Development and Evaluation of a Measure of Concerns Related to Raising a Child with a Physical Disability

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Developed a measure of perceived disability-related stress, the Parents of Children with Disabilities Inventory (PCDI). A content analysis of concerns expressed by mothers identified four primary domains: Medical and Legal Concerns, Concerns for the Child, Concerns for the Family, and Concerns for the Self. Item analysis performed on an initial item pool administered to 48 mothers recruited from area spina bifida and cerebral palsy clinics identified 40 items for further investigation. Psychometric evaluation of this final version was performed based on additional data collected from 63 mothers from the same clinics. The organization and reliability of the PCDI were confirmed through traditional measures of internal consistency and test–retest reliability over a 2-month interval. Preliminary support for the construct validity of the PCDI was provided through the confirmation of several hypothesized relationships. Scores on the PCDI were significantly related to maternal mental and physical health. Concerns for the Self scale made a significant unique contribution to these prediction models. Findings provide preliminary support for the PCDI being an appropriate and informative measure of perceived disability-related stress to be used with mothers of children with physical disabilities.

KEY WORDS: mothers; disability; measurement; perceived stress.

Maternal adjustment to the strain of caring for a child with a disability seems to span a wide range from psychological distress to successful adaptation. Numerous

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studies have found that mothers of children with disabilities report significantly more physical health complaints as well as increased levels of depression, anxiety, and overall emotional distress than mothers in control groups (Breslau, Staruch, & Mortimer, 1982; Rutter, Tizard, & Whitmore, 1970; Walker, Thomas, & Russel, 1971; Wallander, Pitt, & Mellins, 1990). A conceptual model has been developed incorporating multiple risk and resilience factors which are proposed to influence adaptation in mothers of children with disabilities (Wallander et al., 1989). Risk factors addressed in the model are disease/disability parameters, functional independence of the child, and psychosocial stressors. The resilience factors believed to be influential are intrapersonal factors, social-ecological factors, and stress appraisal and coping strategies. This model identifies numerous paths of influence of these factors on adjustment. Among the sources of psychosocial stress are a wide range of experiences unique to the role of parenting a child with a disability, termed disability-related stress. La Greca (1994) has called for measures addressing disease-specific concerns. Quittner and DiGirolamo (1995) have also recognized the importance of a more detailed analysis of specific problems that constitute this type of stress. Therefore, a measure that provides information about a parent's concerns based on her/his own report of the occurrence and the impact of disability-related events or states may prove useful.

Existing measures of disability-related stress include the Questionnaire on Resources and Stress (QRS; Holroyd, 1987) and the Handicap-Related Problems for Parents Inventory (HPPI; Wallander & Marullo, in press). Although both measures address specific needs of this population, both contain shortcomings. The QRS is extensive in length, requiring nearly an hour to complete. Shorter versions have been developed but omit categories of concern that appear crucial to its content validity and clinical use. In addition, because the QRS was intended for use with families both with and without a child with a disability, ambiguity in interpreting parental responses is a significant concern. The HPPI is brief, but its authors admit that because its items are theoretically based, they may not well represent stressors experienced by parents raising a child with a disability. In addition, like most measures of life events, the HPPI focuses on the frequency of occurrence of events, omitting any consideration of perceived stress related to this experience.

This is important because every person experiencing the same stressor will not appraise it in the same way (Lazarus & Folkman, 1984; Wallander et al., 1989). Perhaps this is the reason that previous research has been unable to predict maternal adjustment with a high degree of certainty. Although this strategy has been used in the general life events stress area (e.g., Cohen, Kamarck, & Mermelstein, 1983), perception of stress has not been incorporated into an inventory measuring disability-related stress. Prior research suggests this is important. Both Wallander et al. (1990) and Thompson, Gill, Burbach, Keith, and Kinney (1993) measured general perceived stress in addition to the tasks related to caring for a child with a chronic physical condition. Perceived stress from minor events was more predictive of maternal adjustment than was the amount of caretaking tasks.
This research, therefore, proposes to develop an inventory to measure both the amount and perception of stress experienced by a mother with respect to being a parent of a child with a disability. Thus the intent was to address both the frequency of occurrence of disability-related stressors and the perceptions of these.

