University of Alberta

Registered Nurses' Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care

by

Jennifer Orton

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Dedication

This thesis is lovingly dedicated to the babies who have passed away, the families who have endured this difficult journey and the healthcare professionals who have walked alongside each step of the way.

Sometimes love is for a moment.
Sometimes love is for a lifetime.
Sometimes a moment is a lifetime.
Anonymous

Abstract

In this qualitative study, methods adapted from the field of ecologic restoration were used to explore seven registered nurses' perceptions of one Neonatal Intensive Care Unit (NICU) as a place to provide neonatal palliative and end of life care. The study was conducted in two phases. In phase one, data was collected during a unit photo walkabout. A photo-elicitation focus group followed. Transcribed data were coded for themes related to physical spaces, practices and culture that influenced care, and current resources available to support care. Key findings from this study included: participants faced challenges providing palliative and end of life care in a busy NICU, there is a need for continued education in palliative and end of life care principles and the importance of providing grief and bereavement support to families.This improved understanding is a step towards setting goals aimed at improving care for dying neonates and their families.

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It would not have been possible to write this thesis without the help and support of the people in my life who mean the most to me.

My husband Kevin has never let me down. From travelling with me to and from Edmonton to facilitating “Boy’s weekends” so that I had time to work, Kevin has been there for me throughout the entirety of this journey. My baby Finn and my ‘Big Boy’ Parker literally started school before they were born. They fill our home with giggles and joy. Each day I count my blessings.

I must also acknowledge my mother and father. I believe that my professional interests are a blend of my parents own passions. My mother’s strict attention to detail and compassionate approach made her a wonderful palliative care nurse. I believe that my father’s interest in science and technology could easily have been adapted to neonatology had he not discovered Chemical Engineering first. Their support and drive through the years has most certainly shaped me into the person I am today.

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Table of Contents

List of Tables

Chapter One - Introduction

Technological advances have increased the possibility of sustaining life and improving long term outcomes for both premature infants and infants born with previously untreatable conditions (Moro et al., 2006). While this highly technological environment contributes to the survival of these babies, there are babies in the NICU who do not survive despite undergoing life-saving treatment (Kain, 2006). The concept that infants are not supposed to die, that they are the embodiment of new life and hope makes their death feel like a failure (Leuthner & Pierucci, 2001). For this reason, transitioning from care that is focused on cure to care that is focused on palliation and comfort measures can be challenging in the NICU; it "goes against both our physiological instinct and medical training" (p. 45).

In this study I explored registered nurses perceptions of palliative and end of life care in one NICU. Data was collected using methodology and protocols adapted from previous work (Safer Systems Research Program – http://www.nursing.ualberta.ca/SaferSystems). Restoration ecology focuses on studying and repairing systems that have been changed or broken down over time (Society for Ecological Restoration International Science & Policy Working Group, 2004). A powerful research method used in restoration is the collection and study of photographs to identify, assess, and track changes within an environment (Marck, Higgs,Vieira, & Hegadoren, 2008). This study uses photographs and descriptions of various aspects of the NICU that registered nurses deemed to have an impact on the delivery of palliative and end of life care. The purpose of this study was to better understand the potential barriers and supports that exist to the delivery of this highly specialized care.

Statement of the Problem

The underlying etiologies for neonatal mortality are vast, but can be associated with prematurity, genetic syndromes or lethal malformations, severe perinatal depression, and sepsis. Once a guarded prognosis has been made, medical technologies aimed to maintain the life of the neonate are implemented. These strategies include the administration of pharmacotherapeutics, escalating cardiorespiratory support as well as the consultation of specialists. A baby's death, however, may be inevitable despite the best efforts of nurses and the entire interdisciplinary team. When this inevitability comes to fruition, palliative and end of life care are often provided in the same neonatal intensive care setting as curative care. A screen placed around the bed of a terminally ill infant, or curtains pulled between bed-spaces are often substitutes for the privacy and comforts of a home environment, a hospice or a space dedicated for palliative care.

The irony of a baby dying in the same environment that they received life-saving care is difficult for everyone. Shifting focus to provide palliative care with the same vigor and attention to detail can be a difficult task for the interdisciplinary team, and especially for nurses who are providing the direct care (Kain, 2006). In addition, it is difficult for grieving parents to share the same physical space with families whose babies are improving, growing, and progressing toward discharge (Cavaliere, 2007). The challenges to creating an environment that supports palliative care provision within the NICU, where aggressive technological care is the norm, are considerable (Gale & Brooks, 2006). The intent to relocate the dying baby and family to a more serene location is difficult to realize. This thesis research is designed to consider how nurses might work with this space to meet the unique needs of this vulnerable population and their families.

Significance

A perspective to examine the NICU, in terms of its ability to meet the holistic needs of dying infants and their families, might be from a purely ecological standpoint. Organisms require different environmental conditions during different stages of their lifecycle. This idea could be applied to the comprehensive examination of the "life-cycle" of a baby who is born dying from the perspective of nurses.

Nurses with other neonatal interdisciplinary team members determine when intensive therapies no longer offer hope for a cure or recovery, and they then change the focus of care toward optimizing quality of life (National Association of Neonatal Nurses, 2010). Taking an in depth look at the NICU itself as having an impact on the way palliative care is delivered may serve to raise awareness amongst the NICU team of how they could potentially enhance the quality of palliative and end of life care delivered to terminally ill neonates and their families. It is important to understand the perspective of registered nurses who care for infants with life limiting conditions. Looking through their lens and listening to their stories will serve to identify both the supports and barriers that exist to the provision of this highly important work at the end of life. Identifying preexisting supports to palliative and end of life care in the NICU may be the first step to improving care. Equally, barriers to the provision of palliative care in the NICU need to be addressed and overcome so that neonatal nurses' embrace palliative care with the same enthusiasm and dexterity as they embrace curative measures (Kain, 2006).

Purpose and Research Question

The purpose of this study is to explore nurses' perceptions and descriptions of one NICU as a place to provide palliative and end of life care. The research question guiding the study is: How do registered nurses working in a level three neonatal intensive care nursery perceive and describe their experience of the NICU as a place for providing palliative and end of life care?

Chapter Two - Review of the Literature

This review of the literature addresses topics that are central to supporting the purpose of this study as well as the chosen methodology. These include: (1) the underlying definitions, goals and guiding principles of neonatal palliative care and end of life care; (2) the role registered nurses play in the provision of neonatal palliative and end of life care; (3) the barriers and supports to neonatal palliative and end of life care provision; (4) the NICU as a place to provide palliative and end of life care; (5) ethical considerations in neonatal palliative and end of life care; (6) restorative thinking in health care, and (7) how restorative thinking might apply to palliative care provision in the NICU.

Underlying Definitions, Goals and Principles

Before exploring barriers and supports to providing neonatal palliative and end of life care, it is important to define terms. Clarifying these concepts elucidates challenges faced by practitioners in moving from care that is cure orientated to care that is focused on quality of life at the end of life. An understanding of this transition has the potential to improve outcomes for dying infants, their families and the NICU team (Lacefield Lewis, 2012).

Neonatal Palliative Care. With the rapid advancements in neonatology the NICU can be a place of joy at one moment and a place of profound distress at the next moment. Embracing a neonatal palliative care philosophy means redefining care by shifting from curative goals to goals that maximize the quality of life of both the dying infant and their family. Quality of life can be defined as meaningful and valuable experiences and the capacity to have such experiences

(Ferris et al., 2002). Creation of space that supports palliative care provision begins with evaluating everything from the physical place where we practice to the language we use to describe the care we are providing. Changing from a curative approach to a palliative approach does not mean withdrawing care or treatment. Goals of care are instead directed towards enhancing comfort rather than modifying the disease process (Catlin & Carter, 2002). Employment of palliative care philosophies and guidelines shift the focus of patient care away from futile medicine to a more comprehensive and integrated approach aimed at lessening patient suffering (Gutierrez, 2005).

Providing care for infants with life-limiting diagnoses is challenging for both families and professionals. Catlin and Carter (2002) described palliative care for newborns as holistic and extensive care for an infant who is not going to ‘get better’. Successful neonatal palliative care is provided when the interdisciplinary team directs their efforts towards comfort care for the infant and assistance with end of life decision-making and bereavement support for families (Romesberg, 2007). Comfort care can be defined as non-curative interventions that address the physical, emotional, social, cultural, and spiritual needs of the neonate and their family. Palliative care is an entire milieu of care to prevent and relieve infant suffering and improve the conditions of the infant’s living and dying (Catlin & Carter, 2002). Neonatal palliative care is a planned intervention. It is facilitated by trained interdisciplinary staff members that support, with dignity, the infant’s remaining time. The team also supports the family’s experience with empathy and culturally sensitive respect (Catlin & Carter, 2002). This support needs to be made available from the time of diagnosis through the provision of bereavement care.

A statement by pediatric representatives of the American Academy of Hospice and Palliative Medicine (Himelstein et al., 2001) provides a comprehensive description of palliative care, its purpose and goals:

> Palliative medicine is the art and science of child-focused, family-oriented, relationship-centered medical care aimed at enhancing quality of life and minimizing suffering. Palliative care is a model of caring for patients and their families who suffer from life-threatening illnesses. Palliative care focuses on alleviating pain and other symptoms of suffering but also attends to the spiritual, emotional, psychosocial and physical needs of both the patients and the family. Palliative care aims to improve the quality of life of seriously ill children and their families throughout the disease experience and recognizes that helping patients achieve a peaceful death is one of the most important and rewarding services that a healthcare professional can provide. Palliative care completes the developmental circle of competent, compassionate care from birth to death, neither hastening nor prolonging death. Inherent in this definition is the possibility of delivering palliative care in partnership with curative care for children with life-limiting illness, or for children who may not die (pp. 1-2).

Neonatal palliative care is considered in three situations: 1) neonates at the limit of viability, 2) neonates with congenital anomalies considered to be lethal, and, 3) neonates with serious medical or surgical conditions not responding to maximal therapy or for those in which continued treatment may prolong suffering (Bhatia, 2006). Standards of neonatal palliative care have been published (Catlin & Carter, 2002; Carter & Bhatia, 2001). These guidelines include specialized sedation and pain management, provision of warmth, skin-to-skin physical contact (Stringer, Shaw, & Savani, 2004), the creation of memories, and the assigning of meaning to the experience (Carter, 2004). Encouraging parents to become active participants in the care of their dying infant is a way to promote social comfort for both infants and parents. (Walden, Sudia-Robinson, Turnage Carrier, 2001).

Neonatal End of Life Care. Embedded within the scope of palliative care provision is end of life care. End Of Life care focuses on managing the end stages of the medical condition while preparing the family and all involved for the death of the infant. The goal of care is to assure the infant dies free from pain or distress and with dignity (Moro et al., 2006). Often healthcare providers confuse palliative care with end of life care. It is important to clarify that palliative care measures can be initiated in conjunction with interventions aimed at cure. Palliative interventions may initially be combined with cure-oriented care and then intensify when curative interventions are no longer beneficial or appropriate (Catlin & Carter, 2002). Compassionate extubation plays a significant role within the scope of end of life care. Compassionate extubation is the withdrawal of ventilatory life support in the home, a hospice, or a ‘homelike’ setting within the hospital, surrounded by loved ones. The infant is transported while still on life support to the extubation site and the entire procedure is then personalized according to the family's wishes. The family is prepared for what is likely to occur once the endotracheal tube has been removed. The intent of this is to allow the family to plan how they would like to spend this remaining time with their infant (Stokowski, 2005).

End of life care decisions are unique when caring for an infant. Distinctive strategies are often required to help parents through the difficult end of life decision-making process. Facilitation of choice and collaborative decision-making are of paramount importance. It is important for caregivers to recognize, during these difficult times, that parental attachment and parental decision making begin far before the birth of a child. Parental attachment often begins with conception, and the serious illness or death of a child is perhaps the most stressful event imaginable (Himelstein, Hilden, Bolt & Weissman, 2004). Palliative care and end of life decision making has the potential to help parents regain some parental autonomy along with ensuring that the child dies a dignified death. Parents require support so that they do not feel that they alone carry the burden of decision making (Chiswick, 2001).

End of life care planning may take place over several meetings with the interdisciplinary team to ensure that the goals of care are clearly outlined and comprehensively achieved. Families are not expected to embark on this journey alone and thus each step of the way is supported by an educated and experienced team.

Educating parents about death is an important part of end of life care provision. Parents are prepared for the changes in their infant's physical appearance and behavior and potential timelines for the infant's death. Parents are prepared for the possibility that their baby may not die within a few hours of ceasing ventilatory and pharmacologic support. Under these circumstances the care plan is continually adapted and revised to enhance the quality of life of the dying newborn as well to address the ongoing dynamic needs of the family. When the death is protracted, parents are supported in their ability to 'parent' their dying newborn. They are provided with the opportunity to take the infant's temperature, change their diaper, do kangaroo care and nuzzle if appropriate. Parents are encouraged to take pictures and document their child's life in whatever way the desire. Mementoes such as a lock of hair, footprints, handprints, diaper, or measuring tape are collected and held for parents. It may be up to the healthcare professional to be creative and advocate for the creation of memories, as parents may be too distraught to do so at this time. Parents are encouraged to voice concerns surrounding the comfort of their dying infant, and these concerns warrant the same amount of attention as pain that is measured by pain scales and vital signs (Romesberg, 2007).

Family meetings with the interdisciplinary team include discussions surrounding the desire for a postmortem examination or any additional postmortem diagnostic testing that may reveal the infant's cause of death. Families are informed that on occasional circumstances in which the proximate medical condition may be known (organ system failure), but the underlying etiology may be unclear (Chiswick, 2001). At this time parents are also assisted in making plans for memorial services and burial. If appropriate a religious or spiritual community member is also consulted.

The Nursing Role in Neonatal Palliative and End of Life Care

Neonatal nurses play an essential role in the provision of palliative, end of life care (National Association of Neonatal Nurses, 2010). They are a liaison between the family and the rest of the interdisciplinary team. Neonatal palliative nursing embodies care provided to both the dying infant and their family, including grandparents, parents, siblings, other significant relatives and friends. "Palliative and end of life care for infants and their families are an integral component of neonatal care, and neonatal nurses should be trained and participate in providing services involved in this essential care" (National Association of Neonatal Nurses, 2010). Nurses have an opportunity to forge a relationship with parents that fosters trust and mutual respect. This relationship can play a significant role in recognizing and assessing the significance of the loss for the family and may form the basis for the development of additional interventions to facilitate the grieving process.

Nurses who care for dying newborns and infants require special skills and knowledge to competently provide palliative and end of life care. Lack of education in end of life care can limit the nurse's ability to provide beneficent and comprehensive care (Romesberg, 2007).

A hermeneutic phenomenology of healthcare providers' lived experience with infant deaths in newborn intensive care was conducted in 2006 (Epstein, 2008). This study used semi-structured interviews to explore the experiences of eleven physicians and twenty-one nurses. The primary finding from this study was the common overall obligation of both nurses and physicians to create the best possible experience for parents. Despite the commonalities, this study recognized that the two disciplines approached end of life care from unique vantage points. For physicians, focus was placed on the decision-making while nurses focused on the care provision itself. Further qualitative exploration of the unique perspective of nurses is needed to add strength to current literature.

The Barriers and Supports to Neonatal Palliative and End of Life Care Provision

Barriers and supports to neonatal palliative and end of life care have been described in the literature. The barriers may prevent dying neonates from receiving the care they require (Moro et al., 2006). A 2009 study published by Kain, Gardner and Yates examined nurses' attitudes towards neonatal palliative care, using an instrument entitled the Neonatal Palliative Care Attitude Scale (NiPCAS). A sample of 645 nurses completed and returned the NiPCAS to researchers. Five facilitators to care were identified: 1) Support for a palliative care model of care by the health care team; 2) a team that can express values, opinions and beliefs; 3) the availability of counseling support for caregivers; 4) the presences of at least some clinical guidelines to support practice, and 5) the support of parents by the healthcare team. Barriers to care that were identified included: 1) inadequate staffing to support palliative care practice; 2) a physical environment that is not conducive to palliative care practice and 3) technological imperatives and parental demands. A qualitative study is needed to explore these facilitators and barriers and ideally the study would invite nurses to provide solutions to facilitate neonatal palliative and end of life care.

The NICU as a Place to Provide Palliative and End of Life Care

One of the barriers to quality palliative and end of life care provision identified in the literature is the NICU environment itself. In a review article examining the challenges and solutions to dying in an acute hospital setting, Al-Quarainy, Collis and Feuer (2009) described the differences between the hospital and hospice setting. They described the hospital as being impersonal, unfamiliar and not designed for end of life care. They described most wards as being busy, noisy and lacking space for privacy.

The optimal neonatal intensive care environment is one that supports each infant's individualized developmental needs. This list includes need for light and developmentally appropriate sound and handling. However, for neonatal palliative and end of life care to be deemed successful the neonatal intensive care environment must be perceived as more than a physical space. It is a culture and a collective interdisciplinary attitude that values the importance of this delicate work. Reports, from both parents and health care professionals (Catlin & Carter, 2002), identify that the location of palliative care provision is not as important as the "mind set" of the persons involved in end of life care. The attitude of the staff, their desire to care for dying newborns and their families, their training in observation, support, and symptom management, as well as their knowledge of how to apply a bereavement protocol are more important than the physical location of the patient (Catlin & Carter, 2002). That being said, examining the practice area itself is crucial to better understand the physical space and how it influences the "mind set" of practitioners.

