



“The world needs more NIDCAP, and all clinicians and parents need to learn about it.”
—Yamille Jackson

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FAMILY VOICES

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By Yamille Jackson, PhD, PE, PMP

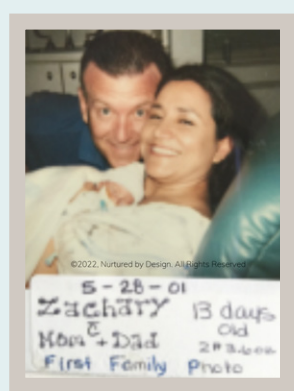
Our True Story of Love, Science, and a Transformative Promise

How it all started

When Larry and I welcomed our son Zachary 12 weeks prematurely in 2001, life changed. It was medically necessary to deliver Zachary early, risking his life to save mine, and while I started feeling better, he struggled. To the NICU staff, Zachary was one of the 13 million babies born prematurely that year, but to us, he was our world.

I owned a consulting firm in risk management engineering for the oil and gas industry. I took an indefinite leave to be with Zach all day, every day, in the NICU (a luxury that, unfortunately, few in the USA have). I was a new and imperfect mother that still believed that nobody should suffer alone. I needed to be there for Zach to nurture and comfort him and,

most importantly, to give him a reason to fight and survive. To this day, my mom has healing and calming superpowers over me, so I figured I had them for Zach too. We were fortunate to be in a progressive hospital, and the staff supported my need to care for our baby.



Our touch turned struggles into possibilities.

The NICU staff encouraged me to ask questions. A nurse shared that when they

grow, former preemies may not like to be touched, and I know isolation is the worst type of punishment. I didn't want that for Zach. Humans learn by association, and I wanted to show Zachary that pain does not always follow touch. Our touch was healing, comforting, and loving. I appreciated it when nurses comforted him verbally before and after painful procedures, as they would with an adult. I appreciated it when they came on their breaks to touch or hold Zachary so he felt loved. Kangaroo Care was introduced the day after he was born as "something nice to do for you and your baby." I remember when the method started when I was a girl in Colombia and heard about it. This started our journey with Kangaroo Care, and we held Zachary daily for hours each day. Kangaroo Care eased my c-section pain and fulfilled my need to nurture my baby as nothing else did. My sadness and worries went away when I held Zachary. Nurses did many interventions while I held him (i.e., blood transfusions, evaluations, change of diapers, heel sticks, and anything I could convince them to do while he was calm on my chest). I fell asleep several times, holding him; it was by far the most restoring sleep since his birth.

The day everything changed.

When Zachary was three weeks old, challenges intensified when Tropical Storm Allison flooded Houston, Texas, and the hospital and life-support equipment lost power we panicked. Larry and I managed to arrive at the hospital, and I held Zachary skin-to-skin for hours, keeping him warm. Larry received a crash course on how to "bag" him and took turns with the staff every 30-45 minutes. In those very dark hours, I promised



Zachary his pain and struggle to survive were not in vain. He was evacuated. A cable television network, TNT made a movie called "14 Hours" about the flood, the evacuation, and Zach's story.

Like most NICU parents, we felt guilt, worry, uncertainty, lack of control, and sadness, among other feelings. Night after night, for five months, we left one of two different hospitals without our baby. My newly found maternal instinct and specialization in ergonomics and human factors engineering helped me be Zach's mom in the NICU.

We were part of a team and had a job to do. The NICU staff cared for Zach's physiological needs for survival. We gave him a sense of security by being present, reassuring, and holding him in Kangaroo Care. Zachary, like every human, likely needed to feel loved to find a reason to fight to survive.

(continued on p. 3)

Editorial



The legacy of Heidelise Als lives on and the breadth of the NIDCAP work represented in this issue is a testament to the strength of NIDCAP. Abstracts from the 33rd NIDCAP Trainers Meeting held in Bad Boll, Germany last October come from nine countries, a truly global effect. Profiles from some of the invited

presenters and their topics raise so many important issues. Kelly Janssens shows how being political can benefit the work we do, and Karl Heinz Brisch, who unfortunately was unable to be with us shares his important work on outcomes. Gretchen Lawhon nicely summarises the meeting in her letter to Heidi highlighting so much of the meeting. I am sure Heidi would love to be kept informed in this way.

Regular features of the work of the NIDCAP Training Centres is demonstrated by the team at the Edmonton Training Centre in Canada. We also learn about how developmental care and NIDCAP is expanding throughout New Zealand.

A new feature has been introduced in this issue – *In Translation*. Maria Maestro Lopez has expertly translated an article written by Jeff Alberts into Spanish. We would like your feedback on this approach and suggestions on how we could expand this feature. We would like to reach out to those members from different language backgrounds.

Kaye Spence AM

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Cover photo used with permission

I kissed him after every stick and painful intervention except when I was not allowed. As bad as we thought we had it as parents, he had it worse, so we kept a positive attitude and concentrated on the good news. There were days when we hung on to the fact that he was breathing.

“I love Zach, but how does HE know I love him?”

I worried that Zachary felt abandoned every night (he didn't know we were not allowed to stay with him at night or how long we would be away). I worried he wondered why I let people hurt him (he didn't know they were trying to save his life). I worried that Zachary felt rejection or guilt when we did not hold him or touch him when he was hurting and needed us the most (he didn't know we were not allowed to touch him). As a human being, he was tiny, but he was a human being nonetheless, and he had the right to be treated with love, compassion, and respect.

“How do you calm a baby?”

Calm humans, especially babies, feel less pain, sleep and eat better, leading to fewer interventions, less medication, better healthcare outcomes, less cost, and increased satisfaction.

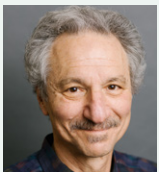
Before a painful procedure, nurses tell adults to relax because “when you relax, it will hurt less.” Since babies do not respond to verbal instructions, I wanted to find ways to calm Zach. Nurses and therapists taught me how to use my hands to comfort him, but who would comfort him when we weren't there?

A turning Point

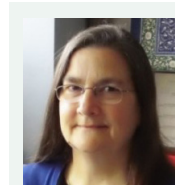
A pair of filled garden gloves simulated the weight, shape, and containment of our hands the way nurses taught me. Larry and I slept with gloves to impregnate our scent so Zachary would feel our presence even when we were not there. The nurses could immediately see the calming effect of “the gloves” on the monitors and how they helped Zachary. However, they could not see how they helped me. Leaving the gloves with our scent made it easier to separate from Zach. A part of us always stayed with him. At night I always left the NICU with the gloves positioned where my hands wanted to stay. The staff also used the gloves to position Zachary and his equipment and soon noticed he was calmer and sleeping better at night or when we were not holding him.

Once at home, a nurse called me requesting “the little gloves I made for Zachary for the rest of the NICU.” This was

Editorial Board



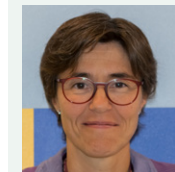
Jeffrey R. Alberts, PhD, is Professor of Psychological and Brain Sciences at Indiana University -- Bloomington (USA). Jeff is also a NIDCAP Professional and blends his lab studies with similar research at Cincinnati Children's Hospital Medical Center.



gretchen Lawhon, PhD, RN, FAAN, is the Clinical Nurse Scientist with Newborn special care associates, at Abington Jefferson Health and a NIDCAP Master Trainer. gretchen has reviewed articles for peer reviewed journals. gretchen has extensive experience as a clinical nurse scientist and has authored numerous articles in her areas of expertise.



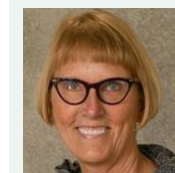
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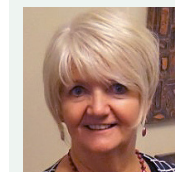
Deborah Buehler, PhD, is a developmental psychologist with expertise in developmental care within newborn and infant intensive care nurseries. Her work has focused on NIDCAP research, education and mentorship, and awareness. Deborah has authored and co-authored papers and manuals pertaining to NIDCAP care.



Debra Paul, OTR/L, is an occupational therapist and NIDCAP Professional at Children's Hospital Colorado in Aurora, Colorado and the Column Editor for the Family Voices section for the *Developmental Observer*. Debra writes policies and guidelines which requires succinct writing and an eye for editing.



Sandra Kosta, BA, NFI Executive Director of Administration and Finance, has been an Associate Editor for the *Developmental Observer* since 2007. As a Research Specialist at Boston Children's Hospital, Sandra has co-authored several papers on the effectiveness and long-term outcomes of NIDCAP Care.



Kaye Spence AM is a clinical nurse consultant and clinical researcher with numerous publications in peer reviewed journals and several book chapters and is a peer reviewer for eight professional journals. She is a past Editor of *Neonatal, Paediatric and Child Health Nursing*. <https://orcid.org/0000-0003-1241-9303>

a turning point...I found a way to give back and solve a need of families and staff in the NICU; however, as a risk engineer, I knew that my homemade and hand-made version had many risks. I could take risks for my baby but not for other babies, so I founded “Nurtured by Design.”

I was in a unique position because I was solving a problem that I lived with, and I had the drive, the education, and the experience to do it. After three and a half years of research and development and the involvement of thousands of stakeholders, we finished our first NICU device, and I called it “The Zaky®.” A pair of The Zaky HUG® extends the touch and scent of the parents and provides a calming and predictable micro-environment for all babies regardless of size, medical condition, or developmental stage. It virtually replaces all developmental care devices and provides a simple and effective tool for NIDCAP as a non-pharmacologic pain management solution, family-integrated care, and effective for babies experiencing opioid withdrawal and for Safe to Sleep.

I first met Dr. Heidelise Als at the Gravens Conference in Florida when she presented information about NIDCAP, and it made sense to me.

Our passion for paying it forward and improving the lives of infants and families

In 2007, Nurtured by Design became my full-time job. I decided to add kangaroo care (KC) to my advocacy work. My research showed two main roadblocks for KC: Safety and Awareness/Education.

To provide safety, we spent three years engineering The Zaky ZAK®, starting with my own experience holding Zachary – I wanted a device that is safe, hands-free, comfortable, easy to wear, unisex, that provides constant containment and a predictable experience for the staff, the parent, and the baby. It offers easy, quiet, and immediate access for transfers, breastfeeding, pumping, and interventions. The stability provided by The Zaky ZAK® reduces risks, prevents injuries (like unplanned extubations and falls), and, as always, considers the entire supply chain (inventory, ordering, storing, maintenance, training, quality control, etc.) It is also the backup for when incubators lose power and evacuations.

In 2010, I was certified as a professional Kangaroo Care-giver by Dr. Susan Ludington and the United States Institute for Kangaroo Care. Soon after, I started the International Kangaroo Care Awareness Day on Zachary’s 10th birthday (May 15th), which is now celebrated globally. www.kangaroo.care provides free resources and information for a fun, non-threatening, non-judgmental way to celebrate Kangaroo Care and increase its Awareness/Education.

In 2014, Oprah met Zach, and she featured our story. The video is on our homepage www.thezaky.com. The Gates Foundation funded us to develop a mobile app for parents called The Zaky® to track kangaroo care and other activities and facilitate Kangaroo-a-thons.



In 2014, Zach met Oprah Winfrey, who featured Zach’s story

In 2018, I was honored to sponsor Dr. Als to present at Mary Coughlin’s conference in Belgium. I saw her again at my first NIDCAP Trainers meeting in October 2019 and met many professionals who told me they love The Zaky®, which warmed my heart. What I remember most about Dr. Als is when she said, “you are one of us,” and she also wrote a letter of support for me for a grant. Her life was well lived, and her legacy will continue to be multiplied by phenomenal professionals worldwide that give every baby the best possible chance of life, not just survival.

I achieved the Trauma Informed Professional (TIP) certification from Caring Essentials, Inc., and realized that The Zaky® was aligned with all the elements of trauma-informed care. I also became more active in research, and the list of publications is on our website.

Our philanthropy includes donating The Zaky® products to the most vulnerable. The most recent large donation of The Zaky® packages went to every baby in seventeen NICUs in Ukraine, where parents and babies are experiencing more than usual trauma and are fighting for their survival and their country. We collaborated with the NIDCAP Federation International, other parent organizations, and the March of Dimes for logistics and delivery. I also host the “In touch with experts: LIVE,” where we talk in layman’s terms with experts about topics that interest parents.

Zachary will never remember, but Larry and I will never forget.

Zach is our CIO (Chief Inspirational Officer) and grew up to

be a loving, intelligent, witty, handsome, funny, caring, talented, and hard-working adult. He has visited over 20 countries with me, takes fantastic photos, and is gifted and creative. Zach is now in college and is passionate about cars.

