The well-being of mothers of adolescents with developmental disabilities in relation to medical care utilization and satisfaction with health care

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Abstract

Parents of children with disabilities have been found to be more likely to experience stress and depressive symptoms than parents of typically developing children as a result of the increased challenges inherent in their parenting role. This study investigated the utilization of and satisfaction with adolescent health care services reported by mothers and their relation to maternal well-being. Participants included 73 mothers and their adolescents with developmental disabilities who had been recruited as infants and toddlers from early intervention programs to participate in a longitudinal investigation, the Early Intervention Collaborative Study. Data were collected through parent reports and structured assessments with adolescents. Regression analyses were conducted to test whether utilization and maternal satisfaction with care related to maternal depressive symptoms or parenting stress after controlling for child and family characteristics. The results demonstrated that both utilization and maternal satisfaction with health care added unique variance in predicting lower levels of maternal stress and depressive symptoms.

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The collaborative relationship between parents of children with developmental disabilities and their children’s physicians has been found to be central to parent satisfaction with children’s health services (Galil et al., 2006; Horrell, MacLean, & Conley, 2006). Parents’ satisfaction with their children’s health care is valuable to examine not only because of its association with

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compliance and continuity of care (Albrecht & Hoogstraten, 1998; Hickson & Clayton, 2002; Lewis, Scott, Pantell, & Wolf, 1986; Mah, Tough, Fund, Douglas-England, & Verhoef, 2006; Squier, 1990) but also because children’s physicians are often the professionals to whom parents turn regarding developmental concerns (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004). The parent–physician relationship and the frequency of medical visits are likely to have particular salience in situations where a child has developmental disabilities and related special health care needs (Committee on Children with Disabilities, 1999). Indeed, in analyses based on the National Health Interview Survey, Newacheck and Halfon (1998) reported that children with disabilities (and presumably their parents or caregivers) have three times the rate of physician contacts compared to children without disabilities. Parent satisfaction with the health care their children with disabilities receive has been investigated recently with respect to the qualities of health care providers that are valued by parents and the unmet needs of families (Liptak et al., 2006; Warfield & Gulley, 2006). Little is known, however, about the implications of levels of utilization of services or parent satisfaction with children’s care on the well-being of these caregivers themselves. This research gap exists despite much empirical evidence on the importance of parent well-being to parenting competence (e.g., Downey & Coyne, 1990; Leung & Slep, 2006). Developmental models of the determinants of parenting (Belsky, 1984) as well as family system models of functioning (Minuchin, 2002; Patterson, 1991) place the psychological well-being of primary caregivers, conceptualized as low levels of parenting stress and depressive symptoms, as central to their functioning as competent parents.

Although most parents are likely to feel challenged in some aspects of their parenting role, many studies have indicated that the stress reported by primary caregivers of children with developmental disabilities is often greater and more variable than that reported by caregivers of typically developing children (Baker et al., 2003; Dyson, 1991; Hodapp, 2002; Roach, Ormond, & Barratt, 1999). Some research has suggested that parental stress varies by the type of disability of the child (Blacher, Neece, & Paczkowski, 2005; Duarte, Bordin, Yazigi, & Mooney, 2005). For example, parents of children with Down syndrome have often been found to experience less parenting stress than parents of children with other types of disabilities (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Most, Fidler, Laforce-Booth, & Kelly, 2006). Child gender has also been related to parental stress in some studies, but the relation is inconsistent (e.g., Scher & Sharbany, 2005; Shin et al., 2006). Most of those studies, however, have focused on parenting stress during the early childhood years. The few longitudinal investigations of parents of children with developmental disabilities indicate that aspects of parenting stress, especially those related to the child’s adjustment, increase significantly from early through middle childhood (Hauser-Cram et al., 2001; Orr, Cameron, Dobson, & Day, 1993).

Greater parenting stress has been associated with a range of behavior problems, inadequate peer social networks, and multiple medical needs among adolescents with developmental disabilities. Behavior problems are more likely to occur in children and youth with disabilities than in those who are developing typically (Baker, Blacher, & Olsson, 2005; Tonge, 1999) and these problems often increase dramatically in the adolescent period (Jacobson, 1990). In a sample of adolescents and young adults with Down syndrome, autism, or fragile X syndrome, Abbeduto et al. (2004) found that the most consistent predictor of maternal well-being was the youth’s behavior. Adolescents who have difficulty regulating their own behavior tend to have poor social relationships (Merrell, Johnson, Merz, Johnson, & Ring, 1992) resulting in inadequate peer networks. Additionally, adolescents with developmental disabilities may require multiple visits to pediatricians and specialists due to special health care needs related to, for example, seizure disorders, cardiac anomalies, or poor mobility (McPherson et al., 1998). These
visits can add to parental stress in the form of daily hassles and disruption to family routines (Gallimore, Bernheimer, & Weisner, 1999) and challenges in dealing with professionals (Perry, 2005).

