

PREMATURITY

Individualized Developmental Care for Preterm Infants

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July 2017, Éd. rév.

Introduction

Individualized developmental care in the Newborn Intensive Care Unit (NICU) originated in the 1980s. Based in theory¹ and supported by scientific evidence, it is referred to as NIDCAP (Newborn Individualized Developmental Care and Assessment Program).² The approach focuses on a detailed reading of each individual infant's behavioural cues. Environment and care are adapted to enhance each infant's strengths and self-regulation collaboratively with the infant and parents, who play the primary role in providing daily nurturance and helping their infant develop trust.

Subject

Of the 3.98 million infants born annually in the United States, 9.6% are born prematurely; for the non-Hispanic black population, the figure is 13.4 percent.³ Up to 52% of children born preterm develop school problems and emotional disabilities.⁴⁻⁸

Premature birth places the brain at significant risk for adverse outcome. The intensive care technology and treatments necessary to save these babies' lives disrupt the fetal brain's

development. The dual stress of being isolated from the mother and experiencing daily pain and discomfort leads to neurotoxic brain-altering events.⁹ The NICU's challenge, therefore, is not only to ensure survival, but also to optimize developmental outcome. NIDCAP's goal is to prevent unexpected sensory overload and pain, and enhance strengths and competence. It adapts intensive medical care and environments to the neurodevelopmental individuality of each infant, thus meeting the infant's medical and developmental needs. NIDCAP fundamentally changes traditional care from task-orientation to relationships. The infant's behavioural communications form the basis for individualized developmental environment and care planning for infant and family. This means all medical and nursing interventions are timed and adjusted to the sensitivity of each infant. The approach simultaneously provides support for the parents and key members of the care team. This requires an understanding of infant, parent and family development, the interplay of medical and developmental processes, multiple disciplines in interaction in hospital intensive care systems, and of oneself as a person and a caregiver. NIDCAP makes it possible to experience NICU environments and care from the infant's, the family's and the staff's perspective and recognizes the infant's and family's complete dependence and trust.

Problems

Some neonatologists continue to question the validity of the extensive scientific evidence for the effectiveness of NIDCAP.^{10,11} NIDCAP cannot be studied in double blind fashion, as the identity of an experimental group subject by definition must be declared to the bedside caregiver and the parent, who receive the direct interventive support of the NIDCAP Professional who seeks to implement the intervention. Outcome measures however are collected objectively by researchers blinded to the subjects' group status. It is challenging to study NIDCAP, which is theory-driven and relationship-based and requires systems integration. Its hardware and technology free nature makes measurement difficult.^{1,12-14} Its essence lies in the continuous resourceful modification of care adapted to the infant's competence and vulnerabilities,^{2,15,16} and the open minds for "doing, learning and coming to know."^{12,17} Common misunderstandings of developmental care include "minimal stimulation" (fully covered incubators, protection from all visual and auditory contact, and "clustered care" of rapid routines at set intervals) and the "developmental decoration approach" (pretty nests and incubator covers, indirect lighting, whispering zones; yet routinized care as before).¹⁸ The change required is internal to the staff and the system, a shift in mind, attitude and seeing anew. Continued challenges exist for cultures and systems where reflection and relationship processes are unfamiliar,^{13,15,19} and medical professionals have the ultimate

authority for making all care decisions.²⁰ Nurseries may differ in financial and leadership stability, staff relationships, patient census, staff/patient ratios, family characteristics, history, traditions and culture, organizational, communication and conflict resolution styles and their distinctive competences.^{12,21} Yet the hopes and expectations of infants and families remain the same worldwide. Combining best technology and intensive care with the most sensitively individualized developmental care is the medical system's responsibility.^{13,16,22} The NIDCAP training program (www.NIDCAP.org) focuses on the education and training of multidisciplinary developmental specialist teams in NICUs, anchored in a system's approach of nursery-wide self-assessment and continued systems improvement, as articulated in the NIDCAP Federation International's (NFI) Nursery Assessment and Certification Program (NNACP)²³ (See also www.nidcap.org; NIDCAP Nursery), which highlights the four main pillars of nurseries' functioning, the philosophy and care of the infant, of the parent, of the staff and of the environment.

Research Context

NIDCAP has been studied in several historical phase-lag and in many randomized controlled trials. Randomized NIDCAP trials require large NICUs to provide the opportunity of geographical distance of control and experimental group subjects in order to limit the contamination effect (spill over) from experimental group care to the care of the control group. Staff requires understanding in behavioural research. While some cross contamination of caregiver implemented interventions is unavoidable, any positive experimental effects by definition exceed all contamination effects. NIDCAP research requires experienced developmental specialists, superb nursing and neonatology leadership, and extensive research expertise for the supervision of intervention integrity, acquisition of complex databases and analysis of large data sets. These all are highly labour-intensive. Result generalizability is limited by population and NICU characteristics.

