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Development



Prematurity

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Table of content

Synthesis 5

Prematurity and Its Impact on Psychosocial and Emotional Development in Children 10
PHYLLIS ZELKOWITZ, EDD, APRIL 2017

Preterm Delivery and Its Impact on Physical Health and Development in Children 15
MARIE C. MCCORMICK, MD, SCD, MAY 2017

Behavioural and Emotional Functioning in Preterm Infants 20
SAROJ SAIGAL, MD, FRCPC, OCTOBER 2007

The State of Research on Extreme Prematurity and Related Vulnerabilities: Comments on McCormick, Saigal and Zelkowitz 27
RÉJEAN TESSIER, PHD, LINE NADEAU, PHD, OCTOBER 2007

Nutrition and Its Impact on Psychosocial Child Development: Perspective on Preterm Infants 32
NAOMI H. FINK, MSC, PHD, STEPHANIE A. ATKINSON, PHD, DSC (HON), FCAHS, APRIL 2017

Family-Centred Developmentally Supportive Care in Neonatal Intensive Care Units 38
BJÖRN WESTRUP, MD, PHD, OCTOBER 2007

Individualized Developmental Care for Preterm Infants 43
HEIDELISE ALS, PHD, JULY 2017

Effective Early Intervention Programs for Low Birth Weight Premature Infants: Review of the Infant Health and Development Program (IHDP) 51
SANGEETA MALLIK, PHD, DONNA SPIKER, PHD, MARCH 2017

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Programs and Services Supporting Infants Born Prematurely: Comments on Als, Westrup, and Mallik and Spiker 61
JEFFREY ROTH, PHD, STEVEN B. MORSE, MD, MPH, OCTOBER 2007

Family-Centered Developmentally Supportive Care of the High-Risk Infant and Family: Comments on Als, Westrup, and Mallik and Spiker 65
MICHAEL F. WHITFIELD, MD, FRCP(C), OCTOBER 2007

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Synthesis

How important is it?

In 1948, the World Health Assembly recommended that all infants with birthweights of 2500 grams (5 pounds 8 ounces) or less, or a gestational age of less than 37 completed weeks, be considered immature or premature. At greatest risk are infants born at 32 weeks or earlier (as early as 23 weeks of gestational age in some cases), and at weights under 1500 g (in some cases weighing as little as 400 to 500 grams). These very low birthweight (VLBW) infants, make up around 8% of live deliveries in Canada. These infants account for the majority of deaths in infancy.

The preterm birth rate has been increasing over the last 20 years, particularly due to the increasing use of assisted reproductive technologies, which has consequently led to an increasing rate of multiple pregnancies. Nevertheless, infant mortality rate has declined sharply and the survival rate for VLBW infants has risen dramatically since the introduction of neonatal intensive care in the early 1970s. Therefore, there has been increasing concern about the potential developmental problems associated with prematurity.

What do we know?

It has long been established that premature infants are at higher risk of developmental problems. These problems are linked to the fact that biological functions (such as the central nervous system and lungs) were unable to reach complete maturity during pregnancy. Incidentally, after birth, the interaction between this biological immaturity and the physical and social environment of the child plays a crucial role in his or her development.

Biological vulnerability

Generally, the lower the gestational age, the higher the impact on biological functions will be. VLBW infants (born at 32 weeks or earlier and weighing less than 1500 grams) are medically fragile and can suffer from many complications. Early studies focused on neurodevelopmental issues, such as cerebral palsy and cognitive delay. Premature infants are also at increased risk for congenital malformations, hearing and visual deficits, reactive airway disease, growth failure

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and behaviour problems. Among VLBW infants, about 10% will have cerebral palsy and 15% will have an IQ in the mentally deficient range.

Premature children with very low birthweights or significant medical complications show more problems with temperament in infancy and toddlerhood. These infants give their caregivers behavioural cues that are faint and much more difficult to interpret than cues given by term-born infants. They demonstrate less adaptability, rhythmicity, activity, attention and persistence than full-term infants. They also tend to be more intense in their moods, more difficult to soothe, more passive and less socially responsive. At preschool age and in the early school years, increased activity and intensity, and lack of persistence remain. This difficult temperament may lead to delayed or impaired self-regulation. However, these temperamental problems seem to be less present in children born at more than 32 weeks of gestational age.

As well, VLBW children have been found to exhibit a variety of emotional and behavioural problems, such as anxiety disorders, excessive shyness and withdrawal, social problems, poor adaptive skills and especially attention deficit hyperactivity disorder, Almost 30% will have clinically significant behaviour problems, generally related to attention deficit. In fact, these children are at more than twice the risk for developing attention deficit hyperactivity disorder, and 25% to 60% will experience difficulty in school, leading to grade repetition or requiring special education services. However, they do not appear to be at risk for developing conduct disorders.

Interaction between biological and socio-environmental factors

It is uncertain whether morbidity from neonatal complications is entirely attributable to prematurity per se. Most researchers think the consequences of prematurity are due to the interaction between the impact on neurological maturation (i.e. the brain has not had a chance to develop fully) and early parent-child problems (caused, for example, by the strain of caring for a very fragile infant or by difficulty in recognizing certain behavioural signs that are harder to identify in premature infants) that consequently affect the development of the child’s social and cognitive functions. The initial hospitalization of premature infants may result in extended separation from parents, increased anxiety and possible interference with parent-infant attachment. Moreover, children born prematurely often continue to experience physical health problems that may require frequent medical visits and re-hospitalization. This may limit their participation in regular childhood activities, which in turn may affect their development of social

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skills. As well, continuing parental worry that the prematurely born infant is at risk for medical and developmental problems may reflect “vulnerable child syndrome”. This syndrome may be associated with less effective parental behaviour, such as overprotectiveness, maternal separation anxiety and failure to set limits, as well as child behaviour problems, such as social withdrawal, somatic complaints, and aggressive and destructive behaviour.

The impact of adverse environmental conditions such as poverty, maternal depression and family stress on behavioural problems may be greater in premature children. On the other hand, when the mother is more responsive to the child’s cues (which are more difficult to detect in these children), VLBW children do better in terms of intellectual and social competence in early childhood.

Unfortunately, we still do not know enough to accurately anticipate the developmental trajectories of these children. More research in neurology and clinical neuropsychology would give us a better understanding of the impact of prematurity on the evolution of various neurological functions. As well, extended research on associated psycho-social factors seems equally important.

What can be done?

While the best way to decrease developmental and physical morbidity due to prematurity would be to reduce the number of such births, our current understanding of the causes of pre-term delivery is too limited to make this feasible. However, there are a number of promising avenues for mitigating adverse outcomes.

First, whenever possible, pre-term infants should be delivered in a hospital equipped to deal with both mother and infant to ensure high quality health services and reduce the risk of complications. Second, continued attention is needed to support normal physical and psychological development in the intensive care unit, for example by ensuring that the infant is not overexposed to loud noises or intense light. Finally, continued attention is needed to identify appropriate support measures for the family during and after the infant’s stay in the intensive care unit.

Two of the most thoroughly researched family-centred interventions for pre-term infants are the Newborn Individualized Developmental Care and Assessment Program (NIDCAP), which starts at

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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.

The goal of NIDCAP is to prevent unexpected sensory overload and pain, and enhance strengths and competence. The approach focuses on a detailed reading of each individual infant's behavioural cues. Repeated formalized observations of the infant's reaction to different types of stimulus (e.g. caregiving,) are used to help caregivers make appropriate and continuous adjustments. 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.

