



The communication experiences of young adult stroke survivors with stroke-related communication difficulties

by
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Declaration

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Abstract

Background: The rising incidence of stroke among young adults has led to a growing population of survivors experiencing communication difficulties. Existing research highlights their frustration and feelings of invisibility, indicating a lack of acknowledgement of their unique needs in rehabilitation. This study employs the International Classification of Functioning, Disability, and Health (ICF) as a holistic framework to explore the significant impact of stroke-related communication difficulties on young adults.

Research aim: The aim was to describe the communication experiences of young adult stroke survivors with mild to moderate stroke-related communication difficulties who attended a public healthcare facility for speech-language therapy services in the Western Cape. The objective was to obtain information about the participants' 1) communication experiences, 2) communication rehabilitation experiences, 3) communication needs and 4) areas to consider in their communication rehabilitation.

Methods: The study employed a cross-sectional, descriptive phenomenological design. The sample of five young adults, who ranged in age from 26 to 49 years was selected through purposive homogeneous sampling from three different healthcare facilities. Males and females were included with various communication difficulties and comorbid stroke symptoms represented. An interview guide was used for data collection via semi-structured interviews. Thematic analysis based on descriptive phenomenology was used as the data analysis approach.

Findings: The data analysis yielded five main themes describing the experiences of these five young adults with stroke-related communication difficulties. The first two themes emphasize emotions they experienced in relation to communication difficulties as well as adaptation to these difficulties, aligning with the holistic perspective of the ICF. The third theme addresses intrinsic factors to consider when addressing communication difficulties in this population, relating to the ICF's focus on personal factors. Subthemes related to this theme include awareness of their communication difficulties, insight related to the impact of these difficulties, help-seeking behaviour, physical abilities, and alternative and augmentative communication (AAC). AAC emerged as a notable coping strategy, highlighting the multifaceted nature of personal factors influencing its successful implementation. Beyond personal aspects, three subthemes related to the environment shaped the participants' experiences, aligning with the ICF's consideration of environmental factors. These include the environment's impact on participation, communication partners' needs, and their influence on the independence of

young adults with stroke-related communication difficulties. Lastly, the research findings illustrate the need for speech-language therapists (SLTs) to integrate the principles of the ICF into their approach to management of young adult stroke survivors with stroke-related communication difficulties. Considering both personal and environmental factors in training, feedback, and support is vital for facilitating participation in communication for young adult stroke survivors with communication difficulties.

Conclusion: By exploring emotional aspects, personal factors, environmental influences, and the contribution of SLTs, it is possible to develop more nuanced and personalised rehabilitation strategies for young adults with stroke-related communication difficulties. Aligned with the principles of the ICF, such strategies hold the potential to enhance the quality of life, communication, and communication rehabilitation experiences for young adults with stroke-related communication difficulties.

Keywords: Young adults, Stroke-related communication difficulties, International Classification of Functioning, Disability, and Health (ICF), Communication rehabilitation, Descriptive phenomenology

Opsomming

Agtergrond: Die stygende voorkoms van beroerte onder jong volwassenes het gelei tot 'n groeiende bevolking van oorlewendes wat kommunikasieprobleme ervaar. Bestaande navorsing beklemtoon hul frustrasie en gevoelens van onsigbaarheid, wat 'n gebrek aan erkenning van hul unieke behoeftes in rehabilitasie aandui. Hierdie studie gebruik die Internasionale Klassifikasie van Funksionering, Gestremdheid en Gesondheid (ICF) as 'n omvattende raamwerk om die beduidende impak van beroerte-verwante kommunikasieprobleme op jong volwassenes te ondersoek.

Navorsingsdoelwit: Die doel was om die kommunikasie-ervarings van jong volwasse beroerte-oorlewendes met ligte tot matige beroerte-verwante kommunikasieprobleme te beskryf wat 'n openbare gesondheidsorgfasiliteit vir spraakterapiedienste in die Wes-Kaap bygewoon het. Die doelwit was om inligting te bekom oor die deelnemers se 1) kommunikasie-ervarings, 2) kommunikasie-rehabilitasie-ervarings, 3) kommunikasiebehoefte en 4) areas om te oorweeg in hul kommunikasie-rehabilitasie.

Metodes: Die studie het 'n deursnee-beskrywende fenomenologiese ontwerp gebruik. Die steekproef van vyf jong volwassenes, wat in die ouderdom van 26 tot 49 jaar wissel, is gekies deur doelgerigte homogene steekproefneming van drie verskillende gesondheidsorgfasiliteite. Mans en vroue is ingesluit met verskeie kommunikasieprobleme en comorbide beroerte simptome verteenwoordig. 'n Onderhoudgids is gebruik vir data-insameling via semi-gestruktureerde onderhoude. Tematiese analise gebaseer op beskrywende fenomenologie is as die data-analise benadering gebruik.

Bevindinge: Die data-analise het vyf hooftemas opgelewer wat die ervarings van hierdie vyf jong volwasse beroerte-oorlewendes met kommunikasieprobleme beskryf. Die eerste twee temas beklemtoon emosies wat hulle ervaar het met betrekking tot kommunikasieprobleme sowel as aanpassing by hierdie probleme, wat ooreenstem met die omvattende perspektief van die ICF. Die derde tema spreek intrinsieke faktore aan om in ag te neem wanneer kommunikasieprobleme in hierdie populasie aangespreek word, wat verband hou met die ICF se fokus op persoonlike faktore. Subtemas wat met hierdie tema verband hou, sluit in bewustheid van hul kommunikasieprobleme, insig wat verband hou met die impak van hierdie probleme, hulpsoekende gedrag, fisiese vermoëns en alternatiewe en aanvullende kommunikasie (AAK). AAK het na vore gekom as 'n noemenswaardige hanteringstrategie, wat die veelsydige aard van persoonlike faktore wat die suksesvolle implementering daarvan

beïnvloed, beklemtoon. Behalwe vir persoonlike aspekte, het drie subtemas wat met die omgewing verband hou, wat ooreenstem met die ICF se oorweging van omgewingsfaktore, die deelnemers se ervarings gevorm. Dit sluit in die omgewing se impak op deelname, kommunikasievennote se behoeftes, en hul invloed op die onafhanklikheid van jong volwasse beroerte-oorlewendes met beroerteverwante kommunikasieprobleme. Laastens illustreer die navorsingsbevindinge die behoefte aan spraak-taalterapeute (SLT'e) om die beginsels van die ICF in hul benadering te integreer. Die inagneming van beide persoonlike en omgewingsfaktore in opleiding, terugvoer en ondersteuning is noodsaaklik vir die fasilitering van deelname aan kommunikasie vir jong volwasse beroerte-oorlewendes met kommunikasieprobleme.

Gevolgtrekking: Deur emosionele aspekte, persoonlike faktore, omgewingsinvloede en die bydrae van SLT'e te ondersoek, is dit moontlik om meer verfynde en persoonlike rehabilitasie-strategieë vir jong volwassenes met beroerteverwante kommunikasieprobleme te ontwikkel. In ooreenstemming met die beginsels van die ICF, hou sulke strategieë die potensiaal in om die lewenskwaliteit, kommunikasie en kommunikasie-rehabilitasie-ervarings vir jong volwasse beroerte-oorlewendes met kommunikasieprobleme te verbeter.

Slutelwoorde: Jong volwassenes, Beroerteverwante kommunikasieprobleme, Internasionale Klassifikasie van Funksionering, Gestremdheid en Gesondheid (ICF), Kommunikasie-rehabilitasie, Beskrywende fenomenologie

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LIST OF ABBREVIATIONS

AAC - Alternative and augmentative communication

A-FROM - Living with Aphasia: Framework for Outcome Measurement

CAQDAS - Computer-assisted qualitative data analysis software

DP - Descriptive phenomenology

EBP – Evidence based practice

GSH - Groote Schuur Hospital

HH - Helderberg Hospital

HREC – Health Research Ethics Committee

ICF - The International Classification of Functioning, Disability and Health

LPAA - The life participation approach to aphasia

NHRC - National Health Research Committee

NHRD - National Health Research Department

NSH - New Somerset Hospital

POPIA - Protection of Personal Information Act

SLT - Speech-language therapy

TBH - Tygerberg Hospital

WCRC - Western Cape Rehabilitation Centre

WHO - World Health Organization

CHAPTER 1: INTRODUCTION

“Frustrated and invisible” is how a growing population of young adult stroke survivors has been described to feel about their rehabilitation experience, as reported in the insightful qualitative research by Rödning et al. (2003, p. 867). The research by Rödning et al (2003) provides a glance into what young adult stroke survivors experience: a rehabilitation setting which “does not acknowledge the different needs of young stroke patients,” (p. 876). The incidence of stroke is increasing amongst the young adult population (Sultan & Elkind, 2012) yielding a variety of sequelae, including communication difficulties. Research has demonstrated how communication difficulties considerably impact an individual’s ability to participate in everyday life, influencing psychological well-being and social health (Armour et al., 2019; Cruice et al., 2003), and even general rehabilitation outcomes (Hilari et al., 2012).

The International Classification of Functioning, Disability, and Health (ICF) offers a holistic approach to conceptualizing an individual’s experience of a health event in context and will be utilized as a theoretical framework for this study. Advances in the treatment of communication difficulties highlights the importance of adopting a holistic approach, like the ICF, to intervention (Armstrong et al., 2015; Brady et al., 2011; Brown et al., 2010). This approach allows for the consideration of the broader context in which individuals operate (Brown et al., 2010). It includes consideration of the contextual factors and the activities in which individuals need to participate in conjunction with their specific communication difficulties. The impact of stroke-related communication difficulties on young adults is particularly significant, as they often face unique challenges that are different to those of older adults. For example, they may be at a different stage of their life, with different social and occupational demands (Teasell et al., 2000). Additionally, they may not have access to the appropriate support and resources, as stroke is often perceived as a condition affecting the elderly (Rödning et al., 2003). There is, therefore, a need to investigate stroke-related

communication difficulties amongst young adults as it is a growing population who has indicated that their needs are not being met (Röding et al., 2003; Zhang et al., 2022) and who also face unique challenges that differ from those of older people.

The rationale for the study

Approaches to intervention for stroke-related communication difficulties acknowledge the importance of placing the person with communication difficulties at the centre of all decision-making regarding therapy (Armour et al., 2019; Chapey et al., 2000; Kagan, 2011; Kagan et al., 2008; Kagan & Simmons-Mackie, 2007). Research in the field of communication difficulties by Brown et al. (2010) emphasises “communication in everyday contexts” (p. 309) and obtaining the “insider perspective” (p. 1269). As concluded by Wray and Clarke (2017), in order to design care that is tailored to the needs of young adult stroke survivors, it is vital to understand their experiences. More specifically, it is necessary to understand the experience of young adult stroke survivors with communication difficulties as they may have unique needs compared to older individuals in this clinical population.

It is, however, challenging to gain accounts of the experiences of this population due to the nature of communication difficulties, which pose challenges to them communicating their experiences. This may explain the paucity of research aiming to contextualize the experiences of young adults who have stroke-related communication difficulties. It must also be recognized that young adult stroke survivors are a small but significant and growing population, who are often underrepresented in research, highlighting the need to include them in research efforts. The perspective of the young adult with stroke-related communication difficulties may provide a narrative to understand the experiences of having stroke-related communication difficulties as a young adult (Sadler et al., 2014).

For these young adult stroke survivors with resulting communication difficulties, personal factors related to their age and life roles as well as environmental factors specific to the South African context and the context in which these young adults operate, may contribute to the unique needs of this population (Cawood & Visagie, 2015). A better understanding of the communication needs and communication-related rehabilitation experiences of young adults with stroke-related communication difficulties in South Africa may provide valuable insights for informing rehabilitation to suit their unique needs and subsequently improve communication rehabilitation outcomes, as well as general health outcomes, for this clinical population.

The prevalence of stroke, which may result in communication difficulties, is rising amongst young adults and rehabilitation has the potential to improve outcomes post-stroke. Unfortunately, Tawa et al. (2020) reported on the lack of stroke rehabilitation services in South Africa. Furthermore, research has reported on the unmet, long-term and social needs of young adult stroke survivors (Sadler et al., 2014; Wray & Clarke, 2017) and poorer prognosis for stroke survivors with communication difficulties compared to those without communication difficulties (Hilari, 2011). Considering all these factors, a compounded need is highlighted for investigating how communication rehabilitation services for young adults with stroke-related communication difficulties can be optimized. It is important that speech-language therapists (SLTs) managing these individuals consider the unique context and needs of young adults with stroke-related communication difficulties to allow them to deliver services accordingly.

The current research thus aims to describe the communication experiences, the communication rehabilitation experience, and the age-related communication needs of young adults with stroke-related communication difficulties. This information could contribute to the understanding of communication rehabilitation for young adults with stroke-related communication difficulties.

Chapter overview

Chapter 1: Introduction. The first chapter introduces the research topic to the reader and provides a short rationale for conducting the research.

Chapter 2: Literature review. The available literature on stroke and resulting communication difficulties are explored and gaps in the research are identified. In addition, the conceptual framework is set out to develop the argument for the aim and objectives of the research.

Chapter 3: Methodology. The methodological aspect of the research is explored, including the ontological, epistemological, and methodological perspectives of the research. This is followed by the research design and procedure as well as an outline of the data analysis process and ways in which the researcher ensured the trustworthiness of the research.

Chapter 4: Findings and Discussion. The findings section includes the findings of the research, including the themes identified and a discussion regarding the findings.

Chapter 6: Conclusion. Finally, the research is concluded and recommendations for future research as well as the clinical implication of the findings are discussed.

CHAPTER 2: LITERATURE REVIEW

The debilitating consequences of stroke are increasingly being faced by young adults in South Africa (Bertram et al., 2013). Contrary to previously held thoughts on stroke, an increased risk for stroke-related mortality and morbidity has also been reported amongst the young adult population (Balci et al., 2011; Maaijwee et al., 2014). This means that more young adults are losing their lives or living with long-term disability following a stroke. Communication difficulties are some of the common sequelae that can arise from stroke (Legg et al., 2007). Rehabilitation is a key component to reduce not only stroke-related morbidities but possibly even stroke-related mortality (Tawa et al., 2020). A recent scoping review in the African context, however, illustrates that services for stroke rehabilitation are generally sub-optimal and that the lack of these services impacts the social and community reintegration of individuals affected by stroke (Tawa et al., 2020).

The burden of stroke amongst young adults in South Africa

Low and middle-income countries account for approximately 70% of death from stroke and 87% of stroke-related disability (Akinyemi et al., 2021). In 2013, it was estimated that there were 535000 new strokes and a total of 2.09 million stroke survivors amongst people over 15 years of age in Africa (Adeloye, 2014). Between 2009 and 2013, an increase of 10,8% in stroke incidence and 9,6% in stroke survivors was also reported (Adeloye, 2014). Even in 2019, the updated global stroke statistics identified a “consistent increase in stroke incidence” in low and middle income countries (Akinyemi et al., 2021, p.634). More specifically, the highest “age-standardized” stroke incidence rates, independent of the mean age of the population, can be seen in sub-Saharan Africa (Sarfo et al., 2018, p. 1116).

While the incidence of stroke increases with age, a significant and growing proportion occurs in young adults (Crichton et al., 2012). The proportion of strokes that occur in young adults, also differs from country to country, ranging from 5% to 20% (Smajlović, 2015). In

developing countries, the proportion of strokes occurring in younger individuals has reportedly risen from 20% to 30% (Kristensen et al., 1997 and Rajeh et al., 2002 as cited in Balci et al., 2011). Epidemiological data for stroke amongst young adults is, however, lacking in many African countries (Boot et al., 2020). One study, specific to Nigeria and Ghana, reported that 24,3% of the total stroke caseload was younger than 50 years of age (Sarfo et al., 2018). Although the reasons for this trend were not explored, the study concluded that stroke incidence amongst young adults in Africa was high and it is continuing to rise (Sarfo et al., 2018). Current data regarding the incidence of stroke amongst young adults in South Africa could not be obtained, however, a study conducted in 2001 in Kwazulu-Natal, reported that 25.4% of stroke patients were between 15 and 49 years of age (Hoffmann, 2001).

Defining a cut-off age limit for what constitutes a ‘young stroke’ is, however, both challenging and arbitrary (Daniel et al., 2009; Maaijwee et al., 2014). Therefore, variations exist in the age limits for defining ‘young strokes’ (Maaijwee et al., 2014; Smajlović, 2015). Upper age limits have been defined as 45, 50 and 55 years (Maaijwee et al., 2014). However, an overall trend has been observed in the decreasing average age of ischaemic stroke, reflecting an increased incidence of stroke amongst young adults (Boot et al., 2020). This is significant as young adults have a longer life expectancy which contributes to the increase of disability-adjusted life-years attributed to stroke occurring in this population.

Risk factors for stroke amongst young adults in South Africa

Similar to stroke in general, the risk factors for stroke amongst young adults also differ between countries (Balci et al., 2011). Common stroke-related risk factors like hypertension, hypercholesterolemia, diabetes mellitus, and obesity are increasingly being seen in young adult stroke survivors worldwide (Maaijwee et al., 2014). In Africa, undiagnosed hypertension in young adults has been proposed as a contributing factor to the increased incidence of stroke amongst this population (Adeloye, 2014). This may relate to hypertension control rates which

are reported to be the lowest in young adults aged 25 – 34 years (Ibrahim, 1996, as cited in Mensah, 2008). In sub-Saharan Africa, hypertension, dyslipidemia, diabetes, stress, cardiac disease, and low-green vegetable consumption were identified as risk factors for stroke amongst the young adult population (Sarfo et al., 2018).

Within South Africa, non-communicable diseases, such as stroke, also disproportionately affect individuals with a low socio-economic status living in urban settings (Mayosi et al., 2009). The reasons attributed to variations in the disease rate of stroke have included social inequalities (Ferrario et al., 2017), as well as variations in health care and social determinants of health (Kapral et al., 2019). A systematic review by Marshall et al. (2015) further details an association between low socio-economic status and poor functional stroke outcomes, with disparities being reflected in both short and long-term outcomes.

The specific risk factors for suffering a stroke at a younger age and the impact of socio-economic factors are important to consider for the current study as the healthcare context in Africa is challenged by low health literacy, urbanisation, and poorly staffed healthcare facilities, especially in rural areas (Urimubenshi et al., 2018). South Africa, specifically, continues to experience poverty and inequality, having been named “one of the three most unequal countries in the world” (Bhorat & Kambur, 2006 as cited in Kathard & Pillay, 2013, p. 84). Tawa et al. (2020) reported on barriers to stroke rehabilitation service delivery in South Africa such as cost of care, lack of appropriate transport and resources, poor referral processes, geographical distance, and uneven terrain, as well as variable skills and attitudes of service providers. They also reported on challenges related to low service frequency and duration, incomprehensive and fragmented services, lack of trained personnel, and infrastructure limitations (Tawa et al., 2020). All these factors may, therefore, impact not only the incidence of stroke, but also the outcomes following a stroke, potentially leaving more South African stroke survivors with long-term stroke-related difficulties.

The International Classification of Functioning in relation to stroke-related communication difficulties amongst young adults.

The ICF was published by The World Health Organization (WHO) as a contextual framework for understanding the impact of health conditions on the everyday life of the individuals affected (World Health Organization [WHO], 2001). As seen in Figure 1, the integrative model maps out the relationship of six components of health: the health condition, body functions and structures, activity, participation, environmental factors, and personal factors (Geyh et al., 2011).

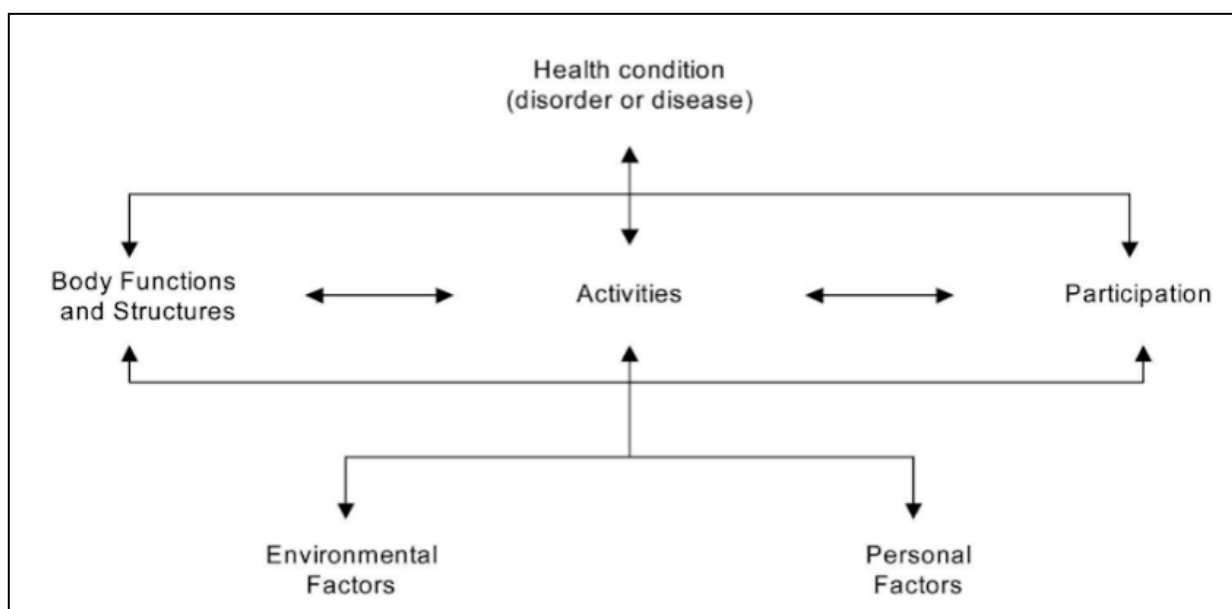


Figure 1. The ICF's integrative model of functioning, disability, and health

The various components will be summarised according to the WHO (2001) descriptions below, with reference to an individual who has suffered a stroke with subsequent communication difficulties. The health condition refers to the disease or disorder, e.g. stroke, aphasia, dysarthria, etc. Body structures refer to anatomical parts, e.g. cortical or subcortical areas of the brain. Body function relates to physiological or psychological functions of the body, e.g. sensory or motor functioning of the speech mechanism, language functioning or cognitive functioning. Activities refer to the functioning of the person and can be defined as

the execution of a task, e.g. answering, or asking a question, making a comment or joke, explaining, or describing, etc. Participation can be described as involvement in a life situation, e.g. sharing ideas, connecting with people, or expressing basic needs. Environmental factors and personal factors are the contextual factors impacting functioning and disability. Contextual factors can either be a barrier (inhibiting factor) or a facilitator (supporting factor) in the rehabilitation process. For example, an individual with a positive attitude may engage better in rehabilitation compared to an individual with a more negative attitude. An individual's attitude can therefore either inhibit desired outcomes or facilitate them.

Personal factors are internal influencers on functioning (WHO, 2001). Personal factors do not occur because of the health condition but rather represent pre-existing traits that can influence an individual's reaction to the changes in their abilities. Subcategories of personal factors have been proposed by the WHO Family of International Classification. These include socio-demographic factors/general personal data, psychological assets/mental factors, personal factors related to disease/disorder (e.g., coping with illness, beliefs about illness), general lifestyle, and school/work-related personal factors (Ciccio & Threats, 2015).

Environmental factors are the external influences on functioning (WHO, 2001). These factors represent the physical, social, and attitudinal environment in which individuals carry out their lives. Environmental factors identified for the person with stroke include their physical surroundings, laws and legislation, policies, social and communicative encounters and society's attitudes and feelings towards the health condition (Green et al., 2015; McCurtin & Clifford, 2015). Cawood and Visagie (2015) identified inhibiting environmental factors specific to South Africa, namely a lack of assets, services, systems, and poor implementation of policies. Approaches based on the ICF may be effective as the framework provides an overarching view of individuals goals while providing a basis for understanding all dimensions of a disabling condition (Worrall, 2001).

SLTs are the health professionals responsible for the communication rehabilitation of stroke patients. Since the development of the ICF in 2001, many researchers in the field of speech-language therapy have used the framework to develop and evaluate treatment approaches for individuals with communication difficulties (e.g. Boles & Lewis, 2004; Brown et al., 2010; Cruice et al., 2003; Howe et al., 2004; Shadden & Hagstrom, 2007).

Long-term and social impacts of stroke-related communication difficulties amongst young adults

Stroke survivors often experience life-long consequences that can significantly affect their daily functioning (Maaijwee et al., 2014; Walsh et al., 2015). As described by the ICF, consequences of stroke can vary widely from physical impairments like motor and sensory deficits, cognitive and communication difficulties, to psychosocial issues like anxiety, depression, and isolation. Communication difficulties are some of the most common impairments resulting from stroke. Around 30% of survivors will present with aphasia, a language disorder, and 42% will be diagnosed with a speech disorder, like dysarthria (Flowers et al., 2013). Language disorders are further classified as either affecting the understanding of language (receptive aphasia), the use of language (expressive aphasia) or both (global aphasia). Motor speech disorders are either related to neuromuscular impairment (dysarthria) or motor planning (apraxia). Communication difficulties can also result from impairment of elementary cognitive processes, such as attention and memory, or more complex cognitive skills, such as thinking, reasoning, and interpersonal communication (Brookshire, 2015).

Communication is a complex skill that involves the exchange of information between two or more individuals, and difficulty with communication can arise from a variety of impairments in function, as described above. The impact of communication difficulties on the everyday life of stroke survivors can be significant as communication is necessary for participation in most activities of daily living (Winstein et al., 2016). Research focusing on

stroke survivors with aphasia indicates that they participate in fewer activities than those without aphasia, even when physical abilities, well-being, and social support are comparable (Hilari et al., 2012). Individuals with aphasia also report that their communication difficulties influence their health-related quality of life (Hilari et al., 2012). Similarly, research on individuals with stroke-related dysarthria reports that the difficulty transcends the physical impairment and that the condition impacts social participation (Brady et al., 2011). It has even been suggested that aphasia is associated with increased mortality rates in the longer term (Laska et al., 2001). These findings highlight the value of considering communication needs in stroke survivors' rehabilitation journeys.

Stroke-related communication difficulties may also be present on a continuum of severity. To illustrate, more severe communication difficulties could be experienced with global aphasia, resulting in severe receptive and expressive language difficulty, or severe apraxia of speech, resulting in little to no functional speech. Less severe communication difficulties, on the contrary, could be experienced with mild dysarthria, which may change the perceptual characteristic of speech only slightly, or mild word-finding difficulty, which could only occur with less frequent words. The degree to which these contribute to activity and participation however relies on the specific needs of the individuals with communication difficulties. For example, if an individual with mild dysarthria has a job like teaching or preaching, it may have a more significant impact on their ability to return to work in comparison to someone who has to return to a job with lower demands to use oral communication.

In a systematic review and thematic synthesis of 32 qualitative studies conducted by Wray and Clarke (2017) on the longer-term needs of stroke survivors with communication difficulties, some of the studies included some young adult participants, however, none of the studies were specific to young adults. Lower age limits of the studies ranged between 29 and

69 years and upper age limits between 69 and 90 years. Their findings highlight consideration of long-term needs and psychosocial factors in the rehabilitation of stroke survivors with communication difficulties. Yet, other researchers have suggested that the difference between stroke in the younger and older population can best be described in terms of the long-term and social impacts of the disease (Cotoi et al., 2018; Maaijwee et al., 2014; Teasell et al., 2000).

The lack of information and psycho-emotional support for young adults is, however, also reported in the acute care setting (Shipley et al., 2020). The study found that young adults faced challenges related to emotions and grief related to their diagnosis but received limited support or counselling. Furthermore, they report the need for their partners to receive information about their mood and emotional challenges as it causes relational strain (Shipley et al., 2020). The long-term consequences of stroke are, however, especially important to consider for young adults as they may have a life expectancy of decades after the stroke.

Wray and Clarke (2017) suggest that stroke survivors feel unsupported and abandoned in the longer term and conclude the need for understanding the experiences of stroke survivors to inform the design of longer-term care tailored to their specific needs. Research on young adult stroke survivors indicates that they experience long-term follow ups as being untailed to their specific needs (Martinsen et al., 2015). Thus, a potential reason for this may be that their experiences are not well understood and therefore their needs cannot be adequately addressed. For the young adult stroke survivor, this translates into feelings of isolation because information and intervention are aimed towards older individuals (Röding et al., 2003; Shipley et al., 2020).

Research further suggests that difficulty in accessing healthcare post-discharge from hospitals significantly contributes to the unmet needs of young stroke survivors (Martinsen et al., 2015). In the African context, the lack of information regarding available healthcare options

has been identified as a major barrier to intervention for the young adult stroke population with communication difficulties (de Beer et al., 2020). Furthermore, individuals with communication difficulties may find it especially difficult to access appropriate healthcare due to challenges scheduling appointments and frequently switching providers due to communication challenges with providers and staff (Stransky et al., 2018). This relates to findings by Morris et al. (2015) suggesting that communication strategies, which can support the effectiveness of communication with individuals with communication difficulties, are rarely being used by healthcare providers.

An important, long-term consequence to consider for young adult stroke survivors is vocation. As Smajlović (2015) indicates, they may be ‘disabled’ for most of their productive working years and many of these individuals are unable to return to work (Daniel et al., 2009; Teasell et al., 2000). Vocation is not only a long-term consequence, but also a known social issue in the rehabilitation of young adult stroke survivors. Young adults are more often still the breadwinner compared to older individuals. They will need to communicate in their current job setting, if they have one, and will need to communicate to be eligible for any job in the future (Wang et al., 2014). In line with this, research specific to the African context identified communicating about finances as an important communication need for the young adult stroke survivor (de Beer et al., 2020). Furthermore, an inability for young adult stroke survivors to return to work has a significant impact on their ability to mobilise and accumulate economic capital (Sadler et al., 2014). This may contribute to the disproportionate economic impact of stroke amongst young adults compared to older individuals, who are more likely to be retired (Smajlović, 2015).

A recent systematic review indicated that 41% of young adult stroke survivors return to work within 0-6 months post-stroke and this number increases to 66% between two- and four-years post-stroke (Edwards et al., 2018). Yet many researchers continue to report on the

lack of sufficient vocational support available for the young adult stroke population (Martinsen et al., 2015; Sadler et al., 2014; Shipley et al., 2020). In addition, stroke survivors with aphasia are less likely to return to work than those without aphasia (Graham et al., 2011). Brown et al. (2011) report that the ability of individuals with aphasia to return to work influences their quality of life. It is, therefore, reasonable to foresee specific and significant communication needs related to vocation for the young adult stroke population with communication difficulties, which need to be considered in rehabilitation aiming to improve quality of life of this clinical population.

