THE LIVED EXPERIENCE OF A NEONATAL HOMECARE NURSE

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ABSTRACT

The neonatal homecare nurse (NNHCN) role delivers care in the home to infants and their families that have been discharged from the neonatal intensive care unit. The autonomous role with its expanding areas of nursing care, require that the NNHCN is at the forefront of knowledge advancement to ensure appropriate care is given to this population. This research project inquires into the life-world of the NNHCN experiences to gain knowledge of a specialised nursing role that leads care in partnership with the parents in their home.

Phenomenology as a methodology has been utilised to inform the research project to gain a deeper insight into the world of the NNHCN. This view allows dimensions of my nursing practice to be uncovered to show how and why I practice in the way I do. The theme of worry, and how it situates me to care and acquire knowledge, helps profile my nursing within the complex and dynamic world of the families I care for. The theme of active listening has also been identified and analysed to illustrate the development in my communication style needed to culturally and competently care and act on my concerns.

This project increases the body of nursing knowledge around a small and isolated area of nursing that has evolved to meet the needs of an increasing preterm population, sick infants and their families. Recommendations are based on the findings and may help in succession planning and recruitment profiling.

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CHAPTER ONE

This study is a research project informed by phenomenology that seeks to describe the essence of my neonatal homecare nursing practice. The neonatal homecare nursing service provides support and care for infants and their families that have been discharged home from the neonatal intensive care unit (NICU). The NICU graduate is susceptible to many health related complications in their first year of life. It is well acknowledged that the parents and families of these infants are under stress during their transition home and for some of them, months after discharge. The aim of this study is to describe and understand the neonatal homecare nurses experiences while providing specialised care for this population in their home.

As my personal experience as a NNHCN provided the original interest and motivation for this research report and my nursing background gave me a philosophical focus on human experiences, I chose to explore the human perspective underlying the experience of being a NNHCN. These experiences threaded together the primary theme of worry which will be discussed in relation to the development of the NNHCN role. The theme of active listening will also be examined as it situates itself hidden within the NNHCN role but plays a major part in developing relationships with others.

Phenomenology allows me to tell my story in my own style while fidelity to the phenomenon is kept by describing and interpreting the phenomena of interest 'being a NNHCN' (Wilson, 2010). Being a NNHCN has never been fully explored in New Zealand (NZ) or internationally. This research project will clarify how my nursing practice is shaped to meet the complex needs of these infants and families. Understanding my experiences in this context can contribute to nurses supporting and recognising the care and work required for this group of families and infants. It will contribute to the body of nursing knowledge by the articulation of my experiences that may help in defining the responsibilities and evolving position of NNHCN.

This research report may inspire others to learn from my study and help in succession planning and recruitment recommendations. This is a personal journey that brings not only me as a nurse but also as a mother, wife, friend, and all other facets of my life, and experiences together. Studying one without reference or concern for the other parts of my life would not only limit the study, but also show little congruence.

HISTORICAL BACKGROUND OF THE NNHCN ROLE

Technology has made significant improvements in obstetric and neonatal medical and nursing management, which allows lower gestational babies survival and discharge home (Ministry of Health, 2005; Craig, Anderson, & Jackson, 2008). The high demand for cot space in NZ and the increasing emphasis on the high cost of neonatal intensive care, draw attention to early discharge if the infant and family are prepared. Internationally NNHCN services were effective in reducing length of stays in the NICU and avoiding hospital readmission (Hummel & Cronnin, 2004; Langely, cited in Cappleman, 2004; Swanson & Naber, 1997). It was in this era over the last twenty years that the NZ NNHCN role developed to provide in home support for these vulnerable infants; some requiring ongoing technological support such as oxygen supplementation, respiratory monitoring, tracheal/airway management and nutritional monitoring and assessment.

The NNHCN service where I work was established in 2000 providing a mobile home visiting and telephone service for all infants and their families discharged from the NICU. The service covers a large rural and urban land area that is dislocated from mainstream tertiary services because of its geographical location with hilly terrain, unsealed roads and unpredictable weather. The NNHCN service is well used as the preterm birthrate continues to rise in NZ (Craig, Anderson, & Jackson, 2008). Preterm infants are infants born less than thirty-seven weeks gestation (Lee, 2010).

FAMILY SITUATION

The birth of a preterm or sick infant has an impact on both parents and family with their continued health requirements after discharge from the NICU, and NNHCN care is extended to encompass the family. Parents have many health appointments to attend and closely monitor their infant's condition at home (Lasby, Newton, & von Platen, 2004). Families experience considerable worry and uncertainty about their preterm infant's progress and outcome as they have an increased likelihood of readmission in their first year of life (Bakewell-Sachs & Gennaro, 2004).

NNHCN care modifies to fit the needs of each family as they adjust to the increased work of caring for their infants at home. The ongoing needs of the preterm infant require close NNHCN follow-up to support optimal growth and development and facilitate timely intervention (Lasby, Newton & von Platen, 2004). The degree of NNHCN support is variable for each infant, mother and family as each has different capacities, circumstances and views on health. By considering each family as unique I enter into partnership with the family to facilitate nursing practice that promotes culturally competent care and allows self-authorship of my family nursing (Hartrick Doane & Varcoe, 2005).

PERSONAL AWARENESS

Becoming self aware of how I am situated in a family health context allows me to consider how my values, beliefs and pre-existing thoughts may impact on relationships and the health outcomes for enabling a family to make decisions (Hartrick Doane & Varcoe, 2005). I need to be aware of my history and that I am a middle aged Pakeha women, married with three teenaged children and both parents in employment which affords a comfortable standard of living. I was raised and educated with Catholic Christianity principles and had a strict family upbringing. I am aware that my view of family does not describe all families as it is for each of us to

define. I am a hospital trained general and obstetric nurse and have completed postgraduate nursing education. I have an understanding that my history reflects a moral and ethical desire to be benevolent and cause no harm, and that it has influenced my choice of career to become a nurse. I also value trust, honesty, fairness and partnership within relationships and that any of these principles may cause me distress when they are compromised within any professional or family relationship I am in.

Self awareness helps broaden my worldview of consciously knowing how I am with others as it defines my bias and allows me to be open to new understandings (Hartrick Doane & Varcoe, 2005). Self awareness strengthens all nursing practice and is central when inquiring about the nature of my nursing knowledge from reflections of my NNHCN experiences (Bulman & Schutz, 2008). Critical self-reflection will be apparent throughout the research project as it adds further meaning to the interpretation of my experiences.

Chapter one introduces phenomenology as a methodology to inform this research project as it helps guide my way of thinking, reflecting and articulating experiences of my nursing practice in the role of NNHCN. The historical background of the NNHCN position, the impact of a preterm birth on the family and information on my personal awareness helps inform the reader why this research is of value. In this study understanding the NNHCN experiences would not only provide a view into my life-world but also illustrate my processes for acquiring the capacity to do this job which give meaning to the overall experience. Nursing research needs to address practice issues that daily concern us and this research may inspire others to learn from my study and provide knowledge to add to nursing.

