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Relationship between caregiver strain and functional independence of people living with stroke in a rural setting in the Eastern Cape, South Africa

Jardine, Jessica

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Relationship between caregiver strain and functional independence of people living with stroke in a rural setting in the Eastern Cape, South Africa

Jessica Jardine

A Research Report submitted to the Faculty of Health Sciences, University of Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Physiotherapy.

Johannesburg, 2024

Declaration

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

Jessica Jardine _____  _____

Name of candidate Signature of candidate

28 day of October 2024 in Johannesburg

Dedication

To the community I served while living in the Eastern Cape. You taught me so much about humility and humanity. I am forever changed and will always be grateful for my time there.

Abstract

Background

High levels of caregiver strain (CS) can impair the quality of life of caregivers as well as the individuals being cared for. This can limit the sustainability of long-term care. Low functional independence (FI) of persons with stroke (PwS) has commonly been associated with CS. Little is known about CS and FI of PwS in rural settings in the Eastern Cape, South Africa. Factors associated with living in rural settings may uniquely influence FI and CS.

Aim

To investigate the level of, and relationship between, CS and FI of PwS living in a rural setting in the Eastern Cape, South Africa.

Method

In a quantitative, cross-sectional study, data was collected from 60 informal caregivers, in a rural setting in the Eastern Cape, South Africa. Participants were selected through random sampling and data pertaining to demographic factors, CS (Caregiver Strain Index (CSI)), and functional independence of PwS (Barthel Index (BI)) was collected. Correlation testing was performed between the BI scores and CSI scores.

Results

Caregiver strain was high. The mean CSI score was 8.17 (SD=±3.26) and 68% (n=41) of caregivers reported strain (CSI score≥ 7). The BI scores were higher in the current study when compared to other rural studies in South African and internationally. The mean BI score was 68 (SD=±23.73). A statistically significant, inverse relationship, of moderate strength was found between the scores of the CSI and the BI (ρ= -0.561 (p=0.001)).

Conclusion

Informal caregivers of PwS in a rural, Eastern Cape setting, experienced high CS. The level of FI of PwS was higher in the current study when compared with other similar studies. There was a significant inverse relationship between the FI of PwS and the CS experienced. Higher caregiver strain was experienced with lower FI of PwS.

Key words: Stroke, Caregiver strain, Functional independence, informal caregiver, Rural

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- Poor cell phone reception introduced unintentional selection bias favouring potential participants who lived in areas with sufficient cell phone signal. 68
- Only the caregivers of PwS that had received treatment from Zithulele Hospital for stroke were included in this study. Any PwS that had received treatment elsewhere and had not been referred to Zithulele Hospital would not have been included. 68
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List of Abbreviations

ADL/ ADLs	Activity/ Activities of daily living
BI	Barthel Index
CS	Caregiver strain
CSI	Caregiver Strain Index
DG	Disability grant
FI	Functional independence
HIC/ HICs	High-income country/countries
LMIC/LMICs	Low-and-middle-income country/countries
OAG	Old age grant
PwS	Person/ Persons with stroke

Chapter 1 Introduction

1.1 Background

Stroke is one of the most significant contributors to long-term disability worldwide (Vos et al., 2020). In 2019, stroke was the third leading cause, globally, of life years affected by disability (Vos et al., 2020). In South Africa, stroke is one of the ten leading causes of disability (Ranganai and Matizirofa, 2020). Cerebrovascular disease, under which stroke is classified, was the fifth leading cause of years of life lost in South Africa, in 2015 (Groenewald et al., 2018). Stroke can lead to impaired motor, sensory, perceptual and/or cognitive functioning in an individual. These deficits can limit the person with stroke's (PwS's) ability to mobilise, perform basic activities of daily living (ADLs) and impair their ability to participate in previously meaningful activities within in their home environment and community (Enright, 2017). This decreased functional independence (FI) of PwS increases their dependence on caregivers (Ogunlana et al., 2014). Rehabilitation after stroke can improve the FI of PwS thereby improving the quality of life of PwS and reducing the dependence on caregivers (Teasell et al., 2020).

There is a disproportionally higher burden of stroke in the rural population of South Africa, compared to the non-rural population (Maredza, Bertram and Tollman, 2015). The rural population of South Africa is estimated to carry a minimum of half of the national stroke burden, despite comprising only one-fifth of the total national population (Maredza, Bertram and Tollman, 2015). In rural settings in South Africa, limited hospital resources and infrastructure often lead to short-stay stroke admissions and limited in-hospital stroke rehabilitation (Scheffler and Mash, 2019). Additionally, out-patient, access to hospital-based rehabilitation is limited in rural settings due to limited healthcare infrastructure and resources, low socioeconomic conditions, mobility limitations of PwS and environmental barriers, such as rugged terrain, limited access to transport and long distances between rural homes and hospital facilities (Vergunst et al., 2017). Decentralised stroke rehabilitation services provided at community healthcare clinics is often interrupted, of low intensity and underdeveloped, due to poor supply of resources that limit the capacity of outreach rehabilitation teams (Scheffler and Mash, 2019). Therefore, out-patient based rehabilitation of PwS is limited in rural, South African settings. This combination of limited in-patient and out-patient rehabilitation, leads to PwS achieving low levels of FI in rural, South African settings (Scheffler and Mash, 2019; Vergunst et al., 2017).

Low levels of FI of PwS increases the dependence of PwS on caregivers (Enright, 2017). In rural, South African settings, it is common for family members to adopt the role of informal caregiver (Scheffler and Mash, 2019). The onset of a stroke is usually abrupt and often unexpected, leaving PwS and their family members unprepared for the major lifestyle adjustments associated with post-stroke recovery (Ogunlana et al., 2014). Family members who become informal caregivers of PwS can experience caregiver strain (CS), as a result of their caregiving role (Hassan, Visagie and Mji, 2011, Mandowara et al., 2020; Yakubu and Schutte, 2018; Zhu and Jiang, 2018). Higher CS is experienced when caring for PwS with lower FI (Zhu and Jiang, 2018). High CS can jeopardise the sustainability of home-based care (Ogunlana et al., 2014). Home-based care provided by informal caregivers, that includes assisting PwS in mobility, toileting, eating, pressure care and administering medication, is heavily relied upon in rural South African settings, due to limited access to post-stroke rehabilitation services (Enright, 2017; Vergunst et al. 2017). Impaired sustainability of home-based care, due to increased CS, can threaten the recovery of PwS as well as decrease the quality of life of both the PwS and their caregivers (Ogunlana et al., 2014).

1.2 Problem Statement

Stroke is a significant contributor to disability in South Africa, especially in rural settings (Maredza, Bertram and Tollman, 2015). People living with stroke in rural, South African settings face many barriers to accessing limited rehabilitation services (Vergunst et al., 2017). This leads to low levels of FI of PwS in these settings, and increased dependence of PwS on informal caregivers (Scheffler and Mash, 2019). Increased dependence on informal caregivers increases CS, which can decrease the quality of life of caregivers and jeopardise the sustainability of long-term care of PwS (Ogunlana et al., 2014).

Studies have been conducted to assess the FI of PwS and CS in rural settings in South Africa, in the Western Cape and Limpopo Provinces (Maredza, Bertram and Tollman, 2015; Scheffler and Mash, 2019). There is limited research on this topic in the Eastern Cape Province, which is considered to be a largely rural Province in South Africa (Ntamo, Buso and Longo-Mbenza, 2013). In this context a rural area is characterised by a low urbanisation rate, a high number of poor households and a low percentage of households with access to sanitation, electricity and water services (Department of

National Treasury, 2011). The majority of the Eastern Cape Province is comprised of areas with these characteristics and includes large areas of former homelands where most of the population depends on natural resources and government social grants for survival (Department of National Treasury, 2011). Cerebrovascular disease was the third leading cause of years of life lost in the Eastern Cape Province, in 2015 (Groenewald et al., 2018). In rural, EC settings, people with disabilities, experience much greater barriers to accessing healthcare, compared to those without disability (Vergunst et al., 2017). Therefore, the topic of low FI of PwS, due to limited access to rehabilitation services, is pertinent to rural, Eastern Cape settings. There is a dearth in available literature examining the relationship between the levels of FI of PwS and the CS experienced by informal caregivers in rural, Eastern Cape settings. Acquiring more insight into this topic will allow better decision-making on how scarce healthcare resources in the Eastern Cape can be used to improve FI of PwS and decrease CS of those living in rural settings, thereby improving quality of life.

1.3 Research Question

What is the level of CS, as well as the FI of PwS, living in a rural setting in the Eastern Cape, South Africa?

1.4 Aims and Objectives

1.4.1 Aim of Study

This study aims to investigate the level of CS, as well as the level of FI, and the relationship between these variables, of PwS living in a rural setting in the Eastern Cape, South Africa.

1.4.2 Objectives of Study

1) To describe the demographic profile of the study population.

2) To determine the FI of PwS living in a rural, Eastern Cape setting.

3) To determine the CS experienced by caregivers of PwS living in a rural, Eastern Cape setting.

4) To determine the correlation between the scores of the Barthel Index (BI) and the Caregiver Strain Index (CSI).

1.5 Significance of the Study

This study will provide insight into, and provide new knowledge about, an under-researched area of literature, regarding CS and FI of PwS in rural settings in the Eastern Cape, South Africa. This will contribute to a more comprehensive understanding of the recovery of PwS in rural settings in South Africa.

In the District Health Barometer report from 2019-2020, the Eastern Cape was scored at 32.5% in terms of infrastructure, staffing, medicine and supplies, bulk supplies and administrative processes, of public health facilities in the Province (Massyn et al., 2020). This was well below the national average of 54.9% and was second from last overall (Massyn et al., 2020). Therefore, healthcare resources in the Eastern Cape are low compared to the other Provinces of South Africa. Results from this study will provide insight into the areas of stroke rehabilitation and caregiver support that require more attention within this rural setting. This information will aid in decision-making about how scarce resources in the Eastern Cape should be distributed to assist PwS and informal caregivers in rural settings. Comparison of the results from this study with literature from other rural, South African settings, will either provide support of existing knowledge or provide guidance for future research.

1.6 Outline of this Research Report

The outline of this research report is summarised below:

Chapter 1: Serves as an introductory chapter, providing background information about stroke in rural, South African settings. The purpose of, and rationale for, the study is presented. The aim and objectives to investigate the level of CS, as well as FI of PwS, and the relationship between these variables in a rural setting in the Eastern Cape, South Africa are outlined.

Chapter 2: Is a literature review of the key concepts relevant to the study, highlighting the literature gap that this study aims to address. These key concepts include stroke epidemiology and the high burden of stroke in low-and-middle income countries (LMICs); The limited healthcare resources and health services and physical barriers to healthcare access typical of rural settings in South Africa; The experience of CS by informal caregivers and factors that contribute to this CS; Functional independence of PwS and contributing factors and the relationship between FI of PwS and CS. Outcome

measures that can be used to assess CS as well as the FI of PwS are reviewed in this chapter.

Chapter 3: The methodology of this cross-sectional study is outlined. The study setting of the OR Tambo district of the Eastern Cape, South Africa is described. This chapter details the inclusion and exclusion criteria used when randomly selecting the 60 participants of the study. The pilot study and main study are described with descriptions of the role of the research assistant, the use of the BI and the CSI, data management and statistical analyses and the ethical considerations applied.

Chapter 4: The results of the study are presented in terms of the demographic data of the PwS, the demographic data of the caregivers, the level of FI, as measured by the BI, the level of CS, as measured by the CSI and the significant, inverse relationship determined between FI and CS, through a Spearman's correlation test. This data is presented with the aid of graphics and visual representations.

Chapter 5: The results of the study are discussed. The demographic factors of the PwS and their caregivers are discussed in terms of age and socioeconomic status, sex and culture and physical environmental barriers to healthcare accessibility. The FI of the PwS is discussed in terms of the BI scores and the role that time since stroke plays in the FI after stroke. The level of CS is discussed in terms of the CSI scores reported. Factors contributing to this CS are detailed including duration of caregiving, cultural roles expectations for female, Xhosa caregivers, low education levels and financial strain.

Chapter 6: Conclusions are drawn about the high CS experienced by caregivers in this rural, Eastern Cape setting, despite the higher FI found in this study, when compared with similar studies and the significant inverse relationship determined between the FI and CS.

Chapter 7: References

Chapter 2 Literature Review

2.1 Introduction

This chapter will review literature relevant to stroke, stroke epidemiology and post-stroke rehabilitation services. The differences between stroke rehabilitation in high-income countries (HICs) and low-and-middle income countries (LMICs) will be highlighted. Caregiver strain (CS), experienced by informal caregivers of persons with stroke (PwS), will be discussed and factors that influence CS will be explored. Functional independence (FI) of PwS and, factors influencing FI will be discussed. The relationship between FI, as measured by the Barthel Index (BI), and CS, as measured by the Caregiver Strain Index (CSI), will be explored. Finally, outcome measures that can be used to assess CS as well as the FI of PwS will be reviewed.

2.2 Search Strategy

To identify relevant and appropriate studies for this review of literature, a search of the following electronic databases was conducted between 1 May 2021 and 12 January 2024: PubMed, African Journal Archive, Cochrane Library, mEDLINE Ultimate, SAGE Journals and ScienceDirect. The Google Scholar search engine was also used to find literature. The following keywords were used during the literature search: stroke, stroke epidemiology/ incidence, LMIC, HIC, rural, Africa, South Africa, Eastern Cape, stroke rehabilitation, informal caregiver, CS, determinants, FI, outcome measures, measurement tools/ instruments.

2.3 Stroke

2.3.1 Definition of stroke

The World Health Organisation (WHO), in 1970, provided a definition for stroke that is still commonly used today. It defines stroke as “Rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin” (Aho et al., 1980, p.114; Coupland et al., 2017, p.10). This definition emphasises clinical symptoms when defining stroke, such as cognitive, motor, sensory and/or perceptual deficits. These deficits, combined with personal and environmental factors, can limit the individual’s functional capabilities leading to disability (Kusambiza-Kiingi, Maleka and Ntsiea, 2017). In 2013, the American Heart Association (AHA) developed an updated definition

of stroke as “Infarction or hemorrhage in the brain, spinal cord, or retina because of thrombosis of a cerebral venous structure. Symptoms or signs caused by reversible edema without infarction or hemorrhage do not qualify as stroke” (Sacco et al., 2013, p. 26). This definition emphasises tissue changes as well as clinical symptoms, where the definition by the WHO relies more on clinical symptoms (Coupland et al., 2017). Specialised neuroimaging equipment is required to provide evidence of tissue changes needed for the definition provided by the AHA. In many settings in LMICs and rural communities, there may not be access to specialised neuroimaging equipment (Feigin et al., 2018). Therefore, it has been suggested that the definition of stroke provided by the WHO is still used in rural settings where neuroimaging equipment is not available (Feigin et al., 2018).

2.3.2 Epidemiology of stroke

Stroke is one of the most significant contributors to long-term disability worldwide (Vos, et al., 2020). From 1990 to 2019 the global incidence and prevalence of stroke, as well as death and disability caused by stroke, increased (Saini, Guada and Yavagal, 2021). Based on the findings of the Global Burden of Diseases Study from 2019, it is estimated that globally, 12.2 million new strokes occur each year and that one in four people who are older than 25 years will have a stroke during their lifetime (Feigin et al., 2022). It is also estimated that more than 143 million years of healthy life is lost every year as a result of death and disability due to stroke (Feigin et al., 2022). Disability post-stroke often results in dependence of PwS on caregivers for assistance during ADLs and mobility. The reintegration of PwS, with residual disability, into previous roles and meaningful activities within their home environment and community, in rural settings, is often limited (Enright, 2017). This increases dependence on caregivers and increases burden of care (Teasell et al., 2020).

Approximately 90% of the global burden of stroke is located in LMIC (Feigin et al., 2022). In Africa, stroke has been estimated to be one of the leading causes of mortality and morbidity (Louw et al., 2020). Sub-Saharan Africa has been reported to bear the highest burden of stroke in the world (Sarfo et al., 2018). In South Africa, the rural population is estimated to carry a minimum of half of the national stroke burden (Maredza, Bertram and Tollman, 2015). The crude incidence rate of stroke in rural South African settings was found to be 259 per 100 000 person year, with an age-

adjusted rural stroke incidence of 347 per 100 000 person year (Maredza, Bertram and Tollman, 2015). The Eastern Cape Province is a largely rural province (Ntamo, Buso and Longo-Mbenza, 2013). Although there is no formal estimate of the stroke burden in the rural population in the Eastern Cape Province, cerebrovascular disease was the third leading cause of years of life lost in this province in 2015 (Groenewald et al., 2018).

A shift in stroke burden from HIC to LMIC has been highlighted by multiple recent studies (Feigin et al., 2022; Hathidara, Saini and Malik, 2019; Katan and Luft, 2018; Kim et al., 2020; Nguyen, Kim and Chow, 2020; Saini, Guada and Yavagal, 2021). The decrease in stroke burden in HIC may be due to improvement in acute treatment, prevention and rehabilitation of stroke in these countries (Katan and Luft, 2018). This difference in stroke burden highlights the limited healthcare resources for stroke in LMIC (Pandian et al., 2020).

2.3.3 Stroke rehabilitation limitations in low-and-middle income countries

Rehabilitation after stroke is essential to provide PwS with the best opportunity to achieve optimal post-stroke recovery (Teasell et al., 2020). In LMIC, PwS receive insufficient in-hospital rehabilitation, due to short duration hospital admission (Rhoda et al., 2015). In South Africa, many district and regional hospitals experience high demand for limited hospital bed space (Scheffler and Mash, 2019). This results in short duration hospital admission of PwS, leading to limited in-hospital rehabilitation and PwS often being discharged home, without receiving sufficient rehabilitation services (Kusambiza-Kiingi, Maleka and Ntsiea, 2017). Sub-optimal in-hospital rehabilitation leads to increased reliance on post-discharge rehabilitation and informal home-based care from family members.

Post-discharge rehabilitation services for PwS in LMICs is often limited or absent due to inadequate infrastructure, poor availability of resources and low affordability of services for most PwS (Pandian et al., 2020). Out-patient rehabilitation services based at district and regional hospitals are available only to those PwS who stay within the immediate geographic area of service of the hospital (Scheffler and Mash, 2019). Due to limited healthcare resources in relation to the large population serviced by these hospitals and access difficulties associated with geographical distance, and limited

availability of transport, it is not feasible for those PwS not living in the direct vicinity of the hospital to access these hospital-based out-patient services (Scheffler and Mash, 2019; Vergunst et al., 2017). Therefore, many PwS are referred from district and regional hospitals to primary healthcare facilities, such as community healthcare clinics, for post-discharge out-patient rehabilitation (Scheffler and Mash, 2019). The rehabilitation services at these community healthcare clinics are not permanent and are usually provided by an outreach rehabilitation team that travels to multiple facilities within the district. As a result, rehabilitation services provided at these facilities are often inconsistent and of low intensity (Scheffler and Mash, 2019).

Community support systems for PwS in LMICs are often ineffective or rarely available (Pandian et al., 2020; Scheffler and Mash, 2019). These community support systems include out-patient services provided at community healthcare clinics and home visits performed by community healthcare workers and multi-disciplinary rehabilitation workers, providing promotive, rehabilitative and palliative services (Scheffler and Mash, 2019). Scheffler and Mash (2019) reported that, in a rural, Western Cape setting, 30% of the PwS that were referred to home and community-based care services, after hospital discharge, did not receive any visits from community healthcare workers. The PwS that did receive visits from community healthcare workers, received a median of 3 (IQR: 2.0–7.5) sessions. The median duration of these visits was 20 minutes (IQR: 15–30). There was no mention of rehabilitation personnel attending these home-based visits. The short duration of these visits and the lack of a presence of rehabilitation personnel, would not provide enough time for training of physical skills and problem solving, as well as the provision of information and emotional support needed by PwS and their caregivers (Mhlongo and Adepeiu, 2020; Scheffler and Mash, 2019).

Accessibility of community-based rehabilitation services is further limited by physical environmental factors associated with rural settings. These factors include rough terrain conditions, long travel distances to healthcare facilities and limited transport availability (Vergunst et al., 2017). These factors are further compounded by the physical disability of the PwS (Rhoda *et al.*, 2015; Vergunst *et al.*, 2017). Vergunst et al. (2017) found that people with disabilities in a rural population in the Eastern Cape, South Africa, experienced much greater barriers to accessing healthcare compared to those without disability. Provision of walking aids and wheelchairs is not enough to

overcome the physical environmental barriers that are characteristic of rural settings. Scheffler and Mash (2019) reported that, despite 80% of the PwS in their study having received wheelchairs and walking aids, only 28% of the PwS mobilised independently. In this study 60% of the PwS reported physical environmental barriers to mobilisation relating to the size, entrance, and layout of the house (Scheffler and Mash, 2019). The barriers to mobilisation formed by these physical environmental factors limit access to healthcare, which can impede functional recovery of PwS. These barriers also increase the dependence of the PwS on informal caregivers, increasing CS (Scheffler and Mash, 2019).

The difficulty of low provision of post-discharge rehabilitation services and fragmented rehabilitation care is not unique to South African, rural communities. Sub-optimal stroke care and limited access to rehabilitation facilities has been reported in studies conducted in Thailand, China, Rwanda, Tanzania and several other African settings (Gbiri, Olawale and Isaac, 2015; Han et al., 2017; Pandian et al., 2020; Rhoda et al., 2015).

Insufficient in-hospital rehabilitation post-stroke, low provision of post-discharge rehabilitation services, fragmented rehabilitation care and physical environmental barriers to healthcare access, increases the dependence of PwS on family members who become informal caregivers (Gbiri, Olawale and Isaac, 2015). This increases strain experienced by these caregivers (Akosile et al., 2018; Gbiri, Olawale and Isaac, 2015; Kurtulus Tosun and Munire, 2017; Mandowara et al., 2020; Scheffler and Mash, 2019).

2.4 Caregiver strain

2.4.1 Definition of informal caregiver

An informal caregiver can be defined as “An unpaid person who is most closely involved in taking care of stroke survivors, but not necessarily living with the patient” (Hung et al., 2012 p.393). Informal caregivers may provide emotional, physical, social and financial assistance to PwS (Yakubu and Schutte, 2018), but have no professional training in caregiving (Zhu and Jiang, 2018). In contrast, formal caregivers are remunerated for their caregiving services and possess specific training in providing caregiving services (Diniz et al., 2018). In rural South African settings, it is more

common for PwS to be cared for by family members, fulfilling the role of informal caregiver (Scheffler and Mash, 2019). Therefore, this study will focus on informal caregivers. Where there is more than one informal caregiver, the primary informal caregiver will be defined as the individual who spends the most time caring for the PwS (Kusambiza-Kiingi, Maleka and Ntsiea, 2017).

