Experiences of stroke survivors with aphasia and their significant others during the COVID-19 pandemic in Ekurhuleni, South Africa

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Declaration

I, ***Nabeelah Ebrahim Kathrada***, hereby declare that this research is my original work and that all the assistance received has been acknowledged and referenced accordingly.

I take full responsibility for the text of this study, the presentation, findings, and conclusions presented. This study has not been submitted before, nor is it to be submitted for a degree at any other university.

Nabeelah Ebrahim Kathrada

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Dedication

To my husband, Fayaaz – your love, strength, commitment, and aid is unmatchable. You are everything. Thank you for holding down the fort over these years and fully supporting my ambitions and academic career. Thank you for believing in me, always.

For my daughter, Myra, you are so precious and wonderful and full of goodness. Thank you for giving up our time, even if you weren't always aware. I hope you grow to see the value in education and pave your own path wisely.

For my parents, who had continuously stimulated my curiosity and learning journey. Thank you for all the opportunities you have provided.

The entire scope and depth of this research is dedicated to:

The loving memory of my grandfather, whose stroke and aphasia robbed him of his words far too soon. It is my fervent wish that this research serves a higher purpose in aiding all of those afflicted by these conditions.

And

For Sarah Niemand, who sadly and suddenly succumbed to a stroke shortly after the completion of this project. Her role and aid as a psychologist in this study were instrumental. I recall when I first reached out for assistance for this study, she agreed without a moment of hesitation – "anything for research". Her loss will be felt both personally and professionally. Her departure from this world further highlights the sudden nature of a neurological event and the need for better healthcare practices to prevent non-communicable diseases.

May she rest in peace.

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Abstract

Background and Aim: Stroke, a neurological condition, can lead to communication impairments, including aphasia, and has been associated with increased burden of care for significant others. With changes in stroke care due to the COVID-19 pandemic, it was considered essential to explore the perspectives of stroke survivors and their significant others. This study aimed to investigate the lived experiences of individuals diagnosed with stroke and aphasia during the COVID-19 pandemic, along with their significant others, within the South African context.

Methodology: Employing a qualitative phenomenological design, this study utilised homogenous purposive sampling. Semi-structured interviews were conducted with seven stroke survivors with aphasia and their significant others. Interviews were conducted individually or as a unit, depending on participant preference. Data analysis followed an inductive thematic approach, with interpretation guided by the biopsychosocialtech model.

Findings: The study's findings reveal challenges faced by participants as a result of the COVID-19 pandemic. These challenges encompass difficulties related to facility admission, interactions with healthcare workers, loss of autonomy, limited communicative abilities, reduced social networks and engagement in pre-stroke activities, struggles with re-entering the work environment, changes within family dynamics and interpersonal relationships, as well as evidence of burden of care for significant others. While technology was acknowledged as a potential valuable resource and telerehabilitation a possible successful intervention approach, their effective use posed challenges and limitations. Although rehabilitation was deemed beneficial, the need for potential transformation within the field of aphasia rehabilitation is outlined, particularly with respect to the active involvement of persons with aphasia and their significant others as well as the use of technology in a South African context.

Implications and Conclusion: This study contributes to the understanding of the lived experiences of persons with aphasia and their significant others within the South African context during the COVID-19 pandemic. The findings have the potential to inform policy and practice by emphasising the importance of addressing client needs based on their lived experiences. Additionally, the study underscores the significance of active family involvement in treatment and highlights the need to investigate barriers to implementation in this regard. The findings further emphasise the necessity of developing policies that outline the use of technology in rehabilitation and call for improved considerations in healthcare workers' interactions with individuals with aphasia.

Keywords: COVID-19 pandemic, stroke, aphasia, third party disability, family dynamics, technology, telerehabilitation, South Africa, policy , biopsychosocialtech.

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Glossary of terms

Stroke survivor: An individual who has been diagnosed with a cerebrovascular accident (CVA) and survived (Franklin et al., 2018).

Significant other: An important nominated person to the person with aphasia (Grawburg et al., 2019).

COVID-19: The coronavirus disease 2019 (COVID 2019) caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) (Greenhalgh et al., 2020).

Aphasia: A neurological language impairment that can impede communicative competency in a spectrum, depending on the site of lesion, type and severity commonly associated post-stroke (Jagoe et al., 2021).

Third-Party Disability: Consequence of an impairment that impacts on significant others (Grawburg et al., 2019).

Speech Language Therapist: A healthcare professional providing speech, language, communication and swallowing rehabilitation (American Speech-Language and Hearing Association [ASHA], 2020).

Communication Impairment: Communication disorder that results in the inability to process, understand and express oneself using verbal or non-verbal techniques (ASHA, 2020).

List of abbreviations

AAC	Augmentative and Alternative Communication
HCW	Health Care Worker/s
LMIC	Low and Middle-Income Countries
MDT	Multidisciplinary Team
PPE	Personal and Protective Equipment
PMR	Physical Medicine and Rehabilitation
PWA	Person/s With Aphasia
SA	South Africa
SLT	Speech Language Therapist
SO	Significant Other
SO PWA	Significant Other of Person with Aphasia

Chapter 1: Background and Rationale

Outline of chapter

This chapter provides an overview of this research study by highlighting stroke and aphasia, the prevalence rates of these conditions, and the implications they have for individuals and their families. Pertinent concepts and contexts of the study are presented. The rationale and significance of the study are also presented by outlining the need for qualitative research on disabilities in the South African context. This chapter also presents an overview of the structure of the dissertation.

1.1 Introductory Perspective

1.1.1 The research context

The coronavirus disease (COVID-19), caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), was initially identified in late December 2019, in Wuhan, China (Schröder et al., 2021). COVID-19 rapidly became a global pandemic, and the first case was identified in South Africa in March 2020. This resulted in decisive action by the South African government to immediately declare a national state of disaster and an enforced nationwide lockdown (Schröder et al., 2021) in order to combat the high transmission rates of the coronavirus (Department of Co-operative Governance and Traditional Affairs, 2020a).

The City of Ekurhuleni, which is located in the Gauteng Province of South Africa, is a bustling metropolitan area with a growing population of over three million people (Department of Co-operative Governance and Traditional Affairs, 2020b). The healthcare system in Ekurhuleni includes both public and private sectors (Department of Co-operative Governance and Traditional Affairs, 2020b), with private healthcare playing a significant role in providing quality healthcare services to those who can afford it. However, the COVID-19 pandemic and the rising burden of non-communicable diseases, have presented significant challenges to private healthcare provision in the city (Department of Co-operative Governance and Traditional Affairs, 2020a).

The COVID-19 pandemic had far-reaching implications for healthcare systems globally, and the city of Ekurhuleni was no exception. Healthcare providers had to adapt to a new reality, characterised by lockdowns, social distancing measures, and increased demand for critical care services (Burns et al., 2022). The pandemic resulted in an economic downturn, leading to increased unemployment and financial constraints for many individuals (Department of Co-operative Governance and Traditional Affairs, 2020a). Private and public healthcare providers had to adopt innovative strategies to maintain service delivery, including telemedicine, home-based care, and the provision of personal protective equipment (PPE) for staff and patients (Burns et al., 2022).

Non-communicable diseases pose a significant challenge to the healthcare system in Ekurhuleni, with cerebrovascular accident (CVA) being a leading cause of morbidity and mortality in South Africa (Taylor & Ntusi, 2019). A CVA is a non-communicable disease commonly referred to as a “stroke” (Van Niekerk et al., 2021). South Africa is known to have a higher incidence of strokes reported in urban areas such as Ekurhuleni (Van Niekerk et al., 2021). The burden of a stroke is exacerbated by risk factors, such as hypertension, diabetes, obesity, and tobacco use (Taylor & Ntusi, 2019), all of which are prevalent in the city. Private healthcare providers are positioned to provide specialised stroke care, including access to advanced diagnostic and treatment modalities, rehabilitation services, and post-stroke management (Louw et al., 2023).

Grawburg et al. (2019) have shown that a sub-group of stroke survivors with communication impairments, such as aphasia, may have drastic, long-term implications that include a reduced quality of life and an inability to participate in community activities or pre-stroke hobbies due to added communication difficulties (Simmons-Mackie & Lynch, 2013; Wray & Clarke, 2017). In addition, like other Low Middle-Income Countries (LMICs), there has been a shift in South Africa to address the need for evidence-based rehabilitation to ensure that the best outcomes are achieved for those with disabilities (Watkins, 2019).

There is a growing need for research in the field of stroke rehabilitation including the perspectives of those with communication impairments (Prior et al., 2020). In recent years, there has been a shift in qualitative research to be more inclusive of those living with communication impairments such as aphasia. This allows for better outcomes with these individual's specific needs in mind (Wray & Clarke, 2017).

Speech-language therapists need to consider the perspectives of persons with aphasia as holistic interventions are likely to be achieved when rehabilitation targets realistic and personal goals (Haley et al., 2019). Multiple qualitative studies specific to aphasiology have been conducted to establish the needs, challenges and experiences of persons with aphasia such as their quality of life (Simmons-Mackie & Lynch, 2013). Few qualitative studies have been conducted globally to explore the impact of the COVID-19 pandemic on stroke survivors and their significant others, with most studies in this regard being published in the United Kingdom (Masuku et al., 2022).

Communication impairments may pose challenges with familial and community relationships (Ntsiea, 2019; Souchon et al., 2020). Due to the unexpected changes post stroke, family members are often expected to provide support and care for the stroke survivor. This process may be demanding and may lead to burn-out due to the physical and psychological strain family members face during the care-giving process (Gawulayo et al., 2021). Everyday life situations change after a stroke and these changes are often seen as unexpected, rapid, and life-altering for both persons with the disability, as well as their significant others (Grawburg et al., 2019).

In summary, specific challenges faced by stroke patients with aphasia and their significant others during their rehabilitation experiences were already present before the COVID-19 pandemic. However, the global health crisis has further exacerbated these challenges or revealed new challenges for facilitators (Zafra-Tanaka, 2022). The limitations imposed by COVID-19, such as social distancing measures, reduced access to in-person therapy, and increased reliance on telehealth services, have also impacted the provision of comprehensive and effective rehabilitation for individuals with aphasia (Lucas et al., 2021).

1.1.2 Positionality of the researcher

As a speech-language therapist, I have been fortunate to have practiced in a variety of settings which include community rehabilitation and neurorehabilitation both in government and private practice. I have therefore had the privilege of coming across many families during post-stroke interventions.

This research study was initially conceptualised in early 2020, before the COVID-19 pandemic era. The COVID-19 pandemic-imposed changes on the traditional experiences of aphasia rehabilitation post stroke and therefore may have influenced the manner in which data collection took place during this period. Within a South African context, the extent of the COVID-19 pandemic was not widely known at the time including the impact it may have on stroke persons with aphasia.

Although we as therapists, had reduced contact time with patients and rarely engaged with families, we continued to provide treatments to in- and out-patient stroke survivors pre and post the COVID-19 pandemic. Hence, I witnessed first-hand the adaptations needed to facilitate rehabilitation during this time. This changed over the course of the pandemic as more policies were drawn up, in particular, for the increased use of technology to aid in alleviating communication and access to healthcare services. There were also limitations to the manner in which rehabilitation and speech therapy were conducted. For example, intervention methods, such as group therapy, were abruptly stopped and unavailable through the duration of the pandemic. Patients were not allowed pass-outs to their homes or communities while family members were unable to visit or participate in therapy sessions in person. Functional therapy, such as community integration, community walks or engaging patients in activities of daily living was stopped. We were also unable to routinely conduct joint sessions with other allied healthcare professionals. In addition, social distancing and mask wearing made it challenging during speech and language intervention sessions. These experiences were the basis of this research study to establish the lived experiences of stroke survivors with aphasia and their significant others during the COVID-19 pandemic. The objective was to uncover the ways that COVID-19 may have impacted or influenced their diagnosis, rehabilitation journeys and re-integration.

1.1.3 Time-line of the research

The time-line of this research provides the context:

- January 2020: Initial conceptualisation of the research
- March – June 2020: Considerations of adapting the study on the influence that the COVID-19 pandemic may have on the ability to collect data as well as the results of the study
- August 2020: Presentation of the study proposal to the post graduate seminar group
- October 2020: Study proposal submitted for ethical clearance and to the faculty readers
- October 2020 – February 2022: Abeyance taken by the researcher due to personal and health related factors
- March 2022 – June 2022: Data collection took place, in conjunction with data analysis
- August 2022 – March 2023: The study was completed and the write-up was conducted, submitted for supervisory review and adapted based on comments thereof
- March 2023: Submitted for examination
- August 2023: Submitted for examination

1.2 Significance of the study

1.2.1 The coronavirus disease 2019 (COVID-19) and its effect on stroke and aphasia

The implementation of the Disaster Management Act resulted in lockdown procedures, economic and trading restrictions, curfews, restricted movement of persons in the country and inter-provincial travel, international restrictions, and the compulsory wearing of a face covering (Department of Co-operative Governance and Traditional Affairs, 2020a). As healthcare was considered an essential service and was operating throughout lockdown, preventative measures were conducted in hopes of sustaining an overwhelming and already fragile health care system in South Africa (Schröder et al., 2021).

The COVID-19 pandemic caused unprecedented challenges to health care systems globally (Burns et al., 2022). It was also expected that the fallout from the pandemic would cause difficulties for those that were diagnosed with a stroke during this time (Burns et al., 2022). The COVID-19 pandemic impacted stroke patients in different ways including making patients more susceptible to infections (Oxley et al., 2020). COVID-19 also affected how the treatment for a neurological event, such as a stroke, was delivered and altered during the pandemic (Markus & Brainin, 2020).

There was a marked reduction in stroke rehabilitation admissions during the COVID-19 pandemic even though there was an increase in incidences (Markus & Brainin, 2020). Additionally, there was a significant impact on the way services to stroke patients were delivered as a direct result of overburden, enforced social restrictions, and reduced access to clients (Markus & Brainin, 2020). Markus and Brainin (2020) show that, internationally, stroke admissions fell between 50% and 80%, which has been attributed to fears of infection during hospitalisation amid the pandemic. This data suggests that patients presenting with mild, moderate, or even severe stroke, who would ultimately benefit from acute care and therapies, were not being treated as early as necessary or even for long enough periods. This would broadly impact long term stroke burden as research has shown early intervention is critical in stroke recovery (Markus & Brainin, 2020).

The COVID-19 pandemic resulted in healthcare shifts worldwide to accommodate medical interventions which, in turn, caused changes in how stroke care and stroke rehabilitation were conducted during this time (Markus & Brainin, 2020). In the wake of the COVID-19 pandemic, rehabilitation outcomes may have been further impacted as resources were redirected to assist with the health crisis (Markus & Brainin, 2020).

Many measures that were put in place to combat the virus may have negatively contributed to the rehabilitation outcomes for persons with aphasia (PWA). These include: 1) the wearing of face masks which at times resulted in the distortion of verbal messages, further impacting on the processing abilities of persons with aphasia, as well as the inability to interpret nonverbal communication cues; 2) social distancing which may have impacted group therapy which is often essential for support and pragmatic aims; 3) a reduction in the use of tactile cues and facilitation techniques that require auditory-verbal-visual feedback; and 4) a no visitation policy which may have further added to psychological and emotional distress often experienced by those with aphasia.

Within the context of the pandemic, telemedicine has facilitated rapid policy and practice changes through government and private professional bodies that were implemented to assist with providing healthcare services remotely or adapting existing practices (Budd et al., 2020). Additionally, family involvement in the rehabilitation process appears to be the most affected due to the COVID-19 pandemic and subsequent restrictions. Families were not able to participate in direct intervention techniques, and family meetings were adapted to teleconferencing (Budd et al., 2020).

The COVID-19 pandemic had severe consequences for the well-being of persons with disabilities across the board (Bailey et al., 2022; Burns et al., 2022; Zafra-Tanaka et al., 2022), including those with stroke and subsequent aphasias. The restrictions brought about by the COVID-19 pandemic added to barriers already experienced by persons with aphasia and their families (Burns et al., 2022). However, not much is known about the specific implications of COVID-19 on aphasic rehabilitation within the South African context (Masuku et al., 2022).

This led the study to explore the impact of the COVID-19 pandemic on the recovery of persons with aphasia and establish the ways in which their diagnosis and rehabilitation may have been impacted in a South African context. It required an understanding of the specific lived experiences of persons with aphasia who were diagnosed with a stroke and subsequent aphasia during the COVID-19 pandemic and received rehabilitation during this time. In addition, it included the lived experiences of patients' significant others due to the prevalence of third-party disability with stroke and stroke-induced aphasia.

1.2.2 Inclusion of persons with aphasia in qualitative research

Qualitative research approaches are used in order to explore complex experiences such as living with aphasia (Simmons-Mackie & Lynch, 2013). Jagoe et al. (2021) suggest that although most studies which are inclusive of those with communication difficulties have been conducted in developed countries, limited findings have been uncovered in developing countries like South Africa where inclusivity may be more challenging. People with communication disabilities, like aphasia, are often underrepresented in research and may be subjected to unintentional research bias in their right to freedom of expression and opinion (McEwin & Santow, 2018). These findings highlight the need for inclusive research methodologies.

Inclusive research, as a methodological practice, shows that, in recent years, there have been methodological shifts from medical research practices to rights-based approaches (Gjermestad et al., 2022; Nind & Strandova, 2020). Qualitative studies that consider insider perspectives of persons with aphasia have been routinely conducted in aphasiology by Blom-Johansson (2012), Blom-Johansson et al. (2022), Cruice et al. (2006), Howe et al. (2004), Howe et al. (2008), Howe et al. (2012), Legg (2010), Parr (2004), Parr (2007), and Parr et al. (1997). Simmons-Mackie and Lynch (2013), in their review of qualitative research in aphasiology, conclude that qualitative research, inclusive of people with aphasia, emphasises the importance of the insider perspective. In addition, the United Nations (2019) recommends the inclusion of those with disabilities in research studies to hasten policy change and practice to provide for populations that are directly affected (Jagoe et al., 2021). This study therefore included those with aphasia and focused on their lived experiences and needs because, even though their communication is impaired, persons with aphasia display communicative intent and the yearning to participate and engage when provided with the opportunity and the ability to express themselves in the ways that they still can (Blom-Johansson, 2012).

Previous literature has documented that the transition between the hospital and integration into the community for stroke survivors, especially those with aphasia, is often difficult (Hersh, 2016; Wray & Clarke, 2017). This is due to the added challenges those with aphasia may have when accessing healthcare as well as trying to re-integrate into previous contexts post-discharge (Grawburg et al., 2019). There have also been reports of feelings of abandonment and a lack of support in the long-term post-discharge by persons with aphasia (Worrall et al., 2011; Wray & Clarke, 2017). Given that the healthcare needs of persons with aphasia are multifaceted, the need for preventative, therapeutic, and rehabilitation services at different levels of care is essential (Akinyemi et al., 2021; Masuku et al., 2022). This study therefore collected qualitative data to further develop policy and practice changes which directly address the needs of those who are afflicted by these conditions (Jagoe et al., 2021; Simmons-Mackie & Lynch, 2013).

COVID-19 has shown the need for sustained investment in global health research, specifically in the post COVID-19 pandemic era, to develop more structured rehabilitation programmes that will yield better outcomes in the event of future pandemics (Reid at al., 2021). The COVID-19 pandemic has also amplified the prevalence of global health inequalities such as access to healthcare and social cohesion. Research seeking to understand and address these inequalities should be a global priority (Reid et al., 2021).

In the post COVID-19 era, health-care workers and academic researchers have the opportunity and responsibility to transform global health by building on the experiences, challenges, and critical awareness made available during the COVID-19 pandemic (Reid et al., 2021). There is also need to ensure better policy and practice implementation so that health gains are continually sustained rather than reversed, particularly in the event of a new pandemic (Reid et al., 2021).

1.2.3 Inclusion of significant others of persons with aphasia in qualitative research

Literature has indicated that the significant others of persons with aphasia need support and often require additional information and knowledge throughout the rehabilitation process and post-discharge. This shows the need for a family-centred approach to aphasia (Gawulayo et al., 2021; Grawburg et al., 2019; Souchon et al., 2020). Significant others, within the South African context, often assume the role of informal care-givers which causes disruptions in their daily lives and can place undue strain on these individuals (Morais et al., 2012). This may affect physical, mental and social aspects of their lives resulting in a poor quality of life (Simmons-Mackie & Lynch, 2013).

The COVID-19 pandemic has increased the demands placed on by family care-givers in supporting stroke survivors (Masuku et al., 2022; Sutter-Leve et al., 2021). Findings by Masuku et al. (2022) further indicate that, due to COVID-19 pandemic restrictions, there were reduced interactions with care-givers within the rehabilitation space. Lucas et al. (2021) report reduced functioning of caregivers as well as increased feelings of isolation as they were unable to effectively observe in-patient rehabilitation and subsequent progress. Also, due to the absence of rehabilitation spaces, family caregivers presented with high levels of concern about the stroke survivors well-being and functioning (Stutter-Leve at al., 2021). Shafer et al. (2023) found that the COVID-19 pandemic impacted on informational support available to family care-givers and, due to regulations and restrictions, they were unable to gain or maintain support systems.

Pre COVID-19 literature on significant others of persons with aphasia, such as a study by Howe et al. (2012), state that significant others want to be actively involved in the rehabilitation of their loved ones, need to develop communication strategies and require support in order to understand the diagnosis. Shafer et al. (2023) found that this need remained consistent even in the presence of the COVID-19 pandemic which posed an additional barrier in this regard.

Third party disability, due to post-stroke aphasia, is well documented within the literature. Findings in the literature indicate that there are effects on the family systems and family relationships together with psychosocial implications such as reduced social engagement (Blom-Johansson, 2022; Grawburg, 2019). There is also an increased burden of care, unmet information needs, increased stress and health conditions (Lucas et al., 2021). What is less known, specifically in the South African context, is how the COVID-19 pandemic may have influenced these effects. Additionally, the reduced role of the family may, in fact, provide an opportunity to show the importance of the role of the family within stroke and aphasia rehabilitation. For this reason, this study explored the experiences of both persons with communication disabilities and their families as neurological impairment and subsequent difficulties impacts both (Grawburg et al., 2019).

1.2.4 Significance of the biopsychosocialtech model

Stroke itself is complex, as is aphasia; both are categorised as functional levels which are continually transitioning (Hersh, 2016). This impacts treatment and further informs the need for an understanding of the underlying neurological changes in order to inform management decisions (Hersh, 2016). High levels of stress, uncertainty and concern with regard to remaining committed are decreased when persons with aphasia are supported effectively and provided with adequate information (Hersh, 2016). This reinforces the idea of treating the whole patient within a patient-centred approach framework such as the biopsychosocialtech model.

Due to the COVID-19 pandemic, there has been a growing reliance on technology in order to facilitate communication as well as rehabilitation (Shafer et al., 2023). Digital technologies, including smartphones, tablets, and computers, have the capacity to facilitate and enhance individuals' involvement in activities after experiencing a stroke either independently or with aid (Narbutaitienė et al., 2023). While telerehabilitation had been documented in the literature before the COVID-19 pandemic, it had not been widely used in the treatment of stroke and aphasia particularly in the South African context and further research was required (Masuku et al., 2022). As the COVID-19 pandemic progressed, individuals maintained social connectedness through online social platforms. Kong (2021) believes that due to the increased interest in using technology in rehabilitation spaces, it is important to consider how these changes may impact persons with aphasia (Kong, 2021).

Considering the aims and objectives of this study, the biopsychosocialtech model was chosen to allow for an in-depth holistic interpretation that would consider all aspects of impairment, functioning, participation, and technology to effectively interpret the experiences of stroke survivors with aphasia and their significant others.

1.2.5 Concluding notes on the significance of this research study

In summary, this research is contextually relevant as it notes how the COVID-19 pandemic influenced the lived experiences of stroke survivors with aphasia during the COVID-19 pandemic as well as their significant others. It highlights the needs of those with communication impairments, based on their lived experiences and perceptions, so that treatment approaches can be developed. It addresses both facilitators and barriers perceived by stroke survivors and their significant others within a South African context, so that these can be addressed, and effective policies can be implemented to assist in better rehabilitation treatments for stroke survivors. As stroke is a non-communicable disease and causes disruptions in ability and functioning in a multifaceted manner, this study used a conceptual framework that would allow for holistic interpretation through the use of the biopsychosocialtech model.

1.3 Outline of the dissertation

This research document consists of six chapters which are detailed below.

Chapter 1: Background and Rationale

This chapter focuses on the introduction of concepts and relevant topics explored in this research. The research aims and rationale are introduced. Additionally, an outline of the study is provided in the closing of this chapter.

Chapter 2: Literature review

A review of the literature is provided in this chapter. A discussion of all concepts that are essential to this research, most notably, stroke and aphasia, are defined and further explored in terms of incidence and prevalence, diagnosis, treatment, and functional limitations. Additionally, third-party disability, within the context of aphasia, is discussed. This includes previous studies in aphasia and their specific methodologies. Lastly, the theoretical framework is further defined and discussed in relation to the research context.

Chapter 3: Methodology

The research question, aim, and specific objectives are outlined in this chapter. An in-depth description of the methodological concepts is provided, namely, the research design, access to participants, the pilot study, methods of data collection, data analysis, ethical considerations, and the rigour and trustworthiness of the study**.**

Chapter 4: Findings

Findings of the research study are outlined and presented in this chapter. An inductive thematic analysis was used. Four main themes were identified: 1) Consequences of stroke on persons with aphasia; 2) experiences within the health care system; 3) reintegration into premorbid contexts; and 4) changes in family context. This chapter makes use of quotes in order to support the data extracted.

Chapter 5: Discussion

A discussion of the findings in relation to the themes and the theoretical framework, namely, the biopsychosocialtech mode, is presented in this chapter. The findings of this research are also compared, contrasted and discussed to relevant studies in the literature.

Chapter 6: Conclusion

A summary of the findings is given. The strengths and limitations of this research are explored. This chapter closes by highlighting implications and recommendations that have arisen from this research study that are linked to policy, practice, and research.

Chapter 2: Literature Review

Outline of chapter

This chapter presents a review of pertinent literature relating to this study. Through the use of literature sources, this chapter provides definitions of concepts used and the relevance of this study in relation to similar studies conducted in the past. It also discusses the gaps in the literature with specific regard to persons with aphasia and aphasia treatment. Additionally, this chapter reviews the use of a biopsychosocialtech model in discussing aphasia as a post-stroke impairment.

2.1 Cerebrovascular accident (CVA)

2.1.1 Definition

A cerebrovascular accident is defined as a focal neurological disorder involving decreased blood flow to and within the brain as a consequence of pathological processes in the blood vessels, making the nervous tissue of the brain incapable of surviving more than a few minutes without oxygen, and causing irreversible brain damage. This is more commonly known as a stroke (Lau et al., 2018).

A stroke occurs when there is a disruption of blood flow either through a blockage of vessels or the rupture of vessels (Lau et al., 2018). Strokes could be caused by a clot obstructing the flow of blood to the brain, termed an ischemic stroke, or it could be caused by a haemorrhagic stroke, which occurs when a blood vessel ruptures. This prevents blood flow to the brain and ultimately leads to neurological impairment (American Stroke Association [ASA], 2020b). When the disruption of blood flow occurs, it leads to an infarct. Clinically, a vast range of neurological symptoms caused by stroke is noted depending on focal area, the extent of the impairment, and the depth of the impairment (Lau et al., 2018). Some studies note that lasting changes in brain function can occur, even if it is distant from the actual site of lesion (Lau et al., 2018).

Left hemisphere infarcts, in most cases, result in speech, language, and communication impairments (ASA, 2020b). These include, but are not limited to, aphasia, apraxia, dysarthria, voice disorders, and auditory processing difficulties (ASA, 2020b).

2.1.2 Summary of stroke incidence and prevalence: Pre- and post-COVID-19 implications

Stroke is of significant concern globally because of its increasing prevalence due to epidemiological transition (Ranganai & Matizirofa, 2020; Watkins, 2019). Epidemiological transition refers to the shift in the pattern of diseases and causes of death that occurs as countries undergo social and economic development (Watkins, 2019). During this transition, there is typically a decrease in the prevalence of infectious diseases and an increase in chronic diseases like stroke, heart disease, cancer, and diabetes (Watkins, 2019). It has also been reported that stroke in low- and middle-income countries (LMIC), such as South Africa, exceeds high-income countries by 20% (Watkins, 2019). These statistics were recorded before the pandemic, and as aforementioned, there has been a link between COVID-19 infection and strokes, which may increase its prevalence (Mochan & Modi, 2020).

In South Africa, like in many other LMICs, stroke is the leading cause of mortality and morbidity (Scheffler & Mash, 2019). This burden is steadily increasing due to socioeconomic factors, urbanisation and transition, and the health profile of citizens (Scheffler & Mash, 2019). A noted increase in the prevalence of strokes has been attributed to many factors, which include an increased life expectancy which inadvertently impacts age groups that are more susceptible to neurological conditions and an increase of associated risks such as smoking, unhealthy lifestyle choices, and genetic conditions such as heart disease, hypertension, and diabetes (Zillmer & Spiers, 2001 as cited in Taylor & Ntusi, 2019). The South African Comparative Risk Assessment Collaborating Group estimated the contribution of eight risk factors to stroke: hypertension (52%), tobacco use (24%), excess body weight (18%), high cholesterol (15%), physical inactivity (12%), low fruit and vegetable intake (12%), diabetes (8%), and alcohol consumption (8%). Stroke management, especially in young South Africans, is often complicated by the high prevalence of the human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS) (Taylor & Ntusi, 2019).

An average daily rate of South Africans experiencing a stroke has been recorded as 240 persons, of which 70 cases are likely to be fatal (Heart Foundation of South Africa, 2020). Those who suffer a stroke can recover spontaneously, however, many stroke survivors face life-altering disabilities, which impact them both physically and cognitively (Heart Foundation of

South Africa, 2020). While a stroke greatly affects the life of the patient, there have also been detrimental effects on the family unit and significant others.

There were reports of neurological involvement resulting from COVID-19 infections from small cohorts in Wuhan, Italy, and New York (Mochan & Modi, 2020). Stroke risk is increased in patients presenting with COVID-19 due to inflammation, hypoxia, and hypercoagulability (Mochan & Modi, 2020). Moreover, those with previous and new strokes are likely to present with more severe symptoms of COVID-19. Stroke appears to be more common in those presenting with severe COVID-19 and is often correlated with hypertension, diabetes, smoking, stroke history, and old age (Mochan & Modi, 2020).

Large vessel strokes have been identified in the younger population aged 30 to 50 years old with no previous history or risk factors. This is attributed to coagulation and pulmonary embolisms (Oxley et al., 2020). Oxley et al. (2020) maintain that, while there has been a notable increase of reported strokes in patients under 50 years of age, all of whom have tested positive for COVID-19, more structured and controlled research needs to be conducted in order to investigate this phenomenon specifically in the younger population. However, it can be inferred that this will directly impact the incidence and prevalence of strokes resulting in an increase in stroke presentations.

As the pandemic progressed, more information became available after thorough investigations of the link between COVID-19 infection and stroke. Stefanou et al. (2023) state that CVA infections are directly associated with COVID-19 infection. The majority of COVID-19 patients, who suffer either an acute ischemic stroke or a haemorrhage stroke, are likely to have vascular risk factors that result in the presentation of stroke (Stefanou et al., 2023). Studies have also found that COVID-19 infection acts as an independent risk factor for stroke (Qureshi et al., 2021; Stefanou et al., 2023). This is likely due to coagulation factors caused by the COVID-19 infection (Qureshi et al., 2021; Stefanou et al., 2023). It has also been found that six months post-infection there is an increased risk for cerebrovascular disease to occur as well as an increased risk within non-vaccinated patients who present with COVID-19 infection (Stefanou et al., 2023).

2.2 Consequences of stroke

2.2.1 Impairment due to stroke

Stroke is the leading cause of long-term rehabilitation and physical disability worldwide (Olasoji et al., 2022). Depending on the site of lesion and severity of the stroke, physical symptoms will differ. Additionally, post-stroke recovery is often influenced by the clinical presentation of a patient. Outlined below is a summary of symptoms that are associated with a stroke incident (Olasoji et al., 2022).

Stroke survivors have an array of movement and coordination difficulties – there are multiple motor impairments that arise from a stroke such as limb weakness or paralysis, muscle weakness, impaired mobility or walking ability, difficult with gait and balance, an increased risk of falling, difficulty with sensation, and difficulty managing and controlling their bladder or bowel (Popkirov et al., 2020). It is possible that there is also limb weakness or limb paralysis. Those with stroke also face difficulty with their psychological well-being and may have post stroke depression, decreased self-worth, and cognitive difficulties (Popkirov et al., 2020). Other symptoms of a stroke can manifest as specific speech, language, or swallowing deficits (dysphagia) where an individual may need enteral feeding or supplemented feeding therapy. Dysarthria is a weakness of muscles which can occur in isolation or with oral and verbal apraxia, which is a motor planning disorder (Popkirov et al., 2020). In addition, neurogenic stuttering and vocal pathology have been noted post-stroke however, this is not likely to occur in isolation (Popkirov et al., 2020). It is also fairly common for dysarthria, apraxia, aphasia and dysphagia to co-occur post-stroke (Popkirov et al., 2020). These disabilities, in turn, may cause reduced functioning in activities of daily living such as feeding, bathing, grooming, toileting, transferring, and mobility. Furthermore, the disability results in reduced participation in different activities (Popkirov et al., 2020).

2.2.2 Aphasia

Aphasia is defined as a disorder caused by an acquired neurological event that causes language impairments and communication impairments (Perrotta, 2020). Most often, aphasia is caused by a stroke however, there are cases of traumatic brain injury or other neurological events which may also cause aphasia. This study focused on participants who have acquired aphasia as a result of a stroke that occurred during the COVID-19 pandemic.

Initial aphasia severity and the recovery during the first few weeks after a stroke are generally good predictors of the outcome and severity of the aphasia the patient will be left with. Spontaneous recovery decreases after three months and plateaus six months after the onset of the disorder (Blom-Johansson, 2012; Hersh, 2016). However, language ability can improve years after onset due to training and treatment approaches (Hersh, 2016). There are different types of aphasia that impact speech, language, and communication ability in a variety of different ways (Blom-Johansson, 2012; Doogan et al., 2018). Aphasia can be detected at all linguistic levels, which are phonological, morphological, syntactic, lexical, and pragmatic. Typical symptoms are seen through paraphasia (literal, verbal, or neologisms), perseveration, circumlocution, anomia, and alexia (Blom-Johansson, 2012). It can be extrapolated that aphasia also results in a decreased ability to process, retain, retrieve, and recall information (Blom-Johansson, 2012). The impairment in language ability due to aphasia can affect a person on multiple levels, which includes verbal expression, auditory comprehension, reading and writing, cognitive-linguistic ability, and higher thought and processing skills (Blom-Johansson, 2012).

Having a stroke-induced aphasia may result in an individual experiencing aphasia while also having other stroke-related symptoms that may include motor, sensory, cognitive, and additional communication impairments such as dysarthria or apraxia that may affect everyday life (Blom-Johansson, 2012). As communication is a fundamental function, a language impairment, such as aphasia, may result in severe participation restrictions and reduced activities (Blom-Johansson, 2012). Persons with aphasia have a reduced quality of life and a higher degree of distress compared to those who have a stroke without aphasia (Blom-Johansson, 2012; Hilari et al., 2015a; Hilari et al.,2015b).

Aphasia is known to have a detrimental impact on an individual’s ability to fully re-integrate and engage in a meaningful way, which may lead to a decreased quality of life (Cruice et al., 2006; Hilari & Northcott, 2006; Parr, 2007). The impact can be immense, with people reporting feelings of personal exclusion such as isolation, depression, low self-esteem, frustration and anger (Parr, 2004; Parr et al., 1997). At the social level, aphasia can make it difficult to engage with family, friends, neighbours, work colleagues and members of previously enjoyed social groups (Hilari & Northcott, 2006; Parr, 2007; Simmons-Mackie et al., 2017; Worrall et al., 2011).

Many stroke survivors with aphasia experience frustration due to their inability to communicate (Grawburg et al., 2019). They have also articulated that, as they are not able to express themselves clearly, they become isolated and tend to withdraw. Hersh (2016) found that survivors with aphasia experience higher stress levels in comparison to stroke patients without aphasia.

2.2.3 The impact of communication impairment and loss of ability in persons with aphasia

Stroke and, as an extension, aphasia can also cause disruptions to a person's self-worth, family, social, and work interactions. Aphasia has a detrimental impact on the quality of life of the person with aphasia, as well as a negative effect on their families in many aspects (Masuku et al., 2018). Changes in communication contexts have been documented and often increase frustration, stress, turmoil, resentment, reduced marital quality of life, and limitations on family life, social roles, and other activities, as well as decreased responsibility (Grawburg et al., 2019; Hersh, 2016; Masuku et al., 2018). Aphasia generally appears to have a limited impact on domestic activities of daily living (ADL) in comparison to significantly disadvantaging complex social activities – which include both work and leisure activities that involve community access and many communication partners (Grawburg et al., 2019).

Living with aphasia usually impedes a person's autonomy and causes an excessive amount of leisure time with no consensus on how to employ it. This is because living with aphasia imposes on a person's ability to plan and organise due to the loss of autonomy (Grawburg at al., 2019). It is often the reality that once a person returns home from the hospital, their hobbies and interests rapidly change or come to an end altogether (Natterlund, 2010; Pandolfo, 2013). Basic communicative tasks found in everyday life become challenging. Mundane activities, such as greeting a neighbour, are heavily reliant on communicative ability, and a reduction therein results in decreased social inclusion and initiation (Pandolfo, 2013).

Vickers (2010) found that social networks are affected after the onset of aphasia. This should be concerning to clinicians as social networks directly link to life participation, mental health, mental well-being, and a better quality of life. There is also a shift in the power dynamic due to a loss of autonomy, resulting in persons with aphasia having negative emotions or contradictory feelings toward their significant others. They may feel powerless, excluded, resentful of expectations, intrusiveness on their autonomy due to their inability to communicate effectively, and guilt because they require assistance and heavily depend on their significant other (Pandolfo, 2013).

A study carried out by Parr (2007) aimed to record the day-to-day life and experiences of people with severe aphasia. The rationale of this study involved the decreased interest and documented academic research on patients with stroke once rehabilitation is completed. The study used ethnography to document instances of social inclusion as well as social exclusion as they occurred in typical everyday settings. Findings of the study concluded that social exclusion was a common theme and experience for all participants with aphasia. It was further found that social exclusion occurred at many different levels which were identified as infrastructural, interpersonal and personal levels. The study further concluded that social exclusion could be remediated by enabling communication partners, as well as establishing and expanding systems to create better communication opportunities and communication access..

A study by Worrall et al. (2011) postulates that goal setting with persons with aphasia is difficult to navigate due to their language and communication impairments, which are often further extended due to processing and cognitive deficits. However, it needs to be constantly stressed, specifically within a rehabilitation setting, that persons with aphasia need to be seen as competent partners in the decision making of their therapy. Persons with aphasia have the right to autonomy and decision-making on their health and well-being and should be provided with opportunities to communicate their needs (Worrall et al., 2011).

A project conducted by Simmons-Mackie et al. (2007), to improve communication access for persons with aphasia within healthcare spaces, targeted healthcare providers in acute care, rehabilitation care and long-term care settings. Qualitative data were collected prior to a 2-day programme as well as after the programme, in addition to a four-month follow-up. A qualitative thematic analysis was used to evaluate the effectiveness of the project. It was found that more success occurred with teams in rehab and long-term care as opposed to acute settings. The authors conclude that targeting systems level change appeared to be a useful approach to improving access to healthcare information and decision making for persons with aphasia.

Findings from a study conducted by Masuku et al. (2018) in Tembisa, a township in South Africa, correlated with international findings which found that family interactions and socialisation were affected due to the neurological event and subsequent aphasia. Caregivers (family members) struggled to communicate with persons with aphasia even if the person was able to initiate communication. Participants found that communication was frustrating, tedious, limiting, and humiliating. The role of support also directly impacted the caregiver and, if people within the family or community could not provide adequate financial or social support, there was an increased feeling of social exclusion and loneliness.

A scoping review by De Beer et al. (2020) in South Africa evaluated current research in Africa relating to the communication needs of stroke survivors. The findings revealed both direct and implied communication needs for stroke survivors, particularly, health knowledge, social considerations, topics, means of communication, accessing resources, vocational communication and culture, and spirituality. The authors of this study further considered the findings within the African context as unemployment, poverty, access to services as well as informal caregivers as factors that may affect the stroke survivor's ability to reintegrate or participate effectively in differing social contexts.

