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Stroke survivor and informal caregiver perceptions of post-stroke depressive symptoms

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BACKGROUND

Stroke is the primary cause of long-term disability in the United States (V. L. Roger et al., 2011). Although stroke causes a myriad of physical, familial and societal burdens, post-stroke depressive symptoms are the most common of the mental sequela associated with surviving a stroke (K. Narushima & Robinson, 2002; Robert G. Robinson & Spalletta, 2010). Symptoms in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) for depression include: depressed mood, lack of interest in previously enjoyable activities, changes in eating patterns, changes in sleeping patterns, apathy, restlessness, feeling slowed down, fatigue, feelings of worthlessness, excessive or inappropriate guilt, diminished ability to think or concentrate, indecisiveness, and recurrent thoughts of death (American Psychiatric Association, 1994). A diagnosis of major depression requires that a person have five or more of these symptoms for at least a 2-week period, and at least one symptom must be the depressed mood or lack of interest in previously enjoyable activities. Post-stroke depression is an episode of major or minor depression as defined in the DSM-IV that commonly occurs in the sub-acute recovery phase, three to six months post stroke (Whyte & Mulsant, 2002). Post-stroke depression is a related but separate illness from the stroke and is treatable. Post-stroke depressive symptoms are extremely deleterious to the stroke survivor and can inhibit or delay recovery (Gillen, Tennen, McKee, Gernert-Dott, & Affleck, 2001; Jorgensen, Engstad, & Jacobsen, 2002; Pohjasvaara, Vataja, Leppavuori, Kaste, & Erkinjuntti, 2001) and even increase stroke survivor mortality (Almeida & Xiao, 2007; Jorge, Robinson, Arndt, & Starkstein, 2003; Williams, Ghose, & Swindle, 2004).

There is some debate in the literature, but consensus remains that post-stroke depression is often undiagnosed by healthcare providers (Dafer, Rao, Shareef, & Sharma, 2008; Eriksson et al., 2004; Ruskin, 2003; Salter et al., 2011; Ytterberg, Anderson Malm, & Britton, 2000). There are a variety of reasons that post-stroke depressive symptoms may be overlooked and thus not treated. Okon et al. (2004) found that one reason is the failure of health care providers (HCP) to assess for depressive symptoms. Some stroke survivors deliberately hide depressive symptoms from their HCP, so purposive screening is essential (Kessler et al., 2003; Kopta, Howard, Lowry, & Beutler, 1994). Another reason for the lack of diagnosis and treatment for post-stroke depression is that post-stroke depressive symptoms are difficult to distinguish from other stroke sequelae and may be misinterpreted by the HCP (National Institute of Mental Health, 2002). Additionally, stroke survivors may have difficulty recognizing their own depressive symptoms. If the stroke survivors are unable to recognize their depressive symptoms, they are less likely to seek treatment for the symptoms (Okon, et al., 2004).

The majority of stroke survivors today return home from the hospital with the aid of a family caregiver (McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Rosamond et al., 2007). Family caregivers may advocate for stroke survivors by recognizing and reporting the stroke survivor's depressive symptoms to the stroke survivor's HCP. However, the caregiver

must first be able to identify post-stroke depressive symptoms and believe that the symptoms are serious enough to be worth advocating for treatment for the stroke survivor. Misconceptions regarding post-stroke depressive symptoms among stroke survivors and informal caregivers may delay treatment seeking.