Our story was possible because we were part of the NICU community caring for him. I am grateful for the work behind the scenes by researchers like Dr. Als. I am aware that she and thousands of professionals influenced the NICU staff that cared for Zach. Globally, we are mourning her loss, but I am confident that NIDCAP will only strengthen.

Dr. Als was an exceptional woman and teacher, who was inspirational, com-



"Zach is our CIO (Chief Inspirational Officer)"

passionate, and approachable. Those who met Dr. Als realize what we lost and feel honored to have been touched by her life. Dr. Als inspired us, taught us, and gave us the knowledge to treat every baby as a human, as someone's child that is part of a family that deserves compassion, respect, and individualized nurturing care.

The world needs more NIDCAP, and all clinicians and parents need to learn about it. My commitment is to continue supporting your work (on behalf of Zach) and offer tools and services that empower you to implement and teach NIDCAP so that every family can have the best possible quality of life for a lifetime.

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Narrative Medicine and NIDCAP: What Can We Learn From Each Other?

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Aim

To present the theoretical background of narrative medicine, highlight its specificities in the neonatal period, and show how NIDCAP is relevant at all stages of the narrative process.

Methods

Comparative analysis of the theory on NIDCAP and narrative medicine.

Results/Findings

The narrative process defined by Rita Charon¹ is divided into three stages.

Attention is the first stage. It refers to the way practitioners listen to the patient's behavior and talk. It needs a special state of mindfulness and attention, focused and open-minded. In the neonatal period, we listen to the baby's behavior and to the parent's story and behavior.

The *NIDCAP observation tool*, naming, describing, and preselecting specific behaviors, helps us to listen to premature babies. With the help of narrative medicine, we can improve the way we listen to parents using our *close reading* session skills. During the close reading session, we learn to be actively aware of how the stories are told: perspective, form, temporal structure, plot, and desire.

Representation is the second stage. It refers to the way practitioners write what they have learned from the patient.

When health professionals write, they discover aspects of the experience that were not evident to them. Writing is revealing what was present but hidden. It reveals some truth about the patient, and about the writer themselves. It could be seen in the words chosen, or in the form of the writing. About the words, Roland Barthes² makes a difference between Denotation and Connotation. In the neonatal period, we write about the baby's behavior, and about the parents' stories.

Considering the baby's behavior, the *guidelines proposed to write the NIDCAP report* reflect the care philosophy supported by NIDCAP. By introducing the baby by his name, we recognize him as a person. By using the active verb, he is a living person in motion. By writing in a fashion that is readily understood by and is supportive of parents, we testify to baby and family-centered care. By describing a baby as available to actively seek well-modulated functioning to approach stimuli, we defined them as an actor of their own development. Respecting and endorsing those writing guidelines is pushing us to change our care philosophy.

Considering the parents' stories, narrative medicine proposes to use a *parallel chart*. In this file, you write what the parents tell you, but also how you feel and react to it. Once written, the parallel chart is used as a starting point for the *reflective practice* recommended during the NIDCAP process.

Affiliation is the last stage of the narrative process. It refers to how the patient and the practitioner share the writing producing an efficient and trustful partnership. This implies that they believe in the power of words, as John Langshaw Austin³ explains in the speech act. In the neonatal period, what is written on the baby by the professional and/or the parents can affiliate parents and health care professionals for the sake of the premature baby.

The way *NIDCAP recommendations* are written is a tremendous example of this speech act. Including parents' preferences is a sign of affiliation with parents. Starting recommendation with the behavior of the baby, and ending it with his developmental goal, is a sign of our affiliation with the premature baby.

Relevance to NIDCAP and Conclusion

To know the theory of narrative medicine helps us to understand how narration plays a powerful role in NIDCAP for the parents, and the professionals.

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3. Oishi E. Austin's Speech Act Theory and the speech situation, *Esercizi Filosofici* 2006, 1 (1):1-14. ISSN 1970-0164

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Quality of Sleep in a Level 3 NICU

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Aim

NIDCAP neurobehavioural observations are conducted routinely in our NICU, and recently have been augmented with video. This project evaluated the quality of sleep of infants in our level 3 NICU, as part of ongoing education and quality improvement.

Methods

A convenience sample of preterm infants were recruited for NIDCAP observations with video. Parents provided informed consent. Infants were observed in their beds and/or while held. These observations occurred while the infants slept, and other interventions were minimal. Behavioural states were assigned during observation according to the NIDCAP Manual for Naturalistic Observation of Newborn Behavior.¹ The number and frequency of state changes, the longest epoch of state and its duration, total time in each state, and length of sleep-wake cycle were calculated. A sleep-wake cycle was defined as a period of sustained Deep Sleep (DS) followed by spontaneous arousal to Quiet Awake.² Parents, nurses, and neonatologists were asked to estimate the length of infants' Sleep Wake cycles.

Results/Findings

Nineteen infants were observed for a total of 38 observations. Infants were observed in their bedspace in the NICU at various times of the day. No attempt was made to modify the environment or to replicate the environment when an infant was observed more than once (13 infants). Twenty-four observations occurred while the infant was in a crib and 14 while held. Twelve of these 14 held episodes were skin-to-skin with a parent. Data are presented for 17 observations; further analysis is ongoing.

- The mean length of time between state transitions was 2 minutes 39 seconds (range 1'12" to 10'15").
- The longest epoch of any one state during any one observation was a mean of 12 minutes 42 seconds (range 3' to 33'). Most of these epochs were of Light Sleep, state 2A.
- DS was observed during 9 of these 17 observations. The infant was being held during 7; the percentage of time in DS while held ranged from 6.6% to 80.5%. For the two observations of infants in the crib, the percentage of time in DS Sleep ranged from 5.1% to 17.5%.
- Of the eight observations for which no DS was observed, the infant was always in the crib.

- Five infants were observed both in the crib and while being held. All five achieved more DS when held (up to 80.5% of the time) compared to the crib (maximum 5.1% of the time).
- Parents, neonatologists, and nurses were unsure of the length of sleep-wake cycle. When asked to estimate, responses varied between 20 minutes and 3 hours.
- Very few infants achieved a sleep-wake cycle, as defined above.

Limitations

- Polysomnographic identification of sleep-wake states was not possible. This could have improved the accuracy of the assignment of behavioural state.
- Only five of 19 infants were observed in both conditions (held and in crib), which may limit the validity of the comparison between "sleep while held" and "sleep in crib".
- The physical environment of each infant's bedspace was not standardized, which may have impacted the quality of sleep.

Relevance to NIDCAP

The NIDCAP Naturalistic Observation is a clinically useful tool to assess the quality of sleep in the NICU. Observation of sleep states and Sleep Wake cycles may be one method of assessing improvements in the quality of neurodevelopmental care in the NICU.

Conclusion

Preterm infants in our NICU had suboptimal organization of sleep, with frequent transitions of state, little if any Deep Sleep, and poorly defined sleep-wake cycles. Infants achieved more Deep Sleep when held than in their crib. Our results demonstrate the critical developmental impact of prolonged close contact with parents and will guide practice change.

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1. Als H. Manual for the naturalistic observation of newborn behavior. Copyright NIDCAP Federation International, 2006, 2015.
2. Graven SN, Browne JV. Sleep and brain development. *Newborn and Infant Nursing Reviews*. 2008;8(4):173-9.

Parents’ Involvement Template: A Tool to Standardize Caregivers’ Approach to Parents In NICU

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DOI: 10.14434/do.v16i1.35771

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Background

Preterm babies and their parents face a long and often complex journey in the newborn intensive care unit (NICU) from admission to discharge. As the parent-baby triad is the core of family centered care, parents should be welcomed in the NICU, integrated, and involved in their baby’s care. NICU staff should support parents in recognizing their baby’s needs and in acquiring parenting skills. This approach could help to promote and establish the bonding between parents and babies, despite obstacles due to early separation and admission to the NICU. Welcoming the parents of hospitalized babies in the NICU is always an important step in a continuous and multidisciplinary process. The nurse becomes the facilitator in the relationship within the triad. To the best of our knowledge, no studies described qualitatively structured parents’ involvement templates to be used in the NICU, but rather checklists that report the knowledge and skills that parents should acquire during the hospitalization of their baby.^{1,2} Welcoming parents in the NICU has a dual function: it offers parents the opportunity to learn and understand their baby’s cues and supports professionals to guide them during their journey until the discharge.³

Aims

Developing a specific and structured parent involvement template has two aims. First, to standardize the approach of the NICU professionals to the care of the babies; second, to support the parents in the process of acquiring their parental skills before discharge and to measure their level of self-efficacy (Table 1).

Methods

The standardization of NICU professionals’ behavior is assessed by identifying the number of professionals who fill out the parents’ involvement template. The level of parental self-efficacy is monitored through a specific tool (PMP S-E).^{4,5}

Results

The standardization of NICU professionals’ behavior reduces the disparities and promotes a family centred approach to the care of babies and families. The active involvement of parents in the care of their baby during hospitalization facilitates and promotes parental early self-efficacy before discharge, greater self-confidence in their parental skills, and a reduction in the risk of subsequent hospitalizations.

Relevance to NIDCAP and Conclusion

The parents’ involvement template should become a central tool of NICU care for preterm infants, and it supports the implementation of family-centered, NIDCAP-oriented care.

Table 1. Parents’ Involvement Template

Birth date	GA at birth	Birth weight
Welcoming		Check in - information - Leaflet - Locker
Date first contact		
Parents Interaction		
Kangaroo Care (KC)	- Duration - Clothing - Mirror - Book - Breastfeeding promotion	Not done due to: - Baby’s clinical condition - Absent parents - Parents’ difficulties
Date KC		
Parents Involvement		
Nappy (diaper) changing	- Caregiver - Caregiver/Parent - Parent	
Abdomen assessment - touch - stooling	- Caregiver - Caregiver/Parent - Parent	
Feeding - Tube - Bottle - Breast	- Caregiver - Caregiver/Parent - Parent	
Hygiene practice - Sponging - Bath	- Caregiver - Caregiver/Parent - Parent	
Special Needs Babies		
Tracheostomy	- Caregiver - Caregiver/Parent - Parent	
Gastrostomy	- Caregiver - Caregiver/Parent - Parent	
DISCHARGE	- Self-efficacy complete - Self-efficacy incomplete	Notes

(references on p. 9)

Practice of Developmental Care During Multilayered Crisis Situation: Lessons Learned from Lebanon

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American University of Beirut, Lebanon.

Background about the Lebanese crisis

Developmental care (DC) was established in 2013 at the Level III NICU of the American University of Beirut Medical Center in Lebanon through the Developmental Care and Early Intervention Program (DCEIP) led by a NIDCAP certified team of neonatologist and NICU nurses. For the past three years, the provision of DC has been markedly affected by the worst economic and financial crisis amid the COVID-19 pandemic followed by the massive Beirut blast "Beirutshima". This multilayered crisis is endangering the well-being of Lebanese citizens including NICU babies, their parents, and their care providers. Admitted infants are unable to receive standard care due to a shortage of certain medications and medical supplies and increasing healthcare costs. Parents are struggling to pay for transportation to visit and to pay for hospital bills. Healthcare providers are working with minimum staffing due to the migration of healthcare workforces.

Aims

To describe the practice of developmental care during the Lebanese multidimensional crisis including the COVID-19 pandemic at a tertiary healthcare center.

Findings

Amid this crisis, the DCEIP team drafted policies to standardize DC practice. Weekly DC observation rounds were maintained, a standardized DC note was embedded in the electronic health record (EHR) and recommendations for DC were shared with nurses and families. Infant positioning was monitored daily using the infant position assessment tool (IPAT) score on all patients. Infants' positions were supported by "ZAKY hands" that were generously donated by the Nurtured by Design following the Beirut blast. The team engaged NICU nurses in quality improvement projects and task forces addressing components of DC such as having a daily "quiet time" for at least one hour daily in each NICU pod. Mothers and fathers were actively supported in their skin-to-skin practice at each opportunity.

To sustain the provision of DC in the unit, the DCEIP team worked on building the capacity of the remaining NICU staff by offering refresher educational sessions and tips on DC. They also organized educational sessions for NICU parents that shifted from in-person to online format for those unable to reach the hospital whether because of COVID restrictions or high fuel prices. The parents were satisfied with the indi-

vidualized sessions which were tailored to fit their needs. A web-based interactive course was developed for the continuous education of nurses and doctors. They liked the content and the pace of the course which was given online and according to their schedule. The DCEIP team was invited to participate in national online webinars focused on developmental care. All the aforementioned interventions were done at no additional cost. The multilayered Lebanese crisis taught us how to adapt and customize individualized interventions for infants, families, and staff without resources.

