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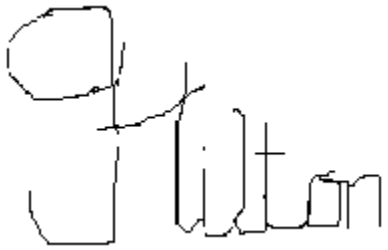
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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, in partial fulfilment of the requirements for the degree of Master of Science in Physiotherapy

August, 2011

DECLARATION

I, Jessica Hilton, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Physiotherapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University



_____ [Signature of candidate]

17th day of August, 2011

DEDICATION

I would like to dedicate the completion of my study to my husband Neil – thank you for your continual support and encouragement

ACKNOWLEDGEMENTS

Thanks are due to Ms Veronica Ntsiea and Dr Witness Mudzi of the University of the Witwatersrand for supervising the study throughout the planning, implementation and write-up of the study, and for continual guidance and support.

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LIST OF ABBREVIATIONS USED

ADL's - activities of daily living

BI - Barthel Index

CBS - Caregiver Burden Score

CRA - Caregiver Reaction Assessment

CSI - Caregiver Strain Index

ESD - early supported discharge

EQ-5D – European Quality of Life Scale-5D

EQ-5D VAS - European Quality of Life Scale -5D Visual Analogue Scale

FIM - Functional Independent Measure

GHQ-28 - 28-item General Health Questionnaire

HADS - Hospital Anxiety and Depression Scale

IADL - instrumental activities of daily living

ICC - inter-class coefficient

Kwallis - Kruskal-Wallis

LOS - length of stay

MCA - middle carotid artery

MBI - Modified Barthel Index

NEADL - Nottingham Extended Activities of Daily Living

RMA - Rivermead Motor Assessment

RMA-A - Rivermead Motor Assessment of Arm

RMA-GF - Rivermead Motor Assessment of Gross Function

RMA-LT - Rivermead Motor Assessment of Leg/Trunk

SBAS - Social Behaviour Assessment Schedule

SCQ - Sense of Competence Questionnaire

SF-6D - Short Form 6D

SF-12- Short Form 12

SF-36 – Short Form 36

SRB - self-rated burden

TTO - Time Trade-Off

WHO - World Health Organisation

ABSTRACT

Background and Purpose

Caregivers of patients with stroke are central in providing for the patient's needs, 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. The strain and ultimate decrease in quality of life of the caregiver can lead to breakdown in the support they provide to the patient. The well-being and quality of life of the caregiver is therefore of vital importance in the rehabilitation of the patient with stroke. It is therefore necessary to evaluate relevant factors in the South African context that affect the quality of life of the caregiver, so as to foresee and prevent possible breakdown in the support provided by the caregiver to the patient with stroke. The objectives of the study are to establish the functional level of patients six to 36 months post-stroke, the level of strain and quality of life of the caregiver six to 36 months post-stroke, and the influence of demographic factors, caregiver strain and patient's functional ability on quality of life of the caregiver.

Method

A cross-sectional study was performed on 35 patients six to 36 months post-stroke and their primary caregiver, obtained from a sample of convenience from six local clinics/hospitals in the Johannesburg area. Demographic information was gathered from both patient and caregiver by means of a questionnaire. The Barthel Index (BI) was used to assess the patients' functional ability at the point of interview. Caregiver strain and caregiver quality of life were measured using the Caregiver Strain Index (CSI) and EQ-5D and EQ-5D VAS respectively.

Results

Of the 35 patients with stroke, 19 (54.3%) were male, and 16 (45.7%) were female, with the mean age of 55.9 years. Of the 35 primary caregivers, 6 (17.1%) were male, and 29 (82.9%) were female, with the mean age of 50.7 years. Sixty percent of patients ranged from being independent in functional ability to being moderately dependent on the

caregiver for their functional ability. Seventy seven percent of caregivers reported severe strain as a result of caring for the patient with stroke. Thirty one percent of caregivers reported midrange (50/100) quality of life using the EQ-5D VAS. No association was established between patient's functional ability and caregiver quality of life (Pearson x^2=0.59). Negative association was established between caregiver strain and quality of life (Kendall's Tau-b=-0.23), however it was of marginal significance (Pearson x^2=0.06). Logistic regression showed caregivers under severe strain were 1.6 times of higher odds to experience a decrease in quality of life than caregivers with less strain. Caregiver age showed a negative correlation with caregiver quality of life (Kendall's Tau-b=-0.48; Pearson x^2=0.009). Logistic regression showed older caregivers were 0.19 times of higher odds to experience a decrease in quality of life than younger caregivers.

Conclusion

There is no association between the patient's functional ability and the quality of life of the caregiver six to 36 months post-stroke. A negative association is shown between caregiver strain and caregiver age, and caregiver quality of life. The realm of caregiver quality of life is both dynamic and contextual. Knowledge of the effects of the contextual factors enables the health services and professionals to respond appropriately to assist in foreseeing and alleviating those factors that negatively affect caregiver quality of life. As it is understood that caregivers provide support for the patient with stroke, promoting the caregiver's well-being in turn will promote patient care and their ultimate well-being.

CHAPTER 1

1. BACKGROUND

1.1 Introduction

Stroke is a major cause of long-term disability, often with devastating consequences for individuals and their families (Lincoln, Francis, Lilley, Sharma, Summerfield, 2003). Research has been done to establish if early home discharge is a feasible option for patients with stroke (Anderson, Rubenach, Mhurchu, Clark, Spencer, Winsor, 2000; Mayo, Wood-Dauphinee, Côtě, Gayton, Carlton, Buttery, Tamblyn, 2000). Benefits for the patients who are discharged home early have been suggested to be the following: satisfying patient choice of being in their home environment; reducing the risks associated with in-patient care through reductions in length of hospital stay; the home setting being more focused toward rehabilitation outcomes, as the patient is more driven to achieve functional goals in their home setting; reintegration to community living; and savings in direct costs (Anderson et al., 2000; Mayo et al., 2000). Although there are benefits to early home discharge, it may also result in the patient with stroke being discharged before they are functionally independent, and therefore requiring much assistance with activities of daily living (ADL's) (Thorogood, Lewando-Hundt, Tollman, Connor, Milne, Casserly, Collinson, Dobson, Kahn, Mokwena, Modi, Ngoma, Warlow, 2004). This results in care of the patient being more physically demanding in activities, such as bed mobility, transfers, and ADL's (Kalra, Evans, Perez, Melbourn, Patel, Knapp, Donaldson, 2004).

Recent years have seen increasing awareness of the role of caregivers in the long-term management of patients with stroke (McCullagh, Brigstocke, Donaldson, Kalra, 2005). Caregivers can take the role of formal or informal caregiving. Formal caregivers are those who perform caregiving as their occupation, and are paid to do so. Informal caregiving may be defined as task-oriented assistance provided by individuals, usually family or friends, that is not part of formal community support services (Dewey, Thrift,

Mihalopoulos, Carter, Macdonell, McNeil, Donnan, 2002). It has been argued that most care and support comes from informal caregivers, particularly those living with the patient (Ko, Aycock, Clark, 2007; Lincoln et al., 2003). Bugge, Alexander and Hagen (1999) refer to informal caregivers as the “backbone of the service provided to stroke patients”. Many studies have shown that family members are affected by the patient’s illness from the outset (Anderson, Linto, Stewart-Wynne, 1995). The family members must overcome the initial shock of stroke, reassess their values, and readjust their own lives and those of their families so that they can provide what is often an extraordinary level of care (Anderson et al., 1995). However, in undertaking this caregiving role, caregivers often experience a significant burden, which, if excessive, can lead to a breakdown in the support provided (Anderson et al., 1995). It is therefore possible that the recovery of patients with stroke may be affected by caregivers, and conversely, patients with stroke may affect caregivers' strain (Bugge et al., 1999; Ko et al., 2007).

Bugge et al. (1999) reported that the percentage of caregivers recorded to be under considerable strain in the early post-stroke phase was notable, and that the percentage of caregivers recorded to have strain increased with time. Other researchers have reported similar findings, stating that considerable stress is experienced by many caregivers from the early post-stroke period, and the stress continues for several years after the stroke (Berg, Palomäki, Lönnqvist, Lehtihalmes, Kaste, 2005; Dewey et al., 2002; Lui, Ross, Thompson, 2005; Visser-Meily, van Heugten, Post, Schepers, Lindeman, 2005).

McCullagh et al. (2005) established that caregivers are central in maintaining improvements gained in rehabilitation and the long-term well-being of stroke survivors. Stroke requires the involvement of family caregivers and their willingness to provide support, for successful rehabilitation of the patient (Anderson et al., 1995, Lui et al., 2005). It is becoming clear that the emphasis in stroke rehabilitation needs to shift from a patient-focused to a combined patient- and caregiver-focused approach (McCullagh et al., 2005). This all suggests that support of the caregiver and patient, and the well-being and quality of life of the caregiver is of vital importance in the rehabilitation of patients

with stroke (Anderson et al., 1995; Visser-Meily, Post, Gorter, Berlekom, Van Den Bos, Lindeman, 2006; Visser-Meily et al., 2005; Wilkinson, Wolfe, Warburton, Rudd, Howard, Ross-Russell, Beech, 1997).

1.2 Problem Statement

A fair amount of research has been done on the effect that caring for a patient with stroke has on the quality of life of the caregiver, yet very limited research could be found that was performed in South Africa. It was important to perform this research in a South African context, so as to add to the limited research, and to establish whether there are any similarities, or interesting South African contextual factors that play a role.

1.3 Research Question

What effect does caring for a patient with stroke have on the quality of life of the caregiver?

1.4 Aim of the Study

To establish the factors that influence the quality of life of a caregiver caring for a patient with stroke.

1.5 Objectives of the Study

- To establish the functional level of patients six to 36 months post-stroke.
- To establish the level of caregiver strain six to 36 months post-stroke.
- To establish the quality of life of the caregiver six to 36 months post-stroke.
- To establish the influence of demographic and contextual factors, caregiver strain and patient's functional ability on the quality of life of the caregiver.

1.6 Introduction to Research Methodology

These study objectives will be measured using the following measuring tools: the Barthel Index measures the patient's functional level; the Caregiver Strain Index measures the level of strain that the caregiver experiences due to his/her caring role; the EuroQol-5D measures the quality of life of the caregiver. Information received from

the demographic questionnaires, the Caregiver Strain Index and the Barthel Index will be related to the information received from the EuroQol to determine whether any of the factors influence the caregiver's quality of life.

1.7 Significance of the Study

Most patients who have had a stroke are in need of assistance from a caregiver post-discharge. It is important to establish the factors that influence the caregiver's quality of life so that more focus can be given to ways that can help negate the effects of those factors that have a negative effect. This would lead to a better quality of life of both the caregiver and the patient. This study will also enable the health professionals to identify caregivers who have a greater risk of strain, and therefore requiring further support or intervention. This would in turn enable patients to receive proper care, to promote independent functioning post stroke.

CHAPTER 2

2. LITERATURE REVIEW

2.1 Introduction

The literature review was done in order to do a critical analysis of available literature relating to the objectives of this study. The following search engines were used to search for literature: PubMed, PEDro, The Cochrane Collaboration, AHA Journals and Google Scholar. The following search words were used in different combinations when searching the literature: stroke, cerebrovascular accident, cerebrovascular incident, cerebrovascular disease, functional level/status/outcome/recovery, length of stay, early discharge, caregiver quality of life, demographic factors, caregiver, and caregiver strain.

This literature review will be divided into the following subtopics:

- Functional level of patients with stroke post discharge
- Caregiver strain from caring for a patient with stroke
- Factors that influence the caregiver's quality of life
    - Patient functional ability
    - Caregiver strain
    - Patient and caregiver demographic factors
- Review of methodology

2.2 Functional level of patients with stroke post discharge

There is little information available concerning the extent of motor recovery after discharge from hospital following stroke (Hendricks, van Limbeek, Geurts, Zwarts, 2002). A systematic review of literature from 1966 to 2001 showed that data concerning motor recovery gathered from the articles was vague, with only a few studies showing a broad range from little to nearly complete motor recovery, which in itself remains vague evidence (Hendricks et al., 2002).

McCullagh et al. (2005) measured baseline Barthel Index (BI) scores of patients with stroke at commencement of in-patient rehabilitation. Baseline BI scores ranged between four and fourteen, which indicates moderate to severe disability (Wade & Hewer, 1987). Most of the patients improved significantly in their functional ability by three-months post-stroke, from measuring a median BI score of nine at baseline, to 18.5 at three-months (McCullagh et al., 2005).

Following in-patient rehabilitation, patients with stroke have significant improvement in their functional ability (De Wit, Putman, Schuback, Komárek, Angst, Baert, Berman, Bogaerts, Brinkmann, Connell, Dejaeger, Feys, Jenni, Kaske, Lesaffre, Leys, Lincoln, Louckx, Schupp, Smith, De Weerdt, 2007). Patients in De Wit et al. (2007)'s study reached 85% of the maximal BI score at six-months post-stroke. De Wit (2007) performed a correlation study which looked at motor and functional recovery after stroke in four rehabilitation units in the United Kingdom and Europe. Patient functional ability was assessed using the Nottingham Extended Activities of Daily Living (NEADL), the Rivermead Motor Assessment (RMA) and the BI. The improvements seen in BI scores were elaborated on between the United Kingdom and Germany centres, where the United Kingdom centre improved the patients' BI score more than at the centre in Germany. De Wit et al. (2007)'s study had a 9% loss of follow-up in the Belgium centre, 13% loss in the United Kingdom centre, 11% loss in the Swiss centre, and 19% loss in the German centre. The vast loss of follow-up in the German centre may result in correlations of poor standard. Despite this loss, the study was good, as it presented level III evidence, included a consecutive 135 patients admitted to the centres who met the criteria, and adjustments were made for the many variables that could have influenced motor and functional recovery in the four different centres.

Patients with stroke are not all functionally independent at discharge from hospital, but their level of function improves over time (Mamabolo, Mudzi, Stuart, Olorunju, Singh, 2009). In a cross-sectional study involving 68 patients with stroke it was established that patients with caregivers were less likely to regain full independent functioning, as compared to those who did not have caregivers (Mamabolo et al., 2009). It was

suggested that the reason for this finding was that those patients without caregivers were more independent in engaging in their environment, as compared to those patients with caregivers. Anderson et al. (1995) determined in their study that some caregivers react to the patient with stroke by being over-protective and over-caring, in an attempt to alleviate feelings of guilt that their actions or negligence caused or contributed to the disability, thereby reducing the patient's ability to reach their full functional potential.

About 80% of all stroke survivors have an upper limb paresis immediately after stroke with only about 30% to 40% regaining some dexterity within six-months following conventional treatment programs (Kwakkel, Kollen, van der Grond, Prevo, 2003; van Delden, Peper, Harlaar, Daffertshofer, Zijp, Nienhuys, Koppe, Kwakkel, Beek, 2009). The prospective cohort study performed by Kwakkel et al. (2003) demonstrated that patients with a middle carotid artery (MCA) stroke, who develop some voluntary movement of the lower limb in the first week after stroke, have about a 74% chance of regaining some dexterity in the flaccid upper limb, whereas absence of voluntary lower limb movement reduced this probability to 14%. If the patient with stroke is without observable movement or measurable hand grip in the affected upper limb one-month post-stroke, they are unlikely to recover any useful function of the affected upper limb (Heller, Wade, Wood, Sunderland, Hewer, Ward, 1987; Sunderland, Tinson, Bradley, Hewer, 1989). After the first week following stroke, the strongest clinical factor that predicts outcome of dexterity at six-months post-stroke is severity of paresis of the affected upper limb (Kwakkel et al., 2003; Wade, Langton-Hewer, Wood, Skilbeck, Ismail, 1983). Functional recovery of upper limb function is concentrated in the early months following stroke (Toschkea, Tillingb, Coxa, Ruddc, Heuschmann, Wolfe, 2010; Wade et al., 1983). After six- months post-stroke, there is a plateau of improvement in upper limb function (Toschkea et al., 2010; Wade et al., 1983), followed by a subsequent slight decline in function thereafter (Toschkea et al., 2010).

Initial walking function is impaired in two out of three patients with acute stroke (Jorgensen, Nakayama, Raaschou, Olsen, 1995). Jorgensen et al. (1995) performed a community-based population study and discovered that initially, 51% of patients had no

walking function, 12% could walk with assistance, and 37% had independent walking function. At the end of the rehabilitation process, 18% of patients had no walking function, 11% walked with assistance, and 50% had independent walking function (Jorgensen et al., 1995). Only 10% of patients with stroke with lower limb paralysis achieved walking function following participation in the community-based study performed at a hospital, where patients with stroke also received acute care and rehabilitation input. The predictors of walking outcome in patients with stroke include the patient's ability to cope with ADL's expressed by the BI scores, and development of lower limb strength during the first week post-stroke (Wandel, Jorgensen, Nakayama, Raaschou, Olsen, 2000). If the BI score is 50 or more and the lower limb strength improves markedly within the first week, the probability of regaining walking function is high, and if the BI score is less than 20 and lower limb strength does not improve rapidly in the first week, the probability of regaining walking function is very low (Wandel et al., 2000). Improvement in walking function may occur as long as six- to twelve-months post-stroke (Olsen, 1990), but the majority of functional recovery occurs within the first three months (Olsen, 1990; Skilbeck, Wade, Langton-Hewer, Wood, 1983). Olsen (1990) suggests that patients with stroke with a low BI score on admission to hospital recover more slowly than patients with a high BI score. Jorgensen et al. (1995) reports that in the 349 patients who had no walking function on admission to hospital, 80% reached their best walking function within six weeks from onset of stroke, and by eleven weeks post-stroke, 95% of the 349 patients had reached their best walking function. In the 98 patients who could walk with assistance, 80% reached their best function within three weeks, and by five weeks post-stroke, 95% of the 98 patients had reached their best function (Jorgensen et al., 1995). These results do not however account for possible further improvement in walking function following completion of the rehabilitation period.

The functional levels that patients attain post-stroke can be influenced by the type of care that they receive. Patients managed in stroke units tend to have better functional outcomes than those managed in general wards or at home (Kalra, Evans, Perez, Knapp, Swift, Donaldson, 2005). Stroke unit interventions are reported to be more likely

to include coordinated multidisciplinary rehabilitation, staff with a specialist interest in stroke rehabilitation, and regular programmes of education and training (Stroke Unit Trialists' Collaboration, 1997). The environment of a stroke unit is aimed at promoting rehabilitation of the patient, and improvement in functional ability. The extent of disability due to stroke in South Africa is not fully understood, which may result in ineffectual planning of rehabilitation facilities and programmes, resulting in too few rehabilitation facilities and therapists in government hospitals (Hale & Eales, 1998). Generally patients with stroke in South Africa are only hospitalised until they are medically stable, thus receiving minimal rehabilitation prior to discharge (Hale & Eales, 1998).

Rousseaux, Daveluy and Kozlowski (2009) suggested that early supported discharge (ESD) may have a positive effect on participation in independent ADL. ESD services aim to accelerate the patient's discharge home and provide an equivalent level of rehabilitation input in the patient's own home in comparison with conventional hospital care and discharge arrangements (Langhorne, Widen-Holmqvist, Taylor, Murray, Askim, Dennis, Anderson, Bautz-Holter, Dey, Indredavik, Mayo, Power, Rodgers, Ronning, Rudd, Suwanwela, Wolfe, 2007). The greatest benefit of a coordinated multidisciplinary ESD team is seen in patients with mild to moderate disability (Langhorne et al., 2007; Rousseaux et al., 2009). ESD patients return home earlier and are more likely to remain at home in the long term and to regain independence in daily activities (Cochrane Review, 2007). In this review, the greatest benefits were seen in those trials with well organised discharge teams and in stroke groups with mild to moderate disability. In South Africa, patients with stroke are not likely to receive adequate rehabilitative community services due to ineffectual planning of rehabilitation facilities and programmes in the government hospitals, which service the general population (Hale & Wallner, 1996; Hale & Eales, 1998). The literature infers that patients with stroke in South Africa may not be provided with the optimal rehabilitative service to encourage involvement in their daily functional activities thereby negatively affecting recovery of independence.

In summary, there is a variety of literature that has looked at various factors concerning functional ability of a patient with stroke at discharge. It has been determined that patients are not all functionally independent at discharge from hospital, but have the ability to improve over time (Mamabolo et al., 2009). Most functional improvement occurs within the first few months following stroke (Olsen, 1990; Skilbeck et al. 1983, Toschkea et al., 2009; Wade et al., 1983).

2.3 Caregiver strain from caring for a patient with stroke

Caregiver strain in the early post-stroke period is notable, although not severe (Bugge et al., 1999). On average, using the Caregiver Strain Index (CSI), caregivers scored 4.5 at one-month, 4.3 at three-months, and 4.5 at six-months post-stroke (Bugge et al., 1999). In Bugge et al. (1999)'s study an increasing proportion of caregivers reported to be under strain from one- to six-months post-stroke (25% of caregivers at one-month, 28% at three-months, and 37% at six-months post-stroke). Participants in the study were identified through general practices in both urban and rural areas, so as to gain access to those patients being managed in hospital and in the home environment (Bugge et al., 1999). No mention was made as to adjustments made to account for different variables that may affect the caregiving experience in the different socio-economic settings. Bugge et al. (1999)'s study was of a fairly good standard with level III evidence, despite these omissions, and the omission of the number of lost participants. Tooth, Mckenna, Barnett, Prescott and Murphy (2005) reported that 44% and 42% of carers had considerable strain (indicated by CSI greater than 6) at six- and twelve-months post-stroke, respectively.

McCullagh et al. (2005) reported caregiver strain reducing significantly between three-months and one-year post-stroke using the Caregiver Burden Score (CBS), where averages of 48.2 and 38.3 were recorded at three-months and one-year post-stroke respectively. McCullagh et al. (2005) suggests the reduction in caregiver strain to be a response shift toward normalisation with time, although no reasoning was provided for why these findings differ from other literature in this regard. Sample selection for the study took place at an in-patient rehabilitation centre, therefore all participants were

initially receiving rehabilitation (McCullagh et al., 2005). It was noted that 50% of the caregivers received formal caregiver skills training while the patient with stroke was receiving in-patient rehabilitation and this resulted in a statistically significant reduction of caregiver strain between three-months and one year post-stroke, measuring CBS scores of 48.2 and 38.3 respectively ($p<0.0001$) (McCullagh et al., 2005). This is a good study performed by McCullagh et al. in 2005, with level III evidence, random allocation of participants into the study, and a blinded assessor. The study did however report a loss of 23% of participants at one-year post-stroke of those included in the original study, which may affect the generalisability of the findings.

The level of strain that caregivers experience as a result of caring for patients with stroke is a dynamic factor that changes throughout the course of the post-stroke period (McCullagh et al., 2005). McCullagh et al. (2005) revealed that caregiver strain in the immediate aftermath of stroke was determined by patient and caregiver anxiety. With time, caregiver strain seems to be determined by functional dependence of the patient on the caregiver, and anxiety and depression of the patient (McCullagh et al., 2005). Caregiver strain also increases with increased caregiver disability, anxiety and depression (McCullagh et al., 2005). At one-year post-stroke, caregiver strain is shown to increase with decreased family support and increased caregiver depression (McCullagh et al., 2005). Bugge et al. (1999) revealed that at one-, three- and twelve-months post-stroke, caregiver strain was associated with the amount of time spent with and time spent assisting the patient, in addition to the physical assistance required by the patient on the caregiver at twelve-months post-stroke.

Anderson et al. (1995) reported that at one-year post-stroke, 88% of caregivers report adverse effects on their lives due to their caring role using the Social Behaviour Assessment Schedule (SBAS), and 55% showed evidence of emotional distress on either the Hospital Anxiety and Depression Scale (HADS) or the 28-item General Health Questionnaire (GHQ-28), particularly if they were caring for patients with dementia and/or abnormal behaviour. At one-year post-stroke dementia and behavioural

abnormalities, rather than physical disability, are characteristics of patients with stroke that are most predictive of emotional illness among caregivers (Anderson et al., 1995).

Caregivers in poorer health are found to be under greater strain due to caring for the patient with stroke (Bugge et al., 1999; van den Heuvel, de Witte, Schure, Sanderman, Meyboom-de Jong, 2001). Bugge et al.'s study in 1999 used the SF-36 to determine caregiver health. The health score using the SF-36 is determined by eight dimensions, namely physical functioning, physical role functioning, bodily pain, general health, vitality, social functioning, emotional role functioning, and mental health. Caregivers in poorer health were found to be under greater strain, even when other patient and caregiver characteristics were taken into account (Bugge et al., 1999). An increasing proportion of caregivers under strain was found (14% of caregivers under strain at one-month, 17% at three-months, and 19% at six-months) even while, in general, caregiver health did not change greatly over the outcome scores taken over one-, three- and six-months post-stroke, measuring on average 4.5 on the CSI at one-month, 4.3 at three-months, and 4.5 at six-months post-stroke (Bugge et al., 1999). One possible explanation was the impact of caregiver health only being seen after caregiving for periods longer than six months (Bugge et al., 1999). A second possible explanation was that there is no simple relationship between caregiver health and strain, and that the caregiver's perception of their health may be dependent on many other life factors (Bugge et al., 1999). Van den Heuvel et al. (2001) on the other hand suggests a different explanation of the relationship between caregiver health and strain which is interesting to note, in that caregivers with better general health were likely to experience positive aspects of caregiving.

Female caregivers experience greater caregiver strain than do male caregivers (Almberg, Jansson, Grafström, Winblad, 1998; Bugge et al., 1999; Miller & Cafasso, 1992). Almberg et al. (1998) performed a study to determine differences between and within genders in caregiving strain, on caregivers of elderly dementia patients and elderly non-dementia patients. Although Almberg et al. (1998) does not name the measuring tool used to determine caregiver strain, it is however interesting to note that

female caregivers, in comparison to male caregivers, reported a higher degree of conflict with other family members, an increase in health problems, relations with family and others being affected ($p<0.01$), and a lack of positive outlook and limitation in social support ($p<0.0001$) (Almberg et al., 1998), which appear to be the factors measured by the strain measuring tool. Due to the fact that the measuring tool is not clearly stated and explained, the validity of these findings may be questionable. Bugge et al. (1999) reported that at one-month post-stroke, decreased caregiver strain was experienced if the caregiver was male ($p=0.006$), thereby indicating that female caregivers were under greater strain at one-month post-stroke. It is difficult to relate this finding to that on Almberg et al.'s study in 1998, as Almberg's study was not focused on patients with stroke and each diagnosis may have different variables that affect caregiver strain, however the similar gender findings are notable. Miller & Cafasso (1992) performed a literature review and similarly reported female caregivers of patients with stroke to be more likely to report greater strain than male caregivers, which the authors related to female caregivers performing more personal care and household tasks than male caregivers, although the effect was quite small. Moritz, Kasl and Berkman (1989) performed a study to determine the health impact of living with an elderly cognitively impaired spouse. Although this study does not report findings on patients with stroke and their caregivers, the findings are interesting to review. The husbands reported greater depressive symptomatology in caring for the wives ($p<0.05$), as compared to the wives when caring for the husband ($p>0.2$) (Moritz et al., 1989). This depressive symptomology can be related to the strain experienced by the caregiver. This finding is not consistent with the above literature. It was suggested that differences in study designs, the lack of control groups, and the predominance of women in prior work may have created the appearance of a greater impact on women in other literature may account for this discrepancy (Moritz et al., 1989). It was also suggested that other studies included both wives and daughters as caregivers, and therefore possible that the lesser impact on men represented a weaker impact on husbands relative to daughters (Moritz et al., 1989).

