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Neonatal individualized care in practice: a Swedish experience

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A family-centred, developmentally supportive approach to newborn intensive care referred to as NIDCAP (Newborn Individualized Developmental Care and Assessment Programme) has caught considerable interest during recent years. In this paper we review the scientific context behind its conceptual framework and summarize our experience from 10 years of training, implementation and research. We present the short- and long-term medical and developmental outcome of our Swedish NIDCAP studies as well as attitudes of nursing staff and neonatologists. Furthermore, ethical issues and scientific obstacles concerning this concept of care are discussed.

Key words: brain development, child development, human, infant, newborn, premature, intensive care, neonatal, practice guidelines, treatment outcome

Background

Over the years the care of babies born prematurely has improved continuously. The survival of very-low-birth-weight (VLBW) infants (<1500 g) was reported to be 70–75% in the late 1980s [1,2] and has increased lately to over 85% [3]. However, a concomitant decrease in long-term sequelae has yet to be clearly demonstrated.

Pulmonary morbidity has been an issue of great concern ever since Northway and associates [4] first described bronchopulmonary dysplasia in 1967. Nevertheless, its incidence seems to have remained unchanged at 25–30%, due to the increasing number of extremely-low-birth-weight infants (<1000 g) who survive [5,6].

Neurodevelopmental outcome is another major issue for VLBW infants. Follow-up studies have reported the incidence of disability to be 15–25% [7–9], a figure which has also remained fairly constant over time [7,10,11]. In addition, as an increasing number of survivors reach school age, more minor impairments cause concern. Difficulties with attention, behaviour, visual-motor integration, language performance and academic skills appear to demonstrate a prevalence of about 40% [12–15].

It has been documented how sensory input influences the structure and function of the central nervous system, as well as the behaviour of the new-born [16–19]. Infants born very prematurely receive inadequate stimulation and care during a critical period when their brains are developing rapidly. In the germinal zone most of the neuronal multiplication and migration is completed, but astrocytes are formed and subsequently migrate to upper cortical layers. Astrocytes destined for the white matter and the subcortical plate are derived from radial glial cells. Myelination begins and a naturally occurring neuronal death by apoptosis is more frequent than at any other period [20]. It has been calculated that up to 70% of neurons in the human cortex undergo apoptosis between the 28th week of gestation and term [21]. Similarly, the most active phase of synaptogenesis is initiated along with the growth of dendritic and axonal arbours.

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The volume of the cortical grey matter increases fourfold from 30 and 40 weeks of gestation [22]. At its maximum, as many as 40 000 new synapses are formed every second [23]. This wiring of neuronal circuits is dependent on endogenous factors as well as on sensory input and experience [23,24].

Bearing all these extraordinary intense activities in mind, it is not surprising that the development of the brain could be disturbed by premature birth, an effect one could expect to be amplified with time if stemcell or progenitor cell proliferation is affected. A recent study of 8-year-old ex-preterm infants demonstrated with magnetic resonance imaging (MRI) technique large (12–35%) regional reductions in brain volume [25]. The strongest predictor of this reduction was not perinatal risk factors such as haemorrhage and severity of illness, or demographic factors such as gender and maternal education, but the degree of prematurity per se.

Nevertheless, the experience of pain and discomfort caused by treatment and caregiving procedures during the hospitalization of VLBW infants is of great concern. It is difficult for VLBW infants to experience restful and undisturbed periods of sleep. During a 24-h observation period, such infants have been reported to be handled on average more than 200 times [26]. Three of four hypoxemic episodes in preterm infants have been reported to be associated with the caregiving itself [27] and increased levels of stress hormones have been observed to occur in association with routine nursing procedures [28]. Moreover, experiences of pain during the neonatal period have been linked with long-lasting accentuated stress responses [29], altered neural circuits [30], learning deficits and behavioural changes in rodents [31].

Infants born with a VLBW are at high risk of receiving developmentally inadequate stimulation. They are reported to demonstrate hypersensitivity to stimuli, greater difficulties in maintaining alertness and to require more help in order to regain stability, in comparison to full-term infants [32–34]. Preterm infants are also less responsive to interaction than are full-term infants and demonstrate lower levels of signalling. Since it is difficult to observe and interpret their weak signals these children are thus more unpredictable for parents and other caregivers [35].

