

# The Health of Primary Caregivers of Children With Cerebral Palsy: How Does It Compare With That of Other Canadian Caregivers?

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**ABSTRACT.** *Background.* Caring for any child involves considerable resources, but the demands for these resources are often increased when caring for a child with a disability. These demands have implications for the psychologic and physical health of the caregiver (CG). Although a number of recent trends in health care stress the importance of studying and promoting the health of CGs of children with disabilities, the literature in this area exhibits 2 major weaknesses, ie, most studies draw conclusions from relatively small, potentially biased, clinic-based samples and the majority of work has focused on the psychologic health of CGs, whereas little research has been undertaken to study their physical well-being. The goal of this study was to compare the physical and psychologic health of CGs of children with cerebral palsy (CP) with that of the general population of CGs.

*Methods.* Data on the physical and psychologic health of 468 primary CGs of children with CP, drawn from 18 of 19 publicly funded children's rehabilitation centers in Ontario, Canada, were collected with a self-completed questionnaire and a face-to-face interview. Identical items and scales had been administered previously to nationally representative samples of the Canadian population in 2 large-scale Canadian surveys, ie, the National Population Health Survey (NPHS) and the National Longitudinal Study of Children and Youth (NLSCY). Subsamples of those data, restricted to adult residents of the province of Ontario who were parents, allowed a comparison of our sample of CGs of children with CP with parent samples from both the NLSCY ( $n = 2414$ ) and the NPHS ( $n = 5549$ ).

*Outcome Measures.* Demographic variables included CG age, gender, education, income, and work-related variables. Psychologic health and support variables included social support, family functioning, frequency of contacts, distress, and emotional and cognitive problems. Physical health variables included the number and variety of chronic conditions, vision, hearing, and mobility problems, and experience of pain.

*Results.* CGs of children with CP had lower incomes than did the general population of CGs (proportion with income over \$60 000: CG: 40.9%; NLSCY: 51.4%), despite the absence of any important differences in education between the 2 samples. Results showed that CGs of children with CP were less likely to report working for pay (CG: 66%; NLSCY: 81.2%), less likely to be engaged in full-time work (CG: 67.5%; NLSCY: 73.2%), and more likely to list caring for their families as their main activity (CG: 37.2%; NLSCY: 28.4%). Measures of support showed no difference in reported social support (CG: mean score: 14.5; SD: 3.4; NLSCY: mean score: 14.3; SD: 2.7) or family functioning (CG: mean score: 8.6; SD: 5.6; NLSCY: mean score: 9.0; SD: 4.9) between the 2 samples, although the CG sample did report a statistically greater number of support contacts (CG: mean score: 4.5; SD: 0.7; NPHS: mean score: 4.2; SD: 0.9). Measures of psychologic health showed greater reported distress (CG: mean score: 4.7; SD: 4.4; NPHS: mean score: 2.2; SD: 2.7), chronicity of distress (CG: mean score: 5.5; SD: 1.4; NPHS: mean score: 5.2; SD: 1.1), emotional problems (CG: 25.3% indicating problems; NPHS: 13.7%), and cognitive problems (CG: 38.8%; NPHS: 14.3%) among CGs of children with CP. They also reported a greater likelihood of a variety of physical problems, including back problems (CG: 35.5% reporting the condition; SE: 2.2%; NLSCY: 12.2%; SE: 0.7%), migraine headaches (CG: 24.2%; SE: 2.0%; NLSCY: 11.2%; SE: 0.7%), stomach/intestinal ulcers (CG: 8.4%; SE: 1.3%; NLSCY: 1.7%; SE: 0.3%), asthma (CG: 15.8%; SE: 1.7%; NLSCY: 6.3%; SE: 0.5%), arthritis/rheumatism (CG: 17.3%; SE: 1.8%; NLSCY: 7.3%; SE: 0.5%), and experience of pain (CG: 28.8%; SE: 2.1%; NPHS: 11.0%; SE: 0.5), as well as a greater overall number of chronic physical conditions (CG: 24.1% reporting no chronic conditions; NLSCY: 55.2%).

*Conclusions.* Although many families cope well despite the added challenges of caring for a child with a disability, our findings suggest that the demands of their children's disabilities can explain differences in the health status of parents and that parents of children with CP are more likely to have a variety of physical and psychologic health problems. Many of these findings are consistent with a stress process model, in which stress from caregiving can directly or indirectly affect a variety of measures of health, although some of the findings (asthma and arthritis) seem to strain this hypothesis.

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Alternate interpretations of these findings include the possibility that parents who are in regular contact with the health care system may have more opportunities to discuss and receive attention for their own health concerns than do comparison adults or that the greater number of health issues reported by CGs is related to the nature of our study, perhaps leading these parents to focus on their health and well-being in more depth than is usually feasible in a population survey. CGs of children with CP also had lower incomes, despite the absence of any important differences in education. The findings are consistent with the idea that the financial burden of caring for a child with a disability results in part from a reduced availability of these parents to work for pay.

