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LACK OF SOCIAL SUPPORT AS MEASURED BY THE FAMILY RESOURCE SCALE SCREENING TOOL IS ASSOCIATED WITH EARLY ADVERSE COGNITIVE OUTCOME IN EXTREMELY LOW BIRTHWEIGHT CHILDREN

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Abstract

Objective—Extremely low birthweight children are at high risk for cognitive impairment.

Study Design—Cognitive outcome of extremely low birthweight children participating in a Neonatal Research Network, randomized trial was evaluated at 18 and 30 months corrected age using the Bayley Scales of Infant Development, 2nd ed. Family resources and social support were assessed using a Family Resource Scale parent questionnaire. Regression analysis was used to determine independent demographic, medical and family resource factors influencing longitudinal cognitive outcome.

Result—Higher Family Resource Scale scores at 18 months were associated with greater improvement in cognitive scores between 18 and 30 months. Cognitive outcome was most adversely affected in children whose families had the least resources and social support. The adverse effect of poor social support was independent of family income.

Conclusion—Poor interpersonal social support has an independent, adverse impact on cognitive outcomes of extremely low birthweight infants.

Background

High risk, extremely low birth weight (ELBW, 1000 grams) infants and their families are impacted by multiple medical and socioeconomic factors that are not modifiable. It is

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important to identify potentially modifiable factors associated with protective or detrimental effects on developmental outcome. Interpersonal or social support for the primary caregiver(s) may be one such factor. Prior studies evaluating the effects of interpersonal social supports on the ELBW population have been limited by either the relatively small numbers of patients studied or by the inclusion of infants with birth weights >1 000 grams, who are less likely to have adverse outcomes.¹⁻⁵

Assessing the adequacy of family support can be facilitated by the Family Resource Scale (FRS), a simple to administer instrument used to evaluate physical, financial and psychosocial resources available to households with young children.⁶ The FRS has been studied in and economically diverse population of families with emotional and behavioral problems.⁷ To date no one has examined whether the responses on the FRS are associated with specific neurodevelopmental outcomes or whether that scale can be used to predict such outcomes. We hypothesized that that higher FRS scores would be associated with higher scores on a standardized measure of cognitive development and that cognitive outcome in early childhood would be adversely affected by limited interpersonal social support for the caregiver.

Methods

Participants

Surviving ELBW (BW <1 000g) children who participated in the multicenter, Eunice Kennedy Shriver National Institute of Child and Human Development (NICHD) Neonatal Research Network (NRN) Randomized Trial of Parenteral Glutamine Supplementation () performed in 1999-2001 were prospectively enrolled in the NRN Follow-up Study to be seen at 18 and 30 months corrected age (CA). Corrected age refers to age based on due date, not birth date and is routinely used in follow-up of preterm infants.

Inclusion criteria for this study were successful administration of the Mental Development Index (MDI) of the Bayley Scales of Infant Development, 2nd ed. and completion of the FRS concurrently at **both** the 18- and 30-month CA visits, as well as collection of all required socio-demographic data elements. Exclusion criteria were the presence of major congenital malformations or syndromes. Institutional Review Board (IRB) approval and consent were obtained by each participating site for each subject, for neurodevelopmental follow-up at 18 and 30 months CA, including all statistical analyses.

Measures

Comprehensive evaluation included a standardized neurodevelopmental assessment, administration of the Bayley Scales of Infant Development, 2nd ed. (BSID-II⁸), the FRS⁶, and questionnaires regarding socioeconomic status at 18 and 30 months CA. All assessments were administered concurrently at each age. The primary outcome variable for the current study was the BSID-II Mental Developmental Index (MDI) score, which assesses cognitive and language function including problem solving skills, abstract thinking, memory learning, mathematical concept formation, mental mapping, verbal communication and complex language. The BSID-II has a mean of 100 with a standard deviation of ± 15 .

