

# Understanding Factors Associated With Work Loss for Families Caring for CSHCN

## abstract

**OBJECTIVE:** Parents of children with special health care needs (CSHCN) are at risk for work loss as a result of the complex health needs of their children. Our objective was to determine how child- and family-level factors and the medical home are associated with work loss for these families.

**METHODS:** We performed secondary data analyses of the National Survey of Children With Special Health Care Needs (NS-CSHCN) 2005–2006. This is a nationally representative sample of CSHCN in the United States. The primary outcome measure was having any family member report work loss to care for a CSHCN. We calculated survey-weighted unadjusted and adjusted odds ratios by using independent variables that included child demographic factors, functional limitation, condition stability, insurance status/type, family income, and criteria of the medical home.

**RESULTS:** Overall, 23.7% of the parents of CSHCN reported work loss as a result of their child's health care needs. Greater functional limitation and condition instability were associated with increased odds of family work loss. The presence of a medical home in the multivariate model was associated with a 50% reduction in the odds of reported family work loss.

**CONCLUSIONS:** Approximately 24% of families with CSHCN have experienced work loss to meet the medical needs of their child. Availability of a system of care support, such as the medical home, is associated with lower work loss reported by families. Therefore, improved systems of care for CSHCN may have the potential to optimize work productivity for families. *Pediatrics* 2009;124:S392–S398

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### KEY WORDS

parental employment, work loss, children with special health care needs, medical home

### ABBREVIATIONS

CSHCN—children with special health care needs  
NS-CSHCN—National Survey of Children With Special Health Care Needs

FPL—federal poverty level

aOR—adjusted odds ratio

CI—confidence interval

OR—odds ratio

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Children with special health care needs (CSHCN) require services that are above and beyond that of typical children.<sup>1,2</sup> For example, they often need continuous primary care and may require significant subspecialty services to maintain optimal health and well-being.<sup>3</sup> In addition to increased contact with medical professionals, CSHCN often need medical care provided at home.<sup>4</sup> These health care demands may greatly affect families and their work choices. Previous studies have shown that families with CSHCN miss more days of work and that CSHCN are less likely to have parents with full-time employment.<sup>5–8</sup> In 1 study, 80% of families with CSHCN reported having to miss days of work to deal with acute illnesses in the previous year.<sup>8</sup> Furthermore, the day-to-day care needs of CSHCN have been cited as a primary reason for long-term parental work loss.<sup>6</sup>

The impact of a child's special health care need on work choices for family members is likely multifactorial. Child-level factors such as age, functional limitations, and condition stability often affect the time demands that families face to meet the needs of their child.<sup>4</sup> Especially for those with significant functional limitations, the time taken to deliver both informal (delivered by family members) and formal (delivered by health care providers) care can be quite substantial. Work choices are also likely affected by family-level factors such as educational attainment, financial circumstances, and the need for health insurance coverage.<sup>9</sup> Families of CSHCN often have lower incomes and lower rates of employer-based insurance.<sup>10</sup> These families, therefore, are at risk for decreased resource availability to care for their children, which may lead to adverse health consequences for their children.<sup>11</sup>

How families can best be supported to meet their children's needs and maintain employment has not been well studied. One model of care that potentially could provide support to families is the medical home. The medical home model was first defined and promoted by the American Academy of Pediatrics and is now recognized as the recommended model of care for all people by most professional health organizations.<sup>12</sup> The medical home has been shown to support families who care for CSHCN by providing integrated health care services and resources for CSHCN that improve access to care.<sup>13</sup> Although research has shown that the medical home can improve access, quality, and satisfaction with care,<sup>14</sup> how the medical home supports families in terms of employment has not been described.

A better understanding of the relationship between parental work loss and child- and family-level factors and the medical home can inform policies and promote programs that can potentially enable families to remain employed while meeting the needs of their children. In this article, we describe the population of CSHCN and their families. We then evaluate work loss experienced by families of CSHCN as a result of their child's medical care needs. We report how child- and family-level factors and the medical home are associated with work loss for these families. We hypothesized that certain characteristics of the child, such as younger age, more severe functional limitations, and condition instability, would be associated with increased work loss. We anticipated that income and insurance characteristics would be associated with work loss as well. We also hypothesized that having care within a medical home would be associated with decreased work loss for families.