Caregivers of younger age experience greater caregiver strain than do older caregivers ($p<0.05$) (van den Heuvel et al., 2001). Van den Heuvel et al. (2001) suggested a possible explanation that younger caregivers often have other obligations (e.g. work, children) in addition to their caregiving role. This would lead to the caregiver needing to manage a number of responsibilities as well as caring for a family member or friend, which would obviously compound their level of strain.

Caregivers caring for patients with stroke with severe emotional, cognitive and behavioral difficulties experience greater caregiver strain ($p<0.001$) (van den Heuvel et al. 2001). Choi-Kwon, Kim, Kwon and Kim (2005) reported caregivers to be under greater strain with increased patient cognitive dysfunction ($p<0.01$) when interviewed between one- and five-years post-stroke (on average 3.4 years post-stroke). As mentioned above, Moritz et al.'s study in 1989 reported husbands and wives to report depressive symptomatology as a result of caring for their congnitively impaired elderly spouse (Moritz et al., 1989). Depressive symptomatology can be related to the strain that the caregiver experiences. Although Moritz et al. (1989)'s study does not assess caregivers of patients with stroke, the impact of cognitive impairment experienced by the care-recipient may be relevant to both care situations.

Increased caregiver strain is also associated with the patient's disability in terms of ADL's and handicap (Anderson et al., 1995; Bugge et al. 1999; Scholte op Reimer, Haan de, Rijnders, Limburg, Bos van den, 1998). Bugge et al. (1999) reported increased neurological impairment to be associated with increased caregiver strain. McCullagh et al. (2005) reported increased caregiver strain to be significantly correlated with increased patient disability in particular at three- ($p=0.007$) and twelve-months ($p=0.028$) post-stroke. Scholte op Reimer et al. reported in 1998 that patients' functional health problems in terms of disability in ADL ($p<0.01$), disability in instrumental activities of daily living (IADL) ($p=0.08$), and handicap ($p=0.02$) appeared to associate with higher caregiver strain.

The strain of caregiving is perceived in a number of ways by the caregiver (Scholte op Reimer et al., 1998). At one-year post-stroke, a variety of adverse emotional reactions are expressed by caregivers, which include anxiety (58%), depression (50%), fear (35%), frustration (32%), resentment (29%), impatience (25%), and guilt (10%) (Anderson et al., 1995). This agrees with Scholte op Reimer (1998)'s findings which showed that caregivers at three-years post-stroke perceive their strain of care in terms of feelings of heavy responsibility, uncertainty about patient's care needs, constant worries, restraints in social life, and feelings that patients rely on only their care. Choi-Kwon et al. (2005) performed a cross-sectional study in South Korea, which similarly demonstrated that at three-years post-stroke, the most significant predictor for overall caregiver strain was caregiver anxiety.

Caregiver strain is a complex and multilayered concept, which is dynamic and changes throughout the post-stroke period. It is important to understand those factors that influence caregiver strain at a variety of time intervals after the patient has had a stroke, so as to provide relevant support in the dynamic process of care. It is important to be able to foresee caregivers at risk of increased strain due to caring for a person with stroke, so as to prevent this strain, which in turn will have an effect on the rehabilitation of the person with stroke.

2.4 Factors that influence the caregiver's quality of life

2.4.1 Patient functional ability

Much research has been performed to establish the influence that patient functional ability has on the quality of life of the patient. Very few studies have investigated the interactions between patient characteristics and quality of life experienced by the caregiver (McCullagh et al., 2005). The interaction between patient functional ability, as one of many patient characteristics, and caregiver quality of life is in need of further investigation.

An improvement in functional ability of the patient causes an improvement in caregiver quality of life (Jönsson, Lindgren, Hallström, Norrving, Lindgren, 2005). This was

demonstrated in a study on 304 consecutive first-ever patients with stroke and 234 caregivers. An increase in patient functional ability (using the BI) was directly correlated with an increase in caregiver social and mental domains on the Short Form 36 (SF-36) assessment tool (quality of life measuring tool). The study performed by Jönsson et al. in 2005 was of a fair standard, with level III evidence. Initially 416 patients with stroke were included in the study, however due to death 304 patients remained in the study at the last interview at sixteen-months post-stroke. Data were only taken from these 304 patients and analysed in the study. There were however an unequal number of caregivers who participated in the study, which may not have skewed the associations reported between caregiver and patient.

McCullagh et al. (2005) demonstrated similar findings to Jönsson et al. (2005). Caregiver quality of life was assessed using the Euroqol Visual Analogue Scale (EQ-5D EQ VAS) at three- and twelve-months post-stroke. Findings showed significant correlation of decreased caregiver quality of life with increased patient disability at three- and twelve-months post-stroke (McCullagh et al., 2005).

Severity of stroke and resulting disability or loss of functional ability is directly related to increased caregiver strain, and caregiver strain being inversely related to caregiver quality of life (Bugge et al., 1999; McCullagh et al., 2005). A conclusion can therefore be made whereby loss of functional ability of the patient with stroke has an inverse effect on quality of life of the caregiver.

Further research is needed to verify these correlational findings between patient's functional ability and caregiver quality of life. It would also be interesting to determine whether this correlation is changeable during the course of recovery of the patient with stroke.

2.4.2 Caregiver strain

Research is clear with regard to the statistical relationship between caregiver strain and caregiver quality of life. An inverse correlation is evident between the two factors,

demonstrating that an increase in caregiver strain results in decreased caregiver quality of life (Bugge et al., 1999; McCullagh et al., 2005; Morimoto, Schreiner, Asano, 2003).

An inverse correlation between caregiver strain and caregiver quality of life was reported at three- and twelve-months post-stroke in patients who received in-patient rehabilitation (McCullagh et al., 2005). Interestingly, at one-year post-stroke, improvements were seen in caregiver strain, but no improvements were seen in caregiver quality of life (McCullagh et al., 2005). This divergence in relationship between caregiver strain and caregiver quality of life may result from a number of factors: it may indicate the interaction of additional factors at different time intervals in the recovery process, relating to the caregiver's perceived quality of life; it may result from a limitation of the measuring tools to capture the interaction between caregiver strain and the capacity of the caregiver; it may result from personal changes as caregivers adapt to their caregiving role over time (such as decreased support, ill health, changing roles), which may have a negative effect on their quality of life (McCullagh et al., 2005).

Bugge et al. (1999) similarly reported an inverse correlation between caregiver strain and caregiver quality of life at three- and six-month post-stroke. Interestingly, however, the study reported increasing proportions of caregivers to be under considerable strain over this time period, with no great change in their quality of life (Bugge et al., 1999), as compared to the findings by McCullagh et al. in 2005. A possible reason for caregiver strain increasing between three- to six-months post-stroke (Bugge et al., 1999) as opposed to improving between three to twelve-months post-stroke (McCullagh et al., 2005) could be that in the longer-term post-stroke, the caregiver has more caregiver experience, and adapts to their role, possibly easier or faster than in the short-term post-stroke.

The varying reports in the relationship between caregiver strain and caregiver quality of life seen in the literature, leads us to believe that there is not such a clear relationship between the two factors. Other factors that influence both caregiver strain and caregiver quality of life need to be taken into consideration. It would also be important to

investigate the variability of the relationship over a period of time intervals, so as to identify the dynamic course along which the relationship runs.

Morimoto et al. (2003) performed a study to explore the relationship between caregiver strain and quality of life of the caregiver. Increased strain was significantly related to decreased quality of life (Morimoto et al., 2003). Fifty seven percent of the caregivers in the study reported having been caring for the patient for less than two years, while 22% had been caring for the patient for more than five years (Morimoto et al., 2003). This study therefore explores the relationship between caregiver strain and caregiver quality of life further along the recovery time period. The study showed that caregivers continued to be under strain and experience a decrease in their quality of life over five years post- stroke. Morimoto et al. (2003)'s study consisted of consecutive participants from randomly selected private neurological hospitals with rehabilitation clinics, which enhances its strength of evidence.

2.4.3 Patient and caregiver demographic factors

Rombough (2007) performed a systematic review to compare studies on the quality of life of primary caregivers of stroke survivors. He discovered that little information was provided on demographic data of the caregivers. Limited information regarding demographic data relating to caregiver quality of life is discussed below.

Increased age of the caregiver is a determinant for a decrease in caregiver quality of life (Jönsson et al., 2005; McCullagh et al., 2005; Morimoto et al., 2003). This relationship has been seen in studies performed at four-months (Jönsson et. al., 2005), three-months, and one-year post-stroke (McCullagh et. al., 2005), and at greater than five-years post-stroke (Morimoto et. al., 2003). Jönsson (2005) elaborates further by stating that in using the SF-36 as a measure of caregiver quality of life, increased age of the caregiver is negatively related to the caregiver's physical and emotional domains, general health and bodily pain domains. This information therefore enlightens us to the particular struggles of the caregiver in their caregiving role, by suffering in physical and

emotional functioning, in their state of general health, and experiencing bodily pain, as a result of increased age in their caregiving role.

Increased age of the patient is a factor influencing a decrease in caregiver quality of life (Jönsson et al., 2005; McCullagh et al., 2005). Increasing age in patients is related to lower scores in physical domains (i.e. worse functioning in the components of physical functioning, bodily pain, general health and role limitation due to physical problems) and higher emotional and mental scores (i.e. better functioning in the components of vitality, social functioning, mental health and role limitation due to emotional problems), as per the SF-36 (Jönsson et al., 2005). Caregiver quality of life components are positively affected by better functional status in patients (Jönsson et al., 2005). Therefore, as the patient gets older, their physical functioning worsens, which in turn impacts negatively on the caregiver's quality of life. Caregivers' social function and vitality (components of the mental score as per the SF-36) are negatively influenced by patients' increasing age (Jönsson et al., 2005), thereby indicating that older patients negatively impact the caregiver's social involvement in their community, and worsens their sense of vitality.

White, Mayo, Hanley and Wood-Dauphinee (2003) reported no significant difference between caregiver quality of life and caregiver age. White et al. (2003) had a well-presented study. 181 patients and 181 caregivers initially participated in the study, but only 97 patients and 97 caregivers were interviewed in both the first and second years post-stroke. Data was therefore only used for the 97 patients and 97 caregivers, while bias was excluded from the initial 181 patients and caregivers' data. It was however unclear as to if the participants were randomly or consecutively assigned to the study. White et al. (2003) addressed the objectives of the study in a very clear manner. This statistical relationship between caregiver quality of life and age was not expounded on in other literature.

The female gender of patients is positively associated with some aspects of the quality of life of the caregiver (Jönsson et al., 2005; McCullagh et al., 2005). Female patients are associated with higher scores for physical role, emotional function, general health,

mental, and vitality domains of the caregiver (i.e. indicating better functioning in these components of quality of life) (Jönsson et al., 2005). This demonstrates that a female patient has less of a negative impact on the caregiver's physical and emotional state, on their general and mental health and their experience of vitality, as compared to those patients who are male. Male caregivers report a limitation in social support and a lack of positive outlook (Almberg et al. 1998), which has a negative effect on their experienced quality of life.

One-month following a stroke, a male caregiver may experience a better quality of life due to experiencing less caregiver strain, than a female caregiver would (Bugge et al., 1999). The gender of the caregiver is one of the patient factors that differed with time in the study performed by Bugge et al. in 1999. No further explanation was given for the relationship between caregiver gender and quality of life one-month post-stroke, except that caregiver gender may be a factor associated with different variables, thereby changing with time post-stroke (Bugge et al., 1999). Caregivers who consistently scored low on the mental score of the SF-36 at seven- and twenty three-months post-stroke were more likely to be female (White et al., 2003). Female caregivers scored 9-21% lower than the age- and sex-matched norms on the mental subscale, and men scored 9-13% lower than the norms (White et al., 2003). The influence that gender has on caregiver strain, and therefore caregiver quality of life, does however appear to differ with time (Bugge et al., 1999). There are several theoretical perspectives on gender effects in caregiving that suggest that gender influences the amount and type of care provided and access to social resources that may alleviate the strain associated with caregiving (Miller & Cafasso, 1992). Women spend more time on caregiving activities and are more likely to perform personal care activities than are men. Instrumental tasks that are time-limited and may be performed at the caregiver's discretion, such as money management, are more likely to be congruent with the roles of male caregivers (Ford, Goode, Barrett, Harrell, Haley, 1997). White (2003) suggests that women are less likely to obtain informal support for caregiving and consequently to report higher levels of burden, and that male caregivers may also be more likely to receive home care services, thereby relieving strain and improving their quality of life.

A patient's household faces financial concerns, as households are required to meet expenses for equipment, services, or architectural improvements on the house in the hope of decreasing the caregiver's strain and improve their quality of life (Béthoux, Calmels, Gautheron, Minaire, 1996). Béthoux et al. (1996)'s study was performed on nine married couples who were discharged from a rehabilitation unit in France. This small sample size may affect the generalisability of the findings. Béthoux et al. (1996) stated that the participants were "selected", and does not elaborate on the manner of the selection. This may affect the relevance of the findings.

Research has yet to identify a more detailed picture of those demographic factors that influence caregiver quality of life. Further research into these relationships are necessary to gain relevant information to strengthen demographically-relevant data.

2.5 Review of assessment tools

2.5.1 Barthel Index

The BI was developed by Mahoney and Barthel in 1965. The purpose of the BI was to measure functional independence in personal care and mobility, and is used for individuals with stroke, among other conditions (Finch, Brooks, Stratford, Mayo, 2002).

The BI is a 10-item performance-based instrument that evaluates ADL's. Scores range from between 0 and 100, with a score of 100 representing the highest level of independence. A perfect score does not mean the person is able to live alone or perform instrumental ADL's (such as cooking and house cleaning) (Finch et al., 2002).

Each item is assigned a score of 0, 5, 10, or 15; each item is weighted differently and hence reflects the relative importance of each type of disability in terms of assistance required (Finch et al., 2002). A total is calculated from all the scores assigned to the items, with 100 being the maximum value that can be attained. Shah et al. (1989) proposed that a total BI score of 0 – 20 suggests total dependence, 21 – 60 severe dependence, 61 – 90 moderate dependence, 91 – 99 slight dependence, and 100 indicates that a patient is independent of assistance from others.

Clinically, the BI has proven value in discriminating between groups of patients (construct validity) and predicting outcome (predictive validity) (Kasner, 2006).
The BI has a Cronbach's α of 0.98 according to Kasner (2006), and of 0.90 according to Shah et al. (1989). Cronbach's α is known as an internal consistency estimate of reliability of test scores. Alpha can take values between negative infinity and one, and the value of α will generally increase as the intercorrelations among test items increase. A Cronbach's α value of 0.98 is therefore an indication of high internal consistency of the BI.

The correlation coefficient of the BI on a sample of 25 in-patients in a neurorehabilitation unit, with mixed diagnoses was 0.99 ($p < 0.001$) (Finch et al., 2002). The correlation coefficient is a measure of the correlation (linear dependence) between variables. It is used as a measure of the strength of linear dependence between variables. The correlation coefficient ranges from −1 to 1. If correlating two variables, a value of one implies that a linear equation describes the relationship between those two variables perfectly. Thus, the BI demonstrates good correlation between its variables.

Richards, Peters, Coast, Gunnell, Darlow and Pounsford (2000) performed a study to determine inter-rater reliability of the BI. The study was aimed at determining whether a non-clinical researcher using the BI was as reliable as a nurse assessor. This study found no significant differences on average between assessors in terms of the total BI score. Individual items which comprise the BI score were examined using the Cohen's kappa statistic. Strength of agreement was generally moderate / good, with a high crude agreement. The BI was found to be reliable and repeatable in skilled and unskilled hands (Shah et al., 1989).

Finch et al. (2002) noted that kappa scores (a statistical measure of inter-rater agreement) among five therapists using the total score to rate seven in-patients with stroke for each patient ranged from 0.70 to 0.88.

There was no significant difference in ratings by patient versus proxy, nor when the interview was done by trained lay persons or health-care professionals, irrespective of the mode of interview (Kasner, 2006).

In another study assessing the intra-rater reliability of the BI, Loewen & Anderson (1988) reported that 83% of the 35 kappa values were in the excellent agreement range, and the range of Spearman rank-order correlation coefficients were 0.95 to 1.00 with a median of 0.99. These results were taken from the total score for two physiotherapists and three occupational therapists administering the BI on seven in-patients with stroke (Loewen & Anderson, 1988).

The Functional Independent Measure (FIM) and BI were found to have similar responsiveness to change in a group of patients recovering from stroke between one and three months post-stroke (Wallace, Duncan, Lai, 2002). Similar findings in the responsiveness of the FIM and BI were also established by Houlden, Edwards, McNeil and Greenwood (2006). The BI is reasonably easy to administer, and requires less time to be administered, while the FIM requires training and certification, and may take a slightly longer time for administration (Wallace et al., 2002).

The literature and resources demonstrate that the BI has value in discriminating between groups of patients (construct validity) and demonstrates predictive validity. The BI also demonstrates high internal consistency and moderate / good inter-rater reliability. The BI has also been a common measuring tool in literature to determine patient functional ability (De Wit et al., 2007; Mamabolo et al., 2009; McCullagh et al., 2005; Wandel et al., 2000), which allows for comparison of results between the study and other literature. Due to these positive attributes of the BI, that it is an easily administered measuring tool, and it takes less time to administer compared to other measuring tools, it was the measuring tool of choice for this study.

2.5.2 Rivermead Motor Assessment (RMA)

The RMA was developed by Lincoln and Leadbitter in 1979 (Zeltzer, Korner-Bitensky, Sitcoff, Marvin, 2011). It is a measuring tool to measure motor performance of patients with acute, sub-acute and chronic stroke (Zeltzer et al., 2011). The RMA measures three subsections, namely the Rivermead Motor Assessment of Gross Function (RMA-GF) of which are thirteen items, the Rivermead Motor Assessment of Leg/Trunk (RMA-LT) of which are 10 items, and the Rivermead Motor Assessment of Arm (RMA-A) of which are 15 items (Zeltzer et al., 2011). The assessor scores a “1” if the patient is able to perform the task, and “0” if the patient is unable to perform the task (Zeltzer et al., 2011). Traditionally, when three consecutive attempts to complete an item are failed within a subsection, the test is stopped as it is assumed that all subsequent items in the subsection will also be failed (Zeltzer et al., 2011). If a patient refuses to perform an item (e.g. due to anxiety), a “0” for that item is scored. The RMA takes approximately 45 minutes to administer to an ambulatory client with a recovering upper extremity (less time with more severely disabled patients), and is typically administered by a physiotherapist (Zeltzer et al., 2011). The RMA should be used with caution with individuals with chronic stroke aged 65 and older, as they may not be able to perform some of the specific tasks but may be able to perform subsequent tasks that are deemed more challenging (Zeltzer et al., 2011). The patients in the current study were not restricted in age to younger than 65, therefore use of the RMA in the current study would not have been appropriate.

The RMA is reported to have excellent internal consistency for all subsections, adequate test-retest reliability of the RMA-GF and excellent test-retest reliability for the RMA-LT and RMA-A (Zeltzer et al., 2011). As per inter-rater reliability of the RMA, it is reported that there were no significant difference on average scores for all patients across all raters scoring the RMA-GF and RMA-LT subsections, yet significant difference was noted across raters as per the RMA-A subsection (Zeltzer et al., 2011). No studies have yet to examine intra-rater reliability of the RMA (Zeltzer et al., 2011).

In relation to construct validity of the RMA, excellent correlations are reported between the RMA-A subsection and the MOtricity Index Upper Extremity subscale (Zeltzer et al., 2011). Excellent correlations are reported between the RMA and the total score of the Fuctional Independence Measure (FIM) and with the FIM Motor subscale (Zeltzer et al., 2011). Adequate correlations are reported between the RMA and the FIM Cognitive subscale (Zeltzer et al., 2011).

2.5.3 Caregiver Strain Index

The CSI was produced by Robinson in 1963, and is a tool that can be used to identify families with potential caregiving concerns. It is a 13-question tool that measures strain related to care provision. Positive responses to seven or more items on the index indicate a greater level of strain (Sullivan, 2004). When a positive screen for caregiver strain occurs (when seven or more items are positive), it is vital for more in-depth assessment to facilitate appropriate intervention to assist in diminishing the strain experienced by the caregiver (Sullivan, 2004).

The CSI is a useful and valid instrument which is easy and quick to administer (van Heugten, Visser-Meily, Post, Lindeman, 2006). When compared to the Caregiver Reaction Assessment (CRA), the Sense of Competence Questionnaire (SCQ), and a self-developed single question on self-rated burden (SRB), the CSI was found to be the most feasible assessment tool to use (van Exel, Scholte op Reimer, BF Brouwer, van den Berg, Koopmanschap, van den Bos, 2004). It is the most commonly used assessment tool for caregiver strain (Visser-Meily, Post, Riphagen, Lindeman, 2004). The CSI was established to have good internal consistency (Visser-Meily et al., 2004).

The CSI has convergent validity (van Heugten et al., 2006). A comparison of the CSI, CRA, SCQ and the SRB showed that the clinical validity of the CSI, SCQ and SRB were the strongest (van Exel et al., 2004).

When comparing the CSI and the CRA, most items of the CSI have showed good reproducibility and the CSI proved to have satisfactory responsiveness (Post, Festen, van de Port, Visser-Meily, 2007).

Therefore the CSI was used in this study as it is a commonly used measurement tool, is easy to use and has good feasibility, strong clinical validity, good reproducibility and satisfactory responsiveness.

2.5.4 EuroQoL-5D (EQ-5D)

The European Quality of Life Scale-5D (EQ-5D) provides a descriptive profile and a single index value of health status for use in clinical and economic evaluation of health care and population surveys (Finch et al., 2002; Oppe, Rabin, de Charro, 2007). The EQ-5D was designed to be a standardised, non-disease-specific instrument for describing and valuing health-related quality of life. The producers of the EQ-5D measuring tool have aimed at a global instrument with the capacity to generate cross-national comparisons (Brooks, 1996). This is an important aspect when deciding to use the EQ-5D instrument in determining health-related quality of life in the South African context.

The visual analogue scale (VAS) is a component of the EQ-5D measuring tool. The EQ-5D VAS records the respondent's self-rated health on a vertical, visual analogue scale where the end points are labeled "Best imaginable health state" and "Worst imaginable health state" with a range of 0 to 100 (Oppe et al., 2007). This information can be used as a quantitative measure of health outcome as judged by the individual respondents (Oppe et al., 2007).

The EQ-5D is a short and 'user friendly' measuring tool (Brooks, 1996). Badia et al. (1999) agrees that the EQ-5D VAS of the EQ-5D takes considerably less time to administer as compared to the Time Trade-Off (TTO) tool, and therefore displaying more feasibility.

Barton, Sach, Avery, Jenkinson, Doherty, Whines and Muir (2008) reported that the ED-5D has greater practicality as compared to the Short Form 6D (SF-6D), as completion rates of the SF-6D were significantly lower than those of the EQ-5D when comparing the two tools with regard to performance.

The EQ-5D and the SF-6D performed adequately with regard to convergent and construct validity (Barton et al., 2008). However when analysing larger sample sizes, Badia et al. (1999) suggests that the TTO measuring tool may have slightly better construct validity, as the scores are able to discriminate better between different health states, as compared to the EQ-5D VAS values which are compressed. The EQ-5D VAS showed better test-retest reliability (mean inter-class coefficient (ICC) of 0.78) when compared to the TTO (mean ICC of 0.73) (Brooks, 1996) and the EQ-5D VAS proved to be slightly more reliable (mean ICC of 0.90) than the TTO (mean ICC of 0.84) (Badia et al., 1999).

In conclusion, due to the fact that the EQ-5D is aimed at global instrumentation and administration, that it presents itself in a 'user friendly' manner, is quick to administer, displays good practicality, has adequate validity and good reliability, it was considered to be a good choice of measuring tool for this study.

2.5.5 Short Form 36 (SF-36)

The SF-36 is a multipurpose, short-form health survey with 36 questions (Ware, 2000). The SF-36 is a comparable measuring tool to the EQ-5D in measuring quality of life. The SF-36 yields an eight-scale profile of scores (namely physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health) as well as physical and mental health summary measures (Ware, 2000). The SF-36 is a generic tool and has been useful in comparing general and specific populations, comparing the relative burden of diseases, differentiating the health benefits produced by a wide range of different treatments, and screening individual patients (Ware, 2000). The SF-36 is suitable for self-administration, computerized administration, or administration by a trained interviewer in person or by telephone, to persons aged 14 years and older (Ware, 2000). The SF-36 has been administered successfully in general population surveys in the United States and other countries as well as to young and older adult patients with specific diseases (Ware, 2000). It can be administered in 5–10 minutes with a high degree of acceptability and data quality (Ware, 2000).

Version 2.0 of the SF-36 was introduced in 1996, to provide simpler instructions and questionnaire items, an improved layout for questions and answers in the self-administered version, greater comparability with widely used translations and cultural adaptations, and five-level response choices in place of dichotomour reponse choices for items in the two role functioning scales (Ware, 2000).

Published reliability statistics have exceeded the minimum standard of 0.70 recommended for measures used in group comparisons, with most exceeding 0.80 (Ware, 2000). Reliability estimates for the physical and mental summary scores usually exceed 0.90 (Ware, 2000). The median reliability coefficients for each of the eight scales was equal to or greater than 0.80 except for the subscale measuring social functioning, which had a median reliability across studies of 0.76 (Ware, 2000). A reliability of 0.93 has been reported for the subscale measuring mental health (Ware, 2000).

The validity, and therefore the interpretation, of each of the eight scales and the two summary measures has been shown to differ markedly (Ware, 2000). Specifically, the subscales measuring mental health, role-emotional, and social functioning and the Mental Component Summary measure have been shown to be the most valid of the SF-36 scales as mental health measures (Ware, 2000). The subscales measuring physical functioning, role-physical, and bodily pain and the Physical Component Summary have been shown to be the most valid SF-36 scales for measuring physical health (Ware, 2000).

The SF-36 has proven to be a widely used measuring tool, and is also expensive to purchase. For this reason, it was not an appropriate tool to use in the current study.

2.6 Concluding thoughts

Patients with stroke are not all functionally independent at discharge from hospital. Most functional improvement occurs within the first few months following stroke, although further improvement can still occur (Mamabolo et al., 2009). Caregiver strain is a

complex and multilayered concept, which is dynamic and changes throughout the post-stroke period. In previous studies, factors that influence caregiver quality of life were established. Improvement in the functional ability of the patient results in improvement in caregiver quality of life. An increase in caregiver strain results in decreased caregiver quality of life. Increased age of the caregiver and patient are determinants for a decrease in caregiver quality of life. A female patient is associated with some aspects of caregiver quality of life in a positive manner, as compared to those patients who are male. A male caregiver may experience a better quality of life than a female caregiver would.