*Implications for Service Providers.* Physicians and other health care professionals should be aware of the important relationship between child disability and CG health. Family-centered policies and services that explicitly consider CG health are likely to benefit the well-being of both CGs and their families. Future work should address the extent to which the family-centeredness of services, as experienced by CGs, is associated with better health outcomes for parents and their families. *Pediatrics* 2004;114:e182–e191. URL: <http://www.pediatrics.org/cgi/content/full/114/2/e182>; caregiver, parent, disability, cerebral palsy, physical health, psychologic health, survey.

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ABBREVIATIONS. NPHS, National Population Health Survey; NLSCY, National Longitudinal Study of Children and Youth; CP, cerebral palsy; CG, caregiver.

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The challenge of caring for any child requires considerable resources, including time and money. In caring for a child with a disability, however, the demands for these resources are often significantly increased. Caring for a child with a disability requires more time from the caregiver (CG),<sup>1,2</sup> and the costs of medical care have been estimated to be 2.5 to 20 times the average costs of caring for children.<sup>3</sup> Although many parents of children with disabilities cope well with these increased demands, the demands may have implications for the psychologic and physical health of some CGs.

One example of a common childhood disability that places added demands on the CG is cerebral palsy (CP). CP describes a group of conditions that result from disorders of the developing nervous system.<sup>4</sup> Although impaired motor function is the hallmark of CP, many children with CP also show evidence of sensory and intellectual impairments and may have limitations in self-care functions such as feeding, dressing, bathing, and mobility. Such limitations, and the long-term dependency they create, can place demands on CGs that far exceed the usual requirements for developing children.<sup>1,5</sup>

In recent years, the incidence of CP has been consistently estimated at 2.0 to 2.5 cases per 1000 live births.<sup>6</sup> These estimates translate into ~15 000 to 20 000 children with CP in Canada and ~150 000 in the United States, the vast majority of whom are cared for at home by their parents and families.<sup>7</sup> At the same time, family units are smaller and less

stable than in the past,<sup>8</sup> with more families requiring 2 wages to maintain their standard of living.<sup>9</sup>

Recently, several initiatives have focused attention on CG health as an area requiring study. First, a recent revision of the World Health Organization International Classification of Functioning, Disability, and Health framework stresses the environment as critical to health and well-being. Such a framework highlights the important relationship between the health of the CG and the health of the child. Second, there has been a shift in health care service delivery away from child-centered models that focus primarily on treating the disability toward family-centered services and family-centered well-being.<sup>10–13</sup> This shift recognizes the primary role of the family in child development but may also serve to increase demands on family members by requiring them to be more active participants in the care of the child. Finally, the international movement to improve the efficiency of resource use in health care systems has demonstrated that learning how to keep CGs healthy makes good economic sense. Poor CG health may result not only in decreased work productivity and health care costs for the CG but also in increased costs associated with provision of services for the care recipient.<sup>14</sup> All of these initiatives indicate an important role for the study and promotion of the health of CGs of children with chronic conditions involving health or development.

Existing literature supports the concept that caring for a child with a disability can have implications for the health of the CG. Psychologic health has been the subject of a number of studies, with evidence showing that CGs of children with disabilities are more likely to experience depression and distress,<sup>15</sup> to report poorer general emotional health,<sup>16</sup> to exhibit stress and feel pessimistic about the future,<sup>17,18</sup> and to feel that their caregiving prevents them from taking time for themselves,<sup>2,16,18,19</sup> compared with CGs of children without disabilities. Poor CG psychologic health is associated with greater child disability,<sup>20–24</sup> child behavior problems,<sup>25</sup> poor child temperament,<sup>26</sup> and specific child cognitive or sensory deficits.<sup>15,17,21,27</sup> However, these stressors on the psychologic health of CGs can be ameliorated by factors such as a feeling of mastery of the CG situation and high self-esteem,<sup>28–30</sup> specific coping strategies,<sup>21,31</sup> social support,<sup>16,20,32,33</sup> family support,<sup>16,27,34,35</sup> and formal support services.<sup>18,32,36,37</sup>

The literature in this field demonstrates 2 major weaknesses. First, the majority of studies that demonstrated a relationship between the caregiving situation and psychologic health based their findings on relatively small samples drawn from specialty centers, which are likely to be limited to children with more severe disabilities. Few studies have examined community-based groups of CGs of children with disabilities or compared their health with that of a population-based sample of parents (but see the study by Cadman et al<sup>15</sup>). The latter approach would avoid the biases inherent in small, clinic-based samples and would be more likely to include both families that cope well and thus need relatively little help from specialty centers and those with more complex

needs. Second, most of the work performed to date on the health of CGs of children with disabilities has focused on psychologic health, with little attention to the physical health of CGs. Two studies demonstrated that mothers of children with physical and psychiatric disabilities reported more physical health complaints than did mothers of children without these disabilities.<sup>19,38</sup> However, both studies examined small, clinic-based samples. To date, no large-sample, population-based studies examining the physical health of CGs of children with disabilities have been reported.

The primary objective of this study was to compare the health of CGs of children with CP with that of a population-based, representative sample of parents. To that end, and because the sample of CGs of children with CP was drawn exclusively from the province of Ontario, we compared the demographic characteristics and health measures of our sample of CGs with those of the corresponding provincial subsamples of 2 large-scale, Canadian studies, ie, the National Longitudinal Survey of Children and Youth (NLSCY) and the National Population Health Survey (NPHS).

