INFORMAL CAREGIVERS' PERCEIVED EFFECTIVENESS OF CAREGIVER TRAINING FOR CAREGIVERS OF INDEX STROKE SURVIVORS.

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

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DECLARATION

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

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DEDICATION

I would like to thank my husband (Etienne Prinsloo), for all his support and for looking after our young children while I was attending class and writing up my research report. Thank you for the many late hours assisting and providing valuable suggestions during the write up of my research report.

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PUBLICATIONS AND PRESENTATIONS ARISING FROM THE RESEARCH REPORT

- Medi clinic monthly magazine by their request
- Rita Henn and Partners group presentations

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ABSTRACT

Introduction: Globally, strokes are considered the third leading cause of disability, with increased caregiver requirements due to long-term disability. Additionally, a stroke not only impacts the survivor but also their family and friends. Thus, there is a need to determine the perceived effectiveness and gaps in training provided to informal caregivers.

Method: A non-experimental prospective longitudinal quantitative approach with a convenience sample of 31 participants was used. Participants were interviewed through face-to-face or telephonic semi-structured interviews. A questionnaire with set parameters was administered on discharge and again at six weeks post-discharge, to determine the perceived effectiveness and gaps of caregiver training provided at a private Rehabilitation Unit in Pretoria (Rita Henn and Partners [RHP]). However it is important to note that the response rate for participation in the follow-up questionnaire was 61%.

Results: The results indicated that caregivers felt prepared to care for the stroke survivor. The informal caregivers perceived the index stroke survivors (ISS) to be independent in completing their activities of daily living (ADL), therefore they perceived caregiver training to be effective. However, when it came to instrumental ADL, the caregivers' perception of the training was either that they did not receive it or that they did not need to assist the ISS in returning to these tasks. In addition, informal caregivers perceive productive participation or return-to-work as insufficient as they still need help when assisting ISSs to return to work. Furthermore, the informal caregivers were able to identify perceived gaps in the caregiver training they received and provided suggestions for improvement.

Conclusion: Informal caregivers are often new to their role and responsibilities. They require informal caregiver training to assist the ISS with the transition from in-patient rehabilitation to home reintegration. Informal caregivers of ISSs perceive caregiver training to have both positive and negative aspects related to occupational performance areas, psychosocial aspects, how the caregiver training is presented as well as the much-needed continuation of caregiver support and follow-up services. Valuable information related to the perceived gaps in caregiver training and the perceived ability of informal caregivers to care for the ISS was obtained from this research study. This could guide future clinical practice, specifically related to caregiver perceptions of training provided at the Rehabilitation Unit.

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NOMENCLATURE

Operational Definitions

Caregiver training – Activities, including practice, demonstration and verbal discussion, that convey knowledge and information about occupation, health, well-being and participation in functional activities, resulting in caregivers acquiring beneficial behaviours, habits and routines enabling them to assist ISS's (The American Journal of Occupational Therapy, 2020).

Effectiveness - The degree to which caregiver training fulfils the intended function of facilitating knowledge and practice on safely caring for ISS while facilitating the independence of the survivor (Harvey, 2020).

Family caregiver - Individuals who care for and/or assist a family member, spouse or friend who has a disability or is ill/frail (Moghimi, 2007) (Pierce, et al., 2007).

Index stroke survivor (ISS) – An individual who has had a stroke for the first time, who is unfamiliar with stroke associated adverse events, rehabilitation programmes, where to obtain caregiver sources and how to prevent a second stroke (Chen, et al., 2015).

Multidisciplinary team - Team of various health care professionals bringing assessment and evaluations together with the same goal of gaining a holistic view of the patient difficulties, to achieve the best possible outcome for the patient (Norrefalk, 2003).

Psychosocial difficulties - Difficulties that individuals experience, which may involve psychological and social aspects, for example, age, education, marital history (Stegman, 2008).

Stroke rehabilitation - A recurrent process that includes the assessment of the stroke survivors' needs, setting realistic goals for improvement of function, intervention in order to achieve the goals for improvement and reassessing the stroke survivor to determine whether goals were achieved (Langhorne, et al., 2011).

Home integration - re-organisation of physical, psychological and social characteristics so that the individual with a stroke can return to mainstream living, namely family life, engaging in normal roles and responsibilities and actively contributing to society (Wood-Dauphinee & Williams, 1987)

ABBREVIATIONS

ADL	Activities of Daily Living
BI	Barthel Index
CME	Caregiver Mediated Exercise Programme
FAM	Functional Assessment Measure
FAME	Family Mediated Exercise Intervention
FIM	Functional Independence Measure
ISS	Index Stroke Survivor
IADL	Instrumental Activities of Daily Living
OT	Occupational Therapy/Therapists
PEG	Percutaneous Endoscopic Gastrostomy
RHP	Rita Henn And Partners
SA	South Africa
SADFM®	South African Database For Functional Measures
SIS	Stroke Impact Scale
STAIR	Stroke Transition After Inpatient Rehabilitation
UK	United Kingdom

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND TO STUDY

In South Africa (SA), strokes are responsible for 25 000 deaths, annually. Around 300 per 100 000 people suffer a stroke in rural SA, with urban areas likely having a higher prevalence (Taylor & Ntusi, 2019). Thus, health care professionals need to have a greater understanding of the disease, as this would enable them to manage it accordingly (Langhorne, et al., 2011). The focus of interventions should not only be on the medical management of strokes but also the reintegration of stroke survivors into their home and community.

Strokes do not only cause physical disabilities but can lead to communication, cognitive and psychosocial difficulties for the individual involved (Langhorne, et al., 2011) (Mellon, et al., 2015). Consequently, stroke survivors often require caregivers to assist them with activities at home as a result of the residual difficulties (Kalra, et al., 2004) (Fens, et al., 2014). Therefore, the impact of a stroke is not only on the survivor but also on family members and friends who are in close contact with them. Indeed, the stroke survivors often look to these individuals, mostly family, spouses and adult children, to assist them with their daily tasks (Moghimi, 2007) (Pierce, et al., 2007).

These family members or informal caregivers report difficulties in caring for stroke survivors, as their loss of independence and need for assistance as well as the physical and emotional challenges can be overwhelming for the caregiver. Moreover, caregivers often report feeling unprepared and abandoned after discharge, having to cope with various aspects of caring for their loved ones, such as financial difficulties, attending follow-up appointments and dealing with the stroke survivor’s reluctance to leave the house (Smith, et al., 2004). Caregiving has social implications and presents the need to cope with depression, anxiety, frustration and loneliness, as well as participation restrictions experienced by both the stroke survivor and the caregiver (Thomas & Greenop, 2008) (King, et al., 2010).

Stroke survivor needs are numerous, therefore caregivers need to be prepared for the task at hand (Clarke & Forster, 2015). The more support the caregiver receives, the greater their ability to cope (Thomas & Greenop, 2008). Hence, some form of training or intervention during the stroke survivor’s in-patient admission to the hospital can provide such support to the caregiver (Given, et al., 2008) (Van den Berg, et al., 2016).

Globally, multidisciplinary health professionals present caregiver training to caregivers of stroke survivors (Kalra, et al., 2004). These professionals include doctors, nurses and rehabilitation professionals with experience in stroke management and the management of residual disabilities related to strokes. The training includes management of the physical difficulties experienced by stroke survivors, as well as dealing with speech, feeding, cognitive and emotional dysfunction (Kalra, et al., 2004)

(Clarke & Forster, 2015). Caregiver training allows for informal caregivers to adapt to their new role of being a caregiver – as they are no longer merely a family member or friend. Occupational therapists (OTs) mostly provide training on how a caregiver can assist the stroke survivor to perform their activities of daily living (ADL). Likewise, they provide caregivers with training regarding appropriate processes for the stroke survivor to return to work, driving again or even facilitating reintegration back into the community (Whitehead & Baalbergen, 2019). The purpose of the caregiver training provided at Rita Henn and Partners (RHP) is to enable informal caregivers to safely care for index stroke survivors (hereafter ISSs) while facilitating independent participation in daily activities.

Therefore, there is a need to determine whether the informal caregiver training provided by the health care professionals to informal caregivers is perceived as effective in preparing them and the ISS for discharge. It is also important to establish the perceived effectiveness of the training once they have been caring for the ISS for a few weeks, in order to determine the relevance of the informal caregiver training in the long term.

1.2 STATEMENT OF THE PROBLEM

In SA, access to inpatient rehabilitation varies and the length of rehabilitation depends on i) the severity of the impairments with which the stroke survivor presents and ii) access to medical aid (Council of Medical Schemes, 2015). Longer-term inpatient rehabilitation with the possibility of providing caregiver training over a longer period is possible when the patient can access private health care services (Bryer, et al., 2011). In addition, a stroke is known to have long-term disability outcomes and necessitates chronic care, therefore informal caregivers will experience the long-lasting effects of ineffective caregiver training well after the initial rehabilitation process (Langhorne, et al., 2011) (Fens, et al., 2014).

Thus, RHP Rehabilitation Unit (or “Unit”) offers an informal caregiver training programme in the Neurology Unit at Muelmed Mediclinic Hospital, Pretoria. As an OT, the researcher is a member of a multidisciplinary team that provides informal caregiver training and enables caregivers to safely care for ISSs while facilitating their independence as part of the rehabilitation service. The question, however, is whether the informal caregiver training provided by the neurology team is sufficient in preparing the caregivers for their role. When informal caregivers can safely care for the ISS while facilitating their independence, caregiver training could be considered sufficient as the purpose of caregiver training has been achieved. If not, this raises the possibility that ISSs may not necessarily receive adequate care at home. Furthermore, it may indicate that the informal caregiver training may not have had the desired effect in meeting the needs of the informal caregiver and preparing them for the caregiver role.

1.3 PURPOSE OF THE STUDY

A study completed with caregivers of stroke survivors in SA reported a paucity of post-stroke information and training from health care workers (Thomas & Greenop, 2008). The caregivers expressed a need to capacitate themselves to assist and manage the stroke survivor at home; they stated a desire to further their skills which would enable them to cope. This forms the background of the study, which allowed for the identification of strengths and weaknesses of the informal caregiver training programme at RHP Rehabilitation Unit to enable adaptations to the programme as necessary, based on essential input from the informal caregivers of ISSs. This should provide valuable information on caregiver's needs regarding training, for health care professionals whether in the public sector or private practice. However, the rehabilitation team at RHP rehabilitation unit would also benefit specifically in terms of their presentation and inclusion of information in the caregiver training program according to the perceptions of informal caregivers of ISSs. Furthermore, the information obtained benefit not only the caregivers of ISS, to improve their ability to care for the ISS but also benefits the ISS's to receive the best possible care from their caregivers. Other stakeholders that benefit from improved caregiver training programs are: Healthcare funders, i.e. medical aids, insurers etc where improved caregiver training programs can possibly reduce or limit further readmission of the ISS or caregivers of ISS due to injury and secondary complications.

1.4 RESEARCH QUESTION

Do informal caregivers of ISSs perceive the caregiver training offered to them at the RHP Rehabilitation Unit as effective in equipping them to safely care for the stroke survivors while facilitating independence post-discharge?

1.5 THE AIM OF THE STUDY

The study aims to determine whether informal caregivers of ISSs perceive the caregiver training offered to them at the RHP Rehabilitation Unit as effective, in equipping them to safely care for the stroke survivors while facilitating independence.

1.6 THE OBJECTIVES OF THE STUDY

1. To determine how effective caregivers perceive the informal caregiver training offered to them at discharge from inpatient rehabilitation to be.
2. To determine the effect of the informal caregiver training as perceived by informal caregivers in preparing them for the caregiver role at six weeks post-discharge, following the implementation of the training they received.
3. To determine the perceived gaps and areas for improvement in the informal caregiver training offered at discharge from inpatient rehabilitation as perceived by informal caregivers.

1.7 THE ASSUMPTIONS TESTED

The perceived effectiveness of the caregiver training provided at discharge to informal caregivers in preparing them to care for ISSs after discharge or after an integration period at home is currently unknown. The perceived gaps in caregiver training can be identified in order to improve the informal caregiver training provided while ISSs are still part of the in-patient rehabilitation programme.

1.8 VALIDATION OR JUSTIFICATION OF THE STUDY

Determining the perceived effectiveness regarding the informal caregiver training caregivers received in preparation for caring for a family member with a stroke after discharge, will enable the multi-disciplinary team to address possible limitations in the current informal caregiver training programmes. This, in turn, will enable the multi-disciplinary team to better prepare informal caregivers for the role they need to fulfil.

This study adds to the body of knowledge regarding informal caregiver training received by caregivers in preparation for caring for ISSs. It also explores the possibility of the training becoming more formalised within a structured programme.

1.9 LAYOUT OF THE RESEARCH REPORT

Chapter 1 - Introduction

The high prevalence of strokes globally and in SA requires health care professionals to provide informal caregiver training to assist both ISSs and their informal caregivers, to manage stroke and its long-term effects. Therefore, determining the perceived effectiveness of informal caregiver training for informal caregivers of ISSs could equip the caregivers to better assist ISSs with integration into their home and community.

Chapter 2 - Literature review

The literature review critically evaluates previous research related to strokes, stroke survivors and their caregivers; specifically researching rehabilitation requirements, current caregiver training practices and outcomes of caregiver training. Furthermore, it reviews information regarding impairments due to stroke and their effect on informal caregivers, providing background to this research study.

Chapter 3 – Methodology

This chapter aims to clearly describe and explain the process followed in completing this study. It provides specific information on the sample population, sample size, data collection and analysis in order to present the data sensibly. This would thus allow other researchers to recreate the research and enable a comparison between studies.

Chapter 4 – Results

This chapter presents the study results according to the objectives. The chapter covers how effective the caregivers perceive the informal caregiver training offered to them at discharge to be, as well as their perception of the effectiveness of the informal caregiver training at six weeks post-discharge. Furthermore, it presents the perceived gaps and areas for improvement in informal caregiver training.

Chapter 5 – Discussion

This chapter discusses important findings and trends as observed in the study results, such as the significance of the results obtained from the perceptions of informal caregivers regarding the effectiveness of their training, both at discharge and six weeks post-discharge. The gaps and areas for improvement in caregiver training are also discussed as per the finding of the study.

Chapter 6 – Conclusion

The last chapter presents recommendations regarding the provision of informal caregiver training programmes to be used in clinical practice. Furthermore, the chapter presents opportunities for future research, to expand on this study and to add to the body of knowledge related to informal caregiver training for informal caregivers of ISSs.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

Literature related to the impact of and rehabilitation for stroke as well as the role of the multidisciplinary team is presented in this chapter. Studies discussing informal caregiving, caregiver training provided to informal caregivers of stroke survivors, the outcomes and principles of this type of training, the role of these caregivers as well as barriers and facilitators of caregiving are reviewed. Thus, the literature review provides background information to better understand the research topic. Literature was sourced from Science Direct, Scielo, Sage, EBSCO Host and Pubmed databases.

2.2 THE IMPACT OF STROKE

The occurrence of stroke has been identified as a major public health concern, as it is the second leading cause of death and the third leading cause of disability, worldwide (Langhorne, et al., 2011) (World Health Organisation, 2016). Alongside the increased stroke incidence, prevalence and mortality since 1990, strokes result in long-term disabilities and the need for chronic care (Fens, et al., 2014) (Feigin, et al., 2017) (Langhorne, et al., 2011) (Pesantes, et al., 2017). In their Global Burden of Disease, Injuries and Risk study, Feigin *et al.* (2017) specify that there are 25.7 million stroke survivors worldwide, resulting in an estimated 6.5 million deaths and an additional 5 million people who are permanently disabled, annually.

It has been found that early rehabilitation can improve functional outcomes for those with a disability after a stroke, which then reduces the burden of care on informal caregivers (World Health Organization, 2006) (Morreale, et al., 2015). This rehabilitation should include caregiver training, which is essential to prepare informal caregivers to care for the stroke survivor at home, enabling them to better manage disabilities after a stroke.

2.3 DISABILITY AS A RESULT OF STROKE

With the improvement in the medical management and reduction of mortality of stroke survivors over the years, an increased number of stroke survivors are sent home with disabilities (Kalra, et al., 2004) (Schure, et al., 2006) (Watanabe, et al., 2015). Consequently, more stroke survivors with a residual disability require caregivers to assist them with home care (Kalra, et al., 2004) (Schure, et al., 2006) (Watanabe, et al., 2015).

The long-term effects, such as residual disability or the extent of recovery after stroke, depend on the site and size of the initial stroke lesion (Langhorne, et al., 2011). The type and level of disability after having a stroke varies amongst stroke survivors and dictates the amount of assistance they require after discharge from in-patient rehabilitation. Up to a third of stroke survivors living in the United Kingdom (UK) are dependent on an informal caregiver post-rehabilitation, emphasising the need for caregivers (Smith, et al., 2004).

In addition to the physical disabilities, cognitive impairments are evident in 50% of stroke survivors immediately after the stroke, with some impairments resolving over time. The prevalence of cognitive impairments five years post-stroke was found to be 22% and remained as high as 21% 14 years post-stroke (Mellon *et al.*, 2015). These percentages highlight the persistence of cognitive impairments, leading to significantly reduced independence levels after a stroke (Mellon *et al.*, 2015). Alongside the persistence of cognitive difficulties, emotional difficulties have often been found to be more challenging to manage than the physical difficulties that stroke survivors experience (Cameron *et al.*, 2014).

2.4 REHABILITATION FOR STROKE SURVIVORS

Early rehabilitation not only improves health outcomes (World Health Organization, 2006) but also functional outcomes of stroke survivors, including mobility and independence in ADL, instrumental activities of daily living (IADL), leisure participation, return to productive activities and community participation (Morreale, et al., 2015). The functional outcomes of the aforementioned are greatly improved by skills training given to informal caregivers. This training also addresses cognitive, emotional and speech deficits. It is thus essential to involve caregivers in goal setting and discharge planning and even more importantly, provide them with information on prevention and survivor management (Kalra, et al., 2004).

2.4.1 Recovery in rehabilitation

The greatest improvement in functional outcomes occurs when rehabilitation is initiated within the first three months after the stroke has occurred (Kwakkel, et al., 1999).

However, recovery can continue for months (even years) after the initial incident (Herbert, et al., 2016). However, Wang *et al.* (2015) indicate that a plateau in stroke recovery may occur around six months post-onset. Recovery is complex and occurs through spontaneous as well as learning-dependent processes, which include restoring, relearning and compensating for the loss of function (Langhorne, et al., 2011). Thus, both medical and stroke rehabilitation teams aim to achieve the same goal of functional independence on discharge.

2.4.2 Role of the multidisciplinary team

Designated stroke units providing stroke rehabilitation often consist of stroke teams that include physicians, nurses, physiotherapists, OTs, speech and language therapists and therapy assistants, all trained to assist therapy team members (Clarke & Forster, 2015). Clinical psychologists, social workers and dieticians from part of the periphery of the stroke team and assist when a specific need has been identified (Clarke & Forster, 2015). Collaboration between these team members is vital for optimal outcomes of stroke survivors (Clarke & Forster, 2015). Furthermore, better sharing and integration of knowledge, skills and roles within teams improve the rehabilitation outcomes of stroke survivors (Clarke & Forster, 2015).

Although team members share rehabilitation responsibilities, the roles amongst team members differ. For instance, physicians are involved with the medical management and wellbeing of a stroke survivor (Clarke & Forster, 2015). The physiotherapists play a role in improving the stroke survivor’s functional mobility through muscle strengthening, maintaining joint range of motion and improving sensation, specifically proprioceptive and vestibular senses, to improve balance and enable walking (Clarke & Forster, 2015). OTs focus on remediating performance skills or body structures, such as upper extremity control, sitting balance, bed mobility, wheelchair skills and transfers (Clarke & Forster, 2015).

The OT also provides intervention for perceptual and cognitive aspects (De Wit, et al., 2006). Ultimately, the aim is to improve functioning in personal ADL (eating, dressing, grooming and bathing) and IADL (home management tasks and car transfers) (Richards, et al., 2005). Notably, interventions focusing on personal ADL reduce the odds of poor outcomes for stroke survivors (Clarke & Forster, 2015). In addition, OTs aim to facilitate community reintegration and return to productive activity (using public transport, social participation and return-to-work) as well as leisure, since a lack of socialisation with others has been reported by stroke survivors and their caregivers as the greatest deficit one-year post-stroke (Richards, et al., 2005) (Ekstam, et al., 2015).

Alongside the multi-disciplinary team's role in facilitating functional improvement during an in-patient hospital stay, is the responsibility of preparing families to continue with rehabilitation at home. Studies have found that caregivers do not feel prepared to care for their family member in terms of their physical, cognitive and emotional requirements. Informal caregivers, who are usually family members, indicate that they require more information on their responsibilities as caregivers to care for stroke survivors (Thomas & Greenop, 2008) (Ogunlana *et al.*, 2014) (Pesantes, et al., 2017).

Furthermore, both the caregivers and stroke survivors have consistently reported the need for a better understanding of the mechanism, cause and consequence of stroke (Clarke & Forster, 2015). Understanding stroke, its causes, the prevention of secondary complications, as well as obtaining external support for caregivers are aspects suggested to be lacking when caregiver training is provided to informal caregivers (O' Mahony *et al.*, 1997).

2.5 CAREGIVING FOR STROKE SURVIVORS

2.5.1 Informal caregivers

Caregivers can either be professionally trained (and are usually not related to the stroke survivor) or they can be informal caregivers, usually either direct or indirect family members. Informal caregivers are defined as individuals who care for and/or assist a disabled, ill and frail family member, spouse or friend (Moghimi, 2007) (Pierce, et al., 2007).

A point often overlooked is that informal caregivers are mostly voluntary, unpaid individuals who have usually not received any previous caregiver training and often live with the stroke survivors (Reinhard, et al., 2008) (Wang, et al., 2015) (Pesantes, et al., 2017). Therefore, Ogunlana *et al.* (2014) consider informal caregivers to be the most important resource of services available to the stroke survivor (Ogunlana, et al., 2014). In addition, the informal caregiver is usually the key person assisting the stroke survivor in performing ADL, making them important role players in the stroke survivor's daily function (Kalra, et al., 2004; Wang, et al., 2015) (Schure, et al., 2006).

Spouses are generally the main informal caregivers. Although Watanabe *et al.* (2015) found no gender differences in spouse caregivers, Schure's (1996) study in the Netherlands indicated that caregivers are often elderly female spouses of the stroke survivors (Schure, 1996) (Watanabe, et al., 2015). This confirmed Morimoto *et al.* (2003) and McCusker *et al.'*s (2007) findings, namely that more stroke caregivers were female. Conversely, studies by Askosile *et al.* (2009) and Ogunlana *et al.* (2014) found more male caregivers, indicating that caregiver populations vary greatly.

However, the gender of caregivers has not been found to significantly predict the impact of the stroke on the caregivers' well-being (Haley, et al., 2015). In instances where the caregiver is a spouse of the stroke survivor, they will often be older, making physical and mental health important aspects for consideration, particularly regarding their role, function and ability to continue with caregiving as they progress in age (Watanabe, et al., 2015). Caregiver training can significantly reduce the burden placed on informal caregivers by the residual disabilities with which stroke survivors present, alongside the implementation of a patient-centred rehabilitation programme (Morreale, et al., 2015).

2.5.2 The role and function of caregivers

Stroke survivors often depend on caregivers for assistance with not only physical needs but also changes in cognitive and behavioural aspects (Grant, et al., 2004). Caregivers often participate or perform basic ADL for and with the stroke survivor, this includes feeding, dressing, bathing and toileting (National Alliance for Caregiving, 2020). In addition, caregivers do not only perform ADL but IADL, such as transportation, shopping, home- and financial management. Furthermore, medical tasks, such as cleaning catheters, providing medication, tube feeding and wound care are also increasingly being performed by caregivers (Rabow, et al., 2004).

2.5.3 Changes in the roles from family member/friend to caregiver

Informal caregivers often have added responsibilities, which leads to changes in their roles. These changes can include juggling between being the caregiver of a stroke survivor and being susceptible to their own ailments and how to manage these issues (Knecht-Sabres, et al., 2016). Additionally, informal caregivers spend less time on themselves, often suffering occupational deprivation and losing important roles (church member, friend, employee, romantic partnerships) (Knecht-Sabres, et al., 2016).

Furthermore, changes in relationships occur, for example, a partner becoming more like a child, or where a child becomes the responsible parentlike figure, taking care of their parent. Role reversals can also take place, where the caregiver might have been the more vulnerable partner but now needs to be the stronger partner (Thomas & Greenop, 2008).

2.5.4 Caregiver training before discharge

Training is essential to assist informal caregivers in their preparedness and the quality of care that they provide. This is particularly because the long-term outcomes for stroke survivors are dependent on the commitment of their caregivers (Pesantes, et al., 2017). Moreover, training informal caregivers in the daily management of stroke survivors is important in decreasing the burden of care and quality of life of the caregiver (Kalra, et al., 2004).

Correspondingly, poor caregiver training and education by healthcare professionals can exacerbate the burden of care experienced by caregivers, as they do not feel equipped to perform the role (Moghimi, 2007). Thus, empowerment of the caregiver to do their ‘job’ effectively ensures the sustainability of care (Talley & Travis, 2004). Therefore, preparing informal caregivers during the rehabilitation process is not only for the benefit of the stroke survivors but also the caregivers.

Worldwide rehabilitation facilities use various strategies to guide their training of informal caregivers to overcome the challenges faced when the stroke survivors are reintegrated into their homes. Such programmes include several approaches, one of which is Stroke Transition after Inpatient Rehabilitation (STAIR). STAIR is a strategy where home-based care with case management of the stroke survivor and their caregiver are included following discharge from the hospital (Goldberg, et al., 1997).

Another programme used in rehabilitation facilities globally is the Caregiver Mediated Exercise Programme (CME), which trains family caregivers as co-therapists from the admission of the stroke survivor in the rehabilitation programme (Van den Berg, et al., 2016). In the same fashion, Family Mediated Exercise Intervention (FAME) is used and includes family members throughout the rehabilitation process. This extends the available therapy time, which is beneficial to the stroke survivors and practical experience for the caregivers of stroke survivors (Galvin, et al., 2008). Similarly, family-led home-based rehabilitation programmes are programmes where family caregivers receive additional rehabilitation training on basic evidence-based rehabilitation strategies which they should continue at home (Lindley, et al., 2017). A combination of these caregiver training strategies is utilised by RHP to train informal caregivers on assisting ISSs with home reintegration and management of the stroke survivors' residual disabilities.

2.5.5 Outcomes of caregiver training

Lack of caregiver training can lead to increased mortality rates for stroke survivors. A study done in rural SA indicates that stroke survivors, hospitalised for an average of six days, were discharged to informal caregivers (Wasserman, et al., 2009). Two-thirds of these informal caregivers did not receive any stroke education or caregiver training before or at the discharge of the stroke survivor from the hospital. Only 6.7% of the participants were independent at discharge (with mobility, transfers and toileting) and 90% of the stroke survivors were bed-ridden or wheelchair dependant. Although caregiver training was not provided to the majority of caregivers, an increase in functionality was observed by the researchers three months post-discharge, in keeping with spontaneous recovery post-stroke (Wasserman, et al., 2009) (Chen, et al., 2010).

Moreover, the results at three months post-discharge indicated that 40% of the participants mobilised independently, 50% transferred independently and 36.7% performed toileting independently. However, the mean score for the Carer Strain Index was in the moderately severe ranges and the mortality rate among patients who suffered a stroke three months post-discharge was also remarkably high (67%) (Wasserman, et al., 2009). Even though significant improvement in the physical functioning of stroke survivors was observed, without having had caregiver training the caregiver burden and mortality rate of the stroke survivors was high.

2.5.5.1 Outcomes for stroke survivors

Globally, several studies have considered the effectiveness of caregiver training programmes on the outcomes for stroke survivors some months after discharge. The results of outcomes achieved vary depending on the type of programme offered, additional training received and the health care professionals involved in offering training and support (Goldberg, et al., 1997) (Galvin, et al., 2011) (Wang, et al., 2015) (Van den Berg, et al., 2016) (Lindley, et al., 2017) (Sheha, et al., 2020). Considering this, the various studies below that discuss the different strategies used to guide caregiver training and their outcomes are valuable to guide the appropriate use of the various caregiver training strategies.

2.5.5.1.1 Home-based care and rehabilitation

Training of caregivers, as well as the support provided for home-based care and rehabilitation, does not have a significant influence on the length of hospital stay and the mortality rate of ISSs. A control trial study was done in India with 1250 participants, to determine whether family-led home-based rehabilitation (shifting rehabilitation tasks to family caregivers) was effective (Lindley, et al., 2017). In this study, caregivers of stroke survivors in the control group received routine stroke management while caregivers in the intervention group received routine stroke management and additional caregiver rehabilitation training. The additional rehabilitation training was provided by a health care professional in the hospital and continued at home, with six home visits being included. It involved training family caregivers on a simplified version of evidence-based rehabilitation, which included impairment assessment by the healthcare provider, information provision as well as joint goal setting with the stroke survivor and the caregiver.

Furthermore, the training involved ADL, communication, training on limb position, encouraging practising task-specific activities and preparing the stroke survivor and the caregiver for discharge. However, the death rate and dependency of stroke survivors with caregivers in the intervention group did not decrease significantly after the six-month follow-up. In the intervention group, 285/607 (47.0%) participants were dead or disabled compared to 287/605 (47.7%) participants in the control group. The study also found that there was not a reduced length of stay in the intervention group compared to the control group and caregiver burden remained the same between the two groups (Lindley, et al., 2017).

However, other studies have shown that home-based care with caregiver training and a case-management component is effective in improving occupational performance in stroke survivors. The effectiveness of home-based care with a case-management component (STAIR) for stroke survivors returning to their community after receiving inpatient rehabilitation was evaluated in a randomised control trial. In this study, data were collected from 55 participants at one week, three months and six months post-discharge. Positively, a significant improvement in stroke survivor activity level in the intervention group was found (Goldberg, et al., 1997). However, psychosocial functioning and quality of life for stroke survivors in the intervention group was not significantly better and no evidence was found for a reduced rate of reoccurrence of stroke, rehospitalisation and institutionalisation. Caregivers reported that aspects of training that were useful included 'education about strokes and resources' (35%) and 'regular contact with professionals' (25%), as well as 'emotional and moral support provided to the caregivers' (20%). These could potentially be areas for further investigation (Goldberg, et al., 1997).

2.5.5.1.2 Caregiver Mediated Exercise Programmes

CME programmes have a significant effect on the length of stay of stroke survivors, their participation in ADL and the communication- and cognitive abilities of stroke survivors. A study by Van den Berg *et al.* (2016) on caregiver training, using early supported discharge through a CME programme coupled with telerehabilitation services showed the potential to decrease hospital length of stay and readmission to hospital post-stroke. Significant changes in the length of hospital stay were observed, with an average reduction of nine days (Van den Berg, et al., 2016). In a proof-of-concept trial, the eight-week CME programme that started in the hospital also demonstrated improvement of the stroke survivors' participation in ADL, with a significant improvement in the communication- and memory domain of the Stroke Impact Scale (SIS). However, changes in the mobility domain were not significant (Van den Berg, et al., 2016).

Conversely, a significant improvement in stroke survivor strength, mobility and general recovery assessed through SIS was reported by Wang *et al.* (2015). These improvements were observed by the researcher in a randomised control which used a CME programme with additional personalised training for the intervention group in their home. The study completed with 51 participants over a 12-week period, which consisted of three phases; the first stage focused on the body function of the stroke survivors; the second phase focused on improving ADL and the third phase focused on community reintegration of the stroke survivor, through participation in outdoor leisure activities (Wang, et al., 2015).

Moreover, a physiotherapist visited the intervention group once a week for 90 minutes to provide caregivers with rehabilitation skills and skills to assist stroke survivors in performing planned tasks. They also provided individual training guidelines with illustrations and demonstration of exercises. The control group maintained their daily routine and received weekly visits or telephone calls from the physiotherapist, where they discussed rehabilitation progress, ADL and general health conditions but no specific instructions or rehabilitation related guidelines were provided. Since this was a study that only included training from a physiotherapist, it is not surprising that there were no significant changes in ADL/IADL participation. The intervention group, did, however, show significant changes in communication, social and general recovery over time, compared to the control group (Wang, et al., 2015).

Similarly, a single-blind randomised control study by Galvin *et al.* (2011) found that additional family mediated exercises can increase the carryover of physiotherapy sessions for stroke survivors at home. The study consisted of 40 participants randomised into an intervention group, receiving routine stroke management from a physiotherapist with additional lower limb family mediated exercises and a control group receiving routine stroke management from a physiotherapist without formal family input (Galvin, et al., 2011). The programme lasted for eight weeks with additional lower limb family mediated sessions provided daily for 35 minutes. The programme also provided caregivers with the opportunity to practice skills informally with the stroke survivor. Assessments of participants were completed at baseline, post-intervention and at a three-month follow-up and found a significant improvement in balance, mobility and ADL in the intervention group (Galvin, et al., 2011).

