

Developmental Observer

The Official Newsletter of the NIDCAP® Federation International

ABSTRACT EDITION

NIDCAP Federation International (NFI)

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

“Averages... seduce us away from minute observation.”

FLORENCE NIGHTINGALE

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Greetings from the Editor

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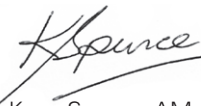
As we start a new decade the future looks bright for the *Developmental Observer*. We have expanded our editorial team to include Debra Paul as column editor for the Family Voices and Maria Maestro Lopez - who brings a European perspective. We took the opportunity to meet as a group together with Graphic Designer, Rob Catalano. This face-to-face meeting gave us the opportunity to discuss future directions for the *Developmental Observer* and develop a plan.

In this issue we have the abstracts from the 30th Annual NIDCAP Trainers Meeting held in Portsmouth, New Hampshire, USA. The abstract topics highlight the breadth of NIDCAP work from the science of Oxytocin, implementation strategies for programs of reading, use of volunteers, the CICU to refugee health. The abstracts and other articles in this issue now have unique DOIs that will enable others to locate the articles easily through the IUScholarWorks platform. We highlight the NIDCAP Germany Training Center Tübingen which hosts the next Trainers Meeting in October. You will be challenged by Marjorie Palmer to consider pacing for infants who have difficulty feeding, and Natascia Bertonecelli takes us through her involvement with the European Standards and highlights this valuable resource. With our regular features from the Science Desk Jeff Alberts explores the fascinating world of epigenetics and NIDCAP work and Debra Paul introduces us to the little warrior of Matilda as told by her mother Tracey. We learn about developmental care in Chile as we explore the globe in each issue.



Kaye Spence, AM

I welcome your feedback and suggestions for future content. I would also like to receive manuscripts on any aspect of NIDCAP work so we can all benefit from innovation and experiences.



Kaye Spence AM

Senior Editor – *Developmental Observer*

Adjunct Associate Professor / Clinical Nurse Consultant

Australasian NIDCAP Training Centre / Sydney Children's Hospitals Network / Western Sydney University / Australia



Editorial Team (from left): Sandra Kosta, Kaye Spence, Rob Catalano, gretchen Lawhon, Debra Paul, Dianne Ballweg, Jeffrey Alberts, Maria Maestro Lopez, Deborah Buehler.

Oxytocin Responsivity During Skin-to-Skin Care and Diurnal Cortisol Predict Depression, Trauma and Bonding Scores at NICU Discharge in Parents of Preterm Infants

Bollen B^{1,2}, Bernagie C^{1,2}, Verhaeghe J^{1,3}, Vanhole C^{1,2}, Naulaers G^{1,2}

¹ Department of Development and Regeneration, Women and Child, University of Leuven, Leuven, Belgium

² Neonatology Department, University Hospitals Leuven, Leuven, Belgium

³ Department of Gynaecology and Obstetrics, University Hospitals Leuven, Leuven, Belgium

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Aims

Preterm birth is a potential traumatic experience for parents. Several studies show a high prevalence of depressive and post-traumatic stress symptoms in mothers of preterm infants.¹ Hormonal changes in cortisol and oxytocin have both been implicated in these stress responses and also in parent-infant biobehavioral synchrony.²

We aimed to predict parental depression, posttraumatic stress and bonding at NICU discharge. We hypothesized that the physiological response of parents to skin-to-skin care (cortisol and oxytocin) would predict emotional distress and feelings of bonding. We also took into account early markers of parental distress (questionnaires postnatal week two).

Methods

Data were collected for the Resilience Study (NCT02623400): a prospective longitudinal cohort study performed in the University Hospitals Leuven. Parents (n=105 parental dyads) of 136 infants (<34w GA and/or BW< 1500 g) were included. Parents completed questionnaires in postnatal week 2 and in the week before discharge. Depressive symptoms (Edinburg Postnatal Depression Scale (EPDS)), acute trauma symptoms (Acute Stress Disorder Scale (ASDS)) and posttraumatic stress disorder (Impact of event Scale (IES) & Traumatic event scale (TES)), and parental stress (PSS-NICU) were measured, both in mothers and fathers. Feelings of bonding were measured using the Postpartum Bonding Questionnaire (PBQ). Furthermore, parental saliva samples were collected to determine diurnal cortisol profile (awakening, 30 min, 4h, 12h later) as well as oxytocin and cortisol response during kangaroo care (KC, before, 20 min, 60 min). Data were analyzed using multiple regression analysis.

Results

Mothers and fathers of preterm infants in our sample show high levels of emotional distress. Results show 76.5% of mothers, and 40.7% of fathers exceed clinical cut-off scores for postnatal depression. In general, these levels of emotional distress decrease during hospitalization.

Both in mothers and fathers, acute stress scores (postnatal week 2) but also diurnal salivary cortisol level (AUC) were significant predictors of parents' post-traumatic stress symptoms at discharge (mothers: $F(2,74) = 25.49$, $p < 0.0001$, $R^2 = 0.41$; fathers: $F(2,64) = 19.31$, $p < 0.0001$, $R^2 = 0.38$). Interestingly, the salivary response in oxytocin level during KC is a significant predictor ($p < 0.01$) of both depression and bonding scores at discharge in mothers: a higher increase in OT during KC care is associated with lower depression scores and with higher bonding scores in mothers.

Conclusion

This study finds high levels of emotional distress in both mothers and fathers of preterm infants. Acute stress scores and diurnal cortisol in postnatal week 2 predicted posttraumatic stress symptoms at discharge, both in fathers and mothers. Changes in salivary oxytocin level during KC predicted bonding and depression scores in mothers. Our findings emphasize the vulnerability of parents of preterm infants and draws attention to physiological responses underlying parental emotional distress. Our findings also highlight the need for specialized and individualized support for NICU parents.

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Senior Editor Kaye Spence AM

Associate Editors Diane Ballweg, APRN, CCNS, Deborah Buehler, PhD, Sandra Kosta, BA
gretchen Lawhon, PhD, RN, FAAN, Maria Maestro Lopez, MD

Associate Editor for Science Jeffrey R. Alberts, PhD

Column Editor Debra Paul OTR/L



Contributions

We would like to thank all of our individual donors for their generous support of the NFI and its continuing work.

Health Care Professionals Beliefs and Perceptions on Family-Centered Care in the NICU

Vittner D^{1,2}, Parker M¹, DeMeo S¹, Baxter A², and McGrath J³

¹ WakeMed Health & Hospitals, Raleigh, NC USA

² University of Connecticut, School of Nursing, Storrs, CT USA

³ University of Texas, Health Science Center San Antonio, San Antonio, TX USA

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Background

The Neonatal Intensive Care Unit (NICU) is a complex, technology-driven environment where health care professionals have many tasks to accomplish throughout the day. Critically ill infants have complex physiological needs requiring advanced medical and nursing interventions to sustain life. Developing parent-infant relationships are influenced by the interactions within these early life experiences.¹ Parents have identified communication and information provided by nurses as important factors influencing their experiences.^{2,3} Prior research establishes that caring behaviors directed at the infant's family are a significant component contributing to parent satisfaction with care.^{4,5} Additionally, the family unit has been identified to impact the health and well-being of the infant and conversely, the health of the infant has been shown to impact the health status of the family.⁶

Aims

The purpose of this study is to examine health care providers' beliefs and perceptions regarding providing family-centered care (FCC) in the NICU as well as variables that may influence provision of FCC.

Methods

This exploratory descriptive study used an online survey format. The survey comprised of 10 items from the Perceived Stress Scale, 10 items related to symptoms of burnout, a subscale of the Professional Quality of Life (ProQOL) scale and 27 items of the Family Nurse Caring Belief Scale (FNCBS).⁷ There were 6 items related to demographic characteristics, and 2 items regarding rationing care. Hospital IRB approval was obtained. An email which contained an information sheet describing the study with a link to a secure anonymous online survey through (www.qualtrics.com) was sent by an administrative assistant. No identifiable information was collected from participants. Consent was implied if respondents connected to the link to access the survey. Two reminder emails were sent after 1 and 3 weeks from the initial email invitation. The questionnaire was available to participants for a total of 4 weeks. SPSS version 25 was used for analysis of descriptive statistics, Pearson's correlation and one-way analysis of variance (ANOVA) were used to analyze participant responses.

Results

The sample consisted of 115 multidisciplinary participants working in a level IV NICU in southeastern United States. Participants report strong levels of beliefs of FCC and value its importance. The majority of participants (82%) strongly

agree that no matter how sick the infant is, he/she needs to be treated as an individual, the remaining 18% agreed with this statement. Participants strongly agreed (68%) being available to families is an essential part of care in the NICU, the remaining 32% of participants agreed with this statement. A significant correlation (.001) exists between participant's stress composite score and FCC composite score indicating higher levels of stress are correlated with lower FCC scores. There were significant relationships between participant's years of experience (0.002) and education levels (0.005) in the NICU and FCC composite scores. There were also significant relationships between participant's years of experience (0.004) and FCC education (0.039) and Perceived Stress Scale composite scores. There were no relationships identified for the Professional Quality of Life (Burnout) Composite scores and demographic characteristics.

Conclusion

Health care professionals care greatly about providing FCC and understand its importance. Results suggest that participants agreed FCC is important yet feel inadequate staffing and inappropriate assignments may lead to rationing of care to infants and their families. Further research is needed given the limitations of this exploratory single-site study. It is essential to continue exploring factors that may lead to rationing of FCC, provision of FCC in the NICU is associated with reduced stress experiences, shorter durations of stay, and ultimately enhanced parent-infant relationships.⁸

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NIDCAP Influences Maternal/Newborn Health in the Embrace Refugee Birth Support Program

Frankel K.

Private Practice, Developmental Specialist, Atlanta, GA, USA
Member of Emory University Perinatal Behavioral Support Project
Friends of Refugees: Embrace Birth Family Mentor

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Aims/Purpose

Approximately 95,000 people are living in refugee camps on the border of Thailand and Burma (Myanmar).^{1,2} Ethnic minorities (Chin, Karen and others) who have fled conflict for over 30 years have registered with the United Nations to be resettled in a third country. Many escaped as children and grew up with limited education, healthcare, and job opportunities. A large group has resettled in Georgia finding employment in chicken processing facilities an hour north of the city. Fathers leave their families 12 hours per day. Pregnant women in this community are at risk for poor prenatal care due to lack of transport, caring for other children, and lapses in Medicaid coverage.^{4,5} New arrivals struggle to learn English and to adapt to American customs. The strengths of the community are apparent in their humble nature, diet of proteins, homegrown vegetables and rice, value of the nuclear family, and nurturing of their children in close contact. This population is vulnerable when encountering the healthcare system due to language, cultural differences and lack of understanding of American healthcare practices.^{4,5}

The Embrace program is a community effort which identifies pregnant immigrant women and pairs them with caring mentors. The mentor accompanies the woman through childbirth and all prenatal, postpartum, and early pediatric appointments. The aim here is to describe how an adaptation of NIDCAP principles can provide a culturally sensitive framework for individualized assessment and care while mentoring a Karen mother. The goal was to minimize the effects of stress of birth and hospital encounters, and improve maternal/infant birth experiences by employing principles of family centered individualized care, observation, and reflection.⁶

Methods

A 28 year-old Gravida 5 Para 4 Burmese mother had two normal deliveries in a refugee camp prior to arrival in the US in 2013. Her third pregnancy ended in fetal demise. During her 5th pregnancy she missed prenatal appointments and was labeled as high risk. English was limited and she had an extremely humble nature in the face of challenges. The Embrace mentor, a NIDCAP trained provider, established trust and friendship by accompanying her to birth classes (instructed by another Karen immigrant) where she was educated on delivery, hospital policies, infant care, and family planning. She developed a pictorial narrative of her birth plan. The mentor transported her to prenatal appointments where there was the opportunity to observe and interpret her responses to medical information, seeing the ultrasound of her baby, and painful procedures.