## METHODS

### Participants and Recruitment for CG Study

The "Caring About Caregivers" study was administered through the CanChild Center for Childhood Disability Research at McMaster University. This study was administered through the CanChild Centre for Childhood Disability Research at McMaster University (Hamilton, Ontario, Canada). Participants for this study were recruited from a cohort of families who had participated in a previous CanChild study, assessing motor development among children with CP.<sup>39</sup> To ensure enrollment of a sample that was representative of children with CP in the province of Ontario, we obtained a stratified random sampling of children of various ages and disability levels from 18 of 19 publicly funded children's rehabilitation centers in Ontario. The time between inception of the original study (1996) and recruitment of participants for the current study was approximately 5 years. Data collection for the current study occurred between March 2001 and May 2002.

Of the initial sampling frame containing 632 children, 42 children were unavailable to participate (ie, they had died or their families were untraceable). A total of 590 families (93%) were contacted and 570 (90%) were eligible; 503 of the 570 (88%) consented to participate. A final sample of 468 primary CGs (82% of the 570 eligible families) provided data. Of those CGs, 445 (95%) were natural parents of the children, 15 were foster parents, 4 were relatives other than parents, and 4 were alternative CGs. The initial recruitment strategy involved mailing families a recruitment letter, a consent form, a brochure describing the study, and a lottery ticket. CGs were then telephoned by trained recruiters, who discussed the study and requested participation. The CG was defined as the person most responsible for the day-to-day decision-making and care for the child. In families in which the parents shared the caregiving, we asked the parents to decide who would participate in the study. Consenting CGs were mailed a questionnaire to complete before a face-to-face interview with a trained interviewer. Questionnaires required ~45 minutes to complete, and the in-home interviews typically required ~1 hour. Participants received a \$50.00 honorarium.

### Comparison with National Surveys

Data from the CG study were compared with the Ontario data from 2 large-scale, prospective, Canadian surveys, ie, the NLSCY and the NPHS. Details of these 2 surveys are provided in the Appendix. After identifying constructs relevant to CG physical and psychologic health during the design phase of the CG study, we proceeded to identify items or scales to measure these con-

structs. During this process, items or scales used in these national studies were considered. If either study included an appropriate item or scale, then it was adopted into the CG study, to allow the planned comparison with a provincially representative sample. If both the NPHS and NLSCY included appropriate items or scales, we adopted that from the NLSCY, because the respondent sample from that study more closely matched the CG study sample. This process yielded a number of demographic variables, as well as indicators of CG psychologic and physical health, for which we had data from the CG study and data from at least 1 of the 2 national studies.

Because the sample of CGs in the CG study was drawn exclusively from Ontario, we chose to make our comparisons with the Ontario subsamples of the NLSCY and NPHS. For some variables, however, these provincially representative subsamples yielded low cell counts, which could not be released because of Statistics Canada confidentiality policies. When this occurred, we resorted to the nationally representative sample to make the comparison; these cases are identified in the tables.

### Instruments

Table 1 describes the variables collected. Demographic information collected included the age and gender of the CG, education, household income, whether the CG worked for pay, the number of hours per week worked, and the reported main activity. These data, with the exception of the question about main activities, were collected as part of the self-completed questionnaire.

In addition to demographic questions, we asked a series of questions pertaining to the psychologic health of the CGs. These included assessments of distress and chronicity of distress, emotional problems, and problems with cognition, the latter 2 being subscales of the Health Utility Index.<sup>40</sup> Social support was measured by using an abbreviated version of the Social Provisions Scale.<sup>41</sup> We also examined the average frequency of contacts, based on the Social Network and Frequency of Contact Index.<sup>40</sup> Finally, we examined family functioning by using the Family Assessment Device.<sup>42</sup> All of these data were collected in the face-to-face interviews, which were conducted by experienced interviewers trained in the use of all instruments and evaluated for reliability before interviewing.

Physical health measures included the presence of specific chronic conditions<sup>40</sup> and the overall number of chronic conditions. A series of subscales of the Health Utility Index<sup>40</sup> were administered, including problems with vision, hearing, mobility, and the presence of pain. In all cases, responses on these subscales were converted to a dichotomous response (none or some). We also collected data from the other Health Utility Index subscales (speech and fine motor); because these problems were rare in both samples, however, these subscales were excluded from analysis. All of these questions were collected during the face-to-face interviews.

### Data Entry and Analysis

Data for this study were entered with the DataFax software program (DataFax Systems, Hamilton, Ontario, Canada) and exported into the Statistical Package for the Social Sciences (SPSS, Chicago, IL) for cleaning and analysis. Missing data were handled on a per-measure basis, using rules specified by the tools' authors. Analyses to examine differences between the CG study and national studies took the form of  $\chi^2$  tests of association for discrete variables and *t* tests for comparison of the means of independent samples.

