

# Level of Caregiver Burden in Jamaican Stroke Caregivers and Relationship between Selected Sociodemographic Variables

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## ABSTRACT

**Objective:** This study sought to determine the level of caregiver burden present in Jamaican stroke caregivers and to investigate the relationship between caregiver burden and selected sociodemographic variables.

**Method:** The Bakas Caregiving Outcomes Scale and a demographic sheet were administered to the caregivers. The stroke survivors completed the Barthel Index and the Geriatric Depression Scale. Interview administration was used for all tools.

**Results:** A total of 48 caregivers with their stroke survivors participated in this study. Preliminary findings showed that caregivers of stroke survivors in Jamaica are experiencing some level of burden with scores ranging from 21 to 62 (mean =  $43.64 \pm 8.73$ ). Lower burden scores indicate greater burden. Caregivers of female stroke survivors had significantly greater levels of burden ( $43.5 \pm 8.87$ ) than those caring for male survivors [ $44.4 \pm 8.3$ ] ( $p = 0.03$ ). There were no significant correlations between caregiver burden and age of the stroke survivor; however, a low correlation was found between depression and caregiver burden ( $r = -0.33$ ,  $p = 0.02$ ). Female survivors were found to have significantly higher levels of depression than males ( $16.72 \pm 6.21$  vs  $11.34 \pm 7.31$ ,  $p < 0.01$ ) and caregivers of survivors who had higher depression scores experienced more burden.

**Conclusion:** Preliminary findings point to depressive symptoms and functional status in the stroke survivor as being a significant contributor to caregiver burden; however, further data collection and analysis need to be completed before more definitive conclusions can be made.

**Keywords:** Bakas Caregiving Outcomes Scale, caregiver burden, stroke

# Nivel de Sobrecarga del Cuidador de Casos de Derrame Cerebral en Jamaica y la Relación entre Variables Sociodemográficas Seleccionadas

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## RESUMEN

**Objetivo:** Este estudio tuvo por objeto determinar el nivel de sobrecarga del cuidador de casos de derrame cerebral en Jamaica y la relación entre variables sociodemográficas seleccionadas.

**Método:** La escala BCOS de resultados para la evaluación de la sobrecarga del cuidado a pacientes (del inglés, Bakas Caregiving Outcome Scale), así como una hoja demográfica, fueron aplicadas a los cuidadores. Los sobrevivientes de accidentes cerebrovasculares respondieron el Índice de Barthel y la Escala de Depresión Geriátrica. La aplicación de entrevistas fue utilizada para todos los instrumentos.

**Resultados:** Un total de 48 cuidadores con sus sobrevivientes de accidente cerebrovascular, participaron en este estudio. Los resultados preliminares mostraron que los cuidadores de sobrevivientes de accidente cerebrovascular en Jamaica están experimentando cierto nivel de carga con puntuaciones que oscilan entre 21 y 62 (media =  $43.64 \pm 8.73$ ). Las puntuaciones más bajas de carga indican mayor carga. Los cuidadores de las mujeres sobrevivientes de accidente cerebrovascular tuvieron niveles de carga significativamente mayores ( $43.5 \pm 8.87$ ) que aquellos a cargo de los sobrevivientes hombres [ $44.4 \pm 8.3$ ] ( $p = 0.03$ ). No hubo correlaciones significativas entre la carga de

*los cuidadores y la edad de los sobrevivientes de accidentes cerebrovasculares. Sin embargo, se encontró una baja correlación entre depresión y carga del cuidador ( $r = -0.33$ ,  $p = 0.02$ ). Se halló que las sobrevivientes presentaban niveles de depresión significativamente mayores que los sobrevivientes hombres ( $16.72 \pm 6.21$  vs  $11.34 \pm 7.31$ ,  $p < 0.01$ ), y los cuidadores de sobrevivientes que tuvieron puntuaciones de depresión mayores experimentaron más carga.*

