Primary Care Supports for Children with Chronic Health Conditions: Identifying and Predicting Unmet Family Needs

Janet E. Farmer, PhD, Wendi E. Marien, MA, Mary J. Clark, RN, MPH, Ashley Sherman, MA, and Thomas J. Selva, MD
University of Missouri Health Sciences Center, Columbia, Missouri

Objective To examine unmet needs among families of children with chronic health conditions treated in primary care settings and to identify predictors of these needs.

Method Primary care physicians referred 83 caregivers of children with chronic health conditions. Mothers completed the Family Needs Survey, as well as other measures of child and family functioning.

Results Mothers reported a high prevalence and broad range of unmet family needs. The most frequent area of need was for information about services and ways to promote child health and development. Predictors of total number of family needs included demographic characteristics, ratings of social support, and appraisals of family burden. Predictors of specific types of family needs varied according to category of need.

Conclusions Innovative psychosocial intervention programs are needed in primary care settings to reduce family needs and promote child health. More intensive family supports may be indicated for those with minority-group or low socioeconomic status, limited social support, or high perceived burden.

Key words children with special health care needs; family needs; primary care.

Parents of children with chronic health conditions are at risk for emotional distress and poor adjustment to the demands of caring for a child with special needs (Cohen, 1999; Silver, Westbrook, & Stein, 1998; Wallander & Varni, 1998). Multiple stressors may contribute to this increased risk, including feelings of uncertainty over child health outcomes, daily hassles associated with medical regimens, social isolation, role restriction, and financial strain. In addition, parents often report significant difficulty navigating the complex system of care to obtain needed medical, mental health, educational, and social services (King, Cathers, King, & Rosenbaum, 2001; Krauss, Wells, Gulley, & Anderson, 2001). These stressors may increase the psychological burden on children and their families, decrease the family’s ability to promote their child’s health, and result in overutilization of available medical services (Drotar et al., 2001; Frankel & Wamboldt, 1998; Janicke & Finney, 2000).

General pediatricians and other primary care providers are in a unique position to promote child and family health through access to needed services and psychosocial supports (Black, 2002; Perrin, 1999). They are a point of first contact for children with many different types of chronic health conditions, including those with physical, developmental, behavioral, and emotional disorders. They also are gatekeepers who manage children’s care. For these reasons, the American Academy of Pediatrics (2002) has urged primary care providers to create a “medical home,” or a stable source of family-centered care for children with special health care needs that promotes accessible, comprehensive, and coordinated care in their home community. Available research suggests that enhancing the scope and coordination of care has a positive impact on child and family psychological adjustment, satisfaction with care, pain management, adherence to medical regimens, and health care utilization (Anderson, Loughlin, Goldberg,

All correspondence should be sent to Janet E. Farmer, Department of Health Psychology, University of Missouri–Columbia, DCO46.46, One Hospital Drive, Columbia, Missouri 65212. E-mail: farmerje@health.missouri.edu.

DOI: 10.1093/jpepsy/jsh039
Journal of Pediatric Psychology vol. 29 no. 5 © Society of Pediatric Psychology 2004; all rights reserved.
Farmer, Marien, Clark, Sherman, and Selva

Thus, primary care providers have the potential to be a key resource for children with chronic health conditions and their families, especially in collaboration with medical specialists, psychologists, educators, and other team members (Perrin, 1999).

However, primary care physicians face barriers to providing such comprehensive care. For example, pediatricians report a lack of training in chronic care management, insufficient time to address nonmedical and family needs, and poor reimbursement for care coordination efforts (Davidson, Silva, Sofis, Ganz, & Palfrey, 2002; Leslie, Sarah, & Palfrey, 1998). Mental health issues often are neglected, as pediatricians have difficulty identifying children with emotional and behavioral problems, assessing parental coping, and responding to psychosocial concerns raised by parents (Brown & Freeman, 2002; Heneghan, Silver, Bauman, & Stein, 2000). With the advent of managed care, time constraints and fiscal limitations have become even more acute and have reduced collaborative practice with other professionals (Perrin, 1999; Schroeder, 1999). Due to these constraints, as well as the relatively high number of children with chronic health conditions treated in primary care settings (Farmer, Marien, & Frasier, 2003), primary care physicians frequently find it challenging to deliver comprehensive and coordinated services to all children with chronic health conditions within their practice.

