people who were there for 8 hrs at a time... being constantly scrutinised all the time and screamed at (Hannah 8).

The following excerpt illustrates the resulting atmosphere of no rapport between a parent and staff.

I think people were very wary when the father was there. It was - obviously they were a very close knit family and so they were there all the time. Usually the father would go off to work for short periods - there was certainly a different atmosphere when dad was there, to when mum was there (Jo 69-70).

Hannah and Chris spoke about parents whose behaviour resulted in the nursing staff avoiding looking after the family.

She had no shoes on and we have a policy that parents must wear shoes... there could be needles, broken glass... so they should wear shoes in the Unit. I came on and stupidly thought she would be a reasonable person so I went over and asked her if she would put some shoes on well... she let me have it in no uncertain terms... the words were flying. She was the worst mother... the mother from hell. So much so that people would be drawing straws to not look after the child. It wasn't just me that couldn't cope with this mother. What ever I said to her didn't make any difference. Some you just can't do anything about. They are not the norm though. Thank God (Hannah 111, 116).

People weren't prepared to get involved there because of the family situation (Chris 55).

Jo described the challenge of caring for a family when a parent was particularly critical of the nursing care.

I think one of the big stresses for the nursing staff was even though they had been there for such a long time, when dad was there he watched, you know, not even after 6 months, he watched and checked every little thing that the nurses did. And he would question everything that you would do and it made things very difficult (Jo 74-75).

The nurses' approach to difficult parents was described.

We choose to have more (of a) relationship with some parents more than others. I don't consciously - but it would be interesting to know - you know there are always some popular parents and some unpopular parents, and for whatever reason but it generally is that it runs right throughout the Unit. I don't mind having difficult parents because I often think it usually comes down to their lack of understanding of what's going on. I mean, if someone can explain simply what is going on and treat their child, perhaps the way they like it to be treated - you know - sitting down with them, chatting about anything in particular and making sure the doctors come in and explain what's going on, then the problems just dissolve (Harry 188-196, 206-215).

I quite enjoy it when the parents are difficult - because I think that is a challenge for me to be - to try and find a way to get to them (Max 114).

Lily explained how an experienced nurse better managed the more difficult situations.

A lot of the younger staff would be uncomfortable with that (Lily 101).

Rose described the behaviour of a parent, when therapies that had become inappropriate were stopped.

Here am I sitting at the bed by myself with nobody else on the floor, nobody else around, and mum comes in and she very... I hesitate to say aggressive, but she really was I think aggressive (Rose 14).

Interactions with some parents remained unsuccessful. Rose and Hannah talked about their relationship with the same mother.

We sort of came to loggerheads, the mum and I, at one stage. I wouldn't say by any means that there was a successful resolution to the situation, in fact I think even after Jack died, it was really difficult (Rose 20).

They did the usual sort of try to rationalise which just didn't work and I don't think no matter what we did it didn't make any difference to her, we were trying to kill her child... it wasn't until she said "fine my child is going to die," her child did die, she just totally changed the minute the child died. She wasn't any nicer to us but she wasn't screaming at us. We would try and rationalise, try to cajole along or try and be stern, try and sit down and talk and say tell me what is the matter and what can we do help you. It didn't make any difference (Hannah 12-13).

The following is an excerpt when Rose felt compelled to confront this difficult mother.

Obviously I was meant to hear I think what she was saying, I think it was intentional, but she had just come from a conflict with one of the medical staff and we had suggested that maybe Jack and the family might prefer it if he was in a single room, they'd be able to have more privacy, they could have all the visitors they want, which we frequently do, you know, if things are getting pretty nasty. And mum seemed to think that we wanted Jack in a side room so we could let him die without anybody knowing about it, so that we could kill him. And mum's patting Jack's head, and I'm just so glad that he was so young and so ill because she just said to him "they hate you Jack, they want you to die. They hate you Jack, they're trying to kill you Jack." I yelled at her because... I just said "how dare you say that, you know that that's not true. You know that's not true, how dare you say that we're trying to hurt Jack. We are here looking after Jack, it's Jack's best interests that we have to look after. I feel really angry to hear you say that because it's not true." And mum went "oh it's not you I mean, it's those doctors, it's not you." So she obviously just felt bitter (Rose 22).

Rose reflected upon how she handled the situation.

I was really angry but ... I didn't really yell, I mean I spoke very assertively and made it really clear to her that I was extremely unhappy about what she said and how I felt about it. But thinking back in retrospect if I had to say it all again I would say exactly the same thing because I think that, you know, like she needed... I needed to say to her that I was there to look after Jack and his best interests and it was really unfair and untrue of her to say that you know that we were trying to hurt him (Rose 26-27).

Max described her strategy to deal with difficult parents.

I am not a very assertive person, so if someone is aggressive to me I will step back and try and calm everybody down, whereas I know some people I work with - lots of different places - are immediately aggressive back - and I could never be like that. I always think there is a reason why they are aggressive, and try to find out what the reason is and sort it out (Max 148).

Chris talked about her interventions when the mother whose child had just died was being prevented from grieving by the father's family.

We were able to encourage the relatives to leave and leave mum alone with her grief for a couple of long periods of time, and we did tend to stay in the room, or got in and out of the room more than we would normally have done because if we hadn't she was getting upset at times because they wouldn't leave her alone or because they were wanting to lay the child on the bed and put her hands by her side and stuff a towel under her chin -things like that so that - I just felt quite able to go in there and say "there's no need for that... you know, constantly diffusing the situation all afternoon -giving her the time she needed -encouraging her to have time alone to nurse the child and different things like that (Chris 70).

Sam talked about some parents whose behaviour was inappropriate such as blaming particular nurses for changes in their child's condition.

We had a child here recently who had bronchiolitis obliterans, this father was a doctor so had quite good knowledge, the child had her own variations of being very sick and being better. If you happened to be on the shift when she was much worse then it was very difficult not to feel that, you gained the sense from the parents that they wished the previous person had been there. They often said that they wished so and so was here because on her shift things were much better and I can interpret that as a family who were encountering a great deal of grief and stress and plucking at straws (Sam 59).

The nurses' response to difficult and inappropriate behaviour could be to ignore it or address it. Ignoring the behaviour could be an initial strategy.

Try and ignore them if I can at first and be really nice and explain things and either try and win them over that way or if they get to the point when it's just not working and becoming quite rude to the staff I say something to them (Kate 67).

Kate pointed out that it was necessary to address the behaviour if the parents were rude to staff.

I say that “I realise they are really stressed and that's fine but you don't need to take it out on our staff” and usually they'll calm down. Other times there is just nothing you can do, really just sit back and do your work and try and get through the shift (laughs) (Kate 69).

Parents with additional problems

Stress caused by the child's illness and PICU admission exacerbated problems in the relationship between parents who had already separated or who did not get on with each other.

The problem of families who have additional problems that make them dysfunctional already and then they have a sick child these issues are exacerbated. That is one of the common situations that we deal with. More and more we see families who are dysfunctional, who don't have support. In those situations nursing staff are a target for peoples misguided anger, frustrations or whatever, they can be particularly difficult situations to deal with (Sam 35-36).

Relationship breakdown as a couple

Even if the parents were together as a couple, the stress could result in the couple not being supportive of each other.

They only had each other to bounce things against, you could see their own communication starting to break down, when I first met them in ** they were very much a couple, very close and very concerned about each other and lots of touching and eye contact. As the week progressed you could see their own relationship changing and they were sitting at opposite sides of the bed, they would take breaks at different times, he had very little conversation and he would start to say something and she would snap at him (Lily 35-36).

It had to be the staff who actually supported the parents and built up a relationship, and although I found them a difficult family, and I found him frustrating and difficult, I felt that at least they deserved some sort of support and especially the mother because she wasn't getting anything from him.(Chris 21).

Chris described how family pressures caused stress to the parents, in particular, the mother.

Chris intervened to support both parents individually.

I supported her and stressed that she really needed to be strong and care for herself -look after herself and her other child in a way that would for both of them be a situation which they could be happy in rather than perhaps continuing in a dead-end situation...She needed a lot of help, she didn't want to do a lot of things that he wanted to do, so she needed support to be able to say that -she had the right to say that -she was unable to express herself -express her rights. Some of it was cultural thing, they tended to take over at times, but eventually when he accepted that she was going to die they sorted the funeral arrangements out amongst themselves without any talk with his partner at all. They decided that the funeral would be in the Catholic Church and she would be buried with one of his sisters who had died - or his father. And of course the mother was absolutely horrified when she heard this. She needed a lot of support from myself and other nurses and priests to encourage her to say "no, this is not what I want. She is going to have a simple ceremony without any fuss and she's going to be buried in the Children's Cemetery." It was really difficult and hard and it was divisive, because to support each person - you had to support them in different ways. I tried more than once, to support them as a couple, and it was just too difficult because he wasn't prepared to be a part of the partnership (Chris 60-62, 66, 72).

Rose talked about supporting parents who were not together as a couple.

Over a period of you know the entire night basically, you know, I had spent probably a good 2 or 3 hours either with mum and dad at the bed side or with them out in the front lounge just you know sitting with them, answering questions, trying to be a comfort to them I guess. And then I don't know if I normally would've done that, apart from they were divorced and very bitterly.... in very bitter circumstances. So I think... and they were very hesitant to sort of comfort one another. I mean I think I spent my time very fruitfully just by being there with both of them (Rose 64).

Parents were encouraged to seek support from each other and their family.

Everything we did was wrong. Everything he did was right. She got better when she had the (iridology) drops. But when she fell in a heap again "oh, we knew this would happen!" So there was no way you could ever reach an agreement -you just couldn't and there was no way that he could face it. He just couldn't. He was completely unable to face anything. A very immature, self-centred person, quite unable to see that he needed to support his wife -and I strongly encouraged him to support his wife (Chris 50).

I offer to call people for them if they want me to call anyone. And I made that offer a couple of times and initially they said no, we don't want you to call anyone, and then sort of later over the night "yes call my dad" (Rose 83-84).

The following excerpts illustrate some supportive strategies for more difficult to support parents.

Try and talk of other things and get them looking at more positive things (Kate 30).

We usually involve them in the ongoing discussions so they know exactly what was going on... a lot of support during that stage is physical support and emotional support and when the actual time... the child is dying or has died... we make sure that we encourage them to get spiritual support ... if they believe that will help them (Lily 51).

I had a joke with mum, I said... she made some comment about him being really naughty and she goes "oh and I'm at him all the time because he's so naughty," and I said "ah well, you go and sit down by his bed," you know, like really trying to... I spent a lot of time encouraging them to sit with him and stroke him and talk to him and one of the things I said was "well when he comes back from theatre you go and sit down by his bed and you tell him he's in for a thrashing of his life when he wakes up." You know, and she laughed and she said "don't you worry about that, I'll thrash him within an inch of his life, he's never going to see the playground again" or something like that (Rose 105).

Transactions

King (1981) identified how transactions are a process of interaction in which individuals communicate to achieve goals. When transactions are made, tension or stress in a situation may be reduced. In this study, King's concept of transaction has been used to explain the caring nursing behaviours to establish rapport with parents. Specific caring behaviours were that the nurses imagined themselves in the parents' situation to feel empathy and displayed caring behaviours. It is once again highlighted that the nurse-parent relationship is not something that nurses are formally taught or prepared for. This interpersonal skill is developed with experience.

Hannah identified that nurses were not prepared in their education for the complex relationship with parents. These skills developed over time and with experience.

I think we need more education... like you said before it is not written in stone what the right thing to say is or do is ... but you need some grounding ... or course there is experience that comes with that. People don't want to put their foot in it so they don't do anything... they don't say anything so they shut up and that makes it

worse. Inexperienced people just want to get them out of the way, because they don't want to be on show in front of them ... whereas once you get to that point where you are confident with your ability then you don't mind them staying and it really helps. It's their choice then and you can explain to them what you are about to do and what sort of process it takes and it won't hurt and often they are happy to leave the if they are confident enough, and the fact that you have told them usually makes them think ...oh fine I am happy with that now... but it is all in your attitude to them. The younger ones aren't confident enough with their own ability to have that attitude (Hannah 77, 69-71).

The following excerpts encapsulate the nurses' empathetic approach towards the parents.

I reckon that having a child in Intensive Care must be the most dreadful experience in most parents' lives, and as far as dealing with the family goes, if I can make that experience slightly less horrific for them then I feel that I've done my job well (Rose 335).

One of the things I think is important when parents come into this environment is to be really calm because often for families this is their first experience in this sort of environment and they are looking for something calm to put it into context, someone who says that "this is a terrible thing but these things do happen to children" (Sam 21).

The rapport between the nurse and parents enabled nursing support of the family during the intimate family time when a child died.

I tend not to say much out of the ordinary. If you are actually watching the child die you may choose to explain to them and try to prepare them, but at the time - what can you say? I mean what's the point in saying - are you saying it for your own benefit or are you saying it for their benefit - it's not necessarily going to make them feel better, the fact that you came up with all these cliches. Probably the only thing I would say is that "we are sorry that we couldn't do more for your child." And that would be about the only thing and only as the parents were leaving. I would just try and continue normal conversation, appropriate conversation, and if the child has died ask the sort of things that they would like to do (Harry 539).

Hannah's and Sam's descriptions illustrate the nurses' empathy towards the parents when their child died.

I think that no matter what you do it (death) is horrible. I suppose less horrible is a good term. It's always horrible but there are degrees of horrible. I think we should just go with the flow and maybe all they need is a cuddle and maybe someone to hold their hand. They certainly don't need someone to say it will be all right. I have in most instances ... my feeling is thank God for that he has died. It is always them

and you know that they are not going to cope with it for a long time and I don't know if you should try to do anything other than let them know that you are there. It depends on the parents... some want you to just get out and leave them alone... that's fine... I don't have to be there with them the whole time when they are trying to say goodbye to their child in a private way. Some of them don't want you to leave because they see you going out the door and they see that that really is the final. I think you just need a bit of intuition to gauge what they need at the time. You need to be able to ask them. So maybe we can make it a bit less horrible but we can't make it not horrid (Hannah 259-265).

One particular day they had left the twins during the day, they were both exhausted and during that period one of the babies deteriorated quite a lot so when the parents came back in, the mother was very distressed that she had left and this had happened and we had quite a good rapport at this stage and I just talked to her that I said ... “ the children own their own lives and their deaths and as much as she may have wanted to hold their lives here by their presence that was something that she in fact wasn't going to be able to do” (Sam 5).

There were specific strategies in particular which were described to achieve rapport; the nurses imagined how they would feel in the parents' situation - put themselves in the parents' position, and displayed behaviours which showed caring.

Put yourself in their situation

Of the many examples provided, the following excerpts illustrate how the nurses used the approach of putting themselves in the parents' position to feel empathy.

I'm always really aware that is a permanent memory and its just going to just another part of your day but its part of their life and they are going to remember exactly what goes on - eventually (Hilda 193).

I always say to them “I will look after your child the way I would like my child looked after.” I know it is a bit of a cliché but -I sort of hope that it makes them feel at ease and the fact that they have got someone prepared to do the things that they would like to (Harry 157-162).

It's sometimes beyond their comprehension also looking at the monitors and the equipment and nothing looks like it's changed... the child can look exactly the same, (when in fact) the child can be brain dead (Hilda 63).

This included supporting parents who were doctors or nurses, appreciating that they were parents first, and health professionals second.

I think it's important to remember that they are on the other end and that they might well need everything saying in words of one syllable as well. Just because they are nurses or doctors ... they can think that way when their kiddy is intensive care (Bree 158).

Max talked about being aware that the parents may be particularly sensitive about what is said.

If it does get complicated and does take a long time, then it seems worse because they are sitting out there for longer than they were thinking and they wonder what is happening. Because I know I've heard some people saying, right at the beginning when new parents come in, they will say "ring the doorbell before you come in because you don't want to walk in on anything that you don't want to see" and I think, well later on if you then ask them to go and sit for 20 minutes while they put in a central line and it goes for an hour, are they then thinking - this could have been something I could have walked in on, and it wouldn't be nice. They are wondering what it is that is going on. I think you really have to be careful what you say at all times (Max 313-314).