CHAPTER TWO

This chapter will explore the use of qualitative research methodology, specifically phenomenology and its application to the phenomenon of interest; the lived experience of being a NNHCN. The methodology provides the philosophical underpinning for which this research project will be informed by and is harmonious with my genuine interest and commitment with the research topic. Ethical and Maori consideration is acknowledged as they walk alongside my practice to support my reflections on my experiences in my nursing practice.

METHODOLOGY

Qualitative research helps nursing to define itself as it explores and describes human experiences in the contexts that are of interest to nursing in everyday life (Schneider, Elliot, LoBiondo-Wood & Haber, 2004; Cody, 2006). Qualitative researchers use a holistic and person focused method that represents a breadth of human experience to understand in depth accounts of human reality (Schneider et al, 2004; Polit & Tantano Beck, 2006). This is important to my nursing as it encompasses the caring, interactional and understanding ethos of the profession, whose focus is on the whole of the human rather than the body part or one specific condition. Qualitative research methodologies connect with nurses as they allow certain kinds of questions to be asked and answered, that share an underlying congruent belief system. These methodologies are based on the belief that knowledge is socially constructed and that multiple realities exist because of the different cultures, beliefs, values and realities of the humans being researched, and because of the researchers perspectives (Cody, 2006; Nicholls, 2009).

Phenomenology, as one of the qualitative research methodologies, has been well utilised in nursing and offers an approach to enable me to think about my experiences and their meanings (Polit & Tatano Beck, 2006). The aim of phenomenology informing this study is to describe how the phenomenon of 'being a NNHCN' is experienced and how I construct meaning within my experiences.

Phenomenology research is most suited to focusing on the whole of the human experience as it helps towards understanding human behavior and expanding the knowledge base of nursing science; commonly undertaken when little is known about a subject (Schneider, Elliot, LoBiondo-Wood & Haber, 2004; Cody, 2006).

Although this work is not a phenomenological inquiry I have utilised van Manen's (2006) description of phenomenology to inform the project as it has provided some clarity around the framework and guided the reflection and interpretation of my everyday experiences to reveal new nursing knowledge. Describing each section of the process has helped me in structuring the work to capture the essence of what it is like for me being a NNHCN.

The descriptions of my experiences will be a true and honest account to reflect the lived experiences of the NNHCN. By remaining focused to the research question 'being a NNHCN' and reflecting what the nature of my lived experience is, ensures that the reflective inquiry into human meaning is informed by phenomenology (van Manen). Phenomenology is the study of the life-world; the world as we immediately experience it pre-reflectively. I will not be reflecting while living the experience but the descriptions are retrospective when reflected upon in phenomenology (van Manen, 2006).

The methodology allows me to take into account my experiences and reflections of being a NNHCN. The method evolves and weaves itself from the framework and thus intertwined staying true to the methodology.

THEORETICAL FRAMEWORK

Drawing on the work of van Manen, the centrality of the work should always be focused around the phenomena; being a NNHCN (Schneider, Elliot, LoBiondo-Wood & Haber, 2004; Polit & Tatano Beck, 2006; van Manen, 2006; Seamon, 1984). I was guided by the phenomena of interest determining the approach to undertake this research project and have applied first-person description and writing for the

experiences of being a NNHCN. First person description and writing when grounded in my experiences can present clarity and understanding of my life world (Seamon, 1984).

METHOD

The work is informed by ideas from phenomenology, particularly those of van Manen (2006). Whilst undertaking a phenomenological study is outside the scope of this project I have been guided by some of the themes described by van Manen. These are:.

1. Turning to a phenomenon which seriously interests us and commits us to the world;
2. Investigating experience as we live it rather than as we conceptualise it;
3. Reflecting on the essential themes which characterise the phenomenon;
4. Describing the phenomenon (van Manen, 2006, p.30-31)

Utilisation of these themes to inform the research project have been illustrated by engaging in research that I am fully interested in through describing and interpreting the lived experience of my NNHCN role. Reflection on the NNHCN themes will capture the nature of my experiences and describe more fully my world and thinking processes to characterise the phenomenon. Keeping focused to describing the lived experience of NNHCN informed by van Manen's approach maintains a connection between the method and the lived experience of a NNHCN. Ongoing reflection throughout the research project shows a commitment to move between my journal entries, exemplars and experiences to gain a deeper insight into the experience of being a NNHCN.

DATA COLLECTION

Benner (1994, p.74) asks "where to begin" if there are no facts or concrete data when studying human issues in nursing? A place of not knowing is where I am situating myself in this research project with no preconceived ideas of the outcome.

The unknowing position is a phenomenological approach that permits me to be open to new understandings by not having taken ideas for granted (Madjar & Walton, 1999). First person phenomenological description and writing uses the researchers own personal experience as a basis for examining its uniqueness, traits (Seamon, 1984) and gaining new knowledge in my nursing field.

There is a historical background of understanding in this research project as the author is the NNHCN under study, and this works favourably by being able to immerse fully in the experiences and text (Seamon, 1984). I am the person with the knowledge of the phenomena who will articulate the experiences and within this context maintain a reflective position (Schneider, Elliot, LoBiondo-Wood, & Haber, 2004). The phenomena I will be describing will be in experiential terms and will be focused on a particular event or situation (van Manen, 2006) gleaned from my nursing journal and experiences. Meanings from my experiences will be developed through not only the individual meaning of a situation, but also the intersubjective experiences of my social and physical environment and personal history (Madjar & Walton, 1999). Personnel awareness of how I am situated contextually aligns with phenomenology as it requires description and understanding (Madjar & Walton) and cultivates self knowledge when used in a reflexive way (Hartrick Doane and Vercoe, 2005).

My nursing practice developed from personal knowledge influenced by my values, beliefs and past experiences. Knowing in my nursing represents personal reflection on experiences to find understanding, meaning and help guide ethical practice. The concept of reflection was introduced to my nursing in an active way in 2002 when I began my postgraduate education and I continued to use a reflective journal to record nursing events. I have found keeping a reflective journal a helpful tool to develop personal strategies to assist in advancing the NNHCN role as it illustrates past learning and why I have made practice changes (Bartter, 2001; Streubert Speziale & Carpenter, 2003). Reflection requires personal awareness of how I am

situated with each nursing journal entry and that these experiences are described, analysed, synthesised and evaluated to story tell what my nursing is about (Bulman & Schutz, 2008). Some of my journal entries started off as notes recording events so I could later go back and use the reflective process outlined above to learn from experience and act upon the realities of practice in my context. I am conscious that my experiences belong to me and that this research project will only be able to capture part of my nursing experiences and that there are other NNHCN with different experiences to mine which are all valid.

