

Developmental Observer

The Official Newsletter of the NIDCAP® Federation International

ABSTRACT EDITION

NIDCAP Federation International (NFI)

Founded in 2001, the NFI is an international, non-profit membership organization. The NFI encourages highly attuned implementation of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) for all intensive, special care and newborn nurseries around the world. The NFI serves as the authoritative leader for research, development, and dissemination of NIDCAP, and for the certification of trainers, healthcare professionals, and nurseries in the NIDCAP approach.

“When I approach a child,
[the child] inspires in me two
sentiments – tenderness for what
[the child] is and respect for what
[the child] may become.”

LOUIS PASTEUR

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NIDCAP Trainers Meeting Abstract Edition

Dear Readers,

Welcome to the Third Abstract Edition of the Developmental Observer. In this issue, we publish the abstracts presented at our 28th Annual NIDCAP Trainers Meeting in Edmonton, Canada, October 21-24, 2017. The peer review process led by NIDCAP Trainer Linda Lacina, MSN, RN, HN-BC selected abstracts for presentation based on their relevance, innovation, results, insightfulness and overall clarity and content.

Abstracts include: Newborn Intensive Care Nursery (NICN) Initiatives (“Baby Love Letters”, free parental parking, family mentor program, rounding with parents, and surgical NICU skin to skin care); Education (foundational neurodevelopmental care program, Positive Oral Experiences Training, sleep care nursing educational program, NIDCAP mentored educational program); Research (neurobehavioral profile preterm and full-term comparisons, maternal administration of the EDIN Pain Scale, and neurobehavioral disorganization); and Beyond the NICN (Newborn Bridge Clinic, developmental care, and parental support).

This body of work reflects our members’ and their colleagues’ wealth of knowledge, scientific curiosity, experience and creativity. We are enriched by learning from one another as we continue to evolve our NIDCAP model and its implementation for future generations. The Developmental Observer’s Editors welcome your comments and feedback.

Developmentally yours,
The Editors
Developmental Observer



Participants from our 28th Annual NIDCAP Trainers Meeting (October 21-24, 2017) in Edmonton, Alberta, Canada

An Enhanced Dynamic and Interactive Mentored Educational Program to Teach NIDCAP Principles in the Critical Care Setting

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Background

Clinical and basic science evidence support early intervention as being protective of the developing brain of hospitalized infants. This support can also be stabilizing and nurturing for families as they encounter the healthcare environment. The purpose of this project is to disseminate the most current developmental practices to rehabilitation professionals working in the critical care environment of infants, address consistency of care, and standardize the provision of assessment, treatment and support to infants and families.

Objective

- Test the effectiveness of an enhanced teaching method that tailors Newborn Individualized Developmental Care and Assessment Program (NIDCAP) instruction to individual healthcare professionals.

Methods

A structured model for creating training programs and involving the five steps of Analysis, Design, Development, Implementation and Evaluation (ADDIE) was used by a NIDCAP Professional (KF) to guide and individualize learning in a mentored peer-to-peer training environment. Non-NIDCAP trained therapists (Physical, Occupational and Speech Therapy trainees) were given pre-mentoring, interim, and post-mentoring surveys to assess perceptions and gaps of knowledge in NIDCAP principles. Trainees completed interim and post-mentoring surveys of the mentor based on the principles of reflective supervision. Survey results were used throughout the intervention period to improve implementation. Knowledge gaps were discussed with each trainee to facilitate an individualized approach to learning. The NIDCAP evaluation form was used to identify coping versus worrisome infant behaviors and how those behaviors would affect the trainee's

interactions with the infant, family and staff. Once permission was obtained from staff to observe an episode of care, the mentor and trainee participated in a series of three bedside observational assessments led and facilitated by the mentor. Sessions included an interactive discussion between mentor and trainee regarding assessment of the physical environment while providing real-time descriptions of infant behaviors related to staff interactions and impact of the environment. At least one of the observation sessions occurred with the infant's family present. NIDCAP training materials were used to guide and structure the peer-to-peer discussion. Learners were guided in the use of a structured format (AMSAS – Autonomic/Motor/State/Attention/Self-regulation) to formulate a NIDCAP evaluation and goals.

Conclusions

Use of a structured, yet individualized training model that includes peer-to-peer interactions at the bedside with ongoing bi-directional mentor-trainee feedback has the potential to improve parent-infant development within a critical care setting by accelerating adoption of NIDCAP principles. This mentored instructional approach may also increase healthy working relationships and create new champions for family-centered developmental care.

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Contributions

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NICU Baby Love Letters

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Background

In supporting the relationship between parents and their baby, it's important for providers in the newborn intensive care unit (NICU) to understand how parents view their baby. Research shows a parent's view of their child will impact how they interact and how they parent. Many parents start to imagine and attach to their baby while the baby is still in the womb. This time is shortened for NICU parents, sometimes nearly in half. It is critical to understand how a NICU parent views their child, how they imagine who the baby already is and to help them create a rich and full understanding of their child's strengths and challenges in the NICU and beyond. As we support NIDCAP, the University of Illinois (UI) Health NICU created *Baby Love Letters* written from the voice of the newborn to help parents bond, understand and support their baby while in the NICU.

Objectives

- Help parents develop an understanding of their infant's unique experience in the NICU.
- Support parents to feel confident interacting and bonding with their baby.
- Provide a sentimental, informational and easy to use tool for parents to foster the emerging parent-infant relationship and support development of their baby.

Methods

The UI Health NICU piloted the *Baby Love Letter* program in January 2017 by crafting templates using *Parenting Based on the Developmental Progression of Preterm Infants* (Children's Medical Ventures 2006) as a guide. Distinct from NIDCAP observations, the templates are written in the first person from the baby to his/her parent(s). The baby's primary therapist, using a synactive theory approach, individualizes the templates. The letters are provided to the family as well as entered into the electronic medical chart.

Since January, parents with a baby born at 29 weeks and younger were invited to receive a love letter every two weeks. All parents, 17 families with 21 babies, opted to receive the letters. Oral feedback regarding the experience of receiving the letters was obtained during hospitalization. Quantitative data was also gathered near discharge using a survey designed to capture the mother's attitude towards her child and her feelings of closeness to her child as well as her role as a mother. During this initial period, two babies in the program died. The letters may be a valuable resource in grieving and remain a keepsake for these families.

Conclusions

The goal of the *Baby Love Letters* is to help parents see their baby as a unique being, and support them in their parenting role. Oral feedback from parents during their NICU stay included:

- A mother of twin boys stated she would like to frame the first letter because it was the first thing she received signed by both her boys. Later, this mother said she used the letters to help engage the anxious father, who at first was skeptical because the letters were written in the "baby's voice", but now he really likes them, especially how they are individualized to each baby. The mother used the letters that discussed skin-to-skin holding with him to help him build the confidence he needed to provide kangaroo care.



Christyn Davis reading a love letter from her daughter, Cailynn

- Another mother posted the first letter on Facebook and proudly reported it received 107 likes. She was excited to have her friends and family read the letter from her very small 26 week baby girl. The mother expressed gratitude, saved the letters in a scrapbook, and reads the letters often, although she reported they make her cry "in a good way." The mother waits to open her letters until her baby's father is with her, like a ritual. He usually reads the letters out loud to her.

Results of the written surveys given at discharge were evaluated. At this time, six surveys have been collected. All mothers' either *Agreed* or *Strongly Agreed* on the following statements:

- I feel secure taking the responsibility of caring for my baby (e.g., changing diapers, bathing, tucking into bed).
- I feel my baby likes to have contact with me in the form of touch, voice, scent, eye contact (all separate questions).
- It was easy for me to assume my role as a mother.

Additional feedback:

- Please describe your experience receiving love letters from your baby:
- "I LOVED THEM! Even though I know it wasn't from her literally, it felt like everything she would say. I always felt warm reading them and they were a huge help in getting me through."
- "Oh my God I loved the letters. They were amazing."
- "I liked it. It was a good experience because I learned things I didn't know she would like - like she likes her head rubbed!"
- "I enjoyed reading them. They helped me feel like I was included in his development. It provided great ideas and clues regarding the things he was going through. Although I know other mothers receive the same letter or are very similar, it felt very personal and went according to my son's development."

Continued on page 11

Newborn Bridge Clinic to Support Infant Transition Home

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Background

High risk and premature infants are discharged from the newborn intensive care unit (NICU) when they consistently gain weight, maintain their body temperature, are able to eat by mouth, have had their medical problems addressed with a plan of care, their parents and family are comfortable with the care required and the discharge teaching has been completed. The decision for discharge home is individualized to best meet the needs of the infant within the context of his or her family's readiness. Despite this, often parents feel this is an anxious and difficult time. The current follow up program, in collaboration with a nearby large hospital system, provides periodic developmental check-ups for infants discharged from the NICU. Parents can arrange for this service through their pediatrician or family medicine physician. The typical schedule begins at three months corrected age. For example, if an infant was born at 28 weeks gestation (three months early), their first visit with the Neonatal Follow-up Program may be when they are six months old in chronologic age. The majority of infants are discharged from the NICU by the time of their original due date and some are discharged even sooner, perhaps a month earlier if they are doing well and have met discharge criteria. This leads to a situation of families, having experienced tremendous therapeutic support for weeks and months in the NICU, being discharged home with a gap of three to four months before they may begin newborn follow up.