Apart from work-related experiences, young adults will go through a variety of phases in their life after a stroke. For example, they may want to get married, start a family, have children and pursue further dreams. Maaijwee et al. (2014) refer to these as important phases in life where life-changing decisions need to be made. When that time comes, individuals with communication difficulties may struggle to discuss and communicate these with the people around them. Therefore, the psychosocial consequences and the communication needs of young adults with stroke-related communication difficulties may change as they progress through these phases of their lives. Sadler et al. (2014) supports this idea, stating that the young adult stroke survivors' expectations of rehabilitative support vary across time points after the stroke.

A variety of additional social issues to be considered for the young adult stroke population have been identified in the research, including effects on family life, childcare issues, high rates of marital separation, anxiety, deterioration of sexual life, and a loss of independence with increased reliance on parents (Daniel et al., 2009; Shipley et al., 2020; Teasell et al., 2000). An understanding of these factors may further aid clinicians to address the low levels of health-related quality of life reported for the young adult stroke population (Naess et al., 2006). For the young adult stroke survivor with resulting communication

difficulties, it may be especially important to consider these factors as Cruice et al. (2003) suggest that individuals' communication abilities can predict their psychological well-being and social health.

In agreement with this, higher rates of depression have been reported amongst stroke patients with aphasia compared to patients without aphasia (Wang et al., 2018). Depression is also independently associated with poorer social and functional outcomes (Clark & Smith, 1998). This means that individuals with stroke-related communication difficulties not only have a poorer prognosis than their counterparts without communication difficulties but that their prognosis may potentially further be compromised due to depression. The identification, prevention and treatment of depression is, therefore, especially important in young adults with stroke-related communication difficulties as the presence of depression might well form part of their experience.

A study specifically focusing on the young adult population with post-stroke aphasia reported a significant change in their social network, or the "structure and 'connectedness'" of their interpersonal relationships (Ellis et al., 2019, p.360). Specific to the South African context, a study indicated that the communication needs of young adult stroke survivors are mostly personal in nature, with the most preferred topic of communication being their stroke and other medical issues (De Grass-Clementson, 2018). The suggestion is that this may relate to young adults' desire to have understanding and empathy from friends and family (De Grass-Clementson, 2018), which may relate to the changes they experience in their social networks.

Social networks have been shown to influence neurological outcomes (Dhand et al., 2016) and the quality of life of stroke survivors (Fotiadou et al., 2014). It is clear how communication difficulties may influence social networks since communication is the basis of social interaction. Therefore, including intervention relating to social networks and social

relationships for young adults with stroke-related communication difficulties, can potentially contribute to improvement in neurological outcomes and health-related quality of life for this population.

In line with the more holistic outlook on disability and health of the ICF, two social approaches to intervention are described in research, namely *The Life Participation Approach to Aphasia* (LPAA) and *Living with Aphasia: Framework for Outcome Measurement* (A-FROM). Both approaches support the idea that outcomes of communication intervention cannot be measured by communicative gains alone (Armour et al., 2019; Boles & Lewis, 2004; Brown et al., 2010; Howe et al., 2004; Kagan & Simmons-Mackie, 2007) and, instead, should also address meaningful participation and quality of life (Armour et al., 2019; Boles & Lewis, 2004).

Chronologically, the LPAA was developed first. More than an approach or model, LPAA is a philosophy of service delivery for individuals with aphasia (Chapey et al., 2000), and also more recently for other communication difficulties (Elman & Holland, 2020). It is composed of several values or principles which aid researchers and clinicians in detailing the communication needs of individuals with communication difficulties. More recently, A-FROM was developed based on the values of the LPAA (Armour et al., 2019).

A-FROM comprises four domains that may describe living with aphasia including the severity of impairment, participation, environmental factors, and personal factors (Kagan et al., 2008). These domains relate closely to the ICF. The severity of impairment relates to the ICF's body functions. Participation relates to the ICF's activities and participation, while environmental factors and personal factors relate to the ICF's contextual factors. Environmental factors relate to the ICF's definition of the environment in which individuals live. The definition for personal factors has been expanded to include personal feelings,

identity, and attitude, in addition to characteristics of the person, such as age, race and gender (Kagan et al., 2008).

As illustrated in Figure 2, the domains as described by Kagan et al. (2008) are broad and overlap with each other, highlighting the interconnectivity of various factors. The figure also demonstrates that each concept relates to the person's experience of 'living with aphasia'. This approach is linked to aphasia, a type of communication difficulty which can be present as a result of a stroke and notably aligns with ICF. Thus, in line with the theoretical framework of this study, exploring the mechanisms by which these domains shape experiences may be needed to describe the essential structure of communication difficulties in young adult stroke survivors.

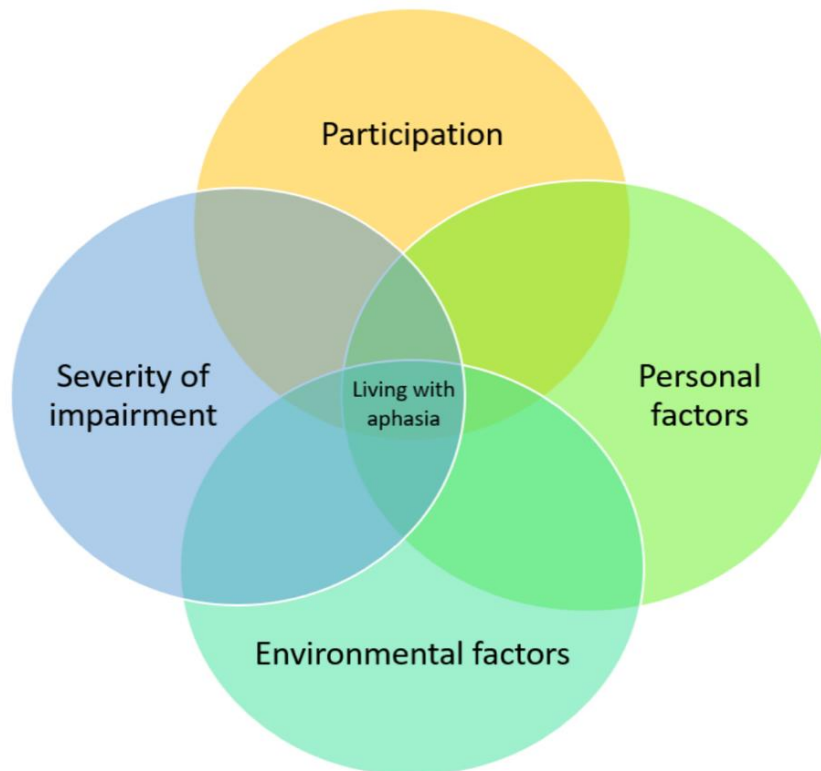


Figure 2. *Living with Aphasia: Framework for outcome measures. Copied from Kagan et al. (2008).*

Conclusion

In conclusion, as supported by the ICF and the related speech-language therapy approach, A-FROM, successful intervention for communication difficulties should move beyond addressing the language impairment itself and includes the broader context of an individual's everyday life (Grohn et al., 2014). Ultimately, understanding the contexts in which young adults with stroke-related communication difficulties communicate is a key step towards the conceptualization of the condition. Research further demonstrates how social participation, emotional health and psychological well-being may influence the quality of life more than language functioning and communication ability (Cruise et al., 2006). Therefore, research focusing on young adult stroke survivors who present with communication difficulties should consider the holistic nature of human experience which would contribute to a true understanding of how communication difficulties impact this clinical population. This is

supported by Brown et al. (2010), stating how a qualitative phenomenological study can be employed to aid understanding of the insider's perspective regarding experiencing communication difficulties. More specifically, they quote Plexico et al. (2005, as cited in Brown et al., 2010, p. 1269) who suggest that the phenomenological approach is important for enriching the understanding of the "complex myriad of personal and experiential factors."

The current study will, therefore, aim to answer the following research question: *What are the communication experiences of young adult stroke survivors with mild to moderate, stroke-related communication difficulties who attended a state-sector health care facility in the Western Cape?*

Research Aim

This study aims to explore the communication experiences of young adults with mild to moderate, stroke-related communication difficulties who received speech-language therapy intervention in a state-sector health care setting in the Western Cape.

Research Objectives

1. To describe the general communication experiences of young adults with mild to moderate stroke-related communication difficulties.
2. To describe the communication rehabilitation experiences of young adults with mild to moderate stroke-related communication difficulties.
3. To describe communication needs of young adults with mild to moderate stroke-related communication difficulties.
4. To identify areas in communication rehabilitation to consider for young adults with stroke-related communication difficulties.

CHAPTER 3: METHODOLOGY

The research methodology will be discussed in the chapter below. It includes the research paradigm, research design, research procedures, and analysis, as well as a discussion on the trustworthiness and ethical considerations of the research.

Research Paradigm

This research study followed a qualitative approach, as this approach is appropriate for obtaining knowledge regarding the experiences of people, everyday practices, and everyday knowledge regarding an issue (Flick, 2007). Certain assumptions must be made clear when undertaking qualitative research to situate the researcher's stance (Creswell & Lewis, 2007). This set of beliefs that guide the research is called a paradigm.

The research paradigm has three major dimensions: ontology, epistemology, and methodology (Sönmez, 2013). Ontology relates to one's belief of what reality is, epistemology entails the belief of how one learns about reality, and methodology is a theorized approach to investigating the reality of a specific problem of a population (Durdella, 2019). Whilst researching paradigms in qualitative research, it was deemed appropriate to situate the research within the constructivist-interpretivist paradigm.

The ontological stance in interpretivism is that reality is socially constructed (Sönmez, 2013). Similarly in constructivism, the belief is that individuals construct their realities based on context, time and culture (Holloway & Galvin, 2021). The epistemological view of constructivist-interpretivism is that one can learn about these realities by assessing the subjective experiences of individuals (Sönmez, 2013). In other words, one can learn about the reality of phenomena by assessing the meaning people assign to them. Therefore, the current research comprises individual interviews with young adult stroke survivors with stroke-related communication difficulties. This research aims to unfold the reality of communication difficulties by assessing the meaning these individuals assign to the phenomenon.

This epistemological stance relates closely to the phenomenological methodology. Phenomenology is used to describe individuals' experiences of phenomena (Jackson et al., 2018). As described by Creswell and Lewis (2007) the phenomenological study reports on the "common meaning for several individuals of their *lived experiences* of a concept or a phenomenon," (p. 57). By situating the research within the phenomenological realm, this research aims to describe what constitutes stroke-related communication difficulties in young adults and thus how this may be experienced by the larger population of young adult stroke survivors with stroke-related communication difficulties, and not just the participants in the study (Creswell & Lewis, 2007).

This paradigm also relates closely to the ICF, a framework to assess the impact of a condition, like communication difficulties, on an individual's level of functioning (WHO, 2001). Within this framework, the influence of contextual factors (i.e., personal and environmental factors) on the reality of having communication difficulties can be conceptualized. The philosophical stance outlined above is thus considered appropriate to ensure that the research remains sensitive to the complex understanding of communication difficulties following a stroke that has already been described in research.

Phenomenology as a research methodology

By designing research on the grounds of phenomenology, the researcher aims to undertake a comprehensive exploration of phenomena, considering both their objective and subjective aspects in full breadth and depth (Davidsen, 2013). Phenomenology is therefore an appropriate methodology for the current study as it aims to describe the communication experiences of young adults with stroke-related communication difficulties. Communication difficulties and related communication rehabilitation are phenomena that are experienced by a growing population of young adult stroke survivors. By following the phenomenological approach, the research aims to describe these experiences as they relate to the younger adult

stroke population who experience communication difficulties. For this population, a greater understanding of these experiences may lead to improved service delivery (Shipley et al., 2020).

Two main categories of phenomenological research exist namely descriptive and interpretive. Chronologically, descriptive phenomenology (DP) was developed first by Husserl, who is considered the father of phenomenology. He originally developed the approach as a philosophy of consciousness which grew into a research methodology aimed at objectively studying human experience (Davidsen, 2013). For Husserl, this was important as he believed that understanding human experience could provide insight into human motivation, as human actions are influenced by their beliefs of reality (Lopez & Willis, 2004). To achieve this objective view, he developed the concept of bracketing. Bracketing refers to putting aside prior knowledge to grasp the *essential structure* of experiences of those being studied (Wojnar & Swanson, 2007).

Building on Husserl's work, a scholar named Heidegger, developed the interpretive approach to phenomenology (Lopez & Willis, 2004). This approach also aims to study human experience but denies the possibility of bracketing. Heidegger believed it impossible for a researcher to remove background understanding from the mind, especially since they developed the research question (Koch, 1995; McWilliam, 2010). Heidegger argues that the expert knowledge of the researcher adds value to the inquiry and deems it to be meaningful (Lopez & Willis, 2004).

Descriptive phenomenology views reality as an individual's subjective conscious experience of the outer world. Researchers bracket out any perceptions they may have of the phenomenon to create an in-depth description that captures the essence of the phenomenon (McWilliam, 2010). Interpretive phenomenology (IP) enquires about experience beyond what is consciously known (Lopez & Willis, 2004). The interpretive phenomenologist will be

concerned with the meaning individuals derive from being in the world and how this influences the choices they make (Lopez & Willis, 2004). This may involve the analysis of historical, social, and political forces that influence the individual's experience (Lopez & Willis, 2004).

Phenomenology is a complex methodology, and a novice researcher may ask whether interpretation does not inevitably involve description and vice versa (McWilliam, 2010). Despite the methodological concerns, the phenomenological approach receives widespread support in the medical field, particularly in stroke rehabilitation. The approach provides a "more complete, holistic, and humanistic framework," of stroke rehabilitation (Goldberg, 2011, p.1). Furthermore, the importance of narrative, adaptations, and the role of context when considering the recovery from stroke, are highlighted with the use of this approach (Goldberg, 2011). Finally, the change in function and transformation of experiences associated with an acquired neurological pathology, like stroke, is appropriate for studying with this approach (Goldberg, 2011).

More contemporary approaches have been developed to overcome some methodological issues, such as Merleau-Ponty's existential phenomenology. In addition, some researchers opt to combine features of both descriptive and interpretive phenomenology (Simeone et al., 2015). However, the methodology relates to the data collection process as well as the analysis thereof, and there are specific differences in how data will be obtained and analysed when using the various approaches. For example, in DP, the interview questions will be very broad and prior knowledge needs to be bracketed, to avoid bias. On the other hand, the interpretive interview will contain specific questions, although still open-ended, as informed by the researcher's knowledge (Lopez & Willis, 2004). Combining approaches is criticized as "mixed discourse" or shifting the philosophical positions "mid-stream" (Giorgi, 1994, as cited in Englander, 2012, p. 14).

To avoid combining the approaches, it was decided to implement DP in the current study. This was considered appropriate as DP lends itself to providing new insight into poorly understood phenomena and research on the experiences of young adults with stroke-related communication difficulties remains limited. As suggested by Brady et al. (2013, p. 194), people with aphasia are “routinely excluded” from research, therefore, the available literature on the population may be limited. The available literature is further constrained as the current research pertains specifically to stroke among young adults. In line with DP, the interview questions were broad to avoid presumptions and the researcher used bracketing whilst analysing the data.

Descriptive Phenomenology

The scientific significance of DP can be understood by a few key concepts outlined below. In DP, the aim is “to provide a foundation for knowledge through the study of ‘*Lebenswelt*’” or Lifeworld (Husserl, 1965 & Husserl, 1999, as cited in Jackson et al., 2018, p. 3311). Within the lifeworld, no separation exists between the subject (participant) and the phenomena. In other words, the phenomena do not exist in isolation and thus the only point of access to the phenomena is through the description of the experiences of participants. For this reason, the primary goal of DP can better be described as developing an understanding of the “phenomenon as experienced by a participant in their lifeworld.” (Jackson et al., 2018, p. 3311). Furthermore, DP aims to capture the ‘essence’ of experiences. In theory, the phenomenologist aims to capture the *universal essence*. However, in research, what would be achieved is the essence as it is generally experienced by a group of people. This is referred to as *morphological essences* as accounts could be different when researched with different participants or at different times (Giorgi, 2009, as cited in Jackson et al., 2018). Accepting this fact defends the trustworthiness of the research by limiting the overgeneralization of findings.

In practice, DP involves analysing concrete and detailed accounts of people’s perceptions and experiences, as described by participants, to derive knowledge. Thus, the aim

is to obtain ‘thick descriptions’ of experiences and not per se descriptions of more people’s experiences. In other words, the richness of descriptions is considered more important than obtaining a larger sample size. All accounts from participants are considered as is, even if fluid or vague (Wertz, 2010). Accepting these characteristics of structures ensures that findings through DP relate more generally to human experiences than merely case studies of participants’ experiences (Davidsen, 2013).

DP also accepts both real and *irreal* accounts of experiences (i.e., objects). “Real objects are located in space, time and causality. An irreal object lacks one or all of these attributes, like a sense of justice or an atmosphere,” (Jackson et al., 2018, p. 3312). In phenomenology, both real and irreal objects are considered to be born out of consciousness, as they are being accounted for by participants. Therefore, both contribute to the understanding of the phenomena. Real objects can exist independently of consciousness, but irreal objects cannot. This again highlights the interconnectedness of the subject and the phenomena. This holistic nature of DP enables the methodology to aim towards understanding the richness and complexity of human experiences.

Husserl labelled the units of consciousness as “intentional acts” or “intentional experiences” (Husserl, 2001, as cited in Jackson et al., 2018). He considers human consciousness as *intentional* as it is always directed towards something. If a subject is conscious, he is aware of something. Therefore, a focus of DP is how consciousness is directed towards objects in the world (Davidsen, 2013). Husserl differentiated between the consciousness directed towards something (noesis) and the ‘act’ of consciousness (noema) (Christensen et al., 2017). The concept of *noema* relates to the significance of how and when the meaning of an experience reveals itself (Jackson et al., 2018). This concept highlights the importance of understanding human consciousness when describing phenomena rather than focusing solely on the objects born from the consciousness.

Research Design

A cross-sectional, descriptive, phenomenological approach was implemented. As detailed above, the DP approach entails the analyses of individuals' accounts of their experiences to identify themes that may relate to the broader population. A cross-sectional study is done at one point in time or during a short period (Levin, 2006). In the current study, semi-structured interviews were conducted to collect data at one point in time. Where necessary, follow-up interviews were conducted to complete the interview schedule. The goal of the follow-up interview was not to obtain information about changes that appeared in the elapsed time but rather to merely complete the interview schedule if it was not completed in the initial interview.

Semi-structured interviews were used in the current study as this method was considered appropriate for studying individuals' perceptions, opinions, complex or emotionally sensitive issues (Kallio et al., 2016), experiences, beliefs, and motivations (Gill et al., 2008). Semi-structured interviews are conversation-based, and the researcher follows the direction of the participant's responses. It provides a natural, yet structured, way to communicate with the participants on a personal level. It allows the researcher to adjust the questions in a way that elicits more descriptive accounts from the participant and to take note of non-verbal information like body language and gestures (Baumbusch, 2010), which would not have been possible with less personal tools, such as surveys.

When using semi-structured interviews, participants' responses are boundless, in contrast to more structured interviews where participants' responses may be limited (Gill et al., 2008). This type of interview structure may facilitate rich and detailed descriptions of the participants' experiences (Baumbusch, 2010). The interview contains a few broad questions related to the topic, with relevant probes that encourage the participant to elaborate on what was said or to redirect them to the topic (Baumbusch, 2010). The questions are broad and open-

ended, which allows for spontaneous and in-depth responses from participants (Baumbusch, 2010; Creswell & Lewis, 2007). Utilising prompting when needed or appropriate further allows for more in-depth information to emerge (Galetta, 2012, as cited in Kallio et al., 2016). It allows for the discovery of issues that are meaningful to the participants themselves and in turn for diverse opinions to be revealed.

One possible limitation of the use of semi-structured interviews is that unnecessary data, not relating to the research question, may be collected (Kallio et al., 2016). This may result in an unnecessarily time-consuming interview. In addition, the ethicality of collecting data that does not relate to the research aims is uncertain (Gibbs et al., 2007). Another limitation of semi-structured interviews is the possible lack of consistency in the way questions are presented and the subsequent impact this could have on the responses from participants (Turner, 2010). This may occur in different interviews with the same interviewer and, more often, where different interviewers conduct the interviews. To maintain consistency in the information received by the participants, a script was formulated for use at the start and end of the interview.

Researcher

The researcher is a 26-year-old female, qualified Speech-Language Therapist (B. Speech-, Language and Hearing Therapy (Hons)) who obtained this undergraduate degree from Stellenbosch University and is pursuing a master's degree from the same institution. During her pursuit of a master's degree, she worked and has continued to work in acute and rehabilitation settings servicing adults with acquired communication and swallowing difficulties. She is fully bilingual (Afrikaans and English). Her special interests include neurogenic communication difficulties in individuals with brain injuries.

By providing a detailed account of the researcher's qualifications, including her age and status as a qualified Speech-Language Therapist with a specific focus on neurogenic

communication difficulties in individuals with brain injuries, the research context becomes transparent. Explicitly mentioning her academic background and professional experiences helps establish a foundation for understanding her potential biases, perspectives, and expertise in the field.

This transparency was considered crucial for promoting bracketing as it allows both the researcher and the audience to acknowledge and, to the best extent possible, set aside any preconceived beliefs or assumptions that might influence the research process. By openly sharing the researcher's background, the aim is to enhance the credibility and reliability of the study by acknowledging potential influences and consciously working towards an unbiased exploration of the research topic. In this way, the researcher aimed to demonstrate commitment to the principles of bracketing, fostering a more authentic and reflexive research process.

Study setting

The research was conducted in the Western Cape in South Africa. The participants were recruited from public healthcare facilities in the Western Cape. Initially, only three facilities were identified as recruitment sites, and included two tertiary level hospitals, Groote Schuur Hospital (GSH) and Tygerberg Hospital (TBH) and an in-patient rehabilitation facility (i.e., Western Cape Rehabilitation Center, WCRC). Following the pilot study, an application was completed for adding 10 additional facilities to the recruitment pool, to expedite the recruitment process. This was considered appropriate as the research was constrained by time, as it formed part of a master's degree programme. The facilities were selected as all provide speech-language therapy services which include services for individuals with stroke-related communication difficulties.

Of the 10 additional sites applied for, approval was received for only four. Approval for recruitment was not obtained from Bishop Lavis Rehabilitation Centre, Mfuleni Clinic, Michael Mapongwana Clinic, Nolungile Clinic, Khayelitsha Hospital, or Karl Bremer

Hospital, despite repeated follow-up on the process by the researcher. Table 1 shows the facility name, location and category of facilities included in the recruitment, pilot study and main study.

Table 1

Facilities included in recruitment and inclusion in current study

FACILITY CATEGORY	FACILITY NAME	LOCATION	INCLUSION IN CURRENT STUDY
Tertiary Hospital	Groote Schuur Hospital	Observatory, Cape Town, South Africa	Pilot Study and Main Study
	Tygerberg Hospital	Bellville, Cape Town, South Africa	Pilot Study and Main Study
Regional Hospital	New Somerset Hospital	Green Point, Cape Town, South Africa	No recruited participants included
District / Provincially Aided Hospital	Helderberg Hospital	Somerset West, Stellenbosch, Boland, South Africa	No participants recruited
Clinic	Khayelitsha Site B Clinic	Khayelitsha, Cape Town, South Africa	No participants recruited
	Macassar Clinic	Khayelitsha, Cape Town, South Africa	No participants recruited
Specialised Health Care Facility	Western Cape Rehabilitation Centre	Mitchells Plain, Cape Town, South Africa	Pilot Study and Main Study

Note. The facility name, location, and facility category of the seven facilities included in the study (Western Cape Government, 2023a).

TBH and GSH are the only two tertiary hospitals servicing the adult population in the Western Cape. Being tertiary hospitals, these facilities provide the highest level of specialist care. Being the only two tertiary care facilities in the province, referrals to the facilities come from across the province, from both primary and secondary care facilities.

New Somerset Hospital (NSH) is one of five regional hospitals in the province. NSH services the Cape Town Central Health District of the Metro Region. A regional hospital provides more specialist services than a district or provincial hospital and services a geographic area larger than a single area. One district or provincially aided hospital was also included,

namely Helderberg Hospital (HH). This facility only services patients from its geographical area, namely Somerset West.

The above-mentioned facilities provide both in-patient and out-patient speech-language therapy services. Thus, participants recruited from these facilities could have been identified in the acute stage following the stroke, or later in their recovery.

Two clinics were added to the recruitment list. Clinics are primary healthcare facilities and provide general, primary care to individual communities. Site B Clinic and Macassar Clinic were added as recruitment sites. These clinics are known to provide speech-language therapy services to adults who have suffered a stroke.

The WCRC is a specialized rehabilitation centre treating, amongst others, patients with acquired brain injury, including strokes. The centre provides in-patient rehabilitation services to patients from across the Western Cape. The facility accepts referrals from primary, secondary, and tertiary-level health services. Patients can also refer themselves to the out-patient clinic for assessment and management. (Western Cape Government, 2023b)

The different categories of facilities were selected as they represent the range of levels of health care facilities in the Western Cape where potential participants could receive speech-language therapy intervention. The specific facilities were also chosen as they were conveniently located for the researcher to access. However, the range of facilities included also covers a comprehensive catchment area as referrals from the tertiary hospitals and the WCRC may come from across the province. Accessibility in terms of time and financial resources was an important consideration for the current study as it was done for degree purposes, which imposed time and resource constraints. The researcher was also familiar with and had clinical experience and insight into the services available at the facilities as she had either worked at some of these facilities as a student or as a qualified SLT or had experience with referring to and receiving referrals from the facilities.

The public healthcare sector services 84% of the South African population (Pillay, et al., 2020). Thus, the vast majority of South Africans make use of healthcare in the public sector. The profile of stroke survivors serviced at public health facilities may, therefore, include individuals of all ages, ethnicity, and languages in the province (e.g., English, Afrikaans and isiXhosa).

Sampling

Sampling method

Purposive sampling was utilized to identify young adults with communication difficulties resulting from a stroke. A purposive sampling method allowed the researcher to find a closely defined group of people to whom the research question is significant (Anney, 2014; Groenewald, 2004). This sampling method is extensively used in qualitative research as it allows for the consideration of how certain characteristics influence a topic. Purposive sampling is a non-probability sampling method where the researcher deliberately chooses participants based on the qualities they possess (Etikan, 2016). The participants were selected based on predetermined selection criteria relevant to the study objectives (Guest et al., 2006). Table 2 provides a summary of the criteria used for the selection of participants.

Homogeneous sampling, which is a form of purposive sampling, was employed in the current study. Here, candidates who share certain characteristics are included to discover how these characteristics relate to the topic under study (Etikan, 2016). This is relevant to the current study, as the research specifically aimed to describe the communication experiences of the young adult stroke population with stroke-related communication difficulties.

A limitation of this sampling method is that the researcher is subjective in the process, thus bias may arise (Etikan, 2016) and this may influence the generalizability of the findings. However, this research aims to provide in-depth descriptions of a specific population's

experiences. The quality of the description of these individuals' experiences is, therefore, more important than the generalizability of the findings.

Inclusion and exclusion criteria

The recruitment and selection of participants were guided by specific criteria aimed at identifying individuals for whom the research question holds significance and who can provide insightful reports on their experiences. The criteria were intentionally broad to encompass a wide range of potential participants, thereby ensuring an inclusive approach and minimizing researcher bias in the selection process. The process of bracketing was rigorously applied to ensure that the researcher's assumptions did not influence participant selection. In addition, the reason for the chosen criteria is made explicit to support the dependability of the finding. This approach was iterative, involving a critical examination of how the sample aligns with the established criteria. Information about this was reported in a comprehensive description of the sample in the results section below. The following criteria were used to guide the recruitment and selection of participants.

Table 2

Participant inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
A diagnosis of a first stroke.	Any additional neurological diagnoses or previous strokes
Diagnosed stroke-related communication difficulties, which included aphasia and/or apraxia of speech and/or dysarthria and/or cognitive-linguistic impairment.	Any additional communication difficulties not related to the stroke such as developmental language delay, voice disorders, fluency disorders, etc.
The severity of the communication disorder is mild to moderate.	Severe communication difficulties.
Received at least two speech-language therapy sessions for stroke-related communication difficulties as an in- or out-patient.	Speech-language therapy input prior to the stroke-related communication difficulties.

Participants had to be aware of their communication difficulties.	Mental health difficulties which influence an individual's perception and insight, e.g., schizophrenia and psychotic disorders and dissociative and somatic disorders.
Participants could be speakers of English and/or Afrikaans, and/or isiXhosa.	Participants are not Afrikaans, English or isiXhosa speakers.
Participants had to be 18-50 years of age.	Participant younger than 18 years or older than 50 years.
Participants had to have spent at least two weeks at home since the onset of their stroke.	Participants spent less than two weeks at home since the onset of their stroke.

Inclusion criteria

A diagnosis of first stroke. For the current study, it was important that the stroke was the first stroke, and that no other neurological diagnosis was present. This was considered appropriate as a previous stroke/s or any other acquired neurological diagnosis may have resulted in previous engagement with the healthcare system, neurological difficulties, and communication difficulties which may influence their experiences of stroke-related communication difficulties.

Communication difficulties. Participants could present with any communication difficulties secondary to the stroke, i.e., aphasia, dysarthria, apraxia of speech, neurogenic stuttering, or cognitive-linguistic impairments.

Severity of communication difficulties. Due to the nature of the data collection process of the study (i.e., an interview), the severity of the communication difficulties of participants had to be mild to moderate. The severity of the communication difficulties was not used as a criterion to study the specific population. Instead, it was considered to ensure that participants could effectively participate in the interview process. The definitions are, thus, not related to what had been reported in research, as the goal of defining the severity levels was merely to include participants who would be able to engage in an interview. As the severity of stroke-related communication difficulties has not been standardized, the definition was

provided to the recruiting SLTs as well as the rationale for it, i.e., to ensure participants are able to participate in an interview, for them to consider the appropriateness of candidates to be referred.

For the current study and considering the rationale for providing a working definition, mild to moderate communication difficulties was described as follows. Receptive language skills needed to be on at least a complex sentence level, in other words, an understanding of more syntactically complex sentences, as well as sufficient working memory to process these. Expressive language skills had to be at least on a sentence level and connected speech had to be intelligible to unfamiliar conversational partners on a sentence level. This ensured that participants could adequately participate in the interview by ensuring comprehension of the interview questions, ability to answer the interview questions, and sufficient speech intelligibility for the researcher to understand their responses.

Speech-language therapy input received. Suitable participants were required to have received at least two speech-language therapy intervention sessions, as their experience of receiving intervention was also being investigated.

Insight and awareness. Participants had to be aware of their communication difficulties as they were required to reflect on their experiences. This would not be possible if they were not aware or in denial of their communication difficulties. This is specifically important for this population of individuals with neurogenic communication difficulties as anosognosia, which is a lack of ability to perceive one's difficulties, may occur due to damage to the brain, specifically damage to the right cerebral cortex (Nurmi Née Laihosalo & Jehkonen, 2014).

