

The communication needs of young and old cerebrovascular accident (CVA) survivors

Jamie de Grass-Clementson

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Supervisor: Alida de Beer

Co-supervisor: Faeza Bardien

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Declaration

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Abstract

Cerebrovascular accidents (CVAs) are a growing epidemic in developing countries such as South Africa, resulting in an increase in CVA-related morbidity, which includes communication impairments. CVAs have traditionally been viewed as a disease of the elderly, but there is an increase in the prevalence of young CVA survivors. This quantitative descriptive cross-sectional research aimed to describe the communication needs of young and old CVA survivors in the following five communication areas: difficult communication situations, difficult communication skills, preferred communication strategies, preferred conversational topics and preferred literacy skills. The results obtained from the 62 participants (i.e. 22 young and 40 old CVA survivors) who completed the Aphasia Needs Assessment (Garrett & Beukelman, 2006) highlight that their personal and social communication needs have to be addressed before those that are environmental in nature. Furthermore, the findings suggest that difficult communication skills have to be identified before difficult communication situations and preferred topics can be addressed. Speech-language therapists working within the South African context are often confronted with challenges such as high unemployment, poverty, poor literacy levels and adverse circumstances, thus making the use of appropriate assessment criteria and management approaches challenging. Speech-language therapists are therefore recommended to identify CVA survivors' unique barriers and facilitators to ensure appropriate intervention.

Keywords: young and old CVA survivors; communication needs; communication impairment; personal, social and environmental needs

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Abstrak

Serebro-vaskulere ongelukke (SVO) is 'n groeiende epidemie in ontwikkelende lande soos Suid Afrika, en veroorsaak verhoging in verwante morbiditeit, wat kommunikasie afwykings insluit.. SVO is tradisioneel gesien as 'n siekte van die ouer populasie maar daar is huidiglik 'n groei in die prevalensie van jong SVO oorlewendes. Die kwantitatiewe, beskrywende deursnee navorsingsontwerp poog om die kommunikasie behoeftes van jong en oud SVO oorlewendes te beskryf in die volgende vyf kommunikasie areas: moeilike kommunikasie situasies, moeilike kommunikasie vaardighede, verkose kommunikasie strategiee, verkose gesprekstemas en verkose geletterdheidsvaardighede. Resultate van die 62 deelnemers (22 jong en 40 oud) wat die Afasie Behoefte Assessering (Garrett & Beukelman, 2006) voltooi het beklemtoon dat persoonlike en sosiale kommunikasie behoeftes eerste geadresseer moet word voor omgewing kommunikasie behoeftes. Verdere resultate stel voor dat moeilike kommunikasie vaardighede eerste geïdentifiseer moet word voor moeilike kommunikasie situasies en verkose temas geadresseer word. Spraakterapeute wat binne 'n Suid Afrikaanse konteks werk, word dikwels gekonfronteer met uitdagings soos: hoë werkloosheid, armoede, swak geletterdheidsvaardighede en omstandighede, en daarom word die gebruik van toepaslike assessering kriteria en behandeling benaderings bemoeilik. Daar word dus aanbeveel dat spraakterapeute die SVO oorlewendes se unieke hindernisse en fasiliteerders identifiseer om toepaslike intervensie te verseker.

Sleutelwoorde: jong en oud SVO oorlewendes, kommunikasie behoeftes, kommunikasie gestremdheid en persoonlikheid, sosiale en omgewing kommunikasie behoeftes

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Glossary

CVA: a life-threatening and disabling event with a long-term illness trajectory.

Young CVA survivor: pertains to CVA survivors from 18 to 45 years of age.

Old CVA survivor: pertains to CVA survivors 46 years and older.

Communication impairment: relates to speech and language impairments.

Communication needs: viewed in terms of the five communication areas (i.e. difficult communication situations, difficult communication skills, preferred communication strategies, preferred topics of conversation and preferred literacy skills) utilised in the Aphasia Needs Assessment (Garrett & Beukelman, 2006).

Personal needs: communication activities which relate to oneself and therefore only concerns the person and not others.

Social needs: relate to communication activities involving familiar communication partners.

Environmental needs: relate to communication activities which occur outside the home environment with unfamiliar communication partners.

Participation: involvement in social or everyday life situations.

Preferred literacy skills: relate to participants' perceived literacy skills and preferred literacy activities.

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CHAPTER 1**INTRODUCTION****1.1. Background information**

A cerebrovascular accident (CVA) is a life-threatening and disabling event with a long-term illness trajectory (Hilari, 2011; Kirkevold, 2002). Although CVAs have traditionally been considered a disease of the elderly, as the incidence doubles with each decade after the age of 50, in recent years this trend has begun to change as young CVA survivors have become more prevalent (Crichton, Wolfe, Rudd, & Mckevittl, 2012; Dalemans, De Witte, Lemmens, Van den Heuvel, & Wade, 2008; Sulta & Elkind, 2012; Smajlović, 2015). Communication impairments following a CVA are known to reduce participation, and increasing participation is therefore one of the most important goals of speech-language therapists (Beukelman, Garrett, & Yorkston, 2007) but is only achievable when based on the specific communication needs of the CVA survivor. However there has been limited research focussing on the specific needs of young CVA survivors (Low, Kersen, Ashburn, George, & McLellan, 2003) and little is known about their specific communication needs. Research related to the communication needs of young CVA population remains limited and fragmented. They often report feeling like an invisible group (Kersten et al., 2009), with the greatest frustration being a lack of participation and a shortage of age-adapted rehabilitation (Musser et al., 2014; Roding et al., 2003).

1.2. Purpose of this study

The study aimed to describe the communication needs of young and old CVA survivors by exploring the five communication areas (i.e. difficult communication situations, difficult communication skills, preferred communication strategies, preferred conversational topics and preferred literacy skills) included in the Aphasia Needs Assessment (ANA) (Garrett & Beukelman, 2006). Guided by the principles of the LPAA and the Participation Model for Augmentative and

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Alternative Communication, participants' communication needs were viewed as personal, social or environmental in nature.

1.3. Research question

Do the communication needs of young CVA survivors differ from the communication needs of old CVA survivors?

1.4. Research objectives

- 1.1. To describe difficult communication situations for young and old CVA survivors.
- 1.2. To describe difficult communication skills for young and old CVA survivors.
- 1.3. To describe the preferred communication strategies of young and old CVA survivors.
- 1.4. To describe the preferred topics of conversation of young and old CVA survivors.
- 1.5. To describe the preferred literacy skills of young and old CVA survivors.

1.5. Chapter overview

1.5.1. Chapter 1: Introduction. This chapter provided the reader with a brief summary of background information and the problem statement related to this research. The research question and objectives of the research study were also introduced.

1.5.2. Chapter 2: Literature review. This chapter provided a background of existing literature relating to the focus of this study. It provided an evaluation and interpretation of existing literature, which focused on: the growing CVA epidemic, the increasing prevalence of young CVAs in Sub-Saharan Africa, their unique needs and the impact of communication impairment on participation.

1.5.3. Chapter 3: Methodology. In this chapter the methodological approach implemented to conduct the research study is described. A quantitative descriptive cross-sectional research design

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was used for this study. The overall aim of this study, material, instrument and data collection procedure as well as ethical considerations were discussed.

1.5.4. Chapter 4: Results. For the purpose of this research, frequency statistics were applied. Results were described and displayed using frequency tables.

1.5.5. Chapter 5: Discussion. This chapter discussed the findings of this study and reflects upon it in relation to existing literature.

1.5.6. Reference list- This section provides a list of all material cited in this report.

1.5.7. Appendices- This section contains supplementary information.

CHAPTER 2**LITERATURE REVIEW****2.1. The impact of cerebrovascular accidents (CVAs)**

A cerebrovascular accident (CVA) is a life-threatening and disabling event with a long-term illness trajectory (Hilari, 2011; Kirkevold, 2002). It occurs when the interruption of blood flow deprives the brain of needed oxygen and causes the affected brain cells to die (Brookshire, 2014). The World Health Organization (WHO) reported that cerebrovascular disease was responsible for 9.7% of total deaths and 3.1% of the burden of disease worldwide (WHO, 2008). The increase in cerebrovascular disease has led high-income countries to prioritise reducing the incidence and negative effects of CVA; however, this is not yet the case in low- and-middle-income countries (Connor, Walker, Modi, & Warlow, 2007; Kengnel & Anderson, 2006).

The impact of CVAs in Sub-Saharan Africa (SSA) is uncertain and overshadowed by attention devoted and resources allocated to the impact of infectious diseases such as human immunodeficiency virus (HIV) (Kengnel & Anderson, 2006). This, however, needs to change as the Global Burden of Disease (2013) confirmed the significant increase in CVA related burden (i.e mortality and morbidity) especially in low- and-middle-income regions of the world, such as those found in SSA (Feigin, Norrving, Mensah, 2017; Connor et al., 2007). This is also likely to increase over the next few decades in these countries (Conner et al., 2007).

CVAs have traditionally been considered a disease of the elderly as the incidence doubles with each decade after the age of 50; however, in recent years this trend has begun to change as young CVA survivors have become more prevalent (Crichton, Wolfe, Rudd, & Mckeivittl, 2012; Dalemans, De Witte, Lemmens, Van den Heuvel, & Wade, 2008; Sultan & Elkind, 2012; Smajlović, 2015).

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Griffiths and Sturm (2011) considered young CVA survivors to be between 18 to 45 years of age. Fewer than 5% of all CVAs occur under the age of 45 years in developed countries, whereas this percentage may be between 19% and 30% in low- and-middle-income countries (Marini, Russo, & Felzani, 2011). The incidence of CVA in adults younger than 45 years may therefore be as high as 30% in low- and-middle-income countries such as found in SSA (Connor & Bryer, 2006)

It has been reported that there are limited accurate longitudinal studies of mortality and morbidity following a CVA in SSA. This is possibly because there are few incidence studies that meet the accepted standards specific to this population (Connor & Bryer, 2006; Connor et al., 2007).

Although accurate longitudinal data is limited, several causes for the increase in young CVA survivors have been established (Cotoi et al., 2016). These causes are, however, not limited to young CVA survivors. They include lifestyle diseases, infectious diseases, genetic risk factors and non-modifiable risk factors such as pregnancy and race (Connor et al., 2007; Cotoi et al., 2016; Owolabi & Ibrahim, 2012; Singers, Valdes-Sueras, Commins, Yong, & Carlson, 2013). Urbanisation occurring in a developing country such as South Africa is predicted to increase the risk factors for lifestyle diseases such as vascular disease, which will lead to a sharp increase in CVAs (Connor & Bryer, 2006). Ischaemic CVAs have also been noted as a significant neurological complication of an infectious disease such as HIV (Singers et al., 2013). Potential causes of CVAs in HIV-positive individuals are opportunistic infections, tumours, atherosclerosis, diabetes, hypertension, autoimmunity, coagulopathies, cardiovascular disease and direct HIV infection of the arterial wall (Singers et al., 2013). Genetic risk factors such as cardiac abnormalities, thrombophilic states, migraine and the use of oral contraceptive have also been listed as known contributors to the causes of CVA in young survivors (Marini et al., 2011). Although uncommon, another risk factor for the young female populations is pregnancy and the postpartum period (Feske, 2007). Race is also identified as playing a significant role in CVA risk and aetiology, particularly with regard to

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CVA in young black patients (Kittner et al., 1993). The aetiologies of young CVA survivors tend to be more heterogeneous than for older CVA patients who are more likely to have the traditional atherosclerotic risk factors (Smajlović, 2015).

As the incidence of CVAs increases, great progress is being made in the medical treatment aiming to decrease mortality (Carod-Artal, 2012). This decrease in mortality, however, results in an increase in CVA-related disability (Carod-Artal, 2012). CVAs are the leading cause of acquired disability in adults and are considered to be a chronic condition that can cause long-term physical, cognitive and psychosocial impairment (Carod-Artal, 2012; Mendis, 2012; Quinn, Murray, & Malone, 2014). These disabilities may require long-term care. CVA survivors may continue to need assistance with at least one activity of daily living, with 15-30% presenting with permanent disability (Carod-Artal, 2012). A population study focusing on CVA survivors found that at five years post CVA, two-thirds had some neurological impairment and disability, 22.5% had dementia, 15% were institutionalised and 20% had experienced a subsequent CVA (Mendis, 2012).

Neurological impairments following a CVA are described as heterogeneous and vary in relation to the particular regions of the central nervous system that sustained damage (Staines, McIlroy, & Brooks, 2012). These neurological impairments and subsequent disability following a CVA may present as physical impairment, cognitive impairment, executive dysfunction, psychosocial difficulties, dysphagia and communication impairments (American Speech-Language-Hearing Association [ASHA], 2014; Connor & Bryer, 2006; Norving & Kissela, 2013).

2.2. Communication difficulties following a CVA

Communication difficulties may be one of the most common effects of a CVA, with approximately one-third of survivors developing aphasia and one-fifth developing dysarthria (Gordon et al., 2004; Legg, Stott, Ellis, & Sellars, 2007). The communication impairments following a CVA can be loosely categorised into language and speech impairments (ASHA, n.d.). Language impairment affects the ability to understand and share thoughts and ideas (ASHA, n.d.). It may affect all verbal

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abilities, including impaired verbal expression, difficulty understanding spoken or written language and problems with repetition, naming, reading and writing (Sinanović, Mrkonjić, Vidović, & Imamović, 2011). Speech impairments can be categorised as a motor speech (dysarthria) or a motor planning (apraxia of speech [AOS]) disorder. Both can negatively affect the ability to produce speech sounds correctly or fluently (ASHA, 2016a). The four most common communication impairments experienced post CVA are aphasia (receptive and/or expressive language disorder), cognitive-communicative disorder, apraxia and dysarthria (Borthwick, 2012). These conditions may occur in isolation or together.

Language impairment such as aphasia is defined as an acquired multimodal language impairment that affects the person's ability to talk, write and understand spoken and written language while other cognitive abilities remain relatively intact (Borthwick, 2012). The ability to understand spoken language is an important aspect of communication. The ability to comprehend spoken language and to respond verbally is vital to independence in all spheres of life. CVA survivors presenting with aphasia who previously functioned independently and effectively will be unable to do so. Aphasia is therefore viewed as a life-changing condition and, in most cases, a lifelong disability following CVA (Borthwick, 2012).

The forms of aphasia observed clinically include Broca's, Wernicke's, global, anomic, transcortical motor, transcortical sensory and conduction (ASHA, n.d.). Broca's aphasia is also known as non-fluent aphasia. The dominant feature is agrammatism (impaired syntax). Content words (nouns and verbs) may be preserved, but sentences are produced with difficulty, resulting in telegraphic speech (ASHA, n.d.). Wernicke's aphasia is also known as fluent aphasia (ASHA, n.d.). Comprehension is poor, and the CVA survivor often produces jargon or nonsensical words and phrases when attempting to speak. These utterances typically retain sentence structure but lack meaning (ASHA, n.d.). Global aphasia can be described as a combination of non-fluent and fluent aphasia. CVA survivors present with severely impaired expressive and receptive language skills,

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and it is considered to be the most severe form of aphasia (ASHA, n.d.). Anomic aphasia is described as a mild form of aphasia. The most prominent difficulty is in word finding, with use of common fillers in utterances, such as nonspecific nouns and pronouns (e.g. ‘thing’), or circumlocution, whereby the person describes the intended word (ASHA, n.d.). Comprehension and repetition of words and sentences are satisfactory. Transcortical motor aphasia is similar to Broca’s aphasia, but CVA survivors are able to repeat words, phrases and sentences well but present with difficulty with spontaneously answering questions (ASHA, n.d.). Transcortical sensory aphasia is similar to Wernicke’s aphasia; however, CVA survivors have intact speech repetition abilities (ASHA, n.d.). A rare type of aphasia is conduction aphasia, which is described as fluent aphasia with the prominent impairment being difficulty with repetition (ASHA, n.d.). Significant difficulty can be experienced when repeating phrases, particularly as the phrases increase in length and complexity (ASHA, n.d.). Another feature may be some word-finding difficulties, but auditory comprehension can be functional. Some of the features found in a classification of aphasia can also occur in isolation. This may be in the form of difficulty with reading (alexia) as well as reading and writing (agraphia) (ASHA, n.d.).

Aphasia may occur in conjunction with AOS, a motor-planning disorder. AOS results in difficulty in the motor programming of movements needed for speech (Borthwick, 2012). With AOS, difficulty is experienced in the planning and execution of the movement of the lips, tongue and jaw to produce sounds and words correctly, in the absence of muscle weakness (ASHA, 2016a). Persons with AOS may present with groping of the tongue and lips, slow speech rate, impaired rhythm and prosody (ASHA, 2016a). In severe cases, an inability to produce any sound at all may be observed (ASHA, 2016a).

Cognitive-communicative disorder may coexist with aphasia, or it may present as a standalone communicative disorder (Borthwick, 2012). It can vary in type and severity and may therefore have different effects on the success of CVA survivors’ independence in their activities of

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daily living and communication (Viscogliosi, Belleville, Desrosiers, Caron, & Ska, 2011). Cognitive-communication disorder could have a significant impact on CVA survivors' ability to communicate independently and efficiently as it involves difficulty with any aspect of communication that is affected by the disruption of cognitive skills, such as attention, memory and executive functions such as organisation, problem solving and reasoning (ASHA, 2014). A study conducted by Lincoln (1998, as cited in Viscogliosi et al., 2011) revealed that up to 55% of CVA survivors presented with episodic memory difficulties, 40% presented with executive functioning difficulties and 23% presented with language impairments.

CVA survivors presenting with language impairments secondary to their cognitive difficulties also experience changes in their social roles (Viscogliosi et al., 2011). Three specific domains of social roles are highlighted by Viscogliosi et al. (2011), namely interpersonal relationships, community life and responsibilities. Further communication impairments possibly affected by cognitive difficulties following a CVA are the ability to participate in social discussions, arguments and debates and the ability to relay instructions or directions (Viscogliosi et al., 2011). Discourse production, a goal-directed and complex task that involves retrieving information from memory, deciding which elements to include or exclude, remembering what has already been said, planning upcoming utterances and accounting for what the listener may or may not know, all while maintaining a topic over time, may also be difficult for CVA survivors (Rogalski, Altmann, Plummer-D'Amato, Behrman, & Marsiske, 2010). CVA survivors who present with a cognitive-communication disorder may therefore experience a reduction in their ability to independently complete tasks of daily living, participate in social roles appropriately and communicate effectively.

The last communication impairment to be outlined is the speech motor disorder known as dysarthria. It may co-occur with aphasia, AOS and cognitive-communicative difficulties. Dysarthria is a collective name for a group of speech disorders caused by impaired control of the musculature that is responsible for speech (Brookshire, 2014). There are six different types: flaccid (upper motor

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neurons), spastic (lower motor neurons), ataxic (cerebellar system), hypokinetic (extrapyramidal), hyperkinetic (extrapyramidal) and mixed (multiple motor systems) (Brookshire, 2014; Duffy, 2013). All six types of dysarthria affect the articulation of consonants, causing the slurring of speech. Hypernasality is frequently present as are problems with respiration, phonation and resonance (McCaffrey, 2013). Symptoms of dysarthria can range from mild imprecision in articulation to an inability to vocalise a single comprehensible sound (Borthwick, 2012). Efforts have been made to develop an understanding of the psychosocial impacts of dysarthria as recent research has highlighted the complex association between the severity of dysarthria experienced by a CVA survivor and the impact on her/his social participation (Brady, Clark, Dickson, Paton, & Barbour, 2011).

