BALANCING HOPE WITH REALITY

CAREGIVING DILEMMAS FOR NEONATAL NURSES IN CARING FOR EXTREMELY PREMATURE BABIES

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A doctoral thesis is an exercise in independent research…or so the theory goes. In practice, however, every thesis is the product of intense collective effort. Mine is no exception.

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ABSTRACT

As the capacity for saving smaller and smaller infants increases, the ethical dilemmas experienced by neonatal nurses who care for the smallest and most fragile of human beings will also increase. The current approaches to the resuscitation and management of extremely premature infants (24 weeks gestation and less) has resulted in the survival of infants with far less than optimal outcome. Neonatal nurses have begun to question saving the lives of extremely premature infants just because the technology exists to do so.

This study explores the ethical issues faced by neonatal nurses caring for infants of 24 weeks gestation and less. The research question arose out of the need for neonatal nurses to articulate the ethical issues that they face in clinical practice when caring for extremely premature infants. The study design takes a dual approach to the research question, namely, a survey questionnaire and a qualitative analysis informed by phenomenology. Given the complexities of the issues within the topic, this combination of methods was deemed to be the most appropriate in gaining a convincing and authentic result. The results of this research are not generalisable to the experience of other nurses, or nurses caring for other groups of premature infants.

In the first stage of the study neonatal nurses, members of the Australian Association of Neonatal Nurses (ANNA), were surveyed using a self-completion questionnaire. Then, in the qualitative component of this study fourteen (14) interviews with neonatal nurses were undertaken. These were either single or focus group interviews. In all, twenty four neonatal nurses from the state of New South Wales (NSW) and the Australian Capital Territory (ACT) were interviewed about their experiences of caring for infants of 24 weeks gestation and less. The questions asked during the interviews were based on findings from the questionnaire.

The interview data was analysed using a qualitative approach informed by interpretative phenomenology. The qualitative analysis revealed that the ethical dilemmas faced by the nurses existed within four themes. The four themes are:

- It's all about this baby
- Having a voice
- Dealing with awfulness
- Reflecting on the outcome.

The qualitative description as given in the four themes reveals structures and meanings about what it is to be the neonatal nurse who experiences ethical dilemmas when caring for extremely premature infants.

The study and its findings are a written account of the experiences of neonatal nurses and their ethical dilemmas in caring for infants of 24 weeks gestation and less. The meanings within the nurses' experiences are offered and the final phenomenological description, Balancing hope with reality, is given. Hope has a buffering effect on the nurses. The nurses inspire and instil hope in themselves and a baby's parents until the reality of a poor outcome dawns. Each time an extremely premature baby is born the nurses are hopeful for a good outcome, but the reality is that they have experienced many instances in which babies die or have a poor outcome. The neonatal nurses, affected by their experiences of ethical distress, attempted to find a pathway to achieve a balance between their emotions and caring for the baby. In doing so the nurses were able to remain productive the neonatal intensive care unit, and give high quality care to the baby and compassion to the parents.

This study makes an important contribution to neonatal nursing knowledge and practice by exploring the ethical dilemmas and complexities associated with extremely premature infants. This study also makes a unique contribution to the body of literature on ethical dilemmas experienced by neonatal nurses.

INTRODUCTION

The pursuit of science and technology and the subsequent advances in neonatal intensive care has meant that more infants are surviving at the extremes of human viability. Where once these infants would have died, because it was impossible to save them, it is now not only possible to save these infants, but it is becoming commonplace in industrialised nations. Saving the extremely premature infant has enabled neonatologists to attempt to edge ever closer to saving infants of twenty-weeks gestation, currently seen as legal viability. Questions have emerged that relate not to the ability to save, but to the morality of such decisions. Even as early as 1986, Vaux (1986, p. 477) suggested that "…the thoughtless benevolence on the part of neonatologists has yielded a sad aftermath". Such heroism in the neonatal nursery is seen more acutely in tiny infants who can be permanently damaged from the very treatment designed to help them. In many cases the effectiveness of this treatment may not have been fully explored (Silverman 1980, p.2). Added to the difficulties with treatment, the general public, through the publication of 'miracle baby' stories, are under the misapprehension that pre-viable fetuses can be saved. Thus the demand for treatment is high. The belief that technology can cure all is misguided, and the consequences of such treatment can therefore be lost on families who demand that their children be saved.

