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NEURODEVELOPMENTAL IMPAIRMENT: PREDICTORS OF ITS IMPACT ON THE FAMILIES OF EXTREMELY LOW BIRTH WEIGHT INFANTS AT 18 MONTHS

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Abstract

Effects on a family of a child with chronic illness have been described. The Impact on Family Scale (IOF) was developed to measure these effects. The impact of extremely low birth weight (ELBW) infants with neurodevelopmental impairment on families is unknown. This study determined IOF scores for families of ELBW infants with increasing degree of impairment at 18 months and identified factors that increase vulnerability to impact. A total of 3,849 ELBW infant survivors born at the 16 centers of the National Institute of Child Health and Human Development Neonatal Research Network between January 1993 and February 2001 were assessed at 18 to 22 months. Infants were divided into four groups by degree of impairment. IOF scores were analyzed by impairment group. Multivariate analyses assessed effects of impairment, social/demographic factors, unmet service needs, and resource utilization on the IOF. A total of 1,624 (42.2%) infants had moderate/severe impairment. Increasing severity of impairment was associated with higher IOF scores. Severity of impairment contributed 6% of variance to the IOF scores. Twenty-one percent of variance was contributed by additional medical needs, low socioeconomic status (SES), and lack of social support. Although increasing severity of impairment impacts families of ELBW infants, significantly more impact is contributed by additional medical needs, low SES, and lack of social support.

The effects on the family of a child with a chronic illness or disability have been described. Emotional impact is seen as a response to initial diagnosis or as a result of the burden that the long-term care of a child with a chronic condition places on families. The more dependent the child on the caregiver, the more emotional impact that caregiver experiences (Breslau, Staruch, & Mortimer, 1982; Jessop, Riessman, & Stein, 1988; Ong, Afifah, Sofiah, & Lye, 1998). This emotional impact can manifest as depression, anxiety, guilt, isolation, or marital conflicts (Hawke, 1967; Sabbeth, 1984). Caring for a chronically ill or disabled child also has a practical impact on the financial, occupational, social, and recreational aspects of family life as well as on family functioning (Breslau et al., 1982; Stein & Jessop, 2003). The costs of caring for a child with chronic illness or disability are manifested both monetarily and in the form of an increased time commitment due to the child's dependence on others. Increased health care

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needs in the form of hospitalizations, frequent visits to healthcare providers, and utilization of special equipment and services add to the financial burden on the family as well as detract from time spent on work, social life, recreation, and interaction with other family members (McCormick, Stemmler, Bernbaum, & Farran, 1986).

The last 20 years have seen a well-documented improvement in the survival of extremely low birth weight (ELBW) infants ($\leq 1,000$ g) (Blaymore-Bier, Pezzulo, Kim, Garcia-Coll, & Vohr, 1994; Hack, Friedman, & Fanaroff, 1996). After discharge from the Neonatal Intensive Care Unit (NICU), ELBW infants remain at increased risk for medical complications (Hack et al., 1991) and have increased utilization of medical services such as rehospitalizations, visits to specialty clinics, and outpatient therapies (Cronin, Shapiro, Casiro, & Cheang, 1995; Leijon, Finnstrom, Sydsjo, & Wadsby, 2003). This results in a 10-fold increase in post-NICU healthcare costs (McCormick, Bernbaum, Eisenberg, Kustra, & Finnegan, 1991). This financial burden may be magnified in families with fewer financial and social resources.

ELBW infants also are at increased risk for both functional and neurodevelopmental impairment (NDI) (Emsley, Wardle, Simes, Chiswick, & D'Souza, 1998; Hack et al., 1996; Lorenz, Wooliever, Jetton, & Paneth, 1998; Vohr et al, 2000; Wilson-Costello, Friedman, Minich, Fanaroff, & Hack, 2005). In fact, one consequence of the increase in survival of these tiny infants has been an increase in the total number of survivors with impairment (Emsley et al., 1998; Wilson-Costello et al., 2005). This has resulted in both concern and debate regarding the management of these infants in the delivery room and in the NICU. While most ELBW infants with motor impairments from cerebral palsy associated with prematurity achieve functional independence, degree of independence is associated with severity of motor impairment and with the presence of cognitive impairment (Msall et al., 1993; Wong et al., 2004).

The goal of this study was to determine the impact of degree and number of NDIs on families of ELBW infants at 18 to 22 months corrected age. In addition, we sought to identify factors that make families more vulnerable to the burden of caring for an impaired child. Finally, we explored the type of NDI with the greatest impact on families. We hypothesized that families of ELBW infants with a higher degree or number of impairments would have higher Impact on Family (IOF; Stein & Reissman, 1980) Scale scores than would families of ELBW infants with a lower degree or number of impairments or without impairment at 18 months, and that families with lower socioeconomic status (SES) and less social support would experience a higher level of impact than would families of higher SES or families with more social support. In addition, because cognitive impairment is associated with functional dependence, we hypothesized that infants with cognitive impairment would have a higher impact than would infants with other types of impairment.