Chloe also talked about not pushing the nurse's opinion.

I just think how I would feel. If I had an opinionated nurse looking after my child, and I hadn't asked for her opinion, then I would find that quite an annoying thing (Chloe 306).

The parent's behaviour sometimes made the nurses' role difficult, until they put themselves in the parents' situation.

Quite often it will be merely that they are so stressed and this will be something to latch on to complain about and we have to just acknowledge that. OK it's a real complaint to you so I will deal with it, speak to the nurse concerned. It may be something stupid but as I say it's real to them and causing them more stress and you can't just sweep it under the carpet and say that they are just imagining it, they are mad, (laughs) even if you think that. It's frustrating sometimes but you have to put yourself in their position, it's very hard to but you have to try and say how would I feel if it was my child. I think I would probably be horrendous but we get so caught up in the Unit with what it's like, every day work to us that sometimes we forget (Alice 191-195).

Show caring

What the nurses meant by showing caring was to demonstrate the human touch, to individualise their care, beyond the technical tasks, so that the parents felt they were special, important and that their child was not just another patient in the bed.

I think that to me (it) is one of the most important things that you explain everything to the parents and try put them at their ease and treat the child as though it's a child and not this body on the bed. Make it look as though you care (Bree 159).

When this behaviour was demonstrated to the parents, they were more comfortable to leave the bedside, knowing that their child was well cared for. Amy talked about some long-term parents.

A lot of them do (leave the hospital)...go off and play a game of tennis ... or go out and have lunch with people from work. A lot of it is knowing that these normal things are happening... reading stories, playing toys, you are not so tied up with all the other stuff that you can see that this is an important part of the daily cares. It's good that they will start resuming their normal life or as normal as they can make it. Especially when they have other kids they have got to get back to the normal world, they have to adapt. I think if you demonstrate and they know that you will do the things that they won't be there to do, then they are more willing to go out without feeling like they are neglecting things. Someone is in there spending quality time with them (the child) (Amy 290, 294).

Amy illustrated how the nurses talked to the unconscious child, to demonstrate caring as well as to encourage this behaviour by the parents.

Holding hands and talking to him even though they ask "can he hear? Does he know I'm here" ... well talk to them and let them know you are here we don't really know what they can understand. It's nice for them to hear a familiar voice or touch or something nice going on rather than all the nasty things that we have got going on (Amy 12).

There were caring behaviours described when a child died. These included washing and dressing the child in some special clothes, taking ink hand and foot prints, cutting a lock of hair and taking some photographs. Attention was paid to making the child look as nice and as cared for as possible.

We have just got this nice little booklet. It has all the usual contact numbers and some blotting paper for foot and hand prints and a place for a lock of hair, Most parents want that. Sometimes they'll do that before the child has died but normally they will be involved in washing them and sometimes we get them to bring in their own clothes and dress them up and take photos of them (Alice 318, 351-353).

Making the child look nice afterwards, really taking care and attention (Hilda 194-196).

Amy illustrated how genuinely showing interest in the family portrayed caring and provided the opportunity sometimes to find out about any other important issues causing parental stress.

Just trying to find out the family dynamics at the start and find out who the main players are and what sort of other kids they had on the scene and things. Trying to get a feel for the family as a whole and then just working out each little thing as it occurred. Just picking up on vibes between the parents and things whether there are any sort of stresses between them. Quite often in innocent conversation you find out lots of other things that have gone on and experiences they have had. There was somebody just recently who had to be flown up with their child, the child was reasonably unwell and the mum was in an absolutely hysterical state because we found out when chatting to her when she came out for a cup of tea that she was terrified of getting in the plane because her father had died 18 months ago in a plane crash. She wasn't so stressed about her sick child but getting in the plane which was a major thing for this woman. Fair enough her child was sick but her major fear at that time was the fact that she had to get in the plane and fly (Amy 5, 260).

Having to think about money was regarded as a stress from which the parents should be protected. The nurses tried to minimise this as a parental concern.

When kids get admitted and parents come and have nothing with them - no money, no toothbrush, basic things like that. So we want to get some family packs that will just have essential toiletries and a phone card (Alice 267-268).

Alice was also concerned about the cost of accommodation for parents, which she believed was inappropriate.

\$18 a night which is pretty tough really we were trying to get that removed, but they said it was a Health Department guideline (Alice 171).

The nurses often called upon the services of the chaplain to support the parents irrespective of the parents' religious beliefs. The support was not necessarily spiritual; the chaplain was seen more as an independent person who could listen to the parents' concerns.

Most people like to have that other person who's not a nurse or a doctor to talk to (Alice 157-158).

Amy described that the nurse identified when it was appropriate to find out whether the parents wished to baptise their child.

It depends where you are at, if the child is gravely ill I usually suggest "have you thought about whether you want a minister or anything" like that in... a baby perhaps you want a christening and just go from there (Amy 120).

Role

King (1981) explained the concept of role as identifying self in relation to others. In the context of this study, the parents' role was abruptly changed when their child was admitted to the PICU. Rather than being their child's care givers and decision makers, the parents now see doctors and nurses taking responsibility and assuming authority for their child. Parents often take on a passive role, particularly during the first few days.

The nurses' role was to promote, encourage and facilitate 'parenting' in the very alien PICU environment. To the nurses, parenting activities included parents being present at the child's bedside, participating in the child's care, being involved in decision making, and involving the siblings. The nurses also perceived that it was not their role to become involved in family conflicts.

Encouraging the parenting role in PICU

The nurses described supporting parents to resume their parenting role whilst their child was in the PICU, if it was appropriate for that child's condition.

A lot of mums feel comfortable doing the nappy changing and the more touchy, feely type stuff, they feel confident with that, and it's really, from my point of view - I don't push it, other than to show them that by my touching the child I'm not going to hurt them and reassuring them that they can't pull tubes out, they can't physically hurt the child, and obviously if you have a child who is extremely unstable, who really does react when you touch them, the encouragement then is quite often to stop the parents from touching (Jane 141).

It's important to try and get them to do what little they can. To make them feel as if they are wanted and needed (Amy 130).

In the PICU setting the meaning of participation in care was interpreted to mean the parents' presence with the child, rather than necessarily providing physical care. Whilst being able to do little things was seen as important for parents, being there for their child was thought to be just as important.

There's limitations to what they can do, eye care, mouth care and changing nappies it's a comfort mainly, that's really important. Talking to their kid is just as important (Hilda 127, 129).

The nurses described how they gauged when the parents were ready to participate in caring for their child.

When they are admitted as emergencies usually we don't introduce that until a couple of days afterwards, after getting them used to the environment. If you look at the literature, parents are most stressed in the first 24 hours so it is not appropriate during that time because they have got so much other information to take in. (Alice 67, 74).

It depends what they feel like they want to do. Sometimes they are very reluctant to touch them at all. They feel that it is going to bring on their demise almost. So it's hard, you have to gauge what they are willing to do ... sometimes they... they want to do any little thing they can to feel involved and other times it's "no I'll really not do it at this stage but maybe tomorrow or something I'll do something." So you have got to suss out what they feel they want to do at the time (Amy 17-18).

Hilda described how she approached the topic with parents.

Often when I first meet them I offer if they want to do something I mean mouth care, eye care - I ask them if they have been doing them - if they have I ask if they are happy to continue if they are not I let them know that they can participate - some parents don't want to or feel able to (Hilda 122-123).

The parents' ability and desire to participate in care was assessed on an individual basis.

It's probably an unconscious thing - I probably judge it on the parents themselves. You need to gauge their ability. Are they just sitting round not knowing what to do with themselves or are they interested in, you know, more participating in care (Harry 44-59).

Parenting decisions

The nurses tried to behave sensitively, to respect parenting decisions. When so many things were out of the control of the parents, it was important to respect the parents' wishes when that was possible. Being flexible to accommodate the parents' preferences was also attempted. The nurses also described guiding the parents' behaviour, when it appeared to be inappropriate, without stepping outside their role.

Respecting parents' wishes was described.

A lot of families aren't into chaplains and ministers but if they are or not then that is up to them (Lily 52).

Lily and Max talked about respecting parents' belief in the healing power of crystals.

I try and encourage the attitude that if they believe it is going to help, and it is not harming their child then that is fine (Lily 148).

I think sometimes, what you say to other nurses is to let off a bit of steam and so the nurses might be making fun of something, but when they are actually talking to the parents they are very different because we had some crystals that were - something special had happened to these crystals and they were put by the child and they had to lie beneath the child's head all the time, and one of the nurses took them - she didn't know what they were - so she just stuck them at the end of the bed and then another nurse came along later on and said "oh they have to be underneath the child's head all the time" so they moved them and put them back, and when the mother came in the girl who was really carrying on about - what a load of rubbish the crystals were and things, was fantastic with mum, asked her to

explain how they worked and I am sure the mother thought that this was a crystal convert, that this woman really believed in them - and she didn't but she portrayed the right image to the mother, that she was supportive of her using the crystals. I think most nurses are like that (Max 192).

It was sometimes necessary to negotiate about the style of care desired by the parents and what was possible in the ICU environment.

So I ... started discussing where we were coming from - things that we were trying to do in simple terminology that the doctors didn't use, about the child's condition - and I just put it on the line, as custodians of their child, made them aware of everything, and I believe at the end of that session we made a compromise with them saying - we don't really mind you using all of these things (alternative therapies) but you've come to this hospital which provides traditional medical care so you know, there's got to be a bit of a compromise with the things that we are having to do and the things that you are wanting to do (Harry 313-325).

Being flexible about the number of visitors at the bedside was described.

If they (the parents) are happy with the number of visitors coming in, it doesn't particularly worry me - even if the child is quite sick (Harry 428-430).

As identified in Chapter Four, the oncology families in particular were used to certain routines and procedures. The PIC nurses discussed being flexible about their care of the child to do it the way the parents wanted.

It takes a bit of negotiation with the parents as to why I'm doing it my way, or whether I am going to do it their way - because there is really no reason why their way is perfectly OK. It takes a bit of talking to them to find out whether they are not just being pedantic or whether they are doing it because it's the logical way the kid copes with it and they cope with it (Jane 327-328, 332).

I think we are quite open to doing things the way that families want. One interesting thing that Agency staff say when they've worked here and other places is that we don't have any rules here. We stick to the principles, we get things done, we are not so protocol bound as some of the places are, so we are quite adaptable. So if the families come in and you know, they want things done in a certain way, we really do try to do things the way that they want (Jo 126-127).

Being flexible meant having an individualised approach to each family.

If they are a chatty family, then I'll talk to them, if they want to be left alone then I won't talk as much (Chloe 283).

A part of the parenting role in hospital included involving the other children of the family in visiting the sick child. The nurses also took a role in caring for the siblings when they visited, although the facilities in the PICU were not ideal for entertaining healthy children.

The parents involving the siblings

Several of the nurses described the parents' reluctance to include their other children in visiting the sick child. All the nurses emphasised the importance of including the siblings and encouraged the parents to do so.

I think parents tend to protect them, they tend to want to hide them from all this bad stuff that is going on and they don't think that they can cope... when it is the parents that can't cope. The kids say "oh yeah that's it" and then want to know what else is going on around them. That very thing happened the other day, there was someone new at the bedside and an alarm was going off, so I went over to help them and this child had had a liver transplant and the sibling was there. They had this baby in a cot with an overhead warmer, and had it all covered up. They were trying to work out the leads ... and I pulled the sheet down and this Mum sort of lost it and the nurse said "Mum doesn't want her to see anything" and then I started to go into "maybe its better that she does see it"...it wasn't a big deal to her, the kid was fine, she saw that there was a big dressing on and said "yeah" (Hannah 245)

Hannah explained that she talked to parents about how children needed to know the truth and their imagination was often worse than the truth.

I try to tell the parents that because they think they are trying to protect their kid and they are trying to make the best decision for the siblings. I say to them what they imagine is much worse than what they could ever see. What if something does happen and they never get to see them again. You can't deny them seeing this baby sick. They need to know there is something wrong with them. He just hasn't been taken away somewhere else. So I say to them that that is my opinion and it up to you it is just the experience that I have had (Hannah 250-251).

The siblings' imagination could trouble them more than facing the truth.

We usually find that the parents who don't bring the kids in remark that the kids are having nightmares (Jane 115).

The nurses guided the parents who might be unsure about what was the best thing to do.

We try and encourage them always to come - because kids will make up stories and make up images in their head about what is happening to their brother or sister, or what they look like. Often they seem quite happy to play by the bedside. They know that their brother or sister is in bed, sick - they just need to know the real story. Is their brother or sister still here or not? (Harry 499-510).

You can often make suggestions and give support but if they don't take you on it you can't say "you must bring your children down here... you must see a bereavement counsellor... you must talk to me when I ring." You can only hopefully put some ideas into their head ... they will pick up on all sorts (Lily 40-42).

Lily related her concern at parents' behaviour of not involving the siblings and the rest of the family.

It was like... the kids are all right up there they are being looked after by grandparents and therefore what they can't see can't hurt them and it was their way of protecting them from their worst fears. That child had been admitted to two hospitals and died and no one had seen him sick and that to me is a worry because I think they are going to need a lot of ongoing support to support those kids through it and the staff here initially... the discussion ... that the older children may wish to seek other services, something other than the funeral directors... it was very much "no no we can (manage) ... that wouldn't be good (for the children to see)" ... but it worries me that the older kids may have difficulty dealing with the past and the loss of this baby (Lily 24-26, 30-31).

Sam described a child's death when all the family had been able to be involved.

We had a death at the weekend which was a really nicely managed death in as far as it was anticipated and there was a lot of discussion with the siblings about what was going to happen and opportunities to prepare them and for them to ask questions. The whole process of withdrawal of treatment was delayed until the family felt those issues had been sorted out. In fact two of the siblings nursed the child as he was extubated (Sam 122-123).

Sam also described the need for support groups for siblings.

I am thinking of starting a sibling support group with the social work department looking at the siblings of children who have died (Sam 112).

The siblings in the PICU

Looking after the siblings when they visited their sick brother or sister, was a further role for the nurses. It was seen as important to first allow the family to explain the child's illness to the siblings, in whatever way was appropriate for that family.

We don't know what the parents' beliefs are. We don't know what the parents would say - whether he's gone up to heaven or if the parents would say "he had a nice life and he's just here for a short time and now he's now going to go under the ground" (Chloe 189).

The nurses helped prepare the siblings for what to expect before visiting the sick child, once there was a clear understanding of what the parents had already said to them.

If I went to the door and there was a parent there with young children, I would say, "have you prepared them?" and then I would go through what they were going to see before they got there. Just so it wasn't a shock, something that would horrify them and stick in their mind. I would go through the parents first, what the parents have told them, because I would hate to tell the child that they were going to die and when the parents had told them something different (Max 228, 232).

Sometimes we will give them a picture of a baby so that you know ... you can take this and show them ... this is what he looks like (Amy 135).

The nurses talked about communicating appropriately to siblings.

It depends on the age but we'll say "he looks a bit different and he's lying in his bed and he's sleeping at the moment. He's got all these tubes" (Alice 200-220).

Talk to them about what is going on in simple terms. Letting them look at things if they want to, touch things if they want to (Hilda 188-190).

Hilda described developing rapport with the siblings.

Usually try and talk to them directly and know their names and address them and let them know what is going on (Hilda 184).

Bree and Chris explained about occupying the siblings to allow the parents to concentrate on being with the sick child.

You can take the kids away a bit you know sit them at the desk and draw with them or play with them or something leaving the Mum and Dad with the sick one for a while on their own. Just so they don't have to think about the other kids tearing around. We certainly try and take them off their hands so they (the parents) can have a few minutes together (Bree 167, 175).

We have a cupboard out there and we try to find things for them to play with and the play therapist will often suggest something for them and what have you, so that they are not struggling all the time -and then it's just up to the parents too as to whether or not they want to bring them in or want to put them into the day care (Chris 141-142).