CHAPTER 3

3. RESEARCH METHODOLOGY

3.1 Study Design

Given the nature of the study, a cross-sectional study was deemed adequate to help answer the objectives of the study. A cross-sectional design is relatively quick, cheap and easy to carry out (Reaves, 1992; Kirkwood & Sterne, 1988). A cross-sectional research design was appropriate for understanding the relationship between caregiver quality of life and other factors as they exist in a specified population at a particular time (Bland, 2001).

3.2 Subjects

3.2.1 Source of Subjects

The subjects were sought from public health facilities in the Johannesburg area, namely: Alexandra clinic in Alexandra, Chiawelo clinic and Mofolo clinic in SOWETO, Helen Joseph Hospital, Chris Hani Baragwanath Hospital and Stroke Aid South Rand. The subjects were assessed in the physiotherapy or therapy departments as out-patients, coinciding with their usual visit to the department. The first 35 participants who met the criteria for the study were selected consecutively.

3.2.2 Sample Selection

For every factor that is considered to have a possibility of influencing the results of the study, at least ten subjects are required (Nunnally, 1978). For this study, it would mean that for every factor considered to have an influence on caregiver quality of life at least ten subjects are required. Three factors were identified as factors that could have more influence on the results of the study, based on the literature review. The identified factors were caregiver age, caregiver strain and patient's functional ability. This determines a sample size of 30. However, during data collection, an additional 5

subjects were incorporated into the study, as they were available and willing to participate in the study. Thus the sample size for this study was 35 subjects.

3.2.2.1 Inclusion Criteria

a) Patients

- Patients with stroke as defined by World Health Organisation (WHO, 2006)
- Aged 18 years and above
- First time stroke
- Six– 36 months after the stroke

  This time frame was chosen in order that the present study can be compared to a number of studies that perform data collection between six and 36 months post-stroke (Bugge et al., 1999, Choi-Kwon et al., 2005, De Wit et al., 2007, Morimoto et al., 2003, Scholte op Reimer et al., 1998, Tooth et al., 2005)
- Required a caregiver to assist in any degree of daily functioning

b) Caregivers

- Aged 18 years and above
- Primary informal caregiver who provided care for the patient with stroke since discharge from the hospital
- Lived in the same household as the patient with stroke

3.2.2.2 Exclusion Criteria

- Patient with stroke with any disability prior to the stroke
- Patient with stroke who required a caregiver prior to the stroke
- Caregiver with disability
- Formal caregiver

3.3 Instrumentation and Outcome Measures

The following instruments were used in the study:

Demographic Questionnaire (Appendix I, J, K, L)

Barthel Index (Appendix M)
Caregiver Strain Index (Appendix N, O)
EQ-5D (Appendix P, Q)

3.3.1 Demographic Questionnaires

Literature reports various patient and caregiver demographic factors to have an effect on caregiver quality of life (Almberg et al., 1998; Béthoux et al., 1996; Bugge et al., 1999; Ford et al., 1997; Jönsson et al., 2005; McCullagh et al., 2005; Miller & Cafasso, 1992; Morimoto et al., 2003; Rombough et al., 2007; White et al., 2003). Not all demographic factors are relevant in different demographic and social environments. To gain a better understanding of the relationship between demographic factors and caregiver quality of life, it was essential that demographically-relevant factors were identified and investigated.

Self-administered questionnaires were developed to capture demographic information of the study population (patients and caregivers) in this study. The questionnaires attempted to capture information that was relevant to the sample population in the Alexandra, SOWETO, Westdene and South Rand areas in Johannesburg.

a) Demographic questionnaire for the patient

The demographic questionnaire for the patient (Appendix K) comprised of four sections.

Section A: This gathered information that included age, marital status and level of education of the patient with stroke.

Section B: This collected information on the socio-economic situation of the patient before and after the stroke.

Section C: This gathered information about the stroke incident including side of body that was affected by the stroke.

Section D: This gathered information on the hospitalization that the patient went through and the rehabilitation that was received prior to discharge.

b) Demographic questionnaire for the caregiver

The demographic questionnaire for the caregiver (Appendix I) comprised of three sections.

Section A: This gathered information that included the caregiver's age, marital status and level of education.

Section B: This covered the socio-economic situation of the caregiver which included the family situation and income.

Section C: This explored the caregiver's role in the rehabilitation of the patient with stroke and the training (if any that was received).

Content and construct validity of the demographic questionnaires were established by a group of experts in the field of neurology rehabilitation who were selected by the postgraduate department. Validity was obtained through thorough debate and fine-tuning of the questionnaires amongst the experts. Reliability of the demographic questionnaire was established in the pilot study (see 3.4.2).

The BI, CSI and EQ-5D are standardized outcome measures and are described in detail in the literature review under review of the methodology.

3.4. Procedure

3.4.1 Introduction

Ethical clearance for both the pilot and main studies was obtained prior to commencement of the pilot study (Appendix A). The development of the following forms occurred prior to commencing the pilot study: information sheet for the patient with stroke and the caregiver (Appendix C, D, E, F); consent forms for the patient with stroke

and the caregiver (Appendix G, H); demographic questionnaires for the patient with stroke and the caregiver (Appendix I, J, K, L).

The CSI and the demographic questionnaires were translated from English into Zulu by one Zulu/English-speaking professional. A second Zulu/English-speaking professional translated the Zulu version of the CSI back into English, so as to assess validity of the Zulu translation. Zulu wording was corrected by the second professional, so as to match the English version more closely.

The EQ-5D had already been translated into Zulu by the developers, therefore the Zulu translation used in this study is an official language version, that has been officially ratified by the EuroQol Group's Translation Committee (Oppe, 2007).

There was no need to translate the BI, as the BI was administered by the interviewer. Validity and reliability of the BI have been established in the South African population in previous studies (Mamabolo et al., 2009; Mudzi, 2010).

3.4.2 Content Validity of the Demographic Questionnaire

The demographic questionnaire that was created for the study was assessed for content validity by a group of experts in the field of neurology rehabilitation. The demographic questionnaire had not been previously used as a measurement tool, and therefore the four experts in neurological rehabilitation selected by the postgraduate department assessed by means of thorough debate and fine tuning of the tool whether the questionnaire represented appropriate content to gather the relevant information of the sample population. Recommended amendments were made to the demographic questionnaire prior to use in the study.

3.4.3 Pilot Study

3.4.3.1 Objectives

A pilot study was performed to:

- determine if subjects understood the translated questionnaires;

- determine the ability of subjects to complete the self-administered questionnaires; and to
- determine the length of time required to administer and complete the questionnaires.

3.4.3.2 Methodology

Permission was sought from Alexandra Clinic to conduct the pilot study and the contact person for this was the therapy manager at the clinic, who gave verbal permission. The purpose of the pilot study was explained to the therapy manager, and a suitable time was decided on, for the pilot study to occur.

The therapy manager suggested that the researcher should attend their weekly physiotherapy exercise class and with the assistance of the physiotherapy and occupational therapy assistants, to locate relevant participants. It became clear that there was only one potentially relevant participant for the pilot study at Alexandra Clinic. Contact was made with this potential participant and arrangements made to administer questionnaires to themselves and their caregivers after attending the exercise class.

The minimum size for an internal pilot study should be ten patients per study group for a two-group study (Birkett & Day, 1994). The current study however had only one study group therefore five participants were required to participate in the pilot study. The same process was therefore performed at Chiawelo, Zola and Mofolo clinics, where the other four potential participants for the pilot study were located.

Once contact was made with the potential participants at their visit to the clinic, the patient with stroke and their caregiver were each given an information sheet to explain the proceedings of the pilot study. Each of the five participants in the pilot study chose to use the English versions of all the forms and tools. During this initial process, one of the participants could not or chose not to read the information sheet, and they requested a verbal explanation of the process of the study. Once a good understanding of the process of the pilot study was gained and the participants agreed to participate in

the pilot study, they each signed a consent form regarding participation in the pilot study.

In the case of the patient having difficulty understanding the explanation of the pilot study by the researcher, the caregiver interpreted the explanation of the pilot study to the patient, and obtained their consent. When consent was given, the researcher and research assistant presented the demographic questionnaire, the EQ-5D and the CSI to the caregiver to complete in English (as this was the preferred translation by all participants in the pilot study). All five of the caregivers chose to complete the questionnaires in English.

The researcher explained the study and administered the measuring tools for three of the participants in the presence of the research assistant. The research assistant then explained the study and administered the measuring tools for the remaining two participants in the presence of the researcher. By observing the administration of the measuring tools, the researcher and research assistant discussed the use of language in their explanation of the research process and administration of the measuring tools, so as to ensure that they were easily understood by the participants.

3.4.3.3 Results and implications of the pilot study

The whole process took a variable length of time between the five participants, varying from 30 to 50 minutes. The Zulu versions of the forms were not chosen for use in the pilot study by the participants and were therefore not piloted, thereby unfortunately not achieving the first objective of the pilot study. Each participant requested additional explanation of the questions from the researcher, apart from reading it as an individual. It was therefore made clear that the tools would most likely not be suitable for self-administration, and that the researcher or research assistant would need to be available for an average of 41 minutes for each interview in the main study. The participants had no difficulty understanding explanations of questions in English, and all questions were answered appropriately.

The content of the demographic questionnaires for the patient with stroke and the caregiver were found to be relevant to all participants from the different clinics. The social and demographic status of the people living in Alexandra and SOWETO are comparable, therefore the demographic questionnaires were reliable in being used in both geographic settings in Johannesburg.

3.4.4 Main Study

Permission was gained by the researcher from Alexandra Clinic, Chiawelo Clinic, Mofolo Clinic, Helen Joseph Hospital, Chris Hani Baragwanath Hospital and Stroke Aid South Rand to conduct the main study. Contact was made with the therapy managers at each clinic and hospital. The study was explained to the therapy manager by the researcher, and suitable arrangements were made for collecting patient information and administering questionnaires.

The therapy managers at each clinic or hospital suggested that the researcher and/or research assistant attend the physiotherapy exercise class and, together with the assistance of the physiotherapy and occupational therapy assistants, locate relevant participants.

Once the researcher had established days when the patients with stroke attended the clinic or hospital for their exercise classes, the researcher and/or research assistant attended the clinic to make contact with potential participants.

On attending the exercise classes at each clinic or hospital, the researcher and/or research assistant made contact with the potential participants before starting the exercise class and arrangements made to administer questionnaires to themselves and their caregivers after they had attended the exercise class. If the patient with stroke or their caregiver could not arrange to spend time with the researcher or research assistant after their class, arrangements were made to administer the questionnaires after the next exercise class they would attend.

Once the researcher or research assistant made contact with the potential participants at their visit to the clinic or hospital, the patient with stroke and their caregiver were each given an information sheet to explain the proceedings of the pilot study. Thirty four of the participants in the main study chose to use the English versions of all the forms and tools, whereas only one caregiver chose to use the Zulu version of the information sheet. As was made clear in the pilot study, it was clear that most of the participants could not or preferred not to read the information sheet, and rather requested a verbal explanation of the process of the study. Even the participant who requested the Zulu translation of the information sheet welcomed further English explanations, therefore there was no need for a translator, although there was one available at each clinic.

Once a good understanding of the process of the main study was gained, and the participants agreed to participate in the main study, the consent form for participation in the study was signed by both the patient with stroke and the caregiver. In the case of the patient with stroke having difficulty understanding the explanation of the main study by the researcher, the caregiver interpreted the explanation of the study to the patient, either in English or their home language, and obtained their consent. When consent was given, the researcher or research assistant presented the demographic questionnaire, the EQ-5D and the CSI to the caregiver for completion.

The research or research assistant presented the patient with a demographic questionnaire to complete. The caregiver assisted with completion of the questionnaire if necessary.

In the case of neither the caregiver nor the patient being able to complete the demographic questionnaires due to insufficient knowledge of a particular question, the caregiver was able to take the demographic questionnaire home and consult a family member who could complete the unanswered questions. The completed questionnaire was returned to a member of staff at the physiotherapy department, or to the researcher or research assistant at their next visit to the clinic.

The researcher and/or research assistant collected the completed forms and questionnaires, and updated the database of participant names and codes allocated to each participant, which only the researcher and research assistant had access to.

3.5 Ethical Considerations

The following ethical practices were taken into consideration during the data collection process:

- Ethical clearance was applied for and obtained from the University of the Witwatersrand Committee for Research on Human Subjects (ethical clearance number M080550) (Appendix A).
- Informed consent was obtained from the patient with stroke and their caregiver individually, prior to data collection.
- The participants had anonymity in the collection and statistical analysis of the data.
- If patients and/or caregivers refused to consent to participate in the pilot study this did not affect their medical or therapeutic management at the clinic.
- Participants had an option of withdrawing from the study at any stage if they so wished without any effect on their medical or therapeutic management.

3.6 Data Analysis

The data analysis began with a descriptive analysis to describe the population, i.e. demographic information regarding the patient with stroke and the caregiver.

Scores were obtained from the various indices, namely functional ability six – 36 months post stroke, caregiver strain index and caregiver quality of life.

These scores were then used to evaluate the effects of various factors of interest, specifically:

- The influence of the patient's functional ability on the quality of life of the caregiver.
- The influence of caregiver strain on the quality of life of the caregiver.
- The influence of demographic factors on the quality of life of the caregiver.

Kruskal-Wallis (Kwallis) statistical tests were performed on non-parametric data. Results of the Kruskal-Wallis statistical tests determine whether there was a relationship between the compared data. Pearson x^2 tests were performed on correlations to determine any association between caregiver quality of life and the various variables. Kendall's rank correlations were performed on data which presented association, thereby indicating positive or negative correlation. On data which was found to have statistical association following the Pearson x^2 test, the Fisher's exact test was performed on the data, which is used in small sample size studies to determine more detailed association between data. 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. In the case of statistical significance being present when relating the various indices, logistic regression was applied to the data to expand on the relationship between factors. Data were presented in tables and graphs as was appropriate.

3.7 Conclusion

Not all patients are functionally independent at discharge from hospital, but their level of function improves over time (Mamabolo et al., 2009). By performing the BI, we will be able to determine the level of function of each patient with stroke on assessment for the study. The study however does not allow for determing any functional improvement the patient may have had since discharge from hospital. Caregiver strain is a complex and multilayered concept, which is dynamic and changes throughout the post-stroke period. Administering the CSI will allow for valuable information as to the caregiver's perceived level of strain due to caring for the patient with stroke. The interaction between the patient's level of function and the caregiver's quality of life has not been extensively explored, however some research has been performed in this field. We will be able to determine if any interaction occurs between the patient's functional level and the caregiver's quality of life by relating the BI to the EQ-5D results in the study. The relationship between caregiver strain and caregiver quality of life are clear in the literature, namely increased caregiver strain results in decreased caregiver quality of

life. By relating the CSI to the EQ-5D, we will be able to determine the relationship between the two factors according to the study sample group. Research has yet to identify a detailed picture of those demographic factors that influence caregiver quality of life. By relating the study sample's demographic factors to the caregiver's quality of life, measured using the EQ-5D, we will be able to determine those contextual demographic factors that influence caregiver quality of life, which are so specific to each cultural setting. Interesting contextual results may be found in the South African context as a result of the study, as differing cultures may display differing results.

CHAPTER 4

4. RESULTS

4.1 Introduction

This chapter presents the results of the study. Thirty-five caregivers of patients with stroke and thirty-five patients with stroke were involved in the study. There was 100% return of questionnaires. Missing data occurred due to either the caregiver or patient being unable to answer a particular question and not taking the form home for another member of the family to complete, or due to the self-administered questionnaires not being checked thoroughly enough by the researcher or research assistant. Missing data was accounted for and percentages were adjusted accordingly.

4.2 Demographic information of the caregivers and the patients with stroke

Table 4.1 below shows the distribution of caregiver and patient gender, age, marital status and educational level.

Table 4.1: Distribution of caregiver and patient gender, age, marital status and educational level

Parameter	**Caregiver (n=35)** **n (%)**	**Patient (n=35)** **n (%)**
Gender (n = 35)		
Male	6 (17.1)	19 (54.3)
Female	29 (82.9)	16 (45.7)
Age	n = 34	n = 35
< 43 years	11 (32.4)	5 (14.3)
≥ 43 years	23 (67.6)	30 (85.7)
Marital Status (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)
Education Level (n = 34)		
None	1 (2.9)	2 (5.9)
Up to Gr 7	12 (35.3)	12 (35.3)
Up to Gr 11	11 (32.4)	11 (32.4)
Gr 12 or equivalent	9 (26.5)	6 (17.6)
Diploma	1 (2.9)	3 (8.8)

Some of the parameters do not total up to 35 due to missing data. More than 80% of the caregivers were women and 54.3% of the patients were male, while 45.7% were female. The majority of the caregivers (62.9%) and patients (62.9%) were married. More than a third of the caregivers and patients (35.4% and 35.4% respectively) were educated up to Grade 7 level. The two age classifications were determined by the statistician to be a meaningful cut off as per the distribution graph, which would provide a clinically relevant age.

Table 4.2 below shows the distribution of the caregivers and patients' ages.

Table 4.2: Distribution of the caregivers' (n=34) and patients' (n=35) ages

	Mean Age	Standard Deviation	Maximum Age	Minimum Age
Caregiver age	50.7	16.2	75	19
Patient age	55.9	11.8	77	28

The mean age of the caregivers was 50.7 years and that for the patients was 55.9 years.

Figure 4.1 below shows the distribution of the relationship of the caregiver to the patient with stroke.

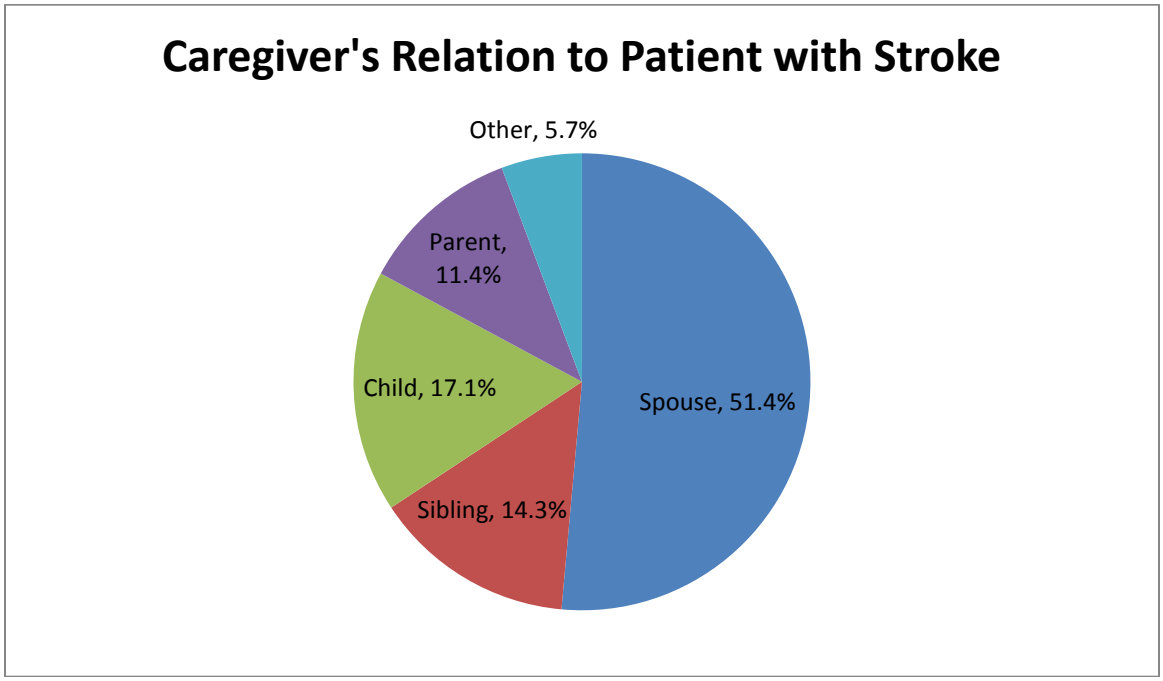


Figure 4.1: The distribution of the relationship of the caregiver to the patient with stroke (n=35)

More than half (51.4%) of the caregivers were spouses.

Table 4.3 below shows the distribution of the household roles of the caregivers prior to the patient having a stroke.

Table 4.3: The distribution of the caregiver's household roles prior to the patient having a stroke (n=35)

Household roles	**n (%)**
Household chores	6 (17.1)
Scholar	2 (5.7)
Contributed financially	7 (20.0)
Domestic work/contributed financially	1 (2.9)
Household chores/child care	4 (11.4)
Household chores/scholar	1 (2.9)
Household chores/contributed financially	10 (28.6)
Household chores/child care/contributed financially	1 (2.9)
Household chores/contributed financially/other	1 (2.9)
Domestic work/household chores/child care/contributed financially	1 (2.9)
Other	1 (2.9)

Of the caregivers, 28.6% performed both household chores and contributed financially to the household prior to the patient having a stroke.

Table 4.4 below shows distribution of the household roles of the caregivers after the patient had a stroke.

Table 4.4: The distribution of the caregiver's household roles after the patient had a stroke (n=35)

Household roles	**n (%)**
Domestic work/caregiver	1 (2.9)
Household chores/child care/caregiver	8 (22.9)
Scholar/caregiver	1 (2.9)
Household chores/scholar/contributed financially/caregiver	1 (2.9)
Household chores/child care/caregiver	8 (22.9)
Household chores/contributed financially/caregiver	14 (40.0)
Domestic work/child care/contributed financially/caregiver	1 (2.9)
Domestic work/household chores/contributed financially/caregiver	1 (2.9)

After the patient had a stroke, 40.0% not only performed the role of caregiver, but also performed household chores and contributed financially to the household. About 40% of the caregivers contributed financially to the household after stroke.

The following graph (Figure 4.2) shows the distribution of the number of people living in the same household as the patient with stroke and the caregiver.

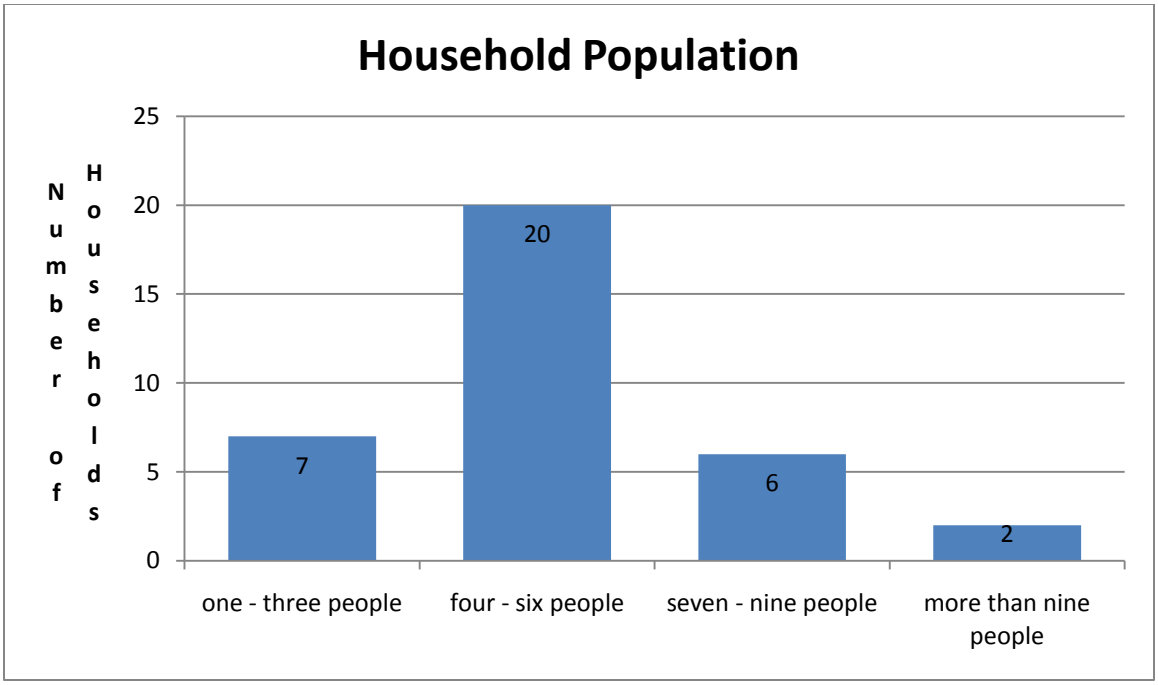


Figure 4.2: The distribution of the number of people living in the same household as the patient with stroke and the caregiver (n=35)

More than 50% of the households in which the patient with stroke and the caregivers lived, had four to six other people staying there as well.

Figure 4.3 below shows the distribution of the number of people with disability living in the same household with individuals with stroke.

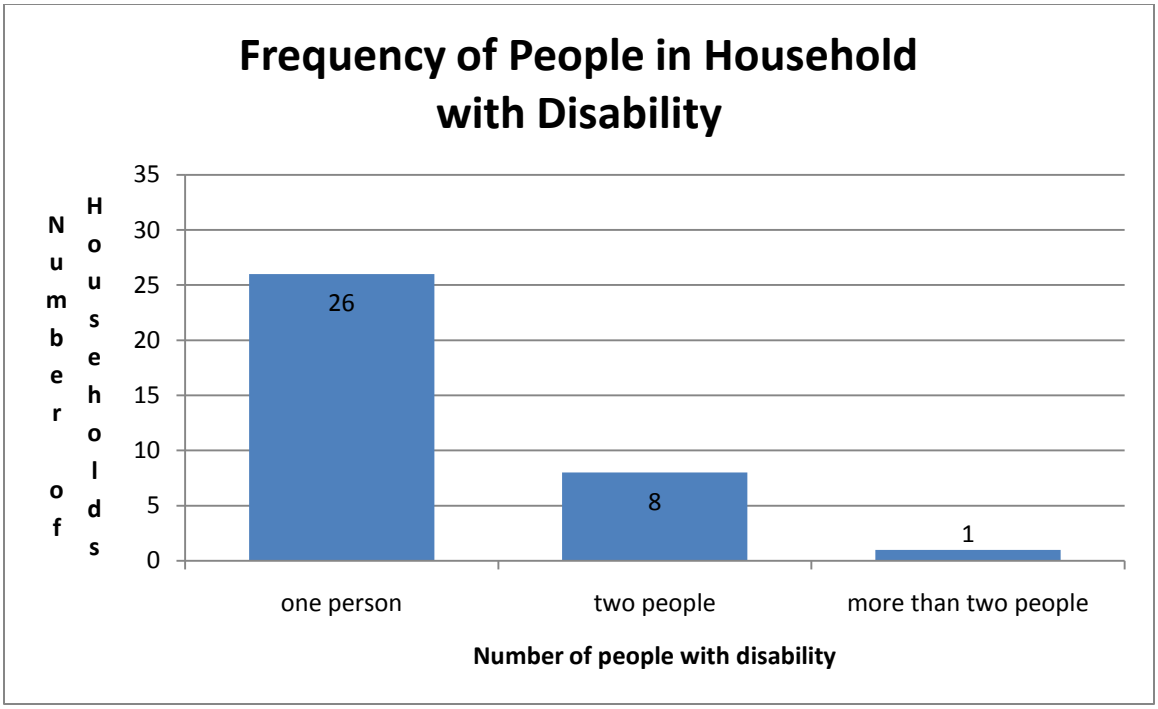


Figure 4.3: The distribution of the number of people with disability living in the same household with individuals with stroke (n=35)

In more than 70% of the households the patient with stroke was the only person with disability.