2.3. Reduced social participation following a CVA

It is also acknowledged that communication impairment following a CVA can reduce the participation of a CVA survivor and can have a negative impact on the person's quality of life (Cruice, Worrall, Hickson, & Murrison, 2003). 'Participation' is described as involvement in life situations (Beukelman, Garrett, & Yorkston, 2007). Participation is an essential element of the WHO's 2001 International Classification of Function, Disability and Health (ICF) framework (Beukelman et al., 2007). Reduced participation in social events could result in feelings of anger, frustration, loneliness and depression (Amundsen, 2014; Fotiadou, Northcott, Chatzidaki, & Hilari, 2014; Haley, Roth, Kissela, Perkins, & Howard, 2011; Hilari & Byng, 2009; Kauhanen, Korpelainen, Hiltunen, Nieminen, Sontaniemi, & Myllylä, 2000; Northcott & Hilari, 2011).

As stated above, the communication impairments of CVA survivors can reduce their participation in life situations, but this can also be influenced by environmental factors. The ICF framework emphasises the central and influential roles of environmental factors in communication (Green, Mophosho, & Khoza-Shangase, 2015). "Environmental factors refer to the CVA survivor's physical surroundings, laws and legislatures, social and communicative encounters and society's

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attitudes and feelings towards the specific health condition” (WHO, 2001, as cited in Green et al., 2015, p. 2). Environmental factors are seen as either a barrier to (negative) or facilitator of (positive) communication. It is for this reason that speech-language therapists cannot address communication difficulties before adequate information is gathered regarding these environmental factors (Howe, Worrall, & Hickson, 2008). In order to improve communication and thus bring about increased participation, the environmental factors that either support or impede social participation need to be explored and addressed (Green et al., 2015).

An approach that focuses on identifying the environmental and personal factors important for increased participation is the Life Participation Approach to Aphasia (LPAA) (Chapey, Duchan, Elman, Garcia, Kagan, & Lyon, 2000). The LPAA is an appropriate approach for persons with communication impairments as it is a consumer-driven, service-delivery approach model whose explicit goal is enhancement of participation (Chapey et al., 2000). The LPAA supports individuals with aphasia in achieving their immediate and longer term goals (ASHA, 2017). The principles of the approach do not necessarily apply only to individuals with aphasia and may be extended to all communication disorders. The LPAA places the life concerns of those affected by aphasia and other communication impairments at the centre of all decision making (Chapey et al., 2000).

Intervention through the LPAA consists of constantly assessing, weighing and prioritising which personal, social and environmental factors should be targets of intervention and how best to provide unrestricted, easier and more autonomous access to activities and social connections (Chapey et al., 2000). The ultimate goal of enhanced participation is to guide management from the initial stages. This is in line with the fundamental principles of the Participation Model for Augmentative and Alternative Communication by Beukelman and Mirenda (2013). The Participation Model for Augmentative and Alternative Communication aims to ensure that persons with communication impairments are supported communicatively so that they can participate in their rehabilitation and decision making (Beukelman et al., 2007). This resonates with the principles

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of the ICF framework, which aim to ensure participation for CVA survivors with communication impairments at all stages of their recovery (Balandin, 2011).

Both the LPAA and the Participation Model for Augmentative and Alternative Communication advocate a combination of immediate and long-term intervention, based on and driven by the CVA survivor's specific communicative needs (Beukelman et al., 2007; Chapey et al., 2000). Interventions for CVA survivors with communication impairments such as aphasia often differ according to phase of recovery, communication needs and the treatment setting (Beukelman et al., 2007). The Participation Model for Augmentative and Alternative Communication provides a systematic and user-friendly method of managing the communication needs of CVA survivors with communication impairments, especially for those who would benefit from an augmentative and alternate communication (AAC) needs assessment, although not limited solely to the assessment of and intervention in these needs (Balandin, 2011).

The Participation Model for Augmentative and Alternative Communication facilitates the overarching purpose of all communication intervention, which is to maximise an individual's ability to communicate and actively participate in events occurring at home and in his/her community (ASHA, 2004). Generally, when applying the Participation Model for Augmentative and Alternative Communication, four different steps are involved, the first being for the speech-language therapist to identify the past and present participation patterns and activities as well as the related communication needs of the CVA survivor with a communication impairment (Beukelman et al., 2007).

Secondly, the speech-language therapist identifies the barriers to participation. The Participation Model for Augmentative and Alternative Communication identifies two main barriers as relating to aspects of opportunity and access (Beukelman & Mirenda, 2013). Opportunity barriers pertain to policies, practices, facilitator skills and knowledge as well as attitudes that may obstruct the achievement of the intervention goals (Beukelman et al., 2007). Access barriers pertain to the

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capabilities, attitudes and resource limitations of CVA survivors' societies or support systems (Beukelman & Mirenda, 2013). Access barriers may also be related to aspects such as lack of mobility or difficulty with manipulation and management of objects, problems with cognitive functions and decision making, literacy deficits and sensory-perceptual impairments (Beukelman & Mirenda, 2013).

The communication partners of CVA survivors with communication impairments could possibly pose an opportunity barrier. This could be the case if communication with a CVA survivor is not approached with respect, tolerance and understanding (Brown, McGahan, Alkhaledi, Seah, Howe, & Worrall, 2006). CVA survivors with communication impairments reported negative and hurtful communicative experiences such as being interrupted, mocked, laughed at and deserted while communicating, which resulted in the avoidance of communicating in different situations (Northcott & Hilari, 2011). CVA survivors with communication impairments also reported that social situations were difficult and less enjoyable and that conversations were less likely to be two way (Fotiadou et al., 2014; Northcott & Hilari, 2011). Other aspects of communication that could be viewed as potential barriers include interrupting the CVA survivor with a communication impairment or guessing the intended message, asking open-ended questions, asking too many questions too quickly, not incorporating all modes of communication (i.e. such as pointing, gesturing, writing or drawing) to aid comprehension of the intended message and not providing the CVA survivor with enough time to understand and respond (Brown et al., 2006).

The literacy skills of a CVA survivor could pose a possible access barrier as literacy is often affected by aphasia and this is known to have a significant impact on participation in daily living (Sinanović et al., 2011). A possible example of reduced participation could be a CVA survivor's inability to shop independently due to difficulty comprehending store names, item labels and prices (Brown et al., 2006). In addition, difficulty with reading impacts not only on the CVA survivor but may extend to her/his family as reading a bedtime story to a child or reading from a religious book

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for family worship may no longer be possible. Furthermore, corresponding through letters used to be a relatively common means of communication; however, with technology, communication via email, instant messaging and social media has become prevalent. The literacy skills needed to make use of these communication platforms may be lacking in CVA survivors.

It is clear that the abovementioned barriers have a significant impact on participation. An important initial step in the management of CVA survivors is therefore to understand their communication needs and the barriers that could hinder their participation and reintegration (ASHA, 2004). The speech-language therapist should also establish the communication ability of the CVA survivor, which is achieved by completing a comprehensive speech-language assessment. Once all the barriers to communication have been identified, the speech-language therapist explores communication options to overcome the specific difficulties. The CVA survivor's potential for further improvement in his/her speech-language ability through regular and intensive speech-language therapy is then determined (Koenig-Bruhina, Kolonko, Atc, Annonid, & Hunzikerb, 2013), which forms the third step in the Participation Model For Augmentative and Alternative Communication. The last step of the Participation Model for Augmentative and Alternative Communication requires the speech-language therapist to evaluate the communicative intervention by monitoring its effectiveness in supporting participation (Beukelman & Mirenda, 2013).

2.4. Young CVA survivors' needs

Through meeting CVA survivors' needs, intervention aims to improve participation as social interaction and building relationships are the foundation upon which CVA survivors rebuild their skills to engage with their communities. Successful rehabilitation and community reintegration is a complex process that requires facilitation of the strengths of the CVA survivor through social support, help from healthcare professionals and understanding from the general public (Walsh, Galvin, Loughnane, Macey, & Horgan, 2015). "Though the rehabilitation offered to young stroke patients are similar to that of older patients, younger patients present many unique problems after

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CVA” (Teasell et al., 2000, as cited in Cotoi et al., 2016, p. 32). Musser, Wilkinson, Gilbert & Bokhour (2014) reported that although studies have started to explore the unique difficulties faced by young CVA survivors, the focus has mainly been on returning to work.

A study reported that approximately 12 000 economically active Australians survived a CVA annually (Hackett, Glazier, Jan, & Lindley, 2009). Coole, Radford, Grant, and Terry (2013) reported that approximately 40% of economically active adults who suffered a CVA were unable to return to work. Many of those able to return found that they were unable to cope with the demands of full-time employment (Graham et al., 2011; McCarthy, Lyons, & Powers, 2012). CVA survivors with aphasia face significant challenges in regaining meaningful employment; furthermore Dalemans et al. (2008) reported an overall decrease in employment when compared with CVA survivors without aphasia. CVA survivors with aphasia who were able to return to work experienced significantly reduced hours and required task modifications (Graham, Pereira, & Teasell, 2011). For CVA survivors in general, it was found that 68% suffered from significant work dysfunction despite good clinical outcomes. Opportunities for vocational rehabilitation are, however, often limited or non-existent for young survivors since the majority of CVAs occur in old individuals who are no longer economically active (Conroy et al., 2009 as cited in Graham et al., 2011). This places young CVA survivors at a significant disadvantage. Young CVA survivors with reduced mobility and who are unable to return to work present with the greatest unmet needs amongst CVA survivors (Kersten, Low, Ashburn, George, & McLellan, 2009).

Another area of concern for young CVA survivors is their psychosocial and social issues, which are different from those of old CVA survivors (Cotoi et al., 2016; Teasell, McRae, & Finestone, 2000). Young CVA survivors reported higher rates of marital separation, anxiety, child care issues, depression and loss of independence (Cotoi et al., 2016; Teasell et al., 2000). Other social difficulties include familial disharmony, stress and the reestablishment of family dynamics and valued roles such as provider and worker, carer and protector (Quinn et al., 2014). Social and

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partner roles can also be affected; young CVA survivors and their partners reported considerable communication difficulties in their relationships (Quinn et al., 2014). A CVA often results in partners' needing to stop working to care for the CVA survivor or to find work to support the family (Quinn et al., 2014). Additionally, the significant impact on their relationship, including a loss of intimacy and familiarity, was recounted by young CVA survivors and their partners, describing it as a one-sided caregiving relationship (Quinn et al., 2014). Consideration should therefore be given to young CVA survivors' unique struggle, with a greater focus on psychosocial issues (Teasell et al., 2000).

The specific struggle of young CVA survivors was explored in a study conducted by Röding, Lindstrom, Malm, & Ohman (2003) that reported that medical doctors and rehabilitation healthcare professionals often ignored cognitive deficits in young CVA survivors and largely focused on regaining their functional ability. "Helpful interventions for young stroke patients may involve the development of active strategies, cognitive behavioural therapy and the involvement of social supports" (Ch'ng et al., 2008, as cited in Cotoi et al., 2016, p. 32). Other interventions that young CVA survivors desired were information regarding their CVA, intellectual fulfilment, family support, assistance with finances, non-care activities and rehabilitation (Kersten et al., 2009). Traditionally, CVAs have been considered a disease of the elderly, and therefore the focus has been on rehabilitation. With the increase in the prevalence of young CVA survivors (Crichton et al., 2012; Dalemans et al., 2008; Sultan & Elkind, 2012; Smajlović, 2015), it is now recognised that they have unique needs as they often make a more complete neurological and functional recovery than old CVA survivors (Teasell et al., 2000) but impairments may still be present. "The needs of young stroke patients are often not being addressed within the context of inpatient rehabilitation which tends to focus on older CVA survivors" (Röding et al., 2003 & Stone, 2005, as cited in Cotoi et al., 2016, p. 4).

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Research related to the population remains limited, fragmented, and lacks evidence related to the social needs, experiences and identities of young CVA survivors with communication impairments (Musser et al., 2014). They often therefore report feeling like an invisible group (Kersten et al., 2009), with the greatest frustration being a lack of participation and a shortage of age-adapted rehabilitation (Röding et al., 2003). There has been limited research focussing on the specific needs of young CVA survivors (Low et al., 2003). Even though communication difficulties are one of the most common effects of a CVA (Gordon et al., 2004; Legg et al., 2007), little is known about young CVA survivors' specific communication needs. A cause for concern is not only the sparse body of research available about young CVA survivors but that it provides limited insight into the recovery process from their point of view (Low et al., 2003). Treatment planning is often based on caregiver reporting rather than self-reporting of challenges noted by the CVA survivors (Henson, 2016). Therefore, this current research is deemed purposeful as it aimed to describe the communication needs as reported by the CVA survivors themselves. Gaining information regarding their communicative needs is a step towards providing age-adapted rehabilitation to increase participation to the unique and growing young CVA population. The research question therefore asked whether the communication needs of young CVA survivors differed to the needs of old CVA survivors.

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CHAPTER 3**METHODOLOGY****3.1. Research question**

Do the communication needs of young CVA survivors differ from the communication needs of old CVA survivors?

3.2. Research aim and rationale

The research aimed to describe the communication needs of young and old CVA survivors. A distinction between young and old CVA survivors' communication needs is necessary as young CVA survivors reported greater unmet needs than old CVA survivors (Morris, 2011). This highlights the need for greater understanding of appropriate, immediate medium- and long-term intervention goals for young CVA survivors to allow for increased participation in everyday life. According to Worrall and Holland (2003), speech-language therapists should focus on functional communication tasks aimed at improving participation through meeting CVA survivors' communication needs. Greater insight into the greatest communication frustrations and hindrances of young CVA survivors is crucial, given the longer length of time that they may live with potentially lasting communication impairments (Healthtalk, 2014).

3.3. Research objectives

1. To describe difficult communication situations for young and old CVA survivors.
2. To describe difficult communication skills for young and old CVA survivors.
3. To describe the preferred communication strategies of young and old CVA survivors.
4. To describe the preferred topics of conversation of young and old CVA survivors.

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5. To describe the preferred literacy skills of young and old CVA survivors.

3.4. Research design

A quantitative research study methodology was followed; this allowed for the gathering of descriptive data of two groups that included young CVA survivors, which are classified as an emerging research area (Babbie, 2010).

A descriptive cross-sectional research design was used for this study. The three characteristics of this study design were as follows: Firstly, the data was collected at a single point in time (Lavarakas, 2008). Secondly, the only variable in this study was the age of the participants; having only one variable is distinctive of descriptive research methodology. Lastly, the aim of this study was solely to describe the communication needs of young and old CVA survivors, not to change their behaviour or communication methods (Babbie, 2010). A descriptive cross-sectional research design also allowed for an easy visual summary of the raw data and description thereof (Trochim, 2006).

3.5. Setting

Public health institutions providing rehabilitative services to CVA survivors were selected. According to Myer, Smith and Mayosi (2012), the public health system in South Africa provides healthcare to more than 80% of the population. As the public healthcare system services the majority of South Africans, it was deemed more suitable than private healthcare institutions for this study.

Participants in the study were sourced from Tygerberg Hospital (TBH) and the Western Cape Rehabilitation Centre (WCRC). TBH is one of three tertiary-level hospitals in the Western Cape. TBH is the largest hospital in the Western Cape and the second largest in South Africa (Western Cape Government, 2016). The dedicated TBH stroke unit provides intensive multidisciplinary rehabilitation to inpatient CVA survivors. After discharge, continued

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rehabilitation services are also provided. TBH is situated in the Tygerberg Eastern Health District of the metro region and services Northern Metro sub-districts, Khayelitsha North, Eastern Tygerberg, West Coast, Cape Winelands and Overberg (Western Cape Government, 2016). The WCRC is a specialised rehabilitation centre that provides specialised, high-intensity rehabilitation and community-reintegration programmes to persons who have sustained injuries, one of the key rehabilitation programmes being for CVA survivors (Western Cape Government, 2013a). The WCRC accepts referrals from all levels of healthcare, including referrals from Groote Schuur Hospital (GSH). TBH and GSH are the only tertiary hospitals in the Western Cape servicing the adult population. As the WCRC accepts CVA survivors for further rehabilitation from GSH and TBH as well as other levels of care, a wide selection of CVA survivors could be sourced at this institution. Furthermore, as both adult servicing tertiary hospitals refer patients to the WCRC, it increased the probability of the sample of young and old CVA survivors being sourced from the entire Western Cape.

3.6. Research sample

3.6.1. Sampling method

The incidence of young CVA survivors is on the rise, but it is still a reasonably small population. Convenience sampling, which allows all those who are willing to participate and who meet the inclusion criteria to participate, was regarded as most appropriate for the descriptive nature of this study (Bejot, Delpont, & Giroud, 2016; *Convenience sampling*, 2009). Convenience sampling allowed the researcher to gather useful information that would not have been possible using probability sampling as it requires more formal access to lists of potential participants, which were not available for this emerging population (Blanche & Durrheim, 1999).

Although convenience sampling was deemed most appropriate for this study, this sampling method presents limitations (*Convenience sampling*, 2009). Participation bias was a concern as willing participants might not have been representative of the population of young and old CVA

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survivors (*Participation bias*, 2016). This in turn could lead to social desirability bias whereby participants structure their answers in a way to be seen positively by the researcher (*Social desirability bias*, 2017). The researcher therefore encouraged all participants to answer truthfully. Convenience sampling may limit generalisation and inferences about the population. However, this was not a concern due to the descriptive nature of the study (*Convenience sampling*, 2009).

3.6.2. Selection criteria

A number of criteria needed to be met prior to CVA survivors' being included as participants. This was necessary to control for any possible extraneous variables. For the purpose of this study, the following criteria needed to be met: Firstly, the study included Xhosa-, Afrikaans- and English-speaking CVA survivors. These languages were selected as they are the most commonly spoken languages in the Western Cape (Brand South Africa, 2015; Steyl & Philips, 2013).

Secondly, all young and old CVA survivors were required to be in the rehabilitation phase post CVA. The rehabilitation phase may begin as early as 24-48 hours after a CVA; however, this may be dependent on the patient's overall medical condition. Patients need to be medically stable prior to beginning the rehabilitation phase (Mayo Clinic, 2015).

Thirdly, CVA survivors needed to have a score of no less than 16/20 or 80% for the comprehension screener (receptive subsection of the Western Aphasia Battery [WAB]). The same inclusion criterion, using the receptive subsection of the WAB, was applied in a study by Cruice, Hill, Worrall, and Hickson (2010). The study focused on investigating how measures of impairment, activity and participation, and measures of quality of life related to each other for persons with aphasia. This inclusion criterion was deemed necessary as the CVA survivors were required to present with sentence-level comprehension in order to provide consent to participate in the study and to ensure that they understood the questions included in the Aphasia Needs Assessment (ANA)(Garrett & Beukelman, 2006).

