

## ORIGINAL ARTICLE

# Stroke Survivors' Behavioral and Psychologic Symptoms Are Associated With Informal Caregivers' Experiences of Depression

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**ABSTRACT.** Cameron JI, Cheung AM, Streiner DL, Coyte PC, Stewart DE. Stroke survivors' behavioral and psychologic symptoms are associated with informal caregivers' experiences of depression. *Arch Phys Med Rehabil* 2006;87:177-83.

**Objective:** To determine the impact of stroke survivors' behavioral and psychologic symptoms (BPS) on informal caregivers' experience of depression in the context of the caregiving situation.

**Design:** Cross-sectional survey using a structured quantitative interview.

**Setting:** Rehabilitation facility outpatient clinic, tertiary care facility outpatient clinic, and community care organizations.

**Participants:** Ninety-four informal caregivers to stroke survivors completed standardized measurement instruments.

**Interventions:** Not applicable.

**Main Outcome Measures:** Measurement instruments included the Center for Epidemiological Studies Depression Scale, Brain Impairment Behavior Inventory—Revised, Caregiver Assistance Scale, Caregiving Impact Scale, and Mastery scale.

**Results:** A substantial percentage (44.7%) of caregivers were at risk of clinical depression. Caregivers experienced more depression symptoms when they cared for stroke survivors exhibiting more BPS of memory and comprehension difficulties, provided less assistance, experienced more lifestyle interference, and had lower mastery ( $F_{5,85}=26.02$ ,  $P<.001$ , adjusted  $R^2=.58$ ).

**Conclusions:** BPS exhibited by stroke survivors contribute to informal caregivers' experience of depression. These results can assist rehabilitation professionals to identify informal care

providers who are at greater risk of experiencing emotional distress and, therefore, may benefit from intervention.

**Key Words:** Behavioral symptoms; Caregivers; Cerebrovascular accident; Depression; Quality of life; Rehabilitation.

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**I**NFORMAL CAREGIVERS PROVIDE essential assistance with stroke survivor rehabilitation and adaptation to community living. Unfortunately, caregivers are rarely prepared for their role and commonly experience elevated levels of emotional distress,<sup>1-3</sup> which can negatively affect stroke survivor rehabilitation<sup>4</sup> and threaten the sustainability of home care.<sup>5</sup> Stroke best practice guidelines suggest that rehabilitation professionals should address the needs of informal caregivers and provide any necessary education and/or training to help them in their caregiving role.<sup>6,7</sup> Therefore, research is required to identify the most stressful aspects of the care situation to help rehabilitation professionals to identify and intervene with caregivers at greatest risk of developing emotional distress.

One aspect of stroke that has received limited attention in stroke caregiving research is the cognitive changes that are a common consequence of stroke. The estimated rate of vascular dementia after first stroke is 28.9%<sup>8</sup> and people diagnosed with the precursor, vascular cognitive impairment, either die (52%) or develop dementia (46%) within 5 years.<sup>9</sup> People with cognitive changes often exhibit behavioral and psychologic symptoms (BPS) and, similar to Alzheimer's disease<sup>10</sup> or traumatic brain injury,<sup>11,12</sup> these symptoms may be challenging and, therefore, emotionally distressing for informal care providers.

Four studies have examined the relationship between BPS in stroke survivors and informal caregiver mental health.<sup>13-16</sup> Overall, they suggest that more BPS are associated with informal caregivers experiencing more emotional distress. Unfortunately, the measures used to examine this relationship were developed for psychiatric<sup>13</sup> and elderly populations,<sup>14</sup> had not undergone psychometric testing,<sup>16</sup> or were not directly assessing BPS.<sup>15</sup> As a result, these measures may not capture the uniqueness of BPS in stroke survivors and, therefore, could underestimate the extent of BPS. In addition, BPS are commonly studied as a global construct but it is more likely that the distinct domains of BPS may differentially affect caregiver outcomes. Recent research has identified 4 domains of BPS exhibited by stroke survivors: apathy, depression, memory and comprehension problems, and irritability.<sup>17</sup> Therefore, the relationship between BPS and informal caregiver depression symptoms requires further research to address these limitations and provide information to inform policy and programs to enhance informal caregiver adaptation to providing care in the community to stroke survivors.