A review of the literature yielded little empirical evidence regarding lay knowledge or perceptions of depressive symptoms in adults. Bunde (2009) examined lay perceptions of purely somatic and combined cognitive and somatic depressive symptoms among the general population. He concluded that adults were generally able to identify depression, especially when both cognitive and somatic symptoms were present, and the symptoms were often attributed to stressful life events and old age. No studies could be found examining the ability of lay persons to recognize depressive symptoms in the presence of co-morbid illness, such as stroke, where rates of depression are substantially higher than in otherwise healthy populations and may be difficult to distinguish from cognitive or mood changes that may result from stroke. In addition, there is no available information how stroke survivors or other lay persons perceive or interpret post-stroke depressive symptoms. The Common Sense Model of Illness Representation (CSM) (Leventhal, Brissette, & Leventhal, 2003; Leventhal, Meyer, & Nerenz, 1980) has been used extensively to guide the exploration of lay illness and symptom perception in both chronic and psychiatric conditions related to symptom or illness 'identity' (i.e. the self-diagnosis label for the symptoms), 'cause' of the symptoms, personal 'control' of the symptoms, 'consequences' of the symptoms or illness, and 'timeline' (acute vs. chronic or cyclical). The CSM was used to guide this exploration of caregivers' and stroke survivors' general knowledge, recognition and perceptions of stroke survivors' depressive symptoms in hopes of directing patient and family education on post-stroke depressive symptoms by neuroscience nurses.

METHODS

A descriptive, cross-sectional design was used to examine caregiver and stroke survivor knowledge, recognition and representation of stroke survivor depressive symptoms during the sub-acute recovery period (3–6 months post stroke). Institutional review board approval was gained from Emory University and all participants gave written informed consent. A convenience sample of stroke survivor and caregiver participants was recruited from seven hospitals or physical rehabilitation sites in the Atlanta metro area. Stroke survivors eligibility criteria were: at least 50 years old, 3–6 months post ischemic or hemorrhagic stroke, did not have global, receptive or expressive aphasia to the extent that they could not sign consent or answer study questions, had a Mini Mental State Exam Scores ≥ 21 (Folstein, Folstein, & McHugh, 1975a), and discharged home after rehabilitation. Caregivers were informal and unpaid, usually friends or family members of the stroke survivors, who were at least 18 years of age. Using a series of questionnaires, stroke survivors and caregivers were separately interviewed later at the stroke survivor's home once the stroke survivor was three to six months post-stroke. Data were collected from 44 stroke survivors and their informal caregivers.

Instruments

The post-stroke Knowledge of Depressive Symptoms Scale (KDSS) is a 24-item, investigator-developed instrument to measure caregivers' and stroke survivors' ability to identify depressive symptoms. The first 20 items were chosen based on available measures of depression and on the DSM-IV criteria for major depression. If respondent correctly identified the symptoms as a one of depression they were given credit for that response. Five of the 20 listed symptoms were not depressive symptoms so were reverse coded. Therefore, one point per question was obtained as either correct or incorrect with a maximum score is 20. The KDSS has *a priori* and *posteriori* content validity. Three clinical experts: a nurse

practitioner, a clinical nurse specialist and a psychiatrist with expertise in late life depression, and a measurement specialist determined item content validity. A calculated content validity index of $>.80$ indicated that the items were valid (Waltz, Strickland, & Lenz, 1986). Reliability was adequate with Kuder Richardson Formula 20 alphas (KR-20) of $.77$ for the stroke survivor and $.86$ for the caregiver.

This scale contains four additional questions assessing whether any information about depression after stroke had been given to stroke survivors or their caregivers while the stroke survivor was in the hospital or rehabilitation center. These questions were analyzed for descriptive purposes only and were not included as part of the overall score.

The Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) was used to measure stroke survivor and caregiver recognition of depressive symptoms in the stroke survivor. The CES-D is a 20-item Likert-type scale that has been used extensively to measure depression in both healthy and non-healthy populations, including stroke survivors (Pickard, Dalal, & Bushnell, 2006; P. R. Roger & Johnson-Greene, 2009). Summed item scores range from 0–60 and scores of ≥ 16 indicate a need for evaluation for possible clinical depression (Radloff, 1977). Internal consistency reliabilities for both uses of the CES-D were $.85$ for caregivers reporting their perceptions of the stroke survivors' mood; $.78$ for stroke survivors reporting about their own mood.