Restorative Thinking in Healthcare

"Ecological restoration is an intentional activity that initiates or accelerates the recovery of an ecosystem with respect to its health, integrity and sustainability" (Society for Ecological Restoration International Science & Policy Working Group, 2004). Arguing that health professionals can learn useful ways to "think like a system" from studying the interdisciplinary field of restoration science, Marck (2005) theorizes that "today's healthcare systems are technologically complex, increasingly vulnerable living systems in urgent need of ecological repair" (p. 104). In 2006, Marck and colleagues developed a framework of research and restoration (Marck, Higgs, Edwards & Molzahn) Embodied within this framework is a summary of four core elements of an adaptive health system: 1) place ethic, 2) citizen science, 3) engaged practice, and 4) adaptive learning and growth. Place ethic is "enacted in the way we treat each other and the places we share" (p. 44). Citizen scientists are those who "work with communities, governing bodies, and others to collaboratively study and adaptively manage nested cycles of systems growth, decline, and renewal" (p. 44). Engaged practices "are critical to good restoration because they embody the ethics and science of restorative thinking into the kinds of rituals, practices, and habits of being that enable organizations, teams, and individual practitioners to deliver safer care" (p. 44). Finally, adaptive learning and growth refers to "restorative cycles of study and practice characterized by learning throughout rather than at the end of projects and natural experiments alike and at all levels of the system, including: individual, team, organization and system levels" (p. 44).

Marck and colleagues subsequently adapted principles and field methods from restoration to study medication safety issues identified by practitioners and managers of an acute inpatient medical ward (Marck et al, 2006). These researchers used a suite of participatory, practitioner-led photographic research methods to engage practitioners to critically re-examine practices within their environment that support or hinder medication safety. This research approach flows from a fundamental conviction that the power of discovery rests with the collective capacity of communities to identify and work on those problems which matter most to them (Marck et al, 2008; Marck et al, 2006). Similar restorative photographic research methods have since been used to study infection prevention and control (Backman et al, under review), nature-based health promotion (Hansen-Ketchum, in press; Hansen-Ketchum et al, 2009), medication safety on a surgical unit (Domm, 2010), medication safety in a Brazilian emergency department (Raduenz et al, under review) and a Brazilian intensive care unit (Gimenes, in progress) and most recently, medication safety in home care (Marck et al, 2010). However, no researcher to date has attempted to use these kinds of participatory visual methods to explore the complex environment of neonatal intensive care.

Applying Restorative Thinking to the Study of Palliative and End of Life Care Provision in the NICU

Commitment, compassion and knowledge are all essential components of good palliative and end of life care. Nurses benefit from specialized tools that allow for the delivery of individualized care. To do this, nurses must be supported by a place and culture that is equally committed to the delivery of individualized, comprehensive care. Technology has enabled amazing advancements in neonatal care provision and these advancements have served to enhance the quality of life for many neonates and their families. At the same time, the availability of these technological advancements can prolong suffering and protract inevitable death for infants. In such cases nurses are often so busy managing equipment and medications that they are physically, emotionally and mentally not available to provide the holistic nursing care that is fundamental to palliative and end of life care practice.

In her dissertation study of registered nurses' work in acute care, Marck observed that "lessons of restoration suggest that to counter the technological practices that presently plague many acute care environments, nurses need to develop an ecological literacy that first reinterprets and then reconstructs our relations with a technological world" (2000, p. 63). Using restorative methods of visual inquiry to study neonatal palliative and end of life care has the potential to engage neonatal nurses to assess their practices as individuals and as a community. It may serve to empower them to examine the physical space in which they work as well as their relationships with this place and with each other. In simple terms, restoration involves amongst other activities removing or modifying disturbances and threats to ecosystem health, thereby enabling ecological processes to bring about an independent recovery (Society for Ecological Restoration International Science & Policy Working Group, 2004). By taking part in identifying specific barriers and supports to the provision of neonatal palliative and end of life care, neonatal nurses may find that they are able to enhance the care environment for these infants and their families.

Chapter Three − Methods

Setting

This study took place in Calgary, Alberta, Canada. The participants were recruited from the Foothills Medical Center NICU, a level three nursery that accommodates acutely ill infants requiring ventilation or high risk monitoring.

Sample/Recruitment and Data Collection

Individuals are selected to participate in qualitative research based on their firsthand experience with a culture, social process, or phenomenon of interest. Participants are selected to describe an experience in which they have participated (Streubert Speziale & Rinaldi Carpenter, 2007). In this study, purposive sampling was used to select key informants who had a minimum of one experience providing neonatal palliative or end of life care. Based on previous research using restorative research methods to study different but also complex phenomenon in health care such as infection control (Backman et al, under review), nature-based health promotion (Hansen-Ketchum, in press), and medication safety (Marck et al, 2010; Marck et al, 2006), it was expected that a total sample of two to four nurses for photographic walkabouts and six to eight nurses for a focus group discussion would be required.

Permission to recruit and hold onsite photo walkabouts and an onsite focus group was obtained by providing a copy of the research proposal to the nursing manager of the Foothills Medical Center NICU as well as to the Foothills neonatology site leader (Appendix A-Letters of Support).

On September 21,2011 an e-mail (Appendix B-Recruitment Materials) was sent to the NICU nursing staff, inviting them to participate in this study. They were provided with information letters for both the photo walkabout and the focus group. They were also provided with a copy of the demographic data questionnaire so that they would be familiar with the information I was seeking before the onset of the study. Later that week recruitment notices (Appendix B-Recruitment Materials) were posted in the staff lounge, near staff lockers and by staff mailboxes, as another means to communicate the need for volunteers.

Within two weeks of the initial e-mail fourteen nurses expressed interest in participating. Only one nurse stated that she would prefer to participate only in the focus group. Participants were selected to participate based on their experience as well as their availability, which was determined through email and telephone conversation. It was important that participants selected had a wide range of experiences to best reflect the diversity that exists among the NICU staff. Only registered nurses working in the neonatal intensive care and who had provided palliative or end of life care to a terminally ill infant, at least one time, were invited to participate in the study. Participants were selected for the two phases of research, the photo walk about and a focus group.

Demographic Data of Participants

Demographic data was collected in a brief questionnaire (Appendix C-Consent Materials) attached to the confirmation letter for photo walkabout participants as well as focus group participants. Participants were asked to disclose the following information; years of nursing experience and approximate number of experiences providing neonatal palliative or end of life care. If the demographic questionnaire was not returned in advance of the scheduled photo walkabout, the information was gathered through confidential email conversation. Additional copies of this demographic questionnaire were available to participants on arrival to the focus group meeting if they were not filled out in advance. To ensure confidentiality of participants, the questionnaires were coded (i.e., Participant A, Participant B, Participant C) so that the demographic data could be linked to the participants' comments during data analysis. Through transcription the digital voice recordings were 'cleaned' and each participant's name was replaced by their assigned code.

Phase One: Photo Walkabouts

In this proposed study, qualitative methods adapted from previous work in restoration and healthcare were used to generate data that comprehensively and collaboratively addressed the research question. Images are a rich source of data for understanding the culture and ecology of a place and for representing our knowledge of that social world. Image-based research has a long history in cultural anthropology and sociology as well as the natural sciences (Hansen-Ketchum & Myrick, 2008). In Phase One, I used a data collection protocol that had been previously used in my co-supervisor's research to conduct two digitally recorded photo walkabouts of the NICU. A sample size of two registered nurses for each of the two photographic walkabouts was a minimally disruptive presence in the unit.

Participants who were selected to participate in each photo walkabout were asked to meet me at the main NICU desk thirty minutes before the our walkabout.

We then met in a nearby office to review the information letter and consent materials together. Each participant provided informed consent for their individual narrations to be audio-taped and transcribed. Before each participant signed the consent document I ensured that they had no unanswered questions and assured them that if they had questions after we were finished they could contact me. Each participant was provided a copy of the signed consent materials for their personal records.

Various aspects of the NICU were photographed, using a digital camera, for the purpose of eliciting discussion during the focus group session. It was important to capture imagery that the registered nurses felt had an impact on the delivery of neonatal palliative and end of life care. This included patient care areas as well as nursing and medical stations.

No identifiable pictures of patients or families were taken at any point during the photo walkabout. The importance of maintaining patient and staff confidentiality was emphasized before the commencement of each walkabout. Participants were asked to dress in a professional manner and have their staff identification visible. Infection prevention strategies and developmental care philosophies were followed throughout the photo walkabout. In other words, no environmental 'footprint' was left behind from our journey through the NICU.

The unit photo walkabouts each took place in the evening as there is a different feel on the unit during the day than there is in the evening. During the day there are more medical team members, nursing management, auxiliary staff and more families present. There also tends to be more procedures and patient transfers occurring. I did not want our walkabout to get in the way of the daily activities in the unit, nor did I want our access to the unit to be affected by availability of the space. I was sure that a walkabout during the day would not have yielded more data than our evening walkabouts. One of the participants worked a twelve-hour day shift on the day of our walkabout, and found this timing to be convenient.

Before each photo walkabout I checked in with the unit clerk to get a feel for what was taking place on the unit and gather information about the unoccupied bed spaces on the unit. It was essential that no photographs of patients, families or staff be taken on either walkabout.

As we traveled together on each photo walkabout, a semi-structured interview guide was used to ask nurse participants to narrate their perceptions of the NICU. These questions aimed to be open-ended, and inviting so that each study participant had the opportunity to share their own perceptions of the NICU. Specific areas within the unit that elicited rich discussion were identified and photographed together (photo narration).

Narratives contain messages and particular experiences felt to be meaningful. At the same time, they are open to multiple interpretations and new meanings (Alvsvag, 2008). They are easy to remember and can easily provide us with both knowledge and insight (Alvsvag, 2008). Digital recording of these photo narrations served to capture the practitioners' stories and relate how specific attributes of this NICU were perceived to influence palliative and end of life care.

Throughout and after each photo walkabout field notes were recorded. These field notes described the path that we took through the unit and a description of the locations where each nurse's 'story' unfolded. I also tried to capture any moments in our journey that caused the study participants to pause for reflection, or elicited 'nonverbal' responses. The 'atmosphere' in the unit at the time of each photo walkabout was also noted.

The photo walkabout images and transcripts were iteratively analyzed using a preexisting data analysis protocol developed by my supervisor for studies that are underway in medication safety (Marck et al, in progress) and infection control (Marck et al, in progress). Images and transcripts were reviewed separately and then together in a stepwise progression over the course of several days. This analysis served to develop preliminary themes that were then used to guide questions asked during the photo elicitation focus group. The photographs taken during our walkabouts visually captured the various places or images in the NICU that held meaning for each participant. Images deemed to hold the most significance were used during the focus group in the manner previously discussed.

Phase Two: Photo Elicitation Focus Group

Using images to elicit other data, such as cultural or personal meaning, is a common form of image-based research (Harper, 2002). Photo elicitation is essentially the process of using the review of photographs during a research interview or focus group to elicit further dialogue with participants on the phenomena under investigation. The underlying premise is that we respond differently to symbols or imagery than we would to words alone (Harper, 2002). Images evoke deeper elements of human consciousness than words (Harper, 2002). In Phase Two, a digitally recorded photo elicitation focus group was conducted to reflect on and examine the existing supports and barriers to palliative and end of life care in the NICU.

A focus group is defined as a semi-structured group session, moderated by a group leader and held in an informal setting, with the purpose of collecting information on a designated topic (Carey, 1994). This methodology is particularly suited to the collection of qualitative data because it has the advantages of being inexpensive, flexible, stimulating, cumulative, elaborative, and assistive in information recall, and of producing rich data (Streubert Speziale & Rinaldi Carpenter, 2007).

It was my hope that the focus group would elicit enhanced detail and stories from the participants about how the NICU supports or impairs the provision of palliative and end of life care. Together we discussed how the physical space (sights, sounds, lighting) and the socio-cultural space together has an impact on this type of care delivery. The moderator's guide (Appendix D- Focus Group Moderators Guide) and the photographic power point presentation, created after the photo walkabout, were used to facilitate this exploration.

A meeting of focus group participants took place in room 780 at the Foothills Medical Center. Although six to eight registered nurses (who met the inclusion criteria) were recruited to participate in this phase of the study, only four participants could attend. The nurses who participated in the photo walkabout phase were not excluded from participating in the focus group. Ten to fourteen photographs from the photo walkabouts were projected, onto a large screen, in a power point presentation format. Careful consideration was made when selecting each photograph. The photographs selected were ones that I had the most questions about; photos that I believed would generate discussion and photos that I felt illustrated important issues related to neonatal palliative and end of life care.

The photographs were displayed one at a time and each one was assigned a number and a simple title. Each photograph was accompanied by one or two quotations provided by photo walkabout participants. These quotations added additional meaning to the photograph. To generate discussion, the presentation was formatted in such a way that less sensitive photographs were displayed first. Photographs deemed to be more sensitive were reserved for the midpoint of discussion, when each participant had had sufficient time to determine what they wished to share with the group. Towards the end of the focus group, images that illustrated support for good palliative care practice were presented to the group for discussion. It was my intent to highlight the fact that the registered nurses who participated in this study had found innovative ways to enhance quality of life at the end of life. At the end of the focus group meeting participants were informed about what would happen to the digital recording and the next stages of the research process. They were again provided with my contact information should they have had any questions or concerns**.**

An additional source of data were my personal field notes. These field notes captured my reflections on participant group dynamics including ‘nonverbal’ communication (silent agreement, obvious body language, indications of group mood, irony or contradictory statements) (Kruegar, 1994). A field note reporting form (Appendix E-Field Note Reporting Form) was used after the focus group to record my observations.

Following a similar approach to data analysis in Phase Two as for Phase One, focus group transcripts and images were analyzed in a stepwise progression. After all the data was transcribed, data components from this study were organized. These components included: images captured during each photo walkabout, a clean transcript from the two photo walkabouts and field notes taken after each photo walkabout, the focus group power point, a clean focus group transcript, and the focus group field notes. In the order they were presented, each photograph used in the power point presentation was reviewed along with the focus group transcript discussion. Preliminary codes, comments and/or theoretical memos related to each image were documented in the ‘Notes’ section of the power-point. Next the photo walkabout transcripts were reviewed. Each one was read first as a whole text and then each transcript was reviewed line by line, noting anything that captured my attention. Preliminary codes, comments and/or theoretical memos about specific places and quotes in the transcript were inserted in the right margin of the online transcript. Preliminary codes from the focus group power point and the photo walkabout transcripts were then compared.

A numbering system beginning with #1 was used to group preliminary codes that I deemed to be the same or related, from either the photo walkabout power point or the photo walkabout transcript. I continued to number across both sets of analyses until divergent codes emerged. At this point further numbers were assigned to divergent codes. The next step was to compare the theoretical memos made on analysis from the photo walkabout power point to those made on the photo walkabout transcript. Areas of convergence or divergence within the memos for these sets of preliminary analyses were noted and then entered into the Data Analysis Table (Appendix F) beside the relevant photo(s) and or transcript lines.

A lettering system was used, beginning with 'A' to choose and label preliminary themes. Each code was classified under the appropriate theme. The last step was to look for themes common across several photographs. Photos that contain the same themes were documented on a separate page. My supervisor and co-supervisor independently reviewed the data, to discuss emerging preliminary themes and areas of convergence and divergence in the data.

Rigour

Member checking was used to enhance the credibility of the study findings. Credibility describes an operational technique that supports the rigour of the work and includes activities that increase the probability that credible findings are generated. One particular activity to establish credibility is to see whether the study participants recognize the findings to be true to their experiences (Yonge & Stewin, 1988). The act of returning to the participants to see whether they recognize the findings is often referred to as member checking. During both the photo walkabout and focus group feedback from the participants was obtained to ensure that I had captured their story. Structured interjections made during the data collection activities assisted in verifying and solidifying the information that participants provided. Participants were asked, through the process of obtaining consent, if they could be contacted during data analysis to confirm the credibility of the study findings.

During the study, I maintained a researcher's journal to record my personal biases, assumptions and reflections about the research. Explication of personal beliefs serves to enhance awareness of the potential judgments that may occur during data collection and analysis based on personal beliefs rather than on the actual data (Streubert Speziale & Rinaldi Carpenter, 2007). Journaling my own thoughts, feelings and perceptions throughout the entirety of this research journey helped me to collect and analyze the data with more self-awareness and rigour. This journal was kept private and will not be a source of data for the completed project. Aspects of this journal were discussed with my supervisor or committee to facilitate my ability to do the research and grow as a researcher.

Ethical Considerations

This research proposal received ethical approval from the Health Research Ethics Board at the University of Alberta, as well as the Conjoint Health Research Ethics Board, at the University of Calgary (Appendix G-Ethics Approvals).

Operational approval was received from the Foothills Medical Center Neonatology site leader and from the NICU nursing unit manager (Appendix A-Letters of Support).

To ensure free and informed consent, study participants were provided with information about the study's purpose and design. Each participant was provided with a Photo Walkabout Information Letter and Consent form and a Focus Group Information Letter and Consent form (Appendix C-Consent Materials) before commencement of their participation. These information letters served to orient participants to the study protocol and outline the ethical implications and protection of privacy provisions. Participants were also informed of the potential benefits to be gained from the study and the study results. They were encouraged to ask questions to achieve comprehensive understanding of the research study. They were informed that there would be no adverse consequences to not participating in the study and the process of obtaining informed consent was free from coercion. Study participants were also informed that they could withdraw from the study at any time.

Concerning confidentiality, study participants were informed how the data would be handled and who would have access to the data. At the beginning of each photo walkabout and focus group sessions study participants were asked to state their name and role so that the transcriptionist could distinguish voices. To assure confidentiality, transcribed materials were free of any personal identifying information and data did not contain any names or other identifying information.

Anonymity of the study participants was upheld throughout the examination and dissemination of the study findings. As complete confidentiality and anonymity could not be maintained through either the photographic walkabouts or focus group participation, participants were reminded of the importance of maintaining the confidence of the group. All collected data, including password protected computerized data were stored in a locked filing cabinet when not in use. All electronic digital recordings and transcripts were kept on a password protected computer drive.

