Neonatal nurses' response to a hypothetical premature birth situation: What if it was my baby?

ASTRACT

Background:

Evolving technology and scientific advancement have increased the chances of survival of the extremely premature baby, however such survival can be associated with some severe long-term morbidities.

Research question: The research investigates the caregiving and ethical dilemmas faced by neonatal nurses when caring for extremely premature babies (defined as ≤ 24 weeks gestation). This paper explores the issues arising for neonatal nurses when they considered the philosophical question of *'what if it was me and my baby'*, or what they believed they would do in the hypothetical situation of going into premature labour and delivering an extremely premature baby.

Participants: Data were collected via a questionnaire to Australian neonatal nurses and semi-structured interviews with 24 neonatal nurses in NSW, Australia.

Ethical considerations: Relevant ethical approvals have been obtained by the researchers.

Findings: A qualitative approach was used to analyse the data. The theme '*imagined futures*' was generated which comprised three sub-themes: '*choice is important', 'not subjecting their own baby to treatment', and 'nurses and outcome predictions'*. The results offer an important and unique understanding into the perceptions of nursing staff who care for extremely premature babies and their family, see them go home and witness their evolving outcomes. The results show that previous clinical and personal experiences led the nurses in the study to choose to have the belief, that if in a similar situation, they would choose not to have their own baby resuscitated and subjected to the very treatment that they provide to other babies.

Conclusion:

The theme '*imagined futures*' offers an overall understanding of how neonatal nurses imagine what the life of the extremely premature baby and his/her family will be like after discharge from neonatal intensive care. The nurses' past experience has led them to believe that they would not want this life for themselves and their baby, if they were to deliver at 24 weeks gestation or less.

INTRODUCTION

There is no argument that the survival of extremely premature babies has improved substantially, however similar improvements have not been noted for long term morbidity,[1] or in the long term problems associated with being born at an extremely early gestation. The minimum age of viability is considered to be as young as 23 weeks gestation, with the occasional survivor reported at 22 weeks gestation.[2] Neonatal clinicians cannot definitively predict the individual prognosis of an extremely premature baby,[3] but it becomes problematic when they cannot predict if survivors will have a chronic or disabling condition.[4] Unsurprisingly, the lower the gestational age the higher the mortality and morbidity,[1] and the greater the chance of long term and severe morbidities.[5]

The current outcomes for extremely premature babies related to major neurological impairments have remained stable, despite improved survival.[6] Such neurological damage may include brain injury with subsequent physical and cognitive disability resulting from intraventricular haemorrhage and periventricular leukomalacia.[7] Other potential problems include chronic lung disease, hearing impairment, sight problems caused by retinopathy of prematurity, and short gut syndrome from necrotising enterocolitis.[8,9] For approximately half of the survivors of extreme prematurity special education services will be needed.[10] The outcomes of extreme prematurity reported in even recent literature published yesterday does not necessarily reflect the outcome that would be reported today, because cohorts may have been from the last ten years, and it might have taken two years for the research to be published. However, it is the best that is available at this point in time. Treatment regimes constantly change, making it difficult to interpret outcomes research. While it is clear that extremely premature babies can develop into healthy, independent children and adults,[11] this is not always the case, and truly 'informed' consent would dictate that any discussions with parents should consider the possibility that an extremely premature baby may survive with a major disability.

A hypothetical situation is one involving or based on a suggested idea or theory that invites us to consider 'What if... .? or 'imagine that... ..?. It involves or is based on a hypothesis with a not real or imagined example. Words associated with hypothetical include suppositional, theoretical and speculative.[12] Hypothetical situations are useful because it is often necessary

to hypothesise in order to explain how people believe they will behave or act in certain situations. Knowing what one would do in a hypothetical situation is often more than an educated guess, and in fact, hypothetical scenarios may not accurately reflect actual behavior, because individuals can have difficulty projecting themselves into the future with accuracy.[13] Human beings weigh up evidence and many other factors when coming to a decision about a particular issue. For neonatal nurses, contemplating the outcome for babies 24 weeks gestation and less, and the perceived burden on their family, could make them consider the hypothetical situation of "What if it was me and my baby"?

RESEARCH DESIGN

Aim

The findings presented in this paper are part of a larger mixed method doctoral thesis[14] that explored the ethical issues and caregiving experiences of Australian neonatal nurses who cared for extremely premature babies of 24 weeks gestation and less. Other publications from this research include the difficulties associated with caring for extremely premature babies who at times look more like a foetus than a human baby;[15] the burden of keeping secrets and how neonatal nurses have to keep information to themselves.[16] Three further papers include caring for parents whose belief in a miracle was all consuming,[17] how neonatal nurses manage the uncertainty associated with caring for extremely premature babies,[18] and the difficulties neonatal nurses face in trying to reconcile hurting with caring, when they inflict pain on extremely premature babies as part of their treatment.[19] The myth of the miracle baby has been challenged in another paper,[20] the anguish and desperation to become parents has been explored,[21] as has the quality of life of extremely premature infant survivors.[22]

The focus of this current paper is the quantitative and qualitative data that explores the neonatal nurses' perception of why they feel that, hypothetically, they would not want their own extremely premature baby resuscitated and treated if they found themselves in the same position as the parents of an extremely premature infant.

