THE PERCEIVED BURDEN OF CARE FOR CAREGIVERS OF POST DISCHARGED CVA PATIENTS WITH FUNCTIONAL IMPAIRMENTS AT A PRIVATE REHABILITATION UNIT IN BLOEMFONTEIN

by

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DECLARATION

I, Lyndall Serfontein, declare that the Master's Degree interrelated, publishable articles that I herewith submit for the Master's Degree qualification in Occupational Therapy at the University of the Free State is my independent work, and that I have not previously submitted it for a qualification at another institution of higher education.

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DISCLOSURE

The researcher received a bursary for part of her studies from the inpatient rehabilitation unit where she is employed and where this study was conducted, as well as from the University of the Free State where she is registered as a postgraduate student. However, capturing of the data were completely objective and the data analysis were done by the Biostatistics department at the University of the Free State.

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LIST OF ACRONYMS AND ABBREVIATIONS

Acronym	**Definition**
CSI	Caregiver Strain Index
CVA	Cerebrovascular accident
FIM	Functional Independence Measure
MCSI	Modified Caregiver Strain Index
RSA	South Africa

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ARTICLE 2

1. INTRODUCTION AND BACKGROUND TO THE STUDY

Cerebrovascular accidents (CVAs), or strokes, are a debilitating condition which causes international concern. Throughout all rehabilitation outcome levels, therapeutic intervention plays a vital role in recovery, starting in the acute hospital and continuing through inpatient rehabilitation as well as post discharge. Unfortunately, not all patients have access to all levels of rehabilitation and healthcare in South Africa. Both public as well private sector healthcare facilities fail to ensure optimal functional recovery for all CVA survivors. More demands are therefore placed on family members and informal caregivers to take on the caregiving of these patients, as well as to re-establish CVA survivors' community integration and productive activity, which often results in a high burden of care. Caregivers experience challenges on many levels and does not always have the necessary support systems to assist them. These challenges can prevent them from participating in occupations that are meaningful to them. Patients' needs are often placed before their own, resulting in a high burden of care and influencing caregivers' health and well-being.

Greater focus should thus be placed on aspects such as caregiver training, structured support, home visits to assess accessibility, outpatient rehabilitation services, home based caregiving services, and support groups post discharge. However, such support structures are not always available everywhere in South Africa (RSA) and are not affordable to all patients. Caregiving thus becomes the unplanned occupation of family members of patients with CVA, and rehabilitation needs to prepare family members/caregivers for their new occupation as caregivers. A survey of extant literature shows a lacuna in terms of available research conducted regarding the co-occupation of caregiving, specifically for patients with CVA in the South African context. Furthermore, there is a distinct lack of studies unique to the South African context regarding determining the burden of care post discharge from a private, inpatient rehabilitation setting. Finally, an exploration of a possible gap between private inpatient rehabilitation and discharge is required, as inpatient rehabilitation does not necessarily address aspects such as community reintegration and productive activity, which can result in increased burden of care for caregivers, if no patient follow up take place post discharge.

This study reports on factors associated with burden of care as experienced by caregivers of people with functional impairments due to a CVA, after their discharge from a private rehabilitation unit in Bloemfontein. This dissertation is structured as two publishable articles. These articles have been prepared for submission to the South African Journal of Occupational Therapy, and the journals' author guidelines (including the Vancouver referencing system) have therefore been followed in the preparation of both articles. The journal was deemed appropriate as a first choice for submission of this content, in view of it's scope to provide contributions related to service delivery in Africa. The articles have not yet been submitted for reviews to this, or any other journal. For examination purposes, the articles are more elaborate than what is usually allowed in the guidelines of this journal and it will be shortened and prepared for publication after the examination process.

The first article, a literature review, discusses caregiving as the unplanned occupation experienced by many caregivers of patients with CVA with functional impairments in South Africa in terms of the impact of CVA on survivors, the importance of rehabilitation for the survivor of CVA, funding of rehabilitation, as well as caregiving and support structures. It further clarifies the occupation and co-occupation of caregiving, as well as the implications of caregiving, such as burden of care experienced by informal caregivers. This is followed by a discussion and recommendations for clinical practice, with the emphasis on caregiver training. The second article reports on a quantitative, descriptive study, focussed on determining the perceived burden of care for caregivers of post discharged patients with CVA with functional impairments at a private rehabilitation unit in Bloemfontein. Telephonic follow-ups were done with caregivers of patients with CVA post discharge in order to determine the burden of care experienced as well as contributing factors. The article highlights the benefits of inpatient rehabilitation (as most patients need minimal assistance upon discharge), but also emphasises the gap between inpatient rehabilitation and discharge, as caregivers still experience a minimal to moderate degree of burden of care after discharge. The article further discusses aspects which caregivers report as contributions to their burden of care at two months after discharge, including financial, physical, psychological, social, and personal aspects. It further highlights how the role and occupations of caregivers relate to their perceived burden of care.

In conclusion, this study highlights the need of establishing guidelines for inpatient rehabilitation units, medical schemes, as well as outpatient therapy services in order to prevent/reduce burden of care within the private inpatient rehabilitation setup, as well as post discharge, through incorporating the necessary programmes and funding in order to overcome the gap between inpatient rehabilitation and discharge.

2. ARTICLE 1 (LITERATURE REVIEW)

Title of Article (Presented as a Literature Review)

Caregiving as an Occupation in the Context of Stroke Rehabilitation in South Africa

2.1 ABSTRACT

Recent surveys show an alarming increase in the number of individuals suffering from strokes annually, resulting in functional impairments. Comprehensive rehabilitation is crucial in order to enhance patients' level of independence in daily activities and to facilitate community integration. Unfortunately, rehabilitation services in South Africa are hampered by several factors, leaving many patients without the opportunity for comprehensive rehabilitation. This place a higher burden of care on informal caregivers and family members, who are often forced to take up the unplanned occupation as caregivers. Not being adequately prepared for this new role results in occupational loss and unbalanced activity profiles. Caregiver education, home-based caregiving services, support groups, and therapeutic home visits should, therefore, take priority. Therapeutic intervention throughout all rehabilitation outcome levels is advised in order to assist with the transition between the rehabilitation and community reintegration phase of patients with strokes, in order to ensure that they will be as independent as possible in their daily occupations and decrease the burden on caregivers. This literature review aims to provide a background of the current rehabilitation services in South Africa for persons who suffered strokes, the occupation of caregiving, caregivers' burden of care, as well as recommendations for clinical practice.

Key words: Strokes, Caregivers, Occupation of Caregiving, Burden of Care, Rehabilitation, South Africa

2.2 INTRODUCTION

The debilitating condition Cerebral Vascular Accident (CVA), or stroke, is suffered by more or less 75 000 people in South Africa (RSA) annually[3-5]. Insufficient and ineffective public health systems often contribute to the causes of CVAs, since lower socio-economic groups are often more exposed to risk factors, being dependent on public health systems for access to preventative treatment[1]. In addition, insufficient public health systems result in patients with CVA being discharged from hospital too soon, due to a shortage of staff and resources. A lack of stroke-specific policies and protocols, a limited number of rehabilitation units, and a lack of specialised care for patients with CVA, further contribute to patients not receiving optimal care, resulting in patients not becoming as functional and independent as possible[2]. As a result, the majority of CVA survivors often experience permanent impairment and need assistance from others in performing daily activities[3-5].

Rehabilitation plays a vital role in hospital[6] as well as post discharge (such as outpatient therapy and home-based care)[7], in order to allow the person who suffered a CVA optimal independence in daily activities, community integration, and a return to productive activities (i.e. paid work) for financial independence[6]. Successful rehabilitation, therefore, needs to allow for 0: physiological instability, I: physiological stability, II: physiological maintenance, III: residential integration, IV: community integration and V: productive activity. These aspects are described in Table I as the six levels (Levels 0 - V) of rehabilitation by Landrum, Schmidt, and McClean (cited by Hassan, C[8]).

In South Africa, pockets of rehabilitation for survivors of CVA are available in both the public and private sectors. In general, however, the provision of comprehensive and sufficient rehabilitation services[8] by the healthcare system in South Africa is hampered by a number of factors. These include a great shortage of medical personnel[1], limited access to in-patient rehabilitation services[6], as well as insufficient finances for and transport to outpatient therapy[4]. In private medical facilities rehabilitation services is hindered in that medical schemes only fund a limited number of therapy sessions[9], rendering patients incapable of completing all levels of rehabilitation. Patients are often discharged from the inpatient rehabilitation unit when they have reached a reasonably functional status, with referral to, but without continued outpatient therapy and rehabilitation services in the community[8]. The transition from hospital to home is therefore often problematic to the patient with CVA and their family/caregivers, as they might be medically stable, but are not yet independent. Patients are mostly discharged from acute hospitals when they have reached rehabilitation levels I - II (physiological stability or physiological maintenance). Those who are admitted to inpatient rehabilitation units mostly reach level III (residential integration). Community-based rehabilitation, including outpatient therapy, is needed to reach levels IV and V (community integration and productive activity)[8].

Although employed caregivers can be provided by professional caregiver associations in South Africa, their services are not available in all South African provinces and towns, and are unaffordable to most patients in need of care[6]. It is the author's experience that certain private medical schemes have programmes that allow patients to qualify for a professional caregiver for up to two weeks after their discharge, although families are still responsible for their own caregiving after that. For patients discharged from public hospitals, there are, however, no such services. Consequently, healthcare systems rely on informal/unpaid caregivers of patients with CVA as the "extension" of rehabilitation care delivery[10]. An increased demand is placed on family members and/or caregivers who are often forced to take up the unforeseen role as caregiver for the patient with CVA[11].

Caregiving thus often becomes the "unplanned" occupation, a full-time job and challenge to family members of patients with CVA[12]. This role transition from family member to caregiver and the preparation for their new occupation has, therefore, become increasingly important in the broader, comprehensive rehabilitation of patients with CVA. Although much has been written about caregiving and burden of care, limited research is available on the occupation (also referred to as co-occupation) of caregiving for patients with CVA in the South African context, specifically from an occupational therapy point of view.

In this literature review, the researcher argues that the currently available rehabilitation services in South Africa for the survivor of CVA are not sufficient, creating a great need for caregiving. The experience of being a caregiver of a survivor of CVA is viewed from an occupational perspective, referring to the implications of caregiving on the caregiver, as well as burden of care. The researcher concludes with recommendations for clinical practice, acknowledging the caregiver's essential and valuable role in the rehabilitation of the survivor of CVA.

2.3 CURRENTLY AVAILABLE REHABILITATION SERVICES IN SOUTH AFRICA FOR THE CVA SURVIVOR

2.3.1 Statistics on CVAs in South Africa

Cerebrovascular accidents (CVAs) are one of the four main non-communicable diseases, including cardiovascular syndromes such as CVAs, diabetes, cancers, and chronic respiratory conditions[13]. Countries with low or middle socio-economic conditions, such as South Africa, are mostly affected by non-communicable diseases. Non-communicable diseases account for 82% of the 16 million annual deaths worldwide[1]. Forty percent of CVAs which occurred in Africa in 2005 were suffered by persons under the age of 70 years[14]. Survivors of CVA seem to mostly be adults over 45 years of age[15]. Women seem to be more affected by CVAs than their male counterparts[7].

According to Statistics SA, 29% of all deaths in the country are due to non-communicable diseases, of which 18% alone are caused by cardiovascular diseases such as CVAs[16]. The survival rate of CVA victims in South Africa is estimated at 243 per 100 000[4]. This low survival rate results in CVA being the second largest leading cause of mortality in the country[5].

2.3.2 Impact of CVA on the Survivor

CVA survivors often experience a variety of cognitive, physical and functional impairments, depending on the severity and area of the brain affected. A full recovery is usually likely in only 45% of said survivors[17]. Most patients need assistance with their daily activities after a CVA and might need assistance from their support systems[3,4]. Patients do, however, show most progress and recovery within three to six months after their CVA[18]. Early intervention is thus crucial in order to optimise functional outcomes of CVA survivors.

Commonly affected cognitive abilities include abstract reasoning, planning, problem-solving skills, visual perceptual skills such as visual-motor integration, spatial relations, and sequencing, concentration, memory, basic mathematics, following of instructions, as well as constructional abilities[19]. Impaired cognition could further be negatively influenced by visual impairments. A study by Cawood, Visagie, and Mji (2016) indicates that 66% of CVA survivors exhibited progressive visual impairments, 8% suffered from hemianopia, and 6% experienced double vision[3]. Cognitive abilities as well as emotional well-being further have a tremendous influence on patients' ability to optimally participate in activities of daily living (such as social activities, managing children or a family, returning to work, and performing basic calculations needed in order to budget or shop for groceries), even if physical impairments are limited[3].

Another impairment often experienced by a significant number of patients who suffered a CVA includes incontinence of bladder and/or bowels[3,7], which have a negative influence on their functional independence[7].

Consequences of CVA are further seen in functional impairments with regard to personal independence tasks, motor skills such as gait or stair climbing, as well as communication, which again can result in impaired social interaction, ability to perform household tasks, recreation, and ability to return to work[3,4].

Applications for disability grants can also be impacted by impaired cognition, due to patients with cognitive impairments struggling to negotiate the process of applying for a disability grant. Moreover, patients might not be able to qualify for a disability grant, as the magnitude and impact of cognitive impairments are not always obvious[3]. Without the support of disability grants, an even higher financial burden is placed on patients' caregivers to take care of them.

It is therefore evident that CVA is a complex and potentially debilitating condition, often leaving patients to experience permanent functional impairments. Rehabilitation through all the rehabilitation levels are thus vital in order to increase their quality of life.

2.3.3 Importance of Rehabilitation for the Survivor of CVA

Rehabilitation is crucial in order to enhance patients' level of independence in their daily activities, facilitate community integration, as well as the process of returning to work and being more financially independent[6]. It is important to refer patients for rehabilitation as soon as possible in order for therapy to be as efficient as possible. Early intervention is crucial for ensuring the best possible functional outcomes and for reducing the possibility of complications arising from aspects such as abnormal movement patterns[16]. Inadequate rehabilitation following a CVA could lead to higher levels of dependence in activities of daily living, increased disability rates, and even higher mortality rates[6], resulting in a higher burden on especially older caregivers, which in turn will place a higher burden on healthcare services in South Africa[20].

The Occupational Therapy Association of South Africa's position paper on rehabilitation[21] supports the fact that rehabilitation needs to empower persons with functional disabilities to become independent, be part of a community, and participate in work. Early intervention in a multi-disciplinary setup is essential in order to limit disability and enable persons to return to their premorbid level of function. It fills the gap between medical management and community reintegration, ensuring quality of life. Apart from the right to access medical care, patients also have the right, from an occupational therapy point of view, to engage in activities in which they find purpose. They should be enabled to participate in their communities and reach their maximum potential. If patients are unable to participate in activities which are meaningful to them, either due to a medical condition resulting in disability or due to environmental factors which limits participation, rehabilitation aims to assist patients in taking up novel, meaningful activities. Rehabilitation should continue after discharge in various environments, such as the workplace, where appropriate employment and adaptations are ensured, while taking mental and/or physical disability into account. Therapy should also focus on the necessary adaptations in the home environment, ensuring accessibility, as well as community reintegration where social interaction can take place[21].

