The Health and Well-Being of Caregivers of Children With Cerebral Palsy

Parminder Raina, PhD*‡; Maureen O’Donnell, MDS; Peter Rosenbaum, MD¶#; Jamie Brehaut, PhD**; Stephen D. Walter, PhD*; Dianne Russell, MSc*‡; Marilyn Swinton, BSc¶; Bin Zhu, MSc*‡; and Ellen Wood, MD‡‡

ABSTRACT. Objective. Most children enjoy healthy childhoods with little need for specialized health care services. However, some children experience difficulties in early childhood and require access to and utilization of considerable health care resources over time. Although impaired motor function is the hallmark of the cerebral palsy (CP) syndromes, many children with this developmental disorder also experience sensory, communicative, and intellectual impairments and may have complex limitations in self-care functions. Although caregiving is a normal part of being the parent of a young child, this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence. One of the main challenges for parents is to manage their child’s chronic health problems effectively and juggle this role with the requirements of everyday living. Consequently, the task of caring for a child with complex disabilities at home might be somewhat daunting for caregivers. The provision of such care may prove detrimental to both the physical health and the psychological well-being of parents of children with chronic disabilities. It is not fully understood why some caregivers cope well and others do not. The approach of estimating the “independent” or “direct” effects of the care recipient’s disability on the caregiver’s health is of limited value because (1) single-factor changes are rare outside the context of constrained experimental situations; (2) assumptions of additive relationships and perfect measurements rarely hold; and (3) such approaches do not provide a complete perspective, because they fail to examine indirect pathways that occur between predictor variables and health outcomes. A more detailed analytical approach is needed to understand both direct and indirect effects simultaneously. The primary objective of the current study was to examine, within a single theory-based multidimensional model, the determinants of physical and psychological health of adult caregivers of children with CP.

Methods. We developed a stress process model and applied structural equation modeling with data from a large cohort of caregivers of children with CP. This design allowed the examination of the direct and indirect relationships between a child’s health, behavior and functional status, caregiver characteristics, social supports, and family functioning and the outcomes of caregivers’ physical and psychological health. Families (n = 468) of children with CP were recruited from 19 regional children’s rehabilitation centers that provide outpatient disability management and supports in Ontario, Canada. The current study drew on a population available to the investigators from a previous study, the Ontario Motor Growth study, which explored patterns of gross motor development in children with CP. Data on demographic variables and caregivers’ physical and psychological health were assessed using standardized, self-completed parent questionnaires as well as a face-to-face home interview. Structural equation modeling was used to test specific hypotheses outlined in our conceptual model. This analytic approach involved a 2-step process. In the first step, observed variables that were hypothesized to measure the underlying constructs were tested using confirmatory factor analysis; this step led to the so-called measurement model. The second step tested hypotheses about relationships among the variables in the structural model. All of the hypothesized paths in the conceptual model were tested and included in the structural model. However, only paths that were significant were shown in the final results. The direct, indirect, and total effects of theoretical constructs on physical and psychological health were calculated using the structural model.

Results. The most important predictors of caregivers’ well-being were child behavior, caregiving demands, and family function. A higher level of behavior problems was associated with lower levels of both psychological (β = −.22) and physical health (β = −.18) of the caregivers, whereas fewer child behavior problems were associated with higher self-perception (β = −.37) and a greater ability to manage stress (β = −.18). Less caregiving demands were associated with better physical (β = −.23) and psychological (β = .12) well-being of caregivers, respectively. Similarly, higher reported family functioning was associated with better psychological health (β = .33) and physical health (β = .33). Self-perception and stress management were significant direct predictors of caregivers’ psychological health but did not directly influence their physical well-being. Caregivers’ higher self-esteem and sense of mastery over the caregiving situation predicted better psychological health (β = .23). The use of more stress management strategies was also associated with better psychological health of caregivers (β = .11). Gross income (β = .08) and social support (β = .06) had indirect overall effects only on psychological health outcome.
whereas self-perception ($\beta = .22$), stress management ($\beta = .09$), gross income ($\beta = .07$), and social support ($\beta = .06$) had indirect total effects only on physical health outcomes.

Conclusions. The psychological and physical health of caregivers, who in this study were primarily mothers, was strongly influenced by child behavior and caregiving demands. Child behavior problems were an important predictor of caregiver psychological well-being, both directly and indirectly, through their effect on self-perception and family function. Caregiving demands contributed directly to both the psychological and the physical health of the caregivers. The practical day-to-day needs of the child created challenges for parents. The influence of social support provided by extended family, friends, and neighbors on health outcomes was secondary to that of the immediate family working closely together. Family function affected health directly and also mediated the effects of self-perception, social support, and stress management. In families of children with CP, strategies for optimizing caregiver physical and psychological health include supports for behavioral management and daily functional activities as well as stress management and self-efficacy techniques. These data support clinical pathways that require biopsychosocial frameworks that are family centered, not simply technical and short-term rehabilitation interventions that are focused primarily on the child. In terms of prevention, providing parents with cognitive and behavioral strategies to manage their child’s behaviors may have the potential to change caregiver health outcomes. This model also needs to be examined with caregivers of children with other disabilities. Pediatrics 2005;115:e626–e636. URL: www.pediatrics.org/cgi/doi/10.1542/peds.2004-1689; caregiver, well-being, disability, cerebral palsy, informal support, stress process model, structural equation modeling.