There were some facilities such as child-care and school for siblings at the various hospitals.

We have sibling care -which is like a day care thing and I think if it is for a lengthy period of time, siblings can be enrolled in the school (Chris 140).

We have creche downstairs with a child minding centre - unfortunately they only work 8.00 - 4.30 and then after that there is nowhere, the parents would basically have to keep the child themselves (Jane 99).

There is also a Hospital Volunteer Service. So, if you need to you can ring the Volunteers and just say can you come and look after this child for a couple of hours because there is a specific need for them (Jo 156).

However the PICU was not seen as an ideal environment for caring for siblings.

There's no food. We've got some - there's no actual play area, we've got toys and a little table and chairs that we can bring out and put in the room somewhere, but otherwise it can be really difficult (Chloe 92).

I think the whole system needs review to make it easier for parents (Lily 138).

Intra family conflict

The nurses tried not to interfere or get involved during intra family conflict, which was not seen to be their role.

That has to be dealt with by themselves, you can't be piggy in the middle between them because you can't do your job properly because it would mean supporting one and not the other. Especially if they have got other partners it's quite difficult because you find that mum and partner come in and mum hates real dad, and dad

and his other partner come in and sometimes you find that you have to keep them separate, separate visiting times or say when the dad arrives mum says "I'll go out" or say at the door... "mum's here can you just wait a few minutes?" They know themselves if there is animosity and you find quite often that they do their own regime you know one will come in the morning and one in the afternoon (Bree 284, 289).

Kate described a situation of family conflict when the nurses didn't take sides or get involved.

There are certain situations where you can see that one side of the family is being incredibly disruptive. We had a situation recently where the grandparents had custody of the child. The child was 14 years and severely burnt making bombs. The mother actually had a psych problem but wasn't getting any treatment for it and the boy had gone to the grandparents who wanted entire custody of him. The mother was interested in her boyfriend and wasn't looking after him. She came in all fighting and saying "how dare my mother let this happen to my son... I knew she couldn't look after him blah blah." The grandparents got really concerned because the son had had a lot of ... had really resented and didn't like his mother and didn't want to have anything to do with her and yet the mother kept coming in. After a while she just stopped and rang once a day and that was about it, eventually she came in to see how he was. It was quite obvious that what the grandparents were telling us was really what was going on as opposed to what the mother was saying. We were getting both sides and we didn't take sides but over the time that he was here it was obvious who was telling the truth. It was the daughter who was being horrid to the grandparents... not wanting to have anything to do with them and being completely irrational really. So we stayed neutral that was all you could do (Kate 151-162, 166-168).

The nurse may have to take charge if a situation got completely out of control.

If they are completely out of control (behaving inappropriately) sometimes we have to talk to the family about it and say that at the moment it is really important for the child that you are both here either you work it out some other way. If you know what's going on you can get on with caring for the child and play whatever role you need to play whether it's police officer or social worker or what ever (Kate 137, 144).

Sometimes we have to calm things, structure the visiting (Hilda 170).

Max had learnt a mediating strategy from a role model.

We quite often have separated parents with very bad feelings between them. And we had a social worker who said to two actually physically fighting parents - that you know "you can't do that. You - both of you were here for this child, and while you are here in the Unit you have to just think about the child. You are not to

touch each other” and so some reason that worked, so I always try that. And you can usually anticipate - if you have been there at the bedside listening to what has been said, you can get in a lot earlier before anything even breaks out. They have a certain amount of time that they can spend by the bedside and it is something that they decide on mutually, and then they have to take it turns if they can't - but usually when I mention that they say “ok we won't” it never actually gets to the stage where one has to leave when the other one comes in (Max 157-158, 162).

The nurses' strategy was to present the perspective of the sick child's best interests and if necessary to regulate each parent's visiting time to keep the peace. Alice indicated that intervening to that extent was really felt to be beyond the nurse's role.

We actually had a child here a few weeks ago whose parents actually separated while the child was in hospital. I think it brought everything to a head and it got quite nasty when the parents didn't want to be there at the same time. We did all those nice things, we negotiated with them and said “how about you come at this time if that's OK with you and you come at that time and we'll be mediators,” which we were which is probably stepping over our role. It needed someone to take charge as it wasn't doing the child any good arguing over the bed (Alice 143-146).

Jane talked about involving the social work department when a situation was difficult to manage.

Occasionally I will ask the social workers to come in - because they've got the counselling skills for that sort of thing to actually say to mum and dad - to say that it is inappropriate to do that at the bedside and that in this situation they have to work together (Jane 215).

Stress

In describing stress, King (1981) used the word ubiquitous - being everywhere at once. Stress is both physiological and psychological in the hospital environment. Patients, their families and nurses can be affected by stress. The nurses identified their perceptions of parental stressors in the PICU environment, and these findings were presented under the subheading of Perception in Chapter Four Personal Systems. The sometimes-difficult relationships between parents and nurses could be stressful for and challenging to the

nurses. Under this subheading are presented some of the nurses' descriptions of the nursing qualities necessary to manage the more challenging interpersonal relationships with parents.

Nurse qualities

The ability to be successful with relationships was related to individual nurses' personalities as well as experience. Lily talked about how some nurses were less successful with all relationships. This was a factor that was considered when allocating nurses to patients whose parents needed support.

I think some people are better at developing a rapport full stop and if they seem to develop a rapport with people then they seem to develop a rapport with any body. Others that don't seem to develop a rapport as easily they have much more difficulty with relationships... so I think if there is a difficult family or a family who are having difficulties there are some people who I would allocate to that family ... a lot of that decision is based on how much support I can give ... if we are really busy and I know that I am not going to be able to support them very much then there are certain people I would allocate (Lily 81-82).

Clinical ability and experience as well as interpersonal skills were all important to be able to manage more challenging parents.

It's more because of ... partly their clinical ability... because they are younger and less experienced and if they are in a tight situation clinically and they are being challenged clinically and you have a family who is saying "what is going on why are you doing this, the last nurse didn't do this" and really challenging them as well I don't think it's a good situation if you can't support them, so I think it does go together. Allocating for that person will need to be, you are not going to put someone junior in a situation like that because she (the mother) seems to capitalise on that and uses it to her advantage (Lily 86, 108).

Feedback

King did not specifically define or describe feedback or evaluation of the process of human interaction. However, the outcomes of transactions were described as the achievement of goals, which may provide a measure of quality or effectiveness of nursing care (1981). Feedback is illustrated in the context of this study (see Figure 4), as occurring as a result of transactions. In reality, feedback or evaluation of the process of human interaction continually takes place.

The nurses frequently used parental feedback to guide their interactions with parents. Feedback was described as often being subtle and indirect. The nurses talked about the feelings they got from parents, and how they gained a sense that parents had benefited from their interactions. Some specific nursing behaviours were described to obtain feedback. Obvious positive feedback was in the form of thanks. Negative feedback was less frequently described, although it was perceived that parents would indicate if they were unhappy about an aspect of the care of the family. Sam talked about how her own need for parental feedback was less than it was when she was less experienced.

We often get feedback from parents. I think that when I first started that was very important to me to get that feedback. I tried very hard, I'm not saying that I try less hard but I am less preoccupied with my own performance now. I see my role as much more peripheral where as before I saw it as much more central. I saw outcomes much more as a result of how well I did and I think believe that nursing staff contribute to the overall experience for parents but I am much less needy, let the parents handle the situation and be the centre and provide what support I can (Sam 71-72).

Indirect feedback

There were many examples, articulated by Harry, Max and Lily, of the nurses recognising subtle and indirect parental feedback.

It's like when you have a good shift - you don't get people coming up and saying "oh I've had a good shift" but you just get a general feeling of how things have gone in the course of the shift and it can be absolute chaos, but you can come away

with the sense that things have gone well, the staff have been supportive and parents have been grateful despite what's out there and what's happened, it's a difficult thing to - not only tangible things (Harry 737-746).

Usually the feelings I get from the parents. If I feel I have communicated well with them and they appear happier or more relieved or they have more knowledge about - so they are not so nervous about - if they can feel comfortable in Intensive Care, then I will feel like I have done a good job. And they feel reassured with the staff. If it looks as though they are happy with the staff (Max 318).

I think you have a gut sense but you don't have any hard information as to what you have done right. I think you do have a sense of... even when the outcome isn't good I think you know with some families that in time they will still feel the same way towards you as they do now (Lily 222-223).

Jane related a scenario when she felt her involvement had been important to the parents.

I was involved in most of her care in that I was the retrieval nurse who went over to get her, I was involved in the counselling and discussion about the prognosis and I looked after her for two or three shifts afterwards, particularly the shift just after she was intubated I came on and looked after her and I felt that my interactions with the family were extremely important in terms of them feeling comfortable with the Unit and being able to talk about what they felt the prognosis was going to be (Jane 5).

Once rapport had been established, the reduction in the parents' stress was recognised.

They might see that you are on and say "oh good you are on great I can go for a cup of coffee then" (Kate 171).

They probably ask you questions, that they are not sitting there dumbfounded, they are asking questions. The fact that they can ask you what they think is a dumb question that they feel confident enough to ask the dumb question. I suppose that you can just tell from their body language that they are relaxed and that if there is problem ... someone comes over and tells them something and they ask you "what did they mean?" Which is often what happens with doctors... especially the registrar not the consultants, when the registrar has spoken to them and they turn to you and say "I didn't understand any of that" and they feel comfortable for you to hear that but not the registrar (Hannah 230-232).

Not only what they say but how they act and things like that. It's when that trust is there and you can be walking through the corridor and you might not be looking after the child and they come up to you and say "hi this has happened and that" (Kate 192-194).

Direct feedback

There were also accounts of nurses' behaviours to directly gain feedback from parents. The following excerpts illustrated how the nurses obtained feedback during conversation.

If they are asking questions you get an idea or if you ask them questions (Hilda 71).

I have a fairly good, broad vocabulary, and I find myself using words - and you see this kind of glazed look come over people's eyes - and you think - oops ok. And you break it down to you getting feedback from them. When they start saying to you "oh that's right, that that's tube over there." It really is looking at facial looks on their faces, whether they seem to be giving you verbal feedback or, if they are comfortable, sometimes they will say "sorry I don't know what you are talking about" and you say "ok fine" and you take it down the next step and keep going until they understand (Jane 61-62, 67-68).

Chris indicated that she would appreciate more feedback.

It would be nice if we knew about feedback -I have had a few letters that have been sent to the Unit -not personally to me but have been sent to the Unit, thanking me, because I have come in -this last situation was so awkward that I actually come in on my day-off - the day that we were going to discontinue treatment -because there was no one (Chris 171).

Harry indicated that he would ask for feedback if he perceived there was a problem.

I don't go looking for feedback but from the general level of conversation from parents and from staff as well, the level of conversation that they offer to you really is an indication of ... you know, people coming to you with their problems, or just asking you - just to want to be around and ask you different things. I think that is a reasonable level of feedback and I think the parents - most of the time I would say that - well I would like to think that it is a bit of an unconscious thing when that happens and you don't have to go and ask the parents directly - but just from - if I wasn't feeling comfortable probably I would go back and ask what they weren't satisfied with (Harry 169-183).

Positive feedback

There were many examples of parents expressing thanks to the nurses. Sometimes the parents would personally thank a nurse or s/he would be mentioned in a card. The following examples articulate the nurses receiving positive feedback.

Several of our children who have died - the hospital Chaplain has actually done the burial services, and she's come back and said how much the family appreciated what went on, or we get sent flowers from the family. Quite often the ones you don't think you have done very much for who will send you a photo of the child and say thank you very much, this is what my child looks like. Well, you are hard pushed to even remember the child, let alone the - but something happened and it was a huge crisis for them and they appreciated it and picked up that we would like to know what happens to the children (Jane 206-208).

She said "you've done a lot for me and I want you to know that I am really grateful." So that was very rewarding, to know that I had actually been able to do all I was trying to do, you know, and her mother -the maternal grandmother -also thanked me, and thanked me in the paper in fact (Chris 71).

Also there were the more tangible examples of positive feedback in the form of thank you letters.

We had a letter from his parents letting us know how they were doing, the fact that they had appreciated what we had done at the time (Alice 373).

The Japanese kids will write and that's nice. They always send you a birthday card, so they celebrate when they have Christmas and their birthday and they have their livers' birthday. That is the day the kind family gave them a new life and they are very appreciative and open about the transplant process, which is surprising because they don't recognise brain death. They celebrate their new life. It's all those little things that keep you going (Lily 231).

Sam talked about positive feedback from other nurses.

We have appraisals here quite often and if someone feels you have done a particularly good job you'll get that feedback. Our CNC recently did a monthly report and she started to list outstanding nursing practice in the Unit which I think is really wonderful... not only the clinical things but the psychological things that we do for family support (Sam 76).

The positive feedback when families came back to visit the staff was valued highly by the nurses.

I think it's nice for them to come back and see that this is the end result of what you did whilst you were here (Amy 255).

We get a lot of kids whose parents bring them back to see us, which is very satisfying. You don't always recognise the kid but recognise the parents. But that is nice we have got parents who live somewhere else and everytime they are down here for outpatients, they visit (Hannah 220-221).

It gives us a bit of a boost to see a child walk in that had been ventilated or on traction or whatever - and usually those are the ones who come back, the ones who were severely ill will come back and show us how they look (Max 245-246).

Negative feedback

In contrast, there were fewer comments about negative feedback or criticisms from parents. Alice and Max described parents who indicated that they were unhappy about an aspect of nursing care such as the level of skill, or the personality of the nurse.

Most parents will say so ... again they will be quick to say when they are not happy with nursing staff, personalities whatever (Alice 187).

Sometimes parents will say “I don't want particular people to look after them because I don't think they know enough, or they are too rough with my baby” and I would like to think that at least they can express that (Max 3200).

Sam described a case conference which included the parents. This seemed to be of value for the parents to express themselves.

We may have a case conference to talk about things and get feedback from parents about what was helpful and what was hard and that feedback is really important to give back to the staff because often that is one of the things that is not always appropriate to get at the time. I can think of one parent who said things that stuck in her mind that people had said and this gave her the chance to talk about it... either it really bugged her or it really helped such as the nurse said to her – “I know exactly how you feel because my cat died today” (Sam 129-130).

Summary of Interpersonal Systems

There were many examples of communication behaviours. The nurses talked about keeping parents fully informed about what was happening to their child, and they encouraged the parents to interact with them and ask questions. Listening to and talking through parental concerns was described. The difficulty of communicating with non-English speaking families was partly overcome by some of the nonverbal communication techniques described. The nurses' communication role included acting as parent advocate

with medical staff, interpreting medical information to parents, and supporting the family during the death of their child.

Under the concept of interaction, the nurses described the more challenging relationships with some parents termed as 'difficult'. Parents' behaviour could be 'difficult' due to the effect of stress, although some parents were thought to be always difficult to interact with. Support was provided individually to parents who were not together as a couple. In transaction, the empathetic nursing behaviour to develop rapport with parents was specifically described. The nurses put themselves in the parents' situation and purposefully showed caring to the parents and patients.

The nursing qualities required to effectively deal with the more challenging parents and demanding situations such as the death of a patient were described under the heading of stress. The parenting role in the PICU was facilitated and encouraged. This included participating in care, decision making, involving the other siblings and respecting parents' wishes. The nurses saw that it was not their role to get involved in intra-family conflict.

Evaluation of how well the nurses had been able to reduce parental stress was based upon indirect as well as direct feedback from the parents. The nurses interpreted their rapport with the parents to be positive feedback and described evidence of reduced stress in the parents' behaviour. Direct feedback as thank you and cards were also described. The nurses appreciated the positive feedback when families came back to visit the staff. There were few descriptions of negative feedback from parents. Those that were described were related to lack of rapport with individual nurses.

