

**THE EXPERIENCES OF PARENTS AND NURSES OF HOSPITALISED
INFANTS REQUIRING OXYGEN THERAPY FOR SEVERE
BRONCHIOLITIS: A PHENOMENOLOGICAL STUDY**

Submitted by

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STATEMENT OF SOURCES

This thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma.

No other person's work has been used without due acknowledgment in the main text of the thesis.

This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All research procedures reported in this thesis received the approval of the relevant Ethics/Safety Committees

Authorship and sources

Signed....

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LIST OF ABBREVIATIONS

CPAP	continuous positive airway pressure
FCC	family centred care
FCS	family centred services
HB	headbox
HDU	high dependency unit
HFNPOT	high flow nasal prong oxygen therapy
HREC	Human Research Ethics Committee
KC	kangaroo care
mmHg	millimetres of mercury
NHMRC	National Health and Medical Research Council
NVIVO	data analysis software
PEEP	positive end expiratory pressure
PICU	paediatric intensive care unit
RSV	respiratory syncytial virus
V/Q	volume/quotient
WHO	World Health Organization

ABSTRACT

SUMMARY OF THESIS

Objectives

Annually, bronchiolitis is a major cause of children's hospital admissions. Children suffering from respiratory distress are provided supplemental oxygen therapy via a headbox. Whilst effective in treating the child physically, the headbox can be very restrictive and limits parental access to their child. This form of oxygen therapy can have a detrimental effect on parental bonding, their relationship with their child, and the parents' ability to fulfil their parenting role. The aim of this study was to investigate the lived experiences of parents and nurses who have had or cared for a child admitted to hospital for severe bronchiolitis and received two types of oxygen therapy; headbox oxygen and high flow nasal prong oxygen therapy. This phenomenon has not been investigated previously.

Methods

A descriptive phenomenological design was used to interview a purposive sample of 12 parents and 12 nurses.

Results

Several themes emerged from data analysis: 1. It was horrific. We didn't know if she would live or die; 2. I didn't know what was happening; 3. I think some parents do get quite upset; 4. All that I wanted to do was hold her and keep her with me; 5. I felt inadequate, more than useless; 6. I needed her to feel my heart beat; 7. Look but don't touch; 8. I stayed with her day and night and; 9. Babies are hard work in the head box because you can't pick them up. These themes were then divided into three domains; Fear, Parent child interaction, and Technical caring.

Conclusions

The mothers found the situation of having a child in a headbox frightening, stating that lack of knowledge and understanding, fear of their child dying, isolation from their child, unfamiliar environments, and the inability to attend to their child's day-to-day care were all contributing factors. Some of these fears were present when their child received high flow nasal prong oxygen therapy but the increased interaction with their baby allowed the mothers to feel more useful and less frightened. The nurses in the study recognised to a degree these themes surrounding the parent child relationship yet were more concerned about clinical issues involved with caring for a child in a headbox such as safety and ergonomic restrictions. The nurses all stated how the high flow nasal prong oxygen system also improved safety and clinical outcomes.

CHAPTER ONE

INTRODUCTION

BACKGROUND

In Australia, the major cause of paediatric admissions to hospital is severe bronchiolitis. The most common form of oxygen therapy used to treat these children is provided using an enclosed headbox. However, a new method of oxygen delivery has been recently implemented in some hospitals around the world; the high flow nasal prong oxygen system. To date, this system has been used in only a few tertiary paediatric settings in Australia. There has been little research that has investigated traditional oxygen delivery systems in paediatrics, and even less with regards to this new oxygen delivery method. A thorough search of the literature revealed only one research project at the commencement of this study that was investigating the physiological benefits of this new system but there is no research that investigates its psychosocial effects from the perspective of parents or nursing staff. Given there are several potential benefits of this therapy over the use of traditional headbox it is also important to investigate its use from the perspectives of families and nurses. Family centred care is promoted in the tertiary paediatric hospital in which I have worked and where these two oxygen therapies are used for children admitted with severe bronchiolitis. After personally being involved in the care of children with severe bronchiolitis and their families, it became evident that headbox oxygen therapy posed particular challenges when nurses tried to involve parents in the child's care, whereas there were fewer restrictions imposed on the child by the high flow nasal prong system. I felt that an investigation into the psychosocial side of these two oxygen therapies was warranted and in particular the experiences of those who had first hand knowledge of both therapies, that is, the mothers and the nurses. Investigating the lived experiences of nurses caring for, and mothers of children admitted with severe bronchiolitis who were treated with both forms of oxygen therapy will add to the body of literature, which informs clinical decision-making about the use of oxygen therapy and how we treat hospitalised children and their families.

Bronchiolitis

Bronchiolitis is usually caused by a viral infection, the most common of which is the respiratory syncytial virus (RSV) which gives rise to widespread small airway oedema, resulting in air trapping (Fitzgerald & Kilham, 2004). The illness affects

infants and young children under the age of two as their small airways are more easily blocked. The peak occurrence is at three to six months of age. It is more common in males, children who have not been breastfed, and children who live in crowded conditions (McNamara & Smyth, 2002). Other viruses associated with bronchiolitis include influenza and adenovirus. Since the identification of RSV infections in the late 1950s, it has been recognised as an annual phenomenon commencing in the autumn months, peaking in winter and ending with the coming of spring (Roche, Lambert & Spencer, 2003).

The World Health Organisation (WHO) recognises bronchiolitis as the number one cause of hospital admissions in children under the age of two in both developed and less developed countries (Louden, 2006). In the United States of America in 1991, disease caused by RSV was estimated to be responsible for the hospitalisation of 100,000 children at a cost of \$300 million (Hall, 2001). Louden states that the disease frequency within other developed countries is similar to that of the United States. Furthermore, the mortality rate is 1-2% of all hospitalised patients and most deaths occur in infants less than six months of age.

Bronchiolitis in infants less than one year of age accounted for 56 per cent of all paediatric admissions to Australian hospitals in the year 2000 (Roche, Lambert & Spencer, 2003). Despite the high hospital admission statistics, few publications about the incidence or the impact of this virus in Australia are to be found. Australian papers, since early 1960 onwards, have confirmed RSV as the major pathogen causing bronchiolitis in infants and the seasonal nature of the annual RSV epidemics but not the factors that impact on child or parent wellbeing (McIntosh, De Silva, & Oates, 1993; Murphy, Phelan, Jack, & Uren, 1980). Roche et al (2003) suggest that more targeted research studies on the psychosocial aspects of bronchiolitis and refined means of gathering data are required in Australia.

Disease process for bronchiolitis

Typically, the first symptoms of bronchiolitis are similar to those of the common cold, such as runny nose, cough, and fever. Over the next day or two, the coughing worsens and wheezing sounds may be heard. Sometimes the infant finds it difficult to breathe and may not feed or sleep well. As the infant's breathing worsens their skin may

become bluish in colour (cyanotic) and they may be too exhausted to feed. It is at this point that infants usually present to hospital as an emergency admission. Immediate treatment is in the form of oxygen therapy and fluid support, which may be required for up to five days. In summary, bronchiolitis presents typically as a seven to ten day illness with the peak hospital admissions occurring from day two or three onwards (Sigurs, Bjarnason & Sigurbergsson, 2000).

Treatment of bronchiolitis

Respiratory syncytial virus bronchiolitis is usually a self limiting condition, which often requires no treatment. When treatment is necessary in infants, it is largely supportive and may include administration of supplemental oxygen, mechanical ventilation and fluid replacement. Bronchodilators are often used, however their use has been questioned for over 20 years and further research is needed to provide evidence for their efficacy (Steiner, 2004).

In the management of mild to severe viral bronchiolitis in infants, the single most useful therapy is supplemental oxygen with fluid support (Steiner, 2004; Van Rostenberghe, Kew, & Hanifah, 2006; Wohl & Chernick, 2003; Zwerdling, O'Sullivan, Wainwright, Francis & Wohl, 2003) as the infant is usually too unwell to feed and they are often oxygen deprived due to the increased build up of secretions in their lungs and airways.

Careful observation of airway patency is necessary to facilitate timely introduction of ventilatory support in the few infants who will need it. Ventilatory support may be provided using a mask with continuous positive airway pressure (CPAP), nasopharyngeal CPAP, or mechanical ventilation (Fitzgerald & Kilham, 2004; Fox, 2005). When bronchiolitis is less severe, oxygen is usually delivered via a headbox. This therapy, which is offered by all paediatric hospitals in Australia (Roche, et al., 2003), provides humidified oxygen at different concentrations but limits the child's freedom of movement. A new method of oxygen therapy, currently in use to treat acute respiratory distress/failure in infants, in one large tertiary paediatric hospital in Australia, utilises the delivery of humidified oxygen via a nasal prong system. Using a humidifier, the nasal prong system can deliver oxygen, or a blend of air/oxygen, via a

tubed circuit which consists of an inspiratory heated limb and ordinary shortened nasal prongs attached to a water filled dome and oxygen/gas inlet.

The use of the high flow humidified nasal prong oxygen therapy was initially viewed as potentially dangerous by a senior respiratory paediatrician who voiced concerns about the ability to humidify nasal prongs effectively and the risk of the high gas flow causing nasal trauma or barotrauma to the lungs from over extension. These concerns were investigated in a pilot study (Peeler & Schibler, 2006). Ten participants were recruited from an intensive care cohort of respiratory distressed children. The infants received high flow oxygen via nasal prongs in increments of one litre every fifteen minutes, commencing at two litres per minute oxygen flow up to six litres a minute. A silastic fluid filled feeding tube previously insitu in these patients was pulled back into the oesophagus and attached to a transducer. This fluid filled tube was able to detect changes in thoracic pressures indicating variations in work of breathing. The study was limited by the small number of participants. The interim results suggested that nasal prong therapy provided safe levels of continuous positive airway pressures and decreased the work of breathing. Furthermore, in this study, nasal erosion did not occur and the airways were clearer which in turn reduces the need to suction the nares as frequently as would be required to do with traditional headbox therapy. Humidification is readily achieved by a heated circuit attached to the prongs and there were no occurrences of barotrauma. This pilot study led to a larger study currently under way that is investigating similar parameters in a greater cohort to conclusively define results (Schibler, 2010).

Statement of the problem

There are several perceived advantages of using nasal prong therapy over the traditional headbox. The most important of these is access to the child. When a child is nursed in a headbox their movement is restricted and it is difficult for parents to maintain physical contact with their child in a normal way. For example, cuddling is not possible. Furthermore, because it would necessitate removal from the headbox (resulting in a loss of oxygen to the child) it is not possible for the mother to continue breastfeeding. Although breastmilk can be delivered via a nasogastric tube the important mother-child bonding experience is sacrificed. Again, because of the

potential risk of disturbing oxygen levels, nurses actively discourage parents from attending to their child's emotional and physical needs by restricting their contact with their child. This potential risk limits their ability to participate in their child's care and causes distress to the parents. The inability to participate in caring for their child is likely to affect the quality of the parent-child relationship. When less restrictive therapies, such as nasal prongs are used, it is easier for both parents and nurses to access the child, which may impact on the quality of the parent-child relationship and nurse-patient interactions, as well as allowing the nurses to make more accurate assessments of the infant's physical status and enhance their ability to support parents in a family centred care environment.

Purpose of the study

An extensive search of the literature revealed no research that has investigated the experiences of infants, parents and nurses when a child is treated with oxygen therapy. In addition to the contemporary development of a new oxygen therapy, this gap in the literature provided the impetus for this research study. The purpose of this study was to provide a rich description of the lived experiences of parents and nurses when a child is admitted to hospital with bronchiolitis that required oxygen therapy. The phenomenon of interest is the lived experience of parents and nurses when a child is admitted to hospital with severe bronchiolitis requiring oxygen therapy; headbox oxygen therapy and high flow nasal prong therapy.

Overview of the thesis

Preface

This thesis presents a research study that investigated the experiences of mothers and nurses when an infant was admitted to hospital with severe bronchiolitis requiring oxygen therapy. Their experiences were explored using Husserlian descriptive phenomenology, in which the researcher is required to adopt an objective approach in order to ensure that the 'essential nature' of the phenomenon is described (Paley, 2005). This requires the use of bracketing (see methodology chapter), a process of reflective self-examination by the researcher, through which their biases are revealed so that they may be set aside in order that the researcher's views are not imposed upon

the essential structure of the phenomenon of interest. This requires a conscious endeavour throughout the research process.

Interpretive phenomenology philosophers challenged Husserl's objective stance, proposing that all experiences that are perceived through the senses are subjective and therefore interpretive. Thus, interpretive researchers have challenged the use of bracketing, claiming that it is impossible to achieve because it is not possible for human beings to distance themselves from what they are researching. This reveals a tension involving the descriptive phenomenologist's goal of objective inquiry within an essentially subjective research methodology.

For the researcher, this presents a challenge of how to write about descriptive phenomenology, and whether the first or third person should be used. For the purpose of this research study, in order to maintain congruence with Husserlian philosophy, the third person is used consistently throughout the thesis, but with some exceptions that relate to personal disclosure and experiences of the student researcher. These exceptions are found in chapter three, where the researcher declares her position in relation to the phenomenon of interest, at various points where the student researcher refers to her personal journal, and at various points when her personal experience of conducting the research is described.

Thesis overview

The thesis is presented in six chapters beginning with a background and overview surrounding the study and its significance to paediatric nursing. Chapter two consists of an extensive literature review that examines existing evidence and information regarding oxygen therapy for children with severe bronchiolitis. The literature revealed large gaps in knowledge about paediatric oxygen therapies. The review includes an overview of the literature surrounding the psychosocial aspects of caring for a child with severe bronchiolitis and how admission to hospital affects the parenting role.

Chapter three provides an extensive description and critique of the study design, methodology, and methods used, and details the approach to data analysis.

In chapter four, the findings are presented. This chapter is structured according to the three domains that emerged from the data analysis. It is followed by chapter five, in

which the findings are discussed, along with their implications, the limitations of the study, and recommendations for further research.

Chapter six presents the conclusion to this thesis.

CHAPTER TWO

LITERATURE REVIEW

INTRODUCTION

The lived experience of parents and nurses when a child is admitted to hospital with severe bronchiolitis requiring oxygen therapy is the phenomenon of interest for this research study. This phenomenon was selected for three reasons. First, bronchiolitis is a major cause of hospitalisation of children aged less than two years. Second, there have been recent advances in the development of oxygen delivery systems for children, which impact on the parent-child relationship and thirdly, to explore how oxygen therapy for severe bronchiolitis in infants affects family centred care.

The purpose of this literature review is i) to describe the context in which the study was situated: bronchiolitis as a cause of hospitalisation of infants, and its treatment with oxygen, and ii) to examine the effect on the parent-child relationship when a child is hospitalised, iii) to explore the nurse-family relationship. Initially, the cause and incidence of bronchiolitis, and its treatment with oxygen therapy is described. This is followed by a review of the theories relating to the parent-child relationship and examination of the effects on this relationship when a child is hospitalised.

BRONCHIOLITIS

Bronchiolitis is usually due to a viral infection, of which the most common causative agent is RSV. Since the early 1960s, Australian studies have confirmed RSV as the major pathogen causing bronchiolitis in infants and the seasonal nature of the annual RSV epidemics (McIntosh, et al., 1993; Murphy, et al., 1980). It is as an annual phenomenon commencing in the autumn months, peaking in winter and ending with the coming of spring (Roche, et al., 2003). Other viruses associated with bronchiolitis include influenza and adenovirus. Infection gives rise to widespread small airway oedema, resulting in air trapping and reduced oxygen transfer (Fitzgerald & Kilham, 2004).

The infection predominantly affects infants and young children under the age of two as their small airways can become easily blocked. Bronchiolitis in infants less than 1 year of age accounted for 56 % of all admissions to Australian hospitals in the year 2000 (Roche et al., 2003). The Australian Institute of Health and Welfare (2008) state that bronchiolitis is still the cause for the majority of hospital admissions for children

under the age of two. The peak incidence is at three to six months of age. It is more common in males, children who have not been breastfed, and children who live in crowded conditions (McNamara & Smyth, 2004). Despite the high hospital admission statistics, few publications about the incidence or the impact of this virus in Australia are to be found. Roche et al, (2003) suggest more targeted research studies into bronchiolitis, incidence and causes are necessary as well as a refined means of gathering data in Australia.

In order to understand the treatment of bronchiolitis it is important to understand the disease process and the physiology of oxygen transfer and delivery. Oxygen is transported from inspired air via the lungs and the bloodstream to the body's cells. In general, gases move from an area of high concentration (pressure) to areas of low concentration (pressure) (West, 1990). In a healthy infant's lung the airways branch off from the main bronchus to bronchioles then finally onto small grape like sacs called alveoli. The blood vessels (capillaries) run along side these alveoli and exchange gases in a two way action that results in the blood stream being oxygenated and the lungs expelling carbon dioxide. Oxygen diffuses (moves through the membrane separating the air and the blood) from the high pressure in the alveoli (100 mmHg) to the area of lower pressure of the blood in the pulmonary capillaries (40 mmHg). After oxygenation, blood moves into the pulmonary veins which return to the left side of the heart to be pumped to the systemic tissues. In a 'perfect lung' the partial pressure of oxygen in pulmonary blood would be equal to the partial pressure of oxygen in the alveolus (Elliot, Aitken & Chaboyer, 2007)

In the disease process of RSV, or any lung disease, this balance is disturbed resulting in less oxygen being transferred into the pulmonary circulation. Some alveoli are relatively over ventilated while others are relatively over perfused. This phenomenon is known as a volume/quotient (V/Q) mismatch. The most extreme form of this is called a shunt, where blood flows past alveoli with no gas exchange taking place. Shunt occurs when deoxygenated venous blood from the body passes unventilated alveoli to enter the pulmonary veins and the systemic arterial system with an unchanged partial pressure of oxygen. Atelectasis (collapsed alveoli), consolidation of the lung, pulmonary oedema or small airway closure will cause shunt, which leads to the individual becoming hypoxaemic and retaining carbon dioxide. The brain compensates by stimulating the lungs to breath rapidly in order to exhale excess

carbon dioxide and inhale as much oxygen as possible. Due predominantly to their immature respiratory muscles, infants are unable to compensate for long and require respiratory support in the form of oxygen therapy and/or artificial ventilation depending on the severity of the disease process. Atelectasis and small airway closure require not only oxygen therapy but also positive end expiratory pressure (PEEP), which assists in opening and maintaining airways as well as re-expanding collapsed alveoli.

Treatment of bronchiolitis

Respiratory syncytial virus bronchiolitis is usually a self limiting condition, and often requires no treatment. The treatment of RSV in infants is largely supportive and may include administration of supplemental oxygen, mechanical ventilation and fluid replacement (Steiner, 2004). In the management of mild to severe viral bronchiolitis in infants, the single most useful therapy is supplemental oxygen with fluid support (Steiner, 2004; Van Rostenberghe, et al., 2006; Wohl & Chernick, 2003; Zwerdling, et al., 2003). Careful observation is necessary for high risk and unwell infants to facilitate timely introduction of ventilatory support in the few infants who will need it. Ventilatory support can refer to continuous positive airway pressure (CPAP) delivered via mask, nasopharyngeal CPAP and endotracheal ventilation (Fitzgerald & Kilham, 2004).

Following its discovery by Priestly, oxygen was first used as a therapy for respiratory failure in the 1700s but it was not until the early part of the 20th century that scientists were able to use oxygen in a way that was measurable and effective. For the first century and a half, oxygen therapy was characterised by methods that could not have resulted in much physiological benefit. Therapeutic use of oxygen was sporadic, erratic, controversial, comical, beset by quackery, and only occasionally helpful. Impurities in oxygen, its use on an intermittent basis, and lack of physiological measurement were principle problems (Martin, 2005). Not until the pioneering work of Haldane, Stadie, Barcroft and others, early in the 20th century, was oxygen therapy delivered in a rational, scientific way (Lawrence, 2009). Although the life-supporting role of oxygen was understood early on, it took about 150 years for the gas to be used

as a treatment for unwell patients. There are a number of different methods that can be used to deliver oxygen non-invasively. These are described in the following section.

Oxygen tents

Barach was the first to administer oxygen via a tent in 1922 (Lawrence, 2009). Tents were used for patients with respiratory distress or disease and were once used extensively to treat oxygen deficiencies in infants and children. The care of the patient requiring oxygen tent therapy presented a complex procedure necessitating intensive nursing care and skills. Assembling an oxygen tent required 20-30 minutes. Some hospitals employed technicians to do this in the day but during evening and night hours it became the responsibility of the nurse. Someone nursed in an oxygen tent required extensive monitoring both of the mechanics of the tent as well as the patient's condition. The patient had to be kept dry and oxygen levels and humidity needed monitoring and maintenance. All day-to-day care was clustered into short periods of time to reduce oxygen levels dropping from escaped gases and day-to-day care was performed mainly through a small porthole. Oxygen tents are seldom used today as they are time consuming to assemble and very uncomfortable for the patient as they are hot and claustrophobic (see Figures 1 & 2).



Figure 1. Oxygen tent *circa* 1960



Figure 2. Oxygen tent *circa* 1970

Nasal cannulae

Nasal cannulae, that could deliver oxygen directly to the patient via the airways, were developed in 1949. Invented by Jones and patented by the British Oxygen Company (Lawrence, 2009) (see Figure 3) the cannulae were used to deliver supplemental oxygen to a patient in need of extra oxygen. The device consists of a plastic tube which fits behind the ears, and a set of two prongs which are placed in the nostrils, through which oxygen flows. The cannulae are connected to an oxygen tank, a portable oxygen generator, or a wall connection in a hospital via a flow meter, and can deliver 1–6 litres of oxygen per minute. There are also smaller infant or neonatal nasal cannulae which carry less than one litre per minute. The oxygen fraction provided to the patient is between 24% to 35% (Bukwirwa and Law, 1999).

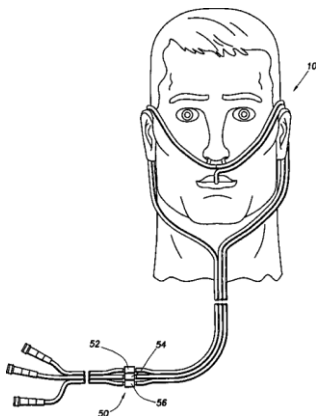


Figure 3. Nasal cannulae

Headbox

Nasal cannulae were mainly used on adults in the early days of oxygen therapy and babies and young children were nursed in oxygen tents up until the 1990s when more advanced headboxes were designed from perspex. The headbox can be small and fits over an infant's head. It can be larger and either fit over the entire body or just the head and torso allowing freedom of movement and accessibility for day-to-day care of the infant. For reasons of clarity in this thesis, all sized boxes will be referred to as headboxes (see Figure 4). The headbox was, and still is a popular choice for treating children who require oxygen therapy as it can be set up quickly and effectively within minutes. The child can be viewed easily and monitoring of the sick infant is feasible, no tape required to hold nasal prongs in place, however accessibility to the infant is difficult. (see Figure 4).



Figure 4 Perspex headbox

High flow nasal prongs

(prongs and cannulae are used throughout thesis interchangeably)

The high flow nasal prong system is assembled using standard nasal prongs which are attached to tubing and humidifier. The gas can be delivered to the sick infant warmed and humidified as well as at a specific concentration. The assembly time is minimal and the patient's comfort is increased (see figures 5 and 6).

The existence of inadvertent positive end expiratory pressure (PEEP) has been recognised in the humidified high flow oxygen delivery system (Peeler & Schibler, 2006). This new therapy uses a humidifier and circuit attached to nasal prongs that

can deliver humidified high flow gases to the infant. It is marketed as an oxygen delivery system (Fisher & Paykel, 2004) using a flow of around 2 litres per minute. However, when it is used at higher flow rates then the system must be observed in a closely monitored setting, such as an intensive care unit or high dependency unit, as there is some evidence to suggest that this will produce a CPAP in the infant (Peeler & Schibler, 2006). Anecdotally, this form of oxygen therapy has been used very successfully with positive physical outcomes for the infant and positive emotional benefits for the parent/guardian.



Figure 5. Baby with nasal prongs



Figure 6. High flow nasal prong circuit

There are several investigations using the high flow oxygen therapy in adults (Groves & Tobin, 2007; O'Shaughnessy, Brown, Gaylard & Thomas, 2008; Parke, McGuinness & Eccleston, 2009; Tiruvoipati, Lewis, Haji & Botha, 2010; Wettstein, Shellady & Peters, 2005). These studies took place in an adult intensive care setting and investigated the effectiveness of high flow nasal prong oxygen therapy in recently post extubated patients or post-operative cardiac adult patients. All studies investigated the physical effects of this therapy with only one describing patient comfort.

The high flow nasal prong therapy has also been investigated in the neonatal population in the last few years (Holleman-Duray, Kaupie & Weiss, 2007; Miller & Dowd, 2010; Ramanathan, 2010; Shoemaker, Pierce, Yoder & DiGeronimo, 2007; Woodhead, Lambert, Clark & Christensen, 2006). Woodhead et al. performed a comparison study of thirty neonates post extubation using high flow nasal prong oxygen therapy (HFNPOT) and another oxygen delivery system. Their study was inconclusive stating that both therapies were as effective as each other though further

studies were required. Another retrospective observational study compared frequency use as well as efficacy and safety (Shoemaker et al., 2007). Neonates were placed on HFNPOT or CPAP and were observed. Researchers concluded by suggesting HFNPOT was as effective as CPAP (Shoemaker et al.). This study did not have enough participants in the study to produce conclusive evidence and further research was suggested. Another comparative study investigated thirty neonates post early extubation. These researchers looked at two types of oxygen delivery systems and concluded that HFNPOT was as effective as other types of CPAP devices being used in neonatal intensive care areas (Holleman-Duray, Kaupie & Weiss, 2007). Again in 2010, Miller & Dowd (2010) did a comparative study of two modalities of oxygen delivery systems, one being the HFNOPT in neonates, investigating extubation success in the premature infant. This study looked at forty premature infants and compared the HFNPOT with another oxygen delivery system and concluded that there was no statistically significant difference between the two.

Paediatric investigations have been slow to emerge but there have been a few studies that have looked at the mechanical effectiveness of the therapy. Kubicka, Limauro and Darnall (2008) performed an observational study investigating the PEEP generated in thirty paediatric patients when using the HFNPOT and suggested that randomised controlled trials should be performed on a larger population. McKiernan, Chua, Visintainer and Allen (2010) did a retrospective chart review of infants with bronchiolitis admitted before and in the season after introduction of HFNPOT. Their objective was to determine whether the introduction of HFNPOT therapy was associated with decreased rates of intubation for infants <24 months old with bronchiolitis admitted to a paediatric intensive care unit (PICU). They hypothesised and found that HFNPOT decreases rates of intubation in infants with bronchiolitis by decreasing the respiratory rate and work of breathing by providing a comfortable and well-tolerated means of noninvasive ventilatory support.

Effectiveness of oxygen delivery methods

There is a dearth of literature on what type of oxygen therapy is best when treating infants. Frey and Shann (2002) reviewed the main methods of oxygen administration to infants. These included headbox oxygen, face mask oxygen, oxygen source near infant's face, nasal prongs, nasal catheter and nasopharyngeal catheter. The aim of their review was to describe the benefits of each oxygen administration method. They

concluded that there was not enough data on the use of headbox, facemask or oxygen source near infants face and concentrated on oxygen delivery by nasal cannulae, nasal catheter and nasopharyngeal catheter. The studies were performed in infants weaned from ventilation for respiratory distress syndrome and heart surgery, and in infants requiring supplemental oxygen flow for apnoea of prematurity, bronchopulmonary dysplasia, and pneumonia. Frey and Shann (2002) concluded that nasal cannulae and catheters were the least expensive form of oxygen therapy (derived by the fact that less oxygen flow is needed) and that they produced an inadvertent PEEP which may or may not impact on lung function. No conclusion was made as to what was the most effective form of oxygen therapy.