2.5.5.1.3 Planned health teaching

Planned education of caregivers improves caregivers’ knowledge and competence to care for stroke survivors after discharge. A study by Sheha *et al.* (2020) consisted of 50 caregivers and 50 stroke survivors, separated into control and experimental groups comparable for socio-demographic characteristics, caregiver education level and monthly income of both stroke survivors and caregivers (Sheha, et al., 2020). Using structured interviews, caregiver knowledge and caregiver competence of home care practice questionnaires were used to collect data from stroke caregivers. The stroke survivors' functional abilities were assessed using the Barthel Index (BI). All participants presented with insufficient score levels concerning their knowledge and practices related to strokes before intervention. Post-intervention, 84% of the experimental group caregivers demonstrated proper knowledge related to strokes and 72% had competence in practices related to strokes. In the control group, however, only 36% of the caregivers demonstrated proper knowledge related to strokes and 32% had competence in practices related to strokes (Sheha, et al., 2020). In addition, a positive correlation between stroke survivor functional ability and caregiver practice were demonstrated (Sheha, et al., 2020).

Thus, the various programs discussed provide detailed information and indicate what caregiver strategies exist, as well as the outcomes of these strategies. This enabled the researcher to relate them to the programme used in the current study.

2.5.5.2 Burden of care

Early active involvement of informal caregivers in the rehabilitation process can potentially reduce "caregiver burden", as rehabilitation provides a social support platform (Karahan *et al.* 2014). Unfortunately, the study did not specify the activities and training that the informal caregivers were involved in during the rehabilitation process. In a randomised control trial to determine the effectiveness of reducing caregiver burden after caregivers received caregiver training, caregivers reported (at three- and six months post-discharge) an improvement in the quality of life and mood of the caregivers. Moreover, regression analyses indicated that providing caregiver training also had a significant effect on caregiver hospital anxiety and depression scores. Thus, training caregivers in mobility and handling skills, facilitating ADL and nursing activities improve quality of life for both stroke survivors and caregivers whilst reducing caregiver burden, thus improving the emotional well-being of caregivers (Kalra, et al., 2004).

When using the CME programmes, caregivers reported increased feelings of self-efficacy with a significant decrease in caregiver burden (Galvin, et al., 2011) (Van den Berg, et al., 2016). In another study, Araujo *et al.* (2018) aimed to determine whether planned education training for practical skills required to provide care for a stroke survivor, can reduce caregiver burden and improve their mental health. Participants consisted of 174 stroke caregivers. The control group received routine stroke management provided at health care units and the experimental group participated in the InCARE programme for one week, one month and three months after the onset of the family members' stroke (Araujo, et al., 2018). They also received telephone support at three-, six-, eight- and ten weeks post-discharge (Araujo, et al., 2018). The InCARE programme included the development of handling techniques for mobility, bathing, (un)dressing, transfers, positioning, eating and drinking in addition to usual stroke management (Araujo, et al., 2018). The experimental group demonstrated significant improvement in practical skills and a decrease in the burden of care compared to the control group. Despite a lack of significant effect on the caregivers' physical health, the experimental group demonstrated improvement in mental health as compared to the control group who demonstrate the opposite (Araujo, et al., 2018).

In summary, CME programmes have a positive influence on stroke survivors' and caregivers' confidence and experience, as well as improvement in stroke survivor functionality. This leads to a reduction in caregiver burden (Galvin, et al., 2011; Sheha, et al., 2020).

2.5.6 Principles of caregiver training

For informal caregivers to i) be involved in the rehabilitation process and ii) better utilise the information given to them during caregiver training, the information should be presented understandably and effectively. In other words, personalised information fitting their circumstances and applied to them should be provided (Hafsteinsdottir, et al., 2011). It was found that an active information session, that encouraged participation from caregivers and stroke survivors, was much more beneficial than a passive information session held only once with no participation or follow-up (Hafsteinsdottir, et al., 2011).

Additionally, caregiver education and training should not only be presented in formal programmes but informally as well, especially when caregivers are present during the stroke survivors in-patient stay - as individual's retain information differently (Herbert, et al., 2016). Van den Berg *et al.* (2016) indicate that structured patient-caregiver interactions through caregiver training are not only beneficial for the stroke survivor but also extend to caregivers' abilities, as families often welcome structured approaches (Van den Berg, et al., 2016). Kalra *et al.* (2004) agree and indicate that using structured caregiver programmes under professional supervision assists in empowering informal caregivers in their future roles by teaching them necessary skills (Kalra, et al., 2004).

Notably, these formal or informal education and counselling interventions should not be limited to information provision but should also include hands-on practice (Schure, et al., 2006). Thus, knowledge should be integrated with intervention programmes and should match the education needs of the stroke survivor and the caregiver (Hafsteinsdottir, et al., 2011). With this in mind, repetition of information might be required but health care professionals often only provide caregiver training mere hours before the stroke survivor is to be discharged (Wilkens, et al., 2001). This can lead to caregiver training being limited to only verbal instructions, with inadequate time to provide an opportunity for practice of the taught skills or even for caregivers to seek clarity on any of the information presented to them (Wilkens, et al., 2001).

Conversely, some caregivers are also frequently sent home with only written information (Grant, et al., 2004). These information leaflets may only be read 2-3 weeks after discharge when caregivers are more willing to change their strategies when initial strategies were unsuccessful (Grant, et al., 2004). Current information booklets were found to be ineffective when providing caregivers and stroke survivors necessary information (Hafsteinsdottir, et al., 2011). Evidence indicates that if information leaflets are given to caregivers, they should be clear, straight forward and consist of concrete suggestions for managing problems (Grant, et al., 2004).

2.5.7 Reports of caregivers on caregiver training received

A systematic review of informal caregivers' reports regarding health care services indicated they felt abandoned due to misalignment of information provided on the stroke survivors' care needs, which change over time. They received inadequate general information about strokes and there was a limited follow-up after discharge with little referral to community-based services (Pindus, et al., 2018). According to caregivers, the rehabilitation programmes post-discharge seemed disorganised and fragmented.

Furthermore, the caregivers indicated that better coordination of rehab services by nurses could benefit their post-hospital rehabilitation journey (Chen, et al., 2015). Several studies (23%) indicated that information provided to caregivers regarding a stroke, its consequences and recovery is insufficient and non-specific. Consequently, caregivers reported that they had to find information by themselves using the Internet or from other caregivers and friends. Often, the information provided was inconsistent and did not cover training from all services (Ski & O'Connell, 2007; Cecil, et al., 2011).

In a study by Almborg *et al.* (2009), 56–68% of informal caregivers reported that they received adequate information and only 33% were satisfied with the information they received. However, more than half (51%) of caregivers indicated they did not receive any information about rehabilitation but 80% reported that the stroke survivors' care and goals for care post-discharge had been discussed with them. The results of the study suggest pre-discharge information and training were not reported as individualised for the caregivers. Implementation of these processes needs to facilitate the caregiver's participation in understanding the impact of stroke on their and the stroke survivors' daily lives and participatory goal setting (Almborg, et al., 2009).

As can be seen below, it is clear that more information and training are needed for discharge and the early weeks at home (Cameron, et al., 2013). Caregivers reported a lack of support from healthcare professionals (due to time constraints on the part of the health care professionals at the time of training), whom they felt assumed that they could provide the majority of care needed with the training received. They still did not feel prepared and reported they were expected to become experts in a very short time, regarding several issues. Lack of information on- and issues regarding caregiving included (Low, et al., 2004) (Talbot, et al., 2004) (Hare, et al., 2006) (Chen, et al., 2015) (Krishnan, et al., 2017):

- Little to no information on routine, organisation and coping mechanisms, as well as specific training in dealing with the stroke survivors' needs;
- Lack of training in accessibility and assistive devices, including mobility devices such as canes, walkers, wheelchairs and safety devices;
- Some caregivers indicated that information was presented too early, leaving them confused;
- Lack of information on the management of specific deficits post-stroke and prognosis, which contributed to hospital readmissions of stroke survivors and added stress to caregivers;

- Stroke survivors' disease process, prognosis, interventions and recovery, as many caregivers felt they were given unrealistic expectations in terms of recovery.

Contrary to the above findings, informal caregivers reported positive outcomes once trained, as they learnt to implement new skills, manage and overcome difficulties and master the difficulties presented by a new role (Greenwood, et al., 2009). In terms of responsibilities, they were able to reciprocate for past caring, provide adequate care that supported the stroke survivors' recovery or prevent further deterioration (Bacon, et al., 2009). They reported that training allowed them to assist the stroke survivors in the resumption of normal activity (Greenwood, et al., 2009).

2.5.8 Homecare and rehabilitation

Caregiver training not only prepares informal caregivers to care for the stroke survivor but also guides them in terms of continuation of home rehabilitation or exercise programmes to (at the very least) maintain the skills gained during rehabilitation and positively impact their cardiovascular risk profile (Mayo, 2016). Langhammer *et al.* (2007) agree and indicate that following such a home programme means that improvement in motor function, ADL and grip strength can be maintained during the first year post-stroke (Langhammer, et al., 2007). Other care needs concerning occupational performance components must be considered. Such needs include interpersonal relationships, community mobility, communication management using phones and computers as well as carrying out leisure activities and employment (Vincent, et al., 2007).

Stroke survivors have many changing needs over time, for which the caregivers need to be prepared. Thus, the level of care the stroke survivor requires at discharge should align with the needs of the stroke survivor at that time, however, the need may decrease/increase if the stroke survivor's functional level improves or deteriorates. Literature reports that aspects such as excretory control, verbal expression, verbal comprehension and the range of their activities may deteriorate with age (Watanabe, et al., 2015). Interestingly, it was found that stroke survivor's ADL, specifically their gait, eating, toileting, dressing and bathing, did not deteriorate over time when given adequate care, even though general ageing of stroke survivors occurred (Mayo, et al., 1999) (Watanabe, et al., 2015).

Additionally, follow up after discharge is important, not only to reassess the physiological stability of stroke survivors but also to follow up on the progression of the home programme - such as functional outcomes and independence at home (Mayo, 2016). Beyond short-term follow-up, a need for longer-term follow-up has been identified, suggesting that stroke survivors should be followed up at six months post-stroke (Clarke & Forster, 2015). Although follow up of stroke survivors post-onset is necessary, the research found that long-term home care for stroke survivors does not seem to continue for longer than 10 years, as only one in five people lives for 15 years post-stroke, often with poor functional, cognitive and psychological outcomes (Watanabe, et al., 2015), (Crichton, et al., 2016).

2.6 BARRIERS AND FACILITATORS TO CAREGIVING

2.6.1 Relationship between caregivers and stroke survivors

The quality of the relationship between the caregiver and the stroke survivor has an emotional impact on the caregiver. Notably, when the caregiving relationship is strained and the caregiver feels mistreated, it is more likely that the caregiver will experience greater emotional distress (Young, et al., 2014) (Pesantes, et al., 2017). Moreover, the relationship of the caregiver to the stroke survivor has a significant effect on the caregiver’s ability to cope with the responsibility of caregiving, initially. Supportive relationships between the stroke survivor and caregivers as well as appreciation from the stroke survivor to the caregiver for what they do creates a positive social environment for both (White, et al., 2007).

Spouses caring for their partner who survived a stroke present with decreased initial stress levels as opposed to non-spousal caregivers, such as children or siblings (Goldberg, et al., 1997). However, non-spousal caregiver stress levels one year post-stroke seem to decrease and are the same as spousal stress levels (Goldberg, et al., 1997). In other words, one year post-stroke, the level of stress among informal caregivers is the same regardless of their relationship to the stroke survivor. Therefore, informal caregivers require support to be able to manage the stress they experience.

2.6.2 Available support structures and burden on caregivers

Coupled with the need for support, caregivers report a positive effect after having contact with other caregivers during support groups (Schure, et al., 2006). Goldberg *et* *al.* (1997) agree and add that stable social support can have beneficial consequences on functional outcomes after a stroke (Goldberg, et al., 1997). Likewise, the need for emotional support for informal caregivers is evident, particularly those caregivers caring for stroke survivors with a lower functional ability (McLennon, et al., 2014).

Improvement in caregiver skill leads to improvement in caregiver self-efficacy, which results in decreased levels of fatigue (Van den Berg, et al., 2016). As alluded to previously, high levels of caregiver burden can threaten the sustainability of home-based care and recovery of stroke survivors (Ogunlana *et al.*, 2014). Caregiver burden describes the level of strain informal caregivers experience when caring for a stroke survivor (Ogunlana, et al., 2014). The greater the severity of disability of a stroke survivor, the higher the burden of care (Scholtz op Reimer, et al., 1998) (Ogunlana, et al., 2014). Mental health difficulties (anxiety, depression and emotional distress) in stroke survivors and the time spent giving care has been positively associated with higher caregiver burden (Rigby, et al., 2009).

Alongside increased levels of caregiver burden, it was found that caregiver quality of life decreases (Ogunlana, et al., 2014). To illustrate this point, the quality of life of a caregiver increases with the improved independence of the stroke survivor in self-care activities, excretory control, transfers and gait (Watanabe, et al., 2015). Coupled with the increased independence of stroke survivors, the provision of caregiver training has also been positively associated with improvement in the quality of life of the informal caregivers (Kalra, et al., 2004). The burden of care for informal caregivers seems to decrease when the caregivers had time away from their caregiving role (having hobbies, for example) (Watanabe, et al., 2015).

2.6.3 Health effects of caregiving on caregivers

Poor mental health, which includes depression, anxiety and emotional distress, was consistently associated with increased burden on caregivers (Rigby, et al., 2009). In light of poorer caregiver health that could result from caregiving, it is important to note aspects of health that could be affected, namely:

- Higher rates of depression (Carnwarth & Johnson, 1987) (Han & Haley, 1999);
- Anxiety (Wade, et al., 1986) (Anderson, et al., 1995);
- Cardiovascular disease (Lee, et al., 2003);
- General ill health (Carnwarth & Johnson, 1987); and

- Mortality (Schultz & S.R, 1999) (Dilworth-Anderson, et al., 2004).

2.6.4 Collaboration with the health care team

High value is placed on timely information, advice, and anticipatory guidance from health care professionals, provided both in hospital and after returning to the home environment and own community (White, et al., 2007). Often, health care professionals do not include stroke survivors or their caregivers in the rehabilitation process, particularly in aspects such as goal setting and decision-making regarding therapy (Young, et al., 2014). This leads to caregivers feeling isolated, further increasing their anxiety levels, especially during the transition from inpatient rehabilitation to home (White, et al., 2007).

2.7 CONCLUSION

The level of participation achieved by stroke survivors on discharge from in-patient rehabilitation may necessitate the need for chronic care, provided for by informal caregivers. Caregiver training is essential to ensure that informal caregivers are well equipped and skilled in providing appropriate long-term care (Pesantes, et al., 2017). Such training ensures sustainable, quality care provided by caregivers (Talley & Travis, 2004). However, the presentation of the caregiver training should be tailored for the caregiver’s requirements. Therefore, attention needs to be given to the training needs of the informal caregivers of stroke survivors (Pierce, et al., 2007). There is a need to determine whether current caregiver training provided at the RHP Rehabilitation Unit at Muelmed Mediclinic is perceived as responsive and adequate by caregivers in ensuring safe reintegration of the stroke survivor into their home.

CHAPTER 3: METHODOLOGY

3.1 INTRODUCTION

In this chapter, the methods and procedures used to conduct this study will be discussed. This includes the specific procedures used to identify, select, process and analyse information in the study and regarding participants.

3.2 STUDY DESIGN

A non-experimental prospective descriptive longitudinal quantitative research study design was used to determine informal caregivers' perception of the effectiveness of informal caregiver training received at RHP Rehabilitation Unit (the Unit). The non-experimental design allows the researcher to look at existing factors and the relationships among these factors, without manipulating the independent variables (Christensen, et al., 2014)(Johnson, 2016). The study was longitudinal as trained informal caregivers were asked to complete a questionnaire on the informal caregiver training at discharge and then again later, after six weeks of home implementation of the informal caregiver training with ISSs. This allowed the researcher to observe change over time (Ployhart & Vandenberg, 2010).

Quantitative research can be used to provide numerical data and insight into aspects that require more in-depth investigation (Meadows, 2003). The goal of quantitative research is to provide a description or picture of a specific situation; in the case of this research project, the perceived effectiveness of caregiver training to informal caregivers at discharge and six weeks later (Christensen, et al., 2014).

3.3 RESEARCH SITE

All ISSs and their informal caregivers were identified and recruited for the study at the Rehabilitation Unit (at RHP, Mediclinic Muelmed Hospital, Gauteng, SA). The Unit provides physical and cognitive rehabilitation for stroke survivors and patients with other neurological and orthopaedic diagnoses. The Unit consists of two wards. The adult neurological ward admits patients with neurological diagnoses including strokes, traumatic brain injuries and tumours. The adult orthopaedic ward admits patients with orthopaedic diagnoses including spinal cord injuries, poly traumas, hip- and knee replacements and general back surgeries. Paediatric patients are also included in the rehabilitation service provided by RHP. However, separate wards do not exist for children, thus all paediatric patients are admitted to the main hospital paediatric unit, which is connected to the Unit.

The Unit consists of 56 beds, of which 36 beds are part of the neurological ward. The average length of hospital stay for stroke survivors is 5.2 weeks. During these 5.2 weeks, caregiver training is completed at least once before the discharge of the stroke survivor. However, informal caregiver training is completed with the informal caregivers when the stroke survivors leave the Unit for a weekend pass-out. Informal caregiver training is completed one to three days before discharge and health care providers aim to present and demonstrate informal caregiver training for at least three sessions. The purpose of caregiver training is to assist informal caregivers to safely care for the ISS while facilitating independence with participation in activities.

However, this is dependent on the availability of informal caregivers. Home and exercise programs are given and discussed with the informal caregivers before or on the day of discharge. Usually, training is arranged by the social worker and presented by the multi-disciplinary team, including the OT, physiotherapist, speech and language therapist, dietician and psychologist (if applicable). Informal caregiver training in the Unit takes on various forms including verbal communication with caregivers, home and exercise programs, demonstration as well as support groups for the informal caregivers to attend (Appendix A).

3.3.1 Outline of caregiver training program for caregivers of stroke survivors at RHP Rehabilitation Unit

The caregiver training program start early in the rehabilitation process and included the multi-disciplinary team. The members of the multi-disciplinary team provided the family of the stroke survivors with written stroke information on admission and requested written consent for therapy and related activities required in the rehabilitation process from the family members of the stroke survivor.

Within the first week or two the social workers at the Unit organised and scheduled a family meeting with the family of the stroke survivor. The meetings were usually attended by the social worker and the key therapist of the ISS, which were either the Physiotherapist, OT or Speech and language therapist. Key members of the ISSs family likely to be involved in the long-term care of the stroke survivor were included in the family meeting. The goal of the meeting were to discuss and provide information on the stroke survivors current condition, the rehabilitation plan as well as to start with discharge planning with the family.

Every two weeks family caregiver training in the form of question and answer sessions, were held. It included the informal caregivers attending educational groups without the ISS being present and consisted of various topics important for discharge, being covered by various members of the multidisciplinary team. One week before discharge all members of the multi-disciplinary team provide individual caregiver training to the caregiver with the ISS present. Caregiver training are done on the day of discharge to recap everything done by therapy team and a home program are given. Furthermore training from nursing staff, dieticians etc were also finalised. ‘

Caregiver training with all members of the multi-disciplinary team, were done with the family of the ISS before a weekend pass to ensure safety of both the ISS as well as the caregiver. The caregiver training include all performance areas, physical abilities like mobility and transfers, the use of assistive devices if used by the ISS as well as cognitive and behavioural aspects required for short term home reintegration. Continues contact with caregivers either by phone or face to face were done by the social workers on a weekly basis. Which included follow up on how weekend out went, carer identification or other thing relative to discharge planning. Lastly Stroke Support groups are held monthly with all stroke survivor as well as caregivers of stroke survivors to ensure home reintegration.

3.4 POPULATION AND SAMPLING

The study population consisted of informal caregivers of ISSs, namely one informal caregiver per ISS, who was to be discharged after a period of inpatient rehabilitation from the Unit, as is the case for all patients. Non-probability convenience sampling was used to find prospective participants and select a sample from the stroke population. Convenience sampling of the stroke survivors who were admitted with their first-ever stroke incident allowed for the identification of the target population of informal caregivers. Severe stroke survivors were excluded, as the discharge recommendation would likely be that they require residential placement or formal caregivers. If these recommendations were not followed, the burden of caregiving is expected to be higher for informal caregivers, which would affect the results of this study. Furthermore, this sampling method was used to accommodate for time and workforce limitations within the setting, as the researcher and therapy assistant were the only people administering the research questionnaire (Etikan & Musa, 2016). Convenience sampling thus allowed for easy access to the sample population for both the initial and follow-up interviews.

3.4.1 Sample size

The sample size of the study was determined by using a survey sample size table, as created by Bartlett *et al.* (2001). Recorded stroke survivors discharged from the Unit between the periods of August 2016 to January 2017, whose caregivers received training before their discharge, was used to determine the sample size. A total of 87 stroke survivors were discharged from the Unit during this time. Based on Cochrane's formula (with the confidence interval set at 95% and a 5% margin of error), the sample size was calculated to be 55 informal caregivers.

It was initially estimated that a total population sample for six months would be used in the study. However, due to decreased number of admissions, thus decreased the number of discharges from the Unit, the period to collect the total population sample was extended to 14 months.

3.4.2 Selection criteria

Inclusion Criteria	Exclusion Criteria
• Caregivers of ISSs discharged from acute rehabilitation over 14 months • Informally trained caregivers • Caregivers of all genders • Caregivers older than 18 years • All informal caregivers of ISSs with or without cognitive, perceptual and speech difficulties (patient information	• Stroke survivors discharged to care or residential facilities • Caregivers of stroke survivors with prior formal caregiver training • Caregivers of ISSs where the stroke survivor has a neurological diagnosis other than stroke

sheets distinguish between these aspects and used in data analysis)	• Caregivers with major debilitating diseases themselves, such as dementia • Severe level ISSs according to SADFM® (Beta) Score of less than 22

3.5 RESEARCH INSTRUMENTS

Three different research instruments were used in this study:

1. The SADFM® (Beta) Scale: Used to determine inclusion criteria;
2. A demographic questionnaire: To gain demographic information of both the informal caregivers and the ISSs; and
3. A caregiver questionnaire: Used to get data about the perceived effectiveness of caregiver training provided at the Unit.

3.5.1 The South African Database for Functional Measures (SADFM®) Beta Scale

The Unit's interdisciplinary neurological rehabilitation team uses the Beta Scale (Appendix C) weekly. It is used to determine the progress of patients with neurological conditions, including stroke survivors. The tool determines the patient's burden of care and assists with discharge planning in terms of placement in facilities, the need for caregivers or independent return to the home environment (Loubser, et al., 2013). Scores related to the level of disability and amount of assistance required with ADL and is therefore a better nursing tool, than a rehabilitation measure. In this study, the Beta Scale was used to determine the severity of the burden of care for the inclusion or exclusion criteria of stroke survivors in the study. Stroke survivors who scored 23 and above were included in the study.

The Beta Scale consists of 18 items divided into 13 motor items and five cognitive items. These items are further divided into smaller components, which include:

- Selfcare Assessment (eating, grooming, bathing, dressing the upper body, dressing lower body and toileting);
- Sphincter Control Assessment (bladder and bowel management);

- Transfers (bed/chair/wheelchair transfers, toilet transfers and bath/shower transfers);
- Locomotion (walking/wheelchair and stairs);
- Communication (comprehension and expression); and
- Social Cognition (social interaction, problem-solving and memory).

Each component is scored between one and seven, according to the stroke survivors' level of independence when performing these tasks. One is completely dependent on assistance and seven is completely independent of assistance (Loubser, et al., 2015).

The construct validity of the Beta Scale was compared to that of the Rash Model, to determine whether the Beta Scale can be used as an interval scale, which provided metric and interval data (Loubser, et al., 2015). It was found that the Beta Scale compared very well to the Rash Model and thus could be used as an interval measure to evaluate change in patients' ADL (Loubser, et al., 2015).

3.5.2 Demographic information

A demographic questionnaire (Appendix B) was compiled and administered by the researcher herself, to ensure adequate completion and to assist with clarification where necessary. The demographic questionnaire was aimed at obtaining general information regarding the informal caregiver and the ISS. It was administered through a semi-structured interview. The demographic questionnaire aimed at the informal caregiver included aspects such as gender, age of the caregiver, marital status, relationship to the ISS, level of education and years involved in education, employment status and occupation of the informal caregiver, as well as prior experience and training as an informal caregiver.

The demographic questionnaire aimed at the ISS included aspects such as gender, age of the stroke survivor, type of stroke and comorbidities before the stroke, date of onset of the stroke as well as the length of stay at the Unit. It also included questions regarding daily functioning before the stroke, the highest level of education and years involved in education, employment status and use of assistive devices prior to the stroke. Lastly, the SADFM® (Beta) Scale Scores (hereafter the Beta Scale) were also recorded to determine whether the ISS could be included in the study according to the exclusion criteria.

3.5.3 Caregiver training questionnaire

The caregiver training questionnaire (Appendix D) was compiled by the researcher based on the literature of previous studies investigating the perceived effectiveness of informal caregiver training. This was used to determine how effective informal caregivers perceived the training to be, as provided by the multidisciplinary team of the Unit. Further, a safety concerns document and discharge-training document developed by staff from the Unit (Appendix E) was used to compile the caregiver-training questionnaire. The aspects of the safety concerns document that was included in the questionnaire consisted specifically of occupational therapy-related aspects, such as the amount of assistance required to perform transfers to and from the wheelchair, bath/ shower transfers, dressing, eating, toileting, grooming tasks and equipment with which the stroke survivor was discharged.

The questions were focused on the perceived challenges and successes by the informal caregivers when caring for the ISS after they had received informal caregiver training. The questions further allowed the participants to identify both their perception of the strengths and areas for improvement in the informal caregiver training they received. Furthermore, the participants were asked to provide recommendations for improvements to the training.

The initial questionnaire consisted of 12 close-ended questions, 19 scaled questions (set parameters), two questions wherein participants needed to elaborate on a subject and eight open-ended questions. The caregiver questionnaire was administered through a semi-structured interview with the informal caregiver, as was the follow-up questionnaire.

The follow-up questionnaire had similar questions but was directed at the participants in the past tense. It included five extra questions to determine whether the informal caregivers of the ISS perceived the need to find additional information on providing care for the ISS. These questions also determined where they sourced the additional information from, as well as whether the informal caregivers felt there was a need to attend further training. The caregivers were required to elaborate on where they continued with training (if they did) and which health care professional provided the training.

3.6 RESEARCH PROCEDURE

3.6.1 Pilot study

The caregiver-training questionnaire was piloted for content validity by three expert OTs working in the neurology rehabilitation field, as well as two informal caregivers caring for people with disabilities. Furthermore, content validity was tested by discussing demographic and caregiver questionnaires with three informal caregivers that could be part of the inclusion criteria of this research; however, they were not included in the study. The discussion related to these questionnaires focused on the use of language to ensure caregiver participants would be able to understand what the researcher was asking.

The pilot study highlighted aspects in the demographic questionnaire that, according to the three therapists, were missing. Stroke survivor occupation before the stroke, comorbidities as well as a history of substance use were aspects that were included following the pilot study, as recommended.

The pilot study also highlighted aspects that were missing from the caregiver-training questionnaire, such as the use of the equipment at discharge and continued use of equipment at the six-week follow-up. It indicated that a distinction between upper and lower body dressing needed to be made. Moreover, it highlighted that some questions required elaboration, specifically when asking how often caregiver training was attended, to obtain further detail on reasons that the caregiver training could not be attended more frequently. The pilot study also indicated that questions needed to be addressed more personally to the participants.

Aspects needed to be broken down to make the questions more understandable and easier for the participants to answer. This was done to obtain a broader perspective regarding the questionnaire, how applicable it was to the outcomes of the research project and to ensure that language used in the questionnaire was simple and appropriate for the target population.

3.6.2 Training of research assistant as an interpreter

After the demographic and caregiver training questionnaires were finalised, a therapy assistant was trained as a research assistant and interpreter. Before the study commenced, the interpreter was provided with information on the purpose of the study as well as the importance of relaying the information exactly as the researcher provided it to the participant and vice versa.

Training of the research assistant included discussion of the questionnaires with the written questionnaires available and written instructions on the order in which the questionnaires needed to be completed. Additionally, the importance of discussing the questionnaires with the participants and not merely providing them with the written document to complete in their own time was emphasised. The training was done twice for 30 minutes with written information and instructions provided to the research assistant.

3.6.3 Data collection

Data collection was done by the researcher through semi-structured interviews with the informal caregivers of the ISSs. The questionnaires consisted of mostly set questions with set parameters to ensure better test reliability as participants could only choose from the parameters given, however the opportunity to elaborate through comments were given to the participants. Thus whether the researcher or therapy assistant conducted the semis-structured interview, questions had to be relayed to participants as indicated on the questionnaire. The data collection, however, was not blinded since the researcher was involved in the department where data collection occurred. Occasionally, the therapy assistant would complete the interviews if a language barrier existed or where the researcher provided informal caregiver training to the caregiver participant. The therapy assistant was never involved in therapy with the stroke survivors, as she holds an administration post at the Unit.

When the researcher requested participation from the informal caregivers, she explained that participation in the study was voluntary and that the study was strictly confidential. Furthermore, she made it clear to the participants that truthful answers were required to improve the service and their input would not affect ongoing therapy to the stroke survivors, in an attempt to limit bias.

Moreover, data collection occurred on the day of discharge after all informal caregiver training and treatment of the ISS were concluded, just before the ISS and informal caregiver left the hospital premisses. Thus, no further action could be taken by either the staff of the Unit or informal caregivers concerning the ISSs' therapy at that stage.

Similarly, all follow-up data were collected by the researcher, on-site and telephonically, thus data remained confidential from other RHP staff members. The researcher again made sure to highlight the confidentiality of the study and the need for truthful responses. Logistically, another person couldn't collect the data due to time constraints and practicality at the Unit. However, it was felt that the time-lapse of six weeks in the study design allowed participants to understand and provide valid information about the informal caregiver training they received. However, the data collection may not have completely excluded bias, although informal caregivers of the ISSs had no contact with the therapists who provided their training six weeks before.

Data collection and capturing was carried out over an extended 14-month period. Despite the extension of the period to obtain the sample population from six months to 14 months (data were collected from August 2018 – October 2019), the sample size of 55 was not obtained during that time. This was due to various factors, such as a decrease in the number of ISSs admitted to the rehabilitation hospital.

The reason for the decrease in admissions may be as a result of increased financial constraints as well as increased control measures imposed by medical aids. Medical aids tend to restrict the number of patients admitted for in-patient rehabilitation. Some of the informal caregivers who were approached also declined the invitation to participate in the study, even after the confidentiality of the study was explained to them. The availability of study participants to complete initial interviews telephonically within the first day or two after discharge was also difficult, as many possible participants indicated that they did not have time to complete the interview, despite it being completed telephonically. Often, the informal caregivers seemed overwhelmed with the added responsibility of answering questions related to the informal caregiver training provided at the Unit and thus rejected the invitation to participate in the study.

The researcher also experienced time constraints in terms of conducting initial interviews with possible participants on the day of discharge after they receive final informal caregiver training. This is because all patients are required by Medi-clinic Muelmed Hospital to leave the premises before noon.

Potential study participants were identified one week before the discharge of the ISSs during the weekly RHP rehabilitation neurology team meetings. The identified participants were contacted either telephonically and/or face-to-face, depending on their availability. The purpose of the study and the study procedure was explained to both the informal caregivers and the ISSs. Written information on the study, in English, was also provided along with a consent form that was completed before the study interview commenced. If information was requested or a need for translation was identified, the research assistant from the department translated for the informal caregiver as well as the ISS. Signed consent to participate in the study was obtained from each participant, with all responses documented on a written informed consent form.

The initial caregiver training questionnaires were mostly administered on the day of informal caregiver training, which usually takes place on the day of discharge. This was done in a private room in the therapy department of the Unit without the ISS present, to preserve the relationship between the informal caregiver and ISS, as well as to ensure the accurate provision of information. Telephonic interviews were also held with informal caregivers who were not available to complete the initial interview face-to-face. This was due to time constraints, owing to i) the lengthy discharge administration at the hospital and ii) allowing therapists time to finalise informal caregiver training on the day of discharge. In such instances, the interviewer scheduled a time with the participants that would suit them better.

The follow-up questionnaire was conducted with the informal caregivers at the ISSs' six-week outpatient follow-up visit to the Unit in the same manner as the initial questionnaire. However, most follow-up interviews were conducted telephonically and done at times suitable for the informal caregiver, commonly during the evenings. Where the researcher was involved in the informal caregiver training, the trained therapy assistant administered the questionnaire to prevent a conflict of interest, limit interviewer and response bias and to ensure a true reflection of the informal caregivers' perception of the training as provided by the neurology team. Where further caregiver training was requested by the informal caregivers, or identified as a need, referrals to community-based OTs were made.

