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“I wouldn’t look at it as stress”: Conceptualizations of Caregiver Stress among Low-Income Families of Children with Asthma

Natalie R. Sampson, MPH,

A doctoral candidate in the Department of Health Behavior Health Education at the University of Michigan School of Public Health (UM-SPH) in Ann Arbor

Edith A. Parker, DrPH, MPH,

Professor and head of the Department of Community and Behavioral Health and is the Director of the Prevention Research Center for Rural Health at the University of Iowa’s College of Public Health in Iowa City

Rebecca R. Cheezum, MPH,

Assistant Professor in the School of Health Sciences at Oakland University in Rochester, Michigan

Toby C. Lewis, MD, MPH,

Assistant Professor in the Department of Pediatrics and Communicable Diseases at UM in Ann Arbor

Ashley O’Toole, MPH, MSW,

Center Manager for the Detroit Urban Research Center at the UM-SPH

Adriana Zuniga,

Community Environmental Specialist with Community Action Against at UM-SPH

Jean Patton,

Community Environmental Specialist with Community Action Against at UM-SPH

Thomas G. Robbins, MD, MPH, and

Professor in the Department of Environmental Health Sciences at UM-SPH

Carla C. Keirns, MD, PhD, MSc

Director of the Program on the History of Medicine and Assistant Professor in the Department of Medicine at Stony Brook University in Stony Brook, New York

Abstract

Low-income caregivers of children with asthma experience multiple stressors, likely worsening family health. As part of Community Action Against Asthma’s community-based participatory research partnership, researchers conducted 40 qualitative semi-structured interviews and quantitative surveys with low-income caregivers of children with asthma in Detroit, Michigan. Participants described daily childhood asthma experiences and completed scales including the Peds Quality of Life Family Impact Module and Zarit Burden Caregiver Scale. Quantitative scale findings suggested participants are moderately stressed or affected by their child’s illness. While there was some accordance between qualitative and quantitative findings, qualitative findings additionally captured many relevant life stressors, seemingly overlooked or conflated in scale responses. Many participants described asthma as part of childrearing, rather than as a stressor or

burden. Findings encourage improvement of clinical, psychometric assessments used to measure and address stressors that shape health for many families with children with asthma.

Keywords

Childhood asthma; caregivers; life stress; economic insecurity

In families below the federal poverty level in the U.S., approximately 13.5% of children have asthma currently, compared with approximately 9.4% of children in the general population.¹ This is a marked increase since the mid-1980s when overall pediatric asthma prevalence was approximately 3.6%.² For all families, managing a child's asthma entails a variety of stressors, situations characterized by change, uncertainty, control, and anxiety.³ Low-income caregivers, in particular, may also experience stressors related to health care, housing, transportation, childcare, discrimination, or other financial needs.⁴ Such chronic stress is associated with diabetes, depression, heart disease, headaches, obesity, and ulcers.⁵ To support caregiver and child health among the continually growing number of low-income families dealing with childhood asthma,^{6,7} theoretical frameworks and subsequent measures of stress must reflect caregivers' chronic stressors, both asthma- and non-asthma-related.

Many psychometrically valid scales are used to measure stress-related constructs experienced by caregivers of children with asthma, including parental stress,⁸ family hardiness,⁹ sense of coherence,¹⁰ and parental quality of life (QL).¹¹ Quality of life, for instance, concerns one's subjective evaluation of his or her mental and physical well-being,¹² and many scales assess how childhood chronic illnesses affect parental QL.^{13,14} While some scales are specific to asthma, many are designed generally in the context of caregiving. These constructs are often measured in clinical practice to inform family health care interventions, typically focused on a child's chronic illness management.¹⁵

Much research on stress-related constructs and childhood asthma acknowledges the family unit but does not consider characteristics of those families with low incomes or with structures other than two-parent-headed.^{16,17} In the U.S., nearly 18% of family households are headed by a single adult.¹⁸ These rates are higher in some regions and likely increasing overall.¹⁹ In Detroit, Michigan, for instance, 39% of family households are single-adult-headed.¹⁸ Income is strongly correlated with family structure, and of single-adult households in the U.S., approximately 33% female-led and 18% male-led were in poverty in 2009, compared with a national poverty rate of 14%.²⁰

Among childhood asthma interventions, those that address caregiver stress often have a greater likelihood of improving management and reducing severity of symptoms of childhood asthma²¹ and reducing caregiver health outcomes than those that do not.²² To inform such health care interventions, scales and related measurements of stress must recognize varied family circumstances. To encourage such theoretical reflection, we draw on our descriptive study findings to discuss stress-related caregiver scales. This study communicates how low-income caregivers in Detroit, Michigan conceptualize stress within the context of their child's asthma and their daily experiences.