**INSTRUMENT DEVELOPMENT**

*Content Analysis*

In a previous study (Wallander et al., 1990), mothers of children with a chronic physical disability were recruited from area clinic rosters and media announcements. That sample comprised 119 mothers of children ages 2 to 18 with a diagnosed disability prior to their second birthday. Mothers were asked on four occasions to describe the most bothersome thing related to their child’s disability that had happened to them in the last 2 months. A total of 246 discrete problem descriptions were provided.

Three assistants independently completed a content analysis of these problem descriptions by organizing them into hierarchical systems (i.e., consisting of main and subcategories) representing different domains of disability-related stress experienced by the mothers. The final system, described in Table I, was determined by the investigators based on a careful analysis of these three independent efforts. This organization of concerns recognized the similarities across the three independently derived initial systems and incorporated the unique strengths of

<table>
<thead>
<tr>
<th>Table I. Hierarchical Organization of Areas of Concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Medical and Legal Concerns (Items 1–10)</td>
</tr>
<tr>
<td>Worsening of illness</td>
</tr>
<tr>
<td>Medical tests and procedures</td>
</tr>
<tr>
<td>Experiences with doctors and hospital staff</td>
</tr>
<tr>
<td>Legal problems</td>
</tr>
<tr>
<td>II. Concerns for the Child (Items 11–20)</td>
</tr>
<tr>
<td>Communication—particularly between mother and child</td>
</tr>
<tr>
<td>School experiences</td>
</tr>
<tr>
<td>Social problems</td>
</tr>
<tr>
<td>Changes in behavior and attitudes of the child</td>
</tr>
<tr>
<td>Striving for equal treatment for the child</td>
</tr>
<tr>
<td>III. Concerns for the Family (Items 21–30)</td>
</tr>
<tr>
<td>Issues with husband</td>
</tr>
<tr>
<td>Issues with siblings</td>
</tr>
<tr>
<td>Changes in life-style</td>
</tr>
<tr>
<td>Financial strains</td>
</tr>
<tr>
<td>IV. Concerns for the Self (Items 31–40)</td>
</tr>
<tr>
<td>Personal feelings and fears (particularly about the future)</td>
</tr>
<tr>
<td>Additional responsibilities and time demands</td>
</tr>
<tr>
<td>Concern over the reactions of others (strangers and friends)</td>
</tr>
</tbody>
</table>
each. Four primary categories were thus identified, each of which had between three and five subcategories (see Table I): Medical and Legal Concerns, Concerns for the Child, Concerns for the Family, and Concerns for the Self. To partly validate this organization, two different assistants were trained to assign the original 246 problem descriptions reported by mothers to the categories of this system. Intercoder reliability was satisfactory for both the main categories ($M$ kappa = .82, $SD = .09$) and the subcategories ($M$ kappa = .75, $SD = .12$). Details of this phase of the research are reported in Wallander and Noojin (1995).

**Item Development**

Based on the 246 original problem descriptions in these categories and subcategories, a pool of 125 items was generated to represent each subdomain (see Table I) with at least three items. Each item describes a disability-related problem identified in the content analysis. Wording captured language commonly included in the descriptions provided by the mothers in the initial phase of this research. Each item stem (see the Appendix for final inventory) is followed by two 6-point rating scales: (a) how often the problem actually occurs (rated from never to nearly everyday or more) and (b) how frequently she is worried about this (hardly ever to almost always).