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Lastly, for CVA survivors receiving inpatient rehabilitation, a minimum two-night stay outside of the institution, informally referred to as weekend leave, was required. This leave of absence was deemed necessary as CVA survivors might not have been aware of their communication needs outside a highly structured communication environment.

All possible CVA participants were allocated to young and old CVA survivor groups depending on their age. Young CVA survivors are considered to be from 18 to 45 years of age (Griffiths & Sturm, 2011). Old CVA survivors are deemed 46 years and older (Griffiths & Sturm, 2011). All potential CVA participants received speech-language therapy at the time of data collection.

3.6.2.1. Inclusion criteria for young and old CVA survivors

1. English-, Afrikaans- and Xhosa-proficient CVA survivors.
2. CVA survivors in the rehabilitation phase of their recovery.
3. Young and old CVA survivors who scored 16/20 or more in the comprehension screener, signifying mild to no comprehension impairment.
4. CVA survivors who had spent a minimum of two nights in their home environment.

3.6.2.2. Exclusion criteria for young and old CVA survivors

1. Young and old CVA survivors who presented with degenerative diseases or previous health, cognitive or physical factors that might have affected the CVA survivors' communication prior to their CVA.
2. Young and old CVA survivors diagnosed with severe global or Wernicke's aphasia (moderate-severe comprehension difficulties).
3. Young and old CVA survivors who had not spent a minimum of two nights or more in their home environment.

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3.7. Study procedure

The researcher and research assistant followed a set study procedure as seen in Figure 3.1. The researcher/research assistant completed the research form, documenting each potential participant's biographical information (i.e. age, gender and communication diagnosis) using the hospital folder. The study procedure firstly ensured participants had received a speech-language assessment which included the language comprehension screener, this generally formed part of the standard operational procedures at the institutions. This was important as participants required an adequate level of comprehension to consent to the study and answer the ANA questions.

CVA survivors who failed the comprehension screener were recommended to continue speech-language therapy at their institution (i.e. TBH or WCRC). CVA survivors who scored 16/20 or higher were invited to participate in the study. If consent was not given, they were recommended to continue with speech-language therapy. Only once consent had been received was the ANA conducted.

A survey, the ANA, was used as the preferred method of data collection. The term 'survey' refers to the act of collecting information and may encompass any measurement procedure that involves asking individuals questions (Kowalczyk, 2003; Trochim, 2006). A survey was seen as an effective method for data collection as it allowed the researcher and the research assistant to collect data with limited effect on its validity and reliability. The results of the survey could also easily be quantified. For the completion of the ANA, the researcher was seated next to the participant. The researcher/research assistant read the instructions and questions to the participant. This was deemed appropriate as participants presented with sentence-level comprehension; participants were allowed to answer verbally or to gesture to answer yes or no. The administration of the ANA for outpatients took place in an office. For inpatients at the WCRC, the administration of the ANA occurred at the

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hospital bedside or in the event that a participant requested more privacy, an office was utilised. The study procedure is graphically represented in Figure 3.1.

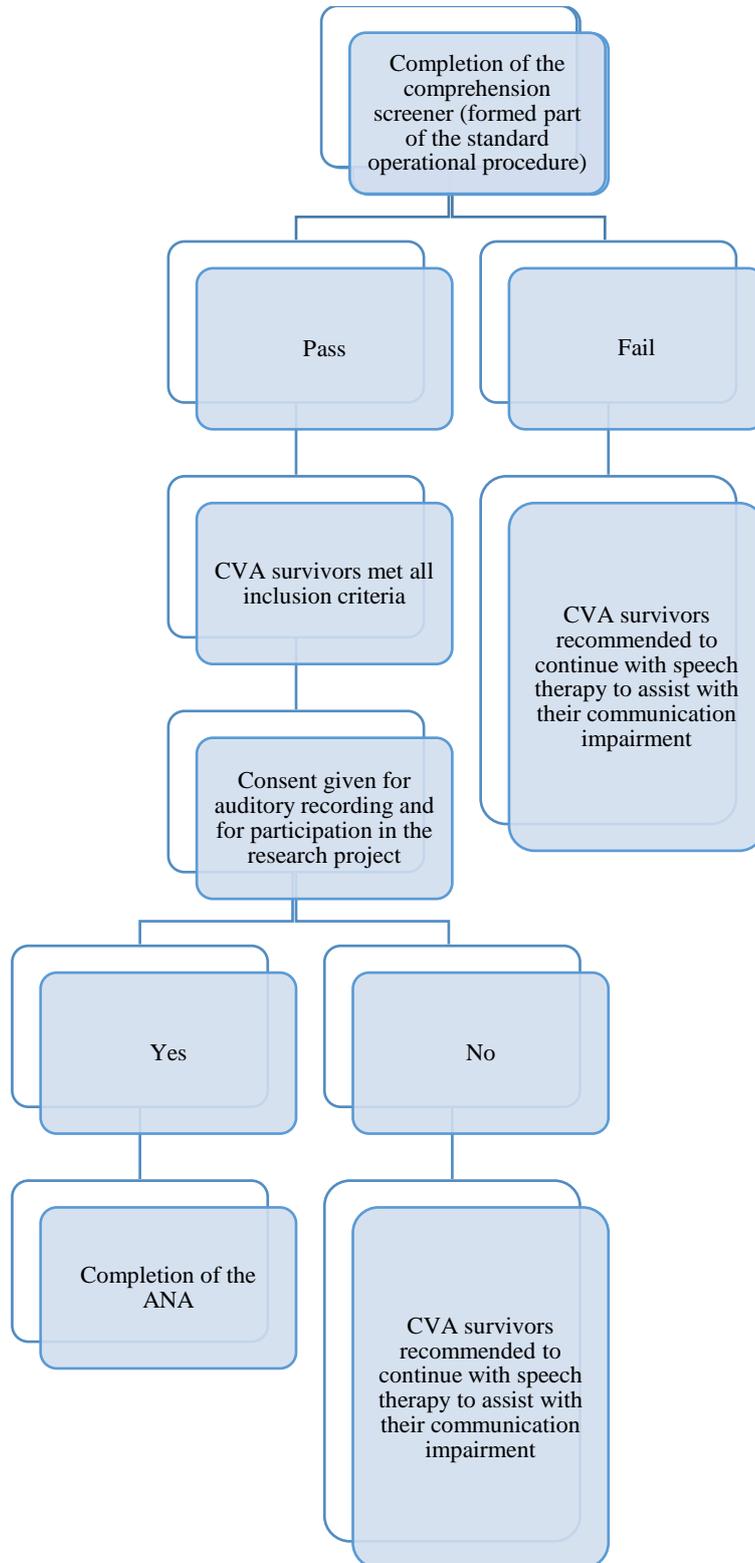


Figure 3.1: Study procedure

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3.7.1. Screening of CVA survivors' language comprehension. Screening was essential as this study required participants to present with language comprehension at a sentence level to fully comprehend and answer the ANA questions. As all participants were receiving speech-language therapy, this comprehension screening instrument was selected as it generally forms part of the speech-language assessment battery. Therefore participants were not required to provide consent prior to completion of the comprehension screener as it generally formed part of the institution's standard operating procedures. Simos, Kasselimis, Potagas and Evdokimidis (2014) reported that the majority of language assessments employed in routine clinical practice were designed to provide a global measure of comprehension of spoken language, including the WAB.

The WAB is a widely used standardised tool mostly used to evaluate linguistic and non-linguistic skills of adults with CVAs (Shewan & Kertesz, 1980). Although the WAB is a standardised tool, for the purpose of this study, the auditory verbal comprehension subsection was used in isolation to determine candidacy for inclusion into the study. The comprehension screener (Addendum 3) is comprised of 20 questions, requiring only yes/no responses. Questions in the screener increase in linguistic complexity; however, they remain semantically simple and short (Shewan & Kertesz, 1980). The 20 questions are divided into three themes: personal (9), environmental (5) and general knowledge (6).

The use of this subtest of the WAB, the comprehension screener, was seen as an adequate measure of comprehension; as Simos et al. (2014) indicate, the comprehension of spoken sentences is considered critical and predictive of overall linguistic and social functioning. The comprehension screener was seen as an appropriate instrument for the purpose of this study and therefore needed to be translated from English to Xhosa and English to Afrikaans.

3.7.1.1. Translation. According to the WHO (2017), the aim of translating instruments is to ensure that instruments are equally natural and acceptable and practically perform in the same way. The aim of the translation procedure was to reorganise the meaning in the target language rather

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than to literally translate the words of the source version. It was agreed that the content of the source version was effectively reflected (Hilton & Skrutkowski, 2002; WHO, 2017).

Speech-language therapists, (working for more than 5 years) and a Xhosa lecturer from the Sitheth Impilo Initiative conducted the procedure for the translation of the comprehension screener including the instructions. The Sitheth Impilo Initiative provides Xhosa lessons specifically to the speech therapy undergraduate students. The course content provided by the Sitheth Impilo Initiative includes input related specifically to the management of clients with acquired communication disorder. The Afrikaans translators as well as the Xhosa back translator were first-language speakers, of the language they were requested to translate. The procedure for the translation of the comprehension screener, as shown in Figure 3.2, was as follows: (1) forward translation of the instrument by speech-language therapists and lecturer from Sitheth Impilo Initiative; (2) back translation of the instrument by speech-language therapists; and (3) review and amendment of the instrument by the translator and researcher through discussion until consensus was reached. After the translation of the comprehension screener, the comprehension screener was peer reviewed.

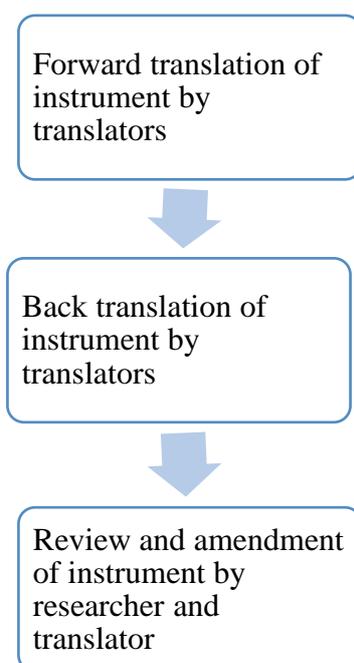


Figure 3.2: Translation of comprehension screener

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3.7.1.2. Peer review. As the comprehension screener had not been developed for the South African population, the researcher included the process of having the comprehension screener peer reviewed by speech-language therapists, as recommended by Steyl and Philips (2013). Although the comprehension screener generally formed part of the operating procedures of the institution, it was deemed beneficial to review the screener for the purpose of this research.

The procedure for the peer review of the comprehension screener, as shown in Figure 3.3, was as follows: (1) The original comprehension screener was given to four speech-language therapists (first-language English, Xhosa and Afrikaans speech-language therapists) who had clinical experience with this clinical population. (2) The speech-language therapists were requested to determine whether the items were linguistically appropriate and to recommend changes for the South African population (all three languages were reviewed). (3) One semantic change was recommended and adjusted in the comprehension screener for the South African population. The item ‘Does it snow in July’ was changed to ‘Is it cold in January’ as it does not snow in Cape Town, South Africa. This change was communicated to both institutions involved in the study.

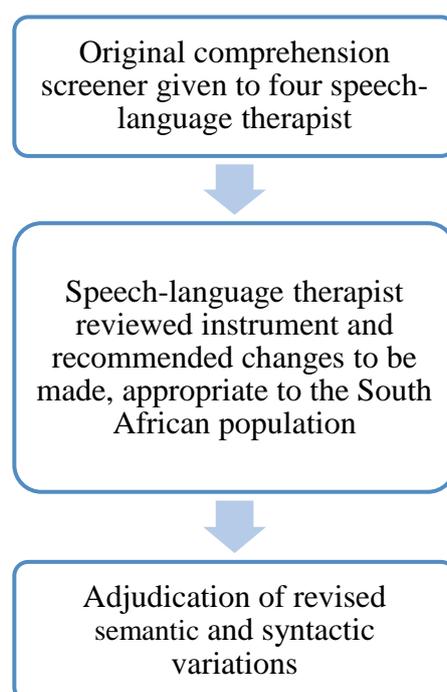


Figure 3.3: Peer review of comprehension screener

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3.7.2 Consent

Those who met the study inclusion criteria were asked to consent to participate in the study. The research purpose, procedure and expectations of the study were explained to each potential participant. The consent form (Addendum 2) was read with the CVA survivors and information expanded on, where necessary, to ensure awareness of the study goal, their role and their rights as a study participant. Closed-ended questions were asked to ensure that participants understood and felt comfortable to proceed.

3.7.3. Aphasia Needs Assessment instrument

3.7.3.1. Instrument. The ANA (Addendum 4) is a non- standardised instrument created to establish the communication needs of CVA survivors. It was originally designed as part of an AAC needs assessment. It is deemed an appropriate instrument to assess the communication needs of CVA survivors as it provides a format for requesting information regarding an individual's current communication needs, context, priorities and abilities. Beukelman et al. (2007) state that a comprehensive communication needs assessment compares the person's communicative participation in all spheres of life.

The ANA may be used with persons who present with severe expressive language impairments as it only requires yes/no responses that can be indicated by verbal output or use of gesturing. The ANA consists of 10 questions: 6 multiple-response questions and 4 Likert scales. The multiple-response questions allowed participants to select all the items that applied to them. The Likert scales allowed the researcher to obtain insight into participants' perception of their own communication abilities (Blanche &Durrheim, 1999).

The ANA allowed the researcher to describe difficult and preferred communication situations and strategies for each individual. The ANA provided insight into five key areas that complemented the aims of the study.

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The first aim focused on recognition of the most difficult communication situations for CVA survivors. A question explored options such as talking on the phone, talking to people, requesting public transport or making money-related inquiries. Communicating with their medical practitioner or other healthcare providers is often difficult for CVA survivors with communication impairment. Communicating directions, understanding others or communicating at a restaurant may not be possible for some CVA survivors (Henson, 2016). Identification of difficult situations therefore warranted the identification of difficult communication skills and the participants' perception of their own communication level.

One question was dedicated to exploring perceived communicative ability by the participant by using a Likert scale. The most difficult communication skills of CVA survivors were determined by using a multiple-response question. The communication skills explored focused on abilities such as asking questions, sharing in conversations, introducing oneself or spelling words. Difficult communication skills needed to be viewed in light of participants' own perception of their communicative ability, and therefore preferred communication strategies needed to be determined.

The question focusing on preferred communication strategies aided in the identification of behaviours that would improve CVA survivors' communication. Communication strategies might also include skills of communication partners to enhance communication. The strategies in question were learning not to interrupt, reaffirming communication messages, categorisation, reduced speech rate and simplification of the message. Using preferred strategies would therefore encourage participants to participate in preferred conversational topics.

Insight into the preferred conversational topics of CVA survivors, which was determined by one multiple-response question, is important as it forms part of human nature and can be seen as a reflection of the individuality of a person. Persons gain and share information based on what is important to them. Feeling frustrated and isolated is common for CVA survivors who are unable to partake in these exchanges (Johansson, 2012). The preferred topics focused on were participants'

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family, growing up, vocation, interests, events and health. Preferred conversation topics would be influenced by perceived reading and writing skills and material.

Four questions, two Likert scale and two multiple-response questions, provided insight into perceived reading and writing ability and preferred literacy activities. This was important as communication impairments associated with literacy interferes with daily living (Sinanović et al., 2011). The reading of stories (such as novels or short stories), magazines and newspapers is often an enjoyable pastime for individuals. Corresponding through writing letters and typing text messages is also an important means of communication for many, and the inability to comprehend as well as respond may add to CVA survivors' feelings of isolation and loneliness (Northcott & Hilari, 2011).

3.7.3.2. Translation of the Aphasia Needs Assessment. South Africa is known for its multicultural and linguistically rich population (Steyl & Philips, 2013). The ANA was translated from English to Xhosa and English to Afrikaans as in the Western Cape; Afrikaans is spoken by the majority of persons, followed by the Xhosa-speaking population (Brand South Africa, 2015; Steyl & Philips, 2013).

Speech-language therapists, (working for more than 5 years), an audiologist and a Xhosa lecturer from the Sitheth Impilo Initiative conducted the procedure for the translation of the ANA, including the instructions. The Sitheth Impilo Initiative provides Xhosa lessons specifically to the speech therapy undergraduate students. The course content provided by the Sitheth Impilo Initiative includes input related specifically to the management of clients with acquired communication disorder. The Afrikaans and Xhosa translators were: first-language speakers, of the language they were requested to translate. The procedure occurred as follows: (1) forward translation of the instrument by speech-language therapists and a lecturer from the Sitheth Impilo Initiative. (2) Back translation of the instrument was completed by speech-language therapists and an audiologist. (3) After the translation had been completed, the translator and researcher reviewed and identified

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problematic words or phrases that did not capture the concepts addressed by the original terms (WHO, 2017).

Two words were identified and reviewed within the Afrikaans translated instrument. In the Xhosa translated instrument, eight word choices were identified, discussed and reviewed.

The translator deemed the word choice not appropriate to the Western Cape Xhosa dialect. The researcher and translator discussed and agreed upon the recommended word choices. It was agreed that the content of the source version was effectively reflected in the translation.

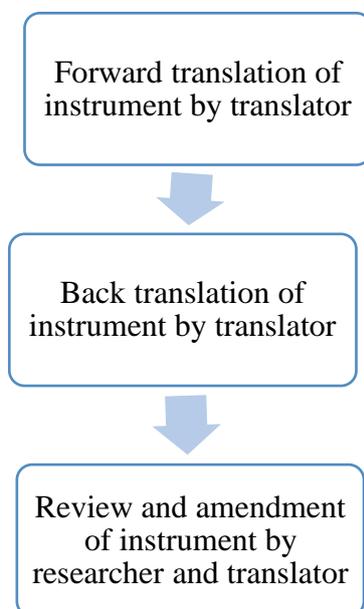


Figure 3.4: Translation of ANA

3.7.3.3. Peer review. As the ANA had not been developed for the South African population, a peer review by speech-language therapists was deemed necessary to evaluate whether semantic as well as syntactic changes were necessary. English, Afrikaans and Xhosa therapists were consulted.

The procedure for the peer review of the research instruments, as seen in Figure 3.5, was as follows:

(1) The original ANA was given to four speech-language therapists (first-language English, Xhosa

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and Afrikaans speech-language therapists) who had clinical experience with this clinical population.

(2) The speech-language therapists were requested to determine whether the items were linguistically appropriate for the South African population and to recommend changes where necessary (all three languages were reviewed). (3) Adjudication of the revised semantic variations took place, and it was agreed that the recommendations were linguistically appropriate for the South African population.



Figure 3.5: Peer review of ANA

Table 3.1 (next page) indicates the recommended pre-pilot ANA semantic and syntactic changes, including removal of items.