The American College of Critical Care Medicine released their updated guidelines for Paediatric Advanced Life Support Program for the treatment of septic shock stating that it is now recommended that high-flow heated and humidified oxygen be provided by nasal cannulae to support respiratory distress until more definitive therapy is available. This reference to high flow nasal prong therapy is unsupported by any literature or studies referenced by their guidelines due mainly to a lack of empirical studies in this field.

THE PARENT-CHILD RELATIONSHIP

Attachment Theory

Attachment theory is based on the work of John Bowlby (1973; 1979; 1982) who argued that the mother-infant relationship was fundamental to emotional stability in the child. Ainsworth and her associates (1978; 1985) developed a widely used system of classifying attachment behaviour into three groups: avoidant/insecurely attached (group A), securely attached (group B), and ambivalent/insecurely attached (group C). Although the names of Bowlby and Ainsworth are often considered synonymous with attachment theory, other psychoanalytic scholars have also contributed significantly to an understanding of attachment with the common belief that attachment is fundamental to emotional health and social relationships (Punthmatharith, 2002).

Goulet, Bell, St-Cyr, Paul, and Lang (1998) identified three attributes as central to attachment: proximity, reciprocity and maternal commitment. The mother is required to participate in her infant's care and engage with her child to promote reciprocity of mother and infant which in turn leads to attachment and bonding (Saunders & Buckner, 2006).

Through attachment and bonding emerges engagement. Engagement requires the mother to participate in the child's care immediately from birth. Experiencing the child requires the proximity of the mother and active participation in the child's life. Maternal commitment is central to both attachment and engagement and is therefore important in the bonding process (Sanders, Markie Dadds, & Turner, 2003).

Separation anxiety

Steinhauer (2004) reviewed the effects on infants of separation from their mothers and found that children were most susceptible to negative repercussions if separation occurred between the ages of six months and four years; the longer the separation the greater the negative impact. Separation anxiety was more obvious in children who were more securely attached previously (Steinhauer). Separation anxiety is described as an excessive increase in anxiety in an individual, due to being removed from

someone with whom they have a strong emotional bond, for example, a mother or father (Siegler, 2006).

Van der Molen, van de Hout, van Dieren, and Griez (2002) explored the hypothesis that childhood separation anxiety was linked with adult-onset panic disorders. The study aimed to examine the association between separation anxiety disorder and mental disorders in a community sample and to evaluate whether separation anxiety is specifically related to panic disorder with and without agoraphobia. The data is derived from a four year, prospective longitudinal study of a representative cohort of adolescents and young adults aged 14-24 years at baseline in Munich, Germany. Researchers concluded that there was a strong association and that separation anxiety disorder played a major role in the later onset of panic disorders in adults.

Parent-infant bonding

Seventy years ago, infectious diseases accounted for the majority of paediatric hospitalisations, and children's hospital stays were lengthy. Parents were allowed very limited contact with their hospitalised children (Douglas, 1975; Knudson & Natterson, 1960; Quinton & Rutter, 1976). Psychology became more widely practiced following its use in the military in World War II. Mental health was a new area of inquiry. Ideas about child rearing were moving away from the Watsonian model (Don't pick up the child; you'll spoil him) (Watson & Watson, 1928) to an American revision of psychoanalytically based ideas popularised by the paediatrician, Benjamin Spock, through his new and widely-read first edition of *Baby and Child Care* in which he proposed the view that children need love and parents should trust their instincts (Spock, 1946). At this time, paediatric psychology did not exist, but the groundwork was being laid by a group of child analysts at the Tavistock Clinic in London. Spearheaded by John Bowlby, and bolstered by the work of Rene Spitz (Spitz, 1945; Spitz & Wolf, 1946).

Children separated from their parents and taken to safety in the English countryside were unexpectedly found to show more adverse psychological reactions than children who remained in London with their parents during the wartime blitz. This work is published in Bowlby's monograph, *Maternal Care and Mental Health*, by the World Health Organization in 1951. Despite Bowlby's acknowledgement of the importance

of fathers and siblings, the major thrust of the work emphasised the central role of mother-love and maternal contact for psychologically healthy development. James and Joyce Robertson extended this work to look at the effects of the separation of hospitalisation on children (1953). Again, it was the separation from the child's mother that was emphasised as psychologically damaging.

In the 1970s, a number of developments occurred that were to have a major influence in psychology. First, the rise of feminism led women to question whether maternal work outside the home was really damaging to children's mental health, as they had been led to believe, thus stimulating research on the effects of maternal employment and alternative care on children's development (Hoffman, 1979). Additionally, the work of Thomas and colleagues on children's temperament changed ideas relating to the mother-child interaction equation (Thomas & Chess, 1977; Thomas, Chess, & Birch, 1968) and a new body of research by Lamb (1976) began to define the role of the father and included him in child development.

Over the past 20 years the evidence supporting a contextualised model for understanding human development and behaviour has continued to build, from Rutter's (1972) work revisiting the notion of maternal deprivation - such as the work of Reed Larson (Larson & Richards, 1994). They find, for example, that fathers' negative mood at work predicts negative mood in mothers and adolescents a few hours later, in the evening, but that mothers do not pass emotions from work to home. In the field of psychology, we are increasingly seeing research reflecting a family perspective (Kazak, 1989; 1997; Kazak, et al., 1997; Kazak, Blackall, Himelstein, Brophy, & Daller, 1995; Kazak, Segal-Andrews, & Johnson, 1995, Alexandra Quittner (e.g., Quittner & DiGirolamo, 1998; Quittner, Espelage, Opiari, Carter, Eid, & Eigen, 1998; Quittner, Glueckauf, & Jackson, 1990; Quittner & Opiari, 1994). Understanding the bonding concept is necessary for nurses and other related health care personnel, as effective parent-infant bonding will improve the quality of infants' lives (Punthmatharith, 2002).

Kangaroo Care

In the healthcare context, 'kangaroo care' (KC) has been a nursing method of promoting parent-infant bonding in neonatal wards for preterm infants since the late eighties in Australia. The practice began in under-developed countries where

incubators were scarce to come by and the mothers were given their infants to hold naked against their chest (skin to skin) so that the mother then acts like a human incubator. Much research has been done on the benefits of such a method (Ludington-Hoe, 2003) and the results suggest the babies not only survive but thrive (Richardson, 1997). Ferber and Makhoul (2004) studied premature infant brainwaves, while experiencing KC, that showed increased alpha waves and delta brushes indicating increased “bliss” and increased synapse construction which is necessary for development. Ferber and Makhoul concluded that Kangaroo care was beneficial for human growth.

Gray, Watt and Blass (2000) explored the benefits of KC and found that kangarooed infants increased in weight and had as much as 50% decrease in length of hospital stay. Again in 2007, Feldman (2007) compared kangaroo care and traditional care and found that the benefits were numerous. Walters, Weinfield and Hamilton (2000) explored KC for full term infants at birth. This was a pilot study to see how full term infants responded with KC. Their results showed an increase in temperature, increased stability of blood glucose and an increased ability to latch onto the breast.

Kangaroo Care has been found to increase mother/infant bonding. Originally KC was introduced to the preterm population but benefits to the term baby such as increased breastfeeding, increased parent-infant bonding and attachment have been identified (Moore & Anderson, 2007).

Hospitalisation of the child

The practice today in hospitals has changed significantly from only allowing parents to visit for two hours a day to that of a parent who does not stay with their child, are thought neglectful (Seagull, 2000). The introduction of unrestricted visiting hours has led to the encouragement of parents to stay and participate in the care of their hospitalised child. Research from two studies (Taylor, 2004; Pratt, 1998) found that if parents stayed with their child in hospital, it significantly shortened the length of stay of the child.

The hospitalised child does not only suffer from their illness but also from the separation from parents, siblings and their familiar environment. Lam, Chang and Morrissey (2006) explored the experiences of parent’s participation in their

hospitalised child's care and found that most parents viewed accompanying their hospitalised child as an unconditional aspect of being a parent and had a strong desire for participation.

Attachment theory, first introduced by Bowlby in 1973, suggested the emotional wellbeing of the child depended on the presence of his or her mother. This new theory, along with parent-infant bonding studies, helped pave the way for parents, especially mothers to spend unlimited time with their hospitalised child.

Parent–infant bonding has been explored in great depth when it comes to the newborn period (Douglas, 1975; Knudson & Natterson, 1960; Punthmatharith, 2002 Quinton & Rutter, 1976; Rutter, 1972; Thomas & Chess, 1977; Thomas, Chess, & Birch, 1968) yet little studies have explored the parent-infant bonding paradigm in the slightly older baby or toddler when he or she has been hospitalised and the relationship with the mother has been disturbed

The emotional well being of hospitalised children has been the focus of reports as early as 1920 when Sir James Spence, who set up the first mother and baby unit in Newcastle upon Tyne in the UK (Court 1975). Control of anxiety, or any heightened emotion, is a self-regulatory function and depends for healthy development on the infant's experience of being calmed and soothed over time by a nurturing mother or attachment figure (Ainsworth et al 1978).

Anxiety or stress is a major concern for all parents who have a child admitted to hospital for treatment of an acute medical disease or surgical procedure (Hatcher & Westin, 1989). Hall (2005) interviewed thirteen parents in a Danish paediatric hospital and questioned them about their experiences during a newborn or small child's critical illness. The results revealed that the parents of critically ill infants described this experience as being in an alien world. They longed to find understanding of their child's illness and when this did not happen, the parents felt anxious and insecure. Hall concluded that there should be more parent and staff interaction and collaboration to help alleviate this stress. Anxiety, parent-infant bonding and family centred care will be discussed in the following paragraphs.

When children's stress levels rise, it has been recognised that they rely on their parents to help them manage this stress and anxiety (Slade 2005, Fonagy and Target 2005), or panic can set in. In later childhood, talking through the situation with a parent, is

thought to be more soothing than rocking or cuddling (Slade 2005, Fonagy and Target 2005). The parent listens to the fear and accepts it, and together parent and child reality-test the situation and perhaps construct strategies to combat the anxiety. The parent is in hospital for this, not to relieve the nurses of physical or medical duties (Priddis & Shields, 2011). There is a large body of literature on the effectiveness of pre-operative preparation of the child and parent (Stone, 1997; Kain, Mayer, O'Connor & Cinchetti, 1996). The importance of written information as a component of that preparation has been identified by researchers: "all parents agree on useful ameliorative factors, general advice and education programme" (Thompson, Irwin, Gunawardene, & Chan, 1996, p.58).

The research into the area of child hospitalisation has produced excellent learning guides and preparation booklets that have assisted in reducing hospital anxiety for both the parent and the child (Thompson et al., 1996). Whelan and Kirby (1998) reaffirmed this in a study which interviewed parents of hospitalised children. Their results reported that if families were well prepared prior to admission then their levels of anxiety would decrease significantly. Another strategy to help with coping mechanisms for the parent of a child being admitted to hospital for surgery is the introduction of parents being allowed into the anaesthetic room while their child is being inducted (Shirley, Thompson, Kenward, & Johnston, 1998).

When a child is admitted to hospital for an acute medical episode such as bronchiolitis, the parent and child rarely have time to be prepared for this unexpected event. There are limited studies about parental stress or anxiety relating to medical admission to hospital of their infant or child for treatment of bronchiolitis (Fosson, Martin, & Haley 1990). The effects of hospitalisation have been explored by Shields, though not identifying bronchiolitis as a cause for admission.

Shields (2001) reviewed the literature on the effects of hospitalisation on children and families in both developing and developed countries. The literature review included all articles and studies relating to effects of hospitalisation on children and families dating from 1952 to 2000. Many of these were from the 1960s and 1970s. Shields concluded that both parent and child were emotionally traumatised by the admission. The child's developmental stage, separation anxiety and the ability for parents to be with the child were factors that affected the anxiety levels. The review stated that this anxiety could be alleviated if the parent could stay with their child, if the

communication is clear and effective with staff and information is given in a way that is easily understood (Shields).

Leidy, Schimer and Jones (2003) explored more specifically the impact of severe respiratory illness on the child, caregiver and family during hospitalisation and recovery. The study was a prospective one which looked at 46 infants under 30 months of age who had been hospitalised for acute bronchiolitis. Caregivers were asked to rate the severity of the child's health and functional status, caregiver's health, stress and anxiety, and family health and functioning. After analysing all their data they concluded that bronchiolitis hospital admissions created significant distress for infants, caregivers and families, with some effects extending as long as 60 days after discharge (Leidy et al.).

In some studies anxiety levels were found to be inversely proportional to social class and levels of education (Murphy et al., 1991). Anxiety levels for both parent and child is a concern for all health care providers. It is necessary to alleviate these anxieties by implementing strategies such as allowing parents to room in, to share the decisions to be made in their child's care and to give clear communication (Shields, 2001). Parents were also found to be keen to participate in their child's care but needed specific delineation of their roles. Parents who were given clear instructions and information, and were involved in decision making, were found to be less stressed than those who did not (Fox, 2005).

Family centred care

Since the 1960s, it has been recognised that parental involvement in the hospitalised child's care has been an effective way of relieving both parent and child anxieties (Brain & Inga, 1968; Julian, Ventola & Christ, 1969). A definition of family centred care is difficult to formulate mainly due to the lack of consensus about its meaning. In developed countries, family centred care is viewed as care which is parent-led in consultation with the nurse (Chenery, 2004).

The terms family centred care (FCC) and family centred services (FCS) are used interchangeably across the continuum of children's healthcare to encompass concepts of:

- i) parental participation in children's healthcare; partnership and collaboration between the healthcare team and parents in decision-making;
- ii) family-friendly environments that normalise as much as possible family functioning within the healthcare setting; and
- iii) care of family members as well as of children (Franck, 2004).

The role of families in caring for their sick children has evolved over the last century. Whereas previously they were banned from hospitals, families now play an integral part in the care of their children, whether in hospital or at home (Thomsen, 1999). Family centred care has been accepted as the ideal philosophy for holistic health care of children, but methods for its implementation are not well established. Exploration into family care has shown that:

“...in paediatric health crises, family care requires special sensitivity to family needs and a type of complex nursing care for which many practitioners are not sufficiently prepared. Developing family sensitive models of intervention and finding a strategy for transfer of this knowledge to clinical practice is an important challenge facing family nursing today.” (Tomlinson, Tomlinson, Peden-McAlpine, & Kirschbaum, 2002).

The advent of the internet changed information gathering dramatically by increasing health literacy. Parents have the power to become informed of their child's disease and treatment. With this knowledge they are able to make an informed decision about how their child should be cared for whilst in the care of the hospital. No longer are parents expected to visit their offspring at assigned times of day but are actively encouraged to stay and care for their child. The nurse's role has become more of a consultant in that they give information about the disease process and expected treatment or care to the child's parent. The nurse monitors the child and administers treatment but the families are able to do more than just feed or bath their child. Some parents are comfortable taking on the nurse's role of administering medication or taking their child's temperature. It is the responsibility of the nurse to supervise this treatment (Shields, Pratt, & Hunter, 2006).

The literature pertaining specifically to family centred care in Australia is limited but there are studies from international researchers that have explored family centred care issues. After reviewing British literature and studies, Coyne (1996) suggested that

family centred care was multi-dimensional and complex. Analysis showed that even though terminology changed for family centred care, the theme of parent participation did not and parent participation was defined as collaboration between the nurse and the parent.

The lack of nursing staff in our hospitals is a cause for greater parent participation in the care of the sick child. MacKean, Thurston, and Scott (2005) explored the concept of a paradigm shift where family centred care was becoming more like care management and family responsibility. The aim of their study was to develop a conceptualisation of family centred care grounded in the experiences of families and direct health care providers. They used focus groups and interviewed both parents and health care providers. They found that parents did not want the responsibility of managing the care of their child but wanted a true collaboration with health care providers that provided a dynamic care plan and treatment options that will work best for the child and families.

SUMMARY

Respiratory syncytial virus is a major cause of lower respiratory tract infection (bronchiolitis) in young children and is the number one cause of hospital admissions for children under the age of two in Australia (Roche et al., 2003). Oxygen therapy is the universal supportive treatment of hospitalised patients admitted with respiratory distress and can be delivered by nasal prongs, face mask, headbox or nasopharyngeal tube (McIntosh et al., 1993). Headbox oxygen therapy is the standard form of oxygen therapy offered by most paediatric hospitals to treat children with respiratory failure due to severe bronchiolitis (McNamara & Smyth, 2002). It provides humidified oxygen concentrations but limits the child's freedom of movement. More recently, a new method of oxygen therapy has been pioneered, which facilitates the delivery of humidified high flow oxygen via a nasal prong system (Fisher & Paykel, 2005). Severe bronchiolitis is usually treated within a paediatric intensive care unit (PICU) where more sophisticated forms of oxygen therapy, such as invasive or non invasive ventilation, may be provided safely. Parents of children admitted to a PICU for supportive treatment of bronchiolitis have stated that this is an extremely stressful time for them (Huckabay, 1999).

Parent participation in the child's care in hospitals has steadily increased since the 1960s where it was first described as a benefit to the wellbeing of the hospitalised child's care (Julian et al., 1969). The early studies recognised parent-child bonding as a factor in reducing parent and child anxiety levels and recommended that parents room in with their sick infant (Leifer, 1971). Family centred care has gradually become the most common way forward in paediatric hospitals worldwide as a way of allowing a collaboration between parents and health care workers to provide a holistic and managed approach to the hospitalised child's care (MacKean et al., 2005).

CONCLUSIONS

This review of the literature has outlined relevant key issues including significant gaps in research relating to oxygen therapy in the paediatric population and the associated psychosocial issues pertaining to them. No research was found that specifically explored parents' or nurses' experiences when looking after a child with bronchiolitis in hospital who has received both headbox oxygen therapy and high flow nasal prong therapy.

The review of literature in this thesis explored the traditional forms of oxygen therapy and the newer high flow nasal prong oxygen. The psychosocial aspects of having a child experience these therapies and the impact on the emotional status of the parents, children and nurses caring was also investigated. There is a dearth of literature describing parents' lived experiences of infants hospitalised with bronchiolitis and treated with oxygen therapy. However, there is a significant body of research which explores parent and child bonding, parental anxieties surrounding hospitalisation of a child and family centred care. Neonatal and premature infant information has been vastly explored and much interest and research has been developed with this population in mind. The review of the literature has identified a gap in knowledge which suggests a need for further research into infants and children that explores both psychosocial and clinical issues.

The following chapter will discuss the methodological approach taken in this research study and relevant ethical considerations.

CHAPTER THREE

METHODOLOGY

INTRODUCTION

The purpose of this research was to explore the lived experiences of parents and nurses who have had, or cared for, a child admitted to hospital with severe breathing difficulties caused by bronchiolitis, who required oxygen therapy. Focusing on this phenomenon, the lived experiences of the parents/guardians of the hospitalised children and those of the nurses who cared for the children were investigated.

This chapter places the study within the qualitative field of research; specifically descriptive phenomenology. It provides an overview of phenomenology, including its philosophical history and its development as a research methodology. Through this methodological exploration, a detailed explanation of why descriptive phenomenology was selected for this research study is given. Philosophical and theoretical justification is provided for the use of the methodology and methods chosen to investigate the participants' lived experiences.

This chapter also describes the sampling, data collection, and data analysis methods that were utilised. The chapter concludes with an explanation of ethical considerations and the steps that were implemented to ensure research rigour.

Research setting

The research setting for this study was a major paediatric teaching hospital in Brisbane, in which children with bronchiolitis requiring headbox oxygen therapy are admitted to the medical ward. Those children with severe bronchiolitis, who do not respond to headbox oxygen therapy are then given high flow nasal prong oxygen therapy. These children are either transferred to the high dependency area of the same medical ward or are admitted to paediatric intensive care unit (PICU) where the average stay lasts less than 48 hours.

Phenomenon of interest

The phenomenon of interest for this research study is the lived experience of parents and nurses when a child is admitted to hospital with severe bronchiolitis requiring oxygen therapy. Descriptive phenomenology, which is both a philosophy and a

research approach, was selected for this study. The following section provides justification for the chosen approach.

METHODOLOGICAL APPROACH

The decision trail when choosing a methodology is of utmost significance. The decision trail that is clearly laid bare will increase rigour and credibility of the study, allowing the reader transparency of the method, data analysis and findings. The first decision is to establish whether the research question or phenomenon of interest is quantitative or qualitative in nature.

Having come from a quantitative background as a research nurse co-ordinator in a PICU, I initially considered quantitative methodology for this study. However, on further exploration of my research topic it became apparent that the unanswered questions that emerged required a qualitative approach. My deliberations about both the focus of my research and the methodological approach that was required to investigate it received considerable attention on my part. For this reason, it is important for me to provide transparency about my decision trail (see section on research rigour pp. 51-54), which began with my exploration of quantitative versus qualitative approaches.

Quantative research is a scientific method that is a general set of orderly, disciplined procedures used to acquire information (Polit & Beck, 2006). It involves the progression through logical steps to find a solution to a problem. This systematic process is generally controlled to minimise biases and ensure validity is maximised (Polit & Beck). It is concerned with gathering empirical evidence, rooted in objective reality, not personal beliefs or experiences (Polit & Beck).

In contrast, qualitative research is a broad term that covers many different research traditions concerned with the study of human experiences in, and in relation to, the natural contexts within which they occur for the purpose of understanding a person's responses and the meanings they bring to the experience (Power & Knapp, 2004). The findings from qualitative research are typically grounded in the real life experiences of people with first hand knowledge of a phenomenon. Lincoln and Denzin (2005) describe qualitative research as a "humanistic commitment to study the world always

from the perspective of the gendered, historically situated, interacting individual” (p. 164).

Qualitative methodology was chosen over a quantitative design as the former has the ability to assist in understanding a phenomenon that has a subjective meaning. Since the phenomenon of interest in this study was subjective in nature, a qualitative approach was most relevant. Qualitative research uses exploratory, descriptive methods to enable the researcher to gain knowledge and understanding about the phenomenon under scrutiny where little is known about the topic (Grbich, 2005). As the phenomenon of interest has not been investigated previously using qualitative methods, this provides further justification for the methodological selection of a qualitative approach.

The aim of this study was to explore the phenomenon of interest through the experiences of parents and nurses who have had or cared for a child admitted to hospital with severe bronchiolitis requiring oxygen therapy. Thus, phenomenology, which explores the ‘lived experience’ of a phenomenon was most relevant to the research study aim. Phenomenological studies result in rich, in-depth information that has the potential to clarify the multiple dimensions of a complicated phenomenon (Polit & Beck, 2006).

Phenomenology

Phenomenology was first offered by Edmund Husserl (1859-1938), a German philosopher, as a response to the critique of positivist science and its incapability of dealing with human experiences. He described the task of phenomenology as returning to and re-examining what people believe they already know and understand, by reflectively bringing into awareness that which has been taken for granted (Power & Knapp, 2004). There have been other philosophers who have inspired different styles and approaches to the study of phenomenology, for example Heidegger’s hermeneutics, and Merleau-Ponty’s existentialism (Grbich, 2005). These philosophical theories spread from Europe and influenced others throughout the world including Giorgi, Colaizzi, and Schutz (Grbich). A phenomenological perspective as a philosophical and theoretical framework was selected to inform this study.

Husserl is generally acknowledged to be the founder of phenomenology. His legacy to the world was his philosophical ideas which gave rise to the descriptive phenomenological approach to enquiry which he described as transcendental phenomenology. Husserl's philosophical ideas informed my study and influenced my methodological approach. Husserl believed in phenomenological reduction; that reflection on existing beliefs served to allow obtaining untainted phenomena that were otherwise unobtainable. Husserl suggests that in order to focus on the essences, one must first set aside one's own preconceptions or bias (Grbich, 2005). In order to obtain this focus, bracketing was used throughout this study. Based on Husserl's philosophy, bracketing (reduction) was introduced by researchers as a way of putting aside one's biases (Giorgi, 1985). However, it is important to note that interpretive phenomenology philosophers argue that bracketing is impossible, as they believe human nature is such that one would not distance oneself from the phenomenon of interest. Further elaboration of bracketing can be found later in this chapter.

From Husserl's philosophy emerged the epistemological elements of phenomenology: the notions of intentionality, transcendentality, and intersubjectivity. Each of these contributes to understanding human experience and determines the way research should be conducted (Drew, 2001). His phenomenological studies "uncovered and described the fundamental structure of our lifeworld" (Cohen & Omery, 1994, p.139). Husserl introduced the term 'lifeworld' implying that everyday experience is the primordial nature of consciousness. The lifeworld is where ordinary day-to-day tasks are conducted that are sometimes referred to as lived experiences (Drew). These notions influenced how data was collected, transcribed, described and analysed throughout this study.

Spielberg (1982) wrote that there are four constants through Husserl's philosophy. The first is *ideal rigorous science*, which Husserl believed (through phenomenology) would enable objective scientists to clarify and critique their fundamental concepts and assumptions. He felt that this would restore contact with the deeper concerns of people and science. The second constant is *philosophic radicalism*. Central to Husserl's belief was that human experience contains a meaningful structure. Philosophy consists of ontology and epistemology. Ontology is concerned with the nature of relations of being. Epistemology is the theory of the nature of knowledge, especially its validity. His epistemology involved the study of essential (a priori)

structures. His descriptive (eidetic) phenomenology sought universal essences, their structure and relations, based on descriptive reduction. Essence asks what makes a thing what it is, and without which it would no longer be what it is. The phenomenology of essences seeks insight into what is experienced. The third constant is the *ethos of radical autonomy* whereby a central focus of this constant was that people are responsible for themselves and their culture. *Respect for wonders*, the fourth constant, has its central focus on the being that is aware of its own being and of other beings (Spielberg).

There are many schools of phenomenology with distinct differences, but many commonalities as well (Dowling, 2005). Following Husserl's movement, emerged Heidegger's movement. Martin Heidegger (1819-1976) was also born in Germany. His hermeneutic phenomenology is also concerned with the "lived experience" but he disputed Husserl's view of the importance of description rather than understanding (Racher & Robinson, 2003). Heidegger's ontological view is that the lived experience is an interpretive process (Racher & Robinson). He believed that the primary phenomenon that concerned phenomenology was the meaning of Being (presence in the world) referring to the way in which we exist, act, or are involved in the world (Cohen & Omery, 1994).

The French phase of phenomenology followed the German phase. The key philosophers during this phase were Marcel, Sartre and Merleau-Ponty. During this time, Merleau-Ponty wanted to reveal that a science of human beings was possible and that through phenomenological approaches positivistic understanding was enhanced (Dinkel, 2005). Each of these philosophers further explored phenomenology as philosophy and this phase of the movement influenced psychology and psychiatry, as the phenomenological descriptions were used to aid in understanding patients' realities and experiences (Dinkel). Therefore, it is clear that throughout the past century European phenomenology (both as a philosophy and research method) has experienced strong influence by differing perspectives of significant individuals.

Based on a thorough reading of phenomenology, descriptive philosophy and methodology were selected as the most appropriate to inform this study. Husserl's focus on ontology, the study of nature, and the relation of being was in keeping with the purpose of my study. Husserl's approach involves the description of the experience, as perceived by the participant. He believed that human experience had

meaningful structure (Munhall & Oiler, 1986). His approach asserts that the interactions with phenomenon form the foundation for the construction of meaning and understanding in the human world (Dinkel, 2005).