Language. English, Afrikaans, and isiXhosa were chosen as the languages included in the study sample. This was partly due to it being the Western Cape's three official provincial languages (Western Cape Government, 2023c). In addition, this inclusion ensured the need for

only an isiXhosa translator and interpreter.

Age. The participants had to be between 18 and 50 years of age. The lower limit of 18 years of age was specified not only to allow potential participants to provide consent but also to afford the widest possible age range to reflect the experiences of young adults. The upper cut off age for describing a ‘young stroke’ is reported in research as 45 years (Smajlović, 2015). More recent literature defines the upper limit of the age range for young stroke as 50 years (George, 2020). In this research study, describing how age-related factors contribute to the communication and rehabilitation experiences of young adult stroke survivors is more important than the absolute age of participants. The upper limit of the age range for the current study was 50 years. This allowed a larger pool of candidates to recruit from whilst still maintaining an age where individuals maintain attributes specific to the young adult population. Age-related factors that may impact stroke experiences include employment, financial liability, dependent children, and an active lifestyle requiring high physical and cognitive functioning (Shipley et al., 2020).

Experiences in the home environment. The participants needed to have at least two weeks of experiencing communication difficulties outside of the hospital context. This would allow time for them to experience communication difficulties outside of the hospital context or following the stroke, for example in their home and community contexts. This was important as the communication needs of individuals depend on their context, such as hospital, rehabilitation centre, home, and community settings (Grohn et al., 2014). The current research aimed to establish a holistic description of the communication experiences of these individuals and therefore deemed it essential for them to have been home for some time to allow them to reflect on and include the hospital, rehabilitation, and home context in their descriptions of their experiences. [Add more](#)

Exclusion criteria

Other neurological diseases. Participants could not present with other neurological diagnoses (e.g., neurosyphilis, dementia, malignancies, etc.) as this could influence or confound their ability to provide information regarding their experience with communication difficulties following the stroke. For example, other neurological diagnoses may have resulted in previous engagement with the healthcare system for neurological difficulties and possible related communication difficulties which may influence their experiences. Furthermore, prognosis and recovery patterns may be different for other neurological conditions, and this can further confound individuals' experiences.

Other communication difficulties. Any other communication difficulties not related to the stroke, such as voice disorders, fluency disorders, developmental language delays, etc., were excluded as this could have an influence on their experiences of the acquired stroke-related communication difficulties. Other pre-existing communication difficulties may have resulted in engagement with an SLT or speech-language therapy services which could influence their experience of receiving speech-language therapy for the stroke-related communication difficulties.

Severe communication difficulties. Stroke survivors with more severe communication difficulties were excluded as they would not have been able to participate in the semi-structured interview employed for the current study.

Previous speech-language therapy intervention. Individuals who received speech-language therapy intervention prior to their stroke onset were excluded as their rehabilitation experiences for stroke-related communication difficulties may have been influenced by previous engagement with speech-language therapy services received.

Mental health difficulties. Individuals with mental health difficulties influencing their perception and insight (e.g., schizophrenia, psychotic disorders, dissociative disorders, and somatic disorders) were also excluded as their ability to perceive or report on experiences could

be reduced. Anxiety and mood disorders are not routinely excluded as perception and insight is not usually affected by these disorders. Anxiety and depression are also known to be highly prevalent in individuals with communication difficulties (Shehata et al., 2015; Wang et al., 2018) and these experiences of depression and anxiety may well form part of the phenomenon of stroke-related communication difficulties in young adult stroke survivors.

Language. Individuals who were not English, Afrikaans or isiXhosa speaking were excluded.

Age. Individuals younger than 18 years and older than 50 years were excluded.

Experience in the home environment. Individual who had not spent at least two weeks in the home environment were excluded.

Sample size

The aim was to conduct interviews until data saturation was reached. In qualitative research, data saturation refers to the point where further data collection or analysis is unnecessary (Saunders et al., 2018). This is when additional data does not add new information or themes. In health science research, this is usually considered the ‘gold standard’ by which sample sizes are established (Guest et al., 2006). Guest et al. (2006) however suggests that designing research in this way may be challenging because it can be impossible to know when this will occur. In their research, Guest et al. (2006) reported that data saturation usually occurs at 12 interviews, therefore an upper limit of 12 was considered appropriate.

Despite initially identifying six as the lower limit due to it being recommended for phenomenological studies (Morse, 1994, as cited in Guest et al., 2006), only five participants were included in the final study. The decision regarding sample size was informed by comprehensive consideration of various factors. As recommended by Vasileiou et al. (2018), the factors considered will be outlined below to support transparency of the research process.

Firstly, in phenomenological studies, a small sample size is appropriate as the aim is to obtain in-depth descriptions of the phenomena rather than descriptions of more people's experiences. This relates to the depth of inquiry outweighing the number of participants included, with some reports including as little as one participant in phenomenological inquiries (Cresswell, 2007).

In addition, considerable time was spent on the recruitment process, with active strategies implemented, like adding additional sites, in an attempt to overcome these challenges. Despite ongoing follow ups with the recruiting SLTs about the recruitment, recruitment challenges were ongoing. The researcher, however, was familiar with the data as she did the interviews and transcriptions as soon as the interviews were completed. Similar meanings were identified across participants' responses, thus, it was considered appropriate to report on the findings related to a sample size of five participants.

Sample description

In total, 15 referrals of potential participants were received from the various recruitment sites. Out of the 15 referrals, 10 participants consented to participate and were interviewed. Of the five who were not interviewed, two could not be reached for an interview, two were excluded based on exclusion criteria identified after the referral has been received, and one could not be interviewed during the allotted time frame. Data collection needed to be completed in April 2023 to allow sufficient time for analysis and documentation of findings. Of the 10 participants who were interviewed, five were considered appropriate for inclusion after the first read-through of the transcriptions.

The five participants who were excluded after an interview was conducted were considered inappropriate for inclusion as certain exclusion criteria became evident during the interview or the initial read through of the transcribed interview. More specifically, three participants were considered to have more severe communication difficulties and they were

unable to adequately participate in the interview. One had pre-existing communication difficulties, and one had significant emotional distress and was unable to reflect adequately on their experience of their stroke-related communication difficulties and rehabilitation. Figure 3 illustrates the number of participants recruited, interviewed, and included in the final analysis of the study.

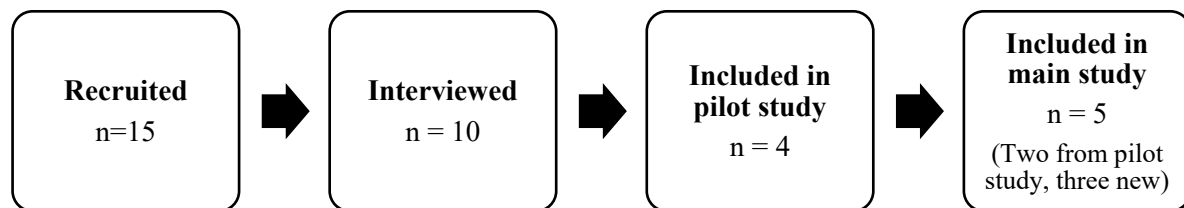


Figure 3. Sample description

The first four participants who were recruited were included in the pilot study. Of those four, two participants were also included in the main study. Table 3 outlines the date of referral, date of interview, recruitment site and outcome of each of the 15 referrals received.

Table 3

Referrals received and outcome

Participant reference	Date of referral	Date of interview	Recruitment site	OUTCOME
R1	02/06/2021	28/07/2021	TBH	Pilot study
R2 (P1)	21/07/2021	06/09/2021	WCRC	Pilot study; Main study
R3 (P2)	08/09/2021	22/09/2021	TBH	Pilot study; Main study
R4	27/10/2021	27/10/2021	TBH	Pilot study
R5	07/04/2022	14/04/2022; 21/04/2022	GSH	Excluded
R6	24/05/2023	31/05/2022; 16/08/2022	TBH	Excluded
R7	24/05/2023	31/05/2022	TBH	Excluded
R8	14/07/2023	n/a	GSH	Excluded
R9	31/08/2023	n/a	NSH	Excluded
R10	06/12/2023	n/a	NSH	Excluded
R11	27/01/2023	n/a	NSH	Excluded
R12 (P3)	20/03/2023	30/03/2023; 04/05/2023	GSH	Main study
R13 (P4)	12/04/2023	13/04/2023; 14/04/2023	WCRC	Main study
R14 (P5)	19/04/2023	19/04/2023	WCRC	Main study
R15	17/05/2023	n/a	NSH	Excluded

Note. ‘R’ refers to referrals received. ‘P’ refers to participants included in the main study.

Research instruments

Semi-structured interview guide

An interview guide was developed for the semi-structured interviews. The five-step framework for developing a semi-structured interview guide was followed as described by Kallio et al. (2016).

The first step was to determine whether a semi-structured interview guide was appropriate for the aims of the study. To use a semi-structured interview, the researcher needs to be able to determine specific areas of the phenomenon before the interview (Turner, 2010). The four domains described by Kagan et al. (2008) which include the severity of impairment, participation, environmental factors, and personal factors, related to the current study.

Environmental factors include services, systems, policies, and attitudes of others. Personal factors include personal identity, attitudes, and feelings. Since these areas have been determined in existing research, using a semi-structured interview guide was considered appropriate. Questions related to their communication contexts and feelings related to environmental and personal factors respectively.

The second step was then to retrieve and use the available knowledge (Kallio et al., 2016) to create a predetermined framework for the interview (Turner, 2010). A comprehensive literature review was conducted to identify relevant concepts related to the topic. Additionally, consultation with two qualified SLTs and lecturers at Stellenbosch University, who acted as the supervisors of the current study, was included to ensure that all facets related to the concept were covered.

The third step was to develop the preliminary semi-structured interview schedule. It was developed to be flexible and to allow the researcher freedom and adaptability to obtain information from the participant (Turner, 2010). The schedule was designed with main questions related to the main themes, and related follow-up questions. This component sets semi-structured interviews apart from informal conversational interviews, which require no predetermined questions and preparation.

The fourth step included “pilot testing” the interview guide via a pilot study to establish whether it was appropriate for obtaining relevant and sufficient data (Kallio et al., 2016, p. 2954). The findings of the pilot study were evaluated in collaboration with the supervisors of the study to identify and remove or change any ambiguous or inappropriate questions. The last step was then to develop the final interview guide. This process is detailed further in the pilot study section.

Mechanical Instruments

Voice recorder

A Huawei Mate 9 cell phone voice recording application was used to record the interviews. Voice recordings were required for the transcription of the interviews. This was considered necessary to ensure that valuable information was not lost. Furthermore, the voice recording was used for revisiting interview content during data analysis. Consent for the voice recording was obtained from each participant.

Computer

The recorded interviews were promptly transcribed and saved as a Word document. Written observational notes were compiled during and after each interview and were added to the Word document containing the transcriptions.

Research procedure

Ethical clearance and permission/ Institutional Consent

Approval to conduct the research was obtained from the Health Research Ethics Committee (HREC) at Stellenbosch University prior to the commencement of the research study (HREC Reference No S20/11/316) (see Appendix E) and from the National Health Research Committee (NHRC) through the National Health Research Department (NHRD). Consent from GSH, Site B Clinic, HH, NSH, WCRC, Macassar Clinic and TBH internal research departments was received (see Appendix G).

Translation

Informed consent. The informed consent form (see Appendix D) was translated into isiXhosa by the Language Centre at Stellenbosch University to ensure that the information was accurately translated. The consent form was translated to Afrikaans by the researcher, who is Afrikaans-English bilingual.

Interview schedule. The interview schedule was translated into isiXhosa in consultation with the interpreter. This was considered appropriate as it provided an opportunity for discussion between the researcher and interpreter regarding the interview guide's structure and content. The researcher translated the interview schedule to Afrikaans as she is Afrikaans-English bilingual. Since she has knowledge about the aim of the questions in the semi-structured interview guide, she was able to ensure that the translation accurately captured the intended meaning. This process demonstrated the researcher's commitment to maintaining the integrity and coherence of the questions in both languages.

Recruitment and consent to share personal information.

The recruiting SLT provided potential participants with basic information regarding the research study and enquired about their interest in participation. Once candidates indicated their interest, the SLT discussed the need to provide consent to share their details with the researcher. The consent to share personal information document (see Appendix B) was then signed by each potential participant who indicated their understanding and consent. Once the document was signed, the recruiting SLT could share the candidate's name and surname, age, contact details, expected or known discharge date, date of stroke, date of admission to the facility, and their communication difficulties with the researcher. This was done as per the requirement of the Protection of Personal Information Act (POPIA) which came into effect on 1 July 2021.

Pilot study

Before commencing with the main study, a pilot study was conducted to validate the mechanism and methodologies planned for the main study (Wray et al., 2019). In accordance with a scientific and ethical obligation, the processes and findings of the pilot study will be reported on below (Thabane et al., 2010; Wray et al., 2019).

The aim of the pilot study was to ensure that the chosen methods were appropriate for achieving the aims of the study (Wray et al., 2019). The data were analysed to determine the nature of the themes and whether they aligned with the aims of the study. Another aim of the pilot study was to provide the interviewers with an opportunity to practice the interview process. This is appropriate for novice researchers (Kezar, 2000), as with the current study where the researcher is a first-time master's student and did not have experience in conducting phenomenological research interviews. The findings of the pilot study including the audio recording, transcription, and analysis of the data were discussed with the supervisors of the study who are more experienced. The process and findings are documented below.

As indicated in Table 3, the participants included in the pilot study were recruited and selected from the initial three recruitment facilities (i.e., GSH, TBH and WCRC). Four participants (P1-P4), who met the inclusion criteria of the study, were recruited over a period of approximately three months (28 June 2021 until 27 October 2021). It was initially planned to possibly include an isiXhosa-speaking participant in the pilot study to afford the interpreter an opportunity to develop confidence and competence in the interview process, as suggested for novice researchers (Kezar, 2000). The main research study, however, forms part of a master's degree and is therefore constrained in terms of time. It was necessary to complete the pilot study to inform the design of the main study. Therefore, the first four participants who were identified during the recruitment process were included in the pilot study and, notably, all the participants chose to have the interview conducted in English.

The interview was generally conducted within two-weeks of the referral or when the participant became eligible for the interview (i.e., two weeks post stroke or post discharge from an in-patient facility). The proposed interview guide (Appendix A2) was utilised in the pilot study interviews. The impact of the participants' communication difficulties on the quality of data extracted from the interviews was an anticipated limitation of the study. The interviewer

implemented communication strategies like repetition, verifying information, asking yes-no questions, and providing options. This was necessary for effective communication with an individual with communication difficulties, however, the impact this has on the authenticity of responses was reflected in the data.

Minor adjustments were made to the semi-structured interview schedule. Table 4 outlines the original questions, adjusted questions, and rationale for the changes. The changes were implemented to adjust how the information was elicited in the interview. The questions were changed to prompt narratives of participants' lived experiences of communication difficulties, rather than interpretations of their experiences. These narratives were prompted with questions pertaining to the context of communication, communication topics, and communication partners. For example, instead of asking the participant to 'describe what your communication is like,' which requires interpretation, participants were rather prompted with 'tell me about your speech after stroke.' The order of questions was also adjusted so that prompts for experiences related to the participants' specific contexts could be implemented.

Table 4

Adjustments made to the interview schedule.

Original questions	Adjusted questions	Rationale for changes
<p>1. Describe to me what your communication is like after the stroke.</p> <p><u>Prompts:</u> Sharing ideas/ symptoms/ concerns/ questions Difficulty talking/ understanding/ structuring thoughts.</p>	<p>5. Tell me about your speech after the stroke?</p> <p><u>Prompts:</u> Tell me about when you talk to partner/ child/ health professional. Tell me about when you talk in the shop/ at home/ at the church. Tell me about when you talk about finances/ emotions/ childcare. How do you feel when you need to talk in above context?</p> <p>6. Is there anything that helps when talking to certain people or in specific situations?</p> <p><u>Prompts:</u> What do you do? What are they doing? What you like them to do?</p>	<p>This question was moved from the first question to the following adjusted question two, three and four. This was considered appropriate as the prompts employed could relate to the communication partner/contexts and topics that participants reported on. Adjusted question number six was also added at this point for the same reason.</p>
<p>2. Tell me a bit about yourself.</p> <p><u>Prompts:</u> age, married/ single/ partner, family, work/ school, hobbies/ day to day routine, other health conditions, something you think contributed to the stroke</p>	<p>1. Tell me a bit about yourself.</p> <p><u>Prompt added in addition to original prompts:</u> Can you tell me a bit about the feelings you have around having difficulty with communication after the stroke?</p>	<p>The position of these questions changed to being the introductory question as it provides a basis for the interviewer to reflect on the participant's context in the questions that follow. The prompt that was added to these questions was considered appropriate as it provided the interviewer with information regarding participants general experiences and context that could be referred to later in the interview.</p>

<p>3. Tell me about when you needed to communicate with someone after the stroke.</p> <p>4. Tell me about doing your daily tasks with communication difficulty.</p>	<p>2. Tell me about who you talk to during the day?</p> <p>3. Tell me about situations during the day where you need to talk?</p> <p>4. Tell me about topics you talk about / like to talk about during the day?</p>	<p>The questions were separated into three separate questions to enquire about communication partners, communication contexts, and communication topics. The phrasing allowed for more authentic reflection of experiences.</p>
<p>5. Tell me about therapy you received for communication difficulty.</p> <p>6. How did your communication change over the course of therapy?</p>	<p>7. Tell me about your experience with speech therapy?</p>	<p>The change in phrasing of these questions invited more authentic responses of individuals' experiences rather than their interpretation thereof.</p>

These changes were deemed necessary as the focus of the research was to describe the experiences of young adults with stroke-related communication difficulties rather than providing further interpretations thereof. Furthermore, answering questions related to daily life routines and interactions as opposed to the interpretation thereof may be easier for individuals with communication difficulties as interpretation requires verbal reasoning, which is a higher-level language function. For this reason, it was decided to evoke information about daily life activities first, followed by prompts to obtain information about their feelings and perceptions regarding their communication experience within the respective activities.

Informing SLTs regarding identification of potential participants

The recruiting SLTs were provided with an information leaflet (see Appendix C) to guide the process of identifying potential participants within their caseload. The researcher visited each recruiting SLT to explain the research and the inclusion and exclusion criteria for recruitment. To facilitate ongoing communication, the researcher shared her email and cell phone contact information with the recruiting SLTs.

Participant recruitment

The SLTs at the respective recruitment sites identified participants who were appropriate for possible inclusion in the study. The recruiting personnel needed to be SLTs working at the recruitment sites who would be able to identify potential study participants from their caseloads. The SLTs were knowledgeable about the communication difficulties and other details which informed the selection criteria of the current study, allowing them to accurately consider the appropriateness of candidates. Weekly contact with the recruiting SLTs was made via email to follow-up on any potential candidates.

Obtaining informed consent from participants

The researcher contacted the potential participants telephonically two weeks after being discharged from the facility to further discuss their possible participation in the study. The researcher provided further detail regarding the nature and focus of the study and the measures put in place to maintain confidentiality. Once they agreed to participate, a time and venue for the meeting was scheduled. Arrangements for compensation for travel costs were also discussed. The informed consent documentation was signed or marked on the day before the commencement of the interview (see Appendix D). The consent form was read out by the researcher with reasonable communication support including additional support in the form of pictures for participants who may not be literate or have difficulties with reading following the stroke. The participant also needed to consent to be audio recorded (see Appendix D).

The interpreter was required to sign a confidentiality agreement (see Appendix I) to ensure the participant's confidentiality by binding the interpreter in a contract that states that he was not allowed to disclose any information disclosed throughout the research process.

Interview procedure

COVID-19 regulations.

During the initial stage of the data collection of the current study, the COVID-19 pandemic required the researcher to employ the necessary guidelines to plan for the interview process to ensure the safety and well-being of all parties involved. In-person interviews were considered the best option for the proposed research, in view of the nature of the communication difficulties of the population under study, as it is the most natural and effective manner of communicating.

The following COVID-19 regulations (South African Government, 2023) were followed to ensure the safety of all parties involved:

- The interviewer, interpreter (when applicable) and participant were positioned at least 1.5m apart from each other.
- All parties were required to wear a mask appropriately.
- The participant and interpreter (when applicable) were provided with a surgical mask if they did not wear an appropriate mask.
- The ventilation of the venue was considered when selecting a designated space.
- The surfaces and objects in the venue were sanitized before and after each interview as per ‘workplace disinfection’ stipulated in COVID-19 environmental health guidelines (Department of Health, 2020, p. 4).
- Refreshments in the form of bottled water and snack bars were provided for off-site consumption only.
- Remuneration of travel costs was provided in a marked envelope at the end of the interview session.

Venue

The participants were interviewed in a private room at a public healthcare facility. The room was usually a designated therapy space or consultation room in use at the facility. The interview rooms were carefully arranged to minimize distractions and the door was kept closed, with the rooms kept inaccessible while the interviews were being conducted. The venue was chosen based on ease of access for the participants. Four of the participants included in the main study were interviewed in a venue at the recruiting site, whilst the remaining one participant were interviewed at the district hospital closest to her home.

Interviews

Before the commencement of the interview, the informed consent documentation was discussed with and signed by the participants. Consent to be audio recorded was also signed.

The recording was started after signing of the document, preceding the introduction on the semi-structured interview guide.

The semi-structured interview guide (see Appendix A) was used to ensure that the information gained from the participants covered all the aspects of the phenomenon under study. The interviewer made a conscious effort to interact without bias to ensure that topics related to the phenomenon did not reflect the assumptions of the researcher. Any opinions raised by participants, that were relevant to the topic, were approached and discussed to obtain rich and descriptive accounts of the experiences of the participants. This approach aligns with the goal of bracketing, as it involves setting aside preconceived notions and actively engaging with the participants' perspectives without imposing the researcher's assumptions.

The interviewer refrained from raising questions or making comments which could have imposed any presumptive position that could discourage participants from sharing their experiences or compromise the trustworthiness of the data (Willis et al., 2016). Written observational notes were compiled during and after the interview. Since non-verbal information may add to the meaning of an account (Willis et al., 2016), this practice contributes to the overall commitment to bracketing, allowing for a more nuanced and unbiased analysis of the collected data. This approach acknowledges the importance of minimizing the impact of the researcher's biases and assumptions, thereby promoting a more rigorous and trustworthy study.

The use of an interpreter

The researcher served as the interviewer when the participant chose to have the interview conducted in English or Afrikaans. The researcher is a qualified SLT with insight and experience in working and communicating with individuals who have communication difficulties. Before the interviews, participants were asked telephonically about their preferred

language for the interview. This was done to identify participants who could potentially be interviewed by the researcher and, thus, without an interpreter. When a participant chose to have the interview conducted in isiXhosa, the interpreter was included in the interview to facilitate interpretation as needed.

The interpreter was carefully selected based on their qualification and experience. The interpreter needed to be a qualified professional with experience in interpreting and working in research in the Faculty of Medicine and Health Sciences. Potential candidates were identified based on recommendations from colleagues in the Faculty of Medicine and Health Sciences who have previously used interpreters during data collection in research. This was considered appropriate as they would have some experience in interpreting health research. The interpreter was extensively briefed regarding the research aims, objectives, and study design implemented. The interpreter was also briefed regarding the content and use of the interview guide as well as the use of prompts.

Two participants who were isiXhosa home language speakers were interviewed (i.e., R2 (P1) and R5). R2 (P1) chose to have the interview conducted in English and R5 chose to have it conducted in isiXhosa. Thus, the interpreter was only used in one interview for R5. The researcher is aware that the interpreter could potentially have been beneficial in both the interviews in which the participant's home language was isiXhosa, as they could have acted as a cultural broker to facilitate cross-cultural communication (Penn & Watermeyer, 2018). However, since the focus of this study is on description rather than interpretation, the more traditional way of interpretation was considered appropriate. Furthermore, the scope of the current study did not include understanding how cultural differences could influence the participants' experiences.

Interpreter-facilitated interviews, as described by Williamson et al. (2011), were used when the interpreter was included. Here, the interpreter acts as an ‘intermediary and facilitator’ of the interview (Williamson et al., 2011, p. 386). The interpreter provided third-person summaries of the participant’s response instead of verbatim translations thereof. This was considered appropriate for a few reasons. Firstly, traditional, triangular interpretation methods of translation would have resulted in prolonged and impersonal interviews (Murray & Wynne, 2001). Furthermore, as the research is qualitative, the aim was to extract meaning from what was said, instead of accounting for exactly what or how it was said.

The interpreter transcribed and translated the isiXhosa sections of isiXhosa interpreter-facilitated interview. The interpreter was also available for consultation during the analysis of the translated data if any clarification of meaning was needed. However, the one interview conducted with the interpreter was not included in the final study. Therefore, this process was not necessary.

Internal testing was implemented before the pilot study. Here, the interpreter assumed the role of the participant and the researcher acted as the interviewer and vice versa. For the interviewer who is not as informed about the topic, this promoted sensitivity to the particular issues under study (Kallio et al., 2016).

The role of the interviewer and researcher was explained to the participant to ensure that the participant was comfortable with and understood the role of everyone present. The researcher made observations regarding body language and other meaningful elements of the interview, such as specific communication difficulties that the participant experienced throughout the interview.

Main study

Following the pilot study, the main study commenced. The same selection criteria were employed. The interview schedule was adjusted as discussed in the pilot study section above. Although the amended interview schedule proved to be more effective and efficient in eliciting the appropriate information, some relevant information was evoked with the interview guide utilized in the pilot study. Considering this and the challenges faced with participant recruitment, it was deemed appropriate to include two appropriate pilot study interviews in the main study (R2 (P10) and R5 (P2)). It was decided to exclude R1 and R4 from the main study as exclusion criteria were identified after the interview was conducted.

A total of six participants was interviewed using the adjusted interview schedule. Three of these were, however, excluded based on exclusion criteria identified after the interview. Thus, two of the pilot study interviews and three additional interviews were included in the main study. A detailed description of the five participants included in the final study is provided in the findings and discussion chapters that follow.

Data handling

The participant names were not used during the transcription and reporting of the data. They were assigned codes based on when they were recruited, e.g., ‘P’ representing participants with the respective number ‘1-5’. Transcribed interviews were stored on a password protected device. This was done to ensure justice through maintaining confidentiality of the participants.

Data management

To ensure privacy and confidentiality, the audio recordings were transferred onto a password-protected external device, whereafter it was deleted from the recording device. Only the researcher, supervisors, and interpreter, where appropriate, had access to the respective recordings. Each interview was transcribed verbatim into a Word document. The transcriptions

were labelled using codes with no identifying information related to the participant. Only the researcher had access to the identifying information which ensured the confidentiality of the collected data. The Word document was then imported to Atlas.ti Windows (Version 23.0.8.0). Atlas.ti is a computer-assisted qualitative data analysis software (CAQDAS) used for arranging, reassembling, and managing large data sets. The programme was used for coding the data. Furthermore, the programme was used to analyse the data and link findings. Excel was used to capture information regarding the sample selection, criteria, and description. The spreadsheets were then developed into the tables used in this research report.

The password-protected external device (memory stick) with the voice recordings and transcriptions, along with the observational notes and the signed informed consent forms, confidentiality agreements, and consent to share personal information documents will be stored in a locked cabinet in an office in the Division of Speech-Language and Hearing Therapy, Stellenbosch University, for five years thereafter it will be destroyed. If at any point a participant decided to withdraw from the research procedure, the data obtained up to that point was destroyed.

Data analysis

A few data analysis approaches are utilized within DP. In a recent scoping review, Shorey and Ng (2022) report on the data analysis approaches mostly used in phenomenological nursing research published between January 2021 and December 2021. These include Colaizzi's (1978) seven-step phenomenological approach (53%), thematic analysis procedures by Braun and Clark (2006), Sundler et al. (2019) and Spielberg (1975 as cited in Shorey & Ng, 2022) (16%), and Giorgi and Giorgi's (2003) five-step phenomenological approach (14%).

Whilst all these approaches could be considered appropriate for the current research aims, it was decided to use only one approach, to ensure rigour in the analysis process.

Thematic analysis is a well-known approach used in qualitative studies. The approach by Sundler et al. (2019) is both recent and considers how thematic analysis could be applied in a phenomenological methodology and was, thus, chosen as the data analysis approach for this study. The methodological principles of “openness, questioning pre-understanding and adopting a reflective attitude” are identified in the article (Sundler et al., 2019, p.735).

Openness to the lifeworld and phenomenon is emphasized when researching lived experiences, meaning that the researcher should maintain curiosity and an open mind when searching for meaning. Openness includes being observant, attentive, and sensitive to expression of experiences. To achieve openness, researchers should question their pre-understanding, meaning they need to become aware of preconceptions which might influence analysis. This involves setting aside one’s own experiences and assumptions and reflecting on the understanding of the data and the phenomenon.

In conjunction with questioning pre-understanding, a reflexive attitude involves shifting from a natural understanding of life to a more self-reflexive and open stance towards the data. This includes reflecting on why certain meanings occur, how meanings are described, and if meaning is grounded in the data. Throughout the analysis process discussed below, the principles of openness, questioning pre-understanding, and adopting a reflexive attitude have been implemented.

Familiarization with the data. The first step was to achieve familiarity with the data. This was done through multiple steps in the research process including conducting the interviews, transcribing the interviews, and listening to the audio recording whilst reading the transcriptions. The principles of openness, questioning pre-understanding, and adopting a reflexive attitude were implemented during the reading to adequately consider possible meanings embedded in the text. In the reading already, the researcher started to explore

experiences expressed in the data by looking at how experiences are narrated and how meaning can be understood. The researcher took care to listen to the participant's tone of voice and mark any signs of emotionality. Whilst keeping the aim of the study in mind, the objective of this step was to identify novel information, rather than what is already known (Sundler et al., 2019).

Searching for meanings and themes. The completed transcripts (Microsoft Word documents) were then uploaded onto Atlas.ti for further exploration of meaning and themes. Meanings related to the study aim were assigned codes using descriptive words to give preliminary names to meaning. This was done in an iterative process and each transcript was considered multiple times to identify co-occurring meanings and code the appropriate text. Differences and similarities between meanings were then analysed by using the co-occurrence function in Atlas.ti. Here, one can consider which codes co-occur and how they relate to one another. This was done to get a sense of patterns of data. These patterns were examined further to identify themes in the data (Sundler et al., 2019).

Organizing themes into meaningful wholeness. Lastly, the themes were organized to achieve a meaningful whole. This was achieved through writing and rewriting while organizing meaning. The researcher remained careful and thoughtful to maintain a reflective mind while organizing data and compared meaning and themes to the original data (Sundler et al., 2019). The themes were then re-ordered to reflect a narrative of participants' experiences that became clear through consideration of the nature of the themes that were identified.

Figure 4 summarizes the data analyses process as outlined by Sundler et al. (2019, p. 736).