**ABBREVIATIONS.** CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; SES, socioeconomic status; OMG, Ontario Motor Growth; SEM, structural equation modeling; LLM, log linear modeling; RMSEA, root-mean-squared error of approximation; NNFI, Nonnormed Fit Index; CFI, Comparative Fit Index.

M ost children enjoy healthy childhoods with little need for specialized services in the health care system. However ~7.7% of children experience difficulties during their developing years and require access to and utilization of extensive health care resources over time.1 Cerebral palsy (CP) is one such developmental disorder that begins in early childhood as a set of functional limitations that stem from disorders of the developing central nervous system.2 The current estimated incidence of CP is 2.0 to 2.5 per 1000 live births in developed countries.3 Although impaired motor function is the hallmark of the CP syndromes, many children also experience sensory, communicative, and intellectual impairments and may have complex limitations in self-care functions such as feeding, dressing, bathing, and mobility. These limitations can result in requirements for long-term care that far exceed the usual needs of children as they develop.4,5 We chose CP as a prototype condition to study the issues that parents who care for a child with a disability face.

Family caregivers often shoulder the principal, multifaceted responsibilities of long-term disability management.6 Although caregiving is a normal part of being the parent of a young child, this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence. One of the main challenges for parents is to manage their child’s chronic health problems effectively while maintaining the requirements of everyday living. In some cases, the provision of such care can prove detrimental to both the physical health and the psychological well-being of parents of children with chronic disabilities and have an impact on family income, family functioning, and sibling adjustment.7

In the past 2 decades, tremendous changes in health care systems have exerted a shift toward outpatient community and home-based settings, which in turn have increased the responsibilities of informal caregivers.8 In addition, several factors that may contribute to the perceived burden and stress experienced by parents of children with disabilities exist. These factors include smaller family units, increased rate of marital breakdown,9 technologic innovations, and pharmacologic advancements in medicine.9 Consequently, the task of caring for a child with complex disabilities at home might be somewhat daunting for caregivers.

The notion of “caregiving as a career” connotes a dynamic process, whereby an individual moves through a series of stages that require adaptation and restructuring of responsibilities over time.4,10,11 These stages might include (1) anticipation for and acquisition of the caregiver role, (2) performance of tasks and responsibilities, and (3) eventual exit from the role.4,10,11 Unlike a conventional career, however, the caregiver role is usually not planned or chosen and is generally not seen as an appealing pursuit for the future.

It is not fully understood why some caregivers cope well and others do not. Stress has been conceived as the balance between external environmental demands and the perceived internal ability to respond and may occur when the demands prevent the pursuit of other life objectives.4,8,9 Modifying factors of caregiver stress include (1) the characteristics of the caregiver (eg, age, marital status, coping ability),10,12 (2) characteristics of the recipient (eg, the degree of disability),12,14 (3) the shared history between the caregiver and the person being cared for,4 (4) social factors (eg, access to social networks and social support),8,12 (5) economic factors (eg socioeconomic status [SES], ability to access formal care, employment),4,12 and (6) cultural context.4 Each of these factors may influence the outcome of the caregiving situation; together they suggest that stress occurs in a broader context than simply the provision of care for a child with a physical disability.

Several conceptual models describe the impact of stress on caregivers.9,15,16 These models have typically used traditional analytic approaches (eg, linear regression) to examine the relationship between a factor and the outcome after adjusting for other variables. The approach of estimating the “independent” or “direct” effects of the care recipient’s disability on the caregiver’s health is of limited value because (1)
single-factor changes are rare outside the context of constrained experimental situations; (2) assumptions of additive relationships and perfect measurements rarely hold; and (3) such approaches do not provide a complete perspective, because they fail to examine direct and indirect pathways that occur between predictor variables and health outcomes. A more detailed analytical approach is needed to understand both direct and indirect effects simultaneously within a theory-based multidimensional model.