The future plans for the unit NIDCAP certification and training of a NIDCAP trainer to establish a training center had to be halted because of financial constraints.

Relevance to NIDCAP

How to adapt in a low resource and crisis setting.

Conclusion

Developmental care becomes even more relevant during a crisis. It tackles all aspects of nurturing care in a humanitarian setting.

(references continued from p. 8)

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Breastfeeding-Related Pain, Sensory Over-Responsivity (SOR), And Exclusive Breastfeeding 6 Months After Birth: A Cohort Prospective Study

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Background

Although exclusive breastfeeding is recommended for the first six months of life, breastfeeding rates in most developed countries are low. Sensory over-responsivity (SOR) is a neuro-developmental condition characterized by exaggerated behavioral responses to sensory stimuli not typically perceived as irritating, aversive, unpleasant, or painful. SOR was found to severely interfere with everyday activities and quality of life, including having an impact on attachment patterns and maternal competencies. SOR and its link to breastfeeding-related pain have not yet been examined as potential barriers to exclusive breastfeeding.

Aims

To explore whether mother breastfeeding-related pain, sensory over-responsivity and daily pain sensitivity are associated with non-exclusive breastfeeding six months after birth.

Methods

Mothers of full-term infants were recruited two days after birth in a maternity ward. For the assessment of breastfeeding-related pain, mothers completed the Visual Analogue Scale and the Short Form-McGill Pain Questionnaire at enrollment (T1), and at 6 weeks after birth (T2). At 6 months (T3), mothers completed the Pain Sensitivity Questionnaire and the Sensory Responsiveness Questionnaire (SRQ) assessing SOR, provided information about their breastfeeding status, and were then divided into two groups accordingly: Exclusive breastfeeding (EBF) and Non-exclusive breastfeeding (NEBF).

Results

A total of 164 mothers reached the third time point: EBF (n=105), NEBF (partial breastfeeding or formula feeding only) (n=59). The incidence of SOR was significantly higher among NEBF mothers compared to EBF mothers (25.4% vs. 11.4%, respectively, $p=.02$). Moreover, between T1 and T2, 72.3% of the EBF mothers had reported at least 30% pain reduction, compared to 44.8% of the NEBF mothers ($p=.001$). Results also revealed positive correlations between breastfeeding-related

pain and the SRQ-aversive score both at T1 ($.268 < r < .378$; $.003 < p < .028$) and T2 ($.296 < r < .380$; $.003 < p < .024$).

Logistic regression modeling revealed that both breastfeeding-related pain reduction between T1 and T2 and SOR were found to predict NEBF at 6 months ($p < .001$), indicating a 3.2-times ($p=.001$) and 2.5-times ($p=.041$) odds ratio for NEBF respectively.

Conclusion

SOR and sustained breastfeeding-related pain predict NEBF 6 months after birth and may emerge as meaningful breastfeeding barriers. Our findings highlight the importance of early identification of women with sensory responsiveness challenges for achieving higher exclusive breastfeeding rates. Early interventions, including modulation of unpleasant and overwhelming sensory stimulation in the NICU, as well as individualized breastfeeding support tailored to the mother's unique sensory profile, are encouraged.

Relevance to NIDCAP

Breastfeeding rates of premature infants are lower than the WHO recommendations despite its proven benefits, specifically for this sensitive population. Promoting breastfeeding in the NICU is a significant challenge that involves both medical and emotional aspects of the infant, the mother, and their developing relationship. The NIDCAP approach to care emphasizes the provision of an optimal sensory environment for the developing infant, as well as the support for early mother-infant interactions. Increased attentiveness to the mother's sensory experience may be especially important in the context of breastfeeding in the NICU, where mothers might be exposed to unfamiliar, distressing and overloading environmental stimuli. Adaptive responses to the mother's sensory needs and environmental adaptation may impact breastfeeding success and as a result increase breastfeeding rates in the NICU and after discharge.

Does Developmental Care Education Alter Nurses' Perceptions of Developmental Care Practices in Surgical Neonatal Intensive Care Units?

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Background

Nurses' perceptions of developmental care (DC) practices have been researched globally for almost 30 years. Yet, little is known of nurse perceptions of DC in surgical NICUs. The stand-alone surgical NICU setting differs from general NICUs. Infants requiring surgery are often cared for by numerous treating teams, which may lead to a fragmented approach to care. They experience pain, stress, interrupted sleep and separation, with their family often required to travel or transfer between multiple facilities. This research on nurses' perceptions of developmental care was undertaken in two surgical NICUs, one with an embedded NIDCAP Training Centre (Site A: 23-bed unit), and one with an alternate unit-based model of developmental care education (Site B: 40-bed unit).

Aims

- To evaluate NICU nurses' perceptions and attitudes toward developmental care in surgical NICUs.
- To explore if the type of developmental care education program provided to nurses influences their perception of developmental care practices in surgical NICUs.

Methods

An electronic survey was distributed by email to 276 nurses permanently employed in a surgical NICU at two hospitals in two states of Australia. The survey was modified with permission from Family and Infant Neurodevelopmental Education (FINE) Level 2 site assessment document and consisted of 36 questions. Content validity was determined by two experienced neonatal nurses and a statistician. Descriptive statistics were used to examine trends in the responses. Data is reported as frequencies and percentages, Chi-square, and Fisher's Exact Test.

Results

One hundred and seventeen (n=117) nurses completed the survey exploring their personal perceptions of developmental care and its application in the surgical NICU. Response rates varied; 55% (Site A), and 30% (Site B) with a combined

response rate of 42%. Demographics differed between the sites for nurses' years of experience and post-graduate qualifications. The majority of nurses in each surgical NICU acknowledged the benefits of DC for infant sleep (>93%), improving caregiving (>88%), and reducing infant stress (>90%). The challenge to consistently apply DC practices and the effect on nurses' workload was similar across both units. The two units differed in the nurses' perceptions of medical staff collaboration with DC (18% vs. 45%) $p=0.006$, nurses' support of DC (47% vs 29%), access to DC education opportunities (55% vs 37%), the inclusion of DC education in organised study days (82% vs 68%), and the inclusion of DC in the orientation of newly employed nurses (81% vs 58%) $p=0.021$.

A greater proportion of nurses at the non-NIDCAP site indicated that communication with families was difficult depending on the parents' communication style (74% versus 51%) $p=0.028$ and was less likely to agree that their nursing peers offered support in the application of DC $p=0.039$. At both sites as nurses' levels of DC education increased, they were more likely to agree that DC education was not consistently applied ($p=0.032$) in the surgical NICU.

Relevance to NIDCAP

The introduction of NIDCAP in surgical NICUs has been a challenge due to the specific population of newborn infants. Various developmental care programs have been implemented as an alternate form of education in these units. These programs can support NIDCAP work through preparation and an understanding of developmental care principles by healthcare professionals. Collaboration between the healthcare team is paramount if NIDCAP is to be seen as a model of practice in surgical NICUs.

Conclusion:

The survey results suggest surgical NICU nurses have a high level of awareness of developmental care and its positive impacts. Despite differences between the units' developmental care education programs, nurses collectively recognised the value of developmental care in reducing stress for infants and supporting families.

From Parental Involvement to a Partnership With Families in Newborn Care: An Improvement Project Using the Bottom-Up Approach

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European Standards of Care¹ state that infant and family-centred developmental care is defined as a partnership between parents and healthcare professionals. This relationship includes shared responsibility for infant care, collaboration, open information sharing, and joint decision-making. Improving healthcare professional skills to support parental involvement during newborn care is highly recommended.

Aims

Design an improvement project to: Improve the skills of NICU staff to establish a collaborative relationship with parents, support professionals in their relationship with parents, and encourage organizational transformations that facilitate and support the process.

Methods

A multi-professional group (NIDCAP Professionals, psychologist, pedagogue, unit leadership), in collaboration with parents' representatives, designed the project that included the following phases:

- Discussion within multi-professional focus groups on current values and strengths of staff in providing assistance in collaboration with parents ("where do we start from", "what not to lose along the way"); future goals and organizational changes required to facilitate the process.
- Un-structured interviews with parents of discharged newborns, conducted by an experienced sociologist, to gather parents' experiences, needs, and suggestions that could help the staff establish a more effective partnership.
- Feedback to the staff about the main topics emerged from the focus group discussion and from interviews with parents.

Scores on the Empathic Questionnaire,² before and after project implementation, were used as indicators.

Results

The main topic that emerged from the focus groups was that doctors and nurses shared awareness about the importance of family-centered care; moreover, both shared the value of cooperation and mutual support. Poor continuity in family care was identified as a contributing factor to compassion fatigue and misunderstanding between parents and staff,

possibly reducing the opportunity for a real partnership with families.

Twelve parents were interviewed. The need for continuity of care in newborns and family assistance was expressed by all parents, while only some of them would have wanted a more extensive involvement during their baby's care in critical situations.

Discussion of the above topics led the staff to create two multi-professional working groups: the first dedicated to the implementation of organizational changes and the second aimed at designing simulation scenarios to be used during educational courses. The first group defined and implemented a primary nurse model; the second organized a simulation training using role-playing with the aim to increase sensitivity and communication skills in the NICU staff.

Statistically, the Empathic median scores were not significantly different before (63 families) and after (27 families) the implementation of the project and reached in both cases the maximum value of six. Analyzing the percentage of the maximum score in the items of the domain "parental participation" we observed a trend toward greater satisfaction in the items "We were encouraged to stay close to our child" and "Nurses helped us to build the emotional bonding with our son".

Relevance to NIDCAP

Parents' involvement in infant care is the highest and most challenging goal of the NIDCAP approach. This goal can best be achieved by listening to and involving parents not only in baby care, but also in its organization; furthermore, a participatory approach from the staff could improve the implementation of the NIDCAP approach.

Conclusions

This project starts from both parents' and staff's points of view, under expert supervision. Insights within focus groups helped us to reinforce the idea of the importance of individualized care, in a new organizational framework of care continuity. Moreover, education by simulation training was organized to increase staff competencies in sensitive communication.

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The Effect of the Empathy Enabling Program on the Nurses' Empathy and Nurse-Parent Communication in the Newborn Intensive Care Unit

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Background

The main roles of nurses are not only to inform about the disease and treatment of the patient but also to establish an effective therapeutic relationship to address concerns, and provide empathy, comfort, and support. This issue is very prominent in newborn intensive care units (NICUs) and doubles the importance of empathetic communication between nurses and parents and promoting empathy skills in nurses working in NICUs.

Aims

The aim of this study was to investigate the effect of empathy-enabling programs on nurses' empathy and nurse-parent communication from the perspective of nurses.

Methods

This cluster randomized trial (CRT) study was performed with the participation of 64 nurses working in NICUs by convenience sampling method. The participants in both groups completed a three-part pre-test questionnaire: a) demographic, b) empathy and c) nurse-parent communication. The intervention was held as online training sessions in the BigBlueButton. The empathy-enabling program was in the form of two-hour interactive lectures on the topic of empathy and empathetic communication skills, in addition to videos, video clips, readings, and practicing scenarios. Discussions were conducted for the intervention group and the control group did not receive any training. Finally, participants in both groups completed the post-tests questionnaires again immediately and one month after the intervention. Data were then analyzed using an independent t-test, repeated measures analysis of variance, and Pearson correlation coefficient test using SPSS software version 16.

Results

The results of the independent t-test showed that the mean score of nurse-parent empathy before and immediately after the intervention in the two groups was not statistically significant, but one month after the intervention this difference in the two groups of control (100.96 ± 13.31) and intervention

(110.08 ± 15.07) was statistically significant ($P = 0.018$). Also, the results of the analysis of variance with repeated measures did not show a statistically significant difference in the empathy score of the control group during different times, but for the mean nurse-parent empathy score during different times in the intervention group, this difference was significant ($P = 0.032$). In addition, the results of the independent t-test revealed that the mean score of nurse-parent communication before, immediately and one month after the intervention was not significantly different between the control and intervention groups. Also, the results of the analysis of variance with repeated measures during different times did not show a statistically significant difference for the intervention group in terms of nurse-parent communication score. However, the results of the Pearson correlation coefficient test showed a significant positive linear relationship between NICU nurses' empathy scores and nurse-parent communication scores, at three times ($P < 0.001$, $R = 0.779$).

Relevance to NIDCAP

The NIDCAP model of care is one of the current priorities of the Neonatal Health Office in the Ministry of Health in Iran and many other countries that emphasize the increasing presence of parents in NICUs and support for them by staff. Parents are one of the essential components of the NIDCAP model and need empathetic communication.