2.2.4 Stroke and aphasia resulting in third party disability

According to Grawburg et al. (2019), decades of research have revealed that third-party disability is prevalent in the family members of persons with aphasia. Secondary to aphasia, family members often experience changes to their emotional functioning, communication, relationships, recreational activities, social lives, work, education, caregiving duties, domestic duties, and finances. These changes impact the dynamic of relationships and often result in frustration (Pandolfo, 2013). A type of dysfunction that exists is a discrepancy between the family's expectations and the stroke survivor's abilities (Kitzmüller et al., 2012).

According to Grawburg et al. (2013), aphasia is associated with adverse changes to family members' physical, mental, and emotional health (reported by 85% of participants); communication (85%); relationships (95%); recreational activities and social life (70%); paid work, volunteer work, and/or education (50%); domestic and care-giving responsibilities (90%); and finances (30%). Grawburg et al. (2019) conducted a follow-up study, adding to the initial research. These results showed that speech-language pathologists should be aware of the impact of aphasia on third party functioning beyond communication and relationship changes, resulting in aphasia rehabilitation directly addressing the needs of family members and thereby achieving optimal outcomes for both the persons with aphasia and their family members (Grawburg et al., 2019).

Within aphasiology, the role of the significant other, as a communication partner, has been documented as an essential tool to contribute to the enhancement of communication competence and communicative opportunity (Kagan, 1995; Parr, 2007; Simmons-Mackie, 1998; Simmons-Mackie & Damico, 1995). This ultimately aids in increasing social inclusion and provides a psychological benefit (Kagan & Gailey, 1993).

According to Blom-Johansson (2012), persons with aphasia value communication and interaction even though they present with impairments. However, significant others may find it challenging to navigate and communicate with them effectively. According to the survey conducted by the Stroke Association (2013), many carers, who are family members or significant others, feel that they have to constantly put the needs of the stroke survivor above their own, whereas survivors of stroke feel that they often have to mask their inabilities and stay strong for the family. Both parties have expressed not feeling comfortable enough to express how they truly feel, which negatively impacts the partnership and the family system.

A qualitative study was conducted by Jacobs-Nzuzi Khuabi et al. (2020) to understand the lived experience of eight informal family caregivers in South Africa. The study revealed five themes, namely, role change, time usage, types of support and the relief it brings, merged identity, and the essence of caring. The findings further suggested that, being a caregiver, brought with it additional responsibilities and reduced time for the caregiver to engage in their own interests. It was further suggested that healthcare workers focus on the needs of the caregiver, given that they have a fundamental role in the lives of stroke survivors.

In South Africa, Masuku et al. (2018) found that caregivers often felt high levels of burnout as well as emotional and psychological difficulties as a direct implication of caregiving. It was difficult for them to navigate and endure lifestyle changes that were thrust on them and that they were expected to carry out as spouses and siblings. Masuku et al. (2018) also stated that caregivers appeared to have a general understanding of stroke. However, they struggled to comprehend the gravity of aphasia and communication impairment that can result from stroke. There is limited insight on how stroke impairment impacts the family and it is important to identify these needs through their lived experiences to improve and reduce caregiver burden (Elloker & Rhoda, 2018). Additionally, Gawulayo et al. (2021) found that, post-stroke, there are changes between the person with stroke and their spouse, as well as the children, as reduced interactions are noted with the immediate and extended family. Caregivers found it emotionally draining to take care of their loved one post stroke as well as the financial implications due to the stroke. Gawulayo et al. (2021) also highlighted the detrimental impact that communication impairment has on a family.

2.3 The South African rehabilitation context

In the context of stroke rehabilitation, the best practice is described as consistent multidisciplinary services to assist patients in retaining or achieving the highest potential functioning post-stroke (Watkins, 2019). Stroke rehabilitation should focus on practical intervention in previously meaningful contexts such as work, education, hobbies, and leisure activities (Watkins, 2019). International best practice guidelines for stroke treatment entail a continuum of acute stroke unit care, closely followed by a multidisciplinary team (MDT) in an in-patient step-down facility and out-patient or home-based rehabilitation delivered by an MDT (Scheffler & Mash, 2019). These services are seen as continued, intensive, and highly coordinated (Scheffler & Mash, 2019). In South Africa, citizens may have access to private healthcare and rehabilitation services through self-funding or medical aids; however, stroke care in South Africa still appears to be limited with an urban bias even with best practice guidelines (Van Niekerk et al., 2021).

There are three tiers within the private healthcare sector – acute hospitals, step-down facilities, and out-patient facilities. These often work together, and transfer between the tiers occurs throughout rehabilitation. Stroke rehabilitation typically begins at the acute phase and continues to community and out-patient contexts. Intervention is usually conducted through individual therapy sessions or group sessions and ideally should involve the carer (National Institute of Neurological Disorders and Stroke, 2019). There are a number of factors that impact therapy outcomes which include pre-stroke functioning and ability, level of interaction in therapy contexts, level of family support, and the environment or therapy setting for rehabilitation (Nelson et al., 2016). It is thereby imperative that rehabilitation be individualised as patients' needs differ even if they may have the same type and severity of stroke (Nelson et al., 2016). An MDT typically includes a physical medicine and rehabilitation (PMR) doctor or a rehabilitation physician, physiotherapists, occupational therapists, speech-language pathologists, nurses, social workers, psychologists, and therapy assistants (Mayo Foundation for Medical Education and Research, 2019). These services, however, are often found in metropolitan areas only (Maredza & Chola, 2016).

In a study estimating the direct cost of stroke services in South Africa, Maredza and Chola (2016) found that the direct costs of stroke rehabilitation were R2.5-million, and 80% of this cost was related to in-patient stay. According to Maredza and Chola (2016), there are direct and indirect costs associated with stroke care – direct costs are termed as medical expenses. Effective healthcare planning and resource allocations are needed to cope with the expected increase in stroke prevalence, the associated healthcare costs, and the psychosocial impact on families and stroke survivors (Watkins, 2019). In addition, patients, especially those with communication disabilities, and their families, are often excluded as active participants of the rehabilitation process (Grawburg et al., 2019).

Additionally, even before the COVID-19 pandemic, within government organisations in South Africa there were poor referral pathways which result in reduced care continuity. This is also impacted by other factors such as bed capacity, and poor communication between health care workers (HCWs) and patients especially with discharge planning and follow-ups (Van Niekerk et al., 2021). There also appears to be long waiting times and higher caseloads within rehabilitation which may impact the efficacy of treatment (Van Niekerk et al., 2021).

Challenges with stroke rehabilitation have been identified as a global concern as the rehabilitation needs of stroke survivors are still not being effectively met (Akinyemi et al., 2021; Masuku et al., 2018; Masuku et al., 2022). There are also multiple factors that may hinder rehabilitation outcomes for those with aphasia within a South African context. They include a lack of rehabilitation personnel (Masuku et al., 2018), cost (Louw et al., 2023), access (De Beer et al., 2020), cultural, social and linguistic implications (Legg, 2010), health literacy (Masuku, 2018), as well as effective rehabilitation programmes that meet the needs of the patient (Khoza-Shangase & Mophosho, 2018).

2.3.1 Adaptation to rehabilitation services during the COVID-19 pandemic

South Africa had four recognisable pandemic waves, each of which was dominated by a particular variant: the first wave was the ancestral strain; the second was the beta variant; the third was the delta variant; and the fourth was the omicron variant (Jassat et al., 2022). In between the waves, an easing of lockdown restrictions was announced in South Africa (Mahase, 2022). The changes in lockdown procedures during stroke rehabilitation had an impact on individual experiences with notable changes due to differing regulations (Burns et al., 2022; Lucas et al., 2021; Masuku et al., 2022; Spinelli & Pellino, 2020; Sutter-Leve et al., 2021). These included: notable delays in stroke care; decreased length of stay in the acute setting due to beds being needed for COVID-19 patients; earlier discharge to post-acute care; effects on a systems level, individual level, and personal level, within the home and community; as well as decreased engagement due to pandemic related restrictions. Other changes and effects were the implementation of specific regulations such as mask wearing; restricted access to hospitalised family members; reduced interaction between MDT and the patient; and a shortage of resources, all which resulted in reduced care and reduced support being provided to patients (Burns et al., 2022; Lucas et al., 2021; Masuku et al., 2022; Spinelli & Pellino, 2020; Sutter-Leve et al., 2021).

The Health Professions Council of South Africa (HPCSA) declared a change in the telehealth policy due to the pandemic (HPCSA, 2020). Telehealth initially required an already established relationship with the patient; however, after suggestions from clinicians, this was changed to include new clients as well (HPCSA, 2020). All health professionals are still bound by all ethical rules and codes of conduct (HPCSA, 2020). According to a position statement by the South African Speech-Language-Hearing Association (SASLHA), all therapists were to make use of personal protective equipment (PPE), prioritise patients, and provide teletherapy where possible (SASLHA, 2020a). Another statement was released and served as a guideline for teletherapy: a secure online platform and informed consent are required; the use of a carer or facilitator is recommended for the client during live sessions; clients need to be informed of the risks; the potential failure of payment by medical aids; professional indemnity is required; and an emergency plan needs to be developed for sessions (SASLHA, 2020b).

Teletherapy has been increasingly used in the treatment of adult neurogenic communication disorders as a possible means to allow access usually due to factors such as distance, unavailability of specialist care, and reduced mobility of patients. Teletherapy has shown promising positive outcomes in the management of conditions like aphasia (Dial et al., 2019).

Dial et al. (2019) show that, as telecommunication technology advances, it will play a greater role in managing chronic health as treatment administered in person or via teletherapy resulted in equal patient outcomes. Dial et al. (2019) illustrated that, in some instances, teletherapy displayed superior gains.

Cassarino et al. (2022) detailed the telerehabilitation practices of a 54-year-old post-stroke aphasia patient with the aim of assessing the feasibility of telerehabilitation in future randomised controlled trials. This study showed that telerehabilitation was a feasible approach offering both persons with aphasia and their families a rehabilitation pathway during the pandemic. However, it was emphasised that further research is needed to verify the effectiveness of the approach.

A qualitative study by Zafra-Tanaka et al. (2022) during the COVID-19 pandemic explored how post-stroke care was managed in a tertiary hospital in Peru. This was facilitated through 11 in-depth interviews with either stroke survivors or their caregivers and seven healthcare workers. The study explored multiple phases such as pre-hospitalisation, the emergency room, hospitalisation, discharge process and the post-discharge process. The main challenges identified were communication between healthcare workers and a lack of training. Potential solutions included added human resources, including the family, electronic health records, improving referral systems and implementation of telerehabilitation services.

A qualitative systematic review of 14 studies conducted by Bailey et al. (2022) evaluated literature findings depicting the experiences of informal carers of people with long-term conditions during the COVID-19 pandemic. Four main themes were identified: i) fear; ii) uncertainty; iii) burden; and iv) staying connected. This review identified that, due to the pandemic, there was an increase in caregiving demands and negative emotions, and less support available to caregivers which led to increased concerns of their coping ability.

A qualitative study conducted by Kylén et al. (2022) in Sweden explored the experiences of post-stroke patients living with the aftermath of a stroke during the COVID-19 pandemic. Semi-structured interviews were conducted with 14 participants. The findings illustrated that post-stroke participants adapted better to the lockdown measures and they were motivated to remain connected to family and to maintain a daily routine. Participants also felt more connected to society as everyone was experiencing restrictive measures collectively.

A scoping review conducted by Masuku et al. (2022) in South Africa explored how the COVID-19 pandemic affected the rehabilitation of persons with aphasia. The findings of the review revealed five themes: the negative impact on rehabilitative care; telehealth and its limitations; impacts on social participation; compromised caregiver involvement; and the prioritisation of mental health challenges for persons with aphasia and their caregivers during a pandemic.

These studies illustrate that there has been a global concern with regard to the manner in which rehabilitation occurred during the COVID-19 pandemic for stroke survivors with aphasia and their significant others. Hence, it is important to consider their specific lived experiences within a South African context.

2.4 Speech-language therapy and approaches to aphasia

Traditional interventions show a medical model approach for aphasia. This type of therapy is often clinician directed and its goals are aimed at treating linguistic challenges (Pluut, 2016). These approaches often exclude the impacts of long-term consequences, as well as psychological and social deficits experienced by persons with aphasia (Worrall et al., 2011).

Studies in the field of aphasiology consider insider perspectives, particularly on the impact of aphasia on the quality of life and on an individual's access to communication, participation and engagement (Simmons-Mackie et al., 2007). Numerous studies have depicted that persons with aphasia are often excluded from obtaining information, making informed life decisions and peer interaction (Kagan et al., 2001; Kagan & Le Blanc, 2002). These studies advocate for intervention approaches to be inclusive and encourage the active participation of persons with aphasia (Kagan et al., 2001; Simmons-Mackie et al., 2007; Worrall et al., 2005; Worrall et al., 2007).

Communication accessibility and the impact of aphasia on social exclusion has become more prominent (Simmons-Mackie et al., 2007) through a focus on functional outcomes, an increase in qualitative research in aphasiology and differing social approaches (Simmons-Mackie et al., 2007). These include: the supported conversation for aphasia method (Kagan, 1998); the Life Participation Approach to Aphasia (LPAA) (Chapey et al., 2000); and the Living with Aphasia Framework for Outcome Measurement (A-FROM). These types of intervention processes focus on the person with aphasia, how they have been affected, and how social contexts impact language processes (Worrall et al., 2011). They view language intervention in a more holistic and patient-centred manner, and allow for the transfer of intervention to personalised contexts, real-life communication, and everyday contexts (Worrall et al., 2011). Social approaches have been further developed from functional approaches and focus on enhancing the quality of life of persons with aphasia by increasing participation and reducing barriers (Bernhardt et al., 2017; Hilari et al., 2015a).

Family-centred care, a derivative of traditional approaches, has been recognised as the best way to include family members of those affected by communication impairments in the rehabilitation process (Grawburg et al., 2019). Family-centred care, as described by Grawburg et al. (2019), is a collaboration between the individual with the health condition, their family, and the healthcare professional. A safe, nurturing environment where individuals can receive support, rehabilitation, and information throughout the process must be fostered (Bamm et al., 2015).

The literature as well as clinical guidelines of stroke treatment emphasise partner communication training approaches that optimise rehabilitation engagement for healthcare professionals, the family and communication partners, and improve autonomy and social participation (Hilari et al., 2015b; Kagan et al., 2008; Simmons-Mackie & Lynch, 2013; Simmons-Mackie et al., 2007). According to Simmons-Mackie et al. (2007), good communication partners are able to initiate and maintain fluent conversations which display features of acceptance, and an understanding of how to maintain communication and make use of adaptive strategies. Whereas poor communication partners are usually dominant in the conversation and focus on the disability of the person with aphasia which may further contribute to communication breakdowns (Simmons-Mackie et al., 2007).

Aphasia-specific approaches can include identifying and using appropriate conversational strategies while consistently reinforcing the idea of valued participation. Individualised goals should be based on the person with aphasia and their family’s desire to participate and engage, as well as an awareness of the hierarchy of essential objectives and their changing needs over time (Grawburg et al., 2019).

Communication access is defined as the processes in which society modifies the environment to provide communicative support to enable interactions with persons with aphasia. These include a variety of supportive strategies such as support training, improving attitudes, providing informational support in accessible formats and nursing the environment to make it conducive for successful communication (Kagan et al., 2001; Kagan & LeBlanc, 2002; Parr et al., 2008; Simmons-Mackie & Damico, 2007; Worrall et al., 2005).

Effective approaches to intervention may have been compromised during the COVID-19 pandemic. Current literature on the implications of COVID-19 on stroke survivors with aphasia and their significant others indicates that there were challenges with access to care, effective rehabilitation, reduced roles of the significant other in intervention, increased challenges post-discharge, and an increased burden of care on significant others (Bailey, 2022; Burns et al., 2022; Lee et al., 2021; Sutter-Leve et al., 2021). Given these findings, it is important to explore insider perspectives on lived experiences during the COVID-19 pandemic and how this may have altered their experiences of diagnosis, rehabilitation and reintegration.

2.5 Theoretical framework

2.5.1 The biopsychosocialtech model

Since the first aphasia trial in 1981, traditional aphasia interventions have been based on medical model approaches that exclude the impacts of long-term consequences, as well as psychological and social deficits experienced by persons with aphasia (Worrall et al., 2011). The biopsychosocialtech model is a derivative of the biopsychosocial model and provides guidance in clinical practice (Galletta & Barrett, 2014; Lehman et al., 2017; Taukeni, 2019) by looking at the person in a holistic manner.

Although the biopsychosocial model is one of the most influential person-centred care framework models, in recent years, it has faced criticism (Taukeni, 2019). It initially viewed the medical model as ineffective at describing and understanding a person's illness (Galletta & Barrett, 2014; Lehman et al., 2017; Taukeni, 2019). The model is rooted firmly in the notion that successful intervention can only be achieved by understanding the dynamic relationship between all factors impacting the individual (Lehman et al., 2017). This model is used for health interventions as it encompasses a holistic view of the individual and their specific contexts (Bernhardt et al., 2017).

In order to reflect recent changes in treatment, Scherer (2020) expanded the model to include technology to better represent patient needs and care. The biopsychosocial model described impairment holistically so that illness, impairment, and disability could be treated in a systematic way to include emotions, behaviour, and environmental factors (Scherer, 2020). The biopsychosocialtech model aims to build upon the previous model by including technology to reflect current intervention practices. In 2020, during the COVID-19 pandemic, there was exponential growth and reliance on technological systems in all spheres as depicted in this model (biomedical, psychological, social, and technological). This model allows all spheres to be interrelated and to change over time in varying degrees. This model was implemented in this study in order to explain stroke and aphasia, as well as to explain third party disability and the manner in which technology interacts with these spheres. The four factors of the model are not only interrelated but also influence and impose on each other, and over time, can impact different levels of an individual's functioning (Scherer, 2020).

The four components are outlined and defined by Scherer (2020) as:

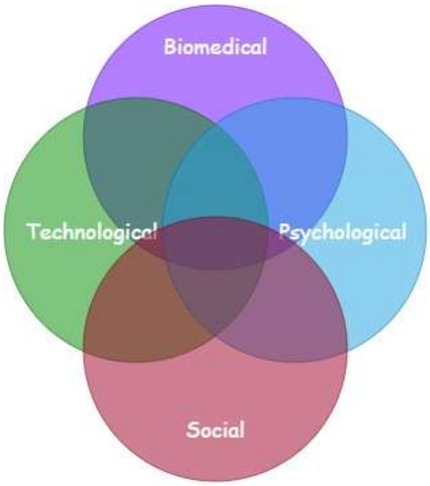
1. Biomedical: Aspects relating to pathology, symptoms, and functioning.
2. Psychological: Focusing on the psychological well-being (moods and related aspects such as depression, anxiety, etc.), one’s outlook, values, coping strategies, goals, resilience, priorities, and preferences.
3. Social: The family and friend support, social contexts that are fulfilling and provide safety and security, as well as community resources and accessibility. This component could also extent to socioeconomic status.
4. Technological: This refers to mechanical, electronic, digital, or computerised devices and systems.

While the biopsychosocialtech model can be used to describe aphasia post-stroke, there are limitations in clinical implementation. The model explains psychological, social, technological factors in treating the whole patient but it does not allow for a structured assessment and intervention plan. The model has been criticised for: lacking quantification, being vague, and being too general (Rosignoli et al., 2022); being idealistic especially in under-resourced health care systems (Lehman et al., 2017); the complexity of explaining cause and effect between the spheres (Lehman et al., 2017); having insufficient evidence to support the existence of MDTs in the implementation of this model; and being time consuming and expensive (Lehman et al., 2017).

Despite the limitations, it is a viable model to treat stroke survivors with aphasia and their significant others. This model demonstrates the interaction of biomedical, psychological, social and technological factors in determining health outcomes. This innate interconnectedness allows this model to fully encompass stroke and the resultant aphasia as there are different impacts of a stroke on multiple levels, which include medical, motor, communication, psychological, and cognitive abilities. This may therefore have a direct impact on participation, activity, access, and the overall quality of life of a patient (Masuku et al., 2022). The use of this model may also allow for a multidisciplinary team to describe and treat the condition holistically.

Therefore, the biopsychosocialtech model can be used to effectively illustrate the needs of persons with aphasia and their significant others which will ultimately lead to better physical and psychological health, improved social connectedness and social context, and the use of technology to improve patient access, outcomes, and communication with healthcare staff.

Figure 1: *A model depicting the relationship of the four components of the biopsychosocialtech model (Scherer, 2020).*



2.6 Conclusion

The direct clinical outcomes related to COVID-19, such as incidence rate, mortality and morbidity, have been closely monitored (Banfield et al., 2022). However, indirect effects of the pandemic are multifactorial and less clearly established in the literature (Banfield et al., 2022), such as the experiences of stroke rehabilitation during the pandemic for both persons with aphasia and their significant others. Qualitative studies, both locally and internationally, in this aspect, have acknowledged the impact of the COVID-19 pandemic on stroke patients such as reduced rehabilitation times, increased caregiver burden, lack of support, reduced social engagement and increased psychosocial fallout (Burns et al., 2022).

The literature has documented that stroke care was affected during the COVID-19 pandemic which has had negative implications across the treatment process. In turn, this may lead to poor community outcomes in those who had survived a stroke during the pandemic (Burns et al., 2022). However, the insider perspectives of lived experiences of stroke and aphasia diagnosis during the COVID-19 pandemic for patients and their significant others within a South African context are less known. In particular, how the COVID-19 pandemic may have altered or influenced rehabilitation and re-integration and how the adaptive strategies undertaken during this time may have impacted this population.

Chapter 3: Methodology

Outline of Chapter

In this chapter, the methods underpinning this research project are discussed in detail. Therefore, this chapter provides pertinent information on the research question, the aims of the study, specific objectives of the study, the research design, a description of the sample, the instruments used to obtain data, data collection procedures, data analysis procedures, as well as ethical considerations and trustworthiness of the study.

3.1 Research Question

What are the lived experiences of stroke survivors with aphasia and their significant others living in the city of Ekurhuleni, South Africa, during the COVID-19 pandemic?

3.2 Research Aim

The aim of the study was to describe the lived experiences of stroke survivors with aphasia and their significant others living in the city of Ekurhuleni, South Africa, during the COVID-19 pandemic.

3.3 Research Objectives

There were four objectives outlined for this study, and these were:

1. To explore the lived experiences of stroke survivors with aphasia within the South African context during the COVID-19 pandemic.

2. To describe the lived experiences of stroke survivors with aphasia in relation to speech and language rehabilitation and changes in their everyday familial, social, community, and occupational communicative contexts during the COVID-19 pandemic.

3. To explore the lived experiences of stroke survivors’ significant others with aphasia in relation to speech and language rehabilitation, communication changes, role changes, and re-integration in their communicative contexts post-stroke during the COVID-19 pandemic.

4. To describe the perceived facilitators and barriers to communication between stroke survivors with aphasia and their significant others during the COVID-19 pandemic.

3.4 Research Design

A qualitative, phenomenological research design was employed for this study. The purpose of phenomenology is to acquire a more profound understanding of daily lived experiences (Vagle, 2018). Phenomenology, as a research approach, may not necessarily lead to the development of comprehensive and generalisable theoretical frameworks (Vagle, 2018). Instead, it focuses on gaining a deep understanding of specific experiences and phenomena, prioritising rich and detailed insights rather than seeking to develop broader, universally applicable theories (Vagle, 2018). This, in turn, allows researchers to be truly immersed and engaged by exploring their lived experiences, thoughts, and perceptions (Neubauer et al., 2019; Vagle, 2018).

Phenomenological research can broaden our understanding of the complex phenomena involved in learning, behaviour, and communication (Neubauer et al., 2019). Due to the nature and aim of this study, a qualitative research design was most appropriate as this study sought to explore the lived experiences, thoughts and opinions of stroke patients with aphasia and their significant others. This research study looked at the way stroke survivors with aphasia, and their significant others, experienced stroke and aphasia hospitalisation, rehabilitation and re-integration during the COVID-19 pandemic to understand their lived experiences of stroke and aphasia and the way these conditions affect their lives.

3.5 Sampling

3.5.1 Sampling strategy

A purposive sampling strategy was used to select both participant groups for this study. The two sub-groups were persons with aphasia and significant others of persons with aphasia. Specifically, homogenous sampling was implemented which is described as a method of purposive sampling that acquires candidates who share the same traits, characteristics, or experiences (Etikan et al., 2016). The purposive sampling technique was a deliberate choice as specific qualities of the participants were required. The idea behind purposive sampling was to concentrate on people with particular characteristics who could better assist with the relevant research. In this instance, it was those who had experienced a stroke which resulted in subsequent aphasia and attended rehabilitation treatment during the COVID-19 pandemic. In addition to this, significant others of those with aphasia, who are familiar with the person with aphasia, and who had a relationship with them, both before and after the neurological incident, were selected as participants.

A non-random sampling technique was used which did not need underlying theories or a set number of participants. It is typically used in qualitative research to identify and select the information-rich cases for the most utilisation of available resources (Etikan et al., 2016). The advantages are that it is less expensive, and there is no need to list all the population elements. However, it is not without limitations, the foremost being variability and bias that cannot be measured or controlled (Acharya et al., 2013).

3.5.2 Access to participants

While there was no specific research site, a private rehabilitation centre in the city of Ekurhuleni was approached (**Appendix A)** in order to assist with the recruitment of participants, as this site works closely with the population required for the purpose of this study in an in-patient and out-patient capacity. Permission was granted by the chief executive officer (CEO) of the facility (**Appendix K**). Permission of the Head of Department (**Appendix B**) was sent once ethics approval was granted for the study.

The following steps then occurred in order to identify participants for this study:

Speech and language therapists at the physical rehabilitation centre were contacted and given a list of the selection criteria (**Appendix C**). These health professionals then contacted persons with aphasia and significant others of the persons with aphasia. Thereafter, participants provided verbal consent to their therapist regarding whether they would have liked to be contacted by the researcher for this study. This was done due to compliancy with privacy and consent laws. In addition, as a communication assessment or communication competency was not objectively assessed in this study, it was important for the treating speech therapist to identify participants that could possibly engage in a qualitative study.

Contact information was provided to willing participants to contact the researcher and vice versa for information and possibly setting up a date for an interview. Participants were provided with information sheets (**Appendices D and G**), written informed consent forms (**see**

Appendices E and **H**) and voluntary participation forms. Provisions and motivations for informed verbal consent for persons with aphasia were also made (**Appendix F**).

3.5.3 Sample Size

Approximately 10 to 50 participants are regarded as sufficient for in-depth interviews within qualitative research (Acharya et al., 2013). Additionally, in qualitative research, the sample size is an estimation and requires changes based on data received and the probability of attaining data saturation. This study considered data saturation as described by Fusch and Ness (2015) who state that data saturation is achieved when there is enough evidence to replicate the study, when there appears to be no new information from the data set, and when further coding is no longer feasible.

In accordance with the literature, a total sample of 14 participants was interviewed in this study. The total number was inclusive of stroke survivors with aphasia (seven participants) and their significant others (seven participants). During the data collection stage, it was noted that findings were becoming repetitive and there was sufficient information from the data set to allow a replication of the current study. In addition, Malterud et al. (2016) state that the sample size is considered sufficient if differing experiences are noted, as well as a small enough sample to ensure effective analysis of the data, which was considered in this study.

3.5.4 Inclusion and exclusion criteria

Participants who could provide key information on the topic were purposefully selected. These were individuals who had experienced a stroke during the COVID-19 pandemic and, as a result, were diagnosed with a communication impairment, namely, aphasia. Furthermore, significant others of those with aphasia were included in this study as research has reflected that aphasia has known implications on third party functioning and may result in third party disability. The inclusion and exclusion criteria are tabulated below and can be found in Table 1 for persons with aphasia and Table 2 for significant others of persons with aphasia. It should be noted that participants of this study were considered a unit, not two separate cohort groups.

Table 1: *Inclusion and exclusion criteria for persons with aphasia*

Criterion	Justification	Measure
Stroke survivors with aphasia whose onset of stroke/diagnosis of aphasia occurred during the COVID-19 pandemic	The research focuses on the personal reflections of stroke survivors and their lived experiences during the COVID-19 pandemic and how this may have implicated their outcomes	Information obtained from the SLT as well as biographical questions.
Stroke survivors with aphasia that have experienced treatment and/or rehabilitation in a private step-down facility/private practice (as an in-patient/out-patient) during the COVID-19 pandemic	South Africa is a LMIC and thereby facilitators and challenges experienced in government and private may differ. Additionally, research in the private sector is necessary and allows for further invocation of policy and practice change within the sector.	A recruitment site was approached for possible participants, participants were accessed from this site with the aid of the SLT.
Stroke survivors with aphasia who live with at least one significant other (family member) who consents to participation	The study aimed to look at perspectives and lived experiences of both a PWA and their significant other. Therefore, it was imperative that both participated in the research as a unit. It was also important the significant other had been familiar with the PWA, had an existing relationship	Participants identified their own significant other. Information obtained from the SLT with accuracy of biographical questions posed to the participants.

	with them before and after the neurological incident.	
Stroke survivors with aphasia who are able to engage at a conversational level (in English) as the research interview was carried out using communication modalities such as verbal speech, supported communication, gestural aid, AAC systems, etc.	The PWA needed to comprehend instructions and questions that were administered in the English language by the researcher.	Eligibility was determined by their speech-language therapist, who recommended the PWA to participate on a specific criterion set out by the researcher (Appendix C).
Stroke survivors with aphasia that do not have a previous history of a reported hearing loss, reported learning difficulties or cognitive impairment before the neurological event. The treating SLT determined this.	Participants were required to follow oral conversation, use visual aids, and reflect on experiences. Additionally, aphasia is termed as a language impairment with intact non-linguistic cognitive ability.	Information obtained informally from the SLT. If the PWA was able to participate, engage and communicate in therapy sessions (45 minutes – 60 minutes) with no reported concerns, they were deemed eligible.
Left hemisphere stroke survivors with aphasia	Right hemisphere stroke survivors were excluded – due to difficulties with memory; language centres are in the left hemisphere and aphasia usually occurs with left hemisphere strokes	Obtained information from the SLT/biographical information

Minimum of six months post neurological incident	At this stage, PWAs are no longer in the stage of spontaneous recovery. Additionally, they are well versed with rehabilitation at this point, re-integration has already happened and therefore goals are likely to differ at this point.	Information obtained from SLT/during biographical questions.

Table 2: *Inclusion and Exclusion Criteria of Significant Others of Persons with Aphasia*

Criterion	**Justification**	**Measure**
Currently living with a stroke survivor with aphasia who has provided consent to participate.	The study aimed to obtain experiences and perspectives of both the PWAs and their significant others. The study aimed to explore the impact of a stroke on the family as well as gain insight on the role of the family in rehabilitation.	Participants nominated their own significant other. Eligibility was provided by the SLT/biographical questions.
Participants could engage in conversational English with the researcher.	The significant other was required to be able to understand and comprehend questions asked in English by the researcher.	Information obtained via the biographical questions posed.

3.5.5 Description of sample

3.5.5.1 Persons with aphasia

The demographics of the persons with aphasia are tabulated and presented in Table 3. The age range of persons with aphasia was between 48 and 78 years. The average age of persons with aphasia was calculated to be 61 years. Four participants with aphasia were female and three were male. Participants' ethnicity varied; there were three participants that are white, two participants who are African and one participant who is coloured. All participants were proficient in English and this was either their home-language or the language they used most commonly. In addition, other languages previously spoken by participants were also identified. One participant was a wife, two participants were life-partners with their significant others and two participants identify as single mothers. All participants experienced their stroke and subsequent aphasia during the COVID-19 pandemic. Hence, all participants presented with a stroke impairment, five participants also presented with physical impairment and required assistive devices for support, all participants had a reduced limb function (in their arms). Three participants presented with anomic aphasia, two participants with global aphasia, and two participants with Broca's aphasia as determined by their speech therapist. However, no other medical reports were given to the researcher hence the severity of aphasia could not be accurately captured and was solely based on observations and interactions during the interviews. Four participants required the use of supportive communication and AAC strategies. Only two participants were currently employed.

3.5.5.2 Significant others of persons with aphasia

Demographics of significant others of persons with aphasia are captured and presented in Table 4. The age range for significant others was 21–68 years. The average age of significant others of persons with aphasia was 47 years. Three participants were male and four participants were female. Four participants were white, two were African and one participant was coloured. All participants cohabitated with the persons with aphasia. All participants spoke English and were able to understand English. One participant identified as a husband, one as a wife, two participants as life-partners and two as adult children of persons with aphasia. Five participants were currently employed. Two participants had additional paid carers to assist with caregiving for the person with aphasia.

3.5.5.3 Coding system

Each participant was given a pseudonym in order to protect their identity. Pseudonyms were provided based on gender identification, which means that, if a participant identified as female, their pseudonym was a name typically associated with a female. The same was used for males. Participants were also matched for language, and similarity of participants' actual names were considered. Numbers were used to illustrate the paired unit which consisted of both the person with aphasia and their significant other. Additionally, each participant was provided with a coded alphabet, the ***letter A*** indicates the person with aphasia within the unit. Whereas the ***letter B*** indicates the significant other within the unit.

Below is an example of the completed code for persons with aphasia:

[pseudonym name] [unit number] [A]

Below is an example of the completed code for significant other of persons with aphasia:

[pseudonym name] [unit number] [B]

Table 3: *Participant demographics: Persons with Aphasia*

Participant Code	**Age**	**Gender**	**Home-Language(s)**	**Relation to significant other**	**Year of stroke**	**Length of inpatient stay**	**South African Alert Level (1-5)**[1]	**Employment Status**	**Physical Presentation**	**Aphasia Type**	**Aphasia Severity**	**AAC User/Supported Communication**	**Attending / Attended Outpatient Intervention**	**Telerehabilitation**
Anne 1A	62	F	English	Wife	2020	6 weeks	Level 5 -Level 4	Retired post stroke	Independent with support aids (walker / crutch if needed) Impaired limb function (arm)	Anomic	Mild-Moderate	No	No	No
Charlotte 2A	48	F	Zulu/Sesotho/English	Mother	2021	8 weeks	Adjusted level 3	Employed	Independent	Anomic	Moderate	No	Yes. OT & ST	Yes
Mary 3A	78	F	English	Life Partner	2020	8 weeks	Level 5- Level 4	Retired post stroke	Physically impaired and wheelchair bound. Impaired arm function	Broca's	Moderate-Severe	Yes	Discharged. PT, OT & ST	No
James 4A	62	M	English	Husband	2020	6 weeks	Level 5- Level 4	Retired post stroke	Physically impaired and wheelchair bound. Impaired arm function	Broca's	Moderate	Yes	Yes. OT & ST	No
William 5A	53	M	Afrikaans/English	Life Partner	2022	8 weeks	Adjusted Level 1	Retired post stroke	Physically impaired and wheelchair bound. Impaired arm function	Global	Moderate impact on receptive ability . Moderate-Severe impact on expressive ability	Yes	Yes. PT, OT & ST.	No
Harry 6A	72	M	Afrikaans/English	Husband	2021	8 weeks	Adjusted level 3 – Adjusted level 1	Retired post stroke	Able to walk short distances - needs support (walker) dependent on support aids (wheelchair) for long distance	Global	Mild - Moderate impact on receptive ability. Moderate impact on expressive ability	Yes	Yes, PT, OT & ST.	No
Elizabeth 7A	53	F	Zulu/Swazi/English	Mother	2022	2 weeks (RHT)	Adjusted level 1	Retired post stroke	Independent	Anomic	Mild-Moderate	No	Yes. OT & ST.	Yes

1. Level 5 is the highest severity and level 1 the lowest severity. Please see Appendix O for an in-depth tabulated presentation of all alert levels during the COVID-19 pandemic in South Africa.

Table 4: *Participant Demographics: Significant Others of Persons with Aphasia*

Participant Code B (significant other)	Age	Gender	Ethnicity	Home – Language(s)	Relationship to significant other	Paid Carer Available to assist significant other
Edward 1B	62	M	White	English	Husband	No
Julia 2B	22	F	African	Zulu/Sesotho/English	Daughter	No
Richard 3B	68	M	White	English	Life partner	Yes
Matilda 4B	58	F	Coloured	English	Wife	Yes
Kate 5B	49	F	White	English	Life partner	No
Meghan 6B	51	F	White	Afrikaans/English	Wife	No
George 7B	21	M	African	Zulu / Swazi / English	Son	No

3.6 Methods of data collection

A semi-structured interview was developed (**Appendix I**) and used as a means of data collection. Semi-structured interviews are used to gather information using a series of predetermined questions while still inviting and allowing for participants to express themselves more freely. This links directly to the research question, which aimed to explore the lived experiences of participants selected for this study (De Jonckheere & Vaughn, 2019). These interviews yielded information-rich, open-ended data. To maintain quality data, the interviews were conducted as conversational interactions between researcher and participants as opposed to asking questions in a transactional manner. Guiding questions were broad in nature and variations within the interviews occurred as the structure and order of questions may have differed.

Participant's preference was adhered to for the interview format, either as a unit or as individual interviews, depending on the preference of the participants. The decision to conduct interviews as a unit was further grounded in literature guidelines for working with participants with aphasia in qualitative studies. Wilson and Kim (2021) state that conducting interviews with both the person with aphasia and their significant other can be a useful method for obtaining data. This approach can also assist in obtaining more contextual revelations and detailed information (Wilson & Kim, 2021). Additionally, significant others can provide aid and make use of communication supports by helping the person with aphasia (Wilson & Kim, 2021). However, they emphasise the importance of ensuring that significant others do not interrupt or speak on behalf of the person with aphasia. It is further recommended that multiple individual interviews be conducted with each participant and a unit interview (Wilson & Kim, 2021). This recommendation was initially proposed within in this research as was the suggestion of multiple shorter interviews; however, due to time-constraints and participants' schedules, this was not feasible.

The following steps were taken when forming the interview guide for this study:

- Open-ended interview questions were developed with limited questions that were broad in nature in order to gain key information on lived experiences.

- During the interview process, based on interactions with participants, their responses were further probed.
- Participants were also continuously reassured that they did not need to answer if they were uncomfortable with the line of the conversation.
- Permission was requested to expand on responses in the event the researcher sought more information.
- A biographical questionnaire was included and conducted verbally as part of the interview.

Please see (**Appendix I** for detailed information on the questions, rationale and prompt questions).

3.6.1 Materials used for data collection

1. **Biographical Questions:** Biographical questions were included in the interview and were asked in order to obtain demographic information.
2. **Interview Schedule:** Semi-structured interview questions were used in order to obtain data from participants. See **Appendix M** which outlines the considerations during the interview schedule for persons with communication impairments.
3. **Audio recording:** Consent for audio recording was obtained. Participants' interviews were audio-recorded using a Samsung note 10; data were then transcribed, analysed, and stored on a password-protected cloud system. Raw data will be destroyed after five years.
4. **Field notes:** In conjunction with audio recordings, field notes were taken to record non-verbal communication cues; AAC with participants who used this as video recordings were not conducted.

3.6.2 Contextual Considerations

Planning logistical aspects: This was maintained by meeting at a convenient place for participants, using shorter interview periods, allowing for interviews to be conducted as a unit, and allowing for interviews to be conducted using video teleconferencing, if preferred. Transport allowances were also provided for participants if need be. However, only one participant requested to be reimbursed for transport. Three interviews were conducted using telecommunications. All other participants scheduled their interviews at a site that was convenient, such as their home or where they receive out-patient therapy or attended in-patient therapy.

Established trust and rapport with participants: For participants to divulge deep personal accounts, it was imperative to maintain a trusting and nurturing relationship with them. Participants were urged to request for repetition, breakdown of information, validation of responses, and rationalisations or explanations to assess if their intent was correctly recorded.

Participant preferences: Semi-structured interviews were conducted with the stroke survivors with aphasia and their significant others. In order to maintain rapport, participants' preferences for conducting a joint interview or an individual interview were considered. Two participants with aphasia requested an individual interview, their significant others agreed. One significant other requested that, in addition to the joint interview, she has an added individual interview.

