

# Health Among Caregivers of Children With Health Problems: Findings From a Canadian Population-Based Study

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Caring for a child with health problems can entail greater than average time demands,<sup>1,2</sup> medical costs,<sup>3,4</sup> employment constraints,<sup>5,6</sup> and childcare challenges.<sup>6–8</sup> These demands may affect the health of caregivers, a notion supported by a variety of small-scale observational studies that have shown increased levels of stress, distress, emotional problems, and depression among caregivers of children with health problems.<sup>1,2,5,9–12</sup>

Whether these problems are caused by the additional demands of caring for children with health problems or by confounding variables is difficult to answer definitively. The literature reports the identification of a variety of factors purported to be associated with caregiver health, including contextual factors such as socioeconomic status<sup>13–17</sup>; child factors such as level of disability,<sup>11,13,18–21</sup> presence of behavior problems,<sup>22–25</sup> and overall child adjustment<sup>26</sup>; and caregiver-related characteristics such as coping strategies<sup>11,22,27</sup> and support from friends and family.<sup>15,17,28,29</sup> In general, this work has been based on small clinic-based samples<sup>9,30</sup> or specific child populations (e.g., cerebral palsy,<sup>5,25</sup> attention-deficit/hyperactivity disorder<sup>31,32</sup>), and typically has been hampered by limited generalizability and a lack of careful, multivariate analysis. Furthermore, most studies have focused on caregivers' psychological health,<sup>1,2,5,9–12</sup> although physical health effects may also exist among caregivers.<sup>5,19,25,33</sup>

One of the few studies to involve large-scale, population-based data compared the health of 468 caregivers of children with cerebral palsy to the health of a population-based sample of Canadian parents.<sup>5</sup> The study showed that caregivers of children with cerebral palsy had poorer health on a variety of physical and psychological health measures. Furthermore, the data were consistent with a stress process model,<sup>5,25</sup> which proposes that additional stresses associated with caring for a child with cerebral palsy directly contribute to poorer

**Objectives.** We used population-based data to evaluate whether caring for a child with health problems had implications for caregiver health after we controlled for relevant covariates.

**Methods.** We used data on 9401 children and their caregivers from a population-based Canadian study. We performed analyses to compare 3633 healthy children with 2485 children with health problems. Caregiver health outcomes included chronic conditions, activity limitations, self-reported general health, depressive symptoms, social support, family functioning, and marital satisfaction. Covariates included family (single-parent status, number of children, income adequacy), caregiver (gender, age, education, smoking status, biological relationship to child), and child (age, gender) characteristics.

**Results.** Logistic regression showed that caregivers of children with health problems had more than twice the odds of reporting chronic conditions, activity limitations, and elevated depressive symptoms, and had greater odds of reporting poorer general health than did caregivers of healthy children.

**Conclusions.** Caregivers of children with health problems had substantially greater odds of health problems than did caregivers of healthy children. The findings are consistent with the movement toward family-centered services recognizing the link between caregivers' health and health of the children for whom they care. (*Am J Public Health.* 2009;99:1254–1262. doi:10.2105/AJPH.2007.129817)

caregiver health. However, these findings were based on a specific subpopulation of caregivers and univariate comparisons that could not control for potentially important confounders such as variation in caregiver education, income, and other demographic factors.

We used population-based data to test the hypothesis that the health of caregivers of children with health problems would be significantly poorer than that of caregivers of healthy children, even after we controlled for relevant covariates. Our approach of using large-scale, population-based data representing a broad spectrum of childhood health problems<sup>34</sup> makes 4 key contributions to the current literature. First, our use of population-based data rather than small-scale, clinic-based studies yielded results that are potentially generalizable to a wide group of caregivers caring for children with health problems. Second, our examination of children with and without health problems allowed us to examine caregiver health effects

across a wide variety of caregiving situations. Third, consideration of physical health outcomes (in addition to more regularly studied psychological outcomes) increased our knowledge of the breadth of caregiver health issues. Finally, controlling for relevant covariates allowed us to rule out a number of alternative explanations for caregiver health effects.

## METHODS

### Survey

Data for this study were drawn from the National Longitudinal Survey of Children and Youth (NLSCY), a long-term study of the physical and social development of Canadian children conducted jointly by Statistics Canada and Human Resources and Social Development Canada.<sup>35</sup> The NLSCY identifies the person most knowledgeable about the child to provide information on the selected child, as well as information about herself or himself and the

individual's spouse or partner (when appropriate). In 90% of cases, the person most knowledgeable about the child was the child's biological mother. Children were sampled from all areas of the country proportionate to the regional population. Exceptions were the northern territories (Yukon, Northwest Territories, Nunavut) and First Nations reserves, which were not included in the NLSCY sample. The first wave of interviews was conducted in 1994 and it has been repeated biennially since.