METHODS

Participants

We performed a retrospective analysis of data from a multicenter cohort of ELBW infants (401–1,000 g) born at the 16 tertiary care centers comprising the National Institute of Child Health and Human Development (NICHD) Neonatal Research Network. All ELBW infants admitted to the 16 centers within 14 days of birth, seen in follow-up at 18 to 22 months corrected age, and whose mothers completed the IOF Scale were included. Between January 1993 and February 2001, there were 12,021 births at the 16 centers, with birth weights $\leq 1,000$ g; 7,574 (63%) survived to 18 to 22 months. Families of 6,200 children (82% of survivors) were seen for an 18-month follow-up visit; 38% were excluded because the IOF Scale was not completed and/or information on NDI was not available. The final study cohort consisted of 3,849 infants. We compared demographics of the final study cohort ($N=3,849$) with children in the sample

who survived to discharge, but were not in our final study cohort. Those in the final study cohort had lower gestational ages (26.2 vs. 26.4, $p=.0160$) and lower birth weights (790.2 vs. 798.4, $p=.0082$) and included fewer males (52 vs. 55%, $p=.0231$) than those who were lost to follow-up. There was no significant difference between the two groups in incidence of multiple births (22 vs. 20%, $p=.1838$). Each center's participation was approved by their respective institutional review boards. Research coordinators prospectively collected demographic and outcome data as previously described (Vohr et al., 2000).

Variables

Neonatal variables included gestational age, singleton versus multiple birth, and presence of neonatal morbidities including bronchopulmonary dysplasia (BPD), defined as oxygen requirement at 36 weeks corrected gestational age; Grades 3–4 intraventricular hemorrhage (IVH) by Papile's grading system (Papile, Burstein, Burstein, & Koffler, 1978); or periventricular leukomalacia (PVL) on cranial ultrasound at 4 to 6 weeks of age.

The children's primary caretakers were interviewed to obtain medical, social, and demographic histories. Medical histories were verified by chart review. Social and demographic history included maternal age, education, insurance (private/Medicaid), employment status, and the number of young siblings (<3 years) living in the home. Presence of NDI in siblings was not collected.

Level of function and medical needs were collected, including need for a gastrostomy tube for feeds, ability to ambulate, and oxygen or ventilator dependence at 18 months. The number of rehospitalizations after discharge from the NICU also was recorded.

Assessments

The 18- to 22-month physical assessment consisted of a developmental evaluation and a comprehensive neurologic examination (Amiel-Tison, 1987). Developmental evaluation was performed using the Bayley Scales of Infant Development II (Bayley, 1993), which were administered by testers trained to reliability and certified annually by gold-standard NICHD Neonatal Research Network examiners after demonstration of accurate performance and scoring of the Bayley Scales on an 18- to 22-month-old child (Vohr et al., 2000). A Mental Development Index (MDI) and a Psychomotor Development Index (PDI) were derived for each child. MDI and PDI scores have a mean of 100 with an *SD* of 15 points in a normal population. Scores less than 70 (>2 *SDs* below the mean) are low, and scores less than 50 are extremely low. Neurologic examinations were performed by certified examiners trained to reliability in an annual certification meeting by reviewing videos of neurologic assessments and establishing reliability. The exam included an assessment of tone, strength, reflexes, angles, and posture.

Data from the developmental and neurologic examinations were used to classify children into four categories based on level of impairment: normal, mild impairment, moderate impairment, and severe impairment. Normal was defined as no cerebral palsy (CP), MDI and PDI ≥ 85 (within 1 *SD* of the mean), and no vision or hearing impairment. To assess the impact of increasing severity of impairment on the family, we modified the standard network definition of NDI as follows. Mild impairment was defined as an MDI and/or a PDI of 70 to 84 (between 1 and 2 *SDs* below the mean), with or without mild CP. Moderate impairment was defined using the standard network definition of NDI (presence of one or more of the following: moderate to severe CP, MDI or PDI >2 *SDs* below the mean (<70), bilateral blindness, and/or hearing impairment requiring amplification), with one exception: Those infants with the lowest MDI and/or PDI were excluded from the moderate impairment group and placed in a fourth group—severe impairment—defined as an NDI with an MDI and/or a PDI <50 .

CP was defined as abnormalities in the classical neuromotor exam and/or aberrations in primitive reflexes and postural reactions accompanied by a delay in motor milestones or function. CP was defined as moderate if it resulted in impairment in motor function that interfered with age-appropriate gross motor activities (i.e., no ambulation or ambulation only with assisted device), and severe if it resulted in significant impairment in motor function that interfered with all age-appropriate motor activities (i.e., no ambulation, no sitting, and no supported sitting).

Parents were asked if their child had received any services since discharge, including a visiting nurse, early intervention (EI), any additional physical therapy, occupational therapy, or speech therapy not included in EI, social work, specialty medical clinic, or additional neurodevelopmental evaluation. In addition, they were asked if their child needed one of these services. If they answered “no” to receiving a service and “yes” to needing it, this was considered an unmet service need. Parents were not asked whether unmet needs were due to denied or unrequested services.