As described so far, the consequences of a CVA are vast, and comprehensive rehabilitation is required. Landrum, Schmidt and McClean (cited by Hassan et al.[8]) describe rehabilitation as a process consisting of six levels through which a patient must progress in order to successfully complete their rehabilitation. Table I indicates the rehabilitation outcome levels according to Landrum, Schmidt and McClean (cited by Hassan et al.[8]) through which a patient must progress in order to experience successful rehabilitation:

Table I: Rehabilitation Outcome Levels according to Landrum, Schmidt, and McClean (cited by Hassan, et al.[8])

LEVEL	DESCRIPTION	TASKS THAT SHOULD BE MASTERED TO ACHIEVE THE LEVEL
Level 0: Physiologic instability	Acute diagnostic and medical issues are not addressed and managed	• Directly following a health incident such as a stroke
Level I: Physiologic stability	All major acute diagnostic and medical issues are appropriately addressed and managed	• Diagnosis made • Treatment plans decided on and implemented, e.g. hypertension controlled through medication
Level II: Physiologic maintenance	Achievement of basic rehabilitation outcomes necessary to preserve long-term physiological health	• Client and family educated and trained • Rehabilitation and long-term management plans in place • Strategies to prevent secondary complications in place: ○ Bladder and bowel ○ Diet, swallowing and aspiration ○ Prevention of chest infections Pressure sore prevention ○ Prevention of contractures ○ Emotional support ○ Pain management ○ Limited physical and cognitive outcomes, such as mobility and communication can be achieved, but are not the focus of this level
Level III: Residential integration	Achievement of status where the person can function reasonably and safely in a residential setting	• Self-care tasks performed • Mobile in and around dwelling • Effective general communication system • Safe in-home activities, such as self-care, can be performed by another person, but must be directed by the client
Level IV: Community integration	Achievement of an appropriate level of function within the person's community, i.e. participating in social activities such as	• Manage personal affairs and finances • Socially competent • Community mobility

	shopping, church, and sport according to individual needs	- Complex home-making abilities - Self-directed health management
Level V: Productive activity	Work at a competitive level within physical, functional, and/or cognitive capabilities appropriate to life stage and interests. This can be vocational, avocational, or educational	- Environment, disabilities, and job requirements play a role - Work & skills assessment - Vocational training - Employer education - Reasonable accommodations
Note that at all levels, tasks can be performed by a caregiver, but all must be client-directed		

For successful rehabilitation to take place, it is recommended that patients should progress through all six rehabilitation levels (levels 0 - V), up to productive activity. However, patients are mostly discharged from acute hospitals when they have reached physiological stability (Levels I – II) and from the inpatient rehabilitation unit when they have reached residential integration (Level III). Outpatient therapy and rehabilitation services in the community are then usually required in order to achieve community integration and productive activity (Levels IV and V)[8].

2.3.4 Rehabilitation for Patients with CVA in another Country In Contrast With What Is Offered in South Africa

As an example of what comprehensive management of patients with CVAs could look like, the researcher investigated the National Institute for Health and Care Excellence (NICE) principles used in England for management of patients with CVAs in lieu of any relevant guidelines from third world countries. According to these principles, patients with CVA will receive rehabilitation in an inpatient unit dedicated to patients with CVA. Aspects such as cognition, emotional status, swallowing, as well as work assessments are addressed by the team. An assessment is also done by a social worker before the patient is discharged from the hospital, in order to determine their needs at home and in their work environment, accessibility to transport and their community, as well as their needs in terms of caregiving. Once patients can safely transfer from a bed to a chair, and the home environment is regarded as safe and adequately adapted, patients are discharged with support from the community therapy team. Caregiver training is done, caregiver services are arranged where necessary, and necessary assistive devices are provided. Home visits with the patient and his/her caregiver are also carried out, unless the patient is independent in all activities of daily living. Follow-up opportunities are arranged, including rehabilitation services for patients discharged to care facilities. Follow-up with patients and their caregivers take place within 72 hours by the specialist stroke rehabilitation team, after which the same intensity of therapy is applied in the hospital where necessary. All patients are then re-assessed after 6 months, and then annually after their discharge[22].

In contrast, it seems that most patients in the South African context do not receive adequate medical services, rehabilitation, caregiver training, or referrals to outpatient therapy during their hospital stay in acute hospitals, even though the speed, degree of recovery, and outcomes mostly depend on early intervention[6]. Most hospitals do not dedicate any hospital beds or protocols to patients with CVA, and patients are often discharged home as soon as they are medically stable (after an average of 5 – 10 days) due to a lack of beds, limited staff, and finances[2,6,20]. Although rehabilitation units and therapy services are available in both private and public health sectors, they are not necessarily well coordinated with an inter-professional approach[23] or exclusively for patients with CVA[3]. They are also not always conveniently located and accessible to all patients in South Africa. The availability and accessibility of inpatient rehabilitation thus do not seem to be optimal in the local context, either in the private or the public health sector[23].

2.3.5 Funding of Rehabilitation in South Africa

Intervention is available for CVA survivors in the public, private, and non-governmental organisation sectors in South Africa[24]. Unfortunately, according to the Human Resource Strategy for the Health Sector[1], there is a great shortage of medical personnel (including doctors, nursing staff, and rehabilitation therapists) who can provide comprehensive rehabilitation services to all South African patients with CVA. An estimated 19% of patients with CVA do not receive any intervention[5], in spite of the Department of Health emphasising the importance of involving a multi-disciplinary team in rehabilitation, including patients and their caregivers or family members, in order to achieve rehabilitation goals[25].

A limited number of South African citizens are members of medical schemes. Only 23.2% of households have one or more medical aid members and, in total, only 17.4% of South Africans have medical aid memberships. 27% of South Africans make use of private medical services[26]. In the private sector, the primary funders of rehabilitation are usually medical schemes. These funders determine the duration of patients' rehabilitation (which is usually limited), in line with the prescribed minimum benefits of an individual's particular medical scheme plan or option[27]. Although CVA is listed as a Prescribed Minimum Benefits condition, which stipulates that therapy must be funded for patients with this condition, the number of therapy sessions approved are not indefinite. Rehabilitation units are required to report patient progress to relevant medical schemes, in the form of an admission report upon admission, which includes their goals as a team and an estimated time frame needed to achieve these goals. Weekly progress reports with patients' Functional Independence Measure (FIM) scores are also sent to medical schemes. As patients progress or reach a plateau, the focus and intensity of therapy for these patients may shift as their needs change (for example from intensive rehabilitation to caregiver training, prevention of complications, or maintenance of current abilities). Effective communication between medical schemes and healthcare providers in terms of patients' progress, goals, and needs usually result in sufficient rehabilitation for patients and are also affordable to medical schemes, as therapy is terminated or decreased once patients reach a plateau[9].

Unfortunately, patients cannot always stay in rehabilitation units long enough to reach all their rehabilitation goals. If patients reach a plateau or do not show sufficient progress for a certain amount of time, they might have to be discharged before reaching a level of independence in their daily living activities. Although some patients might benefit from ongoing intervention after discharge, such as home-based caregiving and weekly outpatient rehabilitation, this type of care is often not funded by medical schemes. Therapists and service providers can provide motivation to medical schemes for additional funding in order to complete the therapy goals set for a patient[9], but it is the experience of the author that, in most cases, medical schemes do not cater sufficiently for patients' out of hospital rehabilitation needs. If patients can then not fund these services themselves, they have to do without.

2.3.6 Caregiving and Support Post Discharge

Although early intervention, such as inpatient rehabilitation, is crucial for patients to optimise their functional outcome and to lay a solid foundation for skills that need to be developed, it is only the first step in the patients' journey to return to their premorbid function. It provides a safe environment for patients to make sense out of what happened to them and provides them with the necessary tools to start rebuilding their lives after discharge. Financially, inpatient rehabilitation is also beneficial to patients and funders to prevent future complications and to optimise patients' functional outcomes with early intervention. However, rehabilitation is an ongoing and inter-professional process, and if inpatient rehabilitation is not followed up with outpatient therapy and referrals to the necessary healthcare providers in the community, the rehabilitation programme and therapeutic outcomes will not be optimal[23]. Furthermore, inpatient rehabilitation units often only provide rehabilitation up to rehabilitation outcome level III (residential integration) as described by Landrum, Schmidt and McClean (cited by Hassan et al.[8]; *cf.* Table I), which implies that patients are discharged before achieving community integration and productive activity levels where they might be able to participate in social activities or return to work[8]. It further implies that patients often still need to continue with outpatient therapy services and have stronger support systems in place, thus creating a need for, for instance, home-based caregivers.

Unfortunately, the transition between inpatient rehabilitation, discharge, and living at home often seems to be problematic to patients and caregivers in South Africa. Although limited studies are available regarding patients who received private inpatient rehabilitation services, it seems to be of great concern at the Western Cape Rehabilitation centre, serving patients from both public and private healthcare services. According to Hassan et al.[8], no patients in their study were able to continue with outpatient therapy after discharge, and patients thus did not receive the necessary support to achieve levels IV and V in their rehabilitation process[8]. Consequently, caregivers are often confronted with many unresolved matters, such as insufficient adaptations to the home environment and changes in the patient's functional abilities[28], which cannot be adequately addressed by caregiver training alone[4].

Unresolved matters can further be seen in other studies where patients with CVA show poor community reintegration at 12 months post discharge from acute hospitals[29]. This seems to be the case even with patients who complete intensive inpatient rehabilitation at the Western Cape Rehabilitation Centre in Cape Town (serving public and private healthcare patients)[30]. Patients' ability to perform household tasks, such as meal preparation, sustain interpersonal relationships, take part in recreational activities, social interaction, use of transport[29], mobility, work, as well as activities which they find meaningful, all seem to be impaired[30].

The reasons for poor continuation of rehabilitation following discharge include poor availability in rural areas[28] and a shortage of healthcare workers. Sometimes, due to poor communication and discharge planning, patients are not referred for outpatient therapy after discharge. Even if they are referred, and services are available, patients often experience challenges with finances and transport needed in order to attend therapy sessions[4], and patients who were admitted to private inpatient rehabilitation units might not have the finances to continue with private outpatient rehabilitation services. Limited insight from caregivers, differences in expectations, as well as underestimating the level of difficulty of therapy (patients think they can do their own rehabilitation or their caregivers can help them at home), are all reasons why patients are not always able to attend their outpatient therapy sessions[31]. Although patients seem to recover to some degree without receiving therapy, recovery is not optimal, and patients are not able to reach their full functional capacity as soon as possible after a CVA. For reasons discussed throughout this article, patients often remain on a low functioning level. Consequently, family members are often forced to take up unplanned roles as caregivers[11], and caring for patients with CVA becomes a full time "job" with many challenges[12]. Caregivers thus have an important role to play in the rehabilitation of CVA survivors[32].

2.4 THE OCCUPATION OF CAREGIVING

2.4.1 Informal Caregivers

According to Rosalynn Carter at The American Occupational Therapy Association 2014:[33:1]

> There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.

Caregivers, carers or informal carers can be described as someone who provides help and support to a partner, child, relative, friend, or neighbour, who could not manage without their assistance[34]. For the purpose of this article, a caregiver mostly refers to an extended family member, friend or person who volunteers to take care of a patient with CVA after discharge from a private inpatient rehabilitation unit. The caregiver, who may be paid or unpaid[10]; trained as a caregiver or untrained, takes care of the patient at home and not in an institution. This caregiving usually includes/requires assisting the survivor of CVA in activities not generally expected from a family member or friend[35].

The experience of being a caregiver, especially an unpaid, untrained family caregiver, has been well described in literature from several disciplines. It is usually described in terms of "burden of care", describing the strain involved in acting as a carer for the survivor of CVA. For the purpose of this literature review, the researcher focusses on literature allowing better understanding of caregiving as an occupation, and of maintaining an occupational perspective on caregiving in the South African context, where caregivers are usually family members of CVA survivors.

2.4.2 Caregiving as Occupation/Co-Occupation

Not only patients, but all persons, including caregivers, are viewed as occupational beings, and should be allowed to participate in activities which they find meaningful[21]. Caregiving is described by authors as an everyday occupation[36], but more often a co-occupation[37-41], and also a collective occupation[42].

Caregiving as a co-occupation, as described by Pickens and Pizur-Barnekow, involves aspects of shared physicality, shared emotionality, and shared intentionality, embedded in shared meaning[38]. Co-occupation occurs when, for example, a caregiver physically helps a patient to eat, with both working towards the same goals and accepting each other's roles[38,40]. They are both involved in an activity at the same time and it is interactive – both parties are affected by the other's performance of the ativity[39].

Occupations within a relationship are categorised by Doidge[41] as co-occupations where the persons are 'doing with', 'doing to', 'doing for', and 'doing because of', each other. These four categories of co-occupations are present in all relationships[41]. 'Doing with' occupations involve two people participating in an activity at the same time and place, with the same aim and purpose. 'Doing to' also involves two people at the same time and place, although one person is more involved in the activity than the other. Participants' aims and purposes might also vary. 'Doing for' occupations are described as one person doing something for another, not necessarily at the same time or place. 'Doing because of' involves one person participating in an activity because of another person's existence, but does not include the person being aided in the activity[41]. Although Doidge[41] uses examples to describe above mentioned occupations through the relationship of a dog-owner with his/her dog, the researcher will attempt to use examples relating to the context of this article, thus applicable to a caregiver and a patient with CVA. An example of 'doing with' might be a caregiver and patient cooking together where both participate in the same time and place. 'Doing to' might entail a caregiver washing a patient who cannot do it him-/herself. 'Doing for' might comprise a caregiver buying necessities for the patient such as food and clothes. 'Doing because of' might be a caregiver attending an information session regarding CVA.

Although research regarding co-occupations focusses mainly on interactions between mothers and children, the researcher is of the opinion that the principles can also be applied to a survivor of CVA and their caregiver, e.g. if a caregiver assists a patient to dress himself, they are both engaged in the physical activity and intention of getting the patient to dress himself. Emotional responses when achieving their goal may be that of joy or accomplishment, depending on the level of mastery, which results in a sense of meaning for both the caregiver and patient. If the patient needs maximal or total assistance with the activity, the physicality involved will be very high at first. As the patient makes progress, the physicality required will decrease. At first, the emotionality might be high as the patient feels frustrated, but as the activity is mastered, the patient might experience joy and confidence will increase, which will most likely also result in the caregiver experiencing shared joy with the patient and both will find it meaningful. The same principles can be applied for any activity shared by two or more people who have a shared intention, emotion, and physicality in which they find meaning, even when participating in activities such as visiting a doctor or planning a meal together (*cf.* Pickens & Pizur-Barnekow[38]). When participating in co-occupation, two persons thus affect the response of each other within the activity they participate in[43].

In the co-occupation of caregiving, the patient may experience increased disability if not allowed optimal participation in meaningful activities[38], and if not involved in decision-making about activity participation. If patients are not involved in the decision-making process, it may lead to occupational deprivation or injustice for the patients. On the other hand, both the caregiver and patient may find great meaning in their participation in this co-occupation, which may prevent occupational injustice[40].

It is thus important to understand that not only caregivers, but also survivors of CVA are at risk of experiencing occupational injustice, since they are dependent on others to provide them with the opportunity to participate in meaningful activities. McDougall et al.[44] reiterates the importance of understanding the impact of caregiving on both parties involved – the patient and caregiver - in order to be able to enhance occupational balance and justice for both the patient and caregiver[44].

Although it is recognised that caregivers might have positive experiences when fulfilling their role as caregivers and in finding meaning in their occupations as caregivers, it is also important to consider the implications of caregiving, the burden of care, as well as other challenges experienced by caregivers of people with CVA. The occupation of caregiving comes at a potentially very high cost for the person who provides the care, which can then result in occupational loss, occupational disruption, as well as deprivation. It also comes with high expectations from family members and medical staff. However, in South Africa the vital role played by caregivers is not well acknowledged and recognised, and little training and support is provided. In comparison, the United Kingdom has a governmental policy aimed at caregivers as well as available resources, such as telephone helplines, formalised carer training, as well as emergency support[45].