The five components of illness representation were measured using the Symptom Perception Questionnaire for Post-stroke Depressive Symptoms (SPQ), a version of the Revised Illness Perception Questionnaire (IPQ-R) that was adapted with permission (Moss-Morris et al., 2002). The IPQ-R was developed specifically for the Common Sense Model and contains subscales for each domain of illness representation (identity, cause, consequences, personal control/cure, timeline). Persons completing the form are given a statement regarding how they perceive their illness and are asked to respond using a Likert scale of 'strongly agree' to 'strongly disagree' format. The IPQ-R has been used to measure a wide range of illnesses including mental illness (Lobban, Barrowclough, & Jones, 2003), and spouses' beliefs about their partners' illness (Weinman, Petrie, Sharpe, & Walker, 2000).

The SPQ used in this study contains 55 items and 8 subscales: symptom identity, cause, timeline acute-chronic, timeline cyclical, consequences, control, cure, and illness coherence. The identity subscale offers six explanations, or identities, for the cluster of depressive symptoms the stroke survivor is experiencing. One of the identity questions is open ended. Responses to these identities are Yes/No/Unsure format. Neither the identity or cause subscale can be scored, but are used for descriptive purposes. The remainder of the subscales are comprised of 32 questions using the same traditional 5-point Likert scale 'strongly agree' to 'strongly disagree' response categories as the IPQ-R. Maximum SPQ total score is 160 with higher scores indicating more negative symptom perception (i.e. longer or more cyclical timeline, more severe consequences, less control, less potential for treatment or cure, less illness coherence). Overall reliabilities for the 32 item SPQ containing the six subscales of timeline acute-chronic, timeline cyclical, consequences, control, treatment, and illness coherence were adequate with Cronbach's alphas for the stroke survivor of $.83$ and for the caregiver of $.80$.

Individual and clinical characteristics were collected by self-report for both caregivers and stroke survivors, except for type and location of stroke which were obtained from the medical record. These characteristics included demographic variables and characteristics of the post stroke situation.

Stroke survivor functional ability was measured in order to describe the sample of stroke survivors using the Barthel Index (BI) (Mahoney & Barthel, 1965). The BI is a 10-item scale

frequently used to assess stroke survivor functional ability to perform ADLs. Activities are scored according to how much help is required for the stroke survivor to perform the activity, with scores for each item ranging from 'unable to perform the activity' to 'can perform the activity independently'. The instrument is scored by summing the responses. Maximum score is 100 and higher scores indicate more independence. Data for the BI were provided by the caregiver. BI scores using data obtained from relatives of stroke survivors correlated with data obtained from occupational therapists, providing support that caregiver report is an acceptable method of collecting data on this variable (Wyller, Sveen, & Bautz-Holter, 1995). Cronbach's alpha for the Barthel index in this study was .85.

All stroke survivors were screened for cognitive ability with the Mini Mental Status Exam (MMSE), a commonly used, quick (5–10 minutes) screening tool for mental status (Folstein, Folstein, & McHugh, 1975b). The maximum score is 30. The MMSE is commonly used in stroke research for purposes of screening and assessing cognitive impairment in stroke survivors (Kenji Narushima, Chan, Kosier, & Robinson, 2003; Toso et al., 2004; Winstein et al., 2003). The MMSE cut point score of ≤ 21 was chosen based on literature suggesting that ratings of MMSE scores of 26–30 are adequate and 21–25 are borderline for dementia in older adults (Launer, Dinkgreve, Jonker, Hooijer, & Lindeboom, 1993; Siu, 1991). Because stroke survivors tend to score lower on the MMSE than the normal population (Launer, et al., 1993), borderline cases were enrolled to increase the generalizability of the findings.

Data Analysis

Descriptive statistics were computed for sample characteristic and both the caregiver's and stroke survivor's knowledge, recognition and representations of the stroke survivor's depressive symptoms. Independent t-tests were calculated to determine differences in depression knowledge scores for those caregivers and stroke survivors who received information regarding post-stroke depression while the stroke survivor was in the hospital of rehabilitation center with those who did not. Frequencies were calculated for depression symptom recognition. Tertiles of potential scores were computed for ease of interpretation of the six subscales of the SPQ: timeline acute-chronic, timeline cyclical, consequences, control, treatment, and illness coherence.