Data collection

Two data collection methods were used in this research. In the first stage of the study, Australian neonatal nurses (n=414) were surveyed using a self-completed questionnaire that was analysed using SPSS. In the second stage, purposive sampling was used and data collected through 14 semi-structured interviews with 24 neonatal nurses from the state of

New South Wales (NSW) and the Australian Capital Territory (ACT).

The questionnaire was a 64 point likert, paper based survey that sought to explore the attitudes and the legal, ethical, social and technological issues experienced by neonatal nurses when providing care to extremely premature babies. The questionnaire was modified with permission from a study undertaken by Armentrout.[23] Questions were based on a literature review that determined current issues and concerns surrounding the provision of care to extremely premature babies. The questionnaire addressed neonatal nurses' demographics, age and years of experience in caring for extremely premature babies. Both open and closed questions were included, with opportunities for participants to comment on their experience and issues of concern about caring for extremely premature babies.

Fourteen interviews were conducted involving 24 participants. There were eight single interviews and six focus groups comprising between two and six neonatal nurses. All data was collected by the first author, an experienced neonatal nurse. The interview questions explored the nurses' experiences of caring for babies of ≤24 weeks gestation. The interview questions were constructed from the significant issues arising from the questionnaire, content analysis of the open ended philosophical questions from the questionnaire, and other issues that emerged during the interviews.

The interviews were semi structured, however time was also allowed for unstructured conversation. The interviews occurred in different locations; the interviewer's home (4), in the participants' own homes (5), or a quiet room at the participant's hospital of employment (5). The duration of the interview was between 60 and 90 minutes. The full interviews were transcribed prior to in-depth analysis to identify major themes. This paper draws on the questionnaire data, the qualitative data from the questionnaire and the interviews.

Setting and participants

Participants who were interviewed included Registered Nurses who were currently employed in a neonatal intensive care unit where extremely premature babies are cared for, a paediatric intensive care unit where babies are cared for, or members of the newborn emergency retrieval team. The nurses required greater than five years' experience in caring for babies ≤ 24 weeks gestation. They needed to be English speaking, willing to participate in the research and to agree to have the interview recorded. The extremely premature baby, especially in the

first 24 hours, can be fragile and critically ill, thus requiring the most experienced and skilled nursing staff to care for them. These babies are not given to inexperienced nurses to care for, therefore, those nurses with 5 years or more experience with caring for extremely premature babies would have the experience required to be interviewed. All 24 of the nurses interviewed were female, 10 were mothers, 14 were childless but within childbearing age (33 – 45) years.

Ethical Considerations

Questionnaire and interview participants were provided with a participant information sheet. Verbal and written consent was obtained from the interview participants, and they were given the option to ask questions for clarification or withdraw from the study. The confidentiality of all participants was assured, firstly by the anonymous procedures associated with the questionnaire. Secondly, the names of the interview participants were not included on the transcripts, and the thirdly the data was secured in a locked drawer. This research project was approved by the Flinders University of South Australia Social and Behavioural Research Ethics Committee (Approval Number 1924). The topic of this research is considered a sensitive one, therefore, counselling was made available to the interview participants if required, although none of the nurses required this service.

Data analysis

A qualitative method informed by phenomenological insights, and the work of Van Manen [24] was considered the most appropriate way to interpret the interviews, because of the need to understand the nurses' experiences of caregiving dilemmas surrounding extremely premature babies. Phenomenology is the study of lived experience and asks the question "what is this or that kind of experience like." [24](p.9) Van Manen's [24] approach is that reflecting on the lived experience cannot occur while the person is still living it. The researcher is required to capture the retrospective reflection of the nurse who has provided care to extremely premature babies.

The procedural component of phenomenology requires that the text from the interviews be examined carefully and systematically. Formal phenomenological analysis requires line-by-line analysis, and the discovery and construction of themes. Creating themes is an active interpretative process, in keeping with the work of Van Manen. [24] Creating themes helps the

researcher identify the significant issues in the data. The search for the "big picture" according to Braun and Clarke [25] (p.12) means that the theme is authentic and provides an accurate understanding of the nurses' experience. Accounts of the nurses' experiences were structured to form the whole, or a full description of the phenomenon.

A qualitative study needs to be rigorous. The specifics of rigour is about how the research paradigm's ontology and epistemology inform the interpretative methodology in the study, and whether or not it is able to answer the question under investigation. The validity of a qualitative study is about trustworthiness, and how the researcher describes and interprets what has been told to them by the informant. [26] If the lived experience is captured, there will be richness in the description, which will lend credibility to the research and study. Readers also establish the trustworthiness if they consider the study is transferable to another context, and are able to follow the decision trail of the researcher. The researcher should be able to provide confirmability of the study, or how the qualitative interpretations came to fruition. All data sources were collected by the first author, and all data and interpretations were regularly audited and validated by the co-authors.