The Family Resource Scale, a 30 item, self-administered parent/guardian questionnaire, is a reliable and valid instrument for assessing family needs which is highly predictive of different aspects of parent and family functioning⁹. The FRS is used to determine the types of resources available to a family including physical and health necessities, disposable income, personal resources, and social support. Respondents rate the availability of a given resource on a Likert Scale ranging from 1 “not at all adequate” to 5 “almost always adequate”. Resources are grouped into seven subscales. The “growth and support subscale”, specifically includes eleven items most related to interpersonal supports (e.g., “someone to talk to”, “time to socialize”). Subscale items are summed to compute the total score; higher scores represent greater resources. Overall FRS scores can range from 30 to 150, growth and support subscale scores can range from 11 to 55. The overall FRS scale and growth and support subscale have good internal consistency and reliability with Cronbach’s alphas of 0.89 and 0.84, respectively, although the original sample was small. Psychometric properties of the FRS were subsequently investigated with a sample of 990 and found to be strong with alphas of 0.93 (total) and 0.89 (growth and support subscales)¹⁰. The FRS was found to have good validity with other measures of family function.

Sample size determination

We estimated the sample size needed to achieve sufficient power for a one-way analysis of variance (ANOVA) of MDI scores among participants split into approximately equal-sized groups based on quartiles of family resource scale scores. Assuming a p-value of 0.05, a sample size of 600 would provide 88% power to detect a small effect size ($f=0.15$), defined as the ratio of the standard deviation of group means to the overall standard deviation (Cohen, 1988). Similarly, we found a sample size of 600 would provide 96% power for detecting a standardized mean difference of 0.15 between MDI scores at 18 and 30 months, based on a repeated measures ANOVA with a p-value of 0.05.

Statistical analyses

Bivariate analyses using ANOVA were conducted to compare the mean MDI scores at 18 and 30 months by scores on the overall FRS scale, the Growth and Support FRS subscale, and maternal and child characteristics. Multilevel models using PROC MIXED in SAS version 9.4 to determine whether FRS scores at 18 months predicted changes in MDI scores from 18 to 30 months while accounting for repeated measurements and clustering by center were conducted. Models included time (30 months vs. 18 months), FRS scores, and a time by FRS interaction to determine whether the amount of change in MDI scores over time varied depending on perceived resources. Backwards stepwise regression with retention criterion $p < 0.10$ was used to determine which maternal and child demographic variables were included in the models as predictors for MDI. Before conducting the ANOVAs and regression analyses, the distributions of MDI and FRS scores were examined to ensure they met the assumptions of the statistical tests (i.e., normality, equality of variances) using diagnostic tests and graphics.

Results

There were 943 infants from 12 different Neonatal Research Network sites participating in a randomized, controlled trial of Glutamine supplementation eligible at discharge for follow-up of whom 160 were lost to follow-up and 5 died. Of the 778 remaining children with neurodevelopmental follow-up data, 621 had both FRS scores and an MDI recorded at 18 and 30 months corrected age and were included in this study. The mean gestational age and birth weight of the study group were 26.5 ± 2.5 weeks and 788 ± 131 grams, respectively. The study sample was ethnically diverse; 43% were male (Table 1). Maternal demographics at 18 months are shown in Table 1. Seventy-four percent of mothers had completed at least high school education at 18 months and 45% of the mothers had at least some college education. Families were primarily from lower socioeconomic status groups; 58% of children were enrolled in Medicaid and 57% of families at 18 months reported annual household incomes below \$20,000. Education and income levels were stable from 18 to 30 months.

Children who were lost to follow-up were significantly more likely to be male, a multiple birth, delivered after labor, have a family income $< \$20,000$, and less likely to have been treated for a patent ductus arteriosus, or to have received human milk. There was no difference between children who were followed and those lost to follow-up in gestational age, birth weight, or receipt of antenatal or postnatal steroids, insurance type, race, ethnicity, maternal age or marital status.

The mean MDI for the 621 children seen at 18 and 30 months CA increased slightly from 80.3 ± 18.1 at 18 months CA to 82.2 ± 18.8 at 30 months CA ($p < 0.001$). Fewer children had MDI < 70 at 30 months than at 18 months CA [22% (137) vs. 29% (179), $p < .001$] while more had MDI ≥ 85 at 30 months than at 18 months [49% (303) vs. 41% (257), $p < .001$]. Higher MDI scores were associated with female gender, gestational age of ≥ 27 weeks, 5-minute Apgar score of ≥ 7 , having received human milk, being of white/non-Hispanic ethnicity, mother who was married, or mother with \geq high school education. Lower MDI scores were associated with Medicaid enrollment, intrauterine growth restriction, receipt of surfactant or postnatal steroids, more days of supplemental oxygen or ventilation, chronic lung disease, threshold retinopathy of prematurity and seizures.

