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Promoting Development and Integration of Infants Experiencing Neonatal Intensive Care

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With the advent in the early 1960s of neonatal intensive care technology for low birthweight, premature, and other biologically vulnerable and medically fragile infants, there has been an associated professional, parental, and general public interest in the health and developmental outcomes of the survivors of this highly specialized care. Concerns about the short- and long-term neurodevelopmental prognoses for graduates of neonatal intensive care have increased as the accepted medical intervention strategies—such as mechanical ventilation, continuous positive airway pressure (CPAP), parenteral nutrition, central nervous system shunting, and drainage procedures—have become continually more complex and more aggressively utilized.

This growing concern has been accompanied by an increase in both the number of clinicians involved and the number of programs that are implementing specific interventions aimed at optimizing the developmental recovery during the following neonatal hospitalization. Increasingly, these efforts have affected the home environment, where family and community are taking over the support for these survivors of “high-tech” care. This chapter delineates the scope and magnitude of these issues, addresses the most prominent clinical challenges that confront professionals in neonatal developmental care, and critically examines the results of intervention research.

Nature of the Population and Associated Problems

There are approximately 240,000 low birthweight ($\leq 2,500$ g) infants born each year in the United States, constituting 6% to 7% of all births. As a subdivision within this group, approximately 1% to 2% of all births are classified as very low birthweight ($\leq 1,500$ g). The incidence of both low birthweight and very low birthweight in nonwhite populations is more than twice that encountered in the white population. Because the estimated low birthweight incidence has remained discouragingly stable

over the past 20 to 25 years, contemporary reductions in neonatal mortality are steadily increasing the prevalence of biologically vulnerable infants and toddlers in the overall population. Much medical, legal, ethical, and economic debate continues to occur over the effects of neonatal intensive care on the long-term health and neurodevelopmental status of low birthweight survivors. Most investigators are in current agreement that the single clearest outcome of this technically enhanced care has been a dramatic and continuing reduction in neonatal mortality since the early 1960s, particularly for very low birthweight infants since the mid-1970s (Hack, Fanaroff, & Merkatz, 1979; Lee, Paneth, Gartner, Pearlman, & Gruss, 1980; McCormick, 1985). Simply stated, with present standards of practice in the neonatal intensive care unit (NICU), many more very premature, very low birthweight infants are surviving than was the case even 5 to 10 years ago. A 40% survival rate for infants with a birthweight between 500 and 750 g recently has been reported (Hack & Fanaroff, 1986). Figure 7.1 (Bennett, 1987) illustrates this dynamic phenomenon and emphasizes that although survival continues to increase in all low birthweight categories, the greatest impact of neonatal intensive care technology in recent years has clearly been on the smallest, sickest, and most medically fragile infants.

With continued reductions in the neonatal mortality of low birthweight, premature infants, serious concerns persist that this improved survival may be accompanied by an increase in the number of children with permanent health and/or neurodevelopmental impairments. Health complications that frequently result in prolonged and repeated medical care and hospital usage include bronchopulmonary dysplasia (i.e., chronic lung disease, which has an approximately 20% prevalence following severe respiratory distress syndrome); progressive hydrocephalus; necrotizing enterocolitis (i.e., acute bowel disease, which may necessitate intestinal resection); recurrent apnea requiring cardiorespiratory monitoring; and failure to thrive.

The major neurosensory handicapping conditions associated with prematurity are cerebral palsy (particularly the spastic diplegia type); mental or developmental retardation; sensorineural hearing loss; and visual impairment (primarily the consequence of retinal scarring, i.e., retinopathy of prematurity). These handicaps frequently occur together in the same child and are occasionally complicated by a chronic seizure disorder. They are usually clinically apparent by 2 years of age and vary in severity from mild to profound. As a group, their prevalence increases with decreasing birthweight and gestational age; the handicap rate in males consistently exceeds that in females. Table 7.1 (Bennett, 1988) provides current combined prevalence estimates and ranges by birthweight group for these chronic neurosensory impairments. Epidemiological investigations appear to document that reductions in neurodevelopmental morbidity have *not* paralleled or kept pace with reductions