The important role of the family in caring for VLBW infants has also been emphasized and the concept of family-centred care has been strongly advocated [36]. Minde and collaborators [35] have shown that neonatal illness may have a lasting negative effect on parent–infant interactions.

In an attempt to address these different issues, Als has formulated a theory on the development of the prematurely born infant, the synactive theory [37]. Accordingly, she has also developed an early intervention programme, called the Newborn Individualized Developmental Care and Assessment Programme (NIDCAP) [38], which puts focus on the individuality and respect of the very tiny human being and his/her family. The major tool employed is repeated formalized naturalistic observations of the infant before, during and after caregiving procedures, e.g., feeding, collection of blood samples, etc. The observer assesses the infant's current ability to organize and modulate the five highly interactive subsystems formulated in the synactive theory, i.e., the autonomic physiological, motor, state organizational, attention-interactive and self-regulatory systems.

On the basis of the regular observations caregiving plans are formulated including recommendations concerning individualized care and environmental changes based on the current developmental stage of the infant and needs of the family. As the infant matures, these recommendations are altered in an appropriate manner. The programme is described in more detail elsewhere in this issue [39].

NIDCAP is reported to have a considerable positive impact on VLBW infants by decreasing their requirement for ventilatory assistance and length of stay, by enhancing weight gain and by improving development [40–42]. However, critical comments on the published studies have been raised [42–45]. Even so, the use of the programme has been recommended by others [46–48]. For more than 10 years we have been engaged in family-centred developmentally supportive care in forms of NIDCAP. In this paper we will summarize our Swedish experience from a scientific, training and practical perspective.

Short-term findings

The first Swedish NIDCAP study [49] was performed at the Falun Hospital, which is a small level II–III unit serving a predominantly rural population. We studied two groups of singleton inborn infants with birth-weights of $\leq$1500 g. Due to the small size of the unit we did not use a randomized

Table 1. Primary outcomes (ventilatory assistance, growth and hospitalization) of the randomized controlled NIDCAP trial at the Karolinska Hospital [50]

Survivors	NIDCAP group n=11	Control group n=10	*P*
Mechanical ventilation (days)	2.8 (0–36.7)	4.8 (0.1–29.8)	ns
CPAP (days)	26.1 (6.9–52.0)	43.9 (5.0–65.1)	0.045
PCA at O_2 withdrawal (weeks)	33.0 (29.3–35.7)	38.1 (33.1–44.9)	0.007
Bronchopulmonary dysplasia (no.)† none-mild/moderate-severe	11/0	4/6	0.024‡
Weight gain up to 35 weeks PCA (gm/day)*	13.0 (6.7–21.0)	9.8 (6.8–16.6)	ns
Head growth up to 35 weeks PCA (cm/week)*	0.73 (0.56–1.3)	0.63 (0.56–0.77)	ns
PCA at discharge (weeks)	38.3 (36.1–57.7)	41.0 (36.9–48.4)	ns

Median (range); Mann–Whitney U test if not otherwise indicated; *P*-values adjusted for multiple tests according to Holm [66]; ns: not significant.
†Chest X-ray findings at 36 weeks PCA; ‡Fisher's exact test; *including an infant who died at 37 weeks of PCA.

design, instead, we chose two study periods. Group 1 (born 1990; n=21; gestational age of 28.5 (1.9) weeks; mean (SD)) was born before the implementation of NIDCAP in the unit and Group 2 (born 1992–93; n=21); gestational age of 28.6 (2.6) weeks) was recruited after a year of preparation. The NIDCAP group had formalized NIDCAP observations every 10 days up to a post-conceptional age (PCA) of 36 weeks. In the newborn period we did not find any statistically significant group differences in requirement for ventilatory support or daily weight gain. Although, there was a difference in the post-conceptional age at discharge in relation to birth-weight, sex and educational level of the father, 40.3 weeks (0.50) for the controls vs. 38.2 weeks (0.55) for the NIDCAP group (mean ± SE; $P=0.03$ (ANCOVA)) this finding has to be cautiously interpreted due to the multiple comparisons.