Descriptive methodology based on philosophical inquiry has been criticised as being unsuitable for nursing enquiry (Paley, 2004). However, Dinkel (2005) concludes that phenomenology is both a philosophy and a method for qualitative enquiry and places nursing in the field of social sciences, citing phenomenology as a suitable way of exploring lived experiences for nurses. Giorgi (1985) states that if one is a nurse, then a nursing attitude should be adopted and if one is a psychologist, then a psychological attitude should be adopted, and so forth. He argues that this adopted attitude brings a sensitive discipline to the analysis and enables the data to be manageable. Therefore, as a nurse myself, I adopted a nursing attitude to this descriptive phenomenological inquiry.

Since descriptive phenomenology is suited to the exploration of phenomena that have not been described previously (Koch, 1995) it was appropriate for this study which investigated the lived experiences of parents and nurses who have had or cared for a child admitted to hospital for severe bronchiolitis requiring oxygen therapy. This is the first time that this phenomenon has been examined.

Aim

The aim of the research study was to describe the lived experiences of parents of children admitted to hospital with severe bronchiolitis and who received oxygen therapy and the lived experiences of the nurses who cared for these children.

DESIGN

The design for this research study is descriptive. Specifically, descriptive phenomenology methodology has been selected to describe the lived experiences of parents and nurses.

Phenomenology is regarded as both a method and a way of perceiving (Speziale & Carpenter, 2003). The descriptive phenomenological approach that was used was informed by Husserl's philosophy, as described above. Data collection and analysis

employed the seven steps described by Colaizzi (1978), which are described in detail below.

Bracketing

Husserl stated that in order to attain an accurate focus on essences one must first purge oneself of all inessential factual assumptions (LeVasseur, 2003). When this philosophical position is applied to phenomenological research, the researcher is required to identify all or any preconceptions and assumptions in respect of the phenomenon (Speziale & Carpenter, 1995). Bracketing is a way of keeping one's own views and biases separate from those of the participant (Grbich, 2005). In descriptive phenomenology the researcher is required to declare their position with regard to the phenomenon of interest and attempt throughout the research process to suspend any bias that might influence their perception of the phenomenon as an essential structure.

Bracketing is a specific technique proposed by descriptive phenomenologists to achieve this (Dowling, 2005). Gearing (2004) suggested that descriptive bracketing represents the refinement of the technique's earliest Husserlian conceptualization into a more pragmatic form. As such, descriptive bracketing was used in this study and involved the researcher setting aside preconceptions and personal knowledge when listening to and reflecting on the lived experiences of those being studied.

Unfortunately, there are few clear guidelines for carrying out bracketing. As such, bracketing is a continuous process that is used to facilitate the clear emergence of the phenomenon under investigation.

Parahoo (2006) suggests that bracketing is hard to achieve as it can be difficult for researchers to suspend their presuppositions totally, particularly if they are not aware they have them. The bracketing researcher must strive to acknowledge that being unaware has major implications for the rigour of the research and that every possibility should be made to bring these presuppositions to the fore, acknowledged and then bracketed (Hamill & Sinclair, 2010). Wall, Glenn, Mitchinson, and Poole (2004) have demonstrated how using a reflective journal can be an effective tool for developing bracketing skills.

Hamill and Sinclair (2010) argue that bracketing can be achieved and is essential in Husserlian phenomenological studies. They believe that bracketing should be

considered throughout the entire study not just at data collection or analysis phase. This will assist the researcher when aiming to produce data and descriptions that are considered to be 'absolute truths'. The essence of the phenomenon remains accurate in that it has not been adjusted, embellished or manipulated in any way (Hamill & Sinclair). Giorgi (1985) criticises the term 'absolute truth' and asks the question can there ever really be an 'absolute truth'? Hamill and Sinclair suggest that this 'absolute truth' refers to the participant's described experience as she or he perceived it. Bracketing aims to ensure that the emerging essences of the phenomena remain purely those obtained from the experiences of the participant, not sullied by the researcher. The following section provides an open and honest account of the student researcher's position in relation to the phenomenon of interest: the experiences of parents and nurses who have had, or cared for, a child admitted to hospital with severe bronchiolitis requiring oxygen therapy, in particular headbox oxygen therapy and high flow nasal prong therapy. By bringing to the surface the researcher's beliefs, he or she is in a better position to approach a topic honestly and openly (Speziale & Carpenter, 2007). This section will be written in the first person, which is appropriate to describe aspects of the research that require a personal account and represent a personal viewpoint (Fulbrook, 2003).

My position in regard to the phenomenon of interest

As a paediatric registered nurse, I have had many opportunities to care for children admitted to hospital for severe bronchiolitis. I began my nursing career in the 1980's and was employed in a paediatric ward following my graduation as a registered nurse. The parent-child relationship has been an ongoing interest for me over these many years of nursing. Mothers have always played a crucial role in the care of their children and as hospitals have become more parent care orientated, their role has increased significantly. I am pleased to see that hospitals are moving towards family centred care.

Bronchiolitis has been a contributing factor leading to hospital admissions of infants and children since the establishment of paediatric hospitals. I have had many years experience caring for these children and have seen the history of family involvement in their hospitalised child's care evolve. I have realised in recent years that

improvement and further evolution in practice is possible with the introduction of a new way of delivering oxygen therapy to these children.

Infants with breathing difficulties were originally given oxygen via an oxygen tent as described in the literature review in chapter two. They were incredibly hot and humid and the infants appeared very irritable. Some mothers chose to lie in them with their babies to try and settle them. This seemed very uncomfortable for the parent however the child was often more settled for them being there. The condensation inside these oxygen tents was copious and caused the plastic to 'fog up' making viewing of the child difficult.

For me, nursing these children was unpleasant and difficult at times. The children were often very sick and the oxygen delivery device not always accurate or efficient. An oxygen analyser needed to be employed to assist in regulating oxygen levels within the tent. The setting up of the tent and oxygen analyser were time consuming and difficult to maintain. The inability to assess the patient was reduced due to decreased clarity of the plastic. Settling the baby or attending to his or her nursing care was also difficult due to the fact that access was limited and the risk of escaping gases was high.

The parents were not encouraged to attend to their child and often were not even allowed to stay in overnight. The mothers were very upset to see their child in this contraption but it was big enough for them to fit in there with their baby. As uncomfortable as this was for them, some were determined to comfort their child at whatever cost. The cost was usually the mother's physical comfort but their emotional comfort was increased by being able to support their child. I was empathetic towards mothers yet did not take in the enormity of being able to hold one's child and comfort him or her when ill.

In the late eighties and onwards, perspex boxes were introduced to replace these oxygen tents and access and visibility of the patient improved. However a lot of the previous problems remained and new ones were produced. They were easier to set up and place over the child. An oxygen analyser was still used to determine the oxygen content of the box but these too have become more modern and easier to use. These perspex boxes also produced condensation and viewing of the patient was limited at times and the same problems with access to the child remained as did the problem of

gases escaping when the box was accessed. Interestingly enough, the parents had now even less contact with their baby as they could no longer lie inside the tent with them. In my experience, parents have continued to feel isolated from their child and many expressed their desire to do more to help their infant. They have stated over the years that they feel helpless and non-supportive (to their child). As a mother myself, I was able to identify with these women and as a nurse I believed we could achieve more for them.

Several years ago, a newer form of oxygen delivery system was introduced which consisted of a humidified circuit attached to nasal prongs where the oxygen levels could be accurately adjusted without the need of an oxygen analyser. The baby was no longer required to be separated from their mother and parent interaction was increased. The nasal prongs require a high flow of gases at times and this was seen as a potential danger to the child, hence the use of this device was limited to the paediatric intensive care unit and then to a children's private ward where specially trained nurses were allowed to care for these children.

I worked in intensive care when the nasal prong system was introduced. As the nurse educator at the time, it was due to my suggestion that the unit used this device for bronchiolitic patients. Subsequently the high flow nasal prong system was used with increasing success. Success was measured anecdotally by the reduction in children requiring ventilation and by nurse and parent satisfaction surveys. I have a strong belief that this system is the more effective way of treating infants with bronchiolitis. This oxygen therapy allows the infant to be held and comforted in times of distress. The parents are afraid and stressed when in intensive care yet they are usually comforted by holding their sick infant. It is as if they feel they can somehow cure or heal their child simply by holding them close. I also believe that the high flow oxygen system allows for greater involvement from the parent in the child's day-to-day care which in turn aligns well with the hospital's philosophy of promoting family centred care.

Having the above beliefs renders me biased against the headbox oxygen system. I believe that the headbox system works well in treating bronchiolitis but does not endeavour to be family friendly in its approach. I have been very aware to keep my likes or dislikes hidden and compartmentalised when interviewing the participants. It

was challenging to bracket my beliefs and to remain neutral in my outlook and interactions or analysis.

I used a journal throughout the research study in order to identify and reflect on my own thoughts and subjectivity. By keeping a journal, I was able to write down how I felt and how I reacted when interacting with participants and the issues that arose from our conversations (see Appendix VII). I played back the tapes of my interviews and identified any bias that may have been evident. Again this self reflection was journalled along the way. When analysing the data, I was careful to identify significant statements and convert them to formulated meanings without variance as to what the participants said. These were taken back to the participant for confirmation of their meaning. This ensured the rigour of my analysis and helped with the decision making trail.

Journaling

Holloway and Wheeler (2002) suggest that one of the ways that researchers can ensure that they are conscious of their own subjectivity is to use a journal to reflect upon their thoughts. Wall et al., (2004) have devised a reflective framework to guide the research process and demonstrated how using a reflective diary can be an effective tool for developing bracketing skills. Visual imagery, practising neutral non-verbal behaviour, and honing active listening skills facilitate bracketing in preparation for research. Throughout data collection and analysis the researcher is required to acknowledge and set aside biases during the process and about the process through the use of a reflective diary and conversations with mentors (Wall et al.).

Burns and Grove (2003) suggest writing everything in a journal that the researcher knows about the topic and the issues involved, thereby bringing them into consciousness. These can be revisited throughout the study process to ensure that the researcher's values, culture and beliefs do not override those of the participant.

Documenting thoughts, feelings and perceptions throughout a research study in a journal can help to examine the researcher's position on issues raised or emerging themes. Hamill and Sinclair (2007, p. 16) ask the question "who are the emerging themes important to - you or the participant?" in order for the researcher to reflect on his or her own biases.

Keeping a reflective journal also helps develop an audit trail which can provide a framework for establishing trustworthiness of the study (Cohen, Kahn, & Steeves, 2000). The study needs to be credible and auditable as well as dependable and transferable (Guba & Lincoln, 1985). Cohen et al. suggest that a research journal is a record of the researcher's involvement in a project. While the contents of the journal are sometimes used as data, they are different from the information, observations, records or other data which are collected because they may yield other information about the phenomenon under study. The journal contains information about the researcher, what the researcher does, and the process of research. It complements the data yielded by the research methodology. Some authors suggest a framework is necessary to guide reflective thought and encourage deep and critical thinking (Wall et al., 2004).

In this research study, the main reasons for keeping a research journal were that it provided material for reflection and a pathway to bracketing. The journal also provided a historical trail of the project including decisions made along the way, provided data on the research process, and documented development of the researcher's research skills.

Participants

Most qualitative research uses a purposive sample, which is sometimes referred to as criterion-based sampling; using this approach, participants are purposefully selected because they have knowledge of the setting or phenomenon under study (Holloway, 1997). In this research study, purposive sampling was used. It is used to select research participants according to the needs of the study (Glaser & Strauss, 1967; Morse, 1991), in that researchers choose participants who have experience of the phenomenon of interest. Purposive sampling is used to seek and collect descriptive data that describes the lived experience of a particular phenomenon (LoBiondo-Wood, Haber & Krainovitch-Miller, 2002). Therefore, an essential criterion for purposive sampling is that the participant has experienced the phenomenon of interest, so that they are able to provide rich information that is suitable for detailed research (Patton, 1980).

For the purpose of this research study, participants were purposively sampled according to the following criteria:

Inclusions

- They had experienced the phenomenon of interest:
 - I. Parents/guardians of children under the age of two (as headbox oxygen therapy is not used with older children) admitted to a tertiary children's hospital with severe bronchiolitis who were treated with both types of oxygen therapy.
 - II. Nurses who have cared for children under the age of two admitted to a tertiary children's hospital with severe bronchiolitis and who were familiar with both types of oxygen therapy.
- They could communicate their experience of the phenomenon.
- They provided voluntary consent.

Exclusions

Parents/guardians of children with life-threatening/terminal illnesses were excluded from the research study, as it was felt that participation would be too stressful for them.

Data saturation

When researching qualitatively, although it is possible to estimate the number of research participants before the research commences, the researcher can never be sure how large the sample must be in order to collect the required information. One method that has been developed in qualitative research is data sampling until a point of saturation is achieved. "Saturation refers to the repetition of discovered information and confirmation of previously collected data" (Morse, 1991). Therefore, in qualitative research, when the key themes and concepts within the data are consistently repeated a point of data saturation has been achieved (Speziale & Carpenter, 2007). Daniels (2004) state that when the same categories or codes keep recurring throughout the interviews, then data saturation has been reached. Hein

(2001) suggests that it is important for the researcher to state how saturation was achieved and not just report that it was.

Sample size

Initially, it was anticipated that a purposive sample of six parents and six nurses would achieve data saturation. However, the first twelve interviews did not yield the quantity and depth of information that was required to achieve saturation, and therefore a further six parents and six nurses were recruited. Also, the initial interviews, through journal reflection, revealed my influence by sometimes using leading questions or introducing my own preconceptions into the interview. This affected the objective quality of these interviews. As I performed more interviews, I became a better listener and my interview data became thicker and richer. Although recurring themes were evident after interviewing nine mothers and ten nurses, as a relatively novice researcher I felt that by interviewing the full cohort of twelve mothers and twelve nurses, I would ensure that saturation had been achieved, and this provided me with reassurance that no further themes were likely to emerge. The final sample consisted of 12 mothers and 12 nurses.

Recruitment process: parents

Children who were admitted to the hospital requiring oxygen therapy were identified over a period of three years during their hospital admissions. The mother or guardian of these particular children was approached whilst their child was in hospital and the researcher sought verbal consent to ring them later on (up to 12 months later) to invite them to participate in the study. The participants verbally agreed and gave their personal contact details to the researcher for future use. Recruitment began with a phone call inviting them to join as a participant for the study. The researcher explained the study and what would likely occur in the interview. A time and date was then arranged. The parent participants were provided with a choice of venues to meet with the researcher; their work, home or place of their choice. All parent participants stated they would like the student researcher to visit them in their home. On meeting with the participant, the study was explained in detail and the information sheet given to them (Appendix I). The parent participants were asked if they understood the study or needed to ask further questions before they were asked to sign a consent (Appendix I). After consent was received the interview commenced. The researcher had

previously explained over the phone that the interview would last up to one hour and that it would be face to face with the researcher asking the participant to describe their experience of having a child in hospital with severe bronchiolitis that was prescribed oxygen therapy. Prompt questions were asked if further information needed to be extracted (Appendix V). The interview was recorded using two data recorders. All participants could withdraw at any time and were advised that counselling services would be available if the need arose (see Appendix I). All parent participants were informed that they might be contacted a second time to explore their experiences further. Not all were contacted due to change of address and contact information.

Recruitment process: nurses

The nurses were purposefully selected to participate in this study. The nurse unit managers of the selected ward/unit were approached initially as the hospital ethics department stated that the potential nurse participants were required to be interviewed in work hours within the hospital environment. Nurses who were interested in participating were given information on the proposed research and consent documentation (see Appendix II). All nurse participants were informed that they might be contacted a second time to explore their experiences further. However, this was not necessary.

Parent participants

Although both parents were initially invited to participate in the study, only mothers accepted the invitation. All participants experienced having a child admitted for the first time with a mean age of four months (Range 2-6 months). All participants had a child experience both types of oxygen therapy. All children commenced their hospital stay in the medical paediatric ward where they received headbox oxygen and then they either went to the high dependency unit (HDU) of that same ward or were transferred to paediatric intensive care unit (PICU). Most infants spent less than 48 hours in PICU or HDU; no infant was cared for in both these areas.

Most mothers were married and several had more than one child. All nurse participants had paediatric experience. Each participant is described in chapter four and summary details about each participant are given in appendix VIII. In order to ensure confidentiality, the names of all 24 participants have been changed to pseudonyms.

DATA COLLECTION AND ANALYSIS

Colaizzi's method of analysis was used to collect and analyse data about the phenomenon of interest and to develop understanding of the essence of lived experience. His method of analysis is congruent with the philosophical underpinnings of this study.

Colaizzi's (1978) theoretical framework was influenced by earlier philosophers, such as Husserl. His aim was to produce rich descriptive data about a particular phenomenon. He did this by first interviewing the participant and then reading the transcript to obtain a feeling for their ideas. He then extracted words and sentences related to the phenomenon and attempted to formulate a meaning from them. After exhausting all descriptions of the phenomenon, he then reduced them to an essential structure. These findings were taken back to the participants for final validation.

Giorgi (1985) criticised Colaizzi's methodology and challenged the need for the researcher to present their findings to the participant for the purpose of verification. He contested the participant's expertise with regard to the phenomenological process. If the researcher adopts a particular attitude, as described above, then the findings are developed through this attitude. Thus, the participant who does not possess the same attitude is not qualified to offer a different version.

Colaizzi's structured approach to the process of data collection and analysis is described in further detail below.

Data collection method

Choosing a data collection method depends on the type of research question identified (if there is one) and the selected methodological approach. There are several methods of data collection that are used in qualitative research, of which the most common are interview and observation. The former is most relevant in phenomenological research, as it is a more effective medium to enable participants to describe personal experiences. Since descriptive phenomenology was selected, the most congruent data collection method was individual interviews (Todres & Holloway, 2004).

Interviews can be unstructured, semi-structured, and structured. Unstructured interviews simply provide the participant with a topic to talk freely about. They do not

use prescribed questions or a framework. They allow for the greatest flexibility of conversation between the participant and researcher and usually result in rich data, however they produce the highest amount of information which may be of no use to the researcher. This unwanted information has been referred to as dross (Morse & Field, 1996).

Consistent with descriptive phenomenology, semi-structured interviews were used in this study. The semi-structured or focused interview allows for in-depth discussion of the phenomenon and uses guided questioning to ensure the participant remains focused on the phenomenon of interest. Several open-ended questions are usually planned, although they may not all be used during each interview. They are supplemented with prompt questions such as, “Can you tell me more about that?” to facilitate in-depth exploration of the phenomenon. This enables the collection of rich data, whilst maintaining a strong focus on the phenomenon of interest. For this reason, the semi-structured interview method was selected for this research study (Taylor, 2004).

Semi-structured interviews

Phenomenological interviewing is much like other qualitative interviewing as it involves some sort of relationship between interviewer and interviewee (Taylor, 2004). The semi-structured interview technique is used to collect qualitative data by setting up a situation (the interview) that allows a participant the time and scope to talk about their opinions on a particular subject. The focus of the interview is decided by the researcher and there may be areas the researcher is interested in exploring (Lindlof & Taylor, 2002).

The first step to data collection is to articulate the experiential phenomenon of interest (Giorgi & Giorgi, 2003; Taylor, 2004; Todres & Holloway, 2004). This was identified for this study as the experiences of parents and nurses who have had, or cared for, a child admitted to hospital for severe bronchiolitis that requires treatment with oxygen therapy.

Once the experiential phenomenon is clearly identified there is the need to establish how descriptions of the phenomenon may be gathered. It is important to clearly articulate the stimulus questions to be posed so that the descriptions gathered give a detailed account of the area of interest or phenomenon (Taylor, 2004; Todres &

Holloway, 2004). Todres (2005) makes it clear that the stimulus questions should lead the person to describe a specific kind of experience. The following stimulus question was asked of the parents: "Please describe the experience of having your child receive oxygen therapy when he/she was admitted to hospital for severe bronchiolitis". Other focused questions were asked throughout the interview such as: "Please can you describe how much involvement you had with your child and how this felt for you?" Nurses were asked similar questions about what it was like for them caring for a child receiving oxygen therapy, such as: "Please can you describe the parents' relationship with their child when it was receiving oxygen therapy?"

The objective of the phenomenological interview is to understand the participant's point of view rather than make generalisations about behaviour. Semi-structured interviews use prepared questions as well as questions that occur to the researcher during the interview. Open-ended questions are used, such as: "Please can you think back to the time when your child was in hospital receiving oxygen therapy and describe what this experience was like for you?" These are usually pre-determined within the interview schedule whereas others arise naturally during the interview, for instance, "You said a moment ago...can you tell me more?" These are often referred to as 'prompt' questions. The wording of questions will not necessarily be the same for all participants (Lindlof & Taylor, 2002). The researcher tries to build a rapport with the respondent and the interview should flow like a conversation and questions are asked when the interviewer feels it is appropriate to ask them. The qualitative interviewer also needs to have well developed communication skills; particularly listening.

The phenomenological approach to interviewing is one of collecting descriptions of experiences to develop understanding of the participant's lived experience. Taylor (2004) offers a description of phenomenological interviewing, stating that it should be non-directive and not be contaminated with the researcher's own assumptions. This concept of non-contamination is similar to bracketing, which was discussed earlier in this chapter, and is discussed further in the data analysis section. Husserl, in his philosophical phenomenology, describes different levels of phenomenological reduction or reduced attitude, which can be achieved by bracketing. His writing indicates that the philosopher must be in the reduced attitude (to bracket out all

previous knowledge and experience) when seeking to explore their lifeworld (Paley, 1995).

Qualitative approaches, such as phenomenology, that use a person-centred approach are thought to meet scientific criteria when they are rigorous and systematic as well as open to peer review and public scrutiny (Giorgi, 1997; Holloway & Fulbrook, 2001). Semi-structured interviews allow the interviewer to retain control and to create rapport with participants so that the interviews remain open and honest in a relaxed atmosphere. This helps to elicit rich descriptive data. By listening to the words of participants, researchers can gain an understanding of the way they perceive and interpret a phenomenon by providing access to their feelings and thoughts (Holloway & Fulbrook).

There are strengths and weaknesses associated with the interview method. It is a practical and efficient way to obtain information about things that cannot be observed such as emotions or feelings. People are able to talk in detail and in depth about issues, allowing for high validity as the participant is able to speak freely without the interviewer giving them specific direction. This also allows for the meanings behind an action to be revealed. With semi-structured interviews complex questions and issues can be discussed or clarified. The researcher can probe areas suggested by the participant's answers, picking up information that had either not occurred to the researcher or of which they had no prior knowledge (Lindorf & Taylor, 2002).

The semi-structured (or unstructured) interview allows for all information to be discussed without the researcher pre-determining what is not important. There is no pre-judgement with few pre-set questions involved. These interviews are easily recorded with either a video camera or an audio tape, however they can be very time consuming and expensive to undertake (Kvale, 1996).

A disadvantage of the research interview is that it depends on the skill of the interviewer (the ability to think of questions during the interview, for example) and articulacy of the respondent. The interviewer may also give out cues or unconscious signals that may guide the participant to give answers agreeable to the interviewer. The reliability, generalisability and validity of these interviews are questioned as they cannot be repeated exactly. Because not all questions asked are standardised and the respondents are often asked different questions depending on what they decide to talk

about it may be argued that the results of the interview may be more related to the particular questions the interviewer asks (Lindorf & Taylor, 2002).

Another disadvantage is that participants may not divulge relevant or accurate recollections of their experiences. However, although this may be the case, it is still their perception; and this is what is important.

Interviews: setting and process

The parent participants were given the choice of where they would like to meet with me. For example, they had a choice of the hospital, their home or some other place of their choice. All parent participants chose to have the interview conducted in their own home. A time was arranged to fit in with the parent's schedule and each interview lasted up to two hours.

Interviews attended in the participants' homes were usually conducted in the lounge room or at the dining table. The mothers all offered coffee and I always accepted one in order to put the participant at ease and to create a relaxed atmosphere. The mothers were a little anxious about the interview and this was a way of relaxing and getting to know each other a little. They all had a toddler with them and some had two small children with them. The interviews were occasionally interrupted by an incident to do with the children or by their demand for their mother's attention. I told the participants to attend to their child/ren if need be and I would filter out any unnecessary recorded data. The interviews were chaotic at times and sometimes very peaceful.

I was aware of my responsibility to ensure my personal safety and always informed someone of where I was going prior to interviewing these women just in case something untoward should happen.

The hospital ethics committee required the nurse participants to be interviewed in the hospital during work time (see Appendix III). The nurse unit managers of the medical ward and the PICU also gave permission for their staff to be interviewed. Each interview lasted no more than an hour.

Interviews were recorded digitally and transcribed verbatim. I employed assistance with transcribing due to the large amount of data from 24 participants interviewed and the time constraints. The transcriptions were returned to the student researcher within a week or two of the interviews. The digital recordings were backed up on a

computer hard disk protected by password. A hard copy and computer disk copy were kept with the accompanying digital files to allow for revisiting the data as necessary throughout the stages of analysis. During data collection and analysis, electronic data were stored on my own computer and paper-based data were kept in a locked office in my home. The transcripts were typed into a word processing package (Microsoft Word) and participants were de-identified using pseudonyms. The Word documents were then imported into NVIVO[®] software for analysis.

Data analysis

Data analysis was undertaken using NVIVO[®] software to organise the data, and was guided by Colaizzi's seven step approach: i) checking the transcripts; ii) extracting significant statements; iii) formulating meanings; iv) grouping formulated meanings; v) developing and clustering themes; vi) exhaustive description; and vii) returning to participant for final validation. Colaizzi (1978) developed his approach from the Duquesne (Husserlian) School (Cohen & Omery, 1994). His method is frequently utilised in descriptive phenomenological research (Forest, 1989).

Checking the transcripts

The first task of the researcher is to read the participants' transcripts to acquire a feeling for their ideas in order to understand them (Colaizzi refers to transcripts as protocols). I read and re-read the verbatim transcriptions and compared them to the voice recordings to ensure that the transcriptions were accurate and to make sense of them. Each transcript was read several times, as the digital recording of the interview was replayed, to gain a sense of total content. An extract from one of the transcripts is located in Appendix V.

Extracting significant statements

The next step involved extracting words and sentences relating to the phenomenon under study by further reading and re-reading of the transcripts. Phrases and sentences were identified that were congruent with the study. Colaizzi calls this process extracting significant statements. Significant statements and phrases pertaining to the phenomenon being studied, the lived experiences of parents of children treated with oxygen therapy and nurses who cared for them, were extracted from each transcript and coded. In total 385 significant statements were identified.

Formulating meanings

I then formulated meanings for each significant statement through immersion in the data. Colaizzi (1978) describes this step as a “precarious leap” (p. 59). This leap refers to the researcher taking the next step of analysis that has significant impact on emerging themes and Colaizzi believes this stage is crucial to understanding statements significant to the phenomena under study. Colaizzi explains that this is done by the researcher intuiting, describing and analysing the data. The underlying meaning of each statement was then written. This step moves from what the participant said to what they ‘mean’ (Forest, 1989, p.817). It involves the researcher being mindful of appropriate factors that modify the meanings of verbatim transcription of the interviews. The research participants’ use of jargon, sarcasm, economy of phrase or use of strong emotions can alter the meanings of the verbatim transcripts.

Next, all the coded formulated meanings from all the interviews were combined. (See table 1 example.)