3.6.3 Considerations for working with persons with communication impairments

Informed consent can be difficult to establish in participants who present with communication impairments, like those with aphasia (Palmer & Paterson, 2013). There is a growing awareness of using accessible formats to enhance communication; however, individualistic and patient specific needs should be considered depending on the skill set and ability to process and understand information (Palmer & Paterson, 2013). AAC has the ability to increase the communicative environment for the person with aphasia while also reducing the pressure of relying on independent retrieval strategies (Dietz et al., 2020). Since stroke survivors with aphasia are a vulnerable population, adapting the interview process and providing communication strategies to assist participants were considered. These included specialised forms (aphasia friendly information letters and consent forms), provision of verbal consent, shorter interview periods, breaks if needed, breaking-down or summarising information, and the use of alternative communication methods (AAC) that included gestural communication, the use of YES/NO questions to validate, choice-making, and picture aids (such as a spelling board, picture signs, and a low-tech emotion board). Additionally, if the participant had their own AAC system, this was used.

Logistical aspects and participants' abilities were taken into consideration. This was maintained by meeting at a convenient place for participants (considering physical ability, mobility, and transport), using shorter interview periods (considering fatigue and endurance), allowing for interviews to be conducted as a unit (considering the use of supported communication with known partners), and allowing for interviews to be conducted using video teleconferencing, if preferred (considering the COVID-19 pandemic and participant preferences during this time). Transport allowances were also provided for participants if required. However, only one participant requested to be reimbursed for transport. Three interviews were conducted using telecommunications. All other participants scheduled their interviews at the site where they receive out-patient therapy, and also scheduled the interview to coincide with the day of treatment.

In the initial proposal, interviews were to be broken up over time in order to maintain considerations for those with aphasia and would take place over two or three short interviews. However, during the data collection process, this was not necessary as all participants managed to engage for extended periods in one sitting. Interviews were therefore between 45 and 90 minutes long. In total, 10 interviews were conducted with 14 participants. 10 participants chose to be interviewed together as a unit, which resulted in five interviews being conducted with participants as a unit. In addition, five individual interviews took place with five participants (two persons with aphasia and three significant others). Interview questions were asked verbally and additional materials to support AAC communication were used to assist those with communication difficulties. See **Appendix M** for a detailed review on the specific communication strategies used for each participant.

Wording of questions were kept as simple and as short as possible to ensure that persons with aphasia were able to comprehend them. Furthermore, if questions were not understood, the questions were reformulated or supported by the significant other of the persons with aphasia or additional communication aids (through low tech AAC). If a response was considered insufficient, the researcher reframed the question, asked for clarification, and used repair strategies such as increasing time for processing, as well as providing additional time for the person with aphasia to formulate a coherent response. Additionally, the significant other of the person with aphasia assisted in obtaining a response.

3.7 Pilot Study

A pilot study was conducted with one stroke rehabilitation patient and their significant other. The aim was to evaluate the effectiveness of the methods outlined and allow for amendments to be made before data collection could begin. The selection criteria for participants in the pilot study were the same as those identified in section 3.5: Sampling. The person with aphasia was a male who was 41 years old; he had chosen his significant other to be his mother who was 64 years of age. He presented with mild receptive and expressive language difficulties and was deemed as anomic aphasic. These participants opted to have their interview conducted together. Outlined in **Table 5** is a detailed description of the aims, procedures, results, and specific outcomes of the pilot study.

***Table 5**: Outline of pilot study*

Aim 1:
To establish the efficacy of obtaining informed consent from the person with aphasia.
Procedure 1:
Information was verbally explained to the adult with aphasia and his significant other. Additionally, the information letter and consent form (Appendix D and E) were adapted to better assist those with aphasia through the use of visual aids. The person with aphasia was given the opportunity to read the information letter and consent form by himself or to choose to have the researcher or his significant other assist him. He was encouraged to ask for repetition or clarification, if needed. In addition, he was encouraged to complete

the form by circling the appropriate answers and signing the form.

Outcome 1:

It was noted that the person with aphasia requested that the researcher go through both the information letter and consent form. Additionally, the information contained in the information sheet needed to be repeated and broken down into smaller pieces.

The person with aphasia was more attuned to using the visual aid (on the consent form to indicate understanding) but further communicated that this was too small and a larger print would be preferable. The person with aphasia was able to express that he understood the nature of the study and was able to effectively express voluntary participation in the study.

Adaptation to the main study 1:

The researcher read the information sheet and consent form with the person with aphasia if this was requested and particularly if it was perceived that they had some difficulty with comprehension. Additional aid was provided if the person with aphasia needed assistance with writing their biographical information on the consent form.

The researcher included an additional aid which had YES/NO prompts visually represented. This was used to allow the person with aphasia to request repetition as well as indicate if they had understood what had been said.

Aim 2:

To evaluate the use of biographical questionnaires to capture information of each participant.

Procedure 2:

Participants were provided with a biographical questionnaire to complete – significant others or the research could assist the person with aphasia.

Outcome 2:

The person with aphasia had difficulty with answering and filling the form. He also expressed frustration because it was a basic task but it was difficult for him to complete.

Adaptation to the main study 2:

Biographical information was included as a part of the open-ended questions; to allow the person with aphasia autonomy and to obtain a better rapport by decreasing initial demands of the research process.

Aim 3:

To determine the efficacy of using supported conversation practices and additional visual aids in order to obtain rich information from the person with aphasia.

Procedure 3:

Specific contextual considerations were taken into account. The person with aphasia was allowed to stop the research to ask for clarification, repetition or to initiate a break from the interview. In addition, the person with aphasia was allowed to use all modalities of communication at his disposal. He was also asked to confirm whether the researcher efficiently and accurately understood what he had communicated.

Outcome 3:

The person with aphasia was able to participate in the interview well. He expressed that he had some difficulty following the conversation at times; he was encouraged to request repetition and clarification. He appeared to have had better understanding when his significant other repeated questions to him in a communication style he was familiar with. Additionally, the person with aphasia did not always stop the conversation even when he wanted to – he expressed he was unsure how to request this while the conversation was still on-going between the significant other and the researcher.

The participant did request for a water break but communicated that he did not feel any fatigue after approximately 60 minutes.

Adaptation to the main study 3:

Additional visual aids were made available during the data collection stage of the interview. These included a spell board; YES/NO visual aid; pictures illustrating emotion; a stop sign; a skip the question sign; a sign to indicate the person with aphasia did not understand the question; a sign to ask for repetition and clarification; a visual aid of emotions to assist with questions that may evoke distress.

In addition, the researcher actively asked the person with aphasia if there was any topic they would like to repeat and continually asked if they would like to elaborate on responses from the significant other, if they would like repetition and if they would like a break.

Significant others were also encouraged to repeat questions which often yielded better responses from the person with aphasia due to their familiarity.

Provision was made if participants preferred to consent verbally/via communication aids.

Aim 4:

To determine if the interviews should take place as a unit (person with aphasia and their significant other) or individually.

Procedure 4:

During informed consent, both the person with aphasia and the significant other of the person with aphasia were asked their opinion on this separately.

Outcome 4:

Both the person with aphasia and significant other of the person with aphasia wanted a joint interview. The person with aphasia indicated that he felt a sense of ease with his significant other around as she could assist with communication breakdowns.

The significant other of the person with aphasia wanted the joint interview to display support and also corroborate the journey they had together. Additionally, the significant other remained respectful and tried to assist the person with aphasia in a meaningful way without trying to dismiss them or take over the conversation entirely.

Adaptation to the main study 4:

No changes were made. All participants had a choice to conduct the interview as a unit or separately if preferred.

Aim 5:

To determine if the line of questioning was appropriate as outlined in (Appendix I)

Procedure 5:

The semi-structured interview questions were used and remained open-ended and broad in nature.

Outcome 5:

Participants responded well to this line of questioning. Participants guided the interview with their responses. This allowed for better expansion, more rich and personal reflections and accounts of their experiences.

Adaptation to the main study 5:

No changes were made. Questions remained open ended and broad in nature.

3.8 Data analysis

3.8.1 Unit of analysis

Research by Dietz et al. (2020) and Hilari et al. (2015) highlights the importance of considering both individual and collective perspectives when studying aphasia and its impact on communication and relationships. Previous studies demonstrated that individuals with aphasia and their caregivers often have differing perceptions of communication effectiveness, quality of life, and the emotional impact of aphasia. By examining each participant's perspective individually, researchers can capture the nuances of their experiences, shedding light on their unique needs and challenges (Wilson & Kim, 2021). Consequently, exploring shared experiences, common themes, and patterns of communication provided a deeper understanding of the interplay between individuals with aphasia and their significant others, highlighting the collaborative nature of their coping strategies and the potential impact on their overall well-being (Wilson & Kim, 2021).

By considering both individual and collective perspectives, the analysis approach employed in this study aimed to provide a comprehensive and nuanced understanding of the experiences of individuals with aphasia and their caregivers. This holistic perspective enabled the researcher to identify both the individual needs and challenges faced by persons with aphasia, as well as the relational and collaborative aspects of their communication and support networks.

Therefore, within this study, the analysis approach took the perspectives of each individual participant into consideration. Hence, while interviews may have been conducted with participants as a unit, their individual perspectives relating to the phenomenon were considered. Additionally, this method of analysis was necessary to account for interviews that were conducted individually with persons with aphasia and significant others. However, the analysis showed that collective perspectives existed even if the individual experiences differed. Hence a dual focus on individual and collective perspectives allowed for a holistic understanding of the experiences and dynamics within the units.

3.8.2 Thematic analysis

A thematic analysis, as outlined by Braun and Clarke (2006), was used to analyse themes within the data. The thematic analysis allowed for the interpretation of various aspects of the data. "A theme captures something important about the data in relation to the research question and represents some level of patterned response" (Braun & Clarke, 2006, p.82). An inductive approach was used to interpret the data collected. The researcher used detailed readings of raw data to derive concepts and themes that emerged from the data collected (Braun & Clarke, 2006). These concepts were then developed into a discussion within the biopsychosocialtech model that explained the underlying structure of experiences evident in the data (Braun & Clarke, 2006).

According to Braun and Clarke (2006), there are six phases in this process: (1) the researcher was immersed in the data by repeatedly reading in an active way to search for patterns; (2) the researcher constructed initial codes by organising data into meaningful groups; (3) the researcher conducted interpretive analysis. This phase involved actively searching for themes in the data after the initial coding process was completed (Braun & Clarke, 2006). This allowed for a re-focus on analysis and how different codes combined to form an overarching theme. The researcher also needed to consider the relationship between codes, themes, and different levels of themes. At that point, all data extracts were coded in relation to candidate themes and sub-themes (Braun & Clarke, 2006); (4) this phase consisted of refining themes that may have overlapped or did not have enough data to support them as a construct (Braun & Clarke, 2006). It was important for the analysis to be more profound and more meaningful at this phase. Data extracts were needed to form a coherent pattern; if that occurred, then the validity of individual themes in relation to the data set could ensue (Braun & Clarke, 2006). The entire data set had to be reread to ensure that themes worked in relation to the data set and that any additional themes that may have been previously missed were explored (Braun &

Clarke, 2006). Once this was completed, the researcher could devise a satisfactory thematic map; (5) this consisted of defining, naming, and analysing themes into a coherent, consistent account with accompanying supporting data and detailed analysis for each constructed theme (Braun & Clarke, 2006). These then had to be linked to the research question and specific objectives; (6) the final analysis and write up, where sufficient evidence for each theme, vivid examples, perceptions, quotes, and extracts embedded with an analytic narrative were analysed to form an argument in relation to the research question (Braun & Clarke, 2006) (see Chapter 4 of this thesis).

Responses were audio recorded digitally and then transcribed verbatim. All interviews were conducted in English and made use of additional communication strategies, if needed.

As five of the interviews were conducted individually and five interviews as a unit (based on participant's preference), during the analysis phase, the researcher dissected the specific perspectives of both the person with aphasia and their significant other separately to ensure congruency of the data. In addition, the data were further analysed to seek information that captured the collective lived experiences of the person with aphasia and their significant other, as there were instances were these experiences converged. Hence, in the findings in Chapter 4, the data are presented in two separate sections. Section A details the themes and subthemes categorised from perspectives of persons with aphasia; section B details the themes and subthemes categorised from collective perspectives of persons with aphasia and significant others.

3.9 Ethical considerations

This study applied for ethical clearance for research involving human subjects. Ethical clearance was obtained via the Human Research Ethics Committee (HREC – Medical) and a certificate and clearance number (M201138) issued. See **Appendix L** for the ethical clearance certificate.

In maintaining ethical research throughout this study, the following ethical considerations were maintained for the purpose of the study as outlined by the declaration of Helsinki (World Medical Association, 2001):

3.9.1 Autonomy

i) Informed consent

All participants were briefed on the nature and purpose of this study. Participants were made aware that the research findings would be presented in a master's thesis. Furthermore, participants were briefed on their rights as participants and assured of confidentiality.

Participants were also asked to sign a consent form that identified them as participants and were made aware that there would be no risks or repercussions if they chose to withdraw from the study. People with aphasia often struggle with processing information as well as understanding concepts therefore, special forms using picture descriptions, short phrases, repetition, validation, and introduction through a short story occurred in conjunction with standard forms. Provision was also made to obtain verbal consent from stroke survivors with aphasia if this was easier for them.

ii) Confidentiality

Confidentiality was maintained throughout the process of this research study. Only the main researcher has access to participants' identifying information. Participants' names were not mentioned in either the written report or the oral presentation. Participants' names were coded during the analysis and interpretation process, and their identities were hidden. This process guaranteed anonymity through the analysis and interpretation process. Raw data are stored on a password-protected, cloud-based storage system, which is only accessible to researchers associated with this study. Records will be stored for five years and destroyed thereafter.

iii) Right to withdraw

All participants had the right to withdraw from this study at any given point during the research process. Participation was voluntary and there were no implications for participants who chose to withdraw from this study. This was upheld throughout the research process and participants were made aware of this. It was also further explained and highlighted in all participant information forms.

3.9.2 Justice

i) Maintain dignity and respect

The researcher upheld respect for diversity and was sensitive to the cultural differences, decisions, views, and confidentiality of each of the participants involved in the study. The researcher maintained ethical behaviour in the process of this study by not imposing her own beliefs and values on the participants and remaining an objective listener throughout the research process.

ii) Communication considerations

The researcher considered additional communication and processing difficulties that stroke survivors with aphasia may experience. Therefore, the research used multi-modal communication (gestures, repetition, visual-verbal feedback, pictures, and written transcriptions) to ensure that participants were effectively engaged in the process. Compensatory strategies, such as short sentences, repetition and visual aids, were also used to assist the researcher in attaining comprehensive data.

3.9.3 Beneficence

i) Relevance

This study aimed to assist persons with aphasia and their significant others with better communication outcomes in long-term rehabilitation by including their lived experiences and identifying their needs through their own lived experiences.

3.9.4 Non-maleficence

i) Contextual considerations

As stroke survivors are more susceptible to COVID-19 infections, they are considered a vulnerable population, and face-to-face interactions would not have been safe. If this was the case and the pandemic still persisted or participants had fear and anxiety due to this, data collection was conducted electronically to prevent harm to this population. Most participants agreed to face-face interviews; however, provisions were made for participants who preferred electronic engagement.

ii) Benefits and risks

The benefit of this study is that it will assist in policy and practice change, aiming to highlight the needs of persons with aphasia and their significant others. On the other hand, distress was highlighted as a potential risk, and therefore a distress protocol and referral process were set up to adequately prepare for this during the interview itself in the event the participant presenting with any concerning or distressful behaviour:

Distress Protocol (see Appendix J)

The researcher made use of a distress protocol during the interview as outlined by Haigh and Witham (2015). This indicated that, during the interview, the researcher needed to be aware if the participant was experiencing distress by communicating this or displaying visible signs of distress. In this event, a sequence of steps was to be followed to ensure safety. Firstly, the researcher would stop the interview, and offer immediate support as outlined by the protocol. Thereafter a review would be made and if a participant was able to continue, the interview would continue. However, if a participant was unable to continue, a discussion should be held in a quiet space about a referral for assistance through a mental health care provider. In this instance, a clinical psychologist was nominated for a free counselling session, as was a church counselling group that assisted those with disabilities. In the event that participants needed a referral due to distress from the interview, a follow up call was made to ensure their status.

None of the participants showed significant signs of distress during the interviews. However, based on findings in the research, there were participants who were identified to be struggling with their mental health due to stroke related impairments and it was recommended to them that they receive help in this regard. Upon follow up all three participants had booked consulting sessions with a mental health professional of their choice.

iii) Debriefing of participants

Participants, who provided consent, were briefed by the researcher concerning the results of the research once the study was completed. The findings of this study are available to participants, and verbal feedback was provided to the participants who requested it.

3.10 Rigour and trustworthiness of the study

In establishing trustworthiness, Guba and Lincoln (1989) provide stringent criteria in qualitative research, known as credibility, dependability, confirmability, and transferability (Nowell et al., 2017). The study used these criteria to evaluate the study critically.

3.10.1 Credibility

i) Member checks

Extracts of the transcripts were emailed to participants to clarify if the persons with aphasia's responses were correctly depicted in the transcript. Participants reiterated that this was sufficiently recorded (four participants with aphasia had difficulty with email and reading, but they were assisted by their significant others in this regard).

ii) Peer review

This study used a peer review process to evaluate validity and suitability as this method assisted in quality control. Throughout the research process, supervision occurred to assist in the conception, follow through and write-up of this dissertation. In addition, two peers, a speech language therapist and a doctor of philosophy at the University of the Witwatersrand were asked to peer review once the data were collected and analysed to assess the integrity of the study.

iii) Reflexivity

Reflexive accounts were documented after each interview so that the researcher could record thoughts, opinions, and formations. This was recorded to assist the researcher to organise thoughts and allowed deeper, more critical interpretations of the data. This also assisted in reducing situational bias and the researcher's own bias as a proclaimed feminist, person of colour, with a neuro-divergent disability, of Islamic faith, and a speech-language therapist in South Africa.

3.10.2 Dependability

Qualitative research could attribute to research bias in the context of this study – the researcher's bias as a speech-language pathologist often working with persons with aphasia, a feminist, a person of colour, and Islamic faith, with a neuro-divergent disability, could have impacted the interpretation and analysis of data. To combat this possible bias, reflexivity was used throughout the research process.

3.10.3 Transferability

Transferability was maintained by recording the research process in a research report so that it may be applicable to other contexts and populations.

3.10.4 Confirmability

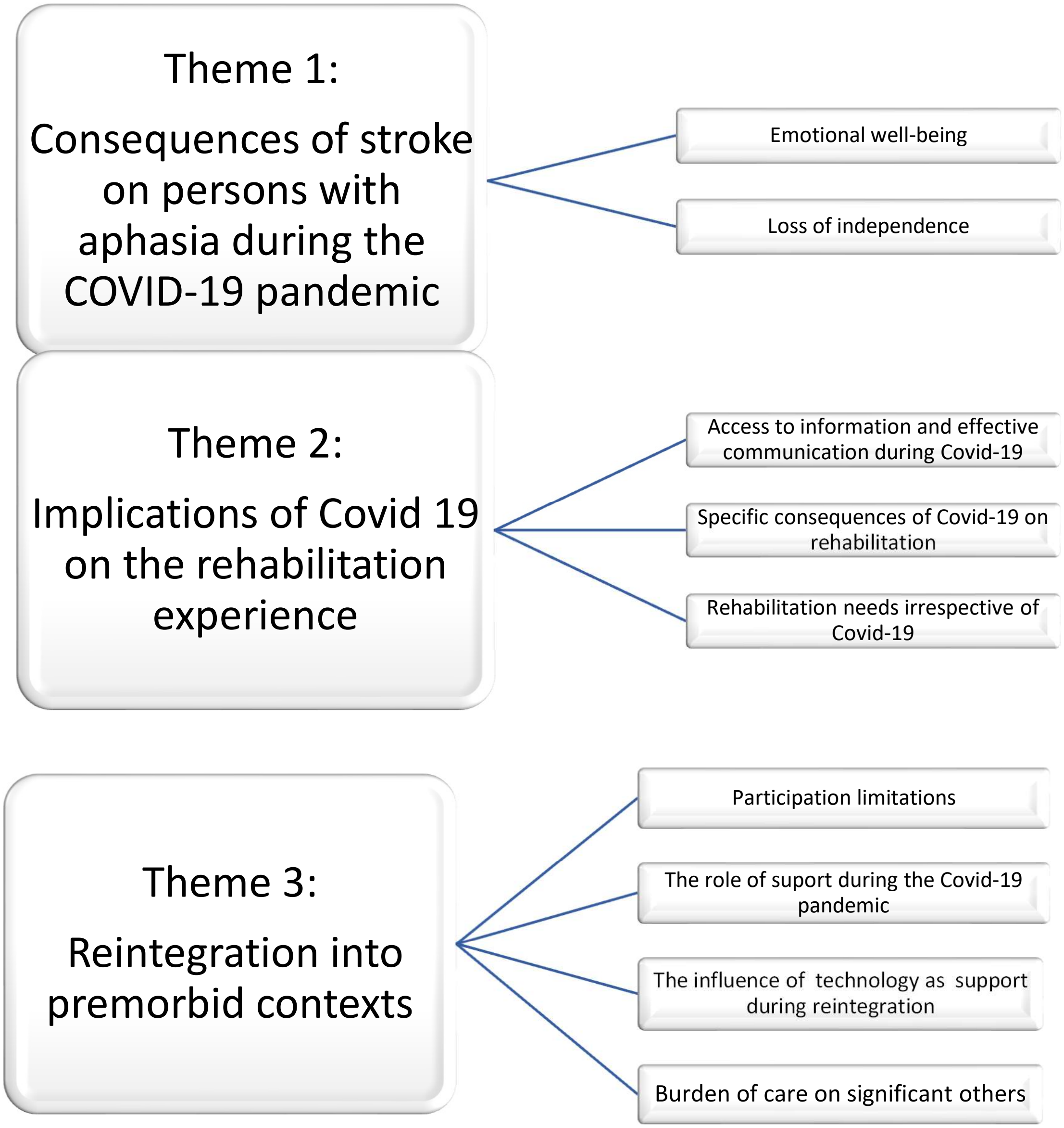
Confirmability was established when credibility, transferability, and dependability were achieved (Guba & Lincoln, 1989). Confirmability was achieved through recording and detailing of the above measures.

Chapter 4: Findings

Outline of chapter

This study set out to explore the lived experiences of stroke persons with aphasia and their significant others, who were diagnosed with a stroke and attended rehabilitation during the COVID-19 pandemic. The data were analysed using thematic analysis, with an inductive approach with guidelines developed by Braun and Clark (2006; 2021) as outlined in Chapter 3. This research study intended to report on these challenges in the specific context of aphasia and communicative rehabilitation. However, during the data collection process, this route was found to be unsuitable. Evidently, participants had difficulty in isolating their experiences specifically in the context of speech and language rehabilitation. This was likely due to the multiple effects a stroke has on an individual. Furthermore, rehabilitation occurs within a multidisciplinary team in order to address deficits in all areas such as motor, communication, psychological, cognitive, and social participation (Masuku et al., 2022). The initial intention was to collect data during the peak of the COVID-19 pandemic. However, due to the changes in the time-line of this research, this was no longer possible. Data collection only took place in 2022 after most restrictions had been lifted, which may have had an influence on the results obtained. Three themes emerged from the analysis of the data. See Figure 2 which outlines the emergent themes.

Figure 2: Representation describing themes and subthemes



Section A: Perspectives of persons with aphasia regarding their experiences with the diagnosis of stroke and aphasia during the COVID-19 pandemic

4.1 Consequences of a stroke on persons with aphasia during the COVID-19 pandemic

This theme focuses on reported experiences and perspectives of persons with aphasia. This study found that there were direct implications of participants' diagnoses on their psychological and social functioning which were possibly exacerbated by the COVID-19 pandemic. The main reported emotions were disbelief, fear, anger, sadness, anxiety or panic attacks, frustration, negative moods and difficulty sleeping. This research also found that persons with aphasia were continually working on accepting their stroke and aphasia, and the limitations brought upon them by these difficulties. It appears that their psychological well-being and emotional capacity fluctuated in this regard.

Living with a stroke was challenging for many of the participants. This theme is reported in two subthemes, namely, emotional well-being and loss of independence.

4.1.1 Emotional well-being

When participants were asked about the ways in which the stroke and aphasia had affected them, their responses seemed to focus on their psychological well-being as opposed to their functional disability. Their emotions varied and included disbelief, feelings of unease, guilt, negative moods and acceptance. In addition, due to being hospitalised during the pandemic – Anne 1A, Charlotte 2A, Mary 3A and James 4A reported additional feelings of unease.

Disbelief was felt by four participants with aphasia, as depicted by Anne 1A*, "For a long time I didn't believe I had a stroke"* and further emphasised by William 5A who indicated through AAC prompts using a low-tech communication board that he was "*shocked, surprised, and scared*." Fear was reported by three participants in relation to not remembering the incident*, "It scares me because I don't know what happened exactly,"* – Charlotte 2A and by James 4A "*It's uh … it's uh … blank, scary to lose a day of [my] life".*

Fear of reoccurrence was a common feeling shared by all participants, "*scared of another this … [stroke]"* – James 4A. In addition to fear that their condition may worsen, *"If I have another stroke and become completely paralysed, how would I live then?"* – Anne 1A.

Anger was expressed by two participants as they believed they were health conscious, "*I was angry. Yeah, anger, 'why me?' you know. Now I would say I'm afraid"* – Elizabeth 7A. The anger eventually changed to fear of a recurring stroke, for both participants.

There were increased feelings of isolation for persons with aphasia as they were unable to lean on their support systems due to COVID-19 pandemic regulations as Anne 1A said: "*It was tough being isolated. It was one of those things, but it was tough."* Four participants with aphasia agreed that the COVID-19 pandemic added an additional layer of anxiety as they were fearful of contracting the disease, or fearful of their loved ones contracting the disease, fearful of other patients in the hospital being carriers, as well as being surrounded by death as a result of the COVID-19 pandemic. Charlotte 2A shared her reflection, "*Yoh, I was scared. I was going to have COVID-19 plus the granny next to me I thought she was dead [from COVID-19]."* Three participants also mentioned feeling worry and sadness due to being hospitalised during COVID-19 pandemic. This is supported by Charlotte 2A's explanation*, "My isolation period extended because the patient next to me tested positive. It was a worry."* She further added*, "I didn't see my kids for eight weeks. It was sad."*

Low mood and inactivity were reported, "*I don't do much of the things I used to. Don't want to"* – Harry 6A (who used hand and body gestures in conjunction with voicing). This was also captured by Anne 1A*, "I can't explain but sometimes I don't really feel. I don't know. Maybe it's just negative feelings that I need to deal with but it's not every day. It's different."*

Challenges were experienced by most participants with regard to re-entering previous contexts: *"The first time I went to the mall with my son, I told him I was going to die – I had a panic attack and it felt like the day of the stroke and (it all) came rushing back."* – Elizabeth 7A.

Charlotte 2A reported that she experienced the stroke at work, which caused anxiety upon her return to work: "*Going back to the hospital where I work was a little difficult. That is where the stroke happened; it was difficult to be there in the same ICU, having nurses come up to me, saying they thought I wasn't going to make it. It hurt a lot."*

Feelings of frustration were commonly attributed to both the physical and communication limitations. *"It's difficult [for me to] communicate with my kids. I get frustrated. I can't talk"* – Harry 6A. Anne 1A shared*, "Well, I have to concentrate to keep [my] balance. It's not something natural now it's frustrating."* Frustration was also felt by participants as they were dependent on others for basic needs. "*I do get frustrated more. I don't mean to. I just want to … be me"* – James 4A.

Guilt was reported in terms of no longer contributing financially or helping out with daily chores. *"Yeah, it's a lot. Everything was fine then it wasn't. I feel bad because [my husband] takes on so much now"* – Anne 1A. Guilt was also felt because of how dependent they are, as expressed by Mary 3A who also explained via AAC strategies, gestural aid, and a spelling board that it is difficult to visit her daughter because they have to assist her in so many ways: "*No like, being [a] burden."*

Participants in this study reported that they are still working on acceptance. "*It's not just like where you become okay, it's a process. It takes a while. I'm still very emotional"* – Anne 1A and *"I feel like I have become a stronger person. I am more confident. I go out. I talk, I don't keep things in, I'm up the skies, sissie''* – Charlotte 2A who later added*, "I have good days and bad ones"* – Charlotte 2A. Elizabeth 7A *"I struggle to accept this new me; I don't always feel like me in my head or body but I am learning to."*

4.1.2 Loss of independence

Loss of independence was felt in terms of autonomy and functional dependence. In terms of autonomy, this was a direct result of persons with aphasia feeling excluded from decision making.

This was illustrated by Mary 3A*: "Loss of independence. So, I like having choices. It makes me feel like I have a choice"* who responded to the insinuation by her significant other that she was difficult during lunch and morning routines when food or clothes were prepared for her without consulting her. The same point was also highlighted by Anne 1A who shared her thoughts on not being able to decide for herself whether she should have attended rehabilitation: "*Look, I understand why I had to do it. But, for me, it was a bit of a grey area. No* *one explained to me. No one said why they're taking me to rehab, or what the outcome of that would be."* There was a sense of loss of control over their own lives: "*I don't like being told what to do"* – Harry 6A.

Loss of independence was felt by all persons with aphasia, in terms of functional capacity such as physical ability and communication ability. Harry 6A indicated with AAC prompts and verbal communication, "*I don't like using the wheelchair."* In addition, William 5A indicated: "*[I] get frustrated. [I] can't talk"* whereas James 4A stated: *"The [paid carer] helps bath [me]." Mary 3A* illustrated how her loss of independence was further felt by the physical impairment and lack of ability to drive, "*Miss [my] car. Just [sits) there. Can't drive,"* which was something felt strongly by five other participants as well. Mary 3A further indicated via gestural aid and a spelling board, *"Miss him [her partner]. Used to be. Just do [things on my own]. Drive. Self, I do."*

Loss of independence was also felt as a result of needing assistive devices or not achieving pre-stroke functioning. "*I think I will never move like I used to. But I can walk at least. I still use the walker. I have tingling, numbness, and my balance is slowly improving"* – Anne 1A.

Charlotte 2A and Elizabeth 7A live with their adult children (and in Charlotte's case, minor children as well). Both participants found it challenging to adjust to the dependence on their children. They felt they were still responsible for their children and the role reversal brought them feelings of inadequacy and guilt. This was pointedly highlighted by Charlotte 2A:

> *And remember, while I was here, everything was like … keep on forgetting. Sometimes, I would ask them to bring this, and my child is still small, can't drive, the other one was working but also doesn't [drive]. But now she's no more working anymore. But that one, the 16-year-old, was the one doing everything for me.*

Elizabeth 7A reported her lived experience as such:

> *(sighs) … what can I say? What can I say? The guilt, knowing how much I put on my sons now, it eats me up. It's not supposed to be this way you know? They lean on me. They already been through enough with me. Especially [George 7B], he lives with me. For me, I*

> *was always independent. I managed everything. My whole life. But now, it's challenging. Yeah, it's challenging. My other son is married. But he isn't far away and I know it can cause uhm ... like pressure on his wife also. So yes, I feel bad, I feel guilty.* ***I am*** *their mother after all.*

Section B: Themes outlining the collective perspectives of persons with aphasia and significant others on their experiences on rehabilitation and re-integration

4.2 Implications of COVID-19 on the rehabilitation experience

This theme explored the collective experiences of both the person with aphasia and their significant others through their rehabilitation.

This theme consists of three sub-themes which are: access to information during COVID-19; consequences of COVID-19 on rehabilitation; and unmet rehabilitation needs irrespective of COVID-19. For ease of reading, each of the sub-themes are presented using specific categories as sub-headings within the section.

4.2.1 Access to information and effective communication during COVID-19

4.2.1.1 Understanding the condition

Persons with aphasia reported that their doctors did not initially discuss the diagnosis with them, "*I waited for him [the doctor] to explain and then the following day I just asked, what happened to me?"* – Charlotte 2A. Six participants attributed challenges with direct consults with the doctors due to the COVID-19 pandemic and a constrained health care system at the time. "*Communication was really difficult because we couldn't be there and the doctor was not always available to discuss telephonically"* – Richard 3B. He later added, "*we knew she had a stroke but we were not aware of her specific abilities or health condition at the time."*

Participants were provided with input on new medications, "*there was a page that had everything written down like the dosage and the medication. The nurse explained it to me and told me they will give the info to the rehab"* – Matilda 4B.

Five significant others also reported that they had tried to source their own information via digital platforms and the internet: *"I thought all strokes were the same. I never* *knew you wouldn't able to speak or swallow,"* and further expanded, *"I did research on aphasia [online] and I can't believe how much we take for granted when our brain is okay"* – Meghan 6B. All participants with aphasia were unsure of the treatment received and four significant others were also uncertain of this. None of the participants were explicitly told about their aphasia at the acute stage, *"I mean, I thought it was just maybe a memory loss, but it wasn't"* – Kate 5B.

There also appeared to be a lack of stroke awareness before the stroke. *"She had a history of heart disease but I wasn't aware it was a risk for stroke until after I sought information [online]"* – Richard 3B. Participants also reported obtaining information on lifestyle and preventive measures themselves, "*I Googled hypertension after the stroke to help"* – Anne 1A.

Twelve out of 14 participants reported that this was their first experience with stroke and the first time seeing the consequences it had on a person. The following identifies the need for increased stroke education and awareness: *"[We need] better education about stroke. I'm in nursing and didn't know about all the ways stroke affects you"*– Charlotte 2A.

4.2.1.2 Communication

Four persons with aphasia recounted that, at the acute stage, they were "recommended" rehabilitation but were not adequately informed about the process itself or how rehabilitation may aid in treatment of the resultant stroke impairments. Elizabeth 7A shared*: "The doctor said, 'you know, I'm going to recommend that you go to the rehab before you go home'. He said it's intense brain therapy – but what is this 'intense brain therapy?' No one explained."* This sentiment was echoed by Anne 1A as well, who further reiterated that medical staff did not consider her personal circumstances, needs, or wants: *"'They wanted to send me to Pretoria, but my all my friends and family are in Benoni."* These participants' experiences show that informed consent, holistic needs of the patient and person-centred care are critical. It is also plausible that these aspects may have been further impacted by the COVID-19 pandemic, due to the use of face-masks as well as not having significant others present resulting in added miscommunications.

In the step-down facility where participants were admitted, communication and feedback were provided via a WhatsApp group to all significant others in this study, in order to mitigate challenges brought upon by the COVID-19 pandemic. However, this was reported as insufficient by five participants due to inconsistent or intermittent communication and being unable to physically witness their loved ones' difficulties and progress. This was evident through reports: "O*kay, so we did receive some input via reports. But I was concerned, was she being treated well? Was it beneficial? I'd have liked to know what's going on, seeing is better – you can see the progress. We could use technology"* – Richard 3B. However, Kate 5B felt that using WhatsApp was effective and she was well informed as reported through her experience: "*We were on a 'caring for [William 5B]' WhatsApp group. And everything that happens they would put it on the group. He had a fall and they informed me. They also allowed me to call on the nurses' phone and they would put us on a video call."*

Edward 1B felt that being informed this way throughout the COVID-19 pandemic lacked depth, and added that perhaps video conferencing would enable better facilitation:

> *It [WhatsApp] was fine but I wasn't really given any information on daily progress or what she was struggling with. It would be better to be given videos or to have voice notes from the different people. She was seeing so many. Communication was more about the restrictions – how visiting hours were changing or when to pick up washing and things like that.*

He also shared:

> *But we had a group session [virtual family meeting with therapists]. It was myself and a couple of the therapists. And they obviously gave their views. Anne 1A was present at the time too. It wasn't a video call. It was only an audio call. And then they said what was their concerns and so on [due to not discharging her yet].*

Due to the differing experiences reported by participants, there were conflicting reports on the satisfactory use of technology and communication during COVID-19. Higher satisfaction with communication was reported by Kate 5B and Meghan 6B whose life partner and husband were hospitalised during lower alert levels. These differences were evident in participants' reported experiences: "*I was allowed to visit through the window. There was no real communication initially, and it actually got pretty heated. We had absolutely no idea what was happening with [Mary 3A]" – Richard 3B.* Whereas Meghan 6B reported, "*I didn't have any problems; I could call or message (via WhatsApp) and was always informed."*

4.2.2 Consequences of COVID-19 on rehabilitation

Participants reflected that COVID-19 may have changed the rehabilitation process in some ways. Hence, findings may not be exhaustive and were largely dependent on participants' prior knowledge of the usual rehabilitation process which, understandably, may have been limited.

4.2.2.1 Access to healthcare services during the COVID-19 pandemic

One participant mentioned that, at the acute stage, the doctor did not visit her until two days after the incident and she believes this is why the stroke date was incorrectly captured on her medical records. She was not sure of the reason as to why this was the case, but attributes it to the possibility of hospitals being full to capacity at the time. This is supported by Elizabeth 7A's statement:

> *They [the doctors] did not come there the first day, and then only came the following day; that's probably why the date where they say the stroke hit me is two days later from when I had it. I think the hospital was full [due to COVID-19 cases].*

Anne 1A shared her experience:

> *They said I had the stroke and they had to put me over [refer me] to another hospital because there was no place or beds available. That was because of the COVID. So, they moved me over to [name of hospital].*

4.2.2.2 Impact of isolation periods, PPE, Hospital zones and disruptions to therapy

"*I was in isolation on admission. So, no therapy could happen at gym. It was a waste of days"* – Charlotte 2A who later reported*, "Physio was then done in bed. Speech therapy was difficult in the ward. Because of masks and because of risks [of transmission]."* James 4A reported via speech and AAC board*, "I was frustrated and alone. I couldn't use a phone. It* *[isolation] was hard. The tests were done … uh … every third day or so. I went into isolation again during [my stay]."* He also later explained: *"Speech therapy was very difficult in that time of COVID."* When further probed, he responded: "*I couldn't see their faces. It was hard [for me] to understand … uhm, instructions and so on*."

Anne 1A shared her experience*:* "*We couldn't move like freely in the hospital. There were zones. For example, to the physical therapy area, it was restricted."* Mary 3A reported through speech and gestural aid*, "Not go. Outside. Why? [shrugs]."*

Anne 1A also shared:

> *What we did experience is with the COVID, that there were cases there while we were over there [in the in-patient facility]. They had to move us around. We were six people that were in different stages of our rehab, whatever the case was. And they had to move us to the other end of the corridor to try and keep us out of the group that had the COVID virus at that stage. So, it was a bit difficult. There were interruptions.*

Psychological intervention was reportedly not consistently available to all participants in hospital for extended periods due to the pandemic. "*Some of the therapists were on rotation or something [due to COVID-19]. He was supposed to see psychology but she could only see him once a week, on a Monday I think, because she was from out the hospital"* – Matilda 4B. This was also similar to Anne 1A's experience: "*I saw psychology maybe two times in rehab".* In addition, disruptions to therapy were reported, as recorded by Charlotte 2A's experience: "*There was an outbreak [of COVID-19 at the facility]. Therapies were stopped because staff was absent. But then, from the day after or the next, I can't remember properly, the other speech therapist treated me. And [an]other OT."*

None of the participants attended group therapy or had joint multidisciplinary sessions within the rehabilitation setting during this time. When asked about this during the interview, James 4A responded: "*No, never",* as did William 5A who displayed via gestural aid "*no*". This was further established by Kate 5B who stated, "*To my knowledge, he did not participate, no. I think with the joint ones we might do OT and speech together soon."*

Charlotte 2A, along with Kate 5B, Harry 6A and Meghan 6B said they were generally satisfied with their rehabilitation experience and the care received. "*Everything they did, even with COVID-19, I really appreciated it. It was such good care and I watched him progress, to me that was just wonderful*" – Meghan 6B. Kate 5B shared: "*I wouldn't really say it [COVID-19] changed much. We received excellent care*." Elizabeth 7A was not satisfied with her in-patient rehabilitation experience but agreed that out-patient rehabilitation had been beneficial and preferred. Two participants (Anne 1A and her significant other, Edward 1B) shared the view that COVID-19 undoubtedly affected the process: *"If it wasn't for the Covid, I'm sure the experience and recovery would be better. Also visiting more frequently would be better"* – Edward 1B. Anne 1A added: "*They (the hospital) blocked us all off. We couldn't exactly go out or anywhere. We were allowed to stay basically inside. It would have definitely been a bigger help if there was more freedom for visitation and that."*

4.2.2.3 Functional therapy and family engagement

Due to the on-going pandemic, functional therapy, such as community walks and pass-outs to the home, were affected and either not conducted or minimally available. Participants were not acutely aware that these practices may have shaped their rehabilitation had it been a traditional rehabilitation experience (pre COVID-19). Hence, participants reported that they lacked functional rehabilitation due to the lack of these opportunities, "*I think, for therapy to be better, there must be more real-life things like mock ups and home visits to make it real because, with stroke, there is just too many things like social factors and life factors"* – Charlotte 2A. Charlotte 2A added that "mock ups" referred to simulated functional therapy within the facility as explained by her: "*The OT had me take blood pressure for patients in my ward. I had to record it and see how I cope. That helped me prepare for work* [as a nurse]." She also added, "*That was one time, but it was good. More things like that would help*."

