What Makes Family Caregivers Happy During the First 2 Years Post Stroke?

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

Background and Purpose—This study aimed to identify aspects of the caregiving situation contributing to family caregivers’ psychological well-being.

Methods—Longitudinal cohort study with structured quantitative interviews 1, 3, 6, and 12 months post stroke. A subset of participants also completed surveys 18 and 24 months post stroke. Participants included individuals hospitalized for their first stroke and their family caregivers. Psychological well-being was assessed by the Positive Affect Scale.

Results—A total of 399 stroke survivor, caregiver dyads completed the 1-year follow-up and 80 dyads completed the second year of follow-up. Using mixed effects modeling for longitudinal data, caregivers reported more psychological well-being when they provided more assistance to stroke survivors who had fewer symptoms of depression, better cognitive functioning, and who had more severe strokes. In addition, caregivers who maintained participation in valued activities had more mastery, gained personally providing care, were in better physical health, were older, and were from Quebec reported more psychological well-being. Caregivers followed for a second year post stroke reported better psychological well-being when caring for stroke survivors with fewer symptoms of depression and more severe strokes and when the caregivers had a greater sense of mastery and gained more personally providing care.

Conclusions—Our findings contribute to the caregiver intervention development literature by identifying aspects of the caregiving situation that are associated with positive outcomes. Incorporating specific aspects, for example, strategies to enhance caregiver mastery into programs and services offered to caregivers may enhance their positive experiences with providing care and ultimately enhance the sustainability of the caregiving situation. *(Stroke. 2014;45:1084-1089.)*

Key Words: caregivers ■ cohort studies ■ longitudinal studies ■ psychological adaptation ■ stroke
The use of a theoretical framework enhances our ability to make a comprehensive assessment of factors influencing caregiver well-being. Pearlin’s Stress Process Model of family caregiving suggests providing care affects many aspects of caregivers’ lives, positively and negatively, and these outcomes are influenced by aspects of the caregiving situation and caregivers’ abilities to draw on existing resources. To facilitate our understanding of the factors contributing to caregivers’ psychological well-being, we adopted the Stress Process Model. Pearlin proposes that there are contextual factors (eg, sociodemographic characteristics of caregiver and stroke survivor, caregivers’ own physical health), primary (eg, stroke severity, 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.

Guided by Pearlin’s model of family caregiving, the objectives of this research were to (1) identify aspects of the caregiving situation that contribute to caregivers’ psychological well-being and (2) examine changes in caregiver psychological well-being during the first year post stroke. The specific hypotheses were (1) caregivers who have more positive experiences providing care (eg, personal gain) and fewer negative experiences (eg, interference with participation in valued activities, stroke survivor with more severe stroke) will report more psychological well-being and (2) caregiver psychological well-being will increase during the first year post stroke.

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. Participants completed standardized measurement instruments by telephone 1, 3, 6, and 12 months post stroke (year-1 sample). A subset of participants from the Toronto site consented to be interviewed again 18 and 24 months post stroke (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 stroke survivors and confirmed that this was their first hospitalization for either a hemorrhagic or ischemic stroke. Caregivers were identified as the person who was most likely to be a key provider of support and assistance when the stroke survivor was discharged home. Participants had to be able to speak and read English or French (Montreal).

Measurement Instruments

We obtained stroke survivors’ and caregivers’ sociodemographic information, including age, sex, primary daily activity (eg, caregiver, homemaker, working for pay, retired, etc), marital status, and income. Caregivers also provided information about their relationship to the stroke survivor (eg, spouse) and their living situation. Province of recruitment was considered because of the differences in healthcare systems. 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 determined stroke severity with scores ranging from 1.5 to 11.5 and lower scores indicating more neurological damage.

Stroke survivors’ physical disability, including indicators of overall strength, hand function, activities and instrumental activities of daily living, and mobility, was assessed by the physical domain of the Stroke Impact Scale. A sum of z scores from the communication and memory subscales of the Stroke Impact Scale and the Mini-Mental Status Exam provided an estimate of cognitive impairment. The Charlson index provided an estimate of comorbidity. Caregivers rated the presence of behavioral and psychological symptoms in the stroke survivor using the 18-item Brain Impairment Behavior Inventory—Revised. This scale assesses 4 domains (apathy, depression, memory/comprehension, and irritability) as identified by exploratory factor analysis.