The impact of stroke survivors' BPS on informal caregivers' experience of emotional distress must be considered in the

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context of the caregiving situation. The Pearlin stress process model aims to identify aspects of the system of informal care that influence caregiver well-being. Consistent with this approach, important contextual variables (ie, the situation in which care is provided) include the age and sex of the caregiver, their relationship to the care recipient and characteristics of the care recipient. Research suggests that caregivers who are female,<sup>18</sup> younger, and daughters<sup>19</sup> are more likely to experience higher levels of emotional distress. Secondary stressors (ie, objective aspects of the care experience directly associated with the stroke) include BPS and level of care provided by the caregiver. In addition to BPS, providing more care is associated with more depression symptoms.<sup>20</sup>

Secondary stressors arise from and, therefore, mediate the relationship between primary stressors and health outcomes. The most commonly studied secondary stressor is subjective burden, a multidimensional concept assessing the impact of caregiving on caregiver health, financial situation, activities, social life, and self-esteem.<sup>21</sup> More recent research recognizes the importance of identifying specific aspects of burden that are most problematic for caregivers and do not overlap with commonly examined outcomes of caregiving.<sup>22</sup> Lifestyle interference, which includes an element of burden—activity restriction—is a concept that receives much attention in the disability<sup>23-25</sup> and caregiving<sup>14,22,26-28</sup> literature. Essentially, it entails disruption or interference with participation in valued activities and interests due to providing care. The original conceptualization of this construct<sup>25</sup> included important aspects of life identified by early quality of life research.<sup>29</sup> In stroke, available research suggests more lifestyle interference is associated with poorer caregiver outcomes.<sup>13,14,30</sup>

Psychosocial resources and the characteristics of the individual and/or the individual's environment may moderate the impact of caregiving (ie, decrease the impact of the stress when such resources are present). A consistent psychosocial resource that protects caregivers from experiencing emotional distress is having a high sense of mastery or control over their own life.<sup>20,31</sup>

The objective of this research was to identify the specific domain(s) of BPS (ie, apathy, depression, memory and comprehension, irritability) that contribute to informal caregivers' experience of depression. This relationship was examined in the context of other important aspects of the caregiving situation, including the level of care provided, interference with caregivers' lifestyles, sociodemographic characteristics, and caregivers' sense of mastery, as highlighted in the theoretical model. Results from this line of inquiry will aid rehabilitation professionals to target interventions to aid informal caregiver adaptation.

## METHODS

### Participants and Procedure

In this study, we used a cross-sectional design with a convenience sample of informal caregivers to stroke survivors. Informal caregivers were defined as the person primarily responsible for providing and/or coordinating care in the home for the stroke survivor. If more than 1 caregiver was identified per patient, a discussion with the stroke survivor and/or family identified the person who had the most responsibility for providing and/or coordinating care in the home. This person was invited to participate in the study.

Participating organizations, rehabilitation facility outpatient clinic (rehabilitation), tertiary care hospital stroke outpatient clinic (clinic), and 6 community care organizations (community), identified potential participants. Contacts in each organization identified individuals with a clinical diagnosis of ischemic or

hemorrhagic stroke. Rehabilitation and hospital contacts approached stroke survivors and their family members in the clinic waiting area, briefly explained the study, and asked family members if they were willing to speak with the research assistant about the study. The research assistant then provided additional information about the study and asked the family members if they provided assistance with any of the activities on the Caregiver Assistance Scale (CAS). If they provided assistance with at least 1 activity, the research assistant introduced the consent form and asked the family member if they would be willing to complete a telephone or in-person structured quantitative interview or mailed survey. Community care contacts telephoned their clients' family caregivers, briefly explained the study, and asked for permission to send their contact information to the research assistant who then mailed a study introduction letter and copies of the consent form to potential participants. This was followed up with a telephone call to determine caregiving status, answer any questions about the study or the consent form, and either to arrange an interview or to mail a copy of the questionnaire. Informal caregivers were included if they were able to read and speak English and were willing to provide written informed consent. Institutional research ethics boards approved the study protocol.

Between August 2000 and June 2001, 142 informal caregivers to stroke survivors were identified and 94 completed the interview, representing a 66% participation rate. Participants were recruited from rehabilitation (n=61), community (n=18), and clinic (n=15). Caregivers completed their surveys by telephone (n=34), mail (n=35), in a clinic waiting room (n=23), and at home (n=2).

### Measures

Participants provided sociodemographic information, including, sex, age, marital status, primary daily activity, education level, and some information about patient demographics including age, sex, and date of stroke. Time since stroke represents the difference between date of stroke and date of caregiver interview. Caregivers also completed standardized questionnaires as described below.

We used the Brain Impairment Behavior Inventory–Revised to assess the presence of BPS exhibited by the stroke survivor.<sup>17</sup> The original measure was developed through a literature review in the areas of stroke, traumatic brain injury, and dementia, and through clinical experience and consultation with stroke informal caregivers.<sup>32</sup> This revised 18-item measure includes 4 factor analytically derived domains: apathy, depression, memory and comprehension, and irritability.<sup>17</sup> Caregivers were asked to rate "How often during the past two weeks did you observe the care receiver behaving this way?" on a scale from 1 (never) to 5 (all the time). The scale is summed to yield a total score between 18 and 90 with higher scores indicating more BPS. The mean rating across the items in the subscales provide domain scores ranging from 1 to 5, with higher scores indicating more frequently observed symptoms. Internal consistency (Cronbach  $\alpha$ ) was good for the total and subscales, ranging from .78 to .91.<sup>17</sup> The total and subscales were stable over a 2-week period with intraclass correlation coefficients ranging from .75 to .88.<sup>17</sup> In the present study, internal consistency for the subscales and total scale ranged from .76 to .92.

