“Sharing and Surviving the Resuscitation”

Parental Presence During Resuscitation of a Child in PICU: The Experiences of Parents and Nurses

Fiona J C Maxton

Thesis submitted for the Degree of Doctor of Philosophy

The University of Western Sydney, 2005

© Fiona Maxton 2005
Statement of Authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

....................................................
(Signature of candidate)
Acknowledgments

In acknowledgment of their generous support, contributions and wisdom, many thanks are expressed to:

- Associate Professor Louise O’Brien, Dr Sue Nagy and Dr Anne Adams whose intellectual support and supervision fostered this study;
- my first nurse tutor, Professor Philip Darbyshire, who remains a mentor to this day. I am grateful to him for his ongoing inspiration and encouragement – and his call to “question everything”;
- to all the parents of the children – all of whom suffered but survived during their child’s critical illness and freely gave their stories. I am eternally grateful and forever in awe.
- the nursing and medical staff of the Paediatric Intensive Care Unit at the Children’s Hospital, Westmead, Sydney, Australia who readily supported this project, and to those nurses who offered their experiences;
- The Children’s Hospital, Westmead for financial support in the form of a 3 year scholarship from PICU and the 2003 John Yu Scholarship;
- to the New South Wales Nurses’ Association for additional financial support;
- finally to my family and friends who supported me and put up with me through, at times, very trying periods. In particular, my mum Dorothy, my husband Steve and my adorable daughter Sophie. A special thank you also to my good friend Val Wilson who continued to inspire me when I was down, made me realise this was a study worth pursuing and who believed “we can make a difference”.

Table of Contents

ABSTRACT .......................................................................................................................................... 8

CHAPTER 1: INTRODUCTION ................................................................. ERROR! BOOKMARK NOT DEFINED.

1.1. INTRODUCTION .................................................................................. ERROR! BOOKMARK NOT DEFINED.
1.2. BACKGROUND .................................................................................. ERROR! BOOKMARK NOT DEFINED.
1.3. AIM OF THE STUDY .......................................................................... ERROR! BOOKMARK NOT DEFINED.
1.4. SIGNIFICANCE OF THE STUDY ......................................................... ERROR! BOOKMARK NOT DEFINED.
1.5. DEFINITION OF RESUSCITATION IN THE PAEDIATRIC INTENSIVE CARE UNIT ERROR! BOOKMARK NOT DEFINED.
1.6. STRUCTURE OF THE THESIS .......................................................... ERROR! BOOKMARK NOT DEFINED.

CHAPTER 2: PARENTS AND PARTICIPATION - A LITERATURE REVIEW ........ ERROR!
BOOKMARK NOT DEFINED.

2.1. INTRODUCTION .................................................................................. ERROR! BOOKMARK NOT DEFINED.
2.2. THE EVOLUTION OF PAEDIATRIC NURSING AND PARTNERSHIP IN CARE ERROR! BOOKMARK NOT DEFINED.

2.2.1. Unequal power relationship............................................................... Error! Bookmark not defined.
2.2.2. Role of parents and nurses in a partnership model......................... Error! Bookmark not defined.
2.2.3. Lack of formal negotiation................................................................. Error! Bookmark not defined.
2.2.4. Parenting in public ........................................................................... Error! Bookmark not defined.
2.2.5. Parental participation during invasive procedures ......................... Error! Bookmark not defined.

2.3. PARENTAL STRESS AND COPING IN PICU ........................................... ERROR! BOOKMARK NOT DEFINED.

2.3.1. Stress and coping ............................................................................. Error! Bookmark not defined.
2.3.2. Parental stressors ............................................................................ Error! Bookmark not defined.
2.3.3. Meeting Parental Needs ................................................................. Error! Bookmark not defined.

2.4. PARENTAL PRESENCE DURING RESUSCITATION ......................... ERROR! BOOKMARK NOT DEFINED.

2.4.1. Relatives’ Views ............................................................................. Error! Bookmark not defined.
2.4.2. Health Professionals’ Views .............................................................. Error! Bookmark not defined.
2.4.3. Parental presence during resuscitation of a child in PICU . Error! Bookmark not defined.

2.5. CONCLUSION ..................................................................................... ERROR! BOOKMARK NOT DEFINED.

CHAPTER 3: PHENOMENOLOGICAL INQUIRY ...... ERROR! BOOKMARK NOT DEFINED.

3.1. INTRODUCTION .................................................................................. ERROR! BOOKMARK NOT DEFINED.
3.2. PHENOMENOLOGY: A PHILOSOPHICAL MOVEMENT ............. ERROR! BOOKMARK NOT DEFINED.

3.2.1. Husserl’s transcendental descriptive phenomenology.............. Error! Bookmark not defined.
3.2.2. Heidegger’s interpretive phenomenology ...................................... Error! Bookmark not defined.
3.2.3. Van Manen’s hermeneutic human science approach................. Error! Bookmark not defined.
CHAPTER 5: THE PARENTS’ EXPERIENCE OF RESUSCITATION IN PICU

BOOKMARK NOT DEFINED.

5.1. INTRODUCTION ................................................................. ERROR! BOOKMARK NOT DEFINED.
5.2. BEING ONLY FOR A CHILD .............................................. ERROR! BOOKMARK NOT DEFINED.
  5.2.1. Being there ............................................................... ERROR! BOOKMARK NOT DEFINED.
5.3. CARING FOR A CHILD .................................................... ERROR! BOOKMARK NOT DEFINED.
  5.3.1. Knowing the child ...................................................... ERROR! BOOKMARK NOT DEFINED.
  5.3.2. Advocating for a child ................................................. ERROR! BOOKMARK NOT DEFINED.
  5.3.3. Comforting a child ...................................................... ERROR! BOOKMARK NOT DEFINED.
  5.3.4. Being vigilant ............................................................ ERROR! BOOKMARK NOT DEFINED.
  5.3.5. Protecting a child ....................................................... ERROR! BOOKMARK NOT DEFINED.
  5.3.6. Letting a child down .................................................. ERROR! BOOKMARK NOT DEFINED.
  5.3.7. The ultimate betrayal ................................................ ERROR! BOOKMARK NOT DEFINED.
  5.3.8. SUMMARY ................................................................. ERROR! BOOKMARK NOT DEFINED.
5.4. MAKING SENSE OF A LIVING NIGHTMARE .......................... ERROR! BOOKMARK NOT DEFINED.
  5.4.1. Witnessing the resuscitation ....................................... ERROR! BOOKMARK NOT DEFINED.
  5.4.2. Understanding the resuscitation .................................. ERROR! BOOKMARK NOT DEFINED.
  5.4.3. Waiting for news ....................................................... ERROR! BOOKMARK NOT DEFINED.
  5.4.4. Imagining the resuscitation ....................................... ERROR! BOOKMARK NOT DEFINED.
  5.4.5. Finding a place ......................................................... ERROR! BOOKMARK NOT DEFINED.
  5.4.6. Hindering the resuscitation ....................................... ERROR! BOOKMARK NOT DEFINED.
  5.4.7. Parents as participants ............................................. ERROR! BOOKMARK NOT DEFINED.
  5.4.8. Summary ................................................................. ERROR! BOOKMARK NOT DEFINED.
CHAPTER 8: SUMMARY, DISCUSSION AND RECOMMENDATIONS

8.1. Introduction ..............................................................................
8.2. Summary of findings .............................................................
8.3. Discussion and meanings .....................................................
  8.3.1. Being there: The ontological sense of being a parent in the resuscitation..............................
  8.3.2. The Parents’ role .................................................................
  8.3.3. The nurses’ role .................................................................
  8.3.4. Connectedness .................................................................
8.4. Implications and recommendations .................................
  8.4.1. Implications for clinical practice and education ..........
  8.4.2. Strengths and limitations of the study ............................
  8.4.3. Implications for further research: more questions....
8.5. Concluding comments .......................................................}

APPENDIXES .................................................................

APPENDIX A: LETTER OF INTRODUCTION TO PARENTS WHOSE CHILD HAS DIED, GENERALLY SENT 3 MONTHS FOLLOWING CHILD’S DEATH IN PICU ........................................

APPENDIX B: SAMPLE SCRIPT FOR TELEPHONE RECRUITMENT FOR PARENTS WHOSE CHILD HAS DIED.

APPENDIX C: PARENTAL CONSENT FORM ................................

APPENDIX D: PARENT INFORMATION SHEET ..........................

APPENDIX E: NURSING CONSENT FORM ............................

APPENDIX F: NURSING PARTICIPANT INFORMATION SHEET ....

APPENDIX G: WRITTEN INFORMATION TO BE GIVEN TO PARENTS WHOSE CHILD HAS DIED AT TIME OF INTERVIEW ..................................................

REFERENCES .................................................................
Abstract

Parents’ presence and participation in their child’s care in the paediatric intensive care unit (PICU) is now commonplace. Despite parents expressing a deep need to be with their child particularly during periods of crisis, it is precisely at these times that they are often prevented from staying. The growing debate regarding family presence during a cardiopulmonary (CPR) resuscitation attempt continues to be controversial and conflicting. Current knowledge is mostly derived from quantitative studies conducted in the adult intensive care or emergency environments. The experiences of parents of children in the PICU, and the nurses caring for them are unknown.

Using van Manen’s hermeneutic phenomenological approach, this study describes the phenomenon of parental presence during resuscitation of a child in PICU for eight Australian parent couples and six nurses. Experiential descriptions, obtained in tape-recorded unstructured interviews were subjected to two layers of analysis. Thematic analysis provided the phenomenological description in seven themes. Four themes refer to the parents’ experience in Being only for a child; Making sense of a living nightmare; Maintaining hope: facing reality and Living in a relationship with staff. Three themes describe the nurses’ experience: Under the parents’ gaze; Walking in their shoes and Holding parents in mind. A second layer of hermeneutic analysis revealed parents’ and nurses’ collective experience to have their being in four elements of
the phenomenon. These elements are **Being in chaos; Struggling to connect; Being for another** and **Being complete.** The final description of the parents’ and nurses’ experience of parental presence during resuscitation in PICU as **Sharing and surviving the resuscitation** is drawn from the findings from each of these layers of meaning.

The findings from this study conclude that the parents’ inherent need to be with their child overrode their anxieties of the resuscitation scene, curbing their feelings of chaos. Parental presence however, was a complex and dynamic concept that required a new relationship between parents and nurses. While resuscitating under the parents’ gaze was emotionally challenging for nurses, a greater sense of fulfillment and connection was evident. Parents and nurses strove together to achieve the most successful outcome possible for the child and in doing so described the phenomenon as an experience of **Sharing and surviving the resuscitation.** Implications of this study include recommendations for improving staff knowledge and education, as well as practical interventions for enhanced support for both parents and nurses.
Chapter 1

Introduction

1.1. Introduction

Family centred care has become the guiding principle in the care of children in hospital. Since the publication of the Platt Report in the United Kingdom (UK) (Ministry of Health, 1959) supported the presence of parents when their children were in hospital, the trend towards greater parental involvement has resulted in the evolution of a partnership approach. Encouraging parents to live in with their sick child and to work in partnership with nurses is now widely accepted. However, while the principles of a partnership approach are espoused, the implementation has, in reality, been more difficult to achieve.

The difficulty in embracing the important parental role in the care of sick children in hospital is even more apparent in the critical care setting. Realistically, there is little that parents can physically do for their child in intensive care. However, a partnership approach does not merely concentrate on the physical tasks which parents can learn, but instead encompasses the underlying philosophy of the partnership model – that is that parents have a right to be with their child at all times, and contribute to decisions made on the care of their child. Researchers have frequently investigated the main stresses and needs for parents when a child is admitted to intensive care and meeting these needs is certainly addressed in much of the literature. One of the central needs is for parents to stay with their child and take part in some aspects of care whenever they wish.
However, it is at a time when a child is most critically ill, suffers a cardiac arrest and requires cardiopulmonary resuscitation that parents’ needs are often not met effectively. These are the times when the parents’ need to stay close to their child is frequently ignored. Furthermore, advances in retrieval and paediatric intensive care medicine have resulted in larger numbers of children with greater acuity surviving to admission to the intensive care unit. Therefore, it has become commonplace for critically ill children to suffer a cardiac arrest in the unit. Yet frequently, parents are still denied the opportunity to stay with their child at this time (MacLean, Guzzetta, White, Fontaine, Eichhorn, Meyers & Desy, 2003; Meyers, Eichhorn, Guzzetta, Clark, Klein, Taliaferro & Calvin, 2000).

Most previous research conducted, particularly in the adult environment, has been quantitative. These studies have questioned relatives, nurses or occasionally both about relatives’ presence during resuscitation. Such quantitative studies have provided limited insights into the nature of the experience for parents or nurses, with limited responses either in favour or opposed to the idea of relatives’ presence. The question of the experience of parental physical presence during resuscitation has remained unexplored. A clear understanding of what it is like to be a parent who is present or indeed absent during their child’s resuscitation, as well as the meaning for nurses is essential if we are to provide care that is congruent with family needs and wishes; a partnership approach.

The primary aim of this study was to deepen understanding of the experience of the phenomenon of parental presence during resuscitation in the paediatric intensive care unit (PICU). This investigation is concerned with an aspect of human existence and was
devised because a detailed and complete description of the human experience of parental presence was not available. An approach which satisfies the epistemological and ontological requirements for in-depth and insightful investigation of human experience has been selected. A phenomenological approach, which draws on the hermeneutic traditions has been used in this study. This thesis presents the findings of a hermeneutic phenomenological study that examines eight parents’ and six nurses’ experiences of parental presence during resuscitation in the PICU. This introductory chapter describes the background, purpose and significance of the study and provides an overview of the thesis.

1.2. Background

My earlier work for a masters degree critiquing the partnership model in the PICU and the development of an alternative series of conditions of practice, paved the way for the evolution of this thesis. For the past 15 years, I have worked as a clinical nurse in intensive care units in two major paediatric hospitals, both in Scotland and Australia. During these years, I was aware that during resuscitation of a child, our care of families was not always optimal. As I became more experienced in the area, I was frequently in a position where I was the person who would be with parents following a resuscitation attempt, whether the child had survived or died. Originally, in my unit, as in other centres, parents and other family members were not only discouraged, but actively prevented from being present during the resuscitation (Hanson & Strawser, 1992; Van der Woning, 1997). The reasons for this were vague, but it was felt that it would not benefit them to witness a resuscitation attempt. However, I believed, having been with
parents not at the bedside, that they became as distressed by not being with their child at the most critical time in their lives. Frequently, parents expressed that they waited outside the intensive care unit for an eternity, wondering what was happening to their child. Often, they would be escorted in only after resuscitation had ceased and their child had died. However, by 1995 changes to the unit’s policy stated that parents would not be asked to leave the unit at any time, including a cardiac arrest, unless the doctor felt it appropriate that they leave. It has now become the norm that parents are given the option to stay with their child during the resuscitation in the PICU setting for the current study, although this guideline continues to be questioned by some staff. At this time, other authors around the world were beginning to question the notion of preventing relatives from being with their loved one during resuscitation (Hanson & Strawser, 1992; Jarvis, 1998; Meyers, Eichhorn & Guzzetta, 1998; Morse & Pooler, 2002; Powers & Rubenstein, 1999).

During this study’s evolution, I became a parent for the first time and it has become clear to me that since that time, my understanding of the parents’ stories has changed dramatically. While I do not suggest that nurses cannot fully understand a health care experience unless they have lived it themselves, I can now appreciate the added dimension that the birth of a healthy baby has brought to my own lived experience and so to the interpretation of these parents’ stories. One cannot fully understand the trauma a parent must endure when their child suffers a cardiac arrest, but understanding the deep love a parent has for a child has helped me to better appreciate what it may “be like”.
1.3. Aim of the study

This phenomenological study, then, begins with the question: *What is the nature and meaning of parental presence during resuscitation in PICU?* Thus the focus is on parental presence as a lived experience. Therefore, I sought to examine the lived experiences of those who were able to inform most comprehensibly; parents and nurses in the PICU. The broad aim of the study was to provide an in-depth interpretive account of the phenomenon of parental presence that would enable a better understanding of what it means for parents and nurses who are engaged in the resuscitation process of a child in PICU. I am also orientated to the phenomenon both as an experienced PICU nurse and as a researcher who stands within the experience of paediatric resuscitation in intensive care.

1.4. Significance of the study

Ultimately, the main purpose of the study was to provide all those who work in the paediatric environment with a clearer understanding of what the experience is like for parents to witness or not witness a resuscitation attempt on their child and what it means for nurses who perform resuscitation while parents are present or absent. In addressing these central issues and getting to the meaning of the lived experience, this study aims to continue to develop and improve the care of critically ill children and their families, by informing nurses of the experience as it is lived.

It is anticipated that the findings of this study will enhance understanding of parents’ and nurses’ experiences of parental presence during what is an intensely stressful time for many. It is hoped that this will provide an impetus for staff to consider their current
practices and beliefs so that care provided is more closely informed by parents’ experiences and wishes. This will assist in the provision of a more embracing, family-centred approach at not only the critical time in PICU but subsequently, where relationships between parents and nurses may be tense.

It is also hoped that information gained from this study will provide better support and guidance for nurses who may be reluctant to accept parents in the resuscitation setting.

1.5. Definition of resuscitation in the paediatric intensive care unit

Essential to understanding the study’s context is the act of resuscitation. Cardiac arrest is defined as cessation of heart beat with no palpable pulses. This state requires immediate initiation of cardiopulmonary resuscitation (CPR) – that is, the child requires either external or internal cardiac compressions and respiratory support in the form of hand or mechanical ventilation. They may also, but not always, require pharmacological support and/or defibrillation. For the purposes of this study, the resuscitation period is defined as the times immediately preceding a cardiac arrest, the arrest itself, the mechanics of the resuscitation and the aftermath of the resuscitation. That is the period following the event, whether successful or not. This time may be up to several hours following completion of CPR and incorporates the achieving and maintenance of stability of the child. Their condition may remain critical at this time, with dramatic fluctuations in blood pressure, yet no further actual arrest. Furthermore, some incidents of CPR are described in the text within the context of “chest opening”. This specific procedure refers to those children who, following cardiac surgery via coronary artery bypass (open heart surgery) are nursed with their sternum open although the skin is closed. When the child arrests,
usually as a result of cardiac tamponade in this situation, the wound is reopened, giving the team direct access to the heart. Thus, open cardiac massage is performed. This procedure requires as sterile a technique as possible, within the intensive care unit and is performed by the intensive care medical and nursing team. Team members scrub and don masks and gowns just as in the operating room.

Generally the resuscitation procedure is initiated after the nurse caring for the child alerts other members of the staff by calling out and ringing the ‘arrest’ bell, located at each bedside. Those staff members not responsible for delivering direct care to another child, including the nurse in charge of the shift – the team leader - will immediately assist. The team leader generally delegates roles within the team. One important role is that of support person for the parents if they are present. A senior nurse, usually the team leader takes responsibility for supporting parents, if there are sufficient experienced staff to deal with the resuscitation procedure. When this is not possible however, less experienced nurses struggle to support parents. Additionally, approximately three medical registrars and at least one senior intensive care consultant are on the floor at all times during the day. Medical backup is covered 24 hours a day by registrars. In the first instance, a rush of personnel congregates at the resuscitation scene. It is up to the nursing team leader to take charge, removing extraneous members of staff to simplify the procedure, as well as ensuring the remaining patients are adequately cared for and supervised.

1.6. Structure of the Thesis

This thesis is presented in eight chapters. This introductory chapter has provided the background to the study, its aims and significance.
The review of the current literature in Chapter Two provides a starting point to understanding the concept of family centred care in the intensive care unit along with the notion of relatives’ presence during a resuscitation attempt. Chapter Three provides a description of phenomenological inquiry and its significance in nursing research in general and its use for this study in particular. The research process is discussed in Chapter Four, and includes descriptions of the participants, the setting and the procedures used in the collection of the information, as well as exploring the significant ethical considerations to be addressed when investigating a sensitive area of research.

The findings of the study are arranged in sequence of analysis. Analysis was carried out in two stages to uncover the full meaning of the phenomenon. Chapters Five and Six present the themes, which make up the phenomenological description of the phenomenon individually from the parents’ and nurses’ experiences. Chapter Seven presents a hermeneutic interpretation of the experience of parental presence during resuscitation as lived by the participants as **Sharing and surviving the resuscitation**. In Chapter Eight, conclusions of the study and the implications for parents and health professionals are presented.
Chapter 2

Parents and participation - a literature review

2.1. Introduction

Advances in emergency treatments and tertiary referral centres have greatly improved the survival of children who become critically ill through accident or illness. As a result, greater numbers of critically ill and often haemodynamically unstable children are admitted to the paediatric intensive care unit, who otherwise may not have survived for transfer and ongoing treatment. Cardiac arrest and subsequent cardiopulmonary resuscitation attempts are thus becoming more common in the PICU. In addition to the increased intensity of the PICU, the evolution of a partnership in care approach has led to parents becoming part of the PICU setting, with many often staying 24 hours a day. These changes have impacted on the physical, emotional and psychological issues confronting parents and nurses when a child is admitted to PICU.

This review begins by outlining changes in practice as a result of a partnership, or family centred, approach; how these changes have impacted on research and shaped our current understanding of the issues confronting parents during their child’s illness. This outline provides a context within which to discuss the challenges both parents and nurses face in the demanding intensive care environment in which the findings of the current study can be better understood.

As the research regarding parental presence during resuscitation is limited, analysis of the literature on parenting and partnership in the care of the hospitalised child has been
reviewed in order to give a clearer understanding of the issues and stressors confronting parents who are faced with taking on an altered role of parenting a critically ill child.

The review then addresses the literature on parental involvement in PICU that has revealed two main areas of investigation; identifying parental stressors and ways in which to minimise these stressors by meeting parents’ needs, and the notion of parental presence during procedures, as an extension of the partnership ideal. This review, therefore, is organised according to these areas.

2.2. The evolution of paediatric nursing and partnership in care

The care of children in hospital has evolved dramatically during the past 50 years, resulting in the current paradigm of partnership-in-care. It is now recognised that the care of children in hospital is greatly enhanced by the presence of their parents (Antice, 1979; Bowlby, 1953; Darbyshire, 1994; Hardgrove & Dawson, 1972; Johnson & Lindschau, 1996; Young, 1992). Parents are seen as the best carers for their child, and when the child is sick, can work in partnership with the nurse. This partnership approach has come to not only mean to be resident with their child, but to participate in care. Parents are not only encouraged but often expected to participate in their child’s care when in hospital. The United Kingdom Welfare of Children and Young People in Hospital (Department of Health, 1991) is emphatic on the philosophy, stating that:

    The cardinal principle of hospital services for children is complete ease of access to the child by his parents and other members of the family. As well as a mother or father, a parent could be a grandparent, uncle, aunt, sibling, nanny or close friend of the family. This is not a luxury. (p. 2).

Parental participation generally implies, to nurses, that parents may perform the physical tasks for their child, such as bathing and feeding, leaving the nurse to perform the more
technical aspects of care. It is now recognised, however, that parents want to more fully participate, often taking on what were previously seen as nursing tasks. This change in focus has, at times, resulted in a blurring of roles leaving many nurses and parents uncertain of what is expected of them. The focus of the partnership paradigm remains on the physical aspects of care, rather than encompassing the meaning of parental presence (Coyne, 1995).

Casey (1988) viewed participation in terms of a partnership with parents and developed the Partnership model of paediatric nursing, to provide a framework for nurses, with the aim of addressing the confusion around the changing philosophy. Casey (1988) proposed that:

The paediatric nurse complements parental care by doing things for the child, or his parents, to meet the child’s needs. This care may take the form of family care or it may be nursing care (that extra care given in relation to health needs). (pp. 8-9).

The very flexibility of the model, intended for adaptation to a variety of health care settings, tended to prompt nurses to focus merely on the physical tasks that parents could learn. The underlying philosophy of partnership although the most important focus, continues to be overlooked by nurses. The tendency to direct attention to physical tasks is evident with the recent development of negotiated care models that rely on a checklist paper record. It is clear that, despite the continuing task-orientated focus, the use of a tangible piece of information, such as a checklist, can assist nurses in grasping the concept of a partnership approach, prompting them to consider the families’ needs (Casey, 1993).
Whilst the partnership model of care was purported in practice, it became apparent that it describes an ideal (Casey, 1993). Casey suggested that in areas where nurses had professional autonomy, traditional and routine practices continued to prevent progress in equality in decision-making and sharing of expertise between parents and nurses. Subsequent research undertaken by Casey (1995) investigated the extent to which families were involved in the care of their children in two paediatric hospitals in the UK. Findings from this study confirm that communication and nursing style affect the level of parental care involvement, suggesting a “communicating to non-communicating continuum and a person-centred to a nurse-centred continuum” (1995, p. 1060). Four approaches were identified and included ‘permission’, ‘exclusion’, ‘assumption’ and ‘negotiation’ as the ways in which parents and nurses attempted to work together. Casey (1995) admits partnership in care may be an ideal in any health care context, but maintains that understanding more about the relationship between parents and health professionals will move the ideal closer to reality. Although this study provides valuable insight into the way in which to work closer towards a partnership approach, it has several limitations. Casey gave no indication as to why parents decided to become involved or not, nor how nurses’ expectations of the parents’ role influenced parents’ responses.

In addition to focussing merely on the physical aspects of parental participation, further barriers, such as an ongoing unequal power relationship, role confusion, lack of formal negotiation strategies (Casey, 1995; Coyne, 1996) and parenting in public (Darbyshire, 1994) inhibit the successful implementation of the partnership approach in the general paediatric environment. The expectation that a partnership approach would be
unproblematic and easy to establish was erroneous, not allowing for the enormous changes to roles that were required. In addition to an examination of these barriers, the following section will consider how parental participation during invasive procedures attempts to enhance a family centred philosophy.

2.2.1. Unequal power relationship

While nurses believe they implement the model of partnership in practice, there remains an imbalance of power in the parent-nurse relationship (Casey, 1995; Coyne, 1995; Kawik, 1996). Parents often adopt a passive role when they perceive professionals to be more powerful than themselves. Nurses “allow” parents to participate in care, “letting” them bath and feed their child (Neill, 1996). The terminology disputes this belief indicating that nurses remain in control in their approach to parents. When parents are viewed as visitors by staff, they are at once in an inferior position when they often view themselves as inadequate (Raines, 1998). Nurses practicing in a nurse-centred way were found to be authoritative and controlling, although assessed parental wishes and allowed involvement on the nurses’ terms. Casey (1995) suggests that “nurses who feel threatened by knowledgeable and experienced parents are more likely to be controlling and to limit involvement to retain their professional status or self-image”. Nurses practicing in this way found it “difficult to 'relinquish' professional skills and responsibility to a lay person” (p. 1061).

Callery and Smith (1991), in a study of role negotiation between nurses and parents of hospitalised children, used a critical incident technique to investigate 64 nurses’ responses in small focus groups. They also suggested that the relationship between
parents and nurses was unequal, as power was not evenly distributed and issues of territory, stress, anxiety, uncertainty, control and conflicts arising from parental competence all placed the parent in a weaker position. Casey (1995) acknowledged that the presence of the family has altered the role of the nurse, but suggested that nurses must recognise the valuable contribution they can make as educators and supporters of parents, empowering them to become more proficient in caring for their child. Whilst this inequality of power is not addressed and acknowledged it is difficult to negotiate a partnership between parents and health professionals.

2.2.2. Role of parents and nurses in a partnership model

While many nurses espouse the philosophy of family centred care, there is often an unspoken assumption by nurses that parents will also understand and embrace it. However, Taylor (1996) and Neill (1996) both note that, too often, parents view themselves as untrained carers, who are useful to nurses in carrying out basic tasks only when the nurses are too busy. Indeed, as Neill (1996) comments in reporting findings of a qualitative exploratory study of parents following discharge of their child from hospital, Parents often view nurses as “doers” of care, rather than “facilitators” of care. Furthermore, in Neill’s small study, parents wanted to participate but at the level of their choosing and wanted the nurses to remain responsible for clinical care. Little explanation was given by Neill (1996) as to the level of discussion held in hospital about the roles parents and nurses would adopt. In an Australian study of nurses’ perceptions of partnership, Johnson and Lindschau (1996) also concluded that there was an unspoken assumption that parents will want to participate in their child’s care without any formal
discussion or negotiation between the nurse and parents. Both nurses and parents often experience difficulties in identifying their roles.

In a descriptive, two-phase study to determine parents’ participation in hospital, Kawik (1996) undertook a postal survey of 65 nurses was undertaken in three children's wards in the UK and 12 in-depth interviews were completed with parents in their own homes following their child's discharge from hospital. The findings of this study confirm that parents and nurses had different perceptions of their roles which was not always conducive to a partnership approach.

2.2.3 Lack of formal negotiation

The partnership approach requires continuous formal negotiation with parents (Casey, 1988; Farrell, 1992; Johnson, 1996). Dearmun (1992) explored the boundaries of the concept of ‘partnership’ and concluded that both equality and negotiation were central issues in a partnership approach. Yet Dearmun (1992) found that while some nurses participated in some form of informal negotiation, none explicitly asked to what extent parents wished to be involved. Many parents were waiting for nurses to tell them what to do. Meanwhile, nurses took it for granted that parents were present because they wanted to take part in the care of their child. Nurses and parents have continued to have differing beliefs towards the concept of partnership in care.

Callery and Smith’s role negotiation study (1991) reported a tendency for less experienced staff to adopt a non-negotiation approach, describing encouragement, explanation and advice, while experienced nurses more frequently described themselves as responding to parents by negotiating. These findings are not surprising, but are
noteworthy when considering which level of nurses work more closely on a day to day basis with families in hospital. Similarly, Brown and Ritchie’s (1990) study of nurses’ perceptions of parent and nurse roles found less experienced nurses were more likely to adopt non-negotiation methods. A more recent study of negotiation in the care of children with complex health needs by Kirk (2001) confirmed that professionals’ expectations of parental participation can act as a barrier to negotiation of roles. This grounded theory study of 33 parents and 44 community-based nurses found that initially parental roles were rarely negotiated but gradually parents accepted responsibility for their child’s care and entered into negotiation in response to the child’s changing needs and their experiences of caregiving. These parents were in a more powerful position to negotiate their role once they were at home, on their own territory. This study, however, is limited by investigating only the community-based nurses’ perspectives. The views of hospital-based nurses are unknown.

2.2.4. Parenting in public

Most parents now live in hospital with their child and attend to their child’s basic daily needs. Darbyshire (1994), however suggests that encouraging parents to live-in with their child tends to underestimate the implications of increased parental presence. Darbyshire’s (1994) phenomenological study of the experiences of parents and nurses remains one of the very few which has sought to understand the meaning of being a live-in parent of a sick child. His narratives of “parenting in public” have provided valuable insights into parents’ behaviours, feelings and fears. Parents in Darbyshire’s study (1994) described the strangeness of the new situation, not only in terms of the physical environment, but also the culture and rules and regulations of the hospital, with which
they were expected to comply. This study also identified the defensive parenting phenomena: parents being in the “presence of experts” (p. 60). They were uncertain and confused when carrying out previously unproblematic activities, such as feeding or changing their child for fear of being judged by the nurses, particularly in the early stages of adjustment to the situation. Feelings of being judged on their parenting abilities and skills by the nurses, was also confirmed in Farrell’s extensive literature review (1989). Casey’s (1995) description of assumption further alienates uncertain parents who are in the presence of the experts. Nurses in Casey’s study made judgements based on subjective opinions and assumptions were not adequately explored. Assumptions were made about the families’ wishes and abilities. While one of the limitations of this study was that no parents were interviewed; the study using case notes and interviews with nurses; the defensive parenting phenomena could be exacerbated by this report of non-communicating assumptive practice.

While no studies have specifically investigated this phenomenon of parenting in public within the paediatric intensive care unit, this feeling may be further exaggerated in that environment. Parents are lost, uncertain of their role in this unfamiliar environment and afraid that their child may not survive. Nurses are constantly present at the child’s bedside, performing highly skilled tasks. Parents are often in awe of these experts and become even more unsure of their abilities to perform basic tasks with the ever-present nurse watching.
2.2.5. Parental participation during invasive procedures

Despite the barriers often encountered, the increased participation of parents is widely considered to have improved the care of children in hospital (Darbyshire, 1994). Parents can now regain some control over their child’s care when they are admitted to hospital if they are provided with adequate and appropriate support. An extension of a partnership approach is the assumption that parents will therefore want to be with their child during invasive or distressing procedures (Kawik, 1996). Indeed, it has become commonplace for parents to accompany their child to a treatment room for insertion of intravenous cannulae or painful debridement and dressings. Parents can regain some of their parental role as a comforter, supporter and advocate for their child during these procedures. The child can benefit from having a parent provide emotional support to them and therefore being present is also beneficial to the parents who are able to feel useful in doing something for their child in hospital.

Neill (1996) offered a different view, surmising that parents may find it particularly upsetting to witness the distress in their child during procedures. Parents believed their stress would communicate itself to their child, making the situation and the procedure more distressing and time consuming. Indeed parents often commented that they would prefer to provide comfort for their child after the procedure, and not be seen by the child as not protecting them from harm by allowing the nurse to perform the task. Neill (1996) suggested that nurses may find themselves taking on an additional role in caring for the parent who becomes distressed during a procedure. Yet this call suggests that the concept of participation and partnership is implemented successfully. Coyne (1996), in a concept analysis of parent participation, concludes that the definition ‘family centred
care’ may preclude participation if it is not conducive to family functioning. For example, providing support for the family, essential to a family centred philosophy, may mean that parents are in need of additional support during procedures and that nurses should embrace that within a family centred philosophy and consider the participatory role of the individual parent at that time.

Parental presence alone is not sufficient to reduce the child’s distress. Kleiber and McCarthy (1999), when studying the relationship between parental behaviours and child distress during urethral catheterisation, found that children showed an increase in distress when the parents used behaviours of bargaining, explaining or reassuring. Distraction techniques used when the child was not distressed helped them to remain calm. Kleiber and McCarthy (1999) called for strategies to help parents learn effective distraction techniques to minimise their young child’s distress. Most studies investigating the role of parents in procedures have focussed on the child’s distress and are limited to paediatric oncology patients or ‘minor’ invasive procedures such as cannulation, catheterisation or lumbar puncture. A smaller number have investigated parental presence and participation during burns debridement and dressings (Foertsch, O’Hara, Stoddard & Kealey, 1996; George & Hancock, 1993).

George and Hancock (1993) evaluated a parent participation program in a paediatric burns unit. Including parents in the daily burns dressings was found to significantly reduce the child’s experience of pain and allow the family relationship to continue throughout the hospitalisation. A greater understanding and compliance was also reported by parents. While the body of evidence relating to participation during invasive
procedures offers contradictory findings, the importance of the family in the child’s hospitalisation is undeniable.

The parents’ role, however, is often unclear with a dynamic nurse-parent relationship that is not always unproblematic. Nurses assume that parents will want to participate fully in their child’s care. However, during invasive procedures, little is known of the parents’ needs. Several studies have investigated how parents cope during procedures (Brennan, 1994); their role (Callery, 1997), and some have studied the differences in the child’s anxiety when the parent is either present or absent during procedures (Doctor, 1994). Indeed, higher levels of distress in children have at times been identified when parents have been present (Foertsch et al., 1996; Naber, Halstead, Broome & Rehwaldt, 1995).

Naber et al. (1995) conducted a qualitative exploratory study and videotaped responses of 17 children undergoing procedures during cancer diagnosis or treatment to identify patterns of conversation between parents and children. The findings of this study suggest that during periods of quiet, non-child centred communication occurred, that changed to child-centred when a child’s distress increased. The authors of this study recommend that nurses encourage parents to be more actively involved and physically close and to stay focused on the child, suggesting that parents were not fully engaged during less distressing times. It is not clear in this study, however, what types of parental support communication were observed, or the nurses’ role in supporting the child. The literature on children’s distress levels with parental presence is limited. In particular there is a lack of prospective research on parents’ responses to being present or asking them what role the wish to take on if they are with they child. However, children themselves, despite
showing increased distress with parental presence, have identified that they overwhelmingly want and need their parents to be with them (Foertsch et al. 1996). It is unclear why children then demonstrate higher distress, but it has been suggested that they feel more confident in articulating their distress with a familiar parent beside them, and these findings are consistent with other work (Doctor, 1994; Foertsch et al., 1996; Gonzalez, Routh & Armstrong, 1993; Jay, Ozolins, Elliott & Caldwell, 1983).

A large quantitative study conducted by Boie, Moore, Brummett and Nelson (1999) found that, given five hypothetical scenarios, most parents wanted to stay with their child during invasive procedures, although with increasing invasiveness, this desire to be present decreased. Seventy five percent of respondents in this study were mothers. Like much of the research on parents, the imbalance in numbers of fathers studied prevents any firm conclusions regarding mother-father differences being drawn.

In the paediatric intensive care unit there remains little that parents can physically do for their child. Attempts have been made to encourage parental participation in this environment, although the barriers to achieving more of a partnership relationship are multiplied in PICU, by the very nature of the technology-laden clinical environment and the very real fear that a child may not survive. The focus of this chapter now examines the parental stressors and needs at a time when they are most uncertain about their child’s future in an area where all control is taken from them and remains in the hands of the experts.
2.3. Parental stress and coping in PICU

Admission of a child to intensive care is a highly stressful experience for the whole family, with prognoses often uncertain (Miles, Carter, Riddle, Hennessey & Eberly, 1989a). Excessive stress can reduce the parents’ ability to function effectively and could potentially impede the recovery of the child (Proctor, 1987). Reducing parental stress and anxiety by meeting their needs therefore, helps parents to function in the crucial role therapeutic to them and their child (Fisher, 1994; Proctor, 1987). It is necessary first to consider what admission to a PICU means to parents. Meyer, Snelling and Myren-Manbeck (1998) and Miles et al. (1989a) both identified the initial concerns for parents as the fear of their child’s death, risk of physical handicap, brain damage and the pain their child may be experiencing. These fears then, would seem to be at the forefront of parents’ concerns when their child is admitted to PICU, particularly when the admission is unplanned.

2.3.1. Stress and coping

Stress is defined as a particular relationship between an individual and an environment that is appraised by the individual as exceeding personal resources and endangering well being (Lazarus & Folkman, 1984). Stress is subjective, and what is perceived to be stressful to one individual may not be perceived in the same way as another. Lazarus and Folkman (1984) go further with this concept, suggesting that the occurrence of a major, intrusive stress experience may increase the capacity of other stressful events to generate distress. For example, when a child is admitted to PICU, other stressful events, such as
loss of earnings, behaviour of the siblings or even the unfamiliar setting of the parents’ hostel may elevate the stress level of the experience.

Coping with a stressful event is influenced by both person and situation factors and has profound implications for a parents’ adaptation to the situation (LaMontagne, Johnson & Hepworth, 1995). Coping devices, identified by Menninger (1963), include self control, humour, crying, swearing, boasting, talking it out, thinking through and working off energy. These characteristics are regarded as normal. However, if they are used to extreme, Menninger (1963) suggests they lose their status as coping mechanisms and become symptoms of dyscontrol and disequilibrium. Lazarus and Folkman (1984) define coping as the cognitive and behavioural efforts used to manage external and/or internal stressors that are appraised to exceed the resources of the person. Coping is a process that changes as the individual’s appraisal of the situation changes. This dynamic process serves two major functions, according to Lazarus and Folkman (1984). Firstly the cessation of the emotions or distress produced by the event, described as emotion-focused coping; and secondly, the management of the problem that is causing the stress, described as problem-focused coping. Individuals may use either or both coping strategies simultaneously during stressful events.

Emotionally-focused coping styles include positive reappraisal or optimism, self-controlling, escape-avoidance, accepting responsibility and distancing. Problem-focused coping includes seeking social support, planning, problem solving, and confronting behaviours. Byers and Smyth (1997) suggest that while both strategies are used, the use of problem-solving strategies to decrease stress is more advantageous to families of
critically ill patients. Several researchers have used Lazarus and Folkman’s (1984) transactional model as a basis for understanding, assessing and intervening to reduce parental stress and enhance coping (Byers & Smyth, 1997; LaMontagne et al., 1995; Melnyk & Alpert-Gillis, 1998). The transactional model does not assume that threat or harm is inevitably stressful. Indeed, major stress causes some people to draw on adaptive resources they did not think they had, gaining strength that may be used in subsequent stresses (Lazarus & Folkman, 1984). Byers and Smyth (1997) note the key to understanding an individual’s stress level is their perception following appraisal of the potential stressful event and therefore their ability to cope.

An examination of the use and effectiveness of coping responses of family members of critically ill adults by Twibell (1998), found that confrontive and optimistic coping mechanisms were most commonly used and were more effective than other responses. Strategies were proposed to facilitate effective coping and identifying high risk family members, based on the Jalowiec Coping Scale (JCS). Twibell’s (1998) study, however, failed to explain how the coping styles were demonstrated by family members. The strategies recommended for facilitating coping were well intentioned but overly simplistic, prescriptive and at times unrealistic.

Increased life experiences may develop and refine more effective coping mechanisms. Therefore, it is pertinent to consider what previous experiences the family may have encountered. This will have a direct impact on the responses on which they draw to cope with the current situation of critical illness. Furthermore, the ways in which people actually cope also depends on the resources available to them and the constraints that
may inhibit the use of these resources in the specific situation (Lazarus & Folkman, 1984). Understanding the concepts of coping is imperative when considering the current study of parental presence during resuscitation within the paediatric intensive care context.

The definition of coping, for the purposes of this study is taken from Lazarus and Folkman (1984), who described it “as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p. 141).

2.3.2. Parental stressors

Parental stress in the PICU has been studied extensively over the past two decades. One of the first, and largest studies by Miles, Carter, Riddle, Hennessey and Eberly (1989a) utilised the Parental Stressor Scale (PSS: PICU) (Miles & Carter, 1983; Carter & Miles, 1989), to compare scores between parents who experienced a planned admission and those whose child was admitted under unexpected circumstances. Four hundred and ninety five parents completed surveys while in the PICU. This scale was used to assess perceived stress stimuli arising from physical and psychosocial aspects of the PICU: sights and sounds, child’s appearance, child’s behaviour, procedures, staff communication, anomie and parental role alteration. While all seven dimensions contributed to stress levels in parents, the change in the child’s behaviour and the alteration in parental role were the most significant. Findings from this study indicate that, perhaps not surprisingly, parents whose child was admitted unexpectedly experienced greater stress than those more adequately prepared. (Eberly et
Further development of the PSS: PICU (Carter & Miles, 1989) led to a continuing programme of research investigating stress in parents of children admitted to five major paediatric intensive care units in the Midwestern USA was undertaken and validation of the theoretical framework confirmed the research team’s findings (Miles et al., 1989a).

Investigation into stressors perceived by mothers and fathers revealed that mothers experienced greater stress than fathers, but that both were less stressed by the physical environment than the interpersonal dimensions (Riddle, Hennessey, Eberly, Carter & Miles, 1989). Parents indicated that it was their child and their relationship with them that were the major sources of stress. The parents’ relationship to the child emerged as a significant factor in subsequent studies. Heuer (1993) surveyed 32 parents in a paediatric intensive care unit in the USA, using a revised PSS: PICU tool, reporting similar findings but stressed that parents’ inability to be constantly with their child was a predominate stress. Many studies have confirmed the main stressors for parents as being change in parental role, the change in the child’s behaviour and appearance and separation from their child (Board & Ryan-Wenger, 2002; Brussen & Miles, 1996; Curley, 1988; Myer et al., 1998; Wereszczak, Miles & Holditch-Davis, 1997). These stressors are discussed in the following section.

2.3.2.1. Role change for parents

A change in parental role is a source of great stress identified by parents (Curley, 1988; Eberly et al, 1985). Indeed, the transition from being a parent of a healthy child to being one of a sick child is enormous even within the general paediatric ward environment
(Darbyshire, 1994) and this transition is greater when the child is critically ill with an uncertain future (Curry, 1995; Farrell & Frost, 1992; Rennick, 1986).

LaMontague and Pawlak (1990) in an examination of stress in PICU adopted a mixed methodological approach, using Folkman and Lazarus’s Ways of Coping questionnaire along with semi structured interviews. The four point Likert scale was designed to identify actions which individuals may use to cope with a stressful situation. Data were collected from 30 parents. Loss of parental role was identified as one of the most predominate stressors and reflected similar findings by Curley (1988), and Miles, Carter, Spicher and Hassanein (1984). Traditional parental roles included protecting, comforting, advocating, educating and providing for their children. When a child is critically ill, parents are no longer in control of their children’s lives at a time when the child is in danger; the very time when parents want most to protect their child (Meyer et al., 1998). They are unable to perform those parental roles effectively, if at all. Miles et al. (1989a) and Miles, Carter, Hennessey, Riddle and Eberly (1989b) noted that this change in role and the resultant stress is more acute during long periods of separation from the child, either imposed or otherwise, being prevented from being with their child during procedures, being afraid to touch and not being able to take care of their child themselves.

In a recent study of paternal stress in PICU, Board (2004) utilised the PSS: PICU in combination with the Symptom Checklist-90-Revised (SCL-90-R) (Derogatis, 1994), to compare stress symptoms of fathers with a child in PICU with those of fathers with a child in a general care unit (GCU). The findings of this study indicate that fathers of
children in PICU demonstrated significantly more stress than fathers in the GCU from the sights and sounds of the unit and by the procedures their child underwent. These stressors were more predominant than role change for the fathers in this study. Board did not elaborate on the reasons for these findings, yet they were similar to Miles et al’s (1989a & b) body of work which found a difference in fathers’ and mothers’ stress in role change and suggested that fathers experienced less role change stress than mothers. It is not known in Board’s (2004) reporting why fathers experienced more stress related to the environment rather than role change, but as this is a recent study, it may postulated that ongoing advances in ICU technology may result in greater levels of environmental stress in all parents, including fathers, while they typically show less alteration in role change and associated stress than mothers.

2.3.2.2. Change in child’s behaviour and appearance

A change in the child’s behaviour was also identified by Miles et al. (1989a & c) as a source of great stress in their survey of 510 parents in five PICUs utilising the PSS: PICU. These parents were generally unprepared for the confusion, uncooperativeness, combativeness, withdrawal, anger, acting as if in pain or restlessness exhibited by their child. These behaviours are frequently displayed as a result of the abnormal environment, drug therapy or the altered physiology as a result of the illness, but parents felt powerless to eliminate them. This powerlessness was confirmed by Farrell and Frost (1992) in their survey approach to elicit the needs of parents. Stress may become overwhelming and interfere with the parents’ ability to provide adequate emotional support for their child and to cope effectively with the experience themselves. Added
stresses such as personal and situational factors contribute to compounding the overall inability to cope.

A change in the child’s appearance also contributes to parental stress (Curley, 1988; Rennick, 1986; Seideman, Watson, Corff, Odle, Haase & Bowerman, 1997), with the child often unable to move due to muscle relaxants or coma. The child is generally ventilated with a variety of invasive monitoring equipment in place and may require the presence of drains, catheters, and intravenous lines and is often nursed exposed. Situational stressors as well as emotional stressors can impact on how parents perceive the intensive care experience. This stress is reported as less intense than role change for parents and Miles et al. (1989a) suggest that any intervention for reducing stress in PICU should be directed at the altered parent-child relationship, rather than solely on the physical and interpersonal characteristics of the PICU. Therefore, facilitating parent-child contact, by increasing participation and giving back some control is advocated.

More recently however, Heuer’s (1993) study found that factors such as the child’s appearance, and sights and sounds appeared not to stress parents unduly. Heuer (1993) suggests that earlier work by Carter and Miles (1989) may have influenced changes in paediatric intensive care practices and as a consequence the stressors and needs of parents are better understood and addressed. However, Heuer’s (1993) study was limited by a sample size of 32 parents and included both emergency and planned admissions. It is not known whether parents were given pre-admission information, nor whether the modified PSS: PICU was piloted. Modification to the tool included a further dimension relating to
social support as well as an open-ended question section, leading to further speculation about the validity of the instrument.

2.3.2.3. Separation

Being separated from their child, particularly during invasive procedures, is a predominant source of stress and anxiety for parents (Miles et al., 1989a & b; Curley, 1988), yet these are often the times when they particularly express the desire to be present (Farrell & Frost, 1992). Fears that parents will not cope effectively when witnessing traumatic procedures are often the reasons cited for preventing parental presence. Wereszczak et al. (1997), in one of very few studies exploring the long term effects of intensive care on parental stress, conducted a retrospective longitudinal study with data collected from 44 mothers whose children had previously been hospitalised in one neonatal intensive care unit (NICU) in the USA. They reported that three years after the birth of their premature infants, mothers had vivid memories of the stress they encountered related to the pain and procedures the infants endured and the change in parental role. The stress was seen particularly in separation from the infant, difficulties associated with visiting and inability to participate in their infant’s care. This study has serious implications for family centred care in the intensive care setting, as the long term effects on the family have previously been overlooked (Wereszczak et al, 1997). A three-group prospective comparative study to examine long-term effects and family adaptation by Board and Ryan-Wenger (2002) confirmed the long term detrimental effects on the family unit. One of the limitations of this study, however, was that while data collection occurred at four separate points, only one set of data was collected during the child’s hospitalisation. Furthermore, data were only collected for a period of up to six months
following discharge. Board and Ryan-Wenger (2002) reported parental stress related symptoms and difficulties with family functioning during that time. Little research has continued to follow up parents for longer periods of time post discharge from PICU. Further prospective, longitudinal research is required in order to support these findings with confidence.

2.3.2.4. Parental stressor scale

Investigating parental stress has most commonly been undertaken by the use of the PSS: PICU data collection tool (Board, 2002, Board & Ryan-Wenger, 2003; Miles, et al., 1989a). A recent review by Noyes, (1998), however has cast some doubt on its validity, despite the recognition that the work of Miles et al. (1989a, b & c) has influenced many to replicate studies of stress and coping. One of the main concerns raised by Noyes (1998), is that since the development in the USA of the PSS: PICU in 1979, many technological advances have changed the nature of intensive care units. Noyes speculates that the stresses parents experienced in 1979 were fundamentally different from those a parent may experience in the late 1990s. Additionally, the advent of family centred care may have a significant impact on parental stress (Heuer, 1993). Noyes (1998), however appears to suggest that the detrimental effects of separation and the loss of parental role are diminished. While it is possible to criticise the development of the PSS: PICU tool, the early work was one of the first to recognise and identify the importance of parental stressors and needs. Many researchers have replicated their work with similar results adding to the apparent validity of the instrument. Furthermore, the PSS: PICU continues to be adapted to suit the needs of the population and has been modified to elicit culturally specific information (Haines, Perger and Nagy, 1995); a modification that incidentally
Noyes suggests raises methodological and validation concerns. Analysis and interpretation of the mean scores reported by Miles, Carter, Spicher and Hassanein (1984) were also scrutinised in Noyes’s review (1998).

Development of the PSS: PICU as a useful tool in testing parental stress continues. Despite the changes in intensive care and family centred nursing, stressors such as the dramatic change in parental role and separation, with parents continuing to report a loss of control and feelings of helplessness (Board, 2004; Curley & Wallace, 1992; Miles & Mathes, 1991).