**Conclusión:** *Los hallazgos preliminares apuntan a los síntomas depresivos y el estado funcional en el sobreviviente de accidente cerebrovascular como aspectos importantes que contribuyen a la carga del cuidador. Sin embargo, se requiere recoger y analizar más datos antes de que se pueda llegar a conclusiones más definitivas.*

**Palabras claves:** Escala BCOS de resultados, carga del cuidador, accidente cerebrovascular

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## INTRODUCTION

Stroke management is a complex process requiring intervention at multiple levels physiologically, psychologically, socially and environmentally (1). Stroke caregivers have to deal with not only stroke patients' difficulties in mobility, self-care and communication, but also their cognitive impairment, depression and personality changes (2). Roles are revisited as caregivers become burdened with new responsibilities and encounter a range of problems including financial difficulties, social isolation, lack of information and poor physical and mental health (3–7). Studies show family caregivers are at risk for negative health outcomes such as depression, psychosocial impairments and mortality as a result of providing care (8–11).

Although care-giving will always be influenced by a range of subjective factors, some objective measures of identifying those at adverse risk are required. It is suggested that high physical dependence, advancing age and increased anxiety in caregivers or patients and poor family support are simple and easily assessable measures of caregiver risk, which could be used in clinical practice to target caregiver interventions (12). Caregiver burden in the immediate aftermath of stroke was found to be determined by patient and caregiver anxiety rather than by the level of disability, age, gender, or support from family or social services. At one year post-stroke, caregiver depression and lack of family support became additional determinants of the care-giving burden (11).

In the American population, subjective burden was found to be affected by worsening in the patient's neurological, but not physical, functioning within the first year post-stroke (13). Similar findings were reported in a Brazilian population (14). The majority of caregivers were females who were significantly younger than the stroke patients and had more years of formal education. The prevalence of anxiety disorders was significantly higher in female caregivers and they also had significantly higher burden than males. Caregiver burden was also significantly higher in wives who were the primary caregivers compared to other relatives. Patient's disability and caregiver factors

such as female gender and depression were found to be independent predictors of caregiver burden (14).

Other studies have also reported that physical function of the stroke patients was not necessarily the best predictor of caregiver burden, but rather the psychological and emotional factors (8, 15). Burden was most heavily related to feelings of heavy responsibility, uncertainty about patients' care needs, constant worries, restraints in social life, and feelings that patients rely on only their care (8). Spouses who were caregivers spent more time with the stroke survivor than other caregivers and had less home help services; however, even though they experienced the same total burden as children and other caregivers, they had a higher degree of disappointment and isolation (15).

Overall trends from all the studies reviewed indicated that caregivers of stroke patients are more likely to be females and all caregivers tend to have some degree of burden regardless of the specific instrument that was used to measure burden. Spouses tend to have the highest degree of burden compared to other types of caregivers. Psychological and emotional aspects of both the caregiver as well as the stroke survivor were also shown to be stronger predictors of burden as opposed to physical status of the patient. A major problem with the literature reviewed was the fact that each study used a different instrument to assess caregiver burden and there were also variations in the instruments used to assess depression and functional status of the stroke survivor. This therefore makes it difficult to make reliable comparisons between the different populations.

In order to achieve optimal rehabilitation outcomes for stroke patients, all factors impacting on recovery must be considered and caregiver burden is no exception. To date, no information has been identified on caregiver burden in relation to stroke patients in Jamaica. This study sought to determine the level of burden present in persons caring for stroke survivors in Jamaica and to explore the relationship between selected sociodemographic variables, of both the caregiver and the stroke survivor, and burden. The study also sought to explore the relationship between level of disability and depression of the stroke survivor and caregiver burden.

## SUBJECTS AND METHODS

A non-experimental cross-sectional design was used to evaluate the burden experienced by primary caregivers of stroke survivors in Jamaica after the proposal received ethical approval from the Ethics Committees of the University Hospital of the West Indies/University of the West Indies/Faculty of Medical Sciences and the Ministry of Health, Jamaica. A stroke in this study was defined as the sudden death or damage to a portion of brain cells due to either a blockage in or rupture of one of the blood vessels in the brain. The primary caregiver was defined as the person who was primarily involved in helping the person who has suffered the stroke to live independently at home. The person may have been providing financial help, physical help with activities of daily living and/or psychosocial support for coping. This included caregivers who were family members as well as paid caregivers.

