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# Need for and Use of Family Leave Among Parents of Children With Special Health Care Needs

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## ABSTRACT

**OBJECTIVE.** Parents of children with special health care needs are especially vulnerable to work–family conflicts that family leave benefits might help resolve. We examined leave-taking among full-time–employed parents of children with special health care needs.

**METHODS.** We identified all children with special health care needs in 2 large inpatient/outpatient systems in Chicago, Illinois, and Los Angeles, California, and randomly selected 800 per site. From November 2003 to January 2004, we conducted telephone interviews with 1105 (87% of eligible and successfully contacted) parents. Among the sample's 574 full-time–employed parents, we examined whether leave benefits predicted missing any work for child illness, missing >4 weeks for child illness, and ability to miss work whenever their child needed them.

**RESULTS.** Forty-eight percent of full-time–employed parents qualified for federal Family and Medical Leave Act benefits; 30% reported employer-provided leave benefits (not including sick leave/vacation). In the previous year, their children averaged 20 missed school/child care days, 12 doctor/emergency department visits, and 1.7 hospitalizations. Although 81% of parents missed work for child illness, 41% reported not always missing work when their child needed them, and 40% of leave-takers reported returning to work too soon. In multivariate regressions, parents who were eligible for Family and Medical Leave Act benefits and aware of their eligibility had 3.0 times greater odds of missing work for child illness than ineligible parents. Parents with >4 weeks of employer-provided leave benefits had 4.7 times greater odds of missing >4 weeks than parents without benefits. Parents with paid leave benefits had 2.8 times greater odds than other parents of missing work whenever their child needed them.

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### Key Words

chronic disease, family leave, parents

### Abbreviations

CSHCN—children with special health care needs

FMLA—Family and Medical Leave Act

UCLA—Mattel Children's Hospital at UCLA

CMH—Children's Memorial Hospital

PedsQL—Pediatric Quality of Life Inventory

MHI-5—Mental Health Inventory 5

OR—odds ratio

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**CONCLUSIONS.** Full-time–employed parents of children with special health care needs experience severe work–family conflicts. Although most have leave benefits, many report unmet need for leave. Access to Family and Medical Leave Act benefits and employer-provided leave may greatly affect leave-taking.

**F**AMILY LEAVE PROGRAMS are intended to balance the demands of the workplace with the needs of families. Parents of chronically ill children or of children with special health care needs (CSHCN) are particularly vulnerable to difficulties with balancing work and family. CSHCN make up ~15% of US children<sup>1,2</sup> and account for nearly half of US child health care expenditures.<sup>3–5</sup> CSHCN average ~3 times as many medical encounters, hospitalizations, hospital days, and school absences as other children.<sup>6</sup> During such medical encounters and hospitalizations, children and parents often need or want to be together,<sup>7</sup> and when absent from school or child care as a result of illness, children need care or supervision.<sup>8</sup> Therefore, employed parents of CSHCN may have a much greater need for time off than parents of healthy children.<sup>9,10</sup>

Access to leave may be either provided by employers or created by federal or state legislation. Employer-provided leave is the major mechanism by which parents can take time off to care for ill children. Some employers grant leave to care for sick children, whereas some employees use their own sick leave or vacation, either surreptitiously<sup>11</sup> (because their employers do not allow it) or in accordance with employer policies or state requirements.<sup>12</sup> Parents with access to paid leave take more time off than other parents.<sup>13,14</sup> However, parents of CSHCN tend to hold lower-paying jobs than parents of healthy children,<sup>6</sup> and such jobs typically provide less access to paid leave and less ability to afford unpaid leave.<sup>11</sup>