Key Research Questions

The main research questions concern NIDCAP's effectiveness in terms of medical, neurobehavioural, neurophysiological and brain structural outcome; effects on parents; long-term outcomes; and the effects on staff and systems. Some studies investigate change processes and differential effectiveness for infant subgroups. A European multi-centre trial is planned and a U.S. trial appears indicated. Given the well-developed criteria and qualifications for the certification of NIDCAP nurseries, wide-spread adoption by different health-care systems and insurance companies are the next steps. Applicability to other health-care areas includes pediatric and

cardiac intensive care, geriatrics, psychosomatic medicine and medical intensive care, among others.

Recent Research Results

Five historical²⁴⁻²⁸ and nine randomized controlled trials²⁹⁻³⁶ have investigated the effectiveness of NIDCAP. Aside from the one poorly designed and negatively reviewed study,³⁷ the results provide consistent evidence of improved lung function, feeding behaviour and growth, reduced length of hospitalization, lowered post-conceptual age at discharge, improved neurobehavioural and neurophysiological functioning, and enhanced brain fibre tract development in the frontal lobe and internal capsule. The 2003 three-centre trial³³ that involved two transport and one maternity hospital NICUs, additionally showed lowered parental stress, enhanced parental competence and higher infant individualization. Several studies have demonstrated significantly better Bayley^{38,39} mental and psychomotor developmental scores at 3, 5²⁶, 9, 18 and 24 months^{24,29,34,35,40} corrected age, as well as improved attention, interaction, cognitive planning, affect regulation, fine and gross motor modulation and communication (Kangaroo-Box paradigm).^{24,29} At three years corrected age, a Swedish study⁴¹ documented better auditory processing and speech [Griffith Developmental Scales⁴²], fewer behaviour symptoms [Höök-Cedarblad Child Behaviour Interview, in Kleberg,⁴¹] and better mother-child communication [Parent-Child Early Relational Assessment Scale-ERA⁴³]; at six years corrected age,⁴⁴ higher survival rates without developmental disabilities, specifically mental retardation and attention deficits; and at 8 years better mental executive function (EF) as well as better EEG connectivity especially in regard to the frontal lobe and its long distance connectivities,^{45,46} and MRI-based measures of better fiber tract development in cortico-spinal tract⁴⁵ and of increased cerebellar volumes.^{45,46}

Conclusions

The NIDCAP model is based on solid scientific evidence and appears to lead to savings in NICU and educational costs. NIDCAP training, while requiring up-front financial and time investment for training, is cost-effective, with documented care cost reductions of U.S. \$4,000 to \$120,000 per infant.^{27,29,31} A team consisting of at least two NFI-certified NIDCAP Professionals, one with a medical and the other with a developmental professional background, effectively guide the care as tested in the various studies. Detailed weekly bedside observations are followed by written documentation, discussion and guidance to families and caregivers in support of the infants' strengths and reduction of stress. Daily problem-solving leads to environmental and care

modification geared to enhance infants' and families' unique strengths and reduce vulnerabilities. The main ingredient of the intervention's success lies in the reliable developmental support to the caregivers and the system-wide integration of NIDCAP principles into care and environment over time. This ensures steady increments of progress in emerging strengths and guards against setbacks in terms of infants and family functioning as well as of nursery progress, often due to misinformation, misunderstanding and miscommunication regarding current sensitivities, reactivity and stress in infants, parents and staff. Guided serial nursery system self-assessment and planning of step-wise change lead to nursery-wide sustainable care improvement and transformation for infants, families and the staff as well as for the nursery environment.

Implications

Given the encouraging results of the NIDCAP studies, and the availability of proven detailed quality-assured staff training and nursery consultation personnel and materials, it behooves those responsible for Newborn Intensive Care to be knowledgeable and well-educated in the NIDCAP model. The introduction of NIDCAP into a system involves considerable investment at all levels of an organization. It may over time involve physical changes and adaptations. These often are the most readily accomplished. Funding for designs with individual private family infant care rooms are on the rise. However, while such innovations may facilitate NIDCAP care, the first and foremost investment concerns substantive educational efforts and changes in the practice of care from task and schedule orientation to individualized relationship-based orientation of care. Since NIDCAP is also highly compelling from an ethical perspective and in direct keeping with family-integrated care, it is becoming the standard of care for increasing numbers of NICUs. The individualized approach requires leadership support aside from staff training, education and role redefinition.¹³ A formally established international teaching program focuses on such education and provides on-site consultation towards institutional change, leadership and reflective process capacity. NIDCAP requires development in professional self-awareness and capacity to be present in the moment, to "hold" complex relationships and interactions. The developmentally skilled NICU professional combines highest medical technological knowledge and skill, embedded in highest interactive affective relationship education and skill. All NICU work involves human interaction at many levels and in the complex interface of physical and emotional vulnerability. At its core are the immature, fully dependent, highly sensitive and rapidly developing fetal infants and the infants' hopeful, open and vulnerable parents, trusting and counting on well-educated and emotionally highly differentiated caregivers' attention and investment. Herein lays the challenge

and the opportunity of developmental NICU care.

Acknowledgement: Supported by a grant from the Irving Harris Foundation Chicago to H. Als; and an Intellectual and Developmental Disabilities Research Center Grant P30HD18655 to S. Pomeroy.

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