**Item Analysis**

The initial item pool was evaluated based on responses provided by a sample of 48 mothers recruited from the outpatient spina bifida and cerebral palsy clinics at Children’s Rehabilitation Service (CRS) in Birmingham, AL, which is a public health program. Mothers were recruited through personal contact while attending a clinic. It was carefully explained to the mothers that each item required two ratings that could be quite independent from one another. All mothers had children between the ages of 2 and 20 who had been diagnosed with a disability prior to their second birthday. Because the characteristics of this sample were highly similar to that of the sample in the subsequent instrument evaluation phase (see Table II), they are not detailed here.

Post hoc interviews indicated that none of the mothers reported significant concerns that were not included among these 125. Item analysis evaluated four scales corresponding to the content domains generated in the previous phase (Medical and Legal Concerns, Concerns for the Child, Concerns for the Family, and Concerns for the Self) and the degree to which the items on each scale contributed to scores on that scale. Item response distribution, item–total correlations for each scale, and interitem correlations were evaluated. Following these steps, the PCDI could be reduced to 40 items, with 10 in each domain (see Appendix). Considering the number of subcategories included in each domain,
10 items for each was believed to strike a balance between brevity while maintaining content validity, especially for clinical use. Correlations between the four domain scale scores from the original 125-items and this 40-item version of the PCDI were very high (all $r > .90$), suggesting the shorter version would be as effective in assessing the concerns of this population as the original version.

**INSTRUMENT EVALUATION**

**Method**

*Subjects and Procedures*

Mothers of children with physical disabilities were recruited from the same clinics using the same procedure as described previously. Seventy-one mothers
agreed to participate, with completed materials being returned by 63 (89%).
Demographic characteristics and child disability status are described in Table II.
Even considering that CRS is a public agency, there was a broad distribution of
families. In summary, the average participant in the study was a 34-year-old high
school graduate with an 8-year-old child with spina bifida. The average family
included four people with an income between $10,000–19,000.

After informed consent was obtained, mothers completed the measures in
the waiting room of the clinic. Verbal administration of the measures was neces-
sary for only four (6%) mothers. When this was needed, an investigator read the
questions aloud from an additional copy of the measures while the mother
marked the responses on her copy out of the investigator’s view to minimize
social desirability responses. A follow-up assessment including only the PCD1
occurred 2 months after the initial assessment for a random 49% of the sample
n = 31). Because most children visit CRS irregularly, this was performed over
the telephone.

**Measures**

**Demographic status** was measured with a checklist used in previous studies
of mothers of children with disabilities (e.g., Wallander et al., 1990), which
requests information about the mother’s age, marital status (2 categories), edu-
cation completed (5), ethnic status (5), family income (7), family size, and
child’s age.

**Child disability status** was measured with a modification of the Severity of
Physical Handicap scale (SPH; Rutter et al., 1970). Mothers were asked to rate
the level of their child’s functioning in the areas of everyday activities (5 catego-
ries), motor ability (5), and dietary needs (3), with higher ratings indicate a
greater severity of disability. An overall rating of the severity of the child’s
disability is also obtained from these ratings.

**Maternal mental health problems** was measured with the Brief Symptom
Inventory (BSI; Derogatis, 1975), where subjects rate on a 5-point scale the
presence of each of 53 symptoms. It is a short form of the Symptoms Check-
list-90-Revised (SCL-90-R). Internal consistency coefficients range from .71 to
.85 and test–retest reliability over a 2-week interval ranges from .68 to .91. The
BSI and SCL-90-R have validity support from extensive use in research (e.g.,
Derogatis & Melisaratos, 1983). The General Severity Index was used here,
which is the sum of item ratings.

**Maternal physical health problems** was measured with the Wahler Physical
Symptoms Inventory (WPSI; Wahler, 1968). Respondents are asked to rate how
often they have had each of 42 physical symptoms, using a 5-point scale. Internal
consistency ranges from .85 to .94. Test–retest reliability decreases over time,
ranging from .94 to .45, because the WPSI assesses a changing state. Satisfactory validity is reported (Wahler, 1968). Total scores on the WPSI are determined by calculating the sum of item ratings.