## METHODS

### Data Set

We used the National Survey of Children With Special Health Care Needs 2005–2006 (NS-CSHCN).<sup>15</sup> We received institutional review board exemption for this analysis through the University of California, San Francisco Committee on Human Research.

### Variables

#### *Primary Outcome Measure: Work Loss*

The NS-CSHCN contained 2 questions regarding work: “Have you or other family members stopped working because of (sample child)'s health?” and “[Not including the family members who stopped working], have you or other family members cut down on the hours you work because of (sample child)'s health?” To indicate whether family members experienced any form of work loss, we created a composite measure of having either cut back or stopped work and referred to this composite measure as “work loss.” Although we report on both “stopping work” and “cutting back work,” only the composite variable was used in the regression models.

#### *Child-Level Factors*

We included several child-level factors that may affect the need for a family member to cut back on work or stop working. We report the child's demographics (gender, race, and age). In this study, age was classified into 4 categories: 0 to 3 years (infant/toddler); 4 to 7 years (preschool/early school aged); 8 to 13 years (school aged); and 14 to 17 years (high school aged). In addition to demographic characteristics, we included 2 health-related factors: functional limitation and condition stability. Functional limitation of the child was measured by whether a family member reported that the condition limited activity “a

great deal,” “some,” “very little,” or “not at all.” Condition stability was measured by “whether a child’s health care needs changed all the time,” “changed once in a while,” or “was usually stable.”

### Family-Level Factors

We measured the following family-level factors: family structure (2 parent [biological, adoptive, or stepparent], single parent, and other); highest educational attainment level in family; income; and insurance status. We used the multiple imputation data files provided<sup>16</sup> to generate the federal poverty level (FPL) values<sup>17</sup> listed in Table 1, because there were 18% missing data in the household file used to report FPL. Because the final CSHCN file also had 9% missing in the FPL variable, we used the provided FPL imputation values in our regression analyses.

### The Medical Home

The presence of a medical home was operationalized by using the Maternal and Child Health Bureau criteria of having a personal doctor or nurse, having a usual source of care, receiving family-centered care, having no problem with getting referrals when needed, and receiving effective care coordination when needed.<sup>12</sup> All of these 5 criteria must be met for the subject to be classified as having received care in a medical home. For our analysis evaluating the individual aspects of the medical home, having a usual source of care, having a personal doctor or nurse, and having family-centered care were dichotomized as present or not. The variables of having no problems with referrals and receiving care coordination were measured as yes, no, and did not require.

### Analyses

We used Stata 9.2 (Stata Corp, College Station, TX) to appropriately apply sur-

**TABLE 1** Characteristics of CSHCN and Their Families

	Percentage (95% CI) (N = 40 723) <sup>a</sup>
Gender	
Male	59.3 (58.7–60.0)
Female	40.7 (40.0–41.3)
Age group, y	
0–3	11.1 (10.6–11.6)
4–8	27.3 (26.7–28.0)
9–13	33.7 (33.0–34.3)
14–17	27.9 (27.3–28.5)
Race	
White, non-Hispanic	65.3 (64.5–66.2)
Black, non-Hispanic	16.1 (15.5–16.8)
Hispanic	11.8 (11.2–12.4)
Multiracial, non-Hispanic	3.7 (3.4–4.0)
Other	3.0 (2.7–3.3)
Functional limitation: how much does condition affect child’s ability to do things?	
None	12.1 (11.5–12.7)
Very little	27.2 (26.4–27.9)
Some	22.9 (22.2–23.6)
A great deal	37.8 (37.0–38.6)
Stability of child’s health care need	
Child’s health care needs are usually stable	65.9 (65.1–66.7)
Child’s health care needs change only once in a while	27.9 (27.2–28.7)
Child’s health care needs change all the time	6.2 (5.8–6.6)
Family structure	
2-parent biological, adoptive, or step	64.9 (64.1–65.7)
Single parent	30.0 (29.1–30.7)
Other	5.2 (4.8–5.6)
Education (highest level attained in household)	
Less than high school	6.4 (6.0–6.8)
High school graduate	23.1 (22.4–23.8)
Some college or above	70.5 (69.7–71.2)
Family income as reported, % FPL	
>400	28.8 (28.0–29.5)
200–400	30.1 (29.4–30.9)
<200	41.1 (40.3–41.9)
Insurance type	
Private	59.1 (58.3–60.0)
Public	28.0 (27.3–28.8)
Private and public mix	7.3 (6.9–7.8)
Other comprehensive insurance	2.0 (1.8–2.2)
Uninsured	3.5 (3.2–3.8)