In the mid 1990s we performed a randomized controlled trial at the level III unit of the Karolinska Hospital in Stockholm [50]. In this trial we studied infants at somewhat higher risk with a gestational age less than 32 weeks and requirement of ventilatory support (CPAP or mechanical ventilation) at 24 h of postnatal age. The randomization took place before birth and the infants allocated to the intervention were assigned to a special room on the unit and cared for by a specially trained team of nurses from the moment of birth and throughout the whole length of stay. Moreover, NIDCAP observations were performed weekly up to a PCA of 36 weeks.

The short-term findings are summarized in Tables 1 and 2. The infants receiving care according to NIDCAP required significantly less ventilatory support in comparison with the control infants. The respective mean values (SD) for days on CPAP were 27.0 (12.0) vs. 44.1 (16.5) and for PCA at the time of oxygen withdrawal 32.9 (1.8) vs. 38.1 (3.6) weeks. Among the survivors at 36 weeks of PCA, six of the 11 infants in the NIDCAP group had mild signs of bronchopulmonary dysplasia (BPD) on chest X-ray but none required supplementary oxygen. Of the ten infants in the control group there were two with mild, four with moderate and two with more severe signs of BPD and all eight needed extra oxygen at 36 weeks of PCA.

The discrepancy in the short-term results (respiratory outcome) between our two studies is in line with previous NIDCAP studies, which indicate that the impact of the intervention on the medical outcome variables is correlated to the degree of prematurity and the severity of illness [40,41,51,52]. It was our impression that the intervention infants were more stable and subjected to fewer 'work-ups '. This is reflected by the trend of fewer apnoeas and days on antibiotics among the NIDCAP infants, despite the obvious lack of difference in the number of sepsis episodes (Table 2). Moreover, growth has been shown to be positively affected by developmental care in a recent meta-analysis [42]. A possible explanation for these effects could be that the intervention enhances the infants' ability of self-regulation and thus

Table 2. Clinical observations in the randomized controlled NIDCAP trial at the Karolinska Hospital [50]

	NIDCAP group	Control group
All subjects	n = 12	n = 13
Survival (at discharge)		
Alive/deceased	11/1	10/3
Intraventricular haemorrhage†		
None/gr I/gr II/gr III/gr IV	9/2/0/1/0	8/0/2/3/0
Neonatal survivors	n = 11	n = 10
Antibiotic treatment (iv; − days)	18 (6–53)	31 (18–55)
Sepsis (non/1/≥2)‡	1/3/7	0/2/8
Apnoeas (number)	33 (4–162)	49 (2–158)
Retinopathy of prematurity ≥stage 3#	4	8 (n = 11)*

Median (range); none of the differences were statistically significant.
†According to Papile [67]; ‡a positive blood culture and/or antibiotic treatment for more than 6 days in combination with clinical symptoms and elevated C-reactive protein; #according to the International Committee for the Classification of ROP [68]; *including an infant who died at 37 weeks of PCA.

provides means of maintaining autonomic and motor stability, which, in turn, enhances health and preservation of energy. Accordingly, Als and collaborators reported improved autonomic and self-regulatory performances among the intervention infants at term [40].

Family support, developmental and behavioural outcome

NIDCAP is a programme of intervention which aims to provide appropriate stimulation during the newborn period in order to facilitate the infant's neurological maturation and thus promote development.

The infants in the Karolinska study were assessed at 1 year of corrected age employing the Bayley Scales of Infant Development (BSID) [53]. The Mental Developmental Index (MDI) of children who had received care according to NIDCAP was higher (88 (72–114)) (median (range)) than the corresponding value for the control children (75 (50–82)) ($P=0.01$). The odds ratio for being alive with a MDI >80 was 14 (95% CI: 1.4–141.5) in favour of the intervention group. There was no statistically significant difference in the Psychomotor Developmental Indices (PDI). However, the NIDCAP children had a higher score than the control children (85 (61–108) and 69 (50–114), respectively) ($P=0.23$). The 5-year follow-up study is presently in progress.