A sample of convenience was used consisting of all stroke patients being seen at the outpatient physical therapy department of the Cornwall Regional Hospital, and the Sir John Golding Rehabilitation Centre who agreed to participate in the study and whose caregivers also agreed to participate. The caregivers had to be the primary support person/caregiver for the stroke victim and only those 18 years or older were included.

Participants were excluded if there were any orthopaedic injury affecting function or if there were other neurologic co-morbidities. Both the caregiver and stroke patient were excluded if the stroke patient had a score of less than 25 on the Mini Mental State Examination (a brief screening test used to identify whether persons have impaired cognition).

Upon receiving ethical approval, patients that were being seen at the departments between the period January and April 2010 were approached by the researchers and were invited to participate in the study. For those who expressed an interest, they were screened to ensure that they met the inclusion criteria and an appointment was set for them to attend their respective physical therapy department for a single session that lasted approximately 45 minutes. At the time of the appointment, the participants were required to sign an informed consent form.

The caregivers were required to complete a demographic sheet and the Bakas Caregiving Outcomes Scale. The stroke patients completed the Barthel Index and the Geriatric Depression Scale. All instruments were interviewer administered by the researchers.

A sociodemographic data sheet was developed to obtain background information on the caregiver and the stroke survivor. Caregiver burden was assessed with the Bakas Caregiving Outcomes Scale. This is a 15-item instrument which has been validated for measuring life changes in family caregivers of stroke survivors (16). Total scores range from 0 to 100 with higher scores indicating less burden.

Depressive symptoms in the stroke survivor were assessed with the Geriatric Depression Scale. This instrument was designed as a screening test for depression in elderly people. Total scores range from 0 to 30 with higher values reflecting greater depression. The instrument has been shown to have good validity and reliability (17).

Functional independence was assessed with the Barthel Index measures. This instrument has been widely used in evaluating stroke patients and has good validity and reliability (17). Scores range from 0 to 100 with higher scores indicating greater independence.

Data analysis was done using SPSS version 12 for Windows. The relationship between caregiver burden and the following variables were assessed with the Pearson's correlation coefficient: caregiver age, age of the stroke survivor, quality of life of the stroke patient, levels of disability and depression. An independent Student's *t*-test was used to determine the relationship between burden and the gender of the caregiver and burden and gender of the stroke survivor. The relationship between caregiver burden and income, educational level and relationship to the stroke victim was assessed with analysis of variance (ANOVA). All analyses were done at an  $\alpha$  level of 0.01.

## RESULTS

A total of 48 caregivers with their stroke survivors participated in the study. The mean age of caregivers was  $49.68 \pm 13.62$  years. The majority of caregivers were females (89.6%), were directly related to the stroke survivor (77.1%) and were educated at secondary school level (47.9%). A small majority were either self-employed (14.58%) or employed (37.5%), with the majority (85.6%) earning less than \$JA40 000 per month.

The mean age of the stroke survivors was  $68.5 \pm 13.04$  years and the mean post-stroke time was  $22.5 \pm 31.42$  months. The majority of the stroke survivors were males (54.2%) and were educated at secondary level (50%).

Caregiver burden scores were found to range from 21 to 62 (mean score  $43.64 \pm 8.73$ ). Almost half of the sample (45.83%) had burden scores between 40 and 50. The mean score for the stroke survivors on the Barthel Index was  $56.77 \pm 29.95$  with males having higher scores ( $63.26 \pm 31.8$ ) compared to females ( $49.09 \pm 26.26$ ); however, this was not statistically significant. The mean score on the Geriatric Depression Scale was  $13.81 \pm 7.3$  with female survivors having significantly higher levels of depressive symptoms than males ( $16.72 \pm 6.21$  vs  $11.34 \pm 7.31$ ,  $p < 0.01$ ).