<sup>a</sup> Race, gender, and age were derived from the screener file. Education and poverty level (FPL) were derived from the household file. FPL estimates were derived by using the multiple imputed data files provided by the State and Local Area Integrated Telephone Survey (SLAITS).<sup>16</sup>

vey weights in all our analyses. We generated survey-weighted proportions to describe the characteristics of CSHCN and their families. We then generated the weighted proportions of CSHCN who had family members who reduced or stopped work to care for the child’s medical needs, after which we determined the proportion of families who experienced work loss if they had care within a medical home and components of the medical home compared with those who did not. We then ran a logistic regression model on experiencing work loss. The model included the following independent variables: age; race; gender; stability of the child’s health needs; child functional limitation; family structure; highest family educational attainment; income and insurance status and type; and having a medical home. Codes provided by the Maternal and Child Health Bureau were used to define the variables that comprise the medical home.<sup>18</sup> We performed a sensitivity analysis to the above-described model that varied only by the use of the individual components of the medical home rather than the composite measure. We then report the adjusted odd ratios (aORs) of each individual component of the medical home from the sensitivity analysis in the results section. As part of the sensitivity analysis we also used a regression model that included the use of home health services. There was no effect on the main outcomes of the model.

## RESULTS

### Characteristics of CSHCN and Their Families

Characteristics of the study population are listed in Table 1. Nearly 60% of the CSHCN were male. More than 50% of the CSHCN had “some” or “a great deal” of functional limitation because of their condition, and 35% reported having health care needs that changed

**TABLE 2** Proportion of Families With CSHCN Who Experienced Work Loss if They Met Criteria for Having a Medical Home Versus Those Who Did Not Meet the Medical Home Indices

	% of Families With Work Loss if Criteria Met, % (CI)	% of Families With Work Loss if Criteria Was Not Met, % (CI)
Has care within a medical home (meets full criteria)	13.9 (14.1–15.9)	31.3 (30.3–32.5)
Medical home indices according to domain		
Has a personal doctor or nurse	23.7 (23.0–24.4)	24.8 (21.7–28.1)
Has a usual source of care	23.4 (22.7–24.2)	27.6 (24.7–30.6)
Family-centered care	19.8 (19.0–20.6)	32.3 (30.9–33.8)
Has no difficulties with referrals (for those who required referrals)	29.2 (27.8–30.7)	44.6 (41.3–47.9)
Care coordination with community resources easily attained (for those who required care coordination)	19.9 (18.8–20.9)	39.7 (38.3–41.2)

once in a while or all the time. Most CSHCN lived in 2-parent households (64.9%). Most households reported having had at least some college education (70.5%), whereas ~6% reported having had less than a high school–level education. We found that 41.1% of the CSHCN lived in households at  $\leq 200\%$  of the FPL. Nearly all CSHCN were insured (96.5%). Approximately half of the CSHCN had their medical care in a medical home. Nearly all CSHCN had a personal doctor or nurse (93.5%), whereas only 40.8% had adequate care coordination (data not shown).

### Work Loss

Work loss related to a child's health care needs was reported at 23.7% (95% confidence interval [CI]: 23.0–24.5). Because 16.1% (95% CI: 15.8–16.9) of the families reported that a family member had to cut back work and 13.3% (95% CI: 12.7–13.9) of the families reported that a family member had to stop work, a subset of CSHCN lived in families in which more than 1 adult family member had to cut back or stop working to meet their child's needs. We list in Table 2 the proportion of families who experienced work loss if they did or did not meet criteria of having a medical home or components of the medical home. There was a near doubling in the proportion of families who experienced work loss if they did

not have adequate care coordination. In addition, there was a significant increase in the proportion of families who experienced work loss if they lacked a usual source of care, had difficulty with referrals, or lacked family-centered care. The lowest proportion of work loss experienced by families was found among those who met the full criteria of having a medical home (13.9% vs 31.3% of families who did not meet full medical home criteria).