### Sample

The study sample was drawn from the first NLSCY cohort of children aged 0 to 11 years who were interviewed in 1994 and 1995 ( $n=22\,831$  children). The sample for our study was limited to children aged 4 to 11 years ( $n=13\,790$ ) to ensure consistency of health outcome items, because items differed for younger children. In 1994 and 1995, the NLSCY interviewed multiple children per selected household, up to a maximum of 4 children. To eliminate repeated measures of the same caregiver, we selected 1 child per household. In households in which all children were healthy (3722 households, representing 4903 children) 1 child was randomly selected. In households in which all children were defined as having a health problem (4087 households, representing 5301 children) 1 child was randomly selected. In households in which there was a mix of healthy and non-healthy children (1592 households, representing 3586 children) we selected only the children who met our criteria for having a significant health problem. If more than 1 such child existed in the household, 1 was randomly selected. After these exclusions, our sample included 9401 child-caregiver pairs.

### Categorizing Child Health Problems

Categorizing childhood health problems in the context of large-scale population-based surveys is a challenge, with no consensus on the best approach.<sup>36,37</sup> In the past, chronic condition checklists have been widely used in surveys because of their simplicity.<sup>7,30</sup> However, weaknesses of such an approach (e.g., exclusion of rare diseases, inconsistency of diagnostic labels, low reliability when categorizing children) have been noted.<sup>38</sup> An alternative approach used increasingly in the United States involves

grouping children with diverse conditions according to the consequences of their disorders (e.g., increased use of health care services, functional limitations) rather than categorically by clinical condition.<sup>38,39</sup> Another approach commonly used in Canada and elsewhere considers chronic conditions along with functional limitations in a manner broadly consistent with the International Classification of Functioning Disability and Health.<sup>40,41</sup> Arguments have been made for using both concepts in the context of childhood disability.<sup>33,42</sup>

A recent systematic review of measures and definitions of chronic health conditions in childhood<sup>43</sup> identified at least 20 different definitions of chronic health conditions, which yielded prevalence estimates ranging from 0.22% to 44%. The included studies targeted different aspects of childhood health with a variety of categories, and prevalence estimates differed accordingly. Aaronson et al. argued for a clarification in terminology and increased transparency of methodology to facilitate an understanding of how these different aspects of childhood health are related. Furthermore, they proposed an initial framework in which chronic conditions comprised the most comprehensive category of childhood health problems, those with activity limitations forming a subset of this larger category, and those with high use of services constituting a subset of the first 2 categories.

In a recent article,<sup>44</sup> we examined the relationship between different constructs related to childhood health problems (i.e., chronic conditions, activity limitations, functional problems, use of services) with the NLSCY. Our results suggested a different relationship between constructs than that suggested by the van der Lee et al. classification.<sup>37</sup> Of those with activity limitations, 15% did not report a chronic condition; for those with elevated service use, more than 40% did not report a chronic condition or activity limitation. Rather than supporting a classification in which limitations and services use are subsets of chronic conditions, our findings suggested that each indicator identifies quite different subgroups of children and families.

In this study, we examined how caregiver health was related to poor child health broadly defined, at the population-based level. Although different candidate child health indicators yielded subgroups with very different

characteristics, focusing instead on children identified by at least 2 of the 4 available indicators yielded a sample that (1) had considerably poorer health than those classified by 0 or 1 indicators, and (2) incorporated a wide range of childhood health problems and, therefore, caregiving situations.<sup>44</sup> Consequently, we compared caregivers of healthy children—i.e., children who were not identified by any of the 4 key indicators—to caregivers of children with health problems, defined as those who were identified by 2 or more of the key indicators. We excluded from our analyses those individuals identified by 1 indicator alone, because this group is highly heterogeneous in terms of child factors, family composition, and child health status, and is likely to be less sensitive to caregiver group differences.<sup>44</sup>

### Key Indicators

Activity limitation was based on an item that asked whether the child had any long-term conditions that limited participation at home, school, or at play, or in any other activity common for a child his or her age. A second question asked specifically about limitations caused by asthma. A positive response to either question indicated an activity limitation.