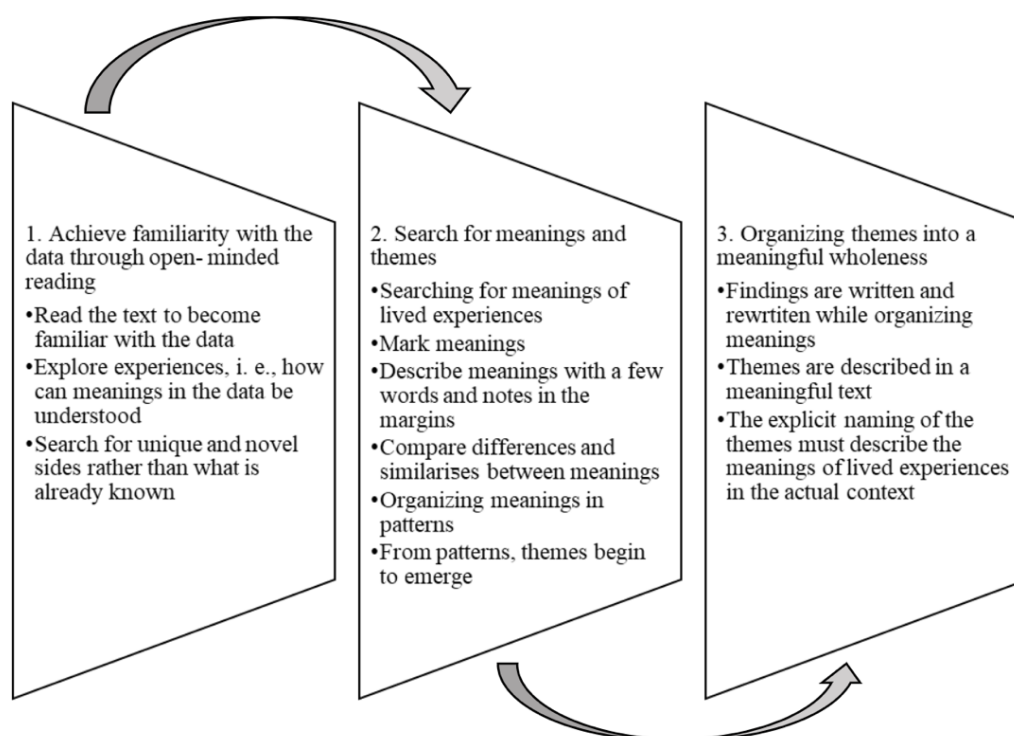


Figure 4. A summary of Qualitative Thematic Analysis Based on Descriptive Phenomenology

Trustworthiness and rigour

In qualitative research, the researcher is seen as an instrument in the research process because of the dynamic and reflexive engagement of the researcher in the data. Subjective personal experiences, knowledge about the topic, and set aims of the researcher, can reduce the trustworthiness of qualitative research. Various evaluation strategies were implemented in the qualitative research process to ensure trustworthiness and ultimately good quality research. The factors, as they relate to this study, will be detailed below: credibility, transferability, dependability, conformability, and authenticity (Elo et al., 2014).

Credibility

Credibility can be compared to internal validity in quantitative research (Morrow, 2005). It describes the internal consistency of the research. In qualitative research, this means that reasonable information is drawn from original data and that interpretation of the

participants' views are correct (Anney, 2014). To ensure the credibility of this study, the context of the research, the sample, and the sampling procedure were described accurately and in detail. By using thick descriptions, i.e., detailed, and rich description, participants' views, experiences, the context of experiences, and all the contextual factors were transcribed thoroughly and authentically. The responses from the semi-structured interviews were transcribed verbatim with appropriate punctuation. Non-verbal aspects exhibited by the participant were noted in real-time during the interview procedure and added to the transcription and the meaning they add to the data was analysed.

In addition, peer researchers and triangulation were implemented to ensure credibility: The use of peer researchers provided the researcher with an opportunity to receive feedback which can improve the quality of the findings. Triangulation was implemented by using a variety of investigators, sources, and theories, which further reduced bias (Anney, 2014). The researcher is aware of member-checking as a strategy to achieve credibility, however, due to the participant's communication difficulties it was considered too difficult to perform these telephonically. To mitigate this, the researcher used the strategy in the interview to ensure that her understanding of the participants' reports was accurate.

Transferability

Transferability refers to the possibility to safely assume that findings can be generalized or transferred to other settings or groups (Anney, 2014). This was ensured by describing the participants, research-participant relationship, research setting, and procedures using thick descriptions to add to the truthful representation of the context of the research. The selected descriptions of participants', which are not related to the criteria used to select the participants, is described in the findings section to ensure that the degree to which the findings can be generalized to other contexts can be critically analysed. For example, although all participants

are young adults and they all have children, the age of their children differ and may impact their experiences. Therefore, the age of participants' children is made explicit so that it can be considered when comparing the findings of this study with other research related to young adult stroke survivors with communication difficulties.

In addition, the researcher critically reflected on herself, as the research instrument, throughout the research process. This was noted in a journal and significant aspects were included when reporting on findings. To add to the truthful representation of the study, the report of findings is not implying to be generalizable to other populations or settings. The reader may decide, based on the description of the study methods, whether the finding can be generalized to their specific population.

Dependability

Dependability relates to the concept of reliability in quantitative research. It refers to the stability of data over time. To achieve this, the research process should be as explicit and repeatable as possible (Morrow, 2005). This was established by accurately describing the inclusion criteria used to select participants, the sampling procedures, materials, and methodologies used.

A code-recode strategy, triangulation, and peer examination were also implemented to ensure the dependability of the study. A code-recode strategy refers to coding the data twice with a few weeks in between. The codes were compared to check for differences and similarities (Anney, 2014). Peer examination refers to discussing the finding with neutral parties, like the supervisors of this study who were not involved in interviewing of participants and who has experience in qualitative research (Anney, 2014). This helped the researcher to be honest about the study and assisted her to achieve a deeper reflective analysis.

Conformability

Conformability refers to the objectivity about the accuracy, relevance, or meaning of the data (Elo et al., 2014). Conformability thus refers to the extent to which two or more independent people can agree on the accuracy, relevance or meaning of the data obtained. This was achieved by following the process of DP as described in the data analysis section. By following the methodological framework of DP, the researcher engaged in the research in an iterative but systematic way. Furthermore, qualified, and experienced researchers involved in the supervision of this master's degree study were also involved in auditing the data through peer-review analysis of the data. Their knowledge regarding qualitative research methods, as well as knowledge about communication difficulties, added to the conformability of the study.

Authenticity

Authenticity refers to the degree to which the researcher shows a variety of realities fairly and faithfully (Elo et al., 2014). This was achieved by objectively considering and describing all possibilities of differences in the meaning of the data. The researcher implemented evaluation and reflexivity throughout the process. Reflexivity refers to the process of self-awareness (Mitchell et al., 2018). The researcher aimed to be self-conscious, critical, and acknowledge her bias. By acknowledging biases and making them explicit, a degree of transparency regarding the data analysis process was achieved.

The interpreter was also briefed in this regard to ensure that the data obtained from the respective interviews were of good quality and did not display bias. Furthermore, the researcher included the peer-reviewed audit in the writing up of the research and reflected on the change of meaning that came to light in this phase.

Ethical considerations

Potential harm/benefit to participants

The four ethical principles namely autonomy, non-maleficence, beneficence, and justice were followed. Firstly, participation was completely voluntary, no participants were forced to participate or prompted to participate for additional benefits, e.g., remunerative goods or services, which related to autonomy. Participants could withdraw at any time and their confidentiality was maintained, relating to justice. There were minimal resulting negative consequences for participants and potential harm, e.g., emotional responses, were anticipated and the necessary referral process was in place should any participant need counselling, which relates to non-maleficence. Participants were made aware that the study held no direct benefits to them, but that the research may inform treatment of individuals like them in the future, which relates to beneficence.

Participant remuneration

The participants received compensation for travelling to the venue as well as refreshments, as a sign of gratitude for their willingness to participate as well as to sustain them for any travelling or appointment they may have had before or after the interview. This relates to non-maleficence, ensuring participants do not experience financial or physical constraints to participate in the study. The travel cost was reimbursed in cash but was not used as an incentive for participation. Where applicable, the travel compensation amount was provided after the interview in cash, in an envelope marked travelling cost. This was done to ensure autonomy, i.e., ensuring participants participate out of free will and not due to a financial incentive.

Data dissemination

The research will be presented at the annual research day of the Division of Speech-Language and Hearing Therapy at Stellenbosch University. Participants will also be presented with an infographic of the research findings. In addition, one academic article will be published in a peer-review journal.

CHAPTER 4: FINDINGS AND DISCUSSION

The current study explored communication experiences, communication rehabilitation experiences, communication needs, and areas of communication rehabilitation to consider in speech therapy for young adults with mild to moderate stroke-related communication difficulties. To achieve this, a descriptive phenomenological methodology was employed. The findings were obtained from semi-structured interviews with five young adults with stroke-related communication difficulties.

As discussed in the methodology, providing thick descriptions of the context ensures that it can be compared to other contexts, supporting the transferability of the research findings (Anney, 2014). Each participant's biographical and diagnostic information, as outlined in Table 5, and their speech therapy rehabilitation journey, as outlined in Table 6, are provided to support this. In addition, a description of each participant's background information is provided. The main themes with related subthemes are outlined in Table 7. Quotations are provided verbatim to ensure confirmability of the study findings.

The following conventions will be used when reporting on the findings below:

- Quotations are indicated in italic (*example*).
- Contextual information not stated in quotations is added in square brackets to reflect the complete meaning ([example]).
- Asterixis are used to redact personal information.
- Repetitions and unnecessary information are removed from quotations in the text for ease of reading.
- Quotations are presented in English after translation from Afrikaans by the researcher for the two Afrikaans participants (P2 and P4).

- Quotations that were translated from Afrikaans to English, are numbered in square brackets at the start of the quotation. Appendix H contains the original Afrikaans quotation, English quotation and the participant involved.
- Afrikaans quotations appear in brackets after the English translation in the case of quotations that are of special relevance due to the sentence structure or vocabulary used by the participant.

Table 5 indicates the biographical participant information, the participants ranged in age from 26 – 49 years old. Three males and two females were included. The communication diagnoses include Broca's aphasia, anomia, apraxia of speech, dysarthria, and neurogenic stuttering. Participants were interviewed between two- and four-months post-stroke onset. Physical impairments ranged from none to marked difficulty with upper and lower limb functioning.

Table 5

Biographical, timeline and diagnostic information of participants

Participant number	Age and sex	Date/s of interview/s	Time post-stroke	Communication diagnosis	Other impairments/ difficulties/ functional status at the time of the interview (based on ST/interviewer observation)
P1	26 (F)	06/09/2021	Four months	Apraxia of speech	Upper limb: Affected, with impact on function. Lower limb: Affected, walking independently with reduced speed.
P2	45 (M)	22/09/2021	Two months	Neurogenic stutter	Upper limb: Affected, with impact on function. Lower limb: Unaffected, walking without assistance.
P3	40 (M)	30/03/2023 & 04/05/2023	Two months & three months	Apraxia of speech	Upper limb: Mildly affected, with impact on function. Lower limb: Unaffected, walking without assistance.
P4	49 (F)	13/04/2023 & 14/04/2023	Three months	Broca's aphasia with anomia	Upper limb: Unaffected Lower limb: Unaffected, walking without assistance.
P5	41 (M)	19/04/2023	Three months	Dysarthria	Upper limb: Affected, with impact on function. Lower limb: Severely affected, difficulty walking even with a mobility device.

Table 6

Speech therapy rehabilitation journey of participants

Participant number	Acute phase	In-patient rehabilitation	Out-patient rehabilitation
P1	Yes - Tertiary hospital for two weeks, received speech therapy, frequency unclear.	Yes - Specialized rehabilitation centre, six weeks	No
P2	No - Tertiary hospital for two days but did not receive speech therapy.	No	Yes – Fortnightly, three sessions and ongoing at the time of the interview
P3	Yes - Tertiary hospital for one week, received speech therapy daily.	No	Yes – Fortnightly, five sessions in total
P4	Yes - Tertiary hospital for two weeks, received ST daily	Yes - Specialized rehabilitation centre, eight weeks	N/A – Still admitted at in-patient rehabilitation centre at time of interview. At least two weeks spent at home in between acute hospital discharge and rehabilitation admission and on weekends.
P5	Yes - Tertiary hospital, no information regarding length of stay. Received speech therapy, reportedly only for dysphagia	Yes - Specialized rehabilitation centre, eight weeks	N/A – Still admitted at in-patient rehabilitation centre at time of interview. At least two weeks spent at home in between acute hospital discharge and rehabilitation admission and on weekends.

Information related to the participants’ speech therapy rehabilitation journey is provided in Table 2 and notes that all the participants were admitted to a tertiary hospital in the acute phase following their stroke although not all received speech therapy while admitted to hospital. P5 reported only receiving speech therapy for dysphagia intervention, while P2 did not receive any speech therapy in the acute setting. The length of stay and the frequency of speech therapy intervention received in the acute phase varied among the participants. Following discharge from the tertiary hospital setting, three participants received rehabilitation at an in-patient facility, and two received speech therapy intervention in an out-patient setting.

Two of the three participants who received in-patient rehabilitation were still admitted there at the time of the interview. At the time of the interview, one participant who had already been discharged from the in-patient facility reported not receiving any further speech therapy intervention after being discharged from the facility.

In addition to the information above, additional background information is provided to contribute to the thick descriptions of the context and as orienting information for the themes identified in the study's findings. The report includes participants' support structures, occupation, knowledge, and attitudes towards stroke, and general stroke-related communication experiences.

P1 is a mother of two young children and had the support of her parents and boyfriend. Her living arrangement was unclear at the time of the interview, but she was seemingly living with her parents. She was unemployed at the time of her stroke but had previous work experience. During her interview, she came across as friendly, and her positive attitude was evident in her responses. Her pre-morbid knowledge of stroke was not established during the interview. She enjoys dancing and plans to pursue it post-stroke. Her communication diagnosis was apraxia of speech. During the acute stages of stroke recovery, she had initially been non-verbal however, by the time of the interview, had progressed to being able to produce sentences, although it was evident that it required considerable effort.

P2 has the support of his aunt, with whom he lives. He also noted receiving support from his friends and a cousin who is a physiotherapist. He is the father of two children and they reside with his ex-wife. He noted that he saw them infrequently and occasionally communicated with them telephonically. He was unemployed at the time of his stroke. He was well informed about stroke symptoms as he received treatment for high blood pressure well before the onset of his stroke. He came across as determined and motivated to participate in

speech therapy. His communication diagnosis was neurogenic stuttering. He reported that the severity of his stuttering was notably worse during the acute stages following the stroke in comparison to the time of the interview. He noted that speech-language therapy had a significant impact on the improvement of his speech.

P3 has a supportive family with whom he had lived prior to the stroke. He also has a teenage son who resides with his mother and came to visit him on weekends. Two interviews were conducted with P3 with an approximate one-month interval. As the scope of the interview schedule could not be completed during the initial interview, a second interview was necessitated. Due to logistical constraints, the second interview could only be conducted one month after the initial interview. His communication diagnosis was apraxia of speech although he also reported difficulties with writing. His sister accompanied him to the first interview. The improvement in his speech prompted him to feel confident enough to travel and attend appointments, such as the second interview, on his own. He was working as a dancer and had returned to dancing by the time of the second interview. He reported not having knowledge about what a stroke is and did not realize that this was what had happened to him when he presented with the symptoms of a stroke. In addition, the health professionals did not immediately explain his medical diagnosis to him. In this regard, he reported on the benefit of the counselling and education he received from the SLT. He was initially shy and avoided social interaction due to his communication difficulties but was motivated by the progress he has made in speech-language therapy.

P4 has two adult children. Her 30-year-old son lives with her and her husband, while her daughter lives close to her. Although her family seemed supportive, she reported their lack of understanding of her communication difficulties and other stroke-related experiences. She was permanently employed as an administrator at the time of her stroke, and at the time of the

interviews, she was liaising with the human resources department at the company to explore accommodations that could facilitate her return to work. She was knowledgeable about the risk factors for stroke. She was motivated to participate in speech-language therapy as she was determined to improve. Although she became emotional talking about her difficulties, she was aware of and grateful for her progress. She seemed sociable, as she reported making friends during her time at the hospital and at the in-patient rehabilitation facility and reflected on the friends at her workplace. The referring SLT indicated a communication diagnosis of Broca's aphasia with anomia although signs of speech motor-planning difficulties were noted during the interview. Her communication abilities were severely affected during the acute stages of her recovery, with subsequent significant improvement which enabled her to engage in discourse-level conversations.

P5 has the support of his parents, partner, and family, specifically his cousin who is a psychologist. Prior to the stroke, he lived with his children and partner but needed to make alternative living arrangements due to the assistance he needed following the stroke. He moved in with his parents as they were able to provide the assistance he needed. His partner moved to her parents so that she could be supported in caring for their children. He has four young children ranging from age four to 14 years. His pre-morbid knowledge of stroke was not indicated in the interview. His physical limitations following the stroke were of particular concern to him. At the time of his stroke, he was unemployed. He reported that his employment was terminated due to memory difficulties from a transient ischemic attack (TIA) that he experienced a few months before his stroke. He also reported having renal failure, which may be associated with cognitive impairments not resulting from his stroke. It is acknowledged that ongoing memory difficulties may indicate a neurological event more significant than a TIA and that he may be experiencing cognitive difficulties due to renal failure. However, this

information only came to light during the interview and was not reported on by the referring ST who was aware of the selection criteria of the study. Furthermore, he reports on many experiences aligning with the phenomena under study and therefore including it in the findings was imperative. His communication diagnosis was moderate dysarthria, which had improved from being severe initially. He also had difficulties with pragmatic skills, which were addressed by the SLT through intervention focusing on body language and non-verbal communication skills.

Including extensive information about the participants was necessary for the current study within the constructivist-interpretivism paradigm in which the analyses were approached based on the ontological stance that reality is socially constructed and based on context, time, and culture. Conforming to the ICF, which was used as the theoretical framework of the research, the impact of contextual factors on the participants' experiences of having communication difficulties can be conceptualized. To protect participant confidentiality and ensure justice, only personal information and information received during the interview could be used to describe the participants. This information was considered throughout the analysis when considering the experiences of participants. In keeping with this, five main themes with related sub-themes emerged from the data analysis process and are outlined in Table 3.

Table 7

Summary of main- and subthemes

Theme 1: Emotional experiences of young adults with stroke-related communication difficulties.
Theme 2: Transitioning and adapting to changes in roles and activities.
Theme 3: Personal factors to consider for young adults with stroke-related communication difficulties.
Subthemes: 3.1 Understanding and addressing knowledge, awareness, and insight into stroke symptoms. 3.2 The role of intrinsic factors in coping and engagement in rehabilitation. 3.3 The balance between independence and help-seeking strategies. 3.4 Communication experiences in relation to physical abilities. 3.5 Alternative and augmentative communication as a coping or participation strategy.
Theme 4: Environmental considerations for young adults with stroke-related communication difficulties.
Subthemes: 4.1 The influence of the communication environment on participation. 4.2 Addressing information needs of communication partners. 4.3 The role of communication partners in supporting independence and autonomy.
Theme 5: The role of training, feedback, and support from the SLT concerning the communication rehabilitation process of young adults with stroke-related communication difficulties.

The first theme considers the emotional experiences of young adults with stroke-related communication difficulties. Followed by theme two which focuses on changes that young adults with stroke-related communication difficulties report because of the stroke. This theme examines how these individuals adapt to changes in their roles and activities. Theme three reports on the personal factors to consider for young adults with stroke-related communication difficulties. The subthemes related to this include their knowledge, awareness, and insight into stroke-related difficulties, the role of intrinsic factors in coping and engagement in

rehabilitation, the balance between independence and help-seeking strategies, communication experiences concerning their physical abilities, and alternative and augmentative communication as a coping strategy. The fourth main theme is focused on environmental considerations for young adults with stroke-related communication difficulties. Here, the influence of the communication environment on participation is considered, as well as information needs of communication partners and the role of communication partners in supporting independence and autonomy. The final theme is focused on the role of input provided by the SLT in relation to the communication rehabilitation needs of young adults with stroke-related communication difficulties.

Theme 1: Emotional experiences of young adult stroke survivors with stroke-related communication difficulties

The emotional experiences that young adults with stroke-related communication difficulties reported on are explored in this theme. The experiences shared by participants revealed the profound emotional impact of their communication difficulties. A range of negative emotions, such as distress, anger, sadness, frustration, and feelings of imprisonment, were mentioned due to the resultant stroke-related communication difficulties. The participants also reported limitations in what they could talk about, highlighting specific challenges with talking about their emotions. The participants also reported negative emotions relating to communicating in specific contexts and with specific communication partners, or when communication strategies were ineffective or had failed.

Participants, however, also reported positive emotions relating to experiencing progress with their communication abilities and having successful communication interactions. The latter highlights that the attitude of communication partners can result in a positive or negative emotional response for the young adult with stroke-related communication difficulties.

Furthermore, it appeared that the participants' overall outlook and attitude towards their communication difficulties influenced their emotional experiences, with some using these intense emotions as motivation to improve. This complex range of emotions and their motivation affected their experiences and shaped their choices in dealing with their communication difficulties.

Participants reported feeling fearful or ashamed when speaking in specific communication contexts, as reported by P4, [1] *"I was so embarrassed luckily there were no other people at the store because I struggled,"* or with specific communication partners as noted by P1 about communicating with an English-speaking individual, *"my English it sounds like it's broken that's why [I'm] scared to talk English."* It even led to some participants choosing to avoid these difficult communication contexts, as P3 noted, *"[having difficulty in English] are the things that are making me just to avoid talking to most people..."* Due to negative emotions such as fear and feeling imprisoned by their communication difficulties, participants also reported choosing to be isolated, as illustrated by P3 who indicated, *"I don't want to speak to anyone, I just want to lock myself in my room,"* and P5 who mentioned succumbing to isolation, *"I am very quiet so I'm fine with not talking but I was worse off."*

Participants reported negative emotions like frustration due to experiencing communication breakdown, as reported by P3, *"things that are making me angry is that I know what I want to say but now I can't say it."* Negative emotions like sadness also arose when communication was effortful due to participants needing to repeat what they are saying to help communication partners understand, as reported by P1, *"if I want to say something I must repeat it and again and again so it hurt me."* Sadness was also noted when communication strategies failed with specific communication partners, as with P5 who could not use writing

with his four-year-old daughter who was unable to read, *“I could still communicate with the others, I would write and say what I want, but my daughter, I couldn’t. That killed me.”*

Positive emotions like pride, gratitude and happiness were reported by participants about their speech-language therapy rehabilitation experience and subsequent improvements in their communication abilities. Based on the participants' experiences, recognizing one's progress may lead to positive emotions, as illustrated by reports from P4, [2] *“but now I can say potatoes so for me it's a big thing,”* and P5, *“I am very proud of myself. Cause there was a vocal recording of myself, and it was a big noise compared to now where I can hear the words myself.”* These positive emotions are reported mainly in the later stages, although relative to the ongoing journey, of the participants' rehabilitation. Although in the 'later stages' of rehabilitation, the participants still presented with communication difficulties, but an attitude of acceptance was evident in their responses as noted by P3, *“I feel I am very happy now seriously even with the speaking now I have accept that now this is the new normal for me,”* and P1, *“I’m not sad, I have to accept the way I am.”*

The attitude of various communication partners, including family, friends, and even health professionals, also had an impact on participants' emotional experiences. Negative emotions such as anger were reported, as reflected in the example of P5's engagement with the nursing staff, *“they speak to you in a certain way and like you’re an idiot.”* Conversely, P5 noted the positive feeling of appreciation towards his friends, *“I appreciate them for... accommodating me,”* he specifically mentioned that he appreciates their accommodations because they do it *“without making it condescending.”* P4 also preferred a similar, respectful attitude from her communication partners, stating her discomfort with individuals who expressed pity toward her, [3] *“...because some people want to feel sorry for you.”*

It also became evident that young adults with stroke-related communication difficulties find it difficult to talk about their emotions. P5 indicated, *“when I speak about my emotions, I’m very limited because I speak and I get emotional then I can’t talk,”* while P4 also mentioned, [4] *“...it was very difficult for me to talk about my emotions.”* Additionally, P5 reported on experiencing difficulty with communication when he was emotional, *“[I] couldn’t [tell my daughter] cause I had to be consoled.”*

The notion of emotions influencing individuals with communication difficulties to behave in a certain way also became apparent in participants' reports. Participants noted how anxiety and frustration impacted the strategies they used in communication, as reflected by the statement by P4, [5] *“My nerves were on edge when I got in. I thought what should I say to the man now. Then I thought, I’m going to tell him I had a stroke so I can’t speak well,”* and P5’s report, *“I don’t like writing when I am irritated.”* In addition, it appears that striving to reduce negative emotions like fear and anxiety, is a desirable outcome. This was illustrated in P4’s account where she expressed, [6] *“I think the more I talk, the better it will become, and then I don’t have to worry about whether they will understand me.”* This suggests that by addressing or mitigating anxiety, it could potentially facilitate and enhance communication.

These findings shed light on the patterns of emotions experienced by young adults with stroke-related communication difficulties. The importance of considering the interplay between emotions and communication difficulties to adequately support these individuals during their rehabilitation journey is highlighted. Understanding how emotions impact an individual's overall functioning is crucial for assessing and addressing their health and well-being. This holistic perspective aligns with the ICF, emphasising the need to consider individuals as complex beings whose lives are largely embedded in emotional experiences.

A large body of research on individuals with stroke-related communication difficulties supports the emotional impact of stroke-related communication difficulties (Doyle et al., 2003; Hilari, 2011; Hilari et al., 2012; Wray et al., 2019). While research involving young adult stroke survivors, not relating specifically to communication difficulties, has addressed the emotional needs of this population (Cotoi et al., 2018; Shipley et al., 2020), the current study focuses specifically on young adults with stroke-related communication difficulties. This distinction is deemed necessary, as the findings illustrate that factors related to communication, such as communication partners, contexts, strategies, and topics, influence these individuals' emotional experiences.

Moreover, the age-specific difference between young and older individuals becomes evident when we consider their unique life circumstances and responsibilities. Young adult stroke survivors often find themselves raising children, pursuing careers, and actively participating in social and recreational activities. Consequently, their emotional experiences are intricately tied to their ability to communicate effectively with their children, maintain their employment, or engage in activities pertinent to their age group. An illustrative example of this age-specific contrast was found in P5's report, detailing their unsuccessful attempt in applying their suggested alternative written communication strategies when communicating with their not yet literate young child. This exemplifies how the age-specific disparities play a central role in shaping the emotional experiences of young adult stroke survivors with stroke related communication difficulties.

This emphasis on the emotional experience of young adult stroke survivors becomes imperative as their communication partners are often younger in age. They may encounter more frequent breakdowns in communication as children may not readily grasp the communication strategies used by the adults with stroke-related communication difficulties. Thus,

communication strategies can fail more frequently in these situations, intensifying the emotional challenges faced by the stroke survivors.

A scoping review by de Goumoëns et al. (2018) reports that emotional support and education are core components of intervention directed at family. For young adult stroke survivors, the findings of this study demonstrate that their children are important communication partners to consider. Blom Johansson et al. (2013) report that individuals with stroke-related communication difficulties need emotional support most in the early rehabilitation phase. The current findings related to young adult stroke survivors, however, suggest a potential need to focus on the sustained emotional well-being for these individuals as difficulties communicating with children may persist over an extended period. As a result, the need for sustained emotional support and intervention remains crucial. The challenges arising from communication breakdowns and difficulties communicating to comfort their children may continue, necessitating ongoing efforts to address the emotional needs of young adult stroke survivors and their younger communication partners.

The findings indicated positive emotions coming to light during the later stages of recovery. This seems to be in response to experiencing improvement in communication abilities and developing acceptance toward the changes in their communication. Notably, this improvement in communication may not only result in better self-expression but also lead to more frequent and meaningful interactions with an expanded range of communication partners, including their children. The widening scope of communication contexts and the reduced sense of isolation that often accompanies improved communication could further contribute to the emergence of positive emotions.

Considering young adults with stroke-related communication difficulties within the ICF, it becomes evident that their present emotional state can exert a significant influence not

only on their activities and participation but also on their physical well-being. For instance, emotional responses can have far-reaching effects, such as impacting bodily functions, like appetite. This understanding underscores the critical link between emotional responses and physical and functional aspects of young adults' stroke-related communication difficulties. In this context, improved communication skills play a pivotal role, not only by enhancing activities and participation but also by positively affecting emotional responses. As observed in the research by Grohn et al. (2014), there is a clear connection between the perceived enhancement of communication skills and overall living experiences for individuals with aphasia, which encompasses their emotional well-being.

Furthermore, this concept is reinforced by broader research findings, such as those highlighted by Zhang et al. (2022), which indicate that young adult stroke survivors gradually adapt to the challenges of stroke, resulting in positive growth experiences. Therefore, understanding how communication difficulties can trigger emotional responses and, subsequently, impact bodily functions, participation in activities, and overall well-being, is paramount in providing comprehensive support and interventions for young adult stroke survivors. The notion of experiencing and adapting to changes in communication will be explored further in the theme below.

Theme 2: Transitioning and adapting to changes in roles and activities.

Navigating life as a young adult stroke survivor with communication difficulties is a journey marked by profound changes and transformations. When experiencing such a life-altering event, individuals often grapple with multifaceted challenges, from redefining their roles and activities, to entering on a path of recovery and rehabilitation. Theme two explores the unique experiences of young adults with stroke-related communication difficulties as they confront, adapt to, and aim to conquer the changes they experience.

The participants' reports illustrate how the experiences because of having a stroke impose transition and adaptation in various aspects of their lives. Young adult stroke survivors with communication difficulties specifically highlight adapting in relation to socialization patterns, preferred activities, living arrangements, and vocation and employment. Changes in their role as a parent, friend, and spouse were also highlighted. The emotional impact of the stroke experience on the participants' identity was also illustrated in their reports. Their experiences also highlight the importance of acknowledging their needs, hopes, and willingness to adapt.

Participants experienced significant changes after stroke as illustrated by P3, referring to it as "*the thing that changed my life*". The onset of the stroke related difficulties is also sudden which may make it more difficult for individuals to adjust to the multitude of changes they experience. This was illustrated by P3 who noted, "*this thing didn't maybe like gave me a warning you the one minute I was taking a bath the other minute I can't speak I can't pick up soap*". These changes are particularly eminent for younger individuals who are usually more independent, as reported by P2, [7] "*it is frustrating because you were independent and now you cannot do the things you want to do.*" Adjustment to change may also vary depending on the stage of recovery. For example, P4, who was in the earlier stages of recovery, expressed difficulty adapting to the changes, [8] "*it is depressing sometimes if you think about how you were before the stroke and how it is now.*" whilst, P1 who was interviewed somewhat later, expressed acceptance towards the changes "*I'm not sad, I have to accept the way I am.*"

Participants indicated changes in their vocation, as noted by P4 [9] "*...Unfortunately I can not do the same work as I did previously.*" and their ability to fulfil their roles in the family, which included their ability to provide and contribute to the household. This change was noted by P3 who stated, "*since my stroke, only my sister who's taking care of the*

household's things... because ...I was helping my sister to buy things that are needed at home."