Methods

Community Action Against Asthma (CAA)

This study occurred under guidance of CAAA, a community-based participatory research partnership begun in 1998. Community Action Against Asthma is a partnership between community organizations and academic partners focused on understanding and addressing

household and environmental triggers of asthma in Detroit and Dearborn, Michigan. It has conducted research on household²³ and community²⁴ interventions to reduce asthma and epidemiological research on the relationship between air pollution exposure and asthma.^{25–27}

Study procedures

Caregivers of children with asthma were sampled from two ongoing CAAA studies in low-income neighborhoods, a household intervention and an exposure assessment research project. Both of these projects used recruitment methods that entailed door-to-door and community-wide distribution of screening questionnaires to seek families with children with asthma symptoms. Of the approximately 100 candidates screened to participate in these studies at that time, Community Housing Works (CHWs) conducted a convenience sample to identify and call those who they thought were most likely to participate in this study. This was done gradually, until 40 interviews were conducted and researchers experienced theoretical saturation²⁸ where few, if any, new major conceptual insights continued to surface. Due to a variety of reasons, including disconnected phone numbers, discontinued engagement in other CAAA studies, general non-response, and other work or family obligations, 20% of 50 contacts did not result in an interview. In instances where households had multiple caregivers, researchers asked individuals or families to self-identify as primary caregivers to complete surveys and interviews. Forty caregivers expressed interest and were interviewed in their homes between May and August of 2009. The interview consisted of 27 open-ended questions lasting approximately one hour followed by administration of a 148-item quantitative survey lasting approximately 30–45 additional minutes. All participants provided informed consent to be interviewed, and 39 of the 40 participants also consented to having their interview audio-taped. Participants received \$30 (U.S.) at the conclusion of interviews. The University of Michigan Institutional Review Board approved this study.

Data collection

Interviewers asked open-ended questions (see Box 1) about experiences with a child's asthma and asthma's effects on family life and caregiver health. Subsequent quantitative surveys involved questions to understand asthma severity,²⁹ demographic characteristics, caregiver health, and caregiving obligations, including the Zarit Burden Caregiver Scale³⁰ and PedsQL Family Impact Module¹⁵ reported here. The PedsQL Family Impact Module ($\alpha=0.97$) entails 36-items assessing the frequency of child health effects on physical, emotional and cognitive functioning, worry, daily activities, communication issues, and family relationships over the last month, using on a five-item Likert scale ranging from *never* to *almost always*. In an exploratory manner, we used nine of the 22 items on the Zarit Burden Caregiver Scale ($\alpha=0.88$, for the full scale), originally developed for caregivers of impaired adults to assess frequency, in general, of the emotional, social, physical, and financial burden of caregiving on a five-item Likert scale ranging from *never* to *nearly always*. For both of these full scales, Cronbach's α (indicated above as α) was calculated as a ratio between 0 and 1, with .97 and .88 signifying relatively high reliabilities, or internal consistency.^{31,32}

Box 1

SAMPLE SUBSET OF 27 SEMI-STRUCTURED QUALITATIVE INTERVIEW QUESTIONS

1. Tell me about how things are going with [CHILD's] asthma.
2. How does [CHILD'S] asthma affect your everyday life?

3. Can you describe a time when you feel like you managed a crisis with asthma well?
4. Can you describe a time when you have been overwhelmed with taking care of [CHILD's] asthma?
5. Is there another adult who helps you take care of [CHILD]? Please explain.
6. What help do you need to make things easier for you?