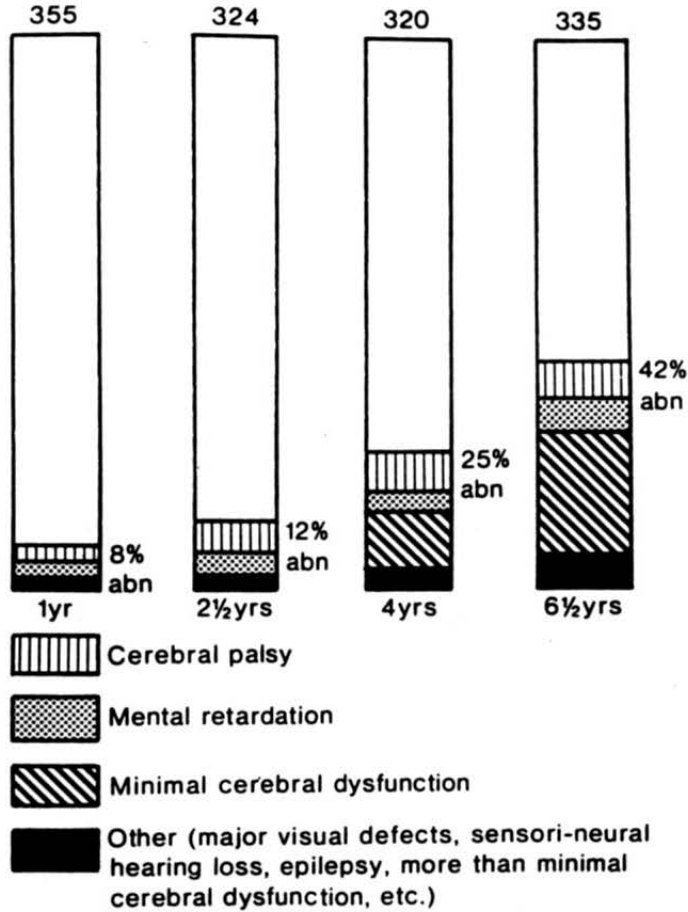


FIGURE 7.1 Comparison of NICU survival for mid-1970s and mid-1980s.

Reprinted, by permission, from Guthrie: Neonatal Intensive Care, Churchill Livingstone, New York, 1988.

in neonatal mortality. In fact, actual increases in both the incidence and prevalence of major handicaps have recently been reported among the smallest and sickest survivors (Hagberg, Hagberg, & Olow, 1984; Paneth, Kiely, Stein, & Susser, 1981).

Although major handicapping sequelae are the easiest for NICUs to quantify and report, numerous long-term follow-up studies clearly indicate that so-called minor neurodevelopmental and neurobehavioral sequelae are at least as prevalent, if not more so, in surviving low birthweight, premature infants. These relatively minor developmental sequelae become increasingly apparent in a variety of clinical manifestations with advancing age during the first 6 years of life (Bennett, 1984). These early, often subtle, developmental and behavioral delays and differences are not necessarily outgrown but frequently portend future

TABLE 7.1 Surviving low birthweight infants with one or more major handicaps. Reprinted, by permission, from Guthrie: *Neonatal Intensive Care*, Churchill Livingstone, New York, 1988.

Birthweight (g)	Major Handicapping Conditions
1,501–2,500	8 (5%–20%)
1,001–1,500	15 (5%–30%)
≤1,000	25 (8%–40%)

school dysfunction and may therefore become major impediments to normal academic and social progress (Blackman, Lindgren, Hein, & Harper, 1987). Collectively, these problems, which typically manifest themselves during the preschool and early school years, have been termed the “new morbidity” of NICU graduates.

Specific types of “minor” developmental sequelae include borderline intelligence (Rubin, Rosenblatt, & Balow, 1973); speech and language disorders (Largo, Molinari, Comenale-Pinto, Weber, & Duc, 1986); persistent neuromotor abnormalities including difficulties with balance and coordination (Nickel, Bennett, & Lamson, 1982); and perceptual problems (Klein, Hack, Gallagher, & Fanaroff, 1985). Specific areas of suboptimal behavioral style and performance include neonatal behavior (Kurtzberg et al., 1979); infant and toddler temperament (Field, 1983); emotional maturity (Malatesta, Grigoryev, Lamb, Albin, & Culver, 1986); social competence (Crnic, Ragozin, Greenberg, Robinson, & Basham, 1983); and selective attention (Dunn, 1986). As with major handicaps, the overall prevalence of these “minor” handicapping conditions increases with decreasing birthweight and gestational age, and is also greater in male survivors. Current prevalence estimates in very low birthweight infants vary between 15% and 25%. Accordingly, when the 15% to 20% prevalence of major handicapping conditions is also considered, between 35% and 45% of very low birthweight survivors demonstrate a residual neurodevelopmental problem that compromises their age-expected function. Dunn et al. (1980), in one of the most extensive longitudinal follow-up studies in this area, reported minimal cerebral dysfunction (i.e., “minor” developmental and behavioral abnormalities) to be the single most prevalent (20%) handicapping syndrome at school age in a population of over 300 low birthweight premature children. Furthermore, the authors stressed the difficulty in adequately predicting or identifying such dysfunctions prior to school entry at age 5. This important group of sequelae is consequently liable to be missed when the outcome of NICU graduates is assessed before that age. Figure 7.2 illustrates this diagnostic evolution and increase in developmental/behavioral problems over time.

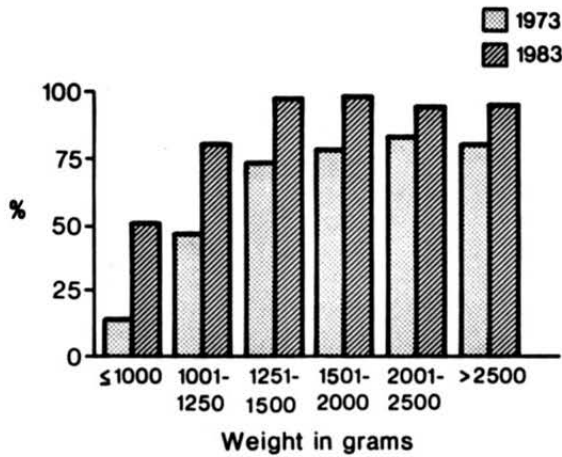


FIGURE 7.2 Evolution of developmental dysfunction in preterm/low birthweight children.

Modified from H.G. Dunn et al., (1980), Neurological, psychological, and educational sequelae of low birthweight. *Brain and Development*, 2, p. 62.