Participant responses during structured interviews were recorded in writing on pre-set questionnaires. A number code was allocated to each questionnaire to ensure anonymity. Responses from the demographic questionnaire, initial caregiver training questionnaire and follow-up questionnaire were captured electronically in Excel. Thereafter, figures and graphs were compiled to interpret the data collected on the spreadsheets.

3.7 DATA ANALYSIS

The demographic data were summarised using frequencies and percentages for the population sample as obtained from the initial interview, upon discharge of the stroke survivor from the Unit. Frequencies were used to analyse the data from the caregiver training questionnaire and these were presented in tables and graphs. Allowance for comparison between percentages obtained at discharge and six weeks later was achieved by establishing the change in the responses of caregiver participants answering the questions. To determine the significance of these differences, chi-squared tests were used and calculated using Statistica v13.2. Significance was set at 0.05.

3.8 ETHICAL CONSIDERATIONS

3.8.1 Autonomy

A research information sheet (Appendix H) was given to each participant before the initial interview, inviting potential participants to the research study. It provided information on the aim of the study, namely to determine the perceived effectiveness and gaps in training provided at the Unit. Correspondingly, the research information sheet provided information on the duration of the data collection, which included two interviews. The initial interview was performed at the discharge of the ISS from the hospital and the second approximately six weeks later, after integration into the home environment. It explained that the interviews would be carried out with the informal caregiver separate from the ISS and would take approximately 45 minutes to complete. The interview consisted of a questionnaire with set parameters and occasional open-ended questions to obtain more information on the informal caregiver's perception of the training they received.

The written informed consent form (Appendix I) consisted of the title of the study, a short paragraph of who the researcher is and the aim of the research study as indicated in the research information document. In the same way as the research information sheet, the informed consent gave a brief highlight of the duration of the study and the research procedure of having two interviews done through the completion of a questionnaire with set parameters.

The research information sheet further provided information on voluntary participation without consequence if withdrawal should occur. The informed consent form also provided the contact details of the researcher as well as the chairperson of the Human Ethics Research Committee (medical) of the University of Witwatersrand, Johannesburg.

3.8.2 Veracity

Contact details of the researcher, the research supervisor as well as the chairperson of the Ethics Committee of the University of Witwatersrand was provided in the research information sheet. It indicated that the project was approved by the Human Ethics Research Committee (medical) of the University of Witwatersrand, Johannesburg. Participants were free to contact any of the ethics committee members if they felt the research did not meet ethical standards and the researcher had not presented a true reflection of the study.

3.8.3 Confidentiality

Ethical considerations included in the research information sheet were how the confidentiality of information would be maintained. In other words, all documentation related to the research study would be kept on the hospital premises in a locked cabinet and all names of participants would be substituted with codes. Another key point included in the ethical considerations discussed in the research information sheet was withdrawal from the research study. Withdrawal from the research study could be done at any time, without consequence. A confidentiality agreement was included in the informed consent form and participants were made aware of it before the interview commenced. The electronic Excel spreadsheet was saved on a personal laptop, which is password protected.

Finally, the participant’s name, identity number and contact details were requested, with their signature and date as well as the signature of a witness observing them sign the written informed consent form. This was in no way linked to their actual questionnaire, to maintain anonymity.

3.8.4 Beneficence

The research information sheet discussed the possible benefits of participating in the study. Whilst participating in the research study, if the need for further caregiver training was indicated, it was provided and referrals were made to a community OT that would assist the caregiver at home. Equally important is that no physical discomfort, side effects or possible risks for participating in the research study could be identified for the potential participants.

3.8.5 Ethical clearance and permission to perform research study

Ethical approval was obtained from the Human Research Ethics Committee of the University of the Witwatersrand, with clearance number M170930 (Appendix F). Written permission to perform the study from the CEOs of all involved institutions or parties was obtained before the research study commenced (Appendix G). Parties involved included Mediclinic Muelmed Hospital; Rita Henn and Partners; Dr Terry and Associates; Marelise De Wet and Associates and Charis psychological services.

CHAPTER 4: RESULTS

4.1 INTRODUCTION

During this research study, 31 participants took part in the initial interview and completed the demographic and initial caregiver training questionnaire. The follow-up interview consisted of 19 participants who also completed the follow-up caregiver-training questionnaire. Thus, the response rate for participation in the follow-up questionnaire is 61%.

This chapter will first discuss the demographic information collected, starting with the informal caregivers of ISSs. It will then look at the ISSs' demographic information, to demonstrate the possible burden of care and informal caregivers' perceptions. The chapter will continue to discuss the informal caregivers' perception of caregiving and awareness of strokes.

Further evaluation of the informal caregivers' perceived effectiveness of the caregiver training on discharge will be discussed in this chapter. The usability of informal caregiver training, approximately six weeks post-discharge after home reintegration of the ISS will also be examined.

4.2 DEMOGRAPHIC INFORMATION

4.2.1 Caregiver demographics

Table 1 indicates that over 70% of the caregiver participants were female, with a distribution between the three working adult age groups being similar. Notably, the number of caregiver participants decreases as their age increases. A similar percentage of participants were in the working adult age groups (30 – 59 years), however, the percentage of caregiver participants was lower for the elderly age groups (60 – 79 years) and much lower for participants in the young adults' age group (18 – 29 years).

The majority of the caregiver participants were married. More than half of the participants indicated a spousal relationship to the ISSs, of which 41.9% were wives to the ISSs. Of the remaining participants, one indicated to be the ISS's fiancé, two were mothers, one was a mother-in-law, four were daughters, two were sons and one was a sister-in-law.

Table 1: Demographics of caregiver participants (n=31)

		n	%
Gender	Male	8	25.8%
	Female	23	74.2%
Age groups- years	20 - 29	1	3.2%
	30-39	8	25.8%
	40-49	7	22.6%
	50-59	7	22.6%
	60-69	5	16.1%
	70-79	3	9.7%
Marital status	Married	23	74.2%
	Single	4	12.9%
	Divorced	0	0
	Live together	4	12.9%
Highest level of education	Primary school	1	3.2%
	Secondary school	4	12.9%
	Matriculated	7	22.6%
	Diploma	12	38.7%
	Trade	2	6.5%
	Degree	5	16.1%
Duration of education	6-10yrs	4	12.9%
	11-15yrs	18	58.1%
	16-20yrs	9	29.0%
Employment status	Work full time	16	51.6%
	Work part-time	3	9.7%
	Not applicable	12	38.7%
Location	Urban area	17	54.9%
	Semi-urban area	9	29.0%
	Rural area	5	16.1%

Half the caregiver participants live in an urban area while 29.0% live in a semi-urban area and 16.1% live in a rural area. More than 50% of the participants had post-secondary training at a diploma, trade and degree level, with less than 16% of participants having an education level lower than matric; 22.6% of the caregiver participants have matriculated. Thus, more than half the participants had between 11-15 years of education.

Half of the caregiver participants indicated that they worked full time while just under 40% indicated employment status was not applicable since these caregiver participants were unemployed (19.4%), pensioners (16.1%) and housewives (3.2%), Only three participants worked part-time.

4.2.2 Index stroke survivors' demographics

Table 2 indicates that a greater percentage of the ISSs (58.1%), were male with an age distribution between two age groups being similar (age group 50-59 and age group 60-69). These age groups comprise more than half (58.1%) of the population. In addition, more than two-thirds of the ISSs were between 40 and 69 years of age, with an age range from 26 to 84 years. Two-thirds of the ISSs hold a diploma as their highest level of education, while those with a trade or a degree made up 74.2%.

Table 2: Demographics of ISSs (n=31)

		n	%
Gender	Male	18	58.1%
	Female	13	41.9%
Age groups- years	20-29	2	6.5%
	30-39	2	6.5%
	40-49	5	16.1%
	50-59	8	25.8%
	60-69	10	32.3%
	70-79	3	9.7%
	80-89	1	3.2%
Highest level of education	No formal schooling	1	3.2%
	Secondary school	2	6.5%
	Matriculated	5	16.1%
	Diploma	8	25.8%
	Trade	6	19.4%
	Degree	9	29.0%

4.2.2.1 Medical history and functional status of ISSs

Table 3 indicates that more than half of the ISSs had an ischaemic stroke (54.8%), with the most common comorbidities being hypertension (48.4%), diabetes (29.0%) and cardiac conditions (25.8%). The length of hospital stays for the ISSs was generally between 5-8 weeks (67.7%).

Before having the stroke, the majority of ISSs (87.1%) were actively participating in ADL, where 71.0% participated in productive activity, which included work. Furthermore, 16.1% of the ISSs were previously active members of their communities.

Table 3: Medical history and pre stroke functional status of patients (n=31)

		n	%
Type of stroke	Ischaemic stroke	17	54.8%
	Haemorrhagic stroke	8	25.8%
	Not specified	6	19.4%
Comorbidities	No known comorbidities	6	19.4%
	Cardiac conditions	8	25.8%
	Cholesterol	4	12.9%
	Diabetes	9	29.0%
	Epilepsy	1	3.2%
	Hypertension	15	48.4%
	Previous TBI	1	3.2%
Length of stay in the hospital:	2-4 weeks	8	25.8%
	5-8 weeks	21	67.7%
	9-15 weeks	2	6.5%
Pre-stroke functioning	Productive work	22	71.0%
	Community participation	5	16.1%
	Perform home tasks only	4	12.3%

4.3 CAREGIVER PARTICIPANTS' PERCEPTION OF CAREGIVING AND AWARENESS OF STROKE AT DISCHARGE

Table 4 indicates that the majority of caregivers participants (74.2%) had no prior experience as caregivers. However, it is important to note that generally informal caregivers either perceived that they had 'no experience' (74,2%) or 'a lot of experience' (16.1%) with caregiving. Most caregiver participants (80.6%) indicated that they had never received any prior caregiver training and where caregiver training had been received, it was informal training through their work as caregivers (9.7%) or through previously looking after a family member (6.5%). Nursing staff (9.7%) were sighted as having provided the training to caregivers.

Table 4: Caregiver participants' perception of caregiving and knowledge of impairments in stroke, specifically the ISS they take care of (n=31)

		N	%
Prior experience as a caregiver	No prior experience as a caregiver	23	74.2%
	Little experience (less than 3 months)	1	3.2%
	Moderate experience (less than a year)	2	6.5%
	A lot of experience (more than 1 year)	5	16.1%
Previous training as a caregiver	Yes	6	19.4%
	No	25	80.6%
Training received	Not applicable	26	83.9%
	Training through work	3	9.7%
	Looking after a family member	2	6.5%
Provider of caregiver training	Doctor	1	3.2%
	Other health care professionals	1	3.2%
	Nurse	3	9.7%
Knowledge of what is wrong with the stroke survivor	Know exactly	15	48.4%
	Have some idea	15	48.4%
	Don't know at all	1	3.2%

Table 5 indicates that a small number of caregiver participants (3.2%) did not know what was wrong with the ISS at all. Of the remaining caregiver participants, nearly half of the caregiver participants indicated that they knew exactly what was wrong with the ISS while the other 48.4% had some idea of what was wrong with the ISS.

4.4 EVALUATION OF CAREGIVER TRAINING ON DISCHARGE

4.4.1 Caregiver participants perceived understanding of stroke information

The first section of the questionnaire dealt with the caregiver participants' understanding of the training, how it was presented to them and any additional sources of information that they may have accessed. Participants were permitted to select more than one option so the n-value for some questions is greater than 31.

On discharge, while almost one-third (32.4%) of caregiver participants indicated they only understood a little bit of the information given during informal caregiver training. The same percentage of caregiver participants indicated they understood all of the information (Figure 1).

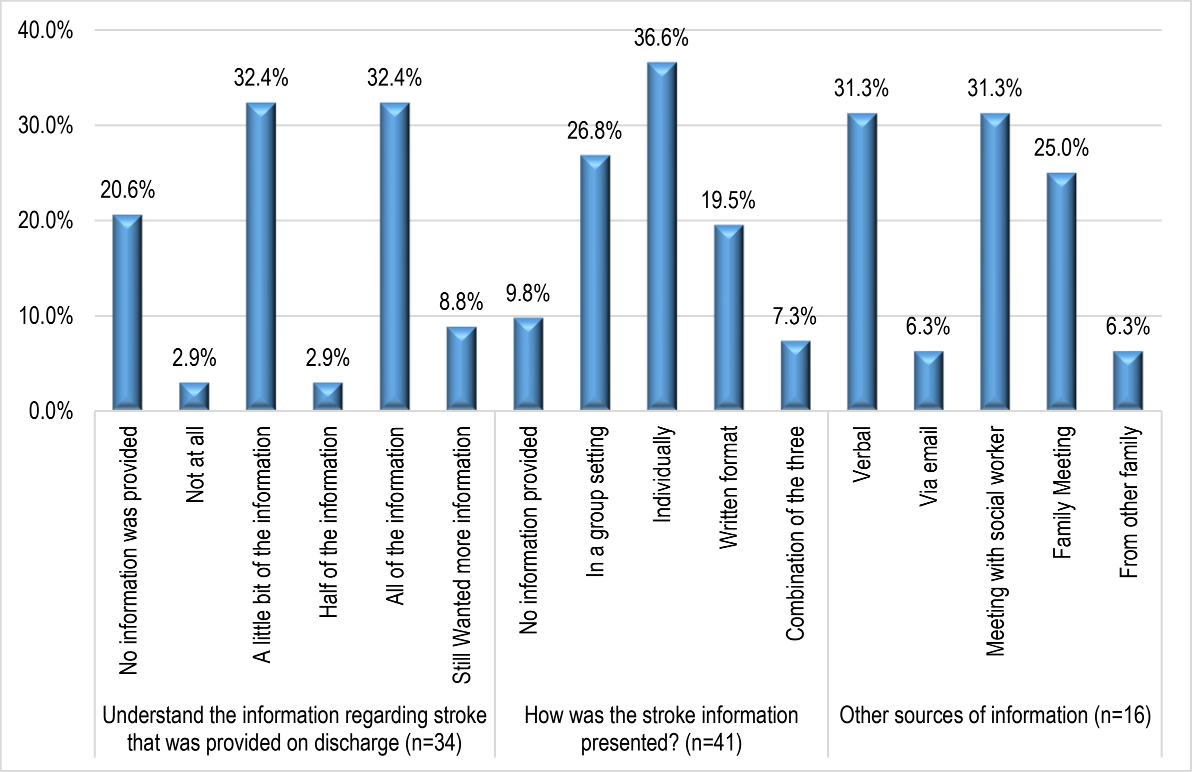

Figure 1: Understanding and presentation of twining at discharge (n=31)

It is concerning that 20.6% of caregiver participants felt they had received no information on strokes. Informal caregiver participants indicated receiving additional information from a wide range of alternate sources at this stage to supplement the information.

Most commonly, the informal caregiver training was done individually and presented in a written format to the informal caregiver. Group training was used with just over a quarter (26.8%) of the informal caregivers and a combination of methods was indicated as used less than 10% of the time.

4.4.2 Perceived caregiver competency related to specific components of functionality after training and assistance required by ISSs on discharge

Informal caregivers received informal caregiver training if the ISS was not independent in transfers, personal hygiene, dressing, toileting, bathing and eating. Informal caregivers were asked to indicate their competency with caregiver training according to these categories of ADLs. Some indicated their ISS was independent, so they did not receive informal caregiver training, while others indicated they were comfortable or uncomfortable with assisting the ISS, could not assist them or did not receive training.

4.4.2.1 Transfers

Informal caregivers indicated (Table 5) that during informal caregiver training, less than half of the ISSs (35.5% for both wheelchair transfers and toilet transfers and 25.8% for car or taxi transfers) were independent. The informal caregivers of these ISSs did not require informal caregiver training on transfers at discharge. For the rest of the ISSs, most informal caregivers indicated that they were comfortable with transferring the ISS to a wheelchair (51.6%), toilet (38.7%) and car or taxi transfers (48.4%) after informal caregiver training was provided.

However, after informal caregiver training, 6.4% of caregiver participants indicated that they performed wheelchair transfers as well as toilet transfers but were not comfortable in doing so. A further 3.2% of the informal caregivers indicated that they performed car or taxi transfers but were not comfortable with the task after informal caregiver training was provided. Furthermore, after informal caregiver training was provided on toilet transfers, 3.2% of the caregiver participants indicated that they were unable to perform toilet transfers and 3.2% indicated that they still require assistance for toilet transfers, as well as car and taxi transfers. The informal caregivers' perception included that informal caregiver training on wheelchair transfers was not provided to 6.4% of the informal caregivers, while 12.9% of the informal caregivers indicated not to have received training on toilet transfers and 19.4% of the informal caregivers did not receive training on the car or taxi transfers, altogether.

On discharge, ISSs had improved and 54.8% of the informal caregivers of ISSs indicated they did not need to assist the stroke survivor with either transfers to the wheelchair or a toilet on discharge. However, assistance with transfers to and from a car or taxi was required.

Table 5: Caregiver competence after informal caregiver training and assistance required by ISSs on discharge

		Transfers to and from the wheelchair		Transfers to and from the toilet		Transfers to and from a car/taxi		Toilet hygiene		Managing clothing after toileting		Bathing		Using assistive devices for bathing		Grooming		Dressing and undressing upper limbs		Dressing and undressing lower limbs		Eating	
		n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
After caregiver training	Stroke survivor independent	11	35.5%	11	35.5%	8	25.8%	16	51.6%	12	38.7%	10	32.3%	10	32.3%	16	51.6%	13	41.9%	11	35.4%	16	51.6%
	It was not shown to me	2	6.4%	4	12.9%	6	19.4%	5	16.1%	6	19.4%	8	25.8%	10	32.3%	8	25.8%	6	19.4%	6	19.4%	9	29.0%
	Unable to perform	0	0	1	3.2%	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Require assistance	0	0	1	3.2%	1	3.2%	0	0	0	0	1	3.2%	1	3.2%	0	0	0	0	0	0	0	0
	Perform transfer but uncomfortable	2	6.4%	2	6.4%	1	3.2%	0	0	0	0	1	3.2%	1	3.2%	1	3.2%	0	0	0	0	1	3.2%
	Comfortable with the transfer	16	51.6%	12	38.7%	15	48.4%	10	32.3%	13	41.9%	11	35.4%	9	29.0%	6	19.4%	12	38.7%	14	45.2%	5	16.1%
Require assistance on discharge	Yes	12	38.7%	12	38.7%	17	54.8%	7	22.6%	8	25.8%	18	58.1%	14	45.2%	6	19.3%	8	25.8%	12	38.7%	3	9.6%
	No	17	54.8%	17	54.8%	13	41.9%	23	74.2%	19	61.3%	11	35.4%	17	54.8%	21	67.7%	17	54.8%	15	48.4%	22	71.0%
	Sometimes	2	6.4%	2	6.4%	1	3.2%	1	3.2%	4	12.9%	2	6.4%	0	0	4	12.9%	6	19.4%	4	12.9%	6	19.4%

4.4.2.2 Toileting, managing clothing, bathing and using assistive devices and caregiver training done

Informal caregivers indicated (Table 5) that during informal caregiver training less than half of the ISSs (32.3% for both bathing and using assistive devices for bathing and 51.6% for toileting and 38.7% for managing clothes when toileting) were independent. The informal caregivers of these ISSs did not require informal caregiver training on these aspects. Other informal caregivers indicated that toileting (16.1%), managing clothing after toileting (19.4%), bathing (25.8%) and how to use assistive devices for bathing (32.3%) were not part of the informal caregiver training. A small percentage (3.2%) of the informal caregivers indicated that they still require assistance with bathing activities and using assistive devices even after informal caregiver training was provided. A further 3.2% of the informal caregivers indicated that even though they perform bathing and use assistive devices during bathing, they are not comfortable with these tasks. The remaining larger portion of informal caregivers indicated that they were comfortable with toileting (32.2%), managing clothing after toileting (41.9%), bathing (35.4%) and how to use assistive devices for bathing (29.0%).

At discharge, more than half of the ISSs did not require assistance with toilet hygiene (74.2%), managing clothing (61.3%) and using assistive devices for bathing (54.8%). However, for bathing, more than half of the ISSs (58.1%) still required assistance from the informal caregiver. Almost a quarter of ISSs (22.6%) still required assistance with toilet hygiene and with managing clothing after toileting (25.8%). Lastly, when using assistive devices for bathing, 45.2% of ISSs required assistance from their informal caregivers (Table 5).

4.4.2.3 Grooming, dressing and eating

Table 5 shows that the informal caregiver participants indicated that 51.6% of the ISSs they are caring for were independent with grooming and thus training was not required. Of the participants, 19.4% indicated that they were comfortable with grooming after informal caregiver training was provided and 3.2% of the participants were not comfortable completing grooming even after informal caregiver training was provided. However, what is concerning is that a quarter of the participants (25.8%) indicated that they never received informal caregiver training on grooming.

Of the participants, 41.9% and 35.4% indicated that the ISSs they are caring for were independent with upper body dressing and lower body dressing, respectively. This aligned with 38.7% and 45.2% of the participants who indicated that they were comfortable with performing upper body dressing and lower body dressing after they received informal caregiver training. It is, however, unfortunate to note that 19.4% of the participants indicated that they did not receive informal caregiver training on either upper body dressing or lower body dressing.

The participants of the study continued to indicate that more than half of the ISSs (51.6%) were independent with eating, 16.1% indicated that they were comfortable with assisting the ISS with eating but 3.2% indicated that they were not comfortable after informal caregiver training was provided. Concerningly, almost a third of the participants (29%) indicated that they did not receive informal caregiver training related to eating at the discharge of the ISS.

At discharge, the participants perceived that more than half of ISSs did not require assistance from informal caregivers with grooming (67.7%), upper body dressing (54.8%) and eating (71.0%). However, 19.3% of ISSs still required assistance with grooming, 25.8% with upper body dressing, 38.7% with lower body dressing but only 9.6% required assistance with eating.

4.4.3 Use and application of assistive devices

Table 6 shows that more than half of the ISSs (61.3%) make use of assistive devices. More than a third (38.7%) of ISSs were comfortable with the application of assistive devices before the informal caregiver training was provided, thus the informal caregivers did not require training on these aspects. However, 6.4% indicated that they were not comfortable with the application of assistive devices after informal caregiver training was provided. Only 3.2% of participants indicated that they were unable to use assistive devices even after informal caregiver training was provided. Unfortunately, 12.9% of the participants' perception was that they never received training on the use and application of assistive devices.

Table 6: The use of assistive devices and related caregiver training on assistive devices

		n	%
Use of assistive devices by stroke survivor	Yes	19	61.3%
	No	12	38.7%
Caregiver training on application and use of assistive devices	It was not shown to me	4	12.9%
	Unable to apply assistive device	1	3.2%
	Require assistance	0	0
	Apply assistive device but uncomfortable	2	6.4%
	Comfortable with application of assistive device	12	38.7%
	Not applicable – assistive devices not used	12	38.7%

Figure 2 indicates the various assistive devices used by the ISSs. The n-value is higher than 31 as ISSs could indicate that they make use of multiple assistive devices. The majority of ISSs used a wheelchair (41.7%). A variety of assistive devices was used, of which the majority was only used by 2.8% of the ISSs', respectively. It is important to note that 38.7% of the ISSs did not make use of an assistive device at discharge and therefore the informal caregiver did not require training on the use of assistive devices.

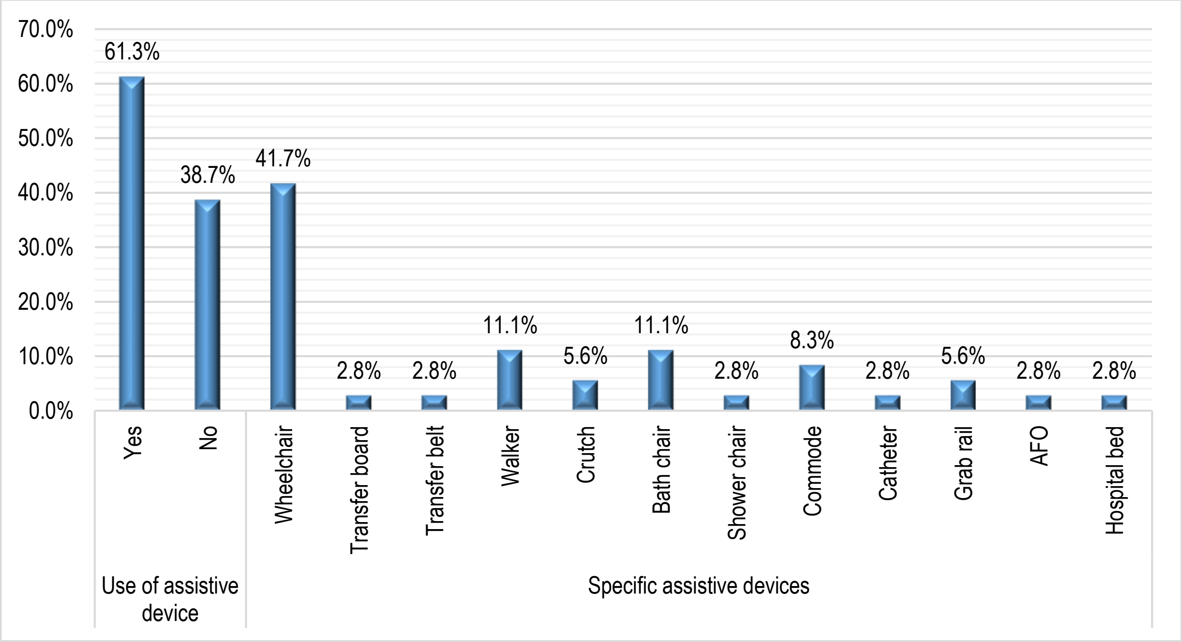

Figure 2: Specific assistive devices used by the ISSs

4.4.4 Identification and application of resources

4.4.4.1 Returning to work and driving

Table 7 indicates that a quarter of the ISSs (25.8%) will not be returning to work. Another quarter of the participants (25.8%) indicated that the return-to-work procedure was not discussed with them during the informal caregiver training. A small percentage of participants (3.2%) indicated that they were not able to assist the ISS with returning to work even though it was discussed during informal caregiver training. Several (12.9%) of the participants indicated that they still require assistance with assisting the ISS to return to work. The same percentage of participants (16.1%) indicated that they are aware of the process of returning to work but still feel unsure how to go about it. The same percentage of participants indicated that they know exactly how to follow the return-to-work procedure.

When considering returning to driving, the largest percentage of participants (41.9%) indicated that this was not discussed with them. Of the participants, 6.4% indicated that they were unable to follow the return-to-driving procedure, while 19.4% still required assistance. A further 3.2% indicated that they were aware of the return-to-driving procedure but felt unsure how to assist the stroke survivor. Finally, only 12.9% of participants indicated that they know exactly how to assist the ISS to return to driving. It is important to note that 16.1% of ISSs will not return to driving because they did not have a licence prior to the stroke.

Table 7: Return-to-work and driving community resources (n=31)

		n	**%**	**n**	**%**
Ability to assist with return-to-work and driving procedure	Ability to follow a return to	Work procedure		Driving procedure	
	Not returning (Pensioner/ No licence)	8	25.8%	5	16.1%
	It was not discussed	8	25.8%	13	41.9%
	Unable to follow procedure	1	3.2%	2	6.4%
	Require assistance	4	12.9%	6	19.4%
	Aware of procedure but not sure how	5	16.1%	1	3.2%
	Know the procedure	5	16.1%	4	12.9%

4.4.4.2 Community resources

Table 8 indicates that almost two-thirds of participants (61.3%) did not know about community resources after discharge. However, almost a third of the participants (29%) indicated that they had knowledge of community resources before discharge. The remaining participants (3.2%) indicated that they were not interested in community resources or it was not discussed with them during the informal caregiver training, respectively. Of the resources identified by the informal caregivers themselves, 22.2% were care facilities and peer support. Another 22.2% were religious facilities and 11.1% were other leisure-related community resources.

However, 12.1% of the participants indicated that the rehabilitation centre referred them to specific community resources. Furthermore, 18.2% of participants indicated that they had previous knowledge of available community resources and 15.2% of the participants indicated that they had to identified community resources themselves after discharge of ISS's, which they were able to access.

Table 8: Knowledge of, sources of knowledge and community resources identified and used by participants

		N	%
Knowledge of community resources	No resources known or identified during the caregiver training	19	61.3%
	Not interested in other resources	1	3.2%
	Not discussed during caregiver training	1	3.2%
	Had knowledge of resources	9	29.0%
Obtain knowledge of Community resources	No resources known	18	54.5%
	Previously known resources	6	18.2%
	Referred by the rehabilitation centre	4	12.1%
	Self - identified resources	5	15.2%
Resources identified and used	Care facilities	2	22.2%
	Peer support	2	22.2%
	Community support	1	11.1%
	Religious facilities	2	22.2%
	Resources not specified	2	22.2%

Participants could choose from more than one option to indicate where they obtained knowledge of community resources. Therefore, the n-value is higher than 31. Notably, more than half of the participants (54.5%) indicated that they did not know of any community resources after attending caregiver training.

4.4.5 Factors influencing caregiver training

4.4.5.1 Attendance of caregiver training

Table 9 shows that 12.9% of participants attended informal caregiver training daily, 19.4% attended informal caregiver training every week, 25.8% attended informal caregiver training more than five times, 38.7% attended informal caregiver training less than five times and only 3.2% of the informal caregivers were unable to attend any informal caregiver training sessions.

Table 9: Frequency of attendance of informal caregiver training (n=31

		n	**%**
Attendance of caregiver training	Daily	4	12.9%
	Weekly	6	19.4%
	More than five times	8	25.8%
	Less than five times	12	38.7%
	Never	1	3.2%

Participants could indicate more than one option for Figure 3, so the n-value is greater than 31. A variety of factors affected a minor percentage of the participants from attending the informal caregiver training. These factors make up more than half (52.3%) of the percentage of caregiver participants. However, the factor with the highest percentage (22.7%) was difficulty in attending informal caregiver training due to work responsibilities. Moreover, a quarter of participants (25%) indicated that nothing prevented them from attending informal caregiver training and that they utilised all the opportunities provided to them.

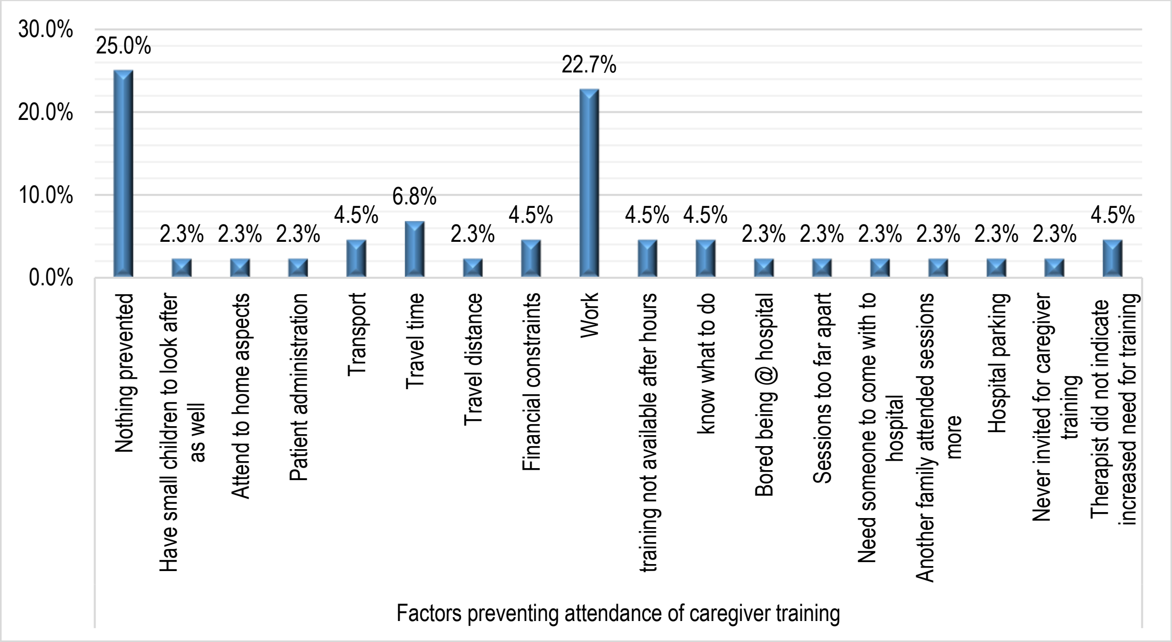

Figure 3: Factors preventing attendance of informal caregiver training

4.4.5.2 Understanding the roles and responsibilities of caregiver participants

Table 10 shows that none of the participants indicated that they never felt prepared to care for the ISS. Only 3.2% of the participants indicated that they only sometimes felt prepared to take care of the ISS. The majority of caregivers indicated that they mostly (29%) or always (67.7%) felt prepared to take care of the ISS. The majority of participants (90.3%) are mostly or always able to assist the ISS with their daily routine. Of concern is that 3.2% of the participants indicated that they are never or are sometimes (6.4%) able to assist the ISS with their daily routine. More than half of the participants (61.3%) felt they have knowledge of their responsibilities as caregivers most of the time, with 32.2% of the participants always and 6.4% of participants sometimes having knowledge of their caregiving responsibilities.