We used the CAS<sup>22</sup> to determine the amount of assistance provided by the caregiver with activities of daily living (eg, bathing, eating), instrumental activities of daily living (eg, finances), and treatment-related activities (eg, administering medications), as described previously.<sup>33-35</sup> A combination of measures captures important constructs that are not covered by any known individual measure. Caregivers rate on a 7-point

scale how much assistance they provided for 17 caregiving tasks over the past 4 weeks ranging from 0 (none) to 6 (a lot). The items are summed to provide a total assistance score with higher scores indicating more assistance. Internal consistency was good in a sample of 44 caregivers to advanced cancer patients ( $\alpha=.87$ )<sup>22</sup> and in the present study ( $\alpha=.85$ ).

We assessed the caregivers' experience of lifestyle interference by the Caregiver Impact Scale,<sup>22</sup> a modification of the Illness Intrusiveness Rating Scale used by Devins et al.,<sup>25</sup> which is based on the illness intrusiveness model. The modified scale assessed the extent to which providing care interfered with participation in 14 domains of the caregivers' lifestyle (eg, health, diet, employment, household responsibilities, active recreation, passive recreation) over the past 4 weeks. One additional domain, "household responsibilities," was added and the original "work" domain was relabeled "employment" because caregiving may differentially impact on employment and housework. Caregivers rate interference with 14 aspects of life on a 7-point scale ranging from 1 (not very much) to 7 (very much). The items are summed to provide a total score with higher scores indicating more lifestyle interference. Good reliability for this scale has been observed in 44 caregivers to advanced cancer patients ( $\alpha=.87$ )<sup>22</sup> and in the current study ( $\alpha=.88$ ).

We assessed depression symptoms by the 20-item Center for Epidemiological Studies Depression Scale (CES-D).<sup>36</sup> Items are rated on a 4-point scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time). Four items are reverse scored and the items are summed to provide a total score. Higher scores reflect more depressive symptoms. Scores of 16 or more indicate participants are at risk of clinical depression.<sup>37</sup> Good internal consistency has been observed for the general population ( $\alpha=.85$ )<sup>36</sup> and in the present study ( $\alpha=.88$ ).

We assessed mastery, an individual's sense of control over her/his life, by the Pearlin 7-item measure.<sup>38</sup> Each item was rated from 1 (strongly disagree) to 4 (strongly agree). Sample items include "I have little control over the things that happen to me," "I can do just about anything I really set my mind to do," and "I often feel helpless in dealing with the problems of life." Five items are reversed and the items are summed with higher scores indicating more mastery. It has displayed good internal consistency in a sample of informal caregivers ( $\alpha=.88$ )<sup>39</sup> and in the present study ( $\alpha=.86$ ).

### Statistical Analyses

Summary statistics were used to describe caregivers and stroke survivors. Pearson correlations and *t* tests described the bivariate relationships between variables. Linear regression analysis was used to identify specific domains of BPS that were significantly associated with caregivers' depression symptoms in the context of other important factors. The most parsimonious model was determined by individually removing nonsignificant predictors starting with the largest *P* value and then rerunning the model until all the variables in the model made a significant contribution to the explanation of depression symptoms.

The assumptions of correlation and regression analyses were tested. Extreme values were identified in conjunction with the multivariate regression analyses, using standardized residuals and Mahalanobis distance scores. A case was identified as an outlier with respect to the dependent variable if, on the plot of the standardized residuals by the standardized predictors, their plotted value was larger than 3 ( $>|3|$ ).<sup>40</sup> Mahalanobis distance scores were used to identify outliers with respect to the predictors or independent variables.<sup>40</sup> Distance scores that were larger than their corresponding critical values with *n* partici-

pants and *k* predictors<sup>40(p115)</sup> were identified as outliers with respect to the predictors. An extreme case was deemed influential if its Cook distance (dependent variable and predictors) was larger than 1 ( $>|1|$ )<sup>40</sup> or if its DFFIT (dependent variable) or DFBETAs (predictors) were larger than 2 ( $>|2|$ ).<sup>40</sup> One case was found to be influential. On closer examination, this caregiver was providing care to a stroke survivor exhibiting a high level of memory/comprehension symptoms. Specifically, they scored the maximum of 5.0 on this subscale and the remaining sample scored, on average, 2.0. The difference between this stroke survivor and the others suggests that this stroke survivor/caregiver dyad is markedly different from the remaining sample and, therefore, this caregiver was excluded from further analyses. Three additional cases were missing data for the dependent variable. Therefore, 4 of 94 (4%) cases were excluded from the analyses. The percentage missing was considered too small a fraction to warrant imputation.<sup>41</sup>