Disability-related stress was assessed with the Questionnaire on Resources and Stress-Short Form (QRS-SF; Salisbury, 1985), consisting of 48-items answered true-false. Overall internal consistency reliability is .76. Construct validity is supported by significant correlations with relevant constructs (Salisbury, 1989). A total score is calculated.

Dissatisfaction with Family Functioning was measured with the Family Adaptability and Cohesion Evaluation Scales III (FACES III; Olson, Portner, & Lavee, 1985). FACES III measures both perceived and ideal family functioning by asking the respondent to answer the same 20 items for each purpose. Two family functioning dimensions are addressed: Cohesion, the degree of closeness in the family; and Adaptability, its ability to adjust to circumstances. Internal consistency is .62 for Adaptability, .77 for Cohesion, and .68 for the Total score, while test–retest reliability over 4–5 weeks is .80 for Adaptability and .83 for Cohesion. Numerous studies support the validity of FACES, such as its ability to discriminate between problem and nonproblem families (e.g., Barnes & Olson, 1985; Olson et al., 1985). Dissatisfaction with the family system was determined by the difference between the actual and ideal total ratings. The greater the difference score, the greater the level of the mother’s dissatisfaction.

Child behavior problems was measured with the Revised Conners Parent Rating Scale (Goyette, Conners, & Ulrich, 1978). The mother rated how much of a problem each of 48 behaviors has been on a 4-point scale. High interparent reliability, test–retest reliability, and construct validity has been documented for the revised version (Goyette et al., 1978). A total behavior problem score was calculated as the sum of item ratings.

Results

Given the thesis of this research that perceived disability-related stress may be more informative than frequency of occurrence of disability-related events, the psychometric evaluation focused on the PCDI total and domain scale concern scores for economy of presentation. However, the predictive validity of these and the frequency of occurrence scores was compared. Means and standard deviations for all measures are presented in Table III.

Reliability

Internal consistency for the PCDI was calculated using Cronbach’s alpha and item-total correlations. They were Medical and Legal Concerns = .67 and
Table III. Means and Standard Deviations of Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents of Children with Disabilities Inventory</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total concern score</td>
<td>78.84</td>
<td>33.16</td>
</tr>
<tr>
<td>Total frequency score</td>
<td>58.18</td>
<td>23.65</td>
</tr>
<tr>
<td>Medical and legal concerns</td>
<td>20.13</td>
<td>9.54</td>
</tr>
<tr>
<td>Concerns for the child</td>
<td>20.90</td>
<td>10.95</td>
</tr>
<tr>
<td>Concerns for the family</td>
<td>15.48</td>
<td>8.73</td>
</tr>
<tr>
<td>Concerns for the self</td>
<td>22.33</td>
<td>11.58</td>
</tr>
<tr>
<td>Brief Symptom Inventory</td>
<td>0.59</td>
<td>0.59</td>
</tr>
<tr>
<td>FACES III-Satisfaction score</td>
<td>15.97</td>
<td>16.67</td>
</tr>
<tr>
<td>Questionnaire on Resources and Stress-Short form</td>
<td>27.03</td>
<td>4.02</td>
</tr>
<tr>
<td>Conners Parent Rating Scale</td>
<td>27.79</td>
<td>14.01</td>
</tr>
<tr>
<td>Wahler Physical Symptoms Inventory</td>
<td>40.57</td>
<td>27.53</td>
</tr>
</tbody>
</table>

.50, Concerns for the Child = .77 and .57, Concerns for the Family = .65 and .49, Concerns for the Self = .84 and .64, and Total = .90. Test-retest reliability over 2 months for the PCDI total score was .60, and for the scale scores: .66, .53, .41, .52, respectively.

Demographic Considerations

Age of the child was not significantly correlated with any of the PCDI scales (r = 0-.22) or with the total score (r = .16). Child age was further categorized into four groups to identify important stages of development: early childhood (< 5 years), middle childhood (5–10 years), early adolescence (10–15 years), and late adolescence (15–19 years). A one-way ANOVA showed no differences in Total PCDI scores across age groups. The age of the parent, however, was found to be significantly positively correlated with Concerns for the Self (r = .26, p < .05) and Total (r = .26, p < .05) scales, with older parents reporting higher levels of concerns. There were no significant associations between PCDI scores and either marital status, type of disability, family income, or ethnic status.