2.4.2 Caregiver strain

Caring for PwS places significant strain on informal caregivers (Akosile et al., 2018; Gbiri, Olawale and Isaac, 2015; Kurtulus Tosun and Munire, 2017; Mandowara et al., 2020; Scheffler and Mash, 2019). Caregiver strain can be described as the discomfort that a caregiver experiences, resulting from the tasks and restrictions involved in their caregiving role (Mandowara et al., 2020). Strain experienced by informal caregivers is complex and multidimensional, involving social, financial, psychological, emotional and physical factors (Bhattacharjee et al., 2012; Gbiri, Olawale and Isaac, 2015). Caregiver strain may occur when caregivers perceive difficulty in performing caregiving tasks or feel overwhelmed in their caregiving role (Yakubu and Schutte, 2018). Informal caregivers are often required to adjust their personal lifestyle to accommodate their new caregiving role, while still trying to meet their own needs, which contributes to increased CS (Gbiri, Olawale and Isaac, 2015).

Caregiver strain is a topic that is commonly reported in literature, in studies conducted in various countries and multiple settings (Gbiri, Olawale and Isaac, 2015; Kusambiza-Kiingi, Maleka and Ntsiea, 2017; Mandowara, et al., 2020; Scheffler and Mash, 2019; Zhu and Jiang, 2018). In an urban setting in Johannesburg, South Africa, Kusambiza-Kiingi, Maleka and Ntsiea (2017) reported that 55% of 45 caregivers of PwS experienced CS, as measured on the CSI (CSI score ≥ 7). In a rural setting in Western India, 59% of 70 caregivers experienced CS (Mandowara et al., 2020). In a prospective longitudinal study in a rural, Western Cape setting in South Africa, 33% of 91 caregivers experienced CS at baseline (Scheffler and Mash, 2019). Three months later, thirteen participants were lost to follow up and 26% of the remaining caregivers experienced CS (Scheffler and Mash, 2019). A mean CSI score of 7.35 (SD=±2.9), indicating CS, was reported in a study in China where 164 caregivers of PwS were assessed (Han et al., 2017). The reporting of CS in various settings and various countries highlights the pertinence of CS in the context of caregiving for PwS.

Caregiver strain can lead to caregivers experiencing poor physical and emotional health, lowered sense of well-being and increased depressive symptoms (Zhu and Jiang, 2018). This can jeopardise the effectiveness and sustainability of informal caregiving for PwS, which can in turn threaten the recovery of PwS as well as decrease the quality of life of caregivers (Ogunlana et al., 2014). This study will investigate the strain experienced by caregivers in terms of financial, social, physical, psychological and personal domains.

2.5 Factors associated with caregiver strain

Caregiver strain is a multidimensional phenomenon. Various factors pertaining to caregivers may influence an informal caregiver's experience of strain, including socioeconomic status, sex and culture, joint family systems and the duration of caregiving (Bhattacharjee et al., 2012; Gbiri, Olawale and Isaac, 2015).

2.5.1 Socioeconomic status

Low socioeconomic status has been repeatedly linked to increased CS C Yakubu and Schutte (2018) studied informal, female caregivers in two low-income communities in Cape Town, Western Cape, South Africa and found that caregivers with lower income experienced more CS than those with higher income (Yakubu and Schutte, 2018). Mandowara et al. (2020) corroborate these findings in their study, in a rural setting in Western India, where higher socioeconomic status was significantly associated with decreased CS. Financial stability has been reported to be an important factor in alleviating CS, due to the long term recovery after stroke (Mandowara et al., 2020). Yakubu and Schutte (2018) suggest that caregivers with higher income have access to more resources which can decrease the strain of caregiving.

Lower socioeconomic status can result from loss of, or resignation from, employment (Yakubu and Schutte, 2018). The demands that the caregiving role places on the caregiver's time may increase the caregiver's time away from work or lead to resignation from employment. This can increase financial strain, resulting in higher CS (Yakubu and Schutte, 2018). Resignation from employment has been found to increase CS at a statistically significant level (Hassan, Visagie and Mji, 2011). Yakubu and Schutte (2018) reported a statistically significant relationship between caregiver

employment and decreased CS. Hassan, Visagie and Mji, (2011) found that 19% of the caregivers in their study needed to resign from their employment to fulfill a caregiving role. Caro, Costa and Da Cruz (2018) reported that 37.9% of the participants in their study left employment after becoming informal caregivers to PwS. Therefore, adoption of the caregiver role may lower socioeconomic status through loss of employment, and this may increase CS.

Low education levels are a component of low socioeconomic status, and are linked to increased CS (Mandowara et al., 2020). Education levels in rural settings in the Eastern Cape are low (Statistics South Africa, 2023). In the O.R. Tamo district, the percentage of the population, aged 20 years and older, that had no schooling in 2022 was 12%, which is almost double the national average of 6.9% (Statistics South Africa, 2023). This highlights the vulnerability of caregivers in rural, Eastern Cape settings to experience low socioeconomic status and increased CS.

It has been shown that CS associated with low socioeconomic status can be alleviated through financial support in the form of social grants (Tosun and Temel, 2017; Yakubu and Schutte, 2018). An association between the receipt of financial support and lower CS was found in a study conducted in Turkey (Tosun and Temel, 2017). In South Africa, Yakubu and Schutte (2018) found a statistically significant association between receiving social grants and lower CS. These studies highlight the role that social grants (such as a disability grant (DG) or an old age grant (OAG)) can play in lowering CS and improving the standard of living of both the caregiver and PwS (Tosun and Temel, 2017; Yakubu and Schutte, 2018).

2.5.2 Sex and culture

Some studies have found a statistically significant relationship between being a female caregiver and increased CS (Mandowara et al., 2020; Zhu and Jiang, 2018). While other studies have found no association between the sex of the caregiver and CS (Gbiri, Olawale and Isaac, 2015; Han et al., 2017; Kazemi et al., 2021). Cultural factors, influencing the life roles adopted by males and females, have been suggested to be responsible for the differing findings on caregiver sex as a determinant of CS (Akosile et al., 2018; Gbiri, Olawale and Isaac, 2015; Kazemi et al., 2021; Mandowara et al., 2020).

Cultural factors that dictate caregiving roles between males and females in Indian culture, were cited by Mandowara et al. (2020), to explain the increased female CS reported in their study. In Indian households, males are usually the breadwinners while females are responsible for homemaking, caring and household duties. When a male breadwinner of a household experiences a stroke, the females of the household must adopt the male's financial responsibility of providing household income, in addition to pre-existing household duties and the new caregiver role. This significantly increases the CS experienced by female caregivers (Mandowara et al., 2020). Gbiri, Olawale and Isaac (2015) agree that cultural factors influence the impact that caregiver sex has on CS. The authors noted that in the culture that is predominant in their Nigerian study setting, the spouse of an individual is expected to take on the primary responsibility of caring for the PwS, irrespective of the sex of the caregiver. This cultural expectation was suggested to be the reason that no association was found between caregiver sex and CS (Gbiri, Olawale and Isaac, 2015). Akosile et al. (2018) contradict this reasoning of Gbiri, Olawale and Isaac (2015), by reporting that in the African culture in Nigeria, the role of informal caregiver is usually considered to be the responsibility of females. Despite these contradicting views on Nigerian culture, both studies consider the culture of the participants to be an important factor impacting CS. Kazemi et al. (2021) reported that in Iranian culture, females are expected to adopt the role of caregiver. The authours suggested that this expectation of females may explain why no difference was found in CS between male and female caregivers in this study (Kazemi et al., 2021).

In the studies by Gbiri, Olawale and Isaac (2015) and Kazemi et al. (2021), the reasoning provided for the lack of relationship between caregiver sex and CS, was that the cultural expectations of who should adopt the caregiving role were clear beforehand, therefore the caregivers transitioned more naturally into their expected caregiving role. Xhosa is the most common language spoken in the Eastern Cape and is the dominant culture in this province (Statistics South Africa 2024). It is known that in the Xhosa culture, adoption of the caregiver role is the responsibility of females (Booi, 2021). Considering the findings of Gbiri, Olawale and Isaac (2015) and Kazemi et al. (2021), one may expect the CS experienced by Xhosa caregivers not to differ between the sexes. In the study by Mandowara et al. (2020) the authors suggested that the increased CS experienced by female caregivers was due to role overload. If

female, Xhosa caregivers in rural settings are required to adopt multiple roles, in addition to the caregiving role, as in the study by Mandowara et al. (2020), there may be significantly more CS reported by female Xhosa caregivers.

2.5.3 Joint family system

Caregivers living in joint family systems can benefit from lower CS, when compared to caregivers living in nuclear family systems (Mandowara et al., 2020). Joint family systems exist where a nuclear family, consisting of one or more parent(s) with children, live together with other family members such as siblings or parents (Statistics South Africa, 2022). Living in a joint family system may allow for the involvement of multiple caregivers, which has been associated with decreased CS (Gbiri, Olawale and Isaac, 2015; Wang et al., 2021; Liang et al., 2022). Multiple caregivers living in a joint family household can allow for responsibilities such as physical caregiving for the PwS, household chores and managing finances, to be divided among several family members thereby decreasing the strain experienced by a single caregiver (Mandowara et al., 2020). Living in joint family systems, in extended households, is common in rural settings in the Eastern Cape, South Africa. In 2021, 41.7% of the households in the Eastern Cape were classified as extended households with extended households being more common in rural areas than urban areas (Statistics South Africa, 2022). This may contribute to decreased CS in rural Eastern Cape settings through division of responsibilities among multiple caregivers within extended households.

2.5.4 Duration of caregiving

Duration of caregiving has been significantly associated with CS (Tosun and Temel, 2017; Yakubu and Schutte, 2018). Tosun and Temel (2017) found that in the first one to five years of caregiving, the initial strain felt by unprepared caregivers decreases slightly as the caregiver builds familiarity and experience with the caregiving role, as well as developing coping strategies. Longer durations of caregiving, of more than five years, may increase CS due to fatigue of the caregiver role or caregiver health problems secondary to care provision (Kurtulus Tosun and Munire Temel, 2017). Yakubu and Schutte (2018) agree that CS increases with increased duration of caregiving. In their study, in a low-income setting in Cape Town, South Africa, the authors found that caregivers who had been providing care for fewer years reported to be in better physical health than the caregivers who had been providing care for more

years (Yakubu and Schutte, 2018). Increased CS over longer durations may highlight insufficient caregiver support and inadequate sharing of the caregiver burden (Kurtulus Tosun and Munire Temel, 2017).

2.6 Functional independence of persons with stroke

2.6.1 Definition of functional independence

Functional independence refers to “The ability to conduct activities of daily living without difficulty” (Fiatarone, 1996 p. 70). The success of rehabilitation is often defined in terms of FI (Pommerich et al., 2023). For PwS, achieving and maintaining independence in activities of daily living (ADLs) is associated with improved quality of life (Zhang et al., 2023) and decreased CS (Pommerich et al., 2023).

2.7 Factors associated with functional independence

Environmental factors characteristic of rural settings (Vergunst et al., 2017) and time since stroke can influence the level of FI achieved by PwS.

2.7.1 Environmental factors

Persons with stroke living in rural, South African settings experience more physical, environmental barriers to FI and infrastructure limitations than those living in urban, South African settings (Vergunst et al., 2017). These factors can increase the dependence of PwS on caregivers, thereby increasing CS (Rhoda et al., 2015). Examples of physical barriers to FI, faced by PwS in rural, South African settings include, outside toilets, uneven outdoor terrain, the influence of poor weather on outdoor mobility conditions, doorway size, house layout, toilet size, the need to fetch water using a bucket and the need to heat water using fire (Scheffler and Mash, 2019). These factors increase the level of independent functioning required to perform ADLs (Scheffler and Mash, 2019). Outdoor terrain conditions and limited access to transportation can limit the ability of PwS to access healthcare facilities, (Vergunst et al., 2017) decreasing access to necessary rehabilitation services. The physical barriers associated with rural living, not only influence the FI of PwS but also affect CS. Scheffler and Mash (2019) reported that caregivers living in informal housing in rural settings experienced doubled CS. Yakubu and Schutte (2018) reported that informal caregivers in poverty-stricken, rural households can experience high CS. Therefore,

physical barriers are important considerations when discussing CS and FI of PwS living in rural, South African settings.

2.7.2 Time since stroke

Increased time since stroke has been associated with greater FI of PwS (Gbiri, Olawale and Isaac, 2015; Mandowara et al. 2020). This increase in FI has been attributed to spontaneous physiological recovery with increased time (Ballester et al., 2019). Rejnö et al. (2019) reported that the improved FI of PwS seen with increased time since stroke is influenced by the death of functionally dependent PwS over time. This is supported by the findings of Mudzi, Stewart and Musenge (2012) who reported that mortality rates of PwS with lower initial BI scores are higher with increased time since stroke. Therefore, the improved FI seen with increased time since stroke may be due to physiological recovery, or it may reflect only those PwS that survive with increased time since stroke.

Increased time since stroke has been associated with decreased CS in several studies (Gbiri, Olawale and Isaac, 2015; Han et al., 2017; Mandowara et al., 2020). In contrast Tosun and Temel (2017) found time since stroke not to be associated with CS. Decreased CS with increased time since stroke has been attributed to the decrease in disability of the PwS as they recover with time, caregivers becoming more accustomed to their new role with increased understanding of the condition of stroke (Mandowara et al., 2020).

2.7.3 Other factors

The pattern of functional recovery after stroke has shown to differ between subtype of stroke (ischaemic versus haemorrhagic) (Alawieh, Zhao and Feng, 2018). The severity of initial stroke injury is a major determinant of extent of functional recovery after stroke (Alawieh, Zhao and Feng, 2018). Intensity, frequency, timing and type of rehabilitative intervention after stroke greatly influences post-stroke functional recovery (Alawieh, Zhao and Feng, 2018). Certain comorbidities, such as uncontrolled diabetes, have been associated with poorer FI post-stroke (Alawieh, Zhao and Feng, 2018). Depression after stroke has been found to interfere with stroke rehabilitation and impede functional recovery (Alawieh, Zhao and Feng, 2018). Data was not collected

on any of these factors in the current study, therefore discussion in terms of their influence on FI after stroke is limited.

2.8 Relationship between functional independence of persons with stroke and caregiver strain

Decreased FI of PwS has been consistently associated with increased CS of informal caregivers (Badaru et al., 2017; Kumar et al., 2022; Kwon et al., 2023; Ngoc and Hsu, 2021; Oliva-Moreno et al. 2018; Scheffler and Mash, 2019; Wang et al., 2021; Zhu and Jiang, 2018). It is possible that caring for PwS with lower FI involves more caregiving tasks and responsibilities than caring for those with higher FI (Wang et al., 2021). This creates more demands on informal caregivers and can interfere with other aspects of the caregivers' life, such as employment, personal privacy and relationships with other family and friends (Yakubu and Schutte, 2018). Witnessing a PwS with low FI experiencing a difficult post-stroke recovery period may cause emotional strain and increase CS (Wang et al., 2021). All these factors contribute to higher CS experienced when caring for PwS with lower FI (Wang et al., 2021; Yakubu and Schutte, 2018).

Zhu and Jiang (2018) conducted a meta-analysis of 22 studies, to determine the strength of the relationships between different predictors of CS and the CS experienced by informal caregivers of PwS. The authors found an inverse relationship of moderate strength between FI in ADLs, of PwS, and CS (Zhu and Jiang, 2018). Inverse relationships of moderate strength were also reported by Boonsin, Deenan and Wacharasin (2021), Mandowara et al. (2020) and Ngoc and Hsu (2021).

Functional independence of PwS was determined to have the strongest influence on CS in the study by Ngoc and Hsu (2021), when compared to caregiver depression and caregiver anxiety. In this study, caregiver depression and anxiety were found to have mediating effects on the relationship between FI and CS. If depression and anxiety symptoms were reduced, the influence of FI on CS was decreased (Ngoc and Hsu, 2021). In contrast to this, Zhu and Jiang (2018) found that, although FI significantly influenced CS (ES=-0.39), caregiver anxiety (ES=0.64) and caregiver depression (ES=0.57) were the strongest influencers of CS in their meta-analysis. Boonsin, Deenan and Wacharasin (2021) found FI of PwS to be the factor with the strongest

influence on CS in their study. Caregiver anxiety and caregiver depression were not investigated in the study by Boonsin, Deenan and Wacharasin (2021).

Boonsin, Deenan and Wacharasin (2021) found FI to influence CS both directly and indirectly. In their study, indirect effects of FI on CS were mediated by caregiving hours and caregiver self-efficacy (Boonsin, Deenan and Wacharasin, 202). The authours note that decreased FI increases caregiving hours, which contributes to increased CS (Boonsin, Deenan and Wacharasin, 2021). Caring for PwS with lower FI may reinforce the self-efficacy of the caregiver thereby decreasing CS (Boonsin, Deenan and Wacharasin, 2021).

In all the studies discussed above, FI had a significant direct influence on CS. Caregiver anxiety and caregiver depression have also been shown to play a significant role in CS and the relationship between FI and CS. Caregiving hours and caregiver self-efficacy may influence the relationship between FI and CS.

2.9 Review of assessment tools (outcome measures)

2.9.1 Caregiver Strain Index

The CSI was developed by Betsy Robinson, studying a population of informal caregivers, caring for persons older than 65 years, who had undergone hip surgery or hospitalization for arteriosclerotic heart disease (Robinson, 1983). The CSI consists of thirteen yes/no questions covering different dimensions of potential strain, including social, financial, physical, psychological and time-related dimensions (Robinson, 1983). Positive responses are scored as 1 and negative responses as 0. The results from each question are summed to give a final score, out of a maximum of thirteen (Robinson, 1983). A total score of seven or more on the CSI indicates an increased level of strain and is considered a risk for CS (Robinson, 1983). The CSI is among the outcome measures most frequently used in literature to assess CS (Pont et al., 2018; Scholten et al., 2019). The CSI has been used widely in both local and international research to assess CS in caregivers of PwS (Akosile et al., 2018; Bhattarcharjee et al., 2012; Hung et al., 2012; Kumar at al., 2022; Kusambiza-Kiingi, Maleka, Ntsiea, 2017; Mandowara et al., 2020; Rajan et al., 2017; Rouillard et al., 2012; Scheffler and Mash, 2019).

The CSI has been found to have good reliability and internal consistency with a Cronbach's alpha value of 0.86 (Robinson, 1983). The CSI has shown sufficient criterion validity, of moderate quality, when used to assess CS experienced by those caring for PwS or people with spinal cord injury (Scholten et al., 2019). The CSI has been shown to have no floor or ceiling effects (van Exel et al., 2004). Van Exel et al. (2004) found that, when used to evaluate CS experienced by those caring for PwS, the CSI was found to be more feasible than, and to have equal validity to, the Sense of Competence Questionnaire and the Caregiver Reaction Assessment, which are both longer and more complex measures of CS. Due to the question design and length, the CSI is concise and brief to administer (van Exel et al. 2004). This is advantageous, as simple and concise instruments are associated with increased response rate (van Exel et al., 2004).

The CSI has been deemed appropriate to be used in the context of primary health care. The instrument can be completed by either the interviewer or the caregiver, it requires no training and is quick and easy to administer (Scheffler and Mash, 2019). The CSI has been translated into Xhosa and used to assess CS of caregivers of PwS in a rural setting in the Western Cape, South Africa (Rouillard et al., 2012). In the study by Rouillard et al. (2012), the authors translated the English CSI into Xhosa and back-translated. The Xhosa version was tested for reliability and validity on a sample of six participants. Although it was not possible to determine statistical results due to the small sample size, no environmental or cultural issues were found that invalidated the use of the Xhosa version of the CSI (Rouillard et al., 2012). The Xhosa version of the CSI was also used reliably in a separate rural, Western Cape setting by Scheffler and Mash (2019). The CSI has been successfully administered telephonically, with no statistically significant differences found between telephonic and face-to-face administration (Eames et al., 2013; Hoffmann et al., 2010). Telephonic administration of outcome measures provides the advantages of being more cost-effective and less time-consuming than in-person interviews, as well as allowing participants to be interviewed from more extensive and diverse geographic areas (Hoffmann et al., 2010). The CSI was chosen for use in the current study due to its widespread use, good reliability, lack of floor and ceiling effects. The CSI is more concise than other measures of CS, such as the Sense of Competence Questionnaire and the Caregiver Reaction Assessment, and provides more ease of administration (van Exel et al. 2004).

The most convincing factor for use of the CSI was the previous use of an Xhosa-translated version in a rural, South African setting and valid telephonic administration.

2.9.2 Barthel Index

Many outcome measures are available for evaluating the FI of PwS (Galeoto et al., 2019). The BI and Modified Rankin Scale (MRS) have been the most frequently and widely used in stroke literature and clinical practice (Liu et al., 2022). The Functional Independence Measure (FIM) has also been identified as a commonly used outcome measure to assess FI in PwS (Meyer et al., 2014). Use of the FIM requires purchasing of a license and undergoing training, while both the BI and MRS are freely accessible and require no formal training before use.

The BI was found to have good internal consistency in people with acute stroke, with a Cronbach alpha value of 0.85 being reported (Hsueh et al., 2002). The BI has been shown to have high concurrent validity with the FIM, with a correlation score of $r \geq 0.92$ and an agreement score of ICC ≥ 0.92 (Hsueh et al., 2002). A ceiling effect has been observed with the BI (Liu et al., 2022)

The BI measures the individual's ability to perform ten ADLs independently (Mandowara et al., 2020; Wang et al., 2022). The scoring system uses increments of five. Two of the 10 ADLs are scored with either 0 or 5 points and another two are scored with either 0,5,10 or 15 points. Six of the ADLs are scored with either 0, 5 or 10 points (Mahoney and Barthel, 1965). The scores for each of the ten ADLs are totaled to give a final BI score out of 100. The higher the total score, the more functionally independent the individual is when performing ADLs (Mahoney and Barthel, 1965). There is inconsistency in literature regarding how the total scores of the BI can be categorized to represent the level of FI of the PwS (Liu et al., 2022). Due to this inconsistency in standardized cut-off scores, the total scores of the BI can be treated as a numeric scale when interpreting the results of the measure (Kamarul and Keegan, 2018).