Conclusion:

Based on the findings, the importance of teaching empathetic communication and the role of empathy in nurse-parent communication, should be more prominent. As the importance of the presence and support of parents in NICUs implementing the NIDCAP model of care, researchers are recommending the use of practical methods to recognize empathetic communication challenges and teach empathy to nurses despite the coronavirus (Covid-19) pandemic crisis and the subsequent possible challenges in nurse-parent communication. Also, the authors recommend that empathetic communication skills should be included in formal and informal training programs for nurses and nursing students working in newborn intensive care units.

Oxytocin and Cortisol Release is Associated With Premature Infant Neurobehavioral Patterns

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Background/Significance

It has been optimistically, yet incorrectly, proposed that healthy preterm infants without major complications eventually catch up developmentally to term infants. Parental touch, especially during skin-to-skin contact (SSC) has the potential to reduce adverse consequences of prematurity. Oxytocin is a neuropeptide that stimulates bonding and parenting behaviors by a bio-behavioral feedback loop. Mothers and fathers with increased oxytocin levels have more reciprocity and synchronicity in their interactions with their infants. Evidence suggests that neurobiologically, oxytocin directs the young infant to preferentially select species-specific social stimuli to form dyadic attachments. Oxytocin is considered critical in the experience-dependent plasticity underpinning auto-regulated functioning in response to experiences during sensitive periods of development.

Aims

The purpose of this research study was to examine salivary oxytocin and cortisol levels related to skin-to-skin contact (SSC) to demonstrate better infant neurobehavioral functioning using the Neonatal Network Neurobehavioral Scale (NNS).

Methods

A randomized cross-over design study was conducted in the Neonatal Intensive Care Unit (NICU). Infant saliva samples for oxytocin and cortisol were collected pre-SSC, 60-min during-SSC, and 45-min post-SSC. Infant neurobehavioral assessment using NNS was collected prior to hospital discharge. Data were analyzed using R version 4.0.3. Linear regression models included four predictor variables: salivary oxytocin and cortisol levels after SSC; two measurements for each based on whether the infant was held by the mother or by the father.

Results

A significant inverse relationship was found for infants who were held SSC, with their mothers demonstrating higher oxytocin levels and lower Stress summary scores ($t = -3.48$, $p < .003$). For these same infants, a significant relationship with higher self-regulatory summary scores ($t = 2.104$, $p < .049$) was also found. Interestingly, infants held SSC by mothers that demonstrated higher cortisol levels also demonstrated higher Asymmetrical Reflexes summary scores ($t = 2.413$, $p < .026$). We found that infants held by mothers demonstrating higher cor-

tisol levels ($t = 2.249$, $p < .037$) also demonstrated similarly high levels with fathers ($t = 2.156$, $p < .044$) that were also associated with higher infant Stress summary scores. There were no significant differences noted between our data and the published normative NNS summary score values identified in Figure 1 (Lester et al., 2004) for the preterm subset despite mean gestational age (36 1/7) being younger corrected post-menstrual age for participants in the current study at the time of hospital discharge. Lester and colleagues reported NNS exams completed at post-menstrual age 42-44 weeks.

Relevance to NIDCAP

This research explores the bio-behavioral mechanisms that modulate high-risk infants' behavioral, autonomic, and stress responses utilizing an individualized developmental family-centered care approach. Skin-to-skin contact is an evidenced-based holding strategy that increases parental proximity to their infant. This physical proximity allows for a continuously interactive environment that is known to enhance infant physiologic stability and affective closeness between parent and infant. Uncovering the neurobiological basis of early parent-infant interaction is an important step in developing therapeutic modalities to increase parent engagement and improve health outcomes.

Conclusions

These findings are an important step in exploring oxytocin as an important biomarker that provides evidence that demonstrates potential improvement in infant neurodevelopmental functioning and competence. The organization of oxytocin availability is critical to the limbic and neocortical systems, and those nervous system structures related to emotion depend on early caregiving experiences. SSC is an intervention that increases oxytocin and decreases cortisol. Nurses can use SSC as a strategy to activate oxytocin release to enhance infant neurodevelopmental outcomes. Additionally, these findings provide further evidence that neurobehavioral assessments can and should be incorporated into the care of preterm infants to identify an individualized plan of care to support the unique strengths of the infant's current level of behavioral functioning.

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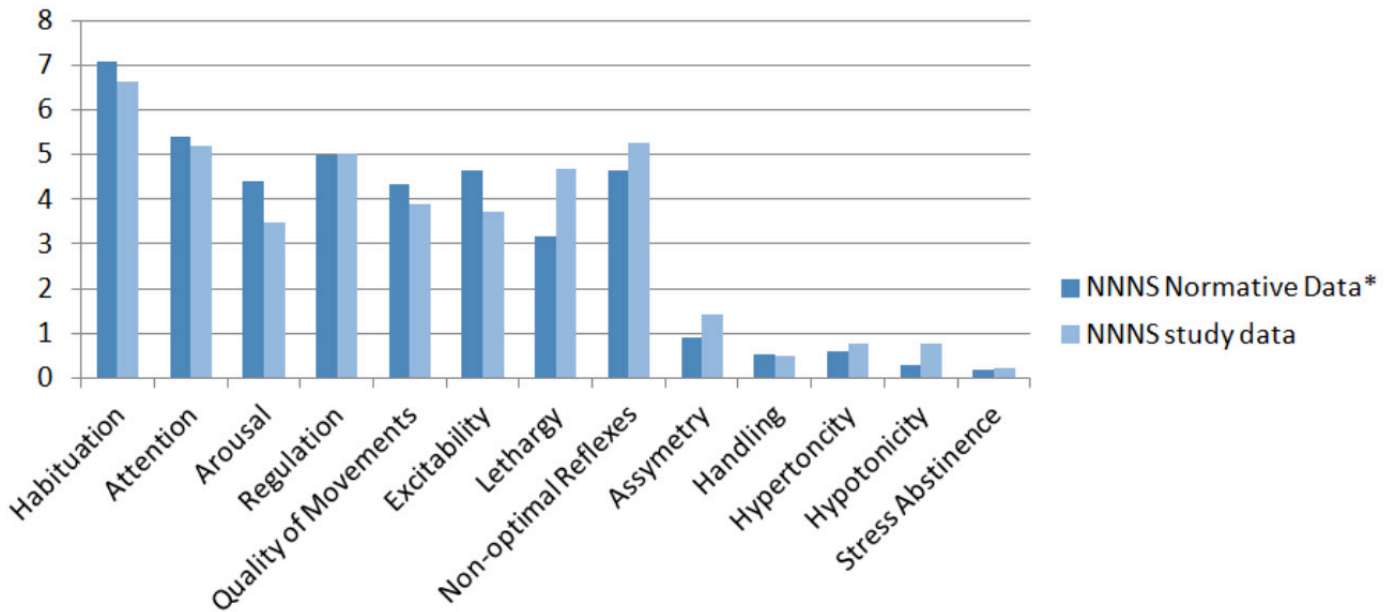
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Figure 1. Neonatal Network Neurobehavioural Scores



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Music Therapy Intervention in an Open-Bay Neonatal Intensive Care Unit Room is Associated with Less Noise and Higher Signals: A Case-Control Study

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Aims

Sustained and intense noise exposure in the Neonatal Intensive Care Unit (NICU) may be a critical negative influencer on neurodevelopmental outcomes in preterm infants¹; often associated with stress responses, alteration in physiological stability, sleep deprivation, autonomic changes, alteration in endocrine and metabolic response, and hearing deficits.^{2,3} Varied strategies including architectural design, special noise-alert or sound-reduction devices, and staff education were reported with inconclusive outcomes.⁴ Nevertheless, the potential influence of music therapy (MT) interventions on noise reduction are missing. This study aimed to evaluate the effect of MT on noise levels in the NICU and to compare the specific effects of individual MT (IMT) and environmental MT (EMT).

Methods

This case-control study was conducted in a level III NICU. Noise levels were recorded simultaneously from two open bay rooms, one with MT and the other without. Each room included a maximum of 10 infants. MT sessions were carried out for approximately 45 minutes with either IMT or EMT, implemented according to the first sounds: Rhythm Breath and Lullaby (RBL) model.⁵ Noise production data were recorded for 4 hours, on 26 occasions of EMT and IMT, and analyzed using R software, version 4.0.2. The analysis compared the ambient noise level in the open bay rooms, and the signal-to-noise ratio (SNR); A measure that compares the level of signals to background noise. When higher than 0dB, the SNR can indicate if there was more signal than noise.

Results

Overall average equivalent continuous noise level (Leq) were lower in the room with MT as compared to the room without MT (53.1 (3.6) vs. 61.4 (4.7) dBA, $p=0.02$, $d=2.1$ (CI, 0.82, 3.42)). IMT was associated with lower Overall Leq levels as compared to EMT (51.2 vs. 56.5 dBA, $p=0.04$, $d=1.6$ (CI, 0.53, 1.97)). The lowest sound levels with MT, occurred approximately 60 minutes after the MT started (46 ± 3.9 dBA), with a

gradual increase during the remaining recording time, but still significantly lower compared to the room without MT. Signal to noise ratio (SNR) was higher (18.1 vs. 10.3 dBA, $p=0.01$, $d=2.8$ (CI, 1.3, 3.86)) in the room with MT as compared to the room without MT.

Relevance to NIDCAP

Current strategies most often used to reduce perceptual sound levels are insulation and isolation. These approaches fall short in that they only address reduction of stressors, but do not contribute towards creating a developmentally appropriated auditory stimulation. Accordingly, the current study relates to core components of the NIDCAP model, namely, modulation of stress in the NICU, infants' sensorial experiences and addressing regulation needs of the NICU's physical environment.⁶

Conclusions

Integrating MT modalities such as IMT and EMT in an open bay NICU room may help in reduction of noise levels. Both MT modalities resulted in higher SNR compared to the control group, which may indicate that they are meaningful for the neurodevelopment of these preterm infants.

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La Importancia de Hacer Doble Diligencia

The Importance of Doing Dual Diligence

Author – Jeff Alberts, Indiana University, NFI Science Committee, Associate Editor for Science

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Artículo objetivo

Maryam Fatollahzade, Soroor Parvizy, Mandana Kashaki, Hamid Haghani & Mona Alinejad-Naeini (2020) The effect of gentle human touch during endotracheal suctioning on procedural pain response in preterm infant admitted to neonatal intensive care units: a randomized controlled crossover study, *The Journal of Maternal-Fetal & Neonatal Medicine*. DOI: 10.1080/14767058.2020.1755649

Poco hay de ordinario en un día normal en una UCIN. Las 24 horas del día, los 7 días de la semana, la tecnología y la biomedicina se combinan con la aplicación experta de otras herramientas de "baja tecnología" y métodos "no tecnológicos". Juntos, funcionan: Los niños que nacen a partir de las 23 ó 24 semanas sobreviven y se desarrollan. El resultado milagroso se convierte casi en ordinario. Pero ¿cómo se producen estos milagros?

Empecemos con uno de los elementos de la fórmula para hacer milagros: Este elemento es el contacto humano. No necesita tecnología.

Nuestro artículo a revisión es un estudio reciente de Fatollahzade¹ que se diseñó para averiguar si una intervención denominada Gentle Human Touch (GHT) reduciría el dolor durante el procedimiento de aspiración de secreciones, comúnmente necesario para mantener abiertas las vías respiratorias de los niños prematuros intubados.

La población del estudio estaba formada por 34 neonatos prematuros (nacidos entre las 27 y las 34 semanas). De forma inteligente, este equipo de investigación utilizó el régimen de cuidados en curso como banco de pruebas, sabiendo que el procedimiento de aspiración, vital para la asistencia respiratoria del neonato intubado, es potencialmente doloroso.

El diseño del estudio fue "cruzado", un enfoque eficaz y estadísticamente potente en el que cada niño se somete a pruebas con y sin la intervención experimental.

El orden fue contrabalanceado, lo que significa que la mitad de los niños recibieron la intervención GHT durante la aspiración en la primera observación y el tratamiento rutinario (sin intervención) durante la siguiente aspiración cuando se precisó. En la otra mitad de los niños se realizó en orden inverso.

La intervención GHT se administró a los niños colocados en decúbito prono en una postura ligeramente flexionada. El investigador colocaba una mano alrededor de la cabeza del niño y la otra alrededor de sus nalgas.

Se proporcionó GHT mientras duró el procedimiento de aspiración. Utilizando la escala de dolor del niño prematuro (PIPP), se realizó una evaluación basal de 15 segundos antes de la aspiración, seguida de una evaluación de 30 segundos después de la aspiración.