Functional problems were based on responses to the Health Utility Index (HUI).<sup>45</sup> The HUI is a multiattribute system and scale used to classify an individual's functional abilities in 8 attributes: vision, hearing, speech, ambulation, dexterity, cognition, emotion, and pain. With an algorithm based on population preferences, a summary score is derived. An HUI score of 1.0 represents perfect health, whereas a score of 0.0 represents death; negative scores represent functional impairments that are considered worse than death by community citizens whose values were used to compute the utility values. According to a cutpoint proposed by Kopec et al.,<sup>46</sup> children with a score of 0.81 or lower on the HUI are considered to have functional problems.

To measure chronic conditions, we used a checklist on which caregivers reported whether the child had been diagnosed by a health professional with any of the following conditions: asthma, allergies, bronchitis, cerebral palsy, epilepsy, heart condition or disease, kidney condition or disease, mental handicap, or "other." For children 6 years and older,

caregivers also reported whether the child had been diagnosed with a learning disability or any emotional, psychological, or nervous difficulties.

Elevated service use was determined using the NLSCY items related to 4 of the 5 concepts in the Children With Special Health Care Needs screener (CSHCN)<sup>47</sup>: (1) need or use of medicine prescribed by a doctor, other than vitamins; (2) need or use of more medical care, mental health, or educational services than is usual for most children of the same age; (3) special therapy, such as physical, occupational, or speech therapy; and (4) treatment or counseling for emotional, developmental, or behavioral problems. The fifth concept in the Children With Special Health Care Needs screener—limitations in ability to do the things most children of the same age can do—was omitted because it was conceptually similar to the activity limitation indicator. Additional information on the derivation of this indicator is provided elsewhere.<sup>44</sup> Caregiver health outcomes, along with family, caregiver, and child covariates, are described in Table 1.

### Analysis

We conducted descriptive comparisons between caregivers of children with health problems and healthy children by using the  $\chi^2$  test (categorical) or *t* test (continuous) as appropriate. We used regression models to assess the independent impact of caring for a child with a health problem on caregiver health over and above the effect of covariates such as single versus 2-parent families, household size, income adequacy, and caregiver gender, age, educational attainment, and smoking status. To account for the complex survey design of the NLSCY, we weighted and estimated all analyses with the bootstrap procedure with SAS-callable SUDAAN version 9 (Research Triangle Institute, Research Triangle Park, NC).

## RESULTS

Table 2 describes family, caregiver, and child characteristics for 3 groups: the total sample ( $N=9401$ ), the subgroup of children who were not categorized by any indicator of health problems ( $n=3633$ , or 38.6% of the total sample), and the subgroup of children categorized as having health problems

( $n=2495$ , or 26.5% of the total sample). The total sample of 9401 families had a mean income of Can\$51 784; 82.0% were headed by 2 parents. Primary caregivers were most often women (90.0%), and usually the child's biological mother (88.0%). Caregivers typically had education levels beyond high school (65.0%), were nonsmokers (67.8%), and had a mean age of 35.8 years (standard error=0.1). Of the 9401 children in the total sample, 6.6% had an activity limitation, 10.8% had functional problems, 37.4% had some kind of chronic health condition, and 43.0% had elevated service use.

The final column of Table 2 compares data concerning the children with health problems with those of healthy children on all demographic variables. Families of children with health problems were similar to families of healthy children on most sociodemographic characteristics, with exceptions that, compared with healthy children, children with health problems more often came from single-parent families (22.5% vs 16.3%;  $\chi^2_1=12.6$ ;  $P<.001$ ), had slightly younger caregivers (35.4 years vs 36.1 years;  $t=2.7$ ;  $P=.007$ ), and were more likely to have a caregiver who was a daily smoker (32.5% vs 24.5%;  $\chi^2_2=20.1$ ;  $P<.001$ ).

Table 3 shows that caregivers of children with health problems more often had a chronic condition themselves (56.6% vs 34.5%;  $\chi^2_1=110.8$ ;  $P<.001$ ) and had more chronic conditions (mean number of chronic conditions: 2.0 vs 1.7;  $t=5.4$ ;  $P<.001$ ) than did caregivers of healthy children. Caregivers of children with health problems also more often had an activity limitation (16.3% vs 7.3%;  $\chi^2_1=50.7$ ;  $P<.001$ ) and less often reported their health status as being excellent or very good (67.8% vs 77.5%;  $\chi^2_1=26.4$ ;  $P<.001$ ). Caregivers of children with health problems indicated more depressive symptoms than did caregivers of healthy children (mean scores: 5.9 vs 4.2 on a range of 0–36;  $t=6.3$ ;  $P<.001$ ), but did not differ on measures of family functioning (mean scores: 8.3 vs 8.0 on a range of 0–36), social support (mean scores: 14.5 vs 14.5 on a range of 0–18), or marital satisfaction (mean scores: 9.4 vs 9.4 on a range of 1–11).

