Stroke Survivor Depressive Symptoms Are Associated With Family Caregiver Depression During the First 2 Years Poststroke

Jill I. Cameron, PhD; Angela M. Cheung, MD, PhD, FRCPC; David L. Streiner, PhD; Peter C. Coyte, PhD; Donna E. Stewart, MD, FRCPC

Background and Purpose—Behavioral and psychological symptoms associated with stroke are gaining increasing attention in a field in which recovery of physical function has dominated. A small body of research has begun to suggest that stroke survivors’ (SSs’) behavioral and psychological symptoms contribute to family caregivers’ experiences of emotional distress. The objective of this research was to determine the unique contribution of SS behavioral and psychological symptoms on caregiver emotional distress during the first 2 years poststroke.

Method—A longitudinal cohort study was conducted of individuals who have survived their first stroke and their caregivers. Participants completed standardized measures by telephone interviews at 1, 3, 6, and 12 months poststroke. A subsample completed additional assessments 18 and 24 months poststroke. These longitudinal data were analyzed using mixed effects modeling.

Results—Three hundred ninety-nine SS/caregiver dyads participated. Overall, caregivers reported more emotional distress when caring for SSs exhibiting more depressive symptoms and more cognitive impairment and when caregivers were younger, female, in poorer physical health, experienced more lifestyle interference, and reported less mastery. SSs’ physical disability, stroke severity, and comorbidity were not significant. The set of significant predictors remained consistent when examined in the subsample followed for 2 years (except SS cognitive impairment).

Conclusions—Interventions aimed at improving caregiver well-being should focus on enhancing clinical management of SSs’ depression and better preparing caregivers to manage behavioral and psychological symptoms. In addition, respite programs that encourage caregivers to maintain participation in valued activities may be beneficial. (Stroke. 2011;42:302-306.)

Key Words: behavioral disturbances ■ caregiver ■ lifestyle ■ longitudinal cohort ■ stroke

The first years poststroke are the most challenging because stroke survivors’ (SSs’) physical disabilities limit their ability to perform activities and instrumental activities of daily living. In addition, between 7% and 41% of SSs will also be diagnosed with dementia. After inpatient care has ended, SSs usually return to the community in the care of a family member. In a time when formal community care is limited, many family caregivers experience stress and emotional distress as a result of taking on this new role. When caregivers are not doing well, SS stroke rehabilitation suffers resulting in poorer recovery of physical functioning, communication, and resumption of participation in valued activities, threatening the sustainability of home care. The impact of SS physical and cognitive disabilities on caregiver emotional health is unclear. The most commonly studied aspect of cognition is changes in SS behavior and psychological well-being. A few studies have examined the impact of physical health alone in which more physical disability in the SS tends to be associated with negative caregiver outcomes. The relationship is less consistent when physical and cognitive abilities were considered together when SS behavioral and psychological symptoms (BPS) were negatively associated with caregiver outcomes but physical disability was not in studies. One problem with this literature concerns the assessment of physical disability and BPS. Physical disability is often assessed using the Barthel Index, which has a ceiling effect in the stroke population. Measurement of BPS relies on individ-

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302
ual questions (eg, Schulz et al\textsuperscript{23}) or a few questions abstracted from larger scales (eg, Anderson et al\textsuperscript{15}). Overall, these findings highlight the inconsistencies in the relationship among BPS, physical disability, and caregiver outcomes as well as assessment of BPS and physical disability.

Consistent with Pearlin’s view of family care as a stressful experience with negative mental health consequences for the caregiver,\textsuperscript{23} there are many additional aspects of the care situation that can affect caregiver mental health outcomes. To facilitate our understanding of the relationship among stroke survivor physical abilities, BPS, and caregiver emotional health, other important factors must be considered. Pearlin proposes that there are contextual factors (eg, sociodemographic characteristics of caregiver and stroke survivor, caregivers’ own physical health), primary (eg, level of care provided) and secondary (eg, impact of providing care on caregivers’ abilities to maintain participation in valued activities) stressors, and psychosocial resources (eg, mastery) that can affect caregiver outcomes. In addition to SSs’ physical abilities and BPS, these factors will be examined as potential contributors to caregiver emotional distress.

