Family Resources and Stress: A Comparison of Families of Children with Cystic Fibrosis, Diabetes, and Mental Retardation

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Assessed patterns of stress in families of children with pediatric conditions that varied on 2 dimensions: (a) fatal vs. nonfatal outcome and (b) presence vs. absence of cognitive impairment. Families of children with cystic fibrosis (n = 23), diabetes (n = 24), and moderate mental retardation (n = 24) were compared to families of well children (n = 24) in 3 age groups. Maternal responses to a multidimensional measure of family stress, the Questionnaire on Resources and Stress—Short Form (QRS-S), indicated that families of children with chronic conditions did not differ from families of well children on scales assessing generic aspects of family stress, such as family conflict. However, diagnostic groups differed on QRS-S scales assessing stressors specific to the child's disability (e.g., families of children with mental retardation were characterized by concerns about caring for the child as an adult). There was no evidence of higher levels of stress for families of older children. Data on the internal consistency of

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QRS-S scales and their relation to measures of maternal and child adjustment are presented.

KEY WORDS: chronic illness; mental retardation; cystic fibrosis; diabetes; stress.

Results of several studies indicate that the nature of stress experienced by families of children with chronic conditions varies by type of impairment (Beckman, 1983; Dunst, Trivette, & Cross, 1986; Frey, Greenberg, & Fewell, 1989; Holroyd & Guthrie, 1986; Holroyd & McArthur, 1976; Minnes, 1988). For example, Wallander, Pitt, and Mellins (1990) found that child disability status (i.e., type of condition) accounted for significant variation in scores on measures of maternal physical and mental health and social functioning. Similarly, the finding that children with conditions involving the brain more frequently have psychological disorder than those with conditions involving only physical disability (Breslau, 1985; Breslau & Marshall, 1985; Seidel, Chadwick, & Rutter, 1975) suggests that the presence of child cognitive impairment may result in particular stressors not experienced by all families of children with chronic conditions. Thus, it is important that research on family adaptation to pediatric conditions consider characteristics that differentiate pediatric conditions and the relation of these characteristics to the nature of stress experienced by the family (cf. Johnson, 1985; Kazak, 1986). Such information is essential in order to determine the extent to which interventions to enhance adaptation may be generic in nature and the extent to which they should be tailored to address needs that vary by the particular type of child impairment.

The present study examined family stress associated with pediatric conditions representing two major parameters that are important in differentiating chronic disorders (cf. Rolland, 1984): (a) fatal versus nonfatal outcome and (b) presence versus absence of cognitive impairment. Cystic fibrosis was chosen to represent a terminal condition. Moderate mental retardation was selected to represent conditions involving cognitive impairment. Diabetes served as a comparison condition that is typically not fatal and is without associated cognitive deficits. The first aim of the study was to determine whether the three conditions differed in relation to each other and in relation to a well comparison group with respect to patterns of family stress. A multidimensional measure of stress, the Questionnaire on Resources and Stress–Short Form (QRS-S; Holroyd, 1987), was used to assess several dimensions of family stress. Subject recruitment targeted families of children in three age groups in order also to investigate the

3In Rolland's typology, incapacitation is conceptualized as a dichotomy representing the presence or absence of incapacitating effects, regardless of the nature of the incapacitation. We have focused on a particular type of incapacitation: the presence or absence of cognitive impairment.

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suggestion that stress increases with the child's increasing age in families of children with chronic conditions (Gallagher, Beckman, & Cross, 1983).

Extensive evidence supports the reliability and validity of the original QRS (Holroyd, 1974, 1987, 1988) but little had been known about the psychometric properties of Holroyd's short form of the QRS. Thus, a second aim of the study was to provide data on the internal consistency and construct validity of the QRS-S. We assessed the internal consistency of each of the 11 scales and the composite (total) scale. Construct validity was assessed by examining the relation of QRS-S scale scores and total scores to demographic variables and to measures of maternal and child adjustment. Consistent with Beckman (1983), we expected QRS-S scale scores to be higher in families of children with higher levels of reported behavior problems. Because family stress is likely to affect maternal well-being, we further expected higher QRS-S scale scores to be associated with higher levels of maternal depression and lower levels of maternal parenting satisfaction and perceived parenting efficacy.