Table 1. Examples of formulated meanings

Significant statements	Formulated meanings
We didn’t know if she would die or not.	The mother feared for her child’s life.
I thought she looked uncomfortable because she was quite soggy looking.	The mother thought her child looked moist in the headbox and this would make her feel uncomfortable.
I was just so happy to be finally holding her. I could even give her a bath. It was wonderful.	The mother was happy to be able to hold her child and be involved in her care.
I didn’t understand what was happening. I was really frightened.	The mother felt scared by seeing her child in a headbox as she did not know what was happening.
I was beside myself with anxiety when I saw her being put in the headbox.	Mother feels beside herself with anxiety seeing her child in the headbox.
It was horrific, we did not know if she would die or not.	Mother was very upset and did not know if her baby would live.
I just cried at first as it was all so scary. I was tired and worried that Stacey might die.	The mother was tired and worried and extremely scared that her baby might die.

Grouping formulated meanings

Formulated meanings were then grouped together from which emerging themes could be identified. As stated by Coward and Cutler (1989), the next step in data analysis was to form themes that were common to the protocols. The formulated meanings were sorted into groups that represent specific themes. Each theme was coded and each formulated meaning that formed part of a particular theme was listed beneath it.

Developing and clustering themes

I repeated the first three steps for each transcription and arranged these formulated meanings into clusters of themes, and then returned to the original descriptions to validate the themes. To ensure no themes had been missed Colaizzi (1978) advises the researcher to resist the temptation to ignore data or themes which do not fit.

Exhaustive description

The next step in analysis is to write an exhaustive description of the phenomenon being studied from the theme categories. According to Patton (1990), an exhaustive description goes beyond mere fact or surface appearances but stops short of becoming trivial and mundane. An exhaustive description should communicate the “voices, feelings, actions and meanings” of the interacting individuals (p.31). This step in analysis produced an exhaustive description of the lived experiences of parents and nurses who have had or cared for a child with severe bronchiolitis in hospital and received two types of oxygen therapy.

I then reduced the exhaustive description of the phenomenon to an essential structure. Colaizzi (1978) describes this as an unequivocal statement of identification of the fundamental structure of the phenomenon. A final validation was made by returning to the research participants and asking them to validate the researchers’ description of their lived experiences. Of the participants who were contactable following data analysis, all responded favourably, thus validating my exhaustive descriptions.

RESEARCH RIGOUR

Trustworthiness

Trustworthiness is a qualitative methodological term that may be used in place of the quantitative terms of validity and reliability. Lincoln and Guba (1985) posited that the trustworthiness of a study is attained if the end result accurately reflects the experience of the study participants. According to Lincoln and Guba, trustworthiness is comprised of four components: credibility, transferability, confirmability, and dependability.

Colaizzi (1978) suggests that trustworthiness of the questions put to the participants depends on the extent to which they tap into the participants' experiences apart from the participants' theoretical knowledge of the topic. Consistent use of method and acknowledging prior knowledge of the topic helps to ensure pure description of data. To ensure complete trustworthiness of data analysis, researchers return to each participant and ask if the exhaustive description reflects their experience. When the participants recognise truth in the findings, trustworthiness of the data is further established. Data analysis must be revised if any findings are unclear or misinterpreted (Speziale & Carpenter, 2007).

Credibility

Activity which increase the possibility that credible findings will be produced is known as credibility (Lincoln & Guba, 1985). As a minimum, the researcher's findings should be compatible with the perceptions of the people under study (Holloway & Wheeler, 2002). Credibility refers to the degree that the themes, which are the end result of the data analysis process, accurately reflect the realities depicted by the contributing participants. Member checking (Denzin & Lincoln, 2003), as described in step seven above, refers to having each participant review the researcher's summary of their interview transcriptions in order to ensure that the participant's statements were accurately described and fairly interpreted.

Readers should be able to trace and follow the line of thinking that the researcher used during data analysis (Speziale & Carpenter, 2007) and the researcher's path to

decisions regarding themes, constructs and interpretations should be clear and transparent.

Trustworthiness continues to be debated between quantitative and qualitative researchers and within each of these approaches. Giorgi (2000) offers a rebuttal to those who criticise the credibility of phenomenology; he suggests that there are many similarities between Husserlian phenomenology and quantitative empirical approaches with both requiring the researchers to use a scientific method. He goes on to suggest, though, that for phenomenology no epistemological claim is made that the situation was the way the subject describes – it is the subject's perception. Giorgi writes that factual verification is irrelevant as phenomenology seeks meaning (interrelationship between person and environment). Therefore, although phenomenology, like quantitative methods, uses a scientific approach, it is unacceptable to suggest that it is untrustworthy due to a lack of generation of facts. Kvale (1996), a phenomenologist, discussed terms like reliability and validity. Indeed, the phenomenological method of Husserl was developed in an attempt to provide a reliable means for examining phenomena.

Guba and Lincoln (1989) felt the need for these terms to be expressed in a language that is congruent with qualitative research yet retain the underlying meaning of the concepts of 'reliability' and 'validity'. Guba and Lincoln suggested that credibility replaced internal validity. They also suggested that transferability or fittingness should replace external validity (generalisation) which means how the findings fit into the world and not necessarily about broad generalisations. Dependability replaces reliability which means method and evidence is displayed in thoroughness (Tuckett, 2005). Dependability also means that the methodological approach is suitable for the research question (Maggs-Rapport, 2001).

Transferability

Compared to empirical researchers, qualitative researchers do not attempt to generalise their findings. Instead, the term 'transferability' is used to define "the extent to which the findings can be applied in other contexts or with other respondents" (Munhall, 1994, p. 300).

Strategies for increasing transferability include collecting rich descriptions of the data. This includes journal entries together with a rich mix of participant quotations.

Purposive sampling maximises the chance of obtaining accurate information about the studied phenomenon for it relies upon choosing those who have both the experience of the phenomenon and also the ability to communicate their experience of that phenomenon.

Transferability refers to the degree to which the findings may be transferable to other settings or respondents. One strategy this study employed to enhance transferability was through the use of 'thick' descriptions of the data (Patton, 1990). Detailed descriptions of the findings, the participants, and their personal contexts (e.g. values, family dynamics, parenting concerns) allow others to assess the extent to which the findings are transferable to their own situation.

Confirmability

Confirmability is a measure of the degree that the study's results reflect the participants' responses as opposed to the investigator's biases. Confirmability can be strengthened by performing an audit trail (Lincoln & Guba, 1985). An audit trail refers to an independent auditor reviewing the analytic procedures of the study.

Confirmability was affirmed by careful record keeping practices, including proper maintenance of files of recorded interviews, transcripts, interview notes, and data analysis worksheets. Journal entries were another source that was used to ensure confirmability of this study (see journal extract in Appendix VII).

Care was taken to ensure that the analysis was not biased by the researcher's acknowledged preconceptions. The most common technique used by Husserlian researchers is to "identify and articulate assumptions prior to data collection and analysis" (Speziale & Carpenter, 2007, p. 97). The student researcher listed and reflected on her own beliefs about the parent-child relationship when oxygen therapy is used in hospital. Another technique is to keep a journal and list biases as they arise whilst interviewing participants or analysing data. A sample entry from the journal is as follows:

I have just finished my first interview with a mother who was very upset when her child was in the headbox. I have listened to the

transcript twice and was surprised to hear my own questions; most were as per written stimulus questions however there appeared every now and then that I asked a leading question. Was I looking to receive a specific answer? Maybe, as I was totally empathetic with the mother about how awful it must have been to have a sick baby in a headbox.

As this was my first interview, I was able to learn from my inexperience and reflect on my journal entry, helping me to be more aware of my questioning technique in subsequent interviews. This helped me be aware of the potential to bias the interview and not to ask leading questions.

Dependability

The application of an appropriate methodology to the phenomenon provides dependability. Dependability and credibility are closely related checks for trustworthiness that tend to overlap. Dependability refers to the extent to which the results would be replicated if the study was repeated with the same participants. If findings are deemed to be credible, then dependability is demonstrated (Seziale & Carpenter, 2007). Colaizzi's methodology based on Husserlian phenomenology was chosen to best investigate the phenomenon under study. The "lived" experience of individuals who had, or cared for a child, admitted to hospital with severe bronchiolitis requiring two types of oxygen therapy was the phenomenon of interest. In order to understand a particular phenomenon, those who had experienced the phenomenon were chosen to interview for the study. The purposive nature of the sample ensures that there is consistency of experience and it is not based upon ideals or imagination of those who have not experienced the phenomenon. The inclusion of as many participants as possible increases the experiential aspects of the phenomenon. In this study, dependability was strengthened by means of creating detailed descriptions of the methods of data collection, data analysis, and situational variables, including factors affecting the selection of participants and the selection of interview sites.

ETHICAL CONSIDERATIONS

Ethical approval

Research projects involving humans must be reviewed by a Human Research Ethics committee (HREC) and must not be undertaken or funded unless and until approval has been granted (NHMRC, 1992). Ethical permission was granted from the Human Ethics Committee of the Australian Catholic University (see Appendix II) and the Mater Health Service's Ethics Committee (see Appendix I).

Consent, when obtained, was voluntary and participants were informed that at any time they could withdraw from the study without penalty, comment or question. Nurse participants were informed that their participation in the study would not impact on their position as employees of the health service and that confidentiality of personal and study information would be maintained and safeguarded. All of the nurses were interviewed in work hours using face to face interview techniques and recorded using two data recorders.

Risk of harm

This study offered minimal risks to the participants, and followed the National Health and Medical Research Council (NHMRC, 1992) National Statement on Ethical Conduct in Research Involving Humans.

The interview would have ceased immediately if participants had become distressed while being interviewed. No participants did become distressed however, if they had, participants would have been offered the opportunity to have a break from the interview, reschedule for another day, or withdraw from the study. A counselling service, funded by the hospital, was arranged in advance to be made available for any participants who might become distressed. Any participant who required ongoing support would have been offered the opportunity to see a qualified psychologist for therapy sessions if needed.

Consent

All research informants were provided with a written invitation to participate in the study, which provided an overview of the intended research. All participants provided

written consent, and were informed both verbally and in writing that they were at liberty to withdraw from the research study at any time without prejudice.

Confidentiality

Confidentiality of all participants in the research was ensured. No records were kept of patients' names or unique identifying details. All paper-based data and tape cassettes will be kept in a locked office. All digital recordings will be kept for five years as per recommendations from NHMRC and then disposed of in a way that renders them unreadable. All computer-based data is protected by a password known only to the researcher. All participants were given pseudonyms to protect identification and maintain privacy. Conference presentations and publications that arise from the study will not identify participants.

Disclosure

If a participant had reported a malpractice during the course of the interview and wished to pursue the matter, the participant would have been asked to write a written report. The report would have detailed the event and would be submitted to the hospital's complaint department, which could investigate the matter and provide legal advice. However, this did not occur.

CONCLUSIONS

This chapter has discussed the methodology adopted in this study of the lived experiences of parents and nurses who have had or cared for a child in hospital receiving oxygen therapy for severe bronchiolitis. The most appropriate methodology was chosen after a comprehensive investigation of the possible methodologies available for qualitative studies. A qualitative approach, using semi-structured interviews and adopting Colaizzi's (1978) method of analysis, was a defining aspect of this study.

The purpose of the phenomenological method is to make sense of the data so that the world of the participant is clearly understood. Each stage of the analysis procedure was designed to ensure the data were rigorously analysed and offered the opportunity for independent validation. This approach suited the research and enabled me to apply the methods to my own area of study.

CHAPTER FOUR

FINDINGS

INTRODUCTION

The purpose of this study was to provide a rich description of the lived experiences of parents and nurses when a child was admitted to hospital with bronchiolitis that required oxygen therapy. The phenomenon of interest is the lived experience of parents and nurses who have had, or cared for a child admitted to hospital with severe bronchiolitis requiring oxygen therapy; headbox oxygen therapy and high flow nasal prong oxygen therapy.

The research setting for this study was a major paediatric teaching hospital in Brisbane, in which children with bronchiolitis requiring headbox oxygen therapy were admitted to the medical ward. Those children with severe bronchiolitis, who did not respond to headbox oxygen therapy were then given high flow nasal prong oxygen therapy. These children were either transferred to the high dependency area of the same medical ward or were admitted to paediatric intensive care unit (PICU).

This chapter describes the participants, and presents the findings. Following analysis, nine themes emerged; these are described in detail, followed by a summary of the findings.

PARTICIPANTS

Twenty-four participants were interviewed: 12 mothers and 12 nurses. In order to ensure confidentiality, the names of all 24 participants have been changed to pseudonyms. Although both parents were invited to participate, only mothers volunteered. All mothers were new to the phenomenon of having a child admitted to hospital for severe bronchiolitis and it was their first experience of their child receiving oxygen therapy. The registered nurses who volunteered to participate in this study had been practising as paediatric nurses for between two and twenty-five years.

In the following section, a summary description is provided of each of the participants.

Mothers

The mothers were of Caucasian background and 11 of the 12 were married or had a partner. Only one participant was a single mother. Most of the women were supported by family members during their child's hospitalisation.

Arlene

Arlene was a young first time mother of a three month old baby. She did not recognise how sick her child was when she was at home and took her to her local doctor when she became listless. The doctor told her to rush to the hospital as soon as possible as he felt her child needed specialised paediatric hospital care. When she arrived at the hospital she was shocked by how her baby was taken from her so quickly, had an intravenous line inserted and was placed in a headbox. She had never had any experience of being in a hospital or having a seriously ill child. She spent two days in a medical ward with her child receiving headbox oxygen. Her child became increasingly ill and was transferred to PICU where he was placed on the high flow oxygen therapy. Arlene's husband and extended family were very supportive during her hospital stay.

Barbara

Barbara was a mother of two. The youngest child of the family (Stacey) was admitted to hospital for bronchiolitis at the age of three months. The older sibling had just recently had a head cold and was recovering. Barbara's husband became concerned for their baby when she did not cry and was hard to arouse. Barbara and her husband rushed their infant to the accident and emergency centre at the hospital nearby where their baby was admitted and given oxygen therapy immediately. She was admitted to the medical ward and received headbox oxygen therapy for two days before being transferred to their high dependency area where she received high flow nasal prong oxygen therapy for the next day and a half.

Crystal

Crystal was a new mother and had only been home from hospital for eight weeks. Crystal had established a good breastfeeding regime prior to her baby's (Jane) admission to hospital. Crystal was married with a supportive husband. She was pleased with her new mothering skills and was disappointed when her baby and herself became unwell, interrupting her newly established regime. She became

concerned for her baby when she stopped feeding. Crystal and her husband took their baby to the hospital where she was promptly admitted and given supportive therapy; intravenous fluids, headbox oxygen for three days (medical ward) and high flow nasal prong oxygen therapy for twenty four (PICU).

Donna

Donna was a mother of a five month old (Jake) who was being bottle fed and was sick for several days at home prior to being admitted to hospital for severe bronchiolitis. The baby was admitted immediately on arrival to the Accident and Emergency Centre and was placed in headbox oxygen and transferred to the medical ward. Donna was married to a supportive man and her parents were also willing helpers. This support was crucial to Donna as her baby was admitted to PICU two days after where he was given high flow nasal prong oxygen therapy.

Esther

Esther was a mother of two. Her youngest, (Rachel), three and a half months old, was admitted to the medical ward and received headbox oxygen for severe bronchiolitis for thirty six hours. She was also anxious about her other toddler at home with his father, as he too had a respiratory infection and she worried that he would end up in hospital as well. She did have support at times from her mother when she was available. Esther's baby was transferred to the high dependency area when she began to deteriorate and received high flow nasal prong oxygen therapy for the following thirty six hours.

Fiona

Fiona was a mother of three children. The youngest, Ryan, was admitted after he had been rushed to hospital for severe bronchiolitis. He had been ill for three days previously. The older two children had already nearly recovered from what the mother thought were just very heavy colds. The baby was four months old at the time and became progressively worse. They had taken Ryan to the doctors who had assured her that all she had to do was keep up the fluids and things would improve soon. He had warned them that if Ryan did get worse or they were particularly worried about him then they should take him to the paediatric hospital. This they did when he developed breathing difficulties. The grandmother was available to care for the older two children while Fiona and her husband went together with their youngest

to the hospital. Ryan was admitted to the medical ward where he received headbox oxygen for two days before being transferred to the high dependency area where he received high flow nasal prong oxygen therapy for a further two days before improvement was attained.

Geraldine

Geraldine was a single mum who had been at home with her sick baby for two days prior to bringing her into the hospital. Polly was only three months old at the time of her admission to hospital for severe bronchiolitis. Polly was admitted to the medical ward and given headbox oxygen initially and within twenty four hours was transferred to PICU where she was placed on the high flow nasal prong oxygen therapy for the following two days. Geraldine was supported by friends as her family lived interstate.

Hayley

Hayley was a mother of two and had never been to hospital with either child before. Her youngest daughter, Jessica, was four months old at the time of her admission to hospital and was still being breastfed. Her husband was able to take time off work and look after their four year old son. Hayley was shocked to see her daughter placed in a headbox to receive oxygen therapy and intravenous line inserted for fluid support. Helen was unable to breastfeed though she was able to provide breast milk which was fed to her daughter via a nasogastric tube. Hayley's baby received three days of headbox oxygen on the medical ward and then received high flow nasal prong oxygen therapy for twenty four hours in the high dependency area.

Isobel

Isobel was a young married mother. Isobel's baby (Layla) was five months old at the time she was admitted to hospital for severe bronchiolitis. Her husband was able to be with her and their baby whenever work allowed. Isobel had never experienced being in a hospital with a child before. Her baby was admitted to the medical ward and was placed in a headbox which provided her baby with the required oxygen she needed. Isobel sat by her baby for two days before she deteriorated and was transferred to PICU where she was placed on the high flow nasal prong oxygen therapy for a further two days.

Jackie

Jackie was a mother of twins. She had previous experience of having her twins in hospital as they were born four weeks premature and spent a few days in special care nursery. They were born healthy and their time in special care was short lived. Jackie described this time in her life as nontraumatic. The babies did not require respiratory support at birth and were able to breastfeed almost immediately. Jackie was allowed to take the twins home after only one week in special care as there were no feeding issues, their weight was good and Jackie had plenty of home support. Eight weeks after their birth, the twins became ill with what she initially thought was a cold. Her mother, a nurse, advised her to continue breastfeeding as often as possible. When one of her babies became floppy and unable to feed, her mother quickly bundled them all off to the paediatric hospital. Tyler was admitted to the medical ward and was placed in a headbox to receive oxygen. His twin brother, Charlie, was cared for by Jackie's mother and husband at home but visited often so as to be breastfed as often as possible. Tyler became increasingly unwell and was transferred to the high dependency area where he received high flow nasal prong oxygen therapy for thirty six hours.

Kelly

Kelly was a married mother of two. Her older son had been unwell with a severe cold for a week and now her baby was also sick. Her baby, named Sally, was only four months old and was being breastfed at the time. When Kelly was told that her baby had severe bronchiolitis and would have to be admitted to the medical ward for treatment, she said that she just broke down and cried. Her husband was unable to stay with her at the hospital as he was needed to care for their older child at home. Both extended families lived interstate and they had some limited support from friends. Sally received twenty four hours of headbox oxygen therapy before being transferred to the high dependency area where she was placed on the high flow nasal prong oxygen therapy for the next forty eight hours.

Larissa

Larissa was a first time mother and her baby (Eli) was six months old when he was admitted to hospital for severe bronchiolitis. She had been married for three years and had a supportive husband. Larissa's mother lived close to her and was described as a

major source of support. Larissa was a mature aged professional woman who was used to being in control of situations. Her baby being admitted to hospital was extremely confronting for her. Larissa's baby was initially given headbox oxygen therapy on the medical ward but after less than twenty four hours later her baby was rushed to the PICU where he was placed on the high flow nasal prong oxygen therapy. Larissa's baby was in PICU for two days.

Nurses

All nurses who volunteered to participate had experience working in medical paediatric wards as well as the PICU or high dependency areas. Six of the nurses had paediatric intensive care certificates, three had paediatric certificates and one had a certificate in geriatrics. Three of the nurses were parents themselves and five were either single women or had no children of their own.

Michelle

Michelle was a nurse who was very experienced in paediatric intensive care work. She had been registered for twenty two years, had a paediatric certificate and appeared to be relaxed and open to conversation. She was very confident about talking about the oxygen therapies and had had many years of experience with children with severe bronchiolitis. Michelle was also a mother herself.

Natalie

Natalie was a nurse who had been registered for ten years. Five years of these were in the paediatric hospital. Two of these five years had been working in a surgical ward and from there she had had three years' experience in the present medical ward that deals with bronchiolitis.

Olivia

Olivia was a nurse who had been registered for ten years. She started out in geriatrics and had a certificate in that area of expertise. Olivia then transferred to the paediatric hospital where she had worked for the past six years in the medical ward. Olivia had nursed many children with severe bronchiolitis.

Penny

Penny was a nurse with five year registered nurse experience. Penny had worked in the paediatric intensive care unit for six months and had worked three years

previously on the medical paediatric ward. Penny was a single woman with no children of her own.

Sueanne

Sueanne had been registered as a nurse for eight years and had five years experience with paediatric patients. She felt she was able to give a good account of the phenomenon as she had had experience looking after children with severe bronchiolitis.

Tania

Tania was a new second year graduate young nurse who had been working in the medical children's ward for the past year. She was young and enthusiastic but had minimal experience with looking after children with bronchiolitis. Tania was a single woman with no children of her own.

Una

Una was a nurse who had been fifteen years registered, was paediatric intensive care trained and had many years' experience looking after children with bronchiolitis receiving oxygen through various means ranging from intubated and ventilated, CPAP mask, headbox, and nasal prongs

Veronica

Veronica was a nurse with twenty years' experience as a registered nurse. Veronica had worked with paediatrics all her working life and had a lot of empathy for mothers of ill children as she too was a mother.

Wendy

Wendy was a nurse who had been registered for twenty-three years. During this time she spent five years working with paediatrics and was presently working on the medical ward. She had been working there for two years and had quite a lot of experience with the headbox therapy and had only looked after a few children on the high flow therapy.

Xavier

Xavier was a registered nurse of twelve years' experience. He also possessed a paediatric intensive care certificate. Xavier was married and was a new father of one. He was highly skilled at looking after severe bronchiolitis patients. He liked the

parents to interact as much as they could with whatever therapy was chosen for their child.

Yanna

Yanna was a nurse who had been registered for ten years and had a paediatric certificate with many years of paediatric experience. Yanna was unmarried with no children of her own.

Zena

Zena was a nurse with many years' experience dealing with paediatric patients. She had been registered for eighteen years and had a paediatric intensive care qualification. Zena was confident with oxygen therapy and had many years interacting with families.

Domains and themes

Participants were asked to describe their experience of either having a child receiving oxygen therapy (parents) or caring for a child receiving oxygen therapy (nurses) for bronchiolitis. Initially, mothers described their child's onset of illness and how they were admitted to hospital, and then focused on their child's treatment with oxygen therapy, and how this impacted on their relationship with their child. Nurses described their experiences in general when caring for a child with severe bronchiolitis. They focused more on aspects of nursing practice.

Following analysis, nine themes emerged: 1. It was horrific, we didn't know if she would live or die; 2. I didn't know what was happening; 3. I think some parents do get quite upset; 4. All that I wanted to do was hold her and keep her with me; 5. I felt inadequate, more than useless; 6. I needed her to feel my heart beat; 7. Look but don't touch; 8. I stayed with her day and night and; 9. Babies are hard work in the head box because you can't pick them up.

These nine themes were clustered into three domains; *Fear*, *Parent-child interaction* and *Technical caring* (see table 2).

Table 2. Domains and themes

Domains	Themes
<i>Fear</i>	<ul style="list-style-type: none"> • It was horrific, we didn't know if she would live or die; • I didn't know what was happening; • I think some parents do get quite upset; • I stayed with her day and night
<i>Parent-child interaction</i>	<ul style="list-style-type: none"> • All that I wanted to do was hold her and keep her with me • I felt inadequate, more than useless • I needed her to feel my heart beat • Look but don't touch
<i>Technical caring</i>	<ul style="list-style-type: none"> • Babies are hard work in the head box because you can't pick them up

The nine themes are shown diagrammatically in Figure 5. The themes are described in detail below, using verbatim quotes from participants. Some of the themes describe experiences that were based primarily on the parents' perspectives; some are focused primarily on nurses' views, whereas others describe shared perspectives.

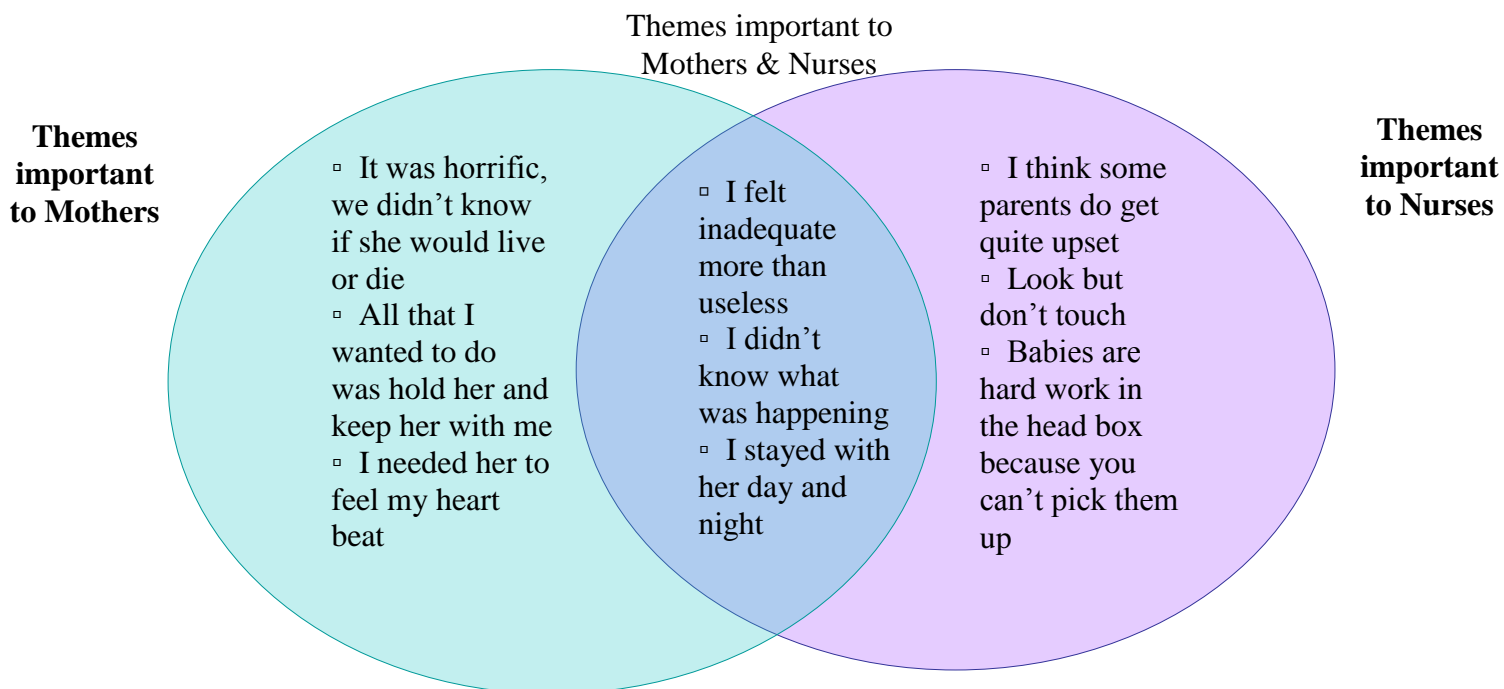


Figure 5 Diagrammatic representation of themes identified by mother and nurse participants.