Table 10: Understanding the roles and responsibilities of a caregiver (n=31)

		N	**%**
Feeling prepared to take care of the stroke survivor	Never	0	0
	Sometimes	1	3.2%
	Mostly	9	29.0%
	Always	21	67.7%
Ability to assist with daily routine	Never	1	3.2%
	Sometimes	2	6.4%
	Mostly	13	41.9%

	Always	15	48.4%
Knowledge of responsibilities as a caregiver	Not at all	0	0
	Sometimes	2	6.4%
	Most of the time	19	61.3%
	Always	10	32.2%

For caregiver responsibilities, participants were allowed to indicate more than one option, hence the n-value for some questions is greater than 31. Of all the perceived responsibilities by the informal caregivers, preparing food and ensuring a healthy diet was identified (19.6%) as the biggest responsibility they have after discharge. Other popular outlying factors identified by caregiver participants to be their responsibility are to ensure that the ISSs follow their home programme and do their exercises (13.1%) and that they take their medication (10.3%). All other responsibilities indicated by caregiver participants were below <10%.

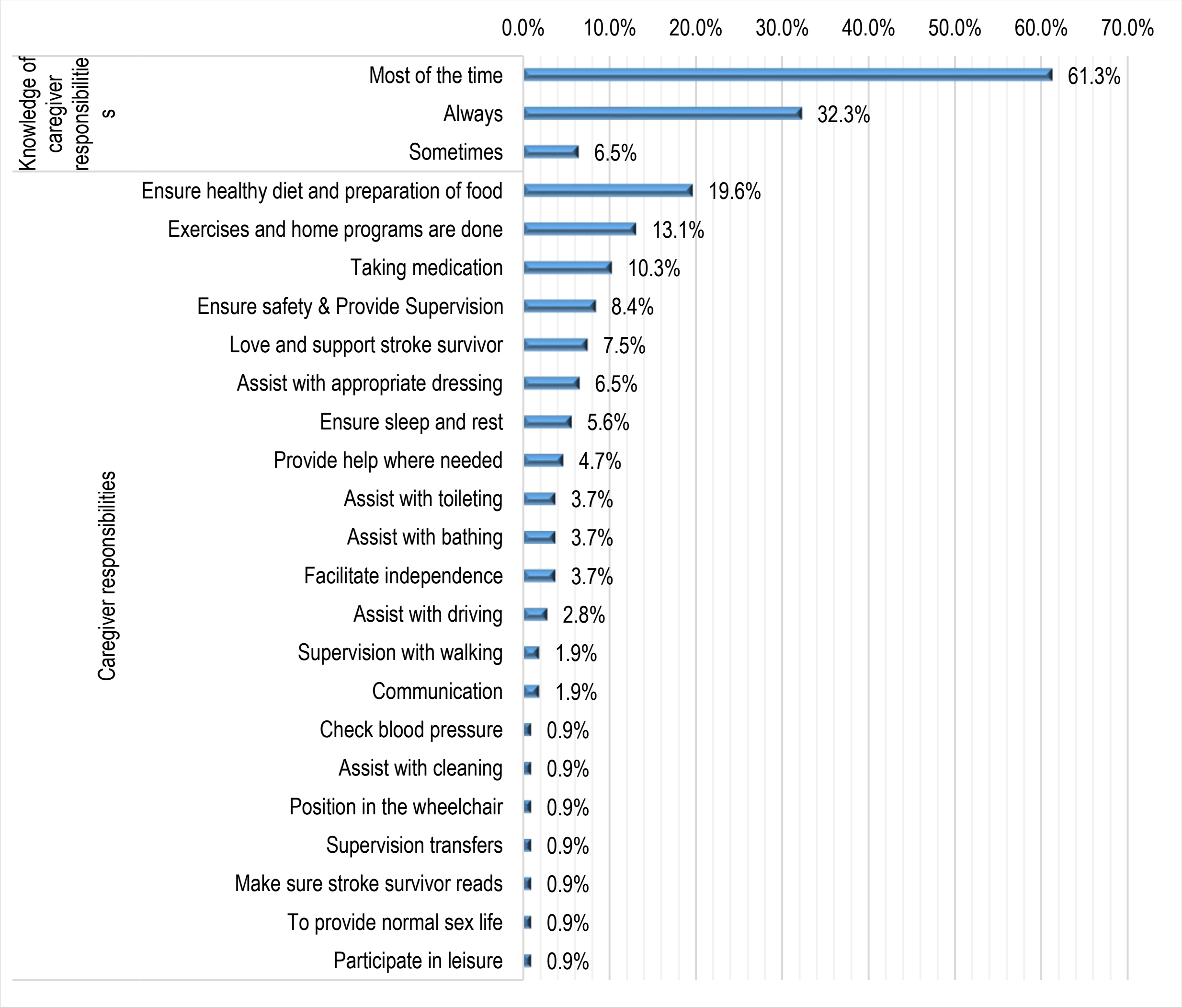

Figure 4: Responsibilities identified by the participants

4.4.5.3 Caregiving activities presenting a challenge

Participants could indicate more than one option, thus the n-value for Figure 5 is greater than 31. Almost half of the participants (48.5%) indicated that they found no difficulty in caring for the ISS. No factor was highlighted as being more difficult than others. The difficult factors were fairly spread amongst the participants.

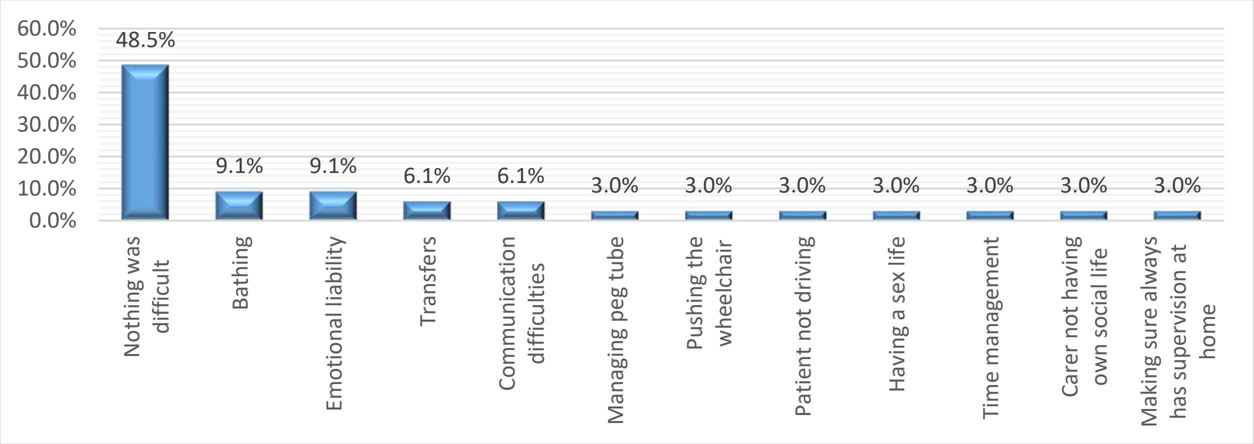

Figure 5: The most difficult factors perceived by caregivers of ISSs

As indicated by Figure 6, participants could indicate more than one option so the n-value for this question is greater than 31. The participants indicated that the following factors were the easiest for them: communication with the ISS (16.7%), preparing food and feeding the ISS (13.9%), 5.6% for the ISSs being cooperative when being cared for, the ISS not being confined to using a wheelchair and being able to take the ISS home after being hospitalised, respectively and lastly, the remaining factors were stipulated at 2.8%.

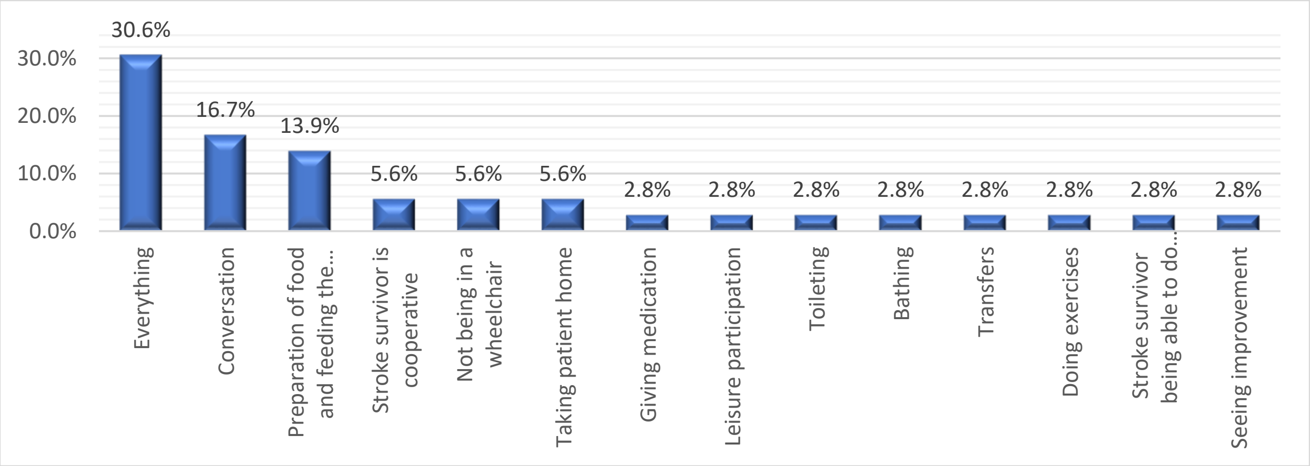

Figure 6: Factors considered to be the easiest part of caring for ISSs

4.4.6 Identifying the gaps in caregiver training

The majority of participants (87.1%) indicated that the informal caregiver training provided in the rehabilitation centre was sufficient in order for the participants to care for the ISS.

4.4.6.1 Aspects in which informal caregivers perceived not to have received training

Participants indicated (Figure 7) that of all the factors provided, they were trained in everything 56.3% of the time. However, they were not trained in 3.1% and 6.3% of the other items, respectively.

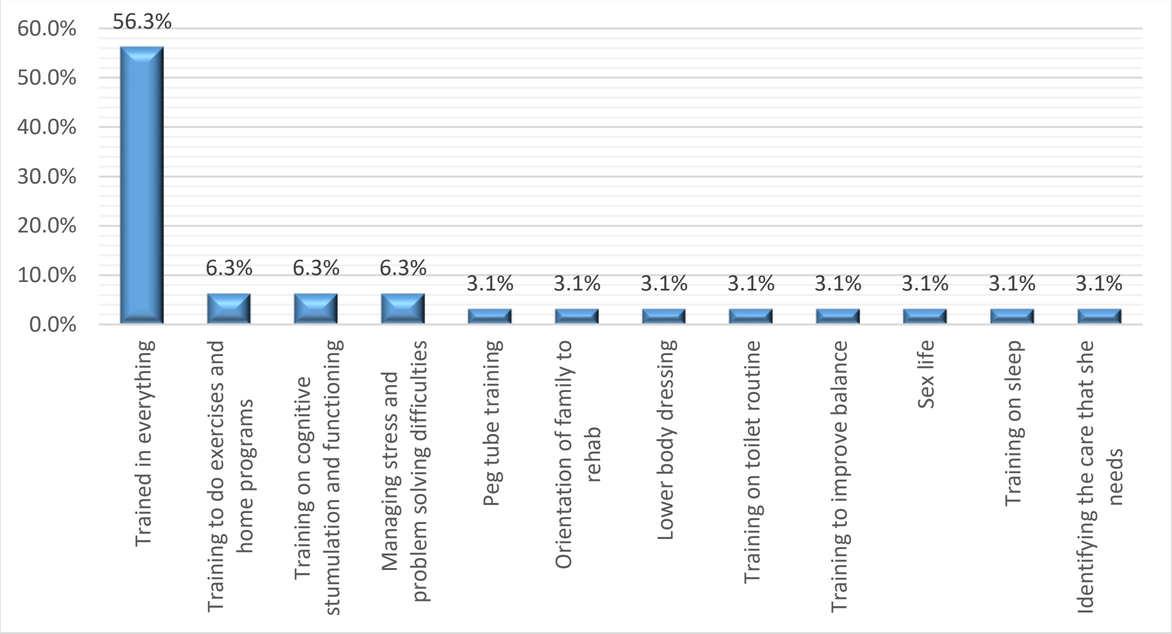

Figure 7: Factors caregivers indicated not to be trained in

4.4.6.2 Aspects perceived by caregivers to require more in-depth training

Participants could indicate more than one option for these aspects. Therefore, the n-value for this next question is greater than 31. In Table 8, participants indicate various aspects requiring more in-depth training. These aspects seem to be very individualised (3% for all factors). However, the aspect considered to be the most important factor, is that no further informal caregiver training was required (55.9%) after the initial informal caregiver training was provided.

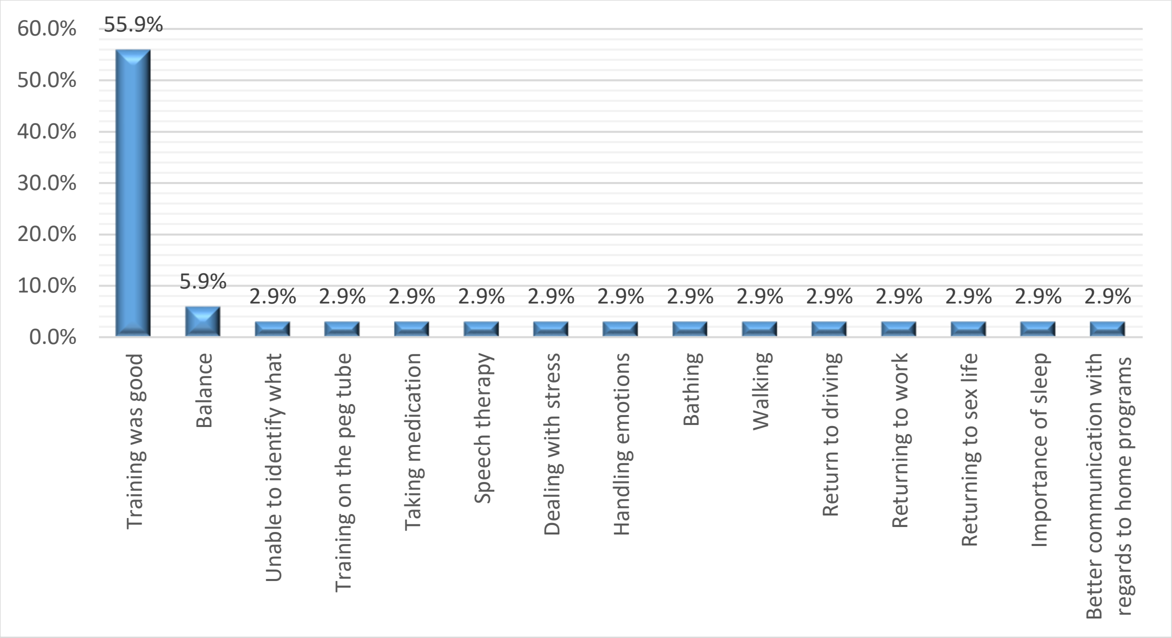

Figure 8: Aspects of caregiver training that require more in-depth training

4.4.6.3 Suggestions to improve caregiver training

Participants were allowed to indicate more than one option so the n-value for this question is greater than 31 (Figure 9). The largest percentage of participants (30.5%) indicated that adjustment to the training sessions is required. The adjustments specifically relate to the formalisation of training sessions, the increase in the duration of training sessions, increased frequency of the sessions, scheduling the training sessions in advance, training sessions to be more specific to the ISS and their caregiver/family, additional training to be provided at home and lastly, training should be done with more than one person.

Of the participants, 20.3% indicated that better communication between informal caregivers and healthcare providers is required; specifically, more frequent telephonic conversations, including the use of other forms of communication such as emails. Furthermore, the participants' perceptions were that family complaints need to be attended to and feedback communicated. More written information should be provided earlier in the rehabilitation process and lastly, opportunities to create awareness outside of the Unit should be provided.

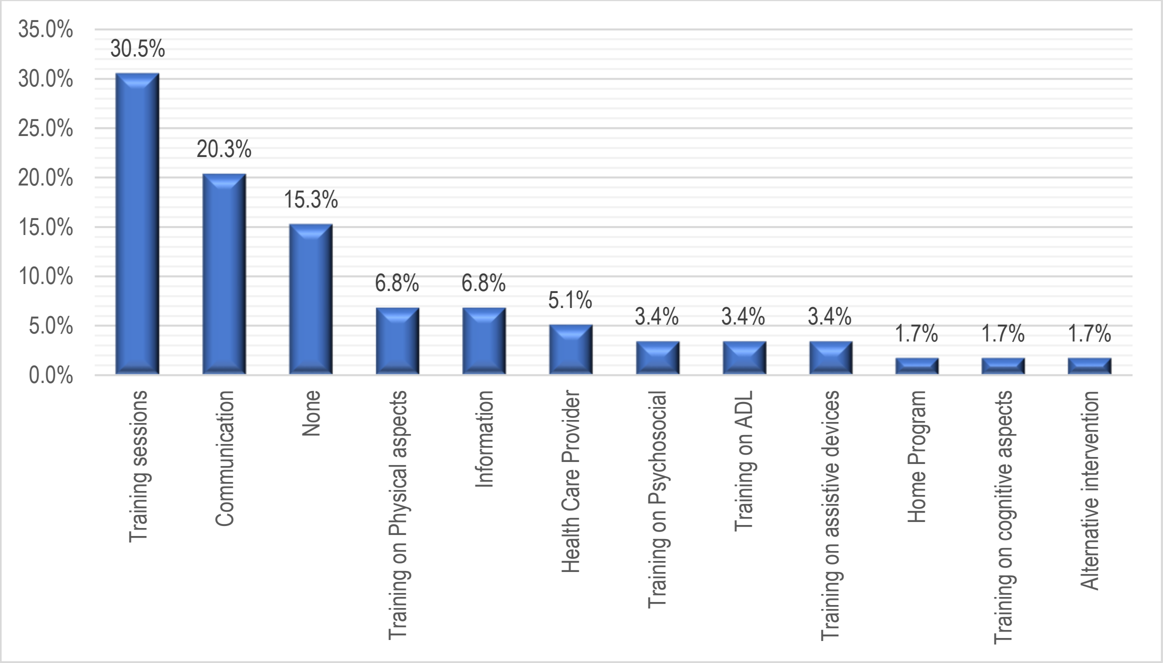

Figure 9: Categorical suggestions to improve caregiver training

Only 6.8% of caregiver participants indicated that more informal caregiver training on walking with the ISS and more hands-on practice for the informal caregivers should be considered. Similarly, 6.8% of caregiver participants also indicated that more information on strokes should be provided to the informal caregivers. Another 5.1% of caregiver participants perceived the need to meet with general practitioners and/or neurologists looking after the ISSs and that health care providers should give their full attention and concentration to the informal caregivers when informal caregiver training is carried out.

A further 3.4% of caregiver participants indicated that both informal caregiver training on ADLs and the use of assistive devices should be provided. This includes transfers to a commode, manipulation of a wheelchair, requirements for bath equipment and where to obtain the required assistive devices. The same 3.4% of the caregiver participants also indicated that informal caregiver training on psychosocial aspects requires attention, specifically on handling difficult behaviour of ISSs and stress management of both parties.

Adjustment to training on home programmes was also suggested by 1.7% of caregiver participants, specifically, that home programmes should be discussed with the family or caregivers, not only with the ISS. Training on cognitive aspects in terms of orientating the ISS to the rehabilitation process was also suggested. Lastly, another

1.7% of caregiver participants indicated that training on alternative therapy modalities or techniques such as pain management should be provided.

4.5 EVALUATION OF CAREGIVER TRAINING AT SIX-WEEK FOLLOW-UP

4.5.1 Number of participants in six-week follow-up

It is important to note that a high number of participants were lost to follow-up, affecting the data presented. Of the original 31 caregivers, only 19 completed the study at six weeks post-discharge with a loss of 39,8% of participants. The loss to follow-up was due to reasons indicated in Table 11.

Table 11: Factors affecting the number of caregiver participants at follow-up

		n	%
Factors affecting several caregiver participants participating in the follow-up	Stroke survivor re-admitted to hospital after discharge from the rehab unit, no further caregiver involvement	3	9.7%
	Formal caregiver was employed thus not part of inclusion criteria anymore	1	3.2%
	Refused to continue with the research project	2	6.5%
	Unable to get hold of the caregiver participant after various attempts	6	19.4%
	Number of participants completing the research project	19	61.3%

4.5.2 Perceived understanding of stroke information at six weeks

There was a significant change in participants' perceived understanding of information about the stroke that was provided (p=0.002). This change included positive and negative aspects. At the six-week follow-up, the percentage of those who indicated they understood all the information had increased by 10%. However, the loss to follow-up must be considered. The number of informal caregivers who indicated that they did not receive information on strokes decreased by 10% but those that did not understand the information provided increased by 8% at six weeks (Figure 10).

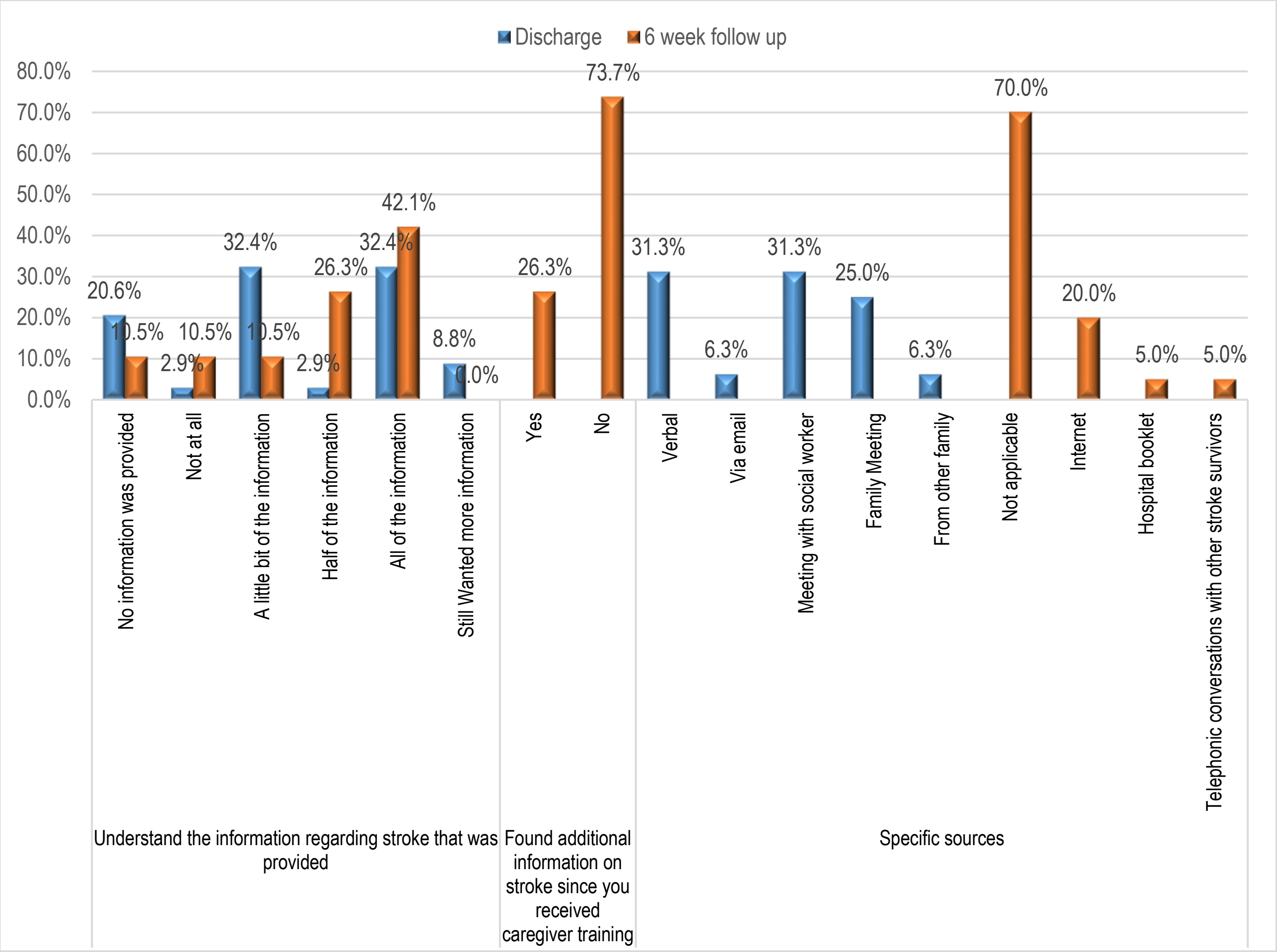

Figure 10: Understanding information

Informal caregivers relied on verbal information and meetings with health care providers at discharge for information on strokes. However, after discharge, they used the Internet for extra information. However, 70% indicated that they did not source additional information.

4.5.3 Perceived caregiver competency related to specific components of functionality after training and assistance required by ISSs on discharge

4.5.3.1 Transfers

Table 12 shows an increase of between 59.2% to 74.2% of ISSs were independent in transfers at six-week follow-up compared to discharge (p=0.001).

Table 12: Change in caregiver competence after training and assistance required by ISSs from discharge to six weeks post discharge (n=19)

		At six weeks	Difference from discharge	At six weeks	Difference from discharge	At six weeks	Difference from discharge	p-value
		n (%)	(%)	n (%)	(%)	n (%)	(%)	
		Transfers to and from the wheelchair		Transfers to and from the toilet		Transfers to and from a car/taxi		
After caregiver training	Stroke survivor independent	19 (100)	64.5%	18 (94.7)	59.2%	19 (100)	74.2%	0.001**
	It was not shown to me	0	-6.4%	0	-12.9%	0	-19.4%	0.049*
	Unable to perform	0	0	0	-3.2%	0	0	
	Require assistance	0	0	0	-3.2%	0	-3.2%	
	Perform transfer but uncomfortable	0	-6.4%	0	-6.4%	0	-3.2%	
	Comfortable with the transfer	0	-51.6%	1(5.3)	-33.4%	0	-48.4%	0.003**
Require assistance with transfer	Yes	0	-38.7%	0	-38.7%	0	-54.8%	0.001**
	No	19 (100)	45.2%	19 (100)	45.2%	19 (100)	58.1%	
	Sometimes	0	-6.4%	0	-6.4%	0	-3.2%	

Significance p≤ 0.05 p≤ 0.01****

All the caregiver participants had perceived competence after training at six weeks as compared to discharge (p=0,049), except one participant who had been uncomfortable but had become comfortable with transfers. The percentage of other caregiver participants who were previously comfortable with transfers changed significantly (p=0.003). None of the participants that participated in the six-week follow-up, indicated that the ISSs they are caring for required any assistance with transfers, including wheelchair, toilet or care/taxi transfers. Compared to the information provided at discharge, a significant increase from 45.2% to 58.1% of ISSs no longer required assistance with transfers at the six-week follow-up (p =0.001).

4.5.3.2 Toileting, managing clothing, bathing and using assistive devices

As indicated in Table 13, when evaluating the informal caregiver training for this aspect of care, 5.3% of caregiver participants indicated that toilet hygiene and the use of bathing assistive devices respectively were not shown to them during the informal caregiver training. Additionally, 0.5% of caregiver participants indicated that they were not shown how to assist the ISSs with bathing during the informal caregiver training. A significantly lower percentage (p=0,001) of caregiver participants indicated that they did not receive informal caregiver training on toilet hygiene, managing clothing, bathing and using assistive devices for bathing at the six-week follow-up, however, it is important to take note of the loss of participants. Regarding being comfortable with tasks, there was a significant decrease (p=0.019), as the informal caregivers no longer needed to assist the ISSs in dressing after toileting and only occasionally after bathing.

The caregiver participants indicated that none (0%) of the ISSs were independent in managing their clothing after toileting. However, between 5%-16% were not independent for toilet hygiene, bathing or the use of assistive devices. The ISSs were significantly more independent at six weeks compared to discharge (p=0.050, but full independence was achieved in the use of assistive devices in bathing. Caregiver participants perceived that they needed to give significantly less assistance (p= 0.003) with toilet hygiene or the use of assistive devices. Only 5.3% required assistance with bathing and sometimes required assistance with toilet hygiene six weeks after discharge from the rehabilitation centre.

4.5.3.3 Grooming, dressing and eating

Table 14 indicates the percentage of independence with dressing and eating increased significantly, with up to over 60% (p =0.050) at six weeks. However, the participants lost at follow up need to be considered. All the ISSs needed significantly less assistance (p=0,016) and only 5.3% of caregiver participants indicated that the ISSs did require assistance with grooming at the six-week follow-up. However, the percentage of ISSs requiring occasional assistance was similar to discharge and 10.5% indicated that the ISSs required occasional assistance. Compared to discharge, the six-week follow-up percentages for evaluation of training showed a significant decrease (p=0.001). For being comfortable with tasks, there was a significant decrease (p=0.050) as the informal caregivers no longer needed to assist the ISSs in dressing and only occasionally with grooming and eating. The ISSs did not require assistance with dressing as they were independent at six-week follow-up, 94% required no assistance with eating and 84.2% no assistance with grooming.

Table 13: Change in informal caregiver competence after training and assistance required by ISSs from discharge to six weeks post discharge for toileting, managing clothing after toileting, bathing and using assistive devices for bathing (n=19)

		At six weeks	**Difference from discharge**	**At six weeks**	**Difference from discharge**	**At six weeks**	**Difference from discharge**	**At six weeks**	**Difference from discharge**	**P-value**
		n (%)	**(%)**	**n (%)**	**(%)**	**n (%)**	**(%)**	**n (%)**	**(%)**	
		Toileting		Managing clothing after toileting		Bathing		Using assistive devices for bathing		
After caregiver training on	Stroke survivor independent	18 (94.7)	43.1%	19 (100)	61.3%	16 (84.2)	51.9%	18 (94.7)	62.4%	0.050*
	It was not shown to me	1 (5.3)	-10.8%	0	-19.4%	2 (10.5)	-15.3%	1 (5.3)	-27.0%	0.001**
	Unable to perform	0	0	0	0	0	0	0	0	
	Require assistance	0	0	0	0	0	-3.2%	0	-3.2%	
	Perform but uncomfortable	0	0	0	0	0	-3.2%	0	-3.2%	
	Comfortable with the task	0	-32.3%	0	-41.9%	1 (5.3)	-30.1%	0	-29.0%	0.019*
Require assistance with	Yes	0	-22.6%	0	-25.8%	1 (5.3)	-52.8%	0	-45.2%	0.003**
	No	18 (94.7)	20.5%	19 (100)	38.7%	16 (84.2)	48.8%	19 (100)	45.2%	
	Sometimes	1 (5.3)	2.1%	0	-12.9%	2 (10.5)	4.1%	0	0	

Significance p≤ 0.05 p≤ 0.01****

Table 14: Change in informal caregiver competence after training and assistance required by ISSs from discharge to six weeks post discharge for grooming, dressing and eating (n=19)

		At six weeks	Difference from discharge	At six weeks	Difference from discharge	At six weeks	Difference from discharge	At six weeks	Difference from discharge	P-value
		n (%)	**(%)**	**n (%)**	**(%)**	**n (%)**	**(%)**	**n (%)**	**(%)**	
		Grooming		Dressing and undressing upper limbs		Dressing and undressing lower limbs		Eating		
After caregiver training on	Stroke survivor independent	16 (84.2)	1.6%	19 (100)	58.1%	19 (100)	64.2%	18 (94.7)	43.1%	0.050*
	It was not shown to me	1 (5.3)	-20.5%	0	-19.4%	0	0	1 (5. 3)	-23.7%	0.001**
	Unable to perform	0	0	0	0	0	0	0	0	
	Require assistance	0	0	0	0	0	0	0	0	
	Perform but uncomfortable	0	-3.2%	0	0	0	0	0	-3.2%	
	Comfortable with task	2 (10.5)	-8.9%	0	-38.7%	0	-45.2%	0	-16.1%	0.050*
Require assistance with	Yes	1 (5.3)	8.70%	0	-25.8%	0	-38.7%	0	-9.6%	0.016*
	No	16 (84.2)	16.5%	19 (100)	45.2%	19 (100)	51.6%	1 8(94.7)	23.7%	
	Sometimes	2 (10.5)	8.1%	0	-19.4%	0	-12.9%	1 (5.3)	9.1%	

Significance $p \leq 0.05$** $p \leq 0.01$**

4.5.4 The use and application of assistive devices after six weeks home

In Table 15, caregiver participants indicated that 79% of the ISSs did not make use of assistive devices. Therefore, the non-applicability of assistive devices also changed significantly from discharge to six weeks (p=0.020).

