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‘Do you people even think about the lives you ruin?’

Perspectives and Influences on the Provision of Care for Extreme Preterm and Periviable Babies in North Queensland.

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Abstract

Objectives and Scope of the Study

This study aimed to investigate the provision of intensive care for periviable and extremely premature infants in North Queensland and understand how decisions are made to offer intensive care. This research included the reflections of parents about antenatal decision-making, and whether parents felt the decision to provide intensive care had been right for them. The parents who had delivered periviable or extremely premature babies were interviewed between two and seven years after their neonatal intensive care experience. A further goal was to examine decision-making in the neonatal intensive care unit (NICU) and the parental experiences of the care received there. The attitudes of the health care professionals (HCP) about the resuscitation of these babies were explored. Later experiences of the family after discharge from the NICU and the perceptions of HCP of babies' progress was sought. Health care professionals included those from a tertiary, regional and remote centre who care for the women at risk of extremely premature delivery – midwives and obstetricians, neonatal staff – neonatologists and neonatal nurses, as well as paediatricians. The study examined palliative care options from the perspective of the neonatal nurses providing palliative care, and the options to redirect care from intensive to palliative from parents and HCP perspectives.

In doing this research, I hoped to achieve an understanding of how the TUH service could improve decision-making so that care could be provided in a way which could lead to a more satisfying parental experience.

Methodology

This study was performed using a complex pragmatic multiphase methodology. Phase One consisted of a retrospective quantitative cohort study examining the outcomes of all live-born babies from 22 completed weeks gestation in North Queensland from January 2010 to December 2016 inclusive. Babies who received care at the Townsville University Hospital (TUH) NICU were reviewed and those whose families were normally resident in North Queensland (NQ) and who did not have a known syndrome at the time of the study were investigated for variables of ethnicity, gender, place of birth, normal family residence, administration of antenatal steroids, age and weight at delivery, survival and the presence of important short term morbidities. Informed by the results of Phase One, Phase Two consisted of a grounded theory study using Charmaz's constructivist principles exploring the family experiences of perinatal, neonatal and later care for their vulnerable baby to ascertain their reflections about the research topics. A second study in Phase Two was a convergent mixed methods study consisting of a quantitative survey of HCP attitudes towards periviable care performed contemporaneously with a grounded theory study using a Charmaz constructivist approach to explore the attitudes of HCP. The last study in this phase was a qualitative study using a phenomenology approach of the experiences of neonatal nurses performing palliative care in the TUH NICU. Phase Three integrated the findings of the studies in Phase Two to derive an understanding of decision-making and the consequences thereof for periviable babies in NQ.

Results

Phase one showed that most babies born at 23 and 24 weeks completed gestation received care at TUH NICU, with a survival and short term morbidity within the range found in the Australia and New Zealand Neonatal Network (ANZNN) figures. Approximately 25% of all extremely preterm babies were born outside the tertiary centre. When corrected for the

variable of the administration of antenatal steroids, there were no differences in the short-term outcome of inborn and outborn babies. The family study showed that parents were mostly happy with the decision to resuscitate their babies and the care which their babies received and could contextualize their experiences in their wider life events as life-changing. Many parents had health, social or spiritual backgrounds which predetermined their desire to have resuscitation for their baby regardless of any medical opinion. Other parents trusted HCP to make decisions in their best interests, often unaware of the variations in HCP opinions or biases. Later almost all the families thrived, with families adapting to disability where this occurred. However, for a few families the child had such severe disability or suffering that the parents regretted that resuscitation had occurred. Redirection of care during NICU complications at parental request had been refused. The HCP survey showed that all HCP were unduly negative about the survival and healthy survival of the most premature babies, particularly below 26 weeks gestation. HCP who cared for women antenatally were more negative than those who cared for the neonate or child. The qualitative study and the mixed methods analysis showed that an expert model of counselling existed at TUH with paternalistic decision-making seen. Role specific implicit bias was found and could be explained as a function of the differing roles in health care. Differences in attitudes towards the regionality of the family were seen, but the social and family advantages of living in a regional or remote centre appeared to outweigh the medical limitations. The concepts of futility lack clarity for both parents and staff, with parental focus on survival but staff focus on quality of life noted. Palliative care was found to be mostly delivered well, with concerns identified around confidence, support and education of staff. The provision of redirection, however, appeared to be clinician dependent.

Principal Conclusions

Care for periviable and extremely premature babies in NQ is provided to an equitable standard compared to other ANZNN centres. The relatively low provision of antenatal steroids in at risk women needs to be addressed. Parents who receive care are mostly satisfied with the care provided, but a model of shared decision-making which engages better with parental values and goals would improve the experience for families, with more accurate data provision where it is requested. It is important for all staff to understand the potential positive outcomes and accurately understand the risks to enable them to interact appropriately with families. Families who would consider limitation of intensive care would be more readily identified. Regular review of an infant’s progress and increased participation in decisions about all aspects of care should occur. Reassurance that families usually cope with a child’s emerging disability might help parents in their decision-making and coping with the NICU stay.

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Abbreviations

Abbreviation	**Name**
ANTS-NQ	Advanced Neonatal Transport Service North Queensland
ANZNN	Australia and New Zealand Neonatal Network
ARIA	Accessibility/Remoteness Index of Australia
BI	Best interest
BMJ	British Medical Journal
FiCare	Family integrated care
HCP	Health Care Professional
HREC	Human research ethics committee
ILO	Indigenous Liaison Officer
IVH	Intraventricular Haemorrhage
MFM	Maternal Fetal Medicine
NQ	North Queensland
NEC	Necrotising enterocolitis
NICU	Neonatal Intensive Care Unit
PVL	Periventricular leukomalacia
ROP	Retinopathy of prematurity
QH	Queensland Health
SCBU	Special Care Baby Unit
SCN	Special Care Nursery
SDM	Shared decision making
TTH	The Townsville Hospital
TUH	Townsville University Hospital
ZPD	Zone of Parental Discretion

Chapter. 1 Introduction

There is a story, likely apocryphal, that Margaret Thatcher, then Prime Minister of the United Kingdom, on being introduced to a neonatologist on a visit to a neonatal unit, is said to have asked ‘Are you the doctor who makes disabled children for a living?’ I have been unable to find a reference for this, but have heard it many times over the past 20 years. Neonatology is a branch of medicine concerned with the treatment and care of newborn babies. It is a rapidly expanding field of medicine, with increasing social and ethical challenges to accepted ways of medically caring for preterm and sick babies (Spencer & Modi, 2013; Zeitlin et al., 2016). This evidence enables care to be provided for babies at increasingly lower gestations, and with complex conditions which would have been considered lethal in the recent past. The recipients of this care are at higher risk of death and disability than healthy babies who are born at term. The provision of care for these babies is considered expensive and carries a high long term financial and emotional cost which is the subject of much ethical debate. Ethical concerns about the provision of care and the costs of and motivation for provision of care are as old as the history of neonatology itself. A brief overview of the history of neonatology provides a background for this thesis; many themes from previous eras are still relevant today.

1.1 A Historic Perspective of the Provision of Neonatal Care

Neonatology has evolved from the mid-19th century, when most babies were born at home, and mothers played the primary role in their care from birth. Later when births moved to the hospital the obstetricians together with midwives were the main medical caregivers (Baker, 2000). Preterm and sick babies had a high mortality, were labelled as ‘weaklings’ and often regarded as being tainted (Leavitt, 1986). Many babies died of respiratory distress, hypothermia, infection and an inability to feed following birth at home (Baker, 2000).

Provision of care for some babies in a hospital setting was enabled by the use of incubators, pioneered by Von Ruehl in St Petersburg in the year 1835 (Budin et al., 1907). Soon afterwards Parisian obstetricians, Tarnier and Budin, adopted advances such as wet nurse feeds which increased the survival of babies. Financial support for these endeavours was politically driven by the need for improved survival of potential future workers and soldiers for the state, rather than any altruistic desire to improve the lot of the poor (Fuchs, 1992). The French eugenics movement led by Pinard, a prominent obstetrician in the latter part of the nineteenth century, opposed the development of improved neonatal care as he decried the funding for babies he perceived would remain frail if they survived (Schneider, 1982). Hence the focus of funding for perinatal care changed to maternal education, rest and hospital care to prevent prematurity. Mortality also improved for the vulnerable baby because of increased maternal involvement in the care of the baby whilst in hospital, and the use of breast milk and medical care during long term follow up, pioneered by Budin (Baker, 2000).

High costs of improving care for neonates lead to the evolution of the preterm neonate as a sideshow for the paying public, with the ‘Child Hatchery’ at the Berlin Exposition in 1896 one of the first and the Coney Island Incubator shows in New York the most well-known (Baker, 2000). Again, mothers had to cede responsibility for their babies to the show physicians in exchange for medical care for their offspring.

Baby units such as that run by DeLee in Chicago from 1900 included obstetric care on site, active resuscitation of babies and even the first known transport service where trained medical staff collected sick babies in an incubator (DeLee, 1902). However, the care was very expensive and relied on public donation to remain viable, subsequently closing after only 10 years. As had happened 20 years previously in Paris, the eugenic movement was gaining pace in the United States with its emphasis on ‘quality’ babies. Survivors of ‘advanced’ neonatal care, often from the poorest families, were perceived as a potential financial drain on society (Kevles, 1985). Funding and development in obstetric care became the focus of obstetric units, with the care of babies increasingly the provenance of paediatricians. Paediatricians regarded their obstetric colleagues as unnecessarily fatalistic towards the survival of the vulnerable baby (Lussky et al.,2005).

The better outcomes of care for babies in the sideshows compared to that in hospitals led to collaborative work between Couney who ran a sideshow in Chicago and a paediatrician, Hess, to improve hospital care, with babies slowly moving back to the ambit of hospitals (Hess et al, 1934; Silverman, 1979). Evidence emerged that outcomes depended in part on the underlying cause of neonatal fragility, with those preterm or small for dates having better outcomes than those with diseases such as congenital syphilis (Hess et al., 1934).

The need for specialization in neonatal care by both nursing and medical staff had been recognised as early as 1923 (Reiss, 1999) with primary responsibility for the care of the neonate finally passing from obstetrician to paediatrician by the mid-20th century (Philip, 2005). Shaffer (1960) is said to have coined the term neonatology in 1960. Following the death of the infant son of President J F Kennedy of the United States from respiratory distress, money for neonatal research surged and advances in neonatal care were rapid. Advances in the past 60 years have included the miniaturisation of blood samples needed to assess the condition of babies, intravenous nutrition and the ability to provide it to very small babies, complex ventilatory modes, exogenous surfactant, pharmacology to manipulate the ductus arteriosus as required, and the use of nitric oxide for pulmonary hypertension (Philip, 2005). These advances have all contributed to the ability to care for increasingly premature and small babies. There has been recognition that involvement of families in caring for the hospitalised baby also contributes to improved outcomes (O’Brien et al., 2015).

Harm to infants has been caused by both social and medical errors throughout the development of the discipline of neonatology (Robertson & Baker, 2005). Social errors such as removing the mother from a primary role in the infant's care led to the need to provide alternative feed for the baby and parental attachment difficulties, which proved harmful to many (Baker, 2000; Drake, 1930). Following Tarnier's initial success, there was a very rapid expansion of the Parisian neonatal service in the 1890s, albeit with inadequate resources, insufficient wet nurses and overwhelmed wards. These services were recognised to be chaotic and regarded with distrust by many who only brought their babies to the hospital in extremis, perpetuating the high mortality rates (Baker, 1996).

In later eras, oxygen was found to improve mortality, but the use in high concentrations caused high rates of blindness from retrolental fibroplasia (Silverman, 1980). Irradiation of the neonatal thymus (which was thought to be related to sudden infant death syndrome) in the late 1940s resulted in high rates of thyroid malignancies (Jacobs et al., 1999). The liberal use of multiple antibiotics induced bilirubin toxicity where the regimes included sulfa drugs (Robertson, 2003). In each instance, there was thought to be sound medical underpinning for the care, but there was a lack of appreciation of the risk due to lack of systematic research. Neonatal research is limited by the logistical and ethical difficulties in assessing if new technology or medicines affect not only the short-term outcomes, whilst the baby is in the neonatal unit, but the long-term outcomes through to adulthood for survivors of the care. Sound evidence for much of the care which I, as a neonatologist, provide for vulnerable neonates is limited, and often guidelines are founded on 'expert opinion' rather than rigorous experimental evidence (Robertson & Baker, 2005).

In summary, the history of neonatology is marked by multiple conflicting motivations which have often been political or driven by high profile personalities, various eugenics movements questioning the facilitation of survival of babies who might be a ‘burden’ to society, harm caused by new interventions which had required better evidence for their place in neonatal care, and friction between paediatricians and obstetricians about the survival of vulnerable babies (Philip, 2005). Parents, as the creators and ultimate caregivers for the babies have had their role determined by the desires of the medical fraternity with mothers often delegated the sole role of provision of milk, or excluded entirely.

Current concerns by many practitioners in the modern era of neonatology focus on whether the provision of care for babies at gestations considered periviable - below 25 weeks completed pregnancy – should occur. In many hospitals, care at 22 weeks gestation is occurring, and the age which is regarded as periviable itself is decreasing. Furthermore, there is debate about who should be making the decisions to offer this care: parents who are well counselled about the potential outcome for the baby, medical staff, societal rules or a consensus decision making involving these stakeholders.

Contemplation about these issues developed into the kernel for my PhD study which explores decision making and the motivation behind decisions made in the neonatal intensive care environment of my own work place.

1.2 Current Limits of Viability; an Ethical Cause for Concern?

Term pregnancy in human babies in Australia is defined as occurring between 37 and 41 completed weeks’ gestation (Australia Institute of Health and Welfare (AIHW), 2019). In 2017, 8.7% of babies were born between 20 and 37 completed weeks gestation (defined as premature), with a median of 35 weeks. Early delivery is more likely for babies of a multiple pregnancy (66%), those from Aboriginal or Torres Strait Islander mothers (14.2%), mothers who smoke during pregnancy (13.6%), and babies born from mothers residing in remote and very remote locations (13.5%). Women under 20 and over 40 years of age are also at risk of premature delivery (AIHW, 2019). Premature babies born before 28 weeks are defined as extremely premature. With increasing prematurity, there is an increasing risk of death or long-term neurodisability. Babies born between 22 and 25 weeks are regarded as being periviable, whilst below 22 weeks the baby is considered non-viable. Those babies born at extreme prematurity are unable to physiologically maintain temperature, unable to suck adequately for nutrition and are vulnerable to infection, so require special care until approximately term, with extremely preterm babies remaining in hospital for many weeks prior to discharge home. Neonatal intensive care is expensive, and often involves considerable family expense and inconvenience, particularly where a family needs to relocate to receive care in a tertiary neonatal unit. Where the risks of death or disability are high, concerns have been raised about the ethical foundation of active care for these babies, and who should decide limits for the provision of this care (Nuffield Council of Bioethics, 2006).

1.3 Context of the Study

North Queensland is a region on the North-East of Australia, with an area of 500 000km^2 and a population of 700 000 (Figure 1.1). There are approximately 10 000 deliveries per year (AIHW, 2019) in the region. There is representation from all socioeconomic strata and a diverse ethnic community. In North Queensland, 10.7% of the population identifies as Aboriginal or Torres Strait Islander (hereafter respectfully referred to as Indigenous), compared with 4% in the Queensland population (Queensland Regional Profiles, 2016). Fourteen percent of babies born in North Queensland are to Indigenous women. Indigenous women have a higher representation in remote and very remote areas (Hugo Centre for Population and Housing, 2020). Most babies are born in Queensland Health public hospital facilities, although a small number are born in the private sector. The only neonatal unit with the ability to care for babies under 29 weeks gestation, or with complex disorders, is at

Townsville University Hospital (TUH) (previously known as The Townsville Hospital, TTH).

In Queensland, there are six levels of service provision across the public health sector, dependent on the services available within that facility. The level of care required for each baby is determined by the gestation, weight and complexity of its health care needs and the baby is cared for in the facility nearest to the baby’s home which can provide that service. In a level six unit, care is provided by a maternal fetal medicine service for complex antenatal care, dedicated neonatal paediatric staff within an intensive care unit, neonatal surgeons and a specialized neonatal transport service (Queensland Health., 2014). A level six unit is analogous to a tertiary neonatal intensive care unit in other countries, and is often referred to locally as a tertiary unit. Eight hundred and fifty babies are admitted to the TUH neonatal service each year, with 250 requiring intensive care, and 50 births under 28 weeks completed gestation (2017 data) (Neonatal unit service profile, 2018).

There is a level five unit caring for babies from 29 weeks gestation and over 1000g in weight 360km to the north of Townsville. Level four units are situated 390 km to the south and 900km to the East – both of these units provide care for babies over 32 weeks gestation and 1500g weight. These three hospitals have full time cover by obstetric, general paediatric and midwifery staff. There are several birthing units throughout the region at smaller facilities which are deemed level 1 to 3 providing care for babies near or at term, and are staffed by general practitioners with extended skills in obstetrics along with midwifery staff. The furthest of these birthing units is on Thursday Island within the Torres Strait, to the north of Australia, which is 1000km from TUH.

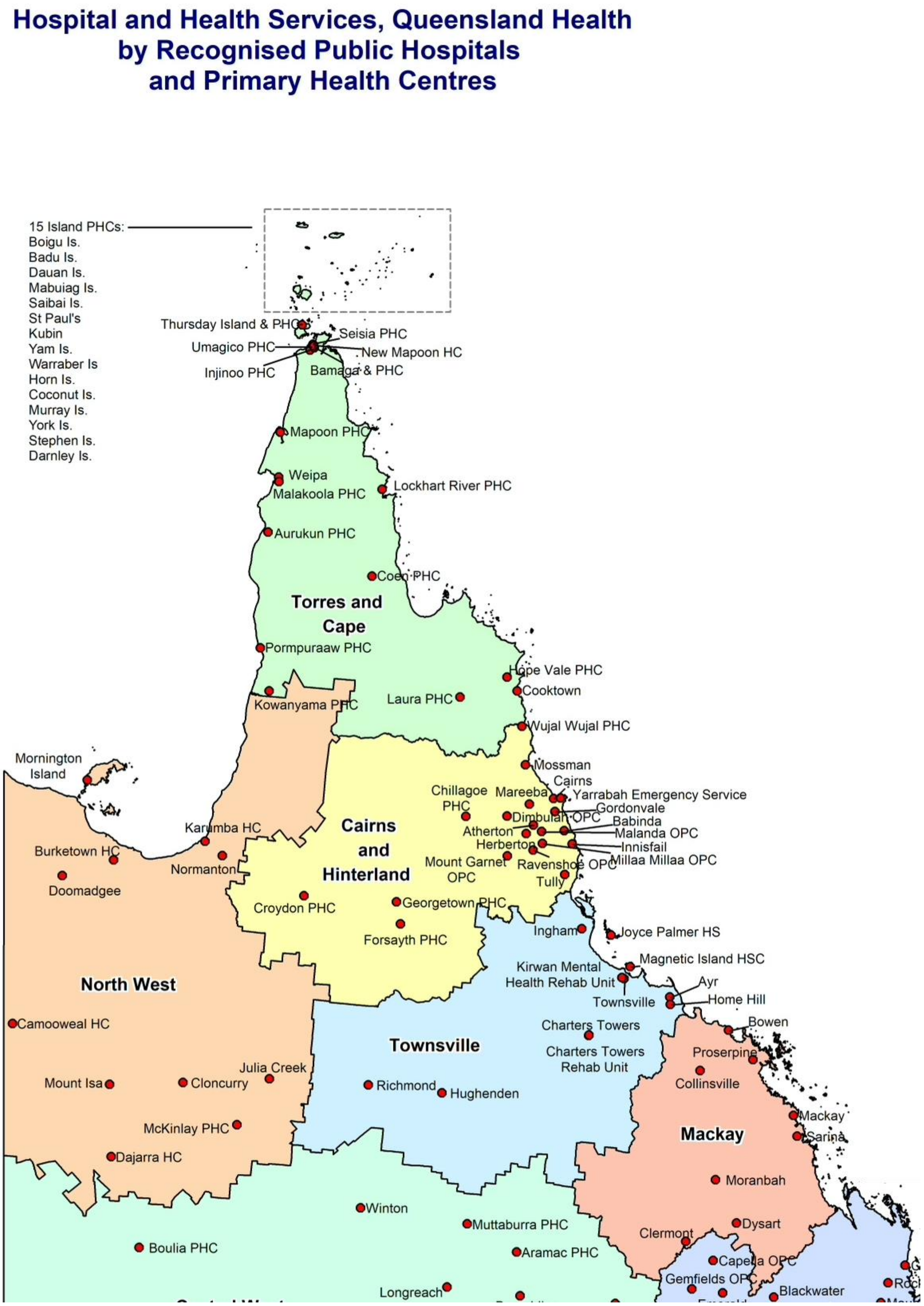

Figure 1.1 Map of the North Queensland districts, including public health facilities, which are serviced by the TUH neonatal unit (Source: Queensland Health. Statistical Services Branch,).

Where a mother is at risk of delivering her baby in a unit which is unable to provide the care required, the mother is transferred to higher level centre. Where antenatal transfer has not been possible, the baby who is born at a centre which is unable to provide the care required, will be transported by a dedicated neonatal transport service based at TUH (Advanced Neonatal Transport Service North Queensland - ANTS-NQ). This service can transport babies from anywhere within North Queensland to the nearest facility to home able to provide care. ANTS-NQ will transport 80-100 babies a year to a variety of destinations including TUH, with some babies travelling to Brisbane if they need subspecialty services not provided in Townsville such as cardiac surgery. Most transports are done by fixed wing or rotary aircraft. Approximately a quarter of all extremely preterm babies born under 28 weeks gestation in North Queensland will require retrieval from another facility to TUH. Nearly forty percent of extremely preterm babies will have an Indigenous mother (Ireland et al, 2019).

1.4 The Townsville University Hospital Neonatal Unit

The neonatal unit at TUH is divided into a neonatal intensive care area and a special care nursery. There are currently (December 2020) 12 funded neonatal intensive care cots, and 26 funded special care cots, although the unit will expand up to accommodate up to 25 intensive care babies where required. Babies who require respiratory support or who are under 30 weeks gestation or 1000g are cared for in the intensive care unit, whilst those of lower acuity are looked after in special care. Families who usually live outside the Townsville area are accommodated within on-site accommodation which also provides social work support to help the families negotiate long stays away from home. When a baby is stable, does not require ongoing surgery, parenteral nutrition or complex care, and there is bed space available, they are repatriated to a unit as close to home as possible if they come from outside the Townsville area. This repatriation is known as ‘backloading’.

At the time of this study, there are 80 full time equivalent nursing staff, five nurse practitioners, six registrars including one senior registrar and four neonatal specialists based at the TUH neonatal unit. Allied health professionals including physiotherapy, occupational therapy, speech therapy, psychology and social workers are available. Lactation consultants and healthy hearing staff also serve the unit.

Most patients on the neonatal unit will have a brief stay, and we will have no further contact after discharge, but some patients will remain for a long time. Extremely preterm babies are likely to remain in the neonatal unit until at least their due date. For example, a 24-week gestation baby will remain approximately 16 weeks. The neonatologist may have met the family antenatally, and during the stay on the neonatal unit will see the family regularly. The parents of an extremely preterm baby will also be relatively isolated as they sit for long stretches of time by the baby’s bedside. It is unsurprising that a relationship builds up between staff and parents. Parents, on reflection of their NICU stay, will often describe the neonatal staff as friends. Complex patients are likely to be followed up by the neonatologist in outpatient clinics and developmental clinics for two years. Frequently the parents will bring their offspring back to the neonatal unit and staff who have cared for the baby will see the child during the visit. The neonatal unit walls are lined with photographic ‘stories’ of babies from their earliest days to well into school age. It is an ecosystem, with staff and families enmeshed.

Parents are patients by proxy. The interaction with parents is a delicate balancing act for both parent and clinician. The parent is not usually acquainted with our miniature world, and are usually devastated when a term baby is ill, or bewildered when they have a tiny baby. The parent needs to be counselled by the clinician who is leading medical decisions for the pregnancy and the future baby.

It is not uncommon for doctors, nurses, allied health and administrative staff to opine as to the potential long term outcome of an individual baby. Where there are indications of a potentially poor outcome, concerns may be made about the ability of the parents to cope with a disabled child and the implications for the family.

Moral distress about continuing to care for a baby whose long-term prognosis is poor is commonly described in the neonatal unit particularly by nursing staff (Prentice et al., 2016). The initial offer of intensive care for periviable babies who are deemed to be in the ‘grey area’ for healthy survival is debated. There is much literature about parental stress and experiences of decision making around resuscitation, and corresponding staff opinions about decision making. There is, however, less literature available about how parents feel about decisions which were made years earlier.

1.5 The Evolution of Research Questions

During my time at TUH, I have often considered staff perspectives and other factors that may influence the provision of care for extremely preterm and periviable babies. This has led to some specific research questions which encompass the journey of the baby at every stage of perinatal care.

My first question was whether the care which is offered at TUH leads to medical outcomes which are comparable to those offered by our peers. If this is the case, then it appears justified to offer this care. Annual data reported through the Australian and New Zealand Neonatal Network (ANZNN) database provides some of this information. However, there is no value added to this in terms of actual numbers of deliveries at the lowest gestations receiving care, and little contextualizing which may reflect changing practices over a longer time-period and encompassing the unique character of the unit.

Next, I wanted to know which voices inform the decision to resuscitate the most vulnerable babies in North Queensland. After adequate antenatal counselling, parents expecting the delivery of a periviable baby may be offered the choice of full resuscitation, may decline active resuscitation and opt for palliative care only, request assessment by the neonatal team at the time of delivery and resuscitation if deemed healthy, or the option of redirection of care to palliation in the neonatal unit should the baby later have complications which increase the risk of severe disability and potentially poor quality of life. My experience was that it was unclear at times how a decision to resuscitate individual babies arose. An understanding from both a staff and parent perspective would be needed to explore this decision-making.

A further question I had was how decisions in the NICU were made by staff and parents. After admission to the neonatal unit, decisions are made on many issues concerning the care of the baby; some major, but many minor. I questioned whether the option to palliate after admission occurred, and if parents consider that it is a reasonable suggestion, given their experiences of the neonatal unit. I wondered how parents felt about decisions including those about resuscitation for their own baby, and if these decisions had been right for the child and family. Once the family has experienced the long-term outcome of neonatal care for a periviable baby, I considered it likely that they would have reflected on their own neonatal unit care.

Thus, my thesis will examine the voices influencing care of the extremely premature and vulnerable baby in North Queensland. In doing this research, I hoped to achieve an understanding of how the TUH service could improve decision-making so that better care could be provided in a way which could lead to a more satisfying parental experience.

1.6 Motivation for the Study – Why Me?

I am a neonatologist, and have been caring for babies at TUH neonatal unit since 2009. Prior to this I had neonatal intensive care experience in the United Kingdom. Whilst I have always been concerned about the critical decisions which are made at the initiation of intensive care for periviable babies, and whether I have made the ethically correct decisions, there are three specific events which have made me particularly concerned about whether decisions I have made or facilitated have been right for the families concerned. The parents of the first two babies have specifically consented to inclusion in this study, whilst the third published a book in the public domain about their experiences.

The first incident concerns a baby of 24-weeks' gestation. I had seen the parents on the day the mother was admitted in preterm labour and discussed the options of either offering intensive care or giving palliation after the baby was born. When I initially met the parents, the mother had been transferred from the local private hospital, with little information other than to be told that TUH was the place where babies at 24-weeks would be cared for. The parents knew little about prematurity, and this was their first child. Both parents were busy professional people. The mother was having painful contractions, and both parents were very anxious. I briefly outlined the likely immediate management of the baby, the expected progress through the neonatal unit, and the long-term risks of disability, should the baby survive. He was born soon afterwards. With the parents' agreement, the baby was admitted to the unit and received intensive care. He made excellent progress in all aspects of his care, except for his respiratory system. He developed chronic lung disease, and remained ventilator dependent. Ultimately the baby died at several months of age from complications of his lung disease. I rarely attend funerals. I did attend the funeral of this baby, as I felt that I had become close to the parents. At the funeral, the father spoke eloquently about how neither parent had understood about the suffering that their baby would have during his neonatal course. They felt that the risks and suffering had been unacceptable, and that they did not truly give informed consent for intensive care. At the time of the funeral, they felt that the decision to accept intensive care had been the wrong one.

A second incident was an interaction I had with a mother of a 23-week gestation baby who had been cared for at TUH. The mother was transferred from another centre when she had a large antepartum haemorrhage. There was little time for antenatal counselling, and the mother delivered on the day of the transfer. This baby had a very stormy course through the neonatal unit and at several months of age developed gram negative septicaemia requiring readmission to intensive care for ventilation and inotropic support. I knew that following discharge from TUH, the baby continued to have frequent severe illness and was found to be severely disabled. The parents needed to fundraise to access the care which they felt might help improve their child's quality of life. I bought several raffle tickets, the prize being something which I neither required, nor wanted, but I often buy tickets for these fundraisers. I won the raffle. I had only placed my first name on the ticket, and the mother phoned me to let me know that I had won. Within a few moments, she realized who I was. The nature of our conversation changed when I enquired about the wellbeing of the child, and the mother told me how difficult life was for the whole family. Her parting words were – 'Do you people even think about the lives you ruin?'

The third incident was one where, as a registrar, I had been involved in the care of a baby with severe birth asphyxia. I had retrieved the baby, who had been born in a smaller centre, to the tertiary unit. The baby did not require ventilation, but remained deeply unconscious, with little spontaneous activity. Ultimately the baby was discharged home. I had known that the baby had developed epilepsy which had been difficult to control. The baby also had spastic quadriplegia. I knew little of the subsequent course until some years later when I encountered a book which the mother had written (Hollander, 2009). The book relayed the subsequent story, and in the telling I am known as ‘the sidekick’. My consultant, for whom I had great respect, had been the primary specialist caring for the baby, and the parents clearly had not liked her, although I had not known this at the time. The part of the book which I found particularly challenging occurred after the neonatal stay, when the baby was fitting continuously, and the parents did not want active care to be given to control these fits as they felt it was in the baby’s best interest to die. The medical team wished to continue treatment, and gained partial control of the seizures with multiple medications. The parents felt disempowered and could not cope with the care of the child, who ultimately went into foster care.

These patients are only some of the more notable patients which led me to wonder if we were ‘doing the right thing’ by our parents, and how decisions were made to offer care in our unit.

1.7 Motivation for the Study – Why Now?

Neonatal care is rapidly changing, as evidence for practice improves and survivors are healthier than in previous eras (Doyle et al,. 2011; Doyle, 2004b). There are also changes socially where patients are gaining more autonomy and access to medical knowledge. Doctors are no longer considered to be ‘all knowing’. Social media also gives parents more insight into the activities on neonatal units, stories of ‘miracle babies’ are found in magazines and Facebook. However, I had become aware that the voices of parents who are not happy about decisions to offer care for their imperilled baby are rarely visible in medical literature or the media, and when they are, it appears we are doing some families harm (McVeigh, 2011). A difficultly arises between the choice to leave a periviable baby to die and avoid suffering, or to provide maximal resuscitation with an uncertain outcome. I needed to turn to ethical principles to help address this dilemma.

Ethical medical practice has evolved over the past century from one which reflected a focus on doctor's actions – 'do no harm' to one where the rights of individuals became included as the recognition of patients' rights to make decisions occurred and the importance of the medical practitioner became more tempered (Beauchamp, 2007). One framework for biomedical ethics defines four principles to use for formulation of moral thought (Beauchamp & Childress, 2001). Beauchamp and Childress outlined their principles to be used as guidelines for what actions are acceptable in specific situations. These principles (or pillars) include a respect for autonomy, whereby individuals have freedom to make choices according to their own personal values and beliefs. Medical practitioners have an obligation to ensure that they respect these autonomous decisions whilst also disclosing all information which foster autonomy. Non-maleficence requires a practitioner to not cause harm in pain or suffering to the patient. A third principle is beneficence where benefit is balanced against risks and cost, with an obligation to act to maximize benefit whilst minimizing pain and suffering. The last of the principles is justice where there is appropriate distribution of benefits, risks and costs fairly, and all are treated equally. The principles are found in universal common morality, but may at times conflict with each other in certain circumstances. Beneficence or justice may compete with respect for autonomy, particularly in neonatal care which is invasive, painful and expensive. Parents are the proxy decision makers for neonates who lack the capacity to make decisions for themselves, but may not always be perceived as making beneficial decisions for their offspring (Streiner et al., 2001). This study reflects a need to consider decision making for the most vulnerable babies in North Queensland through the lens of ethical principles to evaluate how decisions are currently made and what informs these decisions.

1.8 An Outline of the Thesis

The research questions are answered using a multiphase study as outlined in the following chapters. Some of these chapters contain publications which are listed below.

In Chapter Two, I review the literature which provides an overview of the rates and risks for extreme prematurity, a narrative on guidelines for resuscitation of extreme premature babies in Australia, and a specific focus on Indigenous prematurity and regionality within a North Queensland context. A publication arose from this review.

> Ireland, S., Ray, R., Larkins, S., & Woodward, L. (2015). Factors influencing the care provided for periviable babies in Australia: a narrative review. *Reproductive Health*, *12*(1), 1-11.

Chapter Three provides detail about the overarching methodology and methods used in the four studies that contribute to the thesis. The study includes a quantitative study of the outcomes for extreme prematurity at TUH. Next is a qualitative study of parents' experiences and opinions of neonatal care and living with the consequences of a periviable baby in North Queensland. A mixed methods design is used for the study of staff attitudes and opinions towards caring and decision making for periviable babies. This study uses a qualitative design to explore attitudes of a range of health care providers, alongside a quantitative survey of a large group of providers. A study was performed of nursing experiences of palliative care practise on the unit. The last stage of the methods is the integration of all the findings of the studies.

Chapter Four is the first results chapter and explores the outcomes for extreme prematurity in North Queensland. The study, published in the *Journal of Paediatrics and Child Health* examines all live births in North Queensland for a seven-year time frame, focusing on those babies who received care at TUH. This chapter answers the first of my research questions.

> Ireland, S., Larkins, S., Ray, R., Woodward, L., & Devine, K. (2019). Adequacy of antenatal steroids, rather than place of birth, determines survival to discharge in extreme prematurity in North Queensland. *Journal of Paediatrics and Child Health*, *55*(2), 205-212.

Chapter Five, presents the findings of the study of parental experiences of intensive care for extremely preterm and periviable babies in North Queensland. A paper of an aspect of this study has been published. The chapter includes analysis of categories found as part of this study which were not included in the paper, such as the evolution of parental confidence before and after admission, the parent-baby dyad and decision making. The chapter ends with some theory which emerged from the research of parents' experiences and opinions which are specific to aspects of decision making.

> Ireland, S., Ray, R. A., Larkins, S., & Woodward, L. (2019). Perspectives of time: a qualitative study of the experiences of parents of critically ill newborns in the neonatal nursery in North Queensland interviewed several years after the admission. *BMJ Open*, *9*(5), e026344.

Chapter Six contains several studies which all pertain to the attitudes of staff towards periviable care. This mixed methods study of staff attitudes includes a quantitative study that examined the knowledge of outcome, and attitudes towards, extreme prematurity at three centres in North Queensland. This study has been published. The qualitative study explored attitudes towards extreme prematurity. One aspect of the qualitative study has been accepted for publication. Other categories arising from the data analysis are presented. The results of the quantitative and qualitative studies have been merged by integrating the findings. The focus on decision making is maintained in the emerging theories which are found after the section merging the studies.

> Ireland, S., Larkins, S., Ray, R., & Woodward, L. (2020). Negativity about the outcomes of extreme prematurity a persistent problem-a survey of health care professionals across the North Queensland region. *Maternal Health, Neonatology and Perinatology*, *6*, 1-10.

> Ireland, S., Ray, R., Larkins, S., & Woodward, L. (2021). Exploring implicit bias in the perceived consequences of prematurity amongst health care providers in North Queensland–a constructivist grounded theory study. *BMC Pregnancy and Childbirth*, *21*(1), 1-12.

Nursing perceptions of palliative care at TUH are presented as a published article in Chapter Seven.

> Kilcullen, M., & Ireland, S. (2017). Palliative care in the neonatal unit: neonatal nursing staff perceptions of facilitators and barriers in a regional tertiary nursery. *BMC Palliative Care*, *16*(1), 1-12.

Findings from the studies exploring staff and parental perspectives, along with the results of the palliative care study are integrated in Chapter Eight which seeks to answer the research questions about decision making. There is discussion about how ethical principles can be applied and reference to relevant literature.

Reflexivity is an important aspect of this study, and is reported in Chapter Nine. The influence of my own attitudes and the effect of the study on my own practise are explored. Some of the limitations of the study will be explained by my own perspectives on periviable care.

Chapter Ten contains the conclusions of the study. I suggest areas for future research and recommend changes to policy and practice.

Chapter. 2 Literature Review

I was interested in how decisions were made about resuscitation at birth of babies at extreme prematurity and those very vulnerable to a high risk of disability because of known abnormalities. As a relative newcomer to Australia, and located in Townsville, I was aware that there may be factors which were different to my previous work environment so that an appreciation of the specific context I found myself in was required. In this review, I aimed to understand how extreme prematurity was regarded throughout Australia, and then focus specifically on the North Queensland context noting the high rates of Torres Strait Island and Aboriginal peoples, and the extensive geographical area which might be different to the more populous Southern states.

My literature review which was published early in my PhD candidature forms the contents of this chapter. More recent relevant literature is included with the results of the studies, and in the discussion chapter, Chapter Eight. To maintain consistency of thesis presentation, some modifications to the published format of the journal article, including the numbering of tables and figures has been made. The text as published is reproduced word for word.

> Ireland, S., Ray, R., Larkins, S., & Woodward, L. (2015). Factors influencing the care provided for periviable babies in Australia: a narrative review. *Reproductive Health*, *12*(1), 1-11.

Article: Factors Influencing the Care Provided for Periviable Babies in Australia: A Narrative Review

2.1 Abstract

Survival at extreme prematurity is becoming increasingly common. Neurodisability is an increasing risk with decreasing gestation. This review outlines the risks of extreme

prematurity and the attitudes of health care providers and families in Australia of periviable babies. High quality data is difficult to find due to differing definitions and methods of assessment of disability. Meta-analysis of outcomes of prematurity published from 2008 to 2013, including babies born from 1990 onwards, suggest a severe disability rate of around 20% at 22 to 26 weeks gestation, with moderate disability decreasing with increasing gestation. Studies show that Australian health care providers underestimate the survival and positive outcomes of these babies. The majority of Australian health care providers state that parental preference would determine the decision to offer care at 23 weeks gestation, however, all had a threshold above which parental preference would be ignored in favour of resuscitation. This ranged from 22 to 27 weeks gestation. The few studies examining Australian parental involvement in resuscitation decisions, showed that the majority of parents felt that health professionals alone had made the decision to resuscitate their extremely preterm babies and the parents themselves did not want to be the primary decision makers in withholding care. The babies progressed better than parents had expected following antenatal counselling. The attitudes of health care providers, experiences and opinions of parents seem to be at odds with the current move to increase parental decision making at the extremes of gestation. Current Australian guidelines suggest parental decision making below 25 weeks gestation, and primarily clinician decision making over this gestation. The increased risks of prematurity and adverse outcomes for the North Queensland population is also explored. This population has a high proportion of Aboriginal and Torres Strait Islanders who have increased risks which are primarily linked to poor socioeconomic factors and are highest for the most remote residents. Attitudes towards delivery of care to these highest risk babies from the health care professionals and in the populations themselves, have not been studied.

2.2 Introduction

Australia is a wealthy country where a high level of neonatal intensive care is available for all its residents without direct financial charge. Care is provided for babies under 32 weeks gestation in centralized tertiary intensive care units. Technological changes in the field of neonatology have led to the survival of increasingly premature neonates (Costeloe et al., 2000; Keir et al,. 2014; Zayek et al., 2011) leading to the current age of periviability, which is generally considered to be 22 to 26 completed weeks of gestation (Chervenak et al., 2007).

Premature delivery before 37 completed weeks of gestation occurs in 8.3% of Australian pregnancies (Li et al., 2013). Delivery from 20 to 27 weeks gestation is known to occur in 0.8% of deliveries in Australia (Li et al., 2013), which includes stillbirths and pre-viable babies. Within these statistics, the exact figures for periviability between 23 and 26 completed weeks gestation are difficult to determine due to the method of capturing data. The use of antenatal steroids in women with pregnancies at risk of early delivery, and the development of artificial surfactant, have been major advances which have led to an improvement in respiratory wellbeing (Kuschel & Kent, 2011) and survival. Survival rates of 50-80% for babies at 23 to 26 weeks gestation are expected in tertiary neonatal units (Hosono et al., 2006; Kamath et al., 2008; Zayek et al., 2011). However, survival may come at a cost of a significant risk of long term neurological morbidity, exhibited as intellectual impairment, cerebral palsy and sensory impairment (Anderson & Doyle, 2008; Boland et al., 2013; Wood et al., 2005). Studies of long-term outcomes are scarce in the Australian context, but meta-analyses of large international studies suggest a risk of severe disability of approximately 20% below 27 weeks gestation (Moore et al., 2013; Saigal & Doyle, 2008).

Recent discoveries have led to management which reduces the complications that occur after birth. These include the use of magnesium sulphate which is given to mothers prior to delivery and which has been shown to reduce cerebral palsy (Crowther et al., 2003). Probiotics, when given to the extremely preterm newborn, have been shown to reduce necrotizing enterocolitis, which is a major risk factor for long term neurological morbidity (Deshpande et al., 2007). However, there has not been sufficient time to evaluate the long-term effects of these changes on morbidity.

Whilst the long-term goal of neonatal care is to produce healthy infants, the early clinical intensive care course of the extremely preterm neonate is difficult and a degree of suffering is inevitable. Parents of less premature babies describe the stress of the neonatal intensive care and perceive that there is pain and suffering (McHaffie, 2001; Obeidat et al., 2009). At discharge from hospital, the parents will then become responsible for the future care of babies, who may be left with sequelae following the provision of this care. The early suffering of the periviable baby, as well as the potentially severe life-long morbidity are factors which need to be considered when deciding to offer these babies life sustaining intensive care.

This review aims to outline the outcomes of extreme prematurity and the perspectives of health care providers and families of periviable infants in Australia.

2.3 Methods

A search was performed using PubMed, Medline, CINAHL and Google Scholar to identify articles exploring the outcome of perinatal care, resuscitation guidelines, parental perspectives, health care perspectives and Australian specific literature around extreme prematurity. Key words used (including combinations and relevant truncated words and phrases) included ‘premature’, ‘preterm’, ‘periviable’, ‘neonatal resuscitation guidelines’, ‘Australia’, ‘rural’, ‘disabled’, ‘child’, ‘ethics’, ‘parents’. In addition, the search was expanded using references found in the articles identified and other articles citing them. Local and government publications were searched for relevant statistical information. The search was limited to English publications from 1985 to 2014. 538 articles were reviewed Articles were excluded where they were reviews or provided limited information in single small center studies except where innovative design was used. Articles which pertained only to term babies were excluded. Guidelines were included where they pertained to Australia or similarly structured neonatal models of care. 21 articles are discussed in this review. This includes two meta-analyses of outcomes, seven articles reflecting medical and parental opinions in Australia, seven with data pertaining to rural children with disability and five specifically to the population in North Queensland (Figure 2.1, Table 2.1).

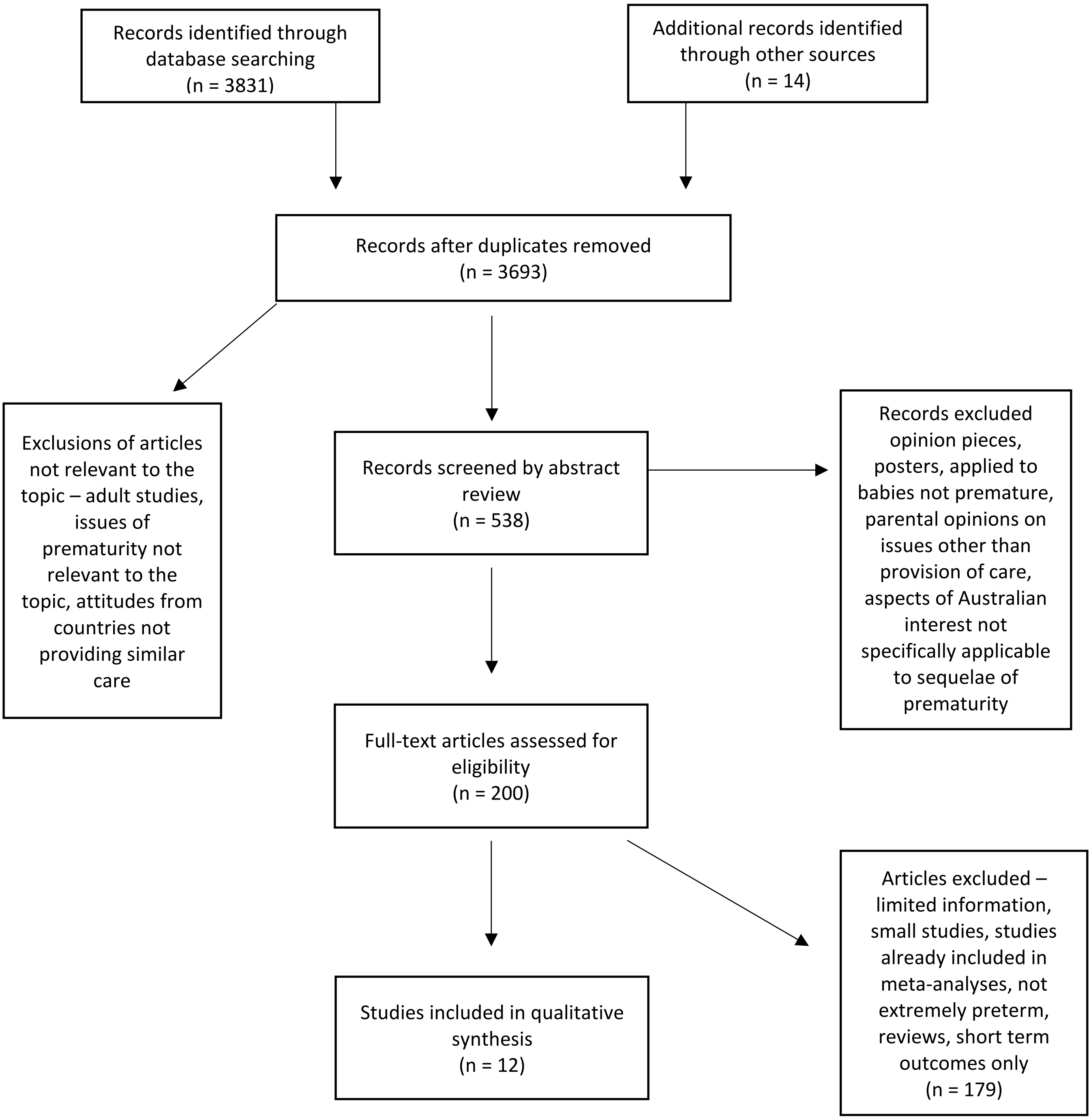

Figure 2.1 Flow diagram of literature search.

2.4 Outcome of Extreme Prematurity

It is difficult to define the current risk of long-term disability in the survivors of the neonatal intensive care unit. Studies often have small numbers of the most premature babies (Wood et al., 2000), follow the participants for insufficient time for the full extent of the outcome to be clear (Hack et al., 2005; Marlow et al., 2005), and use variable definitions of disability (Moore et al., 2013; Saigal & Doyle, 2008). Some report data in relation to birth weight rather than gestation, which allows the inclusion of more mature but lighter infants (Doyle, 2004b). In addition, over time, the medical management of babies has changed and the generalizability of outcome studies to an era where management is different is debatable. There is a paucity of very long term studies that reveal how these vulnerable babies fare into adulthood.

The meta-analysis by Saigal and Doyle (2008), who aimed to investigate the long term outcome of extremely preterm babies, found only nine papers which provided sufficient data to analyse. The study babies were all born between 1990 and 1997 and only three studies had followed the babies up beyond two years of age (Saigal & Doyle, 2008). Each of the studies used a different definition of disability, making comparisons between studies difficult. Definitions varied from ‘cerebral palsy’, to ‘moderate to severe cerebral palsy’ to ‘unable to walk without assistance’. Sensory disability was variably described as ‘unilateral blindness’, or the ‘requirement for hearing aids’, to ‘blind’ and ‘hearing uncorrected with hearing aids’. Not all developmental assessments were performed using standardized psychometric evaluation and thresholds varied from more than ‘two standard deviations from controls or the mean’ to an ‘intelligence quotient of less than 50’. Yet the meta-analysis does demonstrate that, in this era, a significant number of babies had severe handicap with figures ranging from 21% to 35%. It is interesting to note that the only study which follows the patients up beyond five years of age – in this case to age 11, had the lowest rate of disability despite also having a lower threshold required to include disability by definition (Farooqi et al., 2006). The studies which followed babies for the shortest duration appeared to have the highest rates of disability- an observation that has been noted by a number of authors (Marlow et al., 2005; Wood et al., 2005).

A more recent meta-analysis by Moore *et al* (2013) included nine papers where babies were followed up to a minimum of eight years of age. Of note is that 80 studies were excluded, primarily because they contained methodological flaws or because the assessments lacked rigor. Highly selective cohorts, data from clinical trials and review articles were excluded. The papers selected included cohort studies, some with term baby controls, a follow up rate of over 65% and the use of standardized psychometric assessments. Severe disability was uniformly described as an IQ score more than three standard deviations below the mean, non-ambulant cerebral palsy and no useful vision and/or hearing despite amplification. These disabilities are likely to leave the person reliant on others for care-giving throughout life. Moderate disability was defined as IQ two to three standard deviations from the mean, ambulant cerebral palsy, little useful vision, or hearing restored by amplification. The pooled data suggested that from 22 to 26 weeks gestation, gestational age made no difference to the rates of severe impairment (approximately 20%), although the rates of moderate impairment decreased with increasing gestation. The relatively small numbers in the lowest gestation groups limits the reliability of the aggregated statistics leading to wide confidence intervals. Whilst the authors stated follow up to eight years of age in their inclusion criteria, only two studies achieved this. Despite some flaws, this study attempts to provide the highest quality outcome data available to be used clinically when counseling parents. However, there should be some caution in the use of population epidemiology to provide statistical advice to individual parents (Buttner, 2011).

The risk of significant disability has led to well documented ethical concerns about the provision of intensive care to these babies (Kuschel & Kent, 2011; Ross, 2007; Simeoni et al., 2004). The ethical concerns surround the issues of sanctity of life, the immediate suffering of the extremely preterm baby, and the rights of the parents who will ultimately care for the babies after discharge from hospital. Decisions to resuscitate very high-risk babies depend on the country of birth (Partridge et al., 2005; Pignotti & Donzelli, 2008) and reflect differences in cultural and religious beliefs. Australia has similar decision-making processes to other developed countries such as the United Kingdom and parts of the United States of America (Pignotti & Donzelli, 2008). In these countries, discussions with the parents prior to delivery are considered best practice, with the decision to resuscitate and offer care weighted towards parental preference at the most extreme age i.e., 22-23 weeks gestation, but considered to be usually appropriate after 25 weeks of gestation. This is based on the increased expectation of intact survival beyond 26 weeks and is reflected in the guidelines in use in different states in Australia (Lui et al., 2006; Queensland Clinical Guidelines, 2014).

Table 2.1

Table of papers found outlining opinions of medical personnel and families in Australia with regards to the provision of care for extremely preterm babies.

Study author	Population	Sample size	Methodology	Outcome of study
Mulvey et al. [38] 2001	Obstetricians in hospitals with Level 3 NICU, No Northern Australian participants	89 participants, 48 % response rate	Survey	Majority would always discuss resuscitation from 23 weeks. Majority underestimate survival. Paediatric opinion then parental opinion used to inform decisions.
Gooi et al. [39] 2001	Obstetricians from hospitals providing level 2 neonatal care	174 participants, 75 % response rate	Survey	Median for resuscitation 24 weeks gestation. Refer to tertiary unit over 24 weeks except in West Australia and Victoria – 23 weeks
De Garis et al. [36] 1987	Neonatologists from all 18 NICU in Australia	51 participants, response rate not given	Survey, some open ended questions	Majority under estimate survival. Majority offer full resuscitation over 24 weeks gestation, consider later withdrawal of care if neurological concern
Oei et al. [40] 2000	All neonatologists in Australia	71 participant neonatologists 93 % response rate, 41 neonatal nurse participants, 74 % response rate	Survey, some open ended questions	Doctors median age for care 24 weeks- range 22–25 Nurses median age of care 25 weeks- range 23–28 Parental opinion should influence resuscitation but majority would overrule parents at 25 weeks Doctors more accurate estimate of survival and morbidity

Study author	Population	Sample size	Methodology	Outcome of study
Munro et al. [37] 2001	100 neonatologists in Australia	70 % response rate	Survey	Majority always counselled over 23 weeks and would give mortality and morbidity data. Obstetricians' main influence in decision to provide resuscitation. Consider parental opinion from 23 to 25 weeks
Martinez et al. [43] 2005	Part of large Pacific Rim study comparing practice in different countries. Neonatologists throughout Australia	Participant number unclear, 68 % response rate	Survey	Obstetric opinion and previous parental infant loss would be main influences of what counseling provided. Majority said that family should be decision makers for resuscitation where parents and doctor disagreed
Partridge et al. [26] 2005	Part of large Pacific Rim study comparing practice in different countries. Parents in Melbourne Australia. Babies under 1501g, mean gestation 29.2 weeks	51 Australian parents response rate unknown	Survey (by structured telephone interview)	74 % felt that physicians had made all resuscitation decisions alone. Majority of babies had done better than expected from the antenatal counseling prognosis. Less than 50 % felt that ante-natal counseling adequate

2.5 Attitudes of Health Care Providers to Extreme Prematurity

Clinicians in Australia who care for women at high risk of delivering between 22- and 27-weeks' gestation include the primary health team, the midwife and obstetricians. Prior to delivery these women will also come into contact with neonatologists who will care for the baby after delivery, and neonatal nursing staff who will often orientate the parents to the neonatal unit and provide a source of information. Actions by obstetricians prior to a baby's birth may improve the chance of survival and decrease the rate of complications, improving the future morbidity of these babies. Possible interventions include the administration of antenatal steroids and monitoring of the baby with a view to earlier surgical delivery if there are signs of distress (Garel et al., 2004; Guinsburg et al., 2012). Midwives, neonatologists and neonatal nurses also play a significant role in informing parents about the future for their baby (Grobman et al., 2010; Kavanaugh et al., 2010; Roscigno et al., 2012). As current guidelines suggest parental participation in decisions around providing or withholding treatment, parental views are important. Message framing by all members of the treating team may have an effect on parental opinion. A study of adult volunteers, who were posed a vignette involving a 23-week gestation baby whose delivery was imminent, showed that those participants who were presented with a positively framed message were significantly more likely to suggest that resuscitation should be provided when compared with those provided with a negatively framed scenario (Haward et al., 2008). The clinical facts in both scenarios were identical. This study had a number of limitations in that the participants were not in the emotive situation of being faced with making this decision for their own pregnancies. However, despite these limitations, this study shows that the way that information is presented is important, and it is possible that a clinician may influence parental decisions by a positive or negative approach to antenatal counseling.

The attitudes of health care professionals in Australia have been explored in a number of studies (de Garis et al., 1987; Gooi et al., 2003; Mulvey et al., 2001; Munro et al., 2001; Oei et al., 2000). Obstetricians from 18 hospitals with a level 3 neonatal unit (able to provide the highest level of neonatal care) were asked to participate in Mulvey *et al* 2001 study about their personal attitudes towards antenatal counseling, resuscitation and the expected survival rates of extremely preterm babies (Mulvey et al., 2001). Obstetricians from 12 units were enrolled in the study with a response rate of 48% from the clinicians. Responses to hypothetical delivery at different gestations were assessed using a structured questionnaire. From 23 weeks gestation, obstetricians were increasingly likely to discuss resuscitation of the baby with the parents and two thirds said that they would alter the perinatal plan according to parental wishes. It is notable that a third did not include any discussion about the potential death of the baby, or the option to provide only palliative care following delivery. Factors which would influence the counseling given included previous perinatal loss, and concern about the emotional burden of the counseling for the family. Nearly 40%, however, stated that they had their own personal criteria around gestational age and the presence of anomalies as part of their decision to involve the paediatric staff. Where there was disagreement about resuscitation between clinicians and parents, 49% felt that the neonatologists should make the decision about resuscitation, 39% the parents and only 8% felt it should remain in the hands of the obstetrician. In terms of resuscitation, there was a range of responses about the gestational age at which cardiac massage and adrenaline would be considered appropriate for a baby in poor condition at birth. Mulvey et al asked the obstetricians about their understanding of survival and intact survival at different gestations and compared this to those found by Yu in unpublished outcome data for Victoria in 1997. Respondents significantly underestimated the survival and disability free survival of babies at all gestations with the biggest discrepancies being at 23 weeks gestation. The design of the study restricted participants to pre-set questions and did not allow investigation of the obstetricians' rationale for decisions made. The 'personal reasons' why individual clinicians might vary their practice could not be ascertained. The response rate might also provide bias as the characteristics of non-responders are unknown.

Gooi *et al* (2003) explored the attitudes of non-tertiary obstetricians in 2001. This study also used a structured questionnaire, with repeated postings to ensure a higher response rate. They received a 75% participation rate of all obstetricians registered in units providing level 2 neonatal services (able to manage babies over 32 week's gestation) in Australia. Clinicians were asked about their opinions about the gestation at which they would consider transfer and active management. They were posed a clinical scenario, given a list of interventions and asked about which intervention they considered appropriate at which gestation. Knowledge about morbidity and mortality was explored. Most would transfer women to a tertiary level hospital prior to extremely preterm delivery, although this would occur from 22 weeks for the West Australian and Victorian clinicians but only after 24 weeks for the rest of the states. The mean age for suggesting administration of steroids was 24 weeks and surgical delivery at 26 weeks gestation. Most respondents underestimated survival, particularly at the lowest gestations with the West Australian and Victorian clinicians being the least pessimistic. 74% of the obstetricians would involve a paediatrician in antenatal counseling. This study suggested that despite underestimating the outcomes of extremely preterm babies, most clinicians would actively manage and transfer most babies of low gestation. However, where decisions are made by parents, it is likely that the parents being counselled by the clinicians would receive incorrect information and this may affect their decisions. This paper did not have a qualitative component which might have facilitated an understanding of the differences in management seen in different jurisdictions, or the attitudes of the clinicians towards the ethics of resuscitating the extremely preterm baby, which could affect message framing for the parents. Although the obstetricians often asked their paediatric colleagues in level 2 hospitals to consult with the parents, the study made no effort to explore the attitudes of the paediatricians in the same hospitals, and no Australian data was found which evaluated views of non-tertiary hospital paediatricians.

Whilst, despite being the initial counsellors of the parents, obstetricians underestimate survival, Australian neonatologists also underestimate survival and disability free survival, although to a lesser degree (de Garis et al., 1987; Oei et al., 2000). A number of studies have investigated the attitudes of neonatologists, with one also including neonatal nurses (Oei et al., 2000). De Garis *et al* (1987), sent multiple copies of a questionnaire to each neonatal intensive care unit in Australia. They received 51 replies but it is unknown how many neonatologists were in practice at the time, or the units which were represented in the study. Neonatologists were asked about their understanding of mortality and morbidity, treatment at birth for differing gestations, withdrawal of care, and hospital guidelines. Some open-ended questions allowed narrative feedback. They found that the majority of neonatologists would, if called to the delivery of a 24-25-week live baby, invariably initiate resuscitation measures. Others would not do so if the parents were strongly against resuscitation. All, however, would later consider withdrawal of care where they judged that there was a high probability of severe brain damage, a congenital anomaly which would be problematic, or during the neonatal course where there was irreversible respiratory failure or overwhelming sepsis. Most felt that the withdrawal of care decision should be made during a consultative process together with nursing staff and the parents. De Garis commented that if the clinician believes that the baby has little chance of survival, and then withdraws care, this becomes a self-fulfilling prophecy. This study was done in an era where resuscitation at 22 weeks was not considered at all, and survival was below 33% for all gestations less than 26 weeks (Yu et al., 1986). Although participants were invited to offer comments, there is little reporting in the study of any commentary received. Open questions in this type of study may not produce good qualitative data.

A 1997 study by Oei *et al* surveyed all neonatologists, and three registered nurses in each unit, in all neonatal intensive care units in Australia. They asked for opinions about resuscitation at different gestations using 26 graded response questions and three open ended questions. Very high response rates of 93% and 73% were received for the doctors and nurses respectively. Over 20% of neonatologists would occasionally resuscitate 22 week gestation babies and 25% would often resuscitate a 23 weeker. By 24 weeks, 74% of neonatologists would almost always resuscitate the baby. Neonatal nurses were much less likely to suggest resuscitation at all gestational ages to 25 weeks, but more likely over 25 weeks. Survival was underestimated by both groups, but more so by the nurses. This reflects the findings of other studies comparing neonatal doctors and nurses (Anspach, 1987) and obstetricians and midwives (Garel et al., 2004). Doctors accurately reported rates of disability free survival, but not the nurses who underestimated this at all gestations. 85% of neonatologists would have a threshold above which they would resuscitate the baby despite parental request not to do so. The mean threshold was 25 weeks, but ranged from 22 to 27 weeks. As these studies are all done between 1997 and 2004 the findings may no longer represent the current opinion of clinicians as medical management has evolved. The paper tabulates comments given by participants but it is not clear if these comments are representative or are all the comments given, and there is no thematic assessment of the comments. This study is interesting in that it suggests that withholding resuscitation seems to be less likely than consideration of withdrawal of care after resuscitation for those whose prognosis looks worse. A similar study by Munroe *et al* (2001) published in 2001 suggested that 86% of neonatologists often/always followed the wishes of parents at 23-25 weeks gestation. This study also used a questionnaire methodology with graded as well as yes/no questions which was sent to 100 neonatologists.

The results seem at odds with the paper by Oei *et al*, where the mean gestation at which parental decisions would be over-ridden was 25 weeks. It must be assumed that the same relatively small group of neonatologists completed both questionnaires as there is only a small pool of neonatologists in Australia, and the response rates in both studies was high. The latter paper suggested that counseling was often based on 'parents' perceived wishes'. Again, participants underestimate survival. The attitudes of neonatologists in Australia are reaffirmed in the study of practice in Pacific Rim countries by Martinez *et al* (2005). This survey study done in 1999 consisted of questions rated on a Likert scale and received a 68% response from Australian neonatologists. The purpose of this study was to compare the attitudes of clinicians in different Pacific Rim countries, but there is sufficient data to assess the Australian response. This is the only study which differentiates between different components of resuscitation and showed that the mean age for intubation alone was 22 weeks, use of cardiopulmonary resuscitation from 24 weeks and adrenaline over 24 weeks. Concerns about poor quality of life, parental wishes, congenital anomaly and probable death were major factors in determining resuscitation decisions for individual babies. This study includes a more extensive range of factors which the clinician might take into account. Unfortunately, however, a questionnaire is only able to assess the set factors, which are included by the researcher, and the lack of any qualitative component, renders the participant unable to contribute their individual perspectives or beliefs.

2.6 Attitudes of Parents to Extreme Prematurity

Internationally, parents have been asked about the role they feel they should have in the decision to resuscitate and care for their periviable baby. These studies explored the role of the parents both in the initial resuscitation of the baby as well as the withdrawal of care when care is considered futile (Brinchmann et al., 2002; Harrison, 2008; McHaffie, 2001). These international studies suggest that parents themselves do want to be involved in decisions regarding the care of their infants but often do not want to be seen as the primary decision maker. This seems at odds with the guidelines used by clinicians (Lui et al., 2006; Queensland Health Clinical guidelines, 2014; Wilkinson et al., 2009) in Australia and the UK where parental choice is said to inform resuscitation at 22-24 weeks gestation.

Studies which look at the overall experience of parents, are usually done among families who have experienced delivery of either very low birth weight babies (below 1000g) or early gestation. These show that the birth of these very vulnerable babies causes considerable trauma to the family in the acute neonatal period (Alderson et al., 2006; Baum et al., 2012; Fenwick et al., 2001; Garel et al., 2007), followed ultimately by ‘stoic survival’ and for many parents’ adaptation in the longer term regardless of the wellbeing of the surviving child (Lou et al., 2009; Wakely et al., 2010). However, some studies show a much more difficult long-term experience for parents where children have severe disability (Brinchmann, 1999; Harrison, 2008). In these qualitative studies, a number of parents reflect that the quality of life for the child is so poor that it might have been better had they not been offered care at all. This is a theme reflected by a number of authors in both the medical literature (Harrison, 1996), and media (McVeigh, 2011) who themselves have given birth to extreme preterm babies.

The Australian literature on parental experience in extreme prematurity is scant. Partridge *et al* (2005) reported the experiences of 51 Melbourne based parents in a study comparing parental attitudes in the Pacific Rim. This study identified parents who had delivered a baby under 1501g birth weight in 6 countries. The Australian component enrolled only parents who had received care in Melbourne. This confirmed that 74% of the Australian parents who had received antenatal counseling felt that the health professionals alone had made all the decisions about the care of the child, and that, as parents, they would not wish to have had to make a decision to withhold care. 74% felt satisfied with the physician counseling that they had, yet whilst disability was adequately discussed, death was not. Issues of pain, bonding and attachment were also topics that they felt were not discussed adequately. It is interesting to note that most parents felt that their child had progressed much better than they had expected based on the antenatal counseling that they had received. This may be explained by the under-estimation of outcomes which was described in the study of clinician understanding of outcomes by Martinez (2005). The majority of this group of babies was of a gestation older than would currently be considered periviable, so it is likely that the ethics of periviable care would not be relevant. The mean gestation of this cohort was over 29 weeks and 29% were described as having sequelae although the functional outcomes for the babies are not known as this was merely assessed by the presence of neonatal complications. Although the participants were interviewed by telephone, the researchers used a structured questionnaire with fixed questions and all answers were given on a Likert scale. Open-ended questions were only asked about the nursery experience of the participants. This study has the potential for recruitment bias as parents were invited to participate and the total number of eligible parents is unknown. The usefulness of this study in a narrative on periviable babies in North Queensland is questionable. It is, however one of the few studies available on this topic.

2.7 The North Queensland Perspective

Periviable babies in The Townsville Hospital come from families throughout the North Queensland region, and also occasionally from further afield when, for example, holiday makers unexpectedly deliver very early. The neonatal unit is the only tertiary neonatal unit in North Queensland and services both the public and private sectors. 74.5% of 157 babies who were admitted to The Townsville Hospital neonatal unit under 26 weeks gestation from

January 2004 to December 2013 had an address outside Townsville city. Aboriginal and Torres Strait Islander mothers account for 30% of admissions (*Neonatal unit database*, 2014). Despite the large numbers of babies from more regional, rural and remote places, and high proportion of Indigenous babies, which are all risk factors for a poor outcome (Abdel-Latif et al., 2006; Johnston, 2014), survival rates from 2008 to 2013, compare well with other major centers. Survival was over 50% at 23 weeks gestation increasing to 90% at 26 weeks gestational age.

The health statistics branch of Queensland Health report that in Queensland, Indigenous mothers are 4.2 times more likely to be under 20, 3.8 times more likely to attend less than five antenatal visits, 12 times more likely to live remotely or very remotely and 3.6 times more likely to be smoking after 20 weeks gestation than non-Indigenous mothers (Johnston, 2014). In addition, they are 1.7 times more likely to deliver before 37 weeks gestation. The risk of neonatal death for Indigenous babies is 2.7 that for non–Indigenous babies. Prematurity was found to be the strongest predictor of neonatal death in all groups. Queensland Health Statistics confirm the high rate of low birth weight seen in Indigenous groups as found by Kandasamy *et al* (2013) who have investigated the rate of low birth weight and/ or small for gestational age (SGA) in term babies in Townsville. They found that 20.2 ± 5.7% of Aboriginal or Torres Strait Islander babies had low birth weight as opposed to 10.2 +/- 1.9% for non-Indigenous babies.

Very little is known about the experience of women who deliver a preterm baby in regional, rural or remote parts of Australia, and particularly about Aboriginal and Torres Strait Islander women. Australia is a large and geographically diverse country. Outcomes for babies from outside urban areas are worse than those from the urban areas (M. Abdel-Latif et al., 2006). Coory, in his 2003 paper (Coory, 2003) based on routine perinatal data collection in

Queensland, suggested that the excess neonatal mortality found in rural and remote Australia is entirely accounted for by a high level of mortality in Aboriginal and Torres Strait Islander populations which is found regardless of place of residence. A higher proportion of the Aboriginal and Torres Strait Islander population lived in rural and remote areas leading to the difference between urban and non-urban sites. He found that non-Indigenous babies from rural and remote areas had no excess perinatal mortality when compared to their urban counterparts. Steenkamp *et al* (2012) studied births in the Northern Territory of Australia by ethnic classification of the mother and also the remoteness of maternal address. They found that Indigenous women in remote areas had more antenatal risk factors then non-Indigenous women, and their babies had a worse outcome. For Indigenous women, increasing remoteness was associated with worsening outcomes. Their study, unlike the study by Abdel-Latif *et al*, did not show any increase in mortality in non-Indigenous women related to place of residence, which supports the findings of Coory. The majority of the babies in these two epidemiological studies were born at term, and comparison of the findings for ethnicity and usual place of residence for premature babies was sought.

Abdel-Latif *et al* (2006) studied major morbidity and mortality in premature babies born in NSW and ACT from 1992-2002. Babies born in the non-urban centers had the highest mortality, but even when born in the tertiary centre, the babies born to women with a non-urban address did less well. They found that women from rural areas were more likely to be Aboriginal, teenaged or have a previous preterm birth. Prolonged rupture of membranes and spontaneous labour heralded the prematurity. Urban women, however, were more likely to be older, had assisted conception and have multiple births. An antenatal diagnosis of intra uterine growth retardation and delivery by Caesarean section were also more common in urban women. Despite a higher mortality, the rate of serious morbidity during the neonatal period was the same for both groups of babies. Further analysis of the characteristics of the rural women showed an increase in relative prenatal disadvantage in comparison to the urban women.

Only one paper was found which investigated families from a rural area who had the experience of a preterm baby in a neonatal intensive care unit (Wakely et al., 2010). The investigators recruited seven parents from five families in rural NSW who had delivered babies between 26- and 34-weeks' gestation, with a median gestation of 32 weeks. Only one child was described as having a significant disability. The families in this phenomenological study described the initial traumatic phase of hospitalization as one of shock and confusion leading to acceptance of their situation. The transfer and stay in a metropolitan center far from home resulted in leaving other children behind for a period of time. There were financial burdens and concerns about leaving properties untended. After adapting to the metropolitan environment, transfer back to the local hospital was a time of anxiety with concerns that the local hospital may not be able to meet the level of care their child required. At interview sometime later, the families felt that receiving medical care in the local area gave them improved access to local services and allowed clinicians to get to know the children well on a more personal level. The themes identified in the paper were those of 'coping through optimism' in the early days of hospitalization, 'stoic survival' where families were unable to discuss their true emotional turmoil with anyone else, followed by 'striving for normal' where developmental achievements were celebrated and delays were devastating. The limitations to this study may reduce its transferability to North Queensland in that the distance from the metropolitan areas was considerably less than that of many of the Townsville neonatal unit patients. Aboriginal patients were specifically excluded. Lastly, the babies were of a gestation where full medical care was not an ethical issue for all but one. The study is, however, of interest as it suggests that families from rural areas may have challenges related to their place of residence which are not experienced by urban families.

