Relationship of Parental Psychological Distress to Consequences of Chronic Health Conditions in Children

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Objective: To assess whether parents' self-reported psychological distress was related to consequences of chronic health conditions in their children as reflected by three domains: functional limitations, reliance on compensatory mechanisms, and service use above routine care.

Methods: We used telephone survey data on children's health and parents' psychiatric symptoms from an inner-city community sample \( n = 380 \) and a population-based national sample \( n = 398 \).

Results: In the national sample, parents of children with functional limitations were more distressed than parents whose children experienced other types of condition consequences or none. In the inner-city sample, presence of a health condition was associated with greater parental distress, but there were no significant effects by consequence type.

Conclusions: Research needs to determine if parents of children with functional limitations represent a high-risk group and to identify the factors associated with their elevated distress.

Key words: childhood chronic illness; parental psychological distress.

Chronic illness or disability in a child is an enduring and important life stressor that can disrupt the lives of children and their families and put them at risk for disturbances of emotional and social functioning that may be more disabling than the physical conditions themselves. Compared with their physically healthy peers, children with ongoing health conditions have been found to experience higher rates of mental health problems, including a variety of psychiatric and emotional disorders, abnormal behavioral symptoms, and school-related adjustment problems (Cadman, Boyle, Szatmari, & Offord, 1987; Lavigne & Faier-Routman, 1992; Walker, Gortmaker, & Weitzman, 1981).

A child's chronic illness also may influence parents' psychological adjustment. Parents of children with health conditions are responsible not only for the physical care of their children, but for dealing with medical, educational, and other service providers; for helping their children cope with the physical and emotional demands of their illnesses; and for balancing competing family needs. Providing daily care to children with chronic health conditions often presents parents with a variety of burdens and obligations that can increase tension, deplete energy, and be accompanied by symptoms of psychological distress (Breslau, Staruch, & Mor-
Speechley & Noh, 1992; Walker, Ortiz-Valdes, & Newborough, 1989). In addition, most of this research has been conducted on mothers of children with health conditions, and there is very little information available on the extent of mental health effects for fathers (Hauenstein, 1990).

The disparity in study findings and wide range of functioning reported suggest that factors in addition to the child's health status influence parental adaptation. Several conceptual models have been proposed in the attempt to specify more completely the circumstances in which a child's chronic illness is likely to affect parental adjustment (e.g., Mullins et al., 1991; Thompson, Gustafson, Hamlett, & Spock, 1992; Timko, Stovel, & Moos, 1992; Wallander, et al., 1989). These models have incorporated a wide variety of risk and resistance factors, including characteristics of the child's illness, coexisting life stressors, parental coping style, and social support. Although the role of illness severity in parental distress probably has been examined most frequently, most studies fail to demonstrate convincingly that either medical indicators of severity or ratings by health providers relate to parents' psychological status. However, there is some evidence that the presence of condition-related functional limitations in children with chronic illness adds to mental health risks for their parents (e.g., Jessop, Riessman, & Stein, 1988; Silver, Bauman, & Ireys, 1995).

Traditionally, chronic health conditions in children have been identified for epidemiologic and research purposes using checklists of diagnoses and symptoms. However, checklists cannot cover every physical illness or disability that children may have, and they also may miss condition-related symptoms that emerge long before an actual diagnosis or label can be applied. Thus, there has been a conceptual shift toward a more "generic" or "noncategorical" approach that focuses on features and elements shared by different conditions (Pless & Pinkerton, 1975; Stein & Jessop, 1989). Using this approach, efforts to define and identify children with ongoing medical, behavioral, or cognitive disorders typically are based on assessing the consequences of children's health conditions rather than by reference to a diagnostic checklist (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993; Perrin, Newacheck, Pless, Drotar, Gottmaker, Leventhal, Perrin, Stein, Walker, & Weitzman, 1993).

One chronic illness definition based on the noncategorical approach was proposed by Stein et al. (1993). This definition reflects the notion of using consequence-based criteria rather than diagnostic
labels or etiology to identify ongoing health conditions in children. According to the theoretical framework underlying this definition, all ongoing health conditions produce consequences or sequelae that may be classified according to three separate conceptual domains: 1) functional limitations, 2) reliance on compensatory mechanisms, and 3) service use or need above routine care. Specifically, **functional limitations** refer to condition-related restrictions or impairments in age-appropriate function, activities, or social roles in the general areas of physical, cognitive, or emotional growth. **Reliance on compensatory mechanisms** reflects the use of an accommodation or device such as medication, special diet, equipment, or personal assistance to compensate for or minimize limitation of function, activities, or social role. Finally, **service use or need above routine care** specifies the use of or need for medical, psychological, or educational services above what is usual for the child's age.