2.3.3. Meeting Parental Needs

In order to reduce parental stress and facilitate effective coping interventions, dependent on individual factors, it is important to meet the needs expressed by parents. Many authors have identified a hierarchy of needs, to assist parents in coping with the stress associated with PICU. The four main needs identified are to be with their child as much as possible, to participate in their child’s care, to have a place to rest near the ICU and to receive frequent truthful information about their child’s condition (Farrell & Frost, 1992; Heuer, 1993; Miles et al., 1989a; Riddle et al., 1989). To meet these needs, Curley (1988) suggests that open, frequent visitation and parental participation should be promoted by all PICU staff, as indeed is advocated in the general paediatric environment. This acknowledgement of the importance of reducing stress in parents to promote more effective family coping and functioning is in keeping with the family centred philosophy. Being with the child as much as possible and participating in their care are discussed in
the following section, along with the ongoing difficulties encountered by nurses in assisting parents meet these needs.

2.3.3.1. Being with the child

As the change in parental role and separation from their child are two of the most stressful aspects of admission of a child to PICU, it is important that parents are able to spend as much time with their child as they wish and resume some control over their child’s care. It has been suggested that since the 1970s open visiting has become the norm in the paediatric environment. Considering that PICU is the most stressful environment for parents it should thus follow that this acceptance of parental presence should be more prevalent in PICU. Parents express an overwhelming desire to be with their child at all times (Amico & Davidhizer, 1994; LaMontagne & Pawlak, 1990; Meyer et al., 1998; Woodfield, 1997). However, in reality, this need to be present is even now frequently denied by nursing and medical staff (Board, 2004; Maxton, 1997; Raines, 1998). Whilst many PICUs promote 24 hour, open visiting in theory, there remains many restrictions on parents (Youngblut & Shiao, 1993). Restricted visitation may be the greatest barrier to maintaining the parental role (Giganti, 1998). Parents are often prevented from visiting during medical ward rounds, nursing handovers, admission of a child and during many procedures, such as insertion of monitoring lines and drains; many of which can take hours to complete. In effect, parents often may be denied access to their child for up to several hours a day. Further limiting of parental access, and thus the philosophy of family centred care, is demonstrated in an all too common policy of denying access to all visitors, including parents, for a one to two hour rest period (Tughan 1992).
A more recent survey of 125 randomly selected hospitals in the United States reported by Whitis (1994), identified restrictions on visits to brief periods, either limiting visits to a two hour period or allowing timed visits for several periods per day such as ten minutes every two hours. These limitations are described in other reports of visiting, in predominantly adult ICUs (Gurley, 1995; Roland, Russell, Richards & Sullivan, 2001) and suggest that despite an open visiting policy reported in many hospitals, in practice restrictions are still placed on visitors, particularly during emergencies, if their presence is considered detrimental to the patient or during physician rounds (Marfell & Garcia, 1995; Marsden, 1992).

While open visiting is generally readily accepted within the PICU environment and has been for more than a decade (Brilli, 2004), a review of the international PICU Internet discussion forum revealed that this topic of “open visiting” was an ongoing source of divided opinion, (PICU-Nurse-International@yahoogroups.com) While numerous PICUs suggested they promoted an open visiting policy, many of them conceded that in fact there were times when they asked parents to leave the unit. Several centres asked parents to leave during invasive procedures, once the child had been sedated. Centres had differing guidelines for resuscitation, stating “it depended on the physician”, or “we would ask them to leave if they (families) were grieving loudly” (personal communication, PICU forum, 1999, 2000).

As in the general paediatric setting, there are, at times, issues of control that continue to deny parental presence during invasive procedures and ward rounds in the PICU. Knafl and Dixon (1984) found that many PICU nurses feared the loss of control over their
patient. In the highly technical environment, where nurses are the experts and parents often frightened, it was easy for nurses to take control.

In addition to restricting parental access, maintaining control over parents may be manifested in several ways (Bouley, Von Hofe & Blatt, 1994; Chelsa, 1996). Bouley, Von Hofe and Blatt (1994) suggested that nurses offer rewards for correct behaviour and deny access if parents do not conform to an expected behaviour. Nurses were reported to make judgements about parents based on appearances, attitudes and communication skills (Farrell, 1989). Nurses allowed parents to participate in their child’s care as long as they stay within the nurse-designated parental boundaries. It is possible that this exertion of power is as a result of confusion about the role of the nurse in this transitional period of paediatric nursing. However, this control supports the continuing unequal power relationship, not conducive to the establishment of the desired partnership approach.

Communicating with parents was often difficult for nurses in PICU, impeding parental presence. Beck (1991), in a study of nurses’ caring for parents whose child died suddenly and unexpectedly, reported that coping with parents was the most stressful aspect of working in PICU for nurses. Certainly nurses are introduced to parents at a time of crisis, when normal family functioning is often dramatically impaired. Stressed parents may react to their child’s admission in PICU in a number of ways, making it difficult to communicate with them. Guilt about their inability to protect their child from harm and fear of their child’s death can present as either anger, denial or a combination of both, often directed at the nurse caring for their child. Halm, Titler, Kleiber, Johnson, Montogmery, Craft, Buckwalter, Nicholson, and Megivern (1993) investigated
behavioural responses of 52 family members to critical illness, using the IWOA ICU family scale. The findings of this study confirmed that stress was greatest at the time of the ICU admission and began to plateau at approximately day six. Halm et al. (1993) suggest that crisis intervention is important during the early phase of caring for family members. It is little wonder that often nurses comment that it would be easier to care for the child alone, without the parents (Beck, 1991).

Tughan (1992), in a study of perceptions of patients, parents and staff, found that nurses believed patient confidentiality would be compromised if parents were allowed to stay during ward rounds and handovers. Furthermore, they believed that parental presence would inhibit the freedom of discussion about patients during these times. Parents, however, expressed very different views, noting that these were ideal times to ask questions about their child’s progress (Farrell & Frost, 1992). Indeed, parents reported no real interest in other children’s treatment (Tughan, 1992). It is apparent that there are many reasons why parents are denied the opportunity to stay with their child at all times during the day, inconsistent with a partnership approach commonly advocated.

Nursing in public may be a further concept inhibiting the promotion of a family centred approach. Just as Darbyshire (1994) identified that parents found it difficult to function in the perceived spotlight of the ‘experts’, it is possible that nurses, too may be uncomfortable with parental presence, perceiving them to be watching them work. In an ongoing discussion on the PICU internet forum, many nurses commented on the need to have some parent-free time. One stated; “I often believe that nurses fight for the time to
be parent free under the guise of confidentiality, when the real need is for a bit of peace, quiet and relaxation”.

This was confirmed in a previous study of health professionals’ views of parental role and participation in PICU that found restrictions gave staff the opportunity to have a break from parents (Maxton, 1997); with some nurses reporting the absence of parents gave them time to attend to patient care, such as washing and turns. Nurses in this study were able to work more effectively when parents were absent, and equated lack of parents with better care. It is not understood why nurses perceived parents to get in the way of caring for the child, but it is evident that the philosophy of partnership was not the central focus for some nurses in PICU. It is suggested, however, that nurses may experience similar feelings to parents when carrying out tasks under the gaze of the ever-present parent.

Central to the ongoing denial of parental access though, is the continuing belief that parents are visitors to the intensive care unit, demonstrated by the use of the term ‘visitor’ along with the visitation policies often still in use. Although as Browne, Sanchez, Langlois and Smith (2004) point out, recent reviews of NICUs in the USA have indicated more open hours for parents, less restrictive language and a move towards viewing parents as participators in care, reflected in changes to wording from ‘visitation policies’ to ‘parent participation guidelines’.

2.3.3.2. Participating in Care

Along with the need to be present with their child, parents have identified participation as another of their most important needs, resulting in reducing stress (Farrell, 1989; Miles et
Participation has been identified as the best form of coping with feelings of helplessness, role confusion and guilt (Coulter, 1989; Kasper & Nyamathi, 1988; Rennick, 1986). A flexible approach is warranted if this participation is to be achieved effectively. Participation in PICU may include bathing, changing nappies, feeding or other tasks with which parents may feel confident in performing. This participation is in keeping with the partnership paradigm.

It is not sufficient however to suggest that because some parents perform tasks, the partnership approach is working well. In reality there is a limit to the number of tasks, which may be performed by parents in PICU and indeed which parents may feel confident in performing. Indeed, parents’ stress may be so high that participation in physical tasks may increase their stress, particularly if feeling under pressure to perform. While some parents may wish to participate, others do not. It is neither possible nor practical for parents to learn many of the technical skills required in intensive care, nor do they wish to do so. Parents have confirmed that they expect nurses to provide the necessary skill care and take control of the situation (Saunders, 1994; Stanton, 1991). While parents do, at times, want to participate in their child’s care, their most important need is to be with their child and foster the altered parent-child relationship (Curley, 1988; Hill, 1996; LaMontagne, Hepworth, Pawlak & Chiafery, 1992; Scott, 1998). Most commonly, parents participate by taking on the role of Nurturer-Comforter, Vigilant Parent and Protector (Snowdon & Gottlieb, 1989). In a study comparing stress perceptions of parents with children in PICU with those with children in NICU (Seideman et al., 1997), participants in both units considered problem-focused coping
strategies more helpful than appraisal or emotion-focused coping. This study highlighted the need for practical interventions that assisted parents to participate more effectively.

Nursing intervention models have met with some success in meeting the parents’ need to participate more effectively and reduce stress. The Nursing Mutual Participation Model of Care (NMPMC) is a process characterized by an equal partnership between the nurse and parent with the goal of facilitating the parent's ability to reduce his or her stress. Curley and Wallace (1992) used a quasi-experimental design to test the NMPMC. Parents allocated to the experimental group received care from PICU nurses instructed in the NMPMC and, using the PSS: PICU were found to demonstrate lower stress scores than parents who did not receive the intervention. Similarly, Board and Ryan-Wenger (2000) taught parents how to take care of their children's physical needs during the PICU stay and also found that parents who received the intervention had lower stress scores than parents who did not provide care to their child.

More recently, Melnyk, Alpert-Gillis, Hensel, Cable-Beiling and Rubenstein (1997) tested a parent focused intervention program (COPE – Creating Opportunities for Parent Empowerment) with PICU mothers who received audiotape recorded and written information pertaining to expectations of their child’s behaviour and their own parental role. A two-group experimental design was used. The convenience sample of 30 mothers was allocated to one of the two groups. Findings indicated that the mothers in the COPE intervention group provided significantly more support to their children during an invasive procedure, provided more emotional support to their children, and reported less negative mood states, less perceived stress, and fewer stress symptoms than mothers who
did not participate. A series of subsequent studies have validated these findings (Melnyk, Alpert-Gillis, Feinstein, Crean, Johnson, Fairbanks, Small, Rubenstein, Slota & Corbo-Richert, 2001). These findings were further replicated in a recent randomized controlled trial using the validated COPE intervention tool in lowbirth weight (LBW) premature infants (Melnyk, 2004). This was a two study site trial, involving 250 infants and their parents with follow up through to three years of age and reported an improvement in maternal state anxiety, depression and PSS scores as well as babies demonstrating higher cognitive skills and improvement in weight gain. Clearly a parent focused, reproducible intervention program such as this demonstrates significant positive effects on the child and family, yet so far the COPE program has only been implemented in some centres within the United States. Its effectiveness is yet to be tested in organizations in different cultural settings.

In this section, what is known about parental stressors and needs in PICU has been reviewed. Encouraging and supporting participation is clearly essential to working in partnership with parents. However, participation must not merely refer to those physical tasks, but also extend to include being with their child, and taking part in negotiations and decision-making about their child’s care. Parents can offer personal insight into their child’s usual routine and development. It is however, the controversial topic of parental presence during periods of instability and crisis, and in particular during resuscitation of their child, that raises many concerns in this evolving culture of participation in the PICU. A partnership philosophy has been generally embraced by PICU nurses, aiming to work closely with parents in the care of the sick child, yet, its application is questioned during critical events such as resuscitation.
Presence during invasive procedures

Despite many procedures in PICU being more invasive and potentially more distressing, parents have frequently expressed the need to be with their child particularly during these times (Endacott, 1998; Farrell, 1989; Miles, et al. 1989a; Noyes, 1998). Being with their child and providing comforting words, even to a sedated or unconscious child provides the parent with the belief that they are maintaining a comforting, supportive role as a parent; at a time when they can do little for the child and may be experiencing guilt or sorrow for the child’s illness and confusion as to their role. By supporting the parents at this time, nurses can help in meeting their needs and reducing their stress. However, current practice on occasions continues to prevent parents from staying with their child during invasive procedures (Curley & Wallace, 1992; Maxton, 1997; Noyes, 1998). Interestingly, a study by Haines et al. (1995) found that parents of non-intubated children were more stressed by painful procedures inflicted on their child than parents of intubated children, who identified staff communication as more stressful. Intubated children are more likely to be sedated and therefore may not visibly respond as keenly to pain or discomfort as non-intubated children, and therefore it may be supposed that additional factors, such as a more obviously distressed child may account for the increase in parental stress in this study.

Snowdon and Gottlieb (1989) sought to understand how situational factors including occurrence of a procedure, influenced a mother’s role in PICU. In a small exploratory study of 12 participants, they found that during procedures, mothers often assumed the Medical Parent role, most commonly observed as the Advocate-Overseer. Mothers reminded, clarified, informed or called attention to the child’s condition or helped the
physician by holding the child. However, this study failed to identify how often mothers were present during procedures or identify the types of procedures performed or indeed how the meaning of ‘procedure’ was interpreted by the parent. While Snowdon and Gottlieb (1989) provided an example of suctioning, it may be that more invasive procedures would discourage mothers from assuming the Medical Parent role or indeed from remaining with their child. It is also unclear why they chose only to investigate mothers’ responses, although it can be assumed that the mother was the parent most often present with the child at the time of the study.

While witnessing invasive procedures on their child may result in added stress for parents, this stress may be greater if parents are unable to be with their child, unsure of what is happening and how their child is responding and coping with the procedure (Miles et al., 1989a & c; Scott, 1998). There is however, limited research investigating parental participation in the PICU; how parents fulfil their participatory need and whether their needs and expectations are met in participating.

### 2.4. Parental presence during resuscitation

There is a paucity of research pertaining to the specific notion of parents’ presence during resuscitation in the paediatric intensive care setting. As previously identified, parents want to be with their child to provide them with emotional support as well as for their own coping (Farrell, 1989, Miles et al., 1989a; Way, 1993). Despite this knowledge, parents are still denied unlimited access to their child in PICU (MacLean et al., 2003; Meyers et al., 2000; Noyes, 1998). It is not surprising that this denial is more apparent during periods of critical instability, deterioration and in particular during resuscitation
attempts of their child. Until recent times, relatives have been excluded from attending resuscitation procedures (Back & Rooke, 1994; Hanson & Strawser, 1992). Resuscitation of a child may be the ultimate stressful experience to which parents may be subjected. Thus the stressors experienced when a child is admitted to PICU can be assumed to be magnified. The sights and sounds of the chaos of a resuscitation attempt, the child’s deteriorating appearance, staff communications and parent-child separation can be expected to be enormous at this stage, as well as the fear of death of the child. The ability to cope with the event may be restricted, as the parent becomes more anxious, uncertain and loses any control in the care of the child they may have regained temporarily. Coping strategies identified by Lazarus and Folkman (1984) may be of little use to parents when their child suffers a cardiopulmonary arrest; there is nothing they can do to relieve their stress at this time.

While considerable attention in recent times has been paid to the advantages and disadvantages of the presence of family members during resuscitation of an adult relative, predominantly in the emergency department there is a paucity of research pertaining to the specific notion of parents’ presence at this time in the paediatric intensive care setting. For this reason, it is necessary to turn to recent studies that explore the benefits and disadvantages of family members in the adult settings. While this emotionally charged debate is ongoing, there is no definitive evidence either supporting or opposing parental presence.
2.4.1. Relatives’ Views

Hanson and Strawser (1992) were among the first to identify the benefits to relatives who were present with family members who required cardiopulmonary resuscitation in the Emergency Department (ED) of Foote Hospital in Michigan, USA. The program developed in 1982 was as a result of two separate incidents of relatives demanding to stay with their family member during resuscitation. A small postal survey of 18 families whose relatives had died in the ED indicated that 72% would have liked the opportunity to be present during resuscitation when their family member died. Following implementation of the program, another postal survey was conducted to which 47 family members responded. Seventy six percent of those relatives felt their adjustment to the death was made easier by their presence. Sixty five percent felt that their presence had been beneficial to the dying person. These relatives had had the chance to say goodbye and to see that all had been done that was possible in the resuscitation attempt. Ninety four percent of respondents reported they would be present again during CPR if given the opportunity. Many declared that they were sure their dying relative had heard them expressing their love and goodbyes.

Hanson and Strawser’s (1992) evaluation of the presence of relatives was, however, limited by the small sample size (47) and the decision to survey families by means of a simple postal questionnaire. They found the decision to let the family in had certainly been difficult, with the authors experiencing many barriers from staff. Staff were reluctant to change their practices, fearing that grieving relatives may interfere with the resuscitation and staff themselves may find it impossible to control their own emotions and responses during a death with relatives present. After participation in the initial
program, however, 21 staff also completed surveys. Seventy one percent endorsed the practice, despite reporting added stress during the procedure.

The Foote Hospital has continued the program and Hanson and Strawser (1992) report that in the nine years of the experience, there has never been an instance of actual interference with resuscitation activities nor any increase in legal risk, despite staffs’ initial misgivings. Of interest in this study however, is the continuing practice of asking relatives to leave the resuscitation room during invasive procedures, despite advocating relatives’ presence during the actual cardiopulmonary arrest. No reason for this is given by the authors, so one can only presume that the sight of inserting invasive monitoring and life saving interventions such as endotracheal tubes and arterial lines is believed to be more traumatic to witness that the CPR attempt or that the team believe relatives may get in the way of the procedure. Not explained by Hanson and Strawser (1992) was how the family members were present. It appears they were encouraged to enter the resuscitation room during periods when CPR was not actually occurring, but when a degree of stability has been maintained temporarily. Presence was generally limited to five minute periods.

In the 20 years since the Foote Hospital’s program implementation, and despite the ensuing emotionally charged debate, relatives are still often prevented from being with the patient during CPR (Connors, 1996; Meyers et al., 1998; Eichhorn, Meyers, Mitchell & Guzzetta, 1996; Maxton, 1997). Meyers et al. (1998) replicated Hanson and Strawser’s (1992) study, in order to gain information about family members’ desires, beliefs and concerns regarding the option of family presence during CPR. They conducted a telephone survey of 25 family members whose relative had died following
CPR at their institution in the previous 12 months, but had not been given the opportunity to be present. Overwhelmingly, 80% of respondents would have liked the opportunity to be present, supporting Hanson and Strawser’s study (1992).

Interestingly, a significant difference was found between the relationship of the family member and the family member’s belief that their sorrow would have been helped if they had been present. Respondents who were a parent or spouse of the deceased patient believed their sorrow would not have been lessened by being present in the room (Meyers et al., 1998). However, as none of the respondents had been given the opportunity to be there, it is not known whether this response would be the same if they had been present. Additionally, only 4 respondents stated being present would not have helped and it is unclear how many of those respondents were parents of a child who had died. Meyers et al. (1998) suggest that the parent-child relationship is so intense that no intervention may be possible in reducing the grief following the death of a child.

A program of research conducted in the USA by the team of Meyers et al. (1998, 2000), Eichhorn, Meyers, Guzzetta, Clark, Klein, Taliaferro, and Calvin, (2001) and MacLean et al. (2003) has continued to extend understanding of family and health professionals views, and concluded that family presence in the emergency departments during an adult relative’s resuscitation was a beneficial experience regardless of age, gender or education and was viewed as a right and a natural event. Furthermore they confirmed that traumatic memories of the event were not validated at two months after the event.

Since the publication of the program implemented at Foote Hospital and subsequent similar survey-designed studies (MacLean et al., 2003; Meyers et al., 2000, Eichhorn,
1996 & 2001), the family presence movement has generated much discussion in the attempt to validate the efficacy of such programs. Letters to editors of a variety of medical and nursing journals either renounced or extolled the virtues of family presence based on individual experiences (Adams, Whitlock, Higgs, Bloomfield & Baskett, 1994; Alton-Vlahovich, 1993; Chalk, 1994). Osuagwu (1991, 1993) was adamant in the belief, based on her observations in an ED in the USA that “witnessing a code is an experience that is non-therapeutic, regretful and traumatic to haunt the family member for the rest of his/her life” (1991, p. 363). Others have echoed this sentiment (Newton, 2002; Schilling, 1994). A debate in a UK nursing journal argued both positions and while both views were valid, no conclusions were drawn (O’Shea & Dight, 1999). Adams et al. (1994) write of one author’s experience when her brother suffered a fatal horse riding accident and resuscitation was attempted in full public view. She was frequently asked to leave but chose to stay. Adams believed that insisting on staying with her brother helped her to, “…come to terms with his death, although it did upset me when people constantly tried to remove me … the overwhelming desire is to stay close, this overrode any fears I experienced” (1994, p. 1687). A desire to protect families may be the reason for some nurses’ reluctance to accept family presence, but Adams (1994) suggests they may misunderstand the human response to possible death and not give credit for individual’s coping strategies when in a time of crisis.

Having the opportunity to touch and hold her brother’s hand was also important for Adams (1994). These sentiments are emulated by others’ accounts (Back & Rooke, 1994; McPhee, 1987). Personal accounts make an important contribution to this debate.
Consistent among these predominantly quantitative studies, is the desire expressed by
most relatives to have the option to stay with their dying family member. Back and
Rooke (1994) also investigated the presence of relatives in the resuscitation room in an
adult ED from both the relatives’ and nurses’ perspective. Although the majority of staff
interviewed endorsed the practice of family presence in theory, 61% subsequently denied
requests by relatives who wished to be present. Staff expressed concerns about the extent
of trauma to the relatives, and that witnessing a resuscitation attempt would be non
therapeutic. The relatives interviewed by Back and Rooke (1994), however, expressed
similar concerns to those identified in Hanson and Strawser’s (1992) study, confirming
the need to see all had been done and to facilitate grieving. Jarvis (1998) confirmed that
being present helped relatives comes to terms with the reality of death of a loved one.

A recent review, however, put forward a case opposing family witnessed resuscitation
(Newton, 2002), and suggested that most studies, for obvious reasons, had not explored
the patient’s perspective. Newton (2002) questioned the ethical issues regarding human
dignity and personal privacy of the patient. The argument suggested that during a
resuscitation attempt, a patient’s dignity was often the last matter to be considered and
questioned whether a patient would prefer to have relatives remember them as they were
or lying exposed on a bed. The author called for recognition that nurses were bound by a
code of conduct where they were under a duty of care to act in the best interests of the
patient and suggested that in allowing relatives to remain, this duty of care may be
compromised. While Newton (2002) conceded that family presence stemmed from a
desire to help relatives come to terms with their traumatic loss, the long-term effects on
relatives was questioned, suggesting they may not know what is best for their own
coping. Despite a number of studies supporting relatives’ wishes to be with their dying relative, Newton (2002) used patients’ dignity as the main argument to support the proposition that witnessed CPR was a violation of a person’s last movements suggesting it ‘cruel’ to let relatives in who could not understand. Bloomfield (2000) in a review of the literature also suggested that patients’ rights may be compromised in the attempt to provide holistic care for the families.

A recent qualitative study described the experiences of family members of critically ill adults who had survived a cardiopulmonary resuscitation (Wagner, 2004). The findings of this study indicated that health professionals often neglected family information and proximity needs but the study failed to investigate the health care professionals experience at the same time. Furthermore, this study was undertaken in the adult environment. Due to the intense nature of the parent-child relationship, it may be difficult to extrapolate the findings to the paediatric setting.

2.4.2. Health Professionals’ Views

A small number of studies have investigated medical and nursing staffs’ attitudes towards family or parental presence and found conflicting beliefs about the potential benefits to relatives. One of the few studies undertaken in the PICU environment was conducted by Jarvis (1998), who explored why parental presence was not commonplace. This study surveyed 20 doctors and 40 nurses in a small PICU in England but did not investigate parents’ needs and beliefs about being present. Staff held differing beliefs. Advantages identified by staff included the fact that parents could witness everything had been done, thereby reducing the risk of litigation and suspicion. This legal reason has previously
been highlighted (Renzi-Brown, 1991; Tucker, 2002), suggesting this to be the major factor in accepting family presence. Jarvis (1998) also found staff to believe the grieving process may be assisted, helping relatives to gain a realistic view of resuscitation and death.

The disadvantages identified by staff in Jarvis’s (1998) study included the belief that the experience may be too distressing for parents, leaving them with traumatic memories. Furthermore, staff in this study believed parental presence increased their own stress and considered that their actions in the resuscitation effort may be inhibited by the parents’ presence. This notion that the relatives may attempt to interfere with the resuscitation attempt, affecting performance of the team has also been raised by other researchers (Back & Rooke, 1994; Jarvis, 1998; Maxton, 1997; Redley & Hood, 1996). Despite the health care professionals’ fears, researchers found no disruptions in the operations of the team and no adverse outcomes during events where family members were present (Hanson & Strawser, 1992; MacLean et al., 2003, Meyers et al., 2000; Sacchetti, Lichenstein, Carraccio & Harris, 1996).

While McGahey (2002) suggested that parental presence was commonplace when reporting the findings of a 1997 survey in which only three physicians from 27 viewed family presence as negative, it was offered with caution. This study called for staff to evaluate the depth of their feelings of parental presence, as despite the acceptance, staff had reservations about their performance and parents’ coping.

Newton (2002) and Van der Woning (1997) concede that the practice of relatives’ presence in the resuscitation room remains inconclusive and ask whether with such
inconsistencies nurses should invite relatives to watch this potentially traumatic event. Van der Woning (1997) suggested that with no evidence of long-term beneficial effects, we may be putting relatives at greater risk of distress and trauma by allowing them to stay. Until unequivocal evidence is available, however Hadfield-Law (1999) suggests that excluding relatives would seem at best, narrow-minded and at worst, unethical. Finally, throughout the literature, researchers talk of “allowing” or “letting” relatives into the resuscitation room (Connors, 1996; Hadfield-Law, 1999; Van der Woning, 1997). Even a hospital chaplain was reluctant to “permit” a grandmother in to see her dying grandson for fear of upsetting her too greatly (Eichhorn et al., 1996). Despite the growing recognition of family needs particularly during resuscitation, the language used suggests an ongoing unequal balance of power, albeit out of concern for relatives’ protection. There remains a belief that healthcare professionals retain the ultimate decision for allowing relatives to stay.

Tucker (2002) concluded that the concept of allowing families in is receiving more acceptance and attention with their exclusion being challenged by the family presence movement. Programs of family presence will continue to evolve as further research is conducted and Tucker (2002) called for studies that fully explore the benefits and limitations of family presence. The practice of allowing families in will only enhance and strengthen the bond between families and health care providers with a higher degree of trust (Tucker, 2002).

Despite the perceived benefits of family presence during resuscitation attempts, a large survey of chest physicians, nurses and allied health workers attending an International
conference in the USA in 2000 found the majority of the 592 health professionals did not support the current recommendations provided by the emergency cardiovascular care and cardiopulmonary resuscitation guidelines that stated family members should be present (McClenathan, Torrington, & Uyehara, 2002). These findings were supported by Helmer, Smith, Dort, Sharpiro & Katan, 2000), in an extensive survey, sampling a total of 1,629 members from Emergency Nurses Association (ENA) in the USA and the American Association for the Surgery of Trauma (AAST). The results of this study found that the majority of respondents believed family presence was inappropriate during all phases of resuscitation and invasive trauma, with the majority (63% of AAST members and 68% of ENA members) believing the most appropriate time for families to be present was at the completion of invasive procedures. Attitudes towards family presence were significantly different between ENA and AAST members, with ENA members more likely to support family presence. The authors suggested that as a result of these differences, the implementation of a family present policy may create conflict between the trauma team members and interfere with their effectiveness.

Helmer et al’s. (2000) study suggested it was difficult to compare their cohort of trauma patients with patients afflicted with medical conditions, believing the distressing sights of disfigurement were inappropriate for families to witness. The non-response rate in this study was high at 56%, which may have biased the results. Commentary following publication of this study was prolific, with calls from trauma physicians to end the debate, citing the proposal of family presence as ludicrous and a non-issue.
It is clear that despite the evidence supporting generally relatives’ presence in the resuscitation room in the ED, the debate remains unresolved and controversial (Connors, 1996; Helmer et al., 2000).

The research so far has largely focussed on adult patients admitted to the ED and who generally require CPR within the first hour of admission and who have subsequently died. Family members who have been retrospectively surveyed have responded either by postal questionnaire or by telephone; neither method being optimal in obtaining the richness of data required about relatives’ feelings at this time. All have been directed to investigating unsuccessful resuscitation attempts. Other researchers have investigated staffs’ responses and Meyers et al. (2000) have developed a Family Presence Attitude Scale, adapted for family members and healthcare providers in the ED. In addition to retrospective surveys of family members or small groups of health care professionals, anecdotal reports, letters and editorial comments in a variety of nursing and medical journals have been the extent of the evidence (Connors, 1996; Van der Woning, 1997).

Recent reports have called for national and international policy guidelines supported by national nursing organisations such as the Emergency Nurses Association in the USA (ENA) and the American Heath Association in collaboration with the International Liaison Committee on Resuscitation (AHA/ILCR, 2000), yet currently locally written guidelines are limited (Kleinpell, 2003; York, 2004). In the adult environment, it is in the emergency departments where family presence is becoming more routine, although still not a widespread practice, possibly due to the ongoing concerns raised in recent literature findings.
2.4.3. Parental presence during resuscitation of a child in PICU

Paediatric nurses have long recognised the family’s importance to the child. If, as Darbyshire (1994) so succinctly describes, “the child is an inalienable part of the parents and the centre of their world, and vice versa” (p. 167), it would inconceivable to consider excluding parents from the bedside, if up to 20 strangers are present at the child’s death (Lee, 1996). McGahey (2002), in a review of staff members’ attitudes to family presence, further confirms the importance of parents at the resuscitation, considering the child to be an extension of the parents.

Despite the advance of the partnership movement in paediatrics and the frequent debate about the practice of family or parental presence during resuscitation, the research is scant. Few studies have yet explored this unique experience for parents in the intensive care unit. In Boie et al.’s survey of parents in the ED (1999), 80% of parents confirmed they would wish to be with their child during a resuscitation attempt; widely defined in this study as either insertion of central line, intubation, thoracotomy, cardioversion or CPR. However, different responses may have been obtained had the study not consisted of hypothetical scenarios but when faced with reality. It does however, suggest a strong parental desire to stay with their child during procedures in the ED and for that reason cannot be underestimated when considering parental participation in the acute care setting. The study also supports the notion that parents do not want healthcare professionals such as physicians or nurses to unilaterally determine parental presence. Boie et al. (1999) suggest that healthcare professionals must not only facilitate family-centred care in times of extreme crisis but also recognise validation of parental desires to be with their child at these times.
Further work by the team (Beckman, Sloan, Moore, Cordell, Bizendine, Boie, Knoop, Goldman & Geninatti, 2002) surveyed resident physicians and nurses in ten EDs in institutions in the USA that regularly treated children. Once again, as the invasiveness of the procedure increased, fewer physicians and nurses believed parents should be present, with 35% of physicians and 54% of nurses believing parents should be present during resuscitation where death was likely.

Sacchetti, Carraccio, Leva, Harris & Lichenstein (2000) evaluated the effect of prior experience in family member presence during five scenarios including paediatric resuscitation in a three-centre survey of ED personnel. The findings of this study confirm that staff with routine experience in family member presence strongly favour the activity and those from centres with only occasional family presence were more likely to oppose it. Furthermore, results in this study indicate no difference in responses from physicians and nurses; a finding contradictory to many others (Helmer et al., 2000; McClenathan et al., 2002).

Most of the literature explores the beliefs of relatives or health professionals in the ED environment. While resuscitation in the ED, whether adult or paediatric, generally occurs within the first hour of admission to hospital, the intensive care situation is considerably different. Children are admitted to PICU for a variety of life threatening conditions; the majority of whom will recover well with an uncomplicated course. However, of those who do experience complications, many will stay for several days, weeks or at times months in PICU. It may be that CPR for some children may indeed take place after considerable time has been spent in PICU. Parents may have had the opportunity to
develop relationships with the staff and as such it is suggested that a very different perspective is evident in this unique situation. Furthermore, resuscitation of a child in PICU has a greater successful outcome, with lower mortality rates.

The effects of the PICU environment on parents have been extensively studied from the perspectives of stress and coping. Parents now participate in some aspects of their child’s care. Yet the times when they most need to be with their child, are the times they are often denied. Resuscitation, arguably the most stressful time for parents, is the time when parents are often prevented from staying, despite family focused assurances from many paediatric units. While there is a growing debate about relatives, and parents’ presence, these debates are conflicting and emotive.

There is a lack of research investigating parental presence during resuscitation in the PICU. Previous literature relating to paediatrics is limited to quantitative studies with surveys of staff in the PICU (Jarvis, 1998) or in the ED (Beckman et al., 2002; Sacchetti et al., 2000); or investigating parents’ responses, with limited opportunities to explore experiences in great detail (Boie et al., 1999)

No studies were identified that examine the experience of both parents and nurses when parents are present during the resuscitation in PICU. Little is known of the underlying issues that impact on the decision made to either stay or leave the resuscitation. Thus far, researchers have not addressed the meaning for parents and nurses of parental presence that might inform how we can negotiate the complexities of such a stressful period in PICU.
2.5. Conclusion

Parents are able to offer nurses a greater insight into many areas of paediatric nursing research. Parents have frequently expressed the desire to be with their child, particularly during periods of instability in PICU. The notion of parental presence during resuscitation of their child in the PICU is an area currently under debate yet much of the research to date is of a quantitative nature. This approach fails to capture the complexity and richness of what is undoubtedly a unique human experience. As little is known about the experience, both for parents and for nurses who perform resuscitation in the parents’ presence, clearly an in-depth qualitative study is required. Phenomenology, both as a philosophy and a methodological framework was deemed the most appropriate approach for the present study as it would be able to uncover the nature and meaning of the experience of parental presence for both parents and nurses.

This important field of research will provide nurses with a greater understanding of how witnessing this event may assist families in their coping and functioning at a time of crisis, and regain some control in their lives. In understanding such traumatic events, nurses may be able to provide a more holistic approach to caring for the whole family, in line with the fundamental partnership paradigm. Additionally, the experience of nurses has not yet been investigated. A better understanding of their perspective may assist in clarifying the apparent reluctance to parental presence hinted at in questionnaires.

Therefore, this study aims to answer the questions that the research literature has so far fully not addressed. That is, what are the experiences of parents whose child requires CPR in the PICU and what does it mean for them? Furthermore, if the resuscitation
attempt is unsuccessful, this study will explore whether their presence enhanced coping by asking how parents deal with the experience of witnessing the event. The nurses’ experience is also sought in asking the question how is the phenomenon of parental presence during resuscitation experienced? The following chapter reviews the concept of phenomenological inquiry, both as a philosophical orientation and as the method of designing and implementing nursing research.
Chapter 3

Phenomenological Inquiry

3.1. Introduction

The focus of this research was to understand the phenomenon of parental presence during resuscitation in PICU. The study explored the nature and meaning of being a parent or a nurse who is living in the experience of parental presence or absence. The purpose was to provide a descriptive understanding of the everyday lived experiences of parents and nurses and an interpretive understanding of the ways in which they managed and lived in the experience. A hermeneutic phenomenological approach was chosen to guide this study and was considered the most appropriate in order to explore the experiential descriptions of the phenomenon.

The first section of this chapter reviews phenomenology as a philosophical approach to knowing and understanding. The development of hermeneutic phenomenology and its contribution to nursing’s ways of understanding human experience in the context of health and illness is then explored. Finally this chapter describes the use of the practical strategies for using hermeneutic phenomenology as a research method described by van Manen (1990) that guides the method and processes of the current study. Concepts drawn predominantly from Heidegger (1962) and van Manen (1990) have determined the design of the study and guided the formulation of the description of the phenomenon.
3.2. Phenomenology: a philosophical movement

Phenomenology as a philosophy has a history of evolution that continues to develop and be clarified. Therefore, there are multiple interpretations and modifications of phenomenology as a philosophy (Omery, 1983; Spiegelberg, 1982). A brief discussion of the development through the German phase during the first decades of the twentieth century, comparing Husserl’s transcendental descriptive phenomenology and Heidegger’s interpretive phenomenology is presented. Heidegger’s influence on van Manen’s (1990) hermeneutic human science approach provides a necessary understanding of the development of phenomenological thought and its implications for nursing research in general and the current study in particular.

Phenomenology, the study of phenomena, has been variously described as a philosophy, a movement, an approach and a research method. As the goal of phenomenology is to understand the nature and meaning of the phenomenon as an essentially human experience (van Manen, 1990), it is not surprising that in recent times, nursing has employed and embraced phenomenology both as a philosophy and a method for research to extend nurses’ understanding of health and illness related phenomena (Darbyshire, 1994; Munhall, 1994; Ray, 1985; Thornton & White, 1999).

3.2.1. Husserl’s transcendental descriptive phenomenology

Husserl’s transcendental descriptive phenomenology centred on the belief that the true example of what the phenomenon was, was within the things themselves and that the phenomenon could not be separated from the experience of them. There is a phenomenon only when there is a subject who experiences the phenomenon. Phenomenology, for
Husserl (1964) describes how the world is constructed and experienced through consciousness. The purpose, therefore, is the systematic “analysis of consciousness and its objects” (Magee, 1987, p. 254). Thus a return to philosophical questions about subjectivity and consciousness resulted from Husserl’s approach. Husserl’s “back to the things themselves”, was a call to refer to the present account of conscious knowing free of preconceptions (Kockelmans, 1967, p. 29). Such preconceptions were thought to obstruct the realisation of the true meaning of the experience. In his search for knowledge, Husserl believed that in uncovering the essences he could overcome the dualism of Descartes and return to the furtherest point of an experience, exploring the ‘things’ as themselves (Walsh, 1994). Stripping away preconceptions and perceiving things in their original state was described by Husserl as epoch, or bracketing of the natural world (Cohen, 1987; van Manen, 1990). This world of pre-reflective experience is described by Husserl as the lifeworld. Only through reduction of human experience to primary presuppositions could the standards for rigorous science be met (Kockelmans, 1967). Husserl’s scientific method in studying the phenomena in the same way non-human phenomena were studied involved a detached stance from the researcher.

Central to Husserl’s description of everyday experience as being lived and situated in the lifeworld, is the notion that experience and knowledge are so embedded in the natural world that they are taken for granted (Cohen, 1987). Furthermore, consciousness exists in the relationship with objects and is always a consciousness of something (Dreyfus, 1982; Kockelmans, 1967). For Husserl the main characteristic of human thinking was that human thoughts are always directed to objects. The recording of the experiences and not the object was the major concern of Husserl’s method. As Reed (1994) notes; “…
feelings are ‘about’ objects, and Husserl’s interest was not in the nature of these objects themselves, even their existence, but in the objects as they are perceived or they are taken to be” (p.337). Husserl claimed he had discovered the indubitable foundation for all understanding through intentionality (Dreyfus, 1987). Without intentionality, described as the inseparable connectedness of the human being to the world through consciousness of something, Husserl claimed no-one could experience anything.

3.2.1.1. Lived Experience

Another central concept in Husserl’s phenomenology was the idea of the lifeworld, or the world of lived experience. For Husserl, lived experience was how a person immediately experienced the world prereflectively; the pregiven, or the world as already there (Husserl, 1970). Van Manen (1990) confirms that lived experience is the starting point and end point of phenomenological research, “the aim being to transform lived experience into a textual expression of its essence in such a way that the effect is at once a reflexive re-living and a reflective appropriation of something meaningful” (p. 36). The experiences of individuals as they are lived in the world, and the meaning derived from the lived experiences is the essence of the phenomenon. As living persons we have an awareness of things and ourselves which is immediate, direct and non-abstractive. To understand lived experience, according to Benner (1994) is to go beyond the taken-for-granted aspects of life, to uncover meanings in everyday practice that they are not destroyed, distorted, trivialised or sentimentalised. The importance of lived experience is evident in van Manen’s (1990) approach where the relationship between the self and the world frames the experience of the phenomenon and the individual’s understanding of its meaning.
The focus of the intent of this transcendental phenomenology, then is to explore, describe and interpret how a given phenomenon immediately presents itself to human consciousness and what it means for people and their world.

3.2.2. Heidegger’s interpretive phenomenology

Heidegger, a former student and colleague of Husserl’s while also looking to the “things themselves” held that the relationship between subject and object could not be explained by conscious awareness (Dreyfus, 1987), arguing that dimensions of existence such as anxiety and death could not be accounted for as a connection to consciousness. He developed a shift in philosophical thinking regarding the nature of persons and their relationship to the world. Heidegger’s thinking concentrated on the nature of human experience in its ‘everydayness’. It is, he said, through our everyday dealings with things in the world and other people, in our goals and projects, the intentions we hold, and the way we live out our hopes and values, that we are defined. As Kearney (1986) stated, “…he re-opened the brackets and let existence back in” (p. 30). For Heidegger, the relationship was found in being inseparable from the world of existence or Being-in-the-world. Human reality and lived experience is existence in the world, rather than Husserl’s belief that human reality was consciousness of the natural world.

Other concepts of Heidegger’s phenomenology inform van Manen’s contemporary method of inquiry and subsequently are central to the framework of the current study. Briefly, these include Being-in-the-world, hermeneutics, language and the sharing of meaning and time.
3.2.2.1. Being-in-the-world

Heidegger used the word Dasein or “Beingthere” to refer to human existence. Dasein is the aspect of humanness which is capable of wondering about its own existence and inquiring into its own Being (van Manen, 1990). This notion of existence relates to the fact that we are already in the world, and that we are there as we are (Hall, 1993). In Heidegger’s view we are not simply in the world as entities among a world of other entities, we are not things among other things; rather Dasein, self and world are one (Dostal, 1993). Put another way, Heidegger believed that individuals do not encounter objects only by perception or prediction, but that we encounter objects by our very being-in-the-world. Being in everyday life is transparent and without consciousness unless the context is altered. Heidegger used the analogy of hammering. If the hammer was working well and the person was a master at hammering, the hammer became transparent. The person did not have to think about the hammer at all. This primordial understanding and the entities encountered were called ‘ready-to-hand’ (Dreyfus, 1987). Hammering takes place on a whole background of skills and equipment which Heidegger called significance. According to Dreyfus (1987),

Heidegger wanted to point out that in everyday transparent coping, Dasein is orientated to the future, doing something now in order to be in a position to do something later on … this makes sense as orientated towards something which that person is finally up to but probably cannot have in mind (p. 265).

In those moments when people realise how things are in the world, as separate from them and when there is nothing ready-to-hand anxiety is experienced. This notion of the breakdown of ready-to-hand, is described as the concept of uncanniness by Heidegger (1962).
Through his exploration of Dasein and its essential relatedness to “being-in-the-world”, Heidegger shifted the focus of basic philosophical questions about the nature of persons and their relationship to the ‘everydayness’ of their world of existence. Rather than asking epistemological questions regarding ‘what does it mean to know?’ and ‘how do we know what we know?’ he asked the more fundamental question ‘what does it mean to be?’ The concept of Being became central to his work and was one of the major differences from Husserlian descriptive phenomenology. Heidegger’s approach to phenomenology has been variously described as existential (Solomon, 1987), hermeneutic (Barritt, Beekman, Bleeker & Mulderij, 1983; van Manen, 1990) or ontological (Spiegelberg, 1975). Fundamentally, however his quest was an ontological search for the meaning of Being. Dasein is possible because a being can question Being. For Heidegger, Dasein, human existence as it exists in the world, is not made up of conscious structures, but allows for an open world in which consciousness can function (Heidegger, 1978).

Unlike Husserl, Heidegger was not concerned with bracketing the background knowledge or practices. For Heidegger, being in the world and therefore an individual’s experience was shaped by pre-understanding. Social, historical and cultural backgrounds were brought to the experience. Pre-understanding is not the focal, explicit object, but influences present experience and understanding. Heidegger believed that answers to questions about truth and knowledge could be uncovered by understanding Being (Taylor, 1993). Social, historical and cultural backgrounds and ways of being in the world that influence interpretation constitute understanding, and therefore attempts to bracket out a researcher’s influence is antithetical to the generation of understanding.
Researchers cannot ‘eliminate’ their experience, which is inextricably linked to interpretation (Thompson, 1990). Readers, too bring their own horizons to the study and in doing so participate in the process of interpretation.

### 3.2.2.2. Hermeneutics

Heideggerian phenomenology is grounded in hermeneutics, a discipline traced back to the early Greeks (van Manen, 1990). Hermeneutics is the “idea of bringing to understanding, particularly where the process involves language, something foreign, strange and separated in time, space or experience is revealed so as to seem familiar and comprehensible” (Palmer, 1969); to ‘interpret’ (van Manen, 1990). The phenomenology of everydayness is coupled with a hermeneutic or interpretation to bring to light the hidden basis for the intelligibility of the life-world. Heidegger used hermeneutics to interpret human Being, suggesting that hermeneutics is, essentially, “the attempt to understand the phenomena of the world as they are presented to us, the attempt to understand how it is we go about understanding the world as it is presented and the attempt to understand being itself” (Cohen, Kahn & Steeves, 2000, p.5).

By applying the concept of the hermeneutic circle, Heidegger was able to show the necessity for the questioner to have prior knowledge. The hermeneutic circle is a metaphor for the process of inquiry (Kockelmans, 1967; Ricoeur, 1981), marked by a continuous dialectic in analysis. As we move towards an understanding of Being, so then existence in the world (Dasein) is enhanced and further enlightenment is offered (Crotty, 1996). Dreyfus (1991) explains how engagement in the hermeneutic circle takes place. As interpretation unfolds, there must be a moving back and forth between all overall
understanding and an understanding of related parts. Leonard (1994), however, describes the hermeneutic circle as interpreted by nursing researchers differently. She links it to the sharing of culture and language. Knowledge according to Leonard’s interpretation of the hermeneutic circle, comes from people already in the world seeking to understand other persons in the world. Therefore, a person is always within the hermeneutic circle of interpretation and researcher and participant are viewed as sharing common practices, interpretations and everyday understanding by virtue of their common language.

3.2.2.3. Language and shared meaning

A critical assumption of this phenomenological perspective is its emphasis on language. Language imbues, informs and expresses the shared lived experience. It is thus the medium for understanding, interpreting and communicating meaning (Heidegger, 1962). As understanding is a mode of being rather than merely a way of knowing, language and being are not only inextricably linked (Thompson, 1990), but are one. Hermeneutic phenomenological inquiry is, in effect a “language of thinking” because its reflective discourse strives to deepen our understanding of human life (van Manen, 1990). Understanding, that is, naming or likening what is grasped or perceived as or like something else, linguistically discloses, communicates and shares insight of its possibilities and meaning (Heidegger, 1962). As interpreter and text relate, a fusion of horizons of understanding takes place. This fusion of horizons is the authentic achievement of language developed further by Gadamer (1975). Gadamer (1975) believed that understanding is rooted in a tradition and that all tradition is married to language. Language then, is at the core of understanding as the “essence of tradition is to exist in the medium of language” (Gadamer, 1989, p. 389.) and as Gadamer continues
“the fusion of horizons that takes place in the understanding is actually the achievement of language” (1989, p. 378). In Gadamer’s hermeneutics, understanding brings together the horizons of the past and present.

Meanings then, are presented particularly in words and, through language it becomes possible to express the way things are and to convey this to others at other times. The exchange of words capture the way things have appeared and are. It thus becomes the medium for addressing the questions of “what is something really like?” This is particularly relevant in informing nursing studies when researchers can use the narratives from the participants’ experiences to reveal shared meaning.

3.2.2.4. Time and Being-in-the-world

The concept of time was important for Heidegger although the primary focus was not objective or clock time but time as lived. Thus the primary phenomenon for Heidegger was not the world, time and space but rather Dasein’s being-in-the-world, temporality and spatiality (Inwood, 1997). Lived time, or temporality, is subjective or immanent time. Such time is the time that appears to speed up or slow down depending on our experience. It is “our temporal way of being in the world, as a young person oriented to an open future for instance” (van Manen, 1990, p. 104).

The temporal dimensions of past, present and future constitute the horizons of a person’s temporal landscape. Van Manen (1990) explains it thus,

… my past now sticks to me like memories … that leave a trace on my being – the way I carry myself (hopeful, confident, defeated) the gestures I adopted (from my mother, father, friend) the words I speak and the language that ties me to my past (family, school) and so forth … Past changes under the pressures and influences of the present. I reinterpret who I once was and who
I now am. The past changes itself because we live towards a future which we already see taking shape (p. 104).

Time as past, present and future carries different meanings in Heidegger’s Dasein. The past lives on in the present informing the present situation. Dasein then rebounds into the present and equally, it informs the immediate future. The living present, according to Sokolowski (2000), is given as trailing off and also as coming into presence. He suggests that if experience of the present were not like this, “we never would acquire a sense of past or future” (p. 136) and all we would have at any given moment is that immediate experience. Thus temporality is a continuous experience. When we reflect on our experience we find it to be an exposure into the immediate past and future, or as Sokolowski (2000) notes, “the initial absences of pastness and futurity are present in all our experience” (p. 136).

Consequently any moment of human experience has the three dimensions of past, present and future. Heidegger (1962) explained the centrality of the concept of temporality in the analysis of Dasein as any moment as a crossing point of past and future. The present bears within it the past and the future and transcends the merely present that it is, at the same time, future and past (Heidegger, 1984).

Heidegger’s concepts of time are reflected in van Manen’s approach. In questioning the particular temporal aspects of an existence or experience, van Manen (1990) notes the significance and meaning inherent may be disclosed and described. Life is experienced in the present but not interpreted in that same moment. Experience and meanings arising through the experience can only be studied in the past. Indeed, reflection on lived experience is always recollective, it is the reflection on experience that is already passed
or lived through. A person cannot reflect on an experience while living through it. The temporal aspect provided illuminating paths for exploring the phenomenon of parental presence during resuscitation as revealed in later chapters.

3.2.3. Van Manen’s hermeneutic human science approach

Contemporary hermeneutic phenomenology described by van Manen (1990), an educationalist, is committed to understanding the everyday lived experience, seeking descriptions of the way the world is experienced, the nature of conscious knowing and the structures of lived experience. It addresses how things appear and how they become meaningful. Investigating experience as it is lived, rather than how it is conceptualised as existential, is achieved by asking the question ‘what is the meaning’ of a particular experience. Clearly Heidegger’s philosophy informs van Manen’s approach. He agrees with Heidegger’s (1962) desire to expose often unreflected meanings ascribed to phenomena. The intent is to better understand the phenomenon as it is immediately perceived and encountered. Yet concepts drawn from Husserl are also evident in van Manen’s approach. For him, a hermeneutic method is both a descriptive, phenomenological methodology because it wants to be attentive to how things appear and to let things speak for themselves, and an interpretative, hermeneutic methodology because there are no uninterpreted phenomena.

Drawing on Heidegger’s search for the ontological meaning of Being, Van Manen’s (1990) intent is the search for meaning of being in a particular context that can add to meaning of Being in the broader context; being-in-the-world. For van Manen, phenomenology is a human science mode of inquiry that in intent, method and outcome
is “…avowedly phenomenological, hermeneutic, semiotic or language orientated” (p. 2). The hermeneutic direction reflects an interpretation of text descriptions to disclose concealed meanings and thus the lived experience. Its semiotic approach emerges through the use of written reflective analysis of texts and the use of thoughtful language to understand the experience and meaning. This belief that language is a pivotal medium for hermeneutic inquiry is in keeping with Heidegger’s (1962) view.