Guided by Pearlin’s model of family caregiving,\textsuperscript{23} the objective of this research was to determine the unique contributions of SS physical disability and BPS on caregiver emotional distress during the first 2 years poststroke.

**Methodology**

**Research Design**

The data for this study came from a longitudinal cohort study of individuals surviving their first stroke and their family caregivers from Toronto and London, Ontario, and Montreal, Quebec.\textsuperscript{24} Participants were interviewed by telephone 1, 3, 6, and 12 months poststroke (Year 1 sample). A subset of participants consented to be interviewed again 18 and 24 months poststroke (Year 2 sample). Institutional ethics review boards approved this study. All participants provided written informed consent.

**Participants**

Members of the acute care clinical team identified SSs and confirmed that this was their first hospitalization for either a hemorhagic or ischemic stroke. Caregivers were identified as the person who was most likely to be a key provider of support and assistance when the SS was discharged home. Participants had to be able to speak and read English or French (Montreal).

**Measurement Instruments**

We obtained SSs’ and caregivers’ sociodemographic information, including age, sex, primary daily activity, marital status, and income. Caregivers also provided information about their relationship to the SS (eg, spouse) and their living situation. Review of hospital charts provided information about stroke severity, type (ischemic or hemorrhagic), hemisphere (left, right, or both), and location (hemispheric, cerebellum, or brain stem). The Canadian Neurological Scale\textsuperscript{25} determined stroke severity with scores ranging from 1.5 to 11.5 and lower scores indicating more neurological damage. Caregiver physical health was assessed by the physical health domain of the Medical Outcomes Study Short Form-36\textsuperscript{26} in which scores range from 0 to 100 with higher scores indicating better physical health. Province of recruitment was also considered due to the differences in healthcare systems.

Caregivers rated the presence of BPS in the SS using the 18-item Brain Impairment Behavior Inventory–Revised.\textsuperscript{27} This scale assesses 4 domains (apathy, depression, memory/comprehension, and irritability) as identified by exploratory factor analysis.\textsuperscript{27} Total scores were calculated for each domain scale with higher scores indicating more BPS.

SSs’ physical disability, including indicators of overall strength, hand function, activities of daily living/instrumental activities of daily living, and mobility, was assessed by the physical domain of the Stroke Impact Scale.\textsuperscript{28} Scores range from 0 to 100 with higher scores indicating better physical functioning. A sum of z-scores from the communication and memory subscales of the Stroke Impact Scale\textsuperscript{28} and the Mini Mental Status examination\textsuperscript{29} provided an estimate of cognitive impairment. The Charlson index provided an estimate of SS comorbidity.\textsuperscript{30} Higher scores indicated more comorbidity (range, 0 to 6).

The amount of care provided with activities and instrumental activities of daily living and medical care was assessed by the 17-item Caregiver Assistance Scale with higher scores indicating the provision of more assistance (range, 0 to 102).\textsuperscript{31} We examined limitations in caregivers’ abilities to participate in valued activities and interests due to providing care using the 14-item Care-giving Impact Scale with higher scores indicating more interference with participation (range, 0 to 84).\textsuperscript{31}

Caregiver mastery was assessed by Pearlin’s 7-item measure\textsuperscript{32} with higher scores indicating more mastery (range, 7 to 28). Instrumental support was the total number of community services received by the SS during the past month. Due to the large percentage of SSs who did not receive services (range, 35.8% to 76.4%) across the 6 waves of assessment, this variable was dichotomized with 0 indicating the SS received no services and 1 indicating they received at least 1 service.

Caregiver emotional distress was assessed by the 20-item Center for Epidemiological Studies Depression Scale.\textsuperscript{33} Higher scores reflect more depressive symptoms (range, 0 to 60).