FINDINGS

This paper outlines the neonatal nurses' consideration of the hypothetical situation of what would they do if they delivered an extremely premature baby. It is important to emphasise that the results reported in this paper are applicable only to those babies of 24 weeks gestation and less, and are not generalisable to any other neonatal population, as the outcomes for extreme prematurity have a greater complexity than the outcomes for babies of other ages nursed in the NICU. Nor are the results readily generalisable to neonatal nurses other than those interviewed. As there are two data sources comprising the results, the qualitative results of the questionnaire are represented as (Q response number) and the interview transcripts are represented as (Nurse number).

1. Questionnaire data

There were no specific questions in the questionnaire that asked about what the nurses would do if they personally delivered an extremely premature baby, however their experience has led them to believe they would not want their own baby to be resuscitated and treated. The questionnaire data is included to add context to the qualitative data. Only nurses with

experience with caring for babies 24 weeks gestation and less were asked to complete the first part of the questionnaire.

Table 1: Results - ***Caring for babies 24 weeks and less makes me feel Hopeful***

	Frequency	**Percent**
Never	35	10.6
Seldom	**120**	**36.5**
Occasionally	**147**	**44.6**
Almost Always	27	8.3
Total	**329**	**100**

The results show that nurses were rarely hopeful (44.6% occasionally hopeful and 36.5% seldom hopeful) about the survival and outcome for extremely premature babies.

Table 2: Results - ***Caring for babies 24 weeks and less makes me feel Concerned***

	Frequency	**Percent**
Never	1	.3
Seldom	6	1.8
Occasionally	35	10.6
Almost Always	**290**	**87.3**
Total	**332**	**100**

The majority of nurses (87.3%) were concerned about the outcomes for the baby and parents.

Table 3: Results - ***Caring for babies 24 weeks and less makes me feel Positive***

	Frequency	Percent
Never	40	12.1
Seldom	**136**	**41.1**
Occasionally	**130**	**39.3**
Almost Always	25	7.5
Total	**331**	**100**

The results show that nurses usually found it difficult to be positive (39.3% occasionally positive and 41.1% seldom positive) about the survival and outcome of extremely premature babies.

Table 4: Results - ***Caring for babies 24 weeks and less makes me feel Discouraged***

	Frequency	**Percent**
Never	12	3.6
Seldom	43	13.1
Occasionally	**194**	**58.9**
Almost Always	**80**	**24.2**
Total	**329**	**100**

The results show that many nurses were discouraged (58.9% occasionally discouraged and 24.2% almost always discouraged) about the survival and outcome of extremely premature babies.

2. Interview data

The theme '*imagined futures*' offers an overall understanding of how neonatal nurses imagine what the life of the baby and family will be like after discharge from the neonatal intensive care unit. What the nurses had seen in the past had made them believe that they would not want this life for themselves and their baby if they were to deliver at 24 weeks gestation or less. The theme of '*imagined futures*' comprised three sub-themes: 1. '*choice is important*', 2. '*not subjecting their own baby to treatment*' and 3. '*nurses and outcome predictions'*. The first theme *'choice is important'* showed that the neonatal nurses believed that they should have the choice to decide whether their baby born at 24 weeks gestation and less should be resuscitated. They also believed that the parents of other babies in the NICU should also have the same choice. The second theme *'not subjecting their own baby to treatment'* was about the nurses' imagining what might happen, and what they would do if they delivered an extremely premature baby. The third theme *'nurses and outcome predictions'* explores how the nurses' made their decisions about whether they believed a baby would have what they considered to be a good or poor outcome.

1. Choice is important

The nurses expressed that they would not have their own baby treated if they delivered at 24 weeks gestation and less. This issue was noted in the questionnaire when approximately 25% of respondents wrote unsolicited comments, for example, '*every neonatal nurse I know would go bush rather than go to a tertiary centre if they were in prem labour with a pregnancy of 24 weeks gestation or less*' (Q response 106). In colloquial Australian language, the words "go bush" are used to mean that in remote areas (the bush) there would be no access to a neonatal intensive care unit, and hence no chance to save an extremely premature baby.

> I am glad I had term babies. I would hate to have a 23-24 weeker and 'in theory' would actively discourage any member of my family from insisting on full resuscitation and treatment if they were unfortunate enough to go into preterm labour, or require delivery of a

> 23-24 weeker. As I said though that is the theory - I hope I would have the strength in practice. (Q response 199)

Only one of the 24 nurses interviewed stated she would have her baby treated, but the caveat was that only if treatment would be withdrawn if the baby suffered a large intracranial bleed. The nurses all considered treatment of the baby to be a personal autonomous choice. One nurse claimed her decision was an educated one, based on her understanding that an extremely premature baby breathing at birth did not equal sustained life. The decisions the nurses made were seen as recognition of the reality that parents faced during treatment. One nurse summed up the situation when she stated *"if you were given a 10% chance of a successful outcome from surgery, would you take the chance?"* (Q response 368). It was the understanding of the nurses that the mere survival of the extremely premature baby did not constitute a positive outcome.