Data for this research project will be drawn from reflective journals, exemplars and nursing practice experiences from being a NNHCN over the last six years. There will be some experiences that draw on my nursing knowledge prior to this time but this will be done to contrast, compare or show practice advancement from this earlier period of my nursing. The reflections have been constructed in my journal after an event in my NNCHN practice to help me make sense and learn from my nursing. The experiences and narratives will be quoted from the journal to reflect the experiences and language used to uncover deeper understanding. I will use descriptions that are rich and interpretations that are true and reflected in a sensitive caring language (Findlay, 2009). Data collection and analysis occurs simultaneously through "reading and re-reading journal entries and narratives in whole or parts; writing and rewriting" (van Manen, 2006, p.131).

The reasons for choosing the data for the reflective extracts came about because they represented more than one occasion whereby the theme of worry or active listening within the NNHCN role was apparent. All the entries into my journal were highlighted in different colours to represent different meanings of worry and reoccurring themes. The most significant entries were the reoccurring entries chosen to reflect the experiences of being a NNHCN and nursing practice advancement within my NNHCN role. The reading and rereading of different entries and to reflect on the theme that constitutes the nature of this experience "makes a distinction between appearance and essence" (van Manen, p.32). Sometimes what appeared

on the early journal entries showed how my NNHCN initially was laden with worry but the essence of that worry was care. Further into my nursing journal the worries lessened as I gained knowledge and confidence within the role. The literature provides support for NNHCN practice and changes and advancement within the role that reflect what being a NNHCN is like.

THEMATIC ANALYSIS

Identifying themes and patterns of themes as they appear in the data, endeavours to capture the phenomena to inform this project by asking its meaning (van Manen, 2006). When themes have been identified and experiences reflected upon to satisfy what being a NNHCN is really like, then text can be created. Writing and rewriting, going back and forth questioning, to analyse the themes for meaning. This involves textual reflection and succeeds when it lets the reader see the hidden meanings (van Manen).

Reflection is an ongoing movement within the project, to consider the part in relation to the whole of the project and help balance the research and stay true to the phenomena. Moving between my experiences, exemplars and journal entries helps balance the research project by considering how each part contributes to my lived experience of being a NNHCN. An in-depth literature review relating to the themes that have presented and a critical analysis of my advanced nursing practice will run alongside the descriptive text, to contribute to deeper understanding of the phenomena.

ETHICAL CONSIDERATION

The ethics of this research project values the relationship I have with the families, colleagues and community I work and live in. Phenomenology is informing this research project to allow my voice to be heard through rich descriptions and interpretations of my experiences with people and families in relation to their situations and community. This research report does not require research participants or formal ethical approval from an ethics committee but I am mindfully

aware of the dominance of my voice over theirs within my experiences in this study. The protection of these families whether they play a direct or indirect role within this research project is foremost (Schneider, Elliot, LoBiondo-Wood, & Haber, 2004).

NNHCN develops close relationships with some families, especially the mothers and the emotional commitment to the relationship witnesses some of the most intimate moments in families' lives that I must consider when recalling experiences. To research others experiences that you have shared an intimate moment with, is about protecting the relationship and respecting their vulnerability and it may be that all is not revealed because of it (Ellis, 2007). Describing a truthful experience whilst changing details and omitting names helps to protect identities. As I journey through this research I am mindful of the families and people that might become distressed by my relating the experiences (Ellis). I constantly centre myself knowing that ethical practice for me is my particular way of relating in the world that is grounded in an ethic of concern for all (Hartrick Doane & Varcoe, 2005). In respecting others, some experiences may not be told (Ellis, 2007) as these stories also belong to them.

I have a moral and regulatory responsibility to ensure that no harm is placed upon the families that I have or currently are caring for because of my experiences. I am governed by the Health Practitioners Competence Assurance Act (HPCA) which aims "to protect the health and safety of members of the public" (HPCA, 2003, section 1, para. 3). The HPCA is regulated by the Nursing Council of NZ (NCNZ) and requires evidence from me to annually demonstrate my competency within the scope for registered nurses (NCNZ, 2009). In undertaking this research I have a professional responsibility to uphold sound ethical principles and protect human rights by adhering to the New Zealand Nurses Organisation Code of Ethics (2001) and the NCNZ Code of Conduct (2009).

Trustworthiness and credibility of this study is by the data supporting interpretations through thick description of the phenomena (Watt, 2007). Reflection provides further insight into the data presented as themes, and validity is when the reader finds the

descriptions and interpretations believable (Dinkel, 2005). The reader can also experience my process of knowledge construction by engaging in the data, analysing and using literature to determine what I know. This knowledge combined with my personal awareness of biases provides the study with credibility as it allows the reader to evaluate the findings knowing how I am positioned personally and professionally (Watt, 2007).

CONSIDERATION OF TE TIRITI O WAITANGI

Maori are the indigenous people of New Zealand and throughout this research project I respect Maori cultural concepts and their perceptions on health incorporating "te taha tinana (the physical element), te taha wairua (the spiritual element), te taha hinengaro (the emotional and psychological element), and te taha whanau (the family and community elements)" (Health Research Council of New Zealand, 2008, p.20). In addition Te Tiriti o Waitangi guides my approach and any dissemination of findings will ensure that the principles of good governance and tino rangatiratanga are considered.

These concepts are congruent with the relational practice model of care I practice. This allows families to lead their health care, working in partnership with me to deliver care in their world - in their context. I am conscious that generally, Maori health is an interaction of whanau (family), spirit, mind and body and when working with these families often the wider community contributes to the wellness of the infant and family. Having an understanding of not only the health status of the infant but their whanau; and how each member contributes in the healing experience allows me to support the family in a relational way.

As a Pakeha woman I am conscious of my own cultural identity and that my history personally, socially, politically and within a family is different to everyone I visit. My self awareness as discussed on page three and four situates me in relationships with families knowing I am different and utilising critical self-reflection, helps develop

my nursing practice to be relational, ethical and culturally safe (Hartrick Doane & Varcoe, 2005).

When I enter into relationships with Maori families I am mindful of the legitimate differences between us (Ramsden, 2002). I have an understanding of how colonisation has impacted on Maori through violence, poverty, depopulation, dislocation and deprivation of cultural identity (Ramsden, 2002). I have an understanding that the loss of Maori land, language, culture, power and way of life to stay healthy has negatively impacted on Maori health and produced distrust between the indigenous people and the colonisers (Ramsden, 2002). I am aware that it is my responsibility to establish trust within the relationship and cultivate a relationship that empowers the family and that cultural safety is defined by the families I work with (Ramsden, 2002). I am also cognisant that each Maori family communicates culture differently and it is up to me to recognise and find pathways within my nursing to provide care that improves health outcomes for Maori.