Parental mental health appears to follow a more variable course than parenting stress. One set of researchers (Gowen, Johnson-Martin, Goldman, & Appelbaum, 1989) reported that depressive symptoms showed a pattern of waxing and waning in response to having a child with developmental disabilities. Some have noted increased depressive symptomatology for caregivers of children with developmental disabilities in comparison to parents of typically developing children (e.g., Blacher, Shapiro, Lopez, Diaz, & Fusco, 1997) whereas others have found few differences (e.g., Bristol, Gallagher, & Schopler, 1988). Although studies are mixed in relation to whether depressive symptomatology is greater among parents of children with developmental disabilities, the possibility that such a relation exists is reason for concern. The deleterious effects of depressive symptoms on the functioning of parents of children and adolescents has been extensively studied (Downey & Coyne, 1990; Garber & Little, 1999; Gelfand & Teti, 1990; Jaffee & Poulton, 2006). Parental depression has been found to vary by the child’s type of disability, with mothers of children with Down syndrome demonstrating fewer depressive symptoms than mothers of children with autism (Abbeduto et al., 2004) and by child gender, with mothers of girls reporting more depressive symptoms than mothers of boys (Boyle & Pickles, 1997).

The adolescent period has been recognized as a time of multiple transitions, including pubertal, cognitive, self-definitional, and social changes (Steinberg & Silk, 2002), requiring adaptation and adjustment by parents. Adolescent changes, especially their timing and extent, often differ for those with developmental disabilities in comparison to typical adolescents, leading to potentially greater challenges for parents (Hauser-Cran & Krauss, 2004). Health-related issues are often greater for this group, affecting parental worries and daily routines. For example, adolescents with seizure disorders often require multiple medication adjustments (Gadow, 1997), those with cerebral palsy often need many adaptive equipment changes (Zaffuto-Sforza, 2005), and many adolescents with developmental disabilities experience less synchronicity between pubertal and cognitive development as their analytical skills lag far behind the emotional and physical changes they are undergoing (Reeve, 2001).

Both parental stress and depressive symptoms have been found in many studies to relate to family features, such as income and marital status (Brown & Moran, 1997; Cairney, Boyle, Offord, & Racine, 2003; Conger, Rueter, & Conger, 2000; Davies, Avison, & McAlpine, 1997). Although seldom considered as the central predictor in studies of families of children with disabilities, income, as a family contextual factor, has been found to relate inversely to depression in mothers of adolescents with autism, Down syndrome, or Fragile X syndrome (Abbeduto et al., 2004) as it does in families of typically developing children (Shonkoff & Phillips, 2000). Parents of children with disabilities who have less income and support from their spouses have also been found to experience greater levels of stress (Warfield, 2005). Further, greater caregiver psychological health, as defined by low distress scores and few depressive episodes, has been found to relate to higher caregiver socioeconomic status in parents of children with cerebral palsy (Raina et al., 2005).

Features related to health care services that may be associated with the well-being of primary caregivers of adolescents with developmental disabilities have not been studied. In this investigation, we control for selected family and child characteristics thought to be related to the well-being of mothers of adolescents with developmental disabilities and test hypotheses about the added contribution of the utilization of medical services and the mother’s satisfaction with her
child’s health care provider to her well-being. Specifically, the following hypotheses are tested: (1) over and above family and child characteristics, greater medical care utilization will predict greater stress and more depressive symptoms, and (2) over and above family and child characteristics and medical care utilization, greater satisfaction with care will predict less stress and fewer depressive symptoms.

1. Method

1.1. Participants

The children and families represented in this study were enrolled in the Early Intervention Collaborative Study (EICS), a longitudinal investigation of 190 children with disabilities and their families (Hauser-Cram et al., 2001; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). These families were originally recruited when they entered early intervention services in Massachusetts or New Hampshire because of the special needs of their infant or toddler.

The current investigation focused on data collected when the children were 15 years old. A total of 139 adolescents continued to participate in the EICS investigation at age 15. As some were no longer considered to have disabilities, only those adolescents who were receiving special education services due to continuing special needs at the time of data collection were included in these analyses. Only those families in which the primary caregiver completed all measures were included, and, as only one father as primary caregiver was included in this reduced sample, this family was excluded from the analysis for a total of 73 families.