All respondents claimed that just as they had the right to choose, the parents had the same rights, but the ability to make decisions comes with information. It was accepted that parents might make decisions based on how the information was presented to them. One nurse explained the difficulty:

> I don't know what they [Doctors] tell them. They must tell them survival. I don't think they tell them intactness [intact survival]. If someone told me that, `Yes at 23 weeks you've got a 50% chance of survival, but a high chance of being abnormal,' I don't think I'd want my baby resuscitated. (Nurse 19)

This was a hypothetical situation, and it is acknowledged that the nurses would not know in reality what they would do until they were in that situation. It was interesting that they wanted other people's babies to have the opportunity to live, if that is what they chose, yet not want that for their own child. One nurse wrote on her questionnaire *"if I had a baby 24 weeks or less, I would hope the doctor would listen to me about my wishes of not having the baby treated. This has always been my wish, and I do not intend to change it"*. (Q response 296)

Not subjecting their own baby to treatment

Knowledge about the outcomes of extremely premature babies was considered powerful knowledge by the nurses. They were generally emphatic that they would not consent to treatment if they were to deliver an extremely premature baby. There are always difficulties in talking about hypothetical situations. The nurses spoke as if they knew what they would do. They made it clear that if they started to labour, they would avoid any centre capable of providing treatment for an extremely premature baby. They feared having the decision to treat being taken out of their hands. Most nurses said they would present to a tertiary care facility only if they feared for their life. Two nurses in a focus group stated:

> Unless I was bleeding and feared for my own life, I would sit at home. I would labour at home, deliver at home and then wrap it and just cover it until it died. Then present [to hospital] with the dead baby. I would not present in with something you could ventilate. (Nurse 19)
>
> You could still present, it doesn't mean they have to do anything. (Nurse 20)
>
> That would be my fear that it came out and it cried, and they did something and then there was no pulling out [withdrawing treatment]. And if it cried they would take it off me and they would bring it here [a NICU]. That would be my fear. (Nurse 19)

The nurses were convinced they had a realistic perception of extreme prematurity because of their experience in working with these babies every day and seeing babies come back who had a less than favourable outcome, and whose parents had told them of their day-to-day existence. When speaking of her hypothetical reluctance to have a baby of 24 weeks or less resuscitated, one nurse stated in a matter of fact way,

> I wouldn't leave it for dead or anything, but the baby wouldn't survive. I'm afraid I'm not one of those courageous people who can see it as God's plan or anything else. (Nurse 14)

Caring for other people's extremely premature babies, but not wanting their own treated represented a contradiction and a possible conflict for the nurses. One nurse explained she would not present to hospital because of her belief that presentation implied she was seeking treatment. She stated, *'...if I do present at the hospital 24 weeks pregnant, I'm asking for help. Usually the patient, they do want something done'* (Nurse 11). In this situation informed

consent was needed and initial and ongoing consent is required for all treatment. The nurses might be alluding to the emotional aspects of seeking help for an extremely premature baby. Many nurses held that they would stay away so they could not be persuaded to have their baby treated, or have the staff treat the baby without consent. Several stated they had read the book "The Long Dying of Baby Andrew" by Peggy and Robert Stinson,[27] and although this book is old it remains a 'must read' for every member of the neonatal team. The book is about treatment without consent and experimentation in the name of progress. In this current study, fear was a powerful motivator for these nurses. Fear of the technological imperative would keep them away from any centre capable of resuscitating and treating tiny babies. It was not the fear of resuscitation that drove these nurses to essentially avoid their own workplaces, it was their fear that treatment would not be withdrawn when they believed that their baby may have been irreparably damaged. Technology, they felt, seemed to take on a power of its own, and once instituted it could be exceptionally hard to withdraw. The nurses understood that some medical staff would not, '*...pull the plug*' (Nurse 16), and the nurses were not prepared to take the risk.

When the nurses considered what was required to keep an extremely premature baby alive, they were not surprised when some parents chose not to have their baby resuscitated. When asked if she would have her own baby resuscitated, one nurse replied:

> I come back to the amount of intervention at a very basic sense of the word, and I intervene with my large plastic tube [ETT] to keep this child alive. I invade its body, I create holes in it to make this child live. And if I can give out the relationship on that small baby to the size of the plastic and try to say 'how big would that bit of plastic be in relation to me'. I find it completely unacceptable if I had to accept a UAC [umbilical artery catheter], a UVC, [umbilical vein catheter] a peripheral cannula, the size of the endotracheal tube, even a chest drain. All of these things in my baby. I know if I had the decision I would say definitely not. (Nurse 6)

Knowing what to do in hypothetical situations is difficult. It is even more difficult to know what neonatal nurses would do if they were in premature labour. Gaining an accurate picture of what nurses believe they would do in a hypothetical situation is difficult. Unless faced with the situation, it is still very much a nurse believing she would know what to do in a given situation. That said, what is interesting is that the cognitive dissonance of the nurses meant

that they would avoid at all costs the very places where they work, where they practice their profession and where they provide care to 'other parents.'