To examine the independent effect of a child's health status (i.e., healthy or with health problems) on his or her caregiver's health, we conducted a series of regressions on each of the

4 caregiver health outcomes (i.e., presence of chronic conditions, activity limitation, general health status, and depressive symptoms), with control for other family, caregiver, and child characteristics. As shown in Table 4, after we controlled for these characteristics, caregivers of children with health problems had more than twice the odds of reporting a chronic condition (odds ratio [OR]=2.53; 95% confidence interval [CI]=2.14, 3.00) or an activity limitation (OR=2.42; 95% CI=1.88, 3.12) and had greater odds of rating their overall health as relatively poor (OR=1.64; 95% CI=1.35, 1.99) than did caregivers of healthy children. Caregivers of children with health problems also had more than twice the odds of reporting very elevated depressive symptom scores (OR=2.48; 95% CI=1.40, 4.40). Caregiver groups did not differ on measures of family functioning, social support, or (for the subset of 2-parent families) marital satisfaction.

## DISCUSSION

The results of this study suggest that the health of caregivers of children with health problems is significantly poorer than the health of caregivers of healthy children. After we controlled for relevant family, caregiver, and child factors, caregivers of children with health problems had substantially greater odds of reporting chronic conditions, activity limitations, poor general health, and symptoms of depression than did caregivers of healthy children. This work contributes to the existing literature by having used large-scale, population-based data and a broad spectrum of child health problems to ensure generalizability to a wide range of caregiving situations; by broadening our knowledge of caregivers' physical health issues; and by isolating the independent effect of caring for a child with a health problem on caregiver health, after controlling for relevant covariates.

Note that in our effort to examine caregiver health effects at a broad, population-based level, we chose a categorization scheme that grouped together a heterogeneous sample of child health problems and caregiving situations. Our sample of children with health problems, therefore, included both children with mild conditions who nevertheless used a greater number of health services, and severely

**TABLE 1—Description of Study Variables for Comparison of Health Among Caregivers of Healthy Children Versus Caregivers of Children With Health Problems: National Longitudinal Survey of Children and Youth (NLSCY), Canada, 1994–1995**