The sample included 30 children with Down syndrome, 23 children with motor impairments, and 20 children who had demonstrated delays (of unknown etiology) in two or more areas of development at time of enrollment in the original study and again at age 3 years. The average cognitive performance, as measured by a test composite score on the Stanford–Binet Intelligence Scale (Thorndike, Hagen, & Sattler, 1986), for the sample at age 15 was 56.1 (S.D. = 25.88). One half (49.3%) of the adolescents were male. The adolescents were predominantly European–American (93%). This sample differs from both the original sample of 190 children with disabilities at age 3 and the larger sample of 139 adolescents as a result of selecting only those adolescents continuing to receive special education services. The cognitive performance scores of this group are significantly less than that computed for the total sample of 190 children at study entry ($M = 62.6; t(72) = −2.15, p = .04$) and the total sample at age 15 ($M = 64.9; t(72) = −2.89, p = .005$). The most frequently reported health-related problems for this sample (based on maternal report) were allergies (34%), bowel problems (23%), asthma (19%), orthopedic problems (19%), seizures (16%), and motor difficulties requiring assistive equipment such as braces, wheelchairs or walkers (15%). Over two-thirds (71%) of mothers were married. Although the average family income was between $45,000 and $50,000, the reported income ranged from less than $5000 per year to greater than $60,000. All families except one reported that they had health care insurance. These parent demographics are similar to those reported for the total age 15 sample.

1.2. Procedure

Data were collected through home visits by field staff members who were blind to the study’s hypotheses. These visits included interviews with the mother and a multidimensional structured assessment with the adolescent. Mothers also completed self-administered questionnaires.
1.3. Measures

1.3.1. Maternal stress
The Parent Domain of the Parenting Stress Index (PSI) (Abidin, 1995) was completed by mothers. The Parent Domain measures stress related to the experience of parenting and to the sense of emotional equilibrium associated with the parent experience. The Parent Domain of the PSI is a 54-item self-administered Likert scale. Responses range from strongly agree to strongly disagree, with higher scores indicating greater stress in the parent–child system. The Parent Domain score is composed of seven subscales that measure parent attachment, sense of competence, depressive symptomatology, health, social isolation, role restriction, and relations with spouse. Cronbach’s alpha on the Parent Domain score for the PSI for this sample was .85.

1.3.2. Depressive symptomatology
The Center for Epidemiologic Studies Depressive Symptomatology Scale (CES-D) (Radloff, 1977) is a 20-item self-report scale measuring the extent of depressive symptoms. Respondents indicate the frequency of occurrence during the past week of each symptom on a 4-point Likert scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time). Scores range from 0 to 60, with higher scores indicating greater depressive symptomatology. Cronbach’s alpha on the CES-D for this sample was .95.

1.3.3. Child behavior
The Child Behavior Checklist (CBCL) (Achenbach, 1991) is a 115 item measure that assesses a child’s behavioral problems and social competencies. Items are scored 0–2, depending on the degree to which each statement about children’s behavior characterizes the child. A “total problems” T-score was used for this investigation. The Cronbach’s alpha for Total Behavior Problems for this sample was .89.

1.3.4. Cognition
Cognitive performance was measured using the Stanford–Binet Intelligence Scale (Thorndike et al., 1986). Standard scores were calculated using tables from the manual for this measure.

1.3.5. Child disability
Type of disability was drawn from the initial data files at the time of the children’s enrollment in the study and again assessed at age 3 years. The children were categorized into three disability groups: Down syndrome, motor impairment, and developmental delay. These diagnoses were confirmed by medical record review.

1.3.6. Child health
A child health questionnaire entitled, Your Voice Counts: The Health Care Experiences of Families of Children with Special Health Care Needs, was completed by primary caregivers (Krauss, Wells, Gulley, & Anderson, 2001; Warfield & Gulley, 2006). A question from the health questionnaire regarding the extent to which the parent agreed with the statement, “My child is less healthy than other children I know” was used to assess parent perceptions of the child’s current health status. This item was rated from 1 (definitely true) to 5 (definitely false), with higher scores indicating better health. Self-report has been found to be a reliable report of health status (Idler & Benyamini, 1997) and the caregiver’s perception of the child’s health status was critical to assess in this investigation.
1.3.7. Child gender

Child gender was drawn from initial data files.

