

**THE EFFECTIVENESS OF A CAREGIVER SUPPORT
PROGRAMME TO ADDRESS THE NEEDS OF PRIMARY
CAREGIVERS OF STROKE PATIENTS IN A LOW SOCIO-
ECONOMIC COMMUNITY**

by

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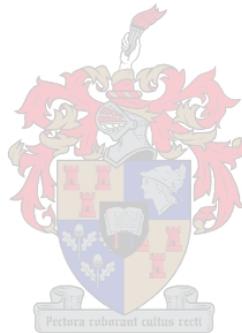
DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

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ABSTRACT

Background

Stroke is a difficult condition to manage because of the complex nature of its effects. Caregivers are therefore, crucial in providing ongoing care for the stroke patient at home. Caregivers experience considerable strain during caregiving, as their needs are often overlooked because therapeutic management tends to focus mainly on the stroke patient. In third world countries like South Africa, there are currently no research studies found describing an optimum support intervention which addresses the caregivers' needs and reduces their strain levels.

Objective

To determine the effectiveness of a caregiver support intervention programme (CSIP) that was developed to address the expressed needs identified by the primary caregiver of the stroke patient in the Bishop Lavis community.

Method

A prospective and descriptive qualitative study design was used to evaluate the effectiveness of the CSIP. A total of 29 caregivers participated in three CSIPs, which were implemented over five sessions each. The Barthel Index was used to measure the functional level of each stroke patient. The needs of stroke caregivers were determined by 15 semi-structured interviews, until data saturation was reached. The Caregiver Strain Index was completed before and after implementation of the CSIP, in order to measure whether the intervention programme had been effective in reducing the caregivers' level of strain. Written or verbal feedback forms was also completed by the caregivers after each of the five intervention sessions. Results were analysed using repeated measures ANOVA and descriptive qualitative analysis.

Results

The qualitative results of this study suggest that the CSIP was effective in addressing mainly the physical needs, as well as the emotional, educational and socio-economic needs of the primary caregivers. The CSIP was also effective in reducing caregiver strain in 61.5% of the sample (N=13). However, an additional finding of this study was the personal and logistical barriers identified which limited the caregivers' attendance of the sessions.

Conclusion

The CSIP was effective in addressing the physical, emotional, socio-economic and educational needs of the primary caregiver. In addition, the results also verified that the CSIP was effective in reducing caregiver strain in the majority of the caregivers, despite a small sample size. The barriers identified which affected the caregivers' attendance, need to be taken into consideration when planning future intervention programmes for caregivers in poor socio-economic communities. Due to the low attendance rate by the caregivers, a larger sample size is recommended to accommodate for the high drop-out rates in such a population.

ABSTRAK

Agtergrond

Beroerte is 'n moeilike toestand om te hanteer as gevolg van die komplekse aard van die effekte daarvan. Versorgers is dus kritiek in die voorsiening van voortgesette sorg vir die beroerte pasiënt by die huis. Versorgers ervaar aansienlike ooreising tydens versorging, aangesien hulle behoeftes dikwels nie in ag geneem word nie omdat die terapeutiese hantering hoofsaaklik fokus op die beroerte pasiënt. In derde wêreld lande soos Suid-Afrika, is daar tans geen navorsingstudies gevind wat 'n optimale ondersteunings intervensie beskryf om die behoeftes van die versorgers aan te spreek asook om hulle ooreisingsvlakke te verminder nie.

Doelstelling

Om die effektiwiteit te bepaal van 'n versorger ondersteunings intervensie program (VOIP) wat ontwikkel is om die spesifieke behoeftes van die primêre versorgers van beroerte pasiënte in die Bishop Lavis gemeenskap aan te spreek.

Metode

'n Prospektiewe en beskrywende kwalitatiewe studie ontwerp is gebruik om die effektiwiteit van die VOIP te evalueer. Nege-en twintig versorgers het deelgeneem aan 3 VOIP's, wat elk oor 5 sessies geïmplimenter was. Die Barthel Indeks is gebruik om die funksionele vlak van elke beroerte pasiënt te bepaal. Die behoeftes van die beroerte versorgers is bepaal deur middel van 15 semi-gestruktureerde onderhoude, totdat data versadiging bereik is. Die Versorger Stresladings Indeks is voor en na die implementering van die VOIP voltooi, om te bepaal of die intervensie program effektief was in die vermindering van die versorgers se ooreisingsvlakke. Geskrewe of verbale terugvoer vorms is ook deur die versorgers voltooi na elk van die vyf intervensie sessies. Resultate is met behulp van herhaalde metings ANOVA en beskrywende kwalitatiewe analise geanaliseer.

Resultate

Die kwalitatiewe resultate van hierdie studie dui daarop dat die VOIP effektief was om die fisiese behoeftes, asook die emosionele, opvoedkundige en sosio-ekonomiese behoeftes van die primêre versorgers aan te spreek. Die VOIP was ook effektief om ooreising van versorgers in 61.5% van die steekproef (N=13) te verminder. 'n Addisionele bevinding van hierdie studie was die identifikasie van persoonlike en logistieke struikelblokke wat die versorgers se bywoning van die sessies beperk het.

Gevolgtrekking

Die VOIP was effektief om die fisiese, emosionele, sosio-ekonomiese en opvoedkundige behoeftes van die primêre versorger aan te spreek. Die resultate het ook bevestig dat die VOIP effektief was om versorger ooreising in die meerderheid van die versorgers te verminder, ten spyte van die klein steekproef. Die struikelblokke wat geïdentifiseer is, en dus die versorgers se bywoning beïnvloed het, moet in ag geneem word wanneer toekomstige intervensie program vir versorgers in swak sosio-ekonomiese gemeenskappe beplan word. As gevolg van die lae bywoningskoers, word 'n groter steekproef ook aanbeveel om voorsiening te maak vir die hoë uitvalkoers in hierdie populasie.

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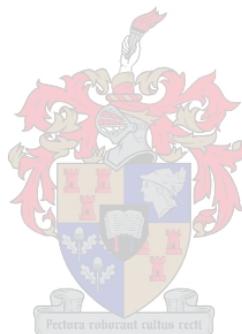
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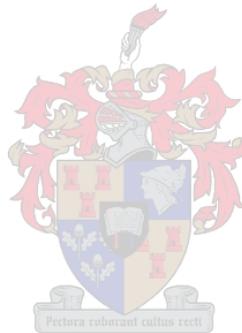


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GLOSSARY

There are several definitions of a **primary caregiver** including the following:

- The person perceived by the stroke patient as being the most responsible for their daily decision-making and care (Lincoln et al, 2003).
- The family or friend taking primary responsibility for managing care of the stroke patient (Teel et al, 2001).
- The closest person who is the main provider of the stroke patients' emotional and physical support (Van den Heuvel et al, 2002).
- The main person helping with activities of daily living and advocating on behalf of the patient (Kalra et al, 2004).

Dependant stroke patient: For the purpose of this study it is a patient who is partially or fully dependant on the primary caregiver for his/her self-care activities of daily living (ADL), i.e. with a Modified Barthel Index score of 18 or below.

CHAPTER 1

INTRODUCTION

Stroke resulted in 5.5 million deaths worldwide, making it the leading cause of death in 2002. The World Health Organization (WHO) statistics show that in South Africa (SA) stroke results in disability in 11 per 1000 of the population and a 0.07% mortality rate per annum, while the United Kingdom (UK) has a disability rate of 4 per 1000 of the population and a 0.1% mortality rate (WHO, 2002). In the UK, 67% of all strokes occur in people over 70 years, with the average age of onset being 75 years.

Stroke is the leading cause of death and disability in SA for persons over the age of 50, and is the third most common cause of death in this country. Stroke mortality rates in SA are similar in both men and women, but the incidence is about 25% higher for males than females (South African Stroke Foundation, 2004). It can be estimated that there are about 6 million people with hypertension, 7 million smokers and 3-4 million diabetic sufferers in SA who are at risk of having a stroke (Department of Health, 2001b).

1.1 EFFECTS OF STROKE ON THE FAMILY

The complex nature of the effects of stroke – which includes motor, sensory, cognitive, perceptual and speech deficits – makes it a difficult condition to manage and caregivers are, therefore, crucial in providing ongoing care for the stroke patient at home. Primary caregivers and families play a major role in the rehabilitation of the stroke patient with as much as 75% of care being provided by family members (Teel et al, 2001). As stroke is the most common cause of adult disability in South Africa, considerable strain is

placed on the caregivers and families of stroke patients (Patel et al, 1997).

According to Evans et al (1994) in the USA, families are responsible for the patients' well-being and, therefore, influence the patients' adjustment to stroke. These authors maintain that caregivers have an important role to play in lifestyle changes in the prevention of a recurrent stroke and ultimately they contribute to the success of the patients' rehabilitation. Involved families tend to be more available for education about stroke and are consequently better able to comply with homecare instructions (Evans et al, 1994). Family members, commonly the spouse or closest female relative, are affected by the patients' stroke from the onset and thus experience a significant level of burden of care (Anderson et al, 1995).

According to the Western Cape's Healthcare Plan for 2010, the intention is that the average length of acute bed stay in hospital should reduce from 4.2 days to 3.7 days, with the overall cost per patient per day decreasing from R858 to R814. The aim is for 90% of patient contacts to occur at primary healthcare level, 8% at secondary healthcare level and only 2% at tertiary healthcare level. Therefore, patients with acute stroke are likely to be managed at their nearest community health centre, and not admitted to any tertiary institution (Department of Health, 2003). This could well place a large strain on the family who would now need to provide care for the acute stroke patient at home. Bresick and Harvey (1997) also emphasised that caregiver burden has increased in SA as early discharge, because of financial and other constraints in the health system, places a large burden on the family caring for the stroke patient at home. This was further emphasised by

King and Semik (2006) in the USA, who stated that the trend toward shorter lengths of hospitalisation may result in stroke caregivers being unprepared for their new roles. Short or no hospitalisation (including rehabilitation) thus results in the caregivers being inadequately equipped or trained to manage a stroke patient (Fawcus, 2000).

1.2 RESEARCH SETTING

Bishop Lavis is a poor socio-economic 'coloured' community situated on the Cape Flats in the Western Cape of South Africa. This community is mainly Afrikaans speaking, with only a small percentage Xhosa-speaking (De Villiers et al, 1999). The 2001 National Census reflected a population size of 26 635 people and a 28% unemployment rate in this community (Statistics SA, 2001). According to a survey by De Villiers et al (1999), 12.5% of the population were unable to read or write and only 2% had higher level qualifications.



Following the onset of a stroke, patients from the Bishop Lavis community are either admitted to a tertiary hospital if medically unstable, or managed as an outpatient at the Bishop Lavis Community Health Centre. If the patient is medically unstable and has a loss of consciousness and/or swallowing problems, they are referred to a tertiary hospital, such as Tygerberg Hospital, for specialist management. According to the stroke units at Tygerberg and Groote Schuur hospitals, hospitalisation stay is short, usually a maximum of two weeks. The majority of stroke patients are then referred as necessary, for rehabilitation at the Bishop Lavis Rehabilitation Centre and/or for follow-up monitoring to the Caring Network, which is a home-

based care agency in Bishop Lavis.

The Caring Network trains volunteers within the Bishop Lavis community to provide a basic nursing care and support service to patients with a variety of debilitating conditions. The WHO defines home-based care as the provision of health services by caregivers in the home to promote, restore and maintain a person's maximum level of comfort, function and health (Department of Health, 2001a). Home-based care, therefore, provides extended nursing care to patients who are discharged early from hospital (Department of Health, 2001a).

The Bishop Lavis Rehabilitation Centre, which was the venue for the current study, was opened in 1994, under the auspices of Stellenbosch University, as an academic primary health care centre within the community-based rehabilitation context. It provides a physiotherapy, occupational therapy, as well as a speech and language therapy service to the surrounding Bishop Lavis community. The departmental statistics at the Bishop Lavis Rehabilitation Centre recorded approximately 3 new stroke patients per month, while the Bishop Lavis Community Health Centre kept no statistics of the number of stroke patients treated per month. The Caring Network home-based care agency operating in Bishop Lavis, also recorded statistics of 2-3 new stroke patients per month.

1.3 PROBLEM STATEMENT AND MOTIVATION FOR THE STUDY

According to Bresick and Harvey (1997), health professionals in SA rarely explore how a stroke affects family members and these authors maintain that failure to adopt a family-centred approach to the care of the stroke

patient may lead to inadequate consideration of the family. This in turn, may compromise the patient's recovery. A family-centred approach, in which the family is encouraged by the rehabilitation team to be actively involved in the planning and decision making of the stroke patient, may in turn prevent caregiver stress (Overs and Belknap, 1967; Patel et al, 1997). The focus should consequently be on the family as the responsible and effective unit in the patient's ultimate adjustment to a stroke. As a physiotherapist working in this community, it is this researcher's observation that because therapeutic management in Bishop Lavis is primarily centred on the stroke patient, the needs of families are often overlooked. Even health professionals may assume that stroke caregivers have the ability to cope with caregiving responsibilities. Furthermore, it has been observed that caregivers experience a great deal of strain while caring for the stroke patient because of their poor understanding of stroke and its management. Caregivers may also assume that it's their responsibility to provide care for the stroke patient, because society may expect it from them, particularly in the non-white South African culture (Mba, 2005).

The researcher could not find any literature describing an optimum support intervention programme for the primary caregiver of the stroke patient. This may be because the unique needs of people in different communities tend to differ. Most of the above studies were conducted in first world countries, such as Australia, UK, USA, Japan, Netherlands and New Zealand, and not in third world countries or populations. The researcher's interest in this topic stems from her observations and concerns while working as a

physiotherapist in this community. Therefore, this leads to the research question of: 'What is the effect of a support intervention programme developed to address the expressed needs identified by the primary caregiver of the dependant stroke patient in the Bishop Lavis community?'

1.4 PRIMARY AIM OF THE STUDY

The primary aim of this study was, therefore, to determine the effectiveness of a caregiver support intervention programme developed to address the expressed needs of the primary caregiver of the stroke patient in the Bishop Lavis community.

1.5 SIGNIFICANCE OF THE STUDY

The significance of the study was to determine the needs of the primary caregivers in order to develop and implement a suitable support intervention programme, to address their needs and reduce their caregiver strain.

The findings of this study could in future assist other health professionals, involved with stroke patients and their caregivers, to implement similar programmes.

CHAPTER 2

LITERATURE REVIEW

This chapter will present an outline of the diagnosis, presentation and management of stroke, as well as a detailed review of the effects of stroke on the family and the role of the stroke caregiver. It will also include a detailed discussion on literature pertaining to the burden of care on the family, the needs of the caregiver, as well as strategies used to address these needs. Finally, barriers to the compliance of stroke caregivers will be reviewed.

2.1 THE DIAGNOSIS AND PRESENTATION OF STROKE

A confirmed stroke, as defined by the World Health Organization, is a condition with a rapid onset of vascular origin reflecting a focal or global disturbance of cerebral function, with symptoms persisting longer than 24 hours or leading to death (WHO, 1988).

There are two main causes of stroke:

- Cerebral infarction: caused by blockage of a cerebral artery by a thrombosis and accounts for 85% of strokes (SASF, 2004).
- Cerebral haemorrhage: caused by a blood vessel in the brain which leaks or ruptures causing damage to the surrounding brain tissue. This is often a result of a complication of hypertension or a defective artery and accounts for 15% of strokes (SASF, 2004).

The diagnosis of stroke is made after the completion of a detailed medical history and neurological examination. Further tests include brain and

vascular imaging, cardiac evaluation and blood coagulation tests. Diagnostic procedures include Computerised Tomography (CT) which detects both cerebral haemorrhage and infarcts, and Magnetic Resonance Imaging (MRI) which has a higher sensitivity in detecting early brain tissue damaged by cerebral infarcts (Fawcus, 2000). In South Africa, cerebral and vascular imaging such as CT or MRI scans, are mainly available at secondary and tertiary hospitals, while local community health centres are not equipped with these facilities. The risk factors of stroke are also considered in the neurological assessment and, therefore, blood pressure, cholesterol and blood sugar levels are tested (Department of Health, 2001b).

The clinical features of stroke include motor, sensory, cognitive, perceptual and speech deficits. Physical problems could include muscle weakness and/or paralysis on one or both sides (depending on the site of the lesion), sensory loss in the face and limbs, swallowing problems, incontinence of bowel and/or bladder, dizziness, visual disturbances and unsteadiness which may result in falls (Fawcus, 2000). Higher functions that could be affected include sudden confusion and difficulty with understanding, speech and communication problems, cognitive and perceptual problems, loss of emotional control and behavioural changes (Fawcus, 2000). Because of the variety of its presentation, stroke is a complex condition to manage and thus a multi-disciplinary team, as well as a family approach, is suggested to optimise rehabilitation (Fawcus, 2000).

In South Africa, one of the aims of service provision stated by the Western Cape's Healthcare Plan for 2010 is the reduction of acute tertiary hospital

stay so that patients can rather be managed at their local community health centre (Department of Health, 2003). As a result, patients with acute stroke are admitted to a tertiary hospital for emergency care and then managed further on an out-patient basis at their local community health centres. Rehabilitation of the stroke patient starts as soon as his/her condition is stable, and continues until maximum functional potential of the patient is achieved (Department of Health, 2001b).

2.2 MANAGEMENT OF STROKE

Management of stroke involves an appropriate combination of any of the members of the multi-disciplinary team which might include a medical doctor, nurse, physiotherapist, occupational therapist, speech and language therapist, dietician, psychologist and social worker. A coordinated and collaborative team approach is fundamental to good quality stroke care and, therefore, it is essential that all team members have clear lines of communication so that optimal benefit may be obtained from their input (Fawcus, 2000; Bresick and Harvey, 1997). Caregivers and family also play a major role in the management team.

Educating the caregivers and families of stroke patients are crucial to the successful homecare of the stroke patient (Pierce et al, 2006). Bresick and Harvey (1997), two health professionals working in a primary healthcare setting in South Africa, also state from their experience that a family-centred approach to stroke management addresses both the carers' and the patients' needs. These authors commented that this approach is not common practice in the South African public health sector where it is needed even more, given

the absence of many of the 'basic facilities'.

2.3 EFFECTS OF STROKE ON THE FAMILY

The majority of patients and their families are totally unprepared for the onset of stroke. Its suddenness and the profound physical and psychological changes in the patient, can lead to serious problems of adjustment for both the patient and family (Fawcus, 2000). These difficulties are often compounded by the lack of adequate information and support received from the rehabilitation team involved. The situation could even be more stressful if the patient is not admitted to hospital or only has a short period of hospitalisation (Fawcus, 2000). Implementation of the Western Cape's Healthcare Plan for 2010 aims at reducing acute tertiary hospital stay, which is likely to further impact on the family of stroke patients (Department of Health, 2003). This is also becoming the trend for Australian rehabilitation facilities to promote early discharge and greater community care (Clark et al, 2003). The shorter lengths of hospitalisation may result in caregivers being unprepared for their new role (King and Semik, 2006).

Family members – commonly the spouse or closest female relative – are affected by the patient's stroke from the onset and, therefore, experience a significant level of burden of care (Anderson et al, 1995). This was further emphasized by Martin et al (1998) who reported that female caregivers experience more anxiety than male caregivers. It is thus important to assess the caregiver's emotional status as well as the family function after stroke, as it has been suggested that poorly functioning families are less likely to comply with treatment programmes, thereby having a negative impact on

the patients' rehabilitation outcomes (Evans et al, 1994). These authors also commented that families that were most in need of supported care were unlikely to participate in support programmes, usually because of practical problems such as not being able to find relief from their caring responsibilities.

Family caregivers tend to be so immersed in the caregiving process that they neglect their own physical and psychological health (Man, 2002). Health professionals, therefore, need to support and educate caregivers to be more aware of their own health status and needs. In addition, rehabilitation professionals should prepare families for the psychological difficulties that may occur with caregiving, as well as teach them techniques to handle the cognitive-behavioural problems of the stroke patient (Man, 2002).

Stroke caregivers have been found to have elevated levels of depression during both the acute and chronic stroke phases (Han and Haley, 1999). These authors reviewed 20 articles related to family caregiving for stroke patients and reported that 85% of these articles examined mainly psychological distress in caregivers, particularly depression. In summary, they stated that caregivers with fewer social contacts and more physical limitations themselves were more likely to be depressed. These authors also found that when stroke patients had behavioural problems, their caregivers were more likely to be depressed (Han and Haley, 1999). In addition, caregivers were also more likely to be depressed if the stroke patients were severely disabled (Martin et al, 1998).

It has long been recognised that primary caregivers and families play a major role in the rehabilitation of the stroke patient with as much as 75% of care being provided by family members (Teel et al, 2001). Similarly, in a study by Bugge et al (1999), 97% of caregivers were family members of whom 73% were female. Spouses were found to be the most common primary caregiver of stroke patients (Kalra et al, 2004). This was also evident in a study by Anderson et al (1995) who examined the impact and burden of caregiving for long-term stroke patients, and found that 58% of caregivers were spouses of whom 82% were female. Bresick and Harvey (1997) observed that women appear to accept the caregiving role more easily than men, for whom the demands of caring are often unfamiliar.

2.4 ROLE OF THE CAREGIVERS

The role of the stroke caregiver was found to be varied and included physical (Grant et al, 2004; Anderson et al, 1995; Bethoux et al, 1996; McLean et al, 1991), emotional (King and Semik, 2006; Hankey, 2004; Grant et al, 2004)) and lifestyle support (Evans et al, 1994). Caregivers also need to assume new roles due to shifted responsibilities after the patient sustains a stroke. (Denman, 1998; Grant et al, 2004)

2.4.1 PHYSICAL SUPPORT

The role of the caregiver includes assistance of the stroke patient with personal care activities, such as dressing, bathing, eating, toileting and ambulating, as well as handling and transfer skills from the bed to the chair. Managing bladder and bowel incontinence was found to be the most distressing problem during the first month after stroke (Grant et al, 2004).

Anderson et al (1995) examined the impact and burden of caregiving for stroke patients and found that 52% of Australian stroke patients required assistance from their caregivers with dressing, 48% with bathing, 36% with feeding, 34% with stairclimbing, 18% with toileting and 12% with transfers. Similarly, Bethoux et al (1996) found that most stroke patients were partially dependent on their caregivers for bathing, bathing transfers, dressing, eating and stairclimbing. In a pilot study by McLean et al (1991) it was reported that 75% of carers needed assistance with physical care activities like lifting, bathing and continence care of the stroke patient.

2.4.2 EMOTIONAL SUPPORT

The caregivers' role also involves providing emotional and psychological support so that the stroke patient can adapt to the effects of stroke and reintegrate into society (Hankey, 2004; Bugge et al, 1999). Caregivers are, therefore, involved in handling the emotional changes and mood swings of the stroke patient, as well as managing the cognitive-behavioural problems which are commonly associated with stroke (King and Semik, 2006; Grant et al, 2004).

2.4.3 LIFESTYLE SUPPORT

Families are responsible for the patients' welfare and can consequently influence the patients' adjustment to stroke (Evans et al, 1994). The degree to which the family adapts after stroke could affect patient recovery. In addition, they have an important role to play in reinforcing lifestyle changes of the patient, which include appropriate nutrition and exercise that contribute to the prevention of a recurrent stroke and to the success of the

patient's rehabilitation (Evans et al, 1994). As the family is ultimately responsible for homecare of the stroke patient, the inclusion of family members in rehabilitation may structure the support system to function more effectively (Evans et al, 1988). The education of families is thus important not only to make families feel better able to cope with the situation, but also because of their key role in reinforcing patient behaviour and compliance to treatment programmes (Evans et al, 1994).

2.4.4 ASSUMPTION OF NEW ROLES

In addition, a role change in the family commonly occurs after stroke, as the caregiver has to take on the extra responsibilities that was previously the domain of the stroke patient. This may include managing the household chores, shopping, cooking, managing the finances like banking, paying bills and completion of paperwork (Denman, 1998). Similarly, Grant et al (2004) found that caregivers also managed work and household responsibilities, scheduling appointments to therapeutic healthcare services and managing the stroke patients' physical symptoms like pain.

Because of the extent of the above-mentioned role of the caregiver, it may well be expected that a high level of burden is experienced by stroke caregivers.

2.5 BURDEN OF CARE

Research into the burden of caregiving, as well as caregiver needs and the effect of strategies to address these needs, will be discussed in the following sections.

Literature pertaining to the burden of care, needs and support of stroke caregivers were found using the following keywords in various combinations: stroke caregivers' needs, caregiver burden, support programme, home-based care and stroke, physiotherapy and stroke, stroke and family support, needs of stroke families and caregiver support intervention.

The search was conducted by means of making use of the following sources:

- An internet search of MEDLINE, CINAHL and PubMed databases;
- The Stroke Foundation of South Africa's website <http://www.stroke.co.za>;
- The British Medical Journal website <http://www.bmj.com>;
- Stroke publications of the American Heart Association website <http://www.strokeahajournals.org>;
- <http://www.freemedicaljournalsonline.com> and
- Hand searches for journals included the International Journal of Rehabilitation Research, Disability and Rehabilitation, Journal of Advanced Nursing and Continuous Medical Education.

In South Africa, Bresick and Harvey (1997) reported that the emotional strain of caregiving is often greater than the physical strain. Caregiving is often associated with a deterioration in the mental health of the carer, with the emotional strain being even greater when the patient's cognition, behaviour and speech is impaired. These authors noted that factors which affect caregivers' burden include their own health and functional ability, the patients' level of function and the extent of social support available. Bresick and Harvey (1997) also suggest that many South African families lack the financial resources to meet even their basic needs, and are placed under

further strain by the cost of rehabilitation.

Most of the literature reveals that the burden of care experienced by the stroke caregiver includes socio-emotional and physical parameters. The following studies conducted in Scotland, USA, France, Australia, New Zealand, Netherlands and Japan address the impact of these two dimensions on caregivers at different stages after stroke. Research into caregiver burden has commonly been undertaken at the following three stages after the onset of stroke:

- within 6 months
- 6 - 24 months
- beyond 2 years.

2.5.1 CAREGIVER BURDEN IN THE FIRST 6 MONTHS AFTER STROKE

Three research articles on the burden of caregiving during this time frame were found.



Caregiving problems experienced by 22 American family caregivers of stroke patients during the first month after hospital discharge, were identified by Grant et al (2004). Their study examined the impact of social problem-solving telephone partnerships (SPTP) which consisted of an initial three hour meeting between a trained nurse and the stroke caregiver, followed by three weekly telephone contacts during that first month. The findings of their study reveal that the three most common problems experienced by stroke caregivers were:

- safety and fear of physically harming the stroke patient;

- difficulty in managing functional deficits of the stroke patient in ADL and
- difficulty in managing cognitive, behavioural and emotional changes, such as mood swings, low motivation, memory loss and depression, exhibited by the stroke patient.

Other problems reported by the caregivers were tiredness, loss of their independence and inadequate time to perform caregiving tasks. Grant et al (2004) reported that caregivers managed multiple caregiver and household responsibilities by performing a large number of the stroke patients' daily activities for them, rather than encouraging their independence in these activities. The first month of caregiving was found to be very stressful as caregivers verbalised that adaptation to the caregiver role, as well as completion of their household responsibilities, were overwhelming.

A study by Bugge et al (1999) in Scotland aimed to identify the level of strain of 110 caregivers at 1, 3 and 6 months after stroke and to assess the relationship between caregiver strain and carer characteristics, patient characteristics and services available. Caregivers reported a considerable increase in strain from 1 to 6 months according to the Caregiver Strain Index (25% of carers reported strain at 1 month, 28% at 3 months and 37% at 6 months). This index identified that caregivers reported the confining nature of caregiving, as well as changes to family life and changes to personal plans, as three common factors that increased their strain. It was found that the amount of time a caregiver spent helping the stroke patient, as well as the caregivers' health were all associated with the level of strain experienced. Caregivers spent an average of six hours per day helping the

stroke patient and reported that they mainly gave emotional support (75% at 1 month, 78% at 3 months and 77% at 6 months) as well as physical support (49% at 1 month, 52% at 3 months and 47% at 6 months). Caregivers in this sample were an average age of 60 years, and had their own health problems. These authors confirmed that caregivers who were in poor health experienced more strain and, therefore, needed to be identified and supported. However, these authors also pointed out that from the structured interviews, it was apparent that available support services for carers were not used frequently and that no particular service reduced caregiver strain (Bugge et al, 1999).

A small study by Pierce et al (2006) in the USA identified the perceived problems of nine stroke caregivers during the first three months of caregiving. All the caregivers participated in an intervention implemented by nurses, which consisted of bi-monthly telephone calls to explore their experience of caregiving. The problem themes of caregivers included high dependency of the stroke patient in ADL (25%), dealing with the emotions of the stroke patient (19%), living with their own physical limitations (15%), managing co-morbid conditions of the stroke patient (13%), role strain and balancing their life (12%), poor compliance of the patient to physiotherapy (10%) and having sleeping problems (6%). A limitation of this study was that it targeted only a small sample of White Americans and did not include other ethnic groups (Pierce et al, 2006).

2.5.2 CAREGIVER BURDEN AT 6-24 MONTHS AFTER STROKE

The following four research articles investigated caregiver burden within this

time frame.

The impact and burden of caregiving was assessed by interviewing 84 Australian carers, one year after the patients' onset of stroke (Anderson et al, 1995). Emotional distress in caregivers was measured using the Hospital Anxiety and Depression Scale (HADS) and the General Health Questionnaire (GHQ-28), while the Social Behaviour Assessment Scale (SBAS) was used to assess the relative impact of caregiving. In this study it was found that as a direct consequence of caregiving, 80% of carers reported both emotional distress and disruption of their social life, 55% reduction in their leisure time and 35% adverse effects on family relationships. One of the main reasons for disruption of the caregivers' social life was fear and anxiety that the patient would die or become more disabled if left unattended at home. Similarly, in a much later study by Grant et al (2004) caregivers also expressed fear in physically harming the stroke patient.

Anderson et al (1995) also suggested that dementia and behavioural abnormalities of the patient, rather than physical disability, are the most predictive sources of emotional distress among caregivers. These authors identified that 52% of stroke patients required help with dressing, 48% with bathing, 36% with eating and 7% with mobility. The physical function of the patient was measured using the modified Barthel Index (BI) and the Frenchay Activities Index (FAI). Since most of the carers in this study were middle-aged or elderly, they had pre-existing illnesses and functional limitations that restricted their ability to manage the physical aspects of caregiving. However, Anderson et al (1995) stated that a limitation of their

study was that since the effects of caregiving were measured only one year after stroke, optimal recovery of physical function could have been achieved at that stage and both the caregiver and patient could have adjusted to the acute event after a period of rehabilitation.

The above findings of Anderson et al (1995) differ from the limited French study by Bethoux et al (1996) who found a correlation between the patients' physical disability and the spouses' quality of life. Physical function of the patient was measured using two scales, namely the Barthel Index (BI) and Functional Independent Measure (FIM), while quality of life of the spouse was measured by a Visual Analogue Scale (VAS) as well as interviews. These authors evaluated the quality of life of nine spouses of stroke patients, six months after the onset of stroke. WHO (1993) defines quality of life as 'an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns'. The nine spouses in this sample described factors influencing their quality of life which were physical burden, psychological burden, financial problems, disturbance of social relationships, reduction of leisure activities and decrease in marital satisfaction. However, physical burden was the main concern as most patients were dependent on their spouses for personal care activities, transfers and mobility. Only 22% of the spouses reported being depressed, but all complained of excessive strain and difficulty coping with their new roles. Bethoux et al (1996) concluded that the impact of stroke affected the quality of life of all the spouses involved in their study, particularly when the patient had an

ambulation deficit. However, these authors stated that a limitation of their study was that their sample size was small and, therefore, could not be generalised to the global population of stroke patients' spouses.

The difficulties and needs of 93 American carers were identified by King and Semik (2006) during the first two years of stroke caregiving. Caregivers identified a variety of distressing factors, such as uncertainty and lack of confidence about caregiving, adapting to new responsibilities, the stress of balancing work and caregiving, as well as handling the stroke patients' negative emotions, that increased their burden in the early stages of caregiving. Additional problems which caregivers also experienced early in caregiving were lack of information and skill regarding stroke, as well as transport difficulties to the hospital. Problems which were later expressed included a plateau reached in the function of the stroke patient, caregiver and patient health problems, emotional distress of the caregiver, financial difficulties, as well as unmet resources.

In a descriptive study by McPherson et al (2000a) the perceived health and reported level of strain of 70 primary carers of severely brain injured patients were explored, 15-18 months after the patient was discharged from inpatient rehabilitation in New Zealand. A semi-structured interview and the Short Form 36 (SF 36) was used to measure the perceived health of the caregiver. The Caregiver Strain Index (CSI) and Relatives Questionnaire (RQ) was used to measure caregiver strain, while the Barthel Index (BI) and the Office of Population and Censuses Scale (OPCS) was used to assess the level of neurological disability in the patient. These researchers found that spouses

had a lower perceived health status than any other family member and that factors which contributed to carers having worse health status included the patients' level of disability, as well as the nature of the carer-patient relationship. Therefore, it was suggested that the nature of the patient-carer relationship needs to be taken into consideration when exploring the well-being of carers, and in planning future services.