Findings

Labor occurred spontaneously at 39 weeks. Careful observation revealed that contractions were coming 10 minutes apart. She was transported to the hospital and assessed as 4 cm dilated. The mentor remained at the mother's side and counted contractions. Labor progressed rapidly with low intensity responses from the mother. The baby was moderately distressed at birth requiring suction and stimulation. The NIDCAP trained mentor supported the infant on the warming table and in transition to the mother's chest. The infant improved his status and was monitored with pulse oximetry. The mentor offered to observe the infant carefully so that mother and baby could have protected skin to skin time. In the 48 hours after the birth, NIDCAP principles of modifying the environment, observation, positioning, supporting with painful procedures, and maximizing skin to skin were instituted.^{6,7}

Conclusion

Family integrated, relationship based, culturally sensitive, and responsive maternal-infant interactions were the NIDCAP principles implemented improving the experience for this mother and infant. As stated in the NIDCAP vision statement, care was individualized, enhancing strengths and minimized the stress of hospitalization of a newborn and his family. An evidence-based approach of observation, evaluation, modification and reflection was employed.^{6,7} It is the hope of this author that NIDCAP training could be used in diverse settings and with people in need of sensitive caregiving.

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Using Newborn Individualized Developmental Care and Assessment Program (NIDCAP) Philosophy and Principles in the Implementation of a NICU Book Sharing Program

Lacina L, Roux M, Kessler C, Jain V

Newborn Intensive Care Unit, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA

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Background

Infants admitted to the Newborn Intensive Care Unit (NICU) are at increased risk of developmental delay; additionally, they are exposed to sounds but relatively little language. Language exposure, such as talking, reading, and singing, is essential for speech and language development. Greater language exposure and shared reading in the NICU is associated with better neurodevelopmental outcomes.^{1,2} As such, the American Academy of Pediatrics (AAP) recommends that parents begin sharing books with infants as soon as possible after birth. Shared book reading can help parents promote literacy and reading achievement in their children; it also enhances parent infant bonding and reduces parental stress.³ Intervening in the NICU encourages parents to continue reading to their infant post-discharge; however, such a book sharing program has not been carried out on a large scale in a heterogeneous and diverse population in the Cincinnati region.

Relevance to NIDCAP

This project supports development of relationships between parents and infants in a NICU. Such early interactions, based upon responsive and synchronous experiences, may positively influence infant short-and long-term outcomes. Staff involvement that embraces parental partnership builds trust and positive unit culture. Embracing the Synactive Theory we know that infant behavior proceeds through continuous balancing of approach and avoidance behaviors across five subsystems, communicated as infant biobehavioral cues. Understanding and utilizing these behaviors is key to the length and timing of book sharing with infants in the NICU, as we individualize our interactions to support the competence of each infant within their family's supportive structure.

Aim

The aim of this project was to increase the adoption of shared book reading between parents and infants by increasing the percentage of parents sharing books with their infants in the NICU and continuing that book sharing post-discharge.

Method

All families from NICUs in the Cincinnati region from June 1, 2018 were approached. Discharged families were administered an Institutional Review Board (IRB) approved questionnaire at their first clinic visit assessing home reading environment and shared reading practices, adapted from a validated measure and from NICU infant-shared reading literature.³

Results/Findings

Before starting the intervention staff and parent reading beliefs and behaviors were assessed, as were the home reading environment for infants recently discharged from the NICU. The pre-intervention outpatient parent survey clinic in 198 families showed that 143 (64%) had infants who were never or rarely read to in the NICU, while 64 (29%) never or rarely read at home. Only 85 (38%) recalled having received anticipatory guidance on shared reading in the NICU, and very few (11%) recalled being shown how to read to their NICU infant. After adjusting for potential confounders, the frequency of reading aloud in the NICU was independently associated with the frequency post discharge ($p < 0.001$). The NICU Bookworm Program was designed with the hypothesis that such a program would increase the frequency of book sharing in the NICU and at home post discharge. Post intervention our data revealed that in 115 families, parents receiving anticipatory guidance increased from 38 to 60%. Parents being shown how to share books with their infant increased from 11 to 56%. Parents regularly reading to their child significantly increased in the NICU (34 to 54%). Parents regularly reading to their child at home increased (71 to 75%), but significant change was seen in the high-risk group (parents who did not enjoy reading) from 46% to 72%.

Conclusion

Despite AAP recommendations, there exist significant gaps on giving anticipatory guidance to parents in the NICU about shared book reading. Healthcare professionals can play a significant role in increasing this practice. In our population a structured book-sharing program increases reading behaviors in the NICU as well as at home post-discharge, with the most significant benefit seen in the high risk group of parents who themselves do not enjoy reading.

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Filling a Significant Gap in the Cardiac Intensive Care Unit (CICU): Quality Improvement Using the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) Approach

Butler S¹, Hartwell L², Thornton J², LaRonde M², Rachwal C²

¹ Psychiatry, Boston Children's Hospital, Boston, MA USA

² Cardiology, Boston Children's Hospital, Boston, MA USA

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Aims

Congenital heart disease (CHD) is among the most common birth defect with approximately 36,000 U.S. infants born annually.^{1,2} More than one-third of infants with CHD will require infant surgery.^{3,4} Neurodevelopmental disabilities are the most common, and arguably the most distressing, long-term morbidity in survivors.^{1,2,5} While mortality rates for children with CHD have significantly declined, neurologic abnormality and neurodevelopmental impairment have increased. Neurodevelopmental deficits are noted from infancy to adulthood including developmental delays, learning disabilities, social and emotional concerns and behavioral problems.⁶⁻¹⁰

There are many causes of the neurodevelopmental concerns in individuals with CHD. One modifiable cause is the in-hospital care and its negative effects on the developing newborn brain. The cardiac intensive care unit (CICU), while necessary to save the life of the infant with CHD, exposes infants to overwhelming stress through noxious stimuli, including painful procedures, invasive lines and tubes, toxic sensory stimulation, and separation from family. Current research advocates for adjustment to medical practice to reduce the detrimental developmental effects.^{11,12} Research also indicates that interventions such as developmental care (DC) are minimal in cardiology due to a need for staff education and a shortage of evidence for the benefits of DC in cardiology.¹³

Individualized DC in the NIDCAP approach¹⁴ attempts to minimize the mismatch between infant neurobiological needs and the CICU environment, thus diminishing the frequency and severity of adverse effects on the infant with CHD. NIDCAP has repeatedly proven to improve neurodevelopment and psychosocial outcomes for high-risk infants and their families.¹⁵⁻¹⁷ The global aim of the current project was to be the first CICU to implement and measure NIDCAP care.

Methods

An interdisciplinary team was convened to implement NIDCAP care in the CICU through quality improvement (QI). Developmental care implementation included: (1) staff education, (2) child neurodevelopment assessment and intervention, (3) clinician support, (4) family support, and (5) QI measurement methodology. Current care practice was evaluated using the NIDCAP Nursery Environment and Care Component Template Manual¹⁸ (Templates) along with additional questions on infant holding and family participation taken from the NIDCAP Nursery

Certification Criterion Scales.¹⁹ A five point rating scale (1=traditional care to 5=highly attuned NIDCAP implementation) was used. Thirty CICU nurses were trained in the basics of NIDCAP and served as champions in the CICU. Seven were additionally trained and reliable on use of the Templates (>90%). Background medical data was also collected. The impact of developmental care implementation was monitored through statistical process control methodology²⁰ to observe changes in care prior to, during, and after NIDCAP implementation. Plan-Do-Study Act (PDSA) methodology was used to refine the process and intensify practice change.

Results

Over two years of intervention implementation, there have been no major adverse events related to NIDCAP care. Template data was measured quarterly (77 templates, ongoing collection). Evidence for significant improvement in mean scores from below the lower control limit to above the upper control limit was noted in bedding and clothing; supports for infant self-regulation; position, movement and tone; timing and sequencing of caregiving; and family participation. (Figure 1) Slight improvement was noted in environment and infant holding. Results led to an individual task force to support environmental change, additional professionals recruited to DC team, and supplementary staff education provided.

Conclusion

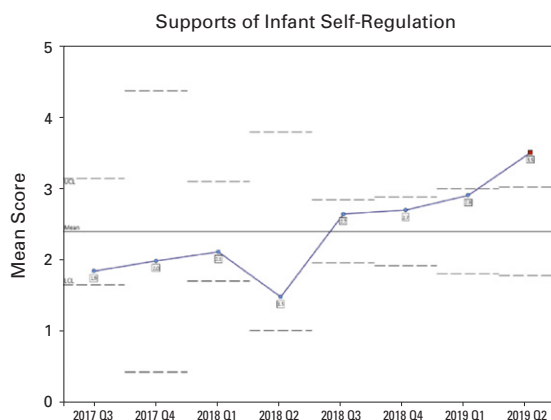
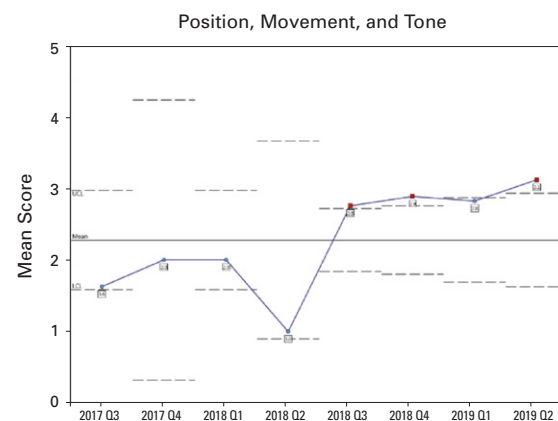
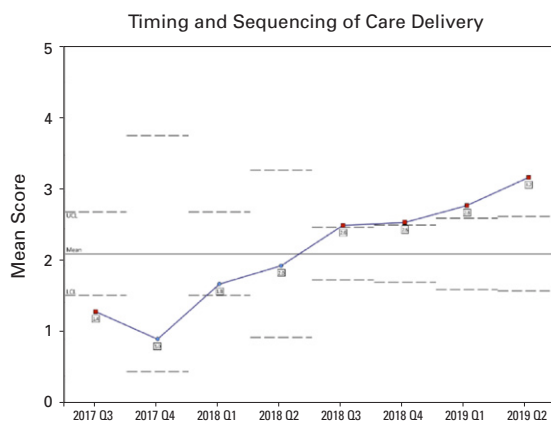
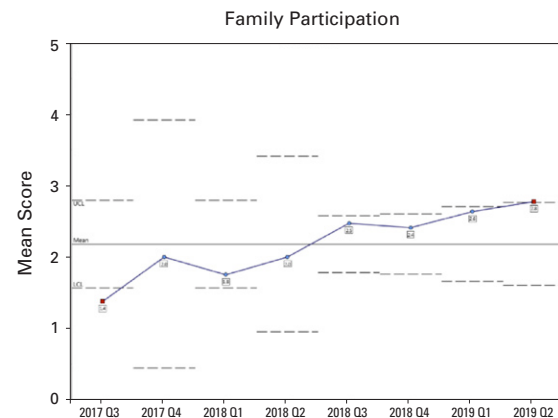
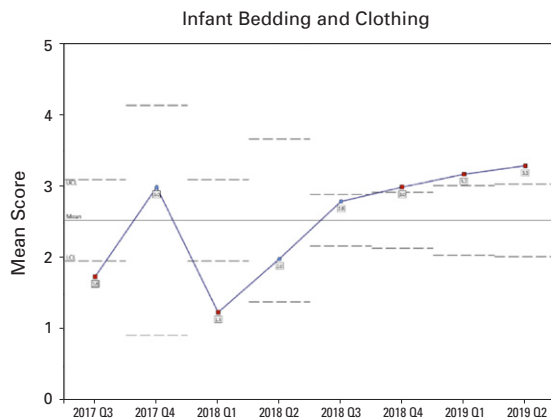
This QI study evaluates the efficacy of NIDCAP in the CICU for newborns with CHD. Evidence for significant improvement in mean scores of DC was noted in infant and family support. NIDCAP care efforts showed meaningful improvement in the CICU through education and staff support with ongoing need for QI science. Our increased performance of developmental care is likely related to current QI efforts and dedicated developmental care team.