2.4.3 Implications and Burden of Care Experienced by Caregivers

Caregivers are often reported as experiencing many challenges, whilst feeling unheard and poorly supported[10]. They may experience emotional, financial, and even health-related challenges on a daily basis[32,46]. Caregivers experience difficulty participating in their 'usual' occupations, as caregiving-related duties are very time-consuming. Most caregivers give up and stop participating in activities which were previously meaningful and important occupations to them; therefore, occupational loss is often experienced after taking up the role of caregiver[47]. Aspects which negatively affect caregivers' occupational balance include insufficient opportunity to return to or start a meaningful career or activities that they find meaningful or enjoyable[44]. Caregivers also frequently perceive that patients' needs should enjoy preference above theirs, causing them to neglect their own occupational needs. Caregivers' participation in occupations which they find meaningful are thus negatively influenced by limited available time and opportunity, or is no longer seen as a priority[44]. Consequences of occupational loss include higher stress levels, higher burden of care, lower energy levels, and decreased psychological well-being[47].

Caregivers' circumstances differ greatly, and factors that may contribute to the burden of care for some caregivers may not be a burden to others[48]. Common themes which can contribute to a high burden of care are identified in this study through survey of literature regarding burden of care experienced by caregivers of CVA survivors[11,32,46,49-63]. These include demographic factors of caregivers and patients, psycho-social and environmental factors, the physical and psychological aspects of caregivers and patients, as well as patients and caregivers' activity profiles.

2.4.3.1 Demographic Factors

Female caregivers, especially spouses of patients with CVA, seem to have a higher occurrence of anxiety related conditions than male caregivers[49] and experience a higher burden of care[50]. Burden of care is also higher with younger caregivers having to care for their in-laws[51] and with caregivers of patients with more serious and debilitating symptoms[49]. Older and male patients, patients with incontinence, as well as those with visual-spatial perception problems, contribute to a higher burden of care[52].

2.4.3.2 *Psycho-Social and Physical Factors*

Caregivers who receive poor support from their families experience a higher burden of care. Their workload and feelings of isolation increase[53]. Social interaction of caregivers is limited due to more caregiver related obligations. Decreased social interaction of caregivers, could further result in decreased participation in recreation and limited interaction and forming of healthy relationships with other people[54].

Furthermore, financial factors associated with caregiver burden include increased medical-related costs, social, and vocational changes, e.g. family members who stop working in order to be able to take care of the patient[32] and loss of domestic income[55] due to the patients' inability to return to work after the incident[56].

Although patients and their caregivers are usually very positive toward the rehabilitation process, they experience a significant difference between the simulated environment in rehabilitation units and their home environment. One month after discharge from an inpatient rehabilitation unit in Australia, patients experience strain in terms of their daily activities and routines[57]. With assessment of the patients' and the caregivers' combined perception of burden of care, it was found that only 52% of caregivers and patients are satisfied with the therapy they received one year after the CVA[58].

The efficacy of discharge preparation conducted in inpatient rehabilitation facilities, as well as bridging the gap between therapy in rehabilitation units and community-based rehabilitation, are thus evident concerns. Emphasis is placed on the importance of determining factors associated with caregivers' burden of care after discharge in order to follow a more client-centred approach in both treatment and caregiver training in the future.

Three main aspects related to burden of care include caregivers' overall strain, loneliness, and level of dissatisfaction. Burden of care increases in relation to increasing emotional challenges. These emotional challenges range from being the only caregiver to the presence of health-related problems[46], which result in physical, psychological, emotional, social, as well as financial challenges[53]. Psychological problems often experienced by caregivers include tiredness, anxiety, despair, frustration, and isolation as a result of caregiving related duties[32]. According to Carod-Artal et al.[49], depression contributes to burden of care; 30% of caregivers experience depression. Furthermore, anxiety often leads to cardiovascular illnesses and even death[53].

Fulfilment of caregivers' personal needs, such as a healthy social life, the availability of stroke prevention information, prevention of their own tiredness, and optimal management of patients' mood fluctuation, mediate the level of burden of care experienced with caregiving[50]. However, specific aspects affecting each individual's psychological health differ greatly[53]. Caregivers of patients with CVA frequently do not feel equipped to handle CVA survivors in terms of their special bodily, psychological, and mental requirements after discharge[46], an issue which should specifically be addressed during rehabilitation. Furthermore, caregivers' view of their problem solving skills before discharge predict their perceived social support and physical health post discharge[64].

Excessive stress experienced by caregivers could lead to unnecessary placement of patients in institutions, which can lead to an even higher burden on the public as well as private health care systems. Unnecessary placement can be prevented by providing the necessary support for caregivers and patients[62], as well as through "learned resourcefulness", which is the ability to manage stressful situations, emotions and problems in a changing environment[63].

2.4.3.3 Activity Profiles

Improvement in patients' physical abilities[59], mental functions, and independence in terms of daily living activities, all positively influence relieving burden of care[52]. The higher the level of patient dependence in activities of daily living, the more time caregivers will have to spend assisting patients[53]. Kamel et al.[60] notes a strong correlation between patients' levels of dependence in daily living activities as well as depression, and caregivers' burden of care. Caregiver burden increases with patients' depressive symptoms, which also directly and negatively influences caregivers' quality of life[60]. The importance of inpatient rehabilitation, as well as occupational therapy intervention after discharge are thus emphasised, in order to ensure that patients reach and maintain their highest level of functional independence. This will not only increase the quality of life of patients, but also reduce the burden of care on caregivers and prevent deterioration of their own health. Patients will thus benefit from maximum therapy funding from medical scheme providers in order to prevent either the re-admission of patients or the admission of caregivers. Caregivers' recreational activities, daily routines, and balance of their activity profiles are often negatively influenced by their caregiver duties, mostly due to patients' slow speed of task completion[57], caregivers' long working hours, high levels of stress, poor quality of sleep, financial difficulties[51], and extreme fatigue[11].

The literature surveyed therefore clearly indicates that, if caregivers are insufficiently trained, are unable to cope with the high demands of their roles as caregiver, or if patients are not adequately taken care of, severe consequences can be expected. Intervention should not only aim to prevent the occurrence of CVA, but also to optimally manage and rehabilitate survivors of CVA and their caregivers through all the rehabilitation outcome levels. Apart from the occupational disruption, challenges, and burden of care experienced by caregiving,

> …everyday occupation holds promise for contributing to the relative well-being of both caregivers and care receivers and for facilitating continuity of relationships and identity for the caregiver[36:9].

Occupation can thus be used as a powerful tool to re-establish identity and meaning in caregivers' new roles that they need to take up/fulfil when caring for survivors of CVA.

2.5 DISCUSSION

Cerebrovascular accidents are a public health problem and a leading cause of disability in South Africa, often resulting in functional impairments. Rehabilitation, therefore, is essential in acute hospitals, in-patient rehabilitation units, as well as at home. Patients should progress through all the rehabilitation levels in order for rehabilitation to be successful[8]. South Africa currently fails to provide CVA survivors with comprehensive rehabilitation services due to the limited availability of therapy services and funding from medical schemes[4,9]. This lack of rehabilitation services, leads to CVA survivors needing family members or caregivers to assist them after discharge from hospitals or rehabilitation units. These individuals need to step into the unplanned occupation of caregivers, which often results in occupational loss and poor well-being of caregivers[47].

Even though the focus of this article is the caregiver, the effect of the carer's well-being on the survivor of CVA cannot be ignored. It is crucial for the well-being of both the patients and their caregivers to focus on optimally empowering caregivers to cope with the burden of taking care of stroke survivors. This can be done through caregiver education, caregiver support (such as stronger outpatient rehabilitation services), home-based caregiving services, support groups, and home visits from therapists[4].

Considering the complexity of caregiving as an occupation, and the implications on the patient, it is important to consider recommendations for clinical practice and future research in order to ultimately assist these caregivers of CVA survivors.

2.6 RECOMMENDATIONS

2.6.1 Therapeutic Intervention for the Survivor of CVA

It is recommended that better collaboration between the different sectors delivering therapeutic intervention (governmental, non-governmental organisations, as well as private healthcare services, including rehabilitation) should be established in order to provide patients with the best possible healthcare services[24]. Better collaboration might involve public healthcare services accommodating patients with medical schemes in order to continue with outpatient therapy, should their medical schemes not be sufficient to fund private outpatient therapy sessions.

Comprehensive in-hospital rehabilitation should be available to all patients with CVA in South Africa. Acute hospitals as well as inpatient rehabilitation units should contain dedicated stroke units with specialised healthcare workers and the necessary equipment to optimally manage patients with CVA.

Factors to consider when planning where the patient should stay after discharge include the accessibility of their homes, the availability of caregivers, as well as progress made by the patient throughout treatment in rehabilitation facilities. This decision should involve the team, patients, and their families[2] in order to ensure that they will be as functional and independent as possible at home or in care facilities, and can perform their daily occupations at the highest possible level of independence[21]. Discharge planning and preparation are thus considered a priority aspect to address and should, therefore, be facilitated from an early stage in the rehabilitation process with the aim to limit the burden of care after discharge.

It is also recommended that patients in the community who are medically stable, who have the necessary prescriptions for medication and follow-up appointments with the necessary healthcare providers, who can be cared for and receive therapy from their home environments, are better followed up by home-based care-workers and community-based rehabilitation services in accordance to the South African guidelines for the management of ischemic strokes and transient ischemic attacks[2].

2.6.2 Family and Caregiver Training

The importance of family and caregiver training during in-hospital rehabilitation, as part of the continuous holistic care plan, is emphasised in literature and by clinicians[32,50,58,60]. Caregiver training should include home programmes which can be used by caregivers in order to maintain and/or improve patients' physical, psychological, and cognitive abilities. Caregivers should also be provided with resources for possible outpatient therapy for the patient[65].

Inpatient rehabilitation facilities might find it meaningful to present workshops for caregivers before and after discharge. These workshops could include the following:

i. Physical handling, transfers and basic activities of daily living techniques for the patient with CVA;
ii. Life skills, including problem-solving techniques[48]; and
iii. Insight into problems they may experience at home, including in their physical and psychological burden of care, to predict possible obstacles and prepare themselves accordingly, and awareness of all the available resources[48].

Occupational therapists can also assist caregivers to balance their activity profiles (occupational balance)[47] in support of these caregivers' daily duties[35]. It is further advised that occupational therapists should work in a family-directed fashion in order to enable caregivers to resume meaningful activities and occupations again after taking up their roles as caregivers[44]. Caregivers and patients should be guided in establishing optimal ways of working together in order to increase their chances to find meaning in activities related to caregiving[38]. When patients actively participate in activities, they, as well as their caregivers, find it meaningful, which is necessary (for both parties) to obtain and maintain good quality of life[40]. Caregivers should thus be identified and included in therapy sessions from the early stages of inpatient rehabilitation.

Caregivers' needs should be assessed holistically, and intervention programmes should be customised for each family or caregiver's individual needs. For example, families might be advised to identify more than one caregiver to alternate caregiving duties. By addressing each caregiver's individual needs, burden of care will be reduced and caregivers will be assisted in functioning better in the community, which will directly contribute to the CVA survivors' quality of life[53]. Caregivers should, however, be motivated to communicate more freely and openly about their expectations or needs with regard to information and caregiver training sessions prior to discharge[64]. It is thus important to not only build a therapeutic relationship with patients, but also with their caregivers, in order to facilitate open and honest communication. This could aid in addressing possible challenges which caregivers might face post discharge from the rehabilitation unit.

In spite of the above recommendations regarding the content of caregiver training, the researcher would also like to point out the danger of overloading caregivers with information and guidelines, even though it may apparently be for their own good. Caregivers sometimes feel overwhelmed by the amount of information and home programmes given to them by therapists upon discharge. Although they might be motivated to follow home programmes, they might struggle to fit it into their full and exhausting daily schedules[19]. Regular telephonic follow-ups might assist in identifying problem areas after discharge and in providing caregivers with the necessary resources to assist them. Caregiver training alone also cannot sufficiently address adaptations needed in the home environment and changes in the patients' functional abilities[4,28] and needs to be supported by home assessments, outpatient rehabilitation services, home-based support services, as well as support groups[4] to assist them with their new occupation as caregivers.

It is also recommended that further research be conducted regarding the perceived burden of care for caregivers of patients with CVA, which aspects contribute to caregiving and how it affects the role and occupations of the caregivers, in order to better address these aspects from an occupational therapy point of view.

2.6.3 Outpatient Therapy

Against the background of this article, describing the importance of considering the needs and experiences of caregivers, the author emphasises the need for appropriate caregiver training and support structures[10]. Perhaps the South African private health sector should plan the distribution of medical funds differently to also allow for the very important level of rehabilitation, namely community reintegration, to take place. By funding more out of hospital services after discharge from an inpatient rehabilitation facility, persons with CVA will be enabled to make use of professional caregiving services such as home-based caregivers, community rehabilitation worker visits, regular outpatient therapy, as well as the continuous availability of assistive devices and/or contextual home adaptations.

2.7 CONCLUSION

As CVA is an incapacitating condition resulting in functional impairments causing great concern in SA, therapeutic intervention through all the rehabilitation levels is crucial to ensure that patients reach their optimal level of function. However, medical schemes do not provide unlimited funding, and patients do not always have enough finances to continue with outpatient therapy after discharge from a private inpatient rehabilitation unit. Patients making use of public services do not always have access to inpatient rehabilitation services and are often discharged home as soon as they are medically stable due to limited resources[2,6,20]. A higher demand is therefore placed on caregivers to assist patients to achieve community integration and productive activity levels[8].

Caregiver training conducted prior to discharge from inpatient rehabilitation units is not sufficient, and more structured support such as outpatient rehabilitation services, home-based support services, as well as support groups[4] are necessary to enable patients to reach their optimal level of function. Consequently, this could also decrease caregivers' burden of care. Caregivers' adaptation to their new occupation and co-occupation has, therefore, become increasingly important in comprehensive rehabilitation and management of patients with CVA in order to prevent occupational loss.

In the South African context, caregivers of patients with CVA are often family members who are not adequately equipped with the necessary skills and training upon discharge[4]. This can put tremendous financial, physical, and psychological strain on these caregivers, as patients' functionality are often still impaired upon discharge[53]. Limited access to community resources, home care services, and support groups are common obstacles after discharge[8]. A gap thus exists in the transition between patients' inpatient rehabilitation with the support of a therapy team, and discharge, characterised by limited support systems. This could potentially lead to complications and even re-admissions of patients at a later stage. If aspects contributing to burden of care for caregivers of patients with CVA are better understood, measures and strategies could be developed in order to not only maintain and promote their health, but also to reduce complications and re-admissions of the patients they take care of.

South African guidelines for stroke management suggest that improvement of home-based care and community-based rehabilitation should be a primary focus in order for the better management of patients with CVA in the community[2]. Caregivers are viewed as an important part of the therapy team, which could be strengthened by assessing and supporting them in their needs as caregivers[65]. In this sense, occupational therapists can contribute in addressing obstacles caregivers face before the patient is discharged, by including psychological and practical aspects in caregiver training in order to prevent a high burden of care[48]. Lastly, it is of utmost importance to provide caregivers with the necessary resources to enable follow-up by occupational therapists in the community[23].