Fortunately, not all families require the same level of support. Many are quite resilient and do not exhibit problematic levels of distress in the face of raising a child with special health care needs (Drotar, 1999; Wallander & Varni, 1998). Previous research has investigated contributors to the variability in family outcomes. These studies link parental distress and psychosocial risk to factors such as family demographics (race/ethnicity, financial resources), specific child characteristics (level of functional impairment, emotional/behavioral problems), social support, and parental beliefs about the chronic condition (Frankel & Wamboldt, 1998; Horton & Wallander, 2001; Kazak et al., 2001; King, King, Rosenbaum, & Goffin, 1999; Silver et al., 1998; Trute & Hiebert-Murphy, 2002; Willis, 2002). Contrary to traditional medical conceptualizations, family outcomes do not appear to be determined simply by the severity of the child’s health condition, but rather are multiply determined by reciprocal interactions between the caregivers and the child, other family members, the community, and the larger social context (Kazak, Segal-Andrews, & Johnson, 1995).

Previous research on family support needs has been conducted primarily in specialty care or community settings (e.g., early childhood education programs) or through large national databases (Bailey, Blasco, & Simeonsson, 1992; King et al., 2001; Krauss et al., 2001; Liptak & Revell, 1989; Silver & Stein, 2001). Little research is available about unmet needs of families of children with chronic health conditions identified in primary care settings. We identified only one other study that conducted a comprehensive assessment of child and family needs in primary care. That study was by Perrin, Lewkowicz, and Young (2000), who identified 123 children with chronic conditions in five pediatric practice groups and asked three respondents (mother, father, and the child’s primary care physician) to indicate which of 23 items/services the child would benefit from. Over two thirds of all respondents indicated a need for information about the child’s condition and services. Approximately half of all respondents also noted specific needs such as arrangements for school programs, social activities for the child, and education for the child about his/her condition or treatment. The least frequent needs were for legal assistance, transportation, and vocational activities for older children, which may be related to the fact that this study examined a middle-class sample of young children.

Parents of children with multiple conditions or more severe conditions described more unmet needs than those with single or less severe conditions. In general, there was a high level of concordance among mothers and fathers about their child’s condition and needs, though mothers reported a higher need for contact with other families of children with chronic conditions than did fathers. In contrast, physicians consistently underestimated child and family needs compared with parents, even though they rated the severity of the child’s condition worse than did parents.

Additional information about the unmet needs of children with chronic conditions and their families has the potential to aid primary care teams in developing resources and services for these families. In addition, to our knowledge, no research has conducted an in-depth examination of child and family variables that may predict unmet needs among this group of families in primary care. Such information might assist primary care providers in targeting the subset of families who may benefit from more intensive, comprehensive care, thus allowing them to use their limited resources more efficiently.
Therefore, the purpose of this study was to (1) identify the types and frequency of unmet needs among families of children with chronic health conditions treated in primary care practices, and (2) determine the child and family risk factors for unmet needs. Based on previous research, we hypothesized that parents of children with chronic conditions seen in primary care would describe a range of unmet needs. In addition, we hypothesized that higher levels of unmet needs would be associated with family demographics, poorer child functioning, less social support, and negative family perceptions about the impact of the chronic condition. One question of particular interest was whether parents’ perceptions of social support and family burden would predict unmet family needs above and beyond demographic variables and level of child functioning, since these perceptions might be particularly amenable to change through psychosocial interventions.

Method
Participants
Physicians from three primary care clinics in a central Midwest region referred 175 children with special health care needs and their parents to participate in a larger medical home research demonstration project. Eligible children ranged in age from 0 to 17 years and had a chronic health condition expected to last for more than 12 months. All chronic conditions were included, with the stipulation that at least one of the following applied: (1) existence of a biologically based health problem in the child involving more than one body system or a severe single system disorder such as kidney or cardiac disease that interfered with everyday functioning (developmental, psychiatric, or psychological disorders were counted as single system disorders), (2) ongoing involvement with multiple medical specialists, (3) more than three hospitalizations within the prior year or a hospitalization that lasted more than 15 days, (4) dependence on medical technology for survival or on a wheelchair for mobility, (5) ongoing need for home or school-based health care services, or (6) great difficulty in coordinating care due to the complexity of the child’s problems. Children with single system behavioral or mental health disorders (e.g., attention deficit/hyperactivity disorder, autism) were not included unless these conditions were severe enough to require a high level of health and related services. Eligible children also had to reside in a specified nine-county region and could neither be in any other research project nor be the sibling of another study participant.

Of the 175 children who were referred, only 149 met these eligibility criteria. Of the parents of these 149 eligible for the study, 37 declined to participate in the project and 29 initially consented to participate but did not complete the required research measures. The final sample size was 83 children (56% of those eligible).