It has been suggested that the scoring system of the BI is crude and limits the sensitivity of the instrument to detect change in FI (Shah, Vanclay and Cooper, 1989). To overcome this limitation, Shah, Vanclay and Cooper (1989) developed the Modified

Barthel Index (MBI), where the ten tested ADLs remained the same as the BI, but the scoring system was altered, such that each ADL is scored using the same five-point Likert scale. (Wang et al., 2022). Like the BI, the maximum total score for the MBI is 100, with higher scores indicating higher FI (Shah, Vanclay and Cooper, 1989). A study was conducted to compare the responsiveness of the MBI to that of the BI, in PwS (Wang et al., 2022). The findings from this study suggest that the BI and the MBI have similar abilities to detect change in the FI of PwS when the changes are relatively large. But when the changes in the FI of PwS are subtle, the MBI is more sensitive in detecting these changes than the BI (Wang et al., 2022). There was no need to measure change in FI for the purposes of this study, as the study aimed to determine the level of FI in relation to CS at one point in time. Therefore, the widely used BI was chosen for this study.

Telephonic administration of the BI was found to be valid and reliable in moderately to severely disabled PwS in India (Prasad et al., 2018). There is a strong agreement between administering the BI telephonically and face-to-face. Using Cohen's weighted kappa analysis, a wK value of 0.9 was reported in one study (Della Pietra et al., 2011) and wK values of 0.63 and 0.72 in another study (Prasad et al., 2018). Wee et al. (2019) found that administering the BI telephonically has excellent interrater reliability with ICC values between 0.995 and 0.997, at a 95% confidence interval. It has been reported that administering the BI telephonically to caregivers of PwS is an accurate method of collecting information about the FI of PwS (Kamarul and Keegan, 2018).

The BI was deemed to be the most appropriate measure for investigating FI for the purposes of this study. Widespread use of the BI will allow the results of this study to be comparable to both local and international literature. The BI has been shown to have good reliability through measures of internal consistency. Although the BI has shown limitations in detecting subtle changes in FI, the objectives of the current study include determining the level of FI of PwS at a single point in time, and not to evaluate the change in FI. The BI has been translated into Xhosa and administered in a stroke population in a rural setting in the Western Cape, South Africa (Scheffler and Mash, 2019). The BI can be administered telephonically to caregivers in a valid and reliable way to collect FI information about PwS. Telephonic administration of the BI allows recruitment of participants from a greater geographic distribution and avoids selection bias of participants that can be physically present for face-to-face interviews.

Telephonic interviews are more cost-effective and require fewer resources than face-to-face interviews (Hoffmann et al., 2010).

2.10 Conclusion

There is a higher burden of stroke in the rural population of South Africa than in the urban population (Maredza, Bertram and Tollman, 2015). Disability post-stroke limits the full integration of PwS back into their home and community environments, resulting in the dependence of PwS on caregivers (Enright, 2017). In rural, South African settings, many PwS do not receive adequate post-stroke rehabilitation services due to limited availability of healthcare resources and physical environmental factors, associated with rural settings, that serve as barriers to accessing healthcare (Scheffler and Mash, 2019; Vergunst et al., 2017). This leads to lower FI of these PwS with increased dependence on caregivers (Enright, 2017; Scheffler and Mash, 2019; Vergunst et al., 2017), which can lead to the experience of CS (Kurtulus Tosun and Munire, 2017; Mandowara et al., 2020). ‘

Various factors relating to caregivers in rural, South African settings can increase the CS experienced. Low socioeconomic status, including low financial income and low education levels (Akosile et al., 2018; Gbiri, Olawale and Isaac, 2015; Kurtulus Tosun and Munire, 2017; Mandowara et al., 2020; Scheffler and Mash, 2019); Role overload of female caregivers within the Xhosa culture (Booi, 2021; Mandowara et al., 2020); Not living in joint family systems, thereby less division of roles and responsibilities (Mandowara et al., 2020) and longer duration of caregiving (Tosun and Temel, 2017; Yakubu and Schutte, 2018) are all caregiver-related factors that can lead to increased CS. Low FI of PwS has been consistently associated with increased CS (Badaru et al., 2017, Kumar et al., 2022; Kwon et al., 2023). Physical environmental factors associated with living in rural settings form barriers to PwS achieving FI (Vergunst et al., 2017), while increased time since stroke has been associated with increased FI (Gbiri, Olawale and Isaac, 2015; Mandowara et al. 2020).

The CSI and BI were deemed to be suitable outcome measures to be used in this study. The CSI is a reliable and valid outcome measure to assess CS (Robinson, 1983; Scholten et al., 2019). The CSI provides ease of administration and is more concise than other measures of CS (van Exel et al. 2004). The BI is a valid and reliable outcome

measure for assessing FI of PwS. There are Xhosa-translated versions available for both the CSI and the BI and both these outcome measures are valid for telephonic administration.

Therefore, high CS is a pertinent issue for caregivers of PwS living in rural, South African settings. The combination of limited healthcare resources, combined with factors unique to rural, South African settings, lead to lower FI of PwS, higher dependence on caregivers and high levels of CS experienced by caregivers. Further understanding the levels of, and relationship between FI of PwS and CS in rural, South African settings is an important step to addressing high CS in these settings. The BI and the CSI are outcomes measures that have been deemed appropriate by the author to collect data on FI and CS in this study setting.

Chapter 3 Methods

3.1 Study Design

A quantitative cross-sectional design was used for this study. A cross-sectional study design allows researchers to describe the features and traits of a population and to determine the prevalence of variables at a specific point in time (Kesmodel, 2018; Wang and Cheng, 2020). A cross-sectional study design would allow the researcher to describe the demographic profile of the study population, determine the caregiver strain (CS) present among informal caregivers and determine the functional independence (FI) of the persons with stroke (PwS), in the study population, at one point in time. The cross-sectional design was deemed to be well suited to address the study objectives, and in addition, it is an affordable and time efficient option (Spector, 2019).

3.2 Study Setting

This study took place within the King Sabata Dalindyebo municipality, situated in the OR Tambo district of the Eastern Cape, South Africa (Figure 3.1). The target population included the informal caregivers of PwS who had received treatment for stroke from Zithulele Hospital. Zithulele Hospital is a government-run, district hospital that provides primary healthcare services within the OR Tambo district. Healthcare services provided to PwS include services provided by medical officers, nursing staff and rehabilitation therapists including physiotherapists, occupational therapists, dietitians and speech therapists. These services are provided as in-patient services, hospital-based out-patient services and community outreach services at local community clinics. The OR Tambo district covers an area of 12 141km² (Department of Corporate Governance and Traditional Affairs, 2020) and had a population of 1 501 702 people in 2022 (Statistics South Africa, 2023). The majority (66.5%) of the population living in the OR Tambo district live in poverty (Department of Corporate Governance and Traditional Affairs, 2020). There is a low urbanisation rate within the district and the district is characterised as being largely rural (Department of Corporate Governance and Traditional Affairs, 2020).

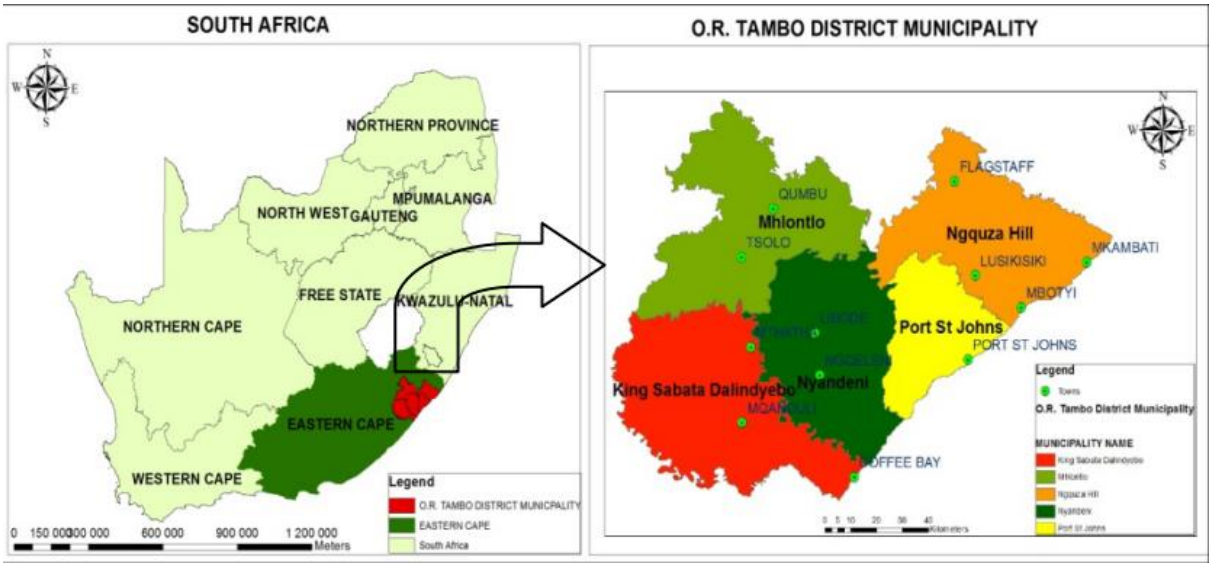


Figure 3.1 Map showing study setting (Buso, Nakin and Abraham, 2014, p.127)

3.3 Participants

3.3.1 Source of Participants

Informal caregivers, of PwS who had received treatment for stroke from Zithulele Hospital, between 1 May2019 and 20 April 2021, formed the population of study participants. Where there was more than one caregiver for the PwS, the primary caregiver, who spent the most time caring for the PwS was asked to participate in the study.

3.3.2 Sample Size

Zithulele Hospital has an electronic database of PwS that was established on 1 May 2019. This database shows that from 1 May 2019 to 30 April 2021, a total of 451 PwS received rehabilitation services from allied health therapists working at Zithulele Hospital. Using a sample size calculator, and a confidence interval of 90%, a sample size of 60 informal caregiver participants, from this population size of 451 PwS, was calculated to provide a representative sample for this study (Raosoft, 2004).

3.3.3 Sample Selection

Random sampling was used to select potential participants. Each PwS on the Zithulele Hospital database was assigned a number from 1 to 451. A random selection of numbers between 1 and 451 was generated using a randomised selector (Research Randomizer, 2021). The PwS corresponding to each number was contacted on the corresponding contact number in the database. The informal caregiver for the PwS

was identified by the PwS. If the caregiver was present at the time of the call, the phone was handed to the caregiver, or an alternative call time was arranged. Caregivers were asked if they would like to participate in the study. Attempts to contact the PwS were conducted at three different times on three different days until the call was answered. If calls were not answered, the PwS corresponding to the next number on the randomly compiled list was selected and contacted. This procedure continued until 60 participants agreed to participate in the study.

3.3.3.1 Inclusion Criteria

- Aged 18 years or older.
- Primary informal caregiver (irrespective of gender), who spent the most time engaged in activities of caring for the PwS, compared to any other individual caring for the PwS. This was subjectively identified by the caregivers of the PwS.
- The informal caregiver cared for a person who fitted the following criteria:
    - The person received treatment at Zithulele Hospital for a stroke.
    - The person was living in the catchment area of Zithulele Hospital at the time of the stroke and was still living in the catchment area post-stroke, at the time of the study.
    - It had been more than 3 months since the person experienced a stroke.

3.3.3.2 Exclusion Criteria

- The informal caregiver received some form of payment for providing stroke care.
- The informal caregiver was not contactable via phone call for a telephonic interview, and they were unable to access the local community healthcare clinic for a face-to-face interview.
- The informal caregiver cared for a person that fitted the following criteria:
    - The person had experienced more than one stroke. Residual impairments from a previous stroke may have reduced the FI of the person prior to the following stroke resulting in need for prior care. Therefore, the FI limitations and CS experienced would not be able to be associated directly with the current stroke.
    - The person had other physical disabilities (occurring before or after the stroke) that were not a direct consequence of the stroke, that limited their FI

(including, but not limited to limb amputations, Parkinson's disease, traumatic brain injury, blindness, peripheral neuropathy and spinal cord injury).

3.4 Research assistant

A research assistant was recruited through networking channels of previous researchers having conducted research in the area. As Xhosa is the dominant language spoken by the study population, the research assistant conducted all interviews in Xhosa (as this was the language preferred by participants). The primary researcher trained the research assistant in conducting the interviews and was present during all face-to-face and telephonic Xhosa interviews, to provide clarification where needed. The primary researcher reflected with the research assistant after each interview and was satisfied that reliable translations and feedback had been provided by the research assistant.

The research assistant had been involved in data collection for multiple research studies, associated with both local and international Universities, from 2012 to the time of the data collection for this study, in 2022. Participants of these previous studies were sourced from populations within the OR Tambo district in the Eastern Cape, which was the same area for participant sampling for the current study. The research assistant had completed a six-week course of data collector training, which included training on communication skills, conducting qualitative interviews, research techniques, research ethics, HIV and AIDS, TB, maternal health and child health. The training on research ethics covered confidentiality, ethical interviewing techniques, how to identify at-risk individuals (as part of mental health awareness), respondent sensitivity, emergency protocol and procedures for cases where participants needed to be referred to healthcare services. Respectful handling of participants and recognizing when to offer participants comfort breaks was also covered. The research assistant had performed various roles in data collection in previous research studies, including conducting qualitative interviews, quantitative interviews and facilitating focus groups. She had worked as a translator and participant recruiter. She had worked both independently and closely with researchers in data collection in previous research studies.

The primary researcher trained the research assistant on the purpose, aims and objectives of the study. All interview documentation and instruments were explained to the research assistant by the primary researcher, including the study information sheet (Appendices A and B), consent form (Appendices C and D), demographic datasheets and both outcome measures. The process of obtaining informed consent, both face-to-face and telephonically, were covered. The research assistant was trained on how to score the Caregiver Strain Index (CSI) and the Barthel Index (BI). The principles of participant confidentiality and voluntary participation among other research ethics were reviewed.

3.5 Instrumentation and Outcome Measures

Two demographic datasheets were used in this study and were given out by the primary researcher to the study participants. One to collect demographic information about the caregiver (Appendix E) and the other to collect demographic information about the PwS (Appendix F). Factors associated with CS and FI that were discussed in Chapter 2 were considered when developing the demographic datasheets. Data relating to age, sex, access to healthcare, socioeconomic status, time since stroke, duration of caregiving and division of caregiving duties was collected through the demographic datasheets. As the preferred language of communication of participants was Xhosa, the research assistant collected this demographic information in Xhosa, with the primary researcher present during all interviews.

The BI was used to collect information about the FI of the PwS. The CSI was used to collect information about CS experienced by the informal caregivers. The primary researcher was granted permission by Scheffler and Mash (2019) to use the Xhosa versions of both the BI and CSI, as used in their study in the Western Cape, South Africa (Appendices G, H, I and J).

The demographic datasheets and the CSI and BI were all administered by the interviewer. Despite the option for these instruments to be self-administered, the primary researcher deemed it preferable to keep all instruments interviewer-administered to ensure consistency between telephonic and face-to-face interviews as well as to accommodate for potential illiteracy of participants with low levels of education.

3.6 Pilot study

3.6.1 Purpose

The pilot study was performed to:

- Determine the time required to complete the interviews.
- Improve researcher and research assistant proficiency in conducting the full interview through repetition, familiarity and streamlining.
- Identify and address any areas of the interview that required adjustment or clarification to ensure questions were well understood by the study participants.

3.6.2 Methodology

Potential participants that lived close to Zithulele Hospital, within reasonable walking distance, were called by the research assistant and invited to take part in the pilot study. Six participants (10% of the main study sample size) were required for the pilot study. Three participants were asked to take part in face-to-face interviews and three were asked to take part in telephonic interviews.

Face-to-face interviews were conducted in a boardroom located in the Philani Training Centre for Research, which is located on the premises of Zithulele Hospital. This provided a quiet, private area for face-to-face interviews. Researchers conducted the telephonic interviews from this boardroom and participants were informed about moving to a private area for the telephonic interview.

Participants were provided with the study information sheet in Xhosa, via the WhatsApp cell phone application, when contacted and invited to participate in the study. If this was not possible, the information sheet was read to the participant, in Xhosa, over the phone on the day of the interview, prior to the interview, for telephonic interviews. For face-to-face interviews, the participant was given the option of reading the information sheet or having it read to them (if literacy levels were low) on the day of the interview, prior to the start of the interview. This was in line with clearance granted by the Human Research Ethics Committee. Any questions about the study were answered and informed consent was obtained. All interviews were timed. Demographic data and the scores for the CSI and BI were recorded on hard copy printed versions of the instruments. Participants were compensated for their time.

3.6.3 Results and implications for the main study

3.6.3.1 Participants

Of the three participants that were scheduled for face-to-face interviews, one arrived on time, one was delayed due to rain, and one did not arrive, with follow-up phone calls going straight to voicemail. Four telephonic interviews were conducted instead of three to ensure the pilot study consisted of six participants. One pre-arranged telephonic interview was not able to be finished due to poor cell phone reception. A new participant was contacted. One face-to-face interview was with a paid caregiver. The interview was included as the participant had already dedicated their time by coming in for the interview. This highlighted the need for the primary researcher to review the inclusion and exclusion criteria with the research assistant prior to contacting potential participants for the main study.

The pilot study demonstrated that cell phone reception and weather conditions may present difficulties and delays during the data collection period of the main study. The unintentional inclusion of a paid caregiver highlighted the importance of thorough screening according to inclusion and exclusion criteria before conducting interviews. The primary researcher reviewed the inclusion and exclusion criteria with the research assistant.

3.6.3.2 Interview duration

The average of the times (rounded to the closest minute) recorded for the face-to-face interviews was 42 minutes and 23 minutes for the telephonic interviews. The shorter time needed for telephonic interviews may have been because of increased researcher and research assistant proficiency with practice of the interviews, as the face-to-face interviews were conducted first. Another potential reason could have been that it commonly takes more time to build rapport during a face-to-face interviews than during telephonic interviews.

3.6.3.3 Proficiency of conducting interviews

Despite the training provided to the research assistant before beginning the interviews, assistance from the primary researcher was required in scoring the responses to the BI. The research assistant required the primary researcher to aid in scoring the item of “dressing and undressing,” by further clarifying how to differentiate between the score

of 0 and 5. Assistance was also required when scoring the item of “moving between the bed and the wheelchair” by clarifying how to differentiate between the scores. The proficiency of conducting the interviews improved with each interview that was conducted. Additional training of the research assistant, highlighting the functional differences between each score on the BI was conducted by the primary researcher to ensure accurate scoring of the BI.

3.6.3.4 Interview adjustments and clarification

The demographic datasheet for the PwS was amended. The changes made included: Under the item of “Means of access to local clinic” for both before and after stroke, the wheelchair option was further clarified to: “Self-propelled wheelchair access” or “Passive wheelchair access”. Under the items “Employment status before stroke” and “Current employment status”, an additional option of “Pensioner” was added.

The demographic datasheet for the caregiver was also adjusted. These changes included: Under the item “Relation to person with stroke”, an additional option was added of “sibling-in-law.” The name of the local clinic referred to that of the PwS, but it was initially on the demographic data sheet for the caregiver (who may potentially use a different clinic). To avoid confusion this item was moved from the demographic datasheet for the caregiver to the demographic datasheet for the PwS. The “Pensioner” option was added to the items “Employment status before caregiving role” and “Current employment status”.

The information sheet was provided to the participant via the mobile application, Whatsapp, where possible, on the day when the participant was invited to participate in the study. This allowed participants ample time to familiarise themselves with the information and to formulate questions regarding the information. This also allowed for more efficient use of interviewer contact time. For participants that were illiterate or did not have the Whatsapp application, sufficient time was provided to read the study information sheet or have it read to them in their preferred language, either on the initial day they were recruited or on the day of the interview, directly before the start of the interview. The participants were provided with as much time as the participant deemed necessary, to be fully familiar with, and to fully understand, the study information sheet.

The results from the pilot study were not included in the results from the main study.

3.7 Main study procedure

Data collection took place from March 2022 to December 2022. When invited to participate in the study, potential participants were asked whether they were able to meet at their local community healthcare clinic to be interviewed face-to-face. Where this was inconvenient or not possible for the participant, telephonic interviews were conducted. A total of 60 participants were interviewed with 42 interviews being telephonic and 18 interviews being conducted face-to-face. The preferred language for interview for all 60 participants was Xhosa, therefore all interviews were conducted by the research assistant with the primary researcher present during all interviews, to provide any clarification when needed.

Telephonic interviews were conducted from the privacy of the boardroom, in the Philani Training Centre for Research. The research assistant contacted potential participants while seated in this private board room with the primary researcher present to provide any clarification where needed (e.g. where any confusion was present whether a participant met inclusion or exclusion criteria, or for clarification on scoring of outcome measures). Participants were contacted ahead of time to schedule a time and date for the telephonic interview that was convenient for them and would allow them to position themselves in a private area for the duration of the interview. Face-to-face interviews were conducted behind a closed door, in a private room, at the community healthcare clinic local to the participant. Only the primary researcher, the research assistant and the participant were present in the room during the interview.

The study information sheet, in the participants' preferred language, was sent to participants, via Whatsapp, before the interview, on the day of initial recruitment, or directly before the interview, where this was not possible. Where this was not possible, the information sheet was read to the participant telephonically or in-person or a hard copy was given to the participant in person. Before each interview, the participant was asked whether they had read and understood the study information sheet. Where appropriate, the study information sheet was read again to the participant. All questions from the participants were answered. Hard copies of informed consent were signed for

face-to-face interviews and informed consent was voice-recorded for telephonic interviews.

The research assistant administered the demographic datasheets, the BI and the CSI in Xhosa. The primary researcher was present for all telephonic and face-to-face interviews and provided clarification where needed. All data pertaining to the demographic information of both the PwS and the caregivers and the answers to the BI and CSI questions, were gathered from the primary caregiver. Where the caregiver did not know specific information, such as the date of birth of the PwS, time was provided for the caregiver to gather this information. Demographic data and the scores for the CSI and BI were recorded on hard copy printed versions of the datasheets and instruments during the interview. As per ethical board recommendations, participants from both telephonic interviews and face-to-face interviews, were compensated for their time with fifty-rand airtime vouchers. These vouchers were only offered once the interview had been completed to avoid coercion prior to participation. Participants from face-to-face interviews were also compensated for any travel costs incurred to attend the interview.

3.8 Data management and reduction

Data obtained during the study was kept confidential. Participant names, phone numbers, community healthcare clinic where they received healthcare services and their corresponding participant numbers were recorded on a password-protected Excel spreadsheet. Demographic data and scores from the BI and CSI were de-identified and recorded in a separate password-protected Excel spreadsheet in a separate Excel workbook. All electronic data was stored in a password protected electronic folder. The hard copies of informed consent, demographic datasheets and the BI and CSI were stored in a box protected by a lock. Recordings of informed consent were stored in a password protected file on a flash drive placed in the same locked box. Only the primary researcher and the research supervisor had access to these data. Before statistical analysis, data was cleaned, and any duplications, omissions or errors were corrected. The non-numerical demographic data was coded to allow for more efficient data analysis. Data was only used for the purposes of this study. All data will be stored for a period of five years, after which the electronic data will be permanently deleted, and hard copy data will be shredded.