Although presence of functional limitations and utilization of medical and related services are illness dimensions commonly used to describe children with chronic health conditions and the consequences they may experience, the notion of including “compensated” function in assessing children's health status has been introduced far more recently (Stein, 1991; Stein et al., 1993). This concept presumes that when functional impairment is compensated for and abilities are maximized, some children with chronic conditions will be indistinguishable from their healthy peers (e.g., the child with epilepsy who is seizure free with regular medication or one with phenylketonuria who can live a normal life as long as a special diet is carefully maintained). However, the successful compensation or accommodation that maintains functioning for the child imposes other consequences that should not be disregarded, including dependency on ongoing medical treatments and interventions, appliances, or personal assistance.

Following the formulation of this noncategorical framework and definition, a practical measurement tool that could be used to identify children with chronic health conditions using consequences was successfully developed and tested (Stein, Westbrook, & Bauman, 1997). In validating this new measure, a range of data on children's and caretakers' health status and adjustment was collected from two large random samples with different sociodemographic compositions, one drawn from an inner-city community and the other selected nationally. The objective of the present investigation was to use these survey data to ascertain whether the types of consequences experienced by children with chronic health conditions, as specified in the three conceptual domains of Stein et al.'s (1993) definition, were a source of variation related to differences in parental psychological functioning.

**Method**

**Sample Selection and Procedures**

The data used for these analyses were collected as part of a larger study of children with chronic health conditions. As noted, this larger study involved the design and test of a 39-item health inventory, the *Questionnaire for Identifying Children with Chronic Conditions* (QuICCC; Stein, Westbrook, & Bauman, 1997), a measure based on the noncategorical approach and specifically designed to identify children with ongoing illnesses and disabilities using condition consequences. More detailed information on the QuICCC is given below in the Measures section; additional information regarding sampling procedures is available in Stein, Westbrook, and Bauman (1997) or may be obtained from the authors on request.

In brief, the data were obtained in 1991 and 1992 in two separate surveys using randomly selected samples: (1) a sample of English- and Spanish-speaking households with children under 18 years drawn from a local northeastern inner-city community (the Bronx), and (2) a population-based national probability sample stratified by geographic region of the country that included English-speaking households with children under 18 years old across the entire United States. Both sets of data were collected from a centralized location by a large public opinion research company. Individual households were selected for the study using list-assisted random-digit dialing (RDD) techniques. These households were telephoned by trained research interviewers who screened for eligibility and conducted the interview. The QuICCC health inventory and several accompanying sociodemographic questions were administered to the person who identified her/himself as the adult who knew most about the health of all children under 18 years old living in the home. Verbal consent to complete the survey was obtained as approved by the Institutional Review Board. The inner-city survey obtained
QuICCCC screening data on a total of 1,275 children living in 657 eligible households. The national sample furnished similar data on a total of 1,388 children who lived in 712 households. These two samples are described more fully in Stein, Westbrook, and Bauman (1997).

One added goal of the larger study was to collect more in-depth data from each survey sample on the health status and adjustment of two subgroups identified through quota sampling: (1) approximately 200 “index” children and caretakers from separate households who were identified as having chronic health conditions based on the QuICCCC, and (2) a comparison group of 200 healthy children and caretakers drawn from households where no child met the QuICCCC criteria. Each of the two larger samples was constructed by screening enough households to complete these two subgroups. If a household had more than one child under 18 years old, the target child was randomly selected from among all eligible children. In these selected households, further information was obtained on the child’s functional status and psychological adjustment and on the physical and mental health of the adult respondent. Only the additional data from children and caretakers selected for the in-depth subsamples were used in the present analyses.