The program has shown positive effects on indices of infant health, with some studies reporting improved lung function, feeding behaviour and growth, and shorter hospital stays. There have also been reports of positive effects on cognitive and behavioural outcomes, as well as on the brain structure itself, still in development at this early age. Because it helps lower parental stress and enhances parental competence, NIDCAP is also likely to foster more functional mother-infant relationships and better parenting. This may in turn have an impact on the developing brain, enhancing the child's cognitive, motor, behavioural and psychosocial development later in childhood. Randomized control studies on NIDCAP should focus on assessing these outcomes.

Introduction of NIDCAP, however, is not a trivial process and involves investment at all levels of the organization, from physical changes in the neonatal intensive care unit to substantial educational efforts and changes in the practice of care. As well, the complexity of the intervention makes it difficult to achieve an optimal experimental design for evaluation.

The Infant Health and Development Program (IHDP) was a multi-site, randomized clinical trial carried out in the United States in the late 1980s, aimed at reducing developmental problems in premature infants. It sought to enhance parenting resources for families and the development status of infants by providing pediatric, educational and family support services (e.g. home visiting, educational programs, support groups for parents). By teaching appropriate developmental stimulation and interactional skills, the goal of the program was to maximize positive social interactions between the child and his or her care-giving environment within the first three years of life.

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At age three, when the intervention ended, results showed that the IHDP was effective in improving cognitive and behavioural development, especially for the heavier infants (those weighing between 2001 and 2500 grams at birth) and those at higher socio-economical risk. Fewer behavioural problems, more pro-social and mother-infant interactions, as well as better parenting skills were found. The effects appeared to have attenuated by five and eight years of age, although this may have been because families living in poverty were unable to sustain the enriched environmental supports needed.

It is unlikely that any single intervention would developmentally “inoculate” a child permanently. The combined action and interaction of multiple factors – biological and socio-environmental –need to be taken into account. The research suggests that there needs to be a commitment to a developmentally sensitive continuum of support from birth through adolescence.

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Prematurity and Its Impact on Psychosocial and Emotional Development in Children

Phyllis Zelkowitz, EdD

McGill University, Canada

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Introduction

A premature birth is a birth that occurs before the 37th week of pregnancy. High-risk premature births occur at 32 weeks of gestation or earlier, at weights under 1500 g. Very-low-birthweight (VLBW, <1500 g) infants, who make up about 1% of live deliveries in Canada, may require treatment in Neonatal Intensive Care (NICU) for up to three months.

Subject

While mortality rates for VLBW infants have declined, there has been increasing concern about their long-term morbidity rates. A small proportion (10% to 15%) of VLBW infants are born with severe neurosensory handicaps such as blindness, deafness, or cerebral palsy, and 30-60% go on to show cognitive deficits, learning disabilities and language impairments.[1,2] VLBW children have been found to exhibit a variety of behavioural problems, such as attention deficit disorder, hyperactivity, excessive shyness and withdrawal, and social problems.[3] About 29% of VLBW children and adolescents exhibit at least one mental health problem.[4] In fact, VLBW children are more than twice as likely to develop attention deficit hyperactivity disorder and autism spectrum disorders, compared to children born at full term.

Problems

VLBW infants are medically fragile, and may suffer from many complications, including respiratory distress syndrome, intraventricular haemorrhage (bleeding in the brain), and retinopathy of prematurity (abnormal growth of blood vessels in the eye). They often continue to experience physical health problems that may require frequent medical visits and re-hospitalization in the early years of life. This may limit their participation in regular childhood activities, which may in turn affect their development of social skills. These infants can also be challenging interaction partners for their parents, due to their fragility, irritability, and lack of

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responsiveness to their social environment. Many parents feel emotional distress following the birth of a VLBW infant, and this may affect parenting behaviour. Maternal anxiety, assessed while the infant was hospitalized in the NICU, has been associated with less effective parenting behaviour in early infancy and in toddlerhood.[5] Depressed mothers have been reported to perceive their VLBW preschoolers as less socially competent, and tend to restrict their participation in extracurricular activities such as sports and creative arts.[6]

Research Context

Developmental outcomes in VLBW infants are best understood as an interaction between biological vulnerability and environmental factors, such as socio-economic status and parental attitudes, and behaviour. Preterm infants may be particularly susceptible to environmental influences in that the impact of environmental factors on infant behaviour is often stronger in preterm infants than it is in full-term infants. Therefore, to assess risk for abnormal outcomes in VLBW infants, it is essential to consider both medical and psychosocial risk factors.

There are still many challenges facing researchers studying developmental outcomes in VLBW infants. Indeed, continuing advances in medical technology have brought about the survival of smaller, sicker babies, making it difficult to compare children from different periods of time. Furthermore, studies demonstrating differences between VLBW and normal birthweight children have shed little light on the processes that lead to such discrepancies.

Key Research Questions

We have identified three main strands for further research:

1. The impact of premature birth on the developing brain
2. The identification of risk factors for behaviour problems and psychiatric disorders
3. Early intervention with parents and their VLBW infants.

Recent Research Results

Magnetic resonance imaging studies have shown reduced brain volume in children who were born preterm as compared to children born at full-term;[7] smaller brain volumes were associated with lower cognitive scores and a higher incidence of attention deficit disorder. Not all preterm infants exhibit brain injuries such intraventricular hemorrhage or ventricular enlargement, but those who do are at greater risk for major depressive disorder and attention deficit disorder.[8]

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Severe brain injuries are more often observe among preterm infants who had lower Apgar scores, and complications of prematurity such as patent ductus aeteriosus (a heart problem) and necrotizing enterocolitis (infection and inflammation of the bowel).[9] Maternal responsiveness (which includes awareness of and sensitivity to an infant's cues) is associated with greater social and intellectual competence among VLBW children in early childhood.[10] By contrast, controlling, restrictive parental behaviour is associated with poorer social skills and cognitive development among VLBW children at age 3.[11] Developmental delays may predict a higher frequency of disorganized attachment patterns in preterm/VLBW infants than in full-term infants.[12] The need to consider both biological and environmental factors in the development of VLBW infants is highlighted in a study that showed that the two strongest predictors of emotional and behavioural self-regulation were moderate to severe white matter abnormalities and parental sensitivity.[13] Relationship satisfaction and social support promote parental responsiveness[14] and thus may mediate the relationship between maternal distress and social and emotional problems in VLBW children.[15]

Interventions with premature infants and their parents have ranged from targeting a specific risk factor (such as the need for supplementary sensory stimulation) to offering a comprehensive package of services (including medical follow-up, parent training, and centre-based care for infants).[16] Recent efforts have focused on promoting maternal competence and enhancing the mother–infant relationship. Kangaroo Care, which encourages mother–infant skin-to-skin contact, has been found to increase parental sensitivity and reduce intrusiveness.[17] Therapeutic interventions designed to reduce maternal distress have shown some benefits,[18] but have not been tested in randomized controlled trials.

Conclusions

Because VLBW children are at greater risk than their full-term counterparts for both learning and behavioural difficulties, it is important to investigate how both psychosocial and biological risk factors may affect child outcomes. Sophisticated imaging techniques can be used to learn more about the impact of prematurity on brain development. The lengthy hospital stays required by most VLBW infants and the separation from their parents that ensues can provoke anxiety in parents about their child's health and uncertainty regarding their ability to parent their fragile infant. The development of self-regulation in VLBW infants may be delayed or impaired because they are difficult interaction partners. Their responses to social stimulation and their behavioural signals are different than those seen in full-term infants. Consequently, caregivers may have

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greater difficulty behaving responsively with their VLBW infants. While VLBW infants may be challenging and somewhat unsatisfying interaction partners, sensitive parental behaviour can produce significant benefits.