Children whose caretakers had higher total FRS scores at 18 months had significantly higher MDI scores at 18 and 30 months (Table 2). Table 3 presents the regression results when examining FRS scores at 18 months as predictors of change in MDI scores from 18 to 30 months, after controlling for other factors. Based on the significant Time x FRS interaction, children whose caretakers reported higher total FRS scores at 18 months had significantly greater increases in MDI scores from 18 to 30 months ($p = .003$). Similar results were found for the Growth and Support subscale ($p = .015$). (Table 3). The mean MDI for those with the lowest levels of support on the FRS fell into the classification of mild to moderate delay while the mean MDI for those with the highest levels of support was within the first standard deviation of the test mean representing typical development. For both total Family Resource Scale and Growth and Support subscale, black race, unmarried marital status, less than high

school education, Medicaid, male gender, neonatal seizures and more days of ventilation were associated with lower MDI scores. (Table 3)

The model-adjusted changes in mean MDI scores by quartiles of FRS scores between 18 and 30 months CA are presented in Figure 1. At both 18 and 30 months CA, children whose families had FRS scores in the highest quartile (144) had the highest model-adjusted mean MDI scores compared to those with FRS of 122-133 ($p=.041$) or FRS <122 ($p<.001$). Children of families with FRS of 134-143 also had higher MDI scores at 18 months ($p=.007$) and 30 months ($p=.031$) compared to children with FRS <122 and, similar to children in the highest FRS quartile, had a 3 point increase in MDI between the two time points. Although children whose caretaker FRS scores were in both the 2nd and 3rd quartile (FRS scores of 122-133 and 134-143) had a similar MDI at 18 months; those with higher FRS scores in the 3rd quartile (134-143) showed greater improvement in their MDI between 18 and 30 months CA.

The effect of social support is shown in Figure 2. The greatest increase in MDI scores between 18 and 30 months CA was found in children whose mothers has the highest social support subscale scores. In contrast, no improvement in MDI scores was found in children whose mothers were in the lowest social support subscale quartile.

Ten items on the FRS, most of which were related to family income, significantly predicted a change in MDI scores (Table 4). For each item, more adequate resources were related to increases in MDI scores over time after controlling for other factors. For families requiring child care, a response of having adequate childcare less than “always” predicted a failure to increase the MDI at 30 months CA. Lack of dependable transportation or access to a telephone, and not “always” having adequate toys predicted a decrease in mean MDI from 18 to 30 months CA. Independent of family income, “always having someone to talk to” was associated with an increase in MDI while the opposite was associated with no change in MDI over time. Of note, younger mothers (< 20 years of age) living in poverty reported higher levels of support than older mothers with similar low income.

Discussion

The risk of adverse neurodevelopmental outcomes for the extremely low birthweight (ELBW) population is well documented¹¹⁻¹³. In this study, as in previous studies, MDI scores were below the population mean. Previous studies have reported the adverse effect of medical problems, financial burden, caretaker responsibilities and demographic factors on cognition and neurodevelopmental impairment in ELBW children.¹⁴⁻¹⁷ Current understandings of the impact and interactions between biological and environmental factors make it increasingly important to identify potentially modifiable factors to promote improved outcomes for premature infants.

This is the first study reporting the positive association between higher reported social support and better cognitive outcome in young, ELBW children, independent of other demographic factors and family income. As measured by the FRS, social support was a predictor of improvement in cognitive development between 18 and 30 months CA with the

BSID-II MDI scores increasing most among those with the highest level of social support and remaining unchanged among those with the least social support. The increase in MDI for was small, but shifted the ELBW mean closer to the overall population mean with 7% more infants within the first standard deviation of the test mean and fewer below, thereby placing more ELBW children in the “average” range. In previous studies, developmental assessments of ELBW children performed later (24 months), have been found to be more predictive of school age cognitive function than those performed at 18 months¹⁸. Our finding of increased numbers in the average range of the BSID II at 30 months associated with higher social support may predict better cognitive outcomes at school age for this population.

The finding of higher levels of social support in younger mothers may reflect resources available to young mothers from extended families or specialized school programs; however, information on these potential social supports was not collected. Alternatively, younger mothers may overestimate their social support.