FEAR

This domain describes how parents felt when their child was admitted to hospital for treatment of bronchiolitis with oxygen therapy. The intense fear manifested from the parents' inability to comfort their child, to understand what was happening to their child and especially the thought that their child might actually die. The parents' fear was also amplified by the unfamiliar environment and nursing staff caring for their child which led to the parents feeling the need to be with their child day and night. This uncertainty and fear is demonstrated in the following four themes: *It was horrific, we didn't know if she would live or die; I didn't know what was happening; I think some parents do get quite upset; and I stayed with her day and night.*

It was horrific, we didn't know if she would live or die

Essential structure

Parents are fearful, frightened and stressed when their child is admitted to hospital with a critical illness. As the child's health deteriorates their fear and stress is heightened.

Exhaustive description

This theme describes parental feelings of absolute fear; their experiences were frightening and stressful. Participants described how their child became ill and the events which took place after their child was admitted to hospital with severe bronchiolitis. Their stories related increasingly anxious concerns for their child's safety and many feared that their child might die.

This was described vividly by Hayley, a mother of two, who had never been in hospital with either child before:

We had taken her to the Doctors and he had said to keep up fluids and that she would get better without any medicine. It didn't work out that way at all. Stacey got worse not better and I was so stressed out and worried because I wasn't sure what I should do for her and she just seemed so miserable. After three days of sleepless nights and cranky days, Stacey ended up not even wanting to breastfeed and she became really floppy and sleepy and she looked like she was having a lot of trouble breathing. We knew then that she had to go to the hospital. When we arrived at the hospital they

quickly attached her to machines and put her in a headbox which gave her oxygen and put a drip in. It was horrific, we didn't know if she would live or die. (Hayley).

The fear also came from the inability to understand what was happening. Some parents felt that the uncertainty of not knowing how their child's illness would progress was the catalyst for this fear of death. This event of having a child admitted for severe bronchiolitis was a first time experience for all mother participants. They did not understand their child's illness nor had they any prior exposure to oxygen therapies.

Another mother of two, Esther, felt that her fear was due to the uncertainty of her daughter's illness, the treatment she was given as well as the inability to hold and comfort her child:

I just cried at first as it was all so scary. I was tired and worried that Rachel might die. My one reaction that I wanted to do was hold her and keep her with me but she was whisked away and put in this headbox thing. It was not what I was expecting. (Esther).

Similarly, Arlene, who was a first-time mother with a three-month old baby, described her fear and uncertainty:

I was incredibly upset and I didn't understand what was happening. I was really frightened. I was quite distressed and upset. It was my second child and I thought I would handle things better because of that but it was really hard to see her in the headbox. It just looked so medical. (Arlene).

Most mothers were fearful for their baby's life. They arrived at the hospital feeling uncertain about their child's illness and outcome. Not knowing what was happening or understanding how the illness progressed as well as how the illness was treated created major anxiety and heartbreak.

I think some parents do get quite upset

Essential structure

The nurses were unaware of the extent of the parent's fear when they had a child admitted for severe bronchiolitis and received oxygen therapy.

Exhaustive description

This theme illustrates how different the perceptions were between parents and nurses. Although, on one hand, nurses were aware of the parents' anxiety, they were not really aware of just how paralysing their fear was that their child might die. Nurses believed that mothers' anxieties were due to not being able to pick up their child and comfort it, for example while the child was in the headbox. They also believed that mothers were anxious about leaving their child when it was so sick.

This is illustrated by the following excerpt from one of the more experienced nurses:

I think some parents do get quite upset and I think the biggest part is not being able to pick up their baby. I think they don't eat or sleep much while the baby's in the box and they need to stay there and some of them are in there for two, three, four days or so, so that sort of thing I think is the hardest for them. And also the child has become quite unwell in that space of time so I think that in itself it is scary for the parents. (Una).

Nurses tended to focus on environmental and treatment factors that they believed caused anxiety to parents. This tendency is evidenced by another nurse, who was less experienced in PICU, who described how oxygen therapy was distressing for parents:

I think they get very anxious because they can't settle them and that's the only way they would normally settle them would be to pick them up, so then as a nurse we will step in and take over so you know, because I think they get very stressed by seeing their child so upset in a box. Especially if the child wasn't upset before they went in the box and it's the box that's making them upset, and you know that because you know the child, it's just that they were deteriorating so they need to go in and then it's clear that it's just that environment that's upsetting them, it can be quite hard and I think sometimes when you weigh it up it is actually benefiting the child by being in the head box when they're so distressed and they're not resting because they hate the environment they're in. So that side of things I think it would be quite distressing for the parents. (Penny).

Although nurses recognised that parents were stressed or anxious they did not demonstrate understanding of the degree of fear that the parents were dealing with. None of the nurses mentioned that they thought the parents feared for their child's life. They did seem to recognise that mothers were in a distraught emotional state however they failed to see that it was connected with fear of death. The nurses all had

prior experience of caring for children with severe bronchiolitis and knew that the majority of them survive and go home after several days or weeks, even when they are seriously ill. They failed to recognise that parents had no prior experience and did not have the same understanding of the disease or its treatment. These views did not vary between nurses who identified as being parents themselves and nurses who were not parents. No nurse participants had ever had a child admitted to hospital.

The mothers' responses included feelings of anxiety and distress but; their emotions became more positive as their involvement with their child increased. Mothers described their relief when they were able to hold their child, comfort it and their happiness at being able to be involved in their care. Donna had a son who had been admitted for severe bronchiolitis and had been treated with headbox oxygen before being given high flow nasal prong oxygen therapy. She illustrates how important it was for her to be able to participate in her son's care:

So I couldn't pick Jake up until that point but now, (on the high flow) I could touch him and I could hold him and I could play with him and hold things above him and give him something to focus on. I felt a lot more useful. There was a certain extent you know I could do things I could still change his nappy I could hold him even if I didn't ask but you'd ask at least. Can I pick him up now? Is it okay to give him a bit of a cuddle? You could rock him to sleep um you could sing to him. You just felt like you were doing something that would help him and you could hold him and you weren't so worried about him. Even though it was a catch twenty two, in the headbox you didn't feel like you could hold him or touch him but still yearned to do so. (Donna).

In contrast to their views about headbox therapy, nurses described their experiences of looking after a child on high flow nasal prong oxygen therapy as mainly positive. They too were happier seeing the mothers being able to hold and comfort their child but their views were tempered by concerns about safety issues and nursing effort involved in looking after these patients. These concerns are explored further in the theme *Babies are hard work in the head box because you can't pick them up* (see below).

Xavier, an experienced PICU nurse, was really excited by the high flow therapy because he realised this would have a great effect on mothers in that they were able to hold their baby, change their nappies, and cuddle them whenever it was appropriate.

However, he still thought that he needed to be in control of the situation and advise the mother when it was appropriate:

I think it makes them a lot more comfortable because they can touch their baby, they can be interactive rather than not touching them and not interacting. I think on some level I think patients, parents do have babies in head boxes probably see their child as a lot sicker than babies who have high flow because they're in a box, like no-one's touching them, do you know what I mean, just leave them alone, whereas high flow oxygen they're wrapped up, they're in their own clothes, they've got their own things around them, stuff like that, so they probably perceive a head box baby a lot sicker than a high flow baby because of the extra equipment that's surrounding the child rather than just next to the child. A couple of patients that I have looked after on high flow have been great, the parents have been able to when they want to, with a nurse assistance or when we think it is appropriate, they pick the patient up and they can cuddle the baby and things like that. (Xavier).

Tania, who was a relatively inexperienced nurse, saw the high flow nasal prong oxygen therapy as a positive treatment for children with severe bronchiolitis in that parents and nurses both had better access to the sick child. The barrier of the headbox was eliminated and emotional issues were less for the parents and safety issues were decreased for the nurses. Tania, a relatively inexperienced nurse, summarised this:

From the nursing side point of view, I do think it's quite beneficial because all of those barriers that were there with the head box have been eliminated. We still encourage parents to have normal handling and let the child rest but if the child's beside themselves - upset - then the parents can pick them up and cuddle them and can do the nursing that they would normally do. Access to the child is easier to do interventions, the suction procedure can be quicker because you haven't got to negotiate a box and position yourselves in a funny position to try and get it done. If you have to get intravenous access again the child is very accessible to all veins rather than having to try to you know try to get the child out of the box, put mask oxygen on, which again is taking the child out of the environment. (Tania).

I didn't know what was happening

Essential structure

Parents of children receiving oxygen therapy when hospitalised felt unknowledgeable about their child's illness, treatment or outcomes.

Exhaustive description

This theme describes parents' feelings of ignorance about their child's illness and their need for knowledge and information. Both the parents and the nurses thought that either giving or receiving information was a way to alleviate parental anxiety and to help establish a trusting nurse client relationship. Mothers described their experience of having a child in a headbox as frustrating, anxiety ridden or fearful as they did not fully understand what was happening to their child, the treatment nor illness. Again this theme is related to fear – the fear of not knowing.

All mothers described their feelings of ignorance in varying degrees however they all agreed that more information would have alleviated some of these fears. As stated previously, these parents experienced having a child admitted for severe bronchiolitis and were treated with oxygen therapy for the first time. Their knowledge of the disease, the treatment, hospital procedures and illness outcomes were deficient. It was not evident in the nurses' descriptions that they recognised the depth of ignorance that these mothers possessed. They did however believe that the more information about what was happening to the child was given to the mother, the less anxious the mother seemed.

Isobel, a young mother of a five month old described this as follows;

It was like I had stepped into another reality - a black hole. This medical world suddenly became my reality and I couldn't get my head around it at first. It was so foreign and I didn't know what was happening. I didn't know if she was going to get better, I didn't understand her illness, I just didn't know anything. I felt so ignorant. (Isobel).

The nurses appeared aware of this need for knowledge and most spoke of keeping parents informed of actions and treatment pertaining to their child. They were sensitive to the needs of parents and realised that knowledge helps lessen the mother's fears and anxieties. Veronica, a very experienced nurse, knew that mothers required knowledge and emotional support in order to decrease their anxiety. She felt that talking parents through all procedures, treatments and outcomes would help the mothers make sense of what was happening to their child, and stated:

If you tell parents what is happening and what to expect, it seems to calm them down and they begin to understand what we are doing for their child. (Veronica).

Wendy, another nurse, described how she asked parents to be involved when the child was in the headbox however they were scared of the equipment and of what some nurses had previously told them about the safety issues. That is, that they might disturb the oxygen levels. Wendy knew that if she educated the parents about how to care for their baby, what the equipment was for and how it worked as well as managed expectations, she could assist in reducing parental anxiety and give them the confidence to be the best carer for their child. This is illustrated in the following excerpt from her interview:

I can tell they'd be very highly anxious and but as long as, you're keeping them informed, and you're trying to help them become calmer or look after themselves, so that you have a more holistic view of nursing where you can't actually involve them in their baby's care, but you can involve them in being the best they can be for their baby. (Wendy).

Michelle was a very experienced nurse and knew the value of educating parents to help reduce their anxieties as well as helping to empowering them. She recognised the emotional state parents were in when having a child admitted to hospital with severe bronchiolitis and was very sympathetic to their cause. She empathised with the parents:

I think it'd be pretty emotional to see your little baby stripped off and put in this weird you know seventies looking fibreglass box with a nice little blue curtain. I think that's one of the main things that I always think about working here is that you're looking after the parent as much as you're looking after the child. You know we explain everything to kids but I think at the same time even more you need to explain it to the adult, oh you don't have to, but you know it's that instinctive protector mode I suppose, but yeah that's one thing that we do do a lot of education with our bronch' parents, as well as post discharge education, I think because otherwise they go home and they come straight back for same symptoms are still there, they're obviously just not as exacerbated. So I find that if you don't do a lot of education on the current situation kind of where the baby's at, then they either just lose it and then I think it just makes the whole situation worse. (Michelle).

All participants experienced both types of oxygen therapy. The mothers described their lack of knowledge regarding therapies, procedures and illness. Twelve mothers were interviewed and six had their child admitted to PICU and the other six had their child transferred to the high dependency area of the medical ward to receive high flow oxygen. The PICU admission added to the mother's fears and lack of knowledge as this was a whole new environment and unfamiliar nurses to care for their child. These mothers described how this uncertainty and unfamiliarity increased their stress and anxiety. Larissa, who had her young son Eli admitted to PICU described her experience as follows:

I was so scared when Eli was admitted to PICU. I felt so lost and alone. I didn't understand what was happening and nobody was explaining anything clearly to me. I was so freaked out and thought he might die. One nurse was OK in that they said he would be fine now and I could hold him soon. That made me feel a whole lot better. He was put on the prongs (high flow nasal prongs) and eventually I was able to hold him and things just felt so much better. I have to say though, nobody was very good at telling me what was happening. I just felt in the dark. (Larissa).

Another mother (Barbara) who had her baby transferred to the high dependency area with her nurse was less stressed by the experience as she was kept informed of proceedings and did not have to deal with an unfamiliar environment or nurse. Barbara explained how this was for her:

Stacey just got sicker and they told me they would have to put her on the high flow prongs and take her to the high dependency area. I was worried sick about her. The nurses were great and my nurse actually stayed with us and looked after us in the high dependency area which I thought was awesome because we had come to like her a lot. She really reassured me that things would be all right and explained everything. She was fantastic. (Barbara).

I stayed with her day and night

Essential structure

Parents of children with severe bronchiolitis were very fearful and distrustful of the ability of the nurse caring for their child. They needed to stay with their child continuously in order to feel more secure.

Exhaustive description

This theme describes parents' lack of trust in nursing staff. The mothers felt that they needed to have a strong trust in the nurse before they felt comfortable with the care they were providing for their child. The parents were feeling isolated, helpless and uneducated. They felt that they were at the mercy of the doctors and nurses and believed that trust was a major issue surrounding the care of their child.

Fiona, a mother of three children, had her youngest child admitted with severe bronchiolitis to hospital for treatment. She was extremely anxious and upset and felt that she could not leave her child at any stage as she did not trust the staff to be there in the same way that she would be. Her fear of her child deteriorating if she left also played a part in her not leaving her child's side. The issue of trust was foremost in her reason for staying beside her child. She described her experience as follows:

I stayed with him day and night. I didn't trust anyone to look after her. For example, would anyone comfort her if she cried? I didn't do much for her. I wasn't allowed. They said it was too difficult and that they would do most of the day-to-day care while she was so sick. (Fiona).

Jackie was a mother of twins. Both of her babies were sick but only one was severe enough to be admitted to hospital. Jackie's mother stayed with the other twin and was a huge support for her daughter leaving her husband able to continue to work. Jackie was distraught at having one of her twins in hospital but was unable to feel secure enough to leave her baby and return home for a night. She described how the nurses suggested she should go home for a rest:

I remember the nurses saying just go and get some sleep, maybe go home for the night. There was absolutely no way I could even consider walking out of the hospital. I needed to be sleeping beside him. I needed to be as close as I could. (Jackie).

Larissa, another mother, felt that nurses should be friendlier and interact with parents in such a way as to allow for a rapport to be established between the two. She felt it was important to trust the nurse who was looking after your child as they were the ones doing most of the day-to-day care, however she felt that some nurses were better

at this than others and that she could trust them more. She describes this relationship in the following excerpt:

I think the nurse probably had to go the extra mile with a parent who's kind of in that situation with a child. Oh, probably from an emotional point of view, making sure the parent's all right rather than just a good standard of care. I knew that there wasn't a great deal of emotional needs that he (my baby) needed from the nurse because it was much more a practical thing. But certainly just a bit of encouragement that she'll be all right and this is okay. Yeah, definitely more my emotional needs than his, was kind of empowering me then to be confident and still being there for him. So the ones that would say to me just talk to her or stroke him and give me ways of connecting with her even though I couldn't hold him. And also the ones that said to me it was okay to cry and to be upset and it was pretty stressful thing. I think I felt like I was always gauging whether this was serious, you know, like I was justified in feeling the way I was feeling. (Larissa).

All of the nurses who were interviewed also recognised the need for good communication between them and the parent in order to establish a good relationship which in turn would promote trust. This trust or nurse/client relationship was also seen as a means of improving patient care. One highly experienced nurse described the importance of establishing trust between the nurse and the mother. She felt that once the mother was able to trust the nurse she was able to relax and feel more comfortable asking questions or going for a break. She summed up her view of trust issues as follows:

You are going to be the one to keep an eye out for their baby, so I think there is a lot of trust there. I think they tell you how they're feeling throughout the day, I think you need to reciprocate that back and give a bit of you, a bit of yourself not just be this stone cold, I'm just here to do this job, I think you do have to, by the end of the day develop, not a friendship but a connection with the person and I think that then they feel, depending on their, how they perceive you and you perceive them I think that improves that working relationship which I think then you improve the care of the baby. (Yanna).

PARENT-CHILD INTERACTION

This domain describes the parents' reactions and feelings associated with seeing their child receiving oxygen therapy in the headbox. They described how the nurses encouraged them not to interfere with their own children whilst in the headbox stating that the child's safety was at risk. This led to the parents' feeling inadequate and useless. They stated that they wanted to be close to their child, to be able to hold him or her and to comfort them when they cried or hugged them when distressed. This inability to hold their child created a sense of futility and uselessness. The parents felt it went against their natural instincts of wanting their child close to their person when he or she was in need however the headbox served as a barrier to this conforming to nature.

All that I wanted to do was hold her and keep her with me

Essential structure

Parents felt that the parent-infant bond was broken when their child was isolated from them when receiving headbox oxygen therapy.

Exhaustive description

This theme describes mothers' feelings of isolation, which were both physical and emotional. In particular, they felt isolated from their child when it was receiving headbox oxygen therapy due to the restrictive nature of the enclosed headbox, which acted as a physical barrier that limited their involvement. The resulting lack of physical contact also increased their emotional anxiety. The themes of bonding and attachment closely followed on from feeling isolated. Mothers instinctively wanted to hold their child and feel close to them.

One mother described her emotional state as being a mix of emotions. These included fear, ignorance and sadness. When asked to describe her interactions with her child while receiving both oxygen therapies, she stated that the headbox was extremely isolating and that it was like a barrier against her being able to hold her baby. She described her inability to care for her child whilst it was in the headbox as being unnatural and that she needed to feel her baby close. Firstly, to comfort her child, and secondly to comfort herself. This is portrayed by the following statement;

I hardly had any involvement at that initial stage. I couldn't breastfeed her or hold her or do anything for her I mean I was anxious and stressed out and I needed to feel Stacey close to me. (Barbara).

Barbara's response to experiencing her child on the high flow was in direct contrast to how she had experienced the headbox oxygen therapy and her response was as follows;

When Stacey was on the high flow system she was able to be held. I had felt so useless when she was in the box (headbox) as I could hardly do anything for her. It was horrible. She was still incredibly sick yet I knew that she needed me to hold her. It felt so much more natural to be able to hold her again. I was a proper mother again. (Barbara).

Crystal stated that when her baby received headbox oxygen she was unable to breastfeed or to hold her child. Not only was her good breastfeeding regime disrupted, Crystal also felt that her bond was broken with her baby and that it was not natural for her baby not to feel her heart beat. She felt it was very important to be able to help her child in some way that was tenable and real. She knew that breast feeding could assist in the treatment of bronchiolitis and was very keen to not allow this disruption to mar that objective. This made Crystal feel angry and isolated:

My one reaction that I wanted to do was hold her and keep her with me but she was whisked away and put in this headbox thing. (Said in angry voice.) (Crystal).

When asked how was it for her when her baby was placed on the high flow nasal prongs, Crystal stated;

I was so relieved to be able to hold her again, even though I couldn't breastfeed her still as she was still too sick, I was able to cuddle her. I was definitely able to express better that's for sure. (Crystal).

Fiona, mother of three had never experienced such a serious illness with any of her children and having Ryan admitted and then put in a headbox was an absolute shock to her. Fiona stayed with her baby and her husband went home to look after the other siblings. The whole experience was overwhelming and it took her days to come to

terms with what was happening to her baby. Fiona experienced a range of emotions and described her experience with seeing her child in the headbox as devastating. Her inability to touch Ryan or assist in his day-to-day care left her feeling isolated and useless.

It made me feel isolated. I was supposed to be breastfeeding Ryan and all I could do was pump out my breast milk for him. I couldn't even hold him. I was so distressed. I cried plenty of times. The hardest thing for me was not being able to touch him or hold him.
(Fiona).

The nurses described parents as wanting to be able to hold their child. Most of the nurses interviewed recognised this need and how it distressed mothers not to do so. Zena, one of the more empathetic of the nurses, described how she perceived parents responses to having their child in the headbox;

I do think that yes it's definitely a barrier because it's something between them and their baby that they can't just usually do what they normally do is pick them up and nurse them. I think a lot of the parents find it hard not to be able to pick up their baby when they're upset and unwell and just nurse them. For the parents, that's probably the hardest aspect that comes with the head box.
(Zena)

One nurse, Sueanne, suggested however that the headbox was a barrier that was actually of benefit to the child in as much that the parents couldn't touch their baby. She felt that the child would get better with less intervention and disturbance from their parents and she says;

I think that at least in the head box it kind of isolates them and there's a physical barrier to over stimulation. I don't like the parents touching them too much. (Sueanne).

In contrast to the headbox acting as both a physical and emotional barrier for the mothers, the high flow nasal prong oxygen therapy provided access to their child. The mothers all described how having their child on the high flow nasal prongs was easier for them to access their child and to provide the day-to-day care necessary to them. This ability to hold their infant made them feel useful again. They felt as if they were finally able to soothe, settle or help their child in a familiar way not

available to them when their child was in a headbox. Kelly expressed her opinions as follows;

Why couldn't my child have been on the high flow nasal prong system from the start? It was so much better and I wouldn't have been half as traumatised by the whole hospital experience as I was. It is definitely the way to go. I was in heaven when I was finally able to hold my baby again. (Kelly).

I felt inadequate, more than useless

Essential structure

Parents of children receiving headbox oxygen felt useless and isolated from their child which was against their instincts to hold and comfort.

Exhaustive description

This theme describes mothers' feelings of helplessness and lack of control. All mothers felt unable to assist their child in any way constructive and described this as either feeling helpless or having no control. This was devastating for them. The isolation from their child made them question their ability to be a "good" mother. Their natural instincts were to be near their child, to hold their upset infant and to attend to their day-to-day care. Not being able to obey their natural instincts led the mothers to feel inadequate. Feelings of uselessness also arose when they couldn't attend to the practical side of caring for their child. Mothering skills, like changing nappies and feeding their child were denied to them.

Donna, mother of a five month old baby named Jake, felt useless as a mother seeing her child in the headbox, unable to touch, hold or do any of his day-to-day care. She felt unable to perform her natural mothering tasks and felt her role as a mother diminished. This left her feeling bereft and inadequate.

I didn't feel that I was being a good mother because a good mother would have been able to comfort her child when her child needed her. I felt inadequate, more than useless. I just cried from frustration a lot of the time as I was not able to touch her. It wasn't the natural thing to do. Who would normally sit by and watch their child suffer without feeling devastated? I had no way of knowing how long she would be there or if she would get better or worse. Not being medical made it further isolating. (Donna)

Donna felt more useful when her baby was placed on the high flow nasal prong system and this is how she described how she felt;

I felt a bit more in control again when she was on the prongs [high flow nasal prongs]. Finally I could be a good mother again. Finally able to do something useful! (Donna).

Larissa, a mature aged new mother felt very helpless and that she had no control of the situation. It was very confronting and frustrating for her at times to have to sit by and watch someone else either attend to her child's day-to-day care or else just sit by and watch her baby cry without being able to comfort her. Larissa had been a career woman prior to the birth of her baby and was used to dealing with crises in the corporate world. This situation was unknown to her and she described her experience as follows;

It was pretty confronting sort of not being able to touch him. Well being able to touch him but not be able to get up and cuddle him. So he would scream and you couldn't do anything apart from tap on the top of the box. So yeah that was probably my greatest memory, just very confronting. We couldn't get him out when he was in the head box. Very helpless. Oh I cried a lot. (Larissa).

In contrast to the previous statement, Larissa described what it was like for her when her child was on the high flow nasal prong therapy by saying;

When Eli was on the prongs [high flow nasal prongs], I was allowed to hold him. It was amazing. I was so happy to hold him. Whenever he cried, I just asked if I could hold him and they usually let me. It was such a relief. (Larissa).

The nurses also agreed parents would feel helpless by not being able to help their child. Most agreed this would be very frustrating and upsetting for them. The majority of nurses thought the mothers would like to be helpful when it came to assisting in the child's day-to-day care or trying to settle the infant. Most nurses attributed this feeling of lack of control by mothers to their inability to assist their child in getting better. They recognised that mothers needed to hold their infant, comfort them when crying, and generally do all those activities that they might do for their own child if it was at home.

Zena, a nurse with many years' experience dealing with paediatric patients was familiar with both types of oxygen therapy and had many years interacting with families. She described the parent child relationship as limited when caring for a child in a headbox. This oxygen therapy did not allow good access to the child and she felt that mothers were distraught about not being able to hold their child. Even though she encouraged parents to participate in their child's care, it was difficult to allow them to do day-to-day care when they were putting the child at further risk. Zena believed that mothers were not skilled enough or quick enough with the tasks involved in their child's care and this would lead to oxygen escaping from the headbox stating;

Well, I mean we encourage the parents to take an active role no matter what they come in for because the whole hospital setting takes a bit of that control away from parents regardless, ok they've got a child that's sick, doesn't matter what they've got, and they've got to come to hospital. The mothers must think-OK I don't know what the rules are and what the boundaries are now, I don't know if I can bath my baby, I don't know if I can bath my baby at 6 o'clock like I do every other night. (Zena).

Olivia, a registered nurse for ten years was happy to explain the clinical side of caring for a child receiving both types of oxygen therapy focusing on the safety and nursing effort issues. When asked about the parent child relationship she was able to describe the limited interactions of the mother when her child was in the headbox. Olivia recognised that headboxes were not conducive to allowing mothers good access to their children and that sometimes it was even dangerous to do so. The nature of the headbox was seen as a barrier to good mothering and she felt sorry for the mothers who were distressed by being isolated from their child and was able to describe this by saying;

Look even though you try and warn them I think it's devastating for them because then I think it really hits home, they can't touch them, or they can touch them but they can't pick them up, they can't cuddle them, they can't and that's I think, when that's when the whole shit just kicks in, this, my baby's really sick and I think that's when it really kicks in because they can't comfort them and they feel completely helpless and hopeless because they can't, now that the baby's in the box, there's apart from tapping them on the bottom, there's nothing that they can do to comfort their baby, and it just must make them feel completely helpless and out of control

and that it's just got to a situation that they have no control over.
(Olivia).

The nurses and mothers both described how much less isolating it was for the parent when the child was given high flow nasal prong therapy. They both described the increased interaction and involvement in the child's care which in turn led to the mothers feeling more in control and useful. Olivia goes on to talk about the high flow therapy as follows;

whereas when they're on nasal prongs they can still do, and in an open cot, they can still do things like change the nappy, give them a cuddle, you know that sort of thing, but when they go into the box a lot of that time, that they can't, or they think that they can't do that sort of thing so yeah, so I think that they can, that's when I think that it really hits home, just how sick their babies are.
(Olivia).

I needed her to feel my heart beat

Essential structure

Parents needed to feel a physical closeness to their child which the headbox therapy did not enable them to do. This was especially important for breastfeeding mothers.