Nurses and outcome predictions

Not every neonatal nurse is directly aware of the outcomes for individual extremely premature babies. The nurses in the current study had all read literature on the outcomes for tiny babies, and had seen babies return for follow-up. It was the opinion of the nurses that, *'...the literature..it's still a bit weighted to make things look really good … . There would probably be hardly any babies that came out unscathed'* (Nurse 19). Not all neonatal nurses are aware of the outcomes of extreme prematurity, however, the nurses in the study knew about the possible long-term outcomes. One nurse explained:

> That's something that we can demonstrate by the amount of reading that we've done and the facts that we have gathered...The experience, what we've seen, what [the babies and families] we have nursed. You know the outcomes that we've seen. (Nurse 1)

Many nurses spoke of how they heard about the outcomes of babies. Word filtered back to the NICU. Most nurses, however, focused on the poor outcomes.

> We do hear of all the follow-ups and there are a lot of positive follow-ups as well. I guess we tend to hear more of the disasters. (Nurse 13)

The nurses did not often see the good outcomes in tiny babies. It was difficult because, *'...we hear more of them [poor outcomes] than the ones who do well. That's the problem isn't it, we hear about the ones who are disasters'* (Nurse 14). In using everyday language this nurse was showing concern about causing damage to the baby during treatment. It is hoped that this form of language would not be used outside the confines of nursing. The nurses spoke of what they call '*disasters*' (Nurse 13, 14 & 19) when referring to outcomes. A disaster implies devastation and distress and three nurses perceived some babies in this way.

The nurses all liked to hear about positive outcomes. One nurse explained:

> Occasionally we get to see how babies are doing years down the track. That's positive. It's not that often, though. (Nurse 14)

Several nurses spoke about their colleagues who were optimistic about extremely premature babies, but who were not familiar with outcomes nor had they attended the follow up clinic. This situation was not uncommon, according to the nurses, because of the way that NICUs are structured, with an acute area separated from another area for less acute babies. Nurses who chose to work in intensive care might not get to see babies come back to the unit once they had been discharged. One nurse stated:

> We see a small facet. We don't see it [the baby] often down the track, or it's walking around blind. We don't see those issues, and if you don't see something you don't realise. (Nurse 5)

Another nurse explained that when she undertook her neonatal nursing course the consultant neonatologist was adamant the nurses should go to the follow up clinic to see the babies they had cared for. Here they, *'...saw the so called bad outcomes'* (Nurse 6). This was beneficial for the nurses, one nurse stating, *'I found that extremely confronting in there...for a long time I'd always thought that the children who didn't survive intact were the mistakes'* (Nurse 6). One nurse emphasised she knew about the poor outcomes, but chose to focus on the positive outcomes. This nurse explained, *'...it's probably a survival mechanism. You switch them out of your brain as much as possible'* (Nurse 24). Another nurse was convinced that constantly focusing on the negative outcomes made it difficult for her to continue working in the NICU. She stated, *'...you just want to see that baby go home and not really think of what's going to happen later on'* (Nurse 11). The nurses felt it was easier for them to concentrate on the positive aspects. Dwelling on the negative aspects might have been too confronting for them professionally.

All nurses interviewed believed they knew which babies would do well, and which babies would have poor outcome. They based their predictions on technical information and the baby's reaction to handling and its response to caregivers. Several nurses acknowledged they had been wrong in their predictions for extremely premature babies. The nurses all spoke of times when they believed a baby would not survive, and yet it survived. They emphasised that survival was not related to outcome. This means they might not be correct in predictions of survival, but were often correct in predictions about outcomes. One nurse explained:

> When it comes back for follow up, you think `Oh yeah you're not as good as what they hoped'. But the fact that you merely survived, is quite miraculous. (Nurse 12)

One nurse, who had seen two of these babies have good outcomes, still had a spark of hope:

> I might think the child needs to be turned off [had treatment withdrawn]. I thought a couple of times babies… I really thought they should be turned off and they should die. They [medical staff] have persevered and these people [babies] have come back OK. (Nurse 24)

DISCUSSION

A large body of literature indicates that children born extremely preterm are likely to experience ongoing problems, however the extent of those problems continues to be debated, and there is much uncertainty. How neonatal nurses manage the uncertainty of caring for extremely premature babies has been elucidated by (XXXXd) [18]. What is known is that a baby born at 24 weeks gestation could be 650 grams, have a head circumference of 22cm and be 31cm long, [28] therefore it is likely to be smaller in all aspects of growth, and have a poorer developmental outcome. Gestational age exerts the greatest influence on the survival [29] and outcome of premature birth. [30] The outcome literature reports on cohorts of very low birth weight infants (VLBW infants = less than 1500 grams), and extremely low birth weight infants (ELBW = less than 1000 grams), however it is difficult to gain a full picture of the babies who were the "microprems" or 24 weeks gestation and less. Lower birth weights and gestation consistently have poorer outcomes, [31] yet it is difficult for the authors of this current paper to specifically identify the population under consideration in the outcomes literature, and make judgements about their outcome to see if the neonatal nurses are correct in their concerns about poor outcome, and why they would not want their own baby resuscitated and treated if they delivered at 24 weeks gestation or less. Significantly perhaps, the outcomes literature reports de-identified cohorts rather than the individual babies that neonatal nurses see in their practice. Perhaps this might explain the discrepancy between the outcomes literature and the views that neonatal nurses express in the current research. Nurses' perceptions of outcomes and their sense of 'What they would do if this was their pregnancy and baby' may be more powerfully shaped by seeing an individual baby with a poor outcome going home with its family. What they have seen in the past has affected how they would envisage their future if they were to go into premature labour.