On average, children in the sample were 7.1 years old (SD = 5.0 years), but age ranged from 0.2 to 17.4 years at the time of enrollment in the study. Approximately half of the sample was male (54%). Seventy percent of the children had more than one diagnosis (median = 2, range = 1–7). Each child’s primary health condition, as determined by the referring physician, was classified into one of six diagnostic categories using the International Classification of Diseases, ninth revision, clinical modification codes (ICD-9-CM) (Medicode, 2000). The largest of these six categories was organ-specific disorders, which included conditions such as diabetes, kidney disease, cancer, and asthma (35% of children with ICD-9-CM codes < 290, 390–739, or > 799). The most frequent single diagnostic category was prematurity and related conditions (23% of children with ICD-9-CM codes 760–779). The four other diagnostic categories were congenital anomalies (18% with codes 740–759), mental disorders (11% with codes 290–319), nervous system disorders (10% with codes 320–389), and ill-defined symptoms and signs (4% with codes 780–799). Based on parent report, average time since onset of the primary condition was 5.3 years (SD = 4.7 years, range = 0.1–17.2).

Ninety-four percent of the children lived with at least one biological or adoptive parent, and the remainder lived with other family members or foster parents. About half of the parents were either married or cohabitating (51%). Slightly more than half of these families (53%) resided in a metropolitan county that included a small city of 79,000 and an academic health center, and the rest lived in eight adjacent rural counties. Children were white (72%), African American (13%), Hispanic (4%), Native American (4%) and other (7%). Those from ethnic/racial minorities were overrepresented in the sample compared with the demographics of the region (28% minority-group enrollment compared with approximately 15% living in the region) (Office of Social and Economic Data Analysis, 2000). Most families were of lower socioeconomic status (SES) (M = 33.23, SD = 14.82) (Hollingshead, 1975), and 52% earned less than $20,000 per year (income range = <$10,000 to >$60,000). All children had health insurance, with primary coverage from either Medicaid fee for service.
(29%), Medicaid managed care (37%), or commercial insurance (34%).

**Procedure**

Consent to participate in the study was obtained by phone, according to a protocol approved by the institutional review board of the study site. Prior to entry into the larger demonstration project, parents completed a set of research measures for this study that assessed demographics, child functioning and health care services, unmet family needs, social support, and family burden. Nearly all the respondents were mothers (94%). The participants were paid $20 for completing the questionnaires.

**Measures**

**Family Needs**
The Family Needs Survey (FNS) (Bailey & Simeonsson, 1988) measures specific, functional needs of families of children with chronic conditions and disabilities. As shown in Table I, the scale contains 35 items categorized into six conceptually derived subscales. For each item, parents were asked to select one of three response choices: 1 = I definitely do not need help with this, 2 = Not sure, and 3 = I definitely need help with this. For the present study, the total number of reported needs for each family was obtained by summing the number of items rated 3 by the parent. Scores could range from 0 to 35, and higher scores indicated more needs. In studies of young children, the FNS has demonstrated adequate internal consistency (coefficient $\alpha$ for the total score = .91) (Sexton, Burrell, & Thompson, 1992) and acceptable test-retest reliability ($r = .67$ for mothers and .81 for fathers) (Bailey & Simeonsson, 1988). An analysis of the parents’ FNS responses for the current sample of children aged 0–17 years also showed strong internal consistency (Kuder-Richardson 20 = .88).

**Health Care Services Assessment**

Parents completed an adapted version of the family survey component of the Shared Responsibilities Tool Kit, version 1.0 (Epstein et al., 1998), a comprehensive assessment of health care service needs and resources for children with chronic health conditions. The present study examined only a subset of items from this measure, including family demographics and parent report about access to and satisfaction with the child’s health care services (i.e., primary care, specialty care, emergency care, inpatient hospital care, mental health care, and therapies and related services). On these satisfaction items, parents were asked to rate the quality of each service that their child had received within the past 12 months on a 5-point Likert scale (1 = excellent to 5 = poor). A rating of overall satisfaction with health care services was obtained by computing the mean of all ratings of health care services that the child had received within the past 12 months, with lower scores indicating greater satisfaction. In addition, parents were asked to rate one item assessing the overall quality of care coordination for their child on the same Likert scale, which was examined as a separate variable in all analyses.

**Child Functional Status**

Parents completed the Functional Status II–Revised (FS II-R), 14-item version (Stein & Jessop, 1991), which assesses the impact of chronic health conditions on various areas of child functioning (e.g., communication, mood, sleep, eating). Scores can range from 0 to 100, and higher scores represent better child functioning. Among a sample of children aged 0 to 16 years with chronic health conditions, a mean of 86.8 ($SD = 15.7$) on the FS II-R has been reported (Stein & Jessop, 1990). The FS II-R has demonstrated adequate internal consistency among children with chronic physical conditions (coefficient $\alpha$ ranging from .81 to .86) and good discriminant, criterion, and construct validity (Dadds, Stein, & Silver, 1995; Stein & Jessop, 1990).