Improved developmental outcome after NIDCAP care has been reported previously [40,42] and several plausible explanations could be considered. First, an enhanced autonomic stability during the perinatal period might bring about a reduced incidence of severe brain lesions as reported by two groups [40,54]. Second, the intervention might provide the prematurely born infants with a more optimal environment for promoting a normal brain development. As discussed above, a major objective for the NIDCAP is to continuously adjust the external stimuli to the developmental stage of the infant. In turn, this could possibly enhance the prospects for normal multiplication and migration of neurons, astrocytes and glial cells, as well as normal cell differentiation by synaptogenesis and apoptosis. All events take place least partly during the hospitalization of an infant born very prematurely. The speculation that NIDCAP might support these processes is strengthened by data from two RCTs employing measurements of neurophysiological functions by evoked potentials and quantified electroencephalogram with topographic

mapping (brain electrical area mapping, BEAM). The first study included infants at high-risk with a gestational age ≤ 30 weeks and all requiring mechanical ventilation [40]. The other trial consisted of infants at low-risk with a gestational age $>30-<34$ weeks without need of mechanical ventilation [51]. In both studies there were significant differences in favour of NIDCAP intervention. Interestingly, in the latter study of the more mature low-risk infants the largest differences were in the frontal lobe area where neuronal organization occurs relatively late. Moreover, the neurophysiological findings of the NIDCAP group were no different from a full-term control group.

Finally, one of the more important objectives of the NIDCAP is to support all caregivers, including parents, nurses and physicians, to become more sensitive and responsive to the infant's cues and to enhance mutual interaction between the caregiver and infant. Parents become more attuned to the needs of the infant and can provide adequate (i.e. neither too much nor too little) stimulation. Accordingly, family-centred developmentally supportive care has been described as belonging to the second-generation interventions, which focus on the interaction between the infant and parents. One might speculate that this way of interaction will continue after discharge and enhance the parent–infant joint attention activities that are considered important for a favourable long-term cognitive development [55]. Achenbach and collaborators have reported positive impact on long-term development in a study of low birth-weight infants employing a somewhat corresponding intervention, the mother–infant transaction programme [56]. Their intervention consisted of seven daily sessions during the last week of hospitalization and four home sessions up to 3 months of age. Similarly, cognition was significantly affected in favour of the intervention group. Interestingly, this difference increased over time up to the final follow-up at 9 years when less behaviour problems and better school performances were noted as well.

The children of the Falun study were followed up at a corrected age of 3 years [57]. There was no significant difference in motor development assessed according to Amiel-Tison [58]. Moreover, the Griffiths' Development Scale II showed no significant difference in developmental quotient (DQ). There was, however, a significant difference in the subscale hearing–speech, the intervention group scored 119 (72–157) (median (range)) and the control group 108 (84–130) ($P=0.02$). As for behaviour assessed on the basis of a parental interview [59] there were significantly fewer problems in general as well as in the cluster of internalizing symptoms in the NIDCAP group in comparison to the control group (total score: 6 (0–20) vs. 16 (0–54), $P=0.03$). Furthermore, we assessed mother–child interaction employing the Parent–Child Early Relational Assessment Scale (ERA) [60]. We could demonstrate a significant difference in favour of the NIDCAP group in the child cluster 'communication' in addition to the individual items of 'parental physical and visual contact' and 'child's motoric competence' [57].

Although the Griffiths' test did not reveal any differences in the overall developmental quotients for these two groups, there was an interesting difference with respect to the subscale for measuring language skills. This result was in agreement with the ERA assessment, which also indicated that the children in the intervention group had better communication skills. The mothers of children in the NIDCAP group appeared to give their children more physical and visual contact than did the mothers in the control group. In addition, the children in the intervention group demonstrated fewer general behavioural problems and less internalizing problems, i.e. were more open and expressed their feelings more readily.

Tentatively, these findings may indicate that the intervention provided a long-lasting enhanced interaction among the NIDCAP mothers that promoted the ability of their children to interact and that a better mutual understanding between mother and child may have helped to reduce behavioural problems. On the other hand, the limited number of subjects and the phase lag design of this study call for caution in the interpretation.

Staff experience

After the NIDCAP had been practised for 2 years at the Falun Hospital, a questionnaire was sent out to all staff who had been employed before the start of the NIDCAP training [49]. They were asked to express their opinions on the impact of NIDCAP in response to 25 statements, dealing with infants' well-being, parental participation and the staff's working conditions. For each statement in the questionnaire the respondent indicated his/her opinion on a visual analogue scale (VAS). The value of -5 was set to correspond to 'worse', 0 to 'unchanged' and $+5$ to 'better'.