Table 15: The use of assistive devices and related caregiver training on assistive devices

		At six weeks	Difference from discharge	P-value
		n (%)	(%)	
Use of assistive devices by stroke survivor	Yes	4 (21.0)	40.3%	0.016*
	No	15 (79.0)	40.3%	
Application and use of assistive devices	It was not shown to me	2 (10.5)	-2.4%	0.842
	Unable to apply assistive device	0	-3.2%	
	Require assistance	0	0	
	Apply assistive device but uncomfortable	1 (5.3)	-1.1%	
	Comfortable with application of assistive device	4 (21.0)	-17.7%	0.312
	Not applicable – assistive devices not used	12 (63.2)	24.5%	0.020*

Significance p≤ 0.05 p≤ 0.01****

There were 21% of the caregivers who indicated that assistive devices were still used by the ISSs at six weeks; they stated they were comfortable with applying and using the assistive device which did not differ significantly from discharge (p=0.312). When evaluating the informal caregiver training, 10.5% of caregiver participants indicated that the application and use of assistive devices were not discussed or demonstrated during informal caregiver training and 5.3% indicated that even though they received informal caregiver training on the application and use of assistive devices they can apply the assistive devices but are not comfortable when doing so. This had not changed significantly at six weeks (p=0.842).

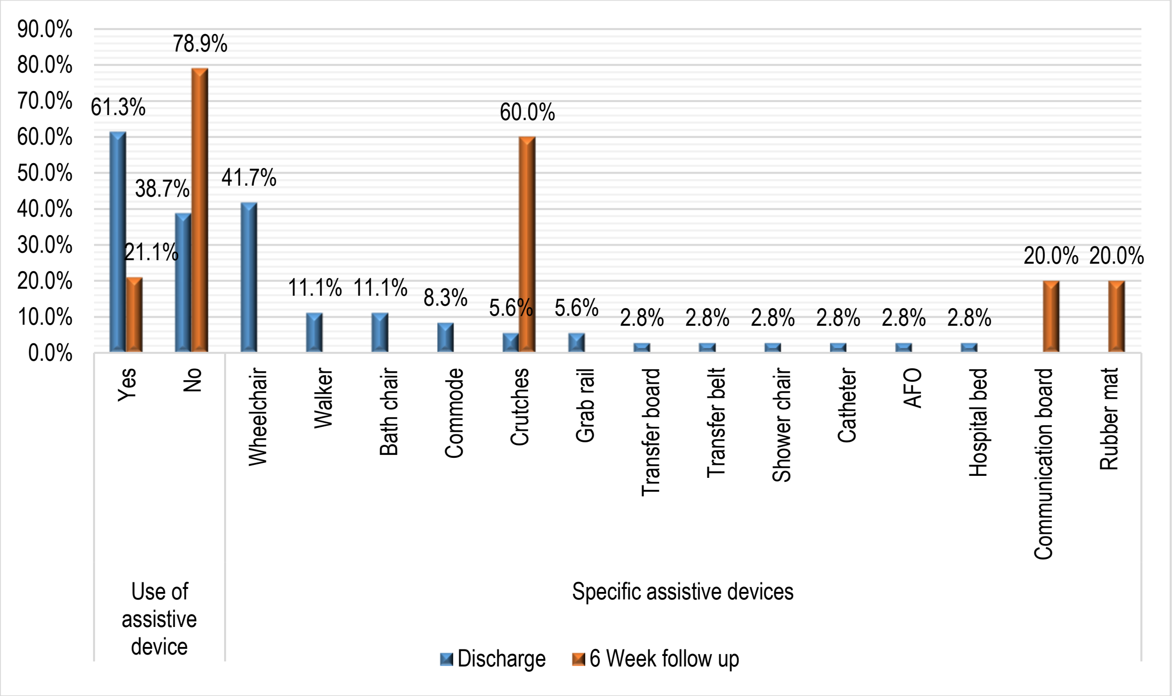

Figure 11: Specific assistive devices used by the ISSs

When comparing this data set with the data obtained at the discharge of the ISS, it is important to note that a significantly higher proportion of ISSs were dependent on assistive devices at discharge than at six weeks. Figure 11 confirms that 40% more ISSs were independent of assistive devices at six weeks with significantly fewer using assistive devices at six weeks (p=0.016). With increased independence, it is worthy to note that no wheelchairs were used after six weeks compared to 41.7% at discharge but a great increase (60%) in the use of crutches was observed at six weeks. The variety of assistive devices used by ISSs were also much less at six weeks than at discharge.

4.5.5 Identification and application of resources

4.5.5.1 Returning to work and driving

According to Table16, the caregiver participants indicated during the six-week follow-up that 36.8% of the ISSs will not be returning to work. Comparing this to the data at discharge, a slightly increased percentage of ISSs (10.5%) will not return to work, however, the difference was found not to be statistically significant. Of the caregiver participants, 5.3% indicated that the return-to-work process was not discussed with them during the informal caregiver training. Notably, the percentage of participants indicating that they did not receive informal caregiver training on returning to work was higher at discharge than at six-week follow-up. Caregiver participants (21%) indicated that they required assistance to assist the ISS to return to work. A further 21% of the caregiver participants indicated that they were made aware of the return-to-work procedure but were not exactly sure how to facilitate the process, compared to 16.1% at discharge but the difference from discharge was not significant.

Of the caregiver participants, 31.6% indicated that the ISS will not be returning to driving, compared to 16.1% at discharge which was not a significant change. Of the caregiver participants, 15.8% indicated that driving was not discussed with them compared to a much higher percentage (41.9%) at discharge. At six weeks, 26.3% of caregivers indicated that they were made aware of the procedure but that they still felt unsure regarding implementation. When comparing this data to the discharge data, there was no significant difference. A small percentage of participants (3.2%) indicated at discharge that they were made aware of the return-to-driving procedure but felt unsure compared to the six-week follow-up (26.3%). None of the caregiver participants indicated that they knew exactly how to follow the return-to-driving procedure during the six-week follow-up.

Table 16: Return-to-work and driving community resources (n=19)

		At six weeks	**Difference from discharge**	**p-value**	**At six weeks**	**Difference from discharge**	**p-value**
		n (%)	**%**		**n (%)**	**%**	
Ability to assist with return-to-work and driving procedure	Ability to follow a return to	Work procedure			Driving procedure		
	Not returning (Pensioner/ No licence)	7 (36.3)	10.5%	0.639	6 (31.6)	15.5%	0.411
	It was not discussed	1 (5.3)	-20.5%	0.600	3 (15.8)	-26.1%	0.488
	Unable to follow procedure	0	-3.2%		1 (5.3)	-1.1%	
	Require assistance	4 (21.0)	8.1%		4 (21.0)	1.6%	
	Aware of procedure but not sure how	4 (21.0)	4.9%		5 (26.3)	23.1%	
	Know the procedure	3 (15.8)	-0.3%	0.086	0	-12.9%	0.310

Significance p≤ 0.05** p≤ 0.01**

4.5.6 Other factors influencing caregiver training

4.5.6.1 Alternative caregiver training since discharge of the stroke survivor

Most of the caregiver participants (94.7%) did not receive more or other caregiver training since the discharge of the ISS. The remaining 5.3% of caregiver participants received training on physical aspects, at home by a physiotherapist.

4.5.6.2 Understanding the roles and responsibilities of a caregiver after being home for six weeks with the stroke survivor

The caregiver participants indicated that most of them (84.2%) always felt prepared to care for the ISS, whilst 10.5% indicated that they felt prepared ‘most of the time’ (Table 17). However, 5.3% only ‘sometimes’ felt prepared to take care of the ISS. Concerningly, this was after they received informal caregiver training and had some practice at home for six weeks. When comparing the six-week follow-up data with the discharge data, fortunately, none of the caregiver participants indicated that they never feel prepared to care for the ISS; however, a larger percentage of caregiver participants indicated that they mostly feel prepared to care for the ISSs and far fewer caregiver participants indicated that they always feel prepared in caring for the ISS, thus an increase in feelings of preparedness was observed.

Table 17: Understanding the roles and responsibilities of a caregiver (n=19)

		At six weeks	**Difference from discharge**	**p-value**
		n (%)	**%**	
Feeling prepared to take care of the stroke survivor	Never	0	0	0.230
	Sometimes	1 (5.3)	2.1%	
	Mostly	2 (10.5)	-18.5%	
	Always	16 (84.2)	16.5%	
Ability to assist with daily routine	Never	0	-3.2%	0.004**
	Sometimes	1 (5.3)	-1.1%	
	Mostly	1 (5.3)	-36.6%	
	Always	17 (89.5)	41.1%	
Knowledge of responsibilities as a caregiver	Not at all	3 (15.8)	15.8%	0.028*
	Sometimes	1 (5.3)	-1.1%	
	Most of the time	2 (10.5)	-50.8%	
	Always	13 (68.4)	36.2%	

Significance p≤ 0.05** p≤ 0.01*

Over 80% of the caregiver participants were always able to complete an ISS's daily routine with them, which is similar to the percentage for the feelings of preparedness (84.2%). When comparing the data with the discharge data, significantly more (p=0.004) caregiver participants indicated that they are always able to complete the ISS's daily routine. Fewer caregiver participants indicated that they could only complete the daily routine most of the time, as they could now always do it.

At six weeks, more than half of the participants (68.4%) always had knowledge of their responsibilities as caregivers which showed a significant increase (p=0.028) since discharge. A further 10.5% of the participants indicated that they had knowledge of their responsibilities as caregivers most of the time; only 5.3% of participants sometimes had knowledge of their responsibilities as caregivers. Concerningly, 15.8% indicated that they do not know what their responsibilities as caregivers were at all, even after they received informal caregiver training at discharge and had experience of caring for the stroke survivor for six weeks. Additionally, only knowing their responsibilities 'sometimes' was also similar at discharge and six weeks. These findings are confirmed in Figure 12.

When viewing the responses collectively, the same percentage of caregiver participants experienced having knowledge of their responsibilities at discharge and at six weeks. The caregiver participants identified a variety of responsibilities, with a lot of the responses not being similar between discharge and six weeks. The three responses that varied significantly, were:

i. ensuring that exercise and home programmes are carried out, which becomes less of a responsibility at six weeks;
ii. to provide help or assistance where needed, which became increasingly important at six weeks compared to discharge; and
iii. assisting with driving the stroke survivor around, which became more important at six weeks compared to discharge.

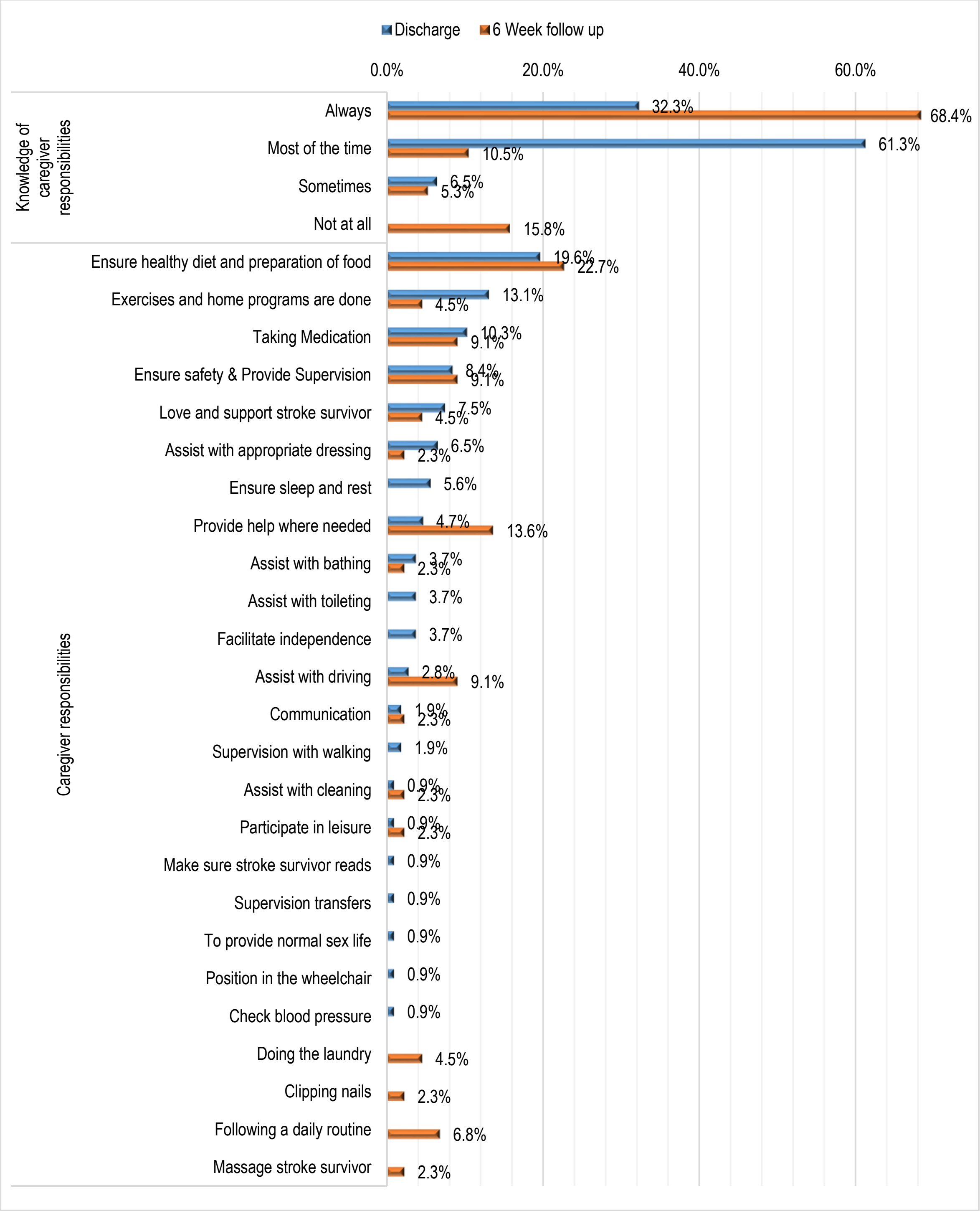

Figure 12: Specific caregiver responsibilities specified

4.5.6.3 Caregiving activities presenting a challenge

Figure 13 demonstrates the difficulties caregiver participants perceived with caring for an ISS. At six weeks, more caregiver participants (10%) indicated that they did not experience any difficulties in caring for the ISS compared to discharge, which is an insignificant difference (p=0.496). A variety of difficulties were mentioned but very little overlap was observed between discharge data and six-week follow-up data.

This indicates that the difficulties perceived changed over time. However, bathing and communication difficulties were the two aspects that were different at discharge and six weeks, with it being perceived as more difficult to do by more caregivers at discharge compared to six weeks later.

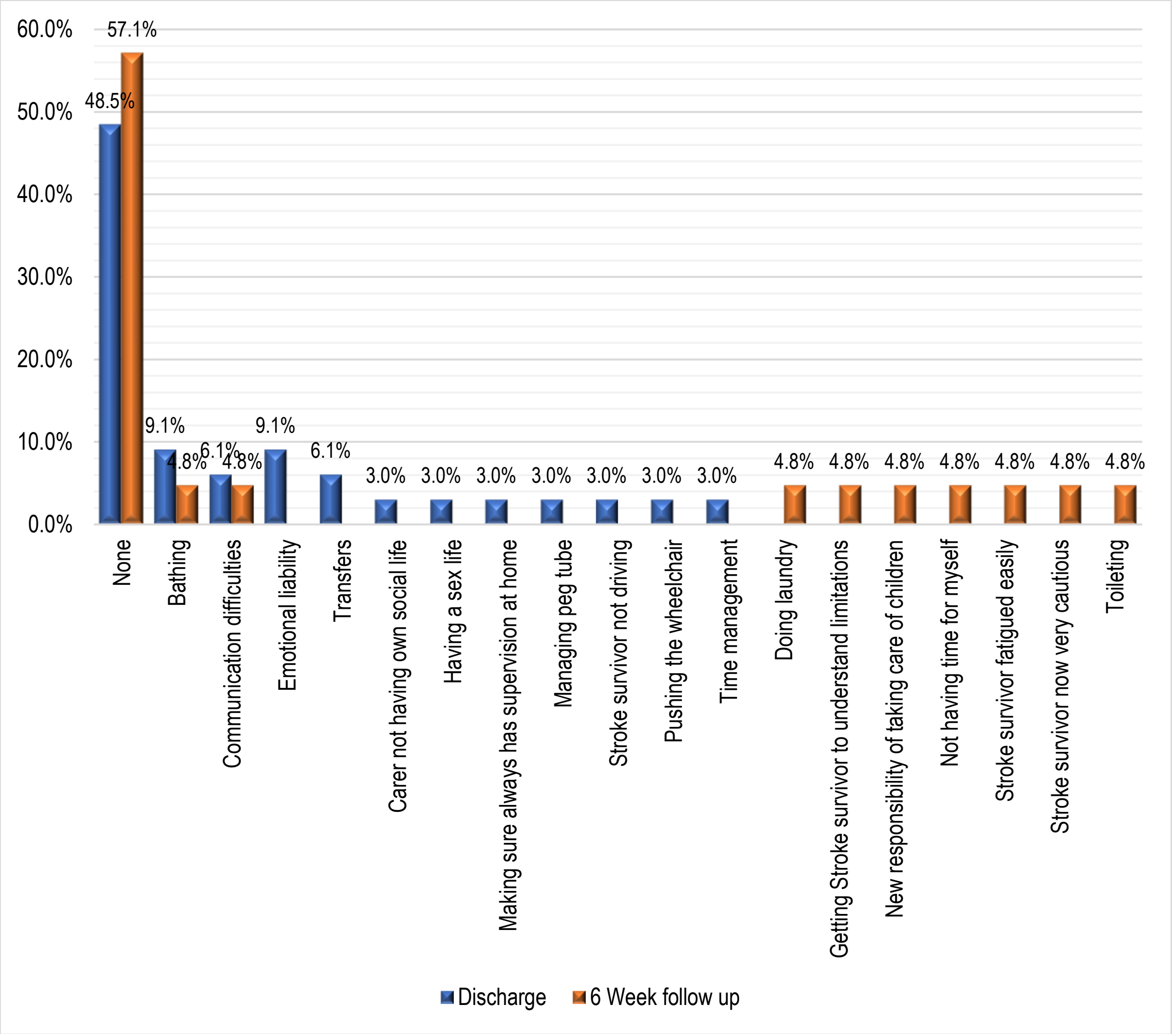

Figure 13: Difficulties with caregiving

Figure 14 shows that at six weeks, 17% more caregiver participants indicated that everything related to caring for the stroke survivor was easy compared to caregiver participants at discharge, the difference however is insignificant (p=0.071). Communication with the ISS was considered to be easier at discharge than at six weeks and preparing food and feeding the ISS was also easier for more caregiver participants at six weeks than at discharge. Importantly, a larger variety of easy aspects (n=13) were provided at discharge compared to six weeks (n=6).

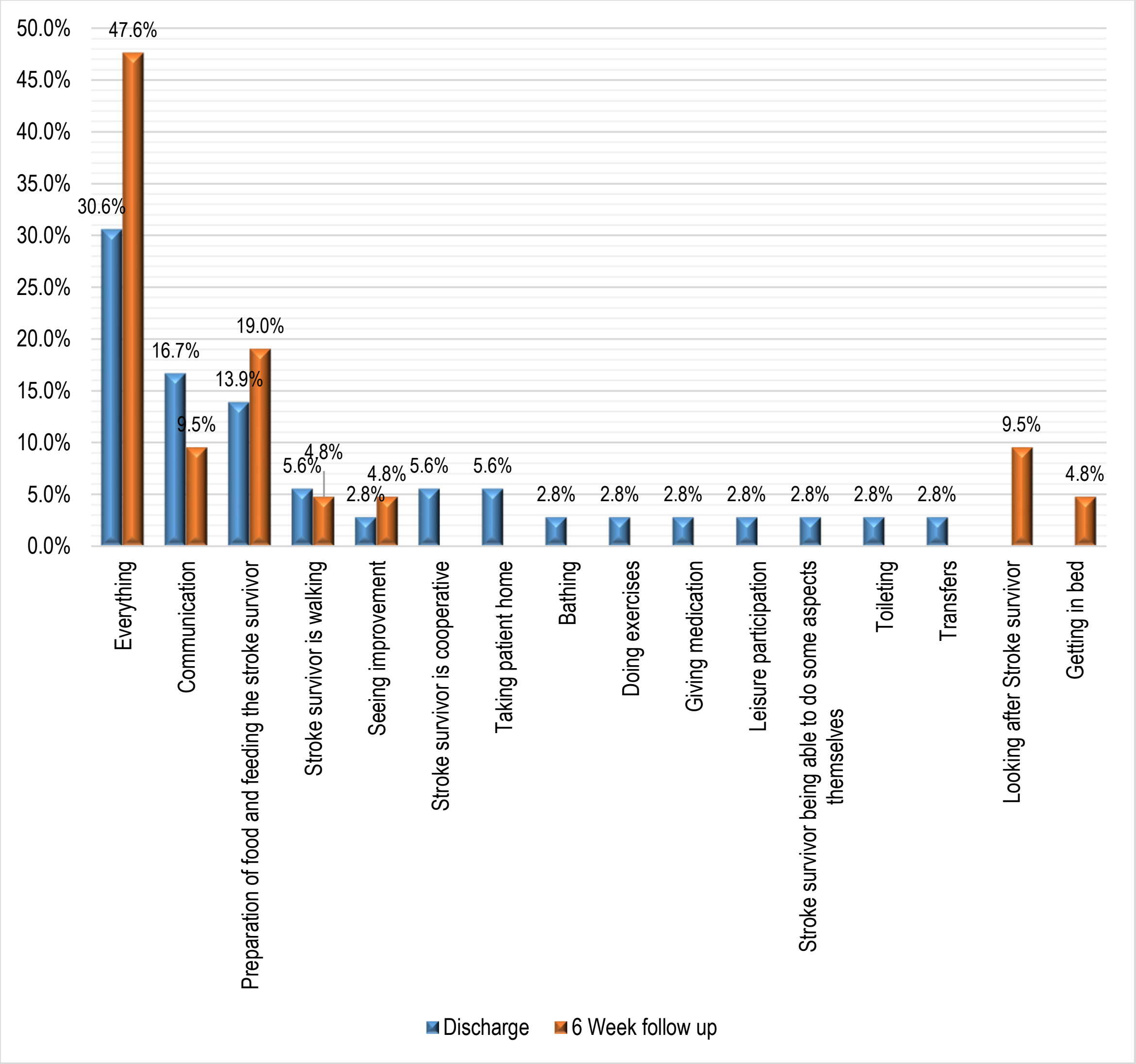

Figure 14: Aspects easily completed as a caregiver of a stroke survivor

4.5.7 Identifying the perceived gaps in informal caregiver training after caring for the ISS for six weeks

4.5.7.1 Perceived gaps in caregiver training

In Figure 15, it can be observed that 20% more caregiver participants at discharge indicated that nothing was missing from the informal caregiver training; however, the difference is insignificant (p=0.107). Only two aspects missing from caregiver training overlapped between discharge and six weeks; i) training on exercise and following a home programme and ii) training on percutaneous endoscopic gastrostomy (PEG) tube feeding and feeding. With both aspects, more caregiver participants at six weeks wanted it to be part of caregiver training. The other topics perceived to be being missing from caregiver training vary much between discharge and six weeks; of which most are of low percentage, thus seemingly very individualised to the different caregiver participants.

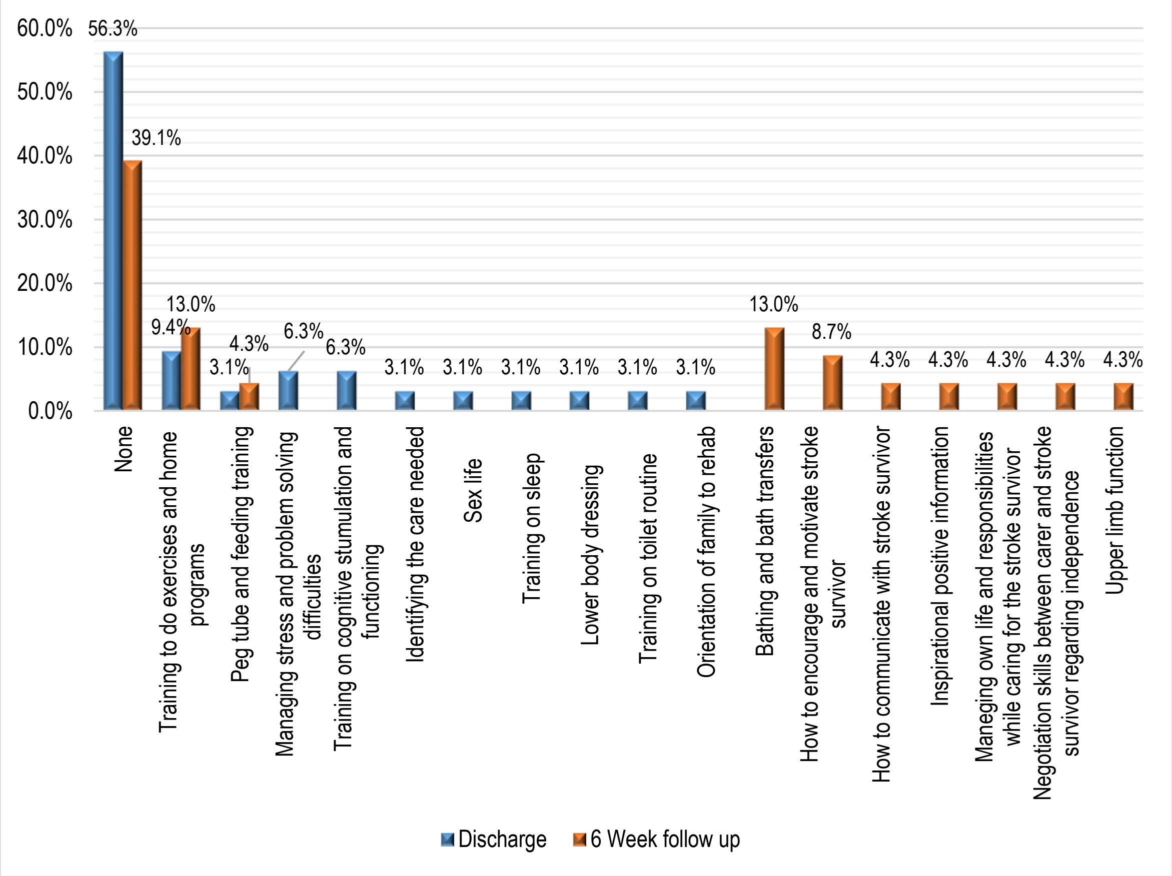

Figure 15: Aspects that was not part of informal caregiver training but after experiencing caring for the stroke survivor at home should be made part of the caregiver training

4.5.7.2 Aspects for more in-depth caregiver training

In Figure 16, an insignificant (20%) number of caregiver participants at discharged indicated that there were no topics covered in informal caregiver training that require more in-depth training (p=0.107). Where an overlapping of topics was observed, more caregiver participants indicated (at six weeks) that a need for more informal caregiver training was required. The specific topics perceived to overlap include training on physical exercise and balance (12.5%), the importance of sleep and sleep patterns (4.2%), bathing (8.3%), effective communication (4.2%) and return-to-work (8.3%). Various other topics were indicated both at discharge and the six-weeks follow-up but these topics do not overlap, indicating that the need differs from discharge to six weeks follow-up.

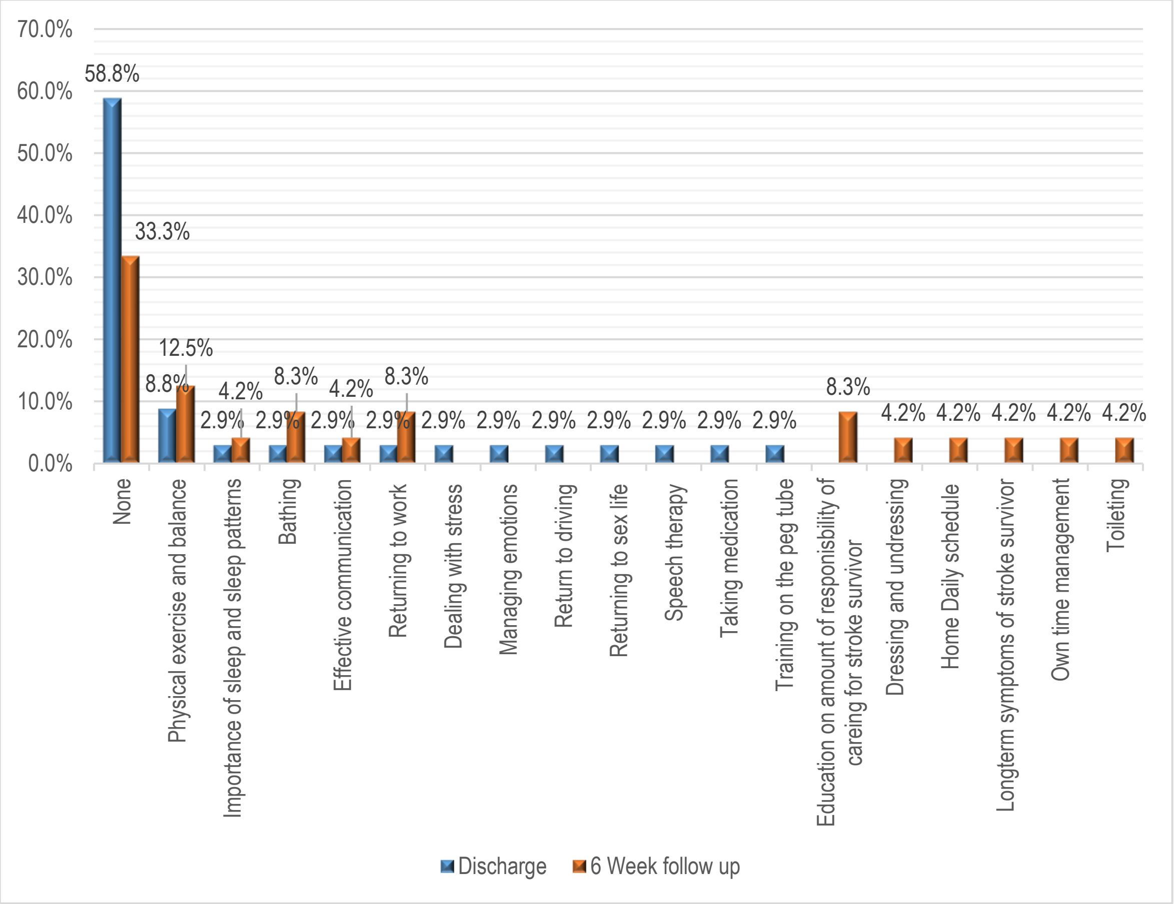

Figure 16: Aspects of caregiver training that require more in-depth focus

4.5.7.3 Suggestions to improve caregiver training

Figure 17 shows various areas of caregiver training that are suggested for improvement. The most important area of informal caregiver training considered by 30% of caregiver participants at discharge and 20% of caregiver participants at six weeks is the presentation of training sessions. This includes several specific aspects:

i. the number of training sessions;
ii. the presentation of training sessions as part of a group as well as the use of videos as part of the training session;
iii. scheduling of specific appointment time for training sessions beforehand; and
iv. informal caregiver training to start sooner in the rehabilitation process.