## RESULTS

### Demographic Variables

Table 2 describes the demographic characteristics of the CG sample and the corresponding population studies (NPHS and NLSCY). The study from which each question or instrument was drawn is indicated. Results show that our CG sample was well matched to the population samples in terms of age (mean age: CG: 40.3 years; NLSCY: 39.9 years; NPHS: 40.2



**TABLE 1.** Summary of Measures Used in the Current Analyses

Variable	Description
Demographic measures*	
Age	In years
Gender	% female
Education	Highest level attained, categorized into less than high school, high school, some postsecondary, diploma, or degree
Income	Household income, categorized into \$0–29 999, \$30 000–59 999, or \$60 000 or more
Work for pay	Yes/no
Hours per week worked	Categorized into <30 h (part-time) or ≥30 h (full-time)
Main activity†	One of caregiving, working for pay, caring and working, school, or other
Psychological health and support††	
Distress	6 items (eg, sad, nervous, or fidgety); range of scale: 0–24; subset of items from the CIDI related to distress (MH Q1A to Q1F) <sup>41</sup>
Chronicity of distress	Range of scale: 1–8; subset of items from the CIDI related to chronicity of distress (MH Q1G to Q1L) (eg, over the past month, have these symptoms been occurring more often than usual, about the same, or less often than usual) <sup>41</sup>
Emotional problems	McMaster HUI in NPHS <sup>41</sup> (describes self as being usually happy and interested in life, somewhat happy, etc.)
Cognitive problems	HUI <sup>41</sup> (ie, memory or problem solving)
Social support	6 items; range of scale: 0–24; abbreviated version of the Social Provisions Scale <sup>42</sup>
Frequency of contacts	Items summarize persons in the caregiver's social network and the average number of caregiver contacts in the past 12 mo with family, friends, and neighbors (SUP-Q7A to SUP-Q7H), Social Network and Frequency of Contact Index <sup>41</sup>
Family functioning	13 items; global assessment of family functioning and the quality of relationships between parents or partners from the Family Assessment Device <sup>43</sup>
Physical health measures†	
Chronic conditions	Presence of 14 different chronic conditions (eg, food allergies, asthma, or back problems), defined as lasting ≥6 mo and diagnosed by a health professional <sup>49</sup>
No. of chronic conditions	Categorized into 0, 1, 2, or ≥3
Physical health problems	Categorized to some/none, subset from HUI <sup>41</sup> (vision, hearing, mobility, or presence of pain)

CIDI indicates Composite International Diagnostic Interview, HUI, Health Utility Index.

\* Data collected as part of a self-completed questionnaire.

† Data collected during interviews.

years). The CG sample did not differ from the NLSCY in gender distribution, with both samples being primarily female (CG: 94.4%; NLSCY: 93.0%), although the distribution of respondents in the NPHS was quite different (53.5% female). The CG and NLSCY samples differed in the distribution of the education categories (overall  $\chi^2 = 15.9$ ,  $P = .001$ ); however, the 2 samples showed similar proportions at the lower (less than high school: CG: 13.5%; NLSCY: 11.2%) and higher (degree: CG: 17.3%; NLSCY: 15.7%) ends of the education spectrum; additional analysis showed that the subjects in the CG sample were less likely to list some postsecondary education as their highest level of education achieved (19.0% vs 28.1%;  $P < .001$ ). Household incomes for the CG sample were lower than those for the population sample (overall  $\chi^2 = 25.75$ ,  $P < .001$ ), with a greater proportion of households making less than \$30 000 per year (CG: 25.0%; NLSCY: 16.1%;  $P < .001$ ) and a smaller proportion making more than

\$60 000 per year (CG: 40.9%; NLSCY: 51.4%;  $P < .001$ ).

A smaller proportion of subjects in the CG sample reported working for pay, compared with the population sample (CG: 66.0%; NLSCY: 81.2%;  $\chi^2 = 54.0$ ,  $P < .001$ ). Furthermore, of those that did work, a smaller proportion of the CG sample reported working full-time (CG: 67.5%; NLSCY: 73.2%;  $\chi^2 = 4.3$ ,  $P < .04$ ). The 2 groups differed significantly in whether they described their main activity as caring for family, working for pay, both, or school (overall  $\chi^2 = 27.1$ ,  $P < .001$ ). Additional analysis showed that those in the CG sample were more likely to list caring for the family as their main activity (37.2% vs 28.4%;  $P < .001$ ) and less likely to list working for pay alone as their main activity (1.1% vs 5.4%;  $P < .001$ ). It should be noted that, because of small numbers in the "other" category of main activity, this category was dropped and the analysis was conducted with the other 4 categories.