In addition, *"there needs to be pass outs to the home. It doesn't make sense to sit there for six weeks without real life input. I can go home and the come back and say, I'm still struggling with this. It would also change the perception of rehab"* – Anne 1A. This was also noted by Meghan 6B, who noticed the difference in her husband (Harry 6A) when he had been allowed for pass-outs, as the COVID-19 regulations relaxed toward the end of his hospital stay.

“I think to be in rehab but be allowed home weekly would be best. Initially, he wasn’t allowed to – but when he did come home, he was good, and he was more easily susceptible to therapy after” – Meghan 6B.

Both persons with aphasia and their significant others felt rehabilitation needed to be more inclusive of the person and family as active participants. This aspect was impacted by the COVID-19 pandemic: “*Of course it was covid, she was in but we weren't allowed to go in. We weren't allowed to go into the hospital even at that stage”* – Richard 3B.

Five significant others of persons with aphasia reiterated that they were not as involved in direct treatment, as well as with goal setting. *“Communication impacts us all, so the whole family, emphasis on the whole family, should be involved”* – Richard 3B. *“We had no input-on goal setting. That would’ve been nice. I may have not known what to say though”* – Meghan 6B, and the experience of Kate 5B who said: “*I don’t know [maybe] if I saw him earlier [in the hospital], if it would’ve been better [to understand his condition] and I could help more.”* Matilda 4B shared:

> *When he was in rehab, the only one I actually interacted with was the speech-language therapist. I wasn’t part of the OT or Physio. He had been receiving it, but I wasn’t involved. The speech-language therapist asked me if I would want to be involved. She would teach me what to do at home. She would show me how to communicate.*

Additionally, persons with aphasia spoke about the importance of having their family present through the rehabilitation journey, as communicated by Mary 3A*: “Always together, need him.”* This was also shared by Anne 1A: “*I think if he [my husband] was involved from the beginning, it would have helped a lot. I don’t know why I’m getting so emotional about it (tears up). If he was with me through the rehab process, it would be better. He has a role to play in it.”*

Richard 3B reported there is a benefit in attending therapy with the person with aphasia. He shared his experience as a significant other: *“When we started doing physio and speech, that’s when basically covid relaxed a little bit*.” He added, “*That was good because, as an out-patient, I came literally every time.”*

4.2.2.4 Telerehabilitation

Two out of seven persons with aphasia had experience with telerehabilitation and were still actively receiving telerehabilitation speech therapy and/or occupational therapy sessions at the time of data collection. Both revealed that they found it as beneficial as face-to-face interactions, *"I have out-patient therapy sessions virtually and it is going well, I am also in my comfort zone which makes me do better"* – Elizabeth 7A. However, Charlotte 2A revealed that she struggled with access due to expensive costs associated with technology use, such as data costs, as well as always having a laptop on hand or a quiet space to conduct therapy: "*I had occupational therapy sessions online. It was fine but costly so that was difficult especially as not working."* Additionally, she noted: "*Like I said, we don't have a stable place even now, so space is tight"* – Charlotte 2A.

Four participants acknowledged both negative and positive aspects regarding the use of technology, "*So ma struggles when it is loading shedding and gets overwhelmed [with teletherapy/work]. But it's great 'coz she can't drive yet"* – George 7B and by Charlotte 2A, *"data is expensive."* Elizabeth 7A said: *"I enjoy working virtually from home, I am comfortable." She later added, "I prefer my online [therapy] sessions because I don't have added worries or trouble my son to take me [to therapy]."*

Seven participants revealed that they thought telerehabilitation was too complex in a South African setting, "*With load shedding I think it would become frustrating"* – Meghan 6B, and for stroke patients, *"[Physical] access would be problematic [due to stroke limitations]. Also, I enjoy coming weekly"* – Kate 5B. On the other hand, six participants were of the view that telerehabilitation is the future and could aid in achieving better long-term outcomes for patients through patient monitoring, "*Rehab online would help because at home it was like starting from scratch"* – Edward 1B.

When asked his opinion on technology in healthcare, Richard 3B stated he was neutral. He revealed that he does see the benefit in using technology in the rehabilitation spaces but was concerned for the overall South African context. Given that factors, such as age, and preference, may impact user ability: *"We used a communication app. It is wonderful and* *she can operate the tablet, but she gets so frustrated and refuses because it takes her long to find the words or letters and to type. Maybe, at our age, we aren't so computer literate"* – Richard 3B. Later he communicated that, within a South African context, access can be seen as a limitation: "*Not everyone can afford to use technology"* – Richard 3B. Meghan 6B shared, *"Interactive sessions via video conferencing would be very helpful. Especially with the time it takes to get ready,* [*I could] insert therapy in the workday. Technology would help."* Yet, at the same time, she further stated, "*I'm not sure if he [Harry 6A] would cope online though with the distraction and difficulty processing. It may be challenging for stroke victims."* In addition, Harry 6A shared that he did not have a personal preference for technology, "*It would be better to have contact."*

Technology was also used as a tool to assist with health literacy (via e-health literacy) as well as to allow patients direct access to their medical records. Edward 1B stated:

> *There was an issue getting medical records like x-rays. It was difficult with communication between the hospitals and medical aid and rehabilitation facility, so I ended up doing it all myself and kept forwarding everything myself. Luckily it is all accessible digitally now.*

4.2.3 Rehabilitation needs irrespective of COVID-19

4.2.3.1 Loss of respect and lack of dignity

Three participants spoke about feeling disrespected in both the acute facility and the rehabilitation facility, and witnessed other patients who may have had more severe difficulties being disrespected. This caused one participant to want to withdraw from therapy and the treatment process. Elizabeth 7A shared her thoughts:

> *I heard them speak about (name of patient) in vernacular, and I just thought if they could say something like that [about the other patient] in front of me who understands Zulu, what respect do they [nurses] have for me?*

Participants reported a loss of respect in interactions with healthcare workers. This change was attributed to being a stroke survivor, as shared by Elizabeth 7A: *"There was this* *thing that OK, because I had a stroke, they think I do not hear them; they think I'm losing my mind or what, you know."*

Two participants with aphasia also felt that the manner in which assessment results were communicated should be done in a more approachable, empathetic way. They also expressed that therapists should consider discussing their limitations in private with colleagues as opposed to within earshot of the person with aphasia, as these conversations would negatively impact the well-being, output, and motivation level of the patient. "*The two OTs were chatting that my cognition is low and what what, in my face, it was humiliating"* said Elizabeth 7A.

Participants reported challenges with being understood by healthcare staff. They indicated via gestural aid and through pointing, and these were put into words and clarification was asked if the indication was correct: *"Upstairs, ward. Need toilet. Not help me. Don't understand me. [Nurses] talk, me cry [until] Speech [the speech-language therapist] come help"* – William 5A.

Three participants with aphasia reported the need for a more compassionate and empathetic approach to communication, where healthcare providers demonstrate an understanding of their condition and show genuine care and concern. Elizabeth 7A shared her experience:

> *Nobody came to me to say, 'OK the intense brain treatment it equals 123'. Obviously when they come, they cannot just say [you are] OK you physically OK [pause]. They need to check that and be sure, you know. But somebody that can sit down with me and say, you know, 'how do you feel?', 'do you feel like you know?' You know, the first time I had a physio, so my physio [said] 'what is your problem?' You know [a healthcare worker] comes to you and says 'we understand that you had a stroke, brain stroke'. How do you feel when a person says 'well what is your problem?, what is your condition?' You know it's like I'm here, this is the hospital so you don't know why I'm here, you know. It's those little things, just those little things.*

In addition, four participants with aphasia reported that the perceived lack of understanding from healthcare workers frustrated them and resulted in reduced motivation or a negative attitude. Elizabeth 7A shared her experience:

> *Then I had an attitude because I just did not want to be there [at the step-down facility] and I did not like the way they [healthcare workers] spoke to me … I just wanted them to speak like normal, you know, like what's wrong how do you feel?*

4.2.3.2 Follow ups and referrals

Thirteen participants indicated that they believed on-going therapy intervention is needed after discharge, as not all their communicative needs had been met. Also, additional challenges were identified post discharge. Participants reiterated that they were still going through the process of rehabilitation and learning to adjust to the differences in their daily lives and, as such, they highlighted the need for long-term rehabilitation. *"Ongoing support is needed. There also needs to be a better national health standard, such as services provided by the government and medical aids"* – Richard 3B. This is further illustrated by Edward 1B: "*[During the discharge meeting],* they *(the professionals) understand what they are talking about, but honestly, you can't take it all in – it's too much. It needs to be paced. It's just a totally different perspective now. You don't really understand what's going on until you start living it."* Meghan 6B also shared that virtual follow-ups would be helpful*: "Instead of having to take him to a doctor, it would be great to just WhatsApp someone professional and say, 'I just need help or advice, that would be excellent."*

Persons with aphasia also added that they felt that additional therapy and support was needed, as seen by Mary 3A who indicated via gestural aid: *"*S*upport from professionals [would be] excellent!"* She also added*: "Need more, need more speech therapy."* In addition, Anne 1A reiterated that being a stroke survivor is a journey that continuously needs assistance, "Y*ou don't always understand. Follow ups would be nice."*

Participants were asked if they attended other allied services. Elizabeth 7A revealed*: "No, I don't see psychology. But I understand I may need it for my panic attacks,"* as well as Anne 1A who was informed that telerehabilitation was available*: "I didn't realise psychology as* *an out-patient is available online, but now that I know it is, I would like to try it."* Participants shared that they believed speech therapy intervention was still important post-discharge as, during re-integration, added help with communication is needed, *"I think the speech one is the most important one,"* – Kate 5B. Meghan 6B shared her experience:

> *I find now, out of the three therapies, the speech is the most important. For me currently because I find he does everything else. Even the physio said, 'he's quite strong'. So why are we doing more physio then, if he is okay? But the speech I still find is [needed]. I would rather the medical aid paid for more speech.*

However, not all participants are able to be approved for speech therapy as an out-patient. This is supported by statements from Richard 3B*, "I pay R8000 for Mary 3A's medical aid. It bugs me that out-patient therapy cover ceased after 12 sessions. In other countries, they have a health standard*." Additionally, James 4A reported via an AAC spelling board, "*I pay [for speech therapy] because the medical aid doesn't pay."*

4.2.3.3 Positive aspects of therapy

All persons with aphasia and their significant others agreed therapy was beneficial, even if they experienced challenges related to the COVID-19 pandemic. Significant others noticed an improvement and considered rehabilitation helpful, "*I have seen a vast improvement, there are still a lot of short falls but hopefully with hard work it can improve"* – Edward 1B.

Meghan 6B reported a similar experience with her husband's treatment, "*But I like to add that we really appreciated the good care and progress."* In addition, Matilda 4B shared*, "When he arrived vs when he left there was vast improvement."* Persons with aphasia shared that improvement and goals achieved led to increased feelings of accomplishment, independence and increased motivation*: "I was very happy to do therapy. I was so stiff first. I was excited to walk and recover, when I did things [functionally] it made me feel better"* – Charlotte 2A*,* and "*Therapy was good. Especially speech and OT"* – James 4A*.* In addition*, "I always did everything on my own, so reaching my goals makes me feel positive again. Like I can do things, even if it is more challenging or takes time. And I can try more"* – Elizabeth 7A.

Participants who were discharged as COVID-19 regulations eased (Mary 3A, James 4A, William 5A and Harry 6A) also shared that home-visits before discharge were beneficial; three of these visits were all done virtually. *"What was really helpful was the inspection to the house before discharge. They provided us with insight on how to make it more accessible" – Richard 3B.*

4.3 Re-integration into pre-morbid contexts

4.3.1 Participation limitations

Participants reported that they had faced difficulties in re-entering pre-stroke contexts. Participation limitations were experienced due to physical limitations, communication challenges, and social and environmental barriers. This sub-theme is reported using specific categories as sub-headings.

4.3.1.1 Physical and Functional Limitations

Participants shared how access is difficult because of physical and medical challenges, as stated by Mary 3A: *"Used to go away but now not safe* [due to physical limitations].*"* This was also shared by Kate 5B*: "The reason why we haven't been for a fishing trip is because, if he needs the toilet, we have to go quickly or he wets himself. When we go out, I have to put a nappy, but it's challenging to do that by a dam."* Richard 3B further reported*:*

> *There is a huge difference between wheel-chair friendly and wheel-chair access and we have quickly come to learn that. We still would love to go away and have gone but not as much. Realistic access does impact us. I wouldn't say we are restricted, but we have to do a lot of planning and, in some cases, it just does not work. It's just easier to stay home.*

Specific challenges, related to functional limitations brought on by stroke, were illustrated by Meghan 6B: "*He does try to do little things still; he makes me a cup of tea but yeah, in general, things have changed. I mean he doesn't come with me to a shop. He gets tired very quickly."* Low activity and fatigue were reported as challenges*, "She isn't as active; she sits around and watches TV"* – Edward 1B. Matilda 4B had a similar experience, *"I'd say, he's just not interested in most things. I mean he can direct me home, but on the way here, asked me* *three times where we going".* Anne 1A reported*, "I don't like going to the shops. [points to hand] [my] co-ordination isn't good so I get flustered in the queue because I hold it up."*

Elizabeth 7A shared her experience on how fatigue can pose as an additional barrier:

> *So, the public transport where you need to catch a taxi is a different situation. It can tire anyone else. So, with my condition it's even more, because you have to wait until the passengers are full, you know. You need to wait for another taxi maybe to connect you, you know, it's draining for [any one] so for me. Like it was not as bad as I thought it would be. But yeah, it is tiring. And challenging because it does not drop you where you going like, like now it got off at the robot and I had to walk.*

The following quote emphasises the challenges that physical disability, as well as communicative impairment impacts relationships: *"Aphasia is difficult. She doesn't laugh as much as she used to. I miss that"* – Richard 3B. He continued, *"I miss holding hands and walking on the beach. Also, something as basic as laying down together requires manoeuvring and planning"* – Richard 3B. It was also explained that it was difficult for significant others to see the person their loved one has become being often so removed from who they used to be. *"It is like having lost and mourning for a person that you love. Because the person in front of you is not the same"* – Matilda 4B.

4.3.1.2 Social and communication barriers

Mary 3A explained through a spelling board that it was difficult to communicate with her friends and family which causes frustration and sadness: "*Don't visit much. Don't talk much. Hard. And sad. With old friends. Just sit sometimes.*" Harry 6A said: *"It's difficult for me to communicate with my kids. I get frustrated. I can't talk."* Matilda 4B shared, *"I think because he can't have a full conversation anymore, people don't come as often."*

Meghan 6B shared her experience*: "Our neighbours come and visit us, but I'm sort of the person that has to do all the talking now. I don't know if that makes it worse for them [that the person with aphasia can't talk] and so they stay shorter. Same with the kids."* William 5A indicated through AAC prompts, which included a low-tech communication board and gestural aid: *"I like to meet family but it is difficult [to communicate]."* Richard 3B:

> *Communication is difficult. I mean, she repeats the word 'no' even when she doesn't mean 'no' so it can be really confusing. It was life-changing when she got the gesture for yes and no right."* And Edward 1B, *"It can be a little frustrating, she might start saying something, like last night she started and then walked around the table and then she sort of forgot what she was saying …*

Participants emphasised that the most difficult aspect for them was communication: *"We try different ways, he'll show me he wants a coke or water – if he's hungry he'll let me know and I give options to choose"* – Matilda 4B. Kate 5B also shared*: "I think the hardest is not being able to speak. He wants to and knows what he wants to say but can't. That's also hard to watch."*

The resultant stroke and aphasia had reportedly impacted participants' intimacy and ability to engage with each other. Meghan 6B shared her thoughts*: "I miss having that person to lean on, to talk to, to support. It can be lonely; even though he is right there, it isn't the same. He isn't the same."* This captures the difficulties that both communication impairment and disability may have on an interpersonal relationship.

Six participants with aphasia shared that they chose to withdraw from different communication contexts, simply because it is just too difficult to try and fail; as well as watch people's reaction of not understanding or knowing how to engage with them: "*People treat me differently. I avoid people"* – Harry 6A. Many became emotional at this stage, especially as they reflected on how the stroke impairment had impacted on their ability to engage and, as a result, caused changes in their relationships (with friends, family, children, the community at large). As such, they often felt a lack of support, as illustrated by Anne 1A*: "People look at me strange when I lose my words, like I'm stupid. I'm not"* and later stated, *"new people is okay, people I know, I'm embarrassed to talk to sometimes."* Whereas other participants revealed they only felt comfortable with a select few who had been on this journey with them, and communication is easier without judgement: "*I have 2 friends that have been with me throughout. I feel at ease with them"* – Elizabeth 7A.

Those who needed to return to work also had more nuanced communication needs and seemed to have additional psychological and social integration difficulties due to the pressure and expectations placed on them at work. This was supported by the statement: *"When I returned to work, they were worried I'm not going to be as effective"* – Charlotte 2A. It was reported that stroke and aphasia had a major impact on the working situation for persons with aphasia – which was also further exemplified by the COVID-19 context even before the stroke diagnosis. Meghan 6B shared: "*Well, with Covid, he was just at home, because then the jobs were so scarce."* Only two out of seven participants with aphasia were able to successfully re-integrate into their previous working context post-stroke.

The participants that had re-entered the work-force were both receiving out-patient vocational rehabilitation. Both participants reported that accommodations were made for them which were successful in allowing them to re-enter the work space. These included: a reduced amount of work hours, assistance/accommodation due to inability to drive (carpooling and working from home), and a line supervisor to discuss any challenges they may face. However, both reported psychological challenges in this aspect (increased anxiety, fear upon re-entering, and paranoia). Communication in corporate contexts was reportedly challenging. Given that there is a reduced awareness of stroke survivors' communication challenges and their inability to effectively respond or provide better opportunities, they need additional time and/or a breakdown of information, as expressed by Elizabeth 7A:

> *At work, they don't really understand stroke, I've got warnings because of things I never would before, like missing an email or a chat discussion and then not following instructions right. They do try to support but not always do they understand. I think to them, stroke is a lot more physical but my things are different like, in a meeting, it is too much talking and I can't focus or if they ask me something and I can't answer properly. I can manage my job but yeah, I struggle with remembering. My head gets sore, like if I look at one spreadsheet with too much information. Or if I'm given something too complex. I tried to explain to give me more like simple tasks, I can do a hundred [simple tasks], instead of one complex query and help take the load off others ...*

There were reports of reduced social engagement. Richard 3B stated: "*There is reduced social activity and we have to think about social gatherings beforehand. I tend not to go either."* A reduction in previous activities was common for all participants. *"I miss things. Vacations. Playing outside with grandkids. Dinner [with family]. Driving. Woodwork"* – Harry 6A. This was further indicated through non-verbal communication (gestures and picture aid) by William 5A who began crying when asked if misses old friends. He further indicated, "*I miss fishing. Was good."'* Persons with aphasia also expressed the emotional toll reintegration takes on them and they believe the community at large needs to be more inclusive. "*Honestly, the problem is not the physical side. Its emotional, communication, understanding. Fatigue. People can't see [those aspects] so they can't understand*. *And they judge"* – Anne 1A who later added *"But the main thing everyone needs to realise I'm still me, I haven't changed (cries)."*

Participants were asked if reduced social interaction was a consequence of both the COVID-19 pandemic and the stroke. All participants agreed that it was, as stated by Meghan 6B, "*a combination [of stroke and COVID-19]".* Meghan 6B further explained: "*I suppose you don't want to go to many places because you're scared that you're going to get exposed and my immune system isn't the greatest. I suppose we were much more outgoing before and now Covid has just made us more cautious."* Kate 5B shared her experience, *"they [the therapist] told us there is a stroke group we can join but, because of COVID-19, they haven't started yet."* Edward 1B answered: "*we're at the farm (laughs) so yes, it did impact us. I was worried about Anne 1A getting sick, and it's much quieter and peaceful here so she can relax."*

4.3.1.3 Financial implications

Financial insecurity, loss of assets, and loss of ability as a result of the stroke made re-integration challenging. This was mainly attributed to the unemployment of the person with aphasia or a lack of funding from the medical aids. One participant, who is a person with aphasia, illustrated that, due to a complete lack of support and being the main breadwinner, finance was a great struggle, especially for basic needs such as transport, food, housing, and schooling, in addition to medical expenses. This can be derived from Charlotte 2A's experience:

> *I was hurt. I was crying like rain. My house was repossessed. We still don't have a stable place. And I only got back to work now. I have debt. There is a lot of financial strain. I have four kids, three children and one grandchild. I was in hospital for so long with a quarter of my salary being paid only. But my expenses increased. Medical aids don't cover everything. It needs to be holistic to help. Financially, there is a lot of strain.*

Participants reported increased financial burden due to medical boarding, "*The work said he can come back after six months even though he can't speak, he can still come back. But he can't manage physically, it's not possible. They were all saddened about that"* – Kate 5B. Being placed on temporary incapacity leave or COVID-19 also contributed to financial challenges; this is depicted by Meghan 6B's experience:

> *He was not getting much work because of COVID. I think, financially, there is added stress. I worry how we will make it month to month. And then, of course, the medical aid as well, they pay for only certain things. All savings gets depleted because now things are coming off which aren't covered or aren't supposed to, which is added admin work too. Because now I've got to phone and ask 'why are you charging this out to us?' Also, to make sure all this out-patient therapy is covered – it is also why he doesn't get psychology even though it would benefit him. Financially, emotionally everything just gets a little too much.*

Significant others explained that there was an increased financial burden thrust on to them*, "I can't leave him alone and I can't not go to work. We have the carer, which is expensive and there's [other] additional things now"* – Matilda 4B. For significant others, balancing work and caring was also a challenge but, when provided with support, these challenges eased slightly. Meghan 6B stated: "*Working from home has helped. There is a blended approach happening but, for the most part, I'm working at home and twice a week I go in. They've been so flexible, but that makes me feel bad obviously."*

4.3.2 The role of support during the COVID-19 pandemic

Five participants shared that support was likely impacted due to health concerns caused by COVID-19: "*I didn't want anyone [friends or family] to meet me because I would come* *to the hospital and maybe he will be at risk"* – Kate 5B. Meghan 6B reported, "*They took him to the hospital, they did a Covid test. We found out that he had Covid. We didn't know because he had absolutely no symptoms. I isolated. And then became paranoid. Maybe that's why our friends distanced also."*

Anne 1A shared her experience and reported that perhaps overall support may have been impacted by COVID-19 regulations:

> *Maybe if it was within normal circumstances where we could have many visitors, our friends, our neighbours coming in and they slowly watch me [post-stroke during in-patient rehabilitation], they would have had a better understanding of stroke. It's difficult. It's not easy. And a lot of people don't realise how difficult it really is to keep waking up and knowing that something is wrong. And then you have to start working on it and try and get your life back and all that. And get going and do things again. Things that, at some point, [I] didn't even feel like doing. It was tough for me and it was tough for Edward 1B too.*

There were differences noted in professional support (by healthcare workers) from those hospitalised earlier in the pandemic compared to participants who were hospitalised later. "*We started from zero at home, there were no follow ups"* – Edward 1B, in contrast to Meghan 6B's experience: "*They (therapists) were also good. They had people phoning me to ask me, I sent photos of my bathroom and shower [for advice on safety]."*

Participants acknowledged the need for support in taking care of a person with aphasia, and noted the lack of support as the process continued, *"I have to say, in the beginning, I had lots of support. But, as time went, so did it [the support]. I guess everyone has their own lives to get back to"* – Meghan 6B. In contrast to the aforementioned, Richard 3B stated that he has continued support which helps with acceptance and coping, "*We are a very bonded family, so I know there is support and also acknowledgement on how this has been taxing on me. Her daughter appreciates all I do which is nice."*

4.3.3 The influence of technology as support during re-integration

Technology was viewed as a support mechanism to stay connected, to work, to have better access and to aid with independence. This view was shared by two participants who both identified as single mothers who had to head a household and ensure that their dependents are taken care of. They were able to use technology to buy groceries, "*Checkers Sixty60 is a Godsend, I use it all the time, I can get what I need independently and not expose myself to a panic attack"* – Elizabeth 7A.

Five participants with aphasia reported technology had aided them in reintegration – albeit not fully, but it allowed them access that would otherwise be restricted to them – both because of the COVID-19 pandemic and their resultant stroke impairments, which are physical and communicative. They also preferred using video conferencing for personal communication during COVID-19, as opposed to telephonic interactions which were more difficult. They were able to gain access to church services online: "*My faith … I needed to work on it. COVID-19 restrictions were rife, but I joined a [church] service online"* – Anne 1A. Participants were also able to keep in touch with family and friends who lived far away, *"we speak to her sister and mine via zoom which is great."* – Richard 3B. Harry 6A recalled how beneficial using video calls to see his grandchildren have been, "*Nice to see grandkids on phone [video calling].*" Technology was also used to re-enter workspaces: "*I think, if it wasn't for the virtual space, I would not be able to return to work, because of my difficulties with driving"* – Elizabeth 7A. While their communicative competencies were still reduced or diminished in these spaces, technology provided an opportunity for access. However, many participants with aphasia still needed aid in using technological devices largely due to physical, communicative, and cognitive impairments associated with the stroke.

Participants reported that technology provided assistance in regaining independence and provided opportunities for social engagement during the pandemic and the resultant stroke impairment, *"Support groups would be nice. Like Facebook groups. Knowing you're not alone. I've recently joined one, not very actively but people post questions and comments"* – Meghan 6B. "*We have become homebodies because of the stroke and COVID. It's nice to chat and call people to stay in touch"* – Matilda 4B.

Harry 6A revealed he was learning to use the remote again so that he can finally make his own choices without having to continually ask for assistance. Mary 3A, on the other hand, stated "*I do (shakes head) (points to phone). No, no* (smiles, indicating that she rather communicates with gestures*).*" She had an AAC speech generating application to use and assist her with communication however it did not appeal to her and reduced her engagement until she began using a gestural modality (Makaton) which appealed to her more. William 5A echoed these thoughts, as he found it difficult to navigate technology due to his physical limitations and preference, hence he preferred to use gestures or low tech AAC aids. *"Like [prefer] this (lifts hands)"* – William 5A. None of the participants interviewed used high-tech AAC for communication.

4.3.4 Burden of care on significant others

This subtheme underscores the perspectives of significant others. It was noted that participants, who are both the carer and the significant other, appear to have difficulty adjusting between these roles, particularly during COVID-19 restrictions which limited the possibility of added help and outside support. Edward 1B shared his experience: "*… but now things have changed. The whole routine of the day has changed."* Meghan 6B also noted: *"He needs supervision all the time because accidents can happen. He isn't able to do his woodwork."* This is also further supported by: "*We used to have shared roles, like shopping, cooking, etc. and I would focus a lot more on the business but that has changed"* – Richard 3B. He later added, "*It could be 2, 3, 4 o'clock, I don't know – she needs the toilet. It's not a minute thing. Get her to the wheelchair, assist … wait for her, get her off the toilet and back to the wheelchair. It breaks your sleep. It can be exhausting."* Matilda 4B also shared her experience: *"We do go out shopping, like yesterday, but it is hard, I have to help him all the time, it is impossible to push a trolley and a wheelchair at the same time."*

Participants reported on the ways they have had increased pressure since their loved one's stroke in trying to juggle all responsibilities, "*I'm looking after him, attend therapies and still do my work. Most days I'm okay but some days I'm not"* – Meghan 6B. Richard 3B shared: "*In some cases, on weekends, she wants to go for a drive, not anywhere specific just go for a drive. Again, to me, it's a waste of time, my time. Her time? No. I do it because she wants to do* *it."* Kate 5B shared*: "I also get tired and even upset but I try not to shout. Because you know, its hard work. It's not easy. You know, sometimes I must get up four times a night to dry the bed and change the nappies. I cope."*

There were a range of emotional impacts relating to caregiving. Exhaustion and depression were reported by Kate 5B*: "I take things day by day, because it can be a lot."* She then later expressed*: "I could say I was depressed [about his condition]. I went to the doctor to get tablets for my nerves."*

Increased anxiety was reported: "*I leave him alone with the carer sometimes but I hurry back because I worry"* – Matilda 4B. *"I'm always scared he may fall or something, so I don't leave him alone"* – Meghan 6B*.* There was also an increased emotional toll on significant others due to conflict as captured here by Meghan 6B*: "I have to always adjust. I know when he does things [increased demands], he doesn't always mean [to be irrational] it but it's hard not to take it personally as a wife."* Later, she expanded: *"It's the little things that drive me insane and then the wife and care-giver sort of have a fight with each other. And that is hard. I don't like fighting with him."* Matilda 4B shared, "*He will struggle and I will try and help him and he will push me away or be upset. And then it hurts, I'm just trying to help."*

Two participants shared that they had experienced increased isolation due to both the stroke and the COVID-19 pandemic: "*It's lonely, I don't have time to do much and its different now, he can't really be there for me"* – Kate 5B. "*With COVID, it is difficult to keep up with others, I often just sit by myself watching TV when he is asleep*" – Meghan 6B.

Guilt was common when they were not assisting their loved ones. "*Look, her daughter has offered to help out and I did it once. The whole time, I felt guilty, but honestly it was great, I did everything I set out to do that week – painting, redecorating yeah"* – Richard 3B. Guilt was also felt by making decisions on behalf of their loved ones, as described George 7B who stated: *"It's (sighs), I don't know, complex? In our culture we have to respect elders' decisions but mom needs help, like with stopping therapy – it wasn't rational but am I disrespecting her? Are we [her children] doing right by forcing her? I don't know.*"

Two significant others communicated that they often felt guilt for “surviving” and not being the one in need, *“I wonder … why not me? It would be great if I could snap my fingers and go backwards but that doesn’t happen. We’ve got to [try to] live with it. Accept it”* – Richard 3B. Meghan 6B shared her experience:

> *If anything, I would’ve thought he would’ve died from a heart attack and then to find him at home. I wasn’t going to go to work. And then I did. And I shouldn’t have. He was ice ice cold when I got home. He would be better than he is now, had I stayed home. It should have been me. I’m younger, stronger. I’d be better. He already went through so many complications with his triple bypass.*

Major decisions are reportedly taken by five significant others post stroke, “*I make most of the financial decisions, we used to do it together before”* – Edward 1A. They also choose to, at times, not disclose sensitive information for fear that it may be too much for the person with aphasia to cope with. So, they took on added emotional difficulties. *“He isn’t aware that the doctors have said he is now terminal, in congestive heart failure. I can’t do that to him. I can’t tell him”* – Meghan 6B.

Additionally, Kate 5B shared: *“I don’t always know what he’s thinking or feeling. Like attending the award ceremony, so I try to do what I think is best for him, even if it may not be his choice.”* This was also echoed by other participants as presented here by Richard 3B*: “She is not able to make difficult decisions so we (her daughter and I) have to.”*

There is less time to focus on their own needs post-stroke, “*I mean, I just don’t have the time to chat or socialise as I used to, I would speak to my sister and step-daughter daily, and now I don’t really get a chance, it’s difficult with him around”* – Meghan 6B.

Reportedly, caring has also led to more physical symptoms in some cases: “*At my age, it’s difficult because my back hurts”* – Richard 3B and “*I sometimes forget to eat and feel dizzy or faint*” – Kate 5B. Similarly, as depicted by Julia 2B: “*I don’t sleep well most days and I get headaches, maybe it’s just the worry that it will happen again”* as well as *“Managing my chronic illness, his illness, and work is taxing on my health”* – Matilda 4B.

All significant others also shared a deep sense of duty toward their loved ones as seen here: *“She is my mother, I will do anything for her”* – George 7B and “*They asked if I wanted a carer here at home because he needs lots of help, but I felt it wasn’t necessary, he is my duty”* – Kate 5B. Participants shared that, while communication is challenging to their relationship, they have found different ways to connect. For some, it was attributed to physical aspects, *“He’ll come and hold my hand or give me a random kiss so there’s been different expressions of love, if you will. Instead of communication [verbal communication]”* – Meghan 6B. All significant others further emphasised they remain committed to the person with aphasia: *“I am completely committed to her. That will never change” – Richard 3B.*

Chapter 5: Discussion

Outline of chapter

This study focused on understanding the lived experiences of persons with aphasia and their significant others during the COVID-19 pandemic. This chapter uses the biopsychosocialtech model of health to interpret the findings as outlined in Chapter 4 of this dissertation. The findings are discussed in relation to current research trends provided in the literature, with regard to the implications of the COVID-19 pandemic on stroke and aphasia. This was done using a theoretical basis for treatment in order to address the needs of individuals at the biological or impairment level, the impact of aphasia on the individual and their significant other at a psychosocial level, the functional and communicative needs at a social level, and the way technology can assist in remediation and ongoing monitoring of this population (i.e., persons with aphasia as well as significant others of persons with aphasia). As this is a holistic model, all factors of the model have been integrated when discussing the key findings.

5.1 The application of the biopsychosocialtech model on the implications of the COVID-19 pandemic

The focus of this dissertation was on understanding the experiences of stroke survivors with aphasia and their significant others during the COVID-19 pandemic. This was important as participants had suffered a stroke incident and navigated aphasia rehabilitation and re-integration into pre-morbid contexts during the COVID-19 pandemic. Using the biopsychosocialtech model to interpret the findings of this study allowed for these specific factors, namely, the biomedical, psychological, social, and technological factors, to be systematically evaluated as this allowed for the understanding of stroke and aphasia to be embedded in patient centred care (Bernhardt et al., 2017). Therefore, it was important to note the specific factors that influenced the lived experiences of an aphasia diagnosis, rehabilitation and re-integration during the COVID-19 pandemic for both stroke survivors and their significant others. It was also necessary to explore the ways in which technology may have influenced rehabilitation as increased reliance on technology was notable during the pandemic.

Participants’ responses from this study suggest that the COVID-19 pandemic altered the manner in which stroke rehabilitation was delivered and seemingly caused additional challenges. In particular, difficulties with communication and informational support from healthcare staff to patients, the lack of visitation from family or friends, the lack of family involvement during the in-patient stay, reduced ability to engage in functional therapy and the need for telerehabilitation. The pandemic may have also inadvertently exacerbated existing challenges such as difficulties experienced by persons with aphasia in communicating with healthcare workers, challenges upon reintegration, access to support systems and increased burden of care experienced by significant others. Within the current study, these added challenges were particularly notable during the early stages of the pandemic. It has been established in the literature that the COVID-19 pandemic brought added challenges to post-stroke care, which heightened pre-existing gaps in healthcare delivery and therefore complicated stroke care and recovery specifically in relation to active involvement of the patient, family, communication within healthcare systems and reduced preparedness upon discharge and reintegration (Shafer et al., 2023; Zafra-Tanaka et al., 2022). The need for alternate models to intervention, such as teletherapy (Kong, 2021), was warranted. Additionally, reduced availability of social support and access to services critical for aphasia rehabilitation, such as group therapy, were curtailed due to the pandemic restrictions (Lucas et al., 2021). Additional distress experienced by significant others due to added responsibilities, increased isolation and lack of social support due to the pandemic were also documented in the literature (Lee at al., 2021).

5.1.1 Challenges with informational support and communication during COVID-19

From participants’ reports in the current study, it emerged that the COVID-19 pandemic impacted informational support and effective communication during in-patient rehabilitation, particularly during the early stages of the pandemic. This resulted in inadequacies for stroke survivors and their significant others in understanding consequences of stroke and the purpose of rehabilitation. Pre-pandemic literature established that persons with aphasia require the opportunity to remain active participants of their treatment in terms of goal setting and decision making (Worrall et al., 2011; Wray & Clarke, 2017). The findings of this study are also consistent with findings in the literature during the COVID-19 era, which state that obtaining information and communication were compromised aspects of therapy (Shafer et al., 2023; Zafra-Tanaka et al., 2022).

Within the current study, persons with aphasia expressed a desire for clearer explanations about stroke and aphasia, its implications and the potential outcomes or benefits of rehabilitation. This aspect appears to have been affected by the COVID-19 pandemic. Underlying socioeconomic factors, family constructs, and support impacted both the biomedical and psychological well-being of all participants. Social exclusion, experienced by participants due to not having their family present within the health care facility, was also perceived as a contributing factor. Specific COVID-19 restrictions, such as lack of visitation, restricted movement within the hospital, social distancing, lack of group therapy and pass-outs, acted as barriers to psychosocial considerations that are necessary and helpful to persons with aphasia and may have otherwise resulted in positive outcomes. The findings are similar to other studies conducted during the pandemic in that additional psychosocial aspects were found to impact the diagnosis and recovery of persons with aphasia as a direct result of pandemic restrictions and changes in policy or delivery during this time (Lee et al., 2021; Lucas et al., 2021; Sutter-Leve et al., 2021; Zafra-Tanaka et al., 2022). These findings display the need to understand aphasia within a holistic model such as the biopsychosocialtech model as there are many factors to consider during intervention.

Within the literature, the need for training and education for health care workers on how to make environments more suitable for those with communication difficulties has been well documented (Hersh, 2016; Kagan, 1998; Kagan & LeBlanc, 2002; Pound et al., 2007; Simmons-Mackie et al., 2007). It is concerning that the effective implementation of these recommendations may have been impacted due to the COVID-19 pandemic. As typical aphasia intervention was disrupted by the COVID-19 pandemic, this is perhaps a plausible explanation as to why additional challenges were experienced by participants – particularly with communication and informational support. Due to participants' reports from the current study in relation to effective communication and informational support, it is suggested that healthcare workers should take time to address concerns and provide detailed information to facilitate better understanding and decision making. Effective communication is essential for providing accurate information about the treatment plan, progress updates, and the benefits of rehabilitation (Lucas et al., 2021; Shafer et al., 2023; Wray & Clarke, 2017) and should be a priority especially in the event of another pandemic or emergency situation (Masuku et al., 2022).

In the current study, technology was used by participants as a means of obtaining information through e-health literacy. This has important implications in trying to further awareness, education, and preventative measures in a digital capacity and has been documented in current literature (De Beer, 2020). This is further supported by findings in the literature as technology appeared to assist in overcoming barriers during the COVID-19 pandemic such as providing improved access to rehabilitation services (Masuku et al., 2022).

Barriers to effective use of technology were also reported by participants in the current study which include access to technology, physical limitations, as well as individual preferences. Given these findings, it is important to consider the ways in which technology can influence and re-shape rehabilitation in a holistic manner. While technology may improve access to information, it may be challenging for persons with post-stroke aphasia to do so independently. Limitations related to both stroke and aphasia may further impact the ability of an individual to engage in a digital manner, such as literacy ability (De Beer, 2020) or physical ability (Tar-Mahomed & Kater, 2022) and these aspects should be systematically evaluated.

The breakdown in communication during the COVID-19 pandemic between healthcare workers and significant others hindered the exchange of vital medical information and also resulted in added feelings of frustration and worry. This has been a common finding in both international and local literature whereby the significant others were not always well informed at both the acute and chronic stage of rehabilitation as a direct consequence of the COVID-19 pandemic which caused additional concern (Masuku et al., 2022; Shafer et al., 2023; Zafra-Tanaka et al., 2022). This has implications on the biopsychosocialtech model, particularly on the psychosocial aspects, as literature has shown that active involvement of the significant other is important and appears to yield a better understanding of the condition which allows for improved care and better outcomes upon discharge and re-integration of persons with aphasia (Kontou et al., 2022).