Validity

Concurrent and construct validity were examined by hypothesizing that certain convergent and divergent relationships among measures would exist. Correlations among all measures are presented in Table IV. Consistent with the purpose of the PCDI as a measure of perceived stress rather than a checklist of the occurrence of stressful problems, PCDI Total scale was only moderately associated with parent ratings of stressors on the QRS-SF. Among the domain
Table IV. Correlations Among Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PCDI total</td>
<td>—</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>2. PCDI medical and legal</td>
<td>.85*</td>
<td>—</td>
<td>.63*</td>
<td>—</td>
<td>.12*</td>
<td>—</td>
<td>.25*</td>
<td>—</td>
<td>.26*</td>
<td>—</td>
</tr>
<tr>
<td>concerns</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. PCDI concerns for the child</td>
<td>.79*</td>
<td>.57*</td>
<td>—</td>
<td>.57*</td>
<td>—</td>
<td>.57*</td>
<td>—</td>
<td>.57*</td>
<td>—</td>
<td>.57*</td>
</tr>
<tr>
<td>4. PCDI concerns for the family</td>
<td>.86*</td>
<td>.59*</td>
<td>.36*</td>
<td>.36*</td>
<td>—</td>
<td>.36*</td>
<td>—</td>
<td>.36*</td>
<td>—</td>
<td>.36*</td>
</tr>
<tr>
<td>5. PCDI concerns for the self</td>
<td>.86*</td>
<td>.59*</td>
<td>.36*</td>
<td>.36*</td>
<td>—</td>
<td>.36*</td>
<td>—</td>
<td>.36*</td>
<td>—</td>
<td>.36*</td>
</tr>
<tr>
<td>6. Brief Symptom Inventory</td>
<td>.40*</td>
<td>.25*</td>
<td>.25*</td>
<td>.25*</td>
<td>.25*</td>
<td>.25*</td>
<td>—</td>
<td>.25*</td>
<td>—</td>
<td>.25*</td>
</tr>
<tr>
<td>7. Wahler Physical Symp. Inv.</td>
<td>.28*</td>
<td>.28*</td>
<td>.28*</td>
<td>.28*</td>
<td>.28*</td>
<td>.28*</td>
<td>.28*</td>
<td>—</td>
<td>.28*</td>
<td>—</td>
</tr>
<tr>
<td>8. QRS-SF&lt;sup&gt;a&lt;/sup&gt;</td>
<td>.26*</td>
<td>.31*</td>
<td>.31*</td>
<td>.31*</td>
<td>.31*</td>
<td>.31*</td>
<td>.31*</td>
<td>.31*</td>
<td>—</td>
<td>.31*</td>
</tr>
<tr>
<td>9. Conner Parent Rating Scale</td>
<td>.27*</td>
<td>.30*</td>
<td>.30*</td>
<td>.30*</td>
<td>.30*</td>
<td>.30*</td>
<td>—</td>
<td>.30*</td>
<td>—</td>
<td>.30*</td>
</tr>
<tr>
<td>10. FACES-III</td>
<td>.12</td>
<td>.07</td>
<td>.07</td>
<td>.07</td>
<td>.07</td>
<td>.07</td>
<td>.07</td>
<td>—</td>
<td>.07</td>
<td>—</td>
</tr>
<tr>
<td>11. PCDI total frequency</td>
<td>.71*</td>
<td>.51*</td>
<td>.51*</td>
<td>.51*</td>
<td>.51*</td>
<td>.51*</td>
<td>—</td>
<td>.51*</td>
<td>—</td>
<td>.51*</td>
</tr>
</tbody>
</table>