**TABLE 2.** Demographic Variables

	CG Study	Population Study (NLSCY or NPHS)	Comparison
Age (y)*†			
Mean (SD)	40.3 (6.7)	39.9 (5.4)*; 40.2 (6.3)†	$t = 1.41, NS^*$ ; $t = 0.3, NS^†$
Range	23–63	18–64*; 18–75†	
Gender, % female*†	94.4	93.0*; 53.5†	$\chi^2_{(1)} = 1.51, NS^*$ ; $\chi^2_{(1)} = 295.3, P < .001^†$
Education,* %			
Less than high school	13.5 (1.6)	11.2 (0.6)	
Finished high school	19.7 (1.8)	16.4 (0.8)	
Some postsecondary	19.0 (1.8)	28.1 (0.9)	
Diploma	30.7 (2.1)	28.6 (0.9)	
Degree	17.3 (1.8)	15.7 (0.7)	$\chi^2_{(4)} = 15.9, P < .001$
Household income,* %			
\$0–29 999	25.0 (2.0)	16.1 (0.5)	
\$30 000–59 999	34.1 (2.2)	32.5 (1.0)	
\$60 000 or more	40.9 (2.3)	51.4 (1.0)	$\chi^2_{(2)} = 25.75, P < .001$
Work for pay,* %	66.0 (2.2)	81.2 (0.8)	$\chi^2_{(1)} = 54.0, P < .001$
Full-time work,* %	67.5 (2.7)	73.2 (1.0)	$\chi^2_{(1)} = 4.3, P = .04$
Main activity,* %			
Caring for family	37.2 (2.2)	28.4 (0.9)	
Working for pay	1.1 (0.5)	5.4 (0.5)	
Caring and working	58.5 (2.3)	62.7 (1)	
School	1.3 (0.5)	1.2 (0.2)	
Other	1.9 (0.6)		$\chi^2_{(3)} = 27.1, P < .001$

NS indicates not significant.

\* Data from the NLSCY.

† Data from the NPHS.

### Psychologic Health and Social Support Outcomes

Table 3 describes the outcomes related to psychologic health, as well as support available to the CG. The CG sample did not differ from the population sample on the basis of available social support (CG: mean score: 14.5; SD: 3.4; NLSCY: mean score: 14.3; SD: 2.7;  $t = 1.3$ , not significant) or family functioning (CG: mean score: 8.6; SD: 5.6; NLSCY: mean score: 9.0; SD: 4.9;  $t = -1.6$ , not significant). The 2 groups did differ in reported average frequency of contacts, with the CG sample reporting more contacts (CG: mean score: 4.5; SD: 0.7; NPHS: mean score: 4.2; SD: 0.9;  $t = 7.7, P < .001$ ). The CG sample reported a greater overall level of distress (CG: mean score: 4.7; SD: 4.4; NPHS: mean score: 2.2; SD: 2.7;  $t = 18.3, P < .001$ ) and chronicity of distress (CG: mean score: 5.5; SD: 1.4; NPHS: mean score: 5.2; SD: 1.1;  $t = -6.1, P <$

.001). Greater proportions of the CG sample reported emotional problems (CG: 25.3%; SE: 2.0%; NPHS: 13.7%; SE: 0.5%;  $\chi^2 = 44.6, P < .01$ ) and problems of cognition (CG: 38.8%; SE: 2.3%; NPHS: 14.3%; SE: 0.6%;  $\chi^2 = 178.3, P < .01$ ).

### Physical Health Outcomes

Table 4 describes results for the physical health-related outcomes. Subjects indicated yes or no to questions about whether they had a number of chronic conditions. As shown in Table 4, for virtually every type of chronic condition except food allergies and chronic bronchitis/emphysema, a greater proportion of the CG sample reported having the condition, compared with the population sample. This pattern was reflected in the overall number of chronic conditions reported, which was significantly

**TABLE 3.** Psychological Health and Social Support Variables

	CG Study	Population Study (NLSCY or NPHS)	Comparison
Support, mean score (SD)			
Social support*	14.5 (3.4)	14.3 (2.7)	$t = 1.3, NS$
Family functioning*	8.6 (5.6)	9.0 (4.9)	$t = -1.6, NS$
Frequency of contacts†	4.5 (0.7)	4.2 (0.9)	$t = 7.7, P < .001$
Psychological health			
Distress,† mean score (SD)	4.7 (4.4)	2.2 (2.7)	$t = 18.3, P < .001$
Chronicity of distress,† mean score (SD)	5.5 (1.4)	5.2 (1.1)	$t = -6.1, P < .001$
Emotional problems,† % yes (SE)	25.3 (2.0)	13.7 (0.5)	$\chi^2_{(1)} = 44.6, P < .001$
Problems of cognition,† % yes (SE)	38.8 (2.3)	14.3 (0.6)	$\chi^2_{(1)} = 178.3, P < .001$

NS indicates not significant.

\* Data from the NLSCY.

† Data from the NPHS.

