

CAREGIVER STRAIN AND QUALITY OF LIFE 6 TO 36 MONTHS POST STROKE

ABSTRACT: Background: Caregivers of patients with stroke are central in providing for the patient's needs post stroke. The well-being and quality of life of the caregiver is important in the rehabilitation of the patient with stroke. This study sought to establish the: functional level of patients, level of strain and quality of life of the caregiver, and the factors that influence caregivers' quality of life six to 36 months post stroke.

Methods: This was a cross-sectional study which included 35 patients six to 36 months post stroke and their primary caregiver utilising a sample of convenience from local clinics/hospitals in Johannesburg. Demographic information was obtained from the patient and the caregiver using a questionnaire. The Barthel Index (BI), Caregiver Strain Index (CSI) and the EQ-5D were also administered.

Results: On the BI, 60% of the patients were moderately dependent to independent while 77% of the caregivers were strained. Older caregivers were 81% more likely to experience a decrease in quality of life than younger caregivers.

Conclusion: A large proportion of patients are discharged from hospital without receiving rehabilitation and are still dependent on caregivers six to 36 months post stroke. Caregivers of patients with stroke need more support from health professionals to mitigate against the high strain and low quality of life that they experience when caring for patients six to 36 months post stroke.

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INTRODUCTION

Stroke is a major cause of long-term disability, often with devastating consequences for individuals and their families (Lincoln et al 2003). The pressure for beds and hospital associated costs result in early discharge home of patients with stroke further negatively impacting on recovery. Consequently, about 66% of patients with stroke need help with activities of daily living (Connor et al 2004). This help comes from caregivers who are largely untrained (informal caregivers). The caregivers play an important role in facilitating participation of the patient in their daily functional ability, maintaining functional improvements gained in rehabilitation and the long-term

well-being of stroke survivors (Hankey 2004; Kalra et al 2004)

The long-term effects of care giving for stroke survivors include complaints of restraints in social life, uncertainty about care needs, constant worries, feelings of the burdens of responsibility and an increased prevalence of depression among stroke caregivers (Larson et al 2005; de Freitas et al 2005; White et al 2003). The burden of caring for a stroke survivor is associated with disruptions of both the integrity of families and quality of life of the caregivers themselves (Hankey 2004; Scholte op Reimer et al 1998). Similarly, it has been observed that the chronic burden of psychological, social, physical, and financial stress coupled with the erosion of precious family and leisure time, poor recognition and support can negatively affect caregivers' quality of life (Scholte op Reimer et al 1998). Considerable stress is experienced by many caregivers from the early post stroke period, and the stress continues for several years

after the stroke (Berg et al 2005; Lui et al 2005; Visser-Meily et al 2005).

There is considerable amount of research that has been done on the effect that caring for a patient with stroke has on the quality of life of the caregiver. However, there is no agreement on how best to reduce the negative impact caregiving has on the quality of life of the caregiver. Unlike in high income countries, there is a dearth of literature on caregivers' strain and quality of life in Africa despite the prevalence of stroke being said to be at high income countries' levels (Connor et al 2004). This information is important for us if we are to ensure relevant interventions are given within the African context to improve caregiver quality of life post stroke. The objectives of this study were to establish the functional level of patients, the level of caregiver strain, the quality of life of the caregiver and the factors that influence the quality of life of the caregiver at six to 36 months post stroke.

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METHODS:

Participants and study design

This study employed a cross sectional study design. The participants for the study were sought from public health facilities in the Johannesburg area that have outpatient rehabilitation services. Participants were given an explanation of the study and written consent was sought. Those who agreed to participate in the study were then assessed in the physiotherapy or therapy departments as out-patients, coinciding with their usual visit to the department. Thirty five participants who met the criteria for the study were selected consecutively (sample of convenience using the central limit theorem). This sample size fits the minimum sample required for use of statistical distributions (Campbell and Gardner 1988). When we tested for normality we found that the data were normally distributed. The inclusion criterion was that the participant was within the six to 36 months post stroke window and was functionally dependent to require the service of a caregiver.