Following discharge from hospital, the high-risk baby will need follow up and monitoring for developmental delay which may be problematic in areas where there are workforce difficulties in recruitment and retention in allied health (Lincoln et al., 2014). Developmental assessment tools which are based on parental self-report have been found to give an inaccurate assessment of the development in some babies especially for remote Aboriginal babies where the testing is neither culturally appropriate nor validated for these populations (D'Aprano et al., 2011). Children with identified disabilities are provided with services for early intervention in order to help reduce the functional limitation the disability poses. Rural families have less availability of services and less choice in services they can access (Dew et al., 2013). Transport is frequently a problem (Dew et al., 2013; Rosier & McDonald, 2011). There has been an attempt to use videoconferencing for routine specialist appointments such as genetic and orthopaedic reviews (Hopper et al., 2011; Smith et al., 2005), which have generally been satisfactory. In addition to the chronic burden of prematurity, acute illness is also more common in babies who have been extremely premature and this will often necessitate transfer to urban or tertiary level services (Klassen et al., 2004). This further adds to the burden for the rural family caring for a baby who was periviable. The additional burden of caring for a high-risk baby after discharge may be great for many families.

2.8 Discussion

This review has explored the literature around the outcomes of extreme prematurity, and the attitudes of clinicians and families to the extremely preterm baby in Australia. The literature reviewed suggests that Australian clinicians, particularly obstetricians and neonatologists have been the decision makers who determine which babies will be resuscitated and which will not, although the importance of parental opinion was stated. It is clear that the clinicians underestimated the outlook for extremely preterm babies, yet what informs the clinicians’ decision-making is not clear. The studies done are all over 10 years old and given the changing nature of neonatal intensive care and the improvement in outcomes, may not reflect current opinion.

Parental decision making is suggested as being of primary importance in all the current resuscitation guidelines at the extremes of periviability. This assumes that parents are in the best position to make a decision for their baby in the role of surrogate decision maker. It assumes that parents are adequately informed and competent to make these decisions. If, however, the counseling clinician is ill informed and has personal bias in their message framing, parents may not be able to accurately assess their options. Research is required to ascertain whether parents in Australia want this burden of choice or not, and how this knowledge might improve clinicians use of the decision making process in preterm babies. Parents who have experienced a baby born on the verge of viability may be well placed to inform the discussion on whether resuscitation has been appropriate for their families. The realities of their lived experiences, whether they are in a metropolitan area or the more remote areas of Australia have not been heard.

In order for clinicians to understand the consequences of resuscitation for families, families who have lived through periviable births need to be able to voice their experiences. This must inform clinician knowledge and hence counseling of future parents in a similar situation. In addition, the reality of clinician-lead decision making and theoretical proposed parental choice needs to be further explored.

2.9 Commentary

The results of the literature review led me to formulate the research questions more coherently as they have been outlined in Chapter One. I recognised that TUH is part of a large and well connected system of care in Australia. I also noted that there have been some studies which had similar aims to my own, but these were generally dated. Similar papers sought to investigate outcomes in terms of short- and long-term morbidity. Incorporating both an approach which explored all deliveries of extremely premature babies, and then the outcomes for North Queensland babies would enable me to compare our outcomes. Studies of attitudes had mostly been done by questionnaire, but I saw value in doing a mixed methods study of staff attitudes to gain quantitative data to answer some of the big questions about knowledge and opinions, and also qualitative data to attempt to understand this data. The North Queensland population reflects a relatively high remote group, with higher rates of Indigenous babies, hence the findings on the literature review would inform an exploration of these aspects of patient experience and staff attitudes.

Hence, using the insights gained from the literature review I was also able to consider the need for a methodology which captured the range of stakeholders and addressed some of the aspects of previous research which I felt could be expanded upon. The methodology chapter, Chapter Three, defends the methodology used in detail.

Chapter. 3 Methodology

Exploring decision making around the provision of intensive care for periviable or vulnerable babies in the TUH NICU, and the consequences of these decisions, is the focus of this thesis. No single study was adequate to fulfil this task. Initially, understanding the scope of intensive care offered within a North Queensland context, together with the outcomes of the care provided was necessary. Studies of the differing perspectives of health care providers (HCP) whose actions led to the provision of intensive care, and the families who live with the consequences of the decision making were also required. A multiphase design, following the principles of Creswell and Clark (2017, p. 100), captured the information required at sequential stages, with each phase used to inform the next phase, capturing all voices of stakeholders in decision-making concurrently. In this chapter, I provide a rationale and overview of the phases of the study and how these strands interlink as represented in Figure 3.1. The rationale and description of the detailed methodologies and methods chosen for each of the component studies are described in separate sections throughout this chapter.

In this complex pragmatic multiphase study, the first phase involved a retrospective cohort study - the acquisition of quantitative data, which provided both quantitative information and a justification for the overall study. I investigated characteristics of babies from North Queensland who were provided with care in the NICU. This study informed the next phase of the overarching project by providing demographic information about the babies and their families as well as aspects of their antenatal course which are relevant for decision making. The study also informed the next phase of research by providing outcome data for the proposed study of HCP’s knowledge about extreme prematurity. This was important, because if the outcomes for these babies was not at a standard which justified offering the intensive care provided, I would have to consider the ethical aspects of providing intensive care at

TUH; decision-making to provide this care then becomes irrelevant. Quantitative methods using audit and comparison is the standard used throughout the health care system to provide data for these purposes.

Informed by Phase One, Phase Two then led to an understanding of the perspectives and opinions of families and staff in several different studies, which were both exploratory and explanatory. These studies were done concurrently. Firstly, I needed data from families who had been affected by extreme prematurity or a vulnerable baby. This provided an understanding of how they had experienced decision making, and the implications for them of having had their babies resuscitated and cared for in the NICU. Qualitative research using a constructivist grounded theory methodology facilitated collection of this data as it gave structure in its design and enabled deeper understanding of the families by allowing the constructing of theory to explain the findings (Charmaz, 2014, p. 12).

As counselling, decision making at the time of birth, and further medical care is done by many HCPs, another other arm of this phase of the study explored the attitudes of HCPs towards extreme prematurity. Mixed methods design offered a rigorous and triangulated approach with a quantitative survey design to capture numerical data from many HCPs. These data were merged with qualitative data from a constructivist grounded theory study, analysing the underlying causes for the attitudes with selected HCPs.

A further aspect to the research examined the provision of palliative care after admission to NICU, as this is often an option given to parents if the baby is showing signs that the outcome will be poor. The perceptions of nurses about how palliative care is delivered might influence continuation of care depending on the nurses' experiences. Nurses are recognised to be the primary care givers in palliative care (Kain, 2006). A phenomenological qualitative study (Kilcullen & Ireland, 2017) provided a narrative which lent itself to thematic analysis of the lived experiences of the nurses providing this care, without the need to find a deeper understanding of these experiences (Gallagher, 2012).

The third phase was the integration of all findings to enable a holistic understanding of decision making from differing perspectives. The combined data from both families and HCP studies were then used to understand how decisions are made as well as any common factors which might influence these decisions. Understanding the impacts on the families' lives might verify or nullify any concerns which HCPs may have in resuscitating periviable babies.

A fourth phase is a transformative one which uses the findings to suggest changes to practice, policy and procedure.

Philosophically, I believe that whilst the overall methodology chosen, with multiple phases and multiple studies provides the necessary complex data, it is also a holistic approach to examine very complex circumstances.

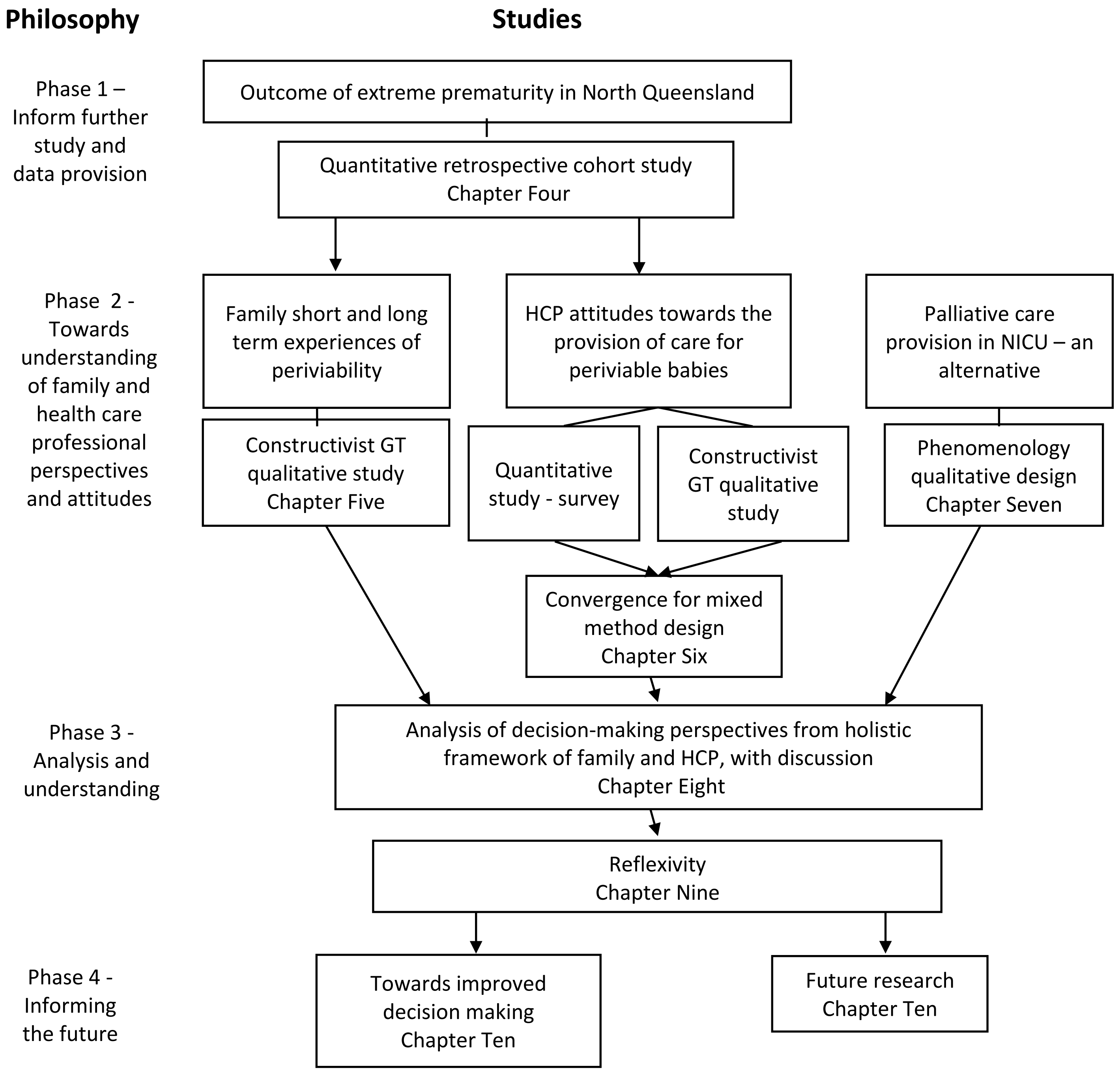

Figure 3.1 Diagrammatic depiction of the pragmatic multiphase study used to explore decision-making.

3.1 Ethics Approval

The ethical implications of a study of this nature are complex and needed careful consideration. The Human Research Ethics Committee (HREC) deemed the Phase One quantitative study to come under the provisions for quality assurance. However, the Phase Two studies raised greater concerns. It was important to address potential distress experienced by the participants in both family and HCP studies. Community resources for counselling were explored and information provided to all participants. Most families were still dependent on ongoing medical care for their children, and assurance that participation in the study would not affect this care was given through clarifying to families that their participation was independent from their care providers.

A power imbalance between myself and other HCPs was addressed by offering participants the option of an alternative interviewer independent of the hospital. As Indigenous families would be included in the family study, I also engaged with an Indigenous Liaison Officer (ILO) to ensure cultural sensitivity would be respected through review of the question guide. The ILO also reviewed the questionnaire sent as part of the HCP study for any cultural issues which may be inadvertently included, and any Indigenous HCP, although Indigeneity of the HCP was not included in the study.

Ethical approval from the hospital took many months. After ethical approval was obtained, site specific research governance approval was obtained across three health services for the HCP studies. The JCU HREC approval was also obtained. For each of the studies I provide an overview of the approach and methodology here, with details of methods in each relevant chapter. Copies of the approvals are found in the appendices.

Phase One: A Quantitative Study of the Outcomes of Care at TUH

3.2 Methodology

The neonatal unit at the Townsville University Hospital caters for all extremely premature babies who receive active care in North Queensland. Data for all these babies are collected by the Australia and New Zealand Neonatal Network (ANZNN), funded by the Australian Government to enable data analysis and quality improvement (National Perinatal Epidemiology and Statistics Unit (NPESU), 2019). These data provide at a basic level the numbers of babies cared for, and collate the rates of complications for comparison between tertiary units within the network. These raw numbers, however, do not allow the reader to understand more detailed information about variables which may be relevant for subgroups of babies. In addition, these data do not capture the numbers of babies who are not offered care. My first study, therefore, needed to:

i. explore the numbers and proportion of periviable babies in the catchment cared for by TUH; and

ii. evaluate the survival and complication rates for these babies.

The first objective was to discover how many of the babies born between 22 and 27 completed weeks gestation were born throughout the catchment area, and how many of these received care in TUH. This was particularly important for those babies born at 23 and 24 weeks, as decisions to offer intensive care would lead to admission where the baby was well enough to transfer to the NICU. By contrast, those not admitted either had a decision for palliation or were not well enough to survive. Whilst it was not possible to ascertain the reasons for the death of babies who were not admitted, it enabled an accurate picture of the proportion of periviable babies receiving intensive care, for whom a decision to opt for intensive care must have occurred.

The second objective was to provide data to evaluate the survival and rates of short-term complications for these babies for comparison to other units within the ANZNN network. These data allowed for an evaluation of variables which might affect intact survival including:

i. location of birth to ascertain how well outborn babies do when compared to inborn babies

ii. Indigenous status to assess if Indigenous babies have comparable outcomes to non-Indigenous babies given the health disparities between these groups

iii. location of usual residence to provide a comparison for those babies from more regional and remote settings, as health outcomes are worse with increasing remoteness from a city

iv. receipt of antenatal steroids should be expected to be similar across all gestations and is an important measure to improve outcome, hence also a variable of interest.

Should any variable significantly alter the outcome of extreme preterm babies, this would need to be factored into counselling and decision making, of relevance to later phases of the study.

3.2.1 Details of methods used for this study

A retrospective cohort study of all babies born alive in North Queensland from 22 completed weeks gestation to 28 completed weeks was undertaken. Births from January 2010 to the end of December 2016 inclusive were included. Time considerations meant that a prospective study was not possible – as obtaining enough data would take several years which was not feasible within the time limits of a PhD study. The time-period chosen reflected a period when there had been significant changes within the unit with more rapid enteral feeding of babies, reduced central line use, use of probiotics, and enhanced methods to control late onset sepsis – with an expectation of improved survival (Doyle et al., 2011). A balance between maximising the numbers of participants and the potential inclusion of babies who may be less healthy due to older practices, was required. Babies who were recruited in this study were also born during this time-period. Electronic record keeping in the latter years enabled easier data collection and verification.

Data were sourced from the Health Statistics branch of Queensland Health to provide the numbers of births and deaths of all babies at differing gestations in each district of North Queensland during the studied period. The data for all deliveries from 22 to 27 completed weeks gestation was given as stillbirth, born with signs of life, and death in the neonatal period. Data about the year of the birth or exact location of the deliveries was not obtained due to ethical issues pertaining to possible identification for babies not cared for at TUH. The de-identified nature of these data did not allow any analysis of the reason a baby did not receive tertiary care, which might include concerns about extreme prematurity, known abnormality or failed initial resuscitation, or enable this information to be obtained from other sources.

Next, data obtained from the neonatal database held on the neonatal unit for all babies who were admitted to TUH and data from the Health Statistics branch were reconciled to check for any babies who were known to have delivered, but not received care and presumably died. No further analysis of babies who had died prior to admission to TUH was possible, so it is not possible to ascertain if they had underlying abnormalities, or whether active decisions to refrain from intensive care had been made. Babies who were admitted, but whose mothers were not usually resident in North Queensland, and those known to have abnormalities which may influence survival, were excluded. Non-residents delivering babies in North Queensland are usually relatively wealthy holiday makers and are not representative of a general sample of North Queenslanders. Data were extracted from each baby's records by myself, together with a senior neonatal registrar.

Patient records were used to collect demographic data including the gestational age in completed weeks, gender, birthweight, place of birth, place of residence of mother and Aboriginal or Torres Strait Islander status. Regionality was defined as regional or remote according to the classification ARIA+ (Accessibility/Remoteness Index of Australia) produced by the Australian Bureau of Statistics (Hugo Centre for Population and Housing, 2020). Inner and outer regional areas are here defined as 'regional', and remote and very remote regions are defined as 'remote'. Variables of inborn/outborn status and adequate antenatal steroids – defined as at least two doses of maternal steroids commencing at least 24 hours prior to delivery in the week prior to delivery, were collected. Short term outcomes were defined as death; intraventricular haemorrhage (defined as grade 3 or 4 by Papil's system) (Papile et al., 1978); necrotising enterocolitis (based on Bell's classification) requiring surgery or leading to death (Bell et al., 1978); retinopathy of prematurity requiring treatment (Gole et al., 2005); and chronic lung disease where the baby was still on supplemental oxygen or respiratory support at 36 weeks gestation.

3.2.2 Statistical analysis

Using SPSS version 23, 2015(SPSS, Chicago, Illinois, USA) data were analysed to explore the variables of interest such as those babies with inadequate steroids, Indigenous status, regionality and retrieval status. Data were presented as numbers and percentages (%), means with 95% Confidence Interval (CI) or median and interquartile range (IQR). Categorical variables were analysed using Fisher's exact test with two-sided *p* values. Non-parametric data were analysed using Mann-Whitney-U test. Binary logistic regression assessed predictors of death and short-term morbidity adjusting for confounding factors of gestation, birthweight, gender, Indigenous status, retrieval status, remoteness of residence and adequacy of antenatal steroids. These statistical calculations were consistent with those undertaken in other similar studies, and within my capacity as a researcher under the guidance of a statistician at TUH.

3.2.3 Ethics approval

The study received approval from the Townsville Human Research Ethics Committee for audit and quality assurance (HREC/16/QTHS/142: Appendix 1). James Cook University acknowledged receipt of the approval from the hospital.

Results for this study were published (Ireland, Larkins, Ray, Woodward, & Devine, K. (2019) and can be found in Chapter Four. The study confirmed that survival and short term outcomes were consistent with the ANZNN data for other units. The research then proceeded as the data showed the care provided was at a level on a par with other units within Australasia; thus offering care for these babies in North Queensland could be ethically justified. Phase One informed the subsequent phase in providing an understanding of the babies cared for in North Queensland, and the data obtained were used in the analysis of the findings from later studies.

Phase Two: Exploring Perspectives and Attitudes of Families and Health Care Professionals Towards Decision-Making

3.3 Methodology

This thesis had several objectives which arose from the research questions following the literature review outlined in Chapter Two. These included exploring how decisions are made for vulnerable babies at TUH, who makes these decisions and what the results of these decisions are for the families who experience them.

Decision-making should be an interactive process between clinicians and patients, and in neonatal care, the patient has the parent as their proxy decision maker. Some decisions require considerable knowledge of medical issues including the nuances of variables which affect situations in which evidence-based knowledge is applied. Parents will incorporate their own preferences and beliefs in their application of this knowledge. Many decisions involved in the care of patients may be minor, but in neonatal care the HCPs need to acknowledge the parental role as primary decision-maker for their child where parental discretion is possible. For the development of my research, an understanding the perspectives of both health care providers and parent groups was required, both in the underpinning attitudes and the experiences resulting from decisions.

As a clinician, I already knew that there were different opinions between staff about who should be offered intensive care. Data from the outcome study showed that most babies at 23 and 24 weeks were receiving active care. This must have resulted from a decision to offer this care rather than palliation, presumably because a decision had been made to resuscitate these babies. It was important to consider all gestations of extreme prematurity, because babies from 25 to 27 weeks may have had life threatening complications and redirection of care might have been considered for some. The parents, having lived through this experience, would have insights into aspects of extreme prematurity of which HCP might not be aware;

which could help in decision making on the unit. The paragraphs below will expand on the specific questions which needed exploration from the parent and HCP groups.

The Family Study

This study is presented in full in Chapter Five.

Some researchers have studied family experiences though the use of closed question surveys, but this type of research is limited by the imagination of the researchers' questions and does not allow the parents to have their voices heard in any depth. Participants of surveys are directed to answer questions controlled by the researcher, with no latitude to direct the research towards aspects of the topic which they, as the authority by experience, may consider to be relevant. A quantitative study alone does not enable nuanced data to emerge which might apply to individual babies, such as the redirection of care options or the place of parents in minor decision-making. Previous quantitative surveys have tended only to focus on resuscitation at the time of birth (Partridge et al., 2005). Data pertaining to the recollections of parents about decisions made about their own children, and their opinions about who should make decisions, and at which gestation, are not easily obtained in a questionnaire. I therefore explored qualitative designs in preparation for the family study.

3.4 Qualitative Designs Explored

3.4.1 Phenomenology

In many ways, descriptive phenomenology would be the easiest design to use to explore the parents' lived experiences and how they interpret specific phenomena. The number of participant families could be chosen at the start of the study, with analysis occurring at the end of the interview phase. I did not feel that this would enable me to fully understand the reasons for the experiences of the parents in the depth that I was looking for. I wanted more than a descriptive phenomenological narrative to explore decision-making and understanding the ‘why’ that parents might have about decisions made.

3.4.2 Grounded theory

The second design I considered was grounded theory (GT). Grounded theory provides more than a descriptive narrative and attempts to answer the ‘why’ of the topic under review (Strauss & Corbin, 1994, p. 273). Ongoing analysis of each interview as it occurred (iterative analysis) with continuous coding, and comparison of previous interviews with parents would enable categories to emerge across the data. In turn, as these categories develop, theoretical sampling would enable other potential parents to be specifically chosen because the family or baby cared exhibited the desired characteristics of interest to develop categories further or refine existing data towards theory generation. This methodology would enable me to find possible outliers to test the emerging theory. The use of memos would assist me to capture insights and thoughts which I had during interviews or analysis about the research question to inform the analysis. This methodology would entail much more screening of potential participant parents to ensure that I was likely to be able to recruit the range required. As a researcher, this overall design seemed more attractive because I wanted to understand the parents’ opinions, insights and thoughts at a deeper level than I perceived phenomenology would offer. However, there are several different approaches to grounded theory methodology which needed to be considered.

I considered two main forms of grounded theory; those of Glaser and Strauss (1967), and Charmaz (2008). The main differences between these are found in the coding procedures, the philosophical positions and the use of literature. Simplistically, using Glaser and Strauss GT, I would do a line by line analysis of the interviews to capture all the data into codes (segments). This focuses the data into small parts, so that no data are excluded from further analysis and parental voices would have their full impact. The codes could then be grouped together into categories allowing their interrelationship to emerge. Selective coding reduces the focus to the core categories and allows theoretical sampling (of further parents) to be done to explore data which are relevant to the categories until no new data are found. Integration of the categories and theoretical coding would facilitate the emergence of theory from these substantive codes and concepts to explain the pattern of data from the parents. The ability to memo would be useful at this point of the study. Philosophically, I would trust that theory would emerge to be 'discovered'.

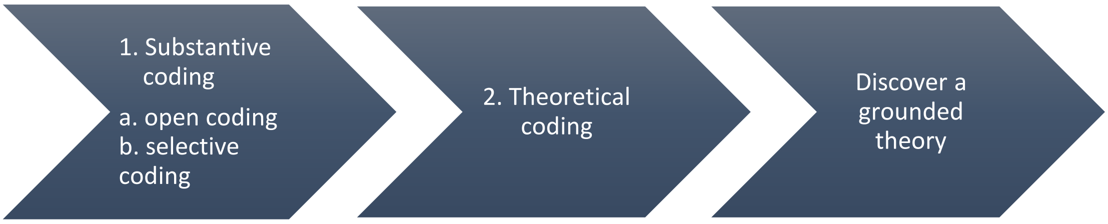

Figure 3.2 The Glaser and Strauss method (Holton, 2010).

Glaser and Strauss GT appealed to me initially as there were clear rules and it seemed simple, if time consuming, to apply. I therefore started to use this methodology, despite already having some knowledge of the literature from my earlier review. However, I rapidly discovered that the rules were too rigid and concrete, and my own knowledge and understanding made me want to think ahead about where the data were going. This made me increasingly aware that I needed to adapt my coding guidelines to allow the codes to progress in a more imaginative way. Memos were also made during individual interviews which I wanted to use contemporaneously. I was rapidly progressing towards using a Charmaz form of GT, which I was aware of from my qualitative theory studies. Charmaz described a much less concrete form of GT which endorses 'imaginative engagement with the data' (Charmaz, 2008, p. 168). Rather than initial open coding becoming selective coding and then theoretical coding, open coding would allow me to code for actions and theoretical cues rather than themes. It allowed me to make connections between codes and to keep analysis active. Here, I would 'construct' the grounded theory by refocused coding leading to identifying recurring and significant codes which explain the phenomena. With the Charmaz design, memos are used more contemporaneously to help look at the codes and categories, ultimately leading to theory. This was a more exciting methodology, more intuitive and allowed me to actively seek codes which linked with others in further interviews. As I was too embedded in the research to detach myself from the interviews to be able to keep to Glasser and Strauss design, a Charmaz-informed approach proved to be the better format. I recognise that this is also a more pragmatic philosophy. The analysis was accompanied by increasingly reviewing the literature during coding, although the full review of the literature did not occur until after the coding was complete. Thus, the family study proceeded, informed by Charmaz's constructivism.

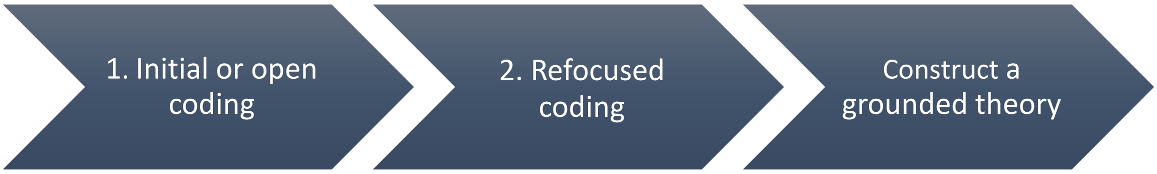

Figure 3.3 Constructivist GT coding procedure (Charmaz, 2008).

3.5 Methodology for the Family Study

A qualitative study informed by a Charmaz's approach to grounded theory was performed as part of Phase Two of the overarching project, to research parental understanding, experience and opinions about care for extremely premature and periviable babies.

3.5.1 Sampling strategy

Potential participants were identified from the TUH NICU database using the criteria of extreme prematurity or complex antenatal surgical diagnosis, family resident in the North Queensland area at the time of admission, fluent in English and delivered between 2010 and 2015. The first eight eligible families of babies born in 2012 - chosen as the approximate mid-point of the study, received a participant information sheet and consent form by post, to initiate the recruitment process (see Appendix 2). If they wished to participate, parents were requested to contact the administration officer by telephone to arrange an interview at their convenience. Three parents responded to the mail-out. Three potential participant families were then snowball recruited from the initial participants. Review of the characteristics of the initial six participants, and the iterative coding of interviews, lead to more purposive recruitment thereafter, to encompass the range of parental age, age of child, rurality of residence and ethnicity, as well as a subjective assessment of the difficulty of the neonatal stay and the impairment of the children. These potential participants received the letter, information sheet and consent form as per the original recruitment, as well as a follow up call from administrative staff. The mother who was the original driver of the project was recruited directly by the primary investigator. There were 15 families approached in the purposive recruitment phase. No suitable interview time could be arranged for one mother, one did not attend the arranged interview and was no longer able to be contacted. The last two interviews were not required as theoretical sufficiency within the categories had been achieved. Eleven of the families sampled participated. In total 17 families were represented including 23 parents.

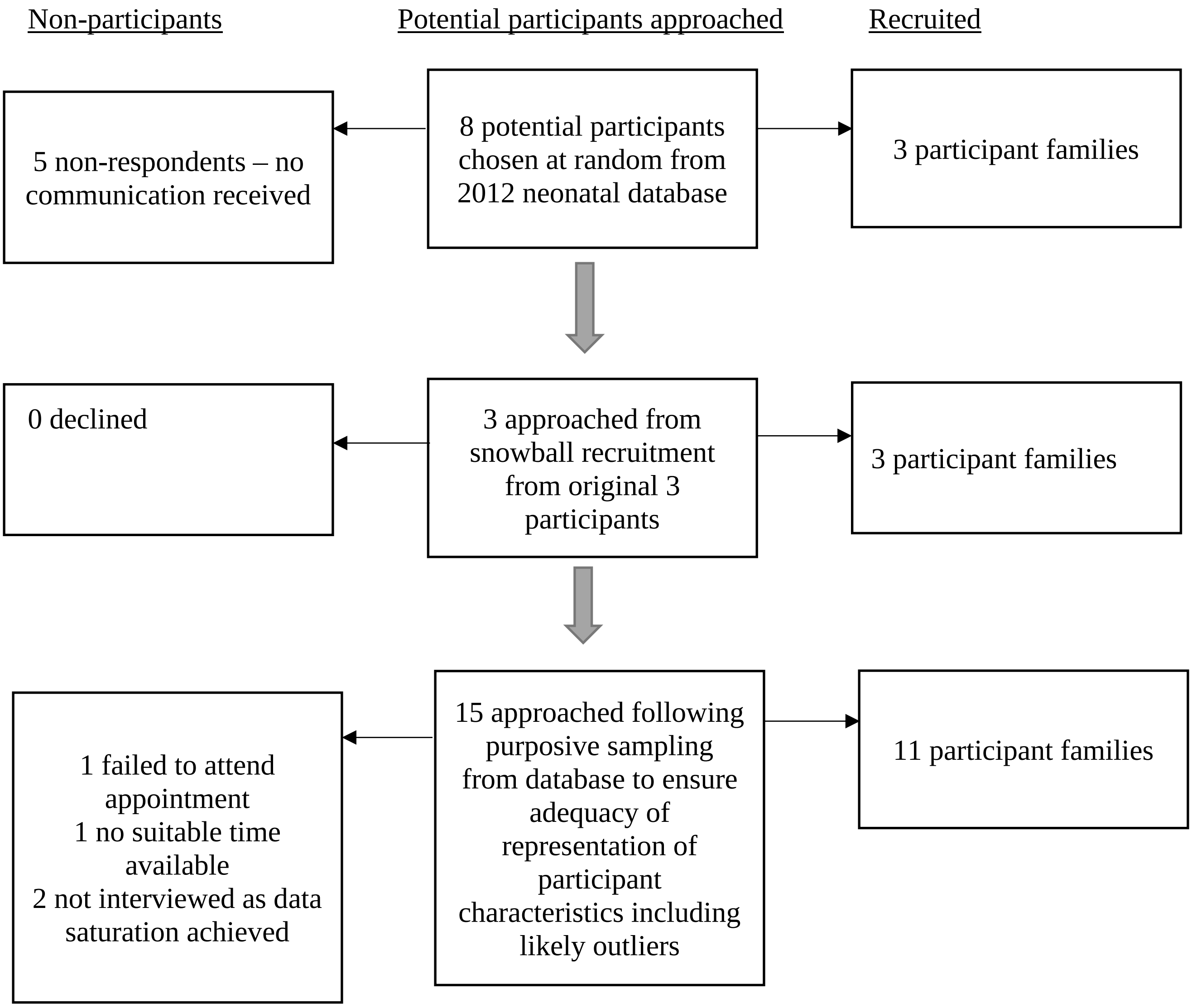

Figure 3.4 Diagram to represent the recruitment of participant families in sequential order. The neonatal unit database was used to recruit a total of 17 families.

All potential participants were offered a choice of interviewer (the primary investigator who is a neonatologist, or an alternative interviewer with a neonatal nursing and research background), but all participants chose the primary investigator. Indigenous participants were offered interviews by, or attended by, Indigenous Liaison Officers with an interest in research, but all declined this.

As a grounded theory study, evolving questions resulted from iterative analysis based on participant responses. Participants were asked if they wished to receive the results of the study, and these participants were sent a copy of the papers resulting from the study.

3.5.2 Data collection

The location of interviews was chosen by the participants, most choosing to be interviewed whilst at the hospital for other appointments. One interview was done by telephone, one arranged for a location at an alternative hospital and one interview at the patient’s home. All interviews were digitally recorded. For half of the interviews the child under discussion was present. All interviews included the mother, for six interviews both parents attended and chose to be interviewed together.

Consistent with grounded theory principles, initial interviews followed an interview guide, which was modified in response to iterative analysis as the interviews progressed (see Appendix 3). The interview guide included asking about the wellbeing of the child and parental perception of disability (where the baby survived), the recollection of the parents of the events leading up to admission of the baby, questions relating to their experiences on the neonatal unit and after discharge. Parents were asked for their opinions about the resuscitation of extremely preterm baby, and who should make resuscitation decisions. Ways to improve the service were explored. In keeping with qualitative research, families could discuss any issues at their own discretion, and the guide was used as a prompt where required Interview length ranged from 20 to 85 minutes, with one interview of 45 minutes being done during a four hour visit to the family home. The home visit was requested by a parent who wanted the researcher to have a more complete understanding of the life lived with a severely handicapped child. Interviews were conducted from late 2016 to late 2017.

3.5.3 Data analysis

The research team met regularly and discussed interviews iteratively. Using NVivo for data management, interviews were analysed using open coding. Categories were identified from the codes using a staged constant comparative process from focused coding to category generation. While the primary investigator did the initial coding, triangulation with the study team was used to develop categories and subcategories.

3.5.4 Ethics approval

Approval for the study was received from the Townsville Hospital Health Service Human Research Ethics Committee (HREC/15/QTHS/195), and from James Cook University Ethics Committee (6484) (see Appendix 4). All participants gave informed consent to participate in the study.

One paper from this study which specifically record the family experiences of neonatal care has been published (Ireland et al., 2019b) and is found in Chapter Five.

Health Care Practitioner Attitudes and Knowledge of Extreme Prematurity

3.6 Methodology

This study was undertaken to provide data about decision making from the perspective of health care providers. During the analysis of the parental perspectives, it became apparent that HCP perspectives on decisions were critical to understanding decision making in the NICU context. When analysed in conjunction with the data from the parental study HCP data could further develop existing categories and identify variances necessary for the formulation of decision making theory. The object for the HCP study was to develop an understanding of HCP involvement in decision making. This part of the research involved contextualising the attitudes of HCP within their accuracy about the predicted outcomes of extreme prematurity, including variables which might modify the outlook for individual pregnancies.

3.6.1 The use of a mixed method design

Most of the research in Australia exploring attitudes and opinions about resuscitation is done with a quantitative design using surveys. A survey offers quantitative methodology which enables a large group of clinicians to participate, is efficient and appeals to readers who value statistics as an important source of information. My concern was that this method alone would offer little understanding of why the participants held these opinions and how these varied or were supported by the data from the parent study. Whilst some text could provide thematic classification using content analysis, I did not feel that this would be sufficient given the restriction of closed questions and the limited time clinicians have to provide written response to free text questions. Continuing with the qualitative study using grounded theory methodology enables a more detailed perspective of the views and understanding of the HCP, but a qualitative study alone would lead to less generalisability of the findings, with fewer participants, more subjectivity and less traditional respect by the medical fraternity who were the most likely end users of the research. Mixed methods research as outlined by Creswell (2014) seemed an option which might allow me to pursue my aims of gathering both quantitative and qualitative data to draw interpretations around the topic of interest gaining the strengths and mitigating the deficits of both types of research. Creswell emphasises the need for rigorous methods, validity and trustworthiness in both types of research in the design, the sampling approach, types of data, organisation of the data and its analysis.

There are several different possible designs in mixed methods research. However, a simple convergent study was a suitable, philosophically pragmatic methodology which could apply for my study. This design is suited to a relatively inexperienced researcher, like myself, who is also embedded within the context of the research and participates with an awareness of biases of my own towards the resuscitation of extremely preterm babies. My survey questions about the knowledge and opinions of HCP about resuscitation would yield quantitative data, whilst the theory constructed from the qualitative study could clarify the reasons for these findings. Data from both studies provided triangulation to validate and confirm for each other. Gathering both types of data at the same time provided a full and nuanced understanding of the research topic and negated some of my bias as the results would emerge in parallel. Applying this methodology to then merge the data strengthened the findings (Figure 3.5).

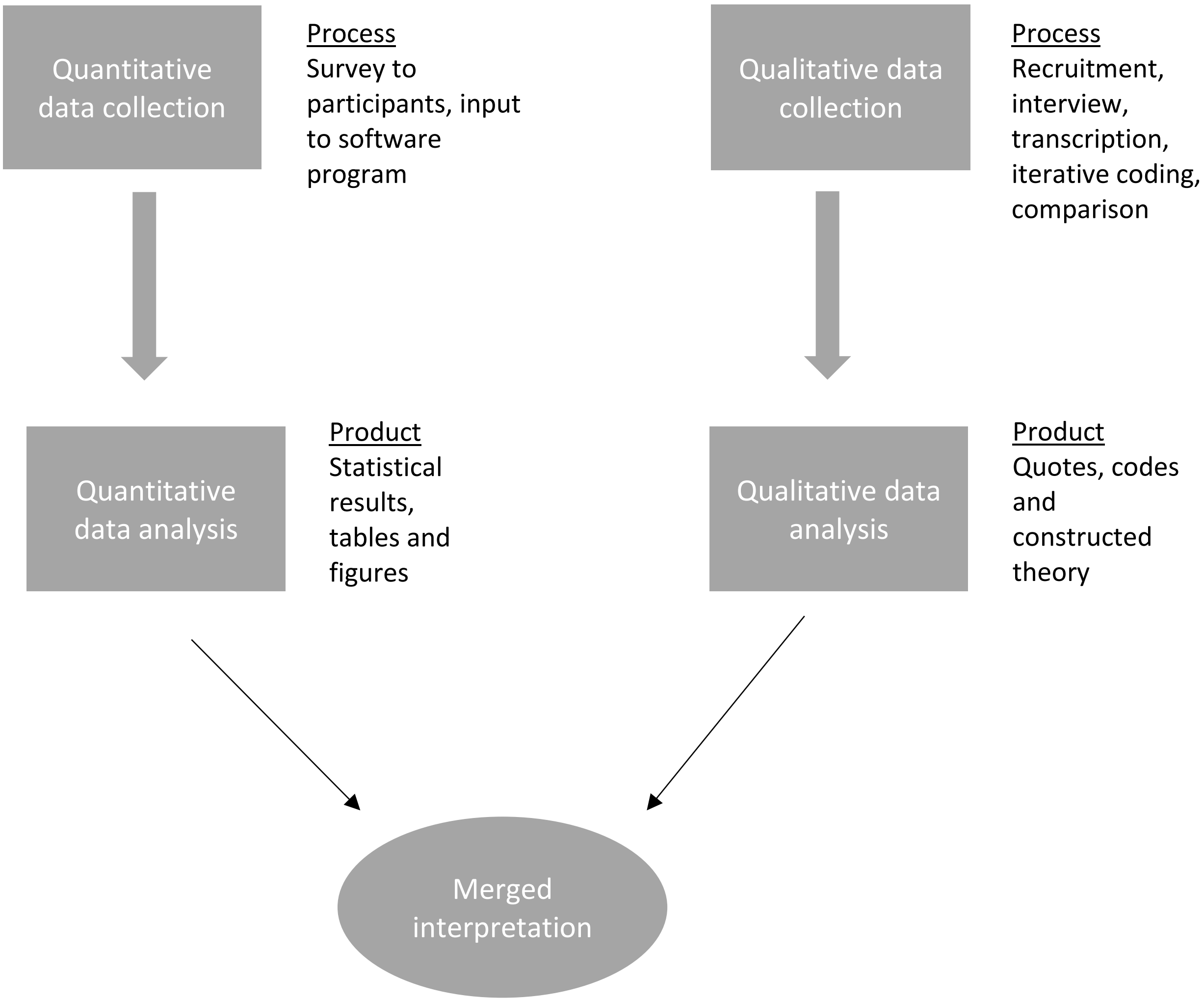

Figure 3.5 Convergent mixed methods design of HCP attitudes and knowledge about extreme prematurity (Creswell, 2014, p. 37).

Two other basic designs of mixed methodology were considered and then abandoned. These included an explanatory sequential design where the survey is done initially with random sampling of HCP, followed by a qualitative study designed to explicitly explore the quantitative study findings using a subset of volunteers from the first study. The benefits of this design are that only the specific areas of interest found in the quantitative study need inclusion, but it also excludes the depth of exploration that the convergent design offers, where unexpected data may emerge from analysis of the qualitative study. Alternatively, an exploratory sequential design would utilise a design with an initial qualitative study with purposive sampling to explore the issue of decision making in periviable babies, analysis of these results, then designing a fresh tool to use in a quantitative study (Creswell, 2014). In this research, a survey using focussed questions about extreme prematurity and vulnerable babies may have been shorter, and been used to investigate the unexpected findings which had not previously been explored on older surveys. Both designs offer advantages with an increased focus in areas of interest, but also limit the ability to sample theoretically which may exclude the emergence of possible contrary findings. The design chosen allows merging with triangulation, rather than one study informing the other.

3.6.2 Choice of location and HCPs of interest

Many of the women cared for at TUH are transferred from other centres prior to delivery, after problems develop during the pregnancy. HCPs at all centres talk with parents and counsel them about the transfer, which should include some discussion about the risks of extreme prematurity. Sometimes babies are born in the referral centres and are cared for initially by the paediatric staff. I felt that the insights of HCP from centres outside of TUH about long term care for the babies outside of a tertiary centre would clarify any potential challenges for these families.

Whilst I was the primary investigator at TUH, I invited potential co-investigators from all three larger referral centres to participate. I was not able to engage clinicians from one regional centre but HCPs from another regional centre and a remote centre, were keen to participate. Whilst I had hoped to include the regional centre who declined to participate, on reflection, TUH, along with the other units, provided a wide enough range of centres providing obstetric and neonatal care to support generalisability.

Historically, as established in Chapter Two, many Australian studies about attitudes towards resuscitation of the neonate focused on senior medical staff. This includes obstetricians and neonatologists (Mulvey et al., 2001; Oei et al., 2000), with some involving senior neonatal nursing staff. Whilst women and their partners received counselling about the risks of extreme prematurity and implications for their families from senior medical staff, literature suggests that other HCP such as midwives and neonatal nurses are turned to by the parents during the time of decision making as these HCP appear more approachable to families. They speak in language more easily understood by parents (Kavanaugh et al., 2010). Hence, I wanted to include these clinicians in both components of this HCP study.

Quantitative Study Using Survey

The quantitative component of this study consisted of a cross-sectional electronic survey of HCPs administered on the SurveyMonkey platform (SurveyMonkey Inc. Ca. U.S.A.). This platform is inexpensive, easy to use, can be edited and shared with others to refine prior to disseminating to participants. Results can be exported and collated (without data entry) on a spreadsheet which can then be transferred to SPSS. There is functionality to perform statistical calculations using the SurveyMonkey platform software, but transfer to SPSS enabled me to perform subgroup analyses more easily as I was already proficient in its use. SurveyMonkey is a popular tool for research in the Australian medical community, acceptable to the Queensland Health information technology system and would not be excluded by the installed anti-virus programs.

3.7 Survey Design

The survey questions were devised after reviewing the literature for similar surveys, adapting some of these and adding some questions to cover areas of interest based on my knowledge and experience of the local environment. Respondents were asked:

i. whether they cared for pregnant women under 28 weeks gestation who were at risk of premature delivery;

ii. if they had ever been asked by a parent for their personal opinion about whether a baby should receive intensive care or palliative care;

iii. their confidence in discussing extreme prematurity with patients.

Further questions explored their knowledge of rates of:

i. survival;

ii. severe disability;

iii. intact survival at different gestations from 22 to 27 weeks completed gestation.

Replies to survival and outcomes were given as one of five quintiles as it was considered less intimidating to participants than asking for exact estimates, whilst still being accurate enough for analysis. Participants were asked to rank their opinion about other factors which may influence the decision to offer intensive care to extremely preterm babies, and give an opinion about the most appropriate gestation from which intensive care should be offered to premature babies, at which gestation parents could be final decision makers, whether staff could override parents' wishes, and the gestation at which the participant would want a potential extremely premature baby of their own to be resuscitated. Their contact with disabled people and religiosity was explored. Free text was allowed for participants to expand on their replies. Although similar studies are found in the literature, the questionnaire was not based specifically on any of these as none captured all the data of interest. All gestations of babies from 22 to 27 completed weeks were included although resuscitation is usually provided at the older gestations.

The survey was piloted with a group of senior nursing and medical staff and a psychologist involved in neonatal care to assess face validity and adapted to ensure clarity. The feedback from the pilot was incorporated into changes made to the survey before it was disseminated to participants (see Appendix 5).

3.7.1 Sampling and survey administration

I asked the nurse unit managers of the midwifery teams and neonatal intensive care unit to disseminate the survey to registered midwives and intensive care neonatal nurses at TUH. Senior nursing and midwifery staff involvement was also important as the participants would need to use their computer work stations to complete the survey, and the senior staff needed to be aware and approve the use of work time for this purpose. This was perceived to be less of an issue for medical staff. A link to the survey was emailed to all neonatal, paediatric and obstetric medical staff specialists or doctors on college training programs. The co-investigators at the other sites sent all the links. After two weeks, a reminder email with the link to the survey was sent to all prospective participants to promote participation. As set group email addresses were used, some potential participants may not have received the email if they were not present at work or did not read their email. The survey remained open for a further six weeks to allow time for responses to occur. It was not possible to identify which staff had responded to the link, beyond the demographic data related to work stream.

3.7.2 Data analysis

The survey data were imported directly from the survey tool and were analysed using IBM SPSS 25 (Armonk, NY, USA). Frequencies were used to analyse numerical data and Chi square was used for categorical variables. Where categorical data arose with multiple ordinal responses, Kruskal-Wallis H test to compare means was utilised. Significance was defined as $p<0.05$. A comparison was made between HCPs who care for women primarily prior to delivery - obstetrics and midwifery staff (referred to as antenatal HCPs), and after delivery – neonatologists, neonatal nurses and paediatricians, (referred to as postnatal HCPs). This latter group were included as they provide counselling at the non-tertiary centres and at the tertiary centre provide neonatal care on the postnatal wards. Questions about factors which may influence opinions positively or negatively towards resuscitation were given as a Likert score, with scores of “very likely” and “likely” to imply a positive influence to offer intensive care, a score of “neutral” was considered to indicate that the factor was not contributory to the opinion, whilst an “unlikely” or “very unlikely” score was considered to indicate the factor would make the HCP less likely to agree with resuscitation. Missing data were excluded from analysis. Content analysis was performed on the qualitative data entered into free text fields using a process of coding for thematic classification (Liamputtong, 2017).

3.8 Comparison Data

TUH had outcomes for survival and all short-term morbidities within the expected range for units within the Australian and New Zealand Neonatal Network (ANZNN) as informed by Phase One of the research (Ireland et al., 2019). Data for survival were obtained from the Phase One study, and collated with 2013 to 2017 data to provide most recent comparison available to ANZNN data. Long term follow-up for babies born from 2011 to 2014 inclusive were also considered. Follow up data for TUH are around 50% for all gestations due to difficulty in getting data from outside the district. The data given in the ANZNN comparative database suggests that outcomes for severe disability for TUH compares positively to the mean for the ANZNN group. The mean rates for severe disability and typical development for the ANZNN have been used for expected long term outcomes because of concerns that the lower follow up rate of TUH might be a source of positive bias where more regional and remote children are excluded.

3.9 Ethics Approval

The study was approved by The Townsville Hospital Human Research Ethics Committee (HREC/15/QTHS/194), and acknowledged by James Cook University (JCU: ref 6485). Governance approval was given by all participating sites and JCU (see Appendix 6).

The Qualitative Exploration of HCP Attitudes and Opinions Study

To link with the parent study, GT offered the most appropriate methodology to manage the process and analysis of the interviews with HCP. Having had some experience by this time, I was more proficient in the methodology, but as a clinician embedded daily with the subject matter, my own engagement with the data were greater in this study. Memoing and frequent discussion with advisors were added measures to address potential influence of my experience on the data and increase trustworthiness of the findings. Whilst the ongoing coding and interviewing occurred, I encountered an interesting tweet on the social media of Twitter from a social medicine account describing bias in health care. Whilst not directly applicable to my topic, constructivism allowed exciting theory to evolve about bias, and then to be sought in future interviews to refine this possible theoretical concept.

3.10 Methods

Healthcare providers caring for pregnant women who are at risk of delivering extremely premature babies, or who care for the babies after they are born were interviewed to assess their attitudes towards caring for babies born extremely premature.

3.10.1 Recruitment strategy

A pragmatic, purposive strategy was used to enrol relevant participants from the three sites. All neonatal and obstetric specialists and trainees, midwifery, neonatal nurses and paediatricians previously invited to participate in the survey were invited to participate in the qualitative study. An email address was provided for potential participants to contact the primary investigator. In addition, all senior staff were sent information about the qualitative study separately to maximise engagement of the HCPs most likely to be involved in counselling parents (see Appendix 7). Midwifery and neonatal nursing staff were purposively chosen to represent the variety of age and experience. Outside the tertiary centre some further potential participants were identified at each centre by a local investigator and approached to ensure a range of participants including midwifery, obstetric, neonatal nursing, and paediatric staff of varying experience at all three centres. Both the survey and this study continued concurrently, and further volunteers from the quantitative study were evaluated to decide if theoretical adequacy of the data and the emerging categories in the qualitative study might benefit by their inclusion. In addition, a focus group was held involving two Indigenous Liaison Officers and an obstetric social worker, who requested a focus group format rather than individual interviews. Recruitment ceased when iterative analysis did not identify any new data that would refine emergent categories.

3.10.2 Data collection

Interviews were performed by myself and a research assistant (a midwife researcher, experienced in qualitative interviewing, but not involved with the NICU). I needed to be continually reflexive about any personal feelings I might have about individual participants. To mitigate potential conflict, I avoided performing interviews with any of the senior HCPs I worked alongside within the neonatal unit and the obstetric department. These participants were interviewed by the research assistant (RA). I had pre-existing knowledge of the attitudes of some of my colleagues, and felt that I might not be able to detach myself from some of their opinions, whilst a neutral interviewer would elicit more impartial data. I sensed that senior staff would feel more able to talk freely about the topic with the RA. All other potential participants were also offered, and several opted for interview by the RA. Interviews were conducted in the workplace or by telephone at a time of the participants choosing and recorded electronically.

An interview guide informed the interview (see Appendix 8). The interviews explored the participants' work experience and their experience in counselling parents at risk of extremely premature delivery. Opinions about decision making around resuscitation of extremely premature babies were explored both as a process and in terms of the actual factors assessed by the HCP when offering intensive care. The interview also explored the relative roles of parents and HCP in decision making at specific gestations was explored. Participants were asked to offer any suggestions for improving decision making processes within the unit and offer any other comments which they might have about the care of periviable babies. Recorded interviews were transcribed by a commercial transcription service and returned to the research team within three days of the interview. Data were then coded and potential modification of the interview guide was considered as necessary to develop emerging categories. Very early modification to the semi-structured interviews added questions specific to the Queensland Health guidelines and possible religious inclinations informing the participants' opinions. Interviews lasted 17 to 90 minutes in duration.

3.10.3 Data analysis and handling

Using NVivo for data management, interviews were analysed using initial and focused coding enabling broad tentative categories to emerge. Focused codes were identified from the descriptive codes within the categories using a staged constant comparative process from focused coding to category generation. While the primary investigator did the initial coding, analytic triangulation in collaboration with the study team was used to develop categories during research meetings.

3.10.4 Application of mixed methodology

I have merged the quantitative and qualitative HCP studies to integrate the results found in both studies. This was done after analysis of each study was completed as a convergence where data from each study was brought together and compared as shown in Figure 3.5.

3.10.5 Ethics approval

The HCP study was approved by The Townsville Hospital Human Research Ethics Committee HREC/15/QTHS/194, and acknowledged by James Cook University (JCU: ref 6485). Governance approval were given by all participating sites and JCU (see Appendix 6)).

The results of these studies are found in Chapter Six along with a publication from the quantitative study (Ireland et al., 2020). A further publication based on one aspect of the findings for the qualitative study which has been published (Ireland et al., 2021) is also found there.

Palliative Care in the Neonatal Unit

Palliation rather than active care is suggested to prospective parents of periviable babies as an option at the time of birth. Where palliation without resuscitation occurs, the midwifery team provide most of the care for the patient, with backup for medication and review if required from the neonatal team. Exploring palliation was not an intended part of the scope of the overarching research. However, data about palliation were evident in both the parental and the HCP arms of the study. During counselling, it is suggested to future parents, that following initial resuscitation, the baby will be constantly reviewed and redirection of care to palliation considered should the risks of a poor outcome increase. The parental study data included discussion around palliation for some babies, and some parents experienced the loss of a baby following redirection of care within the study. An understanding of palliation at TUH was explored to gain further insight into how this option occurs and its possible influence on influence decision making.

3.11 Methodology

The lived experiences of neonatal nurses who care for the baby during palliation provides insight and understanding of the process and performance of palliation on the unit. For this research, a descriptive phenomenology design provided data for thematic analysis necessary to evaluate this lived experience (Hansen, 2006). The participants were staff who provided NICU nursing care for some time, as palliation is relatively uncommon. Hence purposive sampling was an ideal approach to ensure participation from nursing staff with the relevant experience. A semi-structured interview guide with questions to encourage the neonatal nurse to consider the facilitators and barriers to 'good' palliative care was developed, with probing questions to follow up responses.

3.11.1 Recruitment strategy

The study was promoted by the Nurse Unit Manager of the TUH NICU to all nursing staff providing intensive care. Snowball recruitment was then used to encourage participation until a purposive sample of eight neonatal nurses with experience in providing palliative care was obtained. Eligibility criteria included part-time and full-time neonatal nurses with more than five years' experience in neonatal intensive care, who had also been the primary nurse for a baby during at least one episode of palliative care. They represented a varied skill mix. No further demographic information was collected.

3.11.2 Data collection

Interviews were conducted by a clinical psychologist who had previously worked on the neonatal unit. Open ended questions were asked regarding the delivery of palliative care in the neonatal and regional context. Nurses were asked about their perceptions of barriers and facilitators of palliative care in the unit, and whether the unit's regional location of the unit impacted upon the delivery of palliative care. Participants had the opportunity to add any further information about their experiences of neonatal palliative care.

The interviews were conducted at a location of the participant's choice. Consent was obtained and interviews recorded digitally. Data were analysed within an Interpretive Phenomenological Analysis (IPA) framework (Smith et al., 2009). Analysis of all interviews was done at the end of the interview phase.

3.11.3 Ethics approval

Approval for the study was obtained from the Townsville Human Research Ethics Committee

(13QTHS84) (see Appendix 9). Site specific approval was also obtained.

A publication from this study (Kilcullen & Ireland, 2017) is found in Chapter Seven. The results of this study are incorporated into the analysis of all the data from all the studies, in Phase Three shown on Figure 3.1 and presented in Chapter Eight.

3.12 Strategies to Enhance Reflexivity and Rigour

Throughout this research, I have kept a journal of my thoughts and insights gained. I have made memos, which have been used to inform my interpretation of the research in all studies as well as my reflexivity section in Chapter Nine. The memos and journaling along with details of recruitment and the practical performance of each study are expanded upon in the relevant chapters. Coder, data and analytic triangulation occurred during regular discussion with the PhD advisors who were also members of the research team.

Participants in the family study and HCP studies have been offered feedback about the studies. Several of the family participants requested copies of papers arising from the research which will be sent to them after publication of the final study occurs. None of the family participants wished to discuss earlier analysis of the data. HCP participants have received publications contemporaneously as these have occurred. The publications were well received, with suggestions, particularly from nursing and midwifery staff to improve practice within the obstetric and neonatal services. Publications have also been disseminated to the management of the Health and Wellbeing Directorate at the TUH which manages the obstetric, neonatal and paediatric departments, as well as the regional and remote centres.

Chapter. 4 The Outcomes of Extreme Prematurity at Townsville University Hospital

Undertaking a retrospective audit review of the outcomes of extreme prematurity in North Queensland enabled me to establish a holistic overview of all live born deliveries, those who were cared for at TUH, survival and short term morbidities. Data about the retrieval status and the antenatal administration of steroids were both important as these are factors suggested by previous studies to affect outcomes (Chien et al., 2001; Lui et al., 2006). Further, they are likely to be important issues for an area which is geographically large with many babies born in external centres.

The study has been published (Ireland et al., 2019) and is presented below. Some reformatting has been undertaken to maintain consistency throughout the thesis.

Article: Adequacy of Antenatal Steroids, Rather Than Place of Birth, Determines Survival to Discharge in Extreme Prematurity in North Queensland

Ireland, S., Larkins, S., Ray, R., Woodward, L., & Devine, K. (2019). Adequacy of antenatal steroids, rather than place of birth, determines survival to discharge in extreme prematurity in North Queensland. *Journal of paediatrics and child health*, *55*(2), 205-212.

https: doi.org/10.1111/jpc.14184

4.1 Abstract

Background

The Townsville Hospital cares for babies from a large geographical area, many of whom are outborn, of Aboriginal or Torres Strait Islander origin and have families who reside in areas of deprivation. This study examined the outcomes of babies born at all locations in North Queensland to assess the predictors of poor outcomes.

Methods

A retrospective observational study examined the survival of 313 babies born from 22 completed weeks gestation to 27+6 weeks gestation in North Queensland between January 2010 and December 2016. Additional analyses were done for the 300 non-syndromal babies whose mothers usually resided in North Queensland, studying demographics of gestation, gender, birth weight, Indigenous status, regionality of maternal residence and adequacy of antenatal steroids. Short-term morbidities of intraventricular haemorrhage/periventricular leukomalacia (IVH/PVL), surgical necrotizing enterocolitis, retinopathy of prematurity requiring treatment and chronic lung disease, and death, were studied in relation to demographic factors and clinical treatment.

Results

Adequacy of steroids was significantly associated with decreased mortality odds ratio 2.87 (95% confidence interval 1.23-6.72) whilst no difference in outcome was seen by retrieval status or ethnic origin. Babies from remote locations were at increased risk for IVH/PVL 2.33 (1.03-5.26). Male babies suffered more chronic lung disease 1.61 (1.01-2.56) and IVH/PVL 2.57 (1.22-5.45). Aboriginal and Torres Strait Islander babies were at lower risk for IVH/PVL.

Conclusions

Steroids should be administered wherever there is any possibility of provision of intensive care for periviable babies. Place of birth, and ethnicity of mother should not unduly influence antenatal counselling.

4.2 Background

Delivery at extreme prematurity carries an increased risk of mortality and long-term disability in survivors, with worsening prognosis with lower gestations (Bracewell & Marlow, 2002 ; Joseph et al., 2016; Moore et al., 2013). Globally, the rates of survival and disability vary, but are improving with improved antenatal and neonatal care (Ishii et al., 2013; Johnson & Marlow, 2017; Maruyama et al., 2016; Poon et al., 2013; Stensvold et al., 2017). Understanding the outcome statistics for a particular neonatal unit, given various characteristics of the baby, is important for antenatal counselling in situations where extremely preterm birth is likely (Martinez et al., 2005). These data are also important in evaluating the quality of service being provided, and to enable the identification of areas for improvement (Payne et al., 2010; Schulman et al., 2011). Whilst survival figures are usually easy to obtain, long term outcomes to an age where all sequelae of extreme prematurity are evident is much more difficult, particularly where the sequelae may only be apparent late in childhood or even in adulthood (Doyle et al., 2010; Johnson & Marlow, 2017).

The Townsville Hospital (TTH) Neonatal Unit is the largest tertiary referral neonatal unit in Australia outside the major metropolitan centres. It serves North Queensland, in the North East of Australia, which has a population of approximately 700 000 over an area of 500 000 km^2, and only two regional centres with populations greater than 100 000. TTH Neonatal Unit cares for babies of any viable gestation, as well as providing neonatal surgery (excluding cardiac surgery). Over 10 000 babies are born in the region annually. The unit admits approximately 800 babies annually, 40-50 who will be extremely premature (defined as less than 28 completed weeks gestation –from the TUH neonatal database). Where possible, pregnant women who are at risk of delivering an extremely preterm baby are transferred to the tertiary unit prior to delivery. However, when babies are born outside of the tertiary unit because the woman is too unwell to delay delivery, or the labour is too advanced to safely transfer the baby, the baby will be born outside TTH These babies are referred to as ‘outborn’ or ‘retrieved’ babies. A retrieval team from TTH will transfer the baby to TTH. Most retrievals are done using fixed wing aircraft, and most involve distances of 350 to 1000km. In some circumstances the retrieval team will be present at peripheral births prior to the delivery. During the study time frame the TTH retrieval team was led by senior clinicians - mainly consultants or senior registrars with over five years neonatal experience, accompanied by senior nursing staff.

North Queensland has a high proportion of people identifying as Aboriginal or Torres Strait Islander (10.7%) compared to the Queensland average (4.0%) (Office, 2016), and the Australian average (3.0%) (Commonwealth of Australia & of the Prime Minister and Cabinet, 2017). It is known that the perinatal outcomes for Aboriginal and Torres Strait

Islander people (hereafter referred to as Indigenous Australians) are poor compared to non-Indigenous groups, with neonatal death over twice that in Indigenous babies compared to non-Indigenous babies and nationally, disproportionally high rates of prematurity- 14% compared to 8% (AIHW, 2016). TTH has a high proportion of extreme preterm babies who are outborn and subsequently transported to TTH (nearly 25%), whilst just over 25% of extremely preterm babies cared for at TTH reside within the immediate hospital catchment area (data from the TUH Neonatal database).

This study aimed to evaluate the short-term outcome for babies born at less than 28 weeks completed gestation who were cared for at TTH in order to identify the predictors of poor outcome. Aboriginal and Torres Strait Islander babies, those from remote residential locations, and those babies who were retrieved were of interest as these groups are usually perceived as being at higher risk of poor outcomes (Abdel-Latif et al., 2006; Synnes et al., 2017).

4.3 Methods

This retrospective cohort study involved all babies born under 28 completed weeks of gestation who were cared for in The Townsville Hospital Neonatal Unit between January 2010 and December 2016 to assess overall survival data. Patients were identified using the neonatal unit database. Babies were eligible for inclusion for more detailed analysis of short term morbidity where the usual place of residence of the mother was in the North Queensland region forming TTH neonatal service catchment area. Excluded were babies whose mothers did not usually reside in North Queensland as these babies are usually transferred back to their usual area of residence prior to discharge and data is more difficult to obtain from outside the state and country, and babies with identified major congenital anomalies.

Patient records were used to collect demographic data including the gestational age in completed weeks, gender, birthweight, place of birth, place of residence of mother, Aboriginal or Torres Strait Islander status. Regionality was defined as regional or remote according to the classification ARIA+ (Accessibility/Remoteness Index of Australia) produced by the Australian Bureau of Statistics (2017). Inner and outer regional areas are here defined as 'regional', and remote and very remote regions are defined as 'remote'. Variables of inborn/outborn status and adequate antenatal steroids – defined as at least two doses of maternal steroids commencing at least 24 hours prior to delivery in the week prior to delivery were collected. Short term outcomes were defined as death; intraventricular haemorrhage (defined as grade 3 or 4 by Papile's system) (Papile et al., 1978); necrotising enterocolitis requiring surgery or leading to death (based on Bells classification) (Bell et al., 1978); retinopathy of prematurity requiring treatment (Gole et al., 2005); and chronic lung disease where the baby was still on supplemental oxygen or respiratory support at 36 weeks gestation.

Data were also obtained from the Health Statistics branch of Queensland Health, which collects data from all health centres throughout Queensland at the time of delivery of any fetus over 20 weeks gestation, with outcomes given as stillbirth, born with signs of life, and death in the neonatal period. Data utilized included the delivery and mortality of all births from 22 to 27 completed weeks gestation during the study period at all health centres in North Queensland.

4.3.1 Statistical analysis

Data were analysed using SPSS version 23, 2015(SPSS, Chicago, Illinois, USA). Data are presented as number and percentage (%), means with 95% Confidence interval (CI) or median and interquartile range (IQR). Categorical variables were analysed using Fishers exact test with 2-sided p values. Non-parametric data were analysed using Mann-Whitney-U test. Binary logistic regression assessed predictors of death and short term morbidity adjusting for confounding factors of gestation, birthweight, gender, Indigenous status, retrieval status, remoteness of residence and adequacy of antenatal steroids.

4.4 Ethics

The study received approval from the Townsville Human Research Ethics Committee as audit and quality assurance (reference number HREC/16/QTHS/142).

4.5 Results

Three hundred and eighty-three babies between 22 and 27 completed weeks gestation were born in North Queensland between January 1st 2010 and December 31st 2016, with a clear association between increasing gestation and increased odds of survival (Table 4.1).

Table 4.1

Admission and survival of all babies live born in North Queensland from January 2010 to December 2016 inclusive.

Gestation	Born alive in North Qld	Admitted to TTH neonatal unit	% admitted of live born	Survived	% survival for admitted babies	% survival of all liveborn
22	41	4	9.8%	2	50%	4.9%
23	37	18	48.6%	8	44.4%	21.6%
24	76	68	89.4%%	48	70.6%	66.6%
25	58	56	96.6%	50	89.3%	86.2%
26	76	76	100%	71	93.4%	93.4%
27	95	91	95.8%	89	97.8%	93.7%
Total	383	313	82.5%	268	85.6%	70.0%

Seventy babies who were born alive between 22 and 27 completed weeks gestation, were not admitted to the neonatal unit at TTH. Thirty-seven (56%) non-admitted babies were of 22 completed weeks gestation, and 38 of the total occurred outside of TTH (54.7 %). Nearly half the babies born at 23 weeks, and 89% of 24-week gestation babies, were admitted, and offered full intensive care. At 23 weeks gestation there was no significant difference in inborn and outborn babies for admission to the neonatal unit, whilst at 24 weeks outborn babies appeared to be less likely to be admitted for intensive care, although the number of non-admissions is small. At gestations over 24 weeks, non-admission rates for outborn babies do not allow for valid statistical evaluation.

Table 4.2

Admission to TTH NICU by place of birth.

Gestation	Total born	Total admitted TTH	Admitted TTH/ Born TTH	Outborn admitted to TTH/Total outborn	Outborn vs inborn admission P-VALUE
22	41	4	2/19	2/22	0.877
23	37	18	12/23	6/14	0.582
24	76	68	55/58	13/18	0.006*
25	58	56	42/42	14/16	N/A
26	76	76	55/55	21/21	N/A
27	95	91	73/74	18/21	N/A
Total	383	313	239/271	74/112	

Three hundred and thirteen babies born under 28 completed weeks gestation between 1st January 2011 and 31 December 2016 inclusive, were identified on the admission database and analysed for short-term outcomes. Ten babies were excluded because the mother did not usually reside in North Queensland, as were 24-week twins and a 27-week gestation baby with major congenital anomalies. The data from 300 babies is included in the subsequent analysis (Table 4.3).

Table 4.3

Demographics of study group.

Gestation	Admitted	Weight Median (IQR)	Male Number (%)	Retrieved Number (%)	Remote Maternal Origin Number (%)	Indigenous Status Number (%)	Adequate Steroids Number (%)	Survived Number (%)
22	4	580g (482-587g)	2 (50%)	2 (50%)	1 (25.0%)	3 (75%)	1 (25%)	2 (50%)
23	18	632g (597-662g)	5 (27.8%)	5 (27.8%)	6 (33.3%)	8 (44.4%)	3 (16.7%)	8 (44.4%)
24	64	700g (664-770g)	38 (59.4%)	11 (17.2%)	13 (20.3%)	22 (34.4%)	31 (48.4%)	45 (70.0%)
25	55	800g (730-874g)	31 (56.4%)	12 (21.8%)	22 (40.0%)	22 (40.0%)	25 (45.5%)	49 (89.1%)
26	71	900g (830-990g)	35 (49.3%)	20 (28.2%)	19 (26.7%)	28 (39.4%)	39 (54.9%)	66 (93.0%)
27	88	1050g (906-1147g)	42 (47.7%)	18 (20.5%)	21 (23.9%)	32 (36.4%)	56 (63.6%)	86 (97.7%)
Total	300	837g (700-1000g)	156 (52%)	68 (22.7%)	82 (26.7%)	115 (38.3%)	155 (51.7%)	256 (85.3%)

There were 44 deaths during this time period. Fifteen (34%) occurred on the first day of life, 27 in the first week (61%) and 31 by the end of the second week (70%). Early deaths were a result of respiratory failure, early onset sepsis and intraventricular hemorrhage. There were a further eight deaths by the end of 8 weeks of age, primarily from late onset sepsis and necrotizing enterocolitis. The remaining five deaths occurred from chronic lung disease, necrotizing enterocolitis and a very late death at 257 days in a baby with short gut syndrome secondary to necrotizing enterocolitis.

The study showed that there was no difference in outcome (Table 4.4) for babies who were retrieved, compared to babies who were born at TTH although the mothers of babies who were outborn were significantly less likely to receive adequate steroids. It was noted that five of the outborn babies had the retrieval team present for their delivery, all in remote locations, all did well and survived with only chronic lung disease as sequalae, but the numbers were too low to allow separate statistical analysis. Comparison of inborn and outborn babies who had not received adequate steroids showed that the outborn babies were statistically heavier than the inborn group of babies, but there was no significant difference in outcomes.

In separate analysis, babies from areas outside of Townsville but born at TTH were compared with babies who were retrieved. It was found that babies who were delivered in Townsville were significantly more likely to receive adequate steroids, and less likely to sustain IVH/PVL. Babies retrieved from remote locations had no difference in outcome compared to babies retrieved from regional locations.

Table 4.4

Outcomes by variables of inborn/outborn status, adequacy of steroids, maternal origin, place of retrieval.