2.5.3 CAREGIVER BURDEN BEYOND 2 YEARS AFTER STROKE

The next two articles report caregiver burden beyond two years after the onset of stroke.

The level and specific nature of burden in the caregiving of 115 partners of stroke patients were assessed 3 years after the onset of stroke (Scholte op Reimer et al, 1998). The burden of caregiving was assessed using the Sense of Competence Questionnaire (SCQ), while the disability of the patient was measured by the Barthel Index (BI) and Frenchay Activities Index (FAI). These authors found that caregiver burden was perceived in terms of feelings of heavy responsibility, uncertainty about the patients' needs, constant worries, restraints in caregivers' social life and feelings that patients rely only on their care. High levels of burden were experienced by caregivers when they had to provide a significant amount of care for their spouses, and also when their need for psychosocial support were unmet, especially when the stroke patient experienced behavioural problems. The results of the study also demonstrate that partners of severely disabled patients experience high levels of burden, with even more burden experienced when these partners have their own health problems,

particularly psychosocial problems. Martin et al (1998) also confirmed that caregivers of severely disabled patients experienced emotional distress and depression. Scholte op Reimer et al (1998), therefore, suggest that helping to clarify the patients' needs, sharing responsibilities and obtaining relief from caregiving may be important in the support of caregivers at this stage.

The perceptions of caregiver burden was also examined more recently among 200 family caregivers of elderly stroke patients in Japan (Morimoto et al, 2001). The duration of caregiving ranged from about 2-5years. The Zarit Burden Interview was used to measure caregiver burden, while the modified Barthel Index (MBI) was used to measure the stroke patients' degree of functional independence. It was found that, although patients had a moderate level of functional independence according to the MBI (65.98), caregiving took up to 9.43 hours per day and was significantly related to caregiver burden. This study suggested that the amount of caregiving time was not related to the actual physical disability of the stroke patient, but rather the caregivers' subjective assessment of the patients' needs. Similar to the studies of Scholte op Reimer et al (1998) and Bugge et al (1999), the feeling of being overly depended on and a lack of personal time, rather than the actual physical functioning of the patient, were the greatest sources of caregiver burden.

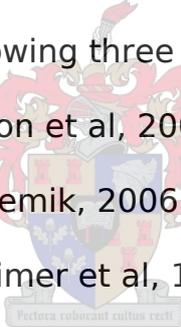
In conclusion, it is evident from the above studies that caregivers experience the most physical strain during the first 18-24 months of stroke, considering that stroke recovery as well as rehabilitation, occurs mainly within the first 18 months after stroke (Pierce et al, 2006; Han and Haley, 1999). As time

progresses beyond 2 years, caregivers tend to experience more the emotional and psychological burden of caregiving.

2.6 CAREGIVERS' NEEDS

It has been seen that stroke caregivers experience a variable burden of care, which includes both physical and emotional strain. In recognition of this burden, research has been undertaken into the perceived needs of caregivers. As it has been a failure in the past to adequately conceptualise the carers' needs, this has led to interventions offered being largely inappropriate and irrelevant (Denman, 1998). Caregiver needs illustrated in the following studies which were conducted in the Netherlands, UK and USA, have been assessed at the following three stages after the onset of stroke:

- within 6 months (McPherson et al, 2000b; McLean et al, 1991;)
- 6 - 24 months (King and Semik, 2006; Denman, 1998).
- at 3 years (Scholte op Reimer et al, 1998)



2.6.1 CAREGIVER NEEDS WITHIN 6 MONTHS AFTER STROKE

McPherson et al (2000b) have observed that current services fail to understand and respond to the needs of caregivers. Their study aimed to achieve a deeper understanding of the information needs of brain-injured patients and their carers, in order to direct future interventions. Eighty two carers were interviewed six weeks after patient discharge from a rehabilitation unit in New Zealand. In addition, the Relatives' Questionnaire was used to document the presence of problems from the carers' perspective. The results have shown that within six weeks after discharge from comprehensive inpatient rehabilitation, which included patient and

carer education, the majority of carers still requested more explanation about brain-injury pathology, medication, social benefits and safety concerns. In this study, the need for information by the carers were found to be unrelated to the severity of the injury or level of functional deficit of the brain-injured patient.

The perceived needs of 20 British stroke patients and their caregivers were assessed in a pilot study by McLean et al (1991). Semi-structured interviews of the carers and patients were conducted in their homes after the patient was discharged from hospital. The Clifton Assessment Procedure for the Elderly (CAPE) objectively measured the disability level of the stroke patient, while the Hospital Anxiety and Depression Scale (HADS) measured anxiety and depression of both the patient and carer. Within the first 6 months of stroke, carers in this study expressed a need for:

- physical help with toileting, lifting and bathing the patient;
- emotional support and counselling;
- improved physical health and vitality;
- respite care;
- more health education about stroke and
- outpatient follow-up appointments.

2.6.2 CAREGIVER NEEDS AT 6-24 MONTHS AFTER STROKE

In a study to determine the needs of spouses caring for aphasic stroke patients, in-depth interviews were conducted with nine British spouses within a year of the patients sustaining a stroke (Denman, 1998). The structured interview schedule covered five main areas, which were:

- the carers' perception of their needs;
- the carers' perception of help available;
- information about the carers' actual access to services;
- the carers' satisfaction with the levels of service available and
- additional services that the carers' felt they would like.

Five main areas of needs were identified by the caregivers, which were similar to the findings of the previous study by McLean et al (1991). These included the following:

- respite care;
- support from family, friends and agencies;
- coping with their new role as caregiver;
- information about stroke and
- training in basic nursing, continence care, lifting and handling skills.

Furthermore, the difficulties and needs of 93 American caregivers were identified during the first two years of stroke caregiving (King and Semik, 2006). The main needs that were expressed by the caregivers included:

- better preparation for caregiving;
- enhancement of the patients' emotional and physical function;
- sustaining the self and family by effective support structures and
- information and education on resources, transportation, finances, nutrition and exercise.

2.6.3 CAREGIVER NEEDS AT 3 YEARS AFTER STROKE

In a study by Scholte op Reimer et al (1998) who measured the level and specific nature of burden in the caregiving of 115 partners of stroke patients

at 3 years after stroke, found that caregivers mainly indicated the need for more psychosocial support, especially when the stroke patient displayed behavioural problems.

In summary, the above literature studies reveal that the perceived needs of caregivers were similar within the first 6 months and 6-24 month stage after stroke. No relevant literature was found on the perceived needs of caregivers within 2-3 years after stroke. The main categories of needs within the first 2 years of stroke were mainly physical, educational and socio-economic needs, while in the later stages after stroke, the psychosocial and emotional needs were predominant. This was anticipated, as functional recovery occurs mainly within the first 18 months after stroke (Pierce et al, 2006; Han and Haley, 1999). Managing physical care and obtaining information were, therefore, not priorities after two years of caregiving (King and Semik, 2006). Dowswell et al (2000) also confirmed that caregivers initially asked for more practical support in the early stages after stroke, whereas the need for more psychological support increased over time.

2.7 STRATEGIES TO ADDRESS CAREGIVER NEEDS

In a British study by Denman (1998), caregivers identified strategies to address their needs and help them to be more effective in their caregiving. These included the following: involvement in support groups, access to someone in a counselling role, provision of information, regular re-assessments of the patient by the medical team and the provision of an emergency service. In response to this, Denman (1998) suggested that it would be beneficial to set up a service that focuses specifically on the

expressed needs of carers in order to be effective and supportive.

In response to the needs expressed by caregivers in the current study, the effects of a variety of strategies for the support of stroke caregivers have been evaluated in the following studies that were conducted in the Netherlands, England, Scotland, USA, Japan, Australia and New Zealand. The different types of strategies suggested by the various authors will be discussed, as well as research addressing the effectiveness of the different types of interventions implemented for stroke caregivers. These strategies include mainly education, as well as counselling, follow-up appointments, support services/groups and respite relief for stroke caregivers.

2.7.1 EDUCATION

Van den Heuvel et al (2002) of the Netherlands compared the effect of a group support programme and an individual support programme to determine which was more beneficial to 212 stroke caregivers. Both programmes aimed at increasing the caregivers' active coping strategies and knowledge about stroke, as well as reducing their strain, improving their well-being and providing social support. The group programme consisted of eight 2-hour sessions and included the following:

- education on the causes and consequences of stroke;
- caring for the patient including lifting techniques;
- education on resources available and social networking and
- stress management.

The individual support programme was shorter and consisted of four 2-hour

home visits, and included the same content as the group programme. There was found to be no significant difference between the two designs. Van den Heuvel et al (2002) concluded that the two intervention programmes improved the caregivers' confidence in knowledge about stroke care and the use of an active coping strategy, but in order to improve physical and mental well-being and reduce caregiver strain, the carers would require longer support programmes or support programmes combined with day care. These authors concluded that a programme focussed on education alone is not sufficient to bring about long term positive effects on the carers' physical and mental well-being.

The effect of a multi-disciplinary stroke education programme (SEP) was evaluated by means of a randomised controlled trial using a sample of 204 acute British patients and their 176 carers, six months after the onset of stroke (Rodgers et al, 1999). Stroke patients and their carers were randomised into two groups; one received an invitation to attend the SEP while the second received conventional stroke unit care. The primary aim of this study was to determine the effectiveness of a SEP in improving patients' and carers' perceived health status through enhancing their stroke knowledge. The primary outcome measure used was the SF-36, which assessed the patients' and carers' perceived health status after stroke. The programme consisted of a 1-hour small group educational session in hospital, followed by six 1-hour educational sessions after discharge. The programme included contributions from nursing, physiotherapy, occupational therapy, speech and language therapy, clinical psychology, social work, the local

carers centre and stroke club. The programme aimed to improve knowledge of stroke, its management and prevention, as well as to increase awareness of services available and to provide patients and carers with professional and peer group support. The main findings were that this service improved patients' and carers' knowledge about stroke and increased satisfaction with services, but had no effect on the carers' perceived health and psychological status. This study suggests that improved knowledge about stroke may not be associated with improved health status. A shortcoming of this study was that the researchers did not describe what conventional stroke unit care involved.

The effectiveness of a stroke family support organiser (FSO) over a 9 month period was evaluated for 126 stroke patients and carers, and was compared to a control group of 124 stroke patients and carers in a randomised controlled trial by Lincoln et al (2003). The control group in this study received conventional stroke care, while the role of the FSO included making carers and patients aware of the emotional support service available, as well as providing carers with an information pack from the Stroke Association on the education of stroke. The FSO made initial contact with the patient in hospital, attended case conferences and assisted with the hospital discharge of the patient. The FSO also carried out home visits to discuss problems, offer information and emotional support to the patient and family, as well as to direct them to appropriate services. Outcome measures were undertaken at 4 and 9 months using the General Health Questionnaire, Caregiver Strain Index, Barthel Index, Extended ADL Scale and a specially designed

questionnaire to determine their knowledge of stroke and satisfaction with services. The main findings were that this service acted primarily as a useful 'information provider', increasing patients' and carers' stroke knowledge and satisfaction with services. However, there was no difference between the two groups with regard to psychosocial benefits, such as emotional support or reduction in carer strain, thereby supporting the findings of Rodgers et al (1999). A shortcoming of this study was that the researchers also did not describe what conventional stroke care involved.

A randomised controlled trial by Kalra et al (2004) evaluated the effectiveness of training 300 stroke patients and their caregivers in a stroke rehabilitation unit in England. The primary aim of the study was to evaluate whether training caregivers in stroke management, would reduce caregiver and patient burden. Outcome measures used to determine the functional status of the stroke patients were the Modified Rankin Scale, Barthel Index and Frenchay Activities Index. The Hospital Anxiety and Depression Scale (HADS) and Caregiver Burden Scale evaluated their emotional health, while the EuroQol VAS measured the quality of life of both the caregiver and patient. Stroke patients and their carers were randomised into two groups; one received training in stroke management, while the second received conventional stroke unit care. Conventional stroke unit care consisted of; teaching the carers and patients about the causes, prevention and management of stroke, involvement in goal setting for discharge planning, nursing and therapy intervention, as well as advice on community resources and benefits available for the stroke patient and carer. Caregiver training

consisted of 3-5 (dependent on need), 30-45 minute sessions of instruction by appropriate professionals on the prevention of common stroke-related problems, prevention and management of pressure sores, continence, nutrition, positioning, gait facilitation, and advice on benefits and resources available. The sessions also included 'hands-on' training in lifting and handling techniques, facilitation of mobility and transfers, continence as well as assistance with personal care ADL and communication, which were tailored to the individual needs of the patient. The main findings was that this intervention reduced caregiver burden and anxiety, as well as improved the quality of life in both patients and caregivers within 12 months after stroke.

Grant et al (2004) suggested that short, clear and straight-forward material which provided guidance on managing the cognitive, behavioural and emotional problems associated with stroke, should be sent to caregivers and patients soon after hospital discharge. These authors examined caregiving problems experienced by 22 American family caregivers of stroke patients during the first month after hospital discharge.

McPherson et al (2000b) who determined the information needs of families of brain-injured patients, recommended that services should be 'sensitively proactive' in determining what information was required in order to provide the best support for brain-injured patients and their families. One of their suggestions were also for the provision of 'information packs' to the families.

2.7.2 COUNSELLING

When families are coping poorly, Evans et al (1988) found that providing supportive family counselling is more productive than family education. In a randomised controlled trial of 188 American carers, education and counselling interventions were compared to routine stroke care. The education sessions consisted of two 1-hour classes for caregivers about basic stroke care principles. The counselling sessions consisted of two hours of education plus seven individual 1-hour problem-solving sessions with a social worker. These authors assessed caregiver knowledge of stroke, as well as family function, use of resources and patient and carer adjustment at 6 months and 1 year after stroke. Both interventions improved caregiver knowledge and family function more than routine stroke care. However, counselling was more effective than education alone and resulted in positive changes in family function, as well as better adjustment of the stroke patients. Education of caregivers was found to mainly promote better family communication, but did not help families to cope with the emotional and behavioural changes associated with the stroke patient (Evans et al, 1988).

A more recent study by Clark et al (2003), who extended on the work of Evans et al (1988), evaluated the effectiveness of a combined education and counselling intervention for families after stroke. Sixty two families were allocated to either an intervention group or a control group. The intervention comprised an information package and three 1-hour visits from a social worker at 3 weeks, 2 months and 5 months after hospital discharge. The information package provided information about stroke, its prevention and

consequences, practical coping suggestions and information about community services and support structures. During the visits, the social worker discussed and reinforced the content of the information package, and also provided individual family counselling on stroke-related stresses. Their results reveal that an education and counselling intervention maintained family functioning, and also improved functional and social outcomes for the stroke patient. Outcome measures used were the Barthel Index to measure functional status of the stroke patient, the Adelaide Activities Profile for social recovery of the carer and the Short Form-36 for perceived health status of both the patient and carer. The McMaster Family Assessment Device (FAD) measured family functioning, while the Geriatric Short Form Scale and Hospital Anxiety and Depression Scale (HADS) measured depression and anxiety of both the patients and carers. These authors recommended that a combined education and counselling support programme was relevant to both stroke patients and carers, due to the growing popularity of early discharge of stroke patients from hospitals (Clark et al, 2003).

King and Semik (2006) who identified the needs of stroke caregivers during the first two years of caregiving, suggested that a peer-mentoring and counselling programme may be useful in the emotional support of caregivers during the early stages of caregiving. Furthermore, Morimoto et al (2001) suggested that counselling services which help caregivers cope with the emotional strain associated with caregiving, may be more beneficial than services that only provide assistance with caregiving tasks. In their study,

these authors examined the perceptions of caregiver burden among 200 family caregivers of stroke patients in Japan.

2.7.3 FOLLOW UP APPOINTMENTS

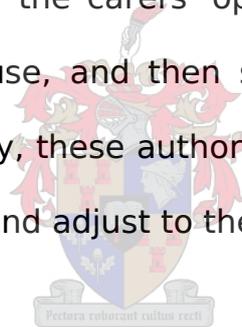
Although a variety of community services such as district nursing, respite care, day care centres and stroke groups were available to carers, Anderson et al (1995) found that carers still experienced emotional distress. In contrast with the physical aspects of care, problems related to behavioural disturbances and emotional illness of the stroke patient are less recognised and addressed by professionals and the public. These authors suggested that assessment of the carers' medical, social and emotional needs could be undertaken by an accessible 'key person' or medical professional, as part of a routine follow-up stroke service, as carers need knowledge about potential stroke-related problems and how to obtain the necessary help and support. These authors concluded that community services need to focus on the neuropsychological aspects of stroke patients as well as the social functioning of their carers. McPherson et al (2000b) who determined the information needs of families of brain-injured patients, also recommended regular follow-up appointments with carers to discuss their main concerns.

Grant et al (2004) examined caregiving problems experienced by 22 American family caregivers of stroke patients during the first month after hospital discharge. These authors found that three weekly telephone contacts appeared to be beneficial in assisting caregivers to cope with the caregiving process during the initial month after stroke. This intervention taught the caregiver effective skills in solving caregiving problems, as well as

controlling negative emotions.

2.7.4 SUPPORT SERVICES/GROUPS

Bugge et al (1999) aimed to identify the level of strain of 110 Scottish caregivers at 1, 3 and 6 months after stroke and to assess the relationship between caregiver strain and caregiver characteristics. These authors suggested two issues to consider when shaping services for caregivers: Firstly, increasing the provision and use of support services to reduce caregiving time and subsequently increase leisure time for the carer. Bugge et al (1999) found that utilisation of support services was low and, therefore, there was a need to identify the carers' opinions about available services, especially barriers to their use, and then subsequently plan services that carers would utilise. Secondly, these authors suggested that the goal should be to assist families to cope and adjust to their new circumstances.



2.7.5 RESPITE RELIEF

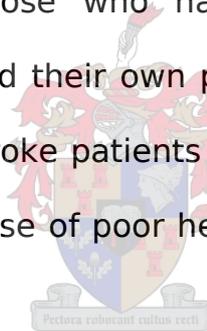
Anderson et al (1995) who assessed the impact and burden of stroke caregiving, suggested that the provision of day hospitals and intermittent respite care was necessary for the support of caregivers. This was further emphasised by Van den Heuvel et al (2002) who suggested that a carer support programme should also include several hours a week of daycare for the patient so that the caregiver could participate in his/her leisure activities. Many caregivers expressed that it was hard for them to find the time to participate in other activities besides caregiving.

2.8 BARRIERS TO THE COMPLIANCE OF CAREGIVERS

In the following section, barriers to the compliance of caregivers as

described in the following three studies will be discussed in order to determine the main reasons why stroke caregivers could not attend the intervention programmes organised for them. These studies were conducted in the UK, USA and the Netherlands.

In a randomised controlled trial by Rodgers et al (1999), the effectiveness of a multi-disciplinary Stroke Education Programme (SEP) was evaluated for 204 British stroke patients and 176 carers. These authors found that the SEP attendance was disappointingly low as only 51 stroke patients and 20 carers attended more than 3 out of the 6 sessions. Nevertheless, it was well received and valued by those who had attended. Reasons for non-attendance by carers included their own poor health, work commitments or lack of interest. Similarly, stroke patients reported that they were unable to attend the programme because of poor health, lack of interest and difficulty getting to the hospital venue.



Evans et al (1994) also commented in his review article that American families who were most in need of supported care were unlikely to participate in support programmes, usually because of practical problems such as not being able to find relief from their caring responsibilities or having transportation problems.

Van den Heuvel et al (2002) compared the effects of a group support programme and an individual support programme for stroke caregivers. In their study, caregivers expressed that it was hard for them to find the time to participate in the group support programme. Consequently these authors

recommended that group programmes should be offered near caregivers' homes so that travelling barriers are reduced and caregivers could continue to maintain contact after completion of the programme.

In conclusion, it is evident from the above literature that stroke caregivers mainly reported physical strain within the first two years after stroke, considering that stroke recovery predominantly occurs within this time frame (Pierce et al, 2006; Han and Haley, 1999). Therefore, in order to address their physical needs, most of the intervention strategies reported in the above literature, included educational programmes for the caregivers. As time progresses beyond 2 years, caregivers tend to experience more the emotional and psychological burden of caregiving.



CHAPTER 3

METHODOLOGY

In the following chapter the primary objective and aims of the study, study design, population, sampling procedure, instrumentation, study procedure and ethical considerations will be discussed.

3.1 RESEARCH QUESTION

What is the effect of a caregiver support intervention programme developed to address the expressed needs identified by the primary caregiver of the dependent stroke patient in the Bishop Lavis community?

3.1.1 PRIMARY AIM OF THE STUDY

To determine the effectiveness of a caregiver support intervention programme that addresses the expressed needs of the primary caregiver of the dependent stroke patient in the Bishop Lavis community.

3.1.2 OBJECTIVES OF THE STUDY

- To identify the expressed needs of the primary caregiver of the stroke patient in the Bishop Lavis community.
- To develop and implement a support intervention programme based on the expressed needs of the primary caregiver.
- To evaluate the effect of a support intervention programme on the strain of caregiving, as measured by the the Caregiver Strain Index.

3.2 STUDY DESIGN

A prospective and descriptive study design utilising both qualitative and quantitative methodologies was used to evaluate the effect of the support

intervention programme. The needs of stroke caregivers were determined by individual, semi-structured interviews.

3.3 POPULATION

The population comprised all primary caregivers of dependent stroke patients residing in the Bishop Lavis community.

3.4 SAMPLING

The sample consisted of 31 primary caregivers of dependent stroke patients who had a confirmed diagnosis of stroke made between November 2003 and August 2005. Convenient sampling was used and the sample size for the caregivers was determined when data saturation was reached.

In order to identify the caregivers for the sample, it was first necessary to identify the stroke patients and then to select subsequent stroke caregivers according to the inclusion and exclusion criteria.



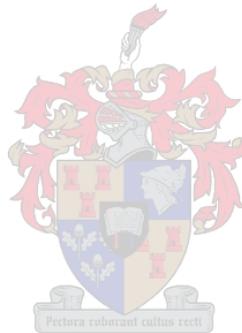
Following the onset of a stroke, patients from the Bishop Lavis community are either admitted to a tertiary hospital if medically unstable, or managed as an outpatient at the Bishop Lavis Community Health Centre (BLCHC). Once the stroke patient is stabilised at a tertiary hospital, he/she is referred for follow-up management to the BLCHC. The majority of patients are then referred for rehabilitation as necessary to the Bishop Lavis Rehabilitation Centre, and/or for follow-up monitoring to the Caring Network home-based care agency.

3.4.1 SAMPLING PROCEDURE

In terms of the above-mentioned process, the sample for this study was

obtained by the following three referral sources:

- Bishop Lavis Community Health Centre (BLCHC) - doctors and nurses recorded the contact details of confirmed stroke patients managed between November 2003 and August 2005.
- Bishop Lavis Rehabilitation Centre (BLRC) – therapists recorded the contact details of stroke patients referred for rehabilitation over that same period on their monthly statistic forms.
- Caring Network home-based care agency (CN) – a nursing sister recorded the contact details of stroke patients referred to them over that same period.



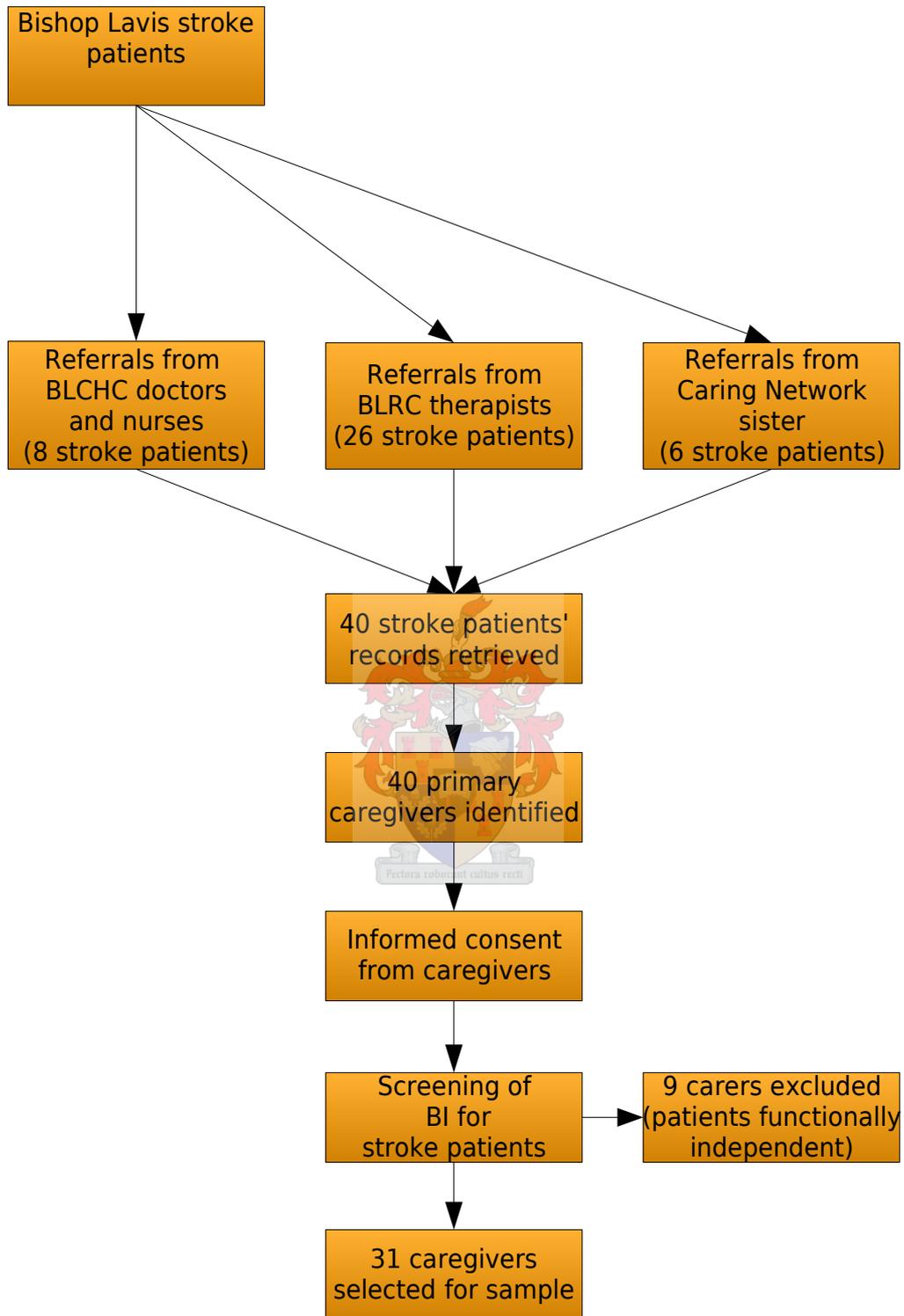


Figure 3.1: Sampling procedure flow chart

In Figure 3.1 above, there has been no duplication in the numbers from the three referral sources, even though the stroke patients could have been

potentially referred from two or even all three referral sources.

The records of these stroke patients were retrieved and the patient was then contacted directly or telephonically. The person who was identified by the stroke patient as the main provider of the stroke patient's emotional and physical support, was deemed to be the primary caregiver. After the primary caregiver had been identified, he/she was contacted either directly or telephonically. They were informed about the aims of the study and requested to participate in an immediate screening interview at the Bishop Lavis Rehabilitation Centre. The purpose of the screening interview was to complete the Barthel Index which was used as a screening tool to select the caregivers of dependant stroke patients for the study. Caregivers who met the inclusion criteria (3.4.2) and who agreed to participate, were included in the study. A written consent form was completed by the caregiver at the first contact session (Addendum A and B).

3.4.2 INCLUSION CRITERIA

Caregivers were included if they were :

- Caring for a stroke patient who had sustained a stroke within 6 months prior to commencement of the study. It has been found that stroke caregivers experience the most strain within six months after stroke (Bugge et al, 1999; Grant et al, 2004).
- Able and willing to participate in the study.

3.4.3 EXCLUSION CRITERIA

Caregivers were excluded if they were :

- Not Afrikaans or English speaking.
- Not residing in the Bishop Lavis community. The Bishop Lavis area was chosen for convenience in selecting the study sample, as well as to minimise transport costs for the caregivers.
- Caring for a stroke patient with a Barthel Index score above 18. Stroke patients with a BI score greater than 18 was considered to have a high functional level (Kalra et al, 2004). For the purpose of this study, the researcher selected lower functioning and dependent stroke patients who were likely to need physical assistance from their caregivers.

Barthel Index (BI) of Activities of Daily Living (ADL)

The BI (Addendum D) was originally developed by Dorothea Barthel in 1955 to measure functional independence before and after rehabilitation, and is simple and quick to use, easily understood and communicated between different professions. It measures the actual ability of the patient to perform self-care activities of daily living, but not the complex movements and skills required to carry out these activities (Wade, 1992). The BI is regarded as the most widely used and best standard measure of ADL and is particularly suitable for stroke patients, as it is sensitive enough to detect changes or improvement in function after stroke (Wade and Collin, 1988).

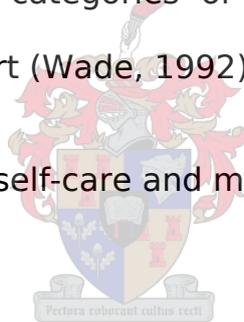
The BI has been shown to have high observer and test-retest reliability, as well as 'construct' validity. In addition, it has been shown to be a valid and reliable measurement scale for function in ADL and follows progress in self-care and mobility skills during neurological rehabilitation (Wade and Collin, 1988). The BI is considered to be most useful in assessing patients who are

moderately or severely disabled (Rodgers et al, 1993).

This index is individually administered by caregivers or staff, and takes about five minutes to complete. It has been found to be reliable in completion by post and over the telephone (Wade, 1992). The original total maximum scoring was 0-100, in five point increments, but was later modified to a total maximum scoring range of 0-20 in one point increments, with higher scores signifying better functioning and outcome after stroke. It is important to note that for both scoring systems the need for physical or verbal help/ supervision, however minor, renders the patient not independent, even with a maximum score. Middle categories of scoring imply that the patient supplies over 50% of the effort (Wade, 1992).

The BI measures 10 items of self-care and mobility:

- bowel function: (0-1-2)
- bladder function: (0-1-2)
- grooming: (0-1)
- toilet use: (0-1-2)
- feeding: (0-1-2)
- transfers: (0-1-2-3)
- mobility: (0-1-2-3)
- dressing:(0-1-2)
- stairclimbing:(0-1-2)
- bathing: (0-1)



The Barthel Index was chosen in this study for the following reasons:

- It is easy to administer and quick to use on stroke patients (Collin et al, 1988).
- It is simple and easily understood in a community with a low level of education (Wade, 1992).
- It is economical, with no usage fee required (Wade, 1992).
- It is reliable for use over the telephone (Wade, 1992).

The Barthel Index has been widely used in the following studies by Kalra et al (2004), Lincoln et al (2003), Morimoto et al (2001), McPherson et al (2000a), Rodgers et al (1999), Bugge et al (1999), Scholte op Reimer et al (1998) and Anderson et al (1995) in order to measure the functional independence of stroke patients and to relate it to the caregiver's level of burden. Bethoux et al (1996) used the Barthel Index to measure independence in personal care ADL for stroke patients, in order to correlate it to the quality of life of both stroke patients and their spouses. The BI has been used in different variations by these authors, but Wade and Collins' (1988) version is highly recommended and has been most commonly used in the above literature studies. Therefore, the researcher chose to use this version of the BI for the current study. The BI was translated into Afrikaans by an experienced translator, for the ease of the caregivers' understanding.

A disadvantage of the Barthel ADL Index is its lack of sensitivity to change in the upper or lower ranges of the scale, for example, a ceiling effect is reached with patients scoring the maximum 20, even though they may still be significantly dependant or handicapped with the potential for

improvement in their quality of movement beyond the limits of the scale. To overcome this, patients with high Barthel Index scores should be assessed with another ADL scale that assesses a broader range of activities (Rodgers et al, 1993). However, for the purpose of determining the level of dependency of stroke patients cared for by the selected sample, the BI was deemed suitable for use in this study as patients scoring a maximum score were not included in the study (see 3.4.3). Due to the complexity of stroke and the resultant need for caregivers, a maximum score of 20 can still indicate that the patient is significantly handicapped, as the need for supervision or verbal input renders the patient not independent. Kalra et al (2004) considered stroke patients with a BI score greater than 18 to have a high functional level. It is for this reason that the stroke patient had to score 18 or below, for their caregivers to be included in the current study.

3.5 INSTRUMENTATION

In order to evaluate the effect of the caregiver support intervention programme (CSIP), the following two instruments were completed by all 31 caregivers:

- Caregiver Strain Index (CSI): to measure caregiver strain before and after implementation of the support intervention.
- Written or verbal feedback forms: to determine positive and negative feedback from each of the five intervention sessions.