Most of the major and minor neurodevelopmental sequelae associated with prematurity and low birthweight are also related to the severity of perinatal/neonatal illness; that is, low birthweight infants experiencing a prolonged hospital course with many medical complications have an increased likelihood of developing some type of developmental dysfunction. Specific events or observations highly associated with suboptimal outcomes include intrauterine growth retardation, intrauterine or intrapartum infection, severe asphyxia, neonatal meningitis/encephalitis, intracranial hemorrhage, neonatal seizures, and severe chronic lung disease with prolonged mechanical ventilation and oxygen requirements. However, it must be emphasized that despite the large number of positive group associations in follow-up studies, individual neurodevelopmental outcome remains very difficult to predict with accuracy in the NICU. Infants with apparently similar neonatal courses may develop remarkably differently. This repeated observation should be a source of both caution and hope to those making critical neonatal care decisions, to those providing hospital-based developmental and family interventions, and to those conducting follow-up evaluations. Counseling and interventions directed at those infants and toddlers who are also at increased risk environmentally (e.g., due to poverty, low socioeconomic status, a single parent, a teenage mother), that is, so-called doubly vulnerable, and specifically focused toward parent training would seem to demand high priority because of the documented importance of family and psychosocial variables in the ultimate prognosis for low birthweight and other medically fragile infants (Escalona, 1982).

The NICU Environment

The contemporary tertiary-care (Level III) NICU is a unique, lifesaving, intensive-medical-care world experienced by the low birthweight, premature newborn for an average duration of 1 to 3 months, and occasionally longer, depending on the degree of prematurity and the extent of complications. Proper care of the many medical complications of prematurity and other medically fragile conditions requires marked invasiveness and disruption of diurnal sleep/wake patterns through the use of isolettes. The infant may experience continuous bright lights; loud noises; mechanical respirators; indwelling catheters for the administration of fluid and calories and for blood sampling; gastric and intestinal tubes for feeding; prolonged phototherapy with eye patching; multiple needle punctures for blood, urine, and cerebrospinal fluid collections; multiple radiologic and ultrasound procedures; countless different examiners and nurses with repetitive, disruptive handling; and, at best, significantly restricted opportunities for normal parent–infant interaction (Gottfried, Hodgman, & Brown, 1984). Dr. Jerold Lucey (1977), a prominent neonatologist, has painted a stark but quite realistic picture of the NICU resident:

Picture yourself in a brightly lit room, nude, defenseless, and your eyes hurting from silver nitrate. You are blindfolded, chilly, and surrounded by a tepid fog. You are gasping for air, fighting to breathe, and choking and gagging every so often on mucus. You are unable to clear your throat or cough. A mask is placed over your face, and blasts of air are forced into your lungs. Somebody sticks a catheter into your mouth, occasionally too far, causing you to retch or vomit. You are startled and frightened by loud, strange noises (beepers, voices, roaring respirators, telephones, radios, incubator noise). Some giant is pouring food into a tube which has been forced through your nose or throat into your stomach. It is uncomfortable and obstructs your nasal airway. You are probably nauseated; you are certainly not hungry, but you are expected to eat—and soon.

You have a headache, probably the worst one of your life. You are sleep deprived. Every time you doze off, somebody gets worried about you. They think you are in a coma. You have to be very careful to breathe very regularly. You are not allowed the multiple long pauses (15 seconds or more) of a sleeping, dreaming adult. If you do pause, a bell goes off, waking you up, and somebody slaps your feet or pulls your hair to see if you will or can cry. If you are exhausted or unresponsive, you are in trouble. If you have any jerky movements, you are suspected of having a convulsion.

Every few hours somebody cuts your foot or sticks a needle into your scalp or one of your arteries. Your arms and legs are taped down to boards. Electrodes are attached to your chest. You are immobilized. You may even have an itch, but you can't scratch. Cool, rude hands probe your abdomen ever so often, feeling for your liver, kidneys, or bladder. After a few days of this "intensive" care you are exhausted and you may need assistance to continue breathing just because you are too tired to do it on your own. (pp. 1064–1065)

This markedly atypical "life-style" is commonplace for those infants who, because of complex medical and/or surgical needs, require extended or repeated intensive care hospitalizations and, in the severest of cases, may spend the bulk of their first years of life in and out of such settings. Considering these factors, the suggestion that the contemporary treatment of newborns receiving intensive care may be responsible for newly recognized complications, and may contribute to the developmental deficits associated with prematurity and other medically fragile conditions, is certainly not surprising.

A major philosophical debate of the past 15 to 20 years concerning the appropriate developmental interpretation of the NICU environment has markedly influenced the rationale and direction of neonatal and other hospital-based developmental intervention approaches (Meisels, Jones, & Stiefel, 1983). Does this unusual medical setting constitute a source of (a) sensory deprivation, requiring a variety of added stimulations; (b) constant overstimulation, requiring less handling and less intervention of all types, and more time for protected, uninterrupted sleep; or (c) an inappropriate pattern of interactions rather than simply too much or too little stimulation, and including aspects of both deprivation and overstimulation?

