



Research Paper

Quality of life of stroke survivors and their informal caregivers: A prospective study

Enkhzaya Chuluunbaatar, M.D., Yiing-Jenq Chou, M.D., Ph.D., and Christy Pu, Ph.D.*

Institute of Public Health, School of Medicine, National Yang Ming University, Taipei, Taiwan

Abstract

Background: Health care improvements have led to increased survival among stroke patients; however, the disability level remains high. These patients require assistance from caregivers, particularly in the first year after stroke. Longitudinal studies of quality of life (QoL) and the factors associated with QoL for both patients and caregivers are limited.

Objectives: To describe the changes in QoL and determine the factors associated with QoL for both stroke patients and their informal caregivers in the first year after stroke.

Methods: This multicenter prospective study was conducted in public hospitals in Mongolia. In this study, 155 first-time stroke patients and their 88 informal caregivers were followed up for 1 year. The WHOQOL-BREF questionnaire was used to assess QoL. The Barthel Index was administered to the patients at the baseline and after 1 year. A generalized estimating equation analysis was used to determine the factors associated with QoL.

Results: The QoL of stroke patients in the domains of physical and environmental aspects improved significantly ($p < 0.05$) after 1 year; however, social relationship and psychological health declined, but the decline was not significant. Among caregivers, psychological health and social relationship domains improved significantly. Factors associated with low QoL among stroke patients were advancing age, male patients, being single and less improvements on BI score, and among caregivers were poor physical health and financial difficulties.

Conclusions: Efficient rehabilitation therapy for poststroke patients can improve their QoL. Disability training and financial support for caregivers of poststroke patients might be helpful; however, further research is required. © 2016 Elsevier Inc. All rights reserved.

Keywords: Stroke; Quality of life; Informal caregivers; Activities of daily living

Stroke is a major health burden worldwide; according to the World Health Organization (WHO), 15 million people experience a stroke annually.¹ Health care improvements have led to increased survival among stroke patients; however, in 2008, 5.5 million stroke patients died, and 5 million patients developed permanent disabilities.¹ In 2012, deaths from stroke increased to 6.7 million worldwide²; hence, stroke is the second leading cause of mortality (13.9% of all deaths in 2013) and first leading cause of disability,³ particularly in low- and middle-income countries. The annual incidence of stroke in Mongolia in 2012 was 290 per 100,000 people,³ which is one of the highest incidence rates worldwide (the incidence ranges from 41/100,000 per year in Nigeria to 316/100,000 per year in Tanzania).⁴ The reasons for the high prevalence of stroke in Mongolia are

lifestyle factors (high salt intake and smoking and drinking habits), a changing climate, and a lack of control of high blood pressure³; thus, the onset of stroke occurs at an earlier age, with a higher prevalence of hemorrhagic stroke (the hemorrhagic stroke to ischemic stroke ratio is approximately 1:1).⁵

The onset of stroke is sudden, and patients and their families are typically unprepared. The support provided by family caregivers to stroke patients has a vital effect on the stroke outcome when patients are not in rehabilitation care.⁶ Caregivers of stroke patients often must cope with the patients' physical and psychological impairments.^{7,8} Physical impairment affects activities of daily living (ADLs), such as eating, bathing, dressing, toileting, and transferring, which require the caregiver's assistance the most.⁹ Psychological impairment comprises cognitive, communication, and behavioral changes and emotional problems.¹⁰ Unlike other countries, Mongolia has no formal caregiving facilities for long-term care; hence, stroke survivors rely on informal caregivers, often family members, to provide care.

* Corresponding author. Institute of Public Health, School of Medicine, National Yang Ming University, No. 155, Linong Rd, Sec2, Beitou District, Taipei 112, Taiwan. Tel.: +886 2 28267994.

E-mail address: cypu@ym.edu.tw (C. Pu).