I also considered the benefits and risks to participants in this study. The intent of this study is to explore the NICU as a place to provide palliative and end of life care. Study participants may benefit from knowing that comprehensive and compassionate neonatal palliative care is important to dying infants, their families and the entire interdisciplinary team. The study participants gained insight into the potential barriers and supports to this type of care provision that exist. Though not one of my specific research goals of this study, it was my hope that the nurses who participated in the study would have gained knowledge and enlightenment to enhance the care they provide as well as their confidence in providing this care. Results of this study will be disseminated and may potentially lead to the recognition that further research and development in the area of neonatal palliative and end of life care provision is necessary.

There are also benefits to participants in that the research procedures can provide an opportunity to be involved in decision making processes (Race, Hotch

& Parker, 1994). Being valued as experts, and working collaboratively with researchers (Goss & Leinbach 1996) can be empowering. If a group works well together, trust can develop and the group may explore solutions to a particular problem as a unit (Kitzinger, 1995) rather than as individuals.

To minimize risks to the participants, an environment of trust that fostered open communication was integrated throughout this entire process. Study participants were encouraged to express concerns or anxieties through open 'nonjudgmental' communication. It was made clear to each study participant that they could exit this study at any time, should they feel uncomfortable, without consequence or adverse effect.

Dissemination Plan

My intent is to disseminate the findings of this study locally and nationally. My thesis will be available to interested readers who access the University of Alberta Library as well as the online database Proquest. I intend have the results of this study published in a neonatal nursing journal. Study findings will be shared with the nursing and medical staff at the Foothills Hospital NICU. I will also present findings to the NICU staff during an education day, when the opportunity and invitation arise. Volunteers who were not selected to participate were sent an email of appreciation and will be invited to attend a future presentation to the unit. The purpose of this meeting with staff and management will be to share my findings and exchange ideas on potential improvements.

Chapter Four - Results

Description of Participants

Seven nurses participated in this study (See Table 1). The participants were all women whose nursing experience ranged from two to over twenty years. Each participant had provided palliative or end of life care at least one time prior to participating in this study, several with extensive experiences in this regard.

Participant Identification n=7	Years of Neonatal Nursing Experience	Number of Experiences Providing Neonatal Palliative or EOL Care	Focus Group (FG) or NICU Photo Walkabout (PW-1 or PW-2)
A	2-5	6-15	PW-1
B	6-10	6-15	PW-1
C & G	6-10	0-5	PW-2 & FG
D	Over 20	Over 50	PW-2
E	2-5	0-5	FG
F	Over 20	16-25	FG
H	11-15	16-25	FG

Table 1: Participant Demographic Data

Two volunteers were selected for each of the two photo walkabouts and six volunteers were selected to participate in the focus group. However, once the date of the focus group neared, there were two late cancellations and one participant had a scheduling conflict that could not be resolved. Participant C/G had expressed interest in participating in both the photo walkabout and the focus group, so this person was contacted at the last minute to achieve a sample size of four for the focus group.

Examination of Places within the NICU for Palliative and End of Life Care

For the purposes of this study I conceptualized barriers as the aspects of the NICU that study participants perceived to be inhibiting, discouraging, impeding and/or preventing them from providing optimal neonatal palliative or end of life care. These barriers included dimensions within the physical space such as equipment, sounds and lighting or as socio-cultural barriers such as the beliefs, values, attitudes and education of the NICU interdisciplinary team members. In contrast, supports were defined as aspects of the NICU environment that study participants described as enhancing, assisting and/or helping them to provide optimal neonatal palliative or end of life care. These supports included dimensions within the physical space such as equipment, sounds and lighting or as socio-cultural supports such as the beliefs, values, attitudes and education of the NICU interdisciplinary team members.

The perceived barriers and supports, to palliative and end of life care as described by the study participants related to specific locations within the NICU. These locations included “The Quiet Room”, two Care by Parent rooms, and spaces within the NICU itself.

Quiet Room. The quiet room is located in the NICU and is accessed from the hallway that extends beyond the initial entrance. The quiet room is a small room furnished with two love-seats, a small table, and a phone. In a bed crisis this room is converted to a patient care space. It is directly adjacent to an area of the unit allocated to patient care and on the other side, a supply storage area. It is situated in the same hallway is the respiratory blood-gas lab. The image

(PW1_P4_QuietRoomDoor_26-10-11) was captured from the hallway access point. During each photo walkabout this room was occupied by charge nurses receiving taped report. For this reason we were unable to gain access and photograph the interior space of this room. Utilization of this room for palliative and end of life care was discussed during the first photo walkabout and the Focus Group. Of note, during one of our photo walkabout discussions, we could hear the charge nurses' taped report from the common hallway that leads to the unit clerk desk.

PW1_P4_QuietRoomDoor_26-10-11

Barriers to Palliative and End of Life Care. Participants on the first photo walkabout articulated concerns around the fact that this room is a multipurpose room. Participant A explained:

> For charge nurses that's where we go to give report...a lot of staff, on night shifts, sleep in there...again it's right by the blood gas room so if you

> are a family in there and...not everyone realises when families are in there because again, it’s not designated as a, a palliative care room. So a lot of staff can be walking...in good spirits so you can hear people laughing and talking.

Participant B also commented that this room used to be thought of as the quiet room and then was converted to accommodate patient beds. She also commented on the physical space being dark, lacking windows and that it was difficult to maintain privacy because sound easily carried to and from the common hallway. Participant B also stated that the furniture was uncomfortable and that she did not feel it to be an ideal place to comfort your baby. She raised concerns about this room being small and not ideal for large families particularly when a baby was still requiring mechanical ventilation.

Similar concerns about this room were echoed during the focus group. Participant F stated:

> There’s probably more than four or five people in there, and at times there’s double that...it does get very warm in the room...there’s no water available, close at hand for if somebody needed a drink or felt faint or anything like that....there is a phone in there, or there was, so...that was useful, because I know a family did talk with other family.

Supports for Palliative and End of Life Care. After an exploration of what nurses would describe as barriers to palliative and end of life care provision in this room, I asked participants if there had been a time that they had used this room and had a positive experience with a family. I also asked them how they might have helped to facilitate this positive experience. Participant A was able to shared an intimate story:

> I have done end of life care in there...with a pastor and...a mom and her other child...you can dim the room....we had the baby very comfortable and very soft blankets...there was no equipment, so it was just myself, the pastor, mom and children".

Participant B used an example of how this room's access from the hallway could be used advantageously. She spoke about a time she was able to use this room to bring the extended family together at the time of the baby's death, when it would have otherwise been impossible. She stated:

> The grandparents all wanted to see them but it was back when...that illness was going around in Mexico and because they were in Mexico they weren't allowed on the unit. So I was able to let them see their granddaughter because we were able to sneak them in...to that room.

Participant A brought a different perspective forward on how this access was better for extended families; allowing them to see their loved ones without exposing them to a busy NICU. She stated:

> It is an advantage too that...you're already dealing with how sick your child, grandchild, niece, nephew...is...so it can really overwhelm you if you actually, physically have to step on to...a NICU to see...big, healthy

> babies that moms and dads are holding, or really sick babies in the isolettes....it’s a very overwhelming place on a good day.

These feeling were echoed during the focus group discussion.

One concern that was raised during our focus group discussion was the difficulty that participants had encountered transporting a dying baby to the quiet room, for palliative or end of life care. The concern was that at times, transport from a remote location on the unit to this room, sometimes felt like a “circus” or garnished unwanted attention from staff or other families, particularly when the baby was still being ventilated.

Care by Parent Rooms. Two Care by Parent rooms are located on the left hand side of the hall that runs parallel to the NICU past the main desk. These rooms are located adjacent to the locked doors leading to the staff room, and directly across from a staff locker room that is also used to process radiologic images. These two rooms are typically reserved for families who are close to discharge and able to provide care to their baby with the nearby support of nursing and medicine. For babies with an extremely guarded prognosis, families are permitted to use these rooms in case an emergency arises. These rooms also provide short stay accommodation for families who have travelled in from out of town in the middle of the night.

PW1_P5_CareByParentRoom_26-10-11

Barriers to Palliative and End of Life Care. Participants on each photo walkabout and in the focus group all commented on the size of these rooms as being a barrier to palliative and end of life care to families. In one particular experience Participant A found it challenging to accommodate the needs of a family whose culture supported the inclusion of a large extended family. She described this time:

> We initially brought the baby in on the ventilator, so we had to ask all the family members to leave...just so that we could get things set up...to take the baby off the ventilator before they could come back in...and even then, it’s just hard with so many people crowded into a tiny room.

In addition to these rooms being small, Participant B also felt that these rooms had a very sterile atmosphere reflective of being in hospital. She states; “this is hospital linen with plastic pillows and plastic chairs and...it’s not like a big comfy chair...to be able to...cuddle with your child and the...blinds are broken and they break”. She also described the bed as being small, feeling as though this may be a barrier to encouraging families to lay together with their dying baby.

On each photo walkabout and during the focus group, participants felt as though the location of these rooms often acted as a barrier to the provision of good care. Participant A states:

> One of the particular rooms is right across from one of the staff rooms so you can hear staff coming and going and again, all the staff doesn’t always recognize this room as, you know, a baby’s in here for end of life care....you do hear people talking and laughing.

The fact that these rooms are also used for families close to discharge was acknowledged as an issue for Participant E who was caring for a family whose baby had passed away while the room next door was occupied by a healthy baby, ready for discharge.

> There was a baby next door [laughingly] that was very loud and crying and I can only imagine how difficult that would be to hear...maybe that was blocked out to them, but of course for me, I picked it up.

Supports for Palliative and End of Life Care. Participants all agreed that these rooms offer families a privacy that cannot always be facilitated in the Quiet Room or on the unit. Participants D also acknowledged that: “families can move in and out...without having to walk into the unit and...be bombarded by all the noise and...it just allows...privacy”.

Participant A articulated a beautiful story of a time she provided end of life care for a family in one of these rooms. She stated:

> We were able to bring the baby in and the parents actually went to bed with the baby, got right into bed, blankets, laid down and were actually asleep with their baby when their baby passed...it was so peaceful and they voiced how special the moment was to them, to be able to do that with their baby.

All participants noted that these rooms have windows and allow for natural lighting during the day. They also acknowledged the importance of having a private bathroom and a place for families to keep their personal belongings and bring in their own food. Participant B again stated the importance of these rooms being away from the locked unit, the fact that families can come and go as they please and that they are not expected to perform a two minute scrub before each entry into these rooms.

On the Unit. The following two images are of bed number 23. This was an unoccupied spot on the unit during photo walkabout number one that was setup for a potential admission. In unit 55 beds, deemed to be a level 3 bed, are always single occupancy. Hanging curtains may be pulled to provide families with privacy or when invasive procedures are being performed at the bedside.

PW1_P11_NICUBed23_26-10-11

This image is also of bed number 23. It captures the nursing workspace, used for computer and paper charting, as well as preparing for infant care. Families will also sometimes share this workspace, when journaling or photographing their newborns. Families and staff are not permitted to bring in bags or purses. For infection prevention these items are locked outside of the unit. Each bedside has its own cart, stocked with NICU essential supplies. In the image below this cart is located underneath the shelf on the right side of the image.

PW1_P12_NICUBed23Workspace_26-10-11

Next is an image of bed 25, also unoccupied. Note that the Giraffe™ isolette was not at this bedside during photo walkabout number two. This image provided perspective on the space limitations of each bed-space.

PW2_P11_NICUBed25_4-11-11

Barriers to Palliative and End of Life Care. When providing palliative and end of life care in the unit many of the participants articulated how difficult it was to maintain the privacy of the bereaved families as well as create an environment of tranquility for them. Participant A stated:

> We just draw the curtain so you hear everything that's going on around you. You hear all the monitors, the alarms, other people talking...I've been in situations where we've been doing end of life care and there's...a mom

> and a baby breastfeeding right next door....that’s really difficult for parents that are saying goodbye, to hear another baby crying right beside.

Participant B echoed similar concerns for these families:

> I just feel bad for the parents when they’re at the bedside and they’re like sobbing and everyone can hear them in their grief and their crying and not everyone wants to...have people hear that or anything...it’s just, it’s not private, at all. Like everyone would know what was going on.

During the focus group Participant E described a time when a baby was coding, and a joint decision was made with the family to stop intervention. She described this situation as being somewhat chaotic and lacking privacy for the family: “It’s very cold and impersonal and back to the whole, like, it’s a freak show, right? Everybody’s looking to see what’s going on because there’s all these doctors there”.

Participant D commented that the actual size of the bed space has proven challenging when providing this type of care to a dying baby and their family. She recalled a time that the decision to withdraw treatment had been made, but the family wanted to spend time with the baby while life support was still in place:

> The bed spaces do feel, at times, a little small,...if you want to facilitate parents holding...the space is limited. You have to really kind of sneak around and hope to goodness you’ll be able to eke yourself between the counter and the chair to get to those IV pumps because you probably are

> still giving some kind of fluids at some point...it can be a little tight and I'm just...wanting to be respectful of space for baby and family and yet still be able to do my job that's required of me at the moment.

The physical location of the family, in relation to the dynamics of the unit, was also found to impact care provision. Participant F acknowledged the how difficult it can be to create a quiet, dimly lit, tranquil space when the bed adjacent is being used to admit a new baby.

Supports for Palliative and End of Life Care. Facilitating the creation of an environment supportive of neonatal palliative care often depended on the bedside nurse enlisting the cooperation of all members of the interdisciplinary team on the unit. Participant C described such a process:

> It is such a loud type of area, but I find that the staff is really quite cognizant of the fact, and we try our best, that even though it is, the pod has four bed spaces in it, if there is one bed space that, you know, there is palliative care taking place, I do find that people are that much faster to answer alarms...to quiet it down a little bit.

She went on to state:

> I do find you usually have enough assistance from your co-workers and like I said, whether it's the docs or the RTs or other nurses, people are usually very respectful of the fact that end of life care is taking place.

Lighting and noise came up quite frequently as features of the environment that could be manipulated to facilitate the creation of such a space.

In positive experiences that were shared by participants, they spoke of how they were able to dim the lights and create a calm space within the context of a busy unit. Participant F described her experience with creating such as space:

> We were...doing palliative care at a bedside and we were able to bring...one chair in where the parents could do skin to skin with their infant for quite a while before the whole process of...extubating....we were able to turn the lights down and make the room quite calm and there were other infants and...I think the parents that did come in were very respectful because they could see that we were trying to keep everything toned down as well, because that's all we really had available.

Of note, through a commitment to creating this safe space and though almost non-verbal communication, the bedside nurse was able to influence unit behavior, not only the other staff, but also the other families visiting.

Examination of Practices and Culture Deemed to be a Barrier to Neonatal Palliative and End of Life Care

Participants described unit practices and culture that served as barriers to neonatal palliative and end of life care. These practices did not pertain directly to the locations of care provision. Inclusive in this discussion are how accessibility to the NICU and certain aspects of preparing for and providing neonatal palliative and end of life care served as potential barriers to care provision.

Accessibility to the NICU. One theme deemed to be a potential barrier to palliative and end or life care for families, that emerged from the unit photo walkabouts was that of difficult accessibility to the unit for families. There were four sub-themes: 1) restricted entry, 2) ‘the long walk’, 3) a place for families to wait, and 4) preparing to enter the NICU.

The NICU at the Foothills hospital is a locked unit. This restricted entry plays a part in ensuring the safety and confidentiality of the babies and their families. The multiple doors allow for a checkpoint at the unit clerk’s desk, at which visitors are educated on the principles of infection prevention before entering the unit. All visitors must pass through the same doors and ‘checkpoints’ regardless of their circumstance. Study participants recognized the difficulty bereaved families faced entering the unit at the same time as families whose baby’s prognosis was less uncertain.

Restricted Entry. This photo showed the double doors that mark the initial entrance to the Foothills NICU – Unit 55 once you have gotten off of the elevators on the fifth floor. Behind these doors is a long hallway that leads to scrub sinks and the unit clerk desk. They are not locked during daytime hours. At night, visitors ring a bell to gain access, to the unit, from the unit clerk.

PW1_P1_NICUentrance_26-10-11

The next photo showed the second set of double doors that mark the entrance to the NICU from the unit clerk desk. They are locked doors that can be opened with either a button, operated primarily by the unit clerk, or by a preprogrammed staff ID card.

PW1_P10_NICUentrance2_26-10-11

Participants agreed that although the doors expressing restricted entry are necessary to protect the privacy of the patients and families in the unit, the doors may be a source of intimidation for families who were entering the unit to be with their baby who was receiving palliative care. One of the participants expressed that the 'Do Not Enter' sign was not welcoming, even "conflictual" and something like this would not be seen in a hospice setting. Her concern for bereaved families was that this restricted access implied that they would not feel welcome.

'The Long Walk'. On the other side of the first set of double doors, in the image labeled PW1_P1_NICUentrance_26-10-11, staff and visitors travel down this hallway towards the main unit clerk desk.

PW2_P1_Hallway_4-11-11

Participants acknowledged that this was an exceedingly long walk for families whose babies were dying. Participant D:

> Just imagining myself, it in some ways seems like a very long tunnel...and if you knew you were coming...because you knew your child was going to pass...I could see it just being, feeling different than if you were just coming in to visit. I kind of sense, you know, this tunnel, this long tunnel.

Participant F wondered how many of the families of infants who were receiving palliative care in the NICU setting actually thought about the walk or were they so focussed on their own grief that they would not notice the distance they were walking.