The adequacy of a family's social support was assessed using the Family Resource Scale (FRS; Dunst & Leet, 1987). The FRS was designed to determine the adequacy of resources/support in families with young children. It covers resources such as food, shelter, transportation, financial resources, and healthcare. It also contains four items related to social support (time to be with spouse or partner, time to be with close friends, someone to talk to, and time to socialize). The scale was administered as an interview. Parents responded on a 5-point Likert scale ranging from 0 (*Not at all adequate*) to 5 (*Almost always adequate*).

The IOF Scale

The child's impact on the family was measured by the IOF Scale. The IOF Scale was developed in 1980 by Stein and Reissman as a formal scale to objectively measure the impact of a child's illness or disability on a family. It was designed to assess “any change in the normative behavior of the family which is directly attributable to the child's illness ...” p. 466. The 1985 PACTS study by Stein and Jessop analyzed its use in over 100 chronic and severe pediatric conditions to establish construct validity and ensure the generalizability of this scale. A modified version of the scale, the Impact on Families Scale Revised (IOF-R), was later created, in which items are worded for use with families of children with and without chronic conditions (Stein & Jessop, 2003). This revised scale has better psychometric properties and greater generalizability to a more inclusive sample than has the original scale. It has demonstrated high internal consistency ($\alpha=0.89$) and strong construct validity. Total IOF scores on the revised scale correlate highly with IOF scores on the original scale (correlation coefficient=0.97).

The IOF Scale assesses four dimensions of impact: financial burden, disruption of planning, family burden, and caretaker burden, and contains 14 items that comprise the total score. An additional six-item Impact on Sibling subscale and a four-item Coping subscale are administered, but not used, in the calculation of the total score. The Sibling subscale assesses perceived impact on other children in the home, and the Coping subscale was designed to assess coping strategies used by families to overcome the stress of the child's condition.

The IOF was administered as an interview and took approximately 10 to 15 min to complete. Parents responded to each item on a Likert scale, scored from 1 (*strongly disagree*) to 4 (*strongly agree*) in order of least to greatest impact. Higher scores indicate a higher degree of impact, with possible total scores ranging from 14 to 56. Example items for each of the six subscales are: (1) Financial Burden: “Additional income is needed in order to cover my child's expenses,” (2) Disruption of Planning: “Sometimes we have to change plans about going out at the last minute because of the children,” (3) Family Burden: “Our family gives up things because of my child,” (4) Caretaker Burden: “It is hard to find a reliable person to take care of

my child,” (5) Sibling: “The school grades of my other children suffer because of this child,” and (6) Coping: “Because of the experiences we've been through we are closer as a family.”

Statistical Analysis

Analyses of variance (ANOVA) or chi-square test were conducted to explore differences across the four groups of infants (normal, mild impairment, moderate impairment, and severe impairment) according to neonatal characteristics, maternal characteristics, level of function, medical needs, unmet needs, FRS scores, mean MDI and PDI scores, and IOF scores at 18 months corrected age. If the ANOVA comparing the four groups was significant at $p < .05$, we then conducted post hoc pairwise comparisons using t tests to identify which of the impairment levels differed from each other. To account for possible Type 1 error rate inflation due to multiple post hoc comparisons, we used a Bonferroni correction for the pairwise comparisons. Therefore, rather than using a p value of .05 to achieve statistical significance, we used an adjusted p value of .008.

Linear regression models were tested to predict effects of degree of impairment (none, mild, moderate, or severe) and number of impairments (0, 1–2, 3+) on IOF scores after controlling for other possible predictors of impact. Each model controlled for neonatal characteristics (gestational age, BPD, Grades 3–4 IVH or PVL, and singleton or multiple birth), maternal characteristics [age, education (>vs.<12 years)], insurance (private vs. Medicaid), employment status, siblings in the home], level of function (gastrostomy tube, ability to ambulate), medical needs (postdischarge hospitalizations, supplemental oxygen or ventilator dependence), number of unmet service needs, and FRS score. FRS scores were entered as low resources (<130) versus high resources (>130) by dividing the cohort at the median score of 130. Birth weight was not included in the model due to its high degree of colinearity with gestational age. Medicaid enrollment was used as a proxy for maternal income because of the high percentage of missing income data in the study cohort.

Stepwise regressions were conducted to explore which type of impairment had the greatest influence on IOF total and subscale scores. The following types of impairment were entered as possible predictors: MDI <70, PDI <70, moderate to severe cerebral palsy, bilateral blindness, or hearing impairment requiring amplification. The criterion for entry and/or retention in the model was a p value <.05.

RESULTS

Characteristics

Of the 3,849 infants in the study cohort, 1,624 (42%) had a moderate or severe impairment. The frequency of each type of impairment is shown in Table 1 as a percentage of the impaired population and a percentage of the total population. Of those with an NDI, 81% had an MDI <70, making this the most common impairment. In addition, 1,077 infants (28%) had a mild impairment.