1.3.8. Family characteristics

Family income was measured using 10 distinct categories, ranging from less than $5000 to $60,000 or above. Marital status was gathered from mothers. Categories of never married, separated, divorced, and widowed were included as “not married” and coded 0; married participants were coded 1.

1.3.9. Medical care

Two measures taken from the Your Voice Counts parent booklet (Krauss et al., 2001; Warfield & Gulley, 2006) were used to investigate the care that children receive from physicians: utilization and satisfaction with care.

1.3.10. Utilization

The first medical care measure included a count of doctor visits that adolescents had made in the previous 12 months. Categories for each type of provider ranged from 0 (no times) to 4 (more than 8 times). These were added to create a proxy measure of total medical visits that adolescents utilized in the past year. The count included visits to the primary care physician or to specialists in the previous 12 months. Excluded from this measure were emergency room visits and hospitalizations, as these occurred infrequently (85% of adolescents had no hospital visits and 75% did not visit the emergency room during the past year) and were not sources of routine care.

1.3.11. Satisfaction with care

The second measure of medical care was created from a series of 15 questions related to the parent’s perceptions of how well the physician was meeting the needs of the parent and child. Mothers were asked to respond to these items in reference to the doctor whom she considered most important to her child’s care. Most parents (73%) considered the adolescent’s primary care physician to be most important, although 25% named a specialist in this role. Two families did not identify which of their teen’s physicians took priority. A large number of parents responded either “don’t know” or “not applicable” to three of the original items: communication with school (36%), communication with other services (52%), and communication with health insurance (53%) and were excluded from later analysis. Factor analysis was run on the remaining 12 questions to explain the dimensions of Satisfaction with Care. Examination revealed one factor, with an eigenvalue of 7.96, accounting for 66.3% of the item variance (Table 1). This factor included eight items: providing reassurance and support to the parent, spending enough time with the adolescent during a visit, overall quality of care, showing respect for the family’s culture, being available to advise over the telephone, explaining health needs in an understandable way, being easy to reach in an emergency, and respecting the adolescent. Cronbach’s alpha for the Satisfaction with Care factor was .96.

1.4. Statistical analyses

Because of the rather limited sample size and resulting power considerations, initial analyses were conducted to determine if specific family and child characteristics were related to the outcomes. We reasoned that if such relations were not significant, then a more limited set of family and child characteristics could be controlled for in the final analyses to test the hypotheses.
about utilization and satisfaction. Correlations among variables were tested to determine
multicollinearity prior to the primary analyses. Hierarchical multiple regression analysis was
used to test hypothesized relations between medical care utilization and maternal satisfaction
with care and the two measures of maternal well-being. The order of variables in the equations
was chosen based on the theoretical model proposed, with family variables entered first and child
variables entered next followed by the main variables of interest: utilization and satisfaction with
care (Pedhazur, 1997).

2. Results

Descriptive statistics were computed on all variables (see Table 2). Maternal satisfaction with
care was generally high, with a mean of 26.61 (S.D. = 4.77) out of a possible score of 32.
Although most adolescents had low to moderate utilization rates for health care visits, a total of
14% of the adolescents in the sample had attended nine or more health care visits in the past year,

Clinical cutoffs for stress, depressive symptomatology, and child behavior problems (i.e.,
scores above which one would recommend referrals) were not used in these analyses but are
reported here for descriptive purposes. The overall mean for the Parent Domain Stress score for
the sample was 111 (S.D. = 23.63), with 14% of mothers scoring above the clinical cutoff score

Table 1
Satisfaction with care factor analysis

<table>
<thead>
<tr>
<th>Factor</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing quality care</td>
<td>.883</td>
</tr>
<tr>
<td>Spending enough time</td>
<td>.890</td>
</tr>
<tr>
<td>Explaining health needs</td>
<td>.849</td>
</tr>
<tr>
<td>Providing reassurance</td>
<td>.912</td>
</tr>
<tr>
<td>Advising over telephone</td>
<td>.862</td>
</tr>
<tr>
<td>Easy to reach in emergency</td>
<td>.812</td>
</tr>
<tr>
<td>Showing respect for child</td>
<td>.773</td>
</tr>
<tr>
<td>Respecting culture</td>
<td>.877</td>
</tr>
<tr>
<td>Eigenvalue</td>
<td>7.96</td>
</tr>
<tr>
<td>% Variance</td>
<td>66.29</td>
</tr>
</tbody>
</table>

Table 2
Descriptive statistics of outcome and predictor variables (N = 73)