RESULTS

Descriptive statistics for stroke survivor and caregiver demographic and clinical characteristics are presented in Table 1. Stroke survivors were approximately 3–6 months post-stroke, cognitively intact (MMSE score range 22–30), and on average were late, middle age (ages ranged 50–84 years). Exactly half of all stroke survivors were male. They were either Caucasian or African American, primarily well-educated, and married. Most stroke survivors had suffered an ischemic stroke and were highly physically functional (Barthel Index range 20–100). Just over half of stroke survivors had left hemisphere involvement.

Caregivers were on average approximately 10 years younger than stroke survivors (range 18–83 years), and they were primarily female, married, and spouses or daughters of the stroke survivor. Caregivers mirrored the stroke survivors in ethnicity, and most were highly educated. Caregivers most often lived with the stroke survivor.

Knowledge of Depressive Symptoms

Caregivers and stroke survivors demonstrated moderate knowledge of depressive symptoms (KDSS) overall. Stroke survivors, on average, scored 13.64 ± 3.98 out of 20 items or 69% and caregivers on average were able to identify 14.81 ± 4.57 of the 20 symptoms or 74%. Caregivers had most difficulty identifying symptoms such as 'difficulty recalling things'

(43% failed to recognize), 'feelings of guilt' (36%), and 'feelings of worthlessness' (31.8%). Stroke survivors had most difficulty identifying 'difficulty recalling things' (54%), 'difficulty concentrating' (43.2%), 'difficulty making decisions' (38.6%), feelings of guilt (38.6%), and 'thinking a lot about dying' (38.6%) as potential depressive symptoms. Additionally, 43.2% of caregivers and 38.6% of stroke survivors incorrectly attributed 'hair loss' to depression. However, 84.1% of caregivers and 72.7% of stroke survivors correctly identified 'general feelings of sadness' and 79.5% of caregivers and 70.5% of stroke survivors correctly identified 'withdrawal from activities of interest' as depressive symptoms.

Stroke survivors and caregivers were also asked whether they had received either verbal or written information about post-stroke depression while the stroke survivor was in the hospital or rehabilitation setting. Stroke survivors who had received and read written materials given to them ($n=10$) had higher scores on the KDSS ($M = 15.2 \pm 2.66$) than stroke survivors who did not read the materials given to them ($n=7$; $x = 11.28 \pm 5.12$) ($t = 2.07$, $df = 15$, $p=.06$). There were no significant differences in depression knowledge for stroke survivors or caregivers who did or did not receive verbal information or for caregivers who read written information.

Depressive Symptom Recognition

Frequency of recognized symptoms by caregivers and stroke survivors are presented in Table 2. The mean CES-D score for stroke survivors fell below the commonly used cut off of ≥ 16 indicating a need for further evaluation for depression (Table 3), but one quarter ($n=11$) of stroke survivors in the sample scored ≥ 16 . Among stroke survivors, the most frequently recognized depressive symptoms were 'feeling like everything was an effort', 'restless sleep', 'difficulty concentrating' and 'talking less than usual'. Caregivers most frequently believed that the stroke survivor was 'feeling like everything was an effort', had 'restless sleep' and 'felt sad' and 'felt depressed' at least some of the time. The most frequently recognized symptoms among the group of stroke survivors who scored above ≥ 16 on the CES-D ($n=11$) were 'being bothered by things that don't usually bother him/her' (91%), 'feeling everything he/she did was an effort' (91%), and 'restless sleep' (82%). The most frequently recognized symptoms among caregivers evaluating the stroke survivor with CES-D scores above 16 ($n=11$) were the stroke survivor's 'inability to shake off the blues' (91%), not 'feeling as good as other people' (91%), and not 'enjoying life' (91%).

