

ABSTRACT

Despite the improvements that have been made in health care over the years, stroke remains a serious public health problem in low, middle and high-income countries. Post-stroke, there are many consequences that manifest and these include mortality, morbidity and socioeconomic, affecting not only the stroke survivor but also the caregiver. These consequences are felt hardest in low and middle-income countries because they are the least able to deal with health related setbacks to development. Pressure for beds and the need to reduce hospitalisation related costs have resulted in early discharge home of patients culminating in caregivers playing a more significant role post-stroke.

The role played by caregivers has of late received much attention and is well documented in high-income regions. Informal caregivers are particularly important in low resourced settings. Caregivers play an important role in the rehabilitation process of the stroke survivor. The discharge home of patients with stroke to unprepared caregivers is associated with burden or strain, which negatively affects the quality of life of not only the caregiver but the stroke survivor as well. The effect of a structured, individualised caregiver training programme on patients with stroke and their carers has not been established in sub-Saharan Africa in general and South Africa in particular.

With this in mind, the aim of the study was to establish the impact of caregiver education on the morbidity of the stroke survivors and on the quality of life of the stroke survivors and their carers. The specific objectives of the study were to establish the: physiotherapy caregiver education programmes and associated content in use for managing patients with stroke at Chris Hani Baragwanath hospital, effect of caregiver education on the mobility of the stroke survivors, effect of caregiver education on the health related quality of life of the stroke survivor and the caregivers, effect of caregiver education on the ability of the stroke survivor to socialise and participate in community issues and also the patient and caregiver characteristics associated with caregiver strain post-stroke.

To achieve the first objective, a self designed questionnaire was used to establish the physiotherapy caregiver education programmes and associated content in use for managing patients with stroke at Chris Hani Baragwanath hospital from the physiotherapists at the hospital. For the rest of the objectives, a stratified randomised controlled trial using concealed allocation with a broad entry and blinded outcome assessment at baseline, three, six and 12 months was used for data collection. The participants for the study were first time ischaemic patients with stroke admitted to Chris Hani Baragwanath hospital, Soweto, Johannesburg, South Africa. A total of 200 patients and their caregivers

participated in the study. These were randomly assigned to either the control group or the experimental group. The caregivers in the experimental group were subjected to an individualised training programme just prior to discharge of the patient with stroke and at the three month follow up. The assessor was blinded to the group allocation of the patients and caregivers until after completion of the study.

From the study, the one-year case fatality was 38%. The mean hospital length of stay for patients with stroke was six days and the average number of physiotherapy contacts for the stroke survivors was one. The content of the rehabilitation programme of patients post-stroke was well structured and appropriate at Chris Hani Baragwanath. However, there was no caregiver involvement or training during in-patient rehabilitation. The barriers to caregiver involvement included perceived high workload by therapists, short hospital length of stay, poor referral systems between clinicians and therapists of patients post-stroke and caregivers being unavailable during working hours for training purposes.

Using the Barthel Index (BI) scores, 78% of the patients were functionally dependent at 12 months post discharge. None of the patients were fully independent in mobility and stair climbing. The experimental group had better mean BI scores at the three and 12 month follow up periods ($p = 0.01$ and $p = 0.05$ respectively) when compared to the control group. Caregiver education had the effect of improving the BI scores by one and 0.7 at the three and 12 months follow ups respectively. However, the functional abilities of the patients from both groups were still low at 12 months with averages of 13.3 and 12.6 for the experimental and control groups respectively (out of a possible 20).

The overall patient mobility scores as measured on the Rivermead Mobility Index were low over the study period with averages of 9.1 and 8.5 for the experimental and control group respectively (out of a possible 15). However, the experimental group had slightly better Rivermead Mobility Index (RMI) scores, which were not statistically significant. Caregiver education had the effect of reducing the risk of death by 27% relative to that occurring among the control group patients.

The health related quality of life of the stroke survivors was generally poor over the study period. The baseline means from their EQ-5D scores (for health related quality of life) were 42.4 and 43.7 for the control and experimental groups respectively, which rose to 67 and 68.8 at 12 months respectively post discharge. Caregiver education had the effect of improving patients' EQ-5D scores by a factor of three and this was only at 12 months.