Making decisions about the resuscitation and treatment of extremely premature babies in industrialised nations are complex, and Australia is no exception. Australian guidelines recommend that from 20-22 weeks gestation, life sustaining treatment should usually not be provided. At 23-24 weeks gestation life sustaining treatment should be guided by parental wishes, and from 25 weeks life sustaining treatment should usually be provided.[32,33] Although the nurses believed that having choices was important for parents of extremely premature babies, they knew from previous experience that such choices were not absolute, and medical staff could override parental decisions. Complexities exist, and Larcher[34] states that decisions made about babies at the limits of viability cannot be made on the basis of clinical facts alone, and should take into account the values and belief of all concerned, including the staff. However, differences in moral beliefs exist, and can be compounded by a power imbalance inherent in the professional-parent relationship[34]. This creates a dilemma, because fifty-five percent of neonatologists in a study by Weiss et al.[35] stated they would not resuscitate within the 22nd week of gestation, which could mean that 45 percent would resuscitate during the 22nd week. Neonatologists in the same study were less likely to consider the parent's opinions all the time when choosing whether or not to resuscitate.[35]

A further complexity in the decision making process is the religious beliefs of the attending neonatologist. Eighty-nine percent of neonatologists in a study by Donoghue et al.[36] reported their religious beliefs influenced their medical practice. Lawrence and Curlin[37] found that doctors with committed religious beliefs gave less weight to patient's expressed wishes. As Paris el.[38] have lamented, physicians can resuscitate no matter how premature, how unlikely to survive, how likely to incur severe disabilities, or how strongly the parents object, showing that parental choice is not absolute.

In decision research the use of imagined or hypothetical situations is accepted as a legitimate way of studying real behavior.[39] When making decisions based on a hypothetical, a subject considers events that may or may not happen, considers feelings that they may or may not have, while anticipating possible outcomes and evaluating those outcomes within preferred options.[39] In research that uses a hypothetical methodology, vignettes are used as the equivalent of a case study where respondents reveal their perceptions and values.[13] In the current research the nurses were not given a vignette, but rather they used their own experiences of caring for extremely premature babies and their families to make the decision

that they would not have their baby of 24 weeks gestation and less resuscitated and treated. These nurses created their own vignette.

It is quite reasonable that the nurses would project themselves into the future in this way. Extrapolation to the psychological literature, shows that although the future is unknowable, humans are able to simulate potential future scenarios or mental representations of the future in their minds.[40] The ability to construct mental representations of episodic future thinking are important cognitive events. The ability to remember past events and imagine future events relies on the storage and retrieval of information in the episodic memory.[40] Knowledge about the future is structured around personal goals and cultural life scripts which are the person's expectations about the order and timing of events in his/her life.[40]

A critical factor to be considered in hypothetical situations is the importance of the decision, because important issues are afforded more cognitive processing which leads to better and more deeply considered decisions.[39] Anticipated emotions such as disappointment and regret can be operative in decisions in both hypothetical and actual situations.[39] There are such things as hot and cold states when it comes to hypothetical decisions. A hot state is important and is when a person makes a hypothetical decision that would have important consequences if made for real.[39] The nurses in the current study were projecting future outcomes. Therefore, they were ultimately considering the consequences of having their own baby given intensive care, and if irreversible damage occurred, it would have significant real world consequences.

The neonatal nurses stated they would not want their babies born extremely prematurely to be treated. This is in conflict with Sanders et al.[41] who found the opposite for neonatologists, albeit over 20 years ago. They found 61% of neonatologists would want their child treated with the same level of aggression with which they treated patients, while 34% would want their child treated less aggressively[41]. Streiner et al.[42] found physicians were more optimistic than neonatal nurses about the outcomes of extremely premature infants. In a large study that included 3425 nurses by de Leeuw et al,[43] it was found that the nurses were more prone than doctors to withhold treatment on a 24 week gestation infant. Not surprisingly, given the importance of choice identified by the nurses in the current study, that the nurses in De Leeuw et al's[43] would ask parental opinion about further treatment choices.

Eighty eight percent of nurses and 85% of neonatologists in a study by Oei et al [44] would almost always resuscitate 24-week gestation infants, however only 24% of neontalogists and six percent of nurses would resuscitate a 23 week gestation infant. These clinicians were more optimistic about survival than the long-term outcome. Janvier et al. [45] authored a paper titled "Nobody likes premies", where they gave a hypothetical scenario to physicians and students. The results make them question whether there is a "systematic devaluation of the newborn due to deeper rooted anthropological, cultural, social and evolutionary factors" [45] (p. 825) There is nothing in the current research that would support Janvier et al's [45] finding. McHaffie and Fowlie [46] found neonatal nurses would not want their own child to go through the painful therapies when the benefits were questionable. The outcomes for extremely premature babies were a similar concern to the neonatal nurses in McHaffie and Fowlie's [46] research.