The multivariate regression assumptions that the residuals are independent, normally distributed with a constant variance<sup>40,42</sup> were tested. Because participants were recruited from 3 different sources (ie, rehabilitation, clinical, community care) and completed either an interview or mail survey, it is possible that caregivers' responses to questions within each of these situations may be similar (ie, violating the assumption of independence). Place of recruitment and method of data collection were not associated with depression symptoms when included as dummy variables in the multivariate regression model (results not shown). Plotting and examining a histogram of the standardized residuals tested the normality assumption. This plot followed a normal distribution with a mean of 0 and a standard deviation (SD) of 1. Plotting the standardized residuals by the predicted values and identifying any patterns tested constant variance. Residuals scattered randomly around a horizontal line ( $r_i=0$ ),<sup>40</sup> supporting the tenability of this assumption. Pearson correlations over .80<sup>40</sup> or .90<sup>42</sup> or tolerance levels less than .10<sup>42</sup> suggest multicollinearity. No multicollinearity was observed.

### RESULTS

The sociodemographic characteristics of the informal caregivers are presented in table 1. A large proportion of caregivers (44.7%) scored above the CES-D cutoff suggesting they were at risk for clinical depression. Patients were on average  $\pm$  SD 67.7 $\pm$ 11.91 years of age, 66% were men, and they had their stroke on average 21.5 $\pm$ 5.82 (median, 12.5; interquartile range, 6.4–24.0) months before their caregiver was interviewed.

Correlations between independent and dependent variables are presented in table 2. Depression scores did not differ between men and women, those with secondary education or less and those with more than secondary education, spouse and nonspouse caregivers, living with or not living with care recipient, working for pay and not working for pay, duration of caregiving, and location of recruitment. Caregivers making less than \$40,000 a year reported significantly more depression symptoms than those making more than \$40,000 (mean, 18.4 $\pm$ 11.6 vs mean, 13.6 $\pm$ 8.4;  $t=2.2$ ,  $P<.05$ ).

The first regression model included the following variables: caregiver age, sex and income, 4 BPS subscales, lifestyle interference, caregiving assistance, and mastery. Deleting the variable with the highest nonsignificant *P* value and then rerunning the model until all variables in the model made a significant contribution to explaining the variability in depression symptoms removed the following variables: BPS depression ( $P>.6$ ), BPS irritability ( $P>.5$ ), caregiver age ( $P>.3$ ), caregiver income ( $P>.23$ ), and BPS apathy ( $P>.21$ ). Variables in the final multiple regression analysis explained 58%

Table 1: Characteristics of the Caregivers (n=94)

Characteristic*	Values
Women	74 (78.7)
Age (y)	60.8±15.41
Education	
Secondary education or less	54 (57.4)
More than secondary	40 (42.6)
Income (\$)	
<40,000	47 (50.0)
≥40,000	38 (40.4)
Living with care recipient full time	79 (84.0)
Relationship to care recipient	
Spouse	62 (66.0)
Daughter/son	18 (19.2)
Primary daily activity	
Working for pay	28 (29.8)
Retired	26 (27.7)
Caregiver	23 (24.5)
Homemaker	11 (11.7)
Score >15 on CES-D	42 (44.7)

NOTE. Values are n (%) or mean ± SD.  
 \*Not all percentages add up to 100 because of missing data.

(adjusted  $R^2 = .58$ ,  $F_{5,85} = 26.02$ ,  $P < .001$ ) of the variability in depression symptoms in informal caregivers and these results are presented in table 3. Overall, more depression symptoms were associated with being a female caregiver, more lifestyle interference due to caregiving, lower levels of mastery, providing less care to the stroke survivor, and the presence of more memory and comprehension BPS in the stroke survivor.

The Pearson correlation between caregiving assistance and depression was .18 ( $P = .08$ ) but the above regression revealed an opposite relationship (standardized  $\beta = -.20$ ,  $P < .05$ ) suggesting the presence of a suppressor variable(s).<sup>42</sup> To identify suppressor variables, the methods of Tabachnick and Fidell<sup>42</sup> were used. Specifically, when a suppressor variable(s) is removed from the regression, the  $\beta$  weight for the suppressed variable is similar in size and direction to its simple correlation with the dependent variable.