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Table 3.1: Recommended pre-pilot ANA semantic and syntactic changes

Pre-pilot study modifications	
Semantic changes	
Original term	Changed to
Conversations	Talking
Communicating specific physical needs	Communicating physical needs
Personal short and long letters	Letters
Community transactions	Money-related inquiries
Hobbies and unique interests	Hobbies and interests
Family history/ancestry/genealogy	Family history
Local events and current events	Local and current events
Talking about present-day and talking about past events	Talking about present-day and past events
Worst job	Work
Fiction – short books and nonfiction long books	Books
Removal of items	Reason
Being in the military	In the Western Cape, CVA participants in the military would not access healthcare at TBH or WCRC
Finding information I know is in my communication system	The majority of CVA participants did not have access to high-tech AAC systems

3.8. Pilot study

Leon, Davis and Kraemer (2011) emphasise the importance of a pilot study as it provides an opportunity to develop consistent practices to enhance data integrity as well as the protection of participants. To test the feasibility, equipment and methods, the researcher used the pilot study to refine source documentation, informed consent procedures and data collection tools (Calitz, 2009; Leon et al., 2011).

The pilot study consisted of 12 participants. The traumatic brain injury (TBI) population was selected due to the limited sample of young CVA survivors, moreover communication difficulties post TBI are common. Some may experience aphasia, AOS, dysarthria or cognitive-linguistic

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difficulties, similar to CVA survivors (National Institute of Neurological Disorders and Stroke, n.d.). All the participants included in the pilot study were receiving speech-language therapy following a TBI. Thabane et al. (2010) highlight the importance for the pilot study population sample to be representative of the target study population. It was therefore deemed important for the pilot sample to be representative of the linguistic variations present in the Western Cape. Participants therefore included English, Afrikaans and Xhosa first-language speakers. The participants also represented the two age groups required for the main research study. As depicted in Figure 3.6, the participants were divided into two age groups, consisting of six participants each – Group 1: 18-45 years of age and Group 2: 46 years and older.

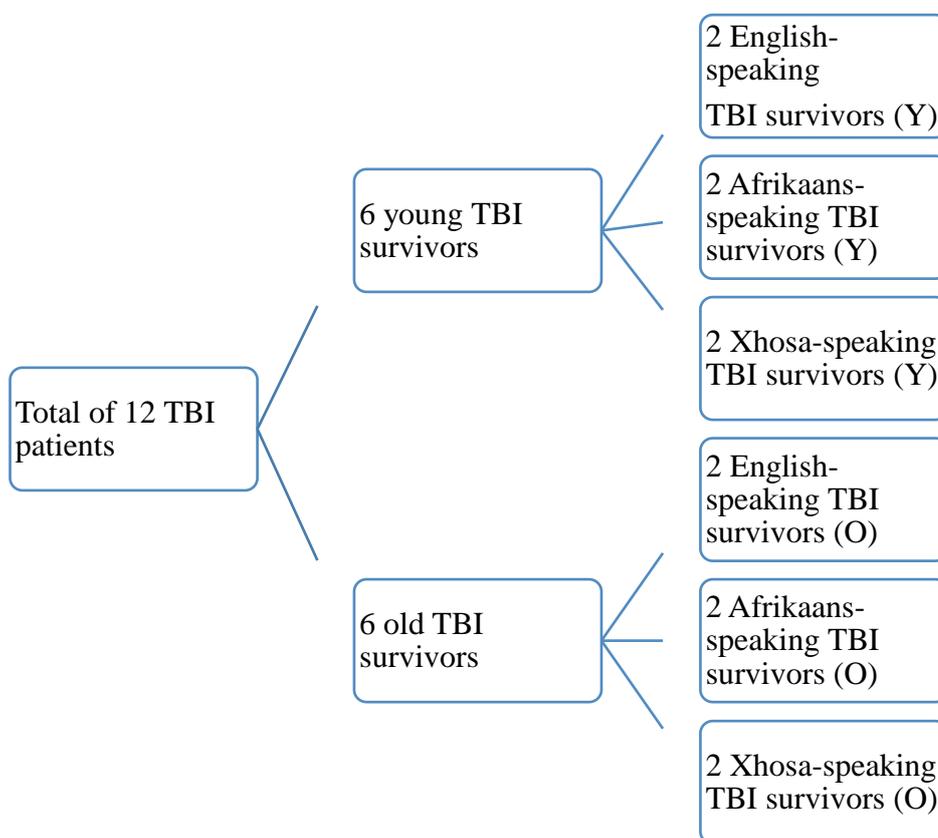


Figure 3.6: Pilot study TBI survivors' age groups and linguistic variations

For the purpose of this study a pilot study was seen as beneficial for the following reasons:

Firstly, the pilot study identified errors in the research instrument. An error noted during the pilot study was that the question numbers in the English, Xhosa and Afrikaans instruments were not

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identical. The researcher had to rectify the oversight on each hard copy of the research instrument during the pilot study. Prior to the main study, the question numbers were uniform.

Secondly, the pilot study identified practical limitations in the execution of the research instruments (Calitz, 2009). A few patients felt that more privacy was required, and the availability of private separate spaces needed to be explored, as recommended by Calitz (2009). This was implemented during the main study.

Thirdly, as there is limited data available regarding the communication needs of young and old CVA survivors in the South African setting, the findings of the pilot study were used as a guide to determining an appropriate sample size required for this study (Thabane et al., 2010). This will be discussed further in the sample size calculation subsection.

Lastly, the pilot study afforded the participants an opportunity to provide input in terms of whether the instrument was inappropriate or too complicated (Calitz, 2009). The researcher asked the participants for feedback to identify ambiguities and questions that were vague. The participants indicated that most of the questions were understandable, but some required examples such as for money-related inquiries. The participants also suggested inclusion of specific items such as religious material, which was added. The feedback received led to further semantic and syntactic revision of and additions to the ANA.

Table 3.2 (next page) indicates the recommended post-pilot ANA semantic and syntactic changes, including addition of items.

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Table 3.2: Revisions made to ANA after pilot study

Revisions made after pilot study	
Semantic revisions	
Original	Modified to
Poorly	Badly
Talking to family and talking to friends	Talking to people
Funny stories about your children	Stories about your children
Present-day or past events	Events
Politics/the economy/the government	The government and politics
Answering familiar, predictable questions and answering questions that require a specific answer	Answering questions
My house/home town/things to fix	My house, things to fix or things to do
Expressing commands	Communicating commands
To guess more efficiently by narrowing down the category of the target message	To improve guessing by breaking down the category or group the specific message falls in
Additions	
Call or requesting public transport	
SMS (writing and reading)	
Bible (reading of)	
Stories (reading of stories such as novels or short stories)	

3.9. Validity and Reliability of Aphasia Needs Assessment

Ensuring validity of the ANA was an important consideration prior to selection of the instrument as the researcher needed to ensure that the items truly measured the communication needs of CVA survivors.

Although the ANA is an informal, non-standardized assessment tool, Beukelman et al. (2007) reported that the instrument asked questions focused on people such as CVA survivors with communication impairments in terms of their communicative ability and desires in daily situations.

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The instrument was therefore designed to aid speech-language therapists in measuring and meeting the communication needs of CVA survivors.

The face validity of the ANA was confirmed by the four speech-language therapists (two English, Afrikaans and Xhosa first language speakers who reviewed the instrument). They judged it to be an appropriate instrument to measure the communication needs of young and old CVA survivors. As face validity is a superficial form of confirmation regarding the appropriateness of the research instrument, content validity was sought.

Content validity was obtained by ensuring that the ANA was a thorough and comprehensive instrument to use in accomplishing the aims of this study. Four speech-language therapists were consulted regarding the review of items and asked to comment on whether the items were representative of the research aims, as recommended by Foxcroft, Paterson, Le Roux and Herbst (2004). All deemed the instrument to present with content validity. Beukelman and Mirenda (2013) noted that the instrument was revised in 2006, which would have involved scrutiny, amendment and improvement of the instrument, which would also have improved the content validity of the instrument.

For a research instrument to be considered reliable, the manner in which data is collected and in which the research instrument is used must be consistent from participant to participant, across settings and at different times (Blanche & Durrheim, 1999). To ensure reliability throughout the study, the following procedure was followed by the researcher and research assistant:

1. Strict adherence to the inclusion and exclusion criteria.
2. To design and implement an administration procedure, to ensure consistency and uniformity during the administration of the research instrument.
3. Audio recording of the administration of the ANA. This allowed for random reviewing of the recording and comparing of the original marked ANA to the audio recording to ensure reliability. Three random recordings were selected and reviewed; no errors were observed.

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A research assistant was used to aid data collection. Although error cannot be completely excluded, the researcher sought to reduce it through the implementation of administration procedures and the implementation of data confirmation and correction procedures (Leon et al., 2011). Reliability was ensured by the following:

1. The research assistant was a qualified speech-language therapist who had clinical experience with this clinical population
2. The data collection tool, methods, and procedural guidelines were explained and demonstrated to the research assistant.
3. Comprehensive feedback was given by the assistant and researcher after data collection.

3.10. Sample calculations

3.10.1. Sample size

Limited research has been conducted regarding the communication needs of young and old CVA survivors in the South African population, and therefore limited information was available to determine an appropriate sample size for a larger study. The pilot study included young ($n = 6$) and old ($n = 6$) TBI survivors. Estimates for different communication needs from the pilot data were used to determine the precision of a larger study that was based on a fixed sample size of young and old adults.

A biostatistician was consulted to assist in the statistical analysis of the pilot study. The following results were obtained:

Thirty-three percent of the young TBI survivors in the pilot study indicated good health and indicated that the following communication situations posed significant difficulty when communicating: talking on a phone and placing orders in restaurants.

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Thirty-three percent of old TBI survivors indicated good health and indicated that the following communication situations posed significant difficulty when communicating: talking on a phone, talking to strangers, making money-related inquiries, such as those concerning disability grants, Unemployment Insurance Fund (UIF) payments or pension, and giving directions.

Fifty percent of the young TBI survivors in the pilot study indicated 'okay' or 'so-so' communication skills and indicated that the following communication situations posed significant difficulty when communicating: talking to family and friends, talking to strangers, talking about personal issues and making money-related inquiries such as those concerning disability grants, UIF payments or pension. With regard to preferred topics of conversation, 50% of young TBI survivors indicated current or previous jobs and sports as preferred topics.

Fifty percent of the old TBI survivors in the pilot study indicated 'okay' or 'so-so' communication satisfaction and indicated that the following communication situations posed significant difficulty when communicating: talking about personal issues, talking about community business, making money-related inquiries, such as those concerning disability grants, UIF payments or pension, and conversing in a medical setting or with medical professionals.

From the calculations made from the pilot study as well as the availability of participants, the sample of 20 young CVA participants and 50 old CVA participants was initially deemed appropriate for this study. For a fixed sample size of 20 young and 50 old participants, at 95% level of confidence, the precision would be 10.5% for young CVA survivors and 6.6% for old CVA survivors, respectively. This was based on roughly 33% of participants presenting with difficulty communicating in different situations.

Furthermore, at 95% level of confidence, the precision would be 11.1% for young CVA survivors and 7% for old CVA survivors. This was based on roughly 50% of participants presenting with difficulty communicating in different situations.

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As discussed above, statistical analysis through comparison was initially preferred for this study. However, after consideration, a descriptive study design was deemed most appropriate; although young CVA survivors are becoming more prevalent, it is still considered an emerging population (Smajlović, 2015). Furthermore, the nature of this study did not allow for reliable statistical analysis through comparison, and therefore it was not imperative for the sample size criterion to be met due to the descriptive nature of this study.

3.11. Data management plan

Data management commenced with the careful processing of personal data collected from each participant. A coding system was applied; each participant was coded as a number. The groups were coded as follows: Y for young CVA survivors and O for old CVA survivors. This was documented directly on the data collection instrument and then transferred to the Microsoft Excel 2010 spreadsheet.

The instrument allowed for the collection of multiple-response data as one question could yield more than one answer. Numbers were used to represent response categories for the questions asked. Zero/0 (no) and one/1 (yes) were used to code responses to questions. Microsoft Excel 2010 was used for the transfer of data to a computer-based data management system, as it provided the standard spreadsheet functionality, which was useful for analysis of the data.

3.12. Data analysis

A frequency distribution table that consisted of the tallied frequencies of each response was created, and the data values were arranged in ascending order of magnitude, as recommended by Andale (2016). Percentages were included in the frequency distribution table to aid in understanding the meaning of the frequency value. Korb (2013) states that frequency statistics should be applied whenever the data is discrete, an example being participants needing to select options from separate categories such as those found in the ANA.

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3.13. Ethical considerations

The protection of participants in any research study is imperative (Orb, Eisenhouer, & Wynaden, 2000). For the purpose of this research, the ethical principles of autonomy, confidentiality and justice were upheld.

Firstly, the autonomy of each potential participant was respected. This upheld the principle that each potential participant had the right to be properly informed regarding the study, the right to choose whether to participate in the study and the right to withdraw without any negative consequences (Orb et al., 2000). Furthermore, no participants were pressured or forced to participate and therefore all participation was voluntary. The researcher respected a participant's decision not to participate or to withdraw from the study at any time (Polonsky & Waller, 2011).

Secondly, the researcher ensured that the participants' confidentiality was protected. This was achieved through a coding system that prevented personal identification. The research assistant gave all hard copies to the researcher. All data was stored in a locked office to which only the researcher had access. The auditory recording was emailed to the researcher and stored on the researcher's password-protected computer.

Lastly, the ethical principal of justice refers to equal share and fairness to all participants; the researcher avoided exploitation and abuse of participants and always had their best interests at heart (Polonsky & Waller, 2011).

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CHAPTER 4**RESULTS**

The research aimed to describe the communication needs of young and old CVA survivors by using a quantitative cross-sectional research design. A survey was used to gather information regarding the communication needs of participants using the five communication areas utilised in the ANA. Participants' communication needs within the five communication areas were considered to be personal, social or environmental in nature. Personal communication needs relate to communication activities relating to oneself and concern the person, for example making money-related inquiries or discussing personal issues. Social communication needs relate to communication activities that include a familiar communication partner, for example talking on the phone, sharing stories and applying different communication strategies. Environmental communication needs pertain to communication activities outside the home or familiar environment or with unfamiliar communication partners, for example talking about the government, politics or weather.

The communication needs of young and old participants were described in terms of the following communication areas:

1. Difficult communication situations
2. Difficult communication skills
3. Preferred communication strategies
4. Preferred topics of conversation
5. Preferred literacy skills

Frequency statistics were applied to describe the multiple-response questions and Likert scales and were displayed using frequency tables.

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4.1. General information

The data for this study was collected over an eight-month period at TBH and a six-week period at the WCRC. A total of 94 CVA survivors received speech-language assessments during the study period; 72 CVA survivors were assessed at TBH, and 22 CVA survivors were assessed at WCRC. The 32 CVA survivors who were not included either refused to participate or did not meet the inclusion criteria. CVA survivors not included in the study continued with speech-language therapy at the respective institutions (i.e. TBH or WCRC). A total of 62 participants were included in this research study, namely 22 young and 40 old participants. TBH accounted for 12 of the young participants and 30 of the old participants. The WCRC accounted for 10 of the young participants and 10 of the old participants.

4.2. Biographical information

The biographical information obtained from each participant's medical folder included age, gender and medical diagnosis. The youngest participant of the young group was 24 years of age and the oldest was 45 years of age. The average age of the young participants was 36 years. The young participants consisted of 14 men and 8 women. The youngest participant of the old group was 46 years of age and the oldest was 79 years of age. The average age of the old participants was 58 years. The average age for old participants is still considered economically active in South Africa. Furthermore, 25 of the 40 old participants were men and 15 were women.

All participants were receiving speech-language therapy for communication impairment at the time of the study. Of the 22 young participants, 54% (12) presented with dysarthria, 36% (8) with aphasia, 5% (1) with AOS and 5% (1) with a cognitive-linguistic impairment. Of the 40 old participants, 55% (22) presented with dysarthria, 32% (13) with aphasia and 13% (5) with AOS. Dysarthria was the predominant communication impairment for both groups; this finding corresponds with the general prevalence of dysarthria, which occurs in between one-third and half of CVA survivors (Miller & Bloch, 2017). Aphasia was prevalent in 36% of young participants and

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in 32% of old participants. Participants needed to present with auditory comprehension at a sentence level. A score of no less than 16/20 or 80% for the comprehension screener was required.

4.3. Difficult communication situations

The first aim of the study was to determine the communication needs of participants by identifying difficult communication situations, one of the communication areas included in the ANA. As seen in Table 4.1, the most prevalent difficult communication situation selected by 59% of young participants was talking on the phone, which can be viewed as social in nature. This was followed by 55% of young participants indicating talking about personal issues as a difficult situation. Money-related enquiries such as those pertaining to disability grants or UIF payments were also selected by 55% of young participants. Both situations (i.e. personal issues and money related inquiries) are personal in nature.

Similarly to the young participants, talking on the phone was the most prevalent difficult situation selected by 60% of old participants, followed by speaking to people, which was selected by 55% of old participants; both can be viewed as social in nature. Furthermore, 50% of old participants also indicated calling or requesting public transport as a difficult situation, which can be seen as environmental in nature.

The least selected difficult communication situation for both young and old participants (i.e. 23% for both groups) was communicating with their doctor or in medical settings, which can be viewed as environmental in nature.

Communicating within a work environment was selected by 45% of young participants and 25% of old participants, which is environmental in nature. Furthermore, in both groups, about a third selected understanding others, which is social in nature.

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Table 4.1: Young participants' most difficult communication situations

Difficult communication situations	Frequency	Percentage
1. Talking on the phone	13	59%
2. Talking about personal issues	12	55%
3. Making money-related inquiries	12	55%
4. Talking to people	11	50%
5. Giving directions	11	50%
6. Communicating at work	10	45%
7. Placing orders in restaurants	9	41%
8. Calling or requesting public transport	8	36%
9. Understanding others	8	36%
10. Communicating with doctors or in medical settings	5	23%

Table 4.2: Old participants' most difficult communication situations

Difficult communication situations	Frequency	Percentage
1. Talking on the phone	24	60%
2. Talking to people	22	55%
3. Calling or requesting public transport	20	50%
4. Talking about personal issues	17	43%
5. Making money-related inquiries	14	35%
6. Giving directions	14	35%
7. Understanding others	13	33%
8. Placing orders in restaurants	13	33%
9. Communicating at work	10	25%
10. Communicating with doctors or in medical settings	9	23%

4.4. Difficult communication skills

The identification of difficult communication skills as a communication area helped to determine the communication needs of young and old participants and related to the second aim of the study. The questionnaire explored participants' perceived communication level (i.e. participants were required to rate themselves using the Likert scale.) in combination with the identification of difficult communication skills.