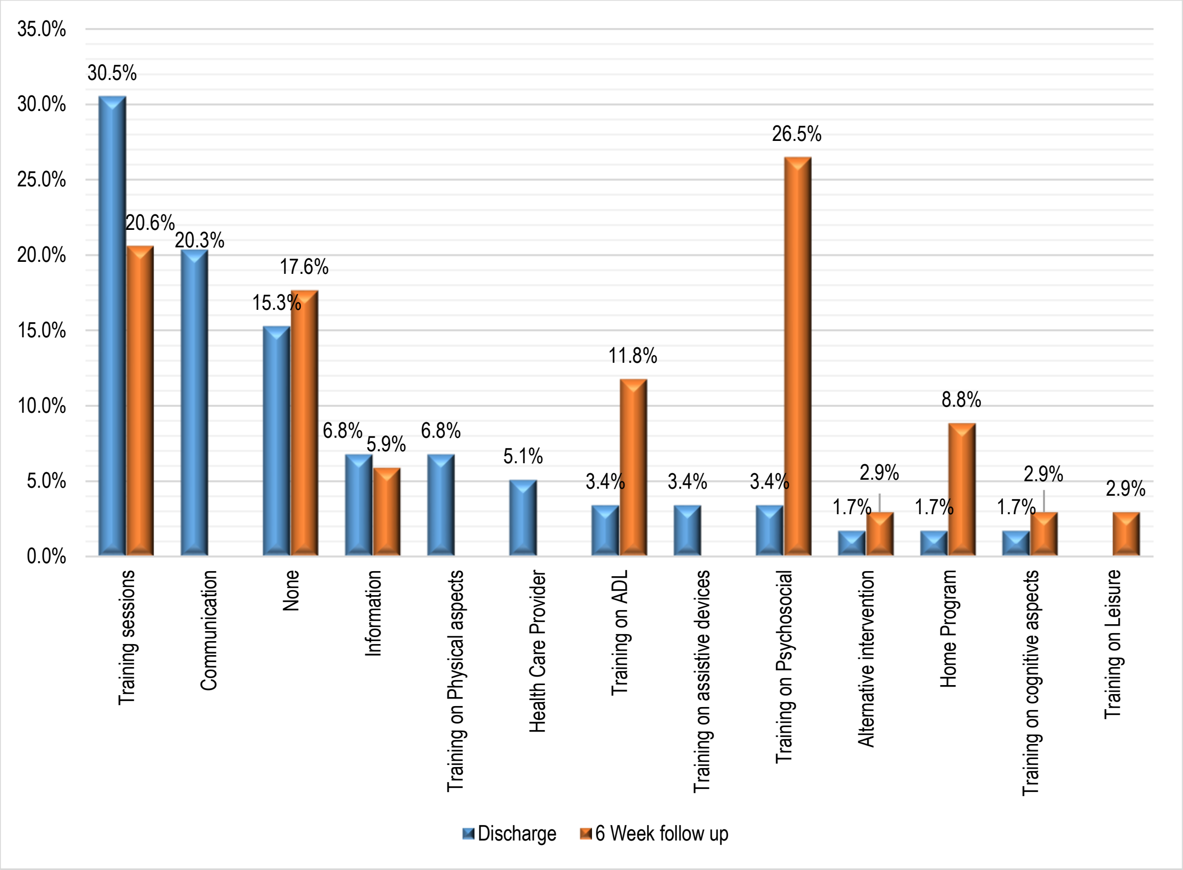

Figure 17: Suggestions to improve caregiver training

Caregiver participants indicated at discharge and six weeks that the general information provided requires improvement. This relates specifically to information provided which the participants felt should be on the specific stroke affecting the ISS. Furthermore, the participants felt that the importance of attending therapy should be explained not only to the family but also to the ISS.

A greater percentage of caregiver participants (8.4%) at six weeks compared to discharge indicated that informal caregiver training on ADLs should be improved, specifically concerning bath transfers, management and removal of a PEG tube, the importance of sleep and prevention of sleep deprivation and resuming a sex life with a partner. As with informal caregiver training on ADLs, more caregiver participants (23.1%) at six weeks indicated a need to improve informal caregiver training provided on psychosocial factors, compared to caregiver participants at discharge. The specific psychosocial factors were safety aspects at home, including relaxation as part of the training programme, how to meet the ISSs’ emotional needs, preparing the family emotionally for life after discharge and the future as well as educating the caregivers on coping skills.

Furthermore, an increased percentage of caregiver participants at six weeks compared to the percentage of caregiver participants at discharge indicated that training on home programmes should be improved through the inclusion of activity ideas the informal caregiver can do at home with the ISS. However, 15% and 17% of caregiver participants at discharge and at six weeks, respectively, indicated that they do not have any suggestions to improve informal caregiver training.

4.6 SUMMARY OF RESULTS

In summary, at discharge caregiver participants indicated (for the most part) that the ISSs were independent in ADL. They also indicated that they were either comfortable with assisting the ISS after they received informal caregiver training or that they did not receive informal caregiver training at all on specific aspects, with the latter occurring at a much lower percentage than the two preceding responses. Almost half of the ISSs used assistive devices at discharge, of which wheelchairs were the most prevalent. At the six-week follow-up, caregiver participants mostly indicated that the ISSs were independent with ADL. Occasionally, one or two caregiver participants indicated that either they were comfortable with assisting the ISS with ADL or that they did not receive informal caregiver training on specific aspects but this occurred much less compared to on discharge. A reduction in the use of assistive devices was observed at six weeks, with crutches being the most prevalent as compared to wheelchairs, thus increased mobility of the ISSs was observed at six-week follow-up.

In terms of IADL at discharge, the majority of informal caregivers indicated that the ISSs were neither returning to work or to driving. Concerningly, they indicated that they did not receive training on return-to-driving or return-to-work. More positively, the majority of caregiver participants indicated that they felt prepared to take care of the ISS and that they were able to follow the ISSs' daily routine. At the six-week follow-up, an increased number of caregiver participants indicated that the ISS will not return to work or driving. However, increased awareness of the procedures was observed; informal caregivers rather indicated that they still felt unsure or require assistance with these procedures. At six weeks, an increased number of informal caregivers (the majority) indicated that they felt prepared to care for the ISS and were able to follow the ISSs' daily routine. Thus, increased feelings of preparedness were observed.

CHAPTER 5: DISCUSSION

5.1 INTRODUCTION

In this chapter, the study results will be discussed in detail, according to the study objectives, supported by relevant literature. The discussion will consider the demographics of the informal caregivers and the ISSs concerning other studies and the perceptions of informal caregivers regarding the informal caregiver training offered to them at discharge by inpatient rehabilitation. The informal caregivers' evaluation of both the weaknesses and strengths in the training at discharge and the changes that they indicated for these factors at six weeks post-discharge will be discussed. Moreover, the perceived gaps in the informal caregiver training and areas for improvement as well as the limitations of the study are presented.

5.2 DEMOGRAPHIC INFORMATION

5.2.1 Caregivers

Most of the caregiver participants were female and were within the working-age group. The gender distribution is in line with previous studies (Moritomo, et al., 2003; McCusker, et al., 2007; Schure, 1996). The majority of the informal caregivers were the ISSs' spouse, however contrary to a study by Shure (1996), the caregivers were not elderly since the caregiver participants were mostly in the three working-age groups (Schure, 1996; Watanabe, et al., 2015). The age of the caregivers (30-59 years) was similar to that reported in another SA study (Mudzi, 2010).

Half of the caregiver participants lived in urban areas, which might be due to convenience sampling because the ISSs were all at a private rehabilitation unit in Pretoria. Coupled with the residential location, half of the caregiver participants were educated post-secondary training, with between 11-15 years of education. Thus, as in other SA studies, the caregivers' education ranged from 6-15 years (Mudzi, 2010). Furthermore, years of education of informal caregivers should be considered when offering the informal caregiver training programme in order to ensure that the presentation is appropriately delivered to the informal caregivers of ISSs.

5.2.2 Index stroke survivors

More than half of the ISSs were male and distributed evenly within two age groups, namely 50-59 and 60-69 years of age, which is the most common group within SA.

In SA, the risk of stroke increases with age and the stroke participants fell into the age groups for which the majority of strokes in SA are reported (Mudzi, 2010) (Taylor & Ntusi, 2019).

About three-quarters of the ISSs had education levels post-secondary training with between 11-20 years of education. In addition, the highest percentage of ISSs were working as professionals. Thus, they can be expected to have high levels of stress as part of their occupation which may be a contributing factor to stroke, which is true for both men and women (Tsutsumi, et al., 2009) (Huang, et al., 2015).

Global data indicates that ischaemia accounts for 68% of strokes and haemorrhagic stroke account for 32% of cases (Taylor & Ntusi, 2019). Indeed, more than half of the ISSs in this study had an ischaemic stroke. Moreover, the most common comorbidities are hypertension (half of the ISSs in this study), diabetes and cardiac conditions (a quarter of the ISSs respectively). These statistics are similar to those reported in another study on stroke in SA (Connor, et al., 2004)

5.3 EVALUATION OF CHALLENGES AND SUCCESSES EXPERIENCED IN CAREGIVER TRAINING ON DISCHARGE AND AT SIX WEEKS POST-DISCHARGE

The first objective was to determine how effective informal caregivers perceive the informal caregiver training offered to them at discharge from inpatient rehabilitation to be. This objective will be discussed with the results from the second objective to allow the caregivers' perception of the effectiveness of the informal caregiver training at six weeks post-discharge to be compared with their perception at discharge. The informal caregivers' previous experience with caregiving, their knowledge of stroke and attendance of informal caregiver training is also considered in this section.

5.3.1 Caregivers' experience with caregiving and awareness of stroke

Informal caregivers are provided with information about strokes in a planned health care component of the training at the in-patient rehabilitation facility used in this study. Most of the caregiver participants had not received previous caregiver training and most have no prior experience with caregiving (Pesantes, et al., 2017). Thus, the importance of providing information and training for the informal caregivers in this context is supported (Clarke & Forster, 2015). Furthermore, while nearly half the caregiver participants indicated that they knew about the deficits related to a stroke, a third indicated at discharge that they received all of the necessary stroke information, which is far less than the 53% reported in the literature (Almborg, et al., 2009).

While Sheha *et al.* (2020) report that planned health teaching with caregivers increases the caregivers' knowledge and competence in caring for the stroke survivor, it appears that providing limited information may have impacted the perceived effectiveness of informal caregiver training in this study. Even though a family meeting is held in which formal information on strokes is provided by the multidisciplinary team to all informal caregivers, White *et al.* (2014) indicate that informal caregivers report a lack of information regarding stroke prevention, as well as signs and symptoms of a stroke (Herbert, et al., 2016).

In this study, participants described feeling overwhelmed by the information, which they felt should be personalised to their context. They felt they could not remember the information they were given (White, et al., 2014). Therefore, it appears that continuous evaluation of the informal caregivers' satisfaction with the information they receive should be included in the weekly family meetings. If necessary, the information provided needs to be repeated to improve the perceived effectiveness of the informal caregiver training (Wilkens, et al., 2001).

Then again, it may well be that caregivers simply require reassurance that they know enough about strokes to care for the stroke survivor. To illustrate this point, after six weeks of being home with the ISS, less than half of the caregiver participants' perception was that all the necessary stroke information was provided and the training was perceived to be effective. This was a significantly different view from what the caregivers indicated at discharge, where only 20.6% indicated that all necessary stroke information was provided.

Correspondingly, the need to source additional information was deemed unnecessary by most of the caregiver participants at six weeks post-discharge. Where additional stroke information was sought, it was mostly done via the Internet, at a point when the informal caregiver required answers to specific questions, consistent with other studies (Ski & O'Connell, 2007; Cecil, et al., 2011). Making use of technology at a stage where the caregivers could have contacted the health and rehabilitation team with questions may provide an effective method to provide information when it is needed. This can also be used to reassure informal caregivers on discharge that they do not need to know everything at this stage.

5.3.2 Client factors and performance skills of ISSs

The informal caregivers were trained at the Unit in transfers and assistance with toileting, managing clothing after toileting, bathing, grooming, dressing and eating using the CME Programme (Van den Berg, et al., 2016). Assisting the ISSs with their occupational performance was practised under the supervision of the health and rehabilitation team using a formal and informal approach (Herbert, et al., 2016). The caregivers implemented the training on weekends at home and after discharge using a home rehabilitation approach (Goldberg, et al., 1997; Lindley, et al., 2017).

However, independence in transfers depends on the severity and site of the stroke and can differ among stroke survivors on discharge (Msengana, et al., 2019). Varying levels of independence in transfers have been reported in other SA studies. (Wasserman, et al., 2009) (Joseph & Rhoda, 2013; Msengana, et al., 2019). Therefore, the need for training in transfers needs to be carefully monitored during the in-patient stay (Hafsteinsdottir, et al., 2011). In this study, more than a quarter of ISSs were independent in transfers at discharge, therefore their caregivers did not require training.

Furthermore, only half of the caregiver participants who received informal caregiver training felt comfortable with completing transfers on discharge and perceived the informal caregiver training as adequate. This indicates the need to ensure that each informal caregiver receives adequate opportunity to practice with transfers before the ISSs’ discharge, until the informal caregiver is comfortable while under the supervision of the therapists, to ensure integration of skills learned during informal caregiver training into the home. Moreover, transfers need to be adequately taught and practised for safety reasons; if informal caregivers are not comfortable and competent, they may injure the ISS if they drop them/allow them to fall. Therapists must train informal caregivers and ensure the informal caregivers perceive that they are comfortable with performing transfers in the programme offered.

At six weeks post-discharge, all the ISSs were perceived to be significantly more independent in transfers, thus requiring significantly less assistance. The informal caregivers did not perceive any deficits with informal caregiver training at six weeks and did not comment on implementing the informal caregiver training received, as they were no longer assisting with transfers. It is difficult to distinguish whether improvement in the ability to transfer was due to informal caregiver training or due to general improvement in ISS functionality without intervention (Goldberg, et al., 1997). An increase in the independence of stroke survivors, even without caregiver training, can be expected (Wasserman, et al., 2009)

When considering other occupational performance components in this study, caregiver participants indicated at discharge that between 46%-36% of the ISSs required their assistance with toileting, managing clothing after toileting, grooming, upper body dressing and eating. This is in accordance with the National Alliance for caregiving AARP (2004), which indicates these are some of the activities with which caregivers are most likely to assist stroke survivors. This level of dependence or modified independence in which ISSs need assistance was similar to that reported by Msengana *et al.* (2019) for patients with stroke on discharge.

Fewer informal caregivers in this study required informal caregiver training on these aspects, confirming the need to set goals according to the ISSs' needs when planning informal caregiver training (Hafsteinsdottir, et al., 2011). Despite 16%-32% of informal caregivers indicating that they were not trained in assisting in these ADLs, only one participant was uncomfortable in providing assistance with bathing, grooming and eating after receiving informal caregiver training. Bathing was the ADL of most concern in the informal caregiver training programme, since more than half of ISSs required assistance with bathing at discharge and over a quarter of caregiver participants indicated that they did not receive education on bathing as part of the informal caregiver training at the Unit.

Although more than a quarter of caregiver participants indicated that they were comfortable with assisting the stroke survivor with bathing after caregiver training, caregiver participants seemed to perceive training as less effective. This could be either because it was not discussed or not consolidated on discharge. Training at the Unit, on bathing is not done due to various reasons, one being time constraints and availability of informal caregivers during rehabilitation team working hours.

Furthermore, the ISSs' family often expects the nursing staff to bathe the ISS, as it is considered part of the nursing job description. Moreover, nursing staff usually bathe the ISSs in the early morning between 4-5 AM, when family members or informal caregivers are not available to observe or participate in bathing activities with the nursing staff.

The caregiver burden may become less with time as the ISSs become significantly more independent in these activities (Kalra, et al., 2004). At six weeks follow-up, most of the caregiver participants indicated that the ISSs needed significantly less assistance with toileting, managing clothing after toileting, dressing upper and lower body. Assistance was only required for grooming and occasionally for toileting and eating. A similar increase in independence for these activities was reported in an SA study (Msengana, et al., 2019). However, other reports, such as the National Alliance for Caregiving AARP (2020) indicate this improvement in stroke survivor independence may not continue as more time passes and they age.

Notably, after six weeks, the caregiver participants perceived to have significantly fewer problems with not being adequately trained and not being able to perform or being uncomfortable in assisting since they were no longer implementing this aspect of the informal caregiver training. Thus, it appears that the informal caregiver training provided at discharge was either perceived to have effectively prepared the caregiver participants to assist stroke survivors as suggested by Goldberg *et al.* (1997) and facilitate independence or that there was an improvement in ISSs' functionality within six weeks so assistance was no longer required.

5.3.3 Use and application of assistive devices

The use of assistive devices was included in the CME and home rehabilitation programmes when it was observed that the ISSs required some form of compensation to function more independently. Most of the assistive devices provided were wheelchairs and walkers to assist with mobility, with a small percentage of ISSs requiring bath and toilet assistive devices. Wheelchairs were also indicated as the most often used assistive devices in the study done by Wasserman *et al.* (2009), where most stroke survivors were either bed or wheelchair dependent.

More than half of caregiver participants indicated that the stroke survivors used assistive devices at discharge. Surprisingly, less than half of the caregiver participants indicated that they were comfortable with the use and application of assistive devices before informal caregiver training was provided. Thus, caregiver training was not perceived to be effective, and it may be that theoretical formal training on the use and care of assistive devices should be offered before practical training with the device is included in the caregiver training. Krishnan *et al.* (2017) support this need for caregivers of stroke survivors to have information on the stroke survivors' equipment needs.

Moreover, caregivers of stroke survivors have difficulty anticipating the equipment and home adaptation required when caring for a stroke survivor and may not understand the importance of the training required in using these devices (Krishnan, et al., 2017). Furthermore, 12.9% of the caregiver participants indicated that they did not receive informal caregiver training on assistive devices at discharge and another 10% indicated that even after informal caregiver training was provided, they were still unable to apply or were uncomfortable with the use of the assistive devices. The lack of informal caregiver training and practice with assistive devices may also be due to wheelchair maintenance and education being listed specifically on the RHP caregiver training checklist used in this study. Assistive device management is currently listed on the RHP caregiver training checklist as one item and should be adapted to include all assistive devices so the rehabilitation team can ensure training on each one.

Notably, at six weeks post-discharge, the percentage of the ISSs requiring assistive devices had dropped significantly from 61% to 21%. At this stage, there was no statistically significant difference in the caregivers whose perception were that they did not receive informal caregiver training or even after informal caregiver training was provided, they were still not comfortable with the use of assistive devices. Thus, informal caregiver training was perceived as ineffective for 15% of caregiver participants. These findings may have been influenced by the change in the use of alternate assistive devices since there was no longer any use of wheelchairs with a 60% increase in the use of crutches at six weeks post-discharge. Thus, it is important to anticipate change and include caregivers in goal setting and in identifying longer-term stroke survivor needs during caregiver training (Almborg, et al., 2009).

5.3.4 Identification and application of resources

This section considers resources required for return-to-work as well as community resources, which can be accessed by the informal caregivers and ISSs post-discharge. For both return-to-work and return-to-driving, a quarter of the ISSs will not return to work as they are pensioners. Additionally, 16% either did not drive or would no longer drive and therefore caregiver training was not provided to their caregivers.

A third of the caregiver participants indicated that they were unsure about the return-to-work procedures and how to assist the ISS with this. Concerningly, a quarter of these caregiver participants' perception were that return-to-work was never discussed with them and two-thirds of the caregiver participants at discharge indicated they were unsure with assisting the stroke survivor to return to driving. Thus, the perceived effectiveness of informal caregiver training at discharge in terms of training on return-to-work and driving were poor, which suggest that return-to-work might not be a focus area of treatment in the Unit. This may reflect return-to-work and driving not being seen as priorities at discharge by the rehabilitation team since these components are not included on the programme checklist used in this study. Return-to-work and driving usually occur some months post-discharge and need further specialist assessment and intervention (Doucet, et al., 2012; White, et al., 2012). However, the procedure to be followed in determining whether the return-to-work and driving should be addressed in informal caregiver training before discharge.

Despite the limited research on informal caregiver training for return-to-work, one of the strongest predictors of return-to-work within 12 months is independence in ADL (Hackett, et al., 2012). Thus, increasing independence and reducing disability for stroke survivors, as was seen in this study at six weeks post-discharge, is very important to facilitate return-to-work (Hackett, et al., 2012). However, at this stage, a similar number of caregiver participants still experienced uncertainty regarding the procedure to be followed in assisting the ISS with returning to work.

Although fewer caregiver participants indicated they had not received informal caregiver training on return-to-driving procedures six weeks following discharge, this could be attributed to the loss of follow-up in the study. None of the caregiver participants indicated that they understood/knew the return-to-driving procedure. This is of particular concern as this training could not be rectified post-discharge for these caregivers, as the researcher cannot contact them. Thus, the perceived effectiveness of caregiver training in terms of driving was poor.

A similar result was indicated for information on the availability of community resources and support systems, the importance of which has been emphasised by Young *et al.* (2014). The lack of community resources and support systems often leads to caregiver fatigue and conflict between caregivers and stroke survivors (Young, et al., 2014). The availability of community resources is something that is addressed in the more formal planned health care component of the informal caregiver training. However, what is of concern is that more than half of the caregiver participants indicated (at discharge) that community resources were not identified during informal caregiver training. Thus, the perceived effectiveness of caregiver training as far as identifying community resources goes, was considered poor; almost a third of caregiver participants also indicated they had to identify community resources themselves. Correspondingly, they indicated that the resources they identified included care facilities, peer support groups and religious facilities that they could access after discharge. Young *et al.* (2014) agree that the discharge plan determined by the multi-disciplinary team should include information on comprehensive community services including home integration, home health care, primary care providers, counselling and social services, case management, transportation and caregiver relief services.

Furthermore, they conclude that these relief services should include adult day-care and in-home respite to allow caregivers to engage in activities that are important to them (Young, et al., 2014). While White *et al.* (2007) concur that navigation of the health care system and having knowledge of resources are important aspects that should be included in caregiver training programs; this aspect appears to be a deficit in the informal caregiver training offered to informal caregivers in the current study.

5.3.5 Factors influencing informal caregiver training.

5.3.5.1 Attendance of caregiver training

Informal caregiver training could be influenced by the attendance of caregiver training, the informal caregivers' knowledge of and confidence in the caregiver role and the challenges they face in implementing their caregiving activities (Smith & Smith, 2000). However, White *et al.* (2007) emphasise that hands-on practical training using a CME Programme is more effective in preparing caregivers of stroke survivors for their caregiver role. The frequency of attendance of informal caregiver training by most of the caregiver participants in this study was less than five times throughout the ISSs' admission to the rehabilitation centre. Only one caregiver participant indicated that they were never able to attend informal caregiver training during the ISSs' admission.

By the same token, almost a quarter of caregiver participants indicated that they were prevented from attending informal caregiver training sessions more frequently due to work responsibilities. Notwithstanding, more than half of the caregiver participants indicated that they attended informal caregiver training more than five times, with a little over a tenth of the sample attending daily training during the five to eight-week in-patient stay of the ISS. These participants indicated that they attended all available informal caregiver training sessions.

Therefore, the difference in the intensity of informal caregiver training must take the time the informal caregiver has available into consideration. Additionally, cognisance must be taken to structure the informal caregiver training in such a manner that all the necessary information, education and practice of caregiver participants can be done in less than five sessions, if necessary. To accommodate everyone, at least one session should be provided at discharge. The limited informal caregiver training sessions attended by less than half of the caregiver participants may have influenced their perception of the effectiveness of the training. Indeed, the programme requires informal caregivers of ISSs to be present to obtain the opportunity to practice caregiving skills (White, et al., 2007)

5.3.5.2 Continuation of caregiver training after discharge

The majority of caregiver participants did not receive further caregiver training after the ISSs' discharge. The reason for this could be that all but one participant felt relatively well prepared to care for the stroke survivor at discharge and continued to indicate feeling this way at the six-week follow-up. Moreover, emphasis is placed on the need for health professionals to understand that informal caregivers do not always understand the role and responsibilities related to caregiving and therefore may refuse or not attend informal caregiver training. This needs to be mediated in the initial family meetings by providing adequate information from the time of admission with emphasis on the need to assist the ISS with home integration (White, et al., 2014).

5.3.5.3 Roles and responsibilities after caregiver training

In terms of their role and responsibilities, almost half of caregiver participants indicated at discharge that they were able to assist the ISS with their daily routine after they received informal caregiver training. Similarly, just over half of the caregiver participants' perception was that they could 'mostly' or 'sometimes' assist the ISS with their daily routine. Another key point is that most of the caregiver participants rated their knowledge of their caregiver responsibilities quite high, which was evidenced in their perception of the informal caregiver training as effective in providing training on the caregiver responsibilities. However, over two-thirds of the participants also indicated that they were still uncertain about certain aspects at discharge, which needs to be taken into consideration as this may speak to their confidence in assuming the caregiver role.

The confidence of caregivers in their ability to enact their caregiver role may be associated with both the training received as well as the amount of assistance the stroke survivor requires (Molloy, et al., 2008). This was confirmed by the significant increase (90%) of caregivers whose perception it was that they were always able to assist the stroke survivor with their daily routine at six weeks post-discharge. Moreover, this increase may be attributed to changes in the roles and responsibilities of caregiver participants within the home integration and the ISSs' increased independence at this stage.

More caregiver participants indicated 'always' for their knowledge of their caregiver responsibilities, while only 10% indicated 'most of the time' and one participant indicated 'sometimes' at this stage. This could be because the informal caregiver training received has probably been adapted to the home environment and the informal caregivers' anxiety has usually decreased at this stage (Cameron, et al., 2013). Therefore, with experience of caring, the perceived effectiveness of the training was consolidated in terms of both the roles and responsibilities of caregiving in this study.

The caregiver participants identified their roles and responsibilities to be to ensure that the ISS integrates back into the home, follows a healthy diet by preparing food for the ISS and making sure they get adequate sleep and exercise both at discharge and at six weeks. The importance of this aspect of caregiving was emphasised by Krishana *et al.* (2017), as there is a need for caregivers to ensure a healthy lifestyle, specifically the importance of proper nutrition with stroke survivors. Performing exercise and home programmes and taking medication were only identified as more important responsibilities at discharge when the ISSs were perhaps still viewed as ill.

However, the caregiving responsibilities that had changed were assisting the ISS only where needed and driving them around. Added responsibilities that informal caregivers indicated they needed to assume over the six weeks included doing laundry, clipping the ISSs' nails, following a daily routine and massaging the ISS. However, many of the previously mentioned responsibilities that the informal caregivers had at discharge, were no longer required at six weeks post-discharge. These responsibilities included ensuring sleep and rest, assisting with toileting, facilitating the ISSs' independence, supervising walking and transfers, positioning the ISS in a wheelchair, checking their blood pressure and providing a normal sex life.

5.3.5.4 Challenges perceived after caregiver training

The responses to the most difficult aspects of caregiving at discharge by almost half of caregiver participants indicated that nothing was difficult and that everything was easy and presented little challenge. Challenges with occupational performance assistance at discharge were indicated by three participants; they were uncertain and not comfortable in assisting with these aspects. They also indicated difficulties with dealing with the ISSs emotional lability, managing time and not having time for themselves (King, et al., 2010).

More than half of the caregiver participants indicated at six weeks post-discharge that they had no difficulties with caregiving and nearly half of the caregiver participants perceived everything to be easy. The easiest aspects of caregiver responsibilities were to communicate with the ISSs and preparing and feeding the ISSs, which did not change over time. They indicated that improvement in the ISSs' independence and function made caregiving easier. These results support the perceived effectiveness of the informal caregiver training since caregiver strain was perceived to decrease as caregiving became easier. This is supported by Bugge's (1999) findings, that caregivers experienced greater strain four weeks after stroke if they do not receive training.

The caregiver participants further perceived challenges that were very different from discharge to six weeks post-discharge; indicating the ISSs' needs change over time. Two participants indicated either ISSs not knowing their limitations or being overly fatigued and cautious as well as caregivers not having time for themselves as challenges at this stage (King, et al., 2010).

Even so, the changes in responsibilities for informal caregivers over six weeks resulted in three caregiver participants indicating they did not have any knowledge of their responsibilities as informal caregivers at this stage. For these caregivers, it appears that change may not have been anticipated or addressed in the informal caregiver training and they were unable to adapt as their responsibilities changed. Thus, informal caregivers should be educated on this possibility of change. Young *et al.* (2014) similarly identified the changes in informal caregivers' needs as time passed and recommend that transition plans should be provided to informal caregivers of ISSs to address both parties' needs. Plans should be made to assist the informal caregivers when new or different responsibilities arise, to help them in adjusting to the changes - ensuring continued appropriate caregiving for the ISS. Plans for continued virtual support for those caregivers who are struggling with change should be built into the training and home programmes (Young, et al., 2014).

5.4 IDENTIFYING THE PERCEIVED GAPS IN CAREGIVER TRAINING

The third objective of the study was to determine perceived gaps in informal caregiver training by the caregiver participants. These include aspects of training completely absent from informal caregiver training and aspects that require more in-depth training as perceived by the informal caregivers of ISSs. This section also discusses the informal caregiver recommendations to improve informal caregiver training to ensure better outcomes for ISS when discharged after receiving inpatient rehabilitation.

5.4.1 Perceived sufficiency of caregiver training at discharge

The majority of caregiver participants indicated at discharge that the informal caregiver training was sufficient in enabling them to take care of and integrate the ISS back into the home. However, an important aspect often overlooked in the provision of informal caregiver training to informal caregivers of ISSs is the preparedness of the informal caregivers most likely to take care of the ISS post-discharge. According to Young *et al.* (2014), caregivers of stroke survivors should be assessed to determine their commitment, capacity, concerns and preparedness, which they found to be lacking in caregiver training (Young, et al., 2014).

5.4.2 Perceived gaps in caregiver training

At discharge, more than half of the caregiver participants indicated that there were no perceived gaps in the informal caregiver training provided. On the contrary, Young *et al.* (2014) found that caregivers are not appropriately assessed and prepared for the role as caregiver; they still present educational needs and have difficulty applying the training and information they received during caregiver training. Unsurprisingly, a variety of gaps were identified by the caregiver participants.

These perceived gaps seemed individualised to specific caregiver participants, although the informal caregiver training regarding exercises and home programmes was identified to be missing at discharge by the caregiver participants. These exercise and home programmes are usually provided as written handouts to the informal caregivers. White *et al.* (2007) show that the provision of written information is less effective to prepare caregivers for their role as caregivers. Even more caregiver participants perceived this as a gap in training at six weeks post-discharge.

Bathing and bath transfers were also added to the perceived gaps by caregiver participants at this stage. However, fewer caregiver participants indicated no gaps in informal caregiver training at six weeks post-discharge.

The difference in perceived gaps in informal caregiver training from discharge to six weeks varies much. However, the perceived gaps at discharge pertain more to the functional abilities and psychosocial aspects of the ISSs' and family orientation to the Unit. This includes identifying the ISSs care needs, managing stroke survivors' stress and problem-solving abilities. The literature indicates that the psychosocial aspects of a stroke survivor are much more difficult to deal with than the physical difficulties, even after the provision of caregiver training (Cameron, et al., 2014).

Furthermore, a lack of informal caregiver training regarding cognitive stimulation was also perceived as well as specific ADLs, ISS's sex life, sleep, lower body dressing and toilet routine. The literature indicates that even though training through family-led rehabilitation was done, it does not significantly change the death rate of stroke survivors or their dependency but reduces the caregiver's burden of care (Wasserman, et al., 2009). (Lindley, et al., 2017). Furthermore, the stroke survivors' ability to perform toileting seemed to improve after discharge and with time passing whether informal caregiver training is provided or not.

The perceived gaps at six weeks post-discharge focus more on the relationship between informal caregivers and ISSs. This includes how to encourage and motivate the ISS, communicate with the ISS, managing the informal caregiver's own life while looking after the ISS and how to negotiate with the ISS regarding their independence. Even though informal caregivers followed a CME Programme in the Unit, which according to Wang *et al.* (2015) should improve communication between the stroke survivors and caregivers. This was not the experience for the caregiver participants in this study.

Interestingly, the perceived gaps by caregiver participants at discharge were different from perceived gaps at six weeks post-discharge; yet again reinforcing the fact that caregiver needs change over six weeks (Tsai, et al., 2015). Young *et al.* (2014) found that initially, the caregivers require information on stroke clinical information (causes, effects and prevention of stroke, recovery and prognosis of stroke and treatment decisions), practical information on ADL (bathing, toileting, nutrition etc) and information on follow-up care and community resources. However, six months later, the caregivers of stroke survivors require information on the emotions and behaviours of stroke survivors, the physical care of stroke survivors and lastly instrumental care and stroke survivors’ responses to caregiving (King, et al., 2010) (Young, et al., 2014).

5.4.3 Aspects perceived by caregivers to require more in-depth training

Despite more than half of informal caregivers indicating that no further in-depth training was required at discharge, by six weeks post-discharge an even larger proportion indicated that there were aspects that required more in-depth training. The most prevalent topic indicated at discharge and six-week follow-up to require more in-depth training was physical exercise and balance. According to the literature, physical exercise and balance should assist in improving the stroke survivors’ functional outcomes (Galvin, et al., 2011) (Morreale, et al., 2015).

Following physical exercise and balance, bathing (National Alliance for Caregiving, 2020), sexual functioning of the ISS and returning to work were perceived by caregiver participants to require more in-depth training at discharge and the six-week follow-up. Moreover, the importance of sleep and sleep patterns were also perceived to require more in-depth training at both periods in time. However, limited research related to caregiver training and sleep were found. Sleep disorders (insomnia or hypersomnia) are evident in ISSs but large variations in sleep occur (Bakken, et al., 2011). Nonetheless, the research indicates that hypersomnia or insomnia influence stroke survivors’ IADL (Seixas, et al., 2019).

Other specific topics perceived to require more in-depth training at discharge include dealing with stress and managing ISSs’ emotions, which is often deemed more difficult to deal with than the physical difficulties of an ISS. Informal caregivers are unprepared and do not know how to deal with common problems such as the cognitive problems, depression and anxiety, emotional lability, anger, aggression, frustration and apathy that occur in ISSs. Caregivers can more easily see and deal with the physical deficits and often do not understand when these improve that the stroke survivor still has problems with occupational performance (Cameron, et al., 2014). Returning to driving was also perceived to require more in-depth training at discharge, which seems to be a general limitation in informal caregiver training, as studies related to caregiver training in return-to-driving is limited.