Chapter two has discussed the use of phenomenology as methodology informed by van Manen to underpin this research describing and interpreting being a NNHCN. The philosophical underpinnings and methodological approach were discussed with the ethical and te Tiriti considerations for this study.

CHAPTER THREE

The following chapter presents the research themes, reflection and data analysis of the lived experiences of being a NNHCN. My lived experience as a NNHCN is with families that have been in the NICU for preterm or sick infants. The main theme of my experiences with the NNHCN role is worry and how it appears and enacts my caring nursing practice. The theme of active listening has emerged and although not as dominant as worry, is important as it makes sense of my everyday actions and contributes to my relationships with families and other health and non health practitioners.

THEMES

Recurring themes capture the phenomenon of being a NNHCN and have emerged using van Manen's (2006) three ways to isolate themes from my journal and personal exemplars. The first approach is holistic which looks at the whole text to identify a phrase to capture the essential meaning. In the second or selective approach, as I am reading or rereading statements, phrases or text are highlighted that are revealing about the phenomena described. The third approach looks at every line of text and paragraphs to reveal the meaning it holds about the experience of being a NNHCN. I have utilised all three styles to immerse myself in the data to uncover the recurring themes of worry and active listening.

Worry within my NNHCN role is experienced as a feeling of concern that I must act on. After reading and rereading my historical journal extracts and exemplars from NNHCN practice a reoccurring theme of worry was expressed as 'concern to act on my worry'. Concern for the families I was caring for and for my nursing practice to maintain safe practice and grow in my new position to fill all the requirements of a new nursing role. At the same time I felt a freedom to craft this new role into new areas of practice and that worried me as I was going where no other nurse had gone within this role in my area of nursing practice. The feeling of isolation was a new concept in my nursing as I had always been surrounded by other nurses and colleagues for support. Because of this I developed relationships with other significant people like social workers outside of my nursing field to support my role.

The feeling of worry also alerted me to deficits within my nursing knowledge. This subsequently was a motivating feeling for me to acquire new knowledge to feel safe within my practice knowing more. I can see how worry within my NNHCN was not an overwhelming feeling that disabled me but ignited my nursing practice to become the best advocate for optimal health outcomes for the infants and families I care for.

Analysis of the themes was informed by phenomenology and concurrent with reflection and literature. This allows a deeper understanding from the experience and illuminates unknown meaning so I become more enlightened about my nursing practice (van Manen, 2006). My experiences from my personal journal and exemplars from my NNHCN practice will be in italics throughout the text.

THE THEME OF WORRY

The Collins dictionary (2003) defines worry as anxiety, unease or concern. Within the thesaurus it displays words that are actually used today to portray how the English language is changing and defines worry as care in the context of a problem. The Dutch language discusses the word for care, 'zorgen' as a sense of being troubled by worries (de Ruiter, 2008). The broader meaning of worry will be analysed in relation to my nursing practice which weaves the thread of worry through my world. One learns a landscape of my nursing practice not by knowing worry but by understanding the relationships in it and getting a sense of the whole (Watson, 1999).

WORRY, RESPONSIBILITY AND AUTONOMY

Being the only NNHCN is personally, professionally and geographically isolating. Some days I go from one crisis to another with families and there were times I worried about what I had taken on in this new job?

The autonomous nature of the NNHCN role situates me in isolation far from the hospital and other health professionals so that decisions in the families' home need to be decisive and of value to the infant and family. The increased responsibility challenges me to utilise my nursing expertise with limited resources and creativity within the home, and manage the loneliness and discomfort of travelling over rough

terrain and through unpredictable weather. Worry is not new in nursing as these similar issues and challenges were faced by remote rural 'backblock' nurses during 1910-1940; they were aware of the significant responsibility they carried and also worried "as many nurses did, about keeping up to date with changing practice and having sufficient knowledge to make independent clinical decisions" (Wood, 2008, p.176). This shared reality helps validate my experience of worry as there is a paucity of nursing literature around worry.

When I commenced this role six years ago my new responsibility was being expressed by worry. Svensson and Fridlund (2008) found in their study that nurses with higher levels of experience had increased responsibilities and their worry was related to that responsibility. Practicing alone in complex family situations represented a change in my personal responsibility and accountability and this may account for the worry I felt (Chadwick & Levitt, 1998). I can see that my personal accountability within the NNHCN role is more predominant than working within the team accountability framework in the NICU. Acting with autonomy and stretching the boundaries of my nursing practice required a period of self adjustment and role development. Although I had in-depth clinical knowledge, skills and neonatal experience and some post graduate education, transitioning to this community role required fostering new professional relationships, collaborating with other health professionals, community services and new learning.

Further analysis of my worry showed that I developed ways of coping with my worry by informal and formal 'ways' of sharing the burden. Professional supervision has not always been possible when situations arise, and I have found debriefing after significant incidents with my manager an effective process to reduce my worry. Keeping a reflective diary also has allowed ethical reflection on my personal and professional values that help guide my reasoning putting my worry into perspective (Bulman & Schutz, 2008). Svensson and Fridlund (2008) found nurses consulting colleagues or debriefing was effective in reducing worry but for some nurses increased their worry. This may be because worry is subjective and the person

listening to your worries does not see them as significant and may dismiss them. I believe the person I choose to share my worry with must be trustworthy and knowledgeable about my role to value it, and be open to assist in supporting my role rather than adding to my worries.

WORRY, PATERNALISM AND ADVOCACY

When I first started this job I worried more for some families and how they were going to cope with their preterm infant at home. I felt this huge responsibility for the infant and their family more so than working in the NICU. I wanted all the babies to go home to warm loving surroundings with a family that would care for them. What I found was that some families were living in poverty with cold homes and a lack of essential items like food, washing machine, beds and vacuum cleaners.

As I reflected on this early journal entry I could see I walked a thin line between advocacy and paternalism for the infant and their family (Zomorodi & Foley, 2009). Community health care has traditionally fostered dependence on the health care worker to provide all the answers to problems of the family in the community (Ervin, 2002), as illness not health has been the main focus of health concern (Cody, 2006). For some families when they accept the nurse interpreting their relationship in this way, it legitimises the nurse's approach and I need to be aware how this disempowers the family by taking away their control (Ryan, Carryer & Patterson, 2003).

My moral dilemma of knowing what was good for an infant and what was possible for the parents to achieve, meant that every home visit faced an unforeseeable situation (Zomorodi & Foley, 2009). I had to be ready to face the unpredictable complex mêlée of families life-worlds affecting an infant's care, not always for the good and this worried me. I had not realised until I reflected on my worry how in the past the NICU provided me with safety and security, with its focus on completing tasks and providing a predictable working environment which gave me some control over the infants care. When I went home from working in the NICU I could guarantee

the quality of care the infant would get, but in the community I had no control. A reflective comment made one year after commencing the NNHCN role showed how I had positioned myself unknowingly in the relationship with the parents as having some control over the infant, by being able to 'give the babies back'.