Federal legislation in 1993 established the Family and Medical Leave Act (FMLA), which provides eligible workers up to 12 weeks of unpaid leave per year to care for ill family members without risk for being fired for taking leave.<sup>13</sup> Overall, it is believed that the FMLA has had only a modest impact on leave-taking.<sup>15</sup> Only 47% of US employees are eligible, and many who are eligible cannot afford to take unpaid leave. In 2000, of the 3.5 million employees who said that they had recently needed family or medical leave but had not taken it, 78% cited inability to afford it as a reason.<sup>13</sup> In July 2004, California became the first and only state to establish a paid family leave program, which aims to address some of the FMLA's limitations; other states are exploring similar options.<sup>16</sup>

In this study, we examined the availability and use of paid and unpaid leave among full-time–employed parents of CSHCN. We also identified factors that are asso-

ciated with whether parents of CSHCN take leave and for how long. We hypothesized that access to the FMLA and employer-provided leave would be associated with greater amounts of work missed by these parents and greater self-reported ability to miss work whenever their child needed them.

## METHODS

### Sampling Frame

We sampled children who had received inpatient care, outpatient care, or both between October 1, 2002, and September 30, 2003, in 1 of 2 hospitals or their associated clinics: Mattel Children's Hospital at UCLA (UCLA) or Children's Memorial Hospital (CMH; Chicago, IL). Both sites are large, tertiary-care referral centers that serve economically and ethnically diverse populations.

The Maternal and Child Health Bureau defines CSHCN as children "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health or related services of a type or amount beyond that required by children generally."<sup>17</sup> We adapted a previously validated approach to identify CSHCN using *International Classification of Diseases, Ninth Revision* billing codes.<sup>18</sup> Researchers have developed a list of codes that are likely to be assigned to CSHCN.<sup>18–21</sup> Not all patients who are identified in this manner, however, have enough health service needs to be considered CSHCN. Because there is a high correlation between illness severity and patient charges,<sup>4,22–24</sup> we restricted the code list to disease categories with the highest average per-patient physician charges. These categories included bronchopulmonary dysplasia, cerebral palsy, chronic anemias, chronic enteritis/colitis, chronic renal failure, congenital heart diseases, cystic fibrosis, degenerative neurologic disorders, hydrocephalus, immunologic disorders, malignancies, organ transplant complications, and rheumatologic disorders.

We used this list to identify all children (younger than 18 years) in both hospitals' billing databases who were (1) assigned 1 of these diagnoses at least once from October 1, 2002, to September 30, 2003, (2) listed as living, and (3) living in their respective states. We identified 1570 at UCLA and 3680 at CMH.

### Stratified Random Sampling

Because our study focused on CSHCN with employed parents, we wanted to sample primarily from that group but without excluding children with poor or unemployed parents. The best proxy for employment/nonemployment status in the hospitals' databases was Medicaid enrollment (among US adults aged 25–44 in 2004, 46% of Medicaid recipients versus 12% of others were not employed).<sup>25</sup> We randomly sampled 800 children from each site, stratifying by their Medicaid status (100 Med-

icaid recipients and 700 Medicaid nonrecipients from each site) to achieve a smaller proportion of Medicaid recipients than in the CSHCN populations of both hospitals (33% Medicaid at UCLA, 31% at CMH). Inclusion of Medicaid recipients enabled inferences about how employment and leave decisions differed across the income spectrum.

### Participant Recruitment and Data Collection

Trained interviewers telephoned the families, obtained informed consent by telephone, and conducted a 40-minute computer-assisted telephone interview in English or Spanish with 1 parent of each child. Our previous experience suggested that in 2-parent households, the mother or the parent who is employed fewer hours (often the same person) is more likely both to answer the telephone (because they are more likely to be home) and to consent to participate. To achieve better balance of employment and gender among household informants in participating 2-parent households ( $n = 915$ ), interviewers asked whether both parents were available. When only 1 was available ( $n = 607$ ), that parent was interviewed. When both were available ( $n = 308$ ), interviewers asked whether 1 parent worked substantially more hours than the other. When 1 worked more hours ( $n = 207$ ), interviewers attempted to enroll that parent. When both worked similar hours ( $n = 101$ ), interviewers attempted to enroll the father. When the selected parent did not wish to participate ( $n = 108$  of 308 2-parent households), the other parent was enrolled.

