A STUDY TO EXPLORE MOTHERS' AND FATHERS' SHARED AND INDIVIDUAL EXPERIENCES OF PREMATURE BIRTH.

A thesis presented in partial fulfilment of the requirements for the degree of

MASTER OF SCIENCE

in

Psychology

at Massey University, Albany, New Zealand

Michele Lomas

2005

Abstract

This qualitative research project using some of the methodologies of Grounded Theory looked at five couples' experiences of premature birth, in particular comparing and contrasting the experiences of mothers and fathers. Significant themes that were identified were: helplessness, related to parents' belief that they were unable to alter outcomes for their baby; issues of control around the care of the newborn baby; communication and relationships with healthcare staff and the impact on parents' perceptions of inclusiveness in the care of their infants; and for fathers in particular, feeling that they missed out on aspects of the parenting of their newborn. The conclusions were that, due to a number of factors within the NICU environment in conjunction with gender specific methods of coping, fathers tend to be marginalised and excluded from the care of their babies. As a result of this, fathers then distance themselves from contact with their newborns, leading to the cyclic exacerbation of the issues of control and helplessness, which further reinforces their disengagement from the situation. Mothers struggled with the same issues, but not to the extent that they withdrew emotionally and physically from the care of their babies.

CONTENTS

CHAPTER ONE: PERSPECTIVES

The birth of a new baby in a family will in the normal course of events cause changes and stressors of which the parents will have had little true conception prior to the baby's birth. Imagine then if you will the effects on parents when the birth of their baby is too early for it to survive outside a specialised unit. In many cases there will be little advance warning of a premature birth or any idea that the birth is frequently associated with major surgery on the part of the mother. There is the incredibly small size of your infant to come to terms with. The machinery and the sheer volume of noise in the neonatal intensive care unit, plus the number of leads, lines and alarms attached to your baby. Initially there will be little opportunity to touch your child let alone pick it up to feed it. There may be long distances to travel to get to the unit, and there is also in a lot of cases the associated worry of how to cope with other members of your family. On top of this all there is also the fear that your baby may not live.

In any new birth, there has long been an emphasis on the establishment of the mother infant bond. The mother tends to be the parent who is around the baby the most, and traditionally plays the major role in infant care. This naturally has lead to the development of family admission policies in special care baby units that reflect the importance of the mother infant bond. While this is a worthy and necessary goal, it may be that in emphasising the mother/child relationship and reflecting on the psychological and sociological importance of this bond, we have failed to acknowledge that premature births also have a psychological and sociological impact on the immediate and extended

family, and particularly the father. This research project is aimed at attempting to determine some of the effects of premature births not only on mothers but also on fathers and on the couple and to explore the differences and similarities between these experiences.

Reflexive Note. Because this research project is driven in some respects by who I am and what I have experienced it may help to put this study into context by taking a quick look at me. Firstly, I am a pakeha, middle aged woman with a tertiary education. I grew up in a very small town in Central Otago, which perhaps fostered my independence and assertiveness. My dad had nine brothers and we were the first girls to be born into his side of the family in 90 years. My mother also came from a large family, and was an assisted war emigrant, who arrived from Scotland in the early fifties. She trained to be a nurse and then met and married my father who was a farmer. I am the middle daughter in a family of three girls. I attended a very small Catholic school and went from there aged twelve to what was considered a much bigger school for my home town. In my Sixth Form class there were four students, all of whom were girls. My class was the first to gain University Entrance for one student, let alone all four of us. The second precedent we set was that none of us were pregnant at the time.

From school I went to work at Cherry Farm, at that time the local Psychiatric Hospital. I became a registered psychiatric nurse in 1981, having trained in a very large hospital in South Auckland, and over the course of the next 21 years I took papers with Massey culminating in a Bachelor of Science majoring in Psychology in 2002. I now have four children, two of whom were home births.

Our fourth child was supposed to be a home birth as well, but he had other ideas, including the desire to act as the main inspiration for my Masters thesis. Fennec was born 8 weeks

early on the 3rd of May 2000. The fact he was going to arrive early was not entirely unexpected: my waters had broken at least five days prior to his birth. Also though he was our fourth child he was not our fourth pregnancy, as we had had a number of miscarriages that had all occurred within the first trimester. Each baby that had successfully managed to make it to birth had also been born closer and closer to the start of the third trimester. Our eldest was born on his due date; the second was born 11 days early; the third managed to arrive three weeks early; and Fenn, well and truly broke the record for an early birth in our family.