**TABLE 4.** Physical Health Variables

	CG Study	Population Study (NLSCY or NPHS)	Comparison
Chronic conditions,* % yes (SE)			
Food allergies	7.9 (1.3)	7.1 (0.5)	$\chi^2_{(1)} = 0.4, P = .54$
Other allergies	35.1 (2.2)	19.9 (0.8)	$\chi^2_{(1)} = 51.4, P < .001$
Asthma	15.8 (1.7)	6.3 (0.5)	$\chi^2_{(1)} = 48.0, P < .001$
Arthritis/rheumatism	17.3 (1.8)	7.3 (0.5)	$\chi^2_{(1)} = 48.1, P < .001$
Back problems	35.5 (2.2)	12.2 (0.7)	$\chi^2_{(1)} = 156.6, P < .001$
High blood pressure	7.1 (1.2)	4.1 (0.4)	$\chi^2_{(1)} = 7.9, P = .005$
Migraine headaches	24.2 (2.0)	11.2 (0.7)	$\chi^2_{(1)} = 56.5, P < .001$
Chronic bronchitis/emphysema	3.2 (0.8)	2.0 (0.3)	$\chi^2_{(1)} = 2.5, P = .115$
Sinusitis	13.5 (1.6)	5.0 (0.5)	$\chi^2_{(1)} = 46.1, P < .001$
Diabetes mellitus	3.0 (0.8)	1.1 (0.1)†	$\chi^2_{(1)} = 13.3, P < .001$
Heart disease	2.8 (0.8)	0.8 (0.1)†	$\chi^2_{(1)} = 18.1, P < .001$
Cancer	2.1 (0.7)	0.5 (0.1)†	$\chi^2_{(1)} = 44.6, P < .001$
Stomach/intestinal ulcers	8.4 (1.3)	1.7 (0.3)	$\chi^2_{(1)} = 63.0, P < .001$
Other	29.8 (2.1)	8.2 (0.6)	$\chi^2_{(1)} = 172.5, P < .001$
No. of chronic conditions,* % (SE)			
0	24.1 (2.0)	55.2 (1.0)	
1	22 (1.9)	23.5 (0.9)	
2	20.9 (1.9)	11.3 (0.6)	
$\geq 3$	32.7 (2.2)	10.1 (0.6)	$\chi^2_{(3)} = 250.6, P < .001$
HUI subscores,‡ % indicating at least some problem (SE)			
Vision problems	47.9 (2.3)	38.4 (0.8)	$\chi^2_{(1)} = 16.1, P < .001$
Hearing problems	2.6 (0.7)	1.4 (0.2)	$\chi^2_{(1)} = 4.1, P = .004$
Mobility problems	1.9 (2.2)	1.5 (0.2)	$\chi^2_{(1)} = 0.4, P = .53$
Severity of pain	28.8 (2.1)	11.0 (0.5)	$\chi^2_{(1)} = 118.9, P < .001$

HUI indicates Health Utility Index.

\* Data from the NLSCY.

† Because of unreliable estimates in the provincial sample, these numbers were derived from the national sample.

‡ Data from the NPHS.

different between the 2 groups ( $\chi^2 = 250.6, P < .001$ ); fewer subjects in the CG group reported having no chronic conditions (CG: 24.1%; NLSCY: 55.2%;  $P < .001$ ), whereas a greater number reported having  $\geq 2$  chronic conditions (CG: 32.7%; NLSCY: 10.1%;  $P < .001$ ). The CG sample also reported greater proportions of vision problems (CG: 47.9%; SE: 2.3%; NPHS: 38.3%; SE: 0.8%; overall  $\chi^2 = 16.1, P < .001$ ) and hearing problems (CG: 2.6%; SE: 0.7%; NLSCY: 1.4%; SE: 0.2%; overall  $\chi^2 = 4.1, P = .004$ ) but did not differ from the population study in reported mobility problems (CG: 1.9%; SE: 2.2%; NLSCY: 1.5%; SE: 0.2%; overall  $\chi^2 = 0.4, P < .53$ ). The CG sample was significantly more likely to indicate the presence of some amount of physical pain (CG: 38.8%; SE: 2.3%; NPHS: 14.3%; SE: 0.6%;  $\chi^2 = 118.9, P < .001$ ).

## DISCUSSION

### Study Objectives

The CG study was designed with 2 major goals. The first was to explore determinants of CG physical and mental health, assessing a conceptual model that explored simultaneously a number of factors known or hypothesized to be important contributors to these outcomes. We are currently addressing this issue by using structural equation modeling and relating all of the measured variables in a single analysis. The second objective of the study, reported here, was to compare the health and well-being of CGs of children with CP with the health and well-being of Canadian parents. The results of this study are discussed first in terms of the substantive and health

services implications of these observations and then in terms of the methodologic challenges involved in contrasting CG data with national health survey findings.

### Main Findings

Our CG sample was very similar to the NLSCY sample in terms of age and gender distribution, with nonsignificant differences between the 2 samples in both variables. However, the match was not as convincing with the NPHS sample; although there was no significant difference in mean age, the NPHS sample included far more men as respondents (46%) than did either the CG sample (6%) or the NLSCY sample (7%). This difference resulted from the inclusion criteria associated with the different studies. For both the CG study and the NLSCY, the respondent was required to be the person most knowledgeable about the child under investigation, who was the mother in the majority of cases. For the NPHS, we limited our sample to subjects who indicated they were parents and to those with a child of the appropriate age in the household. However, the NPHS selected a random member from each sampled household, so that approximately one-half of respondents were male. Implications of this sample difference for the NPHS-derived variables are discussed below.

Analysis of the work-related variables demonstrated the financial burden associated with caring for a child with a disability. Fewer respondents in the CG sample than in the NLSCY indicated that they

worked for pay; of those who did work, fewer reported working full-time. Furthermore, CGs were more likely to indicate caring for the family as their sole main activity and were less likely to indicate working for pay as their sole main activity. The CG sample also reported lower incomes than did the NLSCY sample. All of these results are consistent with the interpretation that caring for a child with a disability reduces the extent to which work for pay, particularly full-time work, is feasible, resulting in lower overall income. These results support previous findings by showing that there is an increased financial burden in providing care for a child with a disability, compared with that of normal caregiving,<sup>3</sup> and the findings suggest that at least some of this financial burden may be attributable to the CG's diminished availability to work or to work full-time.