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FIGURE 1. X-bar control charts showing quarterly mean scores for select NIDCAP Template items

The solid center line represents the average score for the entire time period (CY 2017 Q3 – 2019 Q2). The dashed lines represent upper and lower control limits, which correspond to $\pm 3\sigma$ from the center line. Special cause is indicated by the red square dots above the center line, which suggest significant improvement in mean scores.



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Early Discharge with Home Care Tube Feeding Program Benefits on Two Years Corrected Age Neurodevelopmental Outcomes, Breastfeeding and First Year Hospital Readmissions for Premature Infants

Losbar J¹, Arnaud C², Glorious I¹, Lescure S¹, Casper C¹, Montjoux N¹

¹ NICU, Children's Hospital, Toulouse University Hospital, France

² UMR 1017, INSERM, Toulouse University Hospital France

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Objective

Our objective was to determine the impact of an Early Discharge with Home Care Tube Feeding program (EDHC) – regular discharge on two-years corrected-age (CA) neurodevelopmental outcomes for preterm infants born between 25 and 35 gestational age (GA). Secondary outcome measures were length of hospitalization stay, breastfeeding and first year hospital readmissions.

Methods

This observational study compared 415 EDHC preterm infants from Toulouse University Hospital, born between 2008 and 2015, and 3186 preterm infants of the EPIPAGE 2 study cohort born in all French newborn units in 2011. Neurodevelopmental Ages and Stages Questionnaire (ASQ) was used to assess neurodevelopmental outcomes. Length of hospital stay, breastfeeding rates at discharge and six-months and hospital readmission rates during the first year were compared between the two groups. Differences in the two populations characteristics were adjusted with multivariate multilevel regression analyses.

Results

At two-years CA data on ASQ were available for 125 EDHC and 2066 EPIPAGE 2 preterm children. EDHC preterm singletons had 61% less risk to obtain a total ASQ score below

threshold of 220 (OR = 0.39 [0.32-0.48], $p < 0.001$), less risk to have communication abilities above threshold (OR=0.42 [0.34-0.53] $p<0.0001$), fine motor skills above threshold (OR=0.63 [0.51-0.78] $p<0.0001$), problem solving abilities above threshold (OR=0.53 [0.43-0.66] $p<0.0001$), and personal-social skills above threshold (OR=0.64 [0.52-0.78] $p<0.0001$).

Length of hospital stay was nine days shorter for the EDHC preterm infants ($p<0.0001$).

EDHC preterm children were more likely to be breastfed at final discharge (OR = 3.59 [2.82-4.58], $p < 0.001$ for singletons and OR = 2.25 [1.62-3.14], $p < 0.001$ for multiples), and breastfeeding was more likely to be continued over six months among those same children (OR = 1.76 [1.34-2.32], $p < 0.001$ for singletons, OR = 3.64 [2.10-6.32], $p < 0.001$ for multiples). Finally, EDHC children singletons had less risk to be readmitted in hospital during the first year (OR = 0.65 [0.55 to 0.77], $p < 0.001$).

Conclusion

The Early Discharge with Home Care Program seems to improve neurodevelopmental outcome at two years of age, length of hospital stay and breastfeeding among preterm infants. It seems also to protect from hospital readmission during the first year. Home care should be promoted in newborn intensive care policies.



The WHO has designated 2020 the International Year of the Nurse and the Midwife. Nurses and midwives play a vital role in providing health and caring for mothers and babies. We would like to hear your stories and how NIDCAP has enhanced the role of nurses and midwives.

Supporting Families in the Neonatal Setting: It's Time to Get Creative!

James Nunez K, Griffiths N, Gittany H

Grace Centre for Newborn Intensive Care
Australasian NIDCAP Training Centre
The Children's Hospital at Westmead, Sydney, Australia

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Background

In New South Wales, The Children's Hospital at Westmead (CHW) is part of a regionalised health system where infants who require intensive care for surgery in the newborn period are often transported to the CHW via a Newborn Transport Service or the woman is transferred for delivery at a High Risk Obstetric Unit associated with a Children's Hospital. This often means families are separated and there are competing needs of families, siblings and work commitments many kilometres from the Grace Centre for Newborn Intensive Care (GCNIC). In 2017, staff in the GCNIC started a Family Support Volunteer (FSV) Program designed to help support parents when they need to leave the hospital for periods of time for other obligations which may include work, family commitments and/or geographical distance from the hospital. The priority remains the attachment of the infant to their parents and supporting the family through an individualised approach to care, frequent open communication and promoting opportunities for the parents to be involved in their infants' care.

Aim

To describe the implementation of a unit-based Family Support Volunteer (FSV) Program to support parents and their babies who are in the NICU for surgery.

Methods

Following recommendations from a NIDCAP Advanced Practicum in 2017, a program to support families in instances where it is not possible for them to always be present with their babies was implemented. Twelve FSV's were recruited from the hospital's existing ward volunteer program. Volunteers with prior experience working in hospital clinical areas and with an expressed interest in working in the NICU were each offered six to 12 hours per week in the FSV role. They were provided with a four-hour orientation program facilitated by a NIDCAP Trainer and a social worker. Training included basic skills for: the identification of infant stress signals; support and comfort through positioning; ways to hold and talk to the baby whilst offering support; and acknowledgement of the role of the parents within the NICU. Families and babies were recruited to the program by the FSV using an opt in/opt out parent consent process; bedside documentation identified families who consented for inclusion. The project was endorsed by the Executive Director of Nursing and had ethical approval through the clinical governance unit of the organisation. Following a ten month trial, a survey was distributed to the volunteers, families and staff to gauge the success of

the program and to identify if changes were required. The survey was distributed electronically by the program coordinator and consisted of ten open-ended and yes/no questions. The online survey was open for completion for four weeks.

Results

Ten families were surveyed regarding the FSV program. Eight (80%) of respondents had used the program. All (100%) of families that used the program identified they would recommend the program to other families.

One hundred percent of the FSV's completed the evaluation. They indicated the majority of their time was spent comforting babies, followed by recruiting families to the program.

Ninety-two percent of staff (n=28) indicated a Family Support Volunteer had assisted them by providing comfort to newborn infants under their care. All (100%) of the respondents found the support offered by FSV's useful by reducing periods of crying and distress for babies. Eighty-nine percent of staff identified the presence of FSV's allowed them to complete other tasks.

Conclusion

The Family Support Volunteers provided an important role in the NICU by helping parents when they were unable to be present with their baby. The collaboration between the volunteers, families and staff has resulted in the needs of the babies being met to reduce crying periods and settling the babies following interventions.



The 30th Annual NIDCAP Trainers Meeting

Oxytocin Release is Strongly Associated With Premature Infant Behavioral Patterns

Vittner D^{1,2}, Lawhon G³, D'Agata A^{3,4}, McGrath JM⁶, Young E^{1,4,5}

¹ University of Connecticut, School of Nursing, Storrs, CT

² WakeMed Health & Hospitals, Raleigh, NC

³ Abington Hospital-Jefferson Health System Abington, PA

⁴ University of Rhode Island, Kingston, RI

⁵ Genetics and Genome Sciences, UCONN School of Medicine, Farmington, CT

⁶ Institute for Systems Genomics, University of Connecticut, Storrs, CT,

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Background/Significance

There is growing evidence that the premature infant and the developing brain, is influenced especially in the vulnerable window of time the infant is cared for in the Newborn Intensive Care Unit (NICU). It has been optimistically, yet incorrectly, proposed that healthy preterm infants without major complications eventually catch-up developmentally to term infants. Research suggests as preterm infants mature, many remain increasingly disadvantaged on many neurodevelopmental outcomes. Parental touch, especially during skin-to-skin contact (SSC) has the potential to reduce the adverse consequences of prematurity. SSC is an evidenced-based holding strategy that increases parental proximity and provides a continuous interactive environment known to enhance infant physiologic stability and affective closeness between parents and their infants.

Purpose

The purpose of this research study was to examine bio-behavioral mechanisms; and specifically, to evaluate whether infants with higher oxytocin levels have more competent neurobehavioral functioning.

Methods

This randomized cross-over design study used a three-day timeframe conducted in the NICU. The sample consists of 28 stable preterm infants (30 0/7 – 34 6/7 weeks gestational age between 3 -10 days old) and their mothers/fathers. After informed consent, each triad was randomly assigned to one of two sequences: maternal SSC on day one and paternal SSC on day two; or paternal SSC on day one and maternal SSC on day two. Infants' and parents' saliva samples for oxytocin and cortisol were collected pre-SSC, 60-min during-SSC, and 45-min post-SSC. Infant neurobehavioral assessment using the NICU Neurobehavioral Network Scale (NNS) was collected prior to hospital discharge.

Analysis/Results

Data were analyzed using IBM SPSS version 25; descriptive statistics were used to describe demographic characteristic variables. Paired t-tests were used to examine infant salivary oxytocin levels and infant neurobehavioral functioning. Oxytocin release was activated for mothers ($p<0.001$), fathers ($p<0.002$) and infants ($p<0.002$) during skin-to-skin contact. There was also a relationship identified using Pearson's

correlation between infant oxytocin levels and the infant's neurobehavioral functioning. Infant salivary cortisol levels were correlated to summary scales of infant stress behaviors and higher levels of disorganization. Infants held SSC with their mother with higher salivary oxytocin levels had significant correlations to high self-regulatory summary scores ($r=.544$, $p<0.003$), and a strong negative correlation to excitability summary scores ($r=-.761$, $p<0.001$). These infants with lower salivary cortisol levels had a strong negative correlation to handling summary scores ($r=.594$, $p<0.025$) and stress summary scores ($r=-.534$, $p<0.049$). Infants salivary oxytocin levels, when held SSC by their fathers, had strong correlations with higher self regulatory summary scores ($r=.396$, $p<0.041$), and a moderate negative correlation with infant lethargy summary scores ($r=-.400$, $p<0.039$). There was also a moderate correlation for infants held SSC by their fathers with higher cortisol levels to have higher lethargy summary scores ($r=.459$, $p<0.016$).

Conclusions

Despite advances in the NICU, premature infants remain at risk for adverse neurodevelopmental outcomes. This is an important step in exploring oxytocin as a potential moderator to improve infant neurodevelopmental outcomes and the effects of SSC on mothers, fathers and infants. Nurses can use SSC as a strategy to activate oxytocin and enhance infant developmental outcomes. This study also supports, in conjunction with the views of the American Academy of Pediatrics, the value that all preterm infants and their parents should have the opportunity for SSC every day.