El PIPP proporciona una puntuación numérica del dolor en tres rangos (de leve a grave). Se la considera una escala bien validada y utilizada ampliamente en investigación.²

Los resultados fueron impresionantes. Con el cuidado rutinario, el 85% de los niños mostraron respuestas de dolor moderado al procedimiento de aspiración. El GHT redujo la aparición de respuestas de dolor moderado al 65%. Las respuestas de dolor intenso se manifestaron en cerca del 9% de los ensayos de control y el GHT las redujo a cerca del 3%.

Estos resultados son un primer paso para añadir el contacto humano suave a la lista de métodos no farmacológicos de tratamiento del dolor en la UCIN.

Muchos de nosotros conocemos los poderes del contacto piel con piel (Método Canguro),^{3,4} así como la eficacia del posicionamiento,⁵⁻⁶⁻⁸ la lactancia,⁹ la succión no nutritiva¹⁰ y la sacarosa oral^{11,12} entre muchos otros como métodos para mitigar el dolor.

El artículo que comentamos ofrece una nueva contribución. Se basa en los conocimientos anteriores sobre el GHT y el tacto, abordando de una forma novedosa el abordaje del dolor durante la aspiración; ampliando el alcance de la PIPP para su evaluación.

Queda mucho por aprender sobre el alcance, la magnitud y los resultados inexplorados del uso del GHT. Aunque es preliminar en varios aspectos, el estudio de Fatollahzade et al.1 es elegante, sobre todo, si se considera desde el punto de vista de la ética biomédica básica.

Es importante señalar que el GHT es seguro. No causó ningún daño. Al registrarse explícitamente que el procedimiento no causaba ningún daño al niño, se reconocía formalmente una dimensión vital de su método. En otras palabras, aplicaron la conocida máxima "Primum non nocere", es decir, "lo primero es no hacer daño".

Sin embargo, no basta con considerar que algo es ético porque el riesgo es mínimo. Existe un imperativo ético que debe examinar si el procedimiento realmente "hace el bien"¹³... De hecho, Fatollahzade y sus colegas lo demostraron, el GHT redujo las respuestas al dolor. El suave contacto humano durante la aspiración proporcionó un beneficio real y activo. Centrémonos ahora en "No dañar", en el lenguaje de la ética es la no maleficencia [mə-'le-fə-sən(t)s]. El principio de no maleficencia está muy presente en la ética médica.

Por encima de todo "Priemum non nocere". Los niños atendidos en la UCIN merecen un compromiso de no maleficencia. Todos nuestros pacientes lo merecen. Pero, de nuevo, no basta con evitar hacer daño. Además, las prácticas éticas exigen que, además, promovamos y hagamos el bien. "Hacer el bien" en el lenguaje de la ética es beneficencia [bə-'ne-fə-sən(t)s]. Una hermosa palabra para un hermoso principio.

Mientras que la no maleficencia es principalmente una prohibición del daño; la beneficencia tiene al menos tres formas, cada una de las cuales debemos examinar dentro de nuestra conciencia a la hora de hacer el bien. Como tal, la beneficencia incluye (a.) hacer el bien, (b.) prevenir el daño y (c.) eliminar el daño.

En la UCIN en el momento de enfocar el tratamiento ético de cada niño podemos decir que tenemos una moneda. Esta moneda tiene dos caras: la no maleficencia y la beneficencia. Las dos caras de una misma moneda son inseparables. Debemos mantener la moneda en nuestra mano y hacerla girar continuamente examinando cada cara. Esta diligencia obedece a la necesidad de observar ambas caras.

Por esta razón, estoy a favor de la etiqueta de doble diligencia, que estipula la obligación de respetar ambos principios: la beneficencia y la no maleficencia. Abundan los ejemplos ilustrativos de no maleficencia sin beneficencia.

¡Basta con ir al Developmental Observer ¡.¹⁴ La Dra. Ita Litmanovitz, neonatóloga y formadora del NIDCAP, contribuyó con un comentario reflexivo y experto en la columna destinada a la Ciencia.

Ita examinó un estudio con uso importante de tecnología en su diseño.¹⁵ En dicho estudio, los recién nacidos extremadamente prematuros fueron monitorizados durante sus primeras 72 horas con una combinación de saturación regional de oxígeno cerebral (CrSO₂), mediante Espectroscopia Cercana al Infrarrojo (NIRS), EEG de amplitud integrada (aEEG), ecocardiografía funcional (ECHO), apoyados además por ecografías cerebrales.

Los autores concluyeron que esta monitorización multimodal "es factible, segura y bien tolerada por los niños extremadamente prematuros en las primeras 72 horas después del nacimiento". Cierto, sí, pero ¡recuerda la doble diligencia! El comentario del Dr. Litmanovitz nos guía a través del conjunto de consideraciones críticas en el océano de datos que se recogieron; por supuesto sin dañar la piel de los recién nacidos

ni aumentar los eventos adversos.

A pesar del objetivo de los investigadores con el uso de las medidas multimodales no se previno la hemorragia intraventricular ni se redujeron los resultados adversos. Sin embargo, lo más grave fue que, para realizar estas mediciones, hubo una separación obligatoria de 72 horas entre el niño y la madre. Está bien documentado que tales separaciones pueden tener efectos negativos tanto inmediatos como a largo plazo para el niño y su madre.

La Dra. Litmanovitz se refirió a los costes de perder el contacto postnatal temprano entre la madre y su hijo, al tiempo que se buscaba algún beneficio no logrado de cara a prevenir un evento hemorrágico. La concienciación y la atención a la doble diligencia -reconociendo y documentando tanto la no maleficencia como la beneficencia-puede proporcionar la claridad que necesitamos para realizar una atención ética.

La doble diligencia no sólo es totalmente compatible con la práctica del NIDCAP, sino que está integrada en ella. En la prestación de cuidados, en la formulación de protocolos de tratamiento y en la evaluación de la investigación, es imperativo que examinemos tanto el hecho de evitar el daño como el de hacer el bien. La doble diligencia es la base de una práctica guiada por la ética

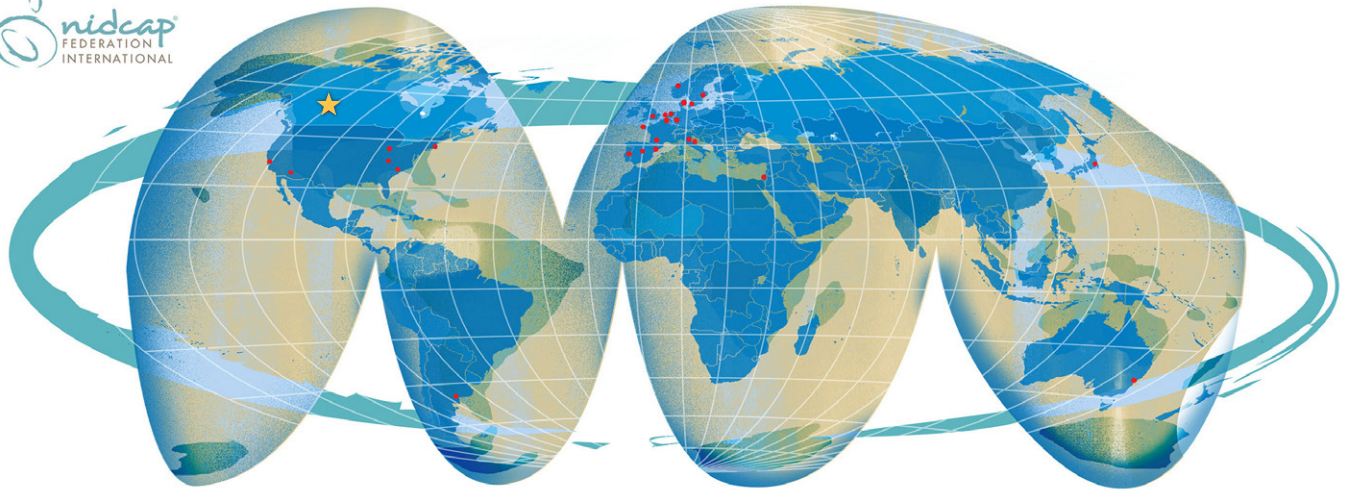
Los milagros que ocurren en la UCIN que permiten un buen desarrollo de los niños surgen de una combinación de alta tecnología, baja tecnología y no tecnología. No sabemos cómo se combinan para lograr el éxito, pero sí sabemos que todos ellos están implicados, y apuesto a que no es mediante una simple suma de factores separados. Cada modalidad apoya a las demás. La alta tecnología médica es crucial. Pero también lo es el amor de los padres y el contacto humano. Recuerda siempre que un día normal en una UCIN se construye desde lo extra-ordinario.

"Ordinarie" en francés antiguo, hace referencia a una regla ó ordenanza, referidas a las reglas que prescriben las formas de acción, de ella se forma la palabra inglesa ordinary o castellana ordinario. Piensa en los protocolos que sigues para hacer un día ordinario. De este modo, todo lo que haces consigue que los milagros sean casi ordinarios. Busca y ve la dualidad de la no maleficencia y beneficencia presente en un simple protocolo. En el cuidado del desarrollo, son el núcleo de lo milagroso.

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(continued on p. 31)



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Edmonton NIDCAP Training Centre, Canada

Andrea Nykipilo and Juzer Tyebkhan, Co-Directors, ENTCC

Our neonatal program in Edmonton, AB, Canada began its journey in 1996 when Dr. Juzer Tyebkhan first learned about NIDCAP. His interest and desire to bring this knowledge to our Edmonton neonatal units led to NIDCAP training and education for a small group of physicians and staff starting with Jean Cole as trainer in 1998. Obtaining a grant for a randomized control trial of NIDCAP in Edmonton followed and the original Edmonton NIDCAP team completed the study in 2004. It was subsequently published in 2009.¹ This series of events was the start of bringing NIDCAP to Edmonton and making it a standard of care in our five neonatal units across the city, which continues to the present day:

Stollery Children’s Hospital sites:

- Philip C. Etches NICU at the Royal Alexandra Hospital (Level 2/Level 3)
- David Schiff NICU at University of Alberta Hospital Site (surgical/cardiac)
- Sturgeon Community Hospital (Level 2)

Covenant Health sites:

- Grey Nuns (Level 2)
- Misericordia (Level 2)

While the group membership has changed over the years, Juzer became the first Canadian Trainer-in-Training (or “TINT” as it was so fondly named) with Dr. Joy Browne as NIDCAP Trainer and APIB Trainer, and Dr. Deborah Buehler as APIB



NIDCAP Team

Trainer. Over the next several years, a total of twelve Edmonton professionals would complete their NIDCAP training under their expertise and mentorship. Once Juzer achieved NIDCAP Trainer, he carried on with all training for NIDCAP in Edmonton. Today Edmonton has seven active NIDCAP Professionals, including Juzer, who is also an APIB Professional.

In 2017, we were honored to host over 100 NFI members for the Annual NIDCAP Trainers Meeting and about 100 additional Edmonton-based professionals for our open scientific forum of NIDCAP. During the meeting, we officially opened the Edmonton NIDCAP Training Centre Canada, or ENTCC. We are so thankful that we had the opportunity for Dr. Heideise Als to cut the ribbon and that we were able to celebrate the momentous occasion twenty-one years in the making with so many of the NFI family present with us in our city. Of course, we must mention that none of this would have been possible without the hard work and dedication of many people over the years.



Heidelise Als officially opening the Edmonton NIDCAP Training Centre



The NIDCAP Trainers Meeting in 2017

So, you might be wondering, what have we been up to since then?

As for most people across the world, the past three years have challenged the Edmonton NIDCAP Team, but as we say in the world of development – the pathway continues because adaptive strategies arise to overcome hurdles. ENTCC has navigated the challenges and looks ahead to the next steps of developmental progress. ENTCC's goals remain:

- Education and NIDCAP training
- Care and advocacy for babies, families, and our neonatal professionals
- Furthering the scholarship of developmental care

Education and NIDCAP Training

We believe that the cornerstone to ensuring that NIDCAP remains a standard of care in all units in Edmonton is a foundational training for staff. In 2018, we began to instruct the FINE (Family and Infant Neurodevelopmental Education) program as the entry to NIDCAP education. Many interdisciplinary participants from across Canada have now attended the FINE Level 1 workshops at ENTCC. This allowed us to bring education and understanding of NIDCAP training to hundreds of people throughout 2018 and 2019. As well, a small number of Edmonton staff are currently taking FINE Level 2. A workshop was held in Mumbai, India in November 2021 attended by 13 professionals from five cities. We are working with our colleagues in the NICUs in India to further this international training collaboration. Slowly, as gathering restrictions have eased, we have started offering the training in Edmonton once again in 2022. As NIDCAP trainer for ENTCC, Juzer continues to do NIDCAP Training for new trainees. We hope to see our foundational education lead to future NIDCAP training opportunities across Canada and elsewhere.