During the focus group the 'Quiet Room' door was identified by study participants as a potential special or alternate entrance into the unit for bereaved families. This door is on the left side of the hallway in image PW2_P1_Hallway_4-11-11. Participant G identified the quiet room door as an "early access" to the unit, an entrance that families could use that provided them with a place to do the required "hand scrub" without having to go by the busy front desk and sink areas. There is a sink in the quiet room. This entrance would also allow family members of babies receiving palliative care to enter the unit without having to be exposed to other babies and other families. The possibility of having a staff member meet families at the front doors was also discussed during the focus group as a means to overcome the barrier of unit accessibility.

The difficultly in this is that you cannot always anticipate when a family will arrive.

A Place for Bereaved Families to Wait. The following is an image of the parent lounge. This lounge is located across from the unit clerk and is not locked to visitors during the day or at night. This is a place for families to wait during shift change, bedside rounds that do not pertain to their baby and during invasive procedures. Bedside visitors are limited to two people at a time and one of those people must be a parent. This lounge also provides large families a place to wait.

PW2_P3_ParentLounge2_4-11-11

Participants stated that this lounge was often the only place extended families could stay while the parents of the baby are in the unit. Participant D articulated that at times this area is "very quiet and conducive to a sense of peace". In her experiences, providing palliative and end of life care to families, she felt that this parent lounge could be a safe space for families to wait or take a break from the unit. While the parent lounge was a safe place for families to wait or take a break from the unit, it was not ideal for parents whose babies were dying. Her concern was for the privacy and care of bereaved families during those busy days, when the lounge is filled with families and perhaps young children. Many of these families are celebrating the birth of a baby with a good prognosis, admitted for any number of reasons. Participant D thought about what it would be like for bereaved families: "how do you sit in a room with children playing and children laughing and you're there and people want to ask you questions and how do you answer the question?" Participant D: "placing myself in that position...you know what, this area was set up for and it certainly wasn't set up for...end of life families".

During the focus group Participant F expressed that ideally there would be a separate place for families who are in crisis or who are experiencing loss to gather and console each other. A place they could share their grief in a more private setting.

Preparing to Enter the NICU. The next image is that of the main desk. This desk is staffed by a unit clerk twenty-four hours a day and seven days a week. At any given time a neonatologist, nurse practitioner or fellow may also be using this space to complete paperwork, look at x-rays or perform telephone consultations. Visitors and staff perform a two minute scrub at these sinks before entering the unit. At certain times of the day, shift change for example, this can be a very busy space. At other times, usually on night shift, this space can be quite quiet.

PW2_P10_SinksMainDesk_4-11-11

Participant D described this space as being “really, really crazy and busy and noisy and confusing at certain times of the day”. Her concerns around this phenomenon were for the family and how this timing could affect or exacerbate their level of stress entering the unit.

Participants agreed that although scrubbing at the sinks for two minutes was absolutely necessary for infection prevention, they questioned whether it was imperative for families who would be holding their baby for the last time. They spoke about how difficult it must be to not only scrub in, but also to wait for the doors to be unlocked. Participant C: “a two minute scrub is absolutely necessary, but it’s probably going to be the longest two minutes of your...you know...while you’re waiting to go in and get to your baby”. Another photo walkabout and focus group participant wondered if it would help families to have a place for them to go that was away from the unit; a place where they would not be exposed to other families or staff at shift change. During the focus group, participants spoke about the possibility of having the bedside RN or another staff member meet the family in the sink area and support them on their final journey into the unit.

Preparing for and Providing Neonatal Palliative and End of Life Care

The following themes emerged as challenges participants have faced preparing for and providing neonatal palliative and end of life care in this unit. There were four sub-themes: 1) palliative care education for staff, 2) bath at the end of life, 3) communicating to the unit staff there has been a death, and, 4) adequate staffing to meet needs of the bereaved family.

Palliative Care Education for Staff. One potential barrier to the provision of palliative and end of life care identified by study participants was lack of education as nurses. Participants agreed that they had received minimal education during their unit orientation. Participant F expressed that even though she has had many experiences with end of life care, she felt as though she could always use a refresher course and expressed how valuable it would be to have an “expert practitioner” available to consult and assist staff members in this regard. Participant D on her experience providing mentorship to novice practitioners:

> I think what they are experiencing is fear...of the unknown. They...don’t know what to expect, just as I didn’t know what to expect. So

> it's...helping guide them through and...help them help the parents, help them help the baby and be a resource,...just be there as a support person for them.

Participants all agreed that they had each turned to an experienced colleague to assist them and ensure that all the tasks had been completed when providing end of life care. Participant F expressed that she has had challenges in the past anticipating the individual needs of the families in her care, particularly different cultural needs.

Bath at the End of Life. One of the unit practices was that of bathing the baby after death. Traditionally it was the beside nurse who gave this bath. Depending on the situation some families do the bath, but it is always up to the nurse to provide the family with the materials and help orchestrate this potentially meaningful event. Below is an image of the stainless steel basin used in this unit for bathing all babies.

PW2_P9_WashBasin_4-11-11

Discussion about the wash basin and bath emerged during the second photo walkabout and both participants reflected on their own experiences bathing babies who had died. Participant C reflected: “it’s kind of a reverent time...you just can kind of continue on with treating...that body, that person with the dignity that you would have...it’s a time to be spent in reverence, almost, of that baby”. She also stated that when families were not present for the bath, it was a time for her to “process...everything that happened” and “just be with that little baby”. She described this time together as a “blessing”.

What emerged as being a barrier was the actual equipment used for the bath. Participant C described the basin as “very utilitarian-looking” a “very sterile-looking object,..very hospital, like something you would put like, discarded sponges into or other kind of bio medical”. Participant D also reflected on the importance of the bath, how it should be gentle and how this time held meaning and “may have been the one and only bath, tub bath that they (the baby) ever had”. Participant D also raised concerns over the equipment used and commented that the towels were “crappy”.

Communicating to the Unit Staff That There Has Been a Death. One challenge participants described during each photo walkabout was that of communicating to other staff that there had been a death in the NICU and that a bereaved family was present. This theme emerged during the first photo walkabout. The image below is that of a sign that is placed on the care by parent room door when in use by parents and family members of a baby who has died.

PW1_P6_SignOnCbPRoom_26-10-11

Below is an image of the sign that may be placed at the bedside of a palliative baby. Of note, participant D brought this sign to our attention, while participant C had never seen it used and did not know where it is typically stored on the unit. To best capture the image, we placed in on the curtain of bedside number 25.

PW2_P12_GentlePresenceSign_4-11-11

The challenges for participants surround communicating and were first identified during photo walkabout number one when Participant B recalled a time when one of the care by parent rooms was being used for end of life care. The noise of voices and laughter from oncoming staff at shift change easily carried across the hall and into the room of the family. Participant A identified the challenges associated with subtle communication, not only to oncoming/outgoing nursing staff, but also to the other hospital employees who frequently access this hallway. Participant B: "we have cleaning staff, we have all kinds of staff that are roaming around the halls, so um, it would be pretty much constant policing to make sure that it was quiet".

During this discussion Participant A acknowledged the use of the "PLEASE DO NOT DISTURB SIGN" (PW1_P6_SignOnCbPRoom_26-10-11) during these situations as not having an impact in terms of communicating the necessity of a quiet environment. There was a feeling that staff become complacent to this signage, because it is also used when families use these rooms prior to discharge. Participant A acknowledged the need for a unique sign or the ability to communicate to staff that there has been a death before reaching this area of the unit. She questioned whether a sign on the door would be seen by staff coming to their lockers, leading me to believe that such a sign might just become 'wall paper'.

During the second photo walkabout challenges around communicating the need for privacy for bereaved families, were presented from a different perspective. Participant C relayed that when end of life care takes place in the unit, there had been times when too many people became involved, and expressed concerns that their curiosity about death might be a barrier to care provision. She stated:

> I think neonatal care has come to a point where we're not having as many deaths as their used to be...which is a positive thing, of course, but it lends to staff that are very fearful of the experience...or curious because that's human nature....

She went on to tell the story of a baby who passed away unexpectedly:

> I really wished that people would just back off, even though it was, yes it was a sudden, unexpected, horrific thing happening to this baby...it's really not the time or place, especially when you have family coming in or out, in and out on a regular basis....if I was that mother and knew that all the staff members were stopping by to see their baby...I don't know how that would resonate with me. I don't think that would make me feel very good.

The challenges she faced during this particular situation aligned with the theme of communicating the need for privacy. The challenge was that the staff needed to grieve the loss of this baby, while she tried to accomplish the actual tasks of end of life care.

> I welcomed the fact that people wanted to come...but there was, there was really no policing...it's a hard thing to do when you're juggling care of the

> baby and you know, you're curtained off and you don't know who's approaching.

Participant C spoke of another experience in which she acted in a supportive role to the nurse providing end of life care to a term baby who had succumbed to perinatal depression. This nurse had confided in her the frustrations she felt when staff, trying to be helpful, took over much of the nursing care. To me this story spoke to the importance of this care provision, not just for the family but also for the care provider. "I remember the bedside nurse expressing to me later on how frustrated she was at how other staff members had come in and literally taken the care away from her". Again Participant C wondered whether this unwanted help was driven by people being "drawn to an event" or being curious about death and care at the end of life. For myself I could not help but wonder if this was an issue resolved with improved communication or was it an issue resolved by improved education.

When I presented this issue at the focus group, participants shared similar experiences of needing to communicate the need for a quiet. Participant F relayed that when end of life care takes place in the unit this task is often delegated to another staff member. She stated:

> You basically end up having to find somebody that's sort of your guard, that'll watch the area, keep an eye open for you, know what's happening, you know, behind the curtain and sort of be your buffer if people are coming or walking or wanting to go through.

Adequate Staffing to Meet Needs of the Bereaved Family. During the first photo walkabout the issue of allocating nursing assignments presented when participants were discussing the logistics of caring for a palliative baby or a bereaved family within the NICU at busy times of the day. I noted the participant's nonverbal communication that suggested their hesitation to express their thoughts and options about staffing to meet needs of the bereaved family. Participants glanced at each other with raised eyebrows and a somewhat tense posture ensued.

Participant B described how she felt managing the care of the bereaved families while trying to adequately meet the needs of the other baby in her care. Her frustrations were both as the bedside nurse as well as being in charge and having to create and support such an assignment. She stated:

> We will singly assign them, and then at crunch time it's like, "Well, we're short staffed, so, this is, this is the deal." So I find it really unfortunate because I've had a lot of...bad experiences where...care of the other baby (who has passed away)...the death care,... the after care, the bathing and the pictures have been significantly delayed because the nurse has other responsibilities.

Participant H expressed her frustrations around having a two baby assignment or anticipating a new admission when providing end of life care. She felt as though she was unable to meet needs of either baby or family under these circumstances. She expressed feelings of being rushed or pressured to complete end of life care because there may be another baby coming in who would be assigned to her care. The group agreed that this was a common phenomenon and that there was rarely, if ever, time for them to either process what had happened or seek emotional support from their peers after completing the tasks associated with end of life care.

Examination of Resources Available to Support the Provision of Neonatal Palliative and End of Life Care

The following is a discussion of findings related to the resources available in the NICU that supported palliative and end of life care. The resources included; 1) the Ronald MacDonald House® Let's Do Lunch Program, 2) streamlined paperwork, 3) creation of memories for bereaved families, 4) photography, and 5) care of the caregiver.

The Ronald MacDonald House® Let's Do Lunch Program. This is a picture of the fridge, located in the parent lounge, featuring posters about the Ronald MacDonald House® Let's Do Lunch Program. This fridge is stocked with complimentary drinks, snacks such as cookies and fruit as well as sandwiches. Families are often made aware of this program when they are first admitted to the NICU.

PW2_P4_RMHLunchProgram_4-11-11

Participants on the second photo walkabout acknowledged the value of this program for all families in the NICU. Participant D stated that:

> The hallway is a very long walk and the coffee shop is even a much longer walk when you don't want to be away from your baby and...food is a comfort in whatever situation you have and it's a bit of a distraction and so having this fridge here, I think is a wonderful thing.

Streamlined Paperwork. Proving palliative and end of life care can be a challenging enough nursing assignment without having to be concerned or overwhelmed with the paperwork associated with a neonatal death. Participant B described her experiences with the current paper charting system:

> Sometimes if you haven't done the paperwork for a while, it can be a little intimidating, because there's a lot to it. But I think they've now...streamlined it a bit more and there's more information available on what you need to do and when and who does what and everything's kind of colour coordinated.

She also stated that in her experience, there had always been someone available to help with this task.

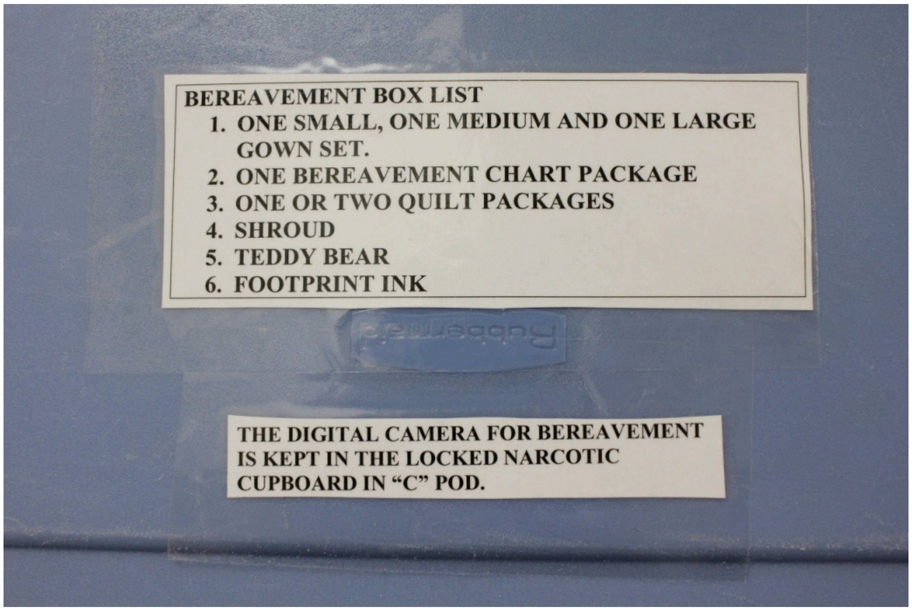
Creation of Memories for Bereaved Families. In this discussion bereavement denotes the sense of grief and loss experienced when someone close to you dies. The creation of tangible memories for bereaved families is a component of bereavement care. PW2_P8_BereavementSupplyStorage_4-11-11 and PW1_P9_BereavementSupplyCupboard2_26-10-11 are images of the bereavement supply cupboard. Packages containing gender specific linens, knitted blankets, knitted hats are stored here. A memory box containing personal items, a journal with a small teddy bear is gifted to each bereaved family. These items can also be found in this storage location.

PW2_P8_BereavementSupplyStorage_4-11-11

PW1_P9_BereavementSupplyCupboard2_26-10-11

In image PW1_P9_BereavementSupplyCupboard2_26-10-11, you will note that there is a plastic tote, labeled Bereavement Box. This box is an extension of the cupboard and in it you will find newborn gown sets, more quilt packages, small teddy bears and footprint ink and embossing materials.

PW2_P6_BereavementBucket_4-11-11



PW2_P7_BereavementBucket2_4-11-11

Participants acknowledged the importance of creating tangible memories and acknowledged that the linens and knits available helped to create a feeling of warmth and safety. Participant A stated:

> I try to go out of my way to always make sure the baby's in the softest blanket we can find and looks warm and snugly, not just in like a stark

> white blanket...it makes the parents, I think, feel that their baby's warm and safe and at peace.

During both photo walkabouts participants acknowledged in the recent years certain cupboards containing blankets and hand painted memory boxes had been locked. At this point I asked participants if they have had any difficulty accessing the key to these locked drawers and none of them had any issues with access.

Participants seemed quite content with the way these cupboards were organized and labeled. They felt that, for the most part, necessary supplies were all kept together in one location. During the focus group Participant F acknowledged that, for her, the time spent gathering supplies was a time she spent thinking about the hours ahead and the process she would be going through.

Photography. Encapsulated within the creation of memories at the end of life, is the use of photography. This supportive care measure was discussed briefly during the second photo walkabout with Participants C and D. Recently a service entitled "Now I Lay Me Down to Sleep©", comprised of volunteer professional photographers had become available to bereaved families to facilitate the creation of tangible memories. Participant D described her experience working with this resource:

> I remember one baby where we...took pictures after she had passed and we tried to make things look as, as nice as we possibly could and you just don't really know, but...the feedback we got from the mom was that they

> were just the most beautiful pictures that she had ever seen...that really, really made us feel really good.

Participant C had not used the "Now I Lay Me Down to Sleep©" program before, but had taken a pregnancy and infant loss seminar through the health region. She expressed how this program emphasized the importance of taking good pictures, the role that proper positioning can have and how capturing small details, such as hands and feet, can mean a great deal to bereaved families in the future. Both participants acknowledged that pictures may not be appropriate for every bereaved family and that this aspect of care provision always needs to be individualized.

Care of the Caregiver. It was obvious to me throughout this experience, how committed each participant was to not only providing the best care possible, but also relaying how supportive they were of each other during these difficult times. Participant A stated:

> Most people are so compassionate on the unit. They want to just help you any way they can, with pictures, baths...footprints, taking around the card and the definitely, there's always someone to help you with the paperwork, if you need a refresher on it.

We went on to discuss that nursing staff will often support each other by ensuring adequate breaks are allocated, time away from the unit is available and even "hugs" when necessary. During the focus group Participant F echoed a similar support and placed emphasis on the supportive role a more experienced staff member can have.

> I think you do heavily use your…senior people that maybe have done it, or, or somebody that has had, maybe, the last palliative baby and you kind of access them. I think together we work good as a team and help each other out...and try and support each other so that we can make it, you know, as comfortable for everyone as possible.