**METHOD**

*Sample*

Subjects were 95 mothers of children in four diagnostic groups: diabetes, cystic fibrosis, mental retardation, and well. For each of the four diagnostic groups, mothers of children in three age groups were recruited: middle childhood (8–10 years of age), early adolescence (11–14 years of age), and late adolescence (15–19 years of age). There were eight subjects in each age group for each condition, with the exception of the oldest age group in the cystic fibrosis condition which was missing a subject (this was due to the high mortality rate for cystic fibrosis and thus lower availability of mothers of older adolescents with cystic fibrosis). An effort was made to recruit equal numbers of boys and girls in each age group for each diagnostic condition. This was achieved except in the case of cystic fibrosis (among early adolescents with cystic fibrosis, there were six boys and two girls; among late adolescents, there were five boys and two girls). Children with intellectual deficits, evidenced by placement in a special class, were excluded from the diabetes, cystic fibrosis, and well groups in order not to confound physical and mental disorder.

All target children were living at home with their families and attending public schools. The mean number of children in the family was 3.3, 2.1, 2.4, and 3.3 for the mental retardation, diabetes, cystic fibrosis, and well groups, respectively. The percentage of single mothers was 29% each for the mental retardation and diabetes groups, 13% for the cystic fibrosis group, and 12% for the well group, $\chi^2 = 3.85$, ns. The percentage of Caucasian families was 100%
each for the cystic fibrosis and diabetes groups, 58.3% for the mental retardation group, and 70.8% for the well group, $\chi^2 = 21.55, p < .001$. The groups did not differ significantly on the Hollingshead Index of Social Status (Hollingshead, 1975), $F(3, 90) = 0.18$, ns. The majority of families were in the middle class, but ranged from the lowest to the highest Hollingshead level within each diagnostic condition. Additional characteristics of each group are described below.

**Diabetes** ($n = 24$). Mothers of children with diabetes were recruited from the Diabetes Research and Training Center of a university medical center and from the private practices of local physicians. All children were insulin-dependent and had been diagnosed with diabetes for at least 1 year. Mothers of children currently hospitalized were excluded.

**Cystic Fibrosis** ($n = 23$). Mothers of children with cystic fibrosis were recruited from the Cystic Fibrosis Clinic of the same university medical center, private practices of physicians in the region, and the local Cystic Fibrosis Foundation. Mothers of children currently hospitalized or in the terminal phase of the disease were excluded. All children had received the diagnosis of cystic fibrosis within the first 2 years of life.

**Mental Retardation** ($n = 24$). This group was recruited through special education classes in local schools. Only classrooms for children classified in the moderate range of mental retardation were used.

**Well** ($n = 24$). Mothers of children with no known mental or physical disorder were recruited from the records of general pediatrics clinics of the same university medical center. Mothers were eligible for the study if their children had been seen recently at the clinic for a routine examination or acute minor illness, provided the child had no current physical complaint, chronic disorder, or intellectual impairment (defined by placement in a special education class for all or part of the school day). Families in which any member had a serious illness or disability were excluded from this group.

**Procedure**

All instruments were administered orally in a personal interview with the mother. The majority of interviews were conducted in the mothers' homes. Some interviews were conducted in other locations (e.g., the clinic, school, or mother's workplace), according to the mothers' preferences and convenience.

**Measures**

**Family Stress.** The QRS-S (Holroyd, 1974, 1987, 1988) is a measure of family stress associated with the care of a dependent family member. Its 66 items compose three scales referring to patient problems (Dependency and Manage-
Family Resources and Stress

ment, Cognitive Impairment, and Physical Limitations); five scales referring to respondent attitudes (Life-span Care, Lack of Personal Reward, Terminal Illness Stress, Preference for Institutional Care, and Personal Burden for Respondent); and three scales focusing on family problems (Limits on Family Opportunities, Family Disharmony, and Financial Stress). Sample items include, “I worry about what will happen to when I can no longer take care of him/her” (Life-span Care scale), “ demands that others do things for him/her more than is necessary” (Dependency and Management scale), and “Other members of the family have to do without things because of” (Limits on Family Opportunities scale). The respondent answers true or false to each item. Items are coded 1 when the response indicates the presence of stress and 0 for the absence of stress. Scale scores, obtained by summing responses to the six items in each scale, can range from 0 to 6. All 11 QRS-S scales were administered to mothers of children with a chronic condition. Six of the QRS-S scales were administered to mothers of well children; the remaining five scales (Life-span Care, Lack of Personal Reward, Terminal Illness Stress, Physical Limitations, Preference for Institutional Care) were not administered to mothers of well children because they refer to care of a family member with a chronic condition and thus were not relevant to this group.