Exhaustive description

This theme describes how important physical contact with their child was for mothers. It illustrates their perceptions of the impact of the different oxygen therapies that were used. Mothers felt that the physical isolation of having their child in a headbox decreased the emotional bond between them and their child. Breastfeeding mothers especially felt the heartbreak of not being able to feed their child. All mothers agreed that it is instinctive to want to hold their child close to comfort and care for them. Mothers wanted to be not only involved in their child's care but also to have their child physically close to them. They described this closeness as a bond that they felt was intrinsic to mothering. They worried that their infant would not know that they loved them and were there for them. They felt that being able to hold and cuddle them would convey this message to them.

Barbara, a mother of two, was in hospital with her three month old baby Stacey. She felt she should have been more prepared because she was an experienced mother and not a naive mother as she had had a previous child. However, she was

unprepared for the magnitude of emotions that were evoked by seeing her child in the headbox. She understood that oxygen therapy would help her child yet she could not believe her child was unattainable and out of reach. All she wanted to do was hold her child. The fact that she could no longer breastfeed was also devastating and that she was bonded with her baby by this. She thought that her attachment to her daughter would somehow assist in making her (both mother and baby) feel better. She described her need for close physical contact:

I needed her to feel my heart beat and for her to know that her mother was near and loved her. She was so isolated from me. It was really, really awful. My breasts were sore and I had to express off. It just wasn't the same as feeding her myself.
(Barbara).

Esther, a mother of a three month old baby (Rachel) who was being breastfed at the time of her admission to hospital, told a similar story. She had expressed milk for the five days in order to tube feed her baby while she was given headbox oxygen. Being able to hold her baby whilst she was receiving nasal prong oxygen was imperative to allow easy expression of milk. This mother was relieved to finally be able to be involved in her baby's care. She was far more active in changing her nappy, changing her bed, and bathing her. This interaction left her feeling more connected and less anxious. She described how the oxygen therapies affected her level of contact:

The prongs made it difficult for her to attach to my breast so it wasn't as successful as they wanted it to be. I was grateful to be near her and feeding her. I had missed holding her and now I could. It was such a relief. We were able to put her normal clothes on and she looked like a normal baby again. When she was in the headbox she was undressed, hot, sweaty and miserable. Sometimes you couldn't even see her due to all the fogging up in the headbox. Then the nurses would have to wipe her down and change her sheets. She just looked so uncomfortable. It was wonderful to see her relax and snuggled up in her clothes and wrap. I didn't care that I couldn't feed her, I was just so happy to be finally holding her. I could even give her a bath. It was wonderful. (Esther).

The nurses were also in agreement that it was necessary for parents to feel close to their child and that physical contact was necessary for breastfeeding or expressing breast milk. Some of the nurses recognised that this was an issue for mothers. They realised that to be able to hold your baby or infant meant increased emotional well

being for the mothers. Veronica, a nurse with over twenty years' experience, believed that mothers would be incredibly stressed and upset by seeing their child in a headbox. She recognised that mothers needed to feel connected to their child either by holding them close, breastfeeding them or attending to day-to-day care. She described how she actively involved mothers in the child's care as much as possible however she recognised that the headbox therapy did not allow for much interaction:

If they're crying they want to pick them up and give them a cuddle and make them feel safe and secure whereas when they're in the headbox they can't do any of that, they need to leave them in the box, the best they can do is pat them on the bottom and that's not really giving that contact at all so I mean especially for breast feeding mothers who require that contact for their milk supply and for their mental stability I guess. (Veronica).

Another of the very experienced nurses, Michelle, described the parent interactions associated with oxygen therapy, focusing on the restriction for nurses and staff when looking after a child in a headbox. As a mother herself, she felt that it was appalling that the mothers of these children were unable to cuddle or comfort their child. She thought that parents would be very upset by not being allowed better access to their child:

The parents are quite distraught at times. I think if I was a mother your first instinct is to cuddle and care for your baby as much as you can. These parents look quite helpless just sitting there not being able to touch their child and us actively discouraging them from doing so as well. They're the ones who are frustrated but of course for different reasons than us. One mother said it felt like her baby was in a gold fish bowl. Look but don't touch. (Michelle).

On the other hand, nurses recognised that disturbing the child could affect their oxygenation and recovery, as described by Veronica:

if you've got a child having lots of blood tests and interventions and things then yes because you can't maintain the oxygen that they need over a great, over the larger period of time so then you're having to always add extra oxygen in and it's never a stable level and plus the child's getting all those intervention, again can upset the child and affect their care and their recovery whereas when they're on nasal prongs they can still care for their child, and in an open cot, they can still do things like change the nappy, give them a cuddle, you know that sort of thing, but when they go into the box a lot of that time, that they can't, or they think that they

can't do that sort of thing so yeah, so I think we discourage parents from doing the cares for their child when it is in the headbox. (Veronica).

Look but don't touch

Essential structure

Parents felt actively discouraged from participating in their child's care when he or she was receiving headbox oxygen therapy. The nurses agreed that this was the case as they thought the parents interference was not safe enough.

Exhaustive description

In contrast to the theme above, which described mothers' need for physical contact with their child, this theme describes the mothers' perception that nurses did not want them to touch their child. This view was supported by the nurses, especially when a child was receiving oxygen therapy via a headbox; they actively encouraged parents not to disturb their child. This isolation and lack of involvement in their child's care was recognised by nurses as distressing for parents and they agreed that it made the parents feel helpless and lacking control.

Crystal was very shocked to have to see her daughter in the headbox after it was admitted to hospital for severe bronchiolitis. She stated that she felt very uninformed about how the illness would progress and whether or not her baby's life was in danger. She felt that the nurses weren't very sympathetic to her feelings and would not let her hold her daughter or even do her day-to-day care. They told her it was unsafe and that it was better if she left the day-to-day care for the nurses to attend to. Crystal voiced her experience of this by saying;

The nurse thought it was safer if they did all the day-to-day care as I would not do it as fast as them and Jane needed a high amount of oxygen and if I did it the oxygen might escape too much. (Crystal).

Yanna, a very experienced nurse described parent interaction with their child as adequate when their child received headbox oxygen. However, she was unmarried and had no children, and this may have influenced her perceptions. She did not really want the mothers to do too much, but allowed them occasionally to be involved in day-to-day care. Yanna did not think that they were too upset yet did believe that they

could be stressed at times. She seemed to think that they were a nuisance almost if they asked too many questions or requested too many things. She said she tried to influence the mothers to go home or go on long breaks but the mothers did not seem to want to. She felt the child would have settled better if the mother had not been so anxious and intense around the child. She believed that all the day-to-day care would be better off being done by nurses as there were issues pertaining to safety, i.e. they let too much oxygen out of the headbox when they opened it to pat their child or change their nappy. Yanna thought the high flow therapy was better and she was more inclined to allow mothers to do the day-to-day care as they were not disturbing the oxygen levels. She felt that the child should still be left alone so did not actively encourage mothers to hold the child too frequently. Yanna was of the opinion that mothers needed to relax more and that they were too intense for the situation, and stated:

Parents are a nuisance sometimes, I know they want to hold and care for their children, but really we are faster and better at it and there is just not the same intensity of feelings. I mean, mothers are so upset and I think they just make the kid worse. I just discourage them from touching them if I can. (Yanna).

Natalie was concerned for parents in a superficial way, she understood that parents wanted to hold children and be involved in their care but thought it was more important that the nurses look after the child and actively discouraged parents from participating in the child's care whilst it is in the headbox stating;

I think parents are a problem at times as they can be in the way and make our jobs just that little bit harder. I don't encourage them to do too much. (Natalie).

The PICU nurse, Una described parent interaction for both therapies as intrusive to what she believed was good care. She felt that the respiratory distressed child should not be picked up and should be left alone and the day-to-day care should be done solely by the nurses with minimal assistance from the mother. She stated:

The parents just need to leave the kid alone. They are always wanting to hold it or touch it. I find this very frustrating as I think they are better off being left alone. I tell the parents to sit and watch but don't touch! (Una).

TECHNICAL CARING

This domain describes the nurses' concerns for their physical health when interacting with the child whilst it is in the headbox. They felt that it was an occupational workplace health and safety issue as they complained of injury to their backs from accessing the child in the headbox. Their other concern was for the safety of the child and describe various limitations of the technical side of caring for an infant in a headbox and how this effected their interactions with the parents.

Babies are hard work in the head box because you can't pick them up

Essential structure

Safety aspects of looking after a child receiving headbox oxygen therapy were revealed. The unstable oxygen levels in the headbox, the obscured vision due to misting in the headbox and Nurses were concerned for their own physical wellbeing when looking after a child in a headbox.

Exhaustive description

Consistently, throughout all interviews, nurses provided examples of how much of their work was focused on technical caring. In particular, they were concerned about safety, especially the potential for the child to deteriorate if oxygen delivery was impaired. Their concerns were focused mainly on the use of headbox therapy. This included the unstable oxygen levels caused by accessing the headbox to do day-to-day care or other activities. They were also concerned about the obscured view into the headbox as they were unable to see their patient as clearly as they would like in order to do an accurate assessment. One nurse thought that the warm moist interior of the headbox combined with the infected child would be an ideal breeding ground for further infection. All nurses believed that caring for a child in a headbox was extremely hard on your back and that they physically could not look after that same patient for more than one or two days in a row.

Nurses described how difficult it was to control the oxygen level in the headbox and how disturbing the child to do day-to-day care or to settle it allowed the oxygen to escape thereby compromising the child's need for a certain level of oxygen to be

utilised. They described how they actively discouraged parents from being involved with their child's day-to-day care as they thought that the parents were not proficient enough and would decrease the safe levels of oxygen that their child needed.

In general, nurses felt that the safety of the child came before the emotional well being of the parent. The headbox did not allow ease of access and if the parents were too slow at doing the child's day-to-day care then the oxygen would escape leaving the child vulnerable to deterioration and perhaps requiring more serious intervention. To prevent this from happening, nurses actively discouraged parents from interacting with their child while it was in the headbox. The constant challenge of maintaining adequate oxygen levels was described by one of the more experienced nurses:

If the oxygen escapes then of course you then have to pump more oxygen to try and maintain the oxygen level that you need for the child to be stable, so it can be, and if you've lost a lot of oxygen, you need to put a lot of oxygen back in quickly so that the child's not getting a low amount of oxygen for a long period of time. So it's difficult you do have to maintain the blanket has to be down as much as possible and you have to keep a close eye on it. It's difficult to maintain oxygen at any rate, it's constantly changing because of you know handling of the child, the blanket moving and so it's not a, it's never stays constantly the same level of oxygenation because it isn't. (Una).

Nurses were also concerned about not being able to see their patient as the inability to do so impeded their nursing assessment of the child which for them could be a real safety issue. They described how the headbox fogged up due to condensation of the heated gases and humidity. This became a visual issue. As described by one of the nurses, having to wipe the inside of the box also led to the disturbance of the oxygen level, further putting their patient at risk:

Yes, it is certainly a safety issue as in doing a proper assessment of the child because there's no way that you can see, if it's fogged up you can't, you can't see, simple as that, you can't see so you can't make an assessment so you need to clear that first. And yes to clear it you do have to interrupt, you try to do it as least as possible but there is, because you're going to stick your hand in there, and you are going to, yes, you will lose some oxygen while you clear that box. (Olivia).

One nurse, Penny, thought that the humid environment of the headbox was not conducive to a healthy, clean or safe area for a patient to be in:

And because it is so humid you have to wipe the inside of the box down frequently as it fogs up the interior. It may also be a breeding ground for other bacteria or fungus! So that's frustrating too. (Penny).

The nurses all expressed that the headbox oxygen therapy was hard to access and extremely painful on their backs when looking after a child for a whole shift. They described the ergonomic dynamics of being unable to maintain work place procedures when lifting, bending or twisting due to the beds being stationary, that is not being able to lower or raise them when need be and the rigid box design that did not allow ease of access. Tania, a nurse who had been registered for two years, described her experience:

Back pain, yeah you get a lot of back pain. You have to try and sort of do the stuff the physio showed you but you can't elevate or raise our beds, our cots up so you're bending over a lot and some of these babies are really needy with attention and settling techniques and day-to-day care, some of them are really, quite unwell and they need a lot of suction and even though you try and leave them for four hours and just do everything at the same time, some of these babies don't settle in that four hour period and you're constantly trying to pacify them with some pats and things. Nappy changes are a bit more difficult in there too washes and things like that. (Tania).

Stephanie, who had also been registered for eight years, was concerned about back pain. She described her frustrating experiences of caring for a child in a headbox:

Another thing that is frustrating is the accessibility to the box. You can really hurt your back because it is hard to reach inside and sometimes you are twisting and turning your back in order to settle the child. The beds aren't very good as they don't lower and for short nurse this is a real problem. I have even seen someone standing on a chair to access the child. Another thing that happens is that the child can get really sweaty and smelly and you have wash them frequently and change their bed linen. This is almost impossible to do by yourself so another nurse may have to hold the child and apply oxygen to their face while you change the bedding etc. (Sueanne).

Xavier, a nurse with over twelve years' experience was also concerned with the effect of poor posture on his back, especially when the child's needs were demanding:

I think when you're on a long day looking after a child in a head box you know it can be quite draining on you especially if the child's unsettled. It's hard on your posture and your back hurts and you know if your child's screaming 24/7 because they hate the environment they're in, it's quite draining. (Xavier).

In addition to access problems, nurses also held the view that looking after a child in a headbox increased their workload and took up more nursing time than was ideal. The effort involved in performing day-to-day care and accessing the headbox increased as they had to remove the child and apply another source of oxygen from a mask or something similar. The bending, stretching and manoeuvring involved in accessing and caring for the child was also very tedious and time consuming.

Veronica, another nurse described some of her difficulties:

Those babies are hard work in the head box because you can't pick them up firstly because you're constantly leaning over the cot and patting, holding a dummy in and then all the other aspects like suctioning and doing your nursing day-to-day care whilst leaning over a bed with a child in a head box is quite hard. It's not an easy, it's not easy to hold a baby and suction whilst they're under, because you have to keep them in the head box while you're doing it. (Veronica).

Summary of findings

Analysis of the interview data revealed several themes: 1. It was horrific, we didn't know if she would live or die; 2. I didn't know what was happening; 3. I think some parents do get quite upset; 4. All that I wanted to do was hold her and keep her with me; 5. I felt inadequate, more than useless; 6. I needed her to feel my heart beat; 7. Look but don't touch; 8. I stayed with her day and night and; 9. Babies are hard work in the head box because you can't pick them up; and these were then further clustered into three domains: Fear, Parent-child interaction and Technical caring.

These issues described what it was like to live the experience of having or caring for a child admitted to hospital for severe bronchiolitis that required oxygen therapy. The experience for the mothers appeared to be an emotional one where feelings of utmost fear, sadness, isolation, ignorance, distrust and uselessness all combined to leave them feeling devastated. These feelings were evident in many of the participants' interview data and can be used to sum up their views on the phenomenon under study.

The parents' fears for their child's mortality due to illness created abject fear in most mothers. They were not aware of what was happening to their child nor what would progressively happen to their child. This uncertainty led to increased stress. The fear of their child dying was evident in all interviews and this fear was not related to one therapy or the other but was associated with their child's illness. The lack of

knowledge and understanding of the illness also added to the fear. There were other reasons that parents were fearful and these were related to unfamiliar surroundings and equipment.

The mothers unanimously stated that they were less involved with their child and their care when it was receiving headbox oxygen therapy. The headbox was described as a barrier which in turn made them feel isolated. This lack of involvement in their child's day-to-day care induced them to question their mothering skills further increasing their feelings of isolation and uselessness. Mothers wanted to be involved in their child's care however were either unable or were actively discouraged from doing so when the child was in the headbox. The mothers mostly felt that the nurses actively discouraged them from being involved in their child's day-to-day care and the majority stated that this was due to the fact that they may put their child at further risk.

All mothers stated that when their child received the high flow nasal prong oxygen therapy they were able to be involved with their child's care. The mothers' all described the joy of being able to hold their child again and this relieved their stress. Mothers were still concerned for their child's mortality when it was receiving HFNPOT however they were less distressed as they felt that they were able to comfort their child and assist in his or her recovery.

The nurses too recognised these parental feelings however their recognition did not take in the parents' intensity of feelings or emotions surrounding the issues that arose regarding their child and the oxygen therapies used. They described the ways oxygen therapy affected the parent and child, focusing on practical issues.

The nurse participants initially described their feelings and views on nursing a child in headbox oxygen. Their concerns centred on the efficacy and the safety of the headbox with further concerns for nursing effort involved with both therapies. The nurses were opposed to the headbox for different reasons. They focused much less on the emotional impact of the therapy on parents and were much more concerned with aspect of safety for both the child and themselves. All the nurses shared the view that the high flow nasal prong therapy had positive benefits such as increased safety aspects and increased parent-child interactions.

Both mothers and nurses who had or cared for a child admitted for severe bronchiolitis requiring two types of oxygen therapy shared concerns over issues such as the parent/nurse relationship, family interactions, the need for knowledge, the comfort of the infant and the perception that the headbox represented a barrier. They all were unified in their perception that high flow nasal prong oxygen therapy provided a more positive method of treating children with severe bronchiolitis.

The following chapter will discuss these findings and what their implications may be for clinical practice and further research.

CHAPTER FIVE

DISCUSSION

INTRODUCTION

The purpose of this research was to explore the lived experiences of parents and nurses who had or cared for, children with severe breathing difficulties caused by bronchiolitis, requiring oxygen therapy. The research explored the phenomenon using a descriptive phenomenological approach guided by Colaizzi's methodology (1978). This chapter will discuss the findings and how they impact on clinical practice.

Descriptive phenomenology based on Husserlian philosophy, using Colaizzi's methodology was chosen for this study. Husserl (1970) proposed that the discussion of the structures of experience is essentially about meaning. It is worth noting that Husserl did not encourage the use of interpretation but neither did he wholesale reject it as he found it important for understanding (Spielberg, 1971). Descriptive phenomenology allows the meaning of the experiences to emerge from the voices and words of the participants whereas interpretive phenomenology relies on the researcher to interpret the findings to his or her personal understanding of the phenomena. Giorgi (2000) says that factual veracity is irrelevant: "the epistemological claim is for the situation as meant and intended by the subject."

Using a Husserlian philosophical approach, it is accepted that there will not only be individual variations based on previous knowledge and experience but differing ways of expressing this. The role of the researcher is to suspend or bracket their previous knowledge and assumptions and offer the underlying essential structure of the participant's lifeworld. In phenomenology the principle is to generate the essence of the phenomenon within its given context in such a way that different possibilities can be demonstrated. This allows for individual variations in lifeworld experience.

In this study, in order to maintain congruence with Husserlian intentions, the student researcher attempted to suspend or bracket her previous knowledge and assumptions so that the underlying essential structure of the participants' lifeworld was described. In phenomenology, the principle is to generate the essence of the phenomenon within its given context in such a way that different possibilities can be demonstrated. This allows for individual variations in lifeworld experience (Cohen & Omery, 1994; Spielberg, 1982). Thus, the findings of this research study were presented in a descriptive manner congruent with descriptive phenomenology.

The findings described the lived experiences of mothers and nurses who have had or cared for a child admitted to hospital for severe bronchiolitis who required oxygen therapy. Whilst both nurses' and mothers' experiences are derived from different perspectives, their convergence provides an understanding of the experience which leads to possibilities for care improvement and practice development. In this chapter, the findings will be discussed in order to make explicit their implications for nursing practice and further research. The study limitations are also addressed.

The experience of parents and nurses of hospitalised infants requiring oxygen therapy for severe bronchiolitis has not been reported in the literature previously. In this study, through exploration of this phenomenon, several key themes have emerged, which have important implications for nursing practice. The findings are also significant in the context of the national incidence of bronchiolitis, as respiratory infections are the main cause of infant admissions to hospital (AIHW, 2008).

Although there have been several developments in the treatment of bronchiolitis over the years, there has been little, if any, research that has explored how the child's hospital admission and, in particular, the use of various oxygen therapies affects the parent-child relationship. In this context, whilst much is known about the physiological aspects of treatment, the broader holistic perspective has, to a great extent, been ignored in the research literature. Probably, in order that optimum health outcomes are achieved for both children and their parents, nursing care strategies should address psychological and sociological aspects of caring too.

In this study, mothers and nurses provided verbal accounts of their experiences, which enabled description of how the relationship between a parent and child is affected, and what is important when a child is admitted to hospital for severe bronchiolitis that requires oxygen therapy. The findings demonstrate that nurses and mothers have somewhat different perspectives. And, whilst there is some convergence, on the whole nurses did not seem to appreciate the magnitude of the event of hospital admission for the parents. For nurses, caring for the child was a fairly routine occurrence. Thus, although they recognised that parents were anxious, they tended to focus on more technical aspects of caring. On the other hand, for the mothers in this study, their child's admission was a critical event – a crisis that they were not equipped to deal with. Their lack of information and understanding brought great fear to their experience – the fear of the unknown.

Nine themes were described in the previous chapter, which were clustered into three domains: *Fear*, *Parent-child interaction*, and *Technical caring*. These domains are used to structure the discussion in this chapter.

Fear

The domain of fear is comprised of four themes: *It was horrific, we didn't know if she would live or die*; *I think some parents do get quite upset*; *I didn't know what was happening*; and *I stayed with her day and night*. Collectively, these titles - on their own - paint a harrowing picture of the mothers' experiences. Thus, the domain of *Fear* is mainly about mothers. The second theme, which draws largely on nurses' perspectives, stands out in stark contrast to the others in its almost contradictory nature by understating the level of concern.

This study enabled mothers to tell their stories of what it was like to have a child admitted to hospital for severe bronchiolitis, including how the condition impacted on their role and responsibilities as mother when the child received oxygen therapy. The findings demonstrate that regardless of what type of oxygen therapy their child received, all mothers feared for their child's life. Boss (1979) described mothers' fears of losing a child. He suggested that 're-framing' anxiety reveals an elemental fear of losing that which is loved - to the point of "... being thrown back entirely upon itself, and ceasing to be, in total isolation" (p. 112). He reminds the reader that human existence "consists solely in its possibilities for relationships" (p. 114) and, using the example of a mother and child, explains the way in which the woman's existence has merged so completely with her child's, that losing the child would be tantamount to destroying her own existence.

Such basic fears seem to be an essential structure of motherhood for the women in this study. They perceived their children to be extremely vulnerable and essentially reliant on them for comfort and support, both of which, in their view, were necessary for survival. However as time passed and they perceived their child to be less likely to succumb to death, the women's uneasiness usually lessened.

The women in this study demonstrated that they experienced the same fears and concerns as those identified in parents of children with other illnesses, such as diabetes, asthma and life threatening allergies. These include risk to life and normal

development, and an uncertain future (Burford, 2004; Dalheim-Englund, Rydstrom, Rasmussen, Moller, & Sandman, 2001; Faulkner, 1996; Faulkner & Clark, 1998; Hatton, Emerson, & Kiernan, 1995; Kieckhefer & Ratcliffe, 2000; Kurnat & Moore, 1999; Lowes, Gregory, & Lynne, 2005; MacDonald, 1996; Maltby, Day, McCutcheon, Gillett, Houran, & Ashe, 2004). Although these illnesses are chronic, they are seen as life threatening, and non routine events still caused acute fear (Deatrick & Thibodeaux, 2007; Sullivan-Bolyai, Knafl, Tamborlane, & Grey, 2003).

Parents have used strategies and resources for coping with chronic medical conditions, including information gathering, control, assertiveness, advocacy, support from others, normalisation, problem solving, taking one day at a time, and maintaining hope (Burford, 2004; Clark & Chalmers, 2003; Deatrick & Thibodeaux, 2007; Lowes & Lyne, 1999; Maltby et al., 2004; Sullivan-Bolyai et al., 2003, Trollvik & Severinsson, 2004). These same strategies may be transferable to the women in this study. When talking about their experience of having a child in a headbox, all of the women expressed feelings of uselessness or lack of control. This was followed by feelings of ignorance and the need for knowledge.

Being a mother means being alert to threats to life or well-being, and maternal work revolves around keeping the child safe and supporting emotional, intellectual, and social growth (Roddick, 1990). Skills, effort, and resources are required to help meet these demands, and at times, such as when a child is in a headbox, the demands are conflicting. In this study, mothers were left feeling useless and helpless; questioning their mothering skills as they were unable to hold their child or to perform their normal day-to-day caring role.

Mothers' fears were more evident when they saw their child receiving headbox oxygen as it did not allow them to employ their coping strategies or resources for overcoming this fear. Their real need was to hold their child and comfort him or her. The isolation from their child made them feel useless and helpless. Being unable to control the situation, left parents feeling fearful and bewildered. Their fear of a life threatening illness was compounded by the therapy the child received, especially the manifested a fear within parents that the high flow oxygen therapy did not. The parents of children receiving high flow oxygen therapy were still able to hold their child, which assisted in decreasing their overall fear levels.

Understanding what is involved in living with the experience of having a child admitted to hospital with a potentially life-threatening disorder can provide paediatric nurses with guidance in anticipating and meeting the diverse and shifting needs of parents as they adjust to caring for their child in hospital. This study has shown that mothers need support, information, and knowledge that people in contact with them and their child understand the fear involved for parents. Thus, the importance is highlighted of nurses (and other health professionals) providing early and clear information, with regular reassurance of the child's prognosis, whilst acknowledging the potential challenges that might be encountered.

Nurses in this study did not talk about or identify parental fears associated with children's mortality. This may suggest that nurses lack awareness of the extent of fear mothers faced when dealing with a seriously ill child. The nurses focused more on the clinical side of nursing, while the psychosocial side of nursing was down-played. Glasper and Thompson (1993), in their work on emotional contagion, expressed that an anxious parent is likely to increase the anxiety of their child. With this in mind, it is of benefit to the nurse if he or she recognises the increased anxiety in mothers and is able to diffuse the mother's high emotions before they begin to affect those of her child.

In an exploratory study by Darbyshire (2003), ten mothers were interviewed about their experiences of having a child recently recovered from surgery. His results showed that parents were incredibly anxious and fearful of their child's possible demise regardless of the severity of surgery. He concluded by saying that nurses need to appreciate that this was not 'minor surgery', but a difficult, uncertain and often traumatic time for parents. Recognition of their role as counsellors and emotional supporters is an area that may need to be further investigated in future studies to help identify ways in which to improve the nurses' roles in the paediatric clinical setting.

Mothers' ignorance of their child's condition and their need for knowledge was recognised by both nurses and mothers. Nurses play a crucial role in supporting parents of children who have been hospitalised by exploring and interpreting medical information, encouraging participation in routine care and by providing health education. Sainsbury, Gray, Cleary, Davies, and Rowland (1986) reported in an observational study at the start of care-by-parents (family centred care) in the hospital

system, that the nurse role changed to a health educator, advising and counselling mothers and fathers.

In this study, mothers realised that their lack of knowledge and understanding of their child's illness, treatment and hospital routines led to their increased fear and anxieties. Uncertainty of their child's health, the unfamiliar environment and outcomes related to their child's condition were major factors that increased mothers fear as did the uncertainty of their parenting roles and the first time experience within the hospital environment. The nurses were aware of this need for knowledge and each participant varied in how she or he conveyed this required information to the parents. Latour, et al., (2009) in their prospective cohort study which interviewed 559 parents of children admitted to PICU, found that knowledge about their child's prognosis, illness, progression and treatment, were of high priority to the parents. Effective communication that is understandable between parents and nurses benefits the child, decreases parental stress and anxiety levels while increasing trust (Co, Ferris, Marino, Homer & Perrin, 2003; Studdert, Burns, Mello, Puopolo, Truog & Brennan, 2003)

Kearvell and Grant (2010), in an observational study exploring how nurses can support mothers in a neonatal unit, indicated that effective communication and engagement between the mother and nurse play a significant role in assisting in information exchange. Based on their randomised survey of fifty families, Hong, Murphy and Connelly (2010), measuring satisfaction of nurses' communication and the parents' satisfaction, found that paediatric patients and caregivers respond better when nurses communicate positively and openly. However, this study showed positive trends only and was not statistically significant. The way nurses communicate is important. This was supported in an American study by Griffin, Polit and Byrne (2008a) who surveyed over three hundred nurses. They reported that parents of paediatric patients prefer types of communication that are easily understood and processed. They concluded that, "paediatric nurses should communicate using normal language instead of medical terminology, and communicate a sense of trust and confidence in the caregiver".