From November 2003 to January 2004 (ie, before the implementation of California's paid family leave program), we completed interviews with 554 parents in California and 551 parents in Illinois. Excluding parents who were not located because of incorrect contact information (11% of all parents), who could not be reached despite repeated attempts (6%), or who were found to be otherwise ineligible (ie, the 3% who were younger than 18 years, who did not speak English or Spanish, who were too ill to participate, or whose child had died), completion rates were 85% at UCLA and 89% at CMH.

Parents who completed the interview received a \$10 gift card. We received Health Insurance Portability and Accountability Act waivers to use hospital databases to obtain necessary private health information. The protocol was approved by all participating institutional review boards.

### Survey Content and Development

Our survey covered parent job characteristics and benefits; parent need for and use of leave; relationships among child illness, parent employment, and parental leave; awareness and use of the FMLA; child quality of life; parent mental health; and family demographics. Some items were drawn from standardized instruments:

(1) the Department of Labor 2000 Survey of Employees,<sup>13</sup> (2) a short version of the Pediatric Quality of Life Inventory (PedsQL),<sup>26</sup> and (3) the RAND Mental Health Inventory 5 (MHI-5).<sup>27</sup> Other items were developed by the research team; reviewed by clinicians, attorneys, and social scientists who were familiar with CSHCN and/or labor issues; and pilot-tested on a convenience sample of parents. Items used Likert scales and close-ended response categories.

### Statistical Analysis

#### Construction of Weights

Combining UCLA and CMH data, we compared responders ( $n = 1105$ ) and eligible nonresponders ( $n = 165$ ) across several variables (*International Classification of Diseases, Ninth Revision* category, child age, site, Medicaid status). Parents at UCLA were more likely to be nonresponders (15% vs 11%;  $P = .05$ ); no other variable significantly predicted nonresponse. Because nonresponse differed only on the basis of site, we constructed poststratification weights by Medicaid status within each site and then gave each site equal weight by standardizing weights to mean 1 within sites. All descriptive and inferential statistics use this weight.

We performed 3 multivariate logistic regressions on the subsample of parents who were employed full time ( $n = 574$ ). For some variables, categories were collapsed to achieve adequate cell sizes or to satisfy model assumptions that were informed by regression diagnostics. We evaluated which factors predicted, in the past 12 months, (1) whether parents missed any work because of their child's illness (1: yes; 0: no), (2) whether parents missed >4 weeks of work because of their child's illness (1: yes; 0: no), and (3) whether parents were always able to miss at least some work when their child needed them to (1: yes; 0: no).

#### Missing Data

No variable was missing for >3% of observations. To prevent the bias that can result from multivariate analyses that are restricted to complete cases,<sup>28</sup> we used the multiple imputations by chained equations approach, a standard technique to impute missing data.<sup>29</sup> The rate of missing data were sufficiently low that multiple imputations were unlikely to improve the efficiency of the imputations substantially, so we used only a single imputation from this method.<sup>30</sup> In addition, the PedsQL is designed for children who are 2 years and older. To prevent dropping children who were younger than 2 years from the sample, we assigned them the mean PedsQL score and marked them with an indicator variable that estimated differences between those who were younger than 2 and those with the mean PedsQL score without biasing the estimate of PedsQL on outcomes.