**Statistical Analyses**

A series of individual growth curve models\textsuperscript{34} were run using the SAS Version 9.2 mixed effect models procedure.\textsuperscript{35} These models treated the intercept and time variables as random effects to represent individual differences in initial emotional distress and rates of change during the first 2 years. The time variable was centered, 0, 2, 5, 11, 17, and 23 to represent the -1, -3, -5, -12, -18, and 24-month poststroke assessments, respectively, so the models’ intercepts represented caregivers’ initial level of depression symptoms. The unconditional means model (A) provided an unadjusted estimate of the level of emotional distress across all participants and all waves of data collection. The unconditional growth model (B) assessed unadjusted change in the dependent variable over time. Model C tested the full set of predictors. Removing estimates with the highest probability value and then rerunning the analyses until all variables in the model made a significant (P<0.10) contribution to caregiver emotional distress determined Model D, the simplest model. Models A to D were conducted with the Year 1 sample. Model E tested the simplest model (Model D) in the Year 2 subsample. Goodness-of-fit indices (eg, Deviance [-2 log likelihood]), Akaike Information Criterion, and Bayesian Information Criterion) facilitated model comparison.\textsuperscript{34}

We tested the assumptions of this method, including ignorable missing data; every observation of the dependent variable having complete observations of the independent variables; linear change over time; linear relationships between the dependent variable and each independent variable; and residuals being normally distributed and homoscedastic. Missing independent variable data were replaced by the individual’s closest available longitudinal datum.\textsuperscript{36} The skew of the dependent variable and a number of the independent variables violated the models’ assumptions. As a result, 2 additional models were run: (1) full model with a transformed dependent variable; and (2) full model with transformed dependent and skewed independent variables. These 2 additional models identified the same set of significant predictors as the untransformed full model (Model C). Therefore, the untransformed model is presented to facilitate interpretation of the estimates.

**Sample Size**

To use the full model approach with 21 independent variables and a minimum of 10 participants per variable, we needed a minimum sample of 210 SS/caregiver dyads.\textsuperscript{37}
The analyses included 399 SS/caregiver dyads and 80 dyads from the Toronto sample that reconsented to complete the 18- and 24-month assessments. Participants were from Toronto (n=171 [43%]), London (n=69 [17%]), and Montreal (n=159 [39%]). Caregiver characteristics are presented in Table 1.

SSs’ characteristics are presented in Table 2. Our sample was representative of the full sample, except those SSs who had a caregiver were younger, more likely to be married and male, and had a slightly more severe stroke (see Table 2).

The results of the mixed effects analyses are presented in Table 3. The intercept in Model A provides the overall mean for the caregivers across the 4 waves of data collection (16.6). Model B indicates that there is a small but significant decrease in caregiver emotional distress over the first year poststroke. Quadratic change was also tested to identify any nonlinear change but was nonsignificant (results not shown).

The full model (C) suggests that caregivers experience more emotional distress when providing care to SSs with more symptoms of depression and when caregivers were younger, female, in poorer physical health, experienced more lifestyle interference due to their caregiving role, had a lower sense of personal control (mastery), and were caring for their spouse. Stroke survivor physical disability, illness severity, and comorbid conditions were not significantly associated with caregiver emotional distress. Changes in caregiver emotional distress over time were no longer significant when considering all the variables in the model.

The simplest model (D) suggests that in addition to those variables mentioned, caring for SSs with poorer cognitive functioning may also be associated with more caregiver emotional distress. Three additional variables were approaching statistical significance (ie, \( P<0.10 \)), including BPS domains irritability and memory/comprehension problems and when the SS was female. Stroke survivor physical disability was not associated with caregiver emotional distress and change over time in caregiver distress was not significant.

Repeating Model D with the subset of caregivers followed for a second year identified the same set of significant predictors except SS cognitive abilities, caregiver age, and caring for a spouse (Model E). In addition, the significance level associated with the SS being female increased. We repeated the unconditional means, growth, and quadratic growth (ie, nonlinear) models with this sample and the effect of time remained nonsignificant (results not shown).

### Discussion

This study highlights the important contribution of SS changes in behavioral and psychological well-being to caregiver mental health. Results demonstrate that SSs’ symptoms of depression were associated with caregivers’ emotional...
distress, but SS physical disability was not. Other important contributors to caregivers’ emotional distress included their inability to maintain participation in valued activities, their sense of control over their life, and their age, gender, and own physical health. Caregiver emotional distress decreased over time; however, when considered in the multivariate model, this change was no longer significant.

SS research suggests that depression is a common consequence of stroke and it persists over time, suggesting that depressive symptoms and cognitive deficits are related to each other in the SS, and that caregiver depression can contribute to SSs’ experience of depression. Our findings suggest that even in this cohort of caregivers to SSs who experienced mild to moderate strokes (ie, median score on the Canadian Neurological Scale was 9.0), depressive symptoms in the SSs were a significant challenge for their caregivers.