As shown in Table 2, mean gestational age decreased and percent of infants with BPD and Grades 3–4 IVH and/or PVL increased significantly with increasing severity of impairment at 18 months corrected age ($p < .0001$). Infants with all degrees of impairment were at significantly greater social and environmental risk than were infants with no impairment. Infants with moderate impairment were most likely to have mothers who had not completed high school, were on Medicaid, were unemployed, and/or had other children less than 3 years of age in the home.

Table 2 also compares the functional status, medical needs, and Bayley scores of infants in the four study groups. With increasing severity of impairment, infants were significantly more

likely to require a gastrostomy tube for feeds and have no functional ambulation, defined as walking 10 or more steps independently. Infants with increasing severity of impairment had significantly more rehospitalizations after discharge from the NICU and were more likely to have continued oxygen or ventilator dependence. By definition, Bayley scores decreased with increasing impairment. The mean Bayley MDI and PDI scores of infants with no impairment were 97 and 98, respectively. Mean Bayley MDI and PDI scores of severely impaired infants were 54 and 51, respectively.

Although parents of all four groups of children reported unmet service needs, parents of children with any degree of impairment were more likely to report unmet needs than were parents of unimpaired children. The most common unmet needs were speech therapy and early intervention.

Families of infants with moderate and severe impairment reported fewer resources and less social support than did families of infants with no impairment (Table 2). Families of infants with mild impairment reported more resources/support.

IOF

Table 3 summarizes the total and subscale IOF scores for each of the four study groups. Mothers reported higher total scores on the IOF Scale with increasing severity of impairment ($p < .0001$). Mean total scores for the four groups were: no impairment (29 ± 6), mild impairment (31 ± 7), moderate impairment (33 ± 7), and severe impairment (34 ± 8). With increasing severity of impairment, mothers reported increasing scores on the Financial Impact, Disruption of Planning, Caretaker Burden, and Family Burden subscales. Families of infants with moderate impairment had the highest Coping and Sibling subscale scores.

Table 4 presents the results of a single regression analysis performed to predict total IOF scores. Each variable was entered simultaneously into the model. The effect of the severity of an infant's impairment on the total IOF score remained significant after controlling for neonatal characteristics, maternal demographic factors, infant functional status and medical needs, unmet service needs, and family resources. This model accounted for 27% of the variance in total IOF scores. Higher IOF scores were most highly associated with lower scores on the FRS. Low FRS scores accounted for 14% of the variance in IOF scores, with a partial R^2 of 0.14 (not shown). Increasing severity of impairment accounted for 6% of the variance in IOF score. Other factors associated with higher IOF scores were multiple births, older maternal age, Medicaid enrollment, unemployment, siblings less than 3 years of age living in the home, gastrostomy tube feeds, inability to ambulate, continued oxygen requirement, and more rehospitalizations after NICU discharge.

While IOF scores increase with severity of impairment on bivariate analysis, this linear relationship no longer exists when neonatal and maternal factors, functional, medical, and resource needs are controlled for. Having a mild impairment increases the IOF score by 0.67 points ($B=0.67, p=.0245$), and having a moderate impairment is associated with a 1.32 point increase in total IOF score ($B=1.32, p<.0001$). But having a severe impairment increases the IOF score by only 1.24 points ($B=1.24, p=.0164$). Having inadequate resources and social supports has much more of an effect, increasing IOF scores by 5.8 points ($B=5.8, p<.0001$).

Regression models also were run to predict IOF subscale scores. Results (not shown) for the Disruption of Planning, Caretaker Burden, and Family Burden subscales were similar to those for total scores, with greater impact reported for children with increasing severity of impairment. Degree of impairment was not a significant predictor of scores on the Financial or Sibling scales, after controlling for the other variables in the model. In all of these models, low FRS score remained the largest contributor to IOF scores.

In the model run to predict the Coping scale score (not shown), only 5% of the variance in IOF score was accounted for, with severe impairment and FRS score each accounting for only 1% of the variance. Coping scores were most highly associated with lower maternal education (<12th grade), which accounted for 2% of the variance in this score.

Similar regression models, run to assess the impact of the number of impairments on the family, indicated that impact increased with an increasing number of impairments. These models (not shown) controlled for the same variables listed in Table 4. Twenty-seven percent of the total IOF score was explained by this model ($R^2=0.275$). Number of impairments accounted for 5% of the variance. The presence of one to two impairments increases total IOF scores by almost 1 point ($B=0.92, p=.0005$), and the presence of three or more impairments increases IOF scores by more than 2 points ($B=2.38, p<.0001$). An increase from one to two impairments to three or more impairments also was significant ($B=1.46, p=.0077$). Similar results were found for the Disruption of Planning and Family Burden subscales.