Implications for Policy and Services

Children born preterm who exhibit cognitive deficits and behaviour problems tax the physical, emotional, and financial resources of their families. Moreover, these children may enter school lacking adequate cognitive and social skills and requiring additional educational and social services. Therefore, in order to plan appropriate interventions for VLBW children, it is necessary to screen early, and specify the determinants of their future social and academic competence. By identifying factors that are associated with poor developmental outcomes (such as parental anxiety or lack of social support) it may be possible to sensitize health and education professionals to circumstances that may facilitate or impede parents' ability to provide sensitive, responsive care to VLBW infants. Preventive interventions that begin in early infancy and that target parental well-being as well as the improvement of parenting skills are likely to be the most useful approaches to ensuring optimal developmental outcomes in the future.

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Preterm Delivery and Its Impact on Physical Health and Development in Children

Marie C. McCormick, MD, ScD

Harvard School of Public Health, USA

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Introduction

Premature birth has become a global priority in reducing the toll of mortality in children under 5.[1] Prematurity is defined as a birth less than 37 completed weeks of gestation; very preterm infants are those born less than 32 weeks. The rate of preterm births is about 12% in the US and 8% in Canada.[2] Prevention of prematurity has proven to be difficult, and decreases in mortality require interventions that improve the survival of these infants.[3] In wealthier countries, the increase in survival among even the smallest and most immature infants has been remarkable, such that almost three-quarters of infants born between 22 and 26 weeks survive to discharge.[4,5]

Subject

Nonetheless, it must be recognized that these infants are born with organs not yet mature enough for extra-uterine life. The infant is maturing in a context that is quite different from the uterus, and may also require intensive therapies of a variety of types to assure survival. Thus, preterm infants are at risk for a variety of health problems, and these problems may place stresses on health, educational, and family resources.[6]

Problems

The potential for preventing preterm delivery appears limited in the near term. Meanwhile, the survival of growing numbers of very premature infants has raised two questions:

1. What is the impact of the increased survival of such infants on child health?
2. Is there potential for decreasing this morbidity with current technology?

Recent Research Results

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Multiple reviews (summarized in reference 6) have documented the 2- to 4-fold risk of many interrelated outcomes of premature and/or low birthweight infants over time. The risk of morbidity is highest among the most premature infants, but even infants close to term may experience some health problems.[7]

Major complications in the neonatal period include chronic lung disease, following respiratory distress, and sepsis. A minority of infants also experience necrotizing enterocolitis, intracranial hemorrhage and cerebral white matter disorder. It has proven difficult to attain third trimester weight gain in the neonatal intensive care units (NICU) so that very preterm infants weigh less than tenth percentile (normal being 50th percentile) of a term infant discharge from hospital, generally close to when the infant should have been born.

In early childhood, documented morbidity reflects some of these neonatal complications. Rates of cerebral palsy range from 6-28%, but children may also experience less severe motor problems with poorer fine motor and coordination. In addition, of those born before 26 weeks, 10% may be blind, 6% deaf, and 13-20% may have IQs <70.

Other health problems affect the respiratory system, with 7% diagnosed with asthma and poorer growth, although the latter is not seen in all studies.

When these children enter school, new developmental challenges reveal other difficulties. Rates of learning disabilities, singly and multiple are higher, with math reasoning being most affected. School success is further compromised in the presence of attention deficit disorder, which is also higher in preterm infants.

The data are beginning to be obtained on preterm infants born in the era of modern intensive care. The severe neurodevelopmental problems persist (e.g., cerebral palsy and blindness). The risk for emotional disorders like depression is unclear. Preterm adolescents seem to be at lower risk for risky behaviours. Although they have poorer lung function, symptomatic asthma does not seem to be a problem. There are some indications that they do experience some evidence of advanced aging with hypertension, metabolic syndrome and earlier hip disease. Despite this list of difficulties, preterm adolescents and adults, while acknowledging their increased health issues, actually rate their health-related quality of life higher than those born at term.

Influences on Morbidity

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In interpreting the data on the health problems in preterm infants, it is important to note that prematurity confers an increased risk not certainty, and many of these health problems are also common in children born at term. Thus, one of the approaches to reducing the risk of morbidity is to identify situations that may increase risk beyond that of being born premature.

Quality of Perinatal and Neonatal Care. It is now very clear that controlling for gestational age and birth weight, outcomes differ among different neonatal intensive care units.[8-10] Moreover, improvements in neonatal intensive care are associated with decreases in morbidity.[4,11]

Quality of the Post-Discharge Environment. An important determinant of health in all children is the home and neighborhood environment.[12] The environment includes the resources that the parents have, financial, educational and emotional, to provide care for a vulnerable infant. It also includes the medical care and other supportive services like early intervention, as well as the school system into which the child will go. Environmental exposures, like lead or pollution, will exacerbate the underlying difficulties that preterm infants experience.

Conclusion

Even with optimal prenatal services, rates in preterm delivery have remained stable or decreased only slightly. Declines in infant mortality reflect the increasing technological sophistication of neonatal intensive care to support these fragile infants. Indeed, the efficacy of neonatal intensive care has permitted reproductive strategies that may result in an indicated preterm delivery to protect the health of the mother and/or infant, and increase the risk of preterm delivery (as may be the case when two or three embryos are implanted in a woman's womb as part of assisted reproductive technology). Thus, it is likely that we will continue to encounter very premature survivors in the foreseeable future. Improving outcomes for these infants should therefore be the focus, where possible.

Implications for Policy and Services

The major public health implication of the higher rates of preterm births is their contribution to infant mortality. Infants born in the extreme stages of prematurity, with the highest morbidity rates, represent a tiny proportion — less than 1% — of births. Therefore, while this high risk of morbidity does not significantly contribute to overall rates of child morbidity, overall rates of cerebral palsy may be more significantly increased.

Clearly, the best way to decrease the incidence of developmental and physical morbidity attributable to prematurity is to reduce the number of such births. However, our current understanding of the factors leading to preterm delivery are apparently of little guidance in developing efficacious interventions. Thus, improvements in childhood outcomes among premature infants will have to be based on the technology that is currently available.

First, such infants should be delivered, whenever possible, in a hospital equipped to deal with both the mother and infant. A substantial body of literature supports the benefits of such a strategy.[13] In addition, the specialists providing this care must engage in quality improvement activities, comparing institutions and seeking to reduce complication rates to the lowest possible level. Thus, perinatal and neonatal services must be organized in such a way as to identify risk early and provide the care needed through referral and transfer.

Second, continued attention is needed in supporting normal physical and psychological development in the intensive care unit. Great strides have been made in reducing the barrage of sound and light on infants' senses that characterized early NICU care using novel technologies.[14]

Finally, after discharge, there should be a robust network of early intervention services to sustain infant and child development, and provide guidance to parents. Substantial evidence has accumulated that such interventions do improve outcomes.[15,16] However, financial and other restrictions create disparities in access to such services.[17]

Finally, we must continue to define the health issues of surviving preterm infants, and understand how they affect these children across the life-span.[18] The interplay of environment and physical vulnerabilities is not well understood, and preventing further problems will require this information to inform more effective interventions.