This study, although using data collected on a cohort of children born in 1999 to 2001, is supported by a conceptual framework that includes the bioecological theory of development¹⁹ and epigenetic factors affecting child development.²⁰ Low birth weight children in high risk social environments have poorer outcomes than normal birth weight children in a similar environment.¹ A study of 175 low birth weight (LBW, <2 500 grams) children found that “family risk,” including measures of social support, parent-child interaction, stressful events and organization of the environment, was equivalent to early medical complications in predicting developmental outcome at 2 years¹. The presence of supportive relationships for parents has been proposed to provide a protective factor for outcome of children living in lower socioeconomic status (SES) neighborhoods²¹. Parents of children with cerebral palsy and other conditions causing developmental disabilities demonstrated better adherence to a home exercise program with higher levels of social support²². A population of 24 very low birth weight (VLBW, <1 500 grams) children whose mothers reported greater social support demonstrated improved receptive language skills at 3 years when compared with those whose mothers reported less support². Van Horn grouped together many of the same individual items that predicted MDI in this ELBW population into a subscale of the FRS labeled “Time for Self.”⁹ In a population of former Head Start families, scores on this subscale predicted variance in the “Social Skills Rating System” at both kindergarten and third grade.

The second important finding in this study is the strong negative effects of parent/guardian report of limited family resources on MDI scores and conversely the improvement in MDI scores associated with higher family resource with increasing age. Economic adversity is known to be associated with adverse health, behavior and developmental outcomes.²³ In this study, additional factors associated with lower Bayley scores in the models were single, black race, less than high school education and Medicaid insurance. Enhanced recognition of preterm infant risk factors other than medical morbidities that negatively impact developmental outcomes may pave the way for future policy change to address these needs.

Thirty three percent of eligible, surviving children enrolled in neurodevelopmental follow-up in the NRN glutamine trial were either lost to follow-up or not included in this study because they did not have FRS and MDI scores obtained at both 18 and 30 months. Whereas Hille²⁴ found that attrition led to underestimation of adverse outcome, others concluded that ELBW survivors compliant with follow-up may have worse outcome on the Mental Scales (MDI) than those who are noncompliant, leading to an over estimation of poor outcome in the population studied.²⁵ Children lost to follow-up in this study was less likely to have received breast milk and more likely to be male, both associated with adverse outcome.²⁶

Participating mothers were not screened for depression which may influence their responses to questions on the FRS. Children, especially boys, of depressed mothers who were of lower SES have been found to have poorer cognitive outcome²⁷. Maternal depression and psychological distress have also been associated with lower developmental outcomes at 5 years in VLBW children.²⁸ Future longitudinal follow up studies should include a screen for maternal or primary caregiver depression.

No data was collected regarding social media or networking. Social media use has been found to increase social support and social capital of adolescent mothers.²⁹ Fathers of preterm infants have found support using various social networking sites.³⁰ Parents of children with special health care needs gained emotional support and education from social media.³¹ Contrary to those findings, perceived social isolation was found to be higher in young adults with high social media use, with those in the highest quartile of frequency of use having markedly increased odds ratio (3.4) of feelings of social isolation.³² Future longitudinal studies of premature infants will need to assess use and impact of social media.

The strength of this study is the inclusion of a large number of ethnically diverse, ELBW children participating in a multicenter, North American, randomized, controlled trial who were prospectively enrolled in neurodevelopmental follow-up at 18 and 30 months CA. Prospective data collection included numerous maternal and infant demographic and medical factors known to be associated with developmental outcome.

Generalizability of this study is limited due to inclusion of only ELBW children and lack of data regarding immigration status, number of languages in the home, and maternal mental health, such as anxiety and depression. Analyses performed did not include interaction between outcome and number of siblings in the home. The psychometric properties of the FRS were validated in 2001.⁹ In 2013, an Arabic language version was found to have good validity³³ and a modified version focusing on material resources was validated for use in young men in 2018³⁴. The FRS was developed prior to widespread use of social media and networking, which may substantially change maternal perception of social support; however the use of social media was not routine during the time period of this study. Future validation of the psychometric properties of the FRS will be important to develop norms in the era of social media. Further studies of the effect of family resources and social support on cognitive and language outcomes of extremely low birth weight, extremely preterm children are warranted, especially in the current era of ubiquitous social media use that may strongly influence maternal perception of social support.