Data analysis

Qualitative data were managed and analyzed using QSR International's NVivo 8.0 software.³³ An independent consultant transcribed all interviews, removing identifying information. To begin, researchers open coded³⁴ to identify codes (or themes). Some of these codes were empirically based, reflecting existing literature on related constructs, and others were derived *in vivo*,²⁸ identified through the words of study participants. Following open coding, the research team coded the same two interview transcripts to improve inter-coder reliability³⁵ among researchers, eventually combining the 100 original codes into approximately 70 codes, such as "others' care for child," "siblings experiences," and "about the caregiver's work life." Codes were entered into NVivo 8.0 software for focused coding³⁴ of all 40 transcripts. Using NVivo 8.0 software, researchers coded by highlighting a section of text and marking it based on the code or codes that best applied to its content. They then ran coding reports that contained all quotations corresponding to each code. Using coding reports, researchers generated subthemes with examples in the data. For instance, for the code "caregiver worry/stress/fear associated with asthma," apparent subcategories appeared within participant responses, such as: asthma diagnosis, increased risk of sudden morbidity or mortality, and controlling asthma, as described in detail below. To identify how demographic factors (e.g., grandparent, parent, aunt status) may have emerged in responses, researchers stratified interviews by these demographic factors for analysis.

Quantitative survey data were entered, cleaned, and analyzed in SPSS 18.0.³⁶ Means, standard deviation, and frequencies were calculated.

Preliminary findings were then shared with the CAAA Steering Committee (SC), including CHWs who work closely with study participants, to assess data validity. To do this, researchers prepared and presented a brief summary report, facilitating a discussion with SC members to identify possible explanations for the results. While there are no formal tests for assessing validity of qualitative data and the SC did not express concerns about invalid results, the researchers used strategies^{37–39} to improve study validity: triangulating results with experiences of SC members and findings of other CAAA studies, memos and study meetings among researchers engaging in reflexive discussions to reevaluate biases and assumptions, and additional meetings with CHWs to offer context to themes and quotations.

Results

Demographic and health characteristics

Demographic characteristics of study participants are summarized in Table 1. Of the 40 study participants, 37 were female. Participants lived in various neighborhoods throughout Detroit, and primarily identified as African American or Black (80.0%). Of the participants, 31 were mothers, six were grandmothers, and three were fathers; 25 were separated, divorced, or never married. On average, there were 4.4 individuals residing in each household with 1.6 adults and 2.8 children, and 2.0 additional children were cared for regularly but did not permanently reside in these households. Twenty households had one

adult, 15 households had two adults married or in a domestic partnership, and the remaining five households with more than one adult had adult children or grandparents in residence.

Participants cared for children with varying severity of asthma ($n=57$). Among these children, 51 (89.5%) had been diagnosed by a health professional, 53 (93.0%) had taken doctor-prescribed medications, inhalers or nebulizers in the past 12 months, and 27 (47.4%) took these treatments daily, regardless of symptoms. Participants reported that 26 (45.6%) children had missed between one and five days of school, nine (15.8%) missed had between six and 10 days, and six (10.5%) missed more than 10 days due to breathing problems during the nearly or recently completed school year (depending on date of interview).

Chronic illnesses were common among participants, with the following prevalence rates: lifetime asthma (41%), arthritis (28.2%), diabetes (17.9%), frequent headaches (48.7%), chronic pain (35.9%), hypertension (28.2%), and difficulty walking (28.2%). Those who were married or in a domestic partnership ($n=15$) reported 3.0 chronic illnesses, on average, and those who were single, divorced, or widowed ($n=25$) reported 3.6 chronic illnesses, on average. Assessed with the Center for Epidemiological Studies Depression Scale,⁴⁰ 42.5% of participants indicated psychological distress (i.e., a score greater than 16). On the CES-D Scale, for those who were married or in a domestic partnership ($n=15$), mean response was 14.57, and for those who were single, divorced, or widowed ($n=25$), mean response was 19.08.

Family and financial stressors

Qualitatively, many participants described financial uncertainties as chronic stressors, a consistent theme regardless of family structure:

Get some depression and a lot of worry, but basically because he's laid off, and I'm the only one working, and I don't make very much ... like we've got all these bills and payments and kids, and that's stress. You know, it's a lot of stress. Pretty much not about the asthma as much as just about how to get through paying this month's bills and stuff.

The median annual family income of participants was significantly below federal poverty guidelines (i.e., \$14,710 for a family of two)⁴¹ with 19 participants reporting an annual income of \$10,000 or less. Seventeen of the participants said that if they lost all current sources of income, they could maintain their current standard of living for less than a month. For those who were married or in a domestic partnership ($n=15$), mean income fell between \$15,001–20,000, and for those who were single, divorced, or widowed ($n=25$), mean income fell between \$10,001 and \$15,000.