Our primary objective was to examine, within a single multidimensional model, a comprehensive set of factors that are relevant to the caregiving situation. The conceptual model (Fig 1) that guided this research is described in detail by Raina et al. The 5 constructs in the proposed model include (1) background and context, (2) child characteristics, (3) caregiver strain, (4) intrapsychic factors, and (5) coping/supportive factors. This research examines the direct and indirect associations between caregiver characteristics, sources of caregiver stressors, family functioning, and informal social support on the well-being of the caregivers of children with CP. Specifically, we hypothesized that an increase in a child’s disability as measured by the Gross Motor Function Classification System (GMFCS); the Pediatric Evaluation of Disability Inventory, Part 1; and the Health Utilities Index, selected questions, and behavioral problems would be associated directly with poorer physical and psychological well-being of primary caregivers. However, we also hypothesized that the direct relationship between a child’s disability or his or her behavioral problems and parental well-being would be mediated by intrapsychic and coping/supportive factors as described in the proposed conceptual model (Fig 1).

**METHODS**

**Setting**

CanChild studies are made possible through a partnership between the provincial government-funded CanChild Centre for Childhood Disability Research at McMaster University and the 19 publicly funded regional ambulatory children’s rehabilitation centers in Ontario, Canada. These regional centers deliver a range of developmental therapies and services (predominantly physical, occupational, speech-language, and recreational therapies) provided by developmental professionals who are trained and experienced in both the assessment and the management of childhood disability. Each center serves the majority of eligible children in their area. The current study drew on a population that was available to the investigators from a previous study, the Ontario Motor Growth (OMG) study, which explored patterns of gross motor development in children with CP and where more details of the sampling process are described.

![Conceptual model of the caregiving process among caregivers of a pediatric population.](image-url)
Sample Caregivers were recruited for the present study from a sampling frame, originally created in early 1996, of families who had participated in the OMG study. For the OMG study, children had been randomly selected in a stratified sampling procedure on the basis of age and level of motor function using the GMFCS from 18 of 19 regional centers and 1 hospital-based therapy program in a community without a regional center. A total of 657 children and their families participated in the OMG study; 632 of whom were still involved at the end of OMG project; these 632 families were invited to participate in the current caregiver study.

Selection Criteria One primary caregiver per household was selected for this study. The primary caregiver was defined as the person who is most responsible for the day-to-day decision making and care of the child; the family determined who was best considered the primary caregiver. Caregivers who were asked to participate in this study had to meet the following criteria: (1) have a child who had participated in the OMG study; (2) identify themselves as a primary caregiver whose child lived with them; (3) give written consent to participate; and (4) reside in Ontario. Initial recruitment involved mailing families a package that contained a letter, a consent form, and a brochure describing the study, along with a lottery ticket as an incentive to participate. Telephone follow-up with families was done by a person who was trained to answer any questions and obtain verbal consent.

Data Collection The data were collected in 2 steps. First, for minimizing the time burden on the caregivers, a package that included an introductory letter, a consent form, and a questionnaire was mailed to them for completion before a face-to-face interview. The self-report questionnaire collected demographic information about the caregiver, the child, and the family; the child’s ability to perform activities of daily living; the child’s day-to-day health; the child’s behavior; caregiver stress management strategies; caregiver perceptions of formal care for the child within the last 12 months; and the caregiver’s perception of his or her own general health and well-being (Table 1 summarizes the measures used).

The second step consisted of a home-based interview with the primary caregiver of the child with CP. Interviewers who were hired and trained specifically for this study conducted the interviews. The structured, face-to-face interview collected information about caregiving assistance provided to the child, the caregiver’s views. The structured, face-to-face interview collected information about caregiving assistance provided to the child, the caregiver’s views. The structured, face-to-face interview collected information about caregiving assistance provided to the child, the caregiver’s views. Telephone follow-up with families was done by a person who was trained to answer any questions and obtain verbal consent.

RESULTS Description of the Sample Of the initial sampling frame that contained 632 families, 42 caregivers were lost to follow-up. A total of 590 (93%) families were contacted, and 570 (90%) were eligible; 503 (88%) of the 570 consented. A final sample of 468 primary caregivers (82% of the 570 eligible families) provided data (Table 3). The results show that the age, gender, and marital status of our sample are similar to those of the OMG study sample. For example, the age, gender, and marital status of our sample are similar to those of the OMG study sample.

Statistical Analysis Descriptive statistics were calculated for all variables in the data set. Structural equation modeling (SEM) was used to test specific hypotheses outlined in our conceptual model. This analytic approach involves a 2-step process. In the first step, observed variables are hypothesized to measure the underlying constructs and tested using confirmatory factor analysis; this step leads to the so-called measurement model. The second step focuses on testing hypotheses about relationships among the variables in the structural model. Several model diagnostic approaches were used to assess the integrity of each phase of the SEM development and the appropriateness of variables included in the model.7–22,24 We used the PROC CALIS procedure in SAS version 8.2 (SAS Institute, Cary, NC), using covariance matrices and the maximum-likelihood estimation method to assess model fit. All of the hypothesized paths in the conceptual model (Fig 1) were tested and included in the structural model. However, only paths that were significant (P < .05) are shown in the final results.