CHAPTER SIX

FINDINGS AND INTERPRETATION: SOCIAL SYSTEMS

King (1981) defined a social system as an organised boundary system of social rules, behaviours and practices developed to maintain values, and the mechanisms to regulate the practices and rules. In this study, the social system, the PICU, had particular rules, behaviours and practices, some of which were outlined earlier in the cultural context of PIC nursing in Chapter One. According to King (1981) the concepts of organisation, authority and power, and decision-making are characteristics of social systems that have relevance for nursing. The remaining findings from this study are presented below using King's concepts as headings in the blue text, and new subheadings that were identified from this study's data in black text (see Figure 6).

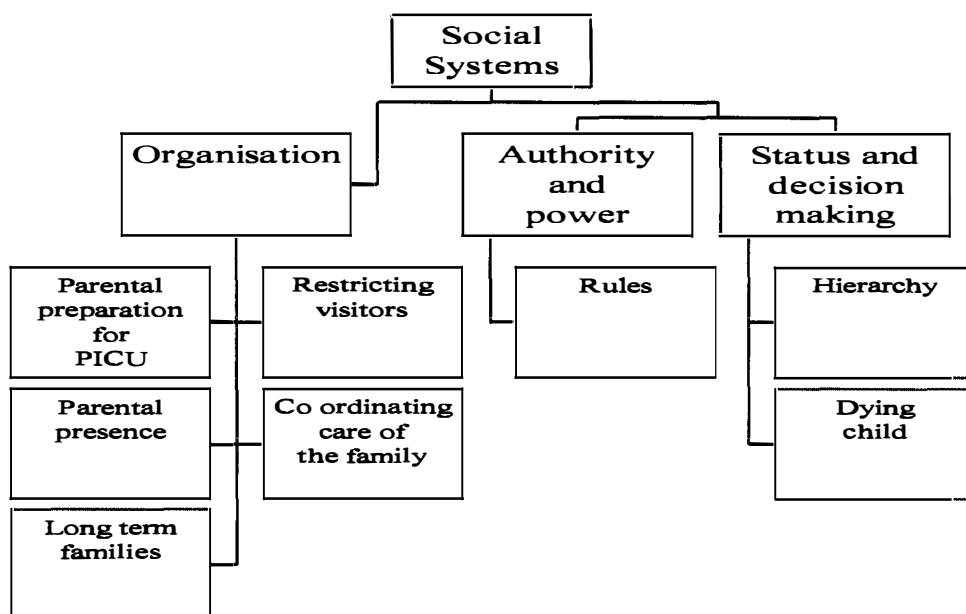


Figure 6. Social Systems

Organisation

An organisation is composed of human beings with prescribed roles and positions using resources to accomplish goals (King, 1981). King perceived that in the health organisation, nurses are the group that provide constancy, continuity and coordinate patient care (1981).

In this study, the nurses described their participation in the organisation of the PICU, many of whose practices directly affected the parents. There were descriptions of how parents were prepared prior to their stay with their child in the Unit. Parents were often required to wait outside the Unit particularly when their child was first admitted, with the intercom system used to enforce the rule that visitors to the Unit requested permission to enter. The number of visitors at the bedside was usually restricted, as was parental presence during patient handover. PICU medical staff usually determined parental presence or absence during procedures, whilst the nurses actively discouraged parental night-time bedside vigils.

The social worker was a team member in some of the Units, and seen to be of practical help at times. When the PICU became home for the long-term patients and their families, they became part of the culture during that time. Rosters and skill mix of nursing staff, which were part of the organisation of the PICU, determined whether consistency of nursing care, seen as the ideal, was possible.

Chris identified a PICU staff attitude of patient ownership.

When a child comes into hospital there is an attitude some people have that says - right you've just relinquished your hold on this little person, it is ours now until they go through those doors ... It's not ours, it's theirs and these people are going through a great deal of anguish because their child, who they love so much, is in intensive care at a children's hospital. To them this means that a child could die, in many cases. For their child to come through those doors as a patient is mind boggling enough, and I think we need to get rid of that attitude (Chris 194-195).

Parental preparation to be with their child in the PICU.

It wasn't always possible to provide information and arrange a visit to the PICU pre-operatively for elective admissions, due to organisational limitations such as low staffing on the ward and in the PICU.

It's sporadic. It depends on how busy it is in the Unit. I think it mainly depends on how busy it is upstairs in the Cardiac Unit, whether they've got time to bring the parents up (Chloe 119).

It was usual practice in the Units for the parents to wait outside the Unit before being able to see their child. During this time, the patient was connected to monitoring equipment and stabilised. It was important to communicate this to the parents so they were prepared to wait outside during this time.

Our only problem with the surgery type patients is that they (the parents) don't seem to understand that they don't spend any time in Recovery, they literally come straight from the operating table through to us and we've had trouble with parents banging on the door five minutes after they've got here and they are still having bleeding problems and other problems that you would probably (otherwise) see in Recovery. So, we have changed our visiting the night before - a little bit - trying to stress to them that there is going to be a time gap between the child hitting the Unit and then being able to come in. Because the surgeons go straight from the operating table and tell mum and dad that the operation has gone fine, and they want to know why they can't come in. And it's not because they are going to see things that we don't want them to see. It's literally they can't get to the bedside, there's usually three or four people settling the child in and there is just no room, no one has time to actually talk to them at that important time (Jane 20-26).

Alice described an occasion when a mother waited outside for several hours, causing her stress.

The mother came with the child and was locked out of the Unit for a considerable length of time probably four hours while they were basically stabilising the child before she was allowed in to see her. I just remember in that instance she was so distraught and so distressed and couldn't understand why she wasn't allowed to see her child just to make sure she was OK that she was still alive because at that stage she was really unstable (Alice 2-4).

Whilst parents were outside the Unit waiting to see their child, they were given information about what was happening to their child. There were descriptions of the nurse acting as a link or liaison between the parents and their child whilst the parents were remained outside.

As soon as the child comes out (from theatre), one of the nurses will usually go and say to them “it is going to take at least half an hour to get them connected to the monitor, our doctor will have a look and explain to them what we are going to be doing.” Then as soon as possible you get them to come in, but if it is taking a while, after 15 minutes you would go out and say “we had to give him a wash or they are a bit sick, they are vomiting” or “we are just giving them something for that” and just let them know the state of things - whether the Registrar is there yet to see them (Max 288-289).

I took them in the Waiting Room, made them a cup of tea, and explained to them that the nurse who was looking after their daughter would be out as soon as they had finished putting the tube down - and they asked why it was taking so long and it turned out that they had been putting in IV lines as well as the tube and other things and I explained that that was probably why it was taking so long (Chloe 260).

The nurses did place importance on the parents being with their child as soon as possible.

I had just presented at a conference talking about parenting, so I was much more aware of it than normal and so I got the mum straight into the room, got her a chair and said “this is what we are going to do.” (Alice 82)

I have difficulty with not letting them come in straight away even if you show them in and say “here you are ...they are alive they are OK we have lots of things to do ... stay if you want to or if you want to go and have a cup of coffee”...as long as they can see that they are there and they are fine. People tend to say let’s just do this and set this (intravenous) line up and three quarters of an hour or an hour later and the parents haven't come in to see the kid (Hannah 301, 302).

Restricting visitors at the bedside

The number of visitors at the child’s bedside was restricted to two at a time, and it was also usual practice to leave for procedures.

We always, at the beginning, say to all the family or anyone who is coming in “two people at a time at the bedside, immediate family, ring the doorbell before you come in,” and everybody reinforces it all the time. But - you know - if it was a new

born baby and Mum wanted to bring her parents in as well to have a look, we don't mind that (Max 110).

Alice described the old policy in her Unit that had since changed to allow parents to be with their child more.

It was only two at a time and they weren't allowed to come in during the admission of the child from the theatre as they had come from the cardiac theatre or ward rounds which were then at the bedside or if another child was arresting or child was arresting or significantly deteriorating. If they were having a chest drain in or a chest drain taken out so ultimately they were again prevented from getting in there for several hours a day Alice (9-10).

Alice and Chloe explained why the rule of two visitors at a bedside existed.

We have three four bedded rooms and depending on the equipment even in the single rooms it can be fairly cramped. It seems to be just in case we need to get to the child in hurry - that seems to be the rationale. In fact if it was necessary the family would be only to pleased to step out of the way to let you get to the child. It seems to be a good excuse (Alice 303-305).

It is difficult to get to the bedside and as the children that are here are that much sicker and you need to be able to get to the bedside to be able to get to things to - there isn't a lot of room around the bedside with the infusions that are running for the chest drains and the drains that are there (Chloe 78).

Parental presence

The nurses talked about their thoughts and practices regarding parental presence during nursing and medical handover, for procedures and at night. They also talked about the need to guide parents in order to leave the bedside to have a break. Rose commented about her view of nurses' attitude to parental presence.

I find that nurses are never satisfied, you know what I mean? Like if the parents are never there they complain, and if the parents are always there we complain as well (Rose 126).

Parental presence during handover

Parents were asked to leave during nursing and or medical handover in several of the PICUs. Hannah felt that this rule was not beneficial for the parents who could worry about there being something wrong.

I think nurses have a bit of a problem trying to hand over as well. In some Units they say that parents shouldn't be in there for handover. I think that just makes them think... what are you saying... what are you talking about...why can't I be there to listen to what is going on with my child and are you talking about us... Suspicious minds... it does make it a bit difficult when there are sensitive issues but it doesn't mean someone can't come in and relieve you so you can go out and handover (Hannah 93).

Chris referred to occasions when parents were present for handover and it had caused a problem. The following excerpt also identified that staff may talk about families in a subjective manner that should not be heard by the parents.

(The parent) joined in, yes. And somebody else did something equally bad, so it was at that stage that it was decided to exclude parents totally. Ask them if they wouldn't mind leaving. And we do ask them - some parents get very upset - then I just say, well "the doctors do discuss all the children in the room - sometimes parents do listen to what is being said about another child apart from their own and therefore it's not fair - you would like your confidentiality respected - and this applies to other people as well - so therefore we had to ask them to leave and to be fair we have ask everyone to leave" - there are some staff who have the stupid idea of allowing them to stay, but I think we really have to have one rule on that. You can't have some staying and some going. Everybody has to agree on it, and on the whole I think they do. I think that sometimes people talk about situations in a judgmental way, and they shouldn't in front of a group of other people, and assume things that are not necessarily accurate (Chris 203).

Parental presence during procedures

Whether the parents remained with their child for procedures such as lumbar puncture, insertion of central line, chest drain, was often beyond the control of the nurses. The decision rested with the doctor who was to perform the procedure. It was sometimes regarded as preferable that the parents were protected from seeing or being involved with

unpleasant procedures, particularly if the child was awake. When it was thought to be appropriate, the parents were given the choice whether to stay or leave the bedside.

If it is one of our consultants doing it, they often let them stay. If it is a new Registrar who probably hasn't done it very often - they will usually ask the parents to leave, but I usually ask the parents how do they feel - sometimes parents will leave, but I always give them the option. "We are about to do this procedure, would you like to stay or would you like to go?" and if it is going to be something invasive, like a chest drain being put in or something I will always ask the Registrar first if they can stay and watch and if he wants them to go I will just ask them to - otherwise I will just explain to them (Max 303, 308).

We tend to leave them in here ...it depends on the person doing the procedure whether they are comfortable with it some of them are more comfortable than others. The nurses are fine... it's just some of the doctors ... putting a central line in doing an LP ... it depends on the doctor... at least they can see that you are sedating the child, you are trying to do the best for their child. I think if they see that it just changes their whole attitude rather than "OK you need to get outside now because we are about to stick something into your child." I think it works better (Hannah 68).

Bree gave her opinion that it was better for the child as well as for the parents not to see what was happening.

Depending on what it is on the whole we invite them to go. Usually they will but if they don't want to we don't force them, but if the kid is awake I certainly prefer them to go out just because they are not there while you are holding the child down and the kid's looking at Mum for protection and I don't think that's the right way to do it. When they come back in they can be the goody. If they are knocked out on drugs and whatever and ventilated we still ask them to go not for something like putting a drip in but say putting a central line in or LP or something. We would ask them to go just so they don't see what we are doing really (Bree 197,201).

Max had some reservations about exposing the parents to everything that was happening to their child.

I don't know, there a few things I have seen happening and I think, I don't know whether I would like to have watched that happening to my child (Max 309).

Some of the medical staff were uncomfortable performing in front of parents.

They weren't having the family around watching what was happening (resuscitation) in that sort of situation in a small hospital (Max 44).

Parents themselves sometimes preferred not to see unpleasant procedures.

Yes some people don't like that sort of thing ... I mean it's up to the parents... some of them are more than happy to ask you to find them and get them to come in (when the procedure has been completed) (Amy 116).

The important point was to give parents the choice, as described by Sam.

Oh, we normally say "we are about to do these, this is what is involved, you can stay if you want to, it might be better to go outside because it gets a bit gruesome" we give them the option (Sam 170).

From the parents' perspective Hannah believed that the unknown caused parents more stress than if they were aware of what the procedure entailed.

We think that we are protecting them because they don't want to see what we are doing to their child but there is nothing more frightening than being outside and not knowing what is happening to your child and I don't know if that is just me and ...you usually find that parents who don't want to see any of that stuff will tell you and that even comes down to "tell me when you are going to suction because I need to go outside." If they are like that at all they are going to tell you about it. I think it's wrong of us to try and push them out of the way when they don't want to be outside (Hannah 63-64).

Parental presence at nighttimes

The nurses identified that generally, it was preferred that parents did not remain at the bedside all night. Parents' wishes were respected, but night time was seen to be the nurses' 'time out', to be parent free and have a break from supporting the parents.

I usually take into account that if they have slept by the bed that they are going to feel pretty revolting the next day...I don't know who it is who needs the break, I think it's the nurses who need the break (Max 72-76).

We do like some time out. Most of us think night duty is our time out and we would like the parents to go. Having said that we don't actually ask them to leave. We have a 24 hour open policy as far as parents are concerned. But outside, amongst ourselves, we also acknowledge that night duty is our time out, and it would be nice if we didn't have parents in the Unit at that time. If they want to sit by the bedside all night, that's their right. We just grumble a bit to ourselves, but that's fine, that's our way of blowing off steam, and then we go back and make them feel welcome. Every Unit has their own culture and what is appropriate and what they are prepared to cope with. Particularly out in the Unit, we can't provide anything other than chairs for parents to sleep in, so it gets a bit crowded at the

bedsides, and you find you have to change your language and your talk and stuff when the family are around (Jane 336-337, 341-342).

I know there are some people - usually they are ones who've here longer who like to get rid of parents at night. I think I tried to work out what's going to be best in that situation for the parent. There are some who desperately need to with a bed somewhere close by and once they have been there for a while, perhaps you can encourage them to go and have a proper sleep on one of the foldout beds so that they are a bit more rested when they see that things are going to be ok (Chris 126).

Harry explained that it was not good for staff to have the parents at the bedside all the time.

From the staff's point of view I don't think it's good that the parents are there all the time, so subtly we would probably suggest that, "OK, you've been here for a long time and you look absolutely exhausted and we've got to look after you, as well as the child and we suggest that you go elsewhere to have a sleep, or go round the park or try and get out and do something different, even if it is for short periods of the day" and just reassure them that we can always contact them and that the child is unconscious and unaware of what is going on (Harry 445-457).

If the child was sicker, it was accepted that the parents were more likely to want to stay overnight.

Probably people do prefer them to go to bed... But I always say that you know, encourage them to make use of the parents' lounge facilities... If you want to sleep by your child's bed you can, and we've got recliner chairs that they can sit in at the bedside. But I wouldn't probably make that offer for kids that are (less sick)... well I guess you know you kind of try and feel them out and see what they want to do (Rose 135-140).

The nurses might not admit to their need for timeout, giving other reasons for not encouraging parents to stay at the bedside.

That sort of thing wouldn't bother me... I think the people who would have problems with it would be people worried about the space we've got - they would say well if there are parents there it would be difficult (Max 294).

Leaving the bedside

The nurses assisted the parents to fit into the environment. It was seen as important to talk to parents about being able to, or feeling confident to, leave the bedside, particularly during the initial time.