Keywords

Skin-to-skin contact; preterm infant; oxytocin; neurodevelopment; NICU Network Neurobehavioral Scale Statement of Financial Support:
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Assessment of Preterm Infants' Behavior (APIB)

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

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

The Mysterious Case of Maternal Heartbeat Sounds

Philbin MK

Independent Researcher, Moorestown, NJ, USA

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Aims and Methods

Many people believe that maternal heartbeat sounds dominate the uterine environment and that the fetus, preterm and term newborn prefer them.^{1,2,3} This presentation critically examines the literature addressing this belief.

Results

In 1962, Lee Salk, a psychiatrist in New York City, took a walk through the zoo and noticed a monkey holding her infant close to her body in her left arm “closest to her heart”.^{1,2} In 40 out of 42 subsequent observations, this one monkey did the same. With these and data from observations of newly delivered women and their infants, Salk concluded that every primate is imprinted to their mother's heartbeat during infancy because each female holds her own infant on the left to experience “the pleasurable sensation of her own heartbeat reflected back from the infant”. Thus, behavior due to each mother's own imprinting passes it to the next generation.^{2,4,5} Extrapolating lavishly, Salk proposed heartbeat sounds as “the basis of all later learning” and that a “universal, ...biological tendency to seek heartbeat sounds has survival value [and] ...involves mutual satisfaction.”² Salk's work was influential in bringing the importance of maternal-infant closeness to professional attention.⁶

With numerous, unwitting errors Salk tested the theory of lifetime heartbeat imprinting in a foundling (orphan) hospital² by comparing tape recorded nighttime sounds emitted in whole rooms of healthy infants or toddlers. One room had broadcast heartbeat sounds and the other had “no sounds” (actually room sounds) or broadcast lullabies. The conditions were not masked, and baby nurse activities were not reported. Because the number of infants making sounds was not determined, even one infant could account for all room sounds. The heartbeat condition always had fewer sounds (more sleep) than the control conditions.

In 1968 and 1970 several obstetricians sought to extend heartbeat imprinting into fetal life by recording sounds *in utero* from unconscious women in labor.^{7,8} Although the results were determined by methodological errors, these are the studies that catapulted intrauterine heartbeat sounds into the popular culture where they remain stuck. The emotionally attractive idea of influential intrauterine sounds accounts, in part, for the dangerous practice of propagating all kinds of sounds in the uterus via speakers attached to the pregnant belly or inserted in the vagina.

A responding study using appropriate methods and equipment did not find heartbeat sounds in the uterus of conscious laboring women with a spinal block but did find room and maternal voice sounds.⁹

Studies of heartbeat recognition in infancy generally show preferential responding to them. However, the findings may be

due to too great a difference between experimental and control sounds;^{10,11,12,13} heartbeat sounds may be preferable only because they are simple. But a newborn's ability to make fine discriminations^{14,15,16,17,18} enables contrast stimuli differing only in rhythm. There is no clear preference indicating that newborns have not had exposure to heartbeats. (Such a study has not been found.)

Giving up a long-held belief is difficult even when alternatives are substantial.¹⁹ Thankfully, the alternative to intrauterine heartbeats is gold, namely mother's voice. It, and not prominent heartbeats, has been found reliably in the pregnant uterus of humans and ewes.^{9,20} Well-known investigators conclude, “mother's voice... [is] the most significant and common mode of potential acoustic stimulation in the uterus.”²⁰

Conclusions

Credible research shows that heartbeat sounds are not distinguishable *in utero* but that discriminable features of mother's voice are prominent – a necessary condition to eventual language acquisition. A broad, moral-of-the-story conclusion is that there is nothing quite like a tour through primary sources to examine a common belief.

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31st Annual NIDCAP Trainers Meeting

*The Impact of NIDCAP on
Infant, Family, and Society*

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Mission

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

Adopted by the NFI Board, July 1, 2019

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

Intervention Strategies for the Poor Feeder in the Newborn Intensive Care Unit: External Pacing versus Imposed Regulation

Marjorie Meyer Palmer MA, NLP, CCC-SLP
NOMAS Licensed professional, Speech Pathologist
Founder/Director, NOMAS International. www.nomasinternational.org

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Prior to the 1980's infants in the intensive care nursery who demonstrated feeding problems were described as "poor feeders" with a "weak" or "poor" suck. There was no distinction available at that time to further describe those infants who were unable to orally take sufficient calories to grow. Consequently, infants remained in the hospital for extended periods of time because of poor feeding. Then the 1980's saw the birth of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP).^{1,2,3} Caregivers were suddenly made aware of the stress cues, signs, and signals that preterm infants demonstrated as they were struggling with feeding. Caregivers then began to provide infants with frequent "breaks" during feeding by removing the bottle from the mouth so that they could breathe, burp, or just rest after a very long sucking burst.⁴ This technique of providing "breaks" became known as External Pacing.

External Pacing has always been based upon the cues, signs, and signals given by the infant to the caregiver during feeding and is a consequence of the relationship between the infant and feeder. Since each caregiver has his/her own individual style and manner of positioning the infant; holding the bottle; and selecting the nipple, the infant may demonstrate different stress cues for each caregiver and the interpretation of these signs and signals is subjective on the part of the feeder. Providing "breaks" during a feeding using this technique of External Pacing has been most effective for older infants who are closer to term and who demonstrate longer sucking bursts such as with a continuous burst pattern of 10-30 sucks per burst with swallow and respiration occurring during the burst followed by only a brief pause.⁵

External Pacing was developed as a cue-based technique to aid infants who were experiencing discomfort or distress during feeding and, since the 1980's, has become very popular and is used effectively and frequently with both late preterm and sick term infants whose sucking bursts consist primarily of more than 10 sucks/burst. This intervention strategy has been effective because breathing appears to be the last function integrated into a successful feeding episode for the preterm infant.⁶

In the 1990's, with the development of the NOMAS® (Neonatal Oral-Motor Assessment Scale), for the first time a distinction was made within the poor feeders; trained examiners were able to diagnose the suck pattern as either disorganized or dysfunctional.⁷ A disorganized suck was defined as "a lack of rhythm of the total sucking activity"⁸ which refers to the incoordination of suck, swallow, and breathe. A dysfunctional suck was defined as "an interruption of the normal sucking activity by abnormal movements of the jaw and tongue".⁹

Those infants who present with a disorganized suck are unable to self-regulate the suck/swallow/breathe due to a lack of neurological maturation and respiratory support secondary to immaturity. Being able to coordinate the pharyngeal swallow with respiration is a difficult task for many young infants. It is possible, however, for the caregiver to regulate the suck/swallow/breathe for these infants during their feeding using Imposed Regulation, a diagnostic-based intervention strategy that may be implemented following a diagnosis of a disorganized suck on the NOMAS®. This does not refer to a specific technique but rather focuses on the goal for the infant and may be implemented differently for each infant.

Imposed Regulation is most effective with young infants who demonstrate too much variability in the number of sucks per burst or a transitional suck.¹⁰ It is difficult for many young infants to inhibit the sucking movement so as to be able to breathe which often results in oxygen desaturation or spells of deglutition apnea.¹¹ Imposed Regulation is based on the definition and description of the normal immature sucking pattern that is demonstrated by preterm infants. This normal pattern is characterized by very short sucking bursts of 3-5 sucks per burst followed by a pause of equal duration during which the infant breathes and/or swallows.⁵ This pattern is a burst/pause pattern in which bursts and pauses are of equal duration which requires that the infant stop the sucking activity to pause and breathe. When an infant is unable to do this the caregiver may implement Imposed Regulation for the first minute of the feeding after which the infant may be able to self-regulate. Imposed Regulation of the suck/swallow/breathe requires that the caregiver stop the transfer of liquid after three nutritive sucks and swallows to allow the infant to pause and breathe. If the caregiver attempts to build in a pause after five sucks/swallows it will most likely not be successful. Some infants will already demonstrate deglutition apnea or oxygen desaturations after just three seconds of sucking and swallowing without breathing. Once the normal immature burst-pause pattern has been imposed for one minute the infant may feed well for the remainder of the feeding. If the infant continues to be unable to self-regulate the caregiver may provide Imposed Regulation for an additional minute always giving the infant an opportunity to self-regulate after each minute of Imposed Regulation.

The technique that is selected to implement Imposed Regulation is infant-dependent and should be carefully selected on an individual basis for each infant. Some of the techniques that have been successfully implemented include: finger feeding; use of alternative utensils; tipping the bottle nipple; removing

the bottle nipple from the mouth; tipping the baby so as to empty the bottle nipple; and pinching the nipple closed to stop the flow, just to mention a few.

It is important to understand the differences in the purpose, goal, patient population, and implementation of these two intervention strategies that are used to improve oral feeding for infants in the intensive care nursery. An understanding of these two intervention strategies is necessary so that the infant's needs can be individually addressed by prescriptive intervention.

External Pacing:

- 1) Cue-Based
- 2) Used with older infants who demonstrate longer sucking bursts
- 3) Provides breaks when infant is stressed, tired, fussy, needs to breathe, etc.
- 4) Usually implemented by removing the bottle nipple from the mouth
- 5) Once the infant has recovered the bottle nipple is re-inserted

Regulation:

- 1) Diagnostic-Based
- 2) Used with younger infants who demonstrate too much variability in the number of sucks per burst or a transitional suck (NOMAS®)
- 3) Provided for first minute of feeding; and re-introduced for one minute intervals as needed if infant is unable to self-regulate
- 4) Follows a diagnosis of disorganized suck (NOMAS®) and prevents stress and discomfort during feeding
- 5) Technique is individualized and infant specific

Imposed Regulation is also an effective intervention strategy for those infants who have problems during the esophageal phase of swallow. The esophageal phase of swallow in infants has received less attention over the years than the oral phase of swallow (sucking). Infants who have difficulty during the esophageal phase of swallow such as esophageal dysmotility; retrograde movement; or gastroesophageal reflux may have significant discomfort with feedings and are at greater risk of developing a sensory-based oral feeding aversion later.¹² Since the average suck/swallow ratio is 1:1 per one second material may be unable to clear the esophagus at that rate. When esophageal nt during feeding and could result in aspiration¹³. Imposed Regulation will allow only three swallows followed by a pause of equal duration during which the material has time to clear the esophagus.

In addition, when Imposed Regulation is used for preterm infants during videofluoroscopic studies it will often serve to prevent aspiration that may occur secondary to inability to coordinate the pharyngeal swallow with respiration; fatigue; and esophageal dysmotility and/or retrograde movement.

External Pacing and Imposed Regulation are just two of the intervention strategies that may be used for infants who present

with poor feeding. The NOMAS® also diagnoses those infants who have a dysfunctional suck for which very different intervention strategies and treatment techniques are recommended and are beyond the scope of this article that focuses on only two of the intervention strategies for infants who have difficulty with the coordination of suck/swallow/ and breathe.

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The 30th Annual NIDCAP Trainers Meeting

Members of the 2018-2019 Board of Directors, Portsmouth, New Hampshire



Global Perspective of Developmental Care – Chile

Marcela Castellanos, MD

Pediatrician, Neonatologist, NIDCAP Professional, Clinica Las Condes & Hospital Santiago Oriente – Dr Luis Tisne

DOI: 10.14434/do.v13i1.29092

The Republic of Chile is a South American country occupying a long, narrow strip of land between the Andes to the east and the Pacific Ocean to the west. Chile is among South America's most economically and socially stable and prosperous nations, and a member of Organisation for Economic Co-operation and Development (OECD) with a high-income economy and high living standards. Recently there have been demonstrations denouncing social inequality.