The direct, indirect, and total effects of factors on health were calculated using the structural model. For example, the impact of stress management on psychological health involves 1 direct path (β13) and 1 indirect path (β13 × β13). The total effect (β13) was estimated by summing the direct effect and the indirect effects [β13 × β13] = β13.

The process of developing and testing a structural equation model is theory and data driven. Nonconverges is not uncommon in the process of parameter estimation in such models. Therefore, a log linear modeling (LLM) analysis was conducted as an adjunct to the SEM analysis to assess the robustness of SEM analysis. LLM requires discrete measurements. Instead of latent continuous variables, categorized data were used in LLM analysis to specify the log linear model. The robustness of the SEM model was comparable to the LLM. However, SEM analyses identified more relationships than the LLM (which are not reported in this article).

### TABLE 1. Child and Caregiver Questionnaire Measures

<table>
<thead>
<tr>
<th>Variable</th>
<th>Measure</th>
<th>Description of Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child</td>
<td>Motor severity</td>
<td>GMFCS48</td>
</tr>
<tr>
<td></td>
<td>Activities of daily living</td>
<td>Pediatric Evaluation of Disability Inventory: Part 119</td>
</tr>
<tr>
<td></td>
<td>Cognitive function</td>
<td>Health Utilities Index: selected questions20</td>
</tr>
<tr>
<td></td>
<td>Child behavior</td>
<td>Survey Diagnostic Instrument48 (SDI)</td>
</tr>
<tr>
<td>Caregiver</td>
<td>Caregiver health status</td>
<td>Medical Outcomes Study: Short Form 36 Health Survey48 (SF36)</td>
</tr>
<tr>
<td></td>
<td>Perception of formal care</td>
<td>Measures of Processes of Care50</td>
</tr>
<tr>
<td></td>
<td>Stress management</td>
<td>Coping Health Inventory for Parents11</td>
</tr>
<tr>
<td></td>
<td>SES of caregivers</td>
<td>National Longitudinal Study of Children and Youth20</td>
</tr>
</tbody>
</table>

An ordinal descriptive scale of the gross motor function abilities of children with CP

Child is rated as capable/unable on 73 self-care and 54 mobility items

Items about child’s ability to learn, remember, think, and solve problems

SDI is a 24-item subset of the Child Behavior Checklist with 3 scales: conduct disorder, hyperactivity, and emotional disorder

The SF36 is a generic measure of health concepts related to functional status and well-being

Caregiver’s perceptions of the extent to which specific behaviors of health professionals occur

Caregiver’s appraisal of their coping responses to management of family life when he or she has a child who is seriously/chronically ill

Items related to education level (EDUC-Q2, EDUC-Q3), occupational status (LFS-Q1, LFS-Q2), and income (INCOMQ3B)
caregiver sample was well matched to the corresponding OMG study. In addition, we compared our study sample with a national population sample in terms of age; gender distribution, with both samples being primarily female; and marital status. Our caregiver sample differed from the national population in the distribution of the educational categories. Both samples showed similar proportions at the lower and higher ends of the educational continuum (Fig 2).25

The mean age of the children was 10.6 (SD: 2.69) years, 56% of whom were boys. Half of the children with CP (49.8%) were first-born. The mean age of caregivers was 40.3 (SD: 6.72) years, and 94.4% were female, 89.7% of which were birth mothers. Language preference of caregivers was English (98.5%). The mean age of the children was 10.6 (SD: 2.69) years, 56% of whom were boys. Half of the children with CP (49.8%) were first-born. The mean age of caregivers was 40.3 (SD: 6.72) years, and 94.4% were female, 89.7% of which were birth mothers. Language preference of caregivers was English (98.5%). The GMFCS levels indicated that of the children, 28% were severely limited even with the use of assistive technology (level V). The range, mean, and SD of the observed variables for caregivers are shown in Table 4. The correlations between latent constructs are shown in Table 5.

**SEM**

**Measurement Model**

Initially, the hypothesized model was created with the predicted paths among the latent structural variables predicted from the literature (see Fig 1). The confirmatory factor analysis was used to test the reliability of the hypothesized measurement model. Testing the fit of the measurement model led to additional refinements to the conceptual model. First, we dropped 2 variables (“chronicity of distress” and “reported health transitions” from SF-36) from the psychological health construct because of small factor loadings (<0.4) from the exploratory factor analysis with the psychological health factor. Second, the perception of formal care (Measures of Processes of Care) construct was dropped because of missing and nonapplicable responses to the questionnaire. Finally, the disability construct was dropped because of its strong correlation with the caregiving demands construct. The caregiving demands construct was collapsed into a single observed variable because the measured variables “caregiver assistance-self care” and “caregiver assistance mobility” were highly correlated. Two variables were relocated in the model: “vitality” from SF-36 was relocated to the psychological health construct from physical health construct, and “social provision scale” was relocated to the family function construct instead of the social support construct.