### Factors Associated With Work Loss (Child- and Family-Level Factors and the Medical Home)

Table 3 lists the unadjusted ORs and aORs of experiencing work loss. Families of younger CSHCN had increased odds of work loss compared with families of older CSHCN, and a clear trend was noted with decreasing odds of work loss as the age of the child increased. The odds of work loss were increased for black and Hispanic subjects in the unadjusted model but were not significant when other factors were controlled for in the multivariate model. Increasing functional limitation and increasing condition instability were significantly associated with increased odds of families reporting work loss in both the unadjusted and adjusted models, although they were somewhat attenuated in the adjusted model. Being uninsured and having public or dual public and private insur-

ance were associated with higher odds of work loss in both models. Living below 400% of the FPL was associated with increased odds of work loss in the unadjusted model but was not significant in the multivariate model. Certain family-level factors were associated with lower odds of work loss, including “other” family structure in the multivariate model and having had more than a high school education in the unadjusted models.

Having had care within a medical home was associated with half the odds of experiencing work loss (aOR: 0.5 [95% CI: 0.5–0.6]) (Table 3). As described in “Methods,” we also analyzed the model by using the individual components of the medical home in lieu of the composite measure (data not shown in table). Using the individual components of the medical home as opposed to the composite measure did not affect the results of the other independent variables in the model. The aOR results of the individual medical home components on work loss from the sensitivity analysis were as follows: having a personal doctor or nurse (aOR: 1.1 [95% CI: 0.8–1.3]); having a usual source of care (aOR: 1.0 [95% CI: 0.8–1.2]); receipt of family-centered care (aOR: 0.8 [95% CI: 0.7–0.9]); having no difficulties with needed referrals (aOR: 0.8 [95% CI: 0.6–0.9]); and receipt of effective care coordination when needed (aOR: 0.6 [95% CI: 0.5–0.6]). Therefore, the individual components of the medical home associated with significantly lower odds of work loss were having received family-centered care, having had no difficulty with referrals, and having received care coordination.

### DISCUSSION

Nearly one quarter of American families raising CSHCN have reported having to cut back or quit work because of their child's health care needs. This

**TABLE 3** Odds of Work Loss for Families of CSHCN

	OR (95% CI)	aOR (95% CI)
Gender		
Male	Reference	Reference
Female	0.9 (0.9–1.0)	1.0 (0.9–1.1)
Age group, y		
0–3	Reference	Reference
4–8	0.8 (0.7–0.9)	0.7 (0.6–0.8)
9–13	0.7 (0.6–0.8)	0.6 (0.5–0.8)
14–17	0.6 (0.5–0.7)	0.5 (0.4–0.6)
Race		
White, non-Hispanic	Reference	Reference
Black, non-Hispanic	1.3 (1.1–1.4)	0.9 (0.8–1.0)
Hispanic	1.7 (1.5–2.0)	1.2 (1.0–1.4)
Multiracial, non-Hispanic	1.2 (1.0–1.5)	1.0 (0.8–1.3)
Other	0.9 (0.7–1.2)	0.8 (0.6–1.0)
Functional severity: how much does condition affect child's ability to do things?		
None	Reference	Reference
Very little	2.3 (2.0–2.6)	2.0 (1.7–2.2)
Some	5.1 (4.5–5.7)	3.9 (3.4–4.4)
A great deal	12.2 (10.6–14.1)	7.9 (6.6–9.3)
Stability of child's health care needs		
Child's health care needs are usually stable	Reference	Reference
Child's health care needs change only once in a while	2.4 (2.2–2.6)	1.6 (1.5–1.8)
Child's health care needs change all the time	6.2 (5.3–7.2)	2.6 (2.1–3.1)
Family structure		
2-parent biological/adoptive	Reference	Reference
Single parent	1.4 (1.3–1.5)	0.9 (0.8–1.0)
Other	0.9 (0.7–1.1)	0.7 (0.6–0.9)
Education (highest level attained in household)		
Less than high school	Reference	Reference
High school graduate	0.8 (0.6–0.9)	0.9 (0.7–1.1)
Some college or above	0.6 (0.5–0.7)	1.1 (0.9–1.3)
Federal poverty, % FPL		
>400	Reference	Reference
200–400	1.3 (1.1–1.4)	1.0 (0.9–1.1)
<200	2.2 (2.0–2.4)	1.1 (1.0–1.3)
Insurance status		
Private	Reference	Reference
Public	2.2 (2.0–2.4)	1.5 (1.3–1.7)
Both private and public	2.9 (2.5–3.3)	1.8 (1.5–2.2)
Other comprehensive insurance	1.3 (1–1.8)	1.2 (0.7–1.8)
Uninsured	2.5 (2.1–3.0)	1.7 (1.3–2.1)
Medical home composite met	0.4 (0.4–0.4)	0.5 (0.5–0.6)