Exploratory stepwise regression analyses run to predict the types of impairment associated with the highest IOF score are summarized in Table 5. MDI <70, PDI <70, moderate/severe CP, blindness, and deafness were included as possible predictors in each model. Among these five impairments, three met criterion for entry into the model for total IOF scores ($p<.05$): MDI <70, PDI <70, and CP. The variables were entered into the model in the sequence shown. Cumulatively, these three impairments contributed 4.5% of the variance in IOF score. MDI <70 had the largest single contribution of 3.6%. In the stepwise regression models run to explore the impact of the type of impairment on IOF subscale scores, MDI <70 was again retained in all of the models and was most predictive of all subscale scores.

DISCUSSION

This study confirms that ELBW infants are at high risk of functional limitations and NDI at 18 months corrected age. Forty-two percent of these infants have moderate or severe impairment, one third have a low MDI, one fourth have a low PDI, and 9% have moderate or severe CP. An additional 28% have mild impairment. Increasing severity of NDI correlates with increasing rates of functional limitations. These limitations result in an increased dependence on others to perform basic self-care. The burden for providing this care falls on the families of these infants, and the impact of this burden can be significant.

This study also confirms that ELBW infants are at high risk of medical complications that result in increased medical needs. The more impaired infants have more needs, with significantly more requiring a gastrostomy tube, oxygen, assistance with ambulation, and rehospitalization after discharge. The result is higher costs and a larger time commitment associated with caring for these infants.

Yet, many infants were not receiving all of the services their families felt they needed. Although unmet needs were identified in all four study groups, they were greater in the impaired infants. Unmet needs for EI ranged from 5% in the no impairment group to 19% in the moderate impairment group. Unmet needs for speech therapy ranged from 11% in the no impairment group to 30% in the moderate impairment group. The reason for these unmet needs is not known. Although some states refer all ELBW infants to EI, other states have more rigid referral criteria. This may account for some of the unmet needs seen in this multisite population. It is not known whether these needs were unmet because they had been denied or because they had not yet been requested.

The families of infants with all degrees of impairment had lower levels of education and higher rates of Medicaid enrollment and unemployment than did families of unimpaired infants, resulting in less financial resources available to care for their infants. They also reported less

resources and social support on the FRS, resulting in less assistance in caring for their medically complex child.

To date, three studies have addressed the question of the impact of an ELBW infant on the family; however, unlike our study, they did not evaluate the impact of severity or the number or type of impairment. Drotar et al. (2006) compared 219 ELBW infants with 176 normal birth weight controls assessed at 8 years of age. They found that impact was greater in the ELBW group, and as in our study, NDI, SES, and functional need predicted the impact on families. Saigal, Burrows, Stoskopf, Rosenbaum, and Streiner (2000) assessed the impact of 12- and 16-year-old former ELBW infants with a variety of impairments on their families and found higher rates of emotional stress reported by parents of teens with impairments than did those without impairments. Taylor, Klein, Minich, and Hack (2001) reported higher IOF scores in families of school-aged children born at <750 g. Unlike our findings, Taylor et al. reported higher scores in families who were sociodemographically advantaged.

Several studies have attempted to assess the impact of impairment in very low birth weight (VLBW) infants (defined as $\leq 1,500$ or $\leq 1,750$ g) on the family; however, each defined impairment differently, and none assessed the impact of NDI. Moreover, these studies show conflicting results. Rivers, Caron, and Hack (1987) reported higher stress levels, more limitations in activities, and more unexpected life changes in 22 parents of 4-year-old neurologically abnormal VLBW infants compared to those without neurologic sequelae. McCormick, Stemmler, Bernbaum, and Farran (1986) found higher IOF scores in 132 VLBW ($\leq 1,750$ g) infants who were more impaired or required more assistance at 1 to 4 years of age. Impact was related to functional limitation (The strongest predictor was the number of activities of daily living limited by the child's health.), increased medical needs, lower SES, and lower maternal education. Cronin et al. (1995) reported higher IOF scores in 2- to 4-year-old VLBW infants than in full-term matched controls. Higher impact was associated with impairment, low family income, and less parental education. Singer et al. (1999) reported higher IOF scores at the 3-year follow-up in mothers of VLBW ($< 1,500$ g) infants with BPD compared to VLBW infants without BPD; however, they did not address the developmental, neurologic, or cognitive status of these infants.

Several investigators have reported no increased impact of more mature preterm infants. Leijon et al. (2003) assessed family function in 39 preterm infants with a mean gestational age of 31 weeks and mild impairments and in 39 full-term controls at 4 years, and found no differences between the groups. Lee, Penner, and Cox (1991) surveyed 144 families of VLBW infants ($\leq 1,500$ g) between 12 and 71 months and found that families with developmentally delayed VLBW infants perceived no greater impact than did those with term, healthy infants. In addition, families of developmentally normal VLBW infants perceived lower impact than did the other two groups, suggesting that families of VLBW infants developing appropriately have a positive perception of their experience.