After respecifying and reestimating the model, “income” was found to have more effect than “education,” and subsequently the latter variable was dropped from the SES construct. We also modified the model by dropping the “social functioning” variable from the social support construct to improve the goodness of fit. The final measurement model of 23 observed variables indicated an acceptable fit.

Several statistical tests and goodness-of-fit indices are used to assess the adequacy of model fit. In this study, the root-mean-squared error of approximation (RMSEA), Bentler and Bonett’s Nonnormed Fit Index (NNFI), and Bentler’s Comparative Fit Index

<table>
<thead>
<tr>
<th>Variable</th>
<th>Measure</th>
<th>Description of Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distress</td>
<td>National Population Health Survey (NPHS)</td>
<td>Subset of items from the Composite International Diagnostic Interview (CIDI) related to distress (MH Q1A to Q1F) and chronicity of distress (MH Q1GQ1L)</td>
</tr>
<tr>
<td>Depression</td>
<td>NPHS52</td>
<td>Subset of items from the CIDI related to major depressive episodes (MH LTH Q2 to Q28)</td>
</tr>
<tr>
<td>Mastery</td>
<td>NPHS53</td>
<td>Scale that measures caregiver self-control and self-concept (MAST-Q1)</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>NPHS52</td>
<td>Six-item scale that measures caregiver self-esteem (ESTEEM-Q1)</td>
</tr>
<tr>
<td>Chronic health conditions</td>
<td>National Longitudinal Study of Children and Youth (NLSCY)</td>
<td>Chronic health conditions that last 6 mo or more and are diagnosed by a health care professional (CHRON-Q1)</td>
</tr>
<tr>
<td>Health status</td>
<td>McMaster Health Utility Index (HUI) in NPHS52</td>
<td>Items that measure health status, health-related quality of life, and producing utility scores (HSTATQ1 to HSTATQ30)</td>
</tr>
<tr>
<td>Caregiving assistance</td>
<td>Pediatric Evaluation of Disability Inventory (PEDI): Parts II and III</td>
<td>Measures amount of caregiver assistance provided to a child during basic functional activities of daily living</td>
</tr>
<tr>
<td>Job-caregiving conflict</td>
<td>Pearlin’s Scale</td>
<td>Five-item scale related to job-caregiving conflicts</td>
</tr>
<tr>
<td>Informal social support</td>
<td>Social Network and Frequency of Contact Index in NPHS52</td>
<td>Items summarize possible people 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)</td>
</tr>
<tr>
<td>Family functioning</td>
<td>Family Assessment Device (FAD) in NLSCY51</td>
<td>Short version of the Social Provision Scale that measures perceived social support from family and friends</td>
</tr>
</tbody>
</table>

**TABLE 2. Caregiver Interview Measures**
(CFI) were used to assess model fit. Typically, an RMSEA value of <0.05 and an NNFI value and a CFI value close to 1 are indicative of good fit. However, it is not necessary for a model to display all of these characteristics to be considered acceptable. In this study, the RMSEA value was 0.06, the NNFI value was 0.90, and the CFI value was 0.92. All factor loadings were substantial in magnitude, and significantly different from 0, indicating that the latent constructs were adequately operationalized by the observed variables. The final standardized loadings of observed variables on the latent constructs are shown in Table 6.

The Structural Model

A path diagram of the structural model of factors that influence the health of caregivers is shown in Fig 3. The latent constructs are denoted by ellipses. Two constructs are each represented by a single observed variable and are denoted by rectangles. Only paths that were significant ($P < .05$) are shown in the diagram.

The RMSEA was 0.06, NNFI was 0.90, and CFI was 0.91, which indicated an acceptable fit. The $\chi^2$ for the structural model was 583.3 with degrees of freedom 215 ($P < .0001$). The standardized regression coefficients and the corresponding $R^2$ statistics for each of the significant hypothesized paths ($P < .05$) are shown in Fig 3. Five constructs influenced caregivers’ psychological health, whereas 3 constructs influenced their physical health. Thus, for example, psychological health has an $R^2$ of 0.50, indicating that child behavior, self-perception, family function, caregiving demands, and stress management together accounted for 50% of the variation in psychological health.