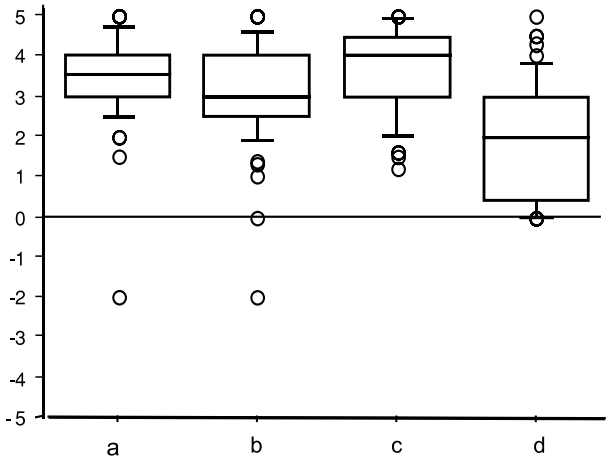

Figure 1. NIDCAPs impact on the infant according to staff survey [49]. 'In comparison to the situation prior to the implementation of NIDCAP, it is my belief that as a result of NIDCAP . . . (a) *the infant's well-being* during its hospital stay has become . . . (b) *my ability to influence the infant's well-being* has become . . . (c) *the infant's chances to rest and sleep* have become . . . (d) *the infant's ability to cope with enteral feeding* has become . . .' (The value of −5 was set to correspond to 'worse', 0 to 'unchanged' and +5 to 'better'). The boxes depict the median and interquartile range and lines extending from each end of the box indicate each variable's 10th and 90th percentile.

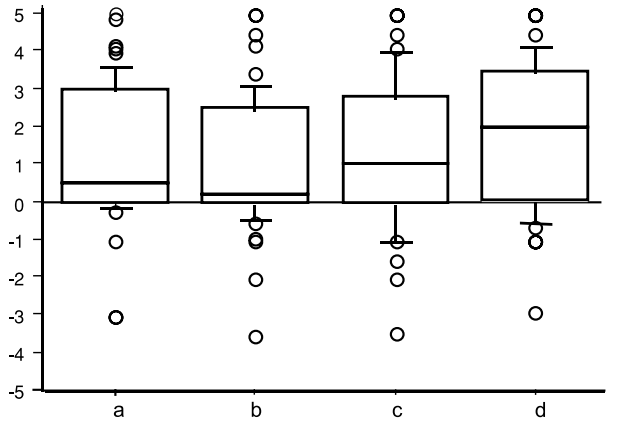

Figure 2. NIDCAPs impact on the working conditions according to staff survey [49]. 'In comparison to the situation prior to the implementation of NIDCAP, it is my belief that as a result of NIDCAP . . . (a) *my confidence in my professional ability* has become . . . (b) the *conditions for performing my job* have generally become . . . (c) my *working conditions in general* have become . . . (d) my *satisfaction* with my work in general has become . . .' (The value of −5 was set to correspond to 'worse', 0 to 'unchanged' and +5 to 'better'). The boxes depict the median and interquartile range and lines extending from each end of the box indicate each variable's 10th and 90th percentile.

The staff was in general positive to the effects of the NIDCAP, experiencing a positive impact on 23 of the 25 issues investigated. They felt that the well-being of the infants was enhanced, that the infants were disturbed less and that the contact between the infants and their parents was improved (Fig. 1). Moreover, despite the demand of changes in the environment of the NICU and the manner of caregiving, the staff had experienced an improvement in their working conditions and an increase in job satisfaction (Fig. 2).

We were also interested in examining staff opinion on the NIDCAP care plans, since the observation of the infant and formulation of these care plans requires training and is time-consuming. The extent to which the staff thought the care plans constituted an important part of the NIDCAP was striking, especially with respect to the infant's rest and sleep and the parents' way of caring for and attaching to their infant (Fig. 3). Such care plans based on observation of the infant are, according to the theoretical framework of the NIDCAP, the very foundation for the practical changes involved. Our study appears to support this, as does our impression that there is a clear decrease in the quality of developmentally supportive care during periods without observations and care plans.