We examined a number of variables relevant to psychologic health. Although previous work demonstrated poorer psychologic health among CGs of children with disabilities, relatively few studies included samples representative of the populations of interest. Consistent with previous findings,<sup>15</sup> the respondents in the CG study scored higher in distress and in chronicity of distress than did respondents to the NPHS. Furthermore, a greater proportion of the CG sample reported indications of emotional problems (eg, unhappy or little interest in life) and cognitive problems (ie, difficulty with memory or problem solving). On the basis of findings that CG psychologic health can be improved with various types of informal support,<sup>16,20,27,32,33,35</sup> we also examined the relative levels of reported support. The 2 samples did not differ significantly in rated levels of social support or family functioning, although the CG sample did score higher with respect to frequency of contacts. Taken together, findings from our large-scale, population-based samples are consistent with previous studies showing that caring for a child with a disability is associated with poorer psychologic health for the CG.

We used a number of measures of physical health in comparing the CG sample with the national samples. The results were striking. For almost all of our measures, the CG sample reported more physical health problems than did the national sample. The CG sample reported more specific chronic conditions of various kinds, as well as a greater overall number of chronic conditions, compared with the NLSCY sample. The CG sample also reported more vision, hearing, and pain problems than did the NPHS sample.

Although alternative explanations for these effects exist and are discussed below, it seems likely that caring for a child with a disability is associated with negative effects on the physical health of the CG. The nature of this association, however, is difficult to determine. We noted that 2 of the chronic conditions least likely to be associated with stress resulting from caregiving (food allergies and chronic bronchitis) did not differ between groups, whereas conditions that might be related to stress (eg, ulcers and migraine headaches) showed some of the strongest effects. It could be that the burden of caregiving increases

stress, which then manifests itself in a variety of chronic conditions. However, the findings regarding other chronic conditions (vision problems and asthma) strain this hypothesis. The causal pathways involving CG health are complex and likely include many factors, including some of those discussed above. We are currently developing a multipathway stress model of CG health elsewhere.

#### Methodologic Issues

Discussions of significant differences between the CG sample and the NPHS group must include the possibility that gender differences account for at least some of the effect. For example, the finding of increased frequency of contacts among the CG sample might be attributable to the greater proportion of women in the CG sample (94%), compared with the NPHS sample (53%), rather than the nature of the caregiving situation. Similarly, although there seems to be a strong association between caring for a child with a disability and physical health problems in the CG, this association may also result from gender differences, if women and men differ in the likelihood of reporting such problems. To examine this issue in more detail, we divided our NPHS sample into 2 groups on the basis of gender and compared the gender subgroups with each other and with the CG sample for all NPHS outcomes. These analyses showed that for hearing, pain, and emotional problems, gender differences did not exist and could not explain the differences. For the other variables, evidence of gender differences did exist, typically with women reporting more problems (and greater frequency of contacts) than men. However, for no variable did gender account for the entire effect. Whenever a significant effect was noted between the CG sample and the NPHS sample, a significant (albeit reduced) effect was evident between the CG sample and both gender-based subsamples. Therefore, whereas gender differences may inflate the observed effects on NPHS-derived variables, we are confident that such effects exist. This claim is supported by the findings for the NLSCY-derived variables, for which a difference in gender distribution was not an issue.

Similarly, the striking differences in reported physical symptoms might have resulted from artifacts of data collection. Although the national samples collected data on CG health in the context of a larger study, the CG group provided this information in the context of a study specifically designed to explore issues of CG health and well-being. The context of the CG study might have encouraged respondents to be more likely to indicate problems than in the national studies. However, we think this explanation is unlikely, because the modes of data collection (face-to-face interviews) were similar in the NLSCY and the CG study and significant differences were not more common for NPHS comparisons, where the data collection conditions were quite different (face-to-face interviews versus telephone survey).

Another possible artifact contributing to the increase in reported chronic conditions for the CG sample might be associated with socioeconomic sta-



tus. Given the effects of lower socioeconomic status on a wide array of health indicators,<sup>27,43–46</sup> it may be that our CG sample reported more physical health problems in part because of their lower socioeconomic category, rather than because they are CGs of children with disabilities. Evidence from using the same data set argues against this hypothesis. This work suggests that there was little evidence to support a direct link between socioeconomic status and CG health outcomes. Gross household income did not directly influence CG health. Instead, higher income was suggested to be primarily predictive of improved child behavior. We addressed this issue specifically in the current study by dividing our NLSCY sample into the 3 income categories (0–\$29 999, \$30 000 – \$59 999, and \$60 000 or more) and comparing the numbers of chronic conditions reported for the income groups. Results showed that income category was not significantly associated with the number of chronic conditions reported, suggesting that our findings of increased physical problems among CGs are not primarily attributable to differences in socioeconomic status.

A final hypothesis that might account for an increase in reported health problems for the CG sample is based on parents in the CG group having more regular contact with the health care system because of ongoing consultations for their children. If these parents do interact more with the system, then they might have more opportunities to discuss and receive attention for their own health concerns, compared with subjects in the comparison sample, and thus might be more likely to report health issues in this study. Although it is impossible to discount this theory with the available data, we think it is unlikely that this could explain the substantial increases for the wide range of physical and psychologic health concerns reported for the CG sample. The most plausible explanation remains the idea that caring for a child with a disability results in a significant increase in a wide variety of both physical and psychologic health concerns.