## Models

For each of the 3 outcomes, we ran bivariate regressions for the following predictor variables, 1 at a time: 5 dichotomous indicators of access to and awareness of leave (availability of sick leave/vacation, availability of employer-provided leave other than sick leave/vacation, whether that leave was paid, FMLA eligibility, and awareness of FMLA eligibility), 8 parent demographic and health measures (respondent MHI-5 score, age, gender, race/ethnicity, education, marital status, household income, and partner's employment status), and 6 measures of child health and demographics (child hospitalization frequency, PedsQL score, age, gender, Medicaid status, and site). To achieve both parsimonious and parallel parameterizations across the multivariate models, we set  $P < .067 = .20/3$  in any of the bivariate regressions as the threshold for admission of a predictor variable into all 3 multivariate models. Using  $P < .067$  preserved the  $P < .20$  family-wise error rate that would have been standard for retention of a predictor variable if we had used just a single multivariate model.<sup>31</sup> Doing so resulted in exclusion of marital status, partner's employment status, child gender, and site from the final regression models. Interaction terms between site and leave-related predictor variables did not significantly improve the overall  $\chi^2$  of the 3 regressions and were not retained.

## RESULTS

### Demographics of Responding Parents

Fifty-two percent of responding parents were female, and 79% were married or living as married (from this point, referred to simply as "married"; Table 1). Fifty-two percent were non-Hispanic white, 27% were Hispanic, 13% were non-Hispanic black, and 8% were "other." Thirty-nine percent had annual household incomes less than \$50 000, 26% had not attended college, and 19% of their CSHCN were Medicaid recipients. Among married respondents, 52% of partners were employed full time. The average MHI-5 score was 71 of 100. Thirty-six percent met usual criteria (MHI-5 < 68) for poor mental health, and 15% met usual criteria (MHI-5 < 52) for severe depressive symptoms.<sup>32</sup>

### Child Illness Burden

On average in the past 12 months, children stayed home from school or child care 20 days because of illness, had 12 doctor or emergency department visits, had 1.7 hospitalizations, and (among the 41% who had any hospitalizations) spent 23 nights in the hospital (Table 1). The mean PedsQL score was 68 of 100.

### Leave-Taking Among Parents

Nineteen percent of parents took no time off in the previous 12 months to care for their ill child, 33%

TABLE 1 Demographics and Child Health Variables

Parameter	Means (SD) or % (N = 574) <sup>a</sup>
Parent variables	
Age, y	41 (7.6)
Female	52
Ethnicity	
Black non-Hispanic	13
Hispanic	27
White non-Hispanic	52
Other	8
Education	
Less than high school graduate	10
High school graduate	16
Some college	35
College graduate	18
Postgraduate training	21
Married/living as married	79
Partner's employment status (if married/ living as married)	
Employed full time	52
Employed part time	16
Not employed	32
Household income (annual), \$	
<20 000	15
20 000–49 999	24
50 000–99 999	33
100 000–149 999	14
≥150 000	14
MHI-5	71 (19)
Child variables	
Age, y	9.3 (5.4)
Female	47
Medicaid enrollment	19
Illness burden (past year)	
School/child care days missed	20 (38)
Doctor/emergency visits	12 (13)
Hospitalizations	
0	59
1	19
2–3	10
≥4	13
Hospital days (if hospitalized)	23 (35)
PedsQL score	68 (23)

<sup>a</sup> Means and percentages are weighted to account for nonresponse and stratification.

missed 1 week or less, 30% missed 1 to 4 weeks, and 18% missed >4 weeks (Table 2). During their longest leave, 60% received at least some pay from their employers.

### Ending Leave Prematurely

Fifty-five percent of responding parents said that, in the past 12 months, they were not always able to spend enough time with their child when he or she was ill. Of the parents who missed any work, 40% said that they returned to work sooner than was needed for their child's health. The 3 most commonly cited reasons for returning to work were that the child was better (81%), the parents wanted to get back to work (66%), and the parents needed the pay (55%). Of the