In addition, we are looking to the future with an innovative mindset by collaborating with Academic Technologies at the University of Alberta to create a platform of online resources for NIDCAP. We continue to create and collect material for future video-based learning of infant neurobehaviour. One main lesson that we learned during the pandemic pivot was that NICU professionals want education that is accessible virtually. We believe that this should not take the place of in-person, relationship-based educational components, and hands-on practice, but online, multi-modal education can augment and enhance our teaching and help us meet the needs of contemporary learners who come to ENTCC for training. We are excited to see what the future holds in this area!

Advocacy, Working with Patients and Families

Despite challenges in the healthcare system in Alberta in recent years and the stress experienced by families and staff related to the pandemic, members of the NIDCAP team have continued to provide care and support to babies and families by doing observations, providing care plans, and advocating for their optimal development. One way that we have done this is through NIDCAP Rounds. Team members at both the David Schiff and the Philip C. Etches sites round at least one to two times monthly to meet with families and provide on-the-spot, real-time developmental guidance in conjunction with observation and support for the infant. This also provides an opportunity for in-the-moment staff education, and it is our goal in the future to expand this offering to other units to reach more babies, families, and staff. As always, the Edmonton NIDCAP Team continues to play an important role in ensuring that the voices of the baby and family are heard and as such, there is a representative from the team on most NICU committees and working groups, from Feeding to Lung Health to Quality Improvement. We ensure that the developmental needs of the infants are always kept at the top of the agenda.



Teaching FINE



Crystal and Julia on developmental rounds

Scholarship of Developmental Care

Over the years, ENTCC team members have remained active NIDCAP community members and participants at the annual NIDCAP Trainers Meetings by presenting abstracts and journal club entries, in addition to facilitating small group discussions. We continue to contribute to research through a developmental lens and participate in quality improvement projects. In 2020, members of the team based out of the David Schiff NICU surgical/cardiac unit published² a paper about a quality improvement project in the surgical/cardiac population entitled Implementing a Skin-to-Skin Care and Parent Touch Initiative in a Tertiary Cardiac and Surgical Neonatal Intensive Care Unit, contributing to the knowledge base around this population.

In conclusion, ENTCC looks forward to 2023 as the start of a new year helping babies and families advance on their

pathways of optimal development. We intend to hold more educational workshops and expand online educational resources and we hope to re-energise formal NIDCAP and APIB training now that restrictions on travel are fading away. ENTCC and its activities continue to be supported by the Stollery Children's Hospital Foundation. We thank them for naming NIDCAP a "Pillar of Excellence" and remain grateful for the ongoing trust and confidence in NIDCAP and the ENTCC in providing the best possible outcomes for babies in our care.

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Mission

The NFI improves the future of all infants in hospitals and their families with individualized, developmental, family-centered, research-based NIDCAP care.

Adopted by the NFI Board, June 29, 2022

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

Global Perspective on Developmental Care

New Zealand: A Nursing Reflection

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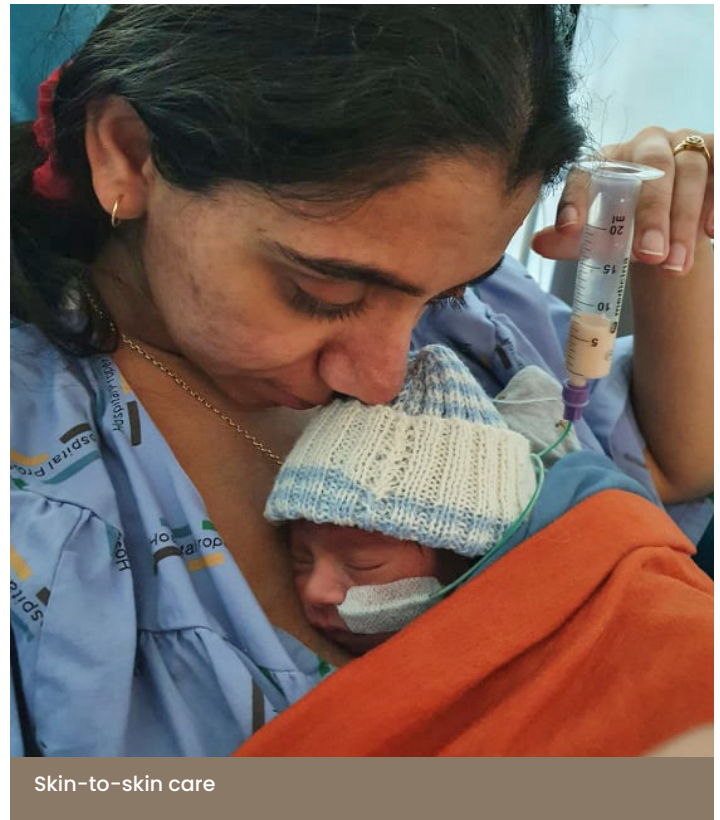
Kia Ora! (hello) from New Zealand

Look closely and you will find our small island country at the bottom of any world map, just below Australia in the southwestern Pacific Ocean. In size, New Zealand has slightly less area than the state of Colorado in the United States and a little more area than the United Kingdom. About two-thirds of the land is economically useful, while the remainder is mountainous. Because of its numerous harbours and fjords, the country has an extremely long coastline relative to its area.

New Zealand is populated by just over five million people. Our Indigenous people, Māori, make up 17% of the national population. Their culture is a big part of New Zealand's identity, so respecting, preserving, and promoting Māori culture is a vital cornerstone of our country's healthcare values. We consistently provide, as a team, quality holistic care with respect for family/whānau, encompassing the concepts of Te Whare Tapa Whā (The four cornerstones of health), Te Taha Wairua (Spiritual), Te Taha Tinana (Physical), Te Taha Whānau (Family), Te Taha Hinengaro (Emotional and psychological) in accordance with Te Tiriti o Waitangi (The Treaty of Waitangi). In tune with the goals of developmental care, promoting and fostering healthy interpersonal relationships between nga mātua/parents, family/whanau, and baby/pēpi is central to neonatal care delivery in New Zealand.

The New Zealand healthcare system is best classified as a variation on the Beveridge model (tax financed healthcare provided by the government) and tends to exhibit outcomes comparable with other developed democracies. This year healthcare delivery in New Zealand is undergoing major reform. The Local District Health Boards are being replaced by one national organisation called Te Whatu Ora Health NZ. A new Māori Health Authority has the power to commission health services and monitors the state of Māori health.

A range of neonatal care is delivered in a total of 23 different localities across New Zealand. Six centres are dedicated Neonatal Intensive Care Units (NICU) where tertiary care for preterm babies born from 23 weeks gestation onward is provided. These NICUs are in the major cities of Auckland, Hamilton, Wellington, Christchurch, and Dunedin, from north to south. Auckland is New Zealand's largest and most populated city with over 1.7 million people and is considered the most cosmopolitan city in the country with ethnic groups



Skin-to-skin care

Image used with permission

from all around the world, including a high proportion of people from Pacific islands and Asian countries. Consequently, with the number of ethnic groups and an excellent climate to grow food, there exists the most amazing cuisine and cultural diversity.

NIDCAP in New Zealand

The concept of developmental care was first introduced in New Zealand by Dr. Heidelise Als. Doctors and nurses were impressed by the positive outcomes reported in early studies by Als, in particular the development of the Synactive theory in the mid-1980s and from this theory the implementation of the Newborn Individualised Developmental Care and Assessment Program (NIDCAP).^{1,2,3} Dr. Als was invited to visit an Auckland NICU in the mid 1990's where she presented her findings. Today, 20 years later, a wide range of developmental care interventions are now embedded as part of everyday care



Family support



Planning care



Swaddled bathing

Images used with permission

in every neonatal unit in New Zealand.

Much of the success of developmental care integration has been due to the passion and persistence of neonatal nurses leading the way in advocating for whanau and pēpi in their care. Neonatal teams, in particular nurses, began to question their contribution to the outcomes of pēpi and whānau in their care. How did the care delivered complement the medical and technical advances in neonatal care? Nurses, partnering with parents, were uniquely placed to establish cultural change within units. This partnership was integral to family-centred care becoming the success it is today.

Developmental care had a natural affinity with the nursing concept of caring making it a philosophy that should have been easily embraced by the nursing team.⁴ In the early days, however, practicing developmental care seemed outside the NICU medical model and was considered by some as an ‘add-on’ to care once the technical and medical tasks had been addressed.⁵

As developmental care initiatives began to be introduced, these initiatives received little acknowledgment from the wider team as contributing to pēpi or whanau outcomes. The science was relatively new about how the growing brain could be so influenced by the way neonatal care was delivered. Additionally, the inability of nurses to articulate their contribution to long-term outcomes suggested a similar conclusion.⁶ NICU environments were changing, with lower lights and less noise being advocated for by staff. Care was also being modified, changing from regimented two and four-hour nursing care handling times to ‘cue based’ or ‘cluster cares’, depending largely on the cultural norms of the unit.

It was clear further education and knowledge were required to support the implementation of developmental care

strategies and to have stakeholder investment. As New Zealand was so far away from many of the research sites, experts, and NIDCAP training sites this proved to be a challenge. Fortunately, the Neonatal Nurses College - Aotearoa (NNCA), the professional body within the New Zealand Nurses Organisation (NZNO) which represents neonatal nurses, stepped up to become strong ambassadors of supporting developmental care practices by providing nursing education opportunities.

It is well recognised that understanding the ‘why’ behind developmental care practices is key to influencing and infiltrating evidence-based best practices in neonatal care delivery. Through funding, NNCA was able to support Dr. Joy Browne, NIDCAP Master Trainer, on several occasions to come to New Zealand to provide Developmental Care workshops. Dr. Browne returned to New Zealand recently as a keynote speaker along with Dr. Heidlise Als at the NNCA-hosted COINN conference in Auckland in 2019. Many nurses unable to attend the international conference were able to instead attend full-day programs provided by Dr. Browne in Christchurch, Hamilton, Auckland, and Whangarei.

In 2014, Inga Warren, Senior NIDCAP Trainer and Co-Director of FINE International presented the Family and Infant Neurodevelopmental Education (FINE) Level 1 at the Auckland Starship NICU. A group of five nurses and allied health team members went on to complete the FINE Level 2 course during the same visit. This program provided ‘stepping-stones’ towards implementing NIDCAP and has been instrumental in providing a road map for fully integrating developmental care practices.

New Zealand is now working closely with Australia, accessing FINE training through the Australasian NIDCAP

Training Centre, Grace Centre for Newborn Intensive Care, The Children's Hospital at Westmead in Sydney. From this Centre, NIDCAP Trainer Nadine Griffiths and NIDCAP Professional Associate Professor Kaye Spence have been integral in facilitating and conducting FINE training for the neonatal teams in New Zealand.

With some fortuitous funding and collaboration between three tertiary units, one in the north Island (Auckland, Starship) and two in the South Island (Christchurch and Dunedin), plans were made to host three FINE 1 Courses. This would be the first time a large cohort of more than 60 neonatal nurses would access FINE training which, in turn, would certainly strengthen best practices across the three sites. Unfortunately, this wasn't to be because in March 2020 a global pandemic took hold and diverted all plans as healthcare facilities shifted into emergency planning unlike any ever experienced before. After a delay of two years, in May 2022 three seminars for FINE 1 were provided online rather than face-to-face. Over 40 neonatal team members from four sites in metro Auckland and Northland attended two workshops while Dunedin hosted another program for local team members. Online training meant that geographical distance was no longer a barrier to excellent education, and opportunities increased.

Impact of Developmental Care Education and Training Across New Zealand

The NICU in Dunedin introduced Family Integrated Care (FiCare) as their care model in November 2018 following involvement as an intervention unit of an international study comparing FiCare with standard NICU care. Christchurch was to follow, and in 2021 Auckland Starship NICU adopted this program as well. While it must be recognised that FiCare is not a developmental care model, it does support the systems in a hospital setting that, in turn, support developmental care strategies ensuring the parent role is integral in the care of their baby.

In the Wellington NICU, developmental care is supported by an excellent suite of pamphlets that share information with parents about how they can respond to their babies' needs at different gestational ages.