SS physical disability was not a significant predictor of caregiver emotional distress. This suggests that caregivers may be more challenged by the emotional and behavioral consequences of stroke as opposed to managing its physical consequences. Because enhancing SSs’ autonomy is a priority for stroke rehabilitation, caregivers may be better prepared to support the physical rather than the behavioral and psychological consequences of stroke. Another possible explanation is that because the SSs in this study experienced mild to moderate strokes, the physical demands of caregiving may not have been as onerous. Previous studies have identified stroke severity as a significant predictor of stroke disability and health-related quality of life as long as 5 years poststroke.

In addition to SS BPS, interference with participation in valued activities and interests due to the caregiving role were significantly associated with caregiver depression. These findings are consistent with previous stroke research and research with caregivers to other clinical populations. In contrast, the level of assistance provided by caregivers was not associated with caregiver depression. Considered together, it is not the amount of assistance caregivers provide that contributes to their emotional distress, but the extent to which they can maintain participation in valued activities and interests.

This study had some limitations. We recruited a sample of first SSs to learn from their families’ first experience caring for someone poststroke and, as a result, our survivors had mild to moderate stroke severity. It would be informative to study BPS with families caring for individuals who have more debilitating strokes to see if other types of behavior changes affect caregiver well-being. In addition, SSs did not complete their own depression scale. Therefore, we were not able to compare symptoms of depression as observed by caregivers with that experienced by the SSs themselves.

Table 3. Summary of Mixed Effects Modeling

<table>
<thead>
<tr>
<th>Fixed Effects Initial Status, $\pi_{0i}$</th>
<th>Model A</th>
<th>Model B</th>
<th>Model C</th>
<th>Model D</th>
<th>Model E</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>16.6 (0.39)$^§$</td>
<td>34.9 (3.0)$^§$</td>
<td>33.2 (2.59)$^§$</td>
<td>29.9 (5.76)$^§$</td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>$-0.14 (0.04)$§</td>
<td>$-0.01 (0.04)$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Province</td>
<td>$-0.48 (0.55)$</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiving Impact Scale</td>
<td></td>
<td></td>
<td>0.14 (0.01)$§$</td>
<td>0.14 (0.01)$§$</td>
<td>0.16 (0.03)$§$</td>
</tr>
<tr>
<td>Caregiver mastery</td>
<td></td>
<td></td>
<td>$-0.52 (0.07)$§</td>
<td>$-0.52 (0.06)$§</td>
<td>$-0.55 (0.11)$§</td>
</tr>
<tr>
<td>Caregiver age</td>
<td></td>
<td></td>
<td>$-0.07 (0.03)$‡</td>
<td>$-0.08 (0.02)$‡</td>
<td>$-0.07 (0.04)^*$</td>
</tr>
<tr>
<td>Caregiver is Female</td>
<td></td>
<td></td>
<td>2.43 (0.74)‡</td>
<td>2.46 (0.72)‡</td>
<td>6.20 (1.78)‡</td>
</tr>
<tr>
<td>Caregiver is working for pay</td>
<td></td>
<td></td>
<td>$-0.08 (0.51)$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver physical health</td>
<td></td>
<td></td>
<td>$-0.24 (0.02)$§</td>
<td>$-0.24 (0.02)$§</td>
<td>$-0.27 (0.05)$§</td>
</tr>
<tr>
<td>BPS–depression</td>
<td></td>
<td></td>
<td>1.47 (0.33)§</td>
<td>1.6 (0.30)§</td>
<td>1.98 (0.73)‡</td>
</tr>
<tr>
<td>BPS–irritability</td>
<td></td>
<td></td>
<td>0.41 (0.28)</td>
<td>0.52 (0.27)*</td>
<td>0.97 (0.55)*</td>
</tr>
<tr>
<td>BPS–apathy</td>
<td></td>
<td></td>
<td>0.41 (0.29)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BPS–memory/comprehension</td>
<td></td>
<td></td>
<td>0.43 (0.38)</td>
<td>0.61 (0.35)*</td>
<td>$-0.70 (0.72)$</td>
</tr>
<tr>
<td>SIS–physical component score¶</td>
<td></td>
<td>$-0.01 (0.01)$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive composite score¶</td>
<td></td>
<td>$-0.20 (0.11)^*$</td>
<td>$-0.22 (0.10)^†$</td>
<td>0.00 (0.23)</td>
<td></td>
</tr>
<tr>
<td>CNS¶</td>
<td></td>
<td>0.06 (0.10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Charlson Index¶</td>
<td></td>
<td>$-0.002 (0.17)$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community service¶</td>
<td></td>
<td>$-0.23 (0.36)$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SS age¶</td>
<td></td>
<td>$-0.02 (0.02)$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SS is female¶</td>
<td></td>
<td>1.20 (0.71)*</td>
<td>1.2 (0.71)*</td>
<td>3.71 (1.78)†</td>
<td></td>
</tr>
<tr>
<td>SS is spouse¶</td>
<td></td>
<td>1.5 (0.74)‡</td>
<td>1.59 (0.65)‡</td>
<td>2.80 (1.49)*</td>
<td></td>
</tr>
</tbody>
</table>