There was also uncertainty noted around some of the changes, P4 reported in relation to vocation, [10] *"I don't know if I am going back to work."*

The unique experience in relation to the life stages and role as a parent of the young adult stroke survivors was highlighted by P5 who reported *"Firstly, I am a father,"* and *"I am a dad so that is a full-time job."* Being a parent is an immensely important life role as shown in these quotations. Participants also reported specific difficulty with fulfilling their role as a parent due to their communication difficulties. P3 reported on talking with his son, *"but with the communication, it was just awful [I] couldn't communicate I can hear what he's saying but [I] couldn't respond."*

Participants in the study also experienced changes in their roles as a parent or spouse, due to forced adaptations in living arrangements, as noted by P5, *"I did move back home now after the stroke..."* When asked about the decision, he reported that it was a *"Mutual decision we spoke about it... and we all decided it's a better thing."* He also recognised the need for this indicating, *"my partner moved back home as well cause she needed a support system, she can't be with the kids alone at home as well."* It is proposed that P5's involvement in this decision and his understanding of the need, may have supported his adaptation to this change. He, however, also reported that his goal is to move back in with his wife, *"[I will live there for] a year and then carry on with my life."* Indicating the dynamic process of adaptation and striving toward regaining pre-morbid levels of functioning.

Participants indicated changes in their preferred activities, which may have imposed changes in their socialization patterns and personal identity. For example, P2 reported, [11] *"I played football... I can't play anymore."* These changes in activities may be accompanied by shifts in communication context in which participants interacted with others and how they

perceived themselves. The changes participants experienced in their socialization patterns had an impact on their sense of identity. P3, who was known for being humorous and talkative, reported, *“I was the person who were telling a lot of jokes... Now I am the person who’s quiet.”* P1 described similar changes, *“I talked a lot before but now I’m quiet.”* Interestingly, these identity shifts were not limited to those who had previously been outgoing. Even participants who identified as quiet individuals before their strokes experienced challenges related to changes in their communication. As P5, who considered himself a 'quiet' person prior to the stroke, explained, *“I am very quiet so I’m fine with not talking but I was worse off.”*

Furthermore, participants also indicated a process of reforming their identity, as their communication abilities improved. For instance, P3 stated in relation to the improvement of his communication ability, *‘now I’m back,’* signifying a regained sense of self. This journey of rediscovering one’s identity in the context of stroke-related communication changes adds depth to the participants' experiences of transitioning and adapting.

The impact of stroke in the young adult population becomes particularly notable in the participants’ reports of age-related factors such as vocation or employment and potentially being a parent to young children, in relation to the challenges they experience because of stroke-related communication difficulties. The added challenge with experiencing stroke-related communication difficulties becomes clear in reports where participants expressed difficulties with socializing and how this relates to identity. The notion of changes in identity due to stroke-related communication is supported by research (Armstrong et al., 2015; Musser et al., 2015). The lack of research pertaining specifically to young adults with stroke-related communication difficulties is, however, also reported. Musser et al. (2015) highlight that a lack of “consistent evidence related to the social needs, experiences, and identities of younger patients with poststroke aphasia” (p.2) remains.

The findings highlight that young adults with communication difficulties perceive these changes as sudden and profound. It is important to note that these experiences may not be unique to young adults, as individuals of any age may experience sudden and drastic changes due to stroke. However, in the case of young adults, youth is often associated with a sense of independence and productivity, and the unexpected occurrence of a stroke may intensify the impact of these changes on their lives. This perspective aligns with existing research, which has documented how young adults commonly view a stroke as “unfair and discordant,” in relation to their young age (Shipley et al., 2018, p. 8). While the experience of sudden and drastic changes is not exclusive to young adults, the additional challenge of adapting to such changes, at a stage in life traditionally associated with vigour and self-reliance, underscores the unique dimensions of their experiences of transition and adaptation.

The participants reported on changes experienced in relation to a variety of domains in their lives including social, physical, emotional, and vocational. As the young adult is likely active in various life activities such as vocation, social, and recreational activities, the loss they experience due to stroke-related difficulties may be more drastic than older people who may have experienced some of these ‘losses’ due to age-related factors. These findings are supported by research suggesting that factors distinguishing younger and older stroke survivors include marital factors, childcare, and employment (Musser et al., 2015; Teasell et al., 2000), which older people are more likely not to be involved in due to their life stage.

The young adults’ experience with changes related to stroke is also illustrated as dynamic, with differences in experiences reported at different stages of recovery. Although most of the participants were interviewed early in the rehabilitation process, they mentioned goals to return to previous roles and activities. These ongoing changes may be more prevalent for the younger person whose goal is to return to various pre-morbid activities and who may

undergo a process of reintegration (Zhang et al., 2022). In line with existing literature, the findings illustrate that there is also uncertainty about these decisions in the initial stages of recovery (Shiple et al., 2020), for example whether they would be able to return to work and, potentially, other roles they fulfilled. The older stroke survivors might not have these uncertainties or have different experiences as they had different pre-morbid roles. Thus, including the young adult with stroke-related communication difficulties in all the decision-making about the rehabilitation process, is suggested as it could foster acceptance and understanding in transitioning to new roles and activities.

The findings show that young adult stroke survivors navigate a complex terrain as they transition into new roles and activities that change throughout their rehabilitation journey. Considering the ICF, this finding highlights the dynamic nature of the stroke experience, with changes in activities, participation, and context happening throughout the recovery process. Participants' reports show that the 'transition' needs to be considered as a distinct concept, not limited to the boundaries of changes in these domains as the experience of change impacts their sense of identity. This leads to the findings and discussion related to the next two themes, where the specific 'contextual factors' that came to light through the descriptions of experiences of this population are described.

Theme 3: Personal factors to consider for young adult stroke survivors with stroke-related communication difficulties.

In the rehabilitation journey of young adults with stroke-related communication difficulties, as they transition and adapt to changes in roles and participate in activities, personal factors play a crucial role in shaping their experiences and influencing their paths toward recovery and adaptation. This theme explores a range of personal factors that warrant consideration for this population. The first subtheme relates to understanding and addressing

awareness and insight into post-stroke symptoms. Addressing limited knowledge and awareness of and insight into stroke-related difficulties, which could be present following a stroke, are important factors to consider for this population as it may impact their participation in communication and communication rehabilitation. It may also influence an individual's attitudes and self-motivation, leading to the next subtheme which is the role of intrinsic factors in coping and engagement in rehabilitation.

Next, the balance between independence and the utilization of help-seeking strategies is considered. This is followed by an exploration of communication experiences in relation to physical abilities. Finally, the role of alternative and augmentative communication as a coping and participation strategy is discussed. Each of the subthemes offers a deeper insight into the multifaceted nature of recovery for this specific demographic, illustrating the significance of a holistic approach in facilitating their journey towards effective communication and improved quality of life.

Subtheme 3.1: Understanding and addressing knowledge, awareness, and insight into stroke symptoms.

The shared experiences of participants suggested that their awareness and understanding of post-stroke symptoms should be considered across a range of domains when addressing stroke-related communication difficulties in young adult stroke survivors. The participants' experiences indicated variations in knowledge and insight related to acute stroke symptoms, stroke presentation throughout the recovery process, and the nature and impact of communication difficulties.

The participants who had knowledge about and demonstrated awareness of their communication difficulties recognized the impact of these difficulties on their social

engagement and interpersonal skills. This awareness enabled them to implement appropriate strategies and monitor their improvement. Moreover, their experiences suggest that being aware of improvements may increase feelings of well-being and that strategies can be implemented in speech-language therapy to facilitate increased awareness of improvements. However, achieving awareness and insight that result in behavioural changes is a process which requires internalizing knowledge.

Participants reflected on their awareness of acute stroke symptoms. For example, P2 reported, [12] *“when I felt it, I could do nothing, I could not even use my arms, that’s when I already knew.”* In contrast to P2, P3 reported that he was unaware that he might be having a stroke upon the onset of his symptoms, *“because I thought maybe its something I ate or I drink maybe I gonna be orait, I’ll be okay again, but stroke never.”* P2 mentioned that his knowledge and awareness of strokes stemmed from knowing other individuals who had experienced it, [13] *“because I already knew people that were involved in stroke”* and because he was diagnosed with hypertension and thus regularly attended a clinic where he received exposure to information about stroke, [14] *“and I come from day hospitals I was aware of the signs... so I already knew I had a stroke.”*

The difference in their experience might be related to their knowledge regarding stroke occurring among young adults. P2 reported that he was aware of the increase of incidence of stroke amongst younger people, [15] *“as I understand, a friend of mines son, he is now 34 or 35, just passed from a stroke. These are the signs lately for young people that are having strokes.”* In contrast to P2, P3 reported *“I don’t think I’ve seen a younger person with a stroke of it’s above fifty you see who I’ve met but I never thought this can happen to people or person this age.”* Knowledge and awareness of the growing prevalence of stroke in young adults as

well as acute stroke symptoms is important to support early identification and subsequent prompt healthcare-seeking.

To reduce the risk of subsequent strokes in the future, it is important that young stroke survivors have the relevant knowledge of risk factors for stroke. The participants' experiences varied in terms of risk factors for stroke with which they presented. The risk factors include hypertension, HIV, smoking, renal disease, Covid-19 infection, head trauma, and stress. Some participants, however, seemed to overestimate stress as a risk factor whilst failing to recognize other health conditions that may contribute to the risk of stroke. An example of this was evident in P2, who was known to have hypertension and had Covid-19, which he described as [16] *“severe and serious...”* at the time of onset of his stroke. Despite these diagnoses, he believed that stress was the cause of his stroke, [17] *“I think it's more the stress that I suffered from.”* Similarly, P5 who had renal failure at the time of onset of his stroke, believed that his stroke was caused by stress. Both participants reported high levels of stress at the time of onset of their strokes, with P2 also indicating that the cause of his stress was unemployment and related finances. He indicated a belief that this is common among young people, [18] *“Young people stress, they can't find work, there isn't work available for you, they are not exposed to work and there is no income.”* His statement might indicate a broader belief that the increase in stroke amongst young adults that he had observed may be due to financial stress they experience due to unemployment.

Participants also showed diversity in their understanding of the prognosis and long-term outcome following stroke. P3 indicated a very limited view of how stroke presents, *“I see a person with a stroke something is not working. You see the leg or arm or both so some their mouth is maybe [skew].”* While, P2 had a broader view of how stroke could present, [19] *“my situation is different, maybe it's on the left side and then it's different, you maybe get it worse*

than I do.” This understanding of the nature and scope of stroke related symptoms can also affect how individuals understand recovery following a stroke, for example P1, who did not know that recovery can be expected after stroke, *“I couldn’t believe that I would talk again.”* Thus, understanding the knowledge and awareness of this population is vital. This understanding is important not only in relation to the prevalence of stroke in young adults and acute stroke symptoms to support early identification, and risk-factors for stroke to reduce the risk of stroke, but also in relation to chronic stroke symptoms, as it may impact their approach to rehabilitation.

The impact of their communication difficulties on socialization or participation was better understood by some participants, as noted by P5, *“in order to speak audibly I have to speak slower so sometimes someone is saying something and someone responds I have to respond within that minute gap before the topic moves on then I am out of breath when I talk.”* In contrast to P5, P1 did not believe that her communication difficulties had any impact on her social interaction. Participants also showed a lack of understanding of the reason for their communication difficulties. This was evident in P5 who presented with right hemisphere syndrome but did not understand the potential impact of pragmatic skills, *“but my personality has changed somehow now, I talk more, even though I can’t talk properly, I talk more.”* This limited understanding of the nature and scope of their communication difficulties was also noted in P1 who presented with apraxia of speech but related her difficulties to an impairment with memory, *“I need to learn more cause [that] is something that I forgot.”*

Some participants, however, showed good understanding of certain aspects of communication difficulties as well as strategies to use. P4 noticed difficulty with specific phonemes, [20] *“yes it is, like potato. I couldn’t say the po/o if I didn’t look at all the words, its potato, r****, social worker uhm br***** there,” “Ja dit is kyk soos aar ta pel ek kon nie*

*die aar gesê het nie as jy kyk na al die woorde neh is aartappel, R****, social worker uhm Br***** so.*” The awareness of specific aspects of communication difficulties translates into their ability to implement strategies, as reported by P2, [21] *“your breathing and how you move your shoulders, you must move your shoulders and not do things too fast and in a rush, you must do things with time”* and P5, *“I found a way around the group thing. So, I always stand at a vantage point where I can see all of them and they can see me so you can catch their attention and it’s to maintain eye contact, very important, otherwise the person doesn’t hear you at all... and speak slower and clearer.”*

Awareness of improvements in communication was also embedded in participants' experiences. P4's report of her experience illustrated how awareness of improvement can promote feelings of wellbeing, [22] *“But now I can say potato so for me that is a big thing (excited tone of voice).”* Additionally, P5 reported on how awareness of improvements could also include awareness of the impact of this on interpersonal interaction, *“So, I can hear what I am saying now which obviously improves for the person listening.”* P5 reported on using a vocal recording as a strategy to improve his awareness of his own difficulties and his improvements, *“cause there was a vocal recording of myself, and it was a big noise compare to now where I can hear the words myself.”* He also indicated how awareness needs to be internalized to ultimately change communication behaviour, *“everything in your head that is imprinted in your mind now, when I speak, I think of that.”*

Considering awareness of the prevalence of stroke in the young adult population may be especially valuable as research reports “the continued lack of awareness of the occurrence in younger age” (Shiple et al., 2018, p. 9) in relation to stroke. The reports from participants underscore that young adults may primarily encounter stroke awareness campaigns within healthcare settings. Additionally, in the young adult population, undiagnosed hypertension is

recognized as one of the factors contributing to the high burden of stroke (Adeloye, 2014). This aspect may contribute to the lack of exposure and, consequently, the lack of awareness of stroke among young adults, as reported by the participants in this study.

Despite the rising incidence of stroke amongst young adults, the current findings indicate that some participants have not been exposed to young adults who experience stroke. This lack of exposure contributes to their limited awareness and understanding of the scope of difficulties that can be experienced because of a stroke. Shipley et al. (2018), also reported not only the lack of awareness of stroke occurring amongst young adults, but also the many ‘faces and forms’ it may have (p. 7). Similarly, in the current research, participants expressed concern about the lack of understanding from the general population regarding the nature and scope of difficulties that may be experienced after stroke. Moreover, the participants had varied insight into the different facets of their difficulties.

Research suggests the need for education about the non-visible effects young adults experience after stroke (Shipley et al., 2018). This may relate to the current findings indicating that individuals have more insight and awareness of physical symptoms, like the ability to produce specific phonemes that are difficult to articulate and breath support, compared to cognitive difficulties, like topic maintenance which may be less obvious. Similarly, the social impact of communication difficulties may be ‘invisible’ explaining the participants’ lack of insight about these.

The findings above indicate the importance of young adults’ awareness of stroke in relation to 1) symptoms, to promote early identification 2) causes of stroke, for the management of risk factors and 3) prognosis for facilitating participation in rehabilitation. In contrast to traditional impairment-based interventions, which predominantly target specific deficits, interventions aligned with the ICF emphasize the importance of considering how insight and

awareness impact the participation of young adults with stroke-related communication difficulties (Geyh et al., 2011). This shift in focus acknowledges the complex interplay between cognitive processes, like insight and awareness, and functional engagement. Notably, the findings of this research align with prior research underlining the critical role of self-awareness in shaping individuals' motivation to participate in therapy and their ability to comprehend how compensatory strategies relate to and support their overall functioning (Baron et al., 2018). Building upon this, the following subtheme delves into the intrinsic factors considering coping and engagement in rehabilitation of young adults with stroke-related communication difficulties.

Subtheme 3.2: The role of intrinsic factors in coping and engagement in rehabilitation.

The importance of intrinsic factors, such as attitudes and self-motivation, in facilitating coping and engagement in rehabilitation for young adults with stroke-related communication difficulties is illustrated by participant's quotations. Attitudes such as acceptance, and determination were reflected in participants' experience when they reported on engaging in speech-language therapy experiences that were difficult. In addition, the experience illustrates how interventions to facilitate resilience and realistic goal setting can further enable young adults with stroke-related communication difficulties in coping and engagement in rehabilitation.

The speech-language therapy experience was effortful for participants. However, in light of this, participants displayed attitudes of determination, as shown in a report by P2, [23] *“my first session with her was very difficult. This cost me two weeks on my own,”* and P4, [24] *“it doesn't help that I go sit and feel sorry for myself, no, I must face the world in its eye,”* Participants' reports also allude to being self-motivated which seemed to relate closely to an attitude of determination, as shared by P3, *“when maybe she was done with me I will continue*

maybe to write something whatever it is that she was uhm teaching me I'll just write," P5, *"I decided to replicate what I was doing there [in therapy] here [in my room],"* and P4, [25] *"I always asked [the speech therapist] for homework."* It is clear how these attitudes facilitated engagement in their speech-language therapy rehabilitation.

Participants' ability to cope seemingly hinged on their acceptance of their new circumstances. The acceptance seemed to evoke a positive outlook and a sense of contentment. This was illustrated by P1, *"I have to accept the way I am,"* and P3, *"I have accept[ed] that now this is the new normal for me."* The idea of acceptance naturally includes acknowledging one's situation but also doing so without resistance, which allows participants to focus on rehabilitation and move forward, as illustrated in P3's report, *"I didn't put myself to that speaking like normal again I just take things step by step."*

Some participants had not yet reached acceptance, but rather relied on hope to cope, as P4 shared, [26] *"I have hope, no one can take that away from me."* Participants' experiences indicated that hope may be a positive motivator, as P4 reported, [27] *"I want to talk better, so I will do anything in my power just to talk better."* Interestingly, P4 reported on hope whilst comparing her communication abilities to that of others, [28] *"If I could talk like you, I would be very happy, but I can't. Although I still have hope that it will happen."* Similarly, participants who reported on acceptance indicated that they were not comparing their communication abilities to others or prior communication abilities, as shared by P3, *"I didn't put myself to that uhm speaking uhm like normal again."*

These findings suggest that young adults with stroke-related communication difficulties tend to draw motivation from comparing their own abilities to those of others or their desired outcomes. Their experiences highlight the interplay of expectations and attitudes and that both need to be considered to ensure the individuals cope in rehabilitation. Notably, research has

indicated higher levels of social comparison in young adults compared to older adults (Callan et al., 2015), indicating that this might be a consideration unique to young adults with stroke-related communication difficulties. Taking this into consideration, it is evident that fostering self-motivation through realistic goal setting can be a valuable strategy to enhance the engagement of young adults in the rehabilitation process.

The findings further indicate that coping and engagement in the rehabilitation process, which is marked by transition, happens by drawing on intrinsic factors like self-motivation. A recent literature review on stroke recovery and motivation supports the finding of the current study, indicating that motivation influences individuals' engagement in rehabilitation (Gangwani et al., 2022). These findings may be particularly pertinent in the context of young adults with stroke-related communication difficulties. For them, self-motivation becomes a crucial driving force, often stemming from pressing needs to return to work, meet family responsibilities (especially when they have young children), and other life demands. The findings show that attitudes of hope and determination may facilitate these individuals in developing self-motivation.

These intrinsic factors are instrumental, not only in enhancing participation in rehabilitation activities but also in everyday activities and communication opportunities crucial for achieving a comprehensive recovery. As supported by the ICF, the findings again highlight that a holistic perspective is crucial when seeking to fully comprehend the unique needs and challenges faced by young adults with stroke-related communication difficulties. The ICF framework underscores the importance of exploring how personal factors, particularly intrinsic factors like attitudes and self-motivation, significantly influence one's ability to participate in various activities. Considering this, the findings of this study show the need to recognize the

role of positive attitudes and self-motivation for young adults with stroke-related communication difficulties.

An approach like the ICF which considers attitudes and motivation, can address their unique needs and aspirations, ultimately helping them regain their independence and reintegrate into their work and family life more effectively. In the next subtheme, independence in communication will be explored further in relation to help-seeking strategies employed by young adults with stroke related communication difficulties.

Subtheme 3.3: Help-seeking strategies and their relationship to independence in communication.

The need for assistance is often a reality for individuals with a multifaceted disease like stroke, which may influence function to various degrees. The participants' experiences illustrate that they recognized the need for assistance with communication and other stroke-related symptoms. They did experience an increased need for help in the acute stages following the stroke when communication difficulties are often more severe. Their reports also illustrate that being reliant on assistance was difficult as it relates to a perceived loss of independence. Achieving independence whilst seeking help, however, seems to rely on balancing these two. To achieve a balance between help-seeking and independence, participants' experiences illustrate that communication difficulties need to be considered in conjunction with individual preferences and values.

Participants' reports highlight that they recognised the need for assistance with communication from communication partners, for example P2 shared, [29] "*they had to help me utter the words and they help with any words in the sentence that I want to say.*" P3 also reported requiring help with communication from communication partners and indicated that

the need for help was greater during the acute stages of the stroke when communication difficulties were more severe, “*when I was [discharged from acute hospital], still I couldn’t speak. So at first I felt like yes, they have to help.*” The increased need for assistance with communication in the acute stages following the stroke was also illustrated in P4’s report of increased reliance on communication strategies during this stage, when communication difficulties were also more severe, [30] “*it was something that I used more when I was struggling.*” However, during later stages of recovery and as communication skills improved, there was a growing desire for independence, as reported by P3, “*I always wanted someone to help me [but now] I wanted to do thing myself without any help with anyone.*”

Receiving the assistance was, however, difficult due to a perceived loss of independence, as P4 reported, [31] “*It wasn’t fun for me because I am used to doing my own thing,*” and, similarly, P2 reported, [32] “*You can’t do things for yourself... it is... frustrating because you were independent and now you can’t do the things you want to do.*” Striving for independence whilst relying on help can, however, be achieved and seemingly depends on finding the balance between independence and help-seeking. For example, P4 reported on an experience in the shop, where she clearly outlined what she was able to do herself, whilst also highlighting, in contrast, that her son had accompanied her, [33] “*my son came with me but I took my things by myself and gave it to the lady behind the uhm, you know there where they weigh... I gave it to her myself and I just told her; hi how are you...*” Similarly, P5 was able to articulate the level of help he required whilst still achieving independence, “*Like small things I can make a cup of coffee, but I can’t walk with it because I limp so it’s going to spill. So it’s good you make coffee for yourself but someone say don’t worry I bring it to you.*”

The preferred level of independence is, however, not always achieved, as illustrated in P4 and P2’s reports of perceived loss of independence. P5 highlighted a possible reason for

this when reporting that communication difficulties may make it difficult to ask for assistance, *“Not being able to [speak] is a problem cause you need help and you can’t say anything.”* Apart from communication difficulties, when asked why he finds it difficult to ask for help, he reported, *“cause I value my independence.”* P3 supported the idea of values or preferences impacting help-seeking, although he indicated differences in these compared to P5. P3 reported *“I don’t feel like there is [anything] wrong with asking for help.”*

This notion of considering patients preferences and values in treatment has been well defined in research and forms part of what is described as evidence-based practice (EBP). The findings of the current study highlighted the importance of preferences and values of young adults with communication difficulties when aiming to achieve a balance between help-seeking strategies and independence. In the current study, young adults with communication difficulties’ increased reliance on help-seeking in the acute stages following the stroke related to an increased need for support from communication partners and use of communication strategies.

Despite research pointing out the challenges of implementing EBP in acute care settings for individuals with communication difficulties, specifically aphasia (Foster et al., 2013), these individuals need to make important health-related decisions during this time. By considering the values and preferences of young adults with communication difficulties regarding assistance from communication partners and the use of communication strategies, interventions can align more closely with EBP principles. In turn, this can also facilitate participation of these individuals in the important decisions that arise early in the rehabilitation journey.

The findings further showed that communication difficulties impact help-seeking and vice versa and that personal preferences contribute significantly when considering how help-seeking can support independence. Interestingly, research reporting on the communication

needs of young adult stroke survivors compared to older stroke survivors indicated that a higher percentage of young adults (82%) compared to older individuals (63%) preferred communicating about stroke and other medical issues (De Grass-Clementson, 2018). The current findings suggest that this preference may be related to young adult stroke survivors' need to indicate their preferences around asking for and receiving help, further alluding to how help-seeking can promote independence for the young adults with stroke-related communication difficulties. This link between patient preferences, EBP, and independence aligns closely with the personal factors dimension in the ICF framework, emphasizing the individual's subjective experience and values within the rehabilitation process (Karhula et al., 2021).

It is also clear that young adult stroke survivors require help beyond communication as stroke affects various domains of functioning. This lays the foundation for a more comprehensive exploration of communication experiences of young adults with stroke-related communication difficulties in relation to physical abilities.

Subtheme 3.4: Communication experiences in relation to physical abilities.

Participants' experiences highlighted that their communication needs are impacted by their physical abilities following the stroke. This shows that communication experiences of young adults with stroke-related communication difficulties cannot be considered without considering their physical abilities. The participants' reports of their experiences indicated that the stroke-related physical and communication difficulties intersect and compound, affecting participation, communication needs, and social interaction.

Participants referenced the consideration of physical difficulties in relation to their communication experience. As noted by P2, when he was asked about his communication

difficulties, [34] *“you know when you get something like that and you can’t do anything and you walk drag foot, it’s difficult,”* and [35] *“that [physical difficulties/stroke symptoms] collects [compound] everything.”* His response to the question indicates that it may be difficult to separate the communication experience from the experience of other stroke-related symptoms.

Moreover, participants reported gratitude for the unaffected physical abilities following the stroke and reported on these abilities in view of their communication difficulties. P4 reported, [36] *“you want to say something but you can’t, it’s almost as if you are a prisoner in yourself because, see I maybe wanted, uhm, luckily for me I can walk so I could go to the toilet,”* and [37] *“because I can read and do stuff for myself I am very happy,”* Similarly, when asking P3 how he overcame communication challenges, he reported relying on his physical abilities when communication failed, *“sometimes asking for help maybe like asking for time, some of the things I just do myself.”* P3’s experience shows that he was able to perform the desired activity independently and did not need to rely on his communication to ask for assistance.

Participants with more severe physical limitations such as P5, had overtly negative experiences of communication in relation to physical limitation. For example, he reported, *“cause your arm and leg is not working. So you need more help so you have to be able to speak. Not being able to is a problem cause you need help and you can’t say anything”* and *“Even the walking and arm made it worse it makes you a prisoner of your mind, you are stuck there.”* His reports indicate that physical limitation may be exacerbated when experiencing communication difficulties, again suggesting that physical limitations may inform the communication needs of young adults with stroke-related communication difficulties.

P5 also highlighted how physical symptoms relating to his communication difficulties (dysarthria) translated into difficulty participating in group settings, *“I have to respond within*

that minute gap before the the topic moves on then I am out of breath when I talk.” The impact of physical limitations on the participants’ ability to participate in social interactions was reported by P2, who felt he was unable to engage in social situations due to pain [38] *“there are times where I was sitting and then I told them [my friend] I quickly need pain pills I quickly need to drink two pills. Then I must go lay down...”* This finding is supported by research indicating that poor physical functioning is associated with reduced participation for stroke survivors with stroke-related communication difficulties (Worrall et al., 2017).

The experiences of the participants highlighted the intricate interplay between physical capabilities and communication needs. The findings show that the physical and non-physical consequences of stroke are intimately intertwined. Moreover, the findings indicate that physical abilities directly influence the communication needs of young adults with stroke-related communication difficulties and their capacity to engage in communication activities actively.

For the young adult who may be unable to return to performing complex daily activities like managing finances, caring for children, or pursuing a career, due to physical limitations, their ability to express their preferences regarding necessary support may play a crucial role in preserving their autonomy. Therefore, their awareness of how their physical concerns not only influence their communication difficulties but also impacts their health-seeking behaviour needs to be addressed. Furthermore, the findings suggest that the scope of what young adult stroke-survivors may need to communicate about should be considered, specifically highlighting tasks where assistance is required due to physical limitations. Consequently, communication intervention for this population should consider these various activities, with a focus on those where physical limitations have influenced their independence as this informs their communication needs.

To achieve holistic communication intervention for this population, it should be recognized that their physical ability and communication needs are inextricably linked. The findings illustrate that physical abilities inform the communication needs and communication opportunities of this population. This highlights the appropriateness of the ICF as a framework to consider the needs of young adults with stroke-related communication difficulties, as stroke influences a variety of body functions and the interplay between these are ultimately dependent on the individual's unique level of functioning and various contextual factors.

This holistic perspective, as grounded in the lived experiences of the participants of this study, should guide future interventions and strategies to ensure more comprehensive and effective rehabilitation for this population. One strategy often used to enhance communication functions for individuals with communication difficulties, is alternative and augmentative communication AAC (Light & McNaughton, 2014). In the next subtheme, the participants' experiences will shed light on how AAC can be a coping strategy for young adults with stroke-related communication difficulties.

Subtheme 3.5: Alternative and augmentative communication as a coping strategy.

Through the participants' reports, it is proposed that AAC can be considered an appropriate coping strategy for young adults with stroke-related communication difficulties as it is seen as something they rely on when experiencing communication breakdown. Most of the participants reported that they employed a form of AAC without receiving instruction or guidance from an SLT. Only P1 reported, "*if I want to say something but words don't come out I must point that thing I want,*" when asked about intervention received from the SLT. Strategies such as pointing, gestures, lexical adaptation, use of writing and circumlocution was reported by participants. They also reported on emotional responses when using AAC, with anxiety and anger resulting in less effective use of strategies. Participants' experiences suggest

that the communication context and communication partners need to be considered when implementing AAC strategies.

Participants reported using alternative communication strategies throughout the rehabilitation process. These are employed as a coping strategy to overcome communication breakdown from the onset of their communication difficulties, as reported by P3 in the acute stages of recovery, *“even then [at the ER] I was just [nodding head yes/no],”* up until much later, as seen in P1 report about communication after discharge from an in-patient rehabilitation, *“I just give the Doctor the papers that I’m given [at] rehab center.”* The use of gestures and pointing occurred more in the acute phases when the presenting communication difficulties were more severe. P1 reported, *“when I was at [the acute hospital] it was difficult for me ... so if I want to say something I have to point.”* While P4 referenced the use of gestures during this stage, [39] *“yes that was something I used more when I was struggling.”* The use of lexical adaptations, noted by P3, [40] *“I’m just going to say cigarettes, [instead of Rothmans]”* and P1’s use of written material, which was provided by the rehabilitation center, however, was employed during later stages of recovery following the stroke.