Most recent ecologic investigations of the NICU support the third viewpoint (Gottfried & Gaiter, 1984; Gottfried, Wallace-Lande, & Sherman-Brown, 1981). Pertaining strictly to physical stimulations, these careful observational studies indicate that NICU residents are not sensorially deprived, but in fact receive large amounts of ongoing stimulation. Infants monitored in these studies were continuously exposed to cool-white fluorescent lighting with illumination not varying across day and night. Likewise, recording of the acoustic environment revealed continuously high sound levels, higher than in a home or even a busy office. Isolettes provided little to no sheltering from this collection of visual and auditory insults, since recordings of light and sound were virtually identical both outside and inside the incubator. Recent reports suggest possible links between these light and noise excesses and subsequent visual and hearing deficits in NICU graduates (Glass, Avery, & Siva Subramanian, 1985; Long, Lucey, & Philip, 1980). NICU observational studies also indicated that infants have extensive contacts with caregivers. However, almost all contacts were with staff members. In spite of open visiting policies, a minimal percentage of contacts involved family members. The contacts were brief (2 to 5 minutes in duration) and occurred on the average of every 18 to 30 minutes. Virtually all of the contacts involved medical or nursing care with some form of handling.

In contrast to the high magnitude of visual, auditory, and tactile stimulation, these time-motion studies found that NICU residents had infrequent social experiences. Despite the fact that medically fragile infants were in contact with other persons, they seldom received social

types of stimulation. The preponderance of contacts between caregivers and sick infants was nonsocial; if social stimulation occurred, it was embedded within routine nursing care and not initiated independently. In more than half the instances in which infants cried during contacts, caregivers did not attempt to soothe them. Additionally, the integration of social and sensory experiences was not impressively high. Often infants were handled but not talked to, and were positioned in such a way that they could not see caregivers. Quite often, social stimulation was given without regard for the infant's behavioral state. For example, in no more than approximately one half of the situations in which social events occurred did the infants have their eyes open. Surprisingly, even in the intermediate care (i.e., for infants growing and gaining weight, with less acute needs) nurseries assessed, the large majority of contacts were devoid of social events. Social touching of, rocking of, or talking to infants, all of which are felt to be developmentally advantageous, occurred during less than one third of all contacts.

In summary, with respect to social stimulation, it appears that many medically fragile infants may indeed be deprived throughout their course of hospitalization. Despite the constant bombardment by visual, auditory, and tactile physical stimuli that it provides, the NICU is often a startlingly nonsocial environment, especially for the smallest and sickest residents. Unfortunately, there is also frequently little or no organization, rhythmicity, or developmentally appropriate pattern of physical and social stimulation incorporated into the plan of intensive care.

Published Practices of Hospital-Based Neonatal and Postneonatal Developmental Interventions

Early Approaches

The theoretical rationale and models guiding early, hospital-based, developmental intervention programs continue to evolve over time. This ongoing evolution of purpose has dramatically altered the focus and form of current intervention strategies, specific procedures, and supporting organizational structures. Throughout the 1970s, three principal objectives variously influenced the types and emphases of developmental intervention efforts: (a) to attempt to normalize and humanize the disruptive effects of the NICU environment so that it more closely resembled the environment of healthy, full-term infants; (b) to correct for presumed sensory deprivation associated with prolonged NICU care by means of specific stimulations; and (c) to compensate for intrauterine experiences lost as a result of premature birth. The determination of which of these three philosophies was functionally dominant in terms of both clinical practice and research activities at a given NICU was predicated on per-

sonal, local interpretations of the developmental needs of hospitalized, medically fragile infants.

Although a review of published efficacy investigations reveals great interstudy variability in terms of the specific developmental interventions (independent variables) utilized, practically all reporting centers in the 1970s employed early supplemental stimulation, environmental modification, or both in one or more of four major sensory areas (Field, 1980). In fact, the majority of investigations are of multimodal (i.e., combined) sensory manipulations in more than one circumscribed area. They are almost exclusively infant-focused, that is, based on "doing something" of a presumed stimulating nature to sick or recovering NICU residents. Nurses in the NICU have been the principal intervention agents in most reports. Other providers include physical therapists, occupational therapists, early childhood special educators, and infant developmental specialists from a variety of training backgrounds who focus on the specific needs of the recovering neonate.

The four major sensory modalities variously incorporated into NICU developmental intervention programs include (a) visual stimulation (e.g., decoration of the surroundings, mobiles with brightly colored objects); (b) auditory stimulation (e.g., singing, music boxes, recordings of the mother's voice and/or heartbeat), (c) tactile stimulation (e.g., non-nutritive sucking, flexing, massaging, handling, positioning); and (d) vestibular-kinesthetic stimulation (e.g., rocking and the use of oscillating beds, including waterbeds). Countless different combinations of these infant-focused interventions have been described and analyzed (e.g., massaging, handling, and rocking; use of a rocking bed and heartbeat recording; visual decoration and body rubbing; and bright mobiles, massaging, rocking, singing, and music boxes—thus representing all four sensory modalities in this case). As can be appreciated, the number of individual protocols is almost limitless, and intervention programs further vary in terms of their specificity (or lack thereof) within a given sensory area. For example, one program may utilize a variety of vestibular stimulations in differing degrees and sequences, whereas another may have chosen to assess the effects of vestibular stimulation as specifically provided by a motorized hammock or, alternatively, by an oscillating waterbed. Such marked variability between individual intervention programs seriously impairs both the interpretation and generalizability of their outcomes.

