ENCYCLOPEDIA
on Early Childhood
Development

Programs and Services Supporting Infants Born Prematurely: Comments on Als, Westrup, and Mallik and Spiker

Jeffrey Roth, PhD, Steven B. Morse, MD, MPH

College of Medicine, University of Florida, USA

October 2007, 2e éd.

Introduction

An array of technologies that came into routine use over the past 15 years has significantly increased the survival of infants born prematurely. The advent of high frequency ventilation and new pharmaceutical agents (surfactant and antenatal steroids) has resulted in lowering the threshold of viability.[1] Premature infants face many dangers, including seizures, infection and stroke, during their long stay in neonatal intensive care. Any of these adverse events, even if arrested promptly, has the capacity to profoundly impair a child's subsequent physical and mental development. Therefore, concurrently with the proliferation of neonatal intensive care units (NICUs), developmental programs for preterm infants have also evolved, their aim being to reduce, as far as possible, unavoidable complications of prolonged exposure to medical treatment.

©2007-2025 ABILIO | PREMATURITY

These programs are also designed to reconfigure interactional patterns that, if left unaltered, would hinder the child's optimal development. Two of the most thoroughly researched family-centred interventions on behalf of preterm infants are the Newborn Individualized Developmental Care and Assessment Program (NIDCAP), which starts at birth and ends at hospital discharge, and the Infant Health and Development Program (IHDP), which begins at hospital discharge and ends at the child's third birthday. In their papers, Heidelise Als, developer of NIDCAP, summarizes 20 years of research on the program; Björn Westrup, Co-director of the Scandinavian NIDCAP Centre in Stockholm evaluates the quality of the research on NIDCAP; and Donna Spiker, co-editor of a book on IHDP, along with Sangeeta Mallik, review studies on three waves of IHDP outcomes, at three, five and eight years of age.

Research and Conclusions

Als developed NIDCAP in part as a response to the growing presence of machine-based therapy in 1980s nurseries that was beginning to save extremely premature infants who previously had been consigned to "do-not-resuscitate" status. She continues to view the highly instrumented environment of NICUs, with their constant automated monitoring and calibrated delivery of therapeutic agents, as a source of stress for infants whose "experiencing daily pain and discomfort leads to neurotoxic brain-altering events." There is no question that certain medical treatments unavoidably cause discomfort, but without blood draws, catheters and ventilation, these highly vulnerable, immature infants would have little chance of surviving. Given the trade-off between survival and stress, Als' major contribution has been to assemble care-providers into a team (including parents) that, through rigorous training emphasizing formal observation, makes adjustments to the care environment to minimize an infant's avoidance responses and maximize approach responses. Components of this individualized care approach, although not spelled out in the review, include sound and light attenuation, flexed positioning, clustering of care to promote rest, non-nutritive sucking and skin-to-skin contact. Because the NIDCAP system of interaction is proprietary, it is difficult to determine the extent to which "individualized developmental care" is different from the standard of care offered at non-NIDCAP NICUs. It is indisputable, however, that Als' program has brought the interactional, as opposed to task-oriented, approach to the attention of neonatal intensive- care practitioners, to the extent that a majority of NICUs now claim to provide developmental, family-centred care.

Westrup provides a little more information about the NIDCAP training program: "caregivers learn to be careful observers and note the infant's reactions to different types of handling and care.

©2007-2025 ABILIO | PREMATURITY

Based on these observations, caregivers can make appropriate adjustments continuously." Like the term "family-centred" applied to NICUs, this description would apply equally well to most nurse training programs. An important contribution that Westrup does make in his review is acknowledging that most published studies on NIDCAP have had "small numbers," and "relatively short follow-up periods." To remedy this situation, the author calls for "larger randomized multi-centre trials." However, both Westrup and Als express doubts about the feasibility of achieving such an experimental design: Despite their methodological reservations, a three-site randomized trial (N=234) was undertaken and demonstrated fewer days of parental feedings, shorter transition to full enteral feedings, higher average weight gain, greater growth, shorter lengths of stay, younger age at discharge to home and lower hospital charges in favour of experimental infants.[2] All these outcomes, however, represent repeated measures at different time points of the same latent variable, infant health. Another recently published randomized controlled trial found no statistically significant differences between NIDCAP and a control group in IQ, disability or mental retardation at 66 months.[3] There continues to be no evidence that NIDCAP has a positive effect on school age outcomes for preterm infants.[4]