3.5.1 CAREGIVER STRAIN INDEX

The Caregiver Strain Index (CSI) was used to detect and measure caregiver strain of each participant before and after the support intervention

programmes (Addendum E). This index is a brief, easily administered 13-question tool (1 point score per item), that measures potential physical and emotional strain related to caregiving, and covers the following domains: employment, financial, physical, social and time (Robinson, 1983). The CSI is individually administered to caregivers of any age and has been shown to have a high internal reliability and construct validity (Sullivan, 2002). Positive responses to 7 or more items on the index indicate considerable strain/stress of the caregiver and a resultant need for a more comprehensive assessment of the caregiving process (Sullivan, 2002). This index was available to the caregivers in English and Afrikaans, and the results were captured by the researcher. The CSI was translated into Afrikaans, for the ease of the caregivers' understanding. The initial CSI was completed 1-2 weeks prior to commencement of the intervention programme. The follow-up CSI was completed 2-4 weeks after completion of the intervention, in order to measure whether the support intervention programme had been effective in reducing the caregivers' level of strain.

3.5.2 WRITTEN / VERBAL FEEDBACK FORMS

A written feedback form, which was developed by the researcher, was completed by each caregiver at the end of every CSIP session, in order to determine what they learnt, as well as what they enjoyed most and least in the sessions (Addendum F). This form was available to the caregivers in English and Afrikaans. Since the researcher was experienced in the use of the colloquial Afrikaans that is commonly used in this community, she translated the feedback form with assistance from her supervisor, who was

an experienced translator. Verbal feedback was taken individually by a research assistant and was documented verbatim to accommodate for caregivers who were illiterate.

3.6 DEVELOPMENT OF THE INTERVENTION

In order to develop a suitable support intervention programme based on the needs of stroke caregivers in Bishop Lavis, the expressed needs of the first 15 caregivers were identified by semi-structured interviews until data saturation was reached (Addendum C).

The flow diagram of the development of the CSIP is set out below:

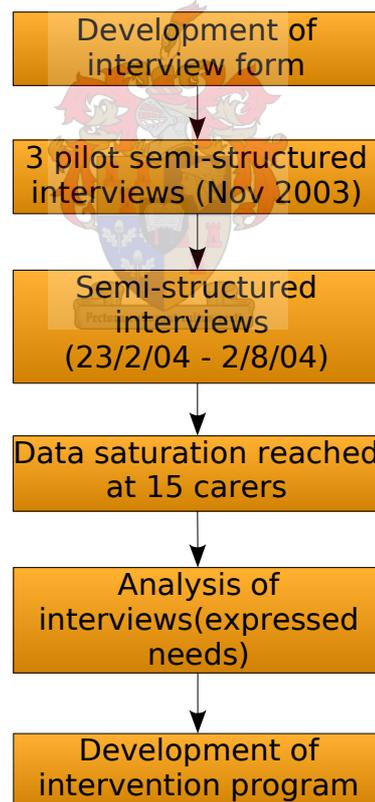


Figure 3.2: Development of CSIP Flow Chart

3.6.1 PILOT INTERVIEW

Individual pilot semi-structured interviews were conducted with three primary caregivers in November 2003. The interview questions were found

to be suitable. However, some of the questions in Afrikaans were re-phrased in order to improve clarity of understanding. Each interview lasted between 40 minutes to one hour, which was within the anticipated time frame. The caregivers selected for the pilot interviews were excluded from the study.

3.6.2 SEMI-STRUCTURED INTERVIEW

Individual semi-structured interviews (Addendum C) were conducted by the researcher at the Bishop Lavis Rehabilitation Centre to identify the perceived needs and concerns of the primary caregivers selected for the study, in order to develop a suitable support intervention programme. The researcher developed the interview outline in English and then translated it into Afrikaans with assistance from her supervisor who, as an experienced translator, verified its accuracy. An interview was chosen above a questionnaire for the ease of the participants' understanding, as this community is reported as having a low education level and there was a possibility that the caregivers would not be able to read and write (De Villiers et al, 1999). Open-ended questions were used, as well as prompts to elicit further information from the carers if they did not understand certain questions. The interview was arranged at a convenient time for the caregiver, lasted approximately one hour for each participant and was recorded for reference purposes. It was conducted by the researcher, who was fluent in both English and Afrikaans and contained the following components:

- Information of the patient such as his/her medical history
- Information of the primary carer such as his/her caring responsibilities

- Caregivers' knowledge of stroke
- Interaction with the rehabilitation team
- Financial status of the patient and caregiver
- Needs and support identified by the caregiver.

The above headings were chosen with reference to literature by McPherson et al (2000b), Denman et al (1998) and McLean et al (1991). The 15 semi-structured interviews were conducted over a period of six months until data saturation was reached. The researcher analysed the data from the interviews by identifying similar themes in order to develop a support intervention programme, which would be implemented three times.

3.6.2.1 Needs of the caregivers

The results of the interviews were analysed qualitatively in order to plan the first caregiver support intervention programme (CSIP) to address the expressed needs of the carers (Addendum G). The expressed needs were grouped in the following categories: physical, emotional, socio-economic and educational needs which will be presented below. Individual typical or atypical qualitative comments to illustrate these categories will also be included. An outline of each of these categories will follow as motivation for the development of the intervention.

Categories of expressed needs

It will be seen from the graph below that the main needs reported by the caregivers were in the category of physical needs, while the need for theoretical knowledge was the least expressed by the caregivers.

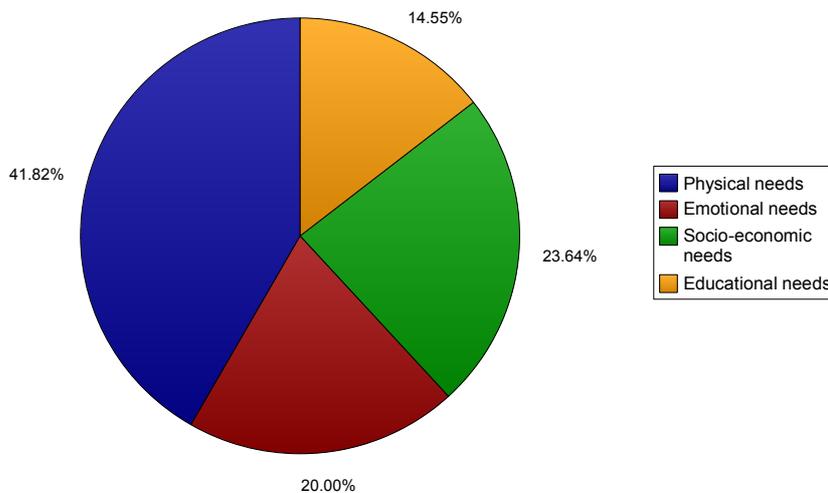
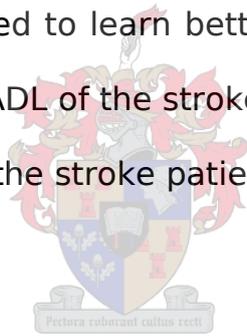


Figure 3.3: Needs of caregivers

Physical needs - 23 comments

Caregivers expressed the need to learn better handling skills with transfers, exercises and personal care ADL of the stroke patient, as well as the need for additional physical help with the stroke patient. These included the following two areas:



a) Handling of the stroke patient (14 comments)

Caregivers wanted to learn better handling skills of the stroke patient which included effective transfer skills, as well as a suitable exercise programme to improve the stroke patients' function and mobility. This was consistent with the findings of Denman (1998) and McLean et al (1991) who identified the needs of British stroke caregivers and found that these caregivers also expressed the need to learn better lifting and handling techniques of the stroke patient. The researcher observed while working in the Bishop Lavis community, that many of the houses were small and had outside toilets, despite the large household sizes. Therefore these caregivers may have struggled with mobility and transfers of the stroke patient in their small,

overcrowded homes (De Villiers et al, 1999). Typical comments included in this category were:

- *'Ek wil leer hoe om haar beter te behandel en te versorg'.*
- *'Ek wil weet hoe om hom die regte manier te hanteer'.*
- *'Ek wil graag hê my ma moet haar swak arm en been meer gebruik'*
- *'Ek wil graag leer hoe om oefeninge vir haar te gee sodat sy sterker kan raak'.*
- *'Ek wil graag hê hy moet gesond word sodat hy weer kan loop'.*
- *'Ek wil haar leer hoe om te praat en ook met die swak been te loop'.*
- *'Ek sukkel om vir hom op sy kant te draai'.*

b) Additional help and support (9 comments)

Caregivers needed additional help from their family, friends or therapists, particularly with toileting and bath transfers. In addition, caregivers also requested more home visits by the therapists. This was consistent with a British study done by McLean et al (1991) where carers expressed the need for additional help during lifting, bathing and continence care of the stroke patient. Typical comments included in this category were:

- *'Ek het hulp nodig om vir hom op die commode te sit en vir hom skoon te maak.'*
- *'Ek sukkel om haar kimbie te verander om haar droog te maak- sy moet opgelig word'.*
- *'Dit is moeilik om vir hom in en uit die bad te kry – ek het hulp nodig'.*
- *'Ek het 'n 'helping hand' nodig om my man beter te versorg'.*
- *'Die carers kan meer gereeld uitkom om te help met aantrek en was van my man'.*

- *'Ek wil graag hê hy moet meer terapie kry sodat hy sy arm en been kan gebruik soos voorheen - die terapeute moet meer tuisbesoeke doen'.*

Emotional needs – 11 comments

The emotional needs were related to the caregivers' stress levels and included the need for more recreational and family time in order to relieve the burden of caring. This was consistent with other studies where carers expressed the need for respite care, as well as more emotional support and counselling from family, friends and staff (Denman, 1998; McLean et al, 1991). Typical comments included in this category were:

- *'Ek het meer tyd nodig vir myself en my familie'.*
- *'Ek het meer vrye tyd nodig om my vriende te besoek en om uit te gaan'.*
- *'I need someone to look after him when I go out - I just need a break'.*
- *'I would like a break from caring to spend more time with my son - a break just for one day would help the family'.*
- *'Ek wil leer hoe om my stres te verminder en meer te ontspan'.*
- *'I would like to learn relaxation techniques for myself and my granny'.*

Educational needs - 8 comments

While it could be argued that many of the physical needs also relate to 'education', this section includes only the expressed needs that were related to the theoretical knowledge of the caregivers. Only a few caregivers in the current study expressed the need to acquire more knowledge about stroke. Previous studies done in the UK and New Zealand show that within the first six months after stroke, most caregivers were interested in health education about stroke which included stroke pathology, medication, safety concerns

and social benefits available (McPherson et al, 2000b; McLean et al, 1991). It was evident from the above studies, that caregivers in first world countries were more specific about their educational needs than evidenced by the observations of the Bishop Lavis caregivers. This could most likely be ascribed to the higher literacy and education levels of carers in first world countries. The following non-specific comments by the Bishop Lavis carers included:

- *'Ek wil meer leer van stroke'*
- *'Ek wil weet wat gebeur met stroke'*.

However, it was evident from Section C of the semi-structured interviews, (Addendum C) that caregivers lacked theoretical knowledge of the warning signs, causes, risk factors and prevention of a stroke. Therefore, the caregiver support intervention programme consisted mainly of an educational component, as lack of theoretical knowledge displayed by the caregivers ultimately influences their management of a stroke patient (Evans et al, 1994).

Socio-economic needs – 13 comments

The socio-economic needs were related to financial burden, as well as the need for better resources such as a transport service, wheelchair supply service and more incontinence supplies for the stroke patient. Caregivers reported that they needed a transport service so that stroke patients could attend their hospital appointments. The researcher observed that because of the poverty in this community, very few families have motor vehicles and, therefore, the majority of stroke patients are pushed in wheelchairs to their

hospital appointments. The lack of transport can even be more challenging to the family if the stroke patient does not have his/her own wheelchair, as reported by some of the caregivers in the interviews. Furthermore, caregivers expressed the need for more incontinence supplies to be available from the Bishop Lavis Community Health Centre, who often had budgetary limitations. Typical comments included in this category were:

- *'Ek het geld nodig vir rent, kos en elektrisiteit'.*
- *'Ek het geld nodig om my drie kinders te versorg - ek is agter met betaling'.*
- *'Ek wil graag hê dat my ma die social worker moet besoek vir 'n toelaag'.*
- *'Hy het 'n rolstoel nodig vir gebruik na die daghospitaal, kerk en familie besoeke'.*
- *'Ons het vervoer nodig om die hom by die daghospitaal te kry'.*
- *'A wheelchair hiring service will be useful in Bishop Lavis'.*
- *'Kimbies moet meer beskikbaar wees by die daghospitaal'.*
- *'My pa het meer linen savers nodig van die hospitaal as hy homself nat maak in die aand'.*

3.6.3 PROGRAMME PRESENTERS AND RESEARCH ASSISTANTS

The presenters were chosen for their specific skill and experience in their various disciplines, in order to make the support intervention programme as effective as possible. All three CSIPs were presented in Afrikaans for the ease of the caregivers' understanding, and all of the presenters were fluent in this language. The research assistant had the role of non-participant observer who provided written or verbal feedback during all fifteen sessions.

The following were the presenters who took part, as appropriate, in each of the three CSIPs:

- The physiotherapist - employed by Stellenbosch University (SU), had 10 years experience and was based at BLRC for the past 5 years.
- The occupational therapist - employed by SU, had 5 years experience and was based at BLRC for the past 3 years.
- The dietician - employed by SU and based at BLCHC for the past 6 years.
- The social worker was based at BLCHC for the past 8 years.

The intention was to have the same presenters and assistants for all three CSIPs, but because of logistical constraints this was not always possible, as seen below.

The speech and language therapist for CSIP 1 and 2, had 10 years experience and was employed as a clinical supervisor by SU. However, she was unavailable to attend CSIP 3, and therefore another therapist who was employed as a lecturer at SU with 12 years experience, was chosen.

The research assistant's role was to observe the group interaction and dynamics, observe whether the content of the sessions were basic enough for the carers to understand, and served in the setting up of the group venue and snacks. The assistant for CSIP 1 was an OT who was chosen because of her experience in group therapy. Unfortunately she was unavailable to attend CSIP 2 and 3 and, therefore, a second observer was used who was employed as an administrative assistant at the BLRC for the past 2 years.

She was chosen because the researcher thought it would be useful to receive feedback from a non-medically trained person. Both research assistants were fluent in English and Afrikaans.

3.7 IMPLEMENTATION OF THE INTERVENTION (CSIP)

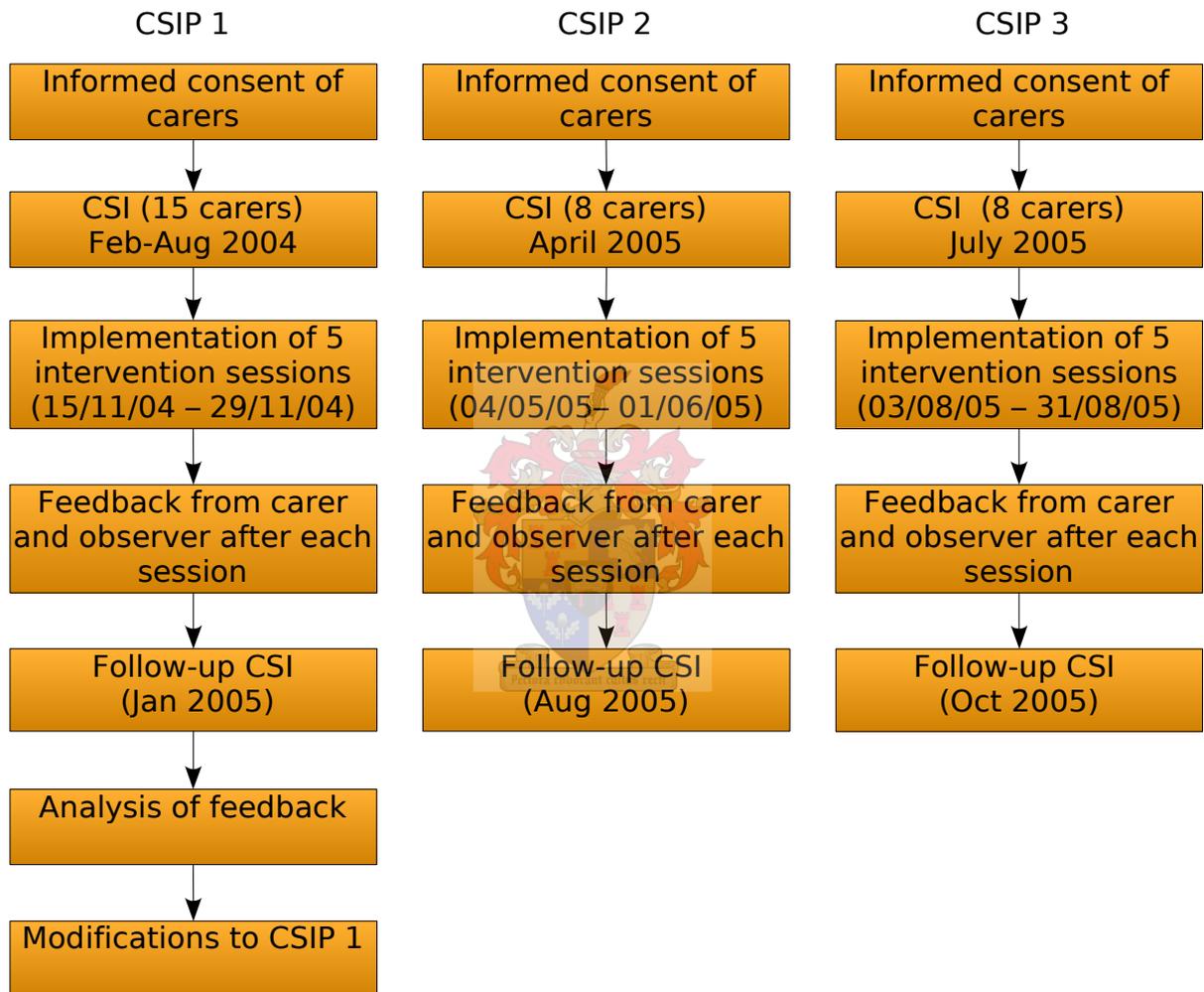


Figure 3.4: Procedure Flow Chart – Implementation of intervention

As seen from the flow diagram (Figure 3.4), three CSIPs were held consecutively. The first CSIP was held for 15 caregivers in November 2004, while the second and third CSIPs were held for a total of 16 caregivers in May 2005 and August 2005 respectively.

3.7.1 FIRST IMPLEMENTATION OF THE INTERVENTION PROGRAMME (CSIP 1)

The first caregiver support intervention programme was arranged on the most convenient days and times for the caregivers (Addendum G). This programme was scheduled on a Monday and Wednesday 14:00-15:30 for 5 sessions from 15 November 2004 until 1 December 2004 and included input from the physiotherapist, occupational therapist, dietician, speech and language therapist and social worker (Addendum G). The order of the sessions was implemented according to the availability of the presenters. An attendance register was kept to record the caregivers' name, contact number, sessions attended, and whether they were literate – able to read or write. At the end of each session, written or verbal feedback was obtained from each caregiver.

SESSION 1: PHYSIOTHERAPIST/ RESEARCHER

15 November 2004

Aims of the session:

- To create an atmosphere in which the caregivers could get to know each other better.
- To educate the carers on what stroke is and its warning signs.
- To teach the carers effective and safe transfers from the bed to chair/ commode, emphasising correct back protection principles.

Motivation for Session 1:

This session included education on what is stroke and its warning signs, as some of the carers expressed the need to learn more about stroke. It was also evident from the interviews (Addendum C) that caregivers lacked

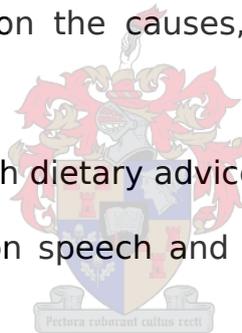
theoretical knowledge of the warning signs, causes, risk factors and prevention of a stroke. In addition, Session 1 also included teaching the carers effective and safe transfers from the bed to chair/commode, as many carers expressed in the interviews that they needed help with toileting of the stroke patient, particularly toilet transfers and changing the patients' nappies.

SESSION 2: PHYSIOTHERAPIST, DIETICIAN AND SPEECH AND LANGUAGE THERAPIST

22 November 2004

Aims of the session:

- To educate the carers on the causes, risk factors and prevention of stroke.
- To provide the carers with dietary advice for the stroke patient.
- To educate the carers on speech and swallowing problems associated with stroke.



Motivation for Session 2:

This session included education on the causes, risk factors and prevention of stroke, as a continuation from the stroke education done in Session 1. The education component was covered over two sessions in order to prevent an overload of information for the carers. In addition, Session 2 also included dietary advice, considering that a large number of stroke patients in the current study had hypertension and diabetes which are major risk factors of a stroke. De Villiers et al (1999) also pointed out that hypertension was the most prevalent chronic disease in the Bishop Lavis community. It was also evident from the interviews that carers lacked sufficient knowledge of a

healthy diet in prevention of a stroke (Addendum C). In addition, this session also included education on speech and swallowing problems associated with stroke, considering that many stroke patients in the current study had some form of speech or language impairment.

SESSION 3: OCCUPATIONAL THERAPIST

24 November 2004

Aim of the session:

- To teach the carers the application of the basic hemiplegic principles in ADL with emphasis on self-care activities.

Motivation for Session 3:

This session included teaching the carers the application of the basic hemiplegic principles in ADL with emphasis on self-care activities. The majority of stroke patients, according to the interviews (Addendum C) and Barthel Index (Addendum D), needed assistance with activities such as washing, dressing, eating and toileting.

SESSION 4: PHYSIOTHERAPIST AND SOCIAL WORKER

29 November 2004

Aims of the session:

To inform the carers of:

- the services and resources available in the Bishop Lavis community for the stroke patient.
- social and financial benefits available for stroke caregivers, like carer dependency grants and respite care options available.

Motivation for Session 4:

This session included input from the social worker in order to make the caregivers more aware of the social and financial benefits available for them like carer-dependency grants and respite care options available. This session informed the carers of the support structures and resources available for the stroke patient in the Bishop Lavis community, as it was evident from the interviews (Addendum C) that most of the carers were not aware of the available benefits and resources.

SESSION 5: OCCUPATIONAL THERAPIST

1 December 2004

Aims of the session:

- To teach the carers about stress management.
- To teach relaxation techniques through a relaxation therapy class.

Motivation for Session 5:

This session aimed to teach the caregivers about stress management and relaxation techniques, as carers expressed the need for stress relief.

3.7.2 SECOND AND THIRD IMPLEMENTATIONS OF THE INTERVENTION PROGRAMME (CSIP 2 AND 3)

The following modifications made to CSIP 2 and 3 (Addendum I) were based on observation, as well as feedback from the first group of caregivers and the non-participant assistant:

- Sessions were held weekly on a Wednesday, instead of twice weekly, as carers expressed difficulty in finding relief from their caring responsibilities while they attended the sessions.
- Sessions were kept strictly to 1hr 30 minutes in length, as it appeared

that the carers' busy schedule and responsibilities made it difficult for them to stay longer.

- Group size was kept to a maximum of eight caregivers, instead of 15, as the researcher and the assistant had noticed that when some caregivers did not attend, a group smaller than ten was more effective in achieving its aims.
- The social work session was not included in CSIP 2 and 3 as only a few carers gave positive feedback about this session in CSIP 1. This session was, therefore, excluded in order to keep CSIP 2 and 3 to a maximum of five sessions.

The second and third caregiver intervention programmes were also arranged on the most convenient day and time for the caregivers. These two programmes were scheduled on a Wednesday 14:00-15:30 for 5 sessions and included input from the physiotherapist, occupational therapist, dietician and speech and language therapist (Addendum I). The order of the sessions was implemented according to the availability of the presenters. At the end of each session, written and verbal feedback was also obtained from the caregiver.

SESSION 1: PHYSIOTHERAPIST/ RESEARCHER

4 May 2005 and 3 August 2005

Aims of the session:

- To create a relaxed atmosphere in which the carers could get to know one another.
- To educate the carers on what stroke is and its warning signs, risk

factors and prevention.

- To teach the carers one home exercise for the stroke patient.

Modifications to Session 1:

This session focussed more on creating a relaxed atmosphere for group interaction and bonding of the caregivers, as the time allocated for this in CSIP 1 was observed to be too short. It was also decided that all the stroke education should be done in the first session. Therefore, this session included education on what stroke is, its risk factors, prevention and warning signs, compared to the first session of CSIP 1 that only included education on what stroke is and its warning signs. The carers were also taught one home exercise as they expressed the need to learn more about stroke exercises.

SESSION 2: PHYSIOTHERAPIST

11 May 2005 and 10 August 2005

Aims of the session:

- To teach the carers effective and safe transfers from the bed to chair/commode, emphasising correct back protection principles.
- To teach the carers two home exercises for the stroke patient.

Modifications to Session 2:

Session 2 focussed on the principles and practice of hemiplegic transfers from the bed to the wheelchair/commode. As seen in CSIP 1, the transfer session was included in the first session, but as carers did not have sufficient time to practice these techniques, it was thus carried over to the second session. The carers were also taught an additional two home exercises in this session.

SESSION 3: OCCUPATIONAL THERAPIST

18 May 2005 and 17 August 2005

Aim of the session:

- To teach the carers the application of the basic hemiplegic principles in ADL with emphasis on self-care activities.

There were no changes made to Session 3.

SESSION 4: DIETICIAN AND SPEECH AND LANGUAGE THERAPIST

25 May 2005 and 24 August 2005

Aims of the session:

- To provide the carers with dietary advice for the stroke patient.
- To educate the carers on speech and swallowing problems associated with stroke.

Modifications to Session 4:

Session 4 consisted only of the speech therapist's and dietician's input. The education on the risk factors and prevention of a stroke was included with the dietician's and speech therapist's input in CSIP 1, but this was observed to be an overload of content for the carers. Therefore, all the stroke education was included in session 1.

SESSION 5: PHYSIOTHERAPIST AND OCCUPATIONAL THERAPIST

1 June 2005 and 31 August 2005

Aims of the session:

- To inform the carers of the resources and services available in the Bishop Lavis community for the stroke patient.
- To teach the carers about stress management.

- To teach the carers relaxation techniques through a relaxation therapy class.

Modifications to Session 5:

In this session the carers were informed about the support structures and resources available in the Bishop Lavis community for the stroke patient, in addition to stress management and relaxation therapy. In CSIP 1, the education on community resources was included with the social work session.

3.8 STATISTICAL ANALYSIS

The services of a statistician were utilised during the development of the protocol and for the analysis of the results. Quantitative data were analysed using the Statistica programme. In order to compare the CSI scores between different groups of carers, analysis of variance (ANOVA), and in some cases analysis of co-variance was used. Repeated measures ANOVA was used to compare the differences between pre- and post-CSI scores. Pearson correlations were calculated to determine possible relationships between ordinal measures such as the number of sessions attended. A 5% significance level was used as a guideline for determining significant differences.

Qualitative data were analysed by identifying and grouping together similar themes of caregiver needs that seemed prominent, as well as considering the individual comments expressed by the caregivers. The caregiver support programme was consequently developed based on the most commonly expressed needs of the caregivers.

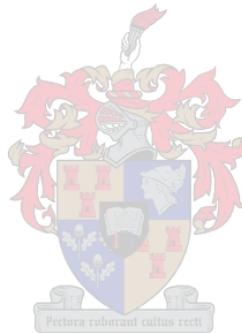
3.9 ETHICAL CONSIDERATIONS

The following ethical aspects were taken into account and addressed throughout the study:

1. Permission was obtained from the Provincial Administration of the Western Cape and Stellenbosch University to access patient records at the Bishop Lavis Community Health Centre and Bishop Lavis Rehabilitation Centre (Addendum K). The nursing sister of the Caring Network recorded the contact details of the relevant stroke patients, therefore no patient records at the Caring Network agency were accessed. The doctors, nurses and therapists all agreed to participate in the study.
2. Informed written consent was obtained from the primary caregiver of the stroke patient. A signed consent form was used (Addendum A and B).
3. The primary caregiver was assured that all information obtained would remain confidential. The results will be included in a thesis, without disclosure of the caregivers' identity (Addendum A and B).
4. The study was registered with the Research and Ethics Committee from the Faculty of Health Sciences, Stellenbosch University (Ref. No. N04/02/027).
5. The results would be made available to the Bishop Lavis Community Health Centre, Bishop Lavis Rehabilitation Centre and to the caregivers upon request.
6. Participation in the study was voluntary and not forced. The stroke patients' rehabilitation was not affected by the caregivers' decision to

participate or not (Addendum A and B).

7. Participation in the study could be withdrawn at any point without fear of reprisal or the stroke patients' treatment being withheld (Addendum A and B).
8. The stroke patients continued as usual with physiotherapy, occupational therapy and speech and language therapy while the caregivers attended the CSIP sessions.
9. After completion of the five intervention sessions, all the caregivers were invited to attend a weekly support group facilitated by the occupational therapist at the BLRC.



CHAPTER 4

RESULTS

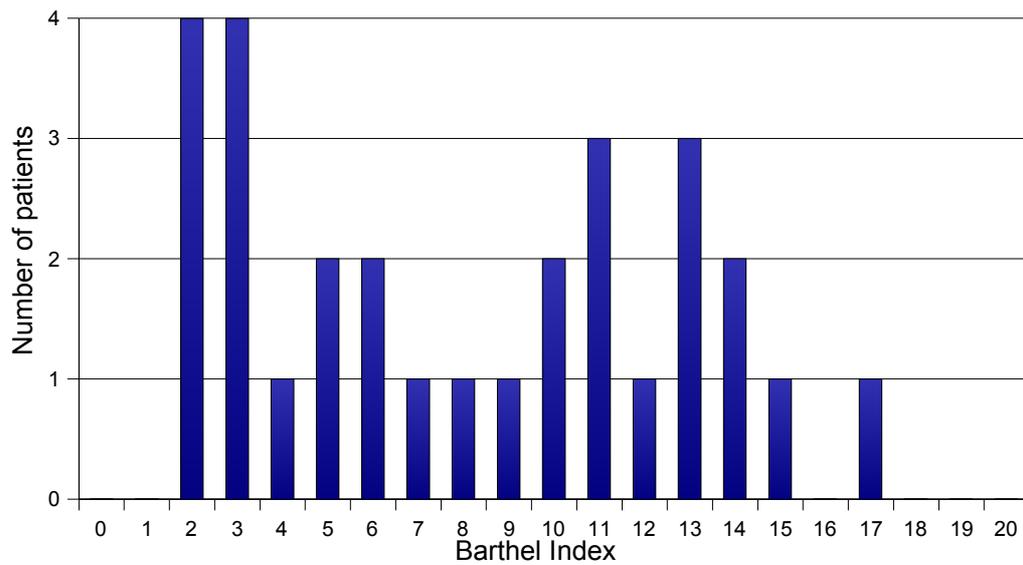
In the following chapter caregiver and patient demographics which may have affected caregiver strain will be presented. Results pertaining to the effectiveness of a caregiver support intervention programme (CSIP) developed to address the expressed needs identified by the primary caregiver and to reduce caregiver strain, will also be presented.

4.1 SAMPLE

Thirty one caregivers qualified to participate in the study, but only 29 caregivers were included (N=29) as two of the selected caregivers did not wish to participate in the study. Although all caregivers included in the sample completed the initial Caregiver Strain Index (CSI), 16 caregivers were not available to complete the follow-up CSI, in spite of having attended and given qualitative feedback after the individual sessions. It will be seen from the following results that caregiver attendance at the CSIP was poor.

4.2 DEMOGRAPHICS

One of the criteria for inclusion of caregivers in the study was the stroke patients' functional dependency level as measured by the Barthel ADL Index. Stroke patients scored an average Barthel Index score of 8, which was calculated from the individual Barthel Index scores (Figure 4.1).



n=29

Figure 4.1: Barthel Index of stroke patients

In order to demonstrate the factors that may influence caregiver strain as reported in the literature (see chapter 2), selected variables relating to both the patient and caregiver will be presented. Therefore, demographic information of both the caregivers and the stroke patients will be included, as either could affect the degree of caregiver strain.

4.2.1 AGE DISTRIBUTION OF CAREGIVERS AND PATIENTS

As seen from Figure 4.2 below, the ages of the stroke patients were higher than those of the stroke caregivers. There is a trend that most of the caregivers were in the younger, working age group.