With this study's data, compared with the simple correlation ( $r = .18$ ,  $P = .08$ ) and the original regression standardized  $\beta$  ( $\beta = -.20$ ,  $P < .05$ ), the regression  $\beta$  weights decreased somewhat by removing memory and comprehension BPS ( $\beta = -.12$ ,

Table 3: Summary of Regression Analysis (n=90)\*

Variable	$\beta$	SE $\beta$	$\beta^{\dagger}$	P	$R^{2\ddagger}$
					.58
Female caregiver	4.0	1.78	.16	.03	
Caregiving assistance	-.008	0.03	-.20	.01	
Lifestyle interference	.21	0.05	.37	.00	
Mastery	-1.2	0.18	-.47	.00	
Memory/comprehension	4.1	0.89	.36	.00	

Abbreviation: SE, standard error.  
 \*Does not equal 94 because of missing values and exclusion of 1 extreme case.  
 $\dagger$ Standardized  $\beta$ .  
 $\ddagger$ Adjusted  $R^2$ .

$P < .20$ ) and lifestyle interference ( $\beta = -.16$ ,  $P < .10$ ) individually from the regression but removing the 2 variables together had a substantial impact on the regression  $\beta$  weight ( $\beta = -.08$ ,  $P < .40$ ). Therefore, controlling for the shared relationship between memory and comprehension BPS, lifestyle interference, and level of care provided reveals an unexpected negative relationship between caregiving assistance and depression symptoms.

DISCUSSION

This study of informal caregivers to stroke survivors provides insight for rehabilitation professionals interested in enhancing informal caregiver adaptation to providing care in the community. It highlights the considerable distress experienced by stroke informal caregivers, because 45% reported elevated levels of depression symptoms. Our caregivers' level of emotional distress was higher than a national sample of American women (24%),<sup>43</sup> higher than a sample of caregivers to individuals 2 years after experiencing a critical illness (31.9%),<sup>44</sup> and only slightly lower than caregivers to recently institutionalized individuals with Alzheimer's disease (48.3%).<sup>45</sup> This comparison suggests that caregivers to stroke survivors are experiencing a considerable amount of emotional distress warranting systematic evaluation and treatment by the health care system.

This study suggested that memory and comprehension BPS poststroke were strongly associated with depression symptoms in caregivers after controlling for other important factors. The other domains, apathy, depression, and irritability, did not make a significant contribution to caregiver depression, suggesting that, in

Table 2: Correlation Matrix of Independent and Dependent Variables

	1	2	3	4	5	6	7	8	9	10	11
Age (1)	1.00										
Time caring (2)	-.11	1.00									
Total behavioral symptoms (3)	-.15	.11	1.00								
Apathy (4)	-.15	.16	.83 <sup>†</sup>	1.00							
Depression (5)	-.07	.02	.73 <sup>†</sup>	.41 <sup>†</sup>	1.00						
Memory/comprehension (6)	-.08	.12	.76 <sup>†</sup>	.53 <sup>†</sup>	.44 <sup>†</sup>	1.00					
Irritability (7)	-.12	.06	.69 <sup>†</sup>	.44 <sup>†</sup>	.39 <sup>†</sup>	.45 <sup>†</sup>	1.00				
Caregiving assistance (8)	.03	.12	.44 <sup>†</sup>	.33 <sup>†</sup>	.36 <sup>†</sup>	.36 <sup>†</sup>	.37 <sup>†</sup>	1.00			
Lifestyle interference (9)	.07	.19	.56 <sup>†</sup>	.44 <sup>†</sup>	.52 <sup>†</sup>	.42 <sup>†</sup>	.40 <sup>†</sup>	.48 <sup>†</sup>	1.00		
Mastery (10)	-.04	-.14	-.25*	-.23*	-.32 <sup>†</sup>	-.15	-.08	-.18	-.35 <sup>†</sup>	1.00	
Depression symptoms (11)	-.08	.13	.57 <sup>†</sup>	.46 <sup>†</sup>	.46 <sup>†</sup>	.45 <sup>†</sup>	.27 <sup>†</sup>	.18	.56 <sup>†</sup>	-.56 <sup>†</sup>	1.00
Mean	60.8	21.5	41.1	2.2	2.8	2.0	2.2	47.4	28.8	19.3	15.8
SD	15.4	25.8	1.5	0.1	0.1	0.1	0.1	26.0	18.7	4.4	10.5

\* $P < .05$ .  
 $\dagger P < .01$ .

this sample, caregivers found stroke survivors' problems with memory and comprehension to be the most distressing. Recent work by Williamson et al<sup>46</sup> suggests that caregivers are more resentful of behaviors attributed to the person as opposed to being attributed to the illness. In stroke, future research may compare the impact of BPS in caregivers who do and do not attribute behavior changes to stroke. Overall in this study, higher levels of depression symptoms in informal caregivers were associated with more memory and comprehension BPS in stroke survivors, more lifestyle interference due to caregiving, less personal control, and providing less caregiving assistance.