I have learnt now to give the babies back to the parents and in doing so some of my worrying has lessened. I have found that letting myself be open to new experiences to feel the mothers and families troubles may be worrying but its worth it…you know you can make a difference and that all families have strengths.

Because of my self awareness I now consciously question my role within these families as they make the daily decisions about their infants' care. Cappleman's (2004) study found that NNHCN relied on parents' observations to make decisions about the infants care and I had to make the transition to trusting the partnership between the parents and me. I recognise the power I have positioned in the relationship with the infants and families, as I am seen having expert knowledge and can connect families to other agencies.

Deeper reflection showed I needed to be aware that the habit of worrying or feeling responsible for families, and the need to fix or do something for them, could inhibit the process of being with them at this time to enable a health promoting response (Hartrick Doane & Varcoe, 2005). By paying attention to the way I behave, not rushing a home visit, being genuinely caring in my intent and actions, showing concern without becoming overwhelmed by a situation, allows reflexive consideration to guide my response and not emotion or habit (Hartrick Doane & Varcoe). This time also allows me to assess and feel the situation that the families are in and how they are coping. For some families in these situations, it is about discussing their choices and enabling their capacitiy to find answers and move on, or to let be. This does not mean I approve or disapprove of their choice, it means I allow myself to communicate to these families that they matter and I will care for them whatever they choose (Hartrick Doane & Varcoe). Self-determination of the

parents to choose how they live with their infant is their right and I have learnt to support their choice rather than rescuing those families (Zomorodi & Foley, 2009). Situations are far more complicated in the community and I had to learn and develop a framework of intervention for the safety of the infant, family and myself.

WORRY AND EDUCATION

The worry comes from me; I just feel lacking at times to be able to help as much as I need to. Sometimes it's about energy and other times I just don't know enough.

Worry in this situation was about feeling inadequate because of not knowing correct pathways or people to contact. It related to not knowing how to manage some situations in the home and the gap of knowledge I perceived I had. Svensson and Fridlund (2008) found that nurses in atypical situations would often feel inadequate and feelings of insecurity would develop.

Worry was the catalyst for new knowledge to be acquired to meet the needs of the family and advance my NNHCN role so that I had the confidence to practice autonomously. Nurses in advanced nursing roles need to develop personal strategies to cultivate their practice to the betterment of their clients and profession (Bartter, 2001). Through critical reflection I identified areas of new learning to facilitate my NNHCN practice. I undertook child protection studies which gave me greater insight in knowing my boundaries of responsibility and enabled networking with police and social services to identify correct pathways in protecting the child. I have come to appreciate that my worry in situations that need attention, is my red flag that actions collaboration with other support agencies. Liaising with Paediatricians, mental health team, Barnardos, social workers from the hospital and Child, Youth and Family, Whanau support and being involved with family group conferences, help protect the child and strengthen the family unit. Having strong relationships with other health professionals secures pathways for support and care for these infants and families (Cappleman, 2004).

To develop my breast feeding skills and extend my help in assisting mothers and their infants at home, I undertook specialised study in the field of human lactation to qualify as an International Board Certified Lactation Consultant. Reflecting on prior experience I can see how I looked more objectively at 'the sore nipple' or 'poor weight gain', without knowing all the other knowledge for the mother to feel success in her breastfeeding. When I home visit now I am able to develop an individual breast feeding plan with the mother alongside medical care for her infant and in relation to what is going on around her in her family. Some infants are discharged home before breast feeding is fully established and breast feeding is not always easy for this preterm, sick, handicapped or low birth weight population. Most mothers need emotional and practical support for their continued breast feeding when weight gains are low and feeding times are difficult. Wheeler (2009) concluded in her study that the hospital needed to provide ongoing support for success in breastfeeding at home if they practiced discharging families from the NICU before breast feeding was fully established. Mothers and babies discharged from the NICU gain from having professionals with all the requisite skills and knowledge in the area of breastfeeding and lactation as they feel supported, gain confidence and breast feed for longer periods (Colaizy & Morriss, 2008; World Health Organisation, 2010).

Improving nutritional outcomes is one of the thirteen population health priorities in the NZ Health Strategy (King, 2000) and forms one of the health targets that the District Health Board and Ministry of Health (MOH) are focusing resources to improve health outcomes (MOH, 2007). The NNHCN role is well positioned to improve breast feeding outcomes for the infant by providing practical lactation assistance for mothers in their homes. Vohr, Poindexter, Dusick, McKinley, Higgins, Langer and Poole (2007) showed the outcomes for low birthweight infants receiving breast milk reduced hospital admission and increased behaviour scores. My nursing practice supports step ten of the best evidence practice guidelines to successful breast feeding, developed under the Baby Friendly Hospital Initiative launched by United Nations Children Fund and World Health Organisation (WHO) in 1992 (WHO, 2010). Step ten is the requirement to offer breast feeding support to mothers after

discharge from the maternity hospital. I also contribute as a stakeholder to updating the local breast feeding policy and participate in the national breast feeding campaign with other health promotion and iwi providers in the community.

WORRY AND HEALTH INEQUITIES

The strength of the relationship between the family and me develops through sharing their worries and the families know I am there for them as they have shared some of their most intimate moments with me and they can trust me to act in their best interests.

I present to the family an authentic presence that is willing to know them in their world and by knowing them I have confidence in taking the right action (Madjar & Walton, 1999). It is the nature of my visit that reveals my way, my being and my attentiveness. In the role of NNHCN, care must be modified for each infant, their family, environment and situation based on the family's needs and not my own. I do not judge their lifestyle as I am a guest in their home and this demonstrates respect (Chadwick & Levitt, 1998; Ervin, 2002). Svensson and Fridlund's (2008) study showed nurses worry more when they can associate with the family's situation because of personal experience.

Reflecting on this, my worry connects to my personal experience of seeing the consequences of health inequalities in my practice on a daily basis. The preterm birthrate has increased over the last twenty years in my region (Craig, Anderson & Jackson, 2008) and because of this my visits to families over the last five years has increased. I visit a variety of families, some that have socioeconomic, geographical, ethnic, disability and gender inequalities. More disadvantaged groups have poorer access to health services (Ministry of Health, 2002) and I recognise that I can reduce stress for these families and increase health outcomes by my actions.