**TABLE 2** Employment Characteristics and Leave-Taking

Characteristic	% (N = 574) <sup>a</sup>
FMLA eligibility	
Ineligible	51
Eligible, self-reported ineligible <sup>b</sup>	18
Eligible, self-reported eligible	31
Access to employer-provided leave	
Sick leave/vacation, d	
0–5	20
6–20	46
>20	34
Other leave, paid or unpaid, d	
0–5	33
6–20	16
>20	14
Parent does not know	37
Paid other leave, d	
>5	15
Work missed because of child's illness (past year), d	
0	19
1–5	33
6–20	30
>20	18
During longest leave (past year)	
Received any pay	60
Returned to work because needed income	55
Returned to work sooner than parent thought was needed for child's health	40
On at least 1 occasion, did not miss work even though parent believed needed to miss because of child's illness (past year)	41
Always able to spend as much time with ill child as parent thought child needed (past year)	45

<sup>a</sup> Percentages are weighted to account for nonresponse and stratification.

<sup>b</sup> Met criteria for eligibility (worked  $\geq 1250$  hours in the past 12 months, worked for the same employer for  $\geq 12$  months, and worked for an employer with  $\geq 50$  employees) but did not believe that they were eligible.

parents who returned to work even though their child was not better, 64% said that they returned because they needed the pay. Sixty-nine percent of parents said that they would have missed more work if they had received some or more pay during their time off.

### Missed Opportunities for Leave

Forty-one percent of responding parents said that, in at least 1 instance in the past 12 months, they did not miss work even though they believed that they needed to because of their child's illness. The 3 most commonly cited reasons for not missing work were that the parents could not afford to miss income (62%), they thought that they might lose their job or business (41%), and they thought that they might hurt their job advancement (37%). Seventy-three percent said that they would have missed work if they would have received some or more pay during that time off.

### Access to Leave Predicts Leave-Taking

#### Access to the FMLA

Forty-nine percent of parents were FMLA eligible, satisfying all 3 criteria: worked at least 1250 hours in the past 12 months, worked for the same employer for at least 12 months, and worked for an employer with at least 50 employees (Table 2). Sixty-four percent of FMLA-eligible parents were aware that they were legally guaranteed time off. In bivariate regressions, parents who were eligible for the FMLA and aware of their eligibility were more likely than parents who were eligible but unaware (89% vs 72%; odds ratio [OR]: 3.1;  $P < .001$ ) and ineligible (89% vs 79%; OR: 2.2;  $P = .005$ ) to miss at least 1 day of work because of their child's illness. This association persisted in multivariate regressions (Table 3). Parents who were eligible but unaware did not differ significantly from ineligible parents in bivariate or multivariate analyses.

#### Access to Sick Leave or Vacation

Eighty percent of parents had access to >1 week of employer-provided sick leave or vacation (34% had access to >4 weeks). Parents with access to sick leave/vacation did not differ significantly from parents without access in bivariate or multivariate regressions.

#### Access to Other Employer-Provided Leave (Paid or Unpaid)

Thirty percent of parents had access to other forms of employer-provided leave (paid or unpaid), such as family or personal time off. In bivariate regressions, parents with access to >4 weeks of other employer-provided leave were more likely than parents with no access to miss >4 weeks of work because of their child's illness (32% vs 13%; OR: 3.1;  $P = .002$ ). This association persisted in multivariate regressions.

#### Access to Other Employer-Provided Paid Leave

Of the parents who had access to other employer-provided leave, 50% had access to at least some pay during some or all of that leave. Contrary to our hypothesis, parents with access to paid leave were actually less likely in bivariate regressions to miss >4 weeks of work (8% vs 20%; OR: 0.34;  $P = .008$ ) than parents without access. In multivariate regressions, however, this association was no longer significant (OR: 0.34;  $P = .11$ ). Moreover, in multivariate regressions, parents with access to paid leave were more likely always to be able to miss at least some work when their child needed them to (OR: 2.8;  $P = .009$ ) than parents without access.