Allowing them to be at the bedside, but at the same time giving them permission to go away. Parents will look to you to say “is it OK if I leave, is it ok if I go and have a cigarette or meal?” or whatever and they just need you to say “it’s OK your child will be fine. Even if something goes wrong, we will look after the child while you are away” (Jane 74 –75).

If the parents chose to leave in a crisis, if possible a support person was with them.

We try to -we have said we don't sometimes feel that they got enough support in their situation, because if you are busy - there isn't a person free who can go out of the room and do it, and in the case of a cardiac arrest, if the child arrests, you have to say “do you mind leaving the room - or do you want to stay?” No matter whether they are out there or in here - and if they are out there we put them in a little side room - you really need to have a nurse with them I think, to support them (Chris 261-262).

The parents weren't judged upon whether they were present or not. In fact it was acknowledged that the parents needed a break, to rest, and to get away from the stress of being in the PICU environment.

Acknowledging the fact that not every parent wants to be there and it's OK to take a break and go out (Alice 104).

I try to encourage them as much as possible to get as much rest as they can ... while their child is in ICU because there is not much they can do, they can help us with the general cares but the child's not running around screaming around the place. They don't need to be in 24 hrs a day so I try to get them to rest and take coffee breaks and if they can't sleep during the night to make sure they go and have naps during the day (Kate 204-205).

Jane described reassuring a mother that her child wouldn't be left alone.

She needed a reasonable amount of reassurance that the reason that she was here, even though - between procedures she was ok but she needed to be watched - just the constant reassurance that the child wouldn't be alone, that she would be able to leave and have meals - and we have mobile telephones so if the family were calling

in, we were able to take phone to her so that she didn't have to leave Sarah which I think reassured her a lot (Jane 45).

Co-ordinating the care of the family

Within the PICU, the nurse was seen as coordinating the care of the family.

They (the nurse) are that pivotal person who can liaise with everybody (Alice 336).

Chris talked about the nurse's role of assessing when it was an appropriate time to involve other support staff; social worker and chaplain, priest or minister.

When you get a feeling of where they are at, introduce other methods of support such as the religious people or the priests or whatever, and the ministers and social workers. And the social workers, even if they don't want to have a lot of involvement with the social workers, the social workers get involved to sort out the things that are time consuming such as car parking, or accommodation, and what you have to do -how you deal with certain situations, and that might be money sometimes, they might need to get a relative from somewhere else in Australia here, (Chris 83-85).

The social worker was seen to provide practical help to the parents, and was referred to many times as someone who the nurses contacted to become involved with the parents. As Alice indicated, this action was part of the culture of many of the Units, rather than assessed on an individual need basis.

Our initial reaction is phone the social worker rather than dealing with it ourselves. It's surprising how many parents ask to speak to a social worker without our suggesting it to them (Alice 147,151).

As Hilda described, there was a benefit to the nurses in that they felt as if they were being helpful.

Makes it feel like you are doing something for them (the parents)(Hilda 77).

Alice indicated the need to be aware that for some parents there was a stigma attached to seeing a social worker.

With other socioeconomic groups it's very much seen as a stigma to have the social worker but we do use them a lot (Alice 153-156).

Harry indicated that he did not think the social worker had a role in the PICU because nurses had a close relationship with the parents and, in the Unit in which he worked, were able to fully support parents.

I prefer to try and organise something myself. I mean, it's difficult to expect someone to come in who has no relationship and set up something when you have looked after them for a long period of time and know them. It is much easier for me to handle. I have got nothing against social workers but in an intensive care setting it is almost impossible for them to set up a relationship with the parents. They are not there at the times when you need them to be there and crises happen all through a child's stay and the nurses are really wonderful caring for them through all those crises and so they just continue. We all know that the different services are available to help these parents and we know how the system works (Harry 521).

Jane commented about the different perceptions of the social work role by the nurse and the social worker. The nurses saw that the social worker was there to provide the practical help to the parents, because the nurses had to remain at the bedside and were unable to leave to organise for example, accommodation.

The social workers see their role as being different to what nurses see the social workers being. The main thing I suppose is just literally, because you are at the bedside constantly, it's providing parents with information as they want it - getting them the access to the room out back so that everything is within calling distance (Jane 73).

The social worker was more involved with families of long-term patients and with complex family issues.

If we have a family come in she will speak with them and do a formal assessment of the family and how she feels they are coping. We tend to observe families quite closely and if we feel that they need additional support we will call the social work department (Sam 28-31).

The social worker was also seen to have a supportive role for the nurses when a child died, as well as a role in bereavement counselling.

Sometimes it's a back up for us as well and they can do the drinks and coffees and camera. (Bree 232).

Social work follows up on all of the deaths and offers a bereavement group (Lily 55).

Long term families in the PICU

Having one or more long term patients and their families in the Unit meant that a different nurse – parent relationship developed during the time that the PICU was ‘home’ for the families.

We have almost not had a long term patient for seven months and sometimes more than one and I think that we cut our teeth and do a much better job now of managing these situations which I think it is essential we do with long term kids. By necessity the Unit has to become that family's home and its one of the areas that has really challenged the way we look after families and has made us be much more flexible and accepting of what the parents want to do in this environment (Sam 80).

Jane described the practice in her Unit of moving long-term patients to one area.

As they get more and more long term they migrate up closer and closer to the front door. When we've got a couple of long term patients - they tend to be put next to each other and for some reason we've just got into the psyche of - this end of the Unit is the long term end and the parents pick up on that (Jane 269, 274).

Jo described some long term parents who felt the PICU staff lacked insight about their feelings. These parents admitted their feelings during one of their regular meetings with PICU staff.

They said that “just because we smile and we look happy and our baby is happy doesn't mean that we are happy” and they said “they can understand that there child is not the sickest child on the ward and doesn't necessarily get the most senior nursing.” They said that “at the end of the day they were concerned that they go home from hospital and everyone is smiling and happy but we don't understand that they go home still with a child on a ventilator in Intensive Care.” So they said that “even though we might look happy, we go home and cry” (Jo 182-184).

Max described how long term families became part of the culture – up to a point. She provided an example of staff joking that could seem inappropriate to parents.

We have a couple of kids who have been long-term over the last few year and they (the parents) know that that is how we blow off steam, but they always make a comment about “did you hear the joke they were telling in the middle of CPR?” or whatever. And you can tell, that even though they understand it, but it still has meant something to them that they even commented about it - it made an impression on them that that's how we behave (Max 329-330).

Max talked about how long term parents picked up and started to use PICU jargon.

After a little while, if you've got a long term patient, the parents start using the jargon themselves! And they feel like they then are part of the team and know what's going on (Max 65-66).

A strategy to meeting the needs of long term patients and their families was to have consistent carers or primary nursing.

In the instances that we do it (primary nursing) we stick to it. I think that you forget that just because they are stable doesn't mean that they are stable all the time. He is in a (single) room too which is even worse... he is isolated (Hannah 172).

Jo explained the pros and cons of having a primary team care for that family.

It's a difficult management decision - just puts the stress of the whole thing on just a group of people. On the one hand, whilst you are really trying to help the family, you must also make sure that you are not doing any disservice to your staff and the patient is only there for 6 months (Jo 81).

Primary nursing could be demanding for the nurses concerned if the parents were difficult to get on with.

The staff ended up having meetings with the Psychiatrist and Psychologist just to help them cope and look at what they could do to manage all of this. And that was a problem. I guess it helped some people, some people benefited. But we used to have regular meetings where we would just say “this is what we are up to, this is what we are doing” and we appointed - well, we had a primary nurse, a primary nurse on the nursing team just so that it just made it smoother for the nurses and the family (Jo 80).

The benefit to the parents of providing continuity of care was illustrated in the following excerpts.

I did (look after the child) for a few days plus I supported (acted as float) as well so I was able to be involved in her care and I think that really helped because as I said before they did begin to trust me and they were a lot calmer as she became more well (Kate 18).

As long as that nurse is happy to be involved with that family we try and match. I think it is a stressful environment enough without having three different nurses looking after someone's child (Sam 58).

It can be quite stressful on the people who initially set it up and decide that they want to be the primary nurses and I think its just with experience with doing those sort of things. It doesn't mean that you look after them every day. You are just there as a resource person, a support person for the people who look after them, update them, a familiar face for the parents if they have any problems they can come to you... and say that "they would like to set up a meeting" or "there is something I don't quite understand can you explain it to me?" (Amy 281).

Hannah had mixed feelings about the value of primary nurses in the case of a current long-term patient.

I don't know if it would make any difference to a two and a half year old. I have mixed feelings about it. Probably with him it helps because he that kind of child. He has got boys looking after him. There is no father around and the male nurses are the absolute be all and end all. So whether some other strange male nurse who came in and looked after him who had never seen him before, I don't know may be he just loves them because he knows them (Hannah 157-168).

Hilda described the problem of not being able to consistently care for a family, over a number of shifts because of other demands in the Unit. In particular, this problem was related to the senior clinical roles of the interviewed nurses who coordinated the shift, were the float or support nurse, or the patient was less sick and could be cared for by a less experienced nurse.

Often you don't look after the same patient consecutively so that (is) quite a difficult thing as far as making a rapport with the parents if you only look after the child for one shift and then looking after a different patient or being the team leader or supporting so you don't have consistent care. That can interfere with parental support if they haven't got consistent care. Particularly with CNSs because

sometimes you are in charge and we have support people who float around and just help out. So patient care days are more limited as you are not always looking after the same patient because the patient is a bit better today so you are looking after another sicker patient (Hilda 232-233, 237-239).

Lily described that it was more difficult to establish a rapport with the parents when not continually at the bedside, such as when coordinating the care of all the patients.

I think that I particularly miss out by doing the co-ordinating because the people at the bedside build up a stronger rapport with the parents than you do as a shift co-ordinator (Lily 9).

However, Lily went on to describe the skilful practice of being able to develop rapport with parents in a limited amount of time.

If you are actually caring for the patient for a long time say an 8 hr shift you get to know more about the family and because you can pick up those cues over a period of time, I think what you develop when you are not doing that is other ways of picking up if not the same information but similar amounts of information in the same amount of time. So you pick up on the subtle cues...I think you become very good at asking the right questions so that you cut out all the chit chat type of stuff and get the information you are looking for but still being able to provide them with enough support (Lily 14-15).

Authority and Power

In defining the concepts of authority and power, King (1981) sees that authority can be observed in every culture, providing order, guidance and responsibility for actions.

Power is closely related to authority (King, 1981). The control exerted by authority and power implies a superior - subordinate relationship among individuals within the culture.

In the PICU culture, the parents are very dependant upon the staff and the environment.

The nurses in this study accepted their superior role as the norm. They talked about enforcing PICU rules upon the parents, and relaxing rules under circumstances such as

when a child was dying. Max acknowledged the staff's authority and power over the parents.

When patients are in Intensive Care you - they are often - by walking in the door they have given you implied consent more or less and we don't say "we are going to take blood now, can we take the blood?" We just say "we are going to take this blood so that we can have a look at the gasses and change their ventilation." And parents would just let you do it. I think that they just think they haven't got a right to - they have a right to ask but they don't have a right to say no for whatever it is you are doing because it is usually way out of their field - so they just feel we are the experts and we'll let them do it (Max 135).

Rules

Rules were enforced upon parents, such as the use of the intercom to seek permission to enter the Unit and placing restrictions upon the number of visitors as presented earlier. Other rules were that single rooms were reserved for dying or infectious patients. The usual rules of the PICU culture were relaxed when a child was dying.

Intercom

The intercom system was used to enforce the rule that visitors requested to enter the Unit each time.

We have the buzzer system so they are not allowed to just come in and out like they do on the wards or most other places, they actually have to wait until we say come in which sometimes if they are kept waiting for a little while... people get upset about but it's a case of as soon as they buzz we find out if they can come in, if we are doing anything particularly with their kiddy we ask them usually to wait outside, but some you go out and explain why they are having to wait (Bree 29).

The purpose of the intercom was described to be for ensuring privacy for all the patients and their families.

It is more for their own safety. They just need to know that that is the policy and it's not for our sake but their sakes. It depends on the manner you say it to them. Someone will go up to them and say "you didn't ring the doorbell... they are the rules" but if you go and say to them "we have lots of kids in here and we need to protect the privacy of everyone not just your own child, the reason why we ask you

to ring the bell is that if there is another procedure going on we may ask you to wait outside.” They are usually fine, but if you tell them it’s a rule and they have them to ring the doorbell just because you want them to, it doesn't go down as well. I think it’s the approach you take... and I think that some people forget that this is the most stressful time in their whole life so far so what we have to think about is a situation in their own life where someone could have said something differently to them and their whole experience could have been different. But that comes with experience (Hannah 120).

Hannah indicated, light-heartedly, that the use of the intercom system to regulate parents being at the bedside, was also a staff coping mechanism.

We have those rules and people get cranky when the rules aren't followed... and I'm one of those. But the rules are there for a reason. I think that intensive care nurses ideally they don't tell you that ... the ideal patient is the paralysed, ventilated with no relatives! (Hannah 85).

Restricting visiting

Although none of the PICUs in which the nurses worked had any visiting times for parents, some restriction was imposed on other visitors. This was perceived to be for the benefit of the parents, as the nurses described how they thought other visitors could become an additional stress for parents.

We do have a policy of parents and siblings only in the Unit after 8 pm. That's really only for parents if they want to get rid of all the other relatives. So we don't enforce that we just say if you want us to we can. I find that many of them just would prefer the rest of the time alone I think we really need to maintain some sort of guideline so that we can say these guidelines are in place not because we want to throw everyone out but because we want to give parents the choice (Alice 285-289, 298).

A lot of parents can't actually say no to visitors - but if I detect that they are getting a bit stressed out with lots of visitors coming in, then I am quite happy to intervene and limit the number of visitors there (Harry 423-427).

Harry described how he would directly ask the parents whether they wanted visitors.

I would ask the parents straight out – “are you happy about all the visitors? - and if not then it's easier coming from me than it is from you”. There are times when

they do feel relieved that they haven't to confront family because they are worried about their reaction (Harry 434–439).

Single room

When a child was dying or likely to die, it was usual practice to move the child into a single room for privacy.

We've only got one single room, and we usually use that for patients either if they are infectious or are immune-suppressed or if they are dying, otherwise long-term patients are generally -we've got 6 rooms and most rooms take 4-6 beds and so we just sort of find a corner in whatever room the patient is in (Chloe 96).

The parents were given the choice about whether they wished to move into a single room.

We ask the parents - it's not a mandatory thing - we say to the parents “we have a private room” and if we've got time, and the patient is stable enough to move, we give them the option. The majority of parents say “yes please.” Basically because the private room is at the end of the Unit so we can also cordon it off a little bit and get them a bit more privacy for coming in and out of the room as well (Jane 163-164).

Relaxing the rules

The nurses described how they adopted a different attitude to supporting the family when a child was dying. The family was able to visit freely, without restrictions on the number at the bedside or the use of the intercom.

I think you can relax the rules and have more people in and do what they want to do. In the main area it can get a bit noisy and crowded so we limit visitors but in the side-rooms and especially if the child is dying - what ever they want (Alice 207, 308).

With dying I think you do change and I think you are much more flexible ... basically what ever they want to do is fine (Amy 212).

In particular, moving the child into a single room enabled the parents to have privacy when treatment was being discontinued.

We always take the dying child -when we expect them to die or we are going to disconnect their tubes -we take them into another room so that the family can spend the night with them or they can just have time there by themselves before it all actually happens (Chris 228).

The privacy of a single room was perceived to be better for the parents as well as for the other families in the Unit who would be aware of what was happening. Jane gave an example when there wasn't a room available and the child died in the main area of the Unit.

The child died in the early hours of yesterday evening and that was a difficult one from the point of view that both of our side rooms which we use often for bereavement had got infectious patients in them. So they couldn't be used. So it had to happen out in the middle of the Unit. That was hard for the family (Jane 159).