No comparisons were done between the gender of the caregiver and burden since the majority of caregivers were females. It was noted, however, that caregivers who were caring for female stroke survivors had significantly more burden ( $43.5 \pm 8.87$ ) compared to those caring for male survivors ( $44.4 \pm 8.3$ ,  $p = 0.03$ ). No significant correlations were found between caregiver burden and age of the caregiver, post-stroke time and functional status of the stroke

survivor. No significant relationships were found with the caregiver's level of education and caregiver burden or between the stroke survivor's level of education and the level of caregiver burden. There was no significant relationship between caregiver's employment status and the level of burden experienced. It was noted that unemployed caregivers had the lowest mean burden score, indicating a higher level of burden, while self-employed caregivers had the least burden. No significant relationship was found between the caregiver's relationship to the stroke survivor and the level of burden experienced. Burden levels, however, were highest when the caregiver was an offspring. A significant negative low correlation was found between the geriatric depression scores and caregiver burden ( $r = -0.33, p = 0.02$ ).

## DISCUSSION

The caregivers who participated in this study were mostly females who were primarily educated at the secondary school level only and were either unemployed, or were earning \$JA40 000 or less per month. This finding was not surprising and is believed to be a true representation of the population. Stroke more frequently affects individuals of lower economical brackets and a much larger proportion of the Jamaican population is educated at the primary and secondary level only, compared to tertiary. The unemployment rates in Jamaica are also high and preliminary statistics for the period 2009 indicate that 14.9% of the female labour force was unemployed (18).

It was not surprising that most of the caregivers in this study were immediate relatives, since cultural norms in the society dictate that family members should care for their own in the face of adversity. In addition to this, the unemployment status and low income levels would have been a significant barrier to the majority of the caregivers in this study being able to employ other full-time care providers. This distribution was similar to that reported by other researchers who also found that the largest percentage of caregivers was females and spouses (5, 14, 15).

All caregivers in the study showed some degree of burden, with the largest percentage of the sample having scores that indicated moderate to high degree of burden. It was noted that the caregivers of female stroke survivors recorded higher burden scores than those of male survivors. This was probably due to the fact that the female patients had poorer levels of function in activities of daily living and were also significantly more depressed than the male patients who participated in this study. This finding was contrary to that of two other studies where it was reported that caregivers of male stroke survivors yielded higher levels of burden (13, 14). One of the studies was conducted in a developing country (14); however, the instrument used to assess burden was different and this may have accounted for the differences noted. The other was conducted in a North American population (13) and therefore cultural differences could explain the variation in findings.

This current study showed that increasing levels of depression in stroke survivors was significantly associated with increasing level of burden for the caregivers. This finding was anticipated as all studies reviewed indicated that psychological characteristics of both the caregiver and survivor were better predictors of caregiver burden. In previous studies, reviewed spouses were shown to have the highest level of burden; however, in this study, offsprings were found to have the highest level of burden. Further investigations of the data showed that the mean depression level of stroke survivors who were being cared for by offsprings was significantly higher than the mean depression level of the stroke survivors who were being cared for by spouses and other caregivers. This finding supports the current literature which indicates that depression in stroke survivors is a reliable predictor of caregiver burden.

Level of education of the caregiver and stroke survivor had no association with the caregiver burden and, furthermore, caregivers with lower levels of education had less burden than those with higher levels of education. It is possible that the caregivers with higher education levels were employed in jobs that were more stressful than those with lower level education and this, combined with the added responsibility of care-giving, could have led to their higher degree of burden. Overall, this study showed no significant findings between other sociodemographic variables and caregiver burden and this may primarily be due to the small sample size. A larger sample is required to properly investigate the relationship between caregiver burden and sociodemographic variables.

## CONCLUSION

This small sample has shown that Jamaican caregivers of stroke survivors are experiencing some degree of burden which appears to be mostly related to depressive symptoms and functional status of the stroke survivor. In order for healthcare professionals to optimize the quality of care provided to stroke patients and consequently, patient outcome, it is important that we conduct further investigations into caregiver burden and develop programmes to address the problems identified.

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