As with the specific combinations of sensory stimulations, great variability also exists in the reported onset, frequency, and duration of interventions. The timing of initial developmental intervention varies from immediately after birth, to some relatively arbitrary starting point such as 14 days of age, to the time when the infant is deemed physiologically stable. Likewise, even though most studies have provided an intervention program taking place at least several times daily, some stimulations were given only during feedings, some were prescribed every 15 minutes

regardless of the infant's readiness or state of alertness, and others were contingent on the infant's own activity and responsiveness. In terms of duration, typical intervention endpoints have included term gestational age, attainment of normal birthweight, or nursery discharge. Furthermore, although most developmental interventions with NICU residents have focused exclusively on manipulating the environment during the infant's initial hospitalization, in recent years an increasing number of programs also provide intervention protocols for parents that continue after hospital discharge into the home.

The comparison of efficacy studies involving NICU developmental interventions is further hampered by limited information about subject selection and sample characteristics. Many studies have exclusively involved families of low socioeconomic status with predominantly young, unmarried mothers. Unfortunately, most have also involved relatively healthy NICU residents; infants who may theoretically benefit the most from intervention—such as those of extremely low birthweight ($\leq 1,000$ g) and those experiencing numerous medical complications—are quite underrepresented in most published investigations. Thus, the bulk of experimental evidence in this area has been accumulated from infants who, biologically and medically, are at relatively lower risk (i.e., larger and healthier) but environmentally are at higher risk (i.e., more socioeconomically disadvantaged). Additionally, study differences abound in such basic infant characteristics as birthweight and gestational age means and ranges, types and severity of medical complications, and duration of hospitalization and in such family demographic characteristics as race and socioeconomic status.

NICU intervention investigations have employed a wide variety of dependent outcome measures. These can be grouped into three broad categories: developmental, medical, and parental. The various developmental outcome measures utilized include (a) performance on standardized neurodevelopmental and neurobehavioral evaluations; (b) performance on specific cognitive-sensory tasks (e.g., visual orienting, auditory responsivity, recognition memory); (c) sleep/wake state organization; (d) temperament characteristics such as activity level and irritability; (e) and neuromotor criteria such as muscle tone and volitional movement. The dependent medical variables that are typically assessed are weight gain, head growth, oxygen requirements, frequency of apnea, frequency of vomiting, and length of hospitalization. Parental outcome measures have included the frequency of parental visitation and evaluation of the quality of the parent-infant interaction. In sum, critical appraisal of the NICU developmental intervention studies of the 1970s involves a search for effects within a complex mixture of structural, methodologic, sampling, and outcome variables (Bennett, 1987).

As might be anticipated, the reported results of these early studies are as various as the methodologies employed, and the outcomes reveal great variability in terms of their exact nature, extent, significance, and dura-

tion. One or more positive developmental, medical, and/or parental outcome is reported in almost every scientifically credible infant-focused study published during the 1970s. However, the benefits of one particular intervention protocol are often not replicated in other investigations, and because of frequently contradictory results, only limited generalizations can be made from most of the individual, isolated outcomes. In most of these early stimulation studies, the actual interventions occurred exclusively while the infant was hospitalized in the intensive care or intermediate care nursery and were administered by hospital staff alone without direct parental involvement.

Two major studies, utilizing very similar multimodal stimulations in all four sensory areas, reported conflicting results. Scarr-Salapatek and Williams (1973) found significantly greater weight gain and superior performance in measures of neonatal behavior for experimental group infants who received visual (mobiles, human faces); tactile (handling, patting); vestibular-kinesthetic (rocking); and auditory (talking) interventions. In contrast, Leib, Benfield, and Guidubaldi (1980) reported no significant improvements in the identical outcome measures following the same types of approaches. The two studies did both report significantly higher scores on assessments of mental and motor development during the first year of life for experimental infants. But even this general agreement in findings must be cautiously interpreted because of its short-term nature, and also because of other studies (Brown et al., 1980) showing essentially no infant performance benefits following similar sensory stimulations.

Current Approaches

Because of the continued lack of consensus about the effectiveness of NICU developmental interventions based solely on an infant stimulation model, there was a clear shift in focus and orientation during the 1980s toward more family-centered interventions emphasizing and facilitating interactions between parents and medically fragile infants (Ramey, Bryant, Sparling, & Wasik, 1984). This more recent, parent-focused model attempts both to facilitate the fragile infant's optimal social functioning and to directly train parents to recognize the important stress and stability signals of their sick infant. NICU interventions aimed at improving the parent-infant relationship have taken various forms, usually including a component of infant preparation and readiness for such intimate contact and a component of parent instruction in initiating dialogue and responding appropriately to the fragile infant's communicative overtures. With this contemporary evolution to more parent-focused strategies, parents and other family members are, naturally, increasingly involved in all NICU developmental interventions.

As an additional impetus to avoid a purely stimulation approach, Gorski, Hole, Leonard, and Martin (1983) and others (Long, Philip, & Lucey, 1980) have carefully documented potentially adverse side effects of indiscriminate intervention. The link between repeated, intrusive handling of the physiologically fragile infant and such deleterious complications as hypoxia (i.e., diminished oxygen supply); apnea (i.e., intermittent cessation of breathing); bradycardia (i.e., slow heart rate); and vomiting has been demonstrated. Increasing numbers of detailed investigations into the typical "life" and ecology of the NICU emphasize both the instability of the sick infant's autonomic nervous system and the surprising ease of exacerbating this instability by continual and unpredictable disruptions of quiet sleep. For example, when the fragile infant becomes overloaded with stimuli, he or she may withdraw, become rigid, or demonstrate signs of autonomic nervous system dysfunction. As a result, the infant becomes unavailable to its environment in terms of obtaining information or giving positive feedback, which in turn may cause the parents and other caregivers to feel less competent and effective. Thus, it becomes critical for fragile infants to engage in interactions without experiencing great physiologic, motor, and state regulatory costs.