I know looking at Fenn lying in the Neonatal Intensive Care Unit (NICU) with a plethora of tubes, monitors and alarms coming out of his body, that we didn't really think beyond the moment. We were just so pleased he was alive. Other concerns did not percolate past this fact. Certainly in that time spent in NICU it never occurred to me that there was a potential for his early birth to have an impact on his neurological functioning. As far as I was concerned, he was breathing at delivery, he was on oxygen thereafter, and the possibility of neurological damage never entered my thinking. Our days in NICU were about feeding him first through a syringe down a nasogastric tube, then getting him onto the breast and watching his body weight, keeping an eye on his body temperature, holding him in such a way that we didn't impair the oxygen flow to his lungs, listening for alarms, checking monitors, and constantly being in awe of this tiny bright red specimen of babyhood. We picked him up like he was the finest porcelain china. We scrupulously scrubbed our hands before touching him or anything that was going to come into contact with him. We monitored our friends and family about potential coughs, colds and any other bugs they may have come in contact with, before we allowed them to come and visit. The contrast between this regime and the two relaxed and happy home births that had preceded it could hardly have been greater.

Preterm Infants: Description

The following terms and definitions are taken from Bradford (2000). Most babies arrive between 38 and 41 weeks gestation, so a premature baby (prem, preemie, etc) is one born before spending 37 weeks in the womb. There is then a series of terms used to define the actual number of weeks a baby has spent in the womb: extremely premature (24 to 28 weeks gestation); very premature (29 to 34 weeks) and moderately premature (35 to 37 weeks). The next most common terminology used in reference to babies deals with their weight, with a low birth weight baby being one who weighs less than 2.5kg at birth. Most prems are also low birth weight babies. A very low birth weight baby is one born weighing less than 1.5kg, and an extremely low birth weight baby is a baby born weighing less than 1kg.

The earlier on in the pregnancy that birth occurs the greater the risks to the infant and unfortunately there are only a limited number of interventions available to prevent a woman going into full labour. Many of these interventions will involve admission to hospital and at the very least will begin with bed rest although recent studies have shown that this may not be efficacious in preventing premature labour and delivery (Yost, Bloom, McIntire & Leveno, 2005). Depending on the number of gestational weeks passed the option over how the birth will progress may be limited to an emergency caesarean. This option is the preferred method of delivery as the baby is often in a breach presentation and caesarean delivery reduces the stress and damage that can occur during delivery (Weissman, Blazer, Zimmer, Jakobi & Paldi, 1988).

Mothers at risk of delivering before 37 weeks will be given a number of steroid injections. These injections are essential if the baby is to develop surfactant (a lung product) which will allow their lungs to mature; without surfactant premature babies are at risk of developing hyaline membrane disease. Preferably there is 24 hours between the second injection and the baby being born as this is the minimum time available for the injections to produce a change in surfactant production in the baby (Sen, Reghu & Ferguson, 2002).

Treatment after birth for a premature infant often means immediate transfer to the special care nursery or neonatal intensive care unit, because of anticipated complications The environment within NICU is designed with the premature infant's particular needs in mind and to reduce the amount of stress placed on the newborn. Premature babies have three specific requirements: warmth, food and an environment where they are protected whilst they undergo the essential growth and development that they have missed in utero (Tunell, 2004; Adan, LaGamma & Browne, 1995; Aucott, Donohue, Atkins & Allen, 2002). As a result of the improvement in neonatal technology over 90% of babies born before 37 weeks and weighing 800 grams or more survive. The chances of survival for those weighing above 500 grams is between 40% and 50%, however their risk of complication is higher (Gomella, 1999).

There are numerous possible causes of premature delivery. It is associated with a number of maternal lifestyle or health factors such as smoking, or not gaining enough weight during pregnancy (Steer & Flint 1999). However, all too frequently the cause is not directly under the mother's control. In particular, preterm delivery is more likely

when a woman is in her teens or above her mid thirties, or where the mother is carrying multiple babies, and sometimes the cause is simply unknown (Martin et al., 2003). Premature infants are more likely to be girls than to be boys. They often have very little body fat and have decreased muscle strength, muscle bulk, and muscle tone and numerous complications may develop, due to birth prior to the completion of development (Boukydis, Bigsby & Lester, 2004). Establishing the baby's actual gestational age can be done on the basis of surveying the infant's physical characteristics (Dubowitz, Dubowitz & Goldberg, 1970), where the amount of creasing on the soles of the baby's feet, genital development, and other characteristics can give an extremely accurate estimate of the number of weeks of gestation. The maternal dates (date of last normal menstrual period) can also give a fairly accurate measurement (Keehn & Lieben, 2004).

As noted earlier the direct result of improving neonatal technology is reflected in the increasing number of babies surviving despite being born early. Over 400,000 prem babies are born annually in the United States, an incidence of 12.1% of all live births in 2002 (Martin et al., 2003). As would be anticipated, the lowest birth weight and frailest babies have the most significant long-term problems and their mortality rates are correspondingly the highest, with infant survival ranging from over 95% for babies born at 30 weeks (with an average birth weight of 1.35kg) down to less than 3% for babies born at 23 weeks (with an average birth weight of 500g) (Gomella, 1999). York and Devoe (2003) outline the potential long-term health implications for premature infants as including chronic lung disease, cerebral palsy, learning disabilities, and vision and

hearing impairments (all of which have since become apparent for Fennec). While doctors have made tremendous advances in caring for babies born too small and too soon, they have yet to find out how to prevent these early births from happening in the first place, despite decades of research. In fact, in the United States of America, the rate of premature birth increased from 9.4% in 1981 to 12.1% in 2002 (Martin et al., 2003).

Preterm Technology

The three most basic requirements for any newborn are breathing, feeding and warmth. These requirements are more of a concern when a baby is born prematurely, because the systems responsible for these three areas have not developed fully in a premature infant. An early baby is often moved to a neonatal intensive care unit where various pieces of technology may be used to assist and monitor the baby. From our own experience, an NICU can be a place of seemingly constant beeping from one monitor or another, with alarms set to go off if a baby's breathing, heart rate, temperature or oxygen saturation falls outside a preset range.

Some examples of the technology that may be employed in the care of a premature baby from our experience and from the experiences of the parents in the current study are as follows. For more detailed descriptions, see Bradford (2000). Different types of monitors include:

- Monitors to measure heartbeat and breathing. These are likely to be attached via soft pads on the baby's chest.

- Oxygen saturation monitors. These measure the level of oxygen in the blood by shining an infra-red light through a baby's hand or foot.

- Blood pressure monitors. These can either be in the familiar form of a pressure cuff around the baby's arm, or may be attached to a line going into an artery.

An incubator will be used to keep the newborn warm and in some cases to control the air the baby is breathing. An incubator in its simplest form is essentially a transparent plastic box on wheels. Depending on the baby's particular needs, a fully enclosed incubator with latching portholes and a lid may be used. For less fragile infants, the incubator may be an open-topped box with a heating pad incorporated into the mattress, or placed over the baby.

There are a number of special pieces of equipment developed to help a baby to breathe, but treatment for breathing will usually have started well before baby was born via the steroid injections mentioned above.

Other methods are employed following the birth of the baby. Essentially there are three different methods.

- For babies who need a little extra oxygen but otherwise can breathe without help, oxygen may be piped into the incubator, or an oxygen mask or head box (that fits over the baby's entire head) may be used. A very common sight in NICU is a baby with a nasal cannula, an oxygen tube leading to two soft prongs that go up each nostril.

- Similar to the nasal cannula is CPAP (Continuous Positive Airway Pressure), a technique where a mixture of air and extra oxygen is pumped through tubes in the baby's nostrils down into the lungs, keeping the lungs partially inflated at all times. This stops the lungs from collapsing inwards, and prevents the inner surfaces (the alveolar sacs) from sticking together. It also means the baby does not have to work as hard to breathe (DePaoli, Morley, & Davis, 2003). One positive benefit of the use of CPAP is that Fennec has the most perfectly formed circular nostrils imaginable, due to the early shaping influence of the nasal prongs.

- A ventilator can either help breathe or completely take over breathing for a baby. A mixture of air and oxygen is pushed down an endotracheal tube, which goes into the mouth, down the throat and into the lungs. As Bradford (2000) describes, there are two main types of ventilator: a positive pressure ventilator, which pushes a mixture of air and oxygen under controlled pressure; and an oscillatory ventilator, which delivers the air oxygen mixture into the baby's lungs but 'vibrates' rather than blows the mixture in. This type of ventilator is very gentle on the lungs.

Many preterm infants have apnoea attacks, where they may stop breathing for 10 to 20 seconds or more. To monitor for this, most babies in NICU will be attached to an apnoea alarm that will monitor the baby's breathing either through a blanket that the baby lies on, or a belt worn around the infant's waist.

There are a variety of methods for feeding premature infants, many of whom will have developed neither the suckling response nor the muscular coordination required to feed from a breast or bottle. An intravenous line may be used to introduce food, hydration or medication directly into the baby's bloodstream. A tube may be used to put food directly into the baby's stomach; this will be either a naso-gastric tube (that enters via the baby's nose) or an oro-gastric tube (that enters via the baby's mouth). In some cases, a transpyloric tube may be used to feed directly into the baby's small intestine.

There are several other pieces of technology that may be used with pre term infants. For example, a common concern with premature babies is jaundice, associated with high levels of bilirubin in a baby's blood, which can lead to brain damage. The treatment for this is to break down the bilirubin by shining bright lights on the baby's skin. This will be done either using a phototherapy unit similar to a suntan bed, or placing the baby on a biliblanket, a special mat composed of brightly lit fibre optic tubes.