Maternal Depression. The Center for Epidemiological Studies Depression scale (CES-D; Radloff, 1977) was used to assess maternal depression. This 20-item self-report scale was originally developed to measure depressive symptomatology in the general population. Each item surveys the frequency of occurrence of a particular symptom in the past week. Item responses are scored using a scale ranging from 0 to 3; higher scores are associated with increased symptomatology. The instrument has high internal consistency (.85 in the general population) and moderate test–retest reliability (ranging from .32 to .67 depending on the time interval between test administrations and whether life event stressors occurred during the intervening time period). Validity has been established by correlation with clinical ratings of depression (Radloff, 1977).

Parenting Self-Esteem. Parenting self-esteem was assessed with a modified version of the Parenting Sense of Competence Scale (PSOC), which was developed for use with parents of infants (Gibaud-Wallston, 1977; Gibaud-Wallston & Wandersman, 1978). The PSOC is a 17-item self-report instrument with a 6-point response scale ranging from strongly disagree to strongly agree. The PSOC has been used frequently in studies of school age children (e.g., Mash & Johnston, 1983; Mash, Johnston, & Kovitz, 1983), with items referring to infants reworded to refer to children. Johnston and Mash (1989) performed a principal components analysis of the PSOC and obtained two oblique factors: (a) Satisfaction, an

*One item from this scale ("I am pleased when others see my care of ______ is important") was inadvertently omitted in preparing the research protocol.
affective dimension reflecting parenting frustration, anxiety, and motivation, and 
(b) Efficacy, an instrumental dimension reflecting perceived competence and 
problem-solving ability in the parenting role. These factors are similar to the 
rationally derived scales described in the original work by Gibaud-Wallston and 
Wandersman (1978). Although several of the original PSOC items were not 
included in the present study, 6 of the 9 items from the Satisfaction factor and 5 
of the 7 items from the Efficacy factor described by Johnston and Mash (1989) 
were available for analysis.5 A factor analysis was performed to determine the 
appropriateness of factor scores for this shortened instrument. Its results repli-
cated findings reported by Johnston and Mash. A two-factor oblique solution 
appeared to be most meaningful and accounted for 34% of the common variance 
in the PSOC item ratings. The items loading on the first factor in this study also 
loaded on the first factor in the analysis by Johnston and Mash, who labeled the 
factor “parenting satisfaction.” Similarly, items loading on the second factor 
were those that loaded on Johnston and Mash’s second factor, labeled “parenting 
efficacy.” Factor scores were computed by summing the items for each factor. 
Alpha reliability coefficients of .70 for Satisfaction and .68 for Efficacy, 
although somewhat lower than the .75 and .76 reported by Johnston and Mash 
(1989), indicated adequate internal consistency for the factors comprising the 
shorter instrument used in this study. A high score on the Parenting Satisfaction 
factor reflects a sense of comfort and satisfaction derived from the parenting role. 
A high score on the Parenting Efficacy factor reflects a sense of competence in 
the parenting role.

Child Adjustment. The Child Behavior Checklist (CBCL; Achenbach & 
Edelbrock, 1983) was used to assess child adjustment. The CBCL provides a 
standardized description of children’s problem behaviors as reported by their 
parents. It consists of 118 behavior problem items, each scored on a 3-point 
scale. The social competence scale was not used in this study. For the purposes 
of data analysis, each child’s raw scores for Internalizing Behavior Problems and 
Externalizing Behavior Problems were converted to T scores according to the 

5Five items from the PSOC that were included in the work by Johnston and Mash (1989) were not 
included in the present study. Item #1, “The problems of taking care of a baby are easy to solve 
when you know how your actions affect your baby, an understanding I have acquired,” was deleted 
because it was difficult for several of our pilot study mothers to understand, probably because it 
contains two different thoughts. Two items particular to parents of infants were deleted rather than 
rewording them for parents of older children as was done by Johnston and Mash (“Considering how 
long I’ve been a mother, I feel thoroughly familiar with this role,” and, “If being a mother of an 
infant were only more interesting, I would be motivated to do a better job as a parent”). Finally, two 
items referring to the parent’s overall sense of accomplishment were omitted because they were 
judged to lack face validity for a measure of competence specific to the parenting domain (“I go to 
bed the same way I wake up in the morning—feeling I have not accomplished a whole lot,” and, 
“Sometimes I feel like I’m not getting anything done” ).
appropriate age and sex group norms of the Revised Child Behavior Checklist Profile.