Sample Description

The inner-city subsample yielded data from 417 adults in total; however, 9% (n = 37) of the respondents were grandparents or other relatives acting as guardians, and we excluded them from the current analyses of parental adjustment. Of the 380 respondents remaining, 94% were biological parents; the others were stepparents, adoptive parents, or foster parents; 92% of the inner-city parents were female. In the national sample, there were 398 adult-child pairs whose health and psychological data were used in the current investigation; the adult respondents were primarily biological parents (95%), with small percentages of stepparents, adoptive parents, or foster parents; 83% of these respondents were female.

Sociodemographic characteristics of the two selected subsamples are given in Table I. As noted earlier, children eligible for the larger study ranged in age from birth through 17 years. Although this range also was evident in both subsamples, children in the inner-city subsample were somewhat younger on average than children in the national subsample (7.7 vs. 8.8 years, p < .01). Their sex distributions did not differ; 52% of children in the national subsample and 55% of the inner-city subsample were male. As expected, the two subsamples differed in race and in socioeconomic status, as measured by parents’ educational attainment and total household income. Children in the national subsample were primarily White, but the inner-city subsample was largely minority; 52% of the inner-city children were identified as Hispanic and 29% as Black, compared with 11% and 6% of the national subsample, respectively. The inner-city subsample had more parents with less than a high school education and fewer who went beyond high school, and also had comparatively more families in the lowest income groups and fewer in the highest. The differences between the national and inner-city subsamples in children’s race, parent education, and household income were statistically significant (p < .01).

There were no apparent differences between the national and inner-city subsamples in the types of health conditions reported by their parents. Both groups included children with consequences resulting from diverse types of physical, behavioral, and mental health conditions. Among the reported conditions and diagnoses, we counted over 50 different disorders. These included but were not limited to: asthma, diabetes, epilepsy, kidney disease, migraine headache, scoliosis, cerebral palsy, hearing loss, speech impairment, attention deficit disorder, learning disabilities, Down syndrome and other forms of mental retardation. As noted earlier, we

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<tr>
<th>Table I. Sample Sociodemographic Characteristics</th>
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<tr>
<td>Child age (yrs) Mean (SD)</td>
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<tr>
<td>Child gender % Male</td>
</tr>
<tr>
<td>Child’s race % White</td>
</tr>
<tr>
<td>Parent education %</td>
</tr>
<tr>
<td>&lt; High school</td>
</tr>
<tr>
<td>HS graduate</td>
</tr>
<tr>
<td>&gt; High school</td>
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<tr>
<td>Household income %</td>
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<td>&lt; $15,000</td>
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<tr>
<td>15,000–30,000</td>
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<tr>
<td>30,000–45,000</td>
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<td>&gt; $45,000</td>
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based our investigation on the noncategorical approach; therefore, we combined data from all children with chronic conditions for our analyses.

**Measures**

The health status inventory used was the QuICCC (Stein, Westbrook, & Bauman, 1997), a household level survey consisting of 39 item sequences. As noted earlier, the QuICCC was specifically developed to identify children with chronic health conditions using consequences rather than a diagnostic list. The QuICCC has been demonstrated to have good test-retest reliability, as well as content, convergent, and criterion-related validity.

Each QuICCC item asks about a specific consequence of having a chronic health condition. If the respondent reports that a child living in the household experiences a particular consequence, subsequent questions in the item sequence are used to determine if it is the result of a medical, behavioral, or other health condition and applies a duration criterion (actual or expected) of one year or more. A child is considered to have a chronic health condition if any QuICCC item is answered “yes” throughout all questions in its sequence. That is, the QuICCC was designed as a tool for identifying children having chronic conditions, not for measuring illness severity (Stein, Westbrook, & Bauman, 1997). In this study, added probes were used to obtain diagnostic information about the children reported to have condition consequences. That is, for each QuICCC item having a positive response sequence, a subsequent question asked the respondent to identify the condition responsible for that consequence. In addition, several standard survey questions accompanying the QuICCC were used to gather sociodemographic information on the adult respondent, the household, and the children (e.g., age, sex, ethnicity, parent education, annual income).