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4.4.1. Perceived level of communication

Young and old participants were requested to indicate their perception of how well they were currently communicating, using a five-point Likert scale. As seen in Tables 4.3 and 4.4, the majority of both the young and old participants (i.e. 95% and 90%, respectively) rated themselves as a 3 or higher, indicating adequate to very good communication post CVA. Ten percent of young and 5% of old participants perceived their communication as being poor (score of 2 and below). All the participants were receiving speech-language therapy at the time of the study, and yet some participants rated their communication as being very good (i.e. a rating of 5 on the Likert scale). Thirty-six percent of young participants and 27% of old participants indicated very good communication. Participants who rated their communication as being very good felt that they presented with no communication difficulties, perceiving themselves as being able to participate in all communication-related interactions as prior to their CVA. Although some participants perceived themselves as very good communicators, 59% of young and 63% of old participants still indicated that they presented with communication difficulties and therefore still required speech-language therapy.

Table 4.3: Communication satisfaction of young participants

How well are you communicating?	Frequency	Percentage
1 Badly	1	5%
2	0	0 %
3 So-so/okay	8	36%
4	5	23%
5 Very well	8	36%

Table 4.4: Communication satisfaction of old participants

How well are you communicating?	Frequency	Percentage
1 Badly	2	5%
2	2	5%
3 So-so/okay	9	23%
4	16	40%
5 Very well	11	27%

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4.4.2. Communication skills

As seen in Table 4.5, the most difficult communication skills selected by 73% of young participants were being involved in conversations and explaining their communication impairment post CVA. Sixty-four percent indicated communicating and following commands as a difficult communication skill. All of the aforementioned difficult communication skills are social in nature. The least selected difficult communication skill was changing from talking to listening, which was selected by 41% of young participants; this can be viewed as social in nature.

Table 4.6 shows that 68% of old participants selected the spelling of words, which relates to tasks such as filling out forms, writing letters or making lists of items to buy, which are personal in nature. This was followed by 60% selecting sharing stories. Lastly, 58% selected fixing their communication breakdowns as a difficult skill. Both of these skills can be viewed as social in nature. The least selected difficult skill at 33% was maintaining their communication partner's attention, which can be described as social in nature.

The communication skill of participating in conversations was selected by 73% of young participants; however, only half of old participants deemed it to be a difficult skill. Furthermore, keeping their communication partner's attention was selected by half of young participants as a difficult skill but was the least selected difficult skill for old participants.

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Table 4.5: Young participants' most difficult communication skills

Difficult communication skills	Frequency	Percentage
1. Being involved in conversations	16	73%
2. Explaining aphasia and how you communicate	16	73%
3. Communicating commands	14	64%
4. Following commands	14	64%
5. Asking questions	13	59%
6. Answering questions	13	59%
7. Telling a joke	13	59%
8. Communicating how you feel	13	59%
9. Introducing yourself and others	13	59%
10. Talking about things that happened today or in the past	13	59%
11. Introducing new topics	12	55%
12. Telling a story	12	55%
13. Spelling of words	11	50%
14. Keeping your communication partner's attention	11	50%
15. Fixing communication breakdowns or misunderstandings	11	50%
16. Getting someone's attention	10	45%
17. Changing from talking to listening	9	41%

Table 4.6: Old participants' most difficult communication skills

Difficult communication skills	Frequency	Percentage
1. Spelling of words	27	68%
2. Telling a story	24	60%
3. Fixing communication breakdowns or misunderstandings	23	58%
4. Communicating how you feel	23	58%
5. Asking questions	23	58%
6. Telling a joke	22	55%
7. Answering questions	22	55%
8. Being involved in conversations	20	50%
9. Talking about things that happened today or in the past	20	50%
10. Explaining aphasia and how you communicate	19	48%
11. Introducing new topics	19	48%
12. Communicating commands	16	40%
13. Changing from talking to listening	15	38%
14. Following commands	15	38%
15. Getting someone's attention	14	35%
16. Introducing yourself and others	13	33%
17. Keeping your communication partner's attention	13	33%

4.5. Preferred communication strategies

The third aim of this study was to describe the communication needs relating to strategies (verbal and/or nonverbal) that young and old participants preferred their communication partners to use. As seen in Table 4.7, the most preferred communication strategies selected by young participants were

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the following: 77% preferred their communication partners to indicate what they understood when the participants experienced difficulty communicating their intended message, 73% preferred their communication partners to ask whether they could guess or fill in words while 68% preferred their communication partners to identify the semantic category of the intended word. All the aforementioned strategies can be viewed as verbal in nature.

As shown in Table 4.8, the preferred communication strategies of old participants were as follows: 78% preferred their communication partners not to interrupt, 75% preferred that they provided affirmation of what they understood and 73% indicated being asked questions or given more opportunities to communicate as a preferred strategy. All the aforementioned strategies can be viewed as verbal strategies.

The least preferred communication strategy of young and old participants was applying a multimodal communication approach such as gesturing, writing and drawing when communicating, which can be viewed as nonverbal. Interestingly, helping one answer questions by tagging them as ‘yes’ or ‘no’ questions, which is a nonverbal communication strategy, was the second least preferred communication strategy of young and old participants. Overall, young and old participants preferred verbal to nonverbal communication strategies.

Table 4.7: Young participants’ preferred communication strategies

What communication partners need to learn to do	Frequency	Percentage
1. Tell you what they do understand when you have difficulty	17	77%
2. Not to guess or fill in words unless you say it is okay	16	73%
3. Improve guessing by breaking down the category that the specific message falls in	15	68%
4. Not to interrupt	14	64%
5. Ask you questions or give you opportunities to communicate	14	64%
6. Slow down when talking to you	13	59%
7. Give one item of information at a time when talking to you	13	59%
8. Help you answer questions by tagging them ‘yes’ or ‘no’	7	32%
9. Write things down, draw or gesture to help you understand	5	23%

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Table 4.8: Old participants' preferred communication strategies

What communication partners need to learn to do	Frequency	Percentage
1. Not to interrupt	31	78%
2. Tell you what they do understand when you have difficulty communicating	30	75%
3. Ask you questions or give you opportunities to communicate	29	73%
4. Give one item of information at a time when talking to you	28	70%
5. Not to guess or fill in words unless you says it is okay	28	70%
6. Slow down when talking to you	27	68%
7. Improve guessing by breaking down the category that the specific message falls in	23	58%
8. Help you answer questions by tagging them 'yes' or 'no'	19	48%
9. Write things down, draw or gesture to help you understand	16	40%

4.6. Preferred topics of conversation

The identification of young and old participants' preferred topics of conversation also helped to determine their communication needs as this would impact on their conversational interest, which related to the fourth aim of this study.

As seen in Table 4.9, their house, things to fix or do, their CVA and other medical issues were selected by 82% of young participants as their preferred topic of conversation, followed by 77% indicating their interests, family history and favourite meals or restaurants. All of these preferred topics can be viewed as personal in nature. The least selected topic by young participants at 18% related to the government or politics and can be viewed as environmental in nature.

As shown in Table 4.10, talking about the weather was selected by 80% of old participants as their preferred topic of conversation, which can be viewed as environmental in nature (i.e. a communication activity that relates to something outside of their home or familiar environment). This was followed closely by talking about their house and things to fix or do, which was selected by 78% of old participants. Furthermore, 70% of old participants selected family history and sport as preferred topics of conversation, which can viewed as personal in nature. The least selected topic by old participants at 30% related to dating or getting married and can be viewed as personal in nature.

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More than half of young participants selected the topic of dating or getting married, which is personal in nature, as their preferred topic of conversation; however, this was the least selected topic of conversation for old participants. Interestingly half of young participants indicated talking about their previous or current job, which is environmental in nature, as a preferred topic of conversation, whereas 65% of old participants selected it as a preferred topic of conversation. This topic can be viewed as environmental in nature.

Table 4.9: Young participants' preferred topics of conversation

Preferred topic of conversation	Frequency	Percentage
1. Your house, things to fix or to do	18	82%
2. Your stroke and other medical issues	18	82%
3. Interests	17	77%
4. Family history	17	77%
5. Favourite meals or restaurants	17	77%
6. Weather	16	73%
7. Adventures as a young child growing up	16	73%
8. Stories about your children	14	64%
9. Sports	14	64%
10. Events	14	64%
11. Dating and/or getting married	12	55%
12. Current or previous job	11	50%
13. Government or politics	4	18%

Table 4.10: Old participants' preferred topics of conversation

Preferred topic of conversation	Frequency	Percentage
1. Weather	32	80%
2. Your house, things to fix or to do	31	78%
3. Family history	28	70%
4. Sports	28	70%
5. Interests	27	68%
6. Favourite meals or restaurants	26	65%
7. Events	26	65%
8. Current or previous job	26	65%
9. Stories about your children	25	63%
10. Your stroke and other medical issues	25	63%
11. Adventures as a young child growing up	23	58%
12. Government or politics	14	35%
13. Dating and/or getting married	12	30%

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4.7. Preferred literacy skills

The fifth and final aim of the study focused on describing the preferred literacy skills of participants; as literacy forms an important part of everyday activities, this can be seen as a communication need for both young and old CVA survivors. The participants' perceived literacy ability was therefore explored in combination with the identification of preferred reading materials and writing activities.

4.7.1. Perceived level of literacy skills

The participants were requested to indicate their perceived literacy ability using a Likert scale. As shown in Tables 4.11 to 4.14, the majority of young and old participants scored themselves as 3 or higher, indicating adequate to very good literacy ability post CVA.

Table 4.11: Young participants' perception of their reading abilities

How well do you read?	Frequency	Percentage
1 Badly	2	9%
2	3	13%
3 So-so/okay	9	41%
4	5	23%
5 Very well	3	13%

Table 4.12: Old participants' perception of their reading abilities

How well do you read?	Frequency	Percentage
1 Badly	5	12%
2	3	8%
3 So-so/okay	9	23%
4	11	28%
5 Very well	12	30%

Table 4.13: Young participants' perception of their writing abilities

How well do you write?	Frequency	Percentage
1 Badly	3	14%
2	3	14%
3 So-so/okay	7	32%
4	5	22%
5 Very well	4	18%

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Table 4.14: Old participants' perception of their writing abilities

How well do you write?	Frequency	Percentage
1 Badly	5	12%
2	6	15%
3 So-so/okay	12	30%
4	9	23%
5 Very well	8	20%

4.7.2. Preferred reading materials and writing activities

As shown in Tables 4.15 and 4.17, all young participants indicated instant messaging or text messages as their most preferred reading material. Eighty-six percent indicated writing instant or text messages as their preferred writing activity. Other preferred literacy activities that were identified included reading of religious books and writing of cards and lists (i.e. shopping lists). The least preferred literacy-related skill was email (i.e. reading: 59% and writing: 45%).

As shown in Tables 4.16 and 4.18, 85% of old participants indicated religious books as their preferred reading material. Eighty-three percent of old participants' preferred writing activity was making lists of things to buy or appointments to remember. The least preferred literacy-related skill was email (reading: 35% and writing: 30%).

Young participants' preferred literacy activities emphasised the importance of technology in meeting their social needs. Interestingly, SMSs and instant messages were some of the least preferred reading materials of old participants. Old participants' preferred literacy activities reflected their personal needs.

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Table 4.15: Young participants' preferred reading materials

Which items would you like to read?	Frequency	Percentage
1. SMSs/instant messages	22	100%
2. Bible or Koran	21	95%
3. Magazines	18	82%
4. Newspapers	16	73%
5. Letters	13	59%
6. Stories (such as novels and short stories)	14	64%
7. Emails	13	59%

Table 4.16: Old participants' preferred reading materials

Which items would you like to read?	Frequency	Percentage
1. Bible or Koran	34	85%
2. Newspapers	26	65%
3. Stories (such as novels and short stories)	25	63%
4. Magazines	25	63%
5. Letters	22	55%
6. SMSs/instant messages	21	53%
7. Emails	14	35%

Table 4.17: Young participants' preferred writing activities

What would you like to write?	Frequency	Percentage
1. SMSs/instant messages	19	86%
2. Cards	16	73%
3. Lists of things to buy or appointments to remember	14	64%
4. Letters	14	64%
5. Stories	13	59%
6. Emails	10	45%

Table 4.18: Old participants' preferred writing activities

What would you like to write?	Frequency	Percentage
1. Lists of things to buy or appointments to remember	33	83%
2. Cards	24	60%
3. SMSs/instant messages	20	50%
4. Letters	16	40%
5. Stories	14	35%
6. Emails	12	30%

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4.8. Conclusion

The study aimed to describe the communication needs of young and old participants within the five communication areas identified, which directly linked with the five aims of this study. The identified communication needs relating to preference or difficulty within a specific communication area will guide the therapist to facilitate participation. In general and most importantly, the results from the study shed light on communication needs within the South African context. Most participants perceived themselves to present with good communication ability; however, participants still identified specific communication needs within the five communication areas. From the results, it can be deduced that personal and social communication needs are a priority compared to communication needs that are environmental in nature.

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CHAPTER 5**DISCUSSION****5.1. Introduction**

The study aimed to describe the communication needs of young and old CVA survivors by exploring the five communication areas (i.e. difficult communication situations, difficult communication skills, preferred communication strategies, preferred conversational topics and preferred literacy skills) included in the ANA. Guided by the principles of the LPAA and the Participation Model for Augmentative and Alternative Communication, participants' communication needs were viewed as personal, social and environmental in nature. Communication impairments following a CVA are known to reduce social participation, and increasing participation is therefore one of the most important goals of speech-language therapists (Beukelman, Garrett, & Yorkston, 2007) but is only achievable when based on the specific communication needs of the CVA survivor. This research aimed to describe the communication needs as reported by the participants themselves as treatment planning is often based on caregiver reporting rather than on self-reporting of CVA survivors' communication needs (Henson, 2016). Gaining information regarding the participants' communication difficulties and preferences was seen as an important step towards understanding and thereafter addressing the nature of their communication needs, which is important to increase their participation. This study suggests that improved participation can be achieved when the personal, social and environmental nature of CVA survivors' communication needs are specifically considered as goals of intervention.

5.2. The nature of communication needs (personal, social or environmental)

The communication needs of participants were viewed according to their personal, social or environmental nature. This is recommended by the LPAA, which entails constantly assessing, weighing and prioritising which personal, social and environmental communication needs should be

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targets of intervention to improve social participation in life situations (Chapey et al., 2000). As proposed in the Participation Model for Augmentative and Alternative Communication and the LPAA, intervention begins with identifying the past and present communication patterns and activities of the CVA survivor, which are viewed as personal in nature as they relate to the CVA survivor (i.e. oneself) (Beukelman et al., 2007). Similarly, the findings of this study support the recommendation for speech-language therapists to always first ensure that the personal communication needs (i.e. talking about personal issues or making money-related inquiries) of CVA survivors are identified and included as goals for intervention (Teasell et al., 2000). Young CVA survivors have unique needs as they often make a more complete neurological and functional recovery than old CVA survivors (Teasell et al., 2000); however, impairments may still be present. This often results in young CVA survivors presenting with unmet personal needs (Low et al., 2003), which was reflected in this study as young participants' communication needs were mostly personal in nature.

As recommended by the Participation Model for Augmentative and Alternative Communication, once the personal communication needs are identified, the social communication needs, which relate to communication activities that include a familiar communication partner (i.e. talking on the phone, sharing stories and preferred communication strategies), and the environmental communication needs, which occur outside the home environment with unfamiliar communication partners (i.e. calling or requesting public transport), are identified. The Participation Model for Augmentative and Alternative Communication aims to facilitate the overarching purpose of all communication intervention, which is to maximise an individual's ability to communicate and actively participate in events occurring at home and in her/his community (ASHA, 2004).

In order to improve communication and thus increase participation, the personal, social and environmental factors that either support or impede participation need to be explored and addressed (Green et al., 2015). This is important as addressing CVA survivors' communication needs must be

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based on individual difficulties and preferences since what could be deemed a facilitator to one CVA survivor may be a barrier to another. Participation is not only negatively affected by the CVA survivor's communication impairment (i.e. a communication skill that can be viewed as personal in nature) but is often also negatively influenced by personal, social and environmental factors. These may refer to opportunity barriers, namely policies, practices, facilitator skills and knowledge as well as attitudes that may obstruct the achievement of the intervention goals (Beukelman et al., 2007), or access barriers, namely capabilities, attitudes and resource limitations of CVA survivors' societies or support systems (Beukelman & Mirenda, 2013). Additionally, the personal, social and environmental factors may also refer to positive facilitators of participation, an example of which could be the communication strategies that CVA survivors prefer their communication partners to employ. It is for this reason that speech-language therapists cannot provide intervention to improve CVA survivors' participation without adequate information regarding their personal, social and environmental communication needs.

In this study, participants preferred verbal (i.e. reaffirming the communicated message) rather than nonverbal (i.e. a multimodal communication approach or tagging of questions as 'yes' or 'no') communication strategies. Nonverbal communication strategies practised by communication partners may therefore be an opportunity barrier for participants; however, an aphasic CVA survivor may deem nonverbal communication strategies as a facilitator for improved communication and therefore participation. If not guided according to the CVA survivors' preferences, communication partners could possibly pose an opportunity barrier (Brown et al., 2006). In order to improve communication and thus increase participation, the personal, social and environmental factors that either support or impede participation need to be addressed according to each CVA survivor's unique difficulties and preferences (i.e. preference for specific verbal communication strategies rather than nonverbal strategies) (Green et al., 2015). The LPAA and the Participation Model for Augmentative and Alternative Communication allow for consideration of these needs as the main aim is to ensure that CVA survivors with communication impairments are

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supported communicatively to ensure participation (Beukelman et al., 2007). This resonates with the principles of the ICF framework, which aim to ensure participation for CVA survivors with communication impairments at all stages of their recovery (Balandin, 2011).

5.3. Perception of communication abilities

The majority of participants perceived themselves to present with good communication abilities, and therefore it could be assumed that they were able to communicate their needs. Sentence-level communication may allow participants to cope with everyday living activities. Therefore, speech-language therapists may regularly focus on bringing CVA survivors to a sentence-level communication; however, participants' greatest difficulties appeared to be at a discourse level (i.e. social in nature). As stated in the inclusion criteria, all participants presented with comprehension at a sentence level; however, roughly 30% of participants still indicated understanding others as a difficult communication situation and more than 70% of young and 50% of old participants indicated being involved in conversations as a difficult communication skill. The aforementioned difficulties suggest that these participants may have experienced difficulty communicating effectively at discourse level. This involves goal-directed and complex tasks, which entail retrieving information from memory, deciding which elements to include or exclude, remembering what has already been said, planning upcoming utterances and accounting for what the listener may or may not know, all while maintaining topic over time (Rogalski et al., 2010). This finding suggests that although participants deemed themselves to be good communicators, higher language function (i.e. discourse level) might have been affected but this might have been undetected by participants. This finding may be due to participants' being involved in fewer conversational opportunities and therefore not being fully aware of their difficulties. Another consideration is that speech-language therapists within South African public health institutions may focus rehabilitation on functional language rather than on higher language functions. This is an important consideration (i.e. speech-

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language rehabilitation goals) for speech-language therapists as rehabilitation goals may not be in agreement with the CVA survivors' needs of conversing at a discourse level.

It was anticipated that participants in this study would present with difficult communication skills as all participants were still receiving speech-language therapy, and therefore specific therapeutic communication goals were identified and being managed. The difficult communication skills identified by participants (i.e. participating in conversations or spelling of words) would directly influence situations and therefore result in difficult (interactive) communication situations. Difficult communication situations could be eased by communication partners' assisting CVA survivors with preferred communication strategies (i.e. facilitating). Therefore, speech-language therapists are recommended to begin therapy focused on the skills that the CVA survivors identify as being difficult.