Hermeneutic phenomenology is also closely tied with the idea of narrative (Cohen et al., 2000) and, as van Manen notes language is the method. For instance, if a description is phenomenologically powerful, it acquires a transparency and permits the reader to ‘see’ the deeper significance or meaning of the lived experience it describes. A description is powerful, according to van Manen (1990) “…if it reawakens our basic experience of the phenomenon and in such a manner that we experience the more foundational grounds of the experience” (p.122). Writing and language therefore, is essential in revealing the lived experience of the person and the meaning ascribed to that experience. Writing is closely fused into the research activity and reflection and interpretation itself. It has the ability to objectify thought into print and at the same time subjectifies our understanding of something that truly engages us. The object of human science is an essential linguistic project to make an aspect of the lived experience reflectively understandable. The process of writing and rewriting is crucial to phenomenology. As Cohen et al. (2000) explain, the movement from identification and comparison of themes to coherent picture of the whole occurs thorough the reflective process of writing and rewriting.
A series of defining statements for hermeneutic phenomenological human science are presented by van Manen (1990), that offer practical means of understanding and writing. Phenomenological research is the study of lived experience which aims to better understand the meaning of everyday experience. It is also an explication of phenomena through conscious experience. It seeks description of experiential meanings while also concerned with the meaning in human experience. The practice of thoughtfulness is central to phenomenological research and appears as an attentive wondering about human living and being. It is a quest for an understanding of what it is to be human. And finally it is a poetizing activity. The sensitive and revealing use of language characterises phenomenological research in that the meaning is offered is words (van Manen, 1990).

The distinction between descriptive and interpretive phenomenologies is difficult if not impossible to maintain in van Manen’s view. He argues that interpretation is present in both as description cannot be achieved without interpretation.

Hermeneutics, or interpretation has long been used as a means for understanding written texts. Dilthey (1976) believed it was possible to collectively understand a given experience through individual descriptions and his influence is evident in van Manen’s (1990) hermeneutic approach. Dilthey’s hermeneutic formula is lived experience, expression (the text as objectification of lived experience) and understanding. Understanding was not the cognitive act but the moment when “life understands itself” (van Manen, 1990. p. 180). In this way, the fundamental thought was not of the other person but the world itself and how it appeared.
Phenomenological inquiry is a written form of intuiting experiential examples of a phenomenon and a thoughtful description and interpretation of meaning. The intent is to make unfamiliar that which is otherwise taken for granted so that a phenomenon may be understood in a fresh new way. As Dilthey (1987) first described, the to and fro of hermeneutic reflection extends understanding from individual or particular to a broader understanding of the collective or general focus.

The means to merge traditional philosophical thought with a practical intent to provide a rich understanding of the nature and meaning of a phenomenon is offered by van Manen (1990). The activity begins with a thoughtful interest in the awareness and experience of a given phenomenon. Through reflective analysis and continuous writing and re-writing, the nature and meaning of the phenomenon is explicated, described and interpreted. His methodology included the concepts of lived experience, understanding and the four existentials of spatiality (lived space), corporeality (lived body), temporality (lived time) and relationality (lived other) that aid reflection in understanding the phenomenon.

Van Manen’s (1990) eclectic approach offers a framework for phenomenological investigation. Incorporating the ideas of philosophical interpretative phenomenology into a practical method has created an accessible method for phenomenological investigation into human science that has readily been embraced by nurses.

3.3. Phenomenology as a Philosophy and Methodology for Nursing Research

It is not surprising that phenomenology with its philosophical basis in human experience has become valued as a useful mode of extending nurses’ understanding of health and
illness. The case for qualitative studies has been convincingly demonstrated when, as Darbyshire (1994) noted, nursing involves a human-to-human relationship. Phenomenology is often the most appropriate approach for the study of concepts and issues within nursing whose meanings have remained unclear or unexplored (Munhall & Oiler, 1986) and the experience and meaning to human beings is sought. In the past two decades, many researchers have adopted phenomenology as a method of inquiry into exploring the nature and meaning of various phenomena (Benner & Wrubel, 1989; Diekelmann, 1992; Koch, 1994; Madjar & Walton, 1999; Omery, 1983; Parse, 1981; Sadala & Adorno, 2002; Thornton & White, 1999). These studies have provided rich understandings of the lived experiences of patients, families or nurses. Such understandings have complemented nurses’ interest in humanistic caring practices (Benner & Wrubel, 1989; Omery, 1983). Furthermore, phenomenology can inform nursing and nurses about the phenomena of its concern (Taylor, 1993).

Phenomenology and nursing share an interest in the experiences of people, beliefs and values about the nature of humanness. Also shared is the quest for understanding human experience and the ways people reveal their everyday being through language and meaning. Individuals assign meaning to their experiences in both a subjective and objective manner, in relation to the context of the experience. The way in which people live in their day-to-day lives and the meanings they ascribe to their experiences is the concern for both nursing and phenomenology. Understanding human experience is achieved through language and meaning. Thus human experience is interpreted through shared language.
The differences between transcendental and hermeneutic phenomenology and their application in nursing research have been examined (Cohen & Omery, 1994). While the differences can be confusing the ultimate goal of phenomenological research holds greater importance, and offerings from a variety of phenomenological philosophies may be used to guide a practical nursing study (Anderson, 1989). The reconciliation of different approaches is less important than the actual doing of phenomenology according to Anderson (1989). Both transcendental and hermeneutic phenomenology can reveal human experience as it is of and in the world. The phenomenon and reflection can illuminate experience and meaning.

Nurses’ use of phenomenology as a research method has been the subject of scrutiny. Crotty’s (1996) well-recognised critique considered the misinterpretation of specific phenomenological principles. His main complaint was that nurses had developed a new phenomenology that bore little resemblance to the original philosophical ideas. He concluded that much of the North American research claiming to be phenomenological was misguided by taking a more subjective approach detailing the individual human experience. Crotty’s (1996) provocative critique argues that nurses claiming to use a phenomenological approach frequently describe an individual’s subjective experience rather than the greater understanding of the experience of the phenomenon. His philosophical focus however, ignores the practical issues inherent in nursing research (Lawler, 1998). While phenomenological research seeks the subjective individual experience, it is the collective meaning of the experience objectively - true to the object (van Manen, 1990), that is the nurses’ central intent.
Other concerns relate to inadequate explanations about the philosophical ideas informing a specific study or the use of methods incongruent with a phenomenological framework. Consistent to all phenomenologists is their commitment to methodological rigour. The process must be held up to critical examination and scientific principles. Phenomenology is a rigorous science that is systematic, explicit and inter-subjective (Cohen, 1987; van Manen, 1990), that now have an established place in nursing research. Sandelowski (1997) however, advises researchers to be vigilant in their application and appropriateness of qualitative methods and to maintain theory in their use of qualitative research.

3.4. The case for phenomenology in the study of parental presence

During resuscitation

There is little doubt that witnessing a child’s resuscitation is a truly unique, subjective experience for each parent. Each member of staff also has a unique perspective on their experience of resuscitating a child when parents are present. Yet, little is known of the experience. Phenomenology provided an appropriate theoretical and practical framework for understanding the phenomenon of parental presence during resuscitation that accepted the importance of individual and context-specific experiences. In adopting a phenomenological perspective, this study approached the question of parental presence during resuscitation of a child not as a problem in search of an answer, but as a complex human experience to be fully explored as it is lived. The aim of this study was to gain in-depth descriptions into the experiences of the parents and nurses as they are lived from an ontological perspective, and to make sense of the experiences, the meaning of the phenomena that make up the experience. I wanted to explore what the experience was
like for both parents and nurses. Thus, the phenomenological question posed in this study was “What is the nature and meaning of parental presence during resuscitation for parents and nurses?” That is, what is it like when parents are present during resuscitation of their child? What is it that makes up this experience as it is lived? And from a hermeneutic perspective, what is it to ‘be’ a parent or a nurse in the experience of parental presence? The question chose the methodology rather than vice versa.

In keeping with the phenomenological approach, participants who had expert knowledge of the phenomenon by experiencing it first hand could provide shared meaning of the experience through face to face interviews. This would allow context rich experiences to be revealed and interpreted simultaneously. When asking a person to turn to an experience, it is important to remain close to a level of experience that is common to everyday life. With this textual data, the researcher conducts a reflective, thematic and written analysis that descriptively interprets the nature and meaning of the phenomenon (van Manen, 1990).

The current study utilised a predominantly hermeneutic framework informed by van Manen’s (1990) human science approach to focus on the significance of how the phenomenon of parental presence during resuscitation is experienced by parents and nurses in PICU. Van Manen’s (1990) synthesis of phenomenology and hermeneutics into a human science provided direction and reassurance for the selection of the approaches to the study method. Offerings from transcendental phenomenology also contributed to the first layer of understanding of the phenomenon in asking the analytical question ‘what are the participants telling me about the nature of the experience of parental presence?’ I
collected and interpreted the experience of the participants as they lived and recounted it. Thematic analysis uncovered the nature of the experience.

A hermeneutic analysis of the phenomenon revealed the meaning of being in the human experience. An understanding of what it is to be in the everyday world, allows a description to be made. As an interpretive research approach, hermeneutic phenomenology requires the researcher to be involved in the process, taking the view that the world of others becomes known through one’s own experience (Walters, 1994). In asking the question ‘what is it to be?’; reflecting on the experience and writing as interpretation, I became immersed in the experience. As language is pivotal to a hermeneutic human science approach and understanding is a mode of being, the use of language and text as the modes of investigation into this study was the means by which being could be uncovered. The participants’ Beingness, in a study of this nature, is held in their language which in turn was transformed into the text and offered to the research process as a source of meaning. As explained later, the current research began with concrete, individual experiential descriptions, progressed to a collective understanding of parents’ and nurses’ lived experiences and concluded with an interpretation of the phenomenon of parental presence during resuscitation as lived.

Van Manen’s (1990) hermeneutic phenomenological human science approach provided support for the study’s method and a practical way of linking phenomenology as philosophy and health care research method. The process of analysis through writing and language was made clear through van Manen’s suggestions for textually organising writing. Organising writing is not concerned with merely arranging the text but in
searching for a sense of form and wholeness of the text consistent with the methodology. Interpretation continues throughout. Five structures are suggested by van Manen (1990) in order that a phenomenological description may be presented into a strong and thoughtful text. A thematic approach structures the description around specific themes. This was the predominant approach adopted in the current study. Analytical, exegetical, existential and exemplificative ways of structuring writing are also suggested. None are mutually exclusive and a combination of approaches may be used dependent on the nature of the phenomenon. An exemplificative approach was adopted in understanding the meaning of being in the current study. Exemplification allows the illustration of thematic understanding by example, anecdote or section of transcript.

3.5. Conclusion

This chapter has provided overviews of the development of phenomenology as philosophy and as the foundation for nursing research methodology. It has provided sufficient background for this study’s methodological decisions and theoretical foundations. Although phenomenological thinking continues to evolve, nursing inquiry using phenomenology as philosophy and method needs to be consistent with its philosophical underpinnings, if nursing research is to continue to offer sound, scientific work.

A hermeneutic phenomenological human science approach was used as the theoretical framework of the study of parental presence during resuscitation of a child in PICU. This enabled me to allow the parents’ and nurses’ accounts to speak for themselves by recognising that there are no uninterpreted data. This method acknowledges that all
aspects of the lived experience are already meaningful to the person. By encouraging parents and nurses to explore their experience, I have been able to identify meanings previously concealed. In revealing the meanings the parents and nurses attribute to their experiences and by making them explicit, a broader knowledge of the scope of nursing practice will follow. The following chapter outlines the organisational processes of the study, drawing on the selected sources of the phenomenological hermeneutic approach underpinning the theoretical method.
Chapter 4

The Research Process – Investigating the Phenomenon of Parental Presence During Resuscitation

4.1. Introduction

This chapter outlines the design, methods and procedures of the study, relating van Manen’s (1990) notions in its explanation of the processes associated with a hermeneutic phenomenological exploration of the phenomenon of parental presence during resuscitation. The research question and aims are provided to demonstrate the steps taken. The collection and analysis will be described in relation to the hermeneutic process. The analysis is presented in the sequence it was undertaken and the section reports on the stages of analysis and its development. Undertaking sensitive research, such as talking with parents about their child’s resuscitation and potential death required specific ethical considerations to be made. These considerations and the strategies employed are described throughout the chapter, as the research plan is presented. The strategies used to ensure the quality of the study in relation to trustworthiness, transferability and the nature of the hermeneutic phenomenological process are outlined. Finally the participants are introduced.

4.2. Research question and aim of the study

The study aimed to investigate parental presence at resuscitation of a child in PICU as a phenomenon of human experience and to provide a full description and interpretation of
the phenomenon. The full phenomenological description was sought from 8 parent couples and 6 PICU nurses. Thus the question posed was:

*What is the nature and meaning of the phenomenon of parental presence in ICU for parents and nurses?*

4.2.1. The study setting

The study setting was a 20-bedded paediatric intensive care unit (PICU) within a tertiary-referral paediatric metropolitan hospital. The unit admitted children from birth to 16 years with a variety of critical conditions, including major burns, motor vehicle accidents, poisonings and sepsis. Additionally, approximately half were planned admissions for correction of complex congenital cardiac abnormalities.

4.2.1.2. Gaining entry to the clinical setting

As a research student who received a full time scholarship from the PICU, I was able to take a break from my previous role as a Clinical Nurse Specialist in the PICU. This was of particular importance when interviewing other staff members, many of whom I had well established working relationships. It was important to be seen as a researcher rather than clinician. Crowley (1986) noted this importance to separate clinical practice from research to minimise the role confusion between nurse as practitioner and nurse as researcher.

However, my experience was undoubtedly beneficial for all participants, as they did not have to explain procedures or routines to me. From my point of view, I saw it necessary to be viewed as a nurse researcher who was also an experienced paediatric intensive care nurse. The parents, too, were grateful that I was able to readily understand exactly what they told me about the unit and the resuscitation. Identification of researcher bias...
through the use of memos and consultation is important in establishing neutrality and thus credibility (Morse & Field, 1996). I had already documented fully my own thoughts and insights as the study progressed and I also discussed the study with my supervisors, as well as with other PhD students. From the beginning, I made participants aware of my own background as a paediatric intensive care nurse, thereby declaring any preconceived notions I may have had.

My previous role as an experienced clinician as well as recent research experience in conducting qualitative interviews provided me with the credibility to undertake this study. The parents were aware of my experience in the intensive care setting. They were, however, also aware that my role was that of a researcher, rather than nurse or counsellor, so were assured of confidentiality.

4.2.2. Ethical considerations

Research on sensitive subjects such as paediatric resuscitation and possible death places participants at particular risk from psychological distress (Kavanaugh & Ayres, 1998). The ethics proposal and the study, therefore, focussed on maintaining the balance between the potential harmful aspects of interviewing grieving parents, the strategies to minimise this harm and the parents’ need to talk and my desire to hear their story in an attempt to understand the phenomenon. Although there were no known physical risks to participating, I was aware that interviewing parents would cause them to recall painful memories. Formal approval to proceed from both the Hospital and the University Ethics Committees was granted in December 1999, with only minimal changes advised to word structure in the parent information sheet. Despite approval being granted on the first
submission, the development of the proposal was by no means hurried, taking 5-6 months to prepare.

4.2.3. Selecting participants

According to van Manen (1990), the primary criteria in selecting participants is that they should have direct, personal knowledge about the phenomenon being explored and be able to readily discuss their experience. Thus parents of children who suffered a cardiopulmonary arrest requiring CPR were invited to participate. Both parents of children who survived and who died and who had been present or absent were included. Including parents who were not present during the resuscitation was necessary, as they too had an experience of the phenomenon. These parents were identified from the in-patient records from PICU. Ten parent couples/single parents were approached and eight were successfully recruited into the study. Six nurses who had participated in a recent resuscitation attempt with parents present were also recruited. There is little advice about the most appropriate number of participants for a phenomenological study and current suggestions range from one participant to a group between five and twelve people (Morse, 1994; Sandelowski, 1995 & 1996). Recruitment continued until data had reached saturation with no new themes emerging in the analysis.

4.2.3.1. Exclusion criteria

Parents with a documented psychiatric, depressive history or other pre-morbid factors identified by discussion with the intensivists and social worker were excluded. Additionally, parents who could not speak English fluently were excluded from the study.
4.2.3.2. Recruitment of participants

Initial contact with the parents of a child who had survived a CPR event was made following consultation with medical, nursing and social work personnel in PICU. If the team believed a family were not able to cope with the interview, the family was not asked to participate. I discussed the suitability of timing to speak with the parents with the social worker. Potential participants in the PICU were then approached; I introduced myself and discussed the study with them to gauge initial interest. Those parents who agreed to participate, were asked to choose a suitable time and place for the interview. The interviews were to take place approximately one week following a successful resuscitation attempt. This time was chosen, to avoid problems with recall and it was anticipated that the children who survived would be progressing well and may have been discharged from the PICU. However, in reality, this proved not to be the case. The first interview was delayed. While the parents agreed to participate and were keen to talk at some stage, after talking with them it was not considered appropriate to conduct the interview as arranged. We had agreed a time and place for the interview, but on arrival, the mother was extremely upset and anxious about her son, who remained critically ill and ventilated with the prospect of returning to theatre for further surgery. The interview was postponed until they felt ready to talk to me, and I continued to visit them on a regular basis to monitor the baby’s condition and progress. I was aware that sensitivity was needed in order to recognise the subtle signs given by parents who did not want to participate but may feel trapped into agreeing to an interview, particularly when still in hospital. My experience as a PICU nurse, establishing trusting relationships with
distressed parents, ensured I was able to recognise these covert signs. For the first
parents, however, postponement did not indicate a reluctance to participate.

I had anticipated that parents whose child died would be more distressed by talking about
the resuscitation attempt than those whose child had survived. I realised, however, that
people construct their own meanings and what may be highly sensitive and emotional for
one person may be viewed as matter-of-fact for another. Consequently, as Hutchinson,
Wilson and Wilson (1994) suggest, the nature of a study topic is not generally a predictor
of participant consent or response. Indeed, several studies identified catharsis, self-
acknowledgment, a sense of purpose, healing and a voice for the disenfranchised as
powerful benefits to continuing research in sensitive areas (Cassell, 1987; Ramos, 1989;
Hutchinson et al., 1994; Kavanaugh & Ayres, 1998). The notion that participating may
assist parents in their grieving was not the purpose of the study and it was therefore
deemed important to examine the potential harm such an interview may cause. The
presence of some distress would not be a sufficient reason to terminate the interview.
Conversely, the absence of distress or tears is not always reassuring. In assessing
potential distress and reducing unnecessary harm, I was guided by the following
recommendations of expertise, process consent, anticipating problems, delaying contact,
support and debriefing and personal safety proposed by Cowles (1988) and Kavanaugh
and Ayres (1998).

If the CPR was unsuccessful, initial contact with the parents was made approximately
three months after the child’s death. After discussion with the social work department
and The Compassionate Friends Association, and following Cowles’ (1988)
recommendations, it was agreed that this time was appropriate so that data could be collected as close as possible to the loss but not necessarily during the crisis period immediately after the loss. The social worker in contact with the family agreed to raise the subject of the study, determine whether there was likely to be resistance to participating and ask if I may contact them by mail (Appendix A). A telephone call was made one week after the letter had been sent to identify parents who wished to participate (Sample script for telephone contact, Appendix B).

Nurses who routinely worked in PICU and had taken part in a resuscitation attempt with parents present at the time were invited to participate. Invitations were extended to all staff. An overwhelming number of staff volunteered to participate. Therefore, participants were selected from those with the most experience of the phenomenon and were interviewed one week after resuscitation when parents were present. There was a range of experience amongst nurses, from novice and beginner intensive care nurses to those who were deemed to be experts. An expert nurse was one who gained experience not only through the passage of time in intensive care, but also accrued clinical skills and knowledge and was able to use this knowledge in acute clinical situations (Benner, 1984; Benner & Wrubel, 1989). Expertise, according to Benner (1984) develops through a process of comparing similar and dissimilar clinical situations with one another, so an expert has a deep background understanding of clinical situations based upon many paradigm cases. These experts demonstrate an intuitive grasp of the situation, not possible without sufficient background and experience and learned knowledge with many similar and dissimilar situations. The nurses in the current study who were identified as expert met these criteria. They had the ability to not only use their deep background
understanding based on a broad knowledge and experience base, but also to insightfully care for families with empathy. For the purposes of this study, the term ‘expert nurse’ draws on Benner’s (1984) definition of ‘expert’. The participants are introduced at the end of this chapter.

4.2.4. Data collection

I anticipated that the interviews would take place over a period of 12 – 18 months. Cardiopulmonary arrests were relatively common in such an acute environment with a number of critically ill children. Over the previous five years, approximately 55 arrests per year had occurred, although in the last year, that number had risen to over 100, as technology improved and more and more critically ill children were stabilised in rural areas and transferred to the tertiary referral PICU, who previously may not have survived to reach admission to the hospital.

In keeping with van Manen’s (1990) recommendations, the primary data for this research took the form of tape-recorded and transcribed experiential descriptions from the participants. One face-to-face interview was conducted with nineteen of the twenty participants, with a total of 14 separate interviews. One mother, after much consideration requested that the interview be conducted over the telephone due to geographical distance from the hospital. While I offered to meet at a place of her choosing, she preferred not have reminders of her child’s death in her home such as staff associated with the hospital. Reassurance regarding the compatibility of telephone interviewing with phenomenological research was established. Sweet (2002) argued that this method of data collection is a methodologically sound and valuable technique, capturing
participants who might not otherwise be in a position to continue. Certainly, the telephone interview conducted elicited a wealth of information, lasting as long as the face-face interviews.

It was not deemed necessary to conduct any further interviews as the phenomenon under investigation focussed specifically on one particular time period; that of resuscitation. Each interview took place over a period of one to two hours.

The tape-recorded conversational interviews were unstructured. The use of a conversational style of interviewing encouraged an open, interactive, reflective and engaged discussion (Kvale, 1983; van Manen, 1990). This discussion elicited rich descriptions of the experience of parental presence during resuscitation, from which meanings were drawn.

4.2.5. Confidentiality and informed consent

Informed consent was obtained (Appendices C & E) and parents were assured that they were able to withdraw from the study at any time, and that refusal to participate or withdrawal during an interview would in no way affect their child’s care or their ongoing relationship with the hospital. Nurses were also assured that refusal to participate would not affect their employment at the hospital, although the response to participate was overwhelming. All participants were given a copy of the consent form and information sheet (Appendices D & F), which gave details of the purpose and design of the study.

Process consent was adopted, to ensure the ongoing consent as the interview progressed through the more distressing areas of discussion. This process, as defined by Munhall
(1988), is the immediate renegotiation of consent as circumstances change during an interview. Limited information was available about how to actually practice with process, but Munhall (1988) and Cowles (1988) both describe using a flexible approach when an emotional response such as anger or crying occurs. I directed the interviews in and out of sensitive areas, depending on the emotional responses of participants. I was able to assess these responses due to my previous experience as a clinical nurse specialist (CNS). I also offered rest breaks to participants or the opportunity to break from the interview permanently if the distress experienced was too great for them. I continued to check with participants if they wished to continue. This was most relevant when interviewing parents of children who had died. I did not, however, wish to give parents non-verbal cues of impatience or disinterest when they became distressed and I explained at the beginning that unless they requested otherwise, I would continue to tape our conversation during periods of distress or crying, as I wanted to hear everything they had to say. I was aware that if I appeared uncomfortable during these times, I may inadvertently ‘punish’ them for their reactions when talking. I reaffirmed that it was ‘okay’ to get upset or cry.

I was reassured in knowing that participants who could not tolerate talking about a subject would not (Hutchinson et al., 1994). They will not consent to participate. Respect for these refusals is critical and keeping track of such refusals is therefore imperative. Boss (1987) however, recommends that researchers must:

… respect participants’ informed consent to participate as this may be a signal they feel they can cope with, or even welcome, our intrusion. These people may sense they can handle the ‘stirring up’ whereas those who refuse know they cannot (p. 152)
Encouragingly, only two of the initial 10 parents I contacted did not consent to the study. Confidentiality of each participant was assured. All participants were asked to choose a pseudonym or were allocated one. Participants’ true identity was only used on the original consent form. The names of any family or friends or other identifying information was also changed, in order to further protect the participants.

I suggested to parents that they might wish to have a support person with them during or following the interview. As crying is not always a cue for intervention and the absence of tears not always reassuring, I maintained an awareness of all behaviours that related to the study, and not just those manifested during the interview. No parent, however, choose to have a third party present.

I began each parent interview by asking them to describe the time when their child became critically ill and required resuscitation. Nurses were asked to talk about a time when they had been involved in a resuscitation attempt when parents were present. Other questions made throughout the interviews did not direct the participants, only encouraged them to expand upon points already made or were reflective. Reflective or clarifying points such as “can you give me an example?” invited elaboration of specific issues.

4.2.6. Debriefing participants and self

Kavanaugh and Ayres (1998) recommended structured debriefing time be incorporated into the interviews. At the end of each interview with participants, I allowed time to discuss the interview and raise any concerns they had about their feelings. I also provided the parents whose child had died with written information about the various community agencies they could contact for ongoing support (Appendix G). These
agencies were those that the Hospital already recommended for support. The opportunity to contact the social worker was again offered at this time.

Disengaging from the study field and terminating the relationship with parents was necessary following completion of the interview. I did not wish to intrude into their lives. If they wished to talk with me again, however, I provided them with my contact details. Any questions regarding medical treatment, I with parental permission, informed the appropriate intensivist who followed up accordingly. As a sense of closure was necessary for participants, I offered to provide them with a copy of the results of the study. As van Manen (1990) noted, participants often develop more than a passing interest in the researcher’s study and care about the outcomes.

A letter of appreciation was mailed to each participant within a few days of our meeting. No parent felt the need for further contact with me. Several however, did contact the liaison social worker to express their gratitude at being able to tell me their story. They did express an interest in reading the completed study.

Finally, as I was to become immersed in the experiences of distressed parents, it was important for my own well-being that I had a professional confidante to talk over any concerns or distress that I may feel. The social work department at the hospital agreed to provide this support for me and I took the opportunity to talk with one social worker on a regular basis.
4.2.7. Personal safety

Interviews conducted within the hospital are usually considered ‘safe’. Home interviews, however, do not have the same guarantees. In the case of questioning bereaved parents, I was stepping into an unknown location with parents who may have become angry or resentful of me. Indeed, Kavanaugh and Ayres (1998) conducted interviews together and carried mobile phones and pagers with them at all times, as their study into peri-natal death took them into neighbourhoods with high crime rates in the USA. Smith (1992) similarly made provisions to ensure personal safety by choosing to start the interviews in the spring when daylight hours were longer. Each journey was planned so she did not place herself at risk by having to ask for directions. Additionally, Smith (1992) ensured that someone knew her movements and expected time of return home. I, too, planned similar strategies for my personal safety. I carried a mobile phone and the address and telephone number of the parents I was interviewing was left with a family member. While they may seem like small details, for a woman alone in a potentially distressing situation, it was important to think critically about such matters.

Such strategic planning was considered fundamental to the success of the study’s progression. It gained me valuable insight into the world I would enter as a researcher. Fortunately, I did not encounter any instances where I felt unable to cope with the parents’ responses. I was able to gauge their reactions and respond accordingly. The parents verified this when they spoke of their appreciation in being able to talk once again about their time in the PICU. While many were distressed at times, they all wanted to continue to tell me their stories, and talk about their child to someone they believed
understood. I was humbled at the parents’ ability to speak so candidly to a stranger and at their ability to accept and attempt to deal with the death of their child.

4.2.8. Documenting the processes

In addition to audio-taping I kept a journal dedicated to the interviews. I kept dated field notes before and after each interview to place each one within its context. These recorded immediate impressions, issues and reflections related to the conversations and included participants’ behaviours and non-verbal responses as well as a physical plan of the interview. This process enabled me to anticipate problems that may arise. I remained aware of the possibility of causing undue distress but believed that the parents whose children had died following resuscitation had largely been ignored in similar research. Their experiences were vital if I was to capture more than a fraction of the experience of witnessing a resuscitation attempt on their child.

I documented all contacts made with potential participants, cancelled appointments or lateness that may indicate a reluctance to be interviewed. If such reluctance was suspected, I left a telephone number for the parents to contact me if they wished to continue to take part in the study. I did not attempt to continue to contact them again. Many researchers advocate this strategy to journal participants’ behaviours (Morse, 1991; Rew, Bechtel & Sapp, 1993).

In keeping with the phenomenological approach, an audit trail systematically detailed the timing and context of practical and methodological decisions, related problems and emergent insights of the analysis process. Advice for preparing an audit trail came from several sources (Koch, 1994; Lincoln & Guba, 1985; Morse & Field, 1996; Rodgers &
An audit trail can give confidence for the quality and credibility of a phenomenological study, tracking all decisions made in the research process. A variety of criteria have been recommended to address such quality and include truth value, applicability, consistency and neutrality (Lincoln & Guba, 1985) designed to meet the broad demands for rigour of qualitative research, not specifically phenomenology. The standards of quality, credibility and plausibility (van Manen, 1990, 1995) framed the current research. These criteria incorporate other suggestions for trustworthiness and transferability of meaning (Guba & Lincoln, 1989; Koch, 1994; Sandelowski, 1995, 1986). The trustworthiness of a study may be endorsed if the researcher describes and interprets the experience (credibility); readers consider that the study is transferable to another context and are able to follow the decision trail (dependability); and the researcher shows how interpretations have been arrived at (confirmability). These processes are endorsed in the current study and visible throughout the text.

The audit trail then consisted of a series of journals (paper and electronic copies) to clearly document practical, ethical and methodological decisions made throughout the course of the study. In addition to the first interview journal, a second was dedicated to the development of themes and interpretations as they were revealed. A third was devoted to my thoughts and decisions about the structure of the study as it progressed. It thus provided a record of early issues, strategies and decisions that may have been forgotten as the focus shifted towards data analysis, interpretation and significance. I documented any problems I encountered along the way, as well as how I felt during each phase of the study. Such recorded reflectivity improves the rigour and trustworthiness of this type of inquiry (Punch, 1986; Koch & Harrington, 1998). Reflections recorded
throughout the study process are analysed and as Koch (2004) notes, often instigate action perhaps reshaping the way in which the research is progressed. Thus journal entries become data for reflection and are woven into the research text, showing how an interpretation was made. In delaying an interview due to the ongoing critical status of a child for instance and reflecting upon my decision, I was able to make a considered judgment regarding the continuing inclusion of the family. Reflecting on my conversations with the parents, and using my expert knowledge in working with families in PICU, I knew the decision to delay but not abandon the parents’ participation was correct.

4.2.9. Transcribing

Each of the interviews was transcribed into text by a research assistant. I chose not to transcribe the tapes myself, as I believed I could still become sufficiently immersed in the data by my listening to the tapes and reading and re-reading the texts. I checked the transcription process of each of the interviews, ensuring they were transcribed accurately. The transcriptions noted not only the spoken words but also the pauses, tears, laughter. In reading and re-reading and continually listening to the participants’ voices, I could visualise every frown, smile or tear on each person as I became immersed in the data. Relevant field notes were transcribed into the left margin. The right margin provided sufficient room for subsequent hand-written statements and reflections. In order to manage the data effectively I entered the texts into the computer program QSR NUD*IST version 4 (QSR NUD*IST, 1995). This program assisted in coding, storage and retrieval of texts. I was able to link the texts, in whole or in part and produce conceptual
classifications of data as well as creating conceptual memos and insights for further consideration.

4.2.10. Analysis

Analysis began during the interviews, in listening and re-listening to the interview tapes. Formal analysis was carried by line-by-line thematic analysis, the development of themes and reflective interpretation processes. It was designed to identify, understand and construct the message about the experience into a whole that would contain the full description of the phenomenon.

The following section describes the phenomenological analysis of the experiential descriptions. Each level of analysis involved extensive re-reading and concentration, reflection and considerable writing and re-writing. Each level differed in its focus, reflection and language. Firstly, the participants’ particular experience was analysed by the construction of thematic statements which led to the analysis of the collective experience through the development of themes. Finally, the focus moved from the individual and collective lived experience to the meaning of the phenomenon of parental presence during resuscitation as it was lived and interpreted.

4.2.10.1. Constructing thematic statements

The individual participants’ experiential description was revealed by the construction of thematic statements. The text of each interview was examined line by line. The essential message in each sentence or phrase was interpreted and written as a thematic statement. I continually asked myself “what is this person telling me about the phenomenon of parental presence?” The answer was then framed in a thematic statement. For example,
when Simone said ‘when I first encountered the situation of having parents there, my first reaction was “oh they’re going to watch me. I’d better not do anything wrong” then I realised “I know what I’m doing just as much as anyone” …’ the thematic statement “A nurse is apprehensive at being watched by parents for fear of making mistakes” was written. Simone’s message was one of apprehension that was transformed into a thematic statement. I had to remain mindful that I was only writing the parents’ and nurses’ messages of the specific nature of the resuscitation, rather than the entire intensive care experience.

4.2.10.2. Constructing themes

Following reflection on the thematic statements and comparisons across the participants, themes began to emerge. For example, it was clear that for the parents, a major aspect of their presence at resuscitation was their child’s inherence to their world. The thematic statements supported a theme of **Being only for a child**. Dimensions of a theme were given subheadings under the main theme. These dimensions were collections of thematic statements that held groups of main ideas. On further reflection several aspects considered to be separate dimensions became part of another dimension under the same theme. For example, in the parents’ accounts, the theme **Living in a relationship with staff** initially had 3 dimensions with several sub-themes for each dimension. The dimension of **Becoming a PICU family** supported several aspects including **Fitting in**, **being accepted** and **being on trial**. On further reflective analysis, the thematic statements supporting these sub-themes could all be contained under one subheading of **Being accepted**. Each theme then was made up of dimensions of varying numbers, with sub-themes that held the theme findings in a rational organisation.
Four themes were identified from the parents’ thematic statements, and three themes from the nurses’ accounts. They were consistent across all accounts of similar participants.

4.2.10.3. Constructing interpretive meaning

The final step of analysis sought a hermeneutic description. This interpretation was concerned with identifying the meaning of being in the phenomenon. Such analysis began with the question **what is it to be in the resuscitation when parents are present?**

In order to reach an answer, I used the description of the phenomenon already revealed and applied questions to the thematic analysis. For example, in the theme **Making sense of a living nightmare**, I asked what is it to be a parent who is making sense of a living nightmare. Following further reflection and checking for agreement across participants, an answer, written as a description of being, was revealed. Each description was considered to be an element of the phenomenon. The description of being for the example above was **being in chaos**. Each theme was subjected to this process, yet in searching for the meaning of the phenomenon, it was clear that both parents and nurses contributed to each element. Thus, for example, nurses’ experiences were also manifested in **being in chaos**.

Extracts from participants’ accounts provide authentic descriptions of their experiences. Quotations reflect only a proportion of the experience and inclusion is driver by the researcher’s choice that best illustrates the experience (Whitehead, 2004). While some participants were more articulate than others, I gave attention to the range of quotations
from all participants yet providing the most illuminating quotations to support a point. In this thesis, quotations from participants are italicised.

The research process and the way in which van Manen’s (1990) philosophical and practical approach to hermeneutic phenomenology have been incorporated have been described in this chapter. Since phenomenological research is primarily a written mode of inquiry, consideration was given to the quality, credibility and trustworthiness of the descriptions presented in the ensuing chapters. By documenting activities and decisions during the process of the research I have demonstrated a reliable audit trail that supports credibility and trustworthiness in the study. Great consideration to the ethical implications in conducting sensitive research has been paid, utilising strategies to minimise harm to the participants, while at the same time uncovering their experiences. This vigilance in planning the research process was rewarded when only two potential participants refused to take part and no adverse effects to participants recorded during the interviews.

4.3. The participants

This section introduces the eight parent couples and the six nurses who participated in the study. Although each participant’s experience is unique, they held a commonality of experience that has provided trustworthiness in the findings of the study. The phenomenological description and the interpretation of that description emerged from each of the participants’ accounts. While each parent was asked initially about the specific nature of the resuscitation, they frequently provided me with their full account of the entire PICU experience. Their experience of the resuscitation was bound up in the
greater experience of the PICU stay. While the analysis had to remain specific to the phenomenon, I could not disregard their entire story – this was their experience of the resuscitation as they lived it. Details about each participant are drawn from my field notes.

4.3.1. The Parents

**Jenny and Mark**

I met Jenny, 36 years of age and Mark, 35, four days after Matthew’s surgery. Matthew was eight months old and had a six year old brother at home. He had been transferred from the neonatal unit in the hospital to the intensive care unit following a second stage in his corrective repair for complex cardiac abnormalities including a ventricular septal defect (VSD), coarctation of the aorta and transposition of great arteries (TGA). Matthew had never been discharged home since birth. When I met Jenny and Mark, Matthew was still in PICU and critically ill but stable. His stay in PICU was long, as he developed sepsis and continued to lose weight. He was fed parenterally. I found Jenny and Mark to be friendly and welcoming when I approached them. Several attempts at conducting the interview, however, were aborted as Jenny could not consider talking while Matthew remained ventilated. My notes at that time said:

*I arrived in PICU at 10am. Jenny was having a cuddle with Matthew who is still ventilated. She appears tearful. I asked how things were going and she told me he wasn’t getting any better and began to cry again. I offered to stay and we talked. We postponed the interview. Jenny’s perception is that Matthew is not going to get better and may die while the nurses’ is that he will improve slowly.*

*Jenny and Mark both said they want to be interviewed and that it might be good for them to talk to me. I said I would continue to visit them and they appreciated that.*

Jenny and Mark then contacted me a week later when Matthew had improved.
Further notes indicate that my decision to postpone the interview, yet demonstrate interest was rewarded:

25 March - I believe I made the right decision. Jenny is too upset to talk now. I hoped that doing the interview one week post arrest they would be out of PICU but he will be there for a while. I don’t believe there will be problems with recall – it’s still at the front of their minds. I am sure their desire to take part at a later date is genuine.

3 April – I was worried Jenny and Mark might not want to be interviewed – I thought that their reluctance was a way of signalling refusal but when I saw Jenny last week she was emphatic that they want to talk to me. I was determined to not pester them yet indicate my interest in their story.

We conducted the interview in a private room used for such purposes on the unit. By this time, I had developed a relationship with them, as I frequently visited to monitor Matthew’s condition and we would talk generally. In the interview Jenny told me about her pregnancy and how Matthew had a ‘blue turn’ in the maternity hospital. Several hours later and Matthew had been transferred to the neonatal unit at the Children’s Hospital, while Jenny remained in the maternity hospital, following a caesarean section. She felt lost and angry at his transfer and resented other mothers who had healthy babies with them. She told me:

*I found it really traumatic … all these mothers walking up and down with their babies … I could hear the babies crying all night and it was heart-wrenching. And I was thinking to myself ‘how come they’ve got their babies and I haven’t, why me?’ but it only lasted for a split second.*

Jenny had begun to experience the separation from her new baby that she would come to know often during the next few months in intensive care. Matthew underwent surgery aged two days for coarctation of the aorta and a shunt. He remained in the neonatal unit until his subsequent surgery at age six months. This was to be the completion stage but it transpired that he would have to return again aged one year. When I interviewed Jenny and Mark, Matthew was progressing and was finally discharged home two days later for
the first time since his birth. Jenny and Mark were anxious about taking him home and were concerned that something may go wrong. Jenny had told me of her attempts to not become too attached to Matthew in case he did not survive. In spite of this, it was clear that both Jenny and Mark’s world centred on Matthew and they loved him. They rejected spiritual support from the hospital chaplain – something they felt was forced upon them and opted for support from close family and friends who visited them frequently.

Throughout their stay in PICU, Jenny and Mark tried to remain positive and shared many laughs with the staff. Indeed, the nurses commented that they appeared to be coping well with Matthew’s state. Jenny however, told me that they had to ‘put on a good front’ in order for them to cope. Mark often chose not to visit, and instead went to work where he would try to forget for a while the enormity of their experience.

Jenny and Mark had been absent when Matthew arrested, and walked in unprepared to see the resuscitation. They both chose not to stay, as they felt they could not possibly watch the drama of the scene. Jenny however, did decide to come and go from the resuscitation scene and spent time in the parents’ room – a room attached to the unit. Matthew then suffered a second cardiac arrest 12 hours later and once again Jenny and Mark chose to spend only brief periods of time at the scene, instead choosing to wait in the parents’ room with other family members. Matthew was successfully resuscitated but Jenny and Mark were then prevented from entering the unit for a long period of time. The explanation given was “the nurses said they had to clean him up, because they’d opened his chest but I don’t know why it took so long to clean him up” said Jenny.
Matthew returned for further surgery at one year of age. Once again he was critically ill on return from the operating room and was placed on left ventricular assist device (LVAD) – in effect, bypass for the left side of the heart until it was deemed appropriate to withdraw its support when his own cardiac function had sufficiently returned. His condition deteriorated, however, and Matthew died 12 hours following his third surgical attempt. I had talked with Jenny and Mark when they returned to the hospital. They remained positive about his prognosis until the very end. I did not see them again, but sent a letter of condolence.

**Dominique**

I met Dominique, 28 years and her husband David, 32 in the PICU four days after Jamie suffered a cardiac arrest. Jamie was nine months old. Dominique had left the unit during his first arrest and on her return; he suffered a second arrest from which he was once again successfully resuscitated. Dominique was prevented from entering the unit during the second resuscitation attempt and was told to wait in the parents’ room until the staff deemed it appropriate for her to enter, despite the unit’s guidelines stating that parents may be present. Dominique was alone. She telephoned David and expressed frustration and anger at being stopped from being with Jamie, which was compounded by her guilt at being out during the first arrest.

I arranged to conduct the interview with Dominique in her home a week after Jamie’s discharge. I telephoned to confirm the appointment. On arriving at their home, however, David decided not to participate in the interview, despite his apparent enthusiasm in the
Dominique believed he did not think it important now that Jamie had been discharged and he wanted to focus on the future. My notes at the time comment:

*I am not sure why David decided not to participate but suspect he didn’t want to recall the events and maybe didn’t feel the need. Dominique had a lot of unanswered questions and some anger about being prevented from being with her child during his arrest.*

*Dominique apologised for David’s withdrawal and said she’d been nagging him for a while but he was busy gardening when I arrived. He was friendly towards me but made it quite clear he didn’t want to talk about it.*

I met Jamie when he awoke from his sleep. He was a lovely alert baby who Dominique clearly adores. She told me her priorities had changed and was not going to return to her previous job but focus on motherhood for a while. She noted how precious Jamie was. I left my contact details with Dominique if she needed to ask any questions about the study. I did not hear from her again.

**Dianne and Simon.**

Dianne and Simon had brought their son Brendan aged 10 months, for elective cardiac surgery. They had travelled from their home in rural New South Wales, approximately an eight hour drive away. The interview was conducted in a parents’ sitting room on the cardiac ward, where Brendan had been discharged to from PICU. They were preparing for discharge home the following day.

I had approached them the previous day when I learned of Brendan’s resuscitation in PICU. They were friendly and agreed to participate. When I arrived to conduct the interview, however, it became clear that until my approach, they had no knowledge of Brendan’s cardiac arrest. They told me they had talked about my study and realised what it meant but until then they believed no-one had told them that he had required to be
resuscitated. On further exploration, it transpired that they had been in the hospital coffee shop and on returning to the unit a nurse met them on her way to find them. She told them Brendan had “had an episode but was okay now”. When they saw Brendan it was as if nothing had happened, although the resuscitation trolley was beside the bed. Simon assumed this was ‘just in case’ and had not realised Brendan had had to be defibrillated.

Dianne and Simon had some questions about the nature of arrest and I answered them as much as I could but passed on their questions to the consultant in charge of their care. While they were alarmed at the extent of Brendan’s condition, Dianne and Simon both agreed that as he was well and ready to be discharged, the importance of the arrest was minimal. They were not able to tell me about their experience of parental presence, or absence, but shed further light on their experience of not knowing. They acknowledged they may have been told but had not comprehended and as they had not witnessed the arrest and were faced with a favourable outcome, their understanding of what occurred was limited.

My notes state:

_Mum expressed concern about brain damage as Brendan appeared sleepy. She was told it was probably due to the sedation still ‘on board’ as he had had some renal impairment but now she obviously is concerned about brain damage due to the arrest. I sent a letter of thanks along with contact details should they have any further questions. They appeared to cope well with the information – probably since Brendan had recovered and was going home._

_Julie_

Julie and Rick’s daughter Sarah was three years old when she was admitted with meningococcal septicaemia. She was immediately transferred to the operating room and
returned to the PICU an hour later. On return she suffered the first of eight cardiac arrests. She eventually died six hours later. Julie and Rick have another two children – Tim aged two years and Lucy aged five years. Julie had just learnt she was pregnant with twins when Sarah was admitted. Julie wanted to take part in the study, but refused either to be interviewed in the hospital or in her home. I offered to meet her at a neutral place, but she wanted only to conduct the interview over the telephone. I agreed. I conducted the interview using a microphone and attached tape recorder. Three and a half months after Sarah’s death Julie told me that she continued to blame herself for Sarah’s illness and death, believing she should have recognised the signs of meningococcal disease more quickly. She explained that both her and Rick were haunted by Sarah’s death. Julie stayed with Sarah for the majority of the time in PICU, although there were times when she had to take a break. In taking breaks, however, Julie continued to punish herself, “I’m annoyed I wasn’t with her more. I couldn’t have her with no-one there”.

Julie was looking forward to the birth of her twins, yet this excitement was tinged with regrets that they would never know Sarah. She told me Sarah was a loving child who would have loved caring for her younger siblings. While Julie was reluctant to meet face-to-face, she appreciated being able to tell me her story. She told me that talking to friends and family was difficult as they were fearful of upsetting her. She believed she was supporting Rick but this support was not reciprocated.

**Yasmina and Mohammed**

Yasmina, 19 and Mohammed, 29, had prepared themselves for Nadia’s admission for repair of atrio-ventricular (AV) canal defect. Nadia was three months old. Yasmina had
arrived in Australia from Kuwait two years previously to marry Mohammed. She had been attending English language classes and I noted that she spoke and understood the language well. She was quiet and was content to let Mohammed do most of the talking. I interviewed Yasmina and Mohammed in their home approximately four weeks after Nadia’s surgery. Nadia survived a cardiac arrest one day after surgery and when I visited them at home, she was a happy smiling baby who was feeding well. Yasmina was pleased with her progress.

When we talked about the resuscitation, they told me Yasmina had been in the parents’ hostel at 9pm when she was telephoned by staff to return to the unit. Mohammed was at home. Yasmina was told that Nadia had “been a bit naughty”. By the time she arrived in the unit, Nadia had stabilised and the drama was over. It was confusing for Yasmina who could not understand what had gone on before, yet she could see the remnants of the resuscitation procedure, with the trolley beside the bed. Mohammed’s parents lived in Australia, but for Yasmina family support was limited and she told me she felt isolated. She was young and reliant on Mohammed’s family for support and friendship, but was beginning to make friends through the language classes.

Neil and Lynne

I spoke with Neil and Lynne when they returned to PICU to talk to medical staff, four months following their son Toby’s death. Toby, aged six months, had been admitted for cardiac surgery, spending 10 weeks in the unit before he died. His stay in PICU had been rocky, with numerous critical periods and a return to the operating room for a pacemaker insertion. Toby had suffered several cardiac arrests from which he was resuscitated, but
during his final week, Neil and Lynne had made the decision not to increase any

treatments if he deteriorated, choosing not to allow any further resuscitation attempts.
When he deteriorated, they were able to have a say in the timing and place of his death,
choosing to remove many of his supports and taking him outside to a private courtyard,
where ventilatory support could be withdrawn. He died outside with his parents, two
siblings and grandparents.

Neil and Lynne were a delight to talk to and spoke for two hours on their thoughts about
Toby’s stay in PICU, the staff and the resuscitation process. They were present for most
of the resuscitations, although talked about the time they were prevented from being
present, during a re-intubation. For them, not staying during the resuscitation was never
considered. They felt part of the team telling me PICU was like an extended family.
They admitted they missed the camaraderie of the unit, having been there for 10 weeks,
and at the time looked to the staff for support rather than family members. They visited
regularly in the first four months after Toby’s death.

My field notes indicate:

Neil particularly was very keen to talk. No tears, a few laughs and obviously they had
reflected a lot and used a positive approach throughout Toby’s illness and death. They
talk openly about Toby with their children. Their 4 year old asks a lot of questions. Mum
is keen to study social work but doesn’t want to begin too soon. She doesn’t want to use
it as therapy for herself, but can see she has a lot to offer other parents.

Melissa and Alan

Melissa, 38 years, and Alan, 40 years, lived in a large country town approximately 870
kilometres, or a five hour drive, from the hospital. After agreeing to take part in the
study, I arranged to meet them at their home. I arrived in the evening and they welcomed
me warmly. Melissa and Alan’s son, Chris aged five years, had died in the PICU three months earlier. Melissa has a sixteen year old son, Andrew, from a previous marriage.

Both Melissa and Alan had lost a parent at an early age.

The circumstances of Chris’ accident were tragic. The family had been at a community football match, where the local children often wander off to play together. Chris, according to Melissa, was a happy, gregarious child with lots of friends. When she had not seen him for a while, however, she began to worry. A friend then discovered Chris, face down in the river, near a hole in the fence. The friend began resuscitation and continued until the paramedics arrived. By this time heart rate and breathing had been re-established, but Chris remained unconscious. He was transferred to the local hospital’s intensive care unit where he remained overnight. The decision was then made to transfer him to the PICU at the Children’s Hospital, despite the grim prognosis. Melissa expressed frustration to me at this decision. She would have preferred him to remain nearby where they could be surrounded by family and friends. She knew even at that time, that Chris would not survive. She could not understand the rationale for his transfer, if PICU would not treat any differently.

Melissa and Alan were struggling with Chris’s death as family meant everything to Melissa. They told me they had a good social network around them, and they had both grown up in the area. Melissa had recently returned to work in her father’s shop. She told me she was grateful that her father had forced her to return as she believed she would not have been able to cope otherwise. Both Melissa and Alan expressed considerable guilt at the accident, as well as anger regarding the circumstances. There was some
suspicion that some older children had pushed Chris in and this had been investigated by the police. Melissa told me that despite Chris’s age, he was sensible and would never have gone near the river.

We spent a lot of time looking at photographs of Chris. When I interviewed Melissa and Alan, I was five months pregnant. I had informed them of this prior to my arrival, fearing they may be reluctant to talk. They told me Chris’s birthday was on the same day of my baby’s expected arrival. They continued to tell me about Chris, showing me home videos. The interview took place over two and a half hours. I left them with my contact details as well as details of community contacts should they need them.

_Amanda and Mick_

The final couple, Amanda, 21 years and Mick, 22, lived an hour away from Melissa and Alan. I had approached them, and organised a time to meet in their home the day following Melissa and Alan’s interview. Their son, Jake, aged seven months had died four months previously. Jake had been diagnosed with pulmonary atresia, tracheomalacia and tallipes on day one of life and was transferred to the neonatal unit at the Children’s Hospital. He underwent primary correction with a shunt until he was old enough to undergo full repair of pulmonary atresia. He was discharged home at three weeks of age and Amanda told me he gained weight well. He frequently had cyanotic periods but Amanda coped well, often informing the local hospital what oxygen saturations were acceptable for him. She laughed when she recalled the nurses’ panic at a blue baby with oxygen saturations of 60%.
Mick was initially quiet but as Amanda talked, so he began to too. Amanda frequently cried and we took some time out, looking at photographs, talking about Mick’s college course and when Amanda would go back to work. When she was able to continue talking about the resuscitation, she did so. I had told them I would leave the tape recorder on unless they indicated they wanted me to switch it off. I did not have to do this.