Variable	Description
<b>Caregiver health outcomes</b>	
Chronic conditions	Caregivers reported via checklist diagnosis of any chronic condition that had lasted, or was expected to last, 6 months or more. Checklist included food allergies, other allergies, asthma, arthritis or rheumatism, back problems excluding arthritis, high blood pressure, migraine headaches, chronic bronchitis or emphysema, sinusitis, diabetes, epilepsy, heart disease, cancer, stomach or intestinal ulcers, effects of stroke, urinary incontinence, Alzheimer disease or other dementia, cataracts, glaucoma, or any other long-term condition.
Activity limitations	Caregivers were asked whether a chronic health condition limited the kind or amount of activity they could do in 5 domains: at home, at school, at work, in caring for children, or in other activities. Those who reported being limited in 1 or more domains were said to have an activity limitation.
General health	Caregivers rated their general health on a 5-point scale, ranging from 1 (poor) to 5 (excellent). Caregivers' general health was dichotomized as being excellent/very good or good/fair/poor.
Depressive symptoms	Shortened version (12 items) of the Center for Epidemiological Studies Depression Scale <sup>48</sup> was used to assess the occurrence and severity of caregiver depressive symptoms in the week prior to the survey. A 4-point rating scale was used: 0=rarely or none of the time (less than 1 day in past week), 1=some or a little of the time (1–2 days), (2) occasionally or a moderate amount of time (3–4 days), and (3) most or all of the time (5–7 days). The scale ranges from 0 to 36, with higher values indicating more—and more frequent—depressive symptoms. Continuous scores were classified according to reported symptom severity: 0–11= minimal symptoms, 12–20=somewhat elevated symptoms, and 21–36=very elevated symptoms of depression. <sup>49</sup>
Family functioning	Twelve-item General Functioning subscale of the McMaster Family Assessment Device was used to assess general family functioning. <sup>50</sup> Caregivers reported degree to which each statement was true with a 4-point scale: 0=strongly agree, 1=agree, 2=disagree, and 3=strongly disagree. The scale ranged from 0 to 36, with higher scores indicating greater family dysfunction.
Social support	Level of social support caregivers received from friends, family, and others was assessed with a shortened version (6 items) of the Social Provisions Scale. <sup>51</sup> Caregivers rated degree to which they agreed with statements of perceived support on a 4-point scale: 0=strongly disagree, 1=disagree, 2=agree, and 3=strongly agree. Scale ranged from 0 to 18, with higher scores indicating a greater perceived presence of social support.
Marital satisfaction	Caregiver's satisfaction with marital relationship was assessed with a single-item scale, ranging from 1= completely dissatisfied to 11= completely satisfied. Item was only asked of caregivers who reported being in a marital relationship, including common-law relationships.
<b>Family, caregiver, and child covariates</b>	
Caregiver smoking status	Single item was used to categorize caregiver smoking frequency at the time of interview: daily, occasionally, or not at all. Categorization method combined former smokers with lifetime nonsmokers.
Caregiver educational attainment	Three questions were asked regarding caregivers' educational attainment: whether graduated from high school, ever attended postsecondary education, and if so, what degree was earned. Highest level of education attained was categorized from the responses: less than secondary school, secondary school graduate, some postsecondary education, and graduation with a postsecondary degree or diploma (including trade, technical, or vocational colleges).
Single- versus 2-parent families	The NLSCY included a roster of individuals in the household and their relationship to the interviewed child. Children were described as living with 1 or 2 parents, including biological, adoptive, step- and foster parents.
Number of children in household	From NLSCY roster, which gave the number of children aged 0 to 17 years living in the household, including the interviewed child.
Household income and income adequacy	Estimate of the total household income before taxes and deductions also used to categorize the income adequacy of the household, which accounts for household size. The NLSCY provided 5 categories of income adequacy: (1) lowest adequacy, a household income less than Can\$10 000 for 1 to 4 persons or less than Can\$15 000 for 5 or more persons; (2) lower-middle adequacy, a household income of Can\$10 000–\$14 999 for 1 or 2 persons, Can\$10 000–\$19 999 for 3 or 4 persons, or Can\$15 000–\$29 999 for 5 or more persons; (3) middle adequacy, a household income of Can\$15 000–\$29 999 for 1 or 2 persons, Can\$20 000–\$39 999 for 3 or 4 persons, or Can\$30 000–\$59 999 for 5 or more persons; (4) upper-middle adequacy, a household income of Can\$30 000–\$59 999 for 1 or 2 persons, Can\$40 000–\$79 999 for 3 or 4 persons, or Can\$60 000–\$79 999 for 5 or more persons; and (5) highest adequacy, a household income of Can\$60 000 or more for 1 or 2 persons, or Can\$80 000 or more for 3 or more persons. For purposes of this study, the 2 lowest income adequacy groups were combined.
Child age and gender	Child's age and gender were examined as covariates related to caregiver health.

**TABLE 2—Descriptive Analysis of Family, Caregiver, and Child Characteristics and Statistical Comparison of the 2 Subgroups: National Longitudinal Survey of Children and Youth, Canada, 1994–1995**

Characteristics	Total Sample (N = 9401), % or Mean (SE)	Healthy Children (n = 3633), % or Mean (SE)	Children With Health Problems <sup>a</sup> (n = 2495), % or Mean (SE)	Healthy Children Versus Children With Health Problems Comparison Test	P
<b>Family characteristics</b>					
Family type					
Single parent	17.99	16.31	22.52	$\chi^2_1 = 12.63$	<.001
Two parents	82.01	83.69	77.48		
Household income, Can \$	\$51 784 (\$686)	\$51 353 (\$965)	\$49 835 (\$1 113)	$t = 1.05$	.29
No. children in household	2.22 (0.02)	2.18 (0.03)	2.19 (0.03)	$t = 0.33$	.74
Income adequacy category <sup>b</sup>					
Lowest or lower middle	17.53	17.25	19.27	$\chi^2_3 = 1.77$	.62
Middle	30.59	31.29	29.74		
Upper middle	36.17	35.98	35.88		
Highest	15.72	15.47	15.11		
<b>Caregiver characteristics</b>					
Women	89.97	89.30	90.87	$\chi^2_1 = 1.60$	.21
Relationship to child					
Biological mother	87.97	87.13	88.25	$\chi^2_2 = 3.04$	.22
Biological father	9.49	10.35	8.56		
Other	2.54	2.52	3.19		
Age, y	35.80 (0.09)	36.12 (0.16)	35.44 (0.18)	$t = 2.68$	.007
Educational attainment of the person most knowledgeable about the child					
Less than secondary school	16.48	15.95	17.89	$\chi^2_3 = 5.75$	.13
Secondary school graduate	18.57	19.59	16.87		
Beyond high school	28.59	28.02	30.65		
College or university degree (including trade)	36.36	36.45	34.59		
Current smoking status					
Nonsmoker	67.83	70.84	63.35	$\chi^2_2 = 20.10$	<.001
Occasional	4.56	4.63	4.12		
Daily	27.61	24.53	32.53		
<b>Child characteristics</b>					
Age, y	7.50 (0.02)	7.43 (0.05)	7.72 (0.07)	$t = 2.98$	.003
Boy	52.27	48.12	60.05	$\chi^2_1 = 33.62$	<.001
Has a chronic health condition	37.38	0	89.99		
Has an activity limitation	6.56	0	23.59		
Has functional problems	10.77	0	29.45		
Has elevated use of health services	43.00	0	93.94		