Parent-nurse relationships centred on trust was another theme that emerged from the data in this study. Parental fear was increased by the unfamiliar environment and their lack of understanding. It is the role of the paediatric nurse to assist in orientating the family to the environment and to inform them of all that is happening, or could

happen to their child. Some of the mothers stated that if they had made a 'connection' with the nurse caring for their child, it was easier to exchange information. Trust of the nurse caring for their child was important for mothers to feel they could leave their child's bedside for any length of time. Mothers remained by their child's bed day and night throughout their hospital stay, sometimes through great discomfort to themselves, as they did not feel comfortable leaving their child in someone else's care. The mothers described how a 'good' nurse should be; non judgemental, happy, open to discussions about themselves and willing to discuss all aspects of the child's care in a way that parents are able to understand, thus humanising themselves. Once a good rapport had been established between the nurse and parent, the parents' anxiety decreased considerably. These findings are supported by the work of Kearvell and Grant (2010) who explored the mother-infant dyad within an Australian neonatal intensive care unit. Their observational study concluded that nurses needed to support the mother-infant dyad by encouraging breastfeeding, kangaroo care and participation in routine care to enhance maternal role, feelings of closeness, inclusion and confidence. It was also acknowledged that nurses who provided psychosocial support, communicated, and engaged with mothers were found to assist in developing positive and trustful relationships.

Another aspect which arose from analysis of the nurses' perspectives in this study is that they would have liked to be primary care givers or provide greater continuity of care to their patients but the clinical workload and concerns about personal chronic injury when caring for children in a headbox prevented them from requesting to look after the same patient the next day. They felt that the pain in their backs was too great to allow for continuity of care. This lack of continuity of care also led to the inability of nurses and parents to establish an effective relationship, which in turn affected parents' trust of nurses.

Parent-child interaction

Four themes emerged from the analysis that were clustered together in this domain: *I felt inadequate more than useless; All that I wanted to do was hold her and keep her with me; I needed her to feel my heart beat and; Look but don't touch.* This domain

describes the importance for mothers to be close to their child and also highlights their feelings of inadequacy when they felt unable to comfort their child.

The mothers' decreased emotional contact was especially highlighted in their descriptions of their child being nursed in a headbox: the physical presence of the headbox emphasised both the physical and emotional barrier they felt between them and their child. This led to the parents feeling isolated and having a lack of control. They were unable to hold their child or perform tasks which would have been natural for them. The bonds between a mother and her child were described as being impeded by this forced isolation.

The mother who is isolated from her child was described by Horchler and Morris (1994, p.154), two writers who interviewed parents about their experiences with sudden death syndrome, as:

Probably the most stressful and anxiety-provoking act in human existence is the separation of a woman from her newborn infant. The response to this, which humans share with most of the animal kingdom, is an overwhelming combination of panic, rage, and distress.

Mothers in the study shared this view and were distraught at not being able to hold their child nor perform normal motherly duties. Their distress was as strong as those described by Horchler and Morris (1994) even though their child was no longer a newborn. The mother-infant relationship was first described by Bowlby (1969) as consisting of two complementary facets: the maternal bond, or the mother's tie to her infant, and infant attachment, defined as the infant's tie to their caregiver. Maternal bonding was also defined by Klaus and Kennell (1976) who described it as a biologically based emotional investment in the infant. They proposed that by providing protection and nurturing, maternal care giving allowed for a longer period of (brain) development.

In this study, mothers expressed a strong maternal instinct to be near their child and to provide care which they would provide naturally if at home. This is congruent with studies involving Feldman and colleagues (Feldman, 2007; Feldman, Weller, Leckman, Kuint, & Eidelman, 1999; Levine, Zagoory-Sharon, Feldman, & Weller, 2007), psychologists who focused their research on maternal bonding characterised by the expression of a clearly defined set of maternal behaviours such as touch, grooming, proximity and breastfeeding. The infant is said to have a clear-cut

attachment formed by the end of their first year of life. This bond is characterised by actively seeking close proximity to a primary care giver (Brazelton & Cramer, 1990). Attachment security can change during infancy when the family environment changes (Thompson & Raikes, 2003; Waters, Weinfeld, & Hamilton, 2000). Based on these studies, the infant who is hospitalised is subject to disturbance of the mother-infant bond. This study was able to demonstrate this disturbance through the voices of the mothers interviewed.

Three observational studies have demonstrated that a parent's strong desire to be with their child does not necessarily translate to their wanting to be highly involved in their care (O'Haire & Blackford 2005; Roden, 2005; Shields et al., 2006) and that parental participation can be a source of stress and confusion for nurses and parents (Neill, 1996; O'Haire & Blackford, 2005). To avoid confusion, Blower and Morgan (2001) recommend the need for clear documentation of parental wishes about care provision.

In this research study, the strong desire of mothers to be with their child at all times throughout their hospital stay was highlighted, and all mothers expressed their desire to participate more in their child's care. In contrast to the research cited above, mothers felt that increased involvement would have decreased their anxiety.

Psychological research on the dyadic mother-infant relationship has mainly focused on infant attachment, yielding a number of empirical assessment tools, while the available methods to investigate the maternal bond are limited. Studies exploring the experiences and needs of parents whose children are admitted to paediatric intensive care units (PICU) have been largely conducted in North America and attempt to quantify parental feelings and experiences. Few qualitative studies have been published. While methodological designs are questionable, consistency across studies supports the importance of certain features of parents' experiences, such as being with their child and role conflict. None of the literature reviewed considered the specific needs of different ethnic and cultural groups, siblings, grandparents or the family as a unit (Noyes, 2001).

Several mothers in this study described their feelings of isolation, linking it to their increased reliance on the nurse to attend to their child. They stated that they felt uncomfortable leaving their child to someone else's care as they did not know that person well enough. In cases where a rapport between the nurse and mother had been

established, the mothers felt less anxious about leaving their child with that nurse. It was important to parents that they should be able to trust the nurse looking after their child. They believed that nurses should be willing to share information about themselves and be open and honest with them. If nurses were friendly and forthcoming in personal information, it was easier to get to know them and to trust them.

Thompson, Hupcey, and Clark (2003) suggested that the paediatric nurse needs to recognise that the family is the constant in the child's life and acknowledge that the parent knows their child best. This would assist in establishing trust between the nurse and the parent. Effective communication should involve negotiation and in this context paediatric nurses should value the parents' expertise in caring for their child. Erenon, Pincombe, and Calabretto,(2010) surveyed 413 parents of infants less than twelve months of age to determine a model of service to meet the needs of parents. They found that parents needed to be respected as a parent, have their parenting skills validated and be supported to make their own infant care choices. Erenon et al. concluded that empowering parents to make their own decisions about infant care was imperative for child health nurses in order for them to support parents effectively. The child health nurses need to build the parents' capacity to make their own decisions through giving relevant information about care options and supporting parents in their decisions.

Lack of effective communication, differences between professional and parent expectations, and issues of power and control often prevent open and mutual negotiation between families and health professionals, especially nurses. Parents look to the nurse for support, empowerment, education and expertise in caring for their child (Newton, 2000) and assume that their role of primary caregiver will be respected or acknowledged. They also expect that nursing care will be collaborative and co-operative (Baucher, 2000; Newton)

An exploratory study by Tourigny, Chartrand, and Massicotte (2008) attempted to identify Canadian and Belgian health professionals' beliefs and attitudes towards parental involvement in their child's care and to determine if these beliefs varied according to cultural background. Health professionals from both countries generally were in favour of parental involvement in their child's care, but were uncertain about

its advantages and disadvantages. They concluded by saying staff education is an important step towards the establishment and maintenance of a real partnership.

Family centred care is a model of care that promotes the parent-nurse partnership, which has become the cornerstone of paediatric nursing practice in many acute hospital settings. It requires a process of negotiation between health professionals and the family, which results in shared decision-making about the care of the child and who will provide it (Corlett & Twycross, 2006; Shields et al., 2006). The findings from this study suggest that headbox oxygen therapy presents a barrier to the enactment of family centred care values in that the care of the sick child was disproportionately swayed toward the nurses caring for the child, making all decisions and not allowing parental involvement in their child's care. On the other hand, high flow nasal prong therapy not only was effective at treating the child but enabling family centred care to take place; parents and nurses negotiated shared care of the sick child and parents were able to be involved in decision making.

In this study, the findings support the assumption that parents expect to be involved in their child's care. This is demonstrated by their common descriptions of frustration at not being more involved with their child, frequently stating that nurses did not impart necessary knowledge and actively discouraged their involvement. Studies of parental participation in the care of the hospitalised child have described how parents want to be involved in care but found that nurses' poor communication, limited information sharing, and a reluctance to relinquish control over their nursing care can lead to parents feeling disempowered and deskilled (Corlett & Twycross, 2006; Kawik, 1996; Shields et al., 2006).. Data from a few nurses in this study revealed an attitude of ownership on the part of the nurse. They felt that their role was to be the protector of the infant and thus took the control, and ownership, away from the parent. Mothers in this study were left feeling powerless and had a sense of helplessness.

Technical caring

The domain *Technical caring* contains a single theme: *Babies are hard work in the head box because you can't pick them up*. It describes how nurses held particular views about caring for the child, which were centred on practical rather than humanistic aspects of nursing practice. It describes how important it was for nurses to

be able to make accurate assessments of a child, as well as the significance they attached to personal considerations such as work-based injury associated with use of oxygen therapy.

Although there have been significant advances in the treatment of children with oxygen, the findings from this study suggest that there are some practical limitations with equipment currently in use. In particular, this study raises concerns about less than ideal aspects of care and safety in regards to headbox use. Although this treatment is effective for delivering oxygen to children with respiratory distress, the delivered gases must be humidified and warmed, which causes condensation. As a result, the Perspex box becomes misty and the view of the child is obscured. This does not permit the nurse to accurately assess the child without first wiping moisture from the internal walls of the box. When the headbox is lifted away from the patient, the gas is diluted by room air, resulting in decreased inspired oxygen for the child. This, in turn, decreases blood oxygen concentration. Oxygen levels are further disturbed each time the headbox is accessed by the nurse to provide care or perform an intervention. This can lead to reduced tissue oxygenation which may have a detrimental effect on the child's outcome (Teague, 2003). Although headbox therapy is used most commonly, Cochrane reviewers suggest that nasal prongs or nasal catheters are the most effective and safe way to deliver oxygen but further studies are needed (Rojas-Reyes, Granados, & Charry-Anzola, 2008)

This study identified problems nursing children with headbox oxygen therapy. The nurses unanimously voiced concerns about the non-ergonomic nature of the headbox and how difficult it was to care for a child without damaging their backs. The headbox is made out of rigid Perspex material and must be accessed from a hinged door on the top. Once the headbox is on the cot, the height becomes greater than most nurses can reach comfortably. The cot cannot be lowered, so in order for the nurse to access the headbox they either have to stretch or stand on a chair beside the bed and reach in. This leads to nurses bending and stretching resulting in lower back pain. Nurses in this study reported that despite work place health and safety training they still experienced back pain when caring for a child in a headbox. They described their back pain as severe enough to require analgesia and to request not to look after the same patient two days in a row. This affected continuity of care and their ability to build a rapport with parents, which affected parents' trust in them.

Safety in the workplace has become a prominent issue for most hospitals in Australia and around the world and workplace injuries account for many hours lost and cost hospitals millions of dollars (Retsas & Pinikahana, 2000). Several schemes have been implemented to decrease workplace injuries. These include educating staff about proper lifting techniques, correct posture and load limits (Maher, 2000). However, despite mandatory nursing education, avoidable injuries continue to occur (Barling, Kelloway, & Iverson, 2003).

Summary

This research study described the psychosocial significance for mothers and the impact on nursing care when a child was admitted to hospital for severe bronchiolitis requiring oxygen therapy. Three domains were described: *Fear*, *Parent-child interaction* and *Technical caring*. The domain of *Fear* encompassed four themes; *It was horrific, we didn't know if she would live or die; I think some parents do get quite upset; I didn't know what was happening*, and *I stayed with her day and night*. Fear was amplified for the mothers of hospitalised infants requiring oxygen therapy for bronchiolitis if factors were present such as: ignorance of the disease and outcome; unfamiliar or sudden change in environment; unfamiliar nurses caring for their child; and being unable to hold their child and it was distressed.

Four themes were clustered in the domain of *Parent-child interaction*; *I felt inadequate more than useless; All that I wanted to do was hold her and keep her with me; I needed her to feel my heart beat* and; *Look but don't touch*. This domain described mothers' need to be involved in their child's care and to feel close to them. Mothers' descriptions of their child receiving headbox oxygen therapy highlighted the physical and emotional barriers that were present for them. Their feelings of inadequacy and lack of involvement with their child identified the limitations of nursing practice. The theme of *Babies are hard work in the head box because you can't pick them up* was assigned to the domain of *Technical caring* and encompassed the nurses' attitudes and beliefs surrounding both oxygen therapies. They focused on the work place health and safety issues and clinical limitations of both therapies.

Family centred care is promoted in most paediatric hospitals in Australia and this study highlighted the inadequacy of the headbox oxygen therapy to provide a method

of treating children with severe bronchiolitis that allowed adequate parent-child interaction or for nurses to feel secure in promoting parent-child interactions. However, the high flow nasal prong oxygen therapy allowed for access to the child by parents and helped to develop stronger relationship between the nurse and the mother, which promoted trust and wellbeing. The HFNPOT therefore provides a segue to possible improvement in the way health care workers treat children in hospitals with severe bronchiolitis. This form of oxygen therapy promotes both physical and emotional wellbeing for the child, their parent and the nurse as caregiver.

The next chapter will provide a conclusion to the thesis and will discuss limitations of the study and the need for future research.

CHAPTER SIX

CONCLUSION

INTRODUCTION

This chapter concludes the thesis by addressing four important areas. It will summarise the study by re-stating its purpose, methodology, structure and key findings. It will consider the discussion of the previous chapter and identify the important implications of the study. Recommendations of the study are included in this chapter along with the limitations of the study. Concluding remarks to the thesis are provided at the end of this chapter.

Summary of the study

The genesis of this study was the desire to explore the lived experiences of parents and nurses who have had, or cared for a child admitted to hospital with severe bronchiolitis requiring two types of oxygen therapy. A dearth of literature was discovered in this area and the need to investigate the phenomenon became increasingly evident. Pursuant to this goal, an extensive exploration of different methodologies was performed and descriptive Husserlian phenomenology, guided by Colaizzi's methodology was identified as the most suitable approach to investigate the phenomenon of interest.

Participants who had experienced the phenomenon were purposively selected to ensure that they had experienced the phenomenon so that information about it would be brought to light. Twelve mothers and twelve nurses were invited to participate in the study and all responded favourably. All participants were interviewed face to face using a semi structured interview approach.

Data analysis using NVIVO® to organise the data, was guided by Colaizzi's seven step approach: i) Checking the transcripts; ii) Extracting significant statements; iii) Formulating meanings; iv) Grouping formulated meanings; v) Developing and clustering themes; vi) Exhaustive description; and vii) Returning to participant for final validation.

Following analysis, three domains emerged: *Fear*, *Parent-child interaction* and *Technical caring*. These domains were comprised of a total of nine themes, which were discussed extensively in chapter five.

Implications of the study

This section synthesises the findings to form a number of recommendations. An emphasis has been placed on those findings for which possible initiatives are evident. Recommendations are noted throughout this section.

Recognition by nurses of the mother's fear for her baby's life when admitted to hospital for severe bronchiolitis

This study showed that the mother's fear of her baby dying was paramount to her child being admitted to hospital for severe bronchiolitis. Therefore, the first recommendation is for nurses to recognise this fear and try to alleviate it. The most appropriate way for nurses to alleviate some of this recognised fear would be to reassure the mothers regarding their child's outcome and impart knowledge about the disease process, the treatment, equipment and the environment. This information should be disseminated on the arrival to hospital and throughout the hospital stay.

The need for nurses to reassure mothers about their child's outcome and impart information about the disease process, treatment, equipment and environment.

This recommendation is routed in the findings of this study where parents have stated that they felt the need for information. When parents feared for their child's life, it is recommended that nurses impart as much knowledge about the disease trajectory and outcome. In order to impart this knowledge or information it is imperative nurses first recognise the parents' fears for their child's life and understand the parents' need to be reassured that the disease trajectory may worsen and then improve. Nurse also need to possess effective communication skills. The nurse must be able to clearly, concisely and constantly communicate with parents in a way that the parents feel comfortable and are able to understand the information being received. Thus, it is recommended that nurses should participate in regular professional development activities that support their development as effective communicators.

The need for mothers to trust the nurse caring for her child.

Mothers stated that they would like to have been able to get to know their child's nurse and become familiar with him or her. They said this would have increased the trust they had in their child's care giver. Trust was important to them as they felt uncomfortable leaving their child in the care of someone unfamiliar. Familiarity between the nurse and the mother was said to decrease stress, fear and anxiety.

Continuity of care also promotes familiarity between the nurse and mother as the nurse has the same patient in consecutive shifts. Therefore the next recommendation is to establish a primary caregiver which would increase trust between parents and staff.

The need to choose an oxygen therapy that has both physical and psychological benefits for the child with severe bronchiolitis.

Focusing on the psychosocial needs of the mother, the findings of this study suggest that high flow nasal prong oxygen therapy (HFNPOT) is the treatment of choice when a child is admitted to hospital for severe bronchiolitis. In the contexts of the particular oxygen therapies the child received, all negative emotions and attitudes were focused on having a child receive headbox oxygen or caring for a child in headbox oxygen. In contrast, positive attitudes were expressed towards HFNPOT. All the mothers agreed that the HFNPOT was more conducive to parent child interaction and decreased their anxieties by allowing them to hold their child. Being able to care for and comfort their child was critically important to them. Furthermore, the nurses in this study all agreed that the HFNPOT increased family interaction allowing for family centred care to occur and was safer to use. Although further research is needed to support the efficacy of HFNPOT, current evidence suggests that it is safe and effective. Thus, in the absence of any contra-indications, it is recommended that HFNPOT should be the oxygen therapy treatment of choice.

The need to involve parents in their child's care.

The findings of this study showed the headbox did not allow mothers or nurses to access the child freely. With the use of the HFNPOT, parents and nurses could access the child without the physical barrier of the headbox to prevent them. Parents felt disempowered and anxious when unable to care or cuddle their child. Therefore, it is recommended that nurses should encourage parents to be involved in their child's care as much as possible. They should reassure mothers that their efforts are effective and warranted whichever type of oxygen therapy their child is receiving. This should assist in empowering mothers to feel confident in caring for their own child in an unfamiliar environment.

If using the HFNPOT, the opportunity for mothers to hold, comfort, cuddle or even breastfeed their child is possible however if headbox oxygen therapy is used then

nurses must be aware of the mothers' need to hold their child. Provided the child is stable and there are no safety concerns, it is recommended that nurses should actively seek out opportunities for parents to hold their child.

Workplace health and safety.

The findings of this study revealed that ergonomic issues were important to nurses. They felt that caring for a child receiving oxygen in a headbox was non-ergonomic at times as the cots were not able to move up or down and they had to stand on a chair in order to access the child. This practice led to back injuries. This strain on their back was not conducive to the nurses requesting a second day of caring for that same child as they were either too sore or too tired, thus primary care practice was not possible. In order to avoid the potential for back injuries, it is recommended that when using a headbox, the height of the cot must be adjustable.

Safety was of major concern to the nurses in the study. They were apprehensive about either themselves or the mothers accessing the child in the headbox causing fluctuations in the oxygen levels. This is a flaw associated with caring for a child in a headbox. This is unavoidable with the present state of the headbox and only improved engineering of the design of the headbox would improve this flaw. In contrast, the HFNPOT is designed to supply oxygen through a closed circuit system which allows for greater stabilisation of the oxygen concentrations delivered to the child. These design considerations further support the recommendation above that HFNPOT is the preferred oxygen therapy when compared to headbox oxygen therapy.

The importance of familiarity.

The mothers in the study stated that when their child deteriorated and required HFNPOT they were either transferred to the high dependency area of the same medical ward or were transferred to PICU. The mothers who were transferred to the high dependency area indicated that even though they were still very fearful for their child's life they were comforted by the familiar environment and care givers. The mothers who were transferred to PICU all stated how traumatic this was as they were not only fearful of their child's life but had to deal with an unfamiliar environment and care givers. Therefore, it is recommended that when a child requires intense nursing care, continuity of care should be provided by a nurse who is known to the

family and who is also competent to care for a child with high dependency needs. See recommendation: *The need for mothers to trust the nurse caring for her child.*

Further research.

There is a dearth of literature pertaining to paediatric oxygen therapy. There are even fewer studies investigating HFNPOT and there are no psychosocial studies regarding children admitted to hospital and treated with oxygen therapy. This study highlighted the need to further assess the psychological aspects of hospitalised children, their families and the health care professionals when a child is hospitalised for severe bronchiolitis. In particular, it raised questions concerning clinical practice.

Improvement in the parent-child relationship involves other factors such as parent-nurse relationship, the environment, technology, and hospital policies. Therefore, research into technology, policies and physical parameters can be added to the long list of possibilities for further research. These research areas should utilise both qualitative and quantitative methodologies to explore the psychosocial aspects as well as the measureable data.

It is therefore recommended that further studies into the clinical and psychosocial aspects of caring for having a child admitted to hospital with severe bronchiolitis requiring oxygen therapy should be undertaken. These are summarised broadly in the following five areas:

- i) Qualitative studies investigating parental fears of a child admitted to hospital with severe bronchiolitis requiring oxygen therapy.
- ii) Qualitative research into effective communication between parents and nurse.
- iii) Qualitative research exploring the emotional impact of headbox oxygen therapy on the parent-child relationship.
- iv) Quantitative research into the efficacy and safety of headbox oxygen therapy and HFNPOT.
- v) Quantitative research into HFNPOT for other medical conditions.
- vi) Quantitative research into HFNPOT as first line therapy for bronchiolitis

- vii) Qualitative and quantitative research exploring workplace safety issues surrounding the use of the headbox oxygen therapy.

Limitations of the study

The purpose of this research study was to describe parents' and nurses' experiences when a child is admitted to hospital with severe bronchiolitis requiring two types of oxygen therapy. Although it is not possible to generalise the findings of qualitative research to the broader population, theoretical generalisation is possible (Sharp, 1998). In contrast to empirical generalisation which is only concerned with showing that some relevant characteristics of a sample are typical of a population, theoretical generalisation enables theoretical relationships to be transferred to other contexts. The researcher has to convince the reader that what is read is presented with truthfulness. Therefore, the researcher has to demonstrate clarity of methods, consistency and applicability.

Credibility

Credibility is about whether something is worthy of belief. I believe that I have achieved credibility of this study in a number of ways. My research was aimed at a real phenomenon describing it as it is presented, rather than force concepts upon it. This does not decry methods of theoretical or conceptual application; instead it aims to describe experience from the point-of-view of the person experiencing it. A focus upon experience required a method that is sensitive and appropriate to examine it. The descriptive method adopted aimed at avoiding unnecessary or inappropriate interpretation; it was to remain faithful to the phenomenon no matter how incomplete (Giorgi, 2000).

Dependability

One point that limits adequacy (but not credibility) is the limited number of parent and nursing interview participants. The fact that a limited number of parents and nurses provided interview data does not threaten credibility because qualitative research accepts small sample numbers. This does not negate the findings; it accepts

that this aspect is incomplete. Some may continue to be concerned that only twelve mothers and twelve nurses were interviewed. These interviews can also be seen to be context bound, as with most psychological phenomenology, but particularly as all the nurses worked in a similar area, for the same organisation and all were paediatric nurses. The study is also limited by the inability to obtain the views of fathers, and culturally diverse families as the mothers were all Caucasian. Fathers and mothers were both invited to participate yet only mothers responded.

The purposive sampling utilised in this study of twenty four participants may not be representative of all mothers and nurses from the population from which the samples are drawn and thus may be associated with certain biases. The limitations of purposive sampling in this study should be kept in mind. The results of this study cannot be generalised to a wider population and caution should be applied when reading these results. However, the findings in this study do provide a basis for the design of further qualitative studies.

The analysis of the interview data was performed through an accepted descriptive phenomenological method. Colaizzi's method of analysis provided a structured pathway. The findings were shared with most of the participants; but not all could be recontacted thus limiting validation of the data.

The aim of this study was to describe the experiences of parents and nurses who have had or cared for a child admitted to hospital with severe bronchiolitis and received two types of oxygen therapy. The findings use the voices of the participants to describe the phenomenon and I, with the assistance of my supervisors have attempted to identify my own personal bias or presumptions and have not influenced the written words but have allowed the true essences to emerge from the data. The use of a journal also allowed for reflection and identified any bias present in the researcher. The role of the researcher is to suspend or bracket their previous knowledge and assumptions and offer the underlying essential structure of the participant's lifeworld (Giorgi, 1985).

CONCLUDING REMARKS

Exploring the lived experiences of parents and nurses who have had or cared for a child admitted to hospital requiring two types of oxygen therapy has been both rewarding and revealing. This study has uncovered themes important to both nurses

and mothers. Through reflection on these themes, recommendations were put forward for possible changes to clinical practice and improvement in patient/family outcomes.

The way health professionals have traditionally treated children admitted to hospital with severe bronchiolitis has been explored and through this research study the voices of those who journey has taken them on this path were heard. Mothers and nurses gave accounts of their perceptions and attitudes towards both oxygen therapies, describing how these therapies affected them and the child receiving them. Mothers described their abject fear for their child's life and how other factors either decreased or increased their anxiety. Both nurses and mothers voiced their concerns about how the headbox interfered with parent-child interactions. The nurses revealed how the safety aspects of the headbox was of major concern to them and how much more effective the HFNPOT system was in both physical and emotional benefits to the child and the families. Their descriptions revealed truths about the phenomenon of interest and it is for the reader of this study to decide and interpret for themselves the true meaning of their words.

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APPENDIX I

INFORMATION LETTER FOR PARENTS

TITLE OF PROJECT

The experiences of parents and nurses of hospitalised infants requiring oxygen therapy for severe bronchiolitis: a phenomenological study

NAME OF SUPERVISORS

Professor Paul Fulbrook

Professor Sue Kildae

NAME OF STUDENT RESEARCHER

I am Alison Peeler a Registered Nurse. I am enrolled in a Master of Philosophy research degree and this research study is part of my studies at ACU National, Banyo

Contact no: 0409745070

Postgraduate Student; MPhil Candidate

We invite you to participate in this study. Before agreeing to participate in this research study, it is important that you read and understand this form. This form describes the purpose, procedures, benefits and risks of the study. It also describes your right to withdraw from the study at any time. If you participate, you will receive a copy of this information sheet to keep for your records. Information contained in these sheets may be difficult to understand, and the researcher is happy to discuss the details of this research with you until you are comfortable in your understanding.

I am seeking to learn more about the experiences of parents or guardians of children who have had a child diagnosed with severe bronchiolitis and were admitted to the Mater Children's Hospital where they were treated with both headbox oxygen therapy and humidified high flow nasal prong oxygen therapy. I am also seeking to learn about the experience of staff members who have looked after these children.