I understand how the social problems of violence, drug and alcohol abuse, low income, crowded housing and unemployment have an impact on some families I

visit. I discuss with mothers and fathers, support to get them to health appointments for their infant from other health providers or myself. I discuss contraception and make appointments for the mother and/or father at family planning, or with their general practitioner. Maintaining regular alcohol and drug counseling is talked about with the parents and smoking cessation programs are offered in a supportive way. I discuss agencies such as Pregnancy Help and Food Bank to provide temporary help and support for struggling families and offer to connect them to social services. Docherty, Lowry and Miles (2007) showed in their study that mothers living in poverty were disadvantaged if they were unable to access social and health services and had no family or friends to support their parenting. I can see how worry situates me to care for these families by supporting, educating and providing timely intervention to other services in the community. Miles (2007) reinforces my practice of accompanying mothers to outpatients clinics, to increase their understanding of their infants treatment by clarifying information they have received to reduce their worry.

Knowing the community in which I work connects me with other health and non health professionals to allow for relationships to grow and in this way I can see how my position of power and connection is used to advocate for the infants and families in my care (Egan, 2007). The flexibility and responsiveness of my actions towards the family helps in forming trusting relationships necessary in therapeutic relationships (Ervin, 2002; Egan) and shows my way of contributing to their health outcomes.

WORRY AND TEACHING

*The mothers would worry that the nurses in the NICU seemed to be able to get so much more milk into their baby than they ever could at home and that the baby's slept longer in the NICU than at home. What was wrong with me (mother)? For other families the demands of tube feeding, home oxygen, "*ostomy cares*", tracheal cares, getting breast feeding right and the gaining of weight was a worry for the parents and I shared that worry.*

Docherty, Miles and Holditch-Davis (2002) found in their study that mothers, especially low educational level mothers of medically fragile infants in the NICU, needed support and understanding from the nurses around them to reduce the distress associated with their worry. This is also my experience with the families in the community and my visits are frequent in the early days and lessen as the family's needs decrease. Confidence in parenting is increased by follow up NNHCN service (Cappleman, 2004) especially in the first week after discharge (Sneath, 2009).

I can see how my worry increases for an infant or family that has multiple complex needs and when I am with the family, my worry alerts me to remind the family to get spare batteries for when the breathing monitor stops working or making sure the family has enough supplies for wound cares at home. Van Manen (2002) suggests that the more I care for an infant or family, the more I worry as it keeps me in touch with them. An essential quality of the role is the sustained link between the families and the NNHCN service which is provided by home visits and phone calls. This link is the families insurance of continued care and access to health care services which assists them with ongoing and new challenges and answering their many questions. Research illustrates that parents still had concerns and unanswered questions leaving the NICU (Sneath, 2009). This correlates with my NNHCN practice as I have found parents have different readiness to learn or absorb knowledge when they are tired or stressed, and I need to be aware that I may need to be accessible to the parents when they are ready to ask questions again.

The NNHCN role teaches the mothers what to expect from their infant and is a large component of my nursing role (Cappleman, 2004). Responding to the mothers concerns about feeding and weight gain and their infant's development dominates conversations and require expert knowledge. The diversity of infants in my practice requires an eclectic view on child development that is not constrained by one theory, as other aspects of child development in relation to the family and culture they live in

may be overlooked (Drewery & Bird, 2004). Knowing the life experiences and situations of the family helps integrate the nursing knowledge with traditional frameworks of child development theory (Hartrick Doane & Varcoe, 2005) and adjustments made for prematurity or illness. This is a helpful tool in determining significant problems or challenges in the context the infant presents in my practice. It allows me to share my knowledge with the mother to reassure her or highlight the need to collaborate with the Paediatrician or visiting neuro-developmental therapists if I am concerned. My worry within this context allows me to try and situate my understanding within this mother's world; to find ways of positively supporting their health (Benner, 1994: Hartrick Doane & Varcoe; Egan, 2007). In this way health action through my clinical expertise enables early detection of changes in infants and their families that require collaboration across health settings.

WORRY AND THE HUMAN CONNECTION

Sometimes I feel I carry the load of the mothers' worries which helps them not only to be able to off load but also know they are not alone in their journey. I reflect back on occasions with mothers where they have said 'that they could not have done it without me, without all the visits and support". I can see how I build relationships with mothers and families to reduce their worry or anxiety.

When the infants are not gaining weight and they are making slow progress, Cappleman (2004) found NNHCN did not change management during the transition process as parents are finding their way and need stability in their daily routine. Understanding the families concerns and stresses helps strengthen the partnership with the family. Cheung and Hocking (2004) emphasise that being more in tune with the family's worries and concerns allows for appropriate care and support to be given to the family. This is true of my practice as I feel in tune with the parents worry, and there is an element of balanced risk taking that allows for the family and infant to grow into each other at home.

The worry I experience may also be what Lindh, Severinsson and Berg (2009) describe as my vulnerability which all nurses expose themselves to when being attentive to families. Vulnerability does not mean a weakness in this context but the courage to face unpredictability in my practice and act with determination in the best interests of the family (Lindh et al.). I have an understanding of the nutritional needs of the infant and need to marry that into the parents' reality of 'getting it all right' at home. With these families I visit daily to make small adjustments to care; it may be adjusting the frequency or volumes of feeds in a day but the pace is slow, so that the parents gain confidence and learn of their infant's capacity. Giving clear instructions on feeding regimes and helping parents identify feeding behaviours, stress cues and sleep-wake patterns reduces their stress (Reyna, Pickler & Thompson, 2006).

I can see how worry protects my nursing practice as it alerts me to act on the issues that concern me. As I am experiencing worrying I am also assessing, monitoring the infant and family's health, safety and progress whilst being present with the family. Because of my worry, action is taken. Van Manen (2002) suggests that worry is the active feature of my attentiveness in caring for a family. Trusting my autonomous practice to know what is best for each family is a union of the family's knowledge and my own; a change from problem focused care to solution finding, with the family leading their care (Hartrick Doane & Varcoe, 2005). Looking at these moments I can see how I worry less now because of my experience, knowing these infants also need time to adjust to going home. Worry is pragmatic in this context and allows my concern to identify the issues and provide helpful solutions knowing the family's situation.

Reflecting further I can see worry acts like glue and shows we are human, as it connects us to the person we are caring for (van Manen, 2002). Some families are weighed down by the effort and worry that caring for their preterm infant at home creates (Lasby, Newton & von Platen, 2004), and I feel that sense of worry. My worry defines my involvement and allows my capacity to care within a therapeutic relationship (Benner & Wrubel, 1989). 'Care as worry' is inevitable in relationships

with people that involve concern (van Manen, 2002). Bates (2007) describes her nursing worries as constant and unavoidable if you are a nurse as it plays with your emotions always present. The emotional work of nurses has been highlighted by Bolton (2000) as a necessary component of nursing to reflect commitment to caring but causes them the most anxiety. This is true of my experience as the responsibility I feel for these families is a moral-emotional connection that surfaces as worry. The significance of worrying is that it is my profoundly human phenomenon and the understanding of it, is one way in which care is experienced by me. The ordinary process of worrying contributes to wellbeing in non-pathological populations (Nichols, 2008) and the credibility of worry enacting care is part of my caring-healing knowledge of nursing (Watson, 1999).