<sup>a</sup>Our definition of children with health problems only included those who had been classified by 2 or more indicators of health problems; children who met only 1 indicator (n = 3273) were excluded from the analyses.

<sup>b</sup>Estimate of the total household income before taxes and deductions. See Table 1 for categorical definitions.

disabled children with complex disorders, functional problems, and activity limitations. Because we included caregivers of children with such a range of conditions in our sample, the observed caregiver health effects are all the more remarkable.

One logical next step of this work is to examine whether increased severity of child health problems is related to poorer caregiver health. Prior to this, however, the relationship between child health problem severity and caregiver burden needs to be clarified.

Caregivers who feel burdened by caring for children with relatively mild conditions may fare more poorly than caregivers who feel less burdened by children with more-severe health problems; that is, it may be “perceived severity” rather than the actual severity of the child’s

**TABLE 3—Caregiver Health and Social Support Outcomes and Statistical Comparison of the 2 Subgroups: National Longitudinal Survey of Children and Youth, Canada, 1994–1995**

Caregiver Outcome	Total Sample (N = 9401), % or Mean (SE)	Healthy Children (n = 3633), % or Mean (SE)	Children With Health Problems (n = 2495), % or Mean (SE)	Healthy Children Versus Children With Health Problems	
				Comparison Test	P
At least 1 chronic condition	44.28	34.45	56.62	$\chi^2_1 = 110.82$	<.001
Number of chronic conditions <sup>a</sup>	1.80 (0.03)	1.65 (0.05)	2.02 (0.05)	$t = 5.41$	<.001
Limitation in at least 1 domain of activity	10.58	7.29	16.32	$\chi^2_1 = 50.74$	<.001
General health status excellent or very good <sup>b</sup>	73.31	77.50	67.76	$\chi^2_1 = 26.36$	<.001
Depression scale <sup>c</sup>					
Mean score	4.86 (0.10)	4.23 (0.16)	5.88 (0.22)	$t = 6.25$	<.001
Minimal score (0–11)	89.03	90.94	85.70	$\chi^2_1 = 15.03$	<.001
Somewhat elevated score (12–20)	8.17	7.03	9.70	$\chi^2_1 = 5.89$	.02
Very elevated score (21–36)	2.80	2.03	4.60	$\chi^2_1 = 8.54$	.004
Social support total score <sup>d</sup>	14.46 (0.05)	14.46 (0.08)	14.47 (0.11)	$t = 0.02$	.98
Family functioning total score <sup>e</sup>	8.06 (0.10)	7.99 (0.14)	8.25 (0.17)	$t = 1.20$	.23
Marital satisfaction <sup>f</sup>	9.38 (0.04)	9.38 (0.06)	9.35 (0.08)	$t = 0.31$	.76

<sup>a</sup>Among those with at least 1 chronic condition.

<sup>b</sup>Reference group is good/fair/poor general health.

<sup>c</sup>Range = 0–36; higher score indicates more symptoms of depression.

<sup>d</sup>Range = 0–18; higher score indicates better social support.

<sup>e</sup>Range = 0–36; higher score indicates greater family dysfunction.

<sup>f</sup>Range = 1–11; higher score indicates greater marital satisfaction; only asked of caregivers in a marriage relationship, including common law.

health problem that affects caregiver health. Alternatively, it may be that the number and complexity of child health problems predict caregiver health better than the severity of a specific child health problem. Such issues are likely to be better addressed in the context of specific childhood conditions, when measures of disease severity have been validated, the prevalence of comorbidities is well understood, and specific caregiving challenges are known.