**Social Support**

Parents completed the Family Support Scale (FSS) (Dunst, Jenkins, & Trivette, 1984), a measure of perceived helpfulness of different sources of support to parents. The measure contains 18 items reflecting potential sources of support (e.g., spouse, parents, friends, professional helpers) and asks parents to rate their helpfulness on a 5-point Likert scale (1 = not at all helpful to 5 = extremely helpful). The mean rating of available sources of support was computed for each participant to obtain an average social support satisfaction rating. Thus, scores could range from 1 to 5, with higher scores reflecting greater perceived social support. The FSS has demonstrated adequate internal consistency (coefficient $\alpha$ ranging from .77 to .87), test-retest reliability, and criterion validity (Dunst et al., 1984; Dunst, Trivette, & Cross, 1986; Dunst, Trivette, & Hamby, 1994; Sheeran, Marvin, & Pianta, 1997).

**Perceived Family Burden**

The Impact on Family Scale (IFS) (Stein & Riessman, 1980) assesses parents’ perceptions of the impact of their
child’s chronic illness on the structure and functioning of their family. The present study employed two subscales of the IFS: (1) familial/social impact (F/S), which reflects negative influences of the child’s illness on family members’ social interactions both within and outside of the family, and (2) personal strain (PS), characterized by the subjective distress and psychological strain experienced by the parent as a result of caring for a child with a chronic illness. These 15 items were rated on a 4-point Likert scale (1 = strongly disagree to 4 = strongly agree). For the present study, the F/S and PS subscales were summed to obtain a total perceived burden score. Both subscales have demonstrated acceptable internal reliability (coefficient α for the F/S ranging from .86 to .87 and for the PS from .81 to .91) and validity (Cronin, Shapiro, Casiro, & Cheang, 1995; Hunfeld, Tempels, Passchier, Hazebroek, & Tibboel, 1999; Stein & Riessman, 1980).

Results
Types and Frequency of Unmet Family Needs
Ninety-three percent of mothers reported one or more unmet needs on the FNS (M = 9.02 needs, range = 0–25). As shown in Table 1, the most frequently endorsed
need was for information about services for their child and ways to promote their child’s health and development. In addition, over half reported a need for caregiver supports, community services, and help with family relationships and/or financial costs. There was no significant difference in the number of unmet needs reported by mothers of younger (0–5 years) versus older (6–17 years) children on either the FNS total score or the six subscales (Wilcoxon rank sum test $p’s = .38$ to .83).

According to mothers’ reports of their child’s health care needs on the health care services assessment, most families had access to and were satisfied with their child’s primary, specialty, inpatient, and emergency care and therapy services. Of the mothers whose child received these services ($n’s = 53–82$), fewer than 13% were dissatisfied with the medical services delivered (i.e., fair/poor ratings). In contrast, access to and satisfaction with mental health and care coordination services were more problematic. Only 23% of children ($n = 19$) had received mental health services in the past year, whereas 30% of mothers ($n = 25$) indicated that their child needed these services. Fifty-two percent of mothers indicated that they needed more help with care coordination. For those who had received mental health and care coordination services, over one third (34–37%) reported dissatisfaction with these services.

**Predictors of Unmet Family Needs**

To determine the predictors of total unmet family needs, a hierarchical multiple regression analysis was conducted in two steps. First, to reduce the number of predictor variables included in the regression analysis, Spearman correlation coefficients were used to examine the relationship between the total number of needs and hypothesized risk factors for unmet needs. As shown in Table II, a higher number of unmet needs was significantly associated with lower SES, worse child functioning, lower perceptions of social support, lower satisfaction with health care services and care coordination, and greater perceptions of family burden. For categorical variables, group differences on the FNS were examined using the Wilcoxon rank sum test. These analyses revealed significant group differences in total unmet family needs based on the child’s race/ethnicity ($p = .03$). Those who were white reported significantly fewer unmet family needs than those from minority groups. As shown in Table II, greater unmet family needs were modestly associated with four other demographic and child variables. These included younger caregiver age, $r(83) = -.17, p = .12$; having Medicaid managed care health insurance rather than Medicaid fee for service or commercial insurance as the child’s primary health plan ($\text{Wilcoxon } p = .08$); and living in a metropolitan area in which the tertiary care hospital was located, rather than in a rural location ($\text{Wilcoxon } p = .09$). In addition, children with congenital anomalies tended to have fewer total unmet needs than those in the other five diagnostic categories ($\text{Wilcoxon } p = .09$). No significant relationships were found between total unmet needs and child age or time since onset ($r = .01$ and $-.04, p = .72–.88$) or for total needs and marital status or child gender ($\text{Wilcoxon } p = .31–.89$).