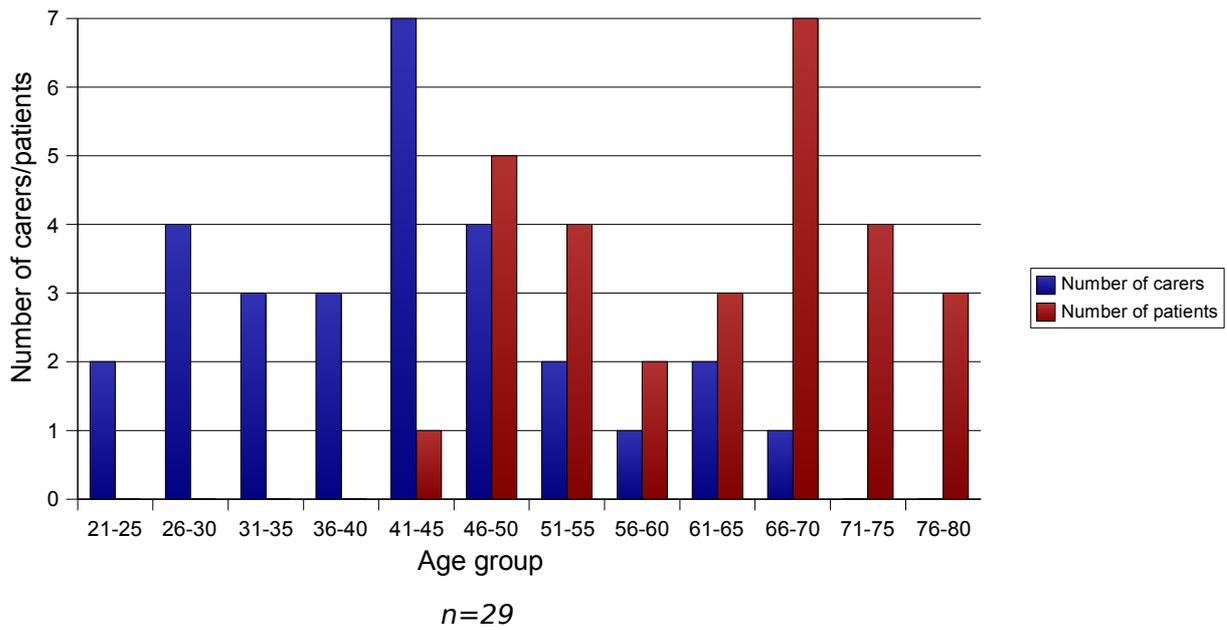


Figure 4.2: Age distribution of caregivers and patients

4.2.2 GENDER OF CAREGIVERS AND PATIENTS

The majority of the caregivers (Figure 4.3) and stroke patients (Figure 4.4) were women.

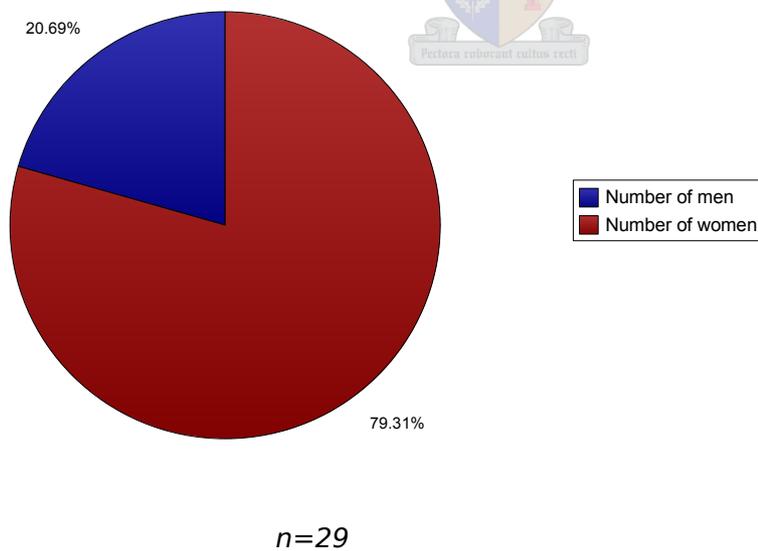


Figure 4.3: Gender of caregivers

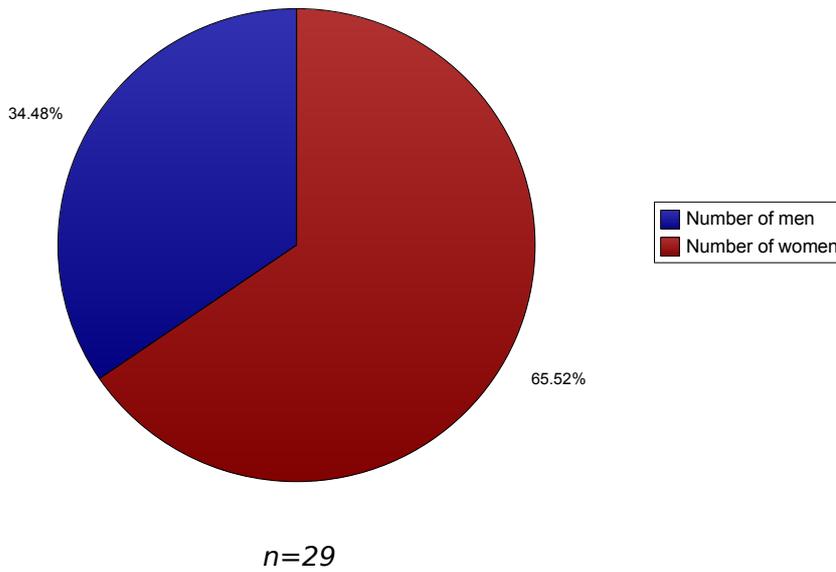


Figure 4.4: Gender of patients

4.2.3 RELATIONSHIP TO THE STROKE PATIENT

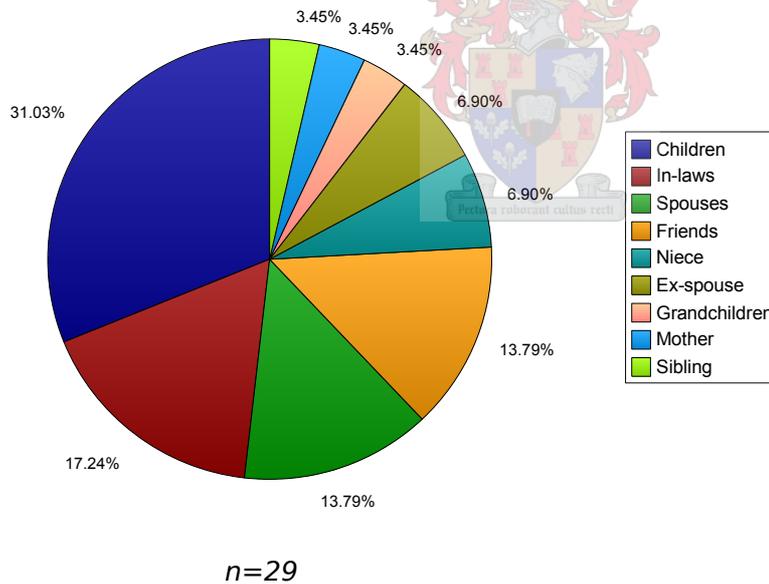
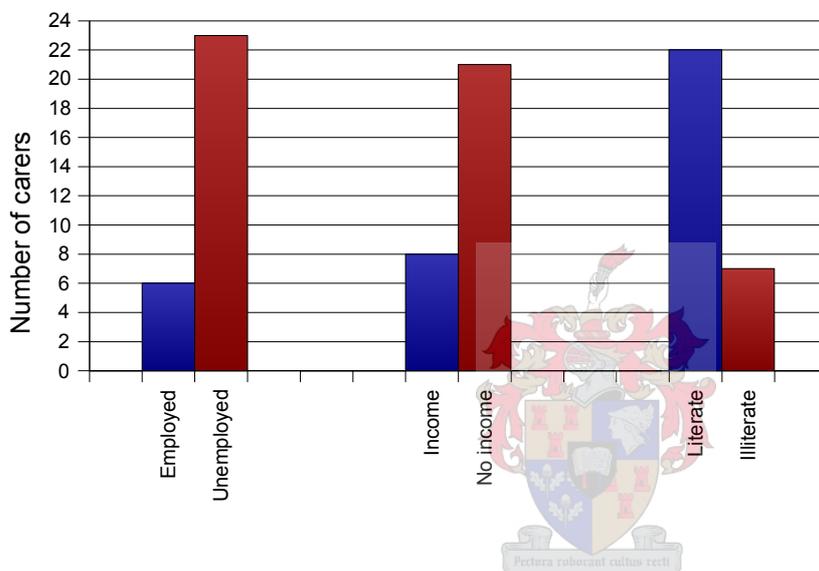


Figure 4.5: Relationship to stroke patient

As seen from Figure 4.5, the majority (31%) of the caregivers were adult children of the stroke patients, while only 13.8% ($n=4$) of the caregivers were spouses.

4.2.4 SOCIO-ECONOMIC STATUS OF THE CAREGIVERS

As seen from Figure 4.6, a large number (79.3%) of the sample population were unemployed, even though only 24.1% (n=7) were illiterate. Although 20.7% (n=6) of the caregivers were receiving an income through employment, an additional 6.9% (n=2) of the caregivers were receiving an income from a carer-dependency grant.



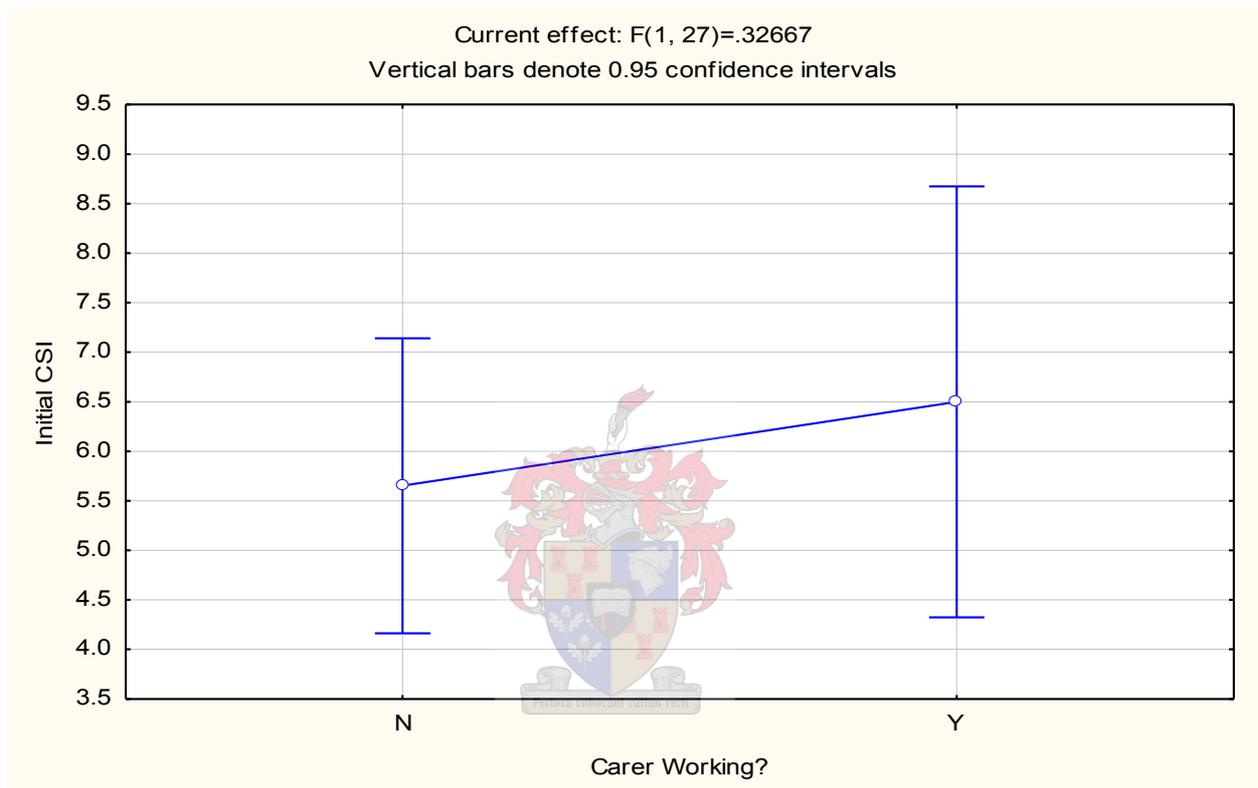
n=29

Figure 4.6: Socio-economic status of caregivers

Socio-economic factors, such as employment status and literacy levels of the caregivers will be compared to the initial CSI scores, in order to determine whether these factors might affect caregiver strain.

4.2.4.1 Comparison between the initial CSI and the employment status of the caregivers

Figure 4.7 below illustrates that caregivers who were employed experienced more strain than those who were unemployed, but this was not statistically significant ($p=0.57$).

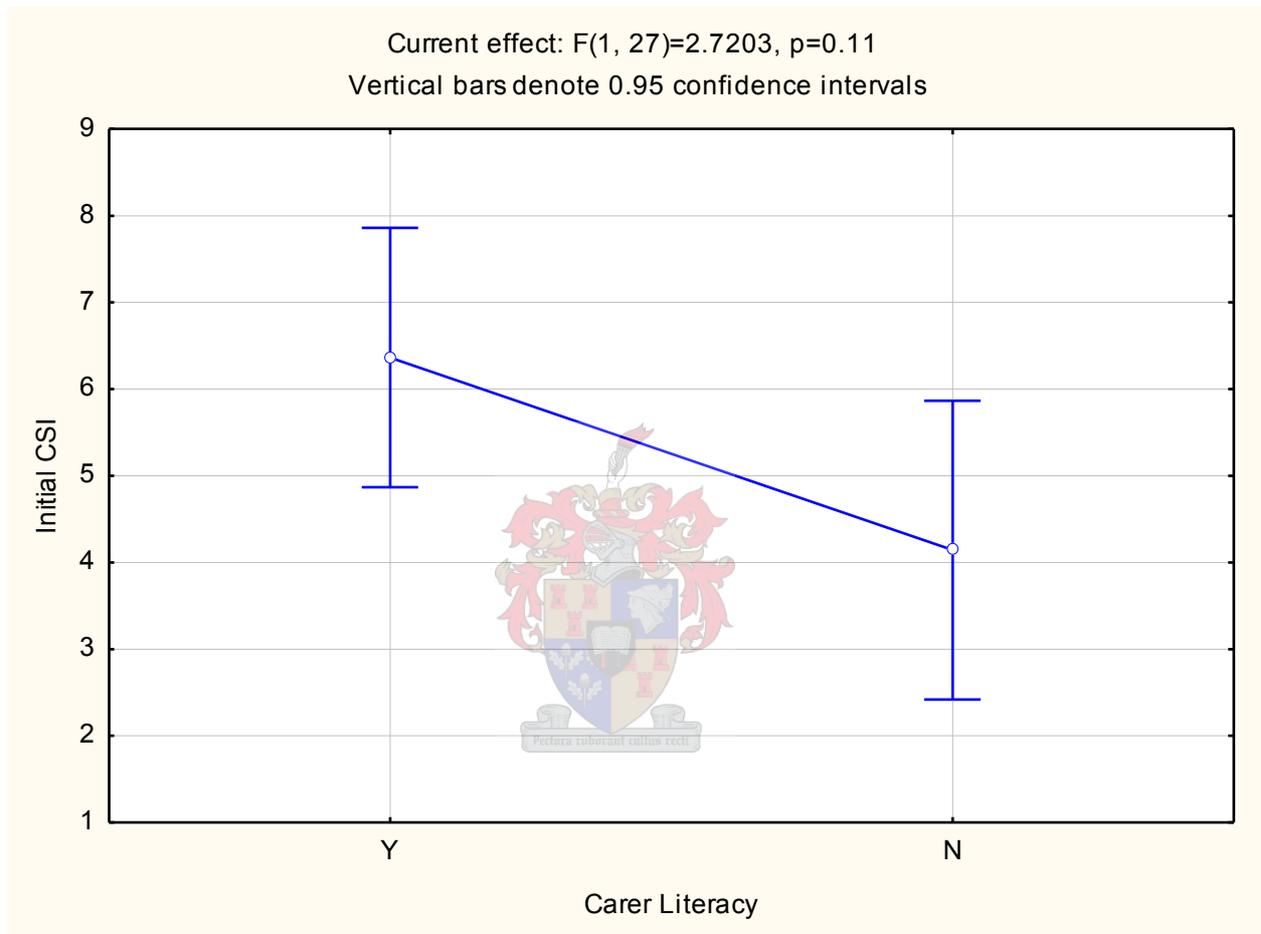


Carer Working	Initial CSI Mean	Initial CSI Std. Err.	N
No	5.65217	0.67473	23
Yes	6.50000	1.32104	6

Figure 4.7: Comparison between the initial CSI and the employment status of caregivers

4.2.4.2 Comparison between the initial CSI and the literacy of the caregivers

Figure 4.8 below illustrates a trend that carers who were literate (able to read and write), experienced more strain than those who were illiterate (unable to read or write), however this was not significant ($p=0.11$).



Carer Literacy	Initial CSI Mean	Initial CSI Std. Err.	N
Yes	6.36363	0.66153	22
No	4.14285	1.17276	7

Figure 4.8: Comparison between the initial CSI and the literacy of caregivers

4.2.5 HEALTH PROFILE AND RISK FACTORS OF STROKE PATIENTS

Figure 4.9 below illustrates that almost half (44.8%) of the patients had sustained multiple strokes over time. It is also reflected that 83% (n=24) of stroke patients had hypertension, 31% (n=9) had diabetes mellitus and 24% (n=7) had cardiac problems. These conditions are all risk factors for recurrence of a stroke. Only one patient reported no additional medical problems.

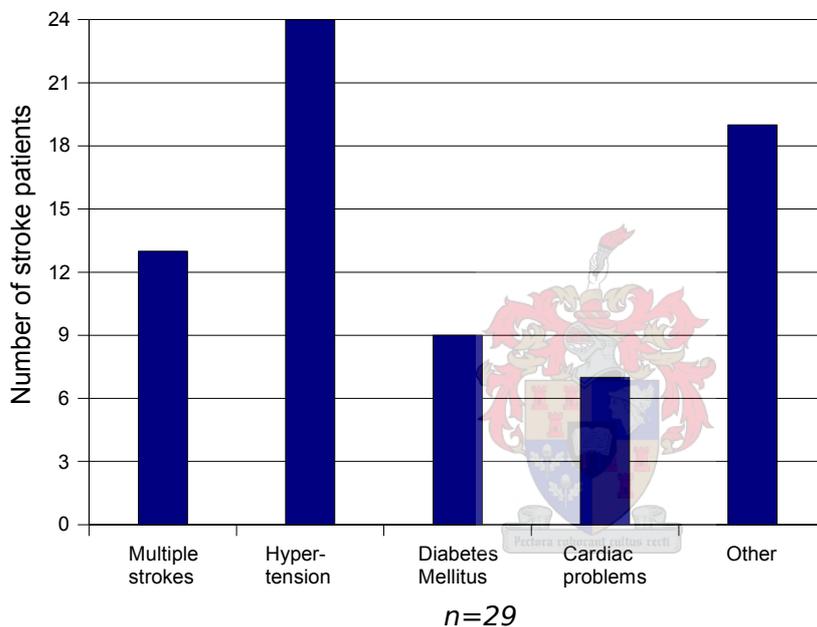


Figure 4.9: Health profile and risk factors of stroke patients

As seen in Figure 4.10, the majority of stroke patients had speech impairments such as dysphasia, dysarthria, etc.

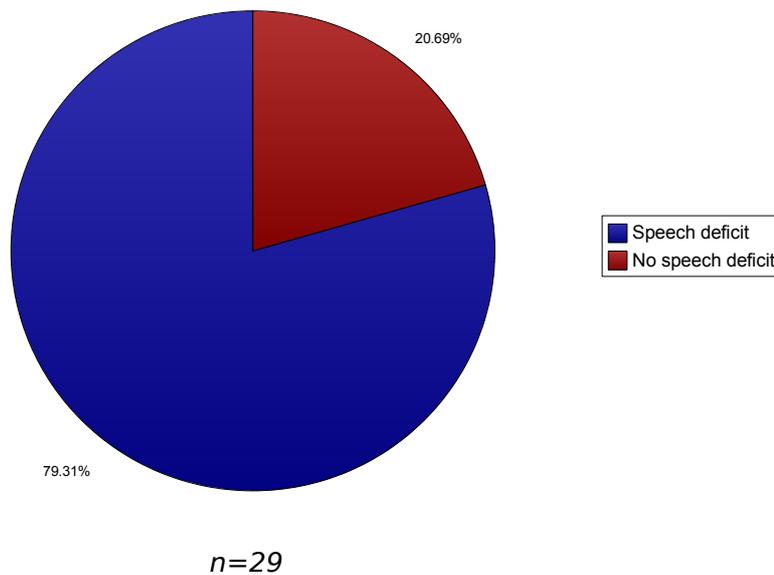


Figure 4.10: Speech impairment of stroke patients

No significant difference was found between the initial CSI scores/caregiver strain and the number of stroke patients who had speech impairments ($p=0.77$).

4.3 ATTENDANCE AT THE CAREGIVER SUPPORT INTERVENTION PROGRAMME (CSIP)

The following results illustrate the low attendance of the caregivers at the three CSIPs, as well as the reported reasons for their poor attendance. Five sessions were implemented at each of the three CSIPs which were held in November 2004, May 2005 and August 2005.

4.3.1 NUMBER OF SESSIONS ATTENDED BY THE CAREGIVERS

As seen from Figure 4.11, 31% (n=9) of carers attended no sessions, while only 10.3% (n=3) attended all five sessions.

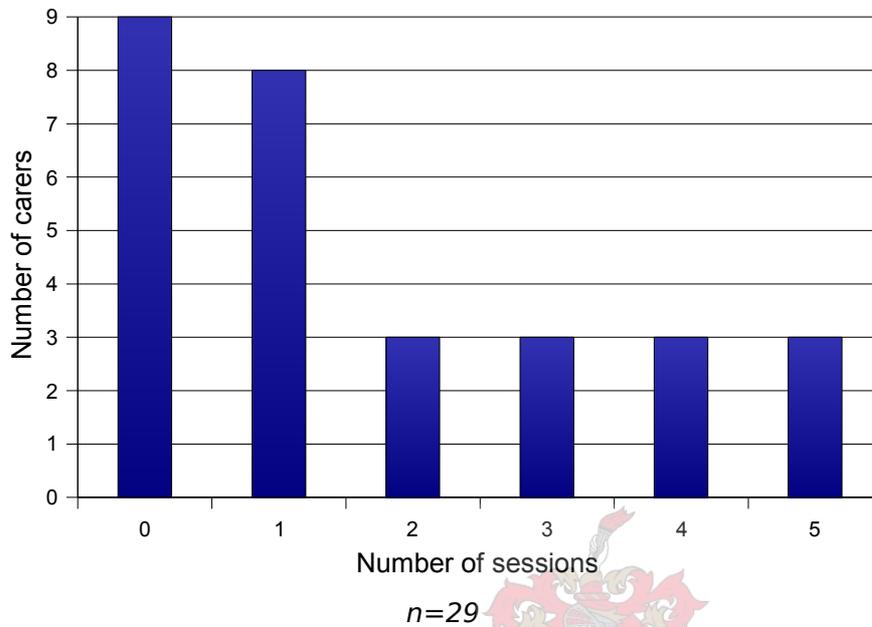


Figure 4.11: Number of sessions attended by caregivers



4.3.2 CORRELATION BETWEEN BARTHEL INDEX AND THE NUMBER OF SESSIONS ATTENDED

Figure 4.12 illustrates that the lower the functional level of the stroke patient, the more sessions the caregivers attended. However this is not statistically significant.

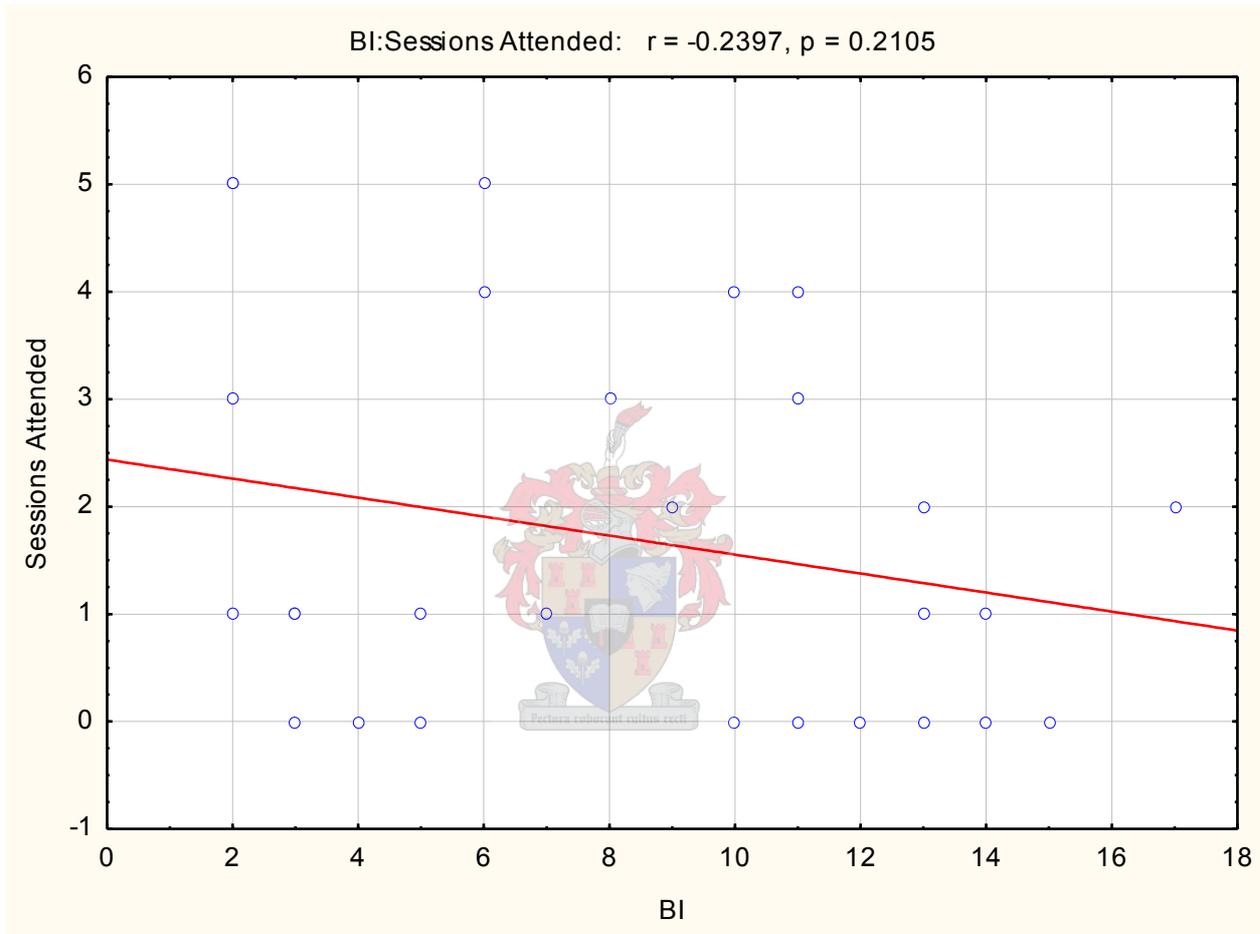


Figure 4.12: Correlation between the Barthel Index score and number of sessions attended by caregivers

4.3.3 ATTENDANCE RATE OF THE FIVE SESSIONS

As seen from Figure 4.13, the first sessions of CSIP 1, 2 and 3 had the best attendance while the fifth / last sessions had the worst attendance.

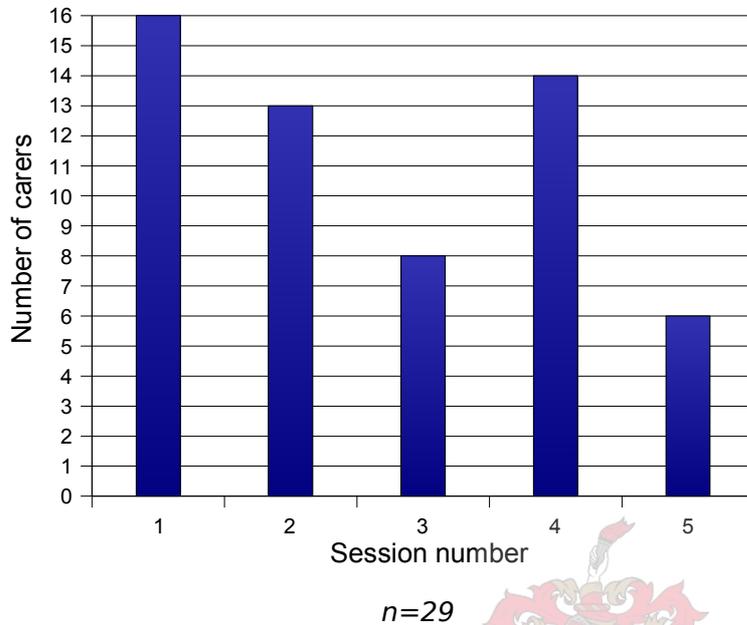


Figure 4.13: Total attendance rate of each session

4.3.4 NON-ATTENDANCE OF THE SESSIONS

Figure 4.14 shows that CSIP 3 had the worst overall attendance of only six carers, as no carers attended session three and five of CSIP 3 possibly because of the cold, wet weather at the time.

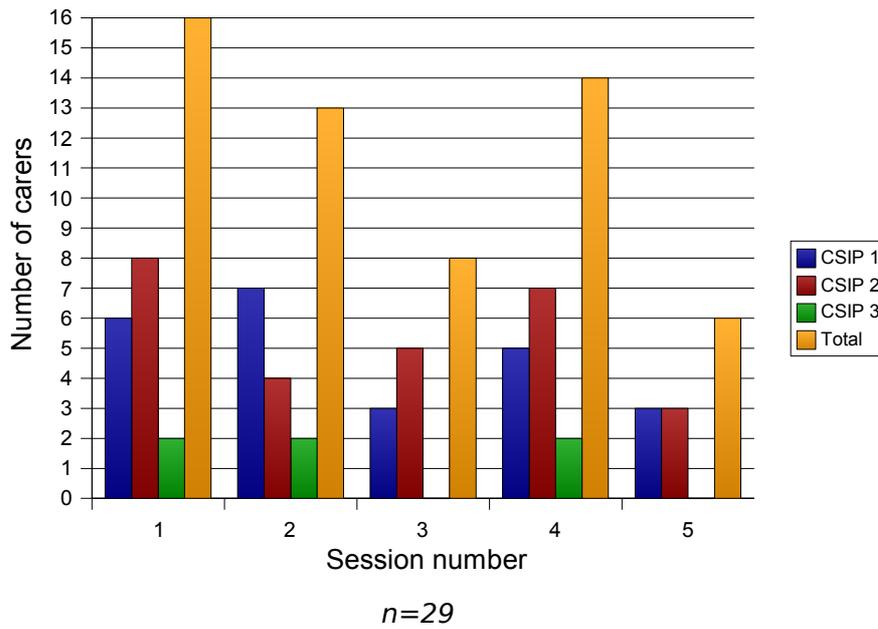
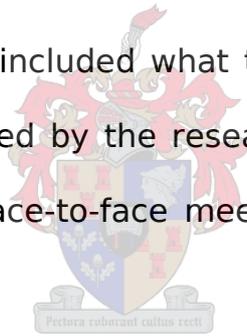


Figure 4.14: Attendance rate of the sessions

Reasons for non-attendance included what the caregivers reported, as well as additional reasons observed by the researcher. This data was recorded by the researcher through face-to-face meetings and telephonic follow-ups after the sessions.



Caregivers reported the following reasons for not attending the sessions:

Table 4.1: Reasons for non-attendance of sessions

Reasons for non-attendance	No of carers
Personal and social responsibilities	
Business or personal appointments	7
Personal stress and family problems	4
No relief from their caring responsibilities	2
Family and household responsibilities	1
Own health problems	1
	15
Change of situation	
Started a full-time job	4
Moved out of the Bishop Lavis area	3
The patient had died	2
Was no longer the primary caregiver	1
	10
Decision to not participate	
Felt that the programme could not be applied at home due to behavioural problems of the patient	2
Changed their mind about participation in the study	2
	4

Additional reasons observed by the researcher for non-attendance of sessions could be ascribed to:

a) Collection of government grants on that day

It was anticipated that if caregivers had to collect the patients' or their own pension/disability grants on the same day as the planned sessions, this could also have affected their attendance. Even though 5 of the 15 CSIP sessions were implemented on paydays for grants, there were found to be no significant difference between the paydays and the number of sessions that the caregivers attended ($p=0.53$).

b) Cold and rainy weather mainly during CSIP 3

A positive correlation was found between the weather conditions and the sessions attended by the carers, indicating that the colder the temperatures, the fewer caregivers attended the sessions (Figure 4.15).