The current edge of viability is represented by infants born at 23 to 25 weeks gestation (Kelly 2006, p.367). At present infants born at 24 weeks gestation and less and/or less than 600grams, also called microprems, micronates, extremely premature babies/infants, fetal infants and infants of marginal or borderline viability cause the most concern for clinicians, both medical and nursing. Premature infants of greater gestation are likely to have a better chance of survival, and subsequently a positive outcome. They therefore, cause fewer moral and ethical dilemmas for the staff concerned. Staff have come to expect positive outcomes in infants of greater gestations (Levene 2004, p.150). It is those infants born at twenty-four weeks gestation and less who are statistically likely to have poor outcomes (Levene 2004, p.150), and generate the greatest moral and ethical dilemmas in the staff caring for them. The use of technology to save the life of a pre-

viable human being can be questioned because of the heavy burdens imposed on the baby, family and society should the baby survive in a damaged state. Although many of these babies eventually go home to lead happy and productive lives with families who treasure their existence, many of these babies are profoundly disabled. Currently less than 25 percent of 24 week gestation babies born alive are considered to be free of major disability (Levene 2004, p.150), while other babies experience other severe and ongoing complications of their extreme prematurity. Money is available for extremely premature babies in the intensive care nursery, yet it seems that when money is needed by families to continue to care for their disabled children bearing the outcomes of technology, the money is not freely available (Gatford 1999, p.33).

For infants born at the edge of viability, birth represents a transition to extrauterine life at a time when they are not physically able to sustain existence without neonatal intensive care. Infants of 24 weeks gestation or less are born at a time when their organ systems are present, but in a state of rapid maturation. Damage can be done to these organs because of their extreme immaturity, and in many cases the damage is inevitable. All organ systems can be affected, but the brain is the most susceptible to damage as blood vessels are extremely fragile. These tiny infants lack the ability to regulate the amount of blood entering the brain. Fluctuations in blood pressure and cerebral blood flow can cause the areas in the brain to rupture and bleed profusely (Paige & Carney 2002, p.671). The outcome will depend on the extent of the bleeding, the area of bleeding, and the damage that is done as blood is reabsorbed by the body. The long-term effects include cerebral palsy and severe cognitive deficits (Carter 2001a, p.1). Damage done to the developing brain will have life long consequences for the baby, should it survive.

The decision to save an extremely premature infant can have profound consequences for the baby, family and staff. A baby can be resuscitated and attached to life support. The baby who survives will be in the neonatal intensive care unit (NICU) for many months, and in some cases for the first year of life. The parents suffer emotional ups and downs, mirroring the baby's physical ups and downs. Even when a baby has a relatively smooth course there are still twists and turns with no one knowing the final outcome. Parents

have the legal and moral right to make decisions on behalf of their children. Parents, however are often asked to make decisions quickly, at a time when they are emotionally vulnerable. Parents will need guidance and emotional support to make these decisions. It is the responsibility of the medical staff to provide the parents with the latest statistics on prognoses and outcomes, however much uncertainty exists.

Neonatal nurses are the main care providers for all infants in the NICU. There seems to be an expectation that they will care for extremely premature babies without considering the ethical issues provoked by such care. As a neonatal nurse for 19 years I am interested in the ethical issues experienced by neonatal nurses in relation to their clinical practice. Situations that involve extremely premature babies who are likely to have a poor outcome can cause moral and ethical distress for nurses (Armentrout 1986, p.25). Nurses represent the largest number of health professionals working in the NICU and, although they are involved in the everyday decision-making surrounding the care and management of these babies, they are not involved in ethical decision making. Monterosso, Kristjanson, Sly, Mulcahy, Holland, Grimwood and White (2005, p.116) found that neonatal nurses' views were not considered by medical staff when making ethical decisions in the NICU. The voices of nurses are relatively silent in such circumstances.

Although neonatal nurses represent the majority, little research has been undertaken on their experiences of ethical dilemmas. Sparse literature addresses the attitudes and feelings of neonatal nurses regarding the moral, ethical, legal, economic and social issues surrounding fetal infants, also called infants of marginal viability (Armentrout 1986; Armentrout Richey 1988). Armentrout (1986) sought to determine the attitudes, beliefs and feelings of neonatal nurses towards the management and care of fetal infants within the context of ethical, legal, economic and societal environments. Substantial changes have occurred since 1986 in relation to the management of fetal infants. Infants of shorter gestation are being saved (ie less than 24 weeks), the birth weights of these infants are much lower, and because of reproductive technologies there are more of these infants (Levene 2004, p.149-150).