<table>
<thead>
<tr>
<th></th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal stress</td>
<td>65</td>
<td>173</td>
<td>111.11</td>
<td>23.63</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>0</td>
<td>60</td>
<td>9.84</td>
<td>11.32</td>
</tr>
<tr>
<td>Marital status</td>
<td>0</td>
<td>1</td>
<td>.71</td>
<td>.46</td>
</tr>
<tr>
<td>Income</td>
<td>1</td>
<td>14</td>
<td>11.01</td>
<td>3.61</td>
</tr>
<tr>
<td>Child health</td>
<td>1</td>
<td>5</td>
<td>3.68</td>
<td>1.15</td>
</tr>
<tr>
<td>Cognitive performance</td>
<td>27</td>
<td>134</td>
<td>56.1</td>
<td>25.88</td>
</tr>
<tr>
<td>Child behavior problems</td>
<td>34</td>
<td>82</td>
<td>56.3</td>
<td>9.80</td>
</tr>
<tr>
<td>Utilization</td>
<td>0</td>
<td>7</td>
<td>2.89</td>
<td>1.56</td>
</tr>
<tr>
<td>Satisfaction with care</td>
<td>14</td>
<td>32</td>
<td>26.61</td>
<td>4.77</td>
</tr>
</tbody>
</table>
of 135. The mean score for depressive symptomatology was 10 (S.D. = 11.32), and 19% of mothers scored above the CES-D cutoff of 16. The mean total score of adolescent behavior on the CBCL was 56 (S.D. = 9.80); 12% of adolescents scored above the clinical cutoff of 70. The most frequent types of problem behaviors for the high scoring adolescents were stubbornness or irritability, argumentativeness, sudden changes in mood, and poor attention span.

Preliminary analyses included group comparisons using analysis of variance (ANOVA) to determine if maternal well-being varied by the adolescent’s type of disability and gender. For maternal stress, main effects for gender ($F(1, 67) = 2.29, p = .32$) and type of disability ($F(2, 67) = 1.16, p = .32$) were not significant, nor was their interaction ($F(2, 67) = .38, p = .69$). Similarly, no differences were found for maternal depressive symptomatology by child’s gender ($F(1, 67) = .24, p = .62$), type of disability ($F(2, 67) = .12, p = .88$), or their interaction ($F(2, 67) = .99, p = .38$).

Correlations among the dependent variables, the remaining child and family variables, and the utilization and satisfaction variables are presented in Table 3. The two outcome variables, depressive symptomatology and maternal stress, were significantly and moderately correlated with one another ($r = .57, p < .001$). Nevertheless, we reasoned that the relation between predictors and criterion variables may differ for these two outcomes, as we have found in prior investigations (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006) so separate analyses were carried out for each. As shown in Table 3, income, behavior problems, utilization, and satisfaction were each significantly correlated with both outcomes. Marital status was associated with depressive symptoms, and child health was correlated with maternal stress.

Thus, regression analyses were conducted to predict maternal parenting stress and depressive symptomatology from both utilization and satisfaction with physician’s care, controlling for the effects of marital status, income, child health, cognitive performance, and behavior problems. As seen in Table 3, marital status was correlated with income level ($r = .59, p < .001$) and was thus entered first in the regression equation to allow for a meaningful test of its significance.

### 2.1. Maternal stress

Maternal stress was predicted by maternal satisfaction with care received from the child’s physician ($\beta = -.23, p = .043$) over and above that predicted by marital status, income, child health, child cognitive performance score, child behavior problems, and the utilization of health care in the past 12 months. Mothers who were more satisfied with care reported experiencing less

| 1. Parent domain stress | – |
| 2. Depressive symptoms | .571** | – |
| 3. Marital status | –.059 | –.287* | – |
| 4. Income | –.249* | –.555** | .592** | – |
| 5. Child health | –.416** | –.150 | .063 | .098 | – |
| 7. Child behavior problems | .380** | .403** | –.188 | –.226 | –.302** | .062 | – |
| 8. Utilization | .282* | .318** | .033 | –.042 | –.182 | –.127 | .341** | – |
| 9. Satisfaction with care | –.365** | –.398** | .220 | .349** | .190 | –.168 | –.198 | .110 | – |

* Correlation is significant at the .05 level two-tailed.
** Correlation is significant at the .01 level two-tailed.
stress than mothers who were less satisfied (Table 4). Utilization, however, was not a significant predictor ($\beta = .15, p = .168$). Family income ($\beta = -.33, p = .024$), child’s health ($\beta = -.40, p < .001$) and child behavior problems ($\beta = .25, p = .029$) added significantly to predicting maternal parenting stress. Parents who had lesser annual incomes and whose children were perceived as being less healthy and having more behavior problems reported greater stress. The marital status of parents ($\beta = -.06, p = .621$) and the child’s cognitive performance score ($\beta = .11, p = .329$) were not significant predictors of parenting stress. Interactions between utilization and satisfaction, behavior problems and satisfaction, and behavior problems and utilization were tested but were not found to be significant predictors of maternal stress.