*Socioeconomic Status.* The Four-Factor Index of Social Status (Hollingshead, 1975) served as the index of family socioeconomic status (SES). This measure is based on the educational and occupational level of both parents. Scores on the measure can range from 8 to 66.

**RESULTS**

*Patterns of Stress in the Diagnostic Groups*

A series of Diagnostic group (diabetes, cystic fibrosis, mental retardation, well) by Age group (children, early adolescents, late adolescents) analyses of variance were conducted with the QRS-S scales as the dependent variables. (The well group was excluded from analyses involving QRS-S scales referring specifically to care of a disabled family member, as these scales were not judged to be meaningful for families without a disabled member.) Means and standard deviations for the QRS-S scales are presented by diagnostic group in Table I.

There were significant effects for diagnostic group on five of the scales: Dependency and Management, $F(3, 83) = 3.51, p < .02$; Cognitive Impairment, $F(3, 83) = 13.66, p < .001$; Physical Limitations, $F(2, 62) = 8.39, p < .001$; Life-span Care, $F(2, 62) = 21.94, p < .001$; and Terminal Illness Stress, $F(2, 62) = 30.99, p < .001$. In addition, the diagnostic groups differed significantly on total QRS-S scores, $F(2, 62) = 4.72, p < .01$. Post hoc analyses using Duncan's multiple range test indicated that mothers of children with mental retardation scored significantly higher than the other groups on the Dependency and Management, Cognitive Impairment, and Life-span Care scales. With respect to the Terminal Illness Stress scale, mothers of children with cystic fibrosis had significantly higher scores than mothers of children with diabetes or mental retardation. Scores on the Physical Limitations scale were higher for mothers of children with cystic fibrosis and diabetes than for mothers of children with mental retardation. Total QRS-S scores were lower for mothers of children with diabetes in comparison to mothers of children with cystic fibrosis or mental retardation. Finally, a significant main effect for child age group was obtained on the Cognitive Impairment scale, $F(2, 83) = 5.33, p < .01$, with mothers reporting greater cognitive limitations in the youngest group ($M = 0.87, SD = 0.83$) than in the oldest group ($M = 0.26, SD = 0.68$), regardless of diagnostic condition. No significant effects for age or diagnostic group were found for the Limits on Opportunities, Family Disharmony, Financial Stress, Personal Burden,
Table I. Means and Standard Deviations by Group on the QRS-S Scales

<table>
<thead>
<tr>
<th>QRS-S scale</th>
<th>Mental retardation</th>
<th>Diabetes</th>
<th>Cystic fibrosis</th>
<th>Well</th>
<th>Significant group differences</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>Dependency and management</td>
<td>2.29</td>
<td>1.76</td>
<td>1.25</td>
<td>1.65</td>
<td>0.92</td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>1.42</td>
<td>1.35</td>
<td>1.29</td>
<td>0.46</td>
<td>0.26</td>
</tr>
<tr>
<td>Limits on family opportunities</td>
<td>1.04</td>
<td>1.08</td>
<td>0.75</td>
<td>0.90</td>
<td>0.96</td>
</tr>
<tr>
<td>Family disharmony</td>
<td>0.54</td>
<td>0.88</td>
<td>0.21</td>
<td>0.51</td>
<td>0.35</td>
</tr>
<tr>
<td>Financial stress</td>
<td>2.42</td>
<td>1.53</td>
<td>1.75</td>
<td>1.48</td>
<td>2.35</td>
</tr>
<tr>
<td>Personal burden for respondent</td>
<td>3.62</td>
<td>1.28</td>
<td>3.17</td>
<td>1.09</td>
<td>3.35</td>
</tr>
<tr>
<td>Life-span care*</td>
<td>4.79</td>
<td>1.18</td>
<td>2.00</td>
<td>1.67</td>
<td>2.70</td>
</tr>
<tr>
<td>Lack of personal reward*</td>
<td>0.42</td>
<td>0.58</td>
<td>0.71</td>
<td>1.12</td>
<td>0.56</td>
</tr>
<tr>
<td>Terminal illness stress*</td>
<td>0.75</td>
<td>0.99</td>
<td>1.37</td>
<td>1.13</td>
<td>3.61</td>
</tr>
<tr>
<td>Physical limitations*</td>
<td>0.12</td>
<td>0.34</td>
<td>0.79</td>
<td>0.66</td>
<td>0.60</td>
</tr>
<tr>
<td>Preference for institutional care*</td>
<td>0.71</td>
<td>0.69</td>
<td>0.92</td>
<td>0.78</td>
<td>0.96</td>
</tr>
<tr>
<td>Total</td>
<td>18.12</td>
<td>6.08</td>
<td>13.21</td>
<td>6.37</td>
<td>16.61</td>
</tr>
</tbody>
</table>