The finding that providing less caregiving assistance was associated with more depression symptoms was not consistent with existing literature. By comparing the Pearson correlation between caregiving assistance and depression symptoms with the regression standardized  $\beta$  weight, we identified a suppression situation.<sup>42</sup> Specifically, a significant inverse relationship between caregiving assistance and depression symptoms was revealed after patient memory and comprehension BPS and caregiver lifestyle interference were held constant. These results suggest that if the aspects of providing care that are related to memory and comprehension BPS and lifestyle interference can be diminished, the remaining aspects of providing care will have a positive impact on caregiver mental health. This also supports the research that suggests aspects of providing care may be personally rewarding to and/or enjoyable for informal caregivers and, therefore, contribute to their emotional well-being.<sup>47,48</sup> This perspective is consistent with role theorists who suggest that if a role is personally valuable or important it contributes to emotional well-being.<sup>49</sup> Aspects of informal caregiving that have a positive impact on mental health should be explored further.

An alternative explanation is that caregivers providing lower levels of care experience more depression symptoms. For example, caregivers may feel guilty that they cannot provide the required level of care, perhaps due to their own physical or emotional ill health, resulting in more depression symptoms. Stemming from our theoretical approach, we assumed that higher levels of care would contribute to depression symptoms, but due to the cross-sectional nature of the current study we cannot test this causal relationship. Longitudinal or experimental research would be required to test the alternative hypothesis that poor emotional or physical health impedes caregivers' abilities to provide care.

The findings that higher levels of mastery and less lifestyle interference were associated with less depression symptoms are consistent with existing literature. Mastery had an inverse relationship with depression symptoms suggesting that caregivers with a greater sense of control over their life are less likely to experience depression symptoms holding other important factors constant. More lifestyle interference has also been associated with informal caregiver depression symptoms in a previous study.<sup>22</sup> A similar relationship has been observed between activity restriction, which is an element of caregiver burden and a subset of lifestyle interference, and informal caregiver distress.<sup>26,28</sup>

Contextual variables, age of caregiver, sex of caregiver, length of time providing care, education, living arrangements, employment status, and income were not significantly associated with caregiver depression. Relatively small sample size and homogeneity of the sample may account for some of these findings. Consistent with existing caregiving literature, 78% of the sample was women and 67% were elderly spouses. This lack of variability limits our ability to identify statistical relationships. Alternatively, these findings suggest the stress of

providing care may have a common effect on caregiver mental health regardless of the context of care.

Future research could entail developing and testing strategies to lessen the negative impact of BPS exhibited by the stroke survivor and to decrease the amount of lifestyle interference experienced by the caregiver. Three strategies emerge from this study. The first is to educate caregivers about the different types of BPS associated with stroke and to provide strategies for effective management of these symptoms where possible. Similar strategies have shown some benefits for caregivers to people with Alzheimer's disease.<sup>50-53</sup> In addition, strategies to allow caregivers to maintain participation in some valued activities and interests would be beneficial. This might include "lifestyle" respite opportunities where caregivers could obtain respite from home care services or adult day care to pursue something that is of value to them. Alternatively, caregivers could be encouraged and/or taught to enlist help from family members and friends that would give them time to pursue valued activities. A third strategy that would benefit both the stroke survivor and caregiver is to enhance clinical management of BPS associated with stroke. Pharmaceutical and/or behavioral interventions could be investigated to decrease the frequency and/or severity of BPS exhibited by stroke survivors.

This study adds to the existing stroke caregiving literature examining the relationship between BPS and informal caregiver depression symptoms. The measure of BPS used in this study was developed specifically for the stroke caregiving population and, as a result, should be more sensitive to the BPS more commonly observed in stroke survivors. This study also used factor analytically derived subscales to examine the differential effect of the domains of BPS on caregiver depression. In addition, we examined the relationship between BPS and informal caregiver depression symptoms after statistically controlling for other important aspects of the informal care situation (eg, level of care provided). Therefore, we are more confident that this relationship does exist.

There are some limitations to the current study. This study used a sample of convenience with a moderate response rate (66%), limiting our ability to generalize to all informal caregivers providing care in the community to stroke survivors. Future research should obtain a more representative sample by conducting a prospective cohort study of first-time stroke survivors, thereby allowing examination of these issues in a more representative sample of caregivers at the same stage of their caregiving career. We were not able to assess any potential nonresponse bias because we did not obtain any information from people who refused to participate. This would also limit the generalizability of our findings. In addition, these relationships were observed as they occurred across individuals and, as such, we were not able to control for all interindividual differences; our findings would be strengthened if we could test these relationships as they occur within individuals using longitudinal repeated assessment methods. Last, we did not interview stroke survivors, so we do not have any information about their illness, thereby limiting our ability to fully characterize this caregiving population.