Status and Decision making

King (1981) referred to status as the position of an individual in a group in relation to other groups. In their familiar environment, the PICU staff are in a more powerful position than the parents. The decision making process requires information (King, 1981). In the PICU environment, parents are in a vulnerable position, where the doctors and nurses have the knowledge and information, and the parents do not. Thus, they are often not able to participate in decision making about their child.

There was a hierarchy of status and decision making, with major patient management decisions generally made by medical staff, based on clinical information provided by nursing staff. This hierarchy was altered when a child was dying; the emphasis of care changed, and parents were encouraged to do what they wished and to make the final hours with their child personal and intimate.

Hierarchy

The nurses described the close working relationship between the nurses and medical staff, in particular the specialist staff rather than the more junior doctors. The closeness was implicit rather than made explicit by the nurses' descriptions of the

relationship. Based on their assessment of parental needs, nurses contacted medical staff to arrange for them to speak to parents, to ensure the parents were kept fully informed. If parents were not informed of their child's condition, it was seen to be the medical staff's responsibility to inform the parents, the nurses reinforcing and explaining, but not for example providing a diagnosis or communicating an important test result. Alice and Jane described withholding providing information that was seen to be medical information.

To be honest I suppose the majority of that is done by the medical staff because they are the ones who break the news. We can't do anything other than suggest that they (medical staff) may recommend withdrawing (Alice 321-324).

There's nothing held back from the parents at the bedside, unless it is something like the diagnosis is poor and they haven't been told, which happens quite frequently, when doctors aren't ready to hand that kind of information over (Jane 152-153).

It was recognised by the nurses as important for the parents to be with their child as much as possible. In practice, medical staff sometimes determined the decision about parental presence.

We have changed our guidelines and we say that parents can stay with their children at any time however we have a lot of problems with medical staff because they would prefer them to wait outside while they are inserting lines. Yeah it is very hard and I have been speaking to them (intensivists) and they are fairly sympathetic towards it but they say that it is their junior registrars who are maybe not so comfortable performing in front of parents. Ultimately it is their decision... and that is what it comes down to ... we still don't have the autonomy to say no it's their child they've got every right to be here (Alice 11,15-16).

Max described a resuscitation situation when parents were prevented from being present because the medical staff were uncomfortable with that.

I thought that was a really hard thing - and I kept saying "can we bring the parents in, can we bring the parents in?" and the doctors didn't want them in because it was really going badly, and I think they were floundering a bit, and they didn't want the parents to see that (Max 39).

Dying child

The emphasis of PICU management changed when a child was dying. Parents were then encouraged to make decisions about the manner of their child's death, who would be present, aspects such as washing and dressing the child etc. Management of the death, such as withdrawing treatment was aimed to be when the parents were ready, and in the manner chosen by them.

If it's a case of turning off a ventilator - the parents get quite a big say in when they want to do it (Chloe 175).

In any sort of situation that we've got any control over we let the parents make the decisions about what they want to happen and if they want to be with the child themselves - we try to get them as much time as possible (Sam 200).

Ask if the parents want to help in that... not all parents want foot and hand prints ... they don't always sometimes they prefer to wait outside whilst you wash and dress them and then come back in (Bree 234).

Whilst a child was dying or had died, the nurses gave the parents privacy whilst still being available to be supportive.

It depends on the parents... some want you to just get out and leave them alone... that's fine. I don't have to be there with them the whole time when they are trying to say goodbye to their child in a private way. Some of them don't want you to leave because they see you going out the door and they see that that really is final (Hannah 261-262).

Even if the child has not been withdrawn at that time we'll shut the door and shut the curtains and hang around outside basically to be there if they want us but give them as much time as they need. Sometimes that can be hours and hours (Alice 355).

Bree described how the nurses continued their support of the parents afterwards.

We don't force them out or sometimes if they want to come back the following day. I'll try to keep the body actually on the Unit rather than taking them down (to the mortuary) (Bree 251).

Summary Social Systems

The nurses described some rationales for some PICU rules and practices. It was acknowledged that some practices benefited the staff rather than the parents. Although parental presence was supported in theory, in practice staff needed some time out to be parent free. It was reported that the medical staff preferred to perform procedures without the parents being present. When a child was dying, staff attitude towards the family, and the focus of care changed. Rules were relaxed, and parents were given more opportunity to make decisions about what happened, such as when and how the death occurred.

CHAPTER SEVEN

DISCUSSION AND IMPLICATIONS

In this chapter, the findings presented in Chapters 4, 5 and 6 are discussed in relation to the research aim and the literature, using King's conceptual framework to articulate the relationship of parental stress and nurse - parent interactions within the PICU culture. The discussion is presented under the following headings; personal systems, interpersonal systems, and social systems. The concepts, which have been already defined, will also be discussed. Finally the limitations of this study, recommendations and suggestions for future research are provided.

Personal systems

King defined the concepts of perception, self, body image, time and space as characteristics that help to explain individuals as personal systems. The findings related to these concepts will be discussed under King's conceptual headings.

Perception

King (1981) described perception as each human being's representation of reality. Perception is a process of human transaction with the environment and gives meaning to one's experience, represents one's image of reality, and influences one's behaviour.

In this study, descriptions of actual and potential parental stressors were as interpreted by the nurses. Parents, as individuals, experienced different stresses in relation to their child's admission to the PICU. The nurses described some common stressors that affected all parents, and more specific causes of stress such as being oncology parents in the PICU, that had not previously been highlighted. There were some common

characteristics to the nurses' descriptions of parents' behaviours in response to stress.

Some of the behaviours, if considered in terms of the response to the loss of their child's health, reflected Kubler Ross' (1969) stages of grieving, consisting of shock, denial, guilt, anger, sadness, resolution and reorganisation.

The nurses in this study described maladaptive behaviours by parents, such as guilt, vigilance, and focusing on small clinical details and changes. Meyer, Snelling, and Myren-Manbeck (1998) suggested such behaviours may be necessary coping strategies, and urged nurses not to be too eager to reassure, to dismiss trivial concerns or push the parents to focus on the bigger picture. It may be that the nurses in this study did not fully appreciate the significance of these adaptive parental behaviours.

Shields-Poe and Pinelli (1997) and Meyer, Snelling, and Myren-Manbeck (1998) reported on parental stressors in neonatal intensive care Units (NICU). The disruption of the parent-child relationship, and alteration in the parenting role, have been identified by parents as the most stressful aspects of the PICU environment (Curley, 1996; Farrell, 1989; La Montagne and Pawlak, 1990; McNab, Emerton-Downey, Phillips, and Susak., 1997; Neill, 1996). In the present study, the nurses' perceptions of parental stressors reflected those reported in the literature, thus indicating that their perceptions were accurate.

The nurses in this study perceived that there were inadequate facilities at the hospital for parents and siblings. They endeavoured to provide for the personal needs of parents. In studies that have identified parental perceptions of their own needs (Farrell, 1989; Graves, and Ware, 1990; Meyer, Snelling, and Myren-Manbeck, 1998; Neill, 1996) parents wanted to be able to be with their child or nearby and often neglected, or seemed unaware of their own needs. Meyer, Snelling, and Myren-Manbeck (1998) conceptualised the needs of parents as a hierarchy, similar to that proposed by Maslow (1968) in which basic needs must be met first before higher needs can be considered. It can be interpreted

that the nurses' concerns were valid and appropriate, because to be able to cope with stress, the parents would benefit from having their own basic needs met.

The nurses in the present study described some parental stresses that they perceived were related to the level of support parents received from PICU staff. Haines, Perger, and Nagy's (1995) findings were that staff may have overlooked the needs of the parents of the non-intubated, less sick children. In the present study, the nurses described some parental behaviour as being inappropriate, when their child was not as sick as another in the Unit. The nurses appeared to perceive that the parents therefore had less stressors, and may have provided less support.

Shields-Poe and Pinelli (1997), and Miles and Carter (1982), found that a high parental stress score was associated with how sick the parent perceived their baby to be. In the present study, it was identified that the parents were always aware that their child could die. However, Chris indicated staff could trivialise the PICU admission, for example 'its just croup' (Chris 82), when, irrespective of the child's condition, because of the fact that the child was in the PICU, the parents needed a great deal of support. It may be true that nurses could underestimate the stress level of the parents, by making their own judgements about the amount of parental stress. Chris advised upon the need to see it from the parents' perspective. The need for an individualised approach is further supported by Shields-Poe and Pinelli's (1997) findings.

The interpretation that the level of parental support provided by nurses is related to the child's severity of illness, is supported by Tomlinson, Kirschbaum, Tomczyk, and Peterson (1993). It was suggested that the parent of the sicker child received more attention from more skilled and experienced nurses assigned to the patient. In this study, similarly, the nurses interviewed were experienced and skillful (clinical practice level of specialist) and identified that they usually cared for the sickest patients in the Unit. Both

the parents' of the sickest children and the children themselves were then receiving the best nursing care. The implication is that parents of children considered by staff to be less sick, may need as much support as the parents of very sick children.

Nurses' perception of Oncology parents as challenging

In describing extra reasons for parental stress, the nurses in the present study identified the stressors experienced by parents whose children had a chronic disease such as cancer. These oncology parents were identified as more of a challenge to support, and were perceived to find the PIC environment more stressful, which is supported in the literature (Knox and Hayes, 1983; Tomlinson, Kirschbaum, Tomczyk, and Peterson, 1993). These parents, already stressed by their child's life threatening illness, in addition, had to face all of the stressors related to their child's admission to the PICU. Considering their stress factors, it is then, not surprising that these parents may appear to be demanding and more difficult to support.

In this study, the nurses' perceptions of parental stress guided their strategies and behaviours. Underestimating the degree of stress may have had negative effects on nurse-parent interactions. The nurses reported that there was less rapport and a sense of discomfort in relationships with oncology parents. It may be that the parents were experiencing more stress than identified, including stress related to their confusion about the parental role in PICU, which will be discussed later in this discussion.

Self

King (1981), described the concept of self in relation to nursing in that self awareness helps one become a sensitive human being who is comfortable with self and with relationships with others. The findings of this study indicated that the nurses

endeavoured to influence the parents' perceptions of themselves as nurses to achieve the goal of establishing rapport with the parents. Hannah described how parents could relate to nurses if they knew that they had children of their own. This could be because they perceived those nurses could better understand their experience of having a child in PICU and resulted in 'connectedness' (Darbyshire, 1994). Perhaps nurses who had children of their own were able to more effectively put themselves in the parents' situation and show empathy. In this study, Harry talked about being a friend to the parents, going beyond the clinical, professional relationship to achieve rapport. Darbyshire (1994) also found that parents appreciated nurses revealing some personal details about themselves as it showed the human side of the professional nurse.

The nurses identified that they felt more comfortable in a relationship with parents whose culture was not unlike their own. It may be that families of different cultural backgrounds from the nursing staff, do not fully have their needs met. There may be an opportunity to further develop the role of PIC nursing in supporting culturally different families. Chris described how it could be difficult for some nurses to develop rapport with parents whose social background differed greatly from their own. This finding further adds to the above discussion, that the nurse must be 'on the same wavelength' as the parents for rapport to occur.

In this study, the nurses also spoke about the difficulty they experienced in caring for the parents of children who had been injured by a family member. Child abuse was viewed as abhorrent and the nurses had to work hard to appear impartial and non-judgemental. The nurses were less open, even putting on a performance or act to develop rapport with the parents. The nurses were aware that their true feelings would prevent the development of rapport. They privately dealt with their feelings, so as to appear supportive to the family. The nurses described interacting with parents as both their professional self

and personal self. The relationship was less open when the nurses' personal feelings conflicted with their role of supporting the family. Although not discussed, this may have impacted on the already stressed parents.

As Kate indicated, there was a pressure to perform every minute of the shift if the parents were present, "it's hard to be happy and cheery all the time" (Kate 186-188).

Within the culture of the PICU, there was also an expectation that a nurse could cope and deal with any situation. When the child's needs were a priority, it may be more appropriate to delegate the care of the parents to someone else. During critical periods in the stabilisation of the child, the needs of parents have been reported as being considered insignificant by nurses (Scott, 1998). Boardman (1995) suggested that in the NICU there may be a feeling of competition between team members. The PICU nurses in the present study did not identify this, but it may have been the nurses' self expectations, or the influence of the PICU culture that resulted in the nurses being reluctant to ask for help.

The use of humour was reported by the nurses in this study to be a coping and stress reducing mechanism for staff. In the literature, parents have perceived this behaviour as being uncaring and being inappropriate (Miles and Carter, 1982). Nurses must be careful only to use this stress relieving technique if parents are not present.

Body image

King (1981), defined body image as a person's perception of their own body, others' reactions to his appearance, and is a result of others' reactions to self. In the context of this study, the child's appearance is discussed as being synonymous with the body image of the parents. The shock of the different appearance of the child in the PICU has been identified as a source of parental stress (Miles and Carter, 1982; Shields-Poe and Pinelli, 1997).

The nurses in this study described minimising this stress by using photos and providing information about the appearance of the child, to prepare parents and family for what to expect, prior to seeing the child. Pre - admission visits (Griffin, Wishba, and Kavanaugh, 1998; Shields-Poe and Pinelli, 1997) were also discussed by the nurses in this study and perceived to be of value when logistically possible, although the organisational needs of the Unit and ward meant that this couldn't always occur. However, it is worth considering whether parental visits to the critical care environments enhance parental adaptation, thus reducing stress or whether the exposure increases anxieties (Etzler, 1984). The nurses also talked about paying attention to making the child look nice, such as putting on booties and a nappy, thereby demonstrating an awareness of the importance of the child's appearance to the parents.

The nurses also reported encouraging the practice of displaying photos of the child when healthy at the bedside for the benefit of the parents and themselves. Macnab, Emerton-Downey, Phillips and Susak (1997) suggested that the practice of displaying photos provided an opportunity for staff to communicate more fully with parents, who may not be able to verbalise their wish for the staff to strive harder in the care of their child. The findings of the Macnab, Emerton-Downey, Phillips and Susak (1997) study had been discussed by one nurse (Alice) in this study, during an interview. However, it is not clear that the other nurses in the present study were aware of the possible meaning inferred from the practice. The nurses in this study described how photos helped them identify with the child and develop rapport with the parents. Although Hannah indicated that there could be more meaning attached to the practice "it may be it is that they want you to see what their child is like... here is my beautiful baby" (Hannah 176), the additional value of the practice as an opportunity to communicate with parents was not identified. It may be that

the nurses took this opportunity without being consciously aware of it, or that the opportunity was being missed.

Space

The nurses in this study identified that there was not much privacy for parents at the bedside. This was because there was the need for close observation of the critically ill child. The lack of personal space can be considered from both the parents' and the nurses' perspectives. Whilst the parents were 'parenting in public' (Darbyshire, 1994), the nurses also performed continuously in the presence of the parents. Nurses reported the issues of privacy and confidentiality as parental stressors, and there were some opposing views about breaching patient confidentiality. Considering the unique environment that exists for patients and their parents, the pragmatic approach identified in the findings would seem the best solution to the difficult professional problem.

Time

King (1981) defined time as the duration between the occurrence of one event and the occurrence of another event. The nurses in this study talked about not having enough time to care for the family as well as the sick child. The lack of time impacted on the nurses' perceived ability to develop rapport with the parents and was less satisfactory for the nurses. Also identified was the need to acknowledge when it was appropriate to delegate some tasks. The specialist nurses appeared to be able to do more than the less experienced nurse, such as talking to parents whilst simultaneously providing physical care to the child. The specialist nurse was also able to perform tasks more proficiently than a less experienced nurse and so had more time to support the parents. Darbyshire (1994) found that parents perceived that some nurses, despite being busy, could still show caring.

Behaviours such as having an unhurried approach, and being warm and friendly could still be displayed during busy periods. Caring behaviours are further discussed under the heading of Transaction: development of rapport. It may be that the nurses' perception of not having enough time to support parents was not accurate, and that they were displaying caring behaviours. There were, in fact behaviours that could enhance the development of rapport without dedicating time solely to the purpose.