*Scale was not administered to the well group.
Lack of Reward, or Preference for Institutional Care scales. There were no significant interaction effects between diagnostic condition and age group.

Questionnaire on Resources and Stress—Short Form:
Internal Consistency and Validity

Only the data from families of children with chronic conditions were used in analyses assessing the psychometric properties of the QRS-S. The Kuder-Richardson-20 (KR-20) reliability coefficient for the total scale was .77, indicating adequate internal consistency. The internal consistency of the individual scales was lower, as might be expected for scales consisting of only six items. Table II presents the mean, range, and KR-20 coefficient for each of the 11 scales. Four scales each had at least one item with zero variability; on these items all respondents indicated the absence of stress. (Items on which the responses of all mothers indicated the absence of stress included the following: ______ is accepted by other members of the family; ______ knows his/her own address; ______ is aware of who he/she is; ______ needs a walker or a wheelchair; ______ can feed him/herself; and We enjoy ______ more and more as a person.)

Construct validity was assessed by examining the correlation of QRS-S scores with demographic variables and measures of maternal and child adjustment. Table III presents the Pearson correlation coefficients. Scores on the QRS-S scales assessing child management problems (Dependency and Management), maternal caretaking burden (Personal Burden), and family problems (Limits on Family Opportunity, Conflict, Financial Stress) tended to correlate

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
<th>KR-20</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limits on family opportunities</td>
<td>0.91</td>
<td>1.04</td>
<td>0-4</td>
<td>.37</td>
</tr>
<tr>
<td>Family disharmony*</td>
<td>0.36</td>
<td>0.68</td>
<td>0-4</td>
<td>.36</td>
</tr>
<tr>
<td>Financial stress</td>
<td>2.17</td>
<td>1.60</td>
<td>0-3</td>
<td>.66</td>
</tr>
<tr>
<td>Child problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dependency and management</td>
<td>1.49</td>
<td>1.58</td>
<td>0-6</td>
<td>.70</td>
</tr>
<tr>
<td>Cognitive impairment*</td>
<td>0.66</td>
<td>1.01</td>
<td>0-4</td>
<td>.65</td>
</tr>
<tr>
<td>Physical limitations*</td>
<td>0.51</td>
<td>0.63</td>
<td>0-2</td>
<td>.00</td>
</tr>
<tr>
<td>Maternal concerns</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal burden for respondent</td>
<td>3.38</td>
<td>1.27</td>
<td>1-6</td>
<td>.42</td>
</tr>
<tr>
<td>Lack of personal reward*</td>
<td>0.56</td>
<td>0.89</td>
<td>0-4</td>
<td>.55</td>
</tr>
<tr>
<td>Preference for institutional care</td>
<td>0.86</td>
<td>0.76</td>
<td>0-3</td>
<td>.04</td>
</tr>
<tr>
<td>Life-span care</td>
<td>3.17</td>
<td>1.91</td>
<td>0-6</td>
<td>.73</td>
</tr>
<tr>
<td>Terminal illness stress</td>
<td>1.89</td>
<td>1.78</td>
<td>0-6</td>
<td>.75</td>
</tr>
<tr>
<td>Total</td>
<td>15.90</td>
<td>6.07</td>
<td>5-29</td>
<td>.77</td>
</tr>
</tbody>
</table>