Our study supports the concept that parents of impaired ELBW infants perceive a higher impact on their family than do parents of unimpaired ELBW infants at 18 months. In contrast to prior studies, our cohort was 20-fold larger and represented 16 different sites in the United States, thus minimizing bias and making our results more generalizable. Unlike previous studies, we also assessed the direct impact of degree of impairment. In addition, we are the first to suggest that cognitive impairment is the impairment most predictive of impact on the family. This study also looked in depth into other factors that make families more vulnerable to the impact of impairment. Although severe impairment was an important contributor to IOF score in our model, other infant factors, parent factors, and social factors contributed to family impact.

Previous investigators have reported that two additional factors, child behavior (Baker, Blacher, Crnic, & Edelbrock, 2002) and maternal depression (Blacher, Lopez, Shapiro, & Fusco, 1997; Blacher, Neece, & Paczkowski, 2005), may have an impact on parental perception of impact on the family. The NICHD Neonatal Research Network, however, did not collect data on child behavior or maternal mental health during the study period.

Our regression model run to predict the Coping subscale score accounted for a small percentage (5%) of the variance in this score. This supports Lee et al.'s (1991) findings that the added stress of having an ELBW infant with an NDI does not decrease the family's ability to cope with this hardship and suggests that there are many other factors involved in a family's ability to cope with the hardship of having an impaired child. Interestingly, maternal education above Grade 12 was the strongest contributor to the Coping score in this model, implying that higher education may provide mothers with more strategies for coping with the stress of having an ELBW infant, impaired or not.

Several studies have demonstrated that parental social supports influence parental attitudes and can even moderate perceived stress and buffer adverse impact (Crnic & Booth, 1991; Crnic & Greenberg, 1990; Dunst, Trivette, Hamby, & Pollock, 1990). In fact, Lee et al. (1991) found that maternal SES did not influence impact but rather the need for social support correlated with higher IOF scores in their VLBW cohort. Our findings support this concept by demonstrating that parents' social support as measured on the FRS accounted for the most variation in IOF scores in this model.

The version of the IOF scale that was used in this study differs from that used in previously published reports. Use of the 14-item IOF Revised version resulted in total impact scores that are lower than previously published scores, which ranged from 37 to 50 (Blaymore-Bier et al., 1994; Hack et al., 1996; Ireys, & Silver, 1996; Jessop, Riessman, & Stein, 1988; Lee et al., 1991; McCormick, Charney, & Stemmler, 1986; McCormick, Stemmler, & Athreya, 1986; Stein, & Jessop, 1985, 2003). However, since the IOF was developed for use with children with and without chronic conditions, we feel that it is the most appropriate for use in our cohort.

Since this study was designed to assess the impact of degree of impairment within a cohort of ELBW infants, the control group was, by choice, unimpaired ELBW infants. In addition, the NICHD Neonatal Research Network does not collect follow-up data on full-term infants.

Our cohort consisted of 3,849 ELBW survivors from participating institutions, seen in follow-up, and thus may not be representative of the population as a whole. Although our study is representative of a large cross-section of mothers with impaired and unimpaired ELBW infants followed prospectively, our findings may not generalize to impact as perceived by fathers of these infants. Additionally, our results are limited by the reliance on parental report of the perception of family impact rather than on direct observation of family functioning. Finally, the observed lack of significant impact of a child who is blind or deaf, as compared to a child with cognitive or motor impairment, may be due to the small number of blind (3%) and deaf (5%) children in this sample.

SUMMARY AND CLINICAL IMPLICATIONS

A combination of child, family, and social factors contribute to IOF scores. NDI in ELBW infants at 18 months has a significant impact on families. The higher the degree of impairment and the greater the number of impairments, the greater the degree of perceived impact. Cognitive impairment has greater impact on the family than do other types of NDI. Not surprisingly, infants with increased healthcare needs and families with lower SES and fewer social supports are particularly vulnerable. In fact, fewer family resources and social supports have the greatest impact on families.

Our findings suggest that families of ELBW infants, especially mothers of impaired ELBW infants, mothers of infants with increased medical needs, and mothers with lower SES, fewer resources, or fewer social supports, should be offered appropriate support services to assist them in coping with the burden of caring for these infants.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Appendix

APPENDIX

NICHD Neonatal Research Network (1993–2001)

Follow-Up Center	Principal Investigator	Follow-Up Principal Investigator	Network Coordinator	Follow-Up Coordinator
Brown University	William Oh, MD	Betty Vohr, MD	Angelita Hensman, RNC	Lucy Noel, RNC
Case Western Reserve University	Avroy A. Fanaroff, MB, BCh	Dee Wilson, MD	Nancy Newman, RN	Bonnie Siner, RN
Emory University	Barbara J. Stoll, MD	Barbara J. Stoll, MD	Ellen Hale, RNC, BS	Ellen Hale, RNC, BS
Harvard University	Ann R. Stark, MD	Ann R. Stark, MD	Kerri Fournier, RN	
Indiana University	James A. Lemons, MD	Anna Dusick, MD	DeeDee Appel, RN	Leslie Richards, RN
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TABLE 1