Although AAC was successfully and intuitively implemented by participants, some perceived it as impeding their functional improvement. As noted by P5, *“I generally used a piece of paper and a pen which helped a lot but in time I didn’t realise it was a crutch and I wanna speak so I can’t keep on doing that so I buried them...”* The use of AAC strategies, specifically gestures, also provoked anxiety in participants, specifically pertaining to how this may be perceived by others, as illustrated in P4’s report on using gestures in communication, [41] *“when I am nervous then I think, must I now really, these people are going to think I am crazy.”* Participants also reported on preparing for communication breakdown and the use of strategies, specifically lexical adaptations, as supported by P4’s report of preparing words to

say before going to the shop, *“because I told [my husband] I’m just going to say cigarettes”* and P3’s report, *“I make sure that I have words that I use words that are easy.”*

Participants’ experiences reflect how AAC provides a means for participation and engagement as it supports communication functions, like indicating preferences, P5 shared, *“Things like asking people to do things for me when I need help... or not to help me”* and requesting, P3 reported, *“let’s say if I want, uhm water, I’ll just say (gestures rounded hand to mouth).”* Participants also indicated good awareness of environmental factors to consider when using AAC. For example, the physical environment, P5 reported, *“I think at rugby games, to use hand gestures is better cause it’s really loud,”* and communication partners, P5 included, *“I would write and say what I want, but [with] my daughter, I couldn’t.”* Personal considerations were also reported on, like individual preferences and the impact of emotions, P5 added, *“I don’t like writing when I am irritated because my arm can’t keep up with my brain... I wanna say it’s like a big scribble.”* Research supports the current findings, indicating that AAC provides a means for participation and engagement and that both personal and environmental factors need to be considered when implementing AAC (Fried-Oken et al., 2012).

The findings indicate that the participants adopted self-selected AAC strategies to bridge communication gaps resulting from stroke-related communication difficulties. Understanding the effectiveness of these strategies, the reasons behind their success or failure, and the personalization of communication support may improve communication abilities. This approach aligns with recommendations from existing research, which emphasize that AAC interventions should be tailored to individual needs (Iacono et al., 2013) and stress the importance of SLTs collaborating with individuals with communication difficulties during AAC implementation (Paterson & Carpenter, 2015). For the young adult stroke survivor, this

approach may empower them to shape their own communication methods, fostering a sense of autonomy and supporting self-motivation. Integrating self-selected AAC strategies into rehabilitation programmes not only enhances their effectiveness but also acknowledges the individuals' active role in their recovery process, ultimately improving their overall quality of life and independence.

Research mainly reports on implementation of AAC for individuals with communication difficulties “when individuals can no longer expect full return of pre-morbid function” (Fried-Oken et al., 2012, p.56). In the current findings, however, participants were interviewed in the acute to subacute phase of recovery and reported on various AAC strategies that were employed during these earlier stages of recovery. Nevertheless, this might explain why using AAC strategies was not targeted in speech-language therapy, as the participants were in the recovery stages where improvement can still be expected (Bernhardt et al., 2017). Early inclusion of communication support is, however, suggested in existing literature (Fried-Oken et al., 2012), and supported by the current findings, showing that AAC was successfully used as a coping strategy during the acute and subacute stages of participants' recovery.

The reference to different stages in stroke recovery alludes to the consideration of the communication environment. The consideration of the communication environment may be unique for stroke survivors journeying through different environments, like the acute hospital setting, rehabilitation setting, and ultimately their homes and communities. In the next theme, the multifaceted aspects of the communication environment and their influence on communication of young adults with stroke-related communication difficulties will be explored further.

Theme 4: Environmental considerations for young adults with stroke-related communication difficulties.

For young adults with stroke-related communication difficulties, the environment in which they communicate plays an integral role in shaping their experiences and outcomes. This theme explores the environmental considerations that affect the lives of these individuals as they strive to communicate effectively and reintegrate into society. Within this exploration, the influence of the communication environment on their participation, addressing the information needs of their communication partners, and the pivotal role played by these partners in fostering their independence and autonomy is considered. These subthemes collectively illustrate the complex interplay between individuals with communication difficulties and their surrounding environments, offering insights into the factors that influence the journey of young adults with stroke-related communication difficulties towards meaningful communication and enhanced quality of life.

Subtheme 4.1: The influence of the communication environment on participation.

The participants' experiences reflected how the different environments relate to different communication opportunities, access, and demands. In turn, it highlights the importance of adapting to different environments through implementing strategies, adjusting alternative modes of communication, and carefully choosing activities. Research on the topic classifies environmental factors as described by the ICF under the following categories: products and technology, the natural environment, support and relationships, attitudes and services, and system and policies (Howe, 2008). The participants' experiences illustrated the factors related to the environment in which young adults with communication difficulties communicate and are reported on below.

The positive impact of a supportive communication environment is reflected in participants' experience. P4 considered the rehabilitation setting as a supportive environment, relating to the communication behaviours of communication partners in this environment, [43] *“here [at the rehabilitation centre] they have patience with me.”* For P4, this relates to improved communication at the rehabilitation centre, compared to the home environment, [44] *“look here [at the rehabilitation centre] I talk a lot easier, but at home it’s something else.”*

Similarly, P1 noted the importance of an environment that offered access to communication partners, *“there are a lot of people around me so I learned there to speak...”* and in turn more opportunity for socialization, *“You see it’s quiet there (acute hospital)... so when I went there to rehab that’s when I learned to speak.”* Participants 3 and 4 also reported on the difficulty they experienced with socialization due to a lack of access to appropriate communication partners and opportunity for communication in both acute and rehabilitation settings, as other patients in the setting also presented with communication difficulties. P4 reported, [45] *“the first two weeks I slept in a room where the people couldn’t speak, I was the only one that could speak. That for me wasn’t nice,”* whilst P3 reported, *“cause all of us here in the ward we couldn’t speak you see ja so I was just reading.”*

The work environment was also mentioned. When prompted to think about difficulties she might encounter upon being discharged, P4 reported, [46] *“To go back to work [is going to be the most difficult], not back home.”* Notably, she refers to the environment and not specific activities or communication partners. Although she does not relate her response specifically to communication, she had minimal physical difficulties and, therefore, her concerns likely related to her expectation of communication demand, and in turn difficulties she may experience with communication in the work environment.

The consideration of the services in the community and its relation to communication expectations and demands were noted in participants' experiences. For example, P4 reported on different shopping environments, [47] *"look if it's at the big store, then I just go fetch the stuff so you're not really talking, but when I'm at a small store where you buy over the counter, then it's difficult."* Notably, smaller shops are usually more accessible in terms of mobility as they are situated closer to individuals' homes in the community. However, P4 identified it as a difficult communication context.

P4 also reported on the difficulty of talking over the phone, which is another communication context with demands or expectations in relation to the communication partner/s, *"a lot of people are very impatient when you talk to them over the phone. So uhm that's why I need to speak better because a lot of people won't understand this,"* indicating the need to consider different technologies and their impact on the communication demands for young adults with stroke-related communication difficulties.

A group communication context, which is a known environmental barrier for individuals with communication difficulties (Howe, 2008), was deemed as a challenging communication environment by P5. He reported that this was due to the increased communication demands, such as having to speak faster, *"the hardest part was being able to speak in a group and keep up with the pace while people are talking."* P5 indicated strategies he implemented for this, *"So I always stand at a vantage point where I can see all of them and they can see me so [I] can catch their attention."* P5 also noted how the sound in the environment, i.e. background noise, determined the communication strategies he employed, *"I think at rugby games, to use hand gestures is better cause it's really loud."*

All three isiXhosa speaking participants made comments prompting the consideration of characteristics of communication partners, specifically in terms of the language of

communication partners. P1 indicated increased hesitance speaking in her second language, *“my English it sounds like its broken that’s why [I’m] scared to talk English.”* Similarly, P3’s report seemed to indicate insecurity related to speaking in his second language following the stroke, *“I wanted to see that if I can speak English now or [not] anymore.”* This may be an especially important consideration in the South African context in which there are multiple official languages resulting in young adults with stroke-related communication difficulties having to engage with communication partners using a language/s other than their first language, throughout their rehabilitation journey. Additionally, services may not always be available in their home-language and could lead to avoidance of communication in these contexts, as participants mentioned their fear, hesitance, and insecurity around communicating in their second language.

Conversely, P5 reported a preference for speaking in his second language (English) compared to his home language (isiXhosa). He reported that he appreciated when his isiXhosa speaking communication partners, like his friends and family, accommodated him by speaking in English. This again alludes to the environment, as the communication partners in these environments were able to accommodate him by speaking in English, however, not all isiXhosa individuals may be able to speak or understand English. This may result in increased difficulties for P5 communicating in such contexts as he reported difficulty producing isiXhosa click sounds, *“some words are difficult and Xhosa is harder because of it took time to get the clicks.”*

In the current study, participants reported on different communication opportunities and demands in relation to different communication contexts such as the rehabilitation centre, hospital, and the work environment. Other contexts like group settings and talking over the phone are mentioned in relation to the communication behaviour of communication partners

in these contexts. Furthermore, the language of the communication partners and access to appropriate communication partners in the environment is considered.

As illustrated, young adults are actively engaged in various activities of life, such as using a phone, shopping, attending sport gatherings, and pursuing careers. For young adults with stroke-related communication difficulties, the participants' reports illustrate how their communication difficulties affected their participation in these environments. They indicated how some of these environments, such as speaking on the phone or at work, translate into increased communication demands. However, the intricate relationship between the environment and its impact on communication demands remains a topic that requires further exploration. Nevertheless, the findings highlight the significance of considering the range of communication environments in which young adults need to participate. It highlights the need to account for the specific communication demands related to each unique communication environment.

These findings align with the ICF which emphasizes modification of environmental factors to enhance individuals with communication difficulties' participation and functioning in society (Threats, 2008). Whilst participants' reports highlight the significance of considering environmental factors, adaptations which can promote participation in relevant contexts was not observed. This approach holds the potential to significantly enhance the quality of life and social participation of young adults with stroke-related communication difficulties. In fact, research has suggested that considering how environmental modifications can support participation "may be the best use of speech-language therapy time to improve quality of life" for individuals with acquired communication difficulties (Elman & Holland, 2020, p. 58).

When considering environmental factors, "the support and relationships domain is a key area for individuals with communication disorders," (Howe, 2008, p.31). In addition to the

communication behaviours of other people, characteristics of other people and the number of other people, general support and relationships, and communication partner training form part of the support and relationship domain in the realm of environmental factors to consider for individuals with communication difficulties (Howe, 2008). Another domain under the environmental factors to consider for individuals with communication difficulties is attitudes. In this domain, attitudes of other people, societal attitudes, and other people's awareness of the communication disorder is considered (Howe, 2008). Relating to these domains, the following two subthemes will consider the information needs of communication partners and how they can support autonomy, and independence of young adult stroke survivors with stroke-related communication difficulties.

Subtheme 4.2: Addressing information needs of communication partners.

The experiences of the participants highlighted a lack of and need for providing information to communication partners about the communication difficulties experienced by young adult stroke survivors. The report includes information on the different communication partners that the population might encounter. Furthermore, the difficulties they experience with providing such information is reported on and highlighted the need for intervention in this regard.

Most participants indicated that the communication partners they engage with in their lives lacked knowledge and an understanding regarding stroke and stroke-related difficulties. P4 reported this about her husband, [49] *"he doesn't understand the stroke."* P2 believed that the variability in the nature and scope of stroke symptoms across different cases can lead to people's confusion regarding or misunderstanding of the difficulties they could present with, he reported [50] *"Sometimes the people don't understand because my situation is different."* Participants also shared their beliefs about other people's knowledge regarding stroke and

communication difficulties. P4 stated that, [51] *“people then think you have a disability because you can’t speak properly,”* [52] *“other people will think, what’s the matter with this woman. Is she drunk or something,”* and [53] *“look a lot of people have that perception that if you had a stroke you are brainless.”* P5 also echoed similar beliefs about negative assumptions by others, *“because people assume you are stupid when you can’t talk and then they’re very condescending.”* However, these statements imply their own beliefs and may be unsupported. Nevertheless, these beliefs play a significant role in shaping their experience and must be considered.

P5 however reported on a concrete experience which illustrated an assumption that a communication partner held, he reported this about an unfamiliar communication partner (i.e., his son’s rugby coach) and more familiar communication partner (i.e., his aunt), *“when you can’t speak they assume you can’t hear, they make sign language with you.”* Here, the communication partners were uninformed and acted on their assumptions, which resulted in inappropriate behaviour from the communication partner that was not well received by the young adult experiencing stroke-related communication difficulties. P5 also mentioned that his father was understanding of his difficulties, in contrast to his mother who provided unsolicited and unappreciated accommodations, *“my dad is very much like me but he understands me but my mom has this habit of putting [post-its] like to tell me [things].”* P5's experience underscored a disconnect between his needs and his mother's perception thereof. While her efforts might have been valued by others, P5 did not appreciate them.

Communication partners' knowledge about and understanding of stroke-related communication difficulties may also affect how they view the recovery of the person with communication difficulties, as indicated by P4’s reports of her family, [54] *“they can’t see that I am making progress. But I know that I have made progress,”* and [55] *“my husband said that*

I am moving backwards and not forward according to him my speech is bad, but look I could not at all speak so for me it's good." Conversely, she reported the following about another patient who was admitted with her at the hospital and rehabilitation centre, [56] *"there is actually a man in my corridor he was in my room in [the acute hospital] and he is one of the people that could see how I am going up and not coming down."* Since another patient at the hospital and rehabilitation centre is experiencing a similar situation, it is reasonable to assume that his knowledge and understanding may be better than her family who is not knowledgeable about the experience. Thus, interventions targeting the knowledge and understanding of communication partners about stroke-related communication difficulties may improve the experiences of young adults with stroke-related communication difficulties.

For young adult stroke survivors with communication difficulties, their experience indicated that their children need to be considered in training and education efforts. This was noted by P3 who raised concern in relation to his son's experiences, *"I was afraid that maybe this will also affect him in school."* Similarly, P4's experience emphasized that the scope of education and training should not exclude even younger children. She reported this about her young grandchildren, [57] *"the grandchildren I have two [one] is 7 and she knows I am sick. [The other one] she is two and a half, she also knows something is not so good with me..."*

The young adults with communication difficulties sometimes provided their communication partners with information regarding their experiences, as P4 reported [58] *"she has an understanding of what I do here because I told her."* While some participants were able to convey information about their communication difficulties to communication partners, some faced challenges doing so. P3 noted this when he was unable to communicate with the doctors, *"I was getting angry cause I want to know what's wrong with me and they busy asking me."* The combination of the participants' communication difficulties and misunderstandings

from communication partners, also resulted in feelings of frustration and anger, *“The nurses speak to you in a certain way like you’re an idiot so as soon as I got my speech back, I put them in place and now the assumption is I’m rude.”* P5's experience further demonstrates that the frustration stemming from his experiences and the resulting behaviour had adverse social repercussions for him.

Seemingly, however, communication partners do have a desire to understand more about communication difficulties. This was reflected in a report by P4, [59] *“My son asked me over the weekend, mommy when you read how does the words sound in your head when you say it to yourself.”* A report by P5 also indicated that communication partners put in effort to educate themselves and others in the environment. He reported this about his father and expressed gratitude towards him in this regard, *“my dad is the type of person when anything happens he reads about it a lot and then makes everyone else read about it so my kids they were trained on how to deal with everything.”* Difficulties seem to arise when the individual with communication difficulties is unable to express their needs and experiences, as reported by P4, [60] *“she was very concerned, because she asked me mom what’s wrong and then I couldn’t speak,”* and P3, *“my girlfriend she kept asking me what is wrong with you I couldn’t I was like I couldn’t answer.”*

As supported in research, relatives of those affected by communication difficulties should be considered as ‘service users in their own right, requiring information, support, and training.’ (Hilton et al., 2014, p.797). The findings of this study support this through illustrating how communication partners contribute to the lived experiences of young adults with stroke-related communication difficulties. Furthermore, the current findings emphasize the significance of involving children of young adults with stroke-related communication difficulties in interventions targeting communication partners. This emphasis is particularly

relevant in the context of young adult stroke survivors, highlighting the unique challenges and dynamics faced by this population. Recognizing and addressing the needs of both young adults and their children could enhance the effectiveness of interventions aimed at improving the overall communication experiences for young adults with stroke-related communication difficulties.

Another important group of communication partners mentioned by participants was rehabilitation professionals, specifically nurses. This topic has been researched, with findings reporting on individuals with stroke-related communication difficulties experiencing ‘inaccessible encounters with medical professionals’ (Manning et al., 2017, p.12). Similarly, Morris et al. (2015) reports that physicians rarely use communication strategies with their patients with communication difficulties. The findings of the current study confirm this for young adults with stroke related communication difficulties. The findings also show that these encounters may be due to lack of knowledge and understanding of communication difficulties and highlights the potential negative impact for the young adults with stroke related communication difficulties.

In summary, it is essential to consider a range of communication partners when addressing the communication needs of young adults with stroke-related communication difficulties. Their experiences highlight the parties involved including spouses, children, grandchildren, other family members, friends, hospital staff, other patients, and the general population. As expressed in P5's account, [61] *“you have the perception that it is only happening to you, that is not true, it’s for all of us to deal with.”* Her statement is a reminder that speech-language therapy rehabilitation efforts should target all the affected parties. The next subtheme further explores how communication partners can support independence and autonomy of young adults with stroke-related communication difficulties.

Subtheme 4.3: The role of communication partners in supporting independence and autonomy.

Independence refers to being self-reliant. Independence in communication will thus encompass the ability to express oneself, convey thoughts and feelings, and engage in meaningful communication. Autonomy is closely related to independence but emphasizes the capacity for self-governance and self-determination. Autonomy in communication relates to an individual's ability to make and enforce decisions about their communication.

Young adults with communication difficulties may require help with communication from communication partners to achieve independence in communication. Thus, when communication partners provide help with communication, they need to ensure they also facilitate autonomy of the person with communication difficulties. This subtheme considers how communication partners can support independence and autonomy of young adults with communication difficulties by allowing them to decide how they communicate, with whom they communicate, and the content and manner of their communication.

The participants' experiences highlighted a few important considerations related to how communication partners could support their independence and autonomy. Firstly, communication partners' knowledge about and attitude towards stroke-related communication difficulties contributed to the participants' independence. Furthermore, the participants' preferences regarding communication partners sharing information about their communication difficulties are considered in relation to autonomy. The findings indicate differences in preferences for the type of information communication partners should share with others and with whom it could be shared. Lastly, how autonomy should also be considered in relation to the familiarity of communication partners is considered. This is proposed as there were differences in how the young adult stroke-survivors accepted support and how the young adult stroke-survivors and their communication partners adapted to each other's needs.

Participants indicated that positive communication experiences were strongly linked to communication partners having knowledge and understanding of their communication difficulties. This knowledge likely empowered the communication partners to provide effective communication support, ultimately contributing to the independence of young adults with stroke-related communication difficulties. For example, P1 reported that her children were able to understand her effectively because her parents had informed them about her communication difficulties before her return home, stating, “[My children] do understand me because my parents told them before I come home that [the way] your mother speak is not gonna be the same.” Similarly, P3’s experience with friends suggested that he felt supported as his sister provided them with knowledge about his communication difficulties, “my sister told them before I came to them that I suffered a stroke so they were very supporting they knew that [I] can no longer speak like before.” These experiences highlight the role that communication partners’ knowledge plays in fostering independence for young adults with stroke-related communication difficulties.

An experience by P4 in the acute hospital setting also shows how knowledge and understanding of communication difficulties translated to successful communication with another person with communication difficulties, [62] “I knew what she was trying to say but the others, especially the nurses, they didn’t know...” When asked why she could communicate successfully with the person while the nurses could not, she reported on noticing the person’s frustration and implementing communication strategies, [63] “because she gets so frustrated because she wants the bedpan or she wants to go to the toilet but they don’t know what she wants to say and then I said bedpan and then she just shakes her head.”

In this context, the linkage of knowledge and understanding to autonomy is proposed. The participant, P4, acted as the communication partner, and the assistance she provided was

a means to enable the other person to express her needs and preferences effectively. The suggestion is that P4's own experience with communication difficulties might have equipped her with the knowledge and understanding necessary to employ appropriate strategies, ultimately fostering successful communication. These experiences highlight how knowledge and understanding can play a significant role in facilitating effective communication, thereby promoting independence in communication. Furthermore, they suggest that individuals with communication difficulties can be sources of support for one another since they share similar situations and can offer valuable assistance in navigating and overcoming communication challenges.

Assistance with communication, as reported on by P2, implies that communication partners would need knowledge of what he wants to say to assist him, [64] *"they had to help me utter the words and they help me with words of the sentence that I want to say..."* P4, however, indicated discrepancies between what she wants to say versus what she wants communication partners to communicate on her behalf. P4's reports relate specifically to disclosing her diagnosis but may potentially relate to other communication topics as well. She reported that she does not want others to disclose her communication diagnosis, [65] *"I told her afterwards I prayed so much now you do not say I had a stroke,"* however, reported disclosing her diagnosis herself, [66] *"I told her I had a stroke I can't speak so well."* In contrast to P4's preferences with regards to disclosing her diagnosis, P3 appreciated when his sister disclosed the information, *"my sister told them before I came to them that I suffered a stroke... I am very happy [she did that]."* These experiences propose the important difference between autonomy and independence, indicating that it is not only about effectively communicating the information (i.e., independence), but also preferences relating to who needs to deliver the information (i.e., autonomy).

In another report, P5 indicated that his cousin shared information about his difficulties with his friends and family, *“My cousin pulled them aside [and told] them.”* He reported that his experience was influenced by the responses of those with whom the information was shared, *“I appreciate them for listening. And accommodating me without making it condescending.”* This report by P5 highlights that the attitude of those being informed should also be considered. Similarly, P4’s preference of communication partners sharing information seems to be related to the response she expected, [67] *“because some people want to feel sorry for you.”* Thus, to promote autonomy, communication partners should be attuned to the attitudes of others, as these attitudes can influence the preferences of young adults with stroke-related communication difficulties.

Participants also appreciate an attitude of patience, for example P4 indicating that she was able to engage in meaningful conversation with a friend as [68] *“she has a lot of patience.”* Another report by P4 illustrates how impatience may impede autonomy in conversation, firstly, by not allowing her to communicate in the manner that she preferred and, secondly, through likely impeding her from communicating what she wanted to convey, [69] *“while I am maybe talking I am struggling to say the word then they rush me.”* In another extract, she also highlighted how impatience increased communication expectations, [70] *“a lot of people are very impatient when you talk to them over the phone. So I must be able to speak better because a lot of them won’t understand this.”* This resulted in increased difficulty participating in these communication contexts, which ultimately hindered independence in such contexts.

Apart from the attitude of communication partners, the participants also reported that the familiarity of the communication partner that shares or receives information needs to be considered. For example, P3 reports, *“I knew those people we were telling that I have a stroke, so I didn’t mind,”* indicating that sharing information with more familiar individuals may be

more accepted. Similarly, P5 also reported on an experience where he appreciated help with communication that he received from his daughter, a familiar communication partner, but indicated that he would not have appreciated it from anyone else, *“the fact that it was my daughter I was proud but if it was anyone else, I’ll be irritated.”* The findings indicate a potential preference for information shared with and help received from more familiar communication partners.

The findings of this study emphasize the critical role of knowledge and understanding in promoting effective communication and autonomy among young adults with stroke-related communication difficulties. Participants reported positive experiences when their communication partners demonstrated understanding of their specific challenges. For example, some participants indicated that their family members and friends were better equipped to communicate with them because they had been informed about their communication difficulties. This knowledge and understanding facilitated effective communication and a sense of support.

Moreover, participants’ responses highlighted the impact of communication partners’ attitudes on autonomy. Patience and a supportive attitude were highly valued by participants, while impatience was seen as a hindrance to autonomy, as it limited their ability to communicate effectively and increased their expectations for improved communication. The familiarity of the communication partner also proved to be a significant factor in the acceptability of sharing information and receiving assistance. Participants expressed a greater acceptance of help from more familiar communication partners, such as family members and close friends, while expressing irritation or discomfort with assistance from less familiar individuals. This underscores the importance of considering not only what information is

shared but also with whom it is shared and by whom, as all these factors contribute to autonomy in communication.

While the findings of this study highlight various factors related to communication partners that need to be considered including their knowledge and understanding, their attitude and their relationship to the young adult with stroke-related communication difficulties, the findings may not be generalizable to the greater population of young adults with stroke-related communication difficulties. Furthermore, the findings illustrate the intricacies of individuals' preferences for receiving help with communication. Thus, it is proposed that, instead of considering all aspects and preferences in various communication contexts, autonomy be supported by ensuring that the person with communication difficulties is empowered to make decisions about their communication. This perspective aligns with the principles of the ICF, ascertaining the importance of considering individuals based on their own unique context, whilst also conforming to EBP through considering individuals' values and preferences. The influence of these decisions about communication on individuals' independence is reflected in how it contributes or impedes successful communication.

In reflecting on the role of communication partners in supporting independence and autonomy among young adults with stroke-related communication difficulties it becomes evident that there is a notable gap in the existing literature. As documented in a review of the literature on individuals with aphasia, Simmons-Mackie et al. (2016) report that most studies predominantly focus on outcomes of communication partner training in relation to impairment, activity, and participation. While these outcomes undoubtedly contribute to fostering independence, they may not comprehensively address the crucial aspect of supporting autonomy. In their review, a few studies considered psychosocial outcomes of individuals with communication difficulties, even fewer have explored the knowledge of communication

partners and only one study had considered quality of life of the person with communication difficulties as an outcome measure (Simmons-Mackie et al., 2016). It is noteworthy that autonomy is a consideration in both psychosocial outcomes and quality of life assessments.

The findings of the current study offer valuable insights into the potential role of communication partners in promoting autonomy among young adults with stroke-related communication difficulties. This emerging perspective, coupled with the limited available literature in this area, underscores the need for a shift in research efforts. A need exists to direct our attention toward investigating how interventions involving communication partners can be tailored to specifically support autonomy within this unique population. As we transition into the next theme, we will explore the practical implications of such interventions and their potential to enhance the autonomy and overall well-being of young adults with stroke-related communication difficulties during their rehabilitation journey.

Theme 5: The role of training, feedback, and support from the SLT in relation to the communication rehabilitation process of young adults with stroke-related communication difficulties.

Participants' collective experiences highlighted the role of the SLT, specifically in relation to providing training, feedback, and support. All the participants reported positive experiences with speech-language therapy input and the SLT. Although some participants reflected on their communication gains, the experiences with the SLT were reported in relation to training, support, and feedback received from them. They reported on how the SLT engaged with them and equipped them with strategies and motivation to engage more effectively in rehabilitation and communication. Their experiences highlight the positive impact of support, encouragement, and reassurance from SLTs in their rehabilitation journey.

The participants recognized the positive impact of receiving speech-language therapy as noted by P3, *“I don’t think I’ll be where I am today cause that really helped me a lot.”* P2 also indicated awareness of the positive impact, although he suggests that other people might not understand the impact, [71] *“it helps quite a lot because there are a lot of people that think, how can I say, that you are doing grade 1 thing but it’s actually things that are going to help you a lot at the end of the day.”* The positive experience seems to transcend direct intervention as reflected by P1’s experience with a SLT, *“if you got a problem like you don’t feel well, they do understand you.”*

Participants indicated difficulties communicating with doctors about their history and symptoms during the acute stages of their stroke. As reported by P3, the doctors attempted to facilitate his communication, but were unsuccessful, *“I couldn’t answer them and I wanted to tell them I was at home taking a bath then I couldn’t say that. So they told me to write I couldn’t write.”* In contrast, participants reported positively on the communication interactions with the SLT. P3 reported receiving counselling and education from the SLT, seemingly indicating that he expected this communication from the doctors, *“I was always asking the doctors here that am I going to speak again is it me now so actually it was (SLT) who told me that you might be able to speak.”* He further illustrated that the SLT aided in setting realistic expectations which motivated him, without having him become discouraged when not reaching perfection, *“she did tell me that when you speak you might [not] be the same as before. So, I didn’t put myself to that speaking like normal again I just take things step by step.”*

Participants’ reports further illustrate how counselling and education provided by the SLT assisted with engagement in the speech-language therapy rehabilitation process. P3 reported an experience in which he became very emotional and was only able to fully participate in rehabilitation after the SLT provided counselling, when stating, *“but she talk to*

me. Look there is nothing wrong with your brain is fine only it's gonna take time but you will get there so don't lose hope. So then after that day she came again then said yeah okay come let's go let's do this. So ever since that day I was just doing good you see in terms of my speech and my writing." Similarly, P5 who relied heavily on writing as a communication strategy, reported that he gained improved awareness of how this inhibited him from practicing his speech, resulting in potential negative communication outcomes, and stated *"I didn't realise it was a crutch and I wanna speak so I can't keep on doing that."* When he was asked how he came to the realization, he said that the SLT had discussed it with him. P5 also reported that speech-language therapy assisted with improving his awareness of his difficulties, *"when I struggle to get the sounds out, I wasn't conscious of what I was saying I was just trying to get the words out but in speech therapy I am able to envision my sentence."* In addition, P4 reported that improved awareness was achieved by the SLT encouraging self-monitoring, *"[The speech therapist] always told me I need to listen when I speak."*

When asked about what was targeted in speech-language therapy, P1 reported *"they taught me that I must cool down if I want to say something or if I want to say something but words don't come out I must point."* Instead of commenting on improvement in communication function, she reported on strategies that the SLT taught her. The fact that she reflected on this in response to the question may indicate the profound impact that these had on her communication outcomes. Although these types of instructions may seem minimally significant, the participant's report shows that it helped her realize the benefit of these speech-language therapy interventions.

Research reports on self-efficacy which 'influences an individual's motivational state to execute behaviours necessary for achieving desired rehabilitation outcomes' (Gangwani et al., 2022, p. 1). Considering this definition of self-efficacy, training, feedback, and support

from the SLT for young adults with stroke-related communication difficulties potentially promotes self-efficacy and motivation. The participants' experiences collectively support this, emphasizing that the SLT fulfils a multifaceted role in the rehabilitation of young adults with stroke-related communication difficulties. They offer education and counselling which facilitates motivation and engagement in the rehabilitation process (Gangwani et al., 2022). Participants' experiences support this, illustrating how training and counselling may result in motivation to engage in speech-language therapy as well as positive communication outcomes beyond improved insight.

Apart from specific personal and environmental considerations addressed in previous themes, this theme captures the value participants found in speech-language therapy. These findings also align closely with the ICF, underscoring the importance of recognizing the influence of personal and environmental factors on the communication experiences of young adults with stroke-related communication difficulties. As illustrated, these factors play a pivotal role in shaping the challenges faced by this population and in turn, their communication needs and, likely, their rehabilitation outcomes. Intervention for individuals with communication difficulties should aim towards facilitating participation in meaningful communication. Therefore, to design effective interventions, it is imperative to consider how personal and environmental factors can support or inhibit participation. It is proposed that speech-language therapy intervention should identify and address the personal and environmental factors of young adults with stroke-related communication difficulties to facilitate successful participation in communication and communication rehabilitation.