3.9 Ethical Considerations

Ethical clearance was obtained from the University of Witwatersrand Human Research Ethics Committee (ethical clearance number: M210857) (Appendix K). The Eastern Cape Health Research Committee granted permission for the study to be conducted within the OR Tambo district (Appendix L). Permission was obtained from the Chief Executive Officer of Zithulele Hospital to access the Zithulele stroke database in order to contact potential participants (Appendix M). All community healthcare clinic managers were contacted to obtain consent for the use of private rooms at the clinics for face-to-face interviews. Permission was granted by the Philani Research team leader, for use of the boardroom at the Philani Training Centre for Research, for telephonic interviews.

Participant autonomy was ensured and respected. All participants took part in the study of their own free will. Participants were able to withdraw from the study at any time without providing any reasons and without any consequences to the participant. Participation in the study did not affect the healthcare services provided to the PwS or the caregiver in any way.

All participants were fully informed about the study and given the opportunity to ask questions and have them answered. Informed consent was obtained from participants before data was collected. All information and documentation that was provided and all interviews that were conducted, were done so in the participant's preferred language of communication.

In accordance with the ethical principle of non-maleficence, a psychology consultation referral pathway was in place, to Nelson Mandela Academic Hospital, if any psychological stress during the interview process was experienced by the participant. None of the participants experienced psychological stress during the interview process that warranted the use of this referral pathway.

Participant identities were kept confidential. Data was de-identified and the participants anonymity was maintained during data recording and statistical analysis.

3.10 Statistical Analyses

Descriptive statistics were used to describe the demographic profile of the caregivers and that of the PwS. Descriptive statistics were also used to analyse the BI scores, in determining the FI of the PwS, and to analyse the CSI scores, to determine the CS experienced by caregivers. The descriptive statistics were presented as means with standard deviations and frequencies with percentages. The Statistical Package for Social Sciences version 28 was used to conduct correlation testing. As the data was non-linear, a Spearman's correlation test was conducted, using a level of significance of 0.01 and a 99% confidence interval, to assess whether the BI scores were correlated to the CSI scores. Although a set standard has not been established in literature to guide the interpretation of the strength of a relationship from a correlation coefficient value, general guidelines are as follows: a very weak relationship is indicated by a coefficient value of < 0.20 ; a fair relationship is indicated by values between 0.30–0.40; a moderate relationship is indicated by values between 0.40–0.70; a strong relationship is indicated by values between 0.70–0.90 and values >0.90 indicate a very strong relationship (Alsaqr, 2021). Direct relationships are represented by a positive correlations coefficient and inverse relationships are represented by a negative correlation coefficient (Alsaqr, 2021).

Chapter 4 Results

4.1 Introduction

This chapter will present the results of this study, relative to the study objectives, as follows: The demographic profile of the caregivers and the persons with stroke (PwS); the functional independence (FI) of the PwS as measured by the Barthel Index (BI); the caregiver strain (CS), experienced by the caregivers of the PwS, as measured by the Caregiver Strain Index (CSI); and the correlation between the scores of the BI and the CSI. Data was collected from 60 caregivers during data collection. Therefore, a representative sample, at a confidence interval of 90%, was attained.

4.2 Demographic information of the persons with stroke

Demographic information of the PwS is presented in Tables 4.1 -4.5 and Figures 4.1 - 4.3.

Table 4.1 Demographic information of the persons with stroke (n=60)

Demographic factor	**n (n=60)**	**%**
Sex		
Female	32	53
Male	28	47
Race		
Black	60	100
Indian	0	0
White	0	0
Coloured	0	0
Other	0	0
Side of hemiplegia		
Right hemiplegia	30	50
Left hemiplegia	30	50
Level of education		
Never schooled	18	30
Some or completed primary school (grade 0- grade 7)	22	37
Started but did not complete high school (grade 8- grade 12)	13	22
Completed grade 12	4	7
Completed tertiary education (tertiary degree/1-3 years)	3	5
Wheelchair		

Yes	20	33
No	40	67
Means of toileting		
Toilet	42	70
Bucket	7	12
Chamber	5	8
Nappies	2	3
Toilet and bucket	4	7

As shown in Table 4.1, all the PwS were Black (n=60, 100%), 53% (n=32) were females and 50% (n=30) had right-sided hemiplegia. The overall education levels of the PwS were low (not having completed grade 12). Only 7% (n=4) has completed grade 12 and only 5% (n=3) had completed tertiary education. The most common level of education was having completed some or complete primary school education (n=22; 37%). The majority (n=40; 67%) of PwS did not have wheelchairs. Of the 33% of PwS that did have wheelchairs, all the wheelchairs were standard folding frame wheelchairs. The most common method of toileting was the use of a toilet (n=42; 70%) and the least used method was use of nappies (n=2; 3%).

Figure 4.1 shows the age distribution of the PwS.

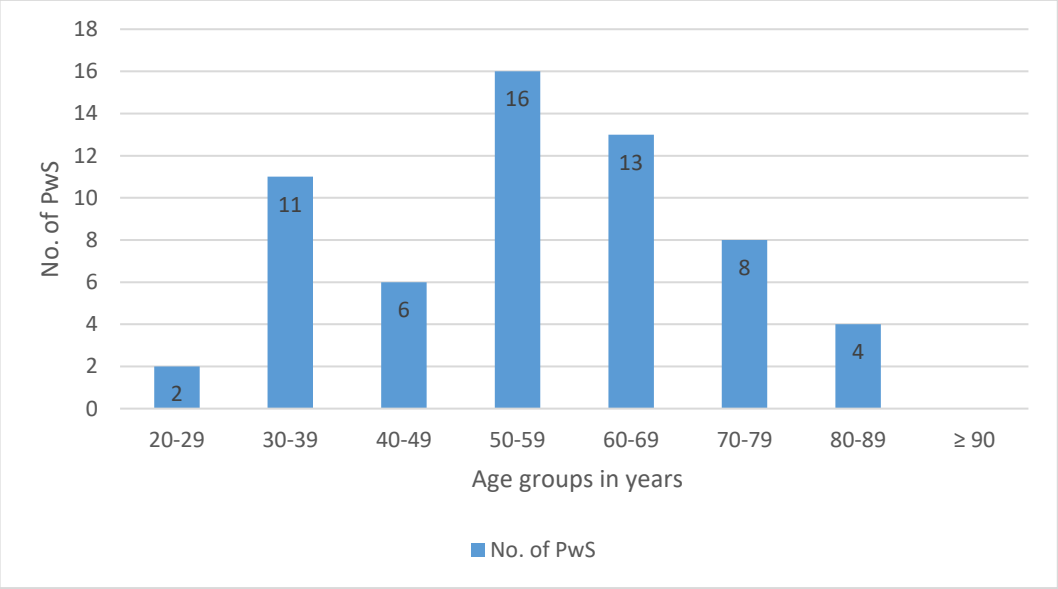


Figure 4.1 Age distribution of the persons with stroke (n=60)

The most common age group of PwS was 50-59 years (n=16; 27%), followed by the age group of 60-69 years (n=13; 22%) (Figure 4.1). None of the PwS were aged 90

years or older, 7% (n=4) were in the age category of 80-89 years and 3% (n=2) were aged between 20 and 29 years (Figure 4.1). The mean age of PwS was 56 (SD=±15.30) years.

Figure 4.2 shows the distribution of time since stroke.

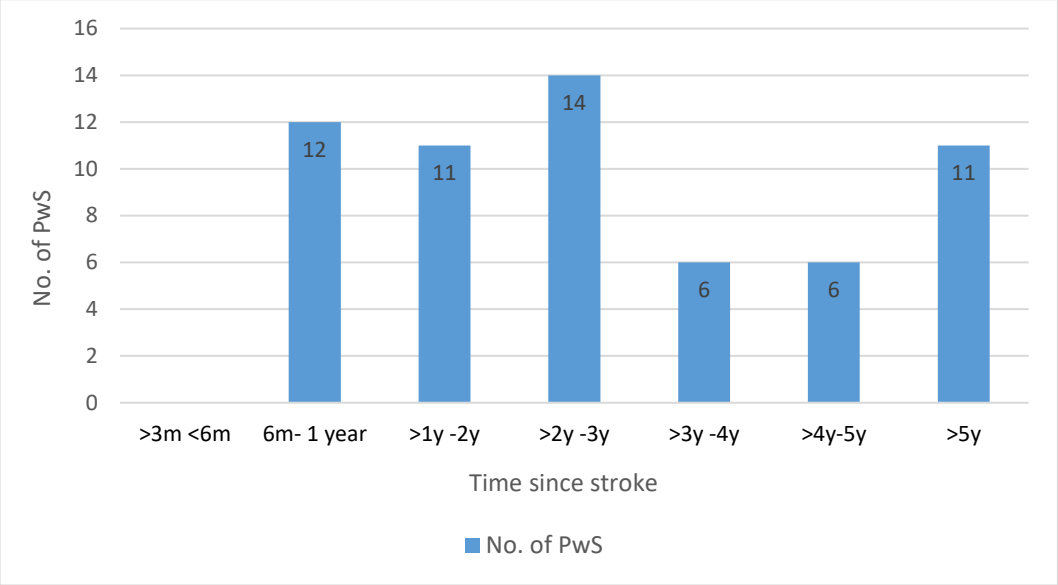


Figure 4.2 Distribution of time since stroke (n=60)

As seen in Figure 4.2, the most common duration of time since stroke (n=14; 23%) was >2years-3years. Twenty percent (n=12) of PwS had experienced a stroke in the last year and 18% (n=11) had experienced a stroke more than five years ago. No PwS had experienced a stroke in the six months prior to data collection. The mean duration of time since stroke was 3.34 (SD=±2.90) years.

Tables 4.2 and 4.3 present the change in means of clinic access experienced by the PwS before and after the stroke.

Table 4.2 Change in means by which clinic was accessed post-stroke (n=60)

Change in means of clinic access	**n (n=60)**	**%**
Change in means of clinic access	38	63
No change in means of clinic access	22	37

Most (n=38; 63%) of the PwS experienced a change in their means of access to their community healthcare clinic after the stroke (Table 4.2).

Table 4.3 Means of clinic access before and after stroke (n=60)

Means of access to clinic	Before stroke		After stroke	
	n (n=60)	%	n (n=60)	%
Unable	0	0	0	0
Walk	26	43	7	12
Taxi	33	55	21	35
Private transport	0	0	27	45
Own vehicle	1	2	3	5
Wheelchair active	0	0	0	0
Other (horse)	0	0	1	2
Wheelchair passive	0	0	1	2

Table 4.3 shows that the most common means of clinic access before stroke were by taxi (n=33; 55%) and walking (n=26; 43%). Hiring private transport was not used by any of the PwS before the stroke to access the clinic but became the most common means (n=27; 45%) of clinic access after stroke (Table 4.3). It is likely that this change of means of access, from those regarding high levels of function (by taxi and walking) to one regarding lower level of function (private transport), is due to the stroke. Only one (2%) of the PwS accessed their clinic through passive wheelchair use after the stroke, despite 20 PwS (33%) having a wheelchair. No PwS accessed their clinics through active wheelchair use, after the stroke. No PwS were unable to access their local clinic either before or after the stroke (Table 4.3).

Tables 4.4 and 4.5 detail the change in employment status experienced by the PwS after stroke.

Table 4.4 Employment status before and after stroke (n=60)

Employment status	Before stroke		Currently	
	n (n=60)	%	n (n=60)	%
Permanently employed	7	12	1	2
Employed on a contractual basis	1	2	1	2
Piece work	11	18	0	0
Unemployed	18	30	29	48
Pensioner	23	38	29	48

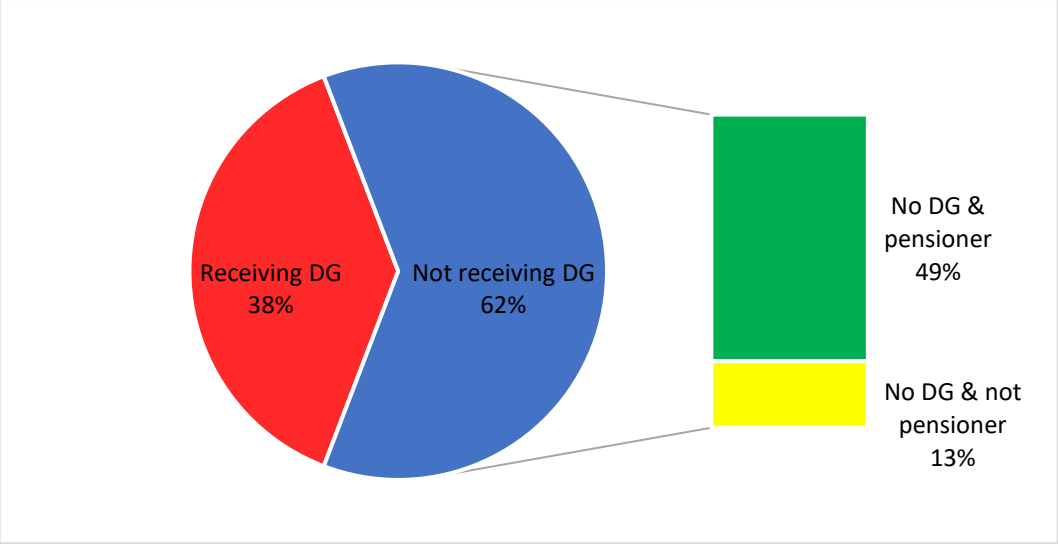
Most of the PwS, were pensioners before the stroke (n=23; 38%), followed by being unemployed (n-18; 30%) (Table 4.4). After the stroke most of the PwS were pensioners (n=29; 48%) or unemployed (n=29; 48%) (Table 4.4).

Table 4.5 Change in employment status of persons with stroke after stroke (n=60)

Change in employment status	n (n=60)	%
No change in employment status	**38**	**63**
Were unemployed before and remain unemployed.	13	22
Pensioner before and after.	23	38
Employed before and after.	2	3
Change in employment status	**22**	**37**
Had some form of employment before and currently unemployed	16	27
Unemployed before and currently employed.	0	0
Not a pensioner before and currently a pensioner.	6	10

Table 4.5 shows that most (n=38; 63%) of the PwS did not experience a change in their employment status after experiencing the stroke. Of the PwS that did not experience a change in their employment status, 38% remained pensioners, 22% remained unemployed and 3% remained employed. Of the 37% of PwS that did experience a change in their employment status after the stroke, 27% lost their employment and became unemployed and 10% became pensioners (Table 4.5).

Figure 4.3 shows the distribution of PwS receiving a disability grant (DG).



*DG= Disability grant

Figure 4.3 Distribution of persons with stroke that do and do not receive a disability grant (n=60)

The majority of PwS (n=37; 62%) were not receiving a DG at the time of data collection (Figure 4.3). Thirteen percent (n=8) of PwS were not receiving a DG, 22% (n=8) and were not pensioners. Therefore, 13% (n=8) of the PwS were not receiving a DG or an old age grant (OAG) (Figure 4.3).

4.3 Demographic information of the caregivers

Demographic information of the caregivers of the PwS is presented in Tables 4.6 -4.9 and Figures 4.4 -4.7.

Table 4.6 Demographic information of caregivers (n=60)

Demographic factor	**n (n=60)**	**%**
Sex		
Female	52	87
Male	8	13
Race		
Black	60	100
Indian	0	0
White	0	0
Coloured	0	0
Other	0	0
Living with the person with stroke		
Yes	60	100
No	0	0
Level of education		
Never schooled	8	13
Some or completed primary school (grade 0- grade 7)	18	30
Started but did not complete high school (grade 8- grade 12)	22	37
Completed grade 12	9	15
Completed tertiary education (tertiary degree/1-3 years)	3	5

As shown in Table 4.6, all caregivers were Black (n=60; 100%) and the majority (n=52; 87%) of caregivers were female. All the caregivers lived with the PwS. The overall level of education of the caregivers was low (not having completed grade 12), with only 15% (n=9) of caregivers having completed grade 12 and only 5% (n=3) of caregivers having completed tertiary education (Table 4.6).

The age distribution of the caregivers is shown in Figure 4.4

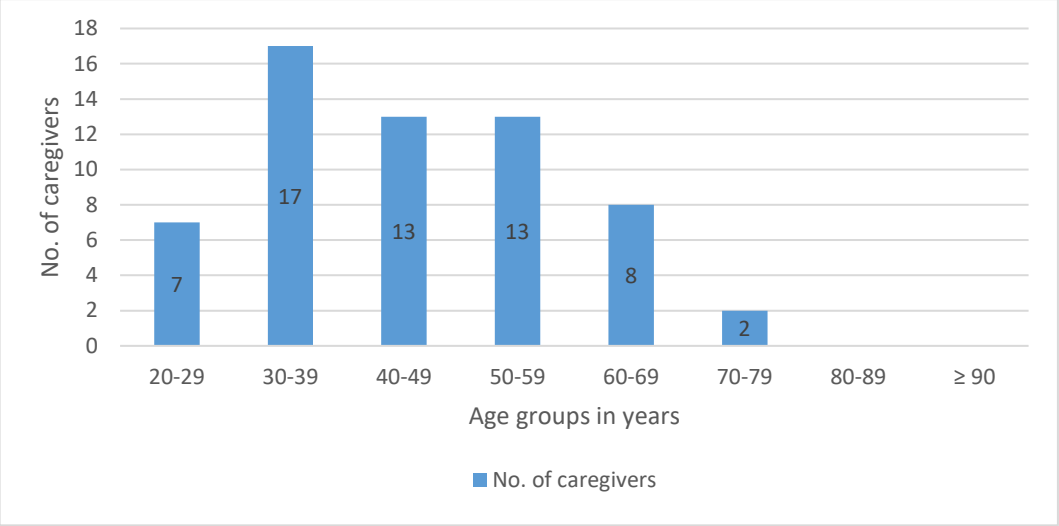


Figure 4.4 Distribution of the age of caregivers (n=60)

The mean age of the caregivers was 45 (SD=±12.97) years old. The age group containing the highest number of caregivers was that of 30-39 years (n=17; 28%) (Figure 4.4).

Figure 4.5 shows the distribution of the caregivers' relationship to the PwS.

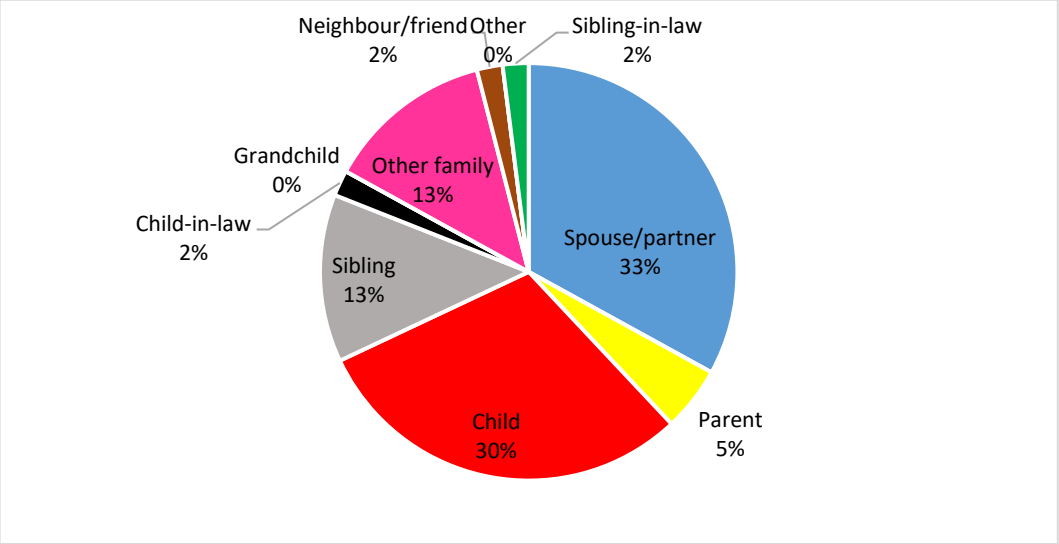


Figure 4.5 Distribution of caregivers' relationship to the persons with stroke (n=60)

As shown in Figure 4.5, the relationship of spouse/partner (n=20; 33%), followed by that of child (n=18; 30%) were the most common relationships of the caregiver to the PwS, with only one (2%) caregiver not being related to the PwS.

The distribution of the duration of caregiving is shown in Figure 4.6.

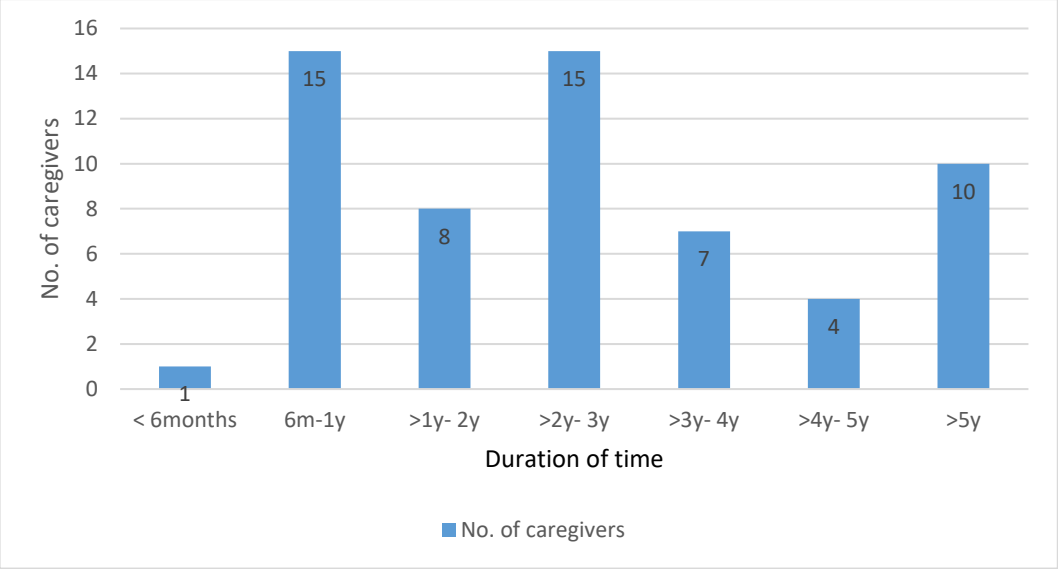


Figure 4.6 Distribution of duration of caregiving (n=60)

The most common durations of caregiving were 6 months-1year (n=15; 25%) and >2 -3 years (n=15; 25) (Figure 4.6). Only 2% (n=1) of caregivers had been providing care for less than 6 months and 17% (n=10) had been providing care for more than 5 years (Figure 4.6). The mean duration of caregiving was 2.99 (SD=±2.61) years.