	No.	Gestation Median (IQR)	Birth-weight Median (IQR)	Male Number (%)	Indigenous Ethnicity Number (%)	Adequate steroids Number (%)	Chronic lung disease Number (%)	IVH/PVL Number (%)	ROP Number (%)	NEC Number (%)	Death Number (%)
Retrieval status											
Inborn	232 (77.3%)	26.0 (24.0-27.0)	822g (700-980g)	122 (52.5%)	86 (37.1%)	151 (65.1%)	115 (49.6%)	27 (11.6%)	11 (4.7%)	20 (8.7%)	34 (14.7%)
Outborn	68 (22.7%)	26.0 (24.0-27.0)	882 (721-1057g)	34 (50.0%)	29 (42.6%)	4 (5.9%)	32 (47.1%)	13 (19.1%)	3 (4.4%)	7 (10.3%)	10 (14.7%)
		p=0.95	p=0.12	p=0.78	p=0.47	P=0.00*	p=0.78	p=0.15	p=1.00	p=0.64	p=1.00
Indigenous status											
Indigenous	115 (38.3%)	26 (24-27)	823g (700-940g)	59 (51.3%)		58 (50.4%)	56 (48.7%)	12 (10.4%)	8 (7.0%)	13 (11.3%)	17 (14.8%)
Non-indigenous	185 (61.7%)	26 (24-27)	866g (719-1000g)	97 (52.4%)		97 (52.4%)	91 (49.1%)	28 (15.1%)	6 (3.2%)	14 (7.6%)	27 (14.6%)
		p=0.63	p=0.64	p=0.91		p=0.81	p=1.00	p=0.30	p=0.16	p=0.30	p=1.00
Maternal origin											
Regional	218 (72.7%)	26 (24-27)	850g (718-1000g)	113 (51.8%)	57 (26.1%)	113 (51.8%)	102 (46.8%)	25 (11.5%)	9 (4.1%)	20 (9.2%)	34 (15.6%)
Remote	82 (27.3%)	25 (25-27)	838g (700-990g)	43 (52.4%)	58 (70.7%)	42 (51.2%)	45 (54.9%)	15 (18.3%)	5 (6.1%)	7 (8.5%)	10 (12.2%)
		p=0.52	p=0.24	p=1.00	p=0.00*	p=1.00	p=0.13	p=0.13	p=0.54	p=1.00	p=0.58

	No.	Gestation Median (IQR)	Birth-weight Median (IQR)	Male Number (%)	Indigenous Ethnicity Number (%)	Adequate steroids Number (%)	Chronic lung disease Number (%)	IVH/PVL Number (%)	ROP Number (%)	NEC Number (%)	Death Number (%)
Inadequate steroids											
Inborn	81 (55.9%)	25 (24-26)	791g (670-885g)	40 (49.4%)	31 (38.3%)		41 (50.6%)	13 (16.0%)	4 (4.9%)	8 (9.8%)	22 (27.2%)
Outborn	64 (44.1%)	26 (24-26)	876g (704-1042g)	31 (48.4%)	26 (40.6%)		30 (46.9%)	12 (18.8%)	3 (4.7%)	7 (10.1%)	10 (15.6%)
		p=0.08	p=0.03*	p=1.00	p=0.86		p=0.74	p=0.67	p=1.00	p=1.00	p=0.11
Retrieval location											
Regional	48 (70.5%)	26 (24-27)	888g (760-1060g)	25 (52.0%)	17 (35.4%)	4 (8.3%)	23 (47.9%)	9 (18.8%)	2 (4.2%)	5 (10.4%)	9 (18.8%)
Remote	20 (29.4%)	26 (24-27)	885g (670-1032g)	9 (45.0%)	12 (60%)	0 (0%)	9 (45.0%)	4 (20%)	1 (5.0%)	2 (10.0%)	1 (5.0%)
		p=0.48	p=0.88	p=0.79	p=0.11	P=n/a	p=1.00	p=1.00	p=n/a	p=1.00	p=0.26
Steroids											
Adequate	155 (51.6%)	26 (25-27)	881g (730-1010g)	85 (54.8%)	58 (37.4%)		76 (49.0%)	15 (9.7%)	7 (4.5%)	12 (7.7%)	12 (7.7%)
Inadequate	145 (48.3%)	25 (24-26)	829g (679-965g)	71 (49.0%)	57 (39.3%)		71 (49.0%)	25 (17.2%)	7 (4.8%)	15 (10.3%)	32 (22.0%)
		p=0.00*	p=0.02*	p=0.36	p=0.81		p=1.00	p=0.06	p=1.00	p=0.56	p=0.00*
Total cohort	300	26 (24-27)	837g (700-1000g)	156 (52%)	115 (38.3%)	155 (51.7%)	115 (49.6%)	40 (13.3%)	14 (4.7%)	27 (9.0%)	44 (14.7%)

Aboriginal and Torres Strait Islander mothers comprised a significantly greater proportion of mothers from remote areas. There were no differences in outcome by ethnicity and no difference in outcome for babies from remote areas on univariate analysis, although Indigenous babies were less likely to have IVH/PVL on binary logistic regression analysis- 0.43 (0.19-0.98).

Babies who received adequate antenatal steroids were significantly more likely to have been born at TTH, were heavier and more mature. Babies born below 25 completed weeks gestation were significantly less likely to have had antenatal steroids than those born from 25 weeks gestation (p=0.02).

Table 4.5

Adjusted odds ratios (with 95% confidence intervals) for poor outcome factors by demographic variables.

	Chronic lung disease	**Retinopathy of prematurity**	**Necrotising enterocolitis**	**Intraventricular haemorrhage/PVL**	**Death**
Gestation	1.00 (0.78-1.28)	1.59 (0.88-2.87)	1.89 (1.15-3.09)*	0.77 (0.53-1.13)	1.60 (1.00-2.32)*
Weight	1.00 (0.99-1.00)	1.00 (0.99-1.01)	0.99 (0.99-1.00)	0.99 (0.99-1.00)	1.01 (1.00-1.00)*
Male	1.60 (1.01-2.56)*	0.41 (0.12-1.43)	0.79 (0.34-1.82)	2.57 (1.22-5.45)*	0.85 (0.40-1.80)
Indigenous status	0.82 (0.49-1.39)	0.50 (0.15-1.68)	0.60 (0.25-1.45)	0.43 (0.19-0.98)*	1.11 (0.50-2.48)
Retrieved	0.93 (0.49-1.79)	0.97 (0.20-4.80)	0.80 (0.27-2.38)	1.40 (0.58-3.41)	1.70 (0.63-4.49)
Remote maternal origin	1.48 (0.83-2.63)	0.93 (0.26-3.38)	1.37 (0.50-3.76)	2.33 (1.03-5.26)*	1.31 (0.53-3.26)
Inadequate steroids	1.0 (0.58-1.75)	0.78 (0.20-2.99)	0.93 (0.35-2.47)	0.63 (0.27-1.43)	2.87 (1.23-6.72)*

Unsurprisingly there was significant odds ratio for death in the most premature babies, lowest weight babies, and those who had inadequate steroids (Table 4.4). The inclusion of confounders in the binary logistic regression clarifies the importance of adequate antenatal steroids, gestational age and retrieval status in survival. Necrotising enterocolitis occurred in the most premature babies. Regression analysis also showed that male babies were at increased risk for chronic lung disease and IVH/PVL. Babies whose mothers originated from remote locations were also more likely to have IVH/PVL.

4.6 Discussion

Analysis of survival data for North Queensland shows that survival from TTH Neonatal Unit at different gestations is on a par with data from the Australian and New Zealand Neonatal Network (Chow, 2016), as well as the survival rates for other developed world countries (Boland et al., 2017; Mahoney et al., 2017; Maruyama et al., 2016; Serenius et al., 2015; Stensvold et al., 2017; Stoll et al., 2015; Younge et al., 2017). Smaller centres often have difficulty in producing valid data, because the time frame required to gather sufficient data for analysis means that neonatal care itself has changed in the interim. Over relatively short time periods, changes in the use of antenatal steroids, mode of delivery, resuscitation, ventilation and approaches to aggressive feeding, have meant that ‘epochs’ of care can show sequential improvements in outcomes (Costeloe et al., 2012; Doyle & Anderson, 2010; Stoll et al., 2015; Younge et al., 2017). This study has used a seven-year time-frame to allow a balance between accepting some changes in practice and having enough data to produce a valid assessment of survival. There is a dramatic difference between admissions at 23- and 24-weeks gestation. It is not known whether this represents a difference in attitudes towards resuscitation of these babies by health care staff, a decision by parents to withhold intensive care, or a group of babies who appear to be ‘compromised’ and therefore a decision has been made at delivery to withhold intensive care. The uncertainty about the reasons for non-resuscitation has been raised in other studies, (Boland et al., 2017; Rysavy et al., 2015) however, in contrast to Boland and Rysavy, we did not find a difference between inborn and outborn status for resuscitation at 23 weeks gestation.

An important part of neonatal care is counseling parents prior to the delivery of extremely preterm babies (Grobman et al., 2010; Kaempf et al., 2009; Kuschel & Kent, 2011). The timing and potential outcomes overall should be an ongoing discussion with parents. Our data showing highest mortality early in the neonatal period are similar to other studies, with death related to complications of prematurity declining over time (Costeloe et al., 2012; Elder et al., 2009). Parents need to be aware of changing prognosis as the baby ages through neonatal care.

Historically, babies who were outborn had worse outcomes than inborn babies (Chien et al., 2001; Lui et al., 2006; Shah et al., 2005). This led to efforts to transfer high risk mothers closer to tertiary centres prior to delivery wherever possible (Lui et al., 2006). There have also been programs to improve resuscitation skills across North Queensland – currently the NeoResus program (The Victorian Newborn Resuscitation Project, 2008). Five of the 20 deliveries which occurred at remote centres –which usually have no paediatric staff, or do not routinely care for babies who require ventilator support, were attended by staff from TTH. The 48 babies from regional centres were cared for initially by paediatrician lead teams in units where some short-term ventilation in larger babies occurs. A large Chinese study (Kong et al., 2014) and a Canadian study showed improved time to optimal therapy and reduced hypothermia when the retrieval team was present (McNamara et al., 2005). However, data from our study was inadequate to support this finding. The only difference found between outborn and inborn infants, in this study, was the high incidence of inadequate steroids for the outborn group. When comparing babies born at the tertiary centre who have had inadequate steroids, with those outborn with inadequate steroids, there is no difference in outcome. It is of interest that a baby born at 23 weeks gestation has an equal chance of provision of intensive care regardless of place of delivery. This has not been the finding in previous studies (Boland et al., 2017; Lasswell et al., 2010; Rysavy et al., 2015). Retrieval of extremely preterm babies appears to lead to the same outcomes as inborn babies under the same steroid conditions, and this should be factored in to decisions made by staff and parents at peripheral centres. A smaller study in Western Australia has also shown that babies outborn between 23- and 26-weeks gestation have higher mortality than inborn babies, but no difference in other short term morbidities (Thompson et al., 2016). Reassuringly, this study includes 1-year Griffiths developmental assessments which shows no difference in surviving outborn and inborn babies at these gestations.

A major finding of this study is that babies at lower gestations are significantly less likely to receive adequate steroids. Inadequate steroids are seen to significantly increase the mortality risk, and are nearing significance for intraventricular haemorrhage – which is a leading cause of death for these babies. It is known that even some steroids will improve outcome (Chawla et al., 2016; Kiechl-Kohlendorfer et al., 2009), and this study has not allowed a more nuanced examination of a steroid dose effect. This confirms the findings in other studies (Chawla et al., 2016; Manktelow et al., 2010; Thompson et al., 2016; Wei et al., 2016; Wong, Abdel-Latif, & Kent, 2014). Studies which have examined the relationship between steroids and long term outcome, show improved long term outcome where antenatal steroids have been given (Doyle et al., 2000; Sotiriadis et al., 2015; Thompson et al., 2016). Not all studies have shown a long-term benefit, but it should be noted that many babies with inadequate steroids will die from intraventricular haemorrhage, so a survivor effect may be present. In addition, IVH/PVL are the single morbidity studied which best predicts poor neurodevelopmental outcome (Linsell et al., 2016; Linsell et al., 2015; Mukerji et al., 2015; Natarajan et al., 2012). The use of antenatal steroids to improve both short and long term outcomes has been a standard of care for extreme preterm babies for a long time. There is a need to examine why steroids are less likely to have been given to more preterm babies in particular. An Italian study (Gagliardi et al., 2017) suggests that inadequate steroids are more likely where there has been late presentation of women who deliver early, less recognition of the imminence of delivery and poor adherence of antenatal guidelines. They did not find a difference between outborn and inborn infants. This study found significant differences in outborn babies – which is to be expected to some extent as some women have been transferred antenatally with enough time to receive steroids, but this does not account for the much lower rates of steroid administration at the lowest gestations in all centres. This study suggested that babies of 25 weeks and over are routinely resuscitated, as per current Queensland guidelines (QCG 2014), but that, as there is more discretion given to parents from 23 weeks to 25 weeks. It is possible that there may be a delay in administering steroids whilst discussion and counseling occurs. It is also possible that previous controversy about the use of antenatal steroids below 25 weeks gestation has reduced their administration (Deshmukh & Patole, 2018). The use of steroids at the lowest gestations has been conclusively shown to reduce mortality from 22 to 25-week gestation in a recent meta-analysis (Deshmukh & Patole, 2018) and to reduce the occurrence of severe IVH and PVL at 23- and 24-weeks gestation. Delays in administering steroids will result in poorer outcomes, and reinforce the impression that these babies at lower gestations do worse than would be the case if care was optimized. It could be possible to administer steroids on presentation of the woman about to deliver without suggesting that this action commits the baby to full intensive care (QCG, 2014).

Resuscitation is shown to be routine in TTH at 24 weeks gestation, however, the debate in the literature is moving towards resuscitation of even younger gestation babies – i.e., 22 weeks, with those places who offer it routinely showing significantly better outcomes when compared to those who do not (Ishii et al., 2013; Maruyama et al., 2016; Park et al., 2016). It is important to note, that there was an attempt to optimize the fetus for survival in these locations, by the use of antenatal steroids, optimal mode of delivery and immediate resuscitation at birth.

Aboriginal and Torres Strait Islander babies are more likely to come from remote regions in North Queensland than non-indigenous babies (Commonwealth of Australia & of the Prime Minister and Cabinet, 2017), although the majority of babies from the Aboriginal and Torres Strait Island people reside in urban areas (AIHW, 2016). This study shows that, regardless of ethnicity, babies are as likely to deliver in a tertiary centre, have adequate steroids, and have the same morbidity and mortality outcome apart from lower rates of IVH/PVL in Indigenous babies. Previous literature had shown a difference in outcomes, particularly in a regional setting (Steenkamp et al., 2012). Studies at more urban centres have more recently shown no difference in outcome by Indigenous status (Kildea et al., 2013; Ruan et al., 2011), but this is the first study with a large Aboriginal and Torres Strait Island population, which serves very remote areas, to show the same outcome. 38.3% of extremely preterm babies in this study were of Aboriginal and/or Torres Strait Islander origin, which is much higher than seen in other Australian studies. This suggests that the access to care after 22 weeks gestation is equitable, and appropriate transfers are occurring despite distance and remoteness. In terms of survival, babies from remote areas fared as well as babies from regional areas, and babies from areas outside of Townsville, who delivered in Townsville, did better than babies who were retrieved. However, this difference can be accounted for by the difference in steroid administration.

There are some limitations of this study. The numbers are lower than seen in other studies as the most contemporaneous picture needs to be given. Data collected from a number of agencies, may not be accurate. There was insufficient data to allow for assessment of whether babies who were born alive but not offered intensive care were sicker babies, which may alter the survival data particularly for outborn babies leading to some selection bias. Babies who have been transferred to their base health centre, may have pathologies which were not entered in the database, especially if these have occurred after discharge from the hospital. It is also possible that some babies, particularly those who have died, had underlying congenital abnormalities which were not identified. Post-mortem rates are exceedingly low in this study group, and no data were found after death for any baby. The gestational age of some of the pregnancies may also be inaccurate where antenatal care was limited, although the vast majority of participants did receive early dating antenatal ultrasound scans.

4.7 Conclusions

This study shows that the single most important predictor of survival to discharge amongst extremely premature babies at TTH is the adequacy of antenatal steroids. There was no effect seen for retrieval status of the baby, ethnicity or regionality for death. The high number of extremely preterm Aboriginal and Torres Strait Islander babies is of great concern and this remains an area where more research is needed

4.8 Completion of Phase One

This study completed Phase One of the research. It was reassuring to find that the outcomes were on a par with peers, which was morally important. Had the aggregated outcomes been poor, I would have had to reconsider whether tertiary neonatal care at the hospital was justified, and any study about processes would be moot. The study also gave valuable information about the proportion of the periviable babies for the whole region who received

NICU care, which was previously unascertained within our local database, but potentially influenced by decision-making to provide intensive care and could provide insight into equity of care provision regardless of delivery location. Phase One not only had a moral aim, but the completion of Phase One also provided data to use for the survey in Phase Two and informed analysis of data in Phase Two, particularly about the attitudes of HCP, where perceptions of outcomes including variables such as location of family residence was explored. These Phase Two studies are reported in Chapter Six. Phase Two of the research could then proceed, with one component being the family study, which is reported in the chapter which follows.

Chapter. 5 The Family Study

The previous chapter described the outcomes of extreme prematurity in North Queensland. The important findings were that outcomes for babies born prematurely in North Queensland are comparable with those from other tertiary neonatal units in Australasia. Babies who originate from regional and remote areas, and retrieved babies all appear to do well. Although the goal of this research was to address decision making, this study was helpful as it confirmed that TUH provides credible care and that it is ethical to offer care for babies of extremely prematurity. The goal of the family study was to gain family perspectives on decision-making related to care for extremely preterm and periviable babies, understand their experiences of perinatal care and the later progress of the family. It was important to hear parental reflections about how perinatal decisions had affected their families. This could help to inform clinicians who counsel parents. Further exploration of the methodology for this study can be found in Chapter Three.

Interviews with parents were performed using open-ended questions loosely following an interview guide that allowed for a wide range of data to be obtained. As the coding of the interviews occurred iteratively and the research group analysed the codes, five major categories emerged. These were; ‘the NICU experience’, ‘the roller coaster evolution of parenthood’, ‘voicing the broken dyad’, ‘decision making’, and ‘the way ahead’ (Figure 5.1). Three of these categories relate to parental experiences. A manuscript focusing on the parental experiences in the NICU, establishing the context for decision making has been published (Ireland et al., 2019). In this chapter, the categories of ‘the roller coaster evolution of NICU parenthood’, ‘voicing the broken dyad’ and ‘decision making’ are presented after the publication on parental experiences. Grounded theory emerging from the study is presented at the end of this chapter. Results pertaining to specific issues regarding decision making will be merged with decision making perspectives of HCPs in Chapter Eight. The category of ‘the way ahead’ is incorporated in Chapter Ten, on improving decision making and information sharing on the neonatal unit.

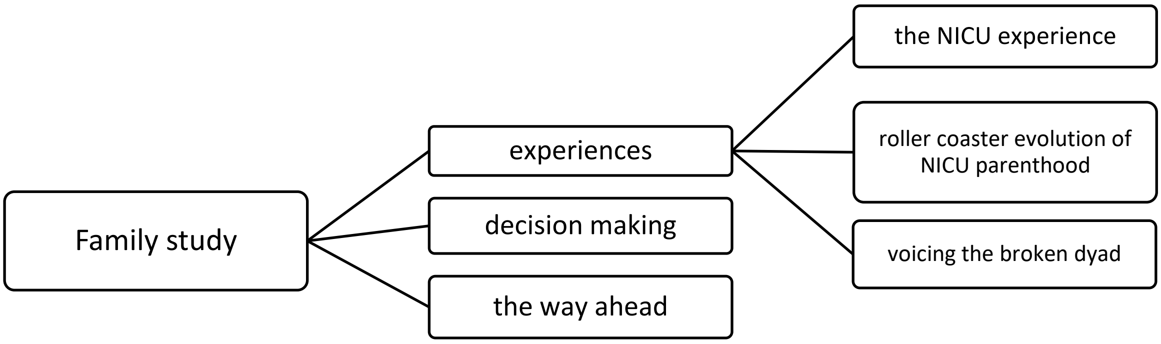

Figure 5.1 Categories of results for the family study.

Publication arising from the category of ‘the NICU experience’:

> Ireland, S., Ray, R. A., Larkins, S., & Woodward, L. (2019). Perspectives of time: a qualitative study of the experiences of parents of critically ill newborns in the neonatal nursery in North Queensland interviewed several years after the admission. *BMJ Open*, *9*(5), e026344. https://dx.doi.org/10.1136/bmjopen-2018-026344

‘The NICU Experience’

Article: The Perspectives of Time – A Qualitative Study of the Experiences of Parents of Critically Ill Newborns in the Neonatal Nursery in North Queensland Interviewed Several Years After the Admission

5.1 Abstract

Design

A qualitative study informed by grounded theory principles to explore the experiences of parents who had extremely preterm babies with antenatally diagnosed life threatening diagnoses who were cared for in a regional tertiary neonatal unit. The study was conducted when the child was old enough to be diagnosed with long term neurodevelopmental or medical sequelae.

Setting

North Queensland is a large area in Eastern Australia of 500 000km^2 which is served by one tertiary neonatal unit.

Participants

Seventeen families representing twenty-one extremely preterm babies and one baby with congenital malformations who was not expected to survive prior to delivery (but did) were interviewed using grounded theory principles. Interviews were coded and themes derived.

Results

Parents who recollect their neonatal experiences from three to seven years after the baby was cared for in the neonatal intensive care described negative themes of grief and loss, guilt and disempowerment. Positive enhancers of care included parental strengths, religion and culture, family supports and neonatal unit practices. Novel findings included that prior pregnancy loss

and infertility formed part of the narrative for parents, and hope was engendered by religion for parents who did not usually have a religious faith.

Conclusions

An understanding of both the negative aspects of neonatal care, and the positive enhancers is necessary to improve the neonatal experience for parents. Parents are able to contextualize their previous neonatal experiences within both the long-term outcome for the child, and their own life history.

Strengths and limitations

- The study documents a range of experiences from parents who represent the full diversity of the population treated including Indigenous families who are rarely included in qualitative neonatal studies.

- The study has been done at a time when the babies who received intensive care were old enough that any major difficulties resulting from their perinatal period is known to the families.

- The richness of the data may be compromised if parents were culturally unacquainted with qualitative research and unable to articulate their experiences.

- Parents of babies with poor neurological outcomes who felt negative towards the unit may be underrepresented as these parents may be less likely to engage with the study.

5.2 Introduction

Following delivery, babies born prematurely will remain in hospital until they are able to survive in a home environment. Those babies born at the verge of viability from 22 to 26 weeks gestation will spend approximately four months as inpatients, much of this time in the neonatal intensive care unit (NICU) where the baby's physiological needs can be met by the use of increasingly complex technology (Wilkinson et al., 2009). Parents who birth a baby at these gestations will need to cede the care of their infant to the medical and nursing team whilst trying to maintain parenthood of the baby in this environment until he/she is discharged to home (Lupton & Fenwick, 2001; Wakely et al., 2015). Anxiety, depression, stress and trauma are described in parents who have had a baby in a neonatal intensive care unit (Busse et al., 2013; Woodward et al., 2014).

To help reduce the suffering of parents, and in turn improve the wellbeing of their offspring, it is necessary to understand which experiences help parents to adapt to the neonatal environment, and which make the stay more difficult. Previous studies suggest that relinquishing the parental role and feelings of inadequacy (Gibbs et al., 2015; Jackson et al., 2003; Medina et al., 2018; Spinelli et al., 2016; Watson, 2011; Woodward et al., 2014) are some of the most stressful experiences of parents of neonates in NICU. Attachment to the child can be difficult (Gibbs et al., 2015; Medina et al., 2018; Widding & Farooqi, 2016) with possible long term consequences of poorer cognition, language and social and emotional outcomes (Johnson & Marlow, 2017). Other negative experiences include difficulty inherent in juggling roles away from the hospital and leaving the baby (Gibbs et al., 2015; Smith et al., 2012). Resentment towards nursing staff for being able to spend more time with the baby has been found (Turner et al., 2015). By contrast, positive experiences include a welcoming attitude of the hospital staff (Abdel-Latif et al., 2015; Russell et al., 2014; Smith et al., 2012), the ability of the parent to help their baby (Rossman et al., 2015), and good family support

(Smith et al., 2012). Nearly all of these studies investigate the parental experiences whilst the baby is still in the neonatal unit, or in the first year of life. These findings are verified by health care providers who care for neonates in intensive care with personal experience of extremely preterm or medically vulnerable babies (Cohn, 2011; Janvier et al., 2016). This group of clinicians describe the need for hope, honesty in delivering prognosis, compassion and facilitating connectedness as important (Janvier et al., 2016). The lack of control that they experienced during their infants' admission was the most negative feature described.

Little is known about how parents reflect on their NICU experience in the context of the baby's long term outcome as the implications for both the child and family becomes evident. With time, early distress related to the early birth may have resolved, replaced with the stressors inherent in caring for the child or sacrifices by the family (Stensvold et al., 2017). These may affect whether parents feel that the difficulties of NICU care were worthwhile, or in fact how they are recalled. This paper explores the experiences of the NICU from the perspective of parents who had babies admitted from two to seven years prior to the study, to allow some contextualization of their experience over time, and inform staff who care for future parents who may be unaware of the adaptation of families.

5.3 Methodology

This is a qualitative study informed by grounded theory methodology as described by Charmaz (Charmaz, 2014). It involves interviews with parents of extremely preterm babies who were cared for in The Townsville Hospital (TTH) NICU, some years after their NICU experience.

5.3.1 Context of setting of study and population

North Queensland has a large geographical area of 500 000km^2, with a population of approximately 700 000 (Queensland regional profile (QRP), 2016). There are four main regional centres where 72% of the population resides, with the remainder living in smaller towns, in remote and very remote locations. Remoteness is defined by the ARIA+ (Accessibility/Remoteness index of Australia) produced by the Australian Bureau of statistics which defines areas by their distance from services including advanced medical care. The population is ethnically diverse including 12.3% Aboriginal peoples or Torres Strait Islanders (hereafter referred to as Indigenous) (QRP, 2016), and has a diverse socioeconomic status. Tertiary level maternal-fetal and neonatal services are provided for the region at TTH, which provides care for babies of any gestation above 23 weeks, and babies with most surgical conditions. Patients requiring cardiac or ophthalmic surgery travel to Brisbane, the capital of the state, which is 1337 km from Townsville. Whilst admitted to TTH, all babies receive care from the on-call neonatologist and do not have an individually named specialist.

Where a pregnancy is likely to result in a baby requiring tertiary neonatal care, or below 28 weeks gestation, attempts are made to ensure delivery at TTH. Babies who deliver outside of TTH who require intensive care, are transferred to the TTH by a retrieval service staffed by the neonatal unit. There are more than 10 000 deliveries per year in North Queensland. TTH admits 800 babies annually for neonatal care including 40 to 50 under 28 weeks gestation. Thirty-eight percent of extremely preterm babies at TTH are of Indigenous origin and 27% are from remote or very remote areas. Twenty five percent of the extremely preterm babies are delivered outside of TTH and require retrieval (Ireland et al., 2019). Once the babies are at an acuity that can be catered for closer to their home, they are transferred back to referring hospitals.

5.3.2 Patient and public involvement

The study is part of a bigger project which investigates parental involvement in decisions made to resuscitate extremely preterm babies. The project was initiated in response to a parent who felt she had been excluded from decisions made to offer intensive care to her preterm baby. The mother became a participant in this study and suggested some of the questions used to guide the interviews. Participants were asked if they wished to receive the results of the study, and these participants will be sent a copy of any papers resulting from the study.

5.3.3 Ethics approval

Approval for the study was received from the Townsville Hospital Health Service Human Research Ethics Committee (HREC/15/QTHS/195), and from James Cook University Ethics Committee (6484). All participants gave informed consent to participate in the study.

5.3.4 Sampling strategy

Potential participants were identified from the TTH NICU database using the criteria of extreme prematurity or complex antenatal surgical diagnosis, families resident in the North Queensland area at the time of admission, fluent in English and delivered between 2010 and 2015. The first eight eligible families of babies born in 2012 - chosen as the approximate mid-point of the study, received a participant information sheet and consent form by post, to initiate the recruitment. Parents were requested to contact the administration officer by telephone to arrange an interview at their convenience if they wished to participate. Three families were recruited from the mail out. Three participants were then snowball recruited from initial participants at the request of one of the original participants. Review of the characteristics of the then six participants, and the iterative coding of interviews, led to more purposive recruitment from the database thereafter to encompass the range of parental age,

age of child, rurality of residence and ethnicity, as well as a subjective assessment of the difficulty of the neonatal stay and the impairment of the children as is appropriate for grounded theory research. These potential participants received the information sheet and consent form as per the original recruitment, as well as a follow up call from administrative staff. There were 15 families approached in the purposive recruitment phase, of whom 11 participated before data saturation was achieved.

All potential participants were offered a choice of interviewer (the primary investigator who is a neonatologist, or an alternative interviewer with a neonatal nursing and research background), but all participants chose the primary investigator. Indigenous participants were offered interviews by, or attended by, Indigenous liaison officers, but all declined this.

5.3.5 Data collection

The location of interviews was chosen by the participants, most choosing to be interviewed whilst at the hospital for other appointments. One interview was done by telephone, one arranged for a location at an alternative hospital and one interview at the patients' home. All interviews were digitally recorded. For half of the interviews the child under discussion was present. All interviews included the mother, and for six interviews both parents chose to be interviewed together.

Consistent with grounded theory principles, initial interviews followed a question guide, which was modified in response to iterative analysis as the interviews progressed. The interview explored experiences, decision making and participant opinions about potential improvements in the service. Interview length ranged from 20 to 85 minutes, with one interview of 45 minutes being done during a four hour visit to the family home. The home visit was requested by a parent who wanted the researcher to have a more complete understanding of the life lived with a severely handicapped child.

5.3.6 Data analysis

The research team met regularly and discussed interviews iteratively. Using NVivo as a data management software, interviews were analysed using open coding. Themes were identified from the codes using a staged constant comparative process from focused coding to theme generation. While the primary investigator did the initial coding, a triangular approach using collaboration with the study team was used to develop themes.

5.4 Results

5.4.1 Summary of participants and outcomes

Seventeen families were interviewed, representing the diversity of developmental outcomes, the ethnic and socioeconomic variation and varied location of usual residence of the parents seen on the unit (Table 5.1). Eleven mothers were interviewed alone, and six couples chose to be interviewed together.

Characteristics of the participants were recorded following chart review.

Table 5.1

Participants and outcome demographic.

Demographic variable	Number/range
Gestation	Median 25 weeks; Range 24-30; Interquartile range (IQR) 24-26 weeks
Birth weight	Median 867g; Range 600-1770g; IQR 650-959g
Gender	Male 10 (45%)
Survived to discharge home	19/22 (86%)
Time from delivery to study interview	Median 3 years; Range 2-7years; IQR 2-5 years
Place of residence of family	Local 7 (37%); Out of Townsville region 10 (63%)
Maternal age at time of birth of baby	Median 31 years; Range 18-37; IQR 23-35
Ethnicity of mother	Caucasian 11, Indigenous 3, Maori 1, Asian 2
Plurality	12 singletons, 5 sets twins

Five mothers had suffered a previous pregnancy loss, and four had undergone fertility treatment. Nine women had spontaneous preterm labour causing the delivery, six had preterm prolonged rupture of membranes, one had an antepartum hemorrhage from placenta praevia, and one was delivered preterm for maternal pre-eclampsia. Ten women were given adequate antenatal steroids, defined as two doses of betamethasone with the second given at least 24 hours prior to delivery. Several babies had complications of intensive care- two had an accidental drug overdose, one a liver laceration during surgery and one had an extravasation of parenteral nutrition into the liver from a misplaced central line. All survived. Three babies had an intraventricular hemorrhage grade three or four, or periventricular leukomalacia, four had necrotizing enterocolitis requiring surgery and three required treatment for retinopathy of prematurity. Three babies died.

From parental report at the time of interview, of the surviving nineteen children, four had severe disability, four had mild to moderate impairments, and eleven had development in the typical range. One child required ongoing bowel and urological surgery for congenital anomalies. One child had a congenital renal abnormality. Parents considered severe disability to encompass mobility problems which required the child to be dependent on an aid or caregivers, and/or intellectual impairment requiring a high level of support or special arrangements for schooling, mild to moderate impairment to include motor, learning and speech delays of a lesser degree which required therapy but no special aids or school assistance. The veracity of the parental reports was not examined.

Themes could be grouped into experiences of negative emotions and positive enhancers. Parents' descriptions of life on the neonatal unit include negative emotions of grief and loss, guilt, and disempowerment (Figure 5.2). The grief and loss are a summation of previous loss or fertility issues, and the loss of the completed pregnancy. They wished that they had more knowledge about the potential for premature delivery, and more assertiveness around the time of delivery to challenge medical decisions that were made. There is parental guilt at the failure to reflect societal expectations of healthy reproduction and parenthood. Themes expressing positive enhancers (Figure 5.3) reflected the family strengths prior to the NICU experience, including intrinsic supports such as culture and religion, as well as new experiences engendered by good staff practice and external supports. For many families, the positive experiences that they had during their neonatal course, helped them to cope, but for some this did not seem to mitigate the failure and guilt which they described. Themes and subthemes are summarized in Figures 5.2 and 5.3, then outlined in more detail with quotes in the following sections.

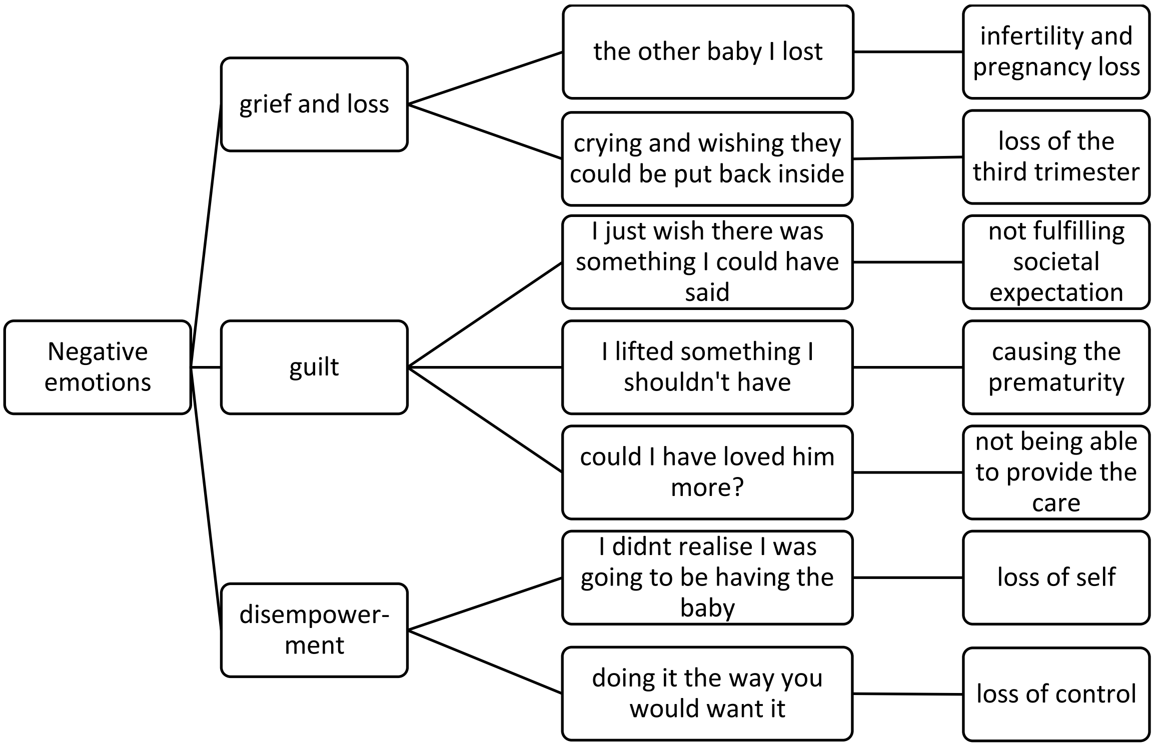

Figure 5.2 Negative emotions.

5.4.2 Negative emotions

5.4.2.1 Grief and loss

‘The other baby I lost’

Parents commonly shared traumatic stories of prior pregnancy loss and fertility difficulties. These stories emerged unprompted when parents were asked to reflect on the birth of the study baby:

> *‘I lost a baby at 18 weeks three months before I conceived L. I thought, oh, here we go again.... I just thought I will let nature take its course, and whatever happens, happens…Having had the experiences that I had before, I just said I’m not having any more babies anyway, so I really don't care’.*
>
> (Mother of a baby born at 25 weeks
> after membranes ruptured at 18 weeks)

> *‘After my first pregnancy, we aborted a pregnancy… That baby could have been a girl, because I wanted a girl, and that baby could have been healthy…. So I personally believe that I've done something wrong’*
>
> (Mother of 24-week baby with severe impairment)

‘Crying and wishing…they could be put back inside’

Mothers particularly mourned the loss of a full third trimester of the pregnancy. The third trimester is a time for preparing for birth, both mentally and physically, with the expectation of a healthy delivery. Societal rituals to celebrate the pending birth such as baby showers occur. Loss at this part of the pregnancy is described by one mother as an horrific experience:

> *'I was just in severe shock. I felt like I was being hacked open and my babies were being stolen from me. It was awful. They had to knock me out in theatre because I couldn't…I just lost it.…I spent the first week - all I can remember is crying and wishing that he could be put back into me - both actually. That they could be put back inside.'*

(Mother who went into preterm labour at 26 weeks
following the death of one twin in-utero)

The loss of a typical term baby was felt by a father who recognized that the baby did not look like a 'normal' baby, but the deviation from typical neonatal progress took a long time to accept:

> *'He looked like a little plucked pigeon. Then I was like, okay, he's just – you know, not knowing because I didn't know. See, I thought it must be normal if that makes any sense. Then as we got into the apparatus and everything on him, I was like, 'yeh, right'. Then we got into more and more of it. It was just dawning on me. Right up until the end.' (when he died)*

(Father of a 24-week baby who died of complications of prematurity
at 3 months of age)

5.4.2.2 Guilt

'I just wish there was something I could have said'

Societal expectations dictate that parents should protect themselves and their families. Many parents perceived that they had been failed by inadequate medical evaluations and decisions. The impotence of parents in the face of medical superiority resulted in feelings of guilt for not challenging these medical decisions antenatally as they felt that this may have altered the outcome:

> *‘Why was I bleeding all the time? This is ridiculous, they were like, ‘oh, we see people bleed all the time. We see worse than this’. Then I’m like, shouldn't I be on bed rest or something or should I be hospitalized? Other people I know are hospitalized. They were like, no, we don't hospitalize until 24 weeks….we see placenta praevia all the time. It moves. It goes. You’ll be fine. Everyone just kept living on the glass half full theory. You’ll be fine. No-one said, oh, you might hemorrhage and have the baby at 24 weeks and you might nearly die. Geez, if someone had actually told me what potentially could happen, I wouldn’t have moved. I wouldn't have stepped off my couch. I would not have left my house. I would have taken so many steps.’*
>
> (Mother of 24-week child who is profoundly disabled)

Several mothers expressed that by delivering their babies early they had not been able to fulfil a natural function and thus had failed societal norms:

> *‘It's just ridiculous. We're here to procreate. That’s our job. That’s our body's job.’*
>
> (Mother of 24-week gestation boy with multiple complications)

> *‘I was devastated and I couldn't believe that my body had failed them both. It was awful. I felt terrible, really, really bad…I hated myself for failing him and I just wanted him back in there. So that was the first week, nightmare and I don't think I thought anything else except for that wanting them both back inside my stomach.’*
>
> (Mother of 26-week twins)

‘I lifted something I shouldn’t have’

Parents discussed guilt at failing to protect the baby both prior and after delivery. Many of the mothers blamed themselves for causing the preterm delivery by actions which they thought may have resulted in early labour, or rupture of membranes:

> *‘I lifted something I shouldn't have and my waters broke probably about an hour after that.’*

(Mother of 26-week gestation baby, who has four older children)

Guilt was expressed by parents with complicated pregnancies, and who had made decisions, which in retrospect, they worry may have caused the extreme preterm delivery:

> *‘if M (twin 1 with multiple abnormalities) makes it to being born, we (the doctor) will not intervene. So we will leave him there to die.’ That's what they had said to that us in those words... But we always have to ask the question now don't we, that if we had just left him alone and hadn't done the foeticide, would B (twin 2) have made it to term.’*

(Parent who delivered 26-week twin pregnancy following the feticide at 23 weeks of the twin with multiple anomalies)

Parental guilt extended to decisions made with parental involvement after the birth of the baby. Often different potential treatment options occur in neonatal care, with no clarity about the best option. However, the outcome – in this case death - led the father to feel guilty about having a role in decision making:

> *‘they talked about steroids stunting growth and that sort of jazz but looking back on it now I wish I just got out of your way a little bit...the advice I’d give a parent now is definitely don't not ask questions but display some trust. Whereas in the beginning I may have got in the way a little bit. That’s just something I have to live with now.’*

(Father of 24-week baby who died after three months
with chronic lung disease)

‘Could I have loved him more?’

Parents felt guilty about being unable to provide the full-time care that the baby required as the level of care for extremely preterm babies is specialized and done primarily by nursing staff. As a result, parents spend many hours sitting beside the cot without being able to handle the baby. The parents needed to continue life outside the unit, but also to escape the stresses of the NICU:

> *‘Like, did I spend enough time there? You know, should I have loved him more? Could I have loved him more? You know, all those sorts of things used to go through my head.’*

(Mother of 25-week baby who had many complications
and long term sequalae)

> *'...and I wouldn't go near it like for two days at a time, because I just couldn't even sit there and listen to the beeping anymore or the crashing…The whole thing just gave me anxiety, because I couldn't protect him.'*

(Mother of severely disabled child)

The act of providing emotional care is also recognized by parents as an important aspect of care, but still leads to guilt when provided by the nursing staff.

> *'Even though I knew the nurses were amazing, I would ring up every time after I'd leave, before bed, five o'clock in the morning. I knew she was in good hands, but it was like, who's there patting her to sleep? Who's there cuddling her? Then when I would come in sometimes and see nurses had been there massaging her and having a cuddle with her, it was like, oh she's - because it's a month before you can take them, and they're in there by themselves every night. Yeah, so it did worry me.'*

(Mother of 24-week girl)

5.4.2.3 Disempowerment

'I didn't realize I was going to be having the baby'

Loss of self and personal autonomy was expressed where some mothers presented in preterm labour and events happened very rapidly over which they had no control. Parents did not recall being aware of the imminence of birth or an opportunity to make resuscitation decisions.

> *'I do remember that I didn't really realise that I was going to be having the baby, until they induced me and I delivered her. Because it wasn't explained very well that I was at high risk of having her.'*

(Mother of 26-week baby admitted
for medical complications of pregnancy)

False reassurance removes the opportunity for parents to be prepared for the delivery.

> *' "That will stop the contractions, everything will be fine." Then as soon as I had the examination, it was lights, camera, action. Oh shit, it's happening. Everyone was pretty highly stressed, I don't remember any options being given to me…They were very reassuring with everything they were doing, but I don't remember many options.'*

(Mother who delivered at 24 weeks,
who had previously had 24-week twins)

'Do it the way you would want it'

Parents describe how having the baby's care provided by others left them disempowered.

> *'You wouldn't really feel like it's your baby, because the nurses are doing everything. You're kind of just doing nothing when you know you're their parents and you're meant to be doing everything for them…. some days you come in, sometimes the nurses will have done everything and you're just kind of like, feel a bit - yeah.'*

(Parents of 27-week twins)

Some had concerns where they felt that some staff members did not provide a quality of care which they as parents would like to observe.

> *'All of that horrible, horrible time when you're forced in this situation to leave your child in the care of people that you would not choose to leave your child with. Some of the nurses, oh my God… there's no way you would let them look after your child in the real world, if you had a say.'*

(Parent of 26-week surviving twin)

Errors in care also caused anger in this mother who felt unable to prevent harm from occurring.

> *'I would put it down to the worst day of my life. [drug overdose]…that she would die through something that could have been prevented.'*

(Mother who delivered after 7 weeks of ruptured membranes)

5.4.3 Facilitators of resilience- positive enhancers

In contrast, a range of factors led to positive experiences on the neonatal unit. Resilience of parents was a result of both intrinsic factors that were inherent in the parents' own abilities to cope, as well as external factors within the community of staff, and the parents' wider social communities.

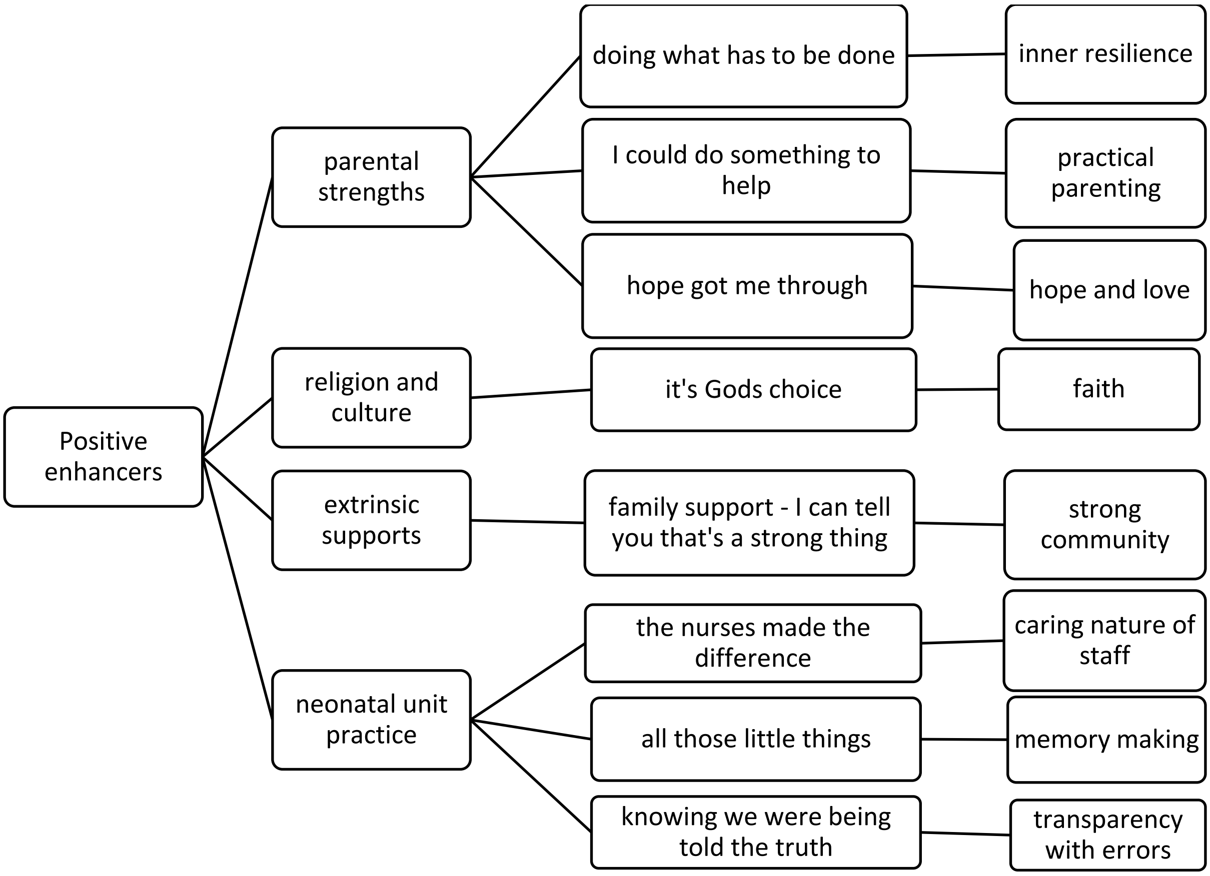

Figure 5.3 Positive enhancers.

5.4.3.1 Parental strength

<u>‘Doing what has to be done’</u>

Parents reflecting all strata of society find themselves in a complex and stressful situation when their baby was admitted to the neonatal unit. An inner resilience described by many parents helped them cope well with the difficulties of the neonatal unit as well as complex medical pathways required for their children after discharge:

> *'People say to me the whole time – "you are such a strong person", and I say "no that's not true, I just do what has to be done", so for me if it has to be done it gets done, you know, like appointments and everything else.'*
>
> (Mother of a 25-week boy who had a long and difficult neonatal admission and who has complex medical needs)

Some mothers reflected that they had themselves had difficulties in their upbringing which made them more resilient:

> *'I guess I knew it wasn't indefinite coming here every day. I'm a pretty resilient person. I just had to stick it out… I guess I've had a pretty hard life.'*
>
> (Mother who birthed a 25-week gestation baby after educating herself extensively about prematurity.)

Inner resilience can be a function of one parent- often the mother, as mothers are usually the main caregivers on the neonatal unit, but also of the parental dyad:

> *'The good thing is we stayed solid through the whole thing. There was never a moment of resentment towards each other. We were solid through the whole thing which is [pretty hard] - I think it brought us closer,'*
>
> (Parents of 24-week gestation boy)

'I could do something to help'

Most mothers learnt how to look after their baby in ways which would be different to that required for a healthy term baby. Real pride in being able to do practical aspects of care that were useful to the baby were clearly articulated:

> *'…when you actually get to pump out your own milk, and it's working and there is actually real milk in there, that's a real achievement.'*

(Young mum, first baby 25-week gestation,
very proactive in decision making)

> *'So I was so glad that I could do something to help because that was really the only thing I did that helped him (bringing in cucumber slices for his sore eyes following an eye screening examination).'*

(Mother of surviving twin)

Having a constant presence on the ward and advocacy for their baby was recognized as resulting in a positive outcome:

> *'I'm not a spiritual person and I don't believe in all that kind of thing but I sit here today and I think the reason why my kids are here is because I was positive, because I was there and because I was fighting for them the whole time I was in here. I honestly do believe that's why they're here and why they're so healthy, because I was their voice. I was there for them. The only advice I can give is to be positive.'*

(Mother of 24-week twins who had an uncomplicated neonatal course)

'Hope got me through'

Hope, love and a belief that their child would survive regardless of the known mortality rate and severity of illness of the baby was described as important and leading to the survival of the baby:

> *'The hope that I had is what got me through and I think what got them through. That's all I could focus on at the time. I just blocked it out. I just didn't want to know that there was anything wrong with them…You've just got to be 100 per cent positive the whole time you're in here to get through it and you've got to be the strong person.'*
>
> (Mother of twins, one of whom had a significant brain bleed)

> *'I just knew deep down that everything was going to be okay, and that's fine…That's probably the first highlight for me, was the fact that she was responding... So it was hour by hour… that was my positive that came out of that, that she was still alive…. I thought she'd always survive'*
>
> (Mother who was quoted less than 1% chance of survival
> for the baby at antenatal counselling)

5.4.3.2 Resilience through religion and culture

<u>'It's Gods choice'</u>

Religious beliefs also helped parents with remaining positive. While few parents described themselves as religious, parents who did have an active faith or spirituality, found that they could turn to their faith, believing that their faith was strengthened and this helped their child to survive:

> *'…like a little inner voice that used to say he'll be okay. Just keep that hope. Keep that faith that he's going to be okay. I used to go to the church all the time here and pray and things like that.'*
>
> (Mother of 25-week gestation boy with
> multiple complications of prematurity.
> Redirection of care to palliation was discussed,
> but declined by the parents)

For parents who described themselves as not religious, improvement in the condition of their babies was ascribed to a religious incident. Belief in a 'higher power' was common:

> *'At work there were Mormons. When the girls were going through a really bad time with the brain bleeds, they had asked if we could have some Mormons come here coming in and just say a prayer and I guess, do the little things that they did. So we did have that and it's not that I don't believe - I mean there's just so much different things. But a few days later they started getting better and everything. We're not religious but I guess we're open to everything, we're just open to everything really.'*

(Parents of 27-week twins,
one of whom had a significant brain haemorrhage)

Cultural beliefs were equally important for some participants. Cultural beliefs lead both this Maori family, and one of the Indigenous mothers, to believe that the babies should be given every chance of survival:

> *'D's Maori. Cultural, very cultural - he's very - with his culture. believing that all babies should be given a chance of resuscitation.'*

(Mother of 24-week girl, who previously had 24-week twins)

5.4.3.3 Extrinsic supports

<u>'Family support- I can tell you that's a strong thing'</u>

Parents described supports extrinsic to themselves, such as family support, community support and other parents on the unit. Strong family support helped many parents to thrive in the neonatal unit:

> *‘So it was a big family support. I can tell you that it was a strong thing. Even in the community where - the few Indians..., the community - because they were the only people I knew,’*

(Mother of 24-week twins, one of whom survived)

Other supports came from parents who were in a similar situation on the neonatal unit and resident in the on-site accommodation was important:

> *‘...when you saw the parents and you talk about - you got to share war stories and things. That was good.’*

(Parents usually resident 800km from TTH)

The on-site accommodation, Ronald McDonald House was appreciated by the parents who resided long distances from the unit:

> *‘I don't even think I realised that Ronald McDonald was even there and I don't know - it just hadn't even crossed my mind of where are we going to be staying and what's the length of time we're going to be here for. So I think the social worker definitely helped a lot. I mean I guess even the staff at the neonatal unit ... even like just emotionally support.’*

(25-week gestation baby who had several admissions
to the neonatal unit for bowel surgery)

5.4.3.4 Positive experiences engendered by neonatal unit practice

In this study, the babies remained in hospital between three and eight months. Parents recognised that the staff did not merely perform a clinical function, and where staff paid attention to things outside of immediate clinical care, parents reflected on this positively. Parents also valued memory making and honesty.

'The nurses made a difference because they are so happy'

Parents appreciated non-clinical aspects of the nurses' activities:

> *'... we had quite a lot of good days and everything. I think the nurses and everything made a difference, because they're so happy and just someone would take - just little things like, I guess, one nurse always matched all the bedding, all their outfits.'*
>
> (Mother of 24-week twins)

> *'…once you got to know them (nurses) you share a joke, it kind of became your second home. That was just very supportive'*
>
> (Father of baby who stayed on the unit for 8 months)

During the period that many of the participants were admitted, the unit participated in a program called 'FiCARE' which enabled participation of the parents in nursing activities. Parents presented the baby on the medical ward rounds and were invited to make suggestions and ask questions:

> *'Love it, love that program. It was so wonderful to feel like you could be involved in your child's care which is exactly how you should feel as a parent when your child is being looked after in a hospital.'*
>
> (Mother of 26-week surviving twin)

'All those little things'

Positive celebrations of the baby's progress through memory cards commemorating milestones such as achieving a weight of 1kg, or having a kangaroo cuddle were meaningful to parents:

> *'Just lots of small things. Coming in on special occasions, Mother's Day, having a card made and stuff like that. When she - they go to a big bed or they get to a kilogram. All those little things. They're small, but they're high moments'*
>
> (Mother of 24-week girl)

'Knowing we were being told the truth'

Disclosure of inadvertent errors were a positive occurrence for some parents such as this mother:

> *'I mean even the time with the drugs, when he went into the coma.., so I remember when X told us what had happened, P started getting angry, and I stopped him, and I said "you know, these people are telling us the truth, and that's what I want" so I guess in a way, that's a high, knowing that we were being told the truth.'*
>
> (Mother of 25-week baby who received an accidental overdose)

5.5 Discussion

This study shows that parents have clear memories of positive enhancers and negative emotions of their neonatal unit experiences some years after their NICU admission. Negative themes of grief and loss, guilt and disempowerment were identified. It is known that negative emotions increase rates of parental anxiety and depression which in turn leads to negative effects on the development of the baby (Woodward et al., 2014). Positive enhancers of their neonatal stay were parental strengths, religion and culture, family support and neonatal unit practices. Resilient parents with strong supports and positive experiences have shown improved family function and neurodevelopment of the child in early childhood (Treyvaud, 2014).

When parents in this study reflected on their neonatal experience, grief expressed for prior infertility and pregnancy losses was an unexpected finding not clearly seen in the literature studied. This suggests that with the perspective of time, parents locate their neonatal experience within a longer life experience of pregnancies that have not followed the typical pattern. Nine of the mothers interviewed had previous difficulties with pregnancy and all spontaneously discussed these. Previous preterm delivery, infertility and assisted conception are risk factors for subsequent extreme prematurity (Frey & Klebanoff, 2016). Resilience in some of these high-risk women was enhanced by their greater knowledge of prematurity and often stronger family support because of the previous problems. Empowerment through education about prematurity and NICU, as well as a focus on social support at the high-risk obstetric clinics where these women are seen may enhance resilience should the women then delivery early.

This study found parents felt guilty about failing to perform within societies expectations by delivering before term, and lacking the skills to look after their preterm baby. In the EPIPAGE study where parents were interviewed during or shortly after neonatal experiences (Garel et al., 2007), guilty feelings were noted to negatively impact on the feelings towards the child and increase parental feelings of physical exhaustion. We did not find this, which may reflect the time frame at which we interviewed the parents. This suggests that although parents still felt guilty, the negative effects of the guilty feelings faded as the fatigue associated with early infancy ceased.

Disempowerment through loss of control over their situation and the care for their babies was universal. This is similar to other studies where disempowerment is described as powerlessness (Cohn, 2011; Watson, 2011). Models of care such as the FiCare program aim to empower parents through sharing the care of the baby with staff, improves neonatal outcomes, and leads to a better understanding by staff about the difficulties that parents face (O'Brien et al., 2015). In this study, parents who perceived the highest levels of disempowerment appeared to have the most difficulty with their acceptance of their children's disabilities. They described more negative emotions, with fewer positive enhancers in their reflections of NICU care than parents of children with similar level of disability.

Parental resilience has been well described in the literature as an enhancer to coping on the neonatal unit (Janvier et al., 2014; Smith et al., 2012). Additionally, studies show that the increased involvement of parents enables them to feel more connected to their baby (Cleveland, 2008; Jackson et al., 2003; Russell et al., 2014; Wakely et al., 2015), and particularly expressed breast milk is seen as something the mother can provide which the nursing staff cannot (Rossman et al., 2015). Parents talked about love for the child and hope for survival as enabling positivity. The personal experience of Janvier and others who had NICU babies, reinforces this finding that hope was the most important positive feature of their experience (Janvier et al., 2016) and enabled them to cope with their difficult situation. Staff can play an active role in enhancing hope and positivity in parents.

Surprisingly little is found in the literature about religious supports. A Turkish study provided 'active spiritual care' in a randomized trial on a neonatal unit (Kucuk Alemdar et al., 2017) and found that there was significantly less stress in mothers who received increased religious observance. Whilst Turkey may be more religious as a country than Australia, our study suggests that even in relatively secular societies, religion, or a spirituality, is a positive enhancer in times of difficulty. Parents in our study who described themselves as religious, even if not devout, increased their own religious observation during this time, and others welcomed people of other religions to visit and pray for their baby as this seemed to enhance their hopes for their baby's survival and wellbeing. This finding has not been described in the literature.

Strong unit practices which support parents in their NICU stay are recognised in other studies. This included good communication (Russell et al., 2014; Smith et al., 2012; Woodward et al., 2014), showing affection for the baby (Smith et al., 2012), being approachable and friendly (Pepper et al., 2012; Russell et al., 2014; Turner et al., 2013), providing parents with adequate information and celebrating milestones. We found that where nurses were noted to be caring, they provided parents reassurance that the baby would be comforted and competently cared for. Parents were helped to recognize that their baby was progressing, by the provision of mementos in memory making rituals.

Trust in staff was engendered by dealing with mistakes in a transparent manner. Whilst honesty is known to be valued by NICU parents (Cohn, 2011; Janvier et al., 2016) this is usually in the context of discussing the baby's wellbeing, prognosis and management. Honesty in transparency and admitting errors to parents has not been described in studies of NICU experiences. In this study, it was spontaneously discussed by three families.

All parents, even those who had more negative experiences and those with children with severe handicaps, described good attachment. This is unlike studies which were done closer to the neonatal stay (Jackson et al., 2003; Medina et al., 2018; Spinelli et al., 2016). This is an important finding. In the same way that some parents have incorporated their previous history of infertility and pregnancy loss, the neonatal course appears to have become part of the family history. With the perspective of time, the parents became more philosophical about any impairment, and described these as an expected cost of prematurity. The family has moved on to function and progress, with healthy attachment, advocating for their children's needs to overcome residual challenges. Reassuring parents that feelings of ambivalence towards the baby will improve may be possible, with appropriate support. Health care staff may recognise the difficulty that families have with a sick neonate, but not realise that families can thrive in time despite long term sequelae. Reassuring staff that families do thrive, may better inform them when counselling families.

The study aimed to include Aboriginal and Torres Strait Islander families as this group of patients have not previously been included in similar studies. Whilst it is desirable for research in Indigenous families to be conducted by Indigenous researchers, all families declined Indigenous support for interviews. We found that Indigenous cultural beliefs gave families a conviction that their child would survive. However, we did not find any other differences between Indigenous and non-Indigenous families in terms of experiences on the neonatal unit. The Indigenous families recruited reside in urban areas and were of varying socioeconomic status. Most of the Indigenous population of North Queensland resides in urban areas. The findings were verified by discussions with the Indigenous colleague as likely to be representative of urban dwelling Indigenous Australians, but may not represent families from remote settings. Further research into the experiences of Indigenous families is essential to fully inform and improve the provision of services for this group.

5.6 Strengths and Limitations

A strength of this study is that it managed to document a range of experiences which largely represented the population of the unit, including Indigenous families, who have often been omitted from Australian studies. The study has been done when the admitted baby is older, and the parents have had time to reflect for longer on their experiences and recover from the experience to some extent. Many had made significant life changes as a result of this reflection. Another strength is that the primary researcher knew all of the families and had cared for the babies as a neonatologist. This may have enabled the parents to be frank in their interviews although concerns could be raised that this might have limited some parents from expressing their views. However, all parents had all chosen to be interviewed by the primary researcher and share negative experiences, indicating that views were not suppressed. Additionally, a good range of regionality of parents was possible due to the opportunistic interviewing of some families during visits for other medical appointments. The primary researcher used reflexivity to consider the potential to bring her personal views and professional lens on the study and influence initial analysis. Reflexive discussion with the research team and collaborative analysis improved credibility and confirmability of results.

A limitation of the study may be that the Aboriginal and Torres Strait Islander representation may be inadequate, as the participants from these groups from very remote areas did not engage in the study. This may be a cultural difference as the families may not have been aware of qualitative research as a scientific method. The families may have felt uncomfortable being interviewed. Recruitment may have been improved by the use of more culturally appropriate workers at the initial recruitment phase. More research involving Indigenous parents from remote communities needs to be done to ensure that this under represented group has an adequate voice in their experiences in this field.

Parents who felt negatively about the unit, either because they had a bad experience, or a poor outcome may not have engaged with the study. A further limitation could be that this is a study from a single regional NICU and the transferability and generalizability of the findings may be limited.

5.7 Conclusion

Parents who have extremely preterm babies describe an intense range of experiences, both positive and negative from their NICU stay. New findings in this study are the parents' ability to contextualize their NICU experience within their wider life experience, suggesting that they can encompass it as something in the past from which they have moved on. Good attachment occurs as families cope with any long-term impairment of the child. Our research adds to the evidence which should help neonatal units to enhance parental experiences. Improved experience will lead to improved long-term outcomes.

5.8 Acknowledgements

The authors would like to thank the mother who encouraged the study in its entirety by raising her concerns to the primary author. The authors thank all the parents who participated in the study, and the staff on the neonatal unit who facilitated appointments. Narelle Draper, Indigenous Liaison Officer and colleagues assisted with Indigenous specific aspects of the study.

Consolidated criteria for reporting qualitative research (COREQ) for this study found as appendix 10.

5.9 Further Categories of Results for the Parent Study

The categories described below include the 'roller coaster evolution of NICU parenting', 'voicing the broken dyad' and 'decision making. These data will be published later.

The categories are presented first, with some reference to the literature and commentary at the end of each section. Further, whilst in the published paper I used the phrases 'themes and subthemes', as seen in some grounded theory literature, I will now revert to the use of categories and subcategories which is Charmaz's preferred phraseology for the remainder of the thesis.

5.10 ‘The Roller Coaster Evolution of NICU Parenting’

A category which emerged in the analysis was the evolution of parenting on the neonatal unit. Subcategories for this category are related to the focused codes of parenting as a function of time in the overall progression from before birth, to well after the baby has been discharged from the neonatal unit for those babies who survived. I describe the time before the admission and how families functioned after discharge of the baby (Figure 5.4). I have represented this category in graphical form, to capture the changes in the confidence that parents expressed as a function of time from the birth of the baby. The data showed an initial growth in confidence in parenting whilst admitted, then confidence declining initially after discharge, although the parent still has some competence and is happy to be home. Over time, the parents adapted, more slowly where parents had to develop medical and therapy skills for children with disabilities, but ultimately these parents appeared to be more confident and competent as they had adapted to a different type of parenting role.

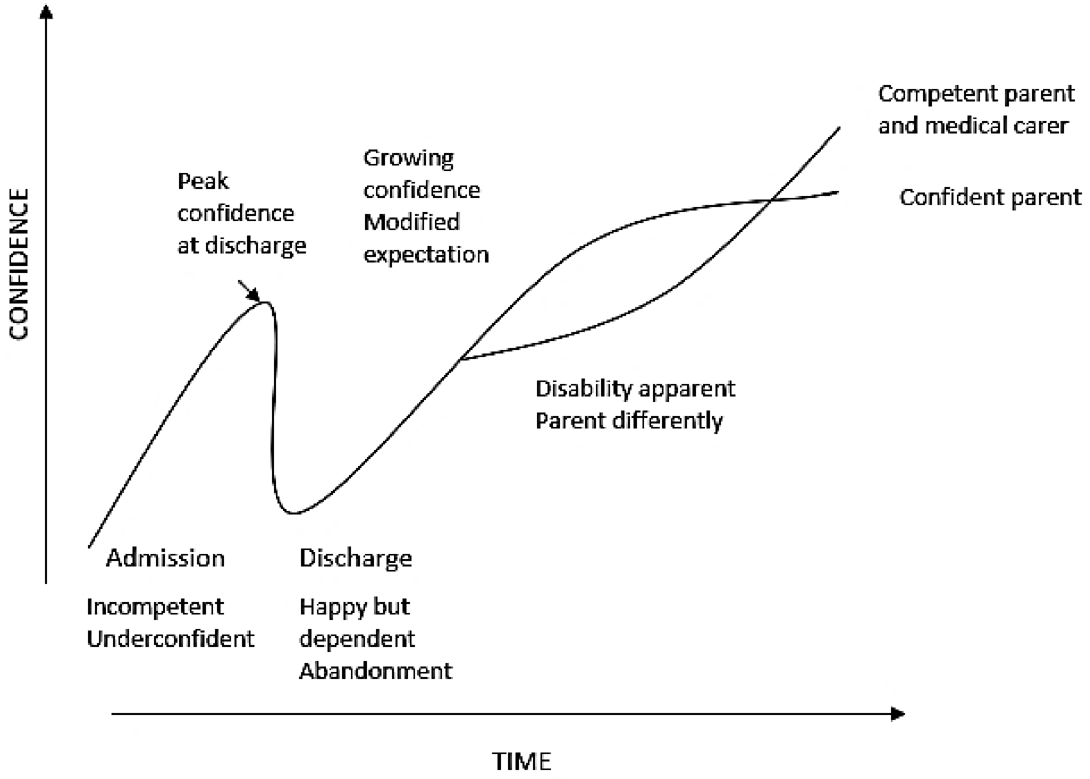

Figure 5.4 Time line of confidence in parenting.

5.10.1 Before the neonatal unit - Incompetent and under confident

Most parents knew little about prematurity prior to the imminent delivery of their baby. For these parents, survival at the lower gestations was a surprise. A parent's description of her knowledge was typical of that frequently heard:

> *'You live in a world where all these babies are just born healthy...where babies come at 40 weeks…you will have your baby and everyone will bring you flowers, and you will go home.'*

(Mother of growth restricted 26-week gestation girl)

Delivery may have been unexpected, as with this mother who had a complication of pregnancy leading to urgent delivery:

> *'I didn't think he would come out alive…I didn't know that you could have a baby at 24 weeks and they survived…I just assumed that wasn't going to be the case and that he wasn't going to [live].'*

(Mother of 23/24-week boy)

Some parents did have time to research and become informed, and one set of parents was aware of the consequences of prematurity from family friends who had a 24-week gestation boy at TUH some years previously. The mother, quoted below, recognised that the reality was far worse than her former perception:

> *'The only thing I knew was from baby S who was here. His father was friends with my husband…I had to Google what NICU was and all that sort of stuff. Yeah, I cried and cried for such a long time. I didn't even know these people. But just thinking "oh my God, that's horrible" … But I don't think you really know a NICU until you have been in a NICU – like it's something that's like, horrible.'*

(Mother of 25-week baby.)

5.10.1.1 During admission

Parental growth in confidence from emotional turmoil to apparent empowerment in parenting was described in the publication presented earlier in this chapter.

5.10.1.2 Following discharge

<u>Abandonment and fear</u>

Parents often described feeling ready to go home before the medical staff were ready to release them, as described earlier, and discussed later in this chapter. For some, going home was comfortable, particularly for this mother who had already had preterm babies, and was now headed home with a 24-week gestation girl:

> *'Amazing. It was bliss. It was so good. I think because the girls had spent so much time - so much time in hospital with her, it was just a feeling of being at home. She was a super-highly sensitised baby, so she didn't sleep very much. She had to be strapped to my chest all the time. All the little sounds, light, anything would stimulate her. She wouldn't even fall asleep in a car. So, she fitted in with the family really well, but it was really hard for her to adjust, just given how highly sensitive she was to stimulation. Any sort of stimulation. Family-wise was so good. She's just loved, - we literally shut down our life a month after she was home. We would just pop out to get food, and we were just happy to be home and not be at the hospital.'*

Following discharge home, however, many parents described great difficulty in adapting to home life.

Most parents, particularly those with their first-born baby, found homecoming stressful and a time of confusion. Caring for the baby was difficult, because control had not been within the remit of the parents in the NICU environment. Parents had become institutionalised in their approach to caring for the baby:

> *'It was just so numbers orientated. Go to sleep now, wake up now, he can sleep in this position…When he started changing and had gone from being a bit squishy that it was, was, like, "oh, hang on a minute, we can make a decision about him now". It took me months to get out of the routine of hospital and going "oh hang on, I can set the agenda now." I felt we were so indoctrinated by the hospital on how to care.'*
>
> (Mother of 27-week boy)

Insecurity and dependence on machines to determine the wellbeing of the baby is described by this father of 27-week twins:

> *'They go, "here's your baby, go home." It's terrifying because when you go home, even though they've been released, you do still think "are they going to stop breathing? Where's the machine that's telling me that they're breathing?" It's terrifying.'*

Beyond fear, exhaustion occurs:

> *'I had no idea what I was doing and I had no help at all. We brought him home at seven o'clock on Monday, 20 April and I looked after him through the night. J went to work the next morning at six or seven o'clock and I was on my own. When he got home that afternoon I was crying, the baby was crying. I don't think I'd been able to pee or eat anything all day. That's pretty much how it was until now…. I didn't know how to put him down. Just in my head I just thought I had to hold onto him.'*

(Mother of 26-week gestation surviving twin.)