*One item had zero variance due to not being endorsed by any subject.
**Two items had zero variance due to not being endorsed by any subject.
Table III. Correlation of QRS-S Scales with Demographic Variables and Measures of Maternal and Child Adjustment (n = 71)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Age</th>
<th>SES</th>
<th>Depression</th>
<th>Efficacy</th>
<th>Satisfaction</th>
<th>CBCL-I *</th>
<th>CBCL-E *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limits on family opportunities</td>
<td>-.07</td>
<td>.17</td>
<td>.17</td>
<td>-.25&lt; *</td>
<td>-.35</td>
<td>.33&lt; *</td>
<td>.34&lt; *</td>
</tr>
<tr>
<td>Family disharmony</td>
<td>-.01</td>
<td>-.20&lt;</td>
<td>.26&lt;</td>
<td>-.31&lt;</td>
<td>-.13</td>
<td>.23&lt;</td>
<td>.19</td>
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<tr>
<td>Financial stress</td>
<td>.19</td>
<td>-.64&lt;</td>
<td>.32&lt;</td>
<td>-.16</td>
<td>-.28&lt;</td>
<td>.38&lt;</td>
<td>.29&lt;</td>
</tr>
<tr>
<td>Child problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dependency and management</td>
<td>.17</td>
<td>-.04</td>
<td>.25&lt;</td>
<td>-.34&lt;</td>
<td>-.62&lt;</td>
<td>.55&lt;</td>
<td>.59&lt;</td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>-.26&lt;</td>
<td>.02</td>
<td>-.16</td>
<td>-.12</td>
<td>-.23&lt;</td>
<td>.09</td>
<td>.30&lt;</td>
</tr>
<tr>
<td>Physical limitations</td>
<td>.09</td>
<td>-.08</td>
<td>.04</td>
<td>-.23&lt;</td>
<td>-.16</td>
<td>.27&lt;</td>
<td>.17</td>
</tr>
<tr>
<td>Maternal concerns</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Personal burden for respondent</td>
<td>.12</td>
<td>.05</td>
<td>-.50&lt;</td>
<td>.21&lt;</td>
<td>-.43&lt;</td>
<td>.53&lt;</td>
<td>.38&lt;</td>
</tr>
<tr>
<td>Lack of personal reward</td>
<td>-.11</td>
<td>-.04</td>
<td>.07</td>
<td>-.14</td>
<td>.05</td>
<td>.06</td>
<td>.05</td>
</tr>
<tr>
<td>Preference for institutional care</td>
<td>.02</td>
<td>.10</td>
<td>-.20&lt;</td>
<td>.01</td>
<td>.22&lt;</td>
<td>-.21&lt;</td>
<td>-.30&lt;</td>
</tr>
<tr>
<td>Life-span care</td>
<td>.16</td>
<td>-.18</td>
<td>.16</td>
<td>-.08</td>
<td>-.33&lt;</td>
<td>.38&lt;</td>
<td>.38&lt;</td>
</tr>
<tr>
<td>Terminal illness stress</td>
<td>.00</td>
<td>-.13</td>
<td>.30&lt;</td>
<td>.13</td>
<td>-.08</td>
<td>.16</td>
<td>-.09</td>
</tr>
<tr>
<td>QRS total</td>
<td>.11</td>
<td>-.25&lt;</td>
<td>.41&lt;</td>
<td>-.30&lt;</td>
<td>-.54&lt;</td>
<td>.62&lt;</td>
<td>.52&lt;</td>
</tr>
</tbody>
</table>

*CBCL-I = Child Behavior Checklist Internalizing Problems T score.
*CBCL-E = Child Behavior Checklist Externalizing Problems T score.
< p < .05.
< p < .01.
< p < .001.
significantly with scores on measures of maternal and child adjustment. For example, mothers who reported more child management problems and greater caretaking burden on the QRS-S also reported higher levels of depression on the CES-D, lower levels of parenting satisfaction and efficacy on the PSOC, and more frequent child behavior problems on the CBCL. As might be expected, higher QRS-S Financial Stress scores were inversely related to Hollingshead SES scores. Concerns about the child's life-span care, as assessed by scores on the Life-span Care scale, were associated with higher levels of internalizing and externalizing child behavior problems on the CBCL. Higher scores on the Cognitive Impairment scale were associated with higher levels of CBCL externalizing problems, while higher scores on the Physical Limitations Scale were associated with higher levels of CBCL internalizing problems. Total QRS-S scores had a significant positive correlation with all measures of maternal and child adjustment, and a significant negative correlation with Hollingshead SES scores.