<sup>*p < .05.</sup>  
<sup>*p < .01.</sup>  
<sup>*p < .001.</sup>  
<sup>*QRS-SF = Questionnaire on Resources and Stress—Short Form.</sup>
Table V. Results from Hierarchical Multiple Regression Analyses

<table>
<thead>
<tr>
<th>Step: Predictors</th>
<th>Statistic</th>
<th>Mental health</th>
<th>Physical health</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PCDI total frequency score</td>
<td>$R^2$</td>
<td>.13*</td>
<td>.11*</td>
</tr>
<tr>
<td>2. PCDI total concern score</td>
<td>$R^2$-change</td>
<td>.04</td>
<td>.00</td>
</tr>
<tr>
<td>1. PCDI total concern score</td>
<td>$R^2$</td>
<td>.16*</td>
<td>.08*</td>
</tr>
<tr>
<td>2. PCDI total frequency score</td>
<td>$R^2$-change</td>
<td>.01</td>
<td>.04</td>
</tr>
<tr>
<td>1. QRS-SF</td>
<td>$R^2$</td>
<td>.00</td>
<td>.03</td>
</tr>
<tr>
<td>2. PCDI total concern score</td>
<td>$R^2$-change</td>
<td>.17*</td>
<td>.06</td>
</tr>
<tr>
<td>PCDI scale scores</td>
<td>Overall $R^2$</td>
<td>.22*</td>
<td>.14</td>
</tr>
<tr>
<td>Medical and legal concerns</td>
<td>$B$</td>
<td>-.09</td>
<td>.23</td>
</tr>
<tr>
<td>Concerns for the child</td>
<td>$B$</td>
<td>.08</td>
<td>-.21</td>
</tr>
<tr>
<td>Concerns for the family</td>
<td>$B$</td>
<td>.04</td>
<td>-.06</td>
</tr>
<tr>
<td>Concerns for the self</td>
<td>$B$</td>
<td>.44*</td>
<td>.34*</td>
</tr>
</tbody>
</table>

*p < .05.

**p < .01.

QRS-SF = Questionnaire on Resources and Stress–Short Form.

Perception of stress, rather than illness-related tasks, has been found to be related to adjustment in mothers of children with a disability (Thompson et al., 1993). The hypothesis that the PCDI Total Concern Score would account for a greater proportion of the variance in mental and physical health than would the Total Frequency Score, however, was not supported. Both scores accounted for significant variance in mental and physical health. Neither made a significant contribution to the prediction of mental nor physical health beyond that provided by the other scale in hierarchical regression analysis (Table V). This lack of
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differentiation is largely explained by the highly significant correlation between these two scales \( r = .71, p < .001 \). Correlations were calculated between the disability and demographic variables and the measures of maternal adjustment. No significant associations were found and, therefore, these variables were not indicated as covariates in the above regression analyses.

Based on previous research on perceived stress (Cohen et al., 1983), it was further hypothesized that the PCDI Total Concern scale would account for a greater proportion of the variance in mental and physical health than would the QRS-SF, a more objective report of disability-related events. Indeed, as indicated above, the PCDI Total Concerns scale accounted for a significant amount of the variance in mental and physical health, but the QRS-SF did not. Even when the QRS-SF was entered in a prediction model first, the PCDI Total Concerns scale accounted for a significant increment in variance in both mental and physical health beyond that accounted for by the QRS-SF (see Table V).

Findings from our earlier research on an independent sample of mothers with children with physical disabilities indicated that reporting higher levels of concerns for the self was associated with lower reported physical health (Wallerand & Noojin, 1995). As can be seen in Table IV, this was confirmed in this study, as the Concerns for the Self scale was highly correlated with both mental and physical health. The Medical and Legal Concerns scale was also significantly correlated with mental and physical health, while the Concerns for the Child and Concerns for the Family scales were significantly correlated only with mental health.