In 2017 there were 219,186 births which is approximately 600 newborn babies born every day. Approximately half of them are male. Forty-two percent were born in Santiago, the capital of Chile. The child mortality rate is 7.1% with 41.2% occurring in the first day of life and 36% between 1-28 days. The neonatal mortality rate fell around 5% in one year from 2016 to 2017. The Total Fertility rate was just 1.6 in 2017 below average generational rate. At present, there are many immigrants, with around 10% of births occurring in this group.

Chile has a mixed public and private health system with approximately 70% of the population using the Public Health System, with the remaining 30% accessing the Private Health System. Neonatal intensive care occurs in both public and private hospitals. Most private neonatal intensive care units (NICU) have 24 hour free access for parents. Unfortunately this does not happen in the public system where there is a lack of staff.

Nevertheless, I have been working with different professionals (Midwives, OT, therapist) training and making changes.

The Clinica Las Condes (CLC) where I work, is a private hospital where parents can stay the whole day with their babies, and siblings and grandparents are also welcome.



We have many preterm babies many of whom are twins since this is a referral hospital for infertility treatments and high risk pregnancies.

Since 2008 we have been working with the NIDCAP concept in our Unit. Parents are encouraged to provide the care for their babies and we have an active skin to skin program.

The Preterm Parents Corporation, named NEOVIDAS, has been working with us to support the preterm parents at the CLC & Hospital Santiago Oriente and is open to offer help to other parents. They work actively with the Health Minister and

have connections to parents abroad. Each November they organize different activities for families and professionals to celebrate World Prematurity Day.

Every year I work with midwives, training new people and doing refresher courses for the other staff. For the past five years Ninoska Cancino, midwife (NIDCAP Professional) and I have been working with different Universities, Pediatric Societies and Nurse's Colleges providing training programs in Developmental Care within the country. Most of the health care professionals who have attended these programs have expressed an interest in foundational programs for developmental care such as Family and Infant Neurodevelopmental Education (FINE).

The Clinica Las Condes is unfortunately not a NIDCAP Training Center but we work with this concept. Our unit is the only one in Chile that has certified NIDCAP Professionals on staff.

If requests for NIDCAP Training are received I recommend for them to apply to Argentina or Spain for training. Presently, we are working together with other Spanish speaking trainers who can help us spread the NIDCAP Philosophy.



Clinica Las Condes



Hospital Santiago Oriente "Dr. Luis Tisné Brousse"



My Little Warrior

Tracey Azzopardi

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Going to be a mum

I was always focused on my career. After six years from working overseas in Hong Kong, Shanghai, and London, I came home to Sydney to have a baby. Having a baby was the one thing that I had always wanted. At 43 and after four rounds of IVF with an anonymous donor, I was ecstatic to find out I was finally pregnant. I was going to be a mum.

23 Weeks~The roller coaster begins

Where to begin. It was still early. I hadn't yet started ante-natal classes or visited a maternity ward. I still had plenty of time to get ready for childbirth, or so I thought. Little did I know it was the start of an unexpected roller coaster journey of uncertainty and emotions.

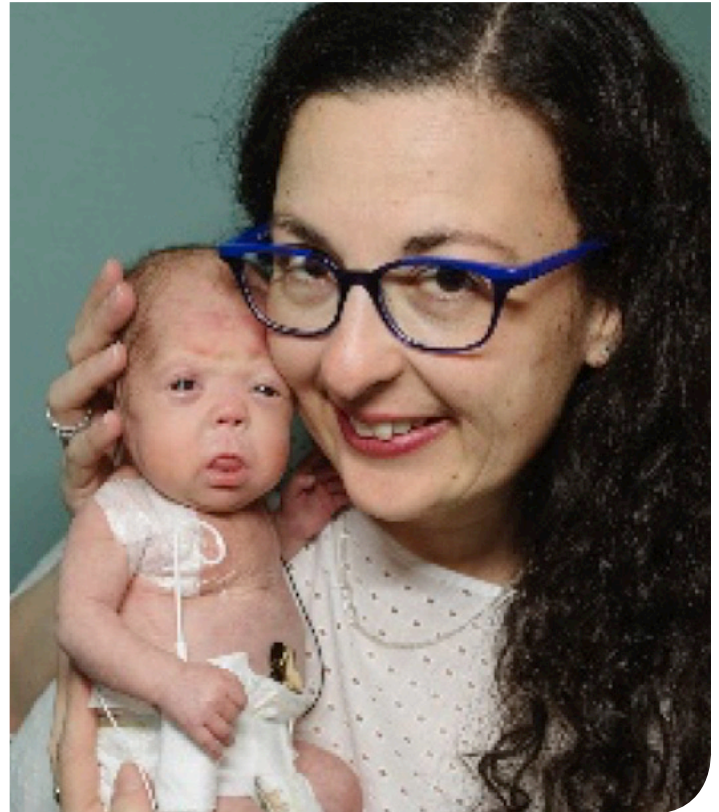
While on my way to work 23 weeks into my pregnancy, I didn't feel right so I visited my obstetrician. Several hours later with ruptured fetal membranes, my doctor explained that it was vital I deliver at a hospital with a neonatal intensive care unit. Thankfully Westmead Hospital had a bed because later my baby would need the Grace Centre for Newborn Intensive Care at the Children's Hospital at Westmead. I was transferred by ambulance to the Westmead Hospital which was only one street away and taken to the delivery suite.

The following day I had an ultrasound. I could not see the monitor that the three doctors were looking at. Clearly, something was wrong. My baby had moved from being ready to deliver to being transverse and the umbilical cord wrapped around my baby's arm. My baby could not move. That afternoon one of the Fellows from the Newborn Intensive Care Unit (NICU) came to sit with me. She was a kind and gentle doctor who took the time to listen and help me understand what was going on and the options available. The doctor explained the probability of survival and the ramifications of a delivery at such an early age. We were at 23 weeks and one day, and every day counted.

What was going to happen next? I was told that one of three things would happen: contractions would start, my baby's heartbeat would slow, or infection would set in as there was not much amniotic fluid. I was started on antibiotics and my baby's heartbeat was checked three to four times a day. Thank goodness for my mum who was with me every day. Confined to bed, I hung on to hope and stayed focused on the positive.

Delivery at 24 weeks

Seven days later while lying in the hospital bed, I experienced rigors and within minutes, several members of the medical team surrounded my bed. Antibiotics, steroids and vitamin K were injected, blood tests were taken, and I was put on oxygen. My



Tracey Azzopardi with her daughter, Matilda

obstetrician and I had a very quick discussion. As much as I wanted to experience childbirth, the only thing that mattered was giving my baby the highest probability of survival, which meant my baby being delivered by emergency caesarean. Before I knew it, I was in the theatre and there were people everywhere.

It's a girl!

I woke midday the following day. The nurse asked me if I knew where I was and I said yes. Then I asked, "My baby...is my baby alive?" Her answer was yes. I then asked, "What did I have?" She responded with "you had a girl." It was a surreal and joyous moment that I will never forget.

Meeting my baby

Taken by wheelchair to meet my daughter, I was excited and scared at the same time. She was born at 24 weeks and 1.5 hours weighing 590 grams and required resuscitation and intubation at birth. Being wheeled into the NICU and meeting my baby was overwhelming as she was in a humidicrib and there were wires and tubes everywhere with multiple pumps and machines beeping.



Too fragile to hold, for the first three weeks of Matilda's life, Tracey placed her hands gently on her through the crib's doors

My baby was so tiny. It was hard to believe. The nurse explained containment holding and where I could place my hands on my daughter. Needless to say, I did a lot of containment holding.

Picking a name

Upon meeting my baby girl, giving her a name was an easy choice...Matilda. The meaning of her name is quite significant and means might and strength in battle. This tiny human had many battles ahead.

On-going challenges

In the following four weeks after Matilda's birth, she faced serious breathing and lung issues. Her x-rays showed lungs that looked like they were covered in clouds and she was given two rounds of steroids to clear them. Matilda's heart valve had not switched over until a day after her second round of treatment. Everything seemed to take a little bit longer.

Too fragile to hold, for the first three weeks of Matilda's life I placed my hands gently on her through the crib's doors. After three weeks, I held Matilda for the first time for one hour. It was our first skin to skin and it was sensational. As Matilda got stronger, I was able to hold her for longer periods. Skin-to-skin or Kangaroo Care was the most precious time I had with Matilda. Transferring Matilda out of her humidicrib was done with extreme care. It took a bit of organising and required three nurses. As soon as I would arrive in the morning, I would touch base with Matilda's nurse, find out how she was overnight, and what was scheduled for the day. Together the nurse and I would figure out the best time for skin to skin. During skin to skin, Matilda's breathing would always be at its best with minimal desats. I made it my mission to do as much skin to skin as possible. Our record was 6.5 consecutive hours. Typically, I would usually do 3 hours each day.

Surgery

On day 28 I arrived to find out that Matilda needed a surgery consult. All I heard was the word surgery. They were going to cut my tiny baby open. Preparations were underway without delay

and Matilda was transferred to The Grace Centre for Newborn Intensive Care at the Children's Hospital, Westmead in Sydney. A battery-operated motor was attached to the humidicrib to power the CPAP and pumps, and Matilda was transferred via a tunnel that connected the two hospitals.

Grace is a surgical NICU, and without a doubt one of the best in the country. Upon admission, tests, x-rays, examinations and so on, a surgical team arrived. The medical team was standing two deep around Matilda's humidicrib. Then the surgeon arrived and examined Matilda and there was rigorous discussion. He introduced himself and explained that after examining Matilda he could not guarantee, however was quite sure he knew what was going on and that there were no tests to confirm it. The only thing that could be done was to go in and have a look. I listened carefully. The surgeon was very clear. There was no doubt how serious it was as Matilda was so distended. She was 28 days old and weighed 790 grams and had already been through so much, yet needed this surgery urgently. Once the surgery was over the surgeon confirmed that Matilda had NEC or necrotising enterocolitis and showed me a diagram. In total, 28 centimetres or approximately a third of Matilda's bowel was removed.

Progress measured in baby steps

Post-surgery the darkest green bile kept coming out of Matilda's oral venting tube for weeks. One of Matilda's neonatologist kept reminding me, Matilda runs on her own time table and we need to patient with her. I'll always be grateful for the generosity of his understanding and ability to explain things and manage my high expectations. Two weeks after Matilda's surgery, she started on one millilitre (ml) of breastmilk over four hours. Every two days we slowly increased her milk by 0.5 mls per hour. It was a slow progression. When Matilda's target was reached, we then had to transition from the four-hour cycle via continuous pump to regular feeds every four hours that I would be able to do via gravity feeding at home.

Taking each day as it comes

Two steps forward and one step back was the term commonly used. Taking one day at a time is the only way to go and not

get ahead of yourself. I refused to go online and read blogs etc. If I had a question, I would put it in my phone and ask the appropriate person on Matilda's medical team. Attending morning and afternoon rounds meant I was always up to date and knew what was going on. It was important to learn how the NICU worked, who was who, and how to find out information or escalate concerns.

A month before coming home, Matilda's nose was finally big enough to have the smallest size nasogastric tube (NG) fitted. Without any tubes in her mouth, during skin to skin with the support of the Speech Therapist and Lactation Consultants, we persisted in encouraging Matilda to latch on and breastfeed. They would put the stethoscope behind her ear, counting how many sucks and swallows she had. Matilda was sucking, but rarely swallowing. Our plan was to keep trying. I really wanted to breastfeed believing it would be the best thing for Matilda's gut and growth as she was still very tiny. My persistence was worth it as I breast fed Matilda until she was 17 months when Matilda was able to use a sippy cup.