Family-related stressors often emerged when participants discussed the assistance they did or did not have in caring for their children, as well as additional or unexpected caregiving duties (e.g., raising a grandchild, niece, or nephew). Many single participants described caregiving without assistance in unanticipated instances of incarceration, child abandonment, and severe morbidity or premature mortality of loved ones. A mother said, "I think the only thing that bothers me emotionally is the part of the support from their father ... he stays over in the area, and he hasn't actually seen the kids since 2004." All grandmother participants were single and described stress from their multiple caregiving roles; one grandmother identified worry as the reason for hair loss, using the idiom of her many "different hats," to describe the diverse responsibilities that generated this underlying worry:

Yeah, I've been under a lot of stress. Trust me. I wanted to cut my hair down real low because my hair has started thinning out, but you know, you supposed to trust

in God and not worry about all this stuff, but sometime when you wear so many different hats in your life then that's just the way it is. You know, like I said, I got a 19-year-old, then 14-year-old grandson and a 13-year-old grandson. I've been raising them since they was babies.

Caregiving-related stressors

Items from two scales commonly used to assess the impact of caregiving on a caregiver, PedsQL Family Impact Module and the Zarit Burden Caregiver scale, suggested low-to-moderate levels of stressors. The nine items from the Zarit Burden Caregiver Scale, summarized in Box 2, asked participants how often they felt burdened by various parts of caregiving. On average for all nine items, participants answered between to 'rarely' and 'sometimes' when asked how burdened they were by various parts of caregiving (Mean = 1.19, SD±.80). For those who were married or in a domestic partnership (n=15), responses averaged 1.10, and for those who were single, divorced, or widowed (n=25), responses averaged 1.09. For all participants, no single item averaged higher than 'sometimes.' Highest group averages included the following items: 'Do you feel that you don't have enough money to take care of your child in addition to the rest of your expenses?' (Mean = 2.13, SD±1.40); 'Are you afraid of what the future holds for your child?' (Mean = 1.77, SD ±1.51); 'Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?' (Mean = 1.70, SD±1.04); and 'Do you feel you could do a better job in caring for your child?' (Mean = 1.67, SD±1.60).

Box 2

PARTICIPANT MEAN RESPONSE TO ZARIT BURDEN CAREGIVER SCALE ITEMS (N=39)^a

Scale Item	
1	Do you feel that because of the time you spend with your child that you don't have enough time for yourself?
2	Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?
3	Do you feel that your child currently affects your relationships with other family members or friends in a negative way?
4	Are you afraid of what the future holds for your child?
5	Do you feel your health has suffered because of your involvement with your child?
6	Do you feel that your social life has suffered because you are caring for your child?
7	Do you feel that you don't have enough money to take care of your child in addition to the rest of your expenses?
8	Do you feel you have lost control of your life since your child's illness?
9	Do you feel you could do a better job in caring for you child?

On average, all items in the PedsQL Family Impact Module assess the impact of caregiving for asthma as between 'almost never' and 'sometimes' (Mean = 2.69, SD±1.05), with individual scale averages shown in Table 2. For those who were married or in a domestic partnership (n=15), mean overall responses were 2.43 (closest to 'almost never'), and for those who were single, divorced, or widowed (n=25), overall responses were 2.84 (closest to 'sometimes'). For all participants, individual items with notably higher impact included: 'I worry about my child's future' (Mean = 3.78, SD±1.39); 'I feel frustrated' (Mean = 3.05,

^aPossible responses included: 'never' (0), 'rarely' (1), 'sometimes' (2), 'quite frequently' (3), 'nearly always' (4).

SD±1.19); and 'I feel tired when I wake up in the morning' (Mean = 2.95, SD±1.41). Items for which participants reported low levels of impact included: 'It is hard for me to talk about my child's health with others' (Mean = 1.60, SD±.93); 'I worry about how my child's illness is affecting other family members' (Mean = 1.67, SD±.97); 'I worry about how others will react to my child's condition' (Mean = 1.68, SD±.94); and 'It is hard for me to tell doctors and nurses how I feel' (Mean = 1.68, SD±1.23).