In this study, participants highlighted that WhatsApp was not always sufficient as communication with healthcare staff and significant others was often brief, lacked depth or personal connection. In particular, it was suggested that video conferencing may be a better digital mode of communication which can improve the understanding of the family. On the other hand, a few participants agreed that this manner of communication was helpful and informative. These differences could be attributed to a number of factors, such as the normalisation of adaptive strategies, as the pandemic progressed or perhaps participants' own abilities to engage on digital platforms. An interesting observation from the current study was that all participants – young and old – were intrigued by the possibility of using technology. Participants within the current study also reported on the benefit of using video conferencing in involving family as active participants, as well as the role of technology in long-term support. It has been documented that the use of technology can aid in improving socialisation, as it may enhance communication through videoconferencing where gestures and non-verbal communication remains prevalent (ASA, 2018). This shows that the use of technology can impact the psychosocial factors (Scherer, 2020) and perhaps improve access for those with aphasia (ASA, 2018; Rose, 2023). Studies by De Beer et al. (2020) as well as Tar-Mahomed and Kater (2022) highlight that technology can be beneficial in supporting rehabilitation outcomes that are inclusive, however there are limitations in a South African context that need to be considered and best practice guidelines still need to be developed.

5.1.2 The effects of COVID-19 on the rehabilitation experience

The psychological impact of compromised communication is important. Uncertainty and a lack of clarity about their condition reportedly led to increased stress and worry among individuals with aphasia and their significant others within the current study. Adequate communication and information provision are crucial in fostering a sense of trust, understanding, and control over the rehabilitation journey (Sutter-Leve et al., 2021). When these elements are lacking, additional psychological distress may arise, impeding the emotional well-being of individuals with aphasia and their significant others (Sutter-Leve et al., 2021).

Data from the current study highlighted effects on the continuity and quality of therapy due to the direct consequences of COVID-19 pandemic regulations. These include aspects such as isolation periods, changeover of staff, restricted zones in hospitals, reduced joint MDT intervention and restricted visitation practices. From a biomedical perspective, while isolation periods may have reduced the number of COVID-19 infections, the impact of isolation periods and disruptions to therapy may have had an impact on the provision of necessary rehabilitation services for individuals with aphasia within the study. The increased demands placed on healthcare systems during the pandemic, may have contributed to reduced therapy sessions or challenges in accessing rehabilitation, as reported, even though the participants of this study had been admitted in an in-patient facility. The study by Lucas et al. (2021) agreed that the COVID-19 pandemic posed multiple challenges to rehabilitation and may have impacted the overall quality of life such as increased isolation, disruptions to therapy, reduced support networks and reduced psychosocial well-being. These findings are also consistent with findings by Masuku et al. (2022) who showed there was increased isolation by participants, inability to effectively access healthcare, disruptions in therapy and decreased physical contact with patients as a direct consequence of the pandemic.

The social implications of limited functional therapy and family engagement during the COVID-19 pandemic within the current study are noteworthy. Restrictions on visits and limited access to support networks may have contributed to a lack of social interaction and a loss of important connections for persons with aphasia. The absence of home visits and caregiver training on discharge reportedly limited the involvement and preparedness of family members to provide support and facilitate rehabilitation outside of clinical settings. This lack of engagement may impede the social reintegration and recovery process. Individuals with aphasia often face additional challenges in adapting to the community, particularly without the necessary support systems in place. In contrast, participants who were discharged as restrictions eased, reported that family involvement within sessions, pass-outs and home-visits were all valued aspects of the rehabilitation process. As support systems were not readily accessible, additional fallout was reported in psychological well-being during the COVID-19 pandemic and is documented in the literature (Lucas et al., 2021).

Best practice guidelines in the literature established the importance of the significant other in rehabilitation (Grawburg et al., 2019; Howe et al., 2012; Shafer et al., 2019; Simmons-Mackie et al., 2017). Additionally, a multitude of qualitative studies during the pandemic found that, due to the COVID-19 pandemic, there was reduced interaction with significant others in the rehabilitation process, which led to additional challenges particularly upon discharge and re-integration (Burns et al., 2022; Lucas et al., 2021; Masuku et al., 2022; Shafer et al., 2023; Sutter-Leve et al., 2021; Zafra-Tanaka, 2022). Considering these findings through the lens of the biopsychosocialtech approach, emphasises the need for a comprehensive approach to address these challenges, particularly in the event of emergency situations or perhaps another pandemic. This includes prioritising staff availability for therapy sessions, minimising restrictions in hospital zones, considering how PPE may hinder communication for persons with aphasia and ensuring the availability of family to enable continuity and quality of therapy (Kong, 2021). Additionally, leveraging technology effectively may help bridge the gap and provide alternative means of therapy (Rose, 2023).

As previously outlined, telehealth and remote therapy sessions became increasingly important during the COVID-19 pandemic to bridge the gap caused by limited in-person therapy. Reports from this current study supports findings that perhaps these measures of technology can be extended to include the family members within active treatment and in the context of the biopsychosocialtech model or, at the very least, include significant others in specific goal setting sessions and training strategies necessary for effective discharge. This finding is similar to findings in the literature whereby the potential of technology in aphasia rehabilitation, in particular for addressing needs holistically and consideration of added factors and family involvement (Rose, 2023). However, technological barriers, such as limited access to reliable internet connections or difficulties in navigating digital platforms, may exacerbate these challenges (Masuku et al., 2022). In addition, the participants of the current study supported the use of technology in rehabilitation and commented on its effectiveness in maintaining independence but also reported concerns such as cost, access, preference and user ability. These are consistent with literature findings, as although telerehabilitation may serve as an alternative; physical communication and contextual factors in South Africa need to be considered (Masuku et al., 2022). Furthermore, while studies have shown superior gains with the use of technology (Dial et al., 2019) within a South African context but there is a lack of effective policy and practice guidelines for this (De Beer et al., 2020; Tar-Mahomed & Kater, 2022).

Through targeted interventions, therapy aims to improve communication skills, enhance functional abilities, and promote overall well-being (Simmons-Mackie et al., 2017). The positive experiences of rehabilitation by participants highlight the effectiveness of therapy in addressing the biomedical dimension of stroke and aphasia, emphasising the importance of tailored interventions that target specific areas of impairment. Another finding was that the participants reported positive experiences resulting from therapy and expressed appreciation and gratitude for healthcare workers despite the challenges brought upon by the COVID-19 pandemic. Participants illustrated that they recognised the value of therapy in improving their communication skills, functional abilities, and overall quality of life. This positive perception suggests that therapy played a crucial role in addressing the needs and goals of individuals with aphasia, even during the challenging circumstances of the COVID-19 pandemic. However, while there have been positive reports on the benefit of therapy, it is important to consider the short falls, challenges and provide active steps in transforming rehabilitation in the South African context (De Beer et al., 2020; Masuku et al., 2022; Watermeyer, 2020). These results, along with other studies in the literature, both pre and post pandemic, raised concerns regarding the psychological well-being of both persons with aphasia and their significant others which suggest that their rehabilitation needs, particularly the psychosocial aspects, require better clinical implementation (Bailey et al., 2022; Burns et al., 2022; Gawulayo et al., 2021; Gillespie & Campbell, 2011; Masuku et al., 2022; Sutter-Leve, 2021; Zafra-Tanaka et al., 2022).

5.1.3 The effects of stroke and aphasia upon re-integration into premorbid contexts

The current study also revealed that some participants viewed the home and community spaces as better environments for therapy as they believed it allowed them to explore and understand their functional capacities better. In addition, this study further highlighted the need for long-term support or community care in a South African context which may yield better outcomes for persons with aphasia. Participants reported they did not feel adequately prepared for discharge and may benefit from added support from healthcare workers. These findings are supported in the literature, as depicted by Watermeyer (2020), who advocates for a model of care that was community-based, rationalised by the multicultural facet in South Africa, as well as the reduced therapeutic resources available. This model emphasises that clinicians should acknowledge the family and community when providing treatment approaches to achieve better outcomes, and that intervention practices should include the person with aphasia as an active participant (Watermeyer, 2020). As this study outlined the potential technology has in stroke recovery, it is important to consider technological influences when planning treatment approaches. This is especially needed for those who return to work and younger stroke survivors who may have better digital literacy (De Beer et al., 2020).

Participants within the current study reported that the role of community, occupation, and family support was essential in assisting them in engaging in their social engagement post-stroke. It was also reported that a lack of social engagement occurred as people in the broader community did not always know how to engage with the person with aphasia, for example, when visiting their extended family, at social gatherings or even within the work environment. Within the current study, persons with aphasia and their families often experienced changes in social engagement, had decreased social networks, and experienced social exclusion due to the stroke as well as the impact of COVID-19. This loss of interaction further resulted in feelings of isolation, shrinkage of social networks, and reduced participation which, in turn, is likely to be related to negative emotions and frustration – for both the person with aphasia as well as their significant other Many participants also highlighted that managing communication outside of the home was difficult. Persons with aphasia tended to withdraw from difficult communication contexts and retreat back to safety or comfort. They appeared to mask communicative competency by avoiding interactions or reducing interactions which, in turn, could have resulted in social exclusion or isolation which is a common finding in the literature (Grawburg et al.,2019; Hilari & Northcott, 2006; Hilari et al.,2015b; Wray & Clarke, 2017). This has implications on their psychosocial well-being and further underscores the need for health care workers to effectively address the needs of persons with aphasia and provide effective management and long-term support in a strategic way that encompasses the biopsychosocial approach (Rose, 2023). However, this requires involvement of multiple healthcare workers and is not squarely the responsibility or scope of speech-language therapists (Rose, 2023).

The current study found that the pandemic appeared to have increased the responsibility faced by significant others in providing continued care post discharge. There also appeared to be less support readily available to significant others during the pandemic. In addition, many significant others reported a decrease in their social interactions due to the COVID-19 pandemic and fear associated with contracting the virus, as well as due to participation limitations experienced by the stroke survivor. The findings correlate with current literature that the pandemic has appeared to exacerbate difficulties with regard to significant others' psychological, physical and financial well-being (Bailey et al., 2022). Additionally, Bailey et al. (2022) also found that significant others were fearful of the virus and had increased burdens, in large part, due to the lack of support available.

The current study reported that significant others struggled with the burdens that came with caregiving but also felt obligated to support their loved one. This brings about the ambivalent feelings they had of guilt, burn-out, and added stressors, as well as a sense of duty and love. The role of support also directly impacted the significant other if people within the family or community could not provide adequate financial or social support. These findings are consistent with the literature which state that significant others often experience increased burden of care due to added responsibilities (Blom-Johansson et al., 2022; Grawburg, 2019; Sutter-Leve et al., 2021).

The caring responsibilities and increased demands of supporting someone with aphasia also limited social interactions and participation in activities outside the home. Participants of this study reported that they experienced social isolation, reduced social support, and changes in their social identity. These findings were common during the COVID-19 pandemic. Engaging in social support networks, providing respite care, and facilitating opportunities for social engagement can ease the negative social impact on significant others

(Sutter-Leve et al., 2021). These findings are similar to other findings within the literature (Bailey et al., 2022; Burns et al., 2022; Lee et al., 2021; Masuku et al., 2022; Sutter-Leve et al., 2021) which found that significant others had additional challenges as a result of the COVID-19 pandemic. This underscores the for identifying and addressing their own needs within the healthcare system (Jacobs-Nzuzi Khuabi, 2020).

The findings from the current study also highlighted the influence of technology post-discharge in maintaining independence and social networks in activities of daily living for both persons with aphasia and significant others. This was particularly important during the COVID-19 pandemic when additional social restrictions were imposed. Narbutaitienė et al. (2023) found that using technology can aid persons with aphasia in everyday activities and maintain independence. These include aspects such as obtaining information, banking, transport, shopping and cooking. However, the authors also outline that there are challenges experienced, in particular, attention span and knowing how to navigate technical challenges that may arise (Narbutaitienė et al., 2023). It is therefore important to identify the ways that this can be implemented as well as to measure individual needs, circumstances, and ability to use technology within a South African context (Masuku et al., 2022; Tar-Mahomed & Kater, 2022). Current studies allude to potential barriers such as cost, access, physical disability, and communication disability, as well as specific aspects, such as load shedding that may impact outcomes (Masuku et al., 2022; Tar-Mahomed & Kater, 2022). On the other hand, the current study also showed that navigating digital applications can be difficult for persons with aphasia, in addition to reduced literacy skills and physical impairments that may affect the use of these systems.

Reports from the current study also found added financial challenges for both the person with aphasia and their significant other. There was also additional strain reported in this regard due to the COVID-19 pandemic. An inability to work or reduced work capacity due to stroke and aphasia-related impairments can lead to financial strain. Accessing rehabilitation services and support networks may also involve additional costs, which are not always covered by medical aids. These financial burdens reportedly added stress and further impacted the overall well-being and quality of life for both individuals with aphasia and their significant others. In particular, this was especially distressing for persons with aphasia within this study who were the main breadwinners.

One participant with aphasia illustrated that, due to a complete lack of support and being the main breadwinner, finance was a struggle, especially for basic needs such as transport, food, housing, and schooling, in addition to medical expenses. It is important to consider her experience particularly in a South African context where socioeconomic concerns are rife and may act as a hindrance to effective reintegration (Gawulayo et al., 2021). It is also important to consider the impact of the lack of financial stability on the functioning of the family, particularly in this case, where there are minors. Gawulayo (2021) also found that additional expenses were warranted to assist stroke survivors. These costs included transport expenses but can also extend to additional demands of caregiving such as conflict with running a business and working, resulting in burnout and exhaustion. This is consistent with the findings in the current study where significant others found additional financial strain. This study found that there are minor challenges in scheduling and planning for significant others and, in some cases, participants had to stop business operations or had different roles in employment. However, the potential use of technology was reported once again as a positive facilitator in this regard. Technology was reported to allow participants to maintain workspaces and some social connections. This is similar to findings in the literature by Blom-Johansson et al. (2022) whose study revealed that significant others reported changes in employment, reduced hours, different work tasks, or had given up work altogether.

Stroke and aphasia appeared to have a major impact on the working situation for persons with aphasia which was further exemplified by the COVID-19 context. In the current study, only two out of seven participants with aphasia were able to successfully re-integrate into the occupational context. The reduction of re-entering the work force was attributed to a number of factors reported, such as vocational rehabilitation recommendations, age, early retirement, and physical and communicative disability impacting on fulfilling job demands. This study showed positive associations of technology and a blended approach to work for both significant others and persons with aphasia who returned to work.

The current study supports findings that the integration of technology plays a vital role in addressing participation limitations. Assistive technologies can facilitate communication and improve participation in various activities or provide increased independence as well as improving access (Rose, 2023). Virtual platforms and telehealth services can also provide opportunities for remote engagement and access to therapy and support networks (Cassarino et al., 2022). However, it is essential to consider technological barriers, such as limited access or digital literacy, and ensure equitable access to technology and necessary training when needed (Tar-Mahomed & Kater, 2022).

5.1.4 Concluding comments on the application of the biopsychosocialtech model

It is imperative to look at stroke survivors with aphasia and their significant others in a holistic manner to provide effective and functional interventions (Doogan et al.,2018). This enables treatment the biomedical symptoms experienced and also the resultant psychosocial factors (Doogan et al., 2018). As technology has emerged as a possible facilitator in neurorehabilitation, it is important to consider its role within intervention in the future (Cassarino et al., 2022; De Beer et al., 2020). Using the biopsychosocialtech model to interpret the findings of this study shows the potential of using this model to allow for increased patient understanding and improve understanding of physical and psychological health which takes into consideration social and technological factors that may impact on stroke survivors and their significant others. The use of this model also displays the value of an MDT in stroke and aphasia care.

The findings of the current study display the multifactorial aspects of a stroke and aphasia diagnosis. These aspects cannot be understood solely within the scope of speech-language intervention. It requires a coordinated effort from different healthcare disciplines and may be difficult to apply consistently across various healthcare settings (Rose, 2023). While the model provides a broad framework on understanding the experiences of a stroke and aphasia diagnosis, rehabilitation and re-integration during the COVID-19 pandemic, it may not offer specific guidelines for interventions or treatments (Kontou et al., 2022). As a result, it might be challenging for healthcare practitioners to identify precisely which factors to prioritise in individual cases (Kontou et al., 2022). Implementing the biopsychosocialtech model effectively requires significant time and resources (Lehman et al., 2017). Implementing technology in healthcare can be expensive, and maintaining up-to-date technology may be challenging for some healthcare facilities. Ensuring the sustainability of technology-based interventions over the long term can be a significant hurdle especially in a South African context.

In the context of the current study, the biopsychosocialtech model proved instrumental in understanding rehabilitation and reintegration during the COVID-19 pandemic. With the pandemic affecting all dimensions of health (biological, psychological, social and technological influence), this model's holistic approach facilitated for the comprehension of the complex interplay of factors influencing patients' well-being during such challenging times. The biopsychosocialtech model's potential to enhance healthcare outcomes through technology integration is promising. Nevertheless, its successful implementation requires a careful understanding of its limitations and the diverse needs of patients and communities.

As evidenced by reports of participants within the current study, the successful implementation of this model requires thoughtful consideration of several factors. Firstly, healthcare providers must be aware of the limitations and potential pitfalls associated with the integration of technology. Secondly, the model's application should be tailored to the specific needs and unique circumstances of each individual and community. Not all patients or communities have the same access to technology or the same level of digital literacy. Therefore, healthcare providers may need to adapt the biopsychosocialtech approach to accommodate these differences and ensure equitable healthcare access.

Findings in the literature have shown that the biopsychosocialtech model can be challenging to implement in practice due to its complexity and the need for seamless integration of multiple factors (Rosignoli et al., 2022). The model's application may vary across different cultural and societal contexts, as social norms, beliefs, and practices can significantly influence health and illness experiences (Rosignoli et al., 2022). Additionally, equal access to the necessary technological resources may pose a limitation, especially in underserved or resource-limited areas, which could create disparities in healthcare (Tar-Mahomed & Kater, 2022). Successful implementation of technology in healthcare requires a level of technological literacy among both healthcare providers and patients (Kong, 2021). Health-related technologies are still continuously evolving, and their effectiveness may not always be thoroughly validated through rigorous research and clinical trials (Rose, 2023).

Despite its limitations, the biopsychosocial model allows for a more integrated and holistic understanding of an individual with post-stroke aphasia while the variable of technology is important to consider especially with the current advances and uses in rehabilitation spaces (Rose, 2023; Scherer, 2020). This model has been widely used in healthcare contexts and therefore is relevant in explaining health and illness while, at the same time, remaining focused on the individual and their specific contexts (Kontou et al., 2022). The biopsychosocialtech approach therefore provides a beneficial framework to explore the lived experiences of persons with aphasia and their significant others during the COVID-19 pandemic. This theoretical perspective allows for multiple factors of the phenomenon to be explored, thus providing comprehensive results which consider interaction across multiple levels as seen within this study.

Chapter 6: Conclusion

Outline of chapter

This chapter summarises the study and provides concluding comments. It further highlights the strengths and limitations of the research study. In addition, this chapter provides policy, practice and research recommendations that are rooted in the findings of this study.

6.1 Summary of the study

This study set out to describe the lived experiences of stroke survivors with aphasia and their significant others during the COVID-19 pandemic through the application of the biopsychosocialtech model. Both the perspectives of the persons with aphasia and their significant others were deemed important. This allowed the researcher to fully understand personal experiences and how stroke and aphasia may impact their daily lives as there are consequences across all spheres for both the stroke survivor as well as their family (Grawburg et al., 2019). In addition, the study considered the biopsychosocial consequences of stroke and aphasia and revealed how technology is reshaping rehabilitation and access for those with disabilities. The research also highlighted facilitators and barriers as perceived by participants and how some of these can be seen as a direct consequence of being diagnosed, hospitalised, and attending rehabilitation for stroke and aphasia during the COVID-19 pandemic.

The research made use of semi-structured interviews to elicit rich and descriptive data in a manner that was most comfortable for participants. Participants' preferences were accommodated, for instance, if the participants chose to be interviewed as a unit versus separately. In addition, accommodations were made for virtual interviews as opposed to face-to-face interviews. Data were then analysed through an inductive thematic analysis approach. The findings were separated into themes and were further outlined and discussed.

This study revealed that persons with aphasia and their significant others have difficulty with the changes that come with a stroke. The diagnosis of stroke and aphasia has consequences for all participants, on multiple impairment levels which include illness, chronic conditions, post-stroke consequences, and physical disability. Psychologically, participants reported difficulties managing the changes of roles, negative emotions, anxiety, sadness, reduced autonomy, and reduced self-worth, whereas socially, participants had challenges with reintegration in previous contexts due to reduced awareness, uncertainty on how to navigate contexts, limitations due to physical and communicative disabilities, financial constraints, and changes in relationships in addition to COVID-19 restrictions hindering access and increasing paranoia. The role of support from professionals, family, friends and the larger community was also said to result in increased feelings of inclusion and positive outcomes.

Given this finding, participants emphasised that long term support from professionals and increased education, as well as inclusion policies, would lead to increased success in reintegration. These are similar to the findings from this study based on the literature by Blom-Johansson (2012) that communication disorders, such as aphasia, may occur after a left hemisphere stroke and have biological and neurological symptoms that have a negative impact on the social experiences of individuals based on the severity and type caused by the neurological impairment. In conjunction, if a person has aphasia, they are most likely to have limitations in everyday communication which, as a result, would impact negatively and greatly on all life domains which include close interpersonal interactions, friendships, social life and social inclusion, occupational life, leisure, independence and being an active part of a community (Blom-Johansson, 2012).

In addition, there appear to be psychosocial consequences for significant others of persons with aphasia. This study mirrored these findings, such as difficulty with communication, changes in relationships, employment changes, changes in roles and responsibilities, impacts on social engagement, and stress and anxiety which, in turn, may result in biological symptoms such as panic attacks (Grawburg et al., 2013). In considering these findings, it is important to ensure ongoing and holistic treatment is provided and that psychology and/or counselling should be a service that is routinely available for both patients and their loved ones, after a traumatic neurological event such as a stroke.

Considering whether to use technology or not within aphasia treatment has an implication for the biopsychosocialtech model as a whole. Technology also has the ability to reconstruct biological functions, personal psychological factors, as well as social interaction

(Scherer, 2020). Interactions with technology occur in almost every sphere of life and re-integration for those with aphasia could benefit from exposure to technology. This includes conducting an MRI scan to diagnose a stroke, to obtain blood results, health and informational literacy, to contact families via cell phones, telecommunications, returning to the workplace, and re-learning how to use a laptop and assistive devices to expand on interactions. Furthermore, mobile health and telerehabilitation services can remotely monitor a person's vital signs and allow for home-based health management (Dial et al., 2019). This can be expanded to monitor outcomes for persons with aphasia to achieve better overall outcomes. However, it also important to consider challenges within the South African context, such as cost, data, accessibility, electricity, as well as patient specific preferences, ability (physical, cognitive, literacy), and age (Masuku et al., 2022; Tar-Mahomed & Kater, 2022).

This research, as well as global studies, has documented that the COVID-19 pandemic had implications for post-stroke and aphasia rehabilitation (Kong, 2021; Lucas et al., 2021; Pandian et al., 2021) due to multiple factors that include reduced physical interaction, reduced social connectedness, difficulties with pandemic regulations such as restricted visits, reduced access, increased stress or anxiety related to the pandemic, and the overall quality of patients' lives post-stroke (Kong, 2021; Lucas et al., 2021; Pandian et al., 2021).

This research shows the difficult journey that persons with aphasia and significant others face in post-stroke life. Findings in the study show similarities with other studies conducted with stroke survivors and their significant others. Participants' personal experiences show that communication impairment has a profound impact on all spheres of life for both the person with aphasia and significant others. This relates to relationships, basic social interactions, community participation, and engagement in leisure and occupation. Furthermore, this study revealed challenges that those with communication impairments face with their healthcare professionals, which demonstrates the need for transformation within health delivery models in South Africa. In addition, the inclusion of technology in rehabilitative spaces should be further explored.

In conclusion, this study illustrated the importance of advocating for stroke survivors with aphasia and their families. It also found the need to ensure that MDT services are routinely available, and inclusive of stroke survivors as active participants in their treatment. Healthcare workers should also consider effective methods of delivery that prioritises providing information, informed consent, autonomy, respect and dignity. Patient centred care and functional goal setting will ensure smoother transitioning upon reintegration into community spaces post-stroke. There is a great need to implement better practices for this subset population of stroke survivors that is inclusive of their families as active members of rehabilitation as outlined in aphasiology. The lack of engagement of significant others due to the COVID-19 pandemic reaffirmed the importance of including significant others in treatment approaches. This has been documented in the literature as it can enhance communication and quality of life, and achieve optimal functional outcomes. Technology and telerehabilitation are valuable tools, however these need to be more structured and better suited to stroke and aphasia patients within the South African health system. This study revealed that COVID-19 did cause additional stressors and challenges for stroke survivors and significant others. It is therefore perhaps important to keep documenting the effects COVID-19 may have had upon rehabilitation and re-integration for this population. Lastly, this study also offered additional insight on the importance of inclusivity in qualitative research of those with communication impairments to allow for an exploration of their specific needs. This will enable tailor-made intervention models that will enable better functional outcomes in stroke and aphasia recovery, which is the ultimate goal of rehabilitation.

6.2 Strengths of research study

- This research had a number of strengths. The study was inclusive of those with aphasia and allowed them to express their first-hand accounts and experiences. This will narrow the gap in literature with regard to the inclusion of persons with aphasia in research. This will also allow insight into their needs so that policy and practice models can be patient centred.

- The study included both persons with aphasia and their significant others in order to provide better rehabilitation treatment outcomes. In addition, even though the study had a relatively small sample size (14), there were diverse demographic factors which allowed for additional exploration on the differing effects of aphasia.

- The study used the biopsychosocialtech model to assist in interpretation of aphasia in a multifaceted context. This allowed for the extension of understanding patients beyond an impairment level, and also took into consideration technological advances within the healthcare setting.
- This study allowed for a deeper understanding of persons with aphasia and their needs, perceptions, and personal experiences with stroke recovery, the way aphasia impacts significant others within a South African context and experiences during the COVID-19 pandemic.

6.3 Limitations of research study

- Due to the study being conducted in a specific context (South African – private rehabilitation), the findings may not be applicable or fully generalisable to other cultural or geographical contexts. The unique experiences of individuals in a particular region may limit the transferability of the findings to different settings, such as the public sector in South Africa or perhaps higher income countries globally.
- The sample was heterogeneous in this study. This means that participants did not present with the same levels of severity of communication impairment as well as physical impairment and therefore this could have influenced functional outcomes and individual experiences.
- The aims of this study were initially formulated during the peak of the COVID-19 pandemic (2020). However, data collection only took place in 2022. This may have inadvertently influenced the results as they may have differed if data collection had taken place during the peak of the COVID-19 pandemic when many of the restrictions and factors were still on-going.

6.4 Recommendations

6.4.1 Policy

- Implementation of evidence-based practices to include policies for telerehabilitation and technology: Healthcare providers should use evidence-based practices when treating individuals with aphasia to ensure the best possible outcomes. These policies need to be inclusive of guidelines and the use of technology within rehabilitation spaces in the South African context (De Beer et al., 2020; Masuku et al., 2022; Tar-Mahomed & Kater, 2022). There are both advantages and disadvantages of using technology therefore it has not been accepted nor rejected as a method of rehabilitation, communication with health care professionals or long-term care within this study. Hence, more research in this area is warranted. Additionally, persons with aphasia, who are returning to work, may require assistance on how to navigate technological systems post-stroke (De Beer et al., 2020). These may include therapy due to physical, cognitive, or literacy demands. Policies and guidelines may allow for improved social reintegration (De Beer et al., 2020; Masuku et al., 2022; Tar-Mahomed & Kater, 2022).

- Increased funding for rehabilitation services: More funding is needed to ensure that individuals with aphasia have access to quality rehabilitation services, including speech and language therapy, psychology, and social work. This research can be used as evidence to policy makers and funders that there is a need for intensive and extensive rehabilitation in this sub-group of patients as there are severe consequences on their psychological and social well-being. Services should be integrated into the national healthcare system to ensure that individuals with aphasia have access to the care they need.

- Awareness and education: There should be increased health professional awareness and education about aphasia to reduce the stigma associated with this condition and to improve access to care that is needed (Hersh, 2016; Pound & Jensen, 2018). Additionally, education should also be inclusive by providing aphasia friendly resources to enhance education with regard to stroke, rehabilitation, and the effects of stroke on the different contexts and spheres of an individual's life, and provide ways in which they can access support (De Beer et al., 2020). Participants identified that they lacked specific information about the rehabilitation process and constantly needed more information about their diagnosis. Persons with aphasia deserve autonomy, dignity, and the right to information about their condition. It is also suggested that health literacy on digital platforms be explored. Policies emphasising patient autonomy and access to information should be implemented. Awareness and education should also enable learning for the community on how to effectively engage with persons with aphasia and provide supportive and inclusive communication (Pound et al., 2007; Simmons-Mackie et al., 2007).

6.4.2 Practice

- To implement pilot programmes consisting of training students and professionals on effective communication strategies to service persons with aphasia. It should also include considerations for informed consent, providing better information, and the manner in which clinical orientation assessments are administered and the results delivered. These trainings should effectively consider the patient needs and how to uphold autonomy and dignity when treating stroke survivors with aphasia. Furthermore, evaluation of the efficacy of these trainings should be investigated.

- To routinely use aphasia severity rating scales (for possible depression), for both patients and families to ensure that holistic interventions are being provided (Hilari & Byng, 2009).

- To consider referrals to psychology as the findings of this study suggest psychosocial well-being is affected throughout the different stages of diagnosis, rehabilitation and re-integration. Additionally, to try and ensure that these resources are standardised to the South African context. Participants relayed psychosocial difficulties and communicated they did not always have access to the recommended treatment or referral pathway with regard to psychology. Their psychological well-being also seems to change with time hence this is seen as vital.

- To provide intervention models, which ideally assess stroke survivors/persons with aphasia's needs and include both the stroke survivor and their family in goal setting and key decision making within the MDT context. Guidance, communication, and education should occur directly and indirectly throughout the rehabilitation journey. Evidence from this research shows that both persons with aphasia and their significant others wish to have more active roles in the decision making and intervention procedures of their rehabilitation journey. It is therefore recommended that intervention models be implemented which take into consideration the patient and the family as active participants (Byng et al., 2000; Chapey et al., 2000; Kagan, 1998; Simmons-Mackie et al., 2007). In addition, in a South African context, broader community goals should be considered therefore, social, cultural and environmental aspects should be considered (Legg, 2010; Legg & Penn ,2013; Penn & Armstrong, 2017; Watermeyer, 2020).

6.4.3 Research

- A similar research study exploring the perceptions and lived experiences of persons with aphasia and significant others of persons with aphasia during the COVID-19 pandemic, could be employed on a larger scale. This can be inclusive of additional demographic factors which may provide a better representation within the South African population (Masuku et al., 2022).

- To expand from this research, it is recommended that future research focuses on speech-language therapists' perceptions of aphasia treatment during the COVID-19 pandemic in South Africa. This will add to the current study by including perspectives of SLTs and the facilitators and challenges they may have in providing treatment to persons with aphasia and significant others of persons with aphasia. This will allow for intervention models that are holistic, realistic, and clinically based while considering patient needs as well as health care workers' needs especially in the event of emergency situations or another pandemic.

- For future stroke studies to include persons with communication impairments in qualitative research (Simmons-Mackie et al., 2007) especially those who use AAC to communicate. Including persons with communication impairments will ensure that their voices are valid, valued, heard, and directly reflect their needs. In addition, if patient-centred care is to be successfully implemented, it is important to include the voices of those it affects most to establish more effective treatment approaches and to understand their specific needs.

References

Acharya, A.S., Prakash, A., Saxena, P., & Nigam, A. (2013). Sampling: Why and how of it? *Indian Journal of Medical Specialities, 4*(2), 330–333. https://doi.10.7713/Ijms.2013.0032

Akinyemi, R.O., Ovbiagele, B., Adeniji, O.A., Sarfo, F.S., Abd-Allah, F., Adoukonou, T., Ogah, O.S., Naidoo, P., Damasceno, A., Walker, R.W., Ogunniyi, A., Kalaria, R.N., & Owolabi, M.O. (2021). Stroke in Africa: Profile, progress, prospects and priorities. *Nature Reviews: Neurology*, *17*(10), 634–656. https://doi.org/10.1038/s41582-021-00542-4

American Speech-Language and Hearing Association (ASHA). (2020). *Speech-language pathologists*. https://www.asha.org/students/speech-language-pathologists/#:~:text=Speech%2Dlanguage%20pathologists%20(SLPs),disorders%20in%20children%20and%20adults.

American Stroke Association (ASA). (2020a). *Effects of stroke*. https://www.stroke.org/en/about-stroke/effects-of-stroke

American Stroke Association (ASA). (2020b). *Types of strokes*. https://www.stroke.org/en/about-stroke/types-of-stroke

Bailey, C., Guo, P., MacArtney, J., Finucane, A., Swan, S., Meade, R., & Wagstaff, E. (2022). The experiences of informal carers during the COVID-19 pandemic: A qualitative systematic review. *International Journal of Environmental Research and Public Health*, *19*(20), 13455. https://doi.org/10.3390/ijerph192013455

Banfield, W.H., Elghawy, O., Dewanjee, A., & Brady, W.J. (2022). Impact of COVID-19 on emergency department management of stroke and STEMI: A narrative review. *The American Journal of Emergency Medicine*, *57*, 91–97. https://doi.org/10.1016/j.ajem.2022.04.033

Bamm, E.L., Rosenbaum, P., Wilkins, S., Stratford, P., & Mahlberg, N. (2015). Exploring client-centered care experiences in in-patient rehabilitation settings. *Global Qualitative Nursing Research*, *2*. https://doi.org/10.1177/2333393615582036

Bernhardt, J., Hayward, K.S., Kwakkel, G., Ward, N.S., Wolf, S.L., Borschmann, K., Krakauer, J. W., Boyd, L.A., Carmichael, S.T., Corbett, D., & Cramer, S.C. (2017). Agreed definitions and a shared vision for new standards in stroke recovery research: The Stroke Recovery and Rehabilitation Roundtable taskforce. *International Journal of Stroke: Official Journal of the International Stroke Society*, *12*(5), 444–450. https://doi.org/10.1177/1747493017711816

Blom-Johansson, M. (2012). *Aphasia and communication in everyday life* [Doctoral Dissertation, UPPSALA Universiteit]. http://uu.diva-portal.org/smash/record.jsf?pid=diva2:516701

Blom-Johansson, M., Carlsson, M., Östberg, P., & Karin Sonnander, K. (2022). Self-reported changes in everyday life and health of significant others of people with aphasia: A quantitative approach. *Aphasiology*, *36*(1), 76–94. https://doi.org/10.1080/02687038.2020.1852166

Brady M.C., Fredrick A., & Williams B. (2013). People with aphasia: Capacity to consent, research participation and intervention inequalities. *International Journal of Stroke, 8*(3), 193–196. https://doi.org/10.111/j.1747-4949.2012.00900.x

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2)*,* 77–101.

Budd, J., Miller, B.S., Manning, E.M., Lampos, V., Zhuang, M., Edelstein, M., Rees, G., Emery, V.C., Stevens, M.M., Keegan, N., Short, M.J., Pillay, D., Manley, E., Cox, I.J., Heymann, D., Johnson, A.M., & McKendry, R.A. (2020). Digital technologies in the public-health response to COVID-19. *Nature Medicine*, *26*(8), 1183–1192. https://doi.org/10.1038/s41591-020-1011-4

Burns, S.P., Fleming, T.K., Webb, S.S., Kam, A.S.H., Fielder, J.D.P., Kim, G.J., Hu, X., Hill, M.T., & Kringle, E.A. (2022). Stroke recovery during the COVID-19 pandemic: A position paper on recommendations for rehabilitation. *Archives of Physical Medicine and Rehabilitation*, *103*(9), 1874–1882. https://doi.org/10.1016/j.apmr.2022.04.004

Cassarino, L., Santoro, F., Gelardi, D., Panerai, S., Papotto, M., Tripodi, M., Cosentino, F.I.I., Neri, V., Ferri, R., Ferlito, S., Modica, D., Fisicaro, F., Pennisi, M., Bella, R., & Lanza, G. (2022). Post-stroke aphasia at the time of COVID-19 pandemic: A telerehabilitation perspective. *Journal of Integrative Neuroscience*, *21*(1), 8. https://doi.org/10.31083/j.jin2101008

Chapey, R., Duchan, J.F., Elman, R.J., Garcia, L.J., Kagan, A., Lyon, J.G., & Simmons Mackie, N. (2000). Life participation approach to aphasia: A statement of values for the future. *The ASHA Leader*, *5*(3), 4–6. https://doi.org/10.1044/leader.FTR.05032000.4

Cruice, M., Worrall, L., & Hickson, L. (2006). Perspectives of quality of life by people with aphasia and their family: Suggestions for successful living. *Topics in Stroke Rehabilitation, 13*(1), 14–24. https://doi.org/10.1310/4jw5-7vg8-g6x3-1qvj

De Beer, A., Gaskin, A., Robbertse, A., & Bardien, F. (2020). A review of the communication needs of persons with stroke within the African context for application within the clinical setting. In Louw, Q. (Ed.), *Collaborative capacity development to complement stroke rehabilitation in Africa: Human Functioning, Technology and Health Series, 1* (pp. 57–96). AOSIS. https://doi.org/10.4102/aosis.2020.BK85.02

Department of Co-operative Governance and Traditional Affairs. (2020a). *Disaster Management Act.* South African Government. https://www.gov.za/sites/default/files/gcis_document/202003/43096gon313.pdf

Department of Co-operative Governance and Traditional Affairs. (2020b). *PROFILE: City of Ekurhuleni.* South African Government. https://www.cogta.gov.za/ddm/wp-content/uploads/2020/11/Ekurhukeni-September-2020.pdf

De Jonckheere, M., & Vaughn, L.M. (2019). Semi structured interviewing in primary care research: A balance of relationship and rigour. *Family Medicine and Community Health*, *7*(2), e000057. https://doi.org/10.1136/fmch-2018-000057

Dial, H.R., Hinshelwood, H.A., Grasso, S.M., Hubbard, H.I., Gorno-Tempini, M.L., & Henry, M.L. (2019). Investigating the utility of teletherapy in individuals with primary progressive aphasia. *Clinical Interventions in Aging*, *14*, 453–471. https://doi.org/10.2147/CIA.S178878

Dietz, A., Wallace, S.E., & Weissling, K. (2020). Revisiting the role of augmentative and alternative communication in aphasia rehabilitation. *American Journal of Speech-language Pathology*, *29*(2), 909–913. https://doi.org/10.1044/2019_AJSLP-19-00041

Doogan, C., Dignam, J., Copland, D., & Leff, A. (2018). Aphasia Recovery: When, how and who to treat? *Current Neurology and Neuroscience Reports*, *18*(12), 90. https://doi.org/10.1007/s11910-018-0891-x

Elloker, T., & Rhoda, A.J. (2018). The relationship between social support and participation in stroke: A systematic review. *African Journal of Disability*, *7*, 357. https://doi.org/10.4102/ajod.v7i0.357

Etikan, I., Musa, S.A., & Alkassim, R.S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics, 5*(1), 1–4. https://doi.org/10.11648/j.ajtas.20160501.11

Franklin, S., Harhen, D., Hayes, M., Manus, S., & Pollock, A. (2018). Top 10 research priorities related to aphasia following stroke. *Aphasiology*, *32*(11), 1388–1395. http://doi.org/10.1080/02687038.2017.1417539

Fusch, P.I., & Ness, L.R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, *20*(9), 1408–1416. https://doi.org/10.46743/2160-3715/2015.2281

Galletta, E.E., & Barrett, A.M. (2014). Impairment and functional interventions for aphasia: Having it all. *Current Physical Medicine and Rehabilitation Reports*, *2*(2), 114–120. https://doi.org/10.1007/s40141-014-0050-5

Gawulayo, S., Erasmus, C.J., & Rhoda, A.J. (2021). Family functioning and stroke: Family members' perspectives. *African Journal of Disability*, *10*, 801. https://doi.org/10.4102/ajod.v10i0.801

Gillespie, D., & Campbell, F. (2011). Effect of stroke on family carers and family relationships. *Nursing Standard (Royal College of Nursing (Great Britain): 1987)*, *26*(2), 39–46. https://doi.org/10.7748/ns2011.09.26.2.39.c8707

Gjermestad, A., Skarsaune, S.N., & Bartlett, R.L. (2022). Advancing inclusive research with people with profound and multiple learning disabilities through a sensory-dialogical approach. *Journal of Intellectual Disabilities: JOID*, 17446295211062390. Advance online publication. https://doi.org/10.1177/17446295211062390

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia. *Aphasiology* *27*(7), 828–848. https://dx.doi.org/10.1080/02687038.2013.768330

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2019). Family-centers care in aphasia: Assessment of third-party disability in family members with the family aphasia measure of life impact. *Topics in Language Disorders, 39*(1), 29–54.