Objectives

- Infants and families receive support during the transition from hospital to home and community.
- Parents gain greater understanding of their infant's behavior with anticipatory guidance for caregiving to enhance maturation and development while strategizing ways to support the infant's vulnerability.
- The neurobehavioral assessment, the Assessment of Preterm Infant Behavior (APIB), will be performed every two to four weeks to monitor the infant's emerging neurobehavioral organization and self-regulation, as well as the parents' increasing degree of both competence and confidence in parenting.
- The infant's primary care provider will be supported with consultation and expertise to monitor the infant's transition.

Implementation

This Newborn Bridge Clinic is a new innovative approach to "mind the gap" and support infants and families as they leave the hospital and transition home during the three to four months before they will be seen in a newborn follow up clinic. The Clinic provides neurobehavioral assessment for screening and intervention, and medical co-management of the infant's medical needs in collaboration with the infant's primary health care provider.

The Bridge Clinic begins within the NICU with the formation of supportive relationships to be continued through the transition to home and the community. The physicians, clinical nurse scientist and nutritionist facilitate this transition and provide the crucial safety net for those with complex medical conditions. Infants born prematurely and/or who have special medical or social problems are seen in the Bridge Clinic one to two weeks after discharge and at intervals ranging from one to four weeks depending on the specific needs until they enter the current neonatal follow up program in collaboration with the larger collaborative hospital.

Individualized care is provided through the multidisciplinary team assessing the infant's health, nutrition, growth, temperament and development as well as the parents' degree of comfort and ability to provide nurturing care especially around the issues of feeding, sleeping and crying. Parents are supported in gaining both confidence and competence in providing the sometimes very complex medical needs for these fragile infants. The provision of positive reinforcement of parenting and anticipatory guidance supports families in their transition from the newborn intensive care unit to their home and community.

The Bridge Clinic provides written summaries to communicate with the infants' primary medical care providers following each clinic visit and collaborate as needed to supplement their primary medical care. This may involve referrals for visiting nurses, early intervention and other programs within the family's community. Management of the special medical needs of these infants' (e.g., medications, feeding problems, chronic conditions such as lung disease, apnea monitor care) and ongoing developmental assessment and intervention assures the infant's best growth and development.

Summary

Success of the Bridge Clinic will be evaluated through statistics and measurements including:

- Number of infants seen in the Bridge Clinic.
- Rate of rehospitalization within the first six months following discharge from the NICU.
- Summary scores of the neurobehavioral evaluation (APIB) to show increasing maturation and neurobehavioral organization.
- Growth patterns of the infants.
- Parent engagement measured through the NICU Parent Risk Evaluation and Engagement Model and Instrument (PREEMI).
- Successful entry into the traditional newborn follow-up program at three months corrected age.

Statement of Financial Support

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The Impact of a New Model for Rounding with Parents on Families and Professionals

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Background

Parental stress impairs parents' ability to interact optimally with their infants and may lead to poor child developmental outcomes.¹ One of the most recommended suggestions for supporting parents' roles as caregivers is parent participation in medical rounds.² Some gaps have been demonstrated, however, between the goals of family centered care and its actual practice.³ There is debate about the pros and cons of facilitating parental participation in the newborn intensive care unit (NICU) and in rounds, with most reports not providing a clear determination of best practice.⁴ Most of these studies were conducted in the United States, Australia, and a large number of countries in northern Europe. Nevertheless, the incorporation of family centered care is not widely used in the countries of southern Europe.⁵

Objectives

The hypotheses of the study was that implementation of a new model for including families in medical rounds based on family-centered care in the NICU, the adapted family-centered care model (AFCR), will not decrease parent satisfaction, will not increase parent stress, and will improve professional satisfaction compared to the traditional rounding model (TR). The primary aims of the study were to compare the level of stress and the degree of family satisfaction, as well as the degree of professional satisfaction between both models of rounds. The secondary aim was to define the characteristics of parents who chose the AFCR model.

Methods

In April 2016, the new AFCR rounding model, which included parent involvement, was implemented in the NICU. From this moment on, parents could willingly choose to participate in clinical rounds. Data collection was performed between June 2016 and December 2016 with surveys given to parents and professionals. Prior to implementation of the AFCR model, prospective data collection was also performed from October 2015 to March 2016, when parent participation in medical rounds (TR model) was nonexistent. Three groups of parents were defined: those who decided to participate willingly in rounds (group 1), those who decided not to participate in rounds when they had the possibility to participate in this (group 2), and the parents of the previous period in which they didn't have the possibility to participate in rounds (group 3). Three groups of professionals were also defined: those professionals whose parents of their patients decided to participate in rounds (group A), those professionals whose parents decided not to participate in rounds when they had the possibility to participate (group B), and those professionals of the previous period whose parents did not have the opportunity to participate in rounds (group C).

The study was performed in a level IIIC NICU with 900 admissions per year and an affiliated NIDCAP Training Center. All resident doctors, assistant physicians and nurses were offered participation in the study. Parents were included if their newborn was in the NICU at least seven days, parents agreed to participate in the study and signed the informed consent. Parents were excluded from the study if there was a language barrier and/or if they were less than 18 years old.

When an infant had been in the NICU at least one week, both parents were offered an assessment. The assessment consisted of two questionnaires: the Parental Stress Scale: Neonatal Intensive Care Unit (PSS:NICU)⁶ and the Neonatal Instrument of Parent Satisfaction (NIPS)⁷, as well as additional questions about education and demographic data. Both questionnaires were completed twice: on the seventh day of hospitalization and on the day of discharge from the intensive care room. A questionnaire was distributed to staff on the day of discharge.

Results

Recruitment included 47, 26 and 63 parents (Groups 1, 2 and 3 respectively) and 37, 29 and 63 professionals (Groups A, B and C, respectively). Response rates were 87.2% for parents and 78.5% for professionals. There were no significant differences in anxiety or satisfaction between the three groups of parents. The professional Group A had higher scores on the satisfaction scales than Group B (4.38 ± 0.64 vs 3.97 ± 0.68 , $p = 0.04$). The parents of Group 1 had baseline anxiety scores generated by alarms higher than those of Group 2 (8.73 ± 4.55 vs 10.79 ± 4.74 , $p = 0.04$). Parents showed significantly higher scores in three of the five questions about the utility of the new model for parents than the professionals.

Conclusion

Implementation of a rounding model that allows participation of parents in a NICU does not increase parental stress or decrease family satisfaction. This practice increases professional satisfaction and was not perceived to further inhibit clinical discussion or teaching in clinical rounds. The parents who were more stressed by the sounds and the alarms of the unit preferred to participate in medical rounds.

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Implementing Skin-to-Skin Care and Alternative Touch Methods in a Surgical Newborn Intensive Care Unit

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Background

Sensory experiences of infants in the newborn intensive care unit (NICU) are vastly different from those that are biologically expected. The NICU environment can adversely impact the preterm infant's rapidly developing brain.¹⁻³ Subsequent alterations in the preterm infant's cognitive, physiological, emotional, and social development may persist beyond the NICU.^{1,4-6} Engaging parents in learning their vulnerable infant's unique abilities and challenges enhances the quality of parent-child relationships, which is critical for optimal neurodevelopmental outcomes.⁷⁻¹² Skin-to-skin care (SSC) promotes parental participation, strengthens the family role in the care of the fragile infant in the NICU, decreases parental feelings of helplessness, and increases responsiveness to the infant's behavioral communication.^{13,14} Improved neurodevelopmental outcomes, autonomic functioning, quality of sleep, growth, physiological stability, and attenuated stress and pain responses are associated with SSC for preterm infants.¹⁵⁻¹⁷

The evidence for SSC is primarily drawn from preterm or healthy term newborns. Despite growing recognition of similar adverse neurodevelopmental outcomes for infants born around term requiring surgery shortly after birth,¹⁸⁻²¹ there is limited literature specifically discussing the use of SSC in this population. Interventions are needed to address potentially modifiable risk factors. Surgical infants may not be able to be held in traditional SSC. Factors related to their specialized care make providing SSC challenging including wires, tubes, machinery, surgical wounds, environmental constraints of the unit, perceived fragility of the infant, and uncertainty of the safety or feasibility of SSC. Parent touch techniques provided in a responsive and synchronous pattern can attenuate infant stress responses and improve parent-child interactions, thus improving family resiliency and functioning beyond the NICU.^{11, 22-24} Support for alternative interventions promoting parent touch may be an important sustainable link in helping these infants achieve optimal neurodevelopmental progress in the surgical NICU and beyond.

Objectives

- Outline implementation of an initiative focusing on SSC and alternative touch methods within the context of a developmental care program in a surgical NICU.

- Discuss educational strategies used during implementation.
- Describe adaptations necessary for success within a surgical NICU.
- Highlight challenges experienced during implementation.
- Outline plans for evaluation.