Armed with this important information, contemporary NICU developmental intervention programs increasingly promote an "infant protection" approach, which minimizes unnecessary handling and times contacts to coincide with infant readiness. Als et al. (1986) have reported very encouraging results based on this type of highly individualized approach in a small group of very low birthweight infants with bronchopulmonary dysplasia (i.e., chronic lung disease). Experimental group infants receiving individualized care had significantly briefer stays on the respirator, improved feeding behavior, better behavioral regulation, and higher mental and motor developmental scores in comparison to control infants receiving standard NICU care. Als et al. taught and trained the incorporation of individualized nursing care plans into the daily routines of the intensive and intermediate care nurseries. The specific components of this "environmental neonatology" model include (a) reduction of excessive environmental stimulations (e.g., light, noise, traffic); (b) a minimal handling protocol; (c) use of facilitative positioning; (d) promotion of self-regulation and state control; (e) timing of daily routines to match autonomic readiness; and (f) parent support and behavioral observation training. As a result of Als et al.'s and others' ongoing efforts in this area, an increasing number of NICUs across the United States are modifying their current practices in light of these new concepts and directions.

The most consistent finding of 1980s studies that were partially or completely parent-focused involved the positive facilitation of parent-infant interactions. Almost all of these studies (Bromwich & Parmelee, 1979; Field, Widmayer, Stringer, & Ignatoff, 1980) reported at least some significant, objective enhancement of the mother-infant relationship,

with only Brown et al. (1980) failing to detect any group differences in interactional quantity or quality. Several of these studies also involved home-based interventions following hospital discharge. Some of the most sustained intervention effects were best demonstrated in those relatively few programs that continued their efforts through the transition process and into the infant's home, with close and considerable parental involvement. Bromwich and Parmelee (1979) provided both free medical and nursing care, including home visitation by nurses and educational intervention by developmental home visitors; Field et al. (1980) provided home visitation by trained interventionists to both educate and support mothers. Brown et al. (1980), discussing their failure with a combined infant- and parent-focused approach to involve socially disadvantaged mothers with their hospitalized infants, enumerated such intervention impediments as mothers' lack of transportation to and from the hospital, need to care for older children at home, inability to leave home because of cultural concerns of their own mothers, and crises of daily living (e.g., inadequate or no housing, lack of financial support). These very realistic observations should serve both to keep individual, limited NICU interventions in perspective and to challenge investigators to develop innovative, comprehensive, coordinated approaches to the complex but essential task of optimizing the developmental and behavioral outcome of low birthweight, premature infants.

Transitions to Posthospital Environments: Family-Focused Intervention

The transition from the highly technological environment of the NICU to home and to the community provokes one of the most stressful moments for families. In addition to the added burden of having a new baby to care for, this stress is increased by those characteristics of children at biologic risk described earlier in this chapter such as sleeping and feeding difficulties, less organization, and general irritability, as well as a continuing need for health care for many infants (see McCormick, Stemmler, Bernbaum, & Farran, 1986; TeKolste & Bennett, 1987). When these factors are combined with the uncertainty that parents feel about the developmental outcome of their child, it is easy to see why the transition to home is so hazardous.

The critical analysis and theoretical framework provided by Sameroff and Chandler (1975), suggesting that the impact of biologic risk factors could be mitigated by sensitive transactions with caregiving environments, have served as important factors for family-focused interventions. Although various refinements of this fundamental principle continue to emerge, research findings support the connection between risk factors and caregiving environments. For example, a long-term follow-up of very

low birthweight children revealed that the degree of neonatal illness was associated with whether or not a normal outcome occurred. However, the severity of an infant's disability itself was associated with parent education and all that that implies about the nature of the caregiving environment (Hunt, Cooper, & Tooley, 1988). In fact, for indigent high-risk newborns cared for in far less than optimal circumstances, the incidence of significant developmental delays is extremely high, affecting as many as one third of the children (Lasky et al., 1987). The results of the latter study do not appear to be linked to the quality of prenatal care, to atypical referral populations, or to race; they continue to suggest that it is the combination of biologic risk and an unfavorable home environment that produces these unusually poor outcomes.

In a very real sense, the problems posed by a child at biologic risk challenge parents' confidence in their ability to care for their child at home and to establish a warm and developmentally supportive relationship, even in environments that appear favorable. As a consequence, the potential exists for mitigating some of the effects of risk factors on developmental outcome through facilitating and supporting certain aspects of the caregiving environment for most families. Moreover, this transition point constitutes the initial experiences that families have with the nonhospital community and its service system. The manner in which professionals interact with families, the quality of their technical skills, their attitudes with regard to the parent-professional relationship, and their encouragement of families to maintain community involvement establishes an important frame of reference for families.

Recent efforts in family-focused preventive interventions for children at biologic risk are characterized by a number of important features (see Guralnick, 1989). These include an effort to provide a supportive parent-professional relationship to enhance the confidence and competence of families in caring for their children and to ensure that families take a productive, active role in all aspects of decision making. How this can be accomplished, what strategies are used, what constitutes the content and framework for preventive intervention efforts, and what the impact is of these programs on parents and children are all issues that will be examined in this section.

