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Family-Centred Developmentally Supportive Care in Neonatal Intensive Care Units

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Introduction

Mortality among prematurely born infants has decreased dramatically over the past decade in developed countries. The survival rate for very-low-birth-weight (VLBW) infants (less than 1,500 g) has risen from 50%[1] to more than 85%[2] since the introduction of neonatal intensive care in the early 1970s. However, a similar improvement in morbidity and long-term consequences among these very prematurely born children has not yet been conclusively shown to have taken place. Hence, there is intense ongoing research addressing possible improvements to medical treatment. The importance of improvements in the caregiving itself and engagement of the family has also gained increasing acceptance in the scientific community.

Subject

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP)[3] is an example of an integrated developmental care intervention for newborn infants that is well documented. The major instrument employed in the NIDCAP is repeated, formalized observations of the infant by a person who is specifically trained and certified in the method. These observations focus on efforts at self-regulation, as revealed by approach or avoidance behaviour. When the sensory input is appropriate, the infant will move towards the stimuli and demonstrate self-regulatory behaviour. In contrast, when the input is overwhelming because of too great intensity or inappropriate timing, the infant exhibits avoidance or stress behaviour.

Consequently, caregiving plans, including recommendations for individualized care and environmental changes, are designed on the basis of the infant's current developmental stage and medical condition, as well as the family's needs. As the infant matures, these recommendations are modified in an appropriate manner.

Accordingly, caregivers learn to be careful observers and note the infant's reactions to different types of handling and care. Based on these observations, caregivers can make appropriate and continuous adjustments. Moreover, NIDCAP is family-centred. The goal is to empower the family by helping them develop such care skills and techniques, thus including the family as part of the health-care team.

Problems and Research Context

The hospitalization of prematurely born infants takes place at a time when important growth and development of organ systems would normally take place in the mother's womb. The crucial development of respiration and brain function is highly active and of greater importance than at any other period of life. Thus, lung function and neurodevelopmental outcome are the two major issues of concern.[4,5] Using the 1980 World Health Organization (WHO) definition of impairments and handicaps, follow-up studies of VLBW infants have reported disabilities in 15% to 25% of these children.[6,7] A recent meta-analysis revealed that at school age, cognitive scores of former VLBW infants are approximately 10 points lower than those of matched control children[7] due to difficulties with attention, behaviour, visual-motor integration and language performance.[8-10]

Key Research Questions

What are the benefits of NIDCAP in terms of:

- - Medical problems during hospitalization, e.g. fewer respiratory diseases and brain lesions
- - Parents' involvement in caregiving
- - Shorter hospitalization and cost savings
- - Long-term mental and motor development
- - Behavioural problems in early childhood and school age
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Research Results

To date, there have been three randomized controlled trials published on the effects on VLBW infants through a *full* implementation of NIDCAP.[11-13] In their recent meta-analysis, Jacobs and collaborators report separately on these three studies and demonstrate a significant reduction in the need for mechanical ventilation of nearly four weeks.[14] A Cochrane Review[15] also reported the risk of moderate-severe chest X-ray findings in approximately one-third of the NIDCAP infants as compared to control infants. In addition, based on our own calculations, the risk of severe brain lesions is reduced by almost 50% for NIDCAP infants.

Jacobs and co-workers also report a mean improvement in cognitive ability at nine to 12 months of age by 16 IQ points.[14]

A recent report[16] on a five-year follow-up of a Swedish study demonstrates a clear significant impact on the NIDCAP group only in the behavioural aspect of development. However, there were positive tendencies in terms of the incidence of mental retardation and overall disability.

Two trials assessed brain function using sophisticated electro-physiological methods.[11,17] Both of these studies revealed significant differences in favour of NIDCAP intervention. Interestingly, in the study on more mature low-risk infants, the largest differences were observed in the frontal lobe area, where the organization of the brain cells occurs relatively late.[17] Moreover, employing new advanced radiological techniques (3D-Magnetic Resonance Imaging, MRI), the same investigators recently presented preliminary data that indicated beneficial changes in the structure of the brain[18] in NIDCAP infants compared with a control group.

The complexity of developmentally supportive care and demand for comprehensive training have caused some concern about its cost-effectiveness.[15] However, several groups have reported that NIDCAP actually reduces costs by $4,000 to $120,000 US per infant, depending on birthweight and

initial illness.[11,12,19]

In addition, studies on the effects of NIDCAP components in *specific* care-giving situations have recently been reported. Sizun and co-worker demonstrated decreased pain response and lung function during a routine nursing procedure in medically stable preterm infants.[20] A preliminary report from the same group of investigators also indicated increased durations of sleep with NIDCAP.[21]

Published studies on the effects of NIDCAP have been relatively few to date, with small numbers and relatively short follow-up periods. The methodology employed has been questioned.[14,15] However, due to the complexity of the intervention, NIDCAP evaluation is complicated in comparison to studies involving, for example, different drug treatments or modes of ventilation. It is difficult to achieve an optimal experimental design. There is no gold standard for nursing care, which makes the definition of the control group variable. The intervention cannot be applied without revealing to which study group a particular infant belongs. In experiments that include several individual approaches, it can be difficult to determine what exactly made the difference – and a single procedure may not be analyzed separately.

Since most developmental-care studies include small numbers of generally healthy preterm newborns, the results are not readily generalizable for infants with acute illness and/or extreme prematurity. The duration of integrated-care procedures, such as NIDCAP, last for months and there is a risk of a spill-over effect on the control group. Moreover, parents share experiences with each other and actively seek knowledge designed to improve the treatment of their infant.

Conclusions and Implications

This kind of intervention is attractive from an ethical point of view.[22] Family-centred developmentally supportive care is based on the recognition that the newborn infant is a human being in his/her own right and on the need to encourage caregivers to be guided by the current needs of the individual infant and its family. The theoretical framework behind family-centred developmentally supportive care/NIDCAP is endorsed by research from various scientific fields, such as neuroscience, developmental and family psychology, medicine and nursing. However, the introduction of NIDCAP is not a trivial process but involves a considerable investment at all levels of the organization. NIDCAP requires some physical changes in the Neonatal Intensive Care Unit, as well as substantial educational efforts and changes in the practice of care. The findings of our

own investigations on the effects of NIDCAP have been encouraging and in line with the results of previous studies. NIDCAP has been very well received by nursing staff, neonatologists and parents.[23] It appears reasonable to recommend that nurseries acquire the know-how to implement NIDCAP in order to be able to engage in new and much warranted investigations of developmentally supportive care in different cultural contexts and with diversified and, if possible, larger randomized multi-centre trials.

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