

PREMATURITY

Family-Centered Developmentally Supportive Care of the High-Risk Infant and Family: Comments on Als, Westrup, and Mallik and Spiker

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Introduction

During the period from 1970 to 1990, there was a dramatic improvement in survival and impairment rates for high-risk newborns thanks to major advances in neonatal physiology, technology and the organization of regionalized neonatal intensive care. The primary focus of intensive care remained medical and physiological, with patients subjected to prolonged periods of repeated medically necessary treatment-related adverse stimuli in an environment very different from that of the womb. Als, one of the strongest proponents of the introduction of baby- and family-centered care,¹ developed a theory-based approach to refocus the pattern of

interactions in neonatal care firmly on the needs of baby and family. Her Newborn Individualized Developmental Care and Assessment Program (NIDCAP),² currently the most widely used neonatal developmental care intervention, involves training staff and parents in the neonatal intensive care unit (NICU) to be aware of, and respond appropriately to, their baby's behavioural and developmental cues. This approach has the appeal of being caring, compassionate and humane, and by reducing stress and promoting mother-infant interactions where both mother and baby are successfully reading and responding to each other's cues ("dyadic interactions"), could be expected to lead to better outcomes. However, at the present time, neonatal specialists hold starkly contrasting views of the evidence for efficacy and cost-effectiveness of NIDCAP, resulting in differing levels of adoption in different parts of the world.

Westrup, the leader in critical evaluation of developmental care in the NICU setting, has conducted a number of careful short- and long-term studies. In addition, he is the co-author of two recent reviews of the literature of evidence for efficacy.^{3,4} Mallik and Spiker, leaders in research into accessibility to, and efficacy of, community-based early developmental intervention after neonatal discharge in high-risk infants and their families in the first three years of life, are currently leaders in the U.S. National Early Intervention Longitudinal Study.⁵

Research and Conclusions

Als gives an articulate summary of her approach to individualizing developmental care of the newborn infant by using NIDCAP to reduce unexpected sensory overload and pain, and enhance strengths, developmental competence for the infant and developmentally sensitive family interaction and participation in care. She discusses the reservations of NIDCAP, based on lack of scientific validation of the elements, and some of the practical and logistical issues that make it more difficult to adopt in some settings than in others. She notes the difficulties of carrying out rigorous randomized controlled trials and summarizes recent published research. Als is convinced of the efficacy of NIDCAP, strongly advocates that it be adopted, and has moved on to develop strategies to enhance acceptance and implementation.

Westrup summarizes current research in five identified areas of potential benefits of NIDCAP; medical problems in the newborn period, parental involvement in care-giving, shorter hospitalization and cost savings, long-term mental and motor development and behavioural problems in early childhood and at school age. There is a scattering of results in the reviewed literature, with a majority of studies being of small sample size, showing marginal or significant

benefit in the NIDCAP group — including diminished severity of lung disease and better developmental scores after short-term follow-up. Westrup views broader acceptance of NIDCAP as dependent on the provision of larger trials to more clearly quantify the benefits of individualized developmental care.

Mallik and Spiker describe the use of a different intervention tool, the Infant Health and Development Program (IHDP), in eight medical institutions that serve diverse demographic populations in different geographical settings. This was an interventional study undertaken on preterm infants beginning at the time of discharge and extended until 36 months with a control group. Evaluation included health and cognitive and behavioural competence, and there was a high follow-up rate in both groups up to age eight. Subjects in the intervention group had higher IQ scores, fewer markers of behavioural difficulties, and a small increase in maternally reported minor morbidity at 36 months. These effects, however, were fading by age five and eight. There were modest positive effects on mother-child interaction patterns and on the quality of the home environment. The authors attribute the disappearance of the beneficial effects of the study to the inability of many of the socially deprived families to sustain developmentally enriched environments after the end of the study. In their work, Mallik and Spiker have repeatedly underlined the importance of social and socio-economic factors in later outcomes.

Implications for the Development of Policy

The determinants of outcome for infants at developmental risk as a result of perinatal and neonatal illness are complex. In addition to neonatal illness variables, populations of families with premature children are of lower socio-economic status than their term-born peers and are developmentally more at risk for that reason. In outcome data analyses, socio-economic status is repeatedly as good or better a predictor of long-term outcomes as most of the conventional neonatal illness variables.

Premature infants give their caregivers behavioural cues that are faint and much more difficult to interpret than cues given by term-born infants. The premature infant and mother are therefore particularly at risk of failing to establish a functional dyadic relationship, which forms the basis for social and developmental learning that follows.⁶ The NIDCAP process alone is likely to foster more functional mother-infant dyadic interaction in the families of high-risk premature children and foster better mother-child interactions, more consistent parenting patterns and less need for infant mental-health services. Randomized controlled studies to evaluate these effects are

difficult but not impossible. In my opinion, this is an area where NIDCAP may likely prove to be cost- effective.

The immature brain is subject to permanent injury and subtle chemical and structural modification by early adverse experiences during neonatal care and early childhood. These are potential precursors of later cognitive, motor, behavioural and psychosocial difficulties. The efficacy of NIDCAP on reducing the effects of pain and stress may also have beneficial effects on the developing brain that will become evident as better behavioural, social and emotional and perhaps cognitive development in later childhood. This has not yet been adequately studied, nor has NIDCAP been compared to other interventions targeted at reducing the effects of pain and stress. Westrup's suggestion for wider adoption of NIDCAP so that it can be better evaluated would provide an opportunity to study such issues.

Neonatal application of the NIDCAP approach, or something similar, does not negate the need to provide infant developmental support for high-risk infants and their families after discharge. The effects are likely to be additive and perhaps quantitatively more important in later health and wellness of NICU graduates than ongoing advances in neonatal intensive care. It is extremely difficult in this area to carry out research that is easily translated from the population studied to a different community setting. As a result, the literature is substantial and confusing. It is difficult to understand which studies might meaningfully relate to a community for which policy is being developed. Of the many studies, the Avon Premature Infant Project⁷ is particularly worthy of review.

As emphasized by Mallik and Spiker, it is unlikely that any single intervention would developmentally “inoculate” a child permanently. If we are truly striving to promote social and developmental success in our high-risk children in addition to providing intensive care, there needs to be a commitment to a developmentally sensitive continuum of support from birth through adolescence.

References

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