When asked, "How does your child's asthma affect your everyday life?" across all participants, there was often a response of "No" or "It doesn't," with explicit indications that asthma is simply part of their life in their parenting role. As one respondent expressed it:

Stresses? I mean, I'm just being honest with you, this probably would be stressing you know if I wasn't, you know what I'm saying? Not really stress ... that's my baby, I love him! I'm just saying, you know, it's not ... I wouldn't look at it as stress ...

Even though most participants did not initially imply that their child's asthma was a stressor, nearly all described asthma-related experiences they identified as stressful, including three distinct themes: changes or worry associated with asthma diagnosis; anxiety from increased risk of their child's sudden morbidity or mortality; and efforts to control asthma to ensure their child's life can be "normal." First, at diagnosis, several participants described trying to understand why *their* child was ill:

It's the first time I've encountered a three-week old baby when they said she has asthma. So when I gave her her first breathing treatment I cried. I could barely hold the mask on her face, I was crying so hard. It was like, what did I do, what did I not do? I kind of faulted myself ...

Participants described stress involved in learning to manage the illness, "If you're not careful, it will consume your life ... I was a nervous wreck." Second, the uncertainty of impending acute care situations or sudden mortality was also apparent. One participant described the episodic nature of asthma: "And you get stressed because you're constantly worried a lot. You don't know if this is going to be a hospital night or what." Six parents mentioned frequent worry about their child's premature mortality, one stating, "I don't want him to drop dead somewhere. That's my biggest fear right now." Finally, many participants also expressed anxiety about their child's ability to live a "normal" life, as asthma can affect a child's daily social activities:

There are times, especially when I'm watching her grow, I cry. I find myself crying a lot because I feel really bad that she's not able to do as much stuff as other children. Secretly, I cry for her because she's missing out on so much, and I don't know what to make of that.

Many participants referred to their child's future and hopes that their child would outgrow asthma.

Caregiver-child relationships

Single participants also discussed how stressful asthma-related experiences led them to relate to their child in positive ways. Emerging in the context of various questions, participants approached this in two ways. For many, joint management of the illness created a special bond between caregiver and child, as a grandmother explained: "And then I don't sleep too well if she's not in the house. We depend on each other, so to speak." Additionally, childhood asthma led many participants to appreciate their children, perhaps in ways they may not have if they had no health problems. A single mother of young twins with asthma explained:

I got my work cut out for me. But it's fun, though. Even though God gave me those — that's a creation that you carry around, for, for seven or eight or nine months ... regardless to what defect or what's going on with their bodies, to see them grow is just something that amazes me. People don't cherish it the way that they supposed to. Children get illnesses. I'm not going to say I always cherish ... parents don't learn faith until it comes.

Discussion

For low-income study participants, qualitative descriptions of financial, family, and asthma-related stressors suggest that combined levels of stress are interactive, nuanced, and noteworthy rather than insignificant, as might be inferred from quantitative analysis of responses to asthma-specific questionnaire items. Stress is highly correlated with depression,^{42,43} and high prevalence of depression (42.5%) and other stress-related health outcomes indicate notable levels of overall stress among participants. Further, given there were many changes in housing and contact information, we speculate that many of the recruited caregivers who did not participate may have had additional household, financial, family, or work obligations or stressors, implying there are still many more stress-related examples we did not capture.

The underlying “I wouldn't look at it as stress” *in vivo*²⁸ theme implies that scales might understate caregiver stress attributable to childhood asthma. The PedsQL Module begins each item focusing on asthma as a stressor, asking “In the past ONE month, as a result of your child's health, how much of a problem have you had with ...” Many participants in this study had difficulty associating stress or burden with their child or grandchild, but qualitative findings illustrate various experiences of asthma-related change, uncertainty, control, or anxiety. Negatively framed, scales may gain from contemporaneous administration of items that encourage caregivers also to describe their children positively.⁴⁴ It is also possible that a social desirability bias occurs, where caregivers are hesitant to identify with the word ‘stress’ when interviewed by researchers. If this occurs, such bias is likely to also affect administration of related scales in health care settings, underestimating prevalence of stress-related constructs.

Qualitative findings implied a variety of stressors across all participants, regardless of marital status or the caregiver's relationship to their child with asthma. Single caregivers, however, offered more qualitative examples of how lack of caregiving assistance was a stressor. In this study, single participants reported slightly lower quality of life, higher depression, lower income, and more chronic illnesses, on average, although true statistical differences cannot be discerned given small group sizes.