To further assess the information provided by the scales of the PCDI, two separate regression analyses were completed to evaluate how well parental adjustment was predicted from these PCDI domain scales when considered together. Both mental and physical health were significantly predicted by this model (see Table V). However, only the Concerns for the Self scale contributed significant unique variance in either case, largely because the scales are substantially correlated with one another (see Table IV). Nonetheless, their tolerance estimates in the regression analyses (.44–.56), suggested that multicollinearity is not such a problem as to invalidate using them jointly in predicting criteria (Norusis, 1993).

DISCUSSION

In response to the need for a measure of perceived stress associated with raising a child with a disability, the Parents of Children with Disabilities Inventory was developed. Internal consistency calculations show that the items on each of the PCDI scales measure a unified but somewhat heterogeneous con-
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Test-retest reliability over a 2-month interval suggests that the PCDI is a relatively stable measure of current disability-related stress. Longer-term stability is not expected because the PCDI was designed to be sensitive to minor variations in the type and degree of concerns of these parents, such as changes in the academic calendar, medical complications and surgical procedures, and family events and holidays. Demographic characteristics were generally not related to PCDI scores. This may be explained by the small amount of variation within some classification groups, but may also suggest that the concerns listed on the PCDI are pertinent to many different types of families.

Although the age of the child was not related to PCDI scores, older mothers reported higher levels of concerns for both their children and for themselves. This may be due to several factors, such as the time since the child was diagnosed with a disability, the life-cycle stage of the family, the age at which the parent started having children, the place of target child in the sibling order, and the age of the siblings. These possible explanations warrant further investigation. However, we feel the influence of time since diagnosis is not likely to be large given the nonexistent relationship with age of the children in this sample, all of whom had been diagnosed with their disability prior to their second birthday.

As hypothesized, the scores on the PCDI were only moderately correlated with scores on the QRS-SF, a more objective record of disability-related events. Although both are purported as measures of disability-related stress, their approach is quite different as reflected by this association. Further investigation of the two measures suggests that the QRS-SF does not predict mental health problems, but is associated mostly with medical and legal concerns as measured by the PCDI. This may question whether the QRS-SF measures a broad range of disability-related stress. Alternatively, the QRS-SF may measure a construct that is more conceptually distinct from adjustment than that assessed with the PCDI. The differentiation between stress and adjustment is a challenging conceptual and measurement issue (e.g., Dohrenwend & Shrout, 1985; Lazarus, DeLongis, Folkman, & Gruen, 1985).

Initial support for the construct validity of the PCDI scales was obtained by examining several relationships. The scale measuring concerns for the child was partly validated through significant correlations with child behavior problems. Similarly, the scale measuring concerns for the family was partly validated through marginally significant correlations with maternal report of dissatisfaction with family functioning. Consistent with the conceptual model underlying this research (Wallander et al., 1989), disability-related stress reported by a mother of a child with a disability was related to her mental and physical health. Because concerns for the self made a significant unique contribution to this model relative to the other domains of concern, it may be that the mother's personal issues with
the experience of raising a child with a disability is the factor most responsible for her adjustment. This hypothesis needs to be further evaluated.

The PCDI requests both frequency of occurrence and level of concern ratings for each specific disability-related problem. We expected that these two rating scales would show discriminant validity. Instead, these ratings predicted adjustment equally well and with little uniqueness. Further examination of item content showed that a subset of items referenced a personal concern in the stem itself, perhaps obscuring the intended distinction between occurrence and concern ratings. Further investigation of the relative contribution of these two aspects of disability-related stress is needed.

The organization of the PCDI into four scales needs to be further examined. A confirmatory factor analysis would be helpful to support its organization, but a larger sample of mothers is required before this is defensible (Tabachnick & Fidell, 1989). Possible directions for additional validation include comparisons with previously established measures of life events stress. Comparison between the PCDI and the original longer version of the QRS should also be illuminating for both measures. It is also recommended that the PCDI be investigated as a correlate of other measures of parental adjustment and family functioning.