THE THEME OF ACTIVE LISTENING

Listening is more than a social practice to establish rapport or passive process to show empathy. Listening is an active means of acquiring information and analysing the reaction to the information received (Hoppe, 2006). Active listening becomes more than hearing, as it uses all of my senses and requires accurate listening for meaning (Egan, 2007). It is about shaping my attitude to see mothers, parents or families world or point of view and risking even for a moment, giving up my beliefs to start thinking in someone else's terms. In understanding the world of another I need to be mindful that my words, thoughts and feelings need to be congruent with my body language and I need to be attentive of effective behaviour cues to reflect the quality of my presence with them (Egan). Active listening reduces the mothers' thoughts being criticised and research has shown sensitive listening can contribute to change in people as they begin to care for themselves when they feel cared for by the other person (Corey, 2009).

As soon as I entered the house I could tell something was not right, it wasn't the organised refreshing atmosphere I had been used to visiting. The look on the mother when she saw me was distressing. I said to the mother that it seemed to me she appeared upset and I asked if she felt comfortable talking about her distress. I

listened to her tell me of the abusive interaction she had with her husband and how vulnerable she felt being alone with him when he gets like this.

Active listening shows its strength in the mother having a sense of being heard by my insight into her world, and verbalising how she and her environment presents nonverbally (Davidhizar, 2004). I utilise broad openings to questions, which allow the mother to choose subjects of interest to her and lead the discussion (Shattell & Hogan, 2005). These subjects can then be discussed and focus can be directed on the areas of interest to discuss topics further (Egan, 2007). It helps the mother to identify what the issue is. I try and use open ended questions which help to provide more information, to see what the issue or problem is (Hoppe, 2006). I listen for meaning for who this mother is and what is her concern; what is she saying when she does not speak; what does her body language tell me? (Hartick Doane & Varcoe, 2005). There are situations where I need to lead and act with the intent of safety for the infant, mother and myself, not knowing where the husband may be. The ethical principles of non-maleficence and beneficence (NZNO, 2001) require me to communicate with other health and social services for protection and care. In this way active listening is respectful, helps understand the mother in her context and builds trust necessary in a therapeutic relationship to act ethically on the mothers' and infants' behalf.

I was visiting a preterm infant now four months old and her family and it was after the family felt they knew me they told me about needing her body tissues back from the hospital as they 'did not want anyone to just do it'.

I was asked by a mother to trace and retrieve body tissue samples taken from a preterm infant hospitalised three months ago in another hospital. I felt privileged the mother trusted me to do this as I know the value she places on honouring her Maori cultural practice. We talked about when the tissues were returned they would be buried in a safe place alongside baby's placenta on tribal land. The samples were returned quickly and the grandmother commented to me "now she will come right". I

remember how much I learn from family's everyday and the grandmothers comments were in relation to her grandchild functioning better now her body parts were reunited with the land; inseparable from her identity. Her smile met mine and we communicated how right this seemed; now all the whanau felt better.

In this experience, I allowed the family to identify what was of concern to them to have a meaningful health experience. The health and the healing of this Maori family are interconnected. If I had just concentrated on the weight and developmental assessment of my visit without actively listening and establishing openness for the family to discuss what was important to them, I may have missed the opportunity for the mother to communicate her whanau needs for wellness. They had waited three months before finding someone that they felt could do this for them. Competence to care for the diverse range of families I see, requires me to spend the time knowing families and in this way respect for the person, family and their culture contributes to the therapeutic relationship (Davidhizar, 2004; Hartrick Doane & Varcoe, 2005).

As I reflect on these moments I can see how my nursing has responded to develop knowledge to be with families in a relational way which involves their world and life experiences and how this impacts on their health or illness experience (Hartrick Doane & Varcoe, 2005). As my knowledge grows and my beliefs may shift, I am more aware of what I am listening for and how I am situated with families. This informs my tactful, and intuitive knowledge of knowing what to do and say as I can see it is discretionary and yet important, as it is not only what you do and say, its also how its said that conveys I care (van Manen, 2006). I can also see how active listening crosses boundaries of culture within my practice and I have general knowledge about different cultures to deliver care in a knowing, sensitive, compassionate and equitable way (Daviahizar, 2004; Hartrick Doane & Varcoe, 2005). I believe I have a different culture to all the families I visit and in this way I respect and accept difference as being unique within each family (Crawford, 2005).

It is important for the families I care for to know me as the quality of my human caring is shared with these families and shows authenticity of my presence (Benner & Wrubel, 1989; Hartrick Doane & Varcoe, 2005). In these situations the power of my language I use is how it is used (Hartrick Doane & Varcoe) and I believe in a respectful genuine caring attitude being reflected in my communication. The language that I use to the mothers and families in the home is inclusive, as I seek to employ words that the family will understand and are less medically orientated. For example in talking over a discussion one family had with a health professional about their smoking I clarified that morbidity meant illness and toxic was not meant to be perceived by the family as 'cool', but as 'not very good for them' in relation to their smoking habits. Meanings can still be conveyed in this manner and displays a willingness on my part to bridge the knowledge and cultural gap between myself and the family. Active listening connects in this way with the family as it is intentional and is an acknowledgement of the differences between myself and a family (Davidhizar, 2004; Hartrick Doane & Varcoe).

Active Listening to the stories of loss, grief, trauma or sorrow some mothers tell me, occurs when I least expect it. I encourage the mothers to share their thoughts and feelings which communicate value and respect, as the mothers are more likely to feel they have been heard when they talk more and I listen (Davidhizar, 2004).

When I talk about discharging a family, for some it's like cutting the umbilical cord that has allowed all of what they have been through to be hidden away permanently if they did not open up at that time. It all comes out their worries and fears, sorrow and grief. I hear the loss of their third trimester when the mother has had a baby born fourteen weeks early; the loss of feeling really big and pregnant. The loss of not having a normal birth process at term as the parents had planned and the stress of not knowing what was happening to their baby when they were transferred to the NICU. The loss of not being able to hold and care for their infant in the NICU as much as they wanted, even though they know there were times it was better for baby to be untouched. The loss of breastfeeding initially, and having to express

breast milk for months and then the struggle for their baby learning to feed. The loss of not having a normal post natal period. The guilt the mother feels for having all of these feelings.

I actively listen intuitively, being aware of my body language, responses verbally and non-verbally to support them telling their story. I am aware I need to remove all prior assumptions to listen fully to the mothers experience (Crawford, 2005), but mindful that in context to my theoretical viewpoint, I am looking for and listening for ways to connect with what she is saying (Hartrick Doane & Varcoe, 2005).