In future studies, therapists might develop comprehensive inter-professional caregiver programmes which could facilitate the transitional process between inpatient rehabilitation units and discharge, starting in the rehabilitation unit prior to discharge and followed up with community-based rehabilitation. Therapists and caregivers should thus join forces and work together for the benefit of both the caregiver and patient.

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3. ARTICLE 2 (SCIENTIFIC ARTICLE)

Title of Article (Presented as a Scientific Article)

Factors associated with Burden of Care as experienced by caregivers of people with functional impairments due to a CVA, after their discharge from a private rehabilitation unit in Bloemfontein.

3.1 ABSTRACT

Introduction

The transition between inpatient rehabilitation and discharge of survivors of strokes from private rehabilitation services in South Africa is often challenging. After discharge, the caregiver role as an extension of rehabilitation, as well as the assistance of patients in daily occupations, becomes important. Although the occupation of caregiving could have positive attributes for the caregiver, it can be perceived as a burden. This study investigates the burden of care as experienced by patients' caregivers post discharge, contributing factors to burden of care, and how occupations relate thereto.

Method

A quantitative descriptive study was conducted with 63 patients and caregivers, using a consecutive, non-randomised sampling method. Patients' Functional Independence Measure (FIM) scores upon discharge were obtained. Telephonic interviews were conducted two months after discharge, using the Modified Caregiver Strain Index (MCSI), as well as a non-standardised questionnaire.

Results

Patients' median FIM scores at discharge were 86, indicating that they needed minimal assistance. Caregivers experienced some burden of care, since the median MCSI score was nine, interpreted as minimal/moderate strain. Contributing factors include financial, physical, psychological, and social aspects. Caregivers also seem to have unbalanced occupational profiles.

Conclusions

The problematic transition between private inpatient rehabilitation and discharge needs to be addressed

Key words: Stroke, Caregivers, Burden of Care, Private Inpatient Rehabilitation

3.2 INTRODUCTION AND LITERATURE SURVEY

Survivors of Cerebrovascular Accidents (CVAs) often experience permanent impairment and need assistance in their activities of daily living[1-3], as a full recovery is usually only observed in about 45% of cases of patients with CVA[4]. Rehabilitation thus plays a vital role in enhancing independence in daily activities, facilitating community integration, and returning to productive activities such as work[5]. Comprehensive, intensive, early intervention from an inter-professional team can decrease the effect of disability and assists patients in reaching their maximum potential. It assists with the transition between medical management and patients' return to their activities of daily living and occupations, which ensures greater quality of life, and in which they find meaning or purpose[6].

Rehabilitation services provided in the private sector are primarily funded by medical schemes. These funders determine the duration of patients' rehabilitation, in line with the prescribed minimum benefits, and time spent in rehabilitation is unfortunately not unlimited[7]. From a financial perspective, early intervention in terms of inpatient rehabilitation is also beneficial to patients and funders in order to prevent complications (such as falls, contractures, shoulder pain/subluxation and pressure sores), and to optimise patients' outcomes[8-9].

The goal of rehabilitation is generally to achieve function at the highest level of independence possible for each individual before discharge[10]. After the inpatient rehabilitation process, most patients are independent or only need minimal assistance with activities of daily living[11]. Furthermore, inpatient rehabilitation may provide a safe environment for patients in order to help them make sense of what happened to them. It further provides the necessary tools to start rebuilding their lives after discharge[8]. However, inpatient rehabilitation usually only focusses on residential integration ("return to home"), but continued support in terms of outpatient rehabilitation is additionally required. Community integration (where patients can participate in public transport if applicable, social interaction, handle financial aspects, household tasks, and manage their health), as well as productive activity (which involves returning to work, learning new skills or adaptations needed in the work setup), all need to be addressed during outpatient therapy[12].

At the specific rehabilitation unit where this study was conducted, patients engage in various types of therapy on a daily basis, offered by the inter-professional team. Family meetings are also conducted with each patient and his/her family to report on the patient's diagnosis, prognosis, therapy goals, progress, and to manage future planning. The accessibility of the patients' homes and the need for assistive devices are also discussed. Caregiver training is usually done in the week before discharge (depending on the amount of training needed and the availability of caregivers). Home programmes are also provided and outpatient therapy is recommended where needed[13].

However, the transition between inpatient rehabilitation and discharge of stroke patients at private rehabilitation services in South Africa (similar to the one described above) presents, in general, salient challenges. The permanent impairment of and continuous support needed by stroke survivors can place a high responsibility and burden of care on their caregivers[11,14].

From an occupational therapy perspective, caregiving is described by authors as an everyday occupation[15], a co-occupation[16-20] and also a collective occupation[21]. It involves aspects of shared physicality, shared emotionality, and shared intentionality, embedded in shared meaning[17] where the caregiver and patient are interactive and both affected by each other's activity performance[17]. Co-occupation are present in all relationships, including caregivers and their patients and can be organised into four categories: 'Doing with' – where two persons participate in the same activity with the same goal and purpose, at the same time. 'Doing to' – one person is more involved in the activity, although it is still happening at the same time and place. 'Doing for' – one person is doing something for the other, not necessarily at the same time and place, and lastly 'doing because of' which include participation in activity because of the other, which does not include one person being assisted[20].

Some caregivers might value this new role as positive and derive pleasure and meaning from it. Yet individual caregivers' circumstances differ greatly, and, for some, caregiving is experienced as a burden. Caregivers who assist patients after discharge are usually family members with no previous experience or training[22]. An increased demand in terms of finances, time, and other caregiver-related activities are placed on family members and/or caregivers, who are often forced by circumstances to take up the unanticipated role as caregiver for the patient with CVA[23]. Not only is it expected of caregivers to assist patients with daily living activities; assisting with maintaining and improving skills learnt in rehabilitation in order to improve patient's quality of life also become part of the caregivers' role[22]. They thus play and important role in and become an extension of rehabilitation delivery post discharge[24].

Previous studies show that caregivers might stop participating in activities which were previously meaningful to them and therefore experience occupational loss after taking up their roles as caregivers[25]. Their caregiving-related duties are very time consuming; a general perception that the patients' needs should be placed before their own often leads to neglect of their own occupational needs[26]. Aspects which negatively affects caregivers' occupational balance are influenced by the daily roles they need to fulfil, their own physical and psychological well-being, the availability of sufficient support systems, as well as their future goals[26]. They can thus face physical, psychological, emotional, social, as well as financial challenges[27]. Consequences of being a caregiver are higher stress levels, higher burden of care, lower energy levels, and decreased psychological well-being[25], as well as tiredness, anxiety, despair, frustration, and isolation[28].

Early identification and involvement of a caregiver in the in-patient rehabilitation process may enhance a patient's recovery towards functional outcomes. Caregiver training, which informs caregivers of the resources available and includes advice on stress management, may lead to a reduced burden of care[29]. Family meetings, caregiver training, and complete discharge reports (including available resources post-discharge) all form part of the rehabilitation process at the inpatient rehabilitation unit where this study was conducted[13].

Inpatient rehabilitation mostly aims to rehabilitate patients up to a residential integration level and does not necessarily address community reintegration and productive activity as described in the rehabilitation outcome levels (*cf*. Landrum, Schmidt, and McClean, cited by Hassan, Visagie, and Mji [12]). Consequently, caregivers might not feel prepared for their new role upon patients' discharge from an inpatient rehabilitation unit, and might experience burden of care[12]. This issue is further problematized by a limited availability of South African specific studies in two fields: firstly, studies determining the burden of care post discharge from a private, inpatient rehabilitation setting, and secondly, research ascertaining whether burden of care is experienced by caregivers of patients with CVA post discharge and after receiving private inpatient rehabilitation. It is also necessary to investigate factors contributing to burden of care post discharge from a private inpatient rehabilitation unit in order to optimally manage it from within that setup.

The aim of this study is to investigate the perceived burden of care for caregivers of patients with CVA with functional impairments, after discharge from a private rehabilitation unit in Bloemfontein. The first objective is to identify the aspects caregivers perceive as contributing factors to burden of care at two months post discharge, including financial, physical, psychological, social and personal aspects. Secondly, this study intends to determine how the role and occupations of caregivers relate to their perceived burden of care.

3.3 METHODS

3.3.1 Study Design

A quantitative descriptive study was conducted.

3.3.2 Population and Sampling

The study was conducted at a private inpatient rehabilitation unit with a rehabilitation therapy team including doctors, nursing staff, physio-, occupational-, and speech therapists, a dietician, and social workers. The patients and their families are viewed as part of the team and are included in goal setting and future planning for the patients. Patients with CVA's duration of stay in the rehabilitation unit depends on the ‘prescribed minimum benefits’ and authorisation granted by their medical schemes, as well as on a team decision regarding patients’ readiness for discharge, or when limited progress is seen. Authorisation from the medical schemes to remain in rehabilitation is usually updated on a weekly basis, depending on progress made according as reflected in patients’ weekly progress reports[7,13].

Patients subscribed to a specific plan from a certain medical aid qualify for a care plan after discharge, where professional caregivers can provide their services for up to two weeks after discharge. The patients can also receive a home visit from an occupational therapist prior to or after discharge in order to make recommendations for adaptions needed. Patients can further qualify for a certain amount of outpatient therapy sessions[30]. Unfortunately, these measures are not subsidised by all medical schemes.

Over the period of June 2017-May 2018, the unit admitted 89 patients with CVA. During the previous year, from June 2016-May 2017, 92 patients with CVA were admitted to the unit. This amounts to an average of seven to eight patients per month[31]. The study was conducted during the period of July 2017-May 2018. The first participants (patients diagnosed with CVA and their primary caregiver) were approached to participate in the study upon their discharge from the rehabilitation unit in July 2018. Telephonic follow up discussions took place in September 2017. The last participants were approached in March 2018 and were followed up with in May 2018.

A total of 68 caregivers of patients with CVA consented to participate, of which a final number of 63 met the inclusion criteria and were included in this study. Those excluded were omitted for reasons such as patients being deceased at the time of the follow up, being re-admitted to a hospital or care facility, or due to caregivers not answering their phones after five attempts to contact them.

A consecutive, non-randomised sampling method was used in selecting participants. Inclusion was regulated based on the following criteria: Patients with ischemic/haemorrhagic CVAs and/or acute/previous CVAs including co-morbidities, from all functional levels; patients who were discharged to a home environment and living with a family member or caregiver. Caregivers who were older than 18 years, identified as the patient’s primary caregiver, and who had been taking care of the patient for at least one month after discharge, were included if they stayed with the patient for at least four hours during day time, had access to a phone, and could understand Afrikaans, English or Sesotho. Caregivers were included regardless of being trained or untrained to be caregivers, paid or unpaid for their caregiving duties.

Patients and their caregivers were excluded if patients were discharged from the rehabilitation unit to a facility, lived alone, or if caregivers did not give informed consent to participate in the study. If caregivers did not answer their phones after five attempts to contact them, they were also excluded.

3.3.3 Data Collection

Prior to or on their day of discharge from the rehabilitation unit, the researcher approached all patients with CVA and their caregivers, informed them of the study, asked whether they would be interested to participate in the study, and obtained their written consent. The first part of data collection then started, namely to capture the necessary background information of the patient on the background information document (*cf.* Addendum D), in order to establish which patients and their caregivers, could be included in the study. Information was gathered from the patient’s file (at that time still in the rehabilitation unit) by the researcher, including the Functional Independence Measure (FIM) scores of the patient as scored by the team upon discharge.

The second part of data collection comprised telephonic interviews with the caregivers of the patients with CVA who met the inclusion criteria. The caregivers were contacted two months after discharge to organise a convenient time for a telephonic interview. If the caregiver was no longer responsible for the patients’ caregiving, the researcher attempted to find out who the current primary caregiver was and contacted him/her. The pilot study was conducted with two previously discharged participants (patients and caregivers) in July 2017, in order to test the feasibility of the two telephonic questionnaires (the standardised as well as the non-standardised questionnaire). The first study participants (patients and caregivers) were then approached, and the study was conducted over a period of 9 months, as described above. During telephonic interviews, both the non-standardised questionnaire (*cf.* Appendix C) and the standardised questionnaire, the Modified Caregiver Strain Index (MCSI) (*cf.* Addendum E), described below in 3.3.4, were administered. The standardised questionnaire could not be translated, as it was standardised in English, but the non-standardised questionnaire used during the telephonic interview was available in Afrikaans, English and Sesotho. Forward-backwards translation was used to translate the questionnaires. A trained research assistant was used to conduct the telephonic interview in Sesotho (in the presence of the researcher) for caregivers who preferred to participate in Sesotho, as the researcher is not fluent in this language. A Sesotho script was provided to the trained research assistant, from which the information and questions were to be read. If a caregiver asked a question, the research assistant made use of free translation in order for the researcher to understand and answer the question. Caregivers’ responses were written accurately and consistently on the questionnaire (in English), in order to ensure that the information gathered is a true reflection of the participants’ perception.

All information recorded on the background information questionnaire, the standardised, as well as the non-standardised questionnaires, were coded and entered into an Excel spreadsheet, after which it was sent for data analysis.

3.3.4 Measuring Instruments

Three measurement tools were used in the study. Firstly, the researcher employed a background information document to gather information from patients' hospital files, including FIM scores upon discharge. Secondly, a non-standardised questionnaire compiled by the researcher was used in the telephonic interviews with the caregivers two months post discharge. Thirdly, a standardised questionnaire, the MCSI, was also used in the telephonic interviews with the caregivers two months post discharge.

The FIM serves as an official tool for assessing patients' level of incapacity It also indicates the amount of assistance needed by patients to perform their daily activities. It aims to assess the patients' level of independence with activities of daily living[32]. The FIM was specifically developed for patients with lower levels of functioning and who were admitted to inpatient rehabilitation units[33]. It makes use of seven-point scale and consists of 18 items (13 items to assess motor abilities and five items to assess cognitive abilities). Each of these items is awarded a score between one and seven. A score of one indicates that the patient needs total assistance in that item, and a score of seven indicates total independence in that particular item[34].

At the rehabilitation unit where this study was conducted, therapists record FIM scores are on a weekly basis, and sends these scores to the relevant medical schemes as part of the patients' weekly progress reports. For the purpose of this study, patients' FIM scores, as scored by trained therapy staff upon discharge, were used in order to determine the patients' level of functional independence at the time of discharge.

The aim of the non-standardised questionnaire was to obtain further contextual information in order to determine which other factors, such as roles and occupations, might contribute to the caregivers' perceived burden of care. The questions in the non-standardised questionnaire were formulated in line with the research objectives by the researcher, based on literature. It consists out of five categories which were compiled as follows: Contextual information[27,35,52,57,58]; Caregivers' occupations, performance patterns and well-being[24-26,37,52,57,59]; Caregivers' performance skills[28,38,58]; Caregivers' view of patients' client factors[27,35,39-44] and Environmental factors[27,28,45,52,58].

In 2003, the Modified Caregiver Strain Index (MCSI) was developed as an improved version of the Caregiver Strain Index. The Caregiver Strain Index (CSI) was initially designed to measure stress as perceived by informal caregivers[46], which could contribute to their burden of care. The CSI has been used with success in a number of studies regarding caregiver burden of patients with CVA and proved to also be of cultural relevance within the South African context[58,59].