### 2.2. Depressive symptomatology

Maternal satisfaction with the care received from their child’s doctor was also uniquely predictive of maternal depressive symptoms ($\beta = -.25, p = .014$), with greater satisfaction related to fewer depressive symptoms (Table 5). In addition, greater utilization was a significant predictor of greater depressive symptoms ($\beta = .24, p = .019$). Marital status ($\beta = -.29, p = .014$), family income ($\beta = -.59, p < .001$), and child behavior problems ($\beta = .29, p = .006$) were significant predictors of depressive symptomatology. Mothers who were not married, had lower incomes, and whose children had more behavior problems experienced greater depressive symptomatology. Neither child health ($\beta = -.10, p = .334$) nor child cognitive performance

### Table 4
Summary of hierarchical regression analysis for variables predicting maternal stress ($N = 73$)

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>$B$</th>
<th>S.E. $B$</th>
<th>$\beta$</th>
<th>$\Delta R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Marital status</td>
<td>-3.05</td>
<td>6.14</td>
<td>-0.06</td>
<td>.00</td>
</tr>
<tr>
<td>2. Income</td>
<td>-2.15</td>
<td>.93</td>
<td>-0.33</td>
<td>.07$^*$</td>
</tr>
<tr>
<td>3. Child health</td>
<td>-8.11</td>
<td>2.18</td>
<td>-0.40</td>
<td>.16$^{***}$</td>
</tr>
<tr>
<td>4. Cognitive performance</td>
<td>.10</td>
<td>.10</td>
<td>.11</td>
<td>.01</td>
</tr>
<tr>
<td>5. Child behavior problems</td>
<td>.60</td>
<td>.27</td>
<td>.25</td>
<td>.05$^*$</td>
</tr>
<tr>
<td>6. Utilization</td>
<td>2.34</td>
<td>1.68</td>
<td>.15</td>
<td>.02</td>
</tr>
<tr>
<td>7. Satisfaction with care</td>
<td>-1.13</td>
<td>.55</td>
<td>-0.23</td>
<td>.04$^*$</td>
</tr>
</tbody>
</table>

Note: Overall model: $R^2 = .36, F = 4.28, p = .043, R^2$ adjusted = .29.

* $p < .05$

$^{***} p < .001$

### Table 5
Summary of hierarchical regression analysis for variables predicting maternal depressive symptomatology ($N = 73$)

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>$B$</th>
<th>S.E. $B$</th>
<th>$\beta$</th>
<th>$\Delta R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Marital status</td>
<td>-7.12</td>
<td>2.82</td>
<td>-0.29</td>
<td>.08$^*$</td>
</tr>
<tr>
<td>2. Income</td>
<td>-1.86</td>
<td>.39</td>
<td>-0.59</td>
<td>.23$^{***}$</td>
</tr>
<tr>
<td>3. Child health</td>
<td>-.95</td>
<td>.98</td>
<td>-0.10</td>
<td>.01</td>
</tr>
<tr>
<td>4. Cognitive performance</td>
<td>.06</td>
<td>.05</td>
<td>.13</td>
<td>.02</td>
</tr>
<tr>
<td>5. Child behavior problems</td>
<td>.33</td>
<td>.12</td>
<td>.29</td>
<td>.07$^*$</td>
</tr>
<tr>
<td>6. Utilization</td>
<td>1.73</td>
<td>.72</td>
<td>.24</td>
<td>.05$^*$</td>
</tr>
<tr>
<td>7. Satisfaction with care</td>
<td>-.58</td>
<td>.23</td>
<td>-0.25</td>
<td>.05$^*$</td>
</tr>
</tbody>
</table>

Note: Overall model: $R^2 = .50, F = 6.44, p = .014, R^2$ adjusted = .45.

* $p < .05$

$^{**} p < .01$

$^{***} p < .001$
were related to maternal depressive symptoms. Interactions between utilization and satisfaction, behavior problems and satisfaction, and behavior problems and utilization were tested but were not found to be significant predictors of maternal depressive symptomatology.