Ethical considerations

Ethical clearance was applied for and obtained from the University of the Witwatersrand Committee for Research on Human Subjects (ethical clearance number M080550). Data were kept under lock and key (confidentiality) and identifying information was not put on the questionnaires or data collection instruments.

Procedure

Data collection was done between January 2011 and June 2011. The responses of the patients and caregivers were collected using a structured questionnaire. The questionnaire gathered information on demographics which included age, marital status and level of education of the patient with stroke and their caregiver. The economic situation of the patient and caregiver were also recorded. Information about the stroke incident including side of body that was affected by the stroke and the hospitalisation that the patient went through and the rehabilitation and associated service that were received

were also recorded.

The patient's functional abilities in activities of daily living were evaluated using the Barthel Index (BI). The BI is a valid and reliable instrument with a reliability coefficient of 2.0 (Green et al 2001). The BI has a Cronbach's α of 0.98 according to Kasner (2006), and of 0.90 according to Shah (1989). The caregiver strain was measured using the Caregiver Strain Index (CSI). The CSI has good reproducibility (0.93; 95% C.I. 0.84 – 0.97) (Post et al 2007). The caregiver quality of life was measured using the EQ-5D. The EQ-5D has good inter-rater agreement with Kappa values of 0.05 to 0.64 (Finch et al 2002). These instruments have been widely used and have proven reliability and validity.

Statistical analysis

Data analyses included descriptive statistics of demographic information of the patient with stroke and the caregiver, patient functional ability six to 36 months post stroke, the caregiver strain and caregiver quality of life. Chi-square (χ^2) test was used to assess the degree of association between caregiver quality of life and the various demographic factors. Kendall's rank correlation was used on data to present correlation coefficients. Tetrachoric correlation was performed on binary data (i.e. yes/no, present/absent). Results of the tetrachoric correlation again determined whether there was a relationship between the caregiver quality of life and demographic details, patient functional ability and caregiver strain. Furthermore, logistic regression was applied to the data to assess the relationship between factors and the outcome measure of interest which was caregiver quality of life. Data are presented in tables and charts as was appropriate. The significance of the study was set at $p \leq 0.05$.

RESULTS

Demographic information

The distribution of the caregiver and patient demographic details is reflected in Table 1. Some of the parameters do not add up to 35 due to missing data. More than 80% of the caregivers were women and 54% of the patients were

male (Table 1). The majority of the caregivers (63 %) and patients (63%) were married. More than a third of the caregivers and patients, (35% and 35% respectively) were educated up to Grade 7 level. Just over half of the caregivers (51%) were spouses of the patients with stroke. Most of the caregivers (80%) did not receive caregiver training while the patient was in hospital prior to discharge.

On the day of the interview 39% of patients were six to twelve months post stroke (Table 1). From the patient sample, 32% had a hospital stay of more than 30 days following stroke but the average length of hospital stay was 5 days and 54% of the patients did not receive inpatient rehabilitation. About 53% rated their perceived quality of life as greater than 50 on the EQ-5D VAS. About 77% of the caregivers complained of pain (Table 2). About 25% of the caregivers reported EQ – 5D VAS of between 0 and 50 when caring for patients who were totally or moderately dependent in ADLs (Figure 2) and about 44% of these caregivers were strained (Figure 3). Older caregivers were 0.19 times more likely to experience severe caregiver strain than younger caregivers (Table 3).

Post discharge functional level of patients with stroke

The BI scores were divided into three categories, namely total dependence (0 – 20), severe dependence (21 – 60), and moderate dependence to independent (61 – 100). The majority of the patients (60%) were moderately dependent to independent in basic activities of daily living with 37% being severely dependent.

Caregiver Strain

Results of the caregiver strain were divided into two categories, namely minimal/moderate (a score of six and below), and severe strain (a score of seven and above). From the sample, 77% of the caregivers were severely strained.

Perceived caregiver quality of life

The EQ-5D components showing the perceived caregiver quality of life are shown in Table 2.