Janvier et al. [47] asked resident doctors and nurses involved in perinatal care if they would resuscitate a 24 week gestation infant "depressed" at birth. They gave a vignette that gave the outcome of extreme prematurity, but does such an outcome change if the baby needs significant resuscitation? 21% said they would resuscitate. The authors wondered if it was the "emotional response to the foetus of 24 weeks that looks barely human" [47] (p. 278). The difficulties for neonatal nurses when caring for the extremely premature baby that does not have the widely accepted look and characteristics of normal 'babyness' has been discussed by (XXXXa). [15] Interestingly, for the current paper the fetal look of the baby had nothing to do with why the nurses would not want their own baby resuscitated. Janvier et al. [47] did not find that nurses were less interventionist than the resident physicians, however they did find that the nurses' attitudes reflected their personal experiences of seeing many babies with complications. These nurses worked in an outborn surgical centre. The nurses in the current study worked in a variety of areas including outborn surgical centres. Janvier et al. [48] (p. 207) in citing the same study that the "more the major complications are seen, the more nurses have a false impression of bad outcomes". Janvier et al. [47] suggest that the unwillingness to intervene for extremely premature infants is out of proportion to the prognosis. Yet, Janvier et al. [47] created the scenario of a depressed baby, meaning needs resuscitation. The poor outcomes of CPR in the premature infant lead Lantos et al. [49] as early as 1988 to believe that CPR is a non-validated therapy in extremely premature babies, and that these infants should not be subject to a standing order for cardiopulmonary resuscitation in the first few days of life. They argue that aggressive support should still be given, but the need for CPR should be

taken as a sign of impending death. Barr and Courtman [50] agree and suggest that CPR be withheld in extremely premature babies who do not have a reversible cause for their cardiac arrest.

McHaffie and Fowlie [51] found neonatal nurses would want fewer interventions for their own extremely premature babies, than that currently offered to patients in their NICU of employment. Perhaps their experience has led them to believe that not all babies can survive, and should it happen to them they would prefer not to be held "hostage to circumstance". [52] (p. 172). Harrison [52] (p. 172) spoke of a midwife who had contingency plans in case of premature delivery, and "...she would drive to a remote area, as far from a tertiary unit as possible, and let nature take its course". The following is a quote from McHaffie and Fowlie [51] (p. 275) where a neonatal nurse explains her beliefs.

> I always try to think, if it was my baby, what would I want, and then weigh that up against what I know as a professional... ..if I delivered a 23-week gestation baby, my heart would want me to do as much as they can to save that baby. But my head says, no, it's not meant to be. And I wouldn't like that child to suffer. And the outcome is quite poor. So I wouldn't want them to pursue any active treatment...

The nurses in the current study were all in agreement that it would have been unbearable for them to deliver an extremely premature baby. They held that this was not about not wanting a child with a disability. Rather, it mirrors McHaffie and Fowlie's [46] finding that nurses did not reject imperfection, they rejected pain and suffering for their own baby. The pain and suffering of extremely premature babies and the effect on neonatal nurses has been explored by XXXXe. [19] The nurses in the current study were not indifferent to the needs of disabled babies and their families. There is much in the data that reflects the opposite, and for the nurses, if society was going to save these babies then a range of resources and supports needed to be available in the community to assist and enable the parents, and help the child achieve its potential, whatever that potential might be.

Neonatal nurses are the main caregivers in the NICU and they are the profession that spends the most time with the baby and family. After meeting with the neonatologist, the parents might have further questions when they return to the baby's bedside, and the nurses answer questions and interpret information. [53] Gallagher et al. [54] wondered if neonatal nurses may be

a major factor in determining how parents are engaged in decision-making, and were not sure if the attitudes that the nurses held in relation to extremely premature babies impacted on their provision of nursing care. This is concerning because conveying unfavourable attitudes and beliefs has the potential to impact decision-making, and that is not within the scope of the role of the neonatal nurse. In fact, there is no evidence in the current research that the nurses even spoke to the parents about their attitudes and beliefs about babies of extreme prematurity. The nurses in the current study were adamant that they would never tell the parents what they would or would not do themselves, and as one nurse stated "*I might not want one [extreme prem] myself, but I would never tell a parent*" (Nurse 8). Another nurse said "*parents ask me what I would do; I tell them I don't know – of course I know. Well, I think I know*" (Nurse 12). Yes, the nurses in the current study experienced difficulty providing care at times (XXXXa; XXXXe), [15,19] however they went to great pains to emphasise that it did not affect how they cared for the baby or the parents. There was however evidence that the nurses advocated for the baby to ensure it had adequate pain relief (XXXXe). [19]