The following graph (Figure 4.4) shows the distribution of household monthly income for the study sample.

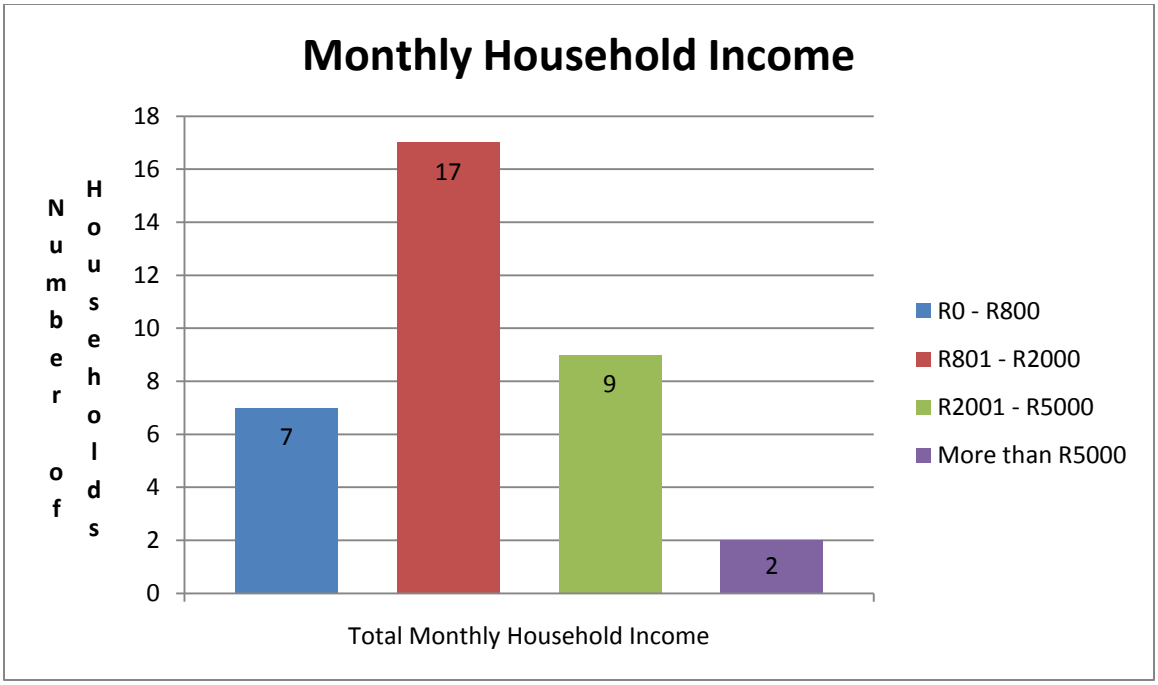


Figure 4.4: The distribution of monthly household income for the study sample (n=35)

Seventeen (48.6%) households in the study sample received a monthly income between R801 and R2000.

Table 4.5 below shows the distribution of regularity of income and caregiver training of the study population.

Table 4.5: Distribution of income and caregiver training of the study population

Item	**Yes** **n (%)**	**No** **n (%)**
Regular monthly income (n=34)	29 (85.3)	5 (14.7)
Recipient of caregiver grant (n=34)	1 (2.9)	33 (97.1)
Received in-patient caregiver training (n=35)	4 (11.4)	31 (88.6)
Received out-patient caregiver training (n=35)	24 (68.6)	11 (31.4)

Twenty nine households (85.3%) received regular monthly income, whereas five households (14.7%) received irregular monthly income. An overwhelming majority of caregivers (97.1%) did not receive a caregiver grant, whereas only one caregiver received a caregiver grant. The majority of caregivers (88.6%) received no training when the patient was in hospital.

The distribution of the frequency of monthly caregiver training is shown in the figure below (Figure 4.5).

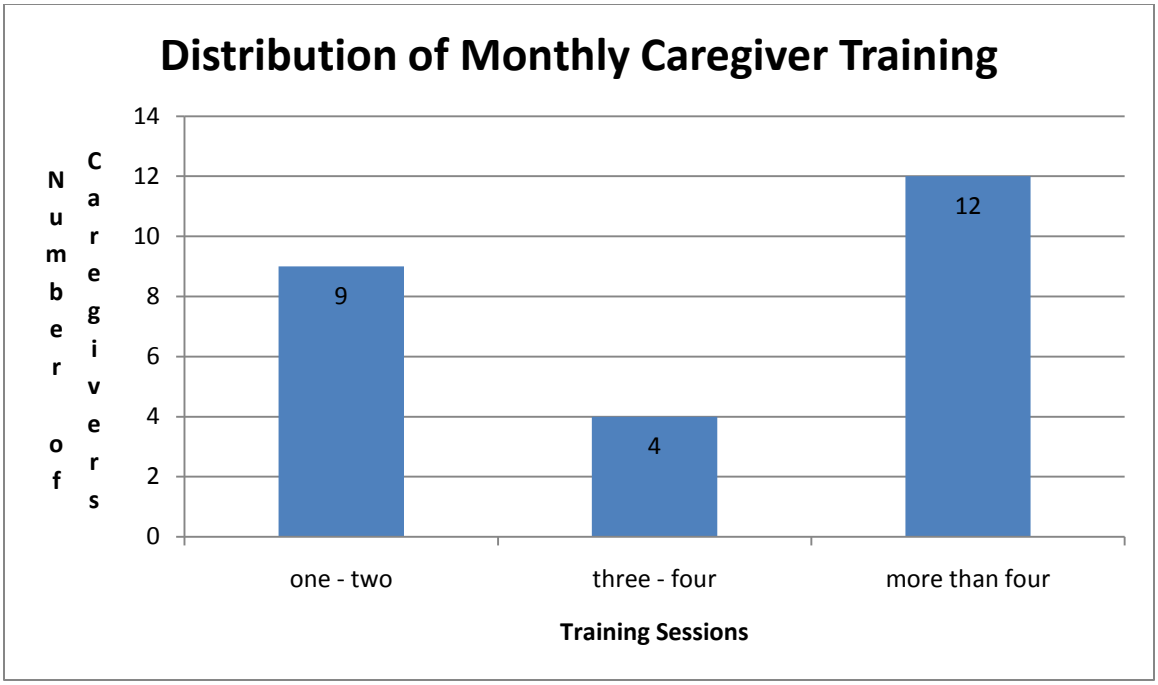


Figure 4.5: The distribution of the frequency of monthly caregiver training (n=24)

Of the 68.6% of caregivers who receive out-patient caregiver training as shown in Figure 4.11, 48% receive more than four monthly training or support sessions at the clinic or hospital.

The distribution of patients' employment status before stroke is shown in Figure 4.6 below.

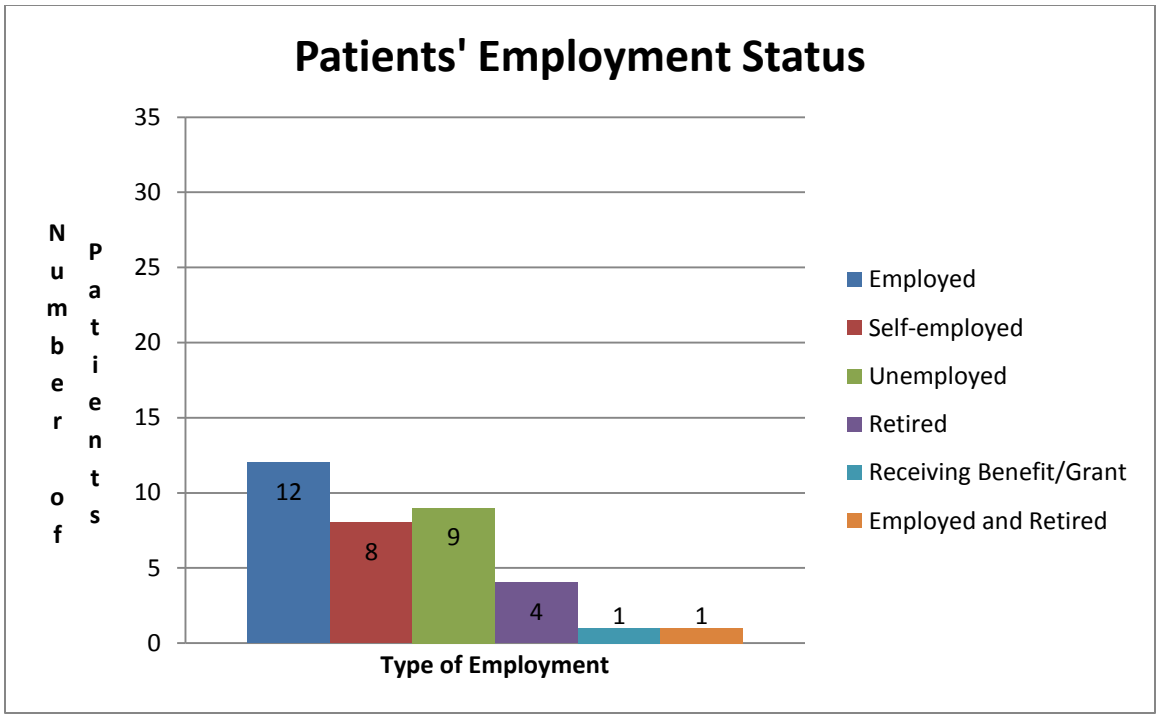


Figure 4.6: The distribution of patients' employment status (n=35)

From the patient sample 34.3% were employed and 22.9% were self-employed prior to the stroke.

Figure 4.7 below shows the distribution of patients' financial contribution to the household prior to the stroke.

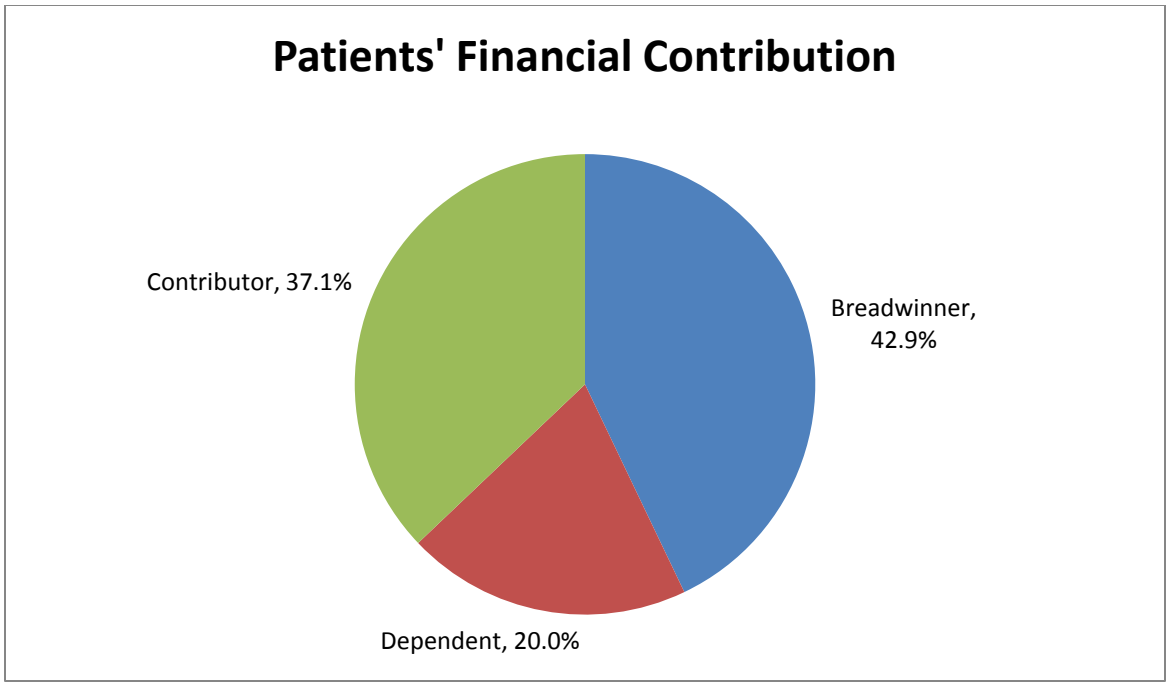


Figure 4.7: The distribution of patients' financial contribution to the household prior to the stroke (n=35)

Prior to the study 42.9% of the patients were the breadwinner in the household.

The distribution of the number of months post-stroke for the patients is shown in Figure 4.8 below.

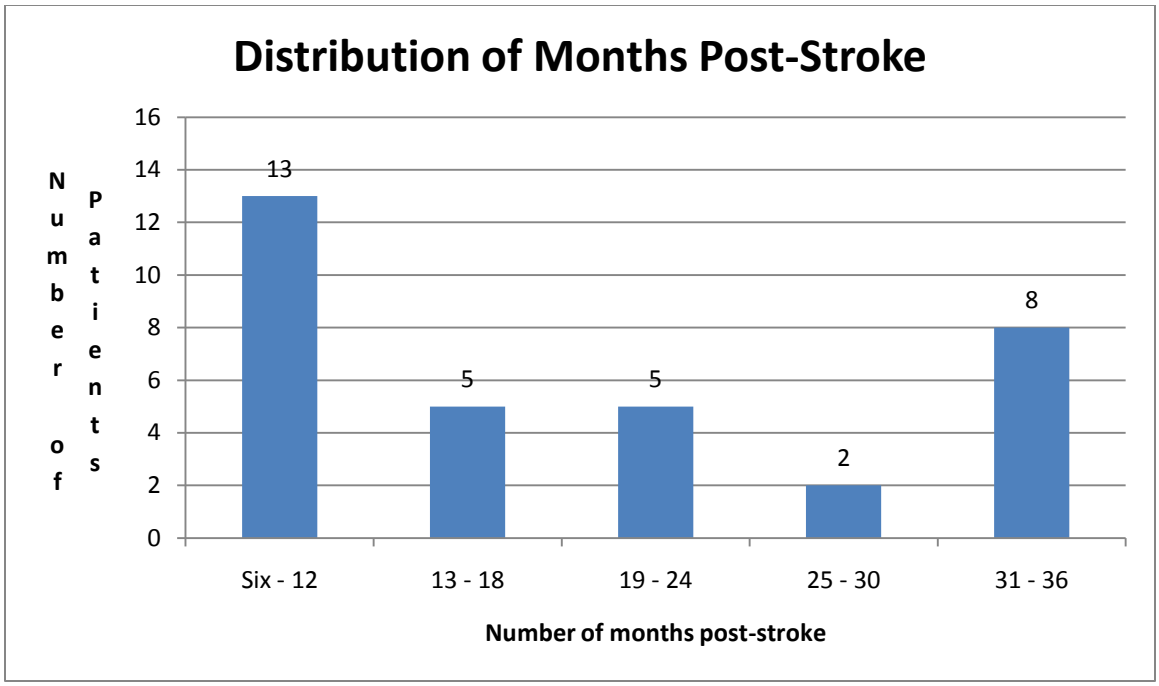


Figure 4.8: The distribution of months post stroke for the patients (n=35)

On the day of the interview 39.4% of patients were six – twelve months post-stroke.

The distribution of the side of body affected by stroke is shown in Figure 4.9 below.

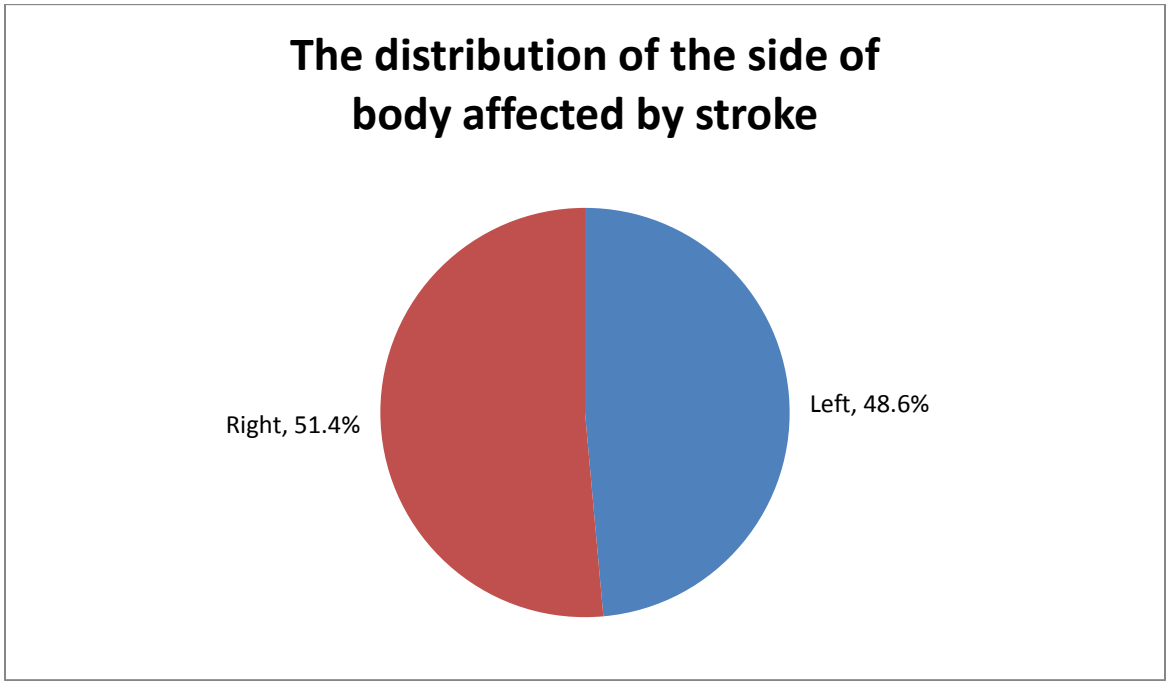


Figure 4.9: The distribution of the side of body affected by stroke (n=35)

There were slightly more patients (51.4%) with weakness on the right side compared to the left side (48.6%).

The distribution of the presence of speech difficulty is shown in Figure 4.10 below.

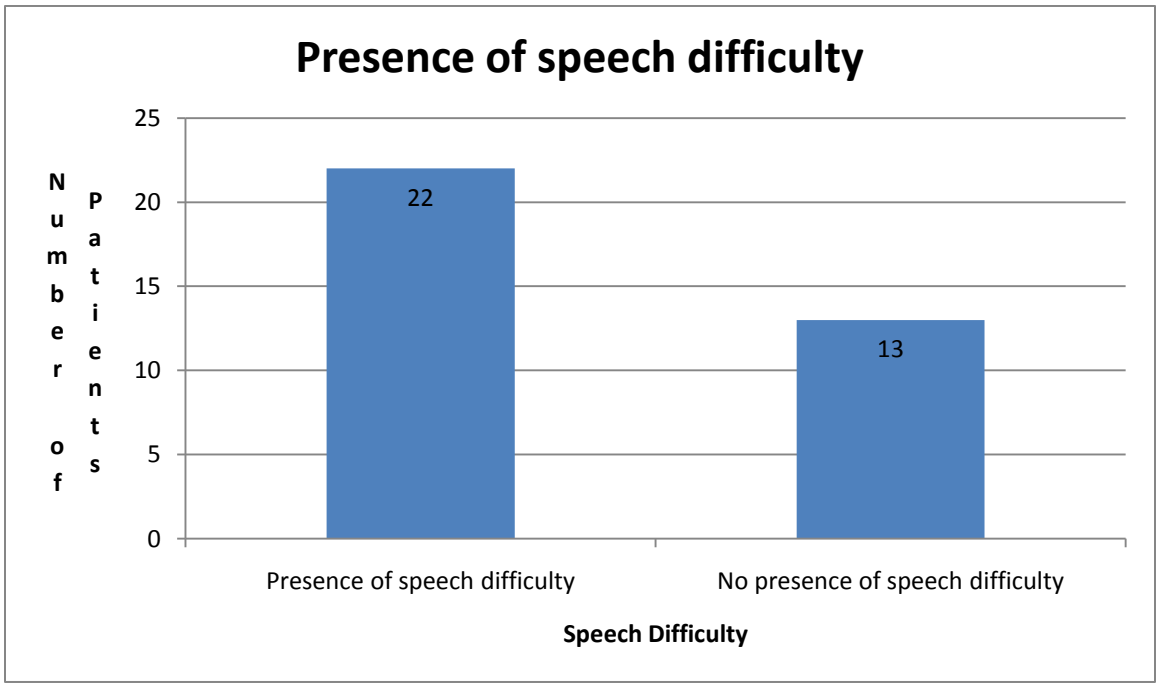


Figure 4.10: Distribution of the presence of speech difficulty (n=35)

The majority (62.9%) of patients had speech difficulty due to the stroke.

Figure 4.11 below shows the manner of speech deficit.

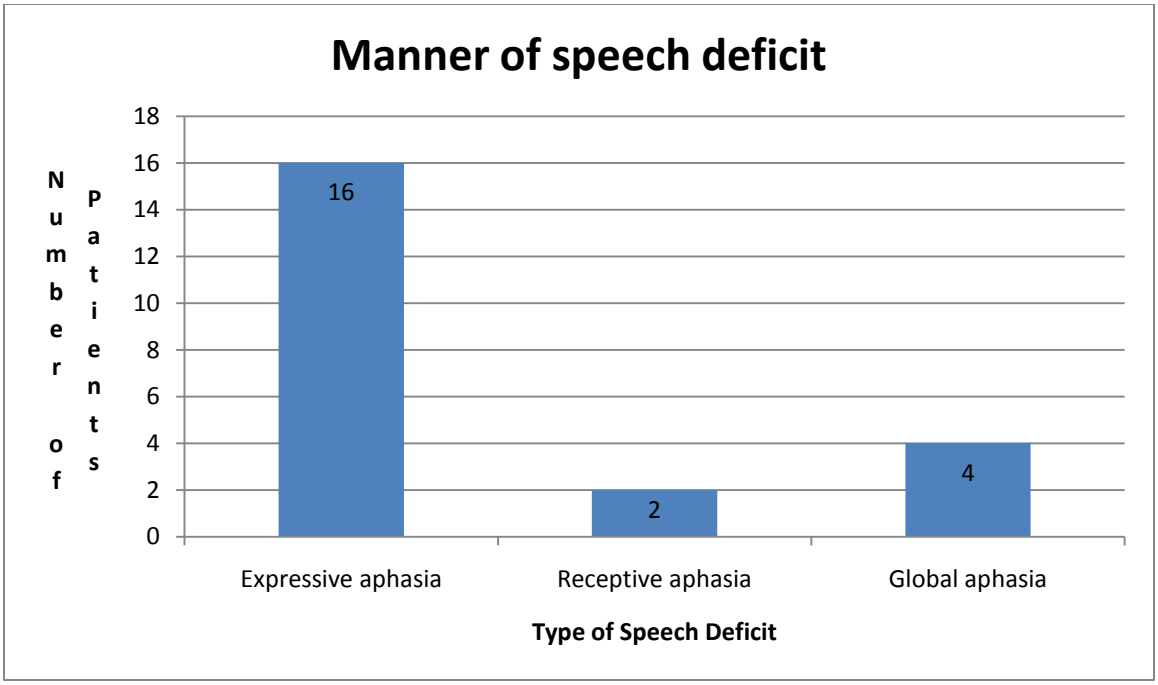


Figure 4.11: The distribution of the manner of speech deficit (n = 22)

The majority (72.7%) of the patients experienced expressive aphasia.

The distribution of patients' premorbid medical conditions is presented in Table 4.6 below.

Table 4.6: The distribution of premorbid medical conditions (n = 35)

Medical Condition	**n (%)**
Hypertension	14 (40.0)
Hypertension / Diabetes	10 (28.6)
Hypertension / Other	3 (8.6)
Hypertension / Diabetes/ High cholesterol	1 (2.9)
Hypertension / Diabetes / Other	2 (5.7)
None	5 (14.3)

Forty percent of the patients with stroke reported having hypertension, and 28.6% reported having hypertension and diabetes.

The distribution of the hospital length of stay following stroke is shown in Table 4.7 below. Four participants were unable to recall their length of stay in hospital, hence n=31.

Table 4.7: The distribution of hospital length of stay following stroke (n = 31)

Length of Stay	**n (%)**
0 – 5 days	7 (22.6)
6 – 10 days	7 (22.6)
11 – 15 days	4 (12.9)
16 – 20 days	0 (0.0)
21 – 25 days	2 (6.5)
26 – 30 days	1 (3.2)
Over 30 days	10 (32.3)

From the patient sample, 32.3% had a hospital stay of more than 30 days following stroke.

The distribution of patients who received in-patient rehabilitation is shown in Figure 4.12 below.

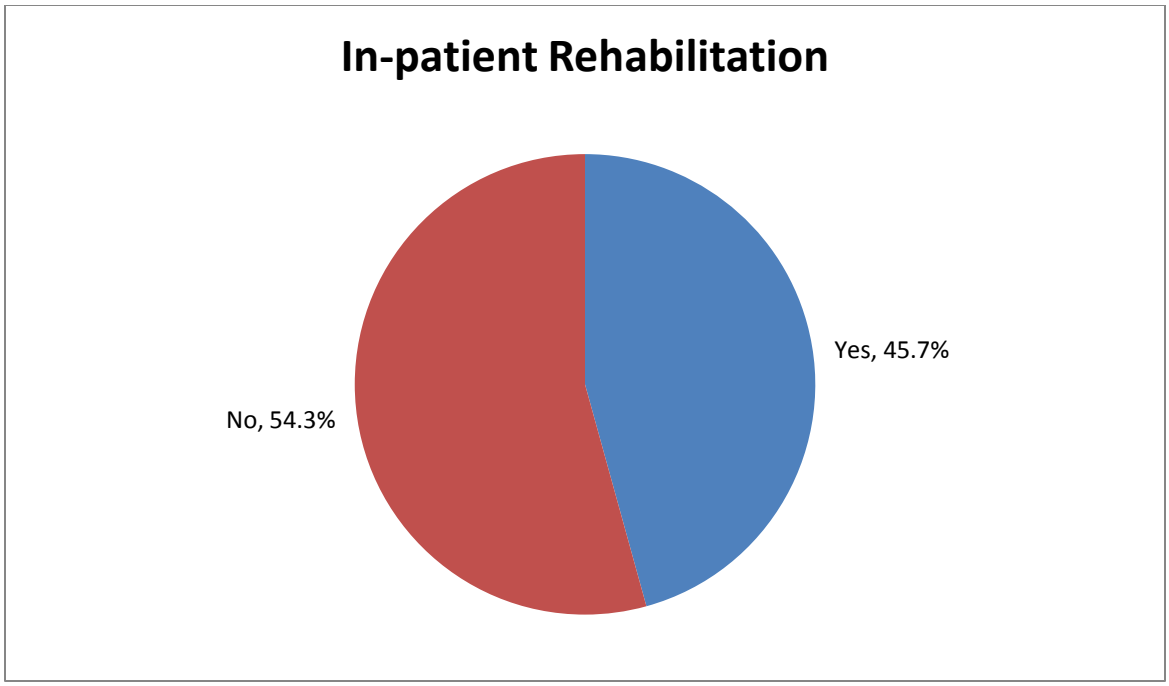


Figure 4.12: The distribution of patients who received in-patient rehabilitation (n=35)

Post-stroke, 54.3% of the patients did not receive in-patient rehabilitation.