The purpose of this study is to explore the ethical issues faced by neonatal nurses who care for infants of 24 weeks gestation and less. The study design takes a mixed-method approach, both quantitative and qualitative, to the research question of 'How are ethical issues experienced by neonatal nurses concerning the care and management of babies of 24 weeks gestation and less?' The study utilises both a survey questionnaire and a qualitative analysis. Given the complexities of the issues, this combination of methodologies is deemed the most appropriate way to answer this question. The outcome for infants of twenty-four weeks gestation and less is the focus of this research. Major physiological differences occur in the week that separates the 24 week and the 25 week fetus and these will influence the outcome. Milligan, Shennan and Hoskins as early as 1984 found that the probability of intact survivors from 25 weeks gestation and above was 50 percent. This figure is much improved to 71.3 and 73.0 percent respectively (Donoghue & Cust 1999, p.35; National Health and Medical Research Council 2000a, p.16). While the prospect for survival of babies of 24 weeks gestation and less to hospital discharge has improved (Lucey, Rowan, Shiono, Wilkinson, Kilpatrick, Payne, Horbar, Carpenter, Rogowski & Soll 2004, p.1561), the long term outcome remains extremely uncertain. The improved survival of infants of 26 weeks gestation in the late 1980s' is now being used as justification for aggressive treatment of 23 week and 24 week gestation infants (Levene 2004, p.151).

Neonatal nurses who were members of the Australian Association of Neonatal Nurses (ANNA) were surveyed using a self-completion questionnaire. Nurses in all states and territories of Australia were included. With permission, Armentrout's (1986) work was the basis of the questionnaire design. The data from the questionnaires was analysed using the software package SSPS version 10.0.

The qualitative component of this study consisted of fourteen interviews with neonatal nurses. These were either individual (eight) or focus group (six) interviews. Twenty four experienced neonatal nurses were interviewed about their experiences of caring for babies of 24 weeks gestation and less. These nurses were from a variety of neonatal settings (perinatal, surgical and the newborn

emergency transport team) from every major centre in New South Wales (NSW) and The Australian Capital Territory (ACT), Australia. The criteria for interview was that the neonatal nurse needed to have over five years experience caring for extremely premature babies. The questions were based on the significant findings which emerged from the questionnaire.

A qualitative approach informed by phenomenology was used to analyse the interview transcripts. Phenomenology is concerned with the study of experience from the perspective of the individual. Phenomenological approaches are based in a paradigm of personal knowledge and subjectivity. They emphasise the importance of personal experience and interpretation. Phenomenological methods are particularly effective at bringing to the fore descriptions of experiences and perceptions of individuals from their own perspectives, thus challenging conventionality (Lester 1999, p.1). Phenomenology is a profoundly reflective inquiry into human meaning (Van Manen 2002a, p.1); therefore a qualitative approach informed by phenomenology offers ways of understanding not offered by other research methodologies.

In coming to a decision about convention, it seemed that the two terms, infant and baby, held distinct and different meanings. I have, therefore, used the word infant when discussing issues that are clinical, scientific, observational or when the nurses distance themselves from ethically troubling situations. The word baby is used to when referring to the humanity of a baby in being an individual and person.

This thesis does not contain the traditional literature review because there is very little literature that specifically addresses this topic. Most of the ethics and nursing literature that explores the issues involved are discussions rather than research. The lack of specific literature led to the decision to explore the field in order to clarify the many complex issues involved in the resuscitation and treatment of extremely premature babies. The first three chapters are devoted to this purpose. The first chapter is designed to provide an insight into the issues surrounding the birth of extremely premature infants. The second

chapter highlights the problems of extreme prematurity including the possible outcomes. The third chapter explores the ethical issues involved in saving tiny babies. In the fourth chapter the research method with its quantitative and qualitative components are described. The fifth chapter contains selected results from the questionnaire (the complete findings are in the appendices) and the qualitative analysis. Four qualitative results chapters follow, chapters six to nine. They contain the descriptions of the phenomenon and show the meaning of the experience for the nurses. Chapter ten is the discussion chapter where one major issue from each qualitative chapter is explored in greater detail, and in chapter eleven issues for practice and conclusions will be addressed.

The debate surrounding which infants are too small and too immature to survive will probably be ongoing, because the issues surrounding the life and death of extremely tiny and fragile human beings will always provoke questions and debate. Deciding on the best course of action is not easy because there may not be agreement where ethical dilemmas are concerned. The way forward for neonatal nurses is to research those ethical issues surrounding their practice. It is only through research that a thorough understanding of the world of the neonatal nurse will be elucidated. Neonatal nurses are in short supply, and helping them deal with their ethical dilemmas may prevent their loss to the area and their pursuit of a less stressful career.