"Imagined futures" has been described by France et al. [55] who looked at men and women who had terminated a pregnancy because of a fetal abnormality. Experiential knowledge of disability and using their imagination about the future of their unborn child, helped them make their decision. [55] The use of hypothetical scenarios to investigate the attitude of people (with experiential knowledge of disability, or experience with a disability or contact with a disabled person) to the termination of pregnancy have been shown to have both positive and negative results. [55] Other studies have shown that expectant parents who had the antenatal diagnosis of potentially disabling conditions, sought out other people's experiences of disability to help make their decision. [56,57,58] Others were inclined to terminate the pregnancy because of concerns about the child's future and how the family would cope. [59] Very few studies have examined the decision that people actually take when a pregnancy is affected by a fetal abnormality. France et al. [55] described a tension between the parent's view of the child's perceived quality of life, and the couple's willingness to parent a disabled baby. Although there is no evidence in the data, the authors of the current paper wonder if this is the reason the nurses would not want to save their baby if they delivered an extremely premature baby. What they have seen in the past, and the struggles of parents has firmly planted ideas of what they want or do not want in their own mind.

All of the nurses in the current study were very experienced with providing care to the extremely premature baby. They were very knowledgeable about all aspects of care, and they have all seen babies and their parents return to the nursery, and they have seen first-hand what the baby looked like and heard stories from the parents and even the grandparents about how they were managing. It would be interesting to uncover if gender is an issue in this type of hypothetical decision making. All of the nurses were female, so perhaps a complete picture would only be gained with a male neonatal nursing perspective. Male neonatal nurses were not excluded from the study; a male neonatal nurse did not volunteer to be interviewed. While much has been made of the differences in moral development between males (Kohlberg 1969) [60] and females (Gilligan 1982), [61] a meta-analysis of gender differences in moral reasoning by Jaffee and Shibley Hyde (2000) [62] showed only a small difference between males and females in relation to care and justice orientation, meaning that male neonatal nurses might be in agreeance with their female colleagues in relation to the hypothetical question under investigation.

In relation to the long term care of surviving extremely premature babies, extrapolation to the literature, show that females are generally the ones with child rearing responsibilities. It was the understanding of the nurses in the current study that it was the mother who provided the majority of care for the baby when discharged. Women provide care in over 75% of situations. [63] Children with profound impairment require complex and specialised around-the-clock care, and it is usually, according to Brett [64] the mother who meets the child's needs. This caregiving could be responsible for the adverse employment outcomes noted in mothers of a child with a disability. [65] Women caregivers also suffer disproportionately with poorer psychological and physical health. [66] Could the issue be about subconsciously not burdening the mother or another woman?

The nurses in the current study have seen the outcomes or survivors of extreme prematurity. McHaffie and Fowlie [46] suggest the NICU is an artificial world, and that staff need to glimpse the realities of NICU survivors to increase their understanding of what families endure. The nurses in the current study stated that medical and nursing staff were occasionally wrong in their predictions of outcomes, but mostly their predictions were correct. All nurses spoke of observing one baby who had defied predictions and do well, but very few spoke of more than one. Doctors and nurses have been found to be wrong in one third of their predictions about

the baby's survival, however, nearly 90% of those predicted to die but who lived developed severe neurological problems. Doctors and nurses were accurate in their predictions of neurologically intact survival.[67]

In the case of the nurses in the current research one cannot investigate their real life decisions, one can only extrapolate to what they believe they would do in a particular life situation. The conclusions from a hypothetical situation may not always be totally correct, but they could serve as a starting point for further research. Therefore, because a hypothetical is just that, there is no reason to preclude a carefully formulated hypothetical thesis if it helps to arrive at a greater understanding. Qualitative method has a valid place in this research, inasmuch as if researchers want to hear the views of 'research subjects' they need to ask them, and give them time to answer fully to explain how they arrive at their understandings.

Hypothetical scenarios are valid in that they are based on hard facts, or difficult realities as perceived by the nurses. The 'facts' for the nurses regarding neonatal outcomes can change with education and accurate awareness of the latest research and outcome data. Neonatal nurses need to keep updating their education about the survival, morbidity and long term outcomes of extremely premature babies because neonatal nurses in a study by Blanco et al.[68] underestimated survival rates and overestimated disability rates. The nurses in the current study thought long and hard about the outcomes of extremely premature babies and their families, and at times they were distressed by seeing what parents were expected to endure. In order for them to continue to be productive members of the NICU team, the nurses could benefit from clinical supervision, reflection and education with members of the multi-disciplinary team,[69] where they can work though issues related to the outcomes of extreme prematurity.

CONCLUSION

Knowledge of the outcomes of extreme prematurity and what they have seen in the past has led the neonatal nurses in this qualitative study informed by phenomenology to believe that they would not want their own baby resuscitated and treated if they delivered at 24 weeks gestation and less. The international implications are clear; with increasing technology and refined techniques the numbers of extremely premature babies will not decrease, and until the outcomes are considered better by the nurses, the primary caregivers of the babies, they

would not choose to walk in these parents' footsteps. Choice was important for the nurses, as was fear of the technological imperative or the snow ball effect of technology; it being easier to start treatment and harder to stop. The empathic response of the nurses to the situation of the parents and the baby was authentic, making the nurses believe that the resuscitation and treatment of an extremely premature baby was not the path they would choose to take themselves.

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