Developmental rounds and individualised developmental care

I would be so disappointed if I missed the Developmental rounds. There were usually three specialists who would assess each baby and give recommendations to the nursing team. What may seem like something small to some, the recommendations for Matilda had a significant impact on her.

I was approached about carrying out an assessment to review and develop an individualised developmental plan for Matilda. This was exciting. Anything that we could do to help Matilda to make her as comfortable as possible and that supported her progress was a great thing. A group of professionals going through training observed a nurse and I doing Matilda's cares. As I was shown, I would always start from Matilda's head and work my way down to her feet.

The written report I received following the observation was brilliant. When changing Matilda's nappy and undoing the Velcro tabs, her body would flinch and her facial expression would change. When these observations were shared in the report and I read it, I modified the way I changed Matilda's nappy. The report provided instructions for all of Matilda's team to follow. One of the trainees on the Developmental team suggested I prepare a shorter version of the report as if it was written by Matilda. It was then attached to the end of her bed for all of her nurses to follow.

Reflections from our NICU experience

There was a night or two when I got all the way to the car park and had to walk back to the NICU. Leaving your baby is a challenge. The best thing to do is focus on getting home, eating and sleeping, staying as healthy as possible and seeing and holding them the next day.

Helping my daughter's voice be heard

Being Matilda's advocate and voice...that is what mums do, right? It is a balancing act. Being respectful of the medical team

is really important. At the end of the day or evening, you have to leave the NICU and leave your baby in the care of this team and trust is really important.

Going home

After spending 161 days (5 ½ months) in the NICU, Matilda was discharged in early December 2017 weighing 3.3kg. For ten months following discharge Matilda required home CPAP and was connected to a mobile corometrics monitor for obstructive sleep apnoea whenever she was sleeping.

The year following discharge was full of appointments and therapy. The combination of attending a feeding clinic, physiotherapy and occupational therapy were all very beneficial. We put everything we had learnt in the NICU into practice at home. She will have glasses in the near future. Matilda has Chronic Lung Disease and will continue to be monitored. Whilst Matilda is delayed and in the low average range for her language, cognitive and gross motor skills, we continue to focus on these areas and I have no doubt that she will continue to improve. She is making great progress with her fine motor skills. Matilda loves books and has them everywhere. We do a lot of reading.



Tracey says Matilda is a very resilient, determined, happy and joyful child

Gratitude

There is no doubt Matilda is alive and doing so remarkably well today due to the care she received from the moment I found out she would be arriving early, and throughout her entire journey. I remain forever grateful and indebted to every person who cared for Matilda and for their amazing skills, patience and empathy. They were a dedicated team of people who worked together and truly cared for Matilda.

Matilda is now two and a half and is a very resilient, determined, happy and joyful child, who has made amazing progress and continues to thrive. She is truly loved and I am fortunate to have such an amazing daughter.

We thank Tracey Azzopardi, Matilda's mother, for sharing her story, and Matilda's journey with us.

European Standards of Care for Newborn Health

Natascia Bertoncelli

Developmental Therapist, NIDCAP Trainer, Neonatal Intensive Care Unit, University Hospital of Modena, Modena, Italy

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Survival rate for preterm infants is continuously improving thanks to advances in medical science. Despite this, preterm birth is still a challenge worldwide. The treatment for preterm and ill newborn infants is very complex and it requires specially trained healthcare professionals. In Europe, there is variation in the provision of care for preterm and ill newborn infants at a national, regional, and hospital level including the education available for healthcare professionals. Moreover, national guidelines, when they do exist, vary from country to country.

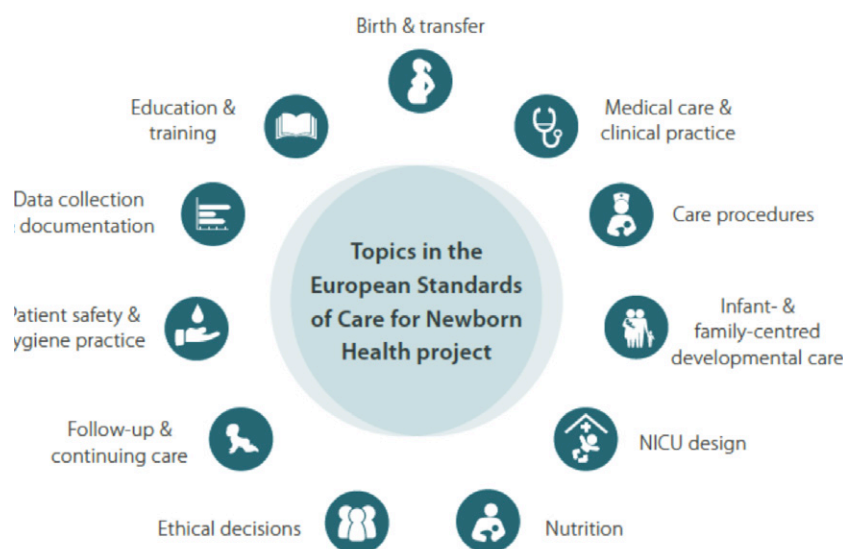
The European Standards of Care for Newborn Health (ESCNH) is an interdisciplinary collaboration project that addressed the disparities in provision and quality of care through the development, and now publication of standards of care for key topics associated with preterm birth and neonatal morbidity. Eleven areas were selected to address, the so-called Topic Expert Groups or TEG (see Figure 1), in which the standards were developed and looked beyond (medical) care of infants and included NICU design, follow-up and continuing care, infant- and family-centred developmental care, and ethical-decision making. ESCNH is a true patient-centred project, and for the first time, patients were involved in every step in the development of standards. In collaboration with parent representatives from more than 30 countries, there were about 220 healthcare professionals from different practice areas involved and worked over several years to create the standards. The standards were launched at the European Parliament in Brussels in November 2018. By that time, 108 healthcare societies and associations as well as 50 parent organisations accepted the European Foundation for the Care of Newborn Infants (EFCNI) invitation and officially supported the newly developed standards. The ESCNH help support the rights of the child of

the UN Convention Assembly by serving as a reference for the development and implementation of standards and guidelines on a national and international level.

I personally took part on the standard in Infant and Family-Centred Developmental Care (IFCDC). The role of the Topic Expert Group on IFCDC was defining practice standards for the implementation of newborn care centred around the infant and his/her family in order to support optimal health and development of preterm and ill newborn infants. This standard is divided in another 10 sub-topics and I was involved mainly in the “Education and training for infant- and family-centred developmental care” section. My group was comprised of a multidisciplinary team from different countries in Europe and we worked together, exchanging hundreds of emails over several years. Our aim was developing educational pathways that ensure that all NICU professionals have educational and training opportunities to develop the knowledge and skills needed to implement high quality infant and family-centred developmental care, which includes guiding of parents as primary caregivers. It was a huge task and incredibly satisfying. I had the chance to work with amazing people that included sharing ideas and reflections. Each email shared was an opportunity to recalibrate my attention on preterm infants and their parents who I care for in my NICU, and I learned a lot.

All the NIDCAP professionals in my team in Modena, and myself, are working to spread the European Standards of Care for Newborn Health in all the NICUS in Italy. This project and the work that came out of the developed European Standards of Care for Newborn Health is a powerful tool to provide all preterm infants and their parents with the best possible care.

FIGURE 1. The 11 Topic Expert Groups





30th Annual NIDCAP Trainers Meeting

Below are some images from the 30th Annual NIDCAP Trainers Meeting held in Portsmouth, New Hampshire, USA.



Thank you to our photographer – Dr Susannah Silva from Porto, Portugal.



A Funny Thing Happened on the Way to the Hospital

Jeffrey R. Alberts
Indiana University, NFI Science Committee, Associate Editor for Science

DOI: 10.14434/do.v13i1.29094

Target article: Montirosso, R. and Provenzi, L. (2015) Implications of Epigenetics and Stress Regulation on Research and Developmental Care of Preterm Infants. JOGNN, 44, 174-182. DOI: 10.11 11/1552-6909.12559

Bodies of knowledge, like ‘flesh-and-bone’ bodies, work best when they are in balance. Today, many bodies of biomedical knowledge are out of balance. For example, the body of knowledge comprising mechanisms of pain and pleasure is large and detailed on the side of pain mechanisms, but knowledge about how pleasure works is sparse and incomplete. Similarly, we study depression more than happiness. In all, we know much more about processes of sickness than of health. There is a pervasive lack of balance!

Biomedical knowledge has distinctly practical, “applied” importance. This kind of knowledge is created, tested, translated, vetted and then sent off to work in hospitals, clinics and other healthcare settings. On its way to the hospital, imbalances appear. Why are bodies of knowledge so lopsided?

Behavioral epigenetics, a field that is nicely introduced by the review article, “Implications of Epigenetics and Stress Regulation on Research and Developmental Care of Preterm Infants” (Montirosso & Provenzi, 2015) provides some insight into the way we define our areas of study and how this shapes our questions and hence the subsequent shape of our bodies of knowledge. It’s a fine paper, worth reading and understanding.

Behavioral epigenetics recently burst onto the science scene as a major disrupter. It’s great to shake things up, and epigenetics does it by challenging the “conventional wisdom” about the relations between genotype and behavior. In the process, epigenetics is re-writing basic rules of inheritance, by making obsolete phrases such as “genetic programs”, or “there are genes for . . .”, or “it’s in their DNA to . . .”. The way that epigenetics forces a change in our vocabulary and thinking is that it reveals mechanisms whereby gene *expression* changes, without the actual genome changing! This is accomplished, as the authors explain, via molecular mechanisms that act “above” the genome (hence *epi*-genetic). Several such mechanisms are now known.

One of the most commonly studied epigenetic mechanisms is *methylation*, a process that “silences” gene expression at specific sites, usually within regulatory regions of gene where a methyl group essentially grabs onto a site and prevents DNA → RNA transcription. In contrast, *histone modification* is a molecular mechanism that promotes gene expression. Histone modification involves an acetyl group acting to unwrap a histone (protein) “tail” in a way that exposes DNA to transcription factors and thus facilitates gene expression. Again, Montirosso and Provenzi do an admirable job describing and illustrating some of these molecular events that comprise the epigenetic “marks” that can

be assayed after various laboratory manipulations of an animal or life events in humans.

Noted in the target article is a well-known example of epigenetic change. The research originated in the McGill University laboratory of Michael Meaney, where he and a group of associates analyzed different styles of maternal behavior in rats. Some mother rats (also called “dams”) spent lots of time licking and cuddling their infants whereas others reared healthy babies but provided much less licking and cuddling. Although equivalent in growth and viability, the offspring of the attentive dams grew up to modulate their stress reactions and display resilient recovery from stress far faster than the offspring of the inattentive dams. When they became mothers, the female offspring of the two types of rat dams (attentive and inattentive) displayed similar styles of mothering. Mothering style and its effects on offspring had been “inherited”. Shocking to some, however, were the results of cross-fostering experiments: When attentive moms reared the babies of inattentive moms, those offspring showed the calmer, stress resilient demeanor whereas offspring of attentive dams reared by inattentive mothers developed into stressed-out, poorly regulated rats. Moreover, when these females became mothers, their mothering style was that of the foster dam, not the biological mother! Yes, mothering style was “inherited” across the generations, but not via the mother’s genes (see Champagne & Curley, 2009; Meaney, 2001).