When Jake was six months old, he was readmitted for a total repair. He was critically ill and unstable on return from the operating room and continued to remain critical with significant fluctuation in blood pressure and oxygen saturations over the next two weeks. He suffered two cardiac arrests, the second unsuccessful. Amanda was present for the first and walked in unexpectedly on the second arrest. She had heard the arrest bell sounding, but believed it to be another child who was critical. At the time Jake was stable. Amanda’s family had visited and she walked with them to their car, leaving the unit only for a short time. Mick had left the unit, as his aunt had been admitted to another hospital and had subsequently died. Mick was near his home town, five hours away. Amanda stayed during Jake’s arrest, choosing to stand at the end of the bed as close as she could be to Jake. She was able to telephone Mick from the room and after talking with him, Amanda asked the medical team to stop the resuscitation. It was clear Jake was not going to survive; the resuscitation had been in progress for 45 minutes. Amanda was grateful for the time she had with Jake prior to his surgery, knowing his condition was life-threatening and appreciative of being present. I was humbled in their presence, when Amanda told me that “there are others much worse off than us; some don’t even get to spend anytime with their baby”. Mick on the other hand, expressed remorse and regret
at not being there with Amanda. Yet Mick, who had experienced considerable death in his family from a young age, was accepting of death. Despite their young years, Amanda and Mick demonstrated extreme maturity and had obviously reflected a lot on life and death. Mick told me his aboriginality helped with his acceptance of death.

They told me of their plans for the future. They wanted to travel and maybe have another child and they were planning their wedding. There was a lot of love and warmth in their relationship and they obviously supported each other. Amanda showed me Jake’s room. It was just as they had left it before Jake had surgery and they were reluctant to change anything, seeking comfort in his familiar smell. Amanda told me that she had good days and bad. When I interviewed them, she told me that day was a bad day but she wanted to carry on and talk to me in the hope it may help other parents. She also acknowledged the need to talk again, to anyone who would listen to her stories about Jake. I was shown photographs and given a poem to pass on to the social work department, who had been following up on their progress.

The experience of each parent was revealed in their accounts. For the parents, admission to the intensive care unit was a frightening experience. Staying with their child during periods of instability, including cardiac arrest and resuscitation was important for their continuing parenting role. Each parent came to the experience with previous experiences that they were able to draw upon in their attempts to cope with being present. These attempts were of varying success.
4.3.2. The Nurses

Elaine

I met Elaine, 28, when she transferred from the oncology ward to PICU. Elaine was 31 weeks pregnant with her first child when the interview took place and she was looking forward to some time away from the stress of working in PICU. The interview took place in the relatives’ room located on the PICU and lasted one and a half hours. She had four years experience since graduation in total, with the last two years in PICU. She told me that it was only now she was finding her feet and could anticipate what was going to happen with critically ill patients. Elaine was resolute in her belief that, while parents had every right to be present, they must adhere to the rules of the unit, which she believed existed for good reason. I began by asking Elaine about a recent experience when a child she had been caring for arrested and the parents had been present. It transpired that it was Jenny and Mark that Elaine was referring to but as she began to talk she recalled numerous other occasions.

Louise

Louise, 26, had worked in the PICU for two and a half years. This was her second experience in paediatrics, having worked a general ward for six months prior to coming to PICU. Prior to that Louise had worked in the adult environment for two years after graduation. I interviewed Louise in the relatives’ room in PICU, when she took time out of her shift. Louise was a very calm, gentle person, who wanted to care well for the families as well as the children in the unit. As Louise began to talk, she was aware of seeing things afresh. She said “gosh, I’ve never thought about it like that before” when
she reflected on how parents’ might feel being left outside the unit. It was as if she hadn’t considered their position in such a way before.

**Simone**

Simone, 49, was an experienced nurse who had worked in the PICU for over 20 years. Her position was that of CNS and considered to be an expert. The two hour interview took place in an interview room after Simone had finished a night shift. I knew Simone well, having worked with her for approximately 10 years, so the interview was relaxed and informal. I was however, mindful of not letting my thoughts guide the interview. I had no concerns as Simone had many stories to share with me and needed no encouragement to talk. Simone had always been a strong advocate of families in the PICU although was wary of their presence during resuscitation. Initially, there were two separate intensive care units – one general and one specifically designated for cardiac surgery. Simone had worked exclusively in the cardiac unit until the amalgamation five years previously. The practice in the cardiac unit had been to exclude parental presence so Simone was familiar with asking them to leave. Initially she was apprehensive, despite her expertise and her understanding of family stress, both as a nurse and a mother herself. Simone told me that now parental presence had become the norm and despite her anxieties at times, it was second nature to provide support for them to stay.

**Caroline**

A very experienced CNS and also considered an expert, Caroline, 45, was initially very much opposed to the notion of parental presence. She too, had come from the cardiac unit and had worked in paediatrics for approximately 11 years, coming from the adult
ICU environment, where she had worked for 20 years. Despite her opposition, Caroline was an extremely caring person who worked hard to support parents. It was not until she suffered a similar tragedy herself, that Caroline’s thoughts on family presence were completely changed. Her partner had suffered a fatal stroke and despite her attempts at resuscitation, her partner died in the emergency department at a local hospital. Caroline was denied access in the resuscitation room and was angry at the lack of control she had in the decision. She was adamant that a relative must have every right to stay with a family member, adult or child, if they so wish. As she talked, it was evident that her previous opposition played on her mind, and that she believed her initial belief was out of the ignorance of not knowing or understanding the parents’ needs.

Jane

Jane, 45, was another senior member of staff considered to be an expert nurse. She had worked in the PICU for 22 years. Like Caroline, Jane was opposed to parental presence at the resuscitation yet demonstrated a deep understanding and caring nature for parents in her storytelling. While Jane believed parents had a right to be present, she thought she was in a position to judge their coping ability, so when she believed they would not cope, she would encourage them to leave. This was all the more apparent if the resuscitation was particularly traumatic, during a chest opening for example. I spoke with Jane two weeks after her involvement with a child who did not survive a resuscitation attempt. As Jane was a senior member of staff, she told me her role was generally that of director of the resuscitation and supporter of the parents. She was the person who would stay with the family, offering information and comfort. She had a great ability to anticipate
parents’ needs. The interview with Jane took place in the relatives’ room in PICU and lasted one and a half hours.

**Annemarie**

Annemarie, 25, had just been involved in an unsuccessful resuscitation attempt. She was considered a novice within the intensive care environment, having worked in the unit for only four months yet this was her third experience of resuscitation during that time.

She graduated four years ago. In my notes, I observed that Annemarie *appeared nervous and ill at ease*. She told me she thought it would “do her good to talk to me” and admitted she was having difficulties in coping with the drama of working in PICU and particularly being involved in three arrests in a short period of time. She however, indicated that she wanted to talk to me. As I observed in my field notes, *I thought at the time that she believed I was trying to catch her out and in the beginning appeared to try to give me the right answers.*

As she became more comfortable, her true beliefs were apparent, at times contradicting herself.

She told me that she found it difficult to know what to do when she was so inexperienced and needed direction in her practice. Annemarie believed that parents had every right to be present, yet tempered it with her own belief that if she felt they were not coping, she would ask them to leave. She admitted she had little experience and did not express how parents may demonstrate a lack of coping other than “falling down in a heap and crying” yet believed with time she would understand and until that time, she would follow the
unit’s practice of ‘allowing’ parents to stay. She needed proof that remaining present during resuscitation was detrimental before making that decision. Annemarie’s interview was relatively short, lasting only one hour. I felt she had limited experience in resuscitation so could only share with me her recent experiences. I believed however, that as a novice nurse, her experiences were important to be heard if we were to support nurses through a difficult time in their career.

4.4. Concluding comments

This chapter has described the phenomenological research process and introduced the participants to the reader. Since phenomenological research is predominantly a written mode of inquiry, consideration is given to the processes used to enhance trustworthiness, credibility and quality of the descriptions presented in the following three chapters. These chapters describe respectively the parents’ lived experience, the nurses’ lived experience and finally the interpretation of the phenomenon of parental presence during resuscitation from the collective experience.
Chapter 5

The Parents’ Experience of Resuscitation in PICU

5.1. Introduction to the findings

As each parent couple began to talk about their experience of being present or not during resuscitation, it was apparent that the resuscitation event formed only part of their experience. It was important for each parent to tell their story from the beginning, whether their child’s admission had been planned or unexpected. For these parents, the start of the experience of witnessing a resuscitation attempt began when their child became critically ill or when they learned their child might require surgery for a congenital cardiac defect. At each interview, parents who had lost their child spent a great deal of time sharing their memories of their child with me, in an attempt to make me understand their life with the child and for me to know their child. I was shown photographs, videos and on some occasions, the child’s bedroom and how he or she lived.

The experience for parents of being present or absent during their child’s resuscitation is grounded in the four major themes of:

- Being only for a child
- Making sense of a living nightmare
- Maintaining hope in the face of reality
- Living in a relationship with staff
The themes were constructed from the thematic statements developed from the parents’ accounts. Within each theme several areas of experience were identified as essential dimensions of the theme. The themes and their dimensions are presented as the whole parental experience of being present or absent during the resuscitation of their child in PICU. In revealing the phenomenological description of the parents’ experience, interpretation and understanding is made known.

5.2. Being only for a child

Being only for a child was identified as inherent in the experience of the resuscitation for all these parents. They spoke about being for their child as though they could not do otherwise. Being a parent identified to a large extent who they were in the world. In identifying what contributed to the theme of **Being only for a child**, it was necessary to explore what aspects of being a parent of a critically ill child contributed to the phenomenon of parental presence during resuscitation.

Three areas of experience were identified as dimensions of the theme, **Being only for a child**; each dimension being drawn from the sense of the thematic statements.

These dimensions and the sub-themes that contributed to their development are:

<table>
<thead>
<tr>
<th>Dimensions</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being There</td>
<td>Fear versus desire</td>
</tr>
<tr>
<td></td>
<td>Time standing still</td>
</tr>
<tr>
<td>Caring for a Child</td>
<td>Knowing a child</td>
</tr>
<tr>
<td></td>
<td>Advocating for a child</td>
</tr>
<tr>
<td></td>
<td>Comforting a child</td>
</tr>
<tr>
<td></td>
<td>Being vigilant</td>
</tr>
</tbody>
</table>
5.2.1. Being there

For the parents in this study, there was no question of leaving their child during a resuscitation attempt, or indeed during many critical events. Their child was the most important person in their lives – an intrinsic part of them, so most parents needed to be there with them and for them particularly during times of crisis. Being there was essential for the parents’ well being, as they attempted to cope with the drama of their child’s critical illness and resulting cardiac arrest.

The parents talked lovingly about their child. At the time of cardiac arrest and possible death, these parents particularly needed to be present; be it physically or ontologically, and it was inconceivable for them to consider not being there when their very being was so innately bound to their child. When reflecting on the possibility of not being there, many of the parents said that it would be impossible for anyone to convince them to leave. Many were adamant and angry at that notion. Amanda expressed this desire strongly, “I was there, like, all the time and then to not be there at the end, I would just, I would never not be there. I was there from when he was born till the day he died”.

The notion of wanting to be there with their child at the beginning and the end of their life was an intense desire that was reaffirmed by others. Neil was adamant that he would not leave his child, if there were a chance he may not survive:

… if someone says your baby’s going to die, you want to be there with your baby … if they think he’s not going to make it you’re not going to leave, you’re going to be there; like they’d have 300 people trying to drag me out, I wouldn’t leave, I would have took the bed and everything … you want to be there and that’s it …
5.2.1.1. Fear versus desire

Not all parents expressed an overwhelming need to physically stay, although it was clear that all parents wanted to be there emotionally for their child. For Jenny and Mark, the horror was too great to stay. They could not watch their baby go through a resuscitation attempt, knowing they were powerless to do anything for him. Furthermore, they held that only in suspending feelings and emotions would a parent ever be able to stay and watch the horror occurring to their child. Jenny believed it was not possible to watch something so horrific happen to a child unless a parent lacked a sense of humanness, describing the horror she experienced when walking in unexpectedly on Matthew’s resuscitation:

*I remember, I just, everyone was around Matthew … I thought, I thought ‘what the hell’s going on?’ and I was scared and I just wanted to run and get out of there because I thought ‘no way, this is not what’s happening?’… it just freaks you out and you couldn’t possibly sit there, physically, and watch your baby going through that, you couldn’t. Unless you’ve got no feelings, that’s the only way you’d be able to do it.*

Jenny and Mark then, felt overwhelmed by the shock of walking in unexpectedly on the resuscitation scene, and held that they could not stay to witness the event throughout its entirety. They were able to cope more readily with the shock of the unexpected resuscitation by choosing to stay only for short periods to monitor the progress, and then leave the scene once more.

Despite the horror of witnessing the resuscitation event, many parents believed the deep need to be with their child overrode any trauma they might have experienced. Dominique had not had the opportunity to be present during her son’s first resuscitation and was prevented from being with him during the second. Jamie survived. Dominique
postulated that despite the horror she desperately needed to be with him, to offer comfort
and in doing so, comforting herself by having a role to play. She explained:

... maybe I would have freaked out but I think if I’d been given the option I
would’ve preferred to have been there ... although I would have been upset I
would have liked to just sort of touched his head or his hand or something ...
just to let him know he wasn’t alone.

For Dominique, the need to maintain close physical contact with her child was essential,
knowing he may not survive.

The parents who were present were able to look past the mechanics of the resuscitation
and focus on their child, offering comfort when able and being there for the child.
Knowing a child may not survive a resuscitation attempt was the motivation for parents
to want to stay despite the trauma. Neil could not recall the details of the resuscitation;
his focus was solely on Toby:

You want to leave because you don’t want to watch but ... you don’t want to
watch but you want to be there for your child ... you sort of look past it...
you’re just more worried about whether your baby’s going to survive... we
never really saw all the stuff ... I can’t remember the bell going off...it’s a bit
of a blur.

For Melissa it became apparent that had her child died and she had chosen not to stay
during the resuscitation, she would have never forgiven herself for abandoning the child.
The grief and guilt at letting the child down, was impetus enough to want to stay in spite
of the awfulness of the scene. As Melissa told, “I wouldn’t have left him for all the tea in
China, no, as hard as it was to witness it all, no way in the world were we walking out”.

She struggled with the conflict arising from fear versus the desire to be with her child, but
reiterated her desire to stay with her child during his last minutes before death, “... it’s
dreadful, looking back, I often think I don’t know how we got through any of it, I really
don’t. ... [yet] ...“I wouldn’t have been anywhere else except with him.”

By putting her child’s needs first, Melissa considered her own needs and traumas as
insignificant by comparison.

Dominique confirmed this inner conflict when she explained:

... if you weren’t there and then they had to tell you “come in because your
baby’s died” then that would be worse … whilst something’s hard, it would
be better to be there ...

Amanda, too, talked of the alternative of facing the death of her child if she had not been
there, “... I mean, if I’d walked in and, you know, he wasn’t there and they’d said ’sorry,
he’s passed away’, it would have been worse than actually walking in on it” [the
resuscitation].

Dianne had not been present when her child was successfully resuscitated, choosing to
take a break when intrathoracic lines were to be removed. It became clear that she had
not fully understood the risks involved in removing the lines, taking the cue from the staff
to leave while they performed the task. Dianne, on contemplating the risks now known
also expressed her desire to stay:

    If there was a risk of anything happening, you know just in case something
terrible happened, I think I would want to be there … I don’t know whether I
would have passed out on the floor when it did actually happen…’ just boot
mum out the way!’ ... I don’t know whether I would have passed out, but I
would have rather been there.

Some parents whose children survived and who had been absent from the hospital
believed the trauma would have been too much to cope with. These parents were grateful
for not having to make the decision to stay or leave. This unwillingness to witness the
resuscitation implied the perception of the event was more traumatic than perhaps the reality, as experienced by others. Despite the relief at not having to be there, some of the parents emphasised that had they walked in on the arrest and resuscitation, they would have found it impossible to leave again. As Mohammed confirmed:

… I was glad I didn’t see it happening … but had I walked in it would have been very hard for me to leave again and it would have been harder … its one of those things where you want to know but then you don’t want to know when something goes wrong because you can’t do anything about it …

The compelling desire to be with and for their child was inherent for all parents, and overrode many anxieties they may have had about the mechanics of the resuscitation. For some parents, the relief at having the decision made for them in a sense, by not being present, and at the successful outcome of the resuscitation, only strengthened the misunderstanding of the event and left them lost and bewildered when they had not been present. Dominique explained, “… it wasn’t until I saw another child’s arrest that I finally realised what he’d gone through, what had happened and how close I came to losing him.”

Witnessing a successful resuscitation often enhanced the parents’ understanding of the critical nature of the child’s illness and did not interfere with their ongoing coping of the whole PICU experience. Julie had no doubts about staying during the resuscitation:

… I had no regrets, I have horrible memories about the disease [meningococcal] but nothing else, not the arrest … it was hard but we had to do that, had to see it to be with her and say goodbye …

Each parent told of their child’s survival being of paramount importance, with their own fears and anxieties of lesser importance. One father spoke of being frustrated at the nurses’ attempts to provide him with ongoing information. He believed that the time
taken to speak with him was time taken away from effectively treating his child. He wanted as many staff as possible to concentrate solely on his child. Parents urged staff on in their quest to save their child, knowing their own questions and needs would be addressed at a later time, once the drama has passed. Neil confirmed the importance of putting his child’s survival first:

… quite frankly if someone had come and started talking to me at that time I probably would have said “look, you know, get out” in a nice way. I think you concentrate on what they’re doing and you don’t want somebody yakking in your ear about you know, how you’re feeling … You’d say “what the **** are you doing? Get over there and bloody do something!”

By demonstrating their need to put their child’s survival paramount to their own feelings, the parents showed their very being was for that beyond themselves. That is, the child’s inherence to their being held strong when the child might not survive the resuscitation attempt.

5.2.1.2. Time standing still

In experiencing the resuscitation of their child, many parents described a feeling of disconnectedness from time. It was as if time had become suspended and all other daily activities were meaningless when a child required resuscitation. The sole focus was on the critically ill child and the willing for that child to survive. Jenny explained this feeling of suspending all other living with her sole focus on her critically ill child:

… well, life seems to, I mean, our life’s been put on ‘hold’, I haven’t even been to – the only shops I’ve been to is the grocers, and I’ve only been to one other shop in seven or eight weeks … its weird, it’s like life doesn’t exist [outside the unit] … it’s your own little world and that’s all that matters … there’s nothing else in your life.

Likewise, Amanda described how time appeared to shift, “… it seemed like an eternity … but when I look back, and it all happened so quick, and then everything was all over.”
These parents descried the notion of living in the present, with time standing still for the entire period of the resuscitation. Nothing else was of concern for the parents whose child required resuscitation. Their sole focus was on the successful outcome and survival of their child. This temporary suspension of time dismantled their way of being in the world and made it difficult for parents to re-orientate themselves to their whole life after living in the resuscitation scene.

5.3. Caring for a child

*Caring for a child* was a further dimension of *Being only for a child*. Not only did the parents express the need to physically care for their child, they also needed to ensure the child had the care that only they could provide. Parenting was revealed as a complex and demanding experience, which continuously changed and evolved to meet their child’s changing needs.

Within the resuscitation scenario, however, there was little that parents could physically do for their child; thus they were frustrated at not fulfilling their perceived parental role. The parents demonstrated a number of ways in which they attempted to reduce the feelings of helplessness and feel useful as a parent when their child required resuscitation. These ways were not always successful. Fulfilling the parenting role within the context of the acute phase of resuscitation was demonstrated by *knowing, protecting, advocating, comforting* and *being vigilant* for their child.
5.3.1. Knowing the child

In demonstrating caring for a child, many of the parents went to great lengths to inform staff of their own child’s individual likes and ways peculiar to them; how their child responded generally. In voicing their knowing of their child, parents were able to ensure that staff also knew the child, in order to make considered judgements about their child’s progress. Parents also talked of knowing when their child was becoming “more like himself”. This knowing the child, however, often resulted in tension between staff and parents, causing parents to feel they had alienated themselves by offering their opinions of their child’s condition.

On the other hand, this intimate knowledge of their child demonstrated to staff the behaviour of a ‘good’ parent. The good parent felt useful in realising when their child was deteriorating or improving and appreciated staff who involved them in their assessment. As Lynne explained:

... I was feeding him, he was a bit puffed. I said “he’s not feeding well, he’s tired” ... we put him back in the bed ... the nurse said “does he normally suck in his chest like that?” ... we said “no, that’s really bad”.

Most parents were also able to demonstrate an acute awareness of a futile prognosis, often before being told of the hopelessness by the PICU staff. This awareness revealed that their intimate knowing of their child was inherent in their world, both as a parent of a well child and as one of a critically ill child. Before Chris was admitted, following his near drowning accident, Melissa knew he would not survive:

... I saw him lying on the bank and two blokes giving resuscitation ... I knew he was gone then ... he was just so lifeless ... I was in two minds ... when the helicopter rose and stayed there for about 5 minutes to get clearance, I knew then he’s not coming home.
5.3.2. Advocating for a child

Further experiences of caring were revealed in the parents’ acts in advocating for their child. In these experiences, parents spoke about the many occasions when they felt the need to speak up for their child. In advocating, parents demonstrated to staff how they could complement their child’s medical care. An example of such advocacy was witnessed in the parents’ knowing when to stop the futile resuscitation. Amanda described her frustration at seeing her baby deteriorate:

... it was towards the end, he started bleeding from the mouth ... so that’s when I said to them to let him go ... I just said it ... I just thought that was too much for him that’s why I said it “let him go” ... and they did ...

For Neil and Lynne, advocating meant seeking out those staff members they trusted to act in their child’s best interests. They told of a time when they had been first to recognise Toby had deteriorated and were keen to point out to a new staff member what they believed had happened:

Some of the new staff thought you were a bit silly ... in the end we’d sort of say … “Toby doesn’t look too well”... and if it was a doctor we didn’t know ... he didn’t know how quickly he could crash ... and we’d sit there for a while and then go and get another doctor ... I’d say “I’ll just go for a wander” because then they’d see me and ask how Toby was and I could say well, he’s going to crash ... you know ...

By searching for a staff member they knew and could trust, Neil and Lynne were quietly advocating for their baby. They knew how quickly he could deteriorate and felt the need to demonstrate this knowledge effectively to new staff members, in order to seek the best care possible for Toby.

Not all parents could successfully advocate for their child, with a number expressing frustration and regret at not being sufficiently confident to do so. Dominique expressed
her frustrations at complying with the staffs’ requests for her to leave the resuscitation scene. She deeply regretted feeling unable to stand up to the staff:

... they wouldn’t let me in, they said “you just wait in the parents’ room” and I was there for 45 minutes ... I was really annoyed and really upset, I rang my husband and said they won’t let me in ... I would just say “okay” to whatever the nurses said, whereas now, I look back and I should have said to them at the time “no, I’d rather go in, I want to go in” ... but you tend to go on what the nurses say and trust their judgment not realising they perhaps were wrong.

For Melissa and Adam, advocating in their child’s best interests was impossible. Despite the affirmation that no additional treatments would be offered, and the recognition that he would die, the decision was made to transfer Chris from a large country hospital to a specialist metropolitan hospital. Melissa expressed confusion and anger at the decision, which she said compounded her distress by moving her and her family a considerable distance from family and friends, with no evident benefits to Chris’s prognosis. Melissa described her frustrations:

... I don’t understand why they have to take him away from your own home town ... I just said to the doctor “what are you going to do?” and he said “nothing for 24 hours” ... well if they weren’t going to touch him for 24 hours why did they take him, why didn’t they leave him here and let him die here so we wouldn’t have to go all the way down there and then leave him there ... that really made me sick ...

... why couldn’t they have left him where we had people around us rather than go down where we knew no-one; that was hard.

In voicing her frustrations, Melissa demonstrated her inability to act in the best interests of her child, believing the medical staff did not consider her needs. Thus some parents were frustrated at not being able to care for their child as effectively as they would have wished.
5.3.3. Comforting a child

Parents in this study were involved in a number of physical activities directed at providing comfort for their child during periods of relative stability, following or between resuscitation efforts. Giving comfort meant also being able to continue to provide a parenting role in a number of ways, as well as seeking comfort themselves by knowing they had done all they could. Lynne described this necessity to provide care:

… we did it all … nappies, mouth care, eye care, bathed him … take his temperature and do his wee and we’d see if they [the nurses] were busy and I’d say to Neil “it’s been an hour, we’d better take his temperature and all that and they can get the results at the end …”

When the parents were able to provide physical comfort and care for their child during periods of stability, they appreciated the time and closeness spent with their child.

Neil’s account is a telling example of the parents’ profound need to comfort their child when he considers another child’s death in the PICU:

… we thought about the other baby [who died alone] and we didn’t want that to happen … he was going to die, we knew that, but we could make the choice about where so we did it a nicer way … gave him a bath and he hadn’t had a bath for 10 weeks … took him to a quiet place …

Many expressed their love to their child when it was clear the end of a futile resuscitation was drawing near. Julie recalled the importance of being present to comfort Sarah:

I’m annoyed I wasn’t with her more … I had to be there to say goodbye … I said to her “it’s alright to go, you’ll be safe” … we had to be there to tell her that we loved her …

The ultimate act of caring for a child was demonstrated in letting go and giving permission to die to end suffering. In giving permission their children to die, the parents were not only providing comfort but seeking comfort in believing the child was at peace and knew they loved them.
5.3.4. Being vigilant

When a child was successfully resuscitated, many parents expressed the importance of maintaining a vigil to ensure no further harm will befall their child. Simon talked about his need to stay close to his son for all subsequent procedures following a successful resuscitation. He said, “I didn’t venture out anywhere ... I actually watched them pull all the lines out ... I wasn’t going to risk it happening again.”

There was a great need for parents to look out for their child, fearing further arrests when they were not present. They spoke of the ultimate fear of letting the child down at this time. Parents took turns to stay with their child, to ensure he was not left alone. Dianne explained her vigilance:

... I wasn’t game enough, we’d take shifts, if one wanted to go out and have coffee the other would wait ... it was the same today, they turned down his oxygen and I thought “I’ll just sit here just for peace of mind...”

Neil and Lynne also expressed the need to ensure someone was with Toby at all times to watch over him, “… we tried to leave someone with him all the time and we’d say ‘if anything changes, even a little, you be sure to ring us.’”

The need to be vigilant was a result of their fear that their child might die. They said they would have never forgiven themselves if they had left the room and their child had died alone. Further, the parents needed to be vigilant for their child in order to ensure optimal care was given at the critical time of arrest. The parents wanted to be sure everything possible had been done in the attempt to save their child.

Additionally, the parents had to satisfy themselves that staff recognised the arrest promptly and would respond quickly enough to save their child a second time. Simon
talked of the premature relief once the danger period had passed, only to be shocked when Toby arrested later:

After the 2 hours (post-operatively) we went ‘ahh’, it’s just a matter of getting better day by day now, then this happened and the tension’s back on … what’s going on here? … is anything else likely to happen, when they pull the next one out, the pacing wires, they’re all in the heart you know … so we’ve been uptight every step of the way since then …

Despite acknowledging the capabilities of the staff, one parent expressed concern when he believed the staff did not appear to pay sufficient attention to his child, focusing on seemingly irrelevant issues. Mohammed anxiously explained his fear of not being there at all times to watch over Nadia:

They’d be watching the TV and not watching what they were doing ... I didn’t get upset but I just couldn’t say anything because you know, I’m sure, you know, they’re doing their job, but …

Mohammed tried to convince himself that the staff were competent but when he observed them paying less attention to his child than he cared, he expressed fear that a subsequent arrest may occur due to a lack of attention. The initial arrest occurred during suctioning and it was during subsequent suctioning that Mohammed expressed most anxiety about the staffs’ inattention. It was as if he had to remain watchful in a time of perceived carelessness. He remained silent however and did not discuss his concerns with the staff. Consequently he needed to stay to watch over but felt helpless to effectively advocate for his child by expressing his concerns, for fear of being labelled a ‘difficult’ parent.

Tension existed between being vigilant and advocating for their child and the need to not alienate staff by criticising their actions for fear of reprisals. These tensions evoked a fear in the parents that staff may not care for their child adequately in the hours and days
following a resuscitation attempt, if they were perceived as judgmental. Dominique explained how she tried to comply with the staffs’ rules:

... the nurse came out and said “you can come in now, we’ve stabilised him.” I was just, the whole time I think I was trying to keep up a good front; I didn’t want to lose it with her ...

Dominique was concerned that by being considered difficult, she may have further restrictions placed upon by the nurse.

5.3.5. Protecting a child

When parents demonstrated being only for their child, they often talked of their desire to protect the child from further pain. It was almost as if they wanted to make things right again. These parents believed they had failed to protect their child from harm when they became ill, so by protecting them from additional harm, they were able to restore their parenting role.

Lynne and Neil were embarrassed as they described their decision to seek complementary herbal therapies for Toby in the frustrated search for improvement:

Neil: … I think you feel like you’re doing something …

Lynne: … You feel like you’ve got to do something. You’re just sitting there, watching ... just that we were doing something ... massaging and doing something, I didn’t feel useless.

Dianne and Simon were unaware of the risk involved when a transthoracic line was to be removed, so chose to leave the unit and take a break. Brendan suffered a cardiac arrest following the line removal but was successfully resuscitated and was stable on their return. Simon made the point clearly that had they known of the risks involved, they would have chosen to stay with Brendan. “… uh, the doctor said it only happens every
few months, that they have that sort of problem … well, I dunno … I think if we’d been
warned, we would have hung around more."

In their desire to eliminate further pain, some of the parents indicated that they would change places with their child if they could. Neil recalled:

… it’s hard to watch, and you sort of, you know, you want to protect your child, you want to jump in the middle and say ‘hang on!’ you know … we even took it in shifts so someone would be with him …

Mohammed felt helpless at not being able to take the place of his child, “… you just felt useless, you couldn’t have done anything to help …"

Further frustrations at the staffs’ failure to efficiently and quickly complete a task such as inserting an arterial line, compounded the helplessness felt by parents, when seeing the assault on their child, yet feeling unable to protect their child. As Neil explained:

… you want to stay if they say your baby’s going to die … but you don’t want to watch, like they’re sticking needles into him and putting in drips and you see them do all these things and you’re distressed but you know they’re doing their best to save him …

Julie confirmed the ultimate need to protect her child from experiencing further pain and suffering in her account, “I asked the doctors how long do you let her suffer? … in the end I told them to stop ….”

While most parents experienced a loss of control and ownership of their child in the intensive care setting, some recognised the frustration at being unable to protect their child after death. So, even the act of dying was taken from them when they had little control over their child’s death. Melissa spoke of this passionately when she told of the discussion to request for an autopsy to be abandoned:
... it was a coroner’s case because of the way he died, they were fighting over his body ... but he’s my child, I had that child, they didn’t own him ... how dare they have the final say, that made me sick ... he’s my child, nobody else’s but mine, I grew that child, how dare they fight over something they didn’t make ... that really pissed me off ...

The parents desperately needed to try to protect their child from any further harm in whatever way they could, yet were thwarted by the enormity of the resuscitation and their inability to physically do anything for their child. For some, protecting the child was achieved by providing a little physical comfort and for others hoping a futile resuscitation attempt would stop soon and being part of the decision to stop gave them back the control they needed to seek comfort in the tragedy. Despite attempting to provide a degree of protection for their child, however, the parents expressed guilt at letting their child down when they were unable to protect them from pain.

5.3.6. Letting a child down

The parents spoke regularly of feelings of letting the child down, either by not being present during the resuscitation or by the child dying and their inability to prevent such death.

The parents experienced guilt when they chose not to stay, or when they were unable to be present during the resuscitation. For them, not being there for a child at a critical time reflected on how they saw themselves as a parent. They believed they were not fulfilling their parental role, as a protector from harm. As Dominique confirmed “… I felt really guilty that I went and had my hair cut and I wasn't there when it happened…”.

When a child survived the resuscitation and the parents were not present, there was a sense of distress at letting the child down. On these occasions, they held the belief that
their child may in some way sense their parents’ willingness to give up on them too easily. Lynne described her need to be with Toby at all times:

... I couldn't think of anything worse than something happening to Toby ... and not being there ... we sat there for 10 weeks with him, and something happens and we’re not there ... I look back and think about that other baby ... they probably have nightmares about not being there when it happened ...

Not being present during the resuscitation, and the guilt endured as a result, led parents to imagine the situation may not have occurred had they been there. It was as if by choosing to spend time away from their child, they were punished by the resultant arrest and resuscitation of their child. As Mohammed explained “... I should have been there ... it might not have happened but I suppose it could have happened anyway”.

In addition, parents were conscious that others might make judgements on their attachment and commitment to their child. They were constantly aware of how others saw their parenting abilities and began to question themselves following their child’s cardiac arrest.

Even when the parents were present, when a child died they felt they had ultimately betrayed that child.

5.3.7. The ultimate betrayal

The ultimate feeling of letting their child down was demonstrated in parents’ essential act of leaving their deceased child alone at the hospital and walking away for the final time. Melissa described leaving Chris alone in the hospital after he had died:

... like I said, the hardest part for me was to put him back in bed and cover him up and leave him there and walk away, that was the hardest part ... if it had been here and I knew he was in our town it would have been different ... because of the autopsy we had to leave him there and come home without him
– that hurt more than anything, to leave that child there, to think he was lying on a slab somewhere without me. I hated that, I hated leaving him there.

Julie, too regretted not having spent more time with Sarah before she died, and expressed guilt at giving up on her child believing she would have known, “I feel awful about it … I said that it’s alright to go…I really wish I hadn’t said that … I feel that I let her down but I couldn’t do anything …”

Letting their child down continued to be a pervasive thought for these parents, despite their presence at the failed resuscitation.

5.3.8. Summary

Being a parent of a critically ill child in intensive care required enormous adjustments to their world. When a child suffered a cardiac arrest requiring resuscitation, the parents’ world was changed forever, whatever the eventual outcome. Their very being as a parent hung in the balance and they were at a loss to know how they could help their child. The parents’ experiences of being present or not during their child’s resuscitation held a range of intense emotions. Overwhelmingly, the parents expressed a deep desire to be with their child during periods of crisis, demonstrating the child’s inherence in their world, when the fear of the resuscitation was overridden by the desire to be with and for their child. The notion of time standing still was a very real phenomenon for the parents who became disconnected with reality.

The parents lived as if they were only for that child. They attempted to provide care and remained present and concerned for their child’s survival. They lived as though this
experience was one of **being complete**. **Being complete** was a state of being in which the parents’ lives were wholly integral to that of the child.

**Being only for a child** was revealed as an important aspect of the parents’ experience being present at the resuscitation. It was however, not the only description of the experience and further understanding is revealed in the following themes **Making sense of a living nightmare** and **Maintaining hope in the face of reality**.

### 5.4. Making sense of a living nightmare

As each of the parents talked of their experiences, their ability to understand, make sense of and manage their feelings dominated their accounts. Their desire to understand the procedure, the process, the terminology and their struggle with their feelings was central to their conversations. They spoke about how they orientated themselves and found their way in a time of great uncertainty and distress. Such acts were interpreted as **Making sense of a living nightmare**. Two areas of experience were identified as dimensions of the theme. These dimensions and the sub-themes that contributed to their development are:

<table>
<thead>
<tr>
<th>Dimensions</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Witnessing the resuscitation</td>
<td>• Seeing every effort has been made</td>
</tr>
<tr>
<td></td>
<td>• Memories of the resuscitation</td>
</tr>
<tr>
<td></td>
<td>• Understanding the resuscitation</td>
</tr>
<tr>
<td></td>
<td>• Waiting for news</td>
</tr>
<tr>
<td></td>
<td>• Imagining the resuscitation</td>
</tr>
<tr>
<td>Finding a place</td>
<td>Hindering the resuscitation</td>
</tr>
<tr>
<td></td>
<td>Parents as participants</td>
</tr>
</tbody>
</table>

#### 5.4.1. Witnessing the resuscitation
In order for them to understand the severity and significance of the resuscitation procedure and to make sense of the traumatic time ahead, the parents needed to be able to see for themselves what happened during the arrest and resuscitation. In witnessing the resuscitation, parents were able to understand in several ways. They were able to see that every effort had been made to save their child. They were also able to understand the difficulties that the staff faced when attempting to save a child who had arrested.

Furthermore, the parents whose children died were able to put the horrific memories of the actual resuscitation aside and focus on the memories of their child. Recollections of dramatic events preceding death were not prominent for these parents.

5.4.1.1. Seeing every effort had been made

All the parents whose children had died, except one father, had been present during the resuscitation. They were comforted in knowing staff had done their best for their child, and could see they could have done no more. Lynne was emphatic in this belief when she said “... we really know in our heart of hearts that they did everything possible, and like there was nothing else that could be done and it was just the thing that happened …”

In witnessing the intensity and concentration, the determination and sole focus of the staff on their child’s resuscitation attempt, many of the parents had very few questions about their child’s death. As Neil confirmed:

>You sit there and see what they’re doing, you know what they’re doing and that they’re doing everything they can and they give 100% ... they don’t go in half-hearted …
The parents speculated that had they not been witnesses to their child’s resuscitation they might have questioned the staffs’ determination to continue to resuscitate for a prolonged period. As Neil explained:

... we never walked away thinking “why didn’t they do this or that?” but if you’re not there it’s probably always in your mind “I wonder if they did all they could How do you really know if they did it?”

For one father who had not been present when his child arrested and died, it was impossible for him to comprehend what went before, and how his child had been one minute alive and the next gone. As Mick struggled with his child’s death, he said, “… I just couldn’t take it in … he was okay when I left to see me auntie … and now that’s him gone ... what happened?”

Witnessing the resuscitation reassured parents that not only had the staff done their best, but also that they themselves had advocated for best care in the attempt to save their child.

The parents demonstrated complete confidence in the staff when they had had the opportunity to witness the resuscitation. It became apparent to the parents that staff put every effort into saving the child as if they were their own.
5.4.1.2. Memories of the resuscitation

On trying to recall the resuscitation, many parents described feelings of unreality, a feeling of not being there but at the same time being there, as if watching it unfolding from a distance. For many the entire event remained a blur, whether their child survived or died during the resuscitation. Mark recalled,

... I don’t remembering being there for the second one, but I think I was there, I don’t remember, I really don’t ... I think it’s the constant pounding you cop, lack of sleep the whole bit that makes you not remember all the bits ...

Neil confirmed this when he said “… It’s all a bit of a blur, all that happened.”

It was though it was happening on television and was not entirely real. The little, incidental things such as a clock stopping, a nurse’s touch, the weather outside, however were recalled with great clarity. As Melissa recalled “... it was Saturday, and the clock on the wall in his room stopped at the time he died, it was weird …”

The parents were able to selectively block out the more horrific recollections over which they had little control. Julie explained,

... we had to be there for her and really I don’t remember all the stuff that was happening, I was just looking at her and trying to tell her we loved her, because I knew she wasn’t going to make it ...

While these parents wanted to be present for their child, they could only do so by detaching themselves from the horror of the reality. Detaching themselves meant for some, leaving the room, and for others being able to focus on their child, and ignore the events occurring around them.

Some of the parents who witnessed a successful resuscitation spoke of being haunted by the memories of the drama of resuscitation. For these parents, they were less able to
eradicate the memories. They were able to realise how close their child came to death, and in doing so, remained anxiously aware of the real possibility of subsequent arrests, which may result in their child’s death. They were aware of the closeness of death for much of the subsequent time in PICU. For some parents, this awareness continued for some time following discharge home.

When a child had not survived, the recollections were those of the child, and not the resuscitation procedure. For instance, when beginning each interview, the parent was asked about the time their child suffered a cardiac arrest, but each time a parent began with the description of their child before illness struck. Furthermore, each parent talked about the entire PICU stay, rather than focussing on the specific experience of the resuscitation and possible death. As Melissa said,

…it was a living nightmare … I just wanted to wake up and it would be okay and he would be our normal happy, cheeky little boy … I could tell you every tube he had every bruise on every part of his body, from every needle and everything …

When a child died, their thoughts were not of the actual death, but of their child’s life, his way of being in the world and to a lesser extent his suffering through the recent illness or accident.

5.4.2. Understanding the Resuscitation

When a child survived the resuscitation, parents who were not present were able to put the resuscitation into context and move on. These parents did not fully recognise the significance of their child’s condition or how close they came to death. It was not until Neil and Lynne witnessed a second resuscitation attempt on their child, that they finally realised the extent of his critical condition. Neil explained:
... he’d stabilised again, so we weren’t actually there when it happened ... so we didn’t realise how sick he was that time until he crashed the second time, we said we both realised that we didn’t understand when they said ‘he’s not real well and he might not make it’ how sick he was. Because we’d missed all that sort of frantic action to try and you know, do what they could for him ...

They felt guilty at trivialising it, and felt obliged to mourn the near death on the previous occasions. It was as if they were making up for not taking it seriously enough the last time. Neil continued:

Even the week before, we didn’t see it, you know ... we knew he was sick but sort of sitting there and seeing everything that happened, we sort of thought, he’s in the middle of dying here ... what would have happened if we’d not been there? We’d never have forgiven ourselves ...

Dominique, too, did not fully appreciate the significance of the resuscitation until she was witness to another child’s resuscitation. Dominique explained:

... it wasn’t until another baby had a cardiac arrest and I was there that I realised how close he came and I thought “that must have been what happened with Jamie” ... I couldn’t believe how close he’d come to dying ...

Others also expressed uncertainty about the event in not being present. There were more unanswered questions about the events leading to the arrest and the decisions made during the resuscitation.

Many of the parents demonstrated a lack of understanding in the terminology used by the staff, which further compounded their ability to make sense of the resuscitation. Often, by the time they returned to the unit, their child’s condition had stabilised to such a degree that it was inconceivable that they had suffered a cardiac arrest. These parents recalled that few staff were direct in their explanations. The explanations were described as “an episode” or of the child “being naughty”, appearing to trivialise the critical nature of the time. Neil and Louise said
We came back and they just said he’d had an episode but he’s alright now … we saw the machine [defibrillator] beside him but we just thought that was there just in case … we didn’t know they’d used it …

Yasmina too described the insignificant manner in which she was told of her daughter’s resuscitation “… I came up in the morning and they said ‘she’s been naughty all night, but she’s okay now…”

It became clear that several parents did not readily equate resuscitation and cardiac arrest with near death, particularly when not witnessing the event. Indeed, it was not until I approached Dianne and Simon to take part in the study, that they finally were informed and understood that Brendan had suffered a cardiac arrest and been resuscitated a week previously. Simon explained,

... we didn’t get told very much, everyone in ICU referred to it as “an episode” it didn’t worry us that much, because I suppose we didn’t know what went on, not being there … we didn’t give much thought to it until you talked to us yesterday … it was a shock knowing that’s what they’d done to it … how close we came to losing him.

Even although Jenny and Mark were present for much of the resuscitation, they described not being able to fully understand what had been said to them. Jenny said,

... they didn’t tell us he’d had 2 cardiac arrests … it was later … they used to come on their rounds … and talk about what happened … then someone actually said he had a cardiac arrest and Mark said “that means he had a heart attack doesn’t it? Did you know he had a heart attack?” and I said I didn’t know that’s what happened to him … they just said he wasn’t doing real well …

These parents believed that the staff played down the drama in order to protect them from further distress, knowing that their child’s condition was then stable. As Simon acknowledged “… it’s over now and he’s fine and going home tomorrow … I guess they didn’t want to worry us when it was all alright in the end …"
Dominique confirmed this belief, saying “... I’m sure they do it to protect parents’ feelings but if anything had happened and I hadn’t been there, I wouldn’t have been impressed …”

The parents needed to be provided with a basic, straightforward explanation. As Julie explained, “I really couldn’t take it all in at the time … I would have preferred them to just say ‘your baby’s heart has stopped … we’re trying to start it again’”

While the parents told of not being fully informed of their child’s resuscitation in words that could be easily understood, and indeed on occasions, denied being told that their child had suffered a cardiac arrest, the parents conceded they might have not grasped the explanations that had indeed been given to them. As Dominique admitted:

... they didn’t actually say … or perhaps they did … I think they glossed over it perhaps they thought I knew what tamponade meant, perhaps they thought someone had already told me … they probably thought they’d explained it on the phone to me or perhaps I didn’t take in what they said before … I know they try to explain but they should take into account that parents are in shock … I put two and two together and realised and thought ‘shit!’ I couldn’t believe it …

Not enough information was as frustrating as too much. Jenny explained:

... they said to us afterwards, you know, he’s got other problems, he’s got a leaking valve after the arrest … and we thought they didn’t tell us but I’m sure they had … we must have forgotten … there’s just too much information.

Being provided with an explanation that the parents could fully comprehend was crucial to their understanding and making sense of the resuscitation procedure.

**5.4.3. Waiting for news**

When the parents were not present, waiting for news was paramount and time infinite. Choosing not to stay during the resuscitation and instead retiring to the parents’ sitting
room close by was torture for some parents, but necessary for them in order to cope with
the perceived trauma. Most parents chose not to leave entirely, preferring to come and go
throughout the time of the resuscitation. In that way, they were able to keep their distress
in check. As Jenny explained,

… when I walked in on it, one of the nurses went to say something to me and
one of the doctors was, not yelling but he said “I told you to get this, you
better go and get it” you know, so at that stage I walked out again because I
was thinking something really bad was going on.

The parents expressed the frustrations and uncertainty that waiting for further news
brought them. Lynne explained her frustrations:

… we sat in here [parents’ room] for the whole time and I was an absolute
mess … I said to Neil “you’re going to have to go down there and find out
what they’re doing … I can’t stand not knowing”… I know they do everything
they can to help but waiting … like, I know it was serious but when you sit
there and you don’t know what’s happening, it’s a horrible feeling, sitting
there waiting … 5 minutes seems like 5 hours.

In waiting for news, some of the parents began to question the staff’s integrity. They
postulated that the staff might have withheld news from them; that maybe their child had
already died but the staff were fearful of breaking the news. For Jenny, waiting seemed
an eternity as she began to believe Matthew might have died after all. She told:

They were supposed to come and get us … It was supposed to be half an hour
and it went on and we thought he was dead … we thought a kid can’t survive
that long … the nurse, Lucy, kept coming out and saying “we’re just cleaning
him up” and we thought how much mess can there be? He’s only little and
this was like, three hours later … and we were waiting and waiting and
waiting …

5.4.4. Imagining the Resuscitation

Parents who were not present spoke of imagining the scene inside. This imagination was
often worse than the reality. Mark confided that he could not contemplate watching staff
“jumping up and down on Matthew’s chest and seeing him suffer the pain and indignity”.

When Mark finally forced himself to enter the room, he was relieved to see the care taken by staff to minimise unnecessary trauma to Matthew.

Mark was surprised at the lack of drama, imagining the resuscitation to resemble major surgery or indeed a horror movie.

Imagining their child had already died, and not being informed by staff of this fact weighed heavily on parents’ minds. Lynne told of this:

… you sit in that room and wait and you think the worst, the longer it is … and your mind races and I was shaking and I wanted to go in and find out but I was scared of what I was going to find … I thought the worst and that was the worst day I’d had … waiting there … worse than watching him being resuscitated because you just don’t know if he’s alive.

The experience of witnessing a resuscitation attempt was made more baffling when parents were subsequently prevented from staying with their child in the period immediately after the resuscitation. Parents on several occasions were encouraged to stay during the arrest, but asked to leave while nurses “cleaned up the baby”. As Mark explained:

They told us, to be honest, they said not to go in … they just kept saying “stay here and when we’re ready … we’ll come and get you” … what were they doing, other than just cleaning him up … I dunno, they didn’t tell us … they didn’t offer for us to go in there at any stage.

5.4.5. Finding a place

Finding a place, both physically and metaphorically, was important for parents to try to understand and make sense of the resuscitation. Being able to be present and being accepted by staff to be present, not only comforted parents, but also ensured they could seek an understanding of what was happening to their child. Having a place and choosing
to stay however, brought with it tensions, with several of the parents fearful of impeding
the resuscitation event and feeling as if they should stay away, letting the experts do their
job uninterrupted. Furthermore, some parents felt trapped into either staying away once
they had left the scene momentarily, or indeed forced into staying when they believed
they could not cope with witnessing their child’s resuscitation. Thus *hindering the
resuscitation* and *parents as participants* were essential components in the parents’
experience of finding a place.

5.4.6. Hindering the resuscitation

The parents went to great lengths to show their willingness not to hamper the efforts by
leaving the unit, despite their overwhelming desire to stay with their child. If staying
were to thwart staffs’ attempts, then they would leave. Neil demonstrated the act of
stepping back:

… well, *I mean we were just standing out of the way, that was the best thing
for us to do … we didn’t want to leave … but you want them to save your
baby and if you’ve got to go outside for them to do it, well then it’s
worthwhile …*

Lynne continued … *we sort of had a little seat in the corner out of the way
which was good … we just sort of stayed out of the way and watched them …
it gave us a different perspective on what they did …*

Simon speculated that if he had been present he would have done all he could to not
hinder the resuscitation. He said “*If that happened, I would just walk out and stand
outside the room until they had finished what they had to do… let them do what they’ve
got to do*”. 
5.4.7. Parents as participants

When parents remained present, many accepted the role as a passive participant of the resuscitation, believing that while they must stay with their child, it was essential for their own well-being to view the resuscitation scene as a spectator and not become involved in the physical aspects of the procedure. This did not mean, however, that as spectators these parents were not emotionally engaged in the experience of the resuscitation. Others became actively involved, by being able to touch and talk to their child. Amanda wanted to let her child know she was there for him during his resuscitation attempt. She described the event, “… I walked around to the end of the bed, I couldn’t get in their way, but I needed to let him know I was there and that was pretty good …”

Julie too, needed to let Sarah know she was there during the resuscitation. “… we had to be there, to tell her we loved her and you have to touch them …”

Throughout the resuscitation, however, no parent attempted to try to physically help to resuscitate or indeed stop staff from their attempts.

Dominique was denied the opportunity to stay with Jamie during his resuscitation. She believed that this inability to participate as a parent was unjust, … it’s when it comes to a crisis … they tend to be a bit evasive … another baby was having complications and they pulled the screen around and that must have been what they did with Jamie … I didn’t see anything but I heard them quickly issuing orders and I knew that if I’d been there with Jamie, I would have just sat there with him and they would have gone about their business … I just wish they’d let me in to be with him … it was so unfair.
5.4.8. Summary

In being present during the resuscitation attempt on their child, the parents acted in ways that attempted to make sense of the resuscitation and find their way in the distressing time.

In *witnessing the resuscitation*, the parents were able to begin to develop an understanding of the significance of the event and the critical condition of their child. In being able to see everything possible had been done for their child, parents could seek comfort in knowing they had done everything possible for their child. Guilt could be lessened in parents’ knowing they had advocated effectively for their child. In recalling the resuscitation procedure, parents considered they had not suffered further trauma by permanent memories of the arrest, but were able to focus on their child during the resuscitation and be there for them.

Understanding the terminology was important in understanding the resuscitation. Interpreting the terminology used by staff to describe the resuscitation was difficult for parents who preferred simple, yet accurate statements at a time of great stress.

The experience of *finding a place for parents* was reassuring for parents as a way of orientating themselves to the scene and thus beginning to understand. Despite their desperate need not to hinder the attempt, the parents believed in their essential role as a passive participant. The parents’ experiences of *witnessing the resuscitation* and *finding a place* contributed to the theme of *Making sense of a living nightmare.*
5.5. Maintaining hope in the face of reality.

