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Research Paper

The modifying role of caregiver burden on predictors of quality of life of caregivers of hospitalized chronic stroke patients

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Abstract

Background: Caregiver burden is an important predictor of quality of life (QoL) among caregivers of stroke patients. While caregiver burden and QoL might be closely related, caregiver burden seems also to be a potential modifier of the associations between patients' and caregivers' characteristics and caregivers' QoL.

Objective: The purpose of this study was to investigate the effect of caregiver burden in caregivers of hospitalized chronic stroke patients and the predictors of caregivers' QoL by level of caregiver burden.

Methods: A total of 238 patients and their caregivers were interviewed using questionnaires consisting of the Zarit Burden Interview and the Korean-version of the World Health Organization Quality of Life-BREF. Multiple hierarchical regression analyses were performed to determine the predictors of caregivers' QoL among caregivers stratified by median caregiver burden score (high/low).

Results: Caregiver burden had a modifying effect on caregivers' QoL. In caregivers with high burden, the patient characteristics of being unemployed and the caregiver characteristics of poor health status, lower income, and being a spouse were negative predictors of caregivers' QoL. In caregivers with low burden, the patient characteristics of being hospitalized for a longer duration and the caregiver characteristics of poor health status were negative predictors of caregivers' QoL (all $ps < 0.05$).

Conclusions: This study found that in South Korea, more attention should be paid to spouses who are caring for hospitalized chronic stroke patients, particularly with regard to their health status and financial problems. Further studies are needed to examine the impact of factors not examined in the Korean cultural context.

Keywords: Stroke; Caregiver burden; Quality of life

A great majority of stroke patients return home or to the community after the initial hospitalization and rehabilitation period, and at least half require permanent or temporary help from their caregivers in performing basic personal care or activities of daily living.[1] Among this majority, such care is mainly provided by family members.[2] Caregiver burden is an all-encompassing term used to describe the physical, emotional, and financial responses of a caregiver to the changes and demands of providing help to another person with a physical or mental disability.[3]

In recent years, caregivers are becoming increasingly aware of what is necessary for long-term management of stroke patients.[2,4,5] The scope of stroke rehabilitation should include a combined focus on patients and caregivers, since caregivers play a pivotal role in preserving stroke survivors' rehabilitation gains and well-being.[6] An increasing number of studies have examined caregiver burden, lack of caregiver support, and interventions focused on relieving caregiver burden, and this increase is likely in part due to greater evidence of caregiver burden being a determining factor in the quality of life (QoL) of caregivers.[1,4–7]

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Several studies have shown an association between the characteristics of patients and caregivers and caregivers' QoL, with caregiver burden serving as an important predictor of QoL.[5,8] Caregiver burden has also been used as an outcome variable instead of a predictor,[5] suggesting that caregiver burden and QoL are closely related. Thus, caregiver burden seems to be a potential moderator of the associations of patients' and caregivers' characteristics with caregivers' QoL. Using a sample of caregivers of hospitalized chronic stroke patients, we investigated the predictors of caregivers' QoL while also considering patients' and caregivers' characteristics, and how these predictors differed with respect to the level of caregiver burden.

Methods

Participants

A cross-sectional descriptive cohort study was conducted using a convenience sample of inpatients with ischemic stroke who were undergoing rehabilitation from university and private rehabilitation hospitals located in a metropolitan area of Seoul and Gyeonggi-Do in South Korea, between October 2013 and April 2014. All patients had been transferred from an acute hospital setting within 1–2 months of stroke onset. As per the norm in South Korea, all patients were allowed to return home on weekends. The participating institutions consisted of general university hospitals ($n = 7$) and private rehabilitation hospitals ($n = 6$) (45% of the 29 hospitals in the metropolitan area). All the facilities agreed to participate in the study and held seminars to help participants understand the purpose and nature of the study and to assess the questionnaires for internal quality assurance. All the participating patients underwent brain computed tomography and magnetic resonance imaging scans to confirm the presence of stroke.

The entry criteria for patients were as follows: age 45 or older with no diagnosis of Alzheimer's disease or dementia, medically stable (i.e. no acute or severe illness or surgery in the preceding 4 weeks and stable pre-existing chronic disease), functionally independent before the stroke (operationally defined as a pre-stroke Modified Rankin Scale score <3),[9] required and had an adult family member as their caregiver, and a score of 23 or above on the Mini-Mental State Examination (MMSE).[10] Patients were excluded from the sample if they had no family caregiver or if they refused to participate. The inclusion criteria for caregivers were as follows: age 18 or older, no severe neurologic or psychiatric condition that might affect the validity of the interview, and a Modified Rankin Score of 2 or below. A detailed explanation of the purpose and nature of the study was given to all eligible patients and their family caregivers by a research assistant before they were asked to sign the consent form.

Three hundred and fifty-seven consecutive stroke patients were screened, and 280 stroke patients (78.4%) and their caregivers met the inclusion criteria for participation in the study. Of the 77 patients excluded, 34 patients had no family caregivers, 17 refused to participate, and 26 had an MMSE score of less than 23. Following this initial screening, only the data of 238 patients (66.7%) and their caregivers were analyzed, as 42 patients had missing values or incorrect data (Fig. 1). There were no significant differences between the included and excluded participants in terms of baseline characteristics (Table 1).

The study was approved by the institutional review board of Seoul St. Mary's Hospital, which is affiliated to the Catholic University of Korea, and written informed consent was obtained from all participants prior to data collection (MC 13QASI0017).

Measures

Caregiver burden was measured with the Zarit Burden Interview (ZBI),[11] which is the most widely used instrument of its kind in the literature.[12] This scale contains 22-items and has 5 subscales assessing subjective burden in caregivers: general strain, isolation, disappointment, emotional involvement, and environment. All items are scored on a scale from 1 to 4, with higher scores denoting higher caregiver burden. In this report, only the total score of the scale was used. The internal consistency of the ZBI has ranged from 0.70 to 0.87 in past studies,[13] indicating good reliability; it has also been found to have good validity in stroke patients and their caregivers.[13] Internal consistency was 0.91 for the total scale and 0.65–0.78 for the five subscales in our study.

QoL was measured using 26 items from the psychometrically and clinically validated Korean-version of the World Health Organization Quality of Life-BREF (WHOQoL-BREF), an abbreviated version of the WHOQoL.[14] The WHOQoL-BREF contains 26 items that assess general health and general QoL, as well as QoL in psychological, physical, social relationships, and environmental domains. This questionnaire was self-completed by respondents with the necessary ability; otherwise, it was administered by an interviewer. The total scores were calculated and raw scores for each domain of the WHOQoL-BREF were transformed into a scale of 0–20, with higher scores indicating better QoL. General health and general QoL were assessed each with one item rated on a 5-point scale. In previous research,[14] the internal consistency of the WHOQoL-BREF was 0.90 for the total scale and ranged from 0.58 to 0.78 for the four domains. In the present study, it was 0.92 for the total scale and 0.68–0.85 for the four domains.

Data were also obtained on other variables that influence caregiver burden and/or QoL according to previous literature, including the patient and caregiver characteristics of gender, age, marital status, education, occupation, and type of health insurance. Among patients, the duration of stroke