Table 1: Distribution of the caregiver and patient demographic information

Parameter	Caregiver (n=35) n (%)	Patient (n=35) n (%)
<u>Gender</u> (n = 35)		
Male	6 (17.1)	19 (54.3)
Female	29 (82.9)	16 (45.7)
<u>Age</u>	n = 34	n = 35
< 43 years	11 (32.4)	5 (14.3)
≥ 43 years	23 (67.6)	30 (85.7)
<u>Marital Status</u> (n = 35)		
Single	7 (20)	8 (22.9)
Married	22 (62.9)	22 (62.9)
Live-in partner	2 (5.7)	1 (2.9)
Widow	4 (11.4)	4 (11.4)
<u>Education Level</u> (n = 34)		
None	1 (2.9)	2 (5.9)
Up to Grade 7	12 (35.3)	12 (35.3)
Grade 8 - 11	11 (32.4)	11 (32.4)
Grade 12 or equivalent	9 (26.5)	6 (17.6)
Diploma or higher	1 (2.9)	3 (8.8)
Caregiver relationship to patient	n (%)	
Spouse	18(51.4)	
Child	6(17.1)	
Sibling	5(14.3)	
Parent	4(11.4)	
Other	2(5.7)	
Distribution of number of months post-stroke	n	
6–12 months	13	
13–18 months	5	
19–24 months	5	
25-30 months	2	
31-36 months	8	

The factors that were associated with and that influenced caregiver quality of life

The frequency of the distribution between BI and EQ-5D VAS is shown in Figure 2.

Figure 3 shows the frequency distribution between CSI and EQ-5D VAS.

The factors that were associated with and that influenced caregiver quality of life are shown in Table 3.

DISCUSSION

Patient functional level six to 36 months post stroke

At the time of the study which was six to 36 months post stroke for this sample, a greater proportion of the patients (60%) were moderately dependent to independent in basic activities of daily living with 37% being severely dependent. Unfortunately the data were not formatted in a manner which would have allowed further analysis of patient functional ability at different time scales, e.g. BI score at six months post stroke, BI score at 12 months post stroke. The larger proportion of patients in the moderately dependent to independent category could be because this cohort of patients had a greater proportion of the patients (61%) more than 12 months post stroke, a period where you would expect most of them to be ambulating. It is however important to note that the patients were not all fully independent with 40% of the total in the severe dependence category. This means that a large proportion of the patients still require rehabilitation and are still dependent on caregivers six to 36 months post stroke. This agrees with previous studies which showed that patients with stroke are not functionally independent post discharge from hospital (Mamabolo et al 2009; Rouillard et al 2012). Rehabilitation post stroke has been shown to improve functional outcomes post stroke (Kalra et al 2004). It is therefore possible that the inadequate in-patient rehabilitation prior to discharge into the community, the short hospital length of stay and possibly inadequate outpatient rehabilitation contributed towards inadequate functional ability (Horn et al 2005; Maulden et al 205).

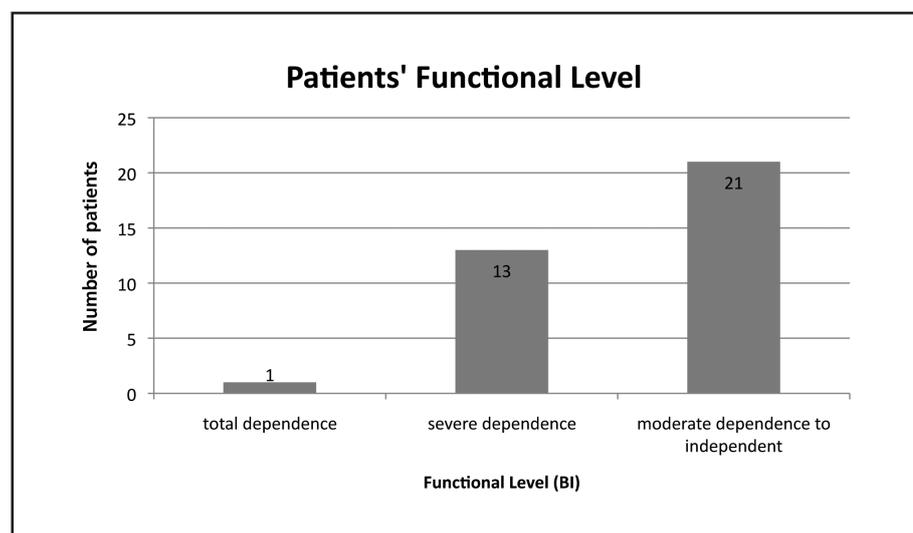


Figure 1: Functional level of the patients with stroke six – 36 months post stroke (n = 35)