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Behavioural and Emotional Functioning in Preterm Infants

Saroj Saigal, MD, FRCPC

McMaster University, Canada

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Introduction

It has now been well documented that premature infants are at significant risk for neurodevelopmental disabilities.[1,2] Studies in this area have typically focused on the motor and cognitive sequelae of prematurity, paying less attention to temperament, behaviour, and emotional disturbances. Recent data suggest that premature infants are also vulnerable to abnormalities in behavioural and social development, which may be the precursors of subsequent learning disabilities and psychiatric disorders which occur during mid-childhood.[3,4]

Subject

Recent improvements in neonatal intensive care have led to an increased number of survivors among infants with very low birthweight (VLBW, <1 500 g) and extremely low birthweight (ELBW, <1 000 g).[2] These infants are at greater risk for behavioural and emotional problems. Our review focuses on problems from birth until preschool age, in infants born at less than 34 weeks of gestational age.

Problems

During the 1990s, several studies were conducted regarding behavioural and emotional functions in preterm infants. However, methodological flaws in study designs precluded any firm conclusions regarding these functions. Flaws included the use of clinical rather than population-based samples, a broad range of gestational ages in relation to the birthweights of subjects, small sample size, lack of psychometrically sound assessment tools, lack of controls, and failure to provide information on medical and psychosocial risk factors.[5,6,7]

In addition, research findings could be deemed inconsistent based on the fact that multiple respondents reported on child behaviour from different contexts. The majority of studies related to infant temperament and behaviour have been obtained through maternal ratings. But

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maternal ratings of temperament have been viewed as reflecting the characteristics of the mother, rather than the infant.[6] Several investigators have reported a substantive association between maternal mental health and behaviour in children.[7-10] Maternal reports of behavioural problems and social competence often differ from those of teachers, who tend to relativise children's behaviour in relation to that of their peers.[11] Similarly, there is often discordance between maternal and clinical ratings. Assessment by clinicians may not reflect a child's usual disposition.

Research Context

Infants who are <1 500 g are more likely to experience significant medical complications, such as severe respiratory distress, haemorrhages in the brain, and poorer nutrition, all of which may have long-lasting effects on the central nervous system. These biological effects are compounded by social risk factors, which are more prevalent among families of infants who are born prematurely.[12] Further, premature infants may be hospitalized for prolonged periods, resulting in extended separation from parents, increased anxiety, and possible interference with parent–infant attachment. Therefore, it is not surprising that behavioural and emotional sequelae are more prevalent among preterm infants.

Key Research Questions

Further initiatives regarding premature infants are required in the following areas:

1. Reviews of evidence supporting increased behaviour and social problems among VLBW and ELBW infants during infancy and preschool years.
2. Examinations of how biological and social factors contribute to the development of behavioural problems.

Recent Research Results

Infant Temperament

Infant temperament is a highly relevant factor in development, as early difficulties may predispose preterm children to subsequent behavioural maladjustments,[13] and affect the quality of their relationships with caregivers.[6] Based on standardized parent report measures, preterm infants and children have typically been found to demonstrate less adaptability, rhythmicity, activity, attention, and persistence than do full-term infants.[14-16] Premature infants have also been

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found to be more intense in their moods, more difficult to soothe, more passive, and less socially responsive.[17] As toddlers, preterm infants have been found to be arrhythmic, less persistent and adaptable, and more susceptible to negativity.[18] At preschool and early school ages, some tendencies towards increased activity and intensity, and lack of persistence remain.[18] Literature in the field indicates that premature infants may initially be more challenging to parents. Changes in temperament over time may be influenced by both biological and environmental factors.[16,18]

However, although premature infants as a group are at greater risk for developing problems with temperament, these problems only occur in a minority of infants. Only those studies that have limited their sample to VLBW infants and infants with significant medical complications are associated with differences in temperament. Prematurity per se does not appear to be a risk factor for abnormalities in temperament.

Behavioural Functioning

Although some studies report negligible findings, overall, the literature suggests that premature infants are particularly vulnerable to behavioural adjustments and emotional problems.

Findings have been much more consistent when the prevalence of ADHD is considered. Marlow et al.[19] reported that at 5 to 6 years or age, both parents and teachers found the children to be more overactive and fidgety than controls. In a study by Szatmari et al.,[20] a higher incidence of ADHD was found in parent reports at age 5, but no significant difference was noted in teacher reports. Other studies on VLBW populations have also found a higher frequency of inattention, hyperactivity, or have diagnosed ADHD by school age.[4,21,22] ADHD appears to be more common among premature infants who exhibit neurodevelopment problems[20] and those with lower birthweights and gestational ages.[4] There seems to be some indication that males are at increased risk, and that adverse social conditions may exacerbate these behaviours.[6] Premature children do not appear to be at risk for conduct problems, as long as adverse environmental conditions are controlled.

Emotional Disturbance

Several studies have found a higher level of anxiety, depression, and emotional dysfunction in children born prematurely.[5,22,23] However, other studies failed to find a similar associations.[4,24,25] These contradictory findings may be attributable to wide-ranging gestational ages among

subjects, differences in socio-economic status, and varying parenting characteristics.

Social Competence and Adaptive Functioning

Premature children tend not to initiate social behaviours,[26] show less pleasure in interacting with their mothers, and are less responsive to social interactions.[27] To some extent, problems with social abilities are a function of lower intellectual levels in VLBW infants.[28] When heavier birthweight infants are included, these problems are less obvious. Children born prematurely appear to be at risk for poorly developed adaptive skills, which become more apparent later in life.[29,30,31]

Contribution of Biological and Social Factors

Most studies demonstrate that behavioural problems are associated with adverse environmental conditions, such as lower socio-economic status, maternal depression, and family stress. The impact of these negative factors may be greater in VLBW than in normal birthweight children. A nurturing home environment fosters development of self-regulatory behaviours.[32] Multiple regression analyses indicate that temperament, environment, and the interactions between development and the quality of the home environment predict attention problems in childhood.[33] Temperament and behaviours were related to gestational age and cognition, showing weak correlations with periventricular leukomalacia, intraventricular haemorrhage, and cerebral palsy.[17,33]

Conclusions

As a group, infants and young children born prematurely are described as being more withdrawn, less adaptable, less persistent, and less temperamentally stable in their infancy compared to full-term infants.[34] These characteristics are more prevalent in infants who are VLBW, and those with medical complications. Children born prematurely also have difficulties in global behaviours, particularly with regard to the prevalence of ADHD, but they do not appear to be at risk for developing conduct disorders. Problems with social competence and adaptive functioning are also more common in these infants than in their full-term peers. Again, these characteristics appear to be restricted to infants under a 1 500 g birthweight, those with neurological and intellectual problems, and those living in adverse environmental and social circumstances. Infants with <750 g birthweights are at greatest risk for developing attentional problems.[35] Recent reports suggest that very premature infants born in the 1990s continue to

have behavioural difficulties and attentional problems[36] that persist to school age.[37]

Implications

Given the higher survival rates among preterm infants, the cumulative toll on the health care system related to behavioural and emotional difficulties will likely grow. In designing effective interventions, it is therefore important to understand the relative contribution of underlying biological and social factors. Further investigation is required to determine whether lending support to parents can alter parental behaviours and improve the quality of mother–infant attachments and infant responsivity. Meanwhile, it is important to inform parents of ELBW infants of the increased likelihood of behavioural problems, so that they are better prepared to cope and seek appropriate remediation. To this end, health care professionals should focus on early diagnosis and treatment.

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The State of Research on Extreme Prematurity and Related Vulnerabilities: Comments on McCormick, Saigal and Zelkowitz

Réjean Tessier, PhD, Line Nadeau, PhD

École de psychologie, Université Laval, Canada, Institut de Réadaptation en Déficience Physique de Québec, Canada

October 2007, 2e éd.