The hierarchical regression analysis was then computed with total number of unmet family needs serving as the criterion variable and with predictor variables entered in four steps: (1) demographics, (2) child functioning, (3) social support, and (4) family appraisals of burden due to the child’s condition (see Table III). In addition to including the predictor variables that were associated with unmet needs at $p < .05$, the other four risk factors that were weakly associated with total family needs were forced into the regression model with other demographic and child functioning variables at Steps 1 and 2. The predictor variables were selected and entered in this way in order to provide a rigorous test of social support and family appraisal variables as unique predictors of family needs at Steps 3 and 4.

The final regression model accounted for 39% of the variance in total unmet family needs, $F(11, 63) = 3.72, p = .0004$. As shown in Table III, demographic variables together accounted for a small but significant percentage of variance in unmet family needs in the first step, although none of the individual demographic variables was a unique predictor of total family needs. Child functioning variables, entered in the second step, did not add significantly to the prediction of unmet family needs. Social support ratings as a group were significant predictors of total needs after demographics and child variables were taken into account, although none of the specific social support variables was a unique predictor of family needs at Step 3. Finally, the mother’s appraisal of family burden also contributed significantly to the prediction of unmet needs, after accounting for demographics, child variables, and ratings of social support.$^1$

Six additional hierarchical regression analyses were then conducted to examine whether predictors of unmet needs differed for each of the six subscales on the FNS. Linear regression procedures were used for the three
subscales on which 60% or more of respondents indicated at least one unmet need. Thus, the criterion variable for the information, support, and community service subscales was the number of unmet needs indicated for each respective category. Logistic regression procedures were used for the other three subscales on which 40–51% of respondents indicated a need. The criterion variable for explaining to others, financial needs, and family functioning needs was whether or not respondents indicated any unmet needs in each of these categories. The predictor variables for all six regressions were the same as those used in the analysis of total unmet family needs, and they were entered in the same steps. Demographic and child functioning variables were forced into each regression model at Steps 1 and 2, but social support variables were included at Step 4 only if they were significant at Step 3.

As shown in Table IV, predictors of unmet family needs differed by type of need. Interestingly, demographic variables entered at Step 1 were a significant predictor only for community service needs. Demographics accounted for 23% of the variance in service needs, due primarily to the ethnic/minority status variable. Other steps in the regression model did not add significantly to the prediction of community service needs. There was a trend for demographic variables to predict whether or not the participant identified financial needs, likelihood ratio \( \chi^2(5, N = 79) = 9.21, p = .10 \), due primarily to SES \( \beta = -.27, p = .08 \). At Step 2 of these regression analyses, child functioning variables as a group contributed significantly to the prediction of information needs, but not to the prediction of other categories of need.

Psychosocial variables entered at Steps 3 and 4 contributed to the prediction of unmet needs on four subscales of the FNS, even after demographics and child functioning variables were taken into account. More specifically, the mothers’ ratings of social support at Step