Perceptions of Depressive Symptoms

Descriptive statistics of both the caregivers' and stroke survivors' representations of the stroke survivors' depressive symptoms are presented in Table 3 with the exception of the identity and cause subscales. There are no pre-determined cut points for representations of symptoms. Therefore, using tertiles as a basis for interpretation of low, moderate, or high severity, both stroke survivors and caregivers perceived that the stroke survivor's depressive symptoms overall would have low severity on the stroke survivor's life. However when examining the SPQ individual subscales for the depressive symptoms of timeline acute/chronic, timeline cyclical, consequences, control, treatment, and illness coherence for those stroke survivors who scored 16 on the CES-D, both stroke survivors and caregivers perceived that the depressive symptoms were moderately cyclical in nature, had moderate consequences and were moderately concerned about the ability to treat the symptoms.

For the identity of symptoms and cause of symptoms subscales, caregivers labeled the stroke survivor's depressive symptoms as the stroke survivor being 'upset' (57%), 'depressed' (45%), 'angry' (38%), or 'feels sorry for himself' (36%). Caregivers believed the depressive symptoms were caused by the 'stroke' (86%), 'stress or worry' (62%), 'aging'

(43%), or 'depression' (41%). When the subset of dyads with caregivers perceiving high levels of depressive symptoms in the stroke survivor (CES-D \geq 16) was examined (n=11), the majority of caregivers (73%) labeled the stroke survivor's depressive symptoms as 'depression'.

Stroke survivors overall were much less clear as to an identity for their symptoms. Ten stroke survivors indicated they thought the symptoms meant they were 'depressed' (23%), eight believed they were 'upset' (19%), and eight indicated that they were 'frustrated at not being able to do what they could before the stroke' (19%). When the subset of dyads with stroke survivors indicating high levels of depressive symptoms (CES-D \geq 16) was examined (n=11), eight (73%) stroke survivors labeled their depressive symptoms as depression. More than one-third of stroke survivors believed their depressive symptoms were caused by the 'stroke', 'stress or worry', or 'family problems'.

DISCUSSION

In the aftermath of a stroke, stroke survivors and informal caregivers have to monitor not only physical symptoms for the stroke survivor's health, but those that may indicate a mood disorder as well. However, in this sample 75% of stroke survivors did not recall receiving any written materials about post-stroke depression while in the acute-care or rehabilitation setting. In general, caregivers and stroke survivors demonstrated moderate knowledge of depressive symptoms. They were fairly knowledgeable about the most important symptoms of generalized sadness and anhedonia as being symptoms of depression. Areas for improvement in knowledge include clarifying that difficulty recalling things, feelings of guilt and worthlessness, difficulty concentrating, difficulty making decisions, and thinking a lot about dying are contributing symptoms of depression. It is important to stress, however, that these symptoms may only be indicative of depression when presented as a part of a cluster with other depressive symptoms. No one symptom individually determines depression and careful assessment is needed to the underlying reason for a symptom (i.e. depression vs. problems in decision making from the stroke). Additionally, clarification regarding misconceptions, such as hair loss as a depressive symptom, may be helpful. Poor individual knowledge about depressive symptoms underscores the need for education of both the stroke survivor and caregiver about depression. The need for caregiver education may be particularly important for caregivers caring for stroke survivors with more functional impairment and communication problems.

Consistent with previous literature on post-stroke depression, one quarter of the stroke survivors in this sample had high levels of depressive symptoms (Hackett, Yapa, Parag, & Anderson, 2005; R. G. Robinson, 2003). Some of the most commonly recognized symptoms among the whole sample, 75% of whom are not depressed, are somatic symptoms that may be part of the stroke itself. For example "feeling like everything was an effort" may be related to the true effort it takes to overcome functional disability and "restless sleep" may be related to sleep apnea or other sleep disorders that are common among stroke survivors. Future research could explore the frequency and severity of these particular symptoms, along with identifying if they coincide with other symptoms of depression, in order to discern whether they represent true post-stroke depressive symptoms or symptoms of other common stroke related sequelae such as post-stroke fatigue. However, mood symptoms such as "feeling sad" and "feeling depressed" are not normal somatic responses to the stroke itself and may be more indicative of post-stroke depression. "Talking less than usual" may be indicative of depressed mood rather than functional disability among this group because stroke survivors with aphasia were excluded from this study. However, speech and language difficulties should be assessed among stroke survivors to rule out functional impairment before attributing these symptoms to depression.