Parents' psychological distress was assessed by the Total score of Psychiatric Symptom Index (PSI; Ilfeld, 1976), a self-report measure of the intensity of 29 common psychiatric symptoms. Subjects respond to a list of complaints by indicating on a four-point scale (“never” to “very often”) how frequently each was a problem in the past two weeks. Scores are standardized based on percentages, providing a possible range of scores of 0 to 100. The measure was developed on a community sample of more than 2,000 men and women. It has good psychometric properties, including both high internal consistency reliability (Cronbach alpha = .91) and concurrent validity with other indices of emotional distress (Ilfeld, 1976). Psychiatric diagnosis is not measured or implied; however, PSI items are consistent with established diagnostic criteria used by clinicians (Okun, Stein, Bauman, & Silver, 1996). PSI Total scores of 20 or above are considered to reflect “high” symptom levels; this cut-off represents the top 15% of scores in the normative sample (Ilfeld, 1976). In addition, Bauman (1994) showed that female respondents with PSI Total scores of 30 or higher were likely to receive a diagnosis of major depression on a structured psychiatric interview.

**Data Analysis**

For our analyses, we grouped parents in each sample according to the types of consequences experienced by their children (see Table II). The 39 QuICCC items asking about consequences of chronic health conditions were sorted into the three separate domains specified earlier: functional limitations, reliance on compensatory mechanisms, and service use or need above routine care. Functional limitations was measured by 15 items that asked whether the child was unable to play with other children; had restrictions in activities; had an impairment in hearing, seeing, communicating; or had difficulty performing activities of daily living (ADLs) such as eating, dressing, washing, or toileting. Reliance on compensatory mechanisms was measured by 12 questions asking about regular medication use, special diets, and use of equipment,

### Table II. Means and Standard Deviations (SD) of Psychiatric Symptom Index (PSI) Total Scores among Two Samples of Parents According to Consequences of Chronic Health Conditions Experienced by Their Children

<table>
<thead>
<tr>
<th>Group</th>
<th>National Mean (SD)</th>
<th>Inner-city Mean (SD)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td></td>
</tr>
<tr>
<td>No condition</td>
<td>193</td>
<td>10.7 (13.5)</td>
</tr>
<tr>
<td>COMP only</td>
<td>29</td>
<td>11.1 (13.5)</td>
</tr>
<tr>
<td>SERV only</td>
<td>40</td>
<td>14.0 (14.0)</td>
</tr>
<tr>
<td>FUNC only</td>
<td>21</td>
<td>19.7 (19.7)</td>
</tr>
<tr>
<td>COMP &amp; SERV</td>
<td>32</td>
<td>10.1 (12.7)</td>
</tr>
<tr>
<td>COMP &amp; FUNC</td>
<td>9</td>
<td>15.4 (25.7)</td>
</tr>
<tr>
<td>SERV &amp; FUNC</td>
<td>24</td>
<td>15.4 (24.8)</td>
</tr>
<tr>
<td>COMP-SERV-FUNC</td>
<td>34</td>
<td>14.2 (18.2)</td>
</tr>
</tbody>
</table>

Higher PSI Total scores indicate greater distress. COMP = reliance on compensatory mechanisms, SERV = service use/need above routine for age, FUNC = functional limitations.
medical technology, or personal assistance to perform ADLs. Service use or need above routine care consisted of 12 items assessing current use or expressed need for hospitalization, doctor visits, nursing care or treatment, physical or speech therapy, and psychological services, and the need for special arrangements at school (e.g., classroom or schedule modifications, special instruction or services). Children were evaluated in each domain and given a "yes-no" categorical determination. Using these individual ratings, we then constructed a single 8-category independent variable representing all possible combinations of consequences, including "none."

Mean PSI Total scores among these eight identified parent groups were calculated and compared using one-way analysis of variance (ANOVA) with post-hoc Student-Newman-Keuls (SNK) tests used to detect significant differences between pairs of groups. We also used ANCOVA to establish whether any group differences in mean PSI Total scores remained after controlling for potential confounding variables such as age and socioeconomic status. Because there is a dearth of information on fathers, we also were interested in determining whether parent sex played a role and added this as another independent factor. All data were analyzed using the SPSS/PC+ Version 5 statistical package (Norusis, 1992).

Results

Table II gives the means (M) and standard deviations (SD) of PSI Total scores among groups of parents in the two subsamples according to the types of condition consequences experienced by their children; these data include the scores of parents with healthy children ("no condition"). We found significant main effects overall in both the national, \( F(7, 374) = 4.97 \), and inner-city samples, \( F(7, 372) = 2.70, p < .001 \). The highest mean PSI Total scores were found in the subgroups of parents whose children had chronic health conditions with functional limitations. This seemed true whether the child's condition was defined by consequences within a single domain or by multiple domains. In addition, the magnitude of these differences appeared to be greater in the national subsample than in the inner-city subsample.