Approach

Prior to December 2016, SSC was infrequently and inconsistently practiced in this unit. The multidisciplinary initiative was implemented over three months in an 18-bed level III NICU that cares for newborns transferred from other facilities with surgical and/or cardiac conditions pre- and post-operatively. When unable to be held in traditional SSC, the initiative encouraged parental alternative touch methods including: (a) cradle holds with skin contact, (b) side-lying SSC, (c) skin contact while infant is in bed using arm encirclement, and (d) responsive parent touch such as supporting finger grasps or hand swaddling based on infant behavioral communication. Although seemingly simple, SSC and alternative touch methods were difficult to integrate into the highly technological, rapid-turnover NICU. Paired with the intensive monitoring and medical support provided to the infants, the physical environment and staff attitudes also presented as challenges. A systematic and adaptive approach was necessary to address the unit's challenges and staff apprehensions, by allowing ample opportunity for engagement, discussion, and critical reflection.

A multidisciplinary team created a comprehensive SSC package. Pictorial and written tools were developed for staff and parents prior to implementation. Parent resources, created with input from the parent advisory council, outlined the benefits of SSC, introduced safety guidelines, and provided a description of both traditional SSC holding and alternative touch methods. Staff guidelines paralleled parent resources, with greater depth and complexity. These tools were used to facilitate discussion and ongoing review between staff and parents. Staff and family collaboratively determined the most appropriate and feasible method of SSC based on a holistic assessment of the infant. These team discussions also addressed perceived barriers and determined any modifications needed to ensure safety and

comfort. Journal articles addressing SSC and touch were posted to the online staff communication forum. Although attempts to engage staff in online critical analysis of the articles were difficult, staff engaged in dialogue about article content during education sessions. Low-fidelity mannequins were used to conduct SSC and standing transfer simulations to support staff in learning to navigate the challenging physical constraints of the environment and problem-solve issues that may arise in a safe and anticipatory manner. Once approximately one-third of staff had participated, simulations were no longer deemed necessary by staff. The focus changed from simulations to learning through peer mentorship, with multidisciplinary SSC champions guiding the team in-the-moment. Those comfortable and supportive of the initiative acted as champions for knowledge translation, modelled the safety and efficacy of the initiative, and began to foster this as a socially acceptable change in practice.

A questionnaire will be distributed to staff to assess attitudes and perceptions surrounding the integration of SSC and alternative touch methods into practice. An audit tool is being developed to assess SSC and alternative touch frequency and to capture challenges experienced by staff and parents. Results will guide continual improvement and future direction.

Summary

The initiative was applied systematically due to the medical complexity and high acuity of the tenuous patient population, the human and material resources needed to facilitate SSC, the challenging physical environment, and staff apprehensions. The healthcare team's clinical judgment was respected in establishing the balance of the infant's medical care with the equally important neurodevelopmental and social-emotional needs to determine the most appropriate and feasible type of touch over time, which fostered participation in the initiative. The fluidity and adaptability in the initiative was critical to providing responsive, infant-centered, and family-inclusive care at all stages of the infant's illness and convalescence. Adoption of these practices has not been fully embraced by all staff. Continued efforts must focus on supporting staff integration of SSC and touch as essential, routine components of care.

It is anticipated the benefits of SSC for cardiac and surgical infants will parallel those observed in the preterm and healthy term populations. Delineating neurodevelopmental outcomes specifically attributed to SSC and alternative touch methods may be challenging given the many potential confounders. Future research and discussion regarding the impact of these interventions on the neurodevelopmental outcomes of infants in the surgical NICU is warranted.

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From TIMP to Toddler: Developmental Care from NICU to Home

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Background

In September 2013, the 20 bed Level II newborn intensive care unit (NICU) at South Health Campus (SHC) opened. This hospital is unique in Calgary in that the mission statement of the care provided at the hospital is based on four pillars of innovation, wellness, collaborative practice and patient/family centered care. These pillars are well aligned with the principles of NIDCAP. Most NICUs in Alberta do not have dedicated full time equivalent (FTE) positions for occupational therapy (OT) or physical therapy (PT) services and provide care only by consultation. In accordance with the mission statement of SHC, pediatric OT and PT roles were developed, and dedicated positions were allocated for both of these allied health professionals. In December 2015, a 0.6 FTE OT was hired, followed by a 0.5 FTE Physical Therapist in July 2016. Their roles were to support the NICU and the two outpatient Pediatric Clinics for consultation including feeding, musculoskeletal conditions and plagiocephaly. Additionally, these therapists, in conjunction with the site lead neonatologist, agreed to pilot a program in the NICU beginning in November 2016. For this program, the therapists assess all babies born at less than 34 weeks gestation and weighing less than 1500 grams using the Test for Infant Motor Performance (TIMP) prior to discharge at approximately 36 weeks post-menstrual age (PMA). The NICU therapists also supported the outpatient Pediatrics Clinic where some NICU graduates are seen by parent choice, usually due to proximity to their home. Parents were encouraged to ask for developmental support if needed; the pediatrician made referrals to OT and PT when indicated. The therapists also started a developmental play group for families who were receiving individual care. Parents attended every two weeks for six sessions. The play group allowed for more frequent visits, while being more financially and time efficient for the therapists.

Objectives

- Use the TIMP as a framework for assessing motor development in the NICU and post-discharge for babies with increased risk for developmental delay.
- Educate parents about typical development and how to promote motor development through play.
- Provide a seamless model of developmental care from NICU to home.
- Highlight opportunities for developmental play at home.

Approach

All babies born less than 34 weeks gestation weighing less than 1500 grams were offered a TIMP assessment which was done

at approximately 36 weeks PMA at the earliest, and was typically done in the week prior to discharge home. If the baby was discharged home over a weekend and the assessment was missed, it could be completed in the Pediatric Clinic post-discharge if they were referred to the Pediatric Clinic at SHC. If they had a community pediatrician, this was not possible.

Parents were encouraged to be present for the assessment. After the assessment, the age equivalent score was provided to the parents as well as some specific developmental suggestions for play, based on the assessment results. A general developmental play handout was developed and provided to the caregiver and reviewed to ensure understanding. Parents were given the therapist contact information and were encouraged to contact therapists if there were further questions or concerns.

Babies who attended the Pediatric Clinic also had the opportunity to be involved with a biweekly play group. All allied health professionals were available to consult at the play sessions, with PT and OT present at every play session. The play group offered not only the opportunity for discussion about motor development, but was also helpful to parents in accessing community services, forming relationships and establishing a support network. Parents' evaluations of the playgroups were very positive. TIMP results and parent evaluation forms from the playgroup were collected.

Conclusion

Initially, there was no defined role for either the OT or PT to participate in daily care in the NICU other than for specific consultations for feeding, musculoskeletal conditions (e.g., club foot, brachial plexus injury) or plagiocephaly concerns. This program at the SHC site highlights the importance of developmental care in promoting motor development for preterm and very low birth weight infants not only in the NICU, but also after discharge home. Parents are gaining a greater understanding about the importance of developmental play from a very early age, as well as how to understand the foundational nature of achieving developmental milestones. Parents are also supported in providing developmentally appropriate play opportunities for their children and help foster improved parent-child interaction.

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Statement of Financial Support

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Implementation of a Newborn Intensive Care Unit (NICU) Family Mentor Program

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Background

Having a preterm or full-term baby in the NICU is a stressful and emotional time for families. Often the most effective family support comes from connecting with other families who have had a similar lived experience. Such peer support has been a priority of the Stollery Children's Hospital's NICU Family Advisory Care Team (FACT) since its inception in 2010.

Objective

- Create a NICU Family Mentor Program

Methods

Following success of the Stollery Family Bedside Orientation Program, a one-to-one bedside peer support program on an inpatient pediatric unit, the NICU Family Mentor Program was created in the 69 bed, non-surgical NICU in June, 2016. The program was designed to further a culture of patient and family centered care, by supporting families in providing care for their infant and engaging with their child's healthcare team through meaningful interactions between inpatient families and peer mentors.

Family Mentors are recruited through the Stollery Patient & Family Centered Care (PFCC) Network and through a Facebook page for NICU graduates. Interested parents are considered for the Family Mentor role if they had experience with a child in the NICU and can commit 10-12 volunteer hours per month over a year. Family Mentors complete eight hours of training and an interview with the Stollery PFCC Coordinator to learn more about peer mentoring and explore their readiness to support families at the bedside. Training includes in-class instruction and role playing activities which emphasize peer mentor skills and attributes, such as:

- Strong listening and communication skills.
- Awareness of the role and of the responsibilities and boundaries of a peer mentor.
- Ability to support families by using inclusive language and without passing judgment, creating emotional dependency or influencing family decisions.
- Ability to recognize when it is necessary to debrief or ask for help from a Stollery PFCC staff member or a health care professional.

All Family Mentors are brought on as hospital volunteers which requires completing criminal record and vulnerable sector clearances,

reference checks, baseline health screening, and signing a confidentiality agreement before interacting with families. Novice Family Mentors complete their first three volunteer shifts in tandem with a veteran Family Mentor before independently visiting families.

Family Mentors visit inpatient families at their infant's bedside every two weeks and engage them by being a listening presence and having open, honest, judgement free conversations fostering strength, empowerment and hope in the inpatient family.

At the beginning of each shift, Family Mentors check in with the charge nurse or unit social worker to learn which families are new to the unit and could benefit from a visit. Other pertinent information is also shared at this time. This professional oversight helps prevent Family Mentors from accidentally entering into emotionally volatile or intense situations requiring conduct and expertise beyond the scope of their role.