Of the 45.7% of patients who did receive in-patient rehabilitation, distribution of the therapy received is shown in Table 4.8 below.

Table 4.8: Distribution of the therapy received as an in-patient (n = 16)

Therapy Received	**n (%)**
Physiotherapy	4 (25.0)
Speech and language therapy	1 (6.3)
Physiotherapy/Occupational therapy	1 (6.3)
Physiotherapy/Speech and language therapy	4 (25.0)
Physiotherapy/Speech and language therapy/ Occupational therapy	2 (12.5)
Physiotherapy/Speech and language therapy/ Occupational therapy/Social work	3 (18.8)
Physiotherapy/Occupational therapy/Social work	1 (6.3)

Twenty five percent of the patients received only in-patient physiotherapy while 25.0% of the patients received a combination of physiotherapy and speech and language therapy.

The distribution of the frequency of monthly clinic visits to the therapy department is shown in Figure 4.13 below.

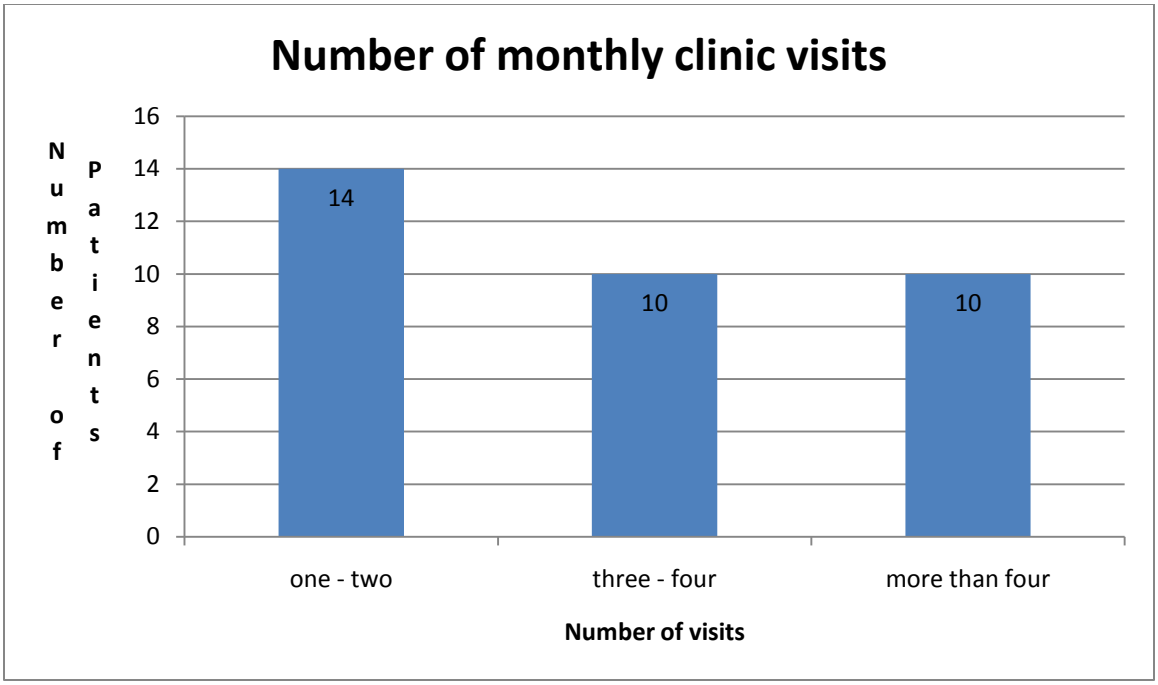


Figure 4.13: The distribution of the frequency of monthly clinic visits to the therapy department (n=34)

From the patient sample, 41.2% attended the therapy department one – two times in a month.

4.3 Post discharge functional level of patients with stroke

Functional level of patients with stroke was determined using the BI measuring tool. The BI scores were divided into three categories, namely total dependence (scoring 0 – 20 on the BI), severe dependence (21 – 60), and moderate dependence to independent (61 – 100).

Figure 4.14 shows the distribution of patients with stroke in the three subgroups of functional ability as measured by the BI.

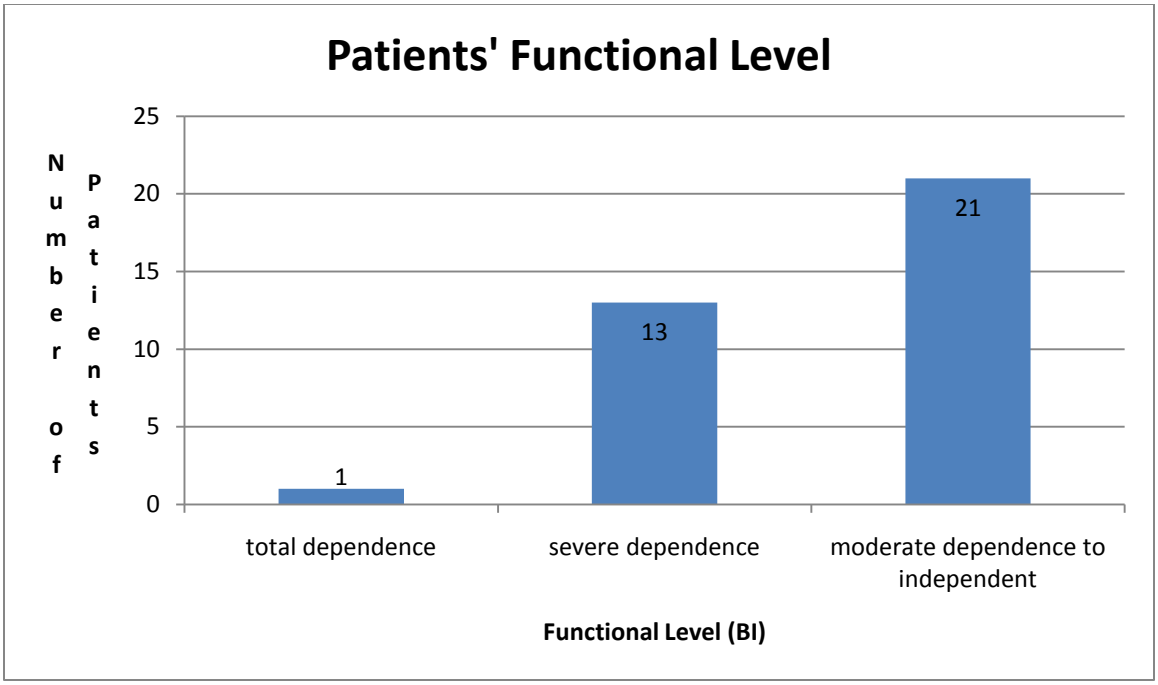


Figure 4.14: Functional level of the patient with stroke six – 36 months post-stroke (n = 35)

The majority of the patients with stroke (60%) were recorded as being moderately dependent to independent in functional ability at the time of interview for the study. The mean BI score was 62.3.

4.4 Caregiver Strain

Caregiver strain was determined using the CSI measuring tool. Results of the caregiver strain were divided into two categories, namely minimal/moderate, and severe strain. Minimal/moderate strain measure on the CSI is a score of six and below, while severe strain is a score of seven and above. The score of seven to divide caregiver strain into two categories is adviced by the producers of the CSI and is highlighted on the CSI itself. Literature has also adopted this method of interpreting CSI results (Bugge et al., 1999; van Exel et al., 2004; Visser-Meily et al., 2004), which makes comparison of the current study to other literature possible.

Figure 4.15 shows the distribution of caregiver strain among caregivers caring for the patient with stroke.

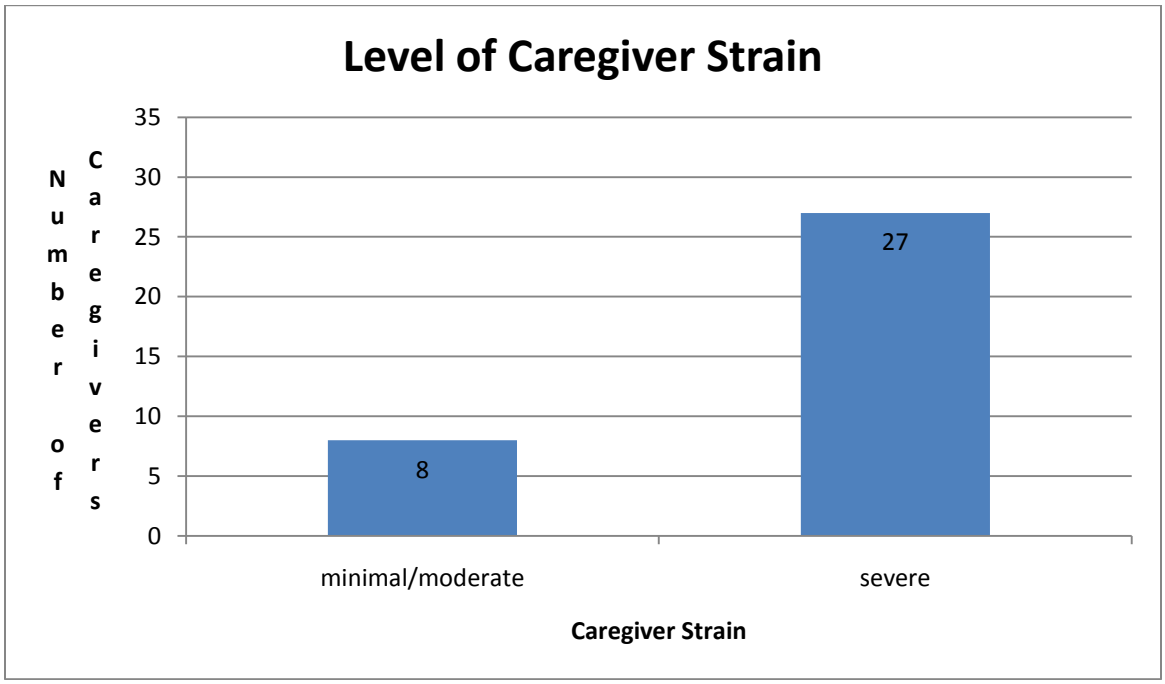


Figure 4.15: The distribution of strain among caregivers caring for the patient with stroke (n=35)

The majority of the caregivers (77.1%) reported experiencing severe strain (scoring seven and above) as a result of caring for the patient with stroke.

4.5 Caregiver quality of life

The caregiver quality of life was assessed using the EQ-5D VAS component. The caregiver recorded their perceived quality of life on a visual analogue scale (VAS). The higher the EQ-5D VAS score, the better the caregiver's reported quality of life. Literature does not define good/normal quality of life using the EQ-5D VAS score, yet for descriptive purposes of the current study, the term "adequate quality of life" was used to describe a score higher than 50 on the visual analogue scale.

Figure 4.16 displays the outcome of the EQ-5D VAS among the caregivers.

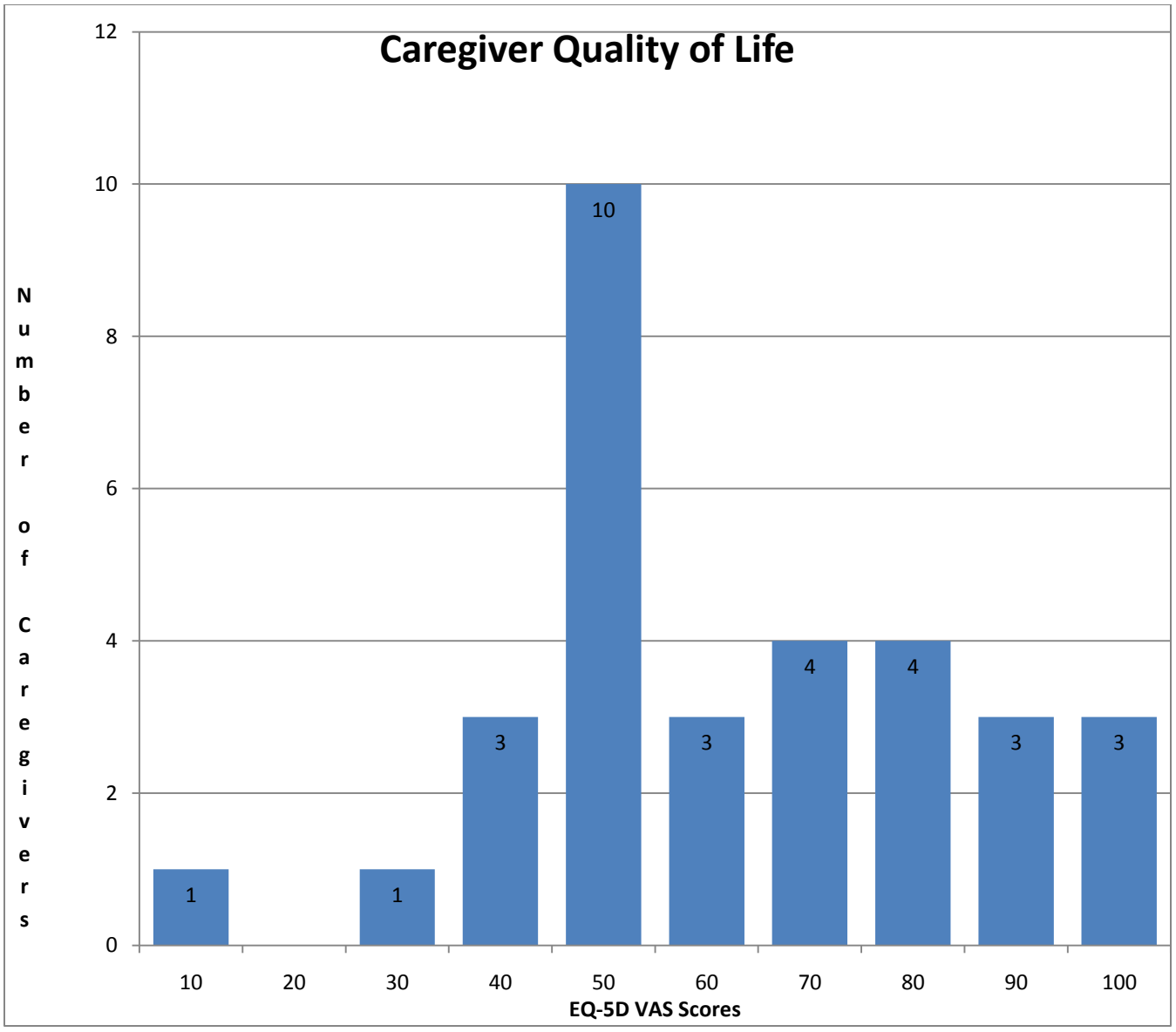


Figure 4.16: Quality of life (EQ-5D VAS) of caregivers caring for patients with stroke (n=32)

Ten caregivers (31.3%) reported their quality of life on the day of assessment to be 50.

The EQ-5D measuring tool further analyses caregiver quality of life with regard to the following components: caregiver's mobility, self care, ability to participate in usual activities, experience of pain and anxiety, and their level of health over the past twelve months. In each category of the EQ-5D, caregivers reported varying degrees of difficulty

or experience within the category. Table 4.9 below shows the distribution of these quality of life components.

Table 4.9: The distribution of the 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)
- confined to bed	0 (0.0)
Self care (n=35)	
- no difficulties	26 (74.3)
- some difficulties	9 (25.7)
- unable to perform	0 (0.0)
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)

Most of the caregivers (51.4%) experienced some problems with their mobility. The majority (74.3%) of the caregivers experienced no difficulties performing their self care tasks. The majority (65.7%) of the caregivers experienced moderate bodily pain, while 11.4% reported extreme bodily pain.

4.6 The factors that influenced caregiver quality of life

4.6.1 The factors that were associated with caregiver quality of life

The frequency of the distribution between BI and EQ-5D VAS is shown in the table below (Table 4.10).

Table 4.10: Frequency distribution between BI and EQ-5D VAS (n=32)

EQ-5D VAS	**Barthel Index**		**Total**
	Independent n (%)	**Total / Moderate dependence n (%)**	
0 – 50	7 (21.9)	8 (25.0)	15 (46.9)
51 – 80	7 (21.9)	4 (12.5)	11 (34.4)
Over 80	4 (12.5)	2 (6.3)	6 (18.8)
Total	18 (56.3)	14 (43.8)	32 (100.0)

Twenty five percent of caregivers reported EQ-5D VAS of 0 – 50 when caring for a patient who is totally or moderately dependent for functional ability. Twenty one percent of caregivers reported scores of 51 – 80 when caring for a patient who is independent in functional ability.

Table 4.11 below shows the frequency distribution between CSI and EQ-5D VAS.

Table 4.11: Frequency distribution between CSI and EQ-5D VAS scores (n=32)

EQ-5D VAS	CSI		Total n (%)
	<7 n (%)	≥7 n (%)	
0 – 50	1 (3.1)	14 (43.8)	15 (46.8)
51 – 80	5 (15.6)	6 (18.8)	11 (34.4)
Over 80	1 (3.1)	5 (15.6)	6 (18.8)
Total	7 (21.9)	25 (78.1)	32 (100.0)

Fourteen caregivers (43.8%) who experienced severe strain due to caring for a patient with stroke, reported EQ-5D VAS scores of 0 to 50.

The factors that were associated with caregiver quality of life are shown in Table 4.12 below.

Table 4.12: The factors that were associated with caregiver quality of life

Factor	Pearson x^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 null hypothesis states that there is no relationship between patient functional ability (BI) and caregiver quality of life (EQ-5D VAS). Pearson x^2 test (0.59) suggests that there is no evidence to reject the null hypothesis, thereby indicating no association between functional ability and caregiver quality of life.

The null hypothesis suggests that there is no statistical relationship between caregiver strain (CSI) and caregiver quality of life (EQ-5D VAS). Person x^2 test (0.06) suggests marginal evidence to reject the null hypothesis, therefore indicating marginal association between caregiver strain and caregiver quality of life. Fisher's exact however indicates a statistically significant association (0.05). Kendall's tau-b (-0.23) suggests a negative

association between caregiver strain and quality of life, thereby suggesting that as caregiver strain increases, caregiver quality of life decreases.

In determining an association between caregiver age and caregiver QOL, Pearson x^2 (p=0.009) indicates evidence to reject the null hypothesis, and thereby indicating a relationship between the two factors. A statistically significant association between caregiver age and QOL following Fisher's exact (p=0.01) was determined. Kendall's rank correlation suggests a negative association (-0.48) between caregiver age and QOL, suggesting that as the caregiver gets older in age, their QOL decreases.

4.6.2 The logistic regression results of the factors that influenced caregiver quality of life

The logistic regression results of the factors that influenced caregiver quality of life are shown in Table 4.13 below.

Table 4.13: Logistic regression results of the factors that influenced caregiver quality of life

Factor	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

The logistic regression suggests those caregivers under severe strain to have 1.6 greater odds of worse quality of life, however this odds ratio has no statistical significance (p=0.6).

Caregivers who were older had 0.19 greater odds of a worse quality of life than younger caregivers (p =0.008).

4.7 Conclusion

Various socio-demographic factors regarding both the patient with stroke and the caregiver were gathered using the demographic questionnaires. Results showed that the large majority of caregivers (97.1%) did not receive a caregiver grant, the majority of caregivers (88.6%) did not receive caregiver training prior to the patient being discharged, while 68.6% report receiving caregiver training as an out-patient, and 54.3% of patients did not receive in-patient rehabilitation prior to discharge. Using the BI, the majority of patients (60%) were recorded as being moderately dependent to independent in their functional ability. By means of the CSI, the majority of caregiver (77.1%) reported experiencing severe strain. Caregiver quality of life results using the EQ-5D VAS reported ten caregivers (31.3%) to have quality of life of 50/100. The EQ-5D components reported majority of caregiver (51.4%) to experience some problems with their mobility, majority (74.3%) to experience no difficulties performing their self care tasks, and majority (65.7%) to experience moderate bodily pain. When determining whether any factors influence caregiver quality of life, no association was reported between caregiver quality of life and the patient's functional ability, marginal negative association was reported between caregiver quality of life and caregiver strain, and a negative association was reported between caregiver quality of life and age of the caregiver.

CHAPTER 5

5. DISCUSSION

5.1 Introduction

The following will be discussed in this chapter: functional level of patients six to 36 months post stroke; level of caregiver strain six to 36 months post stroke; the quality of life of the caregiver six to 36 months post-stroke and the factors that influenced caregiver quality of life.

5.2 Patient and caregiver demographic factors

More than 80% of the caregivers were women and 54.3% of patients were male, while 45.7% of patients were female. Bugge et al. (1999) similarly reported the majority of caregivers (73%) were women, and 54.5% of patients were male. Morimoto et al. (2003) similarly reported the majority of caregivers (74%) were women. McCullagh et al. (2005) also reported the majority of caregivers (64.2%) were women, and 51.7% of patients were male**.** Almberg et al. (1998) suggests that female relatives are often more heavily involved in caregiving activities than male relatives, which may be a reason for the general report of majority of female caregivers in literature.

The mean age of caregivers in the study was 50.7 years, and the mean age of the patients was 55.9 years. Jönsson et al. (2005) reported mean caregiver age to be 64.6 years and mean patient age to be 74.3. Morimoto et al. (2003) reported mean caregiver age to be 60.36 years and mean patient age to be 69.35 years. Bugge et al. (1999) reported mean caregiver age to be 60 years and mean patient age to be 70.5 years. It is interesting to note that the patients and caregivers in the current study were generally younger than those patients in other literature. Connor, Rheeder, Bryer, Meredith, Beukes, Dubb and Fritz (2005) performed a study to determine stroke risk factors in the South African population. Hypertension was one risk factor that was included in the study. Prevalence of hypertension was reported in the male gender in 35-40% of

patients aged 30-49, 60-70% aged 50-69, and 70-90% aged 70+ (Connor et al., 2005). Prevalence of hypertension was reported in the female gender in 35-45% of patients aged 30-49, 60-80% aged 50-69, and 80-95% aged 70+ (Connor et al., 2005). Due to the nature of the sample for the current study, all participants were black of ethnic origin. Connor et al. (2005) noted that white patients were 44% less likely to have hypertension than the black patients. This was also found in the USA where African-American had a higher prevalence of hypertension and developed hypertension at a younger age than their white counterpars (Connor et al., 2005). This could be a possible reason as to the young age of patients with stroke in the current study as compared to other literature.

Eighty eight percent of caregivers did not receive caregiver training while the patient was an in-patient prior to discharge. Along those same lines, the majority of the patients in this study (54.3%) did not receive rehabilitation post-stroke prior to discharge. Research has shown that the rehabilitation or medical care that the patient receives in hospital will determine the speed and extent of functional recovery prior to discharge (De Wit et al., 2007; Kalra et al., 2005). The lack of caregiver training prior to discharge and in-patient rehabilitation may however be due to the short hospital length of stay (LOS). The average hospital LOS in the current study was 5.1 days, which does not allow for adequate time for training to occur. Previous research reported patients with stroke in South Africa were generally only hospitalised until medically stable (Hale & Eales, 1998). This may therefore be a possible reason as to majority of the caregivers having not received training prior to discharge and majority of patients not having received in-patient rehabilitation.

5.3 Patient functional level six to 36 months post-stroke

Six to 36 months post-stroke, the majority of patients (60%) ranged from being independent in functional ability to being moderately dependent on the caregiver for their functional ability. Unfortunately the data was 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. Thirty seven

percent were severely dependent on their caregiver, while 2.9% were totally dependent on their caregiver for their functional ability. This agrees with previous research which showed that patients with stroke are not all functionally independent at discharge from hospital (Mamabolo et al., 2009). This may be due to the lack of in-patient rehabilitation prior to discharge into the community, and due to the short average LOS seen in the current study, which will both be expanded on below.

The majority of the patients in this study (54.3%) did not receive rehabilitation post-stroke prior to discharge. Research has shown that the rehabilitation or medical care that the patient receives in hospital will determine the speed and extent of functional recovery prior to discharge (De Wit et al., 2007; Kalra et al., 2005). The participants in the current study who did not receive in-patient rehabilitation are therefore under great disadvantage, thereby having their functional recovery hindered.

The lack of in-patient rehabilitation may however be due to the short hospital LOS in the current study. The average hospital LOS in the current study was 5.1 days, which does not allow for adequate time for rehabilitation. Previous research reported patients with stroke in South Africa were generally only hospitalised until medically stable (Hale & Eales, 1998). It can therefore be assumed that an average LOS of 5.1 days as reported in the current study is due to patients being discharged home into their communities once medically stable. This short LOS is insufficient time for in-patient rehabilitation to occur, and for any functional improvement to be facilitated prior to discharge, with which Rønning & Guldvog (1998) is in agreement. Early onset of rehabilitation interventions after stroke improve functional outcome (Cifu & Stewart, 1999; Jongbloed, 1986; Shah et al., 1989). The patients in the current study have therefore unfortunately been denied early achievement of good functional recovery due to a short LOS.

5.4 Level of strain the caregiver experiences from caring for a patient with stroke six to 36 months post-stroke

Seventy seven percent of caregivers in the study reported experiencing strain from caring for the patient with stroke (scoring seven and above on the CSI), while 22.9%

reported experiencing less strain (scoring less than seven on the CSI). The extent of caregiver strain in the current study appears to be far greater than what appears in other studies. Ilse et al. (2008) reported 28%, 31% and 29% of the caregivers under strain at two-, four- and six-months, respectively, scoring seven and above on the CSI. Similar results were presented in Bugge et al.'s study performed in 1999, where caregivers reported to be under considerable strain, scoring seven and above on the CSI, from one- to six-months post-stroke (25% at one-month, 28% at three-months, and 37% at six-months). An observation can be made to the fact that the studies performed by Ilse et al. (2008) and Bugge et al. (1999) were in fact collecting data from caregivers under six-months post-stroke, whereas the current study only starts data collection at six-months and includes patients up to 36 months post-stroke. This may indicate that caregiver strain increases with time post-stroke, although unfortunately data analysis in the current study was not performed to determine whether caregiver strain changes with time. McCullagh et al.'s study in 2005 however does not agree with this assumption, which reported a significant reduction in caregiver strain between three- (mean CBS value of 48.2) and twelve-months (mean CBS value of 38.3) post-stroke. It is however difficult to correlate these results with those taken using the CSI, as different strain factors are taken into account in the different measuring tools.

Sixty percent of the patients in the study ranged from being independent in functional ability to being moderately dependent on the caregiver for their functional ability, while thirty seven percent were severely dependent on their caregiver. Research suggests that increased dependence on the caregiver results in increased caregiver strain (Bugge et al., 1999; Choi-Kwon et al.; 2005, Ilse et al., 2008; McCullagh et al., 2005; Scholte op Reimer et al., 1998). The high percentage of dependence on the caregivers in the current study may be cause for the high percentage of caregivers who reported severe caregiver strain (77%).