### Other Important Predictors of Leave-Taking

In bivariate and multivariate regressions, the number of hospitalizations was by far the best predictor of whether parents missed any work and whether they missed >4 weeks (Table 3). In bivariate regressions, women were

**TABLE 3** Multivariate Regressions for Parent Missing Work Because of Child's Illness and Parent's Ability to Miss Work When Child Needed Them to

Parameter	Missed Any Work Because of Child's Illness, OR (95% CI)	Missed >4 wk of Work Because of Child's Illness, OR (95% CI)	Always Able to Miss Work When Child Needed Them to, OR (95% CI)
<b>Parent variables</b>			
Age (unit = 5 y)	0.83 (0.65–1.1)	1.3 (0.97–1.6)	1.1 (0.91–1.3)
Female gender	1.2 (0.68–2.1)	5.2 (2.2–12) <sup>a</sup>	1.1 (0.68–1.8)
<b>Ethnicity</b>			
Non-Hispanic white	1.0 (reference)	1.0 (reference)	1.0 (reference)
Non-Hispanic black	0.70 (0.34–1.4)	0.64 (0.19–2.1)	1.5 (0.72–3.2)
Hispanic	1.1 (0.53–2.4)	1.3 (0.45–3.9)	0.39 (0.21–0.74) <sup>a</sup>
Other	0.29 (0.10–0.83) <sup>a</sup>	1.4 (0.50–4.0)	1.4 (0.67–2.9)
<b>Education</b>			
Less than high school graduate	0.40 (0.10–1.6)	1.6 (0.40–6.0)	3.1 (1.0–9.2)
High school graduate	1.0 (0.46–2.2)	0.50 (0.13–1.9)	1.1 (0.53–2.1)
Some college	1.0 (reference)	1.0 (reference)	1.0 (reference)
College graduate	0.70 (0.34–1.5)	0.26 (0.08–0.87) <sup>a</sup>	1.0 (0.53–1.9)
More than college graduate	0.88 (0.42–1.9)	0.26 (0.07–0.96) <sup>a</sup>	0.73 (0.38–1.4)
<b>Annual household income, \$</b>			
<20 000	0.63 (0.11–3.6)	1.4 (0.30–6.4)	1.9 (0.64–5.9)
20 000–49 999	0.84 (0.41–1.7)	0.75 (0.25–2.2)	0.97 (0.53–1.8)
50 000–99 999	1.0 (reference)	1.0 (reference)	1.0 (reference)
100 000–149 999	0.71 (0.36–1.4)	1.2 (0.39–3.8)	1.6 (0.86–3.1)
≥150 000	1.2 (0.57–2.7)	5.7 (1.4–24) <sup>a</sup>	1.6 (0.77–3.4)
MHI-5 score (unit = SD)	0.79 (0.56–1.1)	0.41 (0.29–0.58) <sup>a</sup>	2.1 (1.6–2.7) <sup>a</sup>
<b>Child variables</b>			
Enrolled in Medicaid	2.9 (0.63–13)	6.7 (1.8–25)	0.73 (0.30–1.8)
Age (unit = 5 y)	0.75 (0.54–1.0)	0.69 (0.43–1.1)	1.1 (0.91–1.3)
Age <2 y	0.24 (0.08–0.76) <sup>a</sup>	5.8 (1.6–21) <sup>a</sup>	3.1 (1.1–9.0) <sup>a</sup>
PedsQL score (unit = SD)	0.52 (0.35–0.76) <sup>a</sup>	1.2 (0.74–1.9)	1.6 (1.2–2.0) <sup>a</sup>
<b>Hospitalizations</b>			
0	1.0 (reference)	1.0 (reference)	1.0 (reference)
1	6.7 (2.8–16) <sup>a</sup>	9.7 (3.7–26) <sup>a</sup>	0.70 (0.39–1.3)
2–3	6.7 (1.9–24) <sup>a</sup>	15 (5.1–43) <sup>a</sup>	0.48 (0.22–1.0)
≥4	18 (2.2–150) <sup>a</sup>	70 (23–210) <sup>a</sup>	0.50 (0.22–1.1)
<b>Leave variables</b>			
<b>FMLA eligibility</b>			
Ineligible	1.0 (reference)	1.0 (reference)	1.0 (reference)
Eligible, self-reported ineligible	1.0 (0.53–2.0)	1.3 (0.44–3.7)	0.63 (0.35–1.1)
Eligible, self-reported eligible	3.0 (1.6–5.6) <sup>a</sup>	1.1 (0.46–2.4)	0.83 (0.49–1.4)
<b>Access to sick leave/vacation, d</b>			
0–5	1.0 (reference)	1.0 (reference)	1.0 (reference)
6–20	1.2 (0.53–2.6)	1.1 (0.39–3.2)	0.71 (0.36–1.4)
≥21	0.81 (0.34–1.9)	1.5 (0.45–5.2)	1.2 (0.56–2.4)
<b>Access to other employer-provided leave, d</b>			
0–5	1.0 (reference)	1.0 (reference)	1.0 (reference)
6–20	0.97 (0.36–2.6)	0.45 (0.13–1.6)	0.64 (0.29–1.4)
≥21	0.72 (0.30–1.8)	4.7 (1.6–14) <sup>a</sup>	1.9 (0.91–4.0)
Parent does not know how many days	1.3 (0.61–2.6)	1.1 (0.47–2.7)	2.5 (1.4–4.5) <sup>a</sup>
Employer-provided leave is paid	0.97 (0.39–2.4)	0.34 (0.09–1.3)	2.8 (1.3–6.2)