Figure 4.7 displays the degree of involvement of other caregivers in the provision of care.

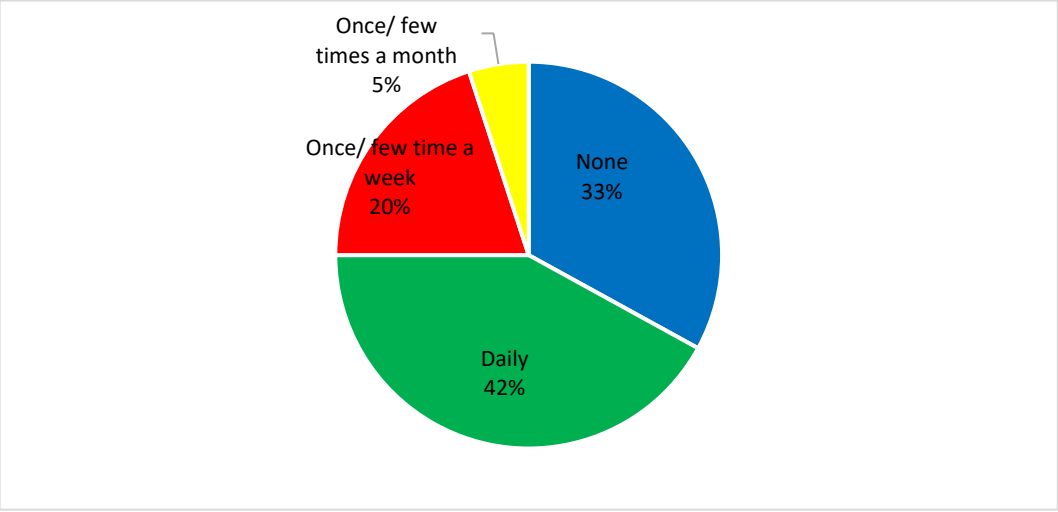


Figure 4.7 Degree of involvement of other caregivers in the provision of care (n=60)

Figure 4.7 shows that 33% (n=20) of caregivers cared for the PwS with no assistance from other caregivers. In 42% (n=25) of the cases more than one caregiver was involved daily (Figure 4.7).

Tables 4.7 and 4.8 detail the current employment status of caregivers and the changes in employment experienced by the caregivers after adopting the caregiving role.

Table 4.7 Current employment status of caregivers (n=60)

Employment status	**n (n=60)**	**%**
Currently permanently employed	0	0
Currently employed on a contractual basis	1	2
Currently performing piece work	5	8
Currently unemployed	45	75
Currently a pensioner	9	15

Most of the caregivers (n=45; 75%) were unemployed at the time of data collection (Table 4.7).

Table 4.8 Change in employment status of caregivers (n=60)

Change in employment status	**n (n=60)**	**%**
No change in employment status	**38**	**63**
Were unemployed before and remain unemployed.	28	47
Pensioner before and after.	8	13
Employed before and after.	2	3
Change in employment status	**22**	**37**
Had some form of employment before and currently unemployed	17	28
Unemployed before and currently employed.	4	7
Not a pensioner before and currently a pensioner.	1	2

The majority of caregivers (n=38; 63%) experienced no change in their employment status after adopting the caregiving role (Table 4.8). Of the 37% (n=22) of caregivers that experienced a change in their employment status, 28% (n=17) lost their

employment, 7% (n=4) became employed after previously being unemployed and 2% (n=1) became pensioners (Table 4.8).

The timing of the adoption of the caregiving role, relevant to the COVID-19 pandemic, by caregivers who experienced a loss of employment is displayed in Table 4.9.

Table 4.9 Timing of adoption of caregiver role by caregivers who lost employment (n=17)

Timing of adoption of caregiver role	**n (n=17)**	**%**
Caregiving role adopted during COVID-19 pandemic (March 2020-April 2022)	10	59%
Caregiving role adopted prior to COVID-19 pandemic (prior to March 2020)	7	41%

Of the 28% (n=17) of caregivers that lost their employment, 59% (n=10) of the caregivers adopted the caregiving role during the time of the COVID-19 pandemic (March 2020-April 2022) (Table 4.9).

4.4 Functional independence of the persons with stroke

Descriptive statistics for the BI scores are presented in Table 4.10 and Figures 4.8 and 4.9.

Table 4.10 Descriptive statistics of Barthel Index scores (n=60)

		n (n=60)	**%**
Maximum score	100	2	3
Minimum score	0	2	3
Mean (SD)	67.83 (±23.73)		

Table 4.10 displays the mean of the BI scores of 67.83 (SD=±23.73). Three percent (n=2) of the PwS were reported to have complete FI (BI score=100/100) and 3% (n=2) of the PwS were reported to be fully functionally dependent (BI score=0/100) (Table 4.10).

The distribution of BI scores achieved by the PwS in this study is shown in Figure 4.8.

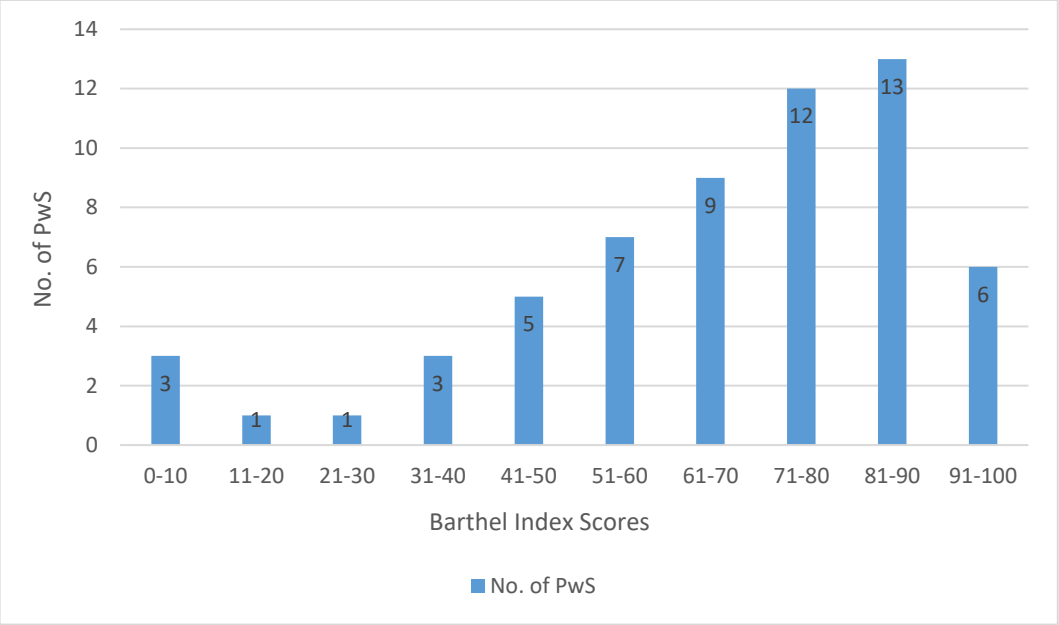


Figure 4.8 The Barthel Index scores achieved by the persons with stroke (n=60)

Ten percent (n=6) of PwS scored between 91-100 on the BI. Five percent (n=3) of PwS scored between 0-10 on the BI (Figure 4.8). The most common BI scores were between 81-90 (n=13; 22%), followed by BI scores between 71-80 (n=12; 20%) (Figure 4.8).

Figure 4.9 shows the percentage of PwS that achieved FI in each item of the BI.

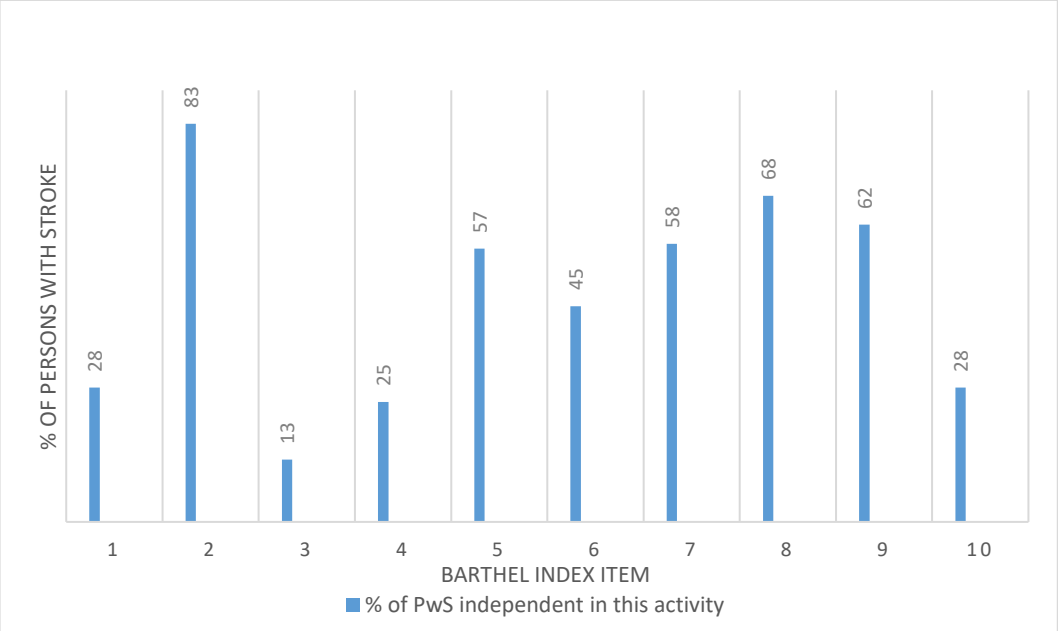


Figure 4.9 Functional independence achieve in each item on the Barthel Index (n=60)

Key for Figure 4.9

1	Bathing
2	Grooming
3	Eating
4	Dressing and undressing
5	Bowel control
6	Bladder control
7	Getting on and off the toilet
8	Moving between the bed and the wheelchair
9	Walking on a level surface, or propelling a wheelchair if unable to walk
10	Ascending and descending stairs

Grooming was the BI item in which most (n=50; 83%) of the PwS were reported to be functionally independent. Eating was the activity with the least reported FI (n=8; 13%) (Figure 4.9).

4.5 Caregiver strain

Information pertaining to the CS is presented in Table 4.11 and Figure 4.10.

Table 4.11 Caregiver Strain Index scores (n=60)

Caregiver strain		**n (n=60)**	**%**
Strained (CSI ≥ 7)		41	68
Not strained (CSI<7)		19	32
Mean (SD) CSI score	8.17 (±3.26)		

Most of the caregivers (n=41; 68%) in this study reported strain (CSI score≥ 7) (Table 4.11). The mean CSI score was 8.17 (SD=±3.26) (Table 4.11).

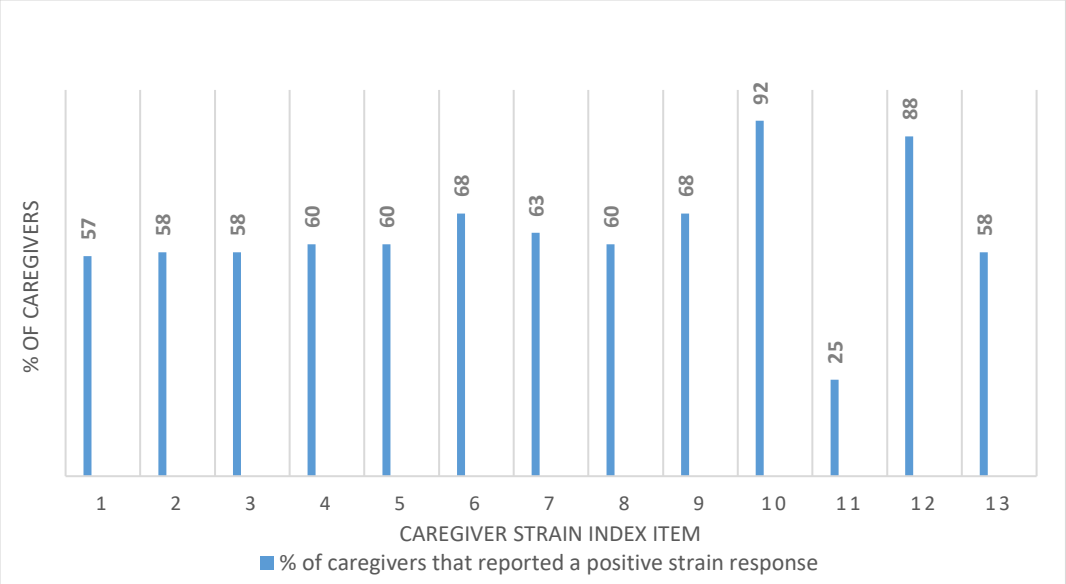


Figure 4.10 Positive strain responses for each item on the Caregiver Strain Index (n=60)

Key for Figure 4.10

1	Disturbed sleep.
2	Caregiving is inconvenient.
3	Caregiving is a physical strain.
4	Caregiving is confining.
5	There has been family adjustment.
6	There have been changes in personal plans.
7	There have been other demands on my time.
8	There have been emotional adjustments
9	Some behaviour is upsetting.
10	It is upsetting to find that my patient has changed so much from his/her former self.
11	There has been work adjustment.
12	Caregiving is a financial strain.
13	I am feeling completely overwhelmed.

Figure 4.10 shows that item 10 on the CSI: The caregiver finds it upsetting to see that the PwS has changed from their former self, was the most frequently reported area of strain (n=55; 92%). The second most commonly reported area of strain, was financial strain (n= 53; 88%) (Figure 4.10). Strain from work adjustments was the least reported area of strain by caregivers (n=15; 25%) (Figure 4.10).

4.6 Correlation between the scores of the Barthel Index and the Caregiver Strain Index

A Spearman's correlation test was conducted, using an alpha value of 0.01, to assess whether the BI scores are correlated to the CSI scores. The results of this Spearman's correlation test are shown in Figure 4.11

Figure 4.11 Results from Spearman's correlation test on scores of the Barthel Index and Caregiver Strain Index (n=60)

Correlations

			Total CSI Score	Total BI Score /100
Spearman's rho	Total CSI Score	Correlation Coefficient	1.000	-.561**
		Sig. (2-tailed)	.	<.001
		N	60	60
	Total BI Score /100	Correlation Coefficient	-.561**	1.000
		Sig. (2-tailed)	<.001	.
		N	60	60

**. Correlation is significant at the 0.01 level (2-tailed).

A statistically significant correlation coefficient was found, ρ= -0.561 (p< 0.001) (Figure 4.11). The p-value of <0.001 is smaller than the level of significance of 0.01, therefore the correlation can be interpreted as significant. The negative nature of the Spearman's correlation coefficient (ρ= -0.561) indicates that an inverse relationship exists between the scores of the BI and CSI. Therefore, higher CS was associated with lower FI, as represented by low scores on the BI. Although interpretations of the strength of the Spearman's correlation coefficient vary in literature, a value between -0.40 and -0.70 can be considered to represent an inverse relationship of moderate strength (Alsaqr, 2021).

Chapter 5 Discussion

5.1 Introduction

This chapter serves to discuss the results of the current study, which aimed to investigate the level of CS as well as FI of PwS living in a rural setting in the Eastern Cape, South Africa and the relationship between this CS and FI. The demographic profile of the persons with stroke (PwS) and their caregivers will be discussed. The functional independence (FI) of the PwS and the caregiver strain (CS) experienced by the caregivers, will be discussed within the context of existing literature. Lastly the correlation between the scores of the Barthel Index (BI) and the Caregiver Strain Index (CSI) will be interpreted to allow conclusions to be drawn about the relationship between FI and CS. Interpreting the results of the current study in terms of existing literature will provide better insight into the findings of this study and how these findings relate to the greater field of research on stroke recovery and CS.

5.2 Demographic profile of the persons with stroke and their caregivers

5.2.1 Age and socioeconomic status

More than 80% of the caregivers and just over half of the PwS, in the current study, fell into an economically active age range (15- 65 years). Despite this, most of the caregivers were unemployed (75%) and almost all of the PwS, that were not pensioners, were unemployed, at the time of data collection (48% unemployed, 48% pensioners). These levels of unemployment are higher than the unemployment rate that was recorded for the O.R. Tambo district of 37.71% (Department of Corporate Governance and Traditional Affairs, 2020). Therefore, the unemployment levels of the study sample were higher than that recorded for the study population. These results indicate that unemployment is higher among PwS and their caregivers in the O.R. Tambo district in the Eastern Cape.

Adoption of the caregiving role was not the likely cause of unemployment for the caregivers in this study, as previously suggested by Caro, Costa and Da Cruz (2018) and Hassan, Visagie and Mji (2011). Most caregivers in this study (63%) experienced no change in their employment status after adoption of the caregiving role, with the majority of caregivers remaining unemployed both before and after becoming caregivers (47%). Of the caregivers that did experience a change (37%), most lost

their employment (28%). More than half of these caregivers that lost their employment began their caregiving role during the time of the COVID-19 pandemic (March 2020-April 2022). During this pandemic, lockdown restrictions were implemented in South Africa that lead to the closure of many businesses and loss of employment for many South Africans. Therefore, it is possible that the loss of employment by caregivers that is seen in this study, may not have resulted directly from the adoption of the caregiving role, but may have rather been a consequence of COVID-19 lock-down restrictions. It is possible that caregivers adopted the caregiving role during this time due to increased availability as a result of being unemployed. It has been estimated that, from February to April 2020, 2.2 and 2.8 million adults in South Africa lost their jobs as a result from suspension of economic activity related to lockdown restrictions (Posel, Oyenubi and Kollamparambil, 2021). Further investigation into the reason for loss of employment by caregivers would provide clarification on whether lockdown restrictions are responsible for the loss of employment of caregivers seen in the current study.

Unemployment in PwS increased after the stroke, with 30% of the PwS being unemployed before the stroke and 48% being unemployed after the stroke. It is known that stroke often leaves the individual with residual disability which limits their productive participation and return to work (Enright, 2017). Therefore, the experience of the stroke impacted the employment rate of the PwS, negatively influencing their socioeconomic status. As discussed above, loss of employment opportunities due to the COVID-19 lockdown restrictions must be considered when interpreting the increase in unemployment of PwS.

The mean age of the PwS in the current study was 56 (SD=±15.30) years. The mean time since stroke at data collection was 3.34 (SD=±2.90) years. These findings on age of PwS contradict the shift of stroke incidence to younger age groups (20-64 years) in LMICs reported by Saini, Guada and Yavagal (2021). It is known that worker migration from rural to urban areas, in search of employment, is common in South Africa (Enright, 2017). This can lead to an older population residing in the rural areas, while the younger working population reside in urban areas (Enright, 2017). This would lead to the inclusion of more individuals of an older age during data collection in a rural setting. It is possible that individuals in this study population that had experienced a stroke at younger ages, had experienced stroke of higher severity and were deceased at the time of data collection, therefore skewing the findings towards an older mean age. In

this case the results of the current study may reflect stroke survival and not incidence. The PwS in this study with higher ages may also experience other age-related impairments or difficulties associated with ageing such as osteoarthritis, age-related dementia, decreased mobility, hypertension, visual and hearing impairments. These age-related impairments would further increase the caregiving needs of these PwS and increase CS to the caregiver. Data on comorbidities, such as HIV and AIDS, hypertension and lifestyles factors, was not collected in this study. These factors are known to influence incidence of stroke (Saini, Guada and Yavagal, 2021) and may have provided better insight into the reason for the age of incidence of stroke in this study as well as whether other impairments experienced by the PwS increased their caregiving needs.

The low levels of education of the caregivers and the PwS in the current study are consistent with the overall low levels of education associated with the study setting (Statistics South Africa, 2023). These low levels of education limit the employment opportunities that this population would be qualified to pursue. Rural settings are characterised by limited employment opportunities due to lack of infrastructure and development. The lack of employment opportunities combined with the low education levels result in lower socioeconomic status of those living in this setting (Enright, 2017). Lower socioeconomic status can limit access to rehabilitative services and assistive devices post-discharge, thereby impeding recovery of FI of PwS (Alawieh, Zhao and Feng, 2018). Low socioeconomic status combined with the increased expenses associated with stroke care, including increased cost of hiring private transport, may lead to financial strain in these households (Hanass-Hancock and McKenzie, 2017). High levels of unemployment, that is common to rural settings are a contributing factor to financial strain (Yakubu and Schutte, 2018).

Similarly to other rural studies, the unemployment levels were high in the current study population. The high percentages of caregivers (47%) that remained unemployed both before and after adoption of the caregiving role, indicate that the high unemployment levels seen are not likely to have resulted directly from the adoption of the caregiving role. Low education levels and limited employment opportunities in the rural setting are more likely to be responsible for the low employment levels. While low FI of the PwS during the acute phase post-stroke is likely to have caused loss of employment, this does not explain the high unemployment levels of these individuals before the stroke

(30%). Therefore, the impact of low education levels and limited employment opportunities, in rural Eastern Cape settings, are important socioeconomic factors that can influence CS and FI of PwS through increased financial strain.

Financial strain has been associated with increased CS (Yakubu and Schutte, 2018). It has been suggested that the provision of social grants to those living in rural settings may alleviate financial strain by providing financial resources for caregiving needs, thereby decreasing CS (Tosun and Temel, 2017; Yakubu and Schutte, 2018). But the results from the current study do not agree with this statement. In the current study, 90% of the PwS were receiving a social grant (either a disability grant (DG) or an old age grant (OAG)), but 88% of the caregivers reported financial strain on the CSI.

Although social grants assist individuals financially, social grants alone are not sufficient for households of PwS to afford everyday household expenses, in addition to the expenses associated with stroke care (Hanass-Hancock and McKenzie, 2017). Limited employment opportunities in rural settings result in many households depending on income from social grants rather than income from employment (Enright, 2017; Rajan et al., 2017). The insufficiency of social grants to cover the expenses in households of PwS, in addition to the high unemployment levels seen in the current study, may explain the high level of financial strain (88%) reported by caregivers despite 90% of the PwS receiving social grants. These results indicate that the provision of social grants alone, is not sufficient to significantly decrease financial strain experienced by caregivers of low socioeconomic status, living in rural, Eastern Cape settings. Financial strain is a significant component of CS (Kumar et al., 2022).

5.2.2 Sex of caregivers and culture

The proportion of female caregivers in this study (87%) was much higher than the estimated female portion of the population in the O.R. Tambo district (53%) (Statistics South Africa, 2023). It was also higher than the proportion of female caregivers reported in the studies by Gbiri, Olawale and Isaac (2015) (48%), Kazemi et al. (2021) (70%) and Mandowara et al. (2020) (57%), as well as other African studies. Akosile et al. (2018) and Badaru et al. (2017) and reported female caregiver percentages of 67.9% and 55.6% respectively.