The Waikato NICU has a developmental care team comprised of senior RNs and members of the multidisciplinary team who report significant changes in the past five years. Their initiatives include a "Positioning Series" poster for developmentally supportive positioning for staff education. Positioning aids are available, although they report many nurses still prefer to make their own 'deep nest' using rolled towels and linen. The Waikato nursing team has found even the simplest ideas work, such as using phototherapy devices which facilitate containment and allow Kangaroo Care, cuddles, and breastfeeding without interrupting the delivery of the phototherapy. They have introduced Quiet Time, every day at 1400

hours when lights are dimmed, and parents are encouraged to provide skin-to-skin holding.

Further north at both tertiary NICUs in Auckland, nursing and allied health teams introduced developmental care rounds. Teams involved report this activity as being an excellent way to engage and encourage nurses by sharing knowledge and mentoring good practice. Parents also benefit, as with the team's guidance they learn how to read the behaviour of their baby and articulate their observations back to the healthcare team on ward rounds.

The Auckland Starship NICU introduced the Infant and Family-Centered Developmental Care (IFCDC) Standards (<https://nicudesign.nd.edu/nicu-care-standards/>). While this is a work in progress, it is envisaged that each standard will be accompanied by a multimedia education segment and video to help translate the standards from theory to practice at this site. The team has also enjoyed the opportunity, and experienced collegiality and networking by attending the Annual Gravens Conference on the Environment of Care for High-Risk Newborns held each year in Florida. This is quite a journey from New Zealand, but certainly worth the effort as it maintains the enthusiasm of the passionate staff who continue to pursue what is best for babies in the NICU environment.

In summary, over the past 20 years developmental care strategies have been successfully introduced to all neonatal centres in New Zealand, although practice variation remains at different hospital sites. With ongoing support from organisations (e.g., NNCA), interest from consumer groups (e.g., The Little Miracles Trust NICU parent peer-to-peer support group), and training from FINE 1 and 2 and potentially NIDCAP easily accessible through the Australasian NIDCAP Training Centre, the road map to ensure developmental care is fully integrated into neonatal care nationally is well on its way to achieving the best outcomes for pēpi and whanau entrusted in our care.

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Reflections on the 33rd Annual NIDCAP Trainers Meeting, Bad Boll, Germany

gretchen Lawhon

DOI: 10.14434/do.v16i1.35779

Dear Heidi,

You wouldn't believe the trip Dorothy and I had to get to the meeting. We flew from Newark, New Jersey to Copenhagen, Denmark to Riga, Latvia, and then to Stuttgart, Germany. It's so amazing that we are coming together in person after three years because of the pandemic. I've been so looking forward to reconnecting with everyone and renewing relationships, and yet, my joy and anticipation are caught and held back by the undeniable absence of you, Heidi, our esteemed leader in all things NFI.

There has been an exhausting effort by so many, especially those here in your native country to ensure a productive and successful meeting, to move forward as best as possible without you, fulfilling the mission of the NFI, and honoring all that is your legacy. Deborah formally dedicated this meeting and our work here to you.

As we were easing back into our in-person format this year, we have managed a hybrid format, which is pretty cool. We have 94 attendees in person plus 54 online for a total of 148 participants from 27 different countries.

Unusually this year, we began with the one-day open symposium looking at NIDCAP on the individual, the family, and the political level. Our German hosts had planned well to create a comfortable and aesthetically pleasing environment. Believe it or not, we are in a beautiful glass building of WALA which researches and develops medicinal and cosmetic products. OMG Heidi, I thought I saw you at breakfast this morning, wishful thinking can be so powerful.

In thinking about NIDCAP on the individual level, Oskar Jenni presented much optimism in terms of improvement of long-term outcomes due to the plasticity of the preterm brain in response to environmental stimuli. It was also a refreshing review of basic brain development. Through Ingeborg Krägeloh-Mann we were able to turn our attention to the various degrees of injury effects in light of the brain's plasticity with fascinating examples correlating brain imaging to long-

“So many of us have grown so much in our understanding of this work”



NFI President Deborah Buehler, PhD

term effects. Jacques Sizun then really got us thinking about how to translate brain development research into practice. Heidi, I couldn't help remembering the infamous slide Jacques showed so long ago with the suggestion that NIDCAP was the new magic tonic being sold in the old west of the United States. So many of us have grown so much in our understanding of this work and Jacques has been such a strong advocate on such a national level for NIDCAP.

Unfortunately, Professor Brisch was unable to join us so we missed the twenty-year outcome presentation. Dorothy Vittner and I filled in with our approach toward NIDCAP enhancing the family experience. As usual, Dorothy managed to get not only a quote from our dear friend John Chappel but also a photo of Cathy Daguio. Even though many people might not have known them as key NFI members who have died. Maybe you have seen them Heidi, I hope so.

While attending NIDCAP on a family level we were all quite impressed with Dominique Haumont's success in getting NIDCAP on a national level and she reminded us that you told her "The object is not to forget, but to remember to go on". That was a lot easier when you were physically present with us Heidi, but we will do our best. Remember Kelly Janssens



The 2022 Trainers Meeting was a hybrid with 94 attendees in person, and an additional 54 attending online

from Leuven? She told us of their amazing journey in getting NIDCAP on to political agendas through the development of personal relationships.

And, as you know Heidi, we could not discuss NIDCAP, families, and a political agenda while in Germany, especially without having Silke Mader share her passion and advocacy for this topic. Honestly, I totally admire Silke's energy and zeal, but I feel inadequate in her estimation. We know political work is critical, but I am totally occupied with my clinical work. Silke continues to be the most powerful family advocate I know. Our one-day open symposium ended in a very fitting manner with a presentation by a family sharing their journey with their son Mattis in newborn intensive care four years ago. They were very effective in communicating important messages to all of us.

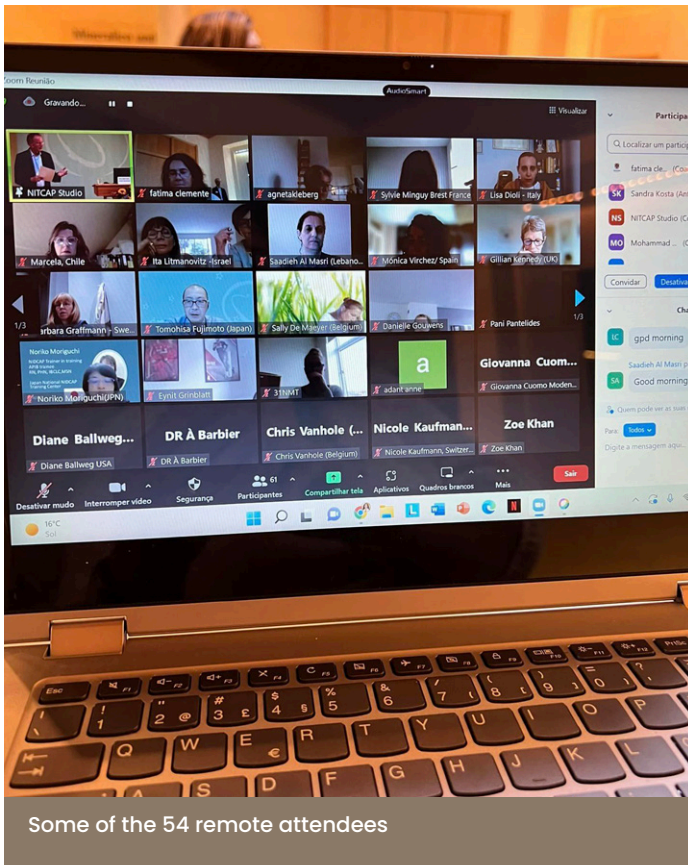
Friday evening, we all turned our attention to you Heidi. First I went on a tour of the WALA medicinal herb garden. Gloria McNulty reminded me that it would be a good connection with you because of your son Christopher and the Camphill philosophy. Then there was a wonderful experience created so that prior to dinner we had the opportunity to walk a candle-lit path with inspirational messages you had given to many of us. In fact, fifty NFI members shared how you inspired each of them. It was a beautiful evening; the moon had risen, and it was a quiet meditative atmosphere. I will admit that for several of us, we actively grieved. I hope you felt the huge outpouring of love from all of us. As our dinner was finishing up, Deborah Buehler gifted us with one of her wonderful slide show retrospectives of your life which ended on a positive note of your love for dancing, which was next on our agenda.

Good morning, Heidi, it's me gretchen, still in Germany, without you. After what nearly everyone felt was a very successful day we then launched into our routine of accomplishments and overview of training. Kaye Spence and Stina

Klemming did a really innovative approach by creating a video of each center's report, both visually and in the representative's own voice. I thought this method was fantastic! Of course, you and Frank were included in the National NIDCAP Training Center's report and, by the way, the Board approved Sam Butler as a NIDCAP Trainer. She will do an excellent job as Center Director having learned everything from you, our best mentor. We continued our meeting with the Quality Assurance Advisory Council session on nurturing NIDCAP trainers with small group work sessions. Thankfully Graciela Basso has agreed to continue as Chair of the QAAC.

As usual, we had quite a few thought-provoking abstracts presented both in person and through Zoom. You would love to know the new directions that Nadine Griffiths and Natascia Simone are taking with nurses' perceptions as well as parental partnerships. We had a good section on breastfeeding and oxytocin from Adi Freund-Azaria in Israel and Dorothy Vittner's ongoing work. Additionally, we had good and interesting presentations on music therapy and on the quality of sleep. This morning both Marzieh Hasanpour, in person, and Saadieh Masri, on Zoom, were able to present their work on empathy and developmental care in Lebanon, respectively. Our journal club continues and this year we had three articles including maternal bonding through therapeutic cooling, a small wins framework, and severe BPD.

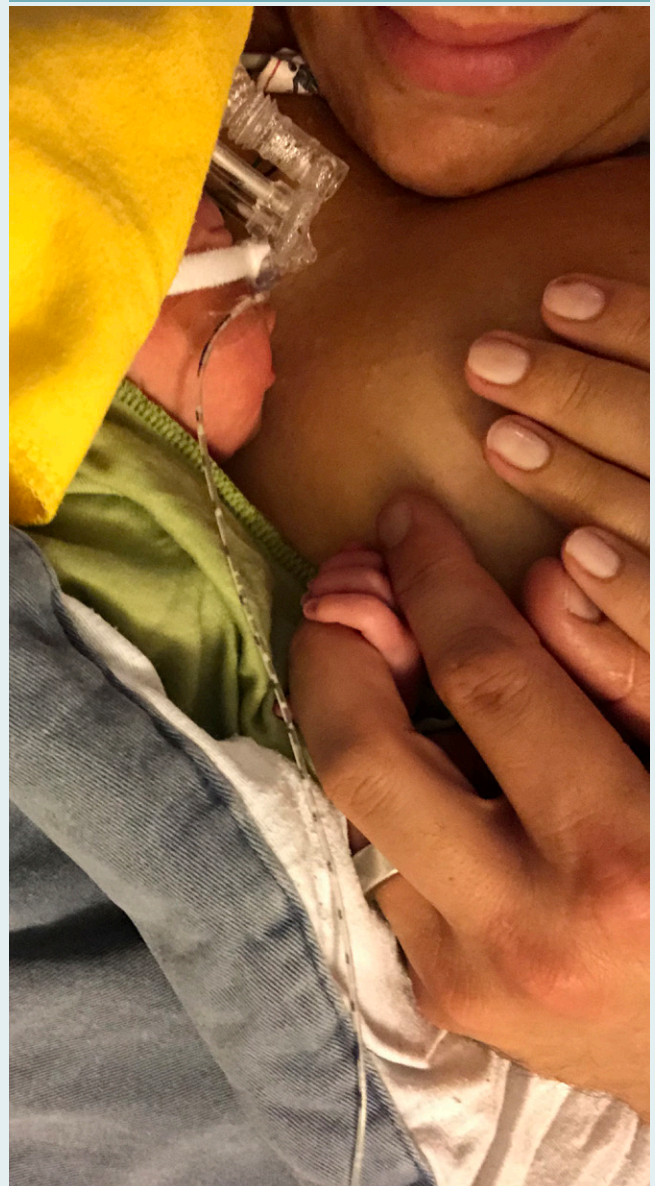
Heidi, it was another very full day and then our hosts took us all to Tübingen for a wondrous evening filled with a punting boat ride, an old city walking tour, and an incredible dining experience. The boats were like authentic primitive swan boats at Boston Public Garden, and there were swans in the canal! I got the best Captain; Captain Jonas and he even sat and played a jazz song on his guitar for us. I have to admit Heidi, that the city walk was quite challenging for me, but so interesting and a perfect



Some of the 54 remote attendees

NIDCAP Care in the Moment

Supporting hands



experience of the town. I can certainly see why you so enjoyed all the time spent training here. I ended up with a bit of a private tour with Christian Poets. The restaurant was just amazing, and we had a wonderful time with memories to last forever.