Greenhalgh, T., Koh, G.C.H., & Car, J. (2020). Covid-19: A remote assessment in primary care. *BMJ, 36*(8). http://do.doi.org/10.1136/bmj.m1182

Guba, E.G., & Lincoln, Y. (1989). *Fourth generation evaluation*. Sage.

Haigh, C., & Witham, G. (2015). *Distress protocol for qualitative data collection.* Department of Nursing: Manchester Metropolitan University.

Haley, K.L., Cunningham, K.T., Barry, J., & De Riesthal, M. (2019). Collaborative goals for communicative life participation in aphasia: The FOURC model. *American Journal of Speech-Language Pathology*, *28*(1), 1–13. https://doi.org/10.1044/2018_AJSLP-18-0163

Health Professions Council of South Africa (HPCSA). (2020, March, 26). *Application of Telemedicine*. HPCSA. https://www.hpcsa.co.za/Uploads/Events/Announcements/APPLICATION_OF_TELEMEDICINE_GUIDELINES.pdf

Heart Foundation of South Africa. (2020). *Stroke.* http://www.heartfoundation.co.za/stroke/

Hersh, D. (2016). Therapy in transit: Managing aphasia in the early period post stroke. *Aphasiology*, *30*(5), 509–519. http://dx.doi.org/10.1080/02687038.2015.1137555

Hilari, K., & Byng, S. (2009). Health-related quality of life in people with severe aphasia. *International Journal of Language & Communication Disorders*, *44*(2), 193–205. https://doi.org/10.1080/13682820802008820

Hilari, K., & Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology, 20*(1), 17–36.

Hilari, K., Klippi, A., Constantinidou, F., Horton, S., Penn, C., Raymer, A., Wallace, S., Zemva, N., & Worrall, L. (2015a). An international perspective on quality of life in aphasia: A survey of clinician views and practices from sixteen countries. *Folia Phoniatrica et Logopaedica*, *67*(3). https://doi.org/10.1159/000434748

Hilari, K., Cruice, M., Sorin-Peters, R., & Worrall, L. (2015b). Quality of life in aphasia: State of the art. *Folia Phoniatrica et Logopaedica: Official organ of the International Association of Logopedics and Phoniatrics (IALP), 67*(3), 114–118. https://doi.org/10.1159/000440997

Howe, T., Worrall, L., & Hickson, L. (2004). What is an aphasia-friendly environment? *Aphasiology, 18*(11), 1015–1037. https://doi.org/10.1080/026870304444000499

Howe, T., Worrall, L., & Hickson, L. (2008). Observing people with aphasia: Environmental factors that influence their community participation. *Aphasiology, 22*(6), 618–643.

Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., & Gilbert, J. (2012). 'You needed to rehab … families as well': Family members' own goals for aphasia rehabilitation. *International Journal of Language & Communication Disorders*, *47*(5), 511–521. https://doi.org/10.1111/j.1460-6984.2012.00159.x

Jacobs-Nzuzi Khuabi, L.-A., Bester, J., Kloppers, M., Crous, B., Crous, K., Petersen, R. et al. (2020). The well-being of family members as informal caregivers of persons with stroke in an African context: Understanding their lived experience. In Louw, Q. (Ed.), *Collaborative capacity development to complement stroke rehabilitation in Africa: Human Functioning, Technology and Health Series, 1* (pp. 171–202). AOSIS. https://doi.org/10.4102/aosis.2020.BK85.05

Jagoe, C., McDonald, C., Rivas, M., & Groce, N. (2021). Direct participation of people with communication disabilities in research on poverty and disabilities in low- and middle-income countries: A critical review. *PloS One*, *16*(10), e0258575. https://doi.org/10.1371/journal.pone.0258575

Jassat, W., Abdool Karim, S.S., Mudara, C., Welch, R., Ozougwu, L., Groome, M.J., Govender, N., Von Gottberg, A., Wolter, N., Wolmarans, M., Rousseau, P., DATCOV Author Group, Blumberg, L., & Cohen, C. (2022). Clinical severity of COVID-19 in patients admitted to hospital during the omicron wave in South Africa: A retrospective observational study. *The Lancet: Global Health*, *10*(7), e961–e969. https://doi.org/10.1016/S2214-109X(22)00114-0

Kagan, A. (1995). Revealing the competence of aphasic adults through conversation: A challenge to health professionals. *Topics in Stroke Rehabilitation, 2*, 15–28.

Kagan, A. (1998). Supported conversation for adults with aphasia: Methods and resources for training conversation partners. *Aphasiology, 12*(9), 816–830.

Kagan, A., Black, S.E., Duchan, F.J., Simmons-Mackie, N., & Square, P. (2001). Training volunteers as conversation partners using "Supported Conversation for Adults with Aphasia" (SCA): A controlled trial. *Journal of Speech, Language, and Hearing Research, JSLHR*, *44*(3), 624–638. https://doi.org/10.1044/1092-4388(2001/051)

Kagan, A., & Gailey, G. (1993). *Functional is not enough: Training conversation partners in aphasia*. In Holland, A. & Forbes, M. (Eds.), *Aphasia treatment: World perspectives* (pp. 199–226). Singular.

Kagan, A., & LeBlanc, K. (2002). Motivating for infrastructure change: Toward a communicatively accessible, participation-based stroke care system for all those affected by aphasia. *Journal of Communication Disorders*, *35*(2), 153–169. https://doi.org/10.1016/S0021-9924(02)00062.x

Kagan, A., Simmons-Mackie, N., Rowland, A., Huijbregts, M., Shumway, E., McEwen, S., Threats, T., & Sharp, S. (2008). Counting what counts: A framework for capturing real-life outcomes of aphasia intervention. *Aphasiology*, 22(3), 258–280. https://doi.org/10.1080/02687030701282595

Khoza-Shangase, K., & Mophosho, M. (2018). Language and culture in speech-language and hearing professions in South Africa: The dangers of a single story. *The South African Journal of Communication Disorders = Die Suid-Afrikaanse Tydskrif vir Kommunikasieafwykings*, *65*(1), e1–e7. https://doi.org/10.4102/sajcd.v65i1.594

Khoza-Shangase, K., & Mophosho, M. (2021). Language and culture in speech-language and hearing professions in South Africa: Re-imagining practice. *The South African Journal of Communication Disorders, 68*(1), e1–e9. https://doi.org/10.4102/sajcd.v68i1.793

Kong, A.P. (2021). The impact of COVID-19 on speakers with aphasia: What is currently known and missing? *Journal of Speech, Language, and Hearing Research (JSLHR)*, *64*(1), 176–180. https://doi.org/10.1044/2020_JSLHR-20-00371

Kontou, E., Thomas, S.A., Cobley, C., Fisher, R., Golding-Day, M.R., & Walker, M.F. (2022). A Biopsychosocial Intervention for Stroke Carers (BISC): Development and description of the intervention. *Health Psychology and Behavioral Medicine, 10*(1), 92–103. DOI: 10.1080/21642850.2021.2016412

Kitzmüller, G., Asplund, K., & Häggström, T. (2012). The long-term experience of family life after stroke*. The Journal of Neuroscience Nursing: Journal of the American Association of Neuroscience Nurses*, *44*(1), E1–E13. https://doi.org/10.1097/JNN.0b013e31823ae4a1

Kylén, M., Von Koch, L., Wottrich, A.W., & Elf, M. (2022). Living with the aftermaths of a stroke in the era of the COVID-19 pandemic: The significance of home and close surroundings. *Health & Place*, *76*, 102852. https://doi.org/10.1016/j.healthplace.2022.102852

Lau, G.K., Pendlebury, S.T., & Rothwell, P.M. (2018). *Transient ischemic attack & stroke: Diagnosis, intervention & treatment* (2nd ed.). Cambridge University Press.

Lee, J.J., Tsang, W.N., Yang, S.C., Kwok, J.Y.Y., Lou, V.W.Q., & Lau, K.K. (2021). Qualitative study of Chinese stroke caregivers' caregiving experience during the COVID-19 pandemic. *Stroke*, *52*(4), 1407–1414. https://doi.org/10.1161/STROKEAHA.120.032250

Lehman, B.J., David, D.M., & A. Gruber, J.A. (2017). Rethinking the biopsychosocial model of health: Understanding health as a dynamic system. *Social and Personality Psychology Compass, 11*(8). https://doi.org/10.1111/spc3.12328

Legg, C. (2010). *An ethnography of adults living with aphasia in Khayelitsha* [Doctoral Dissertation, University of the Witwatersrand]. http://wiredspace.wits.ac.za/bitstream/handle/10539/8858/Carol%20Legg%20PhD%20dissertation%20August%202010.pdf

Legg, C., & Penn, C. (2013). A stroke of misfortune: Cultural interpretations of aphasia in South Africa. *Aphasiology, 27*(2), 126–144. https://doi.org/10.1080/02687038.2012.684338

Louw, Q.A., Conradie, T., Xuma-Soyizwapi, N., Davis-Ferguson, M., White, J., Stols, M., Masipa, A., Mhlabane, P., Mdaka, L., Manzini, C., Kekana, I., Schutte, M., Rabothata, S., & Kleinitz, P. (2023). Rehabilitation capacity in South Africa: A situational analysis. *International Journal of Environmental Research and Public Health*, *20*(4), 3579. https://doi.org/10.3390/ijerph20043579

Lucas, L., Gordon, S., & Heyes, R. (2021). Impact of COVID-19 on the stroke rehabilitation pathway: Multidisciplinary team reflections on a patient and carer journey from acute to community stroke services. *BMJ Case Reports*, *14*(11), e245544. https://doi.org/10.1136/bcr-2021-245544

Mahase, E. (2022). Omicron: South Africa says fourth wave peak has passed as it lifts curfew. *BMJ (Clinical Research Ed.)*, *376*(7). https://doi.org/10.1136/bmj.o7

Malterud, K., Siersma, V.D., & Guassora, A.D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Maredza, M., & Chola, L. (2016). Economic burden of stroke in a rural South African setting. *ENeurologicalSci, 3*, 26–32. https://doi.org/10.1016/j.ensci.2016.01.001

Markus, H.S., & Brainin, M. (2020). A global world stroke organisation perspective. *International Journal of Stroke, 15*(4), 361–364. https://doi.org/10.1177/1747493020923472

Masuku, K.P., Khumalo, G., & Shabangu, N. (2022). The effects of COVID-19 on the rehabilitation of persons with aphasia: A scoping review. *The South African Journal of Communication Disorders, 69*(2), e1–e9. https://doi.org/10.4102/sajcd.v69i2.920

Masuku, K.P., Mophosho, M., & Tshabalala, M. (2018). ‘I felt pain. Deep pain ...’: Experiences of primary caregivers of stroke survivors with aphasia in a South African township. *African Journal of Disability, 7*(0), a368. https://doi.org/10.4102/ajod.v7i0.368

Mayo Foundation for Medical Education and Research. (2019). *Stroke rehabilitation: What to expect as you recover*. https://www.mayoclinic.org/diseases-conditions/stroke/in-depth/stroke-rehabilitation/art-20045172

McEwin, A., & Santow, E. (2018). The importance of the human right to communication. *International Journal of Speech-Language Pathology*, *20*(1), 1–2. https://doi.org/10.1080/17549507.2018.1415548

Mochan, A., & Modi, G. (2020). Neurological involvement with COVID-19 review. *Wits Journal of Clinicial Medicine, 2*(2), 135–140. http://dx.doi.org/10.18772/26180197.2020.v2n2a5

Morais, H.C., Soares, A.M., Oliveira, A.R., Carvalho, C.M., Da Silva, M.J., & De Araujo, T.L. (2012). Burden and modifications in life from the perspective of caregivers for patients after stroke. *Revista latino-americana de enfermagem*, *20*(5), 944–953. https://doi.org/10.1590/s0104-11692012000500017

Narbutaitienė, J., Björklund Carlstedt, A., & Fischl, C. (2023). Stroke survivors' experiences and meaning of digital technology in daily life: A phenomenological study. *Disability and Rehabilitation: Assistive technology*, 1–9. Advance online publication. https://doi.org/10.1080/17483107.2023.2174605

National Institute of Neurological Disorders and Stroke. (2019). *Know Stroke*. https://www.ninds.nih.gov/health-information/public-education/know-stroke?search-term=stroke%20rehab

Natterlund, B.S. (2010). Being a close relative of a person with aphasia. *Scandinavian Journal of Occupational Therapy, 17*(1), 18–28. https://doi.org/10.3109/11038120902833218

Nelson, M.L.A., Hanna, E., Hall, S., & Calvert, M. (2016). What makes stroke rehabilitation patients complex? Clinician perspectives and the role of discharge pressure. *Journal of Comorbidity, 6*(2), 35–41. https://doi.org/10.15256/joc.2016.6.63

Neubauer, B.E., Witkop, C.T., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspect Med Educ, 8*, 90–97. https://doi.org/10.1007/s40037-019-0509-2

Nind, M., & Strnadova, I. (2020). Belonging for people with profound and multiple learning disabilities: Pushing the boundaries of inclusion. *Routledge.*

Nowell, L.S., Norris, J.M., White, D.E., & Moules, N.J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods, 16*(1), 1609406917733847.

Ntsiea, M.V. (2019). Current stroke rehabilitation services and physiotherapy research in South Africa. *South African Journal of Physiotherapy*, *75*(1), 1–10. https://doi.org/10.4102/sajp.v75i1.475

Olasoji, E.B., Uhm, D.K., Awosika, O.O., Doré, S., Geis, C., & Simpkins, A.N. (2022). Trends in outpatient rehabilitation use for stroke survivors. *Journal of the Neurological Sciences, 44*(2), 120383. https://doi.org/10.1016/j.jns.2022.120383

Oxley, T.J., Mocco, J., Majidi, S., Kellner, C.P., Shoirah, H., Paul Singh, I., De Lacey, R.A., Shigematsu, T., Ladner, T.R., Yaeger, K.A., Skliut, M., Weinberger, J., Dangayach, N.S., Bederson, J.B., Tuhrim, S., & Fifi, J.T. (2020). Large-vessel stroke as a presenting feature of Covid-19 in the young. *The New England Journal of Medicine, 382*(20), e(60)3. https://doi.org/10.1056/NEJMc2009787

Palmer, R., & Paterson, G. (2013). To what extent can people with communication difficulties contribute to health research? *Nurse Researcher*, *20*(3), 12–16. https://doi.org/10.7748/nr2013.01.20.3.12.c9491

Pandolfo, S. (2013). *Psychosocial impact of aphasia: A study on sixteen aphasics* [Bachelor's Dissertation, Universita Ca' Foscari Venezia]. https://pdfs.semanticscholar.org/5df6/28095c7ca2305a5d7014044170a99c9013b4.pdf

Parr, S. (2004). *Living with severe aphasia: The experiences of communication impairment after stroke.* Pavilion Publishing.

Parr, S. (2007). Living with severe aphasia: Tracking social exclusion. *Aphasiology*, *21*(1), 98–123. https://doi.org/10.1080/02687030600798337

Parr, S., Wimborne, N., Hewitt, A., & Pound, C. (2008). *The communication access toolkit*. Connect: The Communication Disability Network.

Parr, S., Byng, S., Gilpin, S., & Ireland, C. (1997). *Talking about aphasia: Living with the loss of language after a stroke*. Open University Press.

Pike, C., Kritzinger, A., & Pillay, B. (2017). Social participation in working-age adults with aphasia: An updated systematic review. *Topics in Stroke Rehabilitation*, *24*(8), 627–639. https://doi.org/10.1080/10749357.2017.1366012

Pluut, B. (2016). Differences that matter: Developing critical insights into discourses of patient-centeredness. *Medicine, Health Care and Philosophy,* *19*(4), 501–515. https://doi.org/10.1007/s11019-016-9712-7

Penn, C., & Armstrong, E. (2017). Intercultural aphasia: New models of understanding for indigenous populations. *Aphasiology,* *31*(5), 563–594. http://dx.doi.org/10.1080/02687038.2016.1213788

Perrotta, G. (2020). Aphasia: Definition, clinical contexts, neurobiological profiles and clinical treatments. *Annals of Alzheimer's and Dementia Care,* 4(1), 21–26. https://dx.doi.org/10.17352/aadc.000014

Popkirov, S., Stone, J., & Buchan, A.M. (2020). Functional neurological disorder: A common and treatable stroke mimic. *Stroke,* *51*(5), 1629–1635. https://doi.org/10.1161/STROKEAHA.120.029076

Pound, C., Duchan, J., Penman, T., Hewitt, A., & Parr, S. (2007). Communication access to organisations: Inclusionary practices for people with aphasia. *Aphasiology, 21*(1), 23–38. https://doi.org/10.1080/02687030600798212

Pound, C., & Jensen, L.R. (2018). Humanising communication between nursing staff and patients with aphasia: Potential contributions of the Humanisation Values Framework. *Aphasiology, 32*(10), 1225–1249. DOI: 10.1080/02687038.2018.1494817

Prior, S., Miller, A., Campbell, S., Linegar, K., & Peterson, G. (2020). The challenges of including patients with aphasia in qualitative research for health service redesign: Qualitative interview study. *Journal of Participatory Medicine, 12*(1), e12336. https://doi.org/10.2196/12336

Qureshi, A.I., Baskett, W.I., Huang, W., Shyu, D., Myers, D., Raju, M., Lobanova, I., Suri, M.F.K., Naqvi, S.H., French, B.R., Siddiq, F., Gomez, C.R., & Shyu, C.R. (2021). Acute ischemic stroke and COVID-19: An analysis of 27 676 patients. *Stroke*, *52*(3), 905–912. https://doi.org/10.1161/STROKEAHA.120.031786

Reid, M., Abdool-Karim, Q., Geng, E., & Goosby, E. (2021). How will COVID-19 transform global health post-pandemic? Defining research and investment opportunities and priorities. *PLoS Medicine*, *18*(3), e1003564. https://doi.org/10.1371/journal.pmed.1003564

Ranganai, E., & Matizirofa, L. (2020). An analysis of recent stroke cases in South Africa: Trend, seasonality and predictors. *South African Medical Journal = Suid-Afrikaanse Tydskrif vir Geneeskunde*, *110*(2), 92–99. https://doi.org/10.7196/SAMJ.2020.v110i2.013891

Rosignoli, C., Ornello, R., Onofri, A., Caponnetto, V., Grazzi, L., Raggi, A., Leonardi, M., & Sacco, S. (2022). Applying a biopsychosocial model to migraine: Rationale and clinical implications. *The Journal of Headache and Pain*, *23*(1), 100. https://doi.org/10.1186/s10194-022-01471-3

Rose, M.L. (2023). Elizabeth Usher memorial lecture: Beyond our practice borders—using a biopsychosocial framework to improve long-term outcomes for people living with aphasia. *International Journal of Speech-Language Pathology*, *25*(3), 346–354. https://doi.org/10.1080/17549507.2023.2220995

Scheffler, E., & Mash, R. (2019). Surviving stroke in South Africa: Outcomes of home-based care in a low-resource rural setting. *Topics in Stroke Rehabilitation, 26*(6), 423–434. https://doi.org/10.1080/10749357.2019.1623473

Scherer, M.J. (2020). It is time for the biopsychosocialtech model. *Disability and Rehabilitation: Assistive Technology, 15*(4), 363–364. https://doi.org/10.1080/17483107.2020.1752319

Schröder, M., Bossert, A., Kersting, M., Aeffner, S., Coetzee, J., Timme, M., & Schlüter, J. (2021). COVID-19 in South Africa: Outbreak despite interventions. *Scientific Reports*, *11*(1), 49–56. https://doi.org/10.1038/s41598-021-84487-0

Shafer, J.S., Haley, K.L., & Jacks, A. (2023). Accessing information and adapting to the role of care partner for stroke survivors with aphasia during the early Covid-19 pandemic. *Aphasiology*, *37*(6), 907–928. https://doi.org/10.1080/02687038.2022.2059055

Shafer, J.S., Shafer, P.R., & Haley, K.L. (2019). Caregivers navigating rehabilitative care for people with aphasia after stroke: A multi-lens perspective. *International Journal of Language & Communication Disorders*, *54*(4), 634–644. https://doi.org/10.1111/1460-6984.12467

Simmons-Mackie, N., & Damico, J. (1995). Communicative competence in aphasia: Evidence from compensatory strategies. *Clinical Aphasiology*, 23, 95–105.

Simmons-Mackie, N. (1998). In support of supported conversation for adults with aphasia. *Aphasiology, 12*(9), 831–838.

Simmons-Mackie, N., Kagan, A., O'Neill, C., Huijbregts, M., McEwen, S., & Willems, N. (2007). Communicative access and decision making for people with aphasia: Implementing sustainable healthcare systems change. *Aphasiology*, *21*(1), 39–66. https://doi.org/10.1080/02687030600798287

Simmons-Mackie, N., & Damico, J. (2007). Access and social inclusion in aphasia: Interactional principles and applications. *Aphasiology, 21*(1), 81–97. https://doi.org/10.1080/02687030600798311

Simmons-Mackie, N., & Lynch, K.E. (2013). Qualitative research in aphasia: A review of the literature. *Aphasiology*, *27*(11), 1281–1301. https://doi.org/10.1080/02687038.2013.818098

Simmons-Mackie, N., Worrall, L., Murray, L.L., Enderby, P., Rose, M.L., Paek, E.J., & Klippi, A. (2017). The top ten: Best practice recommendations for aphasia. *Aphasiology, 3*(2), 131–151. https://doi.org/10.1080/02687038.2016.1180662

Souchon, N.M., Krüger, E., Eccles, R., & Pillay, B.S. (2020). Perspectives of working-age adults with aphasia regarding social participation. *African Journal of Disability*, *9*, 713. https://doi.org/10.4102/ajod.v9i0.713

South African Speech-Language-Hearing Association (SASLHA). (2020a, March). *Speech language therapy and audiology services during COVID-19*. https://docs.mymembership.co.za/docmanager/editor/34/UserFiles/saslha%20covid-19%20statement.pdf

South African Speech-Language-Hearing Association (SASLHA). (2020b, March). *Telepractice*. https://docs.mymembership.co.za/docmanager/editor/34/UserFiles/saslha%20info%20on%20telepractice.pdf

Spinelli, A., & Pellino, G. (2020). COVID-19 pandemic: Perspectives on an unfolding crisis. *The British Journal of Surgery*, *107*(7), 785–787. https://doi.org/10.1002/bjs.11627

Stefanou, E., Karvelas, N., Bennett, S., & Kole, C. (2023). Cerebrovascular manifestations of SARS-CoV-2: A comprehensive review. *Current Treatment Options in Neurology*, *25*(4), 71–92. https://doi.org/10.1007/s11940-023-00747-6

Stroke Association. (2013). *Feeling overwhelmed: The emotional impact of a stroke*. https://www.stroke.org.uk/sites/default/files/feeling_overwhelmed_final_web_0.pdf

Sutter-Leve, R., Passint, E., Ness, D., & Rindflesch, A. (2021). The caregiver experience after stroke in a COVID-19 environment: A qualitative study in inpatient rehabilitation. *Journal of Neurologic Physical Therapy (JNPT), 45*(1), 14–20. https://doi.org/10.1097/NPT.0000000000000336

Tar-Mahomed, Z., & Kater, K.A. (2022). The perspectives of speech-language pathologists: Providing teletherapy to patients with speech, language and swallowing difficulties during a COVID-19 context. *The South African Journal of Communication Disorders, 69*(2), e1–e7. https://doi.org/10.4102/sajcd.v69i2.902

Taukeni, S. (Ed.). (2019). *Psychology of health: Biopsychosocial approach*. IntechOpen. https://doi.org/10.5772/intechopen.79036

Taylor, A., & Ntusi, N.A.B. (2019). Evolving concepts of stroke and stroke management in South Africa. *South Africa Medical Journal, 109* (2), 69–71. https://doi.org/10.7196/SAMJ.2019.v109i2.00009

United Nations (UN). 2019. *United Nations disability inclusion strategy*. https://www.un.org/en/content/disabilitystrategy/assets/documentation/UN_Disability_Inclusion_Strategy_english.pdf

Vagle, M. (2018). *Crafting phenomenological research*. Routledge.

Van Niekerk, S., Kamalakannan, S., Inglis-Jassiem, G., et al. (2021). Towards universal health coverage for people with stroke in South Africa: A scoping review. *BMJ Open,* 11, e049988. https://doi.org/10.1136/bmjopen-2021-049988

Vickers, C. (2010). Social networks after the onset of aphasia: The impact of aphasia group attendance. *Aphasiology, 24* (6–8), 902–913. https://doi.org/10.1080/02687030903438533

Watermeyer, J. (2020). Towards a community of care for people with aphasia: Some lessons on working in multicultural settings. *Aphasiology*, *34*(11), 1432–1450. https://doi.org/10.1080/02687038.2019.1702919

Watkins, K. (2019). *What does upscaling rehabilitation mean globally? A qualitative description of international variation in stroke rehabilitation and the influences on evidence based practice* [Masters Dissertation, University of Otago]. https://ourarchive.otago.ac.nz/bitstream/handle/10523/10097/WatkinsKimberleyE2019.pdf?sequence=1&isAllowed=y

Wilson, C., & Kim, E.S. (2021). Qualitative data collection: Considerations for people with aphasia. *Aphasiology*, *35*(3), 314–333. https://doi.org/10.1080/02687038.2019.1693027

World Medical Association. (2001). World Medical Association declaration of Helsinki. Ethical principles for medical research involving human subjects. *Bulletin of the World Health Organization,* 79(4), 373.

Worrall, L., Rose, T., Howe, T., Brennan, A., Egan, J., Oxenham, D., & McKenna, K. (2005). Access to written information for people with aphasia. *Aphasiology*, *19*(10–11), 923–929. https://doi.org/10.1080/02687030544000137

Worrall, L., Rose, T., Howe, T., McKenna, K., & Hickson, L. (2007). Developing an evidence-base for accessibility for people with aphasia. *Aphasiology*, *21*(1), 124–136. https://doi.org/10.1080/02687030600798352

Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., & Davidson, B. (2011). What people with aphasia want: Their goals according to the ICF. *Aphasiology, 25*(3), 309–332. https://doi.org/10.1080/02687038.2010.508530

Wray, F., & Clarke, D. (2017). Longer-term needs of stroke survivors with communication difficulties living in the community: A systematic review and thematic synthesis of qualitative studies. *BMJ, 7*, e017944. https://doi.org/10.1136/bmjopen-2017-017944

Zafra-Tanaka, J.H., Portocarrero, J., Abanto, C., Zunt, J.R., & Miranda, J.J. (2022). Managing post-stroke care during the COVID-19 pandemic at a tertiary care level hospital in Peru. *Journal of Stroke and Cerebrovascular Diseases: The Official Journal of National Stroke Association*, *31*(4), 106275. https://doi.org/10.1016/j.jstrokecerebrovasdis.2021.106275

APPENDIX A: CEO Information Letter

University of the Witwatersrand,
School of Human and Community Development
Department of Speech Pathology and Audiology
Contact Details: 011 717 4577

[redacted]

September 2020

Dear Sir

Re: Permission to conduct research through Nurture Health

My name is Nabeelah Ebrahim Kathrada

I am studying towards a Masters in Speech Pathology in the school of human and community development at the University of the Witwatersrand. I am seeking permission to access participants through your rehabilitation facility.

I am conducting research on the ''***Experiences of stroke survivors with aphasia and their significant others during the Covid-19 pandemic in South Africa.''*** In this study we want to explore the first-hand experiences of stroke survivors with aphasia and their significant others who have had a stroke during the covid-19 pandemic as well as the manner in which these changes may affect their overall quality of life. This information is helpful in understanding the plight of stroke survivors and their significant others, based on first hand experiences of those with communication impairments who are often excluded from qualitative studies. This will allow also for further investigation and studies to develop more effective intervention methods to overcome any challenges and identify facilitators, which will be based on narratives of participants experiences and therefore guided by their needs.

What is involved in this study?

This study is a qualitative study. Data collection will occur during 2021. We will invite participants to face-face interviews at a place that is nominated as convenient for them once they have provided verbal/written informed consent. Interviews will be broken down into two to three sessions of 15-20-minute sessions to accommodate for fatigue ability. These sessions will be audio recorded and transcribed; thereafter coded and analysed. In the event that face-face interaction is not plausible (for eg, due to the nature of the covid-19 pandemic), interviews will take place via video teleconferencing – on a platform that is most optimal for the participants such as whatsapp , zoom , skype , microsoft teams etc.

Ethics will be obtained from the Human Research Ethics Committee (medical), once this is obtained, I will enlist the assistance of the speech therapist at your facility in order to recruit participants. We have identified your institution as recruiting site as rehabilitation is routinely provided to stroke survivors with aphasia. The speech therapist will be provided with a detail selection criterion as well as selection protocol in order to assist us in reaching willing participants. There are two cohorts - in summary, stroke survivors will need to have had their neurological stroke event during the pandemic, participants will have to have had a left hemisphere stroke and be able to engage in conversational communication. Significant others will be recruited if they are currently living with a stroke survivor. Participants will not be included if either stakeholder withholds consent as the study is looking at their experiences as a unit. The study will maintain all aspects of ethics such as providing participants with information, attaining informed consent, confidentiality, autonomy and participant right to withdraw with no implications. Furthermore, all participants as well as facilities will have access to the results of the study and a debriefing will also occur.

There are no immediate benefits of the study, however the study can assist in contributing to current literature as well as allow for further investigation and development of stroke rehabilitation. Distress has been highlighted as a potential risk, to address this, a distress protocol and referral process has been developed. A clinical psychologist will assist the primary research in addressing this aspect, listed below are her details:

Name of professional: Sarah Niemand

Contact details: 072 363 0942

Email: sarahniemand@gmail.com

If you request any more information or would like the results of this study after its completion, please feel welcome to contact the following persons:

Nabeelah Kathrada (Primary Researcher)

Cell: 072 625 9703

Email: nabeelahkathrada@gmail.com **OR**

Dr Joanne Neille (Supervisor)

Telephone: 011 717 4574

Email: Joanne.Neille@wits.ac.za **OR**

Kelly Ann Kater (Co-Supervisor)

Telephone: 011 717 4937

Email: kelly-ann.kater@wits.ac.za

Thank you for your time and consideration.

Sincerely,

…………………………………………………………

Nabeelah Ebrahim Kathrada

(Speech Pathologist and Audiologist)

If you have any concerns on the manner of which this study is conducted, please contact the chairperson of the HREC (medical) committee: Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za. Alternatively, you may contact the secretariats who are Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

APPENDIX B: HOD Information Letter

University of the Witwatersrand,
School of Human and Community Development
Department of Speech Pathology and Audiology
Contact Details: 011 717 4577

[redacted]

November 2020

Dear Madam

Re: Permission to conduct research through Nurture Health

My name is Nabeelah Ebrahim Kathrada

I am studying towards a Masters in Speech Pathology in the school of human and community development at the University of the Witwatersrand. I am seeking permission to access participants through your rehabilitation facility.

I am conducting research on the ''***Experiences of stroke survivors with aphasia and their significant others during the Covid-19 pandemic in South Africa.''*** In this study we want to explore the first-hand experiences of stroke survivors with aphasia and their significant others who have had a stroke during the covid-19 pandemic as well as the manner in which these changes may affect their overall quality of life. This information is helpful in understanding the plight of stroke survivors and their significant others, based on first hand experiences of those with communication impairments who are often excluded from qualitative studies. This will allow also for further investigation and studies to develop more effective intervention methods to overcome any challenges and identify facilitators, which will be based on narratives of participants experiences and therefore guided by their needs.

What is involved in this study?

This study is a qualitative study. Data collection will occur during 2021. We will invite participants to face-face interviews at a place that is nominated as convenient for them once they have provided verbal/written informed consent. Interviews will be broken down into two to three sessions of 15-20-minute sessions to accommodate for fatigue ability. These sessions will be audio recorded and transcribed; thereafter coded and analysed. In the event that face-face interaction is not plausible (for e.g., due to the nature of the covid-19 pandemic), interviews will take place via video teleconferencing – on a platform that is most optimal for the participants such as WhatsApp, Zoom, Skype , Microsoft teams etc.

Ethics will be obtained from the Human Research Ethics Committee (medical), once this is obtained, I will enlist the assistance of the speech therapist at your facility in order to recruit participants. We have identified your institution as recruiting site as rehabilitation is routinely provided to stroke survivors with aphasia. The speech therapist will be provided with a detail selection criterion as well as selection protocol in order to assist us in reaching willing participants. There are two cohorts - in summary, stroke survivors will need to have had their neurological stroke event during the pandemic, participants will have to have had a left hemisphere stroke and be able to engage in conversational communication. Significant others will be recruited if they are currently living with a stroke survivor. Participants will not be included if either stakeholder withholds consent as the study is looking at their experiences as a unit. The study will maintain all aspects of ethics such as providing participants with information, attaining informed consent, confidentiality, autonomy and participant right to withdraw with no implications. Furthermore, all participants as well as facilities will have access to the results of the study and a debriefing will also occur.

There are no immediate benefits of the study, however the study can assist in contributing to current literature as well as allow for further investigation and development of stroke rehabilitation. Distress has been highlighted as a potential risk, to address this, a distress protocol and referral process has been developed. A clinical psychologist will assist the primary research in addressing this aspect, listed below are her details:

Name of professional: Sarah Niemand

Contact details: 072 363 0942

Email: sarahniemand@gmail.com

If you request any more information or would like the results of this study after its completion, please feel welcome to contact the following persons:

Nabeelah Kathrada (Primary Researcher)

Cell: 072 625 9703

Email: nabeelahkathrada@gmail.com **OR**

Dr Joanne Neille (Supervisor)

Telephone: 011 717 4574

Email: Joanne.Neille@wits.ac.za **OR**

Kelly Ann Kater (Co-Supervisor)

Telephone: 011 717 4937

Email: kelly-ann.kater@wits.ac.za

Thank you for your time and cooperation, it is highly appreciated.

Sincerely,

…………………………………………………………

Nabeelah Ebrahim Kathrada

Speech Pathologist and Audiologist

If you have any concerns on the manner of which this study is conducted, please contact the chairperson of the HREC (medical) committee: Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za. Alternatively, you may contact the secretariats who are Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

APPENDIX C: SLT Information Sheet

University of the Witwatersrand,

School of Human and Community Development

Department of Speech Pathology and Audiology

Contact Details: 011 717 4577

Dear Speech Therapist

[redacted]

[redacted]

November 2020

<u>Re: Permission to conduct research through Nurture Health</u>

My name is Nabeelah Ebrahim Kathrada. I am studying towards a Masters in Speech Pathology in the school of human and community development at the University of the Witwatersrand. I am seeking permission to access participants through your rehabilitation facility.

I am conducting research on the ‘’***Experiences of stroke survivors with aphasia and their significant others during the Covid-19 pandemic in South Africa.’’*** In this study we want to explore the first-hand experiences of stroke survivors with aphasia and their significant others who have had a stroke during the covid-19 pandemic as well as the manner in which these changes may affect their overall quality of life. This information is helpful in understanding the plight of stroke survivors and their significant others, based on first hand experiences of those with communication impairments who are often excluded from qualitative studies. This will allow also for further investigation and studies to develop more effective intervention methods to overcome any challenges and identify facilitators, which will be based on narratives of participants experiences and therefore guided by their needs.

I would therefore like to obtain permission in assisting in the recruiting process of participants for this research study. As a speech therapist at this facility, I would appreciate your assistance and input in the recruitment process.

What is involved in this study?

This study is a qualitative study. Data collection will occur during 2021. We will invite participants to face-face interviews at a place that is nominated as convenient for them. Interviews will be broken down into two to three sessions of 15-20-minute sessions to accommodate for fatigue ability. These sessions will be audio recorded and transcribed; thereafter coded and analysed. In the event that face-face interaction is not plausible (for eg, due to the nature of the covid-19 pandemic), interviews will take place via video teleconferencing – on a platform that is most optimal for the participants such as WhatsApp , zoom , skype , Microsoft teams etc.

Ethics will be obtained from the Human Research Ethics Committee (medical), once this is obtained, I would like to enlist your assistance in order to recruit participants. You will be provided with a detailed selection criterion as well as selection protocol in order to assist us in reaching willing participants (stroke survivors with aphasia and significant others of stroke survivors with aphasia). I have attached these criteria at the end of the information sheet as well as a selection protocol. The study will maintain all aspects of ethics such as providing participants with information, attaining informed consent, confidentiality, autonomy and participant right to withdraw with no implications. Furthermore, all participants as well as facilities will have access to the results of the study and a debriefing will also occur.

There are no immediate benefits of the study, however the study can assist in contributing to current literature as well as allow for further investigation and development of stroke rehabilitation. Distress has been highlighted as a potential risk , to address this , a distress protocol and referral process has been developed. A clinical psychologist will assist the primary research in addressing this aspect , listed below are her details :

Name of professional: Sarah Niemand

Contact details: 072 363 0942

Email: sarahniemand@gmail.com

If you request any more information or would like the results of this study after its completion please feel welcome to contact the following persons:

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Cell: 072 625 9703

Email: nabeelahkathrada@gmail.com

OR

Dr Joanne Neille (Supervisor)

Telephone: 011 717 4574

Email: Joanne.Neille@wits.ac.za

OR

Kelly Ann Kater (Co-Supervisor)

Telephone : 011 717 4937

Email : kelly-ann.kater@wits.ac.za

Thank you for your time and cooperation, it is highly appreciated.

Sincerely,

……………………………………………………………

Nabeelah Ebrahim Kathrada

Speech Pathologist and Audiologist

If you have any concerns on the manner of which this study is conducted please contact the chairperson of the HREC (medical) committee: Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Alternatively, you may contact the secretariats who are Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Protocol

Selection Criteria

Cohort 1 : Stroke survivor with aphasia

Participant Selection- inclusion criteria

1. Stroke survivor with aphasia whose onset of stroke/diagnosis of aphasia occurred during the covid-19 pandemic
2. Stroke survivor with aphasia that has experienced treatment and/or rehabilitation in a private step-down facility / private practice (as an inpatient/outpatient) during the coronavirus pandemic
3. Stroke survivor with aphasia who lives with at least one significant other (family member)
4. Stroke survivor with aphasia who are able to engage at a conversational level (in English) and subsequently the research interview using communication modalities such as verbal speech, AAC systems etc. Eligibility will be determined by their speech therapist who will evaluate the stroke survivor with aphasia on a specific criterion set out by the researcher.