This sample of stroke survivors and caregivers also did not perceive the depressive symptoms to be severe. Again, the fact that most stroke survivors did not exhibit high levels of depressive symptoms probably explains this phenomenon. However, among those stroke survivors with high depressive symptoms, the perceived severity of the depressive symptoms was higher for cyclical timeline, consequences on the stroke survivor's life, and the depressive symptoms they were experiencing were perceived as difficult to treat. When compared to patients' perceptions of lower back pain, scores for these domains were similar in their severity (Foster et al., 2008).

In neurological diseases including some cases of stroke, the brain injury may preclude the stroke survivor's ability to accurately analyze his/her mood or abilities. Healthcare providers often use family caregivers as advocates or proxies during assessment of the stroke survivor. Among the subset of stroke survivors with high depressive symptoms, stroke survivors and caregivers differed on the most commonly recognized symptoms. Stroke survivor symptoms centered on their apparent frustration and exhaustion post-stroke recognizing symptoms such as irritability, feeling like everything is an effort and restless sleep. Among the caregivers who perceived high levels of depressive symptoms in the stroke survivor for whom they were caring, caregivers most commonly recognized the mood symptom of an "inability to shake off the blues". Interestingly, the other two most commonly recognized symptoms "not feeling as good as other people", and "not enjoying life", are similar to previously reported lay perceptions of those with a handicap. Phillips (1990) explains that persons with physical handicap often believe they are perceived by others as "damaged goods" (p. 850). It is possible that caregivers perceived that the physical impairment caused by the stroke would inhibit the stroke survivor from fully enjoying life due to their handicap. The stroke survivors in this study were highly physically functional but many had minor residual impairment. It is important for healthcare providers to understand that caregiver proxies may inadvertently project their biases when reporting about the stroke survivor's mood and abilities. Therefore, nurses and other healthcare providers should be sure to gather information regarding the stroke survivor's mood from both the stroke survivor and family caregiver, if available, for the most complete assessment.

Recent guidelines regarding the rehabilitation of stroke survivors recommend that nurses assess stroke patients for depressive symptoms, refer those whom are at risk for depression to a neuropsychologist or psychiatrist, and educate stroke survivors and their families about post-stroke depression and treatment options (Miller et al., 2010). It is recommended, when choosing a screening tool for depressive symptoms among stroke survivors, those with less somatic and more mood symptoms, such as the Geriatric Depression Scale or the CES-D would be appropriate (P. R. Roger & Johnson-Greene, 2009). Education about depressive symptoms is also a key role of the neuroscience nurse. However, the abundance of information that is presented to stroke survivors and their informal caregivers during a brief inpatient hospitalization and/or rehabilitation stay combined with anxiety about the stroke do not lead to ideal learning conditions. In the present study, those stroke survivors who were given written materials, and actually read them, had higher levels of knowledge. Therefore, distributing written or pictorial information that the stroke survivor and caregiver can review at their leisure combined with a thorough explanation by the nurse may be a more effective method for educating stroke survivor and families about post-stroke depression. Educational materials should include information about 1) the signs and symptoms of post-stroke depression, 2) the fact that the whole cluster of symptoms must be examined as a whole, that one or two depressive symptoms may have other stroke-related causes, 3) the cause, consequences, timeline, of the symptoms, and 4) options, availability, and benefits of treatment for post-stroke depression. National organizations such as the American Heart Association and National Stroke Association have educational materials available to stroke survivors and caregivers in a variety of formats including paper and via the World Wide