---

### Table II. Means, Standard Deviations, and Intercorrelations for Total Family Needs and Predictor Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Needs Survey</td>
<td>9.02</td>
<td>6.35</td>
<td>−25**</td>
<td>−17*</td>
<td>−25**</td>
<td>.30***</td>
<td>27**</td>
<td>−22**</td>
<td>.50****</td>
</tr>
<tr>
<td><strong>Predictor variables</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Socioeconomic status</td>
<td>33.23</td>
<td>14.82</td>
<td>−</td>
<td>−</td>
<td>−24**</td>
<td>.05</td>
<td>.07</td>
<td>−.08</td>
<td></td>
</tr>
<tr>
<td>2. Caregiver age</td>
<td>33.16</td>
<td>9.31</td>
<td>−</td>
<td>−</td>
<td>−.09</td>
<td>−.02</td>
<td>.04</td>
<td>−.15</td>
<td>.13</td>
</tr>
<tr>
<td>3. Child functioning</td>
<td>82.70</td>
<td>17.10</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−10</td>
<td>.02</td>
<td>.18</td>
<td>−.36***</td>
</tr>
<tr>
<td>4. Satisfaction with health care providers</td>
<td>2.27</td>
<td>0.69</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>.53***</td>
<td>−.51****</td>
<td>.25**</td>
</tr>
<tr>
<td>5. Satisfaction with care coordination</td>
<td>2.99</td>
<td>1.24</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−.30***</td>
<td>.18</td>
</tr>
<tr>
<td>6. Perceived social support</td>
<td>2.95</td>
<td>0.83</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−.25**</td>
</tr>
<tr>
<td>7. Perceived family burden</td>
<td>36.65</td>
<td>10.34</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
</tr>
<tr>
<td>8. Race/ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.1 White (n = 60)</td>
<td>8.00</td>
<td>5.82</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
</tr>
<tr>
<td>8.2 Other (n = 23)</td>
<td>11.70</td>
<td>7.02</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
</tr>
<tr>
<td>9. Type of health plan</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.1 Medicaid managed care</td>
<td>10.63</td>
<td>6.54</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
</tr>
<tr>
<td>9.2 Other (n = 52)</td>
<td>8.08</td>
<td>6.17</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
</tr>
<tr>
<td>10. Geographic location</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.1 Rural (n = 39)</td>
<td>7.82</td>
<td>6.12</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
</tr>
<tr>
<td>10.2 Urban (n = 44)</td>
<td>10.09</td>
<td>6.43</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
</tr>
<tr>
<td>11. Diagnostic category</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.1 Congenital anomalies</td>
<td>6.47</td>
<td>5.54</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
</tr>
<tr>
<td>11.2 Other (n = 68)</td>
<td>9.59</td>
<td>6.42</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>−</td>
</tr>
</tbody>
</table>

*a* Higher scores represent worse ratings (i.e., more needs, less satisfaction, and more burden).

*b* Higher scores represent better ratings (i.e., better socioeconomic status, better functioning, and greater satisfaction with social supports).

*c* Means and SDs are for total needs on the Family Needs Survey for each variable. There was a significant difference in needs related to race/ethnicity \( p = .03 \) and a trend toward significant differences for type of health plan, geographic location, and diagnostic category \( p = .08–.09 \).

*p* = .12; **p < .05; ***p < .01; ****p < .001.
3 accounted for additional variance in unmet information needs and for the likelihood of needing help with family functioning. At Step 4, the mothers’ appraisal of the impact of the child on the family added significantly to the prediction of unmet information needs, support needs, financial needs, and family functioning needs. Enrollment in a managed care health plan added unique variance to the prediction of information needs at this final step, along with the rating of family burden. If a child has primary health insurance through Medicaid managed care, mothers may face greater barriers in access to health care services and may have more questions about resources for their child and how to promote their child’s development.

**Discussion**

This study highlights the prevalence of unmet needs among families of children with chronic health conditions who are identified in primary care settings. The results are consistent with previous research studies that describe numerous unmet needs among these families (Bailey et al., 1992; Liptak & Revell, 1989; Perrin et al., 2000), inadequate mental health services for their children (Brown & Freeman, 2002; Davidson et al., 2002; Silver & Stein, 2001), and the lack of resources for effective care coordination (King et al., 2001; Krauss et al., 2001). The extent of unmet needs underscores the opportunity for primary care physicians to collaborate with psychologists and other community professionals to provide additional supports that promote child health and family functioning (McMenamy & Perrin, 2002).

As expected, there was considerable variability in level of unmet needs. Greater family needs were associated with demographic factors, including both ethnic minority status and lower SES. Minority-group status was a particularly notable contributor to the prediction of unmet community service needs in areas such as dental/health care, respite care, and preschool/day care services. This was not surprising, since previous research has shown that low-income and minority-group families are at higher risk for having a child with a chronic condition and for having difficulty with access to services that improve child health outcomes (Landgraf & Abetz, 1998; Newacheck et al., 1998; Rosenbach, Irvin, & Coulam, 1999; Silver & Stein, 2001; Smedley, Stith, & Nelson, 2002). As illustrated by the present study, simply having health insurance and a source of primary care for the child may not be sufficient to reduce the disparity between low-income/minority-group families and other groups in terms of unmet needs. Other factors may interfere with these families’ ability to meet child and family needs, such as cultural barriers, lack of transportation, greater psychological distress, and/or disabling conditions in the mother (Lee, Sills, & Oh, 2002; Silver et al., 1998; Smedley et al., 2002).

Child variables did not add to the prediction of total family needs after demographic factors were taken into account. Others also have found that the severity of child disability is not generally a key determinant of family outcomes (Frankel & Wamboldt, 1998; King et al., 1999). However, unmet needs appear to vary somewhat by the complexity of the child’s condition and the type of family need examined. For example, child functioning variables contributed to the prediction of information needs, but not to the other five categories of need. Mothers who rated their child as more severely affected reported greater needs for information about their child’s condition, services available, and ways to interact with the child to promote optimal development. Perrin and colleagues (2000) also found some variation in type of family needs based on the severity of the child’s condition.