The parents approached the experience of being present during their child’s resuscitation further by **Maintaining hope in the face of reality**. This theme describes the ways in which the parents sought to cope with the resuscitation process and its’ meaning for them. Maintaining hope in the face of reality was revealed by the development of two dimensions:

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hope versus Reality</td>
<td>• Facing reality</td>
</tr>
<tr>
<td></td>
<td>• Handing over and trusting staff</td>
</tr>
<tr>
<td></td>
<td>• Crying as therapy</td>
</tr>
<tr>
<td></td>
<td>• Drawing on established coping strategies</td>
</tr>
<tr>
<td></td>
<td>• Being prepared</td>
</tr>
<tr>
<td></td>
<td>• Saying goodbye</td>
</tr>
<tr>
<td></td>
<td>• Coping with death</td>
</tr>
<tr>
<td>Seeking support</td>
<td>• Family &amp; spiritual support</td>
</tr>
<tr>
<td></td>
<td>• Empathic understanding for another</td>
</tr>
<tr>
<td></td>
<td>• Remaining grounded</td>
</tr>
<tr>
<td></td>
<td>• Being abandoned</td>
</tr>
<tr>
<td></td>
<td>• Regaining ownership</td>
</tr>
<tr>
<td></td>
<td>• Taking control: making the choice</td>
</tr>
</tbody>
</table>

5.5.1. Hope versus reality

Maintaining hope and remaining positive even in the face of certain death of their child was important for parents to continue to cope with the immediacy of the resuscitation. While parents often knew their child would not survive, many talked of their desperate need to believe they may be wrong. By willing the child to live they believed they might be rewarded for a successful outcome. As Neil described:

> You’ve got to sort of hope that the outcome … you want the best outcome …. and I think you get involved in it all … we had a cry and you sit there and cross everything you’ve got and you’re thinking “come on mate, come on” you know “do something”
Melissa talked about initially confronting the possibility of her child’s death:

_The nurse just said he was sick, but what made me twig is one the nurses in ICU said “do you want a Polaroid of him?” And I said “I won’t need it” because I know they take Polaroids of kids that are gonna die and I said “No I won’t need it”_

For Melissa, the photograph signified death, so she rejected it as her way of maintaining hope despite the reality of her son’s condition.

Adam demonstrated the need to remain hopeful in spite of knowing Chris would not survive, “... _you have to cling onto that last breath ... you think ‘I don’t care, miracles do happen ...’_”

Avoiding the inevitability of death until the last minutes by maintaining hope ensured parents remained supportive of their child’s life. Neil described an experience of this kind:

_... but we got to the stage when we pretty much chose not to believe it ... we just believed he was going to get better ... and it got to the stage that I said ‘I’m going to say “if you don’t think he’s going to live, just get out ... we don’t want you in the room ...”’ we put a ban on them coming in ... we just didn’t want him to die and didn’t want them all coming in all the time and telling us he would die ..._

Paradoxically, these parents were fully aware of the reality of their child’s condition. Neil recalled:

_We were getting told 5 times a day, he would not make it ... we said “we know what the truth is, we just don’t need you to keep telling us”... You just tune out ... you block it out and you’re thinking I don’t want to hear this ... you’re just going to tell me more negative stuff ...

Several parents clung on to previous experiences of critical illness when their child had recovered. In understanding their child’s ability to survive through previous resuscitation
attempts, they believed they could do so once more. Despite their denial in facing the reality, these parents instinctively knew the final outcome. As Melissa admitted:

\[
I \text{ really thought, I was in two minds, the helicopter sort of rose in the air and stayed there for about 5 minutes, and I thought “he’s not coming home” … But on the other hand I thought “the helicopter ride with his Dad will wake him up and when I get there he’ll be sitting up with a teddy waiting for me” but when I got there, he wasn’t …}
\]

In surrounding themselves with family members and friends with optimistic attributes, the parents further held that positive energy would not only support the child, but also encourage and enhance their own hopefulness. Lynne talked about gaining strength from being positive:

\[
You \text{ think “I’m not going to cry” … and we decided if we were negative in his room or intensive care, that would rub off on him … so if we were going to cry we’d have to go outside … we weren’t going to cry over him … we were going to be positive in his room and the more positive we were, maybe he’ll pick up on that positive …}
\]

So desperate were they to remain positive, that some parents rejected support from those they believed would not agree with their overly optimistic view of their child’s condition. Neil further explained his need to remain positive around his child:

\[
We \text{ even got to the stage where we were saying “these people aren’t real positive, they’re not coming in” … and we’d say, “if you go in and you cry, you’re going to get a kick up the arse” because it didn’t help us to see them coming here and crying.}
\]

Some parents described their use of humour as a way of coping with the immediacy of the critical situation. It was crucial for these parents to, in their words, ‘have a laugh with staff’ to keep going from moment to moment. Lynne on describing her need to maintain positive, postulated that others may not understand her attitude and judge her to be uncaring:
We’d have a laugh or joke with the nurse ... we’d read something funny in the paper and we’d be having a laugh you know, and people must walk past and say “they’ve lost the plot, they don’t care” ... but you know we’d have our cries and still have our laughs with the nurse and still talk about our other kids you know ... you can’t mope around all the time or you’d end up in a straitjacket ... 

Despite the need to maintain hope, all the parents eventually confronted the reality of the resuscitation and what it meant for their child.

5.5.1.1. Facing reality

In facing the reality of the resuscitation, the parents expressed guilt at not previously acknowledging the extent of their child’s critical condition. The parents’ experiences of confronting the reality of their child’s condition were described in the coping strategies they employed. Such strategies were identified as handing over and trusting staff, crying as therapy, drawing on established coping mechanisms, being prepared and saying goodbye.

5.5.1.2. Handing over and trusting staff

Being able to trust staff with their child’s life was essential to the parents’ ability to cope with their loss of control over their child’s life during a resuscitation attempt. Jenny and Mark were relieved when the experts took control:

**Mark:** The doctor was straight and to the point ... you don’t want any indecision or anything ... he was just on the money and that gave me a lot of confidence ... I thought ‘fine you know what you’re doing and that sounds good enough to me …’

**Jenny:** ... he said “this is what we’ll do” ... 

**Mark:** ... yep “and this is how we’ll do it”... totally in control.
5.5.1.3. Crying as therapy

The need to cry was paramount when parents confronted the reality of the resuscitation. Parents sought comfort from crying with family and were able to face the next minutes or hours with greater strength. Neil explained,

You just cope, you have a cry and then cope … you’d go for a walk outside and have a bit of a cry and get it out your system and come back … because you both can’t stay positive the whole time.

Jenny offered a similar description:

... I’d get on the phone and start crying then snap out of it … I didn’t want to be a blithering idiot and cry the whole time; you cry when you go to bed, cry here and there …

Melissa, too, described the feeling of support she received from crying with family, “... it was really good … we sat out on the balcony cried and drank coffee for hours and hours … and that was really good …”

Crying, however, was felt by parents to indicate to staff signs of not coping well, particularly when witnessing the resuscitation, and so were often thwarted in their attempts to express their feelings openly. In one instance, a mother expressed extreme anger at being chastised for crying when her son suffered a second cardiac arrest and she knew the resuscitation attempt was hopeless. Melissa told:

.... I was crying, he’d had a second arrest and she said “hush I can hear your tears all over the ward” and I thought “shut your mouth and get away from me”, we’d been 48 hours without sleep, eat, anything and she tells me to hush and I think “shut up!” she was so hard and my son was dying for god’s sake.

For this mother, anger at staff at not demonstrating empathy at a time of great distress was lasting and destructive to her coping of the event. As she recalled, “she was so hard, I’ll never forget her but I’m trying to remember the good nurses …”
5.5.1.4. Drawing on established coping mechanisms

The parents demonstrated an ability to draw on past experiences of stressful situations in order to cope with the current stress. For some this meant remembering other family members who had died. Mick talked of several of his family members who had died prematurely including his mother and brother. For him, looking for spiritual meaning was a way of accepting death of close family members:

… my cousin died … you’ve got to accept death … I know people think these things are never going to happen to you but they do … and your eyes open up … nothing we can do can change that … if God wants you he’ll take you … no matter how old you are … I’ve had death in family since I was 10 years old …

Mick also believed that fate held he should not be present during his son’s resuscitation:

I wasn’t meant to see it … I wasn’t meant to be there … I think God mustn’t have wanted me there … my auntie died that day and she took him to heaven to look after him … that’s the way we think about it …

For other parents who had not experienced death of a close family member, drawing upon other stressful experiences enabled them to make sense of and cope with the resuscitation. Jenny and Mark had prepared themselves when they learned that Matthew had a congenital heart defect in utero. They were no strangers to the intensive care environment, Matthew having been admitted from birth. Along the way they experienced many stresses that Mark described as a ‘roller-coaster ride’. The resuscitation attempt, therefore, was not the only critical incident, albeit the most serious, to occur during their stay, “… it wasn’t really any worse than everything else that happened … the infections and all that.”
Neil and Lynne also had past experiences of the intensive care area and confirmed the opinion that the whole ICU stay was stressful, rather than the specifics of the resuscitation, which blurred into the whole experience. As Neil explained:

... no-one comes to the intensive care unit with absolutely no other experiences of stress in their lives ... We draw on how we have coped in the past I suppose ... From the minute we’re born, we use experiences to cope with things ... That’s how I suppose we’ve dealt with seeing it [the resuscitation] ... so I think that people shouldn’t think we can’t cope ...

For some parents, knowing they could not cope with witnessing resuscitation was inherent in knowing their previous reactions to their child’s illness or accident. Mohammed was forthright when he confirmed he would not be able to cope with watching the resuscitation and preferred not to think about it.

5.5.1.5. Being prepared

The parents prepared themselves for the possibility of their child’s death. This preparation was explained in being able to see the futility of the attempt, or conversely in seeing how close their child came to death.

In preparing for the reality of possible death some parents talked of loving their child but needing to protect themselves by holding a part of themselves back. This holding back was particularly present when infants had been diagnosed with a life-threatening condition at or soon after birth. In these cases, parents had begun to prepare themselves for death of their child from the beginning and in doing so, attempted to restrict their attachment to their child. Jenny expressed guilt when she described this experience:

... You sort of don’t want to cling, I mean you want to but not too much, you know what I’m saying ... you’ve got love for him but you’re holding some back ... because you don’t want to attach yourself too much ... that’s how I feel ...
In holding back, Jenny attempted to protect herself from the inevitability of her child’s death. Despite this, however, these parents expressed as much distress as any other parent whose child may not survive during a resuscitation attempt. While they may have prepared themselves for their child not surviving to adulthood, the parents were unprepared for the death of their child following a sudden cardiac arrest and failed resuscitation attempt. Neil and Lynne told how while they had had a long time to come to terms with Toby’s inevitable death, they were still shocked at the suddenness of his death following cardiac arrest. Neil explained “Even before he was born, we knew he might not make it but we didn’t expect it when it happened …”

Mick and Amanda were grateful for the time leading up to death, “we had two weeks to sort of accept it … if the surgeon had come out on the day of the operation and said he’d passed away … I think it would have killed us.”

When a child survived, these parents too confronted the reality and in doing so were able to appreciate their child’s desperate will to hold on to life. These parents spoke of being left in awe of a child who survived the near death experience, yet remained on alert for future episodes that may render the child in a similar situation of critical illness. Dominique told “… we’re very lucky to have him … it’s a credit to him really, how strong he is …”

Despite the sudden nature of the cardiac arrest and resuscitation, most of the parents were prepared in some way for what was to come. They had been prepared either by the staff or by knowing of the critical nature of their child’s illness from the start. While the arrests were shocking, they were not completely unexpected.
5.5.1.6. Saying goodbye

Having the opportunity to say goodbye to their child, by being present during resuscitation was important for the parents. Julie repeated this often:

.. the last few hours we weren’t in there much at all ... she was getting worse, but you have to say goodbye, you have to touch them. We had to be there at the end and tell her we loved her ... it was hard to see her chest being pumped but we had to do it to say goodbye ...

By saying goodbye, a parent gave permission to his or her child to die. Julie attempted to comfort her child in giving permission, “… I said to her ‘it’s alright to go, you’ll be safe.’” While experiencing guilt at the prospect of giving up on their child, the parents needed to let go when they could see no more could be done for their child and that by prolonging the resuscitation, suffering would continue needlessly. Giving permission for the child to die was not really giving up on the child but a wish for reprieve for their child, to be allowed to rest and to be free of pain.

The abruptness of the child’s death could never be fully reconciled by parents, with permanent grief and regret at the wasted life. Having the opportunity to stay and participate in the way and time the child dies, brought some control and with it, a degree of resolution.

5.5.1.7. Coping with death

When the parents had been present they were able to see that all had been done in the attempt to save their child; were comforted in knowing they had been with their child at the end; and had in some instances, been involved in the decision to stop. Additionally, the parents coped with the resuscitation and the resulting death of their child by knowing that they would not have coped better by not being there. Furthermore, these parents who
grieved for their child expressed familiar signs of grief such as anger, regret and self blame common throughout all experiences of the death of a child.

While the parents acknowledged that being present when their child died was undoubtedly traumatic, no parent regretted witnessing the resuscitation, as it gave them a last chance to be close to their child and talk to them. As Julie said, “I don’t regret being there at all.”

The parents talked of being comforted in having been present and thus believed they were able to cope with facing the death of their child. Amanda was resolute in her belief that being present during Jake’s resuscitation enabled her to cope with his resultant death, “I don’t think I could have coped as well if I hadn’t been there and seen it … seen that they did everything … I had to stay with him …”

When the parents talked of their child and their ongoing coping with their child’s death, they expressed the ability to lay aside any memories of the resuscitation scene. Their memories were of their child, and their coping focussed on their ability or not to deal with the anger, resentment, regrets and self blame of their child’s untimely death. It appeared that coping with the resuscitation was a small aspect only of the important way of coping with their child’s death.

5.5.2. Seeking support

The parents described their experiences of Seeking support in their bid to cope with the resuscitation experience more effectively. Emotional and practical support was found from a number of sources, but particularly from each other, other family members and
close friends; and to a lesser extent from staff and from spiritual support. In gaining support, the parents were often able to know when to take control over the situation and when to step back and hand over.

5.5.2.1. Family and spiritual support

During times of stress many of the parents described taking turns in providing support for the other who was more vulnerable and less able to cope at that particular time. As Jenny and Mark explained,

Jenny: ... there are times when Mark couldn’t handle it and I was the strong one but there’s other times when I’d be really upset and he’d have to say to me “well, he hasn’t got this and he hasn’t got that you know” it changes, you sort of swap you know ...

Mark [talking to Jenny]: … but it did change didn’t it?… I’d be all down in the dumps and you’d be helping me to see the positives ...

It was apparent throughout the conversations with the parents, that they looked to each other for support, during the resuscitation and indeed when talking about the experience with me. Jenny and Mark, in particular, demonstrated solidarity by finishing each others sentences, and encouraging each other to tell their story.

Lynne and Neil also talked of supporting each other through the resuscitation and periods of instability.

Lynne: you have to cry ... you can’t both stay positive all the time ... you need a fine balance ... when I feel bad, he’s okay but you can’t always help each other though ... we’ve both had times when we feel bad ...

Neil was surprised when some of the staff commented that he and Lynne had not appeared to argue:

Someone said they hadn’t heard us argue or have harsh words ... because it’s stressful and I sort of said “it’s not like that”... we both knew it wasn’t going
to help, us fighting ... it wasn’t going to change things and we needed each other.

He continued ... you have each other, you know how each other is feeling without saying anything ... she was crying and I was cuddling her and saying it would be alright ... I was trying to keep her from breaking down sort of thing ... then an hour later I’d be crying and she’d be over it by then and being strong for me ...

The parents also sought support from other family members and close friends during the resuscitation. This support was often physical, as close family members were often present with the parents at the time of the resuscitation. Neil talked about the support he and Lynne received from their parents:

... when they turn around and tell you your baby’s going to die ... you have a cry ... then one of your family turns up and you have a cry with them and you sort of get over that bit ... I mean all I had to do was ring ... and they were here basically ... my mum’s really positive, like we knew they went home and bawled their eyes out but they wouldn’t do it here ...

Often, though, the parents had no family support physically present. The parents were able to seek comfort by telephoning their own parents. It was a relief for Melissa to know her father was looking after her other child, enabling her to concentrate on Chris’s condition. She explained:

... Andrew didn’t come down here ... he stayed here [at home] with all his mates ... he’s got lots of them and they all stayed with him and my Dad stayed with him to keep an eye on him ... I was glad that Andrew and my Dad stayed here and I knew his mates would look after him and I didn’t want him to see what Chris was going through.

For some parents, seeking comfort in spiritual support was beneficial. Mick confirmed that his belief in God helped him to cope with not being present when his baby died. He had been visiting his aunt who also died that day, when Amanda told him of Jake’s arrest. He believed that fate was responsible for his not being there and comforted himself by believing God had not wanted him to be present for a reason.
5.5.2.2. Empathic understanding for another

The act of resuscitation was often shared with others in similar circumstances. In these cases, some parents were comforted by providing comfort for other parents demonstrating empathic understanding for another. Jenny was comforted by other parents in PICU who had had similar experiences:

> You get, um, other comfort from having other parents, like you see the other parents and they say “be strong, try and be strong” you know … and you sort of pass that information along to others … that’s what I say to others “be strong” and I’d say that to another mother …

Dominique too took comfort from another, “No-one knows how you feel unless they’ve been there too … I talked to other mothers and that was good …”

Recognising others’ experiences was paramount, providing participants with a sense of protection and caring.

5.5.2.3. Remaining grounded

It was important for the parents to be understood as a family, as they attempted to remain grounded in their daily life in PICU. They described their lives and family to staff in order that they would accept them as a real family with other dimensions, merely suspended while a child was critically ill. They recounted stories of their child prior to admission and their relationships with siblings. Talking of everyday events assisted parents in putting aside for a short time the reality of the resuscitation and its aftermath.

Having to deal with the outside world at work was at times beneficial for parents in their attempt to make sense of what was happening to their child. At other times, the difficulties of having to explain to friends and colleagues were immense and parents
retreated into the relatively safe environment of PICU where they did not have to explain their feelings. Mark talked of his difficulties in talking about Matthew’s condition at work,

… not that you want to be melodramatic at all, just sometimes at work, everyone is asking “how is he?” and you can only say it so many times … and you get sick of saying it you know … some days you just don’t want to talk about it … you just want to get on with your work …

Lynne and Neil said they grounded themselves by “… talking about other things with the nurse, like things outside … talk about our other kids and her kids and the things they did.”

In being supported to focus on other aspects of their lives, the parents were able to cope more effectively with the resuscitation attempts. They did not believe, however, that they were always supported adequately. While a staff member routinely stayed with most of the parents during the resuscitation to offer support and information, this support was often not beneficial, causing further distress. Mark became frustrated with the staff,

… I don’t know what they’re trying to do, standing there and talking all the time, telling you what’s happening … I just wish they’d go over and help with resuscitating him and leave us … All that yakking in your ear … I couldn’t take it in anyway …

5.5.2.4. Being abandoned

When the parents were not successful in gaining support, particularly from family members and at times, the staff, some described a feeling of abandonment. It was as if everyone had given up on the child before the parents were willing to accept the inevitability of their child’s death. Neil was disappointed in his perception of the staffs’ negative attitudes towards Toby’s recovery. He said,
We don’t need that negative stuff … we sort of had a few people, sort of trying to tell us we should give up … and we got to the stage when we just didn’t listen to them … we now realise it wasn’t the case, they were just to make sure we understood the truth and what they thought was going to happen … but at the time we felt very alone.

5.5.2.5. Regaining ownership of the child

The parents described their experiences of regaining ownership of their child as well as being able to make the choice to stay or leave the resuscitation scene and actively seek information about their child’s resuscitation.

They were able to know when to take control and when to step back from the resuscitation when they were offered fitting support from the staff. For some, the last chance to touch their child and maintain closeness was essential as a way of comforting their child and letting them know they were there for them. Neil talked of a time when he was with his child when another child in PICU arrested suddenly and died and whose parents were not present at the time,

One thing that was pretty bad for us … the baby next door, then in two minutes, he just crashed and it seemed like for no reason and he just died and his parents weren’t there … we were bathing Toby so we couldn’t leave … it was awful to know he’d died and his parents weren’t there – that’s something that really gets to me … the fact they never got the chance to be there and to say goodbye … that broke my heart to know he’d died and there was nobody there … and we said we wouldn’t let that happen to Toby.

5.5.2.6. Taking control: making the choice

Whatever their decision, all the parents believed it must be their choice to either stay or leave during the resuscitation of their child. When a mother had experienced several resuscitation attempts, she began to understand how she could choose to stay on one occasion but not on another. Lynne said:
... it all depends how you’re feeling on the day ... some days I can cope with it and the next day, I know I couldn’t … so I didn’t stay then and waited outside … you just know if you can deal with it at the time ...

While Lynne appreciated the opportunity to make the decision for herself, Dominique described the feelings of inadequacy and frustration at not being allowed to make the decision, having it made for her by the staff.

For some who found it too traumatic to stay, choosing to leave was the only way to cope with the resuscitation scene. Leaving the room and waiting outside was, for a few parents, the best way of coping and left them with few regrets. For these parents, however, the resuscitation was a successful outcome. Neil wanted to stay but found he was unable to do so:

... the nurse said “oh you can sit and watch it” and I thought I could but in the end I couldn’t and I had to walk out. I just went around the corner and just stood there. I couldn’t watch it, I just couldn’t. It was pretty bad; I thought it was bad anyway. You know, it’s not good ...

Some parents considered it might be that walking in unexpectedly on the arrest was more shocking than had it occurred while they were there. As Neil described,

... I think it was bad seeing it because I walked in on it ... I made the call and they said “you’d better get up here, Matthew’s not well” ... It was the longest trip of my life ... I didn’t know what to expect and everything’s running through your mind and I finally got in and I saw what I saw and I was very worried ...

Amanda confirmed this belief when she told of being unprepared for the resuscitation in progress:

... I had only left for a minute ... I walked down to the car with my Mum and Dad and sister and when I went back all the alarms were going off and I didn’t think too much ... I sort of kept walking and then I saw it was Jake’s room that was all lit up and I just walked in on it and it was really hard to see that going on and I hadn’t been there at the beginning.
Having no preparation at all for the resuscitation that was taking place was even more shocking than for parents who had been present during the preceding deterioration and subsequent arrest.

Some of the parents, however, were discouraged or actively prevented from remaining with their child during the resuscitation. While some were quietly relieved at not having to make the decision, for example when they had been away from the hospital at the time, they strongly reaffirmed their right to choose, rather than the decision being enforced upon them.

Dominique expressed extreme frustration at being prevented from entering the unit during a resuscitation attempt. She was angry and suspicious at the insistence of staff. She explained:

... I buzzed and said “can I come and see Jamie?” They said “no, we’re trying to stabilise him” … I was told to go and wait in the parents’ room and they would come and get me … I was there for 45 minutes and that was pretty unfair … they should have said “if you want you can come in” but I wasn’t given the choice … they wouldn’t let me in … I was annoyed actually and really upset … I rang my husband and said “they won’t let me in” ...

Yet Dominique was fearful at demanding to be with Jamie for fear of further restrictions being placed upon her:

... she came out and got me and said “he’s Okay now, you can come in and see him”, I was just trying all the time to keep up the good front and not lose it with her … usually I’m a very upfront sort of person, but I sort of said “Okay” to whatever the nurses said and I look back and I should have said “No I want to go in with him”

FM: why didn’t you?

Dominique: I think sometimes, you um, tend to go on what the nurses say and trust their judgement … not realising that perhaps they were wrong …
For Dominique, not being offered the chance to stay with Jamie led to feelings of frustration and inadequacy as a mother. Furthermore, she punished herself by believing she should have known the right questions to ask about Jamie’s arrest confirming that the staff did not always offer sufficient explanations of the resuscitation at the time.

Thus parents held that taking control and being supported in their decision to stay or leave during the resuscitation enabled them to cope more effectively with the event.

5.5.3. Summary

Maintaining hope in the face of reality became an important theme of the parents’ experience of being present or not during resuscitation. It was constructed by the two dimensions of hope versus reality and seeking support, which were employed to enable degrees of coping. Throughout the conversations, it became clear that for many parents, the ability to regain some control over child’s condition was essential for their coping and ongoing parenting role. Knowing when to take control and when to step back became clear to the parents, once they had had the opportunity to be present and to be effectively supported throughout the resuscitation.

5.6. Living in a relationship with staff

<table>
<thead>
<tr>
<th>Dimensions</th>
<th>Sub-themes</th>
</tr>
</thead>
</table>
| Becoming a PICU family   | • Being accepted: Fitting in  
                           | • Being supported  
                           | • Being protected  |
| Trusting the experts     | • Being in awe  
                           | • Understanding staff  
                           | • Resuscitating in public |
As each of the parents talked about their experiences in witnessing the resuscitation, they frequently referred to their interactions with staff. They told of their need to establish relationships with them before, during and after resuscitation attempts on their child. For these parents, coping with the resuscitation was made easier when they had had the chance to establish a relationship with the staff prior to their child requiring resuscitation.

The relationship with staff held two main positions. Most interactions were concerned with how the parents became part of the PICU family, and fitted into the culture of the unit, while others were directed at the need to trust in the experts. This section is organised, then, according to these two positions of *Becoming a PICU family* and *Trusting the experts*. The theme is one component of the larger experience of parental presence during resuscitation and as such contributes to the full description of the phenomenon of parental presence during resuscitation in PICU.

5.6.1. Becoming a PICU family

The parents identified a need to fit in with the culture of the PICU and to be accepted by the staff, in order to feel at ease with the unfamiliar environment. Many of the parents demonstrated their ability to quickly pick up on the technical jargon and talk to the staff in their language. Jenny demonstrated her ability to adopt the language of the unit when she talked about Matthew’s day-to-day care following his successful resuscitation:

*Now if Matthew’s monitor starts bleeping, it’s nothing … I just move the wires and it starts going again … it’s no big deal … and now we don’t say “he’s breathing irregular” we say “he's tachypnoeic” … you get so used to the talk.*
5.6.1.1. Being accepted: fitting in

The parents believed they were more readily accepted by the staff when they had been resident for lengthy periods of time. Neil and Lynne expressed this sentiment:

… everyone would come in and check him over … because we were here for a while … you obviously get to know the doctors a bit more personally than what you would if you were only here a day or two … you sort of chat … they’d sort of make sure we knew what was going on … and in the end that was good … you’d chat, you know, what they did at the weekend … and you become part of the furniture.

When Toby suffered a cardiac arrest, Neil and Lynne were more comfortable with handing over responsibility to staff because they had got to know them and knew they would do their best.

Neil also believed that staff were more willing to ensure they participated in the decisions about Toby’s ongoing management if they were familiar to them, “We could talk to them … and we’d pretty much decided we weren’t going to up his drugs anymore … we have to draw the line and stop.”

Likewise, some of the parents were more accepting of the staff once they had established a relationship with them. They could relax their vigilance and did not feel the need to inform them of their child’s uniqueness. The staff would recognise any changes to the child’s condition. Lynne acknowledged this:

… after a while you know the nurses … we’d be up here when they changed over and a nurse that you knew would come in to look after Toby and you’d sleep better than like, a nurse you didn’t know, but might have been here 10 times as long … because you hadn’t met her before and they didn’t know us as well, you tend to not sleep as well … and ring up a few times …

On one occasion when Toby’s endotracheal tube required to be replaced, Neil and Lynne sensed the staff would rather them leave and were untroubled in doing so:
We sort of got the impression they didn’t want us to stay … and we came out and waited … but for some reason I wasn’t as nervous … probably because I knew Rob was with him … and he came back in half the time and said “it’s all done now … he’s fine”… and that was the first time I’d left that I actually felt comfortable.

Dianne, too, demonstrated an awareness of the staffs’ unspoken desires and concerns when she noted: “… you look at their facial expressions to know what’s going on…”

The staff had become familiar to her to the extent that she was able to grasp what was happening without words.

Melissa also identified with becoming part of the PICU family when she was encouraged and supported to provide care for her child:

_The nurse said “come on matey, we’ll wash your mouth and we’ll wipe your eyes” … and he said to me “do you want to comb his hair and do you want to help me bath him?” … and I did and he told me that Brendan could still hear me … and that was good._

She was profoundly grateful to a nurse who took the time to care for her child with compassion:

… he was just so lovely and treated him really well … he explained everything, not in big medical jargon but so we could understand … and he wiped his eyes, God love him … and put a clean nappy on him ’cause he kept dirtying himself, the poor little darling.

Amanda told of the time immediately after Jake’s unsuccessful resuscitation attempt, appreciating the caring side of the nurses after being witness to the more technical aspect of attempting to save him:

_…. I sat with him and after about 2 hours, they said they’d give him a bath and did I want to undress him … and I said “yes” so they ran a bath for me and by the time I undressed him it was getting cold … so they took a little bit out of it and reheated it for me and I gave him a bath and I dressed him._
Neil too appreciated the time taken by the nurses to care for Toby: “... nothing was too much trouble for them ... they were unbelievable.”

Dominique, however, described her inability to seek information at the time of Jamie’s resuscitation, demonstrating the difficulties in establishing an authentic relationship with the staff, when she said “... if you find out what actually happened a few days later ... you feel stupid asking questions three days later, when everything’s fine.”

The length of time in PICU establishing relationships with staff was not always a factor in how the parents felt accepted by the staff. Julie’s daughter, Sarah was admitted for only a few hours before she finally died. In that time Julie had managed to establish an intense relationship with the staff at that time. They engaged with her as a mother and she appreciated that short relationship. She commented, “... they were really good ... I talked to her and she gave me a hug and she knew I wanted to be with Sarah.”

All the parents talked of being accepted by staff when they anticipated their needs. Amanda recalled:

... I remember one asking me to sit down ... there were chairs beside the bed ... and she sort of touched on the shoulder, sort of held my arm ... I didn’t want to sit down ... I walked to the end of the bed so she moved the computer out of the way so I could stand there and mum could see him too ... and after he passed away, they disconnected everything and pulled the seat over so I could sit down ... and told me “for as long as you need, sit there”.

The relationship with staff went further than the resuscitation procedure, the staff engaging fully with the parents. Neil and Lynne appreciated the way a nurse thought of them on her days off, wanting to ring. They welcomed being treated as people of importance within the PICU world.
In fitting in, the parents described their actions of being a ‘good’ parent, by knowing the boundaries. Simon did not want to get in the way of the staff, noting that other parents did, “… some people sit on the side of the bed all the time … I don’t think that’s right, sitting right at the side of the bed … because they’re [nurses] going backwards and forwards.”

Lynne also agonised over doing the right thing:

> … we were outside the room … crying and they said we couldn’t go back in yet … I don’t even remember what they were still doing … we were in the corridor and I thought “any minute now someone’s going to ask us to move” and I thought “well no-one’s going to ask us to move because you know”, but I remember we didn’t …

5.6.1.2. Being Supported

In many instances, the parents were supported by the staff during and after their child’s resuscitation. Mark talked often of his gratitude of the offers of support:

> … I think everyone here has been unbelievable … people come and talk to you all the time … the chaplains, the social workers … I talk to the nurses all the time … they’re incredible.

Jenny appreciated the ongoing care and support from the doctors, even after Matthew had been transferred to another unit:

> … Rob, the doctor, came over to where we were in Extended Care, and I was feeding Matthew and he was so nice, you know … he said, “just seeing Matthew like that has made my day”… he said “I’m so excited, I’m going and tell all the nurses over there how he’s going because they all keep asking me how he’s going” … I thought that was really nice, just the little words that people say to you.

Many of the parents described being supported physically, with a nurse’s touch, or by being provided with accurate facts about their child’s resuscitation and potential to survive the arrest. There were, however, many instances when parents recounted times of
being unsupported by the staff. Jenny’s description illustrated this point when she told of a time when Matthew’s existence appeared to be trivialised:

The nurses, when Matthew was really sick … they must have thought, ‘this kid’s not going to make it’ because a lot of time the nurses would say to me “if Matthew doesn’t survive, would you have another child?”… and I’m thinking “what are you saying to me?” … but they kept saying “we’ve got people you can see in the Hospital if you want to have another one”… it was like they were writing his obituary.

Lynne provided a further example of a poor relationship, when a social worker did not recognise their need to be alone with Toby:

… the social worker wasn’t helpful at all … I didn’t like how she treated us like children … she was a bit of a problem to me … I’d say “oh, she’s coming again” and I’d put my head down … and the doctors would come and try to talk to us and she’d just stand there and listen … she could find out what was happening later and that used to bug me … even if we weren’t talking to her she could see we wanted to be alone but she’d just stand there and I thought “I can’t stand that woman!”…

Lynne and Neil did, however, concede that the social worker was able to help them practically with negotiating the financial maze when one child is critically ill in hospital:

… on the other hand, she helped us out … anything we wanted she got for us … all that practical stuff with our room, money issues, that sort of thing … we were trying to be here and trying to live at home with two kids and we only had one wage … Trying to run two households and we went and spoke to her and nothing was a problem. 15 minutes later it was fixed … she was useful in that respect.

For others, the staffs’ apparent coldness did little to foster a supportive environment. Melissa revealed:

… the nurse said “even if we do resuscitate him, he’s going to be brain damaged” I didn’t care, I wanted him alive and we’d worry about that later … and she said “well, he’s never going to be any better than you see now … I’m telling you, he’s better off dead … most children that come here in his condition are better off not being revived at all”… she was so cold and heartless … and stood against the wall with her arms behind her back.
Indeed, Melissa proposed that nurses should not work long term in PICU, and instead be allocated to other areas to ensure they maintained their perspective, “... you nurses should be rotated out of there ... because it’s just too hard, they get too hard and lose their compassion.”

Dominique also believed that working in the intensive care environment for long periods of time made nurses lose touch with the parents’ reality, “ ... they’re just not as compassionate ... they’re a lot different to just general ward nurses.”

Many of the parents understood that the nurses, too, were distressed. Nevertheless, the needed to rely on their emotional support. Lynne talked of an incident when an inexperienced nurse caring for Toby was not able to provide that support due to her own angst:

... they gave Toby to her because he was supposed to be stable that day ...she was a temp and they were short-staffed ... She was crying at the end, I remember her crying and that wasn’t any good for us was it?

Sympathy from staff was frustrating for the parents, when only they knew how they felt. Jenny was angry when doctors were patronising in their words of support. She recalled,

... they said “we know how you feel, we know it must be hard for you to watch”... I said “you don’t know, you’re doctors ... it’s tearing my heart out” ... you feel like getting up and strangling somebody ... you just feel so angry and useless.

And Julie also noted,

....no-one else really knows how you feel, not the doctors or anyone....what it’s like to happen to your child......no-one can tell you other than other mothers who’ve gone through the same thing.
5.6.1.3. Being protected

The staff protected parents in their attempts to support them during their child’s resuscitation. The parents generally welcomed this protection, but at times it demonstrated a paternalistic practice amongst nurses, who saw the resuscitation only through their own eyes. The insignificant explanation of the resuscitation demonstrated to parents that the staff did not wish to further alarm them when a successful outcome had been achieved. Simon and Dianne told of arriving back at the unit: “… we were going up the hallway and she said “he’s had a bit of an episode, everything’s alright now” … I guess she said that not to panic us too much.

Dominique justified the staffs’ actions in preventing her from staying with her child when she said “I’m sure they do it to protect people’s feelings, but if anything had happened, I wouldn’t have been impressed”.

Many of these parents recognised that the staff were attempting to protect them from further distress by either encouraging them to leave the resuscitation scene or by appearing to make light of the completed procedure.

Yet Jenny admitted to feeling paranoid when she believed the staff were keeping information from her: “… a lot of the time we thought “they’re not telling us the whole story”… I’d say to Mark “they’re keeping secrets from us … they’re only feeding us what they want us to hear.”

Jenny and Mark knew rationally that the staff did provide them with sufficient information and could see they were merely protecting them from being bombarded with
constant updates about Matthew’s condition, yet their distress led them to suspect the staffs’ actions.

5.6.2. Trusting the experts

When the parents had the opportunity to establish a relationship with the staff, they were able to trust in their judgment. As Neil explained, “… you’re more comfortable with the people you get to know … you have the same nurse 2 or 3 times in a row and it helps when they’re being resuscitated by someone they know.”

These parents trusted the staff so implicitly, that when the course of the PICU stay did not go according to plan, they expressed shock and bewilderment. When Brendan’s condition deteriorated as expected Simon was not concerned; “… they said right on the dot … 12 hours later … and he did … It was nothing dramatic, just a balancing game with his medications and things.”

When it happened a second time, Simon and Dianne were unprepared, believing Brendan to be progressing as the staff had implied would happen after the initial ‘danger period’. They pinned their hopes and expectations on believing he would have an unspectacular recovery, “… it was really scary, because they said it would be better after that first 12 hours … then he did it again.”

5.6.2.1. Being in awe

In establishing a relationship with the staff, albeit brief yet intense, the parents described being in awe. Neil, in watching Toby’s resuscitations, said:

… we stayed out of the way and watched them … and that gave us a very different perspective of them about what they do … they’re all working
around the bed, it’s like controlled chaos … busy and frantic … everyone knew their job and what to do …

Conversely, being in awe was detrimental to Dominique’s ongoing relationship with the medical staff and thus her understanding of Jamie’s resuscitation:

… the doctors there are so well trained in paediatrics and things like that … you feel in awe of them and you don’t like to ask questions because you’re interrupting them … and some of them have better bedside manners than others.

5.6.2.2. Understanding staff

Some of the parents were able to recognise the expertise of the staff. Neil described:

You could tell how experienced Leah was because she knew what the doctors were going to ask for before they did it … she had it all set up … by the time their brain was ticking over, she had it all ready to go … just waiting for the “yes” … everyone’s thinking one step ahead all the time … people don’t really know what they do and you can’t really explain … they say “we’ve done a lot for him” and you think I know … you get a different perspective of what goes on.

As the parents recognised the staffs’ expertise, they also developed an understanding of the frailties of the staff. They could identify the human side of PICU, appreciating that staff too, were distressed by a resuscitation attempt. After Matthew’s arrest and resuscitation, Mark described overhearing conflict between two doctors:

… they were having this chin-wag and I was sitting right there … they weren’t raising their voices or anything … but a few words under their breath … One came over later and apologised and said “it’s not necessary for you to see that going on” … I wasn’t worried though … they were getting at each other and I thought “who’s going to win?” … but it was good to see … at least it showed they were caring and concerned for him … and human … if they were going to have a bit of a ‘stoush’ at least they were trying to work out the best thing for him.

Additionally, the parents were aware of a lack of communication amongst the staff at times. Neil, for example, described his experience in this regard:
They kept telling us the same thing: that he was very sick and might not make it … when you think about it it’s not their fault … They don’t know what the previous doctor has said and they’ve got to make sure we understand … they’re trying to do their job the best they can …

Being connected to the child and family was seen as imperative to the nurses’ work and as such demonstrated their humanness to the parents. Lynne held that all the staff could not help but become involved by caring for critically ill children, particularly when they required resuscitation:

A baby dies and they go home and it must get to them a bit … they try to tell us they’re not emotionally attached but I’d like one of them to stand up in front of me and tell me they’re not attached to Toby …

Jenny appreciated the warmth shown by some of the staff, and believed she got on better with them:

All the nurses are unbelievable but some nurses are more motherly and you feel really warm to those … and you know, others are more robotic, you know what I’m saying?

Dominique and Melissa though, both believed that some nurses appeared hard and distant, believing this was inevitable when working in PICU for long periods of time:

Melissa: … they do get hard and I think that’s good for them to a certain extent not to get involved, but when you’re baby’s dying they should be more compassionate … I know some nurses were great but some were only there for the money, it’s just a job … but when your heart’s not in it you shouldn’t be there … it’s as simple as that …

There’s the good, the bad and the ugly! … but Jim [nurse] stayed long after his shift was finished … and so did Jane … that’s compassion.

Despite being disappointed and angry at the lack of compassion shown by some nurses, Melissa, even at the height of her grief, tried to justify their actions:

…. She was really hard and I hated her … like an old matron with arms crossed … but I suppose she could have been having a bad day too … it must be hard working here but it’s no reason to be a bitch …
Simon talked about the difficulties he and Dianne experienced in talking with some members of staff.

... we’re from the country and some of the nurses, they come from different countries ... It was harder for us to understand them and they talked too quickly ... you’d pick up bits and pieces ... they’d get frustrated with us and we’d get frustrated with them ... you’d shake your head and wait for the next shift to come on and hope and pray it was someone you could talk to ...

It was difficult for Simon to establish a trusting relationship with some members of staff with whom communicating was challenging. He did however; solve this difficulty by looking elsewhere for information and support, rather than inflaming the situation. The parents recognised they could seek information from a number of sources, and in doing so, adverse relationships with individual members of staff were not central to their coping ability.

5.6.2.3. Resuscitating in public

Working, and indeed resuscitating, in full view of the parents’ scrutiny was considered by several of the parents. Simon pondered the staffs’ perspective, believing they would prefer parents not to be present:

... like as professionals, I guess I can understand their point of view ... sometimes in any job you’ve got to do things that people shouldn’t see, you’ve got to take shortcuts, that aren’t the right protocol to get results ... I think it’s better if we’re out of the room for that ... and it’s easier for professionals to work on something without the parents, having the feeling that the parents are going to be looking over your shoulder so we’d better do this, you know, as per the book.

Amanda also recognised this phenomenon as potentially harmful to the staff:

... it must be really hard ... to have us there ... they must think we’re watching them ... but it’s hard for us too and I just wanted to be near Jake.
Most of the parents talked often about the need to trust the experts, letting them do their job. Yet they also admitted that they were able to make allowances for the humanness of the intensive care unit. Establishing a meaningful relationship was made easier when the staff were supportive, caring and compassionate. Even when the parents experienced a less than friendly approach, they were able to justify these actions and demonstrated their empathy for the staff in a highly emotional setting.

5.6.2.4. Summary

The parents in this study readily adopted the culture of the unit in order to fit in and be accepted by staff. This supportive relationship established with the staff was described as becoming part of the PICU family. In Living in a relationship with staff, the parents expressed a great need to develop trusting relationships with the staff, despite the often at times, shortness of the intense relationship. They appreciated the humanness of the staff and came to understand their concerns about parental presence during resuscitation.

5.7. Summary and conclusion

The start of the experience of being present during resuscitation began for these parents long before their child suffered a cardiac arrest. The resuscitation then was bound up in the greater, more traumatic experience of the beginning of the child’s illness and stay in the unit. The parents in this study have revealed that parental presence during resuscitation of their child is made up of many acts to which they are held to experience. Four main themes developed as the parents told their stories. In Being only for a child, they told of their child’s inherence to their world. Overwhelmingly, they expressed a deep desire to be with their child, particularly during periods of crisis. The perceived fear
of witnessing the resuscitation was overridden by their compelling desire to be with and for their child for most of the parents. For them, there was no question that they would consider leaving their child knowing they may not survive.

The parents existed only for their child by approaching it in a number of ways. They comforted the child and self by continuing to care for the child in any way they could. This was described by parents as a combination of knowing, protecting, comforting, advocating and watching over. It is as though by being present, the parents were remaining loyal to their role as a parent. When a child died, however, the parents expressed a feeling of betrayal as though they had let the child down, by giving up on them and allowing them to die.

The child’s being was the parents’ absolute focus to their world. It was inconceivable, then, for most of the parents to choose to leave the scene entirely if they had the option to stay. For those who had no opportunity to stay with their child, frustration at being separated from them at that time was extreme and lasting. This enforced separation was at times on the insistence of the staff, despite a purported family friendly environment that embraced parents at all times. The phenomenon of being disconnected from time and place was real for these parents, who described being stuck in time as it stood still during the resuscitation.

Each of the parents then told of the ways in which they were able to function during and after the resuscitation attempt. They revealed how they attempted to understand the resuscitation scene and process in the theme Making sense of a living nightmare. By being present, they were able to more fully understand the process and began to make
decisions about their own well-being, and that of their child’s continuing treatment. When a parent was not present, they demonstrated a lack of understanding about the process, as well as of the severity of the incident, when their child survived.

The parents initially continued to maintain hope for their child’s survival, even in the most futile of instances. Indeed, many of them struggled with this paradox between the need to maintain hope at all costs versus the reality they were faced with. When they finally faced the reality of the resuscitation and potential death, they began to utilise strategies in dealing with the events. The theme, **Maintaining hope in the face of reality**, then describes the ways in which the parents began to cope with the experience of resuscitation. The parents were able to draw on strategies, many of them effective in an attempt to cope. Seeking support from each other, family members and friends, and to a lesser extent, health professionals was beneficial for many of the parents. By being present, they were able to prepare themselves for the potential or actual death of their child. There were few unanswered questions about their child’s last moments and whether all had been done in the attempt to save them.

In **Living in a relationship with staff**, the experience of parents as they interacted with others has been described. These interactions have revealed that parents have specific needs for support and acceptance that are generally met through establishing relationships with the staff. They appreciated being accepted as part of the PICU family and did their best to fit in, by adopting the language and culture of the unit. They wanted to be seen as good parents and were rewarded by being permitted to stay with their child at all times. They were supported by the staff but at times believed this support evolved into
protection, at times misguided, whereby they were denied their right to choose to stay or leave the resuscitation. In choosing to leave, some of the parents described feeling unable to readily return, as if in making the decision, they must adhere to that decision permanently.

The parents, did however, develop trust in the expert role of the staff and were comforted in knowing their child was receiving competent and compassionate care. They were able to leave the scene more readily when they wished to do so, knowing their child was in good hands. When they had been present during a resuscitation attempt, some of the parents expressed awe in recognising the extent of the nurses’ role and responsibility. They held them in higher esteem for seeing their part in their child’s survival or death despite all efforts.

In spite of their distress, many of the parents were able to walk in the nurses’ shoes, when they demonstrated an awareness of the difficulties they must face when working in such an emotionally charged setting. They recognised and experienced the humanness of the staff and often gained strength from that unique relationship. Many of the parents did not have the opportunity to develop long standing relationships with the staff, yet maintained that even several hours was sufficient to establish an intense and often satisfactory relationship that assisted them in coping with the immediacy of the resuscitation and death.

The experience of being present or not being present during their child’s resuscitation is, for parents, an all encompassing Being for a child. The parents lived fully for their child while in PICU, needing to fulfil an essential parenting role despite the critical nature of
their condition. Understanding and coping with the resuscitation and its resulting aftermath was imperative to their experience and in how they continued to be for their child. It was evident that for these parents, being present enabled them to cope more effectively with the resuscitation. Establishing effective relationships with the staff further assisted the parents in their making sense of and coping with the resuscitation and added a crucial component to their experience.
Chapter 6

The Nurses’ Experience of Parental Presence

6.1. Introduction to the findings

The preceding chapter has described the parents’ experience of being present, or absent during resuscitation of their child in PICU. This chapter considers the nurses’ experience. While the parents’ best interests are generally held to be of paramount importance by the nurses, it was important to understand how they themselves functioned during resuscitation when parents were present. It became clear that caring for attendant parents was challenging and frequently described as the most difficult aspect of the role of the nurse.

Many of the nurses were supportive of the practice of parents remaining during the resuscitation, although this support was often conditional on their beliefs of the individual circumstances. Thus if they believed a parent could not cope, they encouraged them to leave. In effect the nurses described seeking a way out of dealing with the challenge of distressed parents. The expert nurses in particular, however, demonstrated enormous insight into the parents’ world and readily acknowledged their own struggles to come to terms with different parents’ needs.

Nurses in this study described three major interconnecting themes of their experience:

Under the parents’ gaze
Walking in their shoes
Holding parents in mind
6.2. Under the parents’ gaze

The nurses’ narratives were filled with descriptions of their awareness of the parents’ gaze. Three areas of experience were identified as dimensions of the theme Under the parents’ gaze; each dimension being drawn from the sense of the thematic statements.

These dimensions and the sub-themes that contributed to their development were:

<table>
<thead>
<tr>
<th>Dimensions</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing self</td>
<td>• Challenges to change</td>
</tr>
<tr>
<td></td>
<td>• Being judged</td>
</tr>
<tr>
<td></td>
<td>• Self protection</td>
</tr>
<tr>
<td>Managing the resuscitation</td>
<td>• Taking control</td>
</tr>
<tr>
<td></td>
<td>• Performance of self</td>
</tr>
<tr>
<td>Managing parental presence</td>
<td>• Parents as spectators</td>
</tr>
<tr>
<td></td>
<td>• Hindering the resuscitation</td>
</tr>
</tbody>
</table>

6.2.2. Managing self

The nurses talked of having to perform the most intense and difficult of tasks in a very public arena and still maintain a proficient demeanour. In order to achieve this, the nurses were called upon to cope with their own responses. Embracing the concept of resuscitating in public meant the staff had to challenge their own practices and beliefs.

6.2.2.1. Challenges to change

Many of the nurses who were initially challenged by the notion of parental presence had previously practiced in an adult unit and were novices in the paediatric setting. Indeed, there was a belief amongst these nurses that parents should just not be allowed to stay. Louise described this when she talked of her first few weeks working in PICU:

I think my initial impression, even before I did an arrest situation with parents and I was told they could be present, I was quite shocked … coming
from an adult experience where you ask people to leave, it was the complete opposite and it was quite confronting … it was shocking to think you could have people there in such a confronting time.

Challenging their ideas by gaining experience in arrest situations, the nurses came to accept parental presence more readily. Caroline, an expert nurse, identified the less experienced nurses as being acutely aware of resuscitating in the parents’ view, and believed the reason for their discomfort was their misunderstanding of their presence:

… the junior nurses aren’t as comfortable with their resuscitation skills so they probably feel like they’re on show … and the stupid thing is that the parents aren’t, you know, checking their skills at all. They’re looking at their child … they’re not sussing out who’s the most experienced and who’s not.

Previous practice had been to exclude parents from the resuscitation scene, or indeed during any invasive procedure. Many of the experienced nurses, therefore, had also had to adapt to the changing culture of the unit. As Simone admitted:

… it’s something I’ve had to become used to after years and years in the cardiac unit when we sent the parents out when anything happened … so there’s a very different concept that I’ve had to get used to …

Caroline, too, talked of the changes to practice and to her own beliefs about parental presence:

Many years ago I was opposed to parents coming in and that was from a different perspective … it’s an ugly scene … and it’s not in their best interests … now I think I took that position out of ignorance …

Caroline emphasised the changes that had occurred over the past 4 years:

… just about all the nurses now, the first thing they think of, after they’ve got help, is to get the parents in … I think the collective feeling of all the nurses has changed … I can remember 10 years ago when we’d go out of our way to get the parents out. Now we go out of our way to bring the parents in.

Even the expert nurses, however, were, on occasions, aware of the parents’ gaze. Many of them were, at times, conscious of their performance and of the parents’ expectations.

Simone, despite her many years of experience, admitted to lasting memories of individual
arrests. These arrests were memorable due to their prolonged resuscitation in the face of futility. She was embarrassed to be on show, when all concerned could see continuing was hopeless:

... the sweat was rolling down us and one of the uncles was staring at me because I visibly had sweat pouring down my face and I was embarrassed ... and it was wrong, particularly with the oncology kids, they push them beyond the limits ...

Simone was threatened by some parents’ extensive knowledge, believing she was insufficiently competent to answer all their questions. By performing under the parents’ gaze, Simone questioned her ability despite her expertise. She explained:

... some parents can be quite threatening or intimidating in their knowledge of how things should be done, because of their experience ... I'm thinking of the oncology patients or long-term in and out cardiac-type of patients ... been there, done that and seen it all.