Introduction

For more than 50 years, science has faced the challenging problem of prematurity and its impacts on the health and development of children. The gradual rise in prematurity rates in Canada and the United States (7.1% and 7.6% respectively at the present time) is forcing clinicians, researchers and policy-makers to work together to determine what actions should be given priority in this area. In addition to providing a realistic assessment of the obstacles involved in studying this particular population, the articles by McCormick, Saigal[a] and Zelkowitz[b] summarize the current state of knowledge and point to possible avenues for research on prematurity. The authors express convergent views and concerns with respect to three main points: (1) the consequences of the rising survival rate among children whose gestational age and birth weight are at the limit of viability; (2) the factors associated with short-term and long-term developmental problems; and (3) the implementation of effective intervention programs for children and their families. We will review and comment on each of these points in the light of the most recent research.

Research and Conclusions

1. Impact of the rising survival rate of extremely premature children

McCormick raises the issue of the rising survival rate among extremely premature children and the deficiencies that extreme prematurity may cause. This is a concern in both ethical and scientific terms, and as McCormick points out, a sensitive matter inasmuch as affected children may be stigmatized despite the absence of scientific evidence associating extreme prematurity with specific deficits. While there has indeed been a decline in perinatal mortality, this is the

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result of aggressive, targeted and balanced medical interventions that have led to an increase in the gross rate of survival among premature children. The progress stops there, however, and today we do not know enough to be able to accurately anticipate the developmental trajectory of these children. Statistical probabilities are the only reassurance we can offer worried parents. The main challenge for research at this point is to estimate the precise effects of perinatal complications on brain functions and on the development of the brain, which is subject to a range of premature stimulations for which it is not prepared by its genetic program of maturation. Research in neurology and clinical neuropsychology that would give us a better understanding of the impact of extreme prematurity on the evolution of various neurological functions needs to become a major priority.

We also know that "less extreme" prematurity is associated with cognitive development problems or behavioural problems and that several hypotheses point to the neurological deficits acquired at the end of the extra-uterine gestation period. We would therefore suggest that a comprehensive picture of the impact of prematurity on development cannot be formed by focusing exclusively on these extreme populations; it also requires, following the example of Amiel-Tison et al.,[1] that we study the "macropremies" (1,500-2,500 grams) who make up 5% to 7% of the neonatal population and 20% to 40% of children who present adjustment problems at school age.

2. *Factors associated with short-term and long-term developmental problems*

In most of the recently published studies, prematurity is associated with short-term and long-term developmental problems. But the very diversity of these problems and their inconsistency from study to study have led researchers to take a cautious approach, avoiding drawing a direct association between prematurity and specific developmental problems. The dominant conceptual framework suggests that the observed deficits are due to biomedical and environmental factors associated with prematurity rather than to prematurity itself. But the findings remain ambiguous because of the low predictive value (less than 10% of the variance is explained by these factors) and because the controlled variables are not consistent from one study to the next. The most recent methodologies seek instead to identify mechanisms whereby the medical and neurological determinants at birth are associated with problems of psychological and social development.[2] The most widely shared hypothesis is that the consequences of prematurity are indirect and are mediated by the cumulative effects over time of immaturity acquired at birth.[2,3,4] These deficits

would become measurable in the child's maturation after a period of latency, the length of which remains to be defined, and would result in subsequent problems of social and academic adjustment. The mediating mechanisms that have been investigated relate primarily to the child's social development (parent-child relationships) and to cognitive and neurological maturation. Two mechanisms have been proposed to explain these indirect effects: (a) prematurity affects neurological maturation and modifies the development of cognitive processes during childhood, thereby increasing the risk of adjustment problems when the child reaches school age; and (b) prematurity induces early (parent-child) problems that affect the development of cognitive and social functions during childhood, thus increasing the risk of social adjustment problems at school age. It is further posited that these two biomedically or psychologically-based processes are influenced by the environment, which is seen as having an additive effect: the quality of the child's environment combines with prematurity to increase or decrease the risk.[5,6]

3. *Implementation of intervention programs*

For Zelkowitz and McCormick, the identification of biomedical and social factors should make it possible to develop early intervention programs designed to improve cognitive capabilities and lower the incidence of behavioural problems. To that end, they propose an experimental rather than an observational approach,[7] in the sense that they advocate more random clinical trials and monitoring of premature populations in order to assess the long-term effectiveness of medical techniques or psychological interventions on the stability of the children and changes in their development. Along the same lines, recent neuro-developmental interventions that modify the intensive-care environment have produced positive effects,[8,9] clearly showing that a properly adjusted extra-uterine environment can indeed be conducive to the normal development of the cortex.[10]

Implications for Policies and Services

The central point of the recommendations made by all three authors relates to the disclosure of risks associated with premature birth to parents. Parents (the whole population, in fact) need to be told about the risk of neuromotor morbidity, the most serious cases of which are diagnosed by the age of two. But they must also be told about the risk of morbidity in the long term as far as their child's behaviour, academic performance and functional capabilities are concerned. We also feel that people in the schools, and particularly the professionals who evaluate these children,

need to be made aware of the potential problems they face. However, any such disclosure must necessarily be based on scientific evidence; hence, research should be considered a priority as a means of continuing the fight against prematurity and evaluating the associated risks.

A better understanding of prematurity and its short-term and long-term effects will enable parents, clinicians, researchers and policy-makers to arrive at a position on the following question: Are we ready, as a society, to provide long-term services to children who are being born more and more prematurely? Rehabilitation departments are facing ever-longer waiting lists, and extremely premature children have needs that are increasingly difficult to meet. Any policy on extremely premature children should be based on the realization that survival at birth is not the end-point but the beginning of a long journey for these children, and that we have a moral obligation to invest the resources required to help them grow.

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Notes:

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[a] Comments on original paper published by Saroj Saigal in 2004. To have access to this article, contact us at cedje-ceecd@umontreal.ca.

[b] Comments on original paper published by Phyllis Zelkowitz in 2004. To have access to this article, contact us at cedje-ceecd@umontreal.ca.

Nutrition and Its Impact on Psychosocial Child Development: Perspective on Preterm Infants

Naomi H. Fink, MSc, PhD, Stephanie A. Atkinson, PhD, DSc (Hon), FCAHS

McMaster University, Canada

April 2017, Éd. rév.

Introduction

Early nutrition, both the amount and the quality of nutrients, is increasingly recognized as having a major influence on the growth and development of preterm infants. Importantly, inadequate early nutrition may profoundly impact preterm infants' neurodevelopment causing impairments in educational and cognitive competency throughout childhood and young adulthood.[1,2] This paper will highlight new research that links specific aspects of nutrition in early life with benefits for early growth and brain function in preterm infants.

Subject

While breastfeeding is associated with optimal neurodevelopment and mother's own milk is universally recommended for preterm infants,[3-5] mothers may elect not to breastfeed or their milk supply is insufficient to meet the baby's needs. If mother's milk is not available, preterm infants are usually fed with commercial formula designed to meet their nutritional needs. However, donor human milk is now being advocated as a substitute for infant formula for in-hospital feeding,[4,6] potentially providing another source of the special components of human milk that are associated with benefits to neurodevelopment.

Problems

Research has consistently found that preterm infants who are fed their mother's milk early in life have greater visual acuity, language skills and developmental outcomes (up to 24 months of age) than do a comparable group of infants fed cow milk-based infant formula or even donor human milk.[3,4,7,8] Further research is necessary to define the specific nutrient(s) and/or socio-environmental factors related to feeding practices that may explain the observed developmental advantages associated with feeding mother's milk.