Perceived level of social support predicted total number of unmet family needs, even after demographic factors and child functioning were controlled statistically. More specifically, social support ratings contributed...
to the prediction of two subcategories of family need: information needs and family functioning. Those mothers who felt more supported by others identified fewer needs for information about how to promote their child's health and well-being, as well as fewer needs for strategies to promote effective family interactions. With adequate professional and informal community supports, families may be able to access more resources and function more effectively, thereby promoting health in the child and reducing overall family needs. These findings are consistent with a large body of research (e.g., Kazak et al., 2001) indicating that higher levels of perceived social support are associated with more positive child health outcomes.

Finally, appraisals of family burden significantly predicted total family needs, even after accounting for all other predictor variables. Such appraisals also contributed to the prediction of four of the six categories of unmet family needs. This calls attention to the importance of mothers' perceptions of the impact of

### Table IV. Results of Six Hierarchical Regression Analyses Predicting Category of Unmet Family Needs

<table>
<thead>
<tr>
<th>Predictor Groupa</th>
<th>Demographics</th>
<th>+ Child Functioning</th>
<th>+ Social Support Ratings</th>
<th>+ Family Burden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs</td>
<td>Demographics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information</td>
<td>ns</td>
<td>$R^2 = .18$</td>
<td>$R^2 = .27$</td>
<td>$R^2 = .33$</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$F(7, 71) = 2.20^*$</td>
<td>$F(10, 66) = 2.47^{**}$</td>
<td>$F(11, 63) = 2.80^{**}$</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$\Delta R^2 = .09$</td>
<td>$\Delta F(3, 66) = 3.17^*$</td>
<td>$\Delta F(1, 63) = 5.12^{*}$</td>
</tr>
<tr>
<td>Support</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>$R^2 = .29$</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>$R^2 = .34^{**}$</td>
</tr>
<tr>
<td>Community service</td>
<td>$R^2 = .23$</td>
<td>$R^2 = .25$</td>
<td>$R^2 = .29$</td>
<td>$R^2 = .30$</td>
</tr>
<tr>
<td></td>
<td>$F(5, 73) = 4.46^{***}$</td>
<td>$F(7, 71) = 3.32^{**}$</td>
<td>$F(10, 66) = 2.69^{**}$</td>
<td>$F(8, 67) = 3.51^{**}$</td>
</tr>
<tr>
<td></td>
<td>RACE/ETHNIC, $\beta = .37^{**}$</td>
<td>$\Delta R^2 = .02$</td>
<td>$\Delta F(2, 71) = 0.61$, ns</td>
<td>$\Delta R^2 = .04$</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$\Delta F(3, 66) = 1.36$, ns</td>
<td>ns</td>
<td>$\Delta F(1, 67) = 3.81$, ns</td>
</tr>
<tr>
<td>Help explaining to others</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Financial</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Help with family functioning</td>
<td>ns</td>
<td>ns</td>
<td>LR $(10, N = 77) = 18.27^{*}$</td>
<td>LR $(11, N = 75) = 23.88^{**}$</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>$X^2(3, N = 77) = 7.82^*$</td>
<td>$X^2(1, N = 75) = 6.04^{**}$</td>
</tr>
</tbody>
</table>

LR = likelihood ratio test; HEALTHPLAN: 1 = Medicaid managed care, 2 = other; RACE/ETHNIC: 1 = minority-group status, 2 = white; BURDEN = rating on the Impact on Family subscales.

Demographic and child functioning variables were forced into each regression model regardless of their significance in predicting the unmet needs in each category. Social support ratings were included at Step 4 only if they were significant at Step 3.

* $p < .05$; ** $p < .01$; *** $p < .001$. 

* Prior research has shown that parents differ in how they interpret caregiving demands and in their level of distress in response to them (Horton & Wallander, 2001; Trute & Hiebert-Murphy, 2002). This study suggests that greater perceptions of personal strain and burden may interfere with the mother's ability to access needed supports and services, potentially resulting in a negative impact on both child and family outcomes over time. These appraisals may be associated with maternal depression, which was not measured in this study but is known to increase the risk of ineffective parenting (Frankel & Wamboldt, 1998; Heneghan et al., 2000). However, the direction of the relationship between perceived caregiver burden and family needs is not clear. It is possible that mothers' difficulty obtaining and coordinating resources to meet their child's needs may cause them to feel overwhelmed and burdened. Regardless of the nature of the relationship between perceived...
family burden and unmet needs, maternal reports of high family burden may indicate an increased need for help with accessing services and supports. Additional research, including longitudinal studies, is needed to better understand the contribution of cognitive appraisals to parental distress and to the mother's ability to obtain needed resources for her child and other family members.