3. Discussion

3.1. Family features

Marital status and income have been emphasized as factors in effective parenting (American Academy of Pediatrics, 2003), and the present study supports their role, particularly that of family income in maternal well-being. Mothers with higher family income reported both lower parenting stress and fewer depressive symptoms than those with lower income levels. Being married was significant in predicting lower maternal depressive symptoms, but no relation was found between marital status and maternal parenting stress. As marital status and income level are generally highly correlated, it is important to disentangle their effects to understand the unique contributions of each to parental stress and depression.

3.2. Child characteristics

Although parents who have a child with a disability are often more likely to experience depression and high levels of parenting stress than parents of typically developing children (Blacher et al., 1997; Deater-Deckard, 2004; Perry, 2005; Seligman, 1999), the factors relating to higher levels of stress and depressive symptoms need to be understood before action can be taken to improve the well-being of mothers of adolescents with disabilities. In this study of adolescents, neither parenting stress nor depression was found to be related to the child’s type of disability, cognitive level, or gender. Health care providers who anticipate that a child’s low cognitive ability or motor impairment will necessarily cause heightened stress may overlook investigating the other child and family climate characteristics that are more likely to relate to parental well-being. Not surprisingly, the child’s overall health was found to be strongly predictive of maternal stress, as worries about a child’s health have been found in other studies to be a frequent source of parenting stress (Turner, Sloper, Cunningham, & Knussen, 1990).

One child characteristic—behavior—was critical in predicting both aspects of maternal well-being. Although the level of behavior problems was not excessively high for the majority of these adolescents, the consistent relation between such problems and maternal well-being is evident. This suggests that rather than focusing primarily on the child’s type of disability or level of cognitive impairment, health care providers should ask about the adolescent’s behavior and be trained to make appropriate referrals to psychologists, social workers, and/or family counselors. Clear relations between behavior problems and maternal stress and depression have been substantiated in the literature (Blacher et al., 2005; Deater-Deckard, 2004; Morgan, Robinson, & Aldridge, 2002). The directional nature of the relation is more difficult to assess, however (Deater-Deckard, 2004; Morgan et al., 2002). A transactional or bidirectional model has been suggested as most appropriate to explaining this relation (Barry, Dunlap, Cotton, Lochman, & Wells, 2005; Black, 2002; Hauser-Cram et al., 2001; Morgan et al., 2002). The transactional model suggests that developmental outcomes are a product of the individual and the environment and that patterns of interaction between a child and a parent can exacerbate or diminish the child’s problem behaviors (Sameroff & Fiese, 2000). Adolescents with disabilities who
demonstrate problem behaviors are likely to create feelings of stress in their mothers, who then may respond using harsh or punitive parenting techniques, aggravating their children’s problem behaviors (Barry et al., 2005; Black, 2002). Thus, intervention into this deleterious set of transactions may be especially important for both the adolescent and the parent.

3.3. Utilization of medical services

Interpretation of the utilization of medical services is complex. While high usage is at times deemed inappropriate (Janicke & Finney, 2003), children with disabilities may require large numbers of visits to both primary care physicians and specialists as a result of their health-related needs. Understanding the factors related to high utilization is critical to managing the care of adolescents as well as to improving the well-being of their families. In this study, although no relation existed between maternal ratings of child health and the number of medical visits the adolescent required, a strong bivariate correlation existed between adolescent behavior problems and utilization of services, suggesting that parents may be looking for help from their children’s doctors for behavior-related issues. This reinforces the idea that health care providers who are better able to assist parents by making referrals regarding the behavior of their children may also be more effective in serving families.

Mothers who reported higher usage of medical services for their adolescent in this study also reported higher levels of depressive symptoms and greater parenting stress. The relation was maintained for depressive symptomatology, but not for parenting stress, in equations after other variables were taken into consideration. It is possible that the relation operates in the direction opposite to that tested here. Mothers with higher levels of depressive symptoms may have looked for relief from their own symptoms through the visits, or their personal anxiety may have increased their fears about their children’s health (Seligman, 1999). Whether the higher utilization is a cause or an effect of the depressive symptoms, the relation suggests the importance of consultation with parents regarding their own well-being (Heneghan, Mercer, & DeLeone, 2004; Heneghan, Silver, Bauman, & Stein, 2000).