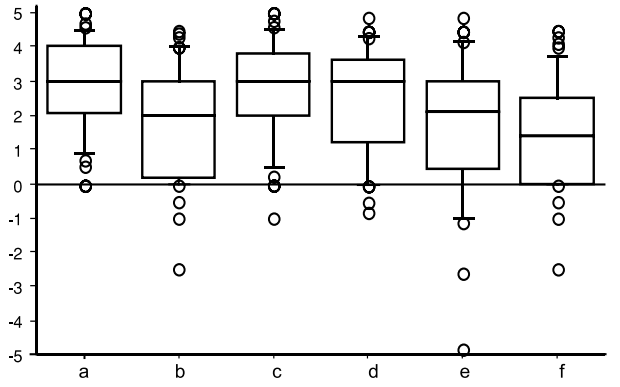

Figure 3. The impact of NIDCAP caregiving plans according to staff survey [49]. 'It is my belief that the NIDCAP caregiving plans have influenced the . . . (a) *infant's chances to rest and to sleep* for the . . . (b) *presence of the parents* at the infants bedside for the . . . (c) *parents' way of giving care* for the . . . (d) *attachment of the parents* to their infant for the . . . (e) *assess the infant's condition* for the . . .' (f) *conditions for fulfilling my tasks* for the . . . (The value of −5 was set to correspond to 'worse', 0 to 'unchanged' and +5 to 'better'). The boxes depict the median and interquartile range and lines extending from each end of the box indicate each variable's 10th and 90th percentile.

View of neonatologists

In 1997 we performed a survey among Swedish neonatologists in order to assess their view on NIDCAP (unpublished). A questionnaire was sent out to physicians involved in neonatal care in 17

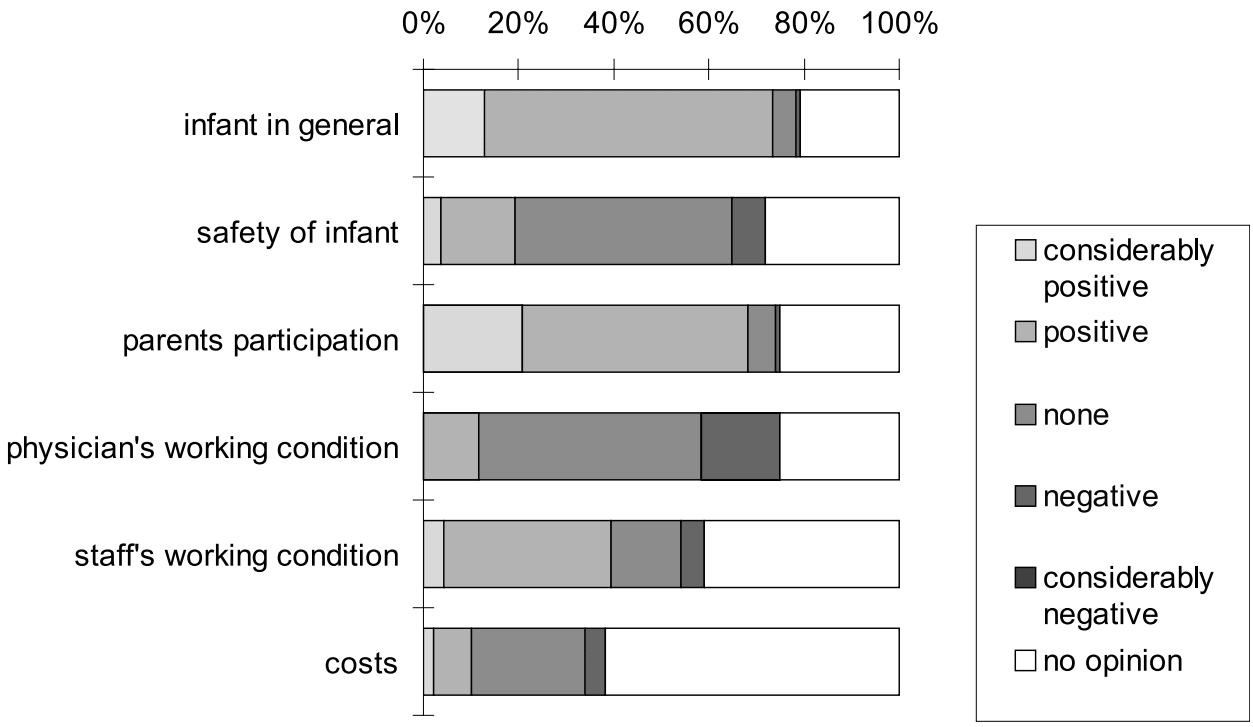

Figure 4. The view of Swedish physicians on the impact of NIDCAP. 'NIDCAPs influence on . . . is . . .'

level II–III NICUs in Sweden. All eleven units affiliated to the medical schools were included in addition to all non-academic units in one of the regions of Sweden. Eighty percent of the questionnaires were returned (139/174). Fifty-four percent of the responders were affiliated to an academic institution. The mean (SD) years of practice in neonatology was 12.5 (6.9) years and their mean age was 46.8 (6.25) years.