Web. If possible, nurses should be sure to read through any written materials aloud with the stroke survivor and caregiver in case the stroke survivor has a low literacy level or is unable to read the information due to low-vision. In addition, neuroscience nurses can explain that post-stroke depressive symptoms may arise after the stroke survivor has left the rehabilitation setting. It is important to note that three quarters of stroke survivors with high levels of depressive symptoms did attribute the symptoms to potential depression. In this case, neuroscience nurses can encourage stroke survivors and caregivers to report any symptoms of potential depression to the stroke survivor's healthcare provider. Due to their 24/7 proximity with stroke patients in the acute and rehabilitation setting, neuroscience nurses are in a unique position to assess and educate stroke survivors and their family members about post-stroke depression and clarify misconceptions. Through patient and family education, neuroscience nurses have the potential to make an enormous positive impact in the stroke survivors' mood and quality of life well past the time they spend in the acute care setting.

This is the first known study to comprehensively examine the factors associated with caregiver and stroke survivor recognition and perception of stroke survivor depressive symptoms. It was theoretically based, using the Commonsense Model of Self-Regulation as a guide to understanding symptom perception. However, this study is not without limitations. The sample size was small, although sufficiently powered. Consistent with previous literature, about one quarter of the stroke survivors had depressive symptoms. This sample may differ than the average stroke population in that they were all cognitively intact, overall highly educated, highly functional, had few to moderate comorbidities on average. It is possible that these factors played a role in the stroke survivors' ability to recognize understand their depressive symptoms. Future studies should examine stroke survivor and caregiver perceptions of post-stroke depressive symptoms in less functional stroke survivors.

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Table 1

Demographic and Clinical Characteristics of the Sample (N = 44 dyads)

Demographic / Clinical Factors	Caregiver <i>n</i> (%)	Caregiver <i>M</i> (<i>SD</i>)	Stroke Survivor <i>n</i> (%)	Stroke Survivor <i>M</i> (<i>SD</i>)
Age (years)		58.73 (15.15)		68.52 (8.87)
Gender				
Male	11 (25)		22 (50)	
Female	33 (75)		22 (50)	
Race				
Black or African American	23 (52.3)		24 (54.5)	
Caucasian	20 (45.5)		20 (45.5)	
Multiethnic	1 (2.3)		0 (0)	
Marital Status				
Married	32 (72.7)		25 (56.8)	
Never Married	6 (13.6)		3 (6.8)	
Widowed	1 (2.3)		10 (22.7)	
Divorced	5 (11.4)		6 (13.6)	
Education				
Some high school	4 (9.1)		4 (9.1)	
High school graduate	14 (31.8)		8 (18.2)	
At least some college	26 (59)		32 (72.7)	
Caregiver and Stroke Survivor				
Living Arrangement				
Live together	33 (75.0)			
Live separate	11 (25.0)			
Relation of caregiver to stroke survivor				
Spouse	25 (56.8)			
Adult Child	11 (25)			
Other Relative	3 (6.8)			
Friend	5 (11.4)			
Stroke type ^a				
Ischemic			39 (90.7)	
Hemorrhagic			4 (9.3)	
Lesion location				
Right hemisphere			20 (45.5)	
Left hemisphere			24 (54.5)	
Stroke survivor functional ability (BI)				87.95 (16.61)
Stroke survivor MMSE score				27.37 (2.30)

Note. BI = Barthel Index; MMSE = Mini Mental State Exam;

^a n=43.