Training on speech therapy-related topics were also perceived to require more in-depth training, although the specific details were not provided. Based on the role of the speech therapist, this can vary between feeding, communication and cognitive stimulation. The literature indicates that limitations in cognitive function affect independence and poor communication between caregivers and stroke survivors affects the quality of caregiving provided to stroke survivors (Mellon, et al., 2015) (Pesantes, et al., 2017). PEG tube feeding, often part of the speech therapist's role and medication management were also indicated to require more in-depth training. Rabow *et al.* (2004) indicate that the caregivers of stroke survivors increasingly perform these activities.

Furthermore, informal caregivers indicated (only at six weeks, after home reintegration), that more in-depth training on the ISS returning to their sex life was required. Often, these caregivers are spouses of the stroke survivors and only realise the paucity in the informal caregiver training when this aspect remains missing from their lives (Schure, 1996) (Watanabe, et al., 2015). Further topics that were indicated at six weeks to require more in-depth training include the amount of responsibility involved in caring for an ISS, maintaining a daily schedule and (un)dressing and toileting. These activities are some of the basic activities that caregivers are responsible for when caring for a stroke survivor (National Alliance for Caregiving, 2020).

Furthermore, caregiver participants had the perception that long-term symptoms of stroke require more in-depth training which is consistently indicated by literature to be important aspects included in caregiver training (Kalra, et al., 2004) (Langhorne, et al., 2011). These persistent long-term symptoms of stroke speak to the continued level of independence or disability of the stroke survivor, which in turn affects the caregiver burden experienced by the caregivers.

Lastly, caregiver participants had the perception that training related to better time management by informal caregivers requires more in-depth training. Being able to manage their time better assists the informal caregivers to manage the ISSs' daily routine better. Improved time management ensures better preparation and provides the opportunity to perform the caregiving well. Thus, the burden of care experienced by the caregiver is likely to be reduced too (Pesantes, et al., 2017) (Talley & Travis, 2004) (Kalra, et al., 2004).

5.4.4 Suggestions to improve informal caregiver training

Of all the possible adjustments to informal caregiver training that were suggested by the caregiver participants at discharge, most of the caregiver participants suggested changes to the training sessions and how they are presented. Herbert *et al.* (2016) indicated that caregiver training should be presented in formal and informal programmes (Herbert, et al., 2016) (Mountain, et al., 2020). Alongside this, communication was indicated to be better addressed in informal caregiver training. White *et al.* (2014) indicate that informal caregivers felt overwhelmed and often did not remember the verbal information provided to them. Where written information was provided, they were often unsure whether the information was given to them or another family member (White, et al., 2014).

However, at six weeks post-discharge, more caregiver participants indicated that informal caregiver training on psychosocial aspects should be included. This is in agreement with Hafsteinsdottir *et al.* (2011) who indicated that all training sessions should consist of active participation with caregivers in the information sessions (Hafsteinsdottir, et al., 2011; King, et al., 2010). Effective education and training include hands-on skills training, opportunity to ask questions, interactive workbooks and follow-up sessions to reinforce information provided at training (Mountain, et al., 2020).

Fewer caregiver participants suggested informal caregiver training on psychosocial aspects at six weeks post-discharge than at discharge. Tsai *et al.* (2015) agrees and indicate that training on the management of behaviour and psychosocial aspects were indicated by caregivers' to be required two weeks and three months post-discharge. At discharge, caregivers required information on education, treatment and rehabilitation of the stroke survivor as well as medication and the stroke survivors' physical difficulties (Tsai, et al., 2015).

Interestingly, a few suggestions overlapped between discharge and six weeks post-discharge. However, fewer suggestions were made at six weeks post-discharge, indicating that caregiver participants perceived the informal caregiver training as effective. There was one additional suggestion, which was not indicated at discharge, namely the inclusion of leisure as part of informal caregiver training. Possibly because it is not deemed as an important aspect at discharge, it was only perceived to be lacking at six weeks post-discharge. Krishnan *et al.* (2017) also identified the caregivers' need for stroke survivors to have a healthy lifestyle, which includes social and leisure activities (Krishnan, et al., 2017). Caregiver support and training could be extended post-discharge through the use of telerehab and home visits. According to Wang *et al.* (2015), telerehabilitation and home visits have a significant influence on the communication, social and general recovery of stroke survivors (Wang, et al., 2015). Telerehabilitation improves caregivers' problem-solving abilities, allowing them to view problem-solving as part of daily life and allowing them to assist stroke survivors with ADLs, also improving the caregiver's motivation (Grant, et al., 2002)

5.4.5 Strengths and limitations of the study

A strength of this study is that a homogenous sample was obtained, thus generalisation to other stroke populations is possible. However, careful consideration for caregiver training programs used at other units should be taken into account e.g. use of CME programme vs STAIR etc. Aspects that are important parts of the role of the OT have been excluded from being formally addressed in the caregiver questionnaires. This includes leisure participation as well as cognitive client factors that are important when considering return-to-work and driving. The decreased response rate affected the ability to compare discharge and six week follow-ups, thus the researcher should have considered having participants be excluded from the research if they haven't completed both discharge and follow-up caregiver questionnaires.

CHAPTER 6: CONCLUSION

6.1 INTRODUCTION

As can be seen throughout the study, the informal caregivers of the ISSs perceived both positive and negative aspects with the caregiver training provided at the RHP Rehabilitation Unit. The overall perception of the informal caregiver training were feelings of preparedness to look after the ISS post-discharge after informal caregiver training was received. They perceived informal caregiver training at discharge to be sufficient in preparing them to care for the ISS at home. However, at the six-week follow-up, informal caregivers were more comfortable with their responsibilities as informal caregivers, after having time to adjust to their new role as informal caregiver. Furthermore, more than half of the informal caregivers indicated that they did not perceive gaps in the informal caregiver training as provided by the health care professionals and rehabilitation team at six weeks.

Specific occupational performance perceived to be adequately addressed was the informal caregiver training on transfers and informal caregivers assisting the ISSs with transfers. Health care professionals' ability to identify the need for informal caregiver training on transfers were appropriate as most ISSs were independent in transfers at discharge (Hafsteinsdottir, et al., 2011).

However, perceived gaps in the caregiver training revealed various aspects that needed to be addressed. Although this may be true, the gaps identified and suggested recommendations were individualised. Information on stroke clinical information (cause, signs and symptoms and prevention of stroke) to caregivers of stroke survivors is needed and should be repeated (White, et al., 2014). Equally, specific education on the roles, responsibilities and changes that arise over time is important, as the survivors' functioning and needs change.

Furthermore, the occupational performance area's perceived gaps in the caregiver training included training on bathing and bath transfers. The use and application of assistive devices were also limited and informal caregivers were not comfortable using assistive devices. However, the majority of ISSs were discharged with either a wheelchair or other mobility aid (Krishnan, et al., 2017). Education on leisure activities that the ISSs could participate in in the future should be part of the informal caregiver training at discharge, as these are important for activities health.

Return-to-work is an area that requires focus as uncertainty and in some instances, lack of training were prominent features. Similarly, return-to-driving and assisting ISSs with the process is an area in which informal caregivers require training.

The need for training on exercise, home programs and personalisation of information and practice of skills in keeping with the informal caregivers and ISSs' needs was expressed. Furthermore, a formal and informal presentation of the informal caregiver training should be employed. This includes written information to guide the discussion, as well as images to simplify the written information and the opportunity for them to ask questions related to the informal caregiver training as a much-needed improvement to the training offered at the Unit.

There is a need to facilitate the continuation of informal caregiver support and education after discharge. This will assist informal caregivers of ISSs to adapt to the changing needs of ISSs and the changing roles and responsibilities of the informal caregivers.

Finally, this research demonstrates the need for health care professionals and the rehabilitation team to encourage informal caregivers to attend more informal caregiver training sessions. More than one caregiver training session is required to consolidate aspects learned in caregiver training.

6.2 LIMITATIONS OF THE STUDY

The initial sample size of the study was small and a high number of caregiver participants were lost to follow-up at six weeks post-discharge. Moreover, the sample only included participants in the private sector due to convenience sampling. Thus, data is limited to ISSs who can attend a private rehabilitation unit and their caregivers.

Furthermore, the personal factors related to the caregivers themselves, which could have influenced their perception of the informal caregiver training, were not included. Although the information provided a clear picture of the informal caregivers' perception of the informal caregiver training, deeper enquiry into the responses given by the participants could have enriched the data and provided an enhanced understanding of their perceptions.

The researcher who is a therapist in the occupational therapy department where the research was conducted, collected the data. Although a research assistant interviewed the informal caregivers who had received training directly from the researcher, it is acknowledged that the data collection may have resulted in respondent bias where the participants may not have felt free to provide truthful evaluations, despite the assurance of no consequences to them in this study.

Although the inclusion criteria specified that informal caregivers should have no formal caregiver training, it would have been beneficial to establish the competencies held by the informal caregivers had before the training was given. This may have affected their evaluation of informal caregiver training, especially if they were already comfortable and competent with the skills taught.

6.3 RECOMMENDATIONS

6.3.1 Recommendations for clinical practice

Flexibility in the presentation of informal caregiver training is important, as it equips caregivers in the best way possible. Therefore, as recommended by Young *et al.* (2014), the caregivers' capacity, willingness, preparedness and concerns in caring for the stroke survivor should be assessed prior to the commencement of training.

The opportunity for interaction between therapists and informal caregivers, where their specific questions and concerns can be addressed to facilitate consolidation of informal caregiver training, needs to be created. Informal caregiver training should not be provided to only one informal caregiver of the ISS but possibly to multiple members of the ISSs family.

Additionally, provision of follow-up support for the informal caregiver and continued functional training appropriate for the ISSs' changing functional abilities should be addressed post-discharge, to facilitate continued appropriate care from informal caregivers and independence for the ISSs. The Unit needs to utilise the information derived from this study to enable them to break down and specify the topics to be covered in the informal caregiver training in more detail, thus adapting the caregiver-training checklist.

OTs should take time to consider the need for assistive devices, especially wheelchairs, as a reduction in the use of wheelchairs were seen. Funds are likely to be spent differently in terms of obtaining equipment permanently or renting for a few weeks if the equipment is not used six weeks post-discharge.

6.3.2 Recommendations for future research

Future research to determine whether caregiver training is provided at the appropriate time in the rehabilitation process and when the most appropriate time is to provide caregiver training is required. Within the context of the COVID-19 pandemic, exploration of the effects of COVID-19 and the limited contact permitted between patients and their family members on caregiver training programmes provided for caregivers of stroke survivors should be undertaken. Finally, further research into the personal caregiver factors and their influence on the experience of caregiver training and implementation of taught skills also need to be explored.

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APPENDICES

APPENDIX A – OUTLINE OF CAREGIVER TRAINING PROGRAM OF RITA HENN AND PARTNERS REHABILITATION UNIT, MEDIC-CLINIC MUELMED

Outline of caregiver training program for stroke survivors at Rita Henn and Partners rehabilitation unit at Muelmed Mediclinic

Caregiver training start early in the rehabilitation process and included the multi-disciplinary team.

A. Stroke information and consent

- Written information provided to the family of stroke survivors
- All family members of stroke survivors sign consent for therapy and related activities required in the rehabilitation process.

B. Family meeting

- Within the first week or two social workers at RHP Muelmed organised and scheduled a family meeting with the family of the stroke survivor (patient).
- Meetings were usually attended by the social worker and key therapist, which usually were the PT, OT or ST and key members of the stroke survivors family, those likely to be involved in the long-term care of the stroke survivor.
- The goal of the meeting were to discuss and provide information on the stroke survivors current condition, the rehabilitation plan as well as to start with discharge planning with the family.

C. Two weekly family education

- Family education consisted of family caregivers attending education groups, which consisted of various topics being covered by various members of the multidisciplinary team.

D. Individual education with the main caregiver of the stroke survivor

- One week before discharge all members of the multi-disciplinary team provide individual training to the stroke caregiver with the stroke survivor present.
- Carer training are done on day of discharge to recap everything done by therapy team, but also includes training from nursing staff, dieticians etc.

E. Weekend passes

- Caregiver training is done with the family of the patient before a weekend pass to ensure safety of both the patient as well as the caregiver looking after the patient.
- Training include all members of the multidisciplinary team
- Training al so include all performance areas, physical abilities like mobility and transfers, the use of assistive devices if used by the patient as well as cognitive and behavioural aspects required for short term home reintegration.

F. Continues contact with caregivers of stroke survivors

- Check in with the family weekly either by phone or face to face done by the social workers.
- Follow up on how weekend out went, carer identification or other thing relative to discharge planning.

G. Home programs

- Each member of the multi-disciplinary team provides the stroke survivor and their family with a home program.

H. Stroke Support Group

- Stroke Support groups are held monthly with stroke survivor as well as caregivers of stroke survivors.

CVA Therapy Carer Training Checklist

Patient:

Carer Name/s:

Carer Contact Numbers:

Areas of Carer Training to be covered:	Taught and demonstrated by therapist (name/signature)	Date	Demonstrated by carer (name/signature)	Date
Bed mobility				
Bed to wheelchair transfers				
Positioning				
MOBILITY;				
Wheelchair Mobility				
Walking				
Stairs				
Community Mobility				
Transport & Car transfers				
SELF-CARE;				
Bath transfers				
Bathing				
Shower transfers				
Showering				
Toilet transfers				
Toileting				
Upper body dressing				
Lower body dressing				

Feeding				
Grooming (oral hygiene/shaving/make-up, etc.)				
UPPER LIMB MANAGEMENT;				
Positioning, passives, stretching, active assisted				
Splints/ Pressure Garments				
FEEDING &SWALLOWING;				
Positioning				
Oral Hygiene				
Diet/Consistency				
Compensatory strategies				
Oral Motor Programme				
COMMUNICATION & COGNITION;				
Method and/or communication support strategies				
Cognition Support Strategies				
OTHER;				
Assistive devices education and management				
Wheelchair maintenance & education				
Leisure				
Additional;				

Home Programme;				

APPENDIX B – DEMOGRAPHIC QUESTIONNAIRE

Appendix B

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

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Wits Education Campus

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Caregiver Demographic questionnaire

1. What is your gender?

Male	Female

2. What is your age? __________

3. What is your marital status

Married	Single	Divorced	Live together	Other

Please specify: ____ ________________

4. What is your relationship to the patient?

Spouse	Family	Friend	Not related

Please specify: ____ ________________

5. What is the highest level of education you completed?

No formal schooling	Primary school	Secondary school	Matriculated	Diploma	Degree

Overall amount of years participated in education: ____

6. Employment status

Permanent employment	Temporary employment	Student	Not employed

Please specify your occupation: ____

Work full time	Work part time	Work shifts	Work from home

7. Where do you live?

Rural area	Semi-urban area	Urban area

8. Prior experience as a caregiver

No experience	Little experience (less than 3 months)	Moderate experience (less than a year)	A lot of experience (more than 1 year)

9. Have you received any previous training as a caregiver

Yes	No

Please specify what training and where have you received the training: ____
____
____

10. Who provided the caregiver training to you?

Doctor	Therapist	Other health care professionals	Other

Please specify other: ____
____
____

11. Are you as a caregiver aware of what is wrong with the stroke survivor?

Yes, I know exactly	Yes, I have some idea	No, I don't know at all

Please indicate what you know: ____
____
____
____
____
____

APPENDIX C – THE SADFM (BETA) SCALE

SummitRehab
Physical Rehabilitation Services

Name:

Surname:

		DATE			
	FIM ITEMS		ADMISSION	WEEK 1	Progress Admission / Wk 1
	SELFCARE ASSESSMENT				
A	Eating				-
B	Grooming				-
C	Bathing				-
D	Dressing upper body				-
E	Dresing - lower body				-
F	Toileting				-
	SPINCHTER CONTROL ASSESSMENT				
G	Bladder Managemnt				-
H	Bowel Management				-
	TRANSFERS				
I	Bed; Chair; Wheelchair				-
J	Toilet transfer				-
K	Bath / Shower transfer				-
	LOCOMOTION				
L	Walk / Wheelchair				-
M	Stairs				-
	TOTAL EXCLUDING SPINCHTER CONTROL		-	-	-
	TOTAL ALL		-	-	-
	COMMUNICATION				
N	Comprehension				-
O	Expression				-
	SOCIAL COGNITION				
P	Social Interaction				-
Q	Problem Solving				-
R	Memory				-
	TOTAL ALL		-	-	-
	GRAND TOTAL		-	-	-

INDEPENDENT	7
EXTRA TIME	6
SUPERVISION	5
MINIMAL ASSISTANCE	4
MODERATE ASSISTANCE	3
MAXIMAL ASSITANCE	2
TOTAL ASSISTANCE	1

OCCUPATIONAL THERAPIST ____________________

SPEECH THERAPIST ____________________

PHYSIOTHERAPIST ____________________

APPENDIX D – CAREGIVER TRAINING QUESTIONNAIRES

Appendix D1

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Caregiver Training Questionnaire ______

1. Did you understand the information regarding stroke that was provided by the therapist?

No information was provided	Not at all	A little bit of the information	Half of the information	All of the information

Comments:

____

2. How was the stroke information presented to you?

No information provided	In a group setting	Individually	Written format	Combination of the three	Other

Please specify the combination or other:

____

3. Do you have to transfer the stroke survivor from the wheelchair to the bed and back?

Yes	No	Sometimes

4. Are you able to transfer the stroke survivor from the wheelchair to the bed and back?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

5. Do you have to transfer the stroke survivor from the wheelchair to the toilet and back?

Yes	No	Sometimes

Comments:

---

6. Are you able to transfer the stroke survivor from the wheelchair to the toilet and back?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

---

7. Do you have to assist the stroke survivor with toileting hygiene?

Yes	No	Sometimes

Comments:

---

8. Are you able to assist the stroke survivor with toileting hygiene?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

---

9. Do you have to assist the stroke survivor with toileting managing clothing?

Yes	No	Sometimes

Comments:

---

10. Are you able to assist the stroke survivor with toileting managing clothing?

Patient Indepedent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

---

11. Do you have to assist the stroke survivor with bathing?

Yes	No	Sometimes

Comments:

____

12. Are you able to assist the stoke survivor with bathing?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

13. Do you have to assist the stroke survivor using assistive devices for washing?

Yes	No	Sometimes

Comments:

____

14. Are you able to assist the stroke survivor with using assistive devices for washing?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

15. Do you have to assist the stroke survivor with grooming tasks (Brushing teeth, washing face, shaving etc)?

Yes	No	Sometimes

Comments:

____

16. Are you able to assist the stroke survivor with grooming tasks (Brushing teeth, washing face, shaving etc)?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

17. Do you have to assist the stroke survivor with eating?

Yes	No	Sometimes

Comments:

____

18. Are you able to assist the stroke survivor with eating?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

19. Do you have to assist the stroke survivor with dressing and undressing of the upper limbs?

Yes	No	Sometimes

Comments:

____

20. Are you able to assist the stroke survivor with dressing and undressing of the upper limbs?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

21. Do you have to assist the stroke survivor with dressing and undressing of the lower limbs?

Yes	No	Sometimes

Comments:

____

22. Are you able to assist the stroke survivor with dressing and undressing of the lower limbs?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

23. Do you have to transfer the stroke survivor to and from a car or taxi?

Yes	No	Sometimes

Comments:

____

24. Are you able to do a car or taxi transfer with the stroke survivor?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

25. Do you know how to communicate with the stroke survivor?

Never	Sometimes	Mostly	Always

Comments:

____

26. Does the stroke survivor make use of any assistive device such as splints, AFO's, build up grasps, wheelchair or bath equipment?

Yes	No	I don't know

Please specify which:

____

27. Are you able to use and apply the assistive devices the stroke survivor use?

It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task	Not applicable

Comments:

____

28. Are you able to assist the stroke survivor to follow the return to work procedure?

Not returning to work/ Pensioner	It was not shown to me	Not at all/ Unable to	Require assistance	Aware of the procedure but not sure	Know the procedure

Comments:

____

29. Are you able to assist the stroke survivor to follow the return to driving procedure?

Not applicable/ No license	It was not shown to me	Not at all	Require assistance	Aware of the procedure but not sure	Know the procedure

30. Do you know of any other resources in your community that could assist in the care of the stroke survivor, Please specify:

____

31. Where did you hear about above resources?

____

____

32. Are you able to perform a daily routine with the stroke survivor?

Never	Sometimes	Mostly	Always

Comments:

____

33. Do you know what your responsibilities are as a caregiver?

Not at all	Sometimes	Most of the time	Always

Please specify these responsibilities:

____

____

____

____

34. What is the most difficult part of caring for the stroke survivor?

____

____

35. What is the easiest part of caring for the stroke survivor?

____

____

36. What aspects where you not trained in, but that you feel should have been part of the caregiver training?

____

____

37. Do you feel prepared in caring for the stroke survivor?

Never	Sometimes	Mostly	Always

Comments:

38. How often did you attend caregiver training?

Daily	Weekly	More than 5 times	Less than 5 times	Never

Comments:

38.1 What prevented you from attending caregiver training:

39. Which areas would you have liked more training in?

Comments:

40. Do you feel the training you received was sufficient?

Yes	No

Comments:

41. Any suggestions to improve caregiver training?

Comments:

Appendix D2

UNIVERSITY OF THE
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Caregiver Training Questionnaire – Follow up

____

1. Did you understand the information regarding stroke that was provided by the therapist?

No information was provided	Not at all	A little bit of the information	Half of the information	All of the information

Comments:

____

2. Have you found additional information on stroke since you received caregiver training?

Yes	No

What sources did you use?

____

3. Do you have to transfer the stroke survivor from the wheelchair to the bed and back?

Yes	No	Sometimes

4. Are you able to transfer the stroke survivor from the wheelchair to the bed and back?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

5. Do you have to transfer the stroke survivor from the wheelchair to the toilet and back?

Yes	No	Sometimes

Comments:

____

6. Are you able to transfer the stroke survivor from the wheelchair to the toilet and back?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

7. Do you have to assist the stroke survivor with toileting hygiene?

Yes	No	Sometimes

Comments:

____

8. Are you able to assist the stroke survivor with toileting hygiene?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

9. Do you have to assist the stroke survivor with toileting managing clothing?

Yes	No	Sometimes

Comments:

____

10. Are you able to assist the stroke survivor with toileting managing clothing?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

---

11. Do you have to assist the stroke survivor with bathing?

Yes	No	Sometimes

Comments:

---

12. Are you able to assist the stoke survivor with bathing?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

---

13. Do you have to assist the stroke survivor using assistive devices for washing?

Yes	No	Sometimes

Comments:

---

14. Are you able to assist the stroke survivor with using assistive devices for washing?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

---

15. Do you have to assist the stroke survivor with grooming tasks (Brushing teeth, washing face, shaving etc)?

Yes	No	Sometimes

Comments:

____

16. Are you able to assist the stroke survivor with grooming tasks (Brushing teeth, washing face, shaving etc)?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

17. Do you have to assist the stroke survivor with eating?

Yes	No	Sometimes

Comments:

____

18. Are you able to assist the stroke survivor with eating?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

19. Do you have to assist the stroke survivor with dressing and undressing of the upper limbs?

Yes	No	Sometimes

Comments:

____

20. Are you able to assist the stroke survivor with dressing and undressing of the upper limbs?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

21. Do you have to assist the stroke survivor with dressing and undressing of the lower limbs?

Yes	No	Sometimes

Comments:

22. Are you able to assist the stroke survivor with dressing and undressing of the lower limbs?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

23. Do you have to transfer the stroke survivor to and from a car or taxi?

Yes	No	Sometimes

Comments:

24. Are you able to do a car or taxi transfer with the stroke survivor?

Patient Independent	It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task

Comments:

____

25. Do you know how to communicate with the stroke survivor?

Never	Sometimes	Mostly	Always

Comments:

____

26. Does the stroke survivor make use of any assistive device such as splints, AFO’s, build up grasps, wheelchair or bath equipment?

Yes	No	I don’t know

Please specify which:

____

27. Are you able to use and apply the assistive devices the stroke survivor use?

It was not shown to me	Not at all/ Unable to	Require assistance	Perform it but I am not comfortable	Comfortable with the task	Not applicable

Comments:

____

28. Are you able to assist the stroke survivor to follow the return to work procedure?

It was not shown to me	Not at all/ Unable to	Require assistance	Aware of the procedure but not sure	Know the procedure	Not applicable/ Pensioner

Comments:

____

29. Are you able to assist the stroke survivor to follow the return to driving procedure?

Not Applicable/ No license	It was not shown to me	Not at all	Require assistance	Aware of the procedure but not sure	Know the procedure

30. Have you come to know any additional resources in your community that could assist in the care of the stroke survivor, Please specify:

____

31. Where did you hear about above resources?

____

32. Are you able to perform a daily routine with the stroke survivor?

Never	Sometimes	Mostly	Always

Comments:

____

33. Do you know what your responsibilities now are, as a caregiver?

Not at all	Sometimes	Most of the time	Always

Please specify these responsibilities:

____

____

____

____

34. What is the most difficult part of caring for the stroke survivor?

____

____

35. What is the easiest part of caring for the stroke survivor?

____

____

36. What aspects where you not trained in, but that you have realised should have been part of the caregiver training?

37. Do you feel prepared in caring for the stroke survivor?

Never	Sometimes	Mostly	Always

Comments:

38. Have you received any other caregiver training since discharge of the stroke survivor?

Yes	No

38.1 What training was further done?

38.2 And where did you receive the caregiver training from?

39. Which areas would you have liked more training in?
Comments:

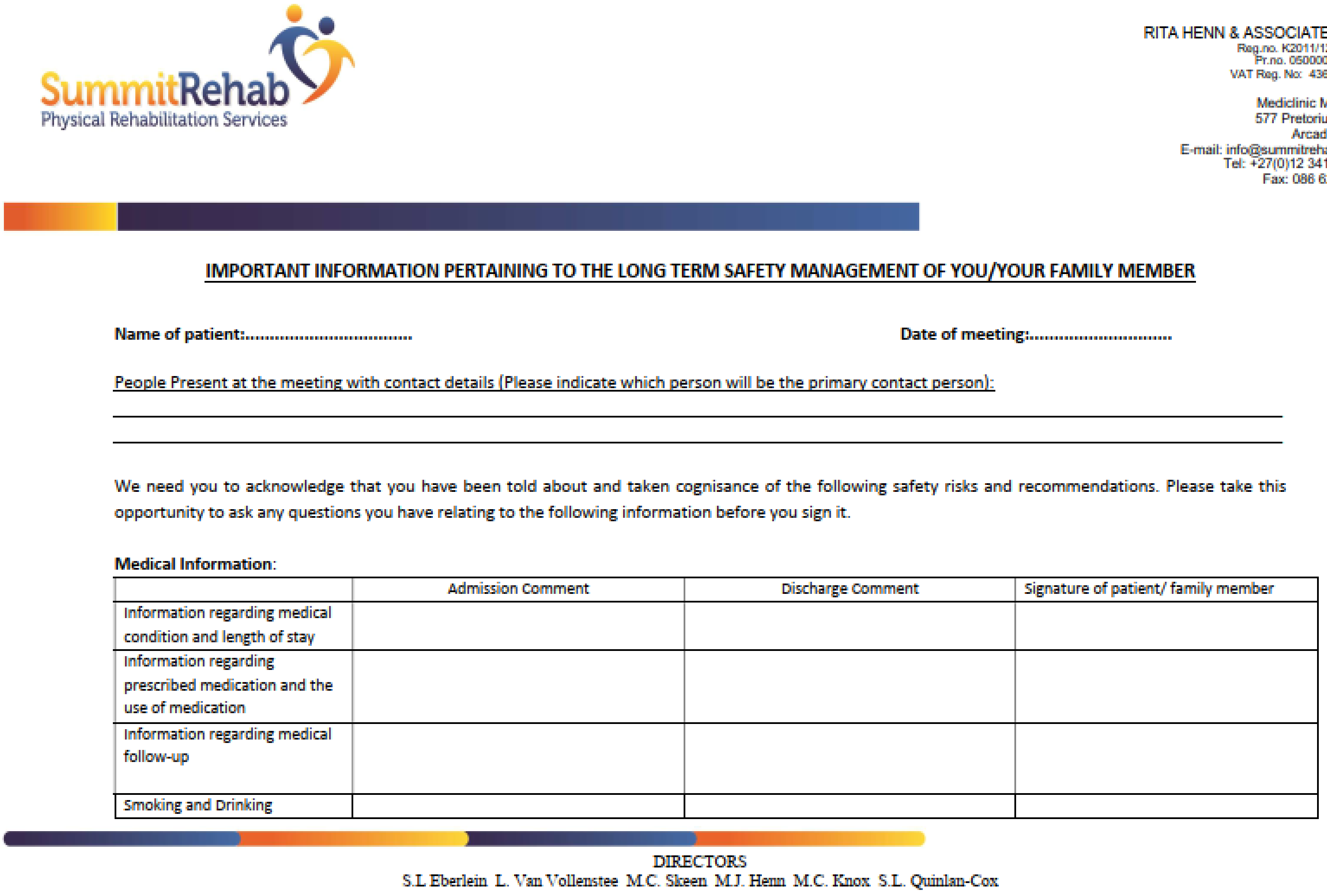
40. Do you feel prepared to care for a stroke survivor?

Yes	No

Comments:

41. Any suggestions to improve caregiver training?
Comments:

APPENDIX E – SAFETY CONCERNS DOCUMENT OF RHP



SummitRehab
Physical Rehabilitation Services

RITA HENN & ASSOCIATES INC.
Reg.no. K2011/122038/21
Pr.no. 0500000523313
VAT Reg. No: 4360265872

Mediclinic Muelmed
577 Pretorius Street
Arcadia, 0083
E-mail: info@summitrehab.co.za
Tel: +27(0)12 341 1909/7
Fax: 086 623 8131

IMPORTANT INFORMATION PERTAINING TO THE LONG TERM SAFETY MANAGEMENT OF YOU/YOUR FAMILY MEMBER

Name of patient:................................. **Date of meeting:.............................**

People Present at the meeting with contact details (Please indicate which person will be the primary contact person):

We need you to acknowledge that you have been told about and taken cognisance of the following safety risks and recommendations. Please take this opportunity to ask any questions you have relating to the following information before you sign it.

Medical Information:

	Admission Comment	Discharge Comment	Signature of patient/ family member
Information regarding medical condition and length of stay			
Information regarding prescribed medication and the use of medication			
Information regarding medical follow-up			
Smoking and Drinking			

DIRECTORS
S.L Eberlein L. Van Vollenstee M.C. Skeen M.J. Henn M.C. Knox S.L. Quinlan-Cox

The use of alternative medicine			
Medical and other administrative functions needed for long term management:			Signature of patient/ family member
Need for chronic medication/chronic medication form signed			
PMB form explained and signed			
Process involved and responsibility take for outpatient therapy should this be indicated			
6 week follow-up			

Nursing:

	Admission Comment	Discharge Comment	Signature of patient/ family member
Information regarding health maintenance			
Bowel and bladder management			
Carer Training needs, responsibility and requirements			
Skin			

Physiotherapist:

	Admission Comment	Discharge Comment	Signature of patient/ family member
Safe transfer techniques			
Physical Impairments and probable implications			
Mobility (in-doors and out-doors)			
Mobility aids needed			

Speech Therapist

	Admission Comment	Discharge Comment	Signature of patient/ family member
Swallowing Precautions, diet and food information.			
Pleasure Feeding and Guidelines/Limitations			
Communication limitations			
Cognitive limitations and decision making ability			

Occupational Therapist

	Admission Comment	Discharge Comment	Signature of patient/ family member
Independence in Self-Care			
Visual limitations			

Fitness to return to Driving			
Fitness to return to work			
Ability to live on own			
Ability to travel unsupervised			
Ability to shop or attend appointments independently			
Process and responsibilities involved in procuring equipment			

Social Worker

	Admission Comment	Discharge Comment	Signature of patient/ family member
Care givers needed/Care suggestions			
Disability grant/Boarding or insurance cover.			

<u>PLEASE NOTE:</u>

DRIVING AFTER STOKE OR HEAD INJURY

Strokes and head injuries result in very similar clinical picture depending on the density of the damage, which areas of the brain were damaged and how large the area of damage was. These include partial or complete paralysis down one side of the body, sometimes with sensory loss resulting in a difficulty knowing where the limb is, or difficulty coordinating movements on that side of the body. Damage to the visual cortex may result in a loss of visual fields. It is very common for people who are affected on the left side of the body to have a blind area on the left and to suffer 'left neglect'. On visual testing you may be able to see in this area, but your brain 'forgets' about this area and you may not notice objects or an activity that is happening on your left hand side. This can be extremely dangerous when driving, so any form of left neglect excludes a person from driving. Even a very mild left neglect becomes exaggerated when driving at speed on the road. Other brain tasks are also affected like attention, concentration and memory resulting in a tendency to get lost, visuo-spatial problems, poor planning judgement and decision making skills and difficulty with multitasking. Often processing a lot of information at once is also difficult which results in slow reaction speeds. Frontal lobe head injuries may result in aggressive and irrational behaviour which may result in road rage. This means that you might not be able to rationally judge the impact that a decision you make may have on another driver which can be extremely dangerous. It is very common for a person to suffer from fits/convulsions/epilepsy, particularly after a head injury. Any form of epilepsy excludes a person from driving until they are stable and there is minimal risk of another fit. The decision as to whether a person is still capable of driving after a stroke or head injury can be extremely difficult. Research has shown that the best way to assess this is by an on-road driving test, done by an experienced driving instructor.