Stress-related scales would benefit from continued psychometric validation to identify and include items that reflect how income status, marital status, and caregiver-child relationships may contribute to underlying stressors and family health outcomes in considerably different ways than seen in current scales typically validated among higher-income, two-parent households. Resultant future studies must also recognize the non-static nature of these demographic characteristics, where incarceration or premature mortality may suddenly alter household structure and finances, for instance. Such validation studies may also warrant inclusion of physiological measures of lifetime stress such as allostatic load.⁴⁵ Updated scales may improve quantitative analyses relating stress to caregiver health outcomes and child asthma severity, and they may indicate more specific points of intervention for caregiver stress reduction among groups or individuals based on their stressors.

While this study had some limitations, we were able to compare descriptive findings, benefitting from mixed method data collection and offering new insight to practitioners and researchers. The scales we used were previously validated in their entirety rather than as separate items as reported. However, discussion of these individual items in the context of qualitative findings encourages critical assessment of the appropriate application of scales generally and underlying construct validity.³⁸ Future studies of new scales that acknowledge lifetime chronic stress will need larger, more demographically diverse samples in varied geographies to enable generalizability. Finally, this study does not assess the role of race or ethnicity, but researchers recognize that all participants were people of color. In addition to income, race/ethnicity is associated with differential experiences of chronic stress.⁴⁶

Developed over the last few decades in response to the relentless growth in pediatric asthma prevalence, validated stress-related scales for caregivers are productive tools to assess a family's ability to manage childhood chronic illness and design fitting public health interventions. However, current tools may be incomplete in their reach and effectiveness for those populations that may need them most. Given the well-known health implications of compounding stressors,⁴⁷ these assessments should also be accurate and comprehensive to inform programs and policies to address caregiver health better. In this regard, theoretical frameworks must evolve to guide measures that better reflect low-income caregivers' conceptualizations and diverse experiences of both asthma and underlying non-asthma related stress.

Notes

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Table 1

SOCIODEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS: GENDER, AGE, RACE, ETHNICITY, INCOME, AND MARITAL STATUS (N=40)

	#	%
Gender (n=40)		
Female	37	92.5
Age (years) (n=39)		
30 or under	5	12.5
31–40	17	42.5
41–50	12	30.0
51+	5	12.5
Race (n=37)		
Black/African American	32	80.0
White	0	0.0
Multi-racial	3	7.5
Other	2	5.0
Hispanic (n=37)	3	7.5
Education (n=40)		
<High school	2	5.0
Some high school	9	22.5
High school graduate/GED	9	22.5
Some college	14	35.0
Associate's or Bachelor's degree	6	15.0
Annual Income (\$) (n=38)		
Less than 10,000	19	47.5
10,001–20,000	9	22.5
20,001–30,000	4	10.0
>30,001	6	15.0
Marital Status (n=40)		
Married	13	32.5
Domestic partner	2	5.0
Single—never married	21	52.5
Divorced or separated	4	10.0

GED = General equivalency degree

Table 2PARTICIPANT MEAN RESPONSE TO PEDSQL FAMILY IMPACT SCALE ITEMS^{ab} (N=39)

Scales (# of Items)	General Content of Items	Mean Response (Standard Deviation)
Physical Functioning (6)	Feeling weak or tired; stomach problems; headaches	2.49 (1.07)
Emotional Functioning (5)	Experiencing anxiety, sadness, anger, frustration, helplessness, or hopelessness	2.15 (1.17)
Social Functioning (4)	Feeling isolated; difficulty getting support; difficulty finding time or energy for social activities	2.25 (1.13)
Cognitive Functioning (5)	Difficulty keeping attention, remembering, or thinking quickly	2.30 (1.04)
Communication (3)	Difficulty communicating family situation or child's health with others	2.21 (1.20)
Worry (5)	Worry about child's medical care, others' reactions, effects on family members, and child's future	3.13 (1.14)
Daily Activities (3)	Difficulty with family activities or household tasks	2.53 (1.29)
Family Relationships (5)	Conflict, lack of communication, or difficulty tackling decisions or problems with family members	2.41 (1.33)

^a All items begin, 'In the past ONE month, as a result of your child's health, how much of a problem have you had with'

^b Possible responses included: 'never' (1), 'almost never' (2), 'sometimes' (3), 'often' (4), 'almost always' (5).