During the second photo walkabout participants spoke about the importance that debriefings can play in minimizing the moral distress nurses can feel when care is deemed futile and ethics are challenged. Participant C:

> I've always appreciated when they do make debriefings available. I feel like it doesn't happen often enough but it, when it does, it's um, it's a huge asset to the people that were there and um, just to get a better sense of kind of the whole event.

Participant D recalled a case she described as being "incredibly hard on the nurses". Despite debriefings both prior to and after the death of this baby, she felt as though many nurses were still "haunted" by this experience. She described the role of nursing in end of life care as having an impact not only on the family of the baby who has died but also on the caregiver:

> You're participating in, in the end of life. You're not an outside participant and it will affect you and it may affect what you do in the future and you can't let it eat, eat away at you, haunt you.

At this point I asked Participants C and D what strategies they had employed in the past to care for themselves and each other during these difficult times. Participant D recalled times that, as a charge nurse, she has tried to "gather people together" to "make sure everybody was okay" and assess how people were coping. She went on to suggest that at times this informal debriefing may start on the unit and carry on to "de-stress" offsite. I also asked if they had accessed any of the resources made available to them through the health region, and neither participant had.

Chapter Five - Discussion

The following chapter serves to reflect on the study methodology as well as discusses the substantive findings of this study, the implications for clinical practice, the limitations of this study as well as the opportunities that exist for future research within the field of neonatal palliative and end of life care.

Methodological Reflection

As a novice researcher I found that conducting a unit photo walkabout was an excellent way to elicit rich data from study participants about their personal experiences providing palliative and end of life care in the NICU. My misgivings about using this research method in a critical care area were not realized. Limiting the number of persons on the photo walk about to two contributed to my strong sense that we were not a disruptive presence in the unit. I was able to effectively facilitate each photo walkabout, through a busy NICU with little to no disruption to the staff or families while generating rich data on a sensitive topic. I concluded that the methodology was an excellent way for me to understand and empathize with the stories each practitioner was sharing. I was physically taken on a journey with participants back to the places of their individual experiences with families of babies who received palliative and end of life care in the NICU setting. During the walkabout there was time for participants to reflect on and share their experiences in a private and intimate way, again partly made possible by doing the walkabout as a small group. Throughout each journey I tried to see palliative and end of life care through the eyes of the study participants. We stopped to examine pertinent and relative aspects of the physical space that had perhaps gone unnoticed before. The participants had time to listen to the sounds of the unit and touch textures within the unit with a different focus.

Whether it was my own inexperience as a researcher or because of the personal and complex nature of this subject matter, I found the focus group methodology to be a greater challenge for data generation. From the start, I had more difficulty with recruitment and commitment of study participants. I also felt that the lack of intimacy, in a group setting, prevented participants from sharing more personal experiences. This could easily be attributed to my lack of experience with moderating and facilitating groups. Despite the challenges I faced as a researcher, insight was gleaned from this discussion. While the focus group perhaps lacked the intimacy required to explore participants' personal experiences with the subject, it was an excellent melting pot for discussions on how previously identified barriers could be minimized and supports could be enhanced, related to palliative and end of life care in the NICU

Substantive Findings

Examination of each of the physical spaces, identified by participants, revealed that there are challenges to providing palliative and end of life care in a busy NICU, both space wise and otherwise. Attributes of the environment, such as space, lighting, traffic and noise were identified as barriers that these participants have had to overcome. Participants gave examples of times they were able to have some control over lighting, traffic and noise, to facilitate the creation of a safe, private space for families of dying newborns. The issue of not enough physical space to satisfy the needs of both the dying baby and their family was present in each location of care. The issue of not enough time was also a key finding of this study. These were barriers participants identified, but had not been able to minimize in their own practice. This finding reflects a potential source of moral distress for nurses in this NICU.

Pendry (2007) defines moral distress as the physical or emotional suffering that is experienced when constraints, either internal or external, prevent following a course of action deemed right. Neonatal healthcare professionals are particularly prone to feelings of moral distress. The experience of failing to cure the patient, in conjunction with lack of training in palliative care principles has the potential to leave health care providers morally and emotionally distressed (Romesberg, 2007).

Though no participant in the study directly expressed that they had experienced moral distress, there were times participants expressed feeling guilty or ‘haunted’ by their past experiences with neonatal death. Although the death of a child is a relatively rare occurrence, healthcare professionals working with children are directly confronted and affected by childhood death. These deaths often occur after extensive ‘lifesaving’ efforts and heroic measures have been taken. It is not uncommon for health professionals to perceive the death of a child as a “triple” failure: first, because they did not have the means, skills, or abilities to save a life; second, because in their social role as adults they were unable to protect the child from harm; and third, because they “betrayed” parents who trusted them with the most valuable being in their life (Papadatou, 1997). As a result of these feelings, health care professionals who care for children with life-threatening conditions may themselves suffer. Nurses have reported feelings of helplessness and sorrow and responses consisting of chronic fatigue, irritability, and being excessively critical (Engler et al., 2004). This suffering may be in response to grief related to the child's circumstances, or because role conflicts, or situations that can cause moral distress or loss of professional integrity (Rushton et al., 2006).

Changing from a curative model of care to a palliative model of care can be difficult for NICU care providers, particularly when the setting of care provision has not changed. The challenges of providing palliative and end of life care on the unit were reiterated by study participants. A quantitative study, published in 2011, aimed to identify the physiologic threshold at which the goal of care for an infant with life-limiting conditions shifts from curative efforts to purely palliative care (Catlin, 2011). This was a Web-based survey of 285 neonatal nurses and physicians who had participated in the care of dying infants. What this study revealed was that although physiological factors were identified, the threshold for transition to palliative care would occur only when parents agreed with the transition. This finding indicates that the moral distress that nurses and physicians feel, when curative efforts are deemed to be futile, will not soon be over. What this study does not speak to is the impact a model care grounded in palliative care principles might have in these situations.

Technological advancements in neonatology may have surpassed our ability to successfully deal with the ethical and moral issues that surround end of life care (Kain, 2006). The precepts of palliative care allow nurses to provide symptom management within a supportive framework (Kain, 2006). This model of care may alleviate some of these ethical and moral dilemmas (Kain, 2006).
In a qualitative nursing study of critical care nurse's perceptions of and responses to moral distress several recommendations to practice were made (Gutierrez, 2005). A qualitative descriptive study was conducted to describe and analyze the phenomenon of moral distress experienced by twelve adult critical care nurses. This methodology yielded rich, detailed data through open-ended question interview format. What was discovered was that critical care nurses experienced suffering as a result of implementing actions incongruent with their moral judgment (Gutierrez, 2005). When these moral concerns were not recognized, nurses in this study were left feeling powerless and questioned the morality of the care they provided (Gutierrez, 2005). Similar research with neonatal intensive care nurses has not been published to date. Considering the vulnerability of nurses working in critical are areas, a research design that generates rich data while validating the experiences of the nurses and providing them with a direct opportunity to transform their practice is essential.

Nurses in this study identified the need for more education in the area of neonatal palliative and end of life care. The participants felt that this additional education would be of particular value to nurses who had never provided this type of care before. The need for continued education, around the philosophies and principles of neonatal palliative and end of life care is well supported in previous literature. Caregivers benefit from being supported in acquiring and using their new knowledge and skills relating to palliative and end of life care (Rushton et al., 2006). Without formalized training in palliative care provision the experience of a family may be jeopardized and the healing and grieving process can be inhibited. A cross-sectional, descriptive correlational mailed survey design was used by Engler et. al. (2004), to study neonatal staff and advanced nurses' perceptions of bereavement and end of life care of families. What they found was that nurses who had more experience and education in bereavement and end of life care who routinely cared for critically ill and/or dying infants, were more comfortable with all aspects of bereavement and end of life care (Engler et al., 2004).

A key finding of my study was that nurses were keen to learn about palliative and end of life care. The participants affirmed the need for NICU staff to have the opportunity to say good-bye to the dying baby. There was a sense, from one participant, that staff who had not experienced end of life care were more likely to seek these opportunities and were perhaps more curious about death and dying in the NICU than those with end of life care experience.

Another key finding, identified by nurses participating in this study, was the importance of grief and bereavement support for the surviving family. Grief and bereavement support for the surviving family after the death of a loved one is a fundamental component of palliative care (Romesberg, 2007). Embedded within bereavement support is the creation of memories. A qualitative study conducted by Branchett and Stretten (2012), examining what parents want from professionals relating to neonatal palliative and end of life care validated the importance of these tangible memories. They identified the memories created as being fundamental, as parents could only take these with them, not the baby they were expecting. For the participants the mementos created were a gift for families.

The thoughtful way in which participants reflected on the creation of these mementos caused me to wonder if the offering of this gift was part of the healing process for the nurses themselves. While the literature confirms the importance of creating tangible memories for families (Branchett & Stretten, 2012; Catlin & Carter, 2002; Romesberg, 2007), there is nothing in the current literature about the impact this activity has on the nurses who care for bereaved families.

Implications for Clinical Practice

Dr. Marck has beautifully demonstrated success implementing change by using adapted restorative methodology in healthcare. The methodology was effective in this study in an NICU setting to generate rich data that were descriptive of the supports and barriers to neonatal palliative and end of life care as well as generative of possible solutions. The themes that emerged from this study concerning barriers to care can be overcome with simple solutions that emerged from nurses who are providing this specialized care.

The results of this study will provide the participating hospital with information that will be helpful in assessing current practice, the need for continuing staff education and acknowledging and sharing the positive work that is currently being done. At the conclusion of the focus group meeting Participant F suggested one step to improving care might be as simple as learning together from past experience: “I think we can only go forward. I think we learn each time we do this and you know...we need to talk about it and discuss things and discuss the good and the bad”.

Taking what has been gleaned from this study and considering each identified barrier and support in terms of our own abilities to minimize identified barriers and maximize identified supports will be the first step in our journey to improved care provision for this special population.

Enhancing educational opportunities for all staff would serve to minimize anxiety felt by new staff and improve communication between the bedside nurse and other staff present on the unit. Palliative care education should include; symptom management, medications, community resources and hospice planning (Catlin & Carter, 2002). Catlin and Carter (2002) suggest that staff should review palliative care protocols at the time of competency training each year.

One aspect of practice identified as a barrier, that I had not previously come across in the literature, was nurses’ delivery of the bath at the end of life and the materials used for this bath. The concerns that participants had surrounding this practice might be easily overcome with the purchase of a different basin and new towels. This might help to facilitate a bathing experience that is felt to be more holistic and less “utilitarian”.

Communicating, to other staff in the NICU, that there has been a death or that there is a bereaved family present also posed a challenge for participants. Because of the physical layout of this NICU health care providers would not necessarily have the opportunity to know that there has been a death before entering the unit itself. Knowing in advance might help foster an environment that supports palliative and end of life care for bereaved families. Practitioners might be better able to adjust noise levels or alter their conversations to create a more sensitive space. Participants agreed that the current signage used does not convey the need for respect, privacy and quiet. The creation of new signs, specific to the need for a space facilitating palliative and end of life care, might serve to enhance communication between all healthcare providers in this NICU. This might help bedside nurses focus more on the care of the bereaved family, and less on policing the noise and traffic around this sacred space.

Critically ill neonates are often a single baby assignment for a nurse in the NICU. Inadequate staffing to support palliative care practice has been identified in the literature as a salient barrier to care provision (Kain, 2006). Again this barrier to care provision was identified by participants in this study. To uphold the principle of justice, assignments could be arranged to equitably satisfy the needs of each patient. When nurses feel as though they are physically and emotionally unable to provide thorough care to all patients they are at risk for burnout and exhaustion.

Limitations of the Study

There are several potential perceived limitations to this study. With the use of purposeful sampling there was a possibility that registered nurses who chose to participate in this study did so because of strong biases, interests and/or opinions about the subject matter. There is also the possibility that the focus group was composed of participants who were more enthusiastic about the research process and thus homogenous in terms of both their professional and personal experiences with the subject material. Given the principles of qualitative inquiry, however, concerning recruiting participants who are most able to speak to the phenomenon of interest (Burns & Grove, 1999, p. 356), these limitations can also be conceived as strengths of the research design.

During our current difficult times of recession and health region restructuring, registered nurses who met the study's inclusion criteria might have been reluctant to volunteer their own time to participate in this study. This limitation was overcome by offering incentives for participation. Complimentary coffee and lunch, group acknowledgment in any publications related to the research study and completion of College and Association of Registered Nurses (CARNA) continuing competence hours were strategies used to encourage participation in this study.

Using a focus group methodology also had limitations. Focus groups can be intimidating at times, especially for inarticulate or shy members. Therefore it was imperative that an environment fostering open communication and peer support was created. Focus group methodology is also vulnerable to a process known as groupthink. ‘Groupthink’ occurs when the stronger members of a group, or segments of the group, have major control or influence over the verbalizations of other group members (Carey & Smith, 1994). This process can be recognized by the moderator and minimized by ensuring that each group member feels valued and enabled to speak freely. The fact that the focus group for this study was a small group, only four participants with similar interests, likely minimized the potential for ‘groupthink’ to occur. Participants were encouraged to speak freely and there were no participants who I felt dominated the discussion.

Another limitation recognized is that this study was conducted at a single institution and therefore the findings might be unique to this unit. Furthering this research at this institution and replicating this study at other institutions are logical next steps to this master’s level research.

Conducting Research as an Insider

Although the time I currently spend working in the NICU where this research was conducted is limited to nights, weekends and four to six weeks of ten hour days spread throughout the year, I do have a long working history in the unit as a bedside nurse. During my clinical hours I am dressed in scrubs and I am wearing Alberta Health Services identification. When I am in the unit doing non-clinical and research work I dressed in street clothes and I used my University of Alberta identification. Despite this effort to identify myself in an alternate role to my clinical role in the unit, I was still perceived as an insider and with that there were benefits and limitations.

The advantage to being an insider was that I did not need to “gain entry” into the culture I was studying. This being said, my capacity in this role was as a researcher. Outside of the recruitment materials (Appendix B-Recruitment Materials), I took no active part in recruiting participants. Before the onset of both the photo walkabouts and the focus group meetings I reiterated my role as a researcher and not as a team member. Participants were asked to reveal no more to me than they would to a stranger. They were also made aware that our professional relationship would be in no way affected by their participation in this study.

Another advantage to being an insider is that I had a profound level of commitment to an in depth and comprehensive reflection of the views and perspectives of each participant. Acknowledging that I was an insider meant that I was acutely aware that I had to step back and learn from each participant and their stories or I would miss valuable insights. Reflexivity has been described as the need to have an ongoing conversation about the experience while simultaneously living the moment (Streubert Speziale & Rinaldi Carpenter, 2007). It was impossible for me to be completely detached and objective through the data collection process; my very presence influenced the research process. Throughout the process I recorded my thoughts and reflections in a journal to account for my influence on the process, this serving as my audit trail (Ortlipp, 2008). I also chose to present both my personal perspective as well as the participants’ perspectives in my final data analysis. Before each step in data collection I consulted with my co-supervisor, Dr. Marck, who had extensive experience with the methodology. We discussed my personal beliefs about the subject and about my role in conducting research in this unit. We discussed how my beliefs and background influenced my abilities as a researcher and what I needed to do to account for my role in data generation and analysis. This served to enhance my self-awareness throughout the research process.

Opportunities for Further Research

It was beyond the scope of this research study to examine barriers and supports to palliative care practices identified by physicians or other neonatal interdisciplinary team members. Using this methodology to listen to and examine narratives of bereaved families might also contribute to enhancing care to this special population of babies.

There may also be further opportunities to adapt this study methodology to examine palliative and end of life care practices in labour and delivery or postpartum nursing units. There may also be opportunities to use this methodology to study palliative and end of life care practices in other NICUs. Comparing and contrasting findings might serve to further recognize barriers and supports to palliative and end of life care. In the long term this exploration has the potential to serve to facilitate collaborative efforts between centers and between disciplines.

Conclusions

The present study was undertaken to gain a better understanding of the barriers and supports that exist to palliative and end of life care, as identified by registered nurses. A review of the current literature indicated that few studies investigate the perceptions of nursing staff regarding the care of neonates with life-limiting conditions. There are some quantitative studies, but few qualitative studies investigating this subject. Subsequent research might incorporate both qualitative and quantitative components.

Many of the barriers to palliative and end of life care that were identified by participants are complex and will take commitment to address. However, there was a spectrum and with time and efforts some of the issues identified could easily be overcome. The importance of further research, practice and attitude change and acknowledgement of the work already being done in this area was beautifully summed up by participant D:

> Death is part of life...we don't want babies to die, but babies do die and as short as their lives are, we, I believe we owe them to have a good death...that's going to be part of what life the family will remember...whether you're doing it at a palliative unit in...the corner when the unit's total chaos or,...a nice quiet little part of the unit, you, we still need to try and do the very best that we can and sometimes that's all you can do. You may not feel great about it, but you do the very best that you can.