CI indicates confidence interval.

<sup>a</sup>  $P < .05$ .

far more likely than men both to miss any work and to miss >4 weeks; the association between gender and missing >4 weeks persisted in multivariate regressions. Finally, higher MHI-5 (better parent mental health) and PedsQL (higher child quality of life) scores were strongly associated with less likelihood of missing any work or missing >4 weeks and greater likelihood of always being able to miss work when their child needed them to; in

each case, 2 of the 3 associations persisted in multivariate regressions (Table 3).

## DISCUSSION

Full-time–employed parents of CSHCN in our study experienced substantial conflict between work and family. Fewer than half reported always being able to spend enough time with their child when he or she was ill, and

nearly half reported not missing work on at least 1 occasion even though their child needed them to. Although most parents had access to employer-provided leave, only 15% had access to paid leave outside sick leave/vacation. A majority of parents cited financial concerns as a major reason both for ending leave and for not taking leave even though their child needed them to. In multivariate regressions, whether parents missed any work was associated with their awareness of FMLA eligibility, whether they missed >4 weeks of work was associated with their access to employer-provided leave (paid or unpaid), and whether they always felt able to miss work was associated with their access to paid leave.

FMLA eligibility, awareness of FMLA eligibility, and access to employer-provided leave (both paid and unpaid) may have a substantial impact on the ability of parents of CSHCN to spend time with their ill children. In our sample, 49% of parents were eligible for the FMLA, and 64% of eligible employees were aware of the law. These numbers are very similar to national estimates of employees (47% eligibility and 58% awareness among eligible employees)<sup>13</sup> and suggest that a large percentage of parents of CSHCN might benefit from both expansion of FMLA eligibility and increased education about the FMLA. Increasing access to employer-provided or state-provided leave, especially paid leave, may also provide benefits to these parents. California's new Paid Family Leave Insurance program and similar programs that are being considered in other states might serve as important tests of this hypothesis.

Moreover, it is possible that some parents of CSHCN in our sample had previously adjusted their employment in response to their child's illness, thereby leading our results to reflect an already-optimized situation with respect to work-family conflict. Therefore, our results would underestimate the degree of conflict among parents of more newly diagnosed CSHCN. In addition, among the 52% of parents with full-time-employed partners, the work-family conflict that was reported by 1 parent may have underestimated the sum of conflicts that are experienced by both parents. In bivariate subanalyses of parents with full-time-employed partners, respondents whose partners missed more work than other respondents' partners actually reported more conflict rather than less with respect to all 3 outcomes. The subsample, however, was too small to support multivariate analyses adequately. Future studies might examine the hypothesis that even though partners may share the burden of caring for ill children, partnership alone may provide only incomplete relief.