Cultural factors have been suggested to influence the adoption of the caregiver role between females and males (Akosile et al., 2018; Gbiri, Olawale and Isaac, 2015; Kazemi et al., 2021; Mandowara et al., 2020). It is known that in the Xhosa culture, that is dominant in the current study population, caregiving is perceived to be a natural responsibility of females (Booi, 2021). This may explain the very high proportion of female caregivers seen in this rural, Xhosa setting. In rural, South African settings, migration of males from rural to urban areas, in search of employment, results in many female-headed households in rural settings (Enright, 2017). The females of these households adopt the role of caregiver in addition to many other household roles (Enright, 2017). This may explain why female caregivers are more common in rural, South African settings (Enright, 2017).

5.2.3 Healthcare accessibility

The rugged outdoor terrain, that is common in rural settings, complicates the independent mobility of PwS (Vergunst et al., 2017). In the current study, walking was a common (43%) means of clinic access before the stroke, but after the stroke, only 12% of the PwS used walking as a means of clinic access. Only 2% of the PwS accessed the clinic through passive wheelchair use, despite 33% of the PwS having a wheelchair. None of the PwS accessed the clinic through active wheelchair use. All the wheelchairs possessed by the PwS in the current study were of the standard folding frame design and therefore not suitable for mobilising over rough outdoor terrain. These findings highlight an area of inappropriate distribution of limited healthcare resources. This is supported by findings from other South African studies in rural settings. In the study by Scheffler and Mash (2019), only 28% of the PwS mobilised independently despite 80% of the PwS having received walking aids and wheelchairs. Enright (2017) reported that the wheelchairs provided to the PwS in their study were inappropriate for the rugged rural terrain of the study setting. One would expect a decrease in clinic access post-stroke with this inappropriate provision of mobility aids and the physical barriers present in rural settings. But in the current study, none of the PwS were unable to access the community healthcare clinic post-stroke. This reflects the dedication of the PwS and their caregivers to their healthcare in the current study. Attention should be directed to the provision of mobility aids and wheelchairs to PwS that are suitable for the rough terrain in rural, South African settings.

The change of clinic access from more affordable means before stroke such as by taxi (55%) and walking (43%), to the much more costly option of hiring private transport (45%) after stroke, highlights the risk for increased financial strain on these households. This increased financial strain may affect access to rehabilitation services and support for these PwS and caregivers, thereby contributing to decreased FI and increased CS.

5.3 Functional Independence of persons with stroke

5.3.1 Total scores of Barthel Index

The FI of the PwS, as measured on the BI, was higher in the current study when compared to other South African and international studies conducted in rural settings (Han et al., 2017; Mandowara et al., 2020; Scheffler and Mash, 2019). This may be due to the increased time since stroke when the data was collected, seen in the current study. Increased time since stroke can be associated with increased physiological recovery (Ballester et al., 2019) as well as increased mortality rate of those with low BI scores, thereby only including those with higher BI scores (Mudzi, Stewart and Musenge, 2012).

In the rural Western Cape, Scheffler and Mash (2019) reported a median (IQR) BI score at baseline and three-month follow-up of 40.0 (IQR: 15.0–70.0) and 62.5 (IQR: 30.0–81.25) respectively. The median (IQR) BI score in the current study was 75 (65-85). In rural China, Han et al. (2017) reported mean (SD) BI scores at one to two days before hospital discharge, three weeks post-discharge, three months post-discharge and six months post-discharge to be 40.12 (SD= ±16.6), 45.67 (SD= ±13.8), 47.87 (SD= ±12.7) and 49.09 (SD= ±11.9) respectively. All of these mean (SD) BI values are lower than the mean (SD) BI score reported in the current study of 67.83 (SD=± 23.73). In rural India, Mandowara et al. (2020) reported mean (SD) and median (IQR) BI scores to be 61.29 (SD=± 22.44) and 65 (55, 75) respectively. These are closer to, but still lower than, the values reported in the current study. The difference between the current study and these studies is that in the current study data was collected at a longer time since stroke. This may have contributed to higher BI scores as a result of physiological recovery (Ballester et al., 2019) and/ or high mortality rates of PwS with low BI scores (Mudzi, Stewart and Musenge, 2012).

5.3.2 Time since stroke

In the current study, data was collected at a considerably longer time since stroke when compared to other studies (Han et al., 2017; Mandowara et al., 2020; Scheffler and Mash, 2019). This may explain the higher BI scores in the current study compared to other studies. The mean time since stroke in the current study was 3.34 (SD=± 2.90) years. The maximum time that had passed since stroke was three months, in the study by Scheffler and Mash (2019), and six months in the study by Han et al. (2017). In the study by Mandowara et al. (2020), less than six months had passed since the stroke in 47.15% of the cases, and in 53% of the cases more than six months had passed, with no maximum time mentioned. In none of the cases in the current study, had less than six months passed since the stroke. Increased time since stroke has been associated with improved functional recovery of PwS due to spontaneous physiological recovery (Gbiri, Olawale and Isaac, 2015; Mandowara et al., 2020). Increased time since stroke may result in higher BI scores of PwS through spontaneous physiological recovery (Ballester et al., 2019). Higher BI scores seen with increased time since stroke may also result from higher rates of mortality of PwS at increased time since stroke, specifically in those PwS with lower initial BI scores (Mudzi, Stewart and Musenge, 2012).

5.3.2.1 Spontaneous physiological recovery

Findings from Ballester et al. (2019) suggest that improvement in body function and structure is possible beyond twelve months post-stroke. Despite these findings, the common trend in literature indicates that the most significant motor recovery post-stroke occurs within the first six months after stroke onset, after which spontaneous motor recovery plateaus (Dromerick et al., 2021; Grefkes et al., 2020; Lang et al., 2021). Considering the mean time since stroke in the current study of 3.34 (SD=± 2.90) years, it is not likely that greater spontaneous motor recovery, with more time since stroke, is responsible for the higher BI scores seen in the current study.

5.3.2.2 Mortality of persons with stroke with lower Barthel Index scores

A study conducted at Chris Hani Baragwanath Academic Hospital in Gauteng, South Africa found that mortality post-stroke was highest at three months post-discharge (25.5%) and that the cumulative mortality rate at 12 months post-stroke was 38% (Mudzi, Stewart and Musenge, 2012). Mortality rate was considerably higher in PwS with lower BI scores. Considering this increased mortality rate with increased time

since stroke, and the higher mortality rate in PwS with lower BI scores, found in the study by Mudzi, Stewart and Musenge (2012), it is viable that those PwS with low BI scores in the current study population were deceased at the time of data collection. Therefore, the longer time since stroke recorded in the current study may have led to the inclusion of more PwS with higher BI scores. This may explain the higher BI scores seen in the current study.

5.3.3 Barthel Index item with the most reported independence

Grooming was the BI item with the most reported FI (83%) in the current study. These findings are not in agreement with other studies investigating the FI of PwS in rural settings.

Bowel control and bladder control are the BI items that have been commonly reported to have the most FI in other rural studies. In the rural, Western Cape, Scheffler and Mash (2019) reported the top two independent BI items, at baseline, to be bowel control (59.1%) and bladder control (47.8%). Grooming was the third most independent BI item (Scheffler and Mash, 2019). Three months later, bowel control was the item with the most reported independence (64.9%), followed by grooming (48.0%) and then bladder control (47.4%) (Scheffler and Mash, 2019). In a rural setting in India, bowel control (65%), followed by bladder control (45%) were the BI items with the most reported independence, on the Modified Barthel Index (Chandran et al., 2017). Grooming was the third most independent item, equal to bathing, toilet-use and mobility. In the current study, bowel control was the fifth, and bladder control was the sixth, most independent BI items. The difference in independence in bowel control and bladder control between the current study and other studies may be due to physical factors influencing access to toilets.

In the rural, Eastern Cape setting of the current study, it is known that toilets are located outside of houses, usually across rugged terrain (Enright, 2017). Enright (2017) reported that at 72.6% of households, in this rural, Eastern Cape setting, the toilet was located more than ten meters from the house and at only 27.3% of households were toilets located within 10 meters from the house (Enright, 2017). Despite the possible distance of toilets from the house in the current study, the most common method of toileting, for the PwS, was the use of a toilet (70%). Considering that only 62% of the PwS were able to mobilise independently across flat even surfaces and only 28% were

able to navigate stairs independently, one can infer that the level of independence of the PwS, in mobilising over uneven surfaces, was low in the current study. Therefore, the higher dependence in bowel and bladder control seen in the current study may have resulted from mobility limitations in accessing outdoor toilets rather than continence difficulties. This is especially relevant when comparing the findings of the current study to those of Scheffler and Mash (2019), where 68.1% of the toilets were located inside of the house, thereby requiring less mobility over uneven outdoor terrain for toilet access, than in the current study. Further data on whether dependence in bowel and bladder control was related to mobilising to the toilet or to continence difficulties would provide more insight into these differences between studies.

5.3.4 Barthel Index item with the least reported independence

Eating was the BI item, in the current study, with the least reported FI (13%), preceded by dressing and undressing (25%). In rural India, Chandran et al. (2017) found transfers to be the activity with the least reported FI, preceded by eating. Eating was the item with the third least reported FI at baseline and fourth lowest at three-month follow up in the study by Scheffler and Mash (2019). Despite these mixed results, it is evident that dependence in eating is common among PwS in rural settings. Eating is an activity of daily living (ADL) that is vital for good nutrition and overall health of PwS (Lieber et al., 2018). Dependence in eating, without sufficient caregiver support, can lead to malnutrition of the PwS and jeopardise the overall well-being and recovery of PwS (Sabbouh & Torbey, 2018). Eating is an activity that occurs frequently during the day. Dependence of PwS on caregivers to assist repetitively in this activity throughout the day may increase the workload for the caregiver. This increased workload may contribute to increased CS (Zhu & Jiang, 2018).

5.4 Caregiver strain

Caregiver strain was higher, and experienced by a greater percentage of caregivers, in the current study, when compared to other South African studies, from both rural and urban settings, as well as international, rural studies (Han et al., 2017; Kusambiza-Kiingi, Maleka and Ntsiea, 2017; Mandowara et al., 2020; Scheffler and Mash, 2019). This higher CS existed despite the higher BI scores seen in the current study. Notable differences between the current study and other comparable literature were the longer

duration of caregiving and the cultural expectations of Xhosa females to adopt multiple household roles in addition to the caregiving role.

5.4.1 Caregiver Strain Index scores

In the current study, 68% of the caregivers reported CS (CSI score ≥7). This is more than the 55% of caregivers in an urban setting in Johannesburg, Gauteng (Kusambiza-Kiingi, Maleka and Ntsiea, 2017), and the 58.9% of caregivers in a rural setting in India (Mandowara et al. 2020) reporting strain, when caring for PwS. In a rural, Western Cape setting, 33% of the included caregivers reported strain at initial assessment (measured at a median of 65 days (IQR: 42-94) after stroke) and 25.8% of the caregivers reported strain three months later (Scheffler and Mash, 2019).

Not only did more caregivers experience strain in the current study, but the degree of strain experienced was also higher. The mean CSI score in the current study was 8.17 (SD=±3.26) while the mean CSI score reported by Mandowara et al. (2020) was 6.93 (SD=±2.94). A longitudinal study conducted in rural China reported mean CSI scores, at all four time points, that were lower than that reported in the current study: 7.35 (SD=±2.9) (one or two days before discharge of the PwS from the hospital), 6.97 (SD=±3.1) (three weeks later), 6.70 (SD=±3.1) (three months later) and 6.34 (SD=±3.4) (six months later) (Han et al., 2017). In rural Western Cape, South Africa, Scheffler and Mash (2019) reported a median CSI score of 3.0 (IQR: 0.0-7.0) that remained unchanged at both baseline and three-month follow-up, while the median (IQR) CSI score reported in the current study was 9 (5.75-11.0). The high CS reported in the current study highlights the persisting needs of caregivers in rural Eastern Cape settings. Increased efforts to reduce CS are required in these settings.

5.4.2 Duration of caregiving

Caregiver strain has been reported to increase with increased duration of caregiving (Yakubu and Schutte, 2018), specifically of five years or longer (Tosun and Temel, 2017). In the current study the mean duration of caregiving was 2.99 (SD=± 2.61) years. Only 17% of the caregivers had been providing care for more than five years. In terms of the findings of Tosun and Temel (2017), one would expect these ten caregivers to report the highest CS, but only half of these caregivers reported CSI scores ≥ 7. Therefore, the findings from the current study are not in agreement with the findings of Tosun and Temel (2017).

Tosun and Temel (2017) reported that the increase in CS, that caregivers experience after five years of caregiving, is due to fatigue of the caregiver role and the development of health complications secondary to caregiving duties. It is possible that the caregivers in the current study began to experience caregiver role fatigue and secondary health complications earlier than five years of caregiving, due to the additional physical requirements that are needed to perform basic care tasks, associated with living in rural settings. This is supported by the findings of Scheffler and Mash (2019) who reported that caregivers living in informal housing in rural settings experienced doubled CS due to environmental factors characteristic of rural settings. Typical homes in rural Eastern Cape settings lack amenities such as electric cooking appliances and running water (Enright, 2017). Therefore, additional physical tasks are required to perform daily household activities, such as walking far distances to water sources to collect water and accessing fuel for cooking. These additional physical activities, that are required to fulfil household and caregiving duties, may increase the strain experienced by caregivers in rural settings (Enright, 2017). This may have resulted in the caregivers in the current study to develop CS at a rate faster than the five years suggested by Tosun and Temel (2017).

The duration of caregiving seen in the current study, with a mean of 2.99 (SD=±2.61) years, was considerably longer than that seen in other rural studies (Han et al., 2017; Mandowara et al., 2020; Scheffler and Mash, 2019). In the study by Scheffler and Mash (2019), baseline data was collected at a median of 65 days post-stroke and the final assessment was conducted at three months post-stroke. The maximum duration of caregiving for the caregivers in the study would have been approximately five months. In rural India, for 47% of the PwS, less than six months had passed since stroke onset and for 53% of the PwS more than six months had passed, but no end time frame was mentioned (Mandowara et al., 2020). In the study by Han et al. (2017), the last time point of data collection was six months after discharge from stroke admission. Therefore, the longest possible duration of caregiving would not have been six months. Due to the longer duration of caregiving seen in the current study, the strain experienced by caregivers, from additional physical tasks associated with living in rural settings, would have been experienced for a longer duration than in other studies. This may have resulted in the higher CS seen in the current study (Yakubu and Schutte, 2018). Tosun and Temel (2017) suggest that increased CS seen with increased

duration of caregiving, highlights insufficient caregiver training and support as well as inadequate sharing of caregiving responsibilities. As discussed earlier, it is common for females in Xhosa culture, living in rural settings, to experience role overload from adopting the role of caregiver, in addition to many other household roles (Enright, 2017; Mandowara et al., 2020). This may lead to inadequate sharing of responsibilities increased CS (Mandowara et al., 2020). The high CS and long duration of caregiving in this study support the findings that CS increases with increased duration of caregiving (Tosun and Temel, 2017; Yakubu and Schutte, 2018). The high percentage (87%) of female caregivers and the caregiver expectations in the Xhosa culture may have resulted in inadequate sharing of the caregiver responsibilities, leading to increased CS. This is in agreement with Tosun and Temel (2017) that insufficient sharing of caregiver responsibilities over an increased duration of caregiving increases CS.

5.4.3 Role expectations for female Xhosa caregivers

As already discussed, female, Xhosa caregivers, living in rural settings adopt multiple roles within the household in addition to the caregiving role, due female-headed households that result from male labour migration (Enright, 2017) and cultural caregiving expectations of females (Booi, 2021). The majority of the caregivers in the current study were female (87%). The adoption of multiple household responsibilities in addition to the caregiver role may have resulted in these female caregivers in the current study to experience the caregiver role fatigue, suggested by Tosun and Temel (2017), at an accelerated rate of less than five years. This increase in CS strain due to female caregivers adopting multiple household roles in addition to the caregiving role was seen in a rural setting in India in the study by Mandowara et al. (2020).

5.4.4 Low education of caregivers

The low education level of the caregivers in the current study may have contributed to the high CS seen. Mandowara et al. (2020) and Akosile et al. (2018) both found significant relationships between decreased CS and higher education levels of caregivers. Higher education levels provide caregivers with better abilities to understand information provided about stroke and the process of recovery and treatment (Mandowara et al. 2020). Higher education levels also equip caregivers with better skills to develop coping strategies and stress management techniques (Akosile et al., 2018). This contributes to reducing the experience of CS (Akosile et al., 2018;

Mandowara et al. 2020). It is possible that in the current study, education and training that was provided to caregivers was not well-received or maintained due to low education levels of the caregivers. Therefore, the education levels of caregivers should be considered when planning caregiver training. The content and delivery of caregiver training and support interventions should be suitable for the educational level of the caregivers (Zhu and Jiang, 2018).

5.4.5 Financial strain

Financial strain is a large component of the high CS seen in the current study. Item 12: Caregiving is a financial strain, was the second most positively answered (88%) item on the CSI, in the current study. Longitudinal studies have shown financial strain, experienced by caregivers of PwS, to increase over time (Kumar et al., 2022; Scheffler and Mash, 2019). Kumar et al., (2022) reported financial strain to be the sixth most positively answered item on the CSI at 30 days after stroke. Six months later, financial strain was the most reported item on the CSI (Kumar et al., 2022). Scheffler and Mash (2019) found that financial strain increased from being the fifth leading item reported on the CSI, at baseline measurement, to being the third leading item three months later. This trend of increasing financial strain over time could suggest that the high report of financial strain in the current study may be associated with the longer time since stroke (mean of 3.34 (SD=±2.90) years) or longer duration of caregiving (mean of 2.99 (SD=±2.61) years) seen in this study.

In an urban, Johannesburg setting, Kusambiza-Kiingi, Maleka and Ntsiea (2017) reported financial strain to be the third least reported item on the CSI. Similarly to the current study, the data was collected at an extended time since stroke, of 26 months (Kusambiza-Kiingi, Maleka and Ntsiea, 2017). Comparing these findings to the current study may suggest that, in South Africa, caregivers in rural settings experience greater financial strain than those in urban settings. This is contradicted by the findings of Enright (2017), where female caregivers in urban settings experienced higher financial strain than those in rural settings. This was due to additional expenses associated with urban living such as electricity expenses (Enright, 2017). Further investigation into the expenses of caregivers in the current study setting would provide better insight into the differences in financial strain, experienced by caregivers in urban and rural settings.

As discussed earlier, the provision of social grants to caregivers and PwS living in rural settings are not sufficient in alleviating financial strain. Financial support methods other

than the existing social grant system should be emphasised. Mandowara et al. (2020) suggested the involvement of Non-Governmental Organisations to aid in the alleviation of financial burden of PwS and their caregivers in rural, low-income settings.

5.5 Correlation between Barthel Index and Caregiver Strain Index Scores

The significant inverse relationship found in this study, between the scores of the BI and CSI, support existing literature that decreased FI of PwS is associated with increased CS of informal caregivers (Boonsin, Deenan and Wacharasin, 2021, Ngoc and Hsu, 2021; Oliva-Moreno et al. 2018; Scheffler and Mash, 2019; Zhu and Jiang, 2018). An inverse relationship of moderate strength, between BI scores and CSI scores, was determined in the current study, which aligns with inverse relationships of moderate strength determined in the studies by Boonsin, Deenan and Wacharasin (2021), Ngoc and Hsu (2021) and Zhu and Jiang (2018).

Despite the significant inverse relationship between the scores of the BI and CSI, that was determined in the current study, the CS in the current study was higher than in other rural studies, while the BI scores were also higher in the current study, than those in other rural studies. This reinforces the idea that, in addition to the FI of PwS, other factors significantly contribute to the CS experienced by caregivers. This is supported by the findings of Boonsin, Deenan and Wacharasin (2021), Mandowara et al. (2020), Ngoc and Hsu (2021) and Zhu and Jiang (2018).

Both Mandowara et al. (2020) and Zhu and Jiang (2018) found that caregiver anxiety and caregiver depression had a stronger direct influence on CS than the FI of PwS. Ngoc and Hsu (2021) found that caregiver anxiety and depression symptoms had mediatory effects on the influence of FI on CS.

While FI was the strongest direct influencer of CS in the study by Boonsin, Deenan and Wacharasin (2021), duration of caregiving, caregiving hours and caregiver self-efficacy also found to have direct effects on CS. Boonsin, Deenan and Wacharasin (2021) found that caregiving hours also indirectly impact CS through interaction with FI of PwS. Longer caregiving hours significantly increasing CS has been reported in multiple studies (Boonsin, Deenan and Wacharasin, 2021; Mandowara et al., 2020; Ngoc and Hsu, 2021, Oliva-Moreno et al., 2018). While the relationship between caregiving hours and CS was found to be weak in the study by Ngoc and Hsu (2021),

Mandowara et al., (2020) found the strength of relationship between caregiving hours and CS to be equal to that between functional disability and CS (both were moderate; r=0.51).

Zhu and Jiang (2018) found that as time since stroke increased, and the PwS entered the chronic phase post-stroke, lower FI had a greater influence on CS than in the acute phase post-stroke. The time since stroke in the current study was considerably longer than in other studies. Therefore, this longer time since stroke influenced the relationship between FI and CS, in the current study, resulting in the FI of more dependent PwS to have a greater influence on CS, than PwS with higher FI (Zhu and Jiang, 2018).

Comparison of the relationship between FI and CS that was determined in the current study to existing literature indicates that, although FI does significantly influence CS, it may not be the strongest influencer, as previously found by Boonsin, Deenan and Wacharasin, 2021 and Ngoc and Hsu, 2021. Attention should be directed to other factors that have been found to have strong significant influence on CS, such as caregiver anxiety and caregiver depression (Mandowara et al., 2020; Zhu and Jiang, 2018), caregiving hours, duration of caregiving (Boonsin, Deenan and Wacharasin, 2021; Mandowara et al., 2020) caregiver self-efficacy (Boonsin, Deenan and Wacharasin, 2021) and time since stroke (Zhu and Jiang, 2018). Further investigation into these other factors may provide insight into the higher CS, experienced by caregivers, despite the higher FI of PwS, reported in the current study when compared to other rural studies.