## CONCLUSIONS

Caregivers experience more depression symptoms when they care for stroke survivors who exhibit more memory and comprehension BPS, experience more interference with participation in valued activities and interests, have less personal control or mastery, and provide lower levels of care. The finding that providing more assistance, after controlling for BPS and lifestyle interference, is associated with fewer depression symptoms, suggests that if the aspects of caregiving as-

sociated with BPS and lifestyle interference can be minimized, the remaining aspects of caregiving may have a beneficial impact on caregiver emotional well-being. Three strategies emerge from these findings: educational programs to help caregivers manage behavioral changes, lifestyle respite, and clinical management of BPS poststroke may yield the greatest benefit to informal caregivers to stroke survivors.

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### References

1. Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 2003;18:250-67.
2. Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist* 1995;35:771-91.
3. Han B, Haley WE. Family caregiving for patients with stroke. Review and analysis. *Stroke* 1999;30:1478-85.
4. Evans RL, Bishop DS, Haselkorn JK. Factors predicting satisfactory home care after stroke. *Arch Phys Med Rehabil* 1991;72:144-7.
5. Arai Y, Sugiura M, Washio M, Miura H, Kudo K. Caregiver depression predicts early discontinuation of care for disabled elderly at home. *Psychiatry Clin Neurosci* 2001;55:379-82.
6. Heart and Stroke Foundation of Ontario. Best practice guidelines for stroke care. Toronto: Heart and Stroke Foundation of Ontario Professional Education; 2005.
7. Gresham GE, Alexander D, Bishop DS, et al. American Heart Association Prevention Conference. IV. Prevention and Rehabilitation of Stroke. *Rehabilitation. Stroke* 1997;28:1522-6.
8. Pohjasvaara T, Erkinjuntti T, Ylikoski R, Hietanen M, Vataja R, Kaste M. Clinical determinants of poststroke dementia. *Stroke* 1998;29:75-81.
9. Wentzel C, Rockwood K, MacKnight C, et al. Progression of impairment in patients with vascular cognitive impairment without dementia. *Neurology* 2001;57:714-6.
10. Gaugler JE, Davey A, Pearlin LI, Zarit SH. Modeling caregiver adaptation over time: the longitudinal impact of behavior problems. *Psychol Aging* 2000;15:437-50.
11. Kreutzer JS, Gervasio AH, Camplair PS. Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Inj* 1994;8:211-30.
12. Anderson MI, Parmenter TR, Mok M. The relationship between neurobehavioural problems of severe traumatic brain injury (TBI), family functioning and the psychological well-being of the spouse/caregiver: path model analysis. *Brain Inj* 2002;16:743-57.
13. Anderson CS, Linto J, Stewart-Wynne EG. A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke* 1995;26:843-9.
14. Draper BM, Poulos CJ, Cole AM, Poulos RG, Ehrlich F. A comparison of caregivers for elderly stroke and dementia victims. *J Am Geriatr Soc* 1992;40:896-901.
15. Kinney JM. Stresses and satisfactions of family caregivers to older stroke patients. *J Appl Gerontol* 1995;14:3-21.
16. Schulz R, Tompkins CA, Rau MT. A longitudinal study of the psychosocial impact of stroke on primary support persons. *Psychol Aging* 1988;3:131-41.
17. Cameron JI. The impact of stroke survivors' behavioural and psychological symptoms on informal caregivers' mental health [PhD dissertation]. Toronto: Univ Toronto; 2004.
18. Yee JL, Schulz R. Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *Gerontologist* 2000;40:147-64.
19. Young RF, Kahana E. Specifying caregiver outcomes: gender and relationship aspects of caregiving strain. *Gerontologist* 1989;29:660-6.
20. Yates ME, Tennstedt S, Chang BH. Contributors to and mediators of psychological well-being for informal caregivers. *J Gerontol B Psychol Sci Soc Sci* 1999;54:12-22.
21. Nijboer C, Triemstra M, Tempelaar R, Sanderman R, van den Bos GA. Measuring both negative and positive reactions to giving care to cancer patients: psychometric qualities of the Caregiver Reaction Assessment (CRA). *Soc Sci Med* 1999;48:1259-69.
22. Cameron JI, Franche RL, Cheung AM, Stewart DE. Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer* 2002;94:521-7.
23. Bloom JR, Stewart SL, Johnston M, Banks P. Intrusiveness of illness and quality of life in young women with breast cancer. *Psycho-oncology* 1998;7:89-100.
24. Devins GM. Illness intrusiveness and the psychosocial impact of lifestyle disruptions in chronic life-threatening disease. *Adv Ren Replace Ther* 1994;1:251-63.
25. Devins GM, Binik YM, Hutchinson TA, Hollomby DJ, Barre PE, Guttman RD. The emotional impact of end-stage renal disease: importance of patients' perception of intrusiveness and control. *Int J Psychiatry Med* 1983;13:327-43.
26. Nieboer AP, Schulz R, Matthews KA, Scheier MF, Ormel J, Lindenberg SM. Spousal caregivers' activity restriction and depression: a model for changes over time. *Soc Sci Med* 1998;47:1361-71.
27. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;30:583-94.
28. Williamson GM, Shaffer DR, Schulz R. Activity restriction and prior relationship history as contributors to mental health outcomes among middle-aged and older spousal caregivers. *Health Psychol* 1998;17:152-62.
29. Flanagan JC. A research approach to improving our quality of life. *Am Psychol* 1978;33:138-47.
30. Periard ME, Ames BD. Lifestyle changes and coping patterns among caregivers of stroke survivors. *Public Health Nurs* 1993;10:252-6.
31. Li LW, Seltzer MM, Greenberg JS. Change in depressive symptoms among daughter caregivers: an 18-month longitudinal study. *Psychol Aging* 1999;14:206-19.
32. Williams A. What bothers caregivers of stroke victims? *J Neurosci Nurs* 1994;26:155-61.
33. Goode KT, Haley WE, Roth DL, Ford GR. Predicting longitudinal changes in caregiver physical and mental health: a stress process model. *Health Psychol* 1998;17:190-8.
34. Lawton MP, Moss M, Kleban MH, Glicksman A, Rovine M. A two-factor model of caregiving appraisal and psychological well-being. *J Gerontol B Psychol Sci Soc Sci* 1991;46:P181-9.
35. Oberst MT, Thomas SE, Gass KA, Ward SE. Caregiving demands and appraisal of stress among family caregivers. *Cancer Nurs* 1989;12:209-15.
36. Radloff LS. The CES-D Scale: a self-report depression scale for research in the general population. *Appl Psychol Meas* 1977;1:385-401.
37. Weissman MM, Sholomskas D, Pottenger M, Prusoff BA, Locke BZ. Assessing depressive symptoms in five psychiatric populations: a validation study. *Am J Epidemiol* 1977;106:203-14.
38. Pearlin LI, Schooler C. The structure of coping. *J Health Soc Behav* 1978;19:2-21.
39. Bibou-Nakou I, Dikaiou M, Bairactaris C. Psychosocial dimensions of family burden among two groups of carers looking after

- psychiatric patients. *Soc Psychiatry Psychiatr Epidemiol* 1997;32:104-8.
40. Stevens J. *Applied multivariate statistics for the social sciences*. 3rd ed. Mahwah: Lawrence Erlbaum Associates; 1996.
  41. Fairclough DL. *Design and analysis of quality of life studies in clinical trials*. New York: Chapman & Hall, 2002.
  42. Tabachnick BG, Fidell LS. *Using multivariate statistics*. 3rd ed. New York: HarperCollins College; 2001.
  43. Bromberger JT, Harlow S, Avis N, Kravitz HM, Cordal A. Racial/ethnic differences in the prevalence of depressive symptoms among middle-aged women: the Study of Women's Health Across the Nation (SWAN). *Am J Public Health* 2004;94:1378-85.
  44. Cameron JI, Herridge MS, Tansey CM, McAndrews MP, Cheung AM. Well-being in informal caregivers of survivors of the acute respiratory distress syndrome. *Crit Care Med* 2006;34:81-6.
  45. Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S. Long-term care placement of dementia patients and caregiver health and well-being. *JAMA* 2004;292:961-7.
  46. Williamson GM, Martin-Cook K, Weiner MF, et al. Caregiver resentment: explaining why care recipients exhibit problem behavior. *Rehabil Psychol* 2005;50:215-23.
  47. Folkman S. Positive psychological states and coping with severe stress. *Soc Sci Med* 1997;45:1207-21.
  48. Yamamoto-Mitani N, Sugishita C, Ishigaki K, et al. Development of instruments to measure appraisal of care among Japanese family caregivers of the elderly. *Sch Inq Nurs Pract* 2001;15:113-35; discussion 137-41.
  49. Martire LM, Stephens MA, Townsend AL. Centrality of women's multiple roles: beneficial and detrimental consequences for psychological well-being. *Psychol Aging* 2000;15:148-56.
  50. Ostwald SK, Hepburn KW, Caron W, Burns T, Mantell R. Reducing caregiver burden: a randomized psychoeducational intervention for caregivers of persons with dementia. *Gerontologist* 1999;39:299-309.
  51. Garand L, Buckwalter KC, Lubaroff D, Tripp-Reimer T, Frantz RA, Ansley TN. A pilot study of immune and mood outcomes of a community-based intervention for dementia caregivers: the PLST intervention. *Arch Psychiatr Nurs* 2002;16:156-67.
  52. Gerdner LA, Buckwalter KC, Reed D. Impact of a psychoeducational intervention on caregiver response to behavioral problems. *Nurs Res* 2002;51:363-74.
  53. Mittelman MS, Ferris SH, Shulman E, Steinberg G, Levin B. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. *JAMA* 1996;276:1725-31.