It was possible to examine neurons in various brain regions of the offspring reared by dams with the distinctly different mothering styles. One dramatic difference was the density of glucocorticoid receptors (GRs) on the neurons in the hippocampus, a brain structure associated with emotion and learning. The studies surrounding this finding indicate that mothering styles by the rats primed the stress responses (described in the target article in terms of the hypothalamic-pituitary-adrenal or HPA activity) of the infants. The baby’s stress responses to the maternal environment, whether from the biological or the foster mom, altered the GR density on the hippocampal neurons and, as a result, altered responses to their own stress hormones. The researchers have found increased methylation at the sites responsible for GR production, pointing the way to the epigenetic shaping of the offspring’s brain.

There are now studies in humans showing results compatible with this rat research. For instance, Lester et. al. (2018) studied healthy, 5-month-old, term infants and their mothers, who either did or did not breastfeed exclusively to the time

of the experiment. They hypothesized that the breastfeeding relationship would serve as a maternal behavior difference to parallel the two groups dams used in the rat research. Lester's group staged a slightly challenging mother-infant interaction (a "still face" test) and measured the babies' stress reactivity via salivary cortisol. They also measured DNA methylation in the GR gene region of the babies' DNA from cheek swabs. Breastfeeding by the human babies was associated with lower DNA methylation and decreased cortisol reactivity. The results provided a striking replica of the rodent studies!

There's another stunning aspect of epigenesis: Epigenetic changes can be inherited! Epigenetic effects are shown to be associated with specific physiological or behavioral traits, typically caused by different types of experience within a lifetime, and then the same epigenetic marks are inherited from the adult via the DNA in the gametes, so that the epigenetic changes are passed to their next generation. But the DNA content of the cells has not been modified. This is transgenerational inheritance with no genetic change! It's a new view of inheritance.

It is a privilege to write a commentary about a new area of knowledge creation. Hopefully, I've conveyed a sense of excitement about epigenetics and inspired you to read the Montrirosso and Provenzi paper, and maybe more on the topic. Nevertheless, I've also lamented an imbalance in biomedical knowledge. I argued that there has developed a culture that emphasizes studying sickness more than understanding health. This imbalance is perpetuating because each preliminary discovery leads to related questions which favors more and deeper questions about sickness and not about health. The field of behavioral epigenetics is nascent and just taking shape. Already, the weight of the evidence-based knowledge is accumulating on the side of toxic stress, effects of poor parenting, bad diet, and other negative factors and forces. Framing the issues this way naturally leads us to seek ways to prevent or undo harm. Yes, there is merit to this, but I believe there is more to promoting health than blocking or remediating damage. There are paths to travel, on which we can acquire knowledge that can deepen our ability to guide, facilitate and maintain healthy development. Many of these paths course through NICUs.

Imagine bodies of knowledge growing and developing on their way to being implemented in the hospital. What if we not only understood how surges of adrenal hormones in combination with painful stimuli silence genes that are part of diminished stress reactions, but we also mapped the epigenetic marks of resilience to adversity, or we could reveal the ways in which NIDCAP facilitates histone modifications associated with a premie's ability to self-regulate?

What if we discovered that processes labelled as remedial or protective are identical to formative accretions in normal development? We might discover that a funny thing happened on the way to the hospital: We shifted emphasis and we lost sight of healthcare and instead saw mainly sickcare. Perhaps we can use behavioral epigenetics as a field with new pathways, ones that

balance studies of health and disease. Indeed, there are instances and insights into the basis of healthful development. These appear in some studies of mother's milk and the development of immune competence, we see examples across the landscape of microbiome research, and in some studies of oxytocin and related neuropeptides in development. The promotion of "nurture science" (Bergman et al., 2019) is encouraging. Indeed, about a decade ago, Professor Heidelise Als wrote an instructive and insightful article in the *Developmental Observer* (Als, 2011), in which she foresaw the important promise and implications of epigenetics on NIDCAP. I recommend reading Montrirosso and Provenzi (2015) along with Als (2011). To continue your education, go on to read the remarkable and beautifully crafted book by David S. Moore (2015) on behavioral epigenetics.

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NIDCAP Care in the Moment

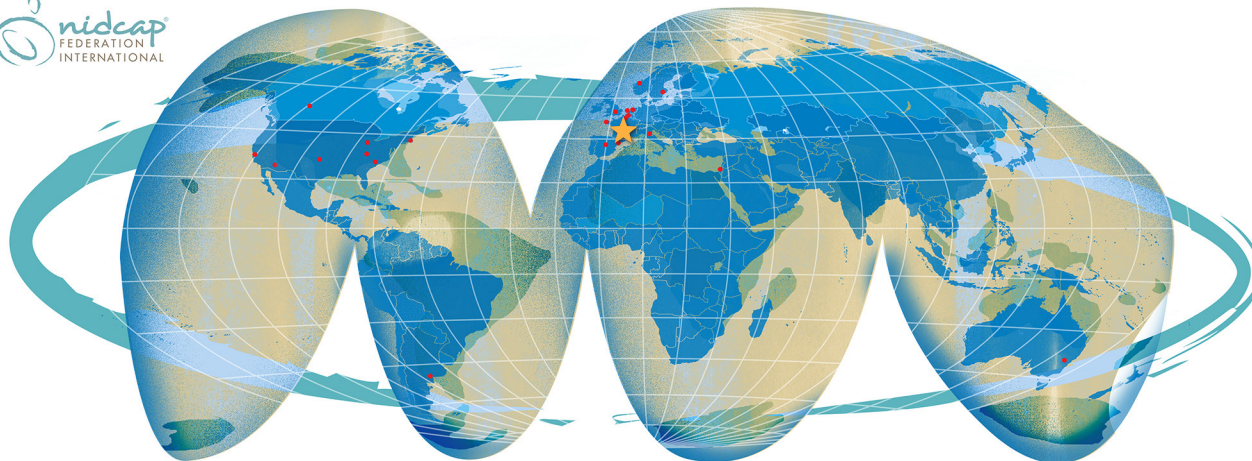


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Sibling care



NIDCAP TRAINING CENTERS WORLDWIDE



NIDCAP Training Centers Around the World

NIDCAP Training Center Tübingen, Germany

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The department of neonatology at Tübingen University Hospital has the capacity of 51 beds, 17 for each level of newborn care. German neonatology, similar to that in the US, is rather decentralized, so that our department, although admitting 120-130 infants <1500 g (VLBW)/year, is among the 6 largest in the country. Four years ago, binding regulations on staffing were introduced in Germany, so that VLBW infants now receive 1:1 or at least 1:2 nursing care (depending on illness severity), which has been very helpful for NIDCAP work and implementation.

Our heritage-listed hospital (built in 1931) is the first ever built in the famous “Bauhaus style*”, but this also means that no changes could be made to its outer structure. Infants admitted to our department are therefore cared for in bedrooms with 2-5 cots/room with quite limited space, which often represents a big challenge for staff and parents.

On an academic level, Tübingen holds one of only 3 academic chairs in neonatology in Germany, meaning that it is comparatively free in deciding on its budget and workforce allocations. For introducing NIDCAP, this certainly helped in assigning parts of this budget to fund our goal of becoming a NIDCAP



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NIDCAP- Team Tübingen (2015) from left to right Kerstin Gründler (MD, NIDCAP-Professional), Tabea Tjhen (Speech Therapist, NIDCAP Professional), Birgit Holzbieter (MD, NIDCAP-Trainer), Natalie Wetzel (RN, NIDCAP-Trainer), Rebekka Bauer (RN, NIDCAP Professional), Prof. Heidelise Als (NIDCAP Master Trainer), Ina Schmollinger (RN, NIDCAP Professional), Eva Jochim (RN, NIDCAP Professional), SuSi Wagner (RN, NIDCAP Professional)

training center. We are convinced that individualized newborn care, focused on the infant's development and integration of its family, is crucial in achieving a good outcome for both the baby and his/her family. Thus, we are grateful that Heidelise Als, our NIDCAP Master Trainer, helped us pave the way to becoming the first German-speaking NIDCAP Training Center, which we opened on World Prematurity Day 2015. By now we have 2 certified trainers heading a multidisciplinary team of 8 NIDCAP professionals,

including nurses, physicians, speech- and physiotherapists, who all have a certain number of hours per month available to do NIDCAP observations and to provide guidance for the families and the team.

Through our work with Heidelise Als we learned to value individual observation sessions, which we carry out every 1-2 weeks in all infants born at <28 week gestation. These observations form the basis for our focus on the experiences and histories of each individual infant and its family. In a stepwise fashion, we recognize



SuSi Wagner observing an infant to learn about the strengths, vulnerabilities and current goals of the infant

each baby's strengths and vulnerabilities as well as his/her current developmental goals and support him/her in the next steps. The knowledge gained from these observations, including the current goals of the infant, are always reported back to parents and staff in written form in addition to being reported during weekly rounds with our head of department.

By observing the infants we became aware early on that implementing NIDCAP and sharpening our view on the needs of the preterm infants and their families would be associated with a variety of changes to our daily work. We therefore established a NIDCAP Steering Committee, comprising medical management as well as front line nursing staff and NIDCAP professionals and trainers, to introduce sustainably and effectively the necessary measures for an individualized, developmentally supportive and family integrated philosophy of care. It has always been our concern to integrate the staff of our units into the ongoing process to benefit from their creativity and knowledge. Throughout the last 10 years our staff, in cooperation with the NIDCAP Team, developed for example new incubator blankets and an innovative positioning aid to assure a comfortable environment for the infant. Moreover, regular training and reflection sessions made it possible that the routines on the ward became more flexible. Amongst other things, we individualized the time for "Kangaroo Care" or adjusted routines like blood taking or ultrasound scans to the rhythm of the baby whenever possible.

Feeding issues, particularly breastfeeding, have received our attention for many years now. In 2015, a multi-disciplinary working group developed a feeding guideline, adapted to the requirements of our department. The aim of this guideline is to support an early breastfeeding relationship with the baby and positive feeding experiences, either at the breast, bottle or via a feeding tube. Last year we established additional weekly feeding rounds that are supported by our breastfeeding consultants. We now increasingly focus on aspects of care related to the integration of the family. In the course of this, we started earlier this year with parents attending our ward rounds once a week. In these particular rounds the parents, not the professionals, report

on their baby's present situation as well as his or her next steps. Our goal is to acknowledge the parental competence and experience of parents as the primary caregivers of their baby to complement our professional view and thus actively involve them in all decision-making and care-planning. We are convinced that this strongly affects parental self-confidence and strengthens the role of the parents within the unit.

In 2021, we expect to open an additional unit in a new building adjacent to the current NICU that is based on the Swedish Karolinska model, where parents can live in apartments that are only separated by a thin wall from their baby receiving intensive care. The babies' care space is designed as a single room. We hope that a more intimate environment accompanied by the proximity between baby and parents and provision of care that is reliably based on NIDCAP principles will contribute to the healthy development of our little patients and their families. Members of our very active Parents' Association are involved in the planning of this new unit. They help us to understand the situation and the needs of parents better and support us with regular feedback and ideas for improvement.

All in all, our progress in the last 10 years wasn't always easy and there were multiple setbacks, but from today's point of view each step, even the smallest one, was and will be a step in the right direction, a step to improve the future of preterm infants and their families. Thus, we simply keep on moving forward.