### CONCLUSIONS

Compared with the general population of CGs, CGs of children with disabilities are likely to have lower incomes, despite the absence of any significant education differences. Our findings suggest that the lower incomes may result from less time available to work for pay. Despite some indication of increased social support, compared with parents in general, CGs reported poorer psychologic health, on the basis of a number of indicators. They also reported far more physical health problems than did the population-based samples, although some of these effect sizes might have been inflated by artificial factors.

The data from this study strongly suggest that the demands of their children's disabilities can explain differences in health status of CGs, compared with other Canadian parents. There are a number of important implications of these observations for service providers and for the service systems from which children and their families receive services. Although many families raising children with disabilities cope

well despite the added challenges they experience, our findings indicate that these CGs generally experience more mental and physical difficulties than do other adult Canadian parents. Services that are family-centered<sup>13</sup> encourage and address parental well-being in addition to child health, recognizing that better parent well-being is related to child health and is thus a worthy goal of such services.<sup>32</sup> A challenge for future research is to explore the extent to which the family-centeredness of services, as experienced by CGs, is associated with better health outcomes for parents and their families. If such an association could be demonstrated clearly, then the findings would have enormous implications for both the structure and content of service delivery programs for children with a wide range of long-term childhood disabilities and health disorders.

### APPENDIX: DETAILS OF THE NLSCY AND THE NPHS

#### NLSCY

The NLSCY<sup>47</sup> is a survey involving both longitudinal and cross-sectional components and a clustered probability sample of Canadian residential households with children who were 0 to 11 years of age at the beginning of the study. Computer-assisted, face-to-face interviews were first conducted in 1994–1995, with longitudinal data being collected every 2 years, along with new cross-sectional data. Excluded households included those situated in remote areas, on First Nations People reserves, or in institutional settings. In each eligible household, 1 child who was 0 to 11 years of age was randomly selected, and information was obtained from the person most knowledgeable about that child. For ~90% of the children, the person most knowledgeable was the biologic mother, with 10% of respondents being fathers and <1% being nonbiologic parents. The person most knowledgeable completed general demographic, parent, and child questionnaires, and standardized measures were administered to the child.

The third cycle of the NLSCY, conducted in 1998 and 1999, was the source of data for the current analyses. We chose to take our data from NLSCY cycle 3 because it was the most recent data set available and because earlier cycles did not include children of the age range (7–15 years of age) that matched our study (NLSCY cycle 1 studied children 0–11 years of age and cycle 2 studied children 0–13 years of age). The initial sampling frame for cycle 3 was 38 035 children who were 0 to 15 years of age. The overall response rate was 88% (87% with complete data and 1% with partially complete data), resulting in a final sample of 31 194, of whom 8658 were from Ontario. To maintain an age distribution comparable to that of our sample, the NLSCY data were restricted to households with a child 7 to 15 years of age. This left a Canadian subsample of 9743 children, of whom 2414 lived in Ontario. The person most knowledgeable about the child completed the survey; 92% of those respondents were female ( $n = 8960$ ) and 8% were male ( $n = 783$ ). The ages of the



respondents ranged from 16 to 68 years (mean: 39.4 years; SD: 5.7 years). Of the Ontario cohort, 93% were female ( $n = 2242$ ) and 7% were male ( $n = 172$ ). The ages of the respondents ranged from 18 to 64 years (mean: 39.9 years; SD: 5.4 years).

## NPHS

The NPHS<sup>41</sup> is a multistage stratified survey of the health of the Canadian population. It began in 1994/1995 and includes both cross-sectional and longitudinal components, with data being collected every 2 years. The data are collected via telephone survey and include sociodemographic and health information for each member of the participating households, with in-depth health information being collected for 1 randomly selected individual per household.

The data used for the current analyses were taken from cycle 2 of the NPHS, conducted in 1996/1997. We chose NPHS cycle 2 data because the changes in the design of the study in later cycles resulted in some variables important to the current analysis not being collected. For this cycle, the overall response rate at the household level was 82.6%, whereas the response rate of the randomly selected individuals within these households was 95.6%. There were 210 377 respondents. We restricted the NPHS sample to the 11% who reported being parents living with children, including those living with a spouse or partner (89%) and single parents (11%). We also restricted our sample to include only those respondents who were living in households with children 7 to 15 years of age (47%), for a final sample of 10 941. It should be noted, however, that, because the relationships among the household members were not recorded, it could not be confirmed that the child of the appropriate age in the household was actually the child of the respondent. Respondents ranged in age from 15 to 75 years (mean: 39.8 years; SD: 6.1 years); 48.3% were male and 51.7% were female. For the Ontario cohort, there were 5549 respondents who were living with a child 7 to 15 years of age (89.6% living with a spouse or partner and 10.4% single). Respondents ranged in age from 18 to 75 years (mean: 40.2 years; SD: 6.3 years); 53.5% ( $n = 2966$ ) were female.

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