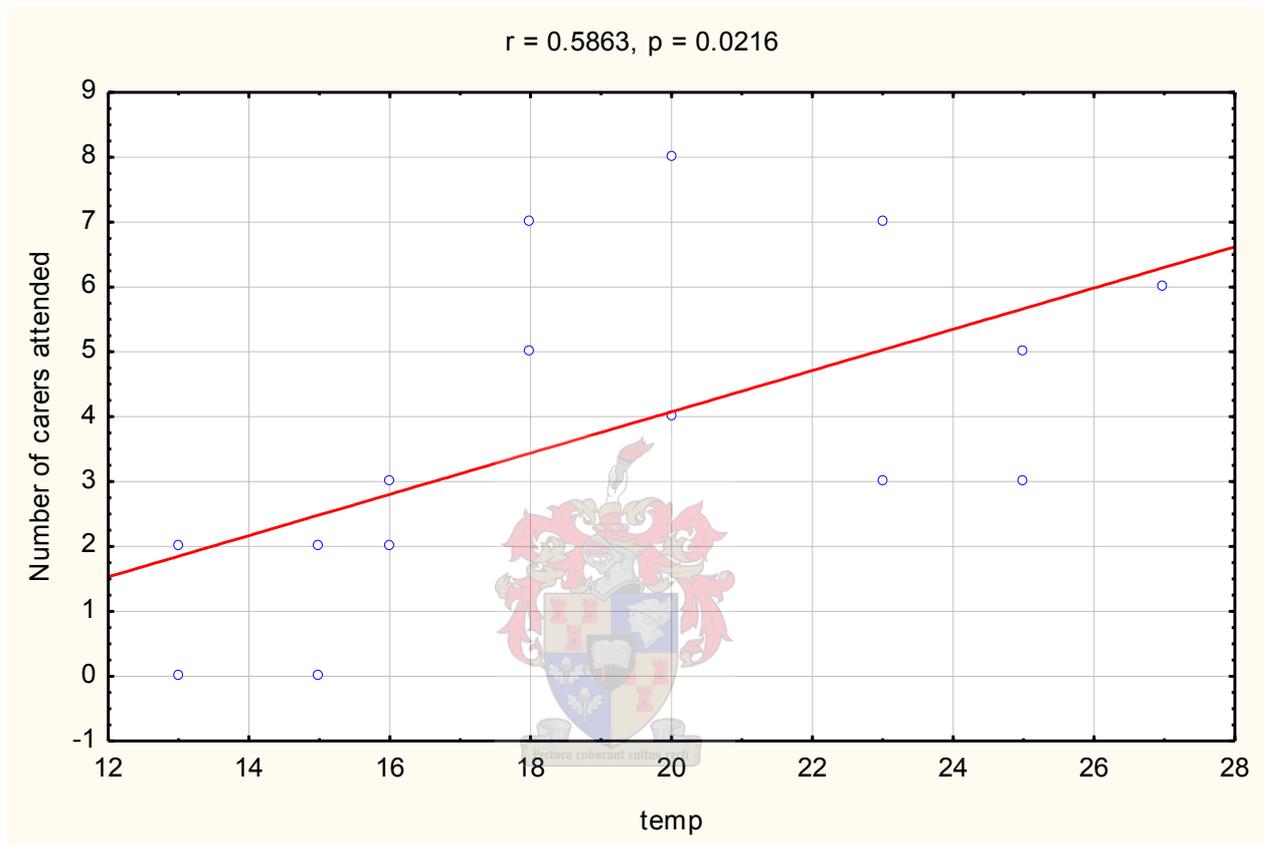


Figure 4.15: Correlation between the weather (temperature) and the sessions attended for CSIP 1, 2 & 3

4.4 IMPACT OF THE CAREGIVER SUPPORT INTERVENTION PROGRAMME (CSIP) ON CAREGIVER STRAIN

In order to determine the effectiveness of the caregiver support intervention programme, the results of the initial and follow-up CSI scores will be presented and compared below.

4.4.1 INITIAL CSI OF THE SAMPLE

All 29 caregivers completed the initial CSI.

As seen from Figure 4.16 below, 65.5% (n=19) of caregivers scored below seven on the initial CSI, which indicates a low level of caregiver strain (Sullivan, 2002).

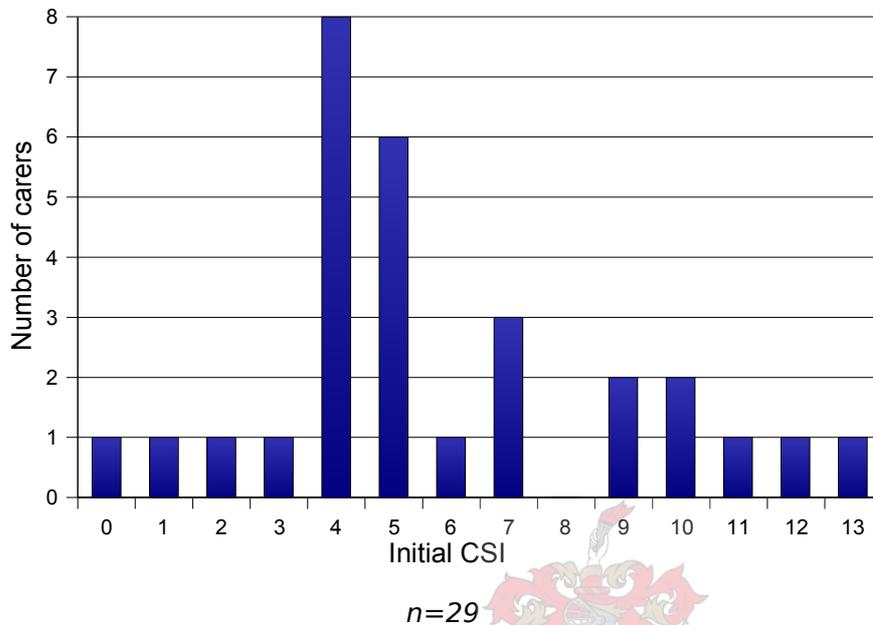


Figure 4.16: Initial CSI of caregivers

4.4.2 REASONS FOR NOT COMPLETING THE FOLLOW-UP CSI

Only 45% (n=13) of caregivers were available for follow-up testing 2-4 weeks after completion of the sessions, due to 16 caregivers being lost to follow-up. The following reasons were reported for unavailability by the caregivers, when attempts were made to contact them for completion of the follow-up CSI.

Table 4.2: Reasons for not completing the follow-up CSI

Reasons for not completing the follow-up CSI	No of carers
Personal and social responsibilities	
Business or personal appointments	1
Personal stress and family problems	2
Family and household responsibilities	3
Own health problems	1
	7
Change of situation	
Started a full-time job	4
Moved out of the Bishop Lavis area	3
Patient had died	1
Was no longer the primary caregiver	1
	9

It will be seen that the reasons given by the carers were similar to the reasons reported for non-attendances of the sessions (see Table 4.1).

From Table 4.1 and Table 4.2 above, the 'change of situation' was likely to have a permanent effect on the caregivers and, therefore, the numbers have been similar in both tables.

4.4.3 COMPARISON BETWEEN THE INITIAL AND FOLLOW-UP CSI SCORES.

Figure 4.17 below illustrates that even in this small sample, there has been on average a 15% reduction in caregiver strain from the initial CSI to the post-CSI scores. However, this was not statistically significant.

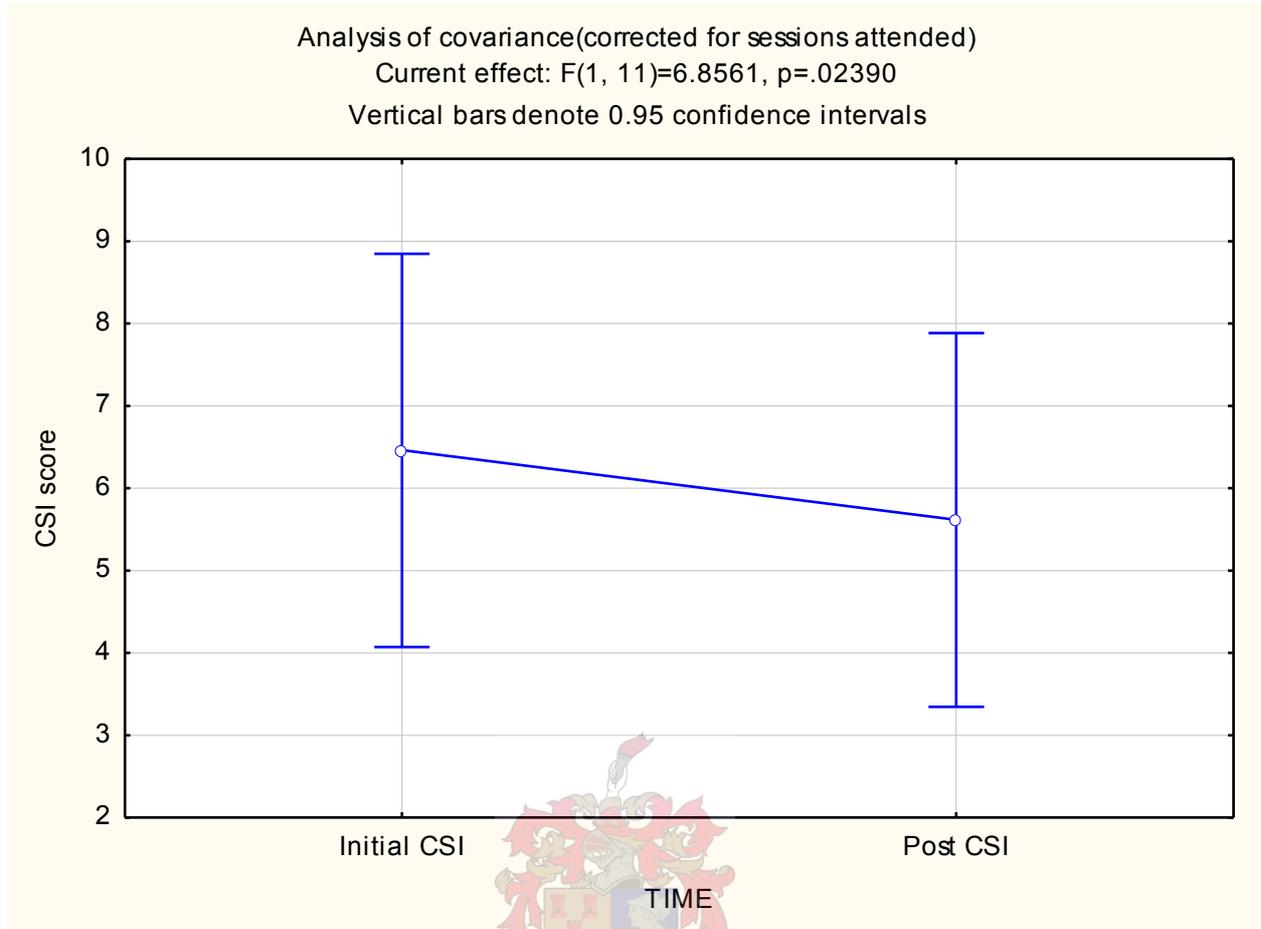


Figure 4.17: Comparison between the average initial and post CSI scores

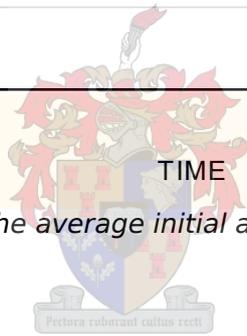


Table 4.3: Comparison between the number of sessions, CSI scores and the Barthel Index of stroke patient

Carer	Barthel Index	Number of sessions attended	Initial CSI	Follow-up CSI	CSI Difference
1	2	5	10	2	+2
2	2	5	3	3	0
3	6	5	4	5	+1
4	10	4	10	9	-1
5	6	4	5	3	-2
6	2	3	7	4	-3
7	11	3	13	12	-1
8	9	2	12	10	-2
9	13	2	5	5	0
10	2	1	4	3	-1
11	5	1	7	4	-3
12	13	1	0	0	0
13	14	1	4	3	-1

As seen from Table 4.3, 61.5% (n=8) of the carers recorded a reduction in their caregiver strain from the initial to the follow-up scores, while 23% (n=3) of the caregivers' level of strain remained unchanged. Two (15.5%) caregivers reported an increase in their caregiver strain.

There was no correlation found between the CSI difference and the Barthel Index scores (p=0.92). There was also no correlation found between the initial CSI and the Barthel Index scores (p=0.48).

4.4.4 CORRELATION BETWEEN THE CSI CHANGE AND THE NUMBER OF SESSIONS ATTENDED.

Figure 4.18 seems to illustrate that the caregivers who attended more sessions experienced an increase in the level of caregiver strain. This correlation was, however, not significant ($r=0.47$; $p=0.11$).

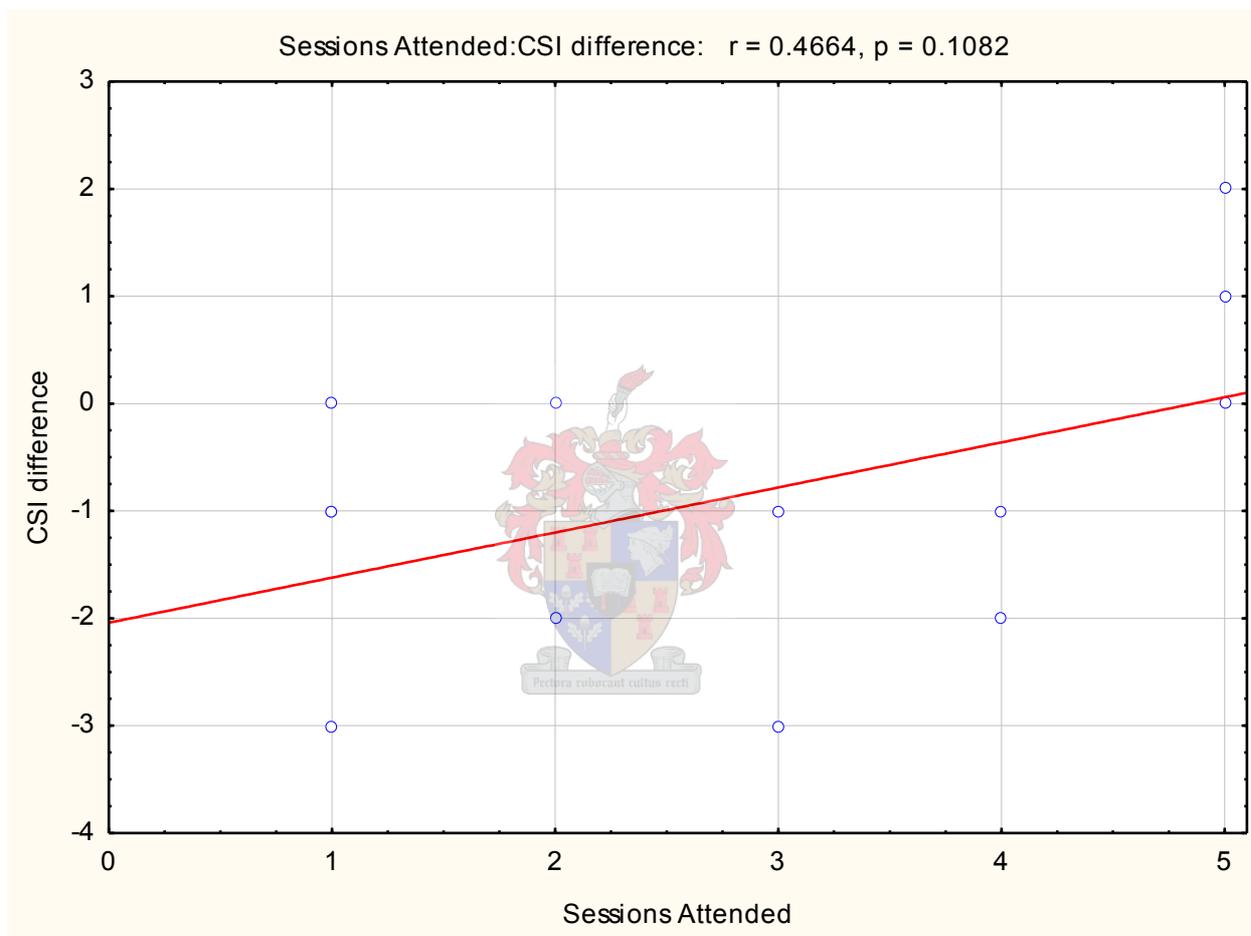


Figure 4.18: Correlation between the CSI change and the number of sessions attended

4.5 EFFECTIVENESS OF THE CAREGIVER SUPPORT INTERVENTION PROGRAMME (CSIP)

The effectiveness of the CSIP was determined using the same categories of physical, emotional, socio-economic and educational needs expressed by the caregivers in the methodology (Chapter 3). Feedback was given by the caregivers through written or verbal comments.

CAREGIVER FEEDBACK

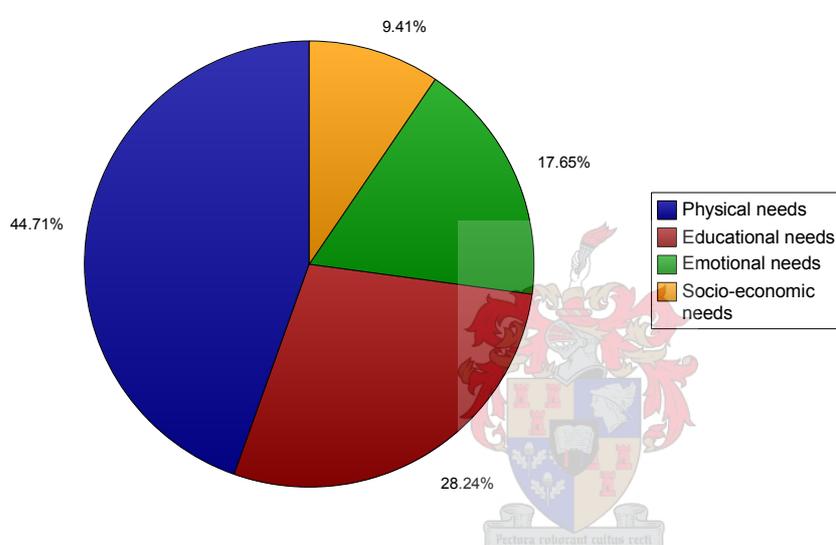


Figure 4.19: Caregiver feedback of expressed needs

It may be seen from Figure 4.19 that the bulk of feedback expressed by the caregivers was in the category of physical needs, while the least feedback was reported in the category of socio-economic needs.

In order to triangulate the effectiveness of the total intervention, 45 feedback forms were completed by the caregivers directly after each session (n=45). Potentially there should have been 145 feedback forms completed (29 carers x 5 sessions), but the low attendances and feedback forms which were taken home by the carers, caused a total of only 45 feedback forms to be available for analysis. The response rate on the feedback forms of those

attending each session was 79% of the total 57 attendances. The results obtained from the feedback forms will be presented below in order to determine whether the expressed needs of the carers have been met. Individual typical, qualitative comments to illustrate the different categories will also be included.

4.5.1 CARER FEEDBACK OF PHYSICAL NEEDS

(38 COMMENTS)

Caregivers expressed the need to learn better handling skills with transfers, exercises and personal care ADL of the stroke patient, as well as the need for additional physical help with the stroke patient. These included the following two areas:

a) Handling of the stroke patient (30 comments)

Caregivers reported that they had learnt better handling skills with transfers, exercises and personal care ADL of the stroke patient. Typical comments included in this category were:

- *'Ek het geleer hoe om die hom te behandel met sy gebreke'.*
- *'Ek het oefeninge geleer om haar sterker te maak'.*
- *'Ek het geleer hoe om my moeder te help met haar spraak en om nie die woorde te gee as sy sukkel nie.'*
- *'Ek het oefeninge geleer vir die tongspiere, wanneer die pasiënt nie kan eet of sluk nie'.*
- *'Ek weet nou hou om hom op die sy te laat rol'.*
- *'Ek het geleer hoe om my ma op die toilet te kry'.*
- *'Ek het geleer hoe om hom op te lig van die bed en op die pot te sit- hoe*

ek eers die gewig moet voel voordat ek iemand optel'.

- *'Ek weet nou hoe om hom met 'n wasplank in en uit die bad te kry'.*
- *'I have learnt practical things on how to help my granny with everyday living like washing and eating'.*
- *'Ek het geleer hoe om my auntie te laat aantrek- begin eers met swak kant en sit die hemp se gaatjie tussen haar bene'.*
- *'Ek weet nou hoe om hom by die tafel te posisioneer as hy eet'.*
- *'Ek het geleer dat die hand wat nie werk nie, moet op die tafel wees sodat dit die bord kan vashou'.*
- *'Ek het geleer van aparate wat gebruik word om pasiënte te help, soos die knoopvasmaker, lepelondersteuner en die nonslip mat'.*

b) Additional help and support (8 comments)

Caregivers reported that they had learnt of the available services in the Bishop Lavis community which could provide additional help for them.

Typical comments given in this category were:

- *'Ek het geleer van die dienste beskikbaar vir die stroke pasiënt soos die home carers'.*
- *'Ek weet nou waar ek nog hulp kan kry'.*

4.5.2 CARER FEEDBACK OF EMOTIONAL NEEDS

(15 COMMENTS)

The emotional needs were related to the caregivers' stress levels and included the need for more family and recreational time, in order to relieve their burden of caring. Caregivers reported that they enjoyed the group interaction as it contributed in reducing their stress levels. Typical

comments reported in this category were:

- *'Ek het nuwe mense ontmoet in die groep'.*
- *'Ek het elkeen se opinies, stories en humor oor die gedrag van die pasiënte geniet'.*
- *'Ek het die emosies geniet wat ons met mekaar gedeel het'.*
- *'Ek was herinner dat ek baie spesiaal is en moet nie van myself vergeet nie'.*
- *'I have learnt how to manage my stress'.*
- *'Ek moet meer ontspan en myself bederf as ek stres het'.*
- *'Ek het die ontspanningsklas geniet'.*

4.5.3 CARER FEEDBACK OF EDUCATIONAL NEEDS

(24 COMMENTS)

The educational needs were related to the theoretical knowledge of the caregivers. Caregivers reported how much they had learnt about stroke, despite the fact that they did not initially recognise it as a need. They also reported that they had learnt about a healthy diet for the stroke patient, as well as the causes, effects and prevention of stress. Typical comments reported in this category included the following:

- *'Ek het meer geleer van stroke en hoe iemand 'n stroke kry'.*
- *'Ek het geleer wat is stroke en die oorsake en voorkoming van stroke'.*
- *'Ek voel nou gelukkiger dat ek meer weet oor die brein'.*
- *'Ek het geleer van die oorsake en voorkoming van hoë bloeddruk'.*
- *'Ek het geleer watter kos te gee as iemand nie goed kan sluk nie en wie hardlywig is'.*
- *'Ek het geleer van verskillende gesonde kossoorte - ek was n bietjie in*

die donker'.

- *'Ek weet nou hoe ek die kos moet voorberei - fyn, sag en klein gesny*'.
- *'Ek het geleer om nie die pasiënt te veel sout of soet te gee nie*'.
- *'Ek het geleer wat is stres, die oorsake en oplossings*'.
- *'Ek weet nou wat stres aan die liggaam doen*'.

4.5.4 CARER FEEDBACK OF SOCIO-ECONOMIC NEEDS

(8 COMMENTS)

The socio-economic needs were related to financial burdens as well as lack of resources available in the community. Carers reported that the CSIP made them more aware of resources and services available in the Bishop Lavis community. Typical comments given in this category were:

- *'Ek het geleer dat ek 'n versorging kan kry vir die pasiënt wat ek omsien*'.
- *'Ek het inligting gekry by die social worker, hoe om aansoek te doen vir 'n versorgertoelaag - ek het nie eens geweet daarvan nie.*'
- *'Ek het so baie geleer van die dienste beskikbaar vir die beroerte pasiënt*'.
- *'Ek weet nou watter hulp is beskikbaar in die gemeenskap*'.
- *'Die social worker het ons geleer wat om te doen en waar ons moet gaan om ons probleme op te los*'.

The above feedback given by the caregivers illustrate that the CSIP was effective in addressing the physical, emotional, educational and socio-economic needs expressed by the primary caregiver of the stroke patient in the Bishop Lavis community. No negative feedback concerning the CSIP was

given by the caregivers. The next chapter will discuss the above results in more detail and compare it to findings in literature.



DISCUSSION

This chapter will present a discussion not only of the effectiveness of the CSIP in addressing the needs of stroke caregivers and in contributing to a reduction in the strain of caregiving, but also of the barriers to the attendance of the CSIP sessions. Comparison to other studies will also be presented in this chapter. This chapter will start with a brief discussion of the demographic representation of the caregivers and stroke patients with reference to those aspects which may have influenced caregiver strain and attendance of the sessions.

The main purpose of this study was to determine the effectiveness of a caregiver support intervention programme (CSIP) that was developed to address the expressed needs identified by the primary caregiver of the dependent stroke patient in the Bishop Lavis community.

The results of this study suggest that the CSIP was effective in addressing the needs of the primary caregivers in this sample, as well as in reducing the strain they experienced. However, an additional finding of this study related to the barriers identified which limited the caregivers' attendance of the sessions. This was a potentially important finding within the low socio-economic community of Bishop Lavis, which differs from the majority of studies done in first world countries. De Villiers et al (1999) described the Bishop Lavis community as being a poor, low socio-economic, predominantly Afrikaans speaking community on the Cape Flats, with high unemployment

figures and low literacy levels.

5.1 DEMOGRAPHIC REPRESENTATION OF CAREGIVERS AND STROKE PATIENTS

It has been reported that the demographics of both the caregivers and patients may influence the strain experienced by stroke caregivers (Han and Haley, 1999; Bugge et al, 1999). Thus the impact of the following caregiver and patient demographics on caregiver strain will be discussed.

5.1.1 AGES AND HEALTH PROFILES OF THE CAREGIVERS AND PATIENTS

The average age of the caregivers in the current study was 45 years, which differed from caregivers in other studies (King and Semik, 2006; Anderson et al, 1995; Morimoto et al, 2001; Grant et al, 2004), where the average ages of caregivers in Australia, Japan and the USA were between 55-60 years. This younger age may be due to caregivers in the current study being predominantly adult children and not spouses of the stroke patients, as seen in studies done in first world countries. As most of the caregivers were in the younger, working age group, they possibly had busy schedules involving their work and families, and therefore may have been less available and motivated to participate in the intervention programme.

When caregivers are middle-aged or elderly, they may have pre-existing illnesses and functional limitations, which could restrict their ability to manage the physical aspects of caring (Anderson et al, 1995). It has also been found that the caregivers' physical health significantly affects the level of caregiver strain experienced (Bugge et al, 1999; Bresick and Harvey,

1997). In addition, caregivers in poor health were also more likely to be depressed (Han and Haley, 1999). Caregivers in the current study, while younger than those in other studies, were approaching middle-age, and may have had their own medical problems which could have limited them in the physical aspects of caring. However, these medical problems were not mentioned in the study.

Almost half of the stroke patients had sustained multiple strokes over time and the majority of them also had pre-existing medical conditions including hypertension, diabetes, cardiac problems and arthritis that may have contributed to their low functional levels. These existing illnesses of the stroke patients may also have made them more difficult to manage physically, thereby increasing caregiver strain. The majority of stroke patients were also approaching old age (average age of 62 years) and may have experienced the common 'aches and pains' of the ageing process, which subsequently may have further increased caregiver strain. This differed to caregivers in other studies where the average ages of stroke patients in Scotland, Japan and the Netherlands were 70 years (Bugge et al, 1999; Anderson et al, 1995; Morimoto et al, 2001; Grant et al, 2004). Stroke patients in the study by Bugge et al (1999) also had a similar pre-morbid medical history to the current study, which included previous strokes, hypertension and heart disease.

The majority of stroke patients in the current study had some degree of speech impairment which could not be specified by the caregivers because of their low educational background and lack of knowledge. Evans et al

(1994) stated that the presence of dysphasia in the stroke patient may increase family communication problems. It was, therefore, anticipated that caregivers who cared for patients with speech impairments could experience more strain due to the communication problems of the patient. However, results from this study show that there was no significant difference between caregiver strain and speech impairments of the stroke patient. It was also emphasised by Han and Haley (1999) that there is insufficient research that examined the effects of communication deficits of stroke patients on caregiving outcomes.

5.1.2 BARTHEL INDEX (BI) OF THE STROKE PATIENT

It has been suggested that the stroke patients' level of functional independence determines the level of caregiver burden (Scholte op Reimer et al, 1998; Bresick and Harvey, 1997). One of the criteria for inclusion of caregivers in the study was that the stroke patients' functional dependency level as measured by the BI, was 18 or below. However, the BI only measures the physical ability of the patient to perform self-care activities of daily living, and not cognitive or speech impairments (Addendum D). The majority of stroke patients from the current study had a low BI score, which could suggest that these patients would be difficult to manage due to their reduced functional level. However, studies in Australia and Japan have found that the physical disability of the stroke patient as measured by the Barthel Index, was not related to caregiver burden (Anderson et al, 1995; Morimoto et al, 2001). This finding was similar to that of the current study which showed that there was no correlation between the CSI and the BI scores,

suggesting that the functional level of the stroke patient did not affect the level of caregiver strain.

5.1.3 EMPLOYMENT STATUS OF CAREGIVERS

South African caregivers who are unemployed and lack the financial resources to meet the basic needs of the family, are more susceptible to social and financial strain (Bresick and Harvey, 1997). The Bishop Lavis community is a low income population group with a high unemployment rate and a large dependency on state grants and state health services (De Villiers et al, 1999). The 2001 National Census reflect a 28% unemployment rate within this community (Statistics, SA). It was also reflected in the semi-structured interviews that financial problems were a real concern to Bishop Lavis caregivers mainly for the provision of their daily needs, whereas in first world countries like France, caregivers experienced financial problems mainly because of the additional expenses of healthcare after stroke (Bethoux et al, 1996). The results from the current study illustrate that even though the majority of the caregivers were unemployed, they experienced less strain as measured by the CSI than those who were employed. This could be ascribed to the significant demand placed on the employed caregiver to earn a living, as well as provide optimal care for the stroke patient, while the unemployed caregiver may have had more time to spend caring for the stroke patient. Considering the high unemployment rate in this community, employed caregivers may have also feared losing their job if they took off too much time from work to care for the stroke patient. This may have further contributed to their level of strain.

5.1.4 RELATIONSHIP OF THE CAREGIVER TO THE PATIENT

Spouses were found to be the most common caregivers of stroke patients (King and Semik, 2006; Van den Heuvel et al, 2002; Morimoto et al, 2001; Bugge et al, 1999) and were also more likely to be depressed than any other caregiver during the acute stroke care phase (Han and Haley, 1999). Spousal caregivers also tend to experience more anxiety than the children or siblings of the stroke patient (Martin et al, 1998; Evans et al, 1994). However, it was found that caregivers in this study were mainly adult children (daughters) of the stroke patients, which differed from the above studies which were done in first world countries, including USA, Scotland, Japan and Holland, where the majority of carers were found to be spouses (King and Semik, 2006; Van den Heuvel et al, 2002; Morimoto et al, 2001; Bugge et al, 1999). The impact of strain on the caregivers depends on how much added responsibility needs to be assumed, the carers willingness to assume those roles and the availability of external support from family and friends (McPherson et al, 2000a). Despite the fact that most of the caregivers in the current study had the added responsibility of providing care for both the stroke patient as well as their own families, they still had the willingness to assume the role as caregiver, as they most likely felt it was their responsibility. A possible reason suggested by Mba (2005) was that the majority of non-white South Africans are compelled to live in extended households because of resource constraints and lack of affordability for separate housing from the apartheid¹ era. A typical qualitative quote from the semi-structured interviews was: *'Ek voel dit is my verantwoordelikheid*

¹ Apartheid: A policy of racial segregation in South Africa. (Oxford Dictionary)

om my ma te versorg'. The high level of poverty in non-white South African households contributes to institutional care usually being unaffordable (Mba, 2005) and, therefore, families are likely to take responsibility for the role as caregiver of the stroke patient.

The caregivers in the current study were mainly female, which is also consistent with other studies done in first world countries (Bugge et al, 1999; Scholte op Reimer et al, 1998; Morimoto et al, 2001; Van den Heuvel et al, 2002). Due to their role as mothers, the responsibility of caregiving normally falls onto women, who are likely to accept the caregiving role more readily than men, for whom the caregiving demands are often unfamiliar (Bresick and Harvey, 1997; Emmett, 2005).

The above-mentioned demographics represented factors which may have influenced caregiver strain. However, these factors are fixed and could, therefore, not be directly influenced by the CSIP sessions. The expressed needs of the caregivers which could have influenced caregiver strain were consequently determined by the semi-structured interviews, in order to plan and implement an intervention that addressed these needs and reduced caregiver strain.

5.2 EFFECT OF THE CAREGIVER SUPPORT INTERVENTION PROGRAMME ON THE NEEDS OF THE CAREGIVERS

After the CSIP, caregivers gave the most positive feedback relating to their physical needs. This could have been attributed to the inclusion of a large practical component in the CSIP which mainly addressed the caregivers' physical needs. However, the least amount of positive feedback was

reported relating to their socio-economic needs. The CSIP sessions informed the caregivers of the available resources in the Bishop Lavis community, as well as how to access these services. However, more time would be needed to follow-up whether these caregivers did actually access the available resources. In addition, positive feedback was given by the caregivers relating to their educational needs, although they did not initially perceive this as a need. The effect of the CSIP on the physical, socio-economic and educational needs will further be discussed in this section, while the effect on the caregivers' emotional needs which was related to caregiver strain, will both be discussed in chapter 5.3.

5.2.1 EFFECT OF THE CSIP ON CAREGIVERS' PHYSICAL NEEDS

The two main categories regarding physical aspects that were addressed in the CSIP were the caregivers' need to learn better handling skills, as well as for additional physical help with the stroke patient.

5.2.1.1 Handling of the stroke patient

According to the feedback given by the caregivers in the current study, their physical needs were met (see 4.5.1), as they had learnt effective transfer skills and stroke exercises during the practical, supervised sessions of the CSIP. A typical comment was: *'Ek het geleer hoe om hom op die toilet te kry'*. An intervention programme which included teaching Dutch caregivers effective lifting techniques for the stroke patient, was effective in improving the caregivers' knowledge about stroke care even though their physical and mental well-being and strain remained the same (Van den Heuvel et al, 2002). This finding differed from the results of the current study as

caregiver strain levels decreased after the CSIP, and in addition according to their feedback, caregivers perceived that their knowledge of stroke had improved.