Parent-Focused Interventions

It is only relatively recently that developmental models (e.g., Goldberg, 1977) emphasizing ways of improving parental confidence, support, and responsiveness to biologically at-risk infants have been translated into specific intervention programs. The pioneering work by Bromwich (Bromwich & Parmelee, 1979) and Kathryn Barnard and her colleagues (1987) at the University of Washington's Child Development and Mental Retardation Center has provided important models for preventive inter-

vention programs for preterm infants. Barnard's group, in particular, has continued to carefully evaluate a program designed primarily for healthy preterm infants. Much of that work has been incorporated into the current version of Nursing Systems Toward Effective Parenting-Preterm (NSTEP-P) concept and protocol manuals (Johnson-Crowley & Sumner, 1987a, 1987b) and has been extensively field-tested (Barnard et al., 1987). This program is designed explicitly to be sensitive to the unique needs of parents yet to impart the necessary information and skills to assist parents to effectively care for their premature child. The intervention protocol generally calls for one hospital visit plus eight additional home visits over the course of a 6-month period. During these visits, four major content areas—health and related concerns, state modulation, behavioral responsiveness, and parent support and community resources—are covered.

The Mother-Infant Transaction Program (MITP) developed by Rauh (1979), was designed to improve the adaptations of mothers to their at-risk infant by:

(a) Enabling the mother to appreciate her infant's unique behavioral characteristics; (b) sensitizing her to the infant's cues, particularly those that signal stimulus overload, distress, or readiness for interaction; and (c) teaching her to respond appropriately to those cues so as to facilitate mutually satisfying interactions. (Rauh, Achenbach, Nurcombe, Howell, & Teti, 1988, p. 546)

Implemented by a neonatal intensive care nurse, the program encompasses a total of 11 one-hour sessions—7 prior to hospital discharge and 4 in the home. All sessions are to be completed before 90 days post discharge (Rauh et al., 1988). The MITP begins with a demonstration of the Brazelton Neonatal Assessment Scale (1973), a strategy that encourages an exploration of parents' perceptions of their infant, their fears, anxieties, and the levels of support provided by family members. The following session is designed to improve parents' knowledge and sensitivity to their infant's innate reflex systems, including respiration, skin circulation, extremity movement, facial movement, and visceral activity. Indications of well-organized and excited states for these five areas as well as techniques that will minimize overly excited states and promote organization are presented. The mother's role in fostering organization is emphasized in a subsequent session focusing on the motor system (posture, tone, and movement). Again, efforts are made to alert mothers to indications of the infant's level of organization, to reduce stress, and to foster organized behavior. Sessions 4 and 5 are devoted to indicators of the infant's state and the varying degrees of the infant's responsiveness in each state. In addition, how infants self-regulate and how mothers can match their interactions to promote well-organized levels and alertness are also part of this session. In Session 6, mothers are shown how they can integrate knowledge of their children's abilities into

caretaking activities of changing, feeding, bathing, and waking. Suggestions to minimize problems for easily stressed infants are provided to mothers for each caretaking area. The final in-hospital session reviews the prior activities and is designed to further prepare the mother to appropriately initiate interactions following discharge. Synchronizing mothers' interactions to support their infant's organization is the central focus.

The four sessions in the home are designed to continue to foster competent parenting in the new environment, "being careful to support [the mother's] sense of control and self-confidence" (Rauh, 1979, p. 14). Additional strategies to enhance mutual play through visual, auditory, and tactile modalities are discussed, including imitation, the use of bright objects for focusing and following, and soothing through rhythmic touching.

In the final two sessions, the concept of infant temperament is introduced. Mothers are assisted in identifying the behavioral patterns of their child and in improving the fit between their interactions and their child's style. Continued emphasis is placed on the mother's initiative in solving problems related to this fit and understanding that difficult temperaments are not caused by parents themselves. The final session consists of a review and provides an opportunity for feedback.

A similar approach, focusing primarily on severely handicapped medically fragile children, is being carried out at the University of Washington's Child Development and Mental Retardation Center. Referred to as the Transactional Family Systems Model (TFSM), a team consisting of a pediatric/perinatal nurse clinician, a pediatric physical or occupational therapist, and an infant educator provides services on a weekly basis to families upon discharge from the neonatal intensive care unit until the child receives regular services from a developmental center. As was the case for the MITP, the emphasis of the TFSM is on improving parental competence and confidence and on promoting satisfying and enjoyable parent-child interactions. This is accomplished in the following five ways:

1. Educating parents in the significance of four types of communication available to the infant (i.e., autonomic or automatic, motoric, state organizational, and attentive/interactional or social).
2. Assisting parents to define and read behavioral cues (i.e., approach, stress, and self-regulatory behaviors) through observation and guided interpretation of their infant's behavior.
3. Training parents to assess, predict, elicit, and respond in an appropriate contingent manner.
4. Assisting parents through guided practice and encouragement to independently change their interactional style to more naturally mesh with that of their developing baby.
5. Encouraging parents to highlight each small developmental step and to see how each incremental step fits into the larger developmental picture. (modified from Hedlund, 1987)

Outcomes of Intervention

Accordingly, the programs described above, as well as others such as the Social Interaction Assessment and Intervention (McCollum, 1984) and the Transactional Model of Early Home Intervention (Barrera, Rosenbaum, & Cunningham, 1986), have a number of common elements. These include (a) their parent-focused nature; (b) interventions designed to build parents' confidence and competence; (c) an emphasis on the infant's self-regulation; and (d) efforts to improve parents' sensitivity to their child's cues to communicate, to promote satisfying "dialogues," and to encourage a match between parent and child interactional styles. In recent years a number of well-designed studies have evaluated the effects of many of these parent-focused interventions and have sought to determine some of the factors that may mediate any changes that might have occurred. A comprehensive review is beyond the scope of this chapter. However, a summary of findings from a few recent studies, particularly those that attempted to assess how parents may have mediated any changes, should provide a fair representation of outcome patterns.