5.4. Difficult communication skills versus preferred communication strategies

Participants' most difficult communication skills (i.e. being involved in conversations, telling stories, communicating commands and fixing communication breakdowns) were mostly social in nature. Furthermore, this finding shows that the greatest difficulty was experienced at a discourse level (i.e. being involved in conversations or telling stories). As the majority of participants were verbal, they might have preferred verbal rather than nonverbal communication strategies to be practised by their communication partners. Nonverbal communication strategies, such as using a multimodal communication approach or tagging questions as 'yes' or 'no', are often used for more severe communication disorders such as global aphasia (Hogrefe, Ziegler, Weidinger, & Goldenberg, 2012). This may be why participants presenting with sentence-level comprehension did not prefer all (i.e. verbal and nonverbal) of the frequently recommended communication strategies employed by speech-language therapists, which attempt to reduce frustration and aid comprehension (Hogrefe et al., 2012). This finding reaffirms the importance of communication strategies being focussed on the preferences of the CVA survivor. The speech-language therapist

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will therefore need to not only facilitate the identification of these preferences but also educate family members of these preferred communication strategies. Communication strategies will only fulfil a facilitating role if they are based on the preference of the CVA survivor.

5.5. Difficult communication skills versus preferred topics of conversation

Their CVA and other medical issues were listed as the most preferred topic of conversation by young participants as well as almost two-thirds of old participants. It could have been a preferred topic for participants as it is reported that CVA survivors view their CVA as a life-altering and traumatic event (Cotoi et al., 2016). As participants' most difficult communication skills suggested difficulty at a discourse level, they might therefore not have been able to discuss their experience with others or explain their current abilities and needs effectively. Young CVA survivors in previous studies have raised concerns regarding personal issues such as poor family support and the limited information received regarding rehabilitation (Low et al., 2003). Young participants in the present study indicated that their preferred topics of conversation were personal in nature. The finding that the young participants in this study wanted to discuss their CVA and medical issues could relate to their desire for more information regarding their CVA and prognosis and, most importantly, to have their family and friends understand, support and empathise with them. This reflects the need noted in a study by Low et al. (2003) that explored the unmet needs of young CVA survivors and found that being provided with information regarding their CVA was their most important need (Low et al., 2003).

Wanting to discuss their CVA and other medical problems alludes to the need that young participants may have for more support following their CVA in the form of stroke support groups, family information sessions and appropriate information packs (Greig, Harper, Hirst, Howe, & Davidson, 2008). Support groups could assist in meeting young participants' personal needs by addressing their need for more information about their CVA and rehabilitation. Additionally, support groups could address young CVA survivors' social needs as they reported that CVA

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support groups enabled them to develop new friendships within the group (Fotiadou et al., 2014). A support group for caregivers and family should also be considered. Providing information, empathising with and creating a support system for the caregivers may directly address the unmet need for family support of the young CVA survivor in particular.

Additionally, half of all young participants indicated dating or getting married as a preferred topic of conversation whereas this was the least preferred topic of conversation for old participants. This preference clearly reflects the different life stages and interests of the two groups.

5.6. Economically Active CVA survivors

The average age for both groups in this study is still considered economically active in South Africa. The average age of the young and old participants was 36 and 58 years, respectively. Although still considered economically active, old participants were close to the accepted South African retirement age of 60 (Steenkamp, 2017) whereas young participants still had many possible economically active years. This could reflect why vocational rehabilitation is scarce for young CVA survivors as traditionally old CVA survivors rarely had a vocational engagement prior to their CVA (Teasell et al., 2000). Interestingly, communicating within a work situation was indicated by less than half of young participants as a difficult communication situation, possibly due to young participants' being unemployed. Old participants selected it as the second least difficult situation, possibly due to old participants' being unemployed or employed informally (i.e. paid employment in an unprotected job such as being self-employed or a temporary/casual worker) (Women in Informal Employment: Globalizing and Organising, 2017) and therefore experiencing no formal communication due to lack of other employees and the possible nature of the job. Old participants did, however, indicate their current or previous work as a preferred topic of conversation. This may relate to old participants' seeking part-time employment and therefore the desire to share information regarding previous work experience. The high cost of living coupled with a shortage of job opportunities has led many South African nearing or of retirement age to look at

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street trading and other informal employment opportunities to generate an income (Polity, 2013). Many participants receiving a state pension still seek temporary or part-time work to supplement their monthly pension. It is also not unlikely for state pension recipients to be the sole providers for their families. South Africa has a high unemployment rate, which has remained between 24% and 30% since 2000 (Polity, 2013), and often old CVA survivors' pension goes towards feeding and clothing their family due to the high unemployment rates amongst working-age adults (Hlati, 2017).

This finding suggests that vocational rehabilitation may need to be provided to both young and old CVA survivors. Previously, opportunities for vocational rehabilitation were limited or non-existent for young CVA survivors since the majority of CVAs occur in older individuals who are no longer economically active (Conroy et al., 2009 as cited in Graham, Pereira & Teasell, 2011). In the South African context, old CVA survivors considered to be no longer economically active often still need to supplement their old-age pension income. Public health institutions therefore need to provide specialised vocational rehabilitation services or partner with private facilities to provide the greatest prospect for both young and old CVA survivors to return to work.

5.7. Preferred literacy skills

Most participants perceived themselves to present with good literacy skills. This suggests that all participants presented with functional literacy skills, although the majority of old participants indicated that their most difficult communication skill was spelling of words.

Young participants selected instant messaging or text messages as their preferred literacy activities (i.e. reading and writing). This finding is supported by Greig et al. (2008) who reported that text messaging was listed as a preferred activity of CVA survivors with limited verbal output. The use of mobile phones and instant messaging was the most preferred literacy activity selected by the young participants. Due to the complexity of mobile telephone designs that has been reported in the literature as a barrier to mobile phone usage for older persons (Greig et al., 2008), activities involving mobile telephones (i.e. instant messaging) were less preferred following their CVA.

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The use of mobile telephones and other forms of technology for the purpose of instant messaging can be seen as a facilitator of improved participation. Instant messaging has a built-in communication strategy, namely predicative text spelling, which would greatly assist CVA survivors, such as aphasic patients, with communication impairments (Greig et al., 2008). This finding highlights the need for speech-language therapists to recognise the importance of including instant messaging platforms at an activity level in rehabilitation (Greig et al., 2008).

Difficulties with mobile telephones that should be addressed by the speech-language therapist are that comprehending the logographic symbols used on mobile telephones requires the same processes as understanding natural language and therefore may be difficult for aphasic patients; the complexity of the mobile telephone software; the multiple alphabet letter allocation to one button, which was described as difficult for CVA survivors; and the monthly costs incurred for a mobile telephone (Greig et al., 2008), which is an important consideration for the South African population.

Young participants' preferred literacy activities were social in nature whereas those of old participants were personal in nature. Old participants' preferred reading material (religious, i.e. the Bible or Koran) and their preferred writing activities (i.e. making lists of things to do or buy) reflected a partiality towards traditional reading and writing materials and activities. The use of mobile telephones or other forms of technology for instant messaging may be a consideration if simple, easily navigated and affordable options are provided for CVA survivors.

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5.8. Considerations for the South African context**5.8.1. Lack of speech-language therapy services**

The findings of this study highlighted the individual nature of the communication needs of participants, particularly young participants. Stroke support groups, family information sessions and appropriate information packages (Greig et al., 2008) were seen as possible solutions to address their unmet personal, social and environmental needs. These solutions may, however, not be sustainable within South African public health institutions due to the shortage of speech-language therapists. Kathard and Pillay (2013) reported that the speech-therapist-to-population ratio may be estimated at 1:25 000. Due to limited accurate data, in reality the situation may be worse as many speech-language therapists registered with the Health Professions Council of South Africa are abroad while others are inactive (Kathard & Pillay, 2013). Furthermore, the majority of speech-language therapists are employed in the private sector. In order to meet the personal, social and environmental communication needs of CVA survivors, they will need to be grouped according to their communication needs and not their medical diagnosis; however, time and resources do not always allow for specialised groups. Although speech-language therapists often attempt to address CVA survivors' specific communication needs within groups, this may not be effective as the study findings have highlighted the importance of identifying CVA survivors' individual barriers and facilitators. As CVA survivors are the priority, family training may not be practised frequently enough possibly due to time and resource limitations. This may be a significant barrier to comprehensive intervention to meet the individual needs of CVA survivors.

5.8.2. Family members as caregivers

CVA survivors' caregivers often realise how ill-informed and poorly prepared they are to assist the CVA survivors once in their home environment (Cotoi et al., 2016). Caregivers may have to provide skilled care for which they are not formally trained and therefore have to learn by trial and error, which may be stressful and unpleasant for both the CVA survivor and the caregiver (Cotoi et

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al., 2016). Within many of the South African public health institutions, family members are often provided with written information on CVA survivors' communication impairment, home programmes and communication strategies for communication partners to practise. This information is often provided in either English or Afrikaans.

In view of the findings of this study, greater emphasis needs to be placed on caregiver training and the materials provided by speech-language therapists. Important considerations within the South African population are: the literacy levels of CVA survivors and caregivers as 11% of the South African population is illiterate (*SA's adult literacy level lags behind*, 2012), the complexity of the language used in the pamphlets and home programmes and lastly the need for the information to be provided in multiple languages as South Africa is a multilingual country (i.e. 11 official languages) (Brand South Africa, 2017).

Within the South African context, providing information regarding CVA survivors' communication impairment in a format that is understandable and relevant to their context is important as often there are many family members within one home. However, due to the cost of public transport, frequently only one caregiver or family member attends speech-language therapy with the CVA survivor. An important consideration for management is that if the main caregiver perhaps does not understand the information provided, they will therefore be unable to educate others in the home and community regarding the communication impairment, intervention goals or communication strategies; this may result in further significant social isolation of the CVA survivor.

5.8.3. Poverty

As previously stated, South Africa has a high unemployment rate and therefore pensioners often supplement their state pension with informal employment to support not only themselves but their extended family as well. Therefore, vocational rehabilitation is indicated not only for young CVA survivors but for old survivors as well as both age groups would greatly benefit from it. Many CVA

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survivors are unable to immediately return to work and therefore receive a temporary state disability grant, which is the same amount as the state pension. According to Statistics South Africa (2017), many South Africans are living in poverty, with the poverty headcount increasing to more than half of South Africans. With the rising unemployment and poverty rates and with pensioners having to support their immediate and extended families, similarly for young CVA survivors' their disability grant may have to be used to provide for the basic needs of a large family. Attending speech-language therapy, although important for the CVA survivors' rehabilitation, is therefore not seen as a priority to the family as basic needs have to be met first. This financial strain impacts on the availability of funds for public transport to attend speech-language therapy, and therefore attendance may be irregular, which ultimately affects rehabilitation outcome. This highlights the need for speech-language therapists and allied health professionals at a community level for CVA rehabilitation.

5.9. Clinical implications

This research has highlighted important considerations for speech-language therapists working within the South African healthcare context.

Firstly, participants' communication needs were mainly personal and social in nature; their least reflected needs were environmental in nature. This study has highlighted the necessity for speech-language therapists to base their intervention on the CVA survivors' acknowledged needs, which are addressed through identifying barriers (i.e. opportunity and access) and facilitators, as recommended in the Participation Model for Augmentative and Alternative Communication (Beukelman et al., 2007). Barriers and facilitators are subjective and are not fixed for all CVA survivors; therefore, CVA survivors need to identify their communication needs and this should form part of speech-language therapists' comprehensive clinical assessment protocol. Speech-language therapy is only effective if the CVA survivor is involved in identifying and prioritising his/her specific communication goals; a barrier to one CVA survivor may be a facilitator to another.

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Therefore, speech-language therapists and CVA survivors should form a partnership to improve survivors' participation.

The second clinical implication relates to the selection of activity-level goals when planning intervention for CVA survivors. This suggests that speech-language therapists should be aware of the possible importance of the use of technology as a tool for improved participation at an activity level. The difficulties experienced with mobile telephone use depend on the CVA survivors' skills and, more importantly, the nature of their needs. Alternate modes of communication are explored within the Participation Model for Augmentative and Alternative Communication (Beukelman et al., 2007). If unfamiliar with the technology options, speech-language therapists can involve companies that specialise in technology for persons with disabilities to better match the communication needs of CVA survivors with an appropriate device. Many of these companies are known to offer evaluations for free and to assist with finding multi-corporate sponsorships. This is important for the South African context because with the high rates of poverty. Furthermore CVA survivors may not be able to buy the data needed for their device and. speech-language therapists should therefore also assist CVA survivors in locating free WiFi hotspots provided by the City of Cape Town (Western Cape Government, 2013b). The government provides 300 MB per user for the first month and 250 MB every month thereafter (Western Cape Government, 2013b). The mobile telephone was a preferred communication tool of young study participants, which would aid participation. Speech-language therapists should therefore be creative in finding solutions to meet this particular communication need of young CVA survivors.

Lastly, a recommendation for speech-language therapists to address CVA survivors' personal, social and environmental needs is to provide group therapy and support groups where they are grouped according to these needs. This would be particularly beneficial for young CVA survivors interested in connecting with others who share similar experiences (Stone, 2007). Group therapy and support groups, if time and resources are allocated, would also assist speech-language

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therapists within the public health institutions to manage their large caseloads without ignoring CVA survivors' specific personal, social and environmental needs.

5.10. Conclusion

Limited literature on the communication needs of young and old CVA survivors within the South African context is available. CVA is a growing epidemic in developing countries such as South Africa, with particular growth in the prevalence of young CVA survivors (Connor et al., 2007). The role of speech-language therapists in providing appropriate assessment and management for this growing population is becoming increasingly essential. The literature has highlighted CVA survivors' known unique and unmet needs (Cotoi et al., 2016) and has therefore forced speech-language therapists to reconsider their approach to management of CVA survivors. For speech-language therapists working within the South African context and contending with social challenges such as high unemployment, poverty, low literacy levels and poor socioeconomic circumstances, finding effective and appropriate assessment criteria as well as management approaches is challenging.

The study findings suggest that the communication needs of participants are more personal and social than environmental in nature. This suggests that speech-language therapists should address the personal (relating to oneself) communication needs of CVA survivors and then progress to the social (communication with familiar others) and environmental (communication outside the home environment with unfamiliar communication partners) needs of CVA survivors. This approach will help the speech-language therapist to base all intervention on the CVA survivor, as recommended by the LPAA and the Participation Model for Augmentative and Alternative Communication. Intervention is only effective if identifying barriers to and facilitators of participation is based on the CVA survivor and not only on the traditional approach to communication intervention.

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Additionally, the difficult communication skills identified by participants (i.e. participating in conversations or spelling of words) directly influence situations and therefore result in difficult communication situations. Therefore, speech-language therapists are recommended to begin therapy focused on the skills that the CVA survivors identify as being difficult.

Furthermore, the study findings highlight the importance of vocational rehabilitation for young as well as old CVA survivors; opportunities for vocational rehabilitation are limited or non-existent for young CVA survivors since the majority of CVAs occur in older individuals who are no longer economically active (Conroy et al., 2009 as cited in Graham et al., 2011).

Young participants' preferred literacy activities also emphasise the importance of technology in meeting their social needs. Old participants prefer traditional reading materials and writing activities. Speech-language therapists will need to address young CVA survivors' literacy preferences within the challenges of the South African context.

5.11. Limitations and recommendations for further research

The first limitation of this study is that the ANA was not a standardized assessment tool, further research is recommended within the South African domain using a standardised communication assessment tool which may be adapted to address the communication needs of CVA survivors with communication impairments within the South African population.

The second limitation of this study refers to the ANA, although the researcher sought to improve the linguistic appropriateness of the ANA for the South African population, some of the items were still deemed to be vague (e.g. changing from listening to talking, keeping communication partners' attention and calling public transport). It is recommended that items more specific and appropriate to the South African population be included (i.e. calling a minibus taxi, buying a train ticket and opening a patient folder at the clinic or hospital) in the ANA. A recommendation for further research would therefore be for amendments to be made to the ANA.

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The third limitation is the study's not having a means to cross-reference the communication needs identified by the CVA survivors. Furthermore, the study did not include a qualitative component, namely to allow participants to add or validate their responses. A recommendation for future research would be a mixed-methodology study looking at the communication needs of CVA survivors.

Participants needed to present with sentence-level comprehension. This was necessary for participants to firstly consent to the study as well as to understand and answer the ANA questions, as the purpose of using the ANA was to identify communication needs from the perspective of the CVA survivor. This could, however, be viewed as a limitation as CVA survivors with more severe communication impairments (i.e. moderate to severe comprehension difficulties) could therefore not be included. Results were therefore only representative of the CVA survivors with less severe comprehension difficulties. For future research to include CVA survivors with moderate-to severe comprehension difficulties, the ANA will need to be revised to ensure it is an aphasia-friendly tool (i.e. pictographic/visual support, simpler wording, and key words in bold and flexible administration).

The fifth limitation is that the findings from this study cannot be generalised to all CVA survivors; however, the study can be viewed as an initial explorative descriptive study of an emerging population (i.e. young CVA survivors).

Lastly, the study provided limited demographic information relevant to the South African population such as education level, living arrangements and employment status. Future research should include the abovementioned demographic information to compare and cross-reference the communication needs of CVA survivors with their demographic information. Demographic information can also be used to draw a parallel between information from CVA survivors and their communication needs such as topic preference.

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COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

ADDENDA

Addendum 1a



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Approval Notice

Response to Modifications- (New Application)

13- Aug -2015

De Grass, Jamie J

Ethics Reference #: S15/02/023

Title: Investigating the communication needs of young Cerebral Vascular Accident survivors compared to older CVA survivors.

Dear Miss Jamie De Grass,

The **Response to Modifications - (New Application)** received on **15-May-2015**, was reviewed by members of **Health Research Ethics Committee 1** via Expedited review procedures on **13-Aug-2015** and was approved.

Please note the following information about your

approved research protocol: Protocol Approval Period:

13-Aug-2015 -13- Aug -2016

Please remember to use your **protocol number** (**S15/02/023**) 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.

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

Addendum 1b



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Ethics Letter

14- Dec -2016

De Grass-Clementson, Jamie J

Ethics Reference #: S15/02/023

Title: Investigating the communication needs of young Cerebral Vascular Accident survivors compared to older CVA survivors.

Dear Mrs Jamie De Grass-Clementson

The Health Research Ethics Committee approved the following annual progress report through an expedited process:

Progress Report dated 26 October 2016

The approval of the research project is extended for a further year

Approval date: 14 December 2016 **Expiry date:** 13 December 2017

Please remember to use your **protocol number** (S15/02/023) on any documents or correspondence with the HREC concerning your research protocol.