The nurse - parent relationship could be uncomfortable for both parties if rapport had not been developed. Under these circumstances, the nurse who was at the bedside for the duration of the shift did not enjoy the parents' continual presence at the bedside. In this situation, time was perceived to be moving slowly. The mutual presence of the nurse and parents at the bedside for long periods of time could exacerbate stress for parents if rapport had not been achieved, and the atmosphere was uncomfortable.

Interpersonal systems

King (1981) identified several concepts which she believed are essential to understand interpersonal systems. Findings related to interpersonal relationships are discussed under the following headings: communication, interaction, transaction, role and stress.

Communication

It is impossible to separate verbal and nonverbal communication, as both aspects of communication must be congruent and send the same message. King (1981) described some barriers to communication as being an inability to listen due to personal or environmental interferences.

Personal interferences can be considered in terms of the nurses' own values/judgement. As discussed earlier, the nurses in this study talked about the difficulty

they experienced when caring for the parents of children who had suffered non-accidental injuries. The approach to communicating with the family was then to consciously display impartiality and work hard to be supportive.

An identified environmental barrier to communication was if the family did not speak English. Most of the nurses perceived that these families missed out on much support and information. Visual imagery such as drawings was used to explain concepts to parents whether or not they understood English. Non verbal communication such as body language, demonstration, facial expression and touch were behaviours described by the nurses to support non-English speaking parents. Nonverbal communication behaviours included promoting an atmosphere that everything was under control and calmness. If nurses and families were of very different social or cultural backgrounds, it could be more difficult to establish rapport, and it was acknowledged that some nonverbal communication behaviours such as touching could be inappropriate for some cultures. The nurses described the frustration they experienced because they felt unable to adequately support non-English speaking families.

The nurses played an interpreting role between medical staff and parents. Miles (1979) and Wereszczak, Miles, and Holditch-Davis' (1997) findings support the findings in this study, where the nurses described interpreting the information provided by medical staff, using simpler terms, repeating information and clarifying meanings. The language level was chosen to be appropriate to the individual parents' understanding. Although medical staff informed parents about prognosis and diagnosis, the nurses' role was to ensure that the parents understood the information. This included speaking to medical staff on behalf of parents to verbalise parents' concerns and clarify issues.

The nurses also prepared parents to receive bad news; "it is possible your child could die", and good news; "your child may be transferred to the ward tomorrow". There

was a clearly a boundary beyond which the nurse did not step in regard to revealing information. Even if the nurse knew information about the child, it was not the nurses' role, for example, to inform parents about a diagnostic test result. The delineation of roles was maintained, despite the nurses describing the junior medical staff's sometimes poor communication techniques and lack of rapport with the parents.

Interaction

King (1981) described interactions as the acts of two or more persons in mutual presence. Purposeful interactions require openness, mutual agreement, an attitude of warmth, caring, liking, interest and respect. All of these behaviours were described by the nurses or were interpreted from the data. In this study, the nurses described the perceived barriers to reducing parental stress if rapport had not developed. It can be interpreted that the factors hindering successful nurse-parent relationships were related to the quality and nature of interactions.

The nurses described the challenge of dealing with 'dysfunctional' or 'difficult' parents. Groves and Beresin (1998) described the social psychology of 'toxic' interactions in the hospital revolving around patients and their families as 'foreign' members entering an established group, such as the PICU staff. The circumstances of having a child in the PICU sometimes brought together parents who were already estranged or separated and now stressed by the child's critical illness. The nurses in this study described several examples of 'difficult' parents who could be categorised as either difficult because of the current crisis, or difficult regardless of what is going on. This concurs with Groves and Beresin's (1998) findings.

In this study, the nurses talked about the challenges and their strategies to deal with difficult parents. Groves and Beresin (1998), indicated that dysfunctional families created

crises even in the most reasonable situations, displaying uncooperative, irrational and irritating behaviour throughout the hospitalisation, never settling into a working alliance with the caregiving team. In the present study, several examples of this type of parent can be identified, for example “the mother from hell”(Hannah 111). It is interesting to note that the nurses acknowledged they did not have any counselling training or preparation to deal with this type of parent. It would appear to be beneficial to parents and nurses if nurses were more formally prepared to manage such complex interactions.

The nurses in this study identified that some parents who were difficult to support were not together as a couple. They also identified that some family dynamics were a source of parental stress and there was the need to support each parent individually and act as mediator when necessary. Although the nurses did not articulate the different needs of parents as described in the literature (Griffin et al, 1998; Meyer, Snelling, and Myren-Manbeck, 1998; Shields-Poe, and Pinelli, 1997), the described behaviours indicated that relationships with some parents involved providing much more support for some and less for others. It may be that the specialist nurses responded to parental cues, and provided more support when needed, and less when parental support needs were being met by spouse, family and friends.

Shields- Poe and Pinelli’s (1997) findings suggest that some parents experience higher stress levels irrespective of their interactions with staff. In this study, some difficult to deal with parents were identified as being ‘dysfunctional’ or having ‘difficult’ personalities; caring for such parents was described as stressful by the nurses. Dealing with highly stressed parents requiring the more highly developed communication skills of the specialist level nurses. Despite the required skills being described in this study, there were several examples when a positive or therapeutic nurse-parent relationship never developed. The problem left the nurses with feelings of inadequacy and frustration.

The situation when a parent was 'difficult' because of the contribution made by the nurse was acknowledged, but was thought to be unusual. The nurses talked about not taking it personally when they didn't get on with some parents. Of course, it is only human nature that everyone won't get on with everyone. It would be a recipe for disaster not to recognise when individuals do not have the right 'chemistry.' Interactions between parents and staff can be complex and difficult when individuals do get on and have good rapport, and so matching up the right nurse to parents appears to be crucial for the experience to be most beneficial for parents as well as satisfying for the nurse.

Transaction : Development of Rapport

The nurses' goal directed behaviours (King, 1981) were to reduce parental stress. As discussed earlier, to achieve this goal a fundamental step was to develop rapport with the parents. If rapport was not achieved, the nurses perceived that they could not reduce parental stress. The relationship was also reported to be less satisfying for the nurses. Many of the challenges to being able to reduce parental stress were related to barriers to achieving rapport.

Non-caring nursing behaviours were reported by Wereszczak, Miles, and Holditch-Davis (1997). Such behaviours provoked more parental stress. In this study, the nurses expressed concern when they were busy providing physical care to the child, and felt unable to adequately support parents. The specialist level nurse was more able to provide care to the child and talk to the parents at the same time. The specialist nurse, whilst talking and doing, was displaying caring behaviours. Both nonverbal as well as verbal communication demonstrated caring behaviours.

The findings of Burfitt, Greiner, Miers, Kinney, and Branyon (1993), and Andrews (1998) support the descriptions of nursing behaviours in the present study, in particular,

those behaviours used to develop rapport. The nurses were aware that the parents felt more secure when the nurse was continually present at the bedside, and identified that confident clinical behaviours conveyed reassurance to the parents. To demonstrate caring, behaviours such as paying attention to detail, making the child look nice, going beyond the basics by being a friend, and being considerate and kind, were described.

Healing behaviours as energy freeing acts (Burfitt, Greiner, Miers, Kinney, and Branyon, 1993) were demonstrated when the nurses described protecting parents from other stresses such as paying for parking, and restricting visiting by other family and friends. Life saving acts (Burfitt, Greiner, Miers, Kinney, and Branyon, 1993) were not referred to explicitly, although the more complex, sick child was cared for by more experienced nurses who could perform the physical care expertly as well as support the parents. The nurses demonstrated mutuality by putting themselves in the parents' situation, to feel empathy, and caring for the needs of the whole family. Burfitt, Greiner, Miers, Kinney, and Branyon (1993) further suggest that a conscious intent on the part of the nurse to be caring is necessary for caring to occur. The present study findings are supported by Burfitt, Greiner, Miers, Kinney, and Branyon's (1993) findings, the assumption being that the stress experience of parents must be very similar to adult patients' stress.

Role

The concept of role is relevant in each of the interacting systems; personal, interpersonal and social. King (1981) included it under interpersonal systems because the parent and nurse roles identify the interactive relationships and affect communication.

At home, the parents' role was to have complete responsibility for their child. If their child was in a hospital ward, the parents' role may be comforting their child, as well as mothering tasks such as feeding and bathing. The parents' role in the PICU was

different again. The sick child may be unaware of their presence, and so parents' physical participation in care of their child was for the benefit of the parents. The nurses in this study described the extra time involved to facilitate parents to carry out mothering tasks. The nurses described that there was little care that parents could provide for their child, but recognised the importance of parental presence and involvement with the child. They expressed that it was their responsibility to act as parent advocate and facilitate parents being with their child as much as possible.

In contrast to Darbyshire's findings (1994), the nurses in this study did value the parents' presence at the bedside. The nurses saw their role as guiding parents, particularly during the initial time in the PICU when parents had reduced ability to make decisions and think clearly. Although the nurses supported the role of parents in making decisions, such as about their other children visiting the sick child, they expressed their own views that it was beneficial to involve the siblings. They talked about not overstepping their role although they strongly encouraged parents to include the siblings in visiting. The nurses were also careful to provide information to the siblings consistent with the family's beliefs about life and death and understanding of the sick child's condition.

The parents' role as decision makers for their child was severely diminished in the PICU. The nurses identified this, supporting parental decision making in areas of parenting, which they felt was not the nurses' domain. The nurses took the same approach in regard to feuding families. They felt that it was not their domain, only intervening if necessary in the interests of the sick child.

In the present study, the nurses talked about being flexible to accommodate, as far as they could, the wishes of parents. This was explained in terms of basing their style of care on principles rather than protocol or routine. The nurses referred to being flexible on mothering issues but were less flexible on technical issues. Darbyshire (1994) described

how nurses categorised care into basic mothering and the technical work, which was considered to be the domain of the nurses. In Darbyshire's (1994) study, nurses did not discuss with parents their expectations of the parental role in hospital. The parents had to find out for themselves. Griffin, Wishba, and Kavanaugh (1998) similarly reported that parents of preterm infants were distressed by not having information about the roles of NICU staff.

In the present study, the nurses did not describe either negotiating with the parents or explaining their role or what the parental role was expected to be. The stressors experienced by parents of chronically hospitalised children such as oncology parents have been discussed earlier. It appeared to be assumed by the PICU staff that, because the child was now in the PICU, the parent role would be to stand back and let the PICU staff take over the total care of their child. Additional parental stress may have been caused by uncertainty about their role in the PICU. The introduction of a suitable model of care (Curley, 1988; Melnyk, Alpert-Gillis, Hensel, Cable-Beiling, and Rubenstein, 1997) to guide Australian PIC nurses' care of the family may reduce some of the stresses caused by the parents' confusion about their role in the PICU.

Stress

Whilst both parents and nurses experience stress in the PICU, under this heading of stress, the qualities of the nurse to manage the stresses are discussed. Parental stresses have been discussed in Personal Systems as the nurses' perceptions of parental stress.

Nurse qualities

Nursing stresses such as performing in front of the parents, and dealing with difficult parents have been discussed earlier. The nurses in this study also talked of

carefully allocating the most appropriate nurse to care for the difficult family or family of a dying child. It would be inappropriate and not in the parents' or nurse's best interest to be cared for by a nurse who didn't have the ability to support the family. Sensitivity, empathy and skill in interpersonal communication were recognised qualities in some nurses.

Darbyshire's (1994) findings that parents viewed professional and personal qualities of a nurse to be inseparable support this study's similar findings. The more stressful nursing roles were reserved for those experienced specialist nurses who could most effectively deal with the situation. This finding highlights that there are qualities of the PIC nurse that are much more than technical and clinical expertise. These are qualities or abilities that some nurses had, whilst others did not. The challenge for PIC nursing is how to promote and develop these skills.

Feedback / Evaluation

In King's process of human interaction, feedback is an important part of the model, which results in linking the continuous process of interaction (1981, p. 61). King did not actually discuss this link in her Theory for Nursing (1981). In this study, feedback indicating the parents' responses to the nurses' behaviours, was an essential aspect of the nurse-parent relationship. The nursing goal of the nurse-parent interaction was to reduce parental stress, by first achieving rapport. The nurses reported receiving indirect and direct feedback from parents. When rapport had developed between the nurse and parents, this was interpreted as positive feedback. Parental cues were important sources of feedback to guide nursing behaviours. These cues could be nonverbal such as more relaxed body language, and eye contact or verbal, when parents began to ask questions, and were able to share a joke.

Whilst the nurses reported several examples of positive feedback from parents, there were fewer examples of negative feedback. This concurred with Boyce, Carreiro and Nolte (1998). Considering the PICU environment and the vulnerable situation in which the parents are placed, it is perhaps not surprising that there was little negative feedback. After all, most parents had not had that experience before, did not have expectations about how staff should perform, and often had little recall about the initial time spent in the PICU. The nurses however did value feedback, both from parents and staff. Although there was little formal feedback provided by other nurses, it was recognised, amongst staff, that some nurses were very good at supporting families.

Social system - the PICU culture

King (1981) defined the concepts of organisation, power and authority, status and decision making as characteristics of social systems having relevance for nursing. The findings related to the social system of the PICU culture are discussed under these headings.

Organisation

The PICU is a little world within the hospital organisation, with its own rules, behaviours, habits, and ways of doing things. Some of the rules of the PICU environment, explicit and implicit, were identified by the nurses and in the literature as potential and actual sources of stress for parents.

Parental presence and participation

Parental presence with their child has repeatedly been found to be a primary parental need (Curley, 1996; Farrell, 1989; McNab, Emerton-Downey, Phillips, and Susak., 1997; Neill, 1996; Noyes, 1999). Yet, the parents' separation from their child

during procedures or handover remained part of the Unit culture. Parent free time was acknowledged to be a coping mechanism for the staff; to be able to care for the child without having to always care for the parents at the same time. Parents were encouraged to go to sleep at night, which was described as being for the parents' benefit, but also nightshift was a preferred parent free time for the nurses. Although expressed lightly during her interview, Hannah said "the ideal patient is paralysed, ventilated with no relatives"(85-86). The comment highlighted that even for the most experienced nurse, continuously providing support to parents at the same time as caring for the critically ill child was demanding.

The nurses in this study expressed that they believed parents should be able to be with their child in the PICU. They thought that by witnessing some procedures or during resuscitation, parents would be distressed, but it was the wishes of the medical staff rather than nursing staff that prevented parents being there. However, there were also several circumstances as described above, when the nurses would prefer parents not to be present. There was acknowledgement that caring for the parents at this time could be extremely demanding. These findings are supported by Callery and Smith (1991) and Maxton (1997). Maxton (1997), also found that staff wanted to protect parents from stressful events such as resuscitation, whilst in a similar study by Jarvis (1998), staff felt inadequately trained to support parents during resuscitation. More training for doctors and nurses to support parents during this stressful time may result in a change in attitude.

Long term families

Long term families temporarily became part of the PICU culture themselves. Darbyshire (1994) described how the demarcation of parental and nursing roles became blurred when patients became long term. It became less obvious that they were guests

within the nurses' domain, although this change was less noticeable in the PICU environment because of the child's condition. The PICU remained different from the ward situation, because the parents usually did not take over the care of their child.

The nurses identified that the PICU became the family's home and required a flexible nursing approach to meet their needs. These parents presented a challenge to the nurses because of the long-term relationship with the staff that was not the norm for the culture, when most patients generally stayed a few days. The challenge was to maintain rapport with parents who were described as 'difficult', and the need to be "much more flexible and accepting of what the parents want" (Sam 80). As discussed earlier, very little negative feedback was received from parents, most of whose stay in the PICU were only a few days. The nurses may have found these long-term parents more difficult to support because they were not the 'run of the mill'. It may be that there were more interpersonal communication problems than the nurses recognised. As parents became more accustomed to, and less stressed by the environment, staff communication and behaviour perhaps became much more important determinants of parental stress (Curley, 1988; Meyer, Snelling, and Manbeck, 1998). Perhaps the short stay parents didn't have the same concerns or didn't bother to complain, but the long-term parents were more 'difficult' because they felt able to voice their concerns and challenge the culture.