represents ~2.4 million CSHCN in the United States with family members who have not fully participated in the workforce because of a child's health care needs.

As we initially hypothesized, younger age of the child, more substantial functional limitations, and condition instability were associated with increased odds of work loss. The only family-level factor associated with work loss was insurance status. We noted that the presence of the medical home was

strongly associated with a lower likelihood of work loss.

Health care and community systems help families meet the medical needs of CSHCN.<sup>19–21</sup> Previous studies have also shown that families with improved social support networks can maintain work more easily than those without such support networks.<sup>22</sup> Our study is the first to our knowledge to show an association between the existence of a medical home and lower likelihood of family work loss. There-

fore, our data imply that improvements in the model of care delivery, which are meant to improve a child's medical care, may potentially help families maintain employment. Although we found that not all of the individual components of the medical home had a strong statistical association with decreased work loss, this may have been because most children had a usual source of care and a personal doctor or nurse. This underscores the importance of promoting the domains of the medical home that are less commonly met for families.

We should also consider, however, that having a medical home may be a proxy measure for other means of support that allow families to maintain work while caring for their children. There are likely other resources that are available to certain families, such as social capital, extended family support, and a robust set of community resources, that are associated with having a medical home. These factors are not measured in this survey but likely affect work choices and the experiences that families have with the health care system. While acknowledging that other factors may play an important role in the relationship between the medical home and work loss, we postulate that medical homes may improve parents' abilities to retain employment through several specific mechanisms. Improved care coordination saves families time and frustration by coordinating appointments and referrals, streamlining communication between primary care physicians and other providers, and reducing duplicative services. Comprehensive care ensures that families have full access to all available public and private resources such as respite care, specialized child care, and school-based services. With continuous and accessible care through the

medical home, families are assured that their child's urgent care needs receive prompt attention by a provider who is familiar with their child's health history.<sup>23</sup> Family-centered care means that the child's care plan will include special considerations for parents' work needs and preferences. All of these critical components of the medical home have potential to contribute to parents' ability to maintain employment.

## LIMITATIONS

Our study had several limitations. We used data from a cross-sectional survey; therefore, causality cannot be determined. The NS-CSHCN is based on parental/caregiver report and recollection may not have been accurate, leading to recall bias. Furthermore, the question of job loss asks about any job loss in the past and may not represent the current work status of the family or capture those who never reentered the workforce after the birth of their child. In addition, we could not

measure the duration of work loss a family experienced. We also acknowledge that work stoppage may be the only appropriate option or completely unavoidable for some families of CSHCN. For instance, children who require extensive in-hospital treatments or require other prolonged specialized care that necessitate a family to travel long distances for medical treatment would likely require a family member to stop work transiently. Last, cutting back or stopping work may be a choice for families that does not impact their economic or social well-being and, therefore, may not be a negative consequence.

## CONCLUSIONS

For many families of CSHCN, the ability to work is affected by the health care needs of their children. Parents of CSHCN often struggle with their work/life balance to meet their child's health needs. The results of our study suggest that the medical home may be an important support structure to help fam-

ilies continue to work while managing their child's special health care needs. Because of the growing prevalence of chronic illness,<sup>2,24–26</sup> the overall amount of parental work loss related to children's chronic health needs is likely to increase. Although child- and family-level factors are certainly important, our findings suggest that the medical home can help support families who care for CSHCN in ways that extend outside of the direct medical benefits to the child. Therefore, policies that promote system-level interventions should be supported, and evaluations of such interventions should include caregiver outcomes in addition to child/patient outcomes.

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