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

Addendum 2a: Informed Consent

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

The communication needs of young and old Cerebral Vascular Accident (CVA) Survivors

REFERENCE NUMBER: S15/02/023

PRINCIPAL INVESTIGATOR:

Jamie de Grass-Clementson

ADDRESS:

Speech-language therapy and Hearing Department

Tygerberg Hospital

Francie Van Zijl Drive

Parow

CONTACT NUMBER: 021 938 4825 (w)

You are being invited to take part in a research project. Please take some time to read the information, which will explain the details of this project. Please ask the researcher about any part of this project that you do not fully understand. It is very important that you are pleased and understand what this research includes and how you could be involved. Also, your participation/input is **voluntary/your decision** and you are free to refuse to join. If you say no, this will not affect you in any way. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be done according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The research study you are invited to be involved in will be looking at the communication needs of young stroke patients compared to older stroke patients.

The research will be conducted at Tygerberg Hospital (TBH).

With this research we would like to find out the communication needs of young CVA/stroke survivors and older CVA/stroke survivors

Procedure:

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

The research method will begin as follows: if you agree to take part in the research you will need to sign the consent forms, next a short receptive language screener will be used to assess your comprehension/understanding of spoken language. You will then complete a survey. Everything done will be confidential (private) and at your own pace.

For outpatients the completion of the screening and survey tool will take place in the speech-language therapy department, in an office. It will take roughly 15-20 minutes of your time.

I will be administering the screening tool and survey.

If you choose not to join the study or do not meet the requirements, you will be given a speech and language outpatient date for assessment and further management of your communication difficulties.

Why have you been invited to participate?

You have been asked to join this research as you match the inclusion criteria for the study: Young stroke patients between the age of 18-45 years of age and older stroke patients older than 45 years of age.

What will your responsibilities be?

You will need to answer the questions honestly.

Will you benefit from taking part in this research?

This research will allow Speech-language therapists to have a clearer idea of the communication needs of young stroke patients and older stroke patients. This will assist in functional communication based therapy.

Are there any risks involved when partaking in this research?

There are no known physical risks involved in taking part in this study, however if you would like to stop at any point you are allowed to.

Who will have access to your medical records?

The information gained is confidential (private) and will be protected. Each participant will remain anonymous. The researcher and research supervisor will have access to the research.

Will you be paid to take part in this study and are there any costs involved? No you will not be paid to take part in the study. As the research involves patients attending allied health appointments at TBH, involvement in the study will only take place when you are attending an appointment at TBH. The study will not result in you coming in especially to participate. However if a mistake has been made and you have been booked without any need for speech-language therapy or allied health service, solely for the purpose of this research, transport costs will be covered.

Is there anything else that you should know or do?

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher. You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled: **The communication needs of young and older Cerebral Vascular Accident (CVA) Survivors**

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (place) on (date) 201

Signature of participant..... Signature of witness:

Declaration by investigator

I, Jamie de Grass-Clementson declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (If an interpreter is used then the interpreter must sign the declaration below.)

Signed at (place) on (date) 2016.

Signature of investigator: Signature of witness:

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

The communication needs of young and old Cerebral Vascular Accident (CVA) Survivors

PRINCIPAL INVESTIGATOR:

Jamie de Grass- Clementson

ADDRESS:

Speech-language therapy and Hearing Department

Tygerberg Hospital

Francie Van Zijl

Parow

CONTACT NUMBER: 021 938 4825 (w)

Dear Participant

To ensure exact/accurate and consistent collection of information, all interviews will be recorded.

This will not be made available to anyone other than the researcher and the researcher's supervisor. No identifying information will be associated with the audio recording or any transcription that may need to occur.

If necessary the recording may be transcribed and discussed in the written product or presentation.

By signing this form you are agreeing to our interview being recorded (audio only).

Declaration by participant

By signing below, I give permission for the interview to be recorded (audio only).

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (place) on (date) 201

Signature of participant: _____ **Signature of witness:** _____

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

Addendum 2b: Informed Consent Afrikaans

DEELNEMER INLIGTINGSTUK EN TOESTEMMING VORM

TITEL VAN DIE NAVORSINGS PROJEK:

Die kommunikasie behoeftes van jong en oud oorlewendes van serebraal-vaskulêre ongelukke (SVO's)

VERWYSINGS NOMMER: S15 / 02/023

HOOFNAVORSER:

Jamie de Grass- Clementson

ADRES:

Spraakterapie en Gehoor Departement

Tygerberg Hospitaal Francie van Zijl Parow

KONTAK NOMMER: 021 938 4825 (w)

U word genooi om deel te neem aan 'n navorsingsprojek. Gebruik asseblief u tyd om die inligting wat hier aangebied word, en wat die besonderhede van hierdie projek uiteensit, te lees. Kontak my indien u enige verdere verduideliking of opklaring van enige aspek van die studie benodig. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is vrywillig en u kan weier om deel te neem. Indien u nee sê, sal dit u op geen manier negatief tref nie. U is ook vry om op enige tydstip van die studie te onttrek.

Hierdie navorsingsprojek is deur die Gesondheidsnavorsingsetiekkomitee (GNEK) van die Universiteit Stellenbosch goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Waaroor gaan die navorsing?

Die navorsing studie gaan oor die kommunikasie behoeftes van jong SVO/beroerte oorlewendes/pasiënte in vergelyking met ouer beroerte pasiënte, en word uitgevoer by Tygerberg Hospitaal (TBH)

Prosedures:

As u instem om deel te neem aan die navorsing projek sal u eers deur al die inligting moet lees, daarna die toestemming vorms voltooi en teken.

Dit sal volg deur 'n kort ontvanklike taal assessering, die assessering evalueer u begrip van gesproke taal. U sal dan 'n kommunikasie vraelys voltooi. Alles wat gedoen word sal vertroulik (privaat) en teen u eie tempo plaasvind.

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

Die voltooiing van die taal assessering en kommunikasie vraelys sal in die Spraak Terapie Departement, in 'n kantoor plaasvind. Dit sal ongeveer 15 tot 20 minute van u tyd neem. Ek, Jamie, sal die administrasie van die taal en kommunikasie vraelys instrument doen.

Waarom is u genooi om deel te neem?

U is genooi om deel te neem in hierdie navorsing projek omdat u voldoen aan die kriterium van die navorsing: Jong beroerte pasiënte tussen die ouderdom van 18-45 jaar en beroerte pasiënte ouer as 45 jaar oud.

Wat sal u verantwoordelikhede wees?

U is verantwoordelik om die antwoorde eerlik te antwoord.

Wat is die voordeel om deel te neem in hierdie navorsing?

Hierdie navorsing sal meebring dat Spraak Terapeute 'n duideliker begrip van die kommunikasie behoeftes van jong en ouer beroerte pasiënte sal hê.

Is daar enige risiko's as u deelneem in hierdie navorsing?

Daar is geen bekende fisiese risiko's wat betrokke is in die navorsing nie, maar as u wil ophou is u vry om dit te doen op enige punt van die navorsing.

Wie sal toegang tot u mediese rekords hê?

Die inligting is vertroulik (privaat) en sal beskerm word. Elke deelnemer sal anoniem bly. Die navorser en navorsing toesighouer sal toegang tot die mediese rekords hê.

Sal u betaal word om deel te neem aan hierdie studie en is daar enige koste verbonde?

U sal nie betaal word vir deelname aan die navorsingsprojek nie. Die navorsing behels beroerte pasiënte wat buite- pasiënt rehabilitasie by TBH kry. Betrokkenheid in die navorsing sal slegs plaasvind wanneer u 'n afspraak by TBH bywoon. Die navorsing sal nie daartoe lei dat u spesiaal inkom om deel te neem nie. Maar as 'n fout gemaak word, en u is bespreek sonder enige behoefte vir Spraak Terapie of enige ander rehabilitasie, uitsluitlik vir die doel van hierdie navorsing, sal vervoerkoste gedek word.

Is daar enigiets anders wat u moet weet of doen?

U kan die GNEK kontak op 021-938 9207 indien u enige kommer of klagtes het wat nie voldoende deur die navorser aangespreek word nie. U sal 'n afskrif van die inligting vorm ontvang vir u eie rekord.

Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek,....., om deel te neem aan 'n navorsingsprojek getiteld: Die kommunikasie behoeftes van jong en ouer oorlewendes van serebraal-vaskulêre ongelukke (SVO's)

Ek verklaar dat:

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te (plek) **TBH Spraak Terapie Departement** op (datum) _____ 201

Handtekening van deelnemer

Handtekening van getuie

Verklaring deur navorser:

Ek Jamie de Grass-Clementson verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan: _____
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek 'n tolk gebruik het/nie 'n tolk gebruik het nie.

Geteken te (plek) **TBH Spraak Terapie Departement** op (datum) _____ 2016.

Handtekening van ondersoeker

Handtekening van getuie

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

DEELNEMERINLIGTINGSBLAD EN -TOESTEMMINGSVORM

TITEL VAN DIE NAVORSINGSPROJEK:

Die kommunikasiebehoefte van jong en ouer oorlewendes van serebraal-vaskulêre ongelukke (SVO's)

VERWYSINGSNOMMER: S15 / 02/023

HOOFNAVORSER:

Jamie de Grass- Clementson

ADRES:

Afdeling Spraak-Taal- en Gehoorterapie

Tygerberg Hospitaal

Francie van Zijl-rylaan

Parow

KONTAKNOMMER: 021 938 4825 (w)

Beste Deelnemer

Om noukeurige/akkurate en konsekwente versameling van inligting te verseker word alle onderhoude opgeneem.

Dit sal nie beskikbaar gemaak word aan enigiemand behalwe die navorser en die navorser se toesighouer nie. Geen identifiseerbare inligting sal met die oudio-opname of enige moontlike transkripsie verbind word nie.

Indien nodig kan die opname getranskribeer word en in die geskrewe produk of aanbieding bespreek word.

Deur hierdie vorm te onderteken stem u in dat ons onderhoud opgeneem kan word (slegs oudio).

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Verklaring deur deelnemer

Deur my handtekening hieronder gee ek, I _____ toestemming dat die onderhoud opgeneem mag word (slegs oudio).

Ek verklaar dat:

- Ek hierdie inligtingsblad en toestemmingsvorm gelees het en dat dit in 'n taal geskryf is wat ek vlot verstaan en waarmee ek gemaklik is.
- Ek die geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan die deelname aan hierdie studie is **vrywillig** en dat daar geen druk op my geplaas is om daaraan deel te neem nie.
- Ek my te eniger tyd aan die studie kan onttrek en dat ek nie op enige wyse daardeur gepenaliseer of benadeel sal word nie.
- Ek gevra kan word om aan die navorsingsprojek te onttrek voordat dit afgehandel is indien die studiedokter of navorser meen dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te (plek) **TBH Spraak Terapie Departement** op (datum) _____ 2016.

Handtekening van deelnemer _____

Handtekening van getuie _____

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

Addendum 2c: Informed consent Xhosa

INCWADANA YEENKCUKACHA YALOWO UTHABATHA INXAXHEBA NEFOMU YOKUNIKA

IMVUME

ISIHLOKO SEPROJEKTHI YOPHANDO:

Izidingo zonxibelelwano zaBasinde kwiStrowukhi abaNcinane nabaDala

INOMBOLO YESALATHISI: S15/02/023

UMPHANDI OYINTLOKO:

Jamie de Grass-Clementson

IDILESI:

Speech-language therapy and Hearing Department

Tygerberg Hospital

Francie Van Zijl Drive

Parow

INOMBOLO YOQHAGAMSHELWANO: 021 938 4825 (w)

Uyacelwa ukuba uthathe inxaxheba kwiprojekthi yophando. Nceda uthathe ixesha ufunda iinkcukacha ezibhalwe apha, eziza kucacisela ngeenkcukacha zale projekthi. Nceda ubuze umphandi ngayo nayiphi na indawo kule projekthi ongayiqondi ngokupheleleyo. Kubaluleke kakhulu ukuba waneliseke kwaye uqonde ngokucacileyo okuqulathwe kolu phando kwanokuba unokubandakanyeka njani. Kwakhona, intatho-nxaxheba/igalelo lakho ulenza **ngokuzithandela/sisigqibo sakho** kwaye ukhululekile ukuba wale ukuzibandakanya. Ukuba uthi hayi, oku akuzi kukuchaphazela kakubi nangayiphi na indlela. Ukhululekile kwakhona ukuba ungarhoxa kolu phando nanini na, nkqu nokuba uyavuma ukuthabatha inxaxheba.

Olu phando luphunyezwe **yiKomiti yeeNqobo Ezisesikweni yoPhandonzulu kwezeMpilo kwiYunivesithi yaseStellenbosch** kwaye luza kwenziwa ngokwemigaqo esesikweni kunye nemiqathango yesiBhengezo saMazwe ngaMazwe sika-Helsinki, iziKhokelo zoMzantsi Afrika ezingoNyango Olulungileyo kunye neziKhokelo zeeNqobo kuPhandonzulu zeBhunga loPhandonzulu ngoNyango (elifinyezwa njenge-MRC).

Lumalunga nantoni olu phando?

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

Olu phando umenywa kulo lubandakanya ukuphonononga izidingo zonxibelelwano kwizigulane ezinestrowukhi zisencinane kuthelakiswa nezo zigulane zinesitrowukhi zindala. *Uphando luza kuqhutyelwa kwisiBhedlele iTygerberg (sifinyezwe njenge-TBH) kunye neZiko loVuselelo laseNtshona Kapa (elifinyezwe njenge-WCRC).*

Ngolu phando singathanda ukuva ngezidingo zonxibelelwano lwezigulane ezinestrowukhi zisencinane kunye nezo zigulane zinesitrowukhi zindala.

Indlela emiselweyo:

Indlela yophando iza kuqala ngale ndlela ilandelayo: ukuba uyavuma ukuthabatha inxaxheba kolu phando kufuneka utyikitye iifomu zemvume, okulandelayo, isikrina sokwamkela ulwimi esifutshane siza kutyenziswa ukuvavanya ukuqonda/ukuqiqa kwakho kulwimi oluthethwayo. Uza kugwalisa uvavanyo. Yonke into iza kuba yimfihlo (eyabucala) kwaye uza kwenza yonke into ngesantya sakho.

Kwizigulane ezingaphandle, ukwenziwa kokuskrina kunye nokusetyenziswa kwezixhobo zovavanyo kuza kwenzeka kwisebe lonyango lwentetho, eofisini. Kwizigulane ezilalisiweyo / ezo zingaphakathi esibhedlele (ukwenziwa kokuskrina nokusetyenziswa kwezixhobo zovavanyo) kuza kusetyenziswa iofisi ethuleyo ekwiwadi okanye kuza kwenziwa ecaleni kwebhedi yomthabathi-nxaxheba. Luza kuthabatha imizuzu engama-20 ukuya kuma-30 ngokwengqikelelo yexesha lakho. Mna, Jamie, ndiza kube ndisebenzisa izixhobo zokuskrina novavanyo.

Ukuba ukhetha ukungathabathi nxaxheba kolu phando okanye awufikeleli kwiimfuneko, uya kunikwa usuku ngokwezigulane zangaphandle zolwimi nentetho ukuze uvavanywe kunye nokulawulwa okongezekileyo kweengxaki zakho zonxibelelwano.

Kutheni uceliwe ukuba uthathe inxaxheba?

Ucelwe ukuba uthabathe inxaxheba kolu phando ngenxa yokuba uyafikelela kwiinqobo zokubandakanywa kolu phando: Izigulane ezinestrowukhi zisencinane ziphakathi kwe-18-45 ubudala kuze izigulane ezinestrowukhi ezingaphezu kwama-45 ubudala.

Luya kuba yintoni uxanduva lwakho?

Kuza kufuneka ukuba uphendule imibuzo ngokunyanisekileyo.

Ingaba uya kuzuzisa ngokuthatha kwakho inxaxheba kolu phando? Olu phando luza kuvumela abanyangi-ntetho ukuba babenoluvo olucacileyo ngezidingo zonxibelelwano lwezigulane ezinestrowukhi zisencinane kunye nezigulane ezinesitrowukhi zindala. Oku kuya kunceda kunyango olugxininise kunxibelelwano olusebenzisekayo.

Ngaba kukho imingcipheko ebandakanyekayo ekuthatheni inxaxheba kolu phando?

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

Akukho mingcipheko kwisiqu eyaziwayo nebandakanyekayo ngokuthabatha inxaxheba kolu phando, nangona kunjalo, ukuba ufuna ukuyeka nangaliphi na ixesha, uvumelekile ukwenza njalo.

Ngubani oza kukwazi ukufikelela kwiingxelo zakho zezonyango?

Ulwazi olufunyenweyo luyimfihlo (lelabucala) kwaye lukhuselekile. Umthabathinxaxheba ngamnye uya kuhlala engaziwa. Ngumphandi kunye nosuphavayiza abaya kufikelela kuphando.

Ingaba uza kuhlalulwa ngokuthatha inxaxheba kolu phando kwaye ingaba kukho iindleko ezibandakanyekayo?

Hayi, awuyi kuhlalulwa ngokuthatha inxaxheba kolu phando. Nanjengoko olu phando lubandakanya izigulane ezinamadinga anxulumene nonyango eTBH, ubandakanyeko kolu phando luya kuthabatha inxaxheba xa isigulane sisiya kwidinga laso eTBH. Uphando alusayi kukunyanzelisa ukuba uze nje ngakumbi ukuza kuthabatha inxaxheba. Kodwa ke ukuba kwenziwe impazamo ngokuthi ubhukishwe kodwa akukho sidingo sanyango lwentetho okanye inkonzo ezinxulumene nonyango, uzele nje injongo zophando kuphela, iindleko zothutho ziya kuhlalulwa.

Ingaba ikhona enye into ekufuneka ukuba uyazi okanye uyenze?

Ungaqhagamshelana neKomiti yeeNqobo Ezisesikweni kuPhandonzulu lweMpilo ku021 938 9207 ukuba kukho nantoni na ekuxhalabisayo okanye onesikhalazo ngayo engaqwalaselwanga ngokwaneleyo ngugqirha wakho okulo phando. Uza kufumana ikopi yezi nkcukacha nefomu yokunika imvume ukwenzela ukuba uzigcinele.

Isibhengezo somthathi-nxaxheba

Ngokutyikitya apha ngezantsi, mna ndiyavuma

ukuthatha inxaxheba kuphando olusihloko sithi: **Izidingo zonxibelelwano zaBasinde kwiStrowukhi abaNcinane nabaDala**

Ndibhengeza ukuba:

- Ndizifundile okanye ndizifundelwe ezi nkcukacha kunye nefomu yokunika imvume kwaye zibhalwe ngolwimi endilwazi kakuhle nendikhululekileyo ngalo.
- Ndiye ndalifumana ithuba lokubuza imibuzo kwaye yonke imibuzo yam iphendulwe ngokwanelisayo.
- Ndiyaqonda ukuba ukuthatha kwam inxaxheba kolu phando ndikwenza **ngokuzithandela** kwaye khange ndinyanzelwe ukuba ndithathe inxaxheba.
- Ndingakhetha ukuyeka kuphando nanini na kwaye andisayi kohlwaywa okanye ndicalulwe nangayiphi na indlela.