Caroline described being watched, yet she believed that she was able to put this watchfulness aside more readily and focus on the resuscitation:

... it makes you feel self-conscious having the parents there ... plenty of doctors don’t like parents to be present, purely because they don’t feel they function as well ... I don’t think it affects the way I function anymore ... the more accustomed to parents being present, the less it affects my performance.

Successfully performing resuscitation is often perceived as the definitive test that nurses must pass to be accepted by their peers as being good enough to work in PICU. While being watched by parents was uncomfortable for some nurses, being watched and judged by their peers was equally arduous. It is as if novice nurses imagined they were given only once chance to prove themselves. As Caroline explained:

... the other thing about junior nurses is they think they’ll fail ... not perform ... I think resuscitation is almost like the ultimate test for the intensive care nurse ... you know, who does well in an arrest and who bombs out.
The additional challenge of performing adequately in front of their peers exacerbated the novice nurses’ discomfort. Not only did they have to efficiently respond to a critical incident and demonstrate proficiency to their peers but also remain concerned for the parents. Supporting each other therefore was an extension of managing self.

6.2.2.2. Being judged

Several of the nurses were fearful of making mistakes in view of the parents, despite confidence in their ability. Simone was acutely aware of this: “… when I first encountered the situation my initial reaction was ‘they’re going to watch me, I’d better not do anything amiss’ but then I realised well, ‘I know what I’m doing.’”

Louise admitted experiencing a great deal of stress in a chaotic situation, which was aggravated when parents were there:

… you don’t want parents to be there full-stop because it’s a time where everybody’s incredibly stressed … even if it was smooth running people still get very anxious in these situations … it’s never a smooth situation and people’s responses can get misinterpreted by parents.

Elaine expressed apprehension when a doctor interrogated the staff about their actions following a successful resuscitation. It was as if she was being judged and had failed:

… I don’t know if Dad realised. He [the doctor] really went off his head at us … “why did you do massage, did you give adrenaline, why did you give just one dose … don’t you know that this is how you kill a child” … it was very uncomfortable for us all … it made us feel like we’d done the wrong thing and that was really hard.

Elaine went on to explain her relief when a subsequent resuscitation was acceptable to the medical staff:

… the second one was much more organised, more staff free to take on roles and much more controlled. We all knew what everyone was doing … Someone bagged, someone massaged, someone got the drugs and someone
scrubbed … we did everything right … and then the doctor came in and someone went through everything with him and showed him what happened and he said “you've obviously done everything possible to save his life. Well done” so that was really good and made us feel better.

Several of the nurses needed to be reassured of their proficiency. Annemarie questioned her abilities in caring for a child prior to his arrest, pondering whether her actions may have led to his deterioration. The doubtful tone in which Annemarie spoke implied her need for reassurance that she had not contributed to the child’s arrest:

… I didn’t feel like I’d done anything wrong at the end of the arrest … there was nothing I didn’t do that was out of the ordinary or that the next person wouldn’t have done the same as me. So I don’t feel I did anything wrong. But later I felt so bad that I hadn’t been able to find mum and dad quickly enough … that made me feel really awful.

Her guilt at not being able to locate the parents, the one task she was given, compounded her uncertainty.

While some of the nurses mentioned being aware of others’ harsh language at a chaotic time, most agreed that the parents would not have been aware. As Louise revealed:

… I know that John sometimes swears and Rob was yelling at us to get the drugs quicker and all that stuff, but I don’t think the parents really take it in all … it’s all frantic.

For the nurses then, parental presence meant they became momentarily more aware of their ability, fearful of making mistakes or being judged.

6.2.2.3. Self-protection

Several nurses demonstrated the need to protect themselves from the horror of the situation. In doing so, they admitted that parents being present hampered their ability to protect themselves. It was as if they needed to distance themselves from the child as a
person in order to focus on the resuscitation and that this was needed when confronted by parents’ distress. Caroline was eloquent in her telling of this protecting of self:

… I think there’s plenty of nurses who feel the way I used to feel and that’s for the protection of the parents, that they shouldn’t be there ... we all feel self-conscious and a part of that is that nurses deal with the guts of these sorts of things, it’s often as an emotional defence in situations of emotional trauma ... you laugh and joke ... you have ways of defending yourself against the horrible reality of the situation you’re in ... to have to protect yourself, you know, elevate yourself about the reality of the scene ... focus on stupid things and I suppose the thing about having parents there is that it makes you focus on the reality of the scene ... so its more emotionally charged when the parents are there ... which is not necessarily a bad thing ... but having parents there makes the scene more sober, emotional and more respectful for the child.

For Caroline, the ability to put aside her need for protection from the reality of the possible death of a child was challenging, but ultimately essential in order for her to care wholly for the family and child. She embraced the emotional aspect of the resuscitation and was no longer afraid of it. Yet despite her acceptance, Caroline still admitted that looking after the parents was difficult as a nurses’ immediate response is to protect parents rather than allowing them to make the decision.

Louise and Elaine both admitted that resuscitating the child was certainly less traumatic when the parents were absent as it let them focus on the technical aspects of the resuscitation. While it did not compromise their performance, having the parents in view made them aware of the human aspect of their task. They were continually confronted by grieving parents. As Louise explained:

I find it very difficult when I’ve known the parents and formed a relationship with them ... it’s emotionally draining ... I find it difficult to distance myself emotionally even when I’ve only known them for a shift and I’ve got connections with them ... it’s certainly a lot easier when they’re not there and you just focus on the job ...
Indeed, Louise admitted that some nurses may find ways to exclude parents as a way of protecting themselves from dealing with the family’s grief:

*In some situations it’s not everyone’s first priority to make sure the parents are phoned or contacted … it may be just another way of not having the parents there, not giving them the opportunity to be there.*

Elaine talked of the need to maintain control over entry to the unit in a bid to protect herself and other staff:

… *I felt bad for the mum coming in on it like that … it was a big shock for her … especially when they’re new to the unit and obviously hadn’t had their “you need to ring before you come in” and that stuff … I still think they do need to ring just in case and at least we could say “could you just wait outside a minute”*

Confronting their feelings about the frailty of life was more profound for the nurses when parents were present. They managed themselves at times by distancing themselves from the child as a human being. The nurses were apprehensive at resuscitating under the parents gaze, conscious of making mistakes. They managed the process, by challenging previous practices, and learning that the reality of parental presence, with experience, was less confronting than expected. They came to embrace the parents’ role in being present. Less experienced nurses worried about parents’ presence, believing they may detect mistakes or hesitations and would often prefer them to be absent. Experienced nurses, however recognise that parents have eyes only for their child.

### 6.2.2. Managing the resuscitation

The nurses’ role and the way in which they managed the resuscitation was held to light when the parents were present. The expert nurses saw their role as being one of controlling the resuscitation, delegating tasks and ensuring parents were cared for. Their
performance was also considered by the nurses and informed the way in which they managed the resuscitation when parents were present.

6.2.2.1. Taking control

It was not always easy to control the resuscitation scene. Simone described a particularly chaotic scene with an abundance of staff present believing the parents were unduly distressed as a result:

It was a child with bronchiolitis … and she suddenly deteriorated and required emergency intubation … it was an over-populated arrest … mum and 3 sisters were there and just about every member of staff attended it initially … my impression family-wise, which is what your orientation is, was that there were too many people there which created a lot of panic in the family.

Simone believed that despite the critical nature of the scene, the resuscitation could have been more effectively managed by controlling the numbers of staff attending, and in doing so, may have calmed the parents.

Jane talked of her responsibility to the parents when their child arrested. She believed that they were at risk of being swamped by the intrusion of many new faces who may ban them from staying:

... the person looking after the patient ... they’re the ones who are ultimately responsible for the child and have built up a relationship with the parents ... and the do-gooders come and take over the whole situation and part of that is that they’re usually the ones that push away the parents and make the decision about who’s coming or who’s to stay and nine times out of ten, it’s the parents who are asked to go.

She believed that only experienced nurses could effectively manage the resuscitation:

... when people jump in and take over they don’t get to learn and it’s not just the mechanics of it ... drawing up drugs and doing resuscitation ... there’s more to an acute situation than that. You’ve also got to manage the situation and I’ve seen some ugly ones that are managed poorly.
She gave an example of a well-managed resuscitation when only three members of staff were involved and the parents remained throughout:

... there were three people ... two nurses and a doctor. The rest of the ward didn't even know what was going on ... beautiful resuscitation ... managed it beautifully and no flapping. Hardly any people there. The parents were there and the grandparents were there on both sides and I said "you don’t need to go" ... we were a bit restricted room-wise but I got them chairs to pull over.

6.2.2.2. Performance of self

The nurses frequently tackled parental presence by attempting to emotionally distance themselves, fearful of being judged and conscious of being watched. Most, however, believed the parents remaining present did not hamper their performance at resuscitation.

Elaine talked about Jenny’s presence: “... it didn’t make me more uncomfortable. I was aware she was there but it certainly didn’t make me feel like I was out of control. I was more concerned with getting some output back on this child.”

Jane made the point that for some nurses, being watched was almost an act of displaying self-worth: “… some people are on an ego trip and that’s fine but …”

So while some were fearful of making mistakes, others enjoyed the boost in confidence that performing under the parents’ gaze gave.

Jane believed, however, that for most junior nurses, parental presence was awkward:

I know it makes people feel uncomfortable ... like they’ve got to clarify, really clarify everything they’re doing ... because they know someone’s explaining what they’re doing ... but I know that the parents realistically don’t take half of that in ...
Yet of her own performance, Jane did not think it was affected by the presence of parents:

... I can honestly say it’s not a problem ... you do your best and if you’re sure you’ve done your best you can just get on ...

She was concerned how other nurses may deal with a similar situation:

... but I think it would be very difficult for less experienced nurses ... you know I was inexperienced once as well and it’s not something you get a lot of experience in; it takes a long time to get experience in that sort of situation ... if you’re not confident that sticks out like a neon sign to other people, parents included, that’s just how it’s always going to be.

Annemarie confirmed Jane’s suspicions when she talked of her lack of confidence in resuscitating and how parental presence exacerbated that:

... I wanted the mum and dad to be there because they wanted to be there ... even though I think it might be easier when they’re not there because if you haven’t been at many arrests, it’s really hard ...

Being on show made Annemarie aware of her inexperience. She wanted to demonstrate to parents that she was competent but was thwarted in her efforts. Being watched would have been more tolerable if she had had a more useful role: “It would have been better if I’d felt more useful and if I’d been there and they could see I was doing something ... I felt like I was wasted.”

6.2.3. Managing parental presence

The nurses described ways in which they accepted parental presence when they talked of how parents reacted to the resuscitation and how they envisaged the parental role. In describing parents as spectators, hindering the resuscitation and failing parents, the nurses demonstrated their ways of coping with being under the gaze of parents.
6.2.3.1. Parents as spectators

Most of the nurses agreed that parents had a place in the resuscitation. This agreement, however, was occasionally tempered with conditions. The parents had to stay within their role as spectators. As Louise expressed:

*They’re like spectators rather than anything else … they don’t get in the way, not trying to get in the bed and do anything. I don’t think they have any other role because there is just no space for them to be there and hold their hand because there’s too much going on at that time and they tend to be back watching.*

Caroline was emphatic in her belief of the parents’ rights to be present and summarised everyone’s position when she said: “*I just think it’s really important for parents to be there.*”

6.2.3.2. Hindering the resuscitation

Just as the parents were conscious of not hindering the resuscitation by remaining present, so too did the nurses talk of the need for parents to let them work unhampered. Louise confirmed that in her experience, parents did not interfere:

*… if there’s no-one there to support them they might feel like they’re getting in the way … I don’t think they do get in the way because the times I have been around they mostly either sit at the side or go out … they’re happy to stand back.*

Louise postulated that when the parents were not physically supported by a staff member they may well feel as if they obstruct the process:

*… they may feel like they are being a nuisance or like they’re getting in the way. There’s often a lot of people about … but I don’t think they get in the way because they mostly sit on the side of the room.*

Considering the diversity of cultures represented in the PICU, Louise expanded:

*I’m sure culturally there’d be some families that wouldn’t allow you to let them stand back … but I haven’t come across that myself. Space is very*
important and there’s a lot of people around and if you’re working between the trolley and the bed you don’t want anyone in the way … if relatives are coming and going I think that can be a problem.

While Louise was supportive of parents remaining present, and could not identify any incidents when they had hindered the resuscitation, she remained adamant that they must adhere to the rules if they were to remain. Parental presence, therefore, was accepted only when the parents abided by the rules, stipulated by the staff. Namely, they could watch, yet maintain physical distance so as not to hamper the efforts and they must continue to follow the rules of entry.

Simone recalled times when parents had hampered the procedure and believed they must be removed from the scene:

... unless they’re physically interfering with the resuscitation, and that occasionally happens, then I would definitely say they have to be taken away from the situation. I’ve seen them jump in and grab [resuscitation] bags and tried to do things … try to kiss them and hug them and bring them back to life … obviously they interfere with the resusc. You have to restrain them. One I remember grabbed the re-breathing bag and kept saying “don’t give up on him” we had to literally drag her away. That was a shocker.

While some nurses gave isolated examples of a parent who may have hampered the resuscitation, for most, the notion of parental presence was so entrenched in their practice that they did not believe the majority of parents would get in the way, either intentionally or unintentionally. As Simone exemplified: “… there’s never any suggestion that they should not be there if they want to … we just accept that they are there and that’s that.”

In accepting the parents’ presence in the role of spectator, the nurses believed they were able to see for themselves that every effort had been made to save their child. They believed in being present, the parents expressed fewer concerns about their child’s care.
Simone told of understanding a parents’ presence: “I don’t remember ever hearing parents say they want to see we did everything, but somehow in body language I think they give that impression … ‘what are you going to do now? What’s next?’”

As Jane confirmed: “… they see how hard you work. That’s how it is for them … they see it all.”

While the nurses were, at times, apprehensive of allowing the parents entry, they conceded that not being present might be worse. Louise pondered how parents may feel had they not been there:

> It’s like two different worlds. They don’t seem to merge unless you’ve got that in-between stage because you can’t comprehend all that has happened in between times. I think my impression is that it’s important for them to realise that the most is being done for their child … so if that means them being present then that is important.

She recognised that the reality of the situation may be beneficial to parents’ understanding if there were present: “… like getting frantic and things … I mean it does express to parents that there is a problem, that this patient is quite sick and that might be helpful.”

Giving the parents the opportunity to stay, ensured that they could see everything had been done and thus, as Elaine believed, supporting their presence was essential:

> … yeah, I think it’s good for them to be there so they can see everything that can be possible done is being done … if it is the last few minutes of that child’s life then at least they’re there.

### 6.2.4. Summary

Nurses were frequently faced with performing resuscitation Under the parents’ gaze. This feeling of being on show was challenging for many nurses who were forced to re-examine their practices and beliefs. Inexperienced nurses worried about how parents
would perceive their skills and abilities and thus often would have preferred them to leave the scene. The nurses admitted protecting themselves from the reality of the situation by distancing themselves from the child as a person. This was made easier when the parents were not present. Parental presence called for the nurses to confront the human aspect of the resuscitation frankly.

The theme was further explained by the nurses’ acts of managing the resuscitation, in which they overrode their anxieties about performing in view of the parents, and took responsibility for the mechanics of the resuscitation. This was easier for experienced or expert nurses who recognised the parents were not watching their actions but were concerned only for their child. Finally, the experience of managing parental presence was confirmed as a way of recognising the importance of the parental role during resuscitation. The nurses’ experience of being held Under the parents’ gaze describes their feelings of being required to resuscitate under intense scrutiny. Yet while the nurses were aware and, at times, uncomfortable with parental presence, they accepted it.

As they demonstrated their desire to meet the parents’ needs and make sense of parental presence, the nurses attempted to place themselves within the parents’ world. This empathic practice was described in the second theme of Walking in their shoes.

6.3. Walking in their shoes

<table>
<thead>
<tr>
<th>Dimensions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empathic understanding</td>
</tr>
<tr>
<td>Drawing on personal experiences</td>
</tr>
</tbody>
</table>
6.3.1. Empathic understanding

The nurses acted in ways that demonstrated their efforts to place themselves within the parents’ world and tried to understand the parents’ experience. Jane was able draw on her expertise when she described her ability to anticipate and understand parents’ needs:

“You’ve only got to see the look on their face if they’re not there and you come out and tell them, it must be horrible for them.”

Jane imagined the feeling of being lost when she expressed concern for parents who had not been present:

*By the time they come back in, it’s all very well if the outcome’s good. But if it hasn’t been good, then they’ve missed all of that transpires in the meantime ... and that’s a lot harder to cope with for some of them ... it’s a very personal thing.*

She continued to put herself in the parents’ world when she considered the parents’ feelings of frustration and stress:

*Some of them, they get fixed on the monitors but I can understand that because what else can they do? Half the time they can’t do anything, you know, mouth care every couple of hours, whoppee!! They’re completely taken away from everything so what else can they do but look at the child and nothing’s changing there except maybe getting sicker and sicker so they fixate on the monitor and start telling you what this should be ...*

Being aware of a parents’ uncertainty by not being present was considered by Jane:

*There are a lot of walls between out there and what’s happening in here and the longer you wait, the more you think things are going ... you know, “what the hell’s going on? Why is it taking so long, nobody’s told me anything” ... that’s a normal response that’s what happens when you’re sitting out there and nobody’s with you ... and another thing is that they need to know in plain English what’s happening, the simplest of terms “the heart’s stopped” sort of thing.*
Not only was Jane able to describe her empathy for parents, she also talked of her ability to convey to the parents that understanding:

*You’ve only got to talk to people to find out how they’re coping ... here’s a good example. A desperately sick little girl, she was septic and mother was very pregnant so she was a nervous wreck. And I walked in and looked at Grandmother and then floods of tears. I just went over and all I said was “she’s got a fever, that’s why she looks like she does. We need to all settle down, we’ll give her some antibiotics; everything will be alright”. Put my arm around her and she stopped crying, mum settled down. Yesterday I walked in and Grandmother didn’t say anything, they just smiled at me and put two thumbs up in the air.*

In demonstrating empathic understanding, Jane could anticipate their needs and provide for them. As she voiced: “*I mean, the bottom line for the parents is they just want to know if their child is alive.*”

It was clear that Jane had developed an authentic relationship with these parents, who appreciated her empathy. As she continued:

*They came back again yesterday and just said “thanks for listening, you know just being there and knowing when to cheer us up and when to tell us what we really needed to hear”. It reiterates that you’re doing something right.*

Imagining the sense of shock that parents felt was considered by the nurses, who also experienced shock at the suddenness of a cardiac arrest. As Elaine explained:

*I think it was a really big shock for them. I mean it was a shock for us that he did that so it must have been a huge shock for them ... walking in on something like that. You don’t expect that to happen when you’re new to the unit and he’d only been back for 3 hours.*

Elaine tried to further imagine the parents’ distress when she considers how the scene must appear for parents:

*I think she was shocked walking in on it because even though there wasn’t that many staff it would have appeared like there was hundreds of people around that bed, being one of those tiny beds and I can’t imagine how it would feel to be a parent to stand there and see that...*
In placing herself in the parents’ shoes, Elaine was able to understand the parents’ essential need to stay, yet admitted to not fully comprehending their grief: “I certainly would want to be there if it was my child … to be there at the end and see everything had been done. I can only really imagine how they must feel. I can’t even contemplate.”

Drawing on life experiences of being parents themselves, meant that some nurses were able to readily imagine the parents’ experience. Simone also considered parental presence from her perspective as a mother:

… the fact that I’m a mum makes a difference … but then again there’s also a bit of a wall … a mental wall with “how far would I go if it were my child and would I want to see this?” I don’t know.

Having the ability to step back from their child to aid the resuscitation effort, prompted awe from the nurses. As Louise expressed:

I imagine parents would feel really awful if they thought they were in the way and would quite happily move for you but mostly they stay back a fair distance … they just seem to do it. I don’t know how they do it.

These nurses could recognise the parents’ emotional dilemma, when on the one hand they want desperately not to hinder the resuscitation attempts, but at the same time need to be present. Furthermore, as parents have previously demonstrated, if they believed their presence may hinder the attempt, they would leave despite the cost to them.

Louise placed herself in the parents’ world when she imagined what it must be like when they had not been present. She drew on previous experiences within the adult environment and described the feelings of being lost:

In adults, they’re not there and that’s that. They sit outside and wait and you have to go and get them after. If it’s been an unfavourable ending – we always tended to clean up everything and nothing would be lying around. It would be like nothing had ever happened. So I think that would be worse for
them – like being in two different worlds, like you need that in-between stage because you can’t comprehend what went on before.

Despite Louise’s belief that presence was essential for parents to fully comprehend what had happened, she maintained her position that watching the resuscitation would have lasting memories:

*It would be very traumatic to deal with later on … to keep remembering. Not so much the busyness, but the actual massage, remembering someone doing that to your child, watching someone do it.*

There existed paradoxes between the nurses’ recognition that parents needed to be present, and their underlying belief that presence may still not be good for long-term coping. Annemarie was concerned for parents whom she believed may often make the wrong decision to stay: “Yeah, I think they should make the decision, but sometimes, I think they have to live with the consequences of having made the wrong decision.”

In establishing relationships with parents, the nurses attempted to understand them. Caroline in talking with parents, recognised that the death of the child or discharge from hospital did not end the experience for the parents:

*… that parents whose children survive resuscitation here may view it in a different light because lots of things happen to them after that lay more memories on top of it. It’s not like it ends there. If it results in death, that’s the end. You can’t lay any more memories on that. Parents I’ve spoken to appreciate the choice to witness the resuscitation and even though they sometimes feel compelled to leave, they’ve always come back. Anything’s better than being left in a room alone for ages and if you’re lucky someone coming in for a couple of minutes. That’s doesn’t mean a lot. At least they have the freedom to go in and out and visualize for themselves.*

Caroline demonstrated an understanding of parents’ needs when she had taken the time to know and listen to them:

*It’s horrible and a shock but they have the right to be there, they want to be able to walk out if they need to and to have somebody they can ask questions*
of. And they want an amount of respect shown to their child while the child’s being resuscitated.

Furthermore, Caroline questioned the parents’ ability to understand the unfamiliar environment of PICU, considering the terminology used:

I don’t think they have any concept … we use so much jargon … you know, arrest means nothing to them, even the most basic terminology like your child’s pressure has dropped or we had to initiate compressions or do resuscitation. I don’t think that means anything to them basically. They see heart things in relation to adult sort of stuff. And often we’re taken by surprise when a child arrests and we don’t remember how loosely we describe things.

Caroline was able to reflect upon how nurses inadvertently place further boundaries on parents at a time of great stress, by adopting the prevailing culture.

Some of the nurses failed to appreciate parents’ expressions of desperate hope in the face of inevitable death. Louise described such an example:

I don’t know if he just didn’t have a realistic view of how poor the prognosis was, like he was thinking “she’s very sick, but” … he was asking questions about surgery, things that would suggest she was going to survive, rather than thinking the here and now.

For Louise, then, a parents’ hopefulness, presented itself as not understanding the reality of the situation. Louise had placed her own values and beliefs on the parents’ experience, rather than trying to further understand them.

6.3.2. Drawing on personal experiences

Drawing on personal experiences in order to step back and see things afresh was described. In portraying such events, the nurses had an added dimension to their understanding of resuscitation and death, which transcended their understanding as a nurse. Caroline’s experience was so traumatic, that her perspective completely changed
to embrace families at all times. Only then was she able to wholly understand the parents’ need to be there:

*I know, that, being in a position where you’re prevented from being involved that you’re personally connected to, that is a life and death procedure impacts on you in a way, that for the first time you realise just how important the decision that someone else makes for you is. Then it’s clear all of a sudden that it’s not your decision to make and it doesn’t matter how many reasons they give, it’s all very paternalistic – basically when it’s someone’s child, its their right to be there.*

Caroline believed that by denying parents the right to stay, nurses let the parents down and their rights were not held up as a priority. She was adamant that the parents had every right to be with their child and considered it paternalistic to make that decision for them.

In having lasting memories of the scene and subsequent death of a loved one, Caroline confirmed: “I think they might take that memory with them and it might not be a positive memory but the absence of it is worse.”

Caroline continued to draw on her experience when she adamantly believed parents had every right to stay with their child. She wanted others to be able to more freely put themselves in the parents’ world:

*I’d hate for anyone to be in that situation but if anyone is opposed to parents staying, if ever they were in the same situation, to someone they were emotionally connected to, I bet they’d change their mind. You feel like you lose ownership of that person you dearly love and that should never happen. That person belongs to you in every other way.*

Jane was able to draw upon her own experiences when she considered the impact of the resuscitation on the family and how much information was able to be considered at that time. She then considered that despite novice nurses discomfort in explaining to parents,
the families themselves may not always need or be able to take in all that is being said.

Jane described her own experience:

> Realistically they don’t take half of it in; I can tell you that now, being on the other side. You don’t hear half of what’s said. They’re saying a hundred things to you but I remember very little that anyone said. I was just there with Dad but it was like I missed 12 hours it wasn’t until the day later that I really took in all of what transpired in that conversation. If you can see and hear, it’s more likely to sink in.

Jane had empathy for parents when she considered her own experience of being denied times with her father. Furthermore, she was not embraced as an important member of the team:

> I think here you’re treating the whole family but having been on the other side it makes me realise how poorly it’s done in the adult world. You’re not given information and they took no account of the fact that we had to travel it took us 3 ½ hours to drive there and we were only allowed to visit from 10am to 12. It just reiterated in my mind how badly it’s done in the adult world.

It was admitted that most families encountered in the PICU would have experienced stressful experiences in the past. Appreciating the extent of their coping abilities was therefore, imperative to the nurses’ acceptance of the parents’ presence. Jane acknowledged this:

> Parents know what each other are like, they’re the ones who should deal with it … if they say ‘I’d rather stay’ then they should stay. We don’t only ever have one crisis in our lives … everyone’s been through a few and they know how to respond, so they make the decision, not us.

### 6.3.3. Summary

In *Walking in their shoes*, the nurses attempted to place themselves within the parents’ experience. They imagined how the other must feel when faced with the potential death of a child following cardiac arrest and acted in ways that demonstrated empathy for the parents. Furthermore, this empathy was conveyed to the parents, who appreciated the
nurses’ acts. Drawing on their personal experiences to further enhance their understanding was extremely powerful for these nurses. It was, however, impossible for the nurses to fully comprehend what it meant to be a parent whose child suffered a cardiac arrest and either chose to stay or to leave during the event. Despite their empathy, the nurses continued to act in ways that supported how they themselves would feel, rather than fully engaging in a relationship that would enlighten them to the parents’ feelings.

The final theme, **Holding parents in mind**, illuminates the ways in which the nurses attempted to further accept and perform the resuscitation procedure by thinking and being for a parent.

### 6.4. Holding parents in mind

It was clear that the nurses held parents in mind during the entire resuscitation process. They demonstrated numerous ways of caring for the parents. Two areas of experience were identified as dimensions of the theme, **Holding parents in mind**. These dimensions and the sub-themes that contributed to them are:

<table>
<thead>
<tr>
<th>Dimensions</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring for parents</td>
<td>• Holding the pieces together</td>
</tr>
<tr>
<td></td>
<td>• Protecting parents</td>
</tr>
<tr>
<td></td>
<td>• Failing parents</td>
</tr>
<tr>
<td>Sharing the child</td>
<td></td>
</tr>
</tbody>
</table>
6.4.1. Caring for parents

The nurses remain concerned for parents even throughout the intense activities of the resuscitation. They remained orientated to the parents’ world and held parents in mind. Louise described being focused on the procedure yet mindful of how the parents may be coping:

…the second time she arrested, the father was there but I don’t remember if the mother was … he just sat stunned while we did it all and sort of said to her to get better … the final time the parents came and went and we were talking to them about the fact she may not survive and I remember then the mother called out that she wanted us to stop … and it was then that we did.

Louise remained concerned for the parents’ welfare throughout the intense activities of the resuscitation:

I think you become very task-orientated in these situations but I’m aware of their presence. I don’t completely block out the fact that they’re there and I try to be conscious of making eye contact with them and occasionally seeing if I can offer them anything else. But I am still fairly task-minded.

Caroline, too, remained concerned for the parents’ well-being throughout the arrest:

I’m senior enough now and I can function quite effectively in an arrest situation and still have room to keep an eye out for the parents and make sure at least someone’s standing with them to guide them through … and if nobody is, I’m happy to step out and do it.

She remained aware of the parents’ presence when she described the brutality of the scene; conscious of the spectacle: “… it’s an ugly scene … the cardiac compressions, the sheets being stripped off the child, it makes it look brutal … it verges on the violent.”

As Elaine described her ability to hold parents in mind, then shift focus to the resuscitation task: “I saw Mum, but I was really more concerned with getting output back
and I could see whoever it was, was talking to her, so I knew she was being dealt with, if that’s the right word.”

The nurses demonstrated numerous ways of caring for parents by their actions of supporting, protecting, and at times, failing them, described in the next section.

**6.4.1.1. Holding the pieces together**

The nurses spoke of the necessity to support parents but whose role this was became enormously significant, placing huge expectations on their abilities to provide comfort and face the emotional challenge of dealing with the families, rather than taking refuge in the actual resuscitation procedure.

The nurses recognised however, that supporting parents during and following an arrest was not only a necessary responsibility, but also integral to their role. For Louise, supporting parents meant a physical presence providing parents with information about the resuscitation process:

> You’ve got to set the scene for them and explain what’s happening … and make sure someone’s free to talk to them and update them … and make sure someone stays with them to support them.

While the notion of supporting parents was a central thought for all the nurses, some of them were anxious at having to be that person. As Louise told:

> For me it’s really hard to be the person who stands there and supports the parents … you have to stand back and be with them … it’s really hard to know what to say or to know how to just be with them at that time or what not to say.
Louise was more at ease when performing a clinical task, rather than confronting the reality of the parents’ distress. She retreated behind the practical jobs of resuscitation, avoiding the raw emotions of the parents and engaging with them.

Although Louise avoided supporting parents, she did so out of a fear of distressing them further by believing she did not have the skills adequately care for them: “… it’s very uncomfortable because it’s not normal [the situation] … and you don’t want to say the wrong thing or give them false hope, but you don’t want to take aware hope from them either.” She expressed relief when another nurse stepped in to support parents:

I’ve only had to do it on a couple of occasions and I really don’t like doing it … it’s good when you’re in the opposite situation when you know someone else is supporting the parents because then you don’t have to worry about it at all.

Jane often performed the support role and considered how less experienced nurses may not be the best people to fulfil this role. She was concerned that they may exacerbate the parents’ distress by not providing accurate information:

If you’re not experienced and you’re not really sure what to say you tend to either say not much or say too much – the over confident ones will say too much and talk a lot of rubbish… get it wrong.

Simone, an expert nurse, could see a mothers’ need for support, offering herself in place of a family member who was rejected:

The baby was rushed up from the ward and arrested as soon as he got to the unit …. There were loads of staff on and two doctors and I wasn’t needed so I sat with mum. And she was totally unsupported. She didn’t want her husband or a minister … she didn’t want anyone. I just sort of basically sat there cuddling her for an hour and she sobbed on my shirt.

Simone embraced the mother offering her the support she believed she needed, holding the pieces together, both physically and emotionally, for this mother, fearing she would
fall apart if she let go. Yet Simone appeared to dismiss herself as an adequate support for this mother who had rejected others, but could see she wanted to be comforted. She had become such an expert in this situation that she took on this role without thought, yet assumed a fundamental function. It is as if the nurses, while acknowledging the importance of supporting parents, maintained that their primary function was to perform effective resuscitation. While this is no doubt their belief, they underestimated their effective role in caring for families. It was as if they felt guilty at not taking an active part in the arrest and others may think they were shirking responsibility.

Even Annemarie was able to provide physical comfort despite her limited role in the resuscitation as a novice nurse:

\[ I \text{ gave her physical support, I put my hand over her shoulder} \ldots I \text{ don't think there's nothing you could say that would make anyone feel better so I think physical support is probably as much as I could offer} \ldots I \text{ don't know what I could say so I don't think I said anything.} \]

Annemarie, uncertain of what to say, was comfortable in remaining silent while offering physical comfort.

For Elaine, a practical nurse, support was offered in the form of offering the parents the opportunity to stay and providing them with factual information:

\[ \text{We did say both times if they wanted to stay they could} \ldots \text{part of the nurses’ role is to take care of the parents and the parents should be wherever they like. As soon as we could we went back to them and explained.} \]

Elaine demonstrated a more practical, less emotional method of supporting parents, but just as Simone believed the parents had every right to be present, so too did she. Supporting parents, for Elaine, was by ensuring they had the chance to be present if they wished:
If they want to be there and there’s someone to talk to them, if doesn’t make me uncomfortable … I rang and said to Dad “get yourself here right this minute because he’s not looking too good”

Indeed, Elaine went to a great deal of effort to ensure a father had every opportunity to return to the unit when his baby arrested:

I’d just come on duty... it was night shift … and had organised for Dad to get the key to his hostel room. He’d gone off there and 10 minutes later the baby dropped his BP … just lost systemic pressure and he stopped pacing so he needed massage … everyone had just left so we had to get security to try to find Dad to make sure he came back.

The parents were further supported to make the decision to stay or leave the scene for themselves. Annemarie, a novice in PICU, recognised the importance of giving parents the option yet considered that they may not be able to make the decision at that stressful time:

Everyone’s different and some are going to want to stay and some aren’t. and I guess at that urgent time they’re not going to know if that was the right thing to do or not but they need to be given the decision to make.

She continued, however, in defending her right to overrule that decision if she believed the parents were not able cope:

I totally agree with if the parents want to be there they should be. That’s my job. I’m a nurse and I accept that but if they want to be there then I have to help them … except if you see they’re really not coping … then I’d ask them to leave.

Jane was concerned when parents chose to leave the scene unsupported:

You see them going out but nobody’s going with them. Nobody tells them what’s happening so you have to go after them and explain what’s happening and then come back in and check

Jane was emphatic in her belief that it was the parents’ right to chose to stay or leave:

I mean, it’s their child, it’s their right to be there, they should know exactly what’s going on and if they want to be there then they should … and if they don’t want to be there they’ll soon tell you. If they don’t want to be there you
have to give clear concise information. And they have to be supported by someone who knows exactly what’s going on and can relay that to them in such a fashion as they can understand.

Witnessing a resuscitation brought home the reality of the situation. Jane talked of an instance when the parents decided to leave after witnessing the drama:

> Even though we said this [resuscitation] was probably what would happen and how it would happen, it really brought it home. And they found it quite distressing. Not from what they really saw, but how quickly it can happen and without warning. And what the outcome is, you know, how stressful it is for everyone. And they actually did leave.

While many of the nurses believed the parents should be supported in making the decision for themselves, few talked of supporting those who chose not to stay. On the other hand, the notion that parents may feel pressured to stay by being offered the opportunity was voiced. Louise told:

> I don’t know whether it’s clear to them that it’s a choice. Maybe some people don’t realise it’s a choice and that they have to be there and maybe if they knew it was a choice they wouldn’t want to sit in there …

Furthermore, once given the choice, parents should be continually offered an alternative if necessary. Louise expressed this when she postulated that once parents had made a decision they may feel locked into that decision: “I think people do give them the choice in the first place, but maybe they need to know they can leave at anytime.”

While a support person was often a nurse, there were times when a social worker or a member of the hospital clergy offered support to the parents. The nurses, however, often viewed this support, as inadequate and intrusive, believing only nursing or medical staff had the expertise to offer informed support. As Jane forthrightly stated:

> You’ve got hysterical parents, so it’s really important that somebody’s primary role is to look after them. It’s the responsibility of the senior nurse … not to take them out but to get support people in and can guide them
through what’s happening. The responsibility for the care of the patient should be the person looking after the patient. The most important thing is they need to know and be told by someone who understands. On occasions that’s happened by default by the chaplain. Now that’s really inappropriate as far as I’m concerned, because they don’t know and don’t have the experience. The parents are given false information ... I really think it’s a nurse’s job to do it ... a social worker doesn’t know what’s going on or what might happen ... and we know the family better.

6.4.1.2. Protecting parents

The nurses further demonstrated care by protecting parents from what they believed to be additional harm. This protection, however, while out of concern for the parents, was often expressed by exerting control over them. Of main concern to the nurses was the effect that perceived horrific memories of the resuscitation might have on the parents’ long-term coping of the event and subsequent death of their child. Although Jane insisted that parents should have the chance to remain, she maintained that there were still times when parents should not be present. She gave the example of chest opening:

... just because it’s gory, it’s a very intense situation ... it’s got to be spur of the moment, everyone got to be firing and sometimes they’re not ... it’s an emergency; I don’t mean that cardiac arrest isn’t but if you actually have to squeeze their heart, that’s pretty awful to see and I wouldn’t be comfortable with the parents in that situation, but anything else, I don’t have a problem with.

As Caroline pointed out, when she was previously against parental presence: “I think I was just trying to protect them from seeing their child in a very vulnerable situation. I thought it was in their best interests not to see that.”

Others also believed that by being present, the parents might have lasting horrific memories that they may be unable to put aside. Louise, while believing that parents should stay to see everything had been done for their child expressed this:
I think afterwards, my impression would be that it would be very difficult to deal with what they’ve seen and that they have to have support to deal with it. I quite clearly remember all those events and I have no bond with them. I don’t know what it would be like if it was your own child whether you’d be able to remember them as they were or it would make it extremely difficult for them to recover.

For Louise the potential lasting memory of a child’s attempted resuscitation was, for parents, more memorable and horrific than a child’s actual death:

The worst part about the whole thing is watching someone do it not so much the busyess but the actual massage remembering someone doing that to your child would be the worst part difficult image to get out of your head.

She did, however, concede that although the scene may hold horrific sights, the fact the child died overshadowed the scene and possibly the parents remembered only their child:

“But in the scheme of things, the loss of their child is still so great that it doesn’t matter how it happened I don’t know.”

Yet, as Caroline postulated, the image of the child being resuscitated may indeed be very different from the parents’ memory: “Our impression of what they see is probably very different from what a lay-person sees when they are there, and it’s their child, not ours.”

Protecting parents from experiencing adverse staff interactions was important for the nurses, who believed these were times when parents should not be present. As Louise explained:

It’s not good for them to be there when there’s some disagreement between staff as to whether you’re doing the right thing or in wanting to protect parents from something you might not want them to see like resuscitation is not normal and it might be psychologically bad for them to remember, I’m not really sure.
Elaine also wanted to protect the parents from witnessing staff conflict. She gave an example when a doctor was incensed at the team’s attempts to resuscitate:

*He was very abrupt with us that day. And dad and mum came in and I’m not sure if they picked up on it but it was very uncomfortable for us all … they shouldn’t have to put up with that.*

It was not until the nurses gained sufficient experience and insight that they conceded they were doing the parents a disservice by taking the decision to stay from them. The parents had to be supported to make the decision for themselves. As Caroline recognised:

*… the more junior nurses think it’s in the parent’s best interest to protect them from that sort of stuff and that’s absolute rubbish when you’re more experienced. You realise no-one can make the decision for you.*

Despite their desire to protect them, the nurses believed the parents experienced lasting guilt and regret when they had not had the opportunity to stay with their child. As Simone explained:

*… the parents who’ve arrived too late have said “I should have been here” yeah, they blame themselves as if it all went wrong because they weren’t here … it just a simple statement “ I should have been by his side; that’s my baby” you know.*

The nurses experienced a complex paradox when they one hand, were desperate to protect parents from what they believed to be long lasting horrific memories, but on the other hand, could empathically imagine the regret at not being present if their child died.

Simone felt frustration when she was unable to protect parents from another staff member who acted in a less than empathic manner. She considered the parents’ needs yet was powerless to act upon them:

*I remember one child, the parents knew us because she’d been in and out a lot … over the next couple of hours, she deteriorated, arrested and died. We were cleaning her up and the social worker bustled in, didn’t know the family but went out to “support” the family. I went out a bit later and there she was*
... both parents corralled on a small sofa and the rest of the family dotted around … but her arm was covering the parents as though she was saying “I’m here, I’m the one who’ll look after you” and stopped the extended family from being the ones to give comfort … she didn’t know them and took over … families need support from staff they know or their families.

The nurses’ experience of protecting parents was centred on feelings of fear on behalf of the family.

6.4.1.3. Failing parents

Supporting the parents to be present did not always extend to providing for them. Louise talked about letting the parents down by not giving them the chance to touch their child and believed it may have helped had they had that opportunity:

I don’t think they had any opportunity to touch them which is probably more what they want to do. I would imagine but if they could just touch their foot, I don’t know if it would make a difference for them to feel like they were actually there with their child rather than just watching.

Despite her best efforts to inform and support the parents, Annemarie expressed lasting regret at her desperate search for a mother when her child arrested:

The thing that made me feel really bad for the next 24 hours, was that I couldn’t find Mum and Dad … and later she kept saying “I wasn’t there for you” I just felt awful … I had let them down … really that was the worst thing about it … I should have been able to find them but because I knew what was happening I was panicking, looking for them and I finally ran upstairs again and it was too late; Mum and Dad had already got there and it was only about a minute before they decided to stop the resuscitation. That really got to me.

Failing parents when a child did not survive was felt by many of the nurses. Annemarie confirmed this: “Having them there makes you feel a bit uncomfortable, if the resuscitation is not successful I’d feel, just more like I’d failed.”
The nurses needed to justify to themselves and to others that their actions had not prompted a child’s arrest, yet still expressed a sense of letting the parents down. As Elaine reasoned, “...he hadn’t been handled or anything. He’d been okay through the night, since the last episode [an arrest] … I don’t know what it was, but I felt bad for them.”

Caroline believed that by accepting the parental role, nurses were attempted to address their feelings of failing parents. She reflected upon the changes that had occurred in the past few years, with a complete about-turn in the practices and culture of paediatric intensive care,

... so it’s gone from, in the 15 years of experience I’ve had in PICU from a priority to get them out the room, to allowing them in (but it not being a priority) to now I feel like its generally accepted that all parents should have the right to participate in the resuscitation of their child and that its also amongst the highest priorities of organizing an arrest.

While accepting parents had become the norm, it was clear that some grappled with the possibility of an overly accepting culture, whereby parents may feel obligated to stay. Annemarie was very aware of her inexperience, yet considered that for some parents, being present may not be beneficial,

I don’t really know if it’s a good thing for parents to stay there … maybe we’ve gone too far … I don’t really know yet … give me another 10 arrests and then I’ll know if it’s good but at the moment I’ve only been involved in two. Until I know differently I think I’d stick with if the parent wants to be there then I would let them.

6.4.2. Sharing the child

The nurses developed a sense of ownership over the child, taking pride in their care for that child. They frequently referred to the child as “my patient” and often carried
thoughts of the child and family home with them after a shift. They engaged with the family and felt a sense of failure and loss when the child did not survive.

Sharing the child meant sharing the grief when they did not survive the resuscitation. For Louise, establishing a relationship with parents, involved becoming connected to them. Connecting with parents made the failed resuscitation more personal and harder to cope with. As Louise explained,

_"I find it very upsetting, even when I’ve only known them for a day you build up that relationship and with this one family it was easier, because I hadn’t had that opportunity to develop any connections with them. I didn’t know them but it is more emotional when it’s a family that I know."_

When they shared the child, they were unable to disengage during the resuscitation, particularly when parents were there. They continued to hold parents in mind, even after their shift had ended, thinking about the family while at home.

**Holding parents in mind** was held by the nurses as a fundamental experience of parental presence during resuscitation. They demonstrated many acts of caring during and after the resuscitation by supporting and protecting. Additionally, nurses expressed regret at failing parents, either when the resuscitation was unsuccessful, or in their belief they had not provided for them at that time. There was a range of reasons that made nurses either support or reject parental presence at specific times. While they were aware of the important need for parents to be close to their child, they worried for their subsequent coping, particularly if the child died. Recalling horrific memories prompted the nurses to try to protect the parents. They remained concerned for parents and worried for their ability to cope with what they saw as horrific scenes.
6.5. Summary and conclusion

This chapter has described the nurses’ experience of parental presence during resuscitation. The nurses’ narratives illuminated three main themes that contributed to the experience. They were often faced with resuscitating Under the parents’ gaze. Being watched was challenging for many nurses who were required to re-examine their practices and beliefs. Inexperienced nurses were often worried about parental presence believing they would detect potential mistakes and therefore preferred parents to be absent. Distancing themselves from the child as a person was a way of protecting the nurses from the reality of the situation. This was made easier when the parents were not present. When the parents were present, however, the nurses had to confront the humanness of the resuscitation.

While initially fearful of making mistakes or parents’ perceptions of their skills, nurses came to understand that parents’ presence did not affect their performance. They believed that if the parents could in some way benefit from seeing every effort had been made to save their child, the cost to their privacy and discomfort was minimal. Being under the parents’ gaze described the nurses’ feelings of being required to resuscitate under intense scrutiny, whether real or imagined.

The nurses then further described their attempts to place themselves within the parents’ world in an attempt to understand their perspective. This practice was described as Walking in their shoes. They drew on past experiences, both as nurses and as human beings when they described being a mother or a daughter in similar situations. They could empathically imagine what a parent might feel when faced with the decision to stay
or leave their child at this time. While less experienced nurses were wary of being under the parents’ gaze, expert nurses recognised that parents had eyes only for their child. The nurses were able to recognise the parents’ need to be present as well as their desire not to hinder the resuscitation. The dilemma in choosing to leave the scene but the emotional cost as a result of leaving, was made clear to nurses, who demonstrated empathy with the parents.

The nurses acted in ways to further understand the parents’ experience by **Holding parents in mind**. While intent on the critical nature of the resuscitation, the nurses remained concerned for the parents, demonstrating an enormous capacity for caring during this traumatic period. They were able to hold parents together, in their support, both physical and emotional and were frustrated and distressed when they believed they had failed parents, by not being able to either save the child or support them adequately.

Many of the nurses also demonstrated a shared ownership of the child, when they took on caring for that child. Establishing therapeutic relationships with the family was essential to the nurses’ engaging with them, yet made managing the resuscitation and their coping with resuscitating in public more challenging.

Despite the nurses’ reluctance to initially accept parents during this critical time in intensive care, they came to embrace their presence. In spite of continued awareness of their presence, the nurses’ performance was not hampered. Not only have the nurses accepted the parents, they have come to expect their presence, in spite of their unease. Caroline summed up this dramatic shift in thinking when she commented: “10 years ago, it was a case of “get them out” now it’s a case of “let them in.”
Chapter 7
Parental Presence During Resuscitation – Sharing and Surviving the Resuscitation

7.1. Introduction

The preceding chapters have described the parents’ and the nurses’ experiences of being present, or absent during resuscitation of a child in PICU. This chapter offers the final layer of findings in which a hermeneutic description is presented. Asking the interpretive question ‘what is it to be a parent or a nurse in this situation?’ provides meaning to how the experiences of parents and nurses illuminate the phenomenon of parental presence during resuscitation.

For both parents and nurses, the fundamental focus was for the child’s survival. The way in which this focus was played out was different, yet for all participants, the meaning of parental presence during resuscitation was found in similar experiences that all participants acknowledged.

The meaning of parental presence during resuscitation for parents and nurses is characterised by the three elements Being in chaos, Struggling to connect and Being for another. A fourth element, Being complete, was solely the parents’ experience in being presence during resuscitation. These elements of the description contribute to the meaning of the participants’ being in Sharing and surviving the resuscitation. The way in which their changing roles impacted and complemented on the meaning for all is explicated. Each element is found in varying degrees according to the parents’ or nurses’
perspective, but without any one element, the interpretation of the phenomenon would be incomplete. The elements are presented here in sections.

7.2. Being in chaos

... it was like controlled chaos ... everyone running around doing stuff. It felt like being on a horror rollercoaster ... (Neil)

A shared meaning of chaos was reflected in the experience and was drawn from the parents’ experiences of making sense of a living nightmare and maintaining hope and the nurses’ experience of being under the parents’ gaze. Chaos was, for both parents and nurses, the feelings of confusion, uncertainty, frustration and awkwardness they confronted in the new experience of parental presence during resuscitation. This presence challenged the parents’ and nurses’ roles and nurse-parent interactions with boundaries blurring at a time of great stress and uncertainty in an already physically chaotic environment. Both parents and nurses, then, lived with a sense of disarray, both physically and within themselves. Parents lacked a part to play and were confused by the nurses’ language and non-verbal messages that conflicted with their verbal reassurances of parental presence. They were conscious of their presence and sensitive to the impact they may have by remaining. Nurses were caught between their belief of the parents’ right to choose to be present and their anxieties about their own coping and nursing skills. Communicating with one another was chaotic in this situation as a result of the uncertainty of the outcome, causing misunderstandings. The result, often, was increased tension that extended beyond that of the resuscitation situation. Paradoxically, a sense of comfort and curbing the chaos was also apparent.
Confusion and its impact on the meaning for both parents and nurses during resuscitation were central to the meaning of chaos. The parents were confused about their role and what was expected of them when, often with little warning, their child deteriorated and suffered a cardiac arrest. As Neil explained,

*It was all a bit of a blur. One minute we were feeding him and playing with him. Then 5 minutes later, the doctor said to us “he’s not good, he’s not going to make it” and we couldn’t do anything, could we?*

Even parents who had become expert in their changing role within the PICU milieu, became helpless during the resuscitation process as they experienced greater stress. Neil went on to explain this confusion,

*... and you feel useless, as if you’re getting in the way. I don’t really know what they were doing, they were all working around the bed, like controlled chaos busy and frantic but everyone knew their job except us, just sitting there.*

Confusion and a lack of understanding left parents feeling stupid and wary of asking questions for fear of losing further control. Understanding was made worse when parents were given poor explanations of what had happened during their absence. Yasmina explained, “... I didn’t know what to think ... they said she’d been a bit naughty but was okay now ... I had no idea.”

When nurses used terms such as ‘an episode’ or ‘being naughty’, it was as if the successful resuscitation was of little significance to them and that parents need not be concerned. It was clear that nurses did not want to cause further concern when they believed the drama was over. Yet appearing to trivialise a major event left parents more confused, with greater feelings of chaos. Dominique expressed this well when she said,
“I didn’t realise what had happened for a while … and I was too nervous to ask in case they thought I was being stupid … asking silly questions.”

The parents expressed an urgent need to remain with their child despite their confusion in this chaotic situation. To them, their place and their responsibility were with their child. Yet parents’ and nurses’ perceptions of the parental role were often very different. For some nurses, like Louise, it was limited, “Parents don’t have any role other than spectator. They can’t have, there’s no room for them to hold their hand or touch their child because there’s too much going on and they tend to be back watching.” Not only were nurses unsure of the parents’ role, they could not understand any benefits to just being there, as Elaine queried, “what do they hope to get out of it?” For these nurses, the parents’ only job was to watch the resuscitation. They could not fully understand the compelling parental need to remain close to their child, yet they believed in the parents’ right to choose to be present. There were then, opposing feelings towards parental presence with which the nurses often struggled.

The nurses were confused about their own changing role when they had to take on a more prominent position in supporting parents for which they felt ill prepared. Communicating with parents was for the nurses, the most difficult job, more difficult even than the technical expertise required for resuscitation because of the emotional aspect they faced. This difficulty resulted in them often underplaying the event by their tentative language. They felt safe with their previous technical responsibilities and were reluctant to take on the role of support. As Louise admitted,

I’d rather be the one who is doing all the technical stuff … I don’t know what to say to parents who are there … what can you say? That’s the hardest job
in the resuscitation – looking after parents. At least if I’m bagging or drawing up drugs or something, I know what I have to do.