**The Bauhaus style was marked by the absence of ornamentation and by harmony between the function of a building and its design.*

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Deborah Buehler, PhD

NIDCAP Master Trainer

APIB Trainer

Director, West Coast NIDCAP and APIB

Training Center

email: nfipresident@nidcap.org

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Senior NIDCAP Trainer

email: dvitt8@gmail.com

TREASURER

Gloria McAnulty, PhD

National NIDCAP Training Center

email: gloria.mcanulty@childrens.harvard.edu

SECRETARY

Jean Powlesland, RN, MS

NIDCAP Trainer

Director, Children's Hospital of University of

Illinois NIDCAP Training Center

email: jpowlesl@uic.edu

Fatima Clemente, MD

NIDCAP Trainer

Co-Director, São João NIDCAP Training Center

email: clemente.fatima@gmail.com

**Mandy Daly, Dip. H Diet and
Nutrition, ACII, DLDU**

Family Representative, Dublin, Ireland

email: mandy.daly@yahoo.co.uk

Jennifer Degl, MS

Family Representative, New York, USA

email: jenniferdegl@gmail.com

Maria Maestro Lopez, MD, PhD

NIDCAP Trainer

Hospital Universitario 12 de Octubre

NIDCAP Training Center

email: mariamastro@gmail.com

Dalia Silberstein, RN, PhD

NIDCAP Trainer

Co-Director, Israel NIDCAP Training Center

email: dalia.silberstein@clalit.org.il

Juzer Tyebkhan, MD

NIDCAP Trainer

Director, Edmonton NIDCAP Training Centre

email: juzer.tyebkhan@albertahealthservices.ca

STAFF

Rodd E. Hedlund, MEd

Director, NIDCAP Nursery Program

NIDCAP Trainer

email: nidcapnurserydirector@nidcap.org

Sandra Kosta, BA

Executive Director of Administration

and Finance

email: sandra.kosta@childrens.harvard.edu

FOUNDER OF THE NIDCAP FEDERATION
INTERNATIONAL, INC.

Heidelise Als, PhD

NIDCAP Founder, Past President 2001-2012

Senior NIDCAP Master Trainer

APIB Master Trainer

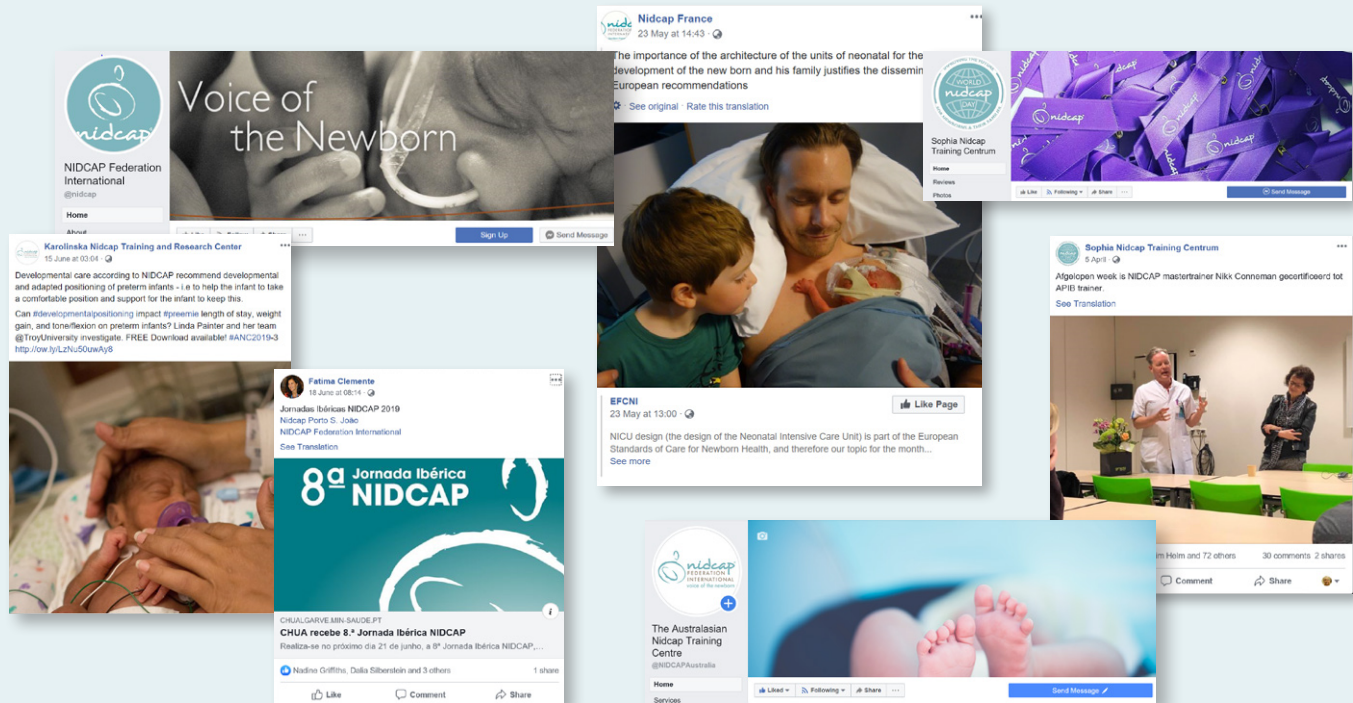
Director, National NIDCAP Training Center

email: heidelise.als@childrens.harvard.edu

NIDCAP on the Web

NIDCAP Training Centers – Facebook Pages

Many of the Training Centers and NIDCAP groups have established their own Facebook pages. These pages provide useful resources for members and by joining the groups and sharing the pages you are helping to spread information about NIDCAP. Here are a few to get you started. If you know of others please send an email to developmentalobserver@nidcap.org for inclusion in the next issue.



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

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AMERICAS

North America

CANADA

Edmonton NIDCAP Training Centre

Stollery Children's Hospital
Royal Alexandra Site
Edmonton, AB, Canada
Co-Directors: Andrea Nykipilo, RN and
Juzer Tyebkhan, MB
Contact: Juzer Tyebkhan, MB
email: Juzer.Tyebkhan@ahs.ca

UNITED STATES

St. Joseph's Hospital NIDCAP Training Center

St. Joseph's Hospital and Medical Center Phoenix,
Arizona, USA
Co-Directors: Bonni Moyer, MSPT and
Marla Wood, RN, BSN, MEd
Contact: Windy Crow
email: windy.crow@dignityhealth.org

West Coast NIDCAP and APIB Training Center

University of California San Francisco San
Francisco, California, USA
Director and Contact: Deborah Buehler, PhD
email: dmb@dmbuehler.com

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

University of Illinois Medical Center at Chicago
Chicago, Illinois, USA
Co-Directors: Doreen Norris-Stojak MS, BSN, RN,
NEA-BC & Jean Powlesland, RN, MS
Contact: Jean Powlesland, RN, MS
email: jpowlesl@uic.edu

National NIDCAP Training Center

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

Carolina NIDCAP Training Center

WakeMed, Division of Neonatology Raleigh,
North Carolina, USA
Director and Contact: James Helm, PhD
email: jimhelm27@gmail.com

NIDCAP Cincinnati

Cincinnati Children's Hospital Medical Center
Cincinnati, Ohio, USA
Director: Michelle Shinkle, MSN, RN
Contact: Linda Lacina, MSN
email: Linda.Lacina@cchmc.org

South America

ARGENTINA

Centro Latinoamericano NIDCAP & APIB

Fernández Hospital
Fundación Dr. Miguel Margulies and
Fundación Alumbarr, Buenos Aires, Argentina
Director and Contact: Graciela Basso, MD, PhD
email: basso.grace@gmail.com

OCEANIA

AUSTRALIA

Australasian NIDCAP Training Centre

The Sydney Children's Hospitals Network
Westmead, Australia
Co-Directors: Alison Loughran-Fowlds MBBS,
DCH, FRACP, PhD and Kaye Spence AM, RN, MN
Contact: Nadine Griffiths - Aust NIDCAP trainer
email: SCHN-NIDCAPAustralia@health.nsw.gov.au

EUROPE

BELGIUM

The Brussels NIDCAP Training Center

Saint-Pierre University Hospital Free University of
Brussels Brussels, Belgium
Director: Inge Van Herreweghe, MD
Co-Director: Marie Tackoen, MD
Contact: Delphine Druart, RN
email: delphine_druart@stpierre-bru.be

DENMARK

Danish NIDCAP Training and Research Center

Aarhus University Hospital, Aarhus N, Denmark
Director and Contact: Hanne Aagaard, RN,
MScN, PhD
Co-Director: Eva Jørgensen, RN
email: aagaard@clin.au.dk

FRANCE

French NIDCAP Center, Brest

Medical School, Université de Bretagne
Occidentale and University Hospital
Brest, France
Director: Jean-Michel Roué, MD, PhD
Contact: Sylvie Minguy
email: sylvie.bleunven@chu-brest.fr

French NIDCAP Center, Toulouse

Hôpital des Enfants Toulouse, France
Director: Charlotte Casper, MD, PhD
Co-Director and Contact: Sandra Lescure, MD
email: lescurer.s@chu-toulouse.fr

GERMANY

NIDCAP Germany, Training Center Tübingen

Universitätsklinik für Kinder- und Jugendmedizin
Tübingen, Germany
Director: Christian Poets, MD, PhD
Contact: Natalie Wetzel, RN
email: natalie.broghammer@med.uni-tuebingen.de

ITALY

Italian Modena NIDCAP Training Center

Modena University Hospital, Modena, Italy
Director: Fabrizio Ferrari, MD
Contact: Natascia Bertoncelli, PT
email: natafili@yahoo.com

THE NETHERLANDS

Sophia NIDCAP and APIB Training Center

Erasmus MC-Sophia Children's Hospital
Rotterdam, The Netherlands
Director: Nikk Conneman, MD
Co-Director and Contact: Monique Oude Reimer, RN
email: nidcap@erasmusmc.nl

NORWAY

NIDCAP Norway, Ålesund Training Center

Ålesund Hospital, Ålesund, Norway
Director: Lutz Nietsch, MD
Contact: Liv Ellen Helseth, RN
email: nidcap@helse-mr.no

PORTUGAL

São João NIDCAP Training Center

Pediatric Hospital at São João Hospital
Porto, Portugal
Director: Hercília Guimarães, MD, PhD
Co-Director and Contact: Fátima Clemente
email: saojoaonidcap@chsj.min-saude.pt

SPAIN

Barcelona NIDCAP Training Center: Vall d'Hebron and Dr Josep Trueta Hospitals

Hospital Universitari Vall d'Hebron, Barcelona, Spain
Director and Contact: Josep Perapoch, MD, PhD
email: jperapoch.girona.ics@gencat.cat

Hospital Universitario 12 de Octubre NIDCAP Training Center

Hospital Universitario 12 de Octubre, Madrid, Spain
Director: Carmen Martínez de Pancorbo, MD
Contact: María López Maestro, MD
email: nidcap.hdod@salud.madrid.org

SWEDEN

Karolinska NIDCAP Training and Research Center

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

UNITED KINGDOM

UK NIDCAP Centre

Department of Neonatology,
University College Hospital, London, UK
Director: Neil Marlow, DM FMedSci
Contact: Gillian Kennedy, MSc, OBE
email: gillian.kennedy4@nhs.net

MIDDLE EAST

ISRAEL

Israel NIDCAP Training Center

Meir Medical Center
Kfar Saba, Israel
Co-Directors: Ita Litmanovitz, MD and Dalia
Silberstein, RN, PhD
Contact: Dalia Silberstein, RN, PhD
email: dalia.silberstein@clalit.org.il

Become a Member of the NFI

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