Frequency of Moderate and Severe Impairment Among Extremely Low Birth Weight Infants

Type of NDI	<i>n</i>	% of Impaired (<i>n</i> =1,624)	% of total sample (<i>n</i> =3,849)
Moderate/Severe Impairment ^a	1,624	100	42
Bayley MDI <70	1,317	81	34
Bayley MDI <50	353	22	9
Bayley PDI <70	954	59	25
Bayley PDI <50	438	27	11
Cerebral palsy	331	20	9
Blind	52	3	1
Deaf	77	5	2
No. of impairments			
1-2	1,349	83	35
≥3	275	17	7

MDI =Mental Development Index; PDI= Psychomotor Development Index.

^aIn addition, 1,077 infants (28%) had mild impairment.

TABLE 2

Sample Characteristics

Variable	No Impairment (<i>n</i> =1,148)	Mild Impairment (<i>n</i> =1,077)	Moderate NDI (<i>n</i> =1,112)	Severe NDI (<i>n</i> =512)	<i>p</i>
Neonatal Characteristics					
Gestational age (weeks) ^{a-f}	26.6±2.1	26.3±2.0	26.0±2.0	25.7±2.0	<.0001
BPD ^{b-f}	367 (32)	372 (35)	529 (49)	349 (70)	<.0001
IVH 3-4/PVL ^{b-f}	165 (14)	156 (14)	245 (24)	255 (53)	<.0001
Multiple birth	238 (21)	217 (20)	253 (23)	128 (25)	.1029
Maternal/Family Characteristics					
Maternal age (years) ^{a,b}	27.4±7.0	26.5±6.9	26.5±6.9	26.9±6.9	.0047
Education <12th grade ^{a-d}	214 (19)	281 (26)	380 (36)	143 (30)	<.0001
Medicaid ^{a-d,f}	499 (43)	663 (62)	803 (72)	334 (65)	<.0001
Unemployed ^{b-e}	564 (49)	589 (55)	670 (60)	326 (64)	<.0001
Siblings in home ^{b,d}	299 (26)	308 (29)	380 (34)	148 (29)	.0003
Level of Function/Medical Need at 18 months					
G-tube ^{b-f}	10 (1)	20 (2)	56 (5)	104 (20)	<.0001
Does not ambulate ^{b-f}	1 (0)	5 (1)	148 (13)	390 (77)	<.0001
Supplemental oxygen ^{b-f}	9 (1)	19 (2)	55 (5)	77 (15)	<.0001
Ventilator ^{c,e,f}	1 (0)	1 (0)	6 (1)	16 (3)	<.0001
No. of hospitalizations since discharge ^{a-f}	0.8±1.3	1.0±1.7	1.5±2.1	1.9±2.5	<.0001
Neurodevelopmental Status at 18 months					
Bayley MDI ^{a-f}	97±9	81±8	65±10	54±11	<.0001
Bayley PDI ^{a-f}	98±9	86±9	71±14	51±7	<.0001
Unmet Service Needs					
Visiting/home nurse	3 (0)	9 (1)	14 (1)	4 (1)	.0619
OT/PT ^{a-c}	24 (2)	64 (6)	98 (9)	30 (6)	<.0001
Speech therapy ^{a-d}	130 (11)	230 (21)	335 (30)	133 (26)	<.0001
Early intervention ^{a-d,f}	60 (5)	131 (12)	216 (19)	68 (13)	<.0001
Social work ^{a-c}	12 (1)	39 (4)	44 (4)	26 (5)	<.0001
Specialty medical clinic ^b	15 (1)	19 (2)	33 (3)	9 (2)	.0338
Neurodevelopmental evaluation	57 (5)	60 (6)	74 (7)	38 (7)	.1553

Variable	No Impairment (n=1,148)	Mild Impairment (n=1,077)	Moderate NDI (n=1,112)	Severe NDI (n=512)	p
Any unmet service need ^{a-d}	227 (20)	342 (32)	487 (44)	193 (38)	<.0001
Family Resources Scale					
FRS Scores ^{a-e}	131±16	137±19	125±20	124±19	<.0001

M±SD; n (%).

Note. NDI=neurodevelopmental impairment; BPD=bronchopulmonary dysplasia; IVH=intraventricular hemorrhage; PVL=periventricular leukomalacia; MDI=Mental Development Index; PDI=Psychomotor Development Index; OT/PT=occupational therapy/physical therapy. Post hoc pairwise comparisons were conducted only when the overall test was significant at $p<.05$. To adjust for multiple comparisons, a p of .008 was required for the pairwise comparisons to maintain an effective Type I error rate of .05.

^aNo vs. Mild ($p<.008$).

^bNo vs. Moderate ($p<.008$).

^cNo vs. Severe ($p<.008$).

^dMild vs. Moderate ($p<.008$).

^eMild vs. Severe ($p<.008$).

^fModerate vs. Severe ($p<.008$).