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Research Context

Due to ethical constraints, there are no randomized controlled trials (RCT) comparing the neurodevelopmental outcomes in preterm infants fed mother's milk versus formula or mixed feeding. However, reviews of prospective and retrospective data are consistent with an overall beneficial effect of mother's milk on brain development and cognitive functioning into childhood compared to infant formula.[4,9] Since required processing of donor milk renders it different to mother's milk, a separate assessment of the effect of donor milk compared to mother's milk on neurodevelopmental outcomes is needed.

Over the past two decades, research has focused on long-chain polyunsaturated fatty acids (LCPUFA), particularly docosahexaenoic acid (DHA) and arachidonic acid (AA), as the factors in mother's milk responsible for neurodevelopmental benefits. DHA and AA play a key role in the structure and function of retinal (eye) and neural (brain) tissues. Preterm birth disrupts the most significant accretion of DHA and AA that occurs during the second and third trimester. Thus, preterm infants must receive these fatty acids in their diet after birth due to insufficient endogenous synthesis.[10] Studies on the effect of LCPUFA on neurodevelopmental outcomes have had inconsistent results due to many variations in study design. Despite current standard practice in many countries that infant formula products contain DHA and AA, cognitive, language and motor advantages still appear to be greater in infants fed mother's milk compared to formula supplemented with LCPUFA.

Key Research Questions

The key research question is whether feeding preterm infants their mother's own milk benefits neurobehavioural development, which in turn, affects intellectual programming and social behaviour; and if so, by what mechanism (nutrients and/or feeding behaviour). If nutrients unique to human milk are found to confer neurobehavioural benefits, then the sequential research question is which (if any) of these factors are inactivated or destroyed during the processing (heating, freezing, thawing) of donor milk. Accordingly, it must be determined whether components labile to processing can be added back to donor milk or infant formula in amounts that will support the same developmental benefits as in fresh mother's own milk.

Recent Research Results

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Mother's milk: The observed positive benefits of breastfeeding compared to formula feeding on short-term visual and developmental outcomes are summarized in several reviews.[4,7,9,11] Persistent beneficial effects of mother's milk during the early postnatal period on cognitive functioning are apparent for preterm infants up to 18,[8] 24[3] and 30 months of age.[12] A dose-response effect for mother's milk has been described in preterm infants, where each 10 mL/kg/day increase in mother's milk results in a 0.59 point increase in the Mental Developmental Index (MDI), a 0.56 point increase in the Psychomotor Developmental Index and the total behaviour percentile score increased by 0.99 points.[12] However, sometimes it is difficult to compare findings across studies due to differences between studies in partial and exclusive breastfeeding, use of fortified and unfortified human milk, differences in the type of cognitive assessments and the age at which they were conducted.

Donor milk: Fresh mother's own milk contains many components that may directly or indirectly facilitate the growth and development of the nervous system.[4] Awareness of the benefits of mother's milk has led to the increased use of donor milk. However, recent studies revealed that donor milk does not confer benefits to neurodevelopment compared to formula in preterm infants. In a recent Canadian RCT (n=363), donor milk-fed preterm infants did not achieve higher cognitive composite scores at 18 months' corrected age compared to formula-fed infants.[5] Furthermore, language and motor composite scores were not different between donor milk and formula-fed infants. Pooled data from a Cochrane systematic review of 9 studies (n=1070) also supports the fact that donor milk does not confer any neurodevelopmental advantage over formula.[13]

LCPUFA supplements: Evidence is inconsistent regarding whether LCPUFA supplementation in early life provides a cognitive advantage in infancy and later childhood. On the positive side, preterm infants who received mother's milk supplemented with DHA and AA compared to mother's milk alone from birth to 9 weeks of age had better recognition memory and higher problem-solving scores at 6 months of age.[14] Further, breastfed preterm infants with higher circulating DHA levels at 4 weeks of age had improvements in psychomotor development at 5 years of age.[15] In contrast, in a large multi-centre RCT (n=657) in Australia, the MDI at 18 months corrected age did not differ in infants supplemented with DHA versus those receiving a standard diet.[16] In the same cohort at 7 years of age (n=604), DHA supplementation did not result in any improvements in overall IQ scores.[17] Interestingly, in a subgroup analyses girls in the high-DHA group showed improvements in the MDI scores at 18 months of age[16] but at 7

years of age had poorer parent-reported executive function and behaviour.[17] Thus, LCPUFA supplementation may accelerate the pace of neurodevelopment in preterm infants without offering any significant advantage in overall developmental outcome, as suggested by a recent systematic review and meta-analysis of 11 RCTs and 2272 participants.[18]

Research Gaps

The specific factor(s) in fresh mother's own milk that confers a developmental advantage for preterm infants remains to be identified. If it is not a specific neurotrophic factor in human milk that contributes to improvements in neurodevelopmental outcomes, thought should be given to how the nutrition source (mother's own milk, donor milk, formula) may be influencing other neonatal morbidities[19] (i.e., extended periods of parenteral nutrition, sepsis, necrotising enterocolitis, bronchopulmonary dysplasia, etc.) that could interfere with neurodevelopment.

Conclusions

Studies published to date provide evidence that mother's own milk confers a developmental advantage when compared to infant formula in preterm infants, but it is not likely that LCPUFA are solely responsible for this benefit. It is absolutely essential for brain and retinal development that preterm infants receive target amounts of LCPUFA (comparable to in utero accretion rates), but there is no strong evidence to support dietary supplementation with high levels of LCPUFA to improve cognitive, language or motor functioning.

Given that some studies have reported no difference in neurodevelopmental outcomes between donor milk and formula (with/without LCPUFA), it is possible that the beneficial effects of human milk are specific to mother's own fresh milk. A consensus on whether donor milk confers any neurodevelopmental advantage over formula is needed, and if it can be considered comparable to mother's own milk.

Implications for Policy and Services

Despite lack of supporting evidence, pregnant and breastfeeding mothers are increasingly encouraged to supplement their diet with LCPUFA to optimize brain development in their offspring. Clear guidelines that detail sufficient, but not excessive, intakes need to be established and communicated to mothers. Recent results suggest that high levels of omega-3 LCPUFA in the perinatal period may even have a negative impact on behaviour[17] and respiratory health in

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preterm infants.[20] Other long-term morbidities potentially associated with LCPUFA supplementation may not be apparent yet given that many of the LCPUFA supplementation trials over the past decade have not had lengthy follow-up periods.

Development of infant nutrition products specifically for preterm infants should consider the influence of specific nutrients on neurodevelopment and not just somatic growth. In order to adequately assess the efficacy of the macronutrient balance, micronutrient levels and other neurotrophic ingredients on neurodevelopmental outcomes, tests are needed that are more sensitive to diet-induced alteration in behavioural and cognitive functions, both in early life and at school age.

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Family-Centred Developmentally Supportive Care in Neonatal Intensive Care Units

Björn Westrup, MD, PhD

Karolinska Institute, Astrid Lindgren Children's Hospital, Danderyd Hospital, Sweden

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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.

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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
-

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

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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

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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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Individualized Developmental Care for Preterm Infants

Heidelise Als, PhD

Department of Psychiatry, Harvard Medical School; Neurobehavioral Infant and Child Studies, Children's Hospital Boston, USA

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Introduction

Individualized developmental care in the Newborn Intensive Care Unit (NICU) originated in the 1980s. Based in theory[1] 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

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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

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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 historical[24-28] and nine randomized controlled trials[29-36] 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-conceptional 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 trial[33] 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, 5[26], 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 study[41] documented better auditory processing and speech [Griffith Developmental Scales[42]], fewer behaviour symptoms [Höök-Cedarblad Child Behaviour Interview, in Kleberg,[41]] and better mother-child communication [Parent-Child Early Relational Assessment Scale-ERA[43]]; 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 tract[45] 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

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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.