We attempted to further specify the groups responsible for these overall effects in each subsample using post-hoc SNK tests, but found that the small

<table>
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<tr>
<th>Group</th>
<th>National</th>
<th>Inner-city</th>
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<tbody>
<tr>
<td>1) With FUNC</td>
<td>88</td>
<td>91</td>
</tr>
<tr>
<td>2) Without FUNC</td>
<td>101</td>
<td>74</td>
</tr>
<tr>
<td>3) No condition</td>
<td>193</td>
<td>215</td>
</tr>
</tbody>
</table>

Higher PSI Total scores indicate greater distress.

Table III. Means and Standard Deviations (SD) of Psychiatric Symptom Index (PSI) Total Scores Among Two Samples of Parents According to Presence of Chronic Health Conditions With and Without Functional Limitations (FUNC) in Their Children

In the national subsample, there were significant differences by group in PSI Total scores, \( F(2, 379) = 14.19, p < .001 \), with post-hoc SNK comparisons supporting the hypothesis that the overall effects could be attributed to the presence of functional limitations in the children. As Table III shows, parents of children having conditions with functional limitations; (2) had chronic conditions without functional limitations, i.e., were identified only by QuICCC items indicating reliance on compensatory mechanisms and/or service use above routine care; or (3) had no identified condition. Table III gives their mean PSI scores.

In the national subsample, there were significant differences by group in PSI Total scores, \( F(2, 379) = 14.19, p < .001 \), with post-hoc SNK comparisons supporting the hypothesis that the overall effects could be attributed to the presence of functional limitations in the children. As Table III shows, parents of children having conditions without functional limitations and parents of healthy children had mean PSI Total scores that were virtually identical. However, post-hoc comparisons revealed that parents in each of these groups scored significantly lower in distress than parents of children with functional limitations (\( p < .05 \)). This pattern was maintained; parent sex, child age, and annual household income were controlled with ANCOVA. We also found that fathers had lower mean scores overall than mothers in this subsample (10.2 vs. 16.1; \( F(1, 352) = 10.9, p < .01 \)). There was no interaction effect of parent sex with type of condition-related consequences, which suggested that the association between children's functional limitations and increased parental distress occurred equally in mothers and fathers in this subsample.
In the inner-city subsample, there also was a significant overall main effect of consequence group on parents' PSI Total scores, $F(2, 377) = 8.90, p < .01$. However, post-hoc tests showed that a child's having any chronic health condition, rather than one specifically involving functional limitations, was the key factor related to parental distress in this subsample. Parents of children with functional limitations still had the highest mean scores, but they did not differ significantly from parents of children experiencing other types of condition consequences ($p = .16$). In addition, both of these groups exhibited more PSI symptoms than parents of healthy children ($ps < .05$). Controlling parent sex, child age, and income had no effect on these results. Again, fathers exhibited fewer symptoms overall than mothers (10.6 vs. 19.0), $F(1, 373) = 6.7, p < .01$, and no significant interaction effects by parent sex were found.

To assess the possible clinical significance of these differences, we also used Chi-square analyses to compare the proportions of parents with "high" scores (i.e., PSI Total $\geq 20$) by presence of functional limitations in their children. The results essentially confirmed the earlier findings. In the national sample, the proportion of respondents with high scores was significantly higher among parents whose children had functional limitations (43%) than among parents of children having conditions without functional limitations (21%) or parents of healthy children (22%); $ps < .001$. In the inner-city sample, the proportions of parents having high scores also varied according whether their children had health conditions with functional limitations (51%), conditions without functional limitations (38%), or no condition (30%), but none of the paired differences between groups achieved a significance level of .05. We found a statistically significant difference in the proportion with high PSI Total scores only when comparing parents of children with and without chronic conditions (45% vs. 30%, $p < .01$).

Discussion

Results of the present study suggest that risks for psychological distress among parents of children with chronic health conditions may depend in part on the types of consequences experienced by their children. Using an operational definition and measure based on the work of Stein et al. (1993), we identified children with ongoing physical illnesses and disabilities and classified them according to three separate domains of condition consequences: functional limitations, reliance on compensatory mechanisms, and service use or need above routine care for age. Although parents of children with health conditions reported higher distress on a self-report measure of psychiatric symptoms than parents of healthy children, we also found differences in parents' responses according to the types of consequences experienced by their children.