Conclusion

In this study we have shown that poor social support for caretakers had a detrimental impact on cognitive outcome of ELBW children independent of the impact of poverty. Unlike neonatal medical risk factors that adversely affect developmental outcome, post-discharge social support for the caregiver is potentially modifiable factor. Assessment of social support as a routine part of well child visits or NICU follow-up visits may be helpful in identifying families in need of increased social support to promote the development of their child.

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Participating NRN sites collected data and transmitted it to RTI International, the data coordinating center (DCC) for the network, which stored, managed and analyzed the data for this study. On behalf of the NRN, Drs. Abhik Das (DCC Principal Investigator) and Carla M. Bann (DCC Statistician) had full access to all of the data in the study, and with the NRN Center Principal Investigators, take responsibility for the integrity of the data and accuracy of the data analysis.

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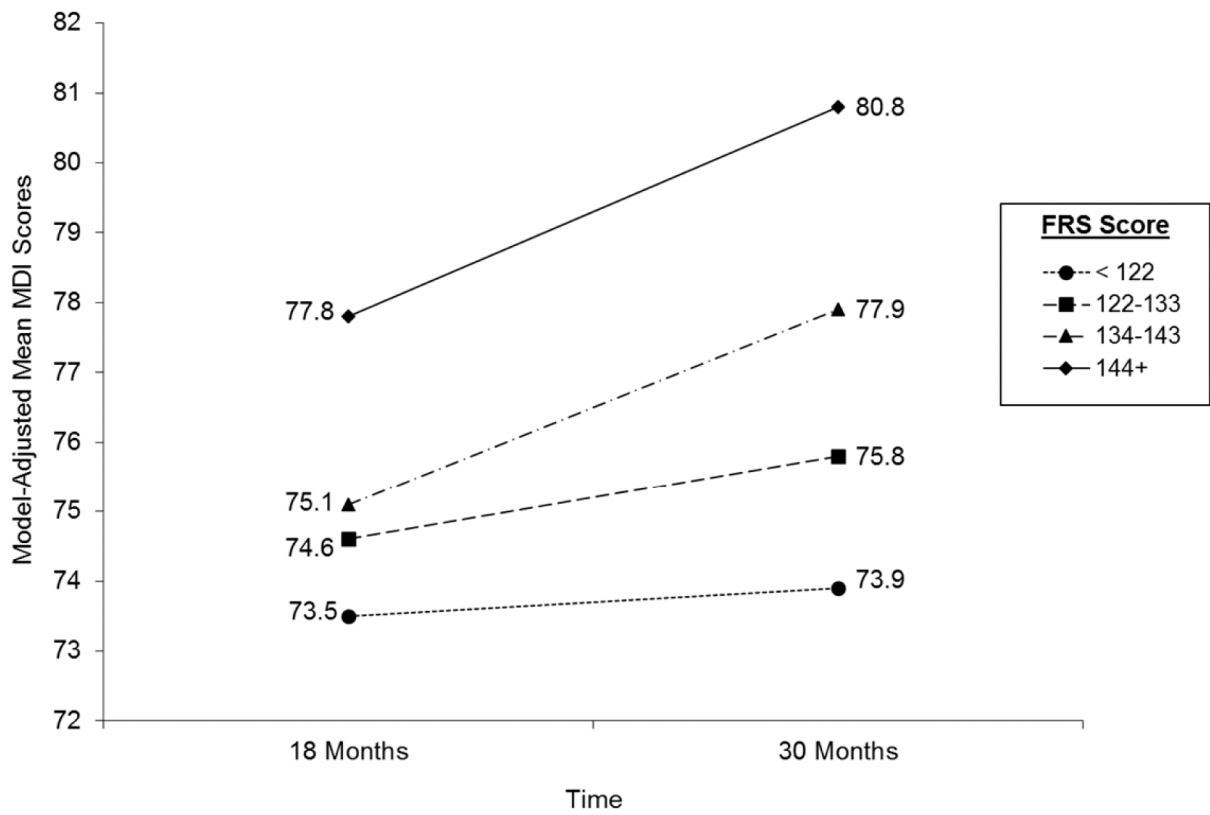