Table 2

Depressive Symptoms Recognized by Caregivers and Stroke Survivors (N=44 dyads)

Stroke Survivor Depressive Symptom	Caregiver Recognition <i>n</i> (%)	Stroke Survivor Recognition <i>n</i> (%)
Felt everything he/she did was an effort	31 (70.5)	31 (70.5)
Restless sleep	25 (56.8)	23 (52.3)
Trouble concentrating	21 (47.7)	21 (47.7)
Talked less than usual	20 (45.5)	21 (47.7)
Bothered by things that don't usually bother	20 (45.5)	20 (45.5)
Felt happy ^a	19 (43.2)	18 (40.9)
Felt depressed	22 (50.0)	17 (38.6)
Could not get going	21 (47.7)	17 (38.6)
Felt sad	22 (54.5)	16 (36.4)
Felt lonely	21 (47.7)	15 (34.1)
Felt hopeful about the future ^a	20 (45.5)	15 (34.1)
Did not feel like eating	15 (34.1)	15 (34.1)
Felt he/she was just as good as others ^a	17 (38.6)	14 (31.8)
Felt he/she could not shake the blues	15 (34.1)	12 (27.3)
Enjoyed life ^a	19 (43.2)	10 (22.7)
Felt fearful	12 (27.3)	9 (20.5)
Had crying spells	8 (18.2)	7 (15.9)
Thought his/her life had been a failure	5 (11.4)	7 (15.9)
Felt people were unfriendly	6 (13.6)	5 (11.4)
Felt people disliked him/her	5 (11.4)	1 (2.3)

Note. Recognition of negative symptoms occurring at least 'some of the time';

^aRecognition of positive symptoms less than 'most or all of the time'

Table 3

Descriptive Statistics Major Study Variables (N = 44 dyads)

Instruments	<i>M (SD) Overall</i>	<i>M (SD) SS CESD ≥ 16 (n=11)</i>	SPQ Tertile Overall; CES-D ≥ 16	Potential Range
CES-D – Stroke survivor	10.80 (7.40)	21.73 (3.95)		
CES-D – Caregiver perception of stroke survivor	12.18 (8.60)	16.73 (11.51)		
SPQ Caregiver ^{a,b}	49.69 (8.27)	53.45 (9.41)	1;1	32–160
SPQ – Timeline Acute/Chronic ^b	8.55 (2.87)	9.55 (3.53)	1;1	6–30
SPQ – Timeline Cyclical	7.43 (2.48)	11.72 (2.90)	1;2	4–20
SPQ – Consequences ^b Mild/severe	10.26 (3.37)	15.45 (4.44)	1;2	6–30
SPQ – Control ^b controllable/ not controllable	8.90 (2.91)	8.82 (3.25)	1;1	6–30
SPQ – Treatment ^b treatable/ not treatable	7.74 (2.54)	12.45 (3.11)	1;2	5–25
SPQ – Illness Coherence ^b understand illness / do not understand illness	6.81 (2.75)	9.73 (2.45)	1;1	5–25
SPQ – Stroke Survivor ^{a,c}	47.95 (8.82)	53.91 (8.49)	1;1	32–160
SPQ – Timeline Acute/Chronic ^c	8.00 (2.87)	8.73 (3.32)	1;1	6–30
SPQ – Timeline Cyclical	6.81 (2.28)	12.64 (2.62)	1;2	4–20
SPQ – Consequences ^c Mild/severe	10.12 (2.38)	16.00 (2.00)	1;2	6–30
SPQ – Control ^c controllable/ not controllable	8.65 (2.49)	9.82 (3.12)	1;1	6–30
SPQ – Treatment ^c treatable/ not treatable	7.37 (2.38)	14.27 (1.85)	1;2	5–25
SPQ – Illness Coherence ^c understand illness / do not understand illness	7.86 (2.91)	11.00 (2.97)	1;1	5–25

Note. SPQ Tertile= potential scores divide into thirds, 1= mean is in lowest tertile scores, 3= mean is in highest tertile scores;

^aSPQ = Symptom Perception Questionnaire and contains eight subscales: identity, cause, timeline acute chronic, timeline cyclical, treatment, personal control, consequences and illness coherence. Identity and cause subscales are not scored, generate frequency data only and are not included in overall scores. All other subscales higher score means worse severity (i.e. longer timeline or less control etc.)

^bn = 42 dyads.

^cn = 43 dyads.