So, Heidi, this is our third day, and everyone is tired and we have the important work of the NIDCAP Nursery Program as well as the NFI Membership meeting. You would have been so proud of Sam Butler for her presentation on using the NNP as a systems change agent tool. Our NFI Membership meeting had many of the usual tensions; some questions about the budget that just needed clarification. Of course, whenever someone does not get elected, it is a little difficult because we want everyone to be satisfied. Then, although it had just been an undercurrent, the tensions between FINE and NIDCAP pulled us underwater a bit. With all our excellent clinicians and NFI members, surely, we can figure this out. If you can send us any good vibrations, please do, Heidi.

The best part of having a hybrid meeting was having some of our old friends such as Elsa Sell and Roger Sheldon join us. We had Bjorn Westrup with us on Zoom throughout the meeting and at one point, he was walking his dog as he chimed in on an issue. Heidi, all in all, this was an excellent although emotionally painful meeting for many of us. Thank you for all you have given us.

Your loving friend, gretchen.

Some Participants' Comments on the 33rd NIDCAP Trainers Meeting

What were the most rewarding experiences for you at the meeting?

- » *The Open day sessions were very interesting. The small group discussion and reflection were the more rewarding parts: and after so long time*
- » *Talking in person with people*
- » *Informal discussions with other trainers on how they do things*
- » *The venue was good, and the audio-visual team was FANTASTIC*
- » *Catching up with everyone, meeting new members, discussing research ideas*
- » *The excursions were excellent even though long and tiring*

Any other considerations?

- » *Could we have a full 3rd day. It was a pity that many left before the meeting finished*
- » *Cost is the main issue.*
- » *The hybrid format MUST continue, even though this may cost something re tech support. Online attendance allows so many more to join*
- » *The membership meeting should NOT be on the last day so that follow-up conversations can occur more privately and also will allow members to think about what was presented*
- » *The venue needs to be easily accessible from the international airport*

What would you like to see more of at the NIDCAP Trainers Meetings?

- » *More research and group discussion/ share experiences*
- » *More practical support for professionals and trainers*
- » *More group sessions with discussion*
- » *More scientific presentations*
- » *More interaction between the members and the members of the board*

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How Can Healthcare Professionals Influence the Political Agenda to Improve Newborn Care? Translation Into Practice

Kelly Janssens

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How did infant and family-centered developmental care ‘come to life’ on the political agenda?

An overview of key events that led to a structural approach to supporting developmental care in Belgium.



Kelly Janssens

working at the FPS, highlighted the importance of qualitative developmental care in neonatology to the policy makers. As a result, in 2013 a developmental care coordination team was formed in parallel with the breastfeeding coaching team. Over and above helping teams evaluate developmental care practices in their neonatal units, the goal was to establish and ensure quality care for preterm born babies by additionally incentivizing training in NIDCAP and FINE.

After financially supporting the French speaking Brussels NIDCAP Training Center, the FPS chose to subsidize the designation of a Flemish counterpart. The UZ Leuven NIDCAP Training Center was officially opened on the 7th of May this year. The Belgian Prime Minister, Alexander De Croo,

and the Minister of Social Affairs and Public Health, Frank Vandenbroucke, were invited to give an introductory welcome speech at the symposium. In preparation of this visit, both Ministers gained detailed information on both projects and were enlightened about the latest evidence on breastfeeding and developmental care. Additional projects unfortunately put on hold, during the corona pandemic, such as the establishment of a donor human milk bank, were brought back to the table to ensure the continued commitment to the overall goal: improving the development for preterm born babies.

Future

With 30 maternity wards certified with a BFHI-label (out of the 93 established maternity wards in Belgium), and 16 (out of 19) Belgian NICUs involved in a NIDCAP-process, the FPS is continually working on strategies to anchor breastfeeding and developmental care projects into a solid national care program for mothers and their newborn babies. One such strategy involves the endorsement of revised qualification standards for maternity and neonatology wards, requiring obligatory staff training in breastfeeding and developmental care.

How it all started

Today the Belgian Federal Public Service (FPS) supports neonatal units and their medical staff (both nursing and medical), to be trained in breastfeeding and developmental care programs such as NIDCAP and Family and Infant Neurodevelopmental Education (FINE). The ultimate goal is to provide (preterm) newborn babies with the best possible start in life. This investment strategy did not however develop overnight. Following the WHO and UNICEF’s global recommendations, the FPS started to subsidize breastfeeding education programs after a law was passed in 1999 to establish a federal breastfeeding committee. To this day the breastfeeding coordination core group is entrusted with the task to promote, protect and support breastfeeding. Its members, with a medical and nursing background, are approved by royal decree. Apart from providing advice regarding breastfeeding policy measures, another of the members’ tasks is to monitor the Baby Friendly Hospital Initiative (BFHI) in hospitals. For the latter function two BFHI-coordinators were assigned in 2005.

How the project expanded with developmental care

In 2012, neonatologists Prof. Dominique Haumont of the Brussels NIDCAP Training Center and Dr. Anne Clercx

Reflection

An important facilitator of bringing developmental care to the spotlight, was the publication of a report in March this year of the Belgian Health Care Knowledge Center (KCE)* on infant- and family-centred developmental care (IFCDC) for preterm newborns. In the comprehensive report, the authors suggested recommendations for the implementation of IFCDC-principles to the FPS, the Minister and hospital boards. A group of experts (neonatologists and specialized nursing staff in neonatology) underlined the importance of these proposals. This collaboration between experts from the working field together with evidence from the literature, convinced policy makers of the necessity to establish a course of action and to continue the support of developmental care in neonatal settings.

The opening ceremony of the NIDCAP Training Center in

UZ Leuven, was the perfect opportunity to invite our Ministers to the NICU to meet the parents of our vulnerable babies as well as the nursing staff personally, and to discuss why IFCDC is so important to sustain. The combination of the scientific report on IFCDC and the opening of the Training Center created momentum for current policy makers to finalize decisions that will result in the consolidation of both projects. We hope this will build a strong foundation on which to build, and to enhance chances for a better future of preterm born babies in Belgium.

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This document is available on the website of the Belgian Health Care Knowledge Centre. <https://kce.fgov.be/en>

Psycho-Neonatology: Working with Parents, Preterm Infants, and Staff. The Outcome of Former Preterm Infants 20 Years Later

DOI: 10.14434/DO.V16I1.35783

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Although neonatology is a technologically sophisticated medical field, its insights are too frequently slighted by parents, medical staff, and psychosocial support personnel. Even today, neonatology lacks any kind of psychological specialisation, which has, for example, been a core component of paediatric oncology for many years. Developing new modes of sensitive, individualized, attachment-based nursing, helping parents to bond with their baby born very preterm, implementing kangarooing for mothers AND fathers, and 24/7 visiting hours should lead to a specialisation on psychological and trauma-related issues. Furthermore, the medical and nursing staff should receive regular supervision as part of psychohygiene in order to foster sensitivity for the infants' and parents' needs, and to facilitate an attachment-based friendly atmosphere in the NICU. All



Karl Heinz Brisch

this should focus on fostering secure infant-parent attachment development, despite the difficulties resulting from preterm delivery, complex newborn intensive care, and familial complications.

Our Ulm study, which started about 20 years ago,¹ was one of the first intervention studies, in which we focused on enhancing the development of attachment security in the preterm infant by supporting the parents through individual support, parent groups, and support during the transition from hospital to home. One aim was to mitigate previous unresolved issues of loss and trauma, as many parents had already experienced a stillbirth before they had to cope with a preterm delivery. We found that if the trauma of a previous loss has not

been resolved, preterm birth triggers several trauma-related symptoms like avoidance of the baby, overanxiety, inability to

separate from the baby, and leaving the infant in the incubator for an extended period of time. Unprocessed mourning of a previous stillbirth impeded the parental bonding process with the preterm baby.

We further found out that in the control group – without any attachment-based intervention – healthy preterm infants had a greater chance of developing a secure attachment to their mothers, while neurologically impaired infants were more likely to develop insecure attachment. On the other hand, in the intervention group, infants had eight times (OR 7.8) higher chance to develop a secure attachment to their mothers, even when they had neurological problems, which implies that their health status no longer predicted their attachment development.

We followed this sample of very low-weight preterm infants (all <1,500 g birthweight; the infant with the lowest birthweight at that time in our sample that survived weighed only 320 g!) for 20 years and have collected data at several age points during their lives. The latest data sampling point for these formerly preterm infants occurred at about 20 years and included their mothers. To the best of our knowledge, ours is the first to investigate into late adolescence the long-term *attachment development* of teenagers born very preterm. We conducted a semi-structured interview that focused on attachment development with respect to their family and to their peers. In adolescence, peers are very important for emotional security and for the separation process from the core family.

The most striking result was that the attachment status of 56% of former very preterm adolescents changed over time. More precisely, a shift was found from attachment security in early childhood (assessed 14 months postpartum, corrected for prematurity) toward insecurity, resulting in a high proportion of insecure-avoidant (36.9%) and to some extent disorganised attachment classifications (21.5%).^{2,3} However, attachment was unrelated to neonatal parameters, neurobiological risk,

or intelligence. Furthermore, in late adolescence, there was an association between psychological distress and behavioural problems in teenagers born very preterm, especially according to those symptoms classified as "preterm behavioural phenotype". These subjects had to be referred to psychotherapy.⁴

In summary, our results reveal that psychological burdens in late adolescence do not primarily arise from the physiological consequences of preterm delivery per se, but rather from feelings of loneliness and isolation, resulting, for example, from having people around, missing close friends, or non-participation in age-appropriate peer groups.

Our findings stress the urgent need to integrate psychosocial attachment-based support for the babies, parents, and staff as a baseline requirement from the very beginning. Promoting attachment security by internalising representations of trust, reliable emotional support in times of need, and dampening the adverse effects of parenting on psychosocial outcome, should be taken into account.

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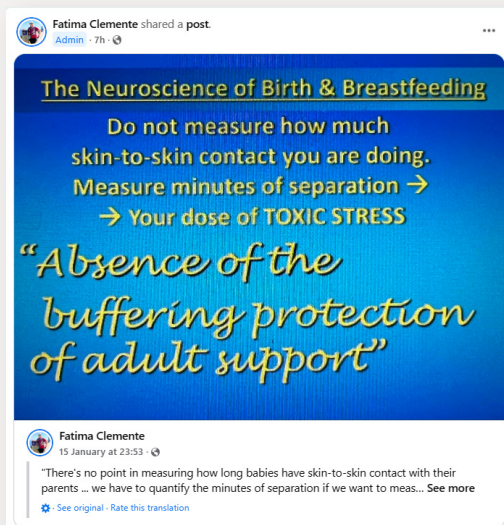
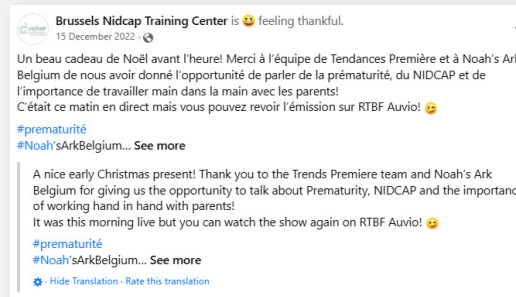
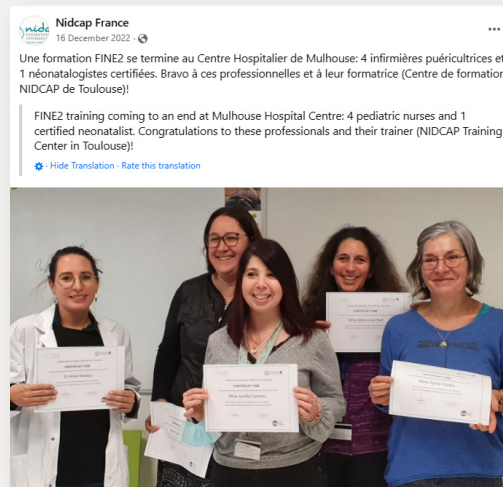
Note: This paper was to be presented at the 33rd NIDCAP Trainers Meeting. Unfortunately Professor Brisch was unable to present his paper.

(continued from p. 18)

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NIDCAP Training Centers – Facebook Pages

The promotion of NIDCAP on Facebook continues with new pages being added. Over the past few months, we have seen these pages promote conferences, seminars and support sessions, helpful information, new publications, achievements, and celebrations of NIDCAP. Please visit these sites and explore other information and achievements to help you celebrate NIDCAP.



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