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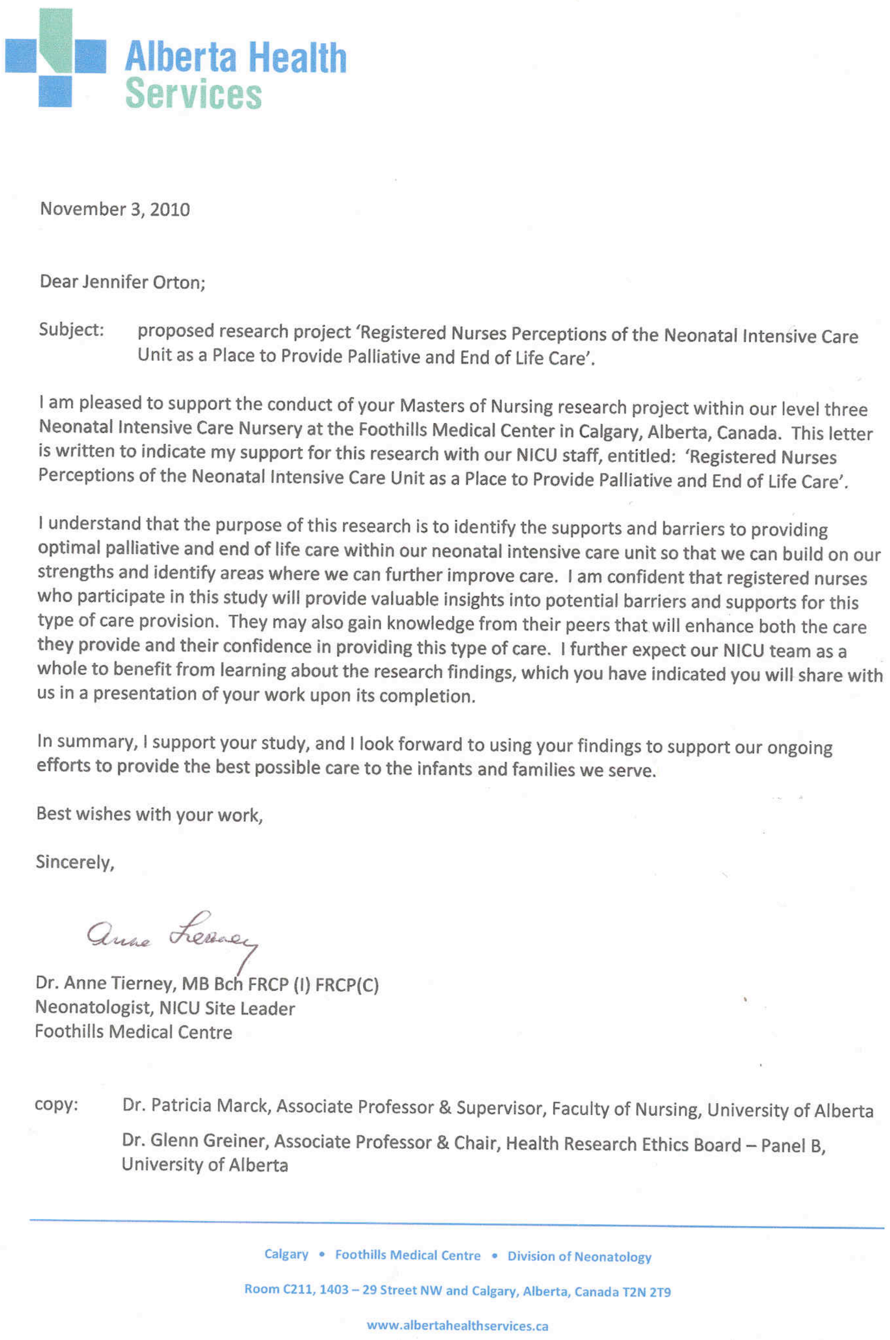
Appendices

Appendix A-Letters of Support

Letter of Support from Neonatology



Alberta Health
Services

November 3, 2010

Dear Jennifer Orton;

Subject: proposed research project 'Registered Nurses Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care'.

I am pleased to support the conduct of your Masters of Nursing research project within our level three Neonatal Intensive Care Nursery at the Foothills Medical Center in Calgary, Alberta, Canada. This letter is written to indicate my support for this research with our NICU staff, entitled: 'Registered Nurses Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care'.

I understand that the purpose of this research is to identify the supports and barriers to providing optimal palliative and end of life care within our neonatal intensive care unit so that we can build on our strengths and identify areas where we can further improve care. I am confident that registered nurses who participate in this study will provide valuable insights into potential barriers and supports for this type of care provision. They may also gain knowledge from their peers that will enhance both the care they provide and their confidence in providing this type of care. I further expect our NICU team as a whole to benefit from learning about the research findings, which you have indicated you will share with us in a presentation of your work upon its completion.

In summary, I support your study, and I look forward to using your findings to support our ongoing efforts to provide the best possible care to the infants and families we serve.

Best wishes with your work,

Sincerely,

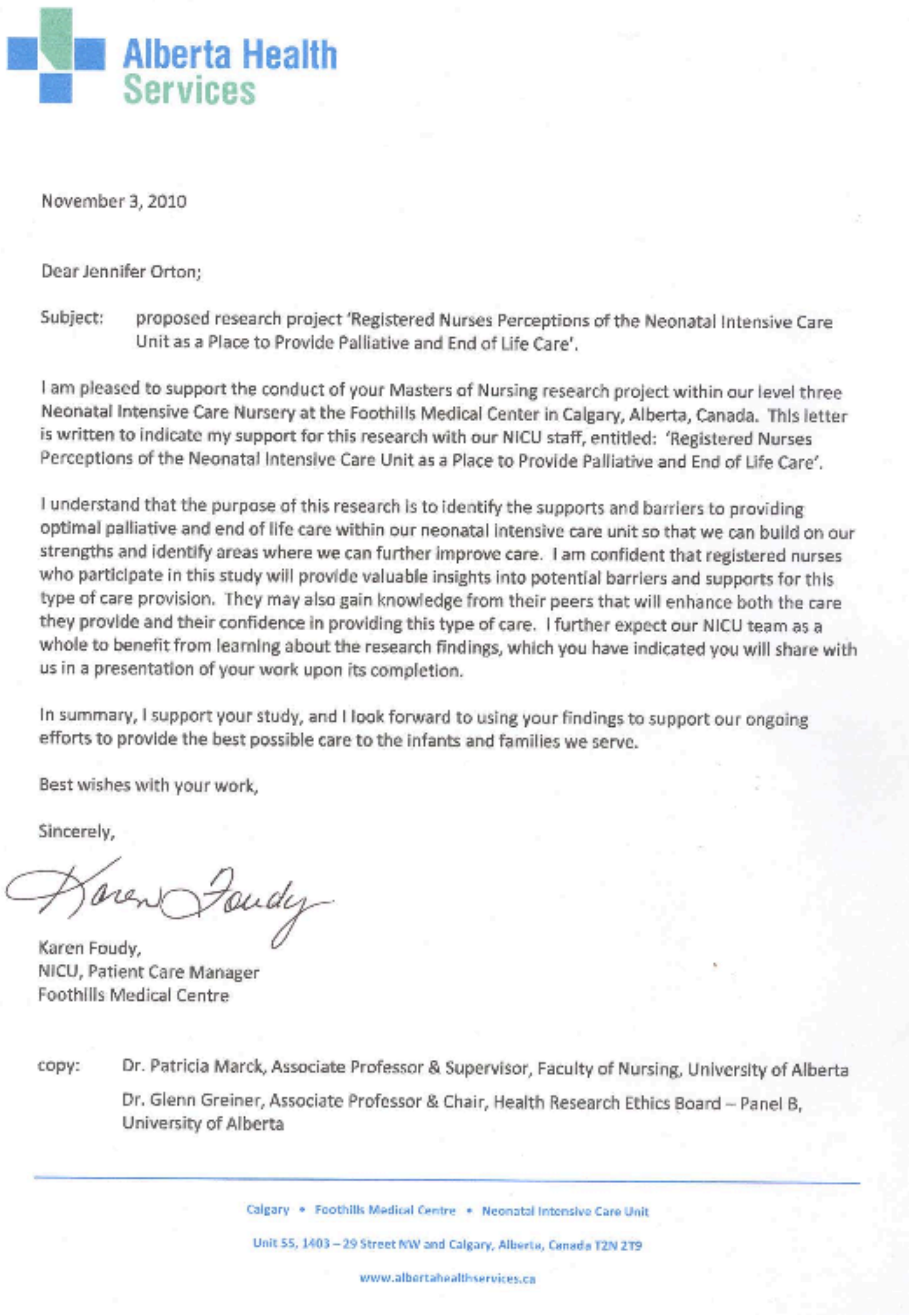
Anne Tierney

Dr. Anne Tierney, MB Bch FRCP (I) FRCP(C)
Neonatologist, NICU Site Leader
Foothills Medical Centre

copy: Dr. Patricia Marck, Associate Professor & Supervisor, Faculty of Nursing, University of Alberta
Dr. Glenn Greiner, Associate Professor & Chair, Health Research Ethics Board – Panel B, University of Alberta

Calgary • Foothills Medical Centre • Division of Neonatology
Room C211, 1403 – 29 Street NW and Calgary, Alberta, Canada T2N 2T9
www.albertahealthservices.ca

Letter of Support from Nursing Patient Care Manager Unit 55



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Services

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In summary, I support your study, and I look forward to using your findings to support our ongoing efforts to provide the best possible care to the infants and families we serve.

Best wishes with your work,

Sincerely,

Karen Foudy

Karen Foudy,
NICU, Patient Care Manager
Foothills Medical Centre

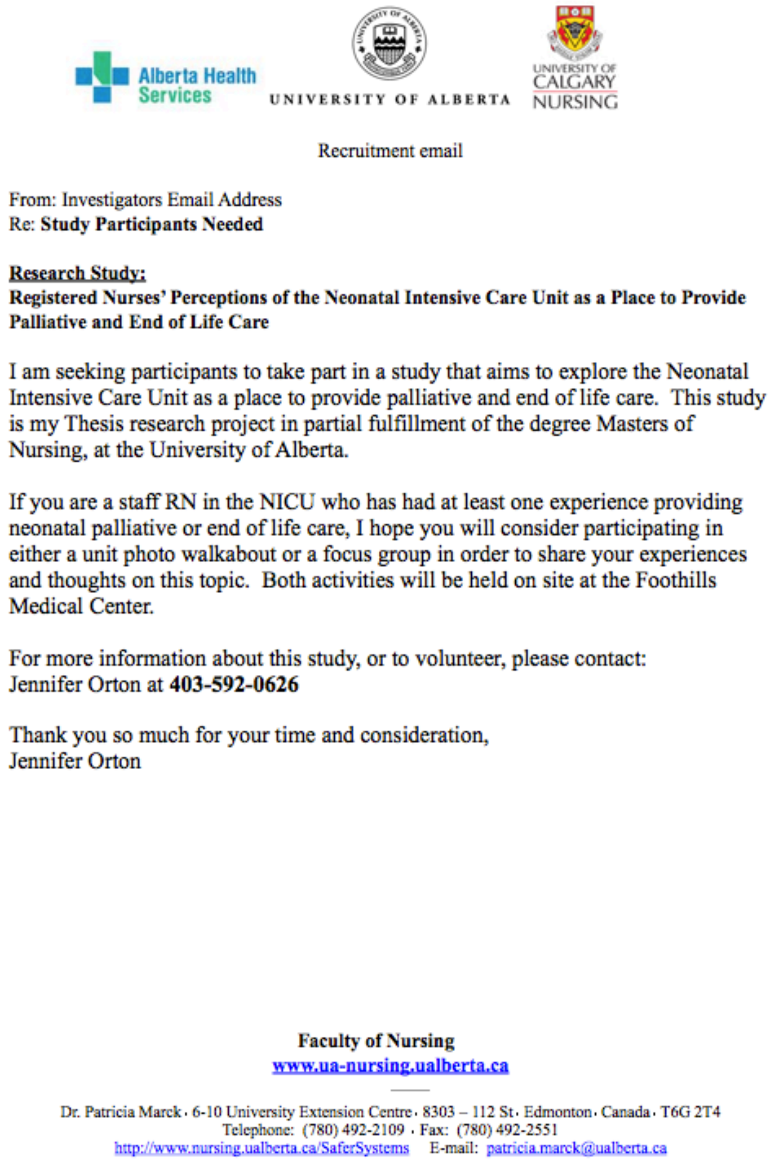
copy: Dr. Patricia Marck, Associate Professor & Supervisor, Faculty of Nursing, University of Alberta

Dr. Glenn Greiner, Associate Professor & Chair, Health Research Ethics Board – Panel B, University of Alberta

Calgary • Foothills Medical Centre • Neonatal Intensive Care Unit
Unit 55, 1403 – 29 Street NW and Calgary, Alberta, Canada T2N 2T9
www.albertahealthservices.ca

Appendix B-Recruitment Materials

Recruitment Email



Alberta Health Services

UNIVERSITY OF ALBERTA

UNIVERSITY OF CALGARY NURSING

Recruitment email

From: Investigators Email Address
Re: **Study Participants Needed**

Research Study:
Registered Nurses' Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care

I am seeking participants to take part in a study that aims to explore the Neonatal Intensive Care Unit as a place to provide palliative and end of life care. This study is my Thesis research project in partial fulfillment of the degree Masters of Nursing, at the University of Alberta.

If you are a staff RN in the NICU who has had at least one experience providing neonatal palliative or end of life care, I hope you will consider participating in either a unit photo walkabout or a focus group in order to share your experiences and thoughts on this topic. Both activities will be held on site at the Foothills Medical Center.

For more information about this study, or to volunteer, please contact:
Jennifer Orton at **403-592-0626**

Thank you so much for your time and consideration,
Jennifer Orton

Faculty of Nursing
www.ua-nursing.ualberta.ca

Dr. Patricia Marck · 6-10 University Extension Centre · 8303 – 112 St · Edmonton · Canada · T6G 2T4
Telephone: (780) 492-2109 · Fax: (780) 492-2551
http://www.nursing.ualberta.ca/SaferSystems E-mail: patricia.marck@ualberta.ca

Recruitment Poster for Lunch/Locker Rooms

Alberta Health Services

UNIVERSITY OF ALBERTA

UNIVERSITY OF CALGARY NURSING

~Study Participants Needed~

I am seeking participants to take part in a study that aims to explore the Neonatal Intensive Care Unit as a place to provide Neonatal Palliative and End of Life Care. This study is my Masters of Nursing Thesis project.

If you are a staff RN in the NICU who has had at least one experience in providing neonatal palliative or end of life care, I hope you will consider participating in either a unit photo walkabout or a focus group in order to share your experiences related to this topic. Both activities will be held on site at the Foothills Medical Center.

For more information about this study, or to volunteer, please contact:
Jennifer Orton at: **403-592-0626**

Faculty of Nursing www.ua-nursing.ualberta.ca

Gwen Rempel RN, PhD
Assistant Professor
Faculty of Nursing, University of Alberta
3rd Floor Clinical Sciences Building
Edmonton, AB, Canada
T6G 2G3
Phone: 780-492-8167 Fax: 780-492-2551
email: gwen.rempel@ualberta.ca

Ethics ID 23645:
This study has been approved by the Conjoint Health Research Ethics Board.

Jennifer Orton 403-592-0626
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Recruitment Poster for Mailboxes

Alberta Health Services

UNIVERSITY OF ALBERTA

UNIVERSITY OF CALGARY NURSING

Study Participants Needed

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If you are a staff RN in the NICU who has had at least one experience in providing neonatal palliative or end of life care, I hope you will consider participating in either a unit photo walkabout or a focus group in order to share your experiences related to this topic. Both activities will be held on site at the Foothills Medical Center.

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Faculty of Nursing www.ua-nursing.ualberta.ca
Gwen Rempel RN, PhD
Assistant Professor
Faculty of Nursing, University of Alberta
3rd Floor Clinical Sciences Building
Edmonton, AB, Canada
T6G 2G3
Phone: 780-492-8167 Fax: 780-492-2551
email: gwen.rempel@ualberta.ca

Ethics ID 23645:
This study has been approved by the
Conjoint Health Research Ethics Board.

Appendix C-Consent Materials

Photo Walkabout Information Letter

Information Letter: Photo-walkabout

Research Project

Registered Nurses' Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care

Principal Investigator:

Gwen Rempel RN, PhD

Assistant Professor
Faculty of Nursing, University of Alberta
3rd Floor Clinical Sciences Building
Edmonton, AB, Canada
T6G 2G3
Phone: 780-492-8167 Fax: 780-492-2551
email: gwen.rempel@ualberta.ca

Local Principal Investigator:

Nancy J. Moules, RN, PhD

Associate Professor
Faculty of Nursing, University of Calgary
Phone: 403-220-4635
email: njmoules@ucalgary.ca

Co-Investigator:

Jennifer Orton, R.N., BN, MN candidate

Phone Number: **403-592-0626**
email: jennifer.orton@albertahealthservices.ca

Committee members for Jennifer Orton's thesis include:

Co-Supervisor: Dr. Patricia Mark: Faculty of Nursing, University of British Columbia
Dr. Leonora Hendson: Faculty of Medicine & Dentistry, University of Alberta
Dr. Nancy Moules: Faculty of Nursing, University of Calgary

Signature of Co-Investigator: ______________________________

INVITATION TO PARTICIPATE AND STUDY PURPOSE

As a registered nurse, you are being invited to participate in a photo-walkabout of the Foothills Medical Center Neonatal Intensive Care Unit. The aim of these activities is to explore your perceptions of the NICU as a place to provide neonatal palliative and end of life care. The study desires to explore both the supports and barriers, potentially existing within the NICU environment, to the provision of palliative and end of life care.

BACKGROUND

The objectives of this study will be to identify the supports and barriers that exist, within the neonatal intensive care unit, to providing optimal palliative and end of life care. The ultimate goal of this research project is to work with registered nurses to identify the means by which these preexisting supports may be maximized and preexisting barriers may be minimized.

Restoration focuses on studying and repairing systems that have been changed or broken down over time. A powerful research method used in restoration is the collection and study of photographs to identify, assess, and track changes within an environment. This study will use photographs and descriptions of various aspects of the NICU that registered nurses have deemed to be impactful to the delivery of palliative and end of life care. This will be done to help understand the potential barriers and supports that exist to the delivery of this highly specialized care.