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. We examined limitations in caregivers’ abilities to participate in valued activities and interests because of providing care using the 14-item Caregiving Impact Scale (CIS).

Caregiver mastery was assessed by Pearlin’s 7-item measure. Personal gain (ie, becoming aware of their inner strengths while providing care) was assessed by the 4-item Personal Gain Scale. We determined the total number of community services received by the stroke survivor during the past month. Because of the large percentage who did not receive services (range, 35.8%-76.4%) across the 6 waves of assessment, this variable was dichotomized with zero indicating that the stroke survivor received no services and 1 indicating that they received ≥1 service.

Caregiver physical health was assessed by the physical health domain of the Medical Outcomes Study Short Form-36. Caregiver psychological well-being was assessed by the 10-item Positive Affect Scale of the Positive and Negative Affect Schedule.

Statistical Analyses

A series of individual growth curve models were run using the SAS version 9.2 mixed-effect models procedure. These models treated the intercept and time variables as random effects to represent individual differences in initial psychological well-being and rates of change during the first 2 years. The time variable was centered by subtracting 1 from each month of assessment, so the models’ intercepts represented caregivers initial level of psychological well-being. The unconditional means model (A) provided an unadjusted estimate of the level of psychological well-being across all participants and all waves of data collection. The unconditional growth model (B) assessed unadjusted change in the dependent variable over time.
(hypothesis 2). Model C tested the full set of predictors (hypothesis 1). Removing estimates with the highest $P$ value and then rerunning the analyses until all variables in the model made a significant ($P<0.10$) contribution to caregiver psychological well-being 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. Estimates are not standardized and indicate the amount of change in the dependent variable corresponding to a 1-point change in the independent variable. Goodness-of-fit indices (eg, deviance [−2 log likelihood], Akaike Information Criterion, and Bayesian Information Criterion) facilitated model comparison with lower scores indicating better fitting models.29

We tested the assumptions of this method, including ignoring 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.31 The skew of some independent variables violated the models’ assumptions. As a result, an additional model was run—full model with transformed independent variables. This model 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. See online-only Data Supplement for a detailed description of the statistical analyses.

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 stroke survivor/caregiver dyads.32

### Table 1. Caregiver Sociodemographic Characteristics (n=399)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Year-1 Sample (n=399)</th>
<th>Year-2 Sample (n=80)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, y</strong></td>
<td>58.4 (14.55)</td>
<td>57.0 (14.23)</td>
</tr>
<tr>
<td><strong>Women</strong></td>
<td>276 (69.2%)</td>
<td>50 (62.5%)</td>
</tr>
<tr>
<td><strong>Relationship to stroke survivor†</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>278 (69.7%)</td>
<td>62 (77.5%)</td>
</tr>
<tr>
<td>Son/daughter/other</td>
<td>121 (30.3%)</td>
<td>18 (22.5%)</td>
</tr>
<tr>
<td><strong>Marital status†</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/common-law</td>
<td>320 (80.2%)</td>
<td>66 (82.5%)</td>
</tr>
<tr>
<td>Single</td>
<td>48 (12%)</td>
<td>10 (12.5%)</td>
</tr>
<tr>
<td>Separated/widowed/divorced</td>
<td>28 (7.0%)</td>
<td>2 (2.6%)</td>
</tr>
<tr>
<td>Provided care previously†</td>
<td>163 (40.9%)</td>
<td>28 (35.0%)</td>
</tr>
<tr>
<td><strong>Primary daily activity†</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working for pay</td>
<td>136 (34.1%)</td>
<td>32 (40.0%)</td>
</tr>
<tr>
<td>Retired</td>
<td>88 (22.1%)</td>
<td>13 (16.3%)</td>
</tr>
<tr>
<td>Caregiver</td>
<td>26 (6.5%)</td>
<td>7 (8.8%)</td>
</tr>
<tr>
<td>Homemaker</td>
<td>70 (17.5%)</td>
<td>8 (10.0%)</td>
</tr>
<tr>
<td>Other</td>
<td>18 (4.5%)</td>
<td>3 (3.8%)</td>
</tr>
<tr>
<td>Live with stroke survivor†</td>
<td>341 (85.5%)</td>
<td>64 (80.0%)</td>
</tr>
</tbody>
</table>

Not all percentages add up to 100% because of missing data.

*Mean (SD) and †n (%).

### Table 2. Stroke Survivor Characteristics for Respondents and Nonrespondents (n=678)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Respondents (n=399)*</th>
<th>Nonrespondents (n=279)*</th>
<th>PValue</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, y</strong></td>
<td>68.2 (56.79–77.04)</td>
<td>71.4 (58.97–79.84)</td>
<td>0.051</td>
</tr>
<tr>
<td><strong>Men</strong></td>
<td>235 (59.0%)</td>
<td>137 (49.1%)</td>
<td>0.010</td>
</tr>
<tr>
<td><strong>Married</strong></td>
<td>268 (71.3%)</td>
<td>95 (36.0%)</td>
<td>0.000</td>
</tr>
<tr>
<td><strong>Working</strong></td>
<td>88 (24.7%)</td>
<td>55 (21.7%)</td>
<td>0.378</td>
</tr>
<tr>
<td><strong>Province</strong></td>
<td></td>
<td></td>
<td>0.765</td>
</tr>
<tr>
<td>Ontario</td>
<td>240 (60.2%)</td>
<td>171 (63.1%)</td>
<td></td>
</tr>
<tr>
<td>Quebec</td>
<td>159 (39.8%)</td>
<td>108 (38.7%)</td>
<td></td>
</tr>
<tr>
<td><strong>CNS</strong></td>
<td>9.0 (7.0–10.5)</td>
<td>9.25 (7.5–10.5)</td>
<td>0.505</td>
</tr>
<tr>
<td><strong>Barthel Index</strong></td>
<td>80 (55–100)</td>
<td>85 (58.75–100)</td>
<td>0.133</td>
</tr>
<tr>
<td><strong>No. of comorbid conditions</strong></td>
<td>2 (1–4)</td>
<td>3 (1–4)</td>
<td>0.278</td>
</tr>
<tr>
<td><strong>Charlson Index</strong></td>
<td>1 (0–2)</td>
<td>1 (0–2)</td>
<td>0.489</td>
</tr>
<tr>
<td><strong>SIS-physical domain</strong></td>
<td>70.5 (40.17–77.8)</td>
<td>71.4 (43.75–88.84)</td>
<td>0.482</td>
</tr>
<tr>
<td><strong>MMSE</strong></td>
<td>21 (19–22)</td>
<td>21 (19–22)</td>
<td>0.238</td>
</tr>
<tr>
<td><strong>Hospital stay, d</strong></td>
<td>11 (6–19)</td>
<td>11 (6–18)</td>
<td>0.210</td>
</tr>
<tr>
<td><strong>Home care services</strong></td>
<td>2 (0–6)</td>
<td>1 (0–4)</td>
<td>0.047</td>
</tr>
<tr>
<td><strong>Side of cerebral lesion</strong></td>
<td></td>
<td></td>
<td>0.855</td>
</tr>
<tr>
<td><strong>Left</strong></td>
<td>173 (43.6%)</td>
<td>120 (43.2%)</td>
<td></td>
</tr>
<tr>
<td><strong>Right</strong></td>
<td>194 (48.9%)</td>
<td>131 (47.1%)</td>
<td></td>
</tr>
<tr>
<td><strong>Both</strong></td>
<td>18 (4.5%)</td>
<td>18 (6.5%)</td>
<td></td>
</tr>
<tr>
<td><strong>Stroke type</strong></td>
<td></td>
<td></td>
<td>0.153</td>
</tr>
<tr>
<td><strong>Ischemic</strong></td>
<td>354 (89.2%)</td>
<td>257 (92.4%)</td>
<td></td>
</tr>
<tr>
<td><strong>Hemorrhagic</strong></td>
<td>43 (10.8%)</td>
<td>21 (7.6%)</td>
<td></td>
</tr>
<tr>
<td><strong>Stroke location</strong></td>
<td></td>
<td></td>
<td>0.905</td>
</tr>
<tr>
<td>Hemispheric</td>
<td>329 (82.9%)</td>
<td>233 (84.1%)</td>
<td></td>
</tr>
<tr>
<td>Cerebellum</td>
<td>44 (11.1%)</td>
<td>29 (10.5%)</td>
<td></td>
</tr>
<tr>
<td>Brain stem</td>
<td>24 (6.0%)</td>
<td>15 (5.4%)</td>
<td></td>
</tr>
</tbody>
</table>

*CNS indicates Canadian Neurological Scale; Charlson, the Charlson Comorbidity Index; Comorbidity, the number of comorbid conditions; MMSE, Mini–Mental Status Examination telephone version; and SIS-physical domain, Stroke Impact Scale Physical Health Domain Score.

*Data from 1-month patient interview; number (percentage) or median (interquartile range).

### Results

The analyses included 399 stroke survivor/caregiver dyads followed for 1 year and 80 dyads from the Toronto sample that reconsented to complete the 18- and 24-month assessments. The percentage of caregivers completing follow-up assessment ranged from 66% at 12 months to 86% at 1 month. Participants were from Toronto (n=171; 43%), London (n=69; 17%), and Montreal (n=159; 39%). Caregiver characteristics are presented in Table 1.

Stroke survivors’ characteristics are presented in Table 2. Stroke survivors who had a caregiver participate in the study were representative of the full cohort except they were significantly younger, more likely to be married and men, and had a slightly more severe stroke (Table 2).

The results of the longitudinal analyses are presented in Table 3. The intercept in model A provides the overall mean psychological well-being score of the caregivers during the first year of data collection (35.9; $P<0.001$). Model B indicates...
no significant change in psychological well-being during the first year post stroke (−0.01; P>0.05). Quadratic change was also tested to identify any nonlinear change but was nonsignificant (results not shown).

The full model (model C) suggests that more psychological well-being was associated with caregivers providing higher levels of assistance (0.06; P<0.001), experiencing less interference with valued activities (−0.05; P<0.01), being in better physical health (0.21; P<0.001), gaining more as a result of providing care (0.35; P<0.001), having greater sense of control over life (mastery 0.62; P<0.001), being older (0.07; P<0.05), and caring for a stroke survivor who has less cognitive impairment (0.31; P<0.01), more severe stroke (Canadian Neurological Scale, −0.35; P<0.01), and less depression (−0.8; P<0.05). Stroke survivor physical disability was not significantly associated with caregiver psychological well-being (0.02; P>0.05). Changes in caregiver psychological well-being over time remained nonsignificant when considering all the variables in the model (−0.05; P>0.05). These findings are consistent with the simplest model (model D). Rerunning the simplest model in the sample of caregivers who were followed for a second year post stroke, higher psychological well-being was associated with stroke survivors having fewer symptoms of depression (−1.89; P<0.05) and more severe strokes (−1.04; P<0.01) and caregivers having greater sense of control over life (mastery, 0.47; P<0.001) and gaining more personally as a result of providing care (0.49; P<0.01; model E).

Discussion

In this sample of family caregivers to individuals who had been hospitalized for their first stroke and using Pearlin’s Stress Process Model as a guide, we were able to consider patient and caregiver factors that influence caregiver psychological well-being. Our caregivers reported more psychological well-being when stroke survivors exhibited fewer depressive symptoms, had better cognitive functioning, and had more severe strokes. They also reported more psychological well-being when they provided more assistance to the stroke survivor, maintained participation in valued activities, were in better physical health, were older, were able to gain personally as a result of providing care, and had higher levels of mastery or control over their lives. Caregiver psychological well-being was stable during the 2-year follow-up period. These findings begin to characterize factors that constitute a positive caregiving situation.

The finding that caregiver psychological well-being was stable during the follow-up period is a new contribution to the literature. Our findings are consistent with those of previous studies that have shown a positive relationship between higher psychological well-being and better caregiver coping strategies, such as problem-solving and emotional support. The results of our study suggest that interventions aimed at improving caregiver psychological well-being could be effective in reducing caregiver burden and improving stroke survivor outcomes. Future research should focus on developing interventions that target the specific factors identified in our study, such as providing assistance, maintaining participation in valued activities, and improving physical and mental health.
the stroke caregiving literature. Only 1 quantitative study has examined positive changes in stroke caregiving over time and this exploratory 4 case study design suggested increases in positive caregiving experiences during a 6-week follow-up period.\(^5\) Our findings suggest that on average, across a larger sample, psychological well-being in family caregivers is stable over time. In contrast, negative caregiver outcomes, for example, depression, have been seen to decrease over time.\(^6\)

Our findings are consistent with the authors of the Positive and Negative Affect Scales who have observed decreases in negative affect and no change in positive affect during a 6- to 7-year period in undergraduate students followed up over time.\(^7\) In addition, caregiver psychological well-being scores in our sample were consistent with reported population norms.\(^8\)

Findings related to characteristics of the patient suggest that caregivers struggle more with the emotional and cognitive consequences of stroke than the physical limitations, and that milder strokes in patients may be related to poorer psychological well-being of caregivers. These findings are consistent with previous research that suggests that cognitive disability and depression symptoms in the stroke survivor are associated with caregivers’ symptoms of depression.\(^9\) In research with survivors of mild stroke and their spousal caregivers, although physical functioning was either good or improving, depression and marital functioning worsened during the year post stroke, suggesting that mild strokes can still have a negative impact.\(^10\) Qualitative research with mild stroke survivors and spousal caregivers also suggests adjustments to lifestyle are made and caregivers feel the need to be vigilant.\(^11\) As a result, caregivers may require more guidance managing the emotional and cognitive consequences of stroke and more guidance on managing and adjusting to life with a mild stroke than is routinely provided by the healthcare system.\(^12\)

Our findings also suggest that when caregivers gain personally as a result of providing care have high levels of mastery, are in good physical health, and provide higher levels of assistance; they report better psychological well-being. These findings begin to delineate the characteristics of a positive caregiving situation. Family caregivers may derive personal happiness and become aware of their inner strengths (personal gain) when they are actively involved in the care of their family member. This is more likely to occur when caregivers are in good physical health and have higher levels of mastery and are caring for stroke survivors with less cognitive impairment and depressive symptoms. Previous qualitative and quantitative research suggest that caregivers feeling needed and appreciated, and gaining a sense of fulfillment and a positive attitude are positive outcomes associated with providing care.\(^13\) This is consistent with our observation that gaining personally as a result of providing care was associated with psychological well-being. Previous studies have also identified strengthened relationships as a positive outcome of providing care.\(^14\) We did not assess relationship quality in our study, but this aspect and its relationship to psychological well-being warrant further investigation.

This study had some limitations. We recruited a sample of first stroke survivors who were able to communicate and cognitively able to consent to participate in the study to learn from their family’s first experience caring for someone post-stroke and, as a result, our survivors had mild-to-moderate stroke severity. It would be informative to explore positive experiences with providing care to individuals who have had more debilitating strokes to see whether our set of significant predictors remains the same, but this is not possible within our study. Our second-year follow-up included a small select sample from Toronto limiting the generalizability of our 2-year findings. A variety of individuals across research sites recruited stroke survivors and their caregivers into the study when patients were admitted to acute care. We did not have standardized processes for recording recruitment information and, therefore, we are not able to comment reliably on the representativeness of this sample. We did not collect any data on the caregivers’ precaregiving psychological state so we are not able to conclude that caregiving results in positive outcomes as it may be that caregivers predisposed to a positive psychological state may be more likely to take on the caregiving role. This study could also have benefited from collecting qualitative data from a subset of the participants to obtain a more in-depth understanding of their positive experiences with providing care and their impact on psychological well-being.

In summary, our research with a large sample of stroke survivor/caregiver dyads followed for the first 2 years post stroke has identified some key aspects of the stroke caregiving situation that are associated with positive outcomes. These findings can begin to characterize good caregiving situations that may inform intervention development so as to assist caregivers to derive benefits from providing care and, ultimately, enhance the sustainability of the caregiving situation.

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Disclosures
None.

References


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