The IHDP used a large multi-centre randomized trial (eight-site, N =985) to test the efficacy of its intervention on low birth weight infants. The treatment group received: a) home visits (weekly during infants' first year; biweekly in the second and third years), b) child development centres for 20 hours a week, 50 weeks a year from 12 months to 36 months; and c) parent support group meetings every other month from 12 months to 36 months.[5] Both treatment and comparison groups received pediatric follow-up consisting of medical and developmental assessments and referral to services if needed. The pattern of self-reported results in the treatment group suggests the presence of a Hawthorne effect[6]: The parents who participated in support group meetings and who also received home visits would be considerably less likely to report behavioural problems in their children because they had received training intended to reduce childhood behavioural problems, unlike control group parents. Another example of possible contamination of study findings due to treatment and control groups' differential exposure to an outcome of interest is the treatment group's significant increase in "maternally reported minor morbidity." Some parent group meetings were likely devoted to noticing signs and symptoms of childhood illnesses. Therefore, the higher incidence of illness reports in the treatment group may have been a function of their induced awareness to an outcome of interest.

Implications for Implementation

©2007-2025 ABILIO | PREMATURITY

Both NIDCAP and IHDP are internationally recognized model programs that have demonstrated significant short-term beneficial effects. Two issues need to be considered by service planners attracted to these programs' positive results. The first is the exclusion by design of seriously ill infants from both programs' study populations. As the threshold of viability is pushed lower, we can expect to see more "fetal infants," those weighing 400 to 500 grams. Already 5,000 are born each year in the U.S. and about 12% survive.[7] While such infants constitute a very small proportion of all births, their long-term prospects are not at all promising, and as a result these developmental care programs chose not to include them. This raises the question: "Should we follow other countries by setting a birthweight and gestational age below which no intensive care is offered?"[7] Until that question is resolved, service planners need to be aware that the greater the infant's prematurity, the less likely she or he would be eligible for one of these developmental care programs. The second issue facing service planners is determining the cost-effectiveness of such programs. While both IHDP and NIDCAP have reported cost savings associated with improved outcomes, neither has been explicit about the average per-infant cost of their intervention. As a result, many NICUs have attempted to secure the benefits of NIDCAP, for example, by partial implementation of its features.[8-9] Because premature infants are so vulnerable, planners have to be careful about implementing any treatment that demonstrates short-term benefits but yields no long-term benefits. They should continue to expect intervention programs to meet the standards of evidence-based medicine.

References

1. American College of Obstetricians and Gynecologists. ACOG Practice Bulletin: Clinical Management Guidelines for Obstetrician-Gynecologists: Number 38, September 2002. Perinatal care at the threshold of viability. *Obstetrics and Gynecology* 2002;100(3):617-624.
2. Als H, Gilkerson L, Duffy FH, McAnulty GB, Buehler DM, Vandenberg K, Sweet N, Sell E, Parad RB, Ringer SA Butler SC, Blickman JG, Jones KJ. A three-center, randomized, controlled trial of individualized developmental care for very low birth weight preterm infants: medical, neurodevelopmental, parenting, and caregiving effects. *Journal of Developmental and Behavioral Pediatrics* 2003;24(6):399-408.
3. Westrup B, Bohm B, Lagercrantz H, Stjernqvist K. Preschool outcome in children born very prematurely and cared for according to the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). *Acta Paediatrica* 2004;93(4)498-507.
4. Jacobs SE, Sokol J, Ohlsson A. The newborn individualized developmental care and assessment program is not supported by meta-analyses of the data. *Journal of Pediatrics* 2002;140(6):699-706.
5. Berlin LJ, Brooks-Gunn J, McCarton C, McCormick MC. The effectiveness of early intervention: Examining risk factors and pathways to enhanced development. *Preventive Medicine* 1998;27(2):238-245.
6. Draper SW. The Hawthorne effect and other expectancy effects: a note. Available at: http://www.psy.gla.ac.uk/~steve/hawth.html. Accessed July 21, 2004.

©2007-2025 ABILIO | PREMATURITY

7. Lucey JF. Debate needed about neonatal intensive care. *Health Affairs* 2001;20(6):313.

8. Ashbaugh JB, Leick-Rude MK, Kilbrid HW. Developmental care teams in the neonatal intensive care unit: survey on current status. *Journal of Perinatology* 1999;19(1):48-52.

9. Brown LD, Heermann JA. The effect of developmental care on preterm infant outcome. *Applied Nursing Research* 1997;10(4):190-197.

©2007-2025 ABILIO | PREMATURITY