No one else may know what they (the mothers) have been through to get to this point. They may feel no one else may care as much or could help them. They are tired and I acknowledge how much it takes for them to tell their story.

Allowing mothers to tell their stories permits them to have a moral voice (Benner, 1994: Lindh, Severinsoon & Berg, 2009) and in this way, supports their mothering. For some mothers, being able to share their story with me helps them to find their own solutions. They come to the point that they know they want help, and active listening provides the mothers with responses from me about things they may not be aware, to increase their options (Davidhizar, 2004). Clarification of mother's feelings or experiences helps validate the mother's reality and provides me with a deeper understanding but Shattell and Hogan (2005) believe clarification is never absolute. I am aware that there are many contributing factors to one situation but my focus at this time is with the mother, hearing her experience. By listening and attending to the mothers experience I find what is meaningful to her, to lead her health care by discussing her options best suited to her and her family. Collaborative health promotion with the mother, father or family being central to their decision making process, shares the power and knowledge of the health professional and in this way self-determination is actualised (Hartrick Doane & Varcoe, 2005).

Literature shows maternal confidence is enhanced by NNHCN service as it supports their parenting and helps them problem solve (Cappleman, 2004; Hummel & Cronin, 2004; Swanson & Naber, 1997). Furthermore knowing that some mothers of preterm infants experience loss, sadness, grief, depression and guilt, months after their time in a NICU, and that relational investment with families in the community takes time, I have made nursing practice adjustments within the NNHCN role. Most families were discharged after four to six months but I often found these families benefited from staying on my caseload until at least one year of age. Within my practice, support for parents reduces their stress and enhances their confidence and knowledge in caring for their preterm infant. It may be a monthly phone call that supports their ongoing care and it is by mutual agreement when discharge occurs.

This chapter has outlined the themes of worry and active listening within my NNHCN role and bought deeper understanding of how these are intrinsic to my way of caring for the infants, families, those around me and myself. The essence of my practice is caring as it is entwined in every experience and reflective moment. Caring as worrying "may not always be pleasant or delightful" but the encounters help me understand the nature of my NNHCN (van Manen, 2002, p.11). Phenomenological reflection has allowed the way I care to be illuminated to show others my ways of being a NNHCN. Articulation of these actions have been analysed with current literature to support active listening and worry, and show new meaning for caring within the NNHCN role.

CHAPTER FOUR

This chapter brings together the findings and recommendations from the study that can be utilised for transitioning to the NNHCN role and for practice advancement in the future.

Phenomenology was utilised to inform the research project to develop a deeper understanding of the NNHCN role. Understanding the NNHCN role required a long period of reflection over personal nursing journals and experiences, to be able to

write the essence of my practice; which is undeniably caring. Interpretation for the meanings of everyday life as a NNHCN has meant I must stop and begin to shape my world by articulating my experiences. I have felt like an actor reading a manuscript for the first time as I saw new meanings in my experiences that I have not seen before. The themes of worry and active listening have been discussed and analysed with current literature to articulate meaning within my advanced nursing role as NNHCN.

Active listening has been utilised in the NNHCN role that ensures the family's needs are met and assists me to provide culturally competent care. Developing relationships through active listening is imperative within the role as I engage with many families of different cultures and backgrounds. Active listening and the role of worry within the relationships between the families and the NNHCN has highlighted some of my invisible moments in nursing practice. These experiences have been illustrated to show the journey of practice advancement in the role over the last six years and the advanced nursing nature of the role.

One significant finding was the lack of literature around nurses and their worry. Literature around worry was often found in other nursing studies not directly focusing on worry but mentioning it as a feeling of moral distress (Zomorodi & Foley, 2009), or the concerns of a nurse regarding moral strength (Lindh, Severinsson & Berg, 2009). Wood (2008) showed worry was not new to nurses and Svensson and Fridlund (2008) looked at nurse's increase in experience relating to an increase in responsibility which is expressed by their worry.

The dominant theme of worry does not espouse itself in nursing literature because it may be seen as a weakness, and not an attribute needed in the scope of advanced nursing. In my practice, I have identified 'worry' around transitioning to a new nursing role. Worry increases because of the increase in responsibility. I have identified how worry connects me with families because of the increased work of caring for their preterm infants and because of health inequities. Worry allows me to situate myself

in the family's world and navigate through the complexities to allow them to lead their health care. Worry actions knowledge to be sought, gained and used so I have the confidence to practice autonomously. Worry keeps me attentive to the changing world of families and the communities they live in. Worry also protects my practice by seeking knowledge and guidance from trusted colleagues. The feeling of worry is because I care.

The first recommendation is for professional supervision to support the transition to an advanced nursing practice role. It will also provide peer support and stress relief alongside professional accountability and knowledge development.

The second recommendation is for recruitment purposes. The applicant must have a willingness to develop active listening to deliver culturally competent care. The applicant must not only have extensive neonatal experience, but have extensive breast feeding knowledge and either be a qualified International Board Certified Lactation Consultant or have a willingness to obtain this qualification. This is necessary when discharging infants home that have not fully established breast feeding prior to discharge.

The third recommendation is that the newly appointed NNHCN needs a mentoring period so they feel supported in the transition and an introduction to the many health and community services is given. New responsibility takes time to adjust to and feel confident in practicing within an extended scope of practice.

The fourth recommendation is that educational opportunities to advance the role in areas of child and family health and protection be required. Knowledge provides security to practice autonomously.

The fifth recommendation is to consider two NNHCN to provide ongoing collegial support and backup when annual leave is taken and to support professional supervision.

CONCLUSION

NNHCN developed to meet the needs of a vulnerable group of infants and their family discharged home from the NICU and is a unique role that sits alone from other nursing. As the role increased and developed to meet the increasing needs of this population the specialised skills of the NNHCN were expanded. The autonomous nature of the role within families homes means this nursing has been hidden and by describing and interpreting my lived experiences as NNHCN it is hoped to reveal the essence of the role. The caring nature of my nursing enjoys the relational partnership between the parents and myself to help families transition from the hospital to the home. Worry and active listening create a caring consciousness in my practice and illustrate the value in taking the time to develop relationships to care for the infant, family, other health and non health professionals and myself.

Many of the benefits of journaling my nursing practice were apparent to me before my research, but I can see how my journal provided me with a holistic view of my nursing, as I was able to travel from the beginning experiences to the present within my NNHCN role. The multiple levels of reflection with each reading of the text have drawn deeper insights and meaning into the themes of worry and active listening in my daily work. The caring actions that have been highlighted to evolve the role is the essence of my practice that meets the needs of the infant, family and myself. These new insights have developed my research skills and I have a greater respect for the time consuming and intimate nature of phenomenology which informed this study.

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