PROCEDURE

If you agree to participate in this study, you will be asked to:

a) Read this information letter and complete the attached consent form. Please keep a copy of this information letter for your records.

b) Participate one of two photo walkabouts conducted at two different time points. Each session will be approximately 50-60 minutes in length. The objectives of the photo walkabout is as follows:

Photo-walkabout

You have been asked to join me for a 'photo walkabout' of the neonatal intensive care unit. During our journey together various aspects of the neonatal intensive care unit will be photographed, using a digital camera, for the purpose of eliciting discussion during the focus group session. You will be asked to dress in a professional manor and at all times have your staff identification visible. Strict attention to infection prevention strategies as well as developmental care philosophies will be followed throughout the photo walkabout. In other words, no environmental ‘footprint’ will be left behind from our journey through the neonatal intensive care unit. The date and time of the walkabout will be negotiated in advance with both the nursing and medical management teams.

As we travel together, a semi-structured interview guide will be used to help you to narrate your perceptions of the neonatal intensive care unit. This “photo narration” will serve to capture your ‘story’ and hopefully serve to relate how specific attributes of this neonatal intensive care unit impact palliative and end of life care provision.

You should incur no monetary cost as a result of your participation at any point in this study. Vouchers for parking will be available if needed.

POSSIBLE RISKS AND BENEFITS TO PARTICIPANTS

You may not receive any benefit from taking part in this photo-walkabout. We do not expect that you will suffer any harm from taking part in this project.

The intent of this study is to explore the neonatal intensive care unit as a place to provide palliative and end of life care. By participating you may provide valuable insight into the potential barriers and supports that exist to this type of care provision. You may also gain knowledge or enlightenment from your peers that will enhance both the care you provide and your confidence in providing this type of care. Your participation in this study can also be used as part of completion of College and Association of Registered Nurses (CARNA) continuing competence hours.

CONFIDENTIALITY

Before each individual photo walkabout begins, you will be reminded that your attendance is voluntary and not concealed. You will also be reminded that what is said will remain confidential. The consent form will also act as a confidentiality agreement. However, ensuring confidentiality is difficult in this type of data collection. Therefore, we cannot guarantee that group members will keep what has been said confidential. If there is something you do not want to talk about you do not have to share it with the group. You should only give information you feel comfortable sharing with the research team. Comments made during the photo walkabout may be used in publications and presentations. However, only the project team’s names will be used. The photo walkabout recording and transcript will be kept in a locked filing cabinet in the Principal Investigator’s office for at least 5 years after the project is finished.

VOLUNTARY PARTICIPATION

Your participation is voluntary and not concealed. You do not need to take part in this photo-walkabout if you do not want to. Your employment will be the same if you take part or not. You should not feel pressured by anyone to take part in this project. You may ask any questions that you have about the project. If you decide to take part, you may still leave the photo walkabout at any time without saying why. However due to the nature of this study, we cannot remove your comments from the record.

CONTACT NAMES AND PHONE NUMBERS

If you have concerns about your rights as a study participant, you may contact

Principal Investigator:
Gwen Rempel RN, PhD
Assistant Professor
Faculty of Nursing, University of Alberta
3rd Floor Clinical Sciences Building
Edmonton, AB, Canada
T6G 2G3
Phone: 780-492-8167 Fax: 780-492-2551
email: gwen.rempel@ualberta.ca

Co-Investigator:
Jennifer Orton, R.N., BN, MN candidate
Phone Number: **403-592-0626**
jennifer.orton@albertahealthservices.ca

University of Alberta Health Research Ethics Board:
Phone Number: **780-492-0302**

University of Calgary:
The Director, Office of Medical Bioethics:
Phone Number: **403-220-7990**

If you decide to take part in this photo-walkabout, please review the attached conditions for consent.

Alberta Health Services

UNIVERSITY OF ALBERTA

UNIVERSITY OF CALGARY NURSING

Consent Form: Photo-walkabout

Part 1:
Title of Project: *Registered Nurses' Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care*

Principal Investigator:
Gwen Rempel RN, PhD
Assistant Professor
Faculty of Nursing, University of Alberta
3rd Floor Clinical Sciences Building
Edmonton, AB, Canada
T6G 2G3
Phone: 780-492-8167 Fax: 780-492-2551
email: gwen.rempel@ualberta.ca

Local Principal Investigator:
Nancy J. Moules, RN, PhD
Associate Professor
Faculty of Nursing, University of Calgary
Phone: 403-220-4635
email: njmoules@ucalgary.ca

Co-Investigator:
Jennifer Orton R.N., B.N. MN candidate
Phone Number**: 403-592-0626**
jennifer.orton@albertahealthservices.ca

Part 2: (To be completed by the study participant)
Do you understand that you have been asked to be in a research project?
YES ☐ NO ☐

Have you read and received a copy of the attached Information Sheet?
YES ☐ NO ☐

Do you understand the benefits and risks involved in taking part in this research project?
YES ☐ NO ☐

Have you had an opportunity to ask questions and discuss this project?
YES ☐ NO ☐

Do you understand that you are free to withdraw from the project at any time without having to give a reason and without affecting the conditions of your employment?
YES ☐ NO ☐

Has the issue of confidentiality been explained to you?
YES ☐ NO ☐

Do you understand who will have access to the information from this project?
YES ☐ NO ☐

I consent to the use of my image in this project in the form of still/digital photographs.
YES ☐ NO ☐

I consent to the use of my image in this project in the form of presentations.
YES ☐ NO ☐

Who explained this project to you?
____

I agree to take part in this project: YES ☐ NO ☐

Signature of Project Participant
____

(Printed Name) __________________________________
Date:______________________________

Signature of Witness
____

I believe that the person signing this form understands what is involved in the project and voluntarily agrees to participate.

Signature of Employee ____

(Printed Name)
__________________________________Date:______________________________

I believe the person signing this form understands what is involved in the project and voluntarily consents to the use of their image in the project.

Signature of Co-Investigator________________________________ Date __________

A COPY OF THIS CONSENT FORM WILL BE GIVEN TO EACH STUDY PARTICIPANT

Focus Group Information Letter

Information Letter: Focus Group

Research Project

Registered Nurses' Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care

Principal Investigator:

Gwen Rempel RN, PhD
Assistant Professor
Faculty of Nursing, University of Alberta
3rd Floor Clinical Sciences Building
Edmonton, AB, Canada
T6G 2G3
Phone: 780-492-8167 Fax: 780-492-2551
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Co-Investigator:

Jennifer Orton, R.N., BN, MN candidate
Phone Number: **403-592-0626**
email: jennifer.orton@albertahealthservices.ca

Committee members for Jennifer Orton's thesis include:

Co-Supervisor: Dr. Patricia Mark: Faculty of Nursing, University of British Columbia
Dr. Leonora Hendson: Faculty of Medicine & Dentistry, University of Alberta
Dr. Nancy Moules: Faculty of Nursing, University of Calgary

Signature of Co-Investigator: ______________________________

INVITATION TO PARTICIPATE AND STUDY PURPOSE

As a registered nurse, you are being invited to participate in a focus group at the Foothills Medical Center Neonatal Intensive Care Unit. The aim of this group is to explore your perceptions of the NICU as a place to provide neonatal palliative and end of life care. The study desires to explore both the supports and barriers, potentially existing within the NICU environment, to the provision of palliative and end of life care.

BACKGROUND

The objectives of this study will be to identify the supports and barriers that exist, within the neonatal intensive care unit, to providing optimal palliative and end of life care. The ultimate goal of this research project is to work with registered nurses to identify the means by which these preexisting supports may be maximized and preexisting barriers may be minimized.

Restoration focuses on studying and repairing systems that have been changed or broken down over time. A powerful research method used in restoration is the collection and study of photographs to identify, assess, and track changes within an environment. This study will use photographs and descriptions of various aspects of the NICU that registered nurses have deemed to impact the delivery of palliative and end of life care. This will be done to help understand the potential barriers and supports that exist to the delivery of this highly specialized care.

PROCEDURE

If you agree to participate in this study, you will be asked to:

a) Read this information letter and complete the attached consent form. Please keep a copy of this information letter for your records.

b) Attend and participate in a focus group. The session will be approximately 50-60 minutes in length. The objectives of the focus group are as follows:

Focus group

You have been asked to join a moderator lead focus group discussion. The focus group will elicit enhanced detail and stories from you about how the neonatal intensive care unit supports or impairs the provision of palliative and end of life care. We will discuss how the physical space (sights, sounds, lighting) and the socio-cultural space together impact this type of care delivery. A moderator's guide will be used in order to facilitate this exploration.

A meeting of focus group participants will take place in a designated location in the Foothills Medical Center. Six to eight registered nurses, who meet the inclusion criteria, will be recruited to participate in this phase of the study.

You should incur no monetary cost as a result of your participation at any point in this study. Food and beverages will be made available to you at no cost during the focus group and vouchers for parking will be available if needed.

POSSIBLE BENEFITS AND RISKS TO PARTICIPANTS

You may not receive any benefit from taking part in this focus group. We do not expect that you will suffer any harm from taking part in this project.

The intent of this study is to explore the neonatal intensive care unit as a place to provide palliative and end of life care. By participating you may provide valuable insight into the potential barriers and supports that exist to this type of care provision. You may also gain knowledge or enlightenment from your peers that will enhance both the care you provide and your confidence in providing this type of care. Your participation in this study can also be used as part of completion of College and Association of Registered Nurses (CARNA) continuing competence hours.

CONFIDENTIALITY

Before each individual focus group discussion begins, you will be reminded that your attendance is voluntary and not concealed. You will also be reminded that what is said will remain confidential. The consent form will also act as a confidentiality agreement. However, ensuring confidentiality is difficult in focus groups. Therefore, we cannot guarantee that group members will keep what has been said confidential. If there is something you do not want to talk about you do not have to share it with the group. You should only give information you feel comfortable sharing with the research team. Comments made during the focus group may be used in publications and presentations. However, only the project team's names will be used. The focus group recording and transcript will be kept in a locked filing cabinet in the Principal Investigator's office for at least 5 years after the project is finished.

VOLUNTARY PARTICIPATION

Your participation is voluntary and not concealed. You do not need to take part in this focus group if you do not want to. Your employment will be the same if you take part or not. You should not feel pressured by anyone to take part in this project. You may ask any questions that you have about the project. If you decide to take part, you may still leave the focus group at any time without saying why. However due to the nature of focus groups, we cannot remove your comments from the record.

CONTACT NAMES AND PHONE NUMBERS

If you have concerns about your rights as a study participant, you may contact:

Principal Investigator:

Gwen Rempel RN, PhD
Assistant Professor
Faculty of Nursing, University of Alberta
3rd Floor Clinical Sciences Building
Edmonton, AB, Canada
T6G 2G3
Phone: 780-492-8167 Fax: 780-492-2551
email: gwen.rempel@ualberta.ca

Co-Investigator:

Jennifer Orton, R.N., BN, MN candidate
Phone Number: **403-592-0626**
jennifer.orton@albertahealthservices.ca

University of Alberta Health Research Ethics Board:

Phone Number: **780-492-0302**

University of Calgary:

The Director, Office of Medical Bioethics:
Phone Number: **403-220-7990**

If you decide to take part in this focus group, please review the attached conditions for consent.

Consent Form: Focus Group

Part 1:
Title of the Project: *Registered Nurses' Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care*

Principal Investigator:
Gwen Rempel RN, PhD
Assistant Professor
Faculty of Nursing, University of Alberta
3rd Floor Clinical Sciences Building
Edmonton, AB, Canada
T6G 2G3
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Phone: 403-220-4635
email: njmoules@ucalgary.ca

Co-Investigator:
Jennifer Orton, R.N., BN, MN candidate
Phone Number: **403-592-0626**
email: jennifer.orton@albertahealthservices.ca

Part 2 (to be completed by the project participant):

Do you understand that you have been asked to be in a research project?
YES ☐ NO ☐

Have you read and received a copy of the attached Information Sheet?
YES ☐ NO ☐

Do you understand the benefits and risks involved in taking part in this research project?
YES ☐ NO ☐

Have you had an opportunity to ask questions and discuss this project?
YES ☐ NO ☐

Do you understand that you are free to withdraw from the project at any time without having to give a reason and without affecting the conditions of your employment?
YES ☐ NO ☐

Has the issue of confidentiality been explained to you?
YES ☐ NO ☐

Do you understand who will have access to the information from this project?
YES ☐ NO ☐

Who explained this project to you? ____

I agree to take part in this project: YES ☐ NO ☐

Signature of Project Participant ____

(Printed Name) ______________________________ Date:___________________________

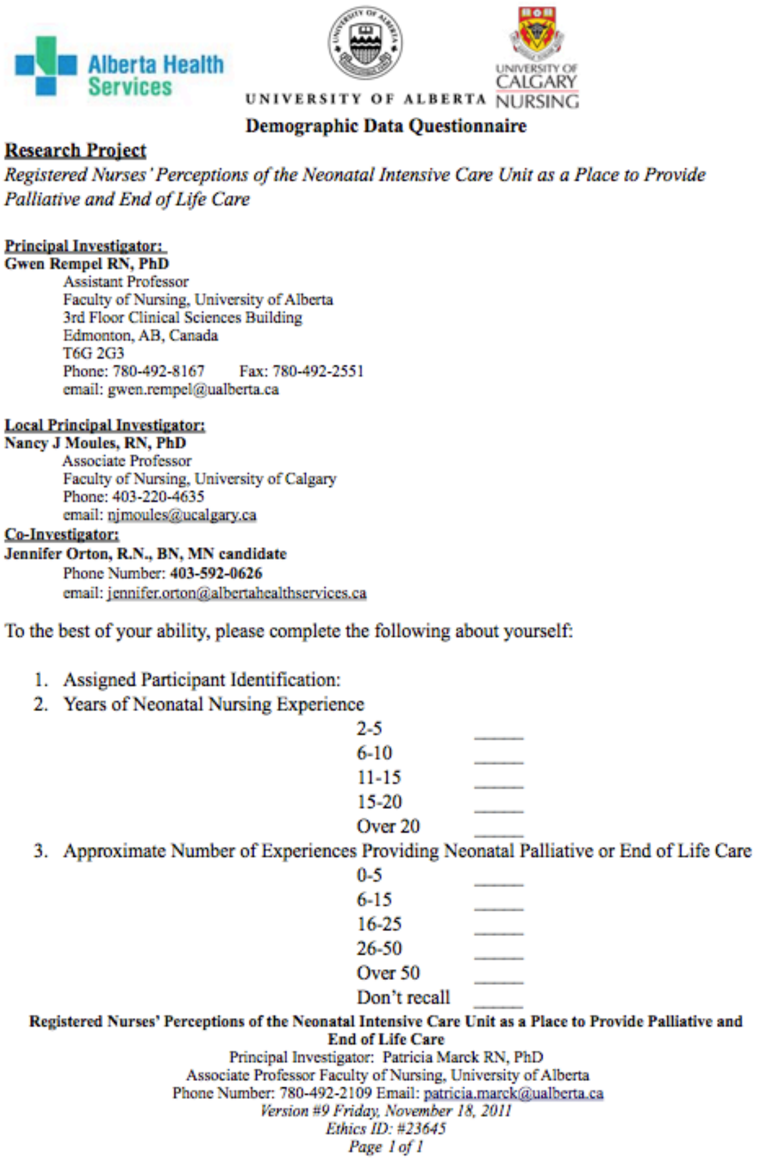
Signature of Witness ____

I believe that the person signing this form understands what is involved in the project and voluntarily agrees to participate.

Signature of Co-Investigator______________________________ Date __________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE PROJECT PARTICIPANT IF REQUESTED

Demographic Data Questionnaire



UNIVERSITY OF ALBERTA

Demographic Data Questionnaire

Research Project

Registered Nurses' Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care

Principal Investigator:
Gwen Rempel RN, PhD
Assistant Professor
Faculty of Nursing, University of Alberta
3rd Floor Clinical Sciences Building
Edmonton, AB, Canada
T6G 2G3
Phone: 780-492-8167 Fax: 780-492-2551
email: gwen.rempel@ualberta.ca

Local Principal Investigator:
Nancy J Moules, RN, PhD
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Faculty of Nursing, University of Calgary
Phone: 403-220-4635
email: njmoules@ucalgary.ca
Co-Investigator:
Jennifer Orton, R.N., BN, MN candidate
Phone Number: **403-592-0626**
email: jennifer.orton@albertahealthservices.ca

To the best of your ability, please complete the following about yourself:

1. Assigned Participant Identification:
2. Years of Neonatal Nursing Experience
   - 2-5 _____
   - 6-10 _____
   - 11-15 _____
   - 15-20 _____
   - Over 20 _____
3. Approximate Number of Experiences Providing Neonatal Palliative or End of Life Care
   - 0-5 _____
   - 6-15 _____
   - 16-25 _____
   - 26-50 _____
   - Over 50 _____
   - Don't recall _____

Appendix D-Focus Group Moderators Guide

Research Project

Registered Nurses' Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care

Principal Investigator:

Gwen Rempel RN, PhD

Assistant Professor
Faculty of Nursing, University of Alberta
3rd Floor Clinical Sciences Building
Edmonton, AB, Canada
T6G 2G3
Phone: 780-492-8167 Fax: 780-492-2551
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Local Principal Investigator:

Nancy J Moules, RN, PhD

Associate Professor
Faculty of Nursing, University of Calgary
Phone: 403-220-4635
email: njmoules@ucalgary.ca

Co-Investigator:

Jennifer Orton, R.N., BN, MN candidate

Phone Number: **403-592-0626**
email: jennifer.orton@albertahealthservices.ca

Thank you for participating in this research study. In this focus group, I would like to gain a better understanding of the palliative and end of life care practices that exist on your patient care unit. It will contribute to a research study that aims to explore registered nurses' perceptions and descriptions of one neonatal intensive care unit as a place for palliative and end of life care. The overarching research question to be investigated is:

How do registered nurses, working in a level three neonatal intensive care nursery perceive and describe their experience of the neonatal intensive care unit as a place to provide palliative and end of life care?