Purpose of the study

The purpose of this research is to explore the lived experience of parents/guardians/staff who have had/looked after a child admitted to a paediatric hospital for bronchiolitis and have been treated with oxygen therapy via the Fisher & Paykel humidified nasal prongs system and headbox.

- What is involved?

If you agree to participate in the study, you along with other parents will be invited to participate in this study. You will be asked to be visited by the researcher to be interviewed either in your own home or a place of your choice. This will involve asking you to tell us about the experiences you have had when the child was admitted to hospital for bronchiolitis and was treated with both types of oxygen therapy and how this experience affected you and the child. The interview may take 30 minutes and will be tape recorded by the researcher.

- What sort of questions will I be asked?

The questions will be about your experiences of what it was like for you and your child while he/she was receiving headbox oxygen therapy and what it was like for you and your child/parent when he/she was receiving high flow nasal prong oxygen therapy. It will be an informal interview process where you will be asked to tell your “story” about your child’s hospital experience.

- Can I change my mind?

You are free to withdraw from the study at any time, and this will not affect your current or future status within The Mater Health Service District in any way.

- What happens to the information I provide?

All information you give in the interviews will be used only for the purposes of the study. Following the interviews any details which identify you (for example your name) will be coded. All records will be kept in a locked cabinet at the Researcher’s place of residence and at the Australian Catholic University, McAuley campus. No names or case histories or identifying personal information will be reported or published in the presentation of the results of the study.

- Will I receive anything for taking part?

Families like you help us carry out this important work. While the study may not benefit you personally, the study aims to improve services provided to local families based on your feedback.

This will ultimately improve the future health and well being of mothers, fathers and infants throughout Queensland, by providing information that will assist in a greater understanding of the experience being studied.

- Who do I contact?

Any questions regarding this project should be directed to the Supervisor and the Student Researcher.

Alison Peeler (Student researcher)

(07) 0409745070

OR

Professor Paul Fulbrook (Supervisor)

(07) 3623 7420

School of Nursing
Australian Catholic University
PO Box 456
Virginia Q 4014

A summary of the results of the study will be forwarded to you as feedback and follow-up after the project is completed.

This study has been approved by the Human Research Ethics Committee at Australian Catholic University and The Mater Health Services Human Research Ethics Committee.

- What if things go wrong?

Participants may contact the Mater Research Coordinator on 3163 1585 should they have any complaints about the conduct of the research, or wish to raise any concerns.

Any complaint or concern will be treated in confidence and fully investigated. The participant will be informed of the outcome.

PARENT CONSENT FORM

TITLE OF PROJECT

The experiences of parents and nurses of hospitalised infants requiring oxygen therapy for severe bronchiolitis: a phenomenological study

NAME OF SUPERVISORS

Professor Paul Fulbrook

Professor Sue Kildae

NAME OF STUDENT RESEARCHER:

Alison Peeler a Registered Nurse.

Contact no: 0409745070

Postgraduate Student; MPhil Candidate at ACU National, Banyo

Signature Page

To become a part of this study, you must sign this page. By signing this page, you as the parent are confirming the following:

- You have read all of the information in this Parent Information and Consent Form, and you have had time to think about it.
- All of your questions have been answered to your satisfaction.
- You have voluntarily agreed to be part of this research study, to follow the study procedures, and to provide necessary information to the researcher as requested.
- You understand that the project is for the purpose of research and not for treatment.
- You have been informed of the possible risks or side effects of the test or procedures being conducted.
- You give permission for access to your child's medical records, for the purpose of this research.
- You may freely choose to stop being a part of this study at any time.
- You have received a copy of this Parent Information and Consent Form to keep for yourself

Signatures:

.....
Parent/Guardian) Date

.....
Investigator (if applicable) Date

APPENDIX II

INFORMATION LETTER FOR STAFF

TITLE OF PROJECT

The experiences of parents and nurses of hospitalised infants requiring oxygen therapy for severe bronchiolitis: a phenomenological study

NAME OF SUPERVISORS

Professor Paul Fulbrook

Professor Sue Kildae

NAME OF STUDENT RESEARCHER:

Alison Peeler a Registered Nurse.

Contact no: 0409745070

Postgraduate Student; MPhil Candidate at ACU National, Banyo

We invite you to participate in this study. Before agreeing to participate in this research study, it is important that you read and understand this form. This form describes the purpose, procedures, benefits and risks of the study. It also describes your right to withdraw from the study at any time. If you participate, you will receive a copy of this information sheet to keep for your records. Information contained in these sheets may be difficult to understand, and the researcher is happy to discuss the details of this research with you until you are comfortable in your understanding.

I am seeking to learn more about the experiences of nurse, parents, or guardians of children who have had/or cared for a child diagnosed with severe bronchiolitis and were admitted to the Mater Children's Hospital where they were treated with both headbox oxygen therapy and humidified high flow nasal prong oxygen therapy.

Purpose of the study

The purpose of this research is to explore the lived experience of parents/guardians/nurses who have had/cared for a child admitted to a paediatric hospital for bronchiolitis and have been treated with oxygen therapy via the Fisher & Paykel humidified nasal prongs system and head box.

- What is involved?

If you agree to participate in the study, you along with other staff members will be invited to participate in this study. You will be asked to be visited by the researcher to be interviewed at your place of work. This will involve asking you to tell us about the experiences you have had when the child was admitted to hospital for bronchiolitis

and were treated with both types of oxygen therapy and how this experience affected you and the child and their family.

- What sort of questions will I be asked?

The questions will be about your experiences of what it was like for you and the child/parent while he/she was receiving headbox oxygen therapy and what it was like you and the child/parent when he/she was receiving high flow nasal prong oxygen therapy. The interview will use semi- structured interviewing methods that will allow you to tell your “story” with minimal prompting from the researcher. The researcher will be the only person other than yourself involved in the interview. A tape recording of the interview will be kept by the researcher and your privacy will be maintained at all times. The interview may take up to 30 minutes of your time.

- Can I change my mind?

You are free to withdraw from the study at any time, and this will not affect your current or future status within The Mater Health Service District in any way.

- What happens to the information I provide?

All information you give in the interviews will be used for the purposes of the study. Following the interviews any details which identify you (for example your name) will be coded. All records will be kept in a locked cabinet at the Researcher’s place of residence and at the Australian Catholic University, McAuley campus. No names or case histories or identifying personal information will be reported or published in the presentation of the results of the study.

- Will I receive anything for taking part?

Families and health professionals like you to help us carry out this important work. While the study may not benefit you personally, the study aims to improve services provided to local families based on your feedback.

This will ultimately improve the future health and well being of mothers, fathers and infants throughout Queensland, by providing information that will assist in a greater understanding of the experience being studied.

- Who do I contact?

Any questions regarding this project should be directed to the Supervisor and the Student Researcher

Alison Peeler (Student researcher)

(07) 0409745070

OR

School of Nursing
Australian Catholic University
PO Box 456
Virginia Q 4014

Professor Paul Fulbrook (Supervisor)

(07) 3623 7420

A summary of the results of the study will be forwarded to you as feedback and follow-up after the project is completed.

This study has been approved by the Human Research Ethics Committee at Australian Catholic University and The Mater Health Services Human Research Ethics Committee.

- What if things go wrong?

Participants may contact the Mater Research Coordinator on 3163 1585 should you have any complaints about the conduct of the research, or wish to raise any concerns.

Any complaint or concern will be treated in confidence and fully investigated. The participant will be informed of the outcome.

STAFF CONSENT FORM

TITLE OF THE STUDY

The experiences of parents and nurses of hospitalised infants requiring oxygen therapy for severe bronchiolitis: a phenomenological study

NAME OF SUPERVISORS

Professor Paul Fulbrook

Professor Sue Kildae

NAME OF STUDENT RESEARCHER:

Alison Peeler a Registered Nurse.

Contact no: 0409745070

Postgraduate Student; MPhil Candidate at ACU National, Banyo

To become a part of this study, you must sign this page. By signing this page, you as the staff member are confirming the following:

Agreed to participate in the project

- You have read all of the information in this Staff Information and Consent Form, and you have had time to think about it.
- All of your questions have been answered to your satisfaction
- You have voluntarily agreed to be part of this research study, to follow the study procedures, and to provide necessary information to the researcher as requested
- You understood that the project is for the purpose of research and not for treatment
- You have been informed of the possible risks or side effects of the test or procedures being conducted
- You may freely choose to stop being a part of this study at any time
- You have received a copy of this Staff Information and Consent Form to keep for yourself

Signatures:

.....
Staff Date

.....
Investigator (if applicable) Date

APPENDIX III

MATER HEALTH SERVICES ETHICS APPROVAL



Exceptional People. Exceptional Care.

MATER HEALTH SERVICES HUMAN RESEARCH ETHICS COMMITTEE

14 May 2007

Ms Alison Peeler
1768 grassdale road
Gumdale 4154

Dear Ms Peeler

Re: The lived experiences of parents of hospitalised infants requiring headbox and humidified high flow nasal prong oxygen therapy for severe bronchiolitis Ref №. 1081C

The Mater Health Services Human Research Ethics Committee reviewed the recommended modifications in relation to this research. *In all future correspondence with the Committee please quote the Mater reference number.*

The Committee endorsed the modifications and granted full approval for the study to commence on 01.05.07. Please accept our very best wishes for the success of this study.

Documents reviewed and approved include:

- Email correspondence dated 17.04.07 in response to final HREC recommendations dated 12.04.07 including:
 - Information letter to participants Version 2 dated 12.04.07;
 - Parent Guardian Consent Form Version 2 dated 12.04.07;
- Email correspondence dated 02.04.07 in response to HREC questions raised 21.03.07;
- Curriculum Vitae;
- Application for Ethics Approval of Research dated 08.02.07;
- Email correspondence dated 15.03.07 in response to SSC questions raised 06.03.07.

This approval is valid until 01.05.08. Please note the following conditions of approval.

- Any departure from the protocol detailed in your proposal must be reported immediately to the Committee.
- When you propose a change to an approved protocol, which you consider to be minor, you are required to submit a written request for approval to the Chairperson, through the Secretary. Such requests will be considered on a case by case basis and interim approval may be granted subject to ratification at the next meeting of the Committee.
- Where substantive changes to any approved protocol are proposed, you are required to submit a full, new proposal for consideration by the Research Ethics Committee.
- You are required to notify the Research Ethics Coordinator of any serious adverse event or complaints.
- Under the *NHMRC National Statement on Ethical Conduct in Research Involving Humans*, research ethics committees are responsible for monitoring approved research to ensure continued compliance with ethical standards, and to determine the method of monitoring appropriate to each project. You are required to provide a written report on the progress of the approved project annually, the first and final report due on 01.05.08. *(The Progress Report can be emailed to you or downloaded from www.mater.org.au; Education & Research; Human Research Ethics Committee).* Please inform the Committee of publications, presentations at Conferences, education and quality improvement outcomes from this study. The Committee may also choose to conduct an interim audit of your research.

Research Ethics Coordinator Room 235 Aubigny Place Ph: +61 7 3840 1585 Fax: +61 7 3840 1571 Email: Odette.Petersen@mater.org.au

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FR621

Mater Health Service Ethics Approval 2010

MATER HEALTH SERVICES HUMAN RESEARCH ETHICS COMMITTEE

20th May 2010

Ms Alison Peeler
Clinical Nurse Educator
Level 6
Mater Mothers Hospital

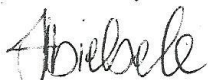
Dear Ms Peeler

Re: **Protocol Ref N^o. 1081C The lived experiences of parents of hospitalised infants requiring headbox and humidified high flow nasal prong oxygen therapy for severe bronchiolitis**

The Mater Health Services Human Research Ethics Committee noted the request for extension of approval. Your approval has been extended to 1st January 2011. Best wishes for the remainder of the study. Please continue to provide at least annual progress reports until the study has been completed.

Should you have any queries please do not hesitate to contact the office of the Research Ethics Coordinator on 3163 1585.

Yours sincerely



Ms Ibinabo Ibiebele
A/Research Ethics Coordinator
Mater Health Services Human Research Ethics Committee

APPENDIX IV

ACU ETHICS APPROVAL

Human Research Ethics Committee

Committee Approval Form

Principal Investigator/Supervisor: Professor Paul Fulbrook Brisbane Campus

Co-Investigators:

Student Researcher: Ms Alison Peeler Brisbane Campus

Ethics approval has been granted for the following project:

The lived experiences of parents of hospitalised infants requiring headbox and humidified high flow nasal prong oxygen therapy for severe bronchiolitis

for the period: 26 July 2007 to 31 May 2008

Human Research Ethics Committee (HREC) Register Number: Q200708 2

The following standard conditions as stipulated in the *National Statement on Ethical Conduct in Research Involving Humans* (1999) apply:

- (i) that Principal Investigators / Supervisors provide, on the form supplied by the Human Research Ethics Committee, annual reports on matters such as:
 - security of records
 - compliance with approved consent procedures and documentation
 - compliance with special conditions, and
- (ii) that researchers report to the HREC immediately any matter that might affect the ethical acceptability of the protocol, such as:
 - proposed changes to the protocol
 - unforeseen circumstances or events
 - adverse effects on participants

The HREC will conduct an audit each year of all projects deemed to be of more than low risk. There will also be random audits of a sample of projects considered to be of negligible risk and low risk on all campuses each year.

Within one month of the conclusion of the project, researchers are required to complete a *Final Report Form* and submit it to the local Research Services Officer.

If the project continues for more than one year, researchers are required to complete an *Annual Progress Report Form* and submit it to the local Research Services Officer within one month of the anniversary date of the ethics approval.



Signed:

Date: 26 July 2007
(Research Services Officer, McAuley Campus)

ACU Ethics Approval 2010

Dear Paul and Alison,

Thank you for returning the Ethics Progress Report for your project Q200708-2 *The lived experiences of parents/nurses of hospitalised infants requiring headbox and humidified high flow nasal prong oxygen therapy for severe bronchiolitis*.

The Deputy Chair of the Human Research Ethics Committee has approved your request to extend the period of data collection. The new expiry date for data collection is the 31 December 2010.

We wish you well in this ongoing project.

Kind Regards,

Kylie

Kylie Pashley

Research Services

McAuley at Banyo Campus

PO Box 456

VIRGINIA QLD 4014

AUSTRALIA

I am available Monday, Thursday and Friday.

Tel (+61 07) 3623 7429 Fax (+61 07) 3623 7328

EMAIL: kylie.pashley@acu.edu.au

Australian Catholic University Ltd

ABN 15 050 192 660

CRICOS Registration codes:00004G, 00112C, 00873F, 00885B

APPENDIX V

SAMPLE INTERVIEW QUESTIONS

Sample questions for parents:

Q. Can you think back to the time when your child was admitted to hospital with severe bronchiolitis and tell me how that journey evolved please?

Q. What sort of interactions did you have with your child when it was receiving either type of oxygen therapy?

Q. You said you were involved with your child's day-to-day care. Could you elaborate on how much and how did that make you feel?

Sample questions for nurses:

Q. Can you think back to a time when you looked after a child with bronchiolitis in a headbox.

Q. What did you mean when you said the parents didn't have much contact with their child.

Q. Can you tell me about your experiences of looking after a child on high flow.

APPENDIX VI

TRANSCRIPT SAMPLE OF AN INTERVIEW WITH A NURSE

Transcript 3

Researcher: Can you think back to a time when you cared for a bronchiolitic baby in a headbox and tell me how that was for you?

Participant: I think for me setting up a headbox is fairly easy. Looking after a child in a head box is frustrating just because they are in the box and it is a barrier. It is not very accurate you would say because you are putting your hands in and out and letting the oxygen out all the time. In most cases it is successful in treating bronchiolitis and helping with work of breathing. Most of the time anyway. Sometimes kids don't handle it or are too sick and require extra support. Other than the frustration of patting the poor child and seeing it upset and unsettled, half dressed and hard to get at, the hb is a useful way to treat these kids.

R: You brought up some good issues. Could perhaps expand on why it is frustrating.

P: With bronchiolitis we tend to group our day-to-day care so that the child is not always being disturbed and we aren't continually letting out the oxygen. We change their nappy, take their temperature, change their clothes or bedding, bath them or suction them every 4 hours however the typical bronchiolitis baby won't sleep for four hours between day-to-day care so you are having to access the hb to try and settle them. You might just want to pop a dummy in to settle them. Our aim is to keep them as settled as possible to reduce their work of breathing and to allow them to regain some strength and stability. The oxygen levels fluctuate constantly the more you try to settle the child especially if they are thrashing around, they will let out a lot of the oxygen which they need and in fact are placed in the box for that reason. Hence the frustration because the really unsettled or sick baby needs more oxygen and it is disturbing its environment every time the nurse or mother have to lift the lid of the hb. Another thing that is frustrating is the accessibility to the box. You can really hurt your back because it is hard to reach in side and sometimes you are twisting and

turning your back in order to settle the child. The beds aren't very good as they don't lower and for short nurse this is a real problem. I have even seen someone standing on a chair to access the child. Another thing that happens is that the child can get really sweaty and smelly and you have wash them frequently and change their bed linen. This is almost impossible to do by yourself so another nurse may have to hold the child and apply oxygen to its face while you change the bedding etc.. And because it is so humid you have to wipe the inside of the box down frequently as it fogs up the interior. It may also be a breeding ground for other bacteria or fungus! So that's frustrating too.

So as therapy it is good but it definitely has its limitations.

R: Can you tell me a bit more about how it affects your back.

P: Well like I said sometimes you have to settle a baby and could be standing by that bed for up to three hours. It is incredibly difficult to maintain a safe posture. It is really un-ergonomic on your back. If the bed it was on was more able to be manipulated the better you could access the hb but even so the square box itself is a rigid contraption that you can bend to adjust for you or the baby.

R; What sort of involvement do parents have in their child's care?

P: We have to explain a lot to them about the hb and what it is doing for their child. They want to be able to care for their child by doing the changes etc but sometimes we do them because we are quicker and the parents let out too much oxygen. This can be too dangerous so we encourage the parents to do the minimum for their child just to be safe.

R: how does this reflect on your wards philosophy of family centred care?

P: It goes against everything we strive to achieve with fcc. The parents are normally encouraged to do as much with their child as they can but not the hb ones as I said it is too risky.

R: how do you think this affects the parents of children in hb?

P: The parents are quite distraught at times. I think if I was a mother your first instinct is to cuddle and care for your baby as much as you can. These parents look quite helpless just sitting there not being able to touch their child and us actively discouraging them from doing so as well. They're the ones who are frustrated but of course for different reasons than us. One mother said it felt like her baby was in a gold fish bowl. Look but don't touch.

APPENDIX VII

SAMPLE JOURNAL REFLECTION

Sample:

The interview today took place in the participant's home. She was nervous about me interviewing her and being recorded. After a while she relaxed and forgot the recording device was in the room with us.

The participant became emotional about talking about her experiences and began to weep gently. I asked if she would like to cease the interview but she was adamant that she would like to continue and be able to share her experiences of her child's time in hospital and what they went through. The participant expressed her appreciation at being able to share this experience and said it made her feel better in fact telling her story even though remembering her child's suffering had made her cry.

I remained open to her emotions and was able to show her understanding and compassion.

When interviewing this mother, I was aware of my own bias and my desire to direct her answers. However, I was careful to not use leading questions and only asked her to describe her experiences. I allowed her talk at her leisure, without interruption about how she felt, reacted or responded to the open ended question I had asked her about the phenomenon under study. I was also aware of how I responded to her story and was very aware of how I either nodded or shook my head. I felt that I used a very neutral tone and neutral facial reactions when interviewing her about her experiences yet appropriately sympathetic. To further assess my bias, I listened to the recorded interview and was relieved to hear very little bias in my tone or answers.

APPENDIX VIII
Participant Summary

MOTHERS

Mother Participants	Married	Child	Multiple children	Child in ICU	Child in HDU
Arlene	■	■		■	
Barbara	■	■	■		■
Crystal	■	■		■	
Donna	■	■		■	
Elizabeth	■	■	■		■
Fiona	■	■	■		■
Geraldine		■		■	
Hayley	■	■	■		■
Isobel	■	■		■	
Jackie	■	■	■		■
Kelly	■	■	■		■
Larissa	■	■		■	

NURSES

Nurse Participants	Children of their own	PICU qualifications	Years registered
Michelle		■	22
Natalie			10
Olivia	■		10
Penny			5
Sueanne			8
Tania			2
Una	■	■	15
Veronica			20
Wendy		■	23
Xavier		■	12
Yanna	■		10
Zena	■	■	18

APPENDIX IX ABSTRACT AND CONFERENCE PRESENTATIONS

PSANZ Conference, 2006, Adelaide- Poster presentation

Abstract

Humidified high flow nasal prong oxygen – better than bubble CPAP for the term baby?

Traditionally, humidified nasal prong oxygen has had limitations due to a lack of reliable humidification monitoring. Problems associated with this oxygen delivery system include 'rain out' and poorly controlled heating. The *850 humidifier model* from Fisher & Paykel appears to address these issues. This new system has various attributes such as a heating element that is sensitive to change and delivers constant heat up to the end of the circuit, which in turn reduces the rainout in the nasal prong tubing. It can also heat gas flows at variable rates, from as little as 0.5 litres per minute up to six litres per minute. Another benefit of this new model is that it seems to produce an inadvertent Positive End Expiratory Pressure (PEEP) when delivered at a higher gas flow rate. The Mater Children's Hospital, Brisbane will be researching the level of PEEP this system delivers and assessing the benefit it may have in respiratory distressed infants. There have been no clinical trials to date that have investigated the PEEP delivered or assessed infants' breathing efforts using high flow nasal prong oxygenation. The observable benefits so far have been encouraging and the hospital has used this system effectively on an infant with chronic lung disease. The child was born at twenty eight weeks gestation and treated with bubble Continuous Positive Airway Pressure (CPAP) for respiratory distress for many weeks. At twenty two weeks of life he was changed to the humidified high flow nasal prong oxygen system. Five litres per minute of mixed gas was needed to maintain the child's saturation levels above ninety five percent. This resulted in the child being able to be nursed outside of the intensive care unit and eventually was transferred back to a peripheral hospital closer to his parents. More research is required to determine the benefits or detriments of this humidification system.

Critical Care Conference, Gold Coast, 2007 -Oral presentation

Abstract

Background: Non-invasive ventilation (NIV) using continuous positive airway pressure via face mask, nasal prong or nasopharyngeal tube bubble has become an integral part of respiratory support in infants. A new form of humidified oxygen delivery technique has been promoted using a high flow nasal prong system (HFNP). The Fisher & Paykel 850 humidifier is able to deliver high flow nasal prong oxygen therapy to respiratory distressed patients. This system produces a Continuous Positive Airway Pressure (CPAP) which at this stage has not been measured scientifically, although Brisbane Mater Paediatric Intensive Care unit is about to commence research into this shortly.

Aim: Does HFNP reduce the need for invasive ventilation?

Methods: All infants admitted to the paediatric intensive care unit for NIV were analysed in the period since HFNP was available (Jan-June 2005) and compared to a historical control group of infants in the same season of the year 2004.

Results:

Twelve infants (aged 0-2yrs) requiring NIV were admitted in 2004 of which 3/12 patients received bubble CPAP and 9/12 mask CPAP/BiPAP. All infants on bubble CPAP required invasive ventilation during their stay in PICU. In 2005 HFNP was offered to 4/18 patients and none of these needed invasive ventilation.

Conclusion:

There is a trend to reduce the number of invasive ventilation using HFNP. In addition nursing care of patients on HFNP is easier, as patients are not connected to cumbersome ventilator tubing systems (or something nice stuff like that....)

All other admissions in either group were either ventilated or were treated with Masked CPAP/BIPAP via a ventilator.

New technology is being produced every year and we, as clinicians are continually investigating the efficacy and safety of these new products. In the past we have used bubble CPAP as a form of non-invasive ventilation to treat similar paediatric patients admitted to the Paediatric Intensive care unit (PICU). We investigated both Systems by studying the data in similar periods of time over two years looking at our use of Bubble CPAP and high flow nasal prong and if invasive ventilation was required in either application. Respiratory distressed patients who were admitted to PICU from January 2004 to July 2004 and in January 2005 to July 2005 were reviewed in a retrospective data study. The later group in 2005 had the high flow nasal prong oxygen delivery system as a choice of treatment where as the 2004 group did not. 12 patients were admitted in 2004 and 18 patients were admitted in a similar time frame in 2005. 3 patients in 2004 were given Bubble CPAP on admission, which was followed by invasive ventilation. In 2005, high flow nasal prong oxygen therapy was offered to 4 patients and none of these needed invasive ventilation. All other admissions in either group were either ventilated or were treated with Masked CPAP/BIPAP via a ventilator. Bubble CPAP has not been used at all in the 2005 group and it appears that the high flow nasal prong system is being in its place and is perhaps more effective. Further research is required.

ACCN Paediatric Intensive Care Conference, Brisbane, 2009- Oral presentation

Abstract

Headbox to High Flow: Where to from here?

Bronchiolitis is an ongoing major factor causing admissions to Children's hospital each year. Traditionally we have treated these patients with headbox oxygen and other supportive measures. This has been effective in treating the child but at the expense of the parents. Most children's hospitals promote family centred care and the question then is- "Do we provide an opportunity for this to happen when we use headbox oxygen as a therapy?". The high flow allows more family interaction and an opportunity to work closely with their child's nurse in order to provide the best possible care. Another question to be asked is- "Is headbox oxygen safe and easy to use for the nurses caring for a child in one?". My study aimed to identify and describe these experiences that would in turn highlight how we manage and treat these children and their families when they have a seriously ill child with bronchiolitis that requires both types of oxygen therapy. Using a phenomenological methodology, interviews of

twelve mothers and twelve nurses were conducted and the data was analysed to uncover common themes, such as patient safety, parent-infant bonding, anxiety and family centred care. These issues were identified and the results exposed safety issues, and the lack of interaction that was allowed when a child was in the headbox in turn causing increased anxiety and stress in both the parent and the nurse caring for the infant.

6th World congress on Paediatric Critical Care, Sydney, 2011- E-poster presentation

A QUALITATIVE INVESTIGATION OF PARENTS' AND NURSES' EXPERIENCES OF HIGH FLOW NASAL PRONG OXYGEN THERAPY

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Objectives

Annually, bronchiolitis is a major cause of children's hospital admission. Traditionally, children suffering from respiratory distress are provided supplemental oxygen via a headbox. Whilst effective in treating the child physically, this is very restrictive and limits parental access to their child. This can have a detrimental affect on parental bonding, their relationship with their child, and their ability to fulfil their parenting role. High flow nasal prong oxygen therapy (HFNPOT) offers an effective contemporary treatment alternative, which is less restrictive. The objective of this study was to investigate parents' and nurses' experiences of using both the headbox and HFNPOT. This has not been investigated previously.

Methods

A phenomenological design was used to interview a purposive sample of parents (n=12) and nurses (n=12).

Results

Several themes emerged from data analysis: patient safety, nurses' occupational health, parent-infant bonding, parental anxiety, and family centred care. In particular, parents identified that lack of interaction with their child caused anxiety and stress.

Conclusions

The findings demonstrated that parents' and nurses' experience of HFNPOT were that it enabled parents to interact with their child and for staff to feel safe letting them do so. The accessibility of HFNOT not only facilitated family centred care but also enabled a greater level of safety of care to be provided by nurses. The findings suggest that HFNOT may provide a better treatment alternative to headbox therapy because in addition to providing effective oxygenation it has added benefits for both the parent-child dyad and the nurses.