Our conceptual model permits the estimation of both direct and indirect effects of constructs on caregiver health. With respect to specific hypothesized relationships in this analysis, the most important predictors of caregivers’ well-being were child behavior, caregiving demands, and family function. An increase in reported child behavior problems was associated with decrease in both psychological ($\beta_3 = -.22$) and physical ($\beta_4 = -.18$) health of the caregivers, whereas fewer child behavior problems were associated with higher self-perception ($\beta_2 = -.37$) and a greater ability to manage stress ($\beta_5 = -.18$; Fig 3). Decreased caregiving demands were associated with an increase in physical ($\beta_2 = .23$) and psychological ($\beta_6 = .12$) well-being of caregivers. Similarly, higher reported family functioning was associated with improvements in both psychological health ($\beta_4 = .33$) and physical health ($\beta_{15} = .33$).
Self-perception and stress management were significant direct predictors of caregivers’ psychological health but did not directly influence their physical well-being. Caregivers’ higher self-esteem and sense of mastery over the caregiving situation predicted better psychological health ($\beta_{1} = .23$). The use of more stress management strategies was also associated with better psychological health of caregivers ($\beta_{11} = .11$). In addition to direct relationships, we observed the important mediating effect of family functioning on several latent constructs. For example, higher levels of self-perception ($\beta_{10} = .56$), social support ($\beta_{12} = .18$), and stress management ($\beta_{13} = .27$) all were associated with better family functioning.

The total effect of hypothesized relationships between the latent constructs on caregiver health outcome can also be calculated using the direct and indirect pathways in the conceptual model (Fig 3). Thus, the total effect of child behavior ($\beta_{1} = -.38$) on psychological health outcome was the sum of one direct pathway ($\beta_{1} = -.22$) and 7 indirect pathways ($\beta = -.16$), whereas the total effect of child behavior on physical health was $\beta_{1} = -.28$. Similarly, the total effect of stress management on psychological health was $\beta_{1} = .20$. Gross income ($\beta = .08$) and social support ($\beta = .06$) had indirect overall effects on only psychological health outcome, whereas self-perception ($\beta = .22$), stress management ($\beta = .09$), gross income ($\beta = .07$), and social support ($\beta = .06$) had indirect total effects only on physical health outcomes.

**DISCUSSION**

Several factors are known or thought to influence the health outcomes of parents who raise a child with a developmental disability. The direct and indirect relationships among these variables were examined using a single comprehensive structural equation model.

The psychological and physical health of caregivers, who were primarily mothers, was strongly influenced by child behavior and caregiving demands. These results reiterate associations made between caregiving and negative health outcomes in previous studies.24,27–30 Our study corroborated earlier findings that child behavior problems are the single most important child characteristic that predicts caregiver psychological well-being.7 However, as with the King et al study7 the children’s behavioral issues

---

**TABLE 4.** Range, Mean, SD, and Sample Size for Observed Variables of Caregivers

<table>
<thead>
<tr>
<th>Variables</th>
<th>Range of Score</th>
<th>High Score Equivalency</th>
<th>Mean</th>
<th>SD</th>
<th>Sample Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distress score</td>
<td>0–24</td>
<td>More distress</td>
<td>4.71</td>
<td>4.35</td>
<td>468</td>
</tr>
<tr>
<td>Role: emotional</td>
<td>0–100</td>
<td>Better health</td>
<td>63.46</td>
<td>18.34</td>
<td>468</td>
</tr>
<tr>
<td>Mental health</td>
<td>0–100</td>
<td>Better health</td>
<td>69.34</td>
<td>42.60</td>
<td>468</td>
</tr>
<tr>
<td>Vitality</td>
<td>0–90</td>
<td>Better health</td>
<td>47.53</td>
<td>22.19</td>
<td>468</td>
</tr>
<tr>
<td>General health</td>
<td>0–100</td>
<td>Better health</td>
<td>67.90</td>
<td>23.04</td>
<td>468</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>0–100</td>
<td>Better health</td>
<td>83.75</td>
<td>21.77</td>
<td>468</td>
</tr>
<tr>
<td>Role: physical functioning</td>
<td>0–100</td>
<td>Better health</td>
<td>68.75</td>
<td>39.02</td>
<td>468</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>0–100</td>
<td>Better health</td>
<td>67.97</td>
<td>25.48</td>
<td>468</td>
</tr>
<tr>
<td>Chronic</td>
<td>0–9</td>
<td>Worse health</td>
<td>2.03</td>
<td>1.89</td>
<td>467</td>
</tr>
<tr>
<td>Netsize</td>
<td>2–8</td>
<td>More support</td>
<td>5.02</td>
<td>0.94</td>
<td>468</td>
</tr>
<tr>
<td>Contacts</td>
<td>6–45</td>
<td>More support</td>
<td>22.31</td>
<td>5.36</td>
<td>468</td>
</tr>
<tr>
<td>Social provision scale</td>
<td>0–18</td>
<td>More provision</td>
<td>14.51</td>
<td>3.40</td>
<td>468</td>
</tr>
<tr>
<td>Family functioning</td>
<td>0–36</td>
<td>More dysfunction</td>
<td>8.59</td>
<td>5.64</td>
<td>468</td>
</tr>
<tr>
<td>Integration</td>
<td>0–57</td>
<td>Better management</td>
<td>37.75</td>
<td>10.62</td>
<td>465</td>
</tr>
<tr>
<td>Support, esteem</td>
<td>0–54</td>
<td>Better management</td>
<td>30.63</td>
<td>10.28</td>
<td>464</td>
</tr>
<tr>
<td>Medical communication</td>
<td>0–24</td>
<td>Better management</td>
<td>13.66</td>
<td>5.78</td>
<td>462</td>
</tr>
<tr>
<td>Mastery</td>
<td>3–28</td>
<td>Superior mastery</td>
<td>14.88</td>
<td>5.63</td>
<td>468</td>
</tr>
<tr>
<td>Caregiving demand</td>
<td>0–100</td>
<td>Less demand</td>
<td>56.56</td>
<td>31.40</td>
<td>468</td>
</tr>
<tr>
<td>Conduct disorder</td>
<td>11–26</td>
<td>Worse behaviors</td>
<td>12.41</td>
<td>2.34</td>
<td>468</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>6–18</td>
<td>Worse behaviors</td>
<td>9.39</td>
<td>2.88</td>
<td>468</td>
</tr>
<tr>
<td>Emotional disorder</td>
<td>7–18</td>
<td>Worse behaviors</td>
<td>9.70</td>
<td>2.56</td>
<td>468</td>
</tr>
<tr>
<td>Gross household income</td>
<td>1–11</td>
<td>Better SES</td>
<td>8.25</td>
<td>2.49</td>
<td>457</td>
</tr>
</tbody>
</table>