Using a nationally selected random sample, we found that parents whose children had chronic health conditions without functional limitations had no more symptoms of psychological distress than parents of physically healthy children. Comparatively higher distress was found only among parents of children whose conditions involved functional limitations, i.e., restrictions or impairment in hearing, seeing, communicating, play, or activities of daily living. Their scores not only were higher on average than the two other groups of parents in this subsample; their mean symptom score of 21.1 also fell above the threshold of 20 that was noted to indicate high symptoms in the large community sample of adults used developing this measure (Ilfeld, 1976). These findings suggest that parents of children with functional limitations may represent a particularly high-risk group among parents of children with chronic health conditions and confirms the results of other studies demonstrating that functional impairment in children relates to poorer parental adjustment (e.g., Breslau, Staruch, & Mortimer, 1982; Canning, Harris, & Kelleher, 1996; Jessop, Riessman, & Stein, 1988; Silver, Bauman, & Ireys, 1995).

In the inner-city community sample, which had younger children and mostly poor and minority parents, a somewhat different pattern emerged. Again, parents of children with functional limitations exhibited the most psychological distress and, similar to the national subsample, their mean symptom score of 23.3 was high in comparison with scale norms. In this subsample, however, parents whose children had chronic conditions without functional limitations also had symptom scores that were somewhat elevated relative to parents of healthy children. Thus, in this subsample only, parental distress was higher when the child had a health condition, but was not significantly related to whether or not the child experienced functional limitations as a consequence of that condition.

Although the difference in results between the
national and inner-city samples is very intriguing and is one that policy makers and program planners may need to understand better, we presently are unable to specify why it occurred. Inner-city parents had higher distress overall, independent of whether or not their children had health conditions. The samples also clearly differed in their sociodemographic characteristics, many of which may heighten the mental health risks for inner-city parents compared with the national sample. Although we might speculate that these sociodemographic differences contributed in some way to the pattern we found, controlling these factors in the analyses did not influence findings within the subsamples. However, our samples also were not adequate to form subgroups of sufficient size to completely disentangle the possible combined effects of variables such as age, race, and socioeconomic status on this relationship. Thus, any attempts to explore this question in greater detail will require further analyses with larger datasets. It would be particularly important to determine if the mental health impact of simultaneous risk factors such as chronic illness and poverty is additive or multiplicative.

The apparent absence of elevated distress in parents of children having health conditions without functional limitations in the national sample still is particularly interesting. It has been noted previously that when limitations are successfully reduced by the addition of compensatory devices or assistance or through the increased use of medical and related services, many children with health conditions may be indistinguishable from healthy peers in terms of their abilities to perform self-care and other daily activities (Stein, 1991). It appears from our national data that parental adjustment also is less likely to be affected adversely in these circumstances. However, as our data suggest, when compensatory mechanisms and/or services are in place but the children still are perceived to limitations of age-appropriate activities, their parents do tend to report more psychiatric symptoms. Several factors could contribute to the increased vulnerability among parents of children with functional limitations, including systematic differences in their children's behavior, in the caregiving activities the parents must perform for them, or the ways in which parents perceive or appraise their own needs and responsibilities. The internal and external resources parents have available, including such things as parenting competence, self-esteem, or social support, also have the potential to influence the stress that parents experience and the level of distress they report. We suggest that these factors as well as others need to be studied further as possible explanatory variables.

In both samples, the associations with psychological distress that were found were consistent across mothers and fathers. There has been little systematic research on the extent of mental health risk for fathers of children with health conditions. In a society where so many new family forms have emerged, mothers still tend to be the main care providers and the most accessible to researchers. In comparison to fathers, mothers typically spend more time at the hospital, have more involvement in the treatment process, and interact more with health care professionals (Barbarin, Hughes, & Chesler, 1985; Hauenstein, 1990; Powazek, Payne, Goff, Paulson, & Stagner, 1980). Mothers also take on more of the caregiving responsibilities at home (Quittner, et al., 1992). However, fathers can experience burdens and distress as well, and emerging literature shows that having a child with a chronic condition may lead to direct emotional effects on fathers (e.g., Fife, Norton, & Groom, 1987; Staudenmayer, 1981). However, studies often find that children's ongoing health conditions do not affect the mental health of fathers as much as they do mothers (Daniels et al., 1987; Engstrom, 1991; Kazak & Marvin, 1984; Quittner et al., 1992; Timko, Stovel, & Moos, 1992). This pattern of lower distress in fathers than in mothers overall also was replicated in our study.