Level of caregiver strain six to 36 months post stroke

A high proportion of the caregivers (77%) were strained due to their caregiving duties. This is higher than has been established in the western world. Ilse et al (2008) found 29% of the caregivers to be strained at six months post stroke while Bugge et al (1999) found 37% to be strained at six months. There is however one huge difference between the cohorts of the studies, for the two highlighted studies, their cut off time was six months while this study started at six months and lasted till 36 months. Studies that were done in fairly similar environments are those by Rouillard et al (2012) and Akosile et al (2009) in South Africa and Nigeria respectively. Their studies also yielded percentages of strained caregivers with 56% in South Africa and 82% in Nigeria. It is possible that the higher strain experienced by caregivers in Africa is due to greater functional dependence in patients post stroke. The strain that the caregivers in this study experienced could stem from the functional dependency that was evident among the patients with 40% of them being severely dependent on their caregivers. Increased dependency on the caregiver results in increased caregiver strain (Bugge et al 1999; McCullagh et al 2005; Ilse et al 2008; Choi-Kwon et al 2005).

Caregiver quality of life six to 36 months post stroke

The mean EQ-5D VAS of the caregivers in this study was 63.4 which is not very different to that found among caregivers in Ilse et al (2008)'s study which was 60 at six-months post stroke. Unlike the patients in this cohort who received no or little inpatient rehabilitation, the participants in Ilse et al (2008)'s study were undergoing rehabilitation in a stroke unit, making this finding in our study a bit surprising. The finding in this study is however lower than that established by McCullagh et al (2005) whose caregivers reported mean EQ-5D VAS of 75.4 at twelve months post stroke. Again it should be noted that the participants in McCullagh et al (2005)'s study were undergoing rehabilitation in a stroke unit and there was a caregiver

Table 2: The distribution of the perceived quality of life (EQ-5D) of the caregivers caring for patients with stroke

EQ-5D Component	n (%)
Mobility (n=35)	
– no difficulties	17 (48.6)
– some difficulties	18 (51.4)
Self care (n=35)	
– no difficulties	26 (74.3)
– some difficulties	9 (25.7)
Usual activity (n=34)	
– no difficulties	15 (44.1)
– some difficulties	18 (52.9)
– unable to perform	1 (2.9)
Pain (n=35)	
– none	8 (22.9)
– moderate	23 (65.7)
– extreme	4 (11.4)
Anxiety (n=35)	
– none	6 (17.1)
– moderate	18 (51.4)
– extreme	11 (31.4)
State of health today compared to twelve months previous (n=35)	
– better	9 (25.7)
– same	13 (37.1)
– worse	13 (37.1)