The MCSI aims to be used as a screening tool in order to identify caregivers' perceived burden of care/strain. The MCSI focusses on the following aspects: financial, physical, psychological, social, and personal, and at least one question is available for each of these aspects. The MCSI consists of 13 questions with examples, where caregivers can answer: yes, on a regular basis (score two points); yes, sometimes (score one point); or no (no points)[60]. The maximum score which patients can obtain with the MCSI is thus 26, and no suggestion is given as to which score indicates a high burden of care. Therapists must use clinical reasoning in deciding when to investigate caregivers' burden of care further, as the MCSI is merely a screening tool[49]. Therefore, for the purpose of this study, the researcher used her own judgment based on the interpretation of the CSI to inform the interpretation of the results of the MCSI and posits that a score of 14 or higher is an indicator of high burden of care.

3.3.5 Reliability and Validity

Interrater reliability was enhanced by the fact that the FIM scores were only completed by staff members who completed a licensed personnel examination using the Uniform Data System for Medical Rehabilitation's Online FIM Credentialing System for the FIM system. This examination is done on a two yearly basis and is completed by all permanent staff members.

The internal validity for the MCSI is higher than the Caregiver Strain Index (CSI) with a good test-retest reliability coefficient of 0.93[49]. A third of the study sample in other studies indicate a test-retest reliability coefficient of 0.88 after two weeks. Internal consistency was also good, and no floor-ceiling effect was found[50].

The researcher attempted to minimise measurement errors, such as non-responder bias, by attempting to contact each participant five times. If the time of the call was not convenient for them, a more appropriate appointment was made. Interrater reliability between the researcher and research assistant were ensured by strictly reading the question as on the questionnaire in a standard format, and documenting the exact answer as answered by the participant. A pilot study was conducted by including two caregivers in order to determine the practical feasibility of the questionnaires using telephonic interviews. However, participants from the pilot study were not included in the results of this study. The phone was used in a quiet environment in order to minimise interruptions.

3.3.6 Ethical Aspects

Approval for this study was obtained from the Health Science Research Ethics Committee of the Faculty of Health Sciences, University of the Free State (reference HSREC 78/2016). Written permission was granted by the practice manager of the private rehabilitation unit where the study was conducted. Informed written consent was obtained from the patients (or next of kin if they were not able to give consent due to their level of cognitive function), as well as the caregivers. All information was kept strictly confidential and stored in a safe, secure environment. Numbers were used instead of names in order to make participants unidentifiable.

3.4 DATA ANALYSIS

Data was entered onto an Excel spreadsheet by the researcher. The data was analysed by the Department of Biostatistics, University of the Free State. Categorical data was reported using frequencies and percentages. The numerical variables, FIM-, and MCSI scores were reported showing the ranges and medians with minimum and maximum values. The median differences between groups were evaluated using appropriate statistical tests for unpaired data, namely the Kruskal-Wallis Test. No categorical biographical variables were compared for both the FIM - and MCSI scores.

3.5 RESULTS

The results are grouped and documented according to common themes present in all the measurement instruments. All the following sub-headings are factors that could contribute to burden of care.

3.5.1 Demographic Information

Demographic information was obtained from the patients included in the study, as well as their caregivers, and is reflected in Table I.

Table I: Caregiver and patient demographic information

ASPECTS	PATIENTS (n=63)	CAREGIVERS (n=63)
Age (Median)	58 years (18 - 82)	52 years (23 - 76)
Gender		
Male	28 (44.4%)	13 (20.6%)
Female	35 (55.6%)	50 (79.4%)

Patients’ ages varied between 18 and 82 years with a median of 58 years. Caregivers’ ages ranged between 23 and 76 years with a median of 52 years. Most patients and caregivers are female.

Of the study sample of 63 caregivers, 32 (50.8%) are spouses, 18 (28.6%) are children of CVA survivors, and all caregivers are related to the patients. Most caregivers stayed with the person they care for, except for one participant. 45 (71.4%) caregivers reported that they had between one and three other persons assisting them with taking care of the patients; these individuals are not necessarily related to the patients. Only 18 (28.6%) caregivers had no additional caregiver assistance.

3.5.2 Patients’ Functional Level Upon and Post Discharge

Data obtained from patients’ files (and included in the background information document) indicated that 54 (85.7%) patients from the study sample (n=63) were admitted with their first CVA, and that nine (14.3%) patients also suffered previous CVAs. Patients displayed a variety of additional medical conditions, and their medical histories differed greatly. Additional commonly occurring medical conditions include hypertension (n=44; 69.8%) and diabetes Mellitus (n=17; 27%). 16 (25.4%) patients suffered from cardiovascular disease or had a history of cardiovascular conditions or cardiovascular interventions.

The table below were taken from literature but was simplified by the examiner. Results of this study were also added in the last column. It indicates the expected hours of care, based on extant literature, which patients need according to the total FIM scores that they obtained. For example, patients who mostly scored level one for each FIM item obtained a total FIM score of 18-35. It is expected that these patients will need from six to more than eight hours of care daily, which is described as total assistance. Four patients (6.4%) in this study had total FIM scores of 18-35, indicating a need for total assistance, or more than six hours of caregiving per day. However, caregivers in this study’s estimation of hours spent on caregiving per day were not necessarily consistent with the expected hours as described in relevant literature, as seen in Table II.

Table II: FIM Rating levels and the expected hours of care needed (Uniform Data System for Medical Rehabilitation 2012[33])

FIM LEVEL	TOTAL FIM SCORE	ESTIMATED HOURS OF CAREGIVING NEEDED PER DAY	AMOUNT OF ASSISTANCE NEEDED	NUMBER OF PATIENTS IN THIS STUDY N=63 (%)
1	18 - 35	6- >8	Total assistance	4 (6.4)
2	36 - 53	5-7	Maximal assistance	3 (4.8)
3	54 - 71	3-5	Moderate assistance	7 (11.1)
4	72 - 89	2-3	Minimal assistance	20 (31.8)
5	90 - 107	<1-2	Supervision / Setup	15 (23.8)
6	108 -125	0	Modified Independence	14 (22.2)
7	126	0	Complete Independence	0

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*Table II: Adapted by L. Serfontein

Patients had a median FIM score of 86 upon discharge, ranging between 18 and 125. This indicates that patients mostly needed minimal assistance (FIM Level 4) upon discharge, implying an average of two to three hours of assistance per day (*cf.* Table II). Of the study sample of 63 patients, 49 (77.8%) needed either minimal assistance, supervision, or were classed as modified independent (FIM levels 4-6). 29 (46%) patients thus did not need any physical assistance upon discharge, as they were considered modified independent or needed supervision only (FIM levels 5 and 6) (Uniform Data System for Medical Rehabilitation, 2012).

At two months after discharge, caregivers were asked to indicate the FIM aspects patients still needed physical assistance or supervision with. Aspects in which patients mostly need physical assistance include bathing (n=30; 47.6%), upper body dressing (n=19; 30.2%), lower body dressing (n=26; 41.3%), and climbing stairs (n=28; 44.4%). However, the researcher wishes to point out that caregivers mentioned mainly significant and relevant areas where patients needed physical assistance or supervision, e.g. when a patient is unable to climb stairs, but is not required to climb stairs in their daily routine; the caregiver would consequently not indicate this as a problematic aspect in daily functioning. Aspects in which patients mostly need supervision include locomotion (mobilisation) (n=18; 28.6%) and climbing stairs (n=12; 19.1%). Furthermore, 52 (82.5%) caregivers felt that the patients' abilities had improved since discharge/since they started caring for the patient, despite the fact that most patients did not receive outpatient therapy after discharge. At two months post discharge, 16 (25.4%) caregivers indicated that patients acquired other illnesses or injuries after discharge, which all varied. Only one (6.3%) patient fell after discharge according to the caregivers interviewed.

3.5.3 Therapy Received

Patients' admission time in the rehabilitation unit varied between less than one week and more than 12 weeks. From the study sample (n=63), 15 (23.8%) patients were admitted to the rehabilitation unit from less than one up to five weeks, 43 (68.3%) between six and nine weeks, and five (7.9%) for 10 weeks and longer. Most caregivers (n=43; 73%) indicated that longer time in rehabilitation would not necessarily have relieved their burden of care.

Most patients (n=43; 68.3%) did not receive any outpatient therapy after discharge, or only continued with their home programme. Frequency of the outpatient therapy sessions varied between less than once a month to more than three times a week.

3.5.4 Environmental Factors

Participants (caregivers and their patients) come from a wide variety of towns and rural areas all over South Africa. However, 22 (34.9%) indicated that they stay in Bloemfontein and seven (11.1%) stay in Kimberley. 14 (22.2%) caregivers indicated that there are eight rooms in the house where they provide care and 57 (90.5%) have an indoor bathroom, of which 32 (56.1%) have both a bath and a shower, although the study did not enquire about the adaptation of these facilities for their needs. 31 (50.8%) caregivers have between one and eight steps in front of the house in which they provide care. Most caregivers (n=56; 88.9%) indicated that the house was adequately adapted for the patient's needs. Caregivers who did not feel that the house was adequately adapted provided reasons such as stairs inside the house, patients struggling to use the outdoor bathroom, having too many residents in the house, or the rooms being too small. Many patients still make use of assistive devices at times, such as a wheelchair (n=31; 49.2%) and/or a walking aid (n=30; 47.6%). Some patients also make use of a commode (n=2; 3.2%), bath board (n=1; 1.6%), grab rail (n=3; 4.8%), and/or transfer board (n=3; 4.8%). 24 (38.1%) patients do not make use of any assistive devices and 61 (96.8%) caregivers feel that the assistive devices that the patients have are sufficient for their needs.

3.5.5 Caregivers' Occupations, Performance Patterns, and Well-Being

Most caregivers (n=49; 77.8%) do not have any previous experience as a caregiver. Their level of education differs between primary school and postgraduate qualifications. 26 (41.3%) caregivers completed school and 15 (23.8%) obtained diplomas. Most caregivers (n=52; 82.5%) attended caregiver training at the rehabilitation unit upon discharge. Four (6.3%) caregivers previously worked as caregivers or nurses.

Of the study sample (n=63), 33 (52.4%) caregivers are not employed or only have a part-time job. 30 (47.6%) caregivers have a full-time job with working hours ranging between four and 12 hours per day. Caregivers who indicated 12 working hours a day (n=5; 13.2%) and still took care of patients for at least four hours during day time, had explanations such as working night shift or flexible hours, or working from home. Responsibilities in addition to their work and caregiving-related duties were divided as follow: 36 (57.1%) had to take care of children, 58 (92.1%) participated in household tasks, and 44 (69.84%) participated in recreational tasks.

Caregivers were then asked to indicate more or less how many hours they spent on caregiving per day and how many hours they spent on responsibilities such as children, household tasks, recreation, or other responsibilities. The researcher wishes to note that estimations done by the caregivers were subjective and that the accuracy of their calculations was not verified. 35 (55.6%) caregivers spend between two to four hours on caregiving per day, and 15 (23.8%) caregivers indicated that they spend five to six hours on caregiving per day. 17 (27%) caregivers spend four hours a day taking care of children, 31 (49.2%) caregivers spend four to five hours on household tasks, and 36 (57.1%) caregivers spend two to four hours a day on recreational activities. Fifty (79.4%) caregivers felt that they spend an adequate amount of time on caregiving related duties (not too much or too little time). However, 45 (71.4%) caregivers indicated that they have between one and three persons assisting them with their caregiving-related tasks, which might have influenced their answers.

Most caregivers (n=51; 81%) indicated that they are healthy at the moment. Caregivers seem to have unbalanced occupational profiles, as 33 (52.4%) caregivers do not have a full-time job, 48 (76.2%) caregivers spent less than four hours a day on recreational activities and 24 (38.1%) caregivers spend more than four hours a day on household tasks.

3.5.6 Caregiver Strain

In this study, the median score of the MCSI was nine, with two as the lowest score and 22 as the highest score, indicating that the burden of care experienced by caregivers differed greatly. As limited guidelines for the interpretation of the MCSI are available, for the purpose of this study, a score of 14 and higher is posited as an indication of a high burden of care, and a score of less than 14 of a minimal to moderate burden of care. Most caregivers (n=51; 81%) experienced a minimal/moderate burden of care (a score of less than 14), and the rest of the caregivers (n=12; 19.1%) experienced a high burden of care (a score of 14 or higher).

The different aspects covered by the MCSI were described by literature[49] and the questions were categorised into the different categories for the purpose of this study. Scores obtained for each aspect of the MCSI are reflected in Table III. See appendix E for examples of each aspect of the MCSI.

3.5.6.1 Financial

Forty five (71.4%) caregivers did not experience any work adjustments. Most caregivers indicated financial strain on a regular basis (n=23; 36.5%), or at times (n=17; 27%).

3.5.6.2 Physical

Forty four (69.8%) caregivers did not experience any sleep disturbances and 45 (71.4%) caregivers did not feel that caregiving is a physical strain.

3.5.6.3 Psychological

Most caregivers indicated that there have been emotional adjustments on a regular basis (n=37; 58.7%), or at times (n=15; 23.8%). Forty (63.5%) caregivers did not find patients' behaviour to be upsetting, although most of them felt upset that the person has changed so much from his/her former self on a regular basis (n=14; 22.2%), or at times (n=26; 41.3%). Most caregivers (n=36; 57.1%) did not feel completely overwhelmed at two months post discharge.

3.5.6.4 Social

Caregivers experienced caregiving to be confining on a regular basis (n=17; 26.98%), or at times (n=20; 31.8%). 34 (54%) caregivers did not experience family adjustments.

3.5.6.5 Personal

Thirty five (55.6%) caregivers did not feel that caregiving is inconvenient and 34 (54%) caregivers did not experience any changes in personal plans. However, caregivers felt that there have been other demands on their time on a regular basis (n=17; 27%), or at times (n=27; 42.9%).

Table III. Answers provided by caregivers in the Modified Caregiver Strain Index

ASPECT	YES, ON A REGULAR BASIS N = 63 N (%)	YES, SOMETIMES N = 63 N (%)	NO N = 63 N (%)
My sleep is disturbed	10 (15.9)	9 (14.3)	44 (69.8)
Caregiving is inconvenient	7 (11.1)	21 (33.3)	35 (55.6)
Caregiving is a physical strain	9 (14.3)	9 (14.3)	45 (71.4)
Caregiving is confining	17 (27)	20 (31.8)	26 (41.3)
There have been family adjustments	14 (22.2)	15 (23.8)	34 (54)
There have been changes in personal plans	10 (15.9)	19 (30.2)	34 (54)
There have been other demands on my time	17 (27)	27 (42.9)	19 (27)
There have been emotional adjustments	37 (58.7)	15 (23.8)	11 (17.5)
Some behaviour is upsetting	10 (15.87)	13 (20.63)	40 (63.5)
It is upsetting to find the person I care for has changed so much from his/her former self	14 (22.22)	26 (41.27)	23 (36.5)
There have been work adjustments	7 (11.11)	11 (17.46)	45 (71.4)
Caregiving is a financial strain	23 (36.51)	17 (26.98)	23 (36.5)
I feel completely overwhelmed	8 (12.70)	19 (30.16)	36 (57.1)

When comparing the MCSI scores obtained from the caregivers with the patients' FIM scores upon discharge (*cf*. Table II), it is found that the 12 (19.1%) caregivers who experience a high (MCSI score of more than 14) burden of care's patients, had a median FIM score of 71, indicating that the patients mostly needed moderate assistance upon discharge (FIM Level 3). The 51 (81%) caregivers who experience a lower (MCSI score of less than 14) burden of care's patients had a median FIM score of 90, indicating that the patients mostly needed supervision/setup only upon discharge (FIM Level 5). There is thus a statistically significant correlation between the patients' FIM scores upon discharge and the burden of care experienced by their caregivers (with $P > 0.0040$). The higher the caregivers' burden of care (and MCSI scores), the lower the patients' level of independence (and FIM scores), and vice versa.