Future validation is also indicated with additional pediatric populations (e.g., insulin-dependent diabetes mellitus, cystic fibrosis). The content of the PCDI appears applicable to various chronic physical disorders with only small changes in wording in some items (see Appendix). It would be interesting to obtain distributions of individual items and scales for different conditions. Data on the use of the PCDI with fathers is also needed.

As in all correlational research, any conclusions regarding the direction of effects among the constructs of interest cannot be made. It must be acknowledged that the psychological status of the mother may influence both her ratings of perceived disability-related stress and adjustment. To partially address this concern, the content of the items on the PCDI was selected to address the mother’s experience specifically associated with raising a child with a disability. In addition, the introduction to the PCDI specifies that the items are to be rated in reference to the child’s disability. The PCDI does not appear to measure generic distress.

The current data suggest that even those mothers experiencing the highest levels of general psychological distress report varying degrees of concern on the different items of the PCDI. Inspection of total and scale scores on the PCDI may provide insight into a mother’s primary areas of concern as well as her overall level of stress associated with raising her child with a disability. Specific needs of the parent, child, and family can be assessed with the PCDI. PCDI scale scores can direct further evaluation to determine the type of intervention from which the family would benefit most.
## APPENDIX

### Parents of Children with Disabilities Inventory

Instructions: Below is a list of things that may have happened to you or your family related to your child's disability. Read each one carefully. Please indicate how often you are worried about it, if at all.

<table>
<thead>
<tr>
<th>I. Medical and legal concerns</th>
<th>II. Concerns for the Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child has trouble with bowel and/or bladder control.</td>
<td>11. I have trouble explaining to my child his/her medical condition.</td>
</tr>
<tr>
<td>2. My child has accidents as a result of his/her disability.</td>
<td>12. My child is falling behind in school.</td>
</tr>
<tr>
<td>3. Some treatments are uncomfortable for my child.</td>
<td>13. School is very frustrating for my child.</td>
</tr>
<tr>
<td>4. We have to wait for test results to come back from the lab.</td>
<td>14. Others tease or call my child names.</td>
</tr>
<tr>
<td>5. My child needs another surgery.</td>
<td>15. My child seems lonely.</td>
</tr>
<tr>
<td>7. Doctors don’t seem to care how I feel.</td>
<td>17. My child cannot play sports or games with the other children.</td>
</tr>
</tbody>
</table>

Almost always | Most of the time | Sometimes | Once in a while | Rarely | Hardly ever | Not applicable |
---|---|---|---|---|---|---|
A | M | S | O | R | H | N/A |
A | M | S | O | R | H | N/A |
A | M | S | O | R | H | N/A |
A | M | S | O | R | H | N/A |
A | M | S | O | R | H | N/A |
A | M | S | O | R | H | N/A |
A | M | S | O | R | H | N/A |
A | M | S | O | R | H | N/A |
A | M | S | O | R | H | N/A |
18. My child has temper tantrums.
19. My child thinks that he/she should always be able to do what he/she wants.
20. My child is afraid of hospitals.

III. Concerns for the Family
21. My husband/wife and I do not get along very well.
22. My husband/wife does not help me with the care of my child.
23. My husband/wife and I do not have much time to spend alone with each other.
24. My child has trouble keeping up with his/her brother or sister.
25. My other child does not understand the disability.
26. My other child is jealous of the time I spend with my child.
27. It is hard to find a sitter who can be with my child.
28. We have to make expensive trips for special treatment.
29. Treatment and care for my child costs a lot.
30. Our health insurance does not pay enough for my child's medical needs.

IV. Concerns for the Self
31. I think about things that my child will never be able to do.
32. I think about the fact that my child will not live very long.
33. No one else but me can really take care of my child.
34. I get very sad that my child has a disability.
35. Sometimes I have trouble being patient with my child.
36. I have to cut back on my hours at my job because of my child.
37. I have little time for the rest of my family.
38. I don't have enough time for myself.
39. I feel like I never have enough time to get everything done.
40. Other people don't know how to treat my child.
REFERENCES