Chronic indicates number of chronic conditions; netsize, existence of possible people to be contacted; contacts, number of contacts for all categories; integration, integration, cooperation, optimism; support, esteem, support, esteem, stability; medical communication, medical consultation and consultation.

**TABLE 5.** Correlations Among Latent Constructs in the Measurement Model

<table>
<thead>
<tr>
<th>variables</th>
<th>Income</th>
<th>Caregiving Demand</th>
<th>Child Behavior</th>
<th>Self-Perception</th>
<th>Social Support</th>
<th>Family Function</th>
<th>Stress Management</th>
<th>Psychological Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving demand</td>
<td>0.08</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child behavior</td>
<td>-0.17*</td>
<td>0.11*</td>
<td>-0.36*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-perception</td>
<td>0.11*</td>
<td>0.01</td>
<td>0.05</td>
<td>0.18*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td>0.02</td>
<td>0.09</td>
<td>0.05</td>
<td>0.18*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family function</td>
<td>0.22*</td>
<td>0.11*</td>
<td>-0.30*</td>
<td>0.66*</td>
<td>0.32*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress management</td>
<td>0.13*</td>
<td>0.08</td>
<td>-0.28*</td>
<td>0.35*</td>
<td>0.17*</td>
<td>0.50*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological health</td>
<td>0.17*</td>
<td>0.15*</td>
<td>-0.42*</td>
<td>0.59*</td>
<td>0.18*</td>
<td>0.62*</td>
<td>0.43*</td>
<td></td>
</tr>
<tr>
<td>Physical health</td>
<td>0.14*</td>
<td>0.25*</td>
<td>-0.24*</td>
<td>0.32*</td>
<td>0.10</td>
<td>0.41*</td>
<td>0.22*</td>
<td>0.71*</td>
</tr>
</tbody>
</table>

* Values were significant from 0 at $P > .05$. 

Downloaded from http://pediatrics.aappublications.org/ by guest on September 23, 2017
were not assessed to be in the "clinical" ranges of severity. These nonclinical behavioral issues of a child with a disability also influenced caregivers' psychological health indirectly through their effect on self-perception and family function. Thus, in planning interventions for the child and the family, it is important for service providers to consider children's behavioral issues as an important determinant of the well-being of both the child and the caregiver. Clearly, it is important for health care providers to assess how caregivers are affected by behavioral as well as "functional" aspects of the child's disability in the provision of comprehensive family-oriented services. In terms of prevention, providing parents with cognitive and behavioral strategies to manage their child's behaviors may have the potential to change caregiver health outcomes.

Caregiving demands contributed directly to both the psychological and the physical health of the caregivers. Despite being a strong predictor of physical health of caregivers, there was no evidence to support hypothesized relationships between caregiving demands and self-perception or social support.31,32 This suggests that it is the practical day-to-day needs of the child that create challenges for parents but that neither their sense of self nor their social supports mediate the impact of their child's level of disability on health outcomes.