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Effective Early Intervention Programs for Low Birth Weight Premature Infants: Review of the Infant Health and Development Program (IHDP)

Sangeeta Mallik, PhD, Donna Spiker, PhD

SRI International Early Childhood Program Center for Education and Human Services, USA

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Introduction

Over several decades, survival rates of low birth weight (LBW) infants have markedly increased. Following a downward trend from 2007 to 2014, the U.S. low birthweight rate (the percentage of infants born at less than 2,500 grams or 5 lbs., 8 oz.) rose in 2015 to 8.07%, up from 8.00% in 2014.[1] The percentage of very low birthweight (VLBW) infants (less than 1,500 grams) was stable at 1.39% in 2015. The percentage of infants delivered at moderately low birthweight (1,500-2,499 grams) rose to 6.67% in 2015, from 6.60% in 2014.[1] These trends are important, keeping in mind that low birth weight premature infants are at higher risk than full-term normal birth weight infants for medical and developmental complications that, in turn, can affect the families and infants well into childhood.[2]

A large body of research since the 1970s has documented the short- and long-term health and developmental consequences of low birth weight.[3,4,5,6,7,8] LBW infants exhibit increased rates of neurodevelopmental, health and academic problems. These include developmental delays and behavioural difficulties in the first three to five years of life, with continuing behavioural problems and academic difficulties at later school ages.[5,6] A recent meta-analysis clearly shows that very preterm and/or VLBW children have moderate-to-severe deficits in academic achievement, attention problems, internalizing behavioural problems and poor executive functioning (EF) skills, which are adverse outcomes that were strongly correlated to their immaturity at birth. Furthermore, even during transition to young adulthood these children continue to lag behind term-born peers.[9] All these problems are more pronounced for the lowest birth weight infants. LBW infants are more likely to die within the first 28 days of life and are at substantially higher risk for increased morbidity and rehospitalization than children born at normal birth weights.[8] Not surprisingly, the risk for neonatal mortality and morbidity increases substantially with decreasing birth weight.[10] Furthermore, a significant body of research

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indicates that negative outcomes experienced by many LBW children are worsened by environments characterized by poverty, low educational attainment of caregivers and poor parental stimulation and interactions with the children.[11]

Early intervention (EI) appears to be an important strategy to improve outcomes in this population.[12,13,14] A landmark intervention study with low birth weight infants that was conducted in the 1980s was the Infant Health and Development Program (IHDP). The IHDP was unique in that it was the first multi-site randomized clinical trial designed to evaluate the efficacy of combining early childhood development and family support services with pediatric follow-up in reducing developmental, behavioural and other health problems among low birth weight premature infants.[15]

Subject

The intervention approach for LBW infants in the IHDP was based on two longitudinal studies of successful early interventions with socially disadvantaged normal birth weight infants.[16] The IHDP intervention began at hospital discharge and continued until 36 months of corrected age (CA) (corrected age is based on the age the child would be if the pregnancy had actually gone to term). By providing pediatric, educational and family support services, the IHDP sought to enhance parenting resources for families and the developmental status of infants. The conceptual model of the IHDP was based on maximizing the likelihood of positive caregiver-child transactional experiences hypothesized to support early cognitive and behavioural development of LBW premature children.[16] It was hypothesized that more developmentally appropriate, positive social interactions, guided by knowledgeable professional educators and parents, would promote the cognitive and behavioural development of LBW children. It was also hypothesized that more frequent participation in the multiple intervention modalities would be associated with more positive child outcomes.

Problems

Intervention studies on LBW infants have had mixed outcomes. Some intervention studies have shown improved outcomes for infants born with low birth weight. However, many were conducted at single sites, had small numbers of subjects and assessed short-term benefits.[15] Other single-site, home-based early interventions had only modest effects on the cognitive performance of LBW children, but other similar programs did not detect any measurable

benefits.[16] The strategy used by the IHDP of combining home visits, parent support and a developmental educational curriculum within child development centres was unique in that it built on earlier findings on disadvantaged children and was comprehensive in its approach.[18,19] It was also the first study to use a randomized design to test the applicability of interventions designed for normal birth weight children on LBW premature children.

Research Context

The earliest EI programs for preterm LBW infants were mostly hospital-based intensive care nursery interventions,[20] some of them including home-visiting components in the first year of life.[13] Other programs with home visiting in the first or second year of life have sought to teach parents appropriate developmental stimulation and interactional skills, as well as to provide general social support.[20] Nevertheless, before the IHDP, there had been no large-scale efforts to implement or evaluate the effects of an intensive long-term intervention with preterm infants. It was in this research context that the IHDP was initiated in 1984.

Key Research Questions

Eight medical institutions serving diverse demographic populations in different geographic locations were selected for the IHDP. The primary analysis group on which the IHDP findings were based consisted of 985 low birth weight premature infants (birth weight 2,500 grams or less; gestational age 37 weeks or less) who survived neonatal hospitalization and lived close to the various sites. The program was initiated on discharge from the neonatal nursery and continued until 36 months of age. The research design included claissification by eight sites and two birth weight groups (those infants weighing 2,001 to 2,500 grams, designated as “heavier,” and those 2,000 grams or less, designated as “lighter”). Infants in the intervention and follow-up groups participated in the same pediatric follow-up, which included medical, developmental and social assessments, with referral for pediatric care and other services as needed. The intervention group also received home visits, child attendance at a child development centre and parent group meetings. The key research questions were:

1. Do the intervention and follow-up groups differ in terms of cognitive development?
2. Do the intervention and follow-up groups differ in terms of behavioural competence?
3. Do the intervention and follow-up groups differ in terms of health status?[16]

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Research Results

The IHDP clearly demonstrated that the children who received the intervention experienced, at 36 months: (a) significantly higher IQ scores; (b) significantly lower behaviour problems as reported by the caregivers; and (c) a small but significant increase in maternally reported minor morbidity (defined as the presence or absence of health conditions), with no evidence of an increase in serious health problems. Subject retention was high in both treatment and follow-up groups (93%).[16]

The largest treatment effect was that the intervention group achieved significantly higher cognitive scores relative to the follow-up group at the corrected age (CA) of 36 months. Birth weight had a main effect on the level of IQ scores, with a greater effect on the heavier LBW infants. The heavier intervention infants scored 13.2 IQ points higher than their follow-up counterparts, and the treatment group difference was 6.6 IQ points for the lighter infants. The positive effects on IQ scores were seen at seven of the eight sites.

Compared with the follow-up group, the intervention group experienced a small, significant advantage in behavioural competence, as indicated by lower behaviour problem scores on the Child Behavior Checklist. Treatment group differences were seen largely in reports from the less educated mothers.

Across six health status measures, only the Mother's Report: Morbidity Index had a significant treatment effect. Higher morbidity scores were reported for lighter-born children in the intervention group relative to the follow-up group. Maternal age interacted with this outcome, with younger mothers in the intervention group reporting higher morbidity scores than younger mothers in the follow-up group.