Given the cross-sectional nature of our study, the findings of an association between child and caregiver health do not unequivocally imply that the additional burdens associated with caring for a child with a health problem cause caregiver health problems. Although we were able to estimate the effect of caring for a child with a health problem after we controlled for important covariates, unmeasured variables (e.g., genetic predispositions) could account for the health differences between caregiver groups.

However, 2 intriguing initial results lead to consideration of some form of causal relationship. First, in a previous study<sup>5</sup> we showed that the pattern of physical chronic conditions reported by caregivers of children with cerebral

palsy was consistent with a stress process explanation. Conditions associated with physical or emotional stress (e.g., back problems, ulcers) were much more prevalent among these caregivers, whereas other conditions less obviously associated with stress (e.g., food allergies, bronchitis) showed much smaller effects. Second, we conducted exploratory analyses with the current data set to see whether group differences in caregiver health remained robust for caregivers who are not biologically related to their children. We reasoned that if both caregiver health and child health problems were caused primarily by a common genetic predisposition, an interaction between type of parent (i.e., biological, nonbiological) and caregiving situation (i.e., healthy, with health problems) on caregiver health would become apparent. No such interaction was evident, although small sample sizes precluded any strong conclusions. These admittedly preliminary data suggest that caregiver health may be affected by the additional stresses associated with caring for a child with a health problem.

### Limitations

A number of limitations warrant consideration. First, although our sample of child–caregiver

dyads was population based and included a wide range of child health problems and caregiving situations, it cannot be considered representative of the Canadian population of caregivers. Threats to representativeness included (1) our decision to exclude the 1-indicator-only group from these analyses; (2) the fact that the NLSCY was designed to obtain a nationally representative sample of children, not caregivers, and thus, the complex sampling strategies necessary to ensure national representativeness were not applied to the sample of caregivers; and (3) by limiting our sample to 1 child per caregiver and to a certain child age range, we may have selected a biased sample.

Indeed, higher rates of caregiver income, education, and 2-parent households compared with national norms<sup>52</sup> suggest that such a bias may be present. Whether such a bias would substantially affect our findings is unknown, although, if anything, an affluence bias might suggest that the true caregiver health effects are underestimated in our study. Replication and related work in other countries (e.g., the United States) with different health care and social systems would allow assessment of the pervasiveness of this association between child and

**TABLE 4—The Effects of Child Health Status on Caregiver Health Outcomes After Control for Family, Child, and Caregiver Characteristics: National Longitudinal Survey of Children and Youth, Canada, 1994–1995**

	Any Chronic Condition (n = 6062), OR (95% CI)	Activity Limitation (n = 6063), OR (95% CI)	General Health Status <sup>a</sup> (n = 6063), OR (95% CI)	Depression Score, <sup>b</sup> OR (95% CI)
Caregiver of child with health problems (Ref = caregiver of healthy child)	2.53 (2.14, 3.00)	2.42 (1.88, 3.12)	1.64 (1.35, 1.99)	2.48 (1.40, 4.40)
<b>Child characteristics</b>				
Male child (Ref = female child)	0.96 (0.80, 1.14)	0.86 (0.66, 1.12)	0.86 (0.71, 1.04)	0.50 (0.27, 0.92)
Child's age <sup>c</sup>	0.99 (0.95, 1.03)	1.06 (0.99, 1.13)	0.99 (0.95, 1.04)	0.92 (0.81, 1.05)
<b>Family characteristics</b>				
Single-parent family (Ref = 2 parents)	1.14 (0.89, 1.47)	1.56 (1.09, 2.21)	1.08 (0.83, 1.40)	2.20 (1.19, 4.09)
Number of children in household <sup>c</sup>	0.90 (0.81, 0.99)	0.88 (0.75, 1.03)	0.93 (0.83, 1.03)	0.96 (0.71, 1.31)
Income adequacy category <sup>d</sup> (Ref = middle adequacy)				
Lowest or lower middle	1.52 (1.16, 1.98)	1.39 (0.95, 2.04)	1.45 (1.08, 1.94)	3.00 (1.40, 6.43)
Upper middle	1.20 (0.97, 1.47)	0.72 (0.52, 1.00)	0.64 (0.50, 0.81)	0.83 (0.38, 1.83)
Highest	1.29 (0.97, 1.71)	0.83 (0.52, 1.34)	0.53 (0.37, 0.74)	0.64 (0.22, 1.84)
<b>Caregiver characteristics</b>				
Men (Ref = women)	0.44 (0.32, 0.59)	0.92 (0.59, 1.43)	1.08 (0.76, 1.53)	0.98 (0.31, 3.05)
Age	1.03 (1.01, 1.05)	1.01 (0.98, 1.04)	1.03 (1.01, 1.05)	1.05 (1.00, 1.11)
Person most knowledgeable about the child had at least secondary school diploma (Ref = less than secondary)	1.09 (0.86, 1.37)	1.07 (0.78, 1.46)	0.53 (0.42, 0.68)	0.89 (0.47, 1.69)
Caregiver's current smoking status (Ref = nonsmoker)				
Occasional	0.83 (0.52, 1.34)	0.96 (0.50, 1.84)	1.35 (0.85, 2.14)	2.78 (0.87, 8.80)
Daily	1.10 (0.92, 1.33)	1.13 (0.86, 1.49)	1.84 (1.50, 2.25)	1.60 (0.85, 3.02)