3.6 DISCUSSION

3.6.1 Demographic Information

Patients' and caregivers' demographic information correlates with literature stating that survivors of CVA mostly seem to be adults over 45 years of age[51], although the median age in literature is slightly older for patients (67 years vs 58 years in this study) and younger for caregivers (45.6 years vs 52 years in this study)[52]. Women seem to be more affected by CVAs[53].

Caregivers reporting that they had between one and three persons assisting them with caregiver-related tasks could have had a positive influence on the burden of care experienced, as caregiver-related tasks could be shared. Some caregivers indicated that the patient's medical scheme supplied a professional caregiver for two weeks after discharge, after which the primary caregiver had to take over, as is the case with patients subscribed to a specific option from one of the medical schemes[30]. Professional caregivers may have assisted with the transition between discharge from the inpatient rehabilitation unit and the home environment.

3.6.2 Patients' Functional Level Upon and Post Discharge

Although the FIM only considers aspects up to a residential integration level, and not at community integration or productive activity levels (*cf.* Landrum, Schmidt, and McClean, cited by Hassan et al.[12]), it is still commonly used to evaluate patients' functional levels during rehabilitation, and can also be used to predict patients functional prognosis after discharge[34]. According to patients' FIM scores, they only needed minimal assistance upon discharge. This is to be expected, given the fact that all patients received comprehensive inpatient rehabilitation at a private in-patient rehabilitation unit with the goal of helping patients to be as functional and independent as possible with individualised therapeutic programmes[10]. This correlates with another South African study, which found that most patients were independent in activities of daily living, or only needed minimal assistance after discharge from an inpatient rehabilitation unit, although that study was not conducted at a rehabilitation unit with a similar programme to the one in this study[11], as described in the introduction.

It is surprising that only one patient was reported to have fallen after discharge, as this contradicts other research indicating that 33% of CVA survivors included in the study reported to have fallen within one year after their CVA; an alarming 70% of these respondents reported that falls occurred at their homes[54]. Possible explanations for this contrast might be that this study was done only two months after discharge, in contrast to information from Schmid et al. [54] where participants reported falls within one year after CVAs. However, patients in Schmid et al.'s [54] study did not necessarily complete a private inpatient rehabilitation programme which includes caregiver training, which might also have prevented falls. It also needs to be kept in mind, that the severity of patients' conditions are not the same.

The fact that most caregivers felt that patients' abilities have improved since discharge, despite the fact that most patients did not receive outpatient therapy after discharge, might indicate the value of returning to a familiar environment and being surrounded by loved ones and a support system, as well as the long time frame in which patients can still show improvement after suffering a CVA. Although most improvement takes place within the first four weeks following a CVA, continuous improvement can still be seen at three months and even at six months post CVA[55]. Caregivers are already identified prior to patient discharge, which can also have a positive effect on patients' progress, as early identification of a caregiver in the in-patient rehabilitation process has been described as a factor contributing to recovery/functional outcomes[29].

3.6.3 Therapy Received

The fact that so few patients continued with outpatient therapy in this study, correlates with literature stating that not many patients continue with outpatient therapy after discharge from hospitals. Various contributing factors are described in literature, such as a shortage of healthcare workers, challenges with finances and transport, a lack of communication upon discharge[2], limited insight from caregivers and patients, as well as differences in expectations, e.g. patients feeling that therapy does not address all of their concerns, or having goals different from therapists'[56].

3.6.4 Environmental Factors

Patients came from a wide variety of geographical areas and from various provinces, which highlights the need for more private inpatient rehabilitation units, as the inpatient rehabilitation unit where the study was conducted, is one of "the only accredited, dedicated acute physical rehabilitation units in central South Africa"[10:1].

3.6.5 Caregivers' Occupation, Performance Patterns, and Well-Being

The fact that most caregivers attended caregiver training possibly contributes to the relatively low burden of care experienced by caregivers in this sample. Caregiver training has been described as assisting in preparing caregivers for their new role as caregivers and assisting with the transition between inpatient rehabilitation and community integration after discharge[57-59].

Caregivers seem to have unbalanced activity profiles, as more than half of them do not have full-time jobs, most of them spend less than four hours a day on recreational activities, and some of them spend more than four hours a day on household tasks. Should caregivers thus spend all their time on caregiver-related duties and neglect other occupations such as sleep, leisure, social participation, or even work, it could affect their health and well-being.

3.6.6 Caregiver Strain

Most of the caregivers experienced a minimal to moderate burden of care. This contrasts another study (making use of the CSI), which found that 56% of CVA patient caregivers experience a high burden of care after discharge from and inpatient rehabilitation unit[11]. However, the rehabilitation unit in that study was not in the private sector, and further studies are needed to determine if burden of care is lower for caregivers of patients with CVA, discharged from other private inpatient rehabilitation units in order to support findings from this study.

The correlation found between patients' FIM scores (indicating their functional levels) and their caregivers' MCSI scores (indicating their burden of care), supports literature comparing the hours of assistance needed from caregivers daily in line with patients' FIM scores. The hours of assistance needed from caregivers, decrease (along with their burden of care) as the patients' FIM scores, along with their functional levels, increase (*cf.* Table II)[33]. The median FIM scores in this study indicate that patients only needed minimal assistance upon discharge, which correlates with the median MCSI score, indicating that caregivers experienced a minimal to moderate burden of care.

The researcher notes that burden of care experienced by caregivers is not necessarily related to the patient's physical function, and caregivers of patients with more cognitive than physical impairments, also experience strain. This correlates with literature stating that cognitive abilities have a palpable influence on patients' abilities to optimally participate in activities of daily living such as social activities, managing children, returning to work, or shopping for groceries, even if limited physical impairments are present. The magnitude of cognitive impairments is not always obvious, which places a high burden on caregivers to take care of patients with said impairments[1]. Patients' cognitive abilities were also found to be a predictor of burden of care[60].

3.7 LIMITATIONS

The limitations associated with this study are firstly, that the answers of the caregivers are subjective and a reflection of their perceived burden of care only. Caregivers had difficulty giving estimations, interpreted questions differently, and it was difficult to obtain an accurate reflection of the exact number of hours spent on each of their responsibilities in order to get a clear picture of their activity profiles, roles, and occupations. One participant, for example, indicated that she spends 24 hours a day on supervision, but that she also spends time on other responsibilities. The number of hours spent on each responsibility might thus add up to more than 24 hours a day. Caregivers' activity profiles might have been unbalanced even before taking up their roles as caregivers. The researcher only aimed to give a description of their current activity profiles.

Secondly, the study sample is fairly small and is not representative of the whole population of patients with CVA, but only of patients and their caregivers discharged from the private inpatient rehabilitation unit where this study was conducted.

It was not within the scope of this study to distinguish between factors such as culture and socio-economic status of caregivers.

3.8 RECOMMENDATIONS

Recommendations with regard to clinical practice include the following. Firstly, it is suggested that the transition between inpatient rehabilitation and discharge of the patient with CVA is improved. This might be done through medical schemes incorporating funded programmes for patients with CVA, not only as inpatients, but also post discharge for therapeutic home assessments, outpatient therapy, support groups for caregivers and funding of professional caregivers.

Secondly, based on the results and conclusions drawn from this research, the researcher makes the following recommendations with regards to future research. A need for further exploration regarding possible intervention methods attempting to prevent/reduce burden of care post discharge exists. Possible avenues or exploration are:

- Re-admissions to inpatient rehabilitation units in order to address problems experienced at home;
- Benefits of allowing patients more opportunities to go on trial leave in order to identify any potential problems at home while still being admitted to the inpatient rehabilitation unit;
- Initiating caregiver training from an earlier stage during the rehabilitation process and involving caregivers in the therapy process;
- Adapting caregiver training programmes in order to better equip caregivers for their new roles;
- Facilitating the formation of support groups for caregivers and bringing them in contact with each other; and
- Appealing to public healthcare services to accomodate patients with medical schemes in order to continue with outpatient therapy, should their medical schemes not be sufficient to fund private outpatient therapy sessions.

Further research is also recommended in order to determine the level of independence of patients and burden of care after discharge from other private inpatient rehabilitation units in order to compare results. This may result in identifying trends regarding burden of care post discharge from private inpatient rehabilitation units and for further investigation into the burden of care phenomenon. A follow-up study can also be done on the same sample group after six or twelve months, in order to see if there were any changes in the burden of care experienced after more time has passed.

The Occupational Therapy Association of Occupational Therapy's (OTASA) position paper[6] explaining occupational therapy's scope of practice in terms of rehabilitation contains limited information regarding occupational therapists' role with regard to family members and caregivers. The researcher recommends that OTASA elaborate on this in future papers, as occupational therapy can play a vital role in family members/caregivers' health and well-being.

3.9 CONCLUSION

CVA often results in functional impairments, which can place a high burden of care on caregivers. However, after completing a comprehensive private inpatient rehabilitation programme, it was found that patients mainly need minimal assistance with activities of daily living upon discharge, and that caregivers experience minimal to moderate strain at two months post discharge. Private inpatient rehabilitation can thus play a crucial role in reducing caregivers' burden of care. However, aspects such as financial, physical, psychological, social, as well as personal factors are indicated as contributing to caregiver strain in varying degrees. Often, caregivers' occupations are affected by their new role of caregiving, putting them at risk of unbalanced activity profiles. Little or no follow up with patients was conducted after discharge, which further limits the support received by caregivers to fulfil their new role and occupation as caregivers. The transition between private inpatient rehabilitation and discharge remains a concern. This needs to be addressed in order to ensure that caregivers find meaning in their daily activities and to prevent occupational loss, -disruption, and -deprivation.

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CONCLUDING NOTES ON THE STUDY

As seen in both articles, high demands are placed on family members and informal caregivers, both in terms of taking over caregiving of patients with CVA, and in establishing community integration and productive activity of CVA survivors. This could cause caregivers to stop participating in occupations they find meaningful, as their caregiver-related duties can be very time consuming. Aspects such as financial, physical, psychological, social, and personal aspects could all further contribute to their burden of care.

The aim of this dissertation was to discuss, firstly, the current rehabilitation services for the CVA patient with functional impairments in South Africa, and, secondly, the collective occupation of caregiving and the burden of care experienced by informal caregivers. Therapeutic intervention is essential through all rehabilitation outcome levels but is not always funded by medical schemes. Family members are often expected to take up the role as caregivers, for which they are not always adequately prepared. Caregiver training alone cannot sufficiently prepare them for their new occupation and co-occupation as caregivers, resulting in a high burden of care. This is discussed in the first article, a literature review.

Secondly, factors associated with burden of care as experienced by caregivers of people with functional impairments due to a CVA, after their discharge from a private rehabilitation unit in Bloemfontein was investigated through a consecutive, non-randomised sample method two months post discharge. Aspects which caregivers see as contributing to their burden of care at two months after discharge, including financial, physical, psychological, social, and personal aspects, were investigated. The role and occupations of the caregiver and how these relate to their perceived burden of care were further highlighted. Patients mostly needed minimal assistance upon discharge with functional independence related tasks, and their caregivers experienced minimal to moderate strain. However, caregivers' occupational profiles seemed to be unbalanced and they had limited support post discharge in terms of home based caregivers or outpatient therapy services.

In drawing the two articles together in this dissertation, it becomes apparent that inpatient rehabilitation is crucial in order to optimise patients' functional abilities. However, the transition between private inpatient rehabilitation and discharge is problematic, as inpatient rehabilitation does not necessarily address aspects such as community reintegration. Furthermore, not all patients have access to funding and further support, such as professional caregivers or outpatient therapy services. A variety of aspects contribute to caregivers' perceived burden of care, resulting in unbalanced roles/occupations of caregivers. This needs to be addressed in the rehabilitation process in order to prevent occupational loss.

The main recommendations, based on these articles, call for strategies which can be put in place in order to prevent or reduce burden of care for caregivers after discharge. This needs to be implemented early on in inpatient rehabilitation units, by implementing strategies such as intensive caregiver training prior to discharge. This could aid in preparing family members/caregivers for their new occupation as caregivers, as well as referrals to outpatient therapy services and support groups, if possible. The value of assisting both patients and caregivers in finding meaning in their daily activities should also be addressed when working with both parties during therapy or caregiver training.

More funding for home visits from home based caregivers or therapists, outpatient therapy services, and professional caregivers is needed from medical schemes in order for patients to afford such services. Acute hospitals, as well as inpatient rehabilitation units in the private sector, should consider the need for specialised stroke units where patients can receive the best possible specialised care as soon as possible after suffering the CVA. However, the efficacy of any or all of these strategies require further research in order to ensure that not only patients, but also their caregivers, can maintain healthy, balanced lifestyles and can reach their maximal potential as occupational beings.

APPENDIX A: INFORMATION DOCUMENT AND INFORMED CONSENT FORM FOR PARTICIPANTS

INFORMED CONSENT DOCUMENT TO RESEARCH RESPONDENTS (PATIENTS)

Study title:

The perceived burden of care for caregivers of post discharged CVA patients with functional impairments at a private rehabilitation unit in Bloemfontein.

To whom it may concern:

Introduction:

I, Mrs Lyndall Serfontein am doing research on the burden of care experienced by caregivers of patients who have suffered strokes.

Invitation to participate:

We request to use your personal information in this research study.

What is involved in the study:

Background information will be obtained from you as a patient's medical file, e.g. your medical history, diagnosis, etc. A telephonic interview will be conducted two months after your discharge from Pasteur, with your caregiver, regarding their experience of caring for you on a daily basis. Some questions might be personal, e.g. if you have shown any progress, what functional problems are experienced by you, etc.

Risks of being involved in the study:

No risks are anticipated for participating in this study, although your personal information will be used in this study.

Benefits of being involved in this study:

By determining the burden of care experienced by caregivers of persons with strokes after discharge, therapists might be helped to give more efficient caregiver training prior to discharge in the future. It will also help to reduce future problems and burden of care experienced at home.

Participation is voluntary and you can withdraw participation at any time.

Reimbursements:
You will receive no reimbursement and no costs are involved for participation in this study.

Confidentiality:
Efforts will be made to keep personal information confidential. Absolute confidentiality cannot be guaranteed. Personal information may be disclosed if required by law. Results of this study may be published, although no names will be made available in publications of this study.

Contact details of researcher – For further information/ reporting of study-related adverse events, contact Mrs Lyndall Serfontein at Pasteur Hospital (051 522 6601).

Contact details of Secretariat and Chair: Health Sciences Research Ethics Committee, University of the Free State – for reporting of complaints/problems: Telephone number (051) 4052812

CONSENT TO PARTICIPATE IN RESEARCH (PATIENTS)

You were requested to use your personal information in a research study.

You were informed about the study by Mrs Lyndall Serfontein

You were informed about all possible risks and that no reimbursement or costs are involved for your participation in this study.

You can contact Mrs Lyndall Serfontein at 051 522 6601 if you have questions about the research or if you are injured as a result of the research.

You may contact the Secretariat of the Health Sciences Research Ethics Committee of the UFS at telephone number (051) 4052812 if you have questions about your rights as a research subject.

Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to terminate participation.

If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.

The research study, including the above information has been verbally described to me as patient. I give permission to my caregiver to make known some information about me in his / her participation in this study. I also give consent that my background information may be obtained from my medical file.

____________________________ ____________________

Signature of patient or family member Date

________________________ ____________________

Signature of witness Date

INFORMED CONSENT DOCUMENT TO RESEARCH RESPONDENTS (CAREGIVERS)

Study title:

The perceived burden of care for caregivers of post discharged CVA patients with functional impairments at a private rehabilitation unit in Bloemfontein.