The primary purpose of the IHDP was to study the efficacy of early intervention in reducing developmental, behavioural and other health problems among LBW premature infants. However, the study also provided an opportunity to gather important data about this population for other purposes. These included additional studies about the growth of these infants, neurologic outcomes, children's prosocial behaviour, mother-child interactions and the quality of the home environment. The IHDP growth studies found that even the largest premature LBW infants had not achieved growth patterns of full- term infants by age three. Neuromotor outcomes, examined at 36 months, showed an increasing incidence of neurologic disability associated with decreasing birth weight. In a study of social competence using the Adaptive Social Behavior Inventory

(ASBI),[21] the intervention group scored higher than the follow-up group on prosocial behaviours and had significantly lower scores on the items tapping noncompliant behaviours. Mother-child interactions were examined at 30 months. Small, significant positive effects were found. Intervention dyads were rated as more synchronous and reciprocal in their interactions.[22] Mothers in the intervention group had higher ratings on quality of assistance when helping children with a problem-solving task, and intervention children had higher ratings on persistence and enthusiasm and on an overall child rating of social competence and involvement. Finally, the quality of the home environment to stimulate the child's development was assessed with the Home Observation for Measurement of the Environment (HOME) inventory when the children were one year and three years old. There were no differences at one year, but differences favouring the intervention group were noted on five of the eight HOME subscales at three years. Further analyses revealed that the positive effects of the intervention on the children's development appeared to be mediated to a certain extent by the home environment.[23]

To evaluate the persistence of intervention effects on the child outcomes after the intervention ended at 36 months of age, annual evaluations were made at age five and again at age eight on behavioural, health and cognitive outcome measures. In the cognitive domain, at age five overall, there were no significant differences between the intervention group and the follow-up group. However, further analyses revealed that children in the heavier LBW intervention group (2,001-2,500,g) had higher full-scale IQ scores and higher verbal IQ scores. No such differences were noted in the lighter LBW group. The intervention and follow-up groups were similar in behaviour and health measures irrespective of LBW stratification.[24] At age eight, there were modest intervention-related differences in the cognitive and academic skills of heavier LBW, premature children. However, attenuation of the largely favourable effects seen at three years was observed in both the heavier and lighter LBW groups.[25] It is also interesting to note that children in the IHDP sample with behaviour problems at age 3 continue to show problematic behaviours at age 5 and 8, based on a cohort study that did not compare treatment and control.[26,27]

A prospective follow-up of the Infant Health and Development Program at 8 sites to assess whether improvements in cognitive and behavioural development seen in preschool educational programs persist was conducted when the subjects were 18 years of age.[28] Cognitive and behavioural development of those children (that were 18 years old at the time of this study) who received the intervention over the first 3 years of life (INT) versus those with follow-up only (FU) at 18 months of age was studied. The two birth weight strata were studied: heavier low birth weight (HLBW; 2001-2499 g) and lighter low birth weight (LLBW; < or = 2000 g). Results

showed that after adjusting for cohort attrition, differences favouring the intervention group were seen on the Woodcock-Johnson Tests of Achievement in math (5.1 points), Youth Risk Behavior Surveillance System (YRBSS) (-0.7 points), and the Peabody Picture Vocabulary Test - 3rd edition (PPVT-III) (3.8 points) in the HLBW youth. In the LLBW youth, the Woodcock-Johnson Tests of Achievement in reading was higher in the FU that INT group (4.2). The findings in the HLBW intervention group provide support for preschool education to make long-term changes in a diverse group of children who are at developmental risk.

The persistence of long-term behavioural problems was also reported in a follow-up of the IHDP sample. Using the Youth Risk Behavior Surveillance System (YRBSS) with known patients that were 17-18-year-old that were originally part of the IHDP as young children, adolescent behaviour was explored in this follow up study (that did not include a treatment versus control group comparison). Of the participants studied, a safety plan was activated for almost a third of the participants (i.e., a safety plan is a prioritized written list of coping strategies and resources for use during a behavioural and/or suicidal crisis). Risk behaviours included binge drinking, alcohol/substance use and driving, depression, hopelessness, and suicidal ideation. Findings were consistent with the literature, for example, higher rates of conduct problems were found in males, more suicidal ideation in females, greater sexual risk in African Americans, more substance use in males and whites, and more alcohol use in youth with mothers with higher levels of education.[29]

The IHDP also demonstrated the impact of poverty and socioeconomic status on cognitive functioning during early childhood. Using longitudinal data from the IHDP, family income and poverty status were found to be significant predictors of IQ scores in five-year-olds, even after accounting for maternal education, family structure, ethnicity and other differences between low- and high-income families. Family income and poverty status were more powerful predictors of IQ scores than was maternal education.[30] Furthermore, poverty status at age three predicted children’s IQ at age five, even after controlling for IQ at age three.

Conclusions

The IHDP clearly demonstrated the efficacy of a comprehensive early intervention in reducing the developmental and health problems of LBW premature infants by age three. However, these effects appear to have attenuated by ages 5, 8 and 18. The modest sustained effects seen for the heavier LBW infants argue against the interpretation of no sustained effect of the intervention.[24]

The results at age three showed that cognitive development could be enhanced, behaviour problems could be reduced and no adverse health effects resulted from high-quality group care beginning at 12 months of age. These effects were strongest for the heavier infants and those from socioeconomically disadvantaged families. Additionally, the intervention program led to modest positive effects on mother-child interaction patterns and the quality of the home environment. The IHDP's randomized design, use of multiple sites, a large socioeconomically diverse sample, and excellent retention of subjects in both treatment and follow-up groups make it a landmark early intervention study with trustworthy results. Noteworthy in the results is the fact that those children and families who participated most fully in the intervention were most likely to experience the best outcomes.

The IHDP results support transactional models of early development that recognize the interactions of biological and social-environmental factors to produce child outcomes. For example, research has clearly shown that income is associated with children's cognitive development, achievement and behaviour during the preschool years.[30] By age three, these effects are more pronounced for children who are experiencing deep poverty. In addition, family processes are also a potential pathway through which income affects children. They operate via home environments and parent-child interactions. The quality of caregiver-child interactions, the physical condition of the home and opportunities for learning all account for a significant portion of the effects of family income on cognitive outcomes in young children.[31]

Implications

"It is probably not possible to 'inoculate' a child against all future risk with a single early childhood education intervention;" indeed, at age 8, IHDP children who received more of the intervention had better outcomes.[32] There are multiple co-occurring factors, such as poverty, poor neighbourhoods or poor caregiver-child interactions, that influence children's developmental outcomes and must be considered when evaluating the efficacy of any early intervention program.[30] Many LBW premature babies, including many of those in the IHDP, face such co-occurring risks. It is also important to remember that the IHDP intervention ended when the children were three years old. Many of the participating children were living in poverty, had mothers with low educational attainment and lived in disadvantaged neighbourhoods. The attenuation of the highly positive intervention effects after the comprehensive intervention program ended does not mean that the intervention was not effective. At age three, the results showed that it was *highly* effective, particularly for the heavier infants and those with higher environmental risk. Rather, the attenuation of effects suggests that the enriched environmental

supports and stimulation needed to sustain and nurture the children's continuing development throughout the preschool years and beyond may have been lacking for many of the participating children.

Designing interventions with higher intensity of program participation, as well as longer program duration, may be necessary for many high-risk children because the consistency and intensity of children's participation in early childhood intervention programs may be crucial for sustained effects.[32] Furthermore, those LBW premature infants born into poverty may have families and neighbourhoods that lack the resources necessary to enable them to support these children and enhance their developmental growth early in life and continuously through the early school years.[33] The IHDP has definitively demonstrated how a high-quality, comprehensive early intervention program for LBW premature infants can be implemented and can produce important outcomes in the early years of life, taking these factors into account.

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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

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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. 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

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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. 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

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.

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

Michael F. Whitfield, MD, FRCP(C)

BC Children's Hospital & University of British Columbia, Canada

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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]

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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.

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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 Project[7] 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.

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