Figure 1. Model-Adjusted Mean MDI Scores by Level of Family Resources

Note: Means are adjusted for time, FRS score, time X FRS score, glutamine supplementation, race, marital status, education, Medicaid enrollment, gender, seizures, and days on ventilation

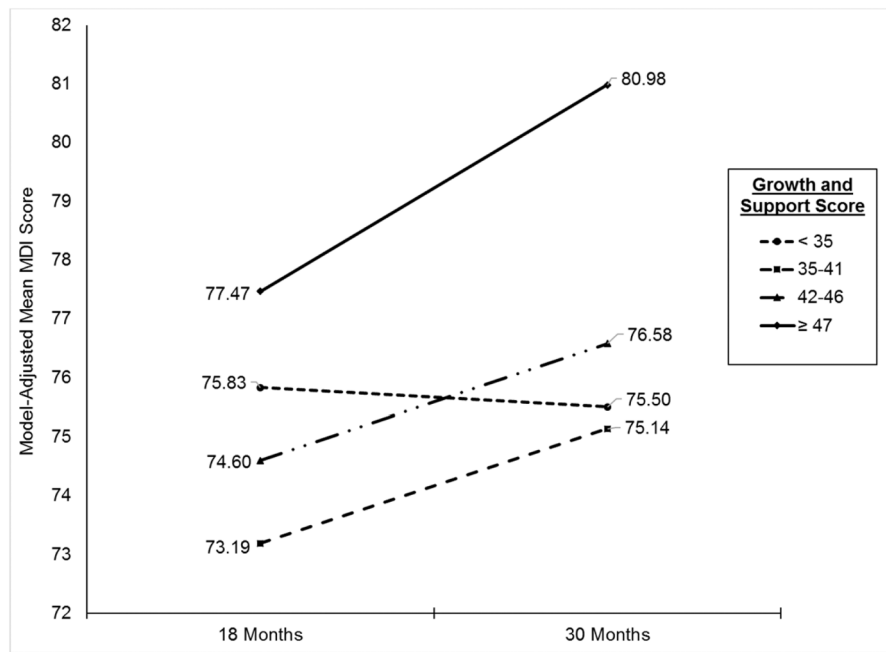


Figure 2. Model-Adjusted Mean MDI Scores by FRS Social Support Subscale
 Note: Means are adjusted for time, FRS score, time X FRS score, glutamine supplementation, race, marital status, education, Medicaid enrollment, gender, seizures, and days on ventilation

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Table 1

Demographics and Family Resources (N=621)

Variable	N (%)
Maternal factors	
Race/ethnicity	
Black, not Hispanic	279 (45)
White, note Hispanic	255 (41)
Other	87 (14)
Marital Status at Birth: Unmarried	332 (54)
Education less than high school	157 (26)
Income <\$ 20,000	260 (43)
Medicaid enrollment	358 (58)
Age at birth	
<20 years old	88 (14)
Child factors	
Male	270 (43)
Multiple birth	114 (18)
C-Section	389 (63)
Birth after any labor	391 (63)
Gestational age <27 weeks	369 (59)
Intrauterine growth retardation	17 (3)
5-minute Apgar score	
0-6	225 (36)
7-10	390 (63)
Glutamine	317 (51)
Antenatal steroids	515 (83)
Seizures	33 (5)
Surfactant	477 (77)
Postnatal steroids	205 (33)
Human milk	483 (78)
Chronic lung disease	289 (47)
Days on supplemental oxygen	
30	153 (25)
31-60	154 (25)
61-90	162 (26)
> 90	152 (24)
Days on ventilation	
0	68 (11)
1-19	255 (41)
20-39	148 (24)
40 or more	150 (24)
Severe Intraventricular Hemorrhage grade 3	62 (10)

Variable	N (%)
Threshold Retinopathy of Prematurity	62 (10)
Family Resources	
Family Resource Scale (FRS)	
< 122	149 (24)
122-133	156 (25)
134-143	157 (25)
144	159 (26)
Growth and Support Subscale	
<35	157 (25)
25-41	146 (24)
42-46	163 (26)
47	155 (25)

Note: Values for child factors are from birth and the neonatal period and maternal factors and the family resources scale are from 18 months

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Table 2

Relationship between Family Resource Scale (FRS) and Mental Developmental Index at 18 and 30 months corrected age