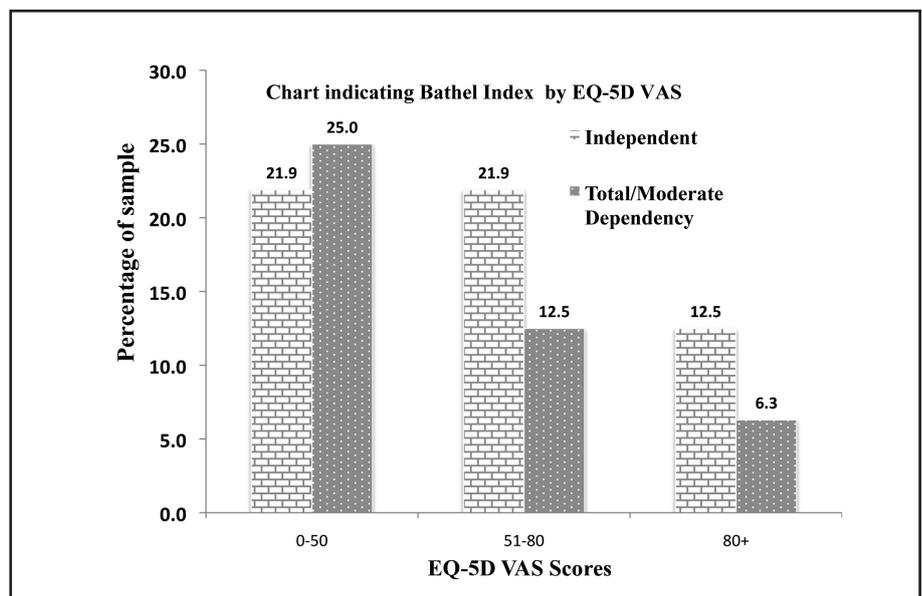


Figure 2: Frequency distribution between BI and EQ-5D VAS (n=32)

training course, which may have affected the caregiver quality of life results. The differing results seen in literature indicate the dynamic nature of quality of life, and leads to the idea that there are many unexplored factors that influence

quality of life in a variety of different settings.

The areas of concern for the caregivers' quality of life were anxiety (83%), bodily pain (77 %) and perceived general health (74%). Caregiving is generally

Table 3: The factors that were associated with and that influenced caregiver quality of life

The factors that were associated with caregiver quality of life					
Factor	Pearson χ^2	Kendall's tau-b	Fisher's exact		
Patient functional ability	0.59	-0.17	0.64		
Caregiver strain	0.06	-0.23	0.05		
Caregiver age	0.009	-0.48	0.01		
The factors that influenced caregiver quality of life					
Output	Odds ratio	Std. error	z	P> z	95% Conf.
Caregiver Strain	1.6	1.6	0.5	0.6	0.2 – 11.1
Caregiver Age	0.19	0.12	-2.64	0.008	0.05 – 0.65

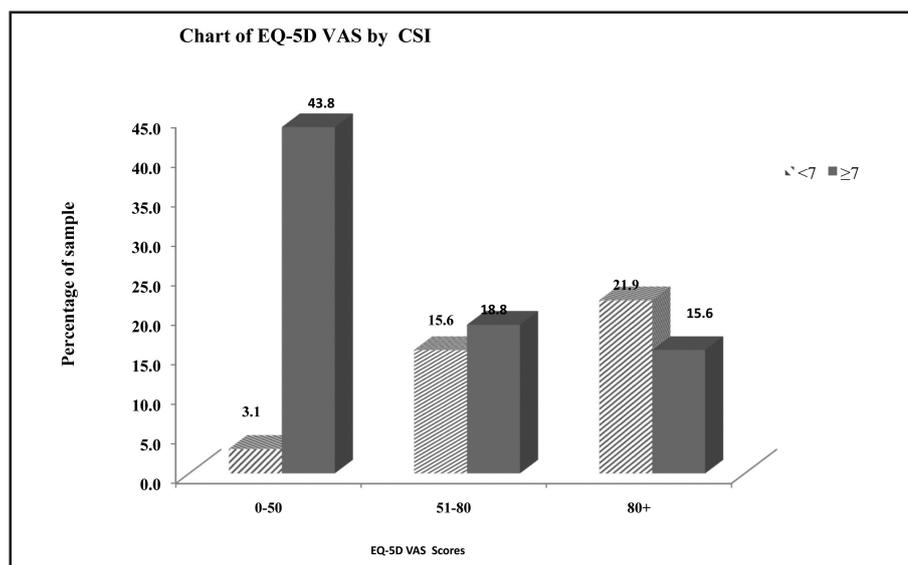


Figure 3: Frequency distribution between CSI and EQ-5D VAS scores (n=32)

physically stressful and these complaints may be linked to the physically demanding nature of caregiving. The absence of caregiver training during patient hospitalisation, the short hospital length of stay and inadequate in-patient rehabilitation could all have contributed to these complaints by caregivers. This finding is similar to that by Mudzi et al (2012) done in Johannesburg as well. The higher the level of independence, the less strain the caregivers had and the reverse is true (Kalra et al 2005). Patient physical deficits are associated with caregiver stress (Ilse et al 2008; Choi-Kwon et al 2005). The patient physical deficits are linked to the neurological deficits with which

they manifest and influence what the patient needed help with during execution of activities of daily living.