The caregivers' quality of life generally declined over the 12 months of the study period (more in the control group than the experimental group) from averages of 92 and 93 at three months (for the control and experimental groups respectively) to 83 and 86 (respectively) at 12 months. However, the experimental group had better mean EQ-5D scores (health related quality of life) than the control group ($p = 0.001$). Caregiver education had the effect of improving EQ-5D scores by factors of 3.4 and 3.6 at the six and twelve month follow up period.

The ability to socialise and participate in community issues was poor. None of the participants could carry out single and multiple tasks without assistance at 12 months post discharge. More than 87% of the patients had mild to moderate difficulty with walking at 12 months post discharge and they were all unable to lift and carry objects, have fine hand use and move around with equipment without assistance. None of the patients was able to carry out domestic activities without any difficulty and consequently they could not prepare meals and do housework without assistance from helpers.

All of the participants had mild to moderate and severe to complete difficulty in basic interpersonal interactions, complex interpersonal interactions and formal relationships. They all had mild to moderate difficulty engaging in recreation and leisure activities while 27% of the control group and 25% of the experimental group had severe to complete difficulty with community life at 12 months post discharge.

The design, construction and building products and technology for both public and private use were cited as barriers to community participation. More than 50% of the patients also cited friends as being barriers to community participation but acquaintances, colleagues, neighbours and community members were cited as being facilitators together with personal care providers (caregivers). Transport services, systems and policies were also cited as barriers by more than 80% of the participants. Caregiver education did not seem to influence patients' ability to participate in community issues given the similarities in percentages between the control and experimental groups.

At three months post discharge, 89% of the caregivers in the control group and 92% of those in the experimental group were strained from caregiving duties. However, these percentages declined to 78% and 43% respectively at 12 months, showing the effectiveness of caregiver education. Caregiver education had the effect of reducing strain by a factor of 2.6 at 12 months.

The patient characteristics that were associated with caregiver strain were the dependency levels in transfers, mobility, dressing, bathing, poor activities of daily living scores, patient anxiety/depression,

pain and poor perceived health state. The only caregiver characteristic that influenced caregiver strain was the level of education.

The reduced hospital length of stay, pressure for beds and possibly inadequate rehabilitation personnel levels means that it's possible that some caregivers are not adequately trained to meet patient needs, although this needs to be confirmed with further controlled research. The current pressure on in-patient services at Chris Hani Baragwanath hospital is resulting in suboptimal exposure to rehabilitation of patients post-stroke. There is insufficient organised caregiver education at present. Structured individualised caregiver training has the effect of positively influencing the health related quality of life of the patients especially at six and 12 months post discharge.

Caregivers for patients with stroke suffer from physical, financial and psychological problems, which negatively affect their health related quality of life. Currently, high levels of caregiver strain persist post-stroke. Caregiver education however has the effect of reducing the decline in caregiver health related quality of life over time.

Caregiver training did not positively influence patient mobility and this is most probably because the patients had very low or poor functional ability levels at discharge from hospital. However, structured and individualised caregiver training has the effect of improving patients' quality of life and can help reduce deaths among stroke survivors.

The patient ability to socialise and participate in community issues post-stroke is currently poor. This mainly stems from the poor functional ability levels, which necessitate dependency on caregivers. Compounding the low functional ability levels are the transport systems, services and policies, attitudes of friends and the design, construction and building products and technology for both public and private use, which are barriers to community participation.

The high patient dependency levels result in caregivers being highly strained. The patient characteristics that influence caregiver strain are dependence in transfers, grooming, mobility, dressing, poor activities of daily living, patient anxiety/depression, pain and poor perceived health state (health related quality of life). The only caregiver characteristic that was associated with caregiver strain is the level of education.

The early discharge home with little caregiver training calls for provision of community rehabilitation services preferably through domiciliary visits. Caregivers of patients with stroke should be assessed and treated for depression given its high prevalence among this cohort.

The referral system between the local community health centres and the discharging hospital need to be strengthened to ensure access to rehabilitation by all patients post discharge from hospital. The referral to social workers during in-patient and out-patient rehabilitation also need to be strengthened to ensure processing of social grants to alleviate financial strain as is appropriate.

Caregiver strain is a complex and multifaceted problem with no single causation or solution. As a result, further research is needed to establish the reasons for poor rehabilitation service provision post-stroke for patients and caregivers and find solutions to these. It is important to explore different methods of caregiver education programmes so that the method that yields the best results for both patients and caregivers can be established in our setting and internationally.

Key words: Stroke, Caregiver, Physiotherapy, Rehabilitation, Quality of life, Burden of caregiving.