Estimate (SD): *$P<0.1$; †$P<0.05$; ‡$P<0.01$; §$P<0.001$.
¶Caregiver provided this information.
SS indicates Canadian Neurological Scale; SIS, Stroke Impact Scale; Province 0, Quebec; Province 1, Ontario; Model A, unconditional means model; Model B, unconditional growth model; Model C, Year 1 sample full model; Model D, Year 1 sample simplest model; Model E, repeat of Model D with Year 2 sample.
Summary

This research identified key aspects of the care situation that interventions could address to improve caregiver well-being during the first years poststroke. Specifically, enhanced clinical management of SS depression and interventions to prepare caregivers to manage BPS may be beneficial. In addition, caregiver respite programs that encourage caregivers to maintain participation in valued activities and interests may also be valuable.

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Disclosures

None.

References

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http://stroke.ahajournals.org/content/suppl/2012/03/12/STROKEAHA.110.597963.DC1

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Clinical Sciences

Abstract 6

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배경과 목적

뇌졸중 발생 후 첫 2년간 뇌졸중 생존자의 우울 증상은 보호자의 우울증과 관련이 있다.

배경과 목적

뇌졸중과 관련하여 물리적 기능 회복이 주요한 여건이 주어진 환자들 중, 총 2년간 뇌졸중 발생 후 첫 2년간, 뇌졸중 생존자의 행동 및 심리 증상이 보호자(환자)의 정서적 고충(behavioral disturbance)의 발생에 기여한다는 것을 제안하였다. 이 연구의 목적은 뇌졸중 발생 후 첫 2년간, 뇌졸중 생존자의 행동 및 심리 증상이 보호자의 정서적 고충에 독자적으로 기여하는지를 결정하기 위한 것이다.

방법

첫 번째 뇌졸중의 생존자와 그 보호자를 대상으로 총 3종의 코호트 연구(longitudinal cohort study)가 진행되었다. 참가자는 뇌졸중 후 1, 3, 6, 12개월 후 전화 인터뷰를 통한 표준화된 설문지를 완료하였다. 일부에서는 뇌졸중 후 18, 24개월에 추가적인 평가를 수행하였다. 이러한 종합 자료는 혼합 효과 모형(mixed effects modeling)을 통해 분석되었다.

결과

399명의 뇌졸중 생존자/보호자들이 참여하였다. 전반적으로 보호자는 뇌졸중 생존자가 더 우울한 증상을 보였으나, 인지 영역과 뇌졸중 생존자의 우울 증상과 관련이 있었다. 보호자의 우울 증상이 뇌졸중 생존자의 우울 증상과 통계적으로 유의하게 연관되었다. 또한, 보호자의 우울 증상은 뇌졸중 생존자의 산업 및 심리 증상과 연관되었다.

결론

보호자의 더 나은 삶을 위한 중재는 뇌졸중 생존자의 우울증에 대한 임상적 치료의 강화와 보호자가 행동 및 심리 증상과 관련된 활동을 조절할 수 있도록 잘 준비시키는 데 친절이 맞추어져야 한다. 더불어 보호자에게 가치 있는 활동 참여를 유지하도록 격려하는 유의 프로그램이 도움이 될 것이다.