Caregivers in the current study who reported a need for the stroke patient to be more functionally independent in their activities of daily living (ADL), indicated that these needs had also been met. Their feedback revealed that the CSIP contributed to improving their skills on how to facilitate the patient with personal care activities like washing, dressing, eating and bathing. A typical comment was: *'Ek het geleer hoe om my ma te help was en aantrek'*. In a study by Kalra et al (2004), caregiver training in basic nursing, lifting and handling, mobility and transfers, as well as personal care ADL reduced caregiver burden and improved their quality of life. The content of the caregiver sessions was similar to that of the current study, but a larger cohort of 300 British caregivers formed the sample for this study (Kalra et al, 2004).

5.2.1.2 Additional help and support

Caregivers in the current study reported a need for additional help from their families, friends or therapists, particularly with toileting and bath transfers of the patient. Their feedback revealed that they had learnt about the available resources in the community, such as home-based care which could assist them in caring for the stroke patient. A typical comment that confirmed this was: *'Ek het geleer van die dienste beskikbaar vir die stroke pasiënt, soos die homecarers'*. The Caring Network, which is the home-based care agency within Bishop Lavis, trains volunteers within the community to provide basic

nursing care for patients with a variety of debilitating conditions, in order to restore, maintain and improve the patients' function. Home-based care usually provides extended nursing care to patients that are discharged early from hospital (Department of Health, 2001a). According to the Western Cape's Healthcare Plan for 2010, R60 million will be allocated to home-based care in the Western Cape, in order to improve the quality and efficiency of this service (Department of Health, 2003). The researcher had observed while working in this community, that many Bishop Lavis families were unaware of the available home-based care service. This was further confirmed, when caregivers had to be prompted about this service in the interviews (Addendum C). In comparison, a British study by McLean et al (1991) reported that British caregivers were aware of home-based care, but some were not regularly using it as they were dissatisfied with the service. A possible reason for this could have been that caregivers in first world countries may have had larger expectations or demands from home-based care, in comparison to many South African caregivers who may not have been aware of this service.

5.2.2 EFFECT OF THE CSIP ON CAREGIVERS' EDUCATIONAL NEEDS

It was evident from the interviews that caregivers lacked sufficient theoretical knowledge regarding the warning signs, causes, risk factors and prevention of a stroke (see 4.5.3). After the CSIP sessions, many caregivers reported how much they had learnt about stroke, although they did not initially recognise it as a need. A typical comment that confirmed this was: *'Ek het geleer wat is stroke en die oorsake en voorkoming van stroke'*. In the

current study, caregivers were unaware of their lack of theoretical knowledge about stroke which may have been due to the comparatively high illiteracy rate found among the caregivers in Bishop Lavis. This in turn could result in the caregivers being unable to access even basic literature on stroke. The higher illiteracy rate (24.1%) found in this study is contrary to the findings of a survey done by De Villiers et al (1999), where only 12.5% of the population of Bishop Lavis were unable to read or write. This difference could be ascribed to the small representation of the sample size of the current study or due to a rising level of illiteracy in Bishop Lavis since 1999.

Another reason for the caregiver's lack of knowledge may have been that health professionals often do not take the time to explain to the family what happened to the stroke patient.

5.2.3 EFFECT OF CSIP ON CAREGIVERS' SOCIO-ECONOMIC NEEDS

Bresick and Harvey (1997) stated that many South African families already lack the financial resources to meet their basic needs such as food and shelter, with further financial strain experienced by the cost of rehabilitation (such as transport expenses and the purchase of assisted devices).

The socio-economic needs of the caregivers were related to their financial burden, as well as to the need for better resources such as a transport service, wheelchair supply service and more incontinence supplies for the stroke patients. Caregivers reported that the CSIP made them more aware of resources and services available in the Bishop Lavis community, such as the social worker who is able to assist in the application of a carer-

dependency grant. This corresponds with the results of studies in the Netherlands and UK that also included in their caregiver programmes, information on resources which were available for the stroke patient and caregiver such as benefit entitlement, support programmes and community services (Van den Heuvel et al, 2002; Lincoln et al, 2003; Rodgers et al, 1999). The above authors found that there was an improvement in the caregivers' knowledge of the available resources. Similarly, caregivers in the current study commented in their feedback that they learnt of the available resources in the Bishop Lavis community. A typical comment was: *'Ek weet nou watter hulp is beskikbaar in die gemeenskap'*. First world countries, such as the UK, appear to have a more structured system of available resources for both the stroke patient and caregiver, in comparison to third world countries such as South Africa that clearly has limited community resources and support, due to financial limitations (Bresick and Harvey, 1997). However, it was not within the scope of this study to determine whether the caregivers actually made use of this new knowledge, as well as of the available resources.

5.3 EFFECT OF THE CAREGIVER SUPPORT INTERVENTION PROGRAMME ON CAREGIVER STRAIN AND CAREGIVERS' EMOTIONAL NEEDS

The emotional needs of the stroke caregiver were mainly related to the caregivers' strain levels and, therefore, included the need for more family time, as well as recreational time in order to relieve their burden of caring. Although the caregivers did not report very high levels of strain, their feedback revealed that they enjoyed the group interaction of the CSIP, as it contributed to reducing their stress levels. In the USA, Evans et al (1988)

evaluated the effects of two interventions which consisted of education and counselling for stroke caregivers. The education intervention consisted of two hours of instruction about the basic stroke care principles, while the counselling intervention included the two hours of education as well as seven problem-solving sessions with a social worker, for the development of coping strategies. Both interventions improved caregiver knowledge about stroke, but the counselling helped in the emotional adjustment of the patients (Evans et al, 1988).

The Caregiver Strain Index (CSI) measures potential physical, emotional, social and financial strain related to caregiving. This index places a larger emphasis on the socio-emotional strain experienced by caregivers, with fewer points allocated to measuring physical strain (Addendum E). Positive responses to 7 or more items on the CSI indicates considerable strain of the caregiver and a resultant need for a more comprehensive assessment of the caregiving process in order to facilitate appropriate intervention (Sullivan, 2002). In the current study, the majority of caregivers scored below seven on the initial CSI, which is indicative of a low level of caregiver strain experienced within the first six months of the patient sustaining a stroke (Sullivan, 2002). This could have been because these caregivers did not experience a high level of socio-emotional strain, since they easily adapted to their role as caregiver. However, caregivers reported in the interviews that they were experiencing physical strain with caregiving. This was the anticipated result, as the majority of patients had low functional levels which may have made them more difficult to manage physically. According to the

findings by Bugge et al (1999), Scottish caregivers also scored a low (4.5) CSI score even though they reported that they were under considerable strain at six months after the patient sustained a stroke. Unfortunately, these authors did not discuss possible reasons for the above finding (Bugge et al, 1999).

The appropriateness of the CSI could be questioned as to whether it is a valid scale for this community that is low on the socio-economic scale, as it has mainly been used in affluent, first world countries such as the UK and Netherlands. Bishop Lavis caregivers may have had difficulty reflecting on the CSI questions, as the strain of caregiving is an accepted part of their culture and therefore they may not have perceived it as a problem (Emmett, 2005). South African caregivers living within a poor socio-economic community tend to be trapped in a 'cycle of poverty', and, therefore, easily adapt to difficult circumstances like poverty and overcrowding (Roller, 2000). The 'cycle of poverty' is a social phenomenon whereby poverty-stricken individuals exhibit a tendency to remain poor throughout their lifespan because they do not have the financial resources to get out of poverty, as a result of their lack of education and social inequality (Wikipedia, 2006).

Despite the CSI scores being low, results of the study showed that the majority of caregivers had a reduction in caregiver strain as measured by the initial and follow-up CSI scores, which indicated that the CSIP sessions had indeed reduced their level of caregiver strain.

The researcher observed that in a non-white community such as Bishop

Lavis, there exists a culture whereby the caregivers willingly accept the responsibility for the care of the stroke patient because they feel it is their duty, particularly observed when the caregiver is the daughter of the stroke patient. This observation is consistent with the findings of Mba (2005), where it is most commonly observed in the non-white South African culture that, because of the deprivation entrenched through apartheid, people are more reliant on members of their families and household for their survival and well-being (Mba, 2005). Therefore it can be expected from the family and friends that the adult children take over the caring responsibilities as an expression of gratitude for all that the parent has done for them over the years. When asked in the interviews (Addendum C) how they felt about caring for the stroke patient, a typical comment was: *'Dis geen probleem nie, omdat ek voel dit is my verantwoordlikheid vir al wat my ma in die verlede vir my gedoen het'*. As caregivers felt indebted to the stroke patient, they appeared not to see the caregiving role as a burden. Another comment was: *'I am used to the responsibility of caring for others. I owe it to her and, therefore, I enjoy it as there is nothing else to do'*. The researcher also observed, while working in this community, that caregivers easily adapted to the role of caregiver, as many of them had the added responsibility of looking after their own children, as well as other family members, who lived in the same 'crowded' household. Due to the high unemployment levels in Bishop Lavis, caregivers may have learnt to find fulfilment and enjoyment in the caregiving role, as many of them may not have had the opportunity to do anything else besides caring.

Family caregivers of Chinese brain-injured patients were found to be creative in developing their own coping strategies for caring demands, which were suited around the functioning of the family (Man, 2002). These coping strategies included acceptance, rationalisation and delegating activities within their households (Man, 2002). South African caregivers in a low socio-economic community tend to become accustomed to living in poverty and overcrowding, therefore, they adapt quickly and learn how to cope in challenging situations (Roller, 2000). This was similar to the findings in Man's study which also reflected a relatively poor community in Hong Kong (Man, 2002). While working in the Bishop Lavis community, the researcher had also observed that stroke caregivers did not have high expectations regarding healthcare, and thus easily accepted their current situation. The above observations could possibly also explain the Bishop Lavis caregivers' low strain levels as indicated in the CSI. In South Africa 'coloured' people live a precarious existence caught between the two extremes of black and white due to the apartheid era, and are still trapped in the poverty cycle, with the majority of them still living in poverty (Roller, 2000).

Furthermore, Bresick and Harvey (1997) from South Africa state that the emotional strain of caregiving is often greater than the physical strain, particularly when the patients' cognition, behaviour and speech are also impaired. Other studies have also shown that emotional and psychological changes – such as behavioural changes or mood disturbances of the stroke patient – are the greatest sources of caregiver burden (Anderson et al, 1995; Morimoto et al, 2001). However, this differed to the current study where

caregivers did not experience a high level of caregiver strain, according to the CSI, despite the emotional and psychological disturbances of the stroke patient. This may have been because the caregiver easily accepted the responsibility of caring for the stroke patient and, therefore, did not see it as a burden.

The findings of the current study illustrate that caregivers who attended more CSIP sessions, also experienced increased levels of caregiver strain. This is contrary to what one would expect, but a possible explanation for this could be that the caregivers were experiencing more strain because of the additional time they had to set aside in order to attend the sessions. Van den Heuvel et al (2002) also reported that caregivers had difficulty finding the time to participate in an intervention planned for them. Another reason that caregivers in the current study experienced increased levels of strain, may have been because they became more aware of their responsibilities and shortcomings the more sessions they had attended.

5.4 ATTENDANCE RATE AND BARRIERS TO THE ATTENDANCE OF THE CAREGIVER SUPPORT INTERVENTION PROGRAMME

The results of the current study showed that the first sessions of CSIP 1, 2 and 3 had the highest rate of attendance, while the fifth and final sessions had the lowest attendance rate. This could possibly be because of the caregivers' lack of time and commitment to the programme as it advanced through the five sessions. Van den Heuvel et al (2002) also reported that caregivers had difficulty finding the time to participate in an intervention planned for them. Another possibility may have been that they lost interest towards the end of the intervention programme. The final session included

stress management and relaxation therapy.

In addition, the results from the current study suggest that the lower the functional level of the stroke patient (lower Barthel score), the more sessions the caregivers attended. This was the anticipated result, because it could be expected that the lower functioning the stroke patients were, the more assistance the caregivers would need and subsequently they would attend more sessions in the hope that they would gain more information and practical experience in the management of stroke. This was comparable to the results of the study by Kalra et al (2004), where British caregivers of low functioning stroke patients were motivated to attend the intervention sessions planned for them. This was possibly because of the practical support provided by the intervention programme. Evans et al (1994) found that families who were mainly in need of emotional support were less likely to participate in a support programme. It was also pointed out by Bugge et al (1999) that the available support services for carers were not used frequently, and that no particular service reduced caregiver strain.

In the current study, the attendance of the caregivers during the three CSIPs was disappointingly low, as only a few carers attended all five sessions while several carers attended no sessions. The main barriers that the majority of caregivers reported as reasons for non-attendance of the CSIP were either personal or logistical barriers. Personal barriers were those that brought about changes in the caregivers' circumstances, such as business and personal appointments, family and household responsibilities, personal and social problems, work commitments, lack of relief or support, the caregivers'

own health problems, as well as lack of interest in the CSIP. Logistical barriers were considered to be the environmental and external obstacles that negatively influenced their attendance, such as bad weather. These two categories of barriers will be discussed below.

5.4.1 PERSONAL BARRIERS

Evans et al (1994) stated in their review article on the impact of stroke on families, that families who were most in need of supported care were unlikely to participate in support programmes. The reasons which these families cited for non-attendance were most commonly practical problems, such as not being able to find relief from their caring responsibilities or having no transportation (Evans et al, 1994). Similarly in the current study, caregivers reported that they were unable to find relief from their caring responsibilities ascribed to a lack of support from family or friends. This expressed need for relief and support by others was likely because the majority of stroke patients had low functional levels, and therefore required assistance from their caregiver for most of the day.

Anderson et al (1995) reported that one of the main reasons for disruption of the caregivers' social life was fear and anxiety that the patient would die or become more disabled if left unattended at home. Similarly, in a much later study by Grant et al (2004), caregivers also expressed fear in physically harming the stroke patient. Therefore, caregivers in the current study may have also experienced fear in leaving the patient unattended at home. This could well have contributed to their poor attendance.

In a study by Van den Heuvel et al (2002) in the Netherlands, caregivers stated that it was difficult to find the time to participate in an intervention planned for them. Therefore these authors reported a tendency of high drop-out rates in small carer intervention groups because of the busy schedules of the carers. The following reasons for non-attendance given by caregivers in the current study also illustrate that they had limited time, based on their busy schedules:

- Business or personal appointments. Typical comments were: '*Ek was uit op besigheid,*' and '*Ek het 'n doktersafspraak gehad*'.
- Family and household responsibilities. Typical comments were: '*Ek moes na my siek baba gekyk het*' and '*Ek was besig met die huiswerk*'.
- Personal and social problems. A typical comment was: '*Daar was familie probleme wat ek moes uitsorteer*'.

In a British study by Rodgers et al (1999), stroke caregivers reported that the main reasons for non-attendance of a stroke education programme was their own poor health, work commitments or lack of interest. These reasons were similar to the current study where the caregivers' health problems, even though not officially recorded in the current study, may have influenced their lack of attendance. A typical comment was: '*Ek was siek en het sleg gevoel*'.

Caregivers also reported that they were unavailable to attend the sessions because they started full-time employment. Considering that unemployment and poverty are prevalent in the Bishop Lavis community (De Villiers et al, 1999), it could be expected that carers would accept a new job opportunity so that they could provide better financial support for their families.

Another personal reason that this sample had in common with the findings of Rodgers et al (1999) was a lack of interest reported by the caregivers. Two caregivers made the decision not to participate, because they felt that the practical components of the programme could not be applied at home due to the cognitive-behavioural problems of the stroke patient. These caregivers, therefore, felt that the sessions would be a waste of time for them, as the stroke patient was difficult and non-compliant. Secondly, a further two caregivers changed their mind about participation in the study possibly because they may have lost interest in the sessions.

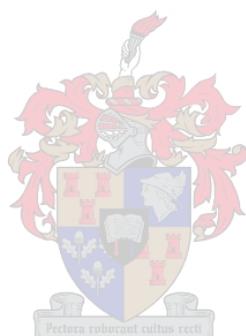
5.4.2 LOGISTICAL BARRIERS

In contrast with Evans et al (1994), caregivers in the current study did not report having any transportation problems to the CSIP sessions. This was because the CSIP was offered at the Bishop Lavis Rehabilitation Centre which was within walking distance of most of the caregivers' homes, in order to reduce travelling barriers. Consideration of lack of transport as a possible barrier to attendance is, therefore, not valid.

In addition, the researcher observed that cold and rainy weather prevailed mainly during CSIP 3, which may have contributed to the low attendance. The third CSIP was held during the winter month of August when the weather was wet and maximum day temperatures ranged between 13-16°C. This CSIP had a high drop-out rate with a total attendance of only six carers, with no caregivers attending session three or five. It may be considered a possibility that the cold, rainy weather at the time made it very difficult for them to attend, as the majority of the caregivers travelled on foot to the

sessions.

The results of the current study indicate that the CSIP was effective in addressing the expressed needs of the primary caregiver of the stroke patient. In addition, the CSIP also reduced caregiver strain, despite the low attendance by the caregivers. The implications of these findings will be discussed in the next chapter. Recommendations for future studies will also be made.



CONCLUSIONS AND RECOMMENDATIONS

The main purpose of this study was to determine the effectiveness of a caregiver support intervention programme (CSIP) that was developed to address the expressed needs identified by the primary caregiver of the dependent stroke patient in the Bishop Lavis community.

6.1 CONCLUSIONS

The results of this study indicate that the CSIP was effective in addressing the physical, emotional, educational and socio-economic needs of the primary caregiver of the dependant stroke patient in this community. In addition, the results also verified that the CSIP was effective in reducing caregiver strain in the majority of the caregivers, despite a small sample size. However, an additional and important finding of this study was the identification of barriers that limited the caregivers' attendance of the sessions.

6.2 LIMITATIONS

A limitation of this study was that only a small sample of 29 caregivers was used, with this sample size reduced even further by the low attendance rate of the caregivers. The results of this study could, therefore, not be generalised to similar populations of stroke caregivers. Since the study was conducted in Bishop Lavis, which is regarded as an area where poverty, low levels of literacy and unemployment exist (De Villiers et al, 1999), also contributes to the fact that these results cannot be generalised, but they

may well prove to be useful to other similar population groups.

Another limitation of this study was that follow-up semi-structured interviews could have been conducted after the CSIP, in order to provide more qualitative feedback on the effectiveness of the CSIP in addressing the caregivers' needs, especially over a longer time-frame. Time constraints led to qualitative feedback from the caregivers being given solely through the feedback forms, which were completed after each session.

The use of the Barthel Index was another limitation of this study, as this instrument purely measures the physical and functional abilities of the stroke patient, but not the cognitive and psychological problems, which may well have contributed to caregiver strain. On this basis, a number of very strained caregivers may have been excluded from the study.

Another limitation of the study was that the caregivers' medical problems were not recorded in the study. Considering that the majority of these caregivers were approaching middle-age, their medical problems may have limited them in the physical aspects of caring, as well as influenced their attendance to the CSIP sessions.

Caregivers reported that their perceived knowledge of stroke care had improved after the CSIP, even though many did not initially express the need to acquire more knowledge about stroke. A limitation of this study was that the caregivers' knowledge of stroke could have been evaluated before and after implementation of the CSIP, in order to objectively measure how much their knowledge of stroke had improved.

6.3 RECOMMENDATIONS

A larger sample size is recommended for future studies in order to accommodate for the high drop-out rates in such a population. The research of a larger sample was also recommended by Van den Heuvel et al (2002) who reported that only a few studies have evaluated the long-term effects of support programmes, due to the small number of caregivers included in these intervention studies, as well as the high drop-out rates.

While caregivers were informed of the resources available in the Bishop Lavis community for stroke patients such as home-based care, it was not within the scope of this study to determine whether the caregivers actually utilised the available resources. It is, therefore, recommended that follow-up appointments are arranged with the caregivers to determine whether they have utilised the available resources, as well as to identify whether they found these services beneficial. Considering that the Western Cape's Healthcare Plan 2010 (Department of Health, 2003) aims to improve the quality and efficiency of home-based care within communities, a suggestion would also be to evaluate the utilisation and effectiveness of home-based care for stroke patients and their families within Bishop Lavis, especially since these caregivers were unaware of this service, as confirmed by the interviews. Bugge et al (1999) reported in their study that available stroke support services in Scotland were not frequently utilised by caregivers, as these services may have been regarded as unsatisfactory by the caregivers. Lack of knowledge and availability of resources, lack of transport, as well as financial difficulties were reported as barriers to resource use (King and

Semik, 2006).

In the current study, the majority of caregivers scored a total of below seven on the initial Caregiver Strain Index, which is indicative of a low level of caregiver strain (Sullivan, 2002). However, in the interviews caregivers reported that they were experiencing physical strain with caregiving. Considering that the CSI is a 13-question tool (with 1 point score per item), that measures potential physical and emotional strain related to caregiving, the individual items on the CSI could also have been further analysed and addressed, as in the study by Bugge et al (1999). The researcher observed from the current study that the total CSI score may not have been a true reflection of the actual level of caregiver strain experienced, as a larger emphasis was placed on the socio-emotional strain, with fewer points allocated to measuring physical strain. Therefore, the most commonly expressed individual items that increased caregiver strain, could in future be identified, analysed and addressed. Another recommendation was for the CSI to be followed up a few months after completion of the intervention programme, in order to determine the long-term effects and carry-over of the CSIP.

The appropriateness of the CSI could also be questioned as to whether it is a valid scale for this low socio-economic community, as it has mainly been used in affluent, first world countries such as the UK and Netherlands. Caregivers in Bishop Lavis may have had difficulty reflecting on the CSI questions as the strain of caregiving is an accepted part of their culture. Therefore, a more appropriate outcome measure could be developed,

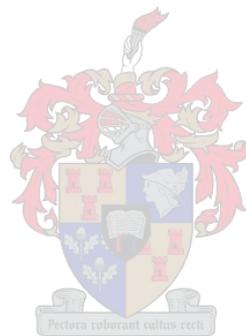
validated and utilised to evaluate caregiver strain within a low socio-economic community. The researcher could not find a more appropriate tool in the literature. The rest of the chosen methodology such as the semi-structured interviews and feedback forms, were appropriate for this community and should be considered in similar research undertaken in low socio-economic communities.

Considering that the third CSIP had a low attendance rate, possibly because of bad weather, it is recommended that future caregiver interventions not be implemented in the winter months, especially in poor socio-economic communities where caregivers are likely to travel on foot to the sessions.

The CSIP would be an appropriate and cost-effective intervention for caregivers in similar communities as the presenters, who were selected for their specific skill and experience in their various disciplines, were paid minimal wages to facilitate the sessions. However, further investigation should be done to determine ways to improve the attendance rate of carers in poor socio-economic communities.

Stroke caregiving is considered a stressful experience, with the additional challenges of high unemployment, poverty and overcrowding in poor socio-economic communities making it even more difficult. Therefore, the barriers discussed in Chapter 5.4, which affect the caregivers' attendance, would need to be taken into consideration when conducting future research that targets poor socio-economic communities. In order to minimise one of the barriers, a possible suggestion for future studies would be for the stroke

patients to attend a group at the same time that the caregivers have their group session. This would alleviate the need for caregivers to arrange relief from their caregiving responsibilities in order to attend the sessions.



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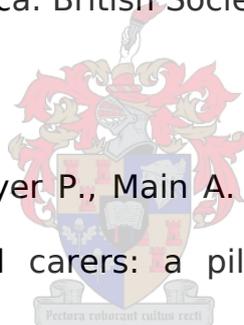
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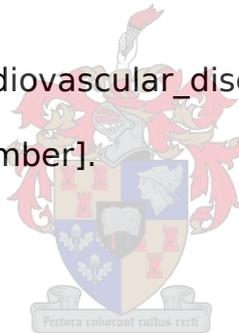
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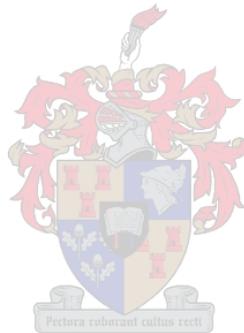
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ADDENDUM A

**PARTICIPANT INFORMATION AND CONSENT FORM
FOR CSIP 1**

English and Afrikaans



PARTICIPANT INFORMATION AND INFORMED CONSENT FORM

TITLE OF THE RESEARCH PROJECT

To determine the effectiveness of a caregiver support intervention programme developed to address the expressed needs identified by the primary caregiver of the stroke patient within the Bishop Lavis community.

REFERENCE NUMBER: N04/02/027

PRINCIPAL RESEARCHER: Mrs Lynn Kleineibst
Address: Bishop Lavis Rehabilitation Centre
Lavis Drive
Bishop Lavis

A. DECLARATION BY THE PARTICIPANT:

I, THE UNDERSIGNED,.....(participant), confirm that:

1. I have been invited to participate in the above-mentioned research project which is being undertaken by the Department of Physiotherapy, Stellenbosch University.

2.1. It has been explained to me that the aims of the study are to:

- Identify the expressed needs of the primary caregiver
- Develop a support intervention programme which addresses the expressed needs
- Implement a support intervention programme
- Evaluate the effectiveness of the support intervention programme.

2.2. I have agreed to participate in a:

- 1- hour interview at the Bishop Lavis Rehabilitation Centre
- Support intervention programme of 5 sessions at the Bishop Lavis Rehabilitation Centre.

2.3. I am aware that about 30 other caregivers will also be involved in this project.

2.4. It has been explained to me that a tape recorder will be used during the interviews for reference purposes.

2.5. It has been explained to me that all the information gathered will be handled confidentially. The results will be used in a thesis and / or publication in a professional journal, without disclosing the identity of the person.

2.6. I will have access to the findings of this study, upon request.

2.7. It has been explained to me that participation is voluntary and refusal or discontinuation will not in any way prejudice mine or the patients' present or future treatment at the Bishop Lavis Rehabilitation Centre.

3. The information above was explained to me by **Mrs Lynn Kleineibst** in English. I was given the opportunity to ask questions and all these questions were answered satisfactorily.

4. No pressure was exerted on me to consent to participation and I understand that I may withdraw voluntarily at any stage without any penalisation.

5. Participation in this study will not result in any additional costs to myself and I am aware that I will not benefit from this study financially.

B. I HEREBY CONSENT VOLUNTARILY TO PARTICIPATE IN THE ABOVE-MENTIONED STUDY.

Signed at.....on.....20.....
(place) (date)

.....
Signature of participant

.....
Signature of witness

STATEMENT BY THE RESEARCHER

I, **Lynn Kleineibst**, declare that:

I have explained the information given in this document to(participant)

He / she was encouraged and given ample time to ask me any questions.

This conversation was held in English and no translator was used.

Signed at on20.....
(place) (date)

.....
Signature of researcher
(Lynn Kleineibst)

.....
Signature of witness



IMPORTANT INFORMATION TO PARTICIPANTS

Dear participant

Thank you for your participation in this study. Should any problems arise as a result of the study, or if you require any further information with regards to the study, please contact me at the following telephone numbers:

021 9346315 (w)
082 8726441 (c)
Mrs Lynn Kleineibst

DEELNEMERS INLIGTINGS- EN TOESTEMMINGSVORM

TITEL VAN DIE NAVORSINGS PROJEK:

Die effektiwiteit van ondersteuningsintervensie wat die behoeftes van die primêre versorger van die beroerte pasiënt in die Bishop Lavis gemeenskap aan spreek, te bepaal.

VERWYSINGSNOMMER: N04/02/027

HOOF NAVORSER: Mev Lynn Kleineibst
Adres: Bishop Lavis Rehabilitasie Sentrum
Lavisweg
Bishop Lavis

A. VERKLARING DEUR DIE DEELNEMER

Ek, die ondergetekende.....(deelnemer) bevestig dat:

1. Ek is uitgenooi om deel te neem aan die bogenoemde navorsingsprojek, wat deur die Departement Fisioterapie, Universiteit Stellenbosch onderneem word.
- 2.1. Daar aan my verduidelik is dat die doel van die studie is om:
 - Die behoeftes van die primêre versorger te bepaal
 - Ondersteuningsintervensie te ontwikkel om hierdie behoeftes aan te spreek
 - Die ondersteuningsintervensie te implementeer
 - Die effektiwiteit daarvan te evalueer.
- 2.2. Ek het ingestem om deel te neem aan :
 - Uur lange onderhoud by die Bishop Lavis Rehabilitasie Sentrum
 - Ondersteuningsintervensie program van 5 sessies by die Bishop Lavis Rehabilitasie Sentrum
- 2.3. Ek bewus is dat ongeveer 30 ander versorgers ook deel sal neem aan hierdie projek.
- 2.4. Daar aan my verduidelik is dat bandopnemer sal gebruik word gedurig die onderhoude vir verwyssingsdoeleindes.
- 2.5. Daar aan my verduidelik is dat alle inligting vertroulik hanteer sal word. Resultate sal gebruik word vir tesis, en / of publikasie in vaktydskrifte, sonder om die identiteit van die persoon te openbaar.
- 2.6. Ek sal toegang hê tot alle bevindinge van die studie.
- 2.7. Daar aan my verduidelik is dat deelname vrywillig is en dat ek mag weier om deel te neem of enige tyd deelname mag staak. Sodanige weiering of staking nie op enige manier my of die pasiënt se huidige / toekomstige behandeling by die Bishop Lavis Rehabilitasie Sentrum sal benadeel nie.
3. Die inligting hierbo is deur **Mev Lynn Kleineibst** in Afrikaans aan my verduidelik en ek is die taal goed magtig. Ek is n geleentheid gebied om vrae te vra en al die vrae is bevredigend beantwoord.
4. Daar is geen dwang op my geplaas om toestemming te gee en ek verstaan dat ek deelname te enige tyd mag staak / weier sonder enige penalisasie.

5. Deelname aan hierdie projek sal geen addisionele koste vir my inhou nie en dat ek ook nie finansieel daarby sal baat vind nie.

B. EK STEM HIERMEE VRYWILLIG IN OM DEEL TE NEEM AAN DIE BOGEMELDE PROJEEK.

Geteken te op20.....
(plek) (datum)

.....
Handtekening van deelnemer

.....
Handtekening van getuie

VERKLARING DEUR NAVORSER

Ek, **Lynn Kleineibst**, verklaar dat ek:

Die inligting vervat in hierdie dokument aan.....(deelnemer) verduidelik het.

Hy / sy aangemoedig het en genoeg tyd gegee om enige vrae aan my te stel.

Hierdie gesprek in Afrikaans plaasgevind het en geen tolk gebruik is nie.

Geteken te.....op.....20.....
(plek) (datum)

.....
Handtekening van navorser
(Lynn Kleineibst)

.....
Handtekening van getuie

BELANGRIKE INLIGTING AAN DEELNEMER

Geagte deelnemer

Baie dankie vir u deelname aan hierdie studie. Indien daar te enige tyd tydens die duur van die projek n probleem ontstaan wat spruit uit die studie, of u verdere inligting aangaande die projek verlang moet u asseblief vir my kontak by:

021 9346315 (w)
082 8726441 (c)
Mev Lynn Kleineibst

ADDENDUM B

**PARTICIPANT INFORMATION AND CONSENT FORM
FOR CSIP 2 AND 3**

English and Afrikaans

PARTICIPANT INFORMATION AND INFORMED CONSENT FORM

TITLE OF THE RESEARCH PROJECT

To determine the effectiveness of a caregiver support intervention programme developed to address the expressed needs identified by the primary caregiver of the stroke patient within the Bishop Lavis community.

REFERENCE NUMBER: N04/02/027

PRINCIPAL RESEARCHER: Mrs Lynn Kleineibst
Address: Bishop Lavis Rehabilitation Centre
Lavis Drive
Bishop Lavis

A. DECLARATION BY THE PARTICIPANT:

I, THE UNDERSIGNED,.....(participant), confirm that:

1. I have been invited to participate in the above-mentioned research project which is being undertaken by the Department of Physiotherapy, Stellenbosch University.

2.1. It has been explained to me that the aims of the study are to:

- Identify the expressed needs of the primary caregiver
- Develop a support intervention programme which addresses the expressed needs
- Implement a support intervention programme
- Evaluate the effectiveness of the support intervention programme.

2.2. I have agreed to participate in a support intervention programme of 5 sessions at the Bishop Lavis Rehabilitation Centre.

2.3. I am aware that about 30 other caregivers will also be involved in this project.

2.4. It has been explained to me that all the information gathered will be handled confidentially. The results will be used in a thesis and / or publication in a professional journal, without disclosing the identity of the person.

2.5. I will have access to the findings of this study, upon request.

2.6. It has been explained to me that participation is voluntary and refusal or discontinuation will not in any way prejudice mine or the patients' present or future treatment at the Bishop Lavis Rehabilitation Centre.

3. The information above was explained to me by **Mrs Lynn Kleineibst** in English. I was given the opportunity to ask questions and all these questions were answered satisfactorily.

4. No pressure was exerted on me to consent to participation and I understand that I may withdraw voluntarily at any stage without any penalisation.

5. Participation in this study will not result in any additional costs to myself and I am aware that I will not benefit from this study financially.