It is important that they work with a therapist who is able to first identify the potential risk areas, before you go onto the road.

DRIVING AFTER SPINAL CORD INJURY

Most people who have suffered a Spinal Cord Injury have the ability to drive an adapted car, however this does depend on the level of injury, upper limb strength and balance and the amount of spasticity present. It is possible to drive with an injury from C5, however a certain level of strength and endurance is required in order to do so and it may be awhile after your injury before this will be possible to attempt. The lower your level of injury the easier it is to learn to drive.

The biggest challenges are transferring into and out of the vehicle, loading the wheelchairs, balance while steering and in higher injuries, steering strength. Where there is paralysis or weakness in both legs the most common adaptations required are hand controls for the brake and accelerator which are fitted to an automatic car. It is important to note that any person who requires any form of adaptation to their vehicle to enable them to drive, is legally required to re-do their driving license.

RETURN TO DRIVING PROTOCOL AT MEULMED:

Step 1: Attend 6 week medical follow-up and get medical clearance to return to driving.
Step 2: Attend a consultation and driving assessment with OPD Team. This assessment will evaluate your vision, cognition and physical abilities as well as visual perceptual abilities.
Step 3: Complete an on-road test with an experienced Driving Instructor.

RETURN TO WORK:

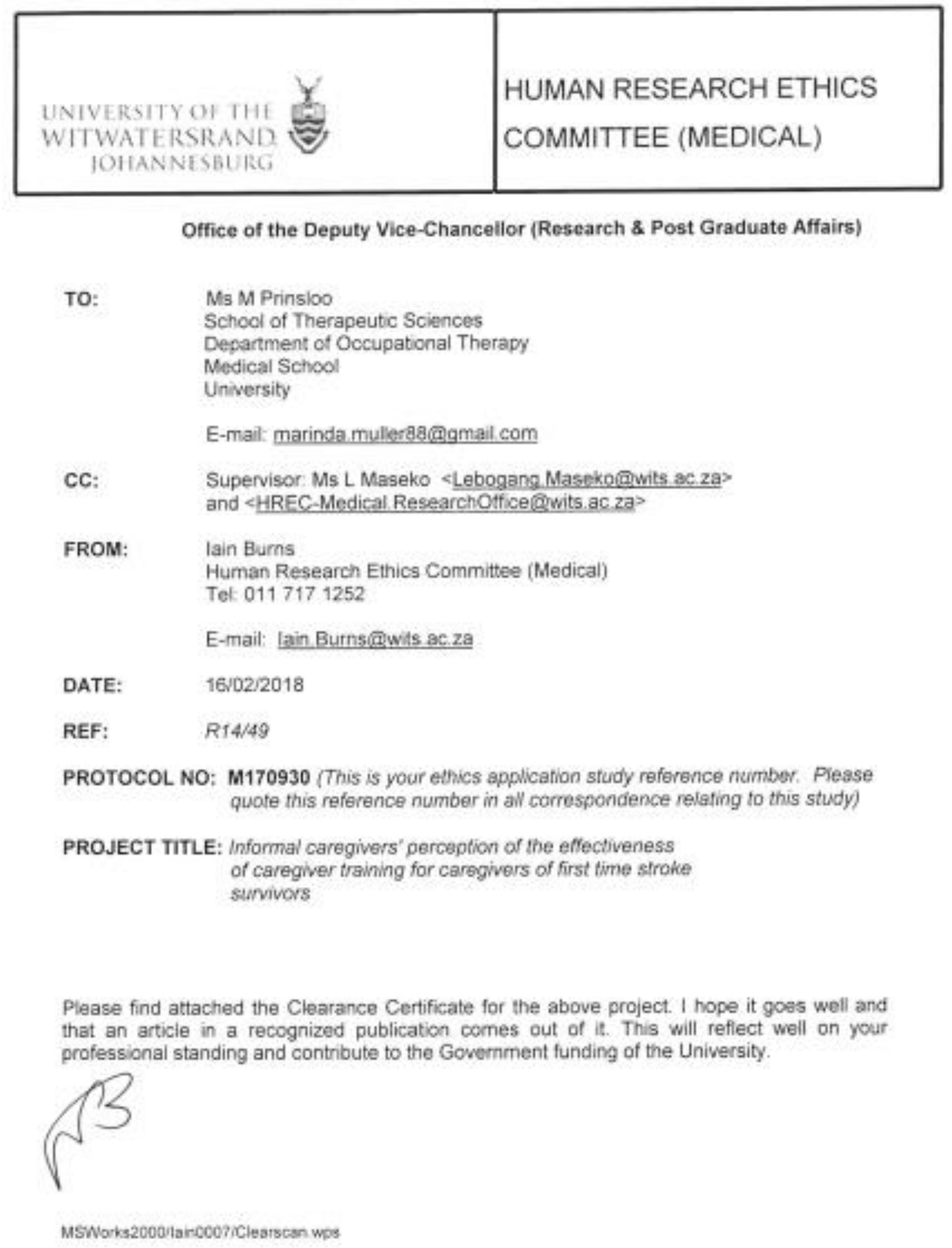
Depending on the physical, cognitive and emotional demands of your work, your fitness to return to work will be determined by the multi-disciplinary team. Once the vocational/work assessment has been completed by the Out-Patient Team and the treating Medical Practitioner and/or Attending Neurologist agrees that the patient is fit to return to work, a graded return to work protocol will be followed for successful return to work.

Feedback from the patient:

Feedback from the family

Should you have any safety concerns or questions relating to the above, please feel free to contact Sister Zenobia on 0845644309 for assistance. If she cannot assist you she will direct you to the right person to do so.

APPENDIX F – ETHICAL CLEARANCE CERTIFICATE



UNIVERSITY OF THE
WITWATERSRAND
JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research & Post Graduate Affairs)

TO: Ms M Prinsloo
School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

E-mail: marinda.muller88@gmail.com

CC: Supervisor: Ms L Maseko <Lebogang.Maseko@wits.ac.za>
and <HREC-Medical.ResearchOffice@wits.ac.za>

FROM: Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 16/02/2018

REF: *R14/49*

PROTOCOL NO: **M170930** *(This is your ethics application study reference number. Please quote this reference number in all correspondence relating to this study)*

PROJECT TITLE: *Informal caregivers' perception of the effectiveness of caregiver training for caregivers of first time stroke survivors*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to the Government funding of the University.

MSWorks2000/lain0007/Clearscan.wps

UNIVERSITY OF THE
WITWATERSRAND
JOHANNESBURG

R14/49 Ms M Prinsloo

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M170930

NAME: **(Principal Investigator)** Ms M Prinsloo

DEPARTMENT:
School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

PROJECT TITLE: Informal caregivers' perception of the effectiveness of caregiver training for caregivers of first time stroke survivors

DATE CONSIDERED: 29/09/2017

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Ms L Maseko

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

DATE OF APPROVAL: 16/02/2018

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on 3rd floor, Phillip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
I/We fully understand the conditions under which I am/we are authorised 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 resubmit to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **September** and will therefore be due in the month of **September** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX G – WRITTEN PERMISSION TO PERFORM STUDY FROM INSTITUTIONS OR PARTIES INVOLVED

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

School of Therapeutic Sciences, Faculty of Health Sciences, 7 York Road, Parktown, 2193, South Africa
Tel: +27 11 717 3701 | Fax: +27 717 3709 | Email: [illegible] | www.wits.ac.za

Date: 22 November 2017

Request for permission to complete research - Charis Psychological services

Manager
Charis Psychological Services

Study title: Informal caregivers' perceptions on the effectiveness of caregiver training for caregivers of first time stroke survivors

To whom it may concern

Introduction to the researcher: I, Marinda Prinsloo, am a practicing occupational therapist employed by Rita Henn and Associates are currently involved in studies for a master's degree in occupational therapy. A requirement for completion of the master's degree in occupational therapy is to complete a research study.

I would like to request your permission to complete the research study at **Muelmed Mediclinic Hospital**, to further the current knowledge of the occupational therapy field in terms of caregiver training.

Information regarding the research study: The research study will investigate informal caregivers perception on the effectiveness of caregiver training provided to the caregivers of first time stroke survivors. It will also assist in identifying the gaps in caregiver training as indicated by the caregivers of stroke survivors. The purpose of this study is to assist with improving the services of caregiver training provided by the rehabilitation team. The study will occur over a period of six months and include 74 participants, in order to collect necessary data. Study participants will be interviewed twice; firstly with the discharge of the stroke survivor from hospital and secondly six weeks post discharge.

The study participant will be expected to complete a researcher administrated questionnaire in the form of an informal interview. The interviews will be done separately from the stroke survivor in a private office, and would last for approximately 45 minutes.

The benefit of participation in the study, could include further caregiver training if the need is identified during the study. No physical discomfort or side effects are expected. No further possible risks has been identified.

All participants will receive the same questionnaire throughout the study therefore no randomisation, placebo or withholding of treatment will occur.

All documentation related to the study will be kept in a locked cabinet off hospital premises and names of the study participants will be substituted with codes in order to ensure confidentiality of information.

Be assured that participation is entirely voluntary and non-participation will be without consequence. Withdrawal from the research study can be done at any time without consequence.

All participants who wish to receive feedback regarding the outcome of the study may receive the information if requested in writing.

If at any point in time during the study a lack of caregiver training is identified the caregivers of the stroke survivor will be referred to a nearby community occupational therapist.

For any further information regarding the research procedure or reporting of study related adverse effects please contact the researcher, Marinda Prinsloo at 061 185 4756, email: marinda.muller88@gmail.com

For ethical questions, concerns or complaints please contact the Chairperson of the ethics committee, Prof P Cleaton Jones at peter.cleaton-jones@wits.ac.za Contact details for the administrative offices: Ms. Z Ndlovu/ Mr Rhulani Mkansi/ Mr Lebo Moeng, Tel: 011 717 2700/2656/1234/1252 or email: Zanele.ndlovu@wits.ac.za; Rhulani.mkansi@wits.ac.za; Lebo.moeng@wits.ac.za

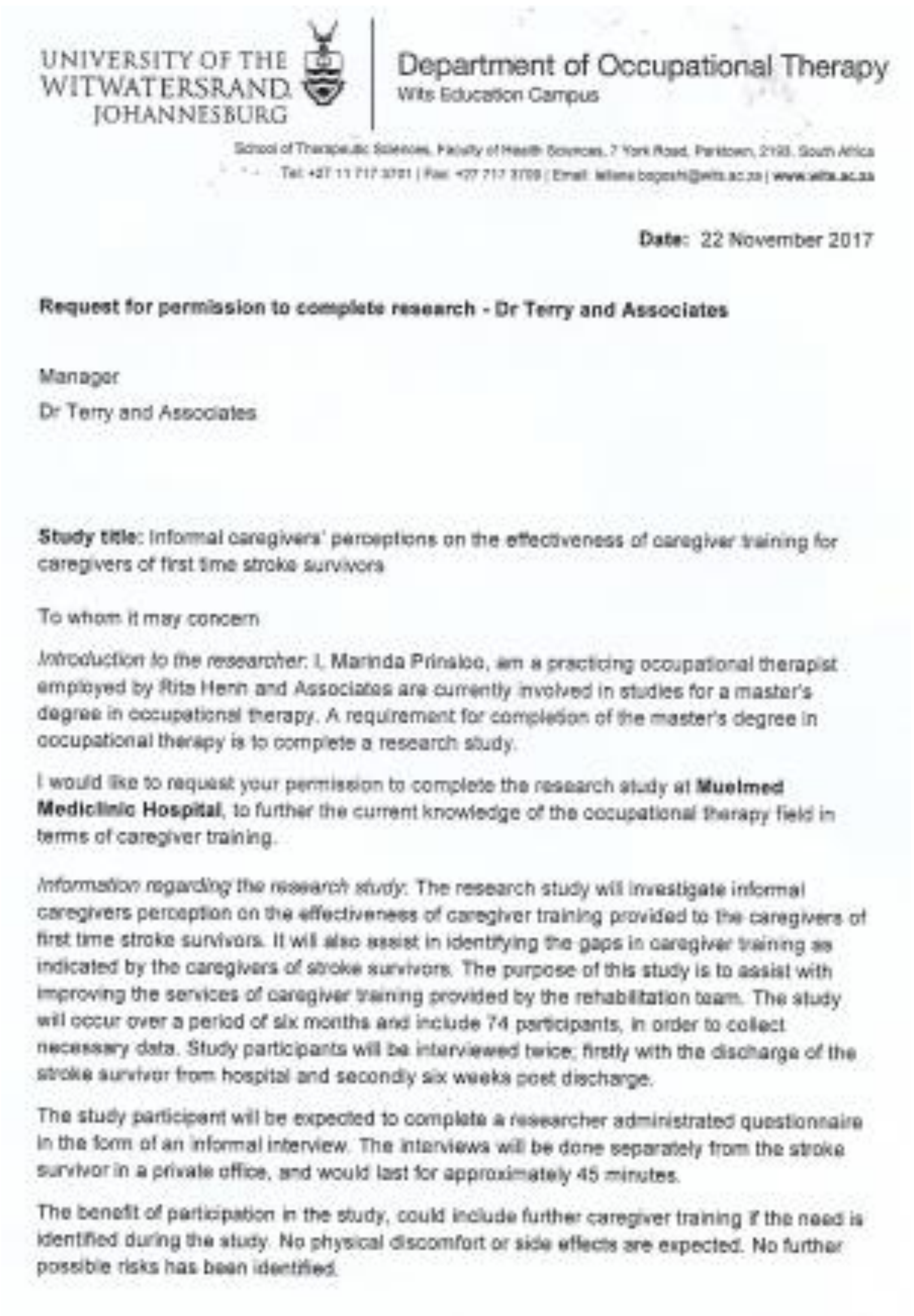
Permission to complete research - Charis Psychological Services

---

Hereby permission is granted to perform the research study at **Muelmed Mediclinic Hospital** from February to August 2018 or until the sample size has been reached.

Signature: ____________________ Date: 29/11 /2017

Witness Signature: ____________________ Date: 29|11|2017



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

School of Therapeutic Sciences, Faculty of Health Sciences, 7 York Road, Parktown, 2193, South Africa
Tel: +27 11 717 3701 | Fax: +27 717 3709 | Email: leliane.bogoshi@wits.ac.za | www.wits.ac.za

Date: 22 November 2017

Request for permission to complete research - Dr Terry and Associates

Manager
Dr Terry and Associates

Study title: Informal caregivers' perceptions on the effectiveness of caregiver training for caregivers of first time stroke survivors

To whom it may concern

Introduction to the researcher: I, Marinda Prinsloo, am a practicing occupational therapist employed by Rita Henn and Associates are currently involved in studies for a master's degree in occupational therapy. A requirement for completion of the master's degree in occupational therapy is to complete a research study.

I would like to request your permission to complete the research study at **Muelmed Mediclinic Hospital**, to further the current knowledge of the occupational therapy field in terms of caregiver training.

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The study participant will be expected to complete a researcher administrated questionnaire in the form of an informal interview. The interviews will be done separately from the stroke survivor in a private office, and would last for approximately 45 minutes.

The benefit of participation in the study, could include further caregiver training if the need is identified during the study. No physical discomfort or side effects are expected. No further possible risks has been identified.

All participants will receive the same questionnaire throughout the study therefore no randomisation, placebo or withholding of treatment will occur.

All documentation related to the study will be kept in a locked cabinet off hospital premises and names of the study participants will be substituted with codes in order to ensure confidentiality of information.

Be assured that participation is entirely voluntary and non-participation will be without consequence. Withdrawal from the research study can be done at any time without consequence.

All participants who wish to receive feedback regarding the outcome of the study may receive the information if requested in writing.

If at any point in time during the study a lack of caregiver training is identified the caregivers of the stroke survivor will be referred to a nearby community occupational therapist.

For any further information regarding the research procedure or reporting of study related adverse effects please contact the researcher, Marinda Prinsloo at 061 185 4756, email: marinda.muller88@gmail.com

For ethical questions, concerns or complaints please contact the Chairperson of the ethics committee, Prof P Cleaton Jones at peter.cleaton-jones@wits.ac.za Contact details for the administrative offices: Ms. Z Ndlovu/ Mr Rhulani Mkansi/ Mr Lebo Moeng, Tel: 011 717 2700/2656/1234/1252 or email: Zanele.ndlovu@wits.ac.za; Rhulani.mkansi@wits.ac.za; Lebo.moeng@wits.ac.za

Permission to complete research - Dr Terry and Associates

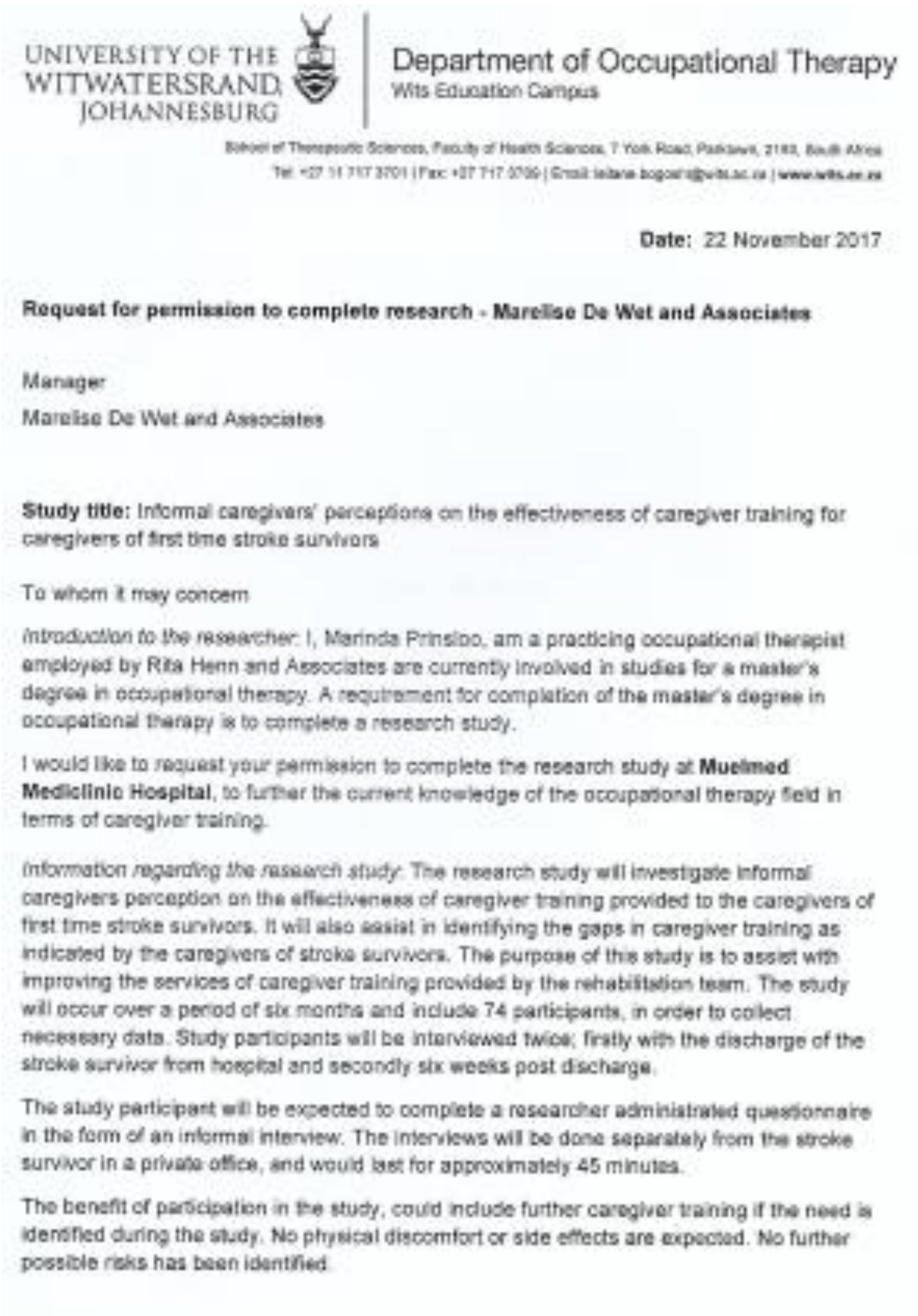
Hereby permission is granted to perform the research study at **Muelmed Mediclinic Hospital** from February to August 2018 or until the sample size has been reached.

Signature: Dr JH Botha

Date: 22/11/17

Witness Signature:

Date: 29/11/2017.



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

School of Therapeutic Sciences, Faculty of Health Sciences, 7 York Road, Parktown, 2193, South Africa
Tel: +27 11 717 3701 | Fax: +27 717 3709 | Email: [illegible] | www.wits.ac.za

Date: 22 November 2017

Request for permission to complete research - Marelise De Wet and Associates

Manager

Marelise De Wet and Associates

Study title: Informal caregivers' perceptions on the effectiveness of caregiver training for caregivers of first time stroke survivors

To whom it may concern

Introduction to the researcher: I, Marinda Prinsloo, am a practicing occupational therapist employed by Rita Henn and Associates are currently involved in studies for a master's degree in occupational therapy. A requirement for completion of the master's degree in occupational therapy is to complete a research study.

I would like to request your permission to complete the research study at **Muelmed Mediclinic Hospital**, to further the current knowledge of the occupational therapy field in terms of caregiver training.

Information regarding the research study: The research study will investigate informal caregivers perception on the effectiveness of caregiver training provided to the caregivers of first time stroke survivors. It will also assist in identifying the gaps in caregiver training as indicated by the caregivers of stroke survivors. The purpose of this study is to assist with improving the services of caregiver training provided by the rehabilitation team. The study will occur over a period of six months and include 74 participants, in order to collect necessary data. Study participants will be interviewed twice; firstly with the discharge of the stroke survivor from hospital and secondly six weeks post discharge.

The study participant will be expected to complete a researcher administrated questionnaire in the form of an informal interview. The interviews will be done separately from the stroke survivor in a private office, and would last for approximately 45 minutes.

The benefit of participation in the study, could include further caregiver training if the need is identified during the study. No physical discomfort or side effects are expected. No further possible risks has been identified.

All participants will receive the same questionnaire throughout the study therefore no randomisation, placebo or withholding of treatment will occur.

All documentation related to the study will be kept in a locked cabinet off hospital premises and names of the study participants will be substituted with codes in order to ensure confidentiality of information.

Be assured that participation is entirely voluntary and non-participation will be without consequence. Withdrawal from the research study can be done at any time without consequence.

All participants who wish to receive feedback regarding the outcome of the study may receive the information if requested in writing.

If at any point in time during the study a lack of caregiver training is identified the caregivers of the stroke survivor will be referred to a nearby community occupational therapist.

For any further information regarding the research procedure or reporting of study related adverse effects please contact the researcher, Marinda Prinsloo at 061 185 4756, email: marinda.muller88@gmail.com

For ethical questions, concerns or complaints please contact the Chairperson of the ethics committee, Prof P Cleaton Jones at peter.cleaton-jones@wits.ac.za Contact details for the administrative offices: Ms. Z Ndlovu/ Mr Rhulani Mkansi/ Mr Lebo Moeng, Tel: 011 717 2700/2656/1234/1252 or email: Zanele.ndlovu@wits.ac.za; Rhulani.mkansi@wits.ac.za; Lebo.moeng@wits.ac.za

Permission to complete research - Marelise De Wet and Associates

---

Hereby permission is granted to perform the research study at **Muelmed Mediclinic Hospital** from February to August 2018 or until the sample size has been reached.

Signature: ____________________ Date: 2017/11/22

Witness Signature: ____________________ Date: 2017/11/22

MEDICLINIC

MEDICLINIC CORPORATE OFFICE
26 DU TOIT STREET
STELLENBOSCH
7600
SOUTH AFRICA

PO BOX 456
STELLENBOSCH
7599
SOUTH AFRICA

T +27 21 809 6500

www.mediclinic.co.za

10 January 2018

Ms Marinda Prinsloo
446 Nieuwenhuyzen Street
Elarduspark
Pretoria
0181

e-mail: marinda.prinsloo88@gmail.com

Dear Ms Prinsloo

PERMISSION TO CONDUCT RESEARCH AT MEDICLINIC MUELMED

Your research proposal entitled *"Informal caregivers' perception on the effectiveness of caregiver training for caregivers of first time stroke survivors (M170930)"* refers.

We provisionally grant you approval to conduct your research at Mediclinic Muelmed, provided that you submit your final ethical approval as soon as possible. Upon receipt thereof we will issue a final approval letter and you may then go ahead and conduct your research.

Looking forward to your soonest reply.

Yours sincerely

Estelle Coustas

DR ESTELLE COUSTAS
Nursing Executive

MEDICLINIC (PTY) LTD

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

School of Therapeutic Sciences, Faculty of Health Sciences, 7 York Road, Parktown, 2193, South Africa
Tel: +27 11 717 3701 | Fax: +27 717 3709 | Email: [illegible]@wits.ac.za | www.wits.ac.za

Date: 22 November 2017

Request for permission to complete research at – Rita Henn and Partners (Summit Rehab)

Manager
Summit Rehabilitation

Study title: Informal caregivers' perceptions on the effectiveness of caregiver training for caregivers of first time stroke survivors

To whom it may concern

Introduction to the researcher: I, Marinda Prinsloo, am a practicing occupational therapist employed by Rita Henn and Associates are currently involved in studies for a master's degree in occupational therapy. A requirement for completion of the master's degree in occupational therapy is to complete a research study.

I would like to request your permission to complete the research study at **Muelmed Mediclinic Hospital**, to further the current knowledge of the occupational therapy field in terms of caregiver training.

Information regarding the research study: The research study will investigate informal caregivers perception on the effectiveness of caregiver training provided to the caregivers of first time stroke survivors. It will also assist in identifying the gaps in caregiver training as indicated by the caregivers of stroke survivors. The purpose of this study is to assist with improving the services of caregiver training provided by the rehabilitation team. The study will occur over a period of six months and include 74 participants, in order to collect necessary data. Study participants will be interviewed twice; firstly with the discharge of the stroke survivor from hospital and secondly six weeks post discharge.

The study participant will be expected to complete a researcher administrated questionnaire in the form of an informal interview. The interviews will be done separately from the stroke survivor in a private office, and would last for approximately 45 minutes.

The benefit of participation in the study, could include further caregiver training if the need is identified during the study. No physical discomfort or side effects are expected. No further possible risks has been identified.

All participants will receive the same questionnaire throughout the study therefore no randomisation, placebo or withholding of treatment will occur.

All documentation related to the study will be kept in a locked cabinet off hospital premises and names of the study participants will be substituted with codes in order to ensure confidentiality of information.

Be assured that participation is entirely voluntary and non-participation will be without consequence. Withdrawal from the research study can be done at any time without consequence.

All participants who wish to receive feedback regarding the outcome of the study may receive the information if requested in writing.

If at any point in time during the study a lack of caregiver training is identified the caregivers of the stroke survivor will be referred to a nearby community occupational therapist.

For any further information regarding the research procedure or reporting of study related adverse effects please contact the researcher, Marinda Prinsloo at 061 185 4756, email: marinda.muller88@gmail.com

For ethical questions, concerns or complaints please contact the Chairperson of the ethics committee, Prof P Cleaton Jones at peter.cleaton-jones@wits.ac.za Contact details for the administrative offices: Ms. Z Ndlovu/ Mr Rhulani Mkansi/ Mr Lebo Moeng, Tel: 011 717 2700/2656/1234/1252 or email: Zanele.ndlovu@wits.ac.za; Rhulani.mkansi@wits.ac.za; Lebo.moeng@wits.ac.za

Permission to complete research at Rita Henn and Partners (Summit Rehab)

Hereby permission is granted to perform the research study at **Muelmed Mediclinic Hospital** from February to August 2018 or until the sample size has been reached.

Signature: ____________________ Date: 22/11/2017

Witness Signature: ____________________ Date: 22/11/2017

APPENDIX H – RESEARCH INFORMATION SHEET

Appendix H

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Department of Occupational
Therapy
Wits Education Campus

School of Therapeutic Science, Faculty of Health Sciences, 7 York Road, Parktown, 2193, South Africa
Tel: (011) 717 2745 | Fax: (011) 717 2119 | Email: leilane.bogoshi@wits.ac.za | www.wits.ac.za

Research Information sheet

Study title: Informal caregivers' perceptions on the effectiveness of caregiver training for caregivers of first time stroke survivors

Greetings Sir/Mam,

I the researcher, Marinda Prinsloo, am a practicing occupational therapist currently involved in studies for a Master's degree in occupational therapy, specifically neurology.

I cordially invite you, to participate in this research study, to further the current knowledge of the occupational therapy field.

The research study will investigate informal caregivers perception on the effectiveness of caregiver training provided to you, the caregivers of your family member. It will also assist in identifying the gaps in caregiver training as indicated by you, the caregivers of your family member. The purpose of this study is to assist with improving the services of caregiver training provided by the rehabilitation team. I hereby request your valued opinion on your experience of the caregiver training and the effectiveness thereof.

The study will occur over a period of six months and include 74 participants, in order to collect necessary data. You, will be interviewed twice; firstly with the discharge of your family member from hospital and secondly with six weeks post discharge. Your consent to access medical records of your family member with a stroke is also requested in order to ensure comprehensiveness of the research study.

You, will be asked to complete a researcher administrated questionnaire in the form of an informal interview. The interviews will be done separately from your family member in a private office, and would last for approximately 45 minutes.

The benefit of participation in the study, includes further caregiver training, for you the caregiver, should the need be identified during the interview. No physical discomfort or side effects are expected as this is a questionnaire completed in the form of an interview. No further possible risks have been identified.

All the participants will receive the same questionnaire throughout the research procedure therefore no randomisation, placebo or withholding of treatment will occur.

All documentation related to the study will be kept in a locked cabinet off hospital premises and your names will be substituted with codes in order to ensure confidentiality of your information.

Be assured that your participation is entirely voluntary and non-participation will be without consequence. Withdrawal from the research study can be done at any time without consequence. If you wish to receive feedback regarding the outcomes of the study, you may receive the information if requested in writing.

If at any point in time during the study a lack of caregiver training is identified, you the caregivers of your family member will be referred to a nearby community occupational therapist.

For any further information regarding the research procedure or reporting of study related adverse effects please contact the researcher, Marinda Prinsloo at 061 185 4756, email at marinda.muller88@gmail.com or my supervisor, Ms Lebogang Maseko, by telephone at 011, 717 3713 or by e-mail at Legogang.Maseko@wits.ac.za

This project has been approved by the Human Ethics Research Committee (Medical) of the University of the Witwatersrand, Johannesburg. 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.

For any ethical concerns please contact the Chairperson of the ethics committee at the University of Witwatersrand, Professor CB Penny on telephone no. 011 717 2301 or by email at “mailto:Clement. Penny@wits.ac.za” Contact details for the Committee secretariat are: Ms. Z Ndlovu or Mr Rhulani Mkansi, telephone nos.: 011 717 2700 or 1234 or email at “Zanele.Ndlovu@wits.ac.za” or “Rhulani.Mkansi@wits.ac.za”

If you are willing to participate in the study outlined above please sign the Consent Sheet below.

Thank you for taking the time to read this Information Sheet.

APPENDIX I – WRITTEN INFORMED CONSENT FORM

Appendix I

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

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Written Informed consent form

Study title: Informal caregivers' perceptions on the effectiveness of caregiver training for caregivers of first time stroke survivors

Greetings
I the researcher, Marinda Prinsloo, am a practicing occupational therapist currently involved in studies for a master's degree in occupational therapy, specifically neurology. I cordially invite you, the caregiver, to participate in this research study.

The research study will investigate informal caregivers perception on the effectiveness of caregiver training provided to the caregivers of first time stroke survivors. The study will occur over a period of six months. You will be interviewed twice, firstly with the discharge of the stroke survivor from hospital and secondly six weeks post discharge. Participation is entirely voluntary and non-participation will be without consequence. Withdrawal from the research study can be done at any time without consequence.

For any questions regarding the research procedure please contact the researcher, Marinda Prinsloo at 061 185 4756, email: marinda.muller88@gmail.com

For any ethical concerns/questions please contact the Chairperson of the ethics committee at the University of Witwatersrand, Professor CB Penny on telephone no. 011 717 2301 or by email at "mailto:Clement. Penny@wits.ac.za" Contact details for the Committee secretariat are: Ms. Z Ndlovu or Mr Rhulani Mkansi, telephone nos.: 011 717 2700 or 1234 or email at "Zanele.Ndlovu@wits.ac.za" or "Rhulani.Mkansi@wits.ac.za"

I,___________________________________,ID ___________________________

hereby give informed consent to participate in the above mentioned research study.

Contact details: ____

Participant signature: Date signed:

________________________ ______________________

Witness signature: Date signed:

________________________ ______________________