The direct effect of self-perception and stress management on psychological health supports the central relationships of the proposed model. Previous research has shown that social support, family functioning, and stress management may constrain resources with regard to caregiver health outcomes.7,12,29,35-41 The proposed direct link between social support and health was not replicated in this study. Clearly, the influence of social support provided by extended family, friends, and neighbors on health outcomes was secondary to that of the immediate family working closely together.

Family function played a central role in both the physical and the psychological health of caregivers. This construct affected health directly and also mediated the effects of self-perception, social support, and stress management. These findings suggest that health care providers who work with families of children with long-term disabilities should develop interventions that support and nurture the family as a whole. Therefore, health care providers should be encouraged to value family functioning as much as the developmental and "technical" aspects of the services that are offered to children with complex disabilities.

The evidence in the literature supporting the link between SES and health is equivocal.30,42-44 It is interesting that in this study, there was little evidence to support the proposed link between SES and caregiver health outcomes. Gross household income did not directly influence caregiver health. Instead, the direct effect of gross income suggests that higher income is predictive of improved child behavior. It is of course possible that there was insufficient socioeconomic variation across the respondents for an SES effect to be detectable in this study.

The SEM method involves testing a theoretically derived model. Data-driven considerations may require changes to the theoretical model that result in a model that does not match the original, intended model.45 In our SEM model, the final measurement model was somewhat different from the hypothe-
sized model as a result of refinements to the conceptual model. Additional refinements led to changes in the path model as well. Ultimately, the goal is to find a model that not only fits the data well from a statistical perspective but also is one in which each parameter of the model has a substantively meaningful interpretation.

CONCLUSIONS

The development of interventions to reduce the stress experienced by caregivers of children with CP is both possible and necessary. The paths that emerged in the structural model provided evidence for the hypothesized relationships between variables that influence caregiver health outcomes. In our model, it seems that the family unit is the key regulating mechanism of health outcomes. Thus, rather than target the child exclusively, interventions and preventive strategies should also target caregivers, who will in turn be able to respond to the unique characteristics of their child, eg, behaviors, temperament, and functional limitations, in ways that should decrease the impact of their child’s disability on them.

The SEM analysis has made it possible to examine potentially important interrelated factors that contribute to caregivers’ health. In future research, it would be interesting to look at direct and indirect effects in this model across the trajectory of the caregivers’ role over time and to explore how changes in individual circumstances influence outcomes. These might include, for example, increase in the size and weight of a child with significant functional limitations associated with their developmental disabilities, at a time in their lives (particularly adolescence) when the physical capabilities of their caregivers

Fig 3. Structural model of factors that influence the health of caregivers.
may begin to diminish with caregivers’ increasing age, or the loss of a person who has shared caregiving responsibilities and moderated the impact of the child’s functional limitations. This method also allows for comparison of our model across varied populations, such as caregivers of children, youths, and the elderly. Additional exploration of the relationships among and between the factors that influence caring for children with other developmental disabilities is also warranted.

ACKNOWLEDGMENTS

Dr Raina holds a National Health Scholar Award from the National Health Research and Development Program and an Investigator Award from the Canadian Institutes of Health Research. Dr Rosenbaum holds a Canada Research Chair in Child-hood Disability from the Canadian Institutes of Health Research. Dr Walter holds a Senior Investigator Award from the Canadian Institutes of Health Research. Dr Bre hairy holds an Ontario Ministry of Health and Long-Term Care Career Scientist Award.

CanChild Centre for Childhood Disability Research is a health system–linked research unit funded by the Ontario Ministry of Health and Long-Term Care.

We thank Susanne King for the input on the conceptual framework of the article, Dr Steven Hanna for the input on structural equation modeling, and the families who participated in our study. We also thank Helen Massel testing, Dulvia Baldassarre, and Roxanne Cheeseman for help in the preparation of this article.

REFERENCES

44. Rogot E, Sorlie PE, Johnson NJ, Glover CS, Treasure DWA. A Mortality...
The Health and Well-Being of Caregivers of Children With Cerebral Palsy
Parminder Raina, Maureen O'Donnell, Peter Rosenbaum, Jamie Brehaut, Stephen D. Walter, Dianne Russell, Marilyn Swinton, Bin Zhu and Ellen Wood

Pediatrics 2005;115;e626
DOI: 10.1542/peds.2004-1689
The Health and Well-Being of Caregivers of Children With Cerebral Palsy
Parminder Raina, Maureen O'Donnell, Peter Rosenbaum, Jamie Brehaut, Stephen D. Walter, Dianne Russell, Marilyn Swinton, Bin Zhu and Ellen Wood

*Pediatrics* 2005;115:e626
DOI: 10.1542/peds.2004-1689

The online version of this article, along with updated information and services, is located on the World Wide Web at:

http://pediatrics.aappublications.org/content/115/6/e626