B. I HEREBY CONSENT VOLUNTARILY TO PARTICIPATE IN THE ABOVE-MENTIONED STUDY.

Signed at.....on.....20.....
(place) (date)

.....
Signature of participant

.....
Signature of witness

STATEMENT BY THE RESEARCHER

I, **Lynn Kleineibst**, declare that:

I have explained the information given in this document to(participant)

He / she was encouraged and given ample time to ask me any questions.

This conversation was held in English and no translator was used.

Signed at on20.....
(place) (date)

.....
Signature of researcher
(Lynn Kleineibst)

.....
Signature of witness

IMPORTANT INFORMATION TO PARTICIPANTS

Dear participant

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Mrs Lynn Kleineibst

DEELNEMERS INLIGTINGS- EN TOESTEMMINGSVORM

TITEL VAN DIE NAVORSINGS PROJEK:

Die effektiwiteit van ondersteuningsintervensie wat die behoeftes van die primêre versorger van die beroerte pasiënt in die Bishop Lavis gemeenskap aan spreek, te bepaal.

VERWYSINGSNOMMER: N04/02/027

HOOF NAVORSER: Mev Lynn Kleineibst
Adres: Bishop Lavis Rehabilitasie Sentrum
Lavisweg
Bishop Lavis

A. VERKLARING DEUR DIE DEELNEMER

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- 2.1. Daar aan my verduidelik is dat die doel van die studie is om:
 - Die behoeftes van die primêre versorger te bepaal
 - Ondersteuningsintervensie te ontwikkel om hierdie behoeftes aan te spreek
 - Die ondersteuningsintervensie te implementeer
 - Die effektiwiteit daarvan te evalueer.
- 2.2. Ek het ingestem om deel te neem aan ondersteuningsintervensie program van 5 sessies by die Bishop Lavis Rehabilitasie Sentrum
- 2.3. Ek bewus is dat ongeveer 30 ander versorgers ook deel sal neem aan hierdie projek.
- 2.4. Daar aan my verduidelik is dat alle inligting vertroulik hanteer sal word. Resultate sal gebruik word vir tesis, en / of publikasie in vaktydskrifte, sonder om die identiteit van die persoon te openbaar.
- 2.5. Ek sal toegang hê tot alle bevindinge van die studie.
- 2.6. Daar aan my verduidelik is dat deelname vrywillig is en dat ek mag weier om deel te neem of enige tyd deelname mag staak. Sodanige weiering of staking nie op enige manier my of die pasiënt se huidige / toekomstige behandeling by die Bishop Lavis Rehabilitasie Sentrum sal benadeel nie.
3. Die inligting hierbo is deur **Mev Lynn Kleineibst** in Afrikaans aan my verduidelik en ek is die taal goed magtig. Ek is n geleentheid gebied om vrae te vra en al die vrae is bevredigend beantwoord.
4. Daar is geen dwang op my geplaas om toestemming te gee en ek verstaan dat ek deelname te enige tyd mag staak / weier sonder enige penalisasie.
5. Deelname aan hierdie projek sal geen addisionele koste vir my inhou nie en dat ek ook nie finansieel daarby sal baat vind nie.

B. EK STEM HIERMEE VRYWILLIG IN OM DEEL TE NEEM AAN DIE BOGEMELDE PROJEEK.

Geteken te op20.....
(plek) (datum)

.....
Handtekening van deelnemer

.....
Handtekening van getuie

VERKLARING DEUR NAVORSER

Ek, **Lynn Kleineibst**, verklaar dat ek:

Die inligting vervat in hierdie dokument aan.....(deelnemer) verduidelik het.

Hy / sy aangemoedig het en genoeg tyd gegee om enige vrae aan my te stel.

Hierdie gesprek in Afrikaans plaasgevind het en geen tolk gebruik is nie.

Geteken te.....op.....20.....
(plek) (datum)

.....
Handtekening van navorser
(Lynn Kleineibst)

.....
Handtekening van getuie

BELANGRIKE INLIGTING AAN DEELNEMER

Geagte deelnemer

Baie dankie vir u deelname aan hierdie studie. Indien daar te enige tyd tydens die duur van die projek n probleem ontstaan wat spruit uit die studie, of u verdere inligting aangaande die projek verlang moet u asseblief vir my kontak by:

021 9346315 (w)
082 8726441 (c)
Mev Lynn Kleineibst

ADDENDUM C

SEMI-STRUCTURED INTERVIEW

English and Afrikaans

Semi-structured Interview

Details of primary caregiver

Details of stroke patient

Name:

Name:

Age:

Age :

Address :

Address :

.....

.....

Tel no.:

Tel no.:

Relationship to the patient :

A. Patient information

1. How long ago did the patient have a stroke? (month and year)

2. Is this the 1st, 2nd, 3rd or 4th stroke? When did the strokes occur? Right or left weakness?

.....
.....

3. What changes have you observed in the patient after the last stroke?
Prompts: behaviour / understanding / mood / movement / speech / swallowing / vision

.....
.....
.....

4. Does the patient have any other medical problems?

Prompts: high blood pressure / arthritis / diabetes / heart problems.

.....
.....
.....

5. Describe what the patient does throughout the day in relation to work and leisure.

.....
.....

B. Primary caregiver information

1. Do you live in the same house as the patient? Yes / No
If not, how far away do you stay?
.....
2. Is this the first time you are caring for a stroke patient? Yes / No
If not, please tell me more about it?
.....
3. How many hours per day do you spend looking after the patient?
4. What time of the day does the patient need you the most?
5. What do you help the patient with?
.....
.....
6. Do you get help from the family, neighbours or friends? Yes / No
How many people help you?
Who helps you?
7. What do you feel you need help with?
.....
.....
8. Do you have any health problems? Yes / No
If yes, please explain.
.....
.....
9. Have you had any new injuries or pains since caring for the patient?
Yes / No
If yes, please explain.
.....
.....
10. How has your life been affected since caring for the patient?
.....
.....
11. What are your hobbies/interests?
.....
12. Are you still actively participating in them? Yes / No

13. Overall, how do you feel about being responsible for the care of the patient?

.....
.....

C. Knowledge of stroke

1. Do you understand what a stroke is? Yes / No

Please explain in your own words.

.....
.....

2. What are the signs and symptoms of a stroke?.....

.....

3. Do you know what causes a stroke? Yes / No

Name a few causes/risk factors

.....
.....

4. What do you think will prevent a stroke happening again?

.....
.....

5. Do you understand why the patient must take his/her medication?

Yes / No. Explain the purpose of the medication.

.....
.....

D. Functioning in the team

1. Whom of the rehabilitation team has the patient seen after his /her stroke?

Prompts: doctor / nurse / therapist / social worker / dietician / psychologist

.....

2. Did you find the appointments useful?

Yes. In what ways?.....

.....
.....

No. Why not?.....

.....
.....

3. Has the patient received physiotherapy and /or occupational therapy?

Yes / No

For how long?

In what ways have you found it useful?

.....
.....

4. Does the patient have a home programme? Yes / No
Have you been shown how to assist the patient with the home programme? Yes / No

5. Do you feel you get enough support from the rehabilitation team?
Yes. In what ways?
.....
No. How would you like more help?
.....

6. Do you experience physical strain when handling the patient? Yes / No
Explain.
.....
.....

7. Has any of the rehabilitation team shown you how to correctly handle or transfer the patient? Yes / No
Who has shown you?
.....

8. Do you know what help is available for the stroke patient within the Bishop Lavis community? Yes / No. (Prompts: stroke group / home-based care).
Do you make use of these services? Yes / No
Please explain.
.....
.....

9. Do you have any suggestions to improve the services for the stroke patient in the Bishop Lavis community?
.....
.....
.....

E. Finances

1. Are you presently: employed / unemployed / given up your job to look after the patient / never worked

2. Are you receiving an income? Yes / No

3. Is the patient receiving an income? Yes / No. What type of income?

4. Are you aware of the financial help available for the stroke patient and carer? Yes / No
If yes, please explain. (Prompts: disability grant / carer-dependency grant)
.....

5. Does the patient have transport problems when he/she needs to attend their appointments?
Yes / No

F. Support / Needs

1. What do you think is your most important need / What are you needing the most help and support with?

.....
.....
.....
.....
.....

2. Would you find it useful to attend a series of 5 sessions at the Bishop Lavis Rehabilitation Centre to help meet your needs? Yes / No

Would you be able to come? Yes / No

What would you like to learn during these sessions?

.....
.....
.....

3. Do you have transport to attend these sessions? Yes / No

4. Lastly, would you be interested in being part of a support group that is involved in; exchanging ideas, gaining information and providing support to those in a similar situation as you are? Yes / No

If no, why not?

.....
.....
.....

Thank you

Semi-gestruktureerde Onderhoud

Inligting van primêre versorger

Inligting van pasiënt

Naam: Naam:

Ouderdom: Ouderdom:

Adres: Adres:
.....

Tel no.: Tel no.:

Verwantskap aan die pasiënt:

A. Inligting van pasiënt

1. Hoe lank gelede het die pasiënt beroerte gehad? (maand en jaar)

2. Is dit die 1ste, 2de, 3de of 4de beroerte? Wanneer het hulle plaasgevind.
Reghter of linker swakheid?

.....
.....

3. Watter veranderinge het u aan die pasiënt opgemerk na die laaste
beroerte?

Wenke: gedrag / begrip / gemoedstoestand / beweging / spraak / sluk /
visie

.....
.....
.....

4. Het die pasiënt enige ander mediese probleme?

Wenke: hoë bloeddruk / artritis / suikersiekte / hartprobleme

.....
.....
.....

5. Beskryf wat die pasiënt besig hou gedurende die dag (t.o.v. werk en
ontspanning).

.....
.....

B. Inligting van primêre versorger

1. Woon u en die pasiënt in dieselfde huis? Ja / Nee
Indien nie, hoe vêr van die pasiënt woon u?
.....
2. Is dit die eerste keer dat u beroerte pasiënt versorg? Ja / Nee
Indien nie, verduidelik
.....
3. Hoeveel ure per dag spandeer u om na die pasiënt te kyk?
4. Watter tyd gedurende die dag het die pasiënt vir u die nodigste?
5. Waarmee word die pasiënt gehelp?
.....
.....
6. Kry u enige hulp van die familie, bure of vriende? Ja / Nee
Hoeveel mense help u?
Wie help u?
7. Met wat het u hulp nodig?
.....
.....
8. Het u enige probleme met u gesondheid? Ja / Nee
Indien ja, verduidelik.
.....
.....
9. Het u enige nuwe beserings of ondervind u pyn vandat u die pasiënt begin versorg het?
Ja / Nee
Verduidelik.
.....
.....
10. Hoe is u lewe beïnvloed vandat u die pasiënt begin versorg het?
.....
.....
11. Wat is u stokperdjies / belangstellings?
.....
12. Doen u dit steeds? Ja / Nee

13.Hoe voel u in die algemeen oor die verantwoordelikheid om die pasiënt te versorg?

.....
.....

C. Kennis t.o.v. beroerte

1. Verstaan u wat beroerte is? Ja / Nee

Verduidelik in u eie woorde.
.....
.....

2. Noem die tekens en simptome van beroerte.

.....
.....

3. Weet u wat beroerte veroorsaak? Ja / Nee

Noem paar van die risiko faktore.....
.....
.....

4. Wat kan voorkom dat die pasiënt nog beroerte kry?

.....

5. Verstaan u waarom die pasiënt sy/haar medikasie moet neem? Ja / Nee.

Verduidelik die doel van die medikasie.
.....
.....

D. Funkzionering as deel van die span

1. Wie van die rehabilitasie span het die pasiënt al gesien na sy/haar beroerte?

Wenke: dokter / verpleegsters / terapeute / sosiale werker / dieëtkundige/
sielkundige
.....

2. Het dit vir u gehelp om die afspraak by te woon

Ja. In watter manier?
.....
.....

Nee. Waarom nie?
.....
.....

3. Het die pasiënt fisioterapie en/of arbeidsterapie ontvang? Ja / Nee
 Vir hoe lank?
 Het dit vir die pasiënt gehelp? Verduidelik.

4. Het die pasiënt tuis program? Ja / Nee
 Is u gewys hoe om die pasiënt daarmee te help? Ja / Nee
5. Kry u genoeg ondersteuning van die rehabilitasie span?
 Ja. Verduidelik op watter maniere.

 Nee. Verduidelik waarmee u meer ondersteuning nodig het.

6. Ondervind u enige fisiese stremming tydens die hantering van die pasiënt?
 Ja / Nee
 Verduidelik.....

7. Het enige lede van die rehabilitasie span u al gewys hoe om die pasiënt te hanteer of te verplaas? Ja /Nee
 Wie het vir u gewys?

8. Weet u watter hulp is beskikbaar binne die Bishop Lavis gemeenskap vir die beroerte pasiënt? Ja / Nee. (Wenke: beroerte groep / tuisversorging).
 Maak u gebruik van hierdie dienste? Ja / Nee
 Verduidelik.

9. Het u enige voorstellings om die dienste vir beroerte pasiënte in die Bishop Lavis gemeenskap te verbeter?.....

E. Finansies

1. Is u tans: werksaam / werkloos / u het u werk opgegee om die pasiënt te versorg / nog nooit gewerk.
2. Ontvang u inkomste? Ja / Nee
3. Ontvang die pasiënt inkomste? Ja / Nee. Watter soort?

4. Is u bewus van finansiële hulp wat beskikbaar is vir die beroerte pasiënt en versorger.? Ja / Nee

Indien ja, verduidelik. (Wenke: ongeskiktheidstoelaag / versorgerstoelaag)

5. Het die pasiënt vervoerprobleme om sy afspraak na te kom? Ja / Nee

F. Ondersteuning/behoefte

1. Wat dink u is u belangrikste behoefte/ Met wat het u die mees hulp of ondersteuning nodig?

.....
.....
.....
.....

2. Sal dit vir u help om reeks van 5 sessies by die Bishop Lavis Rehabilitasie Sentrum by te woon wat aan u behoeftes voorsien? Ja /Nee

Sal u die sessies kan bywoon? Ja / Nee

Wat sal u graag tydens die sessies wil leer?

.....
.....
.....
.....

3. Het u vervoer om die sessies by te woon? Ja / Nee

4. Laastens, stel u belang om deel te wees van ondersteuningsgroep; om idees uit te ruil, inligting te kry en ondersteuning te gee aan mense in dieselfde situasie waarin u is?

Ja / Nee

Indien nee, hoekom nie?

.....
.....
.....

Dankie

ADDENDUM D

BARTHEL ADL INDEX

English and Afrikaans

Barthel ADL Index

Patient's Name: **Date:**

<i>Bowels</i> 0 = incontinent (or needs to be given enemata) 1 = occasional accident (once a week) 2 = continent			
<i>Bladder</i> 0 = incontinent, or catheterised and unable to manage alone 1 = occasional accident (maximum once per 24 hours) 2 = continent			
<i>Grooming</i> 0 = needs help with personal care 1 = independent face/hair/teeth/shaving (implements provided)			
<i>Toilet use</i> 0 = dependent 1 = needs some help, but can do something alone 2 = independent (on and off, dressing, wiping)			
<i>Feeding</i> 0 = unable 1 = needs help cutting, spreading butter, etc. 2 = independent			
<i>Transfer (bed to chair and back)</i> 0 = unable, no sitting balance 1 = major help (one or two people, physical), can sit 2 = minor help (verbal or physical) 3 = independent			
<i>Mobility</i> 0 = immobile 1 = wheelchair independent, including corners 2 = walks with help of one person (verbal or physical) 3 = independent (but may use any aid; for example, stick)			
<i>Dressing</i> 0 = dependent 1 = needs help but can do about half unaided 2 = independent (including buttons, zips, laces, etc.)			
<i>Stairs</i> 0 = unable 1 = needs help (verbal, physical, carrying aid) 2 = independent			
<i>Bathing</i> 0 = dependent 1 = independent (or in shower)			
TOTAL (0-20)			

Wade DT. *Measurement in neurological rehabilitation*. Oxford: Oxford University Press 1992.

Barthel ADL Indeks

Naam van pasiënt: **Datum:**

<p><i>Stoelgang</i> 0 = inkontinent (of benodig enemas) 1 = toevallige ongeluk (een maal per week) 2 = kontinent</p>			
<p><i>Blaas</i> 0 = inkontinent, of gekateteriseer en nie in staat om alleen oor die weg te kom 1 = toevallige ongeluk (maksimum een maal per 24 uur) 2 = kontinent</p>			
<p><i>Persoonlike versorging</i> 0 = benodig hulp met persoonlike sorg 1=onafhanklikegesig/hare/tande/skeer(gereedskap voorsien)</p>			
<p><i>Toilet gebruik</i> 0 = afhanklik 1 = benodig bietjie hulp, maar kan iets alleen doen 2 = onafhanklik (op en af, aantrek, afvee)</p>			
<p><i>Voeding</i> 0 = nie in staat 1 = benodig hulp met sny, botter smeer, ens. 2 = onafhanklik</p>			
<p><i>Verplasing (bed na stoel en terug)</i> 0 = nie in staat, geen sit balans 1 = maksimum hulp (een of twee mense, fisies), kan sit 2 = minimum hulp (verbaal of fisies) 3 = onafhanklik</p>			
<p><i>Mobiliteit</i> 0 = immobiel 1 = rolstoel onafhanklik, insluitend hoeke 2 = loop met behulp van een persoon (verbaal of fisies) 3 = onafhanklik (maar mag enige hulpmiddel gebruik; bv, kerie)</p>			
<p><i>Aantrek</i> 0 = afhanklik 1 = benodig hulp maar kan omtrent die helfde sonder hulp doen 2 = onafhanklik (insluitend knope, ritssluiters, veters, ens.)</p>			
<p><i>Trappe</i> 0 = nie in staat 1 = benodig hulp (verbaal, fisies, dra hulpmiddel) 2 = onafhanklik</p>			
<p><i>Bad</i> 0 = afhanklik 1 = onafhanklik (of in die stort)</p>			
<p>TOTAAL (0-20)</p>			

Wade DT. *Measurement in neurological rehabilitation*. Oxford: Oxford University Press 1992.

ADDENDUM E

CAREGIVER STRAIN INDEX

English and Afrikaans

Caregiver Strain Index

Name of caregiver: **Date:**

I am going to read a list of things which other people have found to be difficult. Would you tell me whether 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 behaviour 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.)		

Robinson B. Validation of a Caregiver Strain Index. *Journal of Gerontology* 1983; 38: 344-348

Versorger Stresladings Indeks

Naam van versorger:..... **Datum:**.....

Ek gaan 'n lys lees van dinge wat ander mense moeilik gevind het. Sal jy my sê of enige hiervan op jou van toepassing is? (Gee voorbeelde)

	Ja = 1	Nee = 0
Slaap is versteur (bv., omdat _____ in en uit die bed is of ronddwaal in die nag)		
Dit is ongerieflik (bv., omdat dit soveel tyd neem om te help of dis 'n lang rit oor om te help).		
Dit is 'n fisiese las (bv., agv in en uit 'n stoel tel; inspanning of konsentrasie word benodig).		
Dit is beperkend (bv., hulp beperk vrye tyd of kan nie kuier nie).		
Daar was familie aanpassings (bv., omdat hulp roetine ontwrig het; daar is geen privaatheid nie).		
Daar was veranderinge in persoonlike planne (bv., moes 'n werk afwys; kon nie met vakansie gaan nie).		
Daar was ander eise vir my tyd (bv., van ander familie lede).		
Daar was emosionele aanpassings (bv., agv hewige argumente).		
Sommige gedrag is ontstellend (bv., agv inkontinensie; _____ sukkel om dinge te onthou; _____ beskuldig mense dat hulle dinge neem).		
Dit is ontstellend om te vind dat _____ so baie verander het van sy/ haar vorige self (bv., hy /sy is 'n ander persoon van wie hy/sy vroeër was).		
Daar was werksaanpassings (bv., omdat verlof geneem moes word).		
Dit is 'n finansiële las.		
Voel volkome oorweldig (bv., agv bekommernis oor _____; besorgdheid oor hoe jy sal regkom).		
TOTALE TELLING (Tel ja response. Enige positiewe antwoord mag 'n behoefte aandui vir intervensie in daardie area. 'n Telling van 7 of hoër dui 'n hoë vlak van stres aan.)		

ADDENDUM F

CAREGIVER FEEDBACK FORM

English and Afrikaans

CAREGIVER FEEDBACK FORM

Date.....

Session

1)What did you learn in today's session?

2)What did you enjoy the most?

3)What did you enjoy the least?

VERSORGER TERUGVOER VORM

Datum.....

Sessie.....

1)Wat het u geleer in vandag se sessie?

2)Wat het u die meeste geniet?

3)Wat het u die minste geniet?

ADDENDUM G

**CAREGIVER SUPPORT INTERVENTION PROGRAMME 1
(CSIP 1)**

Outline for presenters

CAREGIVER SUPPORT INTERVENTION PROGRAMME 1 (CSIP 1)

Outline for the programme presenters

15 November – 1 December 2004

SESSION 1: PHYSIOTHERAPIST/ RESEARCHER

15 Nov 2004: 14h00-15h30

- Welcome and plan for the five sessions. Give a handout to each carer listing the dates, times, topic and speaker for each session (Addendum H). The aims of the first session will be discussed.
- Ice-breaker: each carer to share briefly about their interests and expectations for the group.
- Address the following:
 - Group to start promptly at 14h00 and end at 15h30.
 - Carers to attend all five sessions for optimum learning and support.
 - Personal information shared in the group will be kept confidential.
- Education on what stroke is - explain by visual illustration of a blockage or burst in a pipe.
- Discuss the warning signs of stroke.
- Back protection and kinetic handling principles will be discussed using a poster and practical demonstration. Carers will each get the opportunity to practise lifting 3-5kg boxes, while applying these principles.
- Education and practice of effective hemiplegic transfers from the bed to the chair/commode will be done, emphasizing correct back protection principles. Carers will work in pairs with supervision from the physiotherapist.
- Snacks (tea, crackers and tuna) to be served at the end of the session.

- Written and verbal feedback to be taken at the end of the session.

SESSION 2: PHYSIOTHERAPIST, DIETICIAN AND SPEECH THERAPIST

22 November 2004: 14h00 - 15h30

- A brief recap will be done on the first session while snacks (tea, crackers, tuna and cottage cheese) are served.
- The aims of the session will be discussed.

PHYSIOTHERAPIST

- Education on the causes, risk factors and prevention of stroke will be done by pictorial illustrations on a whiteboard. A pamphlet titled: 'Beroerte is 'n brein aanval' will be handed out to the carers (Addendum H.2).

DIETICIAN

- Feeding problems and dietary advice for stroke patients will be discussed. The dietician will write a variety of different foods on papers for the carers to compile a healthy meal for stroke patients with swallowing and chewing problems. A handout will be given to the carers titled: 'Algemene wenke vir pasiënte met kou en slukprobleme' (Addendum H.3).

SPEECH AND LANGUAGE THERAPIST

- Management of speech and swallowing problems associated with stroke, will be discussed. A handout will be given to the carers on guidelines for communication disorders (Addendum H.4).
- Written and verbal feedback will be taken at the end of the session.

SESSION 3: OCCUPATIONAL THERAPIST

24 November 2004: 14h00-15h30

- A brief recap will be done on the second session.
- The aims of the session will be discussed.
- Application of the basic hemiplegic principles in self-care activities of daily living like eating, washing, dressing and toileting will be demonstrated. The carers will practise these in pairs.
- A variety of assisted devices will be demonstrated to the group like a wash mitten, back washer, non-slip mat, grab rail, etc.
- Snacks (fruit juice, cheese, cucumber and crackers) will served at the end of the session.
- Written and verbal feedback will be taken at the end of the session.

SESSION 4: PHYSIOTHERAPIST AND SOCIAL WORKER

29 November 2004: 14h00-15h30

- A brief recap will be done on the third session.
- The aims of the session will be discussed.

PHYSIOTHERAPIST

- Carers will be informed of the resources and services available for the stroke patient in the Bishop Lavis community. A list of these services will be discussed and handed out to each carer (Addendum H.5).

SOCIAL WORKER

- An ice-breaker will be done where each carer will swap shoes and experience what it's like to be in another persons' shoes.
- Each carer will then be given a lit candle to illustrate how special and unique they are for sacrificing their time to care for the stroke patient.
- Carers will be informed about social and financial benefits/support

available for them like carer-dependency grants, family support and respite care options available.

- Snacks (fruit juice, crackers, tuna and cucumber) will be served at the end of the session.
- Written and verbal feedback will be taken at the end of the session.

SESSION 5: OCCUPATIONAL THERAPIST

1 December 2004: 14h00- 15h30

- A brief recap will be done on the fourth session.
- The aims of the session will be discussed.
- The causes, symptoms and management of stress will be explained by visual aids.
- The carers will have the opportunity to share about their stressors and will be encouraged to pursue their leisure interests and hobbies.
- The principles of relaxation therapy will be discussed. The carers will then participate in a 20-minute session of Jacobson progressive relaxation therapy on the mats.
- A pamphlet will be given to the carers titled: 'Stressed out?' (Addendum H.6)
- Snacks (tea, bran muffins and cheese) will be served at the end of the session.
- Written and verbal feedback will be taken at the end of the session.
- A final round-up will be done and carers will be encouraged to continue in a stroke carer support group facilitated by the occupational therapist at the Bishop Lavis Rehabilitation Centre.

ADDENDUM H

HANDOUTS FOR CSIP 1

- H.1. 'Beroerte versorger program rooster vir November 2004'
- H.2. 'Beroerte is 'n brein aanval'
- H.3. 'Algemene wenke vir pasiënte met kou en sluk probleme'
- H.4. 'Riglyne vir pasiënte met kommunikasie probleme'
- H.5. 'Dienste beskikbaar vir die beroerte pasiënt in die Bishop Lavis gemeenskap'
- H.6. 'Stressed out?'

BEROERTE VERSORGER PROGRAM ROOSTER VIR

NOVEMBER 2004

TYD:2-3.30 NM

MAANDAG 15 NOV

SPREKER: Fisioterapeut

- Wat is stroke en die waarskuwings van stroke.
- Hoe om die pasiënt te verplaas van bed na stoel/commode.

MAANDAG 22 NOV

SPREKER: Fisioterapeut, Dieetkundige en Spraakterapeut

- Die veroorsake en voorkoming van stroke.
- Hoe om die pasiënt te help met sluk en spraak probleme.
- Watter kos is toepaslik vir die beroerte pasiënt.

WOENSDAG 24 NOV

SPREKER: Arbeidsterapeut

- Hoe om die pasiënt te help met was, aantrek, eet en toiletgebruik.

MAANDAG 29 NOV

SPREKER: Fisioterapeut en Maatskaplike werkster

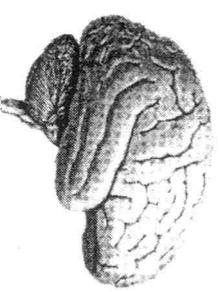
- Dienste beskikbaar in die Bishop Lavis gemeenskap.
- Finansiële en maatskaplike hulp beskikbaar vir die pasiënt en versorger.

WOENSDAG 1 DES

SPREKER: Arbeidsterapeut

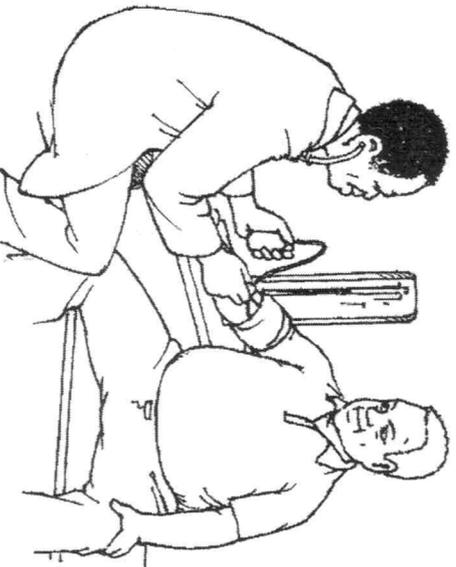
- Streshantering en ontspanningsterapie.

BEROERTE IS 'N BREIN AANVAL



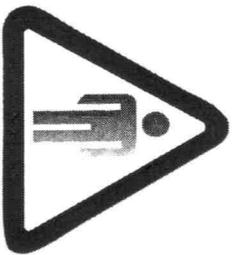
Wat is beroerte / stroke?

- Dit is wanneer 'n bloedvat in die brein bars of verstop.
- Dit veroorsaak dat 'n gedeelte van die brein nie bloed kry nie.
- Sonder bloed word die brein beskadig omdat dit nie suurstof of kos kry nie.
- Dit veroorsaak 'n verlamming / swaakteid in die liggaam.



Hierdie pamflet is opgestel deur Lynn Kleineibst, die fisioterapeut van Bishop Lavis Rehabilitasie Sentrum.
Tel: 934-6315

Waarskuwings van 'stroke'



- Skielike swakheid of dofheid in die gesig, arm en been op een kant van die liggaam.
- Skielike spraak of begrip probleme.
- Skielike probleme met visie.
- Probleme met balans en duiseligheid.
- Erge hoofpyn.

Wat veroorsaak 'n 'stroke'?

- Hoë bloeddruk (hoër as 140/90)
- Rook.
- Hartsiekte.
- Diabetes/suikersiekte.

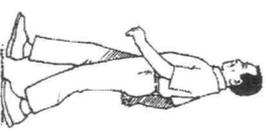


- Hoë cholesterol.
- Oorgewig.
- Oorgebruik van alkohol.
- Onaktiewe lewenstyl.
- Hoë stres vlakke.

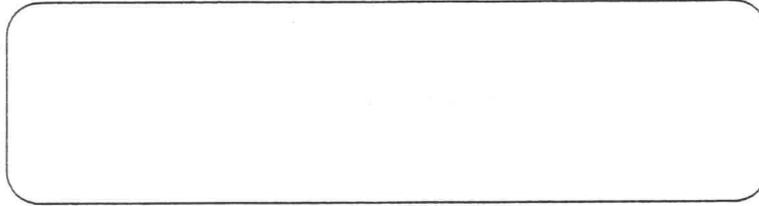


Hoe om 'n stroke te voorkom/'prevent':

- Laat u bloeddruk, bloedsuiker en cholesterol vlakke gereeld neem.
- Neem voorgeskrewe medikasie gereeld.
- Hou op met rook.
- Eet gesond (min vet en sout).
- Oefen gereeld (30min 3 keer / week).
- Beperk alkohol tot 2 glase per dag.
- Beheer stres vlakke.
- Hou gesonde gewig.



**KRY ONMIDDELIK MEDIESE
HELP MET ENIGE VAN HIERDIE
WAARSKUWINGS.**



ALGEMENE WENKE VIR PASIËNTE MET KOU EN SLUKPROBLEME

Die pamflet bestaan uit praktiese idees en voorbeelde van hoe om 'n gebalanseerde ete vir die verskillende maaltye van 'n dag saam te stel, wat bestaan uit voedsel wat maklik is om te kou en te sluk, in die poging om gewigsverlies te voorkom.

ONTBYT EN LIGTE ETES

PAP

- Bedien pap dun of slap en sonder klonte.
- Melk kan in die plek van water in die voorbereiding van gekookte pap gebruik word om dit meer voedsaam te maak.
- Vir ekstra energie kan suiker, melkpoeier, room, margarien, botter, grondboontjiebotter of eier bygevoeg word.

EIERGEREGTE

- Saggekookte eier wat fyngemaak is en bedien word met 'n sous, bv. witsous.
- Roereier wat bedien word met 'n sous, bv. witsous.
- Gebakte eiervla.
- 'n Geklitste eier kan tydens die voorbereiding van gekookte pap bygevoeg word.

SOP

- Tuisgemaakte gort-, lensie-, ertjie- of boontjie-sop wat deur 'n sif gedruk is.
- Verdik sop met gekookte kos wat deur 'n sif gedruk is, om dit meer voedsaam te maak.

HOOFETES

VLEIS, HOENDER EN VIS

- Bedien maalvleis met 'n sous.
- Bedien fyn gesnyde of gemaalde saggekookte hoender, tong of enige ander sagte vleis met 'n sous.
- Vlok gestoomde of gekookte vis en bedien met 'n sous.

STYSELGEREGTE

- Noedelrys of fyn noedels wat bedien word met 'n sous, bv. kaas- of witsous.
- Week brood in sop, melk, tee of koffie.
- Bedien kapokaartappels. Melk, margarien, botter of room kan bygevoeg word vir ekstra energie.

GROENTE

- Saggekookte groente (bv. wortels of patat) wat fyngedruk is.
- Verpulpte groente (bv. ertjies of spinasie) wat bedien word met 'n sous.
- sagte opgekookte groente soos skorsies en pampoens kan net so geëet word.

NAGEREG-IDEES

- Jellie en kitspoedings ("Instant" poedings). Vir ekstra energie kan volroommelk of room gebruik word in die voorbereiding van nageregte.
- Vla.
- Roomys.
- Joghurt.
- Sagte sago- of tapioka-poeding wat bedien word met vla of roomys.
- Vrugte kan ook as nagereg gebruik word (sien vrugte riglyne op die volgende bladsy).