Family Mentors begin each visit by introducing themselves and the Family Mentor Program. They emphasize their role as non-medical staff available to provide a listening presence for families. As well as acting in this role, Family Mentors aim to enhance family knowledge with information about:

- The unit and hospital environment.
- Best practices for patient safety.
- How to participate in a child's care and care team.

A formal evaluation of the Family Mentor Program will soon be available. Anecdotal evidence collected from inpatient families and staff members indicate the program has had a positive effect. Many families indicated their appreciation of Family Mentor visits and one staff member remarked, "It's good to see Family Mentors here. We have lots of new families who could use a visit." Expanding the program to provide peer support for breastfeeding mothers and for families on the antepartum unit is currently being explored.

Conclusion

The Family Mentor Program is a promising model supporting families in their role of actively caring for their infant children and participating in their health care decisions. Through this program, one-to-one bedside peer support has become a complementary but essential resource available to families navigating what at times can be a complex and challenging experience.

Statement of Financial Support

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The EDIN Pain Scale Administered by Mothers in the Newborn Intensive Care Unit (NICU): Validation of a New Pain Assessment Model

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Introduction

Preterm babies in the NICU are exposed to acute and chronic pain. Parents are concerned about the pain of their baby and this concern is associated with a higher level of parental stress. Parents want greater involvement in infant pain prevention and management. The EDIN scale is used by nurses to evaluate prolonged pain and includes only behavioral items routinely observed by parent and nurse caregivers during everyday care (e.g., quality of sleep, facial expression, body movements, interaction with the caregivers, consolability).

Objectives

- Primary objective: Evaluate the feasibility of parental involvement in the use of the EDIN scale by comparing EDIN scores, contemporaneously and blindly recorded by the attending nurse (EDIN-N) and by the mother (EDIN-M).
- Secondary objective: Assess the level of mother's stress at the time of NICU discharge by the administration of the *Parental Stress Scale* (NICU).

Methods

Study Design

An experimental clinical prospective monocentric study design was employed in a level 3 NICU that provides NIDCAP-based care and is open 24 hours a day to parents. Inclusion criteria encompassed newborns receiving pain assessment using the EDIN scale according to NICU protocol and for whom informed consent was obtained. Non-Italian native-speaking mothers and mothers unable to stay for at least four hours with their baby during at least one of the three nursing shifts (morning, afternoon or night shift) were excluded.

Study Phases

Within the first week of hospitalization, the mother or both parents met with two NIDCAP professionals and one nurse. During this meeting, the booklet, "How to help our children to prevent stress and pain in the NICU", supported by multimedia materials subsequently given to parents, was used to show parents how to recognize pain with special attention to the items of the EDIN score and how help to relieve pain. Within one week following the first meeting, a second meeting was proposed

to reinforce the information and to clarify doubts. At discharge the mother's stress level was measured by a psychologist using the *Parental Stress Scale* (NICU).

Data collection and analysis

Maternal and newborn data were collected and recorded in an Excel database file. The type of respiratory support, sedation, surgery, venous lines, feeding mode, postnatal age, and any painful maneuvers were also recorded. Data were analyzed by statistical package SPSS 13.0. Non-parametric statistics were used to analyze EDIN scores that did not fit normal distribution. An alpha error < 5% was considered significant.

Results

Here we present preliminary data on 179 EDIN scores that were contemporaneously recorded by nurses and mothers (8) in twelve newborns at a mean postnatal age of 34 ± 15 days of life (range 11 to 70). Mean birth weight of recruited newborns was 1300 ± 500 grams. Overall, both EDIN-N (median 0, range 0-3) and EDIN-M (median 2, range 0-12) were below the threshold of pain. EDIN-M were significantly higher compared with EDIN-N (Mann-Whitney test, $P=0.000$, fig. 1). The difference between EDIN-M and EDIN-N is shown in fig. 2. In 24% of cases, EDIN-M and EDIN-N were identical, in 64% of cases EDIN-M was higher than EDIN-N, and only in 12% of cases EDIN-N was higher than EDIN-M.

EDIN-M, but not EDIN-N, showed a positive significant correlation with painful maneuvers performed during the period of EDIN score recording (Spearman's rho, $P=0.041$). EDIN-N, but not EDIN-M were significantly lower ($P=0.02$ for EDIN-N) in the morning compared with the afternoon.

The mother's level of stress measured by the *Parental Stress Scale* at discharge was not statistically different from a score obtained from a comparable group of 14 mothers (71 ± 15.6 versus 60.56 ± 16.1 , $P=0.02$) studied before the beginning of this study protocol.

Conclusions

Mothers willingly agreed to participate in the study and their level of stress at discharge was comparable with that of mothers not participating at the study. Even when both median EDIN-N and EDIN-M were below the threshold of pain, mothers' scores

were more modulated compared with nurses' scores. Moreover, EDIN-M scores correlated more with painful procedures. Nurses, but not mothers, attributed lower pain scores during the morning compared with the afternoon shift, maybe underscoring signs of pain and stress during hours with higher level of activity. Our data confirm those reported by other authors who suggested an "institutional insensitivity" of health professionals to signs of stress and pain in infants, with health professionals becoming slightly habituated to patient pain signs due to extended exposure.

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Statement of Financial Support

All authors have no financial relationships with commercial entities to disclose.

FIGURE 1.

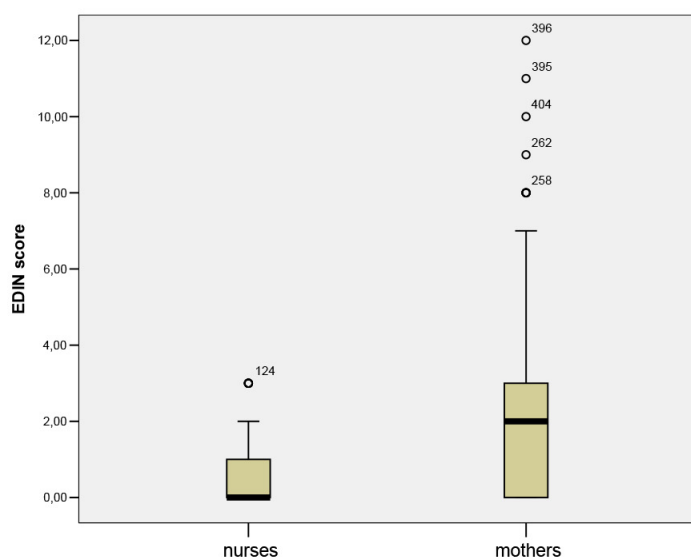
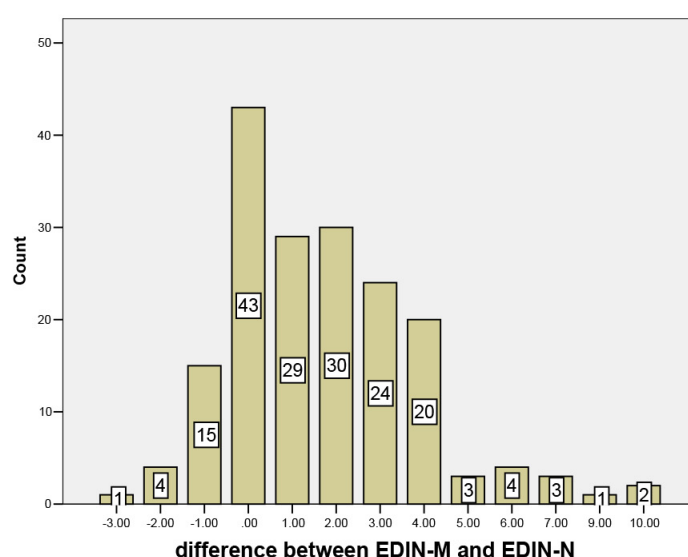


FIGURE 2.



NICU Baby Love Letters Continued from page 3

- Parental examples of "Three words to describe your baby":
 - Silly, quiet, explorer
 - Strong, beautiful, blessing
 - Feisty, precious, demanding
 - Mighty, determined, responsive (aware, receptive)

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Implementing a Foundational Newborn Neurodevelopmental Education Program: One Center's Experience

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Background

Inconsistency in the application of neurodevelopmentally supportive practices continue to be reported in the literature with implementation described as sporadic, variable from setting to setting as well as from one professional to the next.¹ Foundational education is recognized as a core component supporting the provision of care,² yet clinicians frequently do not receive adequate training to differentiate the nuances of infant behavioral communication nor to implement practice change associated with neuroprotective care.³ A gap continues to exist between high level specialist neurodevelopmental care training and the capacity for this training to be offered in all newborn settings. Foundational training programs offer an opportunity to train a broad population and establish a framework for specialization.

Objectives

- Identify the value for NIDCAP Training Centers to facilitate foundational developmental care education programs.
- Consider how foundational education programs can help support practice change.