Consent confirmation:

Before we begin the discussion, I just want to ensure that everyone who is here and wishes to take part has had the opportunity to review the information letter and complete a consent form to participate. I will confirm that with each of you now, if you don't mind, before we begin.

I want to remind the group that what is said here needs to remain confidential and note that the consent form you signed also acts as a confidentiality agreement. However, confidentiality is difficult to maintain with focus groups and I cannot guarantee that group members will keep what has been said confidential. If there is something you do not wish to discuss, please do not feel any pressure to share it with the group.

I also want to remind everyone that, as outlined in your information letter to take part in this group, the discussion today will be audio taped and transcribed so that the research team can incorporate your feedback into the research findings that are reported. No identifying information will be used in the transcript and we will not use individual names in the research report or publications.

Start recording with group introductions:

Now with your permission, I would like to turn the tape on and go around the table and have everyone introduce themselves and their connection to Unit 55: Foothills Hospital Neonatal Intensive Care. (Please note that this is just for identification purposes on the tape; no names will be entered into the transcript).

Part A: Perceptions Of Neonatal Palliative/End of Life Care
Overarching Questions:

1. *How do registered nurses define or describe good palliative and end of life care within the neonatal intensive care unit?*
2. *How do registered nurses define or describe poor palliative and end of life care within the neonatal intensive care unit?*

Part B: Perceptions Of Pre-existing Supports To The Provision Of Palliative/End of Life Care

Overarching Question:

3. *Are there aspects within the neonatal intensive care unit that registered nurses feel act as supports to the provision of good palliative and end of life care?*

Part C: Perceptions of Pre-existing Barriers to the Provision of Palliative/End of Life Care

Overarching Question:

4. *Are there aspects within the neonatal intensive care unit that registered nurses feel act as barriers to the provision of good palliative and end of life care?*

Part D: Thoughts On How Pre-existing Supports Could Be Optimized

Overarching Questions:

5. *In what ways do registered nurses feel that supports, to neonatal palliative and end of life care, could be optimized within the neonatal intensive care unit?*

Part E: Thoughts On How Pre-existing Barriers Could Be Broken Down

Overarching Questions:

6. *In what ways do registered nurses feel that barriers to neonatal palliative and end of life care within the neonatal intensive care unit could be broken down?*

Part F: Ethical Implications Of Palliative/End of Life Care Within The NICU

7. *How do registered nurses describe their ethical experiences of delivering neonatal palliative and end of life care within a neonatal intensive care unit that is primarily focused on resuscitative care?*

Part H: Recap

Before you go, I would just like to recap the highlights of what we discussed (clarify points with participants to ensure adequate understanding of comments)

Is there anything else that we have missed?
Anything we should note that we have not already covered?

Thank you for participating in this focus group. The research team will use the feedback you have given today, along with the data gathered on unit photo-walkabouts to gain a better understanding of palliative/end of life care practices in the NICU.

Appendix E-Field Note Reporting Form

UNIVERSITY OF ALBERTA

Research Project

Registered Nurses' Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care

Principal Investigator:

Gwen Rempel RN, PhD
Assistant Professor
Faculty of Nursing, University of Alberta
3rd Floor Clinical Sciences Building
Edmonton, AB, Canada
T6G 2G3
Phone: 780-492-8167 Fax: 780-492-2551
email: gwen.rempel@ualberta.ca

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Co-Investigator:

Jennifer Orton, R.N., BN, MN candidate
Phone Number: **403-592-0626**
email: jennifer.orton@albertahealthservices.ca

Information about the Focus Group

Date of Focus Group	
Location of Focus Group	
Number of Participants	
Moderator Name/ Phone Number	
Assistant Moderator Name and Phone Number	

Responses to Questions

Q1. How do registered nurses define or describe good palliative and end of life care within the neonatal intensive care unit?

Key Points

Q2.How do registered nurses define or describe poor palliative and end of life care within the neonatal intensive care unit?

Key Points

Q3. Are there aspects within the neonatal intensive care unit that registered nurses feel act as supports to the provision of good palliative and end of life care?

Key Points

Q4. Are there aspects within the neonatal intensive care unit that registered nurses feel act as barriers to the provision of good palliative and end of life care?

Key Points

Q5. In what ways do registered nurses feel that supports, to neonatal palliative and end of life care, could be optimized within the neonatal intensive care unit?

Key Points

Q6. In what ways do registered nurses feel that barriers to neonatal palliative and end of life care within the neonatal intensive care unit could be broken down?

Key Points

Q7. How do registered nurses describe their ethical experiences of delivering neonatal palliative and end of life care within a neonatal intensive care unit that is primarily focused on resuscitative care?

Key Points

Appendix F-Data Analysis Table Template

Code # & Name	Potential Theme	Photo(s) #	PW Transcript Line #s	Notes (from theoretical memos, PW PPT comments, Field notes)

Appendix G-Ethics Approvals

University of Alberta

Approval Form

Date: November 29, 2010

Principal Investigator: Patricia Marck

Study ID: Pro00008809

Study Title:

Registered Nurses Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care

Approval Expiry Date: November 28, 2011

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel . Your application, including revisions received today, has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries regarding Alberta Health Services administrative approval, and operational approval for areas impacted by the research, should be directed to the Alberta Health Services Regional Research Administration office, #1800 College Plaza, phone (780) 407-6041.

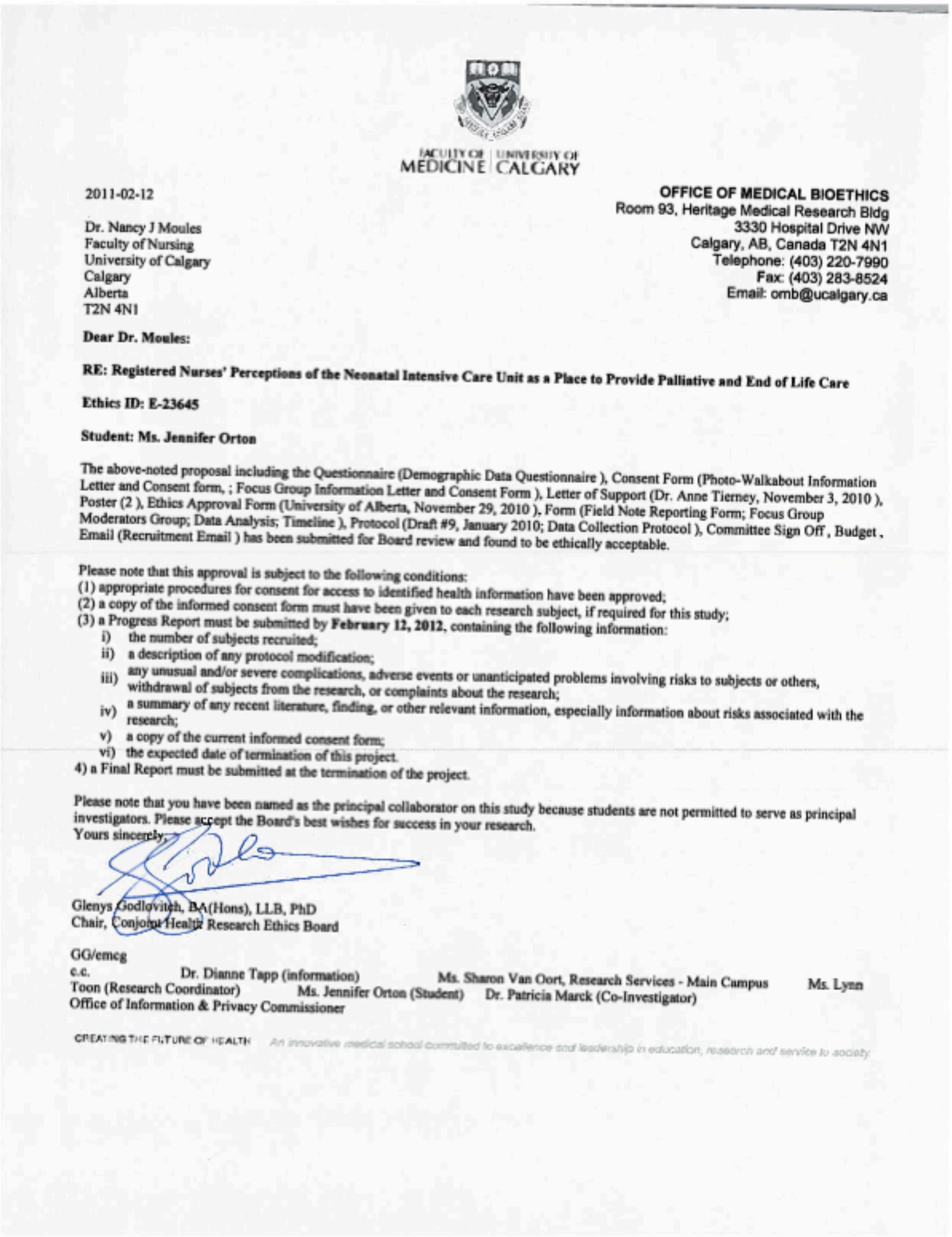
Sincerely,

Doug Gross, Ph.D.

Associate Chair, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).

University of Calgary



FACULTY OF MEDICINE | UNIVERSITY OF CALGARY

OFFICE OF MEDICAL BIOETHICS
Room 93, Heritage Medical Research Bldg
3330 Hospital Drive NW
Calgary, AB, Canada T2N 4N1
Telephone: (403) 220-7990
Fax: (403) 283-8524
Email: omb@ucalgary.ca

2011-02-12

Dr. Nancy J Moules
Faculty of Nursing
University of Calgary
Calgary
Alberta
T2N 4N1

Dear Dr. Moules:

RE: Registered Nurses' Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care

Ethics ID: E-23645

Student: Ms. Jennifer Orton

The above-noted proposal including the Questionnaire (Demographic Data Questionnaire), Consent Form (Photo-Walkabout Information Letter and Consent form, ; Focus Group Information Letter and Consent Form), Letter of Support (Dr. Anne Tierney, November 3, 2010), Poster (2), Ethics Approval Form (University of Alberta, November 29, 2010), Form (Field Note Reporting Form; Focus Group Moderators Group; Data Analysis; Timeline), Protocol (Draft #9, January 2010; Data Collection Protocol), Committee Sign Off , Budget , Email (Recruitment Email) has been submitted for Board review and found to be ethically acceptable.

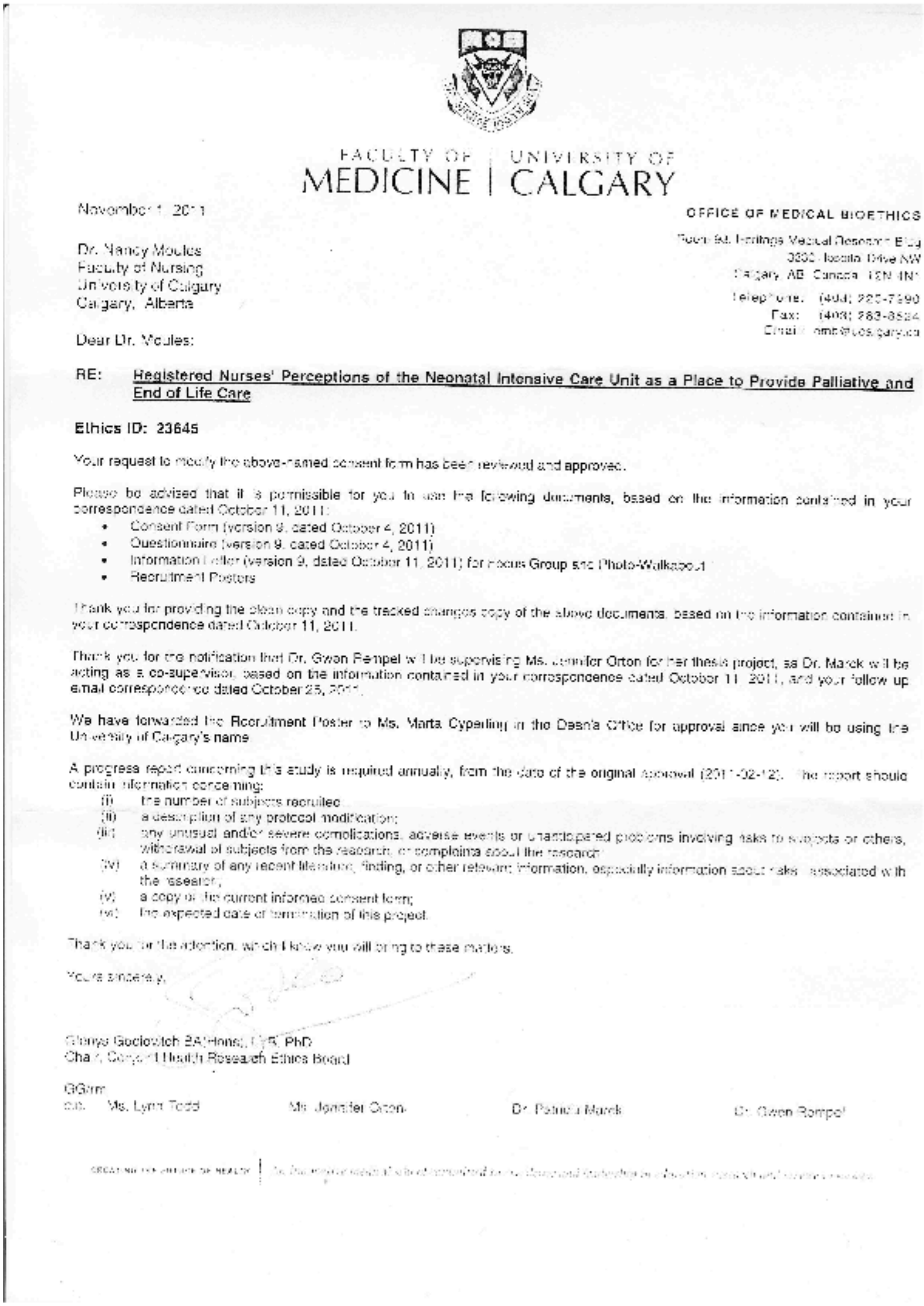
Please note that this approval is subject to the following conditions:
(1) appropriate procedures for consent for access to identified health information have been approved;
(2) a copy of the informed consent form must have been given to each research subject, if required for this study;
(3) a Progress Report must be submitted by **February 12, 2012**, containing the following information:
    i) the number of subjects recruited;
    ii) a description of any protocol modification;
    iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
    iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
    v) a copy of the current informed consent form;
    vi) the expected date of termination of this project.
4) a Final Report must be submitted at the termination of the project.

Please note that you have been named as the principal collaborator on this study because students are not permitted to serve as principal investigators. Please accept the Board's best wishes for success in your research.
Yours sincerely,

Glenys Godlovitch, BA(Hons), LLB, PhD
Chair, Conjoint Health Research Ethics Board

GG/emcg
c.c. Dr. Dianne Tapp (information) Ms. Sharon Van Oort, Research Services - Main Campus Ms. Lynn Toon (Research Coordinator) Ms. Jennifer Orton (Student) Dr. Patricia Marck (Co-Investigator) Office of Information & Privacy Commissioner

CREATING THE FUTURE OF HEALTH An innovative medical school committed to excellence and leadership in education, research and service to society



FACULTY OF | UNIVERSITY OF
MEDICINE | CALGARY

OFFICE OF MEDICAL BIOETHICS

Room 93, Heritage Medical Research Bldg
3330 Hospital Drive NW
Calgary, AB Canada T2N 4N1
Telephone: (403) 220-7990
Fax: (403) 283-8524
Email: omb@ucalgary.ca

November 1, 2011

Dr. Nancy Moules
Faculty of Nursing
University of Calgary
Calgary, Alberta

Dear Dr. Moules:

RE: **Registered Nurses' Perceptions of the Neonatal Intensive Care Unit as a Place to Provide Palliative and End of Life Care**

Ethics ID: 23645

Your request to modify the above-named consent form has been reviewed and approved.

Please be advised that it is permissible for you to use the following documents, based on the information contained in your correspondence dated October 11, 2011:

- Consent Form (version 9, dated October 4, 2011)
- Questionnaire (version 9, dated October 4, 2011)
- Information Letter (version 9, dated October 11, 2011) for Focus Group and Photo-Walkabout
- Recruitment Posters

Thank you for providing the clean copy and the tracked changes copy of the above documents, based on the information contained in your correspondence dated October 11, 2011.

Thank you for the notification that Dr. Gwen Rempel will be supervising Ms. Jennifer Orton for her thesis project, as Dr. Marck will be acting as a co-supervisor, based on the information contained in your correspondence dated October 11, 2011, and your follow up email correspondence dated October 25, 2011.

We have forwarded the Recruitment Poster to Ms. Marta Cyperling in the Dean's Office for approval since you will be using the University of Calgary's name.

A progress report concerning this study is required annually, from the date of the original approval (2011-02-12). The report should contain information concerning:

(i) the number of subjects recruited;
(ii) a description of any protocol modification;
(iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
(iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
(v) a copy of the current informed consent form;
(vi) the expected date of termination of this project.

Thank you for the attention, which I know you will bring to these matters.

Yours sincerely,

Glenys Godlovitch BA(Hons), LLB, PhD
Chair, Conjoint Health Research Ethics Board

GG/rm
c.c. Ms. Lynn Todd Ms. Jennifer Orton Dr. Patricia Marck Dr. Gwen Rempel