VRUGTE

- Vars vrugte soos piesangs en papaja kan fyngedruk word.
- Vars vrugte soos appels en perskes kan gerasper word.
- Verpulpte vars of ingemaakte vrugte (bv. appelmoes).
- Gekookte vrugte kan deur 'n sif gedruk word.
- Gestoofde droë vrugte wat fyngedruk of verpulp is.
- Vrugtesappe.

MELK EN MELKPRODUKTE

Gebruik melk, suurmilk, karringmelk of joghurt daaglik. Volg die onderstaande wenke om te verseker dat u 2 tot 3 koppies melkprodukte per dag inneem:

- Gebruik melk in die plek van water in die voorbereiding van voedsel, bv. gekookte pap, sop en nageregte.
- Maak gereeld melksnysels (melkkos) of pap gemaak van mielieblom en melk.
- Bedien melkskommels tussen etes (sien resepte wat saam voorsien is).

SUPPLEMENTASIE DRANKIES

- Indien u verwys is na die kliniek of die Gemeenskapgesondheidsentrum vir voedingondersteuning, gebruik die produk soos voorsien.
- Verskeie supplementasie drankies is kommersieël beskikbaar. Indien u belangstel, vra gerus u dieetkundige om u van die name te voorsien.
- Resepte van supplementasie drankies wat tuis voorberei kan word, is aangeheg.

Dieetkundige: _____

Datum: _____

Kontaknommer (07:30 – 16:00): 938 - _____ of 938 4477

RESEPTE VAN SUPPLEMENTASIE DRANKIES WAT TUIS VOORBEREI KAN WORD

EIER – MELKSKOMMEL

Bestanddele (2 porsies)
2 koppies volroommelk
1 eier
5 tot 8 teelepels suiker (na smaak)
geursel (vanielje, aarbei of sjokolade)

Metode

Klits alles goed saam en plaas die drankie in die yskas. Bedien koud.

Variasies

Vervang 'n gedeelte van die melk met room. Gebruik koffiepoëier, kakao of jelliepoëier (½ tot 1 teelepel) as geursel.

PIESANG – MELKSKOMMEL

Bestanddele (1 porsie)
1 fyngedrukte piesang
1 koppie volroommelk
2 of meer teelepels suiker (na smaak)
vanieljegeursel (opsioneel)

Metode

Klits alles goed saam en plaas die drankie in die yskas.
Bedien koud.

Variasies

Vervang die piesang met enige ander vrug (rou of gaar) wat fyngemaak kan word. Vervang 'n gedeelte van die melk met joghurt.

VRUGTESKOMMEL

Bestanddele (2 porsies)
½ koppie volroommelk
5 teelepels volroommelkpoëier
1 "scoop" roomys
1 koppie vrugtesap

Metode

Los die melkpoëier op in die melk.
Voeg die roomys en die vrugtesap by en klits alles goed saam. Plaas die drankie in die yskas en bedien koud.

Variasie

Gebruik verskillende tipe vrugtesappe, bv. lemoensap vir 'n lemoenmelkskommel.

ONTBYT-IN-'N GLAS

Bestanddele (volume = 1000 ml)
420 ml volroommelk
275 ml roomys
115 g volroommelkpoëier
4 eiers
210 ml koejawelsap
25 ml suiker

Metode

Klits alles baie goed saam. Plaas drankie in yskas en bedien koud.

GRONDBOONTJIEBOTTER-DRANKIE

Bestanddele (2 porsies)
1 koppie volroommelk
1 koppie roomys
1 geklitste eier
2 eetlepels grondboontjiebotter

Metode

Klits roomys en melk saam. Voeg grondboontjiebotter en geklitste eier by en meng goed. Plaas drankie in yskas en bedien koud.

Disartrie

Wat is dit?

Disartrie is 'n spraakafwyking wat veroorsaak word deur 'n swakheid of 'n onkoördinasie van die spraakspiere. Dit kan voorkom as gevolg van 'n kopbesering of 'n beroerte.

Wenke vir die persoon met disartrie:

Sê waaroor jy gaan praat voor jy in sinne begin praat bv. 'hond'. ' My hond het my skoene gekou'

Praat stadig en hard

Sit genoeg pouses in jou spraak

Vra vir die persoon met wie jy praat of hy jou verstaan

Probeer om nie baie te praat as jy moeg is nie

As die persoon met wie jy praat jou nie kan verstaan nie, gebruik gebare, wys of skryf dinge terwyl jy praat

Wenke vir die luisteraar.

Probeer om afleiding in die omgewing uit te skakel, bv. skakel 'n TV af wat raas

Gee aandag aan die spreker en kyk na hom as hy praat

Wees eerlik en sê wanneer jy nie verstaan nie

Herhaal die deel van die boodskap wat jy nie verstaan het nie, sodat die spreker nie die hele boodskap hoef te herhaal nie.

As jy steeds nie die spreker verstaan nie vra vrae met 'n Ja/Nee antwoord of gebruik 'n boodskapbord

Apraksie

Wat is dit?

Apraksie is 'n afwyking van beplanning. 'n Persoon met apraksie sukkel om die strukture (bv lippe/tong) reg te positioneer om sodoende te kan praat. Hulle weet dikwels wat hulle wil sê. Dit kom soms voor by mense wat 'n beroerte, kopbesering, tumor of sekere siekte toestande het.

Wat kan die luisteraar doen?

Sorggewers kan die mense met Apraksie help met die oefeninge wat deur die spraakterapeut gegee is

Hulle kan die persoon met Apraksie help om op ander manier ook te kommunikeer bv dmv 'n alfabet bord, boek of rekenaar

As 'n persoon met Apraksie praat, moedig hom aan om stadig en ritmies te probeer praat

As 'n persoon met apraksie sukkel om te praat, help hom om klanke te produseer deur vir hulle te wys hoe om die klank te sê

Afasie

Wat is dit?

Die afwyking kom voor as gevolg van 'n besering aan die linker kant van die brein. 'n persoon met Afasie kan probleme ondervind met praat (taal), lees, skryf, herkenning van name van objekte en/of verstaan wat ander mense sê.

Tegniese vir woordvindingsprobleme:

Dit kan eers deur die kommunikasie vennoot gebruik word tydens kommunikasie, maar die persoon met Afasie kan dit self ook later gebruik.

- Sê die 1ste letter of deel van die woord, byvoorbeeld “p...pe” vir “pen”.
- Gee ’n woord wat rym met die woord wat die persoon soek, byvoorbeeld “die woord rym met mat...” vir “kat”.
- Gee ’n sin en laat die woord uit, byvoorbeeld “jy skryf met ’n...” vir “pen”.
- Gee paarwoorde, byvoorbeeld “sout en ...” (“peper”), en “noord en...” (“suid”), en “bacon en ...” (“eiers”)
- Moedig die persoon aan om die woord te beskryf.
Byvoorbeeld “kar” – “Dis ’n ding met 4 wiele, jy klim in en dan ry jy daarmee,ens.”
- Vra dus vrae om bogenoemde beskrywings te ontluk, byvoorbeeld “Wat doen mens met dit?”, “Hoe lyk dit?”

Wat kan 'n kommunikasie vennoot doen?

- **Prat** steeds met die persoon soos voor die ongeluk. Hy is **steeds** 'n volwassene – moet dus nie met hom praat asof hy 'n kind is nie.
- Verminder of neem agtergrondsgeraas weg, byvoorbeeld. sit die TV **af**, staan nader aan die persoon, ens.
- Maak seker jy het die persoon se aandag voordat jy begin praat.
- Prys alle pogings om te kommunikeer. Maak kommunikasie 'n positiewe ervaring en verskaf interessante geselskap.
- Moedig alle vorme van kommunikasie aan: gebare, spraak, skryf, ja/nee antwoorde, keuses, oogkontak, gesigsuitdrukking, ens.
- Gee die persoon genoeg tyd om te praat en gee hulle ook genoeg tyd om te reageer op 'n vraag.
- Vermoed dit om die persoon te kritiseer en sy foute vir hom reg te maak. Respekteer die persoon dus steeds.

Dienste beskikbaar vir die beroerte pasiënt in die Bishop Lavis gemeenskap

Fisioterapie

Bishop Lavis Rehabilitasie Sentrum
Mev. Kleineibst
Tel: 934-6315

Arbeidsterapie

Bishop Lavis Rehabilitasie Sentrum
Mej. De La Cornillere
Tel: 934-6315

Spraakterapie

Bishop Lavis Rehabilitasie Sentrum
Woensdag en Donderdag 8:00 -12.30 (Studente kwartale)
Tel: 934-6315

Maatskaplike Werkster

Bishop Lavis Daghospitaal
Mev. Jacobs
Tel: 934-6050

Communicare (Bishop Lavis & Nooitgedacht)
Tel: 934-5422

Diakonale Dienste (Valhalla Park)
Tel: 932-6721

PAWK Bellville – Voortrekkerweg 107 (Kalksteenfontein, Netreg & Montana)
Tel: 940-7100

Dieëtkundige

Bishop Lavis Daghospitaal
Maandag tot Vrydag 8:00 – 12:30
Tel: 934-6050

Ortopediese Suster

Bishop Lavis Daghospitaal
Laaste Maandagoggend van elke maand
Tel: 934-6050

Lifeline

Bishop Lavis Babakliniek
Tel: 934-4822

Voetsorg

Bishop Lavis Daghospitaal
Een Woensdag per maand
Mev. Hope
Tel: 934-6050

Psigiatryse Suster

Bishop Lavis Daghospitaal
Mr. Kiewietz
Tel: 934-6050

Oogtoetse

Bishop Lavis Daghospitaal
Dokter
Tel: 934-6050

Beroerte Groep

Bishop Lavis Rehabilitasie Sentrum
Woensdag 9:00 – 10:30
Tel: 934-6315

Caring Network – 'Home-based carers'

St. Martins Katolieke Kerk – Kasteelbergweg
Suster Carter
Tel: 934-1244

Dial-a-Ride

Tel: 0800 600 895

Rolstoel huur

S.A. Red Cross Society – Wynberg
Tel: 797-5360

St. Giles – Rondebosch

Tel: 689-8328

Wynberg Pharmacy

Tel: 797-8141

Sonskyn Bejaarde Klub

Kasteelbergweg 59

Ursula Piet
Tel: 934-6200

Rus/Verligting

Conradie Care Sentrum

Tel: 532-3940

St. Luke's Hospice

Tel: 374-1511

Booth Memorial Hospitaal

Tel: 465-4846

Mediese Verskaffers

Bedpan

Medical Supplies – Ysterplaat

Tel: 551-0838

'Nappies'/'Linen savers'

Bishop Lavis Daghospitaal

Suster
Tel: 934-6050

Rolstoel

Bishop Lavis Rehabilitasie Sentrum

Tel: 934-6315

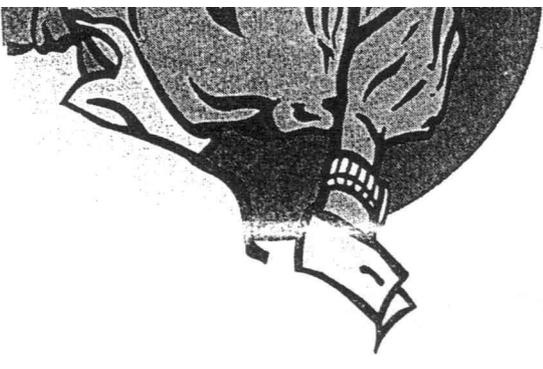
Loophulpmiddels

Bishop Lavis Rehabilitasie Sentrum

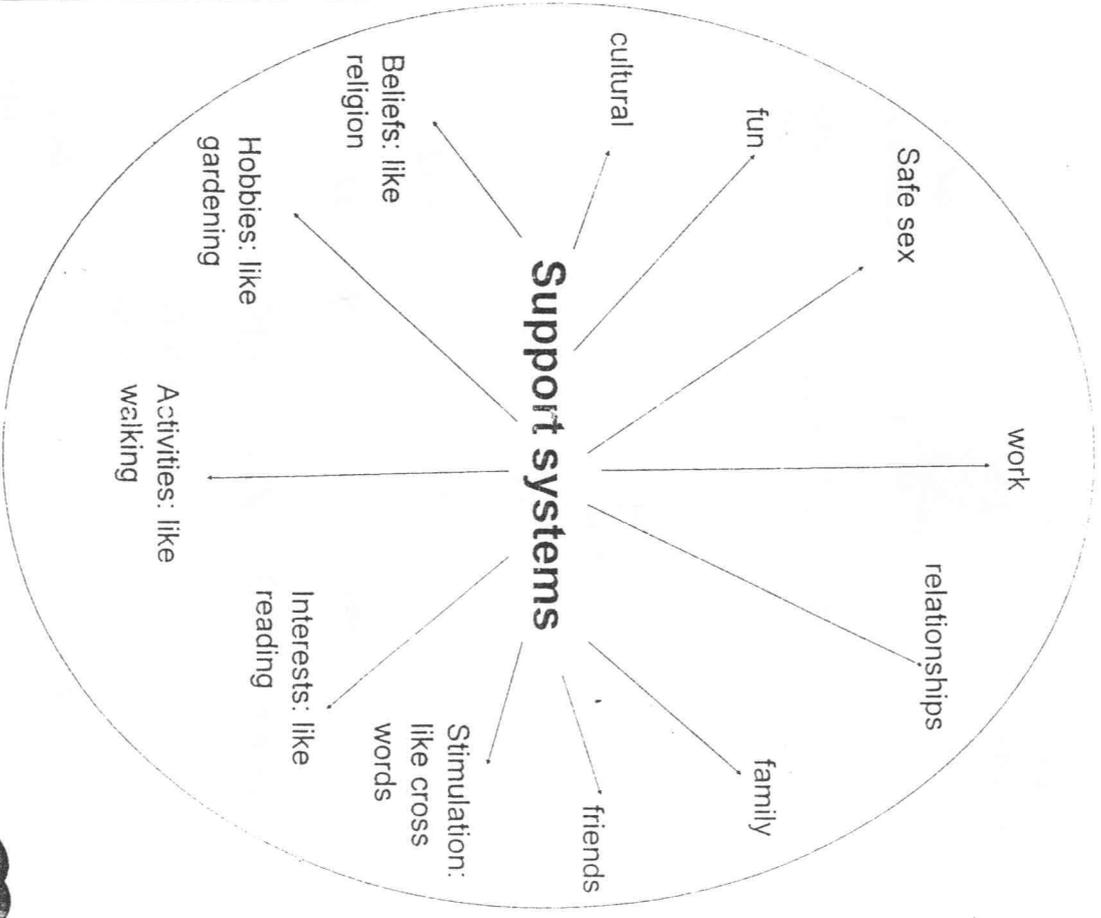
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DO IT!



SS MANAGEMENT.....



STRESS



STRE

?WHAT IS STRESS?

Your bodies health

CHANGE

Daily Routine

SYMPTOMS OF STRESS

BIOLOGICAL

PSYCHOLOGICAL

- Stiff muscles
- Headaches
- Constipation
- High blood pressure
- Heart attack
- Depression
- Irritability
- Aggression
- Can't concentrate

SO, WHAT DO I DO?!

Imagine change (worrying)

FIRST = Identify what the stressor is

SECOND = Take a break

THIRD = One of the following:

Change the way you think

- Think positively
- Like yourself
- Accept other people for who they are

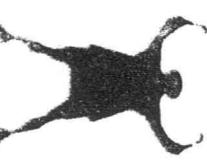
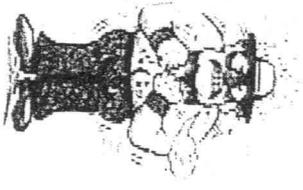
MANAGE STRESS

Change your environment

- Keep your house tidy
- Change your job
- Organize

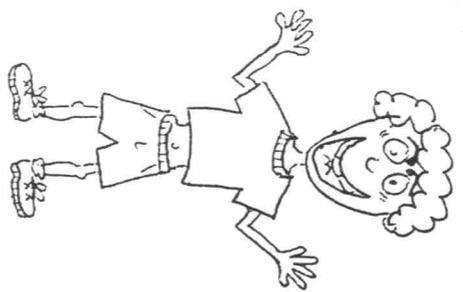
Help your bodies reaction

- Go for a walk
- Relaxation therapy
- Physical exercise
- Watch TV



TYPES OF STRESS

- 1) EMOTIONAL
- 2) ILLNESS
- 3) PUSHING YOUR BODY TOO HARD
- 4) ENVIRONMENTAL FACTORS
- 5) HORMONAL FACTORS
- 6) TAKING RESPONSIBILITY FOR OTHERS



SOME EXTRA TIPS

- Maintain a sense of humor
- Get a message
- Exercise regularly
- Maintain a healthy diet
- Limit alcohol and cigarette's
- Use support systems
- Delegate responsibility
- Take time to manage your time
- Get enough sleep to recharge your 'batteries'
- Avoid conflict with other people
- Accept what can't be changed, don't ignore it
- Plan ahead: plan the night before
- what you will be doing the next day
- Use your power to say NO
- SET UP A DAILY ROUTINE

ADDENDUM I

**CAREGIVER SUPPORT INTERVENTION PROGRAMME
2 AND 3 (CSIP 2 & 3)**

Outline for presenters

CAREGIVER SUPPORT INTERVENTION PROGRAMME 2 AND 3 (CSIP 2 & 3)

Outline for the programme presenters

CSIP 2: 4 May - 1 June 2005

CSIP 3: 3 – 31 August 2005

SESSION 1: PHYSIOTHERAPIST/ RESEARCHER

4 May 2005 & 3 August 2005: 14h00-15h30

- Welcome and plan for the five sessions. Give a handout to each carer listing the dates, times, topic and speaker for each session (Addendum J).
The aims of the first session will be discussed.
- Each carer to share briefly about themselves, as well as their interests.
- Snacks (tea, crackers, cheese and cucumber) will be served at this time.
- Address the following:
Group to start promptly at 14h00 and end at 15h30.
Carers to attend all five sessions for optimal learning and support.
Personal information shared in the group will be kept confidential.
- Ice-breaker: Each of the carers will wear a paper hat with a food type labelled on it. They will each get an opportunity to ask questions to the group, to be able to find out what type of food they are.
- Education on what stroke is - explain a blockage or burst in a pipe by visual illustration.
- Education on the causes, risk factors, prevention and warning signs of stroke will be discussed by visual illustration on a whiteboard. A pamphlet titled: 'Beroerte is 'n brein aanval' will be handed out to the carers (Addendum H.2).

- Demonstration and practice of a home exercise suitable for the stroke patient. The carers will work in pairs with supervision from the physiotherapist.
- Written and verbal feedback will be taken at the end of the session.

SESSION 2: PHYSIOTHERAPIST/ RESEARCHER

11 May 2005 & 10 August 2005: 14h00-15h30

- A brief recap will be done on the initial session.
- The aims of the session will be discussed.
- Back protection and kinetic handling principles will be discussed using a poster and practical demonstration. Carers will each get the opportunity to practise lifting 3-5kg boxes while applying these principles.
- Education and practice of effective hemiplegic transfers from the bed to the commode will be done, emphasizing correct back protection principles. Carers will work in pairs with supervision from the physiotherapist.
- Snacks (tea and cookies) will then be served.
- Explanation and demonstration of two additional home exercises suitable for the stroke patient, will be done. Carers will work in pairs with supervision from the physiotherapist, when practising these exercises. A handout with pictures and a brief explanation of the exercises will also be given to each carer (Addendum J.2).
- Written and verbal feedback will be taken at the end of the session.

SESSION 3: OCCUPATIONAL THERAPIST

18 May 2005 & 17 August 2005: 14h00-15h30

- A brief recap will be done on the second session.
- The aims of the session will be discussed.
- Application of the basic hemiplegic principles in self-care activities of daily living like eating, washing, dressing and toileting will be demonstrated. The carers will practise these in pairs, with supervision from the occupational therapist.
- A variety of assisted devices will be demonstrated to the group like a wash mitten, back washer, non-slip mat, grab rail, bath board, etc.
- Snacks (tea, muffins, crackers and cheese) will be served at the end of the session.
- Written and verbal feedback will be taken at the end of the session.

SESSION 4: DIETICIAN AND SPEECH AND LANGUAGE THERAPIST

25 May 2005 & 24 August 2005: 14h00-15h30

- A brief recap will be done on the previous session.
- The aims of the session will be discussed.

DIETICIAN

- Feeding problems and dietary advice for stroke patients with swallowing problems, constipation, hypertension and poor appetite, will be discussed. A nutritious smoothie consisting of yoghurt, milk, ice-cream and vanilla essence will be made for the carers to taste. The dietician will write a variety of different foods on papers for the carers to compile a healthy meal for stroke patients with swallowing and chewing problems. A handout will be given to the carers titled: ' Voeding ondersteuning vir persone na 'n beroerte' (Addendum J.3).

- Snacks (tea, crackers and cheese) will be served at this time.

SPEECH AND LANGUAGE THERAPIST

- Management of speech and swallowing problems associated with a stroke, will be discussed. A handout will be given to the carers on guidelines for communication disorders (Addendum H.4).
- Written and verbal feedback will be taken at the end of the session.

SESSION 5: PHYSIOTHERAPIST AND OCCUPATIONAL THERAPIST

1 June 2005 & 31 August 2005: 14h00-15h30

- A brief recap will be done on the fourth session.
- The aims of the session will be discussed.

PHYSIOTHERAPIST

- Carers will be informed of the resources and services available for the stroke patient in the Bishop Lavis community. A list of these services will be discussed and handed out to each carer (Addendum H.5).

OCCUPATIONAL THERAPIST

- The causes, symptoms and management of stress will be explained by using visual aids.
- The carers will have the opportunity to share about their stressors and also encouraged to pursue their leisure interests.
- The principles of relaxation therapy will be discussed by the occupational therapist. Carers will then participate in a 20-minute Jacobson progressive relaxation therapy session on the mats.
- A pamphlet will be given to the carers titled: 'Stressed out?' (Addendum H.6).

- Snacks (tea and cookies) will be served at the end of the session.
- Written and verbal feedback will be taken at the end of the session.
- A final round-up will be done and carers will be encouraged to continue in a stroke carer support group facilitated by the occupational therapist at the Bishop Lavis Rehabilitation Centre.

ADDENDUM J

ADDITIONAL HANDOUTS FOR CSIP 2 & 3

- J.1. 'Beroerte versorger program rooster vir Mei en Aug 2005'
- J.2. 'Tuis oefeninge vir beroerte pasiënte'
- J.3. 'Voeding ondersteuning vir persone na 'n beroerte'

STROKE VERSORGER PROGRAM ROOSTER VIR MEI 2005

TYD:2-3.30 NM

WOENSDAG 4 MEI

SPREKER: Fisioterapeut

- Die veroorsake en voorkoming van stroke.
- Tuis oefening.

WOENSDAG 11 MEI

SPREKER: Fisioterapeut

- Hoe om die pasiënt te verplaas van bed na stoel/commode.
- Tuis oefeninge.

WOENSDAG 18 MEI

SPREKER: Arbeidsterapeut

- Hoe om die pasiënt te help met was, aantrek, eet en toiletgebruik.

WOENSDAG 25 MEI

SPREKER: Dieetkundige en Spraakterapeut

- Hoe om die pasiënt te help wat sluk en spraak probleme het.
- Watter kos is toepaslik vir die beroerte pasiënt.

WOENSDAG 1 JUN

SPREKER: Fisioterapeut en Arbeidsterapeut

- Dienste beskikbaar in die Bishop Lavis gemeenskap.
- Streshantering en ontspanningsterapie.

**STROKE VERSORGER PROGRAM ROOSTER VIR
AUGUSTUS 2005
TYD:2-3.30 NM**

WOENSDAG 3 AUG

SPREKER: Fisioterapeut

- Die veroorsaake en voorkoming van stroke.
- Tuis oefening.

WOENSDAG 10 AUG

SPREKER: Fisioterapeut

- Hoe om die pasiënt te verplaas van bed na stoel/commode.
- Tuis oefeninge.

WOENSDAG 17 AUG

SPREKER: Arbeidsterapeut

- Hoe om die pasiënt te help met was, aantrek, eet en toiletgebruik.

WOENSDAG 24 AUG

SPREKER: Dieetkundige en Spraakterapeut

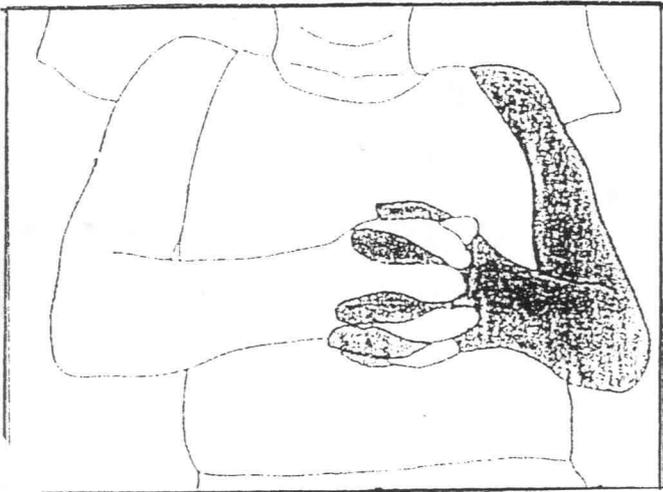
- Hoe om die pasiënt te help wat sluk en spraak probleme het.
- Watter kos is toepaslik vir die beroerte pasiënt.

WOENSDAG 31 AUG

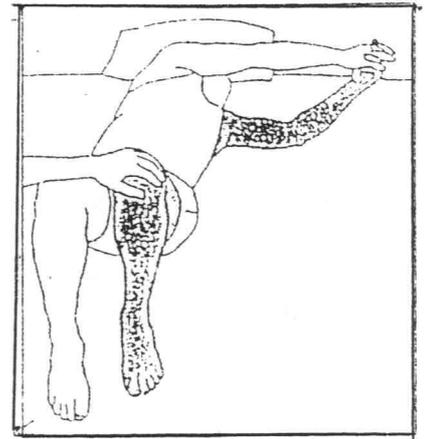
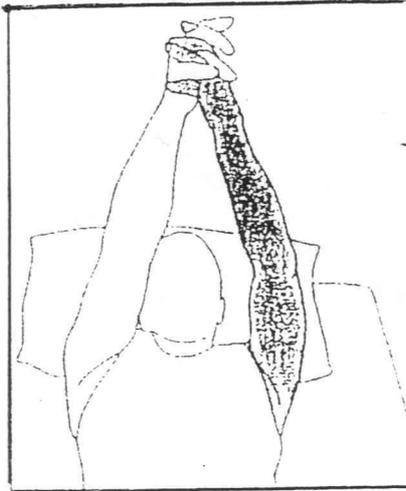
SPREKER: Fisioterapeut en Arbeidsterapeut

- Dienste beskikbaar in die Bishop Lavis gemeenskap.
- Streshantering en ontspanningsterapie.

TUIS OEFENINGE VIR BEROERTE PASIENTE

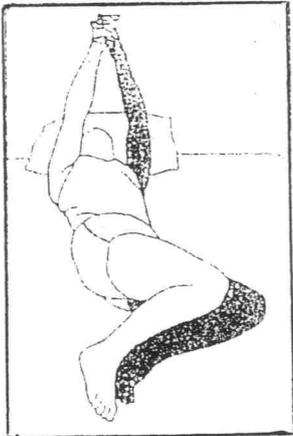


Komprotasies



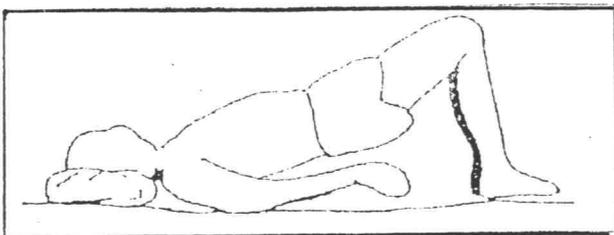
① Ruglê: knieë opgebuig en voete plat op bed.

- Vleg vingers innemekaar
- Strek arms op na dak
- Hou bene stil, terwyl u die bolyf met gestrekte arms so ver as moontlik van kant tot kant beweeg, stadig en met beheer.



② Ruglê: knieë opgebuig en voete plat op bed.

- Hou die bolyf stil terwyl die bene stadig van kant tot kant beweeg stadig en met beheer.
- In Helper kan die skouers en bolyf stabiliseer en ook help met die beenbewegings.



③ Brug

- Lê met die knieë opgebuig
- Trap op beide voete vas en lig die boude
- Kyk dat albei heupe ewe hoog gelig word
- Sak die boude weer stadig terug.

Voeding ondersteuning vir persone na 'n beroerte

Direk na 'n beroerte, sukkel persone dikwels om te sluk, en daarom moet hulle spesiale voeding kry. Dit verbeter dikwels gou, en dan kan hulle weer saam met die res van die huisgesin begin eet. Na 'n beroerte is dit baie belangrik dat 'n persoon gesond moet eet, om bloeddruk te probeer beheer, en om gewig te beheer (hetsy of die persoon ondergewig of oorgewig was/is). Die volgende probleme kom soms voor, en kan hanteer word deur die persoon se dieet aan te pas:

Probleem	Oplossing
Kan glad nie sluk	Persoon moet 'n buisvoeding kry. Produkte is beskikbaar by die daghospitaal.
Sluk moeilik	Gee meer sagte kos of vloeistowwe Dikwels nodig om 'n drankie vir aanvulling te gee Klein gereelde maaltye Verryk kos met ekstra margarine/olie/suiker as persoon nie oorgewig of diabeet is nie
Swak eetlus	Gee voorkeur kosse Klein gereelde maaltye Dikwels nodig om 'n drankie vir aanvulling te gee Verryk kos met ekstra margarine/olie/suiker as persoon nie oorgewig of diabeet is nie Vermy vloeistowwe met min krag / voedingswaarde (bv tee/koffie)
Hoë bloeddruk	Min sout Min vet Verloor gewig indien oorgewig
Hardlywigheid	Vermeerder growwigheid / vesel Gereeld water

Goeie keuses	Vermy:
<input checked="" type="checkbox"/> Tuisgemaakte sop - baie groente, min sout	<input checked="" type="checkbox"/> Lucozade
<input checked="" type="checkbox"/> Suiwer vrugtesap - nie verdun met water, nie suiker bygevoeg	<input checked="" type="checkbox"/> Tee, koffie
<input checked="" type="checkbox"/> Gekookte pap - kook in melk, voeg bietjie margarine / olie by	<input checked="" type="checkbox"/> Cup a soup
<input checked="" type="checkbox"/> Tuisgemaakte drankies - melk met eier en vanilla, melk met piesang fyngedruk, melk met grondboontjebotter, yoghurt en melk gemeng en versoet met suiker of heuning	<input checked="" type="checkbox"/> Fiesta/cabana sap met melk basis
<input checked="" type="checkbox"/> Melkdrankies bv milo	
<input checked="" type="checkbox"/> Tuisgemaakte bredies	

ADDENDUM K

**LETTERS OF CONSENT FROM THE PROVINCIAL
ADMINISTRATION OF THE WESTERN CAPE AND
STELLENBOSCH UNIVERSITY**

ENQUIRIES Dr C. Le Grange
TELEPHONE (021) 4609118
FAX (021) 4476728

PROVINCIAL ADMINISTRATION: WESTERN CAPE
DEPARTMENT OF HEALTH

REFERENCE

PROVINSIALE ADMINISTRASIE: WES-KAAP
DEPARTEMENT GESONDHEID

DATE 08 December 2003
KOLONI

ULAWULO LWEPHONDO: IN' SHONA
ISEBE LEZIMI'ILO

TO WHOM IT MAY CONCERN

Dear Ms. Kleineibst

Re: Permission To Access Patient Records

Permission is hereby given for Ms. Lynn Kleineibst to visit Community Health Centre's managed by C.H.S.O. You can access the records/details of the new stroke patients who will be seen by the doctors and nurses at the Bishop Lavis Community Health Care Centre between November 2003 and June 2004. A letter of permission has been sent to Sr. Anthony, whom you will be working with.

Your co-operation is appreciated.

Yours faithfully


DR C A LE GRANGE
SENIOR MEDICAL SUPERINTENDENT (ACTING)

COMMUNITY HEALTH SERVICES ORGANISATION
GEMEENSKAPS GESONDHEIDSDIENSTE-ORGANISASIE
PRIVATE BAG 7 PRIVAAT SAK 7 WOODSTOCK CAPE TOWN 7915
TELEPHONE 021-4609100 TELEFOON 021-4609100 FAX 021- 471959



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Ms Lynn Kleineibst
Physiotherapist
Bishop Lavis Rehabilitation Centre

Dear Lynn

**PERMISSION TO ACCESS PATIENT RECORDS HELD AT BISHOP LAVIS
REHABILITATION CENTRE**

Following consultation with Mrs Susan Beukes, Head: Department of Occupational Therapy, you are granted permission to access the records of the new stroke patients referred to the above centre between November and June 2004, for the purposes of data collection purposes for the research project for the degree -MSc (Physiotherapy).

The above permission is granted on condition that the project has the ethical approval of the Committee of Human Research, Faculty of Health Sciences, University of Stellenbosch.

Best wishes for the successful completion of this worthwhile project,
Yours sincerely,

MARY FAURE
CHAIRPERSON: DEPARTMENT OF PHYSIOTHERAPY



Fakulteit Gesondheidswetenskappe • Faculty of Health Sciences