Methods

In 2017 a center in Australia implemented a foundational neurodevelopmental care program designed and delivered by certified NIDCAP Professionals. The program is presented as an interactive 1.5 day workshop. Six essential themes are explored in the program which embraces a relationship-based approach to care. The themes include:

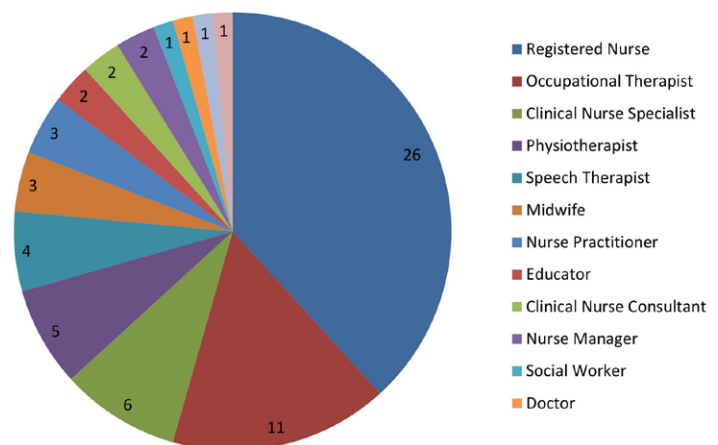
- Development: Fetal and infant growth and development and the influence of experience on development.
- Observation: The importance of seeing and responding to the baby in clinical practice.
- Family: Family participation is essential for the successful implementation of neuroprotective care.
- Reflection: Self-knowledge and learning through experience.
- Systems: Strengths and challenges in work environments.
- Evidence: Best available evidence to support neuroprotective care.

Since its commencement in February 2017, 66 neonatal unit staff (refer to figure one) have attended the program. Feedback from the program has been overwhelmingly supportive with expansion of the program in June 2017 to other states in Australia and to New Zealand. Program attendees were surveyed

and asked to identify their level of confidence on a five-point Likert scale in delivering individualized developmentally supportive care prior to and immediately post completion of the training. Forty eight (72%) of the 66 attendees completed the survey. Nurses indicated the overall lowest level of confidence in delivering developmentally supportive care prior to undertaking the program 3.5/5 (average confidence level). Fifty two percent of respondents indicated a one point increase in confidence after completing the program, with 12% identifying a two point increase and 33% not identifying an effect on their confidence levels.

The overall program was rated as very good by 81% of respondents with the remaining 18% rating the program as good. Eighty one percent of respondents identified they were likely to implement components from the program in their clinical practice or work environment. One hundred percent found the program content relevant to their profession and role in the newborn unit.

FIGURE 1. Outlines program attendance numbers for professional groups



Following completion of the program, participants are enrolled in a Graduate Group and sent a monthly newsletter and journal articles to promote ongoing engagement. A follow-up survey was circulated to program graduates three months after program completion to explore translation of program concepts to clinical practice and clinician/unit based promotion of practice change. Two units in the follow up survey had implemented unit based developmental care work groups (Pediatric Intensive Care and Pediatric Cardiac Unit) to address practice inconsis-

tencies and promote evidence based practice. A speech therapy department reviewed positioning of infants during procedures and incorporated supportive positioning techniques identified in the program. Respondents identified, *'I personally have noticed a significant change in my daily nursing practice already', 'I see babies in ways I hadn't noticed before' and 'this should be a program all staff in neonatal units attend'.*

Conclusions

Implementation of a robust foundational neurodevelopmental education program was found to reinvigorate staff interest in developmentally supportive practice, dispel myths and link evidence to clinical care, promote NIDCAP and raise the profile of a training center and its staff while also providing financial revenue to support maintenance of the center.

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The Gold Standard for Excellence in Newborn Individualized Developmental Care

What All Newborn Infants and Their Families Deserve

Newborn Individualized Developmental Care and Assessment Program (NIDCAP)

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP), originated in 1984 by Heide-ise Als, PhD, is the only comprehensive, family centered, evidence-based approach to newborn developmental care. NIDCAP focuses on adapting the newborn intensive care nursery to the unique neurodevelopmental strengths and goals of each newborn cared for in this medical setting. These adaptations encompass the physical environment and its components, as well as, the care and treatment provided for the infant and his or her family, their life-long nurturers and supporters.

Assessment of Preterm Infants' Behavior (APIB)

The Assessment of Preterm Infants' Behavior (APIB) (Als et al., 1982) is a comprehensive and systematic research based neurobehavioral approach for the assessment of preterm and fullterm newborns. The APIB provides an invaluable diagnostic resource for the advanced level clinician in support of developmental care provision in a nursery.

NIDCAP Nursery Program

The NIDCAP Nursery Program provides a comprehensive resource for the self- evaluation by a nursery system of its strengths and goals for integration of NIDCAP principles into all aspects of their functioning. Highly attuned implementation of NIDCAP care for infants and their families, as well as for the staff, in a developmentally supportive environment is a goal as well as a process. External review and validation by the NFI may be sought when a nursery feels it has achieved this distinction. Nurseries that have achieved NIDCAP Nursery certification serve as a model and an inspiration to others. For information on the nursery self-assessment resources as well as the certification process and its eligibility requirements, please see: www.nidcap.org; and/or contact Rodd E. Hedlund, MEd, NIDCAP Nursery Program Director at: nnacpdirector@nidcap.org or 785-841-5440.

Neurobehavioral Disorganization (NBD) as a result of Targeted Newborn Echocardiography (TNE) in extremely preterm infants – a pilot study

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Background

Stress is a disturbance of the dynamic equilibrium between body systems and environment. Repeated stress, inherent in the newborn intensive care unit (NICU), is related to negative consequences for extremely preterm infants. Various tools are available to identify stressful responses to caregiving in the NICU. These tools could also help clinicians reduce the stress of various interventions. Stress is inferred from the observation of neurobehavioral disorganization (NBD), although the different tools differ in their ability to recognize subtle signs of NBD. The Synactive Theory of Development provides a framework whereby changes in infant neurobehavior can be interpreted in the context of ongoing interventions.¹ The Newborn Individualized Developmental Care and Assessment Program (NIDCAP®) model of caregiving is based on the Synactive Theory and requires caregivers to be observant of these subtle signs of NBD.

Targeted Neonatal Echocardiography (TNE) is frequently used for cardiovascular management of extremely preterm infants. Methods to help infants experience less pain and stress during TNE include oral sucrose or sucking on a pacifier with or without facilitated tucking.² It has been suggested that TNE is neither painful nor disruptive for preterm infants,³ however, our

observations of very preterm infants undergoing TNE were that it often caused profound NBD, leading to this pilot study.

Objective

- Document NBD caused by TNE in extremely preterm infants.

Methods

A convenience sample included preterm infants born at less than 28 weeks gestational age, who underwent TNE when investigators were available. Infants were assessed using the NIDCAP® Naturalistic Observation and were video recorded before, during and after TNE. Neurobehavioral functioning and pain assessments were carried out using the Assessment of Behavioral Systems Organization (ABSO),⁴ the Behavioral Indicators of Infant Pain (BIIP),⁵ and the Astrid Lindgren and Lund Children's Hospital Pain and Stress Assessment - Neonatal (ALPS-Neo).⁶ All TNE's were performed by one investigator trained in TNE (AN). All neurobehavioral assessments were performed by another investigator certified in NIDCAP and APIB (Assessment of Preterm Infants' Behavior) (JMT). Bedside caregivers were not guided to provide neurobehavioral facilitation, but were free to provide whatever support they felt necessary.



Mission

The NFI promotes the advancement of the philosophy and science of NIDCAP care and assures the quality of NIDCAP education, training and certification for professionals and hospital systems.

Adopted by the NFI Board, April 29, 2017

Vision

The NFI envisions a global society in which all hospitalized newborns and their families receive care in the evidence-based NIDCAP model. NIDCAP supports development, enhances strengths and minimizes stress for infants, family and staff who care for them. It is individualized and uses a relationship-based, family-integrated approach that yields measurable outcomes.

Adopted by the NFI Board, October 20, 2017

Results

Seven infants born at 26 weeks or earlier were included in the study. Age at time of TNE varied from four days to five weeks. ABSO and ALPS-Neo scores indicated fairly high degrees of NBD at baseline. NIDCAP observations indicated NBD increased during and after TNE, although the numerical value of the scoring systems used for this study did not change significantly. For example:

- a) ABSO scores for Autonomic /Motor/State were values of 8/8/8 pre-TNE, increasing to 9/9/9 both during and post-TNE.
- b) ALPS-Neo scores were a value of 10 pre-TNE and remained 10 and 10 during and post-TNE.
- c) BIIP scores were difficult to assign accurately, as facial behaviors which are a key part of this scoring were often not well seen due to bedding, TNE operator's hands and/or the probe.

Most babies entered the AA state (severe autonomic and motor dysregulation leading to removal from the sleep-wake state continuum) during TNE and many did not recover from the AA state post TNE. The BIIP does not include the AA state in its descriptors. ABSO and ALPS-Neo do include AA state, but many babies were already at scores of 10, the maximal possible score, for reasons such as motor flaccidity; thus moving into the AA state did not increase their score.

Conclusions

- a) More attentive, individualized supportive care is required at baseline for very preterm infants in the NICU, given the high scores reflective of pre-TNE NBD.
- b) TNE was associated with increased NBD in the extremely preterm infant, which was often due to the infant entering the AA state.

- c) The scoring systems used in this pilot study were not sensitive enough to accurately portray the increased NBD.