Family Resource Score	MDI at 18 months	MDI at 30 months
	Mean (SD)	Mean (SD)
Total FRS		
< 122	76 (17)***	76 (20)***
122-133	78 (18)***	79 (17)***
134-143	81 (17)**	84 (17)**
144	86 (18) ^{REF}	89 (18) ^{REF}
Growth Support Subscale		
< 35	79 (18)**	78 (20)***
35-41	76 (17)***	78 (18)***
42-46	81 (18)*	83 (17)**
47	85 (18) ^{REF}	89 (18) ^{REF}

*
p < .05

**
p < .01

p < .001; REF=reference category

Table 3

Regression Models with 18-Month Family Resource and Growth and Support Scales as Predictors of Change in Mental Developmental Index Scores from 18 to 30 Months

Variable	MDI Scores			
	Model 1: Family Resource Scale		Model 2: Growth and Support Subscale	
	Estimate (SE)	p	Estimate (SE)	p
Time (30 months vs. 18 months)	-11.83 (4.67)	.012	-4.45 (2.64)	.092
Scale	0.06 (0.05)	.158	0.07 (0.08)	.376
Time x Scale	0.10 (0.04)	.003	0.15 (0.06)	.015
Glutamine	-1.31 (1.17)	.263	-1.32 (1.17)	.258
Black	-3.92 (1.44)	.007	-4.20 (1.44)	.004
Mother unmarried	-3.25 (1.43)	.023	-3.16 (1.43)	.028
Less than high school education	-5.10 (1.47)	< .001	-5.06 (1.47)	< .001
Medicaid	-3.75 (1.50)	.013	-4.03 (1.50)	.007
Male	-6.00 (1.18)	< .001	-5.95 (1.18)	< .001
Seizures	-7.98 (2.71)	.003	-8.24 (2.72)	.003
Days on ventilation	-0.21 (0.03)	< .001	-0.21 (0.03)	< .001

Note: N=599. SE=standard error. Model also controls for research center. Reference levels for categorical variables are did not receive glutamine supplementation, not black, married, high school education or more, not on Medicaid, female, and no seizures. Days of ventilation is a continuous variable.

Table 4

Mean Mental Developmental Index Scores at 18 and 30 Months by Selected Items on Family Resource Scale

Item	N	MDI at 18 mos.	MDI at 30 mos.	Change in MDI 30 to 18 mos.	Time x Item Interaction p
		Mean (SD)	Mean (SD)	Mean (SD)	
Someone to talk to					
Always adequate	434	81 (18)	84 (18)	3 (13)	.024
Not always adequate	183	79 (19)	79 (20)	0 (14)	
Enough clothes for your family					
Always adequate	508	81 (18)	84 (19)	3 (13)	.004
Not always adequate	113	77 (17)	75 (18)	1 (14)	
Money to buy necessities					
Always adequate	425	81 (18)	84 (19)	3 (13)	.011
Not always adequate	196	78 (18)	77 (18)	0 (14)	
Dependable transportation					
Always adequate	479	82 (18)	85 (18)	3 (13)	.004
Not always adequate	141	75 (18)	74 (18)	-1 (14)	
Telephone or access to telephone					
Always adequate	586	80 (18)	83 (19)	2 (13)	.005
Not always adequate	33	76 (19)	72 (20)	-4 (17)	
Child care/day care for your children *					
Always adequate	199	82 (17)	86 (17)	3 (12)	.051
Not always adequate	60	77 (18)	77 (17)	0 (12)	
Toys for your children					
Always adequate	511	81 (18)	84 (19)	3 (14)	.014
Not always adequate	110	76 (16)	75 (17)	-1 (13)	
Medical care for your family					
Always adequate	478	81 (18)	84 (19)	3 (13)	.025
Not always adequate	139	76 (17)	76 (18)	0 (15)	
Dental care for your family					
Always adequate	412	82 (18)	85 (18)	3 (13)	.014
Not always adequate	172	76 (18)	76 (19)	0 (15)	
Money for family entertainment					
Always adequate	255	84 (18)	88 (18)	4 (14)	< .001
Not always adequate	357	78 (18)	79 (19)	0 (13)	

* This item is only applicable to caretakers requiring child care.

Note: p-value is the significance of the time by item interaction. Each model controls for time, item, research center, glutamine supplementation, race, marital status, education, Medicaid enrollment, gender, seizures, and days on ventilation.