Sixty three percent of patients in the current study were reported to have a speech deficit as a result of the stroke. Literature reports increased caregiver strain associated with speech difficulty of the patient with stroke (Choi-Kwon et al., 2005; Scholte op

Reimer et al., 1998). This association may be a reason for the high level of strain amongst the caregivers, seeing as though 60% of the patients experienced a speech deficit.

5.5 Caregiver quality of life six to 36 months post-stroke

From the EQ-5D VAS scores, the three most common score ranges were 41 – 50 (31.3% of caregivers), 61 – 70 (12.5% of caregivers), and 71 – 80 (12.5% of caregivers). These results are indicative of adequate quality of life reported by the caregivers. It would be interesting to correlate these quality of life findings with those of the same socio-economic and geographical area, so as to have a control group to which to compare. This may have brought further depth into the field of caregiver quality of life. The mean EQ-5D VAS of the caregivers in this study was 63.4. This is not different from reports made in Ilse et al. (2008)'s study, where mean EQ-5D VAS of 60 at two-, four- and six-months post-stroke were reported. It is important to note that the participants in Ilse et al. (2008)'s study were undergoing rehabilitation in a stroke unit. This setting is however not comparable to the current study setting. It is however interesting to note that the mean EQ-5D VAS scores in Ilse et al. (2008)'s study and in the current study were taken at six-months and less post-stroke, and between six- and 36-months post-stroke respectively. McCullagh et al. (2005) however reported mean EQ-5D VAS of 75.2 at three-months, and 75.4 at twelve-months post-stroke. These results are taken at twelve-months and less post-stroke, which can somewhat relate more positively to the current study's time period, yet the mean EQ-5D VAS value reports a higher caregiver quality of life than do the current study and Ilse et al. (2008)'s study. This may be due to the fact that the participants in McCullagh et al. (2005)'s study were undergoing rehabilitation in a stroke unit and a caregiver training course, which may both affect 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 factors that influence quality of life in a variety of settings.

As mentioned above, research suggests that increased dependence on the caregiver results in increased caregiver strain (Bugge et al., 1999; Choi-Kwon et al., 2005; Ilse et

al., 2008; McCullagh et al., 2005; Scholte op Reimer et al., 1998). The high percentage of dependence (60% independent to moderately dependent and 37% severely dependent) on the caregivers in the current study may be a factor that contributes to the high percentage of caregivers who reported severe caregiver strain (77%). Increased caregiver strain results in decreased caregiver quality of life (McCullagh et al., 2005; Morimoto et al., 2003; Bugge et al., 1999). Therefore, the high percentage of dependence of the patients on the caregivers may have a negative effect on the caregiver quality of life in the current study.

Caregiver quality of life can be further expanded on by the results of the EQ-5D. The only study that could be found that explored quality of life components was a study performed by Morimoto et al. in 2003, which used the Short Form 12 (SF-12) measuring tool. The SF-12 categorises quality of life in the following components: physical health, role limitation due to physical problems, pain, general health, vitality, social function, role limitation due to emotional problems, and mental health. It is not possible to directly relate the EQ-5D components and the SF-12 components due to the fact that they focus on different aspects of quality of life, but interesting comparisons can be derived.

Morimoto et al. (2003) ranks the quality of life categories by level of difficulty to perform. The results from the EQ-5D components in the current study can be ranked in difficulty of performance by combining the distribution of caregivers who had some difficulty with those who were unable to perform the function as seen in Table 4.9. The component of quality of life of greatest difficulty or concern to the caregivers was their experience of anxiety (82.8% of caregivers), followed by their level of bodily pain (77.1% of caregivers), and their perceived general health (74.2% of caregivers). Caregiver's general health is rated the worst in Morimoto's study in 2003 using the SF-12 tool. In the current study, general health is rated the quality of life factor with the third most concern or difficulty using the EQ-5D tool. Both studies therefore agree that perceived caregiver general health impacts their quality of life. Both the current study (51.4% of caregivers) and the study performed by Morimoto et al. (2003) report mobility (or physical function as per the SF-12) to be ranked low in difficulty to the caregiver. Pain however in the

current study is the second highest ranked difficulty experienced by the caregivers, while in Morimoto et al. (2003)'s study it is ranked fairly low. This difference could be due to a number of factors. The mean Modified Barthel Index (MBI) performed by Morimoto et al. (2003) was 66, whereas the mean BI in the current study was 62.3. The participants in the current study were therefore slightly more dependent on their caregiver for their functional ability, which may increase the amount of strain put onto the caregiver, and may therefore increase their experience of bodily pain. Morimoto et al. (2003) reported findings of the Japanese study to be in contrast to literature performed in Western culture, and suggested the contrast may be due to cultural differences between study participants.

5.6 Factors that influence caregiver quality of life

Patient functional ability did not show an association with caregiver quality of life (Pearson x^2=0.59). This was in contrast to the findings in literature which report that as functional ability increases, caregiver quality of life increases as well (Jönsson et al., 2005; McCullagh et al., 2005). This stems from the notion that as patient dependence on the caregiver increases, the caregiver's perceived quality is reduced. In the study performed by Jönsson et al. in 2005, 87% of patients were moderately dependent on their caregiver to independent in their functional ability at sixteen-months post-stroke while McCullagh (2005) reported 100% of patients to be independent in their functional ability at twelve-months post-stroke. The current study showed 60% of patients to be either moderately dependent on their caregiver or independent. The patients in the studies performed by Jönsson et al. (2005) and McCullagh et al. (2005) had better functional ability than those in the current study which makes the findings in this study quite interesting. The poor functional ability of the patients in this study would require more help from the caregivers. One can only assume that there are other factors not explored in this study that are at play.

Caregivers under severe strain due to their caregiving role are at 1.6 times greater odds of experiencing worse quality of life than those caregivers under less strain. Literature does not expand on this relationship by means of logistic regression, yet agrees that as

caregiver strain increases, caregiver quality of life decreases (Bugge et al., 1999; McCullagh et al., 2005; Morimoto et al., 2003). The strong effect that caregiver strain has on their quality of life gives rise to good cause for a clear understanding of those factors that affect caregiver strain. By reducing caregiver strain, it is possible to greatly improve the caregiver's experience of quality of life.

Older caregivers are at 0.19 times greater odds of experiencing worse quality of life than younger caregivers. The result of this logistic regression does not show a very strong effect of caregiver age on their quality of life, yet there is a definite relationship to consider. Jönsson et al. (2005) and McCullagh et al. (2005) do not expand on this relationship by means of logistic regression, yet agree that older caregivers experience worse quality of life. Ory, Hoffman III, Yee, Tennstedt and Schulz (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.

5.7 Limitations of the study

- The sample size for the study was fairly small which makes generalisation to the entire South African population impossible.

- The patients who were assessed in this study were those who were able to attend the local clinic or hospital. The sample selection of the study possibly did not include those patients who were unable to attend the clinic for various reasons. The sample selection also possibly did not include those patients who did not feel that they could participate in an exercise class at the clinic or hospital. It is therefore possible that the patients included in this study sample could be skewed towards those who are independent or moderately dependent on their caregiver for functional ability again questioning the generalisability of the results.

- Cultural differences may occur between subjects from the different clinics or hospitals, which makes generalisation to the entire South African population difficult.

- The Zulu questionnaires were not piloted, which may have had an effect of the outcome of the measuring tools during data collection.

- Not enough detail regarding financial contribution to the household was obtained from the demographic questionnaires.

- The researcher or research assistant did not put into place stringent enough checking of the self-administered questionnaires on all occasions so as to avoid missing data, which may have avoided some statistical errors.

5.8 Conclusion

The study agrees with literature which showed that patients with stroke are not all functionally independent at discharge from hospital (Mamabolo et al., 2009). This may be due to the lack of in-patient rehabilitation which was obvious in the study, and the short LOS. Both factors hinder the patients from achieving early functional recovery.

A vast majority of caregivers reported experiencing severe strain from caring for the patient with stroke. This may be due to the high percentage of patients who required assistance for their functional ability, and for the majority of patients who experience speech deficit as a result of the stroke. Both factors increase the strain experienced by the caregiver due to caring for the patient with stroke.

The caregivers reported experiencing adequate quality of life. The quality of life of the caregiver may however be negatively influenced by the vast majority of caregivers experiencing strain due to their caregiving role. The literature with which to compare the findings to was performed in different settings (i.e. rehabilitation units with caregiver training programmes), which makes ultimate comparisons of data difficult. The differing results between studies indicate the dynamic nature of caregiver quality of life, and the possibility of cultural differences affecting quality of life results.

High degrees of caregiver strain show a clear negative effect on caregiver quality of life, which indicates the need for greater understanding as to those factors which negatively

affect caregiver strain. The older caregivers reported worse quality of life, which may be due to the heavy physical burden of caring for a patient with stroke, which increases the strain the caregiver experiences, which in turn negatively affects their quality of life.

CHAPTER 6

6. CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusion

The objectives of the study were to establish the functional level of patients six to 36 months post-stroke, to establish the level of caregiver strain six to 36 months post-stroke, to establish the quality of life of the caregiver six to 36 months post-stroke, and to establish the influence of patient's functional ability, caregiver strain and demographic factors on the quality of life of the caregiver.

At six to 36 months post-stroke, not all patients were independent in their functional ability. Yet the majority of patients in the study were independent or moderately dependent on the caregiver for their functional ability.

The majority of the caregivers in the study reported to experience severe strain due to their caregiving role six to 36 months post-stroke.

Most of the caregivers reported experiencing midrange quality of life when caring for a patient six to 36 months post-stroke. The component of quality of life of greatest difficulty or concern to the caregivers using the EQ-5D was their experience of anxiety, followed by their level of bodily pain, and their perceived general health.

Caregivers under severe strain due to their caregiving role are at 1.6 times greater odds of experiencing worse quality of life than those caregivers under less strain. Older caregivers are at 0.19 times greater odds of experiencing worse quality of life than younger caregivers.

6.2 Recommendations

6.2.1 Clinical Recommendations

- The finding that the majority of patients with stroke did not receive therapy as an in-patient has implications for the therapists in clinical practice in the government hospital settings. This finding is most likely due to the short LOS at the hospitals. This may require proactive actions to take place in the therapy services, where daily ward rounds may need to occur, so as to recognise patients in need of therapy or caregiver training or advice prior to imminent discharge.

- The current study has discovered various factors that influence caregiver quality of life, which are relevant to the general population of Johannesburg, South Africa. Knowledge of these factors could allow health professionals insight into the complex arena of caregiver quality of life. In identifying these factors in the caregiver's situation, it may be possible to foresee those caregivers who are experiencing contributing factors to decreased quality of life, and to provide appropriate support in response. This in turn will improve the care provided to the patient by the caregiver.

6.2.2 Recommendations for Further Research

- The current study needs to be performed using a larger sample size, so as to gain a better understanding of the variables influencing caregiver quality of life relevant to the general population in South Africa.

- Further research needs to be performed on the South African population to determine whether those factors indicated in the current study to have no influence on the caregiver quality of life indeed have no influence.

- It was speculated that the study may not have included those patients who are more severely disabled and therefore their caregivers would be under greater strain, due to lack of transport to the clinic due to a number of possible reasons. To gain a full understanding of the overall need of all patients across the disability spectrum, it

may be necessary to incorporate home visits into future studies, so as to gain access to those who would ordinarily be excluded from clinic or hospital based studies. This would lead to a more correct representation of the current need of patients with stroke and their caregivers.

- The results of the study have made it clear for the need for a study to follow up patients from admission to discharge, and into their home environment to gain greater understanding of medical care and rehabilitation input at each stage in stroke care in South Africa.

- Further research could gather information regarding the extent of rehabilitation received as an in-patient, functional ability of the patient on admission and discharge and at clinic follow-up, and the extent of any home-based rehabilitation. This information would provide insight into the provision of health services and the rehabilitative and support needs of the patient with stroke and their caregiver in the health sector serving the general population in South Africa. This would also assist health professionals to relevantly support the caregiver throughout the dynamic post-stroke process, so as to assist in alleviating strain and improving quality of life.

REFERENCES

Almberg B., Jansson W., Grafström M., Winblad B. 1998. Differences between and within genders in caregiving strain: a comparison between caregivers of demented and non-caregivers of non-demented elderly people. *Journal of Advanced Nursing*, **28** (4): 849-858. http://0-www3.interscience.wiley.com.innopac.wits.ac.za/cgi-bin/fulltext/119123314/PDFSTART [Accessed 14.04.2010]

Anderson C., Rubenach S., Mhurchu C.N., Clark M. Spencer C., Winsor A. 2000. Home or hospital for stroke rehabilitation? Results of a randomized controlled trial. I: Health outcomes at 6 months. *Stroke*, **31**: 1024-1031. http://stroke.ahajournals.org/cgi/reprint/31/5/1024?maxtoshow=&hits [Accessed 17.03.2008]

Anderson C.S., Linto J., Stewart-Wynne E.G. 1995. A Population-Based Assessment of the Impact and Burden of Caregiving for Long-term Stroke Survivors. *Stroke*, **26**: 843-849. http://stroke.ahajournals.org/cgi/content/full/26/5/843 [Accessed 2.04.2008]

Badia X., Monserrat S., Roset M., Herdman M. 1999. Feasibility, validity and test-retest reliability of scaling methods for health states: The visual analogue scale and the time trade-off. *Quality of Life Research*, **8** (94): 303-310. http://0-www.springerlink.com.innopac.wits.ac.za/content/n1pw5l3836304qt6/fulltext.pdf [Accessed 16.04.2008]

Barton G.R., Sach T.H., Avery A.J., Jenkinson C., Doherty M., Whines D.K., Muir K.R. 2008. A comparison of the performance of the EQ-5D and SF-6D for individuals aged ≥ 45 years. *Health Economics*, **17**(7): 815-32 http://0-www3.interscience.wiley.com.innopac.wits.ac.za/cgi-bin/fulltext/116322779/PDFSTART [Accessed 16.04.2008]

Berg A., Palomäki H., Lönnqvist J., Lehtihalmes M., Kaste M. 2005. Depression Among Caregivers of Stroke Survivors. *Stroke*, **36**: 639. http://stroke.ahajournals.org/cgi/content/full/36/3/639?maxtoshow [Accessed 12.03.2008]

Béthoux F., Calmels P., Gautheron V., Minaire P. 1996. Quality of life of the spouses of stroke patients: A preliminary study. *International Journal of Rehabilitation Research*, **19**: 291–299. http://0-ovidsp.tx.ovid.com.innopac.wits.ac.za/sp-3.2.4a/ovidweb.cgi? [Accessed 26.11.2010]

Birkett M.A., Day S.J. 1994. Internal pilot studies for estimating sample size. *Statistics in Medicine*, **13**: 2455-2463. http://0-onlinelibrary.wiley.com.innopac.wits.ac.za/doi/10.1002/sim.4780132309/pdf [Accessed 26.11.2010]

Bland M. 2001. An Introduction to medical statistics. 3rd ed. Oxford: Oxford University

Brooks R. 1996. EuroQol: the current state of play. *Health Policy*, **37**: 53-72. http://0-www.sciencedirect.com.innopac.wits.ac.za/science? [Accessed 21.12.2009]

Bugge C., RN, Alexander H., Hagen S. 1999. Stroke Patients' Informal Caregivers Patient, Caregiver, and Service Factors That Affect Caregiver Strain. *Stroke*, **30**:1517-1523. http://stroke.ahajournals.org/cgi/reprint/30/8/1517 [Accessed 05.03.2008]

Cifu D.X., Stewart D.G. 1999. Factors affecting functional outcome after stroke: A critical review of rehabilitation interventions. *Arch Phys Med Rehabil*, **80** (5): S35-S39. http://0-www.sciencedirect.com.innopac.wits.ac.za/science? [Accessed 07.07.2009]

Choi-Kwon S., Kim H., Kwon S.U., Kim J.S. 2005 Factors Affecting the Burden on Caregivers of Stroke Survivors in South Korea. *Archives of Physical Medicine and Rehabilitation*, **86**: 1043-1048. http://download.journals.elsevierhealth.com/pdfs/journals/0003-9993/PIIS0003999304013917.pdf [Accessed 07.07.2009]

Connor M.D., Thorogood M., Casserly B., Dobson C., Warlow C.P., SASPI Project Team. 2004. Prevalence of stroke survivors in rural South Africa: Results from the Southern Africa Stroke Prevention Initiative (SASPI) Agincourt Field Site. *Stroke*, **35**: 627-632. http://stroke.ahajournals.org/cgi/reprint/35/3/627 [Accessed 17.06.2011]

De Wit L., Putman K., Schuback B., Komárek A., Angst F., Baert I., Berman P., Bogaerts K., Brinkmann N., Connell L., Dejaeger E., Feys H., Jenni W., Kaske C., Lesaffre E., Leys M., Lincoln N., Louckx F., Schupp W., Smith B., De Weerdt W. 2007. Motor and Functional Recovery After Stroke: A Comparison of 4 European Rehabilitation Centers. *Stroke,* **38**; 2101-2107. http://stroke.ahajournals.org/cgi/reprint/38/7/2101?maxtoshow [Accessed 07.07.2009]

Dewey H.M., Thrift A.G., Mihalopoulos C., Carter R., Macdonell R.A.L., McNeil J.J., Donnan G.A. 2002. Informal Care for Stroke Survivors. Results from the North East Melbourne Stroke Incidence Study (NEMSIS). *Stroke*, **33**: 1028-1033. http://stroke.ahajournals.org/cgi/reprint/33/4/1028?maxtoshow [Accessed 17.03.2008]

Finch E., Brooks D., Stratford P.W., Mayo N.E. 2002. Physical Rehabilitation Outcome Measures. A guide to enhanced clinical decision making. Second Edition. Lippicott, Williams & Wilkins.

Ford G.R., Goode K.T., Barrett J.J., Harrell L.E., Haley W.E. 1997. Gender roles and caregiving stress: an examination of subjective appraisals of specific primary stressors in Alzheimer's caregviers. *Age and Mental Health*, **1** (2): 158-165. http://0-web.ebscohost.com.innopac.wits.ac.za/ehost/pdfviewer/pdfviewer [Accessed 1.12.2010]

Hale L.A., Eales C.J. 1998. Recovery of walking function in stroke patients after minimal rehabilitation. *Physiotherapy Research International*, **3** (3): 194-205 http://0-www3.interscience.wiley.com.innopac.wits.ac.za/cgi-bin/fulltext/112490005/PDFSTART?CRETRY=1&SRETRY=0 [Accessed 08.04.2010]

Hale L.A., Wallner P.J. 1996. The Challenge of Service Provision in South Africa for Patients with Hemiplegia. *Physiotherapy*, **82** (3): 156-158 http://0-www.sciencedirect.com.innopac.wits.ac.za/science?_ob=MImg&_imagekey=B7CVK-4HC7300-3- [Accessed 09.04.2010]

Heller A., Wade D.T., Wood V.A., Sunderland A., Hewer R. L., Ward E. 1987. Arm function after stroke: measurement and recovery over the first three months. *Journal of Neurology, Neurosurgery, and Psychiatry*, **50**: 714-719. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1032076/pdf/jnnpsyc00553-0056.pdf [Accessed 13.04.2010]

Hendricks H.T., van Limbeek J., Geurts A.C., Zwarts M.J. 2002. Motor Recovery After Stroke: A Systematic Review of the Literature. *Archives of Physical Medicine and Rehabilitation*, **83**: 1629-37. http://download.journals.elsevierhealth.com/pdfs/journals/0003-9993/PIIS0003999302002630.pdf [Accessed 13.07.2009]

Houlden H., Edwards M., McNeil J., Greenwood R. 2006 Use of the Barthel Index and the Functional Independence Measure during early inpatient rehabilitation after single incident brain injury. *Clinical Rehabilitation*, **20**: 153-159. http://0-cre.sagepub.com.innopac.wits.ac.za/cgi/reprint/20/2/153 [Accessed 26.11.2009]

Ilse I.B., Feys H., De Wit L., Putman K., De Weerdt W. 2008. Stroke caregivers' strain: prevalence and determinants in the first six months after stroke. *Disability and Rehabilitation*, **30** (7): 523 – 530. http://0-web.ebscohost.com.innopac.wits.ac.za/ehost/pdfviewer/pdfviewer? [Accessed 19.11.2010]

Jongbloed L.1986. Prediction of function after stroke: a critical review. *Stroke*, **17**: 765-776. http://stroke.ahajournals.org/cgi/reprint/17/4/765?maxtoshow [Accessed 11.06.2010]

Jönsson A., Lindgren I., Hallström B., Norrving B., Lindgren A. 2005. Determinants of Quality of Life in Stroke Survivors and Their Informal Caregivers. *Stroke*, **36**: 803-808. http://stroke.ahajournals.org/cgi/reprint/36/4/803?maxtoshow [Accessed 05.03.2008]

Jorgensen H.S., Nakayama H., Raaschou H.O., Olsen T.S. 1995. Recovery of walking function in stroke patients: The Copenhagen stroke study. *Archives of Physical Medicine and Rehabilitation*, **76**: 27-32. http://0-www.sciencedirect.com.innopac.wits.ac.za/science? [Accessed 13.04.2010]

Kalra L., Evans A., Perez I., Knapp M., Swift C., Donaldson N. 2005. A randomised controlled comparison of alternative strategies in stroke care *Health Technology Assessment,* **9** (18). http://www.hta.ac.uk/fullmono/mon918.pdf [Accessed 10.06.2009]

Kalra L., Evans A., Perez I., Melbourn A., Patel A., Knapp M., Donaldson N. 2004. Training Carers of Stroke Patients: Randomised Controlled Trial. *British Medical Journal* **328**: 1099.
http://www.bmj.com/cgi/content/full/328/7448/1099 [Accessed 12.03.2008]

Kasner S.E. 2006. Clinical Interpretation and use of Stroke Scales. *The Lancet Neurology*, **5**: 603-12. http://0-www.mdconsult.com.innopac.wits.ac.za/das/article/body/173360720-8/jorg=journal&source [Accessed 10.04.2008]

Kirkwood B.R., Sterne J.A.C. Essential Medica Statistics. Oxford: Blackwell Science Ltd., 1988.

Ko J.Y., Aycock D.M., Clark P.C. 2007. A Comparison of Working Versus Nonworking Family Caregivers of Stroke Survivors. *Journal of Neuroscience Nursing*, 39: 217(9).
Lincoln N.B., Francis V.M., Lilley S.A., Sharma J.C., Summerfield M. 2003. Evaluation of a Stroke Family Support Organiser. *Stroke,* **34**: 116.
http://stroke.ahajournals.org/cgi/content/full/34/1/116 [Accessed 12.03.2008]

Kwakkel G., Kollen B.J., van der Grond J., Prevo A.J.H. 2003. Probability of regaining dexterity in the flaccid upper limb: impact of severity of paresis and time since onset in acute stroke. *Stroke*, **34**: 2181-2186
http://stroke.ahajournals.org/cgi/reprint/34/9/2181.pdf [Accessed 13.04.2010]

Langhorne P., Widen-Holmqvist L. Taylor G., Murray G., Askim T., Dennis M., Anderson C., Bautz-Holter E., Dey P., Indredavik B., Mayo N., Power M., Rodgers H., Ronning O.M., Rudd A., Suwanwela N., Wolfe C. 2007. Early Supported Discharge After Stroke. *Journal of Rehabilitation Medicine,* **39**: 103–108.
http://jrm.medicaljournals.se/article/pdf/10.2340/16501977-0042 [Accessed 5.11.2009]

Lincoln N.B., Francis V.M., Lilley S.A., Sharma J.C., Summerfield M. 2003. Evaluation of a Stroke Family Support Organiser. *Stroke,* **34**: 116.
http://stroke.ahajournals.org/cgi/content/full/34/1/116 [Accessed 12.03.2008]

Loewen S.C., Anderson B.A. 1988. Reliability of the Modified Motor Assessment Scale and the Barthel Index. *Physical Therapy*, **68** (7): 1077-1081.
http://ptjournalonline.org/cgi/reprint/68/7/1077 [Accessed 20.04.2010]

Lui M.H.L., Ross F.M., Thompson D.R. 2005. Supporting Family Caregivers in Stroke Care. A Review of the Evidence for Problem Solving. *Stroke* **36**: 2514. http://stroke.ahajournals.org/cgi/content/full/36/11/2514?maxtoshow [Accessed 12.03.2008]

Mamabolo M.V., Mudzi W., Stuart A.S., Olorunju S., Singh A. 2009. A Study to Determine Post Discharge Functional Improvements in Patients with Stroke. *South African Journal of Occupational Therapy*, **39** (1): 15-18

Mayo N.E., Wood-Dauphinee S., Côtě R., Gayton D., Carlton J., Buttery J., Tamblyn R. 2000. There's No Place Like Home: An Evaluation of Early Supported Discharge for Stroke. *Stroke*, **31**: 1016-1023. http://stroke.ahajournals.org/cgi/reprint/31/5/1016?maxtoshow [Accessed 17.03.2008]

McCullagh E., Brigstocke G., Donaldson N., Kalra L. 2005. Determinants of Caregiving Burden and Quality of Life in Caregivers of Stroke Patients. *Stroke*, **36**: 2181-2186. http://stroke.ahajournals.org/cgi/reprint/36/10/2181?maxtoshow [Accessed 07.07.2009]

Miller B., Cafasso L. 1992. Gender Differences in Caregiving: Fact or Artifact? *The Gerontologist*, **32** (4): 498-507. http://0-proquest.umi.com.innopac.wits.ac.za/pqdweb?index [Accessed 1.12.2010]

Morimoto T., Schreiner A.S., Asano H. 2003. Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age and Ageing*, **32**: 218–223. http://ageing.oxfordjournals.org/cgi/reprint/32/2/218 [Accessed 12.03.2008]

Moritz D.J., Kasl S.V., Berkman L.F. 1989. The health impact of living with a cognitively impaired elderly spouse: Depressive symptoms and social functioning. *Journal of Gerontology: Social Sciences*, **44** (I): SI 7-27 http://geronj.oxfordjournals.org/content/44/1/S17.full.pdf [Accessed 19.0 1.2011]

Olsen T.S. 1990. Arm and leg paresis as outcome predictors in stroke rehabilitation. *Stroke*, 21: 247-251. http://stroke.ahajournals.org/cgi/reprint/21/2/247?maxtoshow [Accessed 14.04.2010]

Oppe M., Rabin R., de Charro F. 2007. EQ-5D User Guide. Version 1.0 www.euroqol.org

Ory M.G., Hoffman III R.R., Yee J.L., Tennstedt S., Schulz R. 1999. Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerentologist*, **39** (2): 177-185. http://gerontologist.oxfordjournals.org/content/39/2/177 [Accessed 13.02.2011]

Post M.W.M., Festen H., van de Port I.G., Visser-Meily J.M.A. 2007. Reproducibility of the Caregiver Strain Index and the Caregiver Reaction Assessment in partners of stroke patients living in the Dutch community. *Clin Rehabil*, **21**: 1050 - 1055 http://cre.sagepub.com/cgi/content/abstract/21/11/1050 [Accessed 2.12.2009]