The following actions will be considered in the future:

- 1) Determine the most accurate method of documenting NBD during TNE, keeping in mind assessment methods should recognize the AA state as that of profound NBD.
- 2) Disseminate results to clinicians using TNE in their practice.
- 3) Provide caregiver support tailored to individualized, dynamic neurobehavioral status during TNE as this may prevent the severe NBD that was observed. The recently published Validity and Reliability of the Evaluation of Intervention Scale (EVIN tool) may be useful as a means of providing such facilitation, and will be the subject of further study.⁷

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Our Current Sponsor

The NFI thanks its current sponsor, Dr. Brown's for their continued support which helps the NFI raise global awareness of the need for NIDCAP care and enhances opportunities to develop educational programs to broaden the reach of this care to more and more NICU professionals and the 'preterm families' they serve.



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Comparison of Established Neurobehavioral Profiles for Healthy Infants to Preterm NICU Infants

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Background

The burden of stress the human body endures during critical periods of development is postulated as having implications in the development of later life mental health and physical illnesses.¹⁻³ Risks from early life developmental adversity are linked to later life illnesses and diseases of the cardiovascular and endocrine systems, as well as mental health illness.⁴⁻⁸ An early life stress experience that often receives inadequate attention, yet may be of considerable later life consequence, is the caregiving environment of the newborn intensive care unit (NICU). While NICU care is often lifesaving, the intensity and chronicity of these experiences are evolutionarily unexpected and occur during a period of developmental vulnerability. Stress exposure from necessary care in the newborn intensive care unit (NICU) can have profound effects on infant brain development. Interpreting neurodevelopmental effects from adverse early life experiences in the NICU can be challenging.

Objectives

- Explore whether established term infant neurobehavioral profiles may be used to characterize a preterm NICU infant cohort.
- Examine the potential of longitudinal NICU stress exposure to further discriminate profiles.

Methods

A sample of 41 preterm NICU infants, previously described in the primary study,⁹ was analyzed for stress exposure and neurodevelopmental functioning. The primary study explored the relationships between neurodevelopmental outcomes at NICU discharge, FKBP5 genotype and NICU stress exposure. An established algorithm was applied to investigate membership of preterm infants at near term age within three neurobehavioral profiles. Total 21-day and weekly average stress were also examined and found to be correlated to infant neurobehavioral profiles.

Descriptive demographic data and stress data were analyzed using IBM® SPSS® Statistics, version 22.0. The NNNS neurobehavioral profiles were analyzed using the algorithm in R statistical software.¹⁰ Finally, multivariate analysis was used to discriminate the probability of NISS stress scores by week (week one, week two, week three) to predict if the preterm profiles were similar to the healthy infant profiles.

Results

There were significant differences in the distribution of membership within the developmental profiles between preterm infants and healthy full-term infants. An interaction was found between the membership with the three profiles and time within mean range of stress value. Using Pearson Chi-Square test, there was a

statistically significant difference ($p = 0.02$) in the distribution of neurobehavioral profiles between the sample of preterm NICU infants and the comparison to the healthy full-term infant sample from the Sucharew study¹¹.

While statistically significant results were not detected ($p = 0.11$) for preterm infants in the mean value for 21 days of stress across the three profiles, the mean stress score was lowest for the preterm infants categorized into Profile 1 (social/easy-going) and the highest mean stress scores for infants categorized into Profile 2 (hypotonic). There was a statistically significant interaction ($p = 0.03$) between the three neurobehavioral profiles and the mean value of weekly average stress.

Conclusions

Preterm infants' neurobehavioral functioning may be classified with these neurodevelopmental profiles to better understand the influence of early life experiences. Interestingly, the comparison of preterm profiles to the term profiles identified by Sucharew et al.,¹¹ demonstrates a reversed yet near exact matched percentage of Profile 1 (easy-going) and Profile 2 (hypotonic), while the Profile 3 (difficult) percentage remains consistent between the two groups. Stress exposure in the NICU has the potential to discriminate NNNS profile membership.

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Free Parking for Parents of Infants in the Newborn Intensive Care Unit (NICU): A Collaborative Approach with Families

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Background

Parental presence and active participation in caregiving improves both short- and long-term outcomes for preterm infants requiring NICU care.^{1,2} Parents with higher levels of engagement also experience benefits, including lower rates of depression, reduced levels of stress, increased confidence in parenting and responsiveness to infant cues, and improved attachment to their infant when compared to parents whose NICU presence is limited.^{3,4} The provision of free parking is one means of helping parents to be active partners in the care of their infant. It is also one of several accessibility interventions described in the NIDCAP Nursery Assessment and Certification Program's (NNACP) Nursery Assessment Manual.⁵ There has been limited research into this intervention to date.⁶ No association has been found between the provision of free parking, increased parental presence, and length of stay but there are confounding variables which limit the applicability of this particular study.

Objectives

- Provide rationale for the following:
 - Active parental participation in care should be considered part of the treatment provided for preterm infants.
 - Facilitating parents' presence in the NICU should be a high priority objective for improving care and outcomes.
 - Free parking is one method which may increase parental presence and participation in care.
- Describe strategies used in our attempts to acquire free parking for parents.
- Describe the work in progress and our plans to achieve this goal.

Methods

A previous attempt to secure free parking was made in 2011 during the first World Prematurity Day. Presentations were given on this topic and a petition was signed by families and staff at all NICU sites across the city. Unfortunately, systemic changes at senior management levels meant the petition was not presented to the appropriate authorities and free parking was not made available for families.

This initiative became a priority project in 2016 for our NICU Family Advisory Council Team (FACT), which includes parents and staff working on various initiatives through a progressive and collaborative approach. Our first task was to gather data regarding parking use and parental perceptions. Parents are currently eligible for discounted monthly parking passes for

sale at \$71CAD. This compares to the daily parking charge of \$14.25CAD. We performed a cross-sectional survey of parents with infants admitted in two level 3 NICUs.

Survey Results:

Of 51 families who completed the survey:

- 38 (74.5%) used the hospital parkade regularly during their infant's hospitalization.
- 25 (65.8%) of those parents paid for parking by the month at some point.
- At least one parent spent an average of 7.3 hours per day with their infant (range 2-24 hours).
- The cost of parking affected the duration of time spent with their infant for at least one parent in 14 (34.1%) families.
- The cost of parking affected the frequency of visits to the NICU for at least one parent in 12 (29.3%) families.

Participants stated obtaining monthly passes was complicated, given the unexpected and emergent obstetrical admission for some. They also described the parking office as difficult to find, located outside of the main hospital, and having restrictive hours of operation. In addition to this survey, free parking has been discussed in several other forums, leading to this topic being placed on our hospital's Operational Plan and Priority list of key issues. We have also partnered with the Pediatric Cardiology FACT to form a joint working group to address this subject.

Conclusion

We identified parking is a barrier to parental presence and active participation in care of their infant. A joint working group was created to carry this initiative forward.

The joint working group will:

- Establish criteria for free parking and a consistent process for distribution of passes.
- Investigate sources of funding, including corporate and foundation sponsorship.
- Streamline the parking process and work towards an electronic parking system.
- Plan an audit to determine whether free parking increases parental participation in care and improves outcomes for infants and families.
- Plan an economic evaluation to determine whether free parking leads to overall cost savings to the health care system.

- Design further studies to identify other barriers to parental participation in care of their infant and interventions to remove these barriers.

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Support for Parents of Preterm Infants Post-NICU Discharge

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Background

Preterm infants often require additional care and support after discharge and are at higher risk of neurodevelopmental disabilities.^{1–3} Parents of preterm infants have a higher risk for short and long-term mental health issues (anxiety, depression, post-traumatic stress disorder) during newborn intensive care unit (NICU) stays and following discharge.^{1–3} These issues can negatively impact the parent-infant dynamic.^{1–4} The period immediately following NICU discharge is critical for parents as they navigate from the highly supportive NICU environment to an often-isolated home environment.^{1–3}

Objective

- Investigate parental perceptions of supports and services available following NICU discharge, including an exploration of how existing services could be improved and what community supports are perceived to be lacking.

Methods

A qualitative descriptive research design with secondary analysis was employed using two study groups: 1) 13 participants (11 mothers and 2 fathers; 2 couples) with preterm infants born at less than 32 weeks gestational age and, 2) 14 participants (8 mothers and 6 fathers; 6 couples) with preterm infants born at 32–37 weeks gestational age. At the time of the study, the infants were 3–12 months post-discharge. A combination of purposeful and convenience sampling was used. Individuals participated in focus groups with a semi-structured question guide. Thematic analysis of the data was conducted. (See figure 1)

Results

Two main themes were identified in the groups: Parenting Outside the Norm & Imagining Supportive Communities

(Figure 1). The themes spanned the continuum of parental experience from the NICU to home to community.

Parents perceived their experiences of loss, fear, separation and trauma made them vulnerable to mental illness. They, however, often did not see their health as a priority, particularly after discharge when their infant's interests were consistently placed above their own.

“... You tend to ignore yourself... I'll deal with me later.”
(Parent 1, Mother, FG 2).

Encouragement from NICU staff to seek out support was looked upon favorably.

“It really feels like you can't talk to anybody else, when you are in the NICU...” (Parent 4, Mother, FG1, GP1).

Participants identified peer and emotional support as a need in the NICU and community. Parents reported self-imposed social isolation because of fears of illness and the lack of understanding of people who had not experienced preterm birth.