The survey showed that the Swedish neonatologists had a considerable acquaintance with NIDCAP. More than 95% had heard of the programme and a majority had read reviews or original papers. Twenty-two percent of the responders had a personal complete NIDCAP experience, i.e., regular NIDCAP observations and NIDCAP care plans had been employed in their units. The results are summarized in Fig. 4. The lack of experience of the complete NIDCAP among three-quarters of the physicians probably explains the relatively high percentage of 'no opinions'. These responses were omitted in the following analyses in order to get a clearer picture of viewpoints actively expressed in this sample of physicians.

Ninety-three percent of the physicians with a clear opinion believed that NIDCAP care had a positive influence on the infant in general. This view appeared to be a bit less positive among the neonatologists at the academic institutions (88%, $P=0.06$). Sixty-three percent of the physicians did not believe that NIDCAP negatively affected the medical safety of the infant, while 27% scored a positive and 10% a negative impact. As in the previous question the colleagues at the medical schools were more negative (18 vs. 2%, $P=0.01$). On the other hand, the older physicians (>45 years) had a less negative view compared to the younger ones (3 vs. 19%, $P=0.02$). The participation of the parents was positively rated by 91%. The question of most concern to the neonatologists was their own working conditions. Twenty-two percent believed NIDCAP had a negative influence, but a clear majority had a neutral (63%) or positive (15%) view.

The result of this survey showed a very positive view on NIDCAP in general among Swedish neonatologists. There seemed to be a slightly less positive view among the physicians at the universities. One possible reason could be that this group experiences more severely ill infants and thus is more concerned about the safety issues. Another possible explanation could be that physicians at academic institutions have a more sceptical attitude to new methods in general. However, it is also of interest to note that the more experienced neonatologists were less concerned, only 3% believed that there was a negative impact on the safety of the infant. Even so, in introducing developmentally supportive care, the question of safety must be properly addressed. The impact on the working

conditions of the neonatologists was another area of some concern.

The results of this study implied that there were very good premises for interdisciplinary collaboration in the progress of developmental care in Sweden. One important explanation probably is that this strategy of caregiving fits well with the Swedish tradition of family involvement and non-invasive care. Since long ago, there is a widespread awareness of the importance of 'soft care' both among nurses and physicians. Thus, it could be anticipated that the impact of NIDCAP would be less in comparison to what has been presented from North America. Our social security system allows both parents to be present in the NICU during the initial critical period and one parent throughout the entire hospitalization. Moreover, our modes of ventilatory support is traditionally non-aggressive, e.g. most of the VLBW infants are treated with early CPAP instead of being intubated [61] and in need of mechanical ventilation the babies are seldom paralysed with pancuronioum and are weaned off as soon as possible. At this point (2002), approximately one-third of the Swedish nurseries has ongoing observations by official NIDCAP certified observers and another third has observations done by people in training. There are now 22 certified (two physicians) and 63 people in training by Scandinavian NIDCAP Center, a non-profitable organization.

The implementation process

As described by Als and Gilkerson [62], we have experience that introducing developmentally supportive care requires a full commitment from all levels of the unit. The model requires a flexible mind to continuously assess the infant's physiological and behavioural needs and requires a flexible organization that allows one to adapt the caregiving to these needs. NIDCAP requires a highly co-ordinated approach to care, which crosses discipline and shift boundaries. The caregiving will be more process-guided rather than procedural-based, which often is the prevailing situation. In learning to implement NIDCAP most care-givers become more sensitive to infant behaviour and aware of what it stands for. In fact, a successful implementation often requires a change in how medical care professionals think and relate to the patient – the work needs to become less task-oriented and more relationship-based. Such need for change can sometimes be quite challenging, especially for those whose professional identity to a great extent is tied to competence with science and technology.