Note. OR = odds ratio; CI = confidence interval.

<sup>a</sup>Predicting poorer health (poor/fair/good vs very good/excellent).

<sup>b</sup>Very elevated symptom scores.

<sup>c</sup>Continuous measure; baseline = 0.

<sup>d</sup>Estimate of the total household income before taxes and deductions. See Table 1 for categorical definitions.

caregiver health, and perhaps identify interventions, such as family-centered services,<sup>22</sup> that have the potential to improve caregiver health.

Second, interpretation of our results must be tempered by the knowledge that the data were collected cross-sectionally, yet the effects on caregiver health of stress associated with caring for a child with a health problem are likely to be complex, dynamic, and manifest themselves over time. Analysis of the health of the caregiver over time will be necessary to gain a better understanding of these processes. We plan to address this issue, making use of the longitudinal data collection schedule of the NLSCY.

Third, all indicators and outcomes were based on parent-reported measures. Parental reports of children's health conditions may not accurately reflect the child's health problems. Moreover, there is an issue of shared method variance; that is, parents who report poor

health in their children may be more likely to report themselves in poor health. However, parent reports have been shown to be relatively reliable for severe health conditions.<sup>53–56</sup>

Certainly, physician diagnoses and data linked from administrative sources would be a useful area for further study. For the present, our validated method for classifying children with health problems<sup>44</sup> makes the best use of the self-reported data by combining several widely recognized indicators into a broad category of childhood health problems.

Finally, the definition of childhood illness used in our study included many nonspecific health problems and focused on the consequences of childhood health problems (e.g., use of health services) rather than specific child health conditions. This approach ensured that caregivers from very different caregiving situations would be grouped together in our

analyses, potentially masking differences between specific caregiving situations. As described earlier, this practice is garnering support in the caregiver literature and is defensible given that policymakers must make their decisions based on broad categorizations. However, future work will compare subgroups of interest to examine relative effects on caregiver health; for example, children with externalizing behavior problems in addition to other health conditions may pose a particular caregiving challenge that might impact caregiver health.<sup>22,25,57</sup>

## Conclusions

This study shows that after we controlled for differences in relevant family, child, and caregiver factors, caregivers of children with health problems (broadly defined) themselves have substantially greater odds of reporting chronic

conditions, activity limitations, poorer health, and higher depressive symptoms than did caregivers of healthy children. Regardless of the causal pathways leading to poorer caregiver health, the results have implications for health providers and policymakers. Clinicians will be better prepared if they are aware of the increased risk for health problems that is associated with caring for children with health problems. Research examining family-centered services (comprehensive services that address child health and parental well-being together) could detail our understanding of the pathways by which such services improve care. Policy decisions that encourage the use of such family-centered services would underline the importance of healthy families to the care and support of children with health problems. ■

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### Contributors

J. C. Brehaut originated and designed the study, interpreted the data, drafted the article, supervised the study, and supplied administrative, technical, and material support. D. E. Kohen also originated and designed the study, interpreted the data, assisted with the acquisition of the study data, and supervised analysis. R. E. Garner drafted parts of the article; acquired, analyzed, and helped interpret the data; and provided statistical expertise. All other authors provided specific content or methodological expertise throughout the project, including interpretation of the findings and provision of critical revisions of article.

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### Human Participation Protection

This work has been approved by the Ottawa Hospital Research Ethics Board.

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