Caregivers in Mongolia have no formal support; however, a monthly caregiver allowance has been initiated (after this study was conducted) for proven caregivers who have worked for a certain period. Tertiary hospitals have started providing weekly training on caregiving for acute stroke patients. The WHO defined quality of life (QoL) as “an individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns.”¹¹ Thus, QoL is a complex concept that measures physical, emotional, environmental, and social well-being.¹² The first year after stroke is the most challenging year for both stroke patients and their caregivers,¹³ particularly owing to physical and cognitive impairments.^{7,8,13,14} In the first year, stroke patients must accept and cope with persistent disabilities, such as those in ADLs,¹⁵ which require caregiver assistance.^{9,14} Previous studies have shown that the physical function of stroke patients improves at 3¹⁶ and 6 months^{14,16,17} and 1 year after stroke^{8,16}; however, improvement in QoL in other domains such as the environment¹⁴ and psychological health domains varies. For caregivers, difference are observed in caregiver strain at 1, 3, and 6 months of caregiving.⁷ However, few studies have assessed the QoL of both patients and informal caregivers. One study found that patient disability was associated with caregivers’ emotional well-being,¹³ and a population-based study could not identify any predictors for unpaid caregivers.¹⁸ Therefore, this prospective study described the changes in QoL in the physical health, psychological health, social relationship, and environment domains and determined the factors associated with the QoL of both stroke patients and their informal caregivers in the first year after stroke.

Methods

This study had a multicenter prospective design and was conducted in nine public hospitals (three tertiary-level and six secondary-level hospitals) in Ulaanbaatar, Mongolia. All acute stroke cases in Ulaanbaatar receive care in these hospitals; moreover, stroke patients from other provinces are admitted to these tertiary hospitals. Ethical approval was obtained from the ethics committees of National Yang Ming University and local hospitals, and informed consent was obtained from each participant. The caregivers provided consent on behalf of patients who had motor dysphasia or aphasia and borderline consciousness [Glasgow Coma Scale (GCS) scores between 10 and 13].

Participants and recruitment procedure

This study recruited consecutive stroke patients admitted to the hospitals and their main caregivers. The inclusion criteria for the patients were as follows¹: first-time acute stroke (7–10 days after onset¹⁹) and² ischemic or

hemorrhagic stroke, defined according to International Classification of Diseases, tenth revision.²⁰ The pathological subtype was confirmed using brain computed tomography or magnetic resonance imaging scans.¹⁹ The exclusion criteria were as follows¹: transient ischemic attack or subarachnoid hemorrhage,² a Charlson Comorbidity Index (CCI) greater than 5 (which indicates a 1 year mortality rate of 78%²¹), and³ a GCS score less than 8, which represents severe brain injury.^{22,23}

After a patient was selected from medical records, informed consent was obtained, and his or her main caregiver was asked to participate in this study. An informal caregiver was defined as a person who was primarily responsible for providing all types of care required by the patient but who was not paid to care for the patient and who was willing to provide support after hospital discharge. At the baseline, face-to-face interviews were conducted by the main researcher, and the patients were assessed by neurologists by using the modified Rankin Scale (MRS),²⁴ Barthel Index (BI),^{24,25} and GCS.²⁶ The caregivers were interviewed by the main researcher and requested to fill out the questionnaires. If the main caregiver was unavailable at the time of patient interview, the caregiver was contacted the next day or at the next available time. Caregivers were excluded if they cared for patients for less than 1 day.

Follow-up data were collected by the main researcher or a trained doctor through telephone interviews of the patients and caregivers 1 year after the first interview; in addition, the QoL questionnaire was assessed, and BI scores were determined for the patients. Previous studies have reported that the WHOQOL-BREF questionnaire and BI are valid and reliable measurements that can be used for conducting assessments through telephone interviews.^{27,28} Only patients and caregivers with complete baseline and follow-up data were included.

Outcome assessments

The baseline data of the patients were collected at the time of hospitalization or within 10 days of stroke onset, and these data comprised demographic characteristics (age, gender, education, and marital status); stroke characteristics including stroke type, consciousness level (GCS), stroke severity (MRS and BI) (i.e., unable to walk without assistance and unable to attend to own bodily needs without assistance)²⁴; comorbidity (CCI); smoking and drinking habits (yes/no answer); and QoL measured using the Mongolian version (translated by previous researchers and confirmed by the WHOQoL team) of the WHOQOL-BREF questionnaire, in which user agreements were derived from the WHO measurement and Health Information System. The WHOQOL-BREF questionnaire is a shorter version of the WHOQOL-100 and was developed to be sensitive to transcultural measures of evaluation among various countries.¹² This questionnaire

Download English Version:

<https://daneshyari.com/en/article/6238784>

Download Persian Version:

<https://daneshyari.com/article/6238784>

[Daneshyari.com](https://daneshyari.com)