Reaves, C.S. 1992. Quantitative research for behavioural Sciences. New York: Wiley

Richards S.H., Peters T.J., Coast J., Gunnell D.J., Darlow M., Pounsford J. 2000. Inter-rater reliability of the Barthel ADL Index: how does a researcher compare to a nurse? *Clinical Rehabilitation*, **14**: 72-78. http://0-cre.sagepub.com.innopac.wits.ac.za/cgi/reprint/14/1/72 [Accessed 26.11.2009]

Rombough R.E., Howse E.L., Bagg S.D., Bartfay W.J. 2007. A comparison of studies on the quality of life of primary caregivers of stroke survivors: A systematic review of the Literature. *Topics in Stroke Rehabilitation*, **14**(3): 69–79. http://thomasland.metapress.com/content/82q3277030766844/fulltext.pdf [Accessed 19.11.2010]

Rønning O.M., Guldvog B. 1998. Stroke units versus general medical wards, I: Twelve and eighteen-month survival: A randomized, controlled trial. *Stroke*, **29**: 58-62. http://stroke.ahajournals.org/cgi/reprint/29/1/58?maxtoshow [Accessed 9.06.2010]

Rousseaux M., Daveluy W., Kozlowski O. 2009. Value and efficacy of early supported discharge from stroke units. *Annals of Physical and Rehabilitation Medicine*, **52**: 224–233. http://0-www.sciencedirect.com.innopac.wits.ac.za/science? [Accessed 14.04.2010]

Scholte op Reimer W.J.M., Haan de R.J., Rijnders P.T., Limburg M., Bos van den G.A.M., 1998 The Burden of Caregiving in Partners of Long-term Stroke Survivors. *Stroke* **29**: 1605–1611. http://stroke.ahajournals.org/cgi/reprint/29/8/1605 [Accessed 12.11.2009]

Shah S., Vanclay F., Cooper B. 1989. Improving the sensitivity of the barthel index for stroke rehabilitation. *Journal of Clinical* Epidemiology, **42** (8): 703-709. http://0-www.sciencedirect.com.innopac.wits.ac.za/science? [Accessed 20.04.2010]

Skilbeck C.E., Wade D.T., Langton-Hewer R., Wood V.A. 1983. Recovery after stroke. *Journal of Neurology, Neurosurgery, and Psychiatry*, **46**: 5-8. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1027255/pdf/jnnpsyc00129-0013.pdf [Accessed 14.04.2010]

Stroke Unit Trialists' Collaboration. 1997 Collaborative systematic review of the randomised trials of organised inpatient (stroke unit) care after stroke. *British Medical Journal*, **314**: 1151 (19 April). http://www.bmj.com/cgi/content/full/314/7088/1151 [Accessed 08.04.2010]

Sullivan M.T. 2004. Caregiver Strain Index (CSI). *Dermatology Nursing*, **16**(4): 385-386. http://www.medscape.com/viewarticle/488917 [Accessed 5.03.2008]

Sunderland A., Tinson D., Bradley L., Hewer R.L. 1989. Arm function after stroke. An evaluation of grip strength as a measure of recovery and a prognostic indicator. *Journal of Neurology, Neurosurgery, and Psychiatry*, **52**: 1267-1272. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1031635/pdf/jnnpsyc00533-0047.pdf [Accessed 13.04.2010]

Thorogood M., Lewando-Hundt G., Tollman S., Connor M.D., Milne F.J., Casserly B., Collinson M., Dobson C., Kahn K., Mokwena E., Modi G., Ngoma B., Warlow C.P. 2004. Prevalence of Stroke Survivors in Rural South Africa. Results from the Southern Africa Stroke Prevention Initiative (SASPI). Agincourt field site. *Stroke*, **35**: 627-632. http://stroke.ahajournals.org/cgi/reprint/35/3/627?maxtoshow [Accessed 10.07.2009]

Tooth L., Mckenna K., Barnett A., Prescott C., Murphy S. 2005. Caregiver burden, time spent caring and health status in the first 12 months following stroke *Brain Injury*, November; **19** (12): 963–974. http://0-web.ebscohost.com.innopac.wits.ac.za/ehost/pdfviewer/pdfviewer?vid=2&hid=112&sid=0a1c5a04-a017-4b70-983f-90e55849a2e4%40sessionmgr115 [Accessed 18.11.2010]

Toschkea A.M., Tillingb K., Coxa A.M., Ruddc A.G., Heuschmann P.U., Wolfe C.D.A. 2010. Patient-specific recovery patterns over time measured by dependence in activities of daily living after stroke and post-stroke care: The South London Stroke Register (SLSR). *European Journal of Neurology*, **17**: 219–225 http://0-www3.interscience.wiley.com.innopac.wits.ac.za/cgi-bin/fulltext/122545450/PDFSTART [Accessed 13.04.2010]

van Delden A.E.Q., Peper C.E., Harlaar J., Daffertshofer A., Zijp N.I., Nienhuys K., Koppe P., Kwakkel G., Beek P.J. 2009. Comparing unilateral and bilateral upper limb training: The ULTRA-stroke program design. *BioMedCentral Neurology*, **9**: 57. http://www.biomedcentral.com/1471-2377/9/57/ [Accessed 13.04.2010]

van den Heuvel E.T.P., de Witte L.P., Schure L.M., Sanderman R., Meyboom-de Jong B. 2001. Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention. *Clinical Rehabilitation*, **15**: 669-677. http://dissertations.ub.rug.nl/FILES/faculties/medicine/2002/e.t.p.van.den.heuvel/c3.pdf [Accessed 14.04.2010]

van Exel N.J.A., Scholte op Reimer W.J.M., BF Brouwer W.B.F., van den Berg B., Koopmanschap M.A., van den Bos G.A.M. 2004. Instruments for assessing the burden of informal caregiving for stroke patients in clinical practice: a comparison of CSI, CRA, SCQ and self-rated burden. *Clinical Rehabilitation*, **18**: 203 – 214. http://cre.sagepub.com/cgi/content/abstract/18/2/203 [Accessed 3.12.2009]

van Heugten C., Visser-Meily A., Post M., Lindeman E. 2006. Care for carers of stroke patients: evidence-based clinical practice guidelines. *Journal of Rehabilitation Medicine*, **38**: 153 – 158. http://jrm.medicaljournals.se/article/pdf/10.1080/16501970500441898 [Accessed 3.12.2009]

Visser-Meily A., Post M., Gorter J.W., Berlekom S.B.V., Van Den Bos T., Lindeman E. 2006. Rehabilitation of stroke patients needs a family-centred approach. *Disability and Rehabilitation*. **28** (24): 1557-1561. http://0-web.ebscohost.com.innopac.wits.ac.za/ehost/pdfviewer/pdfviewer?hid [Accessed 02.04.2008]

Visser-Meily A., van Heugten C., Post M., Schepers V., Lindeman E. 2005. Intervention Studies for Caregivers of Stroke Survivors: A Critical Review. *Patient Education and Counselling*, **56** (3): 257-267. http://www.sciencedirect.com/science? [Accessed 12.03.2008]

Visser-Meily A.J.M., Post M.W.M., Riphagen I.I., Lindeman E. 2004. Measures used to assess burden among caregivers of stroke patients: a review. *Clinical Rehabilitation*, **18**: 601 – 623 http://cre.sagepub.com/cgi/content/abstract/18/6/601 [Accessed 3.12.2009]

Wade D.T., Hewer R.L. 1987. Functional abilities after stroke: measurement, natural history and prognosis. *Journal of Neurology, Neurosurgery and Psychiatry*, **50**: 177-182. http://0-jnnp.bmj.com.innopac.wits.ac.za/content/50/2/177.full.pdf [Accessed 24.11.2010]

Wade D.T., Langton-Hewer R., Wood V.A., Skilbeck C.E., Ismail H.M. 1983. The hemiplegic arm after stroke: measurement and recovery. Journal *of Neurology, Neurosurgery, and Psychiatry*, **46**:521-524. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1027442/pdf/jnnpsyc00134-0057.pdf [Accessed 13.04.2010]

Wallace D., Duncan P.W., Lai S.M. 2002 Comparison of the responsiveness of the Barthel Index and the Motor Component of the Functional Independence Measure in stroke The impact of using different methods for measuring responsiveness. *Journal of Clinical Epidemiology*, **55**: 922–928. http://0-www.sciencedirect.com.innopac.wits.ac.za/science? [Accessed 10.04.2008]

Wandel A., Jorgensen H.S., Nakayama H., Raaschou H.O., Olsen T.S. 2000. Prediction of walking function in stroke patients with initial lower extremity paralysis: The Copenhagen stroke study. *Archives of Physical Medicine and Rehabilitation*, **81**: 736-738. http://0-www.sciencedirect.com.innopac.wits.ac.za/science? [Accessed 14.04.2010]

Ware J.E. 2000. SF-36 Health Survey Update. *Spine*, **25** (24): 3130–3139. http://0-ovidsp.tx.ovid.com.innopac.wits.ac.za [Accessed 20.11.2007]

White C.L., Mayo N., Hanley J.A., Wood-Dauphinee S. 2003. Evolution of the caregiving experience in the initial 2 years following stroke. *Research in Nursing & Health*, **26**: 177-189. http://0-onlinelibrary.wiley.com.innopac.wits.ac.za/doi/10.1002/nur.10084/pdf [Accessed 26.11.2010]

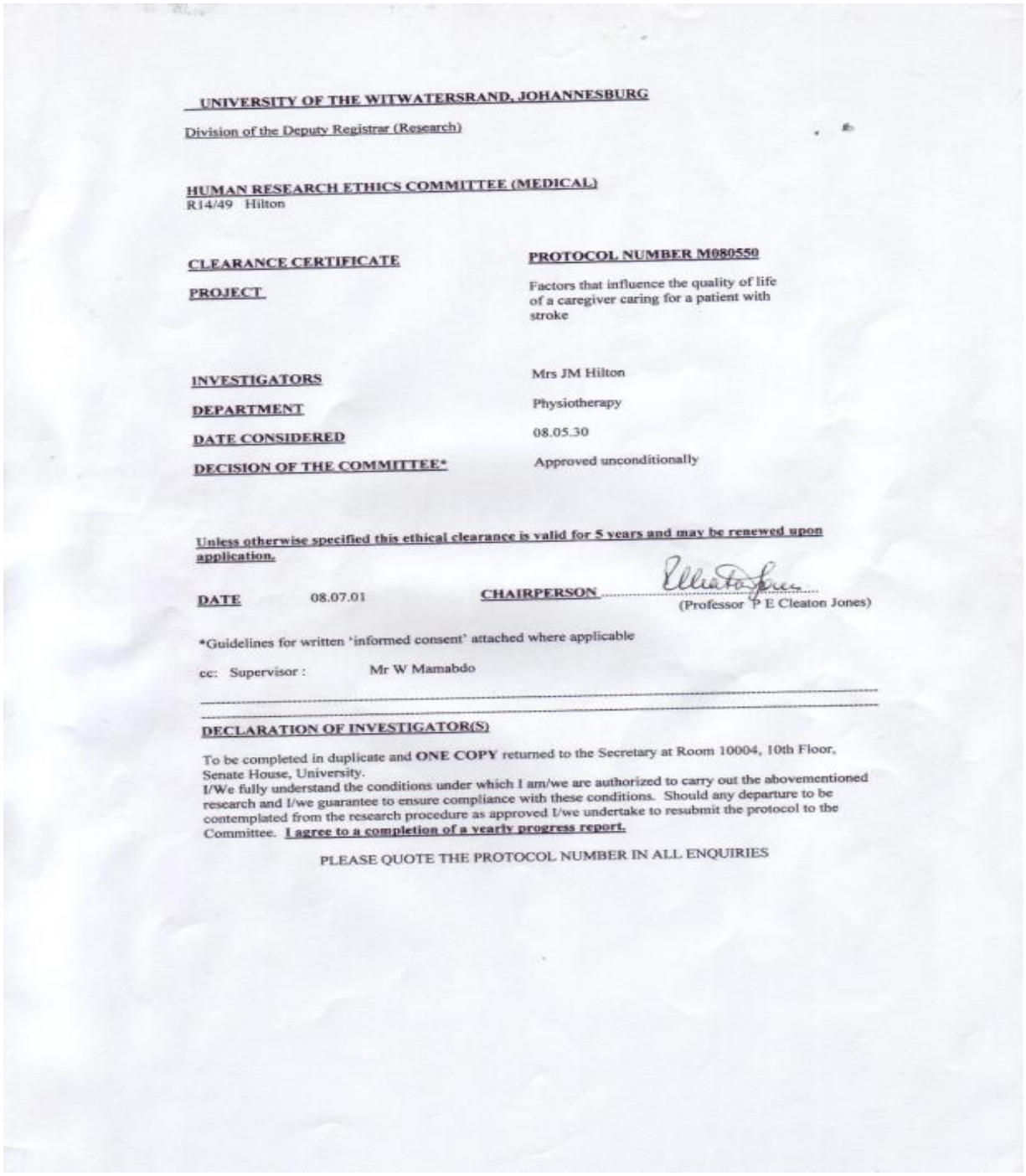
Wilkinson P.R., Wolfe C.D.A., Warburton F.G., Rudd A.G., Howard R.S., Ross-Russell R.W., Beech R.R. 1997. A Long-term Follow-up of Stroke Patients. *Stroke*, 28: 507-512. http://stroke.ahajournals.org/cgi/content/full/28/3/507 [Accessed 2.04.2008]

World Health Organization (WHO) (2006). WHO STEPS Stroke Manual: The WHO STEPwise approach to *stroke surveillance.* Geneva, World Health Organization. http://www.who.int/chp/steps/stroke/manual/en/index.html [Accessed 12.03.2008]

Zeltzer L., Korner-Bitensky N., Sitcoff E., Marvin K. [Updated 22-03-2011]. Rivermead Motor Assessment (RMA). StrokEngine Assess. Canadian Stroke Network. http://www.medicine.mcgill.ca/strokengine-assess/module_rma_intro-en.html [Accessed 14.08.2011]

APPENDICES

Appendix A: Ethical Clearance Certificate



UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Hilton

CLEARANCE CERTIFICATE — **PROTOCOL NUMBER M080550**

PROJECT — Factors that influence the quality of life of a caregiver caring for a patient with stroke

INVESTIGATORS — Mrs JM Hilton

DEPARTMENT — Physiotherapy

DATE CONSIDERED — 08.05.30

DECISION OF THE COMMITTEE* — Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 08.07.01 **CHAIRPERSON** .....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

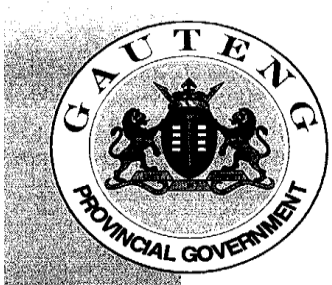
cc: Supervisor : Mr W Mamabdo

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B: Permission to perform study







Department of Health
Lefapha la Maphelo
Departement van Gesondheid
Umnyango wezeMpilo
JHB-WEST RAND REGION
Family Medicine & PHC

MEMO

TO: Ms Jessica Hilton (0842140102)
Physiotherapy
FROM: Dr S. Moosa
DATE: 27th August 2008

RE: Research Project

This is to state that I am giving permission provisionally for you to conduct the in-course research project titled "Factors that influence the quality of life of a caregiver caring for a patient with stroke" in fulfilment of the degree Bachelor of Social Work. Please ensure that a copy of the ethics certificate and protocol are emailed to me to submit to the Research Office at Head Office.

Please note the commitment you make to submit a copy of the report and provide feedback to both facilities, management and research fora of the Department of Health once the study is completed.

Yours truly,

.....

Dr S. Moosa
District Family Physician, Johannesburg Metro District Health Service

Tel: (011) 694-3826/7 Fax: (011) 694-3825
Hillbrow CHC - Administration Block, Corner Klein & Smit Street
Private Bag X21, Johannesburg, 2001

Appendix C: Information Document for the Caregiver of a Person with Stroke

Study Title: Factors that influence the quality of life of a caregiver caring for a patient with stroke

Hello, my name is Jessica Hilton. I am a masters degree student in the department of Physiotherapy at the University of the Witwatersrand.

I, Jessica Hilton, am doing research on people (caregivers) who are looking after a person who has had a stroke. Research is a way to learn the answer to a question. In this study, I want to learn what factors affect the quality of life of the person looking after someone who has had a stroke. The caregiver plays a very important role in helping the person with stroke to have a better quality of life. It is therefore very important to learn how the caregiver is coping with caring for the person with stroke, so that we can give more support to caregivers who are not coping.

I am inviting you to take part in this study, to help us learn what factors affect the quality of life of a person caring for someone who has had a stroke.

During one of your visits to the clinic, the person with stroke will have their normal treatment. When the patient is finished, I, or my research assistant, will then spend some time with you, explaining what it will mean to take part in the research study. I will give you a chance to decide if you would like to take part in the research. If you agree, I will give you a form to sign. I will also ask the person with the stroke that you are caring for if he/she would like to take part in the research. If he/she agrees, I will give him/her a form to sign. If you and the person with stroke agree to take part, I will give you another form to fill out. This form will ask questions about the home and family environment where the person with stroke lives. I will then ask you questions about how much help the person with stroke needs with dressing, eating, moving around etc. You will then fill out another form asking questions to establish if you find any of these tasks difficult. You will then fill out a form which asks questions about your quality of life. This process will take about 30 to 45 minutes. This will then be the end of the questions, and you will not be questioned by me or my research assistant again.

If you decide to take part in the research, the answers will give us a good understanding of how caregivers are coping with caring for a person with stroke. This will help us to develop programmes that will assist those who are not coping well with their caregiving role.

The information that we get from the forms will be available to you after the study, if you would like to see it.

You can decide if you would like to take part in the research or not. If you decide not to take part in the research, you and the person with stroke will still get the same treatment at the clinic. If you decide to take part in the research and then later on decide that you

do not want to continue with the research, that will be fine. You and the person with stroke will still get the same treatment at the clinic as before.

You will not have to travel to the clinic anymore than you would normally do for your treatment sessions.

When you have filled in the forms and I, or my research assistant, have asked the questions, I will take all the information and look at the answers. I will not use your or the person with the stroke's names in any of the reports I write. Your personal information will therefore not be shown to other people or written in reports. I will need to link the answers in the forms you fill out, to the answers of the person with stroke for the purposes of the research. A code will therefore appear on the forms, and only the researcher will know which person is represented by the code.

If you need to make contact with me about the research, you can phone me, Jessica Hilton, on 084 214 0102 between 8:00 am and 3:00 pm.

If you have any complaints about the research, you can contact the Wits research office on (011) 717-1234.

Thank you very much for your time.

Jessica Hilton
BSc Physiotherapy

Appendix D: Information Document for the Caregiver of a Person with Stroke (Zulu)

Isihloko Sophenyo: Isimo esibangela ubuhle bempilo yokunakekela isiguli esishaywe i”stroke”

Sanibonani, igama lami uJessica Hilton. Ngingumfundi osebenza ngeziguli ezinestroke nezingozi zemoto noma ukugula okukhubaza amalunga omzimba, ngiqende izifundo zami eunivesi yase Witwatersrand, ngiqhubeka nezinfundo zami zeziqu ezingeni eliphakemeyo nayo i univesi ya Witwatersrand.

Mina, Jessica Hilton, ngenza uphenyo ngokunakekela iziguli ezishaywe yistroke. Uphenyo yindlela yokufunda impendulo yombuzo. Ngifuna ukufunda ukuthi yini into engahlupha noma ukuhlukumeza umuntu onakekela isiguli esine stroke. Umnakekeli udlala indima ebaluleke kakhulu empilweni yomuntu oshaywe istroke ukuze abe nempilo egculisayo ogulayo. Kusemqoka-ke ukufunda ukuthi umnakekeli uphumumelela kanjani ukunakekela isiguli esinestroke ukuze sikhuthaze labo banakekeli abanga kwazi ukunakekela iziguli zestroke.

Ngiyanimema nibeyingxenye yalolu phenyo, nisisize ukufunda ukuthi yini ehlukumeza noma ehlupha umuntu onakekela isiguli esinestroke.

Ngizokunivakashela emtholampilo ngelinye ilanga.Iisiguli sestroke sizothola ukulashwa njengenhlalayenza, lapho isiguli sesiqedile, mina, noma umsizi kuphenya sizoke sihlale, sichaza imininingwane yokuthi kusho ukuthini ukuthatha ingxenye ekuphenyeni. Ngizonipha ithuba lokucabanga ukuthi nizothanda yini ukuba yingxenye yaloluphenyo, uma nivuma ngizonipha iphepha lokugcwalisa imininingwane wena uzosayinda. Ngiphinde ngibuze oshaywe istroke yena lo omgcinayo ukuba uyafisa yini ukuba ingxenye yaloluphenyo. Uma evuma naye ngokunjalo ngimnike asayinde. Senivumile nobabili ngininike elinye futhi ipheshana nisayinde noma niligcwalise. Lelifomu lizonibuza ngamakhaya enu nangemindeni yenu lapho isiguli sestroke sihlala khona. Ngiphinde ngibuze ukuthi empeleni lungakanani usizo oludingwa isiguli sestroke uma egqokiswa, edliswa, enyakaziswa njalonjalo. Uzophinda futhi ugcwalise elinye ifomu elinemibuzo ukuze sibeno kuqonda ukuba ithola ibunzima obungakunani ekwenzeni lomsebenzi. Emva kwalokho uzobusugcwalisa ifomu elinemibuzo ngesimo sempilo yakho. Lengqubo izothatha uhalufu wehora, noma ngaphezudlwana. Emva kwalokho akuyikubakhona eminye imibuzo.

Uma uvuma ukuthatha ingxenye kuloluphenyo, izimpendulo eniyosipha zona zizosisiza ukuthi siqonde ukuthi abanakekeli beziguli zestroke, baphumelela kanjani. Thina sizosizakala ukubumba imigomo ezoncedisana nalabo abahlulekayo ukugcina abantu abashaywe yistroke.

Lolwazi lizothokala kinina emuva kwalezizifundo, uma nizofisa ukulibona.

Ungasithatha isinqumo sokuvuma ukuba yingxenye yaloluphenyo noma qha. Uma ungathandi ukuthatha ingxenye kuloluphenyo, wena nesiguli sestroke nizoqhubeka nokuthola usizo lona lolo ebenilothola ekuqaleni emthola mpilo. Uma ubususthathile isinqumo sokuba yingxenye yophenyo, kepha uzwe ungasathandi ungahoqisa, kodwa uzothola lona lolosizo owawukade ulithola kuqala. Nobabili nisezothola usizo emtholampilo.

Awuzukudinga ukuya emtholampilo, njengoba uyaye wenze ngezinye izinsuku.

Ngizothanda ukucwaningisisa izimpendulo eziku fomu eligcwaliswe yisiguli sestroke kanye neligcwaliswe ngonakekela isiguli ngenjongo yophenyo. Inombolo elibonakala kuleli fomu lizo kwaziwa ngumphenyi kuphela ukuthi ngubani umnini fomu.

Ngithinte kulenombolo Jessica Hilton 084 214 0102 kulezikhathi 8:00-3:00 ntambama.

Izikhalazo ngalolu cwaningo thintana neWits ihovisi lezophenyo (011) 717-1234.

Ngibonga isikhathi sakho.

Jessica Hilton
BSc Physiotherapy

Appendix E: Information Document for the Person with Stroke

Study Title: Factors that influence the quality of life of a caregiver caring for a patient with stroke

Hello, my name is Jessica Hilton. I am a masters degree student in the department of Physiotherapy at the University of the Witwatersrand.

I, Jessica Hilton, am doing research on people (caregivers) who are looking after a person who has had a stroke. Research is a way to learn the answer to a question. In this study, I want to learn what factors affect the quality of life of the person looking after someone who has had a stroke. The caregiver plays a very important role in helping the person with stroke to have a better quality of life. It is therefore very important to learn how the caregiver is coping with caring for the person with stroke, so that we can give more support to caregivers who are not coping.

I am inviting you to take part in this study, to help us learn what factors affect the quality of life of a person caring for someone who has had a stroke.

During one of your visits to the clinic, you will have your normal treatment. When you are finished, I, or my research assistant, will then spend some time with you, explaining what it will mean to take part in the research study. I will give you a chance to decide if you would like your caregiver to take part in the research. If you agree, I will give you a form to sign. I will also ask your caregiver if he/she would like to take part in the research. If he/she agrees, I will give him/her a form to sign. If you and your caregiver agree to take part, I will give your caregiver another form to fill out. This form will ask questions about your home and family environment. I will then ask your caregiver questions about how much help you need with dressing, eating, moving around etc. The caregiver will then fill out another form asking questions to establish if he/she finds any of these tasks difficult. The caregiver will then fill out a form which asks questions about their quality of life. This process will take about 30 to 45 minutes. This will then be the end of the questions, and you will not be questioned by me or my research assistant again.

If you decide to take part in the research, the answers will give us a good understanding of how caregivers are coping with caring for a person with stroke. This will also help us to develop programmes that will assist those who are not coping well with their caregiving role.

The information that we get from the forms will be available to you after the study, if you would like to see it.

You can decide if you would like to take part in the research or not. If you decide not to take part in the research, you and your caregiver will still get the same treatment at the clinic. If you decide to take part in the research and then later on decide that you do not

want to continue with the research, that will be fine. You and your caregiver will still get the same treatment at the clinic as before.

You will not have to travel to the clinic anymore than you would normally do for your treatment sessions. To be added into the zulu translation

When you have filled in the forms and I, or my research assistant, have asked questions, I will take all the information and look at the answers. I will not use your or your caregiver's names in any of the reports I write. Your personal information will therefore not be shown to other people or written in reports. I will need to link the answers in the forms you fill out, to the answers of your caregiver for the purposes of the research. A code will therefore appear on the forms, and only the researcher will know which person is represented by the code.

If you need to make contact with me about the research, you can phone me, Jessica Hilton, on 084 214 0102 between 8:00 am and 3:00 pm.

If you have any complaints about the research, you can contact the Wits research office on (011) 717-1234.

Thank you very much for your time.

Jessica Hilton
BSc Physiotherapy

Appendix F: Information Document for the Person with Stroke (Zulu)

Isihloko Sophenyo: Isimo esibangela ubuhle bempilo yonakekela isiguli esishaywe i”stroke”

Sanibonani, igama lami uJessica Hilton. Ngingumfundi osebenza ngeziguli ezinestroke nezingozi zemoto noma ukugula okukhubaza amalunga omzimba, ngiqende izifundo zami eunivesi yase Witwatersrand, ngiqhubeka nezinfundo zami zeziqu ezingeni eliphakemeyo nayo i univesi ya Witwatersrand.

Mina, Jessica Hilton, ngenza uphenyo ngokunakekela iziguli ezishaywe yistroke. Uphenyo yindlela yokufunda impendulo yombuzo. Ngifuna ukufunda ukuthi yini into engahlupha noma ukuhlukumeza umuntu onakekela isiguli esine stroke. Umnakekeli udlala indima ebaluleke kakhulu empilweni yomuntu oshaywe istroke ukuze abe nempilo egculisayo ogulayo. Kusemqoka-ke ukufunda ukuthi umnakekeli uphumumelela kanjani ukunakekela isiguli esinestroke ukuze sikhuthaze labo banakekeli abanga kwazi ukunakekela iziguli zestroke.