Confusion was, for the nurses a feeling of chaos and disorder in their previously well-ordered routine of solely focusing on the technical aspect of resuscitation.

Both parents and nurses lived in a sense of awkwardness with their role. The parents were acutely aware of their own presence, concerned they may interfere in the resuscitation and were mindful of the nurses’ often perceived but unspoken desire for them to leave. They were confused by the non-verbal messages that conflicted with the verbal assurances to stay. This created a sense of being intruders into a place where they had no right to be. Lynne explained this awkwardness,

*I know one time they really didn’t want us there but we wanted to stay … we just sat outside the room trying to keep out of their way. We knew they could ask us to leave if they really wanted to.*

Parents were aware of remaining in their role, fearful they would not be allowed to stay yet were unsure of what was really expected of them as Mark illustrated: “They have to get on with the job and don’t need us getting in the way. We can’t do anything and it must be awful for them to have us there watching over their shoulder.”

Parental guilt made awkwardness in the nurses’ presence more acute. Many were of the belief that somehow their negligence had led to their child’s illness. Melissa explained,

*If only I’d been there … I should have been closer to him, to stop it happening … and now I can’t do anything – just sit and wait. It was as if these parents believed they did not deserve to have a role in the resuscitation.*

The nurses too began to question their ability and performance under the perceived watchful gaze of the parents. They were mindful of their actions, anxious to prove themselves yet concerned they may have missed something the parents might notice. As
Elaine pondered, “… you start to wonder if you can do it … you know, ‘I hope I’m doing it right’ when they’re watching you.”

They were challenged in their actions when they believed parents’ main focus was to make judgments on their nursing skills. Annemarie described this awkwardness well when she commented, “You’re very aware that they’re there and they’re watching you and making sure you do it right.” Expert nurses however, were able to curb their awkwardness and place it in the background, bringing concern for the parents and their expert role to the foreground. Simone was successful in demonstrating this ability to place awkwardness aside and so reduce her confusion,

> It was hard at first, but the more you do with parents there, the more used to it you become. My first concern is for getting the child stable …. Most parents just want to be with their child and I am often the one who will support the parents … tell them what’s happening and give them a cuddle if they need it.

Awkwardness in the others’ presence created more tension beyond that of the resuscitation. Yet, it was apparent that both the parents’ and nurses’ perceptions of the others’ focus was erroneous. Neil expressed this in his recognition of the nurses’ unease, “… they think we’re watching them but we’re not … you’re not bothered with anything except your child … you’re just willing for him to survive.” Misapprehensions and confusion contributed to the feeling of chaos experienced in an already physically chaotic environment.

Chaos was further demonstrated by the parents’ uncertainty about their child’s survival. Jenny and Mark expressed this feeling of uncertainty well, highlighting the underlying fear of death of their child,
Jenny: You’ve no idea. You walk in there and it’s like you’re walking in but you’re not really there. An out of body experience ... you just don’t know what’s happening and I wasn’t thinking properly, because everybody’s afraid of the unknown.

Mark: yeah, I didn’t know it was a cardiac arrest at that stage. I just saw everyone freaking out around the bed ... all I knew was he was struggling and people were yelling all around and one of the nurses just said to me, you can sit there, but I couldn’t and I walked out again.

For parents who had not been present, this sense of uncertainty was more evident and the feeling of chaos heightened. Dominique experienced this uncertainty in her understanding of the resuscitation when she said: “I really didn’t know what actually happened until I saw it happening to another child.” Imagining the worst created chaos for these parents who felt helpless. It was a feeling of hanging on and waiting for news. A sense of being up in the air. Mick, who was not present during an unsuccessful resuscitation experienced greatest ambiguity and chaos in what he described as both an “unreal situation but a very real one.”

Yet, even parents such as Neil and Lynne confirmed that despite their presence, their experience was one of unreality. While being present ensured parents were able to have a greater understanding of the resuscitation, these feelings of unreality suggested that parents might never fully make sense of what was happening to their child and their world. In their struggle to understand they felt dislocated from reality and their life-world. Yet this dislocation was not a case of distancing self, as parents remained fully engaged in the experience. The struggle to make sense of not only resuscitation, but also the whole PICU experience was in a sense, dreamlike. The experience was totally alien to the parents who likened it to a horror rollercoaster ride.
The parents questioned their ability to cope with witnessing and understanding the resuscitation. Mark was unsure about what he might encounter,

... I didn’t know what I was going to see ... I thought it was going to be like a horror film ... and I wouldn’t be able to cope with seeing him like that ... but it wasn’t as bad as that. I just felt helpless watching him.

Parents were afraid of their responses when anticipating the first encounter and were secretly glad not to have to make the decision. Mohammed confirmed this fear, “I’m glad I wasn’t there ... I would have stayed if I’d been there but I don’t think I would know what to do ... how I would handle seeing it happen to her.”

Not being present contributed to the parents’ feelings of helplessness, uncertainty, and at times, conflict with staff. Some parents expressed deep regret and anger at being prevented from being with their child, either overtly or covertly. This led them to question the staffs’ dedication to a successful resuscitation and left them with feelings of suspicion and disempowerment. Being disempowered and helpless to care for their own child was, for the parents, the ultimate expression of chaos and futility. Dominique expressed this sense of disempowerment,

I said “can I come in to see him?” and they say “No, wait outside” and I was angry and frustrated ... I was outside for 45 minutes and it was unfair and I couldn’t do anything. I should have insisted but I wasn’t my usual self and you tend to go on what the nurses say and trust them ... and they were wrong to do that.

While the parents’ experience was further characterised by terror, paradoxically they were also comforted by being present. As engaged parents, they wanted to be with their child, yet understanding what was happening was terrifying for them. They lived in fear of the death of their child. The horror of watching the mechanics of the resuscitation was blurred for them as they focused on their child, yet their terror was real in anticipation of
the scene and what the outcome may be. Yet at the same time, parents were comforted by feeling useful in being close to their child. Neil’s story was particularly instructive in revealing the paradox of needing to be near his child yet fearing the experience that ultimately leads to confronting the possibility of his death, “… I just couldn’t go in there … couldn’t bear to see his little body being jumped on … but when I did go in it wasn’t really like that at all … they were really careful with him.”

Nurses struggled to appear confident in the parents’ presence when they, too were uncertain of the outcome. There was a sense of loss of control and helplessness in supporting parents when they themselves did not know what was to happen. Louise gave an example of the added anxiety she experienced when parents were there, … it’s bad enough with all the stress of the arrest and not knowing if we are going to get him back, but it’s much worse with the parents there … you don’t know what’s going to happen, how can they … how can you tell them anything when you don’t know anything yourself? … it’s awful

When they could not anticipate what might happen, the nurses expressed concern for the parents, particularly those who had walked in after the event. Louise confirmed the paradox of unreality for parents, yet understanding the very real situation of death, “it’s like being in two different worlds. You walk in and everything’s cleaned up and tidy and it’s as if nothing had happened … it must seem so unreal to them.”

Nurses were unsure of the parents’ ability to cope with witnessing, what they imagined to be an extremely distressing scene and believed it would leave long-lasting traumatic memories. Annemarie provided an example, “… for people who have no knowledge, it’s confronting. It’s not exactly a nice experience to watch and it’s distressing for them.”

Yet for the parents, this belief was not supported when they confirmed that rather than
traumatic memories, their recollections of the resuscitation were hazy. Distress was for their child’s potential death, rather than the resuscitation. Rather, the parents were comforted by having had the opportunity to stay with their child. As Amanda commented: “It was hard but not being there would have been much worse.

Nurses tended to mistake parents’ distress and crying for their inability to cope with witnessing the resuscitation, rather than the meaning behind the resuscitation, as Annemarie continued, “I’d never ask them to leave, but if I could see they weren’t coping, then I’d ask them to leave … I suppose if they were crying all over the place, then they’re not coping.” Yet, nurses believed, by observing distress, they could identify parents not able to cope and thus ensure they did not remain present. Believing resuscitation to be distressing to parents was sufficient reason for some nurses to question their practice of agreeing to parents’ presence and to coerce them into leaving.

Managing the resuscitation was emotionally demanding for the nurses, who recognised the experience as a more human encounter when parents were present and experienced feelings of turmoil. They were uncertain of their own ability to cope when being watched while at the same time effectively perform the resuscitation. As Louise noted, “It’s much worse with parents there … I get very upset when I know they’re there and getting distressed.” These nurses were in turmoil when parents remained and were distressed.

If chaos was the feeling of ambiguity and dislocation from life and reality, curbing and surviving the chaos was revealed as finding a place and establishing an altered role within the resuscitation. Seeing the resuscitation, and that all had been done to save child, comforted the parents. Amanda described finding a place by remaining present,
... they tried for about half an hour but I could see nothing was working so I asked the nurse if he might die and she said “it’s not looking good” so I said if it’s not looking good just let him go … and I knew they’d done everything they could …

Amanda was comforted by being present at the resuscitation, despite Jake’s death and felt she had been part of it, giving her the chance to say goodbye and believed she had had some time to prepare for Jake’s death by being present.

The parents were comforted by their partners’ support and solidarity, as Jenny showed, “… when one of us is feeling low the other one is stronger … and vice versa. We can help each other.” Further comfort was accepted from those who could understand their experience. Thus they drew strength from other parents as well as the nurses. This common bond of experience provided the parents with a sense of protection and caring as Dominique explained “… I talked to other mothers and that was good.”

By being present, they were able to prepare themselves for the death of their child. Indeed their presence did not worsen their distress and, as Amanda explained: “… I would do the same again …not being there wouldn’t change anything would it?” It was as if she believed she had nothing to lose by being present and everything to gain.

Nurses too were able to manage their feeling of chaos and confusion by their ability to continually shift their focus on the parents from foreground to background, and perform CPR while remaining mindful of the parents’ distress and needs, as Simone confirmed,

You just get on with it … you know they’re there and you’re sort of watching out for them but you have to focus on the arrest. You have to realise that it’s their child and they want to stay.
Nurses like Simone acknowledged the potential benefits to parents by drawing on past experiences. More importantly, they recognised the parents’ compelling need to be with their child and were able to put their own uncertainties aside and keep their feelings of chaos and disarray in check when they attempted to understand the parents’ needs.

Not only did expert nurses accept presence as the parents’ right, but, as Caroline affirmed, they considered it fundamental to paediatric nursing practice: “It’s their right to be there and we can’t and shouldn’t stop them. What right do we have to do that?”

7.2.1. Summary

This section explicates the meanings the participants ascribed to being in chaos. Ultimately, feelings of chaos and confusion were expressed as consequences of the overriding fear of death of the child and of failure, both for the parents and the nurses. Chaos was expressed through the feelings of confusion, uncertainty and awkwardness in the presence of another. These elements give meaning to the parents and nurses experience of their role in resuscitation and the qualities that threaten these roles. Parents lived as if they were striving to lessen helplessness, confusion and disempowerment. Chaos could be curbed in part by seeking comfort in being close to the child and remaining present during the resuscitation. This closeness overrode feelings of terror. Nurses were able to curb their feelings of chaos and confusion at parental presence by continually shifting the focus of the parents from foreground to background. By recognising the parents’ compelling and urgent need to be present, the nurses were able to place their own anxieties aside and focus on the resuscitation. By searching for ways to
lessen the chaos, parents and nurses demonstrated a way of being in surviving the resuscitation.

### 7.3. Struggling to connect

Struggling to connect describes a way of being in which the parents and nurses strove to relate to one another, supported each other and in doing so, shared the common experience of resuscitation that no other could fully understand. The parents’ ways of living in a relationship with staff and the nurses’ experience of walking in their shoes, led me to the conclusion that they lived as if they were struggling to connect with each other. Indeed, not every interaction achieved a positive connection. The nurses struggled to protect themselves and the parents but at the same time, provide for parents’ needs. The parents interpreted these struggles in a number of ways that added to the complexity of the chaotic situation. When parents observed the nurses’ struggle to protect themselves, they perceived coldness and distance. When such disconnection existed parents felt rejected, apprehensive and distrustful of staff. When they saw the nurses’ attempts to establish a connection by helping them to remain present, parents frequently responded by trusting staff and being more ready to hand over the care of their child at the most vulnerable of times. When there was a sharing of the child and trusting of staffs’ abilities, many of the parents also felt valued as important players in the scene and were comforted. Appreciation and respect were important in this context.

Connecting with parents created a greater sense of satisfaction and fulfilment for the nurses, despite the added emotional distress that such a connection caused. The success of the interaction between the parents and the nurses was dependent not only on the
length of time the child had spent in the PICU prior to the resuscitation, but more importantly, the way in which the nurses were able to connect with the parents by supporting, being empathic and accepting of their distress.

Despite some of these interactions being experienced over short periods of time, even a few hours, nurses talked about the importance of establishing relationships with parents. They experienced an intense connection when they nursed a critically ill child whose parents remained present and engaged and could see the parents benefited from such a connection. Nurses also benefited, expressing greater fulfilment and satisfaction in caring for the child and family when a connection was achieved and admitted to functioning more compassionately with parental presence. Yet at the same time, resuscitation was, in these instances, more stressful and emotionally draining for most nurses, who experienced grief more acutely and suffered greater guilt. Louise described this emotionally demanding connection: “It’s so much worse, you get attached to the families and see their distress … it’s harder to get over at the end of the shift.”

To counteract these feelings of grief and guilt, nurses often attempted to protect themselves by distancing. Distancing self however, often led to experiences of greater disconnection that left parents feeling frustrated and powerless. Some, like Melissa, believed intensive care nurses to be distant and cold: “… I think they should rotate on the wards … it makes them cold and hard, working there all the time.” The nurses’ desire to protect parents from further distress was then often mistaken for detachment and coldness by the parents. This misunderstanding further eroded the relationship. Yet, the nurses felt great concern for the parents, rather than the apparent coldness demonstrated as
Elaine explained: “I know they want to be there but it must be awful. You want to make sure they’re alright and not see the horrible bits …”

Connectedness was stronger and more positive in some relationships than others and ease of expression of emotions was dependent on these relationships. Similarly, the parents gave meaning to being connected when they were comforted and confident in handing over their child’s life to the nurses. They were more able to hand over care when they had established a trusting connection with the staff. Like Neil, they were reassured: “We thought ‘thank God it’s her there’ … we knew she knew what to do and we could relax … she’d do her best for Toby.”

Parents and nurses were united in their efforts to provide care for the child, holding a common desire to save the child. The connection extended beyond the resuscitation scene. Jenny described such a connection,

... we were in Extended Care and Rob [doctor] came over [from PICU] to see us … he said “I’m so excited I’m going to tell the nurses over there how he’s going” … I thought that was really nice, just the little words that people say to you.

There was a sense of being valued which the parents ascribed to becoming a PICU family and being connected to the staff, and when resident for a long period of time, felt a sense of loss when their stay had come to an end. Many of them quickly fitted into the unit, adopting the culture and language to understand and be understood. In return, the staff readily accepted the parents as important to the care of the critically ill children. Lynne felt valued when she described being listened to,

The nurse asked me if he was normally like that … I said no, his saturations were usually better … and that he was struggling. She went and got someone else to have a look as she didn’t know him.
When a parent had not established a positive connection, feelings of apprehension and mistrust persisted as Dominique described: “… I couldn’t understand why they would not let me in … had it happened again and they weren’t telling me? How do I know they were doing everything? What was going on?”

The nurses talked of ‘establishing relationships with parents’ and certainly the interaction between them was intense as they shared a harrowing experience. Louise found it more difficult to perform CPR if she had got to know the parents, even if only for a few hours yet at the same time valued the connection: “The mum was there the whole time and we talked a lot … it was much harder even ‘though she’d only been admitted 4 hours ago … but I’m glad she was there.” Knowing a parent made it more difficult and personal for a nurse when a child arrested. They could not easily separate the child and the resuscitation from the humanness of the distressed family, yet at the same time, having the opportunity to establish a link prior to an arrest made it easier to pick up on subtle cues that a parent might give. Louise was grateful for the mother’s presence, despite the emotional distress connecting with a parent frequently provoked.

Nurses felt fulfilled when they had connected with parents, as Elaine described:

Well, that’s what you’re here for … to look after the parents as much as the child and when you do it well, you feel good. It’s good to sit and have a chat with them. You feel like you’ve done your job well.

The length of time the child spent in PICU prior to the resuscitation was less crucial to a successful interaction between parents and nurses than the way in which nurses were able to connect with parents by being supportive and accepting of their distress, as Julie demonstrated: “It was good, they let me stay and talk to her and touch her … they could see I wanted to be there. Louise just gave me a cuddle. I really appreciated that.”
Similarly, Jane exemplified the nurses’ connection with parents, expressing the compelling desire to care and protect them, when she described her way of embracing parents. She acknowledged and comforted their grief and tears and confirmed this was no reason to prevent their presence. Expert nurses, such as Jane were able to make more considered judgements about parents’ coping that less experienced nurses could not; when they understood crying was not always a sign of not coping.

For some nurses, connecting with parents was testing, when they considered them to be encroaching upon their territory. In these instances, there was a sense of losing control of the child’s care, threatening their position as a nurse. Most nurses though, welcomed the experience of sharing the child and in some instances; managing effective communication was easier with parents’ presence. While there was a sense of worsening grief, nurses paradoxically felt relief when parents were present. It was as if having parents present almost took the burden away from them having to tell them the news after the event. Less explanation was required.

When parents and nurses connected, they shared the common experience of a sense of failure. Nurses felt guilty at letting the child and parents down if the child died. Failing them was also an expression of failing self as a nurse, as Simone pointed out: “When they’re there, and the kid dies, it’s awful … you feel for them and you feel bad that you couldn’t do anything more to save the child”. Annemarie too, chastised herself, believing she had failed the parents when she said: “I ran everywhere to find them … when I got back they were already there but it was too late. I should have found them earlier … if only.”
Parents recognised the nurses’ feelings of guilt and failure when they had established a connection with them, as Melissa appreciated:

*He [the nurse] was really cut up about it ... I know he felt he should have done more, but I know he really did as much as he could ... none of them could have done anymore for us.*

Other parents confirmed their recognition of nurses’ guilt and were able to feel for the nurses’ distress at not being able to save the child. This empathic understanding with the nurses, however did not seem to add to the parents’ own distress.

**7.3.1. Summary**

Struggling to connect was a way of being in which the parents and nurses struggled to relate to one another, supported each other and shared the common experience of resuscitation. Parents valued being respected as important members of the team and were comforted in their new role when they had established a connection with nurses. Nurses who connected with the parents experienced satisfaction and fulfilment at being able to provide for them. This satisfaction, however, was tempered with the added emotional distress at seeing the parents’ anguish during the resuscitation, particularly when unsuccessful. Not every interaction between parents and nurses, however, was a successful or positive connection. In these instances, parents were distrustful and apprehensive of staff and nurses were uneasy in their presence. Yet ultimately, both parents and nurses sought for and frequently achieved an intense connection with the other that was able to sustain them through the resuscitation and beyond. Being connected then held meaning in the participants’ experience of sharing and surviving the resuscitation.
7.4. Being for another

Being for another describes a way of being for both parents and nurses in which they were thoughtful for the others’ altered role and ability to cope. While this element was reflected in both groups’ experiences, the degree in which this was demonstrated was greater for the nurses. The nurses’ ways of holding parents in mind and walking in their shoes led me to the conclusion that they lived as if they were being and thinking for another. Placing themselves in the parents’ world enabled nurses to better support and care for parents. They were grateful for the parents’ understanding of their own anxieties. Similarly, the parents recognised the nurses’ caring for and about them in their way of being for another. They lived as if for another in their acts of connecting and empathising with the nurses. So each could see the others’ perspective a little more clearly and contribute to a better, less stressful and shared situation. Thinking and being for another assisted both parents and nurses in their quest for coping and surviving the resuscitation event. This section does not include the specific and important aspect of parents’ being for their child. This fundamental way of being for parents is presented in the subsequent section of their ways of being complete.

Not all nurses sanctioned parental presence at all times. Presence was welcomed, accepted under sufferance or rejected outright. For most nurses, rather than merely accepting parents’ presence, they cared compassionately for them. It was taken for granted that parents would want to stay. Support was not, however, always wholeheartedly given. Even when nurses allowed parents to stay, their words were sometimes harsh and they expected them to conform. As Melissa noted: “She told me to
be quiet, to ‘hush’, my crying could be heard all over the unit … she was nasty.” It was as if some nurses knew they should accept parents but remained apprehensive about their presence and indeed their own performance under perceived scrutiny.

Expert nurses, however, were able to hold parents in mind in the background of the resuscitation, while at the same time bringing the mechanics of the resuscitation to the foreground. They remained acutely aware of the trauma that resuscitation posed for all concerned and did their best to care for parents by supporting their decision to be present. They could grasp the situation as a whole experience and attend to it. Thoughtfulness or being full of conscious thought for and about the parents was demonstrated in their ways of supporting and at times encouraging parental presence. Simone gave an insightful example of being for another, “… she was sobbing and collapsed in the chair … I just put my arms around her and hugged her. She needed that.”

Similarly, Louise demonstrated holding the resuscitation attempt in sharp focus yet remained attuned and mindful of the parents’ needs: “… they’re always at the back of your mind … you know, how they’re coping and if they’re okay … but you just put it to the back and get on with it.”

Several parents, too, were mindful of nurses who had to work under their gaze. They felt for the nurses who they recognised worked under extreme pressure. Each of them wanted to reassure the nurses of their professionalism and expressed understanding and empathy for their performance in the spotlight. Neil articulated this empathy, “… it must be hard to have us there … I feel bad, that we shouldn’t be there to give them time … but we only wanted to be there for Toby, not to see what they were doing.”
Once each had set aside their apprehensions of the others’ gaze, and recognised the others’ needs, both parents and nurses were able to be in the resuscitation with little awkwardness. Simone described it in this way: “… you get used to it, and sort of manage to put them at the back of your mind and get on with the job. They only want to be there.”

The commitment to the child’s resuscitation along with the ability to accept parents’ presence as a way of being was illustrated by Caroline, “The more accustomed I am to parents being in the resuscitation, the less it affects my performance. Junior nurses feel as if they’re on show and the stupid thing is they’re [the parents] not checking their skills.”

There was a belief that the role of the support person should be carefully considered. A social worker or member of the clergy was often thought to be inappropriate both by the nurses and parents, who suggested an expert nurse is ideally suited to provide physical, emotional and practical support in terms of explanations. Support had to be given and received from those who could be seen to fully understand the parents’ immediate needs. Jane considered these needs when she commented,

... the most important thing is they need to know and be told by someone who understands ... sometimes the chaplain does it and that’s totally inappropriate as far as I’m concerned ... because they don’t know and don’t have the experience. They could give false information ... if the child dies that’s the information parents take home.

Neil confirmed this need for the parents when he stressed: “… you really don’t want the social worker fussing around, not really knowing what’s going on but ... they keep trying to hover and it annoyed me. I wanted someone who knew what they were on about.”
The nurses demonstrated their empathic understanding and attempted to place themselves in the parents’ world to more fully appreciate their experience. This empathic understanding and thinking for another further supports the nurses’ meaning ascribed to being for another. Elaine described this feeling of being for another when she tried to imagine how she would feel as a parent: “While I am a little nervous about them being there, I think if it was me, I would certainly want to be there … if it was my child.”

Another level of understanding was sought from expert nurses’ personal experiences. When Caroline’s partner died unexpectedly, she was able to draw on this experience to place herself within the parents’ experience. She felt compassion and sadness for the parents and more fully understood how they might feel the compulsion to remain present.

Expert nurses were able to draw on past experiences unlike novice and beginner nurses and recognise the parents’ need to be there as rightful. Caroline demonstrated this ability when she observed the evolution of understanding of family needs at traumatic events,

*The more junior you are, the more you feel you have to protect parents for their own good. When you’re more experienced you see that that’s rubbish … you realise nobody can make the decision for you and it’s never in their best interests to avoid a situation just because it is not a nice experience.*

7.4.1. Summary

This section gives meaning the participants ascribed to being for another. Nurses were able to place themselves in the parents’ world by empathic understanding, enabling them to better support and care for families in this chaotic situation. They were grateful for the parents’ understanding of their own anxieties. Likewise, the parents could see and understand the nurses’ caring for and about them and were appreciative of that.
Mindfulness and being for another assisted nurses and parents in their goal to cope, share and survive the resuscitation event in the presence of the other.

The final element of the meaning of parental presence during resuscitation emerged as unique to the parents’ experience. It is, however, an important aspect of their experience and one in which informs nurses’ understanding of the dilemmas parents are faced with at this time.

7.5. Being complete

Being complete offers the final meaning to what it is to be parents who are present when their child requires resuscitation. The meaning of being complete was drawn from the parents’ experiences of being only for a child and was held in the parents’ attachment to their child and the desire to parent in this context. Completeness was disrupted when parents were helpless to be able to care for the child. The resuscitation took away the essence of being a parent. It was as if they had lost a part of themselves as a parent as they struggled in this altered situation. They needed to find another way to re-establish their parental role. Being present allowed them to become immersed in the situation. The interpretation of the parents’ experiences has revealed three main elements of being complete. An engaged presence, fearing recurrence and failing the child illuminated what it is for parents to be complete or indeed what makes parents live with a sense of incompleteness.

In being there, the parents demonstrated their unconditional immersion in their critically ill child. This unconditional being can be said to be an engaged presence, contributing to
the experience of completeness, yet this completeness as a parent was threatened when
their child was near death. For them, the notion of leaving their child when they believed
they needed them most was inconceivable despite fear of the trauma they might
experience as a result of choosing to stay. Their child was inherent to their lives and they
expressed a deep desire to do as much for their child’s comfort as possible, as well as
coping with their own distress. Melissa expressed this need for completeness as a parent
with great clarity, “there was no way I was going to leave. Didn’t even cross my mind. I
had to be there for him. I couldn’t let him down, even though it was horrible …”

The parents in this study expressed a deep need to continue to care for their child in their
equations of protecting, comforting and advocating for the child. These acts were seen as
essential to their role and were ways in which the parents could feel useful during times
of crisis. Thus they could focus on tasks they were able to perform while at the same
time maintaining the vital closeness to their child. Parents experienced an essential sense
of security for their child, and when this sense was disrupted, by being unable to protect
their child, it could be suggested that they experienced a sense of incompleteness as a
parent, as Dominique stated “I didn’t know what to do … I just felt lost.” This feeling
was intensified by being prevented from being present at a time when they wished to be
close to their child.

Despite the parents’ concerns about witnessing the resuscitation, their desire to remain
with their child overrode any fears. It is clear that for the parents, their fundamental need
was to be as close as possible to their child, needing to see or touch their child if possible,
and the drama of the resuscitation carried on around them regardless. They were often
unaware of the commotion, the talking or of the personnel around, as if it were of little consequence. Having the chance to say goodbye to their child was essential for parents’ sense of completeness. Julie expressed this completeness in preparing for Sarah’s death,

*I had to be there to tell her we loved her and that she was safe … how could anyone not be there, it’s their child? … our child is going to die and we’re there at the beginning and we should be there at the end.*

When the parents described the notion of time standing still, it was as if the temporal dimensions of past, present and future had been dislocated. For the parents there was no concept of future, merely of being in the present, waiting for the child to essentially come back to them. It was as if part of themselves had also stood still. As Melissa said, “*I just had to be there with him … he was part of me and I couldn’t let him be alone. But it seemed like forever …*”

Being for a child, overcoming the fears by the intrinsic desire to remain close and by the dislocation of a sense of time, was for these parents, the existential experience of completeness.

A sense of completeness was fractured when the parents were not able to be there for and with their child. They felt a sense of loss and vulnerability and in not being part of the possible end of their child’s life it was as if their lives, too, were hanging in the balance. This sense of incompleteness as beings was also felt if the child died, yet having the chance to be with the child during the resuscitation enabled them to feel, that despite their grief, they had been able to do as much as possible for their child and they were comforted by that thought.
Being complete also had meaning in the parents’ experience of fearing recurrence and death. When a child survived a resuscitation attempt, the parents remained on alert, knowing the extent of their child’s condition, and understanding the possibility of recurrence. Thus, they attempted to remain close, both physically and existentially, and in caring for their child, it was as if they could try to prevent a further arrest. Yet they were helpless at not being able to do anything effective for their child and had to rely on others to save their child’s life. Mohammed indicated this helplessness,

*I knew it had happened when they suctioned her … I had to stay for each suction after that … I was frightened it would happen again and I had to be there to try to stop it.*

Even when a child was discharged home, some parents remained vigilant, fearing recurrence, and being alone, without the intensive care environment, fearful of the death of their child. Dominique expressed this vigilance well, describing a life altering experience, “… it’s really changed my world. I know he’s fine and home now but I worry that it might happen again … I’ve got one of those little monitors just in case.”

There was a paradoxical sense of the constant fear of recurrence, yet at the same time an enormous feeling of being lucky that their child had made it. The parents were often in awe of their young child who demonstrated great strength. As Dominique told me, “… I really think, I look at Jamie and I think ‘you are so strong, you’ve been through so much’, like, I haven’t been through anything like that.”

Not only did Dominique express great joy at her child’s survival, but she demonstrated further evidence of her ability to set aside her own needs as less important, in her awe of her child. Thus her child was central to her being and created a sense of completeness.
Yet this was dislocated when she was prevented from being with her child during the resuscitation.

Dominique, then, exemplified the feel of constant alertness and fear of death, despite knowing her child was ‘doing well’. She sought extra comfort from technical monitoring, questioning her ability to care for and inherently know her child.

In striving for a sense of completeness, many of the parents were tortured by their belief they had failed their child. They held that good parents did not abandon their child physically or emotionally, so they attempted to reconcile their feelings of torture and failure by being only for the child. It was as if the parents were demonstrating that by being a good enough parent, they would be forgiven for letting the child down in the first place by allowing them to become critically ill. This sense of failing the child can be said to demonstrate the feelings of incompleteness as parents of a critically ill child requiring resuscitation.

Guilt was an ever-present feeling during every parent act and decision. The parents felt guilty and blamed themselves for their child’s condition, as if they should have been more diligent in identifying the child’s illness sooner or preventing an often unavoidable accident. Furthermore, the parents were guilt-ridden when they were not present during the resuscitation. Dominique chastised herself when she decided to take some time out to visit the hairdressers and felt she was punished for leaving by her child’s subsequent resuscitation, “I should have been there … I shouldn’t have gone away.” This feeling of abandoning the child was more powerful if the child had died. Guilt at not being present at that time and the feelings of letting their child down was the impetus for a parent to
stay despite the trauma of the resuscitation scene. Parents’ guilt would never have let them forgive themselves for this feeling of abandonment. In their eyes, the child’s deterioration and arrest was something that parents should have been able to prevent and postulated they may have noticed the slight changes before a nurse had they had been present. Parents thus conjectured they had allowed the arrest to happen by abandoning their child and subsequently blamed themselves for the result. Abandoning the child or letting them down was considered by the parents to be the act of not being a good enough parent. It is as if they then had to prove themselves worthy of continuing to be a parent and wished for a second chance.

### 7.5.1. Summary

**Being complete** describes the ways in which parents lived for their child. They revealed a constant present, whether physical or emotional. Being present and engaged gave parents a sense of completeness. Their being complete was further expressed in living in fear of recurrence and failing the child. These elements gave meaning to the parents’ experience of their role as parents, and the qualities that threatened their sense of completeness during resuscitation of their child.

### 7.6. Summary and conclusion - Sharing and surviving the resuscitation

The meaning in the parents’ and nurses’ experience of parental presence during resuscitation has been explicated in this chapter. Building on the description of the phenomenon, gained through the conscious experience, a further interpretation of the participants’ experience has revealed them as **Sharing and surviving the resuscitation.**
through their ways of being in chaos, being connected, being for another and being complete. Each element, providing a further layer of meaning, shows what it is to be a parent or nurse living in the world and experiencing resuscitation together. Both the nurses’ and parents’ experiences have contributed jointly to the elements of the phenomenon as a whole.

Both the parents and nurses lived as if they were in chaos, with each struggling to establish a role within the experience of parental presence. Uncertainty created greater confusion for all, with fearing death of the child the underlying, ultimate expression of chaos. Paradoxically, however, there was a compelling and urgent need for parents to be with their child, that no matter how traumatic the resuscitation scene may appear, their living for their child transcended. In redefining their intrinsic parental role, parents could make their way through the chaos and confusion and call into action all emotional strength they could employ in order to be there for their child. This sense of completeness enabled parents to curb their chaos and confusion, focus on their child and enable them to survive the resuscitation experience.

The experience was one shared with the nurses. Parents looked to them to manage their understandings and distress. The nurses, who remained thoughtful of and for the parents while at the same time, placing the resuscitation at the foreground of their attentions, frequently supported them. Both parents and the nurses shared a sense of awkwardness in their role within the resuscitation. Yet this awkwardness was kept in check when a trusting relationship had been established and they were able to share the common goal of saving the child. Nurses showed empathy and attempts at understanding the parents’
compelling need to be there. They not only provided for the parents, but also confronted and accepted their own anxieties at resuscitating in view of the parents. Nurses had a compelling need to metaphorically, hold the parents, in their ways of caring and protecting them.

While the scene was undoubtedly distressing, both overcame their fears by being comforted in knowing they had played their part completely. By sharing and connecting with another, participants were able to more readily embrace parental presence, surviving the trauma of the resuscitation. The experience of parental presence during resuscitation, then, can be encompassed by both parents and nurses, in sharing and surviving the resuscitation. This description is the endpoint of a phenomenological investigation in which philosophical and method theory underpinned the framework and provided direction for the study.

Chapter eight presents the discussion arising from the phenomenological description and draws upon the relevant literature. The implications for clinical practice, education and further research are offered.
Chapter 8
Summary, Discussion and Recommendations

8.1. Introduction

Although the central importance of parents in the care of their hospitalized child is well recognized, little was known of the experience for both parents and nurses when parents are present during resuscitation of their child. This study was built on the premise that, if paediatric intensive care units are to meet the needs of parents, while at the same time consider professional and service needs, an understanding of what the experience is like for those involved is essential. The purpose of this study was to develop an understanding of parental presence during resuscitation in PICU from the perspective of parents and nurses. In telling their stories, parents and nurses have provided not only the means to deepen our understanding of what it is like when parents are present during resuscitation but how we can work with and better support both parents and colleagues through and after the experience.

This chapter provides a review of the study framework and a summary of the findings. A discussion of the main points as they relate to the literature is then presented, along with the implications and recommendations for future practice, education and research.

The study draws on philosophical traditions of hermeneutic phenomenology as the framework for the research method. Two layers of meaning emerged from the analytical processes in the study and together provide the full description. In the search for understanding the phenomenon, a first layer of meaning was uncovered through thematic analysis in which the participants’ accounts were closely examined.
This led to the construction of seven themes which provide a description of the nature of the phenomenon. This description is therefore, drawn from the parents’ and nurses’ experiences as told by them. Themes of the parents’ experience were: Being only for a child; Making sense of a living nightmare; Maintaining hope and Living in a relationship with staff. The nurses’ experience was described in the themes: Under the parents’ gaze; Holding parents in mind and Walking in their shoes. These seven themes are essential components of the description.

Further hermeneutic phenomenological interpretation provided the second layer of meaning by providing understanding of what it is to be a parent or a nurse in this situation. Four elements or ways of being were revealed as Being in chaos, Struggling to connect, Being for another and Being complete. A final step of reflection on the findings from the two layers of meaning gave understanding that parental presence during resuscitation is an experience in which parents and nurses are sharing and surviving the resuscitation.

Figure one (overleaf) illustrates the phenomenon of parental presence during resuscitation, the way in which the descriptions make up the experience for parents and nurses and the association or common meaning for parents and nurses as they share and survive the resuscitation.
Understanding is furthered in this chapter by discussing the findings in relation to the existing literature. The implications of the findings are explored. Recommendations for changes to clinical practice, education and further research are presented.

8.2. Summary of findings

The main finding of the study revealed parental presence during resuscitation to be an experience in which parents and nurses live as if sharing and surviving the resuscitation. Yet sharing and surviving the resuscitation was not a straightforward encounter. Parental presence evoked many paradoxes within the parents’ and nurses’ experiences. In the chaotic environment of the resuscitation there remained confusion about the others’ roles, understandings and needs. At the same time, parents and nurses demonstrated an enormous ability to transcend their own feelings of uncertainty to engage with one another not only for the best interests of the child, but also for a successful outcome of the resuscitation while remaining concerned for the other.
At the core of this study’s findings is the parents’ imperative and urgent need to be present with their child irrespective of their own anguish. The parents lived solely for the child during this time. Being present created a sense of completeness as a parent that being absent did not reach. Their feelings of chaos, frustration and uncertainty were exacerbated when they were not present. Yet parental presence was a complex and dynamic concept that necessitated a new relationship between parents and nurses. Parents’ confidence and reassurance in being present was linked to their connections with nurses prior to the resuscitation, yet their sense of being watched often remained. Being present gave parents a sense of control and assisted them in supporting each other. Their need for information varied during the resuscitation and while being present enabled them to see the events unfolding; many parents maintained a degree of uncertainty requiring further information that was often not supplied.

Nurses’ chaos and awkwardness were managed by their ability to place the parents’ gaze to the background, bringing the immediate focus of the CPR to the foreground while simultaneously remaining mindful of the parents’ needs. While resuscitating in parents’ presence was emotionally demanding for nurses who had often connected with them, a sense of fulfillment and satisfaction was also apparent. Ultimately, both parents and nurses were striving together to achieve a successful outcome for the critically ill child and to manage their own feelings of uncertainty and distress.

The following section presents a discussion of the main findings of the study in relation to the existing literature and discusses the implications for nurses both in their practice and education and for further research. The parents’ perspectives and
meanings are presented first followed by the nurses’ perspectives of the relationship that exists within the resuscitation.

8.3. Discussion and meanings

8.3.1. Being there: The ontological sense of being a parent in the resuscitation

In sharing and surviving the resuscitation, the parents had a deep and unquestionable desire to be with their child as much as possible during their resuscitation attempts. Their focus was not on the actual mechanics of the resuscitation, but on their child’s survival and their urgent and compelling need to be there for and with their child. They needed to be there to feel comforted, to feel they had done as much as they could to contribute to their child’s survival and to say goodbye if necessary. Parents were able to remain present by placing their fears about what they may witness to one side and focus on their child. The need to be there overrode the trauma of the chaotic scene. The child’s inherence to the parents’ world and the essential parent-child attachment transcended any anxieties about the harshness of the CPR.

This instinct of parenting and the need to be with the child particularly during times of trouble is not unexpected when one considers the nature of parenting, both of a healthy child, and the changing role of parents when a child becomes ill. Indeed, the overriding desire to care for and protect the child is, for most, a normal parenting impulse. Parenting was a new role for many in this study; for two parents their first experiences were in the neonatal intensive care unit. These parents had to redefine themselves in terms of identity and function, moving from a dyad to a triad relationship with a sick child under the scrutiny of hospital staff. The physical,
cognitive and emotional components of transition to parenthood were substantial, as indeed they are for all parents (Adams, 1998; Chesler, 1979; Bergum, 1989).

Parenting a sick child in the context of a hospital situation continues to create challenges for both parents and nurses. As a result of Robertson (1962, 1970) and Bowlby’s (1953) work and subsequent attachment and separation research, the right for a parent to stay with a child in hospital is not only no longer questioned; it is expected that parents will participate in their child’s care. Most parents will live-in with their child (Casey, 1988; Neill, 1996). One of the last barriers to a complete partnership approach that remains however is the lack of total acceptance of parental presence during resuscitation.

Parents’ desire to stay irrespective of the possible trauma they may feel is attributed to their essential parenting need and role. Consistent with other studies, it was found that this desire to stay was overriding; leaving the child’s side was not an option. Darbyshire (1994) described this decision for parents to live-in with their child as “… an automatic, almost reflex action … not living-in with their child was simply not an option to be considered” (p.20) and claimed that to consider the parents’ decision to stay as rational and calculated was to misunderstand the essence of the parents’ desire to be with their child at this time.

The child’s arrest and resuscitation brought additional stresses and uncertainty for parents, despite many having become accustomed to PICU. Consistent with other studies (Miles et al, 1989a & b; Coyne, 1995; Farrell & Frost, 1992), their greatest stress was the fear of being separated from their child, particularly during invasive procedures. Bouman (1996) also found uncertainty and danger or fear of death to be the major stressor in a study of uncertainty, stressors and adaptation in family
members of adult patients admitted unexpectedly to ICU. It was not surprising, therefore, that parents had a compelling need to stay during resuscitation; the most invasive and traumatic of times. They understood the child may not survive and had a deep desire to be close and to try to protect the child. It was the very nature and intensity of their relationship with their child that made it so important for parents to be there. This need was a constant feature in the parents’ stories.

Parents were comforted by their ability to continue to parent within the context of the resuscitation when their presence was supported. They believed they had done everything possible for their child, had comforted them and had not abandoned them at their most vulnerable. Parents knew that staff had also done as much as they could to save their child and had fewer unanswered questions about the progression of treatment. Although these benefits have been reported in the literature on adult resuscitation (Maclean et al., 2003; Robinson MacKenzie-Ross, Campbell-Hewson, Egleston and Prevost, 1998; Timmermans, 1997), the implications for both parents and staff have been given little consideration, suggesting few difficulties in the dynamics of the relationship between parents and nurses at a time of heightened tension for all. The findings of this study add to this knowledge by showing that despite the recognition of perceived benefits to parents, the complexity that exists in adjusting to their presence often creates further tension and stress both for parents and nurses if this adjustment is not adequately supported and mentored.

An important element of parents’ memories was that they were no more traumatised by being present. Parents were emphatic that not being present would not and did not minimise distress; rather the opposite, when, not being there, they were left to imagine what was happening. The potential death of a child is undeniably
distressing and by restricting parents’ closeness to their child is to misunderstand the child’s inherence to the parent. This study contradicts those beliefs that witnessing or being present would only further distress parents, leave long-lasting horrific memories and be of no benefit to parents (Newton, 2002; Osuagwu, 1991; 1993; Schilling, 1994). Osuagwu’s (1991) firm belief was based on an informal poll of staff in an emergency department. This opinion was reiterated in a letter to a journal (1993) when she questioned whether by allowing relatives ‘to witness the traumatic event of resuscitation’ (p. 277), health professionals’ primary responsibility to the patient’s wishes was being overlooked. Similarly, Newton (2002) argued for the case against witnessed resuscitation, suggesting that long term effects were unknown. These purported unknown effects are not, however, sufficient reason to continue to deny families access to their relative. The belief that such memories would be detrimental to grieving families has not yet been investigated from a parent-child context. As Mason (2003) however, concluded in a recent review of the literature, there is a lack of research that shows the possible harm we may cause by forcibly removing parents from the bedside. Mason (2003) called for further research into this area.

The current study showed that parents did not harbour long-lasting horrific memories of the resuscitation event. Their memories were of their child both healthy and during the prelude to their intensive care admission. Encouragingly in the literature, no reports of adverse psychological effects were found amongst relatives who were present (Meyers, et al., 2000). Robinson et al. (1998) conducted a randomized controlled trial, allocating relatives of adult patients to a witnessed resuscitation group, where they could choose to stay, or a control group where relatives were not offered that choice. While no adverse psychological effects were found in those who
were present, the effects of not being present or being denied the opportunity to make the decision were not studied. The findings of the current study suggest that the reality of the resuscitation was less distressing than anything the parents might have imagined were they not present and is consistent with Robinson et al.’s (1998) findings.

In addition, the parents could not recall with any great clarity the events that took place during the resuscitation. For them, the process was a blur that occurred around them, as they focused solely on their child. Parents were distressed, not by resuscitation itself, but by the meaning behind the resuscitation. They understood the severity of their child’s condition. They needed the chance to say goodbye to their child when necessary and to a certain extent prepared themselves for potential death by remaining present. Cowles (1996) has shown that relatives welcomed the opportunity to say goodbye and were comforted in knowing that suffering had ended for an adult relative. Likewise, parents of young children were appreciative of this chance. Similar findings of dealing with grief by allowing the family to say goodbye, to hold, kiss or to talk to the dying child have been reported in cases of sudden critical illness or trauma (Parkman, 1992), although this has not been studied during the specific episode of resuscitation. The present study found that by having the chance to say goodbye and remaining present throughout the resuscitation enabled parents to more readily prepare for the reality of their child’s imminent death. These parents had fewer feelings of living in two different worlds with little to connect them.

While many of the parents wanted to stay, they recognized at which point they needed to leave the scene for a moment. For them, identifying their own coping
levels was not a question of merely whether they were becoming distressed. Assessing their coping ability was an instinctive process. They knew at what level of distress to leave the resuscitation scene. Of concern to them however, was the opportunity to return whenever they wished. Returning once they had left the scene was not always easy and parents needed assurances that they could do so without problems. They were aware however, that in reality this may not be simple and several parents chose to remain constantly, in spite of their obvious need to take a break. This finding is of concern when, in an attempt to embrace parents in all aspects of their child’s care, we may inadvertently be once more presuming, and in a sense controlling their needs. While it is the health professionals’ responsibility to offer parents the choice to stay, being seen to force parents to stay when they wish to leave is detrimental to their coping and indeed their ongoing relationship with staff.

The parents in the current study often made the difficult decision to leave the scene, despite their need to stay, if they believed their presence may in any way compromise the team’s efforts, at an emotional cost to the parents.

Perceiving parents’ crying as not coping suggests that some nurses misunderstood behavioural responses of parents during this stressful time. This has significant implications when one considers that knowing they can come back readily, makes parents more likely to leave when they recognise they need to take a break. Thus managing their coping is enhanced when they are not compelled to stay because they fear not being allowed back in if they leave. Parents in the present study however, were incorrectly ‘rewarded’ for assumed coping, by being allowed to stay when in fact they struggled to maintain a stoic front for fear of breaking down and being asked to leave. They would do anything to be allowed to stay. Conversely, the
presence of tears was sometimes ‘punished’, by being asked to leave, when nurses believed them to be an indication of not coping, rather than recognising that the presence of tears is normal (Kavanaugh, Trier & Korzec, 2004; Kavanaugh & Ayres, 1998). Two parents in the current study were chastised for this normal crying response to the resuscitation of their child. Morse and Pooler (2002), in describing responses of family members of adult patients in the trauma room found relatives to exhibit either states of enduring or emotional suffering. Those who exhibited emotional suffering were often held, supported and comforted by others, in contrast to those who were enduring who often stood alone, or with a nurse, in silence without touch. Those who endured were often not ‘coping’ but merely desperately trying to hold themselves together for fear of collapse. Similarly, parents’ coping in the current study was, from time to time, erroneously determined.

Nurses may not be in a position to correctly assess individual parents’ responses to the resuscitation; their ability to make judgements about parents’ ability to cope is clearly under scrutiny. A crying or sobbing parent may be exhibiting more effective coping than one who remains stoic (Morse & Pooler, 2002). A better understanding of the behavioural responses is required if nurses are to anticipate needs and provide for parents effectively, and support parents in their decisions to leave and unhesitantly return.

Parents were acutely aware of the nurses’ non-verbal messages that contradicted their verbal assurances to stay. The nurses often gave the impression that they would rather parents not be present, often by the way in which they appeared to grudgingly offer a chair in the corner. These non-verbal messages conveyed reluctance and uncertainty to parents and were consistent with other studies (Miles, 2003), that led
parents to question the quality of care. Parents needed not only verbal information and communication but emotional care by way of supportive actions. The way in which nurses articulate to parents the opportunity to stay and offer their support needs to be addressed. Parents need reassurance that their presence is an accepted way of being in the world with their child.

Concerns expressed by some staff were the fears that parents remained present to scrutinise their competence, or by not being present, nurses would be able to cover up mistakes. These concerns were not shared by the parents themselves. Indeed, parents acknowledged they had very few unanswered questions by being present and satisfied themselves that all had been done in the attempt to save their child. This finding is distinct from others that cited fear of litigation as a major factor in allowing or prohibiting family presence. Tucker (2002) in supporting family presence, suggested the likelihood of lawsuits could be decreased by increasing family knowledge. In contrast, suggestions that nurses were more at risk from a legal claim based on relatives’ subsequent suffering, potential accidents as a result of relatives getting in the way (Newton, 2002) or indeed in the unlikely event of them suffering a cardiac arrest themselves (Osuagwu, 1993) were proposed as a real reason to deny relatives access. Furthermore, a notion was offered that nurses’ duty of care to the patient and their right to confidentiality may be compromised (Newton, 2002; Boyd, 2000). However, there have been no documented litigation cases referring to a witnessed resuscitation. While the results of the current study support the notion that parents had fewer questions by seeing all had been done, the possibility of litigation was not considered by the parents. Nor were most of the nurses concerned about threats of litigation. In perceiving to be under the parents’ scrutiny, nurses primarily questioned their ability to perform effective CPR. In effect,
nurses were anxious of their ability as good and skilful nurses rather than fearing legal reprisals.

8.3.1.1 Unreality versus rational thought

The parents have shown that their chaos and uncertainty were diminished, but not eliminated entirely by being present. Uncertainty remained about the child’s survival, the changed environment within the urgent resuscitation context and their ongoing coping. These findings are consistent with previous research which has documented uncertainty as one of the multiple stressors for parents in the PICU (Turner, Tomlinson & Harbaugh, 1990). Undoubtedly parents were able to regain some feelings of control by being present, a feeling well described in the literature (Meyer, Snelling & Myren-Manbeck, 1998; Miles et al., 1989a & b), and, in this study particularly by having a say in stopping a futile resuscitation. They were able to see and thus better understand what was happening and were not left wondering and waiting for news.

This study, however, has revealed new dimensions of uncertainty specific to the unique experience of presence during resuscitation, in which feelings of unreality and rational thought competed with each other. These parents described feelings of unreality, where the resuscitation event took on a dream-like quality. It was difficult to believe this nightmare was happening to their child. When they experienced this feeling of unreality, parents were often not able to fully comprehend all that was happening despite being present. These feelings of unreality closely fit the concept of uncanniness described by Heidegger (1962) and can be analysed in terms of his notion of the breakdown of the ready-to-hand. In a state of anxiety, one feels uncanny; a state in which ‘everyday familiarity collapses’ (Heidegger, 1962, p. 233).
Heidegger suggests that people become anxious not about a particular thing, but in the face of Being-in-the-world as anxious. As they focused their attention solely on their child, parents may never be able to fully make sense of the event during such periods of stress. So while being present contributed to their understanding, parents were still unsure of the resuscitation situation and what might happen. They needed better information and support to remain present and cope with their distress at knowing their child might not survive. This has significant implications for nurses, who often believed that parents who were present would understand what was happening merely by being there and were relieved at not having to provide as much information. The need for information was a natural response to a child’s illness and, similar to parents in O’Riordan’s (2002) study when information was withheld or lacking, parents felt a loss of control that generated further fear, mistrust and ongoing uncertainty despite their presence in the unreal situation.

Conversely being provided with too much information throughout the resuscitation, was futile, and indeed caused further tension when parents wanted all staff members to focus on their child rather than be seen to waste time on their distress. Information repeated at regular intervals, generally after the event, is needed in order to comprehend what is happening.

For parents, clearly ‘being present’ was more than their physical attendance. As parents, they believed they had an integral part to play in their child’s resuscitation that could not simply be defined in terms of their physical being. Being a parent was who they were and their way of being in the world with their child. They were conscious of the meaning of being a parent more acutely at this time that others could not fully understand. The difficulty they experienced in facing their changing way of
being was far more of a struggle than the perceived ordeal of merely witnessing the resuscitation process.