“... when you come home you kind of start to process all those feelings and... the trauma of feeling like not knowing if your baby's going to live, you know. And that's... something that other moms don't necessarily understand, that sort of trauma.”
(Parent 2, Mother, FG 1, GP1).

Belonging to support groups helped parents by providing them with hope, encouragement and reassurance; by building their confidence, validating their concerns and providing concrete advice for specific questions. Some found this “experiential knowledge” was “... more useful than [coming from] a health expert” (Parent 3, Mother, FG 1) to address “... specific mom-type questions” (Parent 2, Mother, FG 1).

Parents often perceived community services to lack expertise in preterm infants.

“... he was 2.5 months old and I took him to public health for a

weight and he was down a little bit. And they were like, maybe it was because of his umbilical cord. I was like, he is 2.5 months old – his umbilical cord fell off at 2 weeks old - like read the chart! You know, it was frustrating. So I stopped taking him in altogether and got myself a scale at home ... it was really frustrating to deal with people who didn't get the preemie thing.” (Parent 3, Mother, FG3, GP1).

Lastly, some fathers perceived the NICU environment to be predominately maternal-oriented.

Conclusions

The study findings provide insight into the support parents need following discharge. Peer and emotional support were identified as particular areas of need. Further studies that focus on strengthening existing community resources and integrating peer support are recommended.

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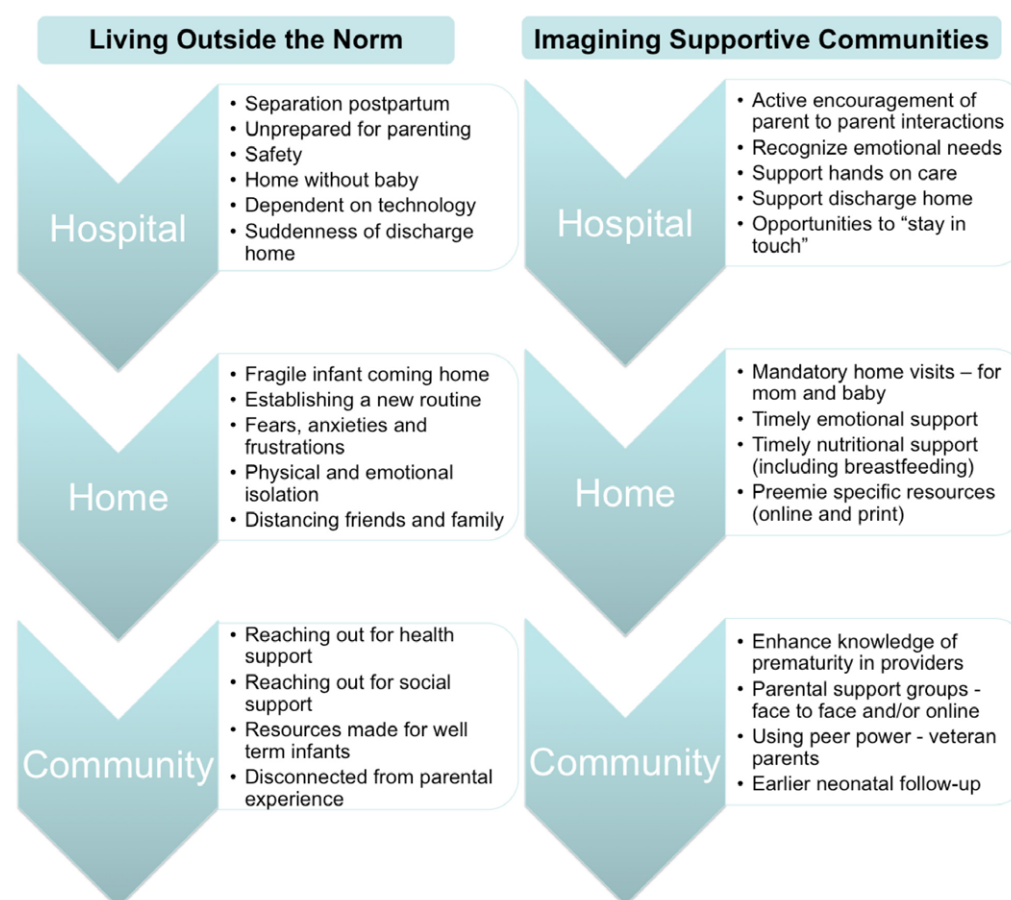
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FIGURE 1.



The Effect of a Sleep Care Educational Program on Nurses' Knowledge and Practice in Newborn Intensive Care Nursery (NICN)

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Background

All infants have important sleep needs, and those born prematurely have their own unique set of sleep habits and needs that are different from those of a full-term baby. Sleep is essential for organizing and maturing the brain in premature infants; it also plays a role in maintaining the natural balance between different nervous system centers. Dr. Heidelise Als' Synactive Theory and the NIDCAP model of care were presented at the 1st International NIDCAP Workshop held in Al-Zahara Hospital in Isfahan, Iran in October 2013.

Objective

- Assess the effect of a sleep care educational program on the nurses' knowledge and practice in the Newborn Intensive Care Nursery (NICN).

Methods

In this quasi experimental pre-post test study structured into three stages, 35 nurses working in a NICN in Isfahan, Iran, were included. The newborn sleep care educational program included oral presentation sessions with questions and answers followed by nurses' exposure to sleep posters and booklets in the NICN. Data was collected by a nurses' knowledge questionnaire having shown validity and reliability through content validity and internal consistency respectively. The questionnaire consisted of 40 multiple choice questions asked prior to, immediately after, and one month after the education program was implemented. Nurses' practice was evaluated prior to and one month after the educational intervention using a 15 multiple choice questionnaire. Data was analyzed by descriptive and inferential statistics using the SPSS16 software.

Results

Results revealed the mean score of nurses' knowledge immediately and one month after the educational intervention was significantly increased as compared to prior to the intervention, 33.33(4.4) vs. 19.33 (4.1) ($P < 0.001$). The score of nurses' practice was slightly improved following the educational intervention although it did not show any significant differences ($P = 0.07$, 42.6 (7.6) vs. 45.1 (7.8)).

Conclusions

According to the results of this study, this method of education

could lead to a significant increase in nurses' knowledge; however it did not significantly improve their practice. This may be due to the low number of educational sessions; therefore, we recommended to NICN administration to invest in a long-term continuous educational program on premature infants' sleep care to enhance nurses' performance. Lastly, this education may result in nurses' support to create a quiet environment to promote good sleep in premature infants and improve their brain development, as well as to decrease infants' developmental problems due to insufficient sleep in the noisy and crowded NICN with excessive handling and distracting procedures by staff.

According to the American Academy of Pediatrics (AAP), premature infants may sleep for as many as 22 hours a day, but only for about an hour at a time. Also according to the NIDCAP model, states of consciousness (sleep & awake) are an important component in the NICN. Nurses have an important role in creating a quiet environment in which premature infants have the greatest opportunity for good sleep and improved brain development. We recommend the NICN administration continues their efforts to improve nurses' knowledge and practice by scheduling appropriate sleep care educational programs as long-term continuing education.

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POETri – Positive Oral Experiences Training: A quality improvement project to foster oral skill development in preterm infants

Matt Hicks on behalf of the POETri Steering Committee, Division of Neonatology, Department of Pediatrics, University of Alberta, Alberta, Canada

Background

The Royal Alexandra Hospital (RAH) is a tertiary perinatal center with an annual delivery rate of more than 7,000 births. The newborn intensive care unit (NICU) promotes family-centered care, minimizing parent-infant separation and promoting breastfeeding. Preterm infants, however, often receive parenteral nutrition for extended periods of time and experience delayed initiation of oral feedings including breastfeeding. One of the reasons for this is staff reluctance to orally feed infants on non-invasive breathing support such as nasal continuous positive airway pressure (CPAP) treatment. Early initiation of oral feeding is associated with increased breastfeeding success, and oral feeding while on CPAP has been safely applied in Canada and internationally.¹ Currently the RAH NICU does not have an oral feeding guideline. A retrospective chart review of infants less than 33 6/7 weeks gestation discharged from the RAH NICU in 2014 indicated fewer than 10% were exclusively breastfed on discharge. Only 50% of infants exclusively received breast milk, 25% were exclusively formula fed and 25% were fed a combination of breast milk and formula.

Objectives

- Implement an oral feeding guideline to promote Positive Oral Experiences Training (POETri) for infants receiving

respiratory support and thereby increase breastfeeding rates at discharge.