Chapter 6 Conclusion and Recommendations

This study provides insight into the functional independence (FI) of persons with stroke (PwS), and the caregiver strain (CS) experienced by their caregivers in a rural, Eastern Cape setting. The low socioeconomic status and physical environmental barriers experienced by the study population were typical of rural, South African settings. The FI of the PwS in the current study was higher than in other comparable studies. Similarly to other studies, a significant, inverse relationship was found between FI and CS. In contrast to these other studies, the CS in the current study was higher and experienced by more caregivers, despite the higher FI compared to other studies. Factors unique to this study that may have contributed to this higher CS, despite the higher FI recorded, include cultural expectations for females in Xhosa culture to adopt the caregiver role, in addition to other household roles, and the longer time since stroke and duration of caregiving seen in the current study. This study has demonstrated that factors other than FI of PwS have a stronger influence on the CS, experienced by the caregivers of PwS, in the chronic phase post-stroke. This study provided new information that is specific to a rural, Eastern Cape setting. Although increased FI of the PwS decreases CS, stroke rehabilitation interventions should not only be patient focused. Resources should be directed toward addressing the emotional and financial aspects of CS.

6.1 Clinical/Practical Recommendations

- Stroke rehabilitation interventions need to take a combined approach toward both the PwS and the caregiver.
- Current social grant systems are insufficient to alleviate financial strain. Focus at a governmental level should be directed toward improving education and infrastructure to promote employment opportunities and employability for individuals living in rural settings. Re-structuring social grant systems at a governmental level may allow for better distribution of funds for social grants.
- Provision of wheelchairs and mobility aids to PwS in rural settings needs to be appropriate for the terrain relevant to the setting, to avoid waste of limited healthcare resources.

6.2 Recommendation for Future Research

- Noting the high emotional strain of caregivers in the current study and the strong influence of caregiver anxiety and caregiver depression on CS, reported by other studies (Mandowara et al., 2020; Zhu and Jiang, 2018), future research can investigate the level of burnout and its relationship to CS and the FI of PwS.
- Further research can be conducted to investigate the number of hours spent caregiving by caregivers in this rural EC setting. The direct effect these caregiving hours have on CS can be determined in addition to the mediating effects these caregiving hours have on the influence of FI on CS.
- Future research into the influence that Xhosa culture has on the caregiving role and the experience of CS can be conducted. Investigation into whether Xhosa cultural factors affect the division of caregiving roles, specifically by spousal caregivers, can be conducted.
- Future research can be conducted to determine the influence that the prolonged duration of caregiving, seen in this rural EC setting, has on CS. Research into whether increased workload associated with performing daily tasks in rural settings compounds the influence of duration of caregiving on CS.
- Future studies investigating the CS and FI of PwS in rural EC settings using a longitudinal design can be conducted. This would provide more insight into the change in CS over time as well as control for individual factors of caregivers.
- Research into the financial structuring of social grants in rural EC settings can be performed. It can be determined whether other options of financial systems or support are viable in this setting to alleviate the high financial strain experienced by caregivers of PwS.

6.3 Strengths and Limitations

6.3.1 Strengths

- Telephonic interviews allowed for the inclusion of participants from varied geographic regions. This overcame the limitation of bias based on access or geographic distribution.
- The study sample size of 60 participants that was achieve provided for a representative sample where the results could be generalised to the study population.

- Only one research assistant assisted in data collection. This allowed for consistency in data collection.

6.3.2 Limitations

- Poor cell phone reception introduced unintentional selection bias favouring potential participants who lived in areas with sufficient cell phone signal.
- Only the caregivers of PwS that had received treatment from Zithulele Hospital for stroke were included in this study. Any PwS that had received treatment elsewhere and had not been referred to Zithulele Hospital would not have been included.
- It is possible that selection bias was unintentionally present due to potential mortality of PwS with lower Barthel Index (BI) scores at the time of data collection.

6.4 Conclusion

A significant inverse relationship exists between CS and FI of PwS in this rural, Eastern Cape setting. Despite the FI of PwS in the current study being higher than in other comparable studies, the CS in the current study was high. The cultural role expectations of female Xhosa caregivers, in addition to the longer time since stroke and longer duration of caregiving, noted in this study, present future research points in order to better understand the high CS despite the higher FI levels and presence of an inverse correlation between CS and FI. Caregiver emotional factors and financial strain are important aspects of the CS experienced in rural, Eastern Cape settings.

Informal caregivers are highly depended upon and form a safety net for stroke care in rural settings, where healthcare resources and infrastructure are low. High CS can jeopardise the sustainability of this vital service provided by informal caregivers. Therefore, the high CS reported by the caregivers in this rural Eastern Cape setting needs to be noted. Interventions to address the CS need to be formulated to ensure sustainable stroke care and improved quality of life of both PwS and their caregivers in rural, Eastern Cape settings.

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STUDY INFORMATION DOCUMENT

Study title: Caregiver strain and functional independence of people with stroke living in a rural setting in the Eastern Cape, South Africa

Good day thank you for taking the time to hear about this research study.

Introduction:
We, Jessica Jardine (physiotherapist), Nicolette Comley-White (supervisor) and the research assistant, are doing research on people with stroke (PwS) and the people that care for them in the Eastern Cape, South Africa. Research is a process used to learn more about a topic. In this study we want to learn about how well PwS are able to do their daily activities at home and how the caregivers are coping in caring for the PwS. Finding out this information will help us understand better what services are needed by PwS and their caregivers who are living in a rural area in the Eastern Cape.

Invitation to Participate: We are asking you if you would like to take part in this research study

What is involved in the study. This could include but would not necessarily be limited to such features as:

1. You will be asked to take part in an interview, where you will be asked questions.
2. You will be asked questions about the person with stroke's ability to eat, wash, groom, get dressed, go to the toilet (defecate), have a wee (urinate), use a toilet/bucket, get out of bed onto a chair, walk, go up stairs.
3. You will also be asked questions about the changes that have happened in your life since you started caring for the person with stroke and will require you to say either "yes" or "no" in response to the question.
4. You will also be asked to provide information about age, education, date of stroke and other demographic information.
5. If you are able to get to the clinic the interview will take place in a private consultation room at the clinic (face-to-face). If you are not able to get to a clinic we can do the interview over the phone. You may feel that you would like to be in a private area before answering the questions.
6. The interview will last roughly 15-20 min.
7. This study will be running from October 2021 to June 2022

Risks of being involved in the study: During the interview you will be asked questions about how you feel about caring for the PwS. You may feel some discomfort when answering some of the questions. For face-to-face interviews all COVID-19 regulations will be followed of keeping a social distance of 1.5m, all parties will wear masks and hand hygiene will be ensured. If answering any of the questions makes you feel upset we can arrange for you to see a councilor to help you work through your feelings.

Benefits of being in the study: There will be no immediate benefit to you for your participation in the study. The results in the long term may help provide motivation for increased support for caregivers and PwS at clinics and in communities. By participating in this study you may help contribute to improving community-based services in the long term.

The Participant will be given pertinent information on the study while involved in the project and after the results are available.

Participation is voluntary. Your choice to participate is voluntary and you can decide not to participate. If you do not participate, it will not affect you negatively. If you decide to participate you can stop and leave the study at any time during the interview without having to provide a reason as to why. Any decision to stop and leave will not affect you negatively in any way and any information that you have provided to us will be destroyed.

Reimbursements for "out of pocket" expenses: If you are able to come to the clinic for the interview you will be paid back the money for transport that you paid to travel to and from the clinic. But other than travel costs you will receive no payment to participate in the study.

Confidentiality: All the personal information will be collected during this study will be confidential. The only people who will have access to this information will be the Principal Investigator (PI) (Jessica Jardine), the research assistant and the research supervisor (Nicolette Comley-White). The only exceptions - and all of them are rare - would normally be:

1. personal information may be disclosed if required by law
2. the Human Research Ethics Committees of the University may exceptionally require personal data to respond to a formal complaint, or for a compliance audit

If results are published, this may, exceptionally, lead to cohort, or more rarely, individual identification. All data collected in the course of the study will be securely retained for two (2) years, if a scientific publication arises from the study and five (5) years, if there is no publication. Thereafter it will be destroyed accordingly.

Anonymity will be ensured by using participant numbers rather than names on all data collected during interviews.

Contact details of researcher/s: If you would like more information about the study you or if you would like to report any concerns or discomfort you may contact:
The principle researcher: Jessica Jardine on 0729339175
Or the study supervisor: Mrs Nicolette Compley-White at niolette.comley-white@wits.ac.za

Outputs
The study aims to determine the level of caregiver strain and functional independence of people with stroke living in a rural setting in the Eastern Cape, South Africa. If you would like to be informed about the final results of this study please indicate this to the principle researcher and the results will be communicated to you upon completion of the study.

Contact details of HREC administrator and chair – for reporting of complaints / problems.

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.
If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

IINKCUKACHA ZOKUFUNDA

Isihloko sokufunda: Unonophelo lomkhathaleli kunye nokuzimela okusebenzayo kwabantu abane-stroke abahlala kwindawo yasemaphandleni eMpuma Koloni, eMzantsi Afrika
Usuku olungileyo enkosi ngokuthatha ixesha lakho ukuva ngolu phando.

Intshayelelo:

Thina, Jessica Jardine (physiotherapist), Nicolette Comley-White (isuphavayiza) kunye nomncedisi wophando, senza uphando ngabantu abane stroke (PwS) kunye nabantu ababakhathaleleyo eMpuma Koloni, Mzantsi Afrika. Uphando yinkqubo esetyenziselwa ukufunda ngakumbi ngesihloko. Kolu phando sifuna ukufunda malunga nokuba i-PwS ikwazi njani ukwenza imisebenzi yabo yemihla ngemihla ekhaya kunye nendlela abanonopheli abahlangabezana ngayo nokunyamekela i-PwS. Ukufumana olu lwazi kuya kusinceda siqonde ngcono ukuba zeziphi iinkonzo ezifunekayo yi-PwS kunye nabo babakhathaleleyo abahlala emaphandleni eMpuma Koloni.
Isimemo sokuthatha inxaxheba: Siyakucela ukuba ungathanda ukuthatha inxaxheba kolu phando

Yintoni ebandakanyekayo kufundo. Oku kunokubandakanya kodwa bekunganyanzelekanga ukuba kuthintelwe kumanqaku anje ngala:

1. Uya kucelwa ukuba uthathe inxaxheba kudliwanondlebe, apho uya kubuzwa khona imibuzo.
2. Uya kubuzwa imibuzo malunga nomntu onesifo sohlangothi sokutya, ukuhlamba, ukuzilungisa, ukunxiba, ukuya kwindlu yangasese (ukuzikhulula), ukuzala (ukuchama), ukusebenzisa indlu yangasese / ibhakethi, phuma ebhedini ungene sihlalo, hamba, nyuka ngezinyuko.
3. Uya kubuzwa nemibuzo malunga notshintsho olwenzekileyo ebomini bakho ukusukela oko wawuqala ukukhathalela umntu onestroke kwaye uyakufuna ukuba uthi "ewe" okanye "hayi" ekuphenduleni umbuzo.
4. Uya kucelwa kwakhona ukuba unikezele ngolwazi malunga nobudala, imfundo, umhla wokubetha kunye nolunye ulwazi lwabantu.
5. Ukuba uyakwazi ukuya eklinikhi udliwanondlebe luya kubanjelwa kwigumbi labucala lokubonisana ekliniki (ubuso ngobuso). Ukuba awukwazi ukuya eklinikhi sinokwenza udliwanondlebe ngomnxeba. Usenokuvakalelwa kukuba ungathanda ukuba kwindawo eyimfihlo ngaphambi kokuba uphendule imibuzo.
6. Udliwanondlebe luya kuhlala malunga nemizuzu eli-15 ukuya kwengama-20.
7. Olu phononongo luza kuqala ngo-Okthobha ka-2021 ukuya kuJuni wama-2022

Umngcipheko wokubandakanyeka kuphononongo: Ngexesha lodliwanondlebe uya kubuzwa imibuzo malunga nendlela oziva ngayo malunga nokukhathalela i-PwS. Unokuziva ungonwabanga xa uphendula eminye yemibuzo. Kudliwanondlebe lobuso ngobuso yonke imigaqo ye-COVID-19 iya kulandelwa yokugcina umgama ekuhlaleni we-1.5m, onke amaqela aya kunxiba iimaski kwaye kucoceke ngezandla. Ukuba uphendula nayiphi na imibuzo kukwenza uzive ukhathazekile singakulungiselela ukuba ubone uceba oza kukunceda usebenze ngeemvakalelo zakho.
Izibonelelo zokuba kolu phononongo: Akusayi kubakho zibonelelo zangoku kuwe ngokuthatha kwakho inxaxheba kolu phando. Iziphumo zexesha elide zinokunceda ukubonelela ngenkuthazo yenkxaso eyandisiweyo yabanonopheli kunye ne-PwS eziklinikhi nasekuhlaleni. Ngokuthatha inxaxheba kolu phando unokunceda ekwenzeni igalelo ekuphuculeni iinkonzo ezisekwe eluntwini kwixesha elide.
Umthathi-nxaxheba uya kunikwa ulwazi olufanelekileyo kwisifundo ngelixa ebandakanyeka kwiprojekthi nasemva kokuba iziphumo zifumanekile.

Ukuthatha inxaxheba kungokuzithandela. Ukhetho lwakho lokuthatha inxaxheba ngokuzithandela kwaye unokuthatha isigqibo sokungathathi nxaxheba. Ukuba awuthathi nxaxheba, ayizukuchaphazela kakubi. Ukuba uthatha isigqibo sokuthatha inxaxheba ungayeka kwaye ushiye isifundo ngalo naliphi na ixesha ngexesha lodliwanondlebe ngaphandle kokunikezela ngesizathu sokuba kutheni. Nasiphi na isigqibo sokuma nokushiya asizukuchaphazela kakubi nangayiphi na indlela kwaye naluphi na ulwazi osinike lona luya kutshabalaliswa.
Ukubuyiselwa kweendleko "ezipokothwayo" Kodwa ngaphandle kweendleko zokuhamba awuyi kufumana ntlawulo ngokuthatha inxaxheba kolu phando.
Imfihlo: Yonke ingcaciso yobuqu iya kuqokelelwa ngexesha lolu phononongo iya kuba yimfihlo. Abantu kuphela abaya kuba nakho ukufikelela kolu lwazi iya kuba nguMphandi oyiNtloko (PI) (uJessica Jardine), umncedisi wophando kunye nomphathi wophando (uNicolette Comley-White). Ukwahluka kuphela-kwaye zonke zinqabile- zihlala zi:

1. Iinkcukacha zobuqu zingachazwa ukuba umthetho ufuna njalo
2. IiKomiti zeeNqobo eziseSikweni zoPhando lwaBantu zeDyunivesithi zinokufuna ngokukodwa idatha yobuqu ukuba iphendule kwisikhalazo esisesikweni, okanye kuphicotho zincwadi zokuthotyelwa.

Ukuba iziphumo zipapashiwe, oku kunokuba, ngokukodwa, kukhokelele kwiqela, okanye kunqabile, kuchongwe umntu. Yonke idatha eqokelelweyo kwikhosi yokufunda iya kugcinwa ngokukhuselekileyo iminyaka emibini (2), ukuba upapasho lwenzululwazi luvela kufundo kunye neminyaka emihlanu (5), ukuba akukho lushicilelo. Emva koko iya kutshatyalaliswa ngokufanelekileyo.
Ukungaziwa kuya kuqinisekiswa ngokusebenzisa amanani abathathi-nxaxheba kunamagama kuyo yonke idatha eqokelelweyo ngexesha lodliwanondlebe.
Linkcukacha zoqhakamshelwano zomphandi: Ukuba ungathanda ukufumana ulwazi oluthe kratya malunga nesifundo okanye ukuba ufuna ukunika ingxelo ngayo nayiphi na inkxalabo okanye ukungonwabi unganxibelelana:
Umphengululi ongumgaqo: Jessica Jardine ku 0729339175

Okanye umphathi wesifundo: UNksk Nicolette Compley-White apha niolette.comley-white@wits.ac.za

Iziphumo

Olu phononongo lujolise ekumiseleni inqanaba lokunyameka kwabanonopheli kunye nokuzimela okusebenzayo kwabantu abane-stroke abahlala kwindawo yasemaphandleni eMpuma Koloni, eMzantsi Afrika. Ukuba ungathanda ukwaziswa malunga neziphumo zokugqibela zolu phononongo nceda uchaze oku kumgaqo-nkqubo wophando kwaye iziphumo ziya kwaziswa kuwe ukugqitywa kophononongo.
Iinkcukacha zonxibelelwano zomlawuli we-HREC nosihlalo-wokuxela izikhalazo / iingxaki. Olu phononongo luvunyiwe yiKomiti yeeNqobo eziseSikweni yoPhando lwaBantu (ezoNyango) zeDyunivesithi yaseWitwatersrand, eRhawutini ("iKomiti"). Umsebenzi ophambili wale Komiti kukukhusela amalungelo nesidima sabo bonke abantu abavumayo ukuthatha inxaxheba kwiprojekthi yophando kunye nokuthembeka kophando.
Ukuba unenkxalabo malunga nendlela oluqhutywa ngayo uphando, nceda unxibelelane noSihlalo wale Komiti onguNjingalwazi Clement Penny, ongaqhakamshelwa kule nombolo 011 717 2301, okanye nge-imeyile kuClement.Penny@wits. ac.za. Iinombolo zomnxeba zoonobhala beKomiti yile 011 717 2700/1234 kwaye iidilesi ze-imeyile nguZanele.Ndlovu@wits.ac.za noRhulani.Mukansi@wits.ac.za

Enkosi ngokufunda eli phepha lolwazi.



6.4.1.1.1 PARTICIPANT CONSENT SHEET

Caregiver strain and functional independence of people with stroke living in a rural setting in the Eastern Cape, South Africa.

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached to this form;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts.

Contact details:

Jessica Jardine, Principal Investigator, telephone no. 072 933 9175, or by e-mail at jessjardine.3@gmail.com

Nicolette Comley-White, Supervisor, on telephone no. 082 393 0834, or by e-mail at nicolette.comley-white@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____



6.4.1.1.2 IPHEPHA LOKUVUMELANA NOKUTHATHA INXAXHEBA

Ukunyameka kwabanonopheli kunye nokuzimela okusebenzayo kwabantu abane-stroke abahlala kwiindawo ezisemaphandleni eMpuma Koloni, eMzantsi Afrika.

1. Ndinikwe uLuhlu lwaBathathi-nxaxheba oluchaza uhlobo kunye neenkqubo ezichaphazelekayo kolu phando, eziqhotyoshelwe kule fomu;
2. Ndinikwe ixesha lokuba ndiyifunde, okanye ndiyifundelwe, ngolwimi endiliqonda kakuhle;
3. Ndanikwa ixesha lokuba ndibuze nayiphi na imibuzo endiyifunayo ndaza ndafumana naziphi na iimpendulo endizinikiweyo ukuba zinengqiqo kwaye ziyanelisa;
4. Ndiyakholelwa ukuba ndiyasiqonda ncam ukuba kutheni olu phononongo lusenziwa nokuba ziziphi iziphumo ekujongwe ukuba zibe zezi;
5. Ndiyaqonda ukuba akusayi kubakho sibonelelo sam ngokukhawuleza, ukuba ndiyavuma ukuthatha inxaxheba, kwaye andizukufumana ntlawulo; ngokuchaseneyo, ukuthatha inxaxheba akuyi kundibizela nto ngaphandle kwexesha lam;
6. Ndiyayiqonda into yokuba, nokuba ndiyavuma ekuqaleni ukuba ndithathe inxaxheba kolu phando, ndingarhoxa nangaliphi na ixesha kwaye kungafuneki ndinike naziphi na izizathu; ukuba oko kwenzekile, nayiphi na idatha eqokelelwe ngam ngeenjongo zesifundo iyakutshatyalaliswa kwangoko, ngaphandle kokuba ndinike imvume yokuba igcinwe
7. Ndinikwe uluhlu lweenkcukacha zonxibelelwano, ezidweliswe apha ngezantsi. Ukuba ndifuna ulwazi oluthe kratya okanye ndixhalabile nangayiphi na into yolu phando ndikhululekile ukuba ndingathetha nalo naluphi na unxibelelwano.

Iinkcukacha zoqhakamshelo:

UJessica Jardine, uMphandi oyiNtloko, inombolo yomnxeba. 072 933 9175, okanye nge-imeyile ku jessjardine.3@gmail.com
UNicolette Comley-White, Umphathi nge-imeyile ku- nicolette.comley-white@wits.ac.za

UNjingalwazi CB Penny, uSihlalo weKomiti yeeNqobo eziseSikweni yoPhando lwaBantu (ezoNyango) kwiYunivesithi yaseWitwatersrand, ngomnxeba. 011 717 2301, okanye nge-imeyile kuClement.Penny@wits.ac.za.
UNks. Z Ndlovu okanye uMnu Rhulani Mkansi, Unobhala weKomiti, iinombolo zomnxeba: 011 717 2700 okanye 1234, okanye nge-imeyile ku: Zanele.Ndlovu@wits.ac.za okanye Rhulani.Mkansi@wits.ac.za

Igama lomthathi-nxaxheba Umhla _____ Usuku _____

Indawo _____

Utyikityo _____

Ingqina ngu:

Igama lengqina Umhla _____ Usuku _____

Utyikityo _____

Demographic Data of Informal Caregiver

Participant Number: ☐

Age/ D.O.B		Ethnicity	Black White Indian Coloured Other
Sex	Male Female		
Relation to person with stroke		Spouse/partner Sibling Child-in-law Sibling-in-law Other family Parent Child Grandchild Neighbour/Friend Other (specify)	
Date of onset of caregiving (duration ofcaregiving)			
Living in the same household as person withstroke		Yes / No	
Other caregivers involved		No Daily Once or a few times a week Once or a few times a month	
Employment status before caregiving role		Permanently employed Employed on contractual basis Piece work Unemployed Pension	
Current employment status		Permanently employed Employed on contractual basis Piece work Unemployed Pension	
Level of education		Never schooled Some or completed primary school (grade 0 to grade 7) Started but did not complete high school (grade 8 to grade 12) Completed matric Completed tertiary education (tertiary degree/ 1-3 years)	

Information pertaining to person being cared for

Age /DOB		Ethnicity	Black White Indian Coloured Other
Sex	Male Female		
Side of hemiplegia	Right Left	Date of admission to Zithulele Hospital for stroke	
Means of access to local clinic before stroke		Unable to access Taxi Own vehicleOther	Walk by foot Hiring of private transport Wheelchair: Self-propelled Wheelchair: Passive
Means of access to local clinic after stroke		Unable to access Taxi Own vehicleOther	Walk by foot Hiring of private transport Wheelchair: Self-propelled Wheelchair: Passive
Employment status before stroke		Permanently employed Employed on contractual basisPiece work Unemployed Pension	
Current employment status		Permanently employed Employed on contractual basisPiece work Unemployed Pension	
Receiving a DG		Yes No	
Level of education		Never schooled Some or completed primary school (grade 0 to grade 7) Started but did not complete high school (grade 8 to grade 12) Completed matric Completed tertiary education (tertiary degree/ 1-3 years)	
Name of local community clinic used			

6.4.2 BARTHEL INDEX QUESTIONNAIRE

INSTRUCTIONS

Please use the scale on the left to score how much the patient is able to do of each activity described below.