Changing self and relationships

With time, parents became more confident and described changes in their world view and relationships regardless of the developmental outcome for their child. Many received formal counselling from a psychologist. Although the parents were only asked broadly what supports they had received after discharge, seven parents discussed this during the interviews:

> *It's had a massive effect on me. The effect it has had on me, it has given me perspective in life itself. But it's not without the heavy pains that have come with it… But the S chapter [the 3 months the baby survived in NICU, before dying] was probably the most painful, beautiful, honest thing I've ever experienced and will ever experience.*
>
> (Father of 24-week gestation boy)

Parental relationships seem to have been strengthened by the NICU admission, with none of the partnerships having broken down since discharge, and several describing a positive change. Many families relocated after admission, some through military relocation, but other families had more complex reasons. For this family, the experience led them to move interstate to a completely self-sufficient lifestyle on a farm, which they had previously considered but never felt confident enough to do. The family had been emboldened to go:

> *‘I think it made us stronger what we went through. Anyway, it made our relationship stronger. But if we got through that we can get through anything else. It was tough being through that. We talked about it and talked about it and it got to the point where we just said let's just do it. Packed everything up. Everything. Five horses, four kids, two dogs and bird.’*

(Mother of 26-week girl)

Similarly, this mother describes relocation to the outback, with the changes to her own attitude towards life. Her baby was born with severe pulmonary hypoplasia and was critically ill after birth from respiratory problems:

> *‘We're going out there for a lifestyle change, just step back and slow down... I guess I don’t really worry about anything anymore unless I absolutely have to. There's a lot of things that we're grateful for that I probably didn’t take for granted, but I'm more conscious of now… I've got an appreciation and - how lucky we are to have M home and to be a complete family. There's a gratitude. Gratitude changes your perspective on things. ..., I listened to my gut more and trust my knowledge and my ability as a mother rather than what other people say.*

(Mother of 25-week girl)

Resentment, anger, resignation – not what I signed up for

The course after discharge seemed more complicated for a few families where severe disability was evolving. The mother whose comments to me about the long-term consequences of extreme disability and the role of the clinician in promoting active care, discussed how families portrayed on the neonatal unit in photographs, and on social media may not represent all families:

> *'Are they the miracle parent though? That's what I find. They're always the miracle parent that's sitting there, banging on about it. I did a degree. I'm a…and I'm not one anymore. I'm a full-time carer. I'm an advocate. I'm a physio. I'm an OT. I'm a speechy. I'm not really a mum. A lot of the time, I don't feel like a mum. I'm just keeping him and fighting the system. That's not what I signed up for.'*
>
> (Mother of 23/24-week gestation boy)

Ongoing grief and loss were seen for some parents, whether the child died or survived impaired. This father described his emotions five years after his 24-week gestation baby died following a long course on the NICU:

> *'For me it's just emotional. It can come out of nowhere for no apparent reason. It's just one minute you are going really, really well and then for some reason - I think, it's if I'm vulnerable or if I'm tired - sorry, if I'm tired and I'm feeling a bit vulnerable it comes up [and I have a meltdown] So instead of fighting it when it does come I just let it come. You know, I'll find myself talking to him as if he was there like when I was back in the NICU and things like that. That still happens to this day. So yes, it's there. It always feels like it is right now, it's under the surface.'*

Grief for the potential of a child who survived with severe impairments was equally visceral. This mother who has described her role as being a therapist rather than being a mother, lamenting the loss of normalcy- her son is a 'patient', rather than a 'child':

> *'He's traumatised and then his trauma runs off our trauma. But his journey hasn't ended yet and to think that he's got to go through a life of - like the next thing we're looking at is a hip operation. He's going to get his hips cut….. He's a little boy who just wants to be a little boy. Even when they tried to put him a physical disability unit, they're forgetting that he's just actually a little six-year-old boy who loves Teenage Mutant Ninja Turtles and all the things that little boys love to do. He just wants to be with kids. He actually doesn't want to be the kid who only does therapy and sees doctors and nurses and spends time in hospital.'*
>
> (Mother of 23/24-week boy)

Modified expectations

All parents of children with significant disability, even where there was still anger and grief, showed acceptance and love for the child, and had modified their aspirations. They voiced pleasure in their attainments. The parents were not minimising their children's difficulties, but allowing their achievements to engender parental pride. Following a long NICU admission, this mother's child was now three years old, only starting to sit, and had other severe delays:

> *‘Yeah it's just magical the amount of love that he brings to me. If ever I'm having a bad day or whatever he just laughs and smiles and calls for me and goes to sit up now because he's trying to sit up. He pushes his elbow out when he's on the ground and he gets up on his arm to push himself up to come to me. So it's all those little things that know that everything that we've been through is so worthwhile. Just playing with him he's learning new skills without analysing everything down. I've got a very healthy child. Yes, his mobility isn't as great as a normal child's.’*
>
> (Mother of 25-weeker)

To help manage her child’s complex needs due to his prematurity and a congenital disorder, as well as to and engage better with the medical profession, this mother became a nurse. She describes her happiness in his successes, but also her need to ensure good care- effectively she has modified both her expectations of the child, and also her own future:

> *'He can communicate to us…It's all about visual aids. So he just tells me, like how he tells me "how do I feel?" So he points at that. So then when you go to different feelings, he points at "I'm sad, I'm happy". My life has changed in a different way. Acceptance is so much. But you know, he's just - I look at kids who can't do anything. My son can walk, is happy, has got a personality. So I'm very happy for what we have. We have to accept some things which are not in our control. Not that I'm going to save him, but I want it to be as close to this field as possible to be able to care for him.'*
>
> (Mother of surviving 24-week twin)

The mother of another child with severe disabilities has similarly engaged extensively in therapies from an alternative medicine paradigm which she feels has helped her child. During the home visit done as part of the study, she allowed him to eat several pieces of chocolate cake, describing this as his only real pleasure in life. He enjoyed it immensely.

Children with slightly less severe special needs engender a similar response from their parents. This mother of a child with cerebral palsy and cognitive delays described her joy at his attainments:

> *'[he is] on the level with his reading as the child at the bottom of his class, so we are kind of like, we think he is at the average range, just at the bottom of it, and that, for us, is brilliant'*
>
> (Mother of 25-week boy)

Many other parents had similar stories, which can be summarised by this father of 27-week twins, one of whom had a severe intraventricular haemorrhage, but who has only mild ongoing learning difficulties:

> *'I think it'd be very naive of any parent to think that they're going to end up with a five star perfectly healthy baby. I think it'd be silly.'*
>
> (Father of 27-week twins)

Advocacy

Parents participating in this study had often raised money towards the neonatal unit funds, formed their own play groups within their cohorts, and even advocated for other mothers at a time of need:

> *'G's mother a couple of weeks ago when she was 24 weeks [in her next pregnancy] because they thought that she was, you know [in preterm labour again] and she's very shy and she wanted me to come with her to advocate for her…So she just wanted a steroid shot and the obstetrician was taking it away from her going "well we like to err on the side of caution rather than over, and not give [steroid injections unnecessarily]…". I said "well in all respects that's not really up to you. You're not sitting in her position and you didn't sit through your child's illness so maybe you should leave that to her"'.*
>
> (Mother of 27-week boy)

Discussion of the roller coaster category

The stages seen during the time course from before admission to well after discharge, mimic much of the adaptation described in paediatric literature about caring for children with complex medical needs (Solan et al., 2015).

Approaching discharge home may be a time of excitement, described as "escaping the hospital" (Granero-Molina et al., 2019). However, as noted by McHaffie (1990), where the family is not ready psychologically to take the baby home, there may be increased risk of poor attachment and difficulty in coping. Fatigue, depression and anxiety is also associated with poor maternal mental health up to a year post discharge (Garel et al., 2007). Previous studies have described similar patterns of fear and anxiety to my findings (Adama et al., 2016).

Some researchers have suggested that the early difficulties which parents experience are related in part to their mental disorientation following prolonged hospitalisation, with distortion of time (Solan et al., 2015), and the disruption of the parental role and the parent-infant relationship (Boykova, 2016). Many parents are initially overprotective, particularly if the baby appears to be evolving differences in their development to typical babies (Granero-Molina et al., 2019).

Increasing confidence, as seen with families in my study, occurs when parents become more assertive in their decision making and experience improvement in parental bonding with the infant until most parents have adapted and maintain a typical healthy relationship with the child (Jackson et al., 2003). Often these parents have developed good support systems, both social and professional (Adama et al., 2016). Ultimately, parents adapt, and are often strengthened by the experience. Their strengthening is born from necessity and the need to provide the best care they can for their child. Improved parental relationships and positivity about life has been found previously (Lindberg & Öhrling, 2008).

For some, the adaptation is accompanied by ongoing anger at their circumstances. Parenting a child with disabilities is challenging. Often these children impose a greater burden on parental time than other children, and require the parent to develop nursing and therapeutic roles (McCann et al., 2012). This can affect the family’s social and work life as participants in my study voiced, and has been recognised by others (Granero-Molina, 2019). Parents can become emotionally distressed when their caregiving involves causing the child physical pain or discomfort (Spiers & Beresford, 2017). Where a child has severe disability, this can result in complex feeling towards that child. Brinchman and colleagues explored the experiences of families and described finding both ‘love and happiness’, ‘pain and sadness’, and reflects some parents as feeling both ‘love and hate’ for their offspring (Brinchmann et al., 2002). Some of our mothers also experience the difficulty of children who have needs which are ceaseless.

Yet, in common with previous studies, adaptation to challenges was seen (Jackson et al., 2003; Wakely et al., 2015). Mothers described resilience and a desire for their children to experience normalcy in the face of severe physical challenge. However, as cautioned by one of our mothers, the difficulties experienced by families with a disabled child must not minimised. This mother cannot escape her relentless caregiving. There is much research done which shows that most ex-premature babies have a good quality of life (Saigal, 2013), but there is both medical and informal literature which challenges this view (Culver et al., 2000; McVeigh, 2011). Adaptation to her child’s difficulties may have strengthened one of the participant mothers, and she rejoices in his achievements, but equally described her own suffering as an outcome of neonatal care for her extremely preterm baby.

Whilst my data did not reveal new knowledge about this topic, it did map out the different stages of parenting more clearly than most studies which investigated only small time frames of neonatal care, here painting a picture of adaptation to change as a repetitive part of parenting a vulnerable baby. This leads to the possibility for future studies to explore whether this roller-coaster experience recurs through different phases of the families’ lives and if it is different to families who have not had vulnerable babies.

5.11 ‘Voicing the Broken Dyad’

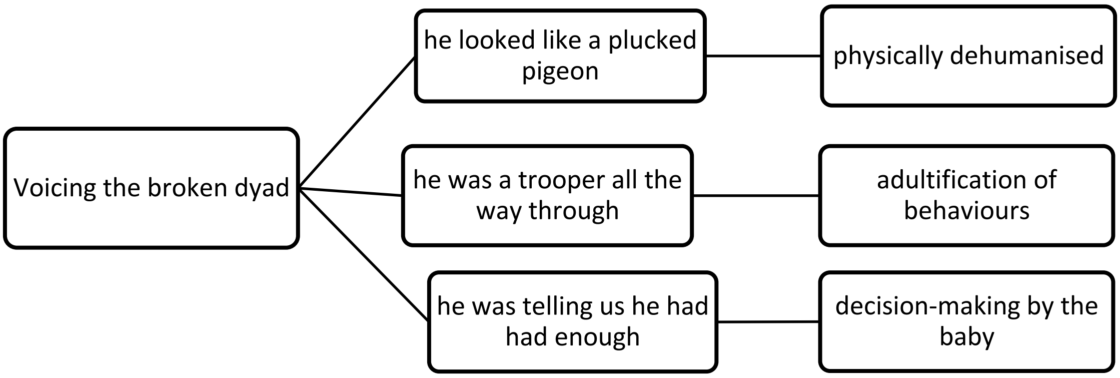

Figure 5.5 The Subcategories and focused codes for ‘Breaking the dyad’.

The third category which evolved from the study was one of ‘hearing the broken dyad’ formed by the mother/parent and baby. This category can be further divided into subcategories of ‘he looked like a plucked pigeon’, ‘he was a trooper all the way through’ and ‘he was telling us he had had enough’ (Figure 5.5). The connection between parent and newborn baby has been partially explored in the previous two categories – parents talked about the difficulty in caring for their babies and their experiences of the NICU, and it is also seen in the evolution of parenting in the NICU. Here we see explicit phraseology used by parents which suggests poor initial attachment to their newborn.

5.11.1 ‘He looked like a plucked pigeon’

Parents had a variety of descriptions of their baby as a newborn, with few suggesting the baby looked like a human baby. Dehumanised descriptions may allow parents to remain detached, and protect themselves from the initial bond seen when parents of healthy term babies look at their children and recognise features of one parent or another. Descriptions varied from similarity to small animals to vegetables:

> *'He looked like a little plucked pigeon'.*

(Father of 23-week boy)

> *'I saw this little red lobster thing come out'.*

(Mother of 24-week boy)

Another parents' description was more unusual, here describing a severely asymmetrically growth restricted baby:

> *'You have all these expectations of what your baby is going to look like, then you have this tiny little skinned potato'.*

(Father of 25-week girl)

5.11.2 'He was a trooper all the way through'

Adultification of behaviour was found to occur. Adultification is the attribution of adult traits and behaviours to children. This is evidenced by comments made by the parents of this baby girl who spent eight months in NICU with multiple congenital abnormalities requiring surgical intervention. They describe how the baby was said to behave prior to planned surgeries:

> *'Then when something was about to go down, and she'd either put a turn on, or you could sense it in her eyes or something that she knew something was going to be up.'*

(Father of 30-week gestation girl)

At other times, a baby was said to have behaviours with a negative connotation. This father suggested that the baby didn't make enough effort with feeding, although she was very small and staff assessed her as physiologically unable to feed adequately at the time:

> *'She was just lazy – I knew she just used it [the nasogastric tube] because it was there, and she just used it because she was lazy'.*
>
> (Father of girl with severe growth retardation)

For this mother, the baby who had many complications of extreme prematurity was described in stoic terms, which made the mother feel that she too must be strong herself to please the baby:

> *'He didn't complain. Like he still was a trooper all the way through it. So who am I to not do the same? I want him to be proud of me as well.'*
>
> (Mother of 25-week boy)

5.11.3 'He was telling us he had had enough'

Some babies were said to have made decisions about their care, or been encouraged to do so. At times this referred to relatively innocuous occurrences such as when the baby's normal primitive grasp reflex leads to the baby pulling at pieces of equipment that became entangled in the baby's hand:

> *'A lot of times she made the decision on her own. She used to rip the cords and everything else off.'*
>
> (Mother of 30-week girl)

Another mother whose baby had been very ill, but who wanted to continue care regardless of the potentially poor outcome voiced how she would give the baby 'permission' to die:

> *'You know life is going to be hard for you. It's going to be really hard. I used to always whisper to him and say you know mate if you want to go that's on your terms…But if you need to go then that's your call…look if you want to stay around there are beautiful people here that are willing to help. But if you need to go then that's between you and God'.*
>
> (Mother of 25-week boy)

5.12 Discussion of the 'Voicing the Broken Dyad' Category

The social and emotional interaction of a term baby and its parents will lead to a bond between them which is described as attachment. Bowlby defined attachment as a "lasting psychological connectedness between human beings' and proposed that this evolves as an adaptation which enhances the baby's chance of survival" (Bowlby, 1969, p. 194). Extremely preterm babies require HCP to deliver their needs, with parents in a passive role of caregiving. There was evidence presented in this study in the category of parental experience which showed disempowerment of the parents, along with feelings of guilt towards the baby's early delivery as well as physical distancing brought about by the admission to the NICU. These factors have been shown to impair attachment to the baby (Medina et al., 2018; Spinelli et al., 2016). The subcategories found exhibit the way in which parents have become detached from their babies with depersonalised description and adultification. This could be a protective mechanism for the parents' psychological wellbeing to protect against the potential grief of loss should the baby die (Medina et al., 2018). The parent appears unable to prevent the suffering of the baby, contrary to the normal parental role. A healthy response for the parent is to in time, adapt to resume the parenting role. One of the parents herself, recognised the origins of the detachment, and she sought psychological counselling after the NICU stay:

> *‘There's quite a large disconnection with the baby being in hospital for so long that, knowing that someone's doing what you would be doing or could be doing and that's the way you do connect with the baby.’*
>
> (Young mother of a 27-week baby)

Even prior to the delivery of a baby, studies suggest that parents may struggle to conceptualise the baby as a distinct entity and this may lead to challenges in antenatal counselling (Payot et al., 2007). After delivery, Medina has described the difficulties in attachment as a result of the early emotional crisis the mother has from the premature delivery, the complexity of the environment and the difficulty in relating to a ‘stranger’ (Medina et al., 2018). Likewise, Spinelli (2016) noted that the maternal identity as a mother is delayed which relates to the initial bonding difficulties. The participants in this study voiced similar emotions.

Few studies, however, have examined the language which parents use to describe their babies. Babies here were likened to animals and vegetables, although extremely premature babies are fully formed, only small and usually with immature skin. An inappropriate assignation of an adult style of behaviour was seen; deeming the baby to behave bravely, which the baby lacks the abstract thinking to do. In addition, some parents described ‘decisions’ of the baby which require an adult understanding and processing to perform. The language used suggests that the baby was not seen by the parent as their small vulnerable child at that time. The term ‘adultification’ has several meanings, including the inappropriate exposure of children to inappropriate adult behaviours, but can also encompass the child adopting the role and responsibility of adulthood. Blackman (2017) described the language used by parents who chose to ignore their crying babies rather than sooth them, describing the baby in a similar adultified manner. In his study, babies whose parents were more sympathetic in their description were more likely to sooth the baby and the babies had a better emotional outcome. Whilst the findings themselves are seen in many other studies, the language of the parents showed similarities to that seen here. The words used by parents provide graphic insight into the perceptions parents have in their relationship to the baby in this data.

As previously discussed in the publication about parental experiences in the NICU, sound attachment is essential to the future mental health of the parents, and poor attachment in this group of babies has been shown to correlate to poor coping, depression and anxiety, whilst improvement in attachment after discharge has been shown to lead to improved development and cognition of the baby, and reduce behavioural problems (Lean et al., 2018).

5.13 Parental Perceptions of Decision-Making at TUH

The previous categories described the experiences of parents within the NICU and how the family evolved after discharge home. I have examined findings which showed that the dyad between parents and babies may be impaired, at least initially, because of extreme prematurity. Presenting the results in this order helps to contextualise the parents' opinions about decision-making. The parents in this study have lived with the consequences of decisions made to offer active care to their babies, as well as decisions on other aspects of care, both large and small. Parents now reflect on decision making, with a retrospective lens of knowing their individual outcomes.

Where the participant's pregnancy had been imperilled prior to 25 weeks gestation, parents were asked about discussions or counselling which they received about resuscitation of their baby. Some parents did not recall relevant discussions when they first presented. All parents were also asked for their opinions about who should make decisions to offer care to periviable babies. All parents had an idea about who should decide on the whether a periviable baby should be resuscitated. Regardless of gestation at birth, parents were prompted to recall any decisions made about their baby's care that they thought were memorable.

This category has subcategories of 'who decides', 'context, culture and character of the family', 'decisions as power' and 'regrets'. Each subcategory is explored with linked focused codes.

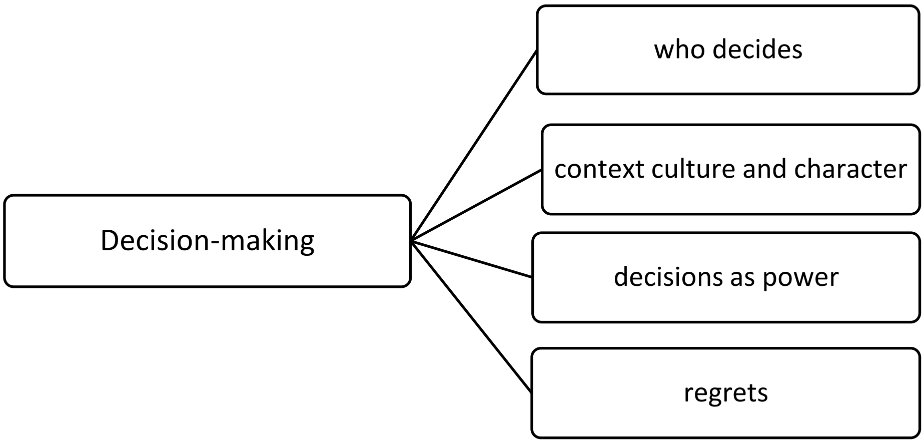

Figure 5.6 The subcategories and focused codes for 'decision-making'.

5.13.1 'Who decides?'

This subcategory of explores the parents' perceptions about decision making for resuscitation or ongoing active care after NICU admission.

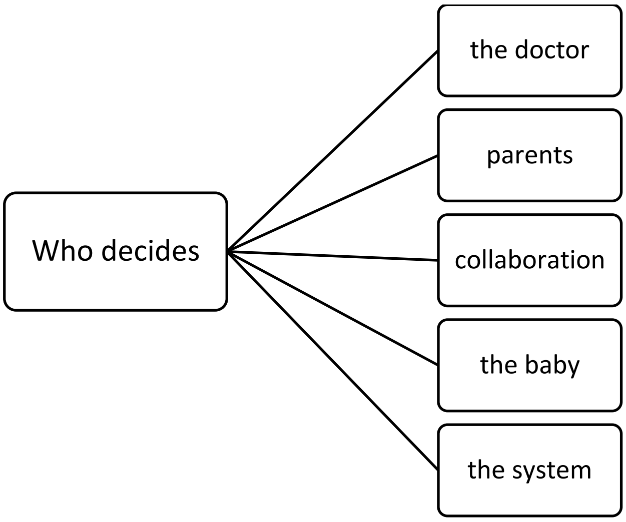

Figure 5.7 Focused codes for the subcategory of ‘who decides’.

5.13.1.1 The doctor

Many parents agreed that the medical staff should make decisions to resuscitate periviable babies. Medical knowledge, and a trust that the doctors concerned would know the best course of management was repeatedly described by participants. For some this trust was in the doctor’s evaluation for potential for survival at delivery, rather than any decision-making around the risks of morbidity:

> *‘But I think it's unless you're well versed in that field of medicine then you have to place your trust and your faith into the advice that's provided. Because I mean they know what's best.’*

(Father of baby not initially considered to be viable,
born with severe congenital anomalies)

Parental choice is given primacy by this mother, but with the onus on the doctor to decline care if they consider the baby has no chance of intact survival:

> *‘Parents should decide if they want to but need to understand there are consequences either way, but doctors should intervene if they think it is a no-go baby’*
>
> (Father of 25-week gestation girl)

Some parents recognised that there were concerns about the resuscitation of periviable babies within the medical profession, and that medical opinions may vary. A mother presented at 24+0 weeks in labour with twins to a regional centre and surgical delivery occurred, without the benefit of antenatal steroids. No discussions about whether the babies should be given active care occurred. The parents voiced happiness at their children’s progress and survival although one baby has residual impairments:

> *‘There were people that wouldn't resus B, for instance, because she came out not breathing. But we had a doctor on that night who had a daughter who had had a premature baby and he did everything in his might to keep both of our children alive. I think if it wasn't for him we wouldn't have two, we'd have one. I honestly believe that he wanted to do everything he could to make our children survive. Whereas if we had a different doctor, maybe he would have decided not to.’*
>
> (Father of 24-week twins)

The father voiced his trust in the medics to cease treatment in the face of an ‘unfavourable outcome’ which seems at odds with his own experience.

> *'There are probably a lot of parents out there which would love to still resuscitate the child regardless of even what medical professionals have to say, but then, I'm one also just if that's an unfavourable outcome then I'd be inclined to listen to the medical professionals.'*

5.13.1.2 The parents

Parental primacy as decision makers was advocated by many, with limitations recognised by some for the concept of the 'fully informed' parents. Mothers who had ample time to consider the resuscitation for their imperilled baby understood the consequences. This mother had a previous early stillbirth, and recognised that she had been in a well-informed situation at the time of her delivery, and requested steroids at a very early date prior to 24 weeks following threatened labour at 20 weeks:

> *'I felt there was a choice but I definitely wanted everything - I was in boots and all – I feel that I had lots of choice but it was all informed choice. That we had all that warning and that preparation whereas lots of the mums didn't know and they just had the babies early. So yeah, I feel that I had lots of choice but it was all informed choice.'*

There were several other responses which argued for more parental latitude – one advocating for choice at later gestations, and one because the suffering and time in NICU might reasonably prevent parents from wishing active care. This mother, who had rupture of membranes at 16 weeks, delivering at 25 stated that the guidelines infringed on parental autonomy:

> *'I think before 23 weeks you probably shouldn't resuscitate a baby. But if the mother is adamant, a baby could be resuscitated [at 23-25 weeks], one hundred percent the parents should choose…That's a really tough question that at 26 weeks, if the parent doesn't want the baby resuscitated you would.'*

Another mother had a similar sentiment, where the likely difficult stay in NICU itself may be something which might discourage parents from opting for active care. She herself had two pregnancies which ended at 24-weeks' gestation and resulted in very long NICU admissions:

> *'I do ultimately think that people should be given the decision because it's their life. They might not be able to, or want to, commit to months in hospital. They might not have the support, the coping mechanisms. Not everybody's mentally strong enough to do that. So, I do think people need to be given that decision and not just, here you go, this is what you're in for.'*

While most parents believed that parental choice was the correct approach, there were concerns about informed consent in parental decision making. Many of the women who delivered early because of spontaneous preterm labour relayed that they had been counselled at a time when they were unable to fully grasp the information given. In some instances, discussions had occurred when it might have been possible to wait until a more suitable time. One couple regretted their apparent agreement for resuscitation of their baby, later believing that the circumstances of counselling had precluded a true understanding of both the NICU course and later potential consequences for their 24-week gestation boy, who died at several months of age after redirection of care:

> *‘It was very blurry for me because all of sudden someone was trying to put cannulas in me. I remember you [the primary investigator] were talking to me and I remember you [the researcher] were saying to me - because it took the young doctor, three times to put my cannula in. I had blood and I was in pain. You were trying to talk to me. There was a lot of information there, a lot to process. I remember they gave me nifedipine …these people just kept coming in and out... Then there was the rollercoaster discussion about what we are in for here. I was like, “yeah.”’*

Mothers may themselves be in a perilous situation, and unable to digest the counselling when consent is sought. This mother delivered at exactly 24-weeks’ gestation (although 23 weeks by her calculations), after an incomplete course of antenatal steroids were given. Whilst she recognised that she was unable to participate actively in decision making, she would not have wanted to pursue resuscitation. Her thoughts about potential considerations in counselling in this situation will be heard later:

> *'At this stage, I thought I was about to die … So I'm like, how could you possibly lose this much blood and live?…They sent in M [neonatologist] and someone, this fellow. They just came in and had a really quick, brief chat and just told us some of the things. But because they were so concerned about my life, their real thing was," but we don't know if you're going to live"…So I was like, "how am I meant to make a decision based on not knowing if I'm going to be here?" So you are asking me what to do and I'm like, so what do I do? What happens? In the end, M said, "we will make the decision based on how we see him when he comes out"…I just couldn't believe that he could have come out and been resuscitated, ended up in NICU. I just assumed I would wake up and they would tell me - if I woke up - that he wasn't here anymore…So I'm like, can we just see if I'm going to be alive first? Because you're asking really big things of me…I didn't know that you could have a child at 24 weeks and they survived.*
>
> (Mother of 23/24-week boy)

Another mother had been admitted in preterm labour four days prior to delivery, but recalls her first discussion about the 26-week gestation baby only occurred when she was in the birthing room just prior to delivery:

> *‘X…came in and spoke to me while I was in the birthing unit already so once my contractions started becoming real and I went into active labour, that’s when X started speaking to me and I think that's a terrible time to talk to anybody giving birth….he could have asked me to jump off a bridge during that time and I would probably just agree so that he would shut up…you are so concentrated on what’s happening next, like you are worrying about the pain…but he did come and speak with us…. and all I could think was that, no, I don't want to push, I don't want her to come out then, I’m not going to do it…she might come out blue, and she might not be breathing, and she might not cry’*

Whilst no decision about the provision of active care was required for this family at 26-weeks’ gestation, the mother reflects how counselling for any decisions in these circumstances would appear to lack informed consent for some women in labour.

5.13.1.3 Collaborative decision-making

There were some examples of collaborative decision making between parents and obstetricians, which seem to be primarily concerning timing of delivery. For those women who presented either in early spontaneous labour or with rapidly worsening complications, parents felt at ease with both the discussions and ultimate decisions made to deliver early.

> *'[discussions were about] getting her out or leaving her in with my high risk of getting an infection. We were given the risks that there could be problems with her being born so early but, I mean, it wasn't really a big choice and we opted to have - to deliver her rather than leave her in for longer (with the risk of infection).'*

(Mother of 26-week girl)

Few comments were found indicating collaborative decision-making by parents with other staff, particularly once on the neonatal unit. This was surprising in a unit where family-centred care is said to be the ethos. Parents participating in the Family Integrated Care (Fi-Care) study were the exceptions as the study encouraged parental involvement in the daily care and ward round decisions.

5.13.1.4 The baby

Parents reflected that the condition of the baby might decide the resuscitation or continuation of care. At times decisions made may be ascribed to the baby itself, both for redirection of Care and for continuation of care. In these instances, it appears that no adult is really making Any decision as the baby is clearly unable to make autonomous decisions about its own survival.

Here the baby died at three months of age following a decision not to escalate care for an infection, when the baby had remained ventilated since birth:

> *'So if you were to say "if your baby could survive but he was going to have a, b, c or d, or your baby didn't survive and he doesn't have to worry about a lifetime of that" [disability]…, maybe he doesn't want the life that is planned for him, which is true. Maybe he didn't want that. So I had to listen to him ultimately. So I feel like we didn't really make the decision, he made it. He said, "enough is enough".'*
>
> (Parent of 24-week boy)

One mother had requested that care was redirected to palliation after several days in NICU as she understood that her baby was making poor progress, had a grade four intraventricular haemorrhage and that this suggested a higher risk for neurodisability. Her request was denied, and the child is now profoundly disabled:

> *'I don't know how many rights as a parent I have, or how many rights as a foetus, the baby has, when it reaches 24 weeks…If you tell me as [the neonatologist] did. "After 24 weeks, we consider this a baby. We go by what the baby says," If the baby says "I'm recovering, I'm good, then I follow that". Irrespective of the consequences because that's the rule for everybody.'*
>
> (Mother of 24-week boy)

5.13.1.5 The system

Mothers transferred to TUH describe that this was initiated for maternal-fetal-medicine (MFM) input or because the baby would not have been able to be cared for at the referral centre with delivery expected below 29 weeks. When asked about her baby this mother, who was sent to TUH at 23 weeks gestation in preterm labour, recalled the transfer:

> *'They just more or less said that they'd have to - get you down there [to TUH] and just more steroids and all that sort of stuff, but there was nothing said about resuscitation, no.'*
>
> (Mother of 26-week twins)

For five mothers at periviable gestation, there was little time between presentation and the birth, including one who was transferred to TUH. Three mothers delivered within two hours of presentation. This Townsville mother who was admitted in labour at 24 weeks recalled:

> *'"That will stop the contractions, everything will be fine". Then as soon as I had the examination, it was lights, camera, action. Oh shit, it's happening. Everyone was pretty highly stressed, I could see that. I don't remember any options being given to me…obviously they were telling me what they were doing as they went. They were very reassuring with everything that they were doing, but I don't really remember many options.'*

For these women, there seems to have been little time for discussions, and they entered a 'conveyer belt' of care, with either transfer at a time when they may have declined care had delivery been imminent, or rapid delivery and resuscitation without seemingly any discussions to inform decision-making

5.13.2 'Context, culture and character' of the family

Data showed that many parents had evidence of previous major decision making about the pregnancy of concern or previous pregnancies or had a cultural context which informed their attitudes towards decisions made. Knowledge about the perspectives of particular families may have enabled richer counselling, more applicable to the parental situation. Shared decision-making (SDM) which incorporates individualised counselling strategies will be addressed later in this thesis. Focused codes for this subcategory reflect aspects of the parent's individual lives, and their belief systems (Figure 5.8).

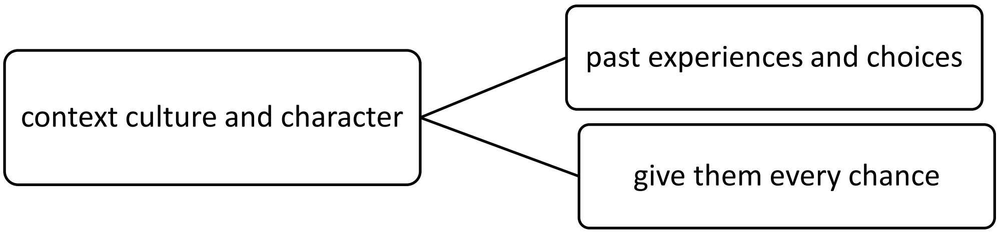

Figure 5.8 The focused codes for the subcategory of 'context, culture and character' of the family.

5.13.2.1 Past experiences and choices

The context of parental decision-making, particularly previous pregnancy loss, informed some mothers' determination for life sustaining treatment for their babies. One mother had previously lost a baby at 21 weeks, and was determined to alter the course of events when she again ruptured membranes at 16 weeks. She refused medical advice for termination and discharged herself from the hospital. Delivery occurred at 25 weeks, the baby had some lung and joint abnormalities because of anhydramnios, but had an otherwise smooth course through the neonatal unit and has no detectable impairments at 5 years of age:

> *'I just went home and laid on the couch to get as much rest as I possibly could. I was thinking ... It was a horrible time, just laying there thinking - I wanted to hang on to L as long as I could because I knew that she was alive and moving… Then I went right into alternate health basically. I was doing lots of things. I was doing really high dose probiotics to prevent infection, because what they did identify was that I had strep in me at that time as well. They said it's notorious for infection. I went on high dose vitamin C, high dose probiotics, no grains, tried an alkaline diet. There's a few things I did. I tried to just raise the bed a bit so no infection was going with gravity, I guess… I just basically waited at home.' (the baby delivered at 25 weeks,)*

Had the mother not challenged the medical advice, the baby would have died. She reported that she was given less than one percent survival chance for the baby.

Another mother also advocated for continued active care during and after pregnancy despite poor prognostic features and a stormy postnatal course. Earlier in the pregnancy she had declined an early anomaly scan. Her son has significant sequelae of prematurity:

> *'So we were told he had to be 800g to save him, so we were pushing for that, and I remember talking to the NICU staff when we did our induction [antenatal nursery tour], and saying 'I want him saved'* – *no one ever asked me the question probably because I was very adamant …I see all the programs where they say you get asked, well I never got asked the question…I think he was 24+5 weeks…if he had Down syndrome that would have been fine…we had discussed it and the decision was no termination. I see other kids with big problems, and if I could have coped with that, well I just would have'*
>
> (Mother of 24-week boy)

Prior to complications which expedited delivery, some parents had considered how they would manage the pregnancy if there was an abnormality on their anomaly scan at 18-20 weeks. This mother delivered at 23/24 weeks gestation and has concerns about the decision to offer active care. She was not able to participate in collaborative decision-making due to her own physical condition. She feels that had it been known how she felt about abnormality, alternative decisions should have been made:

> *'we shouldn't have been offered resuscitation, we knew if the baby had been diagnosed with Downs syndrome at the scans we would have terminated'*

Experience of disability within his family informed one father to quantify what level of disability would be manageable for the parents, with quality of life paramount. These parents of very small 24- week twins, born without antenatal steroids described:

> *'My belief is that it's not fair to put a human through life who is going to have major problems...you don't know what extent…a bit of cerebral palsy, a bit of autism...I've got family members with all that and they have awesome lives...they have a great quality of life…they would have to say 'look its going to be a hundred percent of just a vegetable. There is going to be no communication (for us not to resuscitate a baby)'*

5.13.2.2 'Give them every chance'

A very common sentiment was that babies should be given every chance to survive even if there is a high risk of impairment. Reasons given for this varied, but some mothers described a bond formed prior to birth which led to a need to keep the baby alive where possible. This mother of a baby who had a stormy course and is profoundly disabled has no regrets about the continuation of care:

> *'I think obviously I'd bonded with him being in my belly. I used to sing to him every day and I used to always fondle my belly and things like that…when I was born my father neglected me. So I feel that maybe deep down somewhere part of me felt that how could someone do that to their own child… Because I never deviated from wanting B. Like it was just don't even talk to me. I remember when you guys would come in, "no I don't care. No I want him"...Because I was so certain…So for me it didn't need to be asked that often because I was so adamant about wanting him.'*
>
> (Mother of 25-week boy)

Some parents expressed that the baby deserved the opportunity of life, and this is the human instinct of the parent, with regrets if the opportunity was denied:

> *'You know if you didn't resuscitate it would always be in your mind "what if?" You know you've got to give everything - everything deserves a chance in life no matter what it is - what the problem. Especially in human life you've got to do something. You just can't let someone not have a chance to breathe. You've got to give them that breath of air and see if they want to take it. She took it and she's still here. I wouldn't regret not telling to do that. No, it's just human instinct.'*
>
> (Father of 26-week girl)

This single mother of twins agreed with even the smallest chance of survival. Her family supports helped with the decision to continue active care:

> *'I knew it was going to be hard even if they were perfect, which they are now, to raise them by myself. But then having two and a Down syndrome [there were concerns one baby was at risk of this], it was, I weighed up the odds and I spoke to my older sister, and that's when she said "We are here. I would just say do what you can to save them" ...Even if there is even a one percent chance, I say go for it.'*
>
> (Mother of 24-week twins)

5.13.3 ‘Decisions as a power tool’

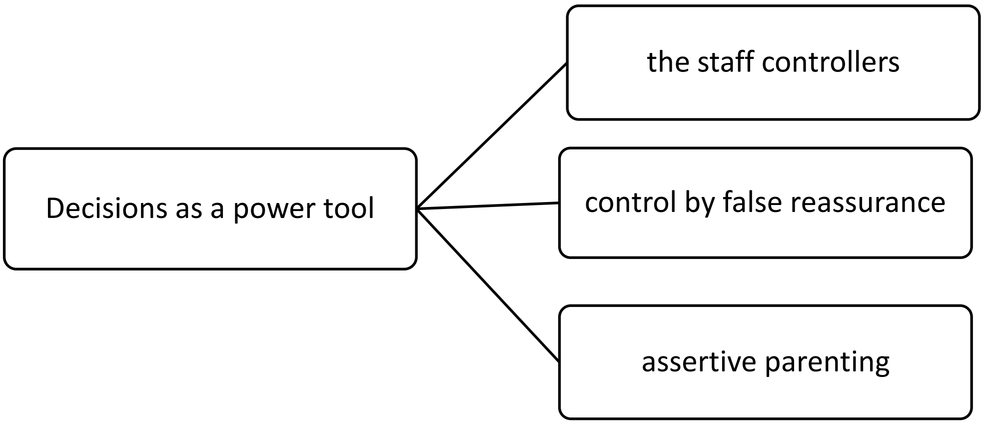

Figure 5.9 The subcategory of ‘decisions as a power tool’.

Data suggesting that staff use their power to make decisions without adequate recognition of parental concerns was evident in most of the interviews. This subcategory is informed by further subcategories of ‘the staff controllers’, ‘control by false reassurance’, and ‘assertive parenting’ (Figure 5.8).

5.13.3.1 The staff controllers

Staff have the specialist knowledge and skills to care for the infants who are too immature to be cared for at home by their parents. Many decisions are made daily to optimise the condition of the baby, and few parents will be able to contribute to the more technical decisions. However, some of these decisions were potentially within parental remit and capacity. There seemed to be a lack of acknowledgement of parental autonomy in these insights and decisions, with the medical staff controlling parents’ decisions by their actions.

One father remained angry when he had booked the airline ticket to return home, but the nursing staff replaced the nasogastric tube overnight, effectively preventing his well daughter remaining on full oral feeds, and delaying discharge:

> *'It was coming close to coming home and I got told if I took my daughter to the airport she would die. There was no: "if you take her there is a possibility she would become severely ill"...so after you have spent two and a half months waiting for your baby to come home and you are told your baby could die…I felt we knew she was ready, we knew she was only there to put on some more weight…It was just us knowing our baby was ready, whereas the nurses were "oh well, we will just keep it, just in case"'*

Whilst the discharge date might be a major decision, some decisions have no real medical significance and occur at relatively arbitrary times during the baby's course. These might appear to be insignificant to staff, but for this mother, some of these 'minor' decisions affected her emotionally as she expressed feelings that she was excluded from participating in the decisions:

> *‘I know a lot of the other parents were doing a lot of reading and stuff and that’s really sweet. I did a bit of that, but my mum always told me you know the best thing you can do to help healing is to rest and so that is the thing I tried to do for him, was to always make sure his cot was covered. Because that room was so bright and everyone would talk about how wonderful it was that we had such a bright room. Maybe if they just discussed those things with me a bit more before they happened, like the move to a bigger cot, and the change into the bath and stuff like that. Really, just to, maybe rather than someone come along and go “Right, we are going to do this now”. Maybe it would have been nice either just the day before to be told “We think he is ready” and make it sound like its more than just one person deciding.’*

(Mother of 26-week boy)

For some there is a recognition that they make few decisions. This mother described an otherwise uneventful and peaceful stay in the unit:

> *‘I don't think you get a lot of decisions once bubby's here’.*

(Mother of 26-week girl)

Other decisions are clearly within the scope of parental autonomy. One concerns immunisations which are routinely offered at the usual time after birth according to the immunisation schedule. This mother reported that she had been coerced into eventually agreeing to have immunisation done at nine weeks of age. Her child is profoundly disabled and she is worries that immunisations may have contributed to the disability as concerns about ‘vaccine damage’ form part of her belief system:

> *'I'm angry that I immunised him. At 32 weeks, I immunised my child with a full-term dose of immunisation. Even though I said, "No, I don't want it", I kept saying, "I don't want to immunise him. Can we just wait till he's meant to be born?" "We'll do it when he's meant to be done. No, no, you're in the NICU. This is where it needs to be done". Like I've spoke to other parents who didn't immunise in the NICU that were in Townsville. I'm like, "How did you get away with that?" I was basically forced. I felt like I didn't have any choices there.'*
>
> (Mother of 23/24-week boy)

5.13.3.2 Control by false reassurance

False reassurance can also be a tool to ensure that parents agree with a management plan. This mother whose child had many poor prognostic features, had asked to redirect care during an episode of severe sepsis:

> *'So if he had had bad scans, I would have not continued…I said that at the time. I was like the only thing keeping me here is those scans, those head ultrasounds…No-one ever came and tapped us on the shoulder and said that this isn't going so well or we're not really sure. It was all very positive. No-one ever said anything negative or discouraged us or told us that really made us acknowledge what we were doing. It was more like, oh, and then you should see them when they're at one. You'll forget all this happened. There's a lot of fairy land going on in there where they're telling you about the miracle stories... Obviously, all the people that they tell you to talk to or your friends are like, I know someone that was born at 24 weeks and he's fine. No-one tells you the other ones…"Well, we have had some children that have left here with clear brain MRIs with significant disabilities who have gone on to need full care, PEGs, lots of support, lots of respiratory issues, lots of ICU stays and the parents have been thrown into turmoil." That's the reality of it, but no-one's telling you that. The only thing that gives you an indictor are those PIPA things [parent information pamphlets from a premature baby parents organisation]. If you actually read the back and you start reading through them, you'll start to see that they're all not fine.'*
>
> (Mother of 23/24-week boy)

5.13.3.3 Assertive parenting

Assertive parenting occurred, often towards the end of the neonatal stay, with decisions being made by parents often conflicting with staff decisions. Discharge is often a point of conflict. One mother indicated that the baby was unnecessarily being detained at the hospital. She challenged this by her actions until the baby was discharged several days later, and earlier than staff had expected:

> *'I made my decision I was bringing my son home from the hospital. Didn't tell them. Went in to the 10 o'clock cares like I did every night. Did his boob feed and then the nurse asked a question something about "Oh when are you coming back?" I said "I'm not going." She goes "what do you mean?" I said "I'm staying…She goes "Oh excuse me" and she went off and came back and she goes "oh well this doesn't mean anything. You're not going home."'*

(Mother of 26-week boy)

Parents realised that participating and understanding decisions was helpful during the stay.

> *'It was good where you would come on and do your rounds and stuff. I think that really important to talk to the consultant because we go on what you say and guys make the decisions and being able to ask questions around why decisions are made and what decisions aren't made and why and "can we look at this or could we not look at that."'*

(Father of baby who died at 3 months)

Parents who became assertive, particularly towards the end of their neonatal stay were noted to have much more confidence when discharged, describing the return home as very positive. Empowerment represents good and appropriate attachment for these families

5.13.4 'Regrets'

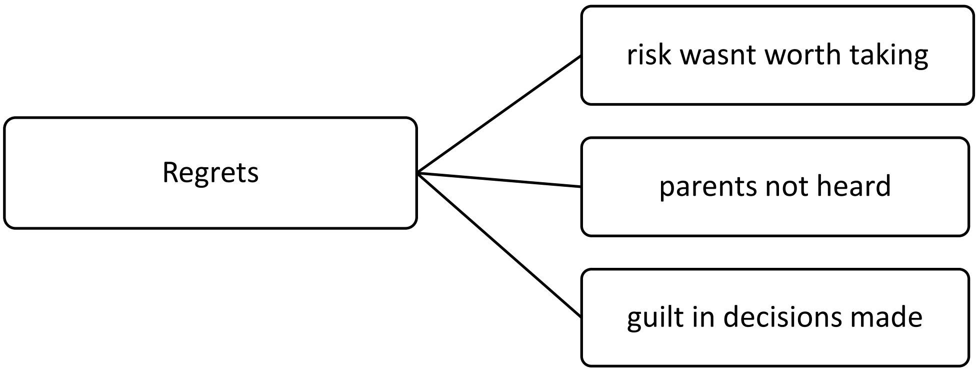

Figure 5.10 The subcategory of 'regrets'.

Parents voiced regrets in decisions made both to continue active care and to redirect care towards palliation. The participation of the parents in these decisions reflects the further subcategorization seen in Figure 5.10.

5.13.4.1 'Risk wasn't worth taking'

Prior to delivery of their periviable baby, few parents had much knowledge about extreme prematurity and the potential outcomes. Some parents, whose babies have done very well described how they 'dodged a bullet' and others indicated that if they had really understood the potential consequences, they would not have opted for active care.

> *'If I had known...now I would say no. "Please do not resuscitate". From a mothers perspective you want this baby to be alive. Because you don't have the knowledge as to what's going to happen in future or what happening in the baby's brain. You want the baby to be alive…But I think the knowledge of knowing the implications would have been different you know.'*
>
> (Mother of surviving 24-week twin boy)

5.13.4.2 Parents not heard

Several parents requested redirection of care during the neonatal course. For two mothers, who had requested this during a time of marked physiological instability of the baby, the doctor decided continuation of care was in the best interest of the baby. The doctor believed that there was no reason to believe that the prognosis warranted redirection despite the worsening condition of the baby due to severe sepsis. Both have severely handicapped children requiring continuous care. One mother discussed this event at length, and her current concerns:

> *'At 2 am N [the neonatologist] came in and chatted to us. That was when I'd said…" I'm not going up there anymore. I can't do it anymore. I'm done. I don't want to play this game. I'm out. I want to go" ... Then they said, "Take a break. Take a day off" ...I'd rang my sister and said, "I'm done. I'm calling it. He's gone back on the ventilator and this is it. If I don't call it now…" I think he was like eight weeks…Even there, just sitting with him, he's like, look, I can't - his [N] stories were also so positive…but, like, kids come in here and I see them crash. I think how could you crash that bad and be okay? Then N goes, "And then they're okay."'*
>
> (Mother of 23/24 week boy)

After discharge from the unit, the baby had multiple health concerns. Here the mother reflects on an interaction with a doctor sometime later:

> *'All they can see is that one hour. Sometimes your kid behaves the best in that hour. It doesn't matter what I tell them. They're looking at him, going,' oh, he looks all right to me'. You're like, 'but he screams all night. He doesn't sleep. He's in pain., He tosses and turns in his sleep. He has to sleep on one of us. We have to sit up - one of us sits up with him all night and then we swap over. We have to drug him and all these things. How can this be life?'*

Admissions to intensive care for respiratory distress have continued. This mother's perspective on decision-making has now changed. She describes how each time he is readmitted to intensive care she is asked if care should continue, but she does not want to have the burden of making this decision as she has a close bond and deciding to redirect care will result in guilt she cannot bear:

> *'I didn't want to make the call. I didn't want to be the one that did it. So when I hear people say that they didn't make it and I think, well, you know what? You're one of the lucky ones, because you didn't make the call. It got made for you. It just happened…. Yes, I needed that. I needed you (the doctors) to hold it and carry it and to say it, how it was going to be, especially when he had the negative Gram infection [in the neonatal unit]…I'm afraid of him living and I'm afraid of him dying. Either way, we've been living it for six years and it's like our NICU experience never ended. It just extended and extended and extended.'*
>
> (Mother of 23/24-week boy)

5.13.4.3 Guilt in decisions made

Parents who make informed decisions may later regret participating in these decisions. Guilt at being the decision maker had remained with several parents where the baby died. Denying their baby life, in retrospect, had led these parents to consider that living would have been preferable for the baby, even with disability.

This father was asked to consent to steroid administration to reduce inflammation and facilitate extubation from the ventilator when his baby was developing chronic lung disease. He had concerns about the potential side effects of the steroids and did not give consent:

> *‘the thing I live with as well is the steroid situation. Part of me wishes I just let you guys do your thing instead of getting in the way, which another thing I regret…I just knew I got in the way because they talked about stunting the growth and that sort of jazz but looking back on it now I wish I just got out of your way a little bit, you know what I mean?…I was in a situation where I knew nothing about what I was in, yet I felt like a father and had to still do what is right for his child. Even though I know I am very open with you guys when we are going all through it but it's just me looking back and saying, M, maybe if you just let them...[give steroids]. I was like, did that set him behind a bit…that was when big decisions had to be made, and I still live with them to this day. They haunt me some of them, you know what I mean.*

Another mother reflects on the death of her 24-week twin from a previous pregnancy, which occurred several years before the birth of the baby who was the participant in the study:

> *'I regret that decision. When it all happened, it was really overwhelming…they showed us the brain scan and said what her possibilities were. In that moment - in 24 hours [before redirection of care] I don't think was long enough to digest that. It was like, okay, well I really - that's a decision that D and I have always regretted, just given that I've seen what the outcome can be. I regret not - sorry. I wish that - I probably would have just said no, to letting her go…I feel like in that instance I was given all the information and I felt like that, okay she wasn't going to have a quality of life, and it was explained very well to me about what her life would be like. She would be a vegetable, she would be all of these things. So, I had all that information but I feel like I made that decision and then it was too late once - afterwards. I always wish that I had just given her a fighting chance… I do think parents should be given the option, because at the end of the day it's the parent that has to care for the child if that's the option. I do think - but maybe a little more time needs to be given, I think…They're going to take the journey, whether it be short or long. They need to be the ones to say, yes push on with that, or no I don't think I can cope with that. Even though it's a highly stressful situation, I think that that's your child. You deserve to have that choice.'*

5.14 Discussion on the 'Decision-Making' Category

Decision-making is the central objective of this thesis, and I situate the findings for this section in Chapter Eight where aspects of decision-making from the studies are integrated. This discussion reflects the data presented here, but most of the positioning within the literature appears in the later chapter.

Delivery at extreme prematurity is a unique experience for each set of parents. Parents' opinions about decisions will reflect their own experiences and, in this thesis, are heard with the benefits of hindsight. Most, but not all, parents were satisfied with decisions made to resuscitate their own baby, regardless of the long-term outcome. The parents who did not feel that decisions around active care were appropriate tended to have severely disabled children, but even parents with healthy children suggested that they had 'dodged a bullet' and one voiced that she would not have wanted her babies to be resuscitated given her current knowledge. The two unhappy parents with severely disabled children had requested redirection of care when the baby was acutely unwell following initial resuscitation, a request which had not been sanctioned by the medical staff. A further baby where redirection did occur, had this redirection to palliation at another hospital where the baby was having a subspecialist opinion on his airway abnormality. The parents of this baby had long been concerned about the potential for developmental impairment.

At the time of initiation of intensive care, many parents indicated that the medical team should have final decision-making around resuscitation, trusting the doctors involved to be able to decide if the baby would have a good outcome. The terms 'no-go' baby and 'unfavourable outcome' suggest a lack of understanding about the nuances in the probability of healthy survival, and may indicate that the parents were discussing futile care, but this was not clear to me from the research. The issue of futility itself was different for different families – several parents indicated a one percent chance of survival, or healthy survival was enough to promote active care within their beliefs. One father recognised that health care professionals may not all follow the same objective measures to initiate active care, and the doctor caring for his children was more aggressive in his management than others would have been. One mother, however, understood that there were rules which regulated what was done.

Other parents said that informed parental decision-making was preferable to health care driven decisions. Where mothers articulated that they had made decisions to initiate or continue active care, all had a history of infertility, pregnancy loss or previous life events which resulted in a determination to promote intensive care for the baby. Most, but not all, of these mothers had had sufficient time to reflect on the potential outcome for the baby prior to the birth. Religious and cultural beliefs of some parents underpinned the belief that active care should always occur.

Informed decision-making could only occur where counselling occurred in situations where the mother was not in pain, distracted, or concerned about her own survival. The importance of appropriate timing was recognised by one participant who discussed that she would 'jump off a bridge' if requested to, to get the neonatologist to stop talking, as she was exhausted and no longer receptive to the discussion.

Where collaborative decision-making occurred, or parental consent was sought, some parents said that they would feel too guilty to decline treatment. For one parent, where parental consent was sought for a treatment with the risk of side effects unacceptable to the parents, the father now has regrets that he declined the treatment, and has guilty feelings that his child died because of his decision.

An underlying impression is that many decisions are made on the health professionals' terms, whether this is the timing of counselling, or the limitations of the decisions which could be made. This occurred for wide range of decisions; about active care, redirection of care, immunizations, the location of the baby and discharge home. This led to disempowerment of the parents.

The consequences of the decisions made were recognised to ultimately lie with the family. For families with severely disabled children, the data showed the all-consuming nature of the disability for the family.

Parents were unable to articulate collaborative decision-making within the neonatal unit, although this was identified antenatally. It is possible that decisions which were made together with parents were not recognised as memorable because the parents were satisfied with the outcome of the decisions.

5.15 Theory Derived from the Family Study

- Most women who deliver at periviable gestations will have predetermined attitudes towards the risk of disability following delivery; associated with their prior fertility history, previous considerations about the potential for abnormality from earlier pregnancy scans or informed by their own cultural and spiritual background. This was seen across all socioeconomic groups and ethnicities. Women may be able to situate themselves in a decision-making position more rapidly if counselling harnessed these preformed attitudes.

- Parents who cede decisions about the resuscitation of their periviable babies trust the HCP to act in their best interests, unaware that a clinician may have their own beliefs and biases and may not themselves know what constitutes the best interest of family and child.

- Disempowerment of parents will occur as the parent cedes care of the baby to the HCPs. This is enhanced by negativity towards the outcome where parents need hope, and the adultification of the baby rather than the acknowledgment of their existence as a vulnerable dependent. Disempowerment allows the HCP to hold power over all decisions, even minor ones. Decisions made under these circumstances may become a source of anger and regret to the parent once they are empowered to parent their child.

- Perinatal suffering and futility of care are concepts which vary for each parent and do not equate with medical concepts of futility. Within this framework, parents may be given some choice about the provision of active care prior to delivery. Following the birth, however, parents are not given the same options at a time when the risks of disability have clearly increased, and the baby remains dependent on external support to survive.

5.16 Summary of the Family Study Chapter

Families who participated in this study had a range of experiences and opinions about both their own neonatal care experience, and periviable care in general. All participants had reflected on the time post birth where decisions were made, and had adapted to life after the NICU admission. Interviewing parents some years after admission allowed sufficient time for these reflections to have occurred once serious consequences of the care were evident. This enabled the parents to position the reflections within their later family experiences with the baby. The next chapter (Chapter Six) explores the attitudes of health care professionals. The findings of Chapter Five, along with the following two chapters will be integrated as phase three of the multi-phase study, in Chapter Eight.

Chapter. 6 Attitudes of Health Care Professionals Towards Extreme Prematurity

The parental perspectives on aspects of neonatal care were presented in the previous chapter. A further component of Phase Two was exploring the perspectives of staff who care for women with vulnerable pregnancies and babies. The convergent mixed methods study researching attitudes of health care professionals (HCPs) towards extreme prematurity is presented in this chapter. The quantitative study has already been published and is presented initially, followed by the qualitative study. One category of the findings of the qualitative study has been published, and all relevant categories are presented here. A merging of the findings rounds out the chapter.

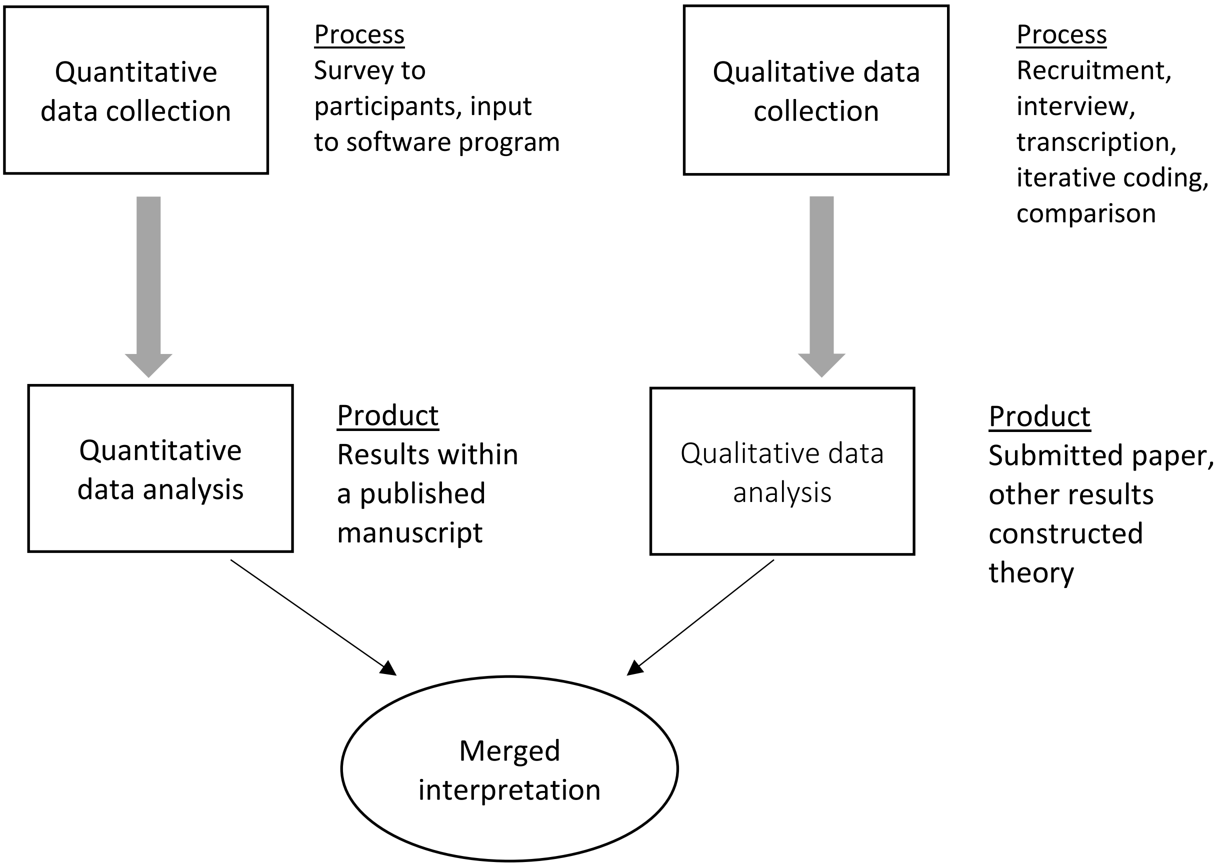

Figure 6.1 Convergent mixed methods design exploring HCP attitudes and knowledge about extreme prematurity.

The Quantitative Study

The outcomes of this study and the importance of message framing and informed judgements about long term survival and chances of disability when counselling prospective parents are discussed in the published journal article. The manuscript has been reproduced word for word but formatted to the style of the thesis, and some of the publication manuscript requirements (for example, funding details) have been omitted.

> Ireland, S., Larkins, S., Ray, R., & Woodward, L. (2020). Negativity about the outcomes of extreme prematurity a persistent problem-a survey of health care professionals across the North Queensland region. *Maternal Health, Neonatology and Perinatology*, *6*, 1-10. https://doi.org/10.1186/s40748-020-00116-0

Negativity About the Outcomes of Extreme Prematurity a Persistent Problem - A Survey of Health Care Professionals Across the North Queensland Region

6.1 Abstract

Background

Extremely preterm babies are at risk of significant mortality and morbidity due to their physiological immaturity. At periviable gestations decisions may be made to either provide resuscitation and intensive care or palliation based on assessment of the outlook for the baby and the parental preferences. Health care professionals (HCP) who counsel parents will influence decision making depending on their individual perceptions of the outcome for the baby. This paper aims to explore the knowledge and attitudes towards extremely preterm babies of HCP who care for women in pregnancy in a tertiary, regional and remote setting in North Queensland.

Methods

A cross sectional electronic survey of HCP was performed. Perceptions of survival, severe disability and intact survival data were collected for each gestational age from 22 to 27 completed weeks gestation. Free text comment enabled qualitative content analysis.

Results

Almost all 113 HCP participants were more pessimistic than the actual outcome data suggests. HCP caring for women antenatally were the most pessimistic for survival ($p=0.03$ at 23 weeks, $p=0.02$ at 25,26 and 27 weeks), severe disability ($p=0.01$ at 24 weeks) and healthy outcomes ($p=0.01$ at 24 weeks), whilst those working in regional and remote centres were more negative than those in tertiary unit for survival ($p=0.03$ at 23,24,25 weeks). Perception became less negative as gestational age increased.

Conclusion

Pessimism of HCP may be negatively influencing decision making and will negatively affect the way in which parents perceive the chances of a healthy outcome for their offspring.

Keywords

Extreme prematurity, attitudes, outcomes, resuscitation, decision-making, mortality, morbidity.

6.2 Introduction

Delivery of an extremely premature infant below 28 weeks completed gestation is uncommon, affecting less than one percent of babies born in Australia (Bolisetty et al., 2015). Depending on the jurisdiction, a ‘grey zone’ exists between 23 and 25 weeks completed gestation where the risk of death or significant disability necessitates careful thought between the provision of intensive care or the option of palliation for these infants, and resuscitation below 23 weeks is usually discouraged (Haward et al., 2017; Lui et al., 2006; QCG, 2014; Wilkinson et al., 2009). The decision to provide intensive care requires consensus between the treating teams and the parents of the baby, and health care professionals (HCP) provide counselling to the parents prior to decision making. Few parents who face early delivery have adequate medical knowledge to enable them to make any decisions alone, therefore the knowledge of the HCP about both the potential outcomes in terms of death and disability for the baby is essential during counselling (Haward, 2017). Where a decision is made to provide active care, obstetric care including antenatal steroids and magnesium sulphate administered to the mother, as well as consideration of operative delivery for babies in distress may improve the prospects of healthy survival (Håkansson et al., 2004; Serenius et al., 2015).

With technological advances and enhanced quality of care, the outlook for these vulnerable babies is improving over time (Doyle et al., 2010b) and thus HCPs need an awareness of contemporaneous and locally relevant data. In addition, parental requests for the provision of active care for babies from 22 weeks completed gestation are recognised in Australia (Sharp et al., 2018) and elsewhere (Mehler et al., 2016; Younge et al., 2017). HCPs will therefore also potentially need an approach to address this parental demand.

Early Australian studies on the knowledge and attitudes of HCP focussed primarily on the tertiary obstetrician and neonatologists (Mulvey et al., 2001; Munro et al., 2001; Oei et al., 2000). However, it is now acknowledged that a wider range of HCPs may also influence parental decision making including midwifery staff and neonatal nurses as well as clinicians involved in care prior to transfer to a tertiary hospital (Boland et al., 2016; Kavanaugh et al., 2010). These studies suggest that HCPs tend to be negative and have a lower expectation of both survival and morbidity than is the case, with obstetricians being the most negative and neonatologists more optimistic. A more recent study (Boland et al., 2016) included obstetric and midwifery staff at level 1 and 2 hospitals but no junior obstetric staff, and the neonatology staff of the retrieval service. This study suggested clinicians continued to overestimate rates of adverse outcomes. Message framing will influence parental decision making and outlook, and clinicians with negative perceptions are likely to both convey this to the parents (Haward et al., 2008) and manage the pregnancy and baby accordingly (Guinsburg et al., 2012; Morse et al., 2000). Individual clinician personality and bias towards poor outcomes will also affect message framing (Morse et al., 2000).

Parents of extremely premature babies who are beyond the ‘grey area’ of decision making will also need accurate information and consistency from HCP about the potential outcome for their child, as extreme prematurity will have a considerable impact on the parents’ future lives (Roscigno et al., 2012), particularly where the care is often provided far from the family home.

This study aims to investigate the knowledge of HCP and ascertain their attitudes towards the provision of care for extremely premature babies, including which factors staff feel should be considered when offering, or not offering, intensive care in North Queensland.

6.3 Methods and Analysis

A cross-sectional electronic survey of HCPs was administered on the SurveyMonkey platform (SurveyMonkey Inc. Ca. U.S.A.). HCP at three centres in North Queensland were invited to participate.

The study centres include the largest provider of tertiary neonatal care in Northern Australia, one of two regional referral centres and a remote hospital. The tertiary hospital provides care for babies of all gestations and offers care for babies with surgical and medical conditions. It cares for all babies who receive neonatal intensive care below 28 weeks gestation in North Queensland. More than half the parents delivering extremely preterm babies reside within other health districts, and nearly a quarter are retrieved following delivery at smaller health care facilities (Ireland, Ray, Larkins, & Woodward, 2019). The regional referral hospital is a regional hospital that offers care for babies over 32 weeks gestation, whist the other referral hospital is a small remote centre which can offer only low acuity care to babies over 32 weeks gestation. The three sites were chosen as they represent the range of hospitals staffed by resident obstetric and paediatric services. The non-tertiary sites often need to refer women with vulnerable pregnancies to the tertiary hospital for care but will be required to provide initial care to periviable babies who cannot be transferred to the tertiary units in-utero.

Following identification of a pregnancy at risk of extreme prematurity, parents are counselled by senior obstetric and neonatal staff, including potential outcomes and the expected neonatal course. Those pregnancies in the ‘grey zone’ are identified, and options to provide full intensive care or palliation are discussed. Parents are also given the option to initiate full resuscitation, with the option of redirecting care either during resuscitation or on the neonatal unit, where the baby is in poor condition or appears to be significantly compromised. Where there is potential for resuscitation, obstetric actions to optimise the condition of the baby are initiated. Decisions to resuscitate often involve several discussions, during which time the woman will be cared for by midwifery staff, and the neonatal unit is toured together with a neonatal nurse. Where the family is from a peripheral centre, often only brief counselling is given prior to transfer and tertiary obstetrician review.

6.3.1 Survey design

The survey was designed with questions about the demographics of the respondent including primary location of work, work stream, experience, social contact with people with disability and whether their religious beliefs influenced their decision making. Respondents were asked; i) whether they cared for pregnant women under 28 weeks gestation who were at risk of premature delivery; ii) if they had ever been asked by a parent for their personal opinion about whether a baby should receive intensive care or palliative care; and iii) their confidence in discussing extreme prematurity with patients. Further questions explored their knowledge of rates of; i) survival; ii) severe disability; and iii) intact survival at different gestations from 22 to 27 weeks completed weeks gestation. Replies to survival and outcomes were given as one of five quintiles in 20% divisions as it was considered less intimidating to participants than asking for exact estimates, whilst still being accurate enough for analysis. Participants were asked to rank their opinion about other factors which may influence the decision to offer intensive care to extremely preterm babies, and give an opinion about the most appropriate gestation from which intensive care should be offered to premature babies, at which gestation parents could be sole decision makers, whether staff could override parents' wishes, and the gestation at which the participant would want a potential extremely premature baby of their own to be resuscitated. Free text was allowed for participants to expand on their replies. Although similar studies are found in the literature, the questionnaire was not based specifically on any of these as none captured all the data of interest. All gestations of babies from 22 to 27 completed weeks were included although resuscitation is usually provided at the older gestations.

The survey was piloted with a group of senior nursing and medical staff and a psychologist involved in neonatal care to assess face validity and adapted to ensure clarity.

6.3.1.1 Participant recruitment

An email link was sent by the primary investigator to all neonatal, paediatric and obstetric medical staff specialist or doctors on college training programs at the tertiary centre. Senior nursing managers sent the link to registered midwives and neonatal intensive care nurses at the tertiary centre and a research co-ordinator at each of the smaller centres sent the link to obstetric, midwifery and paediatric staff. A second email was sent two weeks later to promote participation. It was not possible to identify which staff had responded to the link, beyond the demographic data related to work stream.

6.3.1.2 Data analysis

The survey data were imported directly from the survey tool and were analysed using IBM SPSS 25 (Armonk, NY, USA). Analysis used frequencies for numerical data. Chi square was used for categorical variables. Where categorical data with multiple ordinal responses occurred, Kruskal-Wallis H test to compare means was utilised. Significance was defined as $p<0.05$. A comparison was made between HCP who care for women primarily prior to delivery - obstetrics and midwifery staff (referred to as antenatal HCP), and after delivery – neonatologists, neonatal nurses and paediatricians (who were included as they provide counselling at the non-tertiary centres and at the tertiary centre provide neonatal care on the postnatal wards), referred to as postnatal HCP. Questions about factors which may influence opinions positively or negatively towards resuscitation were given as a Likert score, with scores of very likely and likely to imply a positive influence to offer intensive care, a score of neutral was considered to indicate that the factor was not contributory to the opinion, whilst an unlikely or very unlikely score was considered to indicate the factor would make the HCP less likely to agree with resuscitation. Missing data were excluded from analysis. Content analysis was performed on the qualitative data using a process of coding for thematic classification.

6.4 Comparison Data

The tertiary unit studied had outcomes for survival and all short-term morbidities within the expected range for units within the Australian and New Zealand Neonatal Network (ANZNN). The ANZNN data collection is a collaborative network established under the recommendation of the National Health and Medical Research Councils Expert Panel on Perinatal Morbidity (NPESU, 2019). For this study, data from the tertiary unit database for the years 2013 to 2017 inclusive have been used for survival. Long term follow-up for babies born from 2011 to 2014 inclusive were considered. Follow up data for the tertiary unit are around 50% for all gestations due to difficulty in getting patients long term data from outside the district. The data given in the ANZNN comparative database suggests that outcomes for severe disability for the tertiary unit compares positively to the mean for the ANZNN group. The mean rates for severe disability and typical development for the ANZNN have been used for expected long term outcomes because of concerns that the lower follow up rate of the tertiary unit might be a source of positive bias where more regional and remote children are excluded.

6.5 Ethics Approval

The study was approved by The Townsville Hospital Human Research Ethics Committee HREC/15/QTHS/194, and acknowledged by James Cook University (JCU) ref 6485. Governance approval was given by all participating sites and JCU.

6.6 Results

6.6.1 Participants

E-mails were sent to 174 potential participants, with 113 replies (total response rate 64.9%). Demographic details are shown in Table 6.1. Not all participants answered all questions.

Table 6.1

Demographics of respondents to survey n = number of respondents.

Demographic	Variable	Number
Location – respondents at each site/number invited to participate n =113	Tertiary centre	74/116 (64%)
	Regional centre	17/30 (57%)
	Remote centre	22/28 (79%)
Work stream n =112	Midwifery	41 (36.3%)
	Obstetrics	17 (15.0%)
	Neonatal nurse	28 (24.8%)
	Neonatologist	5 (4.4%)
	Paediatrician	21 (28.6%)
Contact with women at risk of extreme prematurity n =113	Yes	104 (92.0%)
Duration of work experience in years n =112	<1	11 (9.7%)
	1-5	27 (23.9%)
	>5-9	24 (21.2%)
	10+	50 (44.2%)
Confidence in knowledge of implications of extreme prematurity n =112	Not Confident	30 (26.8%)
	Neutral	17 (15.0%)
	Confident	65 (58.0%)
Ever asked for personal opinion about resuscitation by a woman at risk of extreme prematurity (numbers asked/total respondents) n =110	Midwifery	17/41 (42%)
	Obstetrics	13/17 (77%)
	Neonatologist	4/5 (80%)
	Neonatal nurse	13/28 (46%)
	Paediatrician	11/21 (52%)

Some participants did not complete all aspects of the survey – with midwives and those from outside of the tertiary centre less likely to answer all questions. For different gestations, 81-91% of antenatal HCP, and 90-98% post-delivery HCP answered survival questions, 64-72% of antenatal HCP and 83-90% postnatal HCP answered severe disability questions, 59-67% of antenatal HCP and 77-87% postnatal HCP answered questions about intact survival. There was no clear pattern in gestational age for the missing data. Survival questions were answered by 89-97% by the tertiary group and 79-90% by the non-tertiary participants. Severe disability questions were answered by 78-84% by the tertiary group and 62-74% by the non-tertiary group, and the intact survival questions answered by 69-81% by the tertiary and 56-69% of the non-tertiary group.

Whilst 92% of the HCP had contact with women at risk of extreme premature delivery, only 52.8% had been asked for their advice about the resuscitation of a baby. Over half of the study group had personal contact with a person with severe disability, but few acknowledged religious beliefs shaping their opinions. Almost all the neonatologists and obstetricians had been asked for their personal opinions by patients about whether the parent should opt for active care. Excluding them, there were no significant differences between work streams, location or level of experience for being asked an opinion about intensive care provision, or with confidence in knowledge.

Participants were asked to indicate whether specific factors would positively or negatively influence their propensity to offer intensive care to extremely preterm babies (Table 6.2).

Table 6.2

Factors which might influence HCP to be more likely (positive influence) or less likely (negative influence) to consider intensive care to be appropriate.

	Negative influence	Neutral	Positive influence
Parents request intensive care, clinician feels it is not in baby's best interest n=97	21 (21.6%)	9 (9.3%)	67 (69.1%)
Clinician promotes intensive care where parent does not wish provision of NICU n=96	36 (37.5%)	21 (21.9%)	39 (40.6%)
Low socio-economic family n=97	4 (4.1%)	87 (89.7%)	6 (6.2%)
Mother under 20 years of age n=97	2 (2.1%)	89 (91.8%)	6 (6.2%)
Mother over 40 years of age n=97	1 (1.0%)	85 (87.6%)	11 (11.3%)
Children in state care n=97	15 (15.5%)	76 (78.4%)	6 (6.2%)
Known surgical anomaly usually provided care at term n=97	58 (59.8%)	30 (30.9%)	9 (9.3%)
Known trisomy 21 n=97	54 (55.7%)	35 (36.1%)	7 (7.2%)
Previous pregnancy loss n=97	1 (1.0%)	63 (64.9%)	33 (34.0%)
No live children n=97	2 (2.1%)	61 (62.9%)	34 (35.1%)

The gestational age at which the participant would offer NICU to a patient was significantly lower than the gestation at which HCP would choose for themselves. HCP considered that 24 weeks (IQR 24-25) was an appropriate lowest gestation to offer parents, with midwifery and paediatric staff considering 25 weeks (IQR 24-26) and obstetricians and neonatal nurses choosing 26 weeks (IQR 25-26 and 24-26 weeks respectively). There were insufficient neonatologist responses to analyse. For all HCP, a choice from a gestational age of 25 (IQR 24-26) compared to offer for patient 24 (IQR 24-25) was significantly different p=0.00.

Table 6.3

HCP opinion about the gestation at which they considered that parents could be the final decision makers for decisions about care. Data expressed in numbers (percent).

	Informed parent can make final decision n=83	**Clinician can make a final decision regardless of parental preference n=82**	**P value**
Never	32 (38.6%)	13 (15.9%)	0.01*
<25 weeks	45 (54.2%)	53 (64.6%)	0.47
25-28 weeks	6 (7.2%)	16 (19.5%)	0.04*

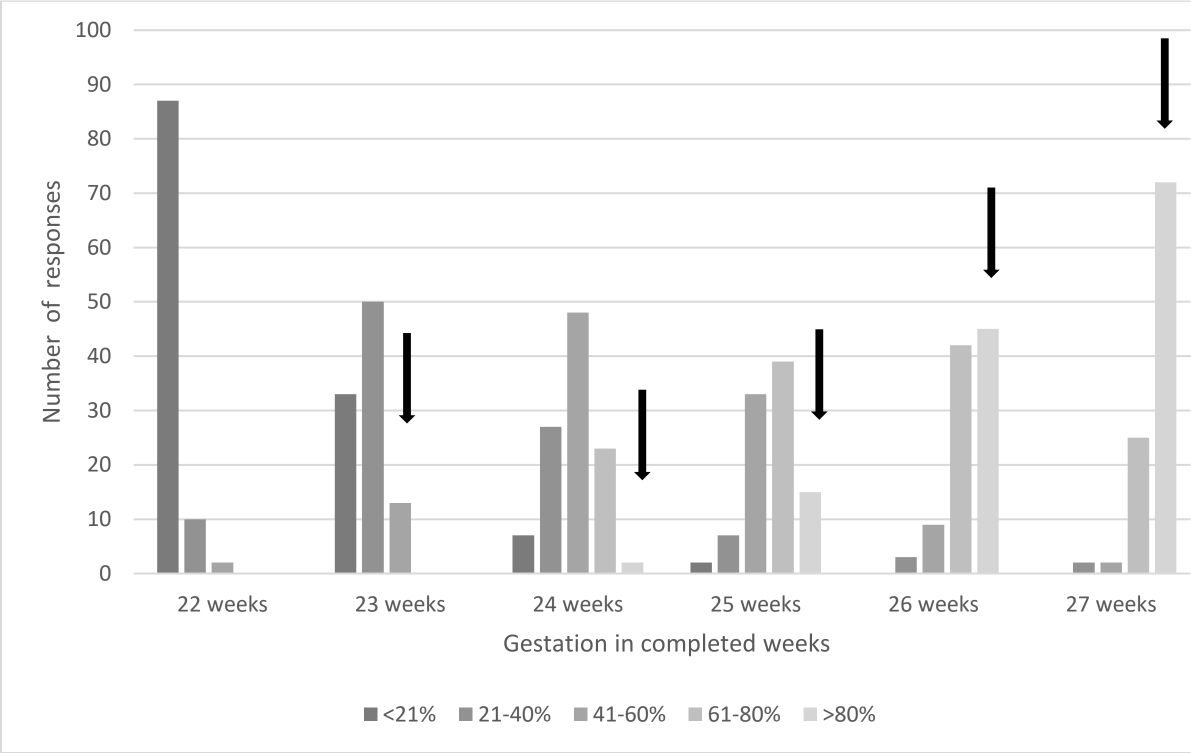

Figure 6.2 Estimates of survival at different completed weeks gestation, with responses given in quintiles.

Accurate survival figures represented by the solid arrow indicating actual survival quintile based on data for the tertiary unit for the years 2013 to 2017 inclusive. Responses to the left of the arrow indicate a negative understanding of the survival rates for each gestation. Data not given for 22-week gestation babies as the numbers treated were small.

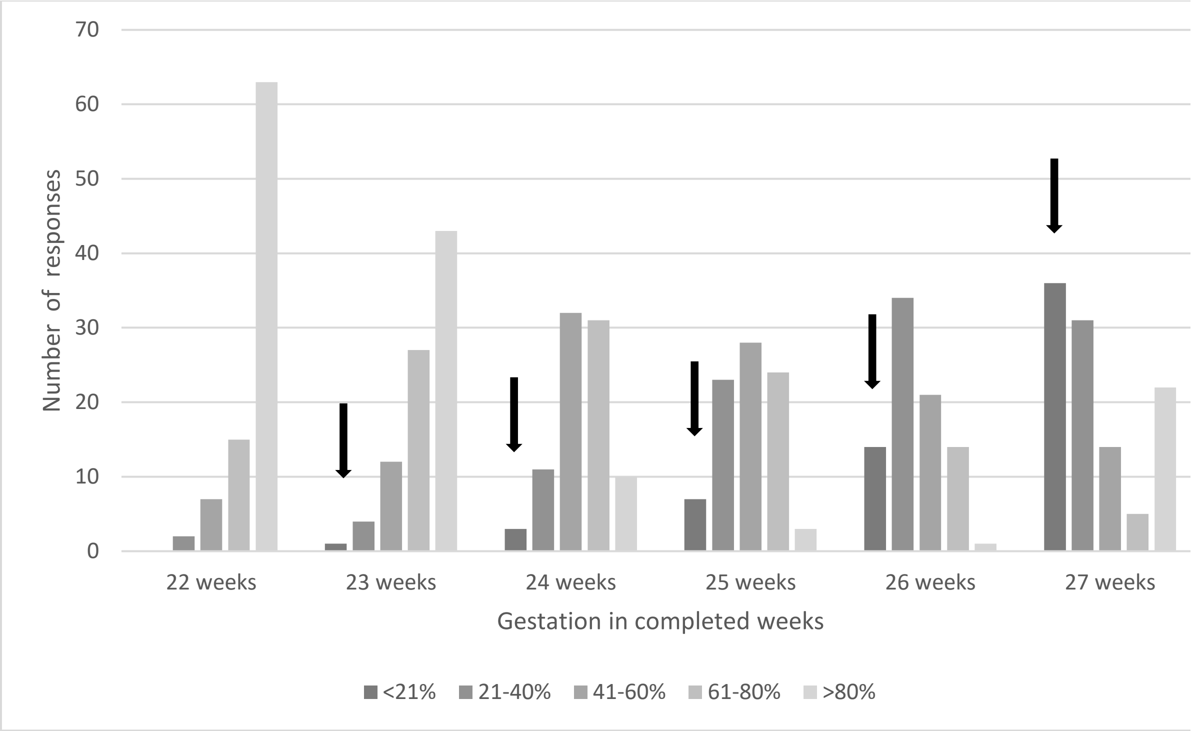

Figure 6.3 Estimates of severe disability in quintiles given by participants.

The quintile based on ANZNN data for babies born from 2011 to 2014 inclusive is represented by the solid arrow. All responses to the right of the arrow represent negative estimates of severe disability. Data for 22-week gestation babies is not given in the ANZNN database.

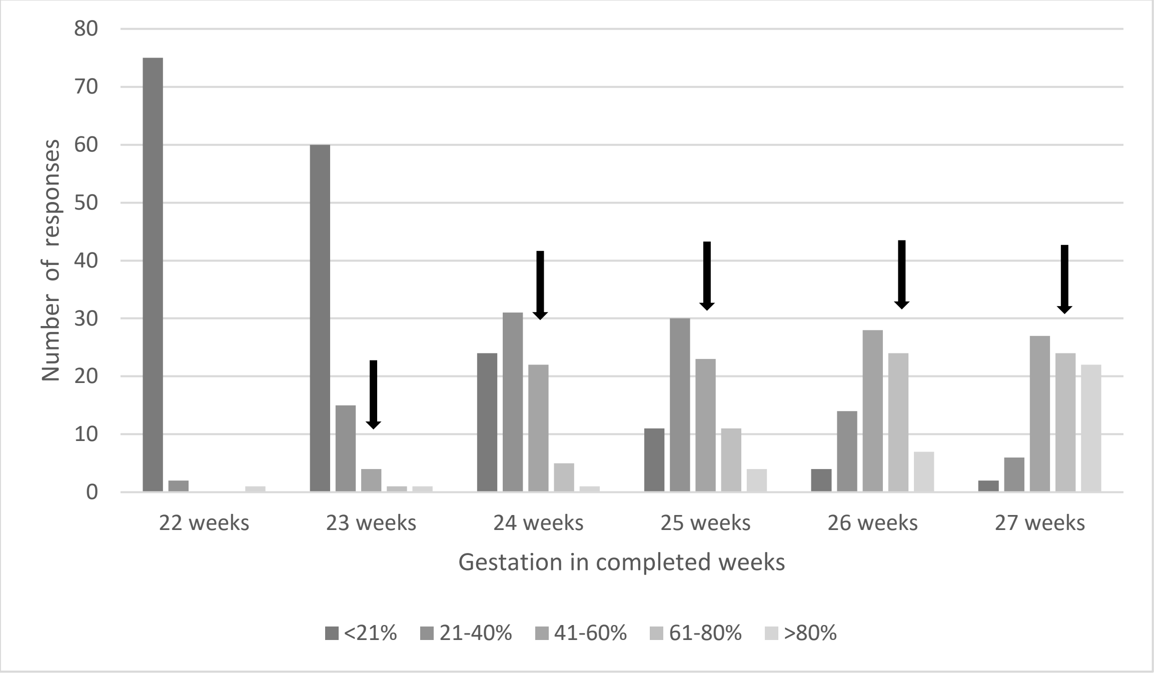

Figure 6.4 Estimates of rates of intact survival in quintiles.

Actual rates of typical development as given by the ANZNN database for 2011 to 2014 inclusive are indicated by the solid arrow. Responses to the left of the arrow for each gestation indicate a negative response. Accurate data omitted for 22 completed weeks gestation as data may be inaccurate because of small numbers of survivors within the group and is not given in the ANZNN database

Comparison was made between the antenatal HCP (58 participants) and the HCP caring for the baby after delivery (53 participants). Analysis showed a significant difference in the perception for survival for most gestations from 23 to 27 completed weeks; 23 weeks p=0.03 (χ^2 [1] 4.64), 25 weeks p=0.02 (χ^2 [1] 4.49), 26 weeks p=0.02 (χ^2 [1] 5.05), 27 weeks p=0.02 (χ^2 [1] 6.76), as well as significant differences in perception for severe disability at 24 weeks p=0.01 (χ^2 [1] 4.64), and intact survival p=0.01 (χ^2 [1] 7.35), with the antenatal HCP more negative for each parameter.

Analysis of tertiary hospital HCP (74 participants) compared to regional and remote HCP (39 participants) showed that the regional and remote HCP were significantly less optimistic about survival at 23 weeks p=0.03 (χ^2 [1] 5.07), 24 weeks p=0.03 (χ^2 [1] 5.13), and 25 weeks p=0.03 (χ^2 [1] 3.95), but there were no other significant differences for estimates of severe disability or healthy outcomes.

One hundred and twenty free text comments were received. These were divided into six themes. (Table 6.4).

Table 6.4

Themes and representative quotes for content analysis of the free text.

Theme	Representative quotation
Every situation is different	The decision should be individualised for every family (Paediatrician)
The burden of guilt is too much for parents	No parent wants to live with the ‘did I kill my baby’ dilemma (Neonatal nurse)
Parental choice is paramount	Will the parents be willing to look after a disabled child they didn't want resuscitated? (Midwife)
	Parents are influenced by lesser degrees of disability and not only severe disability (Obstetrician)
Advocating for the baby	At 24 weeks approximately half the survivors will have only mild or no disability. The uncertainty of outcome combined with uncertainty around exact gestation make any definitive advice around outcome imprecise. Resuscitation is not the last opportunity to withhold treatment from a baby…Choosing death is not necessarily a decision to be rushed. The disabled have rights. (Neonatologist)
	If a healthcare professional believes the chance of survival for an infant is good, full active management should happen regardless of the parental opinion. I believe we have to advocate for the baby when the parents do not have its best interests in mind. (Midwife)
Following the law	When it comes to the wellbeing of a premature infant, there are legal guidelines regarding viability to protect the unborn child (Nurse)
Ways to educate pregnant women about prematurity	Perhaps a basic handout of survival and disability statistics of babies born less than 30 weeks gestation should be given to parents at their first booking-in clinic. If the parents have a basic awareness, they may already have made a decision should they be unlucky enough to have an extremely preterm baby…most parents choose trying to save the baby because they have not had time to think what life would be like caring for a moderately or severely disabled child. (Neonatal nurse)
	If they are healthy this won’t be needed. Why upset the mum as she will think something is wrong…the woman at risk could be identified…and then educated (Midwife)

6.7 Discussion

Given that accurate information is essential for collaborative decision making by parents and medical staff around the treatment for periviable babies this study demonstrates that there is greater pessimism about the outcomes of the most premature babies by all HCP groups than is indicated by the actual outcome figures. Information is also important for enabling parents of babies at older gestations who will still require tertiary level intensive care for their babies to understand the risks to their offspring, and at older gestations, HCP are more accurate in their knowledge. HCP who have the most contact with parents prior to delivery, are the least accurate in terms of both mortality and the risks of a poor outcome at the lowest gestations. This discrepancy is concerning, as proactive antenatal care improves neonatal outcome, and where the antenatal team disagrees with the neonatal team in the provision of care, the outcomes for the baby are seen to be worse (Guinsburg et al., 2012). Where active care is proposed, antenatal steroids, magnesium sulphate, and monitoring of the foetus may optimise the condition of the baby and reduce later morbidity, hence decisions often need to be made well before delivery where possible (Guinsburg et al., 2012; Håkansson et al., 2004).

It is possible that the information as understood by HCPs is merely out of date, however, whilst survival data has improved with time, there have been only modest improvements in the rates of severe disability seen in some studies (Doyle et al., 2010). Even in previous decades, the perceptions found for survival and disability would have been unduly negative, reflecting survival rates found in the late 1990’s (Lorenz et al., 2001; Lui et al., 2006). Studies done in the mid 2000’s reflect improved survival rates for babies offered intensive care (Bode et al., 2009). In the Australian context with both inborn and retrieved babies improved survival rates are seen from the early 2000’s (Thompson et al., 2016). Undue negativity may reflect a reluctance of some HCP to provide care for these babies. Previous studies have shown that pessimistic clinicians are less likely to intervene to provide intensive care for periviable babies (Morse et al., 2000). Hospitals with more optimistic obstetric and neonatal trainees are known to have received training from hospitals who have higher rates of providing care at the lowest gestations, and are found to be more accurate in their outlook (Janvier et al., 2008). Higher rates of offering care led to improved outcomes (Janvier et al., 2008; Rysavy et al., 2015) and in some studies this appears to be regardless of numbers of small babies being cared for (Rysavy et al., 2015). Whilst the tertiary unit described is a smaller tertiary centre in Australia, it has a high rate of offering care to babies under 25 weeks gestation (Ireland, Ray, Larkins, & Woodward, 2019). with comparative survival rates, but with more positivity it is likely that the survival and long term outlook for these babies would improve.

Extremely preterm babies will remain in the neonatal intensive care for months before going home. Parents who have experienced neonatal intensive care have been shown to have high rates of anxiety, depression, stress and trauma (Busse et al., 2013; Woodward et al., 2014) which may result in poorer long term developmental outcomes for the child (Woodward et al., 2014). Parents tell us that they need hope and honesty to help sustain them through their neonatal stay (Janvier et al., 2016). Whilst the potential for an adverse outcome needs to be understood by parents depending on the evolution of events during the baby's care, if parents have been given a very negative outlook for their baby, the realistic hope that the baby may be healthy is removed, and the parent will need to endure the invasive painful treatment of the baby without recognising that the suffering baby has a potentially good outcome.

Staff based at smaller centres were found to be more negative about survival below 26 weeks than the tertiary HCP, but there was no difference in their perceptions of rates of disability. The origins for this are unclear. This has been noted in the Australian context in previous studies (Gooi et al., 2003). Most HCP at all centres were negative about long term outcomes.

The non-tertiary centres will deliver fewer babies at extreme prematurity as an attempt to transfer antenatally to tertiary centres is standard care. Where parents presenting to these centres discuss the prognosis for their extremely premature babies, a more negative impression for potential survival will already have been conveyed to parents prior to transfer, and may have led to less optimisation of the foetus for postnatal survival, such as the administration of steroids (Gagliardi et al., 2017; (Ireland, Ray, Larkins, & Woodward, 2019) at the referring hospital. The parents, in turn will have a more negative outlook for the baby and this may influence their decision making. Work to improve the knowledge at referral centres may improve the wellbeing of the delivered baby as shown in the work by Morse *et al* (2000).

Clinicians who are involved in the care of women prior to delivery are significantly more negative than those who care for the baby in the short and long term. This confirms previous work done and has previously been shown to adversely affect the antenatal care of the extremely preterm foetus (Guinsburg et al., 2012; Mehler et al., 2016). Clinicians caring for the woman presenting with complications will have earlier counselling encounters with families and their more negative knowledge may affect parental decision making. Further research may reveal the origins of the more negative opinions.

All clinicians would offer care for patients at significantly lower gestations than they would wish for themselves, which is not unexpected given their negative perceptions of outcome. This has been described previously in trainee doctors (Janvier et al., 2008) and may reflect a respect for patient autonomy and acceptance that patients may make different choices to the clinician. Furthermore, HCP recognised that there were specific factors about each pregnancy which would alter their risk assessment for the baby, and hence influence whether they thought that intensive care should be provided. Both surgical congenital anomalies and trisomy 21 were recognised as negative factors for survival and neurodevelopment, however, emotional factors such as previous pregnancy loss or the presence of no live born children in the family would positively encourage resuscitation despite no evidence that the difficult previous history will improve the outlook for the pregnancy at risk.

The difficulty in predicting an outcome for an individual pregnancy from large epidemiological studies was reflected in several free text comments. Whilst statistics may be important to clinicians, these reflections of uncertainty may be important factors for parents to understand. In a pilot study of 15 clinicians giving antenatal counselling, Prentice *et al* (2018) showed that most interactions involved the imparting of statistics and information only (60%) and eliciting parental preferences or engaging in deliberation were less frequent (20%). The nuance of the statistics and uncertainty with their application is unlikely to form part of this type of counselling. Previous studies have demonstrated that parents of extremely premature babies perceive the risk of death as more important than the risk of disability for a baby when a decision is made to resuscitate occurs (Boss et al., 2008; Hansen et al., 2003; Lam et al., 2009; Streiner et al., 2001). HCP in these studies felt that the risk of severe disability was more important. Where death usually occurs in extreme prematurity, it is usually in the first days following delivery, so the uncertainty primarily affects the prognosis for disability, and this should be a part of counselling for decision making. Our study suggests that parents in North Queensland will receive a negative message about survival at gestations below 28 weeks, and rates of severe disability at the earliest gestations. At the earliest gestations, intact survival is similarly underestimated.

Most HCP recognise a need to support autonomy in parental decision making. However, this attitude was not consistently reflected in the answers to the range of questions asked. Where parents wanted intensive care provision for their baby but the clinician did not feel that it was in the best interests of the baby, 69.1% of respondents said that this care should be provided whilst 21% said that it should not. However, where parents did not want intensive care for the baby, but the clinician did, 37.5% would follow the parental request, but 40.6% would provide resuscitation despite this preference. Below 25 weeks, over half respondent felt that parents could be the sole decision makers, but 64.6% also said that clinicians could disregard parental choice at this gestation. It seems recognised that risks of death and disability decrease with increasing gestational age, but specific gestational cut offs are relatively artificial. Ethical dilemmas in the relative roles of parents and clinicians are reflected in these findings, with a range of opinions from complete parental autonomy to decline intensive care, even at gestations over 25 weeks, and those which deem that parents should not always be the final decision makers, even if intensive care then occurs for babies whose parents did not want this for their child. The data suggest that the trend is towards clinicians as the final arbiters of decisions. Further research could clarify the underpinnings of HCP beliefs.

Parental involvement in decision making can only be based on accurate information. Most guidelines currently in use in Australia, include parental discretion around the resuscitation of babies below 24- or 25-weeks gestation (Department Health South Australia, 2013; Lui et al., 2006; Queensland Health, 2014). Despite the negativity of clinicians and guidelines discouraging the resuscitation of babies under 24 weeks, many of these babies are receiving intensive care in Australia and a recent review of the use of the consensus guidelines in New South Wales and Australian Capital Territory reflect that resuscitation at 23 and even 22 weeks regularly occurs (Sinclair et al., 2019). In North Queensland, nearly all babies at 24 weeks gestation and nearly half of babies delivered at 23 weeks gestation receive tertiary intensive care, regardless of place of delivery (Ireland, Ray, Larkins, & Woodward, 2019). With increasing parental autonomy, and parental requests for active care at gestations below 23 weeks, the perinatal community as a whole in Australia needs to be aware of improving outcomes and consider if the guidelines need modification to include clarity around resuscitation and provision of care at lower gestations.

There are some limitations to this study. It is a relatively small study based on a self-designed cross-sectional survey from one area of Australia only which may limit the generalisability. However, local examination is important, and the findings are consistent with those found in previous studies both historically and more recent. Another potential limitation is the use of the long term follow up data from the ANZNN. Follow up rates at the tertiary unit are relatively poor, and highest rates of follow up occurs for local babies within the immediate tertiary unit area and only one other regional centre where standardised tests are available.

The strength of this study is that it there was a good response rate, and that participation was invited from regional and remote centres where many patients initially presented with complications in their pregnancy. There are few studies which examine referring HCP knowledge. The survey also included staff whose contribution towards parental knowledge might previously have been ignored such as midwifery and neonatal nursing staff, as well as more junior obstetric staff. Midwifery and neonatal nursing staff will contribute to the parents' perception of the long term with much closer daily contact whilst providing care both antenatally and postnatally and can influence the hope that parents need to cope with their neonatal experience. The inclusion of paediatricians who see these babies long term is also uncommon, but important as they will often have a long-lasting relationship with the children. A further strength of the study is that it has been done in an area with a high Indigenous population where Indigenous babies are over-represented on the neonatal unit. A strength of the study not reflected in most studies is the content analysis of the qualitative data. Qualitative data adds to the richness of the quantitative data in studies of knowledge and attitudes.

6.8 Conclusion

Clinicians who work with pregnant patients need to give accurate information about the chances of survival and long-term disability of babies who deliver at extreme prematurity if they wish to have collaborative decision making. This is most important for the senior clinician providing counselling but also important for other staff who may find themselves in a situation where their opinions will be revealed to the parents. Message framing will influence the parents’ decision making, but also their positivity during the neonatal unit stay. Enhanced positivity, without giving false reassurance, will improve parental experience of neonatal care and reduce the risk of poor mental health outcomes for the parent. Clinician bias needs to be explored to ascertain the source for undue negativity, and individual clinicians need to be responsible for ensuring that both their knowledge and biases are reflected upon. In the area studied, this study shows that improved education about prematurity is essential to improve the outcome of vulnerable babies and families. Units who offer intensive care for extremely preterm babies should be aware that accurate knowledge and positivity will improve outcomes. All tertiary hospitals providing neonatal intensive care need to regularly assess the adequacy of knowledge of their staff about extreme prematurity in this era of rapidly improving survival.

6.9 Declarations

6.9.1 Ethics approval and consent to participate

The study was approved by The Townsville Hospital Human Research Ethics Committee HREC/15/QTHS/194 and acknowledged by James Cook University (JCU) ref 6485. Governance approval was given by all participating sites and JCU. Consent to participate was incorporated in the survey itself.

6.9.2 Acknowledgments

Janene Moore and Michelle McElroy provided invaluable assistance in disseminating the survey to participants as research assistants at their regional and remote centres where they work.

The Qualitative HCP Study

The qualitative study done using grounded theory (Charmaz, 2008) was conducted contemporaneously with the quantitative study in Phase Two of the research. The study took place from February to July 2017. The detailed methodology for this study has been described in Chapter Three. This section of the chapter outlines the categories of results and their placement within the thesis. The second manuscript which documents the construct of implicit bias provides the details of the methods thus avoiding repetition. Following this, further categories of findings are presented.

6.10 Categories, Subcategories and Focused Coding

Categories which emerged from the analysis included: i) ‘who decides’, ii) ‘culture and context of families, iii) ‘to treat a bit or not at all’, iv) ‘the life ahead’, v) ’guidelines’, vi) ‘information sharing’, and a theoretical construct of ‘implicit bias’.

Table 6.5

Outline of focused coding and distribution of data findings in the thesis.

Category	**Contribution to understanding about decision making – focused coding**	**Where presented in this chapter then discussed in Chapter Eight**
Who decides	Opinions about who should make decisions around active care	Allows an understanding of the HCP and their perceived place in decision making (pg. 264)
Culture and context of families	The factors which HCP consider to be important in decision making	How HCP perceive families' decision making abilities and basis for making decisions (pg. 258)
To treat a bit or not at all	HCP insights into initiating active care and withdrawing active care, and consequences of this approach	Addresses aspects of care at delivery and NICU which might influence HCP (pg. 283)
The life ahead	Perceptions of the future consequences of periviable birth and resuscitation for families	How HCP consider decisions will affect families in the future after discharge may influence HCP beliefs (pg. 292)
Guidelines	Opinions about the Queensland State-wide guidelines for management of extreme prematurity (have undergone some minor modification after the study was done)	Some data will be included briefly in Chapter Eight, but the data which emerged did not substantially inform an understanding of decision-making, beyond data already found in other sections
Information sharing	Suggestions for good practice informs future decision making	Ideas found in this category will be incorporated in the Chapter Eight
Implicit bias	Role specific biases towards active care for periviable babies	Hypothesis for the origins of negativity towards extreme prematurity and differences between HCP streams and how these are important in decisions made. Manuscript presented (pg. 213)

6.11 The Construct of ‘Implicit Bias’

A theoretical construct which emerged strongly was that of implicit bias. Differences in attitudes were apparent between HCPs caring for women antenatally, and those caring for the baby after delivery. This section incorporates some data which will later be found in the various categories of findings. A theoretical construct is an explanatory concept which is not directly observable from the codes within the categories of data, but rather is inferred (Charmaz, 2014). This article includes some explanatory writing around the methodology and recruitment strategies of qualitative research which was requested by the reviewers and they had concerns that the journal readers would not be familiar with this form of research. I have provided a figure to show the divisions in the data outlining ‘implicit bias’ (Figure 6.5).

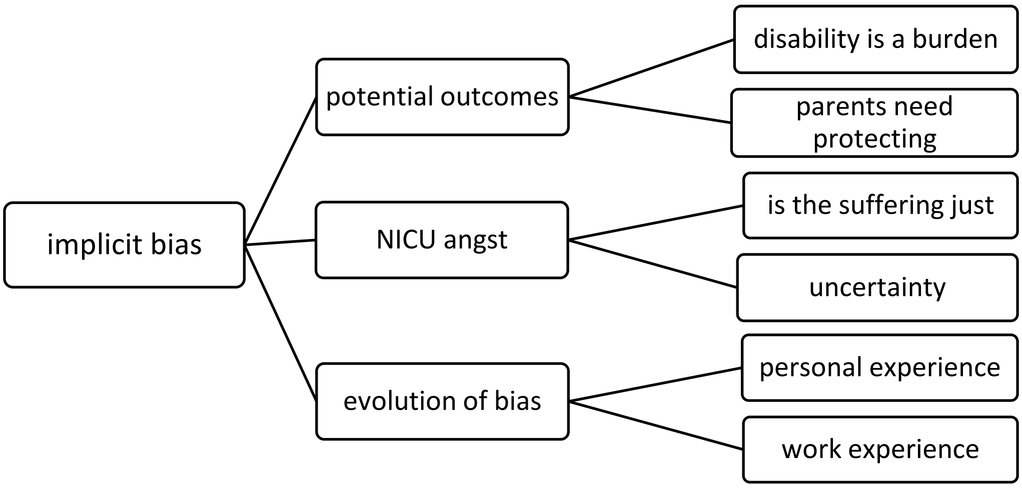

Figure 6.5 *The evolution of the construct for ‘implicit bias’.*

Ireland, S., Ray, R., Larkins, S., & Woodward, L. (2021). Exploring implicit bias in the perceived consequences of prematurity amongst health care providers in North Queensland–a constructivist grounded theory study. *BMC Pregnancy and Childbirth*, *21*(1), 1-12. https://doi.org/10.1186/212884-021-03539-5

Article: Exploring Implicit Bias in the Perceived Consequences of Prematurity Amongst Health Care Providers in North Queensland – A Constructivist Grounded Theory Study

6.12 Abstract

Background

A study was done to explore the attitudes of relevant health care professionals (HCP) towards the provision of intensive care for extremely premature and periviable babies.

Methods/Design

Applying a constructivist grounded theory methodology, HCP were interviewed about their attitudes towards the provision of resuscitation and intensive care for extremely premature babies. These babies are at increased risk of death and neurodisability when compared to babies of older gestation. Participants included HCP of varying disciplines at a large tertiary centre, a regional centre and a remote centre. Staff with a wide range of experience were interviewed.

Results

Six categories of i) who decides, ii) culture and context of families, iii) the life ahead, iv) to treat a bit or not at all, v) following guidelines and vi) information sharing, emerged. Role specific implicit bias was found as a theoretical construct, dependent on the period for which the HCP provided care relative to delivery of the baby. This implicit bias as an underlying cause for negativity seen towards extreme prematurity is presented in this paper. HCP caring for women prior to delivery have a bias towards healthy term babies that involves an overestimation of the risks of extreme prematurity, while neonatal staff were biased towards suffering in the neonatal period and paediatricians recognise positivity of outcomes regardless of neurological status of the child. The implicit bias found may explain negativity towards active care of periviable neonates.

Conclusion

Understanding the origins of role specific implicit bias may enable HCP to work together to improve care for parents preparing for the delivery of extremely premature babies.

Keywords

Pregnancy, extreme prematurity, resuscitation, counselling, attitudes, implicit bias

6.13 Background

The gestation at which a baby can survive has reduced with the evolution of increasingly complex intensive care (Patel et al., 2017). At the lowest gestations, there is a higher risk of death and poor neurological outcomes in those who survive compared to those of longer gestation (Ding et al., 2019; Marlow et al., 2007; Serenius et al., 2013; Wood et al., 2000). These babies are often referred to as periviable (Keogh et al., 2007; Patel et al., 2017; Payot et al., 2007). Periviable babies may receive either palliative care with comfort measures only following delivery or be offered full intensive care. The care a baby receives will depend on collaborative decision making by the parents and health care professionals, after consideration of individual factors pertaining to the pregnancy and baby (Srinivas, 2013). There is some variation in the gestations used to determine when it is considered appropriate to offer resuscitation depending on the country of birth and local organisational recommendations. In Australia, many guidelines deem active care to be inappropriate at 22 weeks completed gestation, and a ‘grey area’ exists from 23 to 24 weeks where resuscitation may be considered. Increasingly, other countries are recognising improved outcomes at 22 weeks gestation where active care is offered (Ding et al., 2019; Ishii et al., 2013; Lemyre & Moore, 2017). From 25 completed weeks gestation, most guidelines used in high income countries suggest that resuscitation should usually occur unless there are specific adverse factors which would increase the risks of a poor outcome. Factors that are considered include expected birth weight, gender, plurality, chorioamnionitis and congenital abnormalities (Lui et al., 2006; QCG, 2014; Wilkinson et al., 2009).

Few parents who find themselves in the position of having to participate in decision making at extremely preterm gestations have the medical knowledge required to make these decisions without the counselling of health care practitioners (HCP) (Al Maghaireh et al., 2016; Medina et al., 2018). Parents are often still coming to terms with the situation and rely on both information and counselling from the HCP which includes an exploration of parental experience and beliefs (Payot et al., 2007; van Manen, 2014). Traditionally, studies have regarded obstetricians and neonatologists as the main sources of information for parents. However, it is apparent that midwives, neonatal nurses and allied health staff also provide support and interpretation for parents (Kavanaugh et al., 2010; Kowalski et al., 2006). Studies have shown that most HCP are inaccurate in their perceptions of the rates of survival and intact survival for those babies in the lowest gestations (Boland et al., 2016; Doucette et al., 2017; Morse et al., 2000; Mulvey et al., 2001). The reasons for this inaccuracy are poorly understood. Although HCP bias with regards to active care according to gestational age has frequently been explored in terms of the different groups of HCPs who offer support to the parents (Barker et al., 2019; Moore et al., 2020), the origins of this bias are less well documented.

Implicit bias is a subconscious attitude formed by the persons’ own background and life experiences, which negatively influences behaviour (Greenwald & Krieger, 2006; Holroyd, 2015). Implicit bias is well recognised in medical literature where the effects on racial and social disparities has been the focus of research (Blair et al., 2013; Green et al., 2007). A meta-analysis of studies shows a positive correlation between implicit bias and lower quality of care (Fitzgerald, 2014).

This paper describes the exposure of role specific implicit bias amongst HCP and the possible contributing factors for this bias. These findings are a component of a larger study investigating attitudes towards extreme prematurity.

6.13.1 Context for the study

Townsville University Hospital contains the only neonatal intensive care unit (NICU) in North Queensland and provides care for all neonates under 28 weeks completed gestation for an area of 500 000 km^2. Approximately two and a half thousand deliveries per year occur at TUH. Over 50% of the babies admitted for extreme prematurity will live outside the immediate tertiary centre catchment area, with 25% retrieved following birth at other centres (Ireland, Ray, Larkins, & Woodward, 2019). Between two and four extremely preterm babies are born at the regional and remote centre studied per year. Retrieval of outborn babies is performed by a dedicated retrieval service based at the NICU. The regional maternal-foetal medicine (MFM) unit and paediatric surgical services are based in the tertiary centre. Ten thousand babies are born in the region annually, with 40–50 extremely preterm babies admitted per year. Aboriginal and Torres Strait Islander (hereafter referred to as Indigenous) people comprise just over ten percent of the North Queensland population, but constitute 38% of deliveries at extreme prematurity (Ireland, Ray, Larkins, & Woodward, 2019). There are higher rates of poverty, remote residence and poor health outcomes for the Indigenous population in North Queensland (Commonwealth of Australia & of the Prime Minister and Cabinet (CAPMC), 2017) than for the non-Indigenous population.

Current Queensland guidelines indicate that resuscitation below 23 weeks should be discouraged, and babies over 25 weeks gestation should receive active care unless there are known congenital anomalies (QCG, 2014). From 23 completed weeks to 23^{+6} weeks parents should be the final arbiters of decisions to offer active care, while a ‘fully informed’ parent may choose to decline active care from 24 to 24^{+6} gestation. Women at risk of delivering babies early will initially have contact with the midwives and obstetricians as complications of the pregnancy develop. They receive counselling from these staff who will then refer the woman and her partner to the neonatal staff for further counselling about the outlook for the baby. Obstetric and neonatal staff then work with the family to establish a plan for the delivery and care of the extreme preterm infant. Where possible, the families visit the NICU prior to delivery, with neonatal nurses providing the tour and later the nursing care for the baby following admission. Social workers and Indigenous Liaison Officers provide support for families and are often present for discussions between HCP and families. Following resuscitation, the baby is transferred to the neonatal intensive care, but if there are complications which increase the risks of long term neurodisability, care can be redirected from intensive care to palliative care and the baby will die. This is considered legal and ethical in this jurisdiction. At antenatal counselling this option is frequently offered. After discharge from the neonatal unit, all extremely preterm babies will be cared for by their local paediatric services.

Referral centres to the tertiary unit include two large regional hospitals 350km to the north and south which can provide care for babies from 29 weeks and 32 weeks respectively. There is a small remote hospital located 900km away, near the western border of the state. Full time obstetric and paediatric staff are in the three main referral centres. Other birthing facilities staffed by general practitioners with obstetric qualifications and midwives are scattered around the North Queensland area. Rarely a baby will be born at a health centre staffed only by experienced rural nurses. Antenatal transfer to the tertiary unit for women at risk of extreme preterm delivery occurs where possible.

6.14 Methods

A convergent mixed methods study was undertaken to explore the attitudes of HCP towards the provision of active care for periviable babies in North Queensland. The quantitative component of this study has been published (Ireland et al., 2020). This qualitative study was informed by constructivist grounded theory methodology as described by Charmaz (Charmaz, 2014). This methodology was chosen as the researcher first explores the behaviour or attitude which is studied and then it allows the researcher to build theories about the underlying causes for these. Building theories to explain the findings is useful in healthcare as it can lead the researchers to suggest ways to change negative behaviours. Healthcare providers caring for pregnant women at risk of delivering extremely premature babies, or who care for the babies after birth, were interviewed to understand their attitudes towards active care for extremely preterm babies. The interviews followed an interview guide adapted through an iterative process of initial coding and focused theoretical interactions with the data to further explore tentative categories (Appendix 6). The consolidated criteria for reporting qualitative studies (COREQ) (Tong et al., 2007) checklist item guide was followed (Appendix 11).

6.14.1 Sampling strategy

A pragmatic, purposive strategy was used to enrol participants from a tertiary, regional and remote hospital. A quantitative survey was sent to HCP who provide care for women at risk of extremely preterm delivery and those caring for the babies after birth to investigate their knowledge and attitudes towards the active care of extremely preterm babies. The survey commenced shortly before this qualitative study (Ireland et al., 2020) and the two then ran contemporaneously with the qualitative study continuing for several months after the survey study was completed. An invitation to participate in the qualitative study was included in the quantitative study. 174 invitations were sent for the survey, with 113 participants (64.9%). Separately, all full time obstetric, neonatal and paediatric specialist medical staff at the tertiary unit were invited individually by email to participate. All invited HCP agreed to participate, although only three out of five obstetric and two of six paediatric staff participated as data saturation had been reached. Outside the tertiary centre potential participants were identified by a local investigator and approached to ensure regional and remote representation in the study, including three paediatricians, an advanced obstetric trainee and a neonatal nurse practitioner, the two remaining volunteers from these sites were not interviewed. The demographics of the participants were monitored contemporaneously. Further potential participants were chosen from the survey volunteers to ensure a range of HCP representing experience, locality and health care roles and to add to the emerging categorical data. Age and ethnicity of participants were not recorded. In addition, a focus group was held involving two Indigenous Liaison Officers and an obstetric social worker, who together requested a focus group format rather than individual interviews. Ensuring a range of participants which represents the demographics of the group to be studied fills the theoretical sampling strategy required for grounded theory. Recruitment ceased when the ongoing analysis of the interviews as they occurred identified that no new data were emerging from the interviews.

6.14.2 Data collection

Interviews were performed by the primary investigator (a neonatologist working at the tertiary centre) and a research assistant (a midwife researcher experienced in qualitative interviewing, but not involved with the NICU). Immediate co-workers of the primary investigator (neonatal medical staff) were all interviewed by the research assistant, whilst all other participants were given the choice of interviewers. Interviews were conducted in the workplace or by telephone and recorded digitally.

The interviews explored the participants' work experience and their experience in counselling patients at risk of extremely premature delivery. Opinions were sought about decision making around resuscitation of extremely premature babies both as a process and in terms of the actual factors the HCP would assess when offering intensive care. The relative roles of parents and HCP in decision making at specific gestations were explored. Participants were asked to offer any suggestions for improving decision making processes within the unit and offer any other comments which they might have about the care of periviable babies. Very early modification to the semi-structured interviews added questions specific to the Queensland Health guidelines and possible religious inclinations informing participants' opinions.

Recorded interviews were transcribed by a commercial transcription service and returned to the research team within three days of the interview.

6.14.3 Data analysis

Using NVivo as a data management software, interviews were analysed applying initial and focused coding enabling broad tentative categories to emerge. Focused codes were identified from the codes within the categories using a staged constant comparative process from focused coding to category generation. While the primary investigator did the initial coding, analytic triangulation in collaboration with the study team was used to develop categories during research meetings.

6.15 Ethics Approval

Ethical approval for the study was obtained from the Townsville Hospital and Health Service Human Research Ethics Committee and James Cook University (HREC/15/QTHS/194, JCU 6485).

6.16 Results

Thirty-three HCP participated in the study (Table 6.6). Interviews lasted from 17 to 90 minutes.

Table 6.6

Demographic characteristics of participants.

Demographic	Variable	Number (percent)
HCP role	Midwife	4/33 (12%)
	Neonatal nurse	5/ (15%)
	Neonatal nurse practitioner	4 (12%)
	Obstetrician	3 (9%)
	Obstetric trainee	2 (6%)
	Neonatologist	3 (9%)
	Neonatal trainee	2 (6%)
	Paediatrician	5 (15%)
	Paediatric trainee	2 (6%)
	Allied health	3 (9%)
Experience in years	1-5 years	6 (18%)
	>5-10 years	9 (27%)
	>10-15 years	9 (27%)
	>15-20	5 (15%)
	>20	4 (12%)
Gender	Female	26 (79%)
	Male	7 (21%)
Location	Tertiary hospital	28 (85%)
	Regional and remote	5 (15%)
Interviewer	Primary investigator	22 (67%)
	Research assistant	11 (33%)

Categories which emerged included i) who decides, ii) culture and context of families, iii) the life ahead, iv) to treat a bit or not at all, v) guidelines and vi) information sharing. Whilst implicit bias based on racial and socioeconomic status was found within several categories, the concept of implicit bias towards prematurity itself emerged as a separate theoretical construct, that is, a theory to explain some of the findings. This manuscript presents the theory of implicit bias towards extreme prematurity with the contributing focussed codes: i) disability is a burden, ii) parents need protecting, iii) is the suffering just iv) uncertainty of outcome, v) disability in remote sites, vi) differing discipline perspectives, vii) influence of personal experience, and viii) evolving implicit bias.

6.16.1 Disability is a burden

Termination of pregnancies because of known abnormality occurs, and the HCP working in the antenatal wards report familiarity with caring for women having this procedure. This midwife described her own experience caring for a woman whose baby had a condition which was not compatible with life, showing surprise that the woman would not end the pregnancy. She went on to describe familiarity with termination for other abnormalities. Caring for patients terminating a pregnancy was difficult for her, but her role was to support, and not get too emotionally close to the patient:

> *'... one baby that was twenty some* - *no I forget how many weeks she was. She was preterm and the baby had anencephaly and not compatible with life and she refused to terminate… I've had plenty. Lots of terminations for abnormalities and things like that…it's really hard when you know someone is terminating on the ward. It's really hard not to bond with them and it's really hard. You've just got to support them and remember why you are here. Remember your role. I think you get better at it with practice. When I was a grad I was awful at it. I would tear up with the women and be a mess.'*
>
> (HCP 20)

Several of the obstetricians stated that the disability brought about by prematurity is a burden to families. They perceived the burden may lead to the clinician making decisions about active care. This clinician connected the concept of adequate counselling to declining resuscitation before the gestation she herself would choose:

> *'I mean it's not up to me but again we'll have to counsel the parents the right thing to do. I have seen a few women who after being properly counselled, understanding their long-term sequelae, say no, up to 25 weeks. Usually it didn't involve the neonatal team…I make the decision on the long-term morbidity that the baby is going to have and the burden on the parents...All they want is the baby to be resuscitated but they don't have things like on looking at the long term how the baby is going to do and what the neurological sequelae they could have like cerebral palsy and things…I try to give them information that is not just survival…if it was me and I was at 24 weeks and if I have a baby who is offered resuscitation I would say no up until I get to 25 weeks.'*

(Senior obstetric trainee, HCP 14)

Whilst discussing resuscitation of babies of 23- and 24-weeks gestation, this obstetrician reflects her concern about the future potential burden of disability:

> *'I'm always terrified for my women that they are going to end up with a severely disabled kid that's alive and that stays alive and they're stuck with for life.'*

(HCP 18)

In the opinion of this obstetrician, even a lower risk of disability may lead a parent to prefer palliation after birth rather than active care. He felt that even above the guideline cut off at 25 weeks completed gestation, parents should be able to opt for comfort care only:

> *'I have issues around 25 weeks being the cut off where we must resuscitate because some parents might not wish that…then to insist that they're resuscitated would, I think, be the wrong thing to do.'*
>
> (HCP 17)

A neonatal nurse expressed how a baby for whom she had provided care has disabilities which she perceives as troubling:

> *'I have seen babies down the track who we've offered withdrawal of care and the parents have refused and have been severely disabled and its quite disturbing to see…It makes you think are we doing the right thing for these families.'*
>
> (HCP 2)

6.16.2 Parents need protecting

HCPs suggested that parents require hope for a positive outcome in order to negotiate neonatal intensive care psychologically intact themselves. This hope may form a barrier to parents absorbing a more negative message which the HCP may be wanting to convey:

> *'I do think they get told in no uncertain terms what the situation is and what might happen…but you have that hope don't you? And that's the trouble with parents.'*
>
> (Obstetrician, HCP 18)

Paediatricians describe how they manage the child within the context of the family until late adolescence. They discussed how families appear to cope. Even where a child has disabilities, most families appear to adapt:

> *'So they struggle but it's not that they ever said they would have changed anything…they seem happy with their children.'*
>
> (HCP 16)

Some participants suggested that families adapt to disability gradually which allows the family to cope with the challenges involved in the care for their child. However, the clinician needs to honestly assess the child's abilities which might lead to increased distress:

> *'It's a journey…that concept of a child growing into their disability…as the physician we know with the history what we are expecting to see, but even if we have said that information to the families, most families will hold onto the positives which is important for positive coping. [The parent is] Looking at day to day gains…I see over a 6 to 12-month period as the child fails to meet developmental milestones that the grief continues. Sometimes it is augmented when you start talking about that difference we talked about as a possibility is happening now.'*
>
> (Paediatrician, HCP 15)

Another clinician reflected how she would choose to dwell on the positives. Her reality has been that most parents will opt for resuscitation and her role is to stabilise the baby prior to transfer to the tertiary centre:

> *'Most of the time when we go to talk to them we usually try to be more positive than negative – when we think of a baby we are already going to resuscitate.'*
>
> (Paediatrician, HCP 29)

Caution about assessing a families' ability to cope with disability prior to the birth was verbalised by a paediatrician:

> *'I don't think we have all the information about families and until the family has been through the situation, you just don't know.'*
>
> (HCP 15)

6.16.3 Is the suffering just?

Nursing staff and junior medical staff reported distress associated with caring for the extremely preterm babies and their part in causing the suffering. These staff all spend significantly more time daily with the baby than more senior medical staff. Two neonatal nurses commented below:

> *'As a nurse ... you're the one who has to deal with the skin sloughing off and the really awful emotional stuff and the parents crying beside the bed your whole shift, you know what I mean, you don't get to get away from that.'*
>
> (HCP 27)

> *'We don't enjoy doing any of the things we have to do to them.'*
>
> (HCP 12)

A senior neonatal trainee expressed an equal amount of distress. Her perception that there are few good outcomes is not supported by the data, but may impact on counselling parents (here discussing 23 and 24-week gestation babies):

> *'Here we've got this awful situation that's going to, in the best case scenario, condemn you to another 16 weeks of living with us all day every…the issue of informed consent is tenuous at best….I think for me I think we do a lot of horrible things to very, very small people and lots of horrible things to families with very small risk of good outcomes in that situation.'*

(HCP 9)

6.16.4 Uncertainty of outcome

Despite the negativity towards resuscitation of periviable babies that was seen throughout the data, many of the neonatal and paediatric staff had experience of babies who had done better than they had thought possible during their perinatal course:

> *' I've had kids come back that have surprised me… that I really thought were going to have severe impairment either at the time of birth or during their time here and they've really surprised me.'*

(Experienced neonatal nurse, HCP 12)

A senior neonatologist described a patient where an unexpectedly good outcome has changed his certainty in prognosis for individual babies and his practise. This self-reflection was not stated by many HCPs:

> *'I don't think we can always predict what's going to happen. That's probably changed my practise a bit, seeing that boy grow up- just because you see something bad on the scan it doesn't necessarily mean that everything is going to be atrocious'.*

(HCP 10)

One paediatrician who specialises in children with developmental problems discussed how most of the children that she sees at later follow up appointments are not severely affected with long term sequelae:

> *‘They are seeing me because they have problems… common problems that I see with those kids are learning problems and a few of them would have cerebral palsy, severe ones, not that many.’*
>
> (HCP 16)

Good progress with intact development in extremely preterm babies led this regional paediatrician to feel uncomfortable offering palliation for 24-week gestation babies where they have to provide care awaiting retrieval, even where the teaching is that these babies are less likely to do well than babies born in the tertiary unit:

> *‘If the parents say that ‘I don't want you to resuscitate my 24 week baby’, I would feel very uncomfortable actually because I’ve seen them doing so well… If they are obviously born in good condition, you want to give them the best go.’*
>
> (HCP 31)

6.16.5 Disability in remote places

Many of the patients cared for in the tertiary facility reside in regional or remote locations. Where potential disability could be a burden, this obstetrician was concerned about the distance from large health facilities:

> *'People from remote areas, you need to keep in mind what's going to happen to the baby once it's born…That will influence me that a morbid baby is not going to do very well, or be high needs in western Queensland. That family sometimes will need to move to a place close to a major centre and it can wreck their lives.'*

(HCP 25)

Interestingly, in contrast, this paediatrician who works in remote locations suggests that a child with a disability may find more acceptance in a smaller remote centre despite disability because there is less negative judgement placed on disability:

> *' In the remote communities, a lot of families do accept children with delayed milestones and whatever, they are accepted and the expectations are not as much as city folk.'*

(HCP 29)

6.16.6 Differing disciplinary perspectives

Differences in perception between the neonatal counsellor and the obstetric counsellor were evident in the data. An obstetrician stated that the neonatologist does not dwell adequately on the negatives of disability, and instead talks about potential positive outcomes:

> *'(The neonatologists) talk about the positives, not the true 24 hours a day, 7 days a week morbidity they truly will be faced with if they have a damaged surviving baby.'*

(HCP 25)

A neonatologist had the view that active steps to optimise the potential for a 23-week gestation baby need to occur before he will consider counselling the parents about whether to resuscitate or not when the obstetrician declined to administer steroids until after a neonatal consultation had occurred:

> *'They requested me to go and see the mum who is 23 weeks. I say, are you going to give mum steroids? They said no. I said in that case I don't need to go and see her.....it's kind of a little bit almost inconsequential for us to be involved if the baby is going to be compromised even before birth.'*
>
> (HCP 7)

6.16.7 Influence of personal experience

Throughout the data, staff added reflections from a personal perspective. Some staff had considered the possibility of pregnancy complications for themselves and how this might influence their opinions:

> *'Am I giving them objective enough information to help them to be able to make a decision without saying 'yes I think we should do everything', because my own fear is getting in the way? But also I think, you can't help but think from my point of view if I was in that situation…it's something that is very commonly discussed, particularly amongst O and G registrars because bad stuff always happens to us in pregnancy.'*
>
> (Obstetric trainee, HCP 30)

An older neonatal nurse recognised that her views have changed with time:

> *'When I was young I would have said that my partner and I wouldn't have ever managed with a disabled kid…since I'm older now I would have loved my child regardless of what they were like and I know that I would have handled whatever.'*
>
> (HCP 27)

The recognition that personal experience may change perspectives was displayed by this junior paediatrician. When initially interviewed, she felt that intensive care should not be provided for babies under 25 weeks gestation and she would not want her own baby to be resuscitated under 27 weeks. A year after initial interview she commented thus:

> *'Immediately upon becoming pregnant and 'seeing' the baby on an ultrasound, it was like a switch had been flicked. Whilst I had been so adamant on my views in the past regarding resuscitation as well as termination of neonates with congenital anomalies, I found myself having had a complete 180. I found myself counting down the days to 24 weeks and on the day of announcing to my colleagues that should the baby present herself early, I would expect them to engage in full resuscitation with whatever this required.'*
>
> (HCP 4)

Participants were asked about their personal experiences of disability. Few had siblings or close contact with disabled people. An obstetrician did have a sibling with moderate disabilities. He did not feel his experience influenced his counselling, although he continued:

> *'I can see the effect that it had on my family, I don't let that impinge on my counselling I don't think….it tends to be about making people – giving people true awareness of what it means.'*
>
> (HCP 17)

6.16.8 Evolving implicit bias

Senior clinicians often had more dogmatic certainty about whether babies should be offered active care. More junior staff were less aware of the expected outcomes, although they may spend more time with the pregnant women and the babies. A junior midwife and obstetric registrar commented respectively:

> *'I don't get to see the babies down the track. I can just go from what we are told really, because we don't get to see the end part.'*
>
> (midwife, HCP 24)

> *'I don't have the knowledge to go into the finer details about what sort of long term disability or impairment an extremely preterm baby might have. I don't know it or I don't feel comfortable discussing it because I just don't have the experience.'*
>
> (Obstetric trainee, HCP 30)

An experienced trainee neonatal doctor had been expected to provide counselling at a centre without senior support earlier in her career:

> *'Year one of training … and you need to go and talk to these parents who are about to deliver a 25 week. Of course that was incredibly confronting because what on earth do you say to people in that situation…I was a youngster at that point myself and I wasn't sure what to do.'*
>
> (HCP 9)

Junior doctors preferred unambiguous guidelines to avoid the requirement for any decision making at different gestations:

> *'It's too much guilt and pressure to put on families. That's why we should have a strict policy on "below this we don't resuscitate. That's our policy".'*
>
> (HCP 4)

The disconnect between the survival and outcomes statistics learnt by more senior staff during their training, and current literature was recognised:

> *‘There’s a lot of work being done to improve outcomes, so if you speak with the more senior obstetricians – when they started practise their survival was 28 weeks.’*
>
> (Neonatologist, HCP 8)

6.17 Discussion

This grounded theory study identified that attitudes of health care professionals concerning extreme prematurity were influenced by discipline specific implicit bias towards extremely preterm babies associated with the risk of prematurity related disability. For some HCPs in this study, disability is perceived as a burden which no parent should risk and disability can be prevented by allowing all at risk babies to die. Parents were deemed to be too emotionally involved to objectively assess the risks for the foetus in peril. Hope and positivity were perceived as negative factors which prevent the family from opting for palliation. Implicit bias was expressed by the language used, for example where the parents should be counselled on the ‘right thing to do’ and ‘proper counselling’, both of which were linked to the belief that parents should decline active care below 25 weeks gestation. HCPs in both the antenatal and neonatal care domains expressed feelings of guilt for playing a part in the survival of disabled children. Rarely did a clinician explicitly state that disabled children have less value as people. However, participants frequently stated that the disabled child may exert an intolerable burden on the family, affect relationships and even cause families to need to leave their homes in the quest for medical care for the disabled child. Genuine compassion is noted in the desire to protect parents from emotional harm and the baby from suffering.

Paediatricians particularly appeared most positive about the future function of many of these families regardless of the outcome for the child.

Thus, data from this analysis suggests that a subconscious bias exists, which is moulded by the background and experience of the clinician. Role specific differences were evident in the form of negative prognostic messaging. Negativity about the long-term mortality and morbidity of babies born at extremely preterm gestations is found repeatedly in other studies (Boland et al., 2016; Morse et al., 2000; Mulvey et al., 2001). These studies also reflect that obstetricians are more negative than neonatologists in their knowledge of survival rates and morbidity, and obstetricians may be less inclined to suggest that the baby receives active care as a result (Guinsburg et al., 2012). Where there is disagreement between the obstetrician and neonatologist about whether a baby should receive active care, the outcome for the neonate is worse (Guinsburg et al., 2012). Greater accuracy in knowledge is found in units with a proactive approach to the perinatal management of more immature babies and this is associated with improved outcomes (Janvier et al., 2008; Rysavy et al., 2015).

Negative attitudes and moral values of HCPs influence decision making at periviable gestations (Leuthner, 2001), partly because of the inaccurate data given to the parents, and also in the message framing of the prognosis (Haward et al., 2008). A review of cognitive bias and heuristics in medical decision making suggests that bias is under-investigated amongst medical personnel (Blumenthal-Barby & Krieger, 2015). These studies, however, do not explore the origins of the negativity or reasons for the discrepancy between groups of clinicians. Our study confirms these differences in terms of role between those clinicians caring for the mother antenatally, the neonatal team and the paediatric team. In addition, experience changes the viewpoints of these groups of clinicians. Junior HCP are less certain and identify more closely with their patients. However, more certainty and paternalism in attitudes was seen in some of the more senior medical clinicians in this study.

The differences between the HCPs who provide care prior to delivery and those after the birth may be explained, in part, by data which emerged from this study. Obstetricians are expected to deliver good health care during pregnancy and ensure the delivery of a full-term healthy baby. As shown in the data, exposure to terminations of pregnancy for abnormality occurs at even a junior midwifery level. The work of a junior midwife incorporates a role to support the patient, but they are expected to keep a distance emotionally from the patient's distress at the termination of the affected foetus. For the senior obstetrician, a disabled baby because of prematurity, may be a personal failure. HCPs with a primarily antenatal role were least likely to trust parents to make objective decisions. There were few variations in attitude between midwifery and obstetric medical groups.

The focus of HCPs involved in care of the baby is different to the HCPs caring for the mother prior to delivery. Some neonatal clinicians reflected that the intensive care required is so burdensome for the baby and the family, that palliation may be a preferable option. This may be a measure of the distress the clinicians themselves are experiencing, particularly where the clinician appears to feel guilty for helping a baby to survive who is later profoundly disabled. The nurses use of the word 'disturbed' when reflecting on a graduate of her care, may reflect her guilt at helping the baby survive, or perhaps that the disability itself is not deemed to be acceptable. This finding concurs with previously described moral distress arising from the care of sick small babies (Janvier et al., 2007). This unease is most noticeable in the staff with the closest day-to-day care of the neonate – the neonatal nurses, and the junior doctors. More senior neonatologists articulated the difficulty in prognostication for individual babies, and the need to be hopeful. It may be that this perspective provides justification for the suffering, whilst opining that ‘even the disabled have rights.’ Extremely premature babies will remain in the neonatal unit for months after delivery and the HCPs in the neonatal unit will form a relationship with the families based on shared care for the neonate (Ireland et al., 2019). Consistent with the literature, a difference in negativity was seen between neonatology medical staff and neonatal nurses (Bucher et al., 2018; Oei et al., 2000), and this may reflect a difference in the immediacy of day-to-day care, and social engagement with families. Families often visit the neonatal unit for many years following admission, and engagement with the family via social media has also enabled the staff to see babies’ progress. This does not often occur for many of the midwifery and obstetric staff who reported that they rarely know the long-term outcome of extremely premature babies. This may account for some of the differences seen between HCPs caring for families antenatally and postnatally and is an area which needs further research.

In contrast to our study however, Lavin *et al* (2006), in a large North American study, however, were able to show that obstetric and neonatal doctors were relatively consistent in their attitudes towards resuscitation except at the gestations below 23 weeks, and also relatively accurate in their knowledge of outcomes. Accuracy in knowledge and optimism towards resuscitation was also reported by Janvier *et al*. (2008) with no difference between obstetric and neonatal trainees in this regard. Accuracy and positivity appear to lead to consistency to an active approach to management towards those babies of a lower gestation in the services studied than in Australian groups (Lemyre & Moore, 2017; Srinivas, 2013). Our study suggests that local variations in positivity seen between HCP roles may be a marker that the care of vulnerable pregnancies may be less proactive and potentially contribute to poorer outcomes amongst the most disadvantaged groups.

Conversely, paediatricians appeared most positive in their attitude towards extreme prematurity. The inclusion in our study of paediatric staff adds evidence that positivity about families and their future coping is warranted. Whilst most had minimal exposure to the extremely preterm baby at the time of birth, they offer care to these children until late adolescence. These paediatric opinions have rarely been included in the literature about attitudes towards extreme prematurity, and this study adds valuable information about their insights. The junior paediatricians appeared less likely to consider active care for extremely preterm babies to be appropriate than their senior colleagues. Trainees had a perception that most of these babies have disability whilst the more senior paediatricians reflected that they did not see many severely disabled children from prematurity. Paediatricians from regional and remote centres were positive about resuscitating smaller babies as they perceive that many will ultimately do well. The paediatric attitude is the most informed in terms of exposure to disability of the child and the effect on the family, and their relative positivity suggests that the more negative perinatal staff may need to consider that their outlook may not reflect the true consequences as seen by those caring for the children later.

Remote residence is often linked with the poor provision of health care resources (CAPMC, 2017; AIHW, 2019). Some HCPs consider that active care should be considered at a higher threshold for these families. Conversely, exposure to working in remote areas was seen to modify one clinicians' opinion, who confirmed that children with disability may be more accepted within the communities in these areas. Another clinician who has worked in remote areas confirmed that limited access to disability resources did not lead most families to leave the area. Perhaps acceptance into the community is more important to some families than having more medical resources (Wakely et al., 2010). Our study confirms that families remain in their communities and find ways to access the care their children need. Thus, families themselves should be involved in decisions where aspects of their life circumstances are considered germane to care offered.

Personal experience of disability was uncommon amongst the participants. However, some participants recognised that they had markedly changed their views as they have become older. One HCP's views changed markedly after her initial interview once she herself became pregnant. Some staff appeared to have reflected on how they personally would cope with a disabled child, and these participants seemed more accepting of disability. Empathy and acceptance seem to have occurred where self-reflection was found. This suggests that HCPs may benefit from these strategies being encouraged within their workplace.

Implicit bias in periviable counselling by neonatologists has previously been demonstrated by Shapiro *et al.*, who suggest that clinicians who show negative bias towards socioeconomic status were more likely than those who did not show bias to recommend palliative (comfort) care when presented with a patient of greater socioeconomic status (Shapiro et al., 2018). The authors hypothesised that this could be because the clinicians identified more closely with these patients and that this reflected what they would choose for themselves. Our study suggests that this finding may be rather a result of implicit bias against the risk of disability, which those clinicians would consider unacceptable. Identification of personal bias is important in counselling parents antenatally using a model of shared decision making (Haward et al., 2017; Lantos, 2018a; Sullivan & Cummings, 2020). The suggested models presented by Sullivan, Lantos, Haward and others remind the practitioner to reflect on biases they may have towards race, socioeconomic status, and disability prior to meeting with parents in need of antenatal counselling.

Previous studies have linked implicit bias to racial minorities (Blair et al., 2013; Green et al., 2007), obesity (Teachman & Brownell, 2001) and gender (Rudman & Phelan, 2010), all with negative implications for patient outcomes. Implicit bias towards the risk of disability, as is seen in this study, should be added to this list and needs further exploration in terms of patient outcomes. It is incumbent on HCPs to identify and be aware of their biases and that they may need specific training in order manage these (Fitzgerald, 2014). Parents ask for hope and honesty from their HCP (Janvier et al., 2016; Jaworski et al., 2018). Negativity induced by the implicit bias towards the extremely preterm because of potential disability may remove hope and thus potentially do harm. The overwhelming majority of parents in this region will opt for full active intensive care for their babies (Ireland et al., 2019) and implicit bias among HCPs may impede their enjoyment of the babies, in situations where they have received a negative view of the long-term prognosis.

6.18 Strengths and Limitations

A strength of the study is that it has included participants who represent a range of experiences and disciplines involved in the care of periviable babies. Most of the senior clinicians in the tertiary service engaged in the interviews, with good representation at all levels of role and experience. The inclusion of paediatricians added information to the study because of their role in being able to review the longer-term implications of extreme prematurity and is an unusual inclusion in a study of this nature.

The study did not aim to investigate the differences in attitudes of various groups of HCPs, these differences emerged from the analysis of the data obtained when studying attitudes of HCP towards extreme prematurity. The constructivist methodology allowed exploration of this category as interviews progressed. This is both a strength of the methodology, but a limitation as deeper exploration may have been possible in a more focussed study.

One further strength of the study was the research team involved. Apart from the PI, the team includes a bioethicist who has studied ethics in the medical and paediatric fields, a senior university academic who specialises in qualitative research and has worked in the midwifery and neonatal fields but reflects regularly on her potential biases in her work, and a senior university academic with a background in general practice who has published extensively in qualitative research. The team provided a dispassionate group of opinions.

Limitations of the study include the geographical restriction of the study to three centres in North Queensland. Some of the findings may be relevant only to the area under study. Transferability of the findings needs to be considered in the specific context of other localities.

A further potential limitation of this study is the role of the primary investigator as a neonatologist working in the tertiary unit. She herself has opinions about the provision of active care for periviable babies, has researched their outcomes and is more positive than most of the participants, although aware of her biases. In addition, she knows all the senior participants having worked with them for several years. As a consequence, in an attempt to mitigate bias, interviews with many clinicians were done by a third-party unknown to the participants. Coding and analysis were done by the research group in conjunction with reflexive memoing.

6.19 Conclusion

Role dependent implicit bias can occur in some HCPs who care for families at risk of extremely preterm birth. Implicit bias may be a cause of inappropriate negativity in antenatal counselling and explain role-dependent differences in negativity as influenced by the function of the role itself. When implicit bias is present, the clinician will be more negative in their counselling and message framing. Identification of the positive benefits of resuscitation may not occur when an emphasis on disability is maintained. As a result, vulnerable families may not receive an accurate picture of the possible outcomes for their baby during antenatal counselling. Self-identification of implicit bias, and non-judgmental institutional efforts to enable staff to recognise their biases and correct these would help shared decision making with parents to ensure that the appropriate decisions are made from the family's perspective. All HCP need to understand how bias may affect their interactions with families, and it is important to ensure that all HCP are aware of the accurate data for babies as well as the potential for their own biases to influence families in decisions and function on the neonatal unit. Further research is needed to investigate whether negativity in attitudes persist when clinicians become aware and address their bias against extreme prematurity, and whether this in turn improves outcomes for our smallest patients.

6.20 Abbreviations

Abbreviation	Name
HCP	Health care professionals
NICU	Neonatal intensive care unit
MFM	Maternal foetal medicine

6.21 Ethics Approval and Consent to Participate

Ethical approval for the study was obtained from the Townsville Hospital and Health Service Human Research Ethics Committee and James Cook University (HREC/15/QTHS/194, JCU 6485). All participants provided written informed consent to participate.

6.22 Acknowledgements

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Moore, co-ordinator at the regional site and Michelle McElroy, co-ordinator at the remote site.

(COREQ see appendix 11)

6.23 Further Categories Arising from the Data

Similar categories arose in both the family and HCP studies.

6.24 ‘Who Decides’

Subcategories of ‘the doctor’, ‘the parents’, ‘collaborative’ and ‘no active decision’ emerged within this category (Figure 6.6). Doctors were most likely to imply that medical practitioners should be the final arbiters of decisions made about the provision of active care while other HCPs mostly agreed with informed parental autonomy or collaborative decision making.

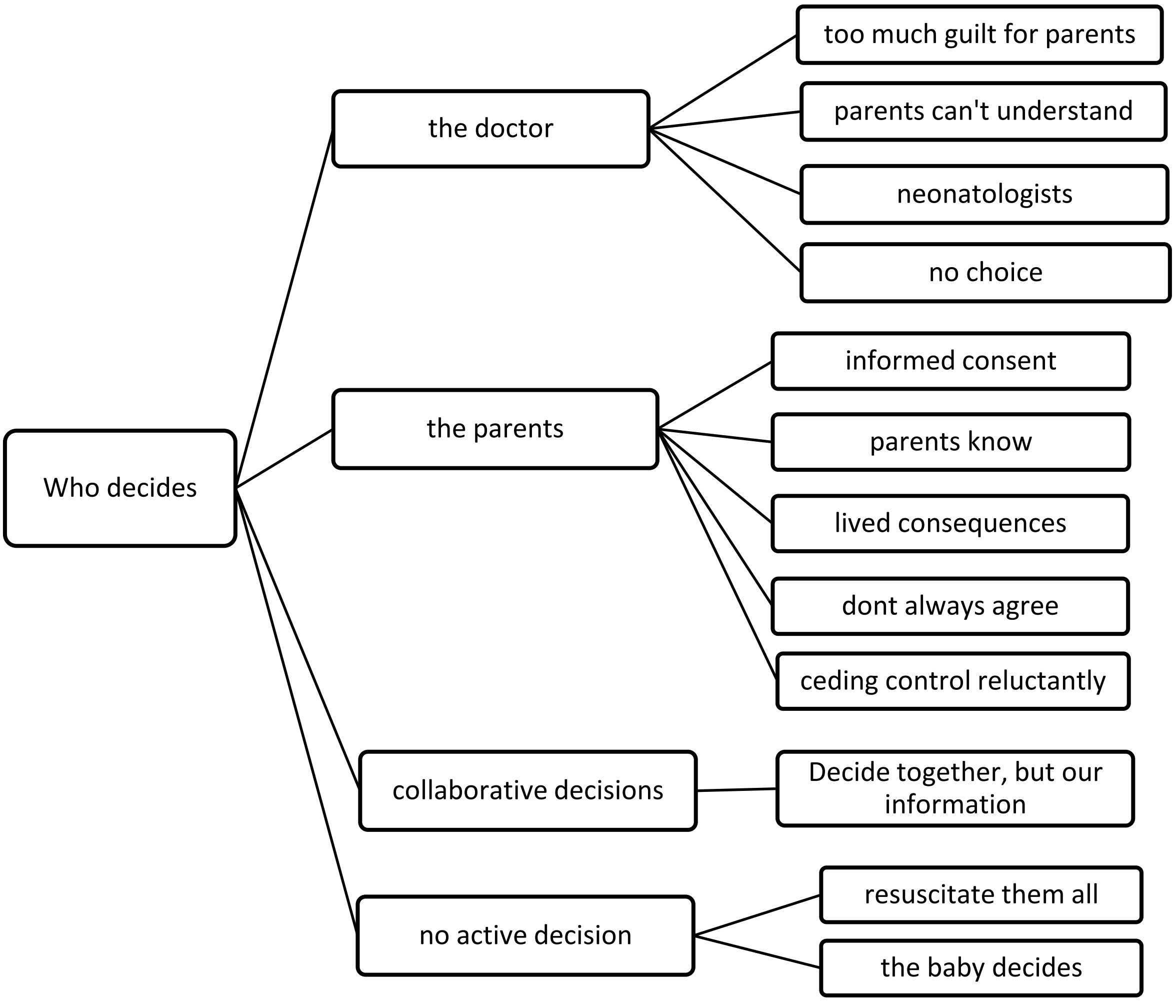

Figure 6.6 Subcategories and focused codes for ‘Who decides’.

6.24.1 The doctor

Data suggest that paternalism in medical decision-making may be the source of the subcategory of ‘the doctor’. Participants said that doctors should make the decision to offer active care because they are better informed of the consequences, less emotional, and the neonatologist is deemed able to decide on the viability of the baby at the time of birth.

6.24.1.1 ‘Too much guilt for parents’

The decisive role of the neonatologist was further reinforced in cases where parental guilt may be a factor:

> *‘I think when things are going badly that decision often should be taken off the parents because they will be living with a world of guilt if they’re the ones that are deciding we should end this and then they’re the ones that are left with the life of what if, what if.’*

(Neonatal nurse practitioner – HCP 27)

This paediatric trainee felt strongly that a policy removing parental choice would be preferable, so there would be no ambiguity about the doctor deciding:

> *‘Where it’s a child under the age of 24 weeks, I think the medical opinion – the medical professionals need to take more of the onus…I just feel that that’s too much guilt and pressure to place on the families. That’s why we* ***should*** *have a bit of a strict policy on below this, we don’t. ‘That’s our policy. We’re taking it out of your hands, so that you don’t have that guilt and emotional thing of, “Why didn’t we do it?”’’*

(HCP 4)

6.24.1.2 ‘Parents can’t understand’

Obstetricians particularly felt that the parents would not be able to appreciate the complexity of the medical situation, and hence the HCP should decide themselves:

> *'I make the decision on is the long term morbidity that the baby is going to have and the burden on the parents...All they want is the baby to be resuscitated but they don't have things like looking at the long term how the babies do and what neurological sequelae they could have like cerebral palsy and things where they have to - so I try to counsel them a lot and try not to be too pessimistic about things. But I try to give them information that it's not just survival but there's more to that. That's the only thing I look at. If it was … I would say no up until I get to 25 weeks.'*
>
> (HCP 14)

Paternalism in decision-making is recognised, yet justified by an obstetric trainee:

> *'I think - it sounds very paternalistic, but how can you ever make a parent understand what it's like to have that child survive for a little while and then die, or - I think there comes a point where we have to use our experience to help make those judgments.'*
>
> (HCP 30)

6.24.2 'Neonatologist takes the lead'

Neonatologists take the lead for the medical provision of care to the sick neonate. Their right to decide to offer or decline care was noted by several HCPs:

> *'At that stage literally all I can do is when your baby is born this is what we're going to do. So, there is no informed consent, there's just this is what we're going to do. It boils down to that resuscitate first and ask questions later in those sorts of situations.*
>
> *I think the senior neonatologist consultant need to be the one to offer because it's the care that they're offering I think the offer needs to be made in conjunction with the parents in question but I think the final decision is up to - should be up to them as to whether they are going to.'*
>
> (Senior neonatal trainee - HCP 9)

This attitude applies equally to decisions to continue care in the NICU:

> *'I would say when it comes to whether to either resuscitate or continue intensive care, it will be a joint decision in our unit. But the majority of the time the neonatologist take the lead.'*
>
> (Neonatologist - HCP 7)

Clinicians identified that they may defer decision-making until the birth of the baby. This is based on a belief that an assessment of the condition in the moments after birth is accurate enough to determine the outcomes for the baby.

Sometimes the decision appears to be with the knowledge of the parents:

> *'In terms of attempting resuscitation, I think my practice has been to at least be there and assess the baby based on the features, condition, some people say the size. But I think within two or three minutes you get a quick idea whether you should be tubing this baby or doing anything more, or just hand the baby to the family and follow the palliative route. I think it's a tricky situation and I think a lot of people put it to the parents…at 23 weeks I don't think that's the right approach to leave it to the parents…Maybe, while you would respect their wishes, still take the responsibility and say, this is a really bad case and it's only very slim chance. I'm going to give your baby a slim chance but it all depends what they do in the first few minutes of life. Then leave it at that.' (Regional paediatrician – HCP 31)*

At other times it may be at the discretion of the clinician:

> *'I mean if your baby is born at 25 weeks with no heart rate, let's say blue, or with a very low heart rate and very poor respiratory effort...I have to be honest with you in my time…I've not intervened for a lot of 25 weekers.'*
>
> (Neonatologist - HCP 7)

6.24.2.1 'They wouldn't get a choice'

Several clinicians voiced clear beliefs about their own right to offer resuscitation, limiting parental discretion to a narrow, clinician dependent, gestational age:

> *'If they are one of the small number of parents who want everything done for their babies then at 22 weeks I refuse… at 24 weeks they - at least with me they get the choice of - I don't really put it to them that it's your choice whether we treat the baby or not but that's the gestation where they get a choice. I would expect to treat most 24 weekers but I would put it to the parents that they've got an option…I've as of yet to come across anybody at 25 weeks or over who doesn't want their baby resuscitated so I've never had to have that argument. But they simply would not - if they came across me, they wouldn't get a choice.*
>
> (Neonatologist – HCP 10)

Similarly, this regional paediatrician expressed that there should be no parental discretion at 24 weeks:

> *'If the parents say I don't want you to resuscitate my 24-week baby, I would feel uncomfortable actually because I've seen them doing so well. If they're obviously born in really good condition, you want to give them the best go…But I think I would feel uncomfortable not doing anything at 24 weeks and above. So that's probably an area I don't agree with the guideline.'*
>
> (HCP 31)

The power of the neonatologist in message framing is recognised by this paediatric registrar:

> *'I think the neonatal team is making the decision to - oh I think the parents are making the decision to do it, but I think the neonatal team is doing it [making the decision] for them in a way.'*
>
> (HCP 6)

6.24.3 Parents

In contrast to the views expressed by senior medical professionals; midwives, nurses and trainees were more likely to advocate for informed parental choice. Parents required information but were deemed to be able to assimilate this information and evaluate their options in the context of their own lives. Parental autonomy was considered positively for most, although with an element of defeatism by some participants who stated that allowing parental autonomy was inappropriately ceding HCP control.

6.24.3.1 'With informed consent'

Informed consent was a recurring theme. Midwives suggested that where options were given, informed mothers should decide providing they knew the consequences. Several noted that midwives were uniquely placed to help facilitate decision making:

> *'I believe that the woman is very much - it's her birth, it's her baby, but also within the family, and we're there to facilitate them to make the right decisions for themselves, rather than me telling her what to do. It doesn't have to be the decision I would make.'*
>
> (HCP 13)

For many participants, the emphasis in information sharing needed to include the potential negative possibilities for parents to be fully informed. Interestingly, no participant included any positive possibilities in their comments:

> *'I think if a parent thinks we should resuscitate, then we do need to put a certain amount of weight in that, particularly if we have educated them regarding the complications that are a – that a potential of this child having epilepsy and long-term disability. If they're understanding of that and want resuscitation then I think we probably should give it a go.'*
>
> (Paediatric trainee - HCP 4)

> *'I think it should, after a lengthy discussion and they understand the implications this preterm infant can have in the future like learning disabilities, oxygen, hearing, eyesight, everything like that; if they understand that then it's their decision. But that's after a lengthy discussion and they know everything, worse possible scenario.'*
>
> (Midwife – HCP 20)

6.24.3.2 'Parents know what they want'

Across the disciplines, a few participants recognised that parents have their own life histories and may have previously considered the possibility of potential impairments. They reflected that parents are aware of their capacity to cope with adversity:

> *'There's some people who definitely have said I can't deal with a disabled child and they're very black and white with - but obviously they've thought about that and they've had something in their history, past family or something that says I can't deal with this.'*
>
> (Neonatal nurse – HCP 3)

> *'They might be happy to have a child that's wheelchair bound and needing frequent suctioning, that will never go to a mainstream school, and have an early death with seizures…On the same thing, if a parent says, I don't want to resuscitate this 25 weeker, I don't think that our family would be able to manage for whatever reason. We've got five other children and we don't have the resources to do that. Whilst you might normally for another family resuscitate a 25 weeker, I think you need to take that family context into understanding as well.'*

(Paediatric trainee – HCP 4)

> *'You will find most of them, at that 20-week scan, if they have found any abnormality or anything, they'll either make an option then of terminating or continuing. I think parents are so well informed about things like these, these days, that they have already made up a decision, and it wouldn't matter what you say at the end.'*

(Regional neonatal nurse practitioner - HCP 22)

Often parents who choose differently to the HCP were deemed too emotional and lacking understanding of the consequences:

> *‘Most of the time parents will make sensible decisions in the light of information we give to them. I can think of a few occasions when the parents insisted on - so one of the things is parents will be very emotional at the time, so they may not be processing the information that’s given. One situation I was involved in, the parents had already been counselled about the poor prognosis, and when I went to clarify what exactly the decision was regarding the care, at that time the parents wanted us to do everything for them.’*
>
> (Senior neonatal trainee – HCP 21)

6.24.3.3 ‘They live with consequences’

There was a general understanding that parents expect to return home with their offspring and regain parental authority. Any consequences from the periviable delivery will be the parental responsibility, which some HCP recognised as the reason for parental autonomy in decision making:

> *‘Because they will have to live with the consequences, but they would have to be the carer of the baby, should the baby survive. I think the treating clinician can give their opinion’*
>
> (Neonatologist - HCP 8)

In recognising the uncertainty individual babies have for the future, and difficulty in predictions, one neonatologist expressed this pragmatic view about parents living with the consequences of decisions to offer and continue active care:

> *'I can't predict the future very well and say some are not as bad as you think. But there are also some babies that are just atrocious and the parents are definitely in denial about what's going to happen. But that's their life, not mine…that's fine for them, they don't mind if their children don't grow up as normal.'*

(HCP 10)

HCPs were cognisant that personally they might not make the same choices because it is not their lives that would be affected. This neonatal nurse often cared for babies where redirection of care might be suggested by medical staff, but rejected by the parents:

> *'At the end of the day as much as it's hard for me to see patients with really, really excessive impairments come back or survive it's the parents that have to look after them and so it's - my values are important but their values are almost more important. I need to know where they're at because the ones who are going to then follow out on those values at home'*

(HCP 12)

Another neonatal nurse practitioner voiced this position succinctly:

> *'I think it should be the parents' decision because it's their body, their baby, their life.'*

(HCP 27)

6.24.3.4 'Parents are not always united'

Parents are not always united, and whilst parental decision-making may have been encouraged, each parent may have a different perspective:

> *'We asked her a couple of times, this - it might have gone on three times where we got to that point [of considering redirection to palliation] and each time he said yes [continue with active care] and each time the mum said "no I can't do this" and she said "well I suppose I'll have to if he wants it to keep going I'll have to." She cried the whole time she was here, she cried for the whole three months.'*
>
> (Neonatal nurse - HCP 3)

6.24.3.5 Ceding control, reluctantly

HCP from across the spectrum perceived parental autonomy negatively, reflecting that doctors no longer had choice to make resuscitation decisions:

> *'I suppose - because the doctors don't take the decision anymore, it's been a long time since that's happened and it's always up to the parents.'*
>
> (Neonatal nurse - HCP 3)

Other HCPs noted that if parents are offered choices, their decisions would need to be accepted.

> *'Once you then offer up the opportunity of choice then it becomes very difficult to take that choice back away from them again.'*
>
> (Senior neonatal trainee – HCP 9)

> *'If you're presenting them with options you're obliged to give them the final decision because otherwise why offer them in the first place.'*
>
> (Obstetrician – HCP 17)

This remote paediatrician was also concerned that there could be a negative backlash from the community in the small centre where she practices if the HCP did not cede to parental request for resuscitation:

> *'If the parents want everything to be done we don't have a choice. I often feel we don't have a choice because of the repercussions.'*
>
> (HCP 29)

6.24.4 Collaborative decision making

Following the provision of accurate information to the parents, collaborative decision-making between HCP and parents was suggested by participants – but rarely by neonatal HCP. The way facts are presented was recognised as important:

> *'(If) they want to resuscitate the baby it needs to be a medical decision as well. Sometimes it has to be a medical decision but it would be good if they can have a collaborative decision but sometimes it depends on how we present too. So we need to present in such a way that helps the family make a decision and we shouldn't leave it up to them to tell us whether they want to resuscitate or not.'*
>
> (Paediatrician - HCP 16)

The appearance of collaboration, however, may also be manipulated to ensure that the HCP preference is followed – in this case by guiding parents to do the 'right thing':

> *'It is not easy…too much information given to them and too little time when they are under extreme stress and distress… So they are looking at us to guide them to make the decision. They are looking towards you although you need to provide the right information and let them make the decision. It is hard for them. So you feel like you help them make the decision but at the same time it looks like you are guiding them into what you think is the right thing.'*
>
> (Obstetrician HCP - 14)

Several participants noted that shared decision-making could help parents to cope emotionally with the consequences of the decision, particularly if active care is not pursued. This Indigenous Liaison Officer reflected that parents need to feel that they were active participants for their own long term mental wellbeing:

> *'I think people need to be - feel that they are part of decisions. If they are taken away from them I think they continue to go through them for years and years yet to come. Where do they blame back, that the doctor didn't tell me that. So I think they need to be along the journey with knowing that information.'*
>
> (HCP 19)

Parental recognition may even be evident in the immediacy after a shared decision is made - in this case to offer only palliation for 24-week twins:

> *‘This instance I am thinking of they very much felt like they were a part of the decision themselves and it was very much - they had felt that they had made the right decision. Although they were distraught with it they were happy that they had made - that it was them and that was a mutual sort of thing.’*

(Midwife – HCP 24)

6.24.5 No-one decides

6.24.5.1 Just resuscitate everything

Several HCPs, particularly junior staff, perceived that there was an underlying assumption that at TUH, resuscitation for periviable babies occurs automatically. This may be in the context where there has been inadequate time for discussions with the parents, but the data were not clear.

> *‘No, I think we go in with the assumption that we’re resuscitating everything.’*

(Paediatric trainee HCP 6)

> *‘At that stage literally all I can do is when your baby is born this is what we’re going to do. So, there is no informed consent, there’s just this is what we’re going to do. It boils down to that resuscitate first and ask questions later in those sorts of situations.’*

(Senior neonatal trainee – HCP 9)

6.24.6 'The baby decides'

> *A recurring code from neonatal staff, medical and nursing data, was that babies decide whether to live or die. This may be at the time of birth: 'if the baby has effort when it's born then we'll resuscitate. If the baby doesn't have effort when it's born then we won't. Then it's like the baby is making a choice.'*

(Neonatal nurse – HCP 12)

> *'Sometimes we don't know what the parents want, so we go ahead and try. Sometimes the baby doesn't survive, so I think there's the decision has been - baby makes the decision. That happens sometimes. The parents say yes and we say yes, but the baby doesn't live.'*

(Neonatologist – HCP 8)

The baby may also be deemed to 'decide' if they die later in the NICU course:

> *'Every now and again there has to be a situation where you go come on, enough is enough, these babies are telling you what they want. I remember his father telling the story of what happened around about the time that this little baby had died and it was that whole kind of - and he basically said something to the effect of "he looked at me and I knew that what he was trying to tell me was that enough was enough and he just wanted to go." These babies just kind of go "I'm done, like seriously, like I'm trying to tell you, you need to let me go."'*
>
> (Senior neonatal trainee – HCP 9)

In communication with parents, nursing staff imply that the baby will indicate that it is time for redirection to palliation:

> *'So I say to parents - because often the doctors will go in and talk to them and then when the doctors go out they will say, "What would you do if it was your child?" I just say to them "No parent should ever have to make that decision. But you as a parent will know when your child has had enough and can't go on." That's telling the parent that you as a parent shouldn't have to choose. Your baby will make its decisions or you will know as a parent.'*
>
> (Neonatal nurse – HCP 3)

It was suggested that if the baby did not die as expected when life support was removed, this indicated a conscious will by the baby to survive:

> *‘Or worse still if the baby decides it’s going to stay alive and it’s got severe brain damage and you turn off the life support and it just won’t die…Outcome-wise it all depends on the baby. I think the babies decide at the end of the day.’*
>
> (Obstetrician – HCP 18)

6.25 Summary of Findings for the Category of ‘Who Decides’

- Most senior clinicians believe that the doctor should make the final decision about whether or not to offer active care. They feel that parents should not have to live with the guilt of decision making and are unable to truly understand the potential negative consequences. Neonatologists are usually the designated doctors for decision making, particularly at the time of birth, in the belief that the condition of the baby at birth will predict of how well the baby will fare in the longer term. Personal opinions voiced suggests that there is a variation between clinicians in their beliefs.

- Midwives, nurses and some junior medical staff were more likely to suggest that informed decision-making by parents allows them to be the final determinants of active care. There was a recognition that parents may know what risks they wish to take, and ultimately need to live with the consequences of the decisions. Emphasising negative outcomes, particularly at the most severe end of the spectrum, was important during counselling for parents to be deemed informed. However, some clinicians were concerned that allowing parental choice was ceding medical authority.

- Allied health and midwifery staff recognised the importance of collaborative decision-making for the future mental health of parents. Whilst some senior clinicians advocated for shared decision-making, they acknowledged that message framing could lead to the appearance that decisions were shared, whilst the clinician may have counselled the parents towards their own preference.

- There was a perceived workplace culture by some junior staff that all periviable babies are resuscitated as a routine at TUH. In addition, babies themselves ‘choose’ whether to be resuscitated.

6.26 ‘The Culture and Context of Families’

Social and demographic factors which might influence counselling, or decisions by either HCP or parents about resuscitation emerged as a category. Subcategories of ‘regional specific’, ‘judging parents’ and ‘social influencers’ (Figure 6.7) were found.

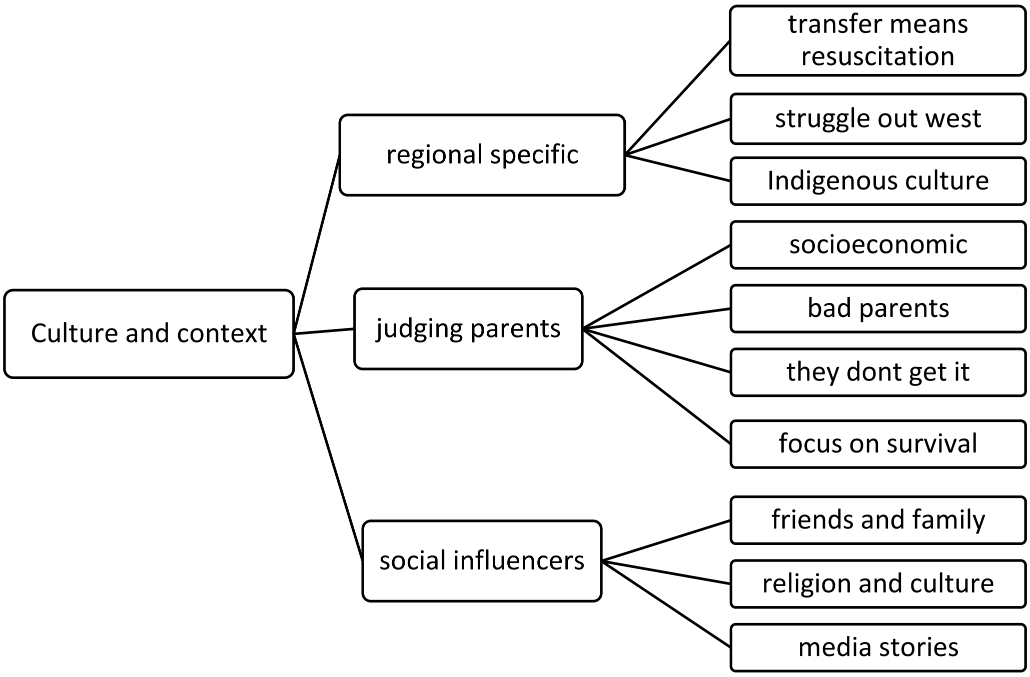

Figure 6.7 Subcategories and focused codes for ‘Culture and context of the family’.

6.26.1 Regional specific

6.26.1.1 Transfer means resuscitation

Many of the patients at TUH are from regional and remote locations. Complications in the pregnancy may entail antenatal transfer to TUH from home at a relatively early gestation, transfer near the time of delivery, or retrieval of the baby after delivery. HCPs reported that transfer into TUH is primarily the decision of the obstetric team, often with no counselling from the paediatrician from the referring hospital, or the neonatal team from TUH. This is perceived by the HCP to lead to inevitability towards active resuscitation for those families from out of the tertiary area.

> *'23, 24-weekers, they're on a plane out of there before we even sometimes get to chat to them as well, from the nursery side or a paediatric side. We get them out - normally it's just the obstetric team that have quickly spoken to them and got them on a plane.'*
>
> (Regional nurse practitioner – HCP 22)

In remote areas, there may be no obstetrician, and a local medical officer may have to provide counselling for imminent deliveries. This obstetric trainee had previously worked in a remote community, and reflected the reality which some HCP face when trying to decide if a periviable baby should have active care:

> *'I've spoken to parents, because I'm the only medical officer in that situation, so when I've worked remotely there's only been me where we've been dealing with fairly imminent deliveries that we expect and prepare for babies to be delivered before the retrieval team arrive. So sometimes I'm the one that's in the position of having to counsel patients about - about what the outcome might be and what they might like to do in terms of resuscitation.'*
>
> (HCP 30)

An obstetrician at TUH suggested that transferred patients have the expectation of resuscitation because they have been transferred in:

> *'When they come to Townsville they expect that when baby is born it will be resuscitated. But only after you counsel them they do get the point that it's not as simple as once they reach 24 weeks everything is going to be okay, so it's depending on the individual situation. So counselling does make a difference but their general impression when they get here is they will be offered resuscitation.'*
>
> (HCP 14)

6.26.1.2 'Struggle out west'

Differing perceptions about health care and community support for families from remote locations were evident. Tertiary based staff were noted to be more negative about offering active care for periviable babies whose parents reside in remote areas than HCPs outside TUH. Some HCPs had the perception that the services in remote areas are very poor, and a child with serious impairment exerts an immense burden on the family:

> *'You see a lot of people coming from western communities, in the middle of nowhere, people struggle with a baby with high needs. I think where you live, what medical supports, what social supports, you're going to rely on for you and the baby, that's very significant for us especially in a somewhat remote area…That's important I think like the people from remote areas, you need to keep in mind what's going to happen to the baby once it's born. If you had a 23 weeker, who comes from western Queensland, and [they live] on property and they need to go back there, that's where their work is. That will influence me that a morbid baby is not going to do very well, or be high needs in western Queensland. That family sometimes will need to move to a place to a major centre, and it can wreck their life.'*
>
> (Tertiary obstetrician – HCP 25)

However, other staff who have remote experience thought that increased hardship because of remote location did not reflect their experience, particularly as the communities themselves were more accepting of difference and rallied around to support the families:

> *'In the remote communities a lot of families do accept children with delayed milestones and whatever. They are accepted in society and the expectations are not as much as our city folk.'*
>
> (Remote paediatrician – HCP 29)

Additionally, support was expressed for using newer technology, and preventing discrimination because of remote residence:

> *'With technology and travel subsidies, those barriers have gone, in my experience, in our region at least. So we can provide telehealth services, families are encouraged to travel to tertiary centres if they need to. I don't think long term it should be any differentiation where your postcode is. I think you should be able to provide the same care wherever the babies come from. I think I'm a strong advocate of that.'*
>
> (Regional paediatrician - 31)

6.26.1.3 'Indigenous culture'

Cultural overlays were found to influence decision making. The over-representation of Indigenous babies in NICU has been previously discussed (Chapter Two). Although differences in decision making for Indigenous families were not specifically sought apart from the focus group, some HCP did mention that they perceived differences because of cultural factors. Indigenous women from remote areas transferring to TUH often come into a stressful environment without supports. An ILO described it thus:

> *'Okay, if I'm living in Doomadgee or Aurukun or Kowanyama chances of me going to see a doctor in my first trimester is low because they fly in, fly out…So you discover late in my pregnancy that I've got something wrong with my baby. You've got to go to Cairns, Townsville. You know what, I'm digging my heels in. "No, I'm not going because I'm scared. You are telling me there is something wrong with my baby and now you want me to go to this place where I know no one, I've got no community, I've got no supports, I've got nothing. Then I'm going to be in this room with all these white people and they are going to tell me all these things. I'm just going sit there and go - because it's easier than having to respond. So I'm just going to say, yep, okay. Okay. Okay." Because you are right, a white person comes into the room and they shut down straight away and they are just nodding yes.'*
>
> (ILO - HCP 19)

Some Indigenous communities have culturally sanctioned practices where shame and blame are negative burdens to carry:

> *'But was it the impact when you go back home, did you kill your child? Did you not want them to do as much as they possibly can, blaming kind of factors?*
>
> *All of a sudden that spotlight's on you. You go, God, I'm so ashamed. So it is that shame thing as well.'*
>
> (ILO – HCP 19)

The burden of decision making is often placed on the mother:

> *'We don't talk a lot about fathers either and what their perceptions are and how in our culture it's sort of women's business and that's left up to a woman to decide'.*
>
> (ILO – HCP19)

A different situation may occur for Indigenous women who live in urban areas. The ILO describes her own daughter's pregnancy, expressing how the individual context of the mother may be different in terms of decision making because of urban differences, rather than being solely defined by her Indigenous status:

> *'I think if you are looking at an urbanised black person if they've got access to lots of resources, they've got social workers, they've got internet, they've got midwives, they've got everything there. But then she is an educated young black person. She sees disability, and it's talked about within her group and at home. So it's talked about like, 'if I ended up in intensive care, don't let me be a vegetable. I don't want that. I don't want to be disabled.'...I think times are changing a little bit.'*
>
> (ILO – HCP 19)

Whilst counselling of Indigenous patients often occurs together with ILOs, the ILO suggested that Indigenous Health Workers would be more helpful in assisting women with decision making as they would have more ability to understand health issues than the ILO:

> *'If you have a health worker with you - not a liaison officer, we need someone clinical here that has got that health work experience. We know bits and pieces about it but if you train a health worker, an Aboriginal person, about pregnancies and abnormalities in pregnancies I think that that person may have a little bit more success than what you or I will ever have.'*
>
> (ILO – HCP 19)

A minority of HCPs described negative stereotypes and racist observations about engagement of Aboriginal and Torres Strait Islander parents in decision making processes. Views varied from this racist view which stood separate to most concerns with Indigenous decision-making and lacked any understanding of the complexities of post-colonial struggles amongst Indigenous populations or how the health sector/NICU might be less than culturally safe and welcoming:

> *'I think the ones [Indigenous parents] who I've come across who are more concerned are the ones that are like white people who have - not high jobs, but are high functioning compared to even the lower functioning Caucasian people...I think there is a difference between the races…I think the Indigenous people don't actually ask much, because I don't know if they have the capacity to understand what that means. Some of them, I've found, don't even really turn up anyway. They're not coming to hospital and they're not really participating very much…they don't seem interested.'*
>
> (Neonatal nurse – HCP 5)

In contrast, the more common view HCPs expressed demonstrated an awareness that there are clear cultural challenges for some Indigenous families:

> *'It's very difficult to gauge what their level of understanding is. You know you get them to repeat what you say, often they are a little bit reticent, or uncomfortable maybe is the word to say. I think the communication styles are different. Obviously, they don't have as much eye contact. But the interesting thing is once they are in the nursery you build up relationship with them very quickly. I think honestly antenatal clinic for the antenatal period when things are likely not going to go well is challenging for any young couple. That in the majority of the time in our unit, we always get parents, even when they are very young, involved. With Indigenous [people] almost always there'll be elders in the equation.'*
>
> (Neonatal nurse – HCP 7)

Decision making was also perceived to be different for some remote residing Indigenous women, with varied reflection about the available supports. Remote residing Indigenous women were considered much less likely to terminate a pregnancy for abnormalities than non-Indigenous women with the extended family more involved in caring for the child:

> *'I think there is much more of a sense of community when you live somewhere small and I think those children are often much better accepted by the community when you live in a small environment. I notice that Aboriginal women, or Indigenous women, are much less likely to terminate a pregnancy based on an abnormal finding, but those children are then very much embraced by the community. Whereas I think you don't have that same sense of community when you live in a bigger place. I think when you live in a community of 200 or 300 or 400 or even 1000 people where everybody knows everybody it's very much that - you know that saying, it takes a village - you really see that in those kinds of places. Those children are often cared for by a very big extended family and parents often have much more support than they would if they lived in a bigger city.'*
>
> (Obstetric trainee - HCP 30)

6.26.2 Judging parents

Perceptions about a parent's abilities or right to choose active care based on the emotionality of parents, their socioeconomic status and their prior parenting record were evident in the data. Most HCPs recognised that the baby was a separate entity and that parental adversity should not be reflected in decisions made.

6.26.2.1 Socioeconomic status

Opinions included some concerns that a family who has financial struggles, or is reliant on government support should not have a baby resuscitated who is at risk of subsequent difficulty because of the possible financial burden:

> *'I don't know whether we should allow parents who are already on welfare to have babies that are going to need support. It's just - if, when they're already on welfare, how can they support a baby who needs disability support? How can they afford that? None of that's really taken into consideration, is it? Not usually.'*
>
> (Neonatal nurse – HCP 5)

Most of the participants recognised that families with adverse social circumstances are disproportionally represented in admissions, but that socioeconomic status should not form part of the data used to assess suitability to resuscitate:

> *'I don't think that you should be saying well you're homeless and live in a park so therefore your baby isn't going to be resuscitated as opposed to the lady next door who spent $10,000 getting her IVF. I have huge issues with that.'*
>
> (Senior neonatal trainee – HCP 9)

6.26.2.2 'Bad' parents

Illicit drug taking and alcohol abuse elicited concern for some HCPs. There was a perception that active care for periviable babies should not be offered where the HCP deemed the parent's ability to care for a baby at risk of disability, would be compromised:

> *'I think whenever we look at a child or any babies, you need to look at them in a context. The community context, the family context, first and the community context. If you think it's a little baby who was born 23, say 23 plus a few days and then there were lots of drug and alcohol issue and lot of other problems in the family. You know they are not going to get the best care and I think that should be influencing our decision.'*
>
> (Tertiary paediatrician – HCP 16)

However, mechanisms to escalate concerns about the future safety of the child were recognised, and these should continue separately to any decisions made about the medical management of the child:

> *'I think that that's harder because certainly it looks like outcomes might be worse if there's a background of a poor family situation already there and if you're worried that they might not do well once going home, but I guess that's an independent child safety concern that we would - that I think would be probably be better to pursue through that - if you actually had concerns…if they were not able to care for the child when they went home, rather than change any of the management while they're in hospital.'*
>
> (Paediatric trainee - HCP 6)

Decision-making about babies from adverse family situations was succinctly summarised by this participant when asked about social and environmental factors for families:

> *'Not at all. It's a baby we're talking about. It's not about the mothers' lifestyle.'*
>
> (Neonatal nurse – HCP 23)

In association with socioeconomic and lifestyle concerns, the term ‘precious baby’ was often used. Usually this was to reflect that the phrase was distasteful and should not influence decision-making.

> *‘Recently someone else was talking, “oh, that baby is precious”. My question is, every baby is precious for every parent, even if it’s their seventh, eighth baby, that’s still for them it’s like the first baby, a precious baby.’*
>
> (Paediatrician – HCP 28)

> *‘Precious baby annoys me intensely. Absolutely frustrates the hell out of me for my own personal reasons I absolutely hate it. I think that every child born should be given an equal chance at life.’*
>
> (Senior neonatal trainee – HCP 9)

Of interest, only one participant provided examples of situations where one baby is more deserving of resuscitation than others:

> *‘Working on the unit you do get the impression, as horrible as it is, that some babies are more precious than other babies to their family. So parents who are older or who’ve been trying to conceive for a really long time and this is their last chance baby, those sorts of situations, yeah, I think that should be taken into consideration when there’s a could go either way situation. I feel like it could be taken into account as reasons to resuscitate but not reasons not to resuscitate.’*
>
> (Paediatric trainee – HCP 6)

6.26.2.3 'They don't get it'

Participants frequently discussed parental capacity for understanding the implications of decision-making. The data suggest that there may be a perception that some parents are too focused on survival to understand information or may be incapable of understanding the implications of disability by virtue of inexperience or emotional stress.

HCPs frequently stated that parents are unable to understand the implications of a poor neurological outcome. Some suggested that this lack of understanding was associated with the emotional turmoil of a sudden need to deliver the baby early, whilst others indicated that parents were unable to comprehend how their lives would be impacted by severe disability:

> *'But I think if someone doesn't know anything about long term outcomes and developmental delays, then they're all going to say yes, I want my baby resuscitated. But are we adequately counselling them and showing them what the picture could be like in five or 10 years? I don't know that we are. I think we would have to use more than just sitting and talking to a family.'*
>
> (Midwife – HCP 11)

> *'I think sometimes, with some people, they would probably be prepared to take that information on board and, most of the time, would make the right decision, but I don't think some people have the intellectual capacity to be - to understand the gravity of if you have the baby at this age - what that means long term. I think for the disabled babies who are known antenatally should really - their discussions should be, really, a bit more - [sighs], I don't know, heavy. They should really be a bit more stronger. I don't know if the neonatal doctors should be there or not, or neonatal nurses, because I don't know who the - obstetrics are doing the discussions or the - it doesn't feel like the people who we've seen really understand until, often, it's too late, like with K's mum: why is he screaming so much. I don't think she really understood.'*
>
> (Neonatal nurse – HCP 5)

For a few of the HCPs, a parental decision to request active care for a periviable baby equated to inadequate counselling. Several participants cited shock tactics such as exposing the family to children with severe disability as a means to enhance a negative view of potential disability, particularly where the postnatal course is complicated by events which may worsen the neurological outcome:

> *'I'm assuming they've had a reasonable amount of information but I honestly think they probably haven't taken it in despite the conversations they've had with neonatologists and consultants and stuff…I've always said it, that I think if babies have had significant bleeds in the brain and they still want to continue treatment that they should go maybe down to kids ward or meet a parent who was in that situation and their child now down the track. Just to say hey, well this is a possibility, a child that might have cerebral palsy or significant issues. I think they need to see what could be because they can't visualise that at this point in time when they're here with us.'*
>
> (Neonatal nurse – HCP 2)

Many HCP considered that parents were generally incapable of understanding how difficult disability could be to manage:

> *'They think the baby is easy to look after, even with disability but they don't look at the long-term prognosis and their disability long term. I don't think they understand,'*
>
> (Paediatrician – HCP 16)

The effect on family function of both the neonatal course and longer term was also raised:

> *'They don't realise the stress it will have on their family situation other or their relationship as a couple often. That's really underestimated. There's often a diverse opinion about - especially if there is an early sign of long-term problem. You often see the two split their opinions and be on separate sides of the fence about how they feel about it and the juggle just to be here.'*

(Neonatal nurse – HCP 12)

The parental need for hope for a typical outcome was noted repeatedly in the data. This junior obstetric consultant described her experience of counselling families at risk of an early birth:

> *'Most times they are not aware of what are the risks, the long-term sequelae that the babies are going to end up with, so how will the baby do. Yeah, it's mostly how will the baby do. They are looking at hope, like they all would say they want the baby to be resuscitated'*

(HCP 14)

However, an obstetrician with more experience voiced concerns that hope, when displayed by parents, could well be misplaced:

> *'The trouble is you always have that hope don't you and I think that's the trouble with parents'*

(HCP 18)

Again, however a senior neonatal nurse reflected on the normality for emotions to impact on decision-making:

> *'They think with their hearts. I think they are very emotionally attached and often they can't see past the baby. I think that's normal.'*
>
> (HCP 27)

6.26.2.4 Focus on survival and impact of emotional stress

The data often demonstrated the impact on parental emotions of decisions made around the time of delivery. This paediatric registrar had previously talked to a set of parents about the early days of the care of their baby who had severe pulmonary hypoplasia. She described how the parents had reflected their experiences to her:

> *'They told me that retrospectively they had no idea that their child was [nearly] dying and that they didn't understand what was going on in that first 24 hours. They were explained it because I was there, but that they just had no idea and that they weren't sure they did the right thing in saying, yeah, sure put them on nitrous. They weren't sure that that was the right decision for them to have made, but retrospectively they were happy with it because their kid had a good outcome, but they felt that they couldn't make good decisions in that first 24, 48 hours.'*
>
> (HCP 6)

During the initial stages of care both antenatally and postnatally, parents are understood to be focused on survival rather than longer term implications of periviability.

> *'How long will the baby be here for? They're focused on the here and the now and is my baby going to live? Has it got bleeds in the head? Is the infection going to get better? They very rarely ask about down the track or have you seen babies born at 25 weeks and are they okay in a year or two? Very rarely do they ask that question in my experience.'*
>
> (Neonatal nurse – HCP 2)

The regional obstetric trainee had noted this focus on survival when she had previously talked to parents of a periviable baby:

> *'They might have a bit of idea about survival, but they don't have any, or a very limited, understanding of the deficits that an extremely premature baby may have in the long run. I think it's something that's very difficult when you're in that situation to talk to them about, because they're focused on whether their baby will survive or not and they're not - they find it hard to comprehend those - what it might be like to raise a child with a disability, because they're so focused on survival or not.'*
>
> (HCP 30)

One of the senior neonatologists has extensively studied the use of audiotaped consultations with parents either antenatally or at a time when adverse events occurred in the NICU. His focus had been on the recollections of parents of discussions about the diagnosis and future implications of current difficulties the babies were having. He raised concerns about the ability of parents to give informed consent in an emotional state. His experience was reflected in this comment:

> *'It's very difficult to be honest. Again, what's the definition of informed consent. I told you how six mothers didn't even remember the conversation happening. Even though it's been recorded. I gave them a copy of the cassette at the end of the trial. I said this is the consent you signed'*
>
> (HCP 7)

Although many participants reported that parents focus on survival, a neonatal registrar commented that this focus may be perceived by parents as their role regardless of the morbidity:

> *'It can be sometimes difficult to tell what is driving their decisions. As you can expect, they'll be looking from the point of view, as a parent they want the best for the baby, and they want everything to be done for them. I think they're fulfilling their role as parents, and they want that baby to survive.'*
>
> (HCP 21)

6.26.3 Social influences

Staff recognise that there are external influences on parental decision making including family and friends, religion, culture and the media. These external influencers will form part of the belief system of the parents and are their support system where decisions need to be made.

6.26.3.1 'Friends and family'

In some situations, where an unborn baby is known to have an abnormality, there is time to consult the family about decisions. A nurse, who herself had faced the prospects of extreme prematurity, reflected about her feeling on external supports when discussing the possibility of a baby with Trisomy 21:

> *'Generally in those situations you have time, you can talk to your family and your friends and they are all going to give their opinion, which it does have an effect on you… so if they have done an amnio or whatever and got Trisomy 21 or 13, they have definitely got it, but if you are resuscitating a microprem it may or it may not, you still have a chance that they are going to be okay, and it's the hope that you probably hold on to…its interesting with the two spina bifida babies we have just had – two very different family situations, does it mean they love their babies any less, no, and the quality of life they expect for their child is relative to their own lives.'*
>
> (HCP 1)

In extreme prematurity there is often insufficient time to engage with family supports and insufficient time to educate the external family about the concerns for the future of the imperilled baby:

> *'Whereas these pre-term babies, often things happen over such a short period of time that parents don't have the time to come to terms with it, to talk with their families and talk with their friends, to talk with their peers. I think it's much more - it's compressed into a much smaller time period and they don't have the adjustment time… I wonder if there's a bit of - I think there's a bit of fear and a bit of guilt associated with not resuscitating, and I think there's a little bit of stigma associated with it. Not that people really talk about it, but to say, well, I had a baby that was born premature and we elected to do nothing, is hard for people to talk about and to come to terms with themselves, which I think is why people don't say no.'*
>
> (Obstetric trainee - HCP 30)

> *'There are often concerns that - you know, well-meaning friends and relatives say, remember that 22 weeker that survived in Brisbane. They did so well. Why couldn't they do anything? Why did they let your baby go? Something could have been done, and you could have had a normal child.'*
>
> (Regional paediatrician - HCP 29)

Broader societal beliefs may also portray non-resuscitation negatively, influencing the parents to opt for resuscitation:

> *'Because that's a really difficult and heart-breaking decision for the family, to say – to actively make the choice to say, I am choosing, effectively – for that family – I am choosing to kill my baby. Because that's what general society may view it as.'*
>
> (Paediatric registrar – HCP 4)

6.26.3.2 Religion and culture

Among the data there was widespread respect for the religious and cultural views of parents:

> *'I very much believe that for some people, it is very reassuring and helpful that they do have religious underpinning and they find that useful. I have no reason why I should pooh-pooh that. I've had women who should have been not well at all, and their prayer circle got going and they basically were normal at the end of it. Who am I to say that that didn't fix them up?'*
>
> (Birth centre midwife – HCP 13)

> *'The parents wanted (it) - they had strong religious beliefs.'*
>
> (Neonatal registrar – HCP 21)

An understanding of the holistic situation of families was also noted:

> *'I think it depends a lot on where they're at with their family, as in have they got three kids already. What are the parents like and Catholic and cultural beliefs as well come into play. I think we're seeing a few more get more and more educated regarding what their babies are really going to be like if you resuscitate them this early and the impacts it's going to have.'*

(Midwife - HCP 20)

Staff too may have their own religious belief about the survival of vulnerable babies:

> *'We do whatever we can, but we shouldn't interfere with God's plan. If he chooses to take the baby away, that is his plan.'*

(Remote paediatrician – HCP 29)

6.26.3.3 Media stories

Media often carries stories about the survival of babies who are born extremely prematurely or with major potential impairments. These are uniformly positive, and often delivered to the mainstream press by the health services, whilst social media such as 'Facebook' may provide families with more information, much of which is unrealistically positive:

> *'But we do a lot of community - we put out something like 14 happy stories every year through the media. We've got a very good media department here.'*

(Neonatologist – HCP 7)

> *'But a lot of that stuff is often very positive, some beautiful stories about how tiny my baby was and how well they're doing now so you don't often see the stories of the babies with severe cerebral palsy.'*
>
> (Neonatal nurse practitioner – HCP 27)

> *'Well most of them are happy stories, these tiny, tiny babies that have gone home. You're not going to put up the other ones, so some of it will give false positive impressions.'*
>
> (Midwife – HCP 13)

Babies who have residual impairments may be portrayed positively, with heroic stories of achievement:

> *'[The media] it's traditionally somewhat unrealistic; over-represented with the good news stories. No one ever talks about baby - people don't usually talk to their friends about babies that have died. They have a positive spin on the damaged baby with the cerebral palsy with all its troubles, and they talk about the positives of those injured babies. But no, everyone's optimistic, they have their scan to know their baby's normal.'*
>
> (Senior obstetrician – HCP 25)

Midwifery and nursing staff, more so than other participants, appeared to recognise the role of social media in the perception of parents about health care outcomes.

> *'I think they think we save a lot more babies and a lot more babies become healthy - well, functioning children. I think that's what is in the Take 5 magazines, it's what gets on the news. The families struggling with a - or loving their developmentally delayed child, that's probably not going to be on the front page of Woman's Day. I think it's probably a little bit of a rose coloured glasses situation through the media. Facebook as well. I think Facebook is how people are getting a lot of information now.'*
>
> (Midwife – HCP 11)

6.27 Summary of Findings of Category of 'The Culture and Context of Families'

- Mothers who are transferred to the tertiary centre are assumed to have a decided in favour of active care for periviable babies, which then occurs, but the evidence is that little counselling occurs prior to transfer.

- Whilst families might struggle to receive adequate health care for their disabled children outside a large centre, the social benefits for these families may outweigh these limitations. Newer modes of delivering health care help to reduce the differences in access.

- Aboriginal and Torres Strait Islander families may have some differences in decision-making, although this was not thoroughly investigated in this work. However, Indigenous women themselves are not a homogenous group and there may be differences in decision-making between those in remote and urban areas.

- Socioeconomic circumstances of parents raised concerns for potential future neglect of a vulnerable child. However, HCP regarded all babies as equal regardless of parental circumstances.

- Parents focus on survival whilst in NICU rather than future disability, and could forget any counselling about poor progress because of their emotional state.

- Staff recognised that each family has a wider family, community, religion and culture which might influence decision-making

- The media, both mainstream and social, portrays the outcomes of extreme prematurity and periviability in a positive light, often fostered by the TUH neonatal unit itself. This may be falsely reassuring.

6.28 ‘To Treat a Bit or Not At All’

At the time of decision-making about initial resuscitation, one suggestion often made to parents is that we can commence active care with the option of redirection of care if: the resuscitation is not progressing well, the clinician feels that the baby will do poorly, or adverse complications occur which raise the likelihood of neurological damage. Participants were asked about their impressions of how this suggestion evolved in TUH perinatal care, and whether they thought it was a sensible option. Three sub-categories emerged; ‘wrong if futile, ‘comforting to try’, and ‘does redirection occur?’ (Figure 6.8).

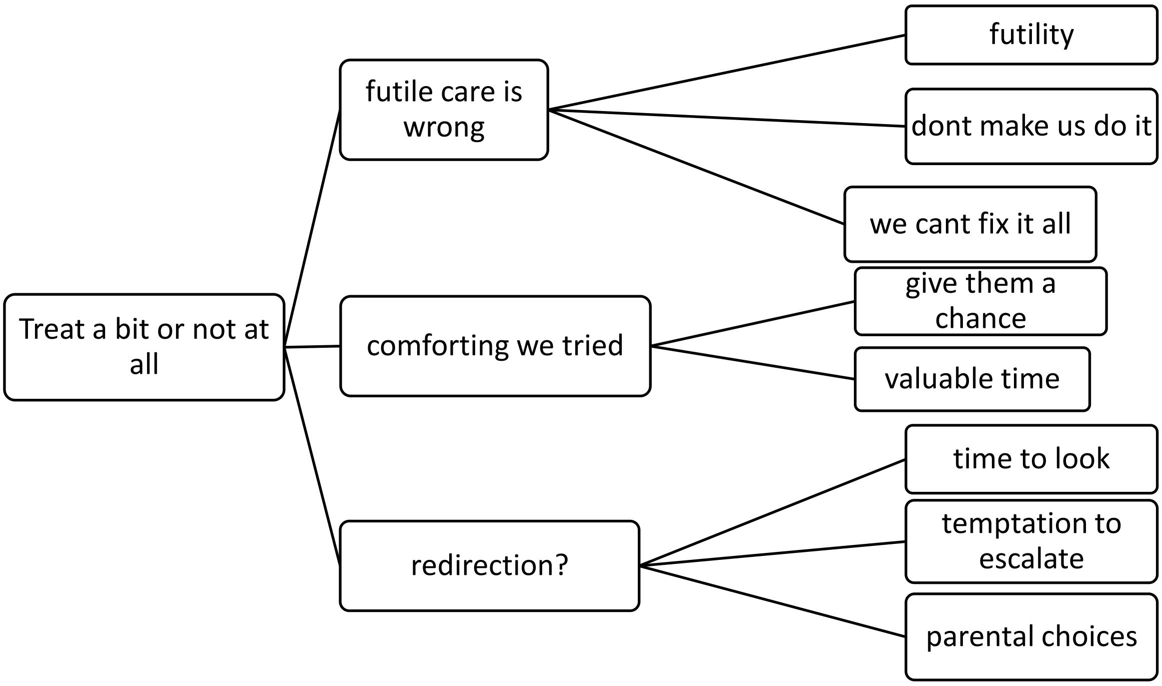

Figure 6.8 The subcategories and focused codes for ‘to treat a bit or not at all?’

6.28.1 Futile care is wrong

6.28.1.1 ‘Futility’

A decision to offer care, knowing that it is likely to be futile, was discussed by several participants, most of whom considered that this was inappropriate. Futility was a reason to decline to offer a ‘trial of active care’:

> *‘So very few conditions where I think that we will say we won’t do anything. These are well-established conditions, with no cure indefinitely, so I think that we will be doing injustice to the patient - babies… I would say “no. This is what we will do.” Some would argue to try so many things. Try so many things again, it’s a - most of them die - so we would again, try to tell [the parents] that the best place is to keep the baby comfortable.’*
>
> (Neonatologist – HCP 8)

Similarly, if there was little hope of reasonable function, active care should not be offered, and even termination of pregnancy was preferable:

> *'Honestly I personally wish that sometimes we would more strongly suggest not to allow some - for babies have no or very little chance of a reasonable neurological function - like if their brain is full of cysts - I feel that we are being cruel to the child for not really any significant purpose, but I don't see how there's any better way of trying to convince people because you can't make people do anything that they want of their own body while the child is still in there'*

(Paediatric trainee - HCP 6)

6.28.1.2 'Don't make us do it'

Providing care for a baby where the HCP considers this to be futile causes distress for the clinician:

> *'I personally struggled with that quite a lot, that there was this baby that I could see we were putting so much effort into, that every person on the team knew there was no way that this was going to end the way that the family or the team might want it to end. So I'm hoping that…the options of palliation are offered to the family, and are seen as something that's not, we've done absolutely everything that we can, and this is our only last resort option.'*

(Paediatric trainee - HCP 4)

This senior neonatal registrar had often felt pressured by the senior clinicians to go beyond what she considered was in the best interests of the baby:

> *'Every and now and again you just kind of go "do you know what it's great that you're saying this for the parents but actually you and I both know that this isn't going to be the way that this is going to work. You're now telling me that I have to do all these awful things to this little person and I'm just not sure that that's the right thing to do and I don't want to"…I think when you're actually doing that with people's lives then it starts to become problematic. If you're treating 100 babies because you can save two of them I think that for me is an ethical concern.'*
>
> (HCP 9)

6.28.1.3 'We can't fix it all'

This midwife suggested that medical staff themselves may be unable to accept the limitations of the care they could provide:

> *'We're never going to fix everything. I think we need to be aware that we can't fix everything, because the medical model for it suggests that we're getting cleverer and cleverer… and therefore communities are expecting so much from us. I think in some ways we have to be honest and say, there's only so much, and then we can't.'*
>
> (HCP 13)

6.28.1.4 At least we tried

'Give them a chance'

A decision to offer the option of a trial of active care was discussed by most staff as an opportunity to evaluate the baby's clinical viability following delivery. For many HCPs, particularly nursing and midwifery staff, this was seen as a chance for the family to spend time with the live neonate and the opportunity for parents to feel that the baby was given the chance of survival:

> *'I do, because I think that gives them a bit of a chance then to process the reality, as opposed to the picture of these miracle babies that go home. It is all part of the grieving process, if things aren't going to be successful, that they actually do still then have some time with their baby. They get to see their baby. They get to see what was tried. I always found it, as a practitioner, to try and fail was better than to have not - than to have told them there's absolutely nothing we can do - they may not be particularly happy memories, but we all need something that - to acknowledge that baby existed, that we did our best. Our best, for whatever reason, wasn't good enough, but we tried. You don't have all those questions afterwards that you then beat yourself up about.'*

(Midwife – HCP 13)

A reflection from a neonatal nurse about a baby who had care redirected appears to confirm that the mother appreciated that the attempt to save her baby helped her to cope after the baby died:

> *'So it was not an ideal situation. Mum wanted a section, so eventually she had the section and the baby did have a massive brain bleed and had to be withdrawn from treatment on day 2. She actually came back and said, "I feel happy that I gave the baby a chance. Imagine thinking, I didn't even give this baby a chance and now it's gone."'*

(HCP 23)

Time with a live baby

Participants recognised that even when the outcome was likely to be poor, spending time with a live baby both to have family time together, possibly to perform cultural practice, may be appropriate for some families:

> *‘Some people wouldn’t be able to say goodbye straight away. I think that’s great if we can support that baby for 24 to 48 hours, get families in to love the baby, have some time, do a baptism, then that’s right for that family.’*
>
> (Midwife – HCP 11)

> *‘The beauty of a little bit of time and a little bit of seeing insight and seeing that is not going to work. From their grieving point of view they perhaps needed that as well.’*
>
> (ILO – HCP 19)

However, a midwife who has cared for women who have babies who receive palliative care throughout – mainly with life limiting anomalies suggests that this option denies the family valuable time with a baby in a more peaceful setting:

> *'But I think the negatives in both, for those babies that we do resuscitate and they go to the nursery, it's great that they can get family around and they can love that baby for a little while and do all those sorts of things. But then, as a midwife, I think that time after birth with that skin to skin and your baby is so loved and protected, I think mothers and fathers lose that to the neonatal environment. So for me as a parent, if I knew that I was having a 23 weeker, I would elect to have my baby with me and not go to NICU and have pain and trauma and then - but that's not the right decision for every family.'*
>
> (HCP 11)

6.28.1.5 Does redirection occur?

<u>'Time to consider'</u>

HCPs discussed the option of a 'trial of life' as a potential decision at the time of birth. They were also asked if they had seen further decision making about continuing care for the imperilled infant. They were mostly positive about the concept of redirection of care after an initial period of active care. This was particularly evident where the events resulting in early birth had been too rapid for considered decision making:

> *'There'll always be individual cases where things happen too quickly and whilst the clinicians might say it's futile or likely to cause significant morbidity for the baby. I think that at the end of the day you will have time later for withdrawal of care discussions.'*
>
> (Obstetrician – HCP 17)

‘Temptation to escalate’

The data suggested that it can be difficult for the doctors to redirect care once it has been started. Increasingly complex modalities of care exist and become further avenues to explore in the face of a deterioration. The option of full active care with potential redirection may be potentially flawed:

> *‘No, not really, because once you start down that path, so you’ve got the baby intubated, ventilated, it is then if the baby deteriorates I think it’s - it’s hard when you’re counselling a mum acutely saying, so what happens when we get into day three, day four and we’re having to think about going on to oscillation ventilation. They go, what’s oscillation?... so you end up setting yourself up for check points of what qualifies as deterioration and when’s your threshold to say we’ve pushed things too far.’*
>
> (Tertiary paediatrician - HCP 15)

Some HCPs themselves do not suggest redirection, although this may have previously been given as an option during antenatal counselling. It was noted that a baby may have increased risk factors for a poor neurological outcome without being clinically unstable:

> *‘Unless a baby is obviously dying, I tend not to bring up the topic. If parents bring it up that’s a different thing’*
>
> (Neonatologist – HCP 10)

Parental choices

One paediatric registrar cited an example where redirection was no longer offered when the parents requested this, despite being an option discussed previously. At the time, the baby was very unstable, requiring numerous tests, and the prognosis had undoubtedly worsened. The baby later had substantial neurological deficit:

> *'Once I had a family suggest to us that they were considering stopping treatment on their child which was because they thought that what we were doing might be cruel.'*

(HCP 6)

Differences in opinion between parents and HCPs regarding redirection may occur. This clinician suggested that parents can choose to continue care if that is their preference:

> *'But equally, we have seen parents who say, no - just continue - which we then continue, which is a bit sad for the baby - to die on the ventilator, but in the absence of any legislation, I think we have to work with parents…who want the babies on the ventilator. Doesn't happen that often. Most parents - the moment they realise the baby is suffering…well they would prefer baby not to suffer.'*

(Neonatologist – HCP 8)

There was also concern that parents may initially state that they wish an option of initiating care but later will find redirection too traumatic, hence clear decision making prior to delivery is preferable:

> *'The positives are sometimes the baby will declare its debilities and the parents are much more happier that they gave it a go, there's not so much guilt, the baby was sick and died, they didn't withdraw care immediately. The downside is, sometimes the babies don't immediately die, and they never quite get bad enough that it's obvious that care is to be withdrawn. The parents then start to feel bad about making big decisions and can never make the decision to withdraw care, it would have been much easier if they made a cold, clean cut at birth, and they never then had to torture themselves'*
>
> (Obstetrician – HCP 25)

6.29 Summary of the Category 'To Treat a Bit or Not at All'

- Most HCPs considered that continuation of futile care was wrong and led to unnecessary suffering. Staff were distressed by contributing to suffering of the baby and family.

- Senior medical staff themselves may be unable to cease care, and often escalate care whilst other members of the team may perceive that continuation is futile.

- Providing a trial of treatment is thought to allow parents time with a live child, and to see that all efforts were made to save the baby. The cost of this might be the loss of early skin to skin contact and peaceful family time within the intense NICU environment.

- HCPs felt that parents could be the decision makers to continue care, even when the baby was progressing very poorly, but that parents are not able to advocate for withdrawal of care when they felt that continuation was not in the best interests of the baby or family.

6.30 ‘The Life Ahead’

Predictions about the potential for poor outcomes for individual babies were repeatedly heard as modifiers for decision-making in favour of performing active care. This category is supported by subcategories of ‘the neonatal unit’, ‘later progress’, ‘what parents tell us’, and ‘it’s their life’ (Figure 6.9).

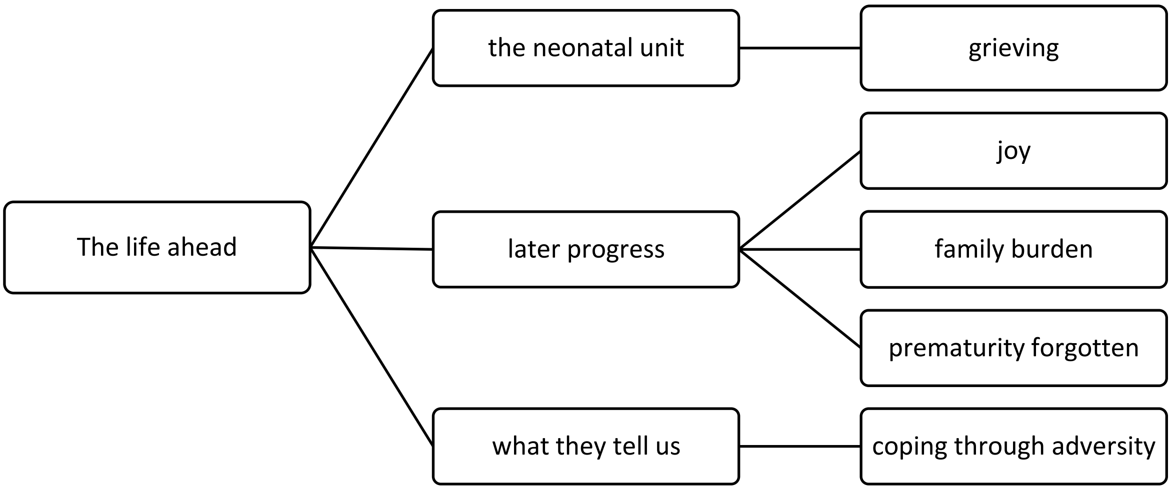

Figure 6.9 The subcategories and focused codes for ‘the life ahead’.

6.30.1 The neonatal unit

Data presented elsewhere in this chapter describe the difficulties and potential suffering of the neonate and family whilst on the neonatal unit. The comment below reflects a perception that the time in the neonatal unit is often one of grief. There was little recognition among participants that there were times of happiness or achievement for families on the unit.

6.30.1.1 Grieving throughout

The course through the neonatal unit was recognised as being difficult for parents.

> *'The microprems, they basically grieve the whole time that they are here. They grieve they are not having the full pregnancy; they are grieving not having a term baby and moving on with life. Not having the newborn baby photographs and all those things that society thinks happens naturally and automatically that everyone should have'*
>
> (Neonatal nurse – HCP 1)

6.30.2 Later progress

Reflections on the progress of periviable babies after discharge were voiced by participants. Narratives of individual babies and their progress and family integration were noted in the data, particularly by paediatricians. Other HCPs may also have had contact from former patients through family visits to the unit or on social media.

6.30.2.1 'Joy'

Reflections were sometimes positive such as this comment about a young child who had a stormy course and is severely disabled in all domains of development. The nurse recognises the positive benefits the mother gains from her child:

> *'But now, he's a few years old, I think he's at school now and he's - just the small little things like when he held a bottle, she had joy and when he smiled, she found joy in that. So she's found a lot of joy in him even though she knew at that stage that she couldn't cope with it (on the neonatal unit). She wouldn't give up on him now.'*
>
> (Neonatal nurse – HCP 3)

One aspect of future family life which was explored by participants was the quality of life the family may have:

> *'There's some families who do fabulously with them and have amazing qualities of life. We're talking about children who don't ever speak and have very poor verbal and basically need two full time adults to move them…Attention deficit, hearing problems, vision problems even though they're minor or partial rather than complete still puts a challenge into their system. If those kids aren't well supported then they feel embarrassed and then they act up and it's a challenging thing to think about long term. I do think about that when I think about some of these children. It's not just about the ones with severe problems.'*
>
> (Neonatal nurse – HCP 12)

6.30.2.2 The burden of chronic needs

The prospect of family breakup as a result of the difficulties of caring for a disabled child was heard from this obstetrician:

> *'You do see parents come back with babies that are morbid and the relationships broken up. There's a social cost to the relationship and then you're there for the mother and the baby that's quite injured and the guy is gone, and she's got to do it all herself.'*

(Senior obstetrician – HCP 25)

The burden for the family was noted frequently to not correlate with the level of disability experienced by the child:

> *'[We are] never actually looking at burden of care to families. Because the level of severity of impairment doesn't always mean how a family's going to cope and what their subjected burden of care is…motor impairment isn't a predictor of carer stress, but it was more if they had sensory impairment - communication impairment is the highest risk factor for stress to carers and stress burnout.'*

(Tertiary paediatrician – HCP 15)

Again, the concept that any childhood illness may affect parental coping and family function is noted:

> *'Any sick child causes significant stress to the family dynamics, and sometimes the parents might separate and that might cause a whole lot of difficulties in the management of the child, that's also altogether different. Any life-threatening condition, I think that's the problem, the most - the sicker the children are, it causes a big stress on the family dynamics: it affects the other children, it affects the parents' relationship, and yes, it causes a lot of stress. So, I don't know whether it's specific only to extremely preterm babies.'*
>
> (Regional paediatrician – HCP 28)

One paediatrician suggested that early childhood bonding, particularly when behavioural problems are a feature, may account for difficulties coping in the future:

> *'I think because they are - mainly I find their behavioural difficulties in ADHD and a few of them got autism as well. So their bonding, it is - it's not the same. But then they also reflect back and say they had like cuddle times and all of that too. I think the neonatal practice actually changed, allowing parents to have bonding time. But they - I have a feeling it's the struggling to bond with the child because these children are hyperactive and they've got developmental problems and so on, rather than that what you would expect, even non-pre-term babies anyway.'*
>
> (HCP 16)

Participants recognised that families who struggle and cannot cope with their children often have predictable markers of socioeconomic adversity, or poor maternal mental health:

> *'A lot of the families who are experiencing this are usually the most vulnerable families. They're usually the families that are younger parents, have poor socioeconomic status, poor support system, drug or alcohol use and I think - thinking regional or remote, the ability to engage with any services if they are there. So how do we judge if someone's going to cope with a child with a disability? [Equally]…the mum who is extremely anxious, has a background of mental health dysregulation and they're the ones that you see them within that first 12 months, 24 months getting really stressed because that's they had had a background of difficulty coping emotionally with life before then adding any extra stress.'*

(Tertiary paediatrician – HCP 15)

6.30.2.3 Prematurity forgotten

The data suggested that when the child is found to have developmental concerns at a later age, for some parents the prematurity has been forgotten and discarded as a potential cause:

> *'But if it sounds like this baby's had all sort of complications under the moon and clearly there's not any dysmorphic features or anything else to suggest there might be an underlying genetic problem, I will - I think families will probably forget that far. But I think it's - then they sometimes will not even mention unless you ask. "Oh they were 24 weeks", okay, now you tell me.'*

(Regional paediatrician – HCP 31)

An experienced paediatrician remarked that periviable babies who have progressed well will not be seen by medical staff in clinics as they are healthy, and relatively few have severe problems:

> *‘Well, that’s an interesting one. Almost all of them will have* - *I guess if you look at it when we are following them up, my long term follow up, ones - the ones I’m seeing because they are seeing me because they have some problems, in that sort of early age group the common problem that I see with those kids is they’re learning problems and few of them would have cerebral palsy, severe ones are not that many.’*
>
> (HCP 16)

Of interest was that every experienced paediatrician interviewed reflected almost identical thoughts of the reality of periviable babies whom they later cared for in their medical clinics. A regional paediatrician places the reflections of all paediatricians regardless of location of the baby into context. She also notes that outcomes are improving as time progresses and presumably medical care has improved:

> *‘I think that I’ve seen a lot of advances in neonates since I’ve started, in terms of chronic lung disease, incidence of bleeds. Whatever we’re doing antenatally in the first few days of life seems to have reduced the incidence of those complications. So I think in terms of the long-term events, we probably lose sight of it and I think the parents lose sight of it. But I’ve had families coming back obviously with behavioural, learning issues or some sort of attachment issues, which you kind of think it’s all related to prematurity...It depends also on the social background, some families are worse than others.’*
>
> (HCP 31)

6.30.3 What families tell us

6.30.3.1 Parents cope through adversity

Many HCPs (particularly paediatricians) appeared to have discussed the decision to offer or continue care for periviable babies with the parents of these children when the child was older. HCPs reported that most families cope and do not appear to regret prior decisions made. A midwife who knows families with older children with severe handicaps reflects that these parents are content, but is aware that there are other parents of a differing view:

> *'No, most of them have been very happy of the time they've had with their child. I don't know any that have said that they didn't appreciate what they had. It may have been hard work, but they - I haven't had any that have said that they regretted - and you then have - watch interesting programs where the children, who are now adults, say - and there are some who say they're happy they're here, but they wished it hadn't, and others who go, why would I not be here?'*
>
> (HCP 13)

One paediatrician is aware that parents with periviable children with difficulties may discuss their regrets with others but not with her as a paediatrician. She also notes that families with children who were known to have genetic differences appear to cope better, presumably because they made a conscious decision to continue a pregnancy with this knowledge:

> *'I guess regrets is "I wish this child had never been born." Nobody actually said that to me. I don't know whether they might be saying to their friends but as a treating paediatrician, nobody said that to me…They seem to be happy with their children. So even knowing, I think maybe, knowing exactly what they're going to have. If you look at the other abnormalities as well. Knowing what's the actual structural genetic problem, maybe that they cope better and prepare the worst and then they cope with it better, maybe.'*
>
> (HCP 16)

The perinatal suffering of the child, and the hard work of the parents afterwards, for most, seems to itself result in parental contentment with their family situation:

> *'So I think those long term learning differences - but it's that storm - it's the storm of my child has survived a really difficult start to life, really sick, am I breathing circulation, ventilation, feeding, anything beyond here isn't so bad.'*
>
> (Paediatrician – HCP 15)

The personality and positivity of parents could be the reason for some parents to believe that the decision to offer care had been the correct one:

'Baby was now two, it was doing really well, and the mother said it was the best thing that could have ever happened to them, which amazed me really. It really depends what your background, I think you take on life is whether you're a glass half full or a glass half empty. But some people are very happy with their lot and cope with what we might see as adversity, and see it as a great positive.'

(Senior obstetrician – HCP 25

6.31 Summary of the Category of 'The Life Ahead'

- The NICU time can be very difficult for parents. There was no recognition by HCPs of any positive aspects to the family NICU experience.

- HCPs acknowledged parents who expressed joy in their children and celebrated the child's achievements, regardless of disability.

- Concern was raised for the potential impact of disabled children on the parental union.

- Poor personal circumstances and supports leads some families to struggle, but most cope and are happy with the resuscitation of their child.

- Parents may not be discussing any negative feelings they have with health care staff.

- Poor attachment between parents and child could lead to behavioral problems of the child.

- Parents may be surprised when difficulties a child is noted to have when older are a result of their extreme prematurity.

6.32 ‘Information Sharing’

The category of information sharing included ideas that HCPs had about counselling parents. However, most did not discuss this in the context of active decision-making. Some of the data about counselling will be introduced in Chapter Eight, which merges the studies to explore decision-making as Phase Three of the study.

6.33 Theory Constructed from the Qualitative Study Which Relate to Decision-Making

- Message framing utilising negative outcomes is used prior to delivery of periviable babies in an attempt to persuade parents to withhold intensive care.
- Role specific implicit bias can be explained by the role the HCP has in caring for the patients, and shows typical characteristics of progression as the clinician becomes more entrenched in the role.
- HCPs understand the culture and context of families and recognise that decision-making can be helped through truthfulness and emotional support. Despite this understanding, medical paternalism is maintained in these decisions by disempowering parents through negativity about the long-term future and elimination of hope so that parents cede decision making to HCPs.
- Where staff feel moral distress at contributing to the suffering for those babies whose outlook they deem to be futile, their distress is valued more than the distress felt by parents who believe that the outlook for the baby is poor. This results in the push to palliate babies at HCP’s behest, while HCPs who have difficulty in dealing with death and dying ignore parental requests to redirect care.

- Suggesting that babies ‘decide’ whether to live or die, positions the baby itself into a position as a decision-maker. This allows the HCP to avoid participating in shared decision-making with parents, whilst themselves still determining how aggressively care is delivered.

Table 6.7

Merging the quantitative and qualitative findings.

Theme	**Merged findings of the quantitative and qualitative studies**
Decision-making at TUH for the provision of active care for periviable babies is complex and tends towards a medical paradigm.	69% of HCPs believed that parental choice to initiate care should positively influence the decision even when the HCP disagrees. It was felt that parents should be accurately informed, but they know what they want, and are the people who live with the consequences. Reflecting a medical paradigm though, most clinicians felt that HCP should be the primary and ultimate decision-makers, and 40% of respondents said that HCPs could provide care even where the parents did not want this over 24 weeks. It was recognised that shared decision-making improves the emotional wellbeing of parents. HCPs accepted the need for individualised decision making. Whilst there were concerns that parents may promote continued care at a time when HCPs believe that care should be redirected, staff themselves may be the drivers to escalate intensive care at times when parents want palliation.

Theme	**Merged findings of the quantitative and qualitative studies**
Negativity in understanding and attitude informs the clinicians.	Almost all respondents were more negative about the outcomes of survival and severe disability and intact survival than is factual based on the data. The negativity is highest at the lowest gestations where HCPs believe that care should be offered at 24 weeks (IQR 24-25) for patients, whilst midwives and paediatric staff would accept active care at 25 weeks (IQR 24-26) for themselves and obstetric and neonatal staff would accept care at 26 weeks (IQR 25-26). The trauma of NICU for the baby and family, and potential burden of disability which results in parental disharmony and separation, endless caring for the baby and poor attachment were the origins of negativity. HCPs caring for the patients in the perinatal period do not recognise positive events in NICU care and believe the negative prospects for the baby should be emphasised. Conversely, paediatricians caring for the baby later suggest that parents experience joy and recognise their baby's achievements with mostly good family function. Paediatricians are more positive about resuscitation. Despite their negativity towards the outcomes, TUH plants only positive stories in the media.

Theme	Merged findings of the quantitative and qualitative studies
Role differences in perceptions of the active care for periviable babies reflects the work role of the HCP.	Significant differences were found between antenatal HCP and postnatal HCP in their predictions of survival below 28 weeks, disability and intact survival at 23 and 24 weeks. HCP caring for the family antenatally are more negative for all. Role specific differences for the origins of these differences were found. Obstetricians and midwifery staff accepted death more easily because of their exposure to termination and stillbirth due to foetal abnormality, hence accepting death due to periviability which might lead to abnormality. The midwives focussed on the maternal experience and choices in decision-making. Neonatal nurses focussed on the trauma of NICU, and showed concern that the difficult course of care for periviable babies negates any future possible healthy outcome. Neonatologists were more aggressive about offering resuscitation, but believed they could predict the baby's survival and outcome at birth. Again the most positive group were the paediatricians who were the most accepting of parental choice and stated that most families cope relatively well with the consequences of periviable care.
Regionality resource differences exist for families but any negative effects of this may be outweighed by positive support.	Regional and remote staff outside Townsville are more negative about the survival below 27 weeks, but there are no differences in the perception of disability between HCP at different locations. Tertiary clinicians assume that mothers who are transferred antenatally all want active intensive care, although non-tertiary clinicians reflect that little counselling occurs prior to transfer because they are concerned about the accuracy of their knowledge. Whilst TUH clinicians perceive that babies who reside outside a tertiary centre have poor provision for care if disabled resulting in family disruption and relocation, staff outside of TUH reflect that community support for families and acceptance of disability is greater in smaller centres which is more important. Newer technology may improve equality of care, allowing families to remain in regional and remote locations, even with severe disability.

Theme	**Merged findings of the quantitative and qualitative studies**
Socioeconomic status is not a barrier to the initiation of intensive care.	Few clinicians believed that poor socioeconomic status (4%) or involvement with child safety services (16%) should negatively influence the provision of intensive care for periviable babies. However, it was acknowledged that the adverse social situation of the baby could lead to neglect and poor coping skills of the parents. Adequate safeguards were thought to be in place to refer these families for support.
Recognition of culture and context of the family occurs.	Individualised care for families was found to be important, recognising the role of religion and culture. Cultural differences for Indigenous families were thought to increase the likelihood of decisions to opt for resuscitation and intensive care. Support for families to adapt in a culturally and appropriate way to NICU was promoted.
Futility of care lacks clarity as a concept with inconsistency in application of redirection	Factors such as chromosomal abnormalities with high impact on survival were recognised to be a negative influencer for resuscitation. Futile care was recognised to be inappropriate as it contributed to suffering of the baby without prospects for a positive outcome. However, differences in opinions about redirection of care when the outlook was increasingly uncertain were found between neonatologists. HCPs advocated for continued care above parental concerns and preferences to redirect care.
Parents’ capacity to make decisions is judged according to their emotions and is valued less than staff opinions.	HCPs believed that the parents’ emotional state at the time of decision-making would lead them to have excessive feelings of guilt if they were allowed to be the primary decision- makers for resuscitation and continued care. Parents were perceived to be too focussed on the survival of the child which impaired their capacity to understand how difficult it would be to care for the child in the future. HCPs, conversely believed they were more objective and understood the potential implications of a poor outcome.

Discussion of these merged findings is found in Chapter Eight, where the findings relating to decision making are integrated with those of the other studies. The final component of Phase

Two is the chapter about palliative care in the neonatal unit which follows in Chapter Seven. Redirection of care was discussed by both parents and HCPs, with findings which are further explored in Chapter Eight. Understanding how palliative care is perceived at TUH helps inform this further exploration of decision making.

Chapter. 7 Palliative Care for Periviable Babies

Previous chapters have contained the findings from studies of families' experiences and opinions about periviable care, and the mixed methods study of HCP attitudes towards extreme prematurity. One option discussed with parents who are at risk of periviable delivery is that of palliative (also known as comfort) care either at the time of birth, or after initial resuscitation, should the baby have features which suggest deterioration towards futile care or poor prognostic signs. A decision to palliate at birth was seen to be most common at 23 weeks gestation in the quantitative study of outcomes of care at TUH in Chapter Four. However, three sets of parents in the family study had a baby for whom care was redirected to palliation, and two requested redirection but this was not offered by the medical staff.

This chapter incorporates a study of palliative care at TUH from the perspective of nursing staff who are the primary carers for babies who have palliation, redirection or who die whilst on full intensive care support in the neonatal unit. The study has been published. The findings of this study enable an understanding of decision making towards palliative care.

This research was initially a project undertaken by the unit psychologist and I who both have an interest in neonatal palliative care. We were aware that some nurses on the unit had been reluctant to be involved in palliation. The research arose from an interest exploring nursing perceptions of palliative care in the NICU with the intent of improving this care. The psychologist was the primary investigator and performed the interviews. MK primarily analysed the data which we then discussed. MK and I wrote the paper together. She appears as the first author. It was clear during the palliative study that the research was relevant to the PhD study which I was in the early stages of conceptualising, so has been incorporated here. I recognise that the writing I have produced has evolved academically since this time.

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Palliative Care in the Neonatal Unit: Neonatal Nursing Staff Perceptions of Facilitators and Barriers in a Regional Tertiary Nursery

7.1 Abstract

Background

Neonatology has made significant advances in the last 30 years. Despite the advances in treatments, not all neonates survive and a palliative care model is required within the neonatal context. Previous research has focused on the barriers of palliative care provision. A holistic approach to enhancing palliative care provision should include identifying both the facilitators and barriers. A strength-based approach would allow barriers to be addressed while also enhancing the facilitators. The current study qualitatively explored perceptions of neonatal nurses about facilitators and barriers to palliative care and also the impact of the regional location of the unit.

Methods

The study was conducted at The Townsville Hospital, which is the only regional tertiary unit in Australia. Semi-structured interviews were conducted with a purposive sample of eight neonatal nurses. Thematic analysis of the data was conducted within a phenomenological framework.

Results

Six themes emerged regarding family support and staff factors that were perceived to support the provision of palliative care of a high quality. Staff factors included *leadership, clinical*

knowledge, and morals, values, and beliefs. Family support factors included *emotional support, communication and practices* within the unit. Five themes emerged from the data that were perceived to be barriers to providing quality palliative care. Staff perceived *education, lack of privacy, isolation, staff characteristics and systemic* (policy and procedure) factors to impact on palliative care provision. The regional location of the unit also presented unique facilitators and barriers to care.

Conclusions

This study identified and explored facilitators and barriers in the delivery of quality palliative care for neonates in a regional tertiary setting. Themes identified suggested that a strength-based approach, which engages and amplifies facilitating factors while identified barriers are addressed or minimised, would be successful in supporting quality palliative care provision in the neonatal care setting. Study findings will be used to inform clinical education and practice.

7.2 Background

Neonatology has made significant advances in the last 30 years. Surfactant therapy, improved ventilators and ventilation strategies, improved surgical techniques and parenteral feeding have enabled survival of vulnerable babies (Costeloe et al., 2000; Keir et al., 2014)   Despite the advances in treatment, not all neonates survive and a palliative care model is required within the neonatal context. Death on the neonatal unit may occur when intensive care support is withdrawn, there is a conscious limitation to the escalation of intensive care, or the baby cannot be kept alive despite all attempts to continue care (Walther, 2005). Australian data suggest that three quarters of deaths in the neonatal context occur after intensive care is withdrawn (Wilkinson, 2009). US data shows similarly high levels of withdrawal as a mode of death, particularly for babies with congenital anomalies, whist withholding s more common in extremely preterm babies.

The aims of palliative care in the neonatal context are to prevent and relieve pain and suffering of neonates and provide support for the families. Such care includes planning with families about the practicalities of the death and continuing family support after the baby dies (National consensus statement, 2015; Uthaya et al., 2014). The timing of withdrawal must allow time for parents to prepare for the death of the baby but be balanced against the suffering of the baby (Epstein, 2010). The obligations for nurses and doctors are to provide options for parents, preparing them for the death, providing physical support for the family, whilst providing comfort for the baby, advocating for the family and providing emotional support (Epstein, 2010). The basic elements of palliative care include the need for warmth, dignity, human contact and pain relief for the neonate and neonatal nurses are at the forefront of such care in the neonatal unit.

Limited research has been conducted that explores neonatal nurses’ perspectives of providing palliative care (Chen et al., 2013; Kain, 2006, 2011; Kain et al., 2009; Mendel, 2014). A systemic review identified attitudinal, clinical, educational, regulatory and financial barriers to providing palliative care (Kain, 2006). Specifically, barriers included nurses’ values and moral dilemmas, beneficence and non-maleficence, nurses’ exposure to death, emotional control and protection, stress, grief, lack of education in palliative care principles. A subsequent Australian study identified facilitators of quality palliative care that included a health care team which is supportive of each member’s opinions and beliefs, availability of counselling for care givers, the use of clinical guidelines and the provision of adequate support for parents (Kain et al., 2009). Barriers were found to be a poor physical environment, technological imperatives and parental demands to continue treatment and concerns about harming the infant or contributing to suffering (Kain, 2006). Similarly, barriers included the negative impact of lack of education including ineffective communication, and the assessment of needs and implementation of palliative care including a lack of guidelines for providing palliative care (Mendel, 2014).

Other research in the Australian context identified barriers to palliative care in neonatal nursing related to staffing, the environment and technological imperatives (Kain, 2011). Inadequate staffing was identified where the labour-intensive nature of palliative care was not acknowledged by organisational structures and insufficient staff were available to help nurses providing the care. The environment negatively impacted care when the physical structure was inadequate and privacy and comfort lacking for families. Additionally, moral distress was reported by nurses when they perceive an escalation of treatment via the use of technology in a futile situation. Moral distress was the result of treating a neonate with no hope of survival and contributing to false expectations of the parents. Moral distress has been identified when nurses perceived continuing intensive care was provided which was not in the best interests of the neonate (Mendel, 2014).

Chen and colleagues (Chen et al., 2013) in Taiwan, used a questionnaire approach to explore the attitudes and beliefs of neonatal nurses towards the dying neonate and to determine the influence of these on nurses’ attitudes towards palliative care. Similar to other studies (Kain, 2006, 2011), barriers to quality palliative care included the lack of information to the parents about their options for palliative care, and nurses’ perception that they were not permitted to voice opinions about palliation. Nurses perceive a lack of resources and also having little palliative care education or guidelines for providing care. A lack of education for nurses has also been noted in the Australian (Kain, 2011) and United States contexts (Mendel, 2014). The nurses perceived an overuse of technology to keep babies alive and parental opposition to palliation (Kain et al., 2009). Cultural influences were noted in Chen’s study including a majority of participants who believed in transmigration of the soul, and a third who believed that palliation was inappropriate as neonates are at the beginning of life (Chen et al., 2013).

Cultural implications of palliative care have been identified within New Zealand Maori and Australian Indigenous communities (Maddocks & Rayner, 2003; Oetzel et al., 2015). While these studies were not in the neonatal context, important considerations for delivering culturally responsive palliative care are highlighted. For example, there are cultural considerations regarding the level of inclusion of family members in planning palliative care, which family members are appropriate to consult (Oetzel et al., 2015), and the impact of perceptions of death and dying and intervening in these processes (Chen et al., 2013; Maddocks & Rayner, 2003). As others have identified (Chen et al., 2013) it is important to consider the influence of cultural influences upon perceptions of providing palliative care particularly at the beginning of life.

A holistic approach to enhancing palliative care provision should include identifying both facilitators and barriers. Previous research has focused on the barriers of palliative care provision (Chen et al., 2013; Kain, 2011; Mendel, 2014). A strengths-based approach would allow barriers to be addressed while also enhancing facilitators of palliative care. It is also important to note that previous studies have also relied on focus groups (Kain et al., 2009), secondary analysis (Kain, 2006; Mendel, 2014) or questionnaire data (Chen et al., 2013) with few individual qualitative interview-based studies conducted. The current study qualitatively explored perceptions of neonatal nurses about facilitators and barriers that impact upon the delivery of palliative care. Such information is key to planning, implementing and evaluation strategies to harness facilitators and reduce effect of barriers in delivery of quality care.

Further, the study explored the impact of regional location of the unit upon delivery of quality palliative care.

7.3 Methods

The study was conducted at The Townsville Hospital (TTH), Australia. TTH Neonatal Unit is the only regional tertiary unit in Northern Australia and has an extensive rural, remote and extremely remote catchment area. It serves an area of approximately 500 000 sq. km. Babies are also referred for surgery, excluding cardiac surgery. In 2015, 255 patients were admitted for intensive care, with seven deaths from complications of prematurity, congenital anomalies, infections or hypoxic ischaemic brain injury. Approximately 75% of neonates are inborn and 25% are retrieved from areas across North Queensland. The study was conducted within a phenomenological framework that seeks to understand individuals 'lived experience' of providing palliative care in a neonatal unit.

7.3.1 Participants

A purposive sample of eight neonatal nurses with experience in providing palliative care participated in the study. Eligibility criteria included part-time and full-time neonatal nurses who had experience providing palliative care in the neonatal context. The participating nurses had more than five years of neonatal nursing experience and were registered nurses. They represent a varied skill mix. No further demographic information was collected.

7.3.2 Materials

Interviews were guided by open-ended questions regarding the delivery of palliative care in a neonatal and regional context. Nurses were asked about their perceptions of barriers and facilitators of palliative care in the unit, and whether the unit's regional location impacted upon the delivery of palliative care. Questions included "What is 'end-of-life- care?"; "What is good ‘end-of-life’ care?”; “What promotes good ‘end-of-life’ care?”; “What do you think we do well on this Unit?”; and “Do you think our Unit being in a regional area affects our palliative care?”. After completion of each interview, participants were offered an opportunity to add any further information about their experiences of neonatal palliative care in order to capture further relevant information.

7.3.3 Procedure

The study was promoted via an email through the Nurse Unit Manager to all nursing staff and snowball recruiting was used to encourage participation. Semi-structured interviews were conducted with nurses at a location of their choice. Verbal and written consent was also obtained to conduct and digitally audio record the interview. Data were analysed within an Interpretative Phenomenological Analysis (IPA) framework (J. Smith, 2009). IPA is a qualitative research methodology which describes the ‘lived experience’ in order to understand people’s perceptions of the study subject. Within the IPA framework, a six stage exploratory thematic analysis process was conducted as described by Braun and Clarke (Braun & Clarke, 2006). The thematic analysis was conducted using an iterative process in order to develop codes, categories, subcategories and themes. Results of this study meet Yardley’s qualitative research validity criteria of 1) sensitivity to context; 2) commitment and rigour; 3) transparency and coherence; and 4) impact and importance (see (J. Smith, 2009) for review of IPA and validity criteria). Ethics approval for the study was obtained from the local human research ethics committee (13QTHS84).

7.4 Results

Results are presented within a framework of the facilitators and barriers of quality palliative care, followed by the effects of regional location and culture on palliative care.

7.4.1 Facilitators of good care

Six themes were identified regarding family support and staff factors that were perceived to support the provision of quality palliative care. Staff themes included *leadership, clinical knowledge, and morals, values, and beliefs*. Family support themes included *emotional support, communication,* and *practices* within the unit (Figure 7.1). Each of these themes includes subthemes that impact upon the delivery of quality palliative care.

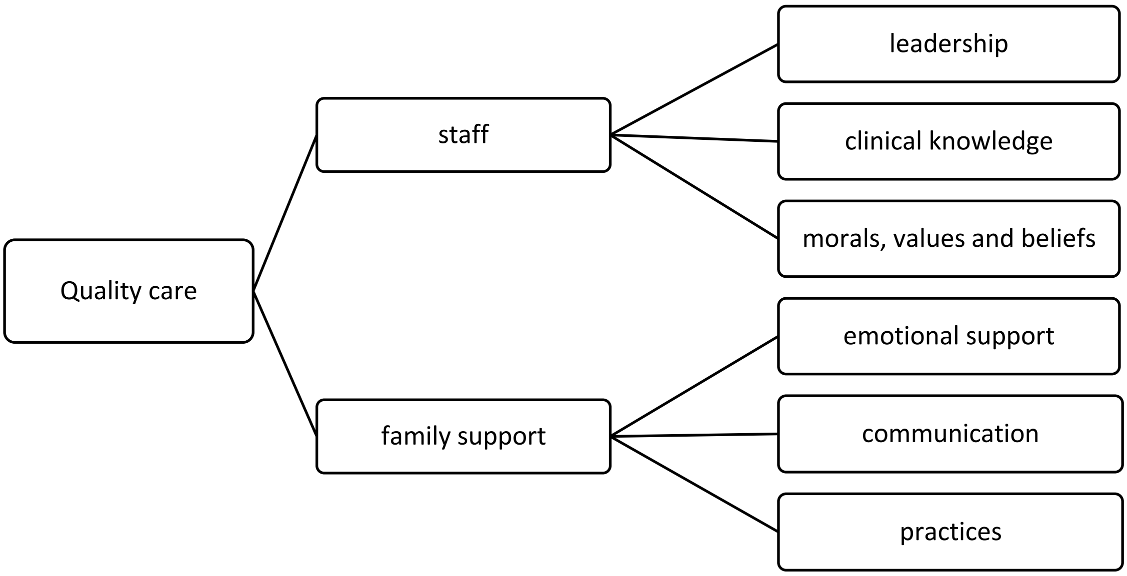

Figure 7.1 Facilitators of quality palliative care.

7.4.1.1 Staff attributes

Leadership

Within the *leadership* theme, six subthemes were identified *–staff suitability and experience, mentorship, communication between staff members, skill mix, and supporting staff.* Quality palliative care was delivered when nursing leadership in the unit understood the interrelated nature of these factors when allocating and supporting staff during the palliative period for an infant and family. For example, leadership recognition of staff who were ***suitable and***

experienced in delivering palliative care was facilitated by those who self-identified as one nurse reported:

> *'I mean you have to be the type of person who will actually handle that and will be able to facilitate it and look after mentally [self and family].'*
>
> (P 8)

Further, staff were considered suitable and experienced when:

> *'People who sort of do read things and don't shy away from the opportunities…and if they seem to continue to be interested then you know that they're not shy of it.'*
>
> (P2)

Leadership in the palliative care also reflected the positive influence of ***mentorship*** of staff during the palliative period. Mentorship was described by nurses as a collaborative way in which to engage with more experienced staff and to navigate their own emotional experiences during the palliative process:

> *'My mentorship [as clinical lead nurse] with someone else if they're doing end-of-life is just being able to provide that staff member with anything they need. You know, if they're doing the end-of-life care and I'm just supporting them as a team lead, "what do you need?"'*
>
> (P2)

Effective leadership in the palliative period also recognised the ***skill mix*** of the staff. Nurses perceived that good leaders were able to identify the skill mix appropriate for both staff and family needs during this period. As one nurse reported:

> *'I think sometimes we do really well like where we do think about the families and allocations.'*
>
> (P5)

Effective leadership facilitated clear ***communication*** between staff members during the palliative period to enhance care. Clear communication allowed staff members to provide integrated and collaborative care to the infant and families. As one nurse noted:

> *'Communication, most definitely…between medical, whatever hospital staff are involved. Definitely between the family and Allied, and I'm talking Allied Health too, whatever hospital people are involved that needs…you and whoever, social worker or whatever.'*
>
> (P3)

Clinical knowledge

Within the theme of *clinical knowledge*, three subthemes emerged – *education, adapting and tailoring care,* and *medical support*. Respondents reported that palliative care was facilitated by the depth of clinical knowledge of nursing staff through ongoing ***education***. This educative process supported staff to ***adapt*** and ***tailor*** care to infants and families' needs. As one nurse reported:

> *'I think mostly we've got a unit where there's a lot of knowledge around and so we can inform the parents, consultants down too, but mostly the senior nurses I'd say. We've got a lot of junior ones but we've got a lot of knowledge about what can happen and explain to parents what can happen.'*
>
> (P1)

Nurses also acknowledged the family-centred ***medical support*** by consultants during the palliative care period. For example, one nurse reported that consultants were good at:

> *'Explaining things easy for them to understand.'*
>
> (P7)

However, the hierarchy was also noted:

> *'You know what they, they obviously dictate to us to a degree what happens with medication, what happens with IV lines, what happens with ventilation, but they are also very good at listening to parents I think too.'*
>
> (P3)

Morals, values and beliefs

Within the theme of *morals, values and beliefs*, *self-reflection* emerged as a key subtheme for delivering quality palliative care. Nurses reported the need to critical *self-reflection* about one's own morals, values and beliefs when providing quality palliative care. Many expressed the need to develop an awareness of their own worldviews through ***self-reflection*** as these had the potential to impact upon their provision of palliative care. This was encapsulated by a nurse who stated:

> *'I don't think you can force your values or put your values onto someone else but I guess your personal approach.'*
>
> (P5)

7.4.1.2 Family support

Within this central theme, family support delivered by staff, the themes of *emotional support, communication,* and *practices* were identified. These factors reflected staff abilities to use their professional skills and knowledge to support families during the palliative care period.

Emotional support

Within this theme, four subthemes were identified – *attunement to family, identifying bonding opportunities, the gift of time, extended family support*. Nurses were adamant about the crucial role of emotional support for families during the palliative care period. They perceived their role to be that of facilitators of family connectedness during this distressing time. Nurses reported ***attunement*** to the family's needs and creating opportunities for families to bond with their infants. A nurse stated simply that:

> *"These parents just need to be able to do things that they would do with their baby if it was at home."*
>
> (P 4)

Nurses' attunement to the infant and families during palliative care facilitated ***bonding*** opportunities. Understanding the needs of the infant and families allowed nurses to provide a safe environment for bonding and memory-making:

> *'Unfortunately, we knew what the outcome would eventually be but it was a matter of facilitating for that family and making sure they were supported and felt safe enough to do that on their own, and to me that's good end of life care.'*
>
> (P6)

Many nurses identified the gift of ***time*** as an important aspect of providing emotional support to families. Nurses reported that families were caught between both bonding with and grieving for their baby. Nurses' capacity to protect this time for families was perceived as important for providing quality palliative care.

> *'I guess we're good about privacy, we're good about creating good moments for each of the families in their own right, and we're good about trying to value time, because, if anything as a practitioner, if that's what you can give them, that's the maximum time with each other.'*
>
> (P2)

During this time, nurses were acutely aware of ***supporting the extended family***, as well as the parents of the infant. Often siblings, aunts, uncles, and grandparents were on the unit at the end of the infant's life. Nurses reported that this support was crucial for immediate emotional support of the family, but also the long-term impact of this support on the family into the future:

> *'So end of life care is about everyone, getting the whole family involved not just the parents, it's not excluding anyone who is directly involved with that baby.'*
>
> (P8)

Communication with parents

Within this theme, four subthemes were identified – clear information, support during decision-making, advocacy for infant, post death information.

Nurses reported good family support was enhanced by providing ***clear information*** to families throughout the palliative care period. Clear information included being honest and truthful with families about the likely process of end-of-life for their infant, and providing education to parents to ***support the decision-making*** process. For example, one nurse reported that:

> *"I'm very honest with families. That's a personal professional choice I make… making sure to be careful with your word choice."*
>
> (P2)

Other nurses stated that supporting families was enhanced:

> *'By telling them the truth [about their infant's condition].'*
>
> (P4)

> *'Empowering the parents to make…that decision at the end of the day but without forcing a particular option on them.'*
>
> (P5)

> *'The number one thing for us is to support them and help them in those decisions.'*
>
> (P6)

Nurses also reported that good family support was facilitated by being an ***advocate for infant***. While many nurses acknowledged the importance of the family during this period, primary nursing of the infant as the patient was also in the forefront of their minds. For example, one nurse reported:

> *'...thinking primarily is the patient in pain?…what are we asking the patient to do as far as quality of life for the time that the family needs to be able to adapt to the circumstances.'*
>
> (P2)

Family support was also provided by nurses through provision of ***post death information***. One nurse reported that written information was important when supporting parents after the death of their infant:

> *'There's questions and things that parents will ask, I can anticipate and I've already got the answers for them.'*
>
> (P6)

Practices

Within this theme, four memory-making practices were identified that were perceived to contribute to good family support during the palliative care period – ***meaning-making*** *(photographs, memento box, memory book,* and *ceremony).* Nurses also acknowledged the importance of *community support* to the provision of resources for these practices.

Nurses reported that the photographs provided by the unit were particularly important for **meaning-making** during and after the palliative care period. As one nurse described:

> *"Photographs, lots of photographs and yes just try and make the families have as best an experience they can in a bad situation."*
>
> (P1)

Nurses also gathered together items into memento boxes, such as locks of hair and footprints, for the families, stating:

> *'I think it's important for that memory, the memories.'*
>
> (P1)

> *'…offering them quite a few after-life memories, like the hair-clippings and memory box.'*
>
> (P5)

Nurses also spoke about their creativity in developing memory books for families about their infant. As a nurse describe:

> *'Well, we're very creative with our resources. It is nice to have the all-in-one booklet now, that we can give families as a memory.'*
>
> (P2)

Additionally, the capacity to offer ceremony to families was also considered to be quality palliative care practice. Nurses reported that ceremonies offered to families did not necessarily have a religious affiliation. As one nurse reported:

> *'Christenings or like name services, maybe less religious than others.'*
>
> (P6)

Nurses also acknowledged the **support of the community** for the unit. Community members provided hand-made items such as clothes to be given to families for their infants. Nurses reported appreciating this support as they perceived it to be a means of community acknowledgement of the difficulties of palliative care in the neonatal unit. As a nurse stated:

> *'I think and also like people in the community must realise or they've had it happened to them for them to make all these little dresses and then it's so nice for the nurses to have.'*

(P7)

7.4.2 Barriers to Care

Five themes emerged from the data that were perceived to be barriers to providing quality palliative care. Staff perceived *education, lack of privacy, isolation, staff characteristics* and *systemic (policy, and procedure)* factors impact upon palliative care provision (Figure 7.2).

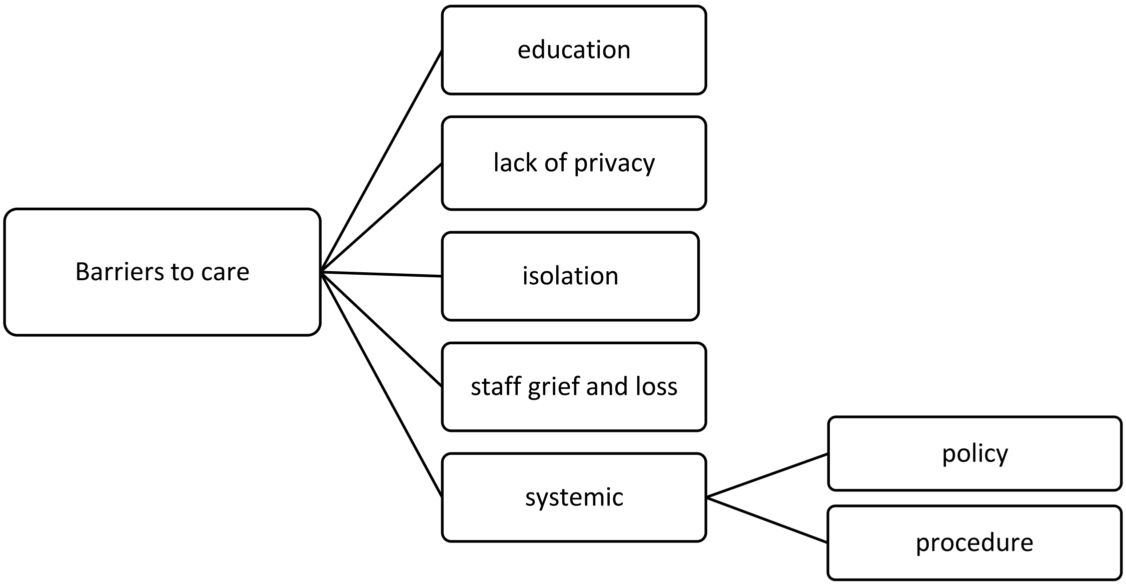

Figure 7.2 Factors nurses reported to be barriers to good care.

7.4.2.1 Education

Staff perceived a ***lack of opportunities*** to engage in the palliative care process as a barrier to providing good care. Given the small number of palliative care cases in the unit, it was perceived that often the most experienced nurses were allocated to these infants and families, and that education was not provided to new staff in order to build their skills in palliative care. As one nurse noted:

> *'I think sometimes we don't maybe educate some of the new staff well enough or involve them enough to be able to…we sort of go off the people who have maybe been there a few years and are more senior staff.'*
>
> (P 5)

Another stated that:

> *'I'd like to know a little bit more about how we do things here…what the actual process is.'*
>
> (P 6)

Another nurse stated that suitability and experience for providing palliative care would be enhanced:

> *'If people are more educated [so] they wouldn't be so apprehensive about caring for babies at the end.'*
>
> (P6)

Further education factors included ***difficulties providing in-service*** to nursing staff. For one nurse this was viewed as a practical difficulty of releasing staff from the floor to attend workshops. This nurse stated:

> *'I'm so enthusiastic…I've tried to give in-services at work but it's only people [off the floor who] can come…so availability of staff.'*
>
> (P8)

7.4.2.2 Lack of privacy

Staff perceived a barrier to care was a lack of privacy in the ***Special Care Unit*** particularly in the event of a death of a twin. For example, as nurse reported this was a difficulty when parents wanted to reunite a twin who had died in NICU with the other twin in Special Care. The nurse reported that this was particularly a difficulty for other parents in Special Care, stating:

> *'[nurse] was taking [infant] it into Special Care to the other baby, and the parents of the other babies were getting upset because there was a dead baby in the Unit.'*
>
> (P4)

A lack of privacy during the palliative care period and after the death of the baby was reported by nurses particularly when parents wanted to take the dead or dying infant out of the neonatal unit into ***public spaces***. Nurses reported that parents often wanted to take their infant to the hospital gardens to experience a moment of normality. However, nurses reported that having these infants in public spaces often caused distress in others in those public spaces stating:

> *'I know that [staff have] taken babies down in to the garden [but] people get upset seeing dead babies. Or dying babies.'*
>
> (P4)

7.4.2.3 Isolation

Nurses also perceived isolation to be a barrier to care. Nurses reported that the palliative care process was often ***hidden from view*** from parents and other staff in order to ***protect*** them from the emotional distress of death and dying. As one nurse reported:

> *'The staff, unless they're actually involved in the end-of-life care, um, often don't know what's going on…because I think you try and protect other people in the unit as well. Other parents…from [the process of] dying. You're try and protect them as well as protect parents by giving them some sort of privacy I think.'*
>
> (P 4)

The perception of isolation as a barrier to care was somewhat contrary to the perceptions of lack of privacy that were also reported. Negotiation of the balance between the privacy and isolation was required by nurses in order to provide quality palliative care.

7.4.2.4 Staff

Barriers to care were also reported to include the ***impact of nurses' own grief and loss*** upon the delivery of care by nurses. Nurses reported that delivering palliative care was emotionally draining and required self-reflection. As one nurse reported:

> *'I've come to understand that that is your own personal stuff that they actually can't deal with…grief, death and dying.'*
>
> (P8)

7.4.2.5 Systemic factors

Barriers to delivering quality palliative care included policy and procedure factors. At the ***policy*** level, nurses perceived a *lack of input into unit guidelines* for palliative care, *a lack of unit evaluation*, and the *need to update ideas and values* about care provision. As a nurse reported:

> *'There were six different policies…so I tried to tie them altogether, write them into one but in a more modern way and then they get shoved into the bowels of the hospital and you never see them again.'*

(P8)

Frustrations were also expressed about the lack of input into palliative care guidelines was also reflected in the perception of a lack of evaluation for the palliative care provided. A nurse noted that:

> *'I don't think we've ever evaluated ourselves.'*

(P4)

Evaluation was also perceived by nurses as a transformative process for changing guidelines and values of the unit that support palliative care. It was acknowledged that community and parents' values about palliative care had changed over time and these changes were not reflected in the unit:

> *'We're just doing [the same palliative care], we've got policy and procedures, but the individuals have changed.'*

(P4)

Procedure subthemes included lack of flexibility, differing levels of support, difficulties in skill mix that interrupts continuity of care, and difficulties in staff changing from model of care from restorative to palliative care. While the policy level guidelines were perceived to be necessary for delivering quality palliative care, a barrier was perceived in the application of these into practice. A **lack of flexibility** in being able to apply the guidelines were perceived by nurses who reported:

> *'I think we've got the resources to do a lot and…we follow the physical withdrawal of care sheet and…we should not have it as a tick box but as a guide.'*
>
> (P5)

Differing levels of support from leadership was also perceived as a barrier to providing quality palliative care. As a nurse stated:

> *'I've had some great CNs on when I've been facilitating and other ones that, you know, want the room cleaned and ready for another baby.'*
>
> (P8)

Further to this perceived difference in support across leadership was the perception of difficulties in care continuity due to ***skill mix***. This was particularly noted when nurses were allocated to support families after their infant had died. One nurse described her discomfort during this process given her minimal connection with the family during the palliative care period:

> *'I might have felt a bit more comfortable if I felt like I should been there more than if I'd been somebody who had more connection with that family, yeah.'*
>
> (P3)

The change from restorative to palliative model of care was also perceived to be a barrier from some nurses. This ***shift in model of care*** was sometimes difficult to navigate as it conflicted with the medical ideals of providing life-saving care. A nurse reported that:

> *'Whereas when they're in a palliative model…in a way totally opposite to what we normally do which is very hard for a lot of them to get their head around.'*
>
> (P8)

7.4.3 Regional Location of the Unit

The regional location of the unit was perceived to present both facilitators and barriers for staff and families. Half of the nurses reported that the regional location of the unit did not affect the quality of care provided by staff. One nurse summed up this perception when stating:

> *'We've got the resources, we've got the ability to access things. I think our staff is fantastic, I don't think there's ever a staffing issue, I don't think there's a resources issue.'*
>
> (P5)

However, this was not the perception of all the nurses. The following outlines facilitators and barriers to providing quality palliative care for families and staff (Figure 7.3).

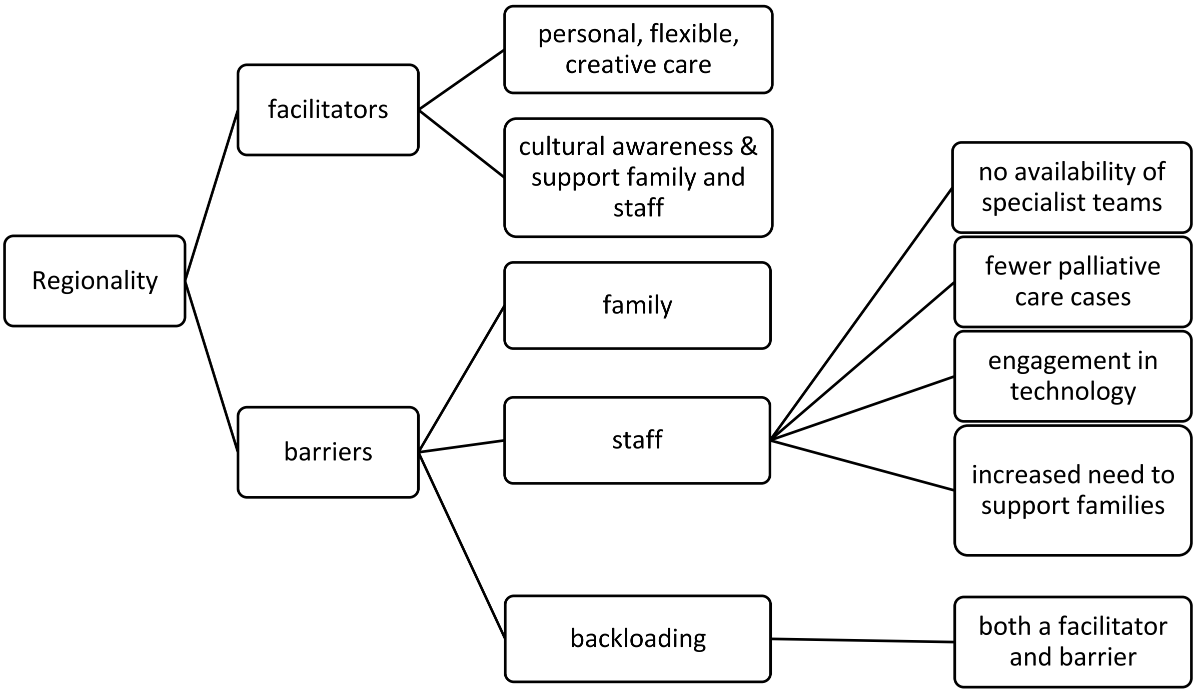

Figure 7.3 Regional location of unit – facilitators and barriers for providing palliative care.

7.4.3.1 Facilitators of care

Nurses perceived that being a regional unit allowed them to personalise care for families and be creative in their care. As one nurse stated:

> *'[being a regional unit] provides us challenges for providing care. I don't think it changes it in a negative way. I think it requires us to be more creative.'*
>
> (P2)

These opportunities to be creative and:

> *'personalise [palliative care] for those parents facilitates a more positive experience for families.'*
>
> (P8)

Being a smaller regional unit:

> *'...provides us a lot of variety again, because we don't see the same clientele all the time, it does help us to be more flexible about what the family might need.'*

(P2)

Cultural awareness and cultural support for staff and families

Working in a regional unit necessitated nurses to develop cultural awareness and culturally safe practices when providing care to Aboriginal and Torres Strait Islander families. Nurses described their understanding of cultural differences, stating:

> *'I think most of the Aboriginal people would prefer to have their babies with them and their families and they can't always do that a lot…it's just that for the parents, I think that they would probably feel more comfortable in their own environment.'*

(P1)

There was a reported awareness of the disruption this caused stating,

> *'...but if their babies are unwell they're out of their own environment and culture, yeah cultural wishes.'*

(P1)

The regional location and concomitant cultural diversity of the unit also necessitated cultural knowledge and support from Indigenous support staff. Nurses reported that this was an important benefit to staff and families, stating:

> *'...having families that come from that far [rural and remote areas] does create challenges for us and we are definitely lucky to have things such as the Aboriginal Liaison Officer.'*
>
> (P2)

Culturally safe practices were also important consideration, with a nurse noting that:

> *'...all the culturally different people that we've got here so we've got to be culturally aware that some people do stuff different.'*
>
> (P7)

In particular it was noted:

> *'...the cultural aspects that sometimes it isn't the parents that look after the baby, sometimes it's a grandma.'*
>
> (P2)

7.4.3.2 Barriers to care

Families

Time pressures due to family location

Time pressure due to rural and remote locations of families was the most mentioned barrier to supporting families during palliative care. This was elegantly articulated when a nurse noted:

> *'I think sometimes it's difficult because we are a regional, we're a tertiary centre, a lot of our mums and dads come from far away and they can't always have their family members with them and they're away from home.'*
>
> (P1)

Nurses were also required to navigate the balance between the need to attend to the baby's medical needs and the needs for parents' support:

> *'I think if it's a long term thing, we often encourage other family members to get here quicker.'*
>
> (P2)

Difficulties in accommodating large extended families upon arrival to the unit were also described as a challenge. This flow-on effect was identified by a nurse who stated that:

> *'...being able to accommodate families from out of town I think is a big thing.'*
>
> (P5)

Staff

Availability of specialist teams

Regional location of the unit also limited the availability of specialist neonatal teams such as cardiac or paediatric palliative teams. In the event of an infant's treatment changing from critical care to palliative care, transfer from regional to metropolitan treatment centres was reported to impact upon families. For example:

> *'If it's a matter of them having to fly somewhere to see that specialist team and then still being given the bad news that you can't do anything…being regional though regardless, you don't have all the specialities, you don't have all the options.'*
>
> (P6)

Fewer palliative care experiences

> *Having fewer palliative cases was identified as a challenge for staff as there were reduced opportunities for staff to develop experience and competence in delivering care. For example, a nurse reported that: 'It's great you don't have as many for the end of life but it also means staff don't have as much experience, you don't have as much exposure to it so that you're not as confident and competent as maybe someone that'd be in the city where there's a lot higher numbers, purely by ratio.'*
>
> (P6)

Engagement with technology

While it was identified that the unit was resourced with technology devices such as iPads, there was a perception that these were not used to their full potential to alleviate the impact of regional location upon families. It was suggested that these devices could be used to connect immediate and extended family who are separated from their infants due to distance from home. As a nurse stated:

> *'We've got these new iPads in the unit, why can't we set up Skype for some of the families overseas and say look grandma do you want to say goodbye when you're in England.'*
>
> (P5)

Increased need to support families

Regional location of the unit also impacted upon the levels of support for families required from staff members. Given the time it takes for family members to arrive at the unit from rural and remote areas, staff reported needing to increase their supportive role in the interim. The impact upon staff members was described by a nurse who stated that:

> *'Sometimes perhaps it's a little more taxing on us as practitioners because maybe we do need to be a little bit more of a support group for some families because a lot of our families do come from outlying regions.'*
>
> (P2)

Transfer to the local hospital dilemma
– a facilitator and barrier to quality of palliative care

The practice of 'backloading' (transferring) infants to hospitals closer to their homes was reported as a facilitator and a barrier to palliative care. This dilemma was identified when a nurse stated:

> *'[When we know that the baby is going to die] we like to send them back to their family. But is that a good thing? Knowing what those hospital's resources are even more stretched than our resources. So, are we, we are in a way doing family support, but [the local hospital] have an even lesser set up [for palliative care]. I think that, than we do. That one's [question], I don't think, we have sent them on further, we've sent them back, and that's a good thing and the parents do appreciate that, but then is that hospital set up to deal with that [dying baby]?'*
>
> (P4)

7.5 Discussion

The results of this study highlight the barriers and facilitators of palliative care provision in a regional tertiary neonatal unit. The focus on both the positive and negative factors is a strength of the study that will allow a dual approach to both addressing the barriers and facilitating quality palliative care. Facilitators to care included staff factors of leadership, clinical knowledge and morals, values and beliefs, and family factors of emotional support, communication and practices. However, identified barriers were education, environment factors of lack of privacy and isolation, staff grief and loss, and systemic issues including policy and procedure factors. Barriers to care are the most commonly researched (Chen et al., 2013; Kain, 2011; Kain et al., 2009; Mendel, 2014). Few studies have included both facilitators and barriers to palliative care provision (Epstein, 2010; Kain et al., 2009).

Facilitators of good care identified in the current study are reflected in previous research (Epstein, 2010; Kain et al., 2009). Nurses in this study identified the importance of clinical knowledge including palliative care education and the ability to adapt and tailor care to families in caring for neonates and families. These nurses reinforced the need for good clinical guidelines, communication, and evaluation of the care provided during palliative care. Establishing effective clinical guidelines provided nurses with a framework within which to deliver care. Further communication included being an advocate for the infant while supporting families to make decisions (Epstein, 2010), and providing post-death information. Further, self-reflection upon one’s morals, values and beliefs allowed nurses to safely practise without becoming overwhelmed by the difficulties of attending to dying neonates and their families. However, staff opinions and beliefs have been previously identified as a barrier to care (Chen et al., 2013). For these nurses, perhaps developing self-reflection has the potential to encourage staff to engage in conversations about aspects of care that are in conflict with their personal values, which may in turn help to alleviate moral distress identified by other research (Mendel, 2014).

Strong leadership was identified by nurses in the current study as a facilitator of quality palliative care. This factor has not been explicitly identified in previous research. Strong leadership was evidenced by senior staff providing mentorship to less experienced staff, and being effective communicators in the team. Leaders in the unit were also perceived to be those nurses who were able to understand staff suitability for and experience of providing care, and being able to balance the skill mix of nursing staff. Previous research has identified inadequate staffing and moral distress to be a barrier to palliative care provision (Kain et al., 2009; Mendel, 2014). Supporting staff in the neonatal unit to enhance their leadership skills may help to address staffing difficulties.

Barriers to palliative care provision identified in the current study are similar to those in previous research. Attitudinal (Kain, 2011), educational (Kain et al., 2009; Mendel, 2014), environmental (Kain, 2011) and institutional (Chen et al., 2013; Kain, 2006) factors were identified by nurses in the current study. For example, these factors included staff grief and loss, in-service provision difficulties, isolation of and lack of privacy for families, policy guidelines and procedural flexibility. It appears that these commonly identified factors negatively impact palliative care provision in neonatal units in various countries. Further, these findings reinforce the need for effective guidelines, staff and family support, education, and evaluation of the care provided during palliative care.

As the only regional tertiary neonatal unit in Australia, it was important to also explore the impact of regional location on palliative care provision. The impact of regional location has not yet been identified in previous research. Nurses identified barriers to care relating to family and staff factors. Nurses were acutely aware of the time pressures upon families to quickly travel long distances at the end-of-life and the concomitant pressures upon staff to balance the needs of the family and the neonate. Further, staff felt the pressures of providing support to extended family members who had travelled to the unit. These pressures may be ameliorated by the use of technology to connect families during this time. For example, families could be connected to the unit using telemedicine technology such as video-link and cameras in order to see their infant.

Nurses also perceived that given the regional location of the unit, exposure to fewer palliative cases impacted upon their development of palliative care skills. Additionally, providing care to neonates without the immediate support of specialist teams was also perceived as a barrier resulting from the regional location of the unit. While development of a paediatric palliative team was proposed, given the few cases of palliative care in the regional unit, the operation of such a team was yet to be clearly defined. More creative use of technology to receive advice from subspecialists in metropolitan cities might be considered within the unit to reduce the need for babies to travel, particularly when the local care givers recognise that continued care is futile.

Given the regional location of the unit, returning neonates to their local non-tertiary referring hospitals presented a dilemma for staff. Nurses were aware that sending neonates to the local hospital would ease access for families and extended families. However, nurses were also acutely aware of the limited resources those hospitals have to provide palliative care for the dying neonate. This delicate balance was at the forefront of nurses’ minds when considering whether or not to transfer the neonate. Communication between the tertiary unit with the local hospitals about their willingness to provide palliative care for individual babies, facilitated by the use of telemedicine to introduce the different staff teams to the family, as well as the use of documented guidelines could facilitate timely transfer for some babies and their families to a location closer to home and community support.

Facilitators of palliative care in the current study included nurses' perceptions of being able to provide personal, flexible and creative care for families. Nurses were able to surmount resource limitations that resulted from being geographically isolated from the nearest metropolitan area. Importantly, given that over a third of neonates in the unit were Aboriginal or Torres Strait Islander neonates, nurses reported that their level of cultural awareness helped to pave the way for culturally responsive care in the unit. There is some data available on the cultural aspects of care in the Australasian setting. Culturally specific practice explored in the New Zealand Maori population shows a desire of families and communities to be involved in palliative care planning, preferences for death to occur at home and the importance of prayer and song at the time of death (Oetzel et al., 2015). Aboriginal and Torres Strait Islander peoples of Australia also have culturally important beliefs around death which need to be respected in order to provide culturally safe and supportive care (Maddocks & Rayner, 2003). Connection to community may lead to a desire for collective decision making with people travelling long distances before decisions surrounding palliative care or withdrawal of care can be made.

Many Aboriginal and Torres Strait Islander people who live in small, very remote communities have strong cultural connectedness including cultural traditions and beliefs. For these Aboriginal and Torres Strait Islander families, authority over the child may not reside with the parent, and discussions need to occur with the appropriate people present. Planning for events following death may need to include the practicalities of getting the infants body back to the home area of the community – often a costly affair- and escorted by a person considered appropriate within the community. Palliative care services themselves often have a low uptake by these communities. Overall, the results of this study identified the need for connection to the area in which the family lives, and the need for cultural sensitivity in the provision of palliative care.

The strength of this study was to explore both facilitators and barriers to providing quality palliative care. The regional nature of the unit also provides a strength in exploring the perceptions in a unit where the many of the extremely sick patients are far from their community supports. There is a large component of Aboriginal and Torres Strait Islander people served by the unit, so aspects of palliative care in a culturally diverse location are investigated. The sample size is small and although this is a potential limitation of the study, this is consistent with qualitative methodology, with data saturation obtained.

7.6 Conclusions

Previous research has predominantly focused on the barriers to providing palliative care in the neonatal environment. The strength of the current study is that it explored both facilitators and barriers to providing quality palliative care, and in doing so, makes an original contribution to the literature. Participants in this study perceived several factors, such as education, to be both a potential barrier and facilitator. Identification is the first step in a strength-based approach and implementation strategies are required to address barriers and amplify facilitating factors in order to provide quality palliative care in the neonatal context. Further, specific facilitators and barriers to palliative care provision unique to regional neonatal units, not previously explored in the literature, were identified. Study results have provided important considerations for regional and geographically isolated neonatal units, and will be used to inform clinical practice improvements, staff education support, and further research relating to palliative care provision for the most vulnerable babies and their families.

7.7 Acknowledgements

The authors acknowledge the valuable and generous contribution of the neonatal nurses who participated in the research.

7.8 Ethics Approval and Consent to Participate

Ethics approval was granted by The Townsville Hospital and Health Service Human Research Ethics Committee, Townsville, Queensland (Approval HREC/13/QTHS/84) and James Cook University Human Research Ethics Committee, Townsville, Queensland (Approval H5349). Written informed consent was obtained from all participants.

(COREQ see appendix 12)

The palliative care study provided important data about decision making for periviable babies at TUH. These data, together with data from all the studies are integrated in the next chapter.

Chapter. 8 Integration of the Studies

8.1 Realities of Decision Making

Although the results of this study often appear to portray a negative impression, parents were reflexive and perceived care to be overall of high quality. They were mostly very appreciative. Equally, HCPs were universally caring and concerned for their patients' wellbeing. The research findings should be considered in this context.

Integration of the findings from different study components allowed exploration of the research questions. For clarity, I initially summarise the findings, followed by paragraphs addressing each question. I then discuss theories generated from the research. The discussion section situates these findings in the current literature about decision-making in periviable care, particularly bioethical aspects of decision-making.

I usually use the term 'woman' when specifying birthing events or those more pertinent to the mother's role where it is more intimate to the baby, 'father' when the issue is related specifically to fatherhood and 'parent' most frequently when both parents are being referenced.

8.2 Summary of Major Findings

Most live-born periviable babies in North Queensland received care at TUH. There was a relatively high proportion of Indigenous, retrieved and remote residing babies admitted, with no difference found for admission based on these variables. Regardless of their socio-economic group, ethnicity or cultural background, or geographical origin, most parents had values which promoted resuscitation and a perception that futility refers to death rather than a potential for neurodevelopmental impairment. Some parents, however, with severely impaired children, regretted decisions made to continue care during their NICU course.

Positivity of parents about the achievements of their children, regardless of impairment, contrasted starkly with the prospective views of pessimistic HCPs. All parents were disempowered by both their inability to parent in the NICU, and by HCP restrictions towards parental decisions during their admission. Following discharge, however, most eventually thrived and often relocated to smaller centres where family and community support outweigh the need to be close to tertiary medical facilities. Of HCPs, only those with recent experience of working in smaller regional and remote areas recognised family decisions to reside in these areas could be facilitated by creative health care options.

Many HCPs believed that parents were too emotional to understand the potential implications of extreme prematurity and hence were not competent to make decisions around initiating intensive care. Parents mostly believed that the correct decisions were made for their own children. Whilst parents thought that parents themselves should have final decision-making discretion, this was based on a belief that advice they were given by HCPs was accurate and in the baby’s best interest. Pessimism, and the focus displayed by HCPs on neurodevelopmental impairment as the defining outcome of periviable babies, suggested that the confidence parents displayed in clinician attitudes may be misplaced. HCP negativity was seen to be influenced by the role of the HCP in caring for the mother or baby. Whilst HCPs were more reluctant than parents to want to provide care for the most premature babies, this contrasted with a reluctance to withdraw active care at parental request after intensive care was initiated.

8.3 Exploring the Research Questions

8.3.1 How are decisions made to resuscitate periviable babies in North Queensland?

Queensland guidelines published in 2014 discouraged resuscitation of babies under 24 weeks gestation unless the fully informed parents wish the baby to be resuscitated. At 24 to 24+6 weeks gestation, these guidelines suggest that fully informed parents can decline resuscitation (QCG, 2014). The implication of these guidelines is that from 23+0 to 24+6 weeks, parental wishes determine the delivery of active care. The guidelines give a framework for counselling of the parents, but use statistics of outcomes from the EPIcure study from a 1995 UK cohort of babies (Costeloe et al., 2000). Current Australian data show much more positive results (Boland & Bowen, 2018; Ireland et al., 2019; Mahoney et al., 2017; Sharp et al., 2018).

Despite the negative data used for counselling, as well as the negativity towards periviable babies exhibited by HCPs in this study, most periviable babies (23/24 weeks) in North Queensland who were born during this study were resuscitated and were admitted to the TUH NICU. The participants in the family study are a biased sample as all these babies were resuscitated. It is possible that babies who died prior to admission were considered too sick to survive, did not have a successful resuscitation, or received palliative care following a decision-making process where parents declined active care.

Parental recollection of antenatal counselling at TUH suggests that counselling is often somewhat haphazard in occurrence and timing, and there was little evidence of joint counselling by obstetricians and neonatologists. When discussing their antenatal counselling experience, some parents acknowledged that their emotional state at the time led to an inability to absorb information or to make decisions. Parental emotional states were also noted by HCPs who offered concerns that consent was not truly informed as parents may have been unable to understand how disabled the child could be in the future. Where the mother had been transferred to TUH, babies were assumed to be for resuscitation predicated by the transfer. Parents who were transferred did not recall any counselling prior to leaving the referral hospital although there were few occasions when there was truly no time for discussions with the parents to have occurred. These factors together suggest a need for counselling and discussions about care to occur earlier when a pregnancy is found to be at risk and repeated at multiple time points to ensure adequate time for families to engage and absorb information. Midwives cautioned against education about extreme prematurity for all women, as unnecessary fear would be engendered for the large majority of women who are not at risk of early delivery, potentially harming those well women who are emotionally vulnerable but are without cause to be concerned.

A clear finding of the study was that the woman’s past experiences, sociocultural background or spiritual beliefs influence their decisions around resuscitation regardless of HCP opinion. These factors may promote decisions towards resuscitation, or towards termination of pregnancy or palliation. These values were present prior to the pregnancy which became imperilled.

Parents mostly agreed that parents themselves should lead decision-making about resuscitation, while clinicians were more likely to consider that HCPs should be the final decision-makers. How the decision was actually made for individual babies appeared to vary widely. A balance of power exists in favour of HCPs who need to provide the care, reducing parental liminality. Counselling perceptions by the clinicians showed some recognition that their message framing would influence the parents. The emphasis of clinicians was for a negative message to be conveyed to the prospective parents, not merely an accurate one, in order to ensure parents would not be too optimistic. The approach of clinicians showed little understanding of the unique situation of each set of parents in antenatal discussions, rendering the pre-existing parental factors void. Understanding the individual biases of the women could have facilitated counselling by the HCPs.

In situations where the parents had adequate time to consider the implications of periviability, there was good evidence that parents had made a positive decision to request active care.

Women who had made a positive decision for resuscitation well before delivery usually also wanted care to continue even after the baby developed life threatening complications on the neonatal unit. Hence there was a group of patients for whom parental choice had clearly determined the resuscitation of their periviable baby.

Where parents had not decided about resuscitation prior to delivery, the HCPs appear to have been primary decision-makers. That the clinicians are the decision-makers to provide active care much of the time seems indisputable, despite the overly pessimistic views of the clinicians as reported in Chapter Six and their own preferences to opt for palliation at the same gestations. Often this clinician-led decision-making was said to be because of the difficulty of the parents had in making decisions, the lack of time available, or because the option exists to review the baby at birth and withdraw active care either then or later if adverse features appeared in the NICU. When parents ceded decisions to HCPs, they did so trusting that the clinician will act in their best interests, usually unaware that the individual HCP may have their own biases. Some parents, however, did realise that some clinicians may make different decisions to others, and that there is an element of subjectivity in decisions made.

Pessimistic outlooks were evident when clinicians underestimated survival and overestimated rates of severe disability. HCPs caring for the women antenatally reflected their role as advocates for the mother, protecting and caring primarily for her medical needs, with neonatologists and paediatricians often taking on a role of keeping the baby alive as the advocate for the baby. There was reassurance that the continuation of intensive care could be discussed after admission, if initial resuscitation was successful. Implicit bias in the care of periviable babies and their families emerged from the study as a theoretical construct

(Chapter Six). Bias towards periviable care is likely to impair the HCP's ability to facilitate parental decision-making by influencing message framing.

Both HCPs and parents described the assumptions made about the ability of the neonatologist to assess the baby's condition at birth and resuscitate accordingly. Studies have shown that this type of assessment is flawed and there is little correlation between poor condition initially and later poor prognosis (Lagatta et al., 2012; Manley et al., 2010). This suggests that withholding resuscitation after brief assessment may violate the tenet of non-maleficence, as the baby who may have done well, will die. Justice in terms of offering equal treatment regardless of economic or ethnic origins was found.

Despite the perception that they did not contribute to decision-making, parents who did not identify that they played an active part in decisions made to resuscitate their baby conveyed that the survival of the baby was their focus at the time of delivery. For most of these parents the decision to resuscitate the baby was thought to be appropriate in retrospect. Some, however, continue to suffer mental anguish where the decision to accept the risks of disability was not their own.

In summary, women of all socio-economic and demographic strata may have reasons for preferences orientated either towards or away from active care at periviable gestations regardless of the immediate circumstances of the birth. HCPs often assume the role of decision-maker, rationalising that parents (especially women) may be incapable of decisions because their emotional turmoil renders them incapable of absorbing negative information. This may represent a form of medical paternalism in decision-making, which denies respect for patient autonomy, and represents an appropriation of the baby by the medical profession. This was found to occur frequently in decisions to resuscitate periviable babies at TUH.

8.3.2 How are decisions made about extremely premature babies during NICU care at TUH?

Parents cede the care of their baby to HCPs when the level of care required exceeds that which the parent can provide. This will occur for every periviable baby who will then usually remain in the NICU for months before discharge home. This course of action inherently removes parental autonomy and disempowers the parents (Janvier et al., 2016). Parents will usually adapt to their new role and ideally work with the HCPs to care for the baby (O'Brien et al., 2015).

Informed parental decision-making rather than HCP driven decisions was desired by parents (Chapter Five). Parents reflected that decisions during neonatal care were made on HCP's terms; including the timing of discussions and the limits imposed on parental scope for decisions. This was seen for major decisions such as those about continuation of care, for some minor decisions such as keeping a room dark or light, and for decisions which were within the zone of parental discretion, albeit issues about which HCPs might hold strong opinions, such as immunisations. Consequently, HCPs appear to hold power over parents unnecessarily, enhancing disempowerment. Parents became institutionalised by the disempowerment, reducing the self-efficacy required to make decisions on discharge.

However, clinicians demonstrated their understanding of the difficult situation the parents found themselves in. HCPs appear to be genuinely empathetic in their care of the babies which suggests that the paternalism is subconscious rather than applied with overt intent. The initial helplessness of parents was recognised; however, clinicians do not appear to adapt to the growing empowerment of the parent in their parenting role that occurs with time. Parents who felt empowered to make decisions often clashed with HCPs. Power struggles ensued where the life of the baby was said to be at stake should the parent succeed in influencing issues such as discharge dates. HCPs perceived that parents lack the knowledge to make decisions, losing sight of the knowledge that parents gain over months of admission, often knowing their own baby’s patterns of behaviour best. Trust in parental perceptions and a recognition of the need for caring and decision-making to transition away from HCPs, was needed.

It may be that enhancing disempowerment of parents helps HCPs to maintain authority over parental decision-making, impacting parental autonomy. Contributing to the disempowerment is the negativity of HCPs and the appropriation of the baby by adultifying aspects of the baby in terms of decision-making. This is found antenatally where the baby may ‘decide’ to live and perpetuated later with the vocabulary used to describe the baby as an autonomous being beyond parental control. The act of HCPs not allowing parents to make minor decisions, which have no consequence for their baby, further leads to parents becoming resigned to a position of powerlessness while on the unit. Attachment to the baby is more difficult for parents in an environment of disempowerment as discussed in Chapter Five. Later decisions towards discharge are also usually controlled by the HCPs and empowered parents may become oppositional and difficult interactions ensue. The appropriation of the baby is similar to other appropriations seen in society and medical care and is used to remove ownership of aspects of identity in order to dilute the original owners. For example, the medical appropriation of the patient’s illness (Frank, 1998), where empowerment needs to be regained through the patient’s own narrative formulation of identity to take care of oneself. In maternity care, appropriation is described in the medicalisation of childbirth leading to similar disempowerment of women (Cahill, 2001).

Attempts to gain parental consent in decision-making often appear to assume that parents will agree to the course of action proposed by the clinician. As demonstrated in Chapter Five, when parents then decided against the HCP’s preference and the baby did badly, the parent carries the guilt for harming their child. Conversely, parents who acceded to repeated HCP requests for consent against their will for aspects of care to which they would usually object, for example, immunisation, felt guilt at allowing themselves to be overridden and perceived that they had failed their child. Consent where the power balance is uneven leaves parents vulnerable. Examples of long-term feelings of guilt were evident as a result.

8.3.3 Is palliative care delivered in a way that reflects the option of redirection of care given to parents at antenatal counselling?

Redirection of care is discussed with parents at the time of counselling for periviable babies, where the suggestion may be made for the neonatologist or paediatrician to review the appearance of the baby at delivery and limit care if they perceive the outlook is very poor. As discussed in Chapter Six, this action has been shown to be have a poor evidence base. It is also suggested at antenatal counselling, that if the resuscitated baby shows signs that there is a worse outcome after admission, redirection can be considered. Redirection of care is the most common action which leads to death in most Western tertiary units for preterm babies (Wilkinson, 2009). In my thesis, redirection was explored in the family and staff studies (Chapters Five and Six), with a side study done on palliative care in the neonatal unit from the nursing perspective (Chapter Seven).

HCPs and many parents considered that redirection following stabilisation would be more difficult for families as they may have false hope and would be too attached to the baby to let it die. Parents were also found to vary in their perception of futility. Despite the negative statistics most parents may have received antenatally, even a small chance of survival was considered enough to continue care for some parents. Other parents did not seem to have been aware of how high the risk of severe disability was for their individual baby at the time. There was evidence that misleading information was sometimes given by clinicians after admission to the NICU, presumably from misplaced optimism in situations where the risks for severe disability were undeniably very high. When advocating for the baby who might potentially have more minor disability than the clinical signs predicted, clinicians denied parents the opportunity to consider withdrawal of care when the baby had an adverse complication or prognostic sign. This was more evident when there was considerable uncertainty for the outcome.

The trigger to withdraw intensive care arose from moral distress amongst the HCPs caring for the baby when the HCPs themselves considered care to be futile. Parents who considered the suffering of the baby to be high with probable poor future quality of life, were not able to advocate for redirection in several cases as clinicians felt that severe disability was not certain. The babies where parental request to redirect care was ignored were severely disabled at the time of the study. However, where HCPs suggested palliation, parents could choose to continue care, and satisfaction with this decision was seen despite subsequent severe impairments.

Uncertainty of outcome prompted some clinician’s reluctance to accept redirection in some cases, whilst other clinicians suggested that HCPs themselves may have difficulty with aspects of death and dying. One way which clinicians removed parental involvement in decision-making and avoided discussions about continued care was to promote the baby into a position of decision-maker about whether to live or die. This allowed clinicians and sometimes parents to avoid decision-making, whilst still enabling the clinician to control how aggressively care was delivered.

Once a decision was made for palliation, good practises occurred with parents able to spend time with their dying babies, and mementos being made, which was greatly valued by parents and recognised by the nurses. Neonatal nurses identified the need for truthfulness and emotional support at the time of the death. However, parents still needed long term support for their mental health, as guilt in redirection was noted even years later.

8.3.4 Long term reflections of parents about decision-making around the birth of their periviable baby

At antenatal counselling, accuracy is required in the information conveyed to parents. Undue negativity of clinicians may bias the parents towards palliation. At 24 weeks gestation at TUH this does not appear to be the case given the high rate of admission (Ireland et al., 2019) at a time when parental choice was the prompt for resuscitation and provision of intensive care. Accuracy is also important for slightly more mature babies as negativity will diminish the hope that parents might have for a healthy outcome. To maintain parental trust, clinicians should neither be overly optimistic nor pessimistic (Janvier et al., 2016).

Parents were mostly happy with decisions made to resuscitate the baby, and concerns that they raised were mostly around the organisation and timing of counselling. However, the opportunity to share the parental values involving quality of life versus survival did not always occur, denying parental autonomy. Several parents felt that the neonatal staff were wrong to decline their request to palliate after initial resuscitation.

Following discharge parents often had initial difficulties with decision-making, having relied on hospital staff for care and having felt disempowered. Support prior to and after discharge might have helped parents to transition to an empowered decision-making role. Adaptation did occur, and the neonatal experience became a life-altering experience for all parents. Parents were very appreciative about the care and often raised funds for the unit after discharge. Likewise, parents have offered to help with plans to improve counselling and information sharing with parents. Bonds between parents have been formed with parent groups meeting for years after discharge, and many parents maintain social media relationships with staff.

Regardless of where parents reside, they received appropriate health services where they chose to engage with ongoing care. Some, however, had chosen to disengage where they themselves perceived the child’s difficulties to be minor. Parents modified their expectations resulting in HCP assessments of wellbeing and development not necessarily equating with their own. The findings in Chapter Six suggest a lack of appreciation by obstetric, midwifery and neonatal staff about the resilience of parents in the longer term. Paediatricians were the most family focused clinicians, understanding that community support was more important than access to health care for families and that care can be provided even in remote locations. Justice is denied to parents where decisions are made to limit periviable care because of the location of residence. Judgemental assumptions that parents will be unable to cope with adversity showed ongoing medical paternalism, even beyond the time that the clinician is responsible for the patient.

Parents cede many decisions to HCPs, presuming that the HCP will act in the family’s long term best interests. However, clinician biases and ignorance of both the medical outcomes, and the values by which parents judge outcomes in the long term, meant that the clinician had a limited foundation for their decisions.

Thus far in this chapter I have attempted to explore the answers to my research questions. I have generated rich data which will enable improvements in the service itself. I have also identified several concepts not previously clearly delineated. These concepts will be explored as theory in the following section.

8.4 Further Theory Making

Four theories emerged from my research which will be discussed here. These reflect the misguided need for control by HCPs, rethinking counselling, parental resilience and the limitations in the perceptions of futility.

8.4.1 Misguided need for control

Effectively HCPs act as gatekeepers for resuscitation and redirection to palliation. The balance of power to enforce decision-making lies with them as the parents are unable to provide the care needed for the baby, and without their management the baby will die. Hence, their actions and beliefs effectively control the decisions made, whilst still suggesting that parents have some choices. HCPs claim their objective informed opinion is the epistemological underpinning of their ability to make decisions for the resuscitation of periviable babies and justifies primacy over decisions made by parents. Parents are diminished as decision-makers due to emotional turmoil, and a lack of understanding. The negativity and implicit bias of HCPs, however, reflects their own pessimism towards potential disability and is of itself inherently emotional. Obstetricians and neonatologists also have largely unacknowledged emotions of guilt around decisions. Evidence for the emotional status of senior HCPs is seen in their perceptions of personal responsibility for ‘creating’ disabled children, or equally for allowing a potentially healthy child to die.

8.4.2 Rethinking counselling

Traditional counselling involved senior HCPs giving information to parents, often using complex calculations to derive exact statistics of risk. Senior obstetric clinicians, neonatologists and more recently midwifery staff and allied health professionals provide support for the parents where decisions about resuscitation need to occur. Certainly, obstetric and neonatal staff know about the processes of delivery and the potential course through the neonatal unit. However, most parents did not need counselling about whether to resuscitate because they already wanted this to occur. A theory of the study was that parents at TUH want counselling to be provided in a way which better reflects their needs and situation. Establishing parental beliefs and their self-perceived capacity was more important than merely information sharing. Parents did need to know accurate risks to make informed choices and have their questions answered. Even after admission to the neonatal unit, information about progress and changing prognosis of the baby was needed. These findings suggest that clinicians may need to develop different formats for counselling.

8.4.3 Parental resilience

Parental resilience was poorly understood by perinatal staff. Few HCPs demonstrated an understanding of the value of the baby, regardless of outcome, to the long-term function and happiness of the family, nor the capacity of particular families to cope with the care of a child with a disability. Neonatologists may have only practiced in general paediatrics until late in their training. Senior paediatricians had different views from their trainees about the care for periviable babies. More senior paediatricians were less concerned about the risks of disability, presumably as they had seen parents coping with their children’s evolving difficulties. Paediatricians showed the most understanding of parental perceptions of outcomes. Parental capacity and willingness to care for children with disability, and their perception of futility, challenges the ethical construct of futility as a function of ability alone. As the group who probably has most understanding of decisions and consequences, experienced paediatricians and, more importantly, parents of previously extremely premature babies, should be involved in helping to inform decisions to resuscitate. These resources could be utilized in the development of a new approach to counselling as discussed above.

8.4.4 Limitations in the perceptions of futility

Conventionally, some ethicists have decided that futility is a prognosis of greater than 90% death or severe impairment (Gillam, 20017). From the results of this study, and medicine as a whole, this does not make sense as very risky procedures are performed, and parents who have been given intact survival probabilities of less than 10% are offered care. Parental perceptions of futility and the value of disabled children challenge the viewpoint of a pure ethicist. Even a very remote likelihood of survival was considered enough for some parents in this study. Parents mostly follow a deontological view of the sanctity of life, which conflicts with the utilitarian viewpoint reflected by HCPs where quality of life and future costs outweigh the replaceability of the fetus in question (Tännsjö, 2018). If true autonomy in making the decision whether to choose to continue with or withdraw active care should lie with parents, then a reconsideration of the concept of futility must occur where parents wish to continue care. Futility is then defined by parental choice.