Although providing consistency of care was identified as being beneficial to long-term and short stay parents by the nurses in this study and in the literature (Meyer, Snelling, and Myren-Manbeck, 1998), this appeared to not always be possible because of the organisational needs of the Unit. Rostering arrangements and the seniority of the nurses necessitated them to coordinate, float and look after the sickest patients rather than being able to continue caring for the same patient and family for several days. Although

recognised as being the ideal, the organisational or cultural demands of the Unit took precedence over what might be best for the parents.

Authority and power

The hospital ward provided a context in which the nurse had a more powerful position than the parent. Being an insider or host explains the nurses' assumption of authority (Rowe, 1996). There was additional parental stress of being a guest in someone else's workplace, where the nurses had a greater degree of control of territory and information (Callery and Smith, 1991). There was an even more exaggerated imbalance of power within the PICU culture, which relied so much on technical expertise, where parents had little or no knowledge. Within the culture, there were rules with which parents were expected to comply. Some of these rules are discussed below.

Whilst the intercom system clearly has a valid purpose in protecting the privacy of patients, the nurses spoke strongly about parents not adhering to the policy. The nurses reported a lack of consistency in the application of rules such as restricting the number of visitors, described as being practiced in all the Units, which they acknowledged could be an additional source of stress for parents. The rules also changed when a child was dying, and the child was often moved into a single room: The parents were asked if they would like to move for more privacy and free visiting. The nurses found the care of the family when a child was dying to be stressful and challenging, yet provided many examples of sensitive, thoughtful and anticipatory nursing behaviours. It appeared that the attitude of the staff changed when a child was dying, when under this circumstance, the focus changed from child and parents to the whole family. Perhaps this approach could be extended to all families in the PICU.

Recurring themes in Maxton's (1997) study of staff's attitudes towards parental presence in PICU were power and control. Maxton found that it was the more experienced staff in that study who expressed concern about parents' ability to cope with distressing sights, which contrasted with Callery and Smith's (1991) findings which found that more experienced nurses were less rigid and had more respect for parents' decision making abilities. There were similar concerns expressed by the experienced nurses in this study, although paternalism, or doing what is thought to be best for parents appeared to be the motivation.

Status and Decision Making

In this study, there was an identified hierarchy in authority from medical staff, to nurses and finally to parents. For example, instead of being able to be with their child, parents were asked to leave for procedures because the doctor preferred it. The parents, in a vulnerable position, were not able to challenge this, and the nurses did not appear able to either. The nurses then tried to explain the reasoning in a positive manner to the parents. In Maxton's (1997), study, new guidelines were introduced in the PICU, that parents at all times had every right to be with their child. It was reported that the medical staff continued to express concern about this. It appears that the nurses in this study also readily accepted the medical model of care, and their behaviours in caring for the family were thus aimed at minimising some of these effects on the parents.

This hierarchy of decision-making changed as the focus of care changed when a child was dying. Parents were then encouraged to make decisions, such as under which circumstances and when the death would occur. It appeared that in the PICU, when the focus was to restore health, it was inappropriate for parents to be the decision makers. This was a specialised area where in fact the medical and nursing staff may know best and

parents had little choice but to agree to the treatment of their child. What is important is that nurses and doctors were aware of the parents' loss of control. Appropriate communication and caring behaviours in this study have illustrated how parents can be involved in the care of their child, and not left to feel as outsiders.

Strengths and significance of this study

In this chapter, some issues raised have been addressed in the discussion using King's conceptual framework to explain the complex interaction of nurse, parent and the environment, the PICU culture. The study has revealed much about how PIC nurses perceived their role and relationship with parents within the PICU environment. It is clear that the nurses' role is demanding, calling upon individuals to examine personal beliefs and values, recognise their own limitations, bias and personal mechanisms for coping, and to sometimes go as far as to put on 'a performance' in order to be able to support parents.

The findings highlight that to be able to support parents the nurse must demonstrate clinical expertise and much more. Also required are sensitivity, empathy, and highly developed skills in interpersonal communication. The nurse must be able to continually evaluate the relationship, picking up and responding to subtle cues and feedback from parents' behaviour, being also aware that his/her own behaviour and the environment impact on the experience of the parent. Whilst the specialist PIC nurses are to be commended on their roles in supporting parents to reduce their stress, there were some findings, such as the organisational rules and hierarchy of power, which reveal practices that could be examined to improve the experience for parents and nurses.

Limitations

The study had a number of limitations related to its design and methodology. The informants self identified their specialist level of practice. Given this limitation, the rich data that resulted from the study have supported the validity of their self-assessment. The use of interviews rather than observation of nursing behaviours resulted in findings dependent on recalled rather than actual observed behaviours. Again the richness of the data has supported the validity of the methodology. Finally this study has revealed nursing behaviours from the perspective of the nurses without confirming their effectiveness from the perspective of the parents. There is an opportunity to pursue this area of further research.

Recommendations

The findings of the study have shown that to be able to support parents and reduce their stress, nurses must practice advanced interpersonal communication skills in combination with clinical and technical expertise. Some practices that appeared to result in increased parental stress have also been revealed. To assist novice and less experienced nurses to be aware of the behaviours that reduce and exacerbate parental stress, there are recommendations to be incorporated into the educational and philosophical preparation for nurses to care for children and their families, the ongoing professional development programmes for PIC nurses, and the role modelling and leadership shown by PIC nurses. In particular the following strategies are recommended:

Educational and philosophical preparation

Developing expertise and experience in interpersonal communication and counselling are important components for all professionals caring for children and their families. There should be more emphasis on this aspect of the PIC nurse's role in PIC

educational programmes. Adopting the philosophical approach of family centred care is fundamental to the preparation of PIC nurses.

Ongoing Professional Development

Whether inexperienced or more experienced, nurses should continue to promote the family centred care philosophy in the PICU. By ongoing evaluation and examination of practices, nurses may ensure they continue to ask parents what they want and take notice of the answers rather than assume to know, and focus on the family as a whole rather than considering the child's needs separately from those of the parents. The PICU nursing staff may consider the introduction of a model of care to guide nurses' care of the family. There is still the need to challenge the customary rules, practices and traditional hierarchy in the PICU to enable parents to be with their child if they want to be.

There is also a need for PIC nurses to acknowledge that their role is demanding and support each other to take time out or a break, and not to be reluctant to delegate or ask for assistance when there is too much to do and there is insufficient time to support the parents.

The role modelling and leadership demonstrated by PIC nurses

PIC nurses have a professional responsibility to promote the development of novice nurses in acquiring the skills to identify the subtle cues and feedback from parents' behaviour. There should be an increased emphasis on role playing, role modelling and mentoring novice nurses in more challenging situations, in particular dealing with difficult parents, families of child abuse, non-English speaking parents, culturally and socially different families, and supporting the family of the dying child.

Suggestions for future research

The study has raised a number of questions about PIC nurses, PIC culture and parental support that could form the basis of future research in this area. Future research may include investigations of the following topics:

- Evaluation of the effectiveness of nursing behaviours to reduce parental stress.
- Strategies to minimise nursing stress particularly in the areas of supporting parents of child abuse, families of a dying child, 'difficult' parents and parents' continual presence at the bedside.
- Explore the supportive role of PIC nurses with oncology parents, non-English speaking, long term and culturally and socially different families.
- Research into junior medical staff developing more advanced skills in interpersonal communication may also be of benefit.

Conclusion

The staff and the families whose children are critically ill only ever experience the culture within the PICU. PIC nurses, who are continually at the bedside, play an important role in assisting the parents to adapt to the environment, meeting the needs of parents and assisting parents to reduce their stress. This aspect of nursing care particularly presents a challenge for novice and less experienced PIC nurses.

The findings of the study have shown implications for all PIC nurses, and indicate the need to practice advanced interpersonal communication skills in combination with clinical and technical expertise. The PIC nurses' ability to quickly establish rapport during a stressful time in the parents' lives was crucial to be able to reduce their stress.

Consideration must also be given to those behaviours revealed that appeared to result in increased parental stress. Thus this study will be able to assist novice and less experienced

nurses be aware of the behaviours that reduce and exacerbate parental stress, and utilise the knowledge to improve their clinical practice.

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APPENDIX A.

Competency Standards For Specialist Critical Care Nurses (CACCN Inc., 1996).

Domain: Professional Practice.

Competency 1. Functions in accordance with legislative and common law affecting nursing practice

Competency 2. Protects the rights of individuals and groups

Competency 3. Demonstrates accountability for nursing practice

Competency 4. Demonstrates and contributes to effective, ethical decision making

Domain: Reflective Practice

Competency 5. Recognises own abilities and level of professional competence

Competency 6. Engages in and contributes to research-based practice

Domain: Enabling

Competency 7. Maintains a physical and psychosocial environment which promotes safety, security and optimal health

Competency 8. Acts to enhance the dignity and integrity of individuals and groups

Competency 9. Facilitates individuals and groups to make informed decisions

Competency 10. Employs the skills of effective communication to guide and achieve optimal outcomes

Competency 11. Effectively manages and coordinates the care of a variety of individuals and groups

Competency 12. Anticipates and plans for effective and efficient utilisation of resources

Competency 13. Manages therapeutic interventions and regimes

Domain: Clinical Problem Solving

Competency 14. Integrates comprehensive patient assessment and interpretive skills to achieve optimal patient care

Competency 15. Evaluates and responds effectively to changing situations

Competency 16. Develops and manages a plan of care to achieve predicted outcomes and considers implications for discharge

Domain: Teamwork

Competency 17. Collaborates with the health care team to achieve desired outcomes

Competency 18. Creates a supportive environment for nursing colleagues and other members of the health care team

Domain: Leadership

Competency 19. Acts to enhance the professional development of self and others

Competency 20. Demonstrates leadership qualities in relationships

APPENDIX B.

Attributes of specialist critical care nurses

Attributes of specialist level critical care nurses include:

- Consistently manages the sickest patient to industry standards
- Respected by peers and others
- Is a role model
- Utilises a sound knowledge base in application and integration of knowledge to practice
- Responds to a continually changing environment
- Utilises research in practice
- Supports less experienced staff
- Displays an awareness of the needs of the whole Unit
- Is professionally active
- Demonstrates effective communication skills
- Demonstrates a high level of assessment skills
- Interprets complex situations
- Acts as a coordinator of care (shift coordinator)

Taken from: (CACCN Inc., 1996, p. 7)

APPENDIX C.

The Organising Committee

4th Australian and New Zealand Paediatric and Neonatal Intensive Care Conference

4 August 1997

Dear Nursing Convenor

I work as Clinical Educator/ Clinical Nurse in the Paediatric Intensive Care Unit (PICU) at Princess Margaret Hospital, Western Australia and I am undertaking a Masters Degree in Nursing at Edith Cowan University, Western Australia.

The purpose of my research is to examine how specialist level Paediatric Intensive Care (PIC) nurses provide care for families of critically ill infants and children. The specialist level of practice is that defined by *CACCN Competency Standards for Specialist Critical Care Nurses (1996)*. I also wish to identify whether this aspect of specialist critical care nursing practice is adequately reflected in the Competency Standards. Thus my research is partly a validation study for the Competency Standards in the context of PIC nursing. I wish to interview 15 specialist PIC nurses to collect evidence of how families are cared for and supported in the PICU.

The assistance of the Organising Committee is requested so that I may access a sample of PIC nurses from each PICU in Australia. I wish to send an introduction letter and consent form to all the nursing registrants for the Paediatric and Neonatal Intensive Care Conference in Hobart. Selection criteria will be provided to assist in identification of potential participants in my research. Volunteer participants will be provided with information about how to contact me during the Conference so that a convenient date, time and venue for the interview can be arranged.

To be able to contact all nursing registrants for the Conference I will require a list of names and either place of work or home addresses at least 3 weeks prior to the Conference. In undertaking this research I am required to observe strict guidelines to preserve confidentiality and privacy of potential participants and I will adhere to those guidelines in regard to the safe disposal of the information.

I hope that the Organising Committee will be able to assist me with my request. If there are any questions or concerns I can be contacted on:

Tel

Email

My primary supervisor is Shirley Perry and she is happy to be contacted on :

Tel

Email

My second supervisor is Gavin Leslie who can be contacted at Royal Perth Hospital, Western Australia.

Thank you for your consideration

Fenella Gill

APPENDIX D.

Participants Consent Form

Paediatric Intensive Care Nursing Care of the Family

Dear colleague

I am undertaking a Masters Degree in the School of Nursing at Edith Cowan University, Perth WA and request your participation in my research.

The purpose of my study is to expand nursing knowledge about how specialist PIC nurses provide care for families of critically ill infants and children. You will be familiar with the national research study which resulted in *The Competency Standards for Specialist Critical Care Nurses* (The Confederation of Australian Critical Care Nurses Inc. (CACCN Inc.), 1996). My study intends to examine the Competency Standards in the context of specialist PIC nursing in caring for the family. The study intends to identify whether the Competency Standards adequately reflect this important aspect of specialist PIC practice.

I hope to take advantage of the gathering of PIC nurses from each state in Australia for the 4th Paediatric and Neonatal Intensive Care Conference in Hobart, October 1997 to make arrangements to interview some specialist PIC nurses. The organising committee of this conference provided me with a list of registrants who may be potential participants for my study.

I wish to interview you if you are currently working in PICU and meet the following criteria in your clinical practice:

- have at least 2 years experience in PIC and are professionally active
- perform at the level of co ordinator of care (shift coordinator)
- support less experienced staff
- utilise a sound knowledge base in application and integration of knowledge to practice
- are able to interpret complex situations

- can consistently manage the sickest patients in the Unit (taken from: CACCN Inc., 1996).

If you wish to participate in this study, and meet the above criteria, please complete the details requested below on this consent form and leave it in the designated box at the conference registration desk. I am staying at the Wrest Point Casino, Hobart, Tasmania from Tuesday 14 until Sunday 19 October if you wish to contact me otherwise once I have received your signed consent form I will ring you to discuss arranging a convenient interview date and time. I will be conducting interviews in Queensland, New South Wales, Victoria and South Australia during November.

If you are willing to participate in the study; prior to our interview please spend some time to reflect upon a significant event in clinical practice which you think typifies your specialist level performance in providing care and support of the family. During an audiotaped interview we will discuss your recollection and interpretation of the event in order to capture evidence of specialist PIC nurse behaviour. Please allow approximately one hour for the interview.

There are no known risks associated with the study, while there may be potential benefits for PIC nurses. If you have any further questions or concerns I can be contacted on 08

. My research supervisor is Shirley Perry who can be contacted on 08

Thank you for your cooperation.

Participants Consent Form

Paediatric Intensive Care Nursing Care of the Family

This is to certify that I have read and understood my involvement in the study in which the audiotaped data collected will be dealt with in a confidential manner and will not identify me. I understand that the tapes will be wiped clean once the interviews have been transcribed and the transcripts will be kept in a locked cabinet. I freely chose to participate in the study and understand I can withdraw at any time without penalty.

Name: _____ Signature: _____

Contact tel no in

Hobart: _____ Date: _____

APPENDIX E.

Interview Guide

The following type of questions will form a broad outline for the interview. The interview will allow the researcher the opportunity to pose questions in response to cues from the informant. The interview guide does not necessarily determine the order of the conversation (Minichiello et al., 1995). The informants will be asked to relate one or more examples of scenarios when they cared for the family in order to minimise parental stress.

Please think back to a scenario during your clinical practice where you believe you provided care to the family (critically ill infant or child and parents) in order to minimise/ reduce (deal with) parental stress.

Can you explain the context of the scenario?

Can you give me a description of the event?

What were your considerations at this time?

What were your goals in caring for the family?

What strategies did you implement to achieve the goals?

What were barriers to achieving the goals?

How did you evaluate the effectiveness of the interventions?