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

- Ndisenokucelwa ukuba ndilushiye olu phando lungekapheli, ukuba ugqirha wophando okanye umphandi ucinga ukuba oko kundifanele ngcono, okanye ukuba isicwangciso sophando andisilandeli ngale ndlela kuvunyelwene ngayo.

Kutyikityelwe (indawo) e..... ngomhla (umhla) we-
..... 2015.

Ukutyikitya kwalowo uthatha inxaxheba:.....

Ukutyikitya kwengqina:.....

Isibhengezo somphandi

Mna, Jamie de Grass-Clementson ndibhengeza ukuba:

- Ndimcacisele u..... ngeenkukacha ezikolu xwebhu.
- Ndimkhuthazile ukuba abuze imibuzo ndaza ndathatha ixesha elaneleyo ukuyiphendula.
- Ndanelisekile kukuba uyiqonda ngokwaneleyo yonke imiba yolu phando, njengoko icacisiwe apha ngentla.
- Ndiyisebenzisile/andiyisebenzisanga itoliki. (Ukuba itoliki isetyenzisiwe kumele ityikitye isibhengezo ngezantsi.)

Kutyikityelwe (indawo) e..... ngomhla (umhla) we-
..... 2015.

Ukutyikitya komphandi: Utyikityo lwengqina:.....

Isibhengezo esenziwa yitoliki

Mna (igama) ndabhengeza ukuba:

- Ndimncedisile umphandi (igama)..... ekucaciseni iinkukacha ezikolu xwebhu ku-(igama lalowo uthatha inxaxheba)
..... ndisebenzisa ulwimi lweAfrikaans/lwesiXhosa.
- Simkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elaneleyo ukuba ayiphendule.
- Ndimxelele eyona nto iyiyo malunga noko ndikuxelelweyo.
- Ndanelisekile kukuba umthathi-nxaxheba ukuqonda ngokupheleleyo okuqulathwe lolu xwebhu lokunika imvume olucacisiweyo kwaye yonke imibuzo yakhe iphendulwe ngokwanelisayo.

Kutyikityelwe (indawo) e..... ngomhla (umhla) we-
..... 2015.

Ukutyikitya kwetoliki:..... Ukutyikitya kwengqina:.....

COMMUNICATION NEEDS OF YOUNG AND OLD CVA SURVIVORS

INCWADANA YOLWAZI LOMTHABATHI-NXAXHEBA KUNYE NEFOMU YEMVUME

ISIHLOKO SEPROJEKTHI YOPHANDO :

Izidingo zonxibelelwano abasinde kwi-Cerebral Vascular Accident (efinyezwa njenge-CVA) abadala nabancinane

UMPHANDI OMKHULU:

nguJamie de Grass- Clementson

IDILESI:

ISebe loNyango loKuva neNtetho

IsiBhedlele iTygerberg

Francie Van Zijl

Parow

IINOMBOLO ZOQHAGAMSHELWANO: 021 938 4825 (w) 083 2106364 (c)

Mthabathi-nxaxheba obekekileyo

Ukuqinisekisa uqokelelo lolwazi olungqinelanayo noluchanekileyo, lonke udliwanondlebe luya kurekhodwa.

Oku akusayi kuze kunikwe naye nabani na ngaphandle komphandi kunye nosuphavayiza womphandi. Akukho lwazi luphawula umntu luya kunxulunyaniswa kunye nokurekhodiweyo okanye nalo naluphi na ukhuphelo-mazwi olungadingeka.

Ukuba kukho isidingo, okurekhodiweyo kungakhutshelwa kwaye kuxoxwe kukwimo okanye isiboniselelo sokubhaliweyo.

Ngokutyikitya le fomula, uyavuma ukuba udliwanondlebe lube luyarekhodwa (kuya kurekhodwa ilizwi kuphela)

Isibhengezo somthabathi-nxaxheba

Ngokutyikitya apha ngezantsi, Mna ndinika imvume kudliwanondlebe ukuba lurekhodwe (kurekhodwe ilizwi kuphela).

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Ndibhengeza ukuba:

- Ndilufundile okanye ndilufundelwe olu lwazi kunye nefomu yemvume kwaye zibhalwe ngolwimi endiluthetha kakuhle kwaye andinangxaki nalo.
- Ndifumene ithuba lokubuza imibuzo kwaye yonke imibuzo yam iphendulwe ngokwanelisayo.
- Ndiyakuqonda ukuba ukuthabatha inxaxheba kolu phando **kukuzithandela** kwaye andikhange ndinyanzeliswe ukwenza oko.
- Ndingakhetha ukulushiya olu phando nangaliphi na ixesha kwaye andisayi kuze ndohlwaywe okanye ndicalucalulwe nangayiphi na indlela.
- Ndingacelwa ukuba ndilushiye olu phando ngaphambi kokuba luphele, ukuba ugqirha wophando okanye umphandi ubona ikukundikhusela okanye andilandeli isicwangciso sophando njengoko kuvunyelwene.

Ityikitywe e(indawo) ngo (umhla) 2016.

Utyikityo lomthabathi-nxaxheba

Utyikityo lwengqina

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Addendum 3: Comprehension screener**Research Study:** Describing the needs of young CVA survivors and old CVA survivors **Participant Profile:****Date:** _____**Participant Number:** _____**Participant Initials:** _____**Participant Group (circle):** Younger / Older**Medical Diagnosis:**
_____**(Communication/Speech-language) Diagnosis:** _____ **Age of participant:**
_____**Research procedure and results:****Consent provided:** Yes/No (ensure signed form is attached)**Auditory recording consent provided:** Yes/No (ensure signed form is attached)**Auditory verbal comprehension screening score:** /20 (participant to receive 16 or more to proceed with assessment tool)**Auditory Verbal Comprehension: PARTICIPANT SHEET**

Item	Target response	Response	Score
1. Is your name Lynn or Michael/ Is U naam Lynn or Michael/ Igama lakho nguLynn/NguMichael? (incorrect name)	NO		1
2. Is your surname Brown / Is U van Bruin/ Ifani yakho nguBrown?	NO		1
3. Is your name/ Is U naam/ Igama lakho ngu _____ (Actual name)	YES		1
4. Do you live in/ Bly U in/ Uhlala e _____ (idolophu ekufuphi esingahlali kuyo isigulane) nearby city/town patient does not live)	NO		1

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5.	Do you live in/Bly U in/ Uhlala e_____ (idolophu ekufuphi esingahlali kuyo isigulane) (patients city/town of residence)	YES			1
6.	Do you live in/ Bly U in Uhlala e..... (idolophu ekufuphi esingahlali kuyo isigulane) Another nearby city/town were patient does live)	NO			1
7.	Are you a man/woman/ Is U n man/vrou / Uyindoda / Ungumfazi?	YES			1
8.	Are you a doctor/ Is U 'n dokter/ Ungugqirha?	NO			1
9.	Am I a woman/ Is ek 'n vrou/ Ndingumfazi?	YES			1
10.	Are the lights on in this room/Is die ligte aan in hierdie kamer/ Izibane zilayitiwe kweli gumbi?	YES/NO			1
11.	Is the door closed / Is die deur toe/ Ucango luvaliwe?	YES/NO			1
12.	Is this a hotel/ Is dit 'n hotel/ Yihotele le?	NO			1
13.	Is this a hospital / Is dit n hospital/ Kuse sibhedlele apha? (Actual location)	YES			1
14.	Are you wearing red pyjamas / Het U rooi slaapklerre aan/ Unxibe ipijama ebomvu?	NO			1
15.	Will paper burn in fire? Sal papier in vuur brand/ Iphepha lingatsha emlilweni?	YES			1
16.	Does the month of March come before the month of June/ Kom Maart maand voor Junie maand/ inyanga uMatshi uphambi koJuni?	YES			1
17.	Do you eat banana before you peel it/ Eet U 'n piesang voor U dit skil/ Utya ibhanana phambi kokuba uyixobule?	NO			1
18.	Is it cold in January/Is dit koud in Januarie/ Kuyabanda ngoJanuary ?	NO			1
19.	Is a horse bigger than a dog/ Is 'n perd groter as 'n hond/ Ihashe likhulu kunenja?	YES			1
20.	Do you cut grass with an ax/ Sny U die gras met 'n byl/ Ingca uyicheba ngezembe?	NO			1
		TOTAL SCORED		MINIMUM SCORE 16/20	
PARTICIPANT ABLE TO CONTINUE WITH STUDY?			YES	NO SPEECH-LANGUAGE THERAPY OPD OR REFER FURTHER	

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Addendum 4: Aphasia Needs Assessment (ANA)**APHASIA NEEDS ASSESSMENT**

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REVISED

INFORMANT: _____ Date: _____

1. HOW ARE THINGS GOING FOR YOU/ HOE GAAN DINGE VIR U/ ZIKUHAMBELA NJANI IZINTO?

Badly/Sleg/Kakubi		So-So/nje-nje		Very Good/Baie Goed/kakuhle kakhulu
1	2	3	4	5

2. HOW WELL ARE YOU COMMUNICATING/ HOE GOED KOMMUNIKEER U/ LUNJANI UQHAGAMSHELWANO LWAKHO?

Badly/Sleg/Kakubi		So-So/nje-nje		Very Good/Baie Goed/kakuhle kakhulu
1	2	3	4	5

3. INDICATE WHICH SITUATIONS GIVE YOU THE MOST DIFFICULTY WITH COMMUNICATION/DUI AAN WATTER SITUASIES DIE MEESTE PROBLEME VIR U SKEP MET KOMMUNIKASIE/ ZEZIPHI IIMEKO EZIKUNIKA INGXAKI XA UGHAGAMSHELANA NABANTU?

- 1. Talking on the phone/ Om op die foon te praat/ Ukuthetha efowunini
- 2. Talking to people/ Om met mense te praat/ Ukuthetha nabantu?
- 3. Talking about personal issues/ Om oor persoonlike sake te praat/ Ukuthetha ngengxaki zakho
- 4. Calling or requesting public transport/ Om publieke vervoer te versoek of roep/ ukuqhakamshela okanye ukucela isithuthi sikawonke wonke
- 5. Money related inquiries such as disability grant or (old age) pension, UIF, airtime/ Geld verwante navrae soos gestremheid subsidie of (ouderdom) pensioen, UIF of airtime / ukufuna incaciselo malunga nemibuzo **encamiselene** nemali; umzekelo, ipensini yokukhubazeka okanye eyobudala, UIF, airtime
- 6. Doctor/Medical settings/ Dokter of mediese omgewings/ Ugqirha / Amaziko empilo
- 7. Work/ Werk/ Umsebenzi
- 8. Giving directions/ Om aanwysings tegee/ Ukwalathisa indlela
- 9. Understanding others/ Om te verstaan wat anders sê/ Ukuqonda abanye abantu
- 10. Restaurants/ Restaurante/ eRestyu(indawo zokutyela)

4. INDICATE WHICH TOPICS WOULD YOU LIKE TO TALK ABOUT DURING CONVERSATIONS/DUI ANN WAAROR SAAL U GRAAG WIL PRAAT TYDENS GESPREKKE/ ZINTONI ONGATHANDA UKUTHETHA / UKUNCOKOLA NGAZO?

- 1. Stories about your children/ Stories oor u kinders/ Amabali ubalisa ngabantwana bakho
- 2. Your adventures as a young child or growing up/ U avonture as jong kind of grootword/ Izenzo zakho zobudela-ngozi usengumntwana/usakhula

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- 3. Dating and getting married/ Uitgaan en trou/ Ezothando nomtshato
- 4. Current or previous job/ U huidige of vorige beroep/ umsebenzi osebenza kuwo ukanye owawusebenza kuwo ngaphambile
- 5. Interests/ belangstellings/ Izinto othanda ukuzenza ezikonwabisayo
- 6. Family history/ Familie geskiedenis/ Imbali - imvelaphi ngosapho - izinyanya
- 7. Events/Gebeurtenisse/imicimbi
- 8. Sports/ Sport / Imidlalo
- 9. Government or politics/ Die regering of politiek/ ukrulumente okanye ipolitiki
- 10. Weather/ Weer/ Imozulu
- 11. Favorite meals or restaurants/ Gunsteling etes of restaurante/ Ukutya okanye lirestyu oyithandayo
- 12. Your house-things to fix or things to do/ U huis -dinge om reg te maak of doen/ Indlu yakho / Isixeko sakho / Izinto ezifuna ukulungiswa
- 13. Your stroke and/or other medical issues/ U beroerte en/of ander mediese probleme/
isi-troku sakho/ Imeko yakho yezempilo

5. INDICATE WHICH COMMUNICATION SKILLS ARE THE MOST DIFFICULT FOR YOU/DUI ANN WATTER KOMMUNIKASIE VAARDIGHEDE IS VIR U DIE MOEILIKSTE/ ZEZIPHI EZONA ZAKHONO ZOQHAGAMSHELWANO EZINZIMA KUWE?

- 1. Getting someone's attention/ Om iemand se aandag te kry/ Ukufumana ukuhoywa ngomnye umntu
- 2. Introducing yourself and others/ Om jouself en andere voor te stel/ Ukuzazisa nokwazisa abanye abantu
- 3. Explaining about aphasia and how you communicate/ Om oor afasie en hoe u kommunikeer te verduidelik/ Ukucacisa nge-Aphasia nendlela endiqhakamshela ngayo
- 4. Introducing new topics/ Om nuwe onderwerpe bekend te stel/ ukuqala isihloko sencoko
- 5. Being involved in conversations/ Om deel teneem aan gesprekke/ Ukuba yinxalenye yencoko
- 6. Asking questions/ Om vrae te vra/Ukubuza imibuzo
- 7. Answering questions/ Om vrae te antwoord/ Ukuphendula imibuzo
- 8. Talking about things that happened today or in the past/ Om oor dinge te praat wat in die teenwoordige of verledetyd gebeur het/ Ukuthetha ngezinto ezithe zenzeke namhlanje okanye kwixa eladlulayo
- 9. Telling a story/ Om 'n storie te vertel/ Ukubalisa ibali
- 10. Telling a joke/ Om 'n grap te vertel/ Ukubalisa into ehlekisayo
- 11. Communicating how you feel/ Om te kommunikeer hoe u voel/ Ukuqhakamshelana malunga nendlela oziva ngayo
- 12. Communicating commands/ Om instruksies te gee/ Ukucacisa imiyalelo
- 13. Following commands/ Om instruksies te volg/ Ukulandela imiyalelo
- 14. Fixing communication breakdowns or misunderstandings /Om kommunikasie afbreekpunte of misverstands reg te stel/ Ukusombulula impambano emva kokuba uqhakamshelwano lungahambanga kakuhle

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- 15. Changing from talking to listening/ Om te wissel tussen praat en luister/ Ukuzitshintsha phakathi kokuthetha nokumamela
- 16. Spelling of words/ speling van woorde/ Ukupela amagama
- 17. Keeping my communication partners attention/ Om u kommunikasie vennoot se aandag te behou/ Ukudcina umlinganisi wam endithetha naye emameli

6. INDICATE WHICH ITEMS YOUR COMMUNICATION HELPER NEEDS TO LEARN TO DO/ DUI AAN WAT MOET U KOMMUNIKASIE HELPER LEER OM TE DOEN/YINTONI INGAFUNDWA NGABALINGANI BAKHO NGOQHAKAMSHELWANO UKUZE BAKUNCEDE?

- 1. Not to interrupt/ Om nie te onderbreek nie/ Ukungaphazamisi
- 2. Not to guess or fill in words unless you say it's OK/ Om nie te raai of woorde in te vul tensy U sê dit is oraaif nie/ Ukungaqasheli into endifuna ukuyithetha okanye ukungafakeli amagama ndide ndivume ngokwam
- 3. Tell you what they do understand when you have difficulty communicating clearly/ Om u te sê wat hulle wel verstaan wanneer u dit moeilik vind om duidelik te kommunikeer/ Bakuxelela into abayiqondayo xa unenxaki yokuqhakamshelana nabo
- 4. To improve guessing by breaking-down the category or group the specific message falls in/ Om meer effektief te raai deur die kategorie van die teiken boodskap te vereenvoudig/ Ukundixelela ukuba yintoni abangayiqondiyo xa ndinengxaki yokuqhakamshelana nabo
- 5. Slow down when talking to you/ Om stadiger met u te praat/ Ukucothisa xa bethetha nawe
- 6. Give one item of info at a time when talking to you/ Om een stuk of deel inligting op 'n slag te gee, wanneer iemand met u praat/ Ukuthetha ngamabizana okanye ngeziqendu xa bethetha nam. Bangathethi yonke into ngexesha elinye
- 7. Write things down, draw, or gesture to help you understand better/ Om dinge neer te skryf, teken, of gebare gebruik om u te help om beter te verstaan/ Ukubhala okanye ukuzoba izinto phantsi okanye ukulinganisa ngomzimba ukuze ndiqonde
- 8. Help you answer yes/no questions by tagging them (yes....or no?)/ Om u te help ja/nee vrae te beantwoord deur hulle te merk (ja of nee?)/ Bandincede ngokundibuza imibuzo efuna impendulo ethi Ewe okanye Hayi ukuze ndiphendule (ngokuthi Ewe okanye Hayi)
- 9. Ask you questions or give you opportunities to communicate/ Om vra vir u te vrae of geleenthere vir u te gee om te kommunikeer/ Ukundibuza imibuzo / ukundinika ithuba lokuqhakamshelana nabanye abantu

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7. HOW WELL DO YOU READ/ HOE GOED LEES U/ UFUNDA NJANI?

Badly/Sleg/Kakubi		So-So/nje-nje		Very Good/Baie Goed/kakuhle kakhulu
1	2	3	4	5

8. INDICATE WHICH MATERIALS YOU LIKE TO READ/ DUI AAN WATTER TIPE MATERIAAL SAL U GRAAG WIL LEES/ UNGATHANDA UKUFUNDA NTONI?

- 1. Magazines/ tydskrifte/ Iimagazini
- 2. Newspaper/ koerante/ Amaphepha-ndaba
- 3. Letters/ Briewe/ Iileta
- 4. Stories/ Stories/Amabali
- 5. SMS' /iSMS
- 6. Email/epos/ I-e mail
- 7. Bible or Koran /bybel of Koran/Imibhalo Engcwele

9. HOW WELL DO YOU WRITE/ HOE GOED SKRYF U/ UBHALA NJANI?

Badly/Sleg/Kakubi		So-So/nje-nje		Very Good/Baie Goed/kakuhle kakhulu
1	2	3	4	5

10. INDICATE WHICH FIVE THINGS YOU LIKE TO WRITE/DUI AAN WATTER TIPE DINGE SAL U GRAAG WIL SKRYF/ UNGATHANDA UKUBHALA NTONI?

- 1. Lists of things to buy or appointments to remember/ Lyste van dinge om te koop of afspraak om te onthou/ Uludwe lwezinto oza kuzithenga okanye uluhlu lwamadinga
- 2. Cards/ Kaartjies/ Amakhadi
- 3. Letters/ briewe/ Iileta
- 4. Stories/ Stories/ Amabali
- 5. SMS' / iSMS
- 6. Email/epos / I-e mail