8.3.2. The Parents’ role

Thus far parents’ experiences of being present have been discussed in relation to the changes that this brought to their way of being in the world with their child. If, as demonstrated by their compelling need to be there, parents are to continue to have a presence in the resuscitation, it is important that nurses understand the complexities of the changing roles that are required. It is clear that parents’ presence changes the scenario, often causing conflict both within themselves and between nurses that makes the experience of parental presence more difficult for parents and nurses. Subsequently, a clear definition of roles and the relationships with one another had a significant impact on the ways in which parents and nurses managed their anxieties effectively.

The findings of this study reveal that parental presence during resuscitation involved a process of rapid adaptation and adjustment as parents accommodated the dramatic change in their role. The impact that their changing role had on their way of being parents and their interactions with others is examined in this section. As the parental role makes little sense in isolation from the role of the nurse because of shared understandings and interactions, the nurses’ role within this context is also explicated.

The parents’ dramatic change in role was affected by the chaos they experienced as well as the physically chaotic environment. They entered the world of the resuscitation as novices, often having just adjusted to the different world of intensive care. There were no rules on how to act. Parents were at a loss to know how to
continue and felt a sense of purposelessness. Being a parent was who they were and
their way of being in the world with their child. Resuscitation changed their
parenting role and subsequently their way of being in the world, threatening their
very being as parents. Fearing death of their child, they were faced with an
unspeakable world in which they were strangers, without the child. It is, therefore,
not unexpected that they want to be with their child as much as possible to try to
protect and care for them. Adjusting to their changing role was defined by their sense
of guilt, awkwardness and understanding; aspects that often made the resuscitation
and the parent-nurse relationship more challenging.

8.3.2.1. Guilt

The implied duty of parents to protect their child meant many saw their child’s
deterioration as their failure as parents. They expressed guilt at letting the child
down, either by not being there to stop the accident or illness or being absent during
the arrest. Guilt was an ever-present emotion for most parents that would not let them
forget that whatever had happened to their child was their fault. Similar expressions
of guilt were found in Darbyshire’s (1994) study of parents of hospitalised children
in the UK.

Parents whose children died following an arrest, remained guilty, yet were comforted
by knowing they had been there at the end and had the chance to talk and touch their
child. Parents’ guilt could not be eliminated merely by being present when their
child died following an unsuccessful resuscitation, but they were reassured they had
done their best to be as good a parent as possible. This sense of being a good parent
contradicts previous findings that reported the ongoing power shift that remained
between parents and nurses and undermined parents’ confidence (Coyne, 1995;
Darbyshire, 1994). As Darbyshire (1994) reported, “… the hospital, its staff, its routines, other parents, their child, themselves, all further erode the parent’s sense of being a good parent” (p. 80). Parents in the current study, however, were able to reconcile feelings of guilt by their actions of being present with their child at the critical time and were ‘good’ parents. Parental guilt has been a reaction widely reported, one that remained with the parents for considerable time (Carter & Miles, 1989; Miles et al., 1989a; Eberly et al., 1985, Miles & Perry, 1985) and that often resulted in anger, denial or, as in Holm, Patterson and Gurney’s (2003) study of parental involvement in the care of a child with cancer, a combination of both in the parents’ inability to protect their child. The findings of the current study shed further light on the experience of parental guilt and the way it may be managed, specifically during resuscitation of a child in PICU.

While guilt could be reconciled to a certain extent, regret at not being present for the entire resuscitation was evident when parents whose children died had taken some time out prior to their death. This remorse that they were not there enough for their child was ongoing.

8.3.2.2. Awkwardness

Parents’ sense of awkwardness further contributed to the difficulties they experienced in finding an altered way of being parents, suggesting they had no real expectations of their role within the resuscitation scene.

While feelings of chaos and confusion were lessened by having the opportunity to be present, parents were often awkward and self conscious, believing nurses would prefer them to leave. Their confidence as parents was shattered when they had little sense of what to physically ‘do’ when, while nurses had specific and immediate tasks
Parents were awkward when they believed they were being watched and judged by the nurses. This feeling of being watched by the experts is confirmed by Darbyshire (1994) and causes greater tension between parents and nurses. Participating in their child’s care can diminish parents’ feelings of being watched and judged as they become more conversant with technical care over time (Casey, 1995; O’Riordan, 2002; Gibson, 1995). The parents in the current study however did not have the opportunity or desire to take on a more participatory role within the specific and intense resuscitation event. It was not possible for parents to become familiar with the actions that occurred during the sudden arrest and indeed, there is no technical task appropriate for them. They remained acutely aware of their awkward presence in this situation and felt unneeded by the staff. Nurses can draw upon this finding of awkwardness in their verbal and non-verbal assurances of parental presence. It is important that we assist parents to adjust to the suddenness of the resuscitation by offering genuine acceptance of their presence in an attempt to allay their awkwardness. However, nurses too are frequently awkward in their role and find it difficult to readily offer such support in the chaotic environment. Their needs are discussed in section 8.3.3.

8.3.2.3 Understanding the jargon

It was clear that understanding, particularly for absent parents, was made harder by the regular use of medical jargon and euphemisms used by nurses to explain the resuscitation. Furthermore, parents were misled when they were provided with information that suggested an apparently insignificant event in their child’s care. Yet the nurses’ use of judicious language in describing a successful, unwitnessed resuscitation was primarily out of concern for the parents’ well-being. They did not
wish to cause further distress following what was a favourable outcome. Furthermore, nurses often assumed an unconcerned manner consistent with a short-lived drama, now passed.

The parents however, wanted accurate, basic words they could comprehend. Receiving and understanding accurate information was important for parents, giving them a sense of control, ensuring their child was being adequately cared for and helped in reducing stress that occurred with an uncertain prognosis and lack of clarity. This incongruence contributed to tension between parents and staff in an already tense environment, at times causing a sense of mistrust in staff. Not being present created greater feelings of helplessness, confusion and uncertainty for the parents.

The ability to assimilate information about the severity of a child’s condition is greatly influenced by ambiguity. Boss and Greenberg (1984) suggest it is that ambiguity, rather than the event itself that predicts the family’s level of stress and ultimately their ability to integrate. While both parents and nurses conceded that a degree of information may well have been given, the parents experienced great stress as a result of the uncertainty about the child’s future and struggled to assimilate the information. Feelings of inadequacy were evident for parents, as they expressed anxiety at seeking clarification of the events for fear of being judged. It is the parents feelings of lack of control, uncertain about child’s survival that made the scenario a stressful experience for them, rather than watching the actual resuscitation. Clear, concise information which can minimise anxieties and assist parents’ understanding is needed.
It is evident from the current study, that the parents’ changing role created challenges that had the capacity to either support or oppose their ongoing presence and coping. Yet to suggest it was the parents alone who faced the challenges of the resuscitation and the ensuing altered relationship with nurses is erroneous. The nurses too had to drastically alter their role and way of being in the world with parental presence. A presence that was often defined by nurses’ awkwardness became a more emotionally demanding role yet at the same time created a more satisfying experience for nurses.

8.3.3. The nurses’ role

The nurses’ changing role was an important component of the experience. They were often confused by their changing role and emotions when they had to not only effectively perform CPR, but at the same time, care for distressed parents who remained. Nurses were challenged and often awkward in the parents’ presence, fearful of being judged or making mistakes. Yet both nurses’ and parents’ main focus, while being on the child, was on different aspects. Neither was concerned with the others’ performance. While the encounters with parents made the resuscitation a more emotional and human experience, at the same time it became more satisfying and authentic when they experienced a sense of connectedness. They were able to better understand the parents’ needs and fears when they could see the benefits to parents.

8.3.3.1. Challenges to nurses’ role

The most challenging aspect of the PICU nurses’ role was to care for and support parents during the resuscitation. For many of these nurses technical management of resuscitation had become second nature to them. The nurses however, were often unsure of how to act in relation to parents and as a result often tended to avoid the
interaction, preferring to assume a more technical role. However, despite the difficulties in supporting present parents, many of the nurses expressed greater fulfillment at being able to care for parents at this their most distressing time. For these nurses, having the chance to share in the parents’ experience was humbling and satisfying. The recognition that the difficult yet fundamental role was to provide support for parents was evident as many embraced that responsibility.

Despite the fear of facing the emotional aspect, nurses were often relieved if parents had been present, as if the burden of explaining was in some way eased. The confusion and distress still experienced by parents in this unreal situation was not always readily understood by nurses.

Interestingly, the parents’ view of the nurses’ role was different from the nurses, who believed a support person should be responsible to stay with the parents at all times, providing ongoing commentary about what was occurring. Parents recognised the nurses’ awkwardness, but would have preferred either an intermittent presence, or merely physical presence without words. Being silent but close was often sufficient support for parents. Furthermore, the parents’ own need for information and support was secondary to their need for all staff to focus their attentions on the CPR procedure. This finding is important in view of the reluctance of some nurses in supporting parents due to lack of confidence in their ability.

Concern was voiced by nurses about who was the most appropriate person to provide support to the parents at the arrest. The participants believed that experienced nurses, who generally took charge of the shift, were the most suitable in providing accurate information as well as having the confidence in reaching out to make a physical connection. Expert nurses also had the ability to recognize the importance
of silence. They did not have to desperately search for the right things to say to provide comfort. For as Louise commented, “nothing you say can make it any better”.

Not only were expert nurses seen as the most appropriate professional support, but other hospital personnel such as chaplains or social workers were often viewed as unacceptable both by nurses and parents, largely because parents needed to know what was going on and the likely outcomes for the child. Parents wanted a person who provided concise, accurate information, at intervals suitable to them, along with a confident, caring touch and the ability to just be there. Support for families during and after a witnessed resuscitation is widely acknowledged as crucial (MacLean et al., 2003; Meyers et al., 1998; Powers & Rubenstein, 1999), yet the way in which this may be achieved successfully has not previously been fully explored. It is clear that the type of support needed during the resuscitation was different from that needed after, when, together with nurses, social workers and chaplains played a larger and ongoing role, particularly if the child had died.

Interestingly, nurses gave little thought to those parents who choose not to stay. It was as if by leaving, the parents’ distress and support was not as significant. Parents had made the decision and nurses may believe that the decision was easy and final for parents. Nurses were able to return to their primary focus of performing the mechanics of CPR without worrying about the parents. Nurses tended to assume parents would be supported by another family member. Yet for parents, waiting usually in the family room and often alone, was torturous when they were left wondering what was happening. Even short periods of time seemed infinite. The notion of suspended or prolonged time fits the concept of Heidegger’s concept of
being and time. Temporality, or lived time was slowed or appeared to stand still when the parents were anxious and waiting for news. The dimensions of past, present and future constituted the parents’ being. For instance, the parents brought their prior experience of illness, the intensive care unit and their understanding of resuscitation to their present being. The past changes itself as they lived towards a future already taking shape (van Manen, 1990); that of the possibility of the death of their child. Hopes and expectations or desperation experienced in the present shape the future perspective on life for the parents after the resuscitation.

8.3.3.2. Awkwardness

Being under the perceived gaze of the parents was uncomfortable for the nurses, particularly those who had limited experience in parental presence. It was clear that these nurses believed that parents were watching and judging their clinical performance, and were fearful of parents’ recognition of their hesitations. Inexperienced nurses, therefore, often preferred parents not to be present. Feelings of being watched previously identified in the literature (Darbyshire, 1994) are in keeping with the experience of these nurses. Expert nurses, however, recognised that the parents’ primary focus was on their child.

A tension that arose here was that while the nurses claimed to understand the parents’ need to be with their child and expressed an acceptance and belief in a partnership approach, this was not always noticeable by their suspicions that parents’ true reason for staying was to ensure the nurses were capable. This tension and suspicion diminished in those expert nurses who had gained experience in resuscitating in the parents’ presence, a practice that eventually became second
nature to them. Nurses new to PICU need more effective mentoring and support to have confidence in caring for parents during resuscitation.

The nurses’ awkwardness and the belief that the resuscitation was traumatic for parents may be the justification needed for apprehensive nurses to restrict parents for ease of their own discomfort and turmoil, both about their performance of managing CPR and their own coping of emotions when interacting with parents. As discussed earlier, the presence of tears was often the way that nurses judged the parents’ ability to cope or not with witnessing the resuscitation, a finding consistent with Kavanaugh’s (1998) study of parents’ experiences of perinatal death. When parents were obviously distressed or crying, the decision was often taken from them. It was as if nurses believed in the parents’ right to make the decision, as long as it was the right one, according to their own beliefs and values. Furthermore, nurses’ other acts of protecting parents, such as either covertly or overtly encouraging them to leave was viewed as suspicious, causing further friction and worry for parents.

Claims that prolonging a futile resuscitation may be evident when families were present (Mitchell & Lynch, 1997) are not substantiated by the current study. Indeed, while staff were conscious of demonstrating every effort had been made, it was often the parents who first voiced suggestions to stop.

8.3.3.3. Professional attunement

The ability to continually shift the focus of the parents from foreground to background was evident by the expert nurses’ skill in recognising the critical nature of the child’s condition but remaining mindful of the parents’ needs. In a recent analysis of perspectives of mindfulness, Hirst (2003) suggests being mindful “… requires the person to attend, to be consciously aware of, the emergent nature of
phenomena in consciousness and to recognize the nature of attachments made to these phenomena as they occur” (p. 359). The nurses in the current study could grasp the situation as a whole and attend to it with professional attunement. They were detached and yet searching and compassionate. This enabled them to manage their own feelings of uncertainty, coping with the emotional aspect of parental presence and effectively perform CPR. While less experienced nurses attempted to cope by detaching themselves from the humanness of the event, they were not able to maintain a mindfulness of the parents. This had the effect of decreasing sensitivity to parents’ needs and is consistent with similar findings that reported distancing as self protection (Nagy, 1999 & 1998). Expert nurses exhibited traits that confirmed their expertise and as Benner, Tanner and Chesla (1992) argued, literally lived in a different clinical world from that of the novice or competent nurse, able to notice and respond to different situations as a whole. This way of being for expert nurses was presented as an expression of responsibility for the resuscitation, the child and the parents simultaneously. Although previous studies report similar findings (Benner, Tanner & Chesla, 1996; Chesla, 1996; O’Malley, Favaloro, Anderson, Anderson, Siewe, Benson-Landau, Deane, Feeney, Gmeiner, Keefer, Mains & Riddle, 1991), rarely are these in the paediatric intensive care setting and never during resuscitation. The current study found that despite the prevalent partnership philosophy espoused, less experienced intensive care nurses found it difficult to accommodate both technical support and family needs simultaneously.

The nurses recognised the parents’ need to be close to their child, yet remained concerned for the potential to suffer from long-lasting horrific memories of the resuscitation. They wanted to protect them from further distress. As previously discussed, however, parents’ recollections were very different, with the mechanics
blurred. They focussed on their child, willing them to live. They were able to place the child to the foreground of their attention and disregard most of the chaos going on around them. For parents who were denied access during the resuscitation, time was infinite, helplessness extreme and they were left waiting to wonder what was happening or indeed whether their child had already died. Restricting access out of concern for parents, therefore, would not and did not minimise distress; rather it was exacerbated.

The nurses’ role within the resuscitation was undoubtedly challenging when parents remained. Awkwardness in their actions made performing CPR and caring for parents harder. Yet many nurses overcame these challenges by their professional attunement. The parents’ and nurses’ roles, while separate, created opportunities for greater connection that frequently shaped a dyadic relationship beneficial to both.

8.3.4. Connectedness

Clearly parental presence creates challenges for parents and nurses in their attempts to function in their altered role within the resuscitation. Connecting with one another, however, created feelings of mutual support and recognition that enabled them to manage their uncertainties and awkwardness more effectively. The emotional cost of connecting with parents was, for nurses, the payoff for establishing the relationship. Empathy and mutual trust contributed to the success of the connection between parents and nurses.

8.3.4.1. The emotional cost of connecting

For nurses, while becoming connected was a fulfilling experience by knowing they had provided for parents, it came at a cost. Supporting parents and witnessing their distress was emotionally draining and accumulated over time. They recognised the
parents as human beings with distressing emotions and needs rather than just “the parents”; an abstract concept. The resuscitation became for some nurses, a more sobering, respectful experience as they were unable to distance themselves and faced the reality of a human connection.

When parents had witnessed an unsuccessful resuscitation, nurses experienced a greater sense of failure and guilt that may have residual effects over time if nurses are not adequately and formally supported and mentored. There was a feeling that, irrationally, nurses had in some way played a part in the child’s death and had let the parents down by witnessing their failure. These findings are in keeping with the experience of others in the general paediatric environment (Costello & Trinder-Brook, 2000), who also identified feelings of guilt and failure and highlighted the difficulties nurses encountered when they tried to foster hope for parents. Costello and Trinder-Brook’s (2000) retrospective study of 44 paediatric nurses who had cared for children dying in hospital in the UK also identified limited support for nurses emotionally affected when a child they had cared for died.

The nurses grieved with and for the parents when they had established a connection with them that made their ongoing work all the more emotionally draining. It is clear that in attempting to care for parents well and accepting their presence, the nurses did not have the opportunity or inclination to emotionally detach from the parent as a person. Consistent with Issak and Paterson’s (1996) study of critical care nurses’ experience of unsuccessful resuscitation, it was found that nurses tried to fortify their defences against the emotional consequences, but individual parents had the capacity to weaken these defences. Dealing with their own grief effectively is essential if nurses are to continue to work within the stressful environment of PICU. Excluding
parents from the resuscitation despite their wish to be present, was a way in which nurses protected themselves from addressing parents’ grief as well as their own. Less experienced nurses attempted to distance themselves emotionally from the trauma of the resuscitation, and while absence of parents made this method more straightforward, none of the participants requested parents to physically leave the scene. Parents however, reported instances of being excluded, both physically and emotionally which led to poorer short term relationships with the nurses involved.

Distancing as a means of protecting themselves is an approach also identified by other researchers (Chesla & Stannard, 1997; Madjar, 1991; Nagy, 1999). Chesla and Stannard (1997), in an interpretative study of 130 nurse participants, identified five nursing approaches that constrained family care in ICU, and included the nurses’ efforts to distance themselves from the patient and family and to distance the family physically from the patient and the bedside. Breakdown in family care can be contributed to the nurses’ response and subsequent actions to the family’s distress.

A phenomenological study of paediatric intensive care nurses’ grief (Rashotte, Fothergill-Bourbonnais & Chamberlain, 1997), found that in order to manage accumulated grief responses, the nurses in their study demonstrated control-taking activities and termination of relationship activities, as well as more positive strategies such as self nurturance and self reflection. Rashotte et al. called for further research into the experiential learning process demonstrated by their participants to cope with multiple losses experiences as well as interventions to enhance the education and support required. Little formal teaching or mentoring on how to deal with the human aspects of resuscitation exists for nurses, particularly in accumulated unsuccessful resuscitation scenarios, and is needed if nurses are to continue to manage the
experience without emotional burnout. Formal support and debriefing therefore, as suggested by Spencer (1994), is necessary in addition to the well recognized success of the informal network.

Likewise, a more formal support for parents whose children survived the resuscitation is necessary when one considers the uncertainty and chaos that remains, despite being present. This may be more readily achieved when a connection has been achieved and may be beneficial in assessing the long term consequences of parental presence and what, if any, impact it may have on the parent-child relationship. Yet currently formal support is not readily available, as it is assumed that parents are merely relieved their child has survived.

8.3.4.2. Empathy

The nurses’ demonstrations of empathy created greater connections with parents, enabling them to more accurately assess parents’ coping and needs. Empathy was defined in La Monica’s (1981) work in the validation of Empathy Construct Rating Scale (ECRS) as “… the accurate perception of the patient’s world, … communication of this understanding to the patient, and the patient’s perception of this understanding” (1981, p. 389). It is clear that while the expert nurses exhibited these traits by their actions of considering parents’ needs accurately with conscious care, an empathic understanding was not always achieved. Despite nurses’ listening to parents, they could not always communicate this understanding to the parents whose perceptions were very different. Parents told of their great need to stay, yet often this was overlooked when a nurse considered the experience too traumatic for parents to cope with. Interestingly in an analysis of empathy of intensive care nurses, Murphy, Forrester, Price and Monaghan (1992), found that as years of
experience increased, the degree of empathy, found to be a significant predictor of family needs assessment, declined. Thus the nurses’ ability to accurately assess family member needs decreased the longer they worked in the area. This may be because despite years of experience, these nurses had not become ‘expert’ clinicians, but merely accumulated years of working in a highly stressful environment. Previous studies also suggest that as nurses become experienced, they tended to lose empathic ability that can be improved with staff development workshops (Molter & Leske, 1983; La Monica, Wolf, Madea & Oberst, 1987). This finding is at odds with the current study, which found expert nurses showed greater empathy for parents in their displays of being for parents. This was confirmed by the parents who appreciated being understood by these nurses and gained great support from them that was often lacking from other family sources. The expert nurses in the current study were attuned to the parents’ needs and accommodated them as best they could.

Nurses were able to draw upon their previous experiences of resuscitation in order to attempt to place themselves in the parents’ world. This was achieved through empathic understanding and suspending their beliefs and anxieties about parental presence, and like Swegle’s (1989) investigation into the nurses’ experience of empathy in nurse-patient interactions, empathy was distinguished by the nurses’ belief that their interventions made a difference to the parents.

The parents, moreover, wanted reassurance that nurses showed empathy towards their critically ill child. They were comforted by expressions of warmth and care and conversely, were thrown once more into chaos when nurses were unsympathetic to their needs and distress, as in the case of being chastised for crying. These concerns over caregiver empathy were an important factor in managing uncertainty and are
consistent with Turner et al’s (1990) study of parental uncertainty in critical care. It should be noted that while that study was based on parents of critically ill children in PICU, its focus was not specific to crisis situations, but rather the first few days after admission (Turner et al., 1990). The current study’s focus was the intense and uncertain nature of the resuscitation. However, the results expand on Turner et al’s (1990) findings of dimensions of uncertainty in paediatric critical care. As previously reported (Mishel & Braden, 1988, 1987; Mitchell, Courtney & Coyer, 2003), uncertainty may be increased and thus reduce the parents’ adaptation to the crisis if nurses were seen to be unsympathetic to either child or parent.

The feelings of connection experienced by some of the parents and nurses were achieved through a process of mutual respect and appreciation for the other that continued to affect the ongoing nurse-parent attachment. Curley (1997) defined the concept of mutuality as a “synchronous, co-constituting relationship that stimulates the process of personal becoming” (p. 210), where the relationship is characterised by shared commonality and mutual respect. Empathy, on both sides, is a prerequisite for the mutual understanding to occur within the relationship. Through a relationship of mutuality, each participant develops greater self understanding, that contributes to their personal becoming, benefiting each participant in the relationship.

Despite the immediate need for nurses to assume a more direct role, the relationships demonstrated between parents and the expert nurses in the present study were ones of mutuality. These nurses provided skilled technical care while at the same time offered sensitive and individual support for each family, which showed a sense of respect for the parents’ wishes and coping based on empathy. Clearly the degree of mutuality or empathy exhibited in the relationships between parents and nurses
varied, with greater empathy displayed by expert nurses, particularly, but not exclusively, in relationships with parents that had been established for a period of time prior to the arrest. However, the length of time spent in PICU was not an essential factor for a relationship of mutuality. There were descriptions of mutuality experienced by both parents and nurses even when a child had scarcely been admitted before requiring resuscitation. In these cases, it was both the personal characteristics of the parents and the nurses that embraced the others’ unique being. An openness and consideration of the uniqueness of each person is imperative as nurses begin this extraordinary relationship during a time of great stress.

Despite the obvious tensions that existed as parents and nurses attempted to live in the resuscitation, it was clear that nurses demonstrated an empathic understanding for the parents that contributed to a unique mutual relationship. They attempted to understand the meaning for parents by reflecting on their personal experiences and past experiences of parental distress during resuscitation. They were able to convey to the parents their attempts in understanding and the parents were appreciative of this. Nurses too gained satisfaction and renewed energy from the positive connections with parents that enabled them to continue to work effectively within the stressful environment of PICU. Bauman (1993) draws attention to Levinas who discussed the difference between ‘being for another’ and ‘being with’ another. Being with, according to Bauman (1993) suggests the nurse is with the patient but apart. The nurse and the patient are ontologically separate. However, in the current study, it is clear that Levinas’ theory of being for precedes ontology. It is transcendental because of its ability to rise above being and being with. Bauman (1993) calls this a moral responsibility because it is not taken on as a contract but taken as though it is there already and always as though it is ours.
8.3.4.3. Trust

Consistent with other studies (Powers & Rubenstein, 1999; Miles & Mathes, 1991), it was found that mistrust of staff was raised in circumstances when parents were denied the chance to stay with their child. Concern was voiced over efficiency and effectiveness of the nurses’ performance even when parents had previously established a relationship with the staff. A trusting relationship may be fractured in these instances, causing further parental stress. Ongoing trust in staff is enhanced and stress lessened when nurses are able to demonstrate expert care and acknowledge the importance and preservation of the parental role (Meyer et al., 1998; Thompson, Hupcey & Clark, 2003). In the present study, when nurses did not recognise the parental role and anticipate their needs, trust was either eliminated or inhibited. Yet, even when parents were trusting of staff, extra vigilance was seen following a successful resuscitation, parents fearing another arrest. The notion that being vigilant is inherent in the parental role and is not an indication of mistrust (Thompson et al., 2003) is in keeping with the experience of these parents.

Although some parents whose children survived reported extra vigilance, both in the PICU and following discharge home, it is not known for how long this vigilance continued and what effect, if any, it may have on the parent-child relationship. It may be that for those parents who were absent when their child survived the resuscitation, excessive vigilance is maintained, making their concern more difficult to manage. On the other hand, it is not known whether being present during a successful resuscitation created vigilance and concern that exceeded that of absent parents.
Connecting with staff enabled parents to more readily hand over and trust staff in their care of the child. They were comforted in knowing their child was in good hands and even if the resuscitation was unsuccessful, parents believed and could see staff had done their best. They trusted the staff who were open and respectful to them when they encouraged them to stay. They were made to feel part of the team, even as far as making the decision to stop the resuscitation effort. A willingness to stop a futile resuscitation was shown when parents had been present, eliminating a prolonged attempt. An intense relationship or connection with staff helped parents to find a place, both physically and existentially, within the chaotic environment. While the experience was more emotionally draining for nurses, they were satisfied and fulfilled at having been able to care for parents at this crucial time in their lives and were respectful of the parents’ part in the resuscitation.

**8.4. Implications and recommendations**

Using interpretative phenomenology I have attempted to uncover the extensive lived experiences of both parents and nurses that have previously remained poorly understood.

This study has shown that parental presence creates new, complex challenges for both parents and nurses. It has further developed understanding and ideas about being a parent or a nurse within the unique experience of resuscitation in PICU. It offers insights into the lived experiences of parents, nurses, and the relationship between the two. Such insight can raise awareness of the possibilities within nursing practice in the attempt to continue to improve family centred care during the most critical time in the PICU. At the same time this study can raise nurses’ consciousness of their fears and anxieties, the conceptualisation and structure of the
altered relationship and the ways in which this may be embraced in the nurses’ pivotal role.

While the general structure of a doctoral study should conclude with a series of specific recommendations for practice, education and research, a list of prescriptive recommendations is considered by some to be inappropriate for an interpretive phenomenological study (Darbyshire, 1994; Diekelmann, 1993), the aim of which is to deepen understanding by illuminating and interpreting important themes. It does not describe an objective reality or discover generalisable facts about a particular situation. However, the findings of this study do have practical implications for nurses working with parents in the paediatric intensive care environment. For this reason, and despite the suggestions that the “so what?” question may be at risk of being answered with a series of set ideas considered by some to be at odds with phenomenology, I will explore the implications understood by such a research approach. My intent is to enhance awareness of parenting a child during resuscitation in the PICU and the possibilities for change within our practice, education and further research.

8.4.1. Implications for clinical practice and education

Parental presence creates challenges for both parents and nurses, despite the well recognized acknowledgement of parental participation in the paediatric setting. This study provides needed information and understanding about these challenges. Understanding the processes for both parents and nurses can inform how the process of parental presence was conducted in PICU and is fundamental to the parent-nurse relationship during and after the resuscitation. This study provides insight into these processes and highlights the following issues that can better inform nursing practice.
The parents’ compelling need to stay as close to their child as possible, despite the perceived horror of the scene needs to be recognised. This need was an instinctive, automatic act. The alternative, not to stay was most commonly not considered and when reflected upon, was often abhorrent. Being present was, for parents, their role as parents within the resuscitation.

The recognition that for most of the parents, the memories of the resuscitation were not traumatic or long-lasting is essential. The reality of the scene is generally less frightening than that imagined by the parents or the nurses. This is an important consideration as nurses often believe it too horrific to watch and deny parents access. Restricting parental presence out of concern does not minimise distress and may intensify it. Respect for parents’ ability to assess their own coping must be given.

The presence of tears is not an indicator of the parents’ lack of coping. A greater knowledge and understanding of differing behaviour responses to crisis and grief is needed if nurses are to more accurately assess parents’ needs and coping during and after the resuscitation. Further formal education in this area is warranted.

Emotional support from nurses, both verbally and by their actions, without judgment or conditions is required by the parents. An environment that routinely supports and facilitates family centred care is essential. Policies and protocols must reflect the central importance of the family and enable parents to be readily accepted throughout the PICU stay, including resuscitation. Whether the parents leave the scene, choose to stay for intermittent periods or throughout the entirety of the resuscitation, allocation of a support person is important.
The most appropriate support person for parents is integral to their coping. Expert clinical nurses are the most appropriate, providing the necessary clear and concise information and support needed by parents during the resuscitation. Other healthcare professionals such as social workers and clergy often do not meet parents’ needs at this time. Consideration must be given to the allocation of a support person, and if possible, negotiated with individual parents. Parental support needs change after the resuscitation when there is clearly a place for additional support personnel such as social workers or clergy that must be assessed on an ongoing individual basis.

Parents did not want a continuous report about what was happening and often appreciated and preferred silent support, where they could focus on their child. Knowing someone was there close by was often sufficient for them. It is important that nurses recognise this need when they attempt to fill awkward silences.

These parents essentially wanted the team’s focus to be on their child’s survival and were distressed by a perceived lack of attention on the resuscitation attempt by the support person. It is vital that parents are assured of the nurses’ role in caring for them as well as their child.

Whether the parents chose to stay or leave the resuscitation, or were absent entirely, clear, concise and repetitive information is essential in order to enhance understanding. When parents chose to leave the scene, the support person needs to continually liaise between the resuscitation team and the parents. Support must be given so as not to exert unnecessary pressure on these parents to attend when they would prefer to stay out of sight of the resuscitation.
When parents arrive during an unexpected resuscitation attempt, they need to be provided with accurate information as soon as possible, and not left to find out covertly. Regular attention must be paid to confirming their understanding of the information given, particularly after the event from all members of the team. It should not be assumed that parents will understand merely by witnessing the event.

If parents chose to leave during the resuscitation, they needed assurances that leaving and returning throughout the event was acceptable and indeed desirable if their coping was to be managed more effectively. It is important that staff actively demonstrate this assurance.

Even when the parents were present, the resuscitation attempt was confusing and unreal. They were often unable to make sense of what was happening yet nurses frequently assumed their understanding was greater. Once again, the need for clear concise information at regular intervals and confirmation of understanding is essential.

Parents may experience difficulties in grasping the information given following a resuscitation attempt when they were not present. Consideration must be paid to the use of medical jargon and euphemisms and succinct explanations about the events that occurred given. For example, these parents would have preferred to have been told their child’s heart had stopped but had been started again with drugs, rather than using terminology such as “arrest” and “resuscitation” in isolation.

Seeing all had been done in the attempt to save their child and having the chance to say goodbye comforted these parents. Potential legal claims that staff failed in some way to save their child were not considered. Nurses must recognise that the parents’
decision to stay is not an attempt to detect mistakes or assess the nurses’ competence in CPR skills.

Extra vigilance following a successful resuscitation is not an indication of the parents’ lack of trust in staff but an inherent desire to be with their sick child and care for them. It is important that nurses are sensitive to this extra vigilance, demonstrate empathy and do not become defensive in their practices.

Providing nurses with ways to increase their empathic ability are necessary. This may be achieved by providing exemplars and role models that can assist nurses to place themselves in the parents’ world, to actively listen to parents’ needs, to recognise them and act accordingly.

Parents should be able to make their own decision whether to stay or leave the resuscitation scene. Nurses must be able to provide the environment that supports their decision. The opportunity to stay or leave must be repeated at regular intervals, without pressure.

This study also provides insight into the process experienced by nurses: Less experienced nurses felt they were working under the parents’ gaze during the resuscitation. Acquiring the skills to incorporate technical and emotional aspects of care is important for all nurses in PICU. Comprehensive and continuing education programmes and regular discussions on parental presence, the nurses’ fears and the reasons why parents need to be present are essential. These sessions should be designed to encourage staff to reflect on their own practices, beliefs and fears of resuscitation and facilitate the development of knowledge and skills to enable nurses to build supportive relationships with parents wherever possible. The PICU
environment must reflect the central importance of the family and enable parents to be more fully involved in collaborative decision-making during periods of crisis.

Clinical education needs to maintain a family focus. The teaching of technical resuscitation skills must be carried out in the context of the technical intervention and the emotional needs of both the parents and the staff simultaneously.

Resuscitating with parental presence was emotionally challenging for nurses, particularly when they had established a connection with these parents. Mentoring and formal debriefing for nurses is required, particularly if novice or inexperienced nurses are to manage the emotional challenges of connecting with and supporting parents, while grasping the highly technical skills required. This is important to consider when resuscitation attempts are frequent events in PICU, yet little emotional preparation is currently provided. Facing the human aspect of resuscitation needs to be more actively taught by expert nurses who have gained much in their connections with parents. Ongoing support, not only for nurses caring directly for the child during the resuscitation but also those allocated to support the parents is needed, both formally and informally.

8.4.2. Strengths and limitations of the study

To date, no study has explored the lived experience of parental presence during resuscitation in PICU. This study provides valuable insight into these experiences and the drastically altered relationship that exists between parents and nurses at this critical time. Furthermore, the previously noted dearth of qualitative research in this area suggests the most important implication for the current study is the need it has shown for such research. There is certainly a trade off between the depth of understanding for the generalisability of an extended testing study. The nature of a
hermeneutic phenomenological study, combined with the small sample size and the recruitment of parents and nurses in the same paediatric intensive care unit mitigates against the generalisation of the findings of this study. However, detailed descriptions of the setting, the participants, data collection and analytical processes used and the extensive use of direct quotes in reporting the findings, enables the reader to apply the findings to make judgments of transferability. The value of a hermeneutic phenomenological study such as this reveals what it means to be a person living in the experience of parental presence during resuscitation.

According to van Manen (1990), language is a pivotal medium of hermeneutic inquiry and “… lived experience is soaked through with language” (p. 38). Thus it is the medium for understanding, interpreting and communicating meaning as well as the medium for the processes of wonder, questioning and reflection. Finally, as “writing is the method” (p.124) and such phenomenological writing creates a form of consciousness required to reflect upon the experience, the process of continuously writing and rewriting led to further interpretation and greater depth of the phenomenon, constructing multiple layers of meaning.

The study setting was a PICU where the practice of offering parents the choice to stay during resuscitation had been established for 4 years prior to the study commencing. This factor may have had an influence on the nurses’ beliefs about parental presence, particularly those expert nurses who had adapted to and accepted the practice. Since the study began, many more centres have begun to offer families the choice to stay during resuscitation. Thus, nurses, and other health professionals’ perceptions of family, and in particular, parents’ presence may have altered to reflect a more inclusive way of being.
I interviewed parents and nurses only once as I was seeking their experience of the specific resuscitation event and did not attempt to contact the parents again unless they requested it. While I aimed to interview participants in a variety of situations, all parents whose child died were present. Therefore, the experience of parents who were absent during resuscitation and their child died is unknown. Furthermore, the interviews were conducted with parents who readily agreed to participate. It may be that these parents coped more effectively and were able to reflect upon their experience. It is not known how those who chose not to participate (2 families) experienced being present. Finally, after consultation with the PICU social worker, 4 families were considered ‘not appropriate’ to recruit. This conclusion was made due to extreme ongoing grief and inability to cope in three cases, or in the case of one family, the pursuit of a legal claim unrelated to the Hospital’s role in the child’s death, but whose anger was deemed too extreme to warrant unnecessary intrusion. The experiences of these families are not known.

The need for parents to speak English limited the recruitment of parents, potentially limiting the diversity of ethnic experiences described. One Muslim couple from Lebanon was included in the study and while the father spoke English well, the mother’s spoken English was limited. She however, contributed a different perspective as a young female whose role was to remain deferential to the males in authority such as the nursing and medical staff and as such did not wish to question their decision not to contact her when her child arrested during the night.

My previous role as an experienced paediatric intensive care nurse who had practiced alongside many of the nurses participating was declared in the study’s introduction. As a researcher who had worked in PICU for many years, I had established a good
working relationship with many of the nurses, who trusted me with their stories. In addition, I was able to demonstrate understanding to the parents who needed to describe the technical aspect of intensive care. These parents were relieved at my understanding. Nevertheless, my status as an experienced PICU nurse required particular ongoing awareness during the study if I were to listen to the stories without bias. Through self-reflectivity, it was possible to stand back from my prior understanding to note the unexpected as well as the familiar when exploring the explicit and implicit meaning in the participants’ descriptions. However, phenomenological research is never an interpretation-free, objectively ‘true’ account of things themselves (Leonard, 1994) but is caught up in the understanding within the context of past experiences.

8.4.3. Implications for further research: more questions

This research is the first phenomenological study to provide the nature and meaning of the experience of parental presence during resuscitation in PICU. It sheds light on the challenges faced by both parents and nurses in an attempt to live together in the experience. The study, however, leaves unanswered some specific questions related to long term coping which warrant further research. This study identified vigilance in parents following a successful resuscitation. It is unclear whether greater vigilance exists in those parents who were not present during the resuscitation or for how long this vigilance continues once the child is discharged home. There is a need to explore the long term coping of parents whose child survived and whether it is greater in parents who were absent during the resuscitation.

Little is known of the experiences of parents whose children died and who did not have the chance to stay while the child was resuscitated. An insight into how being
absent parents impacted on their grief, feelings of unreality and understanding is essential if we are to provide support without conditions within an improved family centred care philosophy. Thus further phenomenological research as well as quantitative studies can continue to improve our understanding of the experience and needs of parents.

8.5. Concluding comments

Resuscitation of a child in PICU creates great uncertainty and distress for parents. Unquestionably, parents need to be able to choose to stay close to their child, yet it is at this time this need is most often denied. There is a growing body of literature that questions this denial and endorses family presence (Mason, 2003; Meyers et al., 1998 & 2000; Morse & Pooler, 2002; Powers & Rubenstein, 1999; Sacchetti et al., 2000). This debate is ongoing but clearly the fundamental right for parents to stay, particularly during cardiac arrest and resuscitation, remains unacceptable to some staff who continue to enforce rules that restrict access to individuals (MacLean et al., 2003). Few centres have written policies or guidelines that support parental presence during resuscitation, despite the verbal assurances from many, and the International Resuscitation Council’s recommendations (AHA/ILCR, 2000; Cummins & Hazinski, 2000). Parental presence remains dependent on the views of the individual staff members attending at the time of the arrest. Prior to this study, little was known of how parents experienced the resuscitation and what made it harder for them to stay despite being offered the choice. It was assumed that if they want to be there, they would somehow manage.

Furthermore little was known about how the nurse-parent relationship may impact on the parents’ decision to stay or leave and the way it must alter if both parents and
nurses are to manage presence effectively and with sensitivity. Parental presence is clearly not about merely witnessing the resuscitation act, or either choosing to stay or leave throughout the entirety of the resuscitation but about how long the parents wish to stay and are supported in that desire without conditions.

The purpose of this hermeneutic phenomenological study was to explore and describe the lived experience of parental presence during resuscitation in PICU from the parents and nurses perspectives. The outcome of the analysis is a description of the phenomenon of parental presence that is detailed, multi-layered, consistently interpreted and an in-depth description of the phenomenon. The results confirm that being present during the resuscitation of their child greatly benefited the parents’ coping by curbing the chaos and uncertainty many experienced. Yet, to assume this altered way of being in the world would be unproblematic was incorrect. The parents and nurses often struggled to adapt to their altered roles within the resuscitation and were awkward in the presence of the other. With effective support and mentoring however, both were able to manage their fears and benefit from the connection they established. Ultimately, the parents’ need to be present overrode any fears they may have had about the trauma of the resuscitation scene. As one parent succinctly expressed it “… not being there would have been worse.” Although parental presence created great challenges, it also brought a new sense of connection that demonstrated that parents and nurses to be living as sharing and surviving the resuscitation.

Working with children and families in the intensive care unit can be challenging especially during crisis times such as resuscitation when decisions to be faced are difficult and immediate. Our role as nurses is to continue to provide improved
family care with sensitivity while at the same time undertake the most difficult of
tasks of performing CPR effectively. In sharing their stories, parents and nurses
have allowed us intimate insight into their worlds and a different perspective of the
lived world. By revealing the first-hand experiences, PICU nurses can more fully
understand the parents’ perspective as well as becoming aware of their own beliefs
and ways of being when parents are present, and develop their practices to more fully
embrace a family centred approach. I have been privileged to hear their stories and
have been touched by the generosity of parents and nurses as they talked candidly
about their experiences.

This research, hopefully encourages readers to thoughtfully reflect on the what it is
like for parents to be present during resuscitation, what the experience is for nurses
who perform CPR in the parents’ presence, and for those who are clinicians, to
consider practice improvements that will enhance the parents’ and nurses’
experiences. The full significance of such reflection will ideally promote further
questioning and inquiry about this and related human phenomena, as the
phenomenological quest can never be conclusive nor complete but is provisional. As
van Manen (1990) noted “It should only make people wonder – that’s the point.”
Appendixes

Appendix A (Printed on Hospital letterhead paper)

Letter of introduction to parents whose child has died, generally sent 3 months following child’s death in PICU.

Fiona Maxton  
Nurse Researcher  
Paediatric Intensive Care Unit

Dear names of parents

Parental Presence During Resuscitation – The Experiences of Parents and Nurses
My name is Fiona Maxton and I am one of the nurses in the intensive care unit at the name Hospital. While I realise that thinking about the hospital may be distressing for you at this time, I would like you to consider taking part in a study that I am undertaking. I would like to try to understand the things that either made you want to stay with him/her at this time or want to leave the room. I am also interested in understanding whether you believe that your decision to either stay or leave during the resuscitation was helpful for you and how you coped. We hope that in having a better understanding of what this traumatic time means for parents, we may be better able to help families in the future.

I would like to telephone you in about one week’s time. If you would like to take part in this study, we can discuss a suitable time for us to meet. If you do not want to take part, I will not contact you again and you may be assured that this decision will not affect any ongoing relationship you may have with the Hospital.

If you decide to participate, I would like to interview you to talk about your experience of this event. These interviews are more like a conversation, where you can talk about your child and how you are feeling. I would like to tape the interview, to avoid taking any notes during our conversation. Everything you say will be treated as confidential. Your names will be changed in any writing of the study.
Sometimes these conversations can raise feelings of distress. These feelings are normal and many other parents experience them. However, if you would like to speak to a counsellor or the social worker you met in the intensive care unit, I can provide you with the information to contact them, or I can ask them to contact you. If you would like to talk about this study please feel free to contact me on (telephone numbers work and home).

Yours sincerely
Fiona Maxton

(Version 2, 4 Jan 2000)
Appendix B

Sample script for telephone recruitment for parents whose child has died.

This is Fiona Maxton, the nurse from the children’s hospital. You may have received a letter from me in the last week after the social worker spoke to you. Do you have time to talk now?

First of all, I want to express my sympathy to you on losing (child’s name). I am sure this must be a very difficult time for you and I appreciate your willingness to hear from me.

Can I explain a little more about the research I am doing? As a nurse I have worked in the PICU for 10 years and cared for a number of parents whose children have died. I would like to talk to you (and your child’s father if appropriate) in an interview to hear what you experienced in the PICU, particularly when (child’s name) needed to be resuscitated.

If you think you might be interested in taking part, I will come to your home or if you prefer we can do the interview somewhere else. I will try to select a day and time that is convenient to you. The first thing I will ask you to do is to sign a consent form as this is a research study. Then I will ask you to tell me what it was like when your child needed to be resuscitated and what it was like to be there (or not). I would like to tape record the interview because it is the best way for me to remember everything you say. I have found in other studies that most parents will talk for about an hour. However, you will not have to talk for that long.

Is this something you think you would be interesting in participating in? (if yes) what day of the week would be best for you? You might find it useful to have someone else there as well as your husband/partner as these interviews may cause you to become upset.

(if no) I will thank them for taking the time to listen, will assure them that I will not contact them again, and offer them the opportunity to speak to the social worker or refer them on to community support.

(Version 2, 4 January 2000)
Appendix C (printed on Hospital letterhead paper)

Parental Consent Form

Name of Study: Parental Presence During Resuscitation in PICU: the Experiences of Parents and Nurses.

Investigator: Fiona Maxton, Paediatric Intensive Care Unit

I have read and understand the Parent Information Sheet, and give my consent to participate in this study, which has been explained to me by

…………………………………………………………………………………………..

I understand that I am free to withdraw from the study at any time, including during the interview and this decision will not affect the care I receive or my relationship with the Hospital

Name of Parent ……………………………………………………….  (Please Print)

Signature of Parent/Guardian ……………………………………………………….

Name of Witness ……………………………………………………… (Please Print)

Signature of Witness ……………………………………………………………..

Date …………………………………………………………………………………
Parent Information Sheet

Parental Presence During Resuscitation – the Experiences of Parents and Nurses

Investigator: Fiona Maxton, Paediatric Intensive Care Unit, the New Children’s Hospital,
Telephone (02) 9845 3002

I would like you to consider participating in a research study entitled “Parental Presence During Resuscitation – the Experiences of Parents and Nurses”. The aim of this study is to understand your experiences when your child required resuscitation (CPR) in the paediatric intensive care unit at the name Hospital. In particular, I would like to understand the things that either made you decide to remain in the room or to leave during the resuscitation. In learning more about this experience we hope to be able to provide families with the support you need at this time.

My name is Fiona Maxton. I am a registered nurse who has worked on the PICU at the name Hospital for the past 8 years, and I will be conducting the study.

If you agree to participate in the study, I will contact you to arrange a suitable time for the interview. The interview will take approximately 1 hour. This interview will take the form of a conversation. I would like to tape the interview to avoid taking notes during our conversation.

All interview material will be treated as confidential and only I will know your name. You will not be identified in any publication about the study. Participation in the study is voluntary and if you decide not to take part or decide to withdraw at any time this will not otherwise affect the care you receive or your ongoing relationship with any personnel from the Hospital. You may withdraw from the study at any time, including during the interview. The social worker from PICU, who you may have met while your child was in PICU is available for support if you become distressed or experience any other feelings of pain. She can be contacted on (telephone number).

If you would like any more information before agreeing to take part in the study, please feel free to contact me on (telephone number). If you have any concerns about the conduct of this study, please do not hesitate to discuss them with me on (telephone number) or with name (telephone number) the secretary of the Ethics Committee that has approved this study. If you have any questions about the medical treatment of your child, please contact Dr , the Head of the PICU (telephone number).
Thank you, Fiona Maxton

Appendix E (printed on hospital letterhead paper)

Nursing Consent Form

Name of Study: Parental Presence During Resuscitation in PICU: the Experiences of Parents and Nurses.

Investigator: Fiona Maxton, Paediatric Intensive Care Unit

I have read and understand the Participant Information Sheet, and give my consent to participate in this study, which has been explained to me by

.............................................................................................................................................

I understand that I am free to withdraw from the study at any time, including during the interview and this decision will not affect my relationship with the Hospital

Name of Participant ................................................................. (Please Print)

Signature of Participant ................................................................

Name of Witness ................................................................. (Please Print)

Signature of Witness ................................................................

Date ...........................................................................

(Version 2, 4 Jan 2000)
Appendix F (Printed on hospital letterhead paper)

Nursing Participant Information Sheet

Parental Presence During Resuscitation – the Experiences of Parents and Nurses

Investigator: Fiona Maxton, Paediatric Intensive Care Unit

I would like you to consider participating in a research study entitled “Parental Presence During Resuscitation – the Experiences of Parents and Nurses”. The aim of this study is to understand your experiences when parents are present during their child’s resuscitation and elicit meanings of these experiences. Therefore you will be eligible to participate only if you have taken part in a resuscitation attempt in PICU when parents have been present for some or all of the time.

It is anticipated that from the nature and meaning of your experiences and those of parents whose child has required CPR in the PICU, we will be able to more fully understand what it means to be a parent who is present when resuscitation was attempted. Understanding how parents cope with this traumatic event, and knowing how health professionals feel about their presence, will assist us to provide optimal care for parents, based on sound research rather than anecdotal evidence.

As a participant, you will be asked to take part in an interview with me at a time suitable to you. The interview will take the form of a conversation and will last approximately 1 hour. The interviews will be audio-taped and then transcribed. All interview material will be treated as confidential and your name will only be known to me. You may choose a pseudonym or will be allocated one.

Participation in the study is voluntary and if you decide not to take part or decide to withdraw at any time this will not otherwise affect your employment at this hospital. If you would like to participate in this study, please contact me at work on extension number xxxx. If you have any concerns about the conduct of this study, please do not hesitate to discuss them with me (telephone number) or with name (telephone number), the secretary of the Ethics Committee that has approved this study.

Thank you

Fiona Maxton

(Version 2, 4 Jan 2000)
Appendix G (Printed on hospital letterhead paper)

Written information to be given to parents whose child has died at time of interview

During this time you may experience a wide range of feelings of sadness, anger, regret, guilt, disbelief, fear and anguish, all of which are normal feelings. Some of the following information may be helpful for you and your family:

Support groups

Compassionate friends
This is a worldwide self help group of parents who have lost a child of any age for any reason. Their information and drop-in centre is at Level 4, 32 York Street, Sydney. Tel. (02) 9290 2355. Also can be accessed on the Internet on compassionatefriends.com providing “chat rooms” to speak to other parents who have lost a child.

Bereavement Care Centre, Epping, NSW.
This centre provides counselling and support services for the recently bereaved. It is not so much a crisis service or self help group as a counselling service for those needing help with their grieving. As well as counselling for parents, there is a specific Bearing Up Club for children aged 6-12 years, who have lost a brother or sister. The cost for some counselling sessions are free. Other sessions are $95 but concessions are available for those experiencing financial difficulties. Tel (02) 9869 3330. They are also available on the Internet on bereavementcare.com.au A Friends Place is the web site aimed at children and young people aged 3-18 years.

SIDA (Sudden Infant Death Association)
While this association was originally established to provide help for parents whose child has died from Sudden Infant Death (also known as cot death), they now provide help for all parents of children under the age of 6 years who have died for any reason. Their 24 hour service tell (02) 9681 4500 or 1800 651 186. If you are calling STD, give the counsellor your number and they will call you back.

National Association for Loss and Grief (NALAG)
NALAG provides general information on bereavement support services available. Tel. (02) 9988 3376.

If you prefer, you can contact the social worker who you met when your child was in the intensive care unit. She can be contacted on (telephone number inserted here).

Many local Community Health Centres also provide support and counselling for parents who have suffered the loss of a child.
References


Spencer, L. (1994). How do nurses deal with their own grief when a patient dies on an intensive care unit, and what help can be given to enable them to overcome their grief effectively? *Journal of Advanced Nursing, 19*, 1141-1150.