The MITP curriculum has actually been carefully evaluated (Rauh et al., 1988) and did include a number of parent-related measures. In this study, a well-defined cohort of low birthweight infants (less than 2,250 g and a gestational age of under 37 weeks) was randomly assigned to a group receiving the MITP curriculum or to a group receiving conventional care. A full-term control group was also available for comparison.

An additional important feature of this study was the fact that the evaluation of impact of this 11-hour preventive intervention program, ending 3 months after the child went home, was evaluated over a 4-year period. Remarkably, the low birthweight group receiving the MITP curriculum scored nearly 13 points higher on the McCarthy Scales of Children's Abilities at 4 years of age than the low birthweight control group. In fact, whereas the treatment and full-term children were not distinguishable from one another in terms of cognitive development by age 4, the low birthweight control group followed the more typical developmental pattern of declining performance over time.

In order to examine possible mediating factors, measures of parent self-confidence in relationship to competent parenting and satisfaction with the mothering role were assessed at 6 months. The outcomes of these scales revealed that, in fact, treatment group mothers considered themselves more self-confident and were more satisfied with their role as parents than control group mothers. These findings are consistent with the contention that it is this confidence in their ability to parent their developmentally at-risk children fostered by the MITP that may have been responsible for the long-term effects.

Similar, although more short-term, results by Resnick, Armstrong, and Carter (1988) also supported the finding that substantial differences in cognitive development occur as a result of preventive intervention efforts.

The intervention activities were both parent-centered and infant-centered (e.g., stimulation and exercise). However, perhaps most important for this discussion is the fact that a variety of measures of parent-child interaction revealed that a close association existed between growth in cognitive development and positive parent-child interactions. Moreover, although it is not possible to separate out the child-focused from the parent-focused components of this study, research by Barrera et al. (1986) suggested the greater value of parent-infant intervention programs.

Individualizing

This pattern of outcomes is certainly consistent with the developmental framework described earlier; that is, the centrality of fostering parent-child relationships and ensuring that parents become confident in their abilities to solve the numerous developmental and relationship problems that are likely to arise. Despite the overall encouraging patterns, considerable variability in outcome has been found. There are many factors, such as initial level of stress or disorganization of the home, available resources, and perhaps severity of child's actual or potential disability, that can moderate the efforts of these general intervention programs. In fact, more recently, Affleck, Tennen, Rowe, Roscher, and Walker (1989) demonstrated how the effects of a hospital-to-home transition program varied in relation to parents' perceived need for support. For parents with a need for high levels of support, the program had positive effects on perceptions of personal control, sense of competence, and responsiveness to their infant. However, for those parents with a perceived need for support below the average level, the program had a negative impact on some of the variables.

Possible explanations for the negative findings include the alternative that in some cases, intervention may be overly intrusive to parents and may actually form a threat to their self-confidence (Affleck et al., 1989). Other parents could question the implication that an optimistic child outcome is unlikely without intervention and implementation of those preventive intervention programs. The major principles, framework, and methods appear sound and results are highly encouraging. However, the identification of those nonprogram factors that must be considered, how they are assessed, and how they modify our interventions are essential problems for future research.

Summary

The dramatic growth and success of neonatal intensive care technologies during the past 25 years have resulted in the survival of ever smaller and sicker infants. These "new survivors" frequently share a wide variety of health and developmental vulnerabilities. In an attempt to prevent

or ameliorate these documented morbidities, a heterogeneous array of developmental interventions has been suggested, implemented, and evaluated. These approaches range from early, infant-focused nursery stimulations to long-term family education and support services. They increasingly utilize an interdisciplinary mix of child-care professionals with diverse training and experience. They increasingly involve parents as the necessary principal agents of eventual outcome and successful community integration. The accumulated clinical research in this rapidly expanding area has already taught us much about the nature and intensity of those interventions most likely to be effective for this unique population.

However, there remains much yet to be learned. We need more precise means of assessing biologic/neurologic risk. Physicians, nurses, therapists, and educators need to unite their focus in the next decade on identifying appropriate "brain care" guidelines for infants experiencing neonatal intensive care or other prolonged hospitalizations. All developmental intervention plans for biologically fragile infants must now take into consideration the frequently coexisting environmental problems of poverty, substance abuse, single parenthood, unemployment, and/or homelessness. These contemporary multiple vulnerabilities must be recognized and addressed as part of the coordinated service provisions described in Public Law 99-457. Without this type of comprehensive, realistic approach, more narrow interventions are unlikely to effectively improve the long-term developmental and behavioral prognosis of low birthweight, premature, and other medically fragile infants.

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