8.5 Discussion

TUH provides high quality care for periviable babies when measured in terms of outcome. Parents express appreciation for the care which they receive and there are few regrets about the neonatal provision or experience when interviewed years after the care is experienced, despite the exceptions which triggered this research. Staff in all specialties involved in the care of these vulnerable babies are concerned for the wellbeing of the families who they look after, and aim to provide the best care for their patients. This study has arisen in part to determine how the initial decision to resuscitate the periviable babies occurs, how later decisions occur in neonatal care, and the longer fate of the families concerned from a family and staff perspective.

8.5.1 Decision making at TUH

Decision-making at TUH follows a pattern which has been described by Leuthner as an expertise model (Leuthner, 2001). In this model, an expert who is objective, understands the medical facts and can prognosticate on an individual situation, makes a decision about the care of periviable babies based on their perception of the best interests of the baby and family. The need for HCP based decisions may reflect the medical patriarchal origins in decision-making from a time when the (usually male) doctor was the decision maker by right of his status and the woman giving birth too emotional and hysterical to do have input into her care (Jenkinson, 2017). However, the risk of the expert model is that it allows the physician moral judgement about the long-term outcome of the baby based on the physicians' own perceptions of quality of life for the baby and family (Leuthner, 2001). My study confirms that this, unsurprisingly, is subject to biases of the clinician and is inherently emotionally driven where the physician has an unrecognised interest in the outcome such as their own subjective self-perception of 'failure' or 'success'. HCP were seen in the research to clearly exhibit these traits in their own perceptions of their contributions to the outcomes of the babies. The need to control these decisions is misguided.

Parents in this study, in common with parents in previous studies (McHaffie et al., 2001) felt that they themselves should be the final decision-makers around the provision of intensive care for the baby. The role of the parents in decision-making has been recognised formally in Western neonatology since at least 1983, when a United States Presidential commissioned report outlined a framework for the ethical, medical and legal treatment of the seriously ill newborn and proposed that the doctor has a responsibility to decide if care is clearly futile or beneficial, in which case the rights of the baby outweigh those of the parents, but that when the benefits are less clear, the parent has a right to decide about care (Abram, 1983). From this report the concept of shared decision making (SDM) evolved (Gaucher et al., 2016). As stated more recently by Sullivan and Cummings (2020 p.218) SDM allows a “reciprocal exchange of information between parties with the goal of facilitating medical decisions that align with the patients’ or surrogates’ preferences, values and goals”. In essence, the decisions around care are determined by the best interests of the baby after discussions occur between staff and families. SDM would be defined by Leuthner (2001) as a negotiated model where the physician guides the family through decision-making based on their own values, assessing the burdens and benefits for the baby and family. Hence the parent’s values define the best interests of the baby. The negotiated model presented as SDM would effectively allow the parental input into most decisions as suggested by parents in my study. Decision making at TUH does not follow this model, but it was clear that parents would like decision-making to move in this direction.

A requirement for SDM is the provision of accurate counselling about the potential outcomes of the baby. Where decisions about resuscitation meet local requirements – for example at 23 to 24 weeks in Queensland where parental decisions determine care, then the goal should be to convey the uncertainties of the baby’s condition and prognosis and prepare the parents for the potential decisions about continuation of care later. Shared decision making has been advocated in the neonatal literature for some years, and aims ‘to involve clinicians and parents working together to make optimal health care decisions that align with what matters most to the patient’ (parent) (Sullivan & Cummings, 2020, p. 218). Several useful tools for SDM in NICU broadly follow similar processes (Haward et al., 2017; Lantos, 2018a; Sullivan & Cummings, 2020). These include ascertaining the individualised risks for a baby prior to discussions with the parents, ascertaining parental values and expectations from the counselling and facilitating discussions about any decisions based on the parents’ own requirements. An important part of SDM is for clinicians to individually examine their own biases to ensure that these do not impinge on the discussions (Gaucher et al., 2016; Haward et al., 2017; Lantos, 2018a; Sullivan & Cummings, 2020). Although the term shared decision making is now in common use, the process needs to be individualised for each family, and the concept of personalised decision making may be preferred (Haward et al., 2017).

8.5.2 Uncertainty in outcome

The provision of the actual risks for an individual baby in SDM also has its challenges. The model acknowledges the uncertainty that often exists for an individual baby. There is a requirement for accurate data about the expected possible outcomes for the patient, so that this information can be incorporated in parental assessment of best interest for the baby. There are a number of tools which can be used to derive an estimate of survival and disability at different gestations which take antenatal factors such as the gender of the baby into account, including the National Institute of Child Health and Human Development (NICDH) Extremely Preterm Outcome Tool found online (https://www.nichd.nih.gov/research/supported/EPBO/use) and local outcome data. However, there are often multiple individual factors which may apply to a baby, and these will change the expected outcome after the baby is born (Gaucher et al., 2016) and complications of prematurity either occur or do not. These make exact prognostication questionable when applied to an individual baby (Krick et al., 2020; Lantos, 2018). Few parents in my study wanted precise data, and when quoted figures for survival had declined to accept predictions given to them by HCP with often very low percent predicted survival considered an acceptable risk.

8.5.3 Best Interest

A further concern with SDM is the concept of the best interest (BI) of the baby. Many definitions of ‘best interest’ can be found in the literature. Leuthner (2001) explains that BI has two aspects – the objective medical facts weighing up risks and benefits of an action, and the subjective and moral facts which are the values or meaning of the actions, determined by the parents. Wilkinson (2006) describes BI where future life will have value or net benefit for the individual. The neonatal intensive care course leading to pain and suffering, the probability of significant physical or cognitive disability and the interaction with the environment determine BI assessments for Kuschel and Kent (2011). Kopelman suggests a standard of reasonableness where the option of the maximal benefits and least harm which would be considered justifiable by reasonable people of good will fulfils the BI test. These definitions appear to be somewhat vague with an element of subjectivity.

Brody and Bartholome (1988) challenge the concept of BI. They suggest that an infant cannot think and has no ‘interest’ regardless of parental decision making, their interest is unknowable. Interest can also be complex and counterintuitive to assess – Brody cites the example of a ‘non-functioning’ child who is not suffering and who has some happiness – they may be deemed to have a life of net benefit, but when the huge cost of care for the child is taken into account, there may be a net loss in benefit for the family and hence the child. Less direct criticism acknowledges the subjectivity of BI (Cavolo et al., 2020) and the difficulty of assigning value to outcomes (Leuthner, 2014). Gillam challenges BI as a concept and suggests that there is no need to accept the absolute best decisions for the child (Gillam, 2016). Rather she suggests that there is a Zone of Parental Discretion (ZPD) where the wishes of the parents can be weighed against a harm principle, when ‘good enough’ decisions are adequate if no harm occurs. Using this paradigm to assess decisions requires the HCP to discover what the parent wishes are, the effect of these preferences and potential harm to the child of the parental choice. These potential harms are weighed up against the harm which might occur if parental wishes are declined. Harm here is defined as a serious set-back to the wellbeing of the child including life, freedom from pain, positive relationships and happiness, but minor set backs are acceptable. These principles can be applied more widely to any parental decisions and are deemed less restrictive than decisions in the neonatal grey zone. It can be argued that some restrictions to decisions are inevitable such as the resuscitation of a 20-week fetus being deemed futile, or the resuscitation of a healthy well grown 26-week female baby where the outlook is good and resuscitation should occur. The constraints to ZPD are widened after the birth of the baby, when events may occur which increase the risks of immediate suffering or long term impairment. Here the uncertainty of the outcome could lead decisions to continue intensive care to be within the ZPD. Many of the apparently minor decisions seen in the neonatal unit can also be viewed through the ZPD lens, and more satisfying parental involvement would be found, with potential benefits for parental long-term mental health.

8.5.4 Futile care and redirection

HCPs in this study were concerned that futile care could be offered at TUH. In extreme prematurity futility has been suggested as greater than ninety percent chance of death or severe disability (Gillam et al., 2017). Offering to provide futile care or even suggesting the option exists is considered unethical (Haward et al., 2011). Haward (2011) considers futile care to indicate treatment failure to consecutive patients. However, it is not clear what treatment failure entails, hence this definition again is vague and subjective. There is an obligation to protect a baby from treatment which involved the risk of inexcusable harm without altering imminent death. However, where death is not imminent, futility might entail weighing up the burden of survival with disability, against the quality of life for the baby, and potentially the effect of the burden on family life (Cavolo et al., 2020; Haward et al., 2011). Broader societal costs will also occur within the finite funds of a health and education system. Du Pont-Thibodeau *et al* (2014) explore various definitions of futility, including quantitative measures where survival is so unlikely that the probability is incalculable, to qualitative measures where life might be considered ‘not worth it’, but is unable to conclude a clear definition. Essentially this is a balance between non-maleficence and beneficence. When balancing these elements, it should be acknowledged that for neonatal care to be provided to increasingly premature babies, care must have occurred in the past to slightly less premature babies at a time when their care was deemed to be futile; with consequent improvements in medical care increasing the intact survival and wellbeing of subsequent babies. Would it now be opined that the HCP at the time were providing unethical care? Certainly, there have been babies included in this study who were thought to have less than one percent chance of survival, who are developmentally normal. Given the lack of clarity in the perceptions of futility in the medical literature, the variations in parental perceptions of futility are not surprising. Perhaps, in the same vein, given that there is variation in parental values in their decision-making to resuscitate a periviable baby, the perception of futility is also within individual parent’s discretion where the outcome is uncertain.

Whilst my research showed that there was a concern about offering futile care prior to the delivery, there were conflicting findings when redirection of care was later considered in the neonatal unit. One possible cause for this was the uncertainty in outcomes which have been shown to lead to moral distress amongst HCPs (Dryden-Palmer et al., 2020; van Zuuren & Manen, 2006). Uncertainty was noted to occur in HCPs at TUH who declined parental decisions to redirect care to palliation in the fear that a potentially well baby might die, ignoring the high risk of severe disability. Moral distress will be explored later. However, as uncertainty in outcome increases, it is argued that parental discretion should increase (Gillam et al., 2017; Harrison, 1996). The role of the HCP in SDM is to recognise the rights of parents to make decisions for their children (Gillam, 2016) and to convey the uncertainty to the parents whilst allowing them to situate the potential risks within a framework of their own values and family capacity (Lantos, 2018a; Sullivan & Cummings, 2020). Beyond the parental claim to the right to make decisions for their child, the parents know their own values, what sort of life they envision for their child to be acceptable and how much the child and family can benefit from the options. The proviso, though is that their decisions are not distorted by misplaced hope (Wilkinson, 2010).

Whilst my study demonstrated that doctors fear that parents may want to redirect care when there is still a chance of a normal outcome, the reality is that the more likely issue is that the doctors want to redirect to palliation and not the parents (Lantos, 2018). The ethical perspectives of the refusal to consider parental requests to redirect care need to be explored. Autonomy in parental decisions is ethical where true informed consent occurs; accurate mortality and morbidity data are given, all options are explored, quality of life is discussed and the impact of the potential disability on baby and family is considered within parental value systems (Cavolo et al., 2020). Parental values are usually adopted by children, so that parents can proxy their values to their decisions about their children (Wilkinson, 2010) and weigh up uncertainty to reach decisions. Giving parental autonomy and ceding control requires giving all available information to the parent, not merely ‘hope’ that the baby will survive. Parents in this study with children with severe disability were content, where the early decisions had remained with the parents.

8.5.5 Counselling and decision-making

The focus of SDM is usually in decisions to resuscitate prior to delivery for periviable babies. Counselling, however, may not merely be to ascertain the decision to resuscitate a baby or not, and many studies have shown that parents themselves do not usually want this to be the goal of antenatal counselling (Kharrat et al., 2018; Payot et al., 2007; Pector, 2009). Parents in this research all wanted antenatal discussions about other aspects of care; how the baby would look, and even just to allay their fears that the baby might die. If parents are asking for more information about their parenting role in the neonatal unit, it seems logical that counselling occurs for babies at high risk not just of death and morbidity at birth, but also those who are at high risk of complications after resuscitation – all extremely preterm babies.

Parental opinions about decision-making have previously been investigated. A systematic review showed that parents value inclusion in decisions to resuscitate their baby (Kharrat et al., 2018), with dissatisfaction about the negativity shown in counselling. Parents wanted to be prepared to participate in the care of their babies, to have hope, understanding and have their spiritual needs met. Most ranked death as worse than survival, even with significant morbidity (Boss et al., 2008; Lam et al., 2009). Parents who later have children with severe disability would advocate for resuscitation if there is a chance of survival at the same rates as parents with healthy children, and are much more likely to suggest this than HCPs (Streiner et al., 2001). Antenatal counselling is perceived by parents as an opportunity for HCPs to provide information and support to parents (Moro et al., 2011; Payot et al., 2007). Honesty, but not false hope, and positivity is valued (Janvier et al., 2016; Roscigno et al., 2012) throughout neonatal discussions. Parents do, however, exhibit optimism bias following hypothetical counselling (Nayak et al., 2020). My study concurs with these outcomes and goes further introducing optimism bias as a factor which can help parents to cope with the difficult times in NICU (Ireland et al., 2019).

8.5.6 Parental resilience and sidelined parents

Parental resilience and ability to function well in the long-term was a prominent finding in my research. Perceptions about disability and the effect of disability differ between HCPs and parents who have disabled children. For example, in my study (Chapter Six) HCPs expressed distaste and even guilt at participating in the care of a child who is later found to be disabled, while the parents themselves were content. Several recent studies have examined the short-term experiences of parents who have had extremely premature babies. Jaworski *et al* (2018) hypothesised that parents of children with more severe neurodisability would be more negative about their children at review at 18 months of age. They found that there was no association between positivity about the child and level of disability, with the personality, happiness, progress and health of the child perceived as positives, and behaviour, slow language development and poor health as concerns. Twenty-seven percent of parents had only positive perspectives. Parents with children with mild to moderate problems had more concerns than those with severe or no disability. Arnolds *et al* (2018) went further and asked parents to describe their experiences of periviable care early in their neonatal unit stay and again at six and 12 months of age. Their focus was on whether it had been worth resuscitating their baby, including extremely preterm babies, those with grade three or four intraventricular haemorrhages, and some with Trisomy 13 or 18. Twenty-six families were recruited and interviewed initially and seventeen seen for follow up interviews. Although many of the babies had died, no parents considered care offered to have been futile and only one parent regretted the care offered at follow up. They found themes of realism about death, optimism and hope and appreciation for the care team. The authors contrasted the lack of regret of the parents with the moral distress described by staff. A similar pattern was seen in my study at TUH, albeit with more parents who did regret decisions made. Clinicians who counsel parents should be more aware of parental resilience and ability to negotiate health care for their children. This was a notable finding (Chapter Five), particularly in the confidence of parents to reside and even relocate to regional and remote areas with their child.

Saigal (2016), a Canadian researcher, has followed up a group of babies for over thirty years who were born with extremely low birth weight. Her studies have been notable for their positivity of both the parents and later the children themselves as adults in terms of ratings of quality of life and satisfaction with their circumstances (Saigal et al., 2006). She examined aspects of life such as parental divorce and found no differences in the families followed up compared to the control term group or national rates in Canada (Saigal et al., 2010) which confirmed similar findings by Singer (2007). In mid adulthood, the extremely low birthweight group studied did exhibit more medical ill health and higher rates of anxiety and depression, but, although rates of employment and income were lower than for healthy term peers, over 80% were employed and 85% living independently of their families (Saigal et al., 2016). Saigal’s work is often quoted at conferences to suggest that the long-term survival of periviable babies results in people who are as satisfied with their productive lives as term born people.

The positivity of parents contrasts with clinical assessments which suggest negativity about disability, and it appears that parents place value on very different parameters to clinicians who primarily quote statistics derived from tests of developmental attainment. However, Saigal’s work is not without critics, and there are parents who do opine that their lives are very difficult and they regret the resuscitation of their children (Culver et al., 2000; Harrison, 2008). Often these parents are heard individually via the media with stories of families in distress, and whilst they may love their children and have no regrets about care provided, they may wish that they had chosen to allow their babies to die at birth (McVeigh, 2011). Similarly, past stories in the legal realm tell of babies who were resuscitated against their parents’ wishes (Gross, 2000; Paris et al., 2005; Stinson & Stinson, 1983). These cases and others have a common theme of parental requests for only palliative care which were met with aggressive neonatal management and tragically sick and impaired infants. All the parents had been counselled about a grim future in terms of survival and disability and declined this care antenatally, but it was provided regardless of the parents’ requests. Where parents express a strong preference for palliation after counselling, this should be heeded as verified in my research. Studies which suggest only positive feelings towards the initial care and no regrets seem to negate this subgroup of parental voices, although these positive studies themselves may be open to some caution in interpretation. For example, Arnolds *et al* (2018) study recruited twenty-six families initially as they claimed this gave them data saturation, but only reviewed seventeen families later, and not at the time frames stated in the initial design. Is it possible that parents who did have regrets declined to be followed up? This was a suggestion by one parent in my study. There remains a divergence in opinions of some parents who remain sidelined by an increasing optimism by some in the medical press. Whilst some of the authors of the optimistic literature are themselves parents of vulnerable babies, the increased advocacy for an optimism focus without heeding these alternative viewpoints may represent the co-opting of parental groups and voices by the neonatal medical fraternity (Landzelius, 2006).

8.5.7 Changing prognoses and changing decisions

Following admission to the neonatal nursery, periviable babies have a changing prognosis based on complications which may arise. The longer the baby lives, the probability of death decreases as most deaths occur in the first weeks of life, but intraventricular haemorrhages, severe late onset sepsis, or extensive necrotising enterocolitis might increase the risks of neurodevelopmental impairment (Wilkinson et al., 2006). Several of the babies in my study did develop complications which were likely to raise these risks. Some parents discussed their awareness of these concerns, but supported continuation where this was discussed. Some did not report any discussions about care options when these complications arose, but assumed that this was because 'the doctors' would have raised these options had they felt that concerns had increased, and some discussed how requests to redirect to palliation were refused by the treating clinical staff. Regular reviews of progress and re-evaluation of the goals of care have been suggested since the work of Harrison in the 1990's (Harrison, 1996, 1997). Harrison's later work includes reflections of the problems of clinging to 'miracle baby' stories and the difficulty clinicians face in redirection resulting in misinformation where the clinicians are dishonest in hiding the negative outlook from the parents (Harrison, 2008). Silverman, long regarded as an early neonatologist philosopher and ethicist, believed even if the odds were 5:1 for a good survival at delivery (or later), parents should have the choice about care as a poor outcome could have severe consequences for the child and family (Silverman, 2005). Boyle argued that only at 26 weeks gestation are the outcomes so good that parents should not have this decision-making option (Boyle et al., 2004).

Although there is a vast amount written about the limits of parental autonomy, it remains one of the ethical dilemmas of neonatology. The consequences for the parents are, however, profound and potentially life changing. De Vos *et al* (2015) found little literature reviewing the situation where parents wish to stop care whilst HCPs wanted to continue, but stated that objective, value-free decision-making was an illusion for both parents and HCPs. Parents who wished to redirect care were most likely to have considered the situation in detail and were making a very difficult decision in their perceived best interests of the child, for whom they had hopes and aspirations. Neonatologists do limit the extent of decision-making, although it has been noted that more experienced clinicians who have contact with children with disability restrict parent liminality less (Albersheim et al., 2010). This aligns with the implicit bias theory found in this study (Chapter Six) which is further explored below. Parents and HCP may have different aims for continued treatment which may be complex (Dupont-Thibodeau et al., 2014). Death and disability should not be conflated, so that even if the complication does not herald imminent death, the increased risks should be conveyed. Whilst parents have different resilience to cope with disability, the choice to do so should be theirs (de Vos et al., 2015; Dupont-Thibodeau et al., 2014). Culver *et al* (2000 p3201) described 'feeling threatened and made to feel like criminals for questioning even the most extreme medical decisions' during the care for their neonates in a letter from a group of parents. Given the powerlessness of parents relative to the HCP, closer collaboration in all decision-making whether it is for major or minor issues, might enable parents to feel like they are at least equal parties in the care for their children.

8.5.8 Implicit bias

The role of implicit bias has already been explored in this thesis; both the differences known historically to exist between disciplines (Lussky et al., 2005), and proposed reasons for these differences (Ireland et al., 2021). There was resistance to publishing these findings by several reviewers who stated that it was inappropriate to accuse medical professionals of bias at all, particularly those the investigator worked with. I discuss the difficulty of acting both as a primary investigator whilst working at the study centre in Chapter 9. Other reviewers, however, recognised that an understanding of both one's own biases and other HCPs' biases and their origins could improve personal practise and enhance co-operative working between specialties. Role-dependent bias was seen which increased as clinicians became more experienced (Chapter Six), and was found, not only in medical roles, but also in midwifery and neonatal nursing staff. The exposure of antenatal HCPs to terminations of pregnancy for abnormality in the fetus and guilt at encouraging potentially impaired survival was somewhat different to the bias of the neonatal clinician who felt guilt at the suffering of the baby with potentially impaired survival. I found that, unlike the obstetric or neonatal staff, paediatricians who care for children who were extremely premature had the most empathy with the parental situation and could contextualise the disabilities seen within the function and contentment of most families. The paediatricians were more likely to suggest resuscitation and advocate for parental decision-making to occur. The experienced paediatrician worried least about disability and showed more awareness of parental abilities to cope in adversity.

8.5.9 Moral distress

A potential cause of bias in the management of the periviable baby in TUH NICU is moral distress. Moral distress occurs in neonatal intensive care. A review of the literature surrounding moral distress in the neonatal and paediatric intensive care unit was done by Prentice *et al* (2016). They reviewed 13 studies which used differing methodologies and differing participant numbers. Prentice derived three themes featured in the studies; causes of moral distress, usually from the perceived use of disproportionate interventions not in the best interests of the child, relational dynamics between health care professionals and the ethical climate and impact of moral distress over time. Ethical concerns were felt by those with moral distress, with few recognising the presence of a moral dilemma where differing ethical principles may be conflicting (Janvier et al., 2007). Much of the work done exploring moral distress focussed on nurses, who are considered to be at higher risk and feel voiceless and powerless. Physicians also had high rates of moral distress when included, with ethical dilemmas, concerns about who should make decisions about starting or continuing care and feeling unable to advocate for the baby being noted. Solomon *et al* (2005) found that 38% of physicians felt that they had acted against their conscience in decisions made with parents. More recent work reflects that moral distress in itself may have some positive aspects in encouraging evaluation of practises and improving individual units use of ethical frameworks (Mills & Cortezzo, 2020; Prentice et al., 2018). Signs of moral distress seen in TUH HCP, are similar to those seen elsewhere, and appear to be an inalienable part of neonatal intensive care. An emphasis on managing distress by changing the moral climate and providing support for clinicians who require this would be beneficial to HCPs and hence to the patients (Prentice et al., 2018).

8.6 Strengths and Limitations of the Study

This study has several strengths. Few studies have occurred in similar locations with the unique characteristics of TUH. This is a smaller regional tertiary unit where the catchment area is very large and many patients are retrieved from more regional or remote locations. Families and staff engaged in the study with no difficulties in recruiting participants, all were willing to help the hospital to evaluate the service and to help in improving the provisions for extremely preterm babies and their parents. It is also the only study with some involvement of Aboriginal and Torres Strait Islander families with preterm babies engaging in qualitative research of this nature on a neonatal unit.

Limitations were also found. The unique location could limit the generalisability of the study to other locations, although the quantity of similar data produced recently suggests that this is not the case. The TUH also has a relatively small staff, which reduces the exposure to novel ideas and hence some of the findings may result from the insular nature of the unit. However, this limitation should be measured against the inclusion of staff surveyed and interviewed at other health services in the catchment. The position of myself as primary investigator is discussed at length in the reflexivity chapter, but it is possible that participants were unable to share fully any concerns they had if they perceived that it might have consequences due to my position either as a doctor for the families, or as a colleague or superior in the work place. All participants were offered an alternative interviewer in an attempt to mitigate this effect, and some HCPs chose this option, although no parents did. Another limitation of the study has been the time taken to perform, analyse and report the findings. The subject was very topical when first conceived, but much has been written by other researchers in the last seven years from different settings. However, it has been reassuring that the findings could be verified.

The limitation of being a primary investigator in my own unit is explored further in the reflexivity chapter which follows.

Chapter. 9 Reflexivity

My Role as Neonatologist and Researcher – a Reflexive Journey

In this chapter I explore the origins in my performance of this study and how being a primary researcher in my own unit has affected my own practice.

Reflexivity is a vital component of qualitative research. Creswell and Creswell (2017) explain reflexivity as a process where the researcher

> "...reflects about how their role in the study and their personal background, culture and experiences hold the potential for shaping their interpretations, such as the themes they advance and the meanings they ascribe to the data. Reflexivity is more than merely advancing biases and values, but how the background of the researcher shapes the study" (pg. 186)

Attia and Edge (2017), building on works of others, further suggest that the researcher is integral to the research process, exhibiting continual growth in cycles of prospective and retrospective reflexivity. Prospective reflexivity is the effect of the researcher on the research, helping the researcher to understand the significance of their background and values on their analytical lens. Retrospective reflexivity is the effect of the research on the researcher, changing their values and beliefs to a different point through the research process.

During the planning of the study, I thought that reflexivity would be important at every stage: ensuring recruitment was adequate, that interviews were done without influence from my own emotions, and through the analyses free of bias arising from my experiences. I soon recognised that reflexivity encompassed more than examining and extricating my own position during the study, and that an understanding and reflection of my own biases was required. The study itself was enmeshed with my work, potentially affecting my own attitudes towards patients being acutely cared for. Day to day work events also informed and had an impact on the research findings. As I am near the completion of the thesis, I find it interesting to note that the insights of Creswell, Attia and Edge were present in my own research. I found that qualitative research was much more difficult to perform than quantitative research because of my own position, and that this required a need for reflexivity to enable me to progress beyond my comfort zone.

Reflections were informed, and used throughout the research. These were contained in memos in my many notepads and transcribed into my reflective journal.

9.1 Prospective Reflexivity

9.1.1 My background, culture and experiences

I was born and brought up in Zimbabwe, which is a Sub-Saharan country of contrasts. My family was somewhat dysfunctional and moved frequently, and I attended many schools before I ultimately went to live with my grandmother. Despite the relatively low income of my family, I had access to the best education because of my race. My own personal values were acquired mostly from my grandmother, a hardworking, practical and strong Scottish woman with views about feminism and racial equality which were not the norm in 1980s Zimbabwe (then Rhodesia). She herself had battled as a single parent, migrating from war torn London to South Africa in 1947 to live with a mixed-race family until they were dispossessed of their house, and then moving to Rhodesia as a result. Having seen the poverty and the disparity between races in Southern Africa, I recognised that there were great inequalities and knew how lucky I was. This has made me favour the underdog, wanting those without advantage to be given the most opportunity, and given me an element of distrust for authority.

I went on to pursue a degree in medicine in South Africa. For several years after graduation, I alternated between working for the public health system in Zimbabwe, and doing locums in the UK where I eventually specialised in paediatrics. I completed subspecialist training in neonatology after migrating to Australia. Neonatology is a discipline where the patients have relatively few diagnoses, there is a need for a good understanding of physiology, and many patients are dependent on support from machines to survive. I had always been particularly good at the basic practical skills required, which earns undeserved respect, as these skills in themselves do not require any inherently exceptional special attributes. I had found a subspecialty where I could thrive in terms of practicing interesting medicine.

There are ambiguities in neonatology that I do not understand: why one zygote which has grown into a periviable human is so precious, while termination of pregnancy is possible at later gestations. Having worked in an environment where people die because of a lack of basic care, it sometimes seems indecent that we spend so much money and emotional energy on a single being. This reflected the contrasts which I had earlier found between working in the UK and Zimbabwe early in my career. It is difficult to practice neonatology without considering some of the ethical difficulties of health care disparity. Whilst I love the intellectual and practical challenges each day brings, I worry that my legacy will be one in which I have done harm to families by enabling the survival of a baby with overwhelming health needs which the family will come to regret.

The many ethical issues which are raised in neonatology led me to this study to try to make some sense of how I work, and if I am engaging in ethically justified practice. My background has biased me towards patients who I perceive to be discriminated against, and against authoritarian figures in the medical field who wield power.

9.2 Reflexivity About my Role as Neonatologist in this Research

My own bias at the commencement of the study was towards the active care of periviable babies. I have always been willing to offer care for the most premature baby. I am usually an optimist – not a half glass full or half glass empty person, but someone who is happy to see the glass. Despite my enthusiasm to offer active care, I have also been biased towards a position that withdrawal of active care should be considered where there are concerns about the future quality of life for the child, which has informed a special interest in perinatal palliative care. I am the most likely neonatologist to be asked to provide antenatal counselling for women who are pregnant with babies at risk of severe disability because of abnormality. Often women will choose to continue the pregnancy when the risks of a very poor outcome are high, and I worry that I may convey optimism bias. These sometimes contradictory biases have likely led me to research this area. However, I acknowledge that qualitative research cannot provide me with the security of objectivity and certainty in an area where subjective decision-making is the reality.

‘Insider’ research as an HCP in NICU allowed a deeper engagement in the subject area by familiarity with the environment. I work with the issues presented and have spent much time thinking about them. I understand the processes of periviable delivery, the NICU course and some of the consequences. Practical opportunities included access to a tertiary unit where I am a senior member of the medical staff. There was trust already established between myself and colleagues as well as staff in allied areas. This has manifest in the relative ease with which I could recruit HCPs for the staff studies.

My research placed me in an unusual position within my workplace. It was difficult to separate the role of the researcher from that of a clinician and colleague. Whilst I was careful to avoid personally interviewing colleagues, I still had access to thoughts and opinions which in some cases were confronting. It remained important for me to resist allowing this to influence my attitude towards these participants in both the data, and in the workplace. Given the small participant pool, I had interviewed some HCPs myself, and even those interviewed by the research assistant were easily identifiable to me from the transcripts. Some statements made by HCP would usually require me to escalate concerns about the HCP themselves, for example racist comments, had I heard them whilst at work. One colleague made statements which were concerning for their practice, but did not reach a threshold which would require referral to the registration authorities. I reached the conclusion that they were not reportable without the ability to discuss them with peers, which I would usually do by utilising the online tools for reportable concerns provided by the Queensland Ombudsman and the Australian Health Professional Registration Authority (AHPRA).

Often disagreements with colleagues arise due to differing attitudes towards periviability, particularly in decisions made with specialists from other fields such as obstetrics. In the context of the study, I needed to recognise that their attitudes had equal value, and understand them as a researcher rather than through the preconceived knowledge that I had as a colleague. I have been careful to try to reflect on the impact of my own bias when analyzing and interpreting the findings and ensuring that I tried to see things from another perspective. I also discussed this with my advisory team during regular research sessions.

In my workplace I hold a position of seniority. I needed to be aware that there was potential for HCP participants who were junior to me to aim to tell me what they perceived I would want to hear. Some junior staff may consider applying for employment within the unit in future years. To address this concern, I needed corroboration – several sources to triangulate the findings until categories were clearly established. I recognise that the trust which had been placed in me by HCPs who willingly participated needed to be met with a high responsibility in managing the data, particularly for confidentiality. Honesty in analysis means that I reflected my findings, seeking deeper meaning to the data, and not biasing the findings towards what HCP participants may want to have represented.

The challenges raised by the family study required reflexivity which had some similarity and some differences to that required in the staff study. I am not an 'insider' from the perspective of periviable delivery, having had three healthy term deliveries. As with the HCP study, my familiarity with the family participants resulted in a relative ease in recruitment. Despite this, I remain concerned that parents who did not participate might have been more critical, and the lack of these voices could be a limitation of this study. Another limitation could have arisen from parents who were interviewed refraining from being more critical because of confusion of my role as interviewer with that of clinician, or a desire to avoid awkwardness due to my presence. When designing the studies, I was aware of this and had ensured that families had the option of an alternative interviewer, and also that the Indigenous patients had the option of either interview by an Indigenous interviewer or in the presence of an Indigenous HCP. No parent chose any of these options. Nevertheless, a number of parents voiced their feelings about my own work, decisions and mistakes in a frank manner. On a personal level, there were some families with whom I had a closer bond and I needed awareness of this in managing the data they provided. Equally, some parents were seen by staff to be 'difficult' parents whist the baby was an inpatient. Interviews with these parents required the same professionalism, and I gained a lot of understanding about why the parents were challenging for the staff to work with.

My own background at times affected my analysis of the studies as I was diverted into areas where the data had no relevance to the research questions. One example of this would be the gender specific roles in parenting. I had to recognise that any tendency I had to explore this would need to wait for subsequent exploration after this thesis was finalised.

9.3 Retrospective Reflexivity

9.3.1 How the research has affected me as clinician

I am much more aware of my own beliefs than I was prior to the study. In the past I saw myself as the advocate for the baby. I still believe in many ways that this is the role of a neonatologist. I now recognise the family perspective differently. Rarely should I interfere with parental autonomy where parental discretion is possible, assuming parents are fully informed and have had the opportunity to consider all the facts about the baby's situation. I have noticed that my bias is to resuscitate every periviable baby, and that in the past almost all parents I counselled would have their baby resuscitated. However, more of the parents where I have tried to be more balanced, and clearer about parental rights to prefer palliation are now opting to do so.

I have a better understanding of parents' experience and how the behaviour of the HCP influences parental satisfaction. I now try to address parents' concerns and requests on daily ward rounds with a more holistic approach, not instructing parents about what they should feel, but rather listening more and reassuring more. I recognise that my views on redirection of care have expanded, and parental views and reasons for wanting to redirect are usually met with redirection; few parents want active care to cease without deep reflection on their own part. I am concerned that my lowered threshold to redirect to palliation is seen as a form of euthanasia by some HCPs, and ensure multi-disciplinary team discussions as part of decisions for individual babies. Futility remains an area where I feel the literature lacks clarity and is subjective to a large degree. I have attended conferences during my research to broaden my ethical framework in decision making. I still struggle with the uncertainty in predicting the long term for individual babies.

As a clinician, I also recognise that the measures by which we judge outcomes are not the same ones used by individual parents – we use charts, tests and scales of development, whereas parents focus on happiness and quality of life and are prepared to credit the baby with latitude for their difficult early start. Parents have also taught me a lot about human resilience, caring and the love they have for their children. The study has enhanced my respect for families and the decisions that they make. Almost every parent cried during the interview, and the interviews were emotionally draining for me as interviewer. We had a shared history, where I was a past participant, but where every family was brave enough to bare their souls without expectation of reward, but always to try to help make the service improve.

I recognise that all the HCPs who work with me have the best of intentions and mean well for their patients. I have been humbled by their involvement and interest. I respect their viewpoints and I can engage more constructively in discussing differences of opinion. However, there is discomfort in finding that there are deficiencies in practice in one’s own workplace, and I am concerned that findings from this research will cause friction there. This is particularly the case for the findings where bias is suggested, and colleagues may perceive that my work has been merely a critical discussion on their practice. It will be a challenge to suggest that we all have bias, which is reflected in our actions, and that there is a need to reflect on how bias influences our decisions.

Reflexivity was integral to the performance of my research. Reflexive awareness was incorporated into all elements of data collection, analysis and interpretation, as well as in my clinical practice.

Chapter. 10 Conclusions and a Way Ahead

North Queensland is a unique environment, covering a huge geographical area of 460 000km^2 and with a high proportion of First Nations people. There is a commendable ability of the staff to strive to provide the best outcome for the babies and their families, even if this does not include the continuation of intensive care. Care provided for periviable neonates in NQ is equivalent in outcomes to the care for babies in the ANZNN region. Regardless of the place of birth, once corrected for antenatal administration of steroids, there is no difference in outcomes for inborn or outborn babies despite the geographical distances experienced. Efforts by the tertiary hospital teams to better engage in the care of the 25% of outborn babies could improve the choices for these families. Improved accuracy around the outcomes for babies born from 22 weeks gestation upwards, and stratification of risks would enable HCPs to better interact with families both antenatally and after the delivery of extremely premature babies. Antenatal counselling using a shared decision-making process with appropriate training to deliver this would enhance parental satisfaction with decisions made, and ensure that parental values and goals are incorporated into care, whether this is to resuscitate the baby initially or to continue active care after admission to the NICU. The counselling would need to incorporate the uniqueness of the NQ region. Increasing HCP understanding of the positive aspects of care, and the different perceptions of disability held by families would lessen their own moral distress at caring for these babies and help parents to cope with the NICU experience with less stress.

10.1 Towards Improving Decision Making in Neonatal Care, and Future Directions for Research

A complexity of my research is that there was much data which has not been presented in the thesis because it was not directly relevant to decision-making. I will restrict this short chapter to some aspects of improvement which are applicable to my research questions. Many of the practical ideas arose from interviews, but I will not include quotations. All had more than one source.

10.1.1 Recommendations for clinical practice

From a practical perspective, counselling can be improved by introducing principles of shared decision making, following strategies outlined previously in Chapter Eight. This work needs to be done on a multidisciplinary basis involving psychology and senior members of staff to ensure that all HCPs understand how to counsel parents ethically. Given that this would be a new strategy, it is likely that HCPs will also need practical strategies on how communication with parents should occur as it has been clear that previously, parents' voices were often not heard. Although continuity of care by a named consultant and named nurses was not raised, this may facilitate communication with parents, and this would ensure that ongoing counselling during the admission is done by those who already know the families and their aspirations.

Moral distress may be mitigated by ensuring that there is an atmosphere conducive to the discussion and consideration of ethical dilemmas. By having regular multi-disciplinary sessions discussing psychological aspects of neonatal care which include difficult decisions, this ethos of the unit can avoid operating on a crisis led model moving to one which would build staff resilience. Addressing individual circumstances where moral distress is voiced by clinicians would continue to be facilitated.

In response to this study, parental communication in the birthing and neonatal unit will be enhanced by pictorial representation of outcomes at each gestation, following the suggestions of the British Association of Perinatal Medicine (BAPM) (Mactier et al., 2020). This will be facilitated using electronic tablets donated by parents who have participated in this project, and who have agreed to act as parent consumers in setting up the project. Parents who have both positive and critical feedback in this research have asked to be involved.

We need to reinstate the lessons learned to empower parents through interventions such as the FiCare trial (O'Brien et al., 2015). Parental involvement in the practical aspects of care could be increased, as well as parents' empowerment to discuss their baby on ward rounds in a parental advocate role. Parental education should occur regularly so that each parent can access the knowledge that they need. Staff working in the neonatal unit need a better understanding of the parental trauma inherent in an extremely premature birth and how we can help improve the bond between parent and baby. 'Difficult' parents need to be recognised as potentially being empowered parents wishing to be heard.

10.1.2 Recommendations for policy, education and training

The Statewide guidelines for the perinatal management of the extremely premature baby are being updated, and will now carry data which is applicable both to the Queensland outcomes and be accurate for recent years. Unfortunately, they do not appear to address the need to engage with decisions around resuscitation of 22-week gestation babies in a proactive manner, and I suspect that this will be a shortcoming with practical implications for many neonatologists.

I recognise that many of the bias and attitudinal problems do not have a simplistic solution. Issues of bias, attitudes and medical paternalism are endemic in medicine. Education on unrecognized bias and the role that it plays in patient care should be incorporated in regular multidisciplinary grand rounds. Many clinicians are likely unaware that they have biases and that there is a need for reflexivity to explore these. Organisational culture needs to recognise and encourage this in a non-judgmental way. This requires leadership by clinicians.

Negativity of HCPs is being addressed through a quality improvement project, with engagement with obstetric and midwifery staff in understanding accurate outcome data. This is being done using a variety of approaches but will need to be ongoing work. The inadequate administration of steroids seems to have improved since the outcome study has been published, however, the introduction of another quality improvement activity whereby each extremely preterm delivery is examined to investigate missed opportunities for steroid administration is planned. This has been advocated for by obstetric leaders, which is important as this is a sign that they are engaged in this issue. Whilst this will be retrospective initially, a prospective study of the management of extremely preterm babies is planned following this initiative.

TUH would benefit from clear policies around the care of extremely premature babies, including engagement with peripheral sites and referral sites to establish a culture of ethical and positive care. These policies should include the use of antenatal steroids once a woman is identified at risk of early delivery. Options such as the use of telehealth between the neonatologist and obstetrician at the tertiary centres for antenatal discussions is now possible with an increase of telehealth facilities, even at home for on-call clinicians.

10.1.3 Future research

There are several studies which need to be done leading from this research. The care for Aboriginal and Torres Strait Island families' needs considerably more work to explore and incorporate culturally appropriate decision-making. Indigenous-led research exploring specific aspects of care, and the use of Indigenous health care workers is needed. This study was unable to fully examine this group and I think a specific focus would be necessary as this is a complex group of patients with concerning health care outcomes (AIHW, 2019).

The fate of those babies who are not admitted to TUH should be studied to complement the data reported here. This would explore aspects of decisions made to withhold care, and whether these decisions resulted from individual factors such as known abnormalities or parents opting for palliation. Some babies may have been too unwell to survive despite an attempt at resuscitation.

Building on some of the findings in this research, further study is required into the role of the media in societal understanding of the consequences of extreme prematurity. Equally the perceptions of parents about the use of media on the unit from their perspective will be important: what they understand about periviable babies from the media and their own involvement in the generation of positive stories. Gender based parenting roles following extreme preterm delivery is also a topic raised by the findings from this study.

This body of work has been a journey of discovery exploring decision-making around periviable birth. Although in many ways this work raises more questions than answers, it has raised issues and potential ways forwards to enable more balanced decision-making, parental autonomy and an atmosphere conducive of reflexivity for HCPs examining their practice at TUH. As society expects to have care provided for babies born at increasingly lower gestations, it may be that the outcomes seen in centres with aggressive antenatal care which optimises the fetal condition for survival will improve. TUH clinicians will need to modify their own practices and decide if care for these babies is to occur in the unit or at centres elsewhere when parents request this care.

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Appendices

Appendix 1: HREC Endorsement as Non-Research for Outcome Study

This administrative form
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Appendix 2: Parent Letter/Information

Townsville Hospital and Health Service
Dr Susan Ireland
Department of Neonatology
The Townsville Hospital
Ph:
Fax:

To:

Dear Parent,

Having an extremely preterm or very sick baby in the neonatal unit is often one of the toughest things a parent can do in life. For many parents, the long term outcome can be a happy, healthy child. Sadly, for others, the outcome may not be as rosy. Some babies may be left with significant problems, whilst others may die. The care of babies in the neonatal unit raises many ethical issues in our day-to-day work. We want to learn whether we are ‘doing the right thing’ for parents and the babies we care for. As part of our reflection, we are asking our past parents how they feel about ethical issues. I would appreciate it if you could take some time to look at the information package about the study, and consider participating.

Kind regards

Sue Ireland

Letter as Cover Letter to Parents

Participant information sheet

Project title: Families' experiences of decision making around the birth of extremely premature or sick babies

You are being invited to take part in a research project about decisions that were made to offer intensive care for your baby cared for in the neonatal unit in The Townsville Hospital, and what this has meant for your family. The study is being done to find out about parents' experience of decision-making before the birth of babies who were expected to be very sick after delivery or at high risk of problems in later life. The study will also look at how having an extremely small or sick baby affects families in the short and long term. Where babies have gone on to have problems, you will be asked how you have coped with these. Parents will also be asked for their thoughts about offering intensive care for very small or sick babies. These are questions that can only really be answered by parents who have had to live through this experience.

The information from this study will be used to help medical staff when they talk to future parents about extreme prematurity. It will also help medical staff, who care for these babies, understand the long-term issues which families face. It is also hoped that the information will be used to advocate for better services after discharge for these babies.

If you agree to participate in this study, you will be invited to an interview, which will be arranged at a time and place that is convenient for you. The study is being conducted by Dr Susan Ireland and will contribute to a Doctorate in Philosophy from James Cook University. Either Dr Ireland, or a suitably qualified person from within the research team who did not have any contact with you whilst your baby was cared for in the neonatal unit can do the interview. You can choose which person you are most comfortable with. Interviews will last around 30 to 40 minutes, and with your consent, be recorded so that all the information can be accurately assessed. The recording will be erased once the interviews are written down, and the written interview will not be identified with your name or your child's name. Instead interview information will have a code number only.

Taking part in this study is completely voluntary. Medical staff who currently care for you or your child will not know if you participate, and any statements which you make will be confidential. Future medical care will not be affected in any way by participation or not. You may withdraw consent from the study at any time, and withdraw any unprocessed data from the study.

The interview will be kept anonymous so that it cannot be identified to you or your child. Data from the study will be presented in research publications, conference papers and reports to James Cook University. You will not be identifiable in any way in these publications.

Please take your time to discuss your participation with your family, friends, or even your family General Practitioner (GP). To arrange to take part in this study, please contact the administration officer on the neonatal unit on 44332982, and you will be contacted within 1 week to organise a time and place which suits you for the interview. Either one or both parents can participate, and where both parents want to participate, this can be done together or separately.

Sometimes people find it difficult to think about a time which may have been difficult or traumatic for them. If you have felt distressed about this letter I apologise. If you are distressed by this study, it is suggested that you contact your General Practitioner who can arrange for you to see a counsellor, or call Lifeline on 131114 who are available 24 hours a day. Queensland Health also provides a 24 hour health helpline to help take the worry out of health concerns. They can be contacted on 13HEALTH – 13432584). Their advice is confidential, qualified and supportive. Your local health facility may also have counselling services such as social work, and their acute services provided by Queensland Health will help you access local services and can also refer you for help from visiting services if necessary.

If you have any questions about the study, please contact Dr Susan Ireland.

Principal investigator
Dr Susan Ireland
The Neonatal Unit
The Townsville Hospital
Also
College of Medicine and Dentistry
James Cook University
Phone
Email : susan.ireland@my.jcu.edu.au

Supervisors
Dr Robin Ray, Dr Sarah Larkins, Dr Lynn Woodward
College of Medicine and Dentistry
James Cook University
Phone

If you have any concerns about the ethical conduct of the study, please contact:
Human Ethics, Research Office
James Cook University
Townsville, Qld, 4811
Phone (07) 47815011 (ethics@jcu.edu.au)

This project has been reviewed and approved by the Townsville Hospital and Health Service Human Research Ethics Committee. For concerns relating the conduct of this project contact:

HREC Chairperson
Phone: 07 4433 1440
Email: TSV-Ethics-Committee@health.qld.gov.au

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Parents’ Information Package

Appendix 3: Interview guide: Families Experiences of the Consequences of Decisions Made About Periviable Babies at the Time Of Birth: Updated Interview Guide 19/9/2016

Interview guide: Families experiences of the consequences of decisions made about periviable babies at the time of birth

(Note this is a prompt for the interviewer)
modified 19/9/2016 grounded theory principles

Review consent
Review counselling options

How is (name of child) getting along?
Exploration of well-being and progress

Can we go back to just before (child) was born. Tell me about what happened.
Prompts: who what when where?

What were you told, by whom? (about immediate management and possible long term outcomes)
What options were you given about the resuscitation of the baby?
Were you asked what you wanted in the care of the child?

Tell me how (child) progressed in hospital. Were there any particularly high/low moments?

What were the interactions/discussions with staff like about the long term outlook for (child)?

How have things been since (child) went home?

What supports are there?
Family
Medical
Education
Religious

How is the family doing?
How has (the child) impacted on family life/family life decisions?

Would you make the same decision at birth now if you were in this situation? Would you interact differently with the staff?

What information do you think would have helped you in making your decision?

What advice would you give to someone having to make the decision about their baby?

Who do you think should make decisions for very vulnerable babies at the time of birth for parents who know what you knew then?

Appendix 4: Ethics Approval TTH Family

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Appendix 5: Survey - Health care professionals knowledge of outcomes and attitudes towards resuscitation of extreme preterm babies/Survey Monkey

What do health providers who look after women who may deliver extremely preterm babies, understand to be the outcomes of extreme prematurity, and which babies do they think should be actively managed?

Thank you for participating in this survey. Your responses will assist in answering the question:

What do health providers who look after women who may deliver extremely preterm babies, understand to be the outcomes of extreme prematurity, and which babies do they think should be actively managed?

Principal investigator: Susan Ireland
Affiliation: James Cook University, The Townsville Hospital

Babies born between 22 and 26 weeks completed gestation are often considered periviable. They have a high risk of death and disability. They will all require intensive care in order to survive. Current guidelines suggest that below 23 weeks gestation, intensive care is not encouraged. From 23 to 24+6 weeks, the parents should decide whether their baby should be resuscitated, and over 25 weeks completed gestation, intensive care should be offered in most circumstances. Parents usually get most of their information from the health care staff who look after them. This study aims to find out what health care providers understand to be the outcomes of extreme prematurity, and will ask the opinions of providers about which factors should be taken into account when decisions about whether intensive care should occur are made.

The survey should only take 5-10 minutes to complete. Taking part in this study is voluntary. You can stop taking part in the study at any time. It is not possible to identify which staff have participated, and no answers to the study can be traced to any individual. As a result, you cannot be identified in any way in the results or any publication which may result. No other member of staff will know whether you have participated or not.

If you feel distressed by the request to participate or any questions within, please seek assistance from the employee assistance helpline, discuss the issue with your General Practitioner, who may refer you to a counsellor, or contact Lifeline on 131114.

The results of the study will be used to identify any gaps in knowledge, and will also form part of a PhD study which is being undertaken by Susan Ireland with the James Cook University, School of Medicine and Dentistry.

If you have any concerns with the study itself, please contact the Principal investigator Dr Susan Ireland at-

susan.ireland@my.jcu.edu.au

or

The Neonatal Unit
The Townsville Hospital

or

College of Medicine and Dentistry James Cook University
Phone
Email : susan.ireland@my.jcu.edu.au

Supervisors
Dr Robin Ray, Dr Sarah Larkins, Dr Lynn Woodward College of Medicine and Dentristry
James Cook University
Phone

If you have any concerns about the ethical conduct of the study, please contact:
Human Ethics, Research Office
James Cook University

Townsville, Qld, 4811
Phone (07) 47815011 (ethics@jcu.edu.au)

Note-

This project has been reviewed and approved by the Townsville Hospital and Health Service Human Research Ethics Committee. For concerns relating the conduct of this project contact:

HREC Chairperson
Phone: 07 4433 1440
Email: TSV-Ethics-Committee@health.qld.gov.au

The survey is being conducted using Survey Monkey which is based overseas. Information you provide on this survey will be transferred to Survey Monkey's overseas server. By completing this survey, you agree to this transfer. The data remains the property of Qld Health and is not on sold or used elsewhere: https://www.surveymonkey.com/mp/policy/privacy-policy/

Townsville Hospital and Health Service Human Research Ethics Committee Telephone +617 4433 1440

If you consent to participate in the study, please continue by pressing the 'next' button.

What do health providers who look after women who may deliver extremely preterm babies, understand to be the outcomes of extreme prematurity, and which babies do they think should be actively managed?

* 1. Where is your primary work location?

○ Townsville
○ Cairns
○ Mackay
○ Mount Isa

2. What is your work stream?

○ Midwifery
○ Obstetrics (medical)
○ Neonatal nursing
○ Paediatric (medical)
○ Neonatal (medical)

3. Do you have contact with women who may deliver before 27 weeks completed gestation, or care for children who have been born before 27 weeks completed gestation?

○ Yes
○ No

4. How many years experience do you have in your current role?

○ Less than 1
○ 1 - <5
○ 5 - <10
○ 10 or more

5. Has a patient ever asked your opinion about whether their unborn preterm baby should be offered intensive care/ resuscitation?

○ yes

○ no

○ prefer not to answer

6. On the scale below, how confident are you in discussing extreme prematurity with patients?

Not at all confident	Not very confident	Neutral	Fairly confident	Very confident	N/A
○	○	○	○	○	○

What do health providers who look after women who may deliver extremely preterm babies, understand to be the outcomes of extreme prematurity, and which babies do they think should be actively managed?

Survivial

7. What do you understand are the survival rates at 22 weeks completed gestation where full intensive care is offered?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

8. What do you understand are the survival rates at 23 weeks completed gestation where full intensive care is offered?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

9. What do you understand are the survival rates at 24 weeks completed gestation where full intensive care is offered?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

10. What do you understand are the survival rates at 25 weeks completed gestation where full intensive care is offered?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

11. What do you understand are the survival rates at 26 weeks completed gestation where full intensive care is offered?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

12. What do you understand are the survival rates at 27 weeks completed gestation where full intensive care is offered?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

13. What do you understand are the survival rates at 28 weeks completed gestation where full intensive care is offered?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

Severe disability

14. Of babies who survive at 22 completed weeks gestation, what do you understand are the rates of severe disability (such as - blind, deaf, unable to walk, or likely to require special school for learning difficulties) ?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

15. Of babies who survive at 23 completed weeks of gestation, what do you understand are the rates of severe disability (such as - blind, deaf, unable to walk, or likely to require special school for learning difficulties)?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

16. Of babies who survive at 24 weeks completed gestation, what do you understand are the rates of severe disability (such as - blind, deaf, unable to walk, likely to require special school for learning difficulties)?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

17. Of babies who survive at 25 weeks completed gestation, what do you understand are the rates of severe disability (such as - blind, deaf , unable to walk, or likely to require special school for learning difficulties)?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

18. Of babies who survive at 26 weeks completed gestation, what do you understand are the rates of severe disability (such as- blind, deaf, unable to walk, likely to require special school for learning difficulties)?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

19. Of babies who survive at 27 weeks completed gestation, what do you understand are the rates of severe disability (such as- blind, deaf, unable to walk, likely to require special school for learning difficulties)?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

20. Of babies who survive at 28 weeks completed gestation, what do you understand are the rates of severe disability (such as- blind, deaf, unable to walk, likely to require special school for learning difficulties)?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

What do health providers who look after women who may deliver extremely preterm babies, understand to be the outcomes of extreme prematurity, and which babies do they think should be actively managed?

Healthy long term survival

21. How many survivors who were born at 22 weeks gestation have typical (normal) development?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

22. How many survivors who were born at 23 weeks gestation have typical (normal) development?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

23. How many survivors who were born at 24 weeks gestation have typical (normal) development?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

24. How many survivors who were born at 25 weeks gestation have typical (normal) development?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

25. How many survivors who were born at 26 weeks gestation have typical (normal) development?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

26. How many survivors who were born at 27 weeks gestation have typical (normal) development?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

27. How many survivors who were born at 28 weeks gestation have typical (normal) development?

○ <20%

○ 21-40%

○ 41-60%

○ 61-80%

○ >80%

○ unsure

What do health providers who look after women who may deliver extremely preterm babies, understand to be the outcomes of extreme prematurity, and which babies do they think should be actively managed?

Other factors in decision making

28. Factors other than gestation may influence survival and wellbeing of babies at extreme prematurity. Which of the following pregnancy or baby factors do you think may adversely affect the survival/developmental outcome? Check all that apply.

☐ Female gender

☐ Multiple pregnancy

☐ Antenatal infection (chorioamnionitis)

☐ Intrauterine growth retardation

☐ Poor condition at delivery

☐ No heart rate at delivery

29. Other factors may be used when considering whether to offer intensive care for babies at any gestation from 22-26 weeks completed gestation. On the scale below, indicate the level of influence upon the decision to resuscitate for each factor (please answer all)

	1 Should definitely not offer resuscitation	2 Less likely to offer resuscitation	3 Should not influence decision	4 More likely to offer resuscitation	5 Should definitely offer resuscitation
Parental wanting full intensive care where clinicians feel it isn't in the babys best interest	○	○	○	○	○
Parental wants comfort care only where clinician feels baby may do well	○	○	○	○	○
Low socioeconomic status of the family	○	○	○	○	○
Mother age below 20	○	○	○	○	○
Mother age over 40	○	○	○	○	○
Previous children in care of the state/foster care	○	○	○	○	○
Presence of known abnormality requiring surgery e.g. diaphragmatic hernia	○	○	○	○	○
Presence of a known anomaly e.g. Trisomy 21	○	○	○	○	○
Previous pregnancy loss	○	○	○	○	○
No live born children	○	○	○	○	○

What do health providers who look after women who may deliver extremely preterm babies, understand to be the outcomes of extreme prematurity, and which babies do they think should be actively managed?

Nearly done!

30. From which gestation do you think the health service should offer full active management if the fetus is otherwise well? (check ONLY ONE)

☐ 22 weeks completed gestation
☐ 23 weeks completed gestation
☐ 24 weeks completed gestation
☐ 25 weeks completed gestation
☐ 26 weeks completed gestation
☐ 27 weeks completed gestation
☐ 28 weeks and over

Add any comments

31. At which gestations should parents be the sole decision makers about whether their baby should be offered full active management ? (check all that apply)

☐ 22 weeks gestation
☐ 23 weeks gestation
☐ 24 weeks gestation
☐ 25 weeks gestation
☐ 26 weeks gestation
☐ 27 weeks gestation
☐ Never

Add any comments

32. At which gestation should the health care professional offer active management to a baby regardless of parental opinion? (check all that apply)

☐ 22 weeks gestation

☐ 23 weeks gestation

☐ 24 weeks gestation

☐ 25 weeks gestation

☐ 26 weeks gestation

☐ 27 weeks gestation

☐ Never

Please feel free to comment

33. What information should be given to the healthy pregnant woman about prematurity, and when?

What do health providers who look after women who may deliver extremely preterm babies, understand to be the outcomes of extreme prematurity, and which babies do they think should be actively managed?

34. Do you have social/personal contact with persons with disability?

○ Yes

○ No

35. Would you describe yourself as having religious belief which would influence your opinions about resuscitating extremely preterm babies?

○ Yes

○ No

36. If you were in the position where you had to consider whether your otherwise healthy unborn baby should be offered intensive care if born prematurely, from which gestation would you want full intensive care to be offered?

○ 22 weeks completed gestation

○ 23 weeks completed gestation

○ 24 weeks completed gestation

○ 25 weeks completed gestation

○ 26 weeks completed gestation

○ 27 weeks completed gestation

○ 28 weeks and over

○ prefer not to answer

What do health providers who look after women who may deliver extremely preterm babies, understand to be the outcomes of extreme prematurity, and which babies do they think should be actively managed?

The end

37. Please add any comments

What do health providers who look after women who may deliver extremely preterm babies, understand to be the outcomes of extreme prematurity, and which babies do they think should be actively managed?

Thank you very much for participating in this study.

It is anticipated that this study will also have an interview component where opinions can be further explored. This would add very valuable understanding about how staff feel about extreme preterm and babies at high risk of disability.

If you would like to participate in an interview about this topic, please contact the principle researcher at susan.ireland@my.jcu.edu.au for further information. The interviews will be conducted by interviewers from either Queensland Health, or from outside Queensland Health at participants request.

Appendix 6: Ethics Approval - Staff Study

This administrative form
has been removed

Appendix 7: Information Sheet and Consent for HCP Qualitative Study

Townsville Hospital
and Health Service

Queensland
Government

Participant information sheet

Project title: Attitudes of healthcare staff towards extreme prematurity and pregnancies at high risk of producing children with significant neurodevelopmental impairment

Babies born between 22 and 26 weeks completed gestation are often considered periviable. They have a high risk of death and disability. They will all require intensive care in order to survive. Current guidelines suggest that below 23 weeks gestation, intensive care is not encouraged. From 23 to 24+6 weeks, the parents decide whether their baby should be resuscitated, and over 25 weeks completed gestation, care should be offered in most circumstances. Parents usually get most of their information from the health care staff who look after them. This study aims to find out what health care providers understand to be the outcomes of extreme prematurity, and will ask the opinions of providers about which factors should be taken into account when decisions about whether care should occur are made.

You are being invited to take part in a research project about how decisions are made to offer care to extremely preterm babies, or those with known serious congenital problems. It is recognised that a broad range of staff come into contact with families who are in this situation both before and after the birth of these babies, and this study aims to reflect this range of disciplines and experiences.

If you agree to participate in this study, you will be invited to an interview, which will be arranged at a mutually agreeable time and place. The study is being conducted by Dr Susan Ireland and will contribute to a Doctorate in Philosophy from the James Cook University. Either Dr Ireland, or an alternative person who has no direct contact with your workplace can do interviews. You can choose which you would prefer. Interviews will last around 30 minutes, and be recorded, with your consent, so that all the information can be accurately assessed. The tapes will be erased once the interviews are written down, and the written interview will not be identified for the analysis, so no comments or opinions can be identified as yours.

Sometimes people find this subject traumatic for a variety of reasons. I apologise if this is the case. If you have felt distressed about this matter, it is suggested that you contact your General Practitioner who can arrange for you to see a counsellor, or contact Lifeline on 131114. There is also counselling available through the Queensland Health employee assistance.

You may withdraw consent from the study at any time, and withdraw any unprocessed data from the study.

Data from the study will be presented in research publications, conference papers and reports to the James Cook University. You will not be identifiable in any way in these publications.

To arrange to take part in this study, please contact the admin officer on the neonatal unit on 44332982, and you will be contacted within 1 week to organise a time and place which suits you.

If you have any questions about the study, please contact Dr Susan Ireland.

Principal investigator
Dr Susan Ireland
The neonatal unit
The Townsville Hospital
Also
College of Medicine and Dentistry
James Cook University
Phone
Email : susan.ireland@my.jcu.edu.au

Supervisors
Dr Robin Ray, Dr Sarah Larkins, Dr Lynn Woodward
College of Medicine and Dentristry
James Cook University
Phone

If you have any concerns about the ethical conduct of the study, please contact:
Human Ethics, Research Office
James Cook University
Townsville, Qld, 4811
Phone (07) 47815011 (ethics@jcu.edu.au)

This project has been reviewed and approved by the Townsville Hospital and Health Service Human Research Ethics Committee. For concerns relating the conduct of this project contact:

HREC Chairperson
Phone: 07 4433 1440
Email: TSV-Ethics-Committee@health.qld.gov.au

This administrative form
has been removed

Appendix 8: Interview Guide Staff Attitudes Study (13/4/17)

Interview guide for staff attitudes study (13/4/17)

(note this is a guide for interviewer)

Review consent for study and consent for recording
Review counseling options

Establish experience and role of participant in the workplace
(eg midwife for x years)

What experience have you had in talking to parents who are expecting an extremely premature or vulnerable pregnancy?
(both formal as part of counseling and also witnessing information sharing or talking to patient outside formal counseling session)

What gestation do you consider is appropriate for the offer of intensive care to be made to parents by the neonatal service?
Why?

The risk of severe disability under 27 weeks is approximately 20%.
“The guidelines for managing premature babies in Queensland, suggests that we should not offer any intensive care to babies under 23 weeks gestation, that parents should have final say if we resuscitate the baby from 23 to 25 weeks, and that we should resuscitate over 25 weeks unless there are other factors eg congenital abnormalities”.
What do you think about the guidelines?
Who do you feel should make the final decision about whether to offer care to babies who will need intensive care after birth?
Why?

Are there any non-medical factors which you think should be taken into account in initially offering intensive care? Eg ‘the precious baby, or where all other kids in care

What do you think most parents know about prematurity before they face the prospects of extreme prematurity, and do you think they are able to give informed consent to allow their baby to be resuscitated?

One of the options we give to parents, is to see ‘how the baby is’ at birth, initiate intensive care, but then review how the baby is doing in the first few days with a view of withdrawal if not doing well. Have you seen this occurring? How does this seem as an approach?
(question only relevant for workers in neonatal unit)

What about babies with known anomalies eg Downs, hydrops? – is this different to extreme prematurity in terms of who should decide to proceed to intensive care – why?

What is you experience of disability outside of hospital?

Are you religious, and does this help shape your opinions?

Would you choose to have your baby resuscitated at 23/24/25 weeks gestation?

Is there anything which you would like to say about this topic?

Appendix 9: Ethics Approval – Palliative Care Study

This administrative form
has been removed

Appendix 10: COREQ for Family Study

COREQ for Family study	**Description**	**Page on manuscript where relevant**
Domain 1:Research team and reflexivity		
Personal characteristics		
1. interviewer	SI – primary investigator	
2. Credentials	MB ChB, FRACP, Grad Cert Clinical research methods	
3. Occupation	Neonatologist	
4. Gender	Female	
5. Experience and training	8 years medical specialist, training in qualitative research	
Relationship with participants		
6. Relationship established	Senior specialist on neonatal unit. Known to all participants	
7. Participant knowledge of interviewer	Known by participants prior to study	
8. Interviewer characteristics	SI has provided care for the babies of all participants as part of the team of neonatologists at TUH.	
Domain 2 :Study design		
Theoretical framework		
9. Methodological orientation	Informed by Charmaz Constructivist Grounded Theory methodology	106
Participant selection		
10. Sampling	Pragmatic, purposive	108
11. Method of approach	Letter, direct approach	108

12. Sample size	17 families	109
13. Non-participation	9 – 7 no reply, 2 not required	109
Setting		
14. Setting of data collection	Hospital office, home environment, telephone	
15. Presence of non-participants	Yes – young children of participants – all unable to hear interview, distracted with toys etc	
16. Description of sample	23 participants 17 mothers, 6 fathers Maternal age at birth 18-37yr Caucasian 11, Indigenous 3, Maori 1, Asian 2 Local 7, out of district 10 Gestation of baby 23-30 weeks 22 babies – 3 deceased 12 singletons, 5 sets twins 2-7 years after NICU	111
Data collection		
17. Interview guide	Semi-structured	Appendix 3
18. Repeat interviews	no	
19. Audio recording	yes	Stored JCU secure server
20. Field notes	yes	
21. Duration	Interview 20-45 minutes 4 hour home visit	
22. Data saturation	yes	
23. Transcripts returned	Not required in this study - offered but declined	
Domain 3: analysis of findings		
Data analysis		

24. Number of data coders	1 primary, 3 for co-analysis	
25. Description of coding tree	Line by line coding, grouping into evolving categories. Categories noted, subcategories included	
26. Derivation of themes	Data on NVivo, but coding by hand. Evolution of categories as per Charmaz theory	
27. Software	NVivo	
28. Participant checking	Discussed with several participants on request. Findings presented	
29. Quotations presented	Yes	114-180
30. Data and findings consistent	Yes	
31. Clarity of major themes	Yes	
32. Clarity of minor themes	Yes	

Appendix 11: COREQ for HCP Study

COREQ for HCP study	**Description**	**Manuscript page where relevant**
Domain 1: Research team and reflexivity		
Personal characteristics		
1. Interviewer	Interviewer 1 –SI (primary investigator)	
2. Credentials	MB ChB, FRACP, Grad cert Clinical research methods	
3. Occupation	Neonatologist	
4. Gender	Female	
5. Experience and training	8 years medical specialist, training in qualitative research	
(Interviewer 2)	Interviewer 2 -JK	
	PhD	
	Research assistant/ senior clinical researcher/midwifery background	
	Female	
	PhD using qualitative methodology, 5 years post doc	
Relationship with participants		
6. Relationship established	SI senior specialist in neonatal unit, known by most participants, JK university employee engaged as research assistant	
7. Participant knowledge of interviewer	SI known to all participants, did not interview immediate colleagues. JK not known by any participants. Participants (other than immediate colleagues of SI) given the option of interviewer.	

8. Interviewer characteristics	SI a neonatologist at tertiary unit. She has researched the topic of staff attitudes towards prematurity, and parental attitudes and has an interest in periviable resuscitation. She is more positive about outcomes of the provision of active care for extremely premature neonates and acknowledges her bias. JK has not worked in neonatal clinical care beyond routine midwifery care, and has no firm opinion about active care for extremely preterm babies.	
Domain 2 :Study design		
Theoretical framework		
9. Methodological orientation	Informed by Charmaz Constructivist Grounded Theory methodology	219
Participant selection		
10. Sampling	Purposive, pragmatic	219
11. Method of approach	Email, invitation on prior survey	220
12. Sample size	33 participants	222
13. Non-participation	6 invited by email not interviewed- 3 did not reply, 3 not required	220
Setting		
14. Setting of data collection	In quiet office setting in the hospital for 30, 3 via telephone	
15. Presence of non-participants	No	
16. Description of sample	Midwife - 4 Neonatal nurse - 5 Neonatal nurse practitioner - 4 Obstetrician - 3 Obstetric trainee - 2 Neonatologist - 3	222

	Neonatal trainee - 2 Paediatrician - 5 Paediatric trainee - 2 Allied health - 3	
Data collection		
17. Interview guide	Semi-structured	Appendix 8
18. Repeat interviews	No, one request to update by participant	
19. Audio recording	Yes	Stored JCU
20. Field notes	Yes	
21. Duration	17 to 92 minutes	
22. Data saturation	Yes	
23. Transcripts returned	No	
Domain 3: analysis of findings		
Data analysis		
24. Number of data coders	4	
25. Description of coding tree	Line by line coding, grouping into evolving categories, Categories noted, category and subcategories included	
26. Derivation of themes	Data on NVivo, but coding by hand. Evolution of categories as per Charmaz theory for all categories except specific category of information sharing	221
27. Software	NVivo	
28. Participant checking	The findings of the study have been presented at an open forum unit meeting to which all participants were invited.	
29. Quotations presented	Yes	224-302

30. Data and findings consistent	Yes	
31. Clarity of major themes	Yes, although only one major theme found in the study is presented in this manuscript	
32. Clarity of minor themes	Yes	

Appendix 12: COREQ for Palliative Care Study

COREQ for palliative care study	**Description**	**Page on manuscript where found where relevant**
Domain 1:Research team and reflexivity		
Personal characteristics		
1. interviewer	MK – primary investigator	
2. Credentials	PhD, Clinical psychologist, Senior university lecturer	
3. Occupation	University lecturer	
4. Gender	Female	
5. Experience and training	6 years post doctoral, clinical psychologist	
Relationship with participants		
6. Relationship established	MK known to all participants	
7. Participant knowledge of interviewer	Known to participants	
8. Interviewer characteristics	Previously psychologist on the TUH neonatal unit, extensive research into infant and parent bonding, health care in neonatal unit	
Domain 2 :Study design		
Theoretical framework		
9. Methodological orientation	Phenomenology	316
Participant selection		

10. Sampling	Purposive	316
11. Method of approach	Direct approach	317
12. Sample size	8	316
13. Non-participation	Nil	
Setting		
14. Setting of data selection	Hospital,	316
15. Presence of non-participants	No	
16. Description of sample	Neonatal nurses at TUH intensive care with over 5 years neonatal nursing experience and experience in palliative care	
Data collection		
17. Interview guide	Semi-structured	
18. Repeat interviews	No	
19. Audio recording	Yes	
20. Field notes	Yes	
21. Duration		
22. Data saturation	Yes	
23. Transcripts returned	Not requested	
Domain 3: analysis of findings		
Data analysis		
24. Number of data coders	1 primary coder, 1 co-investigator	
25. Description of coding tree	6 stage exploratory thematic analysis – Braun and Clarke	318

26. Derivation of themes	Coding by hand following analytic process for themes and subthemes	318
27. Software	No	
28. Participant checking	No – has been presented to unit meeting to assess accuracy of interpretation	
29. Quotations presented	Yes	319-337
30. Data and findings consistent	Yes	
31. Clarity of major themes	Yes	
32. Clarity of minor themes	Yes	