TABLE 3
Means (and SDs) of Impact on Family Scale Scores by Severity of Impairment

Impact on Family Scale	No Impairment (<i>n</i> =1,148)	Mild Impairment (<i>n</i> =1,077)	Moderate NDI (<i>n</i> =1,112)	Severe NDI (<i>n</i> =512)	<i>p</i>
Total Impact ^{a-f}	29.4±6	30.9±7	32.5±7	34.3±8	<.0001
Financial Impact ^{a-f}	4.5±1	4.6±1	4.8±1	5.1±1	<.0001
Disruption of Planning ^{a-f}	10.5±3	11.1±3	11.7±3	12.2±3	<.0001
Caretaker Burden ^{a-f}	6.6±2	7.1±2	7.3±2	7.8±2	<.0001
Family Burden ^{a-f}	7.8±2	8.1±2	8.7±2	9.2±3	<.0001
Coping ^b	6.6±2	6.8±2	7.0±2	6.7±2	.0001
Sibling Impact ^b	11.1±3	11.4±3	11.7±3	11.6±3	.0098

Note. NDI=neurodevelopmental impairment. Post hoc pairwise comparisons were conducted only when the overall test was significant at $p<.05$. To adjust for multiple comparisons, a p of .008 was required for the pairwise comparisons to maintain an effective Type I error rate of .05.

^aNo vs. Mild ($p<.008$).

^bNo vs. Moderate ($p<.008$).

^cNo vs. Severe ($p<.008$).

^dMild vs. Moderate ($p<.008$).

^eMild vs. Severe ($p<.008$).

^fModerate vs. Severe ($p<.008$).

TABLE 4

Regression Analysis Predicting Impact on Family Scale Total Impact Score by Severity of Impairment

Variable	<i>B</i> (<i>SE</i>)	B	<i>p</i>
Impairment Severity			
Severe impairment	1.24 (0.52)	0.06	.0164
Neurodevelopmental impairment	1.32 (0.31)	0.08	<.0001
Mild impairment	0.67 (0.30)	0.04	.0245
Neonatal Characteristics			
Gestational age	-0.02 (0.06)	0.03	.7320
BPD	0.39 (0.24)	0.00	.1010
IVH 3-4/PVL	-0.13 (0.28)	0.05	.6314
Multiple birth	0.96 (0.33)	0.06	.0041
Maternal/Family Characteristics			
Maternal age	0.06 (0.02)	0.06	.0005
Education <12th grade	-0.13 (0.27)	-0.01	.6446
Medicaid	1.01 (0.27)	0.07	.0002
Unemployed	0.77 (0.23)	0.05	.0010
Siblings <3 years old	0.68 (0.30)	0.04	.0249
Level of Function/Medical Need			
G-tube fed	1.13 (0.60)	0.03	.0594
Does not ambulate	1.72 (0.47)	0.08	.0002
Oxygen	1.63 (0.63)	0.05	.0101
Ventilator	0.68 (1.44)	0.01	.6352
No. of hospitalizations since discharge	0.28 (0.06)	0.08	<.0001
Unmet Service Needs			
No. of unmet service needs	0.14 (0.13)	0.02	.2958
Family Resources			
Low family resources	5.80 (0.24)	0.40	<.0001

Note. $N=3,152$. BPD=bronchopulmonary dysplasia; IVH=intraventricular hemorrhage; PVL=periventricular leukomalacia; NDI=neurodevelopmental impairment. Model R^2 is equal to 0.27. Reference categories are no NDI, self-feeding, no supplemental oxygen, no IVH 3-4/PVL, not a multiple birth, high-school graduate or higher education, not on Medicaid, employed, no siblings less than 3 years old, not tube fed, ambulates, no oxygen at 18 months, no ventilation at 18 months, and high family resources.

TABLE 5

Stepwise Regression Analyses: Predicting Impact on Family Scale Total and Subscale Scores by Type of Impairment

Scale	Type of Impairment	Order of entry	Partial R^2	Model R^2
Total				
	MDI<70	1	.036	.036
	Moderate/severe CP	2	.008	.044
	PDI<70	3	.001	.045
Financial subscale				
	MDI<70	1	.016	.016
	Moderate/severe CP	2	.003	.019
Disruption of Planning subscale				
	MDI<70	1	.029	.029
	Moderate/severe CP	2	.006	.035
	Blind	3	.001	.036
Caretaker Burden subscale				
	MDI<70	1	.019	.019
	Moderate/severe CP	2	.005	.023
Family Burden subscale				
	MDI<70	1	.003	.033
	Moderate/severe CP	2	.010	.043
	PDI<70	3	.001	.045
Coping subscale				
	MDI<70	1	.005	.005
Sibling subscale				
	MDI<70	1	.006	.006

Note. MDI=Mental Development Index; PDI=Psychomotor Development Index; CP=cerebral palsy. The following variables were included in each model as possible predictor variables: MDI<70, PDI<70, blindness, deafness, and moderate/severe CP.