Ngiyanimema nibeyingxenye yalolu phenyo, nisisize ukufunda ukuthi yini ehlukumeza noma ehlupha umuntu onakekela isiguli esinestroke.

Ngizokunivakashela emtholampilo ngelinye ilanga, uzonikezwa izindlela zokunakekela impilo njengenjwayelo. Emva kwalokho mina nomncediwami sizohlala nawe isikhashashana sichaza ukuthi kusho ukuthini ukuba ingxenye kwakho kuloluphenyo. Uzonikezwa ithuba lokucabangisisa ngaloludaba. Uma uvuma uzonikezwa ipheshana usayinde. Ngibuze umnakekeli wakho okokuba uyavuma na. Nobabili senivumile niphinde nigcwalise ipheshana. Sizoqala-ke sibuze ngomziwakho nangomndeni wakho. Ngizobuza nangosizo oludingayo uma ugqoka, udla, uzulazula. Aphinde agcwalise ipheshana lemibuzo eqondene nobunzima ahlangabezana nabo lapho enza lomsebeni. Onakekela isiguli sestroke uzogcwalisa ifomu elibuza gesimo sempilo. Lengqubo izothatha uhalufu wehora, noma ngaphezudlwana. Emva kwalokho akuyikubakhona eminye imibuzo.

Uma uvuma ukuthatha ingxenye kuloluphenyo, izimpendulo eniyosipha zona zizosisiza ukuthi siqonde ukuthi abanakekeli beziguli zestroke, baphumelela kanjani. Thina sizosizakala ukubumba imigomo ezoncedisana nalabo abahlulekayo ukugcina abantu abashaywe yistroke.

Lolwazi lizothokala kinina emuva kwalezizifundo, uma nizofisa ukulibona.

Ungasithatha isinqumo sokuvuma ukuba yingxenye yaloluphenyo noma qha. Uma ungathandi ukuthatha ingxenye kuloluphenyo, wena nesiguli sestroke nizoqhubeka nokuthola usizo lona lolo ebenilothola ekuqaleni emthola mpilo. Uma ubusuthathile isinqumo sokuba yingxenye yophenyo, kepha uzwe ungasathandi ungahoqisa, kodwa uzothola lona lolosizo owawukade ulithola kuqala. Nobabili nisezothola usizo emtholampilo.

Awuzukudinga ukuya emtholampilo, njengoba uyaye wenze ngezinye izinsuku.

Ngizothanda ukucwaningisisa izimpendulo eziku fomu eligcwaliswe yisiguli sestroke kanye neligcwaliswe ngonakekela isiguli ngenjongo yophenyo. Inombolo elibonakala kuleli fomu lizo kwaziwa ngumphenyi kuphela ukuthi ngubani umnini fomu.

Ngithinte kulenombolo Jessica Hilton 084 214 0102 kulezikhathi 8:00-3:00 ntambama.

Izikhalazo ngalolu cwaningo thintana neWits ihovisi lezophenyo (011) 717-1234.

Ngibonga isikhathi sakho.

Jessica Hilton
BSc Physiotherapy

Appendix G: Consent Form

Code ☐

CONSENT FORM

I, ……., agree that I understand what the research performed by Jessica Hilton entails and agree with the conditions of the study and to take part in the study.

I also know that all information that I give will be treated with confidentiality and that I will not be paid for taking part in this study.

I, as the participant, have the right to end participation in the study at any time. I will have to tell Jessica Hilton, or her research assistant, that I have decided to withdraw. In this case, my treatment at the clinic will continue as normal.

…….	…….
Signature of the participant	Signature of the researcher
…….	…….
Full name of the participant	Full name of the researcher
…….	…….
Date signed	Date signed
…….	……..
Place at which signed	Place at which signed

Appendix H: Consent Form (Zulu)

Code ☐

IFOMU LOKUVUMA

Mina, ……ngiyavuma ukuba ngiqonda yonke lendaba yocwaningo olwenziwa ngu-Jessica Hilton ngivumelana nemigomo yalolucwaningo nokuba ingxenye yalo.

Ngiyazi futhi ukuthi ulwazi engilunikezayo lizohlonishwa lube imfihlo futhi ngeke ngikhokhelwe.

Mina, ngxenye yophenyo nginelungelo lokumisa ukuzimbadakanya nomanini. Ngizomtshela uJessica Hilton noma umncedisi wakho ngesinqumo sokumisa kwami. Ngalokho usizo ebengilithola ngizoqhubeka nokulithola yize ngimese ukuphenya.

……..	……..
Sayinda	Umphenyi sayinde
……..	……..
Igama lami (elipheleleyo)	Igama lomphenyi
……...	……..
Usuku	Usuku
……..	……..
Indawo	Indawo

Appendix I: Demographic Questionnaire for the Caregiver

Code ☐

Rater name: _____

Factors that influence the quality of life of a caregiver
caring for a patient with stroke
DEMOGRAPHIC QUESTIONNAIRE
CAREGIVER OF PERSON WITH STROKE

Please answer all questions in this questionnaire

Age of caregiver of person with stroke: _____

SECTION A:

Please tick the relevant block(s)

1. Gender

☐ Male ☐ Female

2. Marital Status

☐ Single ☐ Married ☐ Live-in Partner

☐ Divorced ☐ Widow

3. Highest Level of Education

☐ No schooling

☐ Up to Grade 7

☐ Up to Grade 11

☐ Grade 12 or equivalent

☐ Diploma

☐ University degree

SECTION B: Economic Situation

4. How are you related to the person with stroke?

☐ Spouse ☐ Sibling ☐ Child

☐ Parent ☐ Other relative ☐ Friend

5. What was your role in the household before you started caring for the person with stroke?

☐ Domestic work ☐ Household chores ☐ Scholar

☐ Care of children ☐ Caregiver ☐ Contributing to family income

☐ Other (please explain): _____

6. What is your role in the household now as you care for the person with stroke?

☐ Domestic work ☐ Household chores ☐ Scholar

☐ Care of children ☐ Caregiver ☐ Contributing to family income

☐ Other (please explain): _____

7. How many people, including you and the person with stroke, live in the house with you and the person with stroke?

☐ 1-3 ☐ 4-6 ☐ 7-9

☐ More than 9

8. Write down how many children of the different ages live in the house with you and the person with stroke?

Birth to 4 years of age ☐ Number of children

4 to 10 years of age ☐ Number of children

10 to 14 years of age ☐ Number of children

14 to 18 years of age ☐ Number of children

9. Including the person with stroke, how many other people are living in the house with disability?

☐ 1 ☐ 2 ☐ More than 2

10. What is the monthly income of the household?

☐ R0 – R800 ☐ R801 – R2000 ☐ R2001 – R5000

☐ More than R5000

11. Is the source of this income regular or irregular?

☐ Regular ☐ Irregular

12. Do you receive a caregiver grant?

☐ Yes ☐ No

SECTION C: Rehabilitation Situation

13. Is the person with stroke attending the clinic for medical check-ups?

☐ Yes ☐ No

14. If you answered yes to the above question, how many times a month does the person with stroke go to the clinic?

☐ 1-2 ☐ 3-4 ☐ More than 4 Times

15. Did you receive training to help you care for the person with stroke while they were still in hospital?

☐ Yes ☐ No

16. Have you, as the caregiver, gone to support groups or caregiver training since the person had the stroke?

☐ Yes ☐ No

17. If you answered yes for the above question, how many times have you gone in the last 6 months?

☐ 1-2 ☐ 3-4 ☐ More than 4 times

Appendix J: Demographic Questionnaire for the Caregiver (Zulu)

Code ☐

Rater name: _____

Iphepha elinizinhlelo zemibuzo mayelana
nomuntu onakekela umuntu one-stroke

Ngicela uphendule yonke imibuzo ekuleliphepha

Iminyaka yomuntu onakekela umuntu one-stroke: _____

ISIGABA A:
Ngicela ufake uphawu ebhokisini elifanele

1. Ubulili

☐ Isilisa ☐ Isifazane

2. Okuphathelene nokugana

☐ Awuganile ☐ Uganile ☐ Ukipitile

☐ Udivosile ☐ Ungumfelokazi

3. Izinga eliphezulu lemfundo

☐ Awufundanga nhlobo

☐ Uphelele eklasini lesi-7

☐ Uphelele eklasini lesi-11

☐ Unomatekuletsheni noma okulingene

☐ Isitifiketi seziqu

☐ Isiqu sasenyuvesi

ISIGABA B: Isimo somnotho

4. Uhlobene kanjani nalomuntu one-stroke?

☐ Ushade naye ☐ Ngumnawenu ☐ Ingane

☐ Umzali ☐ Ngwsinye isihlobo ☐ Ngumngane

5. Bekuyini indima yakho endlini ngaphambi kokuthi uqale ukunakekela lomuntu one-stroke?

☐ Isisebenzi sasendlini ☐ Imisebenzana yasendlini

☐ Ubungumfundi ☐ Ubunakekela izingane

☐ Ubungumnakekeli ☐ Ubulelekelela ngezomnotho emndenini

☐ Okunye (ngicela uchaze): _____

6. Sekuyini indima yakho endlini manje njengoba usunakekela umuntu one-stroke?

☐ Isisebenzi sasendlini ☐ Imisebenzana yasendlini

☐ Ubungumfundi ☐ Ubunakekela izingane

☐ Ubungumnakekeli ☐ Ubulelekelela ngezomnotho emndenini

☐ Okunye (ngicela uchaze): _____

7. Bangaki abantu, uzibale nawe kanye nalowo one-stroke, abahlala endlini nawe kanye nalowo one-stroke?

☐ 1-3 ☐ 4-6 ☐ 7-9

☐ Beqa u-9

8. Bhala ukuthi zingaki izingane ezineminyaka engafani ezihlala endlini nawe knaye nalowo one-stroke?

Osanda kuzalwa ukuya kwiminyaka engu 4 ☐ Inombolo yezingane

4 ukuya ku-10 yeminyaka ☐ Inombolo yezingane

10 ukuya ku-14 yeminyaka ☐ Inombolo yezingane

14 ukuya ku-18 yeminyaka ☐ Inombolo yezingane

9. Kanye nalowo one-stroke, bangaki abanye abantu abahlala endlini abakhubazekile?

☐ 1 ☐ 2 ☐ Beqa ababili

10. Ingabe ingakanani engenayo nynga zonke?

☐ R0 – R800 ☐ R801 – R2000 ☐ R2001 – R5000

☐ Yeqa u-R5000

11. Ingabe lendlela yokungena kwemali ivamile noma eyijwayelekile?

☐ Ijwayelekile ☐ Ayijwayelekile

12. Uyayithola yini imali yabalekeleli?

☐ Yebo ☐ Cha

ISIGABA C: Isimo sokubuyeliswa ekuqondeni

13. Ingabe lowo one-stroke uyaya emtholampilo ukuze azohlolwa?

☐ Yebo ☐ Cha

14. Uma uphendule wathi yebo, uyakangaki ngenyanga emtholampilo yena lowo one-stroke?

☐ 1-2 ☐ 3-4 ☐ kweqa izinkathi ezingu 4

15. Waqeqeshwa yiningokusizwa kwalowo one-stroke ngale sikhathi bebase sibhedlela?

☐ Yebo ☐ Cha

16. Uke, njengmnakekeli, waya kwiqembu lokusiza noma ukufundiswa kwabanakekeli soloko lowomuntu waba ne-stroke?

☐ Yebo ☐ Cha

17. Umangabe uphendule wathi yebo, usaye kangaki kulezizinyanga eziyisithupha ezidlule?

☐ 1-2 ☐ 3-4 ☐ kweqa izinkathi ezingu 4

Appendix K: Demographic questionnaire for the patient

Code ☐

Rater name: _____

Factors that influence the quality of life of a caregiver
caring for a patient with stroke
DEMOGRAPHIC QUESTIONNAIRE
PERSON WITH STROKE

Please answer all questions in this questionnaire

Age of person with stroke: _____

SECTION A:

Please tick the relevant block(s)

1. Gender

☐ Male ☐ Female

2. Marital Status

☐ Single ☐ Married ☐ Live-in Partner

☐ Divorced ☐ Widow

3. Highest Level of Education

☐ No schooling

☐ Up to Grade 7

☐ Up to Grade 11

☐ Grade 12 or equivalent

☐ Diploma

☐ University degree

SECTION B: Economic Situation

4. What was your employment status before the stroke?

☐ Employed ☐ Self-employed ☐ Unemployed

☐ Retired ☐ Receiving Benefit/Grant

☐ Other (please explain): _____

5. How did you contribute financially to the household before the stroke?

☐ Breadwinner ☐ Dependent ☐ Contributing to the family income

SECTION C: Stroke

6. When did you have your stroke? _____

7. What side of your body has been weakened by the stroke?

☐ Left ☐ Right

8. Has your speech and language been affected by the stroke?

☐ Yes ☐ No

If you answered yes, please indicate in what way it has been affected:

☐ I am unable to speak

☐ I am able to speak, but people find it difficult to understand me

☐ I do not understand everything that is said to me

9. Do you have any of the following?

☐ Hypertension ☐ Diabetes ☐ High cholesterol

☐ Other: (please specify) _____

SECTION D: Hospitalization

10. What hospital were you admitted to when you had the stroke?

☐ Chris Hani Baragwanath ☐ Johannesburg General

☐ Helen Joseph ☐ South Rand

☐ Other: (please specify) _____

11. Did you go to any other hospital other than the one mentioned above after you had the stroke?

☐ Yes ☐ No

12. If you answered yes to question 10. Please specify which other hospital you went to. _____

13. How long did you stay in hospital for after you had the stroke?

_____

14. Did you receive any rehabilitation in hospital?

☐ Yes ☐ No

15. If you answered yes for question 13. Please specify what therapy you received.

☐ Physiotherapy ☐ Occupational Therapy

☐ Speech Therapy ☐ Social Work or Psychology

Appendix L: Demographic questionnaire for the patient (Zulu)

Code ☐

Rater name: _____

Iphepha elinezinhlelo zemibuzo mayelana
nomuntu onakekela umuntu one-stroke

Ngicela uphendule yonke imibuzo ekuleliphepha

Iminyaka yomuntu onakekela umuntu one-stroke: _____

ISIGABA A:
Ngicela ufake uphawu ebhokisini elifanele

1. Ubulili

☐ Isilisa ☐ Isifazane

2. Okuphathelene nokugana

☐ Awuganile ☐ Uganile ☐ Ukipitile

☐ Udivosile ☐ Ungumfelokazi

3. Izinga eliphezulu lemfundo

☐ Awufundanga nhlobo

☐ Uphelele eklasini lesi-7

☐ Uphelele eklasini lesi-11

☐ Unomatekuletsheni noma okulingene

☐ Isitifiketi seziqu

☐ Isiqu sasenyuvesi

ISIGABA B: Isimo somnotho

4. Ubusebenza ngaphambi kwe-stroke na?

☐ Bengisebenza ☐ Bengizisebenza ☐ Bengingasebenzi

☐ Ubusuhlehlile emsebenzini ☐ Ubuthola imali yosizo

☐ Okunye (ngicela uchaze): _____

5. Ubulekela kanjani endlini ngamali ngaphamibi kokuthi nbe ne-stroke?

☐ Nguwekuphela obesebenza ☐ Ubunakekelwa

☐ Ubunesandla emalini yomandeni

ISIGABA C: Stroke

6. Usithole nini i-stroke sakho? _____

7. Yiluphi uhlangothi lomzimba wakho olunciphiselwe amandla yi-stroke?

☐ Ngesokunxele ☐ Ngesokudla

8. Ingabe ulwimi nendlela okhuluma ngayo zithintekile yi-stroke?

☐ Yebo ☐ Cha

Umangabe uthe yebo, ngicela ubonise ukuthi zithinteke ngayiphi indlela:

☐ Angiphoni ukukhuluma

☐ Ngiyakhona ukukhuluma, kodwa kunzima ukungithola

☐ Angitholi lutho olushiwo kimi

9. Unokuthize kuloku okulandelayo?

☐ Hypertension ☐ Isifo soshukela ☐ High cholesterol

☐ Okunye (ngicela uchazisise): _____

ISIGABA D: Ngokwasesibhedlela

10. Wangeniswa kwesiphi isibhedlela ngenkathi uba ne-stroke?

☐ Chris Hani Baragwanath ☐ Johannesburg General

☐ Helen Joseph ☐ South Rand

☐ Esinye (ngicela uchazisise): _____

11. Ukewaya kwesinye isibhedlela ngaphandle kwalesi osishilo ngaphezulu emva kokuthi ube ne-stroke?

☐ Yebo ☐ Cha

12. Uma uphendule wathi yebo kumbuzo 10. Ngicela usho kabanzi ukuthi yisiphi esinye isibhedlela oyewaya kuso.

_____

13. Wahlala isikhathi esingakanani esibhedlela emva kokuthi ube ne-stroke?

_____

14. Wathola ndlela thize yokusiqondisa esibhedlela?

☐ Yebo ☐ Cha

15. Uma uphendule wathi yebo kumbuzo 13. Ngicela uchaze ukuthi nhlobo yini ye-therapy owayithola.

☐ Physiotherapy ☐ Occupational Therapy

☐ Speech Therapy ☐ Social Work or Psychology

Appendix M:Barthel Index

Code ☐

Rater name: _____

The Barthel Index

Activity	Score
FEEDING 0 = unable 5 = needs help cutting, spreading butter, etc., or requires modified diet 10 = independent	_____
BATHING 0 = dependent 5 = independent (or in shower)	_____
GROOMING 0 = needs to help with personal care 5 = independent face/hair/teeth/shaving (implements provided)	_____
DRESSING 0 = dependent 5 = needs help but can do about half unaided 10 = independent (including buttons, zips, laces, etc.)	_____
BOWELS 0 = incontinent (or needs to be given enemas) 5 = occasional accident 10 = continent	_____
BLADDER 0 = incontinent, or catheterized and unable to manage alone 5 = occasional accident 10 = continent	_____
TOILET USE 0 = dependent 5 = needs some help, but can do something alone 10 = independent (on and off, dressing, wiping)	_____
TRANSFERS (BED TO CHAIR AND BACK) 0 = unable, no sitting balance 5 = major help (one or two people, physical), can sit 10 = minor help (verbal or physical) 15 = independent	_____
MOBILITY (ON LEVEL SURFACES) 0 = immobile or < 50 yards 5 = wheelchair independent, including corners, > 50 yards 10 = walks with help of one person (verbal or physical) > 50 yards 15 = independent (but may use any aid; for example, stick) > 50 yards	_____

STAIRS
0 = unable
5 = needs help (verbal, physical, carrying aid)
10 = independent _____

TOTAL (0–100): _____

Appendix N: Caregiver Strain Index

Code ☐

Rater name: _____

The Caregiver Strain Index: I am going to read a list of things that other people have found to be difficult. Would you tell me if any of these apply to you? (Give examples)

	Yes=1	No=0
Sleep is disturbed (e.g., because _____is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g., from other family members)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; _____has trouble remembering things; or _____accuses people of taking things)		
It is upsetting to find_____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)		
TOTAL SCORE (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

Appendix O: Caregiver Strain Index (Zulu)

Code ☐

Rater name: _____

Uhla lwezinto ezidala ubunzima kuMnakekeli: Ngizofunda uhla lwezinto ezinzima abanye abantu abahlangabezana nazo. Shono-ke uma ngabe nawe lobunzima uhlangabezene nabo? (Nika imibandela)

	Yebo=1	Cha=0
Uphazamiseka ubuthongo (isibonelo, kungoba _____ uyangena uyaphuma embhedeni, azulazule ebusuku)		
Akulula (isibonelo, ngoba usizo luthatha isikhathi esiningi, kanti nokushayela imoto kuthatha isikhathi)		
Kuyakhathaza umzimba (isibonelo, ngoba ukumphakamisa nokumbeka esitulweni kudla emandleni ngoba kudingeka ingqondo)		
Ingumfela ndawonye (isibonelo, ukusiza omunye umuntu kudla esakho, isikhathi noma ungakwazi ukuvashela abantu)		
Kubekhona ushintsho emndenini (isibonelo, ngoba ukusiza kuphazamise inhlalayenza emndenini; akukho mfihlakalo)		
Kwabanoshintsho empilweni yami (isibonelo, ngale eminye imisebenzi; angiphumeleli ukuthatha ikhefu)		
Kubekhona ezinye izidingo esikhathini sami (isibonelo, isikhathi sami sadleka, ngenxa yamalungu omndeni wami)		
Kubenoshintsho emphefumlweni nasemoyeni (isibonelo, izingxabano ezinzima kakhulu)		
Okunye ukwenza kwesiguli kukhathaza ngempela (isibonelo, ukungakwazi ukubamba umchamo; ____ ukukhohlwa; noma ____ abeke abanye abantu icala lokuthatha izinto zakhe)		
Kuyaphazamisa impela uthola ____ esengasafani nento ebeyiyo kuqala kubonakala ushintsho olukhulu (isibonelo, yena usehluke ngempela kulokhu ebeyikho)		
Kwabakhona ushintsho kwezomsebenzi (isibonelo, ngoba kwafuneka ngingezi emsebenzini)		
Ubunzima kwezezimali		
Kungaphezu kwamandla ami (isibonelo, ngenxa yokukhathazeka ngo ____; nokuthi, ngizokwazi kanjani)		

AMAPHUZU EPHELELE (Bala “Yebo”. Noma ngeyiphi impendulo enhle ebonisa isidingo sokugaxeka kuleyondawo. Umphumelo ka7 noma ngaphezulu ibonisa ubunzima obukhulu)		

Appendix P: EQ-5D and EQ-5D VAS

Code ☐

Rater name: _____

THE EuroQol (Eq-5D) Health Questionnaire (South African English Version)

By placing a tick in one box in each group below, please indicate which statements best describe your own state of health TODAY.

Mobility

I have no problems in walking about ❑
I have some problems in walking about ❑
I am confined to bed ❑

Self-Care

I have no problems with self-care ❑
I have some problems washing or dressing myself ❑
I am unable to wash or dress myself ❑

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities ❑
I have some problems with performing my usual activities ❑
I am unable to perform my usual activities ❑

Pain/Discomfort

I have no pain or discomfort ❑
I have moderate pain or discomfort ❑
I have extreme pain or discomfort ❑

Anxiety/Depression

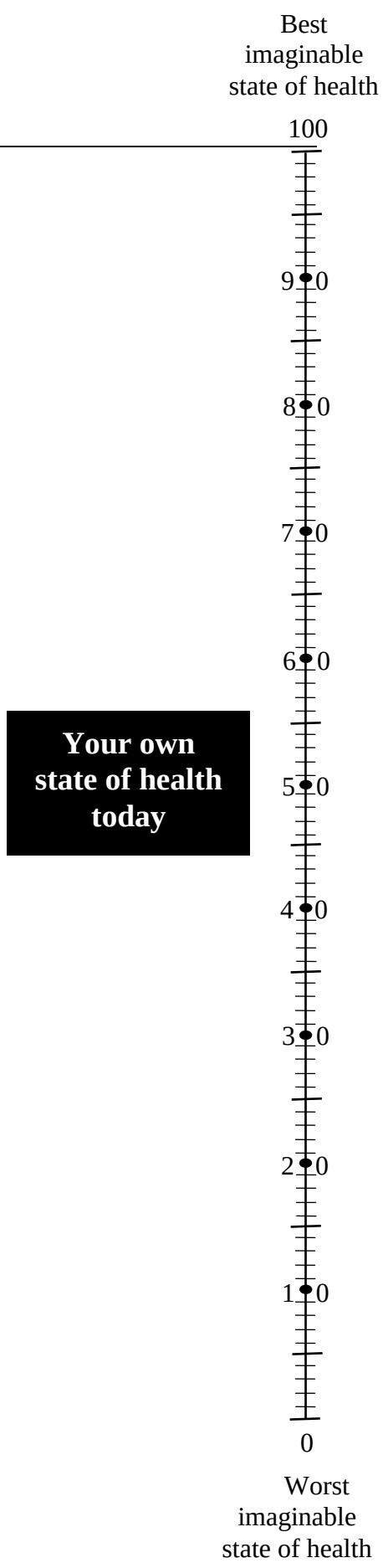
I am not anxious or depressed ❑
I am moderately anxious or depressed ❑
I am extremely anxious or depressed ❑

Compared with my general
level of health over the past 12 months,
my state of health today is:

Better	❑	PLEASE TICK
Much the same	❑	ONE
Worse	❑	BOX

To help people say how good or bad their state of health is, we have drawn a scale on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale, in your opinion, how good or bad your own health is today. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your state of health is today.



Appendix Q: EQ-5D and EQ-5D VAS (Zulu)

Code

Rater name: _____

EQ - 5D

Uhlelo Lwemibuzo Ngempilo

(Zulu version for South Africa)
(Best available)

Ngokufaka uphawu ebhokisini elilodwa kulelo nalelo qoqo elingezansi, sicela ukhombise ukuthi yisiphi isitatimende esichaza kahle kakhulu isimo sempilo yakho namhlanje.

Ukuhamba/ukunyakaza

Anginazinkinga ukuzihambahambela ☐

Nginezinkinga ezithile ukuzihambahambela ☐

Ngihlala ngisembhedeni/ngisocansini ☐

Ukuzinakekela

Anginazinkinga ngokuzinakekela ☐

Nginezinkinga ezithile zokuzigeza noma ukuzigqokisa ☐

Angikwazi ukuzigeza noma ukuzigqokisa ☐

Imisebenzi ejwayelekile (*isibonelo: ukusebenza, ukutadisha, umsebenzi wasendlini, imisebenzi yomndeni noma eyokungcebeleka)*

Anginazinkinga ukwenza imisebenzi yami eyejwayelekile ☐

Nginezinkinga ezithile ukwenza imisebenzi yami eyejwayelekile ☐

Angikwazi ukwenza imisebenzi yami eyejwayelekile ☐

Izinhlungu/ukungaphatheki kahle

Anginazinhlungu noma ukungaphatheki kahle ☐

Nginezinhlungu noma ukungaphatheki kahle okulingene nje ☐

Nginobuhlungu obedlulele nokungaphatheki kahle ☐

Ixhala/ukudangala

Anginalo ixhala noma ukudangala ☐

Nginexhala noma ukudangala okulingene nje ☐

Nginexhala nokudangala ngokweqile ☐

Ukuze sisize abantu basho ukuthi isimo sempilo yabo sihle noma sibi kangakanani, sidwebe isikali (esifana netemometha) okuqoshwe kuso isimo esihle kakhulu ongase usicabange sabekwa ku 100 naleso esibi kakhulu saba ku- 0.

Singathanda ukuba ukhombise kulesi sikali ukuthi yinhle noma yimbi kangakanani impilo yakho namhlanje, ngokwakho ukubona. Siza wenze lokhu ngokudweba umugqa osuka ebhokisini ngezansi uye kunoma yiliphi izinga esikalini elikhombisa ukuthi sihle noma sibi kangakanani isimo sempilo yakho namhlanje.