3.4. Maternal satisfaction with medical care

Consistent with the relations hypothesized in this investigation, the satisfaction that mothers reported with the care that children received from their physicians was a critical aspect of maternal well-being. Satisfaction with care consisted of a number of important components: supporting and reassuring parents, spending enough time in office visits, perception of overall quality, providing support by phone, explaining health needs to parents, being easy to reach, and showing respect for both the child and the family’s culture. Communication and relationships between parents and physicians have been emphasized in other studies (Galil et al., 2006), and when not effective, these aspects of services have been shown to act as barriers to medical care. Health care providers who do not take enough time in visits, who do not communicate well with patients, and who do not take patient concerns seriously can create barriers to families accessing medical care for individuals with developmental disabilities (Reichard & Turnbull, 2004). In this investigation, we found that mothers who were married, who had higher family income levels, and who experienced fewer behavior problems from their adolescents reported greater levels of satisfaction with care. Importantly, mothers who were more satisfied reported both lower parenting stress and fewer depressive symptoms, above and beyond the other predictors. Children’s doctors clearly have an important role in the lives of families of adolescents with disabilities.
Quality of care measures that relate to health status and medical outcomes in patients are critical to improving care for children with disabilities (Perrin, 2002), but the perceptions that parents have regarding the care their children receive may be equally important in affecting the psychological well-being of patients and their parents. Although the challenges to providing sensitive, family-focused care are many, including managed care limitations on the time available to spend with each patient and greater emphasis on physical health than on psychosocial issues in medical training programs (Black & Nabors, 2004), the potential benefits to families are great. The results of this investigation suggest that health care providers must be especially cognizant of the needs of families of adolescents with developmental disabilities as those needs may not be driven by the child’s cognitive or physical limitations but may be related to problem behaviors and parent mental health, both of which are likely to benefit from targeted psycho-social referrals (Black, 2002; Hutchings, Appleton, Smith, Lane, & Nash, 2002).

4. Study limitations and future research

This investigation has a number of limitations. The correlational nature of the relations prevents causal inferences, and statements about the direction of effects can only be made with caution. The sample itself is restrictive, especially in terms of ethnicity and average income, and it lacks the diversity among families seen in many pediatric practices. Also, the mother is only one member of the family, and an understanding of the well-being of fathers and other family members is critical. Additionally, the types of disabilities investigated here are not the full range of those served by health providers, although they are fairly representative of children who initially received early intervention services nationally (Scarborough et al., 2004) and who continue to need special education services.

Despite its limitations, important implications can be derived from the study’s findings. First, the importance of the relation between adolescent behavior problems and maternal well-being continues to deserve attention. The results of this study suggest that more research and training be conducted in ways to encourage health care providers to assist parents of children with disabilities who exhibit problem behaviors. In some cases referral to psychologists, social workers, or family counselors may be needed; in other cases, discussion of managing typical behavioral challenges of adolescents may be sufficient. Our results suggest, however, that even when those problems behaviors are not extreme, they dampen maternal well-being.

Second, utilization of medical services for their adolescents with disabilities relates to the well-being of mothers and the behavior problems of their adolescents, but was not found to be related to mothers’ reports of their adolescents’ overall health. Thus, mothers may be using their children’s medical visits to receive help in dealing with their children’s behavior problems, or they may be over-estimating the severity of their children’s health needs as a result of poor personal well-being. This result, found here with respect to depressive symptoms, is consistent with a model proposed by Janicke and Finney (2003) with respect to parental stress, in which parents who feel unable to cope with high demands turn to others for help, notably their children’s doctors. Health professionals who perceive higher levels of utilization of services than is typical for the level of health concerns of the child should recognize the possibility that parents are in distress. Doctors can help teens and their parents with high utilization rates by asking about the underlying needs of the family system in addition to addressing medical concerns.

Last, maternal perspectives on the care given to their adolescents by their adolescents’ physicians relate to maternal well-being. The satisfaction with care measured in this investigation is broad and includes important features such as cultural competence and
responding to the needs of parents for support and information. Such features are in keeping with the goals of Healthy People 2010 (American Academy of Pediatrics, 2002). In addition, the need for seamless transitions from pediatric care to adult health care services that provide reassurance, responsiveness, and respect for individuals and cultures is clear to ensure that sensitivity to the unique needs of the family is maintained (American Academy of Pediatrics, 2002; Banta, 2004) as adolescents transition to new health providers. The results of this investigation clearly suggest that health care for adolescents with disabilities must go beyond a focus on the disability per se to achieve a broader understanding of the adolescent within the family system.

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References