This study has both limitations and advantages. Because it was done as a telephone survey, we relied on the parent's responses in determining whether a health condition existed and the types of consequences that the child experienced. It is not possible to know whether these parental reports were complete or accurate, as no direct physical examination of the child could be made. However, parents' reports of their children's current health and day-to-day functioning do show high agreement with ratings of teachers, therapists, and other specialists (Bailey, Simeonsson, Buysse, & Smith, 1993) and their recall of health-related events corresponds well to provider records (Pless & Pless, 1995), suggesting that their responses are credible. The parents' psychiatric symptom scores also were based on self-report data. The use of a single data source may call into question the independence of the predictor and outcome measures, a commonly cited problem
in pediatric research (LaGreca & Lemanek, 1996). Although we cannot rule out shared method variance as an explanation for our findings, it has been previously shown that maternal attributions of children's behavioral limitations to a health condition are not influenced significantly by the mothers' own psychological adjustment (Dadds, Stein, & Silver, 1995). Still, the cross-sectional design of the present study cannot specify the causal direction of the relationships that we found between parent distress and perceptions of condition-related functional limitations in their children. As noted earlier, this issue as well as many other explanatory variables needs to be examined further so that the existence and nature of any causal linkages can be determined. Any new research in this also area would be strengthened considerably if assessments of the child's health status and parent functioning could be obtained from independent sources.

Most previous research on the psychosocial functioning of children with health conditions and their families has been criticized for relying on small, easily available, nonrepresentative samples that severely limit generalizability (Glasgow & Anderson, 1995; Levers & Drotar, 1996). Despite the limitations we observed, a rather strong advantage of the present study is that the data were obtained from two comparatively large, randomly selected, population-based samples as opposed to smaller, hospital or clinic-based groups of pediatric patients and their parents. This increases the generalizability of our findings and lessens the likelihood that they may be attributed to site-specific effects (Drotar, 1994).

In summary, our findings suggest that disturbances in mental health among parents of children with ongoing health conditions are not inevitable and may depend to some extent on whether the parent perceives the child to have a health condition that results in limitations of age-appropriate function, activities, or social roles. Additional research is needed to identify the factors associated with functional limitations in children and their relationship to adjustment difficulties of parents. These types of data would be invaluable in designing interventions to address the specific needs of high-risk parents. Further work also might address the impact of condition consequences on other meaningful psychosocial outcomes for children and parents such as marital conflict, family functioning, or quality of life. Our results also indicated that fathers of children with health conditions may be less vulnerable to psychological symptoms than mothers. However, fathers may express their distress in other ways, and this is another fruitful area for further systematic exploration. Moreover, our findings indicated that the patterns we found may depend on other factors, such as the family's socioeconomic status and resources, and it is essential that further studies include these other variables as well.

In addition, investigators should examine the role of other important illness dimensions that may influence adaptation. Because the study data were obtained in order to validate a consequence-based health survey, they were the only illness features we assessed, but there are many other illness characteristics crossing diagnostic boundaries (e.g., visibility, onset, course, prognosis) that also may be important in differentiating parent distress. Finally, an approach focusing on condition-specific characteristics has been favored by other investigators (e.g., Quittner et al., 1992). In our samples, there was considerable degree of overlap in reported conditions by type of consequence, and children also had range of consequences despite the same diagnostic label (Westbrook, Silver, & Stein, 1996). This divergence of characteristics and effects within discrete diagnostic groupings tends to support a noncategorical approach over those recommending greater condition specificity.

Although it appears evident that chronic illness in children is a risk factor for psychological distress in parents, researchers still need to develop and test alternative conceptual models that explain how and when this effect occurs. This will help to identify risk and resistance factors directly affecting psychosocial outcomes and to determine what role, if any, they also may play in the relationship of chronic illness to outcomes such as mental health. Clearly, there is much work that needs to be accomplished.

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