Specific to speech-language therapy intervention for stroke-related communication difficulties, the findings highlight SLTs' role in education and counselling regarding communication difficulties. This is shown to not only address information needs, but also

facilitate engagement in the rehabilitation process. The findings show the importance of enabling young adults with stroke-related communication difficulties to self-monitor to improve participation in communication, and to facilitate engagement in the rehabilitation process through increasing awareness of the benefit of speech-language therapy. Furthermore, the result shows that SLTs facilitated the use of appropriate communication strategies, which proved valuable to participants.

In this context, the final theme of this study highlights the pivotal role played by SLTs when approaching the rehabilitation process from the informed perspective of the ICF. By offering education, counselling, and interventions aimed at improving self-monitoring and self-evaluation, SLTs contribute to enhancing motivation, self-efficacy, and engagement in rehabilitation. These interventions, which were clearly significant for the participant of this study, move beyond improving function and into the realm of supporting participation.

These interventions seemingly relate to supporting independence and autonomy as it equips the young adult with stroke-related communication difficulties with the knowledge and tools to adapt to their communication difficulties. The findings, thus, suggest that SLTs can support adaptation of this population through training, feedback, and support. These findings could support SLTs in delivering evidence-based services to young adults with stroke-related communication difficulties as existing research highlights the need for supporting adaptation of young adult stroke survivors (Shiple, 2018).

CHAPTER 5: CONCLUSION

Young adults with stroke-related communication difficulties are a distinct population with a unique experience. This study aimed to describe the communication experiences, communication rehabilitation experiences, and communication needs, as well as identify areas to be considered in communication rehabilitation, of young adult stroke survivors with stroke-related communication difficulties. A cross-sectional, descriptive phenomenological research design was followed. Interviews based on a semi-structured interview schedule were conducted with five young adults with stroke-related communication difficulties. Five main themes were identified, reporting on the experiences of young adult stroke survivors with communication difficulties. These include consideration of emotional experiences, personal factors, environmental influences, and the role of SLTs.

Young adults' experiences of stroke-related communication difficulties are largely embedded in social and occupational demands related to their young age. They experience sudden and significant changes in relation to employment, socialization, and identity when confronted with stroke-related communication difficulties. The challenges they experience are dynamic as changes in communication occur throughout the rehabilitation process. The study underscores the positive emotional outcomes associated with improved communication skills, highlighting the interconnectedness of emotional well-being, physical health, and functional aspects. Thus, improving the young adults' awareness and understanding of stroke-related communication difficulties, including improvements in communication abilities, can promote emotional wellbeing. The findings also suggest that improved awareness and understanding can promote active participation in rehabilitation through realistic goal setting and progress monitoring. Whilst involvement of young adults in decision-making about their rehabilitation is recommended to foster acceptance during transitions to new roles and activities, improved

knowledge and awareness of communication difficulties may ensure that these practices are effective and productive.

For young adults with stroke-related communication difficulties, coping and engagement in the rehabilitation process are influenced by intrinsic factors like motivation and attitudes. This emphasizes the importance of conforming to a holistic perspective, like the ICF, to support young adults in engaging in difficult rehabilitation processes. Furthermore, the integration of patient preferences and values in the rehabilitation process are shown to promote autonomy and effective interventions for this unique population. Hence, the study highlights the need to incorporate self-selected AAC strategies during acute to subacute recovery phases. Approaching AAC intervention like this for young adults with stroke-related communication difficulties not only fosters autonomy, but also enforces involvement in decision-making about rehabilitation, ultimately fostering acceptance and self-motivation.

Communication experiences for this population also transcend speech and language, including experiences embedded in physical abilities. Informing intervention through comprehensive frameworks, like the ICF, will ensure that the interconnected nature of physical abilities and communication needs are adequately addressed in this population, ultimately promoting participation in various communication settings. The variation in communication demands across contexts are also illustrated including the impact of these demands on participation. The multifaceted aspects of communication environments relevant to young adults, however, remain inadequately described, emphasizing the need for a more nuanced understanding across different contexts.

The impact of environmental factors, such as support and relationships, is however indicated as crucial when aiming to address communication difficulties experienced by young adult stroke survivors. Communication partners, including relatives, especially young children,

and rehabilitation professionals, need to be included in interventions for young adults with stroke-related communication difficulties. These interventions can be extremely valuable since knowledge, understanding, and positive attitudes of communication partners was shown to promote effective communication and autonomy for young adults with stroke-related communication difficulties.

Finally, speech-language therapy intervention should promote self-efficacy, motivation, and autonomy for this population who values independence and self-reliance. Thus, interventions aiming to facilitate successful participation in meaningful communication should target self-efficacy, motivation, and autonomy whilst considering the unique personal and environmental factors of young adult stroke survivors. The findings add depth and nuance to our understanding of the multifaceted challenges faced by young adults with stroke-related communication difficulties, highlighting the importance of considering emotional, physical, and functional dimensions. A comprehensive approach, conforming to a well-established framework like the ICF, can thus serve as a foundation for delivering evidence-based services for young adults with stroke-related communication difficulties.

Clinical Implications, Future Research and Limitations of the Study

The clinical implications stemming from this research are notable. This research offers valuable insights into improving the support and interventions for young adults with stroke-related communication difficulties. However, the practical feasibility of implementing these insights in many healthcare settings may be constrained by limited resources. Therefore, it is essential for further research to focus on establishing the feasibility of implementing these interventions at specific institutions. This research can provide the necessary evidence to guide and support the implementation of these interventions in healthcare settings.

Emotional support for young adults with stroke-related communication difficulties during the acute phases of their recovery is crucial given the significant changes they undergo. A multi-disciplinary approach in the acute setting, involving various healthcare professionals working collaboratively toward common goals can increase motivation and active participation in rehabilitation. Additionally, it is important to consider how communication partners can support autonomy during this phase, fostering adaptation for these individuals. The early introduction of AAC is recommended, with consideration of individual factors and involving communication partners, particularly if there are children in the family.

A need exists to extend awareness campaigns beyond healthcare settings, targeting places frequented by young adults, such as banks, maternity follow-ups, or children's schools. This can educate a broader audience, including potential communication partners, about stroke in young adults and how to engage with those with communication difficulties.

Moreover, addressing the reported lack of awareness of stroke among young adults, peer support interventions can raise awareness about communication difficulties amongst young adult stroke survivors and help them set realistic goals. These interventions, offered by people with disabilities for people with disabilities, expose young adult stroke survivors to different communication modes and strategies, facilitating their autonomy through making informed decisions about their communication. Traditional group therapy, while continuing to address individual needs, provides an ideal platform for support, counselling, and the practical application of skills covered in individual speech-language therapy sessions. The group setting not only fosters mutual support among participants but also offers a safe and structured environment for working on participation in real-life communication scenarios.

The role of communication partners is an integral part of the experiences of young adults with stroke related communication difficulties that should not be overlooked. Their

involvement is crucial in understanding the patient's communication needs and preferences. This collaboration can be integrated into both individual and group therapy settings, ensuring that the entire support network is aligned with the patient's goals and challenges. Furthermore, support groups for communication partners should be targeted toward young adult stroke survivors as they have unique needs compared to older stroke survivors.

The variations in individuals' preferences for help-seeking underscores the importance of engaging young adults with communication difficulties in decision-making regarding how they seek and receive assistance. SLTs can facilitate discussions between individuals with communication difficulties and their communication partners on this topic. This can drive active involvement of these individuals in decision-making processes related to their rehabilitation, promoting autonomy, whilst also educating communication partners about the communication needs of young adults with stroke related communication difficulties.

Furthermore, these individuals can be engaged by their active involvement in setting realistic, person-centred goals and implementing practices to facilitate goal evaluation. The research underscores the potential of self-evaluation, particularly in the context of setting person-centred goals, as a strategy to promote positive emotions and enhance the quality of life for young adults with communication difficulties. A person-centred approach entails a comprehensive exploration of the patient's specific communication demands and needs, the various communication contexts they encounter, their preferred strategies, and the involvement of their communication partners. Furthermore, the inclusion of patient-reported outcome measures is recommended to ensure that primary concerns and needs are addressed effectively, contributing to better outcomes and improved well-being.

In summary, a focused approach within speech-language therapy is recommended, emphasizing individualized assessments, engagement through realistic goal setting and

evaluation, transition to group therapy, and active involvement of caregivers. This should be approached using the ICF framework which allows for the consideration of contextual factors specific to young adults. These contribute to more effective and tailored support for young adults with stroke-related communication difficulties.

While the research emphasizes the importance of the environment, specific modifications that could enhance the participation of young adult stroke survivors with communication difficulties are not extensively described. This highlights the need for future research in this area to develop tailored environmental interventions.

This study offers a comprehensive description of the experiences of young adults with stroke-related communication difficulties. However, several limitations of the study should be acknowledged. While the research was aimed primarily at providing a descriptive account without extensive interpretations, certain constraints were identified:

All participants ended up being interviewed in the subacute stage of recovery. This means that persons in the more chronic stages of recovery is not represented in the description of the phenomena and therefore a holistic description was likely not achieved. It is recommended that research efforts target this population as it is concerning that these individuals were not identified and are possibly not represented on caseloads of a variety of public healthcare speech-language therapists.

The participants in this study exhibited variations in their backgrounds, such as differences in employment status, with some participants working and others being unemployed. While the primary goal of the research was not to specifically consider these factors, the analysis of data might have been simplified further if these differences were minimized or controlled for. Additionally, it is worth noting that all participants in the study

had access to tertiary hospital admission and received either in-patient or out-patient speech-language therapy input thereafter. Future research could shed light on the experiences and needs of individuals who receive only limited speech-language therapy services or those with restricted access to such services.

All participants reported on their experiences of change and adaptation, even though they were interviewed relatively early in their rehabilitation journey. Given the dynamic and evolving nature of the effects of stroke, it could be valuable to explore this topic using a longitudinal research design, which would allow for a more comprehensive understanding of the long-term changes and adaptations experienced by these individuals.

The study did not achieve data saturation, indicating that further insights could be gained with a larger sample size. Expanding the sample size might have provided a more in-depth understanding of the experiences of young adults with stroke-related communication difficulties. It should however be noted that significant time was spent on recruitment, and many sites were included in the recruitment pool. In addition, some of the referrals were inappropriate as individuals' communication difficulties made it impossible for them to effectively participate in the semi-structured interview. Therefore, the information received from this sample size is valuable as there exist many constraints when conducting primary research on this population. A suggestion is, thus, to develop more specific questions based on these findings that, with the use of communication supports, can be used to research young adults with more severe stroke-related communication difficulties. In this way, more young adults with communication difficulties would be able to participate in the research.

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APPENDIX A1: UPDATED SEMI-STRUCTURED INTERVIEW SCHEDULE

The experiences of young persons with communication disorders resulting from stroke: A Phenomenological Investigation

Introduction: Thank you for talking to me today. We would like to find out how you as “a younger adult” have experienced communication difficulty after a stroke. With ‘communication’ I mean your talking, your voice, using and understanding language, reading, and writing language, etc. The reason you were asked to participate in the research is because you are younger than 45 years and you had a stroke which resulted in having communication difficulty and you’re seeing a speech therapist to help you with it. I am going to ask you some questions about this, and you can just answer as honestly and thoroughly as possible. Like I said, the interview will not be longer than 45 minutes, and if you need to stop and take a break, you can do so at any time. You can also say if you don’t want to answer a question. Is that okay? Do you have any questions thus far?

Tell me a bit about yourself.

Age

Married/ single/ partner

Family

Work/ school

Hobbies/ day to day routine

Other health conditions

Something you think contributed to/brought about the stroke

Can you tell me a bit about the feelings you have around having difficulty with communication after the stroke?

Tell me about who you talk to during the day? (communication partners)

-Prompts can be the various communication partners?

Tell me about situations during the day where you need to talk? (communicative contexts)

-Prompts various contexts (e.g., home, hospital, shop)

Tell me about topics you talk about / like to talk about during the day? (topics)

-Prompts can be examples of topics? (e.g., financial, stroke, child care?) See ebook chapter

Tell me about your speech after the stroke?

Tell me about when you talk to partner/ child/ health professional (relate to Q2)

Tell me about when you talk in the shop/ at home/ at the church (relate to Q3)

Tell me about when you talk about finances/ emotions/ childcare (relate to Q4)

How do you feel when you need to talk in above context?

Is there anything that helps when talking to certain people or in specific situations?

Prompts: What do you do? What are they doing? What you like them to do?

7. Tell me about your experience with speech therapy?

Prompts: contexts (services available), frequency (specific to the context), progress

8. Is there any information that you would like to add about your speech therapy journey?

Prompts: communication difficulty, suggestions?

9. Suggestions for the future

Conclusion: Your insight and input are truly appreciated. To provide effective speech therapy services for people with communication difficulties, we need to understand the experiences, needs and concerns of the people. The information you provided here will be used to develop an understanding of these things and possibly improve speech therapy services in the future.

Do you have anything else that you would like to add which we may not have covered during the interview?

APPENDIX A2: PROPOSED SEMI-STRUCTURED INTERVIEW SCHEDULE

The experiences of young persons with communication disorders resulting from stroke: A Phenomenological Investigation

Introduction: Thank you for talking to me today. We would like to find out about how you as “a younger adult” have experienced communication difficulty after having a stroke. I am going to ask you some questions and you can just answer as honestly and thoroughly as possible.

- 1. Describe to me what your communication is like after the stroke.**
 - Sharing ideas/ symptoms/ concerns/ questions
 - Difficulty talking/ understanding/ structuring thoughts.
- 2. Tell me a bit about yourself.**
 - Age
 - Married/ single/ partner
 - Family
 - Work/ school
 - Hobbies/ day to day routine
 - Other health conditions
 - Something you think contributed to the stroke
- 3. Tell me about when you needed to communicate with someone after the stroke.**
 - In hospital/ talking to dr/nurses/therapists
 - In the rehabilitation center
 - At home with family/ friends/medical professions
- 4. Tell me about doing your daily tasks with communication difficulty.**
 - Working/ children/ partner
 - Cooking/ cleaning/ running errands
- 5. Tell me about therapy you received for communication difficulty.**
 - Working with a speech therapist
 - Rehabilitation in hospital/ rehab center/ after d/c home
 - How frequently did you receive therapy?
- 6. How did your communication change over the course of therapy?**
 - Did you notice any changes?
 - What do you think impacted the changes?
- 7. Is there any information that you would like to add about your communication journey?**
 - Suggestions for the future

Conclusion: Your insight and input are truly appreciated. To provide effective speech therapy services for people with communication difficulties, we need to understand the experiences, needs and concerns of the people. The information you provided here will be used to develop an understanding of these things and possibly improve speech therapy services in the future.

Do you have anything else that you would like to add which we may not have covered during the interview?

APPENDIX B: CONSENT FORM FOR SHARING PERSONAL INFORMATION

TITLE OF RESEARCH PROJECT	
The experiences of young adults with mild to moderate communication difficulties resulting from stroke: A Phenomenological Investigation	
DETAILS OF PRINCIPAL INVESTIGATOR	
Title, name & surname: Ms. Néna Bester	Ethics reference number: S20/11/316
Full postal address: Speech, Language and Hearing Therapy Department, Tygerberg Medical Campus, Francie van Zijl Drive, Tygerberg, 7505, Cape Town, South Africa	PI Contact number: (021) 938 9494

My name is Néna Bester, and I am a qualified speech-language therapist and master's student at the University of Stellenbosch. I would like to invite you to participate in a research project that aims to investigate the experiences of young adults with difficulty with communication because of a stroke.

You were identified as a possible participant for this study as you are aged between 18 and 50, and recently suffered a stroke with resulting communication difficulties.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to accepted and applicable National and International ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008.

This document is for permission for your current speech-language therapist, _____, to share your name and surname, age, contact details, expected or known discharge date, date of stroke/ admission to hospital, hospital name and communication difficulty with the researcher, Néna Bester. Your details will be shared via an email and no one else except the researcher will have access to the information.

Please take some time to read the information presented here, which will explain the details of this project and contact me if you require further explanation or clarification of any aspect of the study. Also, your consent to share your information is **entirely voluntary**, and you are free to decline to share information. If you say no, this will not affect you negatively in any way whatsoever. You are also free not to participate in the study, even if you agree to share your information now.

By signing this document, you are not yet agreeing to participate, but only to be contacted by the researcher, who will contact you telephonically.

There will be no direct gains for you in the study. The gains of the study are for persons like you, who are young and living with communication difficulties resulting from a stroke to be better understood in the future and possibly improve rehabilitation services in the future.

The risks to you in this study are that some of the questions might trigger an **emotional response** since a stroke is a traumatic life event but this will be limited by providing information regarding the content of the interview prior to the interview and the interview will be terminated if it becomes too emotional.

Counselling services will be made available if you feel the need for it after the interview. A referral will be made to a state-sector counselling service.

The research will entail an interview between you and the researcher. An interpreter will also be present if you choose to do the interview in isiXhosa.



The interview will be conducted at Tygerberg Hospital, or another public health care facility which is convenient for you to travel to.



You will be compensated for travelling if you come especially for the interview. If you have an appointment at Tygerberg Hospital or the dedicated health care facility, the interview will be scheduled for before or after your appointment.



Yours sincerely,

Néna Bester

Principal Investigator

The following information will be shared:

Name and Surname: _____

Age: _____

Contact number: _____

Additional contact number: _____

Date of stroke or admission to hospital date: ___/___/___

Facility/ Hospital:

-Acute/ In-patient rehabilitation (In hospital): YES/NO ; Name _____

Admission date: ___/___/___ Expected or known discharge date¹: ___/___/___

-In-patient rehabilitation (In rehabilitation facility): YES/NO; Name _____

Admission date: ___/___/___ Expected or known discharge date: ___/___/___

-Out-patient rehabilitation: YES/NO; Name _____

Admission date: ___/___/___ Expected or known discharge date: ___/___/___

Communication difficulty/ies present:

¹ Discharge date refers to discharge home from acute or rehabilitation facilities. This does not refer to discharge from speech-language therapy services.

Declaration by participant

By signing below, I agree that the information stipulated above may be shared with the researcher, Néna Bester, who will contact me in relation to the research project titled: *The experiences of young persons with mild to moderate communication disorders resulting from stroke: A Phenomenological Investigation*

I declare that:

- I have read/ someone read to me the attached information leaflet and it is written in a language with which I am comfortable.
- My name and surname, age, contact details, expected or known discharge date, date of stroke/ admission to hospital, hospital name and communication difficulty will be shared with the researcher.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that sharing my information is **voluntary** and I have not been pressurised to take part.
- I may choose not to talk to the researcher and will not be penalised or prejudiced in any way.

Signed at (*place*) On (*date*) 2021.

Signature of participant

Signature of speech-language therapist

APPENDIX C: RECRUITING SPEECH-LANGUAGE THERAPIST INFORMATION LEAFLET

Please read through the bullet points below before completing the table on page 2.

INCLUSION CRITERIA

For this research, it is important that participants present with a first-time stroke. This is considered appropriate as previous strokes may have resulted in previous engagement with the healthcare system, which might alter their experiences.

The participants must be between 18 and 50 years of age. For the purpose of the present study a 'young stroke' is considered as below 50 years of age. The youngest age range identified in research as a 'young stroke' is 45 years, however due to limited available candidates due to the strict criteria, the study will include participants up to and including 50 years of age. Persons younger than 18 years is excluded as they would not be able to give consent.

Due to the nature of the data collection process of the study (i.e., an interview) the severity of the communication disorder of participants should be mild to moderate. For the purposes of this study, mild to moderate communication difficulty will be defined as receptive language skills on at least complex sentence level, expressive language on sentence level and speech should be intelligible to unfamiliar conversational partners on sentence level. This will ensure adequate participation in the interview by ensuring comprehension of the interview questions, ability to answer the interview questions and sufficient speech intelligibility for the researcher to understand what is said.

Including participants who are aware of their communication difficulties is considered appropriate for this study as participants will need to reflect on their communication difficulties, which may be impossible if they are not aware of their difficulties.

The participants need to be interviewed two weeks post discharge from an in-patient facility, as this would allow time for them to experience communication difficulty in their homes and communities. This is important as communication needs of individuals will depend on their context, e.g., hospital, rehabilitation center, home, and community settings. The current research aims to establish a holistic description of the communication needs of these individuals and therefore including experiences of being back at home is important.

Participants also need to have received at least two speech-language therapy sessions, as their experience of receiving rehabilitation is also being investigated.

EXCLUSION CRITERIA

Neurogenerative disease or pre-existing mental health difficulties may also influence the participant's experiences. For example, neurogenerative SLT management will be long-term, and the prognosis related to these difficulties will affect their experiences. In addition, persons with mental health difficulties might have cognitive or emotional difficulties which may influence their experiences.

Individuals who received any previous speech-language therapy intervention for any condition was also excluded as these experiences with speech-language therapy may confound the speech-language therapy experience related to the intervention received following the stroke.

Selection Criteria (for SLT at sites to consider appropriateness of candidate)

Inclusion criteria*	<input checked="" type="checkbox"/>	Exclusion criteria: **	<input checked="" type="checkbox"/>
A diagnosis of first stroke.	<input type="checkbox"/>	Any additional neurological diagnosis.	<input type="checkbox"/>
A diagnosed stroke-related communication difficulty (aphasia and/or apraxia and/or dysarthria and/or cognitive-linguistic impairment).	<input type="checkbox"/>	Any additional communication difficulties.	<input type="checkbox"/>
The severity of the communication disorder is mild to moderate.	<input type="checkbox"/>	Any previous speech therapy intervention.	<input type="checkbox"/>
The participant is a speaker of English, or Afrikaans, or isiXhosa.	<input type="checkbox"/>	Any mental diagnosis that may influence insights and reasoning (e.g. psychosis, dissociative disorders, and schizophrenia).	
The participant needs to be aware of their communication difficulty.	<input type="checkbox"/>		
The participant is 18-50 years of age.	<input type="checkbox"/>		
Has received at least two SLT therapy sessions as an in- or out-patient.	<input type="checkbox"/>		
Participants will be interviewed at least two weeks post discharge from the in-patient facility (hospital or rehabilitation). ***	DATE		

*For inclusion, all rows in inclusion column need to be answered with YES/✓

** For inclusion, all rows in exclusion column needs to be answered with NO/✗

***This relates to discharge home from an in-patient facility NOT discharge from all speech-language therapy services. Please insert the expected or known discharge date and inform patients that they will be contacted within two weeks post discharge.

APPENDIX D: PARTICIPANT INFORMATION AND CONSENT FORM

IN-PERSON INTERVIEW

Title of Research Project:	
The experiences of young persons with mild to moderate communication disorders resulting from stroke: A Phenomenological Investigation	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Title, first name, surname: Mrs. Nena Bester	Ethics reference number: S20/11/316
Full postal address: Speech, Language and Hearing Therapy Department, Tygerberg Medical Campus, Francie Van Zyl Drive, Parow, 7500	PI Contact number: 021 938 9494

Purpose of this study

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this study. Please ask the researcher or person explaining the research to you any questions about any part of this study that you do not fully understand. It is very important that you are fully satisfied and that you clearly understand what this research is about and how you might be involved. Your participation is entirely voluntary, and you are free to say no to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part now.

The Health Research Ethics Committee at Stellenbosch University has approved this study. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

We want to understand the experiences of young people with stroke regarding their communication difficulties and their communication rehabilitation journey.

The study forms part of a research project in fulfilment of a master's degree in Speech Therapy at the Stellenbosch University.

This study will be conducted in 2021-2023, in the Western Cape and will be done by experienced health researchers trained in speech therapy who are registered at the Health Professions Council of South Africa.

A maximum of ten participants will be interviewed for this study. The participants are selected purposefully based on certain criteria.

Why have you been invited to participate?

You will be included in this study if:

You have a diagnosis of first-time stroke.

You are younger than 50 and older than 18.

Diagnosed with communication disorder, resulting from recent stroke.

You are competent in English, Afrikaans, or isiXhosa.

Your communication disorders are mild to moderate; thus, you have the necessary communication abilities to provide informed consent and to participate in the interview.

You are aware of your communication difficulties.

You received at least two speech-language therapy intervention sessions in a given setting (e.g., in-hospital, rehabilitation, or out-patient).

You are at least two weeks post discharge from an in-patient facility (Hospital or rehabilitation facility).

You will be excluded from this study if:

You have additional neurological conditions (e.g., neurodegenerative diseases or mental illnesses) or pre-existing mental health conditions.

You have received speech-language therapy intervention for any condition in the future.

You have any additional communication difficulty (not related to stroke).

What will be expected of you?

You will be expected to participate in an **interview** of **±45 minutes**. The interview will be with you and the researcher who is a trained speech therapist, for interview done in English or Afrikaans, and a translator if the interview has to be conducted in isiXhosa. The interview will be in an office at B5 West, in Tygerberg Hospital. If Tygerberg Hospital is not accessible to you, a Western Cape Department of Health facility near you will be contacted for availability of a venue to be used for the interview. A follow-up interview might be requested after analysis of the first interview, if any further questions arise.



The interview will include question regarding your recent experiences of having a stroke and the communication difficulties you have had as a result of the stroke. You will be expected to answer the questions in as much detail as possible.

You will be expected to agree to **audio recording** of the interviews. Audio-recording of the interview is necessary so that the data obtained can be transcribed accurately.



Furthermore, you will be expected to be available for telephonic follow-up if there are any questions the researcher has after the interview. The telephonic follow-ups will also be recorded.



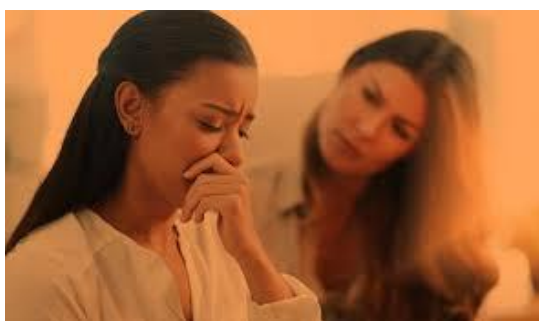
Will you gain anything from taking part in this research?

There will be no direct gains for you in the study.

The gains of the study are for persons like you, who are young and living with communication difficulties resulting stroke to be better understood in the future and possibly improve rehabilitation services in the future.

Are there risks involved in you taking part in this research and what will be done to prevent them?

The risks to you in this study are that some of the question might trigger an **emotional response** since a stroke is a traumatic life event but this will be limited by providing information regarding the content of the interview prior to the interview and the interview will be terminated if it becomes too emotional. Counselling services will be made available if you feel the need for it after the interview. A referral will be made to a state-sector counselling service.



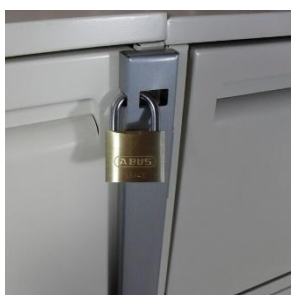
How will we protect your confidentiality and who will see your findings?

Your responses to the questions in the interview will be kept anonymous. Please do not mention any identifying information in the interview. Every effort will be made by the researcher to preserve your confidentiality including the following:

Assigning **code names**/numbers for participants that will be used on all research notes and documents.

Name and Surname: [REDACTED] [REDACTED]
--

Keeping notes, interview transcriptions, and any other identifying participant information in a **locked file cabinet** in an office in the speech therapy department on campus.



The audio recordings will be **password protected** and only the researcher will have access to it.



Participant data will be kept confidential except in cases where the researcher is legally obligated to report specific incidents. These incidents include, but may not be limited to, incidents of abuse and suicide risk.

What will happen with the findings or samples?

The findings of this study will only be used for this study. The voice recordings and transcription will be kept securely for 5 years where after it will be destroyed.

How will you know about the results of this research?

We will give you the results of this research when the research conclusion is completed.

You will be informed of any new relevant findings at the latest December 2021.

Will you be paid to take part in this study and are there any costs for you?

No, you will not be paid to partake in this study and there are no costs related in partaking in this study. The researcher will meet you at a venue in the Stellenbosch University faculty of medicine and health sciences campus. You will be compensated for **travel costs**. The amount will be based on where you travel from and will be agreed upon prior to you travelling to the venue. The researcher will provide you with **refreshments** after the interview.



Is there anything else that you should know or do?

You can contact Néna Bester at 079 244 1532 if you have any further questions or have any problems.

You will receive a copy of this information and consent form for your own purposes.

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH

Declaration by participant

By signing below, I _____ agree to take part in the research study titled: The lived experiences regarding communication and rehabilitation of young people living with communication disorders resulting from stroke in South Africa.

I declare that:

- I have read this information/it was explained to me by a trusted person in a language with which I am fluent and comfortable.
- The research was clearly explained to me.
- I have had a chance to ask questions to both the person getting the consent from me, as well as the researcher and all my questions have been answered.
- I understand that taking part in this study is voluntary and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be handled in a negative way if I do so.
- I may be asked to leave the study before it has finished, if the researcher feels it is in the best interest, or if I do not follow the study plan, as agreed to.

Signed at (place) _____ on (date) _____ 2021

Signature of participant

X

Signature of researcher

X

Declaration by researcher

I (name) declare that:

- I explained the information in this document to or I had it explained by who I trained for this purpose.
- I did/did not use an interpreter
- I encouraged him/her to ask questions and took adequate time to answer them or I was available should he/she want to ask any further questions.
- The informed consent was obtained by an independent person.
- I am satisfied that he/she adequately understands all aspects of the research, as described above.
- I am satisfied that he/she had time to discuss it with others if he/she wished to do so

Signed at (place) _____ on (date) _____ 2021

Signature of researcher

Signature of participant

X _____

X _____

Declaration by interpreter

I (name) declare that:

- I assisted the investigator (name) to explain the information in this document to (name of participant) using the language medium of Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (place) _____ on (date) _____ 2021

Signature of participant

Signature of interpreter

X _____

X _____

INFORMED CONSENT FOR AUDIO-RECORDING OF THE RESEARCH



Declaration by participant

The purpose of the audio-recording of this interview and the use, storage and final destruction of the tapes has been explained to me and I understand the explanation. I have been offered to answer any of my questions concerning the procedures involved in the recording of the interview and I have been given a copy of this form to keep.

Signed at _____ (place) on _____ (date)

Participant Name (printed)

Date of Birth

Signature of Participant

Statement by the investigator

I _____ (print researcher name), declare that I have explained the information given in this document to _____ (print participant's name). He/she was encouraged and given ample time to ask me questions. Conversations were conducted in _____ (print language) and no translator was used OR translator was used

(draw a line through the one that is not applicable)

Signed at _____ (place) on _____ (date)

Signature of Researcher

Signature of Participant

APPENDIX E1: HREC APPROVAL 1



UNIVERSITEIT
VAN DIE WES-KAAP
UNIVERSITY

Approval Notice

New Application

23/03/2021

Project ID :19225

HREC Reference No: S20/11/316

Project Title: The experiences of young persons with mild to moderate communication disorders resulting from stroke

Dear Mrs. Faeza Bardien

The Response received on 10/02/2021 was reviewed and approved by members of Health Research Ethics Committee via expedited review procedures on 23/03/2021.