Exclusion Criteria

1. Stroke survivor with aphasia who are unable to converse at a conversational level in the English language
2. Right hemisphere stroke survivors
3. Stroke survivor’s with aphasia whose significant others’ do not consent to participation

Cohort 2 : Significant others of stroke survivors with aphasia

Participant Selection – inclusion criteria

1. Currently living with a stroke survivor with aphasia
2. Participant has the ability to engage using conversational English with the researcher

Exclusion Criteria

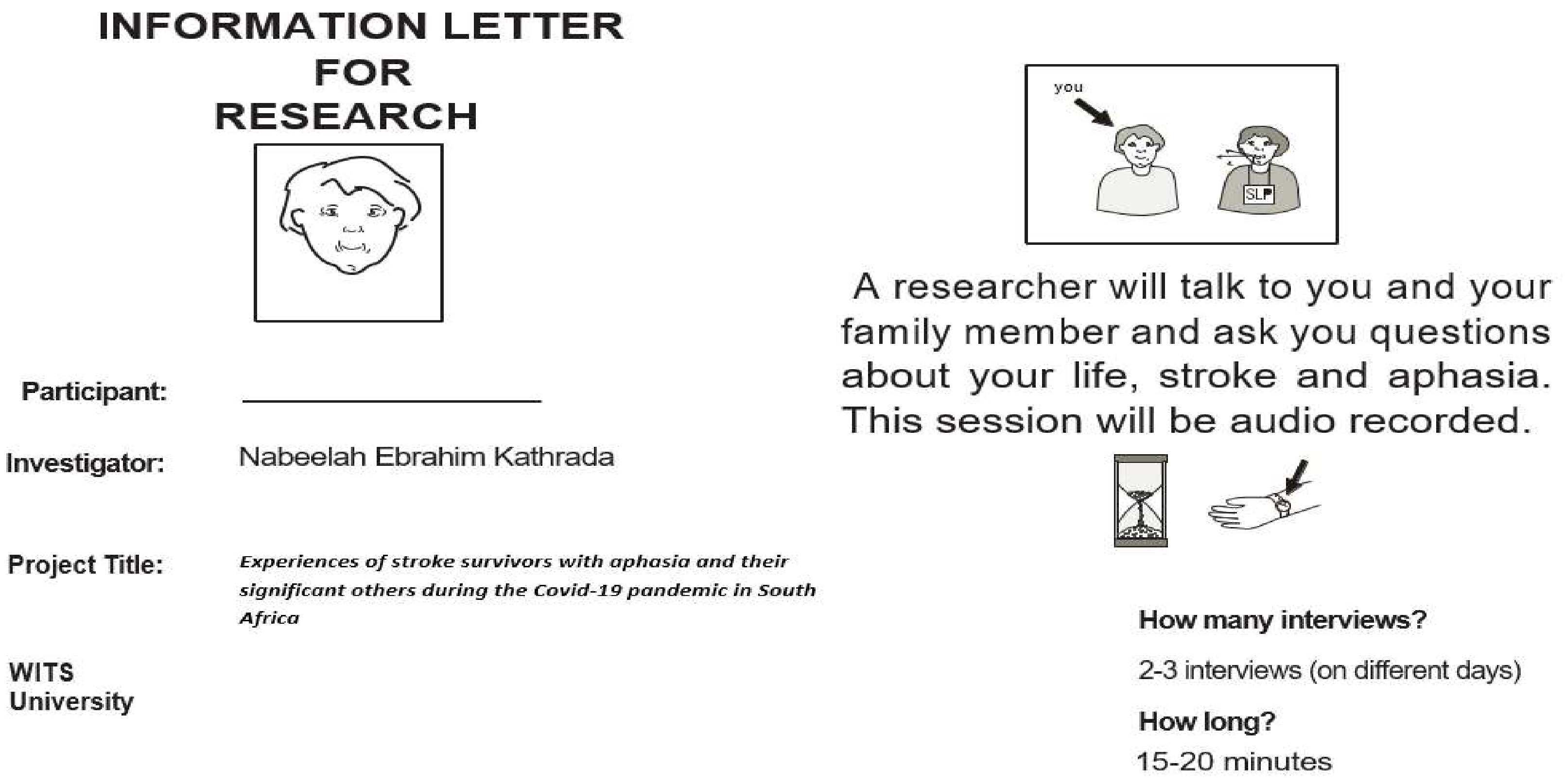
1. Significant others of stroke survivors with aphasia who are unable to converse at a conversational level in the English language
2. If consent is not received from the stroke survivor with aphasia, the significant other will also be excluded from the study

2.Selection Criteria Protocol for stroke survivors with aphasia (for speech therapists to use as a guideline)

As this is a qualitative study it is imperative that the stroke survivor with aphasia is able to:

- Display the ability to comprehend short questions (total communication strategies will be used to enhance receptive ability)
- Display the ability to process auditory / written / pictographic information in order to provide informed consent to participate (through verbal or written consent)
- Display the ability to maintain sustained attention for ***atleast*** 20-minute intervals (breaks will be provided, if need be, thereafter)
- To be able to recall, reflect and express speech rehabilitation experiences using short phrases / sentences (all communication modalities are accepted)
- To be able to protest / express non-compliance to questions they would not like to answer (all communication modalities are accepted)

APPENDIX D: Information Letter : Person with Aphasia



INFORMATION LETTER
FOR
RESEARCH

Participant: ____________________

Investigator: Nabeelah Ebrahim Kathrada

Project Title: *Experiences of stroke survivors with aphasia and their significant others during the Covid-19 pandemic in South Africa*

WITS
University

A researcher will talk to you and your family member and ask you questions about your life, stroke and aphasia. This session will be audio recorded.

How many interviews?

2-3 interviews (on different days)

How long?

15-20 minutes

Right to withdraw

✔ You can stop at any time

✔ It is your choice

Stop

✔ It is ok to stop

You can skip a question

Everything is confidential

Your Answers

Will be safe and protected

It will be stored

For 5 years

Only the primary researcher

can look at it

Potential Benefits

- ✓ This will help research
- ✓ This will help:
  - Other people with aphasia in the community
  - better therapy outcomes
  - change policy
  - hospitals and rehab centres

Potential Risks

If you feel stressed after
the interview. You will be
able to visit a psychologist
for one free counselling session

Do you have any questions?

Yours sincerely,

Researcher:

Nabeelah Kathrada

Cell: 072 625 9703

Email: nabeelahkathrada@gmail.com

Supervisors:

Dr Joanne Neille

Telephone: 011 717 4574

Email: Joanne.Neille@wits.ac.za

Kelly Ann Kater

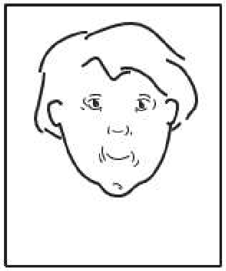
Telephone: 011 717 4937

Email: kelly-ann.kater@wits.ac.za

APPENDIX E: Informed Consent: Person with aphasia

Title of project: ***Experiences of stroke survivors with aphasia and their significant others during the covid-19 pandemic***

Name of researcher: Nabeelah Ebrahim Kathrada



____

Participant Name:

____

Participant Signature

Date: ______________________

I agree to participate in this research project

YES 👍 ________ **NO** 👎 ________

I have a copy of all the research information

YES 👍 ________ **NO** 👎 ________

I understand what this research is about

👍 ☐ YES   👎 ☐ NO

I agree to audio recording

👍 ☐ YES   👎 ☐ NO

Researcher Signature (Nabeelah Kathrada)

Date:

APPENDIX F: Motivation for Verbal Consent for Persons with Aphasia

Aphasia is defined as a disorder caused by an acquired neurological event which causes impairments in language and subsequently communication (Blom-Johansson et al., 2012). There are different types of aphasia which impact on speech, language and communication ability in a variety of different ways (Blom-Johansson, 2012). Aphasia can be detected at all linguistic levels, which are, phonological, morphological, syntactical, lexical and at the pragmatic level. Typical symptoms are paraphasias (literal, verbal or neologisms), perseveration, circumlocution, anomia and alexia (Blom-Johansson, 2012). It can be extrapolated that aphasia also results in the decreased ability to process, retain, retrieve and recall information (Blom-Johansson ,2012). The impairment in language ability due to aphasia can affect a person on multiple levels these include verbal expression, auditory comprehension, reading and writing, cognitive -linguistic ability and higher thought and processing skills (Blom-Johansson, 2012). Those with aphasia require information to be broken down, repeated, summarised or through the use of visual aid. As aphasia usually occurs as a result of a stroke, it can be extrapolated that imposing on the language difficulties to read and write there may also be physical limitations prohibiting / limiting these skills.

It is therefore for this reason; this study aims to maintain participant autonomy by allowing those with additional communication impairments and subsequently additional needs – to read information pertaining to the study in a conducive and summarised format. The study also would make provision by accepting verbal informed consent from participants to engage with the researcher. Verbal consent will be audio recorded as proof that it has been obtained. This information will be stored in a password protected cloud system to maintain confidentiality.

APPENDIX G: Information Letter: Significant other of stroke survivor with aphasia

Participant Information Sheet for Significant others of stroke survivors with aphasia

Dear Sir / Madam,

My name is Nabeelah Ebrahim Kathrada and I am a Masters student at the University of the Witwatersrand, Johannesburg. As part of my studies, I have to undertake a research project, and I am investigating ***''The experiences of stroke survivors with aphasia and their significant others during the covid-19 pandemic''*** under the supervision of Dr Joanne Neille and Ms Kelly-Ann Kater. The aim of this research project is to explore the lived experiences of stroke recovery in stroke survivors with aphasia and their significant others, during the covid-19 pandemic.

As part of this project, I would like to invite you to take part in an interview. This activity will involve speaking to me about your experiences as a significant other to a stroke survivor with aphasia. The interview can be conducted in conjunction with the stroke survivor with aphasia or separately – whichever is preferable. There will be two to three interview sessions and each session will take approximately 15-20 minutes. The interview will be recorded using an audio device, so that this may be later transcribed and coded so that no identifying information of any participants are displayed. The interview will be recorded using a digital device. In the event that face-face interaction is not plausible (for eg, due to the nature of the covid-19 pandemic), interviews will take place via video teleconferencing – on a platform that is most optimal for you, such as WhatsApp , zoom , skype , microsoft teams etc.

There will be no personal costs to you if you participate in this project, you will not receive any direct benefits from participation but there are no disadvantages or penalties if you do not choose to participate or if you withdraw from the study. You may withdraw at any time or not answer any question if you do not want to. The interview will be completely confidential and anonymous as I will not be asking for your name or any identifying information, and the information you give to me will be held securely and not disclosed to anyone else. I will be using a pseudonym (false name) to represent your participation in my final research report. If you experience any distress or discomfort at any point in this process, we will stop the interview or resume another time. If you need some support or counselling services following the interview there will be one free counselling session made available for you. The name of the psychologist is Sarah Niemand and the contact details for the counselling service are : Number : 072 363 0942 and Email: sarahniemand@gmail.com.

If you have any questions during or afterwards about this research, feel free to contact me on the details listed below. This study will be written up as a research report which will be available online through the university library website. If you wish to receive a summary of this report, I will be happy to send it to you. The data collected from this research project will be stored in a password protected cloud based system and will be kept for 5years.Thereafter it will be destroyed. If you have any concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Human Research Ethics Committee (Medical) Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Thank you for your time and cooperation, it is highly appreciated.

Yours sincerely,

Researcher:

Nabeelah Kathrada

Cell: 072 625 9703

Email: nabeelahkathrada@gmail.com

Supervisors:

Dr Joanne Neille

Telephone: 011 717 4574

Email: Joanne.Neille@wits.ac.za

Kelly Ann Kater

Telephone: 011 717 4937

Email: kelly-ann.kater@wits.ac.za

APPENDIX H: Informed Consent: Significant other of stroke survivor with aphasia

Title of project: ***Experiences of stroke survivors with aphasia and their significant others during the covid-19 pandemic***

Name of researcher: Nabeelah Ebrahim Kathrada

I, (your name) ………………………………………., agree to participate in this research project. The research has been explained to me and I understand what my participation will involve. I agree to the following:

(Please circle the relevant options below).

I agree that my participation will remain anonymous	YES	NO
I agree that the researcher may use anonymous quotes in his / her research report	YES	NO
I agree that the interview may be audio recorded	YES	NO

…………………………………… (signature)
…………………………………… (name of participant)
…………………………………… (date)

…………………………………… (signature)
…………………………………… (Nabeelah Kathrada – Primary Researcher)
…………………………………… (date)

APPENDIX I: Interview Questions

Semi Structured Interview Questions

All questions were probed in due of participants' responses. Due to the nature of the interview, there were variations in the order of questions posed and prompts followed as the interviews followed participants lead.

- What was it like being hospitalised during an ongoing pandemic **//** due to covid-19?

(When asking a significant other it was slightly rephrased as: what was it like having a family member / partner being hospitalised during an on-going pandemic)

In the main interview the following prompts were used for this question to further elicit information

a) **The experience as significant other with the stroke and aphasia diagnosis**
b) **The emotions relating to the diagnosis (for both PWA and Significant Others)**
c) **The perception of COVID-19 strategies to combat transmission**
d) **Specific experiences of rehabilitation and adaptive strategies used during COVID-19**

- How has stroke and the resultant aphasia changed **//** impacted your lives?

In the main interview the following prompts were used for this question to further elicit information

a) **What are the particular changes that have occurred in their lives because of the stroke diagnosis**
b) **How has this impacted on their different re-integration contexts (family, work, social)**
c) **How has the COVID-19 pandemic impacted re-integration**
d) **Has technology been used, if so, how and to what extent?**

- What have your experiences on stroke recovery been thus far? **//** especially in the context of the pandemic?

In the main interview the following prompts were used for this question to further elicit information

a) **Family engagement in therapy**

b) **Access to outpatient therapy**

c) **Access to telerehabilitation**

d) **Perception of therapy**

e) **Perception of COVID-19**

- What support have you been receiving **//**or can you comment on any support you would like to receive? (Available to both the person with aphasia and significant other)

In the main interview the following prompts were used for this question to further elicit information

a) **Informational Support**

b) **Professional Support**

c) **Informal Support** (**family support, community support, coping mechanisms)**

d) **Advise for other stroke survivors / significant others**

e) **Opinions on bettering intervention**

// - line breaks to illustrate breaking long sentences for persons with communication impairment

<u>Biographic Information</u>

NB: This statistical information will be used to draw up a participant table, however, these questions will not be specifically asked but rather adhered to in the main interview questions.

Stroke survivor information		**Significant other information**	
Age		Age	
Relationship status to significant other		Relationship status to stroke survivor	
Date of onset of stroke		What is your home language	

APPENDIX J: Distress Protocol

Distress Protocol

Possible referrals with relation to excessive emotional distress:

- The screening protocol as designed by Haigh & Williams (2015) will be used to assess participants for distress.
- The therapist will then refer participants who displayed signs of distress and could not continue with the interview to a clinical psychologist (Sarah Niemand) for a free counselling session

Name of professional: Sarah Niemand

Contact details: 072 363 0942

Email: sarahniemand@gmail.com

Registration number: PS0011150

- The clinical psychologist will decipher if there is a need for further intervention
- A list of 3 names of clinical psychologists will be provided to participants so that they may seek further assistance. It will be expressed to all participants that these sessions will not be financially compensated by the researchers and will have to be funded by the participants themselves.
- If they are unable to attend further intervention due to financial constraints, they will be provided a list of government institution, within their vicinity, to assist with further remediation.
- The therapist will then assist with the booking of appointments to a government institution in their catchment area.
- In the event of long waiting periods, or difficulty obtaining an appointment, participants will be able to access free counselling services through the following organisation:

Northfield Methodist Church

The Well (counselling services)

Contact: 010 140 0217

Email: mike@nmfc.org.za

After Hours Care-line: 082 775 7524

APPENDIX K: CEO Permission Granted

Date: 28 September 2020

Dear Nabeelah Kathrada

Research Approval Letter

I am writing in response to the request for authorisation for the study on "*Experiences of stroke survivors with aphasia and their significant others during the Covid-19 pandemic in South Africa"* as part of your Master's Degree.

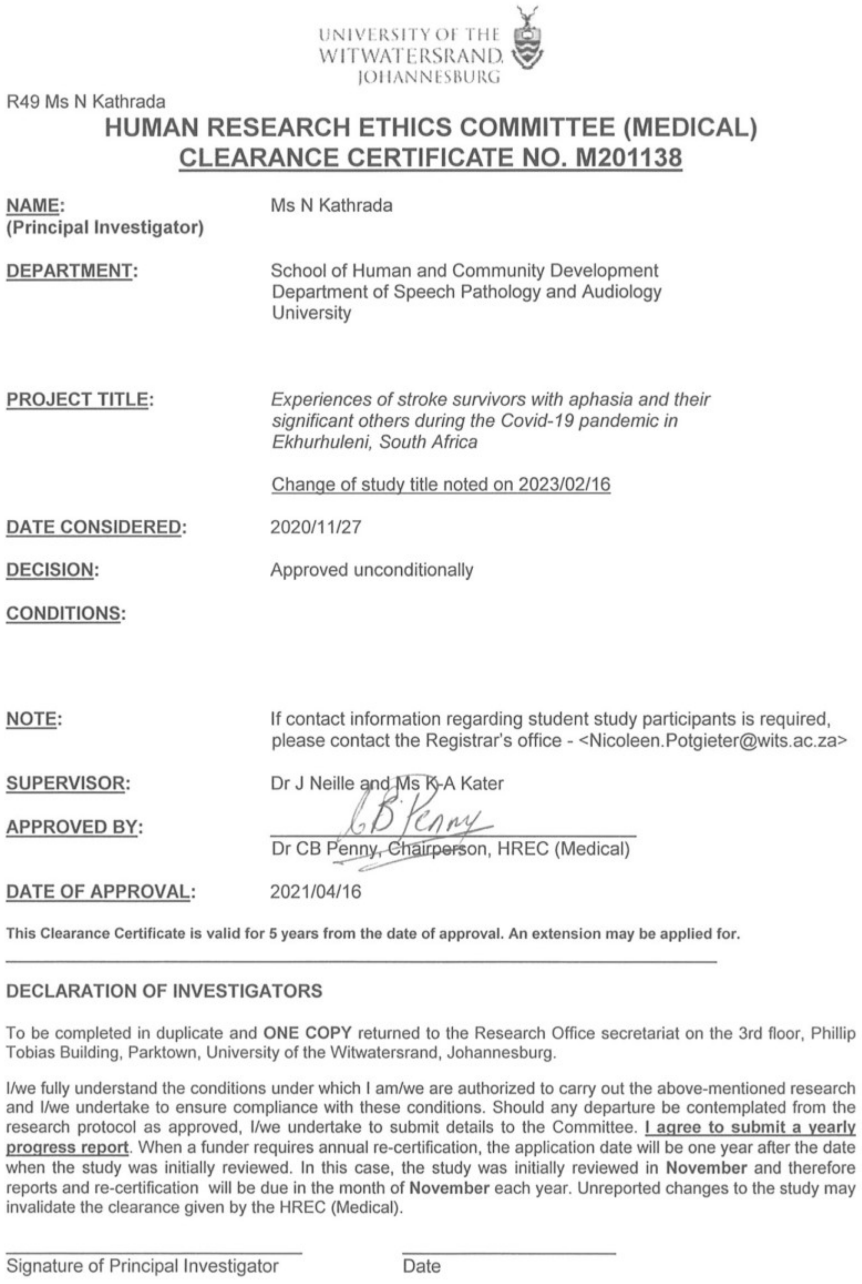
I am glad to inform you that we approve the study at our [redacted] We as [redacted] acknowledges the importance of the study in order to develop our rehabilitation knowledge and improve outcomes in our patients.

Please keep us informed on the outcome of the study.

Kind Regards

[redacted]
CEO

APPENDIX L: Ethics Approval



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

R49 Ms N Kathrada

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M201138

NAME: **(Principal Investigator)**	Ms N Kathrada
DEPARTMENT:	School of Human and Community Development Department of Speech Pathology and Audiology University
PROJECT TITLE:	*Experiences of stroke survivors with aphasia and their significant others during the Covid-19 pandemic in Ekhurhuleni, South Africa* Change of study title noted on 2023/02/16
DATE CONSIDERED:	2020/11/27
DECISION:	Approved unconditionally
CONDITIONS:	
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>
SUPERVISOR:	Dr J Neille and Ms K-A Kater
APPROVED BY:	CB Penny Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2021/04/16

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

DECLARATION OF INVESTIGATORS

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

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

____________________________ Signature of Principal Investigator

____________________ Date

APPENDIX M: Description of participants interview schedule

Participant	Details of interview	Contextual considerations	Use of AAC / Supported conversation strategies	Additional comments / documented notes
Anne 1A & Edward 1B (Wife & Husband)	The interview took place in 2022. The interview was requested to occur via a video tele conferencing platform (zoom). The interview lasted for approximately 70 minutes. The interview was audio recorded and field notes were taken. Participants requested that their interview be joint.	Information sheets and consent forms were emailed beforehand. During the interview it was discovered that participants were not well versed with regard to the study and what it entails. This was then explained to them in detail. Consent was obtained verbally again and all ethical considerations further explained.	Supported conversation techniques were used during the interview. This included breaking down information in smaller chunks, repeating questions, asking participants for clarification, providing pauses or time-delay to allow for the PWA to respond, basic yes/no questions were asked as follow ups to the PWA. AAC was not needed. As this was an online interview , the participant was shown 3 gestures to help during the interview these were (palm up for stop ; a time-out gesture to pause and a swipe gesture to skip a question / topic if needed). The participant made use of the stop sign once to recollect herself.	The significant other was very supportive and patient. He continually encouraged the PWA to add her views and provide her side. The PWA appeared to become emotional when speaking about the feeling of isolation / role of the family / lack of respect. In these instances, there were pauses and the researcher asked if she would prefer to stop, skip or change the topic. The PWA reiterated that she was okay to continue. This participant was referred for psychology due to PWA mentioning difficulties with low mood, self-worth, anxiety and low motivation at times.
Charlotte 2A (Mother to Julia 2B)	The interview took place in 2022. The face-face interview took place at a pre-arranged convenient place for the PWA. This was the rehabilitation hospital where she was currently receiving outpatient therapy. The interview was audio recorded and field notes were taken. The interview was initially requested to be joint. However, on the day of the interview the PWA chose to conduct the interview separately from her SO. The interview lasted approximately 60 minutes.	Information sheets and consent forms were read by the PWA herself – however she did request clarification on certain points and was provided additional information in this aspect. During the interview it came up that the participant had difficulty with transport funds, and therefore the researcher offered to reimburse the uber trip to and from the hospital.	Supported conversation techniques were used during the interview. This included breaking down information in smaller chunks, repeating questions, asking participants for clarification, providing pauses or time-delay to allow for the PWA to respond, basic yes/no questions were asked as follow ups to the PWA	Charlotte 2 A was a PWA. She requested to have an individual interview. She did not need to use any assistive devices. She did require the interviewer to make use of compensatory conversational techniques. These included repeitition , breaking down of information , seeking clarification on an ambigious or wordy response. Participant requested to be referred for family counselling as she was concerned of the impact of her stroke and subsequent difficulties on her family.

Participant	Details of interview	Contextual considerations	Use of AAC / Supported conversation strategies	Additional comments / documented notes
Julia 2B (Daughter to Charlotte 2A)	The interview took place in 2022. The interview was requested to occur via a video tele conferencing platform (WhatsApp). The interview lasted for approximately 30 minutes. The interview was audio recorded and field notes were taken. Participant (PWA) requested that their interview be joint the SO obliged.	The interview took place via WhatsApp to accommodate the participant. The participant did not have any communication challenges	No difficulties with communication	Referred for free family counselling services to a local church
Mary 3A & Richard 3B	The interview took place in 2022. The face-face interview took place at a pre-arranged convenient place for the PWA. This was the rehabilitation hospital where the PWA previously received outpatient therapy. The interview was audio recorded and field notes were taken. The interview was requested to be joint. The PWA had their (professional– non family member) present in addition to her life partner who was her chosen significant other. The professional carer did not participate in the interview. The interview lasted	Information sheets and consent forms were read aloud for the PWA (at her request) – she also required aid to fill the form and sign her name, with additional time she was able to do so. She indicated consent through the use of the visual aid	Participant has been using multiple modalities to supplement communication. This included the use of a communication application on a tablet, gestural aid – the use of signs (Makaton), as well as a spell board which is on her tablet and printed in a file. Supported communication techniques were used to further facilitate engagement. Most notably, picture signs were used to further assist with easy communication, additional time was provided for both processing information and responding, as well as posing questions in smaller chunks, breaking down information and continuously asking the PWA if she would like breaks – additional time – additional clarification.	Mary 3A appeared to get visibly frustrated when Richard 3B would try to encourage her to write her response faster or in a complete sentence. In an attempt to circumvent this , as well as to be able to better communicate with Mary 3A while she used her AAC spell board , the researcher changed positions with Richard 3B. Mary 3A sat next to the researcher while Richard 3B then sat opposite. Mary 3A had some difficulty in expanding on her answers in certain instances , she would often need a moment to recollect herself and reattempt to answer. Richard 3B was mindful and respectful in providing assitance and oppurtunities to counter his perspective. They appeared to have a very open and honest dynamic as they openly admitted their own faults , as well as honestly described difficulties experienced within the relationship. They remained respectful to each other and there were a few moments of good natured teasing

Participant	Details of interview	Contextual considerations	Use of AAC / Supported conversation strategies	Additional comments / documented notes
James 4A & Matilda 4B	The interview took place in 2022. The face-face interview took place at a pre-arranged convenient place for the PWA – their home. The interview was audio recorded and field notes were taken. The interview was requested to be joint. The interview lasted approximately 60 minutes.	Information sheets and consent forms were read aloud for the PWA (at his request) – he was unable to complete the consent form himself and required aid to fill the form from his SO. Consent was done with him using additional visual aid and verbal consent	Participant has been using multiple modalities to supplement communication. This included the use of gestural aid – the use of low-tech pictures and a spelling board as well as verbal expression of speech. Supported communication techniques were used to further facilitate engagement. Most notably, picture signs were used to further assist with easy communication, additional time was provided for both processing information and responding, as well as posing questions in smaller chunks, breaking down information and continuously asking the PWA if he would like breaks – additional time – additional clarification.	James 4A was able to converse fairly well using verbal speech. He did make use a 'communication file' to supplement communication. Initially Matilda 4B was quite reluctant to expand , even when probed. However James 4A coped well in this regard and as the interview progressed Matilda 4B became more comfortable and established a better rapport as well as provided more in-depth and detailed answers. Both participants were respectful of each other. There were instance where Matilda 4B compltected the statement for James 4A.
William 5A & Kate 5B	The interview took place in 2022. The face-face interview took place at a pre-arranged convenient place for the PWA. This was the rehabilitation hospital where the PWA previously received outpatient therapy. The interview was audio recorded and field notes were taken. The interview was requested to be joint. The interview lasted approximately 60 minutes.	Information sheets and consent forms were read aloud for the PWA (at his request) – he was unable to complete the consent form himself and required aid to fill the form from his SO. Consent was done with him using additional visual aid	Participant has been using multiple modalities to supplement communication. This included the use of gestural aid – the use of low-tech pictures and a spelling board. Supported communication techniques were used to further facilitate engagement. Most notably, picture signs were used to further assist with easy communication, additional time was provided for both processing information and responding, as well as posing questions in smaller chunks, breaking down information and continuously asking the PWA if he would like breaks – additional time – additional clarification.	Kate 5B engaged more than William 5A , most likely due to the commuication challenges. William 5A was still able to provide insight into his experience , however his coummunication was usually brief and he did request assistance from Kate 5B to aid in repairing communication breakdowns at times. Additionally Kate 5B provided additional context around William 5B's responses. He became fatigued . During breaks he either wheeled himself out of the room or walked a short distance with aid. William 5A got quite emotional when talking about family. He was asked if he would like to stop the interview , he requested a 10 minute pause. William 5A did not want to attend a session with the psychologist.

Participant	Details of interview	Contextual considerations	Use of AAC / Supported conversation strategies	Additional comments / documented notes
Harry 6A & Meghan 6B	The interview took place in 2022. The face-face interview took place at a pre-arranged convenient place for the PWA. This was the rehabilitation hospital where the PWA currently attends outpatient therapy. The interview was audio recorded and field notes were taken. The interview was requested to be joint. Additionally, the significant other requested an additional separate interview. The interview lasted approximately 90 minutes. The additional separate interview with the participant 6B lasted	Information sheets and consent forms were read aloud for the PWA (at his request) – he was unable to complete the consent form himself and required aid to fill the form from his SO. Consent was done with him using additional visual aid and verbal consent	Participant has been using multiple modalities to supplement communication. This included the use of gestural aid – the use of low-tech pictures and a spelling board as well as verbal expression of speech. Supported communication techniques were used to further facilitate engagement. Most notably, picture signs were used to further assist with easy communication, additional time was provided for both processing information and responding, as well as posing questions in smaller chunks, breaking down information and continuously asking the PWA if he would like breaks – additional time – additional clarification.	Harry 6A & Meghan 6B were very accomodating to each other. They were polite and respectful of each other's views. They would ask each other for confirmation during recalling of events. Both were fairly equal in answering or providing insight , however Meghan 6B's reflections were notably longer and filled with detailed explanations. Harry 6A on the otherhand used shorter sentences. He coped well when probed.
Elizabeth 7A (Mother to George 7B)	The interview took place in 2022. The face-face interview took place at a pre-arranged convenient place for the PWA. The interview was audio recorded and field notes were taken. The interview was requested to be separate by the PWA. The interview lasted approximately 120 minutes.	Information sheets and consent forms were read by the PWA herself –	Supported conversation techniques were used during the interview. This included breaking down information in smaller chunks, repeating questions, asking participants for clarification, providing pauses or time-delay to allow for the PWA to respond, basic yes/no questions were asked as follow ups to the PWA. AAC was not needed	Referred to psychology due to concerns mentioned in the interview about continued panic attacks post reintegration at home and work.
George 7B (Son to Elizabeth 7A)	The interview took place in 2022. The interview took place via video conferencing (zoom) The interview was audio recorded and field notes were taken. The interview was requested to be separate by the PWA the significant other obliged. The interview lasted approximately 30 minutes.	As a significant other he did not need any aid in reading the information sheets or consent forms. No supportive strategies needed during the zoom interview	No difficulties with communication	Participant did not have to be referred for psychology or counselling

APPENDIX N: Sample Interview

Interview 1: Anne 1A & Edward 1B (Wife and Husband)	
Interview Format: Virtual via Zoom	
Researcher	*Hi, my name is Nabeelah Kathrada. I would like to begin by saying thank you for agreeing to meet with me today.* *I know you read through the forms. But do you have any questions?*
Edward 1B	*What is this really all about? What is the end point of this?*
Researcher	*I am master's student at the University of Wits.* *I am conducting research in the area of stroke and aphasia.* *The research study is about your personal, real-life experiences of being a stroke survivor with aphasia and a significant other during the COVID-19 pandemic.* *It's to ask both you (Anne 1A) and your chosen family member (Edward 1B), what has your experience been with stroke rehabilitation? This will then contribute to current literature findings in South Africa.*
Anne 1A	*Okay okay*
Researcher	*If you would like a break, to pause or stop you are welcome to ask as we talk. (pause)* *You may also use these signs through the interview:* *1. If you are tired, we can stop as well. If you feel stressed, we can stop completely or pause. (this is stop- gestures) (this is pause - gestures)* *2. We can also skip a question if you are not comfortable. (This is skip - gestures)*

	Do you have any other questions?
Edward 1B	*No, let's get it going and let's see.*
Researcher	*Mrs (Anne 1A?)*
Anne 1A	*No, I'm fine*
Researcher	*Okay great. I know you signed the form but I am going to ask for verbal consent*
Anne 1A	*Okay…*
Researcher	*Please state your name for me and I will ask if you agree or disagree. Mr Edward 1B would you like to begin?*
Anne 1A	*I'll start. My name is (Anne 1A). I'm the (surname omitted) and he's the (surname omitted). It's a double barrel knife. When we decided to get married, I said it's fine, but I'm taking my maiden name back and I add his surname.*
All	*Laughs*
Anne 1A	*It sort of worked out. Yeah. Sometimes I call him my (omitted) and they say, oh, (name omitted). And then he looks at me and he doesn't know what to say. But yeah, that's basically what we did. We married 20 years this year.*
Researcher	*Wow. 20 years, that's wonderful. Its lovely to meet you both. So, Mrs Anne 1A Do you agree to participate in this research?*
Anne 1A	*Yeah*
Researcher	*Do you agree to an audio recording*
Anne 1A	*Yeah*
Researcher	*Do you agree for your quotes to be used anonymously*
Anne 1A	*Yeah*
Researcher	*Are you aware that you are able to withdraw from this research at any point if you choose to do so?*
Anne 1A	*Yes, I understand.*
Researcher	*Thank you so much.*

Researcher	*Mr Edward 1B, please state your name*
Edward 1B	*I am Edward 1B, as Anne 1A said we married 20 years*
Research	*Amazing, so Mr Edward 1B, do you agree to participate in this research?*
Edward 1B	*Yeah*
Researcher	*Do you agree to an audio recording*
Edward 1B	*That's fine*
Researcher	*Do you agree for your quotes to be used anonymously?*
Edward 1B	*Sure*
Researcher	*And are you aware that you can withdraw from the research at any point if you choose to do so?*
Edward 1B	*Yeah*
Researcher	*Okay let's begin.* ***What was it like being hospitalised during an ongoing pandemic, due to COVID-19?***
Anne 1A	*Okay. Let me start. I had a problem with my hands. Okay. Some feeling in the hands and it was really tough. So, I went to a doctor and they said I've got this...thing*
Anne 1A	*So, I went in for the operation…* *So then when I came out, it was quite a while struggling. The fingers still didn't come right. This hand was better than the right hand and all that. So eventually...* *Yeah. So, when she looked at it, she said, nah, this is not right. I never did the operation correctly and all that story. But I had to first go for a lot of tests.*
Edward 1B	*You had to go to a neurosurgeon and all sorts.*
Anne 1A	*Yeah, so I had to go to a neurosurgeon. They did the test in the... What do you*

	call it? That you go inside...
Edward 1B	*MRI*
Anne 1A	*The MRI. MRI scan. They did some other electrical tests, which was terrible. The one was shocking you. I said, never again, I want to see you again.*
Anne 1A	*But anyway, then they said, okay, so they're going to take me in, do the operation and let's see if everything comes out. So, I went in.*
Anne 1A	*She had an opening and she said, I can do you in a week's time or it's going to take longer if we have to wait. So, I said, the week is fine. So, I went in the morning of the 12th and the afternoon of the 11th and I was done the 12th.*
Anne 1A	*(Points to hand) this hand was very bad. I couldn't actually use this finger and the hand itself was not like it. But I also found out that the muscle was sort of torn loose. It was loose. It wasn't tight to the top.*
Anne 1A	*She had to go in and release this muscle. So, everything went okay. I came out the same day. Everything was fine.* *I was like in the... It was fine. It was painful, but it was okay.*
Edward 1B	*For six weeks, she had to keep her arm strapped up so that the muscle would reattach properly.*
Anne 1A	*So yeah, then on the 22nd (Edward 1B) said there was something not right. He just couldn't understand what it is. The 23rd, the morning, he said, there's something wrong. I'm going to take you into a hospital and check.*
Edward 1B	*I just knew…*
Anne 1A	*So, we went to (name of hospital). To the emergency. The emergency. I was lying there and they said they're going to do a few tests. And they took me through a few tests that I had to do. I can't remember what it was called.*
Anne 1A	*All the tests I had to do.* *did a brain scan or something. I don't know if it was another MRI or something*

Edward 1B	*Yeah, it was another MRI. But anyway, they picked up that she had a stroke. A blood clot on the left.*
Researcher	*I see that you're still very emotional when you speak about it. I just want to ask you.*
Anne 1A	*I am (nods and tears)*
Researcher	*I can see that, are you okay?*
Anne 1A	*Hmm (gestures for pause)*
Researcher	*No problem…*
Researcher	*Are you ready? Okay…* ***Let's talk about the experience of being diagnosed, how did it impact you, Mr Edward 1B? The stroke and aphasia …***
Edward 1B	*It's a big shock. We were planning to retire at the end of last year and so on. And we had all these visions of what we wanted to do and things like that. And because of the stroke, a lot of things have changed.*
Edward 1B	*A different lifestyle and so on*
Edward 1B	*It does get very emotional, especially if she gets a bit excited and she gets emotional.*
Researcher	*But that's understandable. I mean, it's a life changing event. And the impact stays with you for the rest of your life as well.*
Anne 1A	*Yeah, it does. I'm ok now thank you.*
Anne 1A	*They said I had the stroke and they had to put me over to another hospital because there was no place or beds available. That was because of the COVID. So, they moved me over to [name of hospital].*
Anne 1A	*And they put me directly into the ICU. And I lied there for three days. I actually didn't even know I was there. But I was there.*

	(Thank you, directed to someone who brought for her water).
Edward 1B	*And that time that she was in (hospital name), they did all tests. Because of doing the scan at one hospital and giving it over to a neurosurgeon at (the other hospital), it was difficult. It was also COVID.*
Edward 1B	*Everything is electronic, but there was an issue with that. And now they said, OK, she can now go to rehab and so on. And there was a big issue trying to get the x-rays to give it through to the medical aid on it*
Researcher	*My apologies. May I just have clarification. The challenge was because of COVID?*
Edward 1B	*Yes, I think so. There was an issue getting medical records like [the] x-rays. It was difficult with communication between the hospitals and medical aid and rehabilitation facility, so I ended up doing it all myself and kept forwarding everything myself. Luckily it is all accessible digitally now. Like I said everything is electronic.*
Edward 1B	*It was needed before they (medical aid) could approve, or give the go ahead to go over to rehab.*
Researcher	*I see, thank you.*
Edward 1B	*And in the end, I ended up doing everything myself, getting everything and then sending it through to the medical aid and then sorting out with the rehab. Because the lady there, the neurosurgeon, they only worked with places in Pretoria.*
Anne 1A	*Yeah, they wanted to send me to Pretoria, but my all my friends and family are in (name of home town)*
Edward 1B	*And the closest to us was obviously in (name of town), where Anne 1A ended up. But I had to do it*
Researcher	*Yeah. May I ask, during your stay at the hospital in (name) and (name), had you seen Edward 1B?*

Anne 1A	*Nope*
Researcher	*How was he informed of your condition and what was happening?*
Anne 1A	*Everything. He knows about everything. He knows that I was in intensive care for three days.*
Researcher	*Okay, how did the hospital communicate?*
Edward 1B	*Terribly. There wasn't much information, reports via email and telephone calls. I used to run up and down trying to talk.*
Researcher	*Were either of you given information about the stroke or its effect at that point?*
Anne 1A	*Nada.*
Edward 1B	*Well not the specifics but that she had a stroke and high blood*
Anne 1A	*Yeah, but I Googled hypertension after the stroke to help myself understand. I know it has to do something with salt but I wanted more [information]*
Researcher	*And were you allowed visits?*
Anne 1A	*It was restricted*
Researcher	*And how did that make you feel?*
Anne 1A	*It was tough. Because we're are rather old people. But yeah, I had to go through it. It was tough being isolated. It was one of those things, but it was tough*
Researcher	*I can imagine. And Edward 1B, how was it for you – unable to be there physically?*
Edward 1B	*It was a little bit frustrating. Because now you've got to try and pinch a bit of time off of work to be able to try and attend to your loved one. And the work obviously doesn't want to give you off. Because they've also got their own requirements and things like that.*
Edward 1B	*But I didn't have too much problem with that. (Work wise)*
Researcher	*Were you using technology to talk to each other? So, like your cell phones? Did the people at the hospital give you access to video calling or setting up*
Edward 1B	*eventually later on. But not in the first stage.*

Anne 1A	*Yeah, the first three days when I was in intensive care, I couldn't really talk to anybody*
Researcher	*I see. Please continue telling me about what happened afterwards* *Once you got to rehab.*
Anne 1A	*Okay, so I think it was after the first week they moved me back to the general ward. And then the process around the rehab started. So, the specialist wanted to send me to Pretoria.*
Anne 1A	*That's where she (the doctor) knows the rehab. And then nobody's saying anything there, but there's a rehab right here in (Ekurhuleni town). So, he (Edward 1B) did a lot of stuff himself to get the information and where I must go and all that stuff.*
Researcher	*Wow, okay.*
Anne 1A	*It was very frustrating that they didn't consider that my friends and family are here. I needed them you know*
Edward 1B	*It's a bit easier being at (Ekurhuleni City name) because all the family and friends. it's a lot closer than going all the way to Pretoria.*
Researcher	*Hmmm mmm, I see*
Anne 1A	*Yeah. So, I went to the rehab in Benoni and I was there for a good six weeks.*
Edward 1B	*No, maybe a month*
Anne 1A	*It was longer because I came out the first, remember*
Edward 1B	*I don't know when you went in. It was about seven days in hospital when you went there.*
Anne 1A	*Yeah. I said it was six weeks because I came out the first of the month. That they released me. Okay. It was also a story to get released. They didn't want to release me. They keep saying, but I'm not strong enough and I still got some stuff to do and stuff to do.*
Anne 1A	*And I said, I want to go home. And it's normal for anybody to say they want*

	to go home. But I've got no issue with the rehab itself. I had an issue with the way they handled it. Okay. If you know that you have to stay for six weeks, then it's a different story.
Anne 1A	*But they told me I can go home tomorrow and tomorrow morning the doctor says, no, you're staying another two weeks. That's basically one of the negative things.*
Researcher	*Did you feel unheard?*
Anne 1A	*In some way.*
Edward 1B	*Okay maybe. But we had a group session [virtual family meeting with therapists]. It was myself and a couple of the therapists. And they obviously gave their views. Elsa was present at the time too. It wasn't a video call. It was only an audio call. And then they said what was their concerns and so on [due to not discharging her yet].*
Edward 1B	*And I also tended to agree with some of the things. Like she can't eat food because she chokes. And she doesn't swallow because of the stroke and that. And she might not have feeling in her mouth or something. And so, there's a great chance of choking and so on. Okay, so that was one of the problems. And the other one was a little bit disorientated. And I've got a shower in the room there, which is full of glass and that. And with maybe being a bit disorientated, you might just slip and fall and go through the glass. And that was the other major concern I had. So, they wanted it to get a little bit more. And a bit more mobility and speech and things like that before they would sort of release her.*
Anne 1A	*Look, I understand why I had to do it. But for me it was a bit of a grey area. No one explained to me. No one said why they're taking me to rehab, or what the outcome of that would be*