This study has several limitations. First, the small sample size and the modest participation rate (56%) may limit its generalizability to other families of children with chronic health conditions. In addition, the respondents in this study were mostly mothers. Their perceptions of family needs have been shown to differ somewhat from fathers' perceptions, especially in the area of need for support from other families of children with chronic conditions (Perrin et al., 2000). Finally, this study examined responses from mostly low-income mothers, whose needs may be greater due to financial constraints. However, there are strong similarities in the type of unmet needs reported by this low-income sample and the middle-class sample of mothers and fathers from the Perrin et al. (2000) study. For example, both studies show that most parents of children treated in primary care settings have a high need for information about the child's condition and services available. This study also demonstrates that demographic factors contribute to unmet needs primarily for community services and that psychosocial factors (i.e., social support and perceptions of family burden) account for significant variance in total unmet needs even after demographics are taken into account. More research is needed to refine the study of family needs from both mothers' and fathers' perspectives and to clarify optimal approaches to intervention for families with different income levels.

Given their strong ties to primary care, pediatric psychologists have the potential to partner with physicians in developing clinical interventions that promote healthy functioning in children with chronic conditions and their families (Black, 2002; Brown & Freeman, 2002; McMenamy & Perrin, 2002). For example, this study suggests that many caregivers may benefit from psychosocial interventions in primary care settings that enhance their level of social support and promote more positive appraisals of the impact of the child on the family, regardless of family demographics or their child's age, diagnosis, and level of functioning. However, given the range of family needs and limited health care resources, psychologists also must help to tailor psychosocial programs to match family needs.

Kazak and colleagues (2001) and Black (2002) describe a method of tailoring clinic-based psychosocial programs using a public health/health promotion paradigm recommended by the Institute of Medicine (Mrazek & Haggerty, 1994). In this paradigm, programs that promote the health and well-being of target populations are classified into universal, selective, and indicated categories. To illustrate, universal psychosocial programs for the population of children with chronic conditions served in primary care would be provided to all families within a practice, regardless of risk factors or specific concerns. Interventions might include general education about (1) public agency resources, (2) laws that affect their child's care (e.g., the Individuals with Disabilities Education Act), and (3) Internet links to parent-to-parent support groups.

Selective programs would be for families who are at increased risk for unmet needs and psychosocial difficulties, such as those identified in this study who face economic or racial/ethnic disparities in health care, lack social supports, or report a high level of family burden. Such programs might involve referral to a nurse or other designated primary care team member for in-depth evaluation of family needs and links to needed services (Farmer, Clark, & Marien, 2003; Silva, Sofis, & Palfrey, 2000). As part of selective programs, psychologists might provide psychoeducational interventions about ways the child's chronic condition affects growth and development, how to support the child's learning and social integration, self-care strategies for caregivers, and methods of supporting siblings and other family members. Lastly, indicated programs would be for those families with multiple signs of risk for difficulties in meeting child and family needs. These families require intensive, individualized interventions that prevent the progression of family problems and promote healthy functioning, such as the direct services often provided by pediatric psychologists.

Currently, noncategorical methods of identifying children with special health care needs exist and show promise in targeting this population for tailored psychosocial interventions in primary care settings (Bethell et al., 2002; Farmer, Marien, & Frasier, 2003). Future research must develop a stratification tool that primary care teams can use to clarify which level of treatment these families need. Kazak and colleagues (2001) are developing such a tool in a specialty care setting for children with cancer and their families that may serve as a model for primary care. This family-centered approach has the potential to improve service
delivery in primary care settings and to optimize children's health outcomes.

Acknowledgments

This research was supported by a grant from the Robert Wood Johnson Foundation (grant no. 035558) and from the Missouri Department of Health and Senior Services (contract no. AOC00380127).

References


Hollingshead, A. B. (1975). *Four factor index of social status*. Unpublished manuscript, Yale University, New Haven, CT.


**Note**

1 The FNS included eight items labeled *social supports*, so there was the possibility that the relationship between the social support predictor variables and the FNS in the regression analysis was due to shared method variance. For this reason, we removed the social support items from the FNS and conducted the hierarchical regression analysis again with this modified criterion variable. There was no difference in the pattern of predictors of total unmet needs from this adjusted regression analysis (total $R^2 = .42$; demographic, social support, and appraisal predictor variables contributed to significant changes in $R^2$ at Steps 1, 3, and 4).