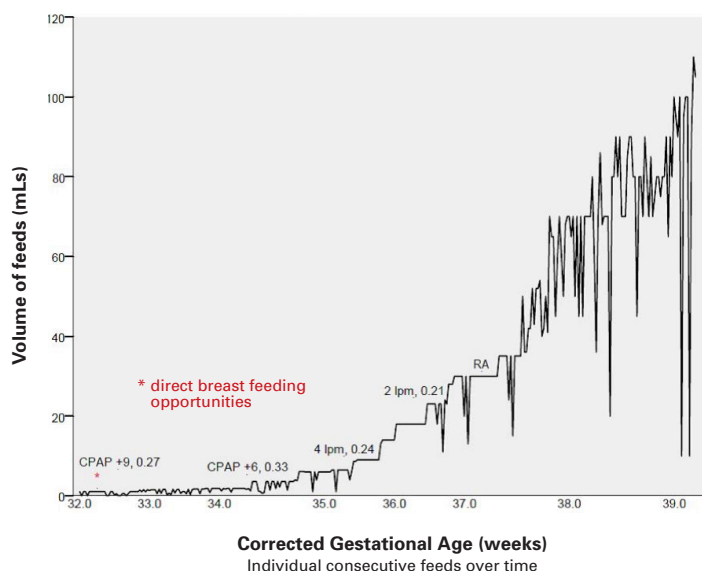
- Decrease the age of preterm infants' first nuzzle at the breast.
- Decrease the age of the first breast feeding for preterm infants.

Method

The POETri team used the QI steps of Plan, Do, Study, and Act. We created, piloted, and revised a data collection and auditing form to identify baseline data, current gaps, and targets as well as track project progress and outcomes. Baseline data were collected on 91 preterm infants born at less than 29 weeks to guide implementation of POETri. Time to first nuzzle and first breastfeeding were identified as occurring much later than expected; these were identified as initial targets to achieve the longer-term goal of increased breast feeding rates at discharge.

The Feeding Babies in SINC (Safe, Individualized Nipple-Feeding Competence) algorithm was developed in Calgary as a QI Project over the last five years and is being adopted in several NICUs in Canada and the United States.¹ Our Team collaborated with the team in Calgary in reviewing and selecting the algorithm for piloting in Edmonton. Training workshops were held with POETri team members and 20 NICU clinical team members were identified as "POETri Champions". Orientation

FIGURE 1. Typical pattern of feedings for an infant using the SINC algorithm and changed to semi-demand feedings at 38 weeks post-menstrual age (PMA).



lunch and learn sessions were provided to bedside nurses to train staff in the POETri Project and SINC algorithm. A pilot of the POETri program was then conducted for two months with 20 infants born at less than 29 weeks gestation. Team members used the SINC algorithm to teach nurses and parents to recognize feeding engagement and disengagement cues.

Results

There was a high degree of concern and discomfort with the idea of feeding infants on CPAP and non-invasive respiratory support. It took much longer than anticipated to introduce the POETri project and concept of feeding on CPAP to the bedside staff and increase their level of comfort to the point that the POETri project could proceed. Collaboration with the team from Calgary was crucial in increasing the comfort of staff members with the concept of POETri and SINC.

The POETri project encouraged team-orientated decision making on progression through the SINC algorithm. Infant-driven strategies and clearly outlined algorithms provide clarity and predictability related to care to all team members and parents and encourages communication.

There can be a tendency to change the feeding method back to prior practice if infants are viewed as not progressing as quickly as desired. Infants, who transitioned to the current unit

standard of semi-demand feeding methodology when they are not ready, had recurrent episodes of regurgitation and greater variability in volume intake as compared with infants who advanced more systematically through the SINC algorithm (see Figure 1).

Key results of the POETri pilot:

- The first feeding for 100% of the infants in the POETri group occurred at the breast versus 40% in the pre-POETri group.
- First nuzzle at the breast occurred at an average earlier age of 786.3 hours in the POETri group as compared to 1454.2 hours in the pre-POETri group. This means mothers could put their babies to the breast to nuzzle four weeks earlier in the POETri group.
- First oral feeding at the breast occurred at an average earlier age of 1118.4 hours in the POETri group as compared to 1477.0 hours in the pre-POETri group. This means mothers could have their babies feeding at the breast 15 days earlier in the POETri group.

Conclusions

The POETri project supported parents to be more involved in the care of their babies and to engage in nuzzling at the breast a month earlier. For the mother of a baby born at 24 weeks, this is the difference between having the first opportunity to have her baby nuzzle at six weeks of age rather than ten weeks.

There is a much higher rate of transfer from the RAH NICU to intermediate care NICUs than is commonly recognized. Projects aimed at attaining a specific outcome by discharge may need implemented across a region rather than at one site. In subsequent iterations of this QI project, the rate of breastfeeding at discharge will be ascertained once the algorithm is introduced to all NICUs in the Edmonton radius for transfers.

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Annual NFI Membership Meeting

Sunday, October 21, 2018

1:30PM – 3:30PM

Sheraton Porto Hotel & Spa
Rua Tenente Valadim, 146,
4100-476 Porto, Portugal



The 29th Annual NIDCAP Trainers Meeting



October 20-23, 2018

Sheraton Porto Hotel & Spa
Rua Tenente Valadim, 146, 4100-476 Porto, Portugal

*Hosted by the São João NIDCAP Training Center, Porto,
Portugal (By Invitation Only)*

NFI Celebrates World Prematurity Day November 17, 2018

About World Prematurity Day

Celebrated internationally on November 17th, World Prematurity Day (WPD) acknowledges the journeys of preterm infants and their families as well as raises awareness of the challenges faced by children born preterm and their families.



Purple is the symbolic color of WPD representing sensitivity and individuality, two of the characteristics of the premature infant.

Please Join Us

In honor of World Prematurity Day 2018 the NIDCAP Federation International (NFI) invites you to pay tribute to newborns, and to their families, nursery staff and hospitals around the world who provide essential NIDCAP care.

It is not too early to begin planning for your WPD 2018 celebrations. A popular way to spread the word is through the purple illumination of landmarks in your communities and the purple illumination of hospital websites. The National NIDCAP Training Center in Boston, Massachusetts has arranged for the lighting of the Zakim Bridge which is traversed by tens of thousands of people every day, and the NFI hopes that each training center will arrange for a similar marking of the day whether it be the lighting of a bridge, a government building, your hospital's website, your NICU's webpage, or your community's local newspaper (print or electronic version). Please consider contacting the programs in your communities that can execute such "illuminations".

Other suggestions for celebrating the day:

- Send the NFI's WPD [information sheet](#) to your local news agencies to inspire a story about preterm birth;
- Sponsor activities for the parents of preemies in your newborn intensive care units and/or your communities;
- Coordinate an educational workshop for your NICU staff on the sensitivities and individuality of preterm infants;

We encourage you to mark World Prematurity Day in your own special way.

Developmental Observer

The Official Newsletter of the NIDCAP®
Federation International

To download the *Developmental Observer*
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NIDCAP on the Web



The NFI [NIDCAP Blog](#) offers observations from many different perspectives on NIDCAP and its implementation, such as NIDCAP and APIB training, Nursery Certification, the science behind the approach, the family experience with NIDCAP, the NFI, and much more. We encourage you to visit the *NIDCAP Blog* and to leave comments for our bloggers and our NIDCAP community in general. If interested in becoming a guest blogger please contact Sandra Kosta at sandra.kosta@nidcap.org.

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Read and participate on our NIDCAP Blog



To learn more about the NFI and its programs please visit us at www.nidcap.org



Please visit the NFI's YouTube Channel to watch videos about NIDCAP (in 13 languages) and the NNACP. www.youtube.com/user/NIDCAPFI

NIDCAP TRAINING CENTERS

by order of establishment

National NIDCAP Training Center

Boston Children's Hospital and
Brigham and Women's Hospital
Boston, Massachusetts, USA
Director: Heidelise Als, PhD
Contact: Sandra M. Kosta, BA
email: nidcap@childrens.harvard.edu

Sooner NIDCAP Training Center

(inactive)
University of Oklahoma Health
Sciences Center
Oklahoma City, Oklahoma, USA
Director: Andrea Willeitner, MD

West Coast NIDCAP and APIB Training Center

University of California San Francisco
San Francisco, California, USA
Director and Contact: Kathleen VandenBerg, PhD
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Carolina NIDCAP Training Center

WakeMed, Division of Neonatology
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Director and Contact: James M. Helm, PhD
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Karolinska NIDCAP Training and Research Center

Astrid Lindgren Children's Hospital at
Karolinska University Hospital
Stockholm, Sweden
Director: Stina Klemming, MD
Co-Director: Björn Westrup, MD, PhD
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email: nidcap@karolinska.se

French NIDCAP Center

Medical School, Université de Bretagne
Occidentale and University Hospital
Brest, France
Director: Jacques Sizun, MD
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Sophia NIDCAP Training Center

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Rotterdam, The Netherlands
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Centro Latinoamericano NIDCAP & APIB

Fernández Hospital
Fundación Dr. Miguel Margulies and
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Buenos Aires, Argentina
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UK NIDCAP Centre

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Children's Hospital of University of Illinois (CHUI) NIDCAP Training Center

University of Illinois Medical Center
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Chicago, Illinois, USA
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NIDCAP Cincinnati

Cincinnati Children's Hospital Medical Center
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The Brussels NIDCAP Training Center

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NIDCAP Germany, Training Center Tübingen

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French NIDCAP Center, Toulouse

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Edmonton NIDCAP Training Centre

Stollery Children's Hospital
Royal Alexandra Site
Edmonton, AB, Canada
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Juzer Tyebkhan, MB
Contact: Trina Cruz
email: NIDCAPEdmonton@ahs.ca

Become a Member of the NFI

The NFI has expanded opportunities for membership. Please join us! For more information and the online application form, visit our website at: www.nidcap.org or email us at nfimembership@nidcap.org