Unexpectedly, higher scores on the QRS-S Preference for Institutional Care scale were associated with fewer child behavior problems, higher parenting satisfaction, and lower maternal depression. Although these correlations were low, they were not in the direction predicted. Examination of the item–total correlations for the Preference for Institutional Care scale revealed one item with a significant negative correlation ($r = -0.30$) which may account for these unexpected correlations and for the scale's low internal consistency. A negative response to the item, "I am afraid ______ will not get the individual attention, affection, and care that he/she is used to if he/she goes somewhere else to live," is scored to reflect a preference for institutional care, apparently because this may indicate that the parent believes the child does not need to be in the home to receive adequate care. During administration of the questionnaire several mothers who responded "false" to this item remarked that the child was so special that he or she would be given love and attention wherever he or she lived in the future (e.g., at college or as a married adult). Thus, in our sample this item and the corresponding scale may reflect a positive appraisal of the child rather than a preference for institutionalization.

We examined the correlation among the individual QRS-S scales to assess the extent to which the scales measured independent constructs. Table IV presents Pearson correlation coefficients showing the relation of scale scores to each other and to total scores. The majority of correlations between individual scale scores were below .30; the highest correlation was .48.

**DISCUSSION**

Results of the present study suggest that families of children with cystic fibrosis, diabetes, and moderate mental retardation may be similar to families of
Table IV. Pearson Correlation Coefficients Among QRS-S Scales (n = 71)

<table>
<thead>
<tr>
<th>Variable</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<th>11</th>
<th>12</th>
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</thead>
<tbody>
<tr>
<td>1. Limits on family opportunities</td>
<td>.04</td>
<td>.15</td>
<td>.38*</td>
<td>.04</td>
<td>.37*</td>
<td>.48*</td>
<td>-.10</td>
<td>-.23*</td>
<td>.29*</td>
<td>.16</td>
<td>.55*</td>
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<tr>
<td>2. Family disharmony</td>
<td></td>
<td>-.26*</td>
<td>.36*</td>
<td>.08</td>
<td>.09</td>
<td>.22*</td>
<td>-.01</td>
<td>-.06</td>
<td>.28*</td>
<td>-.09</td>
<td>.40*</td>
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<tr>
<td>3. Financial stress</td>
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<td></td>
<td></td>
<td></td>
<td>.13</td>
<td>.21*</td>
<td>-.12</td>
<td>.29*</td>
<td>.26*</td>
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<tr>
<td>4. Dependency and management</td>
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<td>-.24*</td>
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<td>5. Cognitive impairment</td>
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<td>-.12</td>
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<td>6. Physical limitations</td>
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<td>7. Personal burden for respondent</td>
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<td>8. Lack of personal reward</td>
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<td>9. Preference for institutional care</td>
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<td>10. Life-span care</td>
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<td>11. Terminal illness stress</td>
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<td>12. Total</td>
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*p < .05.

*p < .01.

*p < .001.
Family Resources and Stress

well children with respect to generic aspects of family stress. According to maternal report, the extent of family conflict, limits on family opportunity, financial stress, and caretaking burden was no greater in families of children with chronic conditions than in families of well children. These findings are consistent with other literature suggesting that basic dimensions of family functioning are not necessarily disrupted by the presence of a child with a chronic condition (e.g., Cadman, Rosenbaum, Boyle, & Offord, 1991; Kazak, 1987; Lewis & Khaw, 1982). However, it should be noted that children in the present sample were not in an acute phase of illness, nor were they severely disabled. Kazak (1988), in a study of families of institutionalized children with mental retardation, reported QRS-S total scores that were nearly twice as high as those in the present study. Similarly, others have presented evidence that the level of child functional disability influences the degree of stress experienced by mothers of children with chronic conditions (Breslau, Staruch, & Mortimer, 1982). Thus, differences in the severity of illness or degree of disability across study samples may account for different findings in the literature regarding the impact of a child's chronic condition on the family.

In contrast to the lack of differences among diagnostic groups on the QRS-S scales assessing generic stressors, there were significant differences on QRS-S scales assessing stressors specific to the child's disability. As might be expected, mothers of children with cystic fibrosis had more concerns regarding the potentially fatal consequences of the child's condition than mothers of children with diabetes or mental retardation. Families of children with mental retardation appeared to face several areas of difficulty not shared by families of chronically ill or well children. Specifically, mothers of children with mental retardation reported more stress associated with child management problems, cognitive impairment, and planning for the child's care as an adult than did mothers of children with other conditions. Although related work suggests that, in comparison to other chronic conditions, child mental retardation is not associated with higher scores on general measures of maternal psychological distress (Walker et al., 1989; Wallander et al., 1989), results of this study and a study using the long version of the QRS (Dunst et al., 1986) demonstrate that parents of children with mental retardation obtain higher scores on scales that assess stress related to child caretaking demands. Thus, future research examining stress in families of children with chronic conditions should control for child cognitive impairment. This was accomplished in the present study by recruiting a sample of families of children at a similar level of mental retardation and comparing them to families of children with conditions not involving cognitive impairment, whereas others