Factors that influence caregiver quality of life

Patient functional ability did not show an association with caregiver quality of life (Pearson $\chi^2=0.59$). This was in contrast to other findings which report that as functional ability increases, caregiver quality of life increases as well (McCullagh et al 2005; Jönsson et al 2005). This stems from the notion that as patient dependence on the caregiver increases, the caregiver's perceived quality of life is reduced. Higher levels of

patient independence have been reported elsewhere with Jönsson et al (2005)'s study reporting 87% of their patients to be moderately dependent to independent in their functional ability at 16 months post stroke while McCullagh et al (2005) reported 100% of their patients to be independent in their functional ability at 12 months post stroke. This study showed 60% of patients to be either moderately dependent on their caregiver or independent. Rouillard et al (2012)'s study yielded an even higher percentage (74%) of independence in activities of daily living but the patients still needed caregiver assistance. The poor functional ability of the patients in this study also implies that they would still require more help from the caregivers. The need for caregiver assistance and the high percentage of strained caregivers despite the fairly high percentage of patients in the moderately dependent to independent category leads one to assume that there were other factors not explored in this study that were at play.

From our study, older caregivers were 81% more likely to experience worse quality of life than younger caregivers. Jönsson et al (2005) and McCullagh et al (2005) do not expand on this relationship by means of a logistic regression, yet agree that older caregivers experience worse quality of life. Ory et al (1999) reported that older caregivers experience more physical strain as compared to emotional strain or financial hardship. The physical aspect of caregiver strain may account for the increased strain that older caregivers experience as compared to younger caregivers.

Patient and caregiver demographic factors

More than 80% of the caregivers were women and 54% of the patients were male. The presence of more women as caregivers agrees with findings in other studies (Bugge et al 1999; Morimoto et al 2003; McCullagh et al 2005). This agrees with Almborg et al (1998)'s statement that female relatives are often more heavily involved in caregiving activities than male relatives.

The mean age of caregivers in the study was 51 years and the mean age of the patients was 56 years. The patient

and caregiver mean ages are lower than those which have been reported elsewhere. Jönsson et al (2005) reported mean caregiver age to be 65 years and mean patient age to be 74 years while Morimoto et al (2003) reported mean caregiver age to be 60 years and the mean patient age to be 69 years. The finding of a younger mean age for stroke implies that stroke occurs at a younger age in this cohort of patients compared to findings from the developed world. This agrees with earlier finds by Connor et al (2004).

The majority of the caregivers (80%) did not receive caregiver training while the patient was in hospital prior to discharge and 54% of the patients did not receive rehabilitation post stroke prior to discharge. This is despite there being evidence that rehabilitation or medical care that the patient receives in hospital determines the speed and extent of functional recovery (De Wit et al 2007; Kalra et al 2005). The lack of caregiver training and in-patient rehabilitation prior to discharge could be due to the short hospital length of stay (LOS). The average hospital LOS in this study was five days, which does not allow for adequate time for rehabilitation to occur.

Limitations of the study

The sample size for the study was fairly small which makes generalisation to the entire South African population impossible. The small sample size also limited the statistical test that could be done in this study.

CONCLUSION

Patients with stroke were not all functionally independent post discharge from hospital. Patients are still being discharged home with inadequate rehabilitation having been provided during hospitalisation. This results in poor patient functional abilities in the long term which puts considerable strain on the caregivers. The older caregivers of patients with stroke require more support from healthcare providers as they are the ones most affected by the caregiving duties. This may be due to inadequate in and out-patient rehabilitation and short hospital length of stay.

RECOMMENDATIONS

The finding that a large proportion of patients did not receive in-patient rehabilitation and were not fully independent 6 to 36 months post stroke has implications for the therapists in clinical practice. More needs to be done to ensure that patients are rehabilitated to functional levels which will lessen caregiver strain. More needs to be done to equip the caregivers with the necessary skills needed to help a stroke survivor without negatively impacting the caregiver quality of life.

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