Although parents with access to paid leave were more likely than other parents to report being able to miss work, they were actually less likely to miss >4 weeks in bivariate analyses. Parents with access to paid leave might tend to hold positions of greater skill, responsibility, interest, or schedule flexibility, any of which could

encourage or coerce employees to return more quickly. This hypothesis is supported by 2 additional findings (Table 3). First, more educated parents were less likely than other parents to miss >4 weeks. Second, parents whose children received Medicaid were more likely than other parents to miss >4 weeks. Therefore, our data may be describing an environment in which the parents with access to paid leave are currently predisposed to limiting their use of it. Whether this self-restraint would change in an environment of expanded access is unclear.

We found associations between higher parent MHI-5 scores and both more ability to miss work when their child needed them to and less likelihood of missing >4 weeks (Table 3). If one were to hypothesize that missing work should have a beneficial effect on parent mental health, then the latter finding might seem to contradict that hypothesis. Our observational cross-sectional study design, however, prevents us from examining whether more ability to miss work or missing less work increased parent mental health, whether better parent mental health reduced parents' need to miss work, or whether some other factor (eg, severity of the child's illness) influenced both. Longitudinal studies that examine change in MHI-5 scores over time would be useful. Regardless, MHI-5 scores among the parents of CSHCN in our study were substantially worse than in a previous nationally representative study of parents.<sup>33</sup> In that study, only 17% of parents had MHI-5 scores <68, compared with 36% here.

We also found associations between higher PedsQL scores and both more ability to miss work and less likelihood of missing any work (Table 3). Again, our observational cross-sectional study design prevents us from examining the causal directionality of these associations. We can conclude, however, that the CSHCN in our study created a substantial illness burden for their parents. Our sample of children had an average quality-of-life score of 68. In previous studies, healthy, nonoverweight children had an average PedsQL score of ~85,<sup>26,34,35</sup> children who were obese or had mild asthma had an average score of ~75,<sup>26,34</sup> and children who had moderate to severe asthma or were receiving treatment for cancer had an average score of ~65.<sup>26,35</sup>

Because we selected children with higher expenditure diagnoses, excluding common but often relatively low-acuity chronic diseases such as attention-deficit/hyperactivity disorder or asthma, our children were somewhat sicker than children in nationally representative samples of CSHCN. CSHCN in the 2001 National Survey of Children with Special Health Care Needs averaged 7 missed school days per year (compared with 20 in our sample),<sup>36</sup> and CSHCN in the 2000 Medical Expenditure Panel Survey averaged 10 doctor or emergency visits per year (compared with 12 in our sample).<sup>37</sup> Nevertheless, the employment status of parents in our complete sample (80% of families had at least 1 parent

employed full time, 8% had at least 1 parent employed part time, and 12% had no parent employed) closely matched that of parents of CSHCN in the 2000 National Health Interview Survey (76%, 10%, and 14%, respectively),<sup>5</sup> suggesting that our sample of parents may have been fairly representative of parents of CSHCN generally.

Full-time–employed parents of CSHCN experience work–family conflict that generates substantial stress on families and employers and seems to have the potential to affect child health and parent mental health. Future research should examine whether interventions that increase access to or awareness of employer-provided or state-provided leave, paid or unpaid, may help to alleviate this conflict and at what cost to employers and society. Research should also address the potential health effects of leave-taking on both children and parents and the potential role of health care providers in increasing awareness of leave policies among the most vulnerable families.

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## Need for and Use of Family Leave Among Parents of Children With Special Health Care Needs

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