Anne 1A	*For a long time I didn't believe I had a stroke*
Anne 1A	*So, once I understood that I need to strengthen up the muscles and what needs to be done and all that, then it was fine. But it's that process around why did I have to do it and what's the outcome of it that, needs to happen. That needs to be communicated.*
Researcher	*I see, being informed helps.* ***May I ask what was your experience with rehabilitation itself, (so speech therapy, physiotherapy, occupational therapy etc) especially during COVID and how that impacted you***
Anne 1A	*No, it wasn't bad. Most of the guys are very good. They were very positive towards getting what needs to be done and to get you strong again and get you out.*
Anne 1A	*What we did experience is with the COVID, that there were cases there while we were over there [in the in-patient facility]. They had to move us around. We were six people that were in different stages of our rehab, whatever the case was. And they had to move us to the other end of the corridor to try and keep us out of the group that had the COVID virus at that stage. So, it was a bit difficult. There were interruptions.*
Researcher	*Did these interruptions happen often?*
Anne 1A	*I would say ja. Also, we were never always told if a break out happens maybe they were worried about our reaction but it was strange you would have a new therapist and wonder, is it COVID? Is it what?*
Anne 1A	*We could move around to a certain point. You couldn't go out and sit outside and stuff like that. And you couldn't exactly just walk straight through to the area and where they went through all the different things and things.*
Researcher	*Sorry to interrupt you Anne 1A, do you mean there were restricted zones? Because of COVID?*

Anne 1A	*Sorry. Hang on… yes. (pause)* *We couldn't move like freely in the hospital.* *There were zones.* *For example, to the physical therapy area it was restricted*
Anne 1A	*So, it was a bit difficult. We were lucky in the group. We were six people that were all clear that none of us had the virus. So that helped a lot in a sense …*
Anne 1A	*they would come in in the morning with their little test kits. And the test kits were just to see if you're still clear. And then they would tell you you're fine or there's an issue or whatever the case is. So that was okay.*
Anne 1A	*What was annoying was the masks. We always had to have it on except when you sleep so it was difficult to chat or hear others for that matter*
Edward 1B	*I think everyone finds the masks troublesome, even now*
Researcher	*Please expand, what was challenging with the masks? Therapy, conversations etc*
Anne 1A	*Uhm…the speech one yeah. It was just a little frustrating*
Anne 1A	*You can't see people's faces and hear well especially when it was noisy*
Researcher	*I see. Was anything done to help this?*
Anne 1A	*I mean I don't think we could do anything. It was just the COVID.*
Researcher	*Hmm mm.* ***Can you perhaps tell me a little about the support you received during this time, or would like to have received?***
Anne 1A	*Look, from my personal view, it was okay to go for the rehab. But I would have done it a bit differently. I would have sat down from day one and say, this is what needs to be done.*
Anne 1A	*Are you up for it? Do you understand it? Is there any issues? Is there anything we need to attend to? Stuff like that. To me, that was not 100% communicated so that you could understand and say, okay, I have to go for*

	the rehab.
Anne 1A	*Because a lot of people, they would always say, I want to go home. So, I was one of them that said, but I want to go home. So, it was difficult.*
Researcher	*Why was it difficult?*
Anne 1A	*I was alone, I was isolated for weeks. I felt abandoned*
Researcher	*Was this because of no visitation?*
Anne 1A	*Yes exactly*
Researcher	*I can imagine how that must have felt*
Researcher	*I'm sorry. I just want to go back for a minute*
Researcher	*May I ask, just to clarify, that you would have gone through with the rehab process if you were given more explanations about it up front?*
Anne 1A	*I think so. They took you the first morning that you got there and they sat down and said, look, we need to make you stronger. You need to do some OT.*
Anne 1A	*You need to spend a bit more time with physio, stuff like that. It wasn't communicated so that you could understand precisely what needed to be done and what the outcome of it should be.*
Researcher	*Hmm mm and do you think that COVID perhaps contributed to these communication challenges?*
Anne 1A	*Uh maybe yes maybe. But I don't see it really. I mean communicating with the patient should be done anyway. I was in hospital before but with the stroke they treated me differently*
Researcher	*How so?*
Anne 1A	*Well, no one gave me the information, like what is the point of all this and things*
Researcher	*I see, thank you. My next question is for you Mr Edward 1B*
Researcher	*What was the process like as the family member or the significant other? Did you understand the process?*
Edward 1B	*I understood it. And there was definitely a benefit for it. Anne 1A's mother*

	suffered a stroke many years ago. But I didn't know at the time or anything.
Anne 1A	*But she never went through rehabilitation. I'm sure if she had done rehabilitation, it would have been maybe a different outcome or something.*
Edward 1B	*Yeah, that's what I say.* *I think the main problem was that people didn't explain to you why is the reason that we're taking you into rehab? What's the result, the outcome that we want to see from it? Not rehab itself?*
Anne 1A	*So that I could understand this is what I need to do. So, from my point of view, I just wanted to go home.*
Anne 1A	*Obviously, everyone just wants to go home. Yeah… (tearing up)*
Researcher	*Are you okay, Mrs. Anne 1A? Would you like to pause?*
Anne 1A	*No, I'm fine*
Researcher	*Are you sure?*
Anne 1A	*Yes yes. We can continue*
Researcher	***Okay. Mr Edward 1B, please share your experience as the significant other?***
Edward 1B	*Well communication was poor overall, like you can see from Anne 1A*
Researcher	*Did healthcare staff meet with you or …?*
Edward 1B	*No no, remember it was all restricted. They made this WhatsApp group to keep us in the loop. I think it was difficult for them to keep answering phones*
Edward 1B	*I mean there are a lot of patients and the nurses are busy so I get that I understand*
Researcher	*I see, yes because of COVID everyone tried different ways to communicate. Were you satisfied with the communication via WhatsApp?*
Edward 1B	*It [WhatsApp] was fine but I wasn't really given any information on daily progress or what she was struggling with. It would be better to be given videos or to have voice notes from the different people. She was seeing so many. Communication was more about the restrictions - how visiting hours*

	were changing or when to pick up washing and things like that.
Researcher	*Were you ever involved in therapy sessions?*
Edward 1B	*Is that for me? I think you mean Anne?*
Researcher	*No as a significant other, were you ever asked to be involved?*
Edward 1B	*Not that I recall*
Researcher	*I see, and were you given any updates on progress?*
Edward 1B	*Yes, via the reports but it would have been nice to watch her progress or even just be there to support*
Anne 1A	*The negative part of it was the fact that no family or friends were allowed. I think anybody that goes through it, if you ask them today, they would tell you [the same], I just wanted to go home*
Anne 1A	*Nobody thought to go through the process to sit down and say, but what will it do to you if you do the rehab? Because that changes your perspective.*
Anne 1A	*If you get that, where somebody sits with you and say, but it's because you had the stroke here (points to head) and its more affected on the right side and you had the numb feeling this side. You couldn't chew properly and whatever the case is.*
Anne 1A	*So, I think there's a lot that you can learn from this. People misunderstand. It's not easy for the patient or for the member that this is necessary to do. They [the staff] need to be more understanding*
Researcher	*Thank you for sharing that with me, I think there is a lot we can learn from your experience*
Researcher	*I'd like to chat a little more about some of the changes that you mentioned… So, you said that the stroke has changed your lives in many ways.* *Would you speak on some of those changes, and you too Mr Edward 1B*
Edward 1B	*You can go.*
Anne 1A	*So, from my side, I had a lot of dead feeling on this side. It was also there*

	were some areas which was sort of numb. The rehab helped a lot with that. Although, like I said, I didn't want to go. But once I agreed to do it and we went through the process slowly and every day did the physio and did the OT and all that stuff. It sorts of started getting better.
Anne 1A	*I think I will never move like I used to. But I can walk at least. I still use the walker. I have tingling, numbness, and my balance is slowly improving.*
Edward 1B	*She was asking about things planned for this year with our retirement and how that sort of affected everything.*
Anne 1A	*Oh…*
Researcher	*No, that's completely fine please continue its all about how you think it has affected you*
Anne 1A	*Well, it affects you a lot. The whole view has changed totally. When I came out of rehab, you could say the first six to eight weeks, I just wanted to stay in bed.*
Anne 1A	*I didn't want to get up. It was like you had to go through the mental negative feelings of what happened to you. It's not just gone. It's not just like where you become okay, it's a process. It takes a while. I'm still very emotional*
Anne 1A	*And what a lot of people said, if you feel to stay in bed, then it's fine. Then you stay in bed. And then this is precisely what happened. You feel like you rather wanted to lie down. And some days I didn't want to get up and I sort of slept all day.*
Anne 1A	*I didn't even get up. So, it changed your whole life. But it's because you suddenly realize something happened to my body which I didn't plan, wasn't supposed to happen.*
Anne 1A	*I can't explain but sometimes I don't really feel. I don't know. Maybe it's just negative feelings that I need to deal with but it's not every day. It's different*
Anne 1A	*A lot of people don't understand why it's changing your life.*
Researcher	*A lot of people, such as your social network? Friends? Family?*

Anne 1A	*Yeah. Maybe if it was within normal circumstances where we could have many visitors, our friends, our neighbours coming in and they slowly watch me [post-stroke during inpatient rehabilitation], they would have had a better understanding of stroke. It's difficult. It's not easy. And a lot of people don't realise how difficult it really is to keep waking up and knowing that something is wrong. And then you have to start working on it and try and get your life back and all that. And get going and do things again. Things that at some point [I] didn't even feel like doing. It was tough for me and it was tough for Edward 1B too*
Researcher	*Hmmm I see, why was it or is it difficult to engage with your friends and family?*
Anne 1A	*It changed a lot. You try to get a different view of things. Feeling I didn't want to exactly express my feelings. I felt negative about it.*
Anne 1A	*People look at me strange when I lose my words, like I'm stupid. I'm not*
Anne 1A	*So, everything changed suddenly. It changed the perspective totally*
Researcher	*Wow. Okay.* *And Mr Edward 1B, from your side as a family member, would you like to speak about your experience specifically? So, what is it like to have to go through this with your wife? How did it affect you?*
Edward 1B	*The thing is, Anne 1A was very strong person and very independent and things like that. And obviously… but now things have changed. The whole routine of the day has changed*
Edward 1B	*On the farm here, we've got a guest house and she's not as active as what she used to be. She isn't as active; she sits around and watches TV where before she hated to sit too long and watch TV. But she is trying to get more and more active*
Edward 1B	*So now I do a lot more of the day-to-day tasks she doesn't really help, or*

	rather isn't able to manage.
Edward 1B	*She was a busy person. And yeah, like her sister said, it's probably because she was too busy. That's maybe what happened. And now she's got me time. She's got to sit down and start thinking of herself.*
Edward 1B	*It's difficult for me but I am happy to help. My priorities have changed now, I put her needs first.*
	[Anne visibly emotional]
Researcher	*I see.* *But Mrs. Anne 1A, I have to say you're a phenomenal person. Watching you and looking at you, I can see how difficult this process has been for you. But you're still standing on the other side, smiling and stronger*
Anne 1A	*You got to. The thing is, you got to be positive. If you're not positive, you're just going to go down there. And the thing is, we push each other on there. We're helping each other every day.*
Edward 1B	*Exactly. I'm doing a lot more assisting. Maybe also because she hasn't got full function of her hand and things like that. But I do try and maybe leave it for her to try and do it herself first.*
Edward 1B	*So, you still have that feeling of being independent. (To Anne 1A)*
Anne 1A	*Yeah, I guess. But others don't see me as they used to.*
Researcher	*What do you mean?*
Anne 1A	*It's just different is all…*
Researcher	*I see. For sure. May I ask you; do you think that having been in the rehab, and you both can give your opinion on that, please. Do you think that you were treated sufficiently and educated properly for discharge?*
Researcher	*So, what to expect once you were discharged, how life would change from the stroke and how you would be able to reintegrate into your old life before the stroke. Were you given enough at rehab to do that? Did you understand enough to do that?*

Edward 1B	*[During the discharge meeting], they (the professionals) understand what they are talking about, but honestly you can't take it all in – it's too much. It needs to be paced. It's just a totally different perspective now. You don't really understand what's going on until you start living it.*
Edward 1B	*I'm sure everything was given over and we understood it. It's just a totally different perspective now. Yes. So, they give you all of this information and to try and take it all in at the same time.*
Edward 1B	*It's not difficult. So, you've got to take it from day-to-day type of thing. They understand what, you know, today I'm talking about the social workers and that they understand what's going on and things like that. And everything is new to you*
Edward 1B	*Okay. And also, being a shock as well. You know, you try to push it aside, but you can't. You may ignore it, but you can't. I mean, it's reality.*
Researcher	*Please clarify, a big shock in terms of?*
Edward 1B	*Well, the difficulties with everything after the stroke. I didn't realise it was going to be so challenging. Or that she would need so much help. Emotionally and physical help. Day to day activities, meeting people you know that sort of thing. So, it is more difficult and I would say sometimes straining on me.*
Researcher	*Hmm. Okay. I see. Sorry, Mrs. Anne 1A, you wanted to add in something?*
Anne 1A	*No, no. Look, I agree with what Edward 1B said. It's a shock to your system, first of all. And then you have to try and cope with it. And then you sit with somebody like one of the OTs that will say, no, but you can't hardly chew on your right side or you can't swallow properly or whatever the case is.*
Anne 1A	*There's lots of things that changes. You don't know it at that stage. So, you think it's still fine. You can chew on your right side and then suddenly you realise, but I can't exactly chew there. I can chew on the left side, but not on the right side. So, you have to start changing your mode every day.*
Anne 1A	*You feel normal. And it doesn't feel like something changed. But it did change because the slightest thing is now a challenge which you don't know then at*

	that point in time. Until you live it.
Anne 1A	*So, people don't understand what changed. And from my perspective, from the point that I realized I had a stroke up to the point now, there was a point where I said I didn't have a stroke.*
Anne 1A	*Anybody said you had a stroke and I said I didn't have a stroke. So, you go into the negative thoughts of, but I didn't have a stroke. It was definitely not a stroke*
Edward 1B	*I think stroke is a small word for a big meaning. You can get the way that Anne 1A's mom had a stroke is totally different to what Anne 1A's experience. That's why I think she says she feels like it wasn't a stroke because her mom's stroke was worse.*
Anne 1A	*But you know, (sorry love). Before I lose it.* *But what I want to say is other people have a stroke and then they get paralysed you know? So now I worry, if I have another stroke and become completely paralysed, how would I live then?*
Anne 1A	*I think before I was very angry because I am not my mother, I don't smoke I don't drink I was active and healthy but it still [the stroke] happened. And now I am so scared that it will happen again and be worse this time*
Researcher	*Wow, thank you for sharing that. I just want to ask; do you need a break? Would you like to pause or stop?*
Anne 1A	*No, its fine*
Researcher	*Okay, thank you.* *Please will you expand on some of the experiences after rehabilitation, so once you got home.*
Anne 1A	*I do have the feeling that at some point, it feels like this side pulls down and that side is pulling up. (Gestures to muscles on the leg)*
Researcher	*Pardon, if possible, please clarify what feeling?*

Anne 1a	*Okay. I would get it from the time at rehab. It started coming back at home too. I still when I, for example, brush my teeth, I still have the feeling this side feels a bit numb and this side feels okay (gestures). So, like numb in my arms and legs.*
Researcher	*So, body pain?*
Anne 1A	*Uhm sometimes yes but what I'm saying now is more like pins and needles, tingling - or numb, no feeling*
Researcher	*Okay I got it thank you for explaining.*
Anne 1A	*Yeah. So, if you look at the inside, there's something happened. You can feel that. As you get tired during the day, you start feeling a bit as if this pulls down and that pulls up. Yeah.*
Researcher	*I see, and any other challenges?*
Anne 1A	*Well, I have to concentrate to keep [my] balance. It's not something natural now it's frustrating.*
Anne 1A	*I don't like going to the shops. [points to hand] [my] co-ordination isn't good so I get flustered in the queue because I hold it up.''*
Researcher	*Does that make you not want to engage?*
Anne 1A	*new people are okay, people I know, I'm embarrassed to talk to sometimes.*
Researcher	*Why is that?*
Anne 1A	*I think it might impact because now that the people know that I had a stroke, they see me differently. They think, oh, your mental health is gone or whatever the case is.*
Edward 1B	*I don't think it's that. I think it's more because once you had the stroke, your whole mode changes. And because now people have to start changing to try and work around you as well. Like what I'm going to talk and what I'm going to say. Also, maybe it's difficult for people to understand how to communicate. Because it can be a challenge.*
Edward 1B	*It can be a little frustrating, she might start saying something, like last night she started and then walked around the table and then she sort of forgot*

	what she was saying…
Edward 1B	*So, if we are socialising others may not be as mindful or considerate*
Anne 1A	*I think people have got the perception that you don't retain who you were as a person.*
Edward 1B	*Yeah. I think it's more a case of how do others handle themselves around you and how do you come out of it? So, accepting the changes positively*
Anne 1A	*Yes, that's also what I mean, and that they would have had a better understanding of stroke if they could visit and stuff you and know*
Edward 1B	*Yeah, definitely. It was a COVID that played a big part in it. I couldn't see her at all*
Anne 1A	*They (the hospital) blocked us all off. We couldn't exactly go out or anywhere. We were allowed to stay basically inside. It would have definitely been a bigger help if there was more freedom for visitation and that. Yeah, it was the COVID that paid to all of that.*
Edward 1B	*If it wasn't for the Covid I'm sure the experience and recovery would be better. Also visiting more frequently would be better*
Researcher	*Yeah…*
Anne 1A	*Yeah. What I think also would help is if it changed the whole perception of you've got to stay in. What I mean by that is, for example, there was one lady with me. She really had a bad stroke.*
Anne 1A	*She was really struggling. She had no one. I said to her, you know what? Let's try. To me, it felt like if you could just understand you have to go through rehab, you have to take it day for day for day and not try and live a normal life just like that. But no one was able to support us well, were on our own because of COVID.*
Anne 1A	*So, if someone says, take it day by day and improve little things day by day, it will change rehab. And if you can get the people to sort of, accept after, say, three weeks, example, okay, you're going to go home, but still as the patient.*
Anne 1A	*But tomorrow morning, seven o'clock, you're back inside. You stay there for*

	the day. This afternoon, your husband or whoever comes and fetches you, you go home. Or maybe they stay with you for the day. And two to three days later, you go back again.
Edward 1B	*That might have been the case in the earlier days prior to the COVID. But because of the COVID, you had all these restrictions.*
Anne 1A	*Yeah, I understand that. But I'm saying if they had that attitude towards after three weeks or two weeks, we allow you to go home, stay overnight and come back the next day or whatever the case is.*
Anne 1A	*That will change the perspective of what I had to go through and how you have to change your lifestyle.*
Researcher	*So, I fully agree with that, Mrs. Anne 1A. And one of the things that were impacted because of COVID was something called pass outs, okay. So along the lines of what you've just explained. You might have been allowed for a weekend etc but due to COVID restrictions this was not possible at the time.*
Anne 1A	*I think that will change the perception of sitting for six weeks in a place where you don't exactly want to be. And actually, be able to go home for a night or two and then go back, say, for three days again or whatever the case is.*
Anne 1A	*You're still part of the process. You just stay home for two days and the third morning you go back and then you stay for another three days and you go home again for a little bit. That would change the process in the sense you have time to sort of relax a bit at home.*
Edward 1B	*Yeah, that would be great. You see what it's all about? Can I handle it? And I can go back and say, OK, I'm still struggling with this and how to help etc and she's still struggling with the right side. Still on tiptoe. Whatever the case is and see how you can get around it.*
Anne 1A	*there needs to be pass outs to the home. It doesn't make sense to sit there for 6 weeks without real life input. I can go home and the come back and say I'm still struggling with this. It would also change the perception of rehab*
Anne 1A	*So that makes a difference. But if you sit there for six weeks and after six*

	weeks, they want to still keep you for another two weeks just for the sake of, I don't know. I don't know if it was money or what.
Edward 1B	*I don't think it was a money thing. Maybe the physical aspects and wanting more movement*
Anne 1A	*yeah, but I think that would change your perception and it will have a positive attitude towards the rehab process.*
Researcher	*So, we have touched on this next topic a little, but now I'd like to ask your opinion.* *Do you think the family should be involved in intervention?*
Edward 1B	*Yeah, we have seen that stroke doesn't just affect you as a person. It affects your family. It affects your lifestyle. There are so many changes.*
Anne 1A	*Yeah, I think if I say if I think about it, I went home first because they couldn't get me into the rehab immediately. There was a waiting period. So, I went home that afternoon after he said he had enough of what's happening at the hospital.*
Anne 1A	*He wanted to rather let me come home. So, I didn't understand the process of rehab maybe. But that's when you start immediately with the process. Immediately.*
Edward 1B	*Yeah. They shouldn't wait until the person is in rehab and then you want to start with the process. That to me is wrong. They should immediately realise, OK, she had a stroke, so let's get the physio in or therapist in or social work person in. They didn't tell us the importance of rehab and we had to basically get things going ourselves*
Anne `1A	*Yeah, and start with the process that I'm going to rehab. That they can sort of help you through the process to say, OK, you need to go for rehab. Because X, Y, Z*
Edward 1B	*Yeah, and this is what's going to happen next.*

	But it's not what she's asking. She's asking about intervention with the family members and all of that. We got side tracked
Anne 1A	*Yeah, that's what I'm saying.*
Researcher	*No no that's okay please carry on*
Edward 1B	*Like I said earlier, the COVID has put a big pay to a lot of the visitation rights and things like that. And I'm sure if it wasn't for the COVID, it would have been a little bit different. I'm sure the outcome might have been a little bit speeded up.*
Edward 1B	*You know, the recovery and things like that. Having a loved one there most of the time, more frequent than that.*
Researcher	*OK, so we spoke a little bit about that. You were had some social video calls with your family while you were in the rehab and things like that. What do you think about using video calls for rehab?*
Edward 1B	*Yes. I think a video call would have been a bigger help in that. You know, everything was just audio and so on. And then you obviously couldn't hear too well.* *So that was also a bit difficult.*
Anne 1A	*I think if he [my husband] was involved from the beginning, it would have helped a lot. I don't know why I'm getting so emotional about it (tears up), if he was with me through the rehab process it would be better. He has a role to play in it.*
Researcher	*Are you okay? Do you want to pause or stop?*
Anne 1A	*No. I am okay*
Edward 1B	*You're were asking about the video calling.*
Anne 1A	*Because you couldn't go and come and join me when we were doing the rehab. In the sense, coming in for the physio session.*
Edward 1B	*Yeah, but that was because of COVID. But like the conference calls and that,*

	if it was video that you could see, then the interaction would be different. It would have been a bit more settling in that I could see and understand what was going on.
Anne 1A	*So, I think that would have helped a lot in the sense, if you enjoyed the rehab process in the sense, okay, I'm going for the rehab for the day. Or physio. So, you join in with the physio, you spend time there and you see what happens and what is done and what needs to be done. All on video*
Anne 1A	*That would change the perspective that you know what is happening. That's what I'm trying to say.*
Researcher	*Both the points are thoughtful thank you for that. The other thing that I wanted to ask was, and this is again for you too, Mr. Edward 1B is if you've noticed communication changes. So, for example, difficulty with understanding or of talking*
Edward 1B	*I think I have to speak slower or repeat myself. Sometimes Anne 1A may also misunderstand what I am asking but we work through it*
Anne 1A	*Look, from myself, I think like I've always been a strong person. I'm actually the strongest person in the family. That's how I felt about it.*
	But it is hard when I can't get the words easily or take too long. *Or not knowing what to expect or knowing what's happening or whatever the case.* *But I think it's good to have that communication, talk about it. And he is very accommodative to me. But not others*
Anne 1A	*Honestly, the problem is not the physical side. Its emotional, communication, understanding. Fatigue. People can't see [those aspects] so they can't understand. And they judge*
Anne 1A	*But the main thing everyone needs to realise I'm still me, I haven't changed*

	(cries)
Researcher	*Is it frustrating for you sometimes?*
Anne 1A	*Yeah, it is. We go to town and it feels like people are ignoring what I'm saying or asking and I'll get frustrated with it because I feel at that point, but you know me, you should know what the situation is.*
Anne 1A	*So, it's frustrating if you said something and you have to either repeat yourself or the person doesn't understand what you're saying. That does happen.*
Researcher	*What could clinicians do better to make it easier for you to transition back into your daily life?*
Anne 1A	*Look, it's difficult to say precisely, but I think the process, so explain it. So, if you can say that for three weeks and after three weeks, you say, OK, we know you're not 100 percent. You say 50 percent there or 60 percent there.*
Anne 1A	*Let's give you the opportunity. You're going to go home. You stay three days at home and you come back. Say again, three days or whatever.*
Researcher	*Once you were discharged from the rehab, were you still being seen as an outpatient? Did you attend more sessions for physiotherapy, occupational therapy or speech therapy?*
Anne 1A	*I did not exactly go back. I got to the point that that was after this. I think it was six weeks. I just that morning said I'm going home.*
Anne 1A	*I don't care what anyone. The social person, the senior person there, she already agreed the concept I can't go home. And I know she was hoping that I would come back as an outpatient, which is fine. Don't see that as an issue. But I saw it as an issue in the sense you get to the point where you get so fed up with the same thing every day. You have to go for OT. You have to go for physio. You have to go for that.*
	You have to go for that. You get to the point where it's just too much. It's just

	getting totally out of hand. So, for us, OK, or three weeks, you're going to go for three days and come back. Three days' time, stay another week or two weeks or whatever the case is.
	That will change the vision of going and have to stay and stay. And that morning when that one doctor was telling me you're staying for another two weeks, I said to her, that will be the day. I'm going home today. *Do you understand me? I'm going home today. Then she went to call the physio guys and the social worker there, the social guy, said she's going home today. And then she sorts of backed off. So that is why I'm saying if everybody is just on the same page from day one, because it didn't seem like good communication.*
Researcher	*Do you think that COVID may have contributed to that?*
Anne 1A	*In what sense?*
Researcher	*Okay. In the sense that the team had to social distance and maybe could not discuss things well in advance?*
Edward 1B	*Hmm, I hadn't considered that. Look logically I could see that, but they have notes and one person saying one thing and another person saying another can't be because of just COVID. They have to do better*
Edward 1B	*Also, they did say they would have to send her elsewhere for outpatient at the time because they didn't know if they would open theirs immediately*
Edward 1B	*But there wasn't anything that came of that*
Edward 1B	*That is perhaps something I would consider saying better support from the therapists. We started from zero at home, there were no follow ups*
Anne 1A	*But I did see the OT lady for the work assessment*
Anne 1A	*So, when I did the test afterwards, now in October, was it October when I had to go for that test? Maybe November. I had to go for the test assessment to see where I am for the work, to see can we go back and work again.*
Researcher	*Did you do therapy with the OT or only the assessment?*
Edward 1B	*Just a once off assessment*

Anne 1A	*That's when I said, OK, test me and some things I'm still totally OK. But in some things, I can see, OK, yeah, I'm a fluster, but yeah, I can't concentrate. I get to the point where something, I get to my, to me and I see something and I totally, totally [go] another route.*
Edward 1B	*And that's the things that you need to work on*
Anne 1A	*Yeah. And those are the things you can't always see because they're not physical. So, people think you're OK, but you're struggling with the attention, the concentration, finding the words, your memory, all of that.*
Researcher	*OK, may I ask you if you were offered as an outpatient video session, so not sessions where you had to go in every week and do physio, OT and speech. But rather virtually?*
Anne 1A	*No,*
Researcher	*Do you think that might help?*
Anne 1A	*But I'm not sure how it would help? Yeah, look, I don't know if, look, it will help. The problem is not the physical side, you know, your brain is still there and you know, you know what you know and all that stuff.*
Anne 1A	*It's to go through the process day by day and take it day by day. So, like not today, there's one we know we're going to have the session with you. So, you get up and you get finished and done and get it out of the way. If you know you have to go sit down and have a session, that's fine.*
Anne 1A	*But I don't think anybody really sit down and say, can we have a session with you once a week and set up the session so that we can have it with you. But I don't think anybody really got to that point to do it.*
Edward 1B	*Yeah, but she's asking, would it help? Yeah, it would help.*
Anne 1A	*But I don't really need physio…*
Researcher	*Oh no. Sorry for the confusion. Let me clarify.* *Virtual sessions of all therapy, not just physical therapy – but speech therapy, occupational therapy, psychology*

Anne 1A	*Oh! Definitely it would help.*
Anne 1A	*I think I would do it on a video call.*
Researcher	*Would you still do it now? So, as you are, would you still see the benefit in starting something like that to have rehab online?*
Anne 1A	*Yeah, I think it will help definitely. It will improve, for example, my concentration, because I know there was at the point where I would look at something and I'm distracted with something else and go somewhere else.*
Anne 1A	*And especially for my emotions* *Out of the hospital, out of rehab, it was like I had to start from scratch and try and get my thoughts together. Difficult because there were some days that I didn't even get up. I just stayed in bed. I just didn't feel like getting up. So many emotions I was going through.*
Edward 1B	*Is there something like that available? Online Therapy?*
Researcher	*There is, yes. So, it's actually something that has come up mainly as a result of COVID. It's called telehealth, where clinicians consult virtually and medical aids have also agreed to pay for these consults. It did exist before, but to my knowledge atleast, it wasn't readily available in SA until now.*
Edward 1B	*Rehab online would help because at home it was like starting from scratch* *I think it will help in all means. I think it's a good suggestion. And even if you just talk about your feelings or your emotions or things that's blowing you, which you might not share with somebody.*
Edward 1B	*We have been going back and forth about seeing psychology but with COVID it hasn't been easy. We here at the farm as well which is in Mpumalanga and far out.*
Anne 1A	*I didn't realise psychology as an outpatient is available online, but now that I know it is, I would like to try it*
Anne 1A	*I saw psychology maybe two times in rehab, she wasn't there always. I found it not worth my while because I could barely hear between the noise, the*

	masks and I yeah...
Anne 1A	*I know I'm struggling with my feelings, for example, or I'm struggling to accept some of the things that happened.*
Edward 1B	*Or just to talk. So, I think in any case, it will help even if you just have these sessions for the sake of having it. But yeah.*
Researcher	*OK, so through this research, there is a counsellor available. She's a psychologist. Her name is Sarah. And she can offer you a free counselling session. If she feels that you would benefit from more ongoing sessions, she will either send you to someone that is close in your area or refer you to herself. There is also a church that has agreed to provide free counselling services in the [Ekurhuleni area]*
Edward 1B	*That would be great. We've got two areas. We've got two areas because, like I said, we're on the farm here. Yeah. This is in Mpumalanga. OK. And this is basically where we spend most of our time now. I have retired at the end of last year and I do a bit of contract work or consulting work for previous suppliers.*
Anne 1A	*And we can also use the video conferencing as an option.*
Anne 1A	*My faith… I needed to work on it, COVID-19 restrictions were rife, but I joined a [church] service online*
Anne 1A	*So, I am used to the way it works. I think I would like sessions online. It would be nice to have that support…I feel like with my church they in Cape Town but I feel connected.*
Edward 1B	*The video conferencing definitely would be a big assistance because you don't have to jump in a car and go out there and the price of fuel and things like that. It's terrible. The road conditions and all of that. And our new technology we bought because of COVID will come in handy*
Anne 1A	*Yeah, we used to have some online meetings before at work so I am familiar. But things like zoom have become so easy now it’s great*
Anne 1A	*We get to stay in touch with everyone. I can also just pretend to freeze if I*

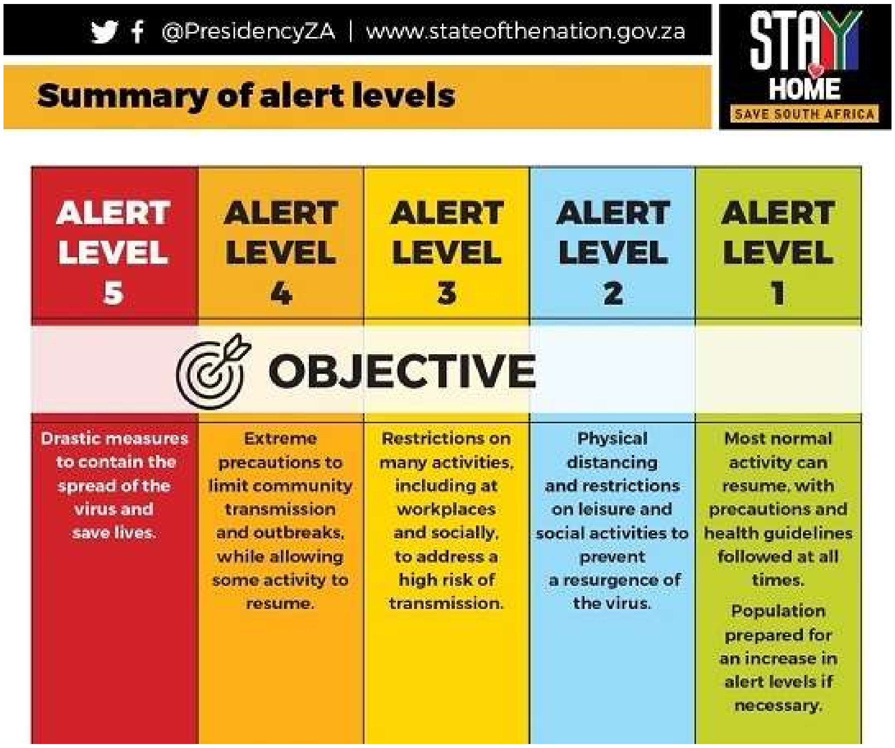
	forget a word (laughs)
Anne 1A	*I'm just kidding I don't really do that*
Researcher	*What are some of the other ways you use technology?*
Edward 1B	*Well now mainly for socials and work connections. There has been lots of changes in the way we socialise*
Anne 1A	*Yeah, we don't see many people now, except online. I do miss that aspect a lot, I was always a very social person*
Researcher	*And has it been affected because of the stroke?*
Anne 1A	*Without question, yes. I think like I said, I feel judged a lot and I sense the discomfort people don't realise they can still make jokes with and things like that. There is a lot of pity which I stay away from then.*
Researcher	*And on your end Mr Edward 1B*
Edward 1B	*we're at the farm (laughs) so yes, it did impact us. I was worried about Anne 1A getting sick, and it's much quieter and peaceful here so she can relax*
Researcher	*But that's because of COVID yes?*
Edward 1B	*Yes of course. But also, with the stroke she sort of fell into her own mind and I just thought the fresh air will do us good*
Edward 1B	*I have also not been able to socialise as before, we were avid golf players so I miss that but we will get back in time*
Edward 1B	*So yes, maybe I will rather say that it has changed because of both COVID and the stroke. She is less comfortable around people and I am anxious about COVID so yes you could say it's both.*
Anne 1A	*Golf golf golf, but we did try…*
Edward 1B	*Yeah, it was a blunder. Sort of felt that she was ready to start swinging a club. Okay. I said, this time, we going to go and play golf. And then she couldn't really get up properly. She got a club and the first thing she hit was me.*
Anne 1A	*But I must say that. It's getting better and better*
Edward 1B	*Yeah, and see she wants to improve on things like that. That's what I think*

	she means by her real-life goals. Golf, farm life those aspects. Obviously. She might maybe need to just go through a little bit of more therapy. And coaching. To help. The swing and things like that. There is definitely an improvement. She gets tired quickly. Yeah. But, I'm sure. With a bit of counselling. And online therapy like that. It can definitely help.
Researcher	*Sorry to back track, what is your opinion on using technology in rehabilitation and healthcare?*
Edward 1B	*I think it's fantastic. I mean maybe not for everyone because of the high costs in obtaining equipment but for us it can work. We can stay on the farm, and login. Unless we have loadshedding*
Anne 1A	*(laughs) maybe it's not the best idea. No, I'm kidding. I like it, I mean I have engaged with technology a lot because of work. But maybe it's not for everyone, like the lady at rehab she couldn't talk much at all I don't know how that can work*
Researcher	*Hmm mm, I see. Sorry I see you checking your watch, can we do a couple more questions or would you like to stop?*
Edward 1B	*No please continue, it's just a habit*
Researcher	*Okay, is there anything else you would like to add from your side? Anything you would like to say? In terms of your recovery process and just your experience.*
Edward 1B	*I have seen a vast improvement, there are still a lot of short falls but hopefully with hard work it can improve*
Anne 1A	*I do think it was good but there is still a lot to learn. You don't always understand. Follow ups would be nice. It's a long journey that I still need to go through*
Researcher	*Mr Edward 1B, what are your thoughts on how this experience has impacted your life?*
Edward 1B	*Well, we were a very co-dependent couple. That has maybe changed a lot, we*

	[the two of them] have spoken about this too. To reduce her stress, I try to do the bulk of things like the grocery runs, driving. Also now, I make most of the financial decisions, we used to do it together before
Anne 1A	*Yeah, it's a lot. Everything was fine then it wasn't. I feel bad because [my husband] takes on so much now*
Edward 1B	*There is no need, we are a team we always have been and we will solider on*
Researcher	*Anne 1A, I just wanted to clarify, are you back at work?*
Anne 1A	*No*
Anne 1A	*Look, we were planning to go off last year, December. That was the plan originally. But then what happened to me, the work sort of said, OK, we've got a disability insurance for things that happened.*
Anne 1A	*And I can help with that. So, I had, you could say for six months that they paid my salary for me. And then they paid me out a portion. And I haven't seen the email yet, but there is an email.*
Anne 1A	*They're going to keep on paying me for another...*
Edward 1B	*Until 65*
Researcher	*And what was your job, Mrs. Anne 1A?*
Anne 1A	*Up to a certain time. I was an IT specialist in software. I did the design for a company and will then go and execute that as a project.*
Anne 1A	*So, in some cases I was the project manager myself. And in some cases, we got a project manager in.*
Researcher	*Okay wonderful hence you said you're at ease with technology*
Anne 1A	*Yeah, I was sad to be unable to continue but you know it just moved up the retirement timeline*
Researcher	*Yes, for sure. And how old are you?*
Anne 1A	*I'm 62*
Researcher	*And you Mr Edward 1B?*
Edward 1B	*Well, I turned 62 last Friday.*

Researcher	*And what is your home language?*
Anne 1A	*English.*
Researcher	*So, Mr Edward 1B, you are English too?*
Edward 1B	*Yes, English*
Researcher	*Is there anything else you would like to add from your experiences with stroke and COVID?*
Anne 1A	*I think we got through everything*
Edward 1B	*Yeah, that was a lot*
Researcher	*Well then that brings us to the end of the interview session*
Researcher	*Thank you so much for your time and speaking to me. I really appreciate it. Thank you for sharing so much. It's been so insightful and such a good learning experience for me. And thank you both for playing such a big role in this. And allowing me insight into your lives. It's very personal. And it's very emotional. And I just, I can't thank you enough.*
Researcher	*I'm sorry. I took so much of your time.*
Anne 1A	*I took so much of your time. As well. Okay. And thank you.*
Anne 1A	*It's not that I'm doing anything much, just sitting still.*
Researcher	*No, thank you so much. And I hope you enjoy the rest of your day. If you have any questions at all, you're most welcome to email me at any time as well.*
Edward 1B	*Thanks.*
Edward 1B	*Have a good day. Take care. Bye.*
Anne 1A	*Bye*
Researcher	*Bye*
	END OF INTERVIEW

APPENDIX O: Alert Levels in South Africa



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STAY HOME

SAVE SOUTH AFRICA

Summary of alert levels

ALERT LEVEL 5	ALERT LEVEL 4	ALERT LEVEL 3	ALERT LEVEL 2	ALERT LEVEL 1
OBJECTIVE				
Drastic measures to contain the spread of the virus and save lives.	Extreme precautions to limit community transmission and outbreaks, while allowing some activity to resume.	Restrictions on many activities, including at workplaces and socially, to address a high risk of transmission.	Physical distancing and restrictions on leisure and social activities to prevent a resurgence of the virus.	Most normal activity can resume, with precautions and health guidelines followed at all times. Population prepared for an increase in alert levels if necessary.

(Department of Co-operative Governance and Traditional Affairs, 2020a)