To whom it may concern:

Introduction:

I, Mrs Lyndall Serfontein am doing research on the burden of care experienced by caregivers of patients who have suffered strokes.

Invitation to participate:

We invite the caregiver of the patient who suffered a stroke, to participate in this research study.

What is involved in the study:

This is a telephonic interview which will be conducted with caregivers of patients who have suffered strokes, two months after discharge from Pasteur, in order to determine what your burden of care is. You will thus receive a telephone call from the researcher or research assistants and asked to answer some questions regarding your experience as caregivers. The interview will take more or less 20 – 30 minutes. The results of the study will be made known to Pasteur after completion of the study. You are welcome to inquire about the results of the study.

Risks of being involved in the study:

No risks are anticipated for participating in this study, although some questions might be experienced as personal or sensitive. However, you are requested to ensure that the patient you are taking care of, is safe during your participation in this study.

Benefits of being involved in this study:

By determining the burden of care experienced by caregivers of persons with strokes after discharge, therapists might be helped to give more efficient caregiver training prior to discharge in the future. It will also help to reduce future problems and burden of care experienced at home.

Participation is voluntary and you can withdraw participation at any time. If the time of the telephonic interview is inconvenient and you prefer to participate in the study at a later stage, an alternative time can be scheduled. If the patient needs your help during the interview, the interview can be stopped and an alternative time can be scheduled.

Reimbursements:
You will receive no reimbursement and no costs are involved for participation in this study.

Confidentiality:
Efforts will be made to keep personal information confidential. Absolute confidentiality cannot be guaranteed. Personal information may be disclosed if required by law. Results of this study may be published, although no names will be made available in publications of this study.

Contact details of researcher – For further information/ reporting of study-related adverse events, contact Mrs Lyndall Serfontein at Pasteur Hospital (051 522 6601).

Contact details of Secretariat and Chair: Health Sciences Research Ethics Committee, University of the Free State – for reporting of complaints/problems: Telephone number (051) 4052812

CONSENT TO PARTICIPATE IN RESEARCH (CAREGIVERS)

You were requested to use your personal information in a research study.

You were informed about the study by Mrs Lyndall Serfontein

You were informed about all possible risks and that no reimbursement or costs are involved for your participation in this study.

You can contact Mrs Lyndall Serfontein at 051 522 6601 if you have questions about the research or if you are injured as a result of the research.

You may contact the Secretariat of the Health Sciences Research Ethics Committee of the UFS at telephone number (051) 4052812 if you have questions about your rights as a research subject.

Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to terminate participation.

If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.

The research study, including the above information has been verbally described to me as caregiver. I understand what my involvement in the study means and I voluntary agree to participate.

__________________________ ____________________

Signature of participant Date

_______________________ ____________________

Signature of witness Date

CONSENT TO PARTICIPATE IN RESEARCH (TELEPHONIC)

Your were requested to participate in the research study as described and informed about the study, including possible risks, that you will receive no reimubursement for participation in this study, that no costs are involved and that your participation is voluntary.

Do you understand and agree to participate in this study? Yes / No

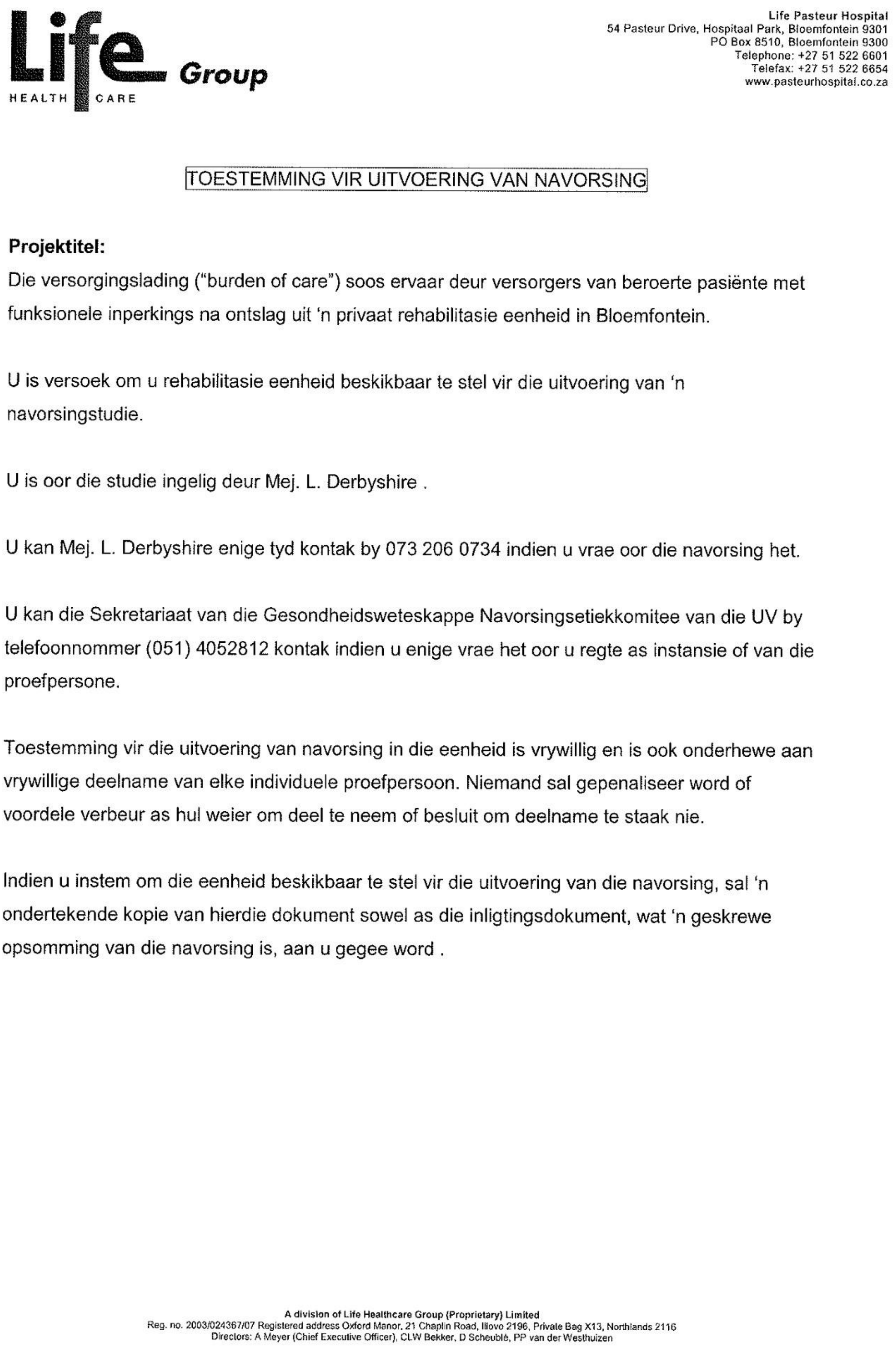
____

Signature of witness

____

Date

APPENDIX B: INFORMATION DOCUMENT AND PERMISSION LETTERS FROM THE HOSPITAL MANAGER



Life Healthcare Group

Life Pasteur Hospital
54 Pasteur Drive, Hospitaal Park, Bloemfontein 9301
PO Box 8510, Bloemfontein 9300
Telephone: +27 51 522 6601
Telefax: +27 51 522 6654
www.pasteurhospital.co.za

TOESTEMMING VIR UITVOERING VAN NAVORSING

Projektitel:

Die versorgingslading ("burden of care") soos ervaar deur versorgers van beroerte pasiënte met funksionele inperkings na ontslag uit 'n privaat rehabilitasie eenheid in Bloemfontein.

U is versoek om u rehabilitasie eenheid beskikbaar te stel vir die uitvoering van 'n navorsingstudie.

U is oor die studie ingelig deur Mej. L. Derbyshire .

U kan Mej. L. Derbyshire enige tyd kontak by 073 206 0734 indien u vrae oor die navorsing het.

U kan die Sekretariaat van die Gesondheidsweteskappe Navorsingsetiekkomitee van die UV by telefoonnommer (051) 4052812 kontak indien u enige vrae het oor u regte as instansie of van die proefpersone.

Toestemming vir die uitvoering van navorsing in die eenheid is vrywillig en is ook onderhewe aan vrywillige deelname van elke individuele proefpersoon. Niemand sal gepenaliseer word of voordele verbeur as hul weier om deel te neem of besluit om deelname te staak nie.

Indien u instem om die eenheid beskikbaar te stel vir die uitvoering van die navorsing, sal 'n ondertekende kopie van hierdie dokument sowel as die inligtingsdokument, wat 'n geskrewe opsomming van die navorsing is, aan u gegee word .

A division of Life Healthcare Group (Proprietary) Limited
Reg. no. 2003/024367/07 Registered address Oxford Manor, 21 Chaplin Road, Illovo 2196, Private Bag X13, Northlands 2116
Directors: A Meyer (Chief Executive Officer), CLW Bekker, D Scheublé, PP van der Westhuizen

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Die navorsingstudie, insluitend die bogenoemde inligting is verbaal aan my beskryf. Ek begryp wat my betrokkenheid by die studie beteken en ek gee toestemming vir die uitvoering van hierdie navorsing in die Life Pasteur rehabilitasie eenheid in Bloemfontein.

Mev. K. Vosloo
Kliniese Dienste Koördineerder: Life Pasteur Rehabilitasie

31/05/2016
Datum

Sr. C. Fourie
Pasteur Praktykbestuurder

31/05/2016
Datum

Handtekening van getuie

31/05/2016
Datum

INLIGTINGSDOKUMENT AAN LIFE PASTEUR REHABILITASIE

Studietitel:

Die versorgingslading ("burden of care") soos ervaar deur versorgers van beroerte pasiënte met funksionele inperkings na ontslag uit 'n privaat rehabilitasie eenheid in Bloemfontein.

Aan wie dit mag aangaan:

Inleiding:

Ek, mej. Lyndall Derbyshire, beplan 'n navorsingstudie ter vervulling van die vereistes vir 'n Meestersgraad in Arbeidsterapie aan die Universiteit van die Vrystaat. Die studie handel oor versorgingslading wat versorgers van persone met beroertes ervaar. In hierdie studie wil ek ondersoek wat die versorgingslading is vir versorgers van persone met beroertes. Soos u weet is ek as arbeidsterapeut betrokke by die opleiding van versorgers van persone met beroertes. Beperkte inligting is egter beskikbaar oor hoe versorgers die lading van hul versorgingsrol na ontslag beleef. Ek wil dus graag met hierdie studie inligting versamel wat terapeute se opleiding van versorgers sal verryk voor ontslag.

Uitnodiging om deel te neem:

Ek rig dus hiermee n versoek om toestemming, om my studie in die Life Pasteur Rehabilitasie Eenheid uit te voer.

Wat behels die studie:

Daar sal van 'n kwantitatiewe beskrywende studie gebruik gemaak word, waar die ervaring van versorgingslading deur versorgers van pasiënte met SVO, twee maande na ontslag van Pasteur, ondersoek gaan word. Ten einde hierdie studie uit te voer, sal ek toegang tot pasiënte se lêers benodig ten tyde van hul ontslag, ten einde demografiese inligting te bekom. Toestemming en agtergrondinligting sal ook by die pasiënte of families, asook hul versorgers verkry word. Telefoniese onderhoude sal dan maandeliks gedoen word met versorgers van pasiënte wat twee maande gelede ontslaan is, ten einde vas te stel wat hul versorgingslading is. Die studie sal oor 'n tydperk van ses maande geskied, bv. vanaf September 2016 tot Februarie 2017. Die tydperk mag egter verleng word indien daar nie 'n voldoende hoeveelheid deelnemers verkry kan word binne daardie tydperk nie. Die navorser sal twee assistente oplei wat as tolke kan optree indien die deelnemers verkies om die telefoniese onderhoud in Suid-Sotho te doen. Elke oproep sal ongeveer 20 - 30 minute duur.

Die volgende word dus versoek van die instansie:

- Toestemming vir uitvoering van die navorsing deur my, Lyndall Derbyshire,'n werknemer van die rehabilitasie eenheid.
- Betrokkenheid van 'n assistent wat as tolk kan optree tydens telefoniese vraelyste indien nodig,
- Toestemming en toegang tot die betrokke pasiënte se lêers indien hul toestemming verkry is.
- Toestemming vir gebruik van die hospitaal se telefoon en onkostes daaraan verbonde.

Risiko's verbonde aan deelname:

Daar is geen risiko's verbonde aan deelname van hierdie studie nie. Sommige vrae mag van 'n persoonlike of sensitiewe aard wees, maar deelnemers kan hulle enige tyd van die studie onttrek.

Voordele van betrokkenheid by die studie:

Deur vas te stel watter faktore bydrae tot die families / versorgers van persone met beroertes se versorgingslading na ontslag, kan terapeute moontlik meer effektiewe versorgeropleiding voor ontslag doen. Daar kan gefokus word op spesifieke aspekte en bekommernisse wat die meerderheid families aangedui het 'n probleem is. Meer effektiewe versorgingsopleiding, kan baie funksionele probleme tuis uitskakel en voorkom dat pasiënte die vaardighede wat hulle in die eenheid aangeleer het, weer verloor. Dit sal dus die pasiënt so onafhanklik moontlik hou, sy vaardighede instand hou, die versorgingslading verminder en die gaping tussen rehabilitasie en ontslag, verminder.

Die resultate van hierdie studie kan ook bydrae tot moontlike voorstelle vir meer effektiewe familievergaderings, wat spesifieke aspekte van die versorgingslading aanspreek en wat die familie reeds vroegtydig kan voorberei om die versorgingslading so effektief moontlik te hanteer. Voorstelle omtrent wat in plek gestel moet word om moontlik die versorgingslading te verminder, sal dus reeds by die familievergadering gemaak kan word. Families sal dan langer tyd kan hê om voor te berei en aanpassings te maak, reeds voor ontslag. Verder kan die resultate van hierdie studie ook dien as motivering vir mediese fondse om die maksimum rehabilitasietyd en / of buitepasiënt terapie te magtig, ten einde langtermyn komplikasies en versorgingslading, te verminder.

Die studie sal dus 'n waardevolle bydrae kan lewer in die rehabilitasie-eenheid waar dit uitgevoer sal word en aanbevelings wat uit die resultate gemaak word, kan ook geïmplimenteer en toegepas word in ander rehabilitasie eenhede.

Verdere inligting rakende die uitslag van die studie sal aan Pasteur beskikbaar gestel kan word, wat ook dan ook toeganklik sal wees vir deelnemers aan die studie.

Vergoeding:

Pasteur, asook deelnemers aan die studie, sal geen vergoeding ontvang vir toestemming / deelname aan hierdie studie nie.

Vertroulikheid:

Daar sal gepoog word om persoonlike inligting vertroulik te hou. Volkome vertroulikheid kan nie gewaarborg word nie. Persoonlike inligting kan bekend gemaak word as die wet dit vereis.

Organisasies wat navorsingsrekords mag ondersoek en/of kopieër vir kwaliteitsversekering en data-analise sluit groepe in soos die Gesondheidswetenskappe Navorsingsetiekkomitee.

As resultate gepubliseer word kan dit lei tot individuele/groepsidentifikasie, alhoewel daar sover moontlik van gemiddelde gebruik gemaak sal word.

Kontakbesonderhede van navorser(s) – Vir verdere inligting / rapportering van studieverwante newe-effekte, kontak gerus vir mej. Lyndall Derbyshire by 073 206 0734.