Please note the following information about your approved research protocol:

Protocol Approval Date: 23 March 2021

Protocol Expiry Date: 22 March 2022

Please remember to use your Project ID 19225 and Ethics Reference Number S20/11/316 on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Translation of the Informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: [Links Application Form Direct Link](#) and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Please note that for studies involving the use of questionnaires, the final copy should be uploaded on Infonetica.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website <https://applyethics.sun.ac.za/ProjectView/Index/19225>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Mrs. Melody Shana

Coordinator

HREC1

National Health Research Ethics Council (NHREC) Registration Number:

REC-120405-012 (HREC1)*REC-230205-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0006240 (HREC1)*IRB0006239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the [World Medical Association \(2013\), Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects](#); the South African Department of Health (2000), [Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa \(2nd edition\)](#); as well as the Department of Health (2016), [Ethics in Health Research: Principles, Processes and Structures \(2nd edition\)](#).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

APPENDIX E2: HREC APPROVAL 2



Approval Letter Progress Report

11/03/2022

Project ID: 19225

Ethics Reference No: S20/11/316

Project Title: The experiences of young persons with mild to moderate communication disorders resulting from stroke

Dear Miss N Bester

We refer to your request for an extension/annual renewal of ethics approval received 25/01/2022.

The Health Research Ethics Committee reviewed and approved the annual progress report through an expedited review process.

The approval of this project is extended for a further year.

Approval date: 23 March 2022

Expiry date: 22 March 2023

Kindly be reminded to submit progress reports two (2) months before expiry date.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: <https://appjethics.sun.ac.za>

Please remember to use your Project Id 19225 and ethics reference number S20/11/316 on any documents or correspondence with the HREC concerning your research protocol.

Please note that for studies involving the use of questionnaires, the final copy should be uploaded on Infonetica.

Yours sincerely,

Melody E Shana
Coordinator: Health Research Ethics Committee 1

National Health Research Ethics Council (NHREC) Registration Number:
REC-130408-012 (HREC 1) + REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0006240 (HREC 1) + IRB0006239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the [World Medical Association \(2013\)](#), [Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects](#); the [South African Department of Health \(2006\)](#), [Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa \(2nd edition\)](#); as well as the [Department of Health \(2015\)](#), [Ethics in Health Research: Principles, Processes and Structures \(2nd edition\)](#).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services; or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

APPENDIX E3: HREC APPROVAL 3



Approval Letter Progress Report

16/03/2023

Project ID: 19225

Ethics Reference No: S20/11/316

Project Title: The experiences of young persons with mild to moderate communication disorders resulting from stroke

Dear Miss N Bester

We refer to your request for an extension/annual renewal of ethics approval dated 09/03/2023.

The Health Research Ethics Committee reviewed and approved the annual progress report through an expedited review process.

The approval of this project is extended for a further year.

Approval date: 23 March 2023

Expiry date: 22 March 2024

Kindly be reminded to submit progress reports two (2) months before expiry date.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, Infonetica, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: <https://app.eyethics.sun.ac.za>

Please remember to use your Project Id 19225 and ethics reference number S20/11/316 on any documents or correspondence with the HREC concerning your research protocol.

Please note that for studies involving the use of questionnaires, the final copy should be uploaded on Infonetica.

Yours sincerely,

Mrs A Fortuin
Health Research Ethics Committee 1 (HREC1)

National Health Research Ethics Council (NHREC) Registration Number:
REC-130406-012 (HREC1)+REC-238208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0006240 (HREC1)+IRB0006239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the [World Medical Association \(2013\), Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects](#); the [South African Department of Health \(2008\), Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa \(2nd edition\)](#); as well as the [Department of Health \(2015\), Ethics in Health Research: Principles, Processes and Structures \(2nd edition\)](#).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

APPENDIX F1: HREC AMENDMENT APPROVAL 1



29/03/2021

Project ID: 19225

Ethics Reference No: S20/11/316

Project Title: The experiences of young persons with mild to moderate communication disorders resulting from stroke

Dear Ms Nena Bester,

We refer to your amendment request received 29/03/2021.

The Health Research Ethics Committee (HREC) reviewed and approved the following amendment through an expedited review process:

- To change the study P.I from Mrs. Faeza Bartlen to Ms Nena Bester.

We acknowledge receipt of the CV and Investigator Declaration Form for Ms N Bester.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: <https://applyethics.sun.ac.za>

Please remember to use your project ID 19225 and ethics reference number S20/11/316 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Mrs. Melody Shana
Coordinator: Health Research Ethics Committee 1

National Health Research Ethics Council (NHREC) Registration Number:

REC-130406-012 (HREC1)*REC-230206-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0006240 (HREC1)*IRB0006239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the

World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2008). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

APPENDIX F2: HREC AMENDMENT APPROVAL 2



01/03/2022

Project ID: 19225

Ethics Reference No: S20/11/316

Project Title: The experiences of young persons with mild to moderate stroke-related communication difficulties

Dear Miss N Bester

We refer to your amendment request dated 03/01/2022.

The Health Research Ethics Committee (HREC) reviewed and approved the amendment as well as the following amended documentation through an expedited review process:

1. Amendment 3_MODS_protocol_20210208
2. Amendment 3_Appendix A_Informed consent documentation_20210208

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, Infonteca, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: <https://applyethics.sun.ac.za>.

Please remember to use your project ID 19225 and ethics reference number S20/11/316 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Melody E Shana
Coordinator: Health Research Ethics Committee 1

National Health Research Ethics Council (NHREC) Registration Number:

REC-130405-012 (HREC1)+REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0006240 (HREC1)+IRB0006239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013), Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2008), Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015), Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 48 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

APPENDIX F3: HREC AMENDMENT APPROVAL 3



24/02/2023

Project ID: 19225

Ethics Reference No: S20/11/316

Project Title: The experiences of young persons with mild to moderate communication disorders resulting from stroke

Dear Miss N Bester

We refer to your amendment request received on 17/01/2023.

The Health Research Ethics Committee (HREC) reviewed and approved the amendment through an expedited review process.

The following amended documentation was reviewed and approved:

1. Amendment 4_Appendix A_Informed consent documentation_20210208.
2. Amendment 4_SLT Information leaflet version 2 dated 16/01/2023.
3. Amendment 4_Consent to share information version 4 dated 16/01/2023
4. Proposal_Amendment 4 dated 16/01/2023.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, Inforetica, to manage ethics applications and the ethics review process. To submit any documentation to HREC, please click on the following link: <https://applyethics.sun.ac.za>.

Please use your project ID 19225 and ethics reference number S20/11/316 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Melody Shana
Coordinator: Health Research Ethics Committee 1

National Health Research Ethics Council (NHREC) Registration Number:

REC-130406-012 (HREC1)+REC-238208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0000240 (HREC1)+IRB0000239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the *World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects*; the *South African Department of Health (2008). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition)*; as well as the *Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition)*. The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 46 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

APPENDIX G1: NHRD SITE APPROVAL TBH



TYGERBERG HOSPITAL
REFERENCE:
Research Projects
ENQUIRIES: Dr GG
Marinus
TELEPHONE: 021 938 5752

Project ID: 19225

Ethics Reference: S20/11/316

TITLE: The experiences of young persons with mild to moderate communication disorders resulting from stroke.

Dear Mrs Faeza Barden

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL

1. In accordance with the Tygerberg Hospital Health Research Policy and Protocol of April 2018, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital for a year based on your JREC approval.
2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).



DR GG MARINUS
MANAGER: MEDICAL SERVICES

Date: 17/6/2024
Administration building, Francie van Zill Avenue, Parow, 7600
Tel: +27 21 938 6267 Fax: +27 21 938 4632

Private Bag 23, Tygerberg, 7500
www.westerncape.gov.za

APPENDIX G2: NHRD SITE APPROVAL GSH



GROOTE SCHUUR HOSPITAL

Enquiries: Dr Bernadette Eick

e-mail: GSHResearch.Request@westerncape.gov.za

Ms. Nena Bester
UNIVERSITY OF STELLENBOSCH

E-mail: nena.bester@gmail.com / gellis@sun.ac.za

Dear Ms. Bester,

RESEARCH PROJECT: The Experiences Of Young Persons With Mild To Moderate Communication Disorders Resulting From Stroke: A Phenomenological Investigation

Your recent letter to the hospital refers.

You are granted permission to proceed with your research, which is valid until 30 March 2022.

Please note the following:

- a) Your research may not interfere with normal patient care.
- b) Hospital staff may not be asked to assist with the research.
- c) **Confidentiality must always be maintained.**
- d) No additional costs to the hospital should be incurred as indicated in your Annexure 2 i.e. Lab, consumables or stationery. If access to TRACK Care/NHLS is required, kindly attach our letter of approval to the application form and approach Information Management to assist with data.
- e) No patient folders may be removed from the premises or be inaccessible.
- f) Please provide the research assistant/field worker with a copy of this letter as verification of approval.
- g) Should you at any time require photographs of your subjects, please obtain the necessary indemnity forms from our Public Relations Office (E45 OMB or ext. 2187/2188).
- h) Should you require additional research time beyond the stipulated expiry date, please apply for an extension.
- i) Please discuss the study with the HOD before commencing.
- j) Please introduce yourself to the person in charge of an area before commencing.
- k) On completion of your research, please forward any recommendations/findings that can be beneficial to use to take further action that may inform redevelopment of future policy / review guidelines.
- l) Please contact Michelle Riley (Patient Fees) at ext. 2276 to ascertain if there will be charges for conducting the Research and to obtain a quote or to discuss charges
- m) **Kindly submit a copy of the publication or report to this office on completion of the research.**
- n) **At no time should any posters encouraging patients to partake in research, be displayed within a clinical area.**
- o) **Please adhere to ALL COVID-19 regulations and Groote Schuur Hospital policies.**

I would like to wish you every success with the project.

Yours sincerely

p.p. DR BERNADETTE EICK
CHIEF OPERATIONAL OFFICER

Date: 28 May 2021

C.C. Mr. L. Naidoo / Ms. N. Allie

G46 Management Suite, Old Main Building,
Observatory 7925
Tel: +27 21 404 6288 fax: +27 21 404 6125

Private Bag X,
Observatory, 7935
www.westerncape.gov.za/health

APPENDIX G4: NHRD SITE APPROVAL NSH AND HH



STRATEGY & HEALTH SUPPORT

Health.Research@westerncape.gov.za
tel: +27 21 483 0866: fax: +27 21 483 6058
5th Floor, Norton Rose House,, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_202103_049
ENQUIRIES: Dr Sabela Petros

**Francie Van Zijl Dr
Parow
Cape Town
7505**

For attention: Ms Nena Bester

Re: The experiences of young persons with mild to moderate communication difficulties resulting from stroke: A Phenomenological Investigation

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries in accessing the following sites:

Macassar CDC

Sr Gail Viana

021 857 2330

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted and the constraints caused by the Covid-19 epidemic above are respected and adhered to.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**Annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion date* which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) and an updated ethics clearance letter to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.
5. You are required to notify the substructure office when you commence with your study at the above-mentioned facility(ies) and inform them when you have completed the study at the facility. **Khayelitsha-Eastern Substructure:** Jill Langeveldt: 021 444 6574 or Jill.Langeveldt@westerncape.gov.za.

Yours sincerely

A handwritten signature in black ink, appearing to read 'V. Zweigenthal'.

**PROF. V ZWEIGENTHAL
DIRECTORATE: HEALTH INTELLIGENCE
DATE: 19 January 2023
CC**

APPENDIX G5: NHRD SITE APPROVAL MACASSAR CLINIC



STRATEGY & HEALTH SUPPORT

Health.Research@westerncape.gov.za
tel: +27 21 483 0866: fax: +27 21 483 6058
5th Floor, Norton Rose House, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_202103_049
ENQUIRIES: Dr Sabela Petros

Francie Van Zijl Dr
Parow
Cape Town
7505

For attention: Ms Nena Bester

Re: The experiences of young persons with mild to moderate communication difficulties resulting from stroke: A Phenomenological Investigation

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following people to assist you with any further enquiries in accessing the following sites:

New Somerset Hospital	Dr Donna Stokes	021 402 6408
Helderberg Hospital	Dr Werner Viljoen	021 850 4700

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

A handwritten signature in black ink, appearing to read 'V. Zweigenthal'.

PROF. V ZWEIFENTHAL
DIRECTORATE: HEALTH INTELLIGENCE
DATE: 12 August 2022
CC

APPENDIX G6: NHRD SITE APPROVAL SITE B



STRATEGY & HEALTH SUPPORT

Health.Research@westerncape.gov.za
tel: +27 21 483 0866; fax: +27 21 483 6058
5th Floor, Norton Rose House,, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_202103_049

ENQUIRIES: Dr Sabela Petros

Francie Van Zijl Dr
Parow
Cape Town
7505

For attention: Ms Nena Bester

Re: The experiences of young persons with mild to moderate communication difficulties resulting from stroke: A Phenomenological Investigation

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries in accessing the following sites:

Khayelitsha (Site B) CHC

Morgan C Voges

Morgan.voges@westerncape.gov.za

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted and the constraints caused by the Covid-19 epidemic above are respected and adhered to.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**Annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion date* which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) and an updated ethics clearance letter to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.
5. You are required to notify the substructure office when you commence with your study at the above-mentioned facility(ies) and inform them when you have completed the study at the facility. **Khayelitsha-Eastern Substructure:** Jill Langeveldt: 021 444 6574 or Jill.Langeveldt@westerncape.gov.za.

Yours sincerely

A handwritten signature in black ink, appearing to read 'VZ', written over a light blue horizontal line.

PROF. V ZWEGENTHAL
DIRECTORATE: HEALTH INTELLIGENCE
DATE: 12 August 2022
CC

APPENDIX H: AFRIKAANS QUOTATIONS AND ENGLISH TRANSLATIONS

Theme 1: Emotional experiences of young stroke survivors with stroke-related communication difficulty

Quotations

1. P4 “So ek was so skaam daar was luckily nie ander mense by die winkel nie, want uhm ek het gesukkel mmmm”.

“I was so embarrassed luckily there were no other people at the store because I struggled.”

2. P4 “...maar nou kan ek aartappels sê so vir my is dit ’n big ding (exciting tone of voice).”

“but now I can say potatoes so for me it's a big thing”

3. P4 “...want party mense hulle wil vir jou bejammer. Mmmm, en ek is nie een van daai nie.”

“...because some people want to feel sorry for you. Mmmm, and I'm not one of those.”

4. P4 “...dit was vir my baie moeilik oor my om oor my emotions en uhm veral ja die wat by die huis gebeur te praat.”

“...it was very difficult for me to talk about my emotions and uhm yes especially those that happen at home.”

5. P4 “Sjoe my my nerves was kla (laughing) toe ek inklim dink ek wat moet ek nou vir die man sê. Toe dink ek jong ek gaan maar vir hom sê ek het ’n stroke gehad so ek kan nie lekker praat nie.”

“My nerves were on edge when I got in. I thought what should I say to the man now. Then I thought, I'm going to tell him I had a stroke so I can't speak well.”

6. P4 “Ek gaan want kyk ek dink hoe meer ek praat hoe beter gaan dit word ja dan hoef ek nie te vrees gaan hulle vir my verstaan nie.”

“I think the more I talk, the better it will become, and then I don't have to worry about whether they will understand me.”

Theme 2: Transitioning and adapting to changes in roles and activities.

Quotations

7. P2 “dit is frustrerend because jy wat independent is op jouself jy kan nie dinge doen wat jy wil doen nie.”

“it is frustrating because you were independent and now you cannot do the things you want to do.”

8. P4 “dit is de pre sing somtyds as jy dink aan hoe jy voor die stroke was en hoe is dit nou.”

“it is depressing sometimes if you think about how you were before the stroke and how it is now.”

9. P4 “...Ek kan ongelukkig nie dieselfde werk wat ek voorheen gedoen het nie.”

“...Unfortunately I can not do the same work as I did previously.”

10. P4 “Ek weet nie gaan ek terug werk toe nie.”

“I don’t know if I am going back to work.”

11. P2 “Ek het football gespeel ek kan nie speel... ek kan nie meer speel nie.”

“I played football... I can’t play anymore.”

Theme 3: Personal factors to consider for young adult stroke survivors with stroke-related communication difficulties.

Subtheme 3.1: Understanding and addressing knowledge, awareness, and insight into stroke symptoms.

Quotations

12. P2 “toe ek dit voel en ek kon niks doen nie toe kon ek dan nie eers vir my ek kon nie my arms gebruik het nie toe weet ek al klaar al.”

“when I felt it, I could do nothing, I could not even use my arms, that’s when I already knew.”

13. P2 “omdat ek al ‘n paar mense geken het wat in stroke in g betrokke was”

“because I already knew people that were involved in stroke”

14. P2 “en ek kon van dag hospitale af was het ek was ek bewus van die tekens van dit al... so ek het geweet al klaar ek het ‘n stroke gekry.”

“and I come from day hospitals I was aware of the signs... so I already knew I had a stroke.”

15. P2 “soos ek nou onder verstaan is ‘n vriend van my se seun hy is nou vyf en der 34 of 35 hy het nou afgesterf van ‘n stroke. Dit is nou deesdae die tekens nou tussen jong mense wat strokes kry.”

“as I understand, a friend of mines son, he is now 34 or 35, just passed from a stroke. These are the signs lately for young people that are having strokes.”

16. P2 “... die covid was hewig en dit was nou ernstig die covid...”

“... the covid was severe and serious...”

17. P2 “ek dink dis meer st am er wat wat gely het aan”

“I think its more the stress that I suffered from”

18. P2 “Jong mense am er, hulle kry nie werk nie werk is nie daar geskikbaar vir jou blootgestel nie daar is nie inkomste nie”

“Young people stress, they can't find work, there isn't work available for you, they are not exposed to work and there is no income.”

19. **P2** “my geval is verskillend dan is jy miskien aan die linker kant dan is dit verskillende jy het dit miskien erger as wat ek dit kry”

“my situation is different, maybe it's on the left side and then it's different, you maybe get it worse than I do”

20. **P4** “ja dit is kyk soos aar ta pel ek kon nie die aar/r gesê het nie as jy kyk na al die al die woorde neh is aartappel, r****, social worker uhm br***** so.”

*“yes it is, like potato. I couldn't say the po/o if I didn't look at all the words, its potato, r****, social worker uhm br***** there.”*

21. **P2** “jou asemhaling jou asemhaling en jou jou jou jou jou jou jou hoe jy jou skouers beweeg jy moet jou skouers beweeg en jy moet nie (audible exhalation) am er en haastig dinge doen nie doen dit met tyd”

“your breathing and how you move your shoulders, you must move your shoulders and not do things too fast and in a rush, you must do things with time”

22. **P4** “Maar nou kan ek aartappels sê so vir my is dit 'n big ding (exciting tone of voice)”

“But now I can say potato so for me that is a big thing (exciting tone of voice)”

Subtheme 3.2: The role of intrinsic factors in coping and engagement in rehabilitation.

Quotations

23. **P2** “my eerste sessie met haar was ek het dit moeilik om dit was baie baie moeilik. Toe kos dit vir my nou vir twee weke op my eie”

“my first session with her was very difficult. This cost me two weeks on my own”

24. **P4** “dit help nie ek gaan in sak en as sit en my myself ga gaan be am er nie nee so ek moet die wêreld vierkant in die oë kyk”

“it doesn't help that I go sit and feel sorry for myself, no, I must face the world in its eye”

25. **P4** “ek altyd gevra gee vir my huiswerk”

“I always asked for homework”

26. **P4** “ek het my hoop, niemand kan dit van my af weg vat nie.”

“I have hope, no one can take that away from me”

27. **P4** “ek wil beter praat so ek sal alles doen in my vermoë om net beter te kan praat.”

“I want to talk better, so I will do anything in my power just to talk better”

28. P4 “maar as ek soos jy kon praat sou ek so ek sou baie ha happy gewees het, maar ongelukkig kan ek nie. Maar ek het nog altyd hoop dat dit sa sal gebeur”

“If I could talk like you, I would be very happy, but I can’t. Although I still have hope that it will happen.”

Subtheme 3.3: Help-seeking strategies and its relationship to independence in communication.

Quotations

29. P2 “hulle moes vir my help die woorde uiter en hulle help met enige sin se woord wat ek wil sê”

“they had to help me utter the words and they help with any words in the sentence that I want to say”

30. P4 “dit was iets wat ek meer gebruk het toe ek gesukkel het”

“it was something that I used more when I was struggling”

31. P4 “Dit was nie my vir my lekker nie want kyk ek is gewoonnd daaraan om self my ding te doen.”

“It wasn’t fun for me because I am used to doing my own thing.”

32. P2 “Jy kan nie vir jouself dinge doen nie... dit is... frustrerend because jy wat independent is op jouself jy kan nie dinge doen wat jy wil doen nie.”

“You can’t do things for yourself... it is... frustrating because you were independent and now you can’t do the things you want to do.”

33. P4 “my seun het saam gegaan maar ek het self my goed gevat en vir die dame agter die uhm, jy weet mos daar waar hulle weeg... ek het dit self vir haar gegee en ek het net vir haar gesê; hi hoe gaan dit...”

“my son came with me but I took my things by myself and gave it to the lady behind the uhm, you know there where they weigh... I gave it to her myself and I just told her; hi how are you...”

Subtheme 3.4: Communication experiences in relation to physical abilities.

Quotations

34. **P2** “jy moet weet as jy so iets kry en jy kan niks doen nie en jy loop sleep voet en is dit gaan moeilik”

“you know when you get something like that and you can’t do anything and you walk drag foot, its difficult”

35. **P2** “dai collect alles”

“that collects everything”

36. **P4** “jy wil iets sê maar jy kan nie so is amper asof jy jy is ‘n gevangene in jouself want kyk ek wou miskien uhm luckily vir my kon ek loop en ek kon toilet toe gaan”

“you want to say something but you can’t, its almost as if you are a prisoner in yourself because, see I maybe wanted, uhm, luckily for me I can walk so I could go to the toilet”

37. **P4** “omdat ek kan lees en goed vir myself doen is ek baie happy”

“because I can read and do stuff for myself I am very happy”

38. **P2** “daars tye wat ek gesit het en dan sê ek vir hulle ek makeer gou pyn pille ek moet gou eers twee pille drink. Dan moet ek gaan lê...”

“there are times where I was sitting and then I told them I quickly need pain pills I quickly need to drink two pills. Then I must go lay down...”

Subtheme 3.5: Alternative and augmentative communication as a coping strategy.

Quotations

39. **P4** “ja dit was iets wat ek meer gebruik het toe ek gesukkel het.”

“yes that was something I used more when I was struggling.”

40. **P4** “ek gaan net sê cigarettes toe sê hy no you must say Rothmans toe sê ek no I can’t”

“I’m just going to say cigarettes, then he said, no you must say Rothmans, then I said, no I can’t”

41. **P4** “as ek senuweeagtig is dan dink ek joh moet ek nou rêrag die mense gaan dink ek is mal”

“when I am nervous then I think, must I now really, these people are going to think I am crazy”

42. P4 “want ek het vir hom gesê uhm ek gaan net cigarettes sê”

“because I told him uhm I’m just going to say cigarettes”

Theme 4: Environmental considerations for young adults with stroke-related communication difficulties.

Subtheme 4.1: The influence of the communication environment on participation.

Quotations

43. P4 “hier het hulle geduld met my”

“here they have patience with me”

44. P4 “Kyk hier praat ek baie makliker maar by die huis is dit iets anders”

“look here I talk a lot easier, but at home it’s something else”

45. P4 “die eerste twee weke het ek in ‘n kamer geslaap waar die mense nie kan praat nie, so ek was al een wat kon praat. En vir my was daai nie lekker nie.”

“the first two weeks I slept in a room where the people couldn’t speak, I was the only one that could speak. That for me wasn’t nice.”

46. P4 “Om terug te gaan werk toe, nie huistoe nie.”

“To go back to work, not back home.”

47. P4 “kyk as dit in ‘n groot winkel is, dan gaan gaal ek mos net die goed neh so jy praat nie rêrag nie maar by die klein winkels as jy oor die toonbank koop dan is dit moeilik.”

“look if it’s at the big store, then I just go fetch the stuff so you’re not really talking, but when I’m at a small store where you buy over the counter, then it’s difficult.”

48. P4 “baie mense is baie ongeduldig as jy met hulle oor die phone praat. So uhm ek moet daarom myself uhm kan ek mo moet meer better kan praat want baie van hulle sal dit nie verstaan nie.”

“a lot of people are very impatient when you talk to them over the phone. So uhm that’s why I need to speak better because a lot of people won’t understand this.”

Subtheme 4.2: Addressing information needs of communication partners.

Quotations

49. P4 “hy verstaan nie oor die stroke nie.”

“he doesn’t understand the stroke.”

50. P2 “Somtyds verstaan die mense nie want my geval is verkillend”

“Sometimes the people don’t understand because my situation is different”

51. P4 “mense dink dan jy het ‘n gebrek omdat jy nie reg kan praat nie”

“people then think you have a disability because you can’t speak properly”

52. P4 “ander menses sal dink wat maker die vrou. Is sy miskien dronk of wat”

“other people will think, what’s the matter with this woman. Is she drunk or something”

53. P4 “kyk baie mense het daai persepsie as jy ‘n stroke gehad het is jy jy is breinloos”

“look a lot of people have that perception that if you had a stroke you are brainless”

54. P4 “hulle kan nie sien dat ek vordering maak nie. Maar ek weet ek het vordering gemaak”

“they can’t see that I am making progress. But I know that I have made progress”

55. P4 “my man het gesê, jong jy gaan agteruit jy gaan nie vorentoe nie volgens hom is my spraak is bad maar kyk ek kon glad nie gepraat het nie so vir my is dit goed”

“my husband said that I am moving backwards and not forward according to him my speech is bad, but look I could not at all speak so for me it’s good”

56. P4 “hier is actually ‘n man in my gang hy was in my kamer by **** (acute hospital) en hy is een van die mense wat kon sien hoe ek opgaan en nie afkom nie.”

*“there is actually a man in my corridor he was in my room in **** (acute hospital) and he is one of the people that could see how I am going up and not coming down.”*

57. P4 “die kleinkinders ek het twee *** en ***. *** is nou sewe sy weet ek is siek. *** sy twee en ‘n half sy weet ook net iets is nie lekker met my nie...”

*“the grandchildren I have two *** and ***. *** is 7 and she knows I am sick. *** she is two and a half, she also know something is not so good with me...”*

58. P4 “sy het ‘n begrip wat ek hier doen want ek het vir haar gesê”

“she has an understanding of what I do here because I told her”

59. P4 “My seun het my uhm oor die naweek gevra mammy jy lees nou hoe klink dit in jou kop as jy die woorde vir jouself sê”

“My son asked me over the weekend, mommy when you read how does the words sound in your head when you say it to yourself”

60. P4 “sy was baie bekommerd, want sy het vir my gevra mom what’s wrong en toe kan ek mos nie praat nie.”

“she was very concerned, because she asked me mom what’s wrong and then I couldn’t speak.”

61. P4 “jy het die die persepsie dat dit net met jou gebeur, dit is nie waar nie, dit is vir ons almal om daarmee te deal”

“you have the perception that it is only happening to you, that is not true, it’s for all of us to deal with”

Subtheme 4.3: The role of communication partners in supporting independence and autonomy.

Quotations

62. P4 “ek het geweet wat sy try om te sê maar ander veral die nurses hulle het nie geweet nie...”

“I knew what she was trying to say but the others especially the nurses, they didn’t know...”

63. P4 “want sy raak so frustrated want sy wil die bedpan hê of sy wil toilet toe gaan maar hulle weet nie wat sy wil sê nie dan het ek gesê bedpad dan skud sy haar kop.”

“because she gets so frustrated because she wants the bedpan or she wants to go to the toilet but they don’t know what she wants to say and then I said bedpan and then she just shakes her head.”

64. P2 “hulle moes vir my help die woorde uiter en hulle help met my met enige sin se word wat ek wil sê...”

“they had to help me utter the words and they help me with words of the sentence that I want to say...”

65. P4 “ek het agterna vir haar gesê joh ek het nou so gebid jy moenie sê ek het ‘n stroke gehad nie...”

“I told her afterwards I prayed so much now you do not say I had a stroke...”

66. P4 “ek het vir haar gesê jong ek het ‘n stroke gehad so ek kan nie lekker praat nie...”

“I told her I had a stroke I can’t speak so well...”

67. P4 “want party mense hulle wil jou bejammer.”

“because some people they want to feel sorry for you.”

68. P4 “sy het baie patience”

“she has a lot of patience”

69. P4 “terwyl ek miskien praat neh nou sukkel ek om die woord te sê dan jaag hulle my aan”

“while I am maybe talking I am struggling to say the word then they rush me”

70. P4 “baie mense is baie ongeduldig as jy met hulle oor die phone praat. So uhm ek moet daarom myself uhm kan ek mo moet meer better kan praat want baie van hulle sal dit nie verstaan nie.”

“a lot of people are very impatient when you talk to them over the phone. So I must be able to speak better because a lot of them won’t understand this.”

Theme 5: The role of training, feedback, and support from the SLT in relation to the communication rehabilitation process of young adults with stroke-related communication difficulties.

Quotations

71. **P2** “dit is nogals baie wat dit help because daars baie mense wat dink dit is uu hoe kan ek sê dit dit dit is klein sub A goedjies wat jy doen but dit is eindelijk dinge wat vir jou gaan help in die einde van die dag.”

“it helps quite a lot because there are a lot of people that think, how can I say, that you are doing grade 1 thing but it’s actually things that are going to help you a lot at the end of the day.”

72. **P4** “sy het vir my altyd gesê jy moet luister as jy praat”

“she always told me I need to listen when I speak”

APPENDIX I: CONFIDENTIALITY AGREEMENT

Interpreters/Translators/Transcribers

As a translator/transcriber working for the '*The experiences of young persons with mild to moderate communication disorders resulting from stroke: A Phenomenological Investigation*' project at Stellenbosch University during 2021, you will have access to confidential information and data from interviews with study participants. These participants have consented to participate in the study with the understanding that their identities and personal information, as well as their interview responses, will be kept confidential. Once you have assisted with/transcribed each interview, the interview transcripts will be anonymised so that participants cannot be identified from their transcripts.

By signing this confidentiality agreement, you agree to treat all information and data that you have access to through this project as confidential.

You agree not to share any of the material with which you will be working with anyone else, whether verbally, physically or electronically.

You agree not to discuss individual participants or their interview responses with anyone else.

You agree to protect the confidentiality of both the data and the study participants.

Where relevant, you agree to delete all audio files and transcripts from your personal computer once you have completed this work, unless otherwise agreed with '*The experiences of young persons with mild to moderate communication disorders resulting from stroke: A Phenomenological Investigation*' project staff.

Name : _____

ID Number : _____

Signature : _____

Date : _____