Consequently, during the introductory phase there is a potential risk for conflicts as some professionals and parents begin to encompass the idea of family-centred developmentally supportive care more readily than others. The model reveals differences in care philosophy in an obvious manner and these issues have to be addressed in a way showing respect for all parties involved. The complex process of introducing and implementing NIDCAP requires a considerable degree of maturity and courage among both staff and unit leadership. This certainly also applies to the change agent – the developmentalist, who needs to be supportive to all levels of organization, from the patient to the director.

Concerns have been expressed that the implementation of this programme would require extra nursing time. This issue has not been investigated, however, it is our experience [49] that NIDCAP increases the competence of both staff members and parents. Caregiving is specifically adjusted to the current medical and developmental status of the infant. It might be speculated that the caregivers become more skilled and detect changes in the infant's status at an earlier stage. This might, in turn, lead to prompt intervention and prevention of further deterioration. Thus, the infants become more physiologically stable and actually require less nursing time, which is in line with the findings of others [52,54].

The complexity of developmentally supportive care and its demand for comprehensive training has caused some concern about its cost-effectiveness [42,45]. Achieving a certification as a NIDCAP observer is an investment of approximately US$ 4000. The total extra nursing time needed for ten weekly observations of an infant born after 27 weeks of gestation, would in Sweden correspond to a cost of approximately US$ 700. On the other hand, at Karolinska we estimated a reduction of hospital charges of approximately US$ 10 000 per infant due to the reduced need of ventilatory assistance. Groups from North America have reported that NIDCAP reduces costs by US$ 4000–120 000 per infant [40,41,54,63,64] depending on birth weight and initial illness.

It should be mentioned that implementation of developmental care in the hands of an unskilled

person involves a potential risk of over-emphasizing the 'protection' of the infant, i.e. to forget the individualized character of the programme. NIDCAP ought not to be implemented unreflectively, e.g. by completely covering of the isolate of a not-yet-stabilized infant, thereby preventing its necessary surveillance; by building containment for the infant which is too rigid; and by over-protecting a stable, competent baby from visual, auditory and social input, thus preventing it from developing its own ability to self-regulate and interact socially. Instead, the intervention should be designed from the viewpoint of each individual infant, i.e. by attempting to determine what is appropriate for this particular infant at this particular time, considering all factors, including the infant's medical status.

Humane aspects

The rapid development of advanced technology in neonatal medicine has been, and will continue to be, a fundamental condition for the dramatic progress seen during the past decades. Undeliberately, this progress has in many instances led to a conflict with the humane aspects of care. This has been addressed by Levin in his call for a Humane Neonatal Care Initiative (HNCI) [65] where he widens the concept of the Baby Friendly Hospital Initiative to also encompass all the ill and prematurely born babies. Like Dr Levin, we believe that focusing on the respect of the very tiny and often fragile human being and his/her family is not only essential for further improvement of medical and developmental outcome as discussed above, but is important from a humane aspect as well.

As pointed out by Kennell [47] and others [48] NIDCAP could be a very effective tool in pursuing the HNCI. The fundament of family-centred developmentally supportive care is to recognize the newborn infant as a human being in his/her own rights and to let the caregivers be guided by the current need of the individual infant and its family. Care and intervention based on the infant's own behaviour make good biological sense and, in addition, is attractive from an ethical point of view. The behaviour of the infant is seen as an activity with a purpose and not as predominantly governed by inherent reflexes. As expressed by Als 'the infant is an active participant who seeks ongoing regulatory support' and 'the behaviour of the infant is its primary way to communicate'.

Summary

The theoretical framework behind family-centred developmentally supportive care/NIDCAP is endorsed by research from several 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 NICU, as well as substantial educational efforts and changes in the practice of care. Moreover, published studies have been relatively few, with small numbers and employed methodology has been questioned [42,45]. Due to the complexity of the intervention, evaluation of NIDCAP 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. Nonetheless, the Swedish experience of developmental care from the last 10 years has been positive. NIDCAP has been very well received by nursing staff, neonatologists and parents. It is attractive from an ethical point, as well. Furthermore, the findings of our own investigations on the effects of NIDCAP have been encouraging and in line with the results of previous studies. Our positive experiences make us believe that, despite anticipated methodological obstacles, the scientific community has an obligation to further explore developmental care in different cultural contexts with diversified, and if possible, with larger, randomized multicentre trials.

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