6 The high proportion of single mothers (29%) in the mental retardation group suggested the possibility that their higher mean scores on these QRS-S scales could be due to the responses of single mothers who may have experienced more stress because of the absence of a partner to share in child care. However, results of t tests indicated no significant difference between single and married mothers on these scales.
have assessed the cognitive level of children with different conditions and used this variable as a factor in data analysis (cf. Dunst et al., 1986; Wallander et al., 1989). The latter approach has the advantage of allowing assessment of the impact of varying degrees of cognitive impairment both within and across diagnostic conditions.

Contrary to expectations, the level of stress reported on the QRS-S scales was not greater for families of older children. Low but significant positive correlations have been reported elsewhere between several QRS scales and age in families of children with mental retardation, but not in other populations (Holroyd, 1988), suggesting that the effect of age may differ by diagnostic group. In this study there were no significant interaction effects between age group and diagnostic group on the QRS-S scales, but small cell sizes prohibited an adequate test of the possibility that child age may be associated with higher levels of stress for families of children with mental retardation in comparison to families of children with other conditions.

With respect to the psychometric properties of the QRS-S, results of this study demonstrate that the QRS-S composite scale is internally consistent and appears to be a valid measure of family stress based on correlations with measures of maternal and child adjustment. Support for the reliability and validity of the individual scales is mixed. The strongest scales, based on adequate internal consistency, significant correlations in the expected direction with measures of related constructs, and utility in discriminating between diagnostic groups, include the following: Financial Stress, Dependency and Management, Cognitive Impairment, Life-span Care, and Terminal Illness Stress. Three additional scales, Limits on Family Opportunity, Family Disharmony, and Personal Burden, had significant correlations in the expected direction with several measures of maternal and child adjustment but had reliability coefficients in a range (.36 to .42) which suggests that these scales may not tap single underlying constructs. Another scale, Physical Limitations, discriminated among diagnostic groups but lacked internal consistency and had a restricted range, probably due to the general absence of physical limitations in this sample. Unexpectedly, the Lack of Personal Reward scale did not correlate significantly with measures of maternal adjustment; the inadvertent omission of one item (see Footnote 4) may have weakened this scale, although low scale scores and item content (e.g., “We enjoy ______ more and more as a person”) suggest the possibility of socially desirable responding. Finally, the Preference for Institutional Care scale lacked internal consistency and correlated with other measures in a direction opposite to that expected. As described in the Results section, anecdotal evidence from administration of the instrument suggests that because their children would not ordinarily be considered for institutionalization, mothers in our sample may have interpreted one or more items on this scale in a manner different from that intended. These unanticipated findings for some of the QRS-S scales may be due
to the nature of our sample, which was characterized by mild to moderate disability. Further work is needed to examine the psychometric properties of the instrument when administered to parents of children with moderate to severe disability.

Holroyd (1988) has suggested that "QRS profile analysis may contribute greater understanding of the problems faced by families than single stress indicators would provide" (p. 345). In comparison to QRS-S total scores, QRS-S profile analysis in this study provided a richer description of the stressors experienced by families of children with chronic conditions and suggested that the pattern of stressors is influenced by whether the condition is characterized by a fatal versus nonfatal outcome and by the presence versus absence of cognitive impairment. Information from such profile analysis may be more useful than total scores in designing interventions to benefit families of children with conditions that vary on these dimensions. In the present study, for example, the finding that QRS-S total scores were significantly higher in families of children with mental retardation or cystic fibrosis than in families of children with diabetes would be of little help in designing an intervention to address the specific needs of these families. In contrast, results from the QRS-S profile of scale scores suggest that programs for families of children with cognitive impairment should focus on child management skills and planning for the child’s care as an adult, whereas programs for families of children with a fatal condition should place particular emphasis on concerns related to the terminal nature of the child’s condition. Thus, it appears that our understanding of the impact of a child’s condition on the family, and our ability to design appropriate interventions, will be enhanced by attention both to patterns of stressors and to dimensions that differentiate chronic disorders.

REFERENCES