Kontakbesonderhede van die Sekretariaat en Voorsitter: Gesondheidswetenskappe Navorsingsetiekkomitee van die Universiteit van die Vrystaat – vir rapportering van klagtes/probleme: Telefoonnommer (051) 4052812

APPENDIX C: NON-STANDARDISED QUESTIONNAIRE

Non-standardised questionnaire for caregivers

For office use

Study number of participant……………………………………………… ☐☐☐ 1-3

Contextual Information

1. Do you give informed consent to participate in this
2. questionnaire?

1	Yes
2	No

☐ 4

2. Date and time of call

1	Attempt 1…………………………………………..
2	Attempt 2…………………………………………..
3	Attempt 3…………………………………………..
4	Attempt 4…………………………………………..
5	Attempt 5…………………………………………..

D	D	M	M	Y	Y	H	H	M	M	
										5-14
										15-24
										25-34
										35-44
										45-54

3. Gender of caregiver

1	Male
2	Female

☐ 55

4. What is your age?

……………………………………………years

☐☐ 56-57

5. What is your relationship with the patient?

1	Spouse
2	Friend
3	Parent
4	Child
5	Sibling
6	Cousin
7	Other, specify………………………………………

☐ 58

☐☐ 59-60

6. How long have you been the patient's caregiver?

	Less than one month
	One to two months
	More than two months

☐ 61

7. Are you the patient's caregiver for at least four hours during day time?

1	Yes
2	No

☐ 62

8. Besides you, are there any other caregivers envolved in the patients care? How many?

1	Yes
2	No

☐ 63

Amount……………………………………………………

☐ 64

9. Is the patient staying with you? ☐ 65

1	Yes
2	No

10. Has the patient acquired any other illnesses or injuries since he / she has been discharged? ☐ 66

1	Yes
2	No

11. If yes, what illnesses or injuries have the patient acquired? ☐☐ 67-68 ☐☐ 69-70 ☐☐ 71-72

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

Caregivers' occupations, performance patterns and well-being

12. Do you have a full time job? ☐ 73

1	Yes
2	No

13. What work are you doing? ☐☐ 74-75

…………………………………………………………………..

14. How many hours do you work per day? ☐☐ 76-77

…………………………………………………………………..

15. More or less how many hours do you spend on caregiving / supervision per day? ☐☐ 78-79

…………………………………………………………………..

16. What other responsibilities do you have besides caregiving duties? ☐ 80 ☐ 81

1	Children
2	Work
3	Household tasks
4	Recreation
5	Other…………………………………………………..

17. How many hours do you spend on your other responsibilities?

Children…………………………..hours	☐☐	82-83
Work……………………………..……..hours	☐☐	84-85
Household tasks…………………hours	☐☐	86-87
Recreation………………………..hours	☐☐	88-89
Other……………….…….……….…..hours	☐☐	90-91

18. Do you think that the burden of care could have been relieved with longer time in rehabilitation? ☐ 92

1	Yes
2	No

19. Do you feel that you are spending too little time, too much time or an adequate amount of time on caregiving related duties? ☐ 93

1	Too little time
2	Adequate time
3	Too much time

20. Are you healthy at the moment? ☐ 94

1 Yes
2 No

21. Do you have any previous experience as a caregiver? ☐ 95

1 Yes
2 No

Caregivers' performance skills

22. What is your level of education? ☐ 96

1 Primary school
2 Secondary school
3 Diploma
4 Degree
5 Post graduate
6 Other, specify………………………………………………….. ☐ 97

23. What training did you receive to prepare you for your role as caregiver? ☐ 98

1 Caregiver training at Pasteur
2 Other, specify……………………………………………………… ☐ 99

24. Did you attend Pasteur's caregiver training? ☐ 100

1 Yes
2 No

Caregivers' view of patients' client factors

25. With which of the following occupations do you physically assist the patient on a daily basis?

1 Eating
2 Grooming
3 Bathing
4 Upper body dressing
5 Lower body dressing
6 Toileting
7 Bladder management
8 Bowel management
9 Bed to chair transfer
10 Toilet transfer
11 Shower transfer
12 Locomotion
13 Stairs

☐ 101
☐ 102
☐ 103
☐ 104
☐ 105
☐ 106
☐ 107
☐ 108
☐ 109
☐
☐☐ 110-111
☐☐ 112-113
☐☐ 114-115
☐☐ 116-117

26. With which of the following activities do you provide supervision to the patient?

1	Eating
2	Grooming
3	Bathing
4	Upper body dressing
5	Lower body dressing
6	Toileting
7	Bladder management
8	Bowel management
9	Bed to chair transfer
10	Toilet transfer
11	Shower transfer
12	Locomotion
13	Stairs

118
119
120
121
122
123
124
125
126
127-128
129-130
131-132
133-134

27. In your opinion, did the patient's abilities improve, deteriorate or remained the same since discharge / since you started caring for the patient?

1	Improved
2	Deteriorated
3	Remained the same

135

28. Does the patient receive outpatient therapy?

1	Yes
2	No

136

29. What therapy does the patient receive?

1	Occupational therapy
2	Physiotherapy
3	Speech therapy
4	Other…………………………………………………………

137
138
139

30. How often do they receive outpatient therapy?

1	Less than once a month
2	Once a month
3	Once every two weeks
4	Once a week
5	2 - 3 times a week
6	More than 3 times a week

140-141

31. In what town do you currently stay?

…………………………………………………………………

Environmental factors

32. How many rooms are in the house where you provide care? ☐☐ 142-143

…………………………………………………………………..

33. Does the house have an indoor bathroom? ☐ 144

1 Yes
2 No

34. If yes, is there a bath, a shower or both a bath and a shower in the bathroom? ☐ 145

1 Bath
2 Shower
3 Both

35. Does the house have stairs in front of your house? If yes, how many? ☐ 146

1 Yes
2 No

……………………………………stairs ☐☐ 147-148

36. Is the house adequately adapted for the patient's needs? ☐ 149

1 Yes
2 No

Motivate your answer:
………………………………………………………………………………………………… ☐☐ 150-151
………………………………………………………………………………………………… ☐☐ 152-153
………………………………………………………………………………………………… ☐☐ 154-155
☐☐ 156-157

37. What assistive devices are the patient currently using?
(Mark all the appropriate options)

1 Wheelchair ☐ 158
2 Commode ☐ 159
3 Walking aid ☐ 160
4 Bath board ☐ 161
5 Grab rail ☐ 162
6 Transfer board ☐ 163
7 None ☐ 164
8 Other, specify……………………………………… ☐ 165

38. Are the assistive devices sufficient for the patients needs? If not, what else do you need? ☐ 166

1 Yes
2 No

………………………………………………………………… ☐☐ 167-168
☐☐ 169-170
☐☐ 171-172

APPENDIX D: BACKGROUND INFORMATION DOCUMENT

Background information of patients with CVA

For Office Use

Study number of patient and his / her caregiver		1-3

1. Language of preference — 4

1	Afrikaans
2	English
3	South Sotho

2. Age of the patient — 5-7

………………………………………..years

3. Gender — 8

1	Male
2	Female

4. FIM scores

(Score of 1-7)

	Eating		9
	Grooming		10
	Bathing		11
	Upper body dressing		12
	Lower body dressing		13
	Toileting		14
	Bladder management		15
	Bowel management		16
	Bed to chair transfer		17
	Toilet transfer		18
	Shower transfer		19
	Locomotion		20
	Stairs		21
	Motor FIM subscore		22-23
	Cognitive comprehensio		24
	Expression		25
	Social interaction		26
	Problem solving		27
	Memory		28
	Cognitive FIM subscore		29-30
	Total		31-32

5. Date of admission (dd/mm/yy)……………………………………

d	d	m	m	y

6. Date of discharge (dd/mm/yy)……………………………………

d	d	m	m	y

7. Time spent in rehabilitation at Pasteur

1	Less than 1 week
2	1-2 weeks
3	2-3 weeks
4	3-4 weeks
5	4-5 weeks
6	5-6 weeks
7	6-7 weeks
8	7-8 weeks
9	8-9 weeks
10	9-10 weeks
11	10-11 weeks
12	11-12 weeks
13	More than 12 weeks

		45-46

8. Was it the patient's first CVA

1	Yes
2	No

	47

9. Other medical conditions and medical history

		48-49
		50-51
		52-53

APPENDIX E: STANDARDISED QUESTIONNAIRE – MODIFIED CAREGIVER STRAIN INDEX

general assessment series
try this:®
Best Practices in Nursing Care to Older Adults
From The Hartford Institute for Geriatric Nursing, New York University, College of Nursing

Issue Number 14, Revised 2013 Editor-in-Chief: Sherry A.
Greenberg, PhD(c) MSN, GNP-BC New
York University College of Nursing

The Modified Caregiver Strain Index (MCSI)

By Lisa L. Onega, PhD, RN, Radford University School of Nursing

WHY: Informal supporters provide the majority of long-term care to chronically disabled older adults. Caregiving has been recognized as an activity with perceived benefits and burdens. Caregivers may be prone to depression, grief, fatigue, financial hardship, and changes in social relationships. They may also experience physical health problems (Thornton & Travis, 2003). Perceived caregiver strain has been associated with premature institutionalization for care recipients along with reports of unmet needs. Screening tools are useful to identify families who would benefit from a more comprehensive assessment of the caregiving experience.

BEST TOOL: The Modified Caregiver Strain Index (MCSI) is a tool that can be used to quickly screen for caregiver strain with long-term family caregivers. It is a 13-question tool that measures strain related to care provision. There is at least one item for each of the following major domains: Financial, Physical, Psychological, Social, and Personal. This instrument can be used to assess individuals of any age who have assumed the caregiving role for an older adult. The Modified Caregiver Strain Index (MCSI) is a more recent version of the Caregiver Strain Index (CSI) developed in 1983. The MCSI was modified and developed in 2003 with a sample of 158 family caregivers providing assistance to older adults living in a community-based setting. Scoring is 2 points for each 'yes' and 1 point for each 'sometimes' response. The higher the score, the higher the level of caregiver strain (Travis et al., 2003; Thornton & Travis, 2003).

VALIDITY AND RELIABILITY: The internal reliability coefficient is slightly higher (=.90) than the coefficient originally reported for the CSI in 1983 (=.86). Two-week retest data for one-third of the caregiving sample (n=53) was available and resulted in a test-retest reliability coefficient of .88 (Thornton & Travis, 2003).

STRENGTHS AND LIMITATIONS: The MCSI is a brief, easy to use, self-administered instrument. Long-term family caregivers were not comfortable with the dichotomous choice on the CSI; the modified instrument provides the ability to choose a middle category response best suited to some situations (Travis et al., 2003). The MCSI clarifies and updates some of the items on the original instrument. The tool is limited by lack of a corresponding subjective rating of caregiving impact. Caregiver strain scores are not categorized as low, moderate, or high, so professional judgment is needed to evaluate by total score the level of caregiver strain. The tool effectively identifies families who may benefit from more in-depth assessment and follow-up.

FOLLOW-UP: The higher the score on the MCSI, the greater the need for more in-depth assessment to facilitate appropriate intervention. Additional items and further efforts to develop and test a set of subscales could enhance the applicability of the instrument for research and practice. The older adult care recipient's cognitive status and problematic behaviors should be assessed, as well as the caregiver's perception of role overload or deprivation in key relationships, goals, or activities. Family conflict, work role-caregiving conflict, financial strain, and caregiver social support are also important variables in the overall caregiving experience. Additional work with highly strained long-term caregivers who are receiving little or no formal services is indicated.

MORE ON THE TOPIC:

Best practice information on care of older adults: www.ConsultGeriRN.org.

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Modified Caregiver Strain Index

Directions: Here is a list of things that other caregivers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, On a Regular Basis=2	Yes, Sometimes =1	No=0
My sleep is disturbed (For example: the person I care for is in and out of bed or wanders around at night)	______	______	______
Caregiving is inconvenient (For example: helping takes so much time or it's a long drive over to help)	______	______	______
Caregiving is a physical strain (For example: lifting in or out of a chair; effort or concentration is required)	______	______	______
Caregiving is confining (For example: helping restricts free time or I cannot go visiting)	______	______	______
There have been family adjustments (For example: helping has disrupted my routine; there is no privacy)	______	______	______
There have been changes in personal plans (For example: I had to turn down a job; I could not go on vacation)	______	______	______
There have been other demands on my time (For example: other family members need me)	______	______	______
There have been emotional adjustments (For example: severe arguments about caregiving)	______	______	______
Some behavior is upsetting (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)	______	______	______
It is upsetting to find the person I care for has changed so much from his/her former self (For example: he/she is a different person than he/she used to be)	______	______	______
There have been work adjustments (For example: I have to take time off for caregiving duties)	______	______	______
Caregiving is a financial strain	______	______	______

I feel completely overwhelmed (For example: I worry about the person I care for; I have concerns about how I will manage)	______________	______________	______________

[Sum responses for “Yes, on a regular basis” (2 pts each) and “yes, sometimes” (1 pt each)]

Total Score =

Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. The Journal of Gerontology, Series B, Psychological Sciences and Social Sciences, 58(2), p. S129. Copyright © The Gerontological Society of America. Reproduced by permission of the publisher.

The Hartford Institute would like to acknowledge the original author of this Try This® issue: M. Terry Sullivan.

APPENDIX F: ETHICAL CLEARANCE DOCUMENT

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IRB nr 00006240
REC Reference nr 230408-011
IORG0005187
FWA00012784

02 August 2016

MS L DERBYSHIRE
DEPT OCCUPATIONAL THERAPY
FACULTY OF HEALTH SCIENCES
UFS

Dear Ms L Derbyshire

HSREC 78/2016
PROJECT TITLE: THE PERCEIVED BURDEN OF CARE FOR CAREGIVERS OF POST DISCHARGED CVA PATIENTS WITH FUNCTIONAL IMPAIRMENTS AT A PRIVATE REHABILITATION UNIT IN BLOEMFONTEIN

1. You are hereby kindly informed that, at the meeting held on 26 July 2016, the Health Sciences Research Ethics Committee (HSREC) approved the above project after all conditions were met.
2. The Committee must be informed of any serious adverse event and/or termination of the study.
3. Any amendment, extension or other modifications to the protocol must be submitted to the HSREC for approval.
4. A progress report should be submitted within one year of approval and annually for long term studies.
5. A final report should be submitted at the completion of the study.
6. Kindly use the **HSREC NR** as reference in correspondence to the HSREC Secretariat.
7. The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

Yours faithfully

....
PROF WJ STEINBERG
VICE CHAIR: HEALTH SCIENCES RESEARCH ETHICS COMMITTEE

Cc: Mrs MM Visser; Ms ME Vermaak

Health Sciences Research Ethics Committee
Office of the Dean: Health Sciences
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APPENDIX G: PROOF OF LANGUAGE EDITING

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BA Hons (Eng) § MA (Eng Ling) NWU
Taalversorging § Language editing
Proeflees § Proofreading
Vertaling § Translation
henningjg@ufs.ac.za
082 448 2726

24 August 2018

DECLARATION

Hereby I, Johanna Gertruida (Hanta) Henning, declare that I carried out the proofreading and language editing of the Master's Degree dissertation by Lyndall Serfontein, titled *The Perceived Burden of Care for Caregivers of Post Discharged CVA Patients with Functional Impairments at a Private Rehabilitation Unit in Bloemfontein*, submitted in accordance with the requirements for the Magister Degree in Occupational Therapy at the University of the Free State.

Henning

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