BATHING

5 The patient may take a bath in a bath tub or a shower, or wash using a basin, bowl or bucket. He/she must be able to complete all the steps of whichever method he/she follows without another person being present.

0 The patient cannot wash him/herself.

GROOMING

5 The patient can wash the hands and face, comb hair and clean teeth. Men must be able to shave, using any kind of razor, and must be able to put in the blade or plug in the razor without help, and get it from the drawer or cabinet where it is stored. If women wear make-up, they must be able to put it on by themselves. Braiding or styling hair is not necessary.

0 The patient needs help with personal grooming.

EATING

10 Independent. The patient can eat a meal from a tray or table when someone puts the food within reach. If assistive devices are used to eat, he/she should manage these devices independently, cut up the food, use salt and pepper, spread butter, etc. He/she must finish the meal in a reasonable time.

5 Some help is necessary, for example with cutting up food, using salt and pepper or spreading butter.

0 The patient is unable to eat by him/herself, even if the food is cut up.

DRESSING AND UNDRESSING

10 The patient is able to put on, take off and fasten all clothing, and tie shoe laces (unless it is necessary to use adaptations for this). This activity includes putting on and removing all assistive devices such as corsets and splints, if they are prescribed. Any special clothing or adapted clothing and shoes may be used when necessary.

5 The patient needs help with putting on, taking off or fastening any clothing. He/she must do at least half the dressing or undressing by him/herself. This must happen in a reasonable time. Women need not put on a bra or other support unless these are prescribed garments.

0 The patient needs help with dressing and undressing and cannot complete at least half of the dressing him/herself.

BOWEL CONTROL

10 The patient is able to control his/her bowels and has no accidents.

5 The patient needs help with using a suppository or taking an enema, or has occasional accidents.

0 The patient has no bowel control or has regular accidents.

BLADDER CONTROL

10 The patient is able to control his/her bladder day and night. Patients who wear a catheter (pipe) and bag must put them on independently, clean and empty the bag, and stay dry day and night.

5 The patient has occasional accidents, cannot wait for the bed pan or get to the toilet in time, or needs help with the catheter and bag.

0 The patient has no bladder control and has regular accidents, or cannot manage the catheter and bag without help.

GETTING ON AND OFF THE TOILET

10 The patient is able to get on and off the toilet, commode or bucket. He/she can unfasten and fasten clothes, prevent soiling the clothes, and use toilet paper without help. He/she may use a wall bar or other stable object for support if needed. If it is necessary to use a bed pan, commode or bucket instead of a toilet, he/she must be able to position it, empty it, and clean it.

5 The patient needs help due to a lack of balance, or needs help to manage clothes or with using toilet paper. If he/she uses a bed pan, commode or bucket, help is needed with positioning it, emptying it or cleaning it.

0 The patient cannot use the toilet at all.

MOVING BETWEEN THE BED AND THE WHEELCHAIR

15 The patient can do all parts of this activity independently. The patient can safely get to the bed in the wheelchair, lock brakes, lift footrests, move safely to bed, lie down, come to a sitting position on the side of the bed, change the position of the wheelchair if necessary to transfer back into it safely, and return to the wheelchair.

10 Either some minimal help is needed with some step of this activity or the patient needs to be reminded or supervised for safety of one or more parts of this activity.

5 The patient can come to a sitting position without the help of a second person but needs to be lifted out of bed, or he/she can transfer only with a great deal of help.

0 The patient is unable to sit up by him/herself and needs a lot of help to transfer.

WALKING ON A LEVEL SURFACE, OR PROPELLING A WHEELCHAIR IF UNABLE TO WALK

15 The patient can walk at least 46 meter without help or supervision. He/she may wear braces or prostheses and use crutches, canes or a walking frame, but not a walking frame with wheels (rollator). If he/she wears braces or splints that need to be locked for standing, he/she must be able to do this without help, stand up and sit down without help, get hold of and position his/her walking devices for use, and let go of them when he/she sits. (Do not score the patient on putting on and taking off splints or braces in this section. This is scored under dressing.)

10 The patient needs help or supervision in any of the above actions, but can walk at least 46 meter with a little help.

5 The patient cannot walk at least 46 meter but can independently move around in a wheelchair. He/she must be able to go around corners, turn around, move the wheelchair to a table, bed, toilet, etc. He/she must be able to push the wheelchair for at least 46 meter.

0 The patient cannot move around independently (cannot walk, even with help, or cannot independently use a wheelchair or push him/herself at least 46 meters, go around corners, turn around etc.).

ASCENDING AND DESCENDING STAIRS

10 The patient is able to go up and down a flight of stairs safely without help or supervision. He/she may and should use handrails, walking sticks or crutches when needed. He/she must be able to carry the walking sticks or crutches by him/herself when going up or down the stairs.

5 The patient needs help with or supervision of any one of the above actions.

0 The patient cannot go up and down stairs at all, or needs to be carried up and down stairs.

6.4.2.1.1 IPHEPHA LEMIBUZO LE-INDEKSI YEBARTHEL

IMIYALELO

Nceda usebenzise isikali esingasekhohlo ukunika amanqaku achaza ukuba isigulane sikwazi kangakanani ukwenza umsebenzi ngamnye ochaziweyo ngezantsi.

UKUZIHLAMBA

5 Isigulane siyakwazi ukuhlamba ebhafini okanye eshawareni, ukuhlamba sisebenzisa ikomu okanye ipheyile. Kufuneka sikwazi ukulandela onke amanqanaba alo naluphi uhlobo esilusebenzisayo ukuhlamba, singancediswanga ngomnye umntu okanye kungekho omnye umntu.

0 Isigulane asikwazi kuzihlamba.

UKUZIHOYA

5 Isigulane siyakwazi ukuhlamba izandla nobuso, sikame iinwele sixukuxe namazinyo. Amadoda kufuneka akwazi ukutsheva, ukusebenzisa nayiphi ibhleyidi, yaye kufuneka akwazi ukusebenzisa ibhleyidi, ukufaka eplagini engancediswanga, nokuyithatha kwidrowa kanye kwikhabhathi egcinwa kuyo. Ukuba amakhosikazi ngabantu abathanda ukuzilungisa baziqhunkqe, kufuneka akwenze oko bengancediswanga. Ukubhreyida okanye ukwenza istayili ezinweleni akusosinyanzelo.

0 Isigulane sifuna uncedo ekuzinakekeleni.

UKUZITYISA

10 Ngokwakhe. Isigulane siyakwazi ukutya ukutya okusetreyini okanye okusetafileni xa umntu ebeka ukutya kwindawo esinokufika kuyo. Ukuba ngaba kusetyenziswa izixhobo zokusincedisa ukuba sitye, kufuneka sikwazi ukuzilawulela ezi zixhobo ngokunokwaso, sicukuceze ukutya, sisebenzise ityuwa nepepile, siqabe ibhotolo, njl njl. Kufuneka sigqibe ukutya ngexesha elifanelekileyo.

5 Uncedo oluthile luyadingeka, umzekelo ekukucukuzeni ukutya, ekusebenziseni ityuwa nepepile nokuqaba isonka.

0 Isigulane asikwazi ukuzityisa, nokuba ukutya sekucukuceziwe.

UKUZINXIBISA NOKUZIKHULULA

10 Isigulane siyakwazi ukuzinxibisa, ukuzikhulula nokuziqhobosha zonke iimpahla, nokubopha imitya yezihlangu (ngaphandle kokuba kukho imfuneko yokuba kwenziwe enye into endaweni yale). Lo msebenzi ubandakanya ukufaka nokususa zonke izixhobo zoncediso ezifana neekhosethi neziplinti, ukuba abezempilo bathe mazinxitywe. Naziphi na iimpahla nezihlangu ezizodwa okanye ezilungiselelwe imeko zingasetyenziswa xa kuyimfuneko.

5 Isigulane sidinga uncedo ngokunxiba, ukukhulula nokuqhobosha naziphi na iimpahla. Kufuneka sizame ukuba sizinxibele sizikhulule ihafu yeempahla ngokunokwaso. Oku kufuneka kwenzeka ngexesha elamkelekileyo. Amakhosikazi akanyanzelekanga ukuba anxibe ibhodi yamabele/ibra okanye ezinye izinto zokuxhasa amalungu omzimba ngaphandle kokuba ezo zimpahla ekuthiwe mabazinxibe.

0 Isigulane sidinga uncedo lokuzinxibisa nokuzikhulula yaye asikwazi nokunxiba ihafu yempahla ngokunokwaso.

UKULAWULA UKUPHUMA KWELINDLE

10 Isigulane siyakwazi ukulawula ilindle laso yaye asivele sizituwele.

5 Isigulane sidinga uncedo lokusebenzisa ipilisi efakwa ezimpundwini okanye lokuzicima, okanye simana sizituwela ngamanye amaxesha.

0 Isigulane asikwazi kulawula ukuphuma kwelindle okanye sizituwela qho.

UKULAWULA UMCHAMO

10 Isigulane siyakwazi ukulawula isinyi saso okanye umchamo waso emini nasebusuku.
Izigulane ezisebenzisa umbhobho wokuchama (icatheter) nesingxobo kufuneka

sikwazi ukuzifaka kakuhle, bazicoce ze bachithenomchamo okwisingxobo ze bahlale bomile emini nasebusuku.

5 Isigulane simana siphulukwa ngumchamo, asikwazi ukulinda itshemba okanye siye kufika kwindlu yangasesekwangethuba, okanye sidinga uncedo ngecatheter nesingxobo sokuchamela.

0 Isigulane asikwazi kulawula ukuphuma komchamo yaye simana sizichamela, okanye asikwazi kusebenzisaicatheter nesingxobo ngendlela eyiyo ngaphandle koncedo.

UKUCHOPHA NOKUPHAKAMA KWINDLU YANGASESE

10 Isigulane siyakwazi ukuchopha nokuphakama endlwini yangasese okanye ebhakethini.

Siyakwazi ukukhulula nokuqhobosha iimpahla, ukunqanda ukuzimosehla nokusebenzisa iphepha langasese ngaphandle koncedo.Uyakwazi ukusebenzisa isixhasi esisedongeni okanye enye into yokubambelela xa efuna ukuxhasa. Ukuba kufuneka esebenzise itshemba okanye ibhakethi endaweni yendlu yangasese, kufuneka akwazi ukuyibeka kakuhle, ayichithe, yaye ayicoce.

5 Isigulane sidinga uncedo kuba asikwazi kuxhathisa okanye sidinga uncedo ukukhulula nokunxiba iimpahla okanye ngokusebenzisa iphepha langasese. Ukuba sisebenzisa itshemba okanye ibhakethi, sidinga uncedo ukuze siyibeke kakuhle, ukuyicoca nokuyichitha.

0 Isigulane asikwazi kusebenzisa indlu yangasese konke konke.

UKUHAMBA-HAMBA PHAKATHI KWEBHEDI NESITULO ESINAMAVILI (WHEELCHAIR)

15 Isigulane siyakwazi ukwenza yonke imisebenzi ehambelana noku ngokunokwaso.
Isigulane siyakwazi ukuyaebhedini ngesitulo esinamavili, sibambe iibhriki, siphakamise iindawo zokuphumza iinyawo, sikhwele
ebhedini, silale, sihlale ecaleni kwebhedi, sitshintshe indawo esikuyo isitulo esinamavili ukuba okokuyimfuneko, yaye sibuyele kuzo.

10 Isenokuba kudingeka uncedo kumanye amanqanaba alo msebenzi okanye isigulane sifuna ukukhunjuzwaokanye sibekwe iliso ukuze sihlale sikhuselekile xa sisenza oku okanye inxalenye yako.

5 Isigulane siyakwazi ukuhlala singancedwanga ngomnye umntu kodwa sidinga ukuphakanyiswa ebhedini,okanye kufuneka sisuswe ngokuthi sincediswe kakhulu.

0 Isigulane asikwazi kuzihlalela yaye sidinga uncedo olukhulu ukususwa kwenye into sibekwe kwenye.

UKUHAMBA KUMGANGATHO OTHEBELELE, OKANYE UKUQHUBA ISITULO ESINAMAVILI UKUBA AKAKWAZI UKUHAMBA

15 Isigulane singahamba iimitha eziyi-46 ngaphandle koncedo. Anganxiba iibreyisi okanye umlenze ofakelwayo ze asebenzise iintonga zokuhamba, iikheyini, okanye ifreyimu yokumxhasa xa ehamba, kodwa angasebenzisi le inamavili (rollator). Ukuba unxiba iibreyisi okanye iziplinti ekufuneka ziqiniswe ukuze zime,
kufuneka akwazi ukwenza oku engafumenanga luncedo, eme ze ahlale phantsi engafumenanga luncedo,afumane ze alungiselele izixhobo zakhe ukuba azisebenzise, aziyeke xa ehlala. (Unganiki amanqaku isigulane ekufakeni nasekukhululeni iziplinti okanye iibreyisi kweli candelo. Amanqaku oku aphaya

10 ekunxibeni.)
Isigulane sidinga uncedo okanye ukugadwa xa sisenza ezi zinto zingentla, kodwa siyakwazi ukuhamba
iimitha eziyi-46 ubuncinane sincediswe kancinci.

5 Isigulane asikwazi ukuhamba kodwa siyakwazi ukuhamba ngesitulo esinamavili.
Kufuneka sikwazi ukujika ezikoneni, sijike, siye ngesitulo esinamavili etafileni, ebhedini, kwindlu yangasese, njl njl. Kufuneka sikwaziukutyhala isitulo esinamavili iimitha ezingama-46 ubuncinane.

0 Isigulane asikwazi ukuzihamba-hambela ngokunokwaso (asikwazi kuhamba, sele sincediswa, okanye asikwazi nokuqhuba isitulo esinamavili okanye ukusihambisa iimitha ezingama-46 ubuncinane, ukujikaezikoneni, ukujika, njalo njalo).

UKUNYUKA NOKUHLA EZITEPSINI

10 Isigulane siyakwazi ukunyuka nokuhla ezitepsini ngaphandle koncedo okanye ukugadwa.
Kufuneka sisebenzise izinto zokubambelela, intonga yokusimelela okanye iintonga zokuhamba, xa oko kuyimfuneko.
Kufuneka sizibambele intonga yaso yokusimelela okanye iintonga zokuhamba xa sinyuka okanye sisihlaezitepsini.

5 Isigulane sidinga uncedo okanye ukugadwa xa sisenza ezi zinto zingentla. Isigulane asikwazi ukunyuka nokuhla ezitepsini konke konke, okanye sidinga

0

CAREGIVER STRAIN INDEX

CAREGIVER STRAIN INDEX
INSTRUCTIONS
Please read the following instruction to the caregiver, and give examples if necessary:
"I am going to read a list of things that other caregivers have found to be difficult. Would you tell me if any of these apply to you?"

1.	My sleep is disturbed (e.g. because my patient is in and out of bed or wanders around at night).	0	No	1	Yes
2.	Caregiving is inconvenient (e.g. because helping takes so much time; it's a long drive or walk to get here to help).	0	No	1	Yes
3.	Caregiving is a physical strain (e.g. lifting the patient in and out of a chair requires physical effort, or concentration is required).	0	No	1	Yes
4.	Caregiving is confining (e.g. because helping takes up my free time; I cannot go visiting or make other trips).	0	No	1	Yes
5.	There has been family adjustment (e.g. helping has disrupted our routine; there is no privacy).	0	No	1	Yes
6.	There have been changes in personal plans (e.g. I had to turn down a job; could not go on vacation).	0	No	1	Yes
7.	There have been other demands on my time (e.g. from other family members).	0	No	1	Yes
8.	There have been emotional adjustments (e.g. because of severe arguments).	0	No	1	Yes
9.	Some behaviour is upsetting (e.g. because of incontinence; my patient has trouble remembering things; my patient accuses people of taking things).	0	No	1	Yes
10.	It is upsetting to find that my patient has changed so much from his/her former self (e.g. he/she is a different person than he/she used to be).	0	No	1	Yes
11.	There has been work adjustment (e.g. because I have had to take time off at work).	0	No	1	Yes
12.	Caregiving is a financial strain.	0	No	1	Yes
13.	I am feeling completely overwhelmed (e.g. because of worry about my patient; concerns about how I will manage).	0	No	1	Yes

IPHEPHA LEMIBUZO LONZINYELO LOMNONOPHELI

IINKCUKACHA ZOMNONOPHELI

II-I NDEKSI YONZINYELO LOMNONOPHELI

IMIYALELO

Fundela umnonopheli le miyalelo ilandelayo, ze unike imizekelo apho kuyimfuneko:
"Ndiza kufunda uluhlu lwezinto abanye abantu abazifumanise zinzima. Ingaba ungandixelela xa ezi zinto zikuchaphazela?"

1. Ubuthongo bam buyaphazamiseka (umz. ngoba isigulane sam singena siphuma ebhedini okanye sizulazule ebusuku)	0	Hayi	1	Ewe
2. Ukunonophela kuyandisokolisa (umz. ngoba ukunceda kuthatha ixesha elininzi; kufuneka ndiqhube okanye ndihambe umgama omde ukuza apha ndize kunceda).	0	Hayi	1	Ewe
3. Ukunonophela kudinisa umzimba (umz. ngenxa yokumane ndiphakamisa isigulane kwisitulo ndiphinde ndisibuyisele, nto leyo efuna ukuba ndisebenzise amandla okanye kufuneke ndigxile kuloo nto ndiyenzayo).	0	Hayi	1	Ewe
4. Ukunonophela kuyandiminya (umz. ngoba ukunceda kuthatha ixesha lam elininzi/ andikwazi ukuya kubona abanye abantu okanye ndiye kwezinye iindawo).	0	Hayi	1	Ewe
5. Kubekhona utshintsho kusapho (umz. ukunceda kutshintshe indlela esenza ngayo izinto; asisenakhusi lilelethu).	0	Hayi	1	Ewe
6. Kubekho utshintsho kwizicwangciso zam (umz. kuye kwafuneka ndincame umsebenzi; andikwazanga kuya eholideyini).	0	Hayi	1	Ewe
7. Kubekho ezinye iimfuno ezidinga ixesha lam (umz. Ezivela kwamanye amalungu osapho).	0	Hayi	1	Ewe
8. Kubekho utshintsho emphefumlweni (umz. ngenxa yokuxambulisana okuninzi).	0	Hayi	1	Ewe
9. Ezinye izenzo ziyakhathaza (umz. ngenxa yokungakwazi ukuzibamba; isigulane sam sinengxaki yokukhumbula izinto; okanye isigulane sam sityhola abantu ngokuthatha izinto).	0	Hayi	1	Ewe
10. Kuyakhathaza ukufumanisa ukuba isigulane sam sitshintshe kakhulu kumntu ebesinguye ngaphambili (umz. Wohlukile kumntu awayenguye ngaphambili).	0	Hayi	1	Ewe
11. Kubekho utshintsho kumsebenzi (umz. ngenxa yokuba kufuneka ndithathe ikhefu ngamanye amaxesha emsebenzini).	0	Hayi	1	Ewe
12. Ukunonophela kudla imali.	0	Hayi	1	Ewe
13. Ndiziva ndonganyelwe kakhulu (umz. ngenxa yokuba nexhala ngesigulane sam; iinkxalabo zokuba ndiza kujongana njani nale meko).	0	Hayi	1	Ewe

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R49 Ms J Jardine

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M210857

NAME: Ms J Jardine

(Principal Investigator)

DEPARTMENT:

School of Therapeutic Sciences
Department of Physiotherapy
Medical School
University

PROJECT TITLE:

Caregiver strain and functional independence of people with stroke living in a rural setting in the Eastern Cape, South Africa

DATE CONSIDERED: 2021/08/27

DECISION:

Approved unconditionally

CONDITIONS:

NOTE: If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>

SUPERVISOR: Ms N Corniey-White

APPROVED BY: Dr CB Penny, Chairperson, HREC (Medical)

DATE OF APPROVAL: 2021/12/23

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. I **agree to submit a yearly progress report.** When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in August and therefore reports and re-certification will be due in the month of **August** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator

Date

Province of the
EASTERN CAPE
HEALTH

Room 31 • 1st Floor• Grosvenor Lodge• 31 Taylor Street• King Williams Town• Eastern Cape
Private Bag X0038 • Bhisho • 5605 • REPUBLIC OF SOUTH AFRICA
Tel.: +27 (0)43 605 4540• 043 6054535 •Email: ncebagixela22@gmail.com

Date: 18 January 2022

Caregiver strain and functional independence of people living with stroke in a rural setting in the Eastern Cape, South Africa. (EC_202111_009)

Dear Ms J. Jardine

The department would like to inform you that your application for the research mentioned above topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having written approval from the Research Ethics Committee.

2. You are advised to ensure, observe, and respect the rights and culture of your research participants maintain confidentiality of their identities, and shall remove or not collect any information which can be used to link the participants.

3. The Department of Health expects you to provide a progress update on your study every 3 months (from the date you received this letter) in writing.

4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Eastern Cape Health Research Committee secretariat. You may also be invited to the department to come and present your research findings with your implementable recommendations.

5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

SECRETARIAT, EAST E HEALIIi RESEARCH COMMITTEE

Request for permission to access names and contact numbers of people with stroke from hospital records to conduct research.

Dear Zithulele Clinical Manager (current acting CEO): Dr Gaunt

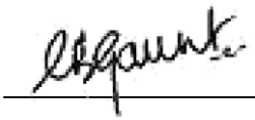
My name is Jessica Jardine, I am employed by the Department of Health to work at Zithulele Hospital as a physiotherapist and I am also studying a MSc in physiotherapy part-time through The University of Witwatersrand.

The research that I would like to conduct in partial completion of my Masters Coursework with Research Report involves determining the level of caregiver strain and functional independence of people with stroke living in a rural setting in the Eastern Cape, South Africa. This study will be conducted under the supervision of Mrs Nicolette Comley-White (University of Witwatersrand, South Africa).

I would like to request your consent for me to access the names and contact numbers of people with stroke from the hospital digital database so that I may contact these individuals and invite them to participate in my study.

Attached to this letter is a copy of my study protocol. Upon completion of this study, I will provide Zithulele Hospital with a copy of the full research report.

If you require any further information, please do not hesitate to contact me at jessjardine.3@gmail.com or on 0729339175.
Thank you for your time in considering my request.
Kind regards
Jessica Jardine

Signature granting permission 

Name Dr Ben Gaunt

Date 